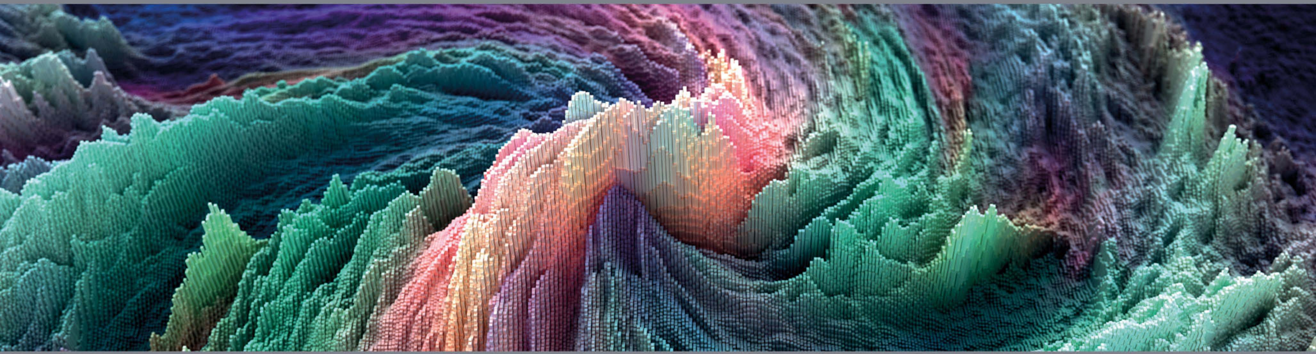
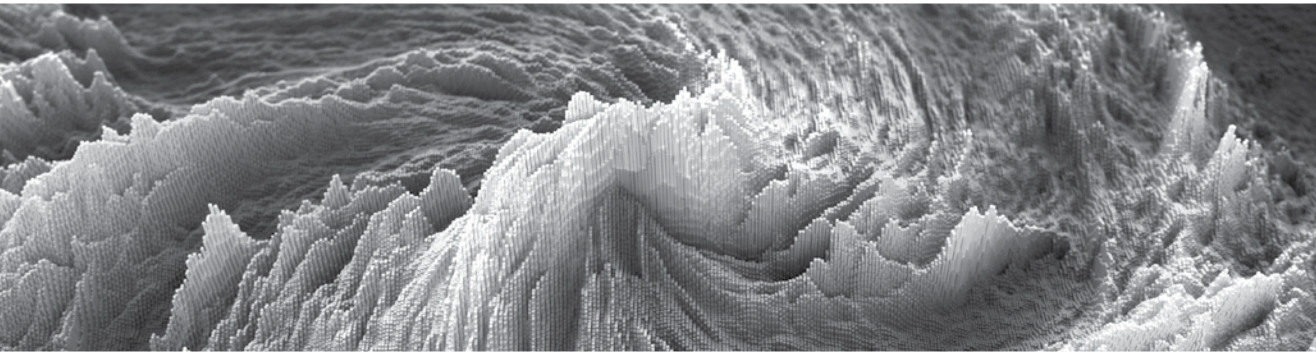
The SAGE Handbook of
Qualitative Research Ethics



Edited by
Ron Iphofen and
Martin Tolich

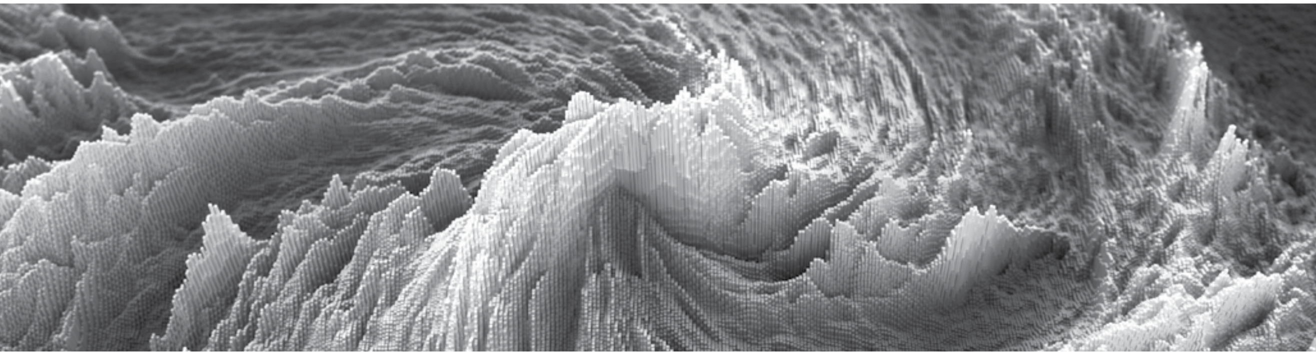
The SAGE Handbook of
Qualitative Research Ethics



SAGE was founded in 1965 by Sara Miller McCune to support the dissemination of usable knowledge by publishing innovative and high-quality research and teaching content. Today, we publish over 900 journals, including those of more than 400 learned societies, more than 800 new books per year, and a growing range of library products including archives, data, case studies, reports, and video. SAGE remains majority-owned by our founder, and after Sara's lifetime will become owned by a charitable trust that secures our continued independence.

Los Angeles | London | New Delhi | Singapore | Washington DC | Melbourne

The SAGE Handbook of
Qualitative Research Ethics



Edited by
Ron Iphofen and
Martin Tolich

SAGE reference

Los Angeles | London | New Delhi | Singapore | Washington DC | Melbourne

Los Angeles | London | New Delhi
Singapore | Washington DC | Melbourne

SAGE Publications Ltd
1 Oliver's Yard
55 City Road
London EC1Y 1SP

SAGE Publications Inc.
2455 Teller Road
Thousand Oaks, California 91320

SAGE Publications India Pvt Ltd
B 1/I 1 Mohan Cooperative Industrial Area
Mathura Road
New Delhi 110 044

SAGE Publications Asia-Pacific Pte Ltd
3 Church Street
#10-04 Samsung Hub
Singapore 049483

Editor: Mila Steele
Editorial Assistant: Colette Wilson
Production Editor: Anwesha Roy
Copyeditor: Sunrise Settings
Proofreader: Derek Markham
Indexer: Cathryn Pritchard
Marketing Manager: Susheel Gokarakondoa
Cover Design: Wendy Scott
Typeset by: Cenveo Publisher Services
Printed in the UK

At SAGE we take sustainability seriously. Most of our products are printed in the UK using FSC papers and boards. When we print overseas we ensure sustainable papers are used as measured by the PREPS grading system. We undertake an annual audit to monitor our sustainability.

Introduction, conclusion & editorial arrangement
© Ron Iphofen and Martin Tolich, 2018

Part I Introduction © Ron Iphofen and Martin Tolich, 2018
Chapter 1 © Martyn Hammersley, 2018
Chapter 2 © David Carpenter, 2018
Chapter 3 © Natasha S. Mauthner, 2018
Chapter 4 © Andrea Doucet, 2018
Chapter 5 © Mark Israel, 2018
Chapter 6 © Helen Kara, 2018
Part II Introduction © Ron Iphofen and Martin Tolich, 2018
Chapter 7 © Sara Delamont and Paul Atkinson, 2018
Chapter 8 © Karen Lowton, 2018
Chapter 9 © Anita Gibbs, 2018
Chapter 10 © Mark Edward, 2018
Chapter 11 © Penelope Kinney, 2018
Chapter 12 © Anne Harley and Jonathan Langdon, 2018
Chapter 13 © Olivia Marcus and Shir Lerman, 2018
Part III Introduction © Ron Iphofen and Martin Tolich, 2018
Chapter 14 © Jon Shefner and Zachary McKenney, 2018
Chapter 15 © Igor Gontcharov, 2018
Chapter 16 © L.L. Wynn, 2018
Chapter 17 © Lynn Gillam and Marilys Guillemin, 2018
Chapter 18 © Gary Allen and Mark Israel, 2018
Chapter 19 © David Hunter, 2018
Part IV Introduction © Ron Iphofen and Martin Tolich, 2018
Chapter 20 © Will C. van den Hoonaard, 2018
Chapter 21 © Chih Hoong Sin, 2018
Chapter 22 © Linda Liebenberg, Michele Wood and Darlene Wall, 2018
Chapter 23 © Julie Mooney-Somers and Anna Olsen, 2018
Chapter 24 © Angel A. Escamilla García and Gary Alan Fine, 2018
Chapter 25 © Fiona Poland and Linda Birt, 2018
Chapter 26 © Emma Tumilty, Catherine M. Smith, Peter Walker and Gareth Treharne, 2018
Chapter 27 © Lucy Pickering, 2018
Part V Introduction © Ron Iphofen and Martin Tolich, 2018
Chapter 28 © Donald Matheson, 2018
Chapter 29 © Dónal O'Mathúna, 2018
Chapter 30 © Bridgette Toy-Cronin, 2018
Chapter 31 © David Calvey, 2018
Chapter 32 © Karin Olson, 2018
Part VI Introduction © Elizabeth Buchanan, 2018
Chapter 33 © Camilla Granholm and Eva Svedmark, 2018
Chapter 34 © Natasha Whiteman, 2018
Chapter 35 © Tom McDonald, Karen Joe Laidler and Marissa Dean, 2018

Apart from any fair dealing for the purposes of research or private study, or criticism or review, as permitted under the Copyright, Designs and Patents Act, 1988, this publication may be reproduced, stored or transmitted in any form, or by any means, only with the prior permission in writing of the publishers, or in the case of reprographic reproduction, in accordance with the terms of licences issued by the Copyright Licensing Agency. Enquiries concerning reproduction outside those terms should be sent to the publishers.

Library of Congress Control Number: 2017944484

British Library Cataloguing in Publication data

A catalogue record for this book is available from the British Library

ISBN 978-1-4739-7097-7

Contents

List of Figures, Tables and Boxes

FIGURES

TABLES

BOXES

Notes on the Editors and Contributors

THE EDITORS

Ron Iphofen is an Independent Research Consultant, a Fellow of the UK Academy of Social Sciences (AcSS), the Higher Education Academy and the Royal Society of Medicine. Since retiring as Director of Postgraduate Studies in the School of Healthcare Sciences, Bangor University, North Wales, his major activity has been as an adviser to the European Commission (EC) on both the 7th Framework Programme (FP7) and Horizon 2020. His consultancy work has covered a range of research agencies (in government and independent) across Europe. He was Vice Chair of the UK Social Research Association and now convenes their Research Ethics Forum. He was scientific consultant on the EC RESPECT project – establishing pan-European standards in the social sciences. He has advised the UK Research Integrity Office; the National Disability Authority (NDA) of the Irish Ministry of Justice; and the UK Parliamentary Office of Science and Technology among many others. He founded, with colleagues, a UK Academy of Social Sciences Working Group on generic principles in research ethics. Ron is founding Executive Editor of the gerontology journal *Quality in Ageing and Older Adults*. He published *Ethical Decision-Making in Social Research: A Practical Guide*, with Palgrave Macmillan (2009/2011). He is Executive Editor of a book series for Emerald publishing: *Advances in Research Ethics and Integrity* and edited Volume 1 in the series: *Finding Common Ground: Consensus in Research Ethics Across the Social Sciences* (2017).

Martin Tolich is an Associate Professor at the University of Otago, New Zealand teaching research ethics and research methods in the Sociology Department. He has been a member of an ethics committee since 1995, first as the Deputy Chair of the Massey University Human Ethics Committee and later as Chair of the Multi-Region Health and Disability Ethics Committee in Wellington. In 2008 he founded an independent ethics committee, the New Zealand Ethics Committee that provides ethics review for any researcher not eligible for formal review from either the health and disability ethics committee or a university institutional ethics committee. He characterises this ethics committee as a non-hierarchical powerless ethics committee (see, Tolich, M. & Marlowe, J., 2016, ‘Evolving power dynamics in an unconventional, powerless ethics committee’, *Research Ethics*). Martin’s first degrees were from the University of Auckland and his 1991 doctorate on the commodification of emotion was awarded from the University of California, Davis. His interest in workplace power relations has gradually transformed over time to exploring power imbalances between researchers and their participants, and equally, between ethics committees and their applicants. In 2012 he was awarded a blue-skies three year Marsden Grant from the Royal Society of New Zealand to study tensions around ethics review (REBs) and indigenous (Maori) Consultation. His recent books are: with Joan Sieber, *Planning Ethically Responsible Research* (Sage, 2013); with Barry Smith, *The Politicisation of Ethics Review in New Zealand* (Dunmore, 2015); and a text he edited, *Qualitative Ethics in Practice* (Routledge, 2015).

THE CONTRIBUTORS

Gary Allen is a Senior Consultant with Australasian Human Research Ethics Consultancy Services (AHRECS) and a Senior Policy Officer (Research Ethics and Integrity) at Griffith University. He has a degree in education and a doctorate in social science. Gary received an Outstanding Thesis Award (QUT/Queensland University of Technology) for his work on constructive intuitional approaches to ethical practice in human research. He also received a national Carrick Citation for his contribution to postgraduate learning. Gary was a member of the Australian Health Ethics Committee of the National Health and Medical Research Council for the 2012–2015 triennium. He is a member of the Australian committee reviewing the National Statement on Ethical Conduct in Human Research and chaired the committee working on a new Chapter Three of the National Statement. Gary has delivered research ethics and research integrity workshops in Australia, Canada, England, New Zealand and Vietnam. He has conducted consultancy work for a number of government departments, government agencies, research bodies and a range of higher education institutions and health authorities.

Paul Atkinson is Emeritus Professor of Sociology at Cardiff University. He is a Fellow of the Academy of Social Sciences and a Fellow of the Learned Society of Wales. Together with Sara Delamont he was founding editor of the journal *Qualitative Research*. His recent books include *For Ethnography* (Sage, 2014) and *Thinking Ethnographically* (Sage, 2017). The fourth edition of Hammersley and Atkinson, *Ethnography: Principles in Practice* (Routledge) is in preparation.

Linda Birt is a Senior Research Associate in the School of Health Sciences at the University of East Anglia (UEA), UK. As a social scientist she has a specific interest in how the processes of qualitative research can provide opportunities to include some of the most vulnerable people in research, not only as participants but as active members of the research community. Most recently she has been working with people with dementia involving them as co-researchers. She has extensive experience of working with older people through her nursing career and through post-doctoral studies exploring the everyday experiences of people living with lifelong conditions and their carers.

Elizabeth Buchanan is Endowed Chair in Ethics and Director of the Center for Applied Ethics at the University of Wisconsin-Stout. She is currently acting Director of Research Administration, where she oversees the Institutional Review Board (IRB), Animal Care and Use Committee (IACUC), Institutional Biosafety (IBS), research misconduct and grants and contracts. Elizabeth's research focuses on the intersections of research ethics and regulations in internet research. She has published and presented extensively in these areas over the past twenty years and continues to explore emerging domains that confound both researchers and IRBs, such as big data, data sharing and scientific freedom. Some highlights from Elizabeth's work include her first anthology in 2003, her 2006–2010 National Science Foundation-funded research on IRBs and Internet research, her 2012 contributions to the Secretary's Advisory Committee to the Office of Human Research Protections entitled 'Recommendations on Internet Research', and to the Association of Internet Researchers' 'Ethics Guidelines for Internet Research'. Elizabeth is actively involved with PRIM&R (Public Responsibility in Medicine and Research), having served as conference faculty, member of the planning committee, co-chair of the SBER (Social, Behavioral, and Education Research) conferences in 2015 and 2017 and member of the Board of Directors. Elizabeth has also been a member of the American Association for the Advancement of Science Committee on Scientific Freedom and Responsibility since 2012. Finally, in a different vein, Elizabeth is currently co-Principal Investigator on her fourth National Science Foundation grant, which is examining the ethics of humanitarian service learning programmes in institutions of higher education. She holds BA degrees from Rutgers University and her MA and PhD from the University of Wisconsin-Milwaukee.

David Calvey is a Senior Lecturer in Sociology at the Manchester Metropolitan University (MMU). Prior to working at MMU he held teaching and research positions at the University of Manchester, Liverpool John Moores University, The Open University, in the UK, and was a Visiting Fellow at the University of Queensland. His publications and research interests span ethnography, covert research, humour studies, martial arts, ethnomethodology, organisational creativity, violence, private security and the night-time economy. He is a member of the British Sociological Association (BSA) and a Fellow of the Higher Education Academy (HEA). His recent book is *Covert Research: The Art, Politics and Ethics of Undercover Fieldwork* (Sage, 2017).

David Carpenter is Senior Lecturer in Moral and Political Philosophy at the University of Portsmouth, UK; he researches in the broad field of research ethics. He is a long-standing chair of an NHS Ethics Committee and regularly contributes to the work of the Health Research Authority in training and research projects. He was Vice Chair of the former Association for Research Ethics, which is now part of the Association for Research Managers and Administrators; he continues to provide training to university research ethics committees, under its auspices. He is a member of the British Psychological Society Ethics Committee. His current research interests centre on the understanding of the philosophical foundations of research ethics from the perspectives of researchers, research participants and ethics committees; in this regard he has a particular interest in the application of virtue ethics. He is currently engaged as an ethics adviser to a Department for International Development (DFID)-funded project in South Asia, exploring links between women's economic empowerment and violence; the focus of his work is on the application of virtue ethics in this large-scale ethnographic project.

Marissa Dean was a Researcher and Lecturer in the Sociology Department at the University of Hong Kong from 2006–2016, from where she received her PhD in 2007. Her area of interest lies in exploring the interaction between gender and information technology against the backdrop of globalisation.

Sara Delamont is Reader Emerita in Sociology at Cardiff University. She was the first woman president of the British Educational Research Association in 1984, and she has been given Lifetime Service awards by the British Education Research Association (BERA) and by the British Sociological Association. Her most recent books are *Key Themes in the Ethnography of Education* (Sage, 2013) and *Embodying Brazil: An Ethnography of Diasporic Capoeira* (co-authored, Routledge, 2017). She is a Fellow of the Academy of Social Sciences and a Fellow of the Learned Society of Wales.

Andrea Doucet is the Tier 1 Canada Research Chair in Gender, Work and Care and Professor of Sociology and Women's and Gender Studies at Brock University in the Niagara region of Canada. She has published widely on care, fathering, parental leave policies, embodiment, feminist methodologies and epistemologies and knowledge making practices. She is the author of *Do Men Mother*? which was awarded the John Porter Tradition of Excellence Book Award from the Canadian Sociological Association (second revised edition, University of Toronto Press, 2018). She is also the co-author (with Janet Siltanen) of *Gender Relations in Canada: Intersectionality and Social Change* (Oxford University Press, 2017) and co-editor (with Nancy Arden McHugh) of a forthcoming edited collection on Lorraine Code and ecological thinking (SUNY Press). She is the Director of the Brock Research Studio on Narrative, Visual, and Digital Methods and a founding member of Brock's Social Justice Research Institute.

Mark Edward is a pracademic and a category dodger. His work is interdisciplinary and explores the intersections between live art, contemporary dance performance, dance theatre and drag queen immersive and guerrilla art practices. Mark is Reader in Dance and Performance at Edge Hill University, Lancashire, UK, a Fellow of the Higher Education Academy and is a board member of both the Performing Arts Departmental Ethics Committee and the Research Committee at Edge Hill University. He has worked for Rambert Dance, Senza Tempo Dance Theatre Company and with the American performance artist Penny Arcade. Mark's principal research areas include gender, sexuality, ageing and wellbeing in performance. At the core of his investigations is the idea of self in research, or, as Mark puts it, 'mesearch'. With a commitment to inclusivity and equality in performing arts, Mark has also researched on mental illness and performance making, boys and men in dance, and queer and class. He is the author of *Mesearch and the Performing Body* (2018, Palgrave Macmillan) and is currently collaborating with Dr Stephen Farrier on an edited volume on drag queens and kings in relation to performance, identity, activism and queer lives.

Gary Alan Fine is the James E. Johnson Professor of Sociology at Northwestern University, Evanston, Illinois. For the past forty years, he has observed the lifeworlds of children and adolescents, examining Little League baseball, fantasy role-playing games and high school debate. He is the author with Kent Sandstrom of *Knowing Children: Participant Observation with Minors* (Sage). Most recently he has examined MFA students in visual arts programmes.

Angel A. Escamilla García is a doctoral student at Northwestern University, Evanston, Illinois. His research focuses on children and youth living in high-risk environments. His most current research uses ethnographic methods to explore the strategies that Central American children and youth use to migrate through Mexico on their way to the United States.

Lynn Gillam is an ethicist with a background in philosophical bioethics, who works extensively in both research ethics and clinical ethics. She is Professor in Health Ethics in the Melbourne School of Population and Global Health at the University of Melbourne and Chair of the University of Melbourne Central Human Research Ethics Committee. She has undertaken a large body of qualitative research related to research ethics practice. Lynn is also Academic Director of the Children's Bioethics Centre at the Royal Children's Hospital Melbourne, where she leads a clinical ethics case consultation service and conducts research into various aspects of the ethics of health care for children and adolescents.

Igor Gontcharov is Member of the University Health Network Rehabilitation Medicine and Science Research Ethics Board in Toronto and Post Doctoral Fellow at the Gilbrea Centre for Studies in Aging at McMaster University in Hamilton, Canada. His research interests include sociology and ethnography of law and knowledge production, science policy and ethics, standard setting in research involving humans, and the governance of alternative, independent and community-based research. He received his LLM and PhD from Osgoode Hall Law School. His doctoral dissertation (2016) is titled *Mandated Ethics: The Limits of Regulatory Innovation in Research Involving Humans*.

Anita Gibbs is Associate Professor in the areas of criminal justice, sociology and social work at Otago University, New Zealand. She is also an adoptive parent of two sons born in Russia and they like to collaborate with her research and presentations. Anita's research interests span mental health, neuro-disabilities, social work research methods and parenting children with special needs. Anita also participates actively in the professional caregiving community in New Zealand.

Camilla Granholm holds a PhD in social work and works as a Lecturer in social work at the Swedish School of Social Science at the University of Helsinki. Her research focuses on applying digital tools in social work practice.

Marilys Guillemin is a sociologist of health and illness and Professor in the Centre for Health Equity, School of Population and Global Health at the University of Melbourne. She has published widely in the areas of sociology of health, illness and technology, innovative research methodologies, research practice, narrative ethics, and ethical practice in research and in health care. She has completed a number of key research projects that include: the management of menopause within specialised clinic settings; mid-age women and heart disease particularly focusing on women's understanding of risk and prevention of heart disease; deafness and genetic testing; research on how ethics committee members and health researchers understand research ethics and how they address ethical issues in practice; and the role of trust in human research from the perspectives of researchers and research participants. Marilys has also undertaken research and published widely in the area of visual and sensory methodologies. She is particularly interested in the ethical and methodological challenges of visual research.

Martyn Hammersley is Emeritus Professor of Educational and Social Research at The Open University, UK. He has carried out research in the sociology of education and the sociology of the media. However, much of his work has been concerned with the methodological issues surrounding social enquiry. He has written several books, including: *Ethnography: Principles in Practice* (3rd edition, with Paul Atkinson, Routledge, 2007); *Educational Research Policymaking and Practice* (Paul Chapman, 2002); *What is Qualitative Research?* (Bloomsbury, 2012); *The Myth of Research-Based Policy and Practice* (Sage, 2013); and *The Limits of Social Science* (Sage, 2014).

Anne Harley is a Lecturer in Adult Education in the School of Education, University of KwaZulu-Natal (UKZN) in South Africa. She teaches and supervises in the field of adult education and participatory development at both undergraduate and postgraduate level. Working in a critical frame, Anne is interested in issues relating to 'development' and, in particular, the relationship between 'development' and the poor; in gender issues; in environmental justice issues; and in the possibilities for change through genuinely grassroots social movements and their thinking and learning. She has researched and published in all of these areas. She heads up the Paulo Freire Institute-SA at UKZN.

David Hunter is Associate Professor in Medical Ethics, Southgate Institute for Health, Society and Equity, Flinders University, Adelaide. He is a philosopher by background and training. He has taught, worked and sat on research ethics committees in New Zealand, Northern Ireland, England and Australia. A major focus of his research is regarding the regulation of research and its justifiability (or lack thereof). He is a co-author of the European Commission (EC) *European Textbook on Ethics in Research.*

Mark Israel is a Senior Consultant with Australasian Human Research Ethics Consultancy Services (AHRECS) and Adjunct Professor at Flinders University, Adelaide and the University of Western Australia. He has a degree in law and postgraduate qualifications in sociology, criminology and education. He has published over 70 books, book chapters and journal articles in the areas of research ethics and integrity, criminology, socio-legal studies, higher education and research policy, political exile and migration. Sage published his book on *Research Ethics and Integrity for Social Scientists: Beyond Regulatory Compliance* in 2015. Mark is a Fellow of the UK Academy of Social Sciences. He has undertaken research ethics and research integrity consultancy for, among others, Australian State and Federal governments, the National Health and Medical Research Council, the Commonwealth Scientific and Industrial Research Organisation and a range of higher education institutions, health authorities and NGOs in Australia, New Zealand, Taiwan and Hong Kong. He also acts as an ethics reviewer for the European Research Council.

Helen Kara has been an independent researcher since 1999 and writes and teaches about research methods. She is the author of *Creative Research Methods in the Social Sciences: A Practical Guide* (Policy Press, 2015) and *Research and Evaluation for Busy Students and Practitioners: A Time-Saving Guide* (2nd edition; Policy Press, 2017). In 2015 Helen was the first fully independent researcher to be conferred as a Fellow of the UK Academy of Social Sciences (AcSS). She is also a Visiting Fellow at the UK's National Centre for Research Methods. She is the author of *Creative Research Methods in the Social Sciences* (Policy Press, 2015), *Research and Evaluation for Busy Students and Practitioners* (2nd edition; Policy Press, 2017) and *Research Ethics in the Real World* (Policy Press, 2018).

Penelope Kinney, MOccTher, NZROT, is a Senior Lecturer at the School of Occupational Therapy, Otago Polytechnic, New Zealand. Penelope is currently completing her PhD exploring how clients psychologically adapt to living in the community after spending significant time within forensic psychiatric hospitals. Her research interest in this transition process has arisen from her time as the occupational therapist within a regional forensic psychiatric service. Penelope's research interests include the use of walking interviews, transition experiences, forensic psychiatric populations and ethical research. Penelope has presented papers on her use of the walking interview at a number of international conferences.

Karen Joe Laidler is Professor of Sociology and Director of the Centre for Criminology at the University of Hong Kong. Her research focuses on drugs, youth gangs, and gender and crime. As a native San Franciscan, she has been involved in criminological research since the 1980s, working with non-profit organisations and government agencies in Northern California. She moved to Hong Kong in the 1990s and has followed the changes in the city's drug market over the past two decades. Her recent projects include a study on how young people obtain their drugs, drug use and risks among young gay men, and parallel trading between Hong Kong and mainland China and its implications for identity politics.

Jonathan Langdon is an Associate Professor in the Development Studies Program and Adult Education Department at St Francis Xavier University, Nova Scotia. He received his PhD in International Development & Adult Education from McGill University, Montreal. He holds a

Social Science and Humanities Research Council Insight Grant supporting participatory research concerning learning in social action in the Songor, in southern Ghana and Gbane in northern Ghana. He has published a book *Indigenous Knowledges, Development and Education* (Sense Publishers) and has authored articles in several journals including the *Canadian Journal of Development Studies*, *McGill Journal of Education*, *Interface: A Journal for and About Social Movements*, *Action Research* and *Studies in the Education of Adults* (UK). Most recently, he and Songor movement members produced a collectively written book, *The Struggle of the Songor Salt People* (Comboni, Ghana) that uses oral testimony to share the people's story of the Songor. In Nova Scotia, he sits on the coordinating committee of the Nova Scotia Fracking Research and Advocacy Coalition (NOFRAC) and is a member of Responsible Energy Action (REA). Jonathan is the Canada Research Chair in Sustainability and Social Change Leadership.

Shir Lerman, PhD, MPH, is a Postdoctoral Fellow in Prevention and Control of Cancer Training in Implementation Science at the University of Massachusetts Medical School. Trained as a medical anthropologist, her research centres on chronic illness syndemics in Puerto Rico, particularly framed within Puerto Rico's political and economic crises. More broadly, her research focuses on mental health, syndemics, and structural inequalities in ethnic minorities and is the coeditor on two volumes on stigma syndemics. She also conducts research on mindfulness in underserved communities and on the Zika virus in Puerto Rico.

Linda Liebenberg is an independent researcher and evaluator with a core interest in children and youth with complex needs and the communities they live in. Her work explores the promotion of positive youth development and mental health through civic engagement and community development, focusing often on initiatives driven by organisations and service providers. As a key component of this work, Linda reflects critically on how best to conduct research and evaluations with children and their communities, including participatory action research using image-based methods; sophisticated longitudinal quantitative designs; and the design of measurement instruments used with children and youth across multiple cultures. Linda consults internationally with organisations such as the WHO, the World Bank and Save the Children, Denmark. She has presented internationally and published extensively on these topics of research and youth.

Karen Lowton is Professor of Sociology (Ageing & Health) at University of Sussex, UK. Her teaching and research expertise centres on using qualitative methods to investigate sensitive issues of ageing, health and dying with people in positions of vulnerability. She served as a member of King's College London's Research Ethics Committee, is a member of University of Sussex's Cross-Schools Ethics Committee, and provides research method and ethics support to organisations including Médecins Sans Frontières. Karen's main research interest is in the care and experiences of 'new' ageing populations; that is, groups of people growing older due to medical innovations that have rescued them from a historically certain early death.

Olivia Marcus, MPH, is a current doctoral student in Medical Anthropology at the University of Connecticut. Her research investigates how rising global interest in traditional Amazonian healing techniques contributes to changes in practice and perceptions of mental health care in the Peruvian Amazon. Before she began her training as an anthropologist, her research focused on prevention of HIV/AIDS and on sexual health. Her continued interest in the social nature of infectious disease led her to co-author several papers on ethnomedical and social media effects of the 2014/2015 outbreak of the Ebola virus.

Donald Matheson is Associate Professor in Media & Communication at the University of Canterbury, New Zealand. He is currently working in two areas: corpus-assisted discourse analysis of social media and the ethics of journalism in social media. Donald is the author of two books, *Media Discourses: Analysing Media Texts* (Open University Press) and *Digital War Reporting* (Polity Press) and joint editor of *Ethical Space: The International Journal of Communication Ethics*.

Natasha S. Mauthner is Professor of Social Science Philosophy and Method at the University of Aberdeen Business School; Associate Director of the Scottish consortium Centre for Research on Families and Relationships; and a Fellow of the Academy of Social Sciences. Her work seeks to articulate a posthumanist philosophy, methodology, ethics and politics of social science drawing on feminist philosophy of science, feminist science studies, new materialist philosophies and poststructuralism. She has written extensively on research governance and data sharing in the social sciences; on the philosophy and methodology of qualitative inquiry including feminist research; and on work, parenting and family life, and its intersections with gender, mental health and emerging technologies. She is author of a monograph with Harvard University Press (*The Darkest Days of My Life: Stories of Postpartum Depression,* 2002).

Tom McDonald is an Assistant Professor at The University of Hong Kong. He obtained his PhD from University College London in 2013, where he also worked on the Why We Post project, a European Research Council funded global comparative ethnographic study exploring the impact of social media use across a range of different societies. He has conducted extensive ethnographic research in rural China. His first solely-authored monograph, *Social Media in Rural China: Social Networks and Moral Frameworks* (UCL Press), was published in 2016. He also co-authored the volume *How the World Changed Social Media* (UCL Press). McDonald is currently working on a new project investigating the use of digital money by migrant workers in China.

Zachary McKenney is a PhD candidate in Sociology at the University of Tennessee. His research interests include political economy and globalisation, social movements and labour movements, cross-movement mobilisation and political sociology.

Julie Mooney-Somers is a Senior Lecturer in Qualitative Health Research at Sydney Health Ethics, University of Sydney. An experienced qualitative researcher and supervisor, she has taught qualitative research to community members, undergraduate and postgraduate students and professional researchers for over a decade (including six years as Director of the Master of Qualitative Health Research). She was a member of a community-based ethics review committee for six years. Julie uses qualitative and participatory methodologies to examine equity in health and health services in relation to sexuality, gender, indigenous status and youth. With colleague Anna Olsen, she is currently exploring the understandings and practices related to the legal limits of participant confidentiality.

Anna Olsen is a Senior Lecturer at the Research School of Population Health, Australian National University, Canberra. She leads a number of qualitative and mixed-methods public health research projects and has published in the fields of illicit drug use, women's health, Aboriginal and Torres Strait Islander health and family violence. Anna regularly partners with community organisations and is interested in the methodological and ethical practices of participatory research. She teaches qualitative research methods, supervises post-graduate students and is an experienced member of university and hospital human research ethics committees.

Karin Olson, RN, PhD, is a Professor in the Faculty of Nursing at the University of Alberta, where she also holds a cross-appointment to the Division of Palliative Medicine in the Faculty of Medicine and Dentistry; is a Distinguished Scholar at the International Institute for Qualitative Methodology; and is the Education Director of the Integrative Health Institute. Her research programme focuses on symptom management in individuals with advanced cancer.

Dónal O'Mathúna has degrees in pharmacy and in ethics and is Associate Professor at Dublin City University, Ireland and The Ohio State University, USA. He is involved in evidence-based practice in the Cochrane Collaboration and was Director of Cochrane Ireland (2013–2017). His research interests focus on ethical issues in disaster research and humanitarian responses. From 2012–2016, he led an EU-funded COST Action on Disaster Bioethics (http://DisasterBioethics.eu), he is an investigator on funded qualitative disaster research projects and is the Director of the Center for Disaster and Humanitarian Ethics (www.ge2p2.org/cdhe). He has contributed to ethics initiatives with international organisations like WHO, UNICEF and UNISDR and spoken and published widely on these topics, including co-editing *Disaster Bioethics: Normative Issues When Nothing is Normal* (Springer, 2014).

Lucy Pickering is a Lecturer in Medical Anthropology at the University of Glasgow. She has worked in Hawai'i and the United Kingdom, working with active and former drug-users in a range of settings relating to recreational and problem drug use. She has been the Ethics Officer for the UK and Commonwealth's Association of Social Anthropologists since 2012.

Fiona Poland is a sociologist and Professor of Social Research Methodology at the University of East Anglia (UEA), UK. Her career concern has been to develop and use qualitative research methods to address the health and wellbeing concerns of individuals and communities particularly older people including people with dementia and carers. She seeks to promote collaborations and respectful working across voluntary, statutory, academic and policy boundaries. She is journal editor of *Quality in Ageing and Older Adults*.

Jon Shefner is the Betty Lynn Hendrickson Professor of Social Science and Head of the Department of Sociology at the University of Tennessee. His areas of specialisation include political economy, globalisation and development, field methods, social movements, political sociology and social movements. He is the author of *The Illusion of Civil Society: Democratization and Community Mobilization in Low Income Mexico* (The Pennsylvania State University Press, 2008) and co-editor of six other books including *Global Connections and Local Receptions: New Latino Immigration to the Southeastern US* (with Fran Ansley, University of Tennessee Press, 2009) and *Globalization and Beyond: New Examinations of Global Power and Its Alternatives* (with Patricia Fernández-Kelly, The Pennsylvania State University Press, 2011). His current research agenda focuses on austerity protest and austerity as a failed global policy.

Chih Hoong Sin is Director of OPM Group, the UK's first public interest company, working with others to improve social outcomes in public services. He is passionate about all aspects of equality and diversity, and is very experienced in issues relating to ‘race’/ethnicity, aging and disability. Chih Hoong was, previously, Head of Information and Research at the former Disability Rights Commission, Great Britain. He is a recognised expert on disability hate crime, and has directed numerous studies on this subject, including the major report on disabled people’s experiences of targeted violence and hostility, commissioned by the Equality and Human Rights Commission, Great Britain. Chih Hoong has written about ethical research practice with older people, children and disabled people.

Catherine M. Smith is a Lecturer at the School of Physiotherapy at the University of Otago, New Zealand. She leads a human-animal interaction research programme about the health and wellbeing benefits of dog-walking. She chairs the School of Physiotherapy Ethics Committee and is a member of the New Zealand Ethics Committee.

Eva Svedmark holds a PhD in Informatics. She is currently Director at the Centre for Educational Development at Umeå University, Sweden. Her research focuses on human and posthuman relations within social media, technoemotions and feminist technoscience.

Bridgette Toy-Cronin is a Senior Lecturer and Director of the Legal Issues Centre at the Faculty of Law, University of Otago, New Zealand. Her primary research interests are access to justice, socio-legal research methods, civil procedure and the legal profession. Before beginning a doctorate she practiced as a human rights lawyer and civil litigator. She completed her PhD entitled *Keeping up Appearances: Accessing New Zealand’s Civil Courts as a Litigant in Person* in 2015.

Gareth Treharne is a Senior Lecturer in the Department of Psychology at the University of Otago, New Zealand. He is an Associate Fellow of the British Psychological Society and the current Vice-Chair of the International Society of Critical Health Psychology. He has a diverse programme of research collaborations grounded in the principles of social justice as applied to health, sexuality and ethnicity.

Emma Tumilty is a Postdoctoral Fellow at the Institute for Translational Sciences in Research Ethics at the University of Texas Medical Branch and an Adjunct Research Fellow in the Department of General Practice and Rural Health at the University of Otago, New Zealand. She has a PhD in Bioethics and has experience as a member and Vice-Chair of research ethics committees/institutional review boards.

Will C. van den Hoonaard of the University of New Brunswick (UNB), Canada, has authored or edited a dozen books on a wide range of topics, including a 700-year history of women in cartography, the Bahá’í Community of Canada, ethnicity, marine resource management in Iceland, and a textbook on sensitising concepts. *National Geographic* featured his research on cartography and his work in Iceland was plotted in an Icelandic novel. He also recently authored a children’s book on the childhood of a Persian prophet. He devotes much attention to exploring ethics in research. His University of Toronto trilogy (*The Ethics Rupture*, 2016; *The Seduction of Ethics*, 2011; *Walking the Tightrope*, 2002) constitute a critical analysis of research ethics regimes. With his wife Deborah, he authored *Essentials of Thinking Ethically in Qualitative Research* (Routledge, 2013). He is Founding Member of Canada’s Panel on Research Ethics. The Health Improvement Institute honored him with an Award for Lifetime Achievement for Excellence in Human Research Protection. He holds the UNB President’s

Medal, a Merit Award and the United Nations Association of Canada Global Citizen Award. Born in the Netherlands, he lived as a child in a cave in France, worked as receptionist in the European Patent Bureau, and, not finishing high school, migrated to Canada, where he worked in a goldmine in Canada's Northwest Territories. He obtained a PhD in Sociology at the University of Manchester.

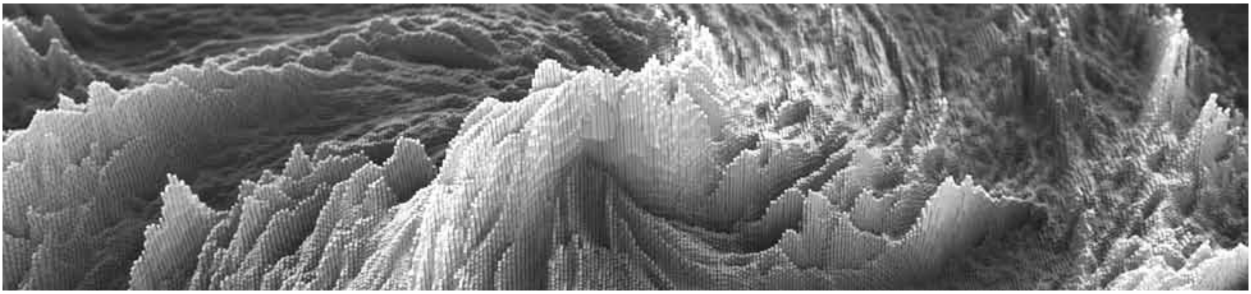
Peter Walker is a Senior Lecturer with Sociology, Gender and Social Work at the University of Otago, New Zealand. His practice background is within community-based organisations and Community Law Centres while his research interests are community development, organisational understandings of the third sector and the utilisation of animals within social service provision.

Darlene Wall is an Indigenous woman from Happy Valley-Goose Bay, Labrador, Canada and is the Social Sector Manager at the NunatuKavut Community Council (NCC). She holds a wide and varied portfolio that includes research, policy, programme development and management. As an active community-based researcher and educator, Darlene is involved in numerous projects that address the social determinants of health and aim to improve the health and wellness outcomes of members in her community. Darlene's focus is on community-based health promotion initiatives as evidenced by her involvement in projects addressing oral health, HIV/AIDS, diabetes, homelessness, poverty, drug use, mental health, identity, traditional knowledge and youth resilience. Through her integrative and holistic approaches, Darlene has facilitated numerous relationships and partnerships between communities, universities, governments and industries that contribute to a vibrant NunatuKavut community. Darlene's emphasis on community-based participatory research and Indigenous methodologies have positioned her well in the role as Chair of the NCC Research Advisory Committee. She is also actively involved in a variety of current research projects as a participant, facilitator, collaborator and partner.

Natasha Whiteman is Lecturer in Media and Communication at the University of Leicester, UK. Her research focuses on ethical issues relating to media research, digital environments and media consumption activity, with a particular interest in the study of online fan cultures. She is the author of *Undoing Ethics: Rethinking Practice in Online Research* (Springer, 2012).

Michele Wood is employed by the Nunatsiavut Government, Department of Health and Social Development, located within the province of Newfoundland and Labrador, Canada. Her responsibilities include liaising with governments and Aboriginal groups to facilitate intergovernmental cooperation and development for health policies and research. She is particularly interested in addressing aspects of food security and community wellness for the communities within the Nunatsiavut region of Labrador. Michele sits on various boards such as the Nutrition North External Advisory Board. She has a Master's degree in Information Management at Dalhousie University, Halifax, Nova Scotia. She is interested in community-based participatory research and knowledge mobilisation.

L. L. Wynn is an Associate Professor and Head of the Anthropology Department at Macquarie University in Sydney. She is the author of the book *Pyramids and Nightclubs* (University of Texas Press, 2007) and, most recently, the co-editor of *Abortion Pills, Test Tube Babies, and Sex Toys: Exploring Reproductive and Sexual Technologies in the Middle East and North Africa* (Vanderbilt University Press, 2016). She received her PhD in Anthropology from Princeton University. In Australia, her research has been supported by grants and fellowships from the Australian Research Council and the Office of Learning and Teaching.



Foundational Issues in Qualitative Research Ethics

Ron Iphofen and Martin Tolich

> Ethics is an ever-present concern for all researchers; it pervades every aspect of the research process from conception and design through to research practice, and continues to require consideration during dissemination of the results. (Goodwin et al., 2003: 567)

The pervasiveness of ethical concerns raised by Goodwin does, of course, matter to all researchers but ethics are often thought of as an even more pressing concern to qualitative researchers. Researchers dealing with quantitative data may momentarily allow a pause in their ethical reflections to handle the 'neutral' numbers, measures, or quantities they have collected; they may even allow themselves further ethical respite when reporting findings. However, the emergent, dynamic and interactional nature of most qualitative research (QR) allows of no such, even temporary, retreat from ethical responsibilities and obligations. While many SAGE Handbooks devote a chapter to ethical considerations, none compare and contrast ethical perspectives between various QR techniques. QR is sufficiently unique to require a handbook that captures its distinctive set of ethical considerations. That is what we offer here.

Qualitative research is itself transforming. In their now classic *Handbook of Qualitative Research* (now in its fifth edition 2017; first published 1994), Denzin and Lincoln characterize the history of QR as having moved through five phases or, in their terms, 'moments': from the 'traditional', to the modernist, through 'blurred genres' and a 'crisis of representation' to their fifth moment – the new age 'where messy, uncertain, multi-voiced texts, cultural criticism and new experimental works will become more common, as will more reflexive forms of fieldwork, analysis and intertextual representation' (Denzin & Lincoln, 1998: 30). They strive to depict a 'sixth moment' but 'There is an elusive center to this contradictory, tension-riddled enterprise … [which] … lies in the humanistic commitment of the qualitative researcher to study the world always from the perspective of the interacting individual' (Denzin & Lincoln, 1998: 407). Given the nature of this 'contradictory, tension-riddled enterprise' it is perhaps foolhardy to attempt both any historical characterization or, more seriously, any anticipation of what the future might hold. But with such illustrious precursors we cannot be blamed for trying: will 'creative research' continue to blur the boundary between QR, art, literary endeavour and journalism? Just how collaborative can ethnography ever be? Does endowing the participant as 'co-researcher' with credit and status make them an authentic researcher? Do post-modern interviews pose genuinely new challenges? And is urban exploration or 'place hacking' really ethnographic?

The many innovative developments in qualitative methodologies explain why QR ethics deserves attention of its own. As research funding diminished globally, QR found itself having to defend its 'worthiness'. The false competition with quantitative data analysis to measure impact has, in turn, been driven by the evidence-based practice/policy movement. Paymasters increasingly require countable outcome measurement. In delivering 'objective numbers' quantitative research has often been privileged over qualitative methods, and this is by no means merely a matter of methodological competition. It is distinctly unethical to only proffer research outcomes that purport to measure impact when all measurement is subject to limitations and an entire swathe of qualitatively-oriented approaches to understanding the world, communities and society is sidelined. More problematic is the danger that in such a 'hierarchy of evidence' approach, gold-standard randomized controlled trials (RCTs) are placed at the pinnacle – an approach that can challenge ethical concerns if misapplied, or applied in the wrong context.

It is not that QR could not 'employ' experimental designs and enhance 'measurement value' – rather that it is probably not appropriate that it should be an RCT (Iphofen, 2012). Similarly, it is not that research outputting qualitative data is not subject to systematic review; rather it *need not* nor *cannot* aspire to meta-analysis and instead should seek to progress via interpretive review processes (Dixon-Woods, 2005).

This introduction to the *Handbook* is organized around five broad themes. We begin by examining the values that underpin research in general and then qualitative research more specifically. Second, we take a broad historical review of the epistemology that underpins qualitative research. Third, we position qualitative research historically against the hegemony of the dominant biomedical model. The fourth theme explores the generic concepts of 'do no harm', informed consent, confidentiality as they are manifest in qualitative research. The final theme examines the diversity of qualitative research techniques and how each produces its unique form of ethical considerations and assurances. Together these five themes go a long way to fulfil Harry Torrance's expectation that 'the very act of compiling a Handbook implies an aspiration to attempt to define the field' (2010: xxv).

I: VALUES, PRINCIPLES AND STANDARDS

Lying behind the principles and standards that apply to research practices of all kinds are values. Values refer to things of importance which are seen to matter and as worth upholding or preserving. Some values are personal so they vary between individuals and, more importantly, they are known to vary across cultures and social groupings. We might hope that some values are universal (such as the ones that 'we' hold dear), but we cannot and should not assume they are. Values are generally regarded not to arise instinctively or in relation to some physiological need, instead they are treated as subjectively derived and affirmed. But even here the source of values is contentious – the avoidance or seeking of pain; self-preservation or altruism; courage or cowardice – could be socially, psychologically and/or bio-physiologically generated. What matters is how those preferences concerning appropriate courses of action, those beliefs about what might be considered ‘right’ or ‘wrong’ or the way things ‘ought’ to be, influence what we conduct research into and how that research is conducted. Equality, respect, dignity are all values which may influence our attitudes and behaviour. These become incorporated into belief structures that then inform the principles we apply to daily life and to our research work. We are motivated to action by our values but constrained in what we can do fully by ethics – which entails the recognition that not everyone shares our values. Ethical considerations require us to respect others’ values. Principles inform our constraints on reciprocal behaviour – in this case, what we can allow ourselves to do when researching other people, who may or may not share our values.

Values and principles combine to set standards for our behaviour and this becomes particularly apt in conducting QR. In many forms of research, engagement values and principles can be assumed or ignored. However, we fundamentally undermine the ethos of QR if we fail to respect the values and principles of those we study. They may even be the substance of our study. Put simply: ‘A principle is a general statement, adherence to which determines the way we view the phenomena we study. … A principle is a statement whose falsity we are not likely lightly to admit’ (Harré, 1970: 206).

At the same time as we cherish and guard our own values and principles, we must be prepared for them to be examined and tested against others’ values. The fundamental ethical dilemmas to be confronted in QR relate to that balance between our own ethics and those of the people we are studying. We may assume concepts such as fairness, justice, equality, truthfulness, and honesty, as universal and as guiding our stand on social issues or events. Yet, other people holding the same principles may have different notions of what *precisely* constitutes justice, fairness and so on. Rigid adherence to principles could pose ethical problems in QR when we fail to address or even be aware of those different notions. Confronting such dilemmas forms the core thesis of all the contributors to this *Handbook*. In advancing QR ethics even those conventional values and principles may need to be challenged. Thus, for example, if our epistemology fails to reflect modifications to what we count as ‘valid’ evidence, we have to wonder if key principles require questioning. In this introduction we hope to offer some initial thoughts about how to address some of these dilemmas.

II: EPISTEMOLOGY AS DIVERSITY

Qualitative research began first in anthropology with Malinowski’s (1935) work on the Trobriand islanders and Whyte’s (1981[1943]) *Street Corner Society*. Neither were methodological treatises (Brinkmann et al., 2014: 4) nor were they bound by extensive ethical considerations. A second beginning, and one that is important to understanding current QR ethics, was the rise of feminist research in what Denzin and Lincoln (2000: 3) label the 1950–1970 ‘golden age’ of qualitative research. Wolcott’s (2009: 8) writing in the 1990s claims not to recall any QR prior to 1960. But to neglect the contributions made by Park (Park et al., 1925) and the Chicago School, Thomas and Znaniecki (1918), Wirth (1938) and, Goffman’s (1956) ethnography of the Shetland Islands is to ignore a rich pre-1960s tradition in QR. Regardless of these precedents, the outcome of 1960s feminist research was a growth of an ethical practice less based on duty or utilitarianism but more on relationships between researcher and researched.

The birth or rebirth of QR found in Oakley’s (1999) critique of positivism led to a more egalitarian, participant-led research allowing an emergent research problem to develop that eventually generated its own ethical assurances as an ethics of care. She locates the (re-)birth of QR stemming from a feminist perspective that women's lives were [not] invisible and inconsequential. She declares that she became a feminist when interviewing women about housework in the late 1960s and early 1970s (Oakley, 1974). Employing in-depth interviewing she generated personal narratives about experiences which, at the time, were viewed within mainstream social science (and society more generally) as unimportant, being private, domestic and belonging to women's lives. One of her most quoted publications, 'Interviewing women: a contradiction in terms?' (Oakley, 1981), came directly out of the transition to motherhood research and showed how interviewing in practice, especially a woman interviewing other women, did not easily fit the textbook ideal-type mould of the interviewer as impersonal data-collector, and the interviewee as subservient data-provider. All this work fed into an emerging and highly vocal literature on social science and women, within which 'qualitative' research came to be highlighted quite unambiguously as the preferred paradigm, with 'quantitative' research being earmarked as the work of the patriarchal devil (see e.g. Mies, 1983; Stanley & Wise, 1983).

Guillemin and Gillam (2004) represent a more recent feminist paradigm change for QR and their ethics within the groundbreaking distinction between 'procedural' ethics and 'ethics in practice'. Procedural ethics refers to formal ethics review and ethics in practice represent the 'big ethical moments' that happen in the field that neither the research ethics committee (REC[1]) nor the researcher predicted during procedural ethics.

Tolich and Fitzgerald (2006) build on Guillemin and Gillam's distinction claiming that a qualitative epistemology means qualitative researchers seeking ethics review must attempt to put a round peg into a square hole. Rather than using reflexivity, Tolich and Fitzgerald (2006) suggested adapting the ethics review process to capture the emergent, iterative epistemology. They suggested the researcher adopt the role of the expert with the REC acting as the learner, and the review process being guided by four core open-ended questions that facilitate a fuller and richer exchange of information. The first three questions a REC could ask qualitative researchers were:

1. What is the research project about?
2. What ethical issues does the researcher believe are raised by this project?
3. How do the researchers plan to address these ethical problems?

Question One is what Spradley (1979) would call a 'grand tour' question, designed to elicit a verbal description of something of significance in the informant's world, in this case the person's research. Question Two tests researchers' knowledge of ethics, the methodology involved, and their interrelationship, gauging their ability to recognize the ethical problems likely to arise in the research project outlined in Question One. Question Three requires researchers to assume the expert role and to address their own problems, using imaginative solutions that show insight into the research context, the nature of the participants, and the nature of the method or methods proposed. How will the potential harm or problems identified in Question Two's response be managed or minimized? Can the researchers think critically and creatively? Do they understand the basic principles of research ethics and apply them?

A fourth question is more open-ended and put to the applicant based on the assumption that the research problem is emergent and many qualitative researchers' ethical issues are unknown at the point of final ethics approval. This question highlights Guillemin and Gillam's (2004) notion of ethics in practice. The ethics committee may ask:

4. What contingencies are in place if the research project changes its focus after the research has been approved and has begun?

This builds on the qualitative assumption that a qualitative research project is not linear but rather iterative and evolving. It assumes that QR is likely to change in design as the research problem develops and asks how the researcher plans to modify or adapt the research as it unfolds.

Together these four questions, if used in procedural ethics, would turn ethics review on its head, recognizing that ethics review is partial and can be made more transparent and meaningful for qualitative researchers. This process also makes researchers more accountable for their research's ethical considerations, both in the present and the future. With such a 'regime change' the power relations between researcher and ethics committee become shared. If ethics committees are willing to dialogue with researchers, the situation can be transformed in ways that make QR more comprehensible for the committee and enable appropriate problem solving to occur. Asking qualitative researchers the right questions is only one part of the ethics review problem. At times qualitative researchers may find themselves speaking past ethics committee members with their, perhaps less than careful, use of jargon.

Ethics in Practice is Endemic to Qualitative Research

Nearly all of our authors in the *Handbook* have pointed out that ethical issues are much harder to set out in advance in ethnographic research. The particular skills required in seeking qualitative data include balancing the control necessary for systematic and rigorous observation against allowing genuine attitudes to be revealed and the behaviour of interest to occur naturally. In this instance, what is assumed within so-called qualitative theoretical perspectives neatly meets ethical requirements – it requires that researchers don't interfere too much! The problem is how to do that in practice and ensure that the required data are actually generated – researchers cannot wait around forever for people to authentically reveal their views and/or spontaneously engage in the behaviour of interest. Many research methods are precisely designed for the attitudes, knowledge and behaviour to be generated when researchers are around to collect them. Anthropology is not like that. One of Iphofen's first undergraduate supervisors told him of his work in studying the Sami people of sub-Arctic Northern Europe. He thought he had acquired a key position in the group when they appointed him chief reindeer herdsman. Unfortunately, the reindeer and the tribe parted company for nine months of the year as the herd travelled the tundra. He learned a great deal about reindeer but much less about the Sami. So a carefully written research protocol in ethnography needs to clarify the areas of uncertainty as well as those that can be reasonably anticipated. Most importantly, the need for flexibility in approach has to be written in to the proposal and fully understood by reviewers.

Indeed, many of our authors have demonstrated the inevitability of 'interfering' in the lives of the participants to a study. The theoretical and methodological variety for conducting that interference is extremely wide. From 'Observation' through 'Participant Observation' to 'Participatory Action Research'; from iterative through interactional to intra-actional; from engagement to disengagement, from informative to performative, reflexive and more…

In all cases the 'quality' researcher is one that can judge the best balance between the data necessary to properly generate an answer to the research questions against the prospect that the gathering and reporting of such data could result in 'measurable' harm to the research subjects[2]. Justifiable design adjustments to minimize the potential for harm can still produce high quality research – but it takes a competent researcher to do that.

At times Guillemin and Gillam suggest taking evasive action during procedural ethics. Rather than hitting heads against a wall and attempting to educate RECs about the non-applicability of the term 'anonymity' for qualitative research, a useful strategy is to adopt Guillemin and Gillam's (2004: 263) suggestion of *ethics committee speak* and explain that all steps will be taken to keep the identity of the participants anonymous, even though this task is impossible. Guillemin and Gillam (2004: 263) describe this innocent subterfuge used in procedural ethics:

> Like many of our qualitative research colleagues, we diligently answer the questions on the ethics application form, even though they may be irrelevant to our research. We have learned to write our responses to the questions in 'ethics-committee speak'. This involves using language that the committees will understand, is free of jargon, but will nonetheless reassure the committees that we are competent and experienced researchers who can be trusted. This also involves explaining methodology to a committee who may be unfamiliar with qualitative methods and in some cases, may be antagonistic toward this type of research.

In some respects all researchers must 'play the game' of using the language and categories appropriate to any approval process they need to go through, whether that be in seeking funding or gaining ethics approval. All are balancing the necessary compliance relationship between autonomous research and those with the authority to prevent it. Competent rhetorical skills have long been a requirement for successful outcomes in 'science' and need not be condemned as lacking moral substance. The alternative is a constant adversarial posture in the hope that the culture of the REC will change accordingly. The next section outlines the history of how qualitative researchers engage with ethics review and why evasion might be justified.

III: QR ETHICS AND THE BIOMEDICAL MODEL AND RESEARCH GOVERNANCE

The growth of formal institutional review boards (IRBs) in the USA led to a backlash as the mismatch of social science with IRB practice became clear. Bosk and DeVries (2004) disclosed how biomedically imbued ethics oversight had contributed to a 'deep misunderstanding' by ethics committees of social science research and how social scientists manage ethics since 'ethnographic research fits this model poorly'. Ethnography does not necessarily want to test a hypothesis but to learn how people make sense of the world (Bosk & DeVries, 2004: 251–253). This divide makes explaining ethics to a committee extremely frustrating for social scientists. Moreover, Bosk and DeVries are not convinced ethics oversight leads to the protection of research subjects. 'We do not think that the system of prospective review … does much to protect subjects from harm' (2004: 259–260).

The emergence of national statements on ethics in Canada and Australia led to a significant critique from social scientists of the biomedical/positivist paradigm. In Canada, Haggerty (2004) and van den Hoonaard (2001) were vociferous in their critique of the original *Tri-Council Policy Statement* (*TCPS 1*) document. Van den Hoonaard (2001: 25) likens the social science relationship to the first *TCPS* as a moral panic occurring throughout a research ethics review. The *TCPS* relies heavily on the deductive model of research as normative, proclaiming the rest as non-normative. Epistemologically, the *TCPS 1* represented a biomedical model of research as a positivist, linear, hypothesis-driven design 'which tends to erode or hamper the thrust and purpose of qualitative research' (van den Hoonaard, 2001). This led to social sciences being colonized by a *TCPS* policy that remained alien to how many social scientists conduct research, requiring hypothesis-testing experiments rather than an iterative and emergent research design. Core ethical considerations like anonymity, the signing of consent forms, seriously disadvantaged QR in particular. Van den Hoonaard (2001: 21) questioned if it was appropriate to use the *TCPS* code to judge the ethical merit of QR by using criteria derived from other research paradigms. For example, the intimate world of qualitative research usually entails knowing the research participant(s), and the best ethical assurance researchers can give is for a degree of confidentiality and a pseudonym. Rigid enforcement that informants remain anonymous is difficult to achieve and, in context, perhaps inadvisable.

In his seminal piece on 'ethics creep' Haggerty (2004: 400) claims that the risks highlighted in the *TCPS* are exaggerated, thus leading to a

> dual process whereby the regulatory system is expanding outward to incorporate a host of new activities and institutions, while at the same time intensifying the regulation of activities deemed to fall within its ambit. The outcome is rule fetishization that has reduced the ethical review process to a form of conformity. (Haggerty 2004: 410)

The irony for Haggerty is how open-ended these rules are:

> Few of the central concepts set out in the *Policy,* including those of 'research', 'researcher', or 'harm', have clear referents that unproblematically direct how the regulations should be applied in different situations. Instead, they are empty signifiers, capable of being interpreted in a multitude of ways, and occasionally serving as sites of contestation. (2004: 411)

Iphofen's (2011) refinement of this mission creep recognizes distinctions between research ethics and research governance, the latter merely ensuring that risk is minimized to the institution. Research ethics protection of the research participant is important but only in as much that their protection ensures less chance of litigation against the institution. The biomedical model fails to address that all researchers have problems with the ethics police (Klitzman, 2011).

In contrast to Canada the US federal ethical policy was even more dismissive of QR. *The Belmont Report* (1979) defined QR as not fitting the traditional definitions of research, let alone research ethics. *The Belmont Report* deemed qualitative research a 'non-person' stating, '"research" designates an activity designed to test a hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge'. Under this definition QR's emergent research design is not research.

In Australia, Israel and Hay's (2006) critique of the biomedical hegemony of RECs began with the charge that:

> Social scientists are angry and frustrated. They believe their work is being constrained and distorted by regulators of ethical practice who do not necessarily understand social science research. (p. 1)

Here too social science, specifically QR, was as invisible as it was in Oakley's critique of positivism. In the 1999 Australian National Statement[3], qualitative research was defined in terms of what it was not. 'Any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification'. This by no means defines QR. The fundamental problem when defining QR ethics stems from qualitative research's unique epistemological research design: inductive, non-linear, emergent and iterative – producing 'idiosyncrasies' that don't fit a deductive model.

Subsequent to the Canadian critiques of the 1999 *TCPS*, the 2010 *TCPS 2* showed signs of absorbing these critiques as the nuance of qualitative epistemology is embedded in *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (*TCPS 2*). For example, section 10c under the sub-heading 'Dynamic, Reflective and Continuous Research Process' states:

> The emergence during the course of the research itself of questions, concepts, strategies, theories and ways to gather and engage with the data (e.g. emergent design research, see Article 10.5) requires a constant reflective approach and questioning by the researcher. Such flexibility, reflexivity and responsiveness contribute to the overall strength and rigour of data collection and analysis.

Even though these changes in *TCPS 2* achieve recognition of QR epistemology, social scientists remain skeptical of how much respect for humans RECs actually show. The editors of this *SAGE Handbook* participated in one such critique at the 2012 Ethics Rupture Summit held at the University of New Brunswick. This was a gathering of international scholars interested in research ethics overview. Item five of the eight-part New Brunswick Declaration highlighted the sense of a lack of respect for qualitative researchers; the codes did not reflect practice nor 'encourage regulators and administrators to nurture a regulatory culture that grants researchers the same level of respect that researchers should offer research participants'.

Stark (2012) found evidence for this disconnect between codes of ethics and REC practice. Practice she found was not only eccentric but also idiocultural. Committees rarely referred to a code of ethics preferring to establish rules based on precedent; using previous decisions made by the same REC. Some practices Stark found were irrational as RECs deem a clearly written protocol as the first indicator of rigorous research. Good grammar was seen to be an indicator of moral character. Thus, ethics applications must be proof read, as when IRBs that meet behind closed doors tend to assess applicants' trustworthiness by their syntactical skills. Grammar, typographical errors and incomplete sentences are read 'like tea leaves' for signs of good character: Stark inquired why the sloppiness of an application was relevant to an ethics review and received the response: 'If [a researcher's] attention to detail is not sufficient to know that the major heading, the words aren't spelled right, I'm worried about [other things as well like], do I have to read this thing carefully enough to make sure all the does, for example, are correct, that they have written the protocol correctly?' (Stark, 2012: 17).

IV: ETHICAL CONSIDERATIONS

a) First Do No Harm

Many research ethics texts attempt to explore the balancing of harms and benefits. We take a different tack, unbalancing the equation in favour of 'the subject'. A different assumption is to suggest that researchers assume that without benefit there should be no risk. The idea here is to think through the project before starting it with colleagues, academic supervisors and/or a REC to ensure that risks are exposed and minimized. We know that this best guess is incomplete.

The heart of ethical research and, indeed of research ethics scrutiny, is the attempt to balance the risk of harm against the potential for benefits that can accrue to individuals, groups, communities, organizations and even societies from research participation. Consideration has to be given to the different kinds of harm, the likelihood of their occurrence and the ways in which they can be minimized. Concurrently ways of maximizing both short and long-term benefits have to be explored. While it is often thought that such benefits should particularly be sought for those communities or groups considered disadvantaged and societies viewed as less developed, it is immediately evident how patronizing such a view may seem to those on the receiving end. And yet, the very essence of considering the needs of 'others' as part of ethical contemplation is necessarily patronizing.

At times it is extremely difficult to anticipate harms in spite of the conventional precautionary practices taken by even the most experienced qualitative researchers. The Boston College oral history tapes with those who had been 'activists' during the Northern Ireland 'troubles' offer a case in point (Marcus, 2012: 20). In some respects even experienced researchers can turn out to be highly naïve:

> No guarantee of confidentiality, no matter how judiciously worded or by whom, can stand under the law, so when writing up their results, researchers need to be extremely careful not to advertise to the world that they are in possession of highly sensitive 'guilty knowledge' … If they fail to be discreet, they shouldn't be surprised when the inspectors call. (Brewer, 2012: 33)

It was noteworthy that the archiving of these highly sensitive documents did not seek ethics review from the Boston College IRB. Had they done so, the limits of confidentiality of these documents would have been realized. All documents are subject to subpoena – highlighting the limits of all confidentiality assurances.

As with all other such situations the researcher in the field might find themselves balancing morality with the law in attempting to make the right decisions about disclosures. The prime dilemma is to balance the moral stance of confidentiality, with the legal position, while also judging the 'seriousness' of any reported offence and balancing that against the potential danger to 'as yet unknown' others who could be harmed by non-reporting.

But there is a temptation to appeal to a 'caveat emptor' for anticipated harm – the participants should have enough knowledge and responsibility to be aware of what they are 'letting themselves in for'. As Hollway and Jefferson suggest:

> the ethical touchstone should be to ensure that the level of harm that might be predicted is no greater than that to which they have anyway been exposed. (2000: 92)

Hollway and Jefferson's work was focused on individuals in therapeutic situations and so should be assessed in terms of the cathartic function of narrative disclosure and considered to be less 'political' since it was not operating on a collective level:

> [D]istress is the midwife to truth when researching anxiety-provoking subjects … The 'no harm to participants' principle effectively precludes any interpretative work which assigns motives other than those admitted to by the participants themselves, since the impact of such revelations can never be wholly predicted. That position would make much published work 'unethical', including virtually all psychoanalytic, family therapeutic and psychological case histories. The idea of a critical social science could hardly survive such an ethical strait-jacket. Harm must be evaluated independently of distress. (2000: 99)

The question remains: who does the evaluation of the relative harms and benefits? And even this does not evade the researcher's responsibility for taking the appropriate ethical decisions 'processually': 'ethical issues must be resolved individually, taking account of the specific research context' (Goodwin et al., 2003: 268). As Punch reminds us:

> [They] often have to be resolved *situationally*, and even spontaneously, without the luxury of being able to turn first to consult a more experienced colleague. [Moreover], the generality of codes does not help us to make fine distinctions that arise at the *interactional* level in participant observation studies, where the reality of their field setting may feel far removed from the refinements of scholarly debate and ethical niceties. (1994: 89)

b) Intrusion and Inclusion

Qualitative research covers a spectrum of intrusion from anthropological immersion through ethnographic participation to detached textual interpretation. Intrusion merely entails varying degrees of 'entering' subjects' lives. Research is inevitably intrusive, but that variable intrusiveness is dependent upon just how much of the subjects' time, energy and so on it takes up and just how intimate the research questions might be; just how much embarrassment is entailed or unwelcome attention via dissemination of findings. Whatever the degree of inevitable intrusion, good reasons have to be given for 'interfering' in people's lives to whatever extent. The question: 'Is this research really necessary?' is essentially an ethical one. Primary anthropological research is likely to take up considerable amounts of participants' time, entail a fair amount of intimate questioning and/or observation of their behaviour and attitudes. For these sorts of reasons a full rationale would have to be offered for the research being conducted with those particular people, at the chosen site, with the specified forms of research engagement (research 'instruments') and for the proposed length of time. Providing such a rationale offers an opportunity to clarify the benefits accruing to the research participants or the communities or groups to which they belong. At the other extreme it should not be assumed that textual interpretation lacks an intrusive character. Who asked 'us', as researchers, to consider the meanings embedded in, say, a social media interaction that the participants assumed to be somehow 'private'?

Research ethics committees often ask whether a piece of research is likely to be excessively intrusive and so 'disturbing' the subjects' normal life routines. It also needs to be balanced against the concerns addressed above – thus, ironically, the more covert a piece of research, the less intrusive in ordinary lives it is likely to be. It might become more intrusive depending upon how and where research findings are published – but that merely generates another set of ethical concerns. RECs have been criticized in the past on the grounds of the lack of sophisticated understanding of the balance of ethics with appropriate methodologies. That critique is certainly justified when RECs fail to think through the moral complexities that are a normal part of human life and charge some qualitative strategies with lacking moral awareness.

With the growth of participative enquiry, the notion of intrusion takes on another dimension. Those 'subjects of research study', who agree to a participative engagement, essentially become complicit in any intrusion even if that intrusion might later be considered as 'excessive' – inclusiveness enables intrusiveness, indeed may even encourage it. Of course, this does not mean that those who permit or desire to be 'included', fully understand the implications of such a commitment. It is in such cases that the dynamic consenting and ongoing processual reconsenting comes into its own.

In some cases, RECs position subjects at the extreme arm of vulnerability. Tolich (2016: 18) has likened the recruitment of the bereaved into research projects as a 'third rail'. Research into death has no equal threat, and ethics committees treat it as if it were an untouchable third rail. In the United States, Social Security is the untouchable third rail for politicians. In Canada, no government dares to touch health care. In research ethics, the third rail is RECs' resistance to permitting researchers to engage the bereaved in research, working from the self-fulfilling prophecy that any study investigating the vulnerability of the bereaved is undermined by the participants' acute vulnerability. RECs see unforeseen and imagined vulnerabilities for researchers, their ethics committees, and their participants. Death manifests itself to ethics committees as an acute form of research governance (Iphofen, 2011), where the ethics committees' natural inclination is to manage risk by protecting the institution and, more likely, rejecting the ethics application (Dyregrov, 2004). Issues of intrusion and inclusion necessarily raise problems of vulnerability. The excluded may be vulnerable due to their non-inclusion, but inclusion can give rise to excessive intrusion. Our co-authors return to this issue frequently throughout the chapters that follow.

c) Information and Consenting

Research ethics committees sometimes seem happy to mechanically insist upon the provision to research subjects of an information leaflet and a written, signed (possibly witnessed) consent form. That represents a failure to recognize that consent can never be simply given or 'gained' at the outset to a project; it has to be managed and negotiated in a continuous fashion throughout the course of a research project – whatever the research design. This is an issue raised by many of the chapters that follow where consent is gained at both the beginning and the end of a research project.

A difficulty with gathering qualitative data is that while the participant might not fully know what they are agreeing to given the emergent research design, the researchers may know only a little more since the research can be allowed, or even encouraged, to move in directions that only become appropriate when the research is under way. This means that consent has to be ongoing, and information-giving conceived as dynamically integrated into the life of the project (see, for example, Miller & Bell, 2002).

Managing the consenting process can become even more complicated if third parties or gate-keeper are involved, undermining the autonomy of those invited to take part in the research. In the following excerpt, Tina Miller (Miller & Bell, 2002: 62–63) describes the convoluted and unsatisfactory path she followed when recruiting Bangladeshi women into her study via a gate-keeper:

> The [UK based] Bangladeshi women who came to the group where, amongst other activities, English language classes were offered – were both vulnerable and largely powerless. The context in which they experienced and exercised agency was regulated by religious and cultural practices that encompassed all aspects of their lives. When, at the next meeting, Tina was introduced to the women she realized that in effect wholesale access had been provided by [J] the gate-keeper. These women would find it difficult not to agree to participate in the study as it was J who had 'let her in'. J was not only responsible for setting up the women's group but she also occupied a respected position in the local community: She was more powerful than the other women in terms of her perceived social class and status. However, although the women had been volunteered and access given to a hard-to-reach group, the interviews themselves provided an opportunity for the women to exercise some agency and to resist talking about certain aspects of their lives. But in situations where those in more powerful positions, for example line managers, are asked to act as gate-keepers to potential respondents, how feasible is it for them subsequently to resist taking part? Similarly when powerful gate-keepers are used, notions around access, coercion and, more importantly, consent can become very difficult for the researcher and participants to disentangle who is actually giving consent and to what?

As indicated earlier, this example is what Guillemin and Gillam (2004) call a 'big ethical moment'. Although the gate-keeper gave *consent* the research could have sought the *assent* of each of the persons involved. Assent is, of course, more often used when recruiting children as research participants.

When researching children under the legal age of consent, consent or assent will need to be taken from both the child subject and the parent/guardian, or in highly hierarchical communities consent to interview a subordinate may be needed from a superior. If the former consents and the latter objects, the researcher will probably have little choice but to respect the parent/superior's objection and there may be a reasonable assumption that the parent/superior is acting in what they perceive to be the child/subordinate's best interests. However, there are real complications to sustaining consent throughout the project if matters of concern arise to either and not both of the consenting parties. Hence the need for a researcher to be reflexive; a skilled diplomat and negotiator in ensuring the fairest outcome to all stakeholders; and, in order to maintain transparency, able to record fully the rationale upon which the decision was based.

Chih Hoong Sin's (2005) work studying dementia across a range of different ethnic groups, with a mixed methods approach and a large team of researchers illustrates the difficulties involved in the complex management of a multi-level and repeated consenting process. He challenges the formulaic requirements of ethical review committees: 'The fluidity of consent demands a more reflexive approach to its engagement' (p. 277). He extends consideration of these issues in his contribution to this *Handbook*.

Addressing consent and capacity together shows how they overlap. Thus we judge those lacking the capacity to consent as being more vulnerable. But our subjects certainly may not see it that way and we may be doing more harm by making the assumption that they are made more vulnerable by consenting to participate. It is disingenuous to ever claim fully informed consent when even the researcher may not, indeed cannot, be fully informed. If researchers cannot anticipate all the things that could go wrong in research then how can the research subjects be expected to? Even to get the subject to be 'as informed as' the researcher would theoretically require that they be educated/trained to the same level of competence. So the requirement ought to be that the subject is as informed as is necessary to ensure they remain as free as possible in making their own judgements about how engaged in the research they wish to be – from 'not at all' to 'fully', with no obstructions to their discontinuance in the research that could harm them.

d) Private Domains and Public Presence

A colleague of ours wished to conduct a general ethnographic observation of routines in a hospital ward setting where there were lots of ongoing visitors and turnover of patients. A REC required them to formally consent anyone who might be observed in that setting even though they weren't collecting any individually-identifying details. Of course, that would make the study maximally invasive rather than less invasive than interviewing disparate individuals. They wanted to let people know that 'researchers are carrying out some general observation of life on this ward, but will not be seeking to record personal details without also seeking your permission'. That was intended to allow them to 'zoom out' but then go and formally inform and consent where they did want to 'zoom in' and conduct 'in-depth interviews or observations'.

At times RECs go to ridiculous lengths to force researchers to announce their research intentions. In the following Pope (Pope et al., 2010) must previously announce his intention to photograph a public event even though the rowing regatta he was filming was broadcast on television:

> In addition to gaining approval from the School Rowing Association and the principals of four selected secondary schools, the REC stipulated the author place notices around the regatta venue advertising the intention of the research project. This notification was reinforced by periodic announcements over the public address system during the week's competition detailing the purpose of the research and who was conducting it.

This problem overlaps several issue areas. The primary concern is whether or not these constitute 'public spaces'. Any health agency responsible for the ward situation would likely think not. However, seeking consent in the way suggested would probably damage the project methodologically and, more seriously, would heighten the 'intrusion' on patients. The REC would need to be convinced that the value of the project outweighed the 'formal' notion of consenting and that, as with many ethnographic studies, a more flexible notion of gaining consent should be required. Thus, in fact, the researchers should have been arguing that they were behaving 'more ethically' in order to achieve valued outcomes.

The common method in such semi-public spaces, as in the rowing regatta example, is to put up a notice explaining what is going on and contact details for more information if required. Thus, proxies, relatives and care staff could reassure themselves by talking directly to the researchers if necessary. Obviously, if follow-up interviews were necessary then the researchers should move into a more formal consenting position. Once again, it's a 'balance' between maximizing a robust project with valid outcomes, while minimizing any unnecessary 'intrusion' or disturbance into potentially vulnerable lives.

Obvious challenges to our understanding of what constitutes 'public space' occur in direct observation studies. Where social and/or individual behaviour is being observed without the subjects' knowledge, researchers must take care not to infringe what may be referred to as the 'private space' of an individual or group. The problem is that this varies between cultures and subcultures. Some societies and sub-cultures establish very clear demarcations between what is considered personal and, therefore, private space, and what is made more generally visible for others. The American Sociological Association *Code of Ethics* (ASA, 1999) gives clear guidelines on when research in public places without consent is permissible:

> 12.01: (c) Sociologists may conduct research in public places or use publicly-available information about individuals (e.g. naturalistic observations in public places, analysis of public records, or archival research) without obtaining consent. If, under such circumstances, sociologists have any doubt whatsoever about the need for informed consent, they consult with institutional review boards or, in the absence of such boards, with another authoritative body with expertise on the ethics of research before proceeding with such research.

e) Deception/Covert Research

In QR it may be impossible to maintain a neat distinction between covert and overt research. Settings are often more complex and changeable than can be anticipated (Murphy & Dingwall, 2001: 342). Covert observation is often seen to necessarily imply deception since letting people know they are being observed evidently might result in an alteration of their behaviour.

Deception cannot be simply ruled out as morally unacceptable since it is ubiquitous in modern life (Feldman, 2010). Indeed, biomedical researchers routinely employ a form of deception in the ‘ethically secure’ randomized control trial. RECs should simply ask: ‘Would the form of deception proposed here harm the research participants, the researchers and/or society in general in any way?’ If deception leads to an undermining of trust, and thus reluctance to participate in research, there is then a risk to the success of future research projects. Or the risk may be to a private company as when, in 2008, a group of researchers publicly released profile data collected from the Facebook accounts of an entire cohort of college students from a US university. While good-faith attempts were made to hide the identity of the institution and protect the privacy of the data subjects, the source of the data was quickly identified, placing the privacy of the students at risk (Zimmer, 2010).

> The question … is not simply whether it (the research) does or does not use deception, but whether the amount and type of deception are justified by the significance of the study and the unavailability of alternative (that is, deception-free) procedures. (Kelman, 1967 in Bynner and Stribley, 1979: 190)

In New Zealand, Herbert Green’s study (from 1966 to 1982) had enrolled women with carcinoma in situ into a trial without their knowledge or consent. The backlashes led to widespread disillusionment with research in general, and to the establishment of medical ethics committees. By default, all social science research was also reviewed under a biomedical frame. The 1987 Cartwright Inquiry of the treatment of cervical cancer at National Women’s Hospital concluded:

> [Green’s study] was an attempt to prove a theory that lacked scientific validity and little attention was given to ethical considerations. (Cartwright, 1988: 69)

Another way of addressing this is to consider deception alongside the issues of consent and vulnerability. Thus, if the form of deception proposed in a research project minimizes the research subjects’ capacity to consent and makes them more vulnerable to harm without substantially contributing to societal benefit then it becomes harder to ethically justify it going ahead. Such complex questions are not simply dealt with by suggesting that deception in research is inherently wrong. Perhaps paradoxically, given the condemnation of covert research in some circles, it could be argued that observation could be the least intrusive way of researching aspects of the lives of vulnerable people since it is less likely to challenge them emotionally and physically. A range of naturalistic observation methods could be employed for which in some cases they need not be made aware and, in others, might be positively enjoyed (Clark, 2007). Thus, in the hospital ward case raised earlier, the element of 'covertness' to the work, by reducing its intrusiveness, could appear as ethically more robust.

Urban exploration is the most recent manifestation of qualitative covert research that focuses more on places people have inhabited rather than people themselves. As a topic it is easy to see how attractive this 'place hacking' could be to novice, adventurous researchers seeking an innovative method and/or to 'make a difference'. Replications of conventional topic and method can appear unexciting and lacking the kind of challenge offered by a more radical ethnography.

How well can trespassing urban exploration expect to fare with RECs? Existing cases are rare but it would not be surprising if reservations, cautions, concerns or monitoring were proposed. The place hackers' flouting of the law in 'invading' private space is nothing new in social science. In *Street Corner Society*, Whyte (1981[1943]) documented how he voted twice in a local body election. In *On the Run*, Alice Goffman (2014) discloses that she took part in an unsuccessful drive-by shooting. When Venkatesh (2008) was a *Gangleader for a Day* he participated in beatings of other gang members. Breaking the law would only hold some justification if the law was seen as morally wrong or unjust and deserved to be challenged; or any 'harms' caused by breaking the law could be seen as minimal or as involving minimal risk.

Motives for research in social science must be justified by a balance between advancement of knowledge *and* benefits for society and constituent communities. If knowledge were advanced to the detriment of societal consequences one would have to judge the value/worth of that knowledge relative to the societal harms. One cannot help but appreciate any ethnographer who displays the virtue of 'courage' – but that has to be tempered by wisdom, moderation and justice. The work of adventurous ethnographers may excite curiosity above and beyond their intellectual value. The problem arises when the adventure takes on more import than the insights, knowledge or scientific advances to be gained.

As our authors reiterate throughout this *Handbook*, approval from an ethics committee, supervisors and examiners does not remove the burden of ethical responsibility from the researcher. Such 'advisers' can only be such since they were not conducting the research 'in the field' and cannot know all that may be occurring in the necessarily fluid research setting. It is not that boundaries shouldn't be pushed when it is important to do so – but that this is not something that should be done lightly or without due consideration of the potential consequences. Poorly considered research consequences, unnecessary ethical risks, harm to research participants can all give research a bad name. The resulting contamination of the field sets up obstacles to risky research sites, vulnerable subjects and, even, the general public as potential future research participants (Iphofen, 2014).

f) The Appeal, Promise and Problems of Practitioner Research

Problems arise if researchers hold more than one active 'role' since the motives for each might be in conflict. Thus, for example, the motives of a political activist might indeed involve a 'search for truth' (advancing knowledge) but in such a case that might run contrary to existing societal interests and concerns. Moreover, the goals that activists seek might predominate over the knowledge advancement goal. The motives of academic, journalist, research student/researcher, author and, indeed, 'place hacker' are not necessarily congruent. To claim that one is a detached/objective social researcher when one has, for example, a politically disruptive agenda is to compromise the status of social science. It is a challenge to professional integrity, could undermine the profession and lead politicians to challenge the grounds for its continued funding.

Conflict of interest is an ethical issue. With the spread of research awareness and the incorporation of research in professional educational curricula, practitioners in health, social care, government and the law are increasingly active in research. It may be linked to the trend towards evidence-based policymaking and the attempt to improve practice more directly. In adopting multiple roles – researcher, practitioner, subject and principal disseminator – there is a great deal of tension about which one of the roles takes primacy at any one time. And while qualitative research practice seems particularly attractive to the caring professions, investigating a practice-related problem does not necessarily lead to its solution. Rather, it may raise challenging ethical conflicts. Think of a police officer researching policing organizations, prison officers investigating the prisoner's experiences, teachers exploring the educational system and clinicians exploring how 'the system' treats their patients (e.g. Sapsford, 1999: 41; Iphofen, 2005). Full transparency with and for practitioner colleagues would represent a challenge, as would the role of research subjects who were also clients in the dissemination of findings (Iphofen, 2011: 128–129).

Even the disclosure of a practitioner status to client/participants will have both ethical and methodological consequences. Respondents are likely to say and do different things for researchers they know to have other professional or legal obligations. Health and care workers conducting research might be perceived as having more power in the research relationship than if they had not been practitioners. Ensuring participants have, and perceive themselves to have, adequate power to determine their role in the research is ethically necessary in practitioner research:

> [R]esearchers who are, in fact, conducting projects on behalf of such authorities have a tricky balance to maintain: garnering such information as is required by the focus of the research without being 'duped' by the subject or by misleading the subject as to the potential value of the research in return. (Iphofen, 2011: 59–60)

V: DIVERSITY IN TECHNIQUES; VARIETY IN ETHICAL ASSURANCES

The *Handbook* features a diversity of research techniques. The techniques include:

- Action research
- Autoethnography
- Conversation analysis
- Covert research
- Digital and social media research
- Discourse analysis
- Ethnography
- Focus groups
- Groups interviews
- Grounded theory
- Online ethnography
- Me(re)search
- Participant action research
- Participatory observation
- Visual ethnography

For illustration we compare three techniques here: a one-on-one interview, focus groups and autoethnography. Each of these techniques manifests different ethical assurances.

One-on-one unstructured interviews as a rule offer research participants informed consent and confidentiality directly and so minimize harm. A participant in a private interview has opportunities to withdraw a remark during the interview or sometimes, if the participant reads an interview transcript, they can delete the remark. The researcher can promise confidentiality, as some details of what the person tells the researcher can be deleted or amended.

Focus group researchers have less control over these basic ethical assurances. Focus groups have an unwieldy nature, as the discussion is more than the sum of separate individual interviews with participants both querying and explaining themselves to each other. Group interaction, rather than what each person says, is the hallmark of the method. Group participants are encouraged to pursue their own interests in relation to the proposed topic. Martha Ann Carey (1994) labels this interaction the *group effect*, 'which require(s) the researcher to cede a degree of control to group members'. The outcome is that focus group subjects may discuss topics outside what was outlined in the participant information sheet.

A second and more important ethical assurance standard in a one-on-one interview and less likely achieved in a focus group is confidentiality. While researchers may promise not to disclose what people said in the group to others, they have no control over what group members tell others outside the group. Tolich (2009) suggests focus group ethics are best characterized with the principle of *caveat emptor* (let the buyer beware). It may be a more useful tool for those involved in focus group research: that is, let the researcher, the participants and the ethics committee beware that the only ethical assurance that can be given to focus group participants is that there are few ethical assurances. Participants must be made adequately aware of these endemic ethical dilemmas *in advance*, to allow them to consent to share responsibility for any ensuing harm. The focus group moderator is not their sole protector (Tolich, 2004).

Autoethnographers assume that the word 'auto' implies their story is only about them. They have rights to their story, but so do the others mentioned in the text. Clandinin and Connelly (2000) challenge all self-narrative writers with a pointed question: Do they own a story because they tell it?

> As you play a multi-faceted role as researcher, informant, and author, you should be reminded that your story is never made in a vacuum and others are always visible or invisible participants in your story. (Chang, 2008: 69)

In response, finding others routinely drawn into another's autoethnography, Tolich (2010) wrote ten foundational guidelines for autoethnography as a starting point. These guidelines focus on consent, vulnerability and consultation, but the main learning was that what makes autoethnographies evocative are the others who helped forge this life's story. Those names have the right to be consulted about their participation and the right to read what the author creates.

The *Handbook*'s six parts address both the diversity of qualitative research techniques as well as how the ethical assurances are manifest in diverse techniques and settings.

Notes

1 We use the term research ethics committees (RECs) to denote any ethics review bodies known as in Australia as HRECs (Human Research Ethics Committees), in the UK as RECs (Research Ethics Committees), in Canada as REBs (Research Ethics Boards), in USA as IRBs (Institutional Review Boards), and in New Zealand as HDECs (Health and Disability Ethics Committees).

2 Labelling the research volunteer as a 'subject' must now be seen as a deliberate act, if not a political one. Rather than labelling people 'informants' or 'participants' as many in the later parts of the book do, by using the term subject we take as a starting point the power inequality that exists between a researcher and those that volunteer and, given this assumption, the researcher is responsible for protecting the subject from harm.

3 www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e35.pdf

REFERENCES

American Sociological Association (ASA) (1999) *Code of Ethics*. http://www.asanet.org/sites/default/files/code_of_ethics.pdf

Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1979) http://www.fda.gov/ohrms/dockets/ac/05/briefing/2005-4178b_09_02_Belmont%20Report.pdf

Bosk, C.L. and DeVries, R.G. (2004) Bureaucracies of mass deception: Institutional review boards and the ethics of ethnographic research. *The ANNALS of the American Academy of Political and Social Science*, 595, 249–263.

Brewer, J.D. (2012) Letter in *Times Higher Education*, 9 February, p. 33. (The Boston College tapes incident).

Brinkmann, S., Jacobsen, M.H., and Kristiansen, S. (2014) Historical overview of qualitative research in the social sciences, in P. Leavy (ed.), *The Oxford handbook of qualitative research*. Oxford University Press. pp. 17–42.

Carey, M.A. (1994) The group effect in focus groups: Planning, implementing, and interpreting focus group research, in J.M. Morse (ed.), *Critical issues in qualitative research methods*, pp. 225–241. Sage.

Cartwright, S. (1988) *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters*. Auckland: Government Printing Office.

Chang, H. (2008) *Autoethnography as method*. Walnut Creek, CA: Left Coast Press.

Clandinin, D.J. and Connelly, F.M. (2000) *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.

Clark, A. (2007) *Making observations: The potential of observation methods for gerontology*. London: Centre for Policy on Ageing.

Denzin, N.K. and Lincoln, Y.S. (eds) (1994, 2017) *The SAGE handbook of qualitative research*, 5th edn. Thousand Oaks, CA: Sage.

Denzin, N.K. and Lincoln, Y.S. (eds) (1998) *The landscape of qualitative research*. Thousand Oaks, CA: Sage.

Denzin, N.K. and Lincoln, Y.S. (eds) (2000) *Handbook of qualitative research*, 2nd edn. Thousand Oaks, CA: Sage.

Dixon-Woods, M. (2005) Systematic review and qualitative research – uneasy partners? *SRA News*, November, p.12.

Dyregrov, K. (2004) Bereaved parents' experience of research participation. *Social Science & Medicine*, 58(2), 391–400.

Feldman, R. (2010) *Liar: The truth about lying.* New York: Virgin Books.

Goffman, A. (2014) *On the run.* University of Chicago Press.

Goffman, E. (1956) *The presentation of self in everyday life*. New York: Doubleday.

Goodwin, D., Pope, C., Mort, M., and Andrew, S. (2003) Ethics and ethnography: An experiential account. *Qualitative Health Research*, 13(4), 567–577.

Guillemin, M. and Gillam, L. (2004) Ethics, reflexivity, and 'ethically important moments' in research. *Qualitative Inquiry*, 10(2), 261–280.

Haggerty, K.D. (2004) Ethics creep: Governing social science research in the name of ethics. *Qualitative Sociology*, 27(4), 391–414.

Harré, R. (1970) *The principles of scientific thinking*. London: Macmillan.

Harré, R. and van Langenhove, L. (eds) (1999) *Positioning theory.* Oxford: Blackwell.

Hollway, W. and Jefferson, T. (2000) *Doing qualitative research differently: Free association, narrative and the interview method*. London: Sage.

Hollway, W. and Jefferson, T. (2012) *Doing qualitative research differently: A psychosocial approach*. Sage.

Iphofen, R. (2005) Ethical issues in qualitative health research, in I. Holloway (ed.), *Qualitative research in health care*. Maidenhead, UK: Open University Press. Chapter 2, pp.17–35.

Iphofen, R. (2011) *Ethical decision making in social research*. London: Palgrave Macmillan.

Iphofen, R. (2012) Applying the 'gold standard'. *SRA News*, April, p.1.

Iphofen, R. (2014) Risk management. *Times Higher Education*, 3 July, p. 26.

Israel, M. and Hay, I. (2006) *Research ethics for social scientists*. London: Sage.

Kelman, H.C. (1967) Human use of human subjects: The problem of deception in social psychological experiments. *Psychological Bulletin*, 67(1), 1–11; republished in J. Bynner and K.M. Stribley (eds) (1979) *Social research: Principles and procedures*. London: Longman.

Klitzman, R. (2011) The ethics police?: IRBs' views concerning their power. *PLoS One*, 6(12).

Malinowski, B. (1935) *Coral gardens and their magic: A study of the methods of tilling the soil and of agricultural rites in the Trobriand Islands. Vol. 1, The description of gardening*. Routledge.

Marcus, J. (2012) Law and academy clash in the long shadow of the gun. *Times Higher Education*, 16 February, p. 20 (The Boston College IRA tapes).

Mies, M. (1983) Towards a methodology for feminist research, in G. Bowles and R. Duelli Klein (eds), *Theories of women's studies*. Boston, MA: Routledge & Kegan Paul. pp. 117–139.

Miller, T. and Bell, L. (2002) Consenting to what? Issues of access, gate-keeping and 'informed' consent, in T. Miller, M. Birch, M. Mauthner, and J. Jessop (eds), *Ethics in qualitative research*. 2nd edn. London: Sage. pp. 61–75.

Murphy, E. and Dingwall, R. (2001) The ethics of ethnography, in P. Atkinson, A. Coffey, S. Delamont, J. Lofland, and L. Lofland (eds), *Handbook of ethnography*. London: Sage. pp. 339–351.

Oakley, A. (1974) *The sociology of housework*. New York: Pantheon.

Oakley, A. (1979) *Becoming a mother*. Schocken.

Oakley, A. (1981) Interviewing women: A contradiction in terms, in H. Roberts (ed.), *Doing Feminist Research*. Routledge. pp. 30–61.

Oakley, A. (1999) Paradigm wars: Some thoughts on a personal and public trajectory. *International Journal of Social Research Methodology*, 2(3), 247–254.

Park, R.E., Burgess, E.W., and McKenzie, R.D. (1925) *The city: Suggestions for investigation of human behavior in the urban environment.* University of Chicago Press.

Pope, C.C., De Luca, R., and Tolich, M. (2010) How an exchange of perspectives led to tentative ethical guidelines for visual ethnography. *International Journal of Research & Method in Education*, 33(3), 301–315.

Punch, M. (1994) Politics and ethics in qualitative research, in N.K. Denzin and Y.S. Lincoln (eds), *Handbook of qualitative research*. London: Sage. pp. 83–98.

Sapsford, R. (1999) *Survey research*. London: Sage.

Sin, C.H. (2005) Seeking informed consent: Reflections on research practice. *Sociology*, 39(2), 277–294.

Spradley, J.P. (1979) *The ethnographic interview*. New York: Holt, Rinehart and Winston.

Stanley, L. and Wise, S. (1983) *Breaking out feminist consciousness and feminist research*. London: Routledge.

Stark, L. (2012) *Behind closed doors: IRBs and the making of ethical research*. Chicago: University of Chicago Press.

Thomas, W.I. and Znaniecki, F. (1918) *The Polish peasant in Europe and America*. Boston, MA: The Gorham Press.

Tolich, M. (2004) Internal confidentiality: When confidentiality assurances fail relational informants. *Qualitative Sociology*, 27(1), 101–106.

Tolich, M. (2009) The principle of caveat emptor: Confidentiality and informed consent as endemic ethical dilemmas in focus group research. *Journal of Bioethical Inquiry*, 6(1), 99–108.

Tolich, M. (2010) A critique of current practice: Ten foundational guidelines for autoethnographers. *Qualitative Health Research*, 20(12), 1599–1610.

Tolich, M. (ed.) (2016) *Qualitative ethics in practice*. Walnut Creek, CA: Left Coast Press.

Tolich, M. and Fitzgerald, M. (2006) If ethics committees were designed for ethnography. *Journal of Empirical Research on Human Research Ethics*, 1(2), 71–78.

Torrance, H. (2010) *Qualitative research methods in education*. London: Sage.

van den Hoonaard, W.C. (2001) Is research-ethics review a moral panic? *Canadian Review of Sociology*, 38(1), 19–36.

Venkatesh, S. (2008) *Gangleader for a day: A rogue sociologist takes to the streets.* Penguin Press.

Whyte, W.F. (1981[1943]) *Street corner society: The social structure of an Italian slum*. Chicago: University of Chicago Press.

Wirth, L. (1938) Urbanism as a way of life. *American Journal of Sociology*, 44(1), 1–24.

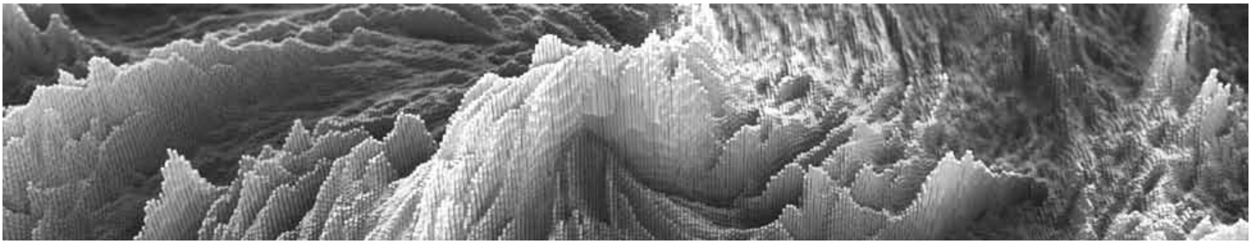
Wolcott, H.F. (2009) *Writing up qualitative research*. 3rd edn. Thousand Oaks, CA: Sage.

Zimmer, M. (2010) 'But the data is already public': on the ethics of research in Facebook. *Ethics and Information Technology*, 12(4), 313–325.

PART I

Thick Descriptions of Qualitative Research Ethics

Ron Iphofen and Martin Tolich



We open this collection with a discussion from **Martyn Hammersley** on a set of concepts which go to the core of ethical discussion generally and which highlight the particular concerns of qualitative researchers – the situational nature of value-decisions. Hammersley is renowned for his stance against the increasingly formalized procedural nature of ethical review and regulation and its consequential tendency to restrict the autonomous practice of qualitative enquiry. Adhering to the core values of this perspective requires interpretation of value principles in the research site or setting itself. The 'thick description' conventionally necessitated in qualitative research helps tease out the values, standards, and principles deemed appropriate with, to and for those participating in the study. Anticipatory applications of such values are entirely innappropriate, ineffective and, worse, might do more harm than good both to participants and to the research products. Hammersley's careful drawing out of the dimensions of complex ethical concepts can help in on-site decision-making and, ultimately, may be reflected in the improved understanding of research ethics regulators.

The in-depth analysis of core ethical concepts is taken further in **David Carpenter's** piece. He compares the methods applied for quantitative and qualitative data collection and analysis with the various moral philosophies employed for justifying researchers' actions. It is clear that the principles derived from biomedical research do not easily transpose to social science and even less so to qualitative methods. By a re-framing of the elements of the key principles, Carpenter demonstrates a resonance with those who stress the importance of reflexivity in research, the continuous application of 'practical reason' to the work being engaged in and, as a consequence, the emergence of virtuous research and the virtuous researcher. Carpenter avoids this becoming the vain search for ideals by drawing on sources of practical guidance as to how these virtues might be accomplished.

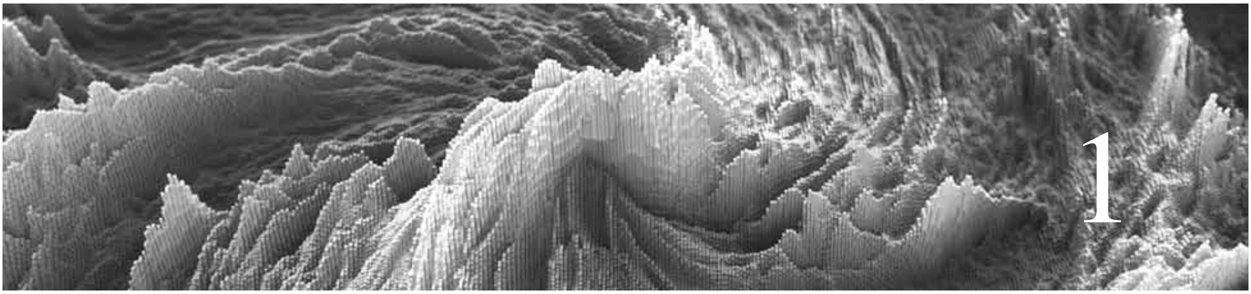
Natasha Mauthner's chapter focuses on reflexivity. In some respects she regards the term as limited as she delves even deeper into the underlying epistemic and ontological concerns of qualitative research ethics in exploring what 'new materialism' can offer the ethical researcher. The approach explicated by Mauthner both challenges some conventional assumptions of qualitative research (social contructionist, naturalist and discursive ontologies) but takes to their furthest extremes other elements of the perspective – the representationalist and the performative. The move from reflexivity to what is known as 'diffraction', since Donna Haraway, requires some shifts in thinking about how moral agency and, therefore, ethical responsibility is constituted in research practice. In fact Mauthner claims 'methods' bring into being the concerns of qualitative research – in drawing on Karen Barad's concept of *agential realism* the world is 'mattered' or 'performed' into existence. Mauthner argues that this delivers a posthumanist rather than a normative ethics in which the focus is on the researcher's practice(s). The conceptual complexity entailed in this new feminist materialist approach may challenge the abilities of qualitative researchers to 'rework their established ways of doing research'.

While there is nothing particularly novel in the advocacy of feminist epistemologies and methodologies, **Andrea Doucet's** chapter traverses the complex contours of what has become a diverse and overlapping range of issues and concerns. Anyone not versed in the multiple threads that constitute feminist research will find this an almost encyclopaedic starting point. But Doucet moves on from these traditions with a development of Lorraine Code's 'ecological imaginaries' and how these influence both making knowledge and ethical research practice. Doucet offers suggestions about how these insights can be applied in practice but, necessarily and once again, the burden of responsibility and 'response-ability' falls on the researcher, in the research setting, to implement the implied epistemic ethics.

Mark Israel examines the impact of research ethics hegemony by way of a geographically global perspective. His primary focus of concern is with the export of Northern and Westernized principlist values to the global South. Additionally, he advocates for further insight into the indigenous ethics of different cultures rather than the imposition of regulatory systems established elsewhere, no matter the temptations of supposedly proven 'convenience'. This geographic ethical imperialism repeats the errors of earlier phases of research ethics development in the North; a privileging of positivist and biomedical approaches to research design. Worse still, novice administrators appear more concerned with the bureaucratic application of principles than with the insight and flexible discretion required of social science in general and qualitative research in particular. Moreover, the prioritization of individual autonomy over collective, communal decision-making, of written over vocalized consenting, and implicit assumptions about linguistic competence all represent a certain universalist principlism that fails to recognize the specific needs and wants of indigenous people. All of these elements are instructive to understanding the ethical concerns of qualitative researchers documented throughout the rest of this *Handbook.*

It is often in response to this 'global capital' (in Mark Israel's terms) and the dominance of principlism that qualitative researchers have sought to be innovative both in method and in sensitivity to the needs of their participants. **Helen Kara's** chapter continues to challenge the ethical imperialism raised by all the Part 1 authors by drawing out the elements of emancipatory research and assessing how each of these elements contributes to ethical qualitative research practice. The two key underlying elements that Kara draws on in understanding the goals of 'democratizing research' are social justice and care. The resistance to 'colonialized' research brings together a broad range of communal and activist topic areas relating to feminism, disability, linguistic dominance, sexuality, ethnicity and socioeconomic status. There seems little doubt that such an approach is necessarily activist, participatory and political and that it lends itself more easily to qualitative approaches than to any other paradigm. Kara closes with a consideration of insider/outsider research roles and notes that the latter may be necessary for fully democratizing research without requiring any drive to objectivity and/or neutrality that is implied by those of a more principlist persuasion.

Taken together these six chapters in Part 1 reveal a thick description for the positions taken by the authors in the rest of the *Handbook*. All of the elements raised here are re-visited by the authors that follow in diverse settings, with diverse peoples and covering the breadth of methodologies that characterizes qualitative research.



1

Values in Social Research

Martyn Hammersley

INTRODUCTION

There is an understandable tendency today for many qualitative researchers' interest in ethical issues to focus heavily on gaining approval from ethics committees, this generally being required before any investigation can proceed. Yet, of course, ethical research conduct cannot be reduced to compliance with the dictates of ethics committees. Indeed, it should not be assumed that such compliance is always ethical (Hammersley, 2006, 2009a). Furthermore, social scientists' concern with ethics predates the introduction of ethical regulation.

My focus here will be on some of the key values that researchers take into account, and should take into account, in making decisions during the course of their inquiries. It is important to be as clear as possible about the nature of these values, about their implications, and about how they relate to the situations in which researchers must act. In the context of ethical regulation, there is a propensity for these values to be turned into procedural requirements, but this is to misconstrue their character, and to misunderstand the practice of social, and especially qualitative, inquiry.

The role of values in social science has long been a contested issue. Some have insisted that research is, or should be, *value-free*, but in recent times this idea has generally been rejected. Certainly, if what is meant by 'value-freedom' is that research should involve *no* value commitments then this is unachievable, and even attempting to achieve it would be undesirable. There can be little human activity that is value-free in this sense, because valued goals are almost always involved. However, in fact, the main advocates of value-freedom or value-neutrality, notably Max Weber, did not put forward this misguided proposal: their argument was that the goal of research should be restricted to the production of factual knowledge, specifically excluding practical evaluations of the phenomena being investigated, and restricting policy recommendations to the conditional identification of effective means for achieving given goals (see Weber, 1949). What Weber rejected, then, was the idea that research should be directly geared to pursuing practical outcomes or political causes (Hammersley, 2017a). It was necessarily committed to epistemic values, notably truth, but should be neutral as regards the practical values that its findings might serve. Furthermore, those on both sides of this debate have recognized that there are also *ethical* restrictions on how social research should be pursued; though there is less agreement about which ethical values ought to be given priority, and what role(s) they should play.[1]

So, against this complex background, my main purpose in this chapter is to try to provide a clear conception of some of the key values informing qualitative research, and of how they function in relation to it.

WHAT ARE VALUES?

The term 'value' has come to be used in a variety of ways. In one sense it is an economic concept, relating for example (in terms of much current economics) to what consumers wish to buy and their preferences amongst different goods. A broader version of this same sense concerns calculation of benefits against costs associated with various potential courses of action. Proposed research projects are sometimes evaluated in these terms, not least by ethics committees. A rather different meaning of the term relates to what ought to be valued over and above what is likely to be found immediately satisfying, or even what is judged to be in the general interest: here the focus is on standards concerning how people should be treated *on principle*.

Whichever sense of the term is adopted, values serve as standards by which we evaluate outcomes, people, and actions. Yet determining their implications in particular situations always requires interpretation, which may or may not be a matter of conscious deliberation. So, there is a distinction to be drawn between value *principles*, which are general in nature, and value *judgments*, which assess particular courses of action, people, situations, etc. according to one or more values. At the same time, we must not see principles as completely independent of their application: they are typically associated with notional exemplars that guide decisions about when they are relevant, and shape what they are taken to mean. The exemplars associated with a particular value principle may change over time, and can vary amongst those making evaluations. Indeed, the relationship between value principles and particular value judgments is a dialectical one. We can think of principles as sedimented knowledge about dimensions that have been found relevant in interpreting particular types of issue in the past. For example, the principle of minimizing harm may be associated for many people with the harm that is potentially involved in some medical trials, and this will shape the application of this principle in other contexts. In the case of respecting autonomy, this principle may be associated with ideas about what are regarded as unacceptable instances of covert surveillance. And, once again, this will influence how that principle is interpreted. Principles serve as important reminders, but we must be careful not to reify them.

The most fundamental point here is that it is a mistake to assume that value principles carry immediate injunctions for action: as already noted, they always have to be interpreted in the context of particular situations. Furthermore, their interpretation may well

---

[1] Thus, the translation of Weber's term 'Wertfreiheit' as 'ethical neutrality' is as misleading as the phrase 'value freedom'. In the field of philosophy, there *are* those who seem to reject entirely the claims of morality, *as conventionally understood*. This is true of Nietzsche (see Leiter, 2001), and more recently of Bernard Williams (2011).

involve complex and contentious matters. For example, there can be disagreement not just about what is serious as against minor harm, but even about what is and is not harmful. Is asking a question that an informant finds distressing harmful? Consider two cases: a question about parents or guardians that upsets a young child who has recently lost her father, and a question to a teacher accused of sexual harassment about the allegation. In the first case the distress is inadvertent, and difficult to avoid if basic information about family background is to be collected. And, indeed, even discussions of children and bereavement may give relatively little attention to this issue (see, for instance, Brewer and Sparkes, 2011). In the second example, even if the teacher has given consent, this may not avoid the distress that results. And in both cases we can ask whether the distress is harmful; and, if it is, how serious the harm is. The child will face reminders every day that a parent has been lost; and the teacher will not be able to escape awareness of the accusation. Furthermore, in the latter case, if the accusation is true, then there is surely an obligation to face up to the matter; while, if it is false, having an opportunity to talk about it in a non-threatening context may be beneficial (see Sikes, 2010). Similar complexities can arise in relation to other aspects of the research process, for example publishing a report that documents what could be evaluated as negative discriminatory practices in occupational recruitment may damage an organization's reputation, but it can also be argued that such practices ought to be exposed in order to prevent any further harm they cause. I will elaborate on the complexities surrounding the notion of harm later.

What all this highlights is how important it is to distinguish value principles from value judgments, in the sense of specific interpretations of particular values as they apply to particular situations. Principles must never be treated as if they were categorical imperatives: injunctions that must *always* be followed. Decisions about what should be done, or what ought or ought *not* to have been done, must take into account interpretations of *all* the values relevant to a case, giving each appropriate weight, as well as allowing for what is practicable and prudent in the circumstances.

It is also necessary to note that, while some decisions facing researchers can be preceded by substantial deliberation, others will have to be made on the spot, as they arise. For instance, in the course of interviewing the manager of an organization I was studying, she took a phone call requesting a reference for a member of staff whose work I had observed. After putting down the phone she asked me directly for my opinion of this person. This presented me with a dilemma, since I had promised the staff confidentiality. I declined to answer, as politely as possible; though it could be argued that, in return for her agreeing to give me access to the organization, I ought to have been prepared to offer an opinion, and perhaps this would even have been in the interests of the staff member concerned. It would certainly have been more prudent as regards preserving my access to the organization. However, I had little time to evaluate these various considerations.

Up to now I have referred to 'research ethics' as if the set of values coming under this heading were obvious or agreed, but this is not entirely true. Central to most discussions of the topic are values concerned with how researchers should treat the people they are studying, or those from whom they obtain data (these two categories may or may not overlap completely). The values often mentioned here include minimizing harm, preserving privacy, respecting personal autonomy, honouring commitments such as promises, and equity in dealing with different people. Discussions of 'research ethics' sometimes also cover researchers' dealings with other types of people: from academic colleagues and fellow research team members, through funders and gatekeepers, to audiences for and users of research findings. And much the same values often apply in dealing with these people. However, there is also a rather different set of values that are occasionally included in discussions of research ethics: what I referred to earlier as epistemic values, which are concerned with the goal of research – the production of knowledge – and how it can be pursued effectively. These are sometimes listed under the heading of 'researcher integrity', where the main concern is often to highlight the dangers of plagiarism and academic fraud. I will begin with a brief discussion of epistemic values, before turning to the values that have been the main, if not sole, focus of most discussions of research ethics.

EPISTEMIC VALUES AND VIRTUES

In my view, commitment to epistemic values has been subject to erosion over the past 40 years amongst qualitative researchers. One cause of this is the influence of what is often referred to as 'constructionism', and associated forms of relativism and scepticism. Another source is the widespread belief that aiming to produce knowledge is, in itself, insufficient warrant for the pursuit, or for the funding, of social research. In other words, it has come to be believed by many qualitative researchers that all inquiry must be geared to pursuing some practical or political goal; whether this is, say, improving the services provided by a welfare organization or challenging social inequalities. A third factor downgrading the salience of epistemic values, it seems to me, has been an exaggerated emphasis on what is taken to be an ethical requirement to equalize power relations, in the sense of minimizing the power of researchers in relation to the people they study (see Mertens and Ginsberg, 2009).

Yet epistemic values define the central task of research, and are built into the role obligations of researchers. The main value here is truth: the unique operational goal of all forms of inquiry is to produce knowledge; and, as a matter of semantics, the word 'knowledge' refers to what is true.[2] However, it is not uncommon to find reluctance on the part of researchers to use the words 'truth', 'true', or 'fact', preferring near synonyms like 'valid', 'cogent', 'sound', 'reliable', etc.; these serving effectively as euphemisms. And where 'truth' or 'fact' *is* used it is often clothed in scare quotes, not mention quotes as here, to indicate that the author is at the very least suspending any commitment to what it implies. Nevertheless, in practice, researchers cannot avoid at least some commitment to epistemic values. And it is worth noting that there is also commitment to these on the part of people engaged in many other activities, from those participating in a murder trial to those providing travel information. However, since researchers have a distinctive occupational goal – the production of new and worthwhile knowledge – this makes truth, as a value, a *central* commitment for them.

There are some good, as well as not so good, reasons for the hesitant attitude towards this value. It often seems to be assumed that it implies the availability of absolutely certain knowledge. If this were the case, there would be much reason to avoid terms like 'true' and 'fact', since there can be no such knowledge – at least if we take 'absolutely certain' to

---

[2] It is important to distinguish between the goal of research as an activity, namely to produce worthwhile knowledge, and the motives that researchers may have for engaging in research or for researching particular topics. The latter justify engagement in a research project, but they do not and should not define its goal. If they do this, bias is likely to be introduced through a concern to ensure that the research findings serve those motives. For example, I may engage in research on poverty because I want to highlight the importance of this problem and what I take to be its causes. But if I collect and analyse data specifically to serve that goal I am not doing research but engaging in political activity (albeit perhaps highly desirable); furthermore I may be tempted to exaggerate the scale of poverty and to oversimplify its causes because this will serve my political goal more effectively than a more cautious academic inquiry.

mean 'beyond all possible doubt'. All claims about the world are fallible – and therefore, in the context of social inquiry especially, we should be cautious about accepting them at face value; even though some of them would be regarded by most of us as beyond all *reasonable* doubt (for example, that in 2015 the United States had a larger population of people than the UK, that there was a financial crisis in Western countries towards the end of the first decade of this century, and so on). However, avoidance of 'true', 'truth', and 'fact' often seems to stem from a tendency to assume that, since there are conflicting views about many factual matters, all knowledge claims are arbitrary, and that competing ones must be respected as 'true in their own terms'. This is what is sometimes referred to as a 'post-truth culture'. I do not have the space here to engage with such epistemological scepticism, but a moment's thought should indicate that no human activity could proceed if there were a consistent and thoroughgoing disbelief in all fact, even assuming that this is an intellectual possibility, which it is not (Hammersley, 2009b).

A second, closely related, epistemic value is justifiability. While the task of research is to discover the truth about some matter – to find true answers to questions – researchers must also show that belief in the truth of their answers is warranted. In other words, they are required to supply evidence for the validity of any of their conclusions that may reasonably be doubted on the basis of existing knowledge, and to indicate the strength of this evidence judiciously. It is important to recognize that we can believe the truth without our being justified in doing so; and we can be justified in believing something even though it is false. For instance, my suspicion that an organization is engaging in tax avoidance may be correct without my having strong evidence to warrant it; alternatively, I may have what I *regard* as strong evidence, but the claim could turn out to be false – perhaps I have overestimated the organization's profit level or misunderstood some relevant feature of its internal organization.[3]

A third epistemic value, of a rather different kind, concerns what we can refer to as the 'relevance', or to put it more strongly the 'importance', of the research questions being addressed or the findings produced. Commitment to this value arises from the fact that not *all* knowledge is worthwhile. It is only of worth if it refers to matters that are of interest to human beings in some way.[4] The most obvious kind of relevance is where some type of knowledge addresses issues which are crucial for policy or practice; whether this relates to an international, national or local context. A strong interpretation of this value was applied by Auguste Comte to sociological research: he required that control be exercised over researchers to 'prevent them from wasting time and ingenuity on inquiries and speculations of no value to mankind […] and to compel them to employ all their powers on the investigations which may be judged, at the time, to be the most urgently important to the general welfare of mankind' (Mill, 1969: 326).

However, it is important to recognize that there are *degrees* of importance, and that there is likely to be disagreement about the priority to be assigned to different issues that could be researched.[5] Furthermore, there can be non-pragmatic relevance, arising from intellectual interest in puzzling features of our environment (Hammersley, 2004). And, given that

---

[3] One issue involved here is what threshold should be adopted in deciding that evidence is strong enough to warrant confidence in the truth of a conclusion (see Hammersley, 2011: chapter 5).

[4] The production of a plethora of facts that are trivial has sometimes been a criticism made of the sort of research encouraged by positivism (see, for example, Voegelin, 1952: 8).

[5] Particular research projects are sometimes attacked for being a waste of public funds, often with no justification: see, for instance, http://www.theaustralian.com.au/higher-education/author-lisa-wynn-defends-muslim-sex-study-waste/story-e6frgcjx-1226716354517

practical relevance varies across contexts, and can change over time, the distinction between pragmatic and non-pragmatic relevance is by no means always clear-cut or stable. It has been argued, not unreasonably, that research motivated by intellectual concerns can turn out to have great practical relevance, and that the knowledge it produces would not have been available if research had been tied directly to immediate practical problems.[6]

The final epistemic value I will mention is feasibility. The importance of this was highlighted many years ago by the biologist Peter Medawar (1967: 7), who was awarded the Nobel Prize for his work on acquired immune tolerance, which provided the basis for successful organ transplants. He wrote:

> Good scientists study the more important problems they think they can solve. It is, after all, their professional business to solve problems, not merely to grapple with them. The spectacle of a scientist locked in combat with the forces of ignorance is not an inspiring one if, in the outcome, the scientist is routed. That is why some of the most important biological problems have not yet appeared on the agenda of practical research.

This concern with feasibility must be applied in the social as well as the biological field.

Closely associated with these four epistemic values are what we can refer to as epistemic *virtues*.[7] A virtue is a personal disposition that is desirable, in contrast to ones whose possession is undesirable (vices). Since Aristotle, it has been recognized that many virtues stand midway between extremes. So, we could say that it is an epistemic virtue for researchers to be neither over-confident nor under-confident in the validity of the inferences or background assumptions employed in their research. Similarly, researchers should be neither perfectionist nor cavalier in going about their investigations: the first is likely to result in the inquiry never being completed, while the second increases the chances that false conclusions will be reached.

However, there are other epistemic virtues that do not seem to have the character of golden means. One of these would be honesty in reporting how the research was done. This is crucial if fraud and/or plagiarism are to be avoided or minimized. Another could be a willingness to follow an argument wherever it leads, even if the conclusions are uncomfortable or ‘inconvenient’ (though it is also a virtue to recognize that improbable conclusions may indicate that a false route has been taken). As a final example of an epistemic virtue, there is the willingness to engage with criticism of one’s work by colleagues and to give it due weight. It is perhaps worth saying that these virtues are often not on full display amongst qualitative researchers today, nor have they always been in the past.

As already noted, discussions of research ethics have varied in the values covered, but most have focused primarily on those relating to how researchers deal with the people they study, or from whom they obtain data. In line with this tendency, I will refer to these as ‘ethical values’. While these do not form part of the *goal* of research, they *do* indicate necessary and important external constraints on how it should be pursued.

ETHICAL VALUES

There are many ethical values, but discussions of social research ethics have tended to focus on a relatively small number that are judged to have central importance in the research context, in particular: minimizing harm, protecting privacy, and respecting

---

[6] This was the basis for Vannevar Bush’s science policy recommendations to the US Federal Government in the mid twentieth century, which were influential for several decades (see Bush, 1945). Unfortunately, this justification for scientific research has come increasingly to be rejected in favour of a demand for a specifiable ‘return’ on every ‘investment’ in research.

[7] These relate to an important field of philosophical investigation called virtue epistemology, see Greco and Turri, 2015.

autonomy. At the same time, these values are not, of course, unique to research: they apply to people's dealings with one another more generally, to the operation of various kinds of organization, including governments, and to the work of service occupations.[8]

In general these values are employed in the evaluation of *actions*, either retrospectively or prospectively, such as the adoption of a particular research method or strategy. It is important to reiterate that none of these values, individually, tell us what is good or bad, right or wrong, in particular situations. Even less do they tell us what should or should not be *done*; because decisions must take account of all relevant values, epistemic and ethical, as well as what is (or was) possible and prudent in the circumstances. This raises questions about the injunctions frequently found in research ethics codes and in the decisions of ethics committees, for instance about securing informed consent or anonymizing participants and places. As I noted earlier, there is a tendency to conflate ethical principles with standardized procedures for realizing them, in a way that can have undesirable consequences in ethical as well as other terms.

The ethical values usually treated as central to research ethics mostly depend upon two influential modes of argument. One is to do with the consequences a decision or course of action is likely to have, or has had; these being evaluated as good or bad for the people directly affected, and/or in more general terms. This is often labelled consequentialism. For example, the importance of maintaining confidentiality – of researchers not revealing who has told them what – stems largely from a concern about negative consequences for informants if this information is revealed.

The other mode of argument, often given the label 'deontological', concerns ideas about what forms of action are right in themselves, irrespective of whatever consequences they have had or are likely to have. For example, it may be argued that promises ought never to be broken, including those involved in initial contracts (implicit or explicit) between researchers and the researched. Or it may be insisted that researchers should always be honest. One aspect of this concerns the accuracy of the information they provide to participants at the start of their research. Perhaps not surprisingly, Huggins et al. (2002) did not tell the Brazilian police officers they sought to interview that they were investigating torture and murder by the police, but said instead that they were 'conducting a comparative study about policemen's lives in times of conflict and crisis'. From a 'deontological' point of view, such a strategy could be judged wrong, however prudent it might have been.

There has been much philosophical debate about which of these two approaches – consequentialist or deontological – is the proper basis for ethics, about whether they are actually distinct, or could be integrated, and about whether some alternative is superior. However, most people in their everyday ethical evaluations employ both these modes of argument, in one way or another, and probably with good reason. And much the same is true of researchers.[9]

In fact, it seems to me that a single consequentialist value (minimizing harm) and a

---

[8] Earlier I mentioned a couple of other values – honouring commitments and equity in dealing with different people. There is also sometimes mention in discussions of qualitative research of values relating to relationships in the field such as friendships (Taylor, 2011; Duncombe and Jessop, 2012), which may generate mutual obligations, or to what we might call researcher 'authenticity' (Hammersley, 2005). I do not have the space to address these here, but many of the considerations I will be discussing apply to them as well.

[9] A further type of argument sometimes used, concerns how an action does or would fit into the notion of what it is to live well, in terms of certain virtues – what it would be, for example, to be an excellent social researcher. This relates to what is referred to as 'virtue ethics'. For an exploration of these ideas, see Macfarlane, 2009.

single deontological value (respecting autonomy) cover between them a very large proportion of the ethical issues that researchers face in doing their work. A third commonly discussed ethical value, respecting privacy, seems reducible to the first two: we seek to protect people's privacy because not doing this may result in harm and/or because we believe that as persons they have a *right* to privacy, which relates to the value of autonomy.

Focusing on each of these two main ethical values, it is worth elaborating further some of the complexities involved in applying them.

Minimizing Harm

We should note, first of all, that there are different ways in which the issue of harm can arise in research. A study may involve an intervention, as for example with some kinds of action research, which promises benefits but may also entail the risk of harm of particular kinds. Moreover, while many qualitative studies do not involve such interventions, the actions of a researcher can still have unintended consequences that could be beneficial or harmful to participants: normal patterns of activity may be disrupted in ways that could be evaluated negatively; attention may be focused on people who normally do not receive much, and this could be good or bad; information may be dispersed that has a negative effect on people's reputations; and so on. A third way in which the issue of harm arises is when the researcher becomes aware of harm done to, or by, one or more of the people being studied. Here the researcher is, directly or indirectly, a witness to, rather than a cause of, harm. Nevertheless, questions clearly arise about whether and when a researcher should intervene, and how (for an example, concerned with witnessing physical abuse, see Taylor, 1987). And, of course, there are ethical and prudential issues bound up together here, the prudential ones relating not just to the consequences for the research (for example, threatening continued access) but also for the participant(s) involved, and for other people.

I have formulated the value principle involved here as '*minimizing* harm', on the grounds that avoiding all risk of any kind of harm is probably unrealistic. There are three component judgments involved in any interpretation of the principle of minimizing harm. These concern: what the consequences of the action being evaluated have been or are likely to be, given that other factors are always involved; whether these consequences constitute benefit or harm, in what sense, and to what degree; and, where the evaluation is prospective, what is the *likelihood* of the harmful consequences occurring, and what is and is not an acceptable level of risk for different degrees and types of harm.[10]

The first of these judgments is factual in character, but it operates within a value-relevance framework indicating for what a researcher could and could not reasonably be deemed responsible. And it should be clear that there is scope for disagreement even here. For example, what if the presentation of interim research findings on an organization to its members is followed immediately by the sacking of two of them whose activities were referred to, albeit anonymously, in the presentation? Assuming that their sacking constituted harm, could the researcher reasonably be held responsible for this? After all, perhaps they were going to be sacked anyway, or perhaps they were very likely to be dismissed and the research presentation was simply a trigger, or even an excuse to sack them. Judgments of this kind necessarily rely upon rather speculative, counterfactual assessments of what would have happened if the researcher had acted differently and other factors had remained the same.

---

[10] For a detailed discussion of types and degrees of harm in relation to qualitative research, see Hammersley and Traianou, 2012:ch 3. Of course, where harm has occurred it may be possible for the researcher to remedy or mitigate it.

The second type of judgment is even more obviously open to dispute. In the example just used, we could acknowledge that people losing their jobs has negative consequences for them without accepting that they have been harmed either by the researcher or even by the person who sacked them. It might be argued that they harmed themselves by doing what the researcher reported. Alternatively, it could be claimed that they were not competent in doing their jobs and that it is in their own interests, as well as that of the organization, that they find different employment. Indeed, they may look back later and conclude that being sacked was beneficial for them; though, of course, it is equally possible, and perhaps more likely, that they will not.[11]

My point is simply that there are usually different views as regards any judgment about what constitutes harm, and how serious it is. So, there is often room for disagreement about what is and is not harmful, as well as about who is (or would be) responsible for it, and about what is minor and serious harm. For instance, there have been interesting debates about whether some categories of person, such as children, are especially vulnerable, and about the implications of this for research that involves them (see, for example, Nutbrown, 2010; see Chapters 20 and 24).

It is also important to underline that frequently our judgments about these matters will be highly sensitive to what information we have available about the situation in which the action took place, or in which it will take place. This is one reason why the judgments of ethics committees about what would and would not be ethical, or standard protocols that purport to determine this, are frequently likely to be mistaken.

Finally, in relation to prospective evaluations, there is the issue of the level of risk that particular harms will actually occur. Once again, there can be differences in view about this, and about what is an acceptable level of risk for specific kinds of harm. Indeed, such disagreement underpins many of the disputes about ethics amongst researchers, and also differences in attitude towards ethical regulation. Some commentators, of whom I am one, believe that the level of harm likely to result directly from qualitative research is usually low, both by comparison with that involved in some experimental research, such as medical trials, and with the kinds of harm that people risk in many routine aspects of their everyday lives. Of course, this can easily lead to complacency, so what is required is judicious assessment of *all* the relevant considerations. And this points to the fact that there are virtues associated with ethical as well as with epistemic values – above all what Aristotle calls ‘phrónēsis’, which can be translated here as ‘wisdom’. This is required in assessing the likelihood of different outcomes, as well as the benefits and costs they entail, and the implications of the values involved in their assessment (Hammersley, 2018).

The fact that benefits as well as harms can result from research indicates that it may be necessary to ‘weigh’ the two against one another; though this should not be taken to imply that the process could be reduced to a form of calculation. Such comparative assessment may be necessary as regards the consequences for the people being studied, but perhaps also in terms of some judgment about what would be in the general interest. Here, for example, it may be necessary to include an assessment of the value of the research results that are likely to be produced. However, such judgments usually cannot avoid being *extremely* speculative: here, as elsewhere, interpretations and assessments are shrouded in uncertainty. Moreover, if too much is expected of research, none will be judged warranted.

In relation to these complexities surrounding the notions of harm and benefit, all that can reasonably be expected of researchers is that they try to make the best judgments in the circumstances, and that they are able to justify or excuse their actions with reasonable cogency.

---

[11] One of the issues here, of course, is that benefits and harms are often differentially distributed across the various parties involved.

The Deontological Concern with Respecting Autonomy

A main implication often derived from the principle that people's autonomy ought to be respected is that they should be able to choose whether or not they are included in the focus of a study and/or whether they supply data for it; and perhaps also that they should be able to withdraw from the study at any time, and in doing so withdraw all of the data they have supplied. Interpretations of this principle are sometimes extended even beyond this to suggest that people have a right to participate in the decision-making associated with any research project that focuses on them: that research should be carried out *with* them rather than *on* them; on the grounds that the latter amounts to an infringement of respect for their right to control their own lives.

If we begin by considering the issue of informed consent, and the right to withdraw, we need to recognize a number of points. One is that very often researchers are not in a position to *command* informants to supply data, for example to insist that they be interviewed: so that, usually, gaining consent is not, first and foremost, an ethical matter, it is a necessity. In these circumstances, ethical considerations only arise as regards what information is provided about the research and whether or not informants' consent decisions have been subject to illegitimate constraint. And there are complexities involved regarding what information should be supplied, and what counts as consent (see Hammersley and Traianou, 2012: ch 4).

If we turn to the case of observation, there are important similarities and differences. Even in relatively public settings, it may be necessary in practical terms to obtain consent from a gatekeeper in order to carry out observation. For example, if one tries to video-record what is going on in a shopping arcade, or perhaps even if one stands around watching and taking notes, security personnel may prevent this. And, in that context and others, there could be hostile reaction from those being observed, up to and including physical violence. For these reasons, it may often be prudent to obtain permission (from at least some of those involved), irrespective of any ethical considerations.

Furthermore, whether or not people in public places, or in settings to which the researcher has negotiated access via a gatekeeper, have a right to decide whether observation can take place is a relevant question, but one to which varied answers can be given, depending at least in part on the nature of the setting and of the observation. It is important to note, though, that very often the effects of the decisions of the various people involved are not independent of one another. If one person refuses to be observed, this may mean that those who *have* consented cannot be observed. Similarly, if consent is withdrawn during or after observation has taken place, the data of all participants involved on that occasion may have to be discarded. Much the same is true with group interviews and focus groups.

Given this, in observational research, including that carried out online, there may sometimes be grounds for *not* seeking informed consent from all of those involved (see Chapter 31). Indeed, in studying some organizations or communities it may be very difficult to seek the informed consent of all participants, at least without effectively challenging the authority of the gatekeeper concerned, and impossible to ensure that, if asked, people will be able freely to consent or to refuse consent. This gives the lie, incidentally, to the idea that researchers typically have great power that must be curbed on ethical grounds: often, they are in a relatively weak position, and this may affect their ability to satisfy ethical principles.

There is clearly scope for different interpretations of what respect for autonomy entails, as well as of how it is to be 'weighed' against other considerations. For example, I regard the suggestion that people *must* be invited to participate in the decision-making process of a research project in which they are involved – so that research is carried out *with* rather than *on* them – as unwarranted, even though there may be some circumstances where this would be ethical or prudent. This is because, usually, people's participation or non-participation in a research project plays an insignificant role in any assessment of the extent to which they are in control of their own lives.

Autonomy or freedom in abstract terms is, in any case, a meaningless concept: it only gains meaning when we specify from what people are, or should be, free and/or what they are, or should be, free to do. And while many of us are free in a variety of respects, there are always others in which – to varying degrees, and in various ways – we are constrained (and sometimes for the best). It follows from this, I suggest, that in assessing the implications of research for participants' autonomy, we must take account of the patterns of freedom and constraint that operate in their lives, and in our own; rather than assuming an ideal of absolute autonomy in relation to research participation. We must also make an assessment of how central the research is likely to be to their lives, and how consequential it is for their life chances, in relevant respects. There is a tendency sometimes to adopt an exaggerated view of the significance of research for the lives of those being studied.[12]

CONCLUSION

In this chapter I have discussed some of the main values that should guide qualitative, and other kinds of social, research. I distinguished between value principles and value judgments, and between epistemic and ethical principles. I emphasized the fact that all values require interpretation in deriving implications for particular situations; and that they will sometimes be open to conflicting assessments. For example, there can be divergent judgments about degrees, types, and risks of harm, and/or about what kinds of autonomy should be respected, in particular studies. Equally important, there is clearly the potential for conflict between epistemic and ethical values: the most effective way that a research project could be pursued may involve a serious risk of harm or invade privacy excessively, for example. And there can also be conflicting implications from different ethical values, or between these values and what is practically feasible or prudent. These conflicts sometimes generate dilemmas that are difficult to handle. However, in my view most qualitative research does not involve major ethical problems – certainly, we must take care not to exaggerate them.

Research is not carried out in an ideal world, from the point of view of any value, nor can it bring about such a world – indeed, because they can conflict, it is doubtful that all of our values could be fully realized in any *conceivable*, not just in any practically achievable, world. A realistic stance is required, therefore, focusing on the main responsibility of the researcher, which is to seek to produce worthwhile knowledge. This highlights the fact that research ethics is a form of professional ethics, parallel to those relating to other occupations.[13] For this reason, the nature of the research task properly shapes the priorities among relevant values, as well as judgments about their implications in particular situations.

---

[12] Involving participants in research decisions can also have consequences for the quality, as well as the ethical propriety, of the research. For a discussion of these issues, see Hammersley, 2017b.

[13] It also sometimes entwined with these, most notably in the case of practitioner research. There is a parallel here with doctors' participation in randomised controlled trials of treatments.

REFERENCES

Brewer, J. and Sparkes, A. (2011) 'Young people living with parental bereavement: insights from an ethnographic study of a UK childhood bereavement service', *Social Science and Medicine*, 72, 2, pp283–90.

Bush, V. (1945) *Science, the Endless Frontier: a Report to the President on a Program for Postwar Scientific Research*, Washington DC, United States Government Printing Office.

Duncombe, J. and Jessop, J. (2012) '"Doing rapport" and the ethics of "faking friendship"', in T. Miller, M. Birch, M. Mauthner, and J. Jessop (eds) *Ethics in Qualitative Research*, Second edition, London, Sage.

Greco, J. and Turri, J. (2015) 'Virtue epistemology', *The Stanford Encyclopedia of Philosophy* (Fall 2015 Edition), Edward N. Zalta (ed.), http://plato.stanford.edu/archives/fall2015/entries/epistemology-virtue/

Hammersley, M. (2004) 'Action research: a contradiction in terms?', *Oxford Review of Education*, 30, 2, pp165–81.

Hammersley, M. (2005) 'Ethnography, toleration and authenticity: ethical reflections on fieldwork, analysis and writing', in G. Troman, B. Jeffrey, and G. Walford (eds) *Methodological Issues and Practices in Ethnography* (pp37–56), Amsterdam, Elsevier.

Hammersley, M. (2006) 'Are ethics committees ethical?', *Qualitative Researcher*, 2(Spring), p4. http://www.cf.ac.uk/socsi/qualiti/QualitativeResearcher/QR_Issue2_06.pdf

Hammersley, M. (2009a) 'Against the ethicists: on the evils of ethical regulation', *International Journal of Social Research Methodology*, 12, 3, pp211–25.

Hammersley, M. (2009b) 'Challenging relativism: the problem of assessment criteria', *Qualitative Inquiry*, 15, 1, pp3–29.

Hammersley, M. (2011) *Methodology, Who Needs It?*, London, Sage.

Hammersley, M. (2017a) 'On the role of values in social research: Weber vindicated?', *Sociological Research Online*, 22, 1, 7. http://www.socresonline.org.uk/22/1/7.html

Hammersley, M. (2017b) 'Childhood Studies: A sustainable paradigm?', *Childhood*, 24, 1, pp113–27.

Hammersley, M. (2018) 'Is phrónēsis necessarily virtuous?', in N. Emmerich (ed.) *Virtue Ethics in the Conduct and Governance of Social Science Research*, Bingley, UK, Emerald.

Hammersley, M. and Traianou, A. (2012) *Ethics in Qualitative Research*, London, Sage.

Huggins, M., Haritos-Fatouros, M. and Zimbardo, P. (2002) *Violence Workers: Police Torturers and Murderers Reconstruct Brazilian Atrocities*, University of California Press.

Leiter, B. (2001) 'Nietzsche and the morality critics', in J. Richardson and B. Leiter (eds) *Nietzsche* (pp221–54), Oxford, Oxford University Press.

Macfarlane, B. (2009) *Researching with Integrity: The Ethics of Academic Inquiry*, London, Routledge.

Medawar, P. (1967) *The Art of the Soluble*, London, Methuen.

Mertens, D. and Ginsberg, P. (eds) (2009) *The Handbook of Social Research Ethics*, Thousand Oaks, CA, Sage.

Mill, J. S. (1969) 'Auguste Comte and positivism', in *Essays on Ethics, Religion, and Society*, Collected Works Vol. X (pp261–368), (ed. J. M. Robson), Toronto, University of Toronto Press.

Nutbrown, C. (2010) 'Naked by the pool? Blurring the image? Ethical issues in the portrayal of young children in arts-based educational research', *Qualitative Inquiry*, 17, 1, pp3–14.

Sikes, P. (2010) 'Teacher-student sexual relations: key risks and ethical issues', *Ethnography and Education*, 5, 2, pp143–57.

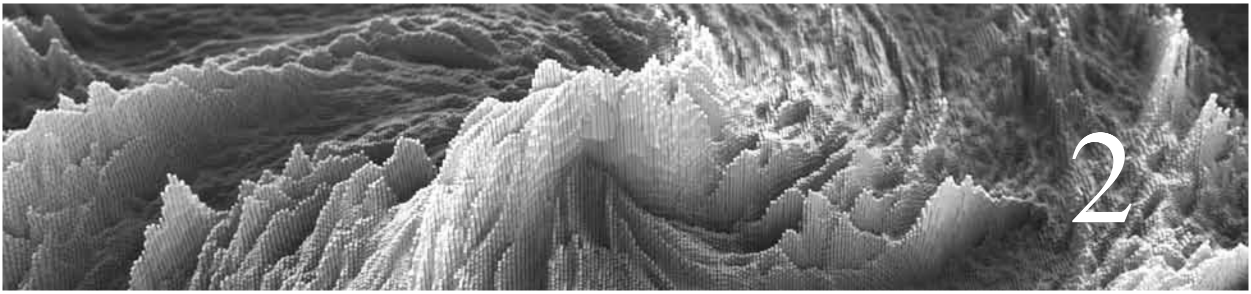
Taylor, J. (2011) 'The intimate insider: negotiating the ethics of friendship when doing insider research', *Qualitative Research*, 11, 1, pp3–22.

Taylor, S. (1987) 'Observing abuse: Professional ethics and personal morality in field research', *Qualitative Sociology*, 10, 3, pp288–302.

Voegelin, E. (1952) *The New Science of Politics*, Chicago, University of Chicago Press.

Weber, M. (1949) *On the Methodology of the Social Sciences*, Glencoe, IL, Free Press.

Williams, B. (2011) *Ethics and the Limits of Philosophy*, London, Routledge.



2

Ethics, Reflexivity and Virtue

David Carpenter

INTRODUCTION

Ethical analysis of quantitative research including experiments typically focuses on stated methods and outcomes. Scrutiny of methods will facilitate an understanding of ethical issues, including recruitment strategies, gaining consent from participants, data storage arrangements and measures taken to ensure that no, or at least minimal, harm befalls participants. A consideration of outcomes will permit an evaluation of the worthwhileness of the research. Experiments, for example, can be evaluated in terms of the risks they might pose to participants and the suitability of the data they generate as measurements of pre-determined outcomes. Ethical evaluation can be quantified, often following a utilitarian analysis, using criteria such as risk:benefit ratios and considering matters such as the likely statistical significance of any results. Utility is at least potentially calculable – what net benefit will the proposed research result in?

Qualitative research is rarely designed with pre-determined, measurable outcomes, and methods might only be loosely described at the design stage. A utilitarian analysis is likely to be unhelpful and might arrive at a negative conclusion that it would be wrong to expend resources in pursuit of unknown outcomes. This is not to suggest that qualitative research lacks structure or direction, but clearly the focus of ethical analysis needs to be appropriate. Qualitative research typically takes the form of an iterative, in-depth enquiry. The enquiry might be led by one or more key questions, but these are often refined as the research proceeds and methods are often introduced or adapted so that the research questions can be addressed. Ethical analysis of this sort of research cannot be easily based on what the researcher plans to do – the plans are rightly fluid; it can, however, be based on how they intend to do it, in terms of their motives and dispositions. In the absence of readily predictable outcomes, utilitarian analysis is difficult. Deontological analysis is helpful to some extent. At the minimum, researchers will treat others as they would wish to be treated themselves; some codes of research conduct are constructed with this duty in mind. Virtue ethics, however, demands more than duty; it entails the continuous pursuit and development of personal virtues, perhaps best understood as perfectible dispositions. The idea of a virtuous researcher is relatively easily grasped – though obviously the practical pursuit is a lifetime challenge. It is equally possible to use the idea in the context of the research itself – some research is clearly virtuous and, perhaps should be morally driven; some research is not only morally defensible, it can be argued to be morally desirable.

This chapter identifies key ethical issues associated with qualitative research. The chapter includes an analysis of principles, designed to guide the ethics of social research, and suggests that their primary value is in informing research design whereas qualitative research requires more focus on the researcher and their conduct. Principles allude to matters of conduct, including the need for constant reflection throughout the lifecycle of a project, but, all too often, their use is limited to providing an ethical defense for the benefit of the research ethics committee. In contrast, virtue ethics, including continuing reflection, is argued as being the best source of guidance for the qualitative researcher.

Any consideration of the application of virtue ethics will have an impact on the roles of ethics committees and the materials produced for them by researchers. Ethics committees tend to focus their attentions on what researchers intend to do – procedural aspects of their work, often focusing on participant-facing documents such as consent forms and information sheets – and frequently analyzing these procedures with regard to the degree to which they reflect conformity to principles of research ethics. It is argued that ethics committees and researchers need to rethink their respective positions in the case of qualitative research: the focus should be on how the researchers intend to conduct their work – matters of process. This change of focus reveals the value of virtue ethics; qualitative research is best conducted virtuously.

The chapter concludes with an illustrative case example, summarizing the main points raised in the foregoing discussion.

ETHICAL ISSUES IN QUALITATIVE RESEARCH

Hammersley and Traianou (2012) describe qualitative research as 'research that employs relatively unstructured forms of data, whether produced through observation, interviewing, and/or the analysis of documents' (p. 1). They note that the 'production of such data can involve researchers in quite close, and sometimes long-term, relationships with people' (p. 1), and that 'data collection usually takes place in "natural" settings, rather than in situations specifically set up for research purposes' (p. 1). This sort of endeavor is quite distinct from quantitative research where data are necessarily structured in a manner such that they can be used to objectively measure outcomes of pre-determined objectives. Similarly, in quantitative research, close relationships might well compromise the validity of data or lead to bias – it is not difficult to conceive of a situation in which a participant, consciously or unconsciously, wishes to please a researcher by providing the data they seek rather than being a neutral, passive, source of data. In many examples of qualitative research validity is actually dependent on close, enduring relationships with individuals and communities. Oakley (2013) is probably the best-known exponent of meaningful relationships in the context of the research interview. In her seminal work on the social research interview she advocates a two-way exchange, going beyond a mere conversation to a meaningful relationship, sometimes leading to a long-term friendship. The participant is not to be viewed as some sort of data machine; rather they should be valued as collaborators.

Whilst it is clear that qualitative research raises particular ethical issues it should not be concluded that it comprises an oppositional paradigm in relation to quantitative research. In an earlier paper, Oakley (1998) argues against such a position:

> Many of the supposed differences between qualitative and quantitative ways of knowing are not a matter of a hard-and-fast distinction, but of a continuum, with points on where one would find it difficult to say which method was in the ascendant. For example, either 'quantitative' or 'qualitative' research may include the development and progressive (or unprogressive) testing of theory, or it may not.

Qualitative research is often methodologically eclectic; it is quite common for research to have an early qualitative exploratory phase that is used to refine quantitative questions and hypotheses. Whilst methods might not be as distinct as first imagined, there remains the observation that qualitative methods often require the researcher to become personally immersed in their work. The question of how the researcher conducts their work leads to considerations of their personality, their attitudes and dispositions towards others, including research participants.

ETHICAL GUIDELINES FOR RESEARCHERS

Ethical issues in research are typically identified and addressed by reference to discipline-specific codes; principles promulgated by learned societies and other organizations or through the application of practical ethical theory such as deontology and utilitarianism. What guidance should qualitative researchers consult when designing their research?

Discipline-specific codes are abundant; the Academy of Social Sciences lists more than forty member societies and most of these offer guidance on ethical conduct for researchers. Some of these codes offer general guidance to researchers, for example the British Sociological Association (2002) and the Association of Social Anthropologists (2011). Others, for example the British Psychological Society (2010) derive guidance from sets of principles. These principles are often reflected in the design and execution of research. Principles and the associated theory of principlism, are open to criticism (Carpenter, 2013, 2016), this is discussed in more detail below. Principlism is based on the idea that there are foundational ethical principles, which are self-evidently necessary and sufficient to ensure good ethical conduct. These principles are often seen in similar light: goods-in-themselves, knowable a priori, by reason alone. Professional institutions, academic disciplines and learned societies, have adopted ethical principles.

There is a possibility of research, in terms of its design, being judged as good or ethically sound insofar as it embraces the relevant principles. This leaves little room for consideration of the role of principles in researcher conduct and, more importantly, their place in research which has a prima facie objective of achieving some social good through continuous iterative processes, adopted by the researcher in the lifecycle of a project. Principlism as a theory and a tool for ethical analysis was developed by Tom Beauchamp and James Childress and used to structure their text *Principles of Biomedical Ethics,* now in its sixth edition (2009). The four principles are Beneficence, Non-Maleficence, Respect for Autonomy, and Justice (distributive). Reference to the four principles is relatively commonplace, particularly in biomedical contexts; however their application is more widespread, particularly an emphasis on respect for autonomy. This emphasis reflects underlying individualism, upon which the principles rest. Their widespread application in social science is questionable given this underlying individualism. Nevertheless, researchers often frame their proposals accordingly and ethics committees might check compliance (perhaps in contrast with ethical evaluation) by using the same four headings. Beauchamp and

Childress have many critics but among the most outspoken are Bernard Gert (1997) and, more recently, Stephen Hanson (2009) who highlight the limitations of the principles in a secular, pluralistic society. The main objections are summarized by Gert (p. 71):

> The dominant view in question we have labelled 'principlism'. It is characterized by its citing of four principles which constitute the core of its account of biomedical ethics: beneficence, autonomy, nonmaleficence, and justice. So entrenched is this 'theory', that clinical moral problems are often grouped (for conferences, papers, and books) according to which principle is deemed most relevant and necessary for solving them. It has become fashionable and customary to cite one or another of these principles as the key for resolving a particular biomedical ethical problem. Throughout much of the biomedical ethical literature, authors seem to believe that they have brought theory to bear on the problem before them insofar as they have mentioned one or more of the principles. Thus, not only do the principles presumably lead to acceptable solutions, but they are also treated by many as the ultimate grounds of appeal.

Notwithstanding this critique of principlism and principles, it is worth considering principles promulgated by key organizations in an attempt to consider their potential contribution to the key themes of this chapter – reflexivity and virtue.

The UK Academy of Social Sciences (AcSS) adopted five guiding principles in March 2013. Those principles were identified following a project which involved most of the Academy's learned societies' members, working together to explore how far it was possible to agree a common set of principles aimed at guiding researchers. Social science research spans a variety of methodologies but certainly includes examples of the most ethically challenging research methods, such as ethnography, commonly adopted by social anthropologists. The Five Principles are:

1. Social science is fundamental to a democratic society and should be inclusive of different interests, values, funders, methods and perspectives.
2. All social science should respect the privacy, autonomy, diversity, values, and dignity of individuals, groups and communities.
3. All social science should be conducted with integrity throughout, employing the most appropriate methods for the research purpose.
4. All social scientists should act with regard to their social responsibilities in conducting and disseminating their research.
5. All social science should aim to maximize benefit and minimize harm.

The UK Economic and Social Research Council (ESRC) more recently (January 2016), promoted six key principles

a. Research should aim to maximize benefit for individuals and society and minimize risk and harm.
b. The rights and dignity of individuals and groups should be respected.
c. Wherever possible, participation should be voluntary and appropriately informed.
d. Research should be conducted with integrity and transparency.
e. Lines of responsibility and accountability should be clearly defined.
f. Independence of research should be maintained and where conflicts of interest cannot be avoided they should be made explicit.

Furthermore, the ESRC (p. 2) argues that the scope of these principles should be considered widely:

> Researchers, ROs [Research Organizations] and RECs [Research Ethics Committees] should consider ethics issues throughout the lifecycle of a research project and promote a culture of ethical reflection, debate and mutual learning. The lifecycle of research includes the planning and research design stage, the period of funding for the project, and all activities that relate to the project up to – and including – the time when funding has ended. This includes knowledge exchange and impact activities, the dissemination process – including reporting and publication – and the archiving, future use, sharing and linking of data.

Also in the UK, the Association for Research Ethics (AfRE, 2013) identifies a similar set of principles:

- *Autonomy*. The participant must normally be as aware as possible of what the research is for and be free to take part in it without coercion or penalty for not taking part, and also free to withdraw at any time without giving a reason and without a threat of any adverse effect.

- *Beneficence*. The research must be worthwhile in itself and have beneficial effects that outweigh any risks; it follows that the methodology must be sound so that best results will be yielded.
- *Non-maleficence*. Any possible harm must be avoided or at least mitigated by robust precautions.
- *Confidentiality*. Personal data must remain unknown to all but the research team (unless the participant agrees otherwise or in cases where there is an overriding public interest, or where participants wish their voices to be heard and identified).
- *Integrity*. The researcher must be open about any actual or potential conflicts of interest, and conduct their research in a way that meets recognized standards of research integrity.

In the introduction to their text Miller et al., (2012, p. 1) note that:

> As researchers [they] had found that [they] were faced with the inherent tensions that characterize qualitative research – fluidity and inductive uncertainty – and that could not be met by ethical guidelines, which were static and increasingly formalized.

At first glance these sets of principles would appear to be static and formalized, however, following a synthesis and subsequent analysis of them, at least some elements appear to offer more dynamic guidance which could readily accommodate the fluidity of qualitative research.

A synthesis of the foregoing sets of guiding principles might be summarized as:

Maximizing Benefit

This principle implies a utilitarian analysis, probably needing to be considered first at the design stage of a project; as argued earlier, this would pose difficulties for qualitative research where outcomes are not normally predictable. On the other hand, if interpreted dynamically, a requirement to maximize benefit might be seen as a guiding principle to be adopted throughout the lifecycle of a qualitative project. A good example of this would be participatory action research:

> [T]here are underlying tenets that are specific to the field of PAR and that inform the majority of PAR projects: (a) a collective commitment to investigate an issue or problem, (b) a desire to engage in self- and collective reflection to gain clarity about the issue under investigation, (c) a joint decision to engage in individual and/or collective action that leads to a useful solution that benefits the people involved, and (d) the building of alliances between researchers and participants in the planning, implementation, and dissemination of the research process. (McIntyre, 2008, p. 1)

It is relatively straightforward to envisage maximization of benefit when participants are collaborators or co-researchers, engaged in research aimed at benefiting all involved. Action research requires continuous evaluation of data and subsequent feeding back in to the research field. The overarching aim is typically to improve a situation for a community or a group of professionals wishing to develop their practices. It is commonly seen in educational research and anthropological ethnography, where working collaboratively with members of communities is ethically preferable to simply collecting data from them. It might be observed that maximization of benefit for the qualitative researcher is not a simple matter of calculation of risk or harm:benefit ratios. Rather it is a matter of personal engagement with participants and constant reflection. Focusing solely on what the researcher intends to do methodologically cannot capture this sort of research activity; it is more about how they intend to conduct the research and the personal dispositions they will require to do so ethically.

Respecting Rights

The rights of individuals, groups and communities should be respected. This will entail respect of values (some of which might be culturally specific), preservation of dignity and a commitment to respecting and maximizing autonomy. The latter should be understood as reaching beyond necessary measures such as ensuring consent, to striving to enhance autonomy by empowering individuals and communities. The ethical challenge for the qualitative researcher goes beyond just ensuring that the autonomy of participants is not compromised; autonomy should be enhanced as participant collaborators become empowered through the research process.

Ensuring Inclusivity

There is an overriding ethical imperative to ensure that all voices are heard, whilst paying proper regard to the need to respect privacy, promised confidentiality and dignity. It is ethically desirable to maximize participation; to include people and organizations from all sectors of society. Again, participatory action research provides an excellent example of such an endeavour; there is an ethical imperative to ensure that no voices are lost and benefit is enjoyed by all.

Researching with Integrity

All research should be undertaken with integrity, ensuring that the most appropriate methods are adopted and all data are honestly reported and used to the maximum benefit of the individuals and communities from which they are collected. Data analysis must be transparent and results should be disseminated in a socially responsible fashion. Researchers must be mindful of the need to properly manage any conflicts of interest and sustain their independence.

One of the themes running throughout this analysis of principles is the importance of reflection in qualitative research. The ESRC (2016) urges researchers, research organizations and ethics committees to ‘promote a culture of ethical reflection’ and McIntyre (2008) emphasizes the need ‘to engage in self- and collective reflection’.

Annink (2017, p. 3) discusses the importance of reflection:

> Reflexivity emphasizes an awareness of the researcher’s own presence in the research process, with the aim of improving the quality of the research. Over the past few years, a researcher’s positionality, his identity, conceptions, origin, and gender have been considered factors likely to influence the choice of research topic, field work, data analysis, and presentation (Weiner-Levy and Popper-Giveon, 2013). Gokah (2006) argues, based on his own experiences, how (naïve) researchers are likely to be confronted with field realities that may threaten their wellbeing or research work. Borg (2001) notes that emotions too are an undeniable part of the human researcher’s work. Usually, reflexivity in the literature is discussed as an individual activity. Furthermore, thinking reflexively is often portrayed as an afterthought in qualitative analysis, an exercise to conduct once the data has been collected and the results have been written up (Browne, 2013). Reflective data, however, may show relevant findings that would otherwise have been missed (Weiner-Levy and Popper-Giveon, 2013).

Annink continues, to recommend the use of a research journal:

> Reflection by solo researchers is often done in written forms such as journals (or diaries) and case records (Boutilier and Mason, 2012). The case record is based on a problematic situation and includes a factual description of an event and reflection on the nature of the situation, the action taken, the alternatives considered, and the possible outcomes (Kottkamp, 1990). Journal writing expands the scope of such reflection beyond problematic situations. In addition to a case record, it contains a critical analysis of the (political) context in which actions unfold, the researchers’ knowledge, skills, expertise, values, assumptions, and the emotions evoked by the research.

FROM PRINCIPLES TO VIRTUOUS PRACTICE

The foregoing analysis of principles reveals a need for qualitative researchers to possess certain personality characteristics if they are to conduct their work effectively and ethically. The qualitative researcher cannot be an objective bystander, collecting data in a personally disinterested fashion; they should become immersed in their work and be aware of the emotions it evokes and the presence and impact of their personal values. The case for meaningful relationships with participants as collaborators has been argued. These relationships should be empowering and respectful. The need for continuing reflection has also been identified. It seems that the qualitative researcher not only requires knowledge and skills but also needs certain dispositions. These dispositions include, for example, respectfulness, commitment, honesty, friendliness, social responsibility, critical self-reflectiveness and, perhaps more contentiously, the courage to pursue social justice as an activist. These dispositions are often seen as virtues, in the context of Aristotelian virtue ethics.

What are these virtues? Virtues are dispositions, reflecting the character of the possessor; they are deeply entrenched within the individual, part of their being. The virtues are identified through a mechanism known as the 'doctrine of the mean'. Spheres of action or feelings are established and then the vices of excess and deficiency described; the requisite virtue is seen as a midpoint between the vices. For a more detailed exposition and critique of the doctrine see MacIntyre (1998). A fairly typical example is reproduced in Table 2.1.

Aristotle's starting question related to what might comprise the 'good life'; the answer was derived from the identification of the purpose of life – its *telos,* which he concluded to be *eudaimonia*. *Eudaimonia* is not easily translated but it reflects the contentment associated with a life of contemplation, growing wisdom and the development of virtue. In general terms it can be seen as flourishing as a human being; our *telos* is to flourish. Modern understandings of 'virtuous' suggest comparisons with others, typically being 'better than'. The Aristotelian concept of virtuousness is rather different; being virtuous is to adopt a way of understanding, hence its association with wisdom. Virtues are:

> acquired dispositions of character that can be determined for all rational animals since they, as do all species, have certain conditions under which they flourish. Aristotle's conception of human flourishing is manifested in his description of the several virtues that serve as means to and as constitutive of the good life. (Carden, 2006, p. 12)

The pursuit of virtue moves through stages. Initially it is not much more than the copying of others' acts but gradually an understanding of why those acts are virtuous emerges, as a

Table 2.1 Aristotle's Ethics: Table of Virtue and Vice

Sphere of action or feeling	*Excess*	*Mean*	*Deficiency*
Fear and Confidence	Rashness	Courage	Cowardice
Pleasure and Pain	Licentiousness/Self-indulgence	Temperance	Insensibility
Getting and Spending (minor)	Prodigality	Liberality	Illiberality/Meanness
Getting and Spending (major)	Vulgarity/Tastelessness	Magnificence	Pettiness/Stinginess
Honour and Dishonour (major)	Vanity	Magnanimity	Pusillanimity
Honour and Dishonour (minor)	Ambition/empty vanity	Proper ambition/pride	Unambitiousness/undue humility
Anger	Irascibility	Patience/Good temper	Lack of spirit/unirascibility
Self-expression	Boastfulness	Truthfulness	Understatement/mock modesty
Conversation	Buffoonery	Wittiness	Boorishness
Social Conduct	Obsequiousness	Friendliness	Cantankerousness
Shame	Shyness	Modesty	Shamelessness
Indignation	Envy	Righteous indignation	Malicious enjoyment/Spitefulness

Source: Aristotle (1955).

result of continuous reflection and contemplation. Carden (2006) notes Aristotle's explanation 'all creatures learn by imitating; the novice learns the practice by imitating the master, just as the child learns to be a good person by imitating the right role model.' According to Aristotle, virtues are developed through a process referred to as *phronesis*; we have natural virtue but continuous exercise of practical reason (*phronesis*) leads to their further development, increasingly towards perfection – a life of 'being the best'. Living a life of virtue requires continual striving, recognizing our perfectibility and aiming for moral excellence. MacIntyre (1998) summarizes this idea by noting that we 'become just men by performing just actions and courageous by performing courageous actions and so on'.

Macfarlane (2009) has developed virtue ethics into a form of practical guidance for researchers; he starts by constructing a framework identifying phases of research enquiry (Table 2.2).

The phases comprise the lifecycle of a research project, identifying the key activities involved. The model is not necessarily linear; in most qualitative, iterative, projects the phases are best seen as circular – after some reflection, the researcher should consider re-framing key aspects of the project and recommencing the cycle. Thus the fluidity and inductive nature of qualitative research is captured (Miller et al., 2012). Action research provides a paradigmatic example of such an approach (McIntyre, 2008).

The virtues demanded in each phase are identified in Table 2.3.

None of these virtues was *explicitly* stated in the principles, which were analyzed earlier, however the analysis showed that they might be seen as implicit. In fact it might be argued that it would be difficult to adhere to, or perhaps comprehend, principles in the absence of virtues. This should not be taken as a criticism of those principles or principlism in general. Rather the observation reflects a complex, underlying philosophical debate, largely articulated by communitarian thinkers. A full explication of this debate cannot be provided here but briefly: Communitarians reject universal expositions

Table 2.2 Research phases

Phase	*Meaning*
Framing	questions, problems, hypotheses, issues, projects, proposals
Negotiating	access, consent, permission, time, support
Generating	data, materials, ideas, inspiration
Creating	results, interpretations, models, concepts, theories, critiques, designs, artefacts
Disseminating	through publication, exhibition, performance
Reflecting	on epistemological and personal learning

Source: Macfarlane (2009)

Table 2.3 The virtues and vices of research

Phase	*Vice (deficit)*	*Virtue*	*Vice (excess)*
Framing	Cowardice	*Courage*	Recklessness
Negotiating	Manipulativeness	*Respectfulness*	Partiality
Generating	Laziness	*Resoluteness*	Inflexibility
Creating	Concealment	*Sincerity*	Exaggeration
Disseminating	Boastfulness	*Humility*	Timidity
Reflecting	Dogmatism	*Reflexivity*	Indecisiveness

Source: Macfarlane (2009)

of moral principles and universal moral theories as a guide to moral life. They see these as reductionist and individualistic, obscuring rather than illuminating what it is to live the good life. Principlism, statements of principles and codes of practice, and for that matter, utilitarianism and deontology, require the adoption of an objective, disembodied self. Thinkers such as Taylor (1989) and MacIntyre (1984) reject this idea. Living the good life requires being part of a community; morality comes from that experience, so communities become a source of virtue rather than being shaped by external morality derived from theoretical analyses. Communitarians point out that we have lost touch with old-fashioned virtues and they no longer have a place in popular discourse; our moral language has been replaced with individualistic ideas such as rights. It then becomes clearer why virtues are not frequently explicitly stated in the principles that guide research today.

This sort of thinking is particularly apposite in the context of qualitative research ethics. In ethnography, for example, researchers will need to immerse themselves in communities rather than looking on as disembodied selves. Imposing moral ideas derived from principles misses the important idea that morality might be found within a community. This throws light on the need for cultural awareness and collaborative engagement with participants.

Macfarlane (2010) goes on to elaborate the virtues, thereby providing clear descriptions of required conduct. Living out virtues reflects the Aristotelian idea of *phronesis* – the development of virtues through practicing them (Table 2.4).

Table 2.4 Living out research virtues

Courage

- seeking to challenge one's own presuppositions or conventional wisdom
- developing a project that might not necessarily attract funding or represent a 'fashionable' topic
- pursuing a line of research without undue regard to career and other financial imperatives
- freely admitting when research does not go to plan or when you feel your previous research was factually or conceptually mistaken

Respectfulness

- being respectful to others including vulnerable individuals and communities
- being aware of the temptation to take advantage of organizational, social or intellectual power over others
- taking care not to cede too much power to others who may wish to distort the research process for their own ends

Resoluteness

- being transparent about circumstances when the extent of data collection or creative endeavour has been compromised from original intentions
- being aware of the temptation to start analysing data or other results before a representative sample or case study has been completed

Sincerity

- ensuring that the results of research are based on an accurate representation of all the relevant information collected
- resisting overt or covert pressure from a powerful sponsor or stakeholder to skew results to meet their needs or expectations
- being aware of the temptation to conceal or exaggerate results in order to gain some advantage, either materially and/or to reputation

Humility

- fully acknowledging one's intellectual debt to others
- ensuring all research partners are fairly represented in being accorded publication credit corresponding with their relative contribution
- inviting others to challenge your own thinking and/or results

Reflexivity

- being self-critical about one's own research findings or personal performance as a researcher

Source: Macfarlane (2010)

THE ETHICS COMMITTEE AND ETHICAL REVIEW

Ethics committees are not generally familiar with protocols adopting a virtue ethics approach. The expectation of the committee is that the ethical defense (and all too often this is the correct description) will be presented in terms of adherence to research ethics principles; it then typically tests compliance and forms an opinion accordingly. Miller et al. (2012, p. 1) note:

> Ethics approval processes scrutinize the familiar ethical principles of protection, informed consent, confidentiality and anonymity across the research design that in turn provide new ways to justify and judge the integrity and quality of social research…. Developments in the regulation of research ethics across the UK, mainland Europe and North America has resulted in greater external control exerted at the institutional, organizational and funding body levels over research projects and processes. Through this process there has been a discernible shift from a discourse of moral integrity and researcher self-regulation guided by professional codes of practice, to one of external regulation and governance. (Haggerty, 2004; Miller & Boulton, 2007)

The 'shift from a discourse of moral integrity' suggests a drift away from concerns about the virtuous conduct of research towards regulatory compliance. The review is often front-loaded, taking little account of researcher conduct throughout the lifecycle of a project. Roberts (2015, p. 316), in considering qualitative research involving online communities, distinguishes between procedure and process, making the point that ethics committees are more inclined to focus on research procedures than processes:

> As researchers within new spaces, it is likely that in the *process* (emphasis in original) of research we will come across ethical issues that neither we, nor the ethical reviewing body, have considered prior to the research commencing. In exploring the ethical issues associated with possible harm in virtual communities, it is important to note that ethical considerations continue beyond the procedural ethics involved in obtaining ethical approval prior to commencing research. '*Ethics in practice*', (emphasis in original) also known as process ethics, situated ethics (Calvey, 2008), and embedded ethics (Whiteman, 2012), are broader concerns, relating to the consideration given to ethics throughout the research process as events or issues arise. (Guillemin & Gillam, 2004)

Clearly both researchers and ethics committees need to take a new approach (Carpenter, 2017). The familiar principles should not be abandoned but more emphasis should be placed on how they will be met by the virtuous researcher. A researcher embracing the virtues of courage, respectfulness, resoluteness, sincerity, humility and reflexivity is not likely, for example, to disregard the need for consent. In similar vein, the ethics committee should look for evidence of consent beyond the ubiquitous consent form compiled in accordance with a standardized template. Given the iterative nature of qualitative research, researchers and ethics committees should rethink the idea of ethical review as a hurdle to be negotiated before research commences. Ethical review should be a dynamic process involving dialogue between the researcher and the ethics committee, as the research unfolds. The virtuous, reflexive researcher will not and should not retain rigid adherence to a static protocol.

Of course no ethics committee will be content with a simple promise to conduct research virtuously. The oft rehearsed argument that ethics committees are not needed – 'It is time that responsibility for the ethical conduct of research is clearly transferred to researchers, except possibly in that small proportion of cases where prospective research participants may be so intrinsically vulnerable that their wellbeing may need to be overseen' (Dyck & Allen, 2013), because researchers conduct their work with integrity, is not persuasive. The committee should seek evidence of the application of virtue and its continuing development, it should also require regular reports as a project progresses. It should also consider the researcher's experience, bearing in mind the concept of *phronesis;* in the case of a novice researcher, supervision and mentorship will be important considerations. In the case of larger scale projects, the ethics committee might consider internal arrangements for ethical management; the presence of an on-board ethics adviser or panel is increasingly common. The application of virtue ethics is illustrated in the case example, below.

CASE EXAMPLE[1]

The following example provides a vehicle for summarizing the foregoing discussion of virtue and reflexivity by providing an illustrative context and practical applications from the perspectives of researchers, participants and the ethics committee.

This ethnographic study, in three Asian Countries, comprised an exploration of links between women's employment and empowerment and risks of them suffering violence. The research team adopted the Association of Social Anthropologists' Ethical Guidelines for good research practice (ASA, 2011) in designing the project and informing its execution. Essentially, self-regulation was seen as preferable to and extending beyond regulatory governance (Miller et al., 2012). The project followed a multi-method approach including both quantitative and qualitative elements. This illustrative example is limited to a discussion of the main qualitative element, involving interviewing women and representatives of organizations. Key questions included that of how improved economic status might be used to reduce the incidence of violence. Pursuit of this and similar questions required in-depth engagement with various agents and organizations but, most importantly, the women themselves. The research context was complex with numerous social, political and cultural factors in play.

The project's overarching research question was: how can approaches to increase women's economic engagement also tackle violence against women?

The aims and objectives were:

Aim

To generate data that will support a range of stakeholders across a range of contexts in promoting and supporting women's economic empowerment (WEE) as a driver for social change in relation to violence against women (VAW).

Objective

To understand the complex, reciprocal relationship that VAW has with WEE. This was broken down as follows:

- To understand how normative violence currently shaped women's economic engagement patterns, and to ascertain how best to address this;
- To uncover the complex ways in which earning or generating an income shaped/altered (both positively and negatively) the forms of violence that women experienced, and how it affected their levels of vulnerability.

There were 3 strands within the qualitative research phase:

- An in depth study of a working class community – essentially involving women belonging to the lowest 3 economic quintiles.
- A study of middle/upper class women – aiming to compare experiences and perceptions across a range of differences. This strand included the compilation of work-life histories.
- A case study of either a private, public or a civil society organization which positively engages with promoting WEE and is receptive to the project because they were concerned to promote the wellbeing of their female employees and in particular reduce/end violence in their lives.

ETHICAL ISSUES

The researchers did not focus on 'negative' ethical issues in a defensive presentation of the project, they took the view that it would be unethical to not undertake this work given the ethical worthwhileness of its projected outcomes. A reasonable analysis, founded upon a broadly utilitarian philosophy, started from the position that this research *ought* to proceed given the self-evident benefits. The ethical imperative was to maximize benefit. This was largely achieved by adopting an action research design (McIntyre, 2008), driven by respectful and sincere relationships with all communities and individuals involved in the research, at its heart. The project was virtue ethics based, involving local researchers, trained to work collaboratively with participants, mindful of underpinning virtues and sustaining a reflexive approach throughout (Annink, 2017). Evidence of the role and influence of virtue ethics can be seen in the following discussion.

The research team worked with the premise that, as action research, participation should have some inherent benefits. These were loosely summarized as:

- Establishing interest in and ownership of the research amongst the participating community, resolutely striving for inclusivity and remaining constantly mindful of members' rights
- Raising awareness of the links between VAW and WEE within the community, aiming to empower its members as research collaborators in the advancement of their autonomy
- Influencing policy and practice
- Sharing their knowledge with local researchers and practitioners
- Supporting women who participate in the research by strengthening capacity amongst local, national researchers to engage with VAW.

The research team was resolved and committed to bringing about positive changes in the lives of poor women. It recognized that this was a long-term aim that required a range of other initiatives and changes. It focused on the immediate term, during which it aimed to produce robust evidence, which could contribute to debates around VAW, and WEE, and inform policy, practice and programming. It also resolved to widen communications through varied traditional and social media and potentially having a secondary impact on public attitudes and social norms through the documentation and discussion of varied sociocultural practices and relationships.

In adopting a virtue ethics approach the project team ensured that researchers and the women participants embarked on a shared learning experience. This diminished the effect of power relationships across the researcher/researched divide, and opened up the possibility for transformation to happen on multiple levels. This transformation included shaping new, shared perspectives on the issues under focus, and deeper insights into the challenges and barriers these women faced. The researchers were sensitive to and aware of the potential to cause harm by introducing discussion of topics of a highly sensitive nature. By adopting a virtue ethics process, researchers were required to be reflexive from the outset, and to think through the impact of their positioning and approach, as an ongoing part of the research methodology.

There were important safety considerations in this project, relevant to fieldworkers as well as participants. The women participants were vulnerable and at risk of repercussions as a result of disclosure of violence they might have experienced. These issues were addressed by adhering to published guidance (WHO, 2001).

- The safety of respondents and the research team was paramount, and guided all project decisions.
- It was recognized that as, in part, a prevalence study it needed to be methodologically sound and build upon current research experience about how to minimize the under-reporting of violence.
- Protecting confidentiality was seen as essential to ensure both women's safety and data quality.
- All research team members were carefully selected and received specialized training and on-going support.
- The study design included actions aimed at reducing any possible distress caused to the participants by the research.
- Fieldworkers (all of whom had local knowledge) were trained to refer women requesting

assistance to available local services and sources of support. Where few resources existed, the study team created short-term support mechanisms.

- Researchers recognized their ethical obligation to help ensure that their findings were properly interpreted and used to advance policy and intervention development.

Methods were adopted to ensure that this guidance was scrupulously followed. Safe channels of recruitment were established using local intelligence and relationships whilst remaining mindful of the imperative of inclusivity; any form of public recruitment would have risked the welfare of potential participants. The women were all interviewed in private settings – talking at home would have raised obvious dangers. Furthermore, it was agreed that only one woman per household would be interviewed. The location and timing of the interviews were completely within the control of the women and they were given complete freedom to reschedule/relocate the interview, if they wished. The interviewers were prepared with safe questions that they could ask should the interview be interrupted – for example, questions about general health issues. The women were not identified, either personally or through their feedback, i.e. as a deduction using their particular feedback – all data were carefully assessed to ensure that they did not identify subjects. To ensure that the women could readily identify the researchers, they carried simple ID cards.

Early in the design stage of the research it became obvious that written information sheets and consent forms, would, paradoxically, expose the women to risk. A naïve attempt to respect autonomy could, in fact, result in serious deprivation of liberty and risk of harm. Respect for the women and their safety was clearly more important than following procedural, regulatory conventions. It was agreed that verbal consent should be obtained following a careful explanation of the project. Every woman was given an explanation of why she had been approached, including any trusted gatekeeper who had been involved in the process. They were told that they need not answer any question they preferred not to and it was made clear that they could terminate the interview at any time. They were assured that their identity would not be revealed. Most importantly they were encouraged to speak freely in an attempt to find ways in which members of their community could be empowered without risk of violence; relationships were deliberately personal and close and respect was shown throughout. The importance of the women learning about the results of the project was recognized though names and addresses were not recorded for obvious reasons, rather they were directed to sources of information. Most importantly the women were given verbal advice about where and from whom they could seek ongoing advice and support.

The ethics committee could not be provided with the standard suite of documents: invitation letters, information sheets, consent forms and interview topic lists. In fact it was not possible to provide it with a fully formed protocol given the necessity of constant development following continuous reflection. The research question was, however, clear and the ethical case for its pursuit were readily accepted. The committee was content that the focus of ethical review should not be upon the procedures of the project (how it would be undertaken) but on the processes to be adopted (Roberts, 2015). The committee was impressed by the underpinning virtues to be adopted and continually developed reflectively throughout the lifecycle of the project (Macfarlane, 2009, 2010). It was clear that the project as a whole was courageous in its endeavor to seek the factors which would permit women to enjoy the empowerment which would accompany employment without risk to their safety. It equally recognized the courage of the women in participating in the research and that of the researchers who would also face risks, albeit mitigated as far as possible. Respectfulness was evidenced in the researchers' determination to involve participants as collaborators, not just sources of data (Oakley, 2013). Respect was equally demonstrated in the attention given to rights of individuals and communities and attempts to understand cultural contexts. The committee was also reassured by the researchers' resoluteness and sincerity; it could be seen that answers to the research question would not be obtained easily and researchers could easily face pressure to breach integrity and not report results honestly. Finally, the committee observed the researchers' undertaking to adhere to guidance produced by their associated learned society (ASA, 2011) and internationally developed recommendations for research investigating domestic violence (WHO, 2001).

The research was conducted following a virtue ethics model and there were no reports of any unforeseen ethical problems. No doubt some aspects of this positive experience could be attributed to good fortune. The project did, however, benefit from some practical aspects of governance and management that are not necessarily commonplace. First, the project was sufficiently funded to allow field researchers to be fully trained and supervised. Second, the project had a well-developed ethics protocol, which guided research ethics processes throughout the lifecycle of the project; this practice could be easily emulated in other projects. Finally, the project funding included the provision of a technical advisory group, which gave advice and support as and when it was needed. That group included an ethics adviser who was the main author of the ethics protocol, and steered the project through ethical review, providing convincing arguments for the benefit of the ethics committee. He also provided immediate support as needs arose. For example, part way through the project there was a debate about the value of interviewing mothers and daughters from the same household. On the one hand the opportunity would have been valuable in investigating intergenerational differences and providing a source of validity; on the other hand doing so would have breached the WHO (2001) recommendations. It would have been difficult to ensure the safety of both women; the fact that both had been interviewed about violence, including domestic violence, would have been self-evident. Moreover, it was at least possible that one woman might have been the perpetrator of violence and the other her victim. The advice offered was that commitment and resoluteness regarding the project could not override the need to respect the women and assure their safety.

At the time of writing, data collection has been completed and early top level findings have been cautiously articulated. The research question was: how can approaches to increase women's economic engagement also tackle violence against women? Obviously, in exploring approaches to increased economic engagement, the researchers were investigating putative links between the two issues. Early interim findings indicate that there is no direct link between income (in any form) and either greater resilience to violence or greater ability to mitigate against it. Clearly the research has not identified an obvious 'magic bullet'. In depth analysis of the data continues, in a committed and resolute quest to understand the genesis of violence against women and girls.

Note

1 *Women, work and violence. Violence against women and women's economic empowerment: understanding gender dynamics within domestic and public work spaces*. The author is grateful to the Principal Investigator, Dr Tamsin Bradley, University of Portsmouth, for permission to use this case. The author (of this chapter) was the ethics adviser for the project throughout its lifecycle. The research was commissioned by DFID (Department for International Development) in late 2015 as part of a wider portfolio of research on violence against women and girls in South Asia. It was implemented by IMC Worldwide (lead), the University of Portsmouth, and the International Center for Research on Women (ICRW). Additional institutional collaborators were the Lahore University of Management Sciences (LUMS), HERD in Nepal, MSR in Myanmar and the University of Delhi.

REFERENCES

Academy of Social Sciences (2013). *Professional Briefings* (October 2013, Issue 3): *Generic Ethics Principles in Social Science Research*. Retrieved from: http://acss.org.uk/wp-content/uploads/2013/11/pb3_generic-ethicsprinciples.pdf

Association for Research Ethics (AfRE) (2013). Framework for Research Ethics. Retrieved from: https://www.arma.ac.uk/resources-1/research-ethics/Framework-of-policies-and-procedures.pdf/view

Annink, A. (2017). 'Using the research journal during qualitative data collection in a cross-cultural context'. *Entrepreneurship Research Journal*, 7 (1). doi: 10.1515/erj-2015-0063.

Aristotle (1955). *The Ethics of Aristotle: The Nichomachaen Ethics* (revised edition) (J. K. Thomson, trans.). New York: Viking (p. 104). Retrieved from: http://www.cwu.edu/~warren/Unit1/aristotles_virtues_and_vices.htm

Association of Social Anthropologists of the UK and the Commonwealth (ASA) (2011). *Ethical Guidelines for good research practice.* Retrieved from: https://www.theasa.org/ethics.shtml

Beauchamp, T. and Childress, J. (2009). *Principles of Biomedical Ethics.* New York: Oxford University Press, 6th edition.

Borg, S. (2001). 'The research journal: a tool for promoting and understanding researcher development'. *Language Teaching Research*, 5 (2), 156–77. Cited in: Annink, A. (2017) 'Using the research journal during qualitative data collection in a cross-cultural context'. *Entrepreneurship Research Journal*, 7 (1). doi: 10.1515/erj-2015-0063.

Boutilier, M. and Mason, R. (2012). 'The reflexive practitioner in health promotion: from reflection to reflexivity'. In Rootman, I., Dupéré, S., Pederson, A., and O'Neill, M. (eds), *Health Promotion in Canada: Critical Perspective on Practice* (pp. 196–207). Toronto: Canadian Scholars' Press Inc. Cited in: Annink, A. (2017) 'Using the research journal during qualitative data collection in a cross-cultural context'. *Entrepreneurship Research Journal*, 7 (1). doi: 10.1515/erj-2015-0063.

British Psychological Society (2010). *Code of Human Research Ethics.* Retrieved from: www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf

British Sociological Association (2002). *Statement of Ethical Practice for the British Sociological Association.* Retrieved from: https://www.britsoc.co.uk/equality-diversity/statement-of-ethical-practice/

Browne, B. C. (2013). 'Recording the personal: the benefits in maintaining research diaries for documenting the emotional and practical challenges of fieldwork in unfamiliar settings'. *International Journal of Qualitative Methods*, 12 (1), 420–35. Cited in: Annink, A. (2017) 'Using the research journal during qualitative data collection in a cross-cultural context'. *Entrepreneurship Research Journal*, 7 (1). doi: 10.1515/erj-2015-0063.

Calvey, D. (2008). 'The art and politics of covert research: doing "situated ethics" in the field'. *Sociology*, 42 (5), 905–18. Cited in: Roberts, L. D. (2015) 'Ethical issues in conducting qualitative research in online communities'. *Qualitative Research in Psychology*, 12 (3), 314–25.

Carden, S. D. (2006). *Virtue Ethics: Dewey and MacIntyre*. London: Continuum.

Carpenter, D. (2013). Generic Ethics Principles in Social Science Research Discussion – Stimulus Paper (Symposium 1, 5th March 2013). In *Professional Briefings* (October 2013, Issue 3): *Generic Ethics Principles in Social Science Research*. Published by the Academy of Social Sciences, retrieved from: http://acss.org.uk/publication-category/professional-briefings/

Carpenter, D. (2016). 'The quest for generic ethical principles in social science research'. In Iphofen, R. (ed.), *Finding Common Ground: Consensus in Research Ethics across the Social Sciences* (*Advances in Research Ethics and Integrity: Volume 1*, pp. 3–17). Bingley, UK: Emerald.

Carpenter, D. (2017). 'Virtue ethics in the practice and review of social science research: the virtuous ethics committee'. In Emmerich, N. (ed.), *Virtue Ethics and Social Science Research: Integrity, Governance and Practice* (Volume 3, pp. 105–125). Bingley, UK: Emerald.

Dyck, M. and Allen, G. (2013). 'Is mandatory research ethics reviewing ethical?'. *Journal of Medical Ethics*, 39 (8), 517–20.

ESRC (2016). 'Our core principles'. Retrieved from: http://www.esrc.ac.uk/funding/guidance-for-applicants/research-ethics/our-core-principles/

Gert, B. (1997). *Bioethics: A Return to Fundamentals*. Cary, NC: Oxford University Press.

Gokah, T. (2006). 'The naïve researcher: doing social research in Africa'. *International Journal of Social Research Methodology*, 9 (1), 61–73. Cited in: Annink, A. (2017) 'Using the research journal during qualitative data collection in a cross-cultural context'. *Entrepreneurship Research Journal*, 7 (1). doi: 10.1515/erj-2015-0063.

Guillemin, M. and Gillam, L. (2004). 'Ethics, reflexivity and "ethically important moments" in research', *Qualitative Inquiry*, 10 (2), 261–80. Cited in: Roberts, L. D. (2015) 'Ethical issues in conducting qualitative research in online communities'. *Qualitative Research in Psychology*, 12 (3), 314–25.

Haggerty, K. D. (2004). 'Ethics creep: governing social science research in the name of ethics', *Qualitative Sociology*, 27 (4): 391–414. Cited in: Miller, T., Birch M., Mauthner, M., and Jessop, J. (2012) *Ethics in Qualitative Research.* London: Sage.

Hammersley, M. and Traianou, A. (2012). *Ethics in Qualitative Research: Controversies and Contexts*. London: Sage.

Hanson, S. S. (2009). *Moral Acquaintances and Moral Decisions: Resolving Moral Conflicts in Medical Ethics* (*Philosophy & Medicine Vol. 103*). Springer Science & Business Media.

Kottkamp, R. B. (1990). 'Means for facilitating reflection'. New York: *Education and Urban Society*, 22 (2), 182–203. Cited in: Annink, A. (2017) 'Using the research journal during qualitative data collection in a cross-cultural context'. *Entrepreneurship Research Journal*, 7 (1). doi: 10.1515/erj-2015-0063.

Macfarlane, B. (2009). *Researching with Integrity: The Ethics of Academic Enquiry.* New York: Routledge.

Macfarlane, B. (2010). 'Values and virtues in qualitative research'. In: M. Savin-Baden, M. and Major, C. H. (eds) *New Approaches to Qualitative Research: Wisdom and Uncertainty* (pp. 19–27). New York: Routledge.

MacIntyre, A. (1984). *After Virtue*. Notre-Dame: University of Notre Dame Press, 2nd edition.

MacIntyre, A. (1998). *A Short History of Ethics: A History of Moral Philosophy from the Homeric Age to the Twentieth Century*. London: Routledge

McIntyre, A. (2008). *Participatory Action Research* (*Qualitative Research Methods* series). Thousand Oaks, CA: Sage. doi: 10.4135/9781483385679.

Miller, T. and Boulton, M. (2007). 'Changing constructions of informed consent: qualitative research and complex social worlds'. *Social Science & Medicine*, 65 (11), 2199–211. Cited in: Miller, T., Birch M., Mauthner, M., and Jessop, J. (2012) *Ethics in Qualitative Research.* London: Sage.

Miller, T., Birch, M., Mauthner, M., and Jessop, J. (2012). *Ethics in Qualitative Research.* London: Sage.

Oakley, A. (1998). 'Gender, methodology and people's ways of knowing: some problems with feminism and the paradigm debate in social science'. *Sociology*, 32 (4), 707–31.

Oakley, A. (2013). 'Interviewing women: a contradiction in terms'. In: Roberts, H. (ed.) *Doing Feminist Research* (pp. 30–61). London: Routledge.

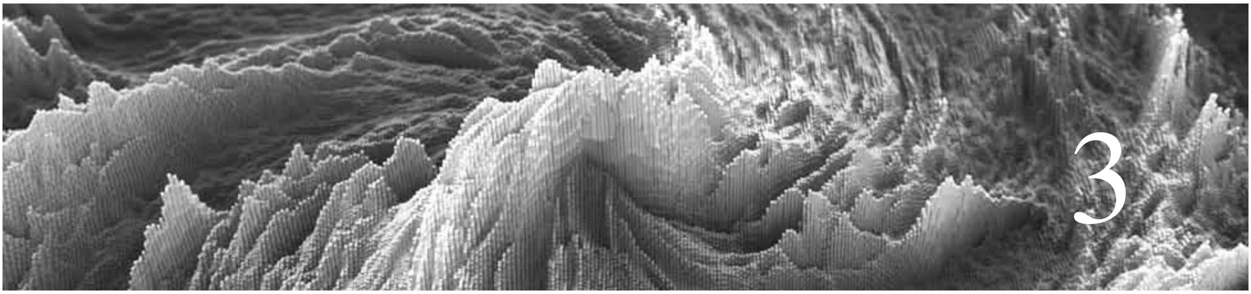
Roberts, L. D. (2015). 'Ethical issues in conducting qualitative research in online communities'. *Qualitative Research in Psychology*, 12 (3), 314–25.

Taylor, C. (1989). *Sources of the Self: The Making of the Modern Identity*. Cambridge: Cambridge University Press.

Weiner-Levy, N. and Popper-Giveon, A. (2013). 'The absent, the hidden and the obscured: reflections on "dark matter" in qualitative research'. *Quality & Quantity*, 47 (4), 2177–190. Cited in: Annink, A. (2017) 'Using the research journal during qualitative data collection in a cross-cultural context'. *Entrepreneurship Research Journal*, 7 (1). doi: 10.1515/erj-2015-0063.

Whiteman, N. (2012). 'Ethical stances in (Internet) research'. In Whiteman, N. *Undoing Ethics* (pp. 1–23), Springer: New York. Cited in: Roberts, L. D. (2015) 'Ethical issues in conducting qualitative research in online communities'. *Qualitative Research in Psychology*, 12 (3), 314–25.

World Health Organisation (WHO) (2001). *Putting Women First: Ethical and Safety Recommendations for Research on Domestic Violence Against Women.* Retrieved from: http://www.who.int/gender/violence/women firtseng.pdf



3

A Posthumanist Ethics of Mattering: New Materialisms and the Ethical Practice of Inquiry

Natasha S. Mauthner

INTRODUCTION

Against a background of renewed interest in materiality in the social sciences, this chapter considers what this 'material turn' might entail for qualitative research and its ethical practice. The notion of materiality has been conceptualized in diverse ways across different theoretical traditions. Reckwitz (2002), for example, suggests that materiality has been variously understood as 'social structures', 'symbolic objects' and 'material artifacts'. In this chapter, I take up a new materialist understanding of materiality as 'materialization'. New materialist theories, however, do not constitute a unified approach, and my specific focus is on the conceptualization of materiality advanced by Karen Barad (2007), one of the most prominent contemporary new materialist scholars. Barad proposes a conceptualization of materiality as ontological processes of materialization. On this approach, materiality is not understood as a material substance that is fixed and given. Rather, it is an ontologically dynamic process that on-goingly remakes itself through processes of materialization. In proposing a notion of materiality that refuses to take its own materiality and existence as ontologically given, Barad's conceptual notion of materiality implies a non-essentialist ontological understanding of materiality.[1] In this respect, Barad puts forward not only a new concept of materiality but also a distinctive non-essentialist ontology. In contrast to concepts of materiality that assume an underlying material and/or cultural essence to the world, Barad's concept does not presume the ontological existence or given-ness of any-'thing'. She develops a metaphysical framework, which she calls 'agential realism', on the basis of this non-essentialist ontology. Agential realism is concerned with the ontological processes of formation through which all entities are brought into being. Critically, agential realism refuses to take its own existence as given and insists that it accounts for the processes of formation through which it materializes itself. Agential realism, then, is a metaphysics that accounts for its own material and ontological existence and for the material role that it plays in materializing the ontology of the world.

Agential realism constitutes a metaphysical departure from major Western philosophical and scientific traditions, albeit one that is also indebted to them. In particular, it diverges from naturalistic and social constructivist approaches in terms of its ontological commitments. Naturalistic inquiry in the social sciences seeks to understand the true nature of the social world. It treats the social world as an objectively fixed reality that awaits human discovery. In this sense it assumes the ontological existence and given-ness of a social world that has an objective and material substance, and that is understood to be already out there. Examples of this approach in qualitative research are studies that treat research participants' accounts of their lives, and researchers' reports of these accounts, as transparent representations of pre-existing empirical realities. Constructivist approaches reject this idea and propose instead that the social world can only be accessed and understood through discursive, interpretive, and cultural meaning-making processes. In this sense, they take the existence of culture as an ontological given, and redefine empirical and material realities in discursive terms. Agential realism contrasts with both naturalistic and social constructivist approaches, and philosophical variations of them, in that it does not commit itself to the ontological existence of material and/or cultural entities.[2]

Taking up an agential realist metaphysics, and its non-essentialist ontology, therefore challenges many long held, normative and often implicit ontological assumptions that are built into the ways in which we conceptualize and practice social inquiry and research ethics. One of the ways in which it reconfigures research is by shifting our philosophical conceptualization of knowledge-making practices from a *representationalist* to a *performative* understanding. As already indicated, naturalistic and social constructivist forms of inquiry assume that knowledge represents pre-existing material and/or cultural worlds. Barad argues that while we have tended to understand naturalism and constructivism as philosophically distinct traditions, they share a commitment to an essentialist ontology: naturalism takes the material world, while constructivism takes the cultural world, as ontologically given. Both traditions, she suggests, ignore practices of representation: that is, the processes through which 'natural' and 'cultural' entities (and the division between them) come to be represented and constituted as such. Agential realism pays attention to these practices of representation, and conceptualizes them as natural-cultural or material-discursive (see below) ontological processes of materialization that perform the world into being by giving it both an ontological existence and an ontological form. That is, practices of representation both materialize the world into existence, and, in doing so, materialize it into specific kinds of entities. For example, research practices – including qualitative inquiry – constitute not only human identities (and therefore also their binary other, non-human identities – such as animals and machines – and the ontological separation between the human and the non-human) but also specific forms of human identities in terms of gender, race, ethnicity, class, sexuality and so on. The argument is that research practices neither discover pre-existing identities, nor do they provide interpretations or constructions of these identities. Rather, research practices, along with many other kinds of practices, help *constitute* specific kinds of identities (humans, animals, machines) as well as specific categories of human identities (men, women, White, Asian, Black, working-class, middle-class, and so on). It is in this sense that agential realism puts forward a performative conceptualization of research practices that contrasts with representationalist (naturalistic and social constructivist) formulations.

Agential realism also requires a different approach to research practice. In contrast to the objective practices of naturalistic inquiry, and the reflexive practices of social constructivist approaches, Barad proposes what she calls ‘diffractive’ practices. Whereas objective and reflexive practices enact commitments to an essentialist ontology, diffractive practices enact a commitment to a non-essentialist ontology by accounting for their own ontological existence and for the role they play in materializing the ontology of their objects of study. Picking up on the example above, diffractive practices account for the concept of identity they embed and enact and for their non-essentialist conceptualization of this concept. Significantly, while reflexivity involves *researchers* accounting for cultural influences on knowledge production systems and objects of knowledge, diffractive practices involve *practices* accounting for their own ontological existence, their ontological assumptions and the ontological entities they help bring into being. Thus, while reflexivity is an epistemological practice that locates epistemological agency, accountability and responsibility with human researchers, diffraction is an ontological – or what Barad (2007: 185) terms ‘onto-epistemological’ – practice that locates ontological agency, accountability and responsibility with practices themselves.

Just as the philosophy and practice of research are reconfigured within an agential realist metaphysics, so too is research ethics. Barad rethinks both how we conceptualize and practice research ethics through her notion of a ‘posthumanist ethics of mattering’. By ‘posthumanist’ she means an ethics that does not locate moral agency and responsibility with the human intentional subject but rather with knowledge-making (and other) practices and their world- and boundary-making powers and effects (Barad, 2007: 136). By ‘mattering’ Barad refers to a practice of inquiry that accounts and takes responsibility for its own ontological existence and for the power it has to materialize the world. Barad therefore reconceptualizes ethics as a practice (not a researcher) that accounts for its own material existence and its material effects in helping to constitute the world. And she proposes that this ethics be enacted through diffractive practices. Following Barad, I suggest that a posthumanist ethical practice of inquiry is a practice that enacts, and accounts for, its commitment to a non-essentialist ontology.

The ethical issues of concern to Barad, then, are the ontological assumptions that underpin knowledge-making practices: assumptions about both what the world is understood to be ontologically made of, and assumptions about the ontological status of these entities. She takes issue with the ethics of an essentialist ontology, an ontology that assumes that entities are immutable, and that fails to account for itself, for the specificity of its boundary-making practices, and for its constitutive role in bringing specific entities into being. To be clear, the focus of her critique is not humans and their ontological assumptions, but rather an essentialist ontology itself, the representationalist practices it gives rise to, and representationalism’s abrogation of ethical responsibility for its world-making powers and effects. Following Barad, *the ontological assumptions that underpin knowledge-making practices are a matter of ethical concern* because it makes a material difference to the world whether practices enact a world of fixed and pre-existing entities, or a world of ongoing processes of materialization that leave open the possibility of contesting and reconstituting existing configurations of the world. Critical to Barad’s (2007: 185) metaphysics is this intertwining of ethics, knowing, and being and a conceptualization of knowledge-making as an inseparably ‘ethico-onto-epistemological’ practice.

Barad illustrates her argument with the case of ultrasound technology used for viewing the fetus inside a pregnant mother’s womb. Barad argues that ontological understandings of ultrasound technology, and the fetus that it helps to visualize, make a material difference to the fetus, the mother, abortion debates, science, the medical profession, politics, the law, and much more. Ultrasound technology is normatively conceptualized and enacted as an innocent tool for viewing the fetus. It enacts the fetus as an autonomous, free-floating, self-contained subject that is separate from its mother's body and her subjectivity. It furthermore enacts this fetus as an ontological given: as pre-existing the ultrasound technology that is used to bring it into being through its visualization. This ontological understanding of the fetus, ultrasound technology, and the relation between them is not innocent. For example, it makes possible the constitution of the fetus as a moral and legal subject, which in turn has a bearing on abortion policy and legislation. Following Barad, the ontological assumptions embedded and enacted in ultrasound technology are a matter of ethical concern in that the technology fails to account and take responsibility for its non-innocent actions and effects. Agential realism calls on ultrasound technology to enact itself in a way that accounts for its specific ontological conceptualization of itself, the fetus, and the relation between them, and for the potential moral and political consequences that follow from this specific configuration. A posthumanist ethical practice of ultrasound technology is a practice that accounts for its own non-innocence and for its non-innocent ontological effects in the world. It is a practice that enacts the fetus as inseparable from a wider network of practices, including ultrasound technology, that help constitute both the *ontological existence* of the fetus and the *specific form* in which it is brought into being (e.g. as an autonomous subject).

A posthumanist ethics contrasts with how we are accustomed to conceptualizing and practicing research ethics in the social sciences and in qualitative research. Current approaches to ethics are implicitly, if not explicitly, informed by the main philosophical traditions that have guided social scientific inquiry. Following the logic of naturalistic inquiry, ethics has been concerned with ensuring that research provides objective and unbiased (value-free) representations of the world, and that it does so without causing harm to research participants. These ethical concerns have given rise to institutional mechanisms (e.g. institutional review boards and ethics committees) for overseeing and regulating research ethics, governance and integrity. They have also led to ethical practices such as seeking participants' informed consent, maintaining confidentiality, anonymizing personal details, and ensuring secure storage of research data. These practices are designed to respect research participants' rights to information, self-determination, dignity, and privacy; and to protect them from physical, emotional, psychological and/or moral harm. Social constructivist approaches have given rise to a futher set of ethical concerns with recognizing the subjectivity of researchers, and the power, and value-laden nature, of historically and culturally-situated epistemological frameworks and research practices. This has resulted in researchers reflexively accounting for the values that inform and influence their research. It has also led to the involvement of research respondents as co-producers of knowledge, and to the development of participatory research models and practices designed to empower research participants and harness their knowledge.[3]

A posthumanist ethics (as developed in this chapter) does not dismiss these ethical approaches, concerns and practices, but sees them as tied to specific metaphysical frameworks and ontological premises. Agential realism, with its distinctive ontological presuppositions, makes possible different ethical questions that are concerned not only with the power relations between, inter alia, researchers, research participants, research ethics committees, and knowledge frameworks but also with the power of practices of inquiry to materialize specific worlds by virtue of the specific concepts they embed and enact, and their specific ontological commitments to essentialist or non-essentialist ontological understandings of these concepts. It is in this sense that Barad's approach to ethics has a posthumanist orientation. This is not to suggest that ethical agency and responsibility lie with non-human entities (animals, plants, rocks, machines, objects), or that ethics should necessarily encompass more-than-human concerns (animal welfare, biodiversity, the ecological state of the planet). Rather, a posthumanist ethics locates moral agency and ethical responsibility with distributed practices at different scales (including but not limited to knowledge, research and ethical practices) and takes as its matter of ethical concern the ontological assumptions that underpin these practices and the specific boundaries and configurations of the world that these practices bring into being. This means that while researchers, research respondents, research ethics regulatory bodies, knowledge frameworks and much more are implicated in the ethical practice of inquiry they do so as part of a much wider set of practices, and they are understood as both participants and constitutive effects of these practices. In this sense a posthumanist ethics differs from normative humanist approaches, which tend to locate moral agency and ethical responsibility with researchers (and research ethics panels and committees), and tend to be directed towards human concerns (typically research participants and their rights).

To be clear, the kind of posthumanist ethics outlined here does not promise better qualitative research or a more ethical practice of inquiry. Rather, it makes possible an ethics that is materially and constitutively excluded by representationalist – naturalistic and constructivist – philosophical traditions and their neglect of the ethico-onto-epistemological dimensions of practices of representation. A posthumanist ethics is an ethical practice that follows from taking up a different – agential realist – metaphysical framework where agential realism is not seen as an improvement on what has come before. Indeed, new materialist philosophies do not conceive of themselves in teleological terms as progressive philosophies in relation to their forebears, as such a move would re-inscribe the essentialist metaphysics they seek to shift (Dolphijn & van der Tuin, 2012). A posthumanist ethics does not reject established research and ethical approaches and practices. Rather, it materializes ontologies and genealogies of these practices and the specific objects of study and matters of ethical concern they make possible. At the same time, this opens up opportunities for reconceptualizing research and ethical practices as diffractive practices underpinned by a non-essentialist ontology. Agential realism therefore entails working both with and against the practices that we have inherited. Following Haraway (2016), it involves ‘staying with the trouble’: working with established practices but reconfiguring their ontology so that they account for their ontological existence, commitments and effects.

I have used these introductory remarks to outline some of the key elements of new materialist philosophies with a focus on the distinctive metaphysics that they propose and how it makes possible new practices of inquiry and approaches to research ethics. In particular, and following Barad, I conceptualize a new materialist or posthumanist ethical practice of research as *diffractive practices of inquiry that account for their ontological existence, commitments and effects.* I use the remainder of the chapter to develop and substantiate this argument in more detail. But before doing so, I want to emphasize that my chapter enters largely uncharted waters and should be read accordingly as a work in progress. This is because new materialist philosophies are very recent, having only come to prominence towards the end of the twentieth century. Despite resonances with other philosophical traditions, new materialist philosophies are breaking new ground by advancing distinctive metaphysical understandings of the world. A growing body of new materialist scholarship is fleshing out the far-reaching implications of these philosophies for our understanding and enactment of the world, including the very nature of life and matter. While this has included discussions of a posthumanist ethics (e.g. Alaimo & Hekman, 2008; Åsberg, 2013; Barad, 2007; Dolphijn & van der Tuin, 2012; Hinton, 2013; Thiele, 2014), there have been fewer attempts to articulate what this might mean for the ethical practice of inquiry.

My chapter is organized in the following way. I begin by discussing some of the ways in which the material turn is inspiring new ways of conceptualizing and conducting research in the social sciences by highlighting two bodies of work in particular: 'post-qualitative inquiry' (Lather, 2015; St Pierre, 2011) and 'the social life of methods' (Law, 2004; Savage, 2013). While these studies draw on diverse notions of materiality, they share an interest in the ways in which attention to the material dimensions of research gives rise to new methods and objects of inquiry. This materiality may take the form of the embodied experiences of researchers and research participants, the material artifacts used by participants, the physical settings of investigations, and the tools and devices used in social inquiries. In the second section of the chapter, I discuss in more detail different theoretical conceptualizations of materiality. To Reckwitz's (2002) three notions – materiality as 'social structures', 'symbolic objects' and 'material artifacts' – I add a fourth new materialist understanding of materiality as 'materialization'. I discuss Barad's specific conceptualization of materiality as ontological processes of materialization, and the non-essentialist ontology that this entails. In the third section, I explore Barad's agential realist metaphysical framework that she elaborates on the basis of her concept of materiality and non-essentialist ontology. I consider how it opens up new and distinctive possibilities for social inquiry and its ethical practice, including how it makes way for what Barad calls a 'posthumanist ethics of mattering'. In the fourth section of the chapter, I explore how Barad's posthumanist ethics can be put into practice through what she calls diffractive practices, and I propose two such practices: 'diffractive genealogies' and 'metaphysical practices'. In the fifth section, I illustrate a posthumanist ethical practice of qualitative research using the *Listening Guide* feminist method of narrative analysis, a method I have been engaged with for twenty-five years.

MATERIALITY, RESEARCH PRACTICE AND ETHICS

A renewed emphasis on the material nature of the world is helping to inspire novel and diverse ways of undertaking research in the social sciences. Two areas of work in particular are formulating innovative approaches to conceptualizing and enacting research methods and ethics.[4] First, the turn to materiality is reinvigorating the field of qualitative research leading to inquiries that are being identified as 'post-qualitative' (St Pierre, 2011). These studies share sensitivity to the material dimensions of research, where attention to materiality is conceptualized and put into practice in different ways. One aspect involves highlighting the human bodies, physical objects, environmental settings and research tools involved in research such as: the sensory experience of archival research and the spatio-temporal features of an archive (Tamboukou, 2014); the bodily experiences and emotions of research participants and the physical spaces and environments (e.g. noise, architecture, IT systems) they inhabit (Lenz Taguchi & Palmer, 2013; Taylor & Ivinson, 2013); and the role of tape and digital recording devices (Nordstrom, 2015). The material turn is seen to provide welcome theoretical and methodological resources for attending to the material aspects of research and considering them alongside discursive dimensions (i.e. human researchers and research participants engaged in meaning making processes). Taylor and Ivinson (2013: 666), for example, suggest that material feminist approaches recognize 'all sorts of bodies, not just human bodies … as having agency' and that in doing so they 'displace the human as the principle ground for knowledge'. Fox and Alldred (2015, 2016), working closely with what they term a 'DeleuzoGuattarian ontology' use the concept of 'research-assemblage' to refer to this bringing together of 'bodies, things and abstractions that get caught up in social inquiry, including the events that are studied, the tools, models and precepts of research, and the researchers' (Fox & Alldred, 2015: 444).

Another dimension of the turn to materiality in post-qualitative research is an insistence on developing philosophically-informed practices as a means of translating philosophical and conceptual assumptions into material research practices (e.g. St Pierre, 2011, 2015). There are two elements to this. One is a call on researchers to make explicit – rather than take for granted – the ontological and epistemological assumptions that underpin their research. The other is an attempt to develop an approach to qualitative research that is grounded within new materialist philosophies, as an alternative to realist, social constructivist and humanist ontologies. For example, several studies have sought to destabilize 'conventional humanist' (St Pierre, 2011) qualitative research through an ontological critique of some of its key concepts (e.g. experience, narrative, voice) and practices (e.g. the interview, ethnography, reflexivity), and through the elaboration of methodological approaches informed by new materialist theories (e.g. Coleman & Ringrose, 2013; Hultman & Lenz Taguchi, 2010; Koro-Ljungberg, 2015). These interventions propose new qualitative research methods by drawing on earlier poststructural, and contemporary new materialist, theories and concepts. There has been a particular focus on the work of Deleuze and Guattari including their concepts of assemblage, affect, becoming, and territories, amongst others. St Pierre (2014) and Jackson and Mazzei (2012), for example, have developed methodological practices – which Jackson and Mazzei (2012), drawing on Deleuze and Guattari (1987), call 'plugging in' – that involve putting poststructural and new materialist concepts to work by asking what analytical questions of data they make possible. The concepts they use include: Foucault's archaeology, genealogy, and power-knowledge; Deleuze and Guattari's rhizoanalysis and schizoanalysis; Derrida's affirmative deconstruction; Lyotard's paralogy; Spivak's marginality; Deleuze's desire; Butler's performativity; and Barad's intra-activity.[5]

There is a further trend to rethink methods within sociology and science and technology studies, which has come to be known as the 'social life of methods' (Law et al., 2011; Savage, 2013). These interdisciplinary studies, influenced in part by actor network theory and its material-semiotic understanding of social networks, take the 'social science apparatus' (Savage, 2010) as an object of critical analysis – including its theories, concepts, and measurement practices (e.g. Adkins & Lury, 2011; Callon, 1998). They seek to understand how this apparatus has been shaped by, and in turn helped to shape, material, social and historical processes. One strand of work takes research methods as objects of study to understand how they emerged; and what kinds of assumptions about individuals and society these methods have implicitly relied on and helped to materialize when put into practice (Back & Puwar, 2012; Law, 2004, 2009; Law & Urry, 2004; Lury & Wakeford, 2012; Ruppert, Law, & Savage, 2013; Savage, 2010, 2013).[6] For example, Savage (2010) argues that the survey and interview methods that became prominent in Britain after the Second World War, and that were used to investigate social change, were not simply capturing or representing national identities – rather, they were contributing to the remaking of them while at the same time helping to constitute sociology as a discipline. These studies therefore challenge dominant instrumentalist conceptualizations of research methods by proposing performative understandings that highlight how methods help to produce the very objects they purport to describe, while also generating other phenomena (e.g. the discipline of sociology).

These various bodies of work touch upon the ethical implications of the material turn, noting that it entails a new way of conceptualizing ethics. Some working within a post-qualitative tradition, for example, argue that new materialist philosophies behoove researchers to recognize that they are ethically implicated in the material effects of their interventions; and that they have a responsibility, through their research, to bring about material changes in the world (Taylor & Ivinson, 2013). For St Pierre, Jackson, and Mazzei (2016: 4) new materialist approaches to qualitative inquiry provide the potential 'to imagine and create a different, more ethical existence' and practice of inquiry. The 'social life of methods' concern with the performative effects of methods, and their inherent values and politics (Adkins & Lury, 2011; Law, 2004, 2009; Savage, 2010), begins to flesh out a different orientation to research ethics that takes as its object of ethical concern the world-making and world-changing potentialities of methods – or what Mol (1999) calls their 'ontological politics'. Gross (2011), for example, opens up a space for thinking about the ethics of ethical practices when she suggests that, by asking participants to relinquish ownership and privacy of their data, the practices of informed consent and data anonymization are implicated in the objectification and commodification of data. These ethical practices, she argues, can also be understood as 'economic devices' in that they 'articulate a particular kind of social data economy' (Gross, 2011: 113).

THEORETICAL CONCEPTUALIZATIONS OF MATERIALITY

As the discussion above suggests, the turn to materiality encompasses a diversity of theoretical and empirical approaches, reflected in different understandings of the concept of materiality. As Reckwitz (2002: 195) points out, 'the idea of "materiality" does not have a common meaning among theorists of culture … it rather occupies the place of the "non-cultural", which is conceptualized in very diverse ways'. Reckwitz identifies three in particular. First, a classical sociological understanding of materiality as '*social structures*' as seen in the works of Marx, Durkheim and Simmel, amongst others. Despite differences amongst these theorists, they share the view that the material is situated in social structures that lie outside culture, and that these structures comprise 'a non-ideational sphere of regularities and patterns that exists and has causal effects independent of subjective or collective interpretations' (Reckwitz, 2002: 197). The material, defined as social structures, is understood as the cause and ultimate foundation of the cultural, including human action and behaviour. Cultural theory provides a second conceptualization of materiality in which it is understood as 'objects of knowledge' or '*symbolic objects*'. This notion is associated with structuralism, semiotics and poststructuralism, phenomenology and hermeneutics, Wittgenstein's philosophy of language-games, and symbolic interactionism. Reckwitz argues that despite profound differences in their conceptualization of the social and of meaning, these approaches share an overarching view regarding the status of the material world: 'The material world *exists* only insofar as it becomes an object of interpretation within collective meaning structures' (Reckwitz, 2002: 202). Material entities are not understood to exist as such. Rather, they come to be defined as, and gain the symbolic quality of, 'material objects' through cultural or discursive systems that describe them as such and that distinguish them from other material or non-material objects. Reckwitz delineates a third conceptualization of materiality as '*material artefacts*', which he associates with actor network theory, practice theory, and science studies including the work of Latour, Pickering and Haraway. This approach represents an attempt to overcome the distinction between the material and the cultural, and to move beyond the idea that these two domains determine one another. This third approach positions the material as neither social structure nor symbolic object but as '"things', which are necessary components of social networks or "practices"' (Reckwitz, 2002: 207) and which participate in these networks just as humans do. These networks, then, are understood as 'material-semiotic' in the sense that they are assemblages of both material and semiotic actors. They 'include *both* what conventional realists think of as referents and *also* what we think of as reference' (Elder-Vass, 2015: 106). As Lynch (2013: 453) explains, actor network theory is 'a semiotic materialism that, unlike the more familiar naturalistic materialism, treats humans and nonhumans alike as relational nodes situated in networks that endow them with agency and voice'.

To Reckwitz's three, I would add a fourth conceptualization of materiality as '*materialization*' proposed by new materialist philosophies (Alaimo & Hekman, 2008; Barad, 2007; Bennett, 2010; Bolt & Barrett, 2012; Braidotti, 1991, 2002; Coole & Frost, 2010; DeLanda, 1996, 2002; Dolphijn & van der Tuin, 2012; Haraway, 1988; Kirby, 2011; Pitts-Taylor, 2016; van der Tuin & Dolphijn, 2010).[7] Although Reckwitz locates the work of Haraway within his third approach, I would position her amongst these new materialist scholars. Like the traditions included in Reckwitz's 'materiality as material artifacts' approach, new materialist theories also seek to rethink the relationship between the material and the cultural. They do so, however, not by reinstating the material (in the form of material artifacts), and suggesting that the material and the cultural are equal participants in the world. Rather, they reconceptualize the very ontology of the material, the cultural, and the relation between them. They refuse an a priori ontological distinction between the material and the cultural, and are interested instead in the material-semiotic (Haraway, 1988) or material-discursive (Barad, 2007) processes through which the 'material' and the 'cultural' come to be constituted as ontologically distinct domains.

This conceptualization of materiality seems to echo Reckwitz's second and third approaches identified above, but there are important differences. In Reckwitz's second approach – 'materiality as symbolic objects' – *cultural processes* are understood to constitute the material, effectively reducing the material to the cultural. New materialist philosophies, however, understand this constitutive process as an inseparably *materialcultural*, rather than a purely cultural, process. And while Reckwitz's third approach – 'materiality as material artifacts' – proposes a notion of the material-semiotic that seems similar to the one put forward by new materialist philosophies, the ontological relation between the material and the semiotic is conceptualized differently. For actor network theory and related traditions the relation between the material and the semiotic is understood in additive terms: already constituted material entities are combined with already constituted semiotic elements. As Elder-Vass (2015: 114) observes, for actor network theory 'the world is out there, but it is out there in the form of assemblages in which the being of material things is inextricably bound up with specific (thus historical), human, subjective conceptions of them'.[8] For new materialist philosophies, however, the material-semiotic refers to a relation of ontological inseparability whereby these domains only come to be constituted as separate and separable through specific ontological material-discursive processes of formation that materialize them as such. In this sense, new materialist approaches differ from other traditions that also take into account material and cultural dimensions but treat these as ontologically separate and already constituted entities that can be combined in synthetic or additive ways through 'dialectic reconciliation' (Coole & Frost, 2010: 8). Barad (2007) introduces the concept of 'intra-action' to convey the nature of this ontological relationship and to contrast it with the notion of interaction that we are more familiar with:

> 'intra-action' *signifies the mutual constitution of entangled agencies.* That is, in contrast to the usual 'interaction', which assumes that there are separate individual agencies that precede their interaction, the notion of intra-action recognizes that distinct agencies do not precede, but rather emerge through, their intra-action. It is important to note that the 'distinct' agencies are only distinct

> in a relational, not an absolute, sense, that is, *agencies are only distinct in relation to their mutual entanglement; they don't exist as individual elements.* (emphasis in original, p. 33)

Thus while new materialist theories have emerged as part of the cultural turn they are also a reaction to the privilege it accords to semiotic processes in the constitution of reality.[9] Similarly, while new materialist philosophies are part of a broader material turn, they are working with a specific conceptualization of materiality that sets them apart from other approaches such as actor network theory. In particular, new materialist philosophies are distinctive from both cultural theory and actor network theory in their ontological conceptualization of materiality, and of the relation between the material and the cultural. New materialist theories define materiality as an active, dynamic and constitutive process of materialization, rather than an inert, fixed or stable material substance (e.g. a physical structure, object or artifact) or the material properties of an entity. Materiality is understood as self-generative: it is a process that on-goingly materializes and makes itself through on-going processes of materialization. If materiality is redefined as materialization then it no longer simply denotes, or is exclusively tied to, what we are accustomed to thinking of as 'the material'. This is because the idea of there being a purely material domain is rejected, not in the sense that the material requires the addition of culture for it to be meaningful, but rather because new materialists refuse to treat the material, the cultural, and the distinction between them as ontological givens. If the material and the cultural are invoked as separate and distinctive domains, then the ontological processes of materialization through which this separation, and its dualist entities, are constituted must be accounted for (and indeed, as I discuss below, becomes the very locus of ethicality). This implies that outside of these materialization processes the world is inseparably material-cultural or what Haraway (2003) refers to as 'natureculture'.

In proposing a new ontological understanding of materiality, new materialist contributions amount to more than providing a new conceptual definition of materiality. Rather, they are proposing a new ontology or metaphysics. This is characterized by many as a non-dualist, monist or relational ontology and metaphysics because of its refusal to take the separation between the material and the cultural as given, along with a host of other related dualisms (e.g. meaning vs. matter, mind vs. body, culture vs. nature, male vs. female) (Dolphijn & van der Tuin, 2012). This non-dualist stance places new materialist approaches within a longer lineage of philosophies that have sought to work against the dualist philosophical traditions that have dominated much of Western philosophy and science. This includes, amongst others, the works of Lucretius, Duns Scotus, Spinoza, Hume, Nietzsche, Marx, Bergson, Whitehead and Heidegger (van der Tuin & Dolphijn, 2010).

Barad's new materialist metaphysics, agential realism, furthermore advances a relational ontology or non-dualist metaphysics that refuses to take itself as an ontological given and insists on accounting for its own ontological existence and commitment to a relational or non-dualist ontology. In this sense, agential realism contrasts with 'a traditional ontology that posits an underlying and coherent unity beneath circumstantial variations' (Lynch, 2013: 459). Barad is not suggesting that *researchers* using an agential realist metaphysics *reflexively* account for their ontological assumptions and practices – an approach that has characterized much social science and qualitative research influenced by the cultural turn, including postmodern approaches to research ethics (e.g. Clegg & Slife, 2009). What Barad proposes is the more counter-intuitive idea that *practices* of research – conceptualized as material-discursive processes of materialization – account for their ontological existence, commitments and effects. I now turn to consider in more detail Barad's conceptualization of materiality and the agential realist metaphysics she elaborates on the basis of it.

BARAD'S NEW MATERIALIST METAPHYSICS: AGENTIAL REALISM AND A POSTHUMANIST ETHICS OF MATTERING

Barad is a physicist and feminist theorist. The new metaphysics that she proposes, agential realism, is in part inspired by the work of Niels Bohr and his interpretation of quantum physics. An enduring puzzle in the field of quantum physics has been how to make sense of the fact that quantum entities – that is, matter – can behave both as particles and as waves depending on the experimental conditions. Physicists have developed different interpretations of these results. Bohr's view was that physical systems (matter) do not have definite properties prior to being measured. That is to say, quantum entities do not have essential or inherent identities whereby they are either particles or waves. Rather, the nature of matter is indeterminate outside of specific experimental practices that measure matter either as a wave or as a particle. Bohr argued that these experimental practices create a relation of ontological inseparability – what Barad calls 'intra-action' – between a measurement device and the object that it measures. One kind of apparatus measures the nature of matter as a particle and a different apparatus measures the nature of matter as a wave. In contrast to classical Newtonian physics, in which the role of measurement is seen as inconsequential, Bohr argued 'quantum physics requires a new logical framework that understands the constitutive role of measurement processes in the construction of knowledge' (Barad, 2007: 67).

Barad (2207: 54) builds on Bohr's 'proto-performative' formulation of the apparatus and proposes a performative ontology in which ontological entities – both the ontological existence of entities and the specific ontological forms they take – are understood to be inherently indeterminate outside of specific, dynamic and constitutive processes and practices of materialization. On this approach, research practices provide neither direct access to, nor partial representations of, nor social constructions of these entities. Rather, research practices help constitute the very existence and nature of these entities. The concept of performativity is used in a strong ontological sense. Practices are not understood as performing pre-existing and already constituted entities. Rather, entities are ontologically constituted only when enacted in practices. The suggestion is not that, for example, an interview provides an occasion for researchers and research respondents to perform (pre-existing) identities. The argument is that interview practices ontologically constitute, or perform into being, the very nature and forms of researcher and respondent identities. Research practices help make the world real, where realism is not understood as the existence of an objectively given material and/or social reality that can be fully known, partially known, or known through its social construction. It is a reality that 'becomes with' (Haraway, 2008) the practices that enact it. It is an agential reality (Barad, 2007): a reality that is only made real through ongoing agential, ontological, and material processes of materialization.

The performativity of practices is a theme that runs through other theoretical traditions (including the work of Althusser, Foucault, Butler, Latour, Mol, and Law). As noted above, studies investigating the social life of methods argue that methods perform the world into being rather than represent it (Law, 2004). Indeed, Law uses the term 'enactment realism' to signal that 'the real is enacted in practices, rather than being reflected through them' (Law, 2004: 168). Mol (2002: 44) similarly argues, 'If an object is real this is because it is part of a practice. It is a reality *enacted*' (emphasis in original, Mol, 2002). In her book, *The Body Multiple*, Mol further develops this argument using the disease atherosclerosis as a case study. Atherosclerosis, she suggests, is what materializes through specific practices: it ontologically becomes something different according to the practices through which it is enacted. In the outpatient clinic atherosclerosis is pain on walking, while in the department of pathology and under the microscope it becomes a thickening of the intima of the leg arteries. Following Mol, these practices do not provide different epistemological understandings, interpretations or constructions of the disease. They constitute different or multiple ontologies of the disease.

Barad's conceptualization of the performativity of practices makes an important contribution to this literature by providing distinctive insights into the ontological nature of practices and the mechanisms through which they perform the world into being. These mechanisms lie in the materiality of practices*:* in their ontological and agential processes of materialization, where these processes are understood to be inseparably material-discursive. Barad's notion of practices as material-discursive ontological processes of materialization is again in part indebted to the work of Niels Bohr. One of Bohr's key insights was to conceptualize the experimental apparatus as a physical-conceptual device that embodies, materializes, and gives meaning to specific concepts to the exclusion of others. He furthermore understood concepts as specific material arrangements of experimental apparatuses and not abstract ideations or inherent attributes of independently existing objects. Barad draws on Bohr's notion of physical-conceptual devices, including his critical insight about the materiality of concepts and his notion that devices are materializations of concepts, and reworks it into 'material-discursive practices'. (For this, Barad draws additionally on Butler's (1993) and Foucault's (1975/1977) account of the material and constitutive nature of discursive practices). Barad therefore argues that practices of inquiry are performative material-discursive practices that constitute their objects of study according to the specific concepts that are built into them and that they materialize when put into practice. It is these specific concepts, and their embodiment in experimental apparatuses, that provide the mechanism through which practices constitute the world. The suggestion, however, is not simply that researchers build concepts into practices (which they reflexively account for). Rather, research practices have their own agency. Through their ongoing materialization of themselves, they embed and enact specific concepts to the exclusion of others. This implies that all practices have a material-discursive specificity that stems from these specific concepts, where these might be concepts of identity, agency, change, time, structure, materiality, relationality, and so on. Furthermore, all practices also embody and enact a concept of being and assumptions about the ontology of concepts themselves: i.e. commitments to an essentialist or non-essentialist ontological understanding of these concepts. For example, I have argued elsewhere that qualitative longitudinal data analysis practices underpinned by a representationalist metaphysics embody and enact not only different theoretical concepts of time (e.g. historical, personal, linear, cyclical, situational, spatial time) but also the ontological assumption that time is an ontological given that pre-exists the practices that are used to investigate it. Time is understood to be 'simply there' in the form of a past, present, and future that research participants are negotiating or narrating, and that researchers are studying and writing about (Mauthner, 2015). My argument is that these specific conceptual and ontological commitments constitute the mechanisms through which practices perform the world into being.[10] On my reading of Barad, a posthumanist ethical practice of inquiry is a practice that materializes and accounts for its conceptual and ontological commitments, and the performative role they play in helping to constitute the ontology of the world.

This way of conceptualizing and enacting research ethics is a departure from established approaches. As I have already indicated, however, a posthumanist ethics does not seek to overthrow or replace these positions. Instead, it highlights how they are contingent on specific metaphysical frameworks and ontological assumptions. In particular, representationalism's commitment to an essentialist ontology and its 'failure to take account of the practices through which representations are produced' (Barad, 2007: 53) constitutively excludes the possibility of positioning its practices of representation as a matter of ethical – or more precisely ethico-onto-epistemological – concern, in the way that agential realism makes possible.

ENACTING A POSTHUMANIST ETHICS THROUGH DIFFRACTIVE PRACTICES

A posthumanist ethical practice of inquiry is a practice that enacts its commitment to a non-essentialist ontology: that is, it is a practice that enacts the ontological inseparability between itself and its objects of study. Barad's concern is therefore to develop practices of inquiry that materialize and account for (rather than take as ontologically given) their own dynamic ontological materialization and that of their objects of study. They neither take themselves nor their objects of study as ontologically pre-existing or fixed, but rather enact themselves and their objects as coming into being together through their intra-action. Barad's notion of 'diffraction' offers a way of conceptualizing and enacting these kinds of practices. In seeking to develop a methodological practice for enacting her agential realist metaphysics, and building on Haraway's (1992, 1997) suggestion of embracing a different optics in science studies – diffraction rather than reflection – Barad (2007, 2014) proposes diffractive practices. In physics, diffraction is 'an intra-active phenomenon, and as such does not hold one set of concerns as pre-existing or stable or primary over another' (Barad, 2011: 449). On my reading, diffractive practices are dynamic material-discursive practices that account for their non-innocent (Haraway, 1991: 121) existence, commitments and effects.

Building on Barad's concept of diffraction I have been seeking to develop diffractive practices for new materialist inquiries (see also Mauthner, 2015, 2016, 2017). I discuss two such practices here: what I call 'diffractive genealogies' and 'metaphysical practices'. I conceptualize these practices as inseparably conceptual-empirical: they are methods for simultaneously conceptualizing and enacting new materialist inquiry. They are also practices that have built-in ethical accountability and responsibility because they account for their own ontology and that of their objects of study. For heuristic purposes, I separate them out into two practices. In the conduct of research, they need not be separated or used in a sequential manner. These practices do not displace established research practices of inquiry. Rather, they investigate the genealogies of these practices, reconstitute their ontology, and in doing so require that they are practised in a different way. The practices that I propose are therefore not understood to provide better ways of doing research, that are more ethical or that generate better knowledge of the world. Rather, they are practices that follow from working within a different metaphysical framework, where this framework is not understood in teleological terms.

My notion of diffractive genealogies is informed by the work of Barad (2007, 2010), as well as Butler (1990), Derrida (1967/1997, 1995), Foucault (1975/1977, 1984, 1990, 1991), Haraway (1992, 1997), and Somers (2008). By diffractive I mean a practice that does not take the ontology of the world as already constituted. By genealogy I mean a practice that can materialize ontological processes of formation 'at different scales' (Barad, 2007: 246). By diffractive genealogies I mean genealogies that account for the ontological practices through which these genealogies, and their objects of study, are constituted. Diffractive genealogies, then, do not innocently go back in time and through space searching for origins and tracing a past and a history that really happened. Diffractive genealogies intra-actively (re)configure the genealogies they produce. They are underpinned by the assumption that neither the genealogical practices that are engaged, nor the genealogies that are thereby generated, nor their spatial and temporal dimensions are ontologically given. Diffractive genealogies take practices of inquiry (philosophical, theoretical, methodological, ethical) as objects of study and inquire into how these practices came into being, what metaphysical (conceptual and ontological) assumptions they embed and enact, and what metaphysical objects they intra-actively produce. Diffractive genealogies are philosophically 'situated' (Haraway, 1988) philosophical histories. They are a materialization of an ontological commitment to a non-essentialist ontology because they enact their object of study as a constitutive effect of historical material-discursive processes of formation.

On a new materialist approach, the ontology of practices of inquiry is not taken as given. Practices of inquiry dynamically and on-goingly make and materialize themselves in conceptually- and ontologically-specific ways. They have a material-discursive or what I call metaphysical specificity, which provides the mechanism through which practices play a part in constituting the world and the specific entities it comprises. I use the notion of practices of inquiry as 'metaphysical practices' to conceptualize and enact this ontological (re)configuration of practices of inquiry. On this approach, these practices are metaphysical because they (necessarily) embody and enact specific metaphysical presuppositions to the exclusion of others. Characterizing practices of inquiry as metaphysical emphasizes that practices of inquiry embody and enact not only specific theoretical concepts (e.g. of time), but, critically, also a concept of being: i.e. metaphysical presuppositions about the ontological nature of these concepts (e.g. time). Practices are therefore materializations of first principles, 'initial conditions' (Kirby, 2012), and the metaphysical terms on which our practices engage/with/as-part-of the world (Mauthner, 2016). Reconstituting practices of inquiry as metaphysical means they no longer enact themselves as readymade conceptual-practical tools and resources for discovering pre-existing natural and/or social worlds. Rather, metaphysical practices perform themselves as ethical, responsible and accountable practices that materialize and account for their own conceptual and ontological existence and assumptions, and for the metaphysically-specific objects they bring into being.

A POSTHUMANIST ETHICAL PRACTICE OF QUALITATIVE RESEARCH

A posthumanist ethical practice of inquiry entails a way of doing research that takes neither its own practices, nor its objects/subjects of study/concern, as ontologically given. This applies equally to philosophical, theoretical, methodological and ethical practices. In this sense, taking up a new materialist metaphysics has implications for all forms of inquiry. Its relevance is not restricted to the natural, social or human sciences, to specific disciplines, or to specific research approaches and methods such as qualitative or quantitative investigations. Indeed, a new materialist metaphysics refuses to take these material-conceptual boundaries as given. Rather, it accounts for how these divisions, and the entities they give rise to – including the distinction between qualitative and quantitative research – come to be constituted in the first place.

For the purposes of this chapter, I want to consider the implications of a posthumanist ethics specifically for qualitative inquiry. I suggest that a posthumanist ethical practice of qualitative research entails enacting qualitative research practices that account for their commitment to a non-essentialist ontology. This is accomplished through the two diffractive practices outlined above: (1) a diffractive genealogy of qualitative research, which materializes the temporally-spatially distributed ontological processes of formation through which qualitative research practices, and their conceptual and ontological assumptions, have come into being; (2) embedding a non-essentialist ontology into qualitative research practices which transforms them into metaphysical practices that take neither their own existence, nor their conceptual and ontological commitments, nor their objects of study as ontologically given. On this approach, a new materialist ethical practice of qualitative research is neither a continuation of, nor a break from, established practices. Rather, it entails an ontological reworking of, and re-engagement with, existing qualitative research practices in which the latter are not conceptualized or enacted as readymade tools for discovering pre-existing (material and/or cultural) realities but as metaphysical practices that have been genealogically constituted, that embed specific conceptual and ontological assumptions, and that perform their objects of study in accordance with these conceptual and ontological commitments. A posthumanist ethical practice of qualitative research is a way of conducting inquiry that materializes its object of study as coming into existence contingently with its specific philosophical history, and its specific conceptual and ontological premises.

Any of the myriad philosophical, theoretical, methodological and ethical practices that are used in qualitative research could be used to illustrate this posthumanist approach to the ethical practice of qualitative research. For the purposes of this discussion I use Brown and Gilligan's (1992) *Listening Guide* feminist method of narrative analysis. This is a method I have been engaged with for 25 years. I first learnt it by working with Carol Gilligan during the period 1992–1995. For the following two decades I used the *Listening Guide* in my own research (Mauthner, 1999, 2002, 2003, 2010), ran workshops on it and taught it to graduate students (Alkhaled-Studholme, 2013; Tonkin, 2013), and wrote about it with my colleague Andrea Doucet (Mauthner & Doucet, 1998, 2003; Doucet & Mauthner, 2002/2012, 2008). Inspired by Barad's agential realist metaphysics, I have recently been revisiting the method in an attempt to reconfigure it in new materialist terms (Mauthner, 2016, 2017). My argument in this chapter is that engaging in a posthumanist ethical practice of the *Listening Guide* requires conducting a diffractive genealogy that takes the *Listening Guide* as an object of study to materialize its conceptual and ontological genealogy and commitments; and using this knowledge to reconfigure the *Listening Guide* into metaphysical practices that are underpinned by a non-essentialist ontology and that enact their objects of study according to their specific conceptual and ontological commitments. On the agential realist approach outlined in this chapter, using the *Listening Guide* entails accompanying it with a diffractive genealogy which has the effect of reconfiguring it into metaphysical practices; that is, diffractive practices that account for their metaphysical existence, commitments, power and effects. I only have space here to give a brief indication of what this project involves, but elsewhere I have elaborated on this in more detail (Mauthner, 2016, 2017).

A diffractive genealogy of the *Listening Guide* is a philosophically situated – specifically, agential realist – philosophical history of the *Listening Guide* that explores how it came into being and with what conceptual and ontological assumptions. The *Listening Guide* was a method developed at Harvard University in the 1980s following the publication in 1982 of Gilligan's highly influential book, *In A Different Voice*. In this book, Gilligan took issue with established theoretical and methodological approaches to understanding moral development. She argued that these supposedly neutral and objective theories and methods carried gender biases and assumptions in that they rated autonomy, independence and separation – characteristics found predominantly in men – as more advanced developmental stages compared to relationality, connectedness and interdependence – characteristics found predominantly in women. Gilligan's objective was to develop what she regarded as less biased theories and methods, based on a concept of moral development heard predominantly in women's accounts, in order to listen to women on their own terms and value their distinctive developmental paths and trajectories. Gilligan and her colleagues developed the *Listening Guide* as a method for hearing and analyzing a broader range of 'different voices', thereby generating more all-encompassing empirical and theoretical understandings of identity formation and moral development (Brown & Gilligan, 1992).

A diffractive (agential realist) reading of this work materializes its underpinning naturalistic orientation. While identity formation and moral development are conceptualized as taking different forms, ontologically-speaking they are understood to have an independent ontological existence and as being ontologically prior to the theories and methods that are used to investigate them. A diffractive genealogy of the *Listening Guide* materializes how this metaphysical assumption is embedded in the method. The *Listening Guide* was designed to generate more complete insights into women's experiences and it entails listening to interview narratives in several stages each time listening for different stories – about identity, relationships, and cultural norms and constraints. The *Listening Guide* therefore constitutes and enacts itself as a progressive method better able to access the realities of women's lives, where these realities are understood to be ontologically pre-existing but out of reach of patriarchal methodological and theoretical approaches. As such the *Listening Guide* embodies and enacts a liberal philosophical, moral and political commitment to women's rights that materializes itself through its specific methodological practices – listening for voices, identities and relationships – and through the specific objects – voices, identities and relationships – that these practices both presuppose and help materialize. In this respect the *Listening Guide,* in this specific metaphysical form, has been constituted in relation to a much broader set of philosophical, theoretical, methodological, moral, and political concerns including second-wave feminism and its identity-politics project. Indeed, the *Listening Guide* has contributed to constituting second-wave feminism by playing a productive role in materializing 'women's voices' in a time and place where these voices were otherwise marginalized.

On an agential realist approach this metaphysical configuration of the *Listening Guide,* and the realities it helps to constitute, are not taken as given, nor are they seen as researchers' subjective constructions or effects of epistemologically-specific frameworks. Rather, they are understood as the materialization of historically- and culturally-specific onto-epistemological inheritances. An agential realist practice of the *Listening Guide* is a practice that materializes and accounts for this inheritance and its metaphysical specificity. It is a diffractive practice in which *Listening Guide* practices are reconstituted into metaphysical practices that account for their own metaphysical existence, specificity and inheritance; for the genealogical processes through which they have been constituted; for the conceptual and ontological assumptions they embed and enact; and for the onto-epistemological and political identities and boundaries they perform into being. My suggestion is that a posthumanist ethical practice of the *Listening Guide*, as outlined in this chapter, entails a shift away from using the method as a readymade tool for discovering pre-existing voices, identities and relationships; and from a reflexive practice which recognizes that the method, and the voices, identities and relationships it gives rise to, are socially constructed. On a posthumanist performative approach, the *Listening Guide* practices themselves materialize and account for the constitutive role they play in generating specific voices, identities and relationships. Importantly, neither the *Listening*

Guide, nor its feminist identity-politics project, are rejected. Rather, they are critically appreciated and affirmed through a diffractive move that ontologically reconfigures this method and project into inherently ethical practices that account for their historically-, culturally- and metaphysically-specific existence, commitments, power and effects.

CONCLUSIONS

This chapter has sought to contribute to the project of developing a new materialist social science through the articulation of a distinctive new materialist approach to conceptualizing and enacting the ethical practice of inquiry, including qualitative research. I have emphasized that there are diverse theoretical conceptualizations of materiality, with new materialist understandings representing one of many strands. Furthermore, new materialist theories themselves do not constitute a unified approach. There are different theoretical interpretations of new materialisms, and empirical translations of new materialisms into research practice are also wide ranging. This chapter has focused specifically on the new materialist philosophy, agential realism, proposed by Barad and how it opens up new and distinctive possibilities for how we understand and practice social inquiry and research ethics. I have suggested that agential realism constitutes a new metaphysics through its advancement of a non-essentialist ontology; a performative conceptualization of knowledge-making that accounts for the material-discursive mechanisms through which realities are performed into being; diffractive practices of inquiry that are ways of enacting a non-essentialist ontology; and a posthumanist ethics of mattering that materializes, accounts and takes responsibility for the performative role that diffractive practices of inquiry play in helping to constitute the very nature of the world. I have emphasized that Barad's posthumanist ethics is not seen as promising a more ethical approach to inquiry. Rather, it is a way of conceptualizing and practising research ethics that follows from taking up a distinctive metaphysical position on the nature and role of knowledge-making.

The critical ethical question that emerges from Barad's posthumanist ethics is whether the social sciences, their material-discursive apparatuses and practices, and their objects of study and concern are seen as ontologically fixed and given, or as dynamic processes that change, adapt, and reconstitute themselves in open-ended ways. Critically, this is as much a matter of politics and practice as it is of ethics and philosophy. This is because the ontological assumptions that are embedded and enacted in the social sciences, and their apparatuses, make a material difference to the world and to the making of potential alternative worlds. It is not simply the case, however, that these alternative worlds will be more ethical or just. Interventions are never innocent or without consequences, and all configurations of the world necessarily entail exclusions and injustices. The ethical and political issue then is not 'political quietism' (Kirby, 2012: 198) but rather engaging in world-making practices that account for their inclusionary and exclusionary boundaries and effects. As Barad (2007: 205) suggests:

> There are risks in putting forward an ontology: making metaphysical assumptions explicit exposes the exclusions on which any given conception of reality is based. But the political potential of deconstructive analysis lies not in simply recognizing the inevitability of exclusions but in insisting on accountability for the particular exclusions that are enacted and in taking up the responsibility to perpetually contest and rework the boundaries.

ACKNOWLEDGEMENTS

I want to thank Ron Iphofen, Martin Tolich, Martyn Hammersley and Lorna McKee for their thoughtful and critical feedback on an earlier version of this chapter.

Notes

1 Essentialism refers to the belief that entities have a set of characteristics that makes them what they are, and that the task of science and philosophy is to discover these essences.

2 A wide range of philosophical traditions, beyond naturalism and social constructivism, inform qualitative research including, for example, positivism, phenomenology, hermeneutics, interpretivism, pragmatism and critical realism. The point I make here, but do not have the space to develop, is that despite their differences these philosophical traditions share an underlying essentialist and dualist metaphysics: a belief in the existence of an ontologically prior and given reality populated with pre-existing dualistic entities such as materiality vs. culture, matter vs. meaning, body vs. mind, and so on.

3 For the purposes of this chapter, I am concerned to show how specific ethical concerns and practices follow from specific metaphysical assumptions underpinning research. Having said this, it is important to acknowledge that there are wide ranging approaches to research ethics. For example, researchers work within different ethical frameworks including consequentialist, principlist, non-consequentialist, virtue ethics, and ethic of care (Israel & Hay, 2006; Wiles, 2013). Furthermore, their discipline (e.g. biomedicine, social science), theoretical stance (e.g. postmodernism, feminism, critical race theory) and empirical methods (e.g. qualitative, quantitative) influence how they approach and experience ethical issues in the field as well as how they negotiate the regulation of research ethics (Brabeck & Brabeck, 2009; Dingwall, 2006; Edwards & Mauthner, 2002/2012; Iphofen, 2011; Mertens & Ginsberg, 2009; Miller et al., 2002/2012; Stark, 2011; Tolich, 2016; van den Hoonaard & Hamilton, 2016; van den Hoonaard & van den Hoonaard, 2013). Discussion of these important contributions to ethical debates and practices lies beyond the scope of this chapter.

4 There are other examples of a material turn in the social sciences, including Daniel Miller's (1987) anthropological research on material artefacts and Sarah Pink's (2009) development of an embodied and sensory ethnography.

5 Post-qualitative inquiry has spawned several special issues of journals including: *Cultural Studies ↔ Critical Methodologies* on 'Data' (2013, Volume 13, Issue 4); *The International Journal of Qualitative Studies in Education* on 'Post-Qualitative Research' (2013, Volume 26, Issue 6); *Gender and Education* on 'Material Feminisms: New Directions for Education' (2013, Volume 25, Issue 6); *Qualitative Inquiry* on 'Qualitative Data Analysis after Coding' (2014, Volume 20, Issue 6); *Cultural Studies ↔ Critical Methodologies* on 'New Empiricisms and New Materialisms' (2016, Volume 16, Issue 2).

6 Interest in the social life of methods has generated several special issues of journals including: *Cultural Sociology* on 'Rethinking Qualitative and Quantitative Methods' (2009, Volume 3, Issue 2); *Sociological Review* on 'Measure and Value' (2011, Volume 59, Supplement 2); *Sociological Review* on 'Live Methods' (2012, Volume 60, Supplement 1); *Theory, Culture & Society* on 'The Social Life of Methods' (2013, Volume 30, Issue 4).

7 The terms 'new materialism' and 'neo-materialism' were first used in the 1990s, independently by Manuel DeLanda and Rosi Braidotti, to propose a cultural theory that privileged neither culture nor nature, but focused on what Donna Haraway (2003) would later call 'nature-cultures' (van der Tuin & Dolphijn, 2010).

8 It is important to note here that, as Elder-Vass (2015) points out, actor network theory is not entirely consistent in terms of its conceptualization of the material, the cultural, and the relation between them.

9 In this sense, new materialist theorists work with and against many of the key poststructuralist thinkers (and indeed scholars working within other traditions as well) including Butler, Deleuze, Derrida, Foucault and Guattari. New materialist scholars are revisiting these texts through a new materialist metaphysics and generating new understandings of them, in particular with regard to how the relation between the material and the cultural has been conceptualized.

10 Agential realism therefore offers both a general metaphysics (i.e. a new theory of matter and what it is) and a theory of the mechanisms through which matter constitutes itself.

REFERENCES

Adkins, L. and Lury, C. (2011) Introduction: Special measures. *The Sociological Review* 59(S2): 5–23.

Alaimo, S. and Hekman, S. (eds) (2008) *Material Feminisms*. Bloomington, IN: Indiana University Press.

Alkhaled-Studholme, S. (2013) *Women Entrepreneurs in Saudi Arabia: Bargaining Within a Patriarchal Society.* Doctoral dissertation, University of Aberdeen, UK.

Åsberg, C. (2013) The timely ethics of posthumanist gender studies. *Feministische Studien*, 1: 7–12.

Back, L. and Puwar, N. (2012) A manifesto for live methods: Provocations and capacities. *The Sociological Review* 60(S1): 6–17.

Barad, K. (2007) *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning.* Durham, NC and London: Duke University Press.

Barad, K. (2010) Quantum entanglements and hauntological relations of inheritance: Dis/continuities, spacetime enfoldings, and justice-to-come. *Derrida Today* 3(2): 240–268.

Barad, K. (2011) Erasers and erasures: Pinch's unfortunate 'uncertainty principle'. *Social Studies of Science* 41(3): 443–454.

Barad, K. (2014) Diffracting diffraction: Cutting together-apart. *Parallax* 20(3): 168–187.

Bennett, J. (2010) *Vibrant Matter: A Political Ecology of Things*. Durham, NC and London: Duke University Press.

Bolt, B. and Barrett, E. (eds) (2012) *Carnal Knowledge: Towards a 'New Materialism' Through the Arts.* London: I.B. Tauris.

Brabeck, M. M. and Brabeck, K. M. (2009) Feminist perspectives on research ethics. In: Mertens D. M. and Ginsberg P. E. (eds) *The Handbook of Social Research Ethics* (pp. 39–53). Los Angeles, CA: Sage.

Braidotti, R. (1991) *Patterns of Dissonance: A Study of Women and Contemporary Philosophy*. Cambridge: Polity Press.

Braidotti, R. (2002) *Metamorphoses: Towards a Materialist Theory of Becoming*. Cambridge: Polity Press.

Brown, L. M. and Gilligan, C. (1992) *Meeting at the Crossroads: Women's Psychology and Girl's Development*. Cambridge, MA: Harvard University Press.

Butler, J. (1990) *Gender Trouble: Feminism and the Subversion of Identity*. London: Routledge.

Butler, J. (1993) *Bodies that Matter: On the Discursive Limits of 'Sex'.* New York and London: Routledge.

Callon, M. (1998) Introduction: The embeddedness of economic markets in economics. *The Sociological Review* 46(S1): 1–57.

Clegg, J. W. and Slife, B. D. (2009) Research ethics in the postmodern context. In: Mertens, D. M. and Ginsberg, P. E. (eds) *The Handbook of Social Research Ethics* (pp. 23–38). Los Angeles, CA: Sage.

Coleman, R. and Ringrose, J. (eds) (2013) *Deleuze and Research Methodologies*. Edinburgh: University of Edinburgh Press.

Coole, D. and Frost, S. (eds) (2010) *New Materialisms: Ontology, Agency, and Politics*. Durham, NC and London: Duke University Press.

DeLanda, M. (1996) The Geology of Morals: A Neo-Materialist Interpretation. http://www.t0.or.at/delanda/geology.htm (accessed 5 September 2016).

DeLanda, M. (2002) *Intensive Science and Virtual Philosophy*. London and New York: Continuum.

Deleuze, G. and Guattari, F. (1987) *A Thousand Plateaus: Capitalism and Schizophrenia.* Minneapolis, MN: University of Minnesota Press.

Derrida, J. (1967/1997) *Of Grammatology*. (Gayatri Chakravorty Spivak, trans.). Baltimore, MD: Johns Hopkins University Press.

Derrida, J. (1995) *Archive Fever: A Freudian Impression.* Chicago: University of Chicago Press.

Dingwall, R. (2006) Confronting the Anti-Democrats: The Unethical Nature of Ethical Regulation in Social Science. *Medical Sociology Online* 1: 51–58.

Dolphijn, R. and van der Tuin, I. (eds) (2012) *New Materialism: Interviews & Cartographies.* Ann Arbor, MI: Open Humanities Press.

Doucet, A. and Mauthner, N. S. (2002/2012) Knowing responsibly: Linking ethics, research practice and epistemology. In: Miller, T., Birch, M., Mauthner, M., and Jessop, J. (eds) *Ethics in Qualitative Research. Second Edition* (pp. 122–139). London: Sage.

Doucet, A. and Mauthner, N. S. (2008) What can be known and how? Narrated subjects and the Listening Guide. *Qualitative Research* 8(3): 399–409.

Edwards, R. and Mauthner, M. (2002/2012) Ethics and feminist research: Theory and practice. In: Miller, T., Birch, M., Mauthner, M., and Jessop, J. (eds) *Ethics in Qualitative Research. Second Edition* (pp. 14–28). London: Sage.

Elder-Vass, D. (2015) Disassembling actor–network theory. *Philosophy of Social Sciences* 45(1): 100–121.

Foucault, M. (1975/1977) *Discipline and Punish: The Birth of the Prison*. New York: Vintage Books.

Foucault, M. (1984) Nietzsche, genealogy, history. In: Rabinow, P. (ed.) *The Foucault Reader* (pp. 76–120). New York: Pantheon Books.

Foucault, M. (1990) *The History of Sexuality: Volume 1: An Introduction*. London: Penguin.

Foucault, M. (1991) Questions of method. In: Burchell, G. Gordon, C., and Miller, P. *The Foucault Effect: Studies in Governmentality* (pp. 73–86). London: Harvester Wheatsheaf.

Fox, N. J. and Alldred, P. (2015) New materialist social inquiry: Designs, methods and the research-assemblage. *International Journal of Social Research Methodology* 18(4): 399–414.

Fox, N. J. and Alldred, P. (2016) *Sociology and the New Materialism*. London: Sage.

Gilligan, C. (1982) *In A Different Voice: Psychological Theory and Women's Development.* Cambridge, MA: Harvard University Press.

Gross, A. (2011) The economy of social data: Exploring research ethics as device. *The Sociological Review* 59(S2): 113–129.

Haraway, D. (1988) Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, 14(3): 575–599.

Haraway, D. J. (1991) *Simians, Cyborgs, and Women: The Reinvention of Nature.* New York: Routledge.

Haraway, D. (1992) The promises of monsters: A regenerative politics for inappropriate/d others. In: Grossberg, L., Nelson, C., and Treichler, P. A. (eds) *Cultural Studies* (pp. 295–337). New York: Routledge.

Haraway, D. J. (1997) *Modest_Witness@Second_Millenium.FemaleMan©_Meets_OncoMouse™: Feminism and Technoscience*. New York and London: Routledge.

Haraway, D. (2003) *The Companion Species Manifesto: Dogs, People, and Significant Otherness.* Chicago, IL: Prickly Paradigm Press.

Haraway, D. J. (2008) *When Species Meet*. Minneapolis, MN: University of Minnesota Press.

Haraway, D. J. (2016) *Staying with the Trouble*: *Making Kin in the Chthulucene.* Durham, NC and London: Duke University Press.

Hinton, P. (2013) The quantum dance and the world's 'extraordinary liveliness': Refiguring corporeal ethics in Karen Barad's agential realism. *Somatechnics* 3(1): 169–189.

Hultman, K. and Lenz Taguchi, H. (2010) Challenging anthropocentric analysis of visual data: A relational materialist methodological approach to educational research. *International Journal of Qualitative Studies in Education* 23(5): 525–542.

Iphofen, R. (2011) *Ethical Decision Making in Social Research: A Practical Guide.* London: Palgrave Macmillan.

Israel, M. and Hay, I. (2006) *Research Ethics for Social Scientists.* London: Sage.

Jackson, E. Y. and Mazzei, L. A. (2012) *Thinking with Theory in Qualitative Research: Viewing Data across Multiple Perspectives.* London: Sage.

Kirby, V. (2011) *Quantum Anthropologies: Life at Large*. Durham, NC and London: Duke University Press.

Kirby, V. (2012) Initial conditions. *Differences: A Journal of Feminist Studies* 23(3): 197–205.

Koro-Ljungberg, M. (2015) *Reconceptualizing Qualitative Research: Methodologies without Methodology*. London: Sage.

Lather, P. (2015) The work of thought and the politics of research: (Post)qualitative research. In: Denzin, N. K. and Giardina, M. D. (eds) *Qualitative Inquiry and the Politics of Research* (pp. 97–117). Walnut Creek, CA: Left Coast Press.

Law, J. (2004) *After Method: Mess in Social Science Research.* Abingdon: Routledge.

Law, J. (2009) Seeing like a survey. *Cultural Sociology* 3(2): 239–256.

Law, J., Ruppert, E., and Savage, M. (2011) *The Double Social Life of Methods.* ESRC Centre for Research on Socio-Cultural Change (CRESC) Working Paper 095.

Law, J. and Urry, J. (2004) Enacting the social. *Economy and Society* 33(3): 390–410.

Lenz Taguchi, H. and Palmer, A. (2013) A more 'livable' school? A diffractive analysis of the performative enactments of girls' ill-/well-being with(in) school environments. *Gender and Education* 25(6): 671–687.

Lury, C. and Wakeford, N. (eds) (2012) *Inventive Methods: The Happening of the Social.* Abingdon: Routledge.

Lynch, M. (2013) Ontography: Investigating the production of things, deflating ontology. *Social Studies of Science* 43(3): 444–462.

Mauthner, N. S. (1999) 'Feeling low and feeling really bad about feeling low': Women's experiences of motherhood and postpartum depression. *Canadian Psychology/psychologie canadienne* 40(2): 143–161.

Mauthner, N. S. (2002) *The Darkest Days of My Life: Stories of Postpartum Depression.* Cambridge, MA: Harvard University Press.

Mauthner, N. S. (2003) 'I was imprisoned in my own prison': A relational understanding of Sonya's story of postpartum depression. In: Stoppard, J. M. and McMullen, L. M. (eds) *Situating Sadness: Women and Depression in Social Context* (pp. 88–114). New York: New York University Press.

Mauthner, N. S. (2010) 'I wasn't being true to myself': Women's narratives of postpartum depression. In: Jack, D. C. and Ali, A. (eds) *Silencing the Self Across Cultures: Depression and Gender in the Social World* (pp. 459–484). Oxford: Oxford University Press.

Mauthner, N. S. (2015) 'The past was never simply there to begin with and the future is not simply what will unfold': A posthumanist performative approach to qualitative longitudinal research. *International Journal of Social Research Methodology* 18(3): 321–336.

Mauthner, N. S. (2016) Un/re-making method: Knowing/enacting posthumanist performative social research methods through 'diffractive genealogies' and 'metaphysical practices'. In: Pitts-Taylor, V. (ed.) *Mattering: Feminism, Science, and Materialism* (pp. 258–283). New York: New York University Press.

Mauthner, N. S. (2017) The *Listening Guide* feminist method of narrative analysis: Towards a posthumanist performative (re) configuration. In: Woodiwiss, J., Smith, K., and Lockwood, K. (eds) *Feminist Narrative Research: Opportunities and Challenges* (pp. 65–92). London: Palgrave Macmillan.

Mauthner, N. S. and Doucet, A. (1998) Reflections on a voice-centred relational method: Analysing maternal and domestic voices. In: Ribbens, J. and Edwards, R. (eds) *Feminist Dilemmas in Qualitative Research: Public Knowledge and Private Lives* (pp. 119–146). London: Sage.

Mauthner, N. S. and Doucet, A. (2003) Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology* 37(3): 413–431.

Mertens, D. M. and Ginsberg, P. E. (eds) (2009) *The Handbook of Social Research Ethics.* Los Angeles, CA: Sage.

Miller, D. (1987) *Material Culture and Mass Consumption*. Oxford: Basil Blackwell.

Miller, T., Birch, M., Mauthner, M., and Jessop, J. (eds) (2002/2012) *Ethics in Qualitative Research. Second edition*. London: Sage.

Mol, A. (1999) Ontological politics: A word and some questions. In: Law, J. and Hassard, J. (eds) *Actor Network Theory and After* (pp. 74–89). Oxford and Keele: Blackwell and *The Sociological Review*.

Mol, A. (2002) *The Body Multiple: Ontology in Medical Practice*. Durham, NC and London: Duke University Press.

Nordstrom, S. N. (2015) Not so innocent anymore: Making recording devices matter in qualitative interviews. *Qualitative Inquiry* 21(4): 388–401.

Pink, S. (2009) *Doing Sensory Ethnography*. London: Sage.

Pitts-Taylor, V. (2016) (ed.) *Mattering: Feminism, Science, and Materialism.* New York: New York University Press.

Reckwitz, A. (2002) The status of the 'material' in theories of culture: From 'social structures' to 'artefacts'. *Journal for the Theory of Social Behaviour* 32(2): 195–217.

Ruppert, E., Law, J., and Savage, M. (2013) Reassembling social science methods: The challenge of digital devices. *Theory, Culture & Society* 30(4): 22–46.

Savage, M. (2010) *Identities and Social Change in Britain since 1940: The Politics of Method.* Oxford and New York: Oxford University Press.

Savage, M. (2013) The 'Social Life of Methods': A critical introduction. *Theory, Culture & Society* 30(4): 3–21.

Somers, M. (2008) *Genealogies of Citizenship: Markets, Statelessness, and the Rights to Have Rights*. Cambridge: Cambridge University Press.

Stark, L. (2011) *Behind Closed Doors: IRBs and the Making of Ethical Research.* Chicago: University of Chicago Press.

St Pierre, E. A. (2011) Post qualitative research: The critique and the coming after. In: Denzin, N. K. and Lincoln, Y. S. (eds) *SAGE Handbook of Qualitative Inquiry*, 4th edition (pp. 611–635). Los Angeles, CA: Sage.

St Pierre, E. A. (2014) A brief and personal history of post qualitative research: Toward 'post inquiry'. *Journal of Curriculum Theorizing* 30(2): 1–19.

St Pierre, E. A. (2015) Practices for the 'new' in the new empiricisms, the new materialisms, and post qualitative inquiry. In: Denzin, N. K.

and Giardina, M. D. (eds) *Qualitative Inquiry and the Politics of Research* (pp. 75–95). Walnut Creek, CA: Left Coast Press.

St Pierre, E. A., Jackson, A. Y., and Mazzei, L. A. (2016) New empiricisms and new materialisms: Conditions for new inquiry. *Cultural Studies ↔ Critical Methodologies*, 16(2): 1–12.

Tamboukou, M. (2014) Archival research: Unravelling space/time/matter entanglements and fragments. *Qualitative Research* 14(5): 617–633.

Taylor, C. A. and Ivinson, G. (2013) Material feminisms: New directions for education. *Gender and Education* 25(6): 665–670.

Thiele, K. (2014) *Ethos* of diffraction: New paradigms for a (post)humanist ethics. *Parallax* 20(3): 202–216.

Tolich, M. (2016) *Qualitative Ethics in Practice*. London: Routledge.

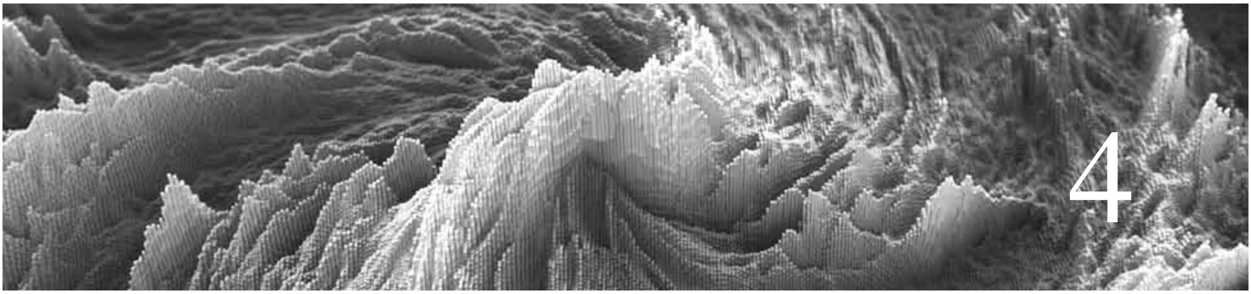
Tonkin, L. (2013) *Fantasy and Loss in Circumstantial Childlessness*. Doctoral dissertation, University of Canterbury, New Zealand.

van den Hoonaard, W. C. and Hamilton, A. (eds) (2016) *The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review*. Toronto: University of Toronto Press.

van den Hoonaard, W. C. and van den Hoonaard, D. K. (2013) *Essentials of Thinking Ethically in Qualitative Research.* London: Routledge.

van der Tuin, I. and Dolphijn, R. (2010) The transversality of new materialism. *Women: A Cultural Review*, 21(2): 153–171.

Wiles, R. (2013) *What are Qualitative Research Ethics?* London: Bloomsbury.



4

Feminist Epistemologies and Ethics: Ecological Thinking, Situated Knowledges, Epistemic Responsibilities

Andrea Doucet

> An ethical judgment is not a quantitative calculation at root but an acknowledgement of responsibility for a relationship. (Haraway, 2000: 147)
>
> [R]esponsibility/accountability issues are … to my mind, both epistemological and ethical. (Code, 1995: xiv)

INTRODUCTION

Every story has many versions and origins. One version of the beginnings of feminist epistemologies, as a field of scholarly attention, was that it began with four seemingly simple, yet deeply provocative concerns that ignited decades of debate. The first arose when Canadian feminist philosopher Lorraine Code posed what she later called (1998: 73) an 'outrageous question' in her piece entitled, 'Is the sex of the knower epistemologically significant?' (Code, 1981). A couple of years later, Sandra Harding and Merrill Hintikka (1983) published a collection where all contributors reflected on how 'feminist concerns and insights' could be 'brought to bear on epistemology, metaphysics, methodology, and philosophy of science – the philosophic fields that were purportedly completely immune to social influences?' (Harding & Hintikka, 2003: xii). Then, in the late 1980s, Lorraine Code and Donna Haraway introduced two concepts that would come to play a central role in discussions of epistemologies and ethics: epistemic responsibility (Code, 1987) and 'situated knowledges' (Haraway, 1988).

These are some of the questions and concepts, in various iterations, that combined to generate a diverse and highly interdisciplinary field that connects feminist epistemologies, methodologies, and ethics. From its earliest days, many contributors to this field have sought to develop conceptual, epistemological, methodological, and ethical approaches to challenge the alleged value neutrality of investigation and researcher distance from its objects as well as the hegemony of dominant 'spectator epistemologies' premised on interchangeable, disembodied knowers and research practices that were 'abstract, "generalized", and disengaged' (Code, 1995: xi; see also Code, 1993, 1996, 2006).

While there was some consensus among feminist researchers about the need to critique and reconfigure mainstream scientific and positivist methodologies and epistemologies, throughout the 1990s questions remained as to the need for distinctly *feminist* approaches to issues of knowledge making. Questions abounded. 'Would a feminist epistemology simply reverse androcentric epistemology to a gynocentric epistemology?' (Duran, 1991: 14–15). 'What does feminism require of an epistemology?' Is there a need for 'a specifically feminist alternative to currently available epistemological frameworks' (Antony, 1993: 187)? Outside feminist circles, different concerns were raised. As Helen Longino (1997) pointed out, 'The idea of feminist epistemology [threw] some philosophers into near apoplexy.' (p. 19). More recently, Phyllis Rooney confirmed that feminist epistemology is still treated with 'hostility and dismissal' in wider 'epistemology "proper"' circles (Rooney, 2011: 6).

Questions about the specifically feminist character of feminist epistemologies have never been fully settled. This is partly because feminism is a highly diverse field that has become even more diverse with its growing attention to intersectionality and the need to think beyond gender (Hill Collins & Bilge, 2016; Siltanen & Doucet, 2017). Linda Alcoff and Elizabeth Potter (1993) hinted at this widening many years ago, arguing in the introduction to their seminal volume, *Feminist Epistemologies*, that 'feminist epistemology should not be taken as involving a commitment to gender as the primary axis of oppression, in any sense of "primary", or positing that gender is a theoretical variable separable from either axes of oppression and susceptible to a unique analysis' (pp. 3–4).

It is also the case that epistemology, as a field, is richly varied, with many of its own intersections with, for example, analytic and continental philosophy, as well as overlaps with other epistemological approaches, including pragmatism, naturalism, contextualism, social epistemology, virtue epistemology, and, more recently, postcolonial and indigenous epistemologies, among many others. Given this diverse terrain, I begin the chapter concurring with Heidi Grasswick (2011: xx), who argues: 'Not only are feminist epistemologists mining the resources of these approaches for their own projects, but their insights are also contributing significantly to the development of these approaches themselves.' After forty years on this terrain, Code admits that she now takes a 'scavenger approach to epistemic resources' (Code, 2011: 218), as she draws on a wide and eclectic array of epistemological and philosophical resources.

To map the connections between feminist epistemologies and ethics, it is important to start by attending to what unites feminist researchers. Drawing on Code's scavenger metaphor, this chapter is underpinned by three key points that, in my view, guide all feminist epistemological work. First, I draw on the oft-repeated argument that '(f)eminism's most compelling epistemological insight lies in the connections it has made between knowledge and power' (Lennon & Whitford, 1994: 1); thus, a key epistemological question for feminist researchers is 'Whose knowledge are we talking about?' (Code, 2006: 21) as well as an enduring focus on knowing marginalized people. Second, I will argue in this chapter that, as noted above, feminist epistemological writing addresses epistemic responsibilities and situated knowledges. In this vein, Grasswick recently confirmed (2011: xvi, emphasis in original): '*Situated knowing* is the single most influential concept to come out of feminist epistemology'. Finally, while 'epistemic responsibility' initially received a 'mixed reception' (Code, 1995: 3) when first introduced by Code, it has since become one of the most important concepts in discussions of knowledge making and ethics. Yet, what is critical to add here – and this point frames my chapter – is that meanings and practices of epistemic responsibilities, as well as situated knowledges, have shifted across time. As I detail in this chapter, this has happened especially in light of evolving social theories and philosophical turns, which have shaped and reshaped the ways that we think about methods, methodologies, epistemologies, ontologies, and ethics, as well as the entanglements between all of these.

This chapter has five sections. First, I lay out my approach to reading key authors, drawing on Donna Haraway's (1997) concept of diffraction and Karen Barad's (2007) 'diffractive readings'. Second, I map out the geography of the field of feminist epistemologies as it unfolded in the 1980s and 1990s, working with Sandra Harding's well-known tripartite classification. I highlight the gradual dissolution of this typology while also identifying some of the enduring ethical issues that were charted by key writers working within and across these approaches. Third, I briefly highlight new mappings of feminist epistemologies as they have intersected with several key social and philosophical turns, and the implications resulting from entanglements of feminist epistemologies, ontologies, and ethics, or what Barad (2007: 185) calls 'ethico-onto-epistemologies'. Fourth, I focus on Lorraine Code's work, especially her recent work on ecological thinking, and on how this approach provides for reconfigured conceptions of knowledge making, subjectivity, and ethics. I highlight how these conceptions deepen and enrich intra-actions between epistemic responsibilities, and situated knowledges. Finally, I highlight the methodological implications of working with Code's ecological thinking approach.

DIFFRACTIVE READINGS

As this is a chapter on ethics, I begin by highlighting the ethics of reading and writing. Here, I draw on what Karen Barad (2007) calls 'diffractive readings', a notion that builds, in turn, on Donna Haraway's concept of diffraction which is about 'heterogeneous history, not about originals' (1997: 273). Unlike reflexivity, whereby one positions oneself as connected to, but ultimately still separate from, one's data and object of investigation, diffraction refers to how we are deeply entangled with the making and remaking of knowledges and worlds. Diffractive reading entails a process of working with different 'politics of possibilities' (Barad, 2007: 46) rather than assuming that we can capture or mirror something that is 'out there', waiting to be found. As Barad notes:

> Diffraction does not fix what is the object and what is the subject in advance, and so, unlike methods of reading one text or set of ideas against another where one serves as a fixed frame of reference, diffraction involves reading insights through one another in ways that help illuminate differences as they emerge: how different differences get made, what gets excluded, and how those exclusions matter. (2007: 30)

I thus conduct diffractive readings of the work of Code and others who have made seminal contributions to feminist epistemologies. In the case of Code, this has meant reading and re-reading her writing, and reviews and critiques of her writing, across forty years of her work (e.g. 1988, 1993, 1995, 1996, 2006, 2008, 2011, 2014) as a process of 'respectful, detailed, ethical engagements' (Barad, 2007: 30). To read diffractively is to read generously and 'to read through, not against; it means reading texts intra-actively through one another, enacting new patterns of engagement' (Barad, 2010: 243; see also Mauthner, 2015).

FEMINIST EPISTEMOLOGIES AND ETHICS: THREE STRANDS ACROSS THREE DECADES

Sandra Harding (1986, 1991) set the tone for at least two decades of feminist methodologies and feminist epistemologies when she laid out what she called three 'successor epistemologies': feminist standpoint epistemologies, feminist empiricism, and transitional (postmodern) epistemologies. As discussed later in this chapter, these epistemological categories have since given way to other, more complex ways of understanding feminist epistemologies. Nevertheless, I briefly review them below in order to illuminate the enduring ethical concerns that were, and are still, addressed by feminist researchers working within these traditions.

Feminist Standpoint

Feminist standpoint approaches were first introduced in the 1970s and 1980s, with Marxist, Hegelian, and second wave feminist roots (Harding, 1986; Hartsock, 1983, 2003; Hill Collins, 1986, 2000; Rose, 1983; Smith, 1987), and authors have argued that they can be viewed as theory, method, and epistemology (see overview in Hekman, 1997; Wylie, 2003). By many accounts, feminist standpoint approaches have been guided by two core propositions (Wylie, 2003). The first, related to 'situated knowledges', is that all knowledge and knowledge-making processes are constituted by the standpoints of both the researcher and the researched. Moreover, standpoint epistemology has continually emphasized how women's lives are the 'places from which to start off knowledge projects' (Harding, 1991: 61). The second proposition details 'epistemic advantage', meaning that some standpoints, specifically the positionalities of marginalized or oppressed groups, can best inform social theory.

According to Joseph Rouse (2009: 201), even with its 'contested history', feminist standpoint approaches still remain 'an indispensable resource for feminist epistemology'. I argue that they make at least three long-standing ethical contributions. First, as Rouse puts it, feminist standpoint epistemologies recognize that 'Knowledge claims and their justification are part of the world we seek to understand. They arise in specific circumstances and have real consequences' (Rouse, 2009: 201). It is this emphasis on the *effects* of knowledge making that is important in longer-term discussions of feminist ethics. Second, standpoint theorist identified the power-saturated character of knowledge making, and the concurrent effects of that power on the world itself. Thus, standpoint feminists claimed from the outset that women's narratives or standpoints must also be located and analyzed within broader relations of ruling or social structures (Smith, 1987, 1999). Third, the attention to marginalized others, as a key characteristic of standpoint approaches, has been an enduring focus for feminist researchers (see Code, 2010).

Feminist Empiricism

According to Harding, feminist empiricism 'argues that sexism and androcentrism are social biases correctable by stricter adherence to the existing methodological norms of scientific inquiry' (Harding, 1986: 24). Unlike with standpoint feminists, who named themselves as such despite their diversity of approaches and views, from the beginning, there were notable difficulties with knowing just *who* fit into the feminist empiricist category. Part of the problem was that Harding initially provided such a slim understanding of what feminist empiricism was (see critique by McLennan, 1995). In her later work, Harding (1991, 1993) distinguished between the 'original spontaneous' feminist empiricism and 'sophisticated and valuable feminist empiricist philosophies of science' (Harding, 1993: 51) (e.g. Longino, 1993, 2002; Nelson, 1993). What seems clear, in hindsight, is that there was some overlap between analytic philosophy, analytic feminism, and feminist engagement with naturalized epistemologies (especially the work of American philosopher W.V.O. Quine, 1966, 1969), as well as feminist critiques of science. In very broad terms, this strand of work aimed to improve mainstream scientific methods by demonstrating and changing sex bias in logical positivistic science practices.

Feminist empiricism has been characterized by at least three elements. First, in a similar way to standpoint epistemologies, it is *contextualist* in its view that all observation, 'facts', and 'findings' are rooted in values, including political values; some have called this 'contextual empiricism' (Rolin, 2011). Second, 'knowers' are not individuals, but communities, and more specifically, science communities and epistemological communities (Campbell, 1998; Longino, 1990, 1993, 2002; Nelson, 1990, 1993). Third, feminist empiricism has highlighted an entanglement of methods with social, ethical, and political values; ethical and political values cannot be eliminated from good epistemic practices because they play a legitimate epistemic role (Anderson, 1995; Longino, 1990; Nelson, 1990). In this vein, feminist empiricism has been described as *normative* in its rejection of traditional dichotomies and binaries 'that have constituted the "value-free" view of science, including the context of discovery/context of justification distinction, the fact/value distinction, and the traditional distinction between cognitive and social values' (Intemann, 2010: 781).

In 1991, Code pointed to the 'subversive potential' of feminist empiricism, arguing that 'it disrupts the smooth impartiality of the standard empiricist credo by introducing a specificity – a declaration of specific interests – to contest the very possibility of a disinterested epistemology' (Code, 1991: 316). This potential for subversion will be taken up later in this chapter when I attend to how situated knowledges and epistemic responsibilities are still key feminist epistemological issues.

Feminist Transitional (or Postmodernism) Epistemologies

It would be an understatement to say that the impacts of postmodernism and poststructuralism on epistemologies, including feminist epistemologies, have been numerous, wide ranging, and lasting. Among them was a deepening of Harding and Haraway's call for situated knowledges, which translated into greater attention to reflexivity in epistemic practices and to the role of the researcher in constructing knowledges (Mauthner & Doucet, 2003). Drawing on Jane Flax's characterization of postmodernism as 'the death of history', the 'death of meta-narratives', and the 'death of man' (Flax, 1990: 204), intersections between feminism and postmodernism also led to articulations of a multitude of perspectives, none of which could claim objectivity or transcend into the 'god-trick of seeing everything from nowhere' (Haraway, 1991: 189). Postmodernism and poststructuralism instigated many bursts of new work, but also introduced new tensions within feminism as some argued that these approaches could weaken feminist politics (e.g. Benhabib, 1995). Over time, however, feminists began to explore the possibilities of combining relativism and realism, including what Code called 'mitigated relativism' (1991: 251), through versions of 'soft', 'skeptical', or 'affirmative' postmodern positions (e.g. Rosenau, 2002).

In concluding this brief overview, it is important to note that all three approaches recognized the significance of situated knowledges, albeit in different ways, and agreed that situated objectivity meant attending to entanglements of ethical and political social positionings in knowledge making practices. As I explore later in this chapter, Code's work has always made important contributions to these discussions.

NEW MAPPINGS OF FEMINIST EPISTEMOLOGIES AND ETHICO-ONTO-EPISTEMOLOGIES

There is now some consensus that, while initially distinguishing between three frameworks, Harding's tripartite categorization of feminist epistemologies has faded since the 1990s – a blurring that Harding herself predicted (Harding, 1987, 1991, 1998). As Code (2008: 88) put it: ‘It is not that the categories have been transcended, but that they are not as distinct as they once seemed to be’. For example, since postmodern and postcolonial critiques have highlighted the importance of multiple or fragmented perspectives, feminist standpoint approaches have become more pluralistic, acknowledging many situated standpoints (Collins, 1997, 2008; Harding, 1998; Reynolds, 2002; Smith, 1999) and some have even called for a form of ‘feminist standpoint empiricism’ (Intemann, 2010: 779).

By the beginning of the millennium, *other* epistemological issues gained attention, including questions about divisions and binaries between subjects and objects, nature and culture, knowers and known, language and materialities, representations and realities, and more widely between epistemologies and ontologies. Building on long and deep tracks of work in various traditions, including phenomenology, metaphysics, feminist science studies, actor network theories, and philosophy of science, to mention only a few, these analyses have been, and continue to be, taken up and reworked in the context of the many different ‘turns’ that have infused theories and practices of knowledge making. These include: the ‘material turn’, as articulated in ‘new feminist materialisms’ and ‘material feminisms’ (e.g. Alaimo & Hekman, 2008; Barad, 2003, 2007; Coole & Frost, 2010; Haraway, 2008a, 2008b; Hekman, 2010); the ‘postconstructionist turn’ (Lam, 2015; Lykke, 2010); and the ‘posthumanist turn’ (Braidotti, 2016a, 2016b). These ‘turns’ have all been accompanied by deepening attention to the ontological (e.g. Ingold, 2011, 2013; Mauthner, 2015; Mol, 2002; Verran, 2001), relational ontologies (Barad, 2007; Code, 2006; Somers, 2008; Tuana, 2008, forthcoming), performativity (Barad, 2007; Bell, 2012; Law, 2004), and non-representational approaches to knowledge making. While these are extraordinarily diverse fields, and there has been much debate and disagreement within and between them, there is some consensus that these approaches, however, share one or more of the following epistemological characterizations: performative, posthuman, ecological, non-representational, relational, and with a recognition of intra-connections between epistemology, ontology, and ethics. There is currently a great multiplicity of alternative approaches, all of which build on or intersect with feminist epistemologies; these include, for example, new materialist feminisms (Alaimo & Hekman, 2008), transcorporeal feminism (Alaimo, 2008, 2010), viscous porosity (Tuana, 2008, forthcoming), agential realism (Barad, 2003, 2007), relational empiricism and ‘ecologies of emergence’ (Verran, 2001, 2002, 2013), decolonizing epistemologies (Kovach, 2010; Simpson, 2011; Tuhiwai Smith, 2012), and ecological thinking (Code, 2006, 2008).

My pathway in this chapter is to work diffractively and respectfully with and from selected points of Code’s ecological thinking. In the next section, I lay out why Code’s work is especially instructive on the subject of feminist epistemologies and ethics, and how, across forty years, there have been both consistencies and expansions in her approach to knowledge making, subjectivities, and ethics.

ECOLOGICAL THINKING AND RECONFIGURED CONCEPTIONS OF KNOWLEDGE MAKING AND SUBJECTIVITY

I chose to focus on Code’s work for three reasons. First, as indicated in the introduction to this chapter, Code was one of the first to begin mapping feminist epistemologies and calling for ‘feminist interventions, both critical and revisionist, in the discourse of epistemology’ (1987: 10). Second, she is widely recognized for her emphasis on intra-connections between epistemology, ontology, and ethics (see Grasswick, 2011; Longino, 2010; Rooney, 2011; Tuana, 2008).

Finally, her recent work on ecological thinking, with its reconfigured notions of knowledge making and subjectivity, builds on and deepens her earlier attention to epistemic responsibility and ethics (Code, 1983, 1987, 1991, 1994, 1995, 2001). As Code admits, this work, which was 'a long time in the making' (Code, 2006: xi), builds on her longstanding 'quest for conceptions of knowledge and subjectivity capable of informing transformative, responsible, and responsive epistemic practices' (Code, 2006: xi).

What then is ecological thinking? As Code puts it, this approach 'is not simply thinking *about* ecology or *about* "the environment"' but rather a 'revisioned mode of engagement with knowledge, subjectivity, politics, ethics, science, citizenship, and agency that pervades and reconfigures theory and practice' (Code, 2006: 5, emphasis in original). Countering hegemonic 'epistemologies of mastery' that are steeped in Cartesian and Neo-Kantian philosophies, Code brings together what Bruno Latour (1993) calls 'matters of fact and matters of concern' with Deleuzian 'ethology' – 'the capacities for affecting and being affected that characterize each thing' (Deleuze, 1988: 125–126; cited in Code, 2006: 26) – and her almost forty years of writing on feminist epistemologies and their intersections with other epistemological traditions (e.g. virtue, social, and naturalized epistemologies). She maintains that ecological thinking reconfigures a wide series of relationships: epistemological, ontological, ethical, scientific, and political, as well as those between and among living beings and between human and non-human subjects and worlds.

Code's approach is guided by a larger discussion of social imaginaries and of how most knowledge making is still governed by a hegemonic social imaginary of knowledge making wherein researcher scientists are witnesses who let 'the facts speak for themselves' (Law, 2004: 120). As Code puts it, these are 'epistemologies of mastery' and 'spectator epistemologies' in which the knower 'stands as a shadow figure invisibly and indifferently apart from discrete objects of knowledge' and '(o)bjects remain inert in and unaffected by the knowing process' (Code, 2006: 41). In Haraway's highly cited words, this is 'the view from above, from nowhere' (Haraway, 1988: 589). The important point that I want to underline in this chapter is that ecological thinking and what Code calls 'ecological imaginaries' aim to reconfigure conceptions of knowledge making, epistemic subjectivities and responsibilities, and ethics.

Knowledge Making

In broad terms, I would argue that Code's approach to knowledge making is 'topologically' performative and non-representational. That is, drawing on Deleuze, but, more precisely, reading Deleuze (1988) through feminist theorist Vikki Bell, it takes 'the concept of performativity into new conversations' (Bell, 2012: 109) and 'elaborate[s] the concerns that are expressed in the concept, but inclining it more boldly towards the complexities of a world whose elements are always in processes of constitution, of reiterative enfolding' (Bell, 2012: 107). In short, ecological thinking means emphasizing 'a process of becoming' (Bennett, 2010: 49), 'the world in its differential becoming' (Barad, 2007: 185), and our entanglements in these becomings. This translates into focusing on the specificity of epistemic practices and on how different practices can bring forth different knowledges, realities, social worlds, and effects. The overarching idea is that we are not just making knowledges but we are 'reconfiguring' worlds (Code, 2006: 48), or participating in the making of 'material-semiotic realities' (Haraway, 1997; Barad, 2007) or 'worldlings' (e.g. Asberrg et al., 2015; Ingold, 2011, 2013; Stewart, 2010; see also Heidegger, 1971).

Code calls for 'ecological social imaginaries' to facilitate knowledge-making practices that, broadly and briefly, can be characterized as a deeper form of 'situated knowing' that brings together knowing, being, and doing. This entails a shift from reflexivity as positioning, to thinking about how that positioning matters not only in the making of knowledges (see Doucet & Mauthner, 2008, 2012; Mauthner & Doucet, 2003), but also in the making of worlds. As Hughes and Lury (2013) write, this is 'a re-turn to situatedness, not as a position or an identity, but as emergent in the diverse processes of differentiation, the patterns of movement, that constitute the moving surface or ground of figures of knowledge' (p. 792). This also means thinking 'not just about objects of knowledge but also about knowers' (Grasswick, 2011: xxii). As Code puts it:

> '[S]ituation' is not just a place *from which to know,* as the language of 'perspectives' might imply, indifferently available to anyone who chooses to stand there. Situation is itself *a place to know* whose intricacies have to be examined for how they shape both knowing subjects and the objects of knowledge; how they legitimate and/ or disqualify knowledge projects. (2006: 40, emphasis in original)

For Code and others, knowledge making is about a deeper set of relational entanglements where relations between the researcher and the researched unfold together, not as 'independently existing objects' but rather as a 'phenomenon in their ongoing materialization' (Barad, 2007: 151) and 'entanglements of relations' (Barad, 2007: 34; see also Mauthner, 2015). This move to view knowing as a relationship is a point that resonates deeply with a growing body of work by indigenous scholars on indigenous epistemologies and relational ontologies (e.g. Craft, 2013; McGuire, 2010; Simpson, 2011, 2014; Watts, 2013).

Ecological Subjects

Ecological thinking 'offers a conceptual frame within which to construct a responsive-responsible theory of knowledge and subjectivity' (Code, 2006: 21) wherein researchers are responsive to, and responsible for, their participation in and accounting of unfolding worlds and dialogically constituted narratives. This challenges us to think differently about our positioning as researchers. Broadly put, this is a shift from data gathering, 'collecting stories' (Code, 2011: 217), and representing data to 'intervening' *in* (Hacking, 2002; Verran, 2002, 2013), and 'intra-action' (Barad, 2007) *with*, data and with research subjects and their worlds. In Longino's words: 'Action, engagement, and projection replace representation' (2010: 737).

Code argues that the ecological subject that she advances resonates with Haraway's 'modest witness' (Haraway, 1997) – a knower who is engaged, partial, political, and humble. Knowledge making 'is always an interpretive, engaged, contingent, fallible engagement' (Haraway, 2000: 167). It means 'casting our lot with some ways of life and not others' (Haraway, 1997: 36). In a similar way, Code posits that even though it is a 'contentious claim ... advocacy often makes knowledge possible' (Code, 2006: 23).

REMAKING EPISTEMIC RESPONSIBILITIES AS ETHICO-ONTO-EPISTEMOLOGICAL PRACTICES

The concept of epistemic responsibility was, as Code recently acknowledged, 'something of a sleeper' (Code, 2015: 2); indeed, her 1987 book entitled *Epistemic Responsibility* 'had an awkward publication history: it did not do well, was subject to vicious attacks at philosophy conferences and in reviews, and is now out of print' (Code, 2015: 2). This was partly because, as Code put it, the concept sat 'uneasily with epistemologists', as the concept and the questions it raised were 'thought not to be properly epistemological at all, but to belong to ethics, or to the softer fringes of everyday talk about knowledge, rather than to the hard center of serious epistemological analysis' (Code, 1991: 3–4).

Code recently confirmed, however, that 'the concept and the practices it signals are acquiring new respect' (Code, 2015: 2). Indeed, over the past decade, epistemic responsibilities, and sister concepts, such as 'ontological politics' (Mol, 1999, 2002), or 'accountability', (Barad, 2007; Kenney, 2015) are receiving growing positive attention. Feminist epistemologist Helen Longino, recently paid tribute to Code's leadership on this issue in her review of a quarter-century of feminist epistemological work. She argues that Code brought 'the responsibility of the knower into the center of epistemological reflection' so that knowledge 'in the hands of these thinkers, becomes an active relationship charged with ethical dimensions, rather than an uninvolved representation of objects' (Longino, 2010: 735). It is evident that the shifting terrains of knowledge making and subjectivity as well as growing attention to entanglements between epistemologies, ontologies, and ethics partly explain the recovery of the concept of epistemic responsibility. Meanwhile, there has also been a deepening and an expansion of the concept in the work of Code and other feminist scholars. In this next section of the chapter, I point to some of these endeavors and develop three points that relate to epistemic practices and ethics.

Epistemic Practices

In her earlier work, Code called attention to the importance of epistemic practices and to our need to take responsibility for the methods that researchers develop and use. She noted that 'ethical-political and epistemological questions are inextricably intertwined' and that 'epistemological questions invoke ethical requirements'. Her commitment to the argument that 'ethical-political action is dependent on the quality of the epistemic activity that informs it' (Code, 1995: xiii) is evident, in my view, in how Code is one of the few feminist philosophers who also actively engages with grounded methodological questions and concrete research practices. For example, in the 1980s and 1990s, she advocated for the development of 'vigilant methods' (Burt & Code, 1995: 33), such as participatory, activist, and experiential research practices. Whereas many feminist epistemologists have written about the philosophical dimensions of knowledge making, Code has thought through the complexities of what this means at the level of practice.

Although she has maintained her focus 'on the ethics and politics of knowing other people responsibly and well, singly and/or collectively', in her recent writing, 'the extension of responsibility injunctions is much broader' (Code, 2011: 207). That is, building on the points I made above about reconfigured knowledge making and subjectivities, Code's work exhibits a stronger focus on epistemic responsibility and ethical issues of knowing in three ways. First, she gives attention to the complexity of knowledge making practices and processes. She acknowledges that epistemic responsibility is still 'about being accountable to the evidence' where evidence is approached as relationally constituted, ontologically relational, and multiple in its meanings and enactments. Being accountable, however, also means thinking expansively about how 'evidence comes to count as evidence'. Code advises undertaking responsive research – slow research that is attentive to unfolding worlds – and resisting 'superimposing a grid upon events, experiences, and situations, tucking in the bits that spill over the edges, letting putative aberrations drop through the cracks' (Code, 2006: 18).

A second point about epistemic practices is that researchers are not only engaged in the making of knowledges, but also in the making of worlds or 'wordlings'. Here Code's ecological thinking approach imbues epistemic practices with 'a large measure of responsibility' in that they are 'about imagining, crafting, articulating, [and] endeavoring to enact principles of ideal cohabitation' (Code, 2006: 24).

Finally, Code attends to the extensive effects and consequences of our knowledge-making practices, processes, and products, thereby invoking an enriched and more urgent sense of our responsibilities as knowers and as epistemic subjects. As Barad writes, accountability 'is not about representations of an independent reality, but about the real consequences, interventions, creative possibilities, and responsibilities of intra-acting within the world' (Barad, 1996: 188).

Choices, Response-ability[1], and the 'Politics of Possibilities'

Code has maintained her long-standing call for researchers to take epistemic responsibility – 'to engage in ways that put his/her subjectivity also on the line; to assume responsibility for what and how he/she claims to know' (Code, 2001: 275). This means that researchers *do* have choices, although 'the extent to which there are genuine choices about *how* to know the world and its inhabitants' are obscured by 'foundational and coherentist theories of knowledge' (Code, 1991: 3). Nancy Tuana recently acknowledged Code's contributions in this regard. She writes: 'we do not simply "read" such distinctions from nature, *but take epistemic responsibility for the distinctions we employ*' (2008: 192, emphasis in original). As Code so persuasively argued, we cannot separate epistemic analysis from ethical analysis. In a similar way, Barad (2007: 93) recognizes our 'boundary-drawing practices, the constitutive exclusions that are enacted, and questions of accountability and responsibility for the reconfigurings of which we are part'. In this vein, I would argue that epistemic responsibility, as an evolving concept, exemplifies Barad's 'ethico-onto-epistemology (Barad, 2007: 185) as an 'ethics of knowing' (Barad, 1996: 183) where 'ethics and politics' are 'co-constitutive' (Code, 2010: 35).

Code's constant concern about our choices as researchers has gained a stronger sense of urgency in recent years. As she details clearly in her Preface to *Ecological Thinking*, one of the largest shifts in her work has been to acknowledge that she had previously relied on an 'excessively benign conception of community' (Code, 2006: v). Extending the insights of feminist empiricism, wherein knowers are not individuals but rather 'individuals-in-communities' (Grasswick, 2004), there are indeed many communities that are part of the making, the possibilities of making, the reception, and the effects of knowledge making.

Using detailed case studies, including that of Nancy Oliveri, a Canadian medical doctor who blew the whistle on the pharmaceutical industry's role in science practices, Code highlights epistemic tensions between researchers and their varied epistemic communities: research subjects and objects; funders and invested parties; and research communities with long established methods, 'inscription devices' (Latour & Woolgar, 1986; Law, 2004), and material-semiotic practices (Haraway, 1991, 1997). She also discusses the ethical issues arising from these tensions and the epistemic responsibilities researchers have towards each of these communities in 'the production, circulation, and acknowledgment of claims to know' (Code, 2006: viii). For Code, these tensions introduce new, or reconfigured understandings of responsibility and accountability.

Wider Socio-Political Responsibilities

Building on her discussion about how she has moved away from her earlier, 'benign' concept of community, Code further asserts that 'epistemic responsibilities have to be negotiated, *much more arduously than* [she] *had assumed*' in order to 'counter the excesses of demonstrably unjust social-political-epistemic orders' (Code, 2006: viii; emphasis added). She argues that thinking about our epistemic responsibilities means thinking about how these ‘could translate into wider issues of citizenship and politics’ (p. 24) and how they might generate ‘innovative, revisionary knowledge projects with the social-political transformations, renewals, and disruptions they may animate’ (Code, 2011: 209). Rouse concurs, reminding us how ‘conceptual understanding and ethical accountability are always entangled,’ and how our wider responsibility as researchers ‘also establishes an accountability for what we become and how we live’ (Rouse, 2016; see also Rouse, 2015).

RESEARCH IMPLICATIONS

In this final section, I briefly highlight six methodological implications that emerge from Code’s work that could guide qualitative and post-qualitative research. First, as Code asserts, there are no ‘precise recipes’, nor ‘clear rules’ (Code, 2008: 80) for putting ecological thinking into practice; rather, each site, discipline, research encounter, and problematic has its own set of issues that researchers must think through. Second, and relatedly, a deeper and wider understanding of ‘situated knowledges’ means recognizing that situatedness is ‘not just a place *from which to know*’ but ‘is itself *a place to know*’ (Code, 2006: 40, emphasis in original). Third, this requires genealogical excavation of our conceptual and methodological practices and a clarification of the underpinning epistemological and ontological assumptions about words and worlds. Fourth, there is a shift from reflexivity to diffraction (Barad, 2007; Code, 2006; Haraway, 1997). Whereas reflexivity is an epistemic practice that holds objects and subjects at a distance so as to enable representation, diffraction is about relationships, intervention, and ‘interacting within and as part of’ (Barad, 2007: 89); it is an ‘optical metaphor for “the effort to make a difference in the world”’ (Code, 2006: 121; citing Haraway, 1997: 16), while also taking responsibility for our interventions. A fifth methodological implication of ecological thinking, which builds on Code’s longstanding roots in philosophical pragmatism (Code, 1995; see also McHugh, 2015), is the need to *negotiate* knowledge making; as she puts it, ‘epistemic responsibilities have to be negotiated’ in order to ‘counter the excesses of demonstrably unjust social-political-epistemic orders’ (Code, 2006: vii). Finally, researchers must sometimes work across, and negotiate, instituted and instituting social imaginaries in order to maximize possibilities for ethical knowing and intervention.

This point about working across social imaginaries is a complex one, but underlines Code’s commitment to feminist epistemological principles of attending to power in knowledge making and how different forms of negotiated evidence can challenge power-infused epistemic practices, institutions, and effects. Put briefly, for Code, the relationship between instituted and instituting imaginaries is not oppositional, fixed, or linear, nor is it a matter of one replacing the other. Rather, the ‘instituted imaginary is never seamless or static … it is always in motion’ while its ‘gaps … open up spaces for the work of the instituting imaginary’ (Code, 2006: 33).

Code provides an excellent example of working pragmatically across social imaginaries in her detailed case study of Rachel Carson, the award-winning author of *Silent Spring* (1962). A scientist, environmentalist, and activist who challenged American pesticide companies over the use of DDT in crop spraying, Carson, as Code describes it, mapped out diverse readings of different kinds of evidence, ‘charting, bringing together, and moving back and forth between/among quite different subject areas’ and ‘various kinds of knowledge with widely differing histories, methods, and assumptions’ (Code, 2006: 40). For Code, Carson needed to be:

> multilingual and multiply literate: to speak the language of laboratory science, wildlife organizations, government agencies, chemical-producing

> companies, secular nature lovers, and many others; to understand the detail of scientific documents and the force of experiential reports; to work back and forth between an *imaginary of mastery and of ecology.* (2006: 44; emphasis added)

Code argues that Carson's epistemic practices were pragmatic, responsive, relational, and responsible and were situated on 'a middle path, working back and forth' (Code, 2006: 43) between instituted and instituting social imaginaries.

Code's approach to knowledge making, subjectivity, and epistemic responsibilities leads to what she calls 'methodological pluralism' (Code, 2006: 19), meaning that researchers must sometimes 'move back and forth between different ways of organizing knowledge that may appear mutually incompatible' (Code, 2006: 284–285). This connects, in turn, with what Patti Lather and Elizabeth St. Pierre (Lather & St. Pierre, 2013; see also Lather, 2006, 2013) call post-qualitative research, which works 'against a linear sense of development' and is a way of working that 'deliberately holds together necessary incompatibilities' (Lather, 2006: 36).

CONCLUSION

From its inception in the early 1980s, the field of feminist epistemologies has been called an 'oxymoron' (Alcoff & Potter, 1993: 1), 'both a paradox and a necessity' (Longino, 1993: 327), and 'marginalized, if not invisible, in "mainstream" epistemologies' (Rooney, 2011: 3). At the same time, feminist epistemologies have made seminal contributions to theories and practices of knowledge making, subjectivities, and ethics. As Rooney (2011: 14–15) argues, the marginality of feminist epistemologies has also translated into a 'metaepistemic advantage' in that it 'affords specific insights into the limited understandings of epistemology'. In this chapter, working mainly with the ecological thinking approach of pioneering feminist epistemologist, Lorraine Code, I have argued that concepts and practices of epistemic responsibilities and situated knowledges are enduring feminist epistemological contributions to debates on ethics in research. I also detailed how radical shifts from a focus on epistemologies to ethico-onto-epistemologies have reconfigured approaches to knowledge making, subjectivities, epistemic responsibilities, and the politics and ethics of knowledge/world making.

Note

1 I remain grateful to Carol Gilligan for pointing out to me, in 1993, the links between responsibility and response-ability.

REFERENCES

Alaimo, S. (2008) Trans-corporeal Feminisms and the Ethical Space of Nature. In: Alaimo, S. and Hekman, S. (eds) *Material Feminisms.* Bloomington, IN: Indiana University Press, 237–264.

Alaimo, S. (2010) *Bodily Natures: Science, Environment, and the Material Self*. Bloomington, IN: Indiana University Press.

Alaimo, S. and Hekman, S. (2008) *Material Feminisms*. Bloomington, IN: Indiana University Press.

Alcoff, L. and Potter, E. (1993) Introduction: When Feminisms Intersect Epistemology. In: Alcoff, L. and Potter, E. (eds) *Feminist Epistemologies.* London: Routledge, 1–14.

Anderson, E. (1995) Feminist epistemology: An interpretation and defense. *Hypatia* 10(3): 50–84.

Antony, L.M. (1993) Quine as Feminist: The Radical Import of Naturalized Epistemology. In: Antony, L.M. and Witt, C.E. (eds) *A Mind of One's Own: Feminist Essays on Reason and Objectivity.* Cambridge, MA: Westview Press, 185–226.

Asberrg, C, Thiele, K., and van der Tuin, I. (2015) Speculative before the turn: Reintroducing feminist materialist performativity. *Cultural Studies Review* 21(2): 145–172.

Barad, K. (1996) Meeting the Universe Halfway: Realism and Social Constructivism without

Contradiction. In: Nelson, J. and Nelson, L.H. (eds) *Feminism, Science and the Philosophy of Science*. Dordrecht: Kluwer, 161–194.

Barad, K. (2003) Posthumanist performativity: Toward an understanding of how matter comes to matter. *Signs: Journal of Women in Culture and Society* 28(3): 801–831.

Barad, K. (2007) Meeting the Universe Halfway: Quantam Physics and the Entanglement of Matter and Meaning. Durham, NC: Duke University Press.

Barad, K. (2010) Quantum entanglements and hauntological relations of inheritance: Dis/continuities, spacetime enfoldings, and justice-to-come. *Derrida Today* 3(2): 240–268.

Bell, V. (2012) Declining performativity: Butler, Whitehead and ecologies of concern. *Theory, Culture & Society* 29(2): 107–123.

Benhabib, S. (1995) Feminism and Postmodernism. In: Benhabib, S., Butler, J., Cornell, D., and Fraser, N. (eds) *Feminist Contentions: A Philosophical Exchange*. New York: Routledge, 17–34.

Bennett, J. (2010) Vibrant Matter: A Political Ecology of Things. Durham, NC: Duke University Press.

Braidotti, R. (2016a) *The Posthuman*. London: Polity Press.

Braidotti, R. (2016b) Posthuman Feminist Theory. In: Disch, L. and Hawkesworth, M. (eds) *The Oxford Handbook of Feminist Theory*. Oxford: Oxford University Press, 673–698.

Burt, S. and Code, L. (1995) *Changing Methods: Feminists Transforming Practice*. Toronto, ON: University of Toronto Press.

Campbell, R. (1998) *Illusions of Paradox: A Feminist Epistemology Naturalized*. Lanham, MD: Rowman & Littlefield.

Code, L. (1981) Is the sex of the knower epistemologically significant? *Metaphilosophy* 12(3–4): 267–276.

Code, L. (1983) Responsibility and the epistemic community: Women's place. *Social Research* 50(3): 537–555.

Code, L. (1987) *Epistemic Responsibility*. Hanover, NH: University Press of New England for Brown University.

Code, L. (1988) Experience, Knowledge and Responsibility. In: Griffiths, M. and Whitford, M. (eds) *Feminist Perspectives in Philosophy*. Bloomington, IN: Indiana University Press, 187–204.

Code, L. (1991) What Can She Know? Feminist Theory and the Construction of Knowledge. Ithaca, NY: Cornell University Press.

Code, L. (1993) Taking Subjectivity into Account. In: Alcoff, L.M. and Potter, E. (eds) *Feminist Epistemologies*. New York: Routledge, 15–48.

Code, L. (1994) Responsibility and rhetoric. *Hypatia* 9(1): 1–20.

Code, L. (1995) *Rhetorical Spaces: Essays on Gendered Locations*. New York: Routledge.

Code, L. (1996) What is natural about epistemology naturalized? *American Philosophical Quarterly* 33(1): 1–22.

Code, L. (1998) How to think globally: Stretching the limits of imagination. *Hypatia* 13(2): 73–85.

Code, L. (2001) Rational Imaginings, Responsible Knowings: How Far Can You See From Here? In: Tuana, N. and Morgen, S. (eds) *Engendering Rationalities*. Albany, NY: State University of New York, 261–282.

Code, L. (2006) *Ecological Thinking: The Politics of Epistemic Location*. New York: Oxford University Press.

Code, L. (2008) Rereading ecological thinking. *Ethics, Place & Environment* 11(1): 76–90.

Code, L. (2010) Testimony, Advocacy, Ignorance: Thinking Ecologically about Social Knowledge. In: Haddock, A., Millar, A., and Pritchard, D. (eds) *Social Epistemology*. Oxford: Oxford University Press, 29–50.

Code, L. (2011) 'They Treated Him Well': Fact, Fiction, and the Politics of Knowledge. In: Grasswick, H.E. (ed.) *Feminist Epistemology and Philosophy of Science: Power in Knowledge*. London: Springer, 205–221.

Code, L. (2014) Feminist Epistemology and the Politics of Knowledge: Questions of Marginality. In: Evans, M., Hemmings, C., Henry, M. et al. (eds) *The SAGE Handbook of Feminist Theory*. London: Sage, 9–25.

Code, L. (2015) *Knowledge and Subjectivity*. Invited Presentation at Guelph Philosophy at 50. Guelph, Ontario: University of Guelph. June 7, 2015.

Collins, P.H. (1997) Comment on Hekman's 'Truth and Method: Feminist Standpoint Theory Revisited': Where's the Power? *Signs: Journal of Women in Culture and Society* 22(2): 375–381.

Collins, P.H. (2008) *Black Feminist Thought: Knowledge, Consciousness, and the Politics* *of Empowerment* (2nd edn). London: Routledge.

Coole, D. and Frost, S. (2010) Introducing the New Materialisms. In: Coole, D. and Frost, S. (eds) *New Materialisms: Ontology, Agency, and Politics.* Durham, NC: Duke University Press, 1–43.

Craft, A. (2013) *Breathing Life into the Stone Fort Treaty: An Anishinabe Understanding of Treaty One*. Saskatoon, Saskatchewan: Purich Publishing.

Deleuze, G. (1988) *Spinoza: Practical Philosophy*. (R. Hurley, trans.). San Francisco: City Lights Books.

Doucet, A. and Mauthner, N.S. (2008) What can be known and how? Narrated subjects and the Listening Guide. *Qualitative Research* 8(3): 399–409.

Doucet, A. and Mauthner, N.S. (2012) Knowing Responsibly: Ethics, Feminist Epistemologies and Methodologies. In: Miller, T., Birch, M., Mauthner, M., and Jessop, J. (eds) *Ethics in Qualitative Research.* Second Edition. London: Sage, 122–139.

Duran, J. (1991) *Toward a Feminist Epistemology.* New York: Rowman & Littlefield.

Flax, J. (1990) *Thinking Fragments: Psychoanalysis, Feminism, and Postmodernism in the Contemporary West*. Berkeley, CA: University of California Press.

Grasswick, H.E. (2004) Individuals-in-communities: The search for a feminist model of epistemic subjects. *Hypatia* 19(3): 85–120.

Grasswick, H.E. (2011) Introduction: Feminist Epistemology and Philosophy of Science in the Twenty-First Century. In: Grasswick, H.E. (ed.) *Feminist Epistemology and Philosophy of Science: Power in Knowledge*. London: Springer, xiii–xxx.

Hacking, I. (2002) *Historical Ontology*. Boston, MA: Harvard University Press.

Haraway, D.J. (1988) Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies* 14(3): 575–599.

Haraway, D.J. (1991) *Simians, Cyborgs and Women: The Reinvention of Nature*. London: Free Association Books.

Haraway, D.J. (1997) Modest_Witness@Second_Millenium.FemaleMan©Meets_Oncomouse™: *Feminism and Technoscience*. New York: Routledge.

Haraway, D.J. (2000) *How Like a Leaf: An Interview with Thyrza Nichols Goodeve*. New York: Routledge.

Haraway, D.J. (2008a) Otherworldly Conversations, Terrain Topics, Local Terms. In: Alaimo, S. and Hekman, S. (eds) *Material Feminisms.* Bloomington, IN: Indiana University Press, 157–187.

Haraway, D.J. (2008b) *When Species Meet.* Minneapolis, MN: The University of Minnesota Press.

Harding, S. (1986) *The Science Question in Feminism*. Ithaca, NY: Cornell University Press.

Harding, S. (1987) Conclusion: Epistemological Questions. In: Harding, S. (ed.) *Feminism and Methodology.* Bloomington, IN: Indiana University Press, 181–190.

Harding, S. (1991) *Whose Science? Whose Knowledge? Thinking from Women's Lives*. Ithica, NY: Cornell University Press.

Harding, S. (1993) Rethinking Standpoint Epistemologies: What is Strong Objectivity. In: Alcoff, L. and Potter, E. (eds) *Feminist Epistemologies*. London: Routledge, 49–82.

Harding, S. (1998) *Is Science Multicultural? Postcolonialism, Feminisms and Epistemologies*. Bloomington, IN: Indiana University Press.

Harding, S. and Hintikka, M.B. (Eds) (1983/2003) *Discovering Reality: Feminist Perspectives on Epistemology, Metaphysics, Methodology, and Philosophy of Science*. Dordrecht, Netherlands: D. Reidel / Kluwer.

Hartsock, N. (1983) The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism. In: Harding, S. and Hintikka, M.B. (eds) *Discovering Reality*. Dordrecht, Netherlands: D. Reidel, 283–310.

Hartsock, N. (2003) The Feminist Standpoint. In: Harding, S. and Hintikka, M.B. (eds) *Discovering Reality*, Second Edition. Dordrecht, Netherlands: Kluwer, 283–310.

Heidegger, M. (1971) *Poetry, Language, Thought*. New York: Harper & Row.

Hekman, S. (1997) Truth and method: Feminist standpoint theory revisited. *Signs: Journal of Women in Culture and Society* 22(2): 341–365.

Hekman, S. (2010) *The Material of Knowledge: Feminist Disclosures*. Bloomington, IN: Indiana University Press.

Hill Collins, P. (1986) Learning from the outsider within: The sociological significance of black feminist thought. *Social Problems* 33(6): S14–S32.

Hill Collins, P. (2000) *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. London: Routledge.

Hill Collins, P. and Bilge, S. (2016) *Intersectionality,* London: Polity.

Hughes, C. and Lury, C. (2013) Re-turning feminist methodologies: From a social to an ecological epistemology. *Gender and Education* 25(6): 786–799.

Ingold, T. (2011) *Being Alive: Essays on Movement, Knowledge and Description*. Abingdon, Oxon: Routledge.

Ingold, T. (2013) *Making: Anthropology, Archaeology, Art and Architecture*. Abingdon, Oxon: Routledge.

Intemann, K. (2010) 25 Years of feminist empiricism and standpoint theory: Where are we now? *Hypatia* 25(4): 778–796.

Kenney, M. (2015) Counting, accounting, and accountability: Helen Verran's relational empiricism. *Social Studies of Science* 45(5): 749–771.

Kovach, M.E. (2010) *Indigenous Methodologies: Characteristics, Conversations, and Contexts*. Toronto, ON: University of Toronto Press.

Lam, C. (2015) *New Reproductive Technologies and Disembodiment: Feminist and Material Resolutions*. Farnham, UK: Ashgate Publishing.

Lather, P. (2006) Paradigm proliferation as a good thing to think with: Teaching research in education as a wild profusion. *International Journal of Qualitative Studies in Education* 19(1): 35–57.

Lather, P. (2013) Methodology-21: What do we do in the afterward? *International Journal of Qualitative Studies in Education* 26(6): 634–645.

Lather, P. and St. Pierre, E.A. (2013) Post-qualitative research. *International Journal of Qualitative Studies in Education* 26(6): 629–633.

Latour, B. (1993) *We Have Never Been Modern*. Brighton: Harvester Wheatsheaf.

Latour, B. and Woolgar, S. (1986) *Laboratory Life: The Construction of Scientific Facts.* Princeton, NJ: Princeton University Press.

Law, J. (2004) *After Method: Mess in Social Science Research*. London: Routledge.

Lennon, K. and Whitford, M. (1994) Introduction. In: Lennon, K. and Whitford, M. (eds) *Knowing the Difference: Feminist Perspectives in Epistemology.* London: Routledge, 1–14.

Longino, H.E. (1990) *Science as Social Knowledge: Values and Objectivity in Scientific Inquiry*. Princeton, NJ: Princeton University Press.

Longino, H.E. (1993) Subjects, Power and Knowledge: Description and Prescription in Feminist Philosophies of Science. In: Alcoff, L. and Potter, E. (eds) *Feminist Epistemologies.* London: Routledge, 101–120.

Longino, H.E. (1997) Feminist epistemology as a local epistemology. *Aristotelian Society Supplementary Volume* 71(1): 19–35.

Longino, H.E. (2002) *The Fate of Knowledge*. Princeton, NJ: Princeton University Press.

Longino, H.E. (2010) Feminist epistemology at Hypatia's 25th Anniversary. *Hypatia* 25(4): 733–741.

Lykke, N. (2010) The timeliness of post-constructionism. *NORA-Nordic Journal of Feminist and Gender Research* 18(2): 131–136.

Mauthner, N.S. (2015) 'The past was never simply there to begin with and the future is not simply what will unfold': A posthumanist performative approach to qualitative longitudinal research. *International Journal of Social Research Methodology* 18(3): 321–336.

Mauthner, N.S. and Doucet, A. (2003) Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology* 37(3): 413–431.

McGuire, P.D. (2010) Exploring resilience and Indigenous ways of knowing. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 8(2): 117–131.

McHugh, N.A. (2015) *Limits of Knowledge: Generating Pragmatist Feminist Cases for Situated Knowing*. Albany, NY: State University of New York.

McLennan, G. (1995) Feminism, epistemology and postmodernism: Reflections on current ambivalence. *Sociology* 29(3): 391–409.

Mol, A. (1999) Ontological politics. A word and some questions. In: Law, J. and Hassard, J. (eds) *Actor Network Theory and After.* Oxford: Wiley-Blackwell, 74–89.

Mol, A. (2002) *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press.

Nelson, L.H. (1990) *Who Knows: From Quine to a Feminist Empiricism*. Philadelphia, PA: Temple University Press.

Nelson, L.H. (1993) Epistemological Communities. In: Alcoff, L. and Potter, E. (eds) *Feminist Epistemologies*. New York: Routledge, 121–159.

Quine, W.V.O. (1966) *The Ways of Paradox and Other Essays*. New York: Random House.

Quine, W.V.O. (1969) *Ontological Relativity and Other Essays*. New York: Columbia University Press.

Reynolds, T. (2002) Re-thinking a black feminist standpoint. *Ethnic and Racial Studies* 25(4): 591–606.

Rolin, K. (2011) Contextualism in Feminist Epistemology and Philosophy of Science. In: Grasswick, H.E. (ed.) *Feminist Epistemology and Philosophy of Science: Power in Knowledge.* London and New York: Springer, 25–44.

Rooney, P. (2011) The Marginalization of Feminist Epistemology and What That Reveals About Epistemology 'Proper'. In: Grasswick, H.E. (ed.) *Feminist Epistemology and Philosophy of Science: Power in Knowledge.* London and New York: Springer, 3–24.

Rose, H. (1983) Hand, brain and heart: A feminist epistemology for the natural sciences. *Signs: Journal of Women in Culture and Society* 9(1): 73–96.

Rosenau, P. (2002) *Post-Modernism and the Social Sciences: Insights, Inroads, and Intrusions*. Princeton, NJ: Princeton University Press.

Rouse, J. (2009) Standpoint theories reconsidered. *Hypatia* 24(4): 200–209.

Rouse, J. (2015) *Articulating the World: Conceptual Understanding and the Scientific Image*. Chicago, IL: The University of Chicago Press.

Rouse, J. (2016) The Conceptual and Ethical Normativity of Intra-active Phenomena. *Rhizomes* 30. Retrieved from http://www.rhizomes.net/issue30/rouse.html

Siltanen, J. and Doucet, A. (2017) *Gender Relations in Canada: Intersectionalities and Social Change*. Toronto, ON: Oxford University Press.

Simpson, L.B. (2011) *Dancing On Our Turtle's Back: Stories of Nishnaabeg Re-Creation, Resurgence, and a New Emergence*. Winnipeg, Manitoba: Arbeiter Ring Publishing.

Simpson, L.B. (2014) Land as pedagogy: Nishnaabeg intelligence and rebellious transformation. *Decolonization: Indigeneity, Education & Society* 3(3): 1–25.

Smith, D.E. (1987) *The Everyday World as Problematic: A Feminist Sociology,* Boston, MA: Northeastern University Press.

Smith, D.E. (1999) *Writing the Social: Critique, Theory, and Investigations*. Toronto, ON: University of Toronto Press.

Somers, M.R. (2008) *Genealogies of Citizenship: Markets, Statelessness and the Right to Have Rights*. Cambridge: Cambridge University Press.

Stewart, K. (2010) Afterword. Worlding Refrains. In: Gregg, M. and Seigworth, G.J. (eds) *The Affect Theory Reader.* Durham, NC: Duke University Press, 339–354.

Tuana, N. (2008) Viscious Porosity: Witnessing Katrina. In: Alaimo, S. and Hekman, S. (eds) *Material Feminisms.* Bloomington, IN: Indiana University Press, 188–213.

Tuana, N. (forthcoming) Being Affected by Climate Change: The Anthropocene and the Body of Ethics. In: Shockley, K. and Light, A. (eds) *Ethics and the Anthropocene.* MIT Press.

Tuhiwai Smith, L. (2012) *Decolonizing Methodologies: Research and Indigenous Peoples.* Second Edition. London: Zed Books.

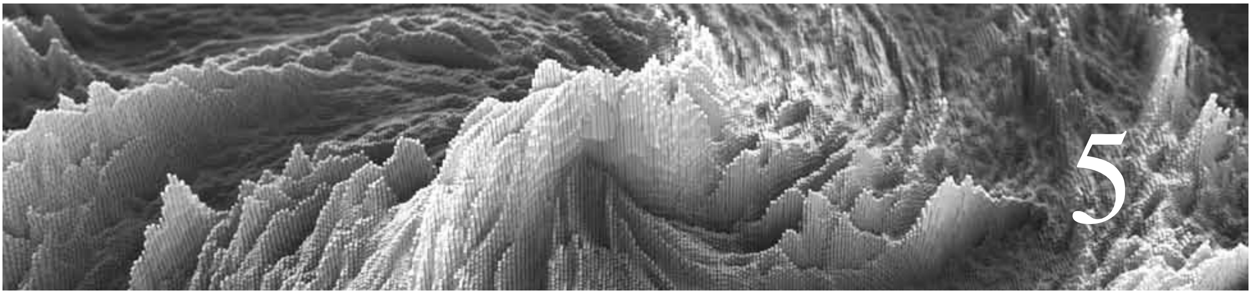
Verran, H. (2001) *Science and an African logic*. Chicago, IL: The University of Chicago Press.

Verran, H. (2002) A postcolonial moment in science studies: Alternative firing regimes of environmental scientists and Aboriginal landowners. *Social Studies of Science* 32(5–6): 729–762.

Verran, H. (2013) Engagements between disparate knowledge traditions: Toward doing difference generatively and in good faith. In: Green, L. (ed.) *Contested Ecologies: Dialogues in the South on Nature and Knowledge.* Cape Town, SA: HSRC Press, 141–161.

Watts, V. (2013) Indigenous place-thought and agency amongst humans and non-humans (First Woman and Sky Woman go on a European world tour!) *Decolonization: Indigeneity, Education & Society* 2(1): 20–34.

Wylie, A. (2003) Why Standpoint Matters. In: Figueroa, R. and Harding, S. (eds) *Science and Other Cultures: Issues in Philosophies of Science and Technology*. New York: Routledge, 26–48.



5

Ethical Imperialism? Exporting Research Ethics to the Global South

Mark Israel

INTRODUCTION

Zachary Schrag's 2010 book on the growth of the regulation of research ethics in the United States portrays a history of mission creep and intensification of the gaze. This has occurred in the guise of reform, concern for the protection of participants and, of all things, deregulation. Schrag interprets the extension of oversight from biomedical sciences to social sciences within his own country variously as bureaucratic empire-building, thoughtless imperialism, and 'merely collateral damage' in the goal to 'contain medical research' (p. 189). Regulations have been extended to cover social sciences on the basis of 'ignorance and power' (p. 9), 'haste and disrespect' (p. 192). Federal officials have had little understanding of the practices of social sciences and have demonstrated scant interest in rectifying the situation. Social scientists have rarely been invited to contribute to the development of regulations that cover their work. The pattern has been for jurisdiction to be extended without consultation and for disciplines to be caught off-guard by a meta-narrative of ethics governance that they don't yet understand and by regulations couched in language that initially appears not to include them.

While wary of over-generalizing from the experiences of the United States, in this chapter I want to take Schrag's idea of 'ethical imperialism' (which is anything but ethical) and assess the value of applying it to the export of patterns of research ethics governance not just between disciplines, but also between countries. I explore the growth of research ethics regulation in Brazil and South Africa, two important regional research hubs, and examine what might be driving research ethics policy transfer from the global North to the global South and how that might be having an impact on the work of social scientists.

RESEARCH ETHICS REGULATION IN BRAZIL AND SOUTH AFRICA

Brazil and South Africa are both members of the major 'emerging' group of nations (BRICS). Each carries significant political and economic weight in its respective region. This position has been reflected in the status of their higher education and research institutions that typically outperform other parts of their continents in international rankings. Over the last few years, however, the contraction of resource-based economies, economic mismanagement, and public and private sector corruption scandals have challenged the image of democratic and economic success stories. As a result, since the 1990s, research ethics regulation in each country has had to respond to intensifying demands on research capacity, increased economic instability as well as tensions between democratic accountability and executive power.

Brazil

The need to regulate research ethics in Latin America in the 1990s and 2000s was driven by a return to civilian government across the continent, regulations connected to Mercosur (the South American regional economic community), a growing capacity for research, and the uncovering of medical research scandals involving researchers from the United States experimenting on the poorest groups in low-income countries. Florencia Luna (2006) argued that Latin American bioethics was ill-prepared to respond to these issues with governments assuming a church-led 'homogeneity that does not exist, ignoring the reality of multiculturalism and moral and religious pluralism' (p. 10). In contrast, Luna identified in Argentina, Mexico, Chile, and Brazil, an alternative, secular view based on philosophy and, in particular, the principlism advocated by Beauchamp and Childress (2013), and the Spanish bioethicist Diego Gracia (1995).

Brazil first issued guidelines for medical experimentation on human subjects in 1988. In 1996, the National Health Council in Brazil adopted *Guidelines and Norms Regulating Research Involving Human Subjects* (Conselho Nacional de Saúde, Resolution 196/96). The document extended its ambit to all research involving human participants, confirmed the importance of the ethical principles of autonomy, beneficence, non-maleficence, justice and equity, and led to a system that included a set of research ethics committees (RECs) under a National Commission for Ethics in Research (CONEP) with consultative, deliberative, normative, and education roles. Biomedical and health scientists, and biologists have dominated the academic membership of CONEP although CONEP has agreed to a gradual rebalancing of membership towards social sciences and medicine (Guerriero, 2016b). By 2010, 596 committees had been registered with CONEP and about two-thirds of these reviewed projects were in the social sciences (Hardy et al., 2010). The Institute of Human Sciences of the University of Brasilia established a specialist committee with specific expertise in social research, partly in order to meet the need of researchers seeking to publish in social science journals that required ethical review (Diniz, 2010). Unfortunately, some Brazilian health research committees felt it unnecessary to draw on the knowledge of any social researchers even when reviewing (and often rejecting) social science-based proposals (Lima, 2010).

Brazilian authorities have strongly supported the deployment of a universal set of research ethics standards for all human research. Indeed, the Declaración de Córdoba drafted by Latin American ethicists advised countries to reject the 2008 revision of the Helsinki Declaration (World Medical Association, 2008) because of its retreat from universalism. In resisting the development of a 'double standard' between developing and developed nations, Brazilian regulations enabled the colonization of social sciences research ethics by bioethics. In the words of anthropologists, Resolution 196/96 privileged one form of research – positivist and medical. For de Oliveira (2004), it 'imposes (arbitrarily) a local, (biomedical) view on research practice, or on ethics in research practice, as if it were universal' (p. 33, my translation, original in Portuguese). It offered little distinction between the collection of myths and the collection of blood (Ramos, 2004) and risked promoting a bureaucratic process that rested on authoritarian foundations (Figueiredo, 2004). CONEP assumed a hierarchy of power and knowledge production between researcher and researched that had been firmly rejected by Brazilian critical scholars in the social sciences. Langdon and her colleagues responded: 'our method is not a matter of "application" of a series of procedures (as seems to be understood in many Committees), but it is above all the adoption of a reflective and critical posture with regard to the research itself' (Langdon et al., 2008: 144, my translation, original in Portuguese). For Brazilian critical scholars, not only have the regulations been wrong, but the processes associated with them have also failed. The bureaucratic apparatus has been unable to grapple with the complexities of social research. For example, the 1996 Resolution gave 'special' status to Indigenous groups and required that both CONEP and the National Indian Foundation (FUNAI) review all research involving them. Resolution 304/2000 subsequently required research on Indigenous peoples 'serve the needs of the individuals or groups that are the subjects of study, or of similar societies, and/or the national society'. While acknowledging the importance of giving Indigenous people a voice in research governance (Santos, 2006), social scientists found their work on health with Indigenous Brazilians 'hampered' by these resolutions which failed to provide appropriate protections while blocking entirely reasonable research proposals.

All research funded or conducted by researchers from outside Brazil was also subjected to CONEP review. Two experimental political scientists from the United States, Cunow and Desposato (2016), were particularly scathing when describing their experience at the hands of Brazilian bureaucracy. The researchers regarded their survey experiment as low risk and had received initial approval from the Institutional Review Board (IRB) at the University of California San Diego. In Brazil, review took over a year and was never properly completed. The researchers recognized their own inexperience with the Brazilian system and accepted they had had some bad luck; however, they were critical of inefficient and ineffective administrative processes, a lack of transparency, poor communication, and limited interest among bureaucrats in supporting social science or possibly *any* research:

> There was never any hint of corruption; it instead seemed that they were either incompetent or uninterested in reviewing our project. In addition, the review itself made no contribution to the safety or cultural sensitivity of our low-risk project; all our experiences with the Brazilian review process involved bureaucratic procedure. (p.134)

The system created by Resolution 196/96 has been resisted by psychologists (Trindade & Szymanski, 2008), anthropologists (Langdon et al., 2008) and other social scientists. In 2006, qualitative researchers met in Guarujá and called for guidelines and review committees sensitive to the needs of different disciplines (Coimbra et al., 2007; Guerriero & Dallari, 2008). They complained committees were reviewing their work as if all research were synonymous with experimentation conducted with established sample frames and predetermined sample sizes. They were also concerned Northern conceptions of individual autonomy were displacing any sense of the social. Although Resolution 196/96 claimed 'to respect the cultural, social, moral, religious and ethical, as well as the habits and customs when research involves communities' (III.3 l), demands were being made by CONEP that completely misunderstood the local context (Bento et al., 2011). For example, one researcher had been asked by a committee to obtain signed informed consent from individual participants using documents translated into Xavánte, an Indigenous language. The requirement compromised a strong tradition among the Xavánte of community decision-making through ritualized daily meetings, and ignored the lack of standardized written form for their language, and a relatively high level of bilingualism among the population. The meeting in Guarujá called for national guidelines that dealt with the concerns of the social sciences and humanities, and with qualitative methodologies in particular.

In 2012, the National Health Council adopted Resolution 466/12 (Conselho Nacional de Saúde, 2012), which provided new guidelines and rules for research involving humans, identifying the rights and responsibilities of the state, researchers, and research participants. The Resolution pointed to the principles of autonomy, non-maleficence, beneficence, justice and equity, albeit ‘among others’ (s I). While some of the 2012 provisions may be more accommodating of qualitative research, the default position remained positivist. For example, the Resolution required free and informed consent to be formalized in a Statement of Consent that must include details of reimbursement and an ‘explanation of the indemnification guarantee in the case of eventual damages caused by the research’ (IV.3 (h), original in Portuguese) with two documents to be provided ‘with all pages initialed and signed at the end’ by participants or their legal representatives and by the researchers (IV.5 (d)). The Resolution went on to allow researchers to request a waiver of this requirement from CONEP and the RECs (IV.8). The difficulty with requiring a waiver is that it portrays a large swathe of social science research as a departure from the norm and requires researchers to apply to a system that has already demonstrated little interest in their research methodologies. Not surprisingly, Resolution 466/12 was rejected by associations of Brazilian anthropologists, sociologists, and political scientists (Associação Nacional de Pós-Graduação e Pesquisa em Ciências Sociais, 2013).

Nevertheless, the 2012 Resolution envisaged a special resolution for social sciences and humanities. In 2013, a Working Group started working on the special resolution but encountered difficulties when it sought to challenge the biomedical ‘colonizing posture’ (Guerriero & Bosi, 2015: 2622) favored by CONEP. CONEP delayed passing on documents created by the Working Group to the National Health Council (CNS) and finally only did so in 2016 once it had formulated and attached its own rejection of key elements of the Working Party proposals (Duarte & Sarti, 2016). Until the special resolution was published, Resolution 466/12 covered social sciences (Guerriero, 2016a). In April 2016, the CNS approved a new Resolution for social sciences and humanities and those disciplines that draw on methodologies from those areas (Guerriero, 2016b). By and large, Resolution 466 no longer applied to social scientists, except in areas where the new Resolution is silent. Among other matters, the new Resolution 510/16 required equitable representation from these areas on CONEP and RECs governed by CONEP. It excluded from review some studies that used publically available or non-identifiable data or were intended exclusively to train students (I). Further resolutions are being drafted to support the creation of review processes whose intensity is proportionate to risk. Resolution 510/16 went further than many other national statements of research ethics in recognizing scientific and academic freedom and human rights, and the role of research in expanding and consolidating democracy (II.3).

Most other Latin American countries have national regulations covering clinical research. However, many Latin American countries do not have a comprehensive system of research ethics committees, and those that do may not have guidelines for overseeing and regulating research, relying on committees with overlapping jurisdictions and inconsistent approaches. As a result, the Brazilian system has been viewed with favor by regulators in other parts of Latin America (well before Resolution

510/16 was adopted), with calls for a national system to be adopted in Argentina, Uruguay, and Peru (for example, Barboza et al., 2010). Given the difficulties Brazilian social scientists have had, their colleagues in other parts of Latin America ought to be wary.

South Africa

Like much of the rest of Africa (Israel, 2015), research ethics regulation in South Africa has been driven by bioethics. South Africa became one of the first countries to respond to the concerns raised by Beecher (1966) and Pappworth (1967) about damaging biomedical research practices in the United States and the United Kingdom. In 1977, the South African Medical Research Council produced its *Guidelines on Ethics for Medical Research*, the most recent edition of which was published in 2015. Moodley and Myer (2007) reported the ethics review system in South Africa was functioning reasonably, but found wide variation in capacity to conduct reviews in a timely and informed manner between committees depending on their geographical location and institutional history. Membership was dominated by white males, scientists, and clinicians and failed to contain adequate representation from those communities from which participants might be drawn (Moodley & Rennie, 2011). As a result, committees might be seen as reinforcing 'the asymmetrical power relationship that already exists between predominantly white researchers and predominantly black participants' (Moodley & Myer, 2007).

Before 2004, there was no statutory national requirement that social science research be subject to ethics review. However, following a scandal involving breast cancer research, nationally binding ethical guidelines for health research were published by the Department of Health in 2004, and s72(6)c of the 2004 *Health Act* implied that all research with humans fell within the Act's purview. The Health Act also established the National Health Research Ethics Council (NHREC) with responsibility for the oversight of local RECs and researchers. The NHREC allows RECs to use different procedures depending on the level of risk (creating a binary division between high and low risk).

Universities responded to the 2004 Act by expanding review to cover social sciences and humanities. Where this occurred, review processes were initially resisted by some researchers (Louw & Delport, 2006) and regarded negatively by others. For example, Mamotte and Wasenaar (2009) surveyed social scientists at one university and one research organization. In the former, 60 percent of researchers reported only negative experiences of the research ethics committee, though the low response rate of 10.1 percent from the combined sample means that any interpretation should be cautious. Researchers in the university were frustrated by the 'slowness of review, inadequate review, and problems that arose as a result of the centralization of review, the review of student research and researcher naivety about research ethics and ethics review' (p. 74).

In 2015, the Department of Health published the second edition of its guidelines, *Ethics in Health Research: Principles, Processes and Structures*. The document specifically warned RECs not to apply a 'so-called "medical model" of ethics review' (s.1.1.6) to social science research. However, once again there appeared to be tensions between its statutory remit, its somewhat confusing concurrently held 'narrow' and 'broad' definitions of health research, and claims that the NHREC intended the guidelines 'to address research more broadly to achieve the specific goal of providing guidance for researchers so that all research involving human participants or animals may be conducted in accordance with the highest ethical norms and standards' (s.1.1.13).

The argument that a health research document produced by a health research ethics council operating under the authority of health legislation might inform all research is not unique to South Africa. It rests on the proposition that principlism offers the possibility of a universal set of standards. This proposition has been rendered uncontestable by South African regulators:

> It is important to recognize that, although research methodologies and analytic paradigms may differ, all research must be judged against the same ethical principles. No philosophical justification exists for judging different methodologies against different ethical standards. (Department of Health, 2015, s.6.1)

Ethics in Health Research drew heavily on Wassenaar and Mamotte's work (2012). While these two scholars have argued in favor of universal principles, they have also recognized that these principles might be difficult to apply in practice since 'context, history, culture, and politics, as well as the social, gender, and economic status of participants, can have implications for how ethical principles are applied in different settings' (p. 274). As a result, the 2015 guidelines acknowledged that RECs that dealt with social science proposals needed to be familiar with social research paradigms, noting that different disciplines had varying accepted methodological standards. Indeed, the document devoted one chapter to qualitative research. This might have been an attempt to protect qualitative researchers, but might also have the effect of presenting qualitative methodologies as departures from the norm of quantitative research.

Social scientists originally argued that the 2004 *Health Act* did not apply to them and this might be part of the explanation for Wasenaar and Mamotte's findings in 2009. There have also been calls, albeit contested, for particular disciplines to build alternatives to principlism. Spiegel (2005), for example, urged his colleagues to call upon both an ethics of care and the 'flexible and responsive' tradition of exposé anthropology that was a legacy of that discipline's opposition to Apartheid. Spiegel argued these might enable anthropologists to maintain an agenda appropriate to the country that continued to explore ethics and a research agenda beyond liberal questions of 'public power and individual rights' (p. 134). Drawing on the ongoing work of Thaddeus Metz (for example, Metz, 2013), other anthropologists have suggested that an 'Afro-communitarian' notion of mutuality, *ubuntu*, might be better suited to sub-Saharan Africa than an imported ethics of care (Morreira, 2012). Metz (2007) has aimed at developing 'a normative ethical theory of right action that has an African pedigree and offers something different from what is dominant in Western moral philosophy' (p. 332). The 2015 *Guidelines* refuted departures from its principles though it is possible for multiple philosophical approaches to underpin principlism.

Senior social scientists have also questioned how research in South Africa might be well served by intensification of regulatory oversight without any accompanying effort to nurture better ways of working through ethical dilemmas. Indeed, Deborah Posel and Fiona Ross (2014) have argued that current regulatory regimes may be suppressing debate about ethical research practices among researchers who fear provoking resistance from reviewers if they present 'an unsettling or unruly picture of the research process' (2014, p. 3). Instead, in South Africa 'the trend toward more intense regulation does not guarantee a correspondingly full or thoughtful debate about questions of research ethics. Often, the regulatory concerns are more technical than ethically substantive' (p. 3).

This argument was supported by De Vries and Henley (2014) who described how, as researchers and as research ethics reviewers, they have witnessed the tension between 'official ethics' and 'ethics on the ground'. As members of a university ethics committee they acknowledged that they had not challenged the former in relation to some highly prescriptive models of informed consent, attributing their silence to: recognition that 'official ethics' may need to meet national or international regulatory requirements; uncertainty whether they knew the best way to obtain consent and, conflict between their role as gatekeepers to research activity and their vested interest as members of an institution seeking to engage in high quality research. They suggested that these might be reason enough,

> But perhaps the real source of our ethical dilemma is that we do not – or perhaps no longer – believe that ethics committees 'do ethics' in the way that we as social scientists think ethics needs to be done in practice. (p. 85–86)

Both Brazil and South Africa have used a legislative mandate to create national regulation of research ethics based on principlism. Explicitly constructed around the needs of health research, the ambit of the regulation might initially have been unclear. Nevertheless, over time and (where necessary) through subsequent iterations of guidelines, regulators have extended their remit and intensified scrutiny of the social sciences. As in the United States, social scientists had little say in the drafting of the guidelines that were to cover their disciplines, and (until the passing of Resolution 510 in Brazil in 2016) have found their objections ignored or deflected. Social scientists were also unable to join the committees that conducted reviews under the regulations. Failure of national guidelines and ethics review bureaucracies to understand the nature of social science research has led to complaints from social researchers that research that they regarded as ethical was being delayed or blocked by unsympathetic reviewers. Even more troubling are stories that RECs have insisted on approaches that researchers regarded as unethical. Nevertheless, despite limited empirical evidence of the effectiveness of research ethics regulation on social scientists and a good deal of criticism within their borders, the Brazilian and South African models may be influencing patterns of research ethics governance in their respective regions.

EXPORTING PRINCIPLISM

The global export of principlism forms part of broader international flows of capital, students and academics, as well as knowledge and ideology. The impact of global capital has had a long-standing impact on research ethics governance. Some of the earliest medical RECs around the world were established to allow medical researchers to compete for US health research grants. US regulators have used this funding as leverage to ensure that both the spirit and the letter of American legislation are followed. More recently, pharmaceutical companies have sought to open up new markets and take advantage of cheaper sites for multicenter drug trials. Multinational research teams have looked to those countries with lower risks of litigation, low labor costs, pharmacologically 'naive' participants, weak ethics review and the absence of other regulatory processes. As a result, research in low- and middle-income countries in Asia, Africa, and Latin America has burgeoned. As developing countries struggle to keep pace, the Declaration of Helsinki (World Medical Association, 2013) and the UNESCO Declaration (2006) have created regulatory templates for those without the infrastructure to create their own, and a range of capacity-building initiatives in research ethics have encouraged researchers in developing countries to follow these models.

One of the drivers for global policy transfer has been the influence of transnational professional networks. These groupings may draw on their shared world view, and use their recognized expertise in particular areas to assert authority over a policy domain, and develop and entrench particular norms and choices. The concept of 'epistemic communities' has been used to analyze the development and influence of such networks (Haas, 1992). Members derive legitimacy by drawing on internationally-recognized approaches to respond to the particular circumstances in their own countries. In turn, these 'successes' are used to garner support for similar initiatives elsewhere.

A critical feature of transnational epistemic communities might be the cohesion that develops from mutual socialization through shared training (Cross, 2013). Growth in internationalization of higher education might play a part in providing access to and mobility within such global communities. Encouraging student and academic international mobility has become a part of many countries' national development plans, either as a way of enhancing local intellectual capital or asset stripping other nations. Student mobility has also become an important source of income for those countries and institutions seen as favored providers of education.

The global North dominates the destination countries for both Brazilian and South African tertiary students: United States, the United Kingdom and the rest of the European Union (UNESCO-UIS, 2012). Movement to other countries in Latin America and Africa has been minimal, though both Brazil and South Africa have become leading regional hubs for Latin American and sub-Saharan African students respectively (UNESCO-UIS, 2012). Brazil, in addition, plays a significant role in hosting students from Lusophone Africa, while South Africa has proved particularly important to internationally mobile students from the Southern Africa Development Community.

Knowledge is not simply transferred from Northern academics to international students. However, there are various ways in which enrolment at Northern institutions might socialize and discipline international students. Having enrolled in international degree programs, students need to meet the requirements of those courses, even if they and their lecturers and supervisors share a common critique of research ethics regulations. For example, a group of international postgraduate education students studying at one institution in the United Kingdom argued the imposition of British-based review on international projects risked reproducing neocolonial practices as a system that

> arises out of the culture and institutions of a former colonizer … sets the standards for good research … measures what is to be thought of as ethical research.… In presenting ethical encounters as a universal standard, an ethics review procedure applied outside of its designated context leaves itself vulnerable to criticisms of cultural reduction and irrelevance. (Allen et al., 2009: 145–146, quoted in Sikes, 2013)

Ideas may be adopted uncritically but they may also be resisted, avoided or shaped through interaction between students in ways that we may not yet understand. Students can also be exposed to the alternatives to principlism that can be found in feminist, critical, postcolonial, and Indigenous writings (Israel, 2015; Denzin et al., 2008; Mertens & Ginsberg, 2009). Not every research student and academic returns from the research heartlands to the research peripheries of the world, but those that do may ease international transfer of a range of research and education policies including those related to research ethics (Shamim & Qureshi, 2013).

Capacity-building programs funded by the global North delivered in the South may also promote policy transfer through epistemic communities. In Africa, for example, funds and training programs have been provided by, among others, the World Health Organization, the Fogarty International Center of the US National Institutes of Health, and the Pan-African Bioethics Initiative and Training and Resources in Research Ethics Evaluation (TRREE) for Africa. In some initiatives, researchers and administrators are brought to designated centers in the global North as groups for specific courses or within faculty exchange programs. In other cases, regional fora are run in developing countries, often with the help of local returnees from courses in the developed world. South Africa has acted as host for two regional health research ethics capacity-building programs – the South African Research Ethics Training Initiative (SARETI), and the International Research Ethics Network for Southern Africa (IRENSA). Over eight years, IRENSA provided a one-year diploma and internship for almost 100 mid-career health care professionals. These professionals included members of 40 research ethics committees, mostly in South Africa, but also drawn from other Anglophone countries on the African continent.

It would be churlish not to acknowledge the importance of ethics capacity-building programs for health research. However, some initiatives might be problematic. Commentators have questioned whether some systems being supported by US-funded research ethics initiatives in lower- and middle-income countries are sustainable and whether they rely too heavily on professionals from the global North, are well-designed or accurate, or are appropriate in these, or even any, setting (Eckstein, 2004). More stridently, De Vries and Rott (2011) portrayed some courses as less of a dialogue and more like 'missionary work', a one-way flow of western ideas and influence. Similarly, in Brazil, Fernando Hellmann and his colleagues (2015) noted that the Fogarty courses acted as a 'as a form of indirect moral imperialism' (p. 515) by continuing to disseminate standards of participant benefit accepted in the United States for lower- and middle-income countries after they had been explicitly rejected by Latin American and Caribbean countries. Not *all* training is necessarily valuable and it is possible that some of these initiatives, by failing to reject the mistakes of US regulation, may be unhelpful to social science research.

The attitudes of some North American and European institutions towards working with Southern partners may also serve to entrench Northern approaches and undercut competing Southern-based claims to expertise. Leslie London and Helen MacDonald (2014) described two cases where Northern regulators had initially appeared to recognize local expertise in South Africa, only to ignore and marginalize recommendations made by those experts. In the first instance, a European funding agency requested South African review of a research proposal from a European-based American anthropologist. The research project would employ a doctoral student to explore HIV healthcare offered through an NGO in South Africa. According to London who was acting as the local reviewer, the South African NGO knew nothing of the research and the proposal failed to demonstrate understanding of local ethical sensitivities or ethics regulatory requirements. Among other matters, London was critical of 'parachute research' and a division of labor whereby Southern researchers gathered empirical data for analysis by Northern theorists, analysis that would not be shared in any obvious way with the South African research or participating community: 'Once shared, the researcher disappears with the knowledge, the experience and the intellectual capital' (in London & MacDonald, 2014: 101). Despite this assessment by South African reviewers, the research was funded by the European agency. In the second example, a US undergraduate student planned an eight-week ethnographic research study of aspects of AIDS-related stigma in the Western Cape. The IRB at her university passed the proposal but required ethics clearance in South Africa and, to enable this, the student negotiated affiliation to the University of Cape Town. MacDonald reviewed the proposal on behalf of the Department of Social Anthropology, found 'glaring' weaknesses and concluded that the form mandated by the IRB had produced a lengthy shopping list of ethics issues to be addressed, but not ones that could elicit the ethical thinking that might be needed by an ethnographer working in this field in South Africa. However, the IRB refused to cede the authority to review modifications to the review committee in Cape Town making it difficult for the local committee to insist on or even allow redrafting in response to changes in the field. In so doing, 'the northern institution made a large investment in ethical oversight but oriented this investment entirely towards limiting its legal liability, with little regard for local ethical practices in South Africa' (in London & MacDonald, 2014: 94).

London and MacDonald blamed the behavior of the two Northern institutions variously on methodological *naïveté*, lack of expertise in ethnography, arrogance, and the trumping of ethics by legal liability. Of course, these behaviors were only able to stand without modification because of the power differentials between European and North American institutions on the one hand and perhaps the highest ranked African research institution on the other. The ways transnational research relationships tackle research ethics needs to be understood within the context of the political economy of research.

Research ethics regulatory policy and practices have been exported from the global North to the South as part of the flows of capital and academic labor. In order to secure grants from the United States, medical institutions in the South have had to establish research ethics guidelines and review structures that reflect arrangements in the United States. These arrangements have been supported by transnational professional networks populated by academics and graduates returning from North America and Europe, as well as by health research capacity-building programs funded by the North. As we have seen, they are not easily challenged by social scientists.

One rationale for the adoption of principlism is that countries in the South need to conform to international conventions in order to either protect their citizens or remain competitive in the market for international research. The assumption appears to be that supranational initiatives are inherently better than local ones. The issue of where the locus of responsibility for developing policy and regulation should rest is not unique to research ethics. Within federal entities such as the European Union (though less so in individual federal states), various conceptions of subsidiarity have supported a countervailing response to pressures for greater centralization of governance. Subsidiarity is based on the premise that moves to centralize authority need to be justified and cannot just be asserted as good. So, only those matters that cannot be dealt with at the state level might warrant international regulation, offering a 'rebuttable presumption for the local' (Føllesdal, 2016). Under a liberal contractual model of subsidiarity, individuals are recognized as having an interest in shaping the social institutions that might control their lives, so that among other things: institutions are responsive to the needs and interests of citizens; local communities can resist external domination; and, members of a community can engage in active citizenship (Føllesdal, 2014). In addition, other groups who have no legitimate interest in the way a community shapes its regulation on a particular matter can avoid excessive interference, though they might provide assistance perhaps in order to avoid a competitive deregulatory spiral (Genschel & Plumper, 1997). Within research ethics, Kotalik (2010) recognized that the principle of subsidiarity might be operating *within* states that had national statements but left the interpretation of those statements to local review bodies. However, he failed to consider how international actors might be ignoring the same principle at national level. Different states might indeed acknowledge the importance of a range of international bodies, declarations and principles but deploy subsidiarity to assert the right of individual states, sub-state communities and individuals to play significant roles in fashioning local policy and regulation in response to their particular social and cultural contexts. Of course, the principle of subsidiarity does pose its own problems, the most obvious being determining at what point and on what basis a higher level might be able to intervene in the decisions of a more local grouping. Nevertheless, it might provide a way for states such as South Africa and Brazil and for disciplines such as the social sciences to resist the universalist claims of supranational bioethical regulation.

CONCLUSION

Research ethics regulations largely: are produced and conducted in the global North; are based on universalist claims about ethics and the primacy of the individual; exclude other belief systems; take advantage of institutionalized power differentials; and erase colonial and neo-colonial experiences. And so, other contexts and experiences are excluded or, if incorporated, seen as offering only inflexible, historical points of reference.

When biomedically-derived regulations are imported, the experience of social scientists in Brazil and South Africa suggests that it may be difficult to influence their initial formation and ambit. Where research infrastructure is underdeveloped, imported codes may even ossify, as regulatory authorities may have neither the will, nor resources or mandate to modify requirements as problems emerge. Researchers who fail to comply with imported ethical requirements risk forfeiting funding, having their papers rejected by publishers or losing their jobs. Even where social scientists have mobilized, changes in the imported regime may be difficult to achieve. Brazilian social scientists now have their own regulations in the form of a Resolution that social scientists in other jurisdictions might envy, but progress was slow and painful.

It is deeply troubling that so many countries have imported regimes from the global North that are flawed within their own context, but also appear incapable of respecting different ethical traditions, learning from local knowledge of context, or engaging with local researchers, institutions, participants and other stakeholders in the world of research. In many ways, Schrag's language of 'ethical imperialism' seems to be a useful analytical device for understanding the export of research ethics regulation from the global North to the global South. It may also hold some rhetorical value.

However, it may also disguise sophisticated patterns of incorporation, accommodation and resistance, which, for us to understand, require a level of empirical research that is yet to be undertaken. In some parts of the world, there is an emerging critique of principlism and a distrust of the motivation for some of the funding for capacity-building in research ethics. When researchers resist the roll-out of universal ethical norms, they may be seeking guidelines that display greater cultural sensitivity. However, for many, opposition is not simply targeted at insensitivity in application but draws on critical ethical traditions to challenge the universal basis for principlism, and calls for a deeper understanding of and engagement with how different societies, cultures and peoples understand ethics, research and ethical research.

ACKNOWLEDGEMENTS

Some of this chapter is drawn from Israel (2015). Thank you to Robert Dingwall for pointing to the value of subsidiarity in this context, to Ron Iphofen and Will van den Hoonaard for their comments on drafts, and to Iara Guerriero for allowing me to keep up to date with changes in Brazilian regulation.

REFERENCES

Allen, A., Anderson, K., Bristol, L., Downs, Y., O'Neill, D., Watts, N., and Wu, Q. (2009) 'Resisting the Unethical in Formalised Ethics: Perspectives and Experiences', in J. Satterthwaite, J. Piper, and P. Sikes (eds) *Power in the Academy*. Stoke-on-Trent: Trentham Books, pp.135–152.

Associação Nacional de Pós-Graduação e Pesquisa em Ciências Sociais (2013) *Por uma regulamentação específica da ética em pesquisa nas ciências humanas e sociais*. http://www.anpocs.com/index.php/ciencias-sociais/destaques/1149-por-uma-regulamentacao-especifica-da-etica-em-pesquisa-nas-ciencias-humanas-e-sociais-

Barboza, M., Minaya, G., and Fuentes, D. (2010) 'Hacia una Comisión Nacional de Ética de la Investigación en Salud en Perú: Apuntes acerca de rutas y procesos en perspectiva comparada (Towards a national ethics committee of health research in Peru: Notes about routes and processes in comparative perspective)', *Revista Peruana de Medicina Experimental y Salud Publica* 27(4): 621–628.

Beauchamp, T.L. and Childress, J.F. (2013) *Principles of Biomedical Ethics* (7th edition). New York: Oxford University Press.

Beecher, H.K. (1966) 'Ethics and clinical research', *New England Journal of Medicine* 274(24): 1354–1360.

Bento, S.F., Hardy, E., Hebling, E.M., de Pádua, K.S., and Osis, M.J.D. (2011) 'The Brazilian Ethics Research Review System: An Evaluation from the Perspectives of Institutional Review Boards', *AJOB Primary Research* 2(3): 28–37.

Coimbra, C., Baldini, C., Silveira, C., Cerveny, C.M.O., Bonilha, E.A., and Concone, M.H.V.B. (2007) *Relatório da reunião sobre ética em pesquisa qualitativa em saúde* (Report on the meeting on ethics and qualitative research in health). São Paulo: Comitê de Ética em Pesquisa da Secretaria Municipal de Saúde (Research Ethics Committee of the Municipal Secretary of Health). http://www.prefeitura.sp.gov.br/cidade/secretarias/upload/arquivos/secretarias/saude/cepsms/0018/Relatorio_Guaruja_out2007_enviado_CNS.pdf

Conselho Nacional de Saúde (1996) Resolução n.196, de 10 de outubro de 1996. Diretrizes e Normas Regulamentado-ras de Pesquisas Envolvendo Seres Humanos. Brasília: CNS. http://conselho.saude.gov.br/resolucoes/1996/Res196_en.pdf

Conselho Nacional de Saúde (2012) Resolução n.466, de 12 de dezembro de 2012. Brasília: CNS. http://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf. English translation http://conselho.saude.gov.br/resolucoes/2012/466_english.pdf

Cross, M.K.D. (2013) 'Rethinking epistemic communities twenty years later', *Review of International Studies* 39(1): 137–160.

Cunow, S. and Desposato, S. (2016) 'Local Review: Confronting the Brazilian Black Box', in S. Desposato, (ed.) *Ethics and Experiments: Problems and Solutions for Social Scientists and Policy Professionals*. New York: Routledge, pp.128–138.

Department of Health (2004) *Ethics in Health Research: Principles, Structures and Processes.* Pretoria, SA: Department of Health.

Department of Health (2015) *Ethics in Health Research: Principles, Processes and Structures* (2nd ed.). Pretoria, SA: Department of Health.

Denzin, N.K., Lincoln, Y.S., and Smith, L.T. (2008) (eds) *Handbook of Critical and Indigenous Methodologies*. Los Angeles: Sage, pp. 439–458.

De Vries, J. and Henley, L. (2014) 'Staying Silent When We Should Speak Up: Informed Consent and the Interface Between Ethics as Regulation and Ethics in Practice', in D. Posel and F.C. Ross (eds) *Ethical Quandaries in Social Research*. Cape Town: HSRC Press, pp. 75–92.

De Vries, R. and Rott, L.M. (2011) 'Bioethics as Missionary Work: The Export of Western Ethics to Developing Countries', in C. Myser (ed.) *Bioethics Around the Globe*. Oxford: Oxford University Press, pp. 3–18.

Diniz, D. (2010) 'A pesquisa social e os comitês de ética no Brasil', in S. Fleischer and P. Schuch (eds) *Ética e regulamentação na pesquisa antropológica*. Brasilia: LetrasLivres/Editora Universidade de Brasilia, pp. 183–192.

Duarte, L.F.D. and Sarti, C.A. (2016) *Relatório de atividades de 2015 Comitê de Ética em Pesquisa da ABA*. http://www.portal.abant.org.br/images/Comissoes_Comites/Comit%C3%AA_de_%C3%89tica_em_Pesquisa_nas_Ci%C3%AAncias_Humanas_-_Relat%C3%B3rio_2015-2016.pdf

Eckstein, S. (2004) 'Efforts to build capacity in research ethics: An overview', *Science and Development Network*. 1 June. http://www.scidev.net/global/policy-brief/efforts-to-build-capacity-in-research-ethics-an-ov.html

Figueiredo, V. (2004) 'Ética e ciência: comissões de ética em pesquisa científica', in C. Víctora, R.G. Oliven, M.E. Maciel, and A.P. Oro (eds) *Antropologia e Ética. O debate atual no Brasil*. Niterói: Editora da Universidade Federal Fluminense, pp. 113–118.

Føllesdal, A. (2014) 'Subsidiarity and the Global Order', in M. Evans, and A. Zimmermann (eds) *Global Perspectives on Subsidiarity*. Dordrecht, Netherlands: Springer, pp. 207–220.

Føllesdal, A. (2016) 'Subsidiarity and International Human-Rights Courts: Respecting Self Governance and Protecting Human Rights – Or Neither?', *Law and Contemporary Problems* 79(2): 147–163.

Genschel, P. and Plumper, T. (1997) Regulatory competition and international co-operation, *Journal of European Public Policy* 4(4): 626–642.

Gracia, D. (1995) 'Hard times, hard choices: Founding bioethics today', *Bioethics* 9(3–4): 183–206.

Guerriero, I.C.Z. (2016a) 'Ethics in social science and humanities research: Brazilian strategies to improve guidelines', in W. van den Hoonaard and A. Hamilton (eds) *Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review*. Toronto, ON: Toronto University Press, pp. 267–281.

Guerriero, I.C.Z. (2016b) 'Approval of the Resolution governing the ethics of research in social sciences, the humanities, and other disciplines that use methodologies characteristic of these areas: Challenges and achievements', *Ciência & Saúde Coletiva* 21(8): 2619–2629. http://www.scielo.br/pdf/csc/v21n8/en_1413-8123-csc-21-08-2619.pdf

Guerriero, I.C.Z. and Bosi, M.L.M. (2015) 'Research ethics in the dynamic of scientific field: Challenges in the building of guidelines for social sciences and humanities', *Ciência & Saúde Coletiva* 20(9): 2615–2624.

Guerriero, I.C.Z. and Dallari, S.G. (2008) 'The need for adequate ethical guidelines for qualitative health research', *Ciência & Saúde Coletiva*, Marzo-Abril: 303–311.

Haas, P.M. (1992) 'Introduction: Epistemic communities and international policy coordination', *International Organization* 46(1): 1–35.

Hardy, E., Bento, S.F., Hebling, E.M., Faúndes, A., Osis, M.J.D., and Sousa, M.H. (2010) 'Twelve years of the Brazilian initiative to create a network of IRBs for the ethical evaluation of research studies involving human subjects', *AJOB Primary Research* 1(4): 19–27.

Hellmann, F., Garrafa, V., Schlemper Jr, B.R., and Bittencourt, S. (2015) 'The Fogarty Training Program in low- and middle-income countries: International research ethics education or moral imperialism?', *Archives of Medical Research* 46(6): 515–516.

Israel, M. (2015) *Research Ethics and Integrity for Social Scientists: Beyond Regulatory Compliance*, 2nd Edition. London: Sage.

Kotalik, J. (2010) 'Examining the suitability of the principle of subsidiarity for bioethics', *Kennedy Institute of Ethics Journal* 20(4): 371–390.

Langdon, E.J., Maluf, S., and Tornquist, C.S. (2008) 'Ética e política na pesquisa: os métodos qualitativos e seus resultados', in I.C.Z. Guerriero, M.L.S. Schmidt, and S. Zicker (eds) *Ética nas Pesquisas em Ciências Humanas e Sociais na Saúde*. São Paulo: Aderaldo & Rothschild, pp. 128–147.

Lima, R. (2010) 'Até onde funciona? Uma breve reflexão sobre a atuação dos comitês de ética em pesquisa no estudo antropológico em saúde', in S. Fleischer and P. Schuch (eds) *Ética e regulamentação na pesquisa antropológica*. Brasilia: LetrasLivres/Editora Universidade de Brasilia, pp. 159–170.

London, L. and MacDonald, H. (2014) 'Transnational excursions: The ethics of northern anthropological investigations going south', in D. Posel and F.C. Ross (eds) *Ethical Quandaries in Social Research*. Cape Town: HSRC Press, pp. 93–110.

Louw, B. and Delport, R. (2006) 'Contextual challenges in South Africa: The role of a research ethics committee', *Journal of Academic Ethics* 4(1–4): 39–60.

Luna, F. (2006) *Bioethics and Vulnerability: A Latin American View*. Amsterdam: Rodopi.

Mamotte, N. and Wasenaar, D. (2009) 'Ethics review in a developing country: A survey of South African social scientists' experience', *Journal of Empirical Research on Human Research Ethics* 4(4): 69–78.

Mertens, D.M. and Ginsberg, P.E. (eds) (2009) *The Handbook of Social Research Ethics*. Thousand Oaks, CA: Sage.

Metz, T. (2007) 'The motivation for "Toward an African Moral Theory"', *South African Journal of Philosophy* 26(4): 331–335.

Metz, T. (2013) 'The Western ethic of care or an Afro-communitarian ethic? Specifying the right relational morality', *Journal of Global Ethics* 9(1): 77–92. http://dx.doi.org/10.1080/17449626.2012.756421

Moodley, K. and Myer, L. (2007) 'Health research ethics committees in South Africa 12 years into democracy', *BMC Medical Ethics* 8(1). DOI: 10.1186/1472-6939-8-1.

Moodley, K. and Rennie, S. (2011) 'Advancing research ethics training in Southern Africa (ARESA)', *The South African Journal of Bioethics and Law* 4(2): 104–105.

Morreira, S. (2012) '"Anthropological futures"? Thoughts on social research and the ethics of engagement', *Anthropology Southern Africa* 35(3–4): 100–104.

de Oliveira, L.R.C. (2004) 'Pesquisas em versus pesquisas com seres humanos', in C. Víctora, R.G. Oliven, M.E. Maciel, and A.P. Oro (eds) *Antropologia e Ética. O debate atual no Brasil.* Niterói: Editora da Universidade Federal Fluminense, pp. 33–44.

Pappworth, M.H. (1967) *Human Guinea Pigs: Experimentation on Man.* London: Routledge.

Posel, D. and Ross, F.C. (2014) 'Opening up the quandaries of research ethics: Beyond the formalities of institutional ethical review', in D. Posel and F.C. Ross (eds) *Ethical Quandaries in Social Research*. Cape Town: HSRC Press, pp. 1–26.

Ramos, A.R. (2004) 'A difícil questão do consentimento informado', in C. Víctora, R.G. Oliven, M.E. Maciel, and A.P. Oro (eds) *Antropologia e Ética. O debate atual no Brasil*. Niterói: Editora da Universidade Federal Fluminense, pp. 91–96.

Santos, R.V. (2006) 'Indigenous Peoples, Bioanthropological Research, and Ethics in Brazil: Issues in Participation and Consent', in G.T.H. Ellison and A.H. Goodman (eds) *The Nature of Difference: Science, Society and Human Biology*. Boca Raton, FL: CRC Press / Taylor and Francis, pp. 181–202.

Schrag, Z.M. (2010) *Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965–2009*. Baltimore, MD: Johns Hopkins University Press.

Shamim, F. and Qureshi, R. (2013) 'Informed consent in educational research in the South: Tensions and accommodations', *Compare: A Journal of Comparative and International Education* 43(4): 464–482.

Sikes, P. (2013) 'Working together for critical research ethics'. *Compare: A Journal of Comparative and International Education* 43(4): 516–536.

Spiegel, A. (2005) 'From exposé to care: Preliminary thoughts about shifting the ethical concerns of South African social anthropology', *Anthropology Southern Africa* 28(3–4): 133–141.

Trindade, Z.A. and Szymanski, H. (2008) 'O impacto dos comitês de ética — CEPs, na atividade de pesquisa em Psicologia', in I.C.Z. Guerriero, M.L.S. Schmidt, and S. Zicker (eds) *Ética nas Pesquisas em Ciências Humanas e Sociais na Saúde*. São Paulo: Aderaldo & Rothschild, pp. 280–304.

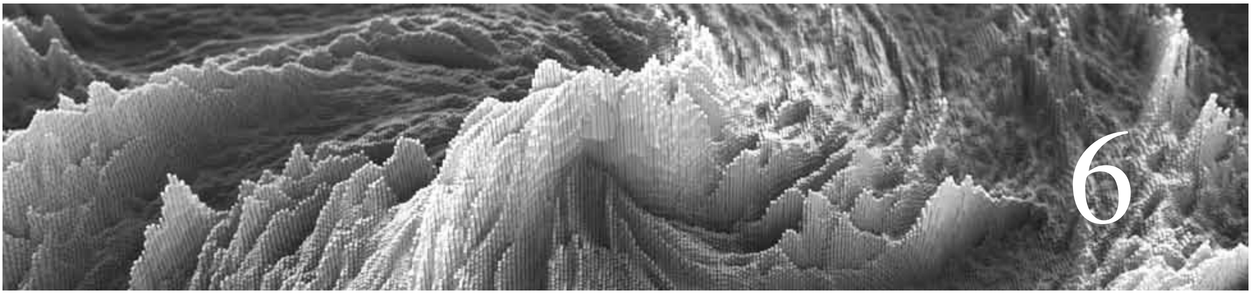
UNESCO (2006) *Universal Declaration on Bioethics and Human Rights*. Paris: UNESCO. http://unesdoc.unesco.org/images/0014/001461/146180E.pdf

UNESCO-UIS (2012) 'New patterns in student mobility in the Southern Africa Development Community', *UIS Information Bulletin* 7. http://www.uis.unesco.org/Education/Documents/ib7-student-mobility-africa-2012-v4-en.pdf

Wassenaar, D.R. and Mamotte, N. (2012) 'Ethical Issues and Ethics Reviews in Social Science Research', in M.M. Leach, M.J. Stevens, G. Lindsay, A. Ferrero, and Y. Korkut (eds) *The Oxford Handbook of International Psychological Ethics*. Oxford: Oxford University Press. DOI: 10.1093/oxfordhb/9780199739165.013.0019.

World Medical Association (WMA) (2008) *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*, as amended by the 59th WMA General Assembly, Seoul.

World Medical Association (2013) *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*, as amended by the 64th WMA General Assembly, Fortazela, Brazil. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/



6

Democratizing Research in Practice

Helen Kara

INTRODUCTION

The term ‘democratizing research’ covers a range of emancipatory approaches to research such as activist research, feminist research, decolonizing methodologies, community-based research and participatory research. These approaches developed separately in the last decades of the twentieth century, so they are still comparatively new, and are not always well understood. Recognition of the similarities between these approaches is very recent (e.g. Craven & Davis, 2013: 1; Jolivétte, 2015: 6).

The terminology used to talk about these approaches to research is not fixed. For example, some people use the term ‘research justice’, while others prefer ‘democratizing research’ or ‘emancipatory approaches’ – and no doubt there are more terms in use around the world. The term ‘research justice’ seems to be used mostly by people who have been oppressed by colonialist and imperialist research practices. I have chosen to use ‘democratizing research’ for two reasons. First, it seems to fit best with my standpoint as a white British researcher, though I realize that ‘democracy’ is a culturally located term and will discuss this in more detail later in the chapter. Second, it seems to me that emancipatory approaches are not only about the ethics of justice, but also – and equally – about the ethics of care.

This chapter will begin by outlining the history and development of these approaches, and identifying their common elements. The ethical difficulties they raise will be considered. The chapter will discuss tensions between the need to operate any emancipatory approach throughout the entire research process, and the constraints which may make this difficult or impossible in practice. The key barriers and enablers to emancipatory approaches will be identified, and ways to overcome the barriers and maximize the enablers will be discussed. Consideration will be given to how and when to use an emancipatory approach to conduct research as an insider, and how and when to do the same as an outsider. The chapter will conclude with a look to the future of research democratization.

THE HISTORY OF EMANCIPATORY RESEARCH

Activist research is a form of insider research where, for example, transgender researchers will investigate the effects of transphobia (Telford & Faulkner, 2004: 549–550). This approach to research grew from political activism and changing conceptions of human rights across Westernized nations in the second half of the twentieth century (Morrow et al., 2012: 8–10). Activist research is intended to empower disadvantaged and marginalized people. A pivotal point in activist research came from the disability movement. Paul Hunt had muscular dystrophy, which necessitated the use of a wheelchair, and he lived in the first Leonard Cheshire home for people with disabilities in Britain (Tanaka, 2007: 21). Hunt was a researcher and activist (Tanaka, 2007: 38). In the 1960s, when the then Ministry of Health commissioned some research into the participation of residents in Leonard Cheshire homes, Hunt and other residents expected the researchers to support their desire to have some control over their lives (Barnes & Cotterell, 2012: 143). Sadly, the reverse was the case, as the researchers largely supported the status quo, in which people living with disabilities were regarded as unfit to participate fully in society. The residents were understandably upset and angry, and Hunt wrote a searing critique of the research, arguing that it was 'profoundly biased and committed *against* the residents' interests' (Hunt, 1981, cited in Barnes and Cotterell, 2012: 144; emphasis in Hunt).

The work of disability researchers such as Paul Hunt and Mike Oliver laid the foundations for the creation of the 'emancipatory research' model. Emancipatory research developed new ethical dimensions by questioning how social research is conducted and who controls its resources (Cotterell & Morris, 2012: 61). This anti-oppressive research practice spread into the fields of mental health, feminist research, community research and numerous other areas. There is increasing acknowledgement of the potential for activism and research to work hand in hand (Zeffiro & Hogan, 2015: 45) although, as we will see later in the chapter, this can also create difficulties.

Feminist research has been described as using 'gender as a lens through which to focus on social issues' (Hesse-Biber, 2014: 3). In the 1970s, researchers in the second wave of feminism, such as Ann Oakley in the UK and Laurel Richardson in the US, began studying aspects of society relating to women, such as housework and single women's affairs with married men (e.g. Oakley, 1974; Richardson, 1979). These and other feminist researchers around the world were asserting that the identity and context of both researchers and participants was central to the research process, and so they were challenging the traditional research principles of objectivity and neutrality (Ryan-Flood & Gill, 2010: 4–5).

In the 1990s, third wave feminists moved beyond using gender as a single lens, recognizing that gender interacts with other loci of inequality such as sexual orientation, ethnicity, and socioeconomic status (Ryan-Flood & Gill, 2010: 4). This is known as 'intersectionality' (Crenshaw, 1993: 1244), a concept used to acknowledge identity as both multifaceted and closely linked with its social and geographical contexts (Naples & Gurr, 2010: 24). After all, nobody is only a woman, or just someone with a disability, or solely a person of color. An intersectional approach aims to accept and reflect the complexity of identity, and to examine the relationships between different aspects of identity and their implications for power relations (Frost & Elichaoff, 2010: 60).

The intricacies of intersectionality create considerable challenges for research methods (Hughes & Cohen, 2010: 189, drawing on Denis, 2008). For second wave feminists, qualitative methods seemed most appropriate, and there is still a strong belief that this is the case, though some feminist researchers, particularly in the US, now recognize the value of quantitative and mixed-methods techniques for answering some research questions (Hughes & Cohen, 2010: 190–191). However, traditional research methods, such as surveys, interviews and focus groups, are rooted in Western colonial cultural ways of knowing (Bonilla-Silva & Zuberi, 2008: 18; Gobo, 2011: 423–427). Emancipatory researchers may choose to use existing community formats, such as the talking circles used by the Wikwemikong (Blodgett et al., 2010: 67), or to develop such formats for their communities, such as the sharing circles used by Oparah and her colleagues such that research can become 'as much a process of collective witnessing and healing, as one of inquiry and documentation' (Oparah et al., 2015: 133, cited in Jolivétte, 2015: 5–12).

Decolonized research is an approach that aims to separate research from imperialism and colonialism (Tuhiwai Smith, 2012: 4–5). There are many ways in which research in much of the world carries colonialist overtones. For example, the English language is dominant in research worldwide (Perry, 2011: 906–907). Non-English speaking researchers may be seen by their English-speaking colleagues and by research ethics committees as vulnerable or incompetent participants, when in fact they may be entirely able to participate in research if the research is conducted in their native language or a translator is provided (ibid.). The dominance of English within research is a colonialist situation that privileges English-speaking researchers and disadvantages those who do not speak English, no matter how clever or skilled they may be (Gobo, 2011: 419–420). Also, research in other languages can run into difficulties if those languages do not include words for all the concepts needed to describe and discuss research. For example, Ndimande conducted research in his native South Africa in indigenous languages including isiZulu, Sesotho, isiXhosa and isiNdebele, which helped him to build rapport with his participants and enabled them to contribute more fully than if the research had been conducted in English (Ndimande, 2012: 216–218). However, Ndimande found that he had to be very careful in translating research questions, originally formulated in English, into indigenous languages that had no research discourse (p. 219; see also Swartz, 2011: 61). Similar problems arise with cross-national surveys and are complex to solve, requiring 'multiple skilled translators and survey specialists within each country working to arrive at an optimal translation' (Smith et al., 2011: 492).

Similar difficulties can also arise for Western researchers in Western countries who are studying minority populations. For example, it is often taken for granted by Western researchers that participants should remain anonymous, and this is a common requirement of research ethics committees (RECs) or institutional review boards (IRBs). However, a researcher working in America with young Sudanese refugee boys found that some of her participants were highly resistant to having their names changed, as her IRB required (Perry, 2011: 899). On further investigation, she discovered that 'forced name-changing was a common tactic of repression by the Sudanese majority' (p. 911). Perry's participants had – and, in at least one case, exercised – the choice of refusing to take part in her research. But some would argue that the IRB should have worked in a way that enabled researchers to respond flexibly to the needs of potential participants, rather than effectively excluding some people purely as a result of its strictures.

Many parts of the world are now multicultural, yet many research methods are monocultural (Gobo, 2011: 418). Western methods are often regarded as universal when they may not be universally appropriate (Smith et al., 2011: 485–486). For example, Western researchers may take it for granted that consent should be given in writing, but this can prove problematic in cultures where oral communication is dominant and few people are able to write (Czymoniewicz-Klippel et al., 2010: 335–336). It is important for any researcher to be sensitive to the potential for the cultural norms and experiences of participants and colleagues to affect the research process. Ultimately, colonized or formerly colonized people do not want their stories told for them by academics from other, more powerful cultures, even if those academics have the best intentions. Nor do non-Western people necessarily accept Western views of situations or concepts (Smith et al., 2011: 499). Indigenous people the world over would prefer to tell their own stories in their own ways. As with emancipatory research, Indigenous academics and researchers are working to redress social injustice and increase self-determination through decolonizing methodologies (Tuhiwai Smith, 2012: 4–6).

Participatory research, also known as participatory action research, is another emancipatory approach. This approach emphasizes the full involvement of participants at every stage of the research process (Bhana, 2006: 432) and should benefit the communities or groups to which participants belong, as well as the researchers (Wassenaar, 2006: 69). Where participatory research is conducted specifically within a community, it may be known as community-based research or community-based participatory research (Goodson & Phillimore, 2012: 3). Whatever the terminology, the aim is to empower disempowered groups, communities and individuals (Bhana, 2006: 432).

Participants' views on the research process may differ markedly from researchers' views, even on key issues such as the value of anonymity (O'Reilly et al., 2012: 220). Yet outside a participatory approach, participants' views on these topics are rarely sought. However, even participatory approaches don't enable unlimited participation: for example, participants' views of research governance mostly go unheard (McAreavey & Muir, 2011: 403). In fact, research governance and participatory research are somewhat oppositional in that, conventionally, work with participants cannot begin until formal ethical approval has been received, while research is not truly participatory unless participants have been involved from the very start of the research design process.

COMMONALITIES AND DIFFICULTIES

The main thing all these emancipatory approaches have in common is their shared aim to reduce imbalances of power within the research process, and beyond. There are notable examples of this succeeding. One is the case of critical communicative methodology (CCM), a specific kind of participatory community-based mixed-methods research that was developed in the late 1990s and early 2000s by Jesús Gómez (Gómez et al., 2011). The aim was to identify and solve social problems through dialogue, and the key principle of CCM, following Habermas, was that everyone has the right to participate in intellectual discussion, regardless of whether they are 'an intellectual' or can speak intellectual language. Gómez believed that everyone has critical analytic abilities, and that we can all learn a great deal from people who have different backgrounds from our own. In the early part of this century, CCM was used with Roma communities in several European countries. Romani people are nomadic, with no territory of their own; they are subject to high levels of individual and structural discrimination, and have long been excluded from social decision-making processes. The Workaló project involved Romani people throughout the process of finding out why they are excluded from the labour market, how job opportunities could be created and how individuals could be helped to become more employable (Munté et al., 2011). Academic and Romani researchers presented that research at the European Parliament. This led (among other things) to more formal recognition of the Roma communities in Europe and the development of a

European strategy to ensure that Romani people can ‘participate effectively in making the decisions that affect the lives and well-being of Roma communities’ (p. 263).

This is a research project that many people would regard as laudable, and one that has made a tangible difference to our world. However, it is not easy to assess how much difference it has made. It certainly did not solve the problem of discrimination against Romani people in Europe, as in 2014 an attitude survey in seven countries found that, in Italy, France, Greece, the UK and Poland, more people held unfavourable than favourable views of Roma; only in Germany and Spain was it the other way around (Pew Research Center, 2014: 30).

Using an emancipatory approach to research will not, by itself, solve any potential ethical problems. For example, it will not remove power imbalances between people of different races, genders, socioeconomic status and so on. Nor does it mean that everyone involved will have the same understanding of what is, or is not, ethical (McAreavey & Muir, 2011: 395). While feminist or disability activist researchers will have undoubtedly experienced oppression, this does not automatically mean those researchers will understand how oppression is experienced by other women or other people with disabilities (Mason, 2002: 193). An emancipatory approach to research may help everyone involved to address power imbalances and differences within the research project, but doing so will still take time and effort beyond that needed for core research tasks.

Also, emancipatory approaches to research can bring ethical difficulties of their own. For example, the idea of using a community-based approach may appeal to a researcher, but be considerably less appealing to potential participants, who have much less to gain. This becomes even more of a challenge in longitudinal research, which has to compete with demands from participants’ employers and families, among others (Weller, 2012: 123). Conversely, little is written about the extent to which participants may expect researchers to continue their relationships with them after the end of a project, and the difficulty this can cause for all concerned. Ethnographers may be more aware of this than most, because typically they spend many months living and working with participants. Some have said that leaving the field was more difficult than arriving (e.g. Cohen, 2015: 141).

Ending research-based relationships can be difficult even when the research method doesn’t involve complete immersion in a community. For example, a UK researcher carried out ethnographic research (as opposed to full-scale ethnography) with sex offenders in a probation hostel. For many participants, the researcher was the only person they could speak to in confidence. When she finished her research, she was unable to keep in touch with participants, because she no longer had permission to enter the hostel, and consent for meetings outside was unlikely to be granted. However, as the researcher lived near to the hostel, she did sometimes run into her former participants. This caused anxiety at times, such as when she was with a female friend and they met a male high-risk sex offender, a known rapist of adult women. For reasons of confidentiality, the researcher couldn’t warn her friend about the dangers this man posed. This made the researcher wary of her former participant, which left her feeling ashamed, as if she had simply used her participants for the benefit of her research. This internal conflict was resolved only very gradually as her former participants were moved out of the area where she lived (Reeves, 2010: 328).

Participants are not often involved in the writing or presenting stages of research – although again there are notable exceptions, such as Ellis and Rawicki (2013), a researcher and participant who co-wrote journal articles, and Munté, Serradell and Sordé (2011) who, as we have seen, involved Romani participants in presenting research to the European Parliament. Participants may be further marginalized, in a variety of ways, by the publication process. For example, in the long and thorough book on participatory action research by Chevalier and Buckles (2013), some participants are mentioned, such as Alberto (pp. 239–242) and the female forestry officer (pp. 300–303). However, these names do not appear in the otherwise excellent index. There are many names in the book's index, but only those of research professionals.

Structural aspects of research, such as project design, timescale and budget, may need to be in place before an emancipatory approach is implemented. This effectively sets up potential inequalities for any research encounter, with a framework being imposed on participants rather than agreed with them (McCarry, 2012: 60–61).

Also, it is important to remember that not everyone views these approaches as ideal. For example, rather than privileging decolonization, some researchers have called for cultural integration in research through a 'geocentric' approach (Li, 2014: 28). And democracy is a culturally located concept that is not universally regarded as positive. Since the last years of the twentieth century there has been an increase in the power and resources held by authoritarian governments in numerous countries across Asia, the Middle East, Africa and South America (Cooley, 2015). Many people in these countries view democratic regimes as hypocritical: e.g. for carrying out military action within authoritarian countries, using high levels of surveillance within their own borders, and sharing blacklists of suspected terrorists and terrorist sympathizers (Cooley, 2015). Within these countries it is likely that emancipatory approaches to research would not find favour at all. And even within more democratically governed countries, some experts ridicule emancipatory approaches as 'not proper science'.

Barriers and Enablers

As we have seen, one of the main barriers to emancipatory approaches is the research governance system and the requirements of formal ethical approval. This is covered in detail in Part 3 of this book, so here I will simply note two things. First, there is an argument that research governance organizations such as RECs and IRBs need to be 'decolonized' so that researchers can be responsible to participants rather than institutions (e.g. Denzin & Giardina, 2006: 35). Second, there is a call for the loci of research governance power to be shared by institutions such as universities with participant groups and communities (e.g. Jolivétte, 2015: 7). These positions indicate that there is little stomach for a complete dismantling of the research governance system, but perhaps considerable appetite for its reform.

Another barrier is conflict. This may be external conflict between paradigms, disciplines etc, or internal conflict between roles. For example, the inevitable power imbalances between academic and community-based researchers can lead to conflict (Ostrer & Morris, 2009: 74–75). Also, conflict can arise through the expression of intersectionality within the research process. For example, a black woman with mental health problems worked as an insider researcher to increase understanding of black African and African-Caribbean women's experiences of mental ill-health in a predominantly white city. She found that her participants identified as 'black women first and then as service users' (Essien, 2009: 70), while the services designed for people with mental health problems identified the people who came to them primarily as mental health service users, with all other aspects being seen as secondary (pp. 64–65).

Then there are the more mundane barriers of money and time. Using emancipatory approaches to research takes longer, and so costs more, than applying conventional techniques. For example, participatory research involves a great deal of investment in support, training and inclusion, particularly with vulnerable participants (Gillard et al., 2012: 252). In some cases, such as when researching highly sensitive topics with vulnerable groups, or perhaps when conducting longitudinal research, it may be more ethical to offer a flexible approach to participation, with options for participants to move through different levels of involvement at different times to suit their needs (McCarry, 2012: 64). While this could bring accusations of misuse of researcher power, it is also true that researchers are trained and supported to do research, and are likely to have many more professional and personal resources than most vulnerable participants, and so have an ethical responsibility to know when and how to offer involvement or participation (p. 65).

There is also ‘the question of who participates and how’ (Lomax, 2012: 107). Factors that may exclude potential participants include logistics (meeting times and locations, access to technology and communication systems, languages spoken and so on) and the requirements of the research, for example level of commitment and abilities required. This raises questions about the extent to which research participants are, or can be, representative of wider communities.

On the other hand, a number of factors can enable the use of emancipatory approaches to research. Political will is very helpful. Research is always a political act; even deciding not to do research is a political decision. Therefore, local political support for emancipatory approaches to research, from key communities and organizations, is a major enabler.

A second enabler is passion, within the research team, for the research topic or question. Arguably, this is necessary for all research. However, given that emancipatory approaches require more time and money, effort and energy, initiative and understanding than conventional ways of doing research, it is essential to focus on something that really matters to everyone involved.

A third enabler is a worldview, or ontological stance, that fits with democratizing research. If you believe, for example, that women are inferior to men, or that being gay is a defect or a sin, you’re unlikely to thrive in a democratizing environment. This is another reason democratizing research is political: it espouses, supports, and works to expand the democratic system.

A fourth enabler is resource. If you have the necessary time and money, it will be much easier for you to use an emancipatory approach.

There are two main keys to overcoming the barriers to democratizing research, and maximizing its enablers. The first is full awareness of what is involved, what is needed, and why. The second is clear communication. These are both far, far easier to state than they are to achieve. Of course they are linked: everyone who is or could be involved in the research needs full awareness of what is or may be involved, and that can only be achieved through clear communication. Also, within emancipatory approaches, ‘communication’ doesn’t mean ‘researchers explaining’; it means a two-way process of dialogue, over time, to build the necessary conditions for the research to take place.

Insider and Outsider

It might seem that the best, or even the only, way to use emancipatory approaches is as an insider researcher, i.e. a researcher who is also a member of the group or community being studied. Certainly insider researchers devised these approaches. However, that does not necessarily mean that insider researchers are always the best people to use these techniques in every context.

Consider a young Indigenous researcher who wants to use decolonizing methodologies for research within her home community. So far, apparently, so straightforward. However, the leaders of her community are the oldest men from three families, and she does not belong to one of those families. Also, in her community, older people command much more power and respect than younger people. Those community leaders are the gatekeepers who she will need to convince of the value of her proposed work, and that may not be easy for her; it may not even be possible.

This example highlights the fact that communities are not homogeneous, but are made up of several smaller sub-communities (Atfield et al., 2012: 79–80). This means that not every 'insider' has the same view of, or access to, their community. So, if a bisexual woman wants to do research with LGBTI groups, she may find difficulty in accessing a group of gay men – and a gay male researcher might have equal difficulty in accessing a group of bisexual women. Another implication of this is that research teams should not expect insider researchers to have privileged access to all members of their community, or even, in some cases, any members of that community (p. 80).

Also, all the usual difficulties faced by insider researchers will still be present when using emancipatory approaches. For example, it can be hard to see the topic clearly if you are close to it yourself, and challenging to develop the detachment necessary to ask tough questions, or to find surprises in your data. Plus the association of insider researchers with institutions, through their involvement with the research, may affect how other members of their community see them – either positively, or negatively (Atfield et al., 2012: 78). Either way, this can lead to role conflict.

Having said that, many of the usual advantages of being an insider researcher may also still be present. For a start, you will have a great deal of knowledge about your community before you begin. You will know who to go to for different kinds of help, and how to approach those people. You will already have a level of rapport with most people that will make it easier to build the trust needed for research. And your knowledge of your community may help you to sensitize the research design and instruments to the needs of potential respondents (Atfield et al., 2012: 79).

On balance, outsider researchers are likely to have more difficulty using emancipatory approaches than insider researchers. For example, they will need to spend time learning about the community, its past and present, norms and customs. Nevertheless, outsider researchers still have value to bring, as long as they can devote enough time and thought to their work to use these techniques properly. As in other research contexts, outsider researchers bring a fresh pair of eyes to the work, and hold fewer preconceptions than insider researchers. This may lead them to ask usefully naive questions that would never occur to an insider researcher.

One potentially useful approach is to form a research partnership, or team, involving both insider and outsider researchers. One very successful example of this involved sports researchers from Laurentian University in Canada working with community researchers from the Wikwemikong Unceded Indian Reserve, also in Canada. They used a community-based participatory action research methodology which was fully collaborative (Blodgett et al., 2010: 58). The research design was approved by both the university's REB and Wikwemikong's governing Band and Council (Blodgett et al., 2010: 60). The aim was to study community members' experiences of engaging in research, both with this team and with previous researchers, and to identify factors that would facilitate research in the community. Co-researchers from the community developed a 'composite vignette' as a form of narrative analysis. Among other things, they concluded that

> researchers need to take extra time to get to know the community. It is imperative that researchers are sensitive of the community's culture, language, customs and protocols before engaging in a project. A community champion needs to be identified and resourced immediately in order to begin the communication and bridging between the community and outside researchers, and to help establish appropriate bench marks and timelines for the research process. (Blodgett et al., 2010: 70–71)

THE FUTURE OF RESEARCH DEMOCRATIZATION

This review of emancipatory approaches to research might give the impression that activism and research are made for each other.

In fact, they can be uneasy bedfellows, particularly when the evidence from research challenges activists' political goals (Dreger, 2015: 27). But it is not, in fact, democratic to put the justice cart before the evidence horse. Those of us in this world who value democracy need to look unflinchingly at evidence and use it to support our work for justice (Dreger, 2015: 262).

Emancipatory approaches are always worth considering. However, they should not be 'bolted on' to a research project in order to put a tokenistic tick in the diversity box. They should only be used in appropriate circumstances, and always need to be used with thought and care.

Emancipatory approaches to research draw on ethics of justice in attempting to redress imbalances of power, and on ethics of care in working to make the research space safe and valuable for everyone involved. When they are effectively implemented, emancipatory approaches are among the most ethical approaches to research.

REFERENCES

Atfield, G., Brahmbhatt, K., Hakimi, H., and O'Toole, T. (2012) Involving community researchers in refugee research in the UK. In Goodson, L. and Phillimore, J. (eds) *Community research for participation: from theory to method*, 71–87. Bristol: Policy Press.

Barnes, M. and Cotterell, P. (eds) (2012) *Critical perspectives on user involvement*. Bristol: Policy Press.

Bhana, A. (2006) Participatory action research: a practical guide for realistic radicals. In Terre Blanche, M., Durrheim, K., and Painter, D. (eds) *Research in practice: allied methods for the social sciences*, 429–442. Cape Town: University of Cape Town Press.

Blodgett, A., Schinke, R., Peltier, D., Wabano, M., Fisher, L., Eys, M., Ritchie, S., Recollet-Saikkonen, D., Pheasant, C., and Pickard, P. (2010) '*Naadmaadmi*': reflections of Aboriginal community members engaged in sport psychology co-researching activities with mainstream academics. *Qualitative Research in Sport and Exercise* 2(1) 56–76. DOI: 10.1080/19398440903510160

Bonilla-Silva, E. and Zuberi, T. (2008) Toward a definition of white logic and white methods. In Zuberi, T. and Bonilla-Silva, E. (eds) *White logic, white methods: racism and methodology,* 3–27. Lanham, MA: Rowman & Littlefield.

Chevalier, J. and Buckles, D. (2013) Participatory action research: theory and methods for engaged inquiry. Abingdon: Routledge.

Cohen, J. (2015) Eating soup without a spoon: anthropological theory and method in the real world. Austin, TX: University of Texas Press.

Cooley, A. (2015) Countering democratic norms. *Journal of Democracy* 26(3) 49–63.

Cotterell, P. and Morris, C. (2012) The capacity, impact and challenge of service users' experiential knowledge. In Barnes, M. and Cotterell, P. (eds) *Critical perspectives on user involvement*, 57–69. Bristol: Policy Press.

Craven, C. and Davis, D.-A. (2013) Introduction: Feminist activist ethnogaphy. In Anglin, M. et al., *Feminist activist ethnography: counterpoints to neoliberalism in North America*, 1–22. Lanham, MA: Lexington Books.

Crenshaw, K. (1993) Mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanford Law Review* 43(6) 1241–1299.

Czymoniewicz-Klippel, M., Brijnath, B., and Crockett, B. (2010) Ethics and the promotion of inclusiveness within qualitative research: case examples from Asia and the Pacific. *Qualitative Inquiry* 16(5) 332–341.

Denis, A. (2008) Intersectional analysis: A contribution of feminism to sociology. *International Sociology* 23(5) 677–694.

Denzin, N. and Giardina, M. (2006) Introduction: ethical futures in qualitative research. In Denzin, N. and Giardina, M. (eds) *Ethical futures in qualitative research: decolonising the politics of knowledge*, 9–43. Walnut Creek, CA: Left Coast Press.

Dreger, A. (2015) Galileo's Middle Finger: Heretics, activists, and the search for justice in science. New York: Penguin Press.

Ellis, C. and Rawicki, J. (2013) Collaborative witnessing of survival during the Holocaust:

an exemplar of relational autoethnography. *Qualitative Inquiry* 19(5) 366–380.

Essien, K. (2009) Identity issues in mental health research. In Sweeney, A. et al. (eds) *This is survivor research*, 63–70. Ross-on-Wye: PCCS Books Ltd.

Frost, N. and Elichaoff, F. (2010) Feminist postmodernism, poststructuralism, and critical theory. In Ryan-Flood, R. and Gill, R. (eds) *Secrecy and silence in the research process: feminist reflections*, 42–72. Abingdon: Routledge.

Gillard, S., Borschmann, R., Turner, K., Goodrich-Purnell, N., Lovell, K., and Chambers, M. (2012) Producing different analytical narratives, coproducing integrated analytical narrative: a qualitative study of UK detained mental health patient experience involving service user researchers. *International Journal of Social Research Methodology* 15(3) 239–254.

Gobo, G. (2011) Glocalizing methodology? The encounter between local methodologies. *International Journal of Social Research Methodology* 14(6) 417–437.

Gómez, A., Puigvert, L., and Flecha, R. (2011) Critical communicative methodology: informing real social transformation through research. *Qualitative Inquiry* 17(3) 235–245.

Goodson, L. and Phillimore, J. (2012) Community research: opportunities and challenges. In Goodson, L. and Phillimore, J. (eds) *Community research for participation: from theory to method*, 3–20. Bristol: Policy Press.

Hesse-Biber, S.N. (2014) What is feminist research? In Hesse-Biber, S.N. (ed.) *Feminist research practice: a primer*, 3–13. Thousand Oaks, CA: Sage.

Hughes, C. and Cohen, R. (2010) Feminists really do count: the complexity of feminist methodologies. *International Journal of Social Research Methodology* 13(3) 189–196.

Hunt, P. (1981) Settling accounts with the parasite people: A critique of ‘A Life Apart’ by E.J. Miller and G.V. Gwynne. *Disability Challenge* 1: 37–50. Cited in: Barnes, M. and Cotterell, P. (eds) (2012) *Critical perspectives on user involvement*. Bristol: Policy Press.

Jolivétte, A. (ed.) (2015) *Research justice: methodologies for social change*. Bristol: Policy Press.

Li, P.P. (2014) Toward the geocentric framework of intuition: the Yin-Yang balancing between the Eastern and Western perspectives on intuition. In Sinclair, M. (ed.) *Handbook of research methods on intuition*, 28–41. Cheltenham: Edward Elgar.

Lomax, H. (2012) Contested voices? Methodological tensions in creative visual research with children. *International Journal of Social Research Methodology* 15(2) 105–117.

McAreavey, R. and Muir, J. (2011) Research ethics committees: values and power in higher education. *International Journal of Social Research Methodology* 14(5) 391–405.

McCarry, M. (2012) Who benefits? A critical reflection of children and young people’s participation in sensitive research. *International Journal of Social Research Methodology* 15(1) 55–68.

Mason, J. (2002) *Qualitative researching* (2nd edn). London: Sage.

Morrow, E., Boaz, A., Brearley, S., and Ross, F. (2012) *Handbook of service user involvement in nursing and healthcare research.* Chichester: Wiley-Blackwell.

Munté, A., Serradell, O., and Sordé, T. (2011) From research to policy: Roma participation through communicative organization. *Qualitative Inquiry* 17(3) 256–266.

Naples, N. and Gurr, B. (2010) Feminist empiricism and standpoint theory: approaches to understanding the social world. In Ryan-Flood, R. and Gill, R. (eds) *Secrecy and silence in the research process: feminist reflections*, 14–41. Abingdon: Routledge.

Ndimande, B. (2012) Decolonizing research in postapartheid South Africa: the politics of methodology. *Qualitative Inquiry* 18(3) 215–226.

Oakley, A. (1974) *The sociology of housework*. London: Martin Robinson.

Oparah, J., Salahuddin, F., Cato, R., Jones, L., Oseguera, T., and Matthews, S. (2015) By us, not for us: Black women researching pregnancy and childbirth. Cited in: Jolivétte, A. (2015) Research justice: radical love as a strategy for social transformation. In Jolivétte, A. (ed.) *Research justice: methodologies for social change*, 5–12. Bristol: Policy Press.

O’Reilly, M., Karim, K., Taylor, H., and Dogra, N. (2012) Parent and child views on anonymity: ‘I’ve got nothing to hide’. *International Journal of Social Research Methodology* 15(3) 211–223.

Ostrer, C. and Morris, B. (2009) First-hand experiences of different approaches to collaborative research. In Sweeney, A., Beresford, P., Faulkner, A., Nettle, M., and Rose, D. (eds) *This is survivor research*, 71–81. Ross-on-Wye: PCCS Books Ltd.

Perry, K. (2011) Ethics, vulnerability, and speakers of other languages: how university IRBs (do not) speak to research involving refugee participants. *Qualitative Inquiry* 17(10) 899–912.

Pew Research Center (2014) A fragile rebound for EU image on eve of European Parliament elections. Washington, DC: Pew Research Center.

Reeves, C. (2010) A difficult negotiation: fieldwork relations with gatekeepers. *Qualitative Research* 10(3) 315–331.

Richardson, L. (1979) The 'other woman'. *Alternative Lifestyles* 2(4) 397–414.

Ryan-Flood, R. and Gill, R. (2010) Introduction. In Ryan-Flood, R. and Gill, R. (eds) *Secrecy and silence in the research process: feminist reflections*, 1–11. Abingdon: Routledge.

Smith, S., Fisher, S., and Heath, A. (2011) Opportunities and challenges in the expansion of cross-national survey research. *International Journal of Social Research Methodology* 14(6) 485–502.

Swartz, S. (2011) 'Going deep' and 'giving back': strategies for exceeding ethical expectations when researching amongst vulnerable youth. *Qualitative Research* 11(1) 47–68.

Tanaka, K. (2007) The roots of the social model: a life history of Paul Hunt (translated by Yuki Kosuge) http://disability-studies.leeds.ac.uk/files/library/Tankana-Life-history-of-Paul-Hunt1.pdf (viewed 2 May 2016).

Telford, R. and Faulkner, A. (2004) Learning about service user involvement in mental health research. *Journal of Mental Health* 13(6) 549–559.

Tuhiwai Smith, L. (2012) Decolonizing methodologies: research and indigenous peoples (2nd edn). London: Zed Books.

Wassenaar, D. (2006) Ethical issues in social science research. In Terre Blanche, M., Durrheim, K., and Painter, D. (eds) *Research in practice: allied methods for the social sciences*, 60–79. Cape Town: University of Cape Town Press.

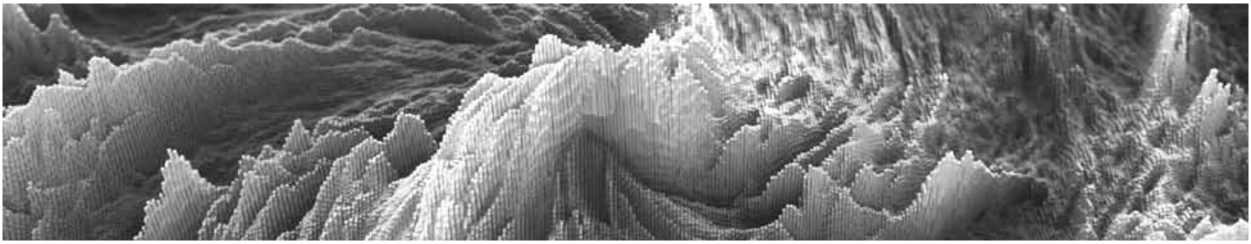
Weller, S. (2012) Evolving creativity in qualitative longitudinal research with children and teenagers. *International Journal of Social Research Methodology* 15(2) 119–133.

Zeffiro, A. and Hogan, M. (2015) Queered by the archive: *No More Potlucks* and the activist potential of archival theory. In Jolivétte, A. (ed.) (2015) *Research justice: Methodologies for social change*, 43–55. Bristol: Policy Press.

PART II

Qualitative Research Ethics by Technique

Ron Iphofen and Martin Tolich



Sara Delamont and Paul Atkinson open this section with a particular focus on ethnographic fieldwork which presages many of the concerns confronted by the authors that follow an emergent epistemology. Ethnography does not encompass all qualitative research, but may use many and all of that ‘diverse array’ to collect, manage and interpret data. Drawing on recent illustrative cases – the work of Alice Goffman and of Sudhir Venkatesh – Delamont and Atkinson show how a reliance on formalized anticipatory protocols offers little help for researchers facing the unexpected exigencies of work in ‘the field’. In most research ethics regulation and review the key focus of concern is with the individual subject or participant rather than the community or group of which those individuals are a part. Ethnography can rarely deal with individuals without understanding their full social dynamic within a group, community, organization or family setting. Ethical recognition has to balance the researcher’s goals with the complex of pressures, obligations and responsibilities not only of individuals but of their collectivities. As a result Delamont and Atkinson see ethnography as inherently ethical, it is emergent and exploratory, it cannot be practised without taking such ‘balances’ into account. The inadequacy of anticipatory regulation is highlighted here and sets the scene for the chapters that follow.

Whichever way these diverse techniques are practised produces idiosyncratic ethical considerations. Visual research, mixed methods, autoethnography, covert research, walking interviews, community-based action research (also known as participatory action research) manifest themselves differently in data collection and analysis. Compare, for example, one-on-one interviews with dyadic interviews and/or focus groups in terms of how confidentiality and recruitment are accomplished. While the researcher using one-on-one interviews has control over the confidentiality of what a person says – being easily expunged from a transcript — participants in a dyadic encounter or members of a focus group research do not have that ability. **Karen Lowton** points out that what is shared in a group of two or more cannot be expunged from other (focus group) participants' memories. The recruitment of couples or dyads also raises ethical issues especially with hard-to-reach groups. Does the recruited member in any way pressgang a second person to the interview? And might this create a power imbalance within the research site? Equally, power imbalances may/will pre-exist within couples' relationships already disrupting ethical considerations. Ethical dilemmas also occur when dyads are interviewed separately. How is the transcript given back to the household? How is the couple, as individuals, presented in the final text? Do they have the potential to recognize one another or effectively challenge the report? **Anita Gibbs's** chapter on autoethnography reviews and revises Tolich (2010) and Tullis (2013) asking if the autoethnographic researcher 'owns' the story because they are the ones now telling it. The essential problem stems from the apparent misnomer that 'auto' implies writing solely about oneself. But there are few human experiences that are completely solitary, even when the focus originates in 'the self', others are necessarily implicated. What are the rights then of other people who become involved in the story the researcher tells? Should those mentioned in the text give their consent after the story has been written as Tullis suggests or does gaining retrospective consent lead to a sense of familial obligation as Tolich suggests? A great deal of risk can be managed in autoethnographic work by following Morse's insistence that autoethnographies published in the *Journal of Qualitative Health Research*, for example, be given a nom de plume. The author believes this action protects the identity of all persons mentioned in the text. In this case study, those protected are vulnerable members of the author's family.

Mark Edward's 'Mesearch' is performance-based and is designed to be presented in real time with a live audience. Thus a Me-research project of this nature not only involves the researcher but the researcher's family and the safety of each of these persons needs to be constantly negotiated. Me-researching has ramifications for self-disclosure and like other insider/outsider projects a great deal of the ethical issues that arise cannot be easily anticipated.

Penelope Kinney's walking interviews are part of the emerging mobilities paradigm and are distinguished from more static forms of data collection e.g. the roundtable focus group or photo elicitation. In a walking interview the researcher and the participant walk and talk together, discovering what is important spatially from the research subject's perspective as they go. The unique ethical dilemmas arising in walking interviews occur in the public arena, outside the confines of a designated space, such as the privacy of an interview room. These ethical dilemmas affect the researcher and the subject alike. Some thought has to go into ensuring the safety of the researcher; conducting the research in daylight hours, notifying a third party both before and after the interview takes place. The public nature of this data collection technique means the researcher must take special care in the recording of information. The chapter demonstrates the complexity of gaining ethics approval with vulnerable persons in a forensic psychiatry ward not just with a research ethics committee or with the hospital administration serving as a gatekeeper but also how unforeseen issues arose in the field.

Sieber and Tolich (2013) claim that in visual research methods the camera adds ten pounds of ethics and this is clearly evident in **Anne Harley and Jonathon Langdon's** chapter. They focus on theorizing relationships within the power of the visual, the power of the photograph. Does the researcher photograph overtly or covertly? How is consent managed? Is consent given for the researcher to take the photograph and/or to reproduce the photograph? There are overlaps with Donald Matheson's journalism chapter given the immediacy of the event to be researched. This chapter ends with a photovoice case study demonstrating that photovoice goes some way towards equalizing the power relationship between researcher and researched.

Olivia Marcus and Shir Lerman demonstrate participant observation as a cornerstone method in ethnographic data collection, yet they show how the template of most institutional ethics protocols do not fit well with the often-unpredictable nature of observational research. This incompatibility creates potential ethical complexities for the researcher, the researcher's ethics committee and research site organization. The authors consider the particular challenges in working with vulnerable populations in a clinical setting. To illustrate this they present a case study in which one of the authors had to balance the expectations of her ethics committee, those of the clinic in which she conducted research, and her own ethical concerns for her participants.

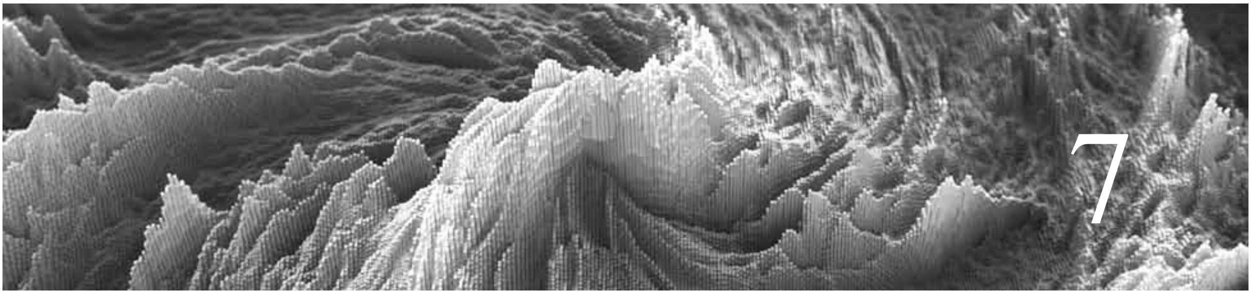
REFERENCES

Sieber, J. and Tolich, M. (2013) *Planning Ethically Responsible Research*. Sage, Thousand Oaks.

Tolich, M. (2010) A critique of current practice: Ten foundational guidelines for autoethnographers. *Qualitative Health Research* 20(12): 1599–1610.

Tullis, J. (2013) 'Self and Others: Ethics in Autoethnographic Research'. In S. Holman-Jones., T. E. Adams, and C. Ellis (eds.) *Handbook of Autoethnography*. Walnut Creek, CA: Left Coast Press. pp. 244–261.

This page intentionally left blank



7

The Ethics of Ethnography

Sara Delamont and Paul Atkinson

INTRODUCTION

In this chapter we explore some of the distinctive and particular ethical issues that arise in the conduct and evaluation of ethnographic research. We shall focus specifically on ethnographic fieldwork and its implications, not 'qualitative' research more broadly. The latter term covers a wide variety of research strategies, some of which (such as interviewing) seem to have simpler ethical issues, while others (such as internet-based research) call for special consideration. We summarize some of the problems and dilemmas that arise from fieldwork; we explore how those issues relate to contemporary approaches to ethical regulation and research governance in the Anglophone world; we develop this argument through an examination of a number of selected cases. We illustrate some aspects of our argument with reference to two recent ethnographies of urban life in the United States. We do so because they have been high profile and controversial. We focus on the conduct of research in 'real', off-line settings. Internet and similar research has its own issues (Boellstorff et al., 2012). We argue inter alia that there is often a tension between ethical protocols and practical research. Moreover, the requirements of scholarly probity can conflict with the exigencies of field research. Recent controversies have highlighted, and even exacerbated, these tensions and problems. We build on a number of discussions of the ethics of fieldwork (e.g. Punch, 1986; Welland & Pugsley, 2002; Goodwin et al., 2003; Tolich & Fitzgerald, 2006: Hammersley, 2009, 2010; Hammersley & Traianou, 2012), although it must be recognized that several key publications relate to the more diffuse category of 'qualitative' research. Taking our somewhat narrower focus, we also refrain from another, broader perspective on alternative ethical frameworks for qualitative research, such as those advocated by Denzin and Giardina (2007) who argue for a positive ethics based on principles of social justice. While their position has the distinct advantage of looking beyond the confines of research ethics committees and procedural matters, it remains too diffuse – its terms too vaguely specified – to provide practical guidance to social researchers (Hammersley & Traianou, 2014).

By ‘ethnography’ we mean sociological, anthropological or cognate research that depends on fieldwork. That is, some degree of participant observation in a chosen research setting, often – but not exclusively – based on long-term engagement with the research hosts. It is, therefore, not based exclusively on interviews, however lengthy and intimate they may be. Fieldwork will often involve interviews and conversations, together with yet other sources of data. Ethnographic fieldwork is inevitably based on ‘mixed methods’, as they are fashionably called, insofar as ethnographers will draw on documents, conversations, interviews, visual and material materials, and indeed any significant aspects of the culture in question (cf. Atkinson, 2014; Delamont, 2014, 2016). But interviews, focus groups and similar approaches on their own do not in themselves constitute ‘ethnography’.

Ethnographic fieldwork does seem to pose particular issues for what are now conventional approaches to ethical approval and regulation. The latter are often predicated on an individualistic approach to research ‘subjects’, and their voluntary participation in the research. But ethnographic fieldwork necessarily rests on the research hosts being involved *collectively* in a social world, organization or joint activity. They cannot be treated as separate, individual participants. They are not enrolled one-by-one. Given the nature of field research, there are further issues of confidentiality – notably when criminal or otherwise deviant activity is discovered. Normal undertakings of anonymity do not readily cover the contingencies of ethnographic fieldwork.

Fieldwork is inherently ethical, and it is potentially problematic precisely because it embodies particular ethical imperatives (Dingwall, 2008; Atkinson, 2009, 2014). Its positive value depends upon an intellectual and personal, even existential, commitment on the part of the researcher. Her or his engagement and participation with the research hosts implies a commitment that is intellectual and ethical, unrivalled by other research strategies among the social sciences, that very rarely depends on the same degree of long-term immersion, or involves the same personal exposure on the part of the researcher (Coffey, 1999; Atkinson, 2014). But the exploratory nature of ethnographic fieldwork and analysis raises possible problems for its ethical conduct and regulatory oversight. The regulation of ethnographic research must include a concern for the safety and welfare of the fieldworker (Bloor et al., 2007; see also the virtual special issue of *Qualitative Research* (Volume 7, Issue 2, May 2007) on the topic). Like all the issues we discuss, there are no simple answers, and checklist protocols cannot substitute for professional decision-making in the light of circumstances in the field. This is not special pleading: we are not suggesting that ethnographic fieldwork should be unregulated, or should escape scrutiny. It does mean that fieldwork should be subject to appropriate and realistic standards, judged by scholars who have firsthand experience. Precisely because ethnographic fieldwork commits the ethnographer to close, even intimate, relationships with her or his hosts, often involving the development of close ties over an extended period of time, issues of values and conduct are embedded in the ethnographic encounter. Unanticipated events and ‘guilty knowledge’ can create dilemmas for the fieldworker, while the personal relationships that develop over time can lead to issues of role-conflict. These arise in essence from the privileged access on which fieldwork depends, and from ethnography’s positive commitments. We shall also discuss some ethical issues that arise from the distinctive forms of ethnographic reportage.

THE FAILURE OF ANTICIPATORY REGULATION

The biomedical model of research and its governance has been widened to apply to many forms of research involving human subjects.

Given their nature, the social sciences are involved in ethical review and approval more than any other field of research outside of biomedicine. Yet the models and their implicit assumptions about the nature of research are themselves sociologically or anthropologically deficient, and they rarely apply in any satisfactory way to the conduct of ethnographic research. This is not merely a technical issue of research design, nor is it simply a narrowly sectarian issue, based on differences in disciplinary cultures. The issues and debates should not be muddied by schismatic disputes about the respective merits of 'qualitative' and 'quantitative' research, or attacks on 'positivist' approaches to social research. The central issues certainly do not derive from any inherent lack of ethical principles on the part of ethnographers; they do demonstrate how poorly research can be served by the cultural dominance of ethical regulation derived from biomedicine.

Bodies known in the USA as Institutional Review Boards, and in the UK as Research Ethics Committees increasingly regulate research. We shall use the latter term to cover all such bodies. Inspection of most research ethics committees' protocols will demonstrate how problematic they can be. It is common for applicants for ethical approval to have to answer a checklist of closed questions. Most ethnographers will, however, know that the answers they give will be at best half-truths, and that they are often at risk of misrepresentation (at least, in the eyes of an unsympathetic and literal-minded investigator). Consider, for instance, the seemingly innocuous question 'Will participants be informed of their right to withdraw from the research at any stage?', some version of which is enshrined in most protocols. At first sight it seems impossible to quibble with the basic right of a research participant to withdraw, and to do so at any stage of the research process. Her or his rights to do so would seem self-evidently to override the interests and convenience of the researcher. From the ethnographer's point of view, however, such an issue is far more complex. It goes back one stage to the nature of 'participation' and 'participants'. For the right to withdraw from a research project is predicated on the assumption that one participates on an individualistic basis, and that any participant is, in principle, equivalent to any other. But the reality of fieldwork suggests that a quite different form of social contract must underpin it. In simple terms, an individual cannot withdraw from an ethnographic project if he or she is a member of a collectivity without in effect vetoing the participation of all others who are willing, even enthusiastic, research hosts. The ethnography of, say, a research laboratory cannot proceed if just one scientist withdraws completely and denies the anthropologist the opportunity to be present in the laboratory, to observe research group meetings and so on. He or she can, of course, decline to be interviewed or otherwise be involved on an individual basis. The difference between the individual interview and membership of the research group is precisely the crux that renders most ethical protocols anthropologically naïve at best. Indeed, the social scientist that is committed to ethnographic fieldwork is necessarily alert to the practicalities of rule use, and the situational nature of documentary realities (Prior, 2003, 2012). Smith's recent contributions on institutional ethnography and the nature of documentary regimes is a persuasive case in point (Smith, 2005, 2006; Smith & Turner, 2014).

The crucial difference is this: Most ethics protocols assume that each participant (such as an experimental subject or an interviewee) will be enrolled and treated as a separate individual, exercising individualistic rights. Moreover, in an experiment or clinical trial each participant is equivalent to every other. Indeed, it is imperative that they are treated in identical ways. In the analysis of the data, each participant is treated separately as a data point. Since each participant is a separate monad within standard biomedical research, it makes perfect sense to treat her or him on this individualistic basis. Ethnographers are normally dealing with social actors because they are *members* of an organization, a subculture, a network, or whatever the collectivity may be. *Membership* of a social world is very different from individual participation. Liberman (1999) made a similar point, when arguing that an emphasis on individuals does violence to the underlying imperatives of ethnographic fieldwork. As he wryly observes, it is individuals who sue universities.

As may be envisaged, the ethnographer – confronted with the research ethics committee's questionnaire with its deceptively simple item – needs to answer 'Yes, but…' or 'No, but…' and expand on the responses at considerable length. Now this is not simply a matter of filling forms, for what is illustrated in a concrete fashion is the profoundly mistaken view of social research enshrined in such protocols. Let us, for instance, consider further the elementary and foundational issue of 'informed consent'. It seems like the sort of ethical principle that we would all want to subscribe to. But in reality it is far from clear what informed consent actually means in most research, and certainly far from clear what it can mean for the conduct of ethnography. We need the sort of analysis of ethics protocols that Cicourel (1964) famously performed for the survey interview. In the context of real-world research, all such questions require considerable interpretative work to render them sensible. However, it is precisely that background understanding that most ethics protocols transform into a 'checklist' form of anticipatory audit, and are therefore hard, if not impossible, to answer in that form and in good faith. Obviously, checklists do not constrain decision-making. Like any rule-like phenomena, they depend upon their practical interpretation by committee members as well as researchers themselves (Iphofen, 2011). On the other hand, they also depend upon the prior assumptions that inform their wording and that therefore impinge on their interpretation. It is not always apparent that either those assumptions or their implementation are in accordance with the ethnographic enterprise. It is for such reasons that the anticipatory regulation of research through the protocols of research ethics committees can be problematic to say the least. Murphy and Dingwall (2007) argue forcefully that the principles that underlie the standard model or 'paradigm case' of ethical approval are especially inappropriate for ethnographic research. They focus particularly on their anticipatory nature. The flexible and emergent nature of ethnographic fieldwork precludes the prior specification of what the research will involve or what its outcomes will be. Moreover, the nature of ethnographic analysis – iterative and emergent – makes it all but impossible to provide fully informed consent as to the purposes and outcomes of the research. Furthermore, caution is required of fieldworkers in explaining the nature and purpose of the research, not least in seeking to avoid making promises about the research that cannot be honored in the event.

That is not because ethnographers wish to engage in covert research, but because the nature of the research is such an emergent property of data collection and research design – themselves unfolding processes – that it becomes all but impossible to solicit consent that is 'informed' in the sense of being predictable and explicable before the research itself is carried out. If the outcomes of an ethnography were entirely predictable, then there would be virtually no point in conducting the research at all. It is, after all, possible to discover issues that lead the ethnographer to produce an account that some in the institution or association studied interpret as critical of them (see below). But such findings may be quite unforeseen and the outcomes cannot be incorporated into undertakings before the event. It may, for instance, be an unanticipated research finding that educational institutions have practices that have deleterious consequences for students, based on gender, ethnicity or social class. One may document similar sources of institutional bias among the police or other agencies of social control. A clinic may implicitly ration health care on the basis of social characteristics. It is hard to guarantee – for the purposes of informed consent – that nothing will be discovered to the disadvantage of the institution, even if individual members' identities are not to be divulged.

Covert research can, of course, uncover phenomena that would otherwise remain inscrutable – see Prokos and Padavic (2002) for an example documenting sexism in a police academy – but our argument is not about that. The problem is, rather, the anthropological impossibility of 'informed consent' (conventionally defined) to any meaningful extent in virtually all real-life research settings. As Parker (2007) summarizes the position: 'The problem with many professional codes, and with the deliberations of many research ethics committees for ethnographers, is that they fail to recognize that consent needs to be thought of differently in ethnography, where the research undertaken is based upon the tentative development of research questions and analysis in the context of emergent relationships of trust' (p. 2252).

It is, therefore, in the nature of ethnographic research that fully-informed consent (as conventionally defined) prior to the fieldwork itself is impossible. Indeed, it remains highly problematic throughout the research. The issues of informed consent are exacerbated by the principles of ethnography, but they are not confined to ethnography alone. An informant may give informed consent to being interviewed. He or she may be perfectly comfortable with the interview itself, personally and ethically. But in consenting to be interviewed, it is far from clear that the informant can possibly have granted informed consent to the analytic possibilities of the data derived from the interview. Prior agreement as to the transcription conventions used is unlikely and impractical. Yet the conventions used can have consequences for how the informant is represented. He or she can be made to look inarticulate, and accent or dialect can be emphasized, even apparently exaggerated. The informant may dislike how she or he appears on the published page. In the same way, if I complete a survey, I give consent to undertaking the task, but I am not normally asked for consent to combining my responses, and to aggregating them with those of other informants, in order to generate a scale of 'entitlement', or 'self-satisfaction' (for the sake of argument). It was never clear that individuals who voluntarily completed a personality inventory consented to being part of a population of 'neurotics'. Consent becomes ever more problematic when large amounts of data (not necessarily 'big data' in contemporary usage) are 'mined' for regularities and patterns that are entirely unforeseen. The problematic nature of informed consent to clinical trials (which are highly regulated) is compounded when one calls to mind that participants are not routinely informed that negative or inconclusive results may be suppressed, making their personal involvement nugatory.

SOCIAL RELATIONS AND THE RESEARCH PROCESS

In the ideal world, the ethics of social research would be predicated on a different set of approaches. It is worth reminding ourselves that the word *protocol* can have different connotations. In the sense most used in today's research communities, it means a prescriptive set of injunctions and prohibitions that regulate research. It captures the sense in which research and its proper management have been treated in *procedural* terms, reducible to checklists and formulae. On the other hand, protocol can also refer to proper conduct. And we ought to think of research conduct in this more general – and indeed more social – sense. We need to work to refine the collective sense of research protocols in terms that are driven by *values* rather than by *procedures*. For instance, many ethnographers spend a good deal of time developing trust with their hosts and informants. The promotion and development of such a positive interpersonal working relationship might provide a more anthropologically and sociologically informed basis for proper conduct than the jejune notion of informed consent based on a single paper-based transaction (which we know to be perfunctory in many biomedical contexts). Likewise, the establishment of social relationships in the field should be recognized for what it is – a *process* rather than an event that can be predetermined and inscribed within a simple research design. It would also take account of the fact that social relations in the field are of different sorts, from the most intimate to merely fleeting encounters and acquaintanceships. They cannot be subsumed under a single category of research participants, and the degree of consent or disclosure simply cannot be the same for all the individuals who might be present in and pass through a research site.

Ethnographic fieldwork inevitably follows the social contours of the chosen setting. Some actors are central; others peripheral. Some are opinion leaders or occupy positions of formal authority; others are subordinate. Some have overt power; others have hidden power. Some are long-term members of the chosen setting; others come and go. For this and related reasons, the ethnographer in the field is often subject to the control of her or his research hosts, rather than being *in* control of the research and its subjects or informants. Likewise, the negotiation of *access* to a research site is very different in kind from the process of recruiting individual participants. Rather than a set statement of research design and outcomes, ethnographers have to establish general relations of trust and reciprocity with their hosts. In that process, the research bargain is a process of negotiation. In some contexts, participants may test the fieldworker's trustworthiness.

The realities and imperatives of ethnographic fieldwork mean that the research itself is dependent on the general conduct of the researcher. The values of fieldwork thus reflect the conventions of ordinary social life: the ceremonial order of encounters and the tactful management of face-work. Consequently, the practical ethics of research mirror the everyday ethics of social life. Respect for one's research hosts, and a commitment to do them no harm are fundamental values for most ethnographers. (Those methodological commitments do not imply uncritical moral endorsement or unqualified celebration.)

Because the ethnographer gives up control, he or she can feel uncomfortable, not least because of the equivalent of role stripping: there are many social settings where the ethnographer's personal or professional standing counts for nothing. Further, there are situations where fieldworker safety is a real issue. It should be an aspect of research planning and strategy, and it should also be recognized as an ethical obligation on the part of research supervisors, principal investigators and research directors. In other words, general oversight of research needs to protect not only research hosts, but researchers themselves too: see Belousov, Horlick-Jones, Bloor et al. (2007), Bloor, Fincham and Sampson (2007).

The extent of indeterminacy and unpredictability in the field ought to be appreciated in the course of research planning, and hence in the process of ethical approval. This is not tantamount to carte blanche based on a claim that nothing can be foreseen. But if research is guided by values and general principles, and their general application outlined, rather than enshrined in highly specific and prescriptive checklists, then research can be carried out humanely, sensibly and in accordance with positive values. Contemporary practice is not congruent with a sociological or anthropological imagination. Because of its individualistic emphases on informed consent, it does not map well onto the realities of ethnographic research, as we have seen. As a consequence, ethical regulation by contemporary research ethics committees can have very undesirable unintended consequences. It can force scholars who have a very thorough commitment to working well with their research hosts into a form of deviance. Because ethics protocols are sometimes half-baked, they force the researchers into half-truths. It is clearly undesirable if ethical issues in general are perceived as something to be worked around, rather than providing a positive framework for practical research conduct. Equally, requirements for formal documentation of informed consent can radically transform emergent (or even established) social relations in the field, by imposing an inappropriate degree of formality on otherwise informal relations that are embedded in the ordinary give-and-take of social life. It transforms the pre-contractual and mutual nature of everyday life into the contractual obligations of individual self-interest and protection. Moreover, there is every temptation towards deviance. There is certainly anecdotal evidence to suggest that ethnographers feel constrained to represent their research as if it were merely a series of extended interviews, accompanied by individual consent by the informants. Any fieldwork is quietly relegated to the background, so that the letter of ethical approval can be sustained while the more bone-headed aspects of regulation can be circumvented.

Needless to say, checklists and protocols do not absolutely determine narrow-minded approaches on the part of research ethics committees, although their shortcomings can be unhelpful. It is abundantly clear that insofar as they use them, those committees should not follow them mechanistically and slavishly. They need to be regarded as representing *examples* of the *sort of* issues a researcher or research team might need to consider. They need to be interpreted and explored more fully than can ever be captured by the checklists alone. Research ethics committees need to cultivate sensitive uses of their own rules.

THE AMBIGUITIES OF HONESTY

Ethnographic conduct and reportage can be shot through with tensions and paradoxes. This is especially true when one confronts the scientific and ethical commitment to 'honesty'. Ethnographers are especially alert to their personal commitment and engagement in the conduct of fieldwork. Their research is dependent on personal relationships of many sorts, and they are themselves often exposed, even vulnerable, while 'in the field'. They may be compelled to reveal more of themselves, not only in conducting the research, but also in reporting it in publications. An honest, personal account of the fieldwork can, however, result in accusations of unethical conduct.

One of the recurrent issues that confront ethnographers seems to arise from the conventions of ethnographic honesty. More than any other methodological tradition, ethnographic research is often accompanied by 'confessional' accounts. There is a now long-established tradition of writing accounts that present personal memoirs, detailing mistakes in the field, errors of expectation, unfortunate stereotypes concerning one's research hosts, and the like. Van Maanen's (1988) account of such texts remains a useful overview. As Atkinson (1996) and Delamont (2010), among others, have pointed out, such confessions are themselves highly artful, contrived to create striking contrasts between the novice fieldworker – a greenhorn who makes social faux pas – and the post-fieldwork analyst who now has a more rounded, subtle or accurate understanding. In pursuit of this rhetorical device, therefore, the author structures things around such errors. In presenting the accounts – which really ought not to be understood as quite unvarnished – the ethnographer points up her or his own errors and transgressions (Bennett deMarrais, 1998). In addition, ethnographers frequently 'confess' to their own emotional engagements and reaction while in the field. They may report feelings of distaste (or something stronger) for the people or the activities they have observed. They may also report experiences of vulnerability, occasionally in the face of actual or imagined threat and danger. Reports of personal privation can also be deployed in constructing the author as an existential hero, overcoming obstacles and problems in the quest for knowledge in the field.

Here we outline just some of the recurrent issues that arise from ethnographic research. We suggest that there are some paradoxes and tensions. Sometimes, ‘bad research ethics’ can appear to arise from ‘good ethical principles’. We do not enter into detailed discussion of specific cases (several of which are the topics of extended and heated debate among social scientists). But we do draw on them in a general sense in order to illustrate our argument in concrete terms. The cases we discuss include Goffman’s *On the Run* (2010) and Venkatesh’s *Gang Leader for a Day* (2008). Both are high-profile monographs that have received popular as well as academic attention. They exemplify the strand of urban ethnography that has been at the heart of sociological work (see Hammersley & Atkinson, 2007) since the emergence of the Chicago School of sociology over a century ago.

Now ‘honesty’ can be dangerous. Paradoxically, honesty can leave the author open to accusations of unethical – or at least unprofessional – attitudes and behaviour. This is especially pressing when critics do not read the confessional aspects of ethnographic writing with sufficient attention to their rhetorical features. A fairly recent and highly visible case is that of Venkatesh, who conducted fieldwork in and around a public housing project in Chicago, and published two monographs. He also published *Gang Leader for a Day* (2008), aimed at a general readership, in which he recounts a personal memoir of his fieldwork in the project. There is a telling review symposium of the book in *Sociological Forum*, in which several critiques take Venkatesh to task over a series of aspects of the book. The general conduct of that research has been controversial (Sieber & Tolich, 2013), but here we focus on this specific topic – the conventions of confession and honesty.

Some of these criticisms seem to stem from a rather po-faced reading of Venkatesh’s text, with no sensitivity to the genre or its distinctive rhetoric. Clampet-Lundquist (2009) is a heavy-handed example. Venkatesh confesses that he entertained inaccurate stereotypes about the kinds of people he was likely to encounter. For instance, on entering a gang member’s mother’s apartment, Venkatesh admits that he was surprised by the domestic scene he met, while going to a top gang-leader’s mother’s house, he suggests he had envisaged half-naked women, a swimming pool, marijuana joints and cold beer. The reality was, of course, rather different. But Clampet-Lundquist takes these excerpts entirely at face value, and then treats them as if they were Venkatesh’s sociological views, and accuses him of perpetuating racist stereotypes. The point of the text is, of course, that he confesses to these stereotypes (and the image of the poolside is undoubtedly an exaggeration, deliberately couched in graphic terms). The implication is – in common with many such confessionals – that the author knows better now that he has actually undertaken the fieldwork. Clampet-Lundquist’s leaden reading, however, assumes that Venkatesh is promoting such stereotypes *sub specie* sociological analysis. In a very similar vein, Charles (2009) picks up on Venkatesh’s confession that he was surprised to find some gang members with educational qualifications and aspirations. Clearly, he should either have known better before he did the fieldwork (in which case why do the research?) or perhaps he should have been less honest about his own naïvety.

The values of confidentiality can conflict with the opportunity to check the descriptive validity of the published account. There are numerous good reasons to try to hide the identity of research participants. It is not possible in all cases, and there are cases where it would be impossible, indeed ludicrous. But when deviant or criminal activity is reported, then the protection of the participants is regarded as an imperative. Alice Goffman (2014) published an ethnography of urban African-Americans and their experience of oppressive policing. The monograph has proved highly controversial, not least by virtue of perceived ethical shortcomings. Goffman claims to have changed key aspects in order to maintain confidentiality, and this is a common practice. But she has been criticized because various individuals engaged in 'fact checking' claim to identify 'discrepancies'. Similarly, Goffman destroyed her field notes and the hard disk drive on which information was stored. So data preservation was not respected, and no secondary analysis or critical scrutiny is possible. Similarly, her actual doctoral thesis was embargoed. So her critics cannot check the accuracy of her account, and they treat this as grounds for lambasting her and querying her overall veracity.

But it is common practice to put raw data beyond scrutiny, when it contains incriminating evidence. Judith Okely, for instance, makes clear the steps she took to protect her traveller-gypsy hosts from possible accusations of criminal activity (Okely, 2012). Ethnographers who have had their field data subject to subpoena know to their cost (and to the cost of their hosts and informants) what can happen to sensitive data. It is, for the same reason, common enough practice to bar access to doctoral theses that contain sensitive information (including commercially sensitive material). Many of us find ourselves falsifying inessential details of persons or of reported events in order to avoid *disclosure by inference*. This makes simple-minded fact checking impossible. The ethnographer is caught in a double bind: damned if she does, damned if she doesn't.

Sensitive data cannot be archived or made available for secondary analysis. While it is possible to falsify some details of individuals or episodes that are used in publications, it is not practical so to redact entire data sets. Indeed, to do so systematically and to a degree sufficient to guarantee anonymity would probably render the data useless for any further analysis. In the course of our own research on doctoral students and their supervisors (Delamont et al., 2000), we found it necessary to change biographical and intellectual details in accounts that we quoted in publications. That was especially important when we reported our research with social anthropologists. Anthropologists have highly individual biographies, based inter alia on where they did their original fieldwork, who supervised them, and at which university. Such biographical details aligned them with schools of thought and lineages of scholars. Because we both had degrees in anthropology, we were able to modify the relatively brief interview excerpts that we quoted. It would not have been possible to modify the tens of thousands of words of transcript in the same fashion, without destroying their intrinsic value. They would have been rendered completely useless for any future scholar wanting to use them as oral testimony of the development of anthropology in British universities. But the graduate students we had interviewed could have been rendered especially vulnerable had they been identifiable individually. (The study also illustrated another general point: although we were very careful not to disclose which departments we had studied, the academic staff and graduate students of course knew we had visited them, and so *they* disclosed it to their friends and colleagues.)

Fieldwork uncovers deviance and can incriminate the researcher. While any criminological research is *about* crime and deviance, ethnography brings the researcher and the researched into especially close proximity. Sometimes, the ethnographer may be thought – or may declare her/himself – to have participated in or abetted criminal behaviour. Goffman's frank (probably ill-advised) account of her participation has led some critics to suggest she could be indicted for conspiracy to commit murder (although no actual murder was committed). That may be an extreme case – or an extreme reaction by critics – but ethnographers can often become complicit, if only by acts of omission, in the deviant acts of others. The preservation of confidentiality often means that the evidential basis of their published accounts has to be compromised in order not to incriminate individuals directly.

At the same time, ethnographers may reveal deviant activity on the part of the powerful, or of official agents. When they do so, the credibility of their work can be thrown into doubt by official denials (see Becker, 1967). Goffman reports police making inquiries about possible suspects in a hospital emergency room. Subsequent criticism has suggested that this did not happen as reported, because such inquiries are prohibited under police procedure. And since it should not happen, it is argued, it could not happen, and therefore it did not happen. Well, of course, it is the business of ethnographers to discover such institutional deviance, and so the denials (or denial by proxy in the case of Goffman's critics) have little weight. But the fact-checking approach to descriptive validity can appear to undermine the veracity of the account. We are aware of a similar phenomenon: a colleague observed an event that senior members of an organization deemed inappropriate. She was told, flatly, 'That did not happen', and instructed to remove it from the record. In that case, the occurrence was not vital to the overall sociological account, and so was never included in any further texts. In effect, it did not happen after all, having been expunged from the record. Insisting upon the veracity of the original account would have threatened the entire fieldwork.

CONSEQUENCES OF ANALYSIS

It is not clear, however, how far beyond data collection most informed consent procedures go in practice, or can go in principle. One may agree to be interviewed about consumption preferences. Consent may be given on the basis that personal information will not be divulged. But to what extent does one give consent for my data to be pooled with that derived from others, and then subjected to statistical manipulation? Should consent be sought to manipulate the data in accordance with basic demographic, face-sheet data? Should consent be sought to have personal information aggregated and cross-tabulated in order to generate, say, gender differences, or ethnic differences in consumption? Should participants be asked for consent to having the information transformed into ideal-typical models of taste and *habitus*, in the style of Pierre Bourdieu? The answer to these questions is that most researchers would find it bizarre to have to predict every possible analytic *outcome* and every unanticipated *finding* of the analysis, while many potential participants or informants would find it virtually impossible to acquiesce to any such consent.

Hammersley (2014) has recently argued that certain forms of analysis may be thought of as unethical: If I have interviewed an informant about some substantive topic – their state of health for instance – they have probably not given informed consent to have their words subjected to discourse analysis or narrative analysis (see the virtual special issue of *Qualitative Research* that contains Hammersley's paper and responses to it). Hammersley discusses discourse research that is based on interviews collected for no other purpose than to examine their discursive features. But similar issues might arise from the secondary analysis of data previously collected. One can examine interviews gathered for their informational content and subsequently use them as data for more specialized analysis. For instance, interviews with scientists about their collective discovery can be examined subsequently for their discursive construction of chance and skill (Atkinson et al., 1997) or their vocabularies of emotion (Sampson & Atkinson, 2011). Such analysis is faithful to what the informants actually said, but not overtly captured in the original understandings and undertakings as to what the research was 'about'. This is not confined to ethnographic research. Fully informed consent concerning the outcomes of analysis is rarely possible in practice. Researchers are not expected or required to go back to their survey respondents to ask their consent to publish the result that many people with their particular characteristic score highly on a scale of authoritarian attitudes (for example). Equally, we do not normally require ethnographers to return to the field and re-negotiate permissions because they have come up with a completely unforeseen line of analysis.

Similar arguments apply to the secondary analysis of ethnographic and similar data. While many ethnographers might be reluctant to see their field notes and transcripts as inert 'data', it is the case that many studies are now deposited in archives and made available for secondary analysis by other scholars. While archived ethnographic data are all ethically 'clean', in the sense that informed consent is provided for the original data collection, it is again uncertain whether participants can have given blanket consent for an unknown student or researcher to use the information they shared, or their observed and recorded activity, in the interests of alternative analyses. Can informed consent ever cover the use of such materials for training purposes? And yet scientific (and ethical) principles also call for raw data to be made available for scrutiny in the interests of checking published results for accuracy, for meta-analysis and comparison with subsequent studies. Again, some scientific values can run counter to some ethical precepts in all forms of social research. One can indeed take the argument further, by suggesting that most informed consent is illusory, since informants, participants and hosts can never be given accurate predictions of all that might be done with data and precisely what kinds of findings are likely to emerge.

Ethnographic analysis is inseparable from the practice of writing (Atkinson, 1990; Wolf, 1992). Consequently, ethical issues extend well beyond the collection of data. While the general point applies to all genres of social research, it is particularly pressing when it comes to ethnographic reportage. The politics and ethics of representation have become prominent topics among ethnographers: see for example Clifford and Marcus (1986) and Behar and Gordon (1995). At issue is the representation of the chosen research setting and its members. The promotion of members' voices and respect for the complexity of their lives may call for textual conventions that reflect 'polyvocality' rather than the unitary perspective of the single omniscient author (Atkinson & Delamont, 2008). Hence rhetorical conventions of ethnographic writing have become thoroughly imbued with ethical interests. Moreover, there is always the potential for ethnographers to feel that they cannot ever quite do justice to the social worlds and social actors they attempt to reconstruct in their texts. By the same token, research participants can also feel that they have not been properly represented in ethnography's written texts. When it occurs, this derives from differences in interest rather than gross misrepresentation on the part of the ethnographer. Participants – if they have any expectations at all – can expect texts that describe and celebrate their lives, or reproduce entertaining stories about them, rather than academic analysis of the ceremonial order, the social construction of reality, or mundane reason (to take just three possible ethnographic frameworks). Consequently, 'when they read what we write' (Brettell, 1993) there is the ever-present possibility of betrayal, notwithstanding the ethnographer's best intentions. There is certainly no guarantee that the ethnographer's priorities and the participants' interests will coincide. Pinter and Zandian (2015), for instance, discovered that when they informed children about the outcomes of the research they had been involved in, the participants were much more interested in issues of representation, pseudonyms and the use of quoted extracts than in the 'findings' themselves. The distinctive styles of ethnographic reportage can raise generic issues of (mis) representation; simply insofar as monographs endpapers can convey graphic, readable and recognizable accounts of everyday life. The ethnographer's hosts and informants can often identify with such accounts very differently from survey respondents, trial participants, or experimental subjects. Disagreements with the interpretation can therefore be much more stark in the case of ethnography.

CONCLUSION

It is not possible to do full justice to all the complexities of fieldwork and their ethical implications. We have tried to reiterate a small number of key issues. It is clear that the conduct of ethnographic research lends itself poorly to the procrustean bed of contemporary ethical regulation. Anticipatory consent, individualized participation and predetermined research designs are all repugnant to the conventions and practice of ethnographic fieldwork. In consequence, there is the danger that would-be ethnographers can be drawn into forms of deviance, in trying to work around the specific requirements of research ethics committees.

However, as we have acknowledged, issues of ethics pre-date research ethics committees and go beyond their requirements. We have suggested that there can be conflicting imperatives in conducting and reporting ethnographic research. The privileged access that fieldworkers are often able to negotiate can imply the acquisition of guilty knowledge. The protection of institutions, groups and individuals often, therefore, implies the suppression or distortion of information. This can sometimes conflict with requirements of honest reportage and factual accuracy. There are recurrent issues surrounding the deliberate falsification of facts in order to ensure no harm to participants. This can sometimes result in a refusal to divulge incriminating evidence.

More generally, any social research needs to be based on ethics and values that are not reduced to a tick-box mentality, nor are predicated on sociologically or anthropologically limited understandings. Social research needs to be guided by positive values and commitments, and should not just rely on one-off anticipatory regulatory procedures. We need a collective recognition that a commitment to positive ethical conduct goes well beyond simple research designs and predicted outcomes. It needs to be responsive to the possibilities of data analysis, and to the conventions of writing. Ethnography is not just a mode of data collection, but a textual genre too. These are not arguments against oversight of research and its values. But they do suggest that those who are responsible for research and for its regulation need to cultivate better-informed and more dialogic approaches. The conduct and consequences of ethnography make such an approach desirable, but they also render it potentially rewarding. By the same token, research ethics committees need to educate their members as to the values and strategies of ethnographic work. Just as we expect students and researchers to undertake research-methods training, we should perhaps expect the same of committee members. We should certainly encourage decision-making based on collegial process rather than bureaucratic procedure, and a continuing relationship between the committee and the project rather than a one-off ethical approval or rejection.

Finally, there is a grave danger that social scientists are hobbling themselves through the imposition of regulatory regimes that render some research (however benign) all but impossible, while the rest of the world, including our own research hosts, press on regardless. We can, for instance, insist on the anonymity of research sites and informants while they themselves share photographs and videos of their activities on social media of all sorts. Journalists, columnists, biographers and writers of fiction can all engage in ‘research’ and disclosure without prior ethical approval from anyone, and can be much less hedged about than social scientists. We sometimes seem to be trying to regulate a social world that does not, or has ceased to, exist.

Inevitably in a discussion of this sort it is easy to emphasize problems, and to under-report achievements and opportunities. Notwithstanding the potential limitations of current regulation and scrutiny, research is not being rendered impossible. Research ethics committees are acquainting themselves with a diverse range of research strategies, while researchers are becoming increasingly aware of the real ethical issues that ought to inform their work. It is clear that the research community must needs move towards a shared understanding of ethnographic research that recognizes its inherent qualities – commitment, engagement, exploration, flexibility – that are grounded in social relationships with research hosts and informants, married with an equally relational and flexible approach to the oversight of practical fieldwork, its analysis and publication.

REFERENCES

Atkinson, P. (1990) *The Ethnographic Imagination: Textual Constructions of Reality*. London and New York: Routledge.

Atkinson, P. (1996) *Sociological Readings and Re-Readings*. Aldershot, UK: Avebury.

Atkinson, P. (2009) Ethics and ethnography, *Twenty-First Century Society: Journal of the Academy of Social Sciences*, 4, 1: 17–30.

Atkinson, P. (2014) *For Ethnography*. London: Sage.

Atkinson, P., Batchelor, C., and Parsons, E. (1997) The rhetoric of prediction and chance in the research to clone a disease gene, in M.A. Elston (ed.) *The Sociology of Medical Science and Technology*. Oxford: Blackwell, pp. 101–125.

Atkinson, P. and Delamont, S. (2008) Editorial introduction: Ethnographic representation and rhetoric, in P. Atkinson and S. Delamont (eds) *Representing Ethnography* (4 Volumes). London: Sage, pp. xix–l.

Becker, H.S. (1967) Whose side are we on?, *Social Problems*, 14: 239–247.

Behar, R. and Gordon, D. (eds) (1995) *Women Writing Culture*. Berkeley, CA: University of California Press.

Belousov, K., Horlick-Jones, T., Bloor, M., Gilinsky, Y., Golbert, V., Kostikovsky, Y., Levi, M., and Pentsov, D. (2007) Any port in a storm: Fieldwork difficulties in dangerous and crisis-ridden settings, *Qualitative Research*, 7, 2: 155–175.

Bennett deMarrais, K. (ed.) (1998) *Inside Stories: Qualitative Research Reflections*. Mahwah, NJ: Lawrence Erlbaum.

Bloor, M., Fincham, B., and Sampson, H. (2007) *Commissioned Inquiry into the Risk to Well-Being of Researchers in Qualitative Research*. Cardiff: Qualiti (ESRC NCRM Node).

Boellstorff, T., Nardi, B., Pearce, C., and Taylor, T.L. (2012) *Ethnography and Virtual Worlds: A Handbook of Method*. Princeton NJ: Princeton University Press.

Brettell, C.B. (ed.) (1993) *When They Read What We Write: The Politics of Ethnography*. Westport, CT: Bergin & Garvey.

Charles, C.Z. (2009) Review of Gang Leader for a Day, *Sociological Forum*, 24, 1: 205–209.

Cicourel, A.V. (1964) *Method and Measurement in Sociology*. New York: Free Press.

Clampet-Lundquist, S. (2009) Review of *Gang Leader for a Day, Sociological Forum*, 24, 1: 202–204.

Clifford, J. and Marcus, G. (eds) (1986) *Writing Culture: The Poetics and Politics of Ethnography.* Berkeley, CA: University of California Press.

Coffey, A. (1999) *The Ethnographic Self: Fieldwork and the Representation of Identity*. London: Sage.

Delamont, S. (2010) Neopagan narratives: Knowledge claims and other world 'realities', *Sociological Research Online*, 14, 5: 18. http://www.socresonline.org.uk/14/5/18.html

Delamont, S. (2014) *Key Themes in the Ethnography of Education: Achievements and Agendas*. London: Sage.

Delamont, S. (2016) *Fieldwork in Educational Settings: Problems, Pitfalls and Paradoxes*, 3rd edition. London: Routledge.

Delamont, S., Atkinson, P., and Parry, O. (2000) *The Doctoral Experience: Success and Failure in Graduate School*. London: Falmer-Routledge.

Denzin, N. and Giardina, M.D. (eds) (2007) *Ethical Futures in Qualitative Research: Decolonizing the Politics of Knowledge*. Walnut Creek, CA: Left Coast Press.

Dingwall, R. (2008) The ethical case against ethical regulation in humanities and social science research, *Twenty-First Century Society: Journal of the Academy of Social Sciences*, 3, 1: 1–12.

Goffman, A. (2014) *On the Run: Fugitive Life in an American City*. Chicago: University of Chicago Press.

Goodwin, D., Pope, C., Mort, M., and Smith, A. (2003) Ethics and ethnography: An experiential account, *Qualitative Health Research*, 13, 4: 567–577.

Hammersley, M. (2009) Against the ethicists: On the evils of ethical regulation, *International Journal of Social Research Methodology*, 12, 3: 211–225.

Hammersley, M. (2010) Creeping ethical regulation and the strangling of research, *Sociological Research Online*, 15, 4, 16. http://www.socresonline.org.uk/15/4/16.html

Hammersley, M. (2014) On the ethics of interviewing for discourse analysis, *Qualitative Research*, 14, 5: 529–541.

Hammersley, M. and Atkinson, P. (2007) *Ethnography: Principles in Practice*. 3rd edition. London: Routledge.

Hammersley, M. and Traianou, A. (2012) *Ethics in Qualitative Research: Controversies and Contexts*. London: Sage.

Hammersley, M. and Traianou, A. (2014) An alternative ethics? Justice and care as guiding principles for qualitative research, *Sociological Research Online*, 19, 3, 24. http://www.socresonline.org.uk/19/3/24.html

Iphofen R. (2011) Ethical decision making in qualitative research, *Qualitative Research* 11, 4: 443–446.

Liberman, K. (1999) From walkabout to meditation: Craft and ethics in field inquiry, *Qualitative Inquiry*, 5, 1: 47–63.

Murphy, E. and Dingwall, R. (2007) Informed consent, anticipatory regulation and ethnographic practice, *Social Science & Medicine*, 65, 11: 2223–2234.

Okely, J. (2012) *Anthropological Practice: Fieldwork and the Ethnographic Method*. Oxford: Berg.

Parker, M. (2007) Ethnography/ethics, *Social Science & Medicine*, 65, 11: 2248–2259.

Pinter, A. and Zandian, S. (2015) 'I thought it would be tiny little one phrase that we said, in a huge big pile of papers': Children's reflections on their involvement in participatory research, *Qualitative Research*, 15, 2: 235–250.

Prior, L. (2003) *Using Documents and Records in Social Research*. London: Sage.

Prior, L. (2012) The role of documents in social research, in S. Delamont (ed.) *Handbook of Qualitative Research in Education*. Cheltenham: Edward Elgar, pp. 426–436.

Prokos, A. and Padavic, I. (2002) 'There oughtta be a law against bitches': Masculinity lessons in police academy, *Gender, Work & Organization*, 9, 4: 439–459.

Punch, M. (1986) *The Politics and Ethics of Fieldwork*. Beverly Hills, CA: Sage.

Sampson, C. and Atkinson, P. (2011) The golden star: Emotion, legacy and scientific discovery, *The Sociological Review*, 61, 3: 573–590.

Sieber, J.E. and Tolich, M.B. (2013) *Planning Ethically Responsible Research*, 2nd edition. Thousand Oaks, CA: Sage.

Smith, D.E. (2005) *Institutional Ethnography: A Sociology for People*. Lanham, MD: AltaMira.

Smith, D.E. (ed.) (2006) *Institutional Ethnography as Practice*. Lanham, MD: Rowman & Littlefield.

Smith, D.E. and Turner, S.M. (eds) (2014) *Incorporating Texts into Institutional Ethnographies*. Toronto: University of Toronto Press.

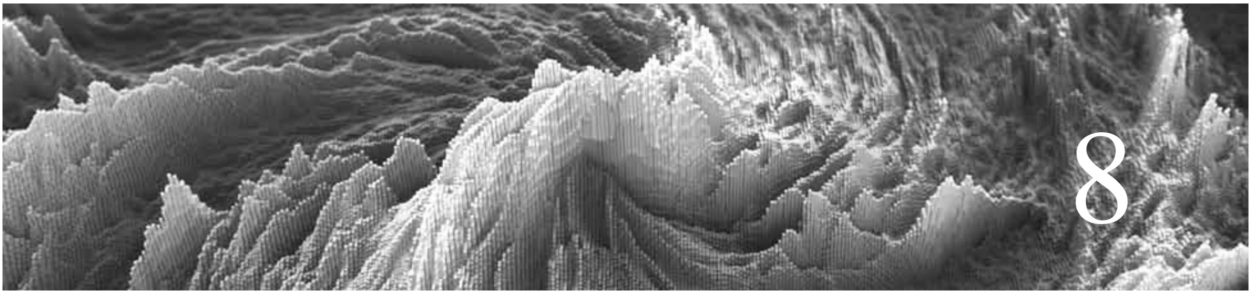
Tolich, M. and Fitzgerald, M.H. (2006) If ethics committees were designed for ethnography, *Journal of Empirical Research on Human Research Ethics: An International Journal*, 1, 2: 71–78.

Van Maanen, J. (1988) *Tales of the Field*. Chicago: University of Chicago Press.

Venkatesh, S. (2008) *Gang Leader for a Day: A Rogue Sociologist Takes to the Streets*. New York: Allen Lane.

Welland, T. and Pugsley, L. (eds) (2002) *Ethical Dilemmas in Qualitative Research*. Aldershot, UK: Ashgate.

Wolf, M. (1992) *A Thrice Told Tale: Feminism, Postmodernism and Ethnographic Responsibility*. Stanford, CA: Stanford University Press.



8

He Said, She Said, We Said: Ethical Issues in Conducting Dyadic Interviews

Karen Lowton

INTRODUCTION

Qualitative research interviews have a relatively short history, arising in the post-war years as realization grew that ordinary people were important sources of knowledge about their own experiences (Gubrium & Holstein, 2003). Interviewers were first conceptualized as ‘miners’, unearthing the knowledge that was deemed to be held within the interviewee, later becoming ‘travellers’, creating new understandings though narratives collected from a number of conversational-style interviews (Kvale, 1996). Until recently, it had been supposed by qualitative researchers that the natural unit of investigation was the individual (Gubrium & Holstein, 2003; Kvale, 1996), who was able to speak both about and on behalf of their partner and other family members and in doing so convey the relational aspects of their lives in an interview (Allan, 1980).

Historically, dyadic interviews had been most commonly used in a psychotherapeutic setting (see, for example, Laing et al., 1996). Although some dyadic qualitative research interviews have been conducted since the 1960s, it has only recently become more common for researchers to interview together two people who are related to each other in some way, in order to understand more fully how a situation is experienced, understood and displayed in a relational context. In capturing two people’s perspectives, researchers move away from ‘imaginative generalizations’ of the couple or family (Valentine, 1999a) towards actual accounts of these experiences and understandings; and in so doing create a ‘credible basis for claims about practices’ (Polak & Green, 2016: 1638). Through this approach, dyadic interviews are likely to provide richer data about a couple’s lives than a single interview alone (Allan, 1980). Early work involving dyadic research interviews has focused on family practices (see, for example, Allan, 1980; Pahl & Pahl, 1971; Pahl, 1995), with understanding of how couples experience and manage health and illness becoming a more recent field of interest. ‘Couple’ relationships in family and health research most commonly include romantic partnerships, although may also include close friendships, siblings, and parents and their children, or an individual and a lay carer who are sharing the work of care. Most commonly, couples are in an established relationship when dyadic interviews are considered, but more rarely interviews may bring together people with a specific shared characteristic or experience who might not have a relationship to each other outside of the interview (see, for example, Morgan et al., 2013) or may involve the interviewer as co-interviewee in a reflexive, dyadic interview (Ellis & Berger, 2003).

There is a relatively small albeit growing literature around the various approaches to dyadic interviews, yet these reports tend to privilege discussion of research design and methodological issues rather than the ethical and practical challenges that the approach presents. Polak and Green (2016) note a lack of consensus around the terms and definitions used to describe the interviewing of two people who have some quality of relationship with one another, which, they note, may be expected in an emerging methodology. Interviews that involve two people who are related to each other in some context are variously known as joint, conjoint, couple or dyadic interviews, and may take the form of the couple being interviewed together, separate interviews with each member of the couple, or use both approaches. In this chapter I use ‘dyadic’ to refer to two people who have some type of relationship being involved as interviewees in general, ‘joint’ when referring to two people being interviewed together, and ‘couple’ to denote separate interviews with two people who are related in some way. Regardless of the interview format, the interviewees’ relationship is most often preexisting rather than being formed through the research, although researchers would not usually know the length and quality of that relationship before data collection commences.

As a qualitative method, dyadic interviews sit between an individual interview and a small focus-group discussion (Polak & Green, 2016), sharing qualities and properties of both methods. For example, the interaction between couples in a joint interview is akin to the interactions that arise within focus groups, yet joint interviews usually aim to cover topics to the degree of intimacy and depth of an individual interview. On the other hand, joint interviews differ from focus groups because they most often take place in a private venue with a known other, for example the home, rather than in a public setting with participants whom interviewees may not know. Joint interviews may be more difficult to arrange than an individual interview, but easier to arrange than a focus group.

Many ethical issues arise in dyadic interviews that need careful consideration by the research team. Although some of these may also arise in individual interviews or focus groups, others will be specific to the dyadic interview format itself. Investigating an element of private family life and needing to protect a couple’s privacy present two significant ethical issues that need to be both thought through and balanced (Larossa et al., 1981). Other issues include recognizing and managing conflict and imbalance within the couple, participant inclusion and not taking sides, and intrusion and maintaining confidentiality (Forbat & Henderson, 2003).

This chapter considers recruitment of couples to research and the ethics of gaining informed consent, before considering the more specific ethical issues that arise when couples are interviewed jointly, separately, or using both methods. The chapter concludes by considering the challenges of maintaining anonymity and confidentiality during data analysis and dissemination of findings.

RECRUITING COUPLES AND GAINING INFORMED CONSENT

In the context of family research, a dyadic interview design may be used as a strategy to recruit more ‘hard to reach’ participants. For example, men may be enabled to participate in discussion of sensitive issues such as infertility, where previously they may have been overlooked (Hertz, 1995). However, in aiming to recruit a couple rather than an individual there is a risk that each member of the couple may perceive the nature or purpose of the research differently, based on their own understanding of the world and of each other (Laing et al., 1966). This might occur despite both receiving the same information about the study and might suggest that each has a different motivation for participating (Forbat & Henderson, 2003). As researchers seek to recruit two people instead of an individual, the difficulty of achieving full recruitment will also arise (Mellor et al., 2013). Furthermore, participant bias may arise through those couples who see themselves in a stable and supportive relationship being more willing to participate in a dyadic interview than those who experience less committed relationships (Torgé, 2013).

The focus of the research topic will influence whether researchers are able to convey information about the study to, and request the participation of, both members of the couple directly. To whom the invitation to participate is addressed and which member of the couple acts as the decision maker for their participation may serve to silence one of the couple's voices or conversely lead to pressure for them to participate. In considering the issue of whether members of a couple are recruited singly or together, Ummel and Achille (2016) suggest that after being sent information about the study separately, each member of the couple should be asked individually whether they would be willing to participate. However, this raises practical and ethical concerns of how the decision to participate is shared within the couple and whether this occurs before or after the decision has been conveyed to the research team, especially where one person is keen to participate but the other is not. It is more usually the case that the individual who is approached for their participation is put in the position of 'gatekeeper' to the second person in the couple (Mellor et al., 2013). For example, in the context of women's reproductive services, the female member of the couple may be approached in the clinic setting and asked to pass on information to their male partner at home. Alternatively, Miller and Bell (2002) detailed a study where women affected by domestic violence were asked by letter to participate in an evaluation of a male therapy centre where their violent male partners were receiving treatment. Recruitment of the couple becomes unlikely if the topic does not interest the gatekeeper or there is a desire not to involve their partner in the research. One partner may ultimately have no knowledge then that a request was made for them to participate. It may be easier therefore to inform both members of a couple about research where the focus is not on a particular characteristic or location of only one member of the couple, or where one partner's attendance at an organization is already known to the other.

Gaining fully informed consent in qualitative research is also an acknowledged difficulty, whatever the data collection method used (Larossa et al., 1981). All participants must be invited to participate without any pressure from researchers or gatekeepers, made aware that their participation is entirely voluntary, and, if they are in receipt of services or other support, that these will not be affected if they choose not to participate. A couple's consent to take part in a dyadic interview might suggest that each member of the couple is willing to discuss a certain topic, although Taylor and de Vocht (2011) caution that for some couples one partner might not be in a position to be able to 'choose to choose'; this is discussed further below.

Rather than being individually given, in a dyadic interview context the decision to consent is likely to be influenced by the partner in the couple who holds the balance of power, be it in a gatekeeping role (Mellor et al., 2013) or through an existing unequal power balance in the relationship with regard to a particular topic or sensitive issue. Using one partner as a gatekeeper therefore means that it is difficult to ensure informed consent is freely given from both members of a couple (Valentine, 1999a). This may be the product of one person exerting subtle pressure or coercing the other in situations where consent was needed for the gatekeeper's own participation, or to ensure that they do not participate (Forbat & Henderson, 2003; Ummel & Achille, 2016). On the other hand, it has been suggested that men in a relationship may find it easier to agree to do something their partner asks them to, rather than to resist (Mellor et al., 2013); a situation equally problematic for the research team. Consent can therefore be influenced by the dynamics of the existing relationship, a desire (or absence of desire) to please a partner, the potential difficulties that participation or its refusal might raise within the relationship, and one partner's persuasion of the other (Mellor et al., 2013).

As with other qualitative research methods, informed consent must be ongoing throughout the research study. The researcher can check this during joint and separate interviews, and also by being aware of consent being given by one partner for the other to disclose something during a joint interview (Taylor & de Vocht, 2011). There is little consideration in the research methods literature however around checking that participants continue to give their consent to the joint interview once it has been completed, and what the research team should do if one person withdraws their consent. For example, although researchers can clarify at the end of separate interviews whether there is any portion of the interview that should be removed from the transcript as opposed to the whole interview, in a joint interview they would need to decide whether and how to convey this decision to the other member of the couple and what the risk of one partner's withdrawal might be in the context of participant harm. Similarly, withdrawing one partner's data from a joint interview raises a question of whether that joint interview should be withdrawn completely and how this should be handled with the person who has not indicated that their interview can no longer be used.

DECIDING TO INTERVIEW COUPLES JOINTLY OR SEPARATELY

It is now widely understood by qualitative researchers that there is not a single 'truth' to be discovered; all interview data are dependent on the context in which they are gathered (Gubrium & Holstein, 2003; Taylor & de Vocht, 2011). Different interview scenarios (joint or individual couple interviews) will therefore reveal different content and perspectives as well as different social performances. As each individual experiences and interprets the social world individually to some extent, the accounts of partners interviewed separately will differ to an account that is jointly produced (Taylor & de Vocht, 2011). In the joint interview, each member of the couple's experience and behaviour will influence their partner's experience and behaviour in producing an account of their lives (Laing et al., 1966). One type of account cannot therefore be seen as a substitute for the other; furthermore the interviewer will influence each type of interview format (Hollway & Jefferson, 2000), discussed below.

Interviewing a couple together is not necessarily better or more ethical than interviewing them separately, but will depend on factors including the quality of the couple's past and current relationship and the nature of the research topic (Allan, 1980). For example, a joint interview may be the most appropriate when the study aims to address an experience or situation that the couple share (Norlyk et al., 2016), yet may influence how participants present themselves and the material they choose to share in an individual or joint interview. Partners may be keen therefore not only to present themselves in a particular light to the interviewer, but also in a particular way to their partner. For instance, a wife might wish to portray herself as being careful with spending money, or a husband that he is keen to balance his career with family life. Although the couple is the focus of data collection, the research team needs to decide whether they are to be interviewed jointly, separately, or both, and, if both, in what order the interviews should occur.

Through each interview format's potential influence on each member of the couple (Allan, 1980; Morris, 2001; Paterson, 2003), these approaches raise ethical, practical and methodological challenges. The choice of dyadic interview format therefore needs to take into account the epistemology of the research team and the nature and focus of the research topic, the study's aims and objectives, the type of couple to be recruited and the sensitivity of the questions to be asked, the nature of accounts that are to be collected, and the availability of the couple for interview, alongside other issues specific to each project. Both joint and single interviews might be preferred for topics that investigate current practices, such as eating habits, and past practices, for example childhood meals (Valentine, 1999a). In the context of money management (see, for example, Price et al., 2014), older couples being interviewed jointly about how they perceive, manage and negotiate money and then separately to follow up on issues raised in the joint interview has yielded much rich data while being conducted in an ethically sensitive manner.

In deciding which interview format to use, one approach has been to ask the participants themselves if they would prefer to be interviewed individually or with the inclusion of their partner (see, for example, Polak & Green, 2016; Norlyk et al., 2016; Radcliffe et al., 2013). Morris (2001) notes the importance of providing people with a choice of separate or joint interview, for example in empowering couples who in the context of illness may have experienced little choice in how it is managed or experienced. In practice however, only one member of the couple is usually asked how they would prefer to be interviewed, with the choice of separate or joint interviews being considered data in itself (Polack & Green, 2016). Nevertheless, the research team needs to consider not only how this might affect the research design and type of data collected but also the ethical issues arising, for example from a partner of an initial contact who subsequently expresses a different preference for their participation or interview format.

The research team also needs to consider whether individual interviews will be conducted when one partner does not attend a planned joint interview. Not only will the structure of the format change but the partner's absence will also influence whether the remaining partner wishes to continue their participation, how they present themselves and their relationship during the interview, and whether the absent partner should be approached later for a separate interview. Another difficulty for the interviewer is how to respond to the unexpected presence of a partner or close relative in what was planned as an individual or separate interview. This may take the form of a person 'loitering' around the interview area or joining in the interview itself, for example if a partner was keen to make sure the other did not say anything compromising or that certain information was not shared (Boeije, 2004). Additionally, researchers need to consider the ethical, practical and methodological implications of their responding to couples asking to be interviewed jointly within a study design that employs individual couple interviews (see, for example, Morris, 2001). The ethical issues arising from the absence or presence of a partner in these contexts are, as Norlyk et al. (2016) note, neglected in the literature, despite presenting complex practical and ethical challenges. For example, the interviewer is in an especially difficult position if they are in the couple's own home. As he or she is effectively a guest, it is not always possible to ask a partner to remove him or herself from the interview or to demand their presence.

Lastly, the research team needs to decide how many interviewers will be needed. Using two interviewers for a couple's separate interviews would enable the interviews to be conducted concurrently, allowing a couple to spend a shorter amount of family time on their involvement in the research, and would prevent probing by one partner into the other's interview content, yet this would be at the expense of the interviewer being able to understand a shared 'couple' story from each individual's perspective. Two interviewers may also enable greater detail and accuracy of notes (Bjørnholt & Farstad, 2014) during joint interviews, although this may be off-putting to interviewees. Alternatively, one interviewer who interviews both members of a couple separately is likely to gain a much better understanding of that couple, yet would need to schedule interviews at different times, thus taking up more of the couple's time. Additionally, the interviewer may be probed by the second member of the couple about what their partner said during their interview (Ummel & Achille, 2016); these issues are discussed further below. Joint interviews may therefore be a more attractive option in terms of the interview taking less family and research time than separate interviews (Bjørnholt & Farstad, 2014). However, these can be difficult to arrange (Valentine, 1999a) due to needing to find a mutually convenient time for the couple and for the interviewer.

INTERVIEWING COUPLES JOINTLY

By their nature, joint interviews are used not only to capture the co-production of knowledge arising from the two perspectives of the couple but also the interaction and performance produced during the interview itself (Allan, 1980; Mellor et al., 2013; Torgé, 2013), which can include confirmatory, complementary and contradictory accounts and new understandings of the topic under discussion (Polak & Green, 2016). The process of recounting stories through negotiating both the storyteller and the narrative arc provides insights that would not be captured by two single interviews (Valentine, 1999a), yet may miss individual perspectives that might provide valuable data (Norlyk et al., 2016). If interaction between couples is to generate rich data there is a greater need for rapport and collaboration (Allan, 1980). However, the couple does not only shape interviews but also the interaction with the interviewer (Heaphy & Einarsdottir, 2012; Hollway & Jefferson, 2000). Although it would be impossible for the interviewer to predict or understand each couple's performance and their response to the interviewer's questions until the interview began, the nature of the research topic and the sensitivity of the questions to be asked can be a helpful starting point in thinking about how the interview and relationship with the interviewer might be experienced by interviewees.

Many couples tend to corroborate each other's stories, co-creating a joint narrative that might be well-rehearsed (Ellis & Berger, 2003), yet shed light on household dynamics and family practices (Bjørnholt & Farstad, 2014) and demonstrate how couples 'display family' (Finch, 2007). For certain topics or situations the couple may corroborate beforehand to produce an account that portrays them positively (Valentine, 1999a) or work to stay safe in the context of 'defending' a sensitive subject while they take time to appraise the interviewer (Hollway & Jefferson, 2000). Alternatively some couples will be more open and frank whereas for others one partner might hinder the depth and quality of the other's account by denying or questioning the story one person is telling (Allan, 1980). The interviewer may anticipate socially acceptable answers for some topics, although needs to be aware that in joint interviews some answers may also be given that are socially acceptable to a partner.

Valentine (1999a) notes the assumption within many households that there is a family 'spokesperson' who can speak on family matters; one person may assume they will take the lead in answering questions when it turns out this is not the case (Larossa et al., 1981). Often one partner will talk more than the other, in effect producing a single account from one person's perspective, or an 'official' account that has been agreed by the couple beforehand (Hertz, 1995). This might reflect an unequal power relationship between the couple and with the interviewer, shown in an imbalance of turn taking or domination of one partner during the interview. For example the quality and quantity of women's talk may be influenced according to whether a male partner is present (see, for example, Seale et al., 2008; Valentine, 1999a). However, a joint interview might permit one of the couple to enable the other's 'blind spot', for example in remembering forgotten memories or those not thought to be relevant, to be brought into the interview (Taylor & de Vocht, 2011) or to supplement information to create a more nuanced account (Allan, 1980). Joint interviews may also provide a more reliable picture of the topic as related to the couple as one person may balance the other's biased perspective (Allan, 1980). In joint interviews, partners can play a role between interviewee and interviewer, for example through probing their partner in the context of their narrative or introducing new topics for discussion.

What is not revealed, for example in one partner silencing an account or conveying a well-rehearsed or previously agreed account, may suggest that one of the couple is being made vulnerable or marginalized in this process. Similarly, one person's account may be undermined or challenged by their partner, such that a negotiated rather than a rehearsed account may be conveyed to the interviewer (Polak & Green, 2016). One member of the couple who remains silent or speaks very little during the interview provides a 'subtle but clear' (Valentine, 1999a) signal that the account that is being conveyed may be being contested. This presents a moral dilemma for the researcher, who needs to be respectful of the participants' wellbeing and consider before the interviews begin how they might manage signs of disquiet (Taylor & de Vocht, 2011), for example whether to draw attention to it or to ask participants if they would like to stop the interview. Alternatively, one partner may need to regularly repeat or clarify what the other has said; this may lead to the partner with communication problems not raising specific problems in the interview because their partner would then be expected to repeat damaging information about themselves (Torgé, 2013). Additionally, one partner may not necessarily feel the need to present as a happy couple, for example in situations where one person is experiencing health problems and their partner is a carer who is struggling to be heard and supported (Boeije, 2004; Radcliffe et al., 2013). The interviewer needs to think carefully in these contexts about how both partners can be respected and supported throughout their research involvement.

When a couple is interviewed together, there may be a risk of greater intimacy than in an individual interview (Polak & Green, 2016). If the joint interview takes place in the home, an informal conversational atmosphere may help to build trust between the couple and the interviewer, but also increase the risk of disclosing more than was originally planned (Larossa et al., 1981). Furthermore, if the couple perceives the interviewer to be more of a therapist than a researcher, for example when the topic of research may focus on the couple's relationship, people may also disclose more than they intended (Larossa et al., 1981). Taylor and de Vocht (2011) note there is a clear potential for harm if during their interview one of the couple discloses something that was not anticipated by the other to be brought out of the private domain or that they were not aware of prior to the interview. The joint interview itself may create vulnerability in a couple through disclosure of 'secrets', as one interviewee reported to Larossa et al. (1981: 311) after their joint interview 'we'll be up all night arguing about this'. This unanticipated disclosure may violate the privacy or consent of the other, and in this way people have much less control over what will be said in a joint interview (Larossa et al., 1981) than in a separate one, although they may have more power to stop a partner continuing with a story than if that person were interviewed separately. Indeed, one partner may use the joint interview to discover their partner's thoughts or feelings on a particular topic, to act as a 'lie detector' or to maintain control of their self-image (Boeije, 2004). These motivations may make it difficult for the researcher to bring out each individual's perceptions and experiences from the co-produced account (Taylor & de Vocht, 2011), both during the interview and data analysis.

In a joint interview, interviewees may merge their own individual differences to produce a 'couple' narrative, reducing any conflict that they might otherwise display towards each other in private. However, although one might feel that joint accounts are rehearsed and consistent, disagreement and discussion often become evident as the interview progresses (Bjørnholt & Farstad, 2014; Radcliffe et al., 2013). Managing conflict that might arise during a joint interview (Bjørnholt & Farstad, 2014) has not yet been fully considered from an ethical standpoint. For example, the conflict may be long-standing and perhaps even anticipated by either one partner or the couple to arise during their interview. Alternatively, conflict may arise from the interview itself, for example from the topic discussed or one partner's response to it. Even in situations where the conflict appears to be of a low level, the interviewer may be unwillingly brought in to the role of a mediator and might unintentionally prioritize one person's perspective over the other's (Morris, 2001). In extreme cases, the interviewer may become caught up in the conflict or asked to adjudicate (Valentine, 1999a). In this situation the interviewer needs to be careful not to cause any new harm, not to take sides in the conflict, and not to report it in any public accounting of the findings (Bjørnholt & Farstad, 2014). In some cases it may become necessary to end the interview at a point where conflict does not seem to be resolving, and allow the couple privacy. However, if the disagreement has escalated into 'full-blown' conflict the interviewer may feel that to leave the couple may increase the vulnerability or risk of harm of one of the partners. At whatever point the interview is brought to an end, the interviewer will need to check whether consent still stands for the interview up to that point and to what extent emotional harm has occurred.

Illness is one of the most ethically difficult subjects to research. It not only affects an individual but the whole family, yet most research to date focuses on the cared-for or carer, but rarely both (Forbat & Henderson, 2003). Joint interviews enable people in poor health to be included in research and therefore researchers to investigate the effect of illness on both the care recipient and care-giving partner (Morris, 2001). Joint interviews may also enable people with substantial physical disability to participate in qualitative research; a population that to date is under-represented. For example, joint interviews enabled those with dysarthria (slurred or slowed speech) arising from Motor Neurone Disease (Lou Gehrig's Disease) to participate with their 'carer' partner (Sakellariou et al., 2013). Here 'carers' were able to help convey their partner's narrative and provide physical care for their body so that the interview could be completed in relative comfort. Not offering joint interviews in these contexts would serve to silence further already marginalized voices. In the context of disability and spousal support when both members of the couple have a health impairment or disability, 'we-talk' (Torgé, 2013) may enable the couple to convey a shared narrative of caring in the context of health problems and how a couple works together on shared difficulties (Radcliffe et al., 2013).

Joint interviews might also be an attractive option for a person with early stage dementia, who may feel overwhelmed in a focus group (Morgan et al., 2013) and might welcome the support of a partner or other familiar person in a more private setting. This more personal way of speaking to an interviewer may also reduce the stress in interacting with people unknown to them in a focus group and may be more useful for a partner assisting in overcoming communication difficulties arising from the condition (Morgan et al., 2013). For the interviewer, a partner may reduce the effort in clarifying or summarizing what a participant with early dementia has said (Morgan et al., 2013). However, in a study including people with dementia where couples were interviewed separately, researchers expressed disquiet about to what extent voluntary participation was actually given by the partner with dementia and the degree of agitation that their wait for the interviewer caused (Hellstrom et al., 2007).

Dyadic interviews may therefore enable the inclusion of marginalized voices or those traditionally excluded from qualitative research. However, the research team needs to be aware that joint interviews may be disempowering to the person with health problems who is not enabled or supported by their partner to have a voice, as Manzo et al. (1995) note in the context of stroke. Here their research uncovered a number of conversational phenomena that illustrated how stroke survivors' narratives became diminished through their lack of agency in the interview: by seeking their partner's approval of what they were saying; by their partner engaging in 'competitive storytelling' or answering questions not directed at them; and by their partner questioning the stroke survivor's own responses (1995: 312). There may also be a reluctance to disclose or discuss details of a health condition or other sensitive or intimate issue in the presence of a partner (Paterson, 2003); this may mean that separate interviews with each of the couple would be more ethically appropriate (Norlyk et al., 2016). Additionally, there are concerns that joint interviews for people with intellectual disability may act to suppress the voices of those with disability. Thus, it is imperative to consider how the partner or supporter is chosen and what the nature of their participation in the interview might be (Caldwell, 2014). Asking the person with intellectual disability to identify the person they would like to be interviewed with may ensure a more equal power relationship in the interview setting (Caldwell, 2014).

INTERVIEWING COUPLES SEPARATELY

In the context of couples being interviewed separately, Allan (1980) notes that the more segregated the couple and the more sensitive the data sought, the more likely it is that interviewees will only reveal intimate information if they are sure it will never be revealed to their spouses. Separate interviews with both members of the couple may be more appropriate if the research team have reason to think one partner may be judged unfavourably by the other, where new information may be disclosed of which one of the couple is unaware, or when it is anticipated that one person might dominate the interview. There may be matters that a couple may not have already discussed together, for example abortion, or issues that may not be appropriate to discuss as a couple, for example previous relationships (Mellor et al., 2013) or one of the couple paying child support for a child that their new partner is not aware of (Tolich, 2004).

Additionally, people who would describe themselves as having an intimate relationship with their partner may have beliefs, experiences or opinions that they might decide not to disclose to their partner yet may feel comfortable sharing with a confidant or stranger. For example, in illness contexts a partner may prefer to share information only with a professional, to protect their partner from distress (Taylor & de Vocht, 2011). Couples affected by a health issue may also prefer separate interviews. For example, Lowton (2002) asked young adults with cystic fibrosis to nominate either their parent or their partner to take part in a separate interview about their perceptions of health with this condition, and the challenges of their child's or partner's care. Some of the young people expressed in their interview that they had not told their parents about certain aspects of their health yet appeared at ease discussing this with a stranger in the understanding of confidentiality. Indeed, some of the parents and partners asked the interviewer what their relative had said and expressed frustration at not being able to always access the latest information about their health.

However, asking couples who would prefer to be interviewed jointly to take part in separate interviews might suggest to them that either their partner or the research team believe there are 'secrets' that they should not hear (Bjørnholt & Farstad, 2014; Eisikovits & Koren, 2010; Morris, 2001). This may give rise to anxiety as it may suggest that these 'secrets' may be discussed individually with each partner or that an interviewee may be willing to disclose information to a researcher but not to their partner (Morris, 2001; Taylor & de Vocht, 2011). Additionally, couples may be concerned that the research team will judge them as a 'bad' or 'unmatched' couple if their separate accounts are not seen to be in agreement or their partner portrays them in a bad light (Valentine, 1999a). Conversely, interviewing separately each member of the couple with assurances of confidentiality may protect partners from worries about what will not be disclosed to their partner and others and may increase participants' assurance of confidentiality and trust with the researcher. Conversely, this may cause one member of the couple to question what the other person disclosed in their interview and lead to feelings of exclusion in couples that have a strong relationship (Morris, 2001; Norlyk et al., 2016).

All information given to potential participants about the study must make clear that no information that one person gives during an individual interview will be disclosed to the other half of the couple or to other people (Valentine, 1999a). When members of a couple have been interviewed one after the other, an interviewer must be mindful to only refer to stories the first of the couple has spoken about with the second interviewee when this is raised by them also (Forbat & Henderson, 2003). Although Forbat and Henderson acknowledge that some research data may be 'lost' by adhering to this principle, this would maintain confidentiality and safeguard against raising private issues with one participant that were previously unknown or distressing for them to hear.

Interviewing couples separately at different times means that potential intrusion is heightened; not only must the interviewee find time to be interviewed, but their partner must make arrangements to stay out of the way, which may be a physically difficult task for some, particularly those with disabilities (Morris, 2001). This may also lead to the non-interviewed partner feeling threatened by two people talking in private about an issue that affects them to some degree. Separate but simultaneous interviews of each member of the couple by two researchers would prevent intrusive questioning of the researcher but would lack the continuity that a single interviewer would possess (Boeije, 2004). If interviewed separately with the same interviewer, the second person's interview risks being influenced in the interviewer's mind by the other member of the couple they have already interviewed (Forbat & Henderson, 2003). Indeed, the researcher might not be aware of the salience of what the first person has revealed, despite assuring them of confidentiality.

INTERVIEWING COUPLES BOTH JOINTLY AND SEPARATELY

There is advantage in using both joint and separate couple interviews within the same study (Morgan et al., 2013) and this approach may present the best option for both researchers and participants (Ummel & Achille, 2016). For example, Heaphy and Einarsdottir (2012) interviewed couples both jointly and separately in the context of how young people understood their civil partnership, to gather data both on how the couple produced a joint narrative of their relationship and how their perspectives of the relationship had been both socially yet individually-shaped. Price et al. (2014) used two interviewers, male and female, for joint interviews of heterosexual older couples, then held individual interviews immediately afterwards with the interviewer and interviewee matched by gender. Yet we must remember that for each study a different narrative might have emerged in separate interviews had the joint interview not occurred, and vice versa.

The ethical issues arising from the order in which joint and couple interviews occur also need to be considered for each project. For example, beginning with interviewing the couple separately may cause difficulties for a researcher who cannot easily forget what participants have individually disclosed and what stories or opinions would be permissible to refer to in the joint interview. Similarly, the joint interview may raise accounts or opinions that cause one person to be anxious about what their partner will discuss in their subsequent individual interview. For each approach, the research team would need to prepare in advance with separate topic guides or interview schedules for the joint and individual couple interviews. Depending on the topic, different topic guides may be required for each member of the couple for their individual interview; for example in a study involving different genders there may be a different focus on questions asked of men and women.

MAINTAINING CONFIDENTIALITY

Protecting research participants' confidentiality is the responsibility of the ethical review board, the research team, and participants themselves (Ummel & Achille, 2016). Ethical guidelines inform the research team's approach and conduct, and information sheets can similarly inform research participants, but these cannot guarantee that people behave ethically in practice (Taylor & de Vocht, 2011). As with all qualitative interview methods, the research team must specifically discuss both confidentiality and the limits to this with participants. This includes both external or traditionally understood confidentiality and internal confidentiality whereby all people interviewed together with others are expected to keep all information confidential (Tolich, 2004).

Maintaining confidentiality in joint interviews bears similarities to that of focus groups; participants need to be made aware of the widespread ethical dilemmas before participating, to allow each member to share responsibility for any harm should confidentiality not be upheld (Tolich, 2004). This is because the research team can only offer participants external, not internal confidentiality, as once data collection has been completed what the participants choose to disclose to others is outside their control. Here, the key challenge is that anonymity and confidentiality cannot be guaranteed (Morgan et al., 2013; Taylor & de Vocht, 2011; Tolich, 2004). However, in practice there may be limited sanctions available for a partner who breaks the confidentiality of the couple or refuses to accept responsibility for ensuing harm. In this context Tolich suggests a foundational ethical principle of 'caveat emptor' for focus group research, which can be applied to couples taking part in joint interviews.

People who publicly reveal themselves to be part of a couple involved in research, thus breaking their anonymity, are also problematic. All participants should be made aware that the risk of exposure by their partner exists, however small this risk might appear initially (Larossa et al., 1981). The risk of public exposure of involvement also occurs if researchers use a snowballing method of recruitment where one couple is asked to pass on information to another couple about the research. The investigators have an obligation to make each couple aware that they may expose themselves as participants if they recommend participation to other people based on their own involvement.

ANALYZING INTERVIEWS AND DISSEMINATING FINDINGS

To date, there is little published guidance on analysis of dyadic data (Ummel & Achille, 2016) and the ethical issues that arise during this process. The research team needs to have worked out a strategy for approaching the analysis of interview data before couples contribute their narratives separately or jointly. For example, sending a joint or separate interview transcript to a couple for checking presents a number of ethical difficulties. A joint transcript may be checked and agreed by one person only, and two separate transcripts posted to people living at the same address may threaten the confidentiality given by the research team were one person to see the other's transcript. This issue is acknowledged for example in individual research interviews with children, where parents may open the child's post or search through their personal possessions (Valentine, 1999b), and with those experiencing domestic violence, where the perpetrator may subject their partner to high levels of surveillance and subsequent abuse (Ellsberg & Heise, 2002).

How the researcher analyses the interviews depends on the specific research questions they aim to address (Heaphy & Einarsdottir, 2012) and whether participants have been interviewed jointly or separately. Although partners may supplement stories told, or correct or challenge an account given during a joint interview (Taylor & de Vocht, 2011), it is likely there will be some contested joint accounts and, in the context of separate interviews, different versions of accounts might be given. For example, in her study of how working couples divide housework and childcare and the conflict that arises from this, Hochschild reported both members of the couple's accounts: Nancy 'said she was doing 80 percent of the housework and 90 percent of the childcare. [Nancy's husband] Evan said she did 60 percent of the housework, 70 percent of the childcare.' (2003: 39). Separate interviews therefore create narratives that both contextualize and complicate the joint account (Gubrium & Holstein, 2009) and researchers must decide whether to treat the individual interviews from two members of a couple as two separate accounts or as two contributions to one joint account, and how to analyze both individual and joint accounts from one couple. In conflicting accounts or instances where a story is recounted by one person but not the partner, the researcher faces ethical difficulties in knowing what weight to give to each member's perspective, and how to analyze the substance of joint accounts where one person has contested the claims-making of their partner. There is a risk that preference may be given to one of the couple's accounts, whether given separately or as part of a joint interview, either in the interview itself and/or in the analysis of data. The research team therefore needs to be aware of forming different connections with each member of the couple on a human or emotional level (Forbat & Henderson, 2003), and how this may influence their analysis of the data.

In separate interviews with couples, it may be necessary to present findings at a group level without anonymized quotations to ensure each participant's confidentiality is upheld (Ummel & Achille, 2016). In considering internal confidentiality, quotations used in publications from separate couple interviews may identify one partner to another through their verbal idioms or other personal styles of speaking. Possible disclosure of an individual's private account arises through this, together with the possibility of harm from that disclosure. Additionally, if one person recognizes their own words in a verbatim quote despite anonymity, they may easily link this to their partner's data and again confidentiality will be broken (Forbat & Henderson, 2003; Tolich, 2004). Smaller research samples and the use of verbatim quotations also make it easier for external readers of research reports to uncover the identity of particular participants, with a risk of emotional and even physical harm should a person learn something about a participant that was not intended to be shared (Ummel & Achille, 2016).

One advantage of interviewing couples jointly is that both partners will be aware of the data used in research reports and other outputs they have consented to. Here there will be no 'piecing together' of information that may lead them to identify what their partner might have disclosed in a separate interview (Bjørnholt & Farstad, 2014; Ummel & Achille, 2016). However, a joint interview may double the amount of information that could identify participants to external readers (Forbat & Henderson, 2003) and may reveal topics or conflicts that may not have been raised in individual interviews.

Furthermore, commenting on a couple's style or content of interaction may pass negative judgement on couples and families that jeopardizes relationships with participants, the research team and the research field (Bjørnholt & Farstad, 2014; Larossa et al., 1981). Thinking about how the findings will be disseminated is a good starting point in considering what interview format and analysis to employ for each dyadic interview study.

CONCLUDING POINTS

All qualitative research methods raise ethical challenges that must be considered carefully. These include the nature of research topic, the study aims and research questions, and the type of participants who will be asked to participate. Dyadic interviews are not a complete solution to overcoming the ethical and practical difficulties involved in other qualitative approaches, but may be a good alternative method for collecting certain types of data (Allan, 1980). Whether couples are interviewed jointly, separately, or by both formats, it is clear that dyadic interviews raise a number of important ethical issues, which may also be found in individual in-depth interviews or focus groups, or be specific to interviewing two people in an existing relationship.

There is a small but growing body of literature focusing on the methodological, practical and ethical issues that dyadic interviewing presents, and a number of recommendations for developing this method further. For example, Morgan et al. (2013) recommends systematically debriefing of participants for feedback on their experiences as a guide for future work. Additionally, the space in which the interviews occur needs further consideration, for example in considering the effects of joint interviews conducted over the Internet or the telephone compared to in person (Morgan et al., 2013).

Ethical principles are universal and abstract and so can only exist to guide researchers, for example how an interviewer should respond when a partner unexpectedly remains with an interviewee for what was anticipated to be an individual interview (Norlyk et al., 2016). A formal code of ethics would oversimplify and obscure specific ethical issues arising from each project (Larossa et al., 1981). However, there are many ethical issues in dyadic research that need careful thought in a more situated ethic of care. These include how internal confidentiality can be maintained (Tolich, 2004), for example by taking time to learn from each interviewee what information would be potentially damaging if shared or read by another 'insider'. As Tolich also notes, no strategy is completely foolproof, yet it is clear that the principle of confidentiality needs to be expanded to protect more strongly the risks to participants from insiders as well as those external to the research.

REFERENCES

Allan, G. (1980) A note on interviewing spouses together. *Journal of Marriage and Family*, 42 (1), 205–210.

Boeije, H. R. (2004) And then there were three: self-presentational styles and the presence of the partner as a third person in the interview. *Field Methods*, 16 (1), 3–22.

Bjørnholt, M. and Farstad, G. R. (2014) 'Am I rambling?': on the advantages of interviewing couples together. *Qualitative Research*, 14 (1), 3–19.

Caldwell, K. (2014) Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14 (4), 488–507.

Eisikovits, Z. and Koren, C. (2010) Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, 20 (12), 1642–1655.

Ellis, C. and Berger, L. (2003) Their Story/My Story/Our Story: Including the Researcher's Experience in Interview Research. In Gubrium, J. F. and Holstein, J. A. (eds) *Inside Interviewing: New Lenses, New Concerns*. London, Sage, pp. 467–494.

Ellsberg, M. and Heise, L. (2002) Bearing witness: ethics in domestic violence research. *The Lancet*, 359 (9317), 1599–1604.

Finch, J. (2007) Displaying families. *Sociology*, 41 (1), 65–81.

Forbat, L. and Henderson, J. (2003) 'Stuck in the middle with you': the ethics and process of qualitative research with two people in an intimate relationship. *Qualitative Health Research*, 13 (10), 1453–1462.

Gubrium, J. F. and Holstein, J. A. (2003) From the Individual Interview to the Interview Society. In Gubrium, J. F. & Holstein, J. A. (eds) *Postmodern Interviewing*. London, Sage, pp. 21–50.

Heaphy, B. and Einarsdottir, A. (2012) Scripting Civil Partnerships: interviewing couples together and apart. *Qualitative Research*, 13 (1), 53–70.

Hellström, I., Nolan, M., Nordenfelt, L., and Lundh, U. (2007) Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14 (5), 608–619.

Hertz, R. (1995) Separate but simultaneous interviewing of husbands and wives: making sense of their stories. *Qualitative Inquiry*, 1 (4), 429–451.

Hochschild, A. R. (2003) *The Second Shift.* Penguin, New York.

Hollway, W. and Jefferson, T. (2000) *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method*. London, Sage.

Kvale, S. (1996) *Interviews: An Introduction to Qualitative Research Interviewing.* Thousand Oaks, CA, Sage Publications.

Laing, R. D., Phillipson, H., and Lee, A. R. (1966) *Interpersonal Perception*. London, Tavistock Publications.

Larossa, R., Bennett, L. A., and Gelles, R. J. (1981) Ethical dilemmas in qualitative family research. *Journal of Marriage and Family*, 43 (2), 303–313.

Lowton, K. (2002) Parents and partners: lay carers' perceptions of their role in the treatment and care of adults with cystic fibrosis. *Journal of Advanced Nursing*, 39 (2), 174–181.

Manzo, J. F., Blonder, L. X., and Bums, A. F. (1995) The social-interactional organisation of narrative and narrating among stroke patients and their spouses. *Sociology of Health & Illness*, 17 (3), 307–327.

Mellor, R. M., Slaymaker, E., and Cleland, J. (2013) Recognizing and overcoming challenges of couple interview research. *Qualitative Health Research*, 23 (10), 1399–1407.

Miller, T. and Bell, L. (2002) Consenting to What? Issues of Access, Gate-keeping and 'Informed' Consent. In Mauthner, M., Birch, M., Jessop, J., and Miller, T. (eds). *Ethics in Qualitative Research*. London, Sage, pp. 53–69.

Morgan, D. L., Ataie, J., Carder, P., and Hoffman, K. (2013) Introducing dyadic interviews as a method for collecting qualitative data. *Qualitative Health Research*, doi: 10.1177/1049732313501889.

Morris, S. M. (2001) Joint and individual interviewing in the context of cancer. *Qualitative Health Research*, 11 (4), 553–567.

Norlyk, A., Haahr, A., and Hall, E. (2016) Interviewing with or without the partner present? – an underexposed dilemma between ethics and methodology in nursing research. *Journal of Advanced Nursing*, 72 (4), 936–945.

Pahl, J. (1995) His money, her money: Recent research on financial organisation in marriage. *Journal of Economic Psychology*, 16 (3), 361–376.

Pahl, J. M. & Pahl, R. E. (1971) *Managers and Their Wives*. London, Allen Lane.

Paterson, B. L. (2003) The koala has claws: applications of the shifting perspective model of chronic illness. *Qualitative Health Research*, 13 (7), 987–994.

Polak, L. and Green, J. (2016) Using joint interviews to add analytic value. *Qualitative Health Research*, 26 (12), 1638–1648.

Price, D., Bisdee, D., Daly, T., Livsey, L., and Higgs, P. (2014) Financial planning for social care in later life: the 'shadow' of fourth age dependency. *Ageing and Society*, 34 (3), 388–410.

Radcliffe, E., Lowton, K., and Morgan, M. (2013) Co-construction of chronic illness narratives by older stroke survivors and their spouses. *Sociology of Health & Illness*, 35 (7), 993–1007.

Sakellariou, D., Boniface, G., and Brown, P. (2013) Using joint interviews in a narrative-based study on illness experiences. *Qualitative Health Research*, 23 (11), 1563–1570.

Seale, C., Charteris-Black, J., Dumelow, C., Locock, L., and Ziebland, S. (2008) The effect of joint interviewing on the performance of gender. *Field Methods*, 20 (2), 107–128.

Taylor, B. and de Vocht, H. (2011) Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research*, 21 (11), 1576–1587.

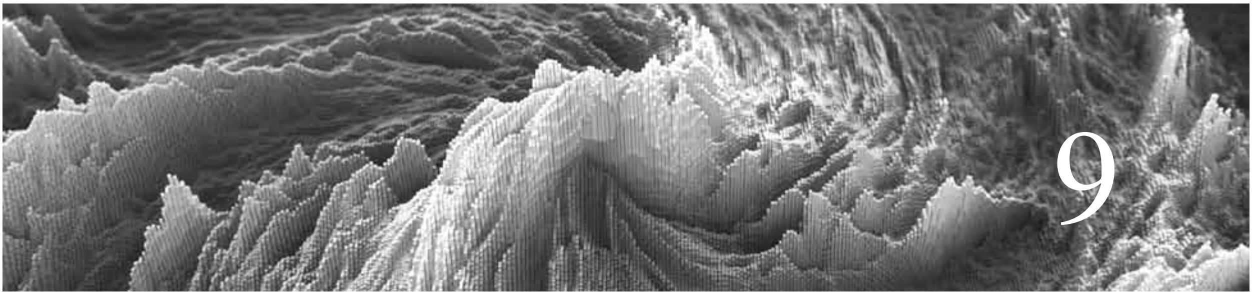
Tolich, M. (2004) Internal confidentiality: When confidentiality assurances fail relational informants. *Qualitative Sociology*, 27 (1), 101–106.

Torgé, C. J. (2013) Using conjoint interviews with couples that have been living with disabilities and illnesses for a long time – implications and insights. *Qualitative Studies*, 4 (2), 100–113.

Ummel, D. and Achille, M. (2016) How not to let secrets out when conducting qualitative research with dyads. *Qualitative Health Research*, 26 (6), 807–815.

Valentine, G. (1999a) Doing household research: interviewing couples together and apart. *Area*, 31 (1), 67–74.

Valentine, G. (1999b) Being seen and heard? The ethical complexities of working with children and young people at home and at school. *Ethics, Place & Environment: A Journal of Philosophy & Geography*, 2 (2), 141–155.



9

Ethical Issues When Undertaking Autoethnographic Research with Families

Anita Gibbs

> Autoethnography is a method of research that involves describing and analyzing personal experiences in order to understand cultural experiences. The method challenges canonical ways of doing research and recognizes how personal experience influences the research process. Adams, Holman-Jones and Ellis (2015: back cover)

INTRODUCTION

This three-part chapter first situates autoethnographic research as an innovative form of qualitative research paying special attention to practices that promote the empowerment and protection of the participants and researchers at the heart of autoethnography. In many fields, autoethnographic accounts are proliferating in academic journals, books, magazines and on social media. To some extent autoethnography has come of age, but there are also controversies. In this first part, the aims and types of autoethnography are identified as well as its limitations. The second part focuses ethics and autoethnography, honing in on the work of Tolich (2010) and Tullis (2013) who both find that autoethnographers do not own their story simply because they are telling it; others appearing in these stories each have the right to consent to participate. A scenario – Jack's story – is included to illustrate the minutiae of these ethical considerations. The third part, further illustrates both the potential of autoethnography and its concern for ethical issues by focusing on examples of family research. These academics are telling their family stories with a critical lens, often advocating social justice and for improved understanding of the needs of vulnerable families. Their stories connect the personal to the literature and research on families, as well as exploring the social and ethical contexts, cultures and broader socio-political level issues that impact such personal stories.

AUTOETHNOGRAPHY 101

There are many ways to define autoethnography. Chang (2016: 444) defined it as 'a qualitative research method that uses a researcher's autobiographical experiences as primary data to analyze and interpret the sociocultural meanings of such experiences'. Put simply, it is the ethnographic and critically reflexive study of the self, as well as of others with whom the researcher might have a close personal or familial connection. It is personal ethnography that critically connects the topic to the wider social, political, cultural, and ethical contexts and discourses of the topic. Autoethnography allows researchers to recount their personal lived experiences. Hence, Sparkes autoethnography is focused on: 'highly personalized accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding' (2000: 21). Autoethnography allows the author to offer their unique lived experience, yet it demands that the author occupy multiple roles as researcher, as data generator, as gatekeeper, as interpreter and more.

The opening quote reflects the aim of autoethnography to connect the personal to the cultural, as well as its need to demonstrate its trustworthiness as a research method. Chang (2016), Ellis, Adams and Bochner (2011), and Whitinui (2014), draw attention to the *auto* (to do with self/personal experience); the *ethno* (to do with culture/insider insight) and *graphy* (to do with writing, documenting or analyzing), and suggest that the kind of autoethnography undertaken depends on the emphasis given to each component.

Autoethnography can be distinguished from autobiography or personal narrative, by being more critical or political, and making the linkages of personal to cultural and organizational. Autobiography is selective writing about past or current experience (Roberts, 2002), whereas in autoethnography 'your life is the data', in other words life events and experiences are treated as data to be collected, analyzed systematically, and critically reflected upon. Having said that, sometimes the lines are blurred and the terms are used interchangeably. In fact, autoethnography has many interchangeable names (Ellis & Bochner, 2000), including: critical autobiography, evocative narrative, reflexive ethnography, ethnographic autobiography, autobiographical ethnography and auto-anthropology.

AIMS OF AUTOETHNOGRAPHY

Adams, Holman-Jones and Ellis (2015) have noted a plethora of aims for autoethnography, including the need to place personal experience in research and writing; illustrating personal mean-making; demonstrating reflexivity; offering resistance narratives; and to seek responses from audiences. There are many reasons why people choose the autoethnographic method. Commonly, it is because writers notice from their own experiences that there is a gap in the published literature so they use their autoethnographies to write that in (Dumbleton, 2013; Murray, Pushor and Renihan, 2012; Wackers, 2016; Wall, 2008, 2012a). Also, a highly motivating factor is a sense of injustice or discrimination, and the need to advocate for resistance or change at a policy, societal, or discourse level (Chang, 2016; Spry, 2001; Whitinui, 2014). For others, autoethnography offers them the chance to narrate a good story in an innovative way. Good autoethnography, according Spry (2001), must demonstrate high quality, well-crafted writing, or other means of high quality communication, must be emotionally engaging, must be critically self-reflective, and must enable the reader to be actively engaged with the material being presented. A good autoethnography will situate personal experiences alongside sociocultural and historical contexts, and will involve comparisons, either comparison with other people's experiences of the same phenomenon, or comparison with the established literature and research base of the phenomenon (Chang, 2016).

AUTOETHNOGRAPHIC STYLES

There are different styles and genres of autoethnography and they may not always embrace the need to situate the story within the broader cultural, social or political context. For example, 'The Academic Tourist: An Autoethnography' (Pelias, 2003), is a highly engaging, almost comedic, autoethnography of life in the Academy in which Pelias explicitly avoids engagement with socio-political-cultural contexts. Autoethnographic material can be presented in the form of poems, plays, songs, performances, speeches, story writing, journal writing, blogs, vignettes and so on – readers of the journal *Qualitative Inquiry* will find numerous examples of these kinds of autoethnographic outputs.

Performative autoethnography or embodied ethnography, using performance, movement and visual representation, is one preferred way to express, as well as critique, identity within dominant spaces (Spry, 2001). Spry considers that performative autoethnography is an excellent means to challenge 'master narratives' with the aim of bringing marginalized discourses into the centre, or frame of reference. Performative examples include Clark/Keefe's (2006) work on academic identity, and Edward's on Drag Queens and 'mesearching' (Chapter 13, in this *Handbook*).

Evocative autoethnography is a style preferred by some to explore highly personalized accounts of experience with little or no application or connection to societal or cultural contexts (Wall, 2006). Evocative accounts might be expressed with a great deal of emotion, or in creative narratives, like song or comedy. Examples include Charlés (2009), Pelias (2003) and Wackers (2016). More recently scholars have identified *indigenous* autoethnography as a form of resistance against colonized discourses, as well as authentic insider-research consistent with indigenous worldviews and styles of communicating (Whitinui, 2014). Indigenous advocates of autoethnography argue that it is highly compatible with insider and native styles of research, and that it should be accepted as a culturally informed research practice (Whitinui, 2014).

In contrast, *analytic* autoethnography is: 'ethnographic work in which the researcher is (1) a full member in the research group or setting, (2) visible as such a member in the researcher's published texts, and (3) committed to an analytic research agenda focused on improving theoretical understandings of broader social phenomena' (Anderson, 2006: 375). In the third part of this chapter, when discussing autoethnographies in adoptive families, I use an analytical framework. As an academic with interests in sociology, social work and ethics, analytic autoethnography allows me to give both narratives with depth but critically situate those narratives within macro environments, and ensure that I can present an in-depth understanding of the theoretical and research base of those narratives.

IS AUTOETHNOGRAPHY RESEARCH?

Lincoln and Guba (1985) have well-established pointers of trustworthiness for qualitative research inclusive of credibility, transferability, dependability and confirmability, and these domains should be considered when evaluating autoethnographies; however, these criteria are not a panacea and we might need to develop specific evaluation criteria for autoethnography. Importantly, these criteria and the notion that autoethnography should be considered research have come under severe criticism. Atkinson and Delamont (2006) argue that autoethnography can become unreflective personal narratives, and that for autoethnographies to gain credibility they must be analytic, and be connected to, and critiqued within, broader social contexts. Anderson (2006) argues that evocative autoethnography is limiting with its foci on emotional accounts of personal lived experience, and that autoethnographers, when they adopt a more analytic stance, will produce a robust research-oriented account of lived experiences that can develop and refine theory.

The debate continues as to whether or not autoethnography is viewed as research (Ellis et al., 2011; Forber-Pratt, 2015). These critiques can be levelled at any research, as all approaches need to demonstrate their credibility. Those who defend autoethnography argue that the data being analyzed or reflected upon are the same material used as if being interviewed; it is just that the researcher doing the interview is the same as the participant (Wall, 2008). Denzin (2006) argues that good ethnographers have always believed in documenting and analyzing their data, and choose the best data, even if it's their own personal data. Jensen-Hart and Williams (2010) also make a strong argument in favor of autoethnography because it allows for critical reflection and reflexivity. Furthermore, the assumptions behind autoethnography reflect social constructionist and postmodern theories and are not those of positivism and they therefore should not be judged with scientific criteria (Jensen-Hart & Williams, 2010).

Autoethnographies have their place to promote understanding and action in the same way as other types of research: 'statistics do not appear to move people; hopefully, one story will evoke a response from people and promote action' (Murray et al., 2012: 45), or, 'Policymakers may value statistical data and analysis in their public discourse, in private, however if you want to convince them of something, tell them a good story' (Donmoyer, 2012: 805).

The link between autoethnography as research and practice is somewhat blurred and sometimes this is viewed as problematic (Jensen-Hart & Williams, 2010), but there are many ways to ensure that autoethnography can address issues of trustworthiness. These include: using a broad range of data sources (not just personal memories); writing up the research in a way that details key research questions, how the research was undertaken, how it was analyzed, what its limitations might be, giving 'thick descriptions', member checking, peer review, ensuring that adequate ethical processes have been followed, protection of, and accountability to, others in the autoethnography; and connecting the autoethnography to literature and multiple contexts (Chang, 2016; Forber-Pratt, 2015; Shenton, 2004).

What we can be sure about is that no research answers all questions, and that while autoethnographies do have their limitations they still have a place at the research table.

IS AUTOETHNOGRAPHY ETHICAL?

In two excellent texts on ethical autoethnography, Tolich (2010) and Tullis (2013) outline the core ethical concerns and guidelines of ethical autoethnography. Tolich's (2010) article: 'A Critique of Current Practice: Ten Foundational Guidelines for Autoethnographers', was motivated, in part, by noticing the need for research students to tell their stories within an ethical mindset, as well as a reaction to stories that had been told by researchers that were harming others or exposing others to harm because they had not considered the ethical challenges. Tolich argues that all researchers must consider the needs of others in a story *before any* writing begins – in other words, undertake anticipatory or situated ethics. He says that it is poor practice to attempt to get retrospective ethics approval because of the potentially coercive nature of such actions. Attempting retrospective approval forces unwitting participants to feel more obliged or guilty than participants who were asked at the outset: 'do you mind if you are in my autoethnography?'. There are a minefield of ethical issues for autoethnography and Tolich outlines the key ones as: the vulnerability of others mentioned or alluded to in the story; the issue of consent and ongoing consent, informed or not, and in what circumstances; the issues of protection and internal confidentiality; and if potential to harm is a real prospect then ethically what should a researcher do?

Tolich's guidelines are grouped into three headings: consent, vulnerability and consultation. For consent, the critical ethical issue here is the need to understand that those mentioned in the autoethnography ideally should be asked for their permission through either formal or informal consent processes, and that consent should be sought before the autoethnography is fully written, and that process consent (ongoing) may be required. Hence, if a family member agrees with your idea by initially giving consent, then reads the narrative that you have prepared, and consequently refuses ongoing consent, then the autoethnography should not be written, or at least, should not be published. Unwitting participants should not feel obliged to help their close family members or friends publish their autoethnographies. This can be somewhat tricky where a person mentioned in the narrative has abused the autoethnographer in the past. Here, a cautious approach would suggest using a nom de plume to disguise all participants so the story can still be told. Informed consent may not have to be via formal ethics procedures but for novice researchers using formalized procedures might be the safest approach. Ellis (2007: 24) suggests using a modified form of informed consent she calls 'process consent' where persons get consent at the start and the end of the research. Of course a problem remains with regard to the potentially wide 'range' of individuals that may need to give consent, given the complexity of any individual's life. One might assume that only those in the person's immediate social network are likely to be affected and, therefore, concerned. But it is impossible to anticipate which individuals connected with the authoethnographer, even to the slightest degree, might consider that they had a 'right' to be consented.

Tolich (2010) advises that autoethnographers document their consent procedures, especially when seeking consent after producing a draft manuscript. Researchers could adopt an audit trail approach to consent, which would at least increase the transparency of the process and provide a record of when and where that could be referred back to if criticisms or challenges were posed at a later date.

With regard to vulnerability Tolich argues that we should treat *all* people mentioned in the text as vulnerable or at risk of harm in some way, including the autoethnographer themselves. By taking this approach, an autoethnography will be focused on the aim of the narrative as well as its likely impacts on a diverse group of participants. Tolich notes that 'no story should harm others' (2010: 1608), and where harm might be possible researchers can take steps to reduce this. This will include the researcher themselves, who should view their autoethnographies as an 'inked tattoo': once a narrative is out there you can't retrieve it, so Tolich cautions autoethnographers to be very careful. The other issue linked to vulnerability is the issue of confidentiality, not so much external confidentiality, as good qualitative researchers will often build in quite clear confidentiality guarantees for participants in research, but internal confidentiality, which Tolich outlines as the risk of exposing confidences amongst the participants themselves. Even if a nom de plume is used, there could be significant harm caused amongst family members, because they recognize themselves and their comments.

With consultation, the important ethical assumption is that autoethnographers should presume that anyone mentioned in the text will read it (not immediately perhaps but at some stage in the future). Tolich (2010) then advises us in his guidelines that autoethnographers should consult with others, and not publish anything they did not feel they could show the people mentioned in the narrative. From an analytic autoethnographic perspective it makes sense to undertake member checking, peer review and diverse consultation, not least with participants, but with ethics review boards, colleagues, and other people who have experienced the phenomenon in question.

Tullis (2013) covers similar ground to Tolich but offers excellent advice born out of her own experience of doing research with extremely vulnerable populations. Of note she reminds us that while many researchers never return to their location of research or even to meet their participants again, the autoethnographer will often do these things. In order to frame ethical autoethnography I would argue that we always start from imagining we could re-meet the people in our narratives, so that whatever we have said about them in our writing and performances we would be willing to say it to them face-to-face.

Tullis (2013) is more flexible on the timing of informed consent than Tolich, arguing that some retrospective consent might be acceptable. Tullis also advocates for process consent, ensuring that benefits for participants outweigh harms, again consistent with Tolich's ethical advice. Tullis adds discussion about autoethnography and audiences, noting that the impact on readers or watchers of performances may be powerful and unpredictable, and that the ethical issues for audiences should be considered. This is a particularly challenging suggestion – imagine if every academic considered the ethics of audience impact…! I am not sure we'd have a great deal of groundbreaking research reported. However, being in tune with audiences is a wise undertaking – knowing what your aim is when writing or reporting your research, and what you are trying to achieve is good practice, and you do need to be sensitive to your audience types. Sometimes autoethnographers do need to critique and challenge and sometimes that can make an audience squirm. Perhaps that level of harm is acceptable, but personal attacks using autoethnography cannot be justified.

Tullis (2013) offers a robust set of questions that most novice autoethnographers would do well to ponder:

> Do you have the right to write about others without their consent? What effect do these stories have on individuals and your relationship with them? How much detail and which difficulties, traumas, or challenges are necessary to include to successfully articulate the story's moral or goal? Are you making a case to write (or not to write) because it is more or less convenient for you? Should you and will you allow participants to read and approve all of the stories about them? Or just those stories that you think are problematic or potentially hurtful? (p. 256)

In the following scenario, Jack's Story, I answer Tullis's questions.

JACK'S STORY

It is almost impossible to write or talk or perform about autoethnography without briefly telling a story, as narratives lie at the heart of the method. Indeed, Ellis, Adams and Bochner (2011) and Whitinui (2014) remind us that narratives or stories are the essential ingredient – 'no story no autoethnography' – and well-written autoethnographies offer detail and thick description. But the story needs to be told in a linked way to the full array of contexts that influence it, this is what makes for an analytic autoethnography, rather than just a stand-alone narrative. When discussing ethical dilemmas in autoethnography it is useful to have an example in mind, so to that end I briefly tell a not-untypical story and by doing so reveal a number of critical ethical questions that must be addressed when doing autoethnographic research. This brief story is based on real life, but is no one's real life story in particular.

> Jack, Jill and Jane are a family unit, and they have experienced life's ups and downs. Jack is male, now a single parent, and was happily married for 20 years, before, sadly, his wife died of breast cancer two years ago. Jill is now 18 years old and she is the biological child of Jack. Jane is now 15 years old and she is the adopted child of Jack. She was adopted from China 14 years ago. Jack works as a GP and part-time University academic, training medical students. Jack has been part of a parent support group of intercountry adoptive families for many years, and he and his children have benefitted from some long term friendships out of that group. Jack wants to do some writing about being a solo parent of birth and adopted children and he is mindful of the need to practice and research ethically. To that end, he plans to ask his children permission to write and publish about aspects of their lives together. Jill is vaguely supportive but she's started her Health Science year at University and doesn't think that story telling is real research. Jane doesn't mind either but says she wants to vet the material about adoption and her mum's passing.

From an ethical standpoint there are many questions that will need to be explored if Jack's writing is to be published. He will have to decide if an application to the ethics committee is made. He will have to think carefully about how consent is sought and maintained. He will need to protect key people in the story, including his beloved wife who can no longer consent. He will need to plan to do no harm or minimize hurt to those in the story, including himself. He will constantly need to question his gatekeeping actions about what information is shared and what is not. Hence, these key questions will be explored and we will advise Jack as to some helpful strategies to undertake ethical autoethnography.

HELPING JACK

Having explored the main features of autoethnography and the key ethical issues I now provide some tentative advice to Jack. Firstly, as a GP, Jack will have a robust set of professional ethics to draw upon. Hopefully, Jack will think carefully about why he wants to develop an autoethnography around fathering, adoption and loss. He will already have noted a dearth of literature and research studies about the topic; this will be one driver but also he might feel that the *personal* voice on the topic is also missing. He would be wise to start talking with Jill and Jane about his initial thoughts, and, or research questions. He will need to develop ideas about making journal entries, whether to use personal memories, whether to note down informal conversations with other family members, and whether to draw on family diaries or other artifacts. He will need to decide if he will reflect on material discussed in his adoption support group and how he will manage that ethically. As Jack is employed by a university and likely to publish as an academic he should probably develop a formal ethics application and submit this to his institutional board. If he chooses to write his autoethnography as a 'lay' person or journalist, not affiliated to any research organization, he could then possibly opt for not making a formal ethics request. Alternatively, he could use other ethics review boards, other than University or Health and Disability Boards. For example, specific adoption support organizations might have their own ethics review boards.

Jack's children are older teenagers so they are less vulnerable than younger children but nevertheless they are still vulnerable. They might not want to turn down their dad's request to be either directly or indirectly mentioned in his autoethnography, because they feel a sense of obligation to him. Jill is 18 years old and can consent as an adult, and Jane is 15 so she will also need to consent in her own right, and ongoing consent will be necessary as Jack begins to write down some of his narrative. It would be good practice for Jack to ask a colleague to double check with his children that they are OK with Jack's ideas, as well as that they have had a chance to read drafts and make changes and have thought through their part in Jack's autoethnography. Ultimately, if Jack does not accommodate his children's wishes he should probably not write the piece. He could of course go ahead with the nom de plume strategy, but given the age of his children even a fully disguised piece might still upset them – after all he still has ongoing significant caregiving responsibilities for Jill and presumably wants to keep going with his unique and special relationship with Jane. Jack would be wise to also check out his material with both other researchers (peer checking), and other fathers with adoption stories (member checking). Jack should also audit trail his procedures. Finally, Jack needs to give consideration as to whom he is trying to reach with his autoethnography, and how others might view him once they have read about his experiences of adoption and parenting.

A noteworthy story offered by Murray, Pushor and Renihan (2012) provides an excellent exemplar for resolving many of Jack's dilemmas. They recount their detailed experiences of gaining ethical approval for a study, which included gaining consent from Lee

Murray's adult but developmentally disabled son. Murray had identified a desire to write an autoethnography on the topics of mothering, developmental disability and sexual abuse as her focus for her PhD, and with the support of her supervisors she applied for formal ethics approval for her study. The main concern of the ethics board was the vulnerability of her adult children, particularly one who had Down's Syndrome; they were anxious about his capacity to fully consent. Murray argued that her son was working, could travel on his own, and was able to take care of himself – he was competent to consent. The committee insisted that a colleague of Murray's undertake a consent-focused interview. They also insisted that each of Murray's adult children give their consent via another researcher, rather than to their mother. The ethics review board was also concerned that Murray herself and her three children might need emotional and psychological support. Murray had offered her social work-qualified sister as a support person and as someone who could gain free and fully informed consent from Murray's three adult children, but the review board worried that the familial connection might induce the adult participants to agree to participate. The review board asked one of Murray's supervisors to gain consent from Murray's children, as well as to include another person in addition to Murray's sister as a support person for the family members. The study was then approved. Murray and colleagues summarize their autoethnography dilemmas in the following quote:

> We recognize that not all ethical considerations apply in the same way in all methodologies. Perhaps, notions of free and informed consent, anonymity, confidentiality, and what constitute data all need to be rethought in regard to methodologies that are situated within the personal. How do we ensure that both procedural and relational ethics will be addressed? How do REBs (research ethics boards) take into consideration the moral responsibilities for this work in addition to the ethical issues? Is it the responsibility of the REB to protect the researcher as well as the characters in the story? It is their responsibility to protect the perpetrators of abuse as well as the victims of abuse? What if the victims want to tell their story? How can an REB facilitate the telling of those very difficult stories when 'not telling' only perpetuates the secrecy and shame surrounding the experience? In the name of protecting the marginalized and vulnerable, we exclude them from research and by protecting the perpetrator we protect them from exposure. (Murray et al., 2012: 54)

FAMILY AUTOETHNOGRAPHIES

In this next section I explore two autoethnographies undertaken by family members occupying multiple professional roles, including academic, social work, and nursing.

Myself and another academic mother who have adopted boys from Eastern Europe have explored the potential ethical issues in our autoethnographies. Between us we have published numerous pieces, one of which under a nom de plume (for example, Gibbs, 2011a & b; Gibbs 2013; Wall, 2006, 2008, 2012a & b). Wall has also produced an excellent webinar on autoethnography (https://www.youtube.com/watch?v=pEWF0SV9F_s&feature=youtu.be). The autoethnographies we each undertook were motivated by the need to address gaps in the literature on undertaking analytic autoethnographies, ethics of adoption, adoptive motherhood, intercountry adoption policy, child rights, and enabling the voice of the child to be heard. The ethical issues transect both formal ethics review and what Guillemin and Gillam (2004) call 'ethics in practice'. Neither the ethics committee nor the research team predicted many of the ethical issues we faced.

WALL'S ETHICS IN PRACTICE…

Wall was quite clear that for her writing autoethnographically was focused on not attempting to '*evoke an emotional response but rather seeking to contribute to the discourse on international adoption through a* *personal but thematically organized and analytical narrative*' (Wall, 2012a: 320, my italics). In Wall (2008) and (2012a) she mentions her family fleetingly in terms of their contribution to her autoethnography about being an adoptive mum; she acknowledges them as co-authors of sorts although they are not listed as such in the title, and they are thanked for their participation in making Wall's life story what it is. Her motivation to undertake autoethnographic writing is the lack of fit between the adoption literature and what she knows about the voice and experience of the adopted family. Wall's early autoethnographic work was completed as part of her doctoral studies at the University of Alberta. Hence, she did seek ethics approval and gain it from her department's ethics committee. She justifies the benefits and pitfalls of autoethnography and explains how her own autoethnography was linked to her PhD training but was not her PhD topic (gender and work). In her first two pieces Wall (2006, 2008) lays out her journey into autoethnography and sets out some of her ethics concerns, for example, protection of anonymity and privacy for those in the story; the power of the teller of the story; and concerns about showing respect to those in the story as well as to those who read and give responses. In her later work, Wall (2012a) told more of her adoptive motherhood story but not in too much personal detail. Her writing about key players in her texts is protective and non-judgemental, and she was critically reflective of her own decision-making processes. In Wall (2012b), she writes about her reflections of mothering, and states explicitly that her adopted son's story is for him to tell if he so wishes. She found writing autoethnography anxiety provoking, always feeling she would be judged by readers. Wall acknowledged that she had no control over how others would view her material and that this made her feel vulnerable and uncomfortable. She questioned her own 'objectivity'/ability to be objective, and whether autoethnography can have degrees of objectivity. She got feedback from her advisors asking her to 'tone' down some of her more emotive comments (which she did, which confirms that it is always good to get others to read your autoethnographies before you submit them for publication). However, Wall (2008) noted that by doing this distancing/toning down she felt she might have undermined the purposes of doing an autoethnography. Having noted this, it should be acknowledged that all peer review results in changes, some of which might compromise specific features of the message intended.

In her work, Wall talks about the importance of using multiple data sources, and has an interesting discussion about using memories as a data source – noting that this is often criticized because of its bias/reliance on one person's views, and that people worry about its accuracy and reliability. She says: 'if a researcher had interviewed me about my experiences as an adoptive mother and had recorded and transcribed it, it would have legitimacy as data despite the fact that both the interview transcript and my autoethnographic text would be based on the same set of memories' (Wall, 2008: 45). She was able to justify her own use of personal memory as a source of rich data but she also undertook peer checking to gauge the authenticity and credibility of her story (Wall, 2008).

Wall concludes that autoethnography is research and that her approach is a middle ground – she deconstructs the literature in the light of her own experience; she also allows the literature and other research studies to challenge and transform her thinking, as would happen in any research. She concentrates on analysis and critical reflexivity with limited use of non-emotive personal reflections. In her most recent work (Stahlke Wall, 2016) Wall calls her middle ground 'moderate autoethnography'.

GIBBS' ETHICS IN PRACTICE

I explored some events that occurred to myself and other family members as service users/recipients of services in the UK predominantly. The most vulnerable events were written under a nom de plume but I also incorporated changes to names, dates, ages, gender, and locations. The policy analysis pieces began as public domain works (they had already been reported in adoption magazines and to my local Member of Parliament and to adoption advocacy groups); so the analysis pieces added the academic dimension to a case study used as an illustration of key child rights and adoption policy issues (Gibbs, 2010; Gibbs, 2011a & b). The nom de plume (which in this chapter I am not referencing for obvious reasons) was the most challenging from an ethical viewpoint. It started with an extensive literature review setting the context for the case study. It focused on one boy's and his family's story about the struggle for educational help and support when schooled in the UK for a few years. I made a point of noting the limitations, and that the story was our construction of events. Of course there is value in that and in giving voice to the voiceless, but other voices were not heard. The ethical question that guided my research was simply, 'Am I exploiting anyone in this research/autoethnography?'.

In these autoethnographies I undertook the following ethical practices: First, I sought to protect the most vulnerable as well as protect professionals who had been involved with our family, even though some of those professionals had been unprofessional and 'abusive'. Next, I invited the most vulnerable to participate, provide comments, read the article, choose pseudonyms, and re-check the article in proof form. Third, I took advice from my most respected academic colleagues. During this informal peer review I was advised to take out one or two emotive phrases, and tone it down, to avoid potential criticism from the formal peer review process. Then, with the most vulnerable family member, I asked another colleague to spend time with that child and go through the article and re-ask their permission to publish. My child actually thought this was *overkill* – in that he was content that he had already given me *enough* permission – he understood that we needed to do this but I think he was somewhat bemused. He also wanted to use his own name but was denied this to protect both his identity and that of others. This issue of anonymity is of course well identified in the literature: Iphofen (2011: 98) notes for example that:

> [i]f a subject wishes their identity to be disclosed as part of the research report, the researcher then has some dilemmas – principally the effect this might have on other subjects of their research (knowing the identity of one participant might help identify others who desire continued anonymity)… The researcher should resist requests for the identity disclosure of any subject when such disclosure could lead to the failure to preserve the anonymity of other subjects who had requested that their identities not be disclosed.

So, this is what I had to do even though no one explicitly asked me to not identify them, I acted as if they had.

I approached my autoethnographies from a position of respect to all those hinted at in the story, and I was fine and comfortable that if people alluded to in the story did read it I had nothing to hide or be ashamed of. However, I was also clear that I was not writing for them or to them specifically but to a wider audience of policy makers, professionals and academics who could apply the lessons more generally in their work with adoptive families like ours. I did provide other avenues for feedback to specific people mentioned indirectly in the autoethnographies, i.e. meetings, emails, and letters. At times I also used criticism of people's practice, but I was never derogatory or behaving in ways that I would consider harmful. I was advocating for the needs of adoptive families, especially the educational needs of adopted children to be addressed through best policy, and best practice. Finally, I did not submit formal ethics applications and I did not supply written information sheets or consent forms. I did undertake these verbally. I was at times very clear that my dual aims of doing and writing autoethnography were social justice and advocacy, and that I took a position of constructive criticism. I used my family's case study to illustrate themes and issues around adoption policy in the UK, and around issues of educational support for children with special needs, and hoped that by doing so an improvement in policy and practice would ensue. The feedback since publication has been positive, although all the feedback has been about material from the articles in my real name. I set up a new email account in my nom de plume but I have not had responses about the article published in that name.

Ethical practices are often situated, contingent, dynamic and biographical (Calvey, 2008). My ethics in practice says as much about me as it does ethics procedures, policies or guidelines, or review board edicts. I chose to operate in accordance with my professional ethics, paying more attention to processes of protection, inclusion, respect and empowerment than to the formalized ethics procedures. I decided that if my institution did not accept my nom de plume in particular as an acceptable research output, it did not matter in the scheme of things as my family members' opinions mattered more and, in my view, the published works did not harm them. I think that each autoethnography needs to be considered as ethically problematic from the start but the ethics in practice action plan needs to be tailor made and will not always involve formalized procedures.

DISCUSSION AND CONCLUSION

One of the other issues peculiar to autoethnography is the taking of multiple roles of the researcher – they data collect, but they are the data; they ask permission of others in the narrative but they also need to 'ask themselves' if they want to participate; and they have to be even more scrupulously ethical than all researchers ought to be for the reasons made clear throughout this chapter. When it comes to writing, they might need to reinvent themselves with a nom de plume, or completely disguise information about others in the story. The self as gatekeeper is an ethical issue. As an autoethnographer belonging to a profession (social work), I find it helpful to first apply my professional code of ethics to a potential autoethnography, and then incorporate the guidance detailed by researchers like Tolich (2010). In order to '*keep the self honest*' when decisions are being made about who or what I might include in an autoethnography, or even how I might get the information, I always ask several people including the obvious participants and colleagues and others who know the field or issue well. I never do an autoethnography alone, which almost sounds counterintuitive but it is not: it is ethical and safe. It is important not to leave ethics to self-regulation, some processes of accountability must be implemented.

As researchers we need to ask tough questions of ourselves each time we decide to write an autoethnography. Ethics always need to be considered – the needs of others, even if they have been abusers! If it's really going to be harmful then either use the nom de plume; don't write it; or just call it an autobiography and be prepared to explain yourself to those you hurt. But let's also not be afraid to include the most vulnerable – if ethics committees are too nervous about autoethnography they might just be being a little over protective. Also let's get people on ethics boards with autoethnographic knowledge, knowledge about rationale, technique and implications, including ethical ones. For those of us with professional backgrounds we should always draw upon our professional ethics, and we should help ethics boards 'get' autoethnography rather than just assume that review boards will not be able, or unwilling, to approve autoethnographic studies. As Iphofen (2011: 172) notes:

> [R]esearchers and research organizations should stay ahead of the game as much as they can by being proactive in research ethics rather than simply, even grudgingly, reactive. Since RECs are largely voluntary bodies, the profession can contribute by

> joining them and engaging in debate. If committee members do not inform themselves adequately, perhaps it is our duty to take the challenge to them and ensure they are informed methodologically and ethically prior to taking key decisions that affect the development of our profession.

In this chapter I have drawn on guidelines for ethics and have presented a number of instructive examples where ethical autoethnography can be achieved, and I have used case studies of families to explore key ethical concerns of undertaking autoethnographic research. Those who would publish autoethnographies need to be always mindful of those others who appear directly or indirectly in their stories, and how these others would feel to read material about themselves at some future point in time. Understanding the potential for personal material to be always misunderstood or to cause harm is a good motivator when starting out on the autoethnographic journey. However, if there is a story that counters oppression and seeks to bring justice and positive change then sometimes in the telling, the greater good is justified. Each autoethnographer must weigh up the pros and cons of their work, and apply core ethical practices to each unique autoethnography.

REFERENCES

Adams, T. E., Holman-Jones, S., and Ellis, C. (2015) *Autoethnography: Understanding Qualitative Research*. Oxford: Oxford University Press.

Anderson, L. (2006) 'Analytic autoethnography'. *Journal of Contemporary Ethnography*, 35(4): 373–395.

Atkinson, P. and Delamont, S. (2006) 'Rescuing narrative from qualitative research'. *Narrative Inquiry,* 16(1): 164–172.

Calvey, D. (2008) 'The art and politics of covert research: Doing "situated ethics" in the field'. *Sociology*, 42(5): 905–918.

Chang, H. (2016) 'Autoethnography in health research: Growing pains?' *Qualitative Health Research,* 26(4): 443–451.

Charlés, L. L. (2009) 'My nine lives as an academic: Narratives of identity storied by a platinum-enhanced brain'. *Qualitative Inquiry*, 15(10): 1592–1611.

Clark/Keefe, K. (2006) 'Degrees of separation: An ourstory about working-class and poverty-class academic identity'. *Qualitative Inquiry,* 12(6): 1180–1197.

Denzin, N. (2006) 'Analytic autoethnography, or déjà vu all over again'. *Journal of Contemporary Ethnography*, 35(4): 419–428.

Donmoyer, R. (2012) 'Two (very) different worlds: The cultures of policymaking and qualitative research'. *Qualitative Inquiry*, 18(9): 798–807.

Dumbleton, S. (2013) 'Goodies and baddies: Equivocal thoughts about families using an autoethnographic approach to explore some tensions between service providers and families of people with learning disabilities'. *Ethics and Social Welfare*, 7(3): 282–292.

Ellis, C. (2007) 'Telling secrets, revealing lives: Relational ethics in research with intimate others'. *Qualitative Inquiry*. 13(1): 3–29. doi: 10.1177/1077800406294947.

Ellis, C., Adams, T. E., and Bochner, A. (2011) 'Autoethnography: An overview'. *Forum: Qualitative Social Research*, 12(1): Article 10 – January 2011. http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095

Ellis, C. and Bochner, A. P. (2000) 'Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject'. In N. K. Denzin and Y. S. Lincoln (eds.) *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, pp. 733–768.

Forber-Pratt, D. (2015) '"You're going to do what?" Challenges of autoethnography in the academy'. *Qualitative Inquiry,* 21(9): 821–835.

Gibbs, A. (2010) '"But I don't want another mummy!" How a British family returning from New Zealand with their adopted children are made to adopt them all over again'. *Adoption Today.* August: pp. 8–9. Banbury: Adoption UK.

Gibbs, A. (2011a) 'Having to adopt children twice is not in the children's best interests: A reflective case study analysis of intercountry adoption policy in the UK'. *Journal of Social Welfare & Family Law,* 33(3): 267–277.

Gibbs, A. (2011b) 'Going to the courts twice: A critical appraisal of the UK's policy of re-adoption for intercountry adoptions'. *Children & Society*, 25(6): 482–488.

Gibbs, A. (2013) 'The Power of One: Why auto-ethnography, solo service-user voice, and reflective case study analysis are useful strategies for researching family-centred social work practice'. *Social Work Review,* 25(4): 15–24.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "ethically important moments" in research'. *Qualitative Inquiry*, 10(2): 261–280.

Iphofen, R. (2011) *Ethical Decision Making in Social Research*. Basingstoke, UK: Palgrave Macmillan.

Jensen-Hart, S. and Williams, D. (2010) 'Blending voices: Autoethnography as a vehicle for critical reflection in social work'. *Journal of Teaching in Social Work*, 30(4): 450–467.

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage.

Murray, L., Pushor, D., and Renihan, P. (2012) 'Reflections on the ethics-approval process'. *Qualitative Inquiry,* 18(1): 43–54.

Pelias, R. (2003) 'The academic tourist: An autoethnography'. *Qualitative Inquiry,* 9(3): 369–373.

Roberts, B. (2002) *Biographical Research*. Berkshire, UK: Open University Press.

Shenton, A. K. (2004) 'Strategies for ensuring trustworthiness in qualitative research projects'. *Education for Information*, 22(2): 63–75.

Sparkes, A. C. (2000) Autoethnography and narratives of self: Reflections on criteria in action. *Sociology of Sport Journal,* 17(1): 21–43.

Spry, T. (2001) 'Performing autoethnography: An embodied methodological praxis'. *Qualitative Inquiry,* 7(6): 706–732.

Stahlke Wall, S. (2016) 'Toward a moderate autoethnography'. *International Journal of Qualitative Methods*, January–December: 1–9.

Tolich, M. (2010) 'A critique of current practice: Ten foundational guidelines for autoethnogaphers'. *Qualitative Health Research*, 20(12): 1599–1610.

Tullis, J. (2013) 'Ethics in autoethnographic research'. In S. Holman-Jones., T. E. Adams, and C. Ellis (eds.) *Handbook of Autoethnography*. Walnut Creek, CA: Left Coast Press, pp. 244–261.

Wackers, G. (2016) 'Recursive health care structures and choice in the manner of our dying: an auto-ethnographic account'. *Qualitative Health Research*, 26(4): 452–465.

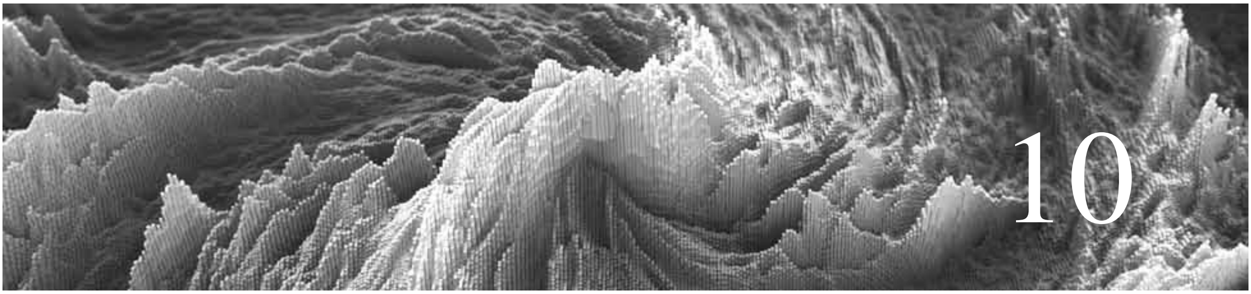
Wall, S. (2006) 'An autoethnography on learning about autoethnography'. *International Journal of Qualitative Methods*, 5(2): 1–11. Retrieved August, 2016 from: https://sites.ualberta.ca/~iiqm/backissues/5_2/PDF/wall.pdf

Wall, S. (2008) 'Easier said than done: Writing an autoethnography'. *International Journal of Qualitative Methods,* 7(1): 38–53.

Wall, S. (2012a) 'Ethics and the socio-political context of international adoption: Speaking from the eye of the storm'. *Ethics and Social Welfare*, 6(4): 318–332.

Wall, S. (2012b) 'Re-Thinking Motherhood and Kinship in International Adoption'. In F. J. Latchford (ed.), *Adoption and Mothering*. Bradford, Ontario: Demeter Press, Chapter 6, pp. 88–102.

Whitinui, P. (2014) 'Indigenous autoethnography: Exploring, engaging, experiencing "self" as a native method of inquiry'. *Journal of Contemporary Ethnography,* 43(4): 456–487.



10

Between Dance and Detention: Ethical Considerations of ‘Mesearch’ in Performance

Mark Edward

INTRODUCTION

Within this chapter, I explore the notion of ‘mesearch’, taking its departure from sociological and performing arts investigations in autoethnography and autobiography. I define ‘mesearch’ as a personalized research paradigm and more importantly I discuss the ethics of ‘doing mesearch’. While exploring the relationship between self and research within performing arts, I have come to the conclusion that there is no neutrality in reflexive research. Having engaged in practice-led research projects, it became clear that an objective lens in such subjective work is neither achievable, nor desirable. Both the subject (self) and objects of study are inextricably connected. This idea is essential to my principle of ‘mesearch’. The emergence of this subjective paradigm offers a platform to explore one’s development of self and, simultaneously, one’s research development. As a ‘mesearcher’ I am committed to the writing up of the self and other personal histories through my own epistemological positioning and theorized subjectivity. I begin with my own story.

BACKGROUND

I grew up as a gay teenager on a working class council estate in a small village just outside of Wigan, in the UK. This was during the 1970s and 1980s and was a harsh time in terms of being openly gay. Early in my childhood I had to become immune to the daily homophobic verbal abuse from the local boys. As I moved into my late teenage years my goals were to escape the homo-negativity and, by now, the gradual monotony of illegal raving and experimenting (to irritate my father) with becoming a drag queen. This boredom resulted in my enrolling at college and two years later going on to university where I achieved a BA in Creative Arts, an MA in Dance Studies and a

PhD titled: *Temporality of the Performing Body: Movement. Memory, Mesearch.* This thesis explored 'mesearching' and age(ing) in western dance and drag queen culture through autoethnography and queer theory.

The PhD was important but it was my undergraduate studies that were formative. I wanted to be the high priestess of modern dance, Martha Graham, who was one of the early twentieth-century pioneers of contemporary dance. As much as I would like to say that she was a childhood heroine of mine that would be untruthful. I discovered Graham when I rebelled against my college tutors' teaching by taking extra classes in the evening in Manchester, UK. I embarked, somewhat later than my peers, on a dance journey that was able to support my developing dance identity. I wanted to be Graham. When I enrolled at university in 1994 I insisted all my university friends call me Martha. Some still do.

It was 19 years later, in 2013, when I got the chance to adopt the persona of this globally recognized dancer. Engaged in a co-collaborative photographic research project, titled *Dying Swans and Dragged Up Dames*, with colleague Professor Helen Newall (Edward & Newall, 2013), I re-enacted Graham's iconic dance poses by doing what I did best: exploring my living archives of memories, digging up embodied dance techniques that are deeply ingrained in my ageing and tired muscles, rummaging through an attic full of costumes that are hosts to a range of scents and stains from my dancing past(s), and working with a research collaborator I knew and trusted. This Martha Graham, me in full drag re-enacting her famous contemporary dance 'pleading' pose from her 1930s work *Lamentation,* had been subverted from traditional norms of contemporary dance history (Figure 10.1). I had put myself out there for bare scrutiny with my fat and ageing body as a bombastic contrast to the renowned slender female American dance pioneer. Dance purists labelled the product of

Figure 10.1 Mark Edward as Martha Graham

Photo: Professor Helen Newall

my 'mesearch' here, iconoclastic. Somehow I felt empowered by this. At the time I was going through personal and professional transformations. The iconoclast remarks only fuelled my need to explore a resistance towards conservative dance through queering and gender disruption.

I was both embracing the serious academic pursuit of dance, which has been a major part of my learning throughout life. I was also reclaiming a low art form by mobilizing drag culture to portray the campiness of early modern dance and a fat ageing dance (vis)ability. Indeed, in academic terms, alongside queer theory, camp seems to have sashayed onto the stage of critical theory. In terms of such burgeoning critical comment, the publication of *Camp: Queer Aesthetics and the Performing Subject* (Cleto, 1999), has attracted contributions from 'celebrities' within queer theory, including Judith Butler and Eve Kosofsky Sedgwick. A less opaque and more amusing definition offered by Sontag is worth adding: 'the hallmark of camp is the spirit of extravagance. Camp is a woman walking around in a dress made of three million feathers' (1983: 112).

Beneath these definitions I propose two main features of camp that are relevant to the beholder: affectation and exaggeration. Both of these can be seen as examples of gender parody, just as drag is seen as such. So, just as drag and queer theory all seek to critique dominant binarisms (Edward, 2018) in gender and sexuality (male/female, gay/straight), camp equally becomes a tactic by which parody and exaggeration can serve as disruptive agendas. The popularity of trans theory is currently emerging as a research paradigm, which addresses the space in between the binaries. The theoretical underpinnings offered above serve as a platform on which idealized and hierarchical notions of dance, expectations of codified forms and body commodities can be critiqued and viewed as camp parody to the ageing performer.

DIPPING MY POINTE SHOES INTO ACADEMIC SUBJECTIVITY

It was during the interview with my prospective PhD supervisor that I was encouraged (by the trends in academia brought about through autoethnography) to write about dance and age(ing) that would embrace selfhood, reflectivity and practice-led art-based investigations. Although my research is underpinned by my own self-identity running throughout written texts and creative research practice, the purpose of my investigations is to not only explore a personal paradigm but to move into a 'new paradigm' (Boud & Griffin, 1987: 113) for me, where I strive to explore the possibilities of performance beyond the culture backdrop. Throughout the documentation of my ongoing publications and practice-based projects, I have negotiated feelings of vulnerability (see Edward, 2014), doubt, self-questioning and ethics of 'doing self' in research. I have engaged with and discarded multiplicities of theories in ways only poststructuralist subjective researchers would. This perspective has been incorporated into my teaching.

As a Senior Lecturer, and now Reader, at a university I have always guided my undergraduate students towards subjectivity in their dissertations and their writing up of practical projects; insisting on an avoidance of using 'one' and adopting 'I' and 'my' throughout their text. Although, in my early lecturing career, I had been surrounded by the dusty ivory towers of traditional researchers and educators, I encountered some colleagues who had largely fixed ideas of what constituted 'valid' forms of writing and 'real' research and who would sniff at the mere mention of subjectivity. The very thought of a DVD, or a creative CD, or a theatre performance, or gallery exhibition, with accompanying exegesis, to be given as much credit as a written dissertation would fill them with horror, thereby demonstrating a complete lack of understanding of the labour-intensive nature of practice-led research and alternative modes of critical enquiry. It was during my collaborations with performing arts colleagues, and my doctoral years, that my academic research embraced my subjective self.

MERGING ME AND RESEARCH

My position throughout my practice-led projects has been to combine autobiographical and personal experiences as integral to the process of creative practice. Over the years, I have explored and mobilized my personal identity as a central process to my research and my collaborative practice-led projects, in particular *Council House Movie Star* (Edward et al., 2012) and *Dying Swans and Dragged Up Dames* (Edward & Newall, 2013), which explore subjectivities of my researcher identity. In these practice-led projects, as well as engaging with related social and cultural theory that directly influences my life experiences, I explore my experiential archives to narrate personal observations. Such individual inquiries are arguably permitted by the social scientific turn to self, which has been a major feature of autoethnographical inquiry.

In the early stages of my practice-led research journey I struggled with the notion of conventional research and found any attempt to shoehorn my practice into neat, delineated areas futile. Originally, under the umbrella of qualitative research, my work began as heuristic inquiry, which shifted paradigms into autobiography and autoethnography. Norman Denzin, the sociologist, describes autoethnography as the production of text from both ethnography and autobiography (2003). I embarked on taking seriously my own research processes that were more reflexive and heuristic. I disembarked on traditional methods, and began to sit more comfortably with performance-based research such as mine being a process of trial and error, an organic process, a 're-searching of the human realm' (Polkinghorne, 1988: 280–281).

As the basis of my practice is a personal development through inquiry, I was initially drawn to heuristics 'involving disciplined self-commitment, rigorous self-searching and self-reflection' (Hiles, 2001: 2). Dobie summarizes heuristic processes neatly, as they 'allow for and indeed demand that the opinions, feelings, moods and intuitions of the researcher are present throughout the period of research' (2010: 178). This process of self-reflection and the self-as-researched subject is one which is organic and evolutional; it cannot be rushed. As a creative practitioner, the downside of this is that it does not always sit well with the rigidity of specific performance deadlines and schedules. Indeed, such research geared towards the investigations and explorations of personal experience, as an organic human science, is often studio-based without a performance output. Douglass and Moustakas agree that such living and biological processes cannot be hurried. Such processes are, they say 'concerned with meanings, not measurements; with essence, not appearance; with quality, not quantity; with experience, not behaviour' (1985: 42).

In its simplest form, heuristic and biographical investigations provide a framework for personal exploration. Performance autoethnographer, Tami Spry argues that, 'your work may open up "different modes of living" for others who may not have lived your experience, or if they have, so that they might engage your story as a catalyst for their own explorations' (2011: 124). Presenting lived experiences to an audience/reader in immersive 'transpersonal paradigms' (Hiles, 2002: 1) is similar to writing. You narrate the personal in crafted (and sometimes re-constructed) ways (Edward, 2018: 39). Therefore, the performative self often adopts and adapts social and cultural constructs in order to engage, and each of these processes require ethical considerations.

I now move to consider how mesearch can be conducted as an ethical enterprise, which can serve other practitioners and researchers. As mesearch can be viewed as introspective and reflexive, it is important to move beyond myself; yet such relationality is wrapped in ethics. My discussion of ethics within mesearch addresses the following concerns: the ethics of 'other', relationality, ethics of embodiment, personal safety, and situational ethics.

THE ETHICS OF 'OTHER', RELATIONALITY, AND THE ETHICS OF 'EMBODIMENT'

The *ethics of 'other',* focusing on how we build relationships with others, how we interact through reading each other's expressions and responding in a manner which is wholly personal and unique to the situation, is how collaborative endeavours (such as the *Council House Movie Star* discussed further on) have been successful. Arguably, performance arts researchers, trained in the reading of and response to others through action, movement, verbal response or physical response, are well equipped to recruit and retain participants, and build successful partnerships. Relationships and the relationality are essential to the dynamics of mesearch ethics.

Martin Tolich (2010) is critical in his discussion of authoethnographic ethics as not being thought out, and consent remaining a polemical issue. He warns that autoethnography cannot be viewed as a piece of work relating solely to the author: 'The word *auto* is a misnomer. The self might be the focus of research, but the self is porous, leaking to the other without due ethical consideration' (2010: 1608). Despite having documented the difficulties for creative practitioners and performance artists to reduce their intent for ethics clearance, I do not advocate such research as exempt from ethical considerations. Rather, the focus of the ethical implications of such work is displaced, as I explore next.

Mesearch as *relational ethics* is captured in Rice's quote:

> My ethical integrity is most clearly expressed in my personal interactions with other people. The process effectively removed my personal, embodied presence from the forum in which my ethical integrity was to be judged […] In artistic work, I believe that the ethical integrity of a research process is best measured by the researcher's ability to respond in person to those with whom they will be engaged. A written appeal to disinterested academics is borne out of a conception of research in which the personality of the researcher is irrelevant. In artistic work, it is paramount. (Rice, 2015, in Freeman, 2015: 106)

Mesearch within creative practice research therefore prioritizes aspects of one's personality and identity. Below is an exemplar of ethical limits in mesearch.

In 2015, I was mentoring a student who wanted to create performances that would involve telling his/her story of their experiencing a sexual assault, and a second student intending to film a relative (who had dementia) as part of performing a scripted monologue. Both students had wanted the material to be part of their art and intertwine their life history. These were my stories of another time. As an artist who in my youth had documented people and 'happenings' through filmed processes and then used this footage in various performances and installations, I was supportive of the ideas.

On a personal level, some of my own earlier creative work delved into my ongoing mental health challenges, which at the time had been brought about through anesthesia, and the stigmatization, isolation and vulnerability that surrounded me during this period. Through the use of multimedia including text, which I had partially 'acquired' by befriending a member of the National Health Service staff, I showcased short pieces in front of a small intimate audience, 'confessing' my psychological struggles through powerful filmed footage. This does raise questions on ethics and also on the issue of deception (see Calvey, Chapter 31 in this *Handbook.*) As Martin Bulmer argues:

> [A] common defence of the use of covert methods of research is to argue that, although some criticisms of it have force, covert methods do not cause harm to those studied if the identities and location of individuals and places are concealed in published results, the data are held in anonymised form, and

> all data are kept confidentially secure. It is proposed that the benefits from greater social scientific knowledge about society outweigh the risks that are run in collecting covert methods. (2001: 55)

The issue of permission and deception can be disputed here within my psychological studies. However, I had been honest with the guy I had befriended and visible with my use of a video camera during my filming processes. So much so during one filming expedition that I was challenged by suspicious security guards who then chased me out of the hospital grounds. Fortunately, I was able to escape without any ramifications – camera still intact. Any filmed footage that was used within my performance project had 'artistic' pixelated faces and a sound score had been incorporated into my editing. This ensured that individual identities could not be recognized. The footage was later destroyed – mainly due to the lack of storage space on my archive shelves rather than me being an accountable researcher.

These subjective filmed and performative accounts of the micronarrative of my (then) past were used to visually 'speak' to the spectators. Yet, years later, I find myself mentoring emerging artists and having to explain the possible relational ethical implications of their work. In the naivety of my early artistic days, I had given no thought or consideration for the wider aftermath of my artistic involvements, such as people being dismissed from their jobs and the possibility of prosecution. I seldom anticipated any consequences of my actions and I gave no consideration for any unsuspecting person mixed into my performance projects. During tutorials my students now had experiences which I had not had as an emerging artist. Their having to follow the institution's procedures of form filling and board review processes ensures that students are more ethically aware of their research and that measures are put in place to protect not only them but their participants. We are all faced with decisions when it comes to social research and there are no '"cut and dried" answers to many ethical issues which face the social researcher' (Bulmer; 2001: 56). As I educate emerging arts-based researchers, I think it is important for me to ethically guide students towards good practice: A multifaceted approach to documenting their material that allows for a sense of artistic research freedom, but at the same time signposting my students to the many ethical issues that can arise out of their decision-making. If a student wanted to replicate my hospital study I would say: have proper planning and permission in place before you start the documentation process; avoid a 'rookie' approach of hijacking spaces; and make sure you have safeguarded yourself and other people. If you are exploring self-narratives (which may evoke unpleasant memories and emotions) then it may be a good idea to have talking therapy (as I sometimes do) alongside your mesearching. Just as I did over 20 years ago, you too should stay true to your story. Always give an honest and accurate account of your findings. Research with passion. Know your current limitations, and as for befriending people for 'insider knowledge', well that is a swinging pendulum between a bomb and a benefit. You run the research risk of not knowing which.

In 2015, I was invited to write about countercultural dance in the UK (published in *Counter Culture UK: A Celebration*) and my experiences as one of the original acid house ravers in 1988. Within this text I openly discuss my coming of age as a gay teenager in a working class community on the outskirts of Wigan, my taking strawberry acid tabs and smoking cannabis while being a teenager. This drug taking and dancing was part of my self-actualizing and (now that I reflect) identity forming among my peers and society. I had moved beyond taking risk in performance, to taking risk in my written work revealing some hidden aspects of my identity as both a performer and academic:

> It is 1988 and I am out with my friends. I have just swallowed a strawberry acid tab whilst thinking *Top of the Pops* [a popular UK TV music chart programme] completely depresses me. It is the year I

> have left school, with no qualifications, although, in all honesty, I had gone AWOL two years earlier by becoming a school refuser. For the last twelve months I have been plagued with the threat of being put into a home by the local education authority and told I run the risk of becoming a 'delinquent'. I had to look that word up in the dictionary. It lies somewhere in between the entries for 'dance' and 'detention'. For years I have been resisting, or catapulting myself away, from engaging with the commodity beige girls and boys in school (with their hair 'don'ts') and their 'take' on popular culture. I am an oddity you see. Not only due to my insolence towards compulsory education but the fact I am gay, and living in working class Wigan (pits, pies and pubs). I have developed my own ability to challenge the queer bashing and daily 'faggotry banter'. (Edward, 2015: 87)

While writing that book chapter, including my own experiences of illegal drug consumption, I cannot deny that I did experience, albeit briefly, anxiety surrounding the possible reactions and ethical implications of this self-disclosure. I was not intending to be an advocate of illegal drug taking nor wanting to encourage my readers to go out and 'drop some acid'. Yet how do I write honestly and reflectively about counter cultural dance happenings and my being part of that movement without mentioning this? It would be a lie if I had said I had swallowed tic tac-style sweets or that I had drank some lemonade to give me the energy needed to dance all night – a sugar rush instead of an acid rush. Other questions came into my mind such as: do I use real names for those who were part of my illegal raving experiences? Yet ethically I could seek consent or anonymize them. As we had subsequently lost contact, anonymity offered the best protection. After all it is nearly 30 years ago so what would be the problem? Surely the licensee of the nightclub would now not be prosecuted. In the book chapter, I openly criticize my former school days resulting in my becoming a 'school refuser' due to the hostile environment from other pupils towards my being gay. This resulting in my being referred to school welfare officers with the constant threat of being put into a home for 'bad boys' due to my lack of attendance and irreverence towards compulsory education. Should I name the school I attended? Would the chapter cause problems within my place of current employment or even future employment? These were the moral and ethical dilemmas I met with while writing on the cultural and social fibres of countercultural dance within the UK. I decided to tell my story.

The *ethics of embodiment* were central concerns, as the drug-taking chapter also examined location, position, history, cultural experiences and the embodiment of dancing within various dance genres. By doing this, I was able to reflect on the ethical and embodied implications of writing about experiences that were interwoven within the historical overview of UK dance culture, helping me to make sense of my life and art. Most importantly, mesearching extends the opportunity for others to connect with similar dance, vulnerability and phenomenological experiences, as Anderson notes:

> Embodied writing brings the finely textured experience of the body to the art of writing. Relaying human experience from the inside out and entwining in words our senses with the senses of the world, embodied writing affirms human life as embedded in the sensual world in which we live our lives. (2001: 83)

We must be careful not to consider embodiment as a unique individualized affair. Within our experiences, histories, and positions, we are intertwined with one another. Our stories overlap. We watch a performance and it draws an emotional response because of our empathy. We express our understanding and relationship with the themes at play or the stories told because we are part of a collective embodiment.

In autoethnographical studies, Carolyn Ellis (1999; Ellis & Bochner, 2000) has explored the ethics of sharing her personal narrative through narrative ethnography when she raised questions on the speaking of/about others and their implication in telling one's story. She considers the ethics of whether or not third persons should consent to their inclusion in the story, or even be given the opportunity to write their own version of the story. Ellis's concern with equity of partnership within the research relates to the final product, the published story. Equity of partnership within mesearch relates to the infinite number of interactions with partners and collaborators as the creative work is being produced. Microanalysis of such interactions would take considerable painstaking documentation, and I advocate that acknowledging that the building and maintaining of positive relations is a presumed component of creative practice. Ellis's view of relational ethics within ethnography can be therefore transferred to autoethnography:

> Relational ethics requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences. (2007: 3)

And the tools for relational ethics are built into our emotional repertoire. Relational ethics demands that we 'take responsibility', to borrow Ellis's words, and prioritize the practice of building relationships and intimacies with others as an ongoing process. Of course, this is nothing new. Relational ethics has been well documented in autoethnography research (see Ellis, 2007, for further discussion), within mesearch however, we take the process one step further back. Relational ethics stem from personal ethics. And herein lies the rub. How can a performance artist stay true to one's personal ethics, yet create engaging practice and reflective writing which has the element of risk? These questions and others are raised in the mesearch description of the *Council House Movie Star*.

COUNCIL HOUSE MOVIE STAR: MESEARCH AND PERSONAL SAFETY

During 2012, I created an immersive gallery installation project titled: *Council House Movie Star*. Within the UK, a 'council house' is a form of social housing provided by and supported by the local authority. My project was interdisciplinary and incorporated a film about a drag queen persona called Gale Force (me), friends, and family and included fine art paintings of me in drag. These paintings also portrayed my naked body. The immersive installation allowed the public to wander in off the streets and walk around the unpoliced gallery space, which hosted a purpose-built life-size council house, while observing the everyday occurrences of a drag queen's private life (Figures 10.2 and 10.3).

Each day different spectators came through the front door or, like a voyeur, peeped through the partially cleaned windows to witness the drag queen persona and my/her extended 'family'. This mainly consisted of other matriarchal drag queens from the 1980s, my (then) 83-year-old mother and former performing arts students. There were no restrictions on entry, and audience members freely entered and exited at their own volition. Building relationships with relative strangers who accessed the space is exactly what a drag queen does on stage. I was experienced in dealing with any potential homophobic taunts, but I was alone if a prejudice-based attack occurred. This arts work had no stage borders and no door security normally associated with nightclubs and bars. This was an immersive live art experience. Surrounding myself/Gale with other performers in the space provided safety in numbers. Indeed I had a duty of care for my elderly mother and that of the other installation spectators and my performance participants. However, this was a queer artwork, which had a highly charged drag persona, akin to drag anarchy with little regard for anything and anyone. It was a telling of a queered life in hardship, poverty, survival, ageing in non-heterosexual culture, memory, discos and destruction. The other participants were equally fuelled with playful and irreverent tactics as the installation progressed over a three-week duration when the arts venue was open from 10am to 5pm daily. On one occasion as I/Gale entered the council house two participants had unexpectedly stripped off their trousers and

Figure 10.2 Installation performance

Photo: Mark Loudon

Figure 10.3 Gale Force in installation

Photo: Olivia du Monceau

were lying around the bedroom 'performing' drunkenness. Another performer in the work had a hearing impairment. She was partially deaf and played the part of 'Dawn Patrol' who was Gale's social worker. Throughout certain scenes Gale would respond to the social worker's questioning only to keep hearing the response: 'What was that?' This went on for three hours. In terms of my own personal safety Gale Force would often receive private Facebook and Twitter messages from men asking if they could pay her to take photographs of her legs or ask if she would be willing to be their mistress and 'use them' by urinating on them or spanking them with her stiletto shoes. On one occasion, late evening, Gale had written on social media: 'I am in need of vodka and jelly babies'. The day after when Gale/I came into the gallery/house the sofa was full of vodka and jelly baby sweets. I had soon realized the public where also following Gale's life away from the house installation. The dilemma lay in the fact that the persona Gale could not have cared less who was asking to photograph her legs or who wanted to be 'used' or spanked by this hyper feminine personality through a dominatrix relationship. She did not care about semi-naked bodies all over the house/installation or had any sensitivity towards a person who is hard of hearing.

And yet, as Mark Edward the researcher, the producer, and the person who had gone through rigorous ethical review for this work to happen I was forced to care.[1] I enjoyed and revelled in the other performers pushing unspoken boundaries and I also enjoyed Gale's 'perverted admirers'. However, as Mark Edward, I did feel the need for self-protection (and protection of others) and ensured the safety of performers at all times through keeping together in the same space. Gallery staff were also available if needed. I was also mindful of Gale's social media conversations and wary of the public finding out where I (Mark) lived. Gale's interactions outside of the arts installation became scarce.

In terms of ethics and possible risk I had to question who is at risk: the performers due to their extremely energetic behaviour? Gale for looking so queer? the spectators? the funding bodies if the 'happenings' move off performance script? (What script?!). As with any qualitative research, just because it is documented on paper does not mean it will translate to real life happenings in an identifiable form. This then poses questions about restriction and performative boundaries: Where do we draw the artistic line within improvisational artwork? Do we draw it at bad language during an improvised moment when representing and retelling the life of a drag queen in a working class Britain? Or maybe the naked derrières briefly on display from the other participants during an improvised re-enacted drunken moment? Or the 9ft-high fine art paintings of my naked body showing my penis and queered with the trimmings of women's stiletto shoes and make-up? And what about consent for use of dead people's photographs such as my grandma, friends and sister pinned up on the walls of the house installation. Would they want to be part of my work and gazed at by the wandering public? Would my 96-year-old grandma want to be juxtaposed with a range of highly charged drag queens and a youth culture that would have seemed so unfamiliar to her? I would like to think she would, of course. However, these are the considered risks I had to take.

SITUATIONAL ETHICS

When we assess risk and look at the ethical implications of art installations and performance, we need to understand that during the course of semi-scripted situations the material differs from day to day. This becomes a question of situation ethics (see Sieber & Tolich, 2013) where the ethical implications change depending on circumstances. As my work is often situational and experiential this is where situation ethics apply, as Sieber and Tolich state '*Situationism* refers to the view that the moral principles should be applied differently in different contexts' (2013: 38, italics in original). Situational contexts therefore require situational ethics, where the element of risk and safety is consciously renegotiated as part of the process.

In *Council House Movie Star*, I also became aware of adult spectators walking into the immersive installation with young children.

As Gale was dancing around to her favourite 1970s disco music and singing on her karaoke machine a young lady came through the front door with a young boy and girl. While this, in itself, appeared to be a 'safe moment', Gale/I glanced over towards the other performers who were (unbeknown to Gale/me) semi-naked and imitating drug taking with the use of baking powder. All I could think is what do I do now? How can I as Gale still maintain my character yet ensure these children are not exposed to this imagery? This, again, is about *situation*, but also needing a responsibility and respect of intimate others, especially where children are concerned. When we platform our lives with the intention of being honest in front of total strangers, we should be 'true to one's character and responsible for one's actions and their consequences on others' (Slattery & Rapp, 2003: 55). Should the element of risk have been assessed by the children's mother? I am not wanting to abdicate my researcher/producer responsibility here, so maybe in hindsight my and the festival promoters inclusion of an age limit in the marketing materials would have offered protection towards children.

CONCLUSION

My consideration of the tenets of 'mesearch' within this chapter shows how such a subjective and introspective enterprise can be a platform for future creative practitioners in terms of ethical considerations. I have demonstrated how future practitioners should be reflective and emotionally equipped with personal and professional ethics, which will serve to foster fruitful collaborations. The importance of relationality signifies that mesearch should not be an individualist endeavour but should rely on the participation of others, as personal stories need listeners, readers and tellers. In research, relationality requires ethics.

An overarching key feature of my work has been to revisit my youth and my past. Journeying into the past allows me to re-enter a safe space, where the memories of place, or the re-creation of such memories, allow me to imagine a place which is free from the pollutions of my present life. In the recreation of the council house for *Council House Movie Star*, the objects and personal artefacts that were used in the setting allowed for the re-imagination of childhood and youthful experiences. They created a feeling of nostalgia that allowed me to remember a time before I began to age, before I began to gain weight, before I had episodes of being mentally unwell, and before I had to negotiate the complexity of life in the postmodern twenty-first century.

My mesearch involves a process of self-exploration and self-examination, and this leads to work that needs to be critically honest and for the mesearcher to be transparent. However, because emerging subjective research is both practical and collaborative, the question of ethics is ongoing and processual. Rather, the research engages in a lengthy process of self-scrutiny in which risk is carefully negotiated, and considered alongside other individual and ethical responses such as emotions, experiences, safeguarding to inform research. For me, mesearchers engage in journeys which explore the self in position to the research area, and this positioning of emotions leads to self-questioning, doubt, concern, personalization, honesty. In terms of self-ethics, facing one's humanity can be a positive and negative experience; it can be joyous and painful, and is often both. Such vulnerability on the part of the mesearcher builds resilience, and this in turn, drives the work. Emotional and experiential engagement with subjective research demands that it is 'true'. Carolyn Ellis says of autoethnography that it 'requires' that

> we observe ourselves observing, that we interrogate what we think and believe, and that we challenge our own assumptions, asking over and over if we have penetrated as many layers of our own defenses, fears, and insecurities as our project requires. It asks that we rethink and revise our

> lives, making conscious decisions about who and how we want to be. And in the process, it seeks a story that is hopeful, where authors ultimately write themselves as survivors of the story they are living. (Ellis et al., 2013: 10)

It is important to not lose sight of the purpose of mesearch. It is not an anarchistic response to traditional research methods, but rather it aims to complement them by exposing the subjective stance of the researcher. Therefore, in acknowledging how the subjective can be vulnerable, we see that it can also be transformative. Individuals who engage with the emerging themes on a social or cultural level engage by questioning their own positions. The personal can be transformative and serve to eliminate boundaries. Yet, Gayle Rubin reminds us how 'history makes fools of us all' (2009: 371), as she acknowledges that social and cultural agendas pass and find their place in history. Rubin advocates a departure from the 'expectation that […] generative and world-shattering moments are supposed to be permanent conditions' (2009: 370). It is through the subjective stance of mesearch, there is the recognition that it is a temporal position, which will come to pass. Like performance work itself, mesearch is not timeless.

Future mesearchers can take sustenance in reading the journeys and ethical challenges faced by others in conducting such personal investigations, which are then made public. Making personal introspections public allows individuals to make sense of the world and art, as research vulnerability engages empathy.

There are clear ethical challenges when researching and producing performance that is saturated in biography and memory. As life stories evolve organically and fluidly, the methodology and situation also needs to be able to bend and stretch to accommodate the creativity that underpins any improvised arts-based activity. Documenting the journey such fluidity takes is an impossible task, but it is imperative to assert that this fluidity should be embraced. Mesearch therefore allows researchers to delve into personal archives of memories, personal experiences, emotional treasures, physical junk, and mobilize such artefacts as part of subjective-based inquiries. At times I experience difficulty in documenting this fluidity in my work. However, the documentation of my practice must bend and flex in order to accommodate the various aspects of the mesearch journey, including reflection and recording processes, thereby enabling the work to be disseminated.

Note

1 'Gale Force' asking for jelly babies and vodka is not something that I had envisaged as part of the performance installation. However, Gale is over the alcohol drinking age limit. My point here, is that as performance work progresses, impromptu acts from performers can and will occur. It is easy for people caught up in the moment to forget what has been written on a form, dating back several months, that has been filed away.

REFERENCES

Anderson, R. (2001) 'Embodied writing and reflections on embodiment' in *The Journal of Transpersonal Psychology,* 33(2), 83–98.

Boud, D. and Griffin, V. (1987) *Appreciating Adults Learning: From the Learners' Perspective.* London: Kogan Page.

Bulmer, M. (2001) 'The Ethics of Social Research' in Gilbert, N. (Ed.) *Researching Social Life. Second Edition.* London: Sage. pp. 45–57.

Cleto, F. (1999) *Camp: Queer Aesthetics and the Performing Subject: A Reader.* Ann Arbor, MI: University of Michigan Press.

Denzin, N. K. (2003) *Performance Ethnography: Critical Pedagogy and the Politics of Culture*. London: Sage.

Dobie, J. F. (2010) 'Heuristic Research: Autoethnography, Immediacy and Self- Reflexivity', in Freeman, J., *Blood, Sweat and Theory: Research through Practice in Performance.* Oxfordshire: Libri Publishing.

Douglass, B. and Moustakas, C. (1985) 'Heuristic inquiry: The internal search to know' in *Journal of Humanistic Psychology*, 25(3), 39–55.

Edward, M. (2014) 'Stop Prancing About: Boys, Dance and the Reflective Glance' in Special issue, *Men Doing (In)Equalities Research*. *Equality, Diversity and Inclusion: An International Journal,* 33(5), 470–479. Emerald Group Publishing. http://www.emeraldinsight.com/doi/abs/10.1108/EDI-03-2014-0018

Edward, M. (2015) 'Dance: Anarchy from the Margins and Free Expression' in Gillieron, R. and Robson, C. (Eds.) *Counter Culture UK: A Celebration*. Twickenham, UK: Supernova Books. pp. 75–94.

Edward, M. (2018) 'Dying Swans and Dragged Up Dames in the book Mesearch and the Performing Body' in Edward, M. (ed) *Mesearch and the Performing Body*. London: Palgrave Macmillan. pp. 75–93.

Edward, M., du Monceau, O., Fong, R., and Fremaux, M. (2012) *Council House Movie Star*, 25 October–11 November, Camp and Furnace, Liverpool, UK.

Edward, M. and Newall, H. (2013) *Dying Swans and Dragged Up Dames*, 3–17 September, Arts Centre, Edge Hill University, Ormskirk, UK.

Ellis, C. (1999) 'Heartful autoethnography' in *Qualitative Health Research,* 9(5), 669–683.

Ellis, C. (2007) 'Telling secrets, revealing lives: Relational ethics in research with intimate others' in *Qualitative Inquiry*, 13(1), 3–29.

Ellis, C. and Bochner, A. (2000) 'Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject' in Denzin, N. and Lincoln, Y. (Eds.) *Handbook of Qualitative Research* (2nd edition), London: Sage. pp.733–768.

Ellis, C., Jones, S. H., and Adams, T. E. (Eds.) (2013) *Handbook of Autoethnography*. Walnut Creek, CA: Left Coast Press.

Freeman, J. (2015) *Remaking Memory: Autoethnography, Memoir and the Ethics of Self.* Faringdon, Oxfordshire: Libri Publishing.

Hiles, D. (2001) *Heuristic Inquiry and Transpersonal Research*. Paper delivered at the CCPE (Centre for Counselling and Psychotherapy Education), October, London. pp.1–13.

Hiles, D. (2002) *Narrative and Heuristic Approaches to Transpersonal Research and Practice*. Paper delivered at the conference CCPE, October, London. pp.1–17.

Polkinghorne, D. E. (1988) *Narrative Knowing and the Human Sciences*. Albany, NY: SUNY Press.

Rice, K. (2015) 'Practice as Research and Ethics Reviews' in Freeman, J. (2015) *Remaking Memory: Autoethnography, Memoir and the Ethics of Self.* Faringdon, Oxfordshire: Libri Publishing. pp. 103–125.

Rubin, G. (2009) 'A Little Humility' in Halperin, D. M. and Traub, V. (Eds.) *Gay Shame*. Chicago: The University of Chicago Press. pp. 369–373.

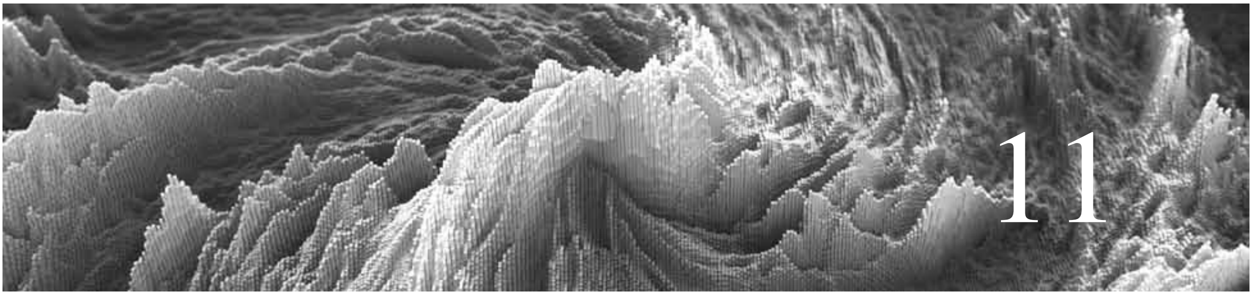
Sieber, J. E. and Tolich, M. B. (2013) *Planning Ethically Responsible Research.* London: Sage.

Slattery, P. and Rapp, D. (2003) *Ethics and the Foundations of Education: Teaching Convictions in a Postmodern World.* Boston: Allyn and Bacon.

Sontag, S. (1983) 'Notes on Camp' in *A Susan Sontag Reader*. Harmondsworth: Penguin. pp. 105–119.

Spry, T. (2011) *Body, Paper, Stage: Writing and Performing Autoethnography.* Walnut Creek, CA: Left Coast Press.

Tolich, M. (2010) 'A critique of current practice: Ten foundational guidelines for autoethnographers'. *Qualitative Health Research,* 20(12), 1599–1610.



11

Walking Interview Ethics

Penelope Kinney

INTRODUCTION

Two comments by Kathy Charmaz frame this chapter. The first came during a keynote presentation at a Qualitative Health Research Conference, 17–19 October 2016, in Kelowna, British Columbia, where she reminded me that as researchers our assumptions shape our standpoints and inform what we do. Necessarily, the methods used to collect data reflect our values. The second comment came more as a question during an informal gathering with others. She asked how the walking interview technique, documented in this chapter, gained ethics approval. The sense given during that discussion was that, in parts of the USA, Institutional Review Boards (IRBs) and, in Eastern Canada, Research Ethics Boards (REBs) take a conservative approach to what seems on the surface, to be a straightforward research method. The research discussed below focuses on forensic psychiatric clients' transitions from hospital to living in the community. The answer to the first comment is that this research was based on an assumption that forensic psychiatric client voices need to be heard within this research and if that was to occur then data collection methods needed to be ones the forensic psychiatric client could engage with. The choice of using walking interviews was a value-based one. The transition the clients underwent is fraught with insecurity and the walking interview captures their uncertain steps.

The body of the chapter provides an account of the complex process undergone in gaining ethics review from my university ethics committee and simultaneously with the hospital where the research took place. An insider status bolstered gaining approval; previously I had six years' experience as a forensic psychiatric occupational therapist. The chapter begins with defining the walking interview, recognizing its strengths and its emergent status, and outlining three of the different formats I used in my research. The goal of transporting a client interviewee to another spatial location is one of its strengths;

photo elicitation by contrast, does the same in a static form and this comparison stresses the walking interview's power of mobility. The next section, on using the walking interview, includes examples of my research in the field. The chapter ends with discussing big ethical moments that emerged when transiting the interval between hospital and the community. One was the need for audience segregation when someone known to the client interviewee unexpectedly met us; this meant having to make decisions on whether to explain what we were doing and managing spatial breaches of confidentiality when the forensic psychiatric client interviewee discusses intimate experiences in crowded spaces. Whilst these and other moments were unexpected, reflexively they were manageable. The challenges that Charmaz and others experience with North American Research Ethics Committeess (i.e. IRBs and REBs) have a great deal to do with the novelty of this robust methodology. Yet even when working with extremely vulnerable forensic psychiatric clients, ethical assurances were manageable.

DEFINING THE WALKING INTERVIEW

In recent years, the newly developing Mobilities Paradigm (Sheller & Urry, 2006) is gaining support across multiple disciplines. The mobility paradigm offers a solution to the increasing interest in aspects of life that are physically mobile and the desire to explore the link between self and place (Evans & Jones, 2011; Hein et al., 2008). There is a need to question the traditional sedentary nature of social research (Sheller & Urry, 2006) and the walking interview, a method used within the mobility paradigm, helps address that challenge.

Located predominantly within geographical literature (Anderson, 2004; Evans & Jones, 2011; Holton & Riley, 2014), social scientists' use of walking interviews (where the researcher walks alongside the interviewee) as a method of collecting data has increased over the past number of years (Butler & Derrett, 2014; Carpiano, 2009; Clark & Emmel, 2010; Hall et al., 2006; Jones et al., 2008; Kusenbach, 2003). Though mobile interviewing is still at the emergent stage as a method of data collection, its methodological roots go much deeper. Interest in how people create and use the spaces and places where they live and work can be seen in Louis Wirth's (1938) work on urbanism and Oscar Newman's (1976) work on crime prevention and neighbourhood safety. The walking interview does show great potential to shed light on how individuals frame and understand the spaces they use in their lives (Jones et al., 2008).

The walking interview can provide the interviewer access to the interviewee's attitudes and knowledge about their physical environment (Evans & Jones, 2011) and the connection or alienation they have to the social networks they have within it (Clark & Emmel, 2010). It provides an opportunity to explore issues the interviewee may have in relation to place (Jones et al., 2008). At the same time the interviewees' narratives regarding their experiences of place can be challenged and reconstructed, the walking interview provides an opportunity to explore how experiences are changed and reframed over time (Holton & Riley, 2014), thus making engaging with the interviewees' understanding of place easier. The interviewer can gain insight into the interviewees' physical capability while engaging in a usual routine, where a description in a sit-down interview may not adequately represent their reality (Butler & Derrett, 2014).

In contrast, interviewees within sedentary interviews can drift from the topic when their knowledge on the given area has been exhausted. Evans and Jones (2011) found interviewees in walking interviews tend to talk more spontaneously, and more specific information regarding the place being explored is produced. By being outside of the formal research format the walking interview can also improve the interviewees' comfortability with being in the research (Trell & Van Hoven, 2010). Talk becomes easier when walking: the natural occurrences when walking replace the unnatural pauses that happen in a sedentary interview. Crossing the road, walking up a hill, turning a corner are natural pauses that will bring the conversation back to the everyday (Hall et al., 2006). Completing walking interviews also pose a number of challenges both ethically and organizationally and these will be explored further in the chapter.

There are a number of different formats the walking interview can take and are seen on a continuum from having the route determined by the interviewee through to the route being undetermined and finally through to the route being completely determined by the interviewer (Evans & Jones, 2011). I will outline the 'going-along' interview, 'participatory' interview and the 'bimble' interview as these are the ones I reviewed for my research.

Go-along Interviews

Go-along interviews are regarded as a mix between an interview and interviewee observation. During the outing the interviewer asks questions, listens and observes the interviewee (Kusenbach, 2003). The go-along interview occurs when the interviewer accompanies an interviewee on an outing that would normally occur. The route is completely determined by the interviewee (Evans & Jones, 2011). It is important during these go-along's that the interviewer is following the interviewee in their natural environment, while they are completing their normal routines ensuring these are occurring on the usual day, at the usual time and following the usual route they would normally take (Kusenbach, 2003).

Carpiano (2009) found the go-along works to reduce the power imbalance, especially in marginalized populations, the interviewee works as a tour guide, deciding what is important and should be shared with the interviewer, allowing the interviewee to have input into the research process. Thus, the go-along interview is viewed as a more inclusive process (as opposed to the sit-down interview); it is more of a partnership.

Carpiano (2009) used the go-along interview as a unique qualitative method to study health issues in the local environment, examining the physical, social and mental dimensions of place and how they interact with each other for an individual over time.

Participatory Walking Interviews

Participatory walking interviews gain an understanding of the interviewee's sense of place and neighbourhood attachment. The interviewee has the opportunity to show their environment and explain the significance rather than using a description with the interviewer. By being in a natural environment the articulation of thoughts become easier, which in turn provides depth to the interviewers understanding (Clark & Emmel, 2010).

The difference from the go-along interview is, rather than following an interviewee on a natural outing that would have occurred if the interviewer was not present, this interview takes place while walking a route that the interviewee has determined is in their familiar neighbourhood (Clark & Emmel, 2010). The routes used for the walking interview are not to be considered representative of people's actual everyday routines and habits but rather indicative of how they think about their neighbourhoods. Interviewees determine the route, length of time and what they want to show the interviewer (Clark & Emmel, 2009, 2010).

Bimbling

Bimbling is described as the practice of going for a walk to blow off steam, that is, walking or wandering with no clear aim (Evans, 1998 cited in Anderson, 2004). Bimbling has now been used as a method for collecting data in qualitative research mainly when exploring activism and when there is a need to remove the interviewee away from an environment, which is politicized due to protests taking place (Anderson, 2004).

This ‘talking while walking’ interview is conducted in a similar fashion to the previous two methods. However, the route taken is not necessarily known by either the interviewer or interviewee. The act of walking provides the opportunity for the interviewee to recollect experiences and to articulate them (Anderson, 2004) rather than being concerned about the specific location (Jones et al., 2008).

Photo Elicitation

Photo elicitation differs from walking interviews but shares some similar elements. Similarities include providing vulnerable interviewees an opportunity to have a voice within research and allowing for the facilitation of inclusive research (Fullana et al., 2014). Those with long-term mental illness can sit passively during traditional qualitative talking interviews, waiting for guidance on how to answer questions (Erdner & Magnusson, 2011). Using photos to direct an interview can overcome the difficulty many people with long-term mental illness can have in regards to spontaneous verbal communication (Erdner et al., 2009).

The significant difference relates to mobility. Photo elicitation is a static method where interviewees sit and look at photos and recall experiences or reflect on their understandings; they are removed from the place they are looking at. The walking interview allows interviewees to engage with the place they are reflecting on while moving through and interacting with the place, and this allows for spontaneous memories that may not have occurred while sitting in a room.

Cannuscio and colleagues (2009) used a walking interview combined with photographs to explore health risks of the environment the interviewees lived in. The researcher carried the camera and took photos of areas the interviewee identified. These photos were then used to elicit further information from the interviewee in a follow-up interview. Fullana and colleagues (2014) used photo elicitation in an aim to improve the participation of people with significant mental illness in research. I believed the use of a walking interview including a camera would be beneficial for my research because it would enable me to gain a fuller picture on how the client interviewee was connecting to the community in which they were living.

TRANSITING THE HOSPITAL

Like the majority of the population, people in forensic psychiatric services undergo a variety of transitions. Many are forced upon them, and their perception, often based on reality, is that they have limited control over these processes. Moving to the community after significant periods of time in psychiatric hospitals is challenging for the majority of those making this transition (Coffey, 2012b; Grusky et al., 1985). Transitioning from a hospital setting to the community requires a person to be aware of the changes occurring and to be able to adapt to the ways of doing a task, as well as to how they think about it.

Leaving the support and structure of a ward, managing budgets, and adapting to new accommodation are just a few of the processes those leaving hospital have to make that can be challenging (Nolan et al., 2011).

Assessment and the management of risk to others is one of the fundamental focuses for mental health professionals within forensic psychiatric services (Coffey, 2012b; Doyle, 2011). Ensuring a successful outcome of transition from hospital to the community is important for both the person and the community. Keeping the community safe and facilitating the recovery of the person is a balancing act for forensic psychiatric services in New Zealand (Pouncey & Lukens, 2010; Simpson & Penney, 2011).

There is an acknowledgement by a range of authors that there is very little literature available regarding moving forensic psychiatric clients to the community. Past research has been focused on risk and recidivism and very little relates to how forensic psychiatric clients attempt to adapt and transition towards an ordinary lifestyle, leading some authors to call for research that incorporates the forensic psychiatric clients' voice (Bjørkly, 2004; Coffey, 2012a; Jamieson et al., 2006; Kaliski, 1997; Viljoen et al., 2011).

The research project aims to contribute to the body of knowledge in this field and to be of use within this clinical area of practice. The main research question asks: How do those moving to the community within a forensic psychiatric service adapt to this situational change? A number of sub-questions will also be addressed including: What influences the transition experiences of those moving to the community within a forensic psychiatric service? Do people and the environment influence how a person engages in their transition? What would transition success look like?

Gaining Ethics Approval

Gaining access to the client interviewees for this research was a complex and multilayered process. I was required to obtain ethics approval through my university's ethics committee and to gain approval and final sign-off from multiple areas within the health board within which the regional forensic psychiatric service (RFPS) was situated. The approval of the Specialist Mental Health Service (SMHS) research committee had to be sought, and once their approval was gained, I was required to obtain the approval of the RFPS's directorate. Finally, the General Manager of the SMHS was required to sign off on the research. Gaining approval for all of these points was a complex process that often took multiple paths and was not a straightforward linear process.

I estimate the process of gaining access to the client interviewees took approximately nine months. My starting point was to make contact with the RFPS, if I was to be successful then the development of the project needed to have them connected with the outcome. I spent many weeks communicating via email and telephone with the service manager. I wanted to ensure the project I was developing would gain the support of the service. The service manager advised that though the service supported the project in principle, I was required to gain the multiple levels of approval listed earlier before I could begin recruitment. I received the advice that the service supported the project in principle via an email, and this ended up being an important document that was used in my subsequent ethics application.

After approximately three months of consultation, I submitted my application to my university's ethics committee and my research proposal to the SMHS research committee. I was required to also send my completed (but not yet approved) ethics application to the SMHS research committee at the same time. The RFPS supported the use of the clinical team to identify appropriate client interviewees who were living in the community or who were on the pathway to moving permanently to the community. The clinical team had the best knowledge of the clients regarding their mental wellness and ability to engage in the research. All eligible client interviewees were invited to join though not all accepted. Each eligible client interviewee was deemed to be capable of making decisions regarding their inclusion in the research because they were either living permanently in the community, and making decisions routinely regarding their day-to-day lives, or were preparing to enter the community in the near future.

There were a number of strategies I applied to aid the approval process. I highlighted the extensive experience I had not only with working within forensic psychiatric services but specifically the service within which I hoped to complete my research. When I first made contact with the RFPS service manager, I had not met the person before as they were new to the position since I had left. That person commented to me they had 'heard good things about me', through conversations with others. My previous experience and my relationships within the RFPS were important factors in allowing me access to the clients. Though I was now an outsider, my previous insider status was what gained me access. That previous insider status also provided the RFPS with confidence in my ability to carry out this research.

I also met with the manager of the university's ethics committee prior to submitting my application. This was to reinforce my knowledge and skills in an attempt to build confidence in my ability to carry out this research. It was an important meeting as it allowed me to build a relationship with the ethics committee. The meeting gave me an opportunity to talk through some of the decisions I had made regarding my project and to discuss with the manager the support I had already from the RFPS for the project. I am in no doubt my experience of working within this specific RFPS aided in my subsequent ethics approval.

The following criteria, which match the code of practice of the safety of social researchers outlined by the Social Research Association (n.d.), were included in my ethics application and related specifically to the walking interview and the use of a camera while on the walking interview. They were included to ensure the safety of the client interviewee, the researcher and the community:

- The client interviewee would indicate what they would like photos to be taken of during the walking interview; however, the camera would be carried and used by myself. Many of the client interviewees are well known publicly due to having a high media visibility. At times members of the public monitor them so it was important they were not put in a position where there might be confusion about what they were doing.
- No photos of people would be taken, even in public places.
- The walking interviews would only occur in the hours of daylight and would not commence close to twilight.
- The walking interview would occur in a public place and would not go through isolated areas. If the client interviewee advised the only place they wanted to walk was in an isolated area, then the walking interview would not commence.
- I would meet the client interviewee at the agreed location to commence the walking distance. I would not transport the client interviewee using my personal vehicle or call them using my personal phone. The client interviewee only had my work contact details.
- Connecting to the client interviewees case manager would occur prior to the walking interview beginning to check if anything had changed for the person and to ascertain if their mental state was settled. This was a check-in only, no information regarding any information the client interviewee had shared in previous meetings was given.

Another factor I included in my project related to the selection of pseudonyms for the research. I wanted the client interviewee to select their own pseudonyms so that they felt connected to them. It was also a way for them to know which quotes came from them when they were going through the final results. They were advised not to select a name that was similar to their real name or to choose a nickname they were known as.

The final ethics approval came through a month after it was first applied for. However, the SMHS research committee wanted more information regarding the project. It was at this point that I experienced the most significant challenge to obtaining my approvals. This committee oversees all research carried out within the SMHS so my research would not proceed without their approval. There was only one qualitative researcher on the committee who was not familiar with walking interviews or how a camera might be used with them. I was advised I needed to reassure this particular member because the rest of the committee would be guided by their viewpoint.

To reassure the SMHS committee, I forwarded literature that showed successful use of both the walking interview and a camera with clients with enduring mental illness and diagnoses similar to those expected within a RFPS. Along with the literature, I also forwarded the final ethics approval I had gained from my university. Soon after these were submitted I learnt I had also gained approval from SMHS research committee. I believe two factors contributed to gaining SMHS research committee approval: the RFPS had reinforced with the SMHS research committee they were supportive of the project and wanted to see it go ahead, and my university's ethics committee had granted final approval.

It took another four months to obtain official approval from the RFPS directorate and the general manager of the SMHS. I was required to provide nothing further to aid with the approval process, this was the time it took to move between the different levels. Only after I had received the final approval from the general manager of the SMHS did I begin the process of recruitment.

USING THE WALKING INTERVIEW

The walking interviews I used for my research were a combination of the three I have outlined above. No interview was distinctly of one particular type: I found some client interviewees wanted to chat about a range of topics while we were walking rather than specifically talking to me about the location we were walking through – they were a combination of the participatory design and the bimbling walking interview. Another took me on a walk he would have done without me, on a route he usually walked on that day and time each week. Once we had arrived at the location, he wanted to show me around, keen to show me where he spent his time and to talk to me about that location. His walking interview was a combination of a go-along and a participatory design.

I carried a camera and was to take photos of areas which the client interviewee indicated were important to them. Those photos were to form the basis of a subsequent interview. I found this did not occur as I had planned. The client interviewees only occasionally indicated when photos should be taken; I found that they were looking to me to direct this process. It may have been because I was carrying the camera, so they were not as connected to the activity. Though they had been prepared regarding the use of the camera on the walk, some of the routes had changed from the original planned walk, so the client interviewee may not have had time to think about what was important on the route that we did take. The ability to think abstractly for this client interviewee group is challenging (Ferguson et al., 2009), so the idea of looking at items and relating them to the importance of their transition to the community may have been difficult too.

The following are examples from some of my walking interviews, they highlight the information that can be gathered from these interviews that do not relate to the specific content of the conversation of the interview. The pseudonyms used are the ones each of the client interviewees chose for themselves.

Peter

Peter had initially indicated he would like to complete his walking interview at the beach. We had agreed a day, time and a place to meet. That was as far as we had organized his walking interview because I had found they worked better if the walking interview was allowed to progress naturally. Peter happened to live in a flat close to another client interviewee, Sebastian. I had arrived at this location to meet with Sebastian. This was already arranged, so he was expecting me. I was scheduled to meet with Peter later that day at the beach to complete the walking interview. Peter was waiting for me when I arrived as Sebastian had told him I was coming. He requested a change in his walking interview location because his car needed petrol and he did not have finances to get more for that day. He wanted to walk around his local suburb so that he did not need to use his car. He also requested an earlier time as the weather was not great and he wanted to complete it before the rain was scheduled to arrive. I agreed to these because I could not take Peter in my personal car to the beach, the transporting of client interviewees in my personal car was not an option, as stated earlier, and this was consistent with the RFPS policy. The walk with Peter around his local suburb was nevertheless very useful and I gathered a lot of information about Peter's hopes and dreams for his future in the community by walking this new route. During the walk, I asked Peter about the beach. I wanted to know the significance of the beach to his transition, especially since we could not walk there. Peter advised he rarely went to the beach and it was not significant to him at all, in fact he said 'oh I don't really spend time there, I just thought you might like to go there'. This spoke volumes to me about Peter's interest in my experience of the walking interview and his desire to show off the points of interest of his city.

Smelly

Smelly was a client interviewee who still remained within the hospital and so our walking interview occurred within the boundaries of the hospital grounds. During the course of the research Smelly increased his time in the community to the point of being discharged to live in the community fulltime; however, at the time we completed his walking interview he was predominantly in hospital. Smelly had advised that he usually completed the walk we were to take each day and sometimes twice a day. He explained he walked the hospital grounds boundary and this usually took approximately 30 minutes. When walking with Smelly I learnt he literally did walk the boundary without ever crossing over it. At times this was beside very high fences and we would walk just a few centimetres from the fence. Even squeezing between parked cars and the fence, rather than walking around the car, to ensure he kept as close to the boundary as he could. At other times there was no fence to indicate the boundary. However, it was clear Smelly was well aware of where the boundary was. When questioned why we were walking on the grass rather than the asphalt path just beside us Smelly advised the grass was within the hospital boundary however the asphalt path was not. It was very important for a client transitioning not to be caught off the hospital grounds or access to future leaves were at risk. Smelly was aware he may be seen off the ground by members of the public and the likelihood of this being then reported to the service was high and that would then likely jeopardize any future access to the community.

Sebastian

Sebastian had recently transitioned to living in the community six nights a week when his walking interview was completed. He had moved from four nights a week to six just a few weeks earlier and spending that amount of time in the community independently was still relatively new for him. Sebastian had requested walking around the botanical gardens for his walking interview as it was a place in which he had spent significant time during his transition; he found it restful and it was a place he could enjoy. My insights on this walking interview relate more to Sebastian's behaviour on the walking interview rather than the location of the walking interview. Sebastian had been advised (as all of the client interviewees were) that at the start of the walking interview he was to direct where we would walk. I was interested in seeing what he wanted to show me rather than directing the walking interview myself. Within the botanical gardens there are multiple paths that cross each other throughout the gardens. Also the public were permitted to walk across the grass. Sebastian set off following the established paths, but I noticed as we got closer to a point where the path we were walking on either split into two or crossed another, Sebastian would slow his walking. As a result, I would slow my pace and then Sebastian would slow his pace even further. At times I would find myself slightly in front of Sebastian rather than walking beside him. I realized Sebastian was waiting for me to direct where we would walk rather than him taking this role. I immediately reminded Sebastian he could decide the direction and we would set off at a normal walking pace again in the direction Sebastian had selected. This happened a number of times during the walking interview. At times I got a sense from Sebastian he viewed the interview more like an escorted outing rather than a walk he was controlling. This may have been due to Sebastian only recently increasing the amount of time he spends in the community. When clients are in hospital and have been given an opportunity to visit the community accompanied by staff, it is the staff who will often make many of the decisions. Sebastian may have automatically returned to previous ways of being without thought and viewed myself similar to a staff member.

The insights I gained into the client interviewees' transitions to the community by completing the walking interviews was invaluable. The act of walking alongside the client interviewee allowed me to connect to their transitional journey. The walking interview provided me with opportunities to observe interactions that could not have been explained in a face to face interview or captured by using photos.

The use of the camera within my research did not prove to be as valuable as I first thought it might. I believe the camera could have been more useful had I prepared the interviewees for its use on the walking interviews better than I did. I discussed the use of the camera with each interviewee prior to them signing the consent form for the research and again immediately prior to the walking interview commencing. However, what may have been helpful was to talk through examples of how the camera could be used on the walking interview, using pre written scenarios unrelated to transition. This may have helped the interviewees with their understanding on why the camera was being used.

EIGHT ETHICAL DILEMMAS

There were many ethical dilemmas either I planned for or had to address as I became aware of them during both the walking interview and the research project as a whole.

First, I was aware that when walking in public spaces there was a likelihood that we could come across a member of the public that was known to either my interviewee or myself. Acknowledging this and putting strategies in place for managing the potential of a person wanting to speak with either the interviewee or myself was important to ensure their safety and confidentiality. Prior to the walking interview occurring we spoke about what the interviewee wanted to do if this situation occurred. We were mindful that this might be different depending on who the person was that approached. (As I was completing the research 400km away from my home, the likelihood of me meeting someone I knew was minimal and didn't occur.) Two interviewees did meet people they knew, one of the interviewees didn't want to engage with the person they knew. I stepped back so he didn't feel like he had to introduce me. The interviewee cut off the member of the public who was attempting conversation, advising them he was busy and couldn't talk. He then started walking away and I followed. We continued with our walking interview as though we had not met the member of the public. The second interviewee had a different response to the member of the public he knew. The interviewee introduced me and explained to them what we were doing. We spent only a few moments speaking before the interviewee said goodbye to the member of the public and then we continued on with the walking interview. Both meetings showed the client interviewee leading how we would respond to members of the public they knew. My engagement with the member of the public was very much directed by how the client interviewee reacted.

Second, all of the walking interviews occurred in public places and most had members of the public milling close by. The client interviewee was aware the walking interviews were being recorded as they were shown the recorder (a small digital recorder) and the lapel microphone I was wearing. The recording device was chosen as it was small and easily worn so as not to be obvious to those passing us by. The recorder was set up to only record within 1–2 metres so it picked up the interviewer's and interviewees' voices only. It was important I kept my voice at a level that was appropriate for the area I was walking through so as not to highlight what we were doing. At times members of the public were close and could potentially hear our conversation. Client interviewees were reminded of this before the interview started. There was only one occasion when we were in such very close proximity to the members of the public that our conversation could be overheard and that was when travelling in the elevator between floors of a building we were walking around. Conversation between the client interviewee and myself stopped for this time and commenced again after exiting the elevator and moving away from the members of the public. Though this had not been discussed prior to the interview it happened naturally. Similarly, the members of the public who entered the elevator with us also stopped talking for the duration.

Third, the use of the camera needed to be considered carefully. Though it was agreed that no photos of people would be taken in public spaces this did present some challenges. During one walking interview where we were walking through the botanical gardens, one client interviewee had indicated a specific area of interest. He had connections to it through his own childhood and during the walking interview he had reminisced about this place and its significance to him. However, taking a photo was going to be impossible due to the number of children that were exploring the area at the time. The photos weren't going to be used anywhere other than as a probe for the next interview; however, protecting the client interviewee and any potential negative impact on him was paramount. No photo of this area was taken. We spent more time talking about the area than I would have done if I could have taken a photo in an attempt to gather as much information as I could. Consideration of the safety of the client interviewee outweighed the benefits that would have come from taking the photo.

Fourth, transportation of the client interviewee to their walking interview location was also a challenge at times. All of the walking interviews were planned to occur away from the client interviewees' homes. This meant they were required to transport themselves to the starting point of the walking interview. Two could walk the short distance, but all others needed to either catch a bus or drive themselves to the starting point. This client group fit within the lower socioeconomic group categories and they have limited funds to spend money on extras. One client interviewee asked to change their location because of a lack of funds to fill his car with the petrol he would need to get him to his original walking interview location. I needed to be flexible to accommodate these requests as I did not want the walking interview to be a burden to the client interviewee. I could have potentially avoided this challenge if I had factored in a budget that would have provided finances to pay for petrol or taxis for the client interviewees.

Fifth, safety of myself was an ethical issue. I had a very clear set of processes in place that I followed prior to commencing a walking interview. My safety plan included checking in with staff regarding the mental wellness of the person, making sure the person was still able to attend, and checking with the person themselves to make sure they still wanted to participate. I carried a phone with me in case of an emergency and advised staff of my location. I also gave an estimation of when I would be returning although this could not be exact because the client interviewee directed the walking interview. Staff also had my contact details if they needed to get in contact with me. On one occasion I cancelled a walking interview because at my check-in with staff I was informed the client interviewee was becoming mentally unwell and they did not recommend going out with him. Though the client interviewee was still living in the community and participating in a range of activities in the community, I did take the staff's advice and waited till the client interviewee had settled mentally as I did not want to add any unnecessary pressure to the person, or put myself at risk.

Sixth, client interviewees were unable to have my personal phone number to call if they wanted to change any of the arrangements. They were heavily reliant on me making contact prior to their interview when I checked in to make sure they still wanted to participate. I did give them my work phone number; however, it was a landline and not a cell phone so once I was travelling it was difficult to get hold of me. Twice I arrived at the location to meet with a client interviewee and they were not present. On speaking with staff I found out the client interviewee had emailed me to advise they needed to change the plans at short notice because of something coming up for them; however, they couldn't ring as I was travelling already. This is another challenge that could have been overcome with forethought. If I'd had a cell phone number which I could have given to the client interviewee that wasn't my personal number, then they could have communicated with me more easily.

Seventh, as a safety precaution, I was required to ensure the walking interview did not occur during the hours of darkness or in isolated locations and on the whole this was not an issue. However, for my walk with Joe I did need to clarify what time his classes were and if I would be walking with him after twilight. Potentially, this could have impacted significantly on the walking interview as his classes were in the early evening. Fortunately, due to the season the light was not an issue; however, the walking interview could have been compromised had I not been able to walk where Joe had wanted. All of the other walking interviews were able to be carried out during the day. None of the client interviewees requested their walking interview to occur in isolated areas. None of the walking routes travelled through isolated areas. This may have been because I had discussed this with each of the client interviewees prior to establishing the rules that governed where we could walk. None of the client interviewees expressed disappointment about not being able to walk where they would have preferred.

Eighth, at times I experienced an insider/outsider conflict of interest (see Toy-Cronin, Chapter 30, this *Handbook*). Due to being employed within the RFPS almost eight years ago I had knowledge of processes within the service, I knew a number of the staff and I also knew a number of the clients who joined the research project. When checking in with staff prior to holding an interview with the client interviewee I would gain extra information about the person that I believe I would not have been given had I been unknown to the service. Knowing this information then influenced how I interacted with the client interviewee; it influenced how I asked questions. For example, when meeting one client for the first time, I checked in with the staff member regarding his mental state. I had not met the client before so I had no previous knowledge of him. I knew the staff member; I had worked with them previously over many years. I was told a lot of information about the client's index offence, what had happened and the staff member's view of how lucky he had been to get the outcome he had. They gave me information regarding the goals the client was working towards and their opinion on whether they were realistic or achievable for him. I went into the initial meeting with the client believing the information I had already gained could influence the direction the interview took and potentially taint the way I received information he gave me. I was aware of this so took reflexive measures to overcome this prejudice.

SECOND THOUGHTS

'If I was to complete this research again, what would I do differently?' is a very difficult question to answer. I believe that ensuring any plans put in place are flexible is important, as many of the factors that will impact on the walking interview will be out of the researcher's control. Making sure anticipated ethical dilemmas have been addressed and being aware there will be other ethical dilemmas that have not been anticipated but will need addressing is crucial.

Some of the decisions that I made that I would do differently include:

- I would ensure I had factored in a budget to cover petrol or taxi expenses for the client interviewees so that they were not burdened by the experience.
- I would ensure I had a method of communicating with me for the client interviewees that was simple, effective and did not cost them anything.
- Keeping the interviews flexible is important; though I had set out to use a specific type of walking interview I soon realized that this was not necessarily useful. Ensuring the walking interview meets the needs of the client interviewee and the research is what is important.
- I would spend more time discussing the use of the camera and use hypothetical examples as a way of increasing the interviewees understanding of how the camera would be used in the walking interview.

Overall, I am happy with the plans I had made to complete this type of interview with this vulnerable research population. I had anticipated the majority of the ethical issues that might arrive and had a plan in place to manage them. The last point I would make is that an ongoing relationship with the ethics committee is vital; being ready to return to the ethics committee to request amendments if necessary is helpful.

CONCLUSION

Within the chapter I have addressed the two comments used to frame this work. Ensuring the voices of the forensic psychiatric client were included into the project was important when looking at how they transitioned from hospital to the community. Including a method that would ensure their engagement was a value-based decision and successfully captured the client voices. The walking interview has a number of ethical challenges that must be addressed to ensure the safety of both this vulnerable population and the researcher. The chapter has outlined the ethical dilemmas I identified and the strategies I used to address these, providing evidence that concerns raised by universities ethics committee and the service can be successfully addressed.

REFERENCES

Anderson, J. (2004). Talking whilst walking: A geographical archaeology of knowledge. *Area*, 36(3), 254–261. doi:10.1111/j.0004-0894.2004.00222.x

Bjørkly, S. (2004). Risk management in transitions between forensic institutions and the community: A literature review and an introduction to a milieu treatment approach. *International Journal of Forensic Mental Health*, 3(1), 67–76. doi:10.1080/14999013.2004.10471197

Butler, M. and Derrett, S. (2014). The walking interview: An ethnographic approach to understanding disability. *The Internet Journal of Allied Health Sciences and Practice*, 12(3).

Cannuscio, C. C., Weiss, E. E., Fruchtman, H., Schroeder, J., Weiner, J., and Asch, D. A. (2009). Visual epidemiology: Photographs as tools for probing street-level etiologies. *Social Science & Medicine,* 69(4), 553–564. doi:10.1016/j.socscimed.2009.06.013

Carpiano, R. M. (2009). Come take a walk with me: The 'Go-Along' interview as a novel method for studying the implications of place for health and well-being. *Health & Place*, 15(1), 263–272. doi:10.1016/j.healthplace.2008.05.003

Clark, A. and Emmel, N. (2009). *The methods used in connected lives: Investigating networks, neighbourhoods and communities*. ESRC National Centre for Research Methods, NCRM Working Paper Series, 06/09.

Clark, A. and Emmel, N. (2010). Using walking interviews. *Realities*, 13, 1–6.

Coffey, M. (2012a). Negotiating identity transition when leaving forensic hospitals. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 16(5), 489–506. doi:10.1177/1363459311434649

Coffey, M. (2012b). A risk worth taking? Value differences and alternative risk constructions in accounts given by patients and their community workers following conditional discharge from forensic mental health services. *Health, Risk & Society*, 14(5), 465–482. doi:10.1080/13698575.2012.682976

Doyle, M. (2011). Risk research. In K. Sheldon, J. Davies, and K. Howells (Eds.), *Research in practice for forensic professionals* (pp. 37–59). London: Routledge.

Erdner, A., Andersson, L., Magnusson, A., and Lützén, K. (2009). Varying views of life among people with long-term mental illness. *Journal of Psychiatric and Mental Health Nursing*, 16(1), 54–60. doi:10.1111/j.1365-2850.2008.01329.x

Erdner, A. and Magnusson, A. (2011). Photography as a method of data collection: Helping people with long-term mental illness to convey their life world. *Perspectives in Psychiatric Care*, 47(3), 145–150. doi:10.1111/j.1744-6163.2010.00283.x

Evans, J. and Jones, P. (2011). The walking interview: Methodology, mobility and place. *Applied Geography*, 31(2), 849–858. doi:10.1016/j.apgeog.2010.09.005

Ferguson, G., Conway, C., Endersby, L., and MacLeod, A. (2009). Increasing subjective well-being in long-term forensic rehabilitation: Evaluation of well-being therapy. *The Journal of Forensic Psychiatry & Psychology*, 20(6), 906–918. doi:10.1080/14789940903174121

Fullana, J., Pallisera, M., and Vilà, M. (2014). Advancing towards inclusive social research: Visual methods as opportunities for people with severe mental illness to participate in research. *International Journal of Social Research Methodology*, 17(6), 723–738. doi:10.1080/13645579.2013.832049

Grusky, O., Tierney, K., Manderscheid, R. W., and Grusky, D. B. (1985). Social bonding and community adjustment of chronically mentally ill adults. *Journal of Health and Social Behavior*, 26(1), 49–63. doi:10.2307/2136726

Hall, T., Lashua, B., and Coffey, A. (2006). Stories as sorties. *Qualitative Researcher*, 3(Summer), 2–4.

Hein, J. R., Evans, J., and Jones, P. (2008). Mobile methodologies: Theory, technology and practice. *Geography Compass*, 2(5), 1266–1285. doi:10.1111/j.1749-8198.2008.00139.x

Holton, M. and Riley, M. (2014). Talking on the move: Place-based interviewing with undergraduate students. *Area*, 46(1), 59–65. doi:10.1111/area.12070

Jamieson, L., Taylor, P. J., and Gibson, B. (2006). From pathological dependence to healthy independence: An emergent grounded theory of facilitating independent living. *The Grounded Theory Review*, 6(1), 79–108.

Jones, P., Bunce, G., Evans, J., Gibbs, H., and Hein, J. R. (2008). Exploring space and place with walking interviews. *Journal of Research Practice*, 4(2), Article D2.

Kaliski, S. Z. (1997). Risk management during the transition from hospital to community care. *International Review of Psychiatry*, 9(2–3), 249–256. doi:10.1080/09540269775466

Kusenbach, M. (2003). Street phenomenology: The go-along as ethnographic research tool. *Ethnography*, 4(3), 455–485. doi:10.1177/146613810343007

Newman, O. (1976). *Design guidelines for creating defensible space*. New York: National Institute of Law Enforcement and Criminal Justice.

Nolan, P., Bradley, E., and Brimblecombe, N. (2011). Disengaging from acute inpatient psychiatric care: A description of service users' experiences and views. *Journal of Psychiatric* *and Mental Health Nursing*, 18(4), 359–367. doi:10.1111/j.1365-2850.2010.01675.x

Pouncey, C. L. and Lukens, J. M. (2010). Madness versus badness: The ethical tension between the recovery movement and forensic psychiatry. *Theoretical Medicine and Bioethics*, 31(1), 93–105. doi:10.1007/s11017-010-9138-9

Sheller, M. and Urry, J. (2006). The new mobilities paradigm. *Environment and Planning A*, 38(2), 207–226. doi:10.1068/a37268

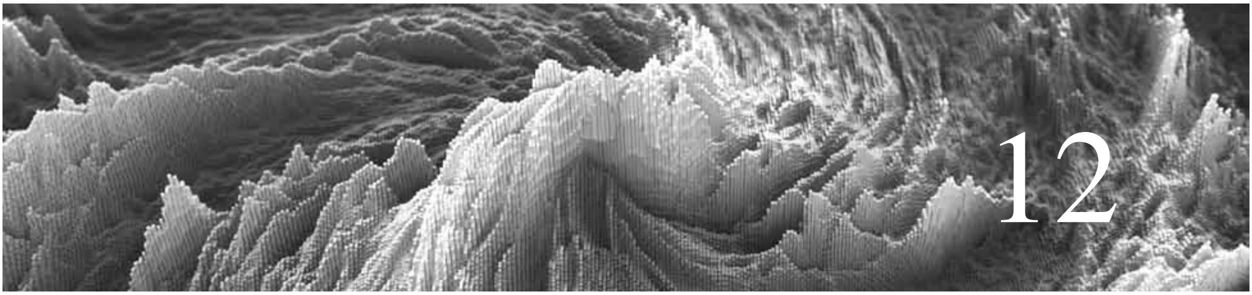
Simpson, A. I. F. and Penney, S. R. (2011). The recovery paradigm in forensic mental health services. *Criminal Behaviour and Mental Health*, 21(5), 299–306. doi:10.1002/cbm.823

Social Research Association (n.d.). *Code of practice for the safety of social researchers*. Retrieved from http://the-sra.org.uk/sra_resources/safety-code/

Trell, E.-M. and Van Hoven, B. (2010). Making sense of place: Exploring creative and (inter) active research methods with young people. *Fennia-International Journal of Geography*, 188(1), 91–104.

Viljoen, S., Nicholls, T., Greaves, C., de Ruiter, C., and Brink, J. (2011). Resilience and successful community reintegration among female forensic psychiatric patients: A preliminary investigation. *Behavioral Sciences & the Law*, 29(5), 752–770. doi:10.1002/bsl.1001

Wirth, L. (1938). Urbanism as a way of life. *American Journal of Sociology*, *44*(1), 1–24. Retrieved from http://www.jstor.org/stable/2768119



12

Ethics and Power in Visual Research Methods

Anne Harley and Jonathan Langdon

INTRODUCTION

The increasing interest in, and use of, visual methods within qualitative research is partially the result of concerns about power relations between researcher and participant; and the methods themselves have also created specific ethical issues. This chapter considers some of the ethical issues related to visual research, arguing that much of the literature related to this fails to sufficiently theorize power in relation to ethics. Using examples from different contexts within different disciplines, as well as case studies drawn from our own work, we argue for an ethics of power that rests on an axiom of equality of all human beings.

The chapter begins by situating our discussion of ethics in the literature on visual methodologies. It then delves deeper into ethical concerns specifically connected to such methodologies. We argue that central to any consideration of ethics is power. The next section of the chapter articulates how we understand power in this context. The chapter then grounds these discussions in two case studies, one from visual research done in South Africa and one from visual research in Ghana. Finally, we explore what taking power and ethics seriously means in visual methodologies. In this discussion, we present a series of questions those engaging in visual research methodologies might consider before embarking on their use.

VISUAL RESEARCH METHODS

Whilst visual methods were used within the field of sociology and anthropology relatively early on (Packard, 2008; Wiles et al., 2008), over the last two decades, visual methods have become increasingly popular in social research in a variety of settings and disciplines (Wiles et al., 2008; Tarr, 2015); and there has been a burgeoning literature on such methods (Pain, 2012).

There have been different accounts provided for why this is. Some writers propose simply that such methods are increasingly possible because of technological advances, which have made it possible to create, access, and disseminate visual images far more easily and cheaply than ever before (for example, the built-in cameras on cell phones) (Packard, 2008; Tarr, 2015). Others suggest that the growing critique of positivist/empiricist research approaches by, inter alia, post-structuralists, feminists and queer theorists, have seen the emergence of more reflexive, participatory, methods, including visual ones (Packard, 2008). Linked to this is the suggestion that the increasing popularity of visual methods is related to inherent qualities of the methods – Gallagher (2008), for example, argues that the increasing use of these methods are based on two (problematic) claims made about such methods, that is, their epistemological validity, and their ethical merits. In a study of studies using visual methods, Pain (2012) found that these two categories of reasons were the most cited reasons for why researchers used visual methods.

In terms of epistemological claims, this rests partly on the broader claims made about participatory methods, that they 'offer epistemological advantages over traditional methods … [producing] "better" knowledge than other techniques' (Gallagher, 2008: 139); knowledge which is more authentic, more nuanced, allowing a deeper understanding of complex phenomena. However, many writers claim that visual methods specifically offer even more, 'promoting reflections that words alone cannot' (Clark-Ibanez, 2007: 171, cited in Guillemin & Drew, 2010: 176); that, by engaging the brain in a different way, they allow a different way into looking at issues (Gauntlett & Holzwarth, 2006, cited in Guillemin & Drew, 2010); and that the process can help bridge cultural (Samuels, 2007, cited in Guillemin & Drew, 2010) or other divides between researcher and researched, thus '[allowing] access to previously unattainable information, perspectives and knowledge' (Packard, 2008: 64). 'Where there is a status difference between parties, photographs can provide a neutral ground and something common to talk about' (Barrett, 2004: 148). This leads to the second claim, according to Gallagher (2008), concerning the ethics of visual methods, in particular their relation to power.

The growing use of visual methods is clearly tied to the growth in participatory research, which is concerned with power relations in the research process: 'Participatory visual methods have been developed as part of an explicit attempt to decrease the power differential between the researcher and the researched' (Packard, 2008: 63). Fine et al. (2004) have argued that participatory research should in fact be the norm to move away from objectivist research, and towards research that is mutually owned. Participatory methods are thus, according to this argument, 'more ethically acceptable than traditional methods' (Gallagher, 2008: 139), precisely because they give 'a voice' to those who are frequently marginalized. This effect is magnified by using visual methods: 'using visual methods provided participants not only with the opportunity of documenting what is meaningful to them, but allows participants to express the unsayable' (Guillemin & Drew, 2010: 178). Such methods are thus 'offered as an emancipatory alternative' (Gallagher, 2008: 139).

This chapter focuses primarily on the ethics of using various visual research methods, but it is worth summarizing briefly what visual research methods actually are. Prosser (2007, cited in Wiles et al., 2008) argues that there are four types of visual data – 'found', 'researcher-created', respondent-created' and 'representations'. These data are collected/created using a number of different methods (and new methods are being developed all the time). Guillemin and Drew (2010) report that participant-generated visual images are of increasing interest to researchers in terms of the analysis and interpretation of these images, rather than the images per se. Currently, literature on methods related to photography dominates.

One of the most-used visual methods is that of photo-elicitation. In this method, participants discuss photographs, which might be taken by themselves, or provided by the researcher, as part of a research interview which covers 'why they had made them, how they were taken, as well as explaining what was being conveyed within individual images or in their image series as a whole' (Guillemin & Drew, 2010: 176). The method has been used with both children and adults, in a variety of settings, to look at a range of issues (Guillemin & Drew, 2010).

Linked to photo-elicitation is photovoice. In theory, this involves research participants (individuals or groups) taking photographs of whatever they are prompted to consider by the researcher (this may be very specific or more open). Participants are trained as necessary. The photographers are then asked to talk about the photographs they took. In this way, people are able to record and reflect what they see as the most important information; and then enter into a dialogue among themselves, and with the researchers. This dialogue enhances the researchers' understanding, as well as their own. Photovoice has become an increasingly popular research tool; Catalini and Minkler (2010: 447, quoted in Harley, 2012: 323) report that 'the practice of photovoice is growing rapidly and the photovoice literature is proliferating'. Reviews of studies using the method show that photovoice has been used with participants of all ages, in different parts of the world, to consider a variety of issues, though most issues relate to health and social justice (Catalini & Minkler, 2010; Hergenrather et al., 2009; both cited in Harley, 2012). Although most of the studies use a fairly similar process, Catalini and Minkler's review found that the majority alter the original method to suit their specific project. Thus, not all include training or group discussion of the photographs (although most include both).

Another popular visual method is that of asking participants to draw something in response to a specific question or themes provided by the researcher; and then talk about the drawings (what they show, and why the participants drew them). Whilst much literature relates to research with children, this method has been used with adults. Guillemin (1999, cited in Guillemin & Drew, 2010), for example, worked with women on their experiences of menopause.

Other visual methods include, inter alia, video diaries (for example, Bates, 2013); model-making (for example, Cox et al., 2013); participatory mapping, which can include the creation of spatial maps (for example, Literat, 2013), or conceptual maps (for example, Bahn & Weatherill, 2011); and so on.

It is clear then, that visual methods are indeed being used across a wide variety of disciplines and settings, with different participants.

ETHICS AND VISUAL RESEARCH METHODS

One of the reasons given for the growth in interest in visual research methods relates to claims made about how such methods are intrinsically 'more ethical' because of the 'moral imperative' of giving people normally marginalized/ excluded/ silenced a 'voice' (Gallagher, 2008). However, there is also an acknowledgement that these methods themselves give rise to specific ethical issues: 'In this [kind of] research, the participant is actively engaged in the process of production and interpretation of the visual image as data. What does this engagement entail and what are its consequences for the participant, the researcher and the research?' (Guillemin & Drew, 2010: 175).

Visual research methods, it is argued, add a new layer of complexity to ethical issues in qualitative research, and raise ethical issues previously unexamined, because visual images are different from other kinds of data: 'Ethics become of greater concern in social research because of the power of the visual, the power of photographs, and the ambiguities, ambivalence and resulting questions of responsibility' (Papademas, 2004: 123).

All research needs to consider ethical issues in relation to both the process of doing the research, and its product. This is equally true of visual methods: 'We need to give as much attention to the processes of image production as to the image itself' (Guillemin & Drew, 2010: 175) (although this varies slightly across methods – for example, in some methods the image produced is tangible, publishable, and easily disseminated; in others, the image may be destroyed as soon as it is created). The process of making images, and the images themselves, however, are inextricably linked:

> [the] process of image production and interpretation may result in the participant reconsidering their understanding of the research in ways that they may not have anticipated or necessarily be comfortable with. This is particularly relevant if the images are to be disseminated or published in public. (Guillemin & Drew, 2010: 175)

Ethical issues are also bound up with methodological ones. For example, Guillemin and Drew (2010) report that in a study where people were required to draw, a common response was 'I can't draw', followed by expressed embarrassment. Participants had to be given time to reflect, silence, and encouragement. This is a methodological issue. However, it potentially becomes an ethical issue – is it okay to ask a person to do something that makes them uncomfortable? In her study in a needle-exchange, in reflecting on why women seemed (initially) reluctant to be photographed, Barrett (2004) wonders whether this might be because women are inherently more averse to being photographed than men. This is a methodological issue; but it clearly raises a number of ethical issues related to how women perceive themselves and their bodies, and how researchers should deal with this. Where researchers are producing an image, some have reported feeling uncomfortably invasive when they were the ones taking photographs. In her study, for example, Barrett says, 'I felt as [if] I was using underhanded means for invading the space and privacy of people in a precarious situation. Collecting data in the special environment of the needle exchange required delicate balancing of the need for obtaining information and photographs with respect for the human subjects of the research' (2004: 149).

Whilst some ethical issues raised by visual methods concern the process of conducting research, most of the ethical issues identified by visual researchers relate to the product, in particular issues of consent, confidentiality and anonymity. Tarr (2015) argues that the process of obtaining informed consent is complicated by visual research. This is because it is not always possible to get this for everyone in a photograph. Anonymity is also a fraught issue – it is very hard to anonymize photographs; the background can give a lot away, and pixelating faces or using a black bar is problematic because this is often associated with criminal activity; and because people may want credit. Barrett (2004) argues that when a researcher is working with people who are stigmatized, the issue of anonymity becomes even more of an issue. There is also the issue of who owns an image that has been created. Legally, it is usually the person who created it; they may consent to the use of the image, but a range of difficult issues relate to the obtaining of consent (we would argue that beyond this issue of legal ownership is an even more important issue of 'ownership' in an ethical sense). There are also issues attached to the display of images. Is it appropriate to display or publish these? Must the aesthetic quality be good? Who chooses what to show, and what not – the researcher or participant? As Prosser, Clark and Wiles (2008) report, many communities have been very upset with how they have been portrayed. Barrett (2004) also reflects on the possibility that people's feelings about whether or not images of themselves should be published might change over time – someone who might be happy to be photographed at a needle-exchange at the time, might feel very differently some years later.

Because of the kinds of ethical issues raised specifically by visual methods, not surprisingly there has been an increase in interest in research ethics related to these methods. For example, Prosser, Clark and Wiles (2008) argue that it is a widespread proposition that whilst most visual researchers try to act ethically, they are unsure about how to do this. The past decade has thus seen the development of a number of codes of practice by, for example, the British Sociological Association's Visual Sociology Study Group (BSA-VSSG, 2006) and the International Visual Sociology Association (Papademas & IVSA, 2009); a special issue of the *Journal of Visual Studies* devoted to ethics (Papademas, 2004); and a special report on *Visual ethics: Ethical issues in visual research* for the UK's National Centre for Research Methods (Wiles et al., 2008). In addition, those working with specific visual methods have also considered ethical issues related specifically to that method. This is particularly the case with photovoice. Tolich argues that photovoice is an 'exemplar of anticipatory ethics' (2012: 1600).

The guidelines, reports and discussion tend to focus attention on the product of visual research – the images themselves, and how they are published, displayed and distributed. This is because, as Wiles et al. (2008: 3) argue, the main issue is 'the types of visual data that produce visually identifiable (or potentially identifiable) individuals'. Even ethical concerns related to the actual process of making the images still tend to focus on the final product. In the BSA guidelines, for example, a single clause considers the potential effects of the method itself:

> 27. Members should note that in various cultures, certain visual research methods may offend the research setting and participants. For instance; the use of photo-documentary in aboriginal communities, or the use of write-and-draw techniques to explore notions of deity in Islamic communities. In these cases the researcher(s) should subject the research strategy to a high level of critical scrutiny and seek advice or comment from a professionally recognized ethics board. Issues that may arise include risk of censorship, threats to freedom of academic speech and offending a community. (BSA-VSSG, 2006)

The guidelines, and the report, tend to focus on extrinsic ethical issues – consent/harm, confidentiality and anonymity/privacy. Edwards and Mauthner (2002) argue that many research ethics guidelines are the result of a concern with litigation; they suggest that a common concern in guidelines appears to be the contract between the research funder/sponsor and the research. 'The aim appears to be to avoid ethical dilemmas through asserting formalistic principles, rather than providing guidance on how to deal with them' (Edwards & Mauthner, 2002: 17). This raises the perennial issue of procedural ethics as opposed to ethics in practice (Guillemin & Gillam, 2004), procedural ethics being those ethical issues that arise which were not predicted by the researcher or research ethics committee at the time of review. Since ethical issues arise throughout the research process, from conceptualization and design, through data gathering and analysis, to the reporting/dissemination phase, these guidelines only go part of the way to helping researchers with the very real ethical issues they encounter. As Tolich (2012) argues, we have to take responsibility for unforeseen ethical issues that emerge in the field. This is something Barret faced in her study: 'Before the onset of my research I certainly had considered the ethical issues around photographing clients [at a needle-exchange], but facing the issues head on became problematic, both emotionally and on a practical level' (2004: 145). So, how do researchers navigate this difficult ethical terrain?

Whilst there is some difference in categorization and naming, research ethics literature tends to classify approaches to research ethics very similarly, with three dominant models identified:

In the *deontological* model, research is driven by externally defined, universal principles such as honesty, justice and respect. This model argues that these principles must govern the researcher's decisions and actions. The ethics of a particular piece of research is thus judged on its intent, not its outcomes (Edwards & Mauthner, 2002). Individual circumstances and context are not seen as pertinent (Boser, 2006). Kvale (cited in Edwards & Mauthner, 2002) comments that this approach, when taken to the extreme, can suggest that as long as you have acted right, the project is ethical, no matter what the consequences are.

The *consequentialist* model places the emphasis rather on the consequences, judging the ethical merits of a piece of research on the 'goodness' of its outcomes (Edwards & Mauthner, 2002). This would take into consideration a specific context and circumstances, and so a standardized set of rules is thus rejected (Boser, 2006). As Edwards and Mauthner (2002) comment, taken to extremes, this could be seen as 'the ends justify the means'.

The *principalist* model combines elements of the previous two. Principles such as autonomy (which relates to things like voluntariness, informed consent, confidentiality and anonymity); beneficence (the responsibility to do good); non-maleficence (the responsibility to avoid harm); and justice (benefits and burdens of research must be equally distributed) are used to guide ethical decisions, accepting that they may conflict with each other (Wiles et al., 2008). This model is one of the most commonly used by institutional ethics committees and professional associations.

These approaches – often termed 'justice approaches' – have been critiqued by many for considering research as 'value-free'; hiding the power relations between researcher and researched (Edwards & Mauthner, 2002). 'Professional association ethical statements also place an emphasis, in an absolutist way, on researchers' responsibilities for ensuring informed consent to participation in research, protecting research participants from potential harm (and sometimes also wider society), and ensuring their privacy by maintaining confidentiality and anonymity' (Edwards & Mauthner, 2002: 17). This implies an either/or approach; and that it is possible to sort out ethical issues at the start; 'and that an ethics committee sanctioned project is by definition an ethical one' (2002: 17). Some of the models have also been criticized from post-structuralist/post-modern perspectives for being 'universalistic'.

POWER, ETHICS AND VISUAL RESEARCH METHODS

One of the key concerns raised by researchers in terms of research ethics is that of the researcher-participant relationship; much of the research ethics literature is about this. Edwards and Mauthner (2002: 17), for example, say that social researchers' concern with ethics is 'rooted in a genuine and legitimate concern with issues of power'. This is particularly true of those working within a critical/emancipatory paradigm; even more so when researchers are working with those considered relatively less powerful; and is one of the key reasons for why participatory research methods were developed (Gallagher, 2008). Not surprisingly then, this is an issue which is also a focus of attention within the literature on visual research ethics.

Part of the reason why there has been such a dramatic increase in the use of visual research methods is precisely because of claims made about how such methods help deal with issues of power (Packard, 2008). Visual methods are described as a 'tool of empowerment enabling those with little money, power or status to communicate' (Hurworth, 2003: 3, cited in Packard, 2008: 64), because 'participatory visual methods offer a way of transferring power and authority from the "researcher" to the "participant"' (Packard, 2008: 68):

> By fostering participation, these methodologies can be empowering, giving voice to those who may not otherwise be heard … [and providing] participants with the opportunity to … portray what is often difficult to express in words. (Guillemin & Drew, 2010: 177–8)

Some writers, however, have questioned the claim that visual methods are inherently 'empowering', in response to their own experiences in using such methods (eg. Gallagher, 2008; Packard, 2008; Harley, 2012).

For example, in his photovoice study with the homeless in downtown Nashville, Packard (2008) asks whether visual methods really 'help researchers to form a more equitable partnership with research participants' (p. 63). Packard gave cameras to the chronically homeless, and asked them to photograph things that were important in their daily lives. He then used photo-elicitation, getting them to talk about the images they had captured. He argues that 'neither [taking photographs or talking about them] *inherently* reduces the power imbalance between researcher and participant' (p. 65). Both could be done in 'traditional' ways (which entrench uneven power relations); although Packard asserts that the method does have the potential to reduce this imbalance to a far greater extent than many other methods. Guillemin and Drew (2010) also point out that participants often take photographs of what they *think* they should show (or what they think the researcher wants them to show), and thus the method does not necessarily mean that the 'voice' of participants is heard.

Packard points to some of ways that the method might in fact entrench power relations – for example, when the researcher has to train the participant in using the method. In his study, one participant was embarrassed by the quality of the photographs he managed to produce. 'In order to equalize power relationships in a project, technical competencies must be similar. An unequal power dynamic is immediately and irrevocably established the moment the researcher must instruct a participant on how to operate a piece of equipment' (Packard, 2008: 64–5) (and yet this is a 'built-in' procedure within the photovoice method). As we have seen, adult participants may be reluctant to draw (Guillemin & Drew, 2010) – asking them to draw may make them feel embarrassed or ashamed, thus entrenching unequal relations.

Gallagher (2008) raises questions about researcher-participant power relations using participatory methods in general, rather than specifically visual methods. In his participatory study with children, he argues that 'participatory techniques may reinforce rather than challenge hierarchical power relations' (p. 137). Part of his concern is simply with the way many researchers conceptualize power – an issue we will explore further.

The concern with power is precisely what has driven many feminist researchers to argue for an entirely different approach to research ethics, what they call an ethics of care, in contrast to the justice models (deontological, consequentialist and principalist). This model emphasizes the relationship between the researcher and the participant, emphasizing care and responsibility and social values. Porter (cited in Edwards & Mauthner, 2002) suggests that the model rests on three interrelated features – personal experience, context, and a nurturing relationship. According to this, ethical perspectives are contingent, affected by daily experiences of social power (gender, class, ethnicity, etc.). Different contexts also create different ethical dilemmas and different choices in resolving these. Such dilemmas are rooted in the specific, emotional, relationship between the researcher and the participant, and thus must be dealt with carefully. This model is thus far more cognizant of issues of power, as well as recognizing the role of emotions in the ethical process (Edwards & Mauthner, 2002).

The ethics of care model rests on the work of feminist writer Carol Gilligan, who argues that girls and women operate in a different ethical space from boys and men, since they are constantly dealing with the dilemma of their own desires in tension with the needs of others and the responsibility of care for others that they feel (Edwards & Mauthner, 2002). Norman Denzin (cited in Edwards & Mauthner, 2002: 23) used Gilligan's work to argue for an alternative 'feminist, communitarian ethical model'. Patricia Hill Collins (cited in Edwards & Mauthner, 2002), writing from a Black feminist position, further developed the model. She argued that there are four criteria that should be used in interpreting claims about truth and knowledge:

- the primacy of lived experience
- the use of dialogue in assessing knowledge claims
- an ethic of caring
- an ethic of personal accountability.

Denzin asserts that emotions need to be privileged in ethical decisions. Denzin's position has, however, been critiqued by others, including Young (1997, cited in Edwards & Mauthner, 2002), who suggests that Denzin assumes a symmetrical relationship. Rather, one needs to work from 'asymmetrical reciprocity' – assume asymmetrical relations, and be open to asking and listening. It is this issue of power and power relations that make us feel that this model does not go far enough because it is still based on problematic assumptions about the nature of power.

Although power is frequently referred to, the exact nature of power, and power theory, is frequently absent from literature on research ethics. Rather, as Gallagher (2008) argues, power is often simply presented as domination, and hence finite – a commodity possessed by a dominant group, and not their subordinates. So dealing with power in the researcher-participant relationship means finding ways to share power, or pass on some power to the participant/s (commonly called 'empowerment') – something which, as we have seen, participatory and visual methods are claimed to do. Gallagher (2008) problematizes this, finding in his study that the participants (children), far from being powerless, 'exploit, appropriate, redirect, contest or refuse participatory techniques' (p. 137). There was no point in choosing a method to 'give' them power – they already had it, and used it:

> 'I want to end with a plea for a more careful thinking about the relationships between power, resistance and domination. I am concerned that power is often seen as a bad thing by researchers: an instrument of oppression, something to be worked around, reduced or, in the ideal case, removed altogether'. This means looking to alternative understandings of power. (Gallagher, 2008: 147)

As Steven Lukes argues:

> How we think about power may serve to reproduce and reinforce power structures and relationships, or alternatively it may challenge and subvert them. It may contribute to their continued functioning, or it may unmask their principles of operation, whose effectiveness is increased by their being hidden from view. To the extent that this is so, conceptual and methodological questions are inescapably political, and so what 'power' means is 'essentially contested'. (2005: 63)

In a departure from the classic understanding of power as dominance, some feminist writers have suggested a different way of looking at power. For example, Hanna Pitkin (1972: 276) argues that the word 'power' in French (*pouvoir*), from the Latin (*potere*), means 'to be able': 'That suggests … that power is a something – anything – which makes or renders somebody able to do, capable of doing something. Power is capacity, ability, or wherewithal'.

These feminist writers say that by reconceptualizing power as a capacity or ability, it is possible to see power as empowering or transformative of both oneself and others. Power can then bring about meaningful change, particularly when it is done collectively with others. This means that we can see ourselves as potentially or actually powerful, as having agency, rather than as always the subjects in unbalanced power relations.

Unfortunately, much of the literature on research ethics and power, we would argue, tends to deny this agency, thus reinscribing unequal relations of power. This can be seen in the claims made about how visual methods give (relatively 'powerless' people) a 'voice'. This assumes that people do not already have a voice, and are not already using it. We're not at all convinced people don't have a voice. Of course they do – any quick look at the level of protest going on all over the world by those so often referred to as 'marginalized', 'powerless', 'voiceless' tells you that. For us, the issue is to shut up and listen. When researchers position themselves as necessary for this voice to be expressed, or to be heard, they simply reinforce their own power and agency and undermine that of the 'participants'.

Connected to this assumption of people being 'voiceless', is that of people lacking the agency to think through their own experiences and theorize these on their own – in stark contrast to the researcher. This is evident even in the writing of those specifically troubled by issues of power in research. Packard (2008), for example, says of his research, 'Almost immediately, the main strength of my method – giving voice to the voiceless – was undermined because of the extreme marginality of my participants and the inherent power discrepancy between a housed researcher and the homeless participant' (p. 74). He makes an immediate assumption that he has more power. One of his conclusions from his experience is that 'Expecting to have one's voice heard and opinion count is a learned skill' (p. 74) – his participants had 'neither the knowledge nor the power to fulfil this role' (p. 75) (in fact, in his study he recounts the opposite – the way the homeless decide whether to participate or not; and how; and how much). Marshall and Batten (2004) also assume this state of powerless/lack of agency of 'the researched'. They argue that many participant groups – Aboriginals, poor, gays and lesbians, youth, the marginalized – lack power, whereas, 'As members of colonial cultures, researchers have traditionally held power in forms of money, knowledge, and "expertise" over their human subjects' (2004, para 17). Even the IVSA statement talks about 'empowering the powerless' (Papademas & IVSA, 2009: 255). Again, this is at odds with all of the evidence we have in this 'revolting' world, as Michelle Fine (2011) puts it. In South Africa, various social movements specifically take on this position, asserting 'We are poor, not stupid' (Cassiem, 2007), and demanding to be treated as thinking beings with the agency to theorize their own struggles and determine their own futures: 'Our masses are not just bodies without land and houses and bodies marching on the street. We can be poor materially, but we are not poor in mind … Some of the intellectuals understand that we think our own struggle. Others still don't understand this' (Zikode, 2006). Social movement militants thus insist on a different way of doing research, from both themselves and others:

> On the question of the real meaning of participatory research, … the researcher mustn't come with their own solutions but instead must be unbiased and flexible and finding out how the community thinks and is planning to address their own issues. One of the benefits of participatory research and development is that it can emphasise that poor people are competent and can do much of their own investigation, analysis and planning. (Figlan et al., 2009: 63)

Like Mohan (1999, quoted in Gallagher, 2008: 143), we need to 'acknowledge that those we view as powerless are not'.

We thus argue for an ethics of power, which starts from an axiom of equality, as expounded by Jacques Rancière (1991). Rancière argues that we are all *already* equal (although obviously we are not treated this way, and do not count this way); and we need to use this as our point of departure. Everyone in this world counts just as much as any other person, whatever their gender, race, ethnicity, geography, sexuality, class position. Everyone is a thinking, intelligent being. When we assume that someone needs some kind of special treatment or research method, we reinscribe the notion that they are somehow 'less than' – less intelligent, less capable, and so on. This requires us to really interrogate why we use specific methods, including specific visual ones; and in particular whether what we claim about them (their epistemological validity and ethical merits) is actually true.

Thus one question we have is the same as Packard's (2008: 67): 'But why photography? Is it necessary or even beneficial to employ visual methods here? Could the same information not be obtained by simply walking around with the participant while observing and talking with them?'. Packard argues not, reaffirming the power of this visual method – but we're not so sure. As we have seen, one of the key claims made about visual methods is about how they help us hear another (relatively powerless) 'voice'. However, increasingly, the literature warns that it is important not to simply assume the meaning of an image, but rather to get the participants to talk about the images they have created, and two of the most used methods, photo-elicitation and photovoice, both rely on this. This begs the question – Why not simply ask, instead of involving images? The claim is made that photographs allow people to say something they would otherwise find difficulty expressing – but what magic process suddenly allows them to speak after looking at the photograph/image? Barrett's haunting hope – 'that they did not avoid coming to the needle exchange because of my presence there' (2004: 149) – really does require us to think carefully about how necessary it actually is to use some visual methods.

And if the process of creating and reflecting on images really do help people to say something they might otherwise not have been able to say, fine – but then why is it necessary to publish them? As has been seen, the product of research using visual methods is one of the primary areas of ethical concern; and much literature proposes anonymizing visual data through, for example, in the case of photographs, pixelating faces or using a black bar to cover features. As Prosser et al. (2008) ask, what is the point of displaying faces that have been made unrecognizable? In addition, increasingly, technology has meant the researcher and participant easily lose control over how an image is disseminated, interpreted, reused (Prosser et al., 2008). We think publishing images used in visual research has far more to do with research 'trends' and 'fashions', and a lot less to do with actual relations of power, than is claimed.

Our ethical task then, as critical researchers, is to work from an assumption of equality of worth and intelligence (research participant as a thinking agent, as opposed to a hapless, unintelligent victim), and ensuring that those we work with in our research have control over the entire research process, from its initial design, to the collection of data, to the analysis, to the dissemination. This means working from values like dignity, respect, that people think, that then forms a useful basis on which to make ethical judgments. Our own work has made us rethink the process and product of visual research, and question the claims made about it in terms of power; and then attempt to use visual research in a different way, using an ethics of power.

POWER, ETHICS AND VISUAL METHODS IN PRACTICE: CASE STUDIES

South Africa

In the mid 2000s, one of us was involved in research intended to examine the extent to which HIV and AIDS are barriers to learning for children and adults, and how they interact with other exclusionary factors or other barriers, in a particular largely rural community (Harley, 2012). The project hoped to extend our knowledge of HIV and AIDS in education at a local level, and to inform school and community policies and strategies in the community.

A variety of methods were used in the study, including photovoice, which was used with three separate groups of research participants: volunteers at a local drop-in centre; members of a support group for people infected and affected by HIV and AIDS; and local Community Health Workers. In each case, we followed the basic photovoice process – training participants in the use of disposable cameras, allowing them time to take photographs, collecting the cameras and developing the film, and finally running a workshop with each group of participants on why they took the pictures they did, and what they thought they showed.

The data arising out of this process consisted of the photographs, participants' written notes about each one, and transcripts of the workshops. The photographs revealed the ways in which the context – of disjointed families, high unemployment levels and low income, and the legacy of violence – directly impacted on the ability of children to attend school, and the extent of this. Thus, the method literally made visible the way in which this community experiences barriers to basic education (including HIV and AIDS) and how these barriers interrelate. The photovoice findings as a whole were confirmed by the data sets deriving from other research methods used in the project as a whole, showing the reliability of the photovoice data (but also questioning the necessity of photovoice as a method).

Photovoice appealed because of the ways in which it subverts researcher-researched power dynamics, but also because of the power of the image, and its potential for political purposes – to show how the 'new' South Africa perpetuated and entrenched poverty and marginalization. The photographs produced indeed did this. However, although all of the basic requirements of ethical practice as regards the method and the university's research regulations were met, the method raised a number of questions about the nature of researcher power and the nature of research ethics.

Ethical concerns related to the nature of images per se (the product), but also to the method (the process). Many of the photographs taken in the project were of people, people who are living extremely vulnerable lives – people in poverty, in crisis; children who have been abandoned, have suffered unimaginable loss; children who have been traumatized by violence. It is their faces we look at when we look at the photographs. Writing about the marginalized, quoting from interviews can be powerful – but somehow not as powerful as an image. This is the very strength of the photovoice method; but also its most disturbing feature. Photographs last much longer than the moment they capture, something which people recognize, which is why even photovoice pictures have a posed quality about them. Can they ever really be a true reflection of a (moment of) reality? And once the photographs exist do they not take on a new reality of their own? Once in the public space, can that reality not be manipulated, be used (and misused)?

In terms of the process, cameras create a distance, however momentary this may be, between the viewer and what is being viewed. The technology objectifies. How much more Object can one become than being the subject of a photograph? By giving certain categories of participants (the volunteers or support group members or community health workers) potentially powerful technology to 'image' the reality of life in the community, did we not simply replace one level of power (ours) with another (theirs)? 'And is getting consent really enough? To what extent can the subjects of the photographs taken in the project really be said to be in a position to exercise full choice in the matter … when they are being photographed by the people who bring their food parcel each month, who provide them with support and help in caring for the sick and dying? And when the letterhead on the piece of paper they are given (and may not be able to read) is that of a university?' (Harley, 2012: 334).

Kellehear (1993) argues that too often research ethics concentrate on the researcher-researched relationship, rather than the researcher-rest of the world. We would argue that even more important is the *researched*-rest of the world relationship. If our aim is not to speak on behalf of the poor and oppressed, but attempt to allow them to speak on behalf of themselves, then why do we publish their photographs, over which they then have no control in terms of interpretation and distribution? Surely not 'for their own good'?

In reflecting on the project, one conclusion was that, if our goal is really emancipatory, photovoice should rather be used to allow others – community members, the poor, women, whoever – to take photographs, and then show them to themselves. The images could then be used in a truly democratic space as Freireian codes, to be analyzed to uncover the multiple layers of oppression the photographs truly represent, and hence allow true conscientization, and enable resistance and subaltern struggle.

Ghana

Another of us was involved more recently in using visual methods in a study of social movement learning in Ada, Ghana. This case provides an illustration of a conscious awareness of power and ethics in such methods, and an alternative way of using them to address some of the above concerns. Informed by differentiating movement-articulated, as opposed to researcher-defined, Participatory Action Research (PAR) (Choudry & Kapoor, 2010), this study is with a movement defending artisanal salt livelihoods from West Africa's largest salt yielding lagoon, the Songor, in Ada. The study is now in its sixth year (cf. Langdon & Larweh, 2015). All ethical processes within the research, including the visual method process, are orally discussed in movement meetings, with collective decisions arising on the use of recordings, movement actions, learnings and outcomes (cf. Langdon & Larweh, 2015), as well as the use of visual representations. The research with the movement has also been through a formal university ethics board process, with an emphasis on oral recording of consent, but also recognition that public meetings, and meetings recorded for broadcast on the community radio (and hence also public) do not need specific consent process. However, the community radio station involved in the research has its own ethical process of always asking what people want broadcast/not broadcast from meetings. This has rarely ended up with any omissions, and instead usually ends up with an insistence that everything be shared. The decision about how to use the visuals created during the particular research process described below constitutes a rare exception – to limit how the visuals would circulate, but not limit the message they carried.

In 2016, the emergence of a new strategy within the overall research was seen, largely led by women within the movement. As part of the development of this strategy, a decision was made by movement members, and their researcher allies from Accra and from Canada, to develop a visual method of analysis that would ensure women from across the 45 communities surrounding the Songor lagoon could analyze their situation, and contribute to this new strategy. It involved community-level focus groups with a two-step process. First, women would analyze the current situation in the Songor, focusing on whether they thought the current individualization of salt pans, called *atsiakpo*, that had emerged should continue, or if the lagoon should return to being a resource for all, as it has been for the past 400 years.

Considering women have been largely excluded from the current *atsiakpo* practice, it is not surprising that the 345 women who participated in these focus group discussions voted overwhelmingly for Songor to return to being a resource for all. These votes were a visual method in themselves, in that the vote began with eyes closed, with arm positions showing how people felt (i.e. arm up if you wanted a return to Songor for all, down if you didn't, and in between if you weren't sure), and then participants would open their eyes to see how they all voted. The visual vote was also then turned into an open discussion where those who voted in different ways explained why they voted the way they did. This open, transparent process meant women in communities surrounding the lagoon could delve into the complex feelings in their midst, while also building a consensus for action. Photographs of these votes also added to the sense of momentum of the movement – but were only shared with movement members who understood their significance.

With this consensus in place, the focus groups then went on to the second step, doing a visual analysis of allies, opponents, and those on the fence in terms of the 'Songor for all' campaign. Using local material (leaf=ally, stick=on the fence, stone=opponent), and an approach designed by women movement leaders and researcher allies, the women grouped those in their community who were on-side for a return to the Songor being 'for all', and then whom amongst their community would be ambivalent, and who would be against it. The methodology then asked women in each of these communities to do the same analysis of those outside their community, including decision-makers, as well organizations that might hinder or help their cause. The analysis was incredibly damning for local and external decision-makers, who were clearly identified as opponents to the efforts and spoke clearly to power relations in this context. In fact, the results were so clear an indictment that a decision was made at the movement leadership level not to share the specifics of the results of the effort publically in case it led to a backlash against the women. To date, this decision is guiding the use of this visual method of information gathering. Crucial here then is a visual methodology that is deeply helpful for movement processes and learning, but is not a fetish to be consumed by outside eyes – the method acted precisely in the Freirean sense alluded to in the reflections on the South African case study. At the same time, sharing the method process and overall results was seen by movement members and researcher allies as a useful contribution to the potential learning of other movement contexts, and therefore is shared here; whilst the images themselves are not. In this case, the process (method) was decided on and controlled by the 'participants', not the 'researchers'; and the product (images) were used to build the agency and thinking and theorizing of the 'participants', not the 'researchers'.

Weis and Fine (2004) note how it is crucial that conversations emerge in participatory research about how research results are used in order to directly address issues of power between participants and researchers. Not everything is for public consumption, as some things are for participants' own use. At the same time, there are important aspects of process and impact that are crucial to share broadly – not publishing images does not preclude writing about research in academic spaces. The power of the visual here was for women to see their own collective knowledge emerge for them to absorb, and for a sense of collective momentum to visually come forth – boosting the confidence and purpose of the movement. These are not things that need to be shared at this time with a wider public, even as the way this collective momentum emerged is relevant to the wider world.

DISCUSSION

The example from Ghana is where we begin to conclude. Visual methods are not a short cut to a more ethical and engaged form of research. The same crucial dimensions that separate movement-articulated PARs from academically framed ones, are at play in delineating ethical uses of visual research methods. We agree with the feminist model of an ethics of care, as discussed, that lived experience must be given primacy; and also that dialogue is essential in assessing knowledge claims. We also like the idea of an ethics of caring and of personal accountability. However, we think we need to go beyond this model, to an ethics of power. If our intention, as researchers, is an emancipatory one, then our research needs to be part of the process of emancipation. This means that we need to be undertaking research which builds power as capacity to act – in other words, builds the agency of research 'participants' to effect meaningful social change. There thus needs to be open dialogue between researchers and participants where collective decisions can be made about the use of particular research processes and products. Is there a sense of mutual commitment to the cause that frames the work – a sense of what role the research can play in not just furthering knowledge, but also furthering the issues participants see as important? Is disseminating the outcomes from the visual method going to help in dealing with these issues, or is it more about fetishizing an easier-consumed product? A picture may speak a thousand words, but are any of them helpful in the struggle being undertaken by participants?

Extending the Rancièrian notion that we are all equal means that research relationships must be founded on a conscious principle of equality in decision-making about how to use visual methods – whose ends they serve. This does not mean that researchers are not part of this conversation, and that there are not important facets of visual methods that can be shared to further knowledge. It means that the decision to do this is arrived at in dialogue. These processes of dialogue allow for discussion of the repercussions of the circulation of particular images, and its potential benefits. The politics of images, and a discussion of them, can then become another facet of research – likely revealing far more of the power of voice and analysis of participants than whatever images may have been unilaterally chosen by a research to 'speak' for people. As Zikode (2006) notes, 'we think our own struggle' and don't need others to do this.

CONCLUSION

The rise of visual methods is linked to the desire of researchers to connect more authentically with participants' understanding of their world. It seems to carry with it a greater control of research analysis by participants. And yet we question this semblance.

The ethical process of visual methods is still rooted in university systems, and their self-serving view of ethical research behavior. This view of ethics is much less interested in ensuring mutual control of the research process and outcomes, and much more interested in minimizing risk for universities (Tobin & Kincheloe, 2006). However, if you reconceive what power means in research in general, and in visual methods in particular, the question of ownership and control become central concerns.

If one begins from the precept that we are all equal, knowers and learners, in the research domain, a transition can emerge where the power of visuals becomes the starting point for deciding what to do with the visual, and who should decide. An open, honest conversation about this, as advocated by Fine et al. (2004), can prevent the fetishization of visuals and collectively navigate which visuals are for internal use, and which ones can serve a purpose in conveying a collective message. A researcher is one voice in this decision-making process – a process that moves from amplifying marginalized voices to marginalized people taking over the broadcast booth and deciding together what goes on the air.

There is no doubt that visual methods are incredibly powerful, especially in our current media-saturated global environment where visuals are expected to carry so much weight. And yet the potential repurposing and coopting of visuals, especially powerful ones, is a consumptive reality. They are a form of fetish, easily disconnected from their source meaning to take on a meaning that supports power structures. Thus they are consumables; powerful but abusable. A strategic, participant framed approach to visual methods process (in other words, an ethics of power) is a crucial way to contend with these dangers, and navigate the power/knowledge nexus at their core.

REFERENCES

Bahn, S. and Weatherill, P. (2011). 'Eliciting data from participants using visual mapping as a collection technique', *Qualitative Social Work*, 11(4): 431–444.

Barrett, D. (2004). 'Photo-documenting the needle exchange: Methods and ethics', *Visual Studies*, 19(2): 145–149.

Bates, C. (2013). 'Video diaries: Audio-visual research methods and the elusive body', *Visual Studies*, 28(1): 29–37.

Boser, S. (2006). 'Ethics and power in community-campus partnerships for research', *Action Research*, 4(1): 9–21.

British Sociological Association–Visual Sociology Study Group (BSA-VSSG). (2006). Statement of ethical practice for the British Sociological Association–Visual Sociology Group. Retrieved on 11 February, 2016 from http://visualsociology.org.uk/about/ethical_statement.php

Cassiem, A. (2007). Letter emailed to NGO. Cited in Gibson, N., Harley, A. and Pithouse, R. (2009). Out of order: A living learning for a living politics. Afterword in Figlan, L., Mavuso, M., Ngema, B., Nsibande, Z., Sibisi, S., and Zikode, S. *Living Learning*. Pietermaritzburg: Abahlali baseMjondolo/Rural Network/Church Land Programme.

Catalini, C. and Minkler, M. (2010). 'Photovoice: A review of the literature in health and public health', *Health Education and Behavior*, 37: 424–451.

Choudry, A. and Kapoor, D. (2010). 'Learning from the ground up: Global perspectives on social movements and knowledge production', in Choudry, A. and Kapoor, D. (eds.), *Learning from the Ground up: Global Perspectives on Social Movements and Knowledge Production*. New York, NY: Palgrave Macmillan. pp. 1–13.

Clark-Ibañez, M. (2007). 'Inner-city children in sharper focus: Sociology of childhood and photo elicitation interviews', in Stanczak, G.C. (ed.), *Visual Research Methods: Image, Society and Representation*. London: Sage. pp. 167–195.

Cox, A.M., Chiles, P., and Care, L. (2013). 'Exploring students' group work needs in the context of internationalisation using a creative visual method', *International Journal of Higher Education*, 1(2): 21–32.

Edwards, R. and Mauthner, M. (2002). 'Ethics and feminist research: Theory and practice', in Mauthner, M., Birch, M., Jessop, J., and Miller, T. (eds.), *Ethics in Qualitative Research*. London: Sage. pp. 14–26.

Figlan, L., Mavuso, M., Ngema, B., Nsibande, Z., Sibisi, S., and Zikode, S. (2009). *Living Learning*. Pietermaritzburg: Abahlali baseMjondolo/Rural Network/ Church Land Programme.

Fine, M. (2011). 'Troubling calls for evidence: A critical race, class and gender analysis of whose evidence counts', *Feminism and Psychology*, 22(1): 3–9.

Fine, M., Torre, M.E., Boudin, K., Bowen, I., Clark, J., Hylton, D., Martinez, M., 'Missy', Rivera, M., Roberts, R.A., Smart, P., and Upegui, D. (2004). 'Participatory action research: From within and beyond prison bars', in Weis, L. and Fine, M. (eds.), *Working Method: Research and Social Justice*. New York: Routledge. pp. 95–120.

Gallagher, M. (2008). '"Power is not an evil": Rethinking power in participatory methods', *Children's Geographies*, 6(2): 137–150.

Gauntlett, D. and Holzwarth, P. (2006). 'Creative and visual methods for exploring identities', *Visual Studies*, 21(1): 82–91.

Guillemin, M. (1999). '"Mauve - that's an old woman's colour": Women's visual representations of menopause', in Feldman, S. and Poole, M. (eds.), *Older Women in Australia*. Sydney: Allen & Unwin. pp. 56–69.

Guillemin, M. and Gillam, L. (2004). 'Ethics, reflexivity, and "ethically important moments" in research', *Qualitative Inquiry*, 10(2): 261–280.

Guillemin, M. and Drew, S. (2010). 'Questions of process in participant-generated visual methodologies', *Visual Studies*, 25(2): 175–188.

Harley, A. (2012). 'Picturing reality: Power, ethics, and politics in using photovoice'. *International Journal of Qualitative Methods*, 11(4): 320–339.

Hergenrather, K. C., Rhodes, S. D., Cowan, C.A., Bardhoshi, G., and Pula, S. (2009). 'Photovoice as community-based participatory research: A qualitative review', *American Journal of Health Behavior*, 33(6): 686–698.

Hurworth, R. (2003). 'Photo-interviewing for research', *Social Research Update*, 40: 1–7.

Kellehear, A. (1993). *The Unobtrusive Researcher: A Guide to Methods*. St. Leonards, New South Wales: Allen & Unwin.

Langdon, J. and Larweh, K. (2015). 'Moving with the movement: Collaboratively building a participatory action research (PAR) study of social movement learning in Ada, Ghana', *Action Research*, 13(3): 281–297. DOI: 10.1177/1476750315572447

Literat, I. (2013). 'Participatory mapping with urban youth: The visual elicitation of socio-spatial research data', *Learning, Media and Technology*, 38(2): 198–216.

Lukes, S. (2005). *Power: A Radical View*. 2nd expanded edition. London: Macmillan

Marshall, A. and Batten, P. (2004). 'Researching across cultures: Issues of ethics and power', *Forum: Qualitative Social Research*, 5(3): Article 39.

Mohan, G. (1999). 'Not so distant, not so strange: The personal and the political in participatory research', *Ethics, Place and Environment*, 2(1): 41–54.

Packard, J. (2008). '"I'm gonna show you what it's really like out here": The power and limitation of participatory visual methods', *Visual Studies*, 23(1): 63–77.

Pain, H. (2012). 'A literature review to evaluate the choice and use of visual methods', *International Journal of Qualitative Methods*, 11(4): 303–319.

Papademas, D. (2004). 'Editor's introduction: Ethics in visual research', *Visual Studies*, 19(2): 122–126.

Papademas, D. and The International Visual Sociology Association (IVSA). (2009). 'IVSA Code of Research Ethics and Guidelines', *Visual Studies*, 24(3): 250–257.

Pitkin, H.F. (1972). *Wittgenstein and Justice: On the Significance of Ludwig Wittgenstein for Social and Political Thought*. Berkeley, CA: University of California Press.

Prosser, J. (2007). ESRC Researcher Development Initiative. Building Capacity in Research Methods, Introduction to Visual Methods. [course handbook]. Leeds: University of Leeds.

Prosser, J., Clark, A., and Wiles, R. (2008). 'Visual research ethics at the crossroads', ESRC NCRM Realities Working Paper, pp. 1–35.

Rancière, J. (1991). *The Ignorant Schoolmaster: Five Lessons in Intellectual Emancipation*. (K. Ross, Trans.). Stanford, CA: Stanford University Press.

Samuels, J. (2007). 'When words are not enough: Eliciting children's experiences of Buddhist monastic life through photographs', in Stanczak, G.C. (ed.), *Visual Research Methods: Image, Society and Representation*. London: Sage. pp. 197–224.

Tarr, J. (2015). Ethics and visual research. Retrieved 11 February, 2016 from http://blogs.lse.ac.uk/thinkingmethods/2015/07/01/ethics-and-visual-research

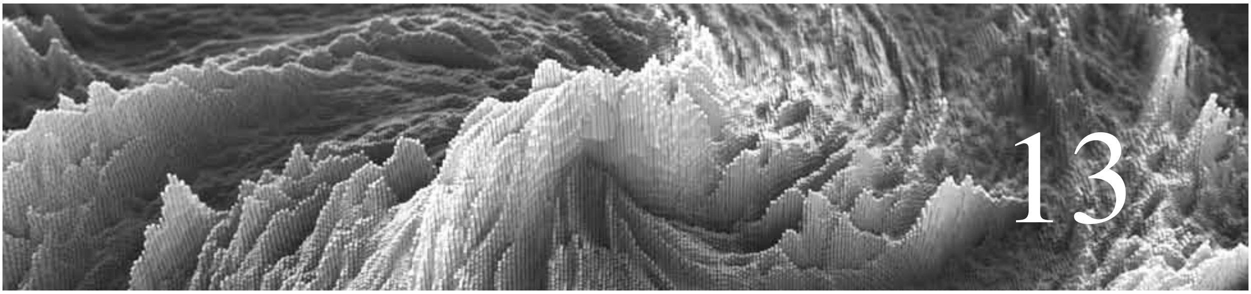
Tobin, K. and Kincheloe, J. (eds.) (2006). *Doing Educational Research*. Rotterdam: Sense Publishers.

Tolich, M. (2012). 'A critique of current practice: Ten foundational guidelines for autoethnographers', *Qualitative Health Research*, 20(12): 1599–1610.

Weis, L. and Fine, M. (eds.) (2004). *Working Method: Research and Social Justice*. New York: Routledge.

Wiles, R., Prosser, J., Bagnoli, A., Clark, A., Davies, K., Holland, S., and Renold, E. (2008). 'Visual ethics: Ethical issues in visual research'. ESRC National Centre for Research Methods Review Paper NCRM/011.

Zikode, S. (2006). Transcribed speech made at the Centre for Civil Society and Rosa Luxemburg Foundation Colloquium, 4 March 2006, University of KwaZulu-Natal, Durban.



13

Ethics Working in Ever-Changing Ethnographic Environments

Olivia Marcus and Shir Lerman

INTRODUCTION

Qualitative research methods pose unique ethical challenges for investigators, whether they conduct fieldwork among high-income business professionals or among more 'vulnerable' populations such as minors, refugees, or people with mental illness. This chapter focuses on the ethical complexities that arise during anthropological research. In particular, we take a critical look at the ethical complexities that anthropologists face as both qualitative observers and as participants in organizational settings. We discuss the challenges of adhering to ethical obligations while conducting participant observation among potentially vulnerable populations, using a fieldwork example of one of the authors' experiences conducting research in a Puerto Rican diabetes clinic. Part and parcel of the research process is the delicacy of obtaining approval from an Institutional Review Board (IRB) to conduct research with vulnerable populations, which involves finding common ground in defining what it means to be a 'vulnerable population'. Beyond the basic challenges of collecting data while remaining sensitive to the needs of the people we work with, we also face the complexities of satisfying IRB requirements in ever-changing ethnographic environments and maintaining confidentiality in clinical settings.

The nature of anthropological data collection methods, namely participant observation, ethnographic interviews, and surveys, brings anthropologists to consider a variety of ethical questions. In exploring ethical concerns that are unique to qualitative research, we must consider what kinds of methods we use and among whom. Participant observation is a hallmark method of ethnographic research, widely considered by anthropologists to be essential for gaining the nuanced, and perhaps even 'insider' perspective of a cultural group or social process (Dewalt & Dewalt, 2010; Garsten & Nyqvist, 2013). In the process of participant observation, we must develop special observer-observed relationships that entail certain formalities, such as introducing our role as a researcher and ensuring informed consent with our interlocutors. In this process, however, we also often develop empathy, experiential understanding, and networks of friends and acquaintances. Some of these relationships may reflect those naturally formed in our site of study, while others are more formal arrangements; nevertheless, all involve power relations in which either we as the researcher are positioned in an authoritative role, or we as 'outsiders' must defer to authoritative figures (e.g. doctors, therapists, nurses, social workers, institutional directors, or ethics committees). In fact, the ethnographer most often finds herself in both roles simultaneously, while also balancing the expectations of an IRB, sometimes multiple IRBs, as well as expectations from colleagues, supervisors, and participants. In seeking to become a worthy confidante for our interlocutors, our engagement in relationships and often highly personal conversations position us in unique ethical spaces, oftentimes blurring the boundaries between professional colleague, friend, and researcher.

There is a long history of anthropologists working within a variety of organizational settings, from corporate offices to scientific laboratories, psychiatric clinics, or other kinds of health centers. Anthropologists, however, often do not merely observe within a field site, but actively participate as volunteers, employees, and practitioners (e.g. Kleinman et al., 1978; Farmer, 1992; Luhrmann, 2000; Ho, 2009; Garcia, 2010). This has become especially common in health clinics, where anthropologists may serve as qualitative researchers, practitioners, or volunteers. While participant observation often leads the researcher toward a deeper understanding of their research site, this method also invites researchers into spaces where boundaries are not easily visible or where confidentiality is not easily maintained. For example, in Angela Garcia's (2010) ethnography of an addiction rehabilitation clinic in New Mexico, Garcia served as a volunteer with the clinic during her research period. As someone involved in dispensing medications to people who also became her informants, it is likely that she confronted conflicts in reconciling her personal feelings as both research scientist and volunteer caregiver. Moreover, we speculate that explaining the nature of this relationship to an IRB may have involved quite a bit of negotiation.

ETHNOGRAPHIC ENCOUNTERS: SHIR'S FIELDWORK IN PUERTO RICO

To illustrate some ways in which anthropologists come up against ethical dilemmas in a clinical setting, what follows is an account of my experiences conducting dissertation fieldwork at a diabetes clinic located on the University of Puerto Rico's Medical Sciences Campus in San Juan, the capital city of Puerto Rico. While my research broadly focused on the syndemic interaction between diabetes, depression, obesity, and the liminal national status of Puerto Ricans; in this chapter I look more specifically to how the subaltern national status of my participants augmented their status as a vulnerable population based on their mental health condition. My research raises questions about the role of the anthropologist in clinical settings, the role of the IRB in approving research protocols, the relationships between the anthropologist and her participants, and how the data are to be used. Typically, research among people with mental health issues present concerns over heightened vulnerability; however, much to my own surprise, the IRB considered my study in expedited review, despite my emphasis on depression. I later learned that this was due to my stated non-interference with access to mental healthcare. Nevertheless, since I conducted recruitment and preliminary interviews at the clinic, both the IRB and the clinic requested that I act as a mandatory reporter, as the clinic did not employ mental health care practitioners and I was often the first (or only) person to openly discuss depression with my participants. The clinic requested that I inform them of any participant who had reported depression to me and did not already see a mental health practitioner. This was in violation of the terms of my original IRB protocol, in which I promised to maintain participant confidentiality. In response, the IRB asked me to amend my protocol to declare that I would report participants with depression to the clinic in order to ensure their well-being. Furthermore, the IRB stipulated that, upon completing data collection, I was to submit a report to the IRB detailing the number of participants with depression I provided to the clinic staff, the clinic staff's follow-up procedures, and whether or not reporting participants to the clinic impacted my recruitment. This report was a guideline for the IRB to determine how to proceed with future research on vulnerable populations. For example, the IRB could incorporate the clinic staff's follow-up procedure into recommendations for future mental health research. I complied with the IRB's stipulation more lightheartedly than I did with their request that I act as a mandatory reporter, for in truth, having a guideline would have been helpful for me in writing my own IRB proposal, and I was willing to let my experiences serve as a guide for future researchers.

I initially worried that my status as a mandatory reporter would influence whether or not my participants reported their depression to me, particularly since depression is a stigmatized disease and participants might not want their healthcare providers to know that they suffer from depression. However, I also wanted to ensure that my participants would receive the help they needed for their depression, and the clinic staff assured me that they would work with their patients to identify appropriate, affordable treatment. I decided to convey my agreement with the clinic and IRB to my participants during the informed consent process, and left it to my participants to decide if they wanted to disclose their depression to me. None of my participants (n=60) withdrew from my study after I conducted informed consent and the reported levels of depression were high (68%), leading me to suspect that my role as a mandatory reporter did not sufficiently deter my participants from disclosing their mental health status. This caused me some surprise, as I knew that if my situation had been reversed, I would have been reluctant to disclose to a stranger that I was suffering from depression, even if I knew that I would never see that stranger again. My participants expressed acceptance of my sharing their depression status with the appropriate clinic staff, which led me to infer that my participants found in our interaction an opportunity to share their experiences with depression with their physicians indirectly through a middle party. This roundabout route of disclosure allowed their physicians to broach the topic instead of the patients needing to do it themselves. My role as a medical anthropologist rather than practitioner put me in a position to serve as a sympathetic listener for my participants, yet a listener who could also translate their depression for the providers, and serve as the providers' translator for the participants. As this process unfolded, I began to reflect on different experiences with depression. As I will discuss later, my participants' experiences with depression are rooted largely in broader social conditions, making me think that depression might have been easier for my participants to discuss if its root causes are shared.

I expected that my arrangement with the clinic was a primary motivation for staff to 'out' patients by telling them to speak with me whenever it was suspected that someone had depression. By doing so, the clinic staff could then verify whether or not their patients had depression before broaching the topic themselves. I would meet with the clinic's medical director to discuss any participants who had reported depression to me, and the clinic director would notify each participant's provider to ensure that the provider would follow up with his or her patient. I met privately with the medical director in order to ensure participant privacy, by ensuring that I would not need to mention participant names in front of all clinic staff. The clinic medical director was appreciative of my efforts, going so far as to admit that this was one of the reasons why they had approved my request to conduct research in the clinic. Meeting privately with the clinic medical director allayed some of my anxieties about breaching my participants' confidentiality, as only the medical director and the participant's provider would know the participant's depression status. The other providers, too, were grateful, stating that it was difficult to broach the topic with their participants without reason due to the stigma surrounding depression.

As one might expect, clinic staff 'outing' participants caused some initial discomfort with me until I could explain the nature of my research, which was not to diagnose them with depression, but rather to learn more about their perceptions of the topic. When I presented myself as a graduate student rather than a mental health practitioner, patients seemed marginally more comfortable with me since I could explain that I wished to learn about depression in Puerto Rico and was not going to prescribe medications or tell their families. These initial conversations, however, also provided my participants with the chance to learn about me as well before disclosing personal information. None of my participants knew what anthropology was, so my explanations of my discipline and, more importantly, that I had voluntarily decided to work in Puerto Rico and spoke fluent Spanish, helped my participants get to know me better. Many of my participants had had experience with Americans who were either tourists merely using Puerto Rico as a cruise hub, or knew so little about the island as to assume that it was not part of the United States. As such, my decision to work in Puerto Rico showed that I genuinely wanted to be there.

Still, I had to maintain the awkward position of gaining my participants' trust and maintaining their confidentiality while working with the clinic to broach the sensitive topic of depression in order to identify patients to their healthcare practitioners. I did so by centering my own research in what Arthur Kleinman and Peter Benson (2006), in citing philosopher Emmanuel Levinas (2000), call the acknowledgment of suffering. This approach, coupled with my position as a non-employee and non-Puerto Rican, contributed to me engaging with my participants in a very different manner than the clinic staff. I expect it was partially for this reason that my participants expressed more comfort in discussing depression with me than with clinic staff. Indeed, the barrier between provider and patient was strong enough that 75% of my participants felt more comfortable disclosing their depression to me than to their providers. For example, Julián (pseudonym), a baggage handler at an airport, told me:

> You're not from here, it's easier to talk to you because you'll eventually go home. We won't need to see you every day for the rest of our lives knowing that you know very personal information about us. Everybody in Puerto Rico knows each other and gossip flies really quickly, even in the medical community. I have friends who will go to the doctor, and the next day someone they barely know will know that they went to the doctor. Besides, you're a student, right? How better to understand what's happening here than to actually talk to people?

With no permanent connection to the Puerto Rican community, I was often perceived as a safer person to discuss a stigmatized disease such as depression than Puerto Rican mental health practitioners. The tight social networks of San Juan prove to be a double-edged sword in this respect: close social networks tend to be associated with better well-being, yet they monitor health-seeking behaviors all too closely. Since healthcare providers would undoubtedly know the patients' families, my being an outsider served as a boon in gaining participants' trust.

Meeting with participants away from the clinic not only provided me with the opportunity to learn more about the participants' lives, but also about living conditions in Puerto Rico and about the political environment that imbued every aspect of life on the island. My participants often framed their depression within terms of Puerto Rico's political milieu, rampant poverty, and the ongoing economic crisis. As a US territory, Puerto Rico has been seen to hold a politically liminal, subaltern status (Grosfoguel, 2003), thus, the political relationship between the US and Puerto Rico made it crucial for me to situate my research within the power relations between myself as an US anthropologist and my Puerto Rican participants.

One of my participants, for example, was a taxi driver named Andrea who allowed me to ride with her to show me a typical workday and demonstrate how her occupation impacted her mental health. Andrea lived with diabetes, which causes frequent urination, but because her salary depended on how many passengers she picked up, she refrained from necessary bathroom breaks to avoid the risk of missing passengers. Through the physical discomfort of holding her bladder and the associated complications that arise from sitting all day with limited breaks, inability to afford high-quality food, and anxiety over keeping her job in order to support her family, Andrea embodied the everyday stresses of being a middle-class Puerto Rican that often lead to episodes of hopelessness and depression. Puerto Rico's unemployment rate hovers at 11.7%, over twice the US federal rate of 5.5% (US Department of Labor, 2016), putting people like Andrea in a very precarious position if she lost her job, which was after all reliable: there were always tourists in need of taxis. Similarly, Julián told me how his odd work hours at the airport affected his sleep cycles and mental well-being. His home environment compounded the stresses of his occupation: he lived in a rough part of town and worried for his safety when returning home late at night.

> How much do you think they pay me to be a baggage handler? Not a lot, that's how much. I do it because it pays and because rich *gringos* like to come here to travel on cruises, which they tell me is good for our economy, although our economy's crap. *You* look alright, though. You speak Spanish pretty well, much better than some Puerto Ricans who were actually born here. Some of these punks are still out and about when I return home at three, four in the morning. They make me afraid to walk down the street in my own neighborhood, and I'm not a small man. It's depressing to watch rich tourists fly into the airport and enjoy the best of what Puerto Rico had to offer, when we could barely make ends meet and do not have any say in what happened on the island.

Bernardo, a convenience store owner, also felt the heavy juxtaposition of wealthy tourists weaving among the lives of poor Puerto Ricans. He recounted how neighborhood residents would hang out in his store for lack of a better place to go and discuss the violence, crime, and unemployment that kept them in an almost constant state of fear or anger, which often led to depression.

Like most of my participants Andrea, Bernardo, and Julián contextualized societal depression within Puerto Rico's economic and political climates. While Puerto Rico's politico-economic climate has its unique qualities, my participants also struggled with life events that contributed to their depression that resonate with almost any sociocultural context in developing countries. Luis, for instance, was an electrician who lost his wife to cancer 19 months earlier. He was left with a staggering amount of hospital bills, three children to raise alone, and a spiraling depression that he could not control:

> I'm still paying off the hospital bills from my wife's cancer. I'm thinking of taking another job to afford the bills, but it's hard to find jobs nowadays. My wife and I were saving up to send our kids to college, but who knows when I'll have enough money for that now. I have two boys and a girl. The boys, they'll be alright, but I need to keep an eye on them to make sure they go to school and treat others with respect. I worry more about my daughter. She needs a feminine role model, and all she sees are her older brothers' girlfriends. What kinds of things is she going to learn from them? I worry so much that it makes me sick. I miss my wife; she was much better at handling the kids. I'm rather useless at such things.

Luis worried especially about his daughter facing domestic violence, and with good cause: domestic violence is high in Puerto Rico, with 31 women killed in 2015 alone – six times higher than Los Angeles, which has a similar population (Coordinadora Paz Para

La Mujer, 2016). Luis' experience stressed the role of Puerto Rico's multiple crises in his individual experiences with depression, demonstrating that mental and political vulnerabilities are oftentimes interconnected.

The clinic permitted me to enter research areas, talk to the patients and sit in on meetings. Although I was not a member of the team, they did take my recommendations seriously when I provided them with the names of participants who had reported depression. This highlighted my equivocal role at the clinic; while the staff did not fully understand why an anthropologist was studying mental health in a diabetes clinic, they nonetheless took my recommendations seriously and followed up with their patients. This arrangement fulfilled my professional obligations but left me feeling that the clinic was using me for my recommendations just as I was using them to recruit participants. I initially felt guilty passing along participant names to the clinic, even though I notified my participants about this procedure during the informed consent process and I was aware that depression identification and treatment were important for the well-being of the patients. Nevertheless, my position as a student researcher-cum-mandatory reporter prompted me to take a critical look at the ethical boundaries between my obligations to the clinic and to my participants. In his research with medical professionals with the Navajo Nation in Arizona, and later with the New York City Department of Welfare, medical anthropologist Clifford Barnett (1985) observed that providers expected him to take some responsibility for patient welfare, despite his role as researcher rather than provider. Anthropologists conducting research in the clinical settings interact with patients who may be in crisis or a heightened state of vulnerability; further, we place ourselves amidst delicate relationships between patients and practitioners, where Barnett reminds us that we have a duty to respect the nature of these relationships and take great caution to avoid alienating either party. It could be easy for the anthropologist to sympathize with the patients through demonizing the often bureaucratic and sometimes sterile behavior of clinic staff. However, such active disruption of patient-provider relationships may do harm to the patient's therapeutic process and cause further stress for the staff. Equipped with Barnett's insights, I more readily identified that part of my responsibility to preserve my participants' welfare included placing their needs above my own qualms about the inner workings of the institution and cooperating more fully to ensure the welfare of staff and patients.

Ultimately, I served as a liaison for the IRB, clinic staff, and my participants. From the perspective of the IRB and the clinic, I was a mandatory reporter and a screener for depression, a way for the providers to identify patients with depression so they could begin the clinical process. My participants, on the other hand, considered me their liaison with the clinic staff as well as a confidante with whom to discuss their struggles with depression without fear of judgment. Keeping with Barnett's recommendations, I used my role as interpreter for my participants to encourage them to talk to their physicians if they had trouble understanding what they had told them. My roles as a mandatory reporter and as a non-Puerto Rican graduate student proved to be key identities for gaining my participants' trust and, ultimately, for data collection. Nevertheless, these roles often came into conflict with my position as an anthropologist who wanted to frame depression within the structural problems in Puerto Rico. The ethical quandaries that arose as a result of these occasionally conflicting identities created situations in which the IRB's and clinic's intentions for my research differed from my own. My experiences navigating the IRB and acting in a multipurpose role as anthropologist, translator, and liaison required me to maintain a delicate balance. My research brought into focus the sometimes conflicting ethical obligations and questions that we as anthropologists have in conducting research with vulnerable populations. My fieldwork experience also made me reevaluate my perspective on the IRB. While obtaining IRB approval was an intricate process, the complexities of conducting research on Puerto Ricans with depression led me to acknowledge the fairness of the IRB's concerns in ensuring that my participants would be protected. I also questioned my own role in my own research. I questioned for whom I am collecting my data and for what purposes the data will be used. These questions are ones I am still discussing with my research collaborators and are as yet unanswered. In the remainder of this chapter, we will discuss how the emergence of ethics committees in the social sciences bears on this fieldwork experience and the ongoing issue of how anthropologists may position themselves during the research process.

THE EMERGENCE OF ETHICS COMMITTEES AND PROTOCOL

The history of ethical concerns that sparked the establishment of ethical committees began relatively recently in the United States and abroad. After World War II, public knowledge of social scientists' involvement in government projects became a point of concern for both the general public and researchers themselves. The violations observed in medical experiments conducted during World War II incited an international process that led to the establishment of the Nuremberg Code (1947) and eventually the Declaration of Helsinki (1964). In the United States, the landmark Belmont Report (1978) followed widespread outrage at the Tuskegee Syphilis Study (TSS) conducted between 1932 and 1972. Before these declarations and reports emerged, however, the effects of Project Camelot were already stirring up ethical concerns among social sciences in the United States. In the 1960s, the military operation Project Camelot would have been the United States' largest investment in social science research had it not been cancelled by 1965 due to international concerns about overt imperial intentions (Solovey, 2001). The project was designed to study revolutionary processes and effective counterinsurgency methods in order to better influence social movements in other countries, particularly in South America and Southeast Asia. Public awareness of Project Camelot led to its dissolution before it was officially carried out and cast an increasingly suspicious eye on the relationship between social scientists and the government. Both researchers and the public exhibited rising concerns about how 'neutral' the sciences actually were. Social scientists have had to grapple with concerns about public image as well as ethical concerns within their respective disciplines. As the quote above explicates, social scientists are not only forced to reckon with a decidedly non-neutral and value-charged scholarly training, but must also openly discuss how close to the government or other organizations they can or should affiliate. As Shir's account demonstrated, this issue is highly relevant to anthropologists who want to augment the voices and agency of their informants while also protecting their privacy. The sciences and academic research are not value-neutral, and social scientists are increasingly vocal about the politically and ideologically influenced production of knowledge that shapes how science is ethically conducted.

The effects of Project Camelot reverberated immediately within the American Anthropological Association (AAA), motivating the Executive Board to submit a report in 1965 that pushed for a detailed investigation of 'ethical dilemmas involving government-funded research' (Hill, 2016/1980). By 1967, the 'Beals Report' was published, which led to the establishment of a AAA code of ethical conduct known as the 'Statement on Problems of Anthropological Research and Ethics'. An official 'Committee on Ethics' was elected in 1970, the formation of which was highly controversial among AAA members. While this chapter does not attempt to discuss a detailed account of the AAA ethical code of conduct or committee formation (see Hill, 2016/1980 and Wax, 2016 for detailed summaries), it is important to note that their formation was directly tied to both internal (i.e. within the AAA) and external concerns over what Mark Solovey (2001) referred to as the *politics-patronage-social science nexus*, which describes the uncomfortably close and often clandestine relationship between social science research and government funding, particularly for military purposes. As James Hill (2016/1980) cogently discussed, the formation of the AAA code of ethics was anchored to national outrage over the unpopular Vietnam War, coupled with implications for closed opportunities for anthropological research in the wake of Project Camelot. The US military's purportedly clandestine hiring and funding of anthropologists continues to be of great concern, particularly when it became known that anthropologists and other social scientists had been working with the US military in the ongoing Iraq War to develop the 'human terrain system' (HTS). The close affiliation between anthropologists and institutions, whether government-related or not, has long been a point of unease for the AAA and anthropologists in general, as these relationships pose a threat to the ethical integrity of anthropological research. In addition to ethical considerations, Ron Iphofen (2011: 59) makes note that methodological issues are likely when health care providers also work as researchers or when 'researchers working for governmental or public agencies … also have service delivery/social policy duties'.

Notorious studies exist in social science that highlight the importance of informed consent and protection of participant identities (e.g. the Milgram experiments (Milgram, 1974)), but as Martin Tolich (2014) notes, most discussion concerning these 'original sins of ethics' fail to critically analyze how the ethics committee could have contributed to minimizing harm either during the study or after study completion. Further, most criticism is aimed solely at the researchers themselves without considering the role that the ethics committee could have contributed toward reducing harm after the study was completed (Tolich, 2016a). A well-rounded critique must also take into consideration the ways in which naturalistic or ethnographic studies differ from experimental and psychology-based studies. Qualitative research, and ethnographic investigation in particular, is a reflexive process for discovery of ethical boundaries as well as for questioning where and why those boundaries are laid down and how flexible they may be. This puts qualitative investigators, participant observers in particular, in unique ethical positions that give rise to what he considers three fundamental issues: (1) assessment of ethical concerns is partial at best, (2) ethical dilemmas are an important part of the research findings, and (3) qualitative research is epistemologically unique and therefore needs its own code of ethics. Each of these points are relevant to the example provided in which Shir came up against ethical dilemmas that may enrich our understanding or cause us to reformulate how we collect or present our data.

This is not to say that qualitative researchers should be exempt from IRB review or that they deserve ethical leniency. Rather, we argue that most institution-based ethical committees and protocols are formed for experimental research designs in which certain harms to participants may be easier to identify and predict. Part of the nature and relevance of qualitative research is an aspect of unpredictability: what kinds of people will speak with you? What information will they share with you? How do we protect their identities or do they want to be identified? These are questions and concerns that are difficult to reconcile with conventional IRB protocols; moreover, confronting these outstanding questions are frequently integral to learning what kinds of social norms are dominant in a certain cultural setting.

QUALITATIVE RESEARCH IN ORGANIZATIONAL SETTINGS

Anthropologists and ethnographers who work in a clinical or institutional setting often confront a unique set of considerations, such as when we are put in the position of 'mandatory reporter' or if we serve a voluntary or professional role in which we have authority over others. Some obligations may make our role clear, while others blur lines and create tensions between our own ethical principles and those of the IRB. In most cases our role is not so clearly defined and our ethical obligations often rest on personal judgment and individual expertise. For example, a nurse-anthropologist will have different obligations than a researcher without a nursing license. In addition to complexities inherent in the process of gaining access to organizations, anthropologists place themselves in the position of serving as both ethnographers and secret-keepers for exclusive groups, committed to both reporting truth and withholding it as the need arises. For example, Jessica Mulligan (2014) conducted ethnographic research at a Health Maintenance Organization (HMO) in Puerto Rico while also working as a manager there. Although this provided her a unique perspective on the privatization of healthcare in Puerto Rico and the changes in the quality of patient care, Mulligan had to reconcile the conflict between her obligations to the HMO and her sympathies for the patients whose health insurance plans left them without affordable healthcare. Anthropologists are often caught within these ethically conflicting spaces, particularly when they serve as representatives of the organization in which they conduct research. The extent to which one feels accountable to a community when collecting and presenting their work is a very personal issue determined by differences in personal background, theoretical influences, and methodological training, which are highly variable among social scientists. In addition, the field site or population that the researcher engages with will determine to what extent he or she takes a role as activist or advocate, or tries to maintain a 'neutral' position if possible. Regardless of which stance a researcher thinks she will choose (for often we are pushed into roles we never expected to have), the ethical implications are varied and often unexpected.

The irresolution of accountability is exemplified when anthropologists turn their ethnographic gazes to the complex power relations that occur among the patients and providers in health clinics (Oeye et al., 2007). Places where people engage with the therapeutic process and health professionals are ethically charged sites in which anthropologists must be extra cautious about breaking participant confidentiality among patients, practitioners, and employees alike. Arthur Kleinman and Peter Benson (2006) expand on philosopher Emmanuel Levinas (2000) by pointing out that the first ethical imperative is to acknowledge a person's suffering, and that ultimately, the moral meaning of suffering is what is at stake for the patient. The anthropologist, therefore, may be perceived as having a moral obligation to acknowledge the experience – suffering or otherwise – of all stakeholders involved in their research. The various roles an anthropologist may have – from psychiatrist to nurse or administrator – will undoubtedly introduce different conflicts of interest and forms of accountability. And yet, anthropological investigation in the clinic offers a unique ethnographically-informed sensitivity to patients' suffering, which is useful in treating patients as well as a powerful tool for acknowledging that suffering requires its own form of healing.

DISCUSSION

Shir's experience at her field site highlights several issues often faced when conducting ethnographic research in a health clinic. First, positioning ourselves as researchers to both the patients and the staff can cause confusion among clientele, who may not understand the difference between a researcher and a clinic employee. This may cause initial skepticism among patients during recruitment and also give staff the impression that we may be there to act as their advocates. Shir used this skepticism to highlight the usefulness of having an anthropologist on staff to serve as liaison between patients and staff. Second, the developing relationship between the researcher and her participants might contribute to confusion, such as when patients shared details with Shir that they had not shared with their health care providers. This put Shir in a sticky position: at which point does she have an obligation as a mandatory reporter to breach the confidentiality she assured her participants? To be clear, mandatory reporting is a straightforward procedure in which the reporter is clear with the patient that certain information will be reported to a professional; nevertheless, there are many other 'non-urgent' situations in which the researcher may feel compelled to intervene as a friend or a concerned bystander, but is also beholden to her role as a researcher. Anthropologists throw themselves into the lives of others, and when these lives flow in and out of health clinics we implicate ourselves within tender moments when people are simultaneously navigating the health system, their own well-being, the well-being of family, as well as political and economic pressures. As a researcher, however, the anthropologist often cannot intervene as a friend might. Rather, we can only 'catch' the person in their moments of vulnerability or strength in order to better understand the events that led up to these moments and what significance they have in the lives affected. It is these moments that inspire anthropologists to develop theoretical frameworks that acknowledge suffering and moral engagement in order to reconcile our roles as scientists and as caring human beings.

Since the advent of ethics committees in the social sciences, there have been salient critiques of the risks involved in creating a rigid code of ethics. Howard Becker (1964: 410) argued outright against a code of ethics for the American Sociological Association on the grounds that such a code 'obscures more than it illuminates'. Rather, he argued that the publication of a symposium on ethical issues would be more productive toward advancing the public debate and knowledge of various ethical concerns, as well as changes in how they are interpreted and coped with. Such changes develop rapidly and unpredictably, particularly in cases of visual or photo-ethnography and auto-ethnography (Sieber & Tolich, 2013). International review boards and ethics committees are important for thinking through what may happen and how the researcher can respond *before* they begin their investigation, but researchers often lack support during and after fieldwork periods when he or she might have questions about unexpected ethical situations. Currently, one can find venues for support in places such as the American Anthropological Association ethics forum (AAA, n.d.), the Macquarie University (2010) online ethics training, the Social Research Association ethics consultancy forum (SRA, n.d.), and The Ethics Application Repository (TEAR, n.d.). These forums and databases do not replace ethics committees, but provide spaces for learning and training amidst the seemingly inexorable growth of codes, policy, and committees concerning ethical conduct in human research.

Another significant issue that Shir confronted was how to explain the nature of her work to the IRB. Part of Shir's dissertation research explored modes of vulnerability among her participants and how this affected their health behavior and perceptions of mental health in relation to politico-economic conditions. When explaining this to the IRB, she found that different conceptions of vulnerability influenced how she could structure her investigation. Since her participants may be considered 'vulnerable' due to their current depression status, she had to agree to be a mandatory reporter. This role, however, raised trust issues between herself and her participants and was further complicated when she would conduct interviews in the home rather than in the clinic. Participant observation necessarily involves spending time with participants in a variety of settings, yet each setting entails its own ethical implications. In the clinic, Shir had to deal with the unexpected issue of the staff 'outing' patients with depression and with gaining the trust of participants who may already feel betrayed. In their homes, Shir was able to develop more empathic relationships that helped participants feel more secure discussing their health with her than with their health care providers. In this second setting, Shir was able to unearth a rich ethnographic understanding of the relationship between depression, community, and society, yet she was also put in the position of being the confidante for people who the clinic and IRB expected her to protect. Ultimately, Shir valued the relationships forged in both settings and the unique perspectives they provided.

Ethnographic research methods such as participant observation are generally considered naturalistic, meaning the researcher is theoretically a neutral observer. However, observing is also a form of participation and anthropologists always do more than merely observe and ask questions. We form relationships and insert ourselves into social dynamics that necessarily change due to our presence and interference. Ethics committees have largely formed and developed in response to experimental studies in which the research team manipulated (sometimes unintentionally) participants. To be sure, anthropologists have often been implicated in schemes of manipulation, but this is also part of everyday sociality that may not be easily avoided. In fact, people in some social milieu *expect* a certain level of manipulation in order for the individual to gain respect or social capital (e.g. Lee, 1969; Numerato & Baglioni, 2012). Thus ethnographic researchers often find themselves trying to adhere to an ethics protocol that was not designed for them. As Tolich (2016b) remarked, designing qualitative studies within the ethical boundaries of most review committees is like trying to fit a square peg in a round hole. Despite the challenges of this conceptual mismatch, qualitative researchers have successfully conducted studies and derived insightful ethnographic accounts for decades. It is through sharing of experiences and learning from others – and our own – mistakes that we can improve the public discussion of research ethics when conducting and analyzing qualitative research.

REFERENCES

AAA (American Anthropological Association). (n.d.) AAA ethics blog: A forum sponsored by the AAA ethics committee. http://ethics.americananthro.org/about/. Accessed April, 2016.

Barnett, C. (1985) Anthropological research in clinical settings: Role requirements and adaptations. *Medical Anthropology Quarterly* 16(3): 59–61.

Becker, H.H. (1964) Against the code of ethics: Letter to the editor. *American Sociological Review* 29(3): 409–410.

Coordinadora Paz Para La Mujer. (2016) Estadísticas. http://pazparalamujer.org/index.php/recursos/estadisticas. Accessed July, 2016.

Dewalt, K.M. and Dewalt, B.R. (2010) *Participant Observation: A Guide for Fieldworkers*, Second Edition. New York: AltaMira Press.

Farmer, P. (1992) *AIDS and Accusation: Haiti and the Geography of Blame*. (Updated with a New Preface). Berkeley and Los Angeles: University of California Press.

Garcia, A. (2010) *The Pastoral Clinic: Addiction and Dispossession along the Rio Grande*. Berkeley and Los Angeles: University of California Press.

Garsten, C. and Nyqvist, A. (2013) Entries: Engaging Organisational Worlds. In *Organisational Anthropology: Doing Ethnography in and among Complex Organisations*, edited by C. Garsten and A. Nyqvist, pp. 1–26. New York: Palgrave Macmillan.

Grosfoguel, R. (2003) *Colonial Subjects: Puerto Ricans in a Global Perspective*. Berkeley and Los Angeles: University of California Press.

Hill, J.N. (2016/1980) The Committee on Ethics: Past, Present, and Future. In *Handbook on Ethical Issues in Anthropology*, edited by J. Cassell and S.-E. Jacobs. American Anthropological Association special publication no. 23. http://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=1942&navItemNumber=731. Accessed August 1, 2016.

Ho, K. (2009) *Liquidated: An Ethnography of Wall Street*. Durham, NC: Duke University Press.

Iphofen, R. (2011) *Ethical Decision Making in Social Research*. London: Palgrave

Kleinman, A. and Benson, P. (2006) Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLoS Medicine* 3(10): e294.

Kleinman, A., Eisenberg, L., and Good, B. (1978) Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine* 88(2): 251–258.

Lee, R.B. (1969) Eating Christmas in the Kalahari. *Natural History*. http://www.naturalhistorymag.com/htmlsite/master.html?http://www.naturalhistorymag.com/htmlsite/editors_pick/1969_12_pick.html. Accessed August, 2016.

Levinas, E. (2000) Useless suffering. In: Smith M.B. and Harshav, B. (translators), *Entre nous: Thinking-of-the-other*. New York: Columbia University Press, pp. 91–101.

Luhrmann, T. (2000) *Of Two Minds: An Anthropologist Looks at American Psychiatry*. New York: Vintage Books.

Macquarie University. Human Research Ethics for the Social Sciences and Humanities http://mq.edu.au/ethics_training/. Updated May, 2010. Accessed April, 2016.

Milgram, S. (1974) *Obedience to Authority: An Experimental View*. New York: HarperCollins Publishers, Inc.

Mulligan, J.M. (2014) *Unmanageable Care: An Ethnography of Health Care Privatization in Puerto Rico*. New York: New York University Press.

Numerato, D. and Baglioni, S. (2012) The dark side of social capital: An ethnography of sport governance. *International Review for the Sociology of Sport* 47(5): 494–611.

Oeye, C., Bjelland, A.B., and Skorpen, A. (2007) Doing participant observation in a psychiatric hospital – Research ethics resumed. *Social Science and Medicine* 65(11): 2296–2306.

Sieber, J. and Tolich, M. (2013) *Planning Ethically Responsible Research* (2nd edition). Los Angeles: Sage.

Solovey, M. (2001) Project Camelot and the 1960s epistemic revolution: Rethinking the politics-patronage-social science nexus. *Social Studies of Science* 31(2): 171–206.

SRA (Social Research Association). (n.d.) http://the-sra.org.uk/research-ethics/ethics-consultancy-forum/. Accessed April, 2016.

TEAR (The Ethics Application Repository). (n.d.). http://tear.otago.ac.nz/. Accessed April, 2016.

Tolich, M. (2014) What can Milgram and Zimbardo teach ethics committees and qualitative researchers about minimizing harm? *Research Ethics* 10(2): 86–96.

Tolich, M. (2016a) Qualitative Ethics in Practice. In *Qualitative Ethics in Practice,* edited by M. Tolich, pp. 13–24. Walnut Creek: Left Coast Press.

Tolich, M. (2016b) Are Qualitative Research Ethics Unique? In *Qualitative Ethics in Practice*, edited by M. Tolich, pp. 33–47. Walnut Creek, CA: Left Coast Press.

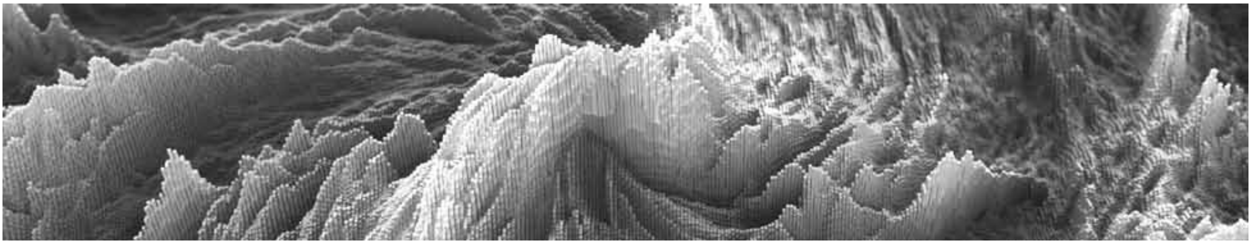
US Department of Labor – Bureau of Labor Statistics. (2016) Economy at a Glance: Puerto Rico. http://www.bls.gov/eag/eag.pr.htm. Accessed July, 2016.

Wax, M.L. (2016) Some Issues and Sources on Ethics in Anthropology. In *Handbook on Ethical Issues in Anthropology*, edited by J. Cassell and S.-E. Jacobs. American Anthropological Association special publication no. 23. http://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=12910&RDtoken=47485&userID=5089&navItemNumber=731. Accessed August, 2016.

PART III

Ethics as Politics

Ron Iphofen and Martin Tolich



Politics takes various forms in qualitative research; on one hand it is subsumed under the hegemony of the risk averse biomedical paradigm and on the other regulated by an ethics review system modelled along positivist epistemology. **Jon Shefner and Zachary McKenney's** chapter shows how a study of community organizing in Latin America presents problems for a western ethnographer; working in a second language and as an outsider present ethical dilemmas not considered by a research ethics committee. In fact, the authors suggest that the procedural ethics advice they received was of little benefit. The researchers need to protect their research subjects reflexively but at the same time they need to protect themselves when in harm's way. Three vignettes are presented and discussed. The first involves the difficulty of gaining consent at a street demonstration when the focus is on demonstrating. The second, how the researcher's very presence collecting information about political processes in itself places all concerned at risk of harm. The third example is the collection of data and its presentation using a triangulated method that ensures scientific rigour but also potentially reveals the subject's identity.

The next three chapters emphasize some of the difficulties that qualitative researchers have when making a formal application to an ethics committee. These range from problems with guidelines to the review process itself to the issues raised by the centrality of reflexivity to qualitative research.

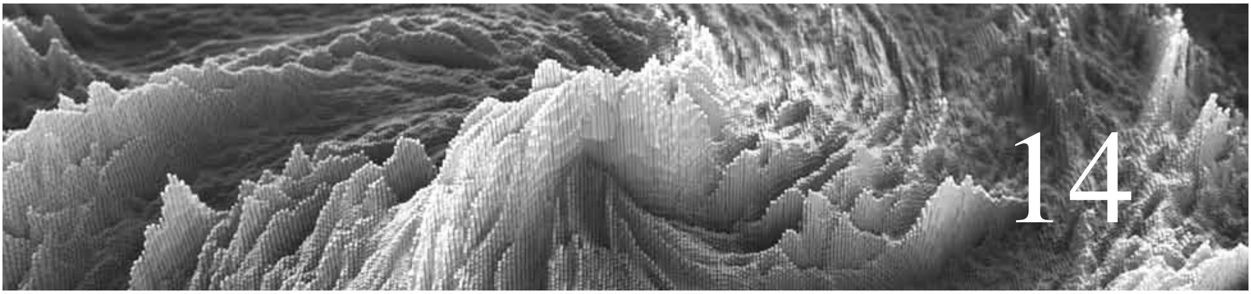
Igor Gontcharov's chapter focuses on the historical evolution of research ethics guidelines in Canada. First, he focuses on the procedural reasons that contributed to the adoption of a one-size-fits-all regulatory model in 1998 and the limited ability of the regulators to respond to the criticisms of social researchers in the subsequent iterations of the *Tri-Council Policy Statement* in 2010 and 2014. Second, he offers an analysis of the positivist conceptual framework, including methodological reductionism, objectivism, and universalism, and its impact on policy making in research involving humans.

Lisa Wynn's chapter reports the results of a 2010 international survey of 315 ethnographers (primarily in the US, UK, NZ, Australia and Canada) about their experiences of interacting with ethics review committees. Ethnographers complain that ethics committees rarely understand participant observation, as evidenced by their requests for control groups, signed consent forms from populations where contracts with foreigners are regarded as politically dangerous, and the availability of counseling for research participants who might be 'traumatized' by talking. Ethics committees have insisted on the anonymization of research participants, even when the participants want recognition, and demanded that researchers never enter private homes, even though ethnographic research is premised on the documentation of everyday life, including private, family life. Ethics committees are typically perplexed by relationships of intimacy between ethnographers and their 'informants', even though ethnographers often consider long-term friendships the ethical ideal. According to many ethnographers, ethics committees are also responsible for obstructing research with vulnerable populations and on sensitive topics, such as abuse, criminal activity, and sexuality. Above all, ethics committees usually demand that the research trajectory, participants, and research questions can be known in advance, which is antithetical to ethnography's iterative nature and which may foreclose the creative, collaborative directions that ethnographers consider to be the research ideal. As a result, many ethnographers report being disillusioned with the ethics review process and engage in strategies of evasion or deception in order to limit the damage that ethics review committees might do to their research. Other ethnographers remain committed to the process of ethics review, even when disappointed by its poor implementation. These different attitudes toward ethics review reflect competing epistemologies about the relationship between researcher, research participant, and academic peers.

Lynn Gillam and Marilys Guillemin were invited to contribute a chapter to update their influential 2004 article distinguishing between procedural ethics and ethics in practice. This new chapter continues to investigate nuances of ethics review. They claim the success of the human research ethics review enterprise is contingent on relationships based on trust and respect between the key stakeholders, namely researchers, participants and research ethics committees (RECs). Recent research demonstrates a persistent sense of mistrust between ethics committee members and researchers. Researchers often perceive the review process as an adversarial one, where ethics committees challenge their professional and personal integrity. Although this sense of frustration and mistrust has been reported for all researchers who deal with ethics committees, qualitative researchers note particular problems associated with misunderstandings about qualitative research methodologies that may be unfamiliar to RECs. In this chapter, Gillam and Guillemin unpick what might be the sources of feelings of being misunderstood and mistrusted. Next they review and extend the concept of reflexivity in qualitative research. In doing so, they highlight its similarities with concepts in standard 'biomedical' research ethics, and unsettle the idea that the standard research ethics paradigm is fundamentally foreign to qualitative research.

Gary Allen and Mark Israel review arrangements that are rule-based and focus on enforcing compliance, arguing that they do not belong in educational institutions. Where national regulations exist, social researchers have had only limited success in shaping the rollout of guidelines, codes and statements that almost always start from a model of research that is alien to much of the social sciences. Even where national arrangements have started to engage with social scientists, they found some local review processes have been even less responsive. They argue that there is some possibility of working to change the ways institutions approach research ethics. They want to move the focus from regulatory compliance towards supporting the ethical conduct of research. However, this requires a shift in the way we see the roles of different stakeholders, alterations in patterns of communication between researchers and ethics review processes, the development of far more sophisticated resource materials, and greater attention to curriculum and pedagogy so that a new generation of researchers and staff seek partnership rather than conflict.

It is no surprise that a number of chapter authors have been critical of formal ethics review. As editors, we felt it necessary to seek a chapter that made a case that justifies ethics review as an essential part of sound ethical research practice. The chapter by **David Hunter** partially fills that criterion but we find we cannot agree with much of Hunter's argument. For one thing he makes a dated argument that qualitative researchers should not have their own ethics committee because they are too close to the subject matter; their objectivity would be in question. That could be said of all researchers. The irony of the chapter and this argument is that the entire Handbook highlights researchers who are managing big ethical moments that arise in the field in situ. It is not that we uncritically endorse everything that has been written that challenges ethical review and regulation. Indeed, both of us are fully supportive of truly independent research ethics review – Tolich founding an independent ethics committee in New Zealand and Iphofen founding and convening the ethics forum for the Social Research Association in the UK. It is an error to suppose as Hunter does that most social scientists argue that their work should be excluded from ethics review, rather that it should be better understood and so more insightfully assessed. Admittedly, some commentators do argue that some methodologies should be excluded from review on the grounds that potential subject/participants should be accorded the 'right' to decide themselves if they wish to participate, how and how long for. If that enduring ethical principle of 'autonomy' is to be observed then to intervene between researcher and researched appears to restrict the autonomy of both and could be seen as undemocratic. Hunter usefully rehearses most of the arguments for best practice in research ethics review and has more faith in the ideals of institutionally-based RECs being fulfilled in the reality of their practice than we do. However, it is not enough to recount personal experience of good, considerate committee practices that 'we' have encountered or delivered, even those critical of REC procedures have experience of that. There remain too many personal anecdotes of quite the opposite. At the very least much more empirical evidence of REC practices, culture and process is required to vindicate RECs from the charges that can be found in this Handbook. There remains a need for a more robust defence of independent ethics review.



14

Confronting Political Dilemmas in Ethnographic Fieldwork: Consent, Personal Safety and Triangulation

Jon Shefner and Zachary McKenney

INTRODUCTION

This chapter suggests that federal regulations and other research standards including the Declaration of Helsinki, the *Belmont Report*, and the Common Rule are biomedically driven and are insufficient to help ethnographers address political and ethical challenges that confront them during their fieldwork. Ethnographic fieldwork poses its own set of ethical and political challenges that researchers must be prepared to deal with in the course of conducting a study. This chapter draws on the senior author's extensive fieldwork in Latin America to examine three vignettes that show the inadequacy of ethical standards in political situations in terms of informed consent, personal safety and triangulating data. These challenges are compounded when the researcher is an outsider, especially with regard to studies conducted in the Global South, where power differentials between the researchers and the researched are often stark. The challenges are further exacerbated when the issue or locale studied is defined by political conflict. How does one separate ethical from political issues and how might the latter be dealt with explicitly? How do researchers navigate the precarious relationship between ethnographic studies and regulatory agencies such as institutional review boards (IRBs) and research ethics committees? How should field research be conducted with respect to political consideration in the host country? Researchers must be able to deal with personal safety issues that become more pronounced in politically contentious situations. How can ethnographers supersede their political positions in order to validate the data they have gathered?

POLITICAL VERSUS ETHICAL DILEMMAS

There is no shortage of scholarship on the ethical dilemmas that ethnographers have faced when conducting field research (Ellis, 2007; González, 2000; Miles et al., 2014; Punch, 1994; Sales & Folkman, 2000). In her ethnographic study of isolated fishing villages on Chesapeake Bay, for example, Ellis (2007) was able to adhere to the ethical guidelines specified by her institution's review board while still coming away from the study feeling as though she had violated the identity and trust of her participants. Although Ellis used pseudonyms to protect the identity of the villagers, the close relationships between the townspeople made it easy to decipher who was being discussed in the study. Similarly, although Ellis believed that she sufficiently identified herself as a researcher, many participants were angry that she had written about the most intimate aspects of their lives. In addition to feeling the scorn of the townspeople, Ellis's actions had the further effect of closing down the field site to future ethnographers.

Thus, one topic that is related to ethical challenges but that has received far less attention in the literature to date is the political dilemmas that arise in certain ethnographic studies. How does one separate ethical from political issues, and when are the latter of high importance? Regulations mandate that researchers 'do no harm', but guidelines regarding who benefits from fieldwork, how to obtain informed consent in the field, and how to conduct research when one holds political commitment are murky at best and do not engage with the spontaneity of challenges encountered in the field.

Guillemin and Gillam (2004) in their twofold typology of procedural ethics and ethics in practice highlight the problems for the types of research described in this chapter. Nothing in three vignettes that follow were predicted by the senior researcher or the IRB procedural ethics guidelines. These 'ethics in practice' encompassed unforeseen issues that emerge within the research context and that may carry both ethical and legal ramifications for the researcher and the researched (Guillemin & Gillam, 2004: 263).

The responsibility of ethics in practice falls on the shoulders of the researcher. How do we differentiate these important research concerns from political concerns within research? By political concerns, we are referring to the stated goals, intentions, and outcomes of the research study, especially when studying issues or locales defined by political conflicts. According to Shefner, 'the political implications of research often extend beyond the ethics of the standards protecting research participants. This focus on politics concentrates more on the impact researchers try to have on the social problem in which he or she is engaged' (2016: 147). The political concerns we advocate are similar to those of feminist standpoint epistemology which illustrates how women's unique vantage point validates the central arguments of feminism and provides a specific research method that can be used to justify the truth claims of groups within society (Collins, 1997; Harding, 2004; Hartsock, 1983; Heckman, 1997). Standpoint theory stresses the primacy of relationships with research participants, an acknowledgement of multiple truths, and an obligation to engage in the research. For us, the political concerns emerge from our engagement in the conflicts within the locale of our field site, whether these are local, national, or global political and economic conflicts. Political challenges are not as much concerned with the treatment of participants during the research process as they are with the end goal of political, social, and economic empowerment of participants during and after the formal research.

For Shefner (2016), research with political aims occurs across a continuum that, broadly construed, consists of four points. At one end, the most politicized, are researchers who are affiliated with an organization or social movement, and whose research agenda is defined by the movement, as in participatory action research. The second point that a researcher can occupy is to serve as a consultant or expert and lend a voice to the movement or organization that the researcher represents, while maintaining her own research agenda. The third point, often referred to as public sociology, is where a researcher is engaged in a project with clear political goals, but neither works beyond the role of researcher with a community, nor has an agenda to disseminate the results beyond an academic audience. Finally, at the other end of the spectrum are researchers who use a model most closely associated with the physical sciences. Although the researcher at this point may be studying a politically relevant topic, no plan or consideration is given to how the study may help or hinder the people under consideration.

Expressly political research differs from the physical science model in key ways. Researchers who are hoping to empower the groups they are studying drop any pretenses of objectivity that usually accompanies strictly scientific studies, while continuing to observe strict methodological guides to assure good data collection, and without suspending critical analytical responsibilities. Additionally, political engagement may require a far greater level of intimacy with the people, group, or organization under study than do traditional research models. Shefner and Gay (2002) argue that politically motivated research further departs from the normal model in four key areas. First, the individuals, organizations, or movements that are under investigation require a great deal of support from the researcher. In most cases, ethnographers must work tirelessly to attend as many meetings, marches, or political activities in which the group is engaged in order to establish their credentials and demonstrate their commitment. Second, the level of involvement incumbent upon the researcher is necessary not only to establish credentials, but also to gain access to key informants, elected officials, and rank and file members. In order to gain access to the data, ethnographers must demonstrate that they have a stake in the outcome. That said, declarations that researchers should have a stake in the outcome of their study can easily be abused, and it is clear that these points extend to nonpolitical examples as well. Duncombe and Jessop (2002), for example, caution researchers against using their rapport with participants to hide their professional motivations. They demonstrate how developing rapport is often misused in order to encourage interviewees to disclose personal information. Having a stake in the outcome must be genuine. Third, an intimate knowledge and high level of involvement with the organization and the issues it pursues is necessary in order to ensure the accuracy and validity of the data being gathered. This practice, broadly referred to as triangulation, will be discussed in greater detail below. Fourth, and relatedly, direct involvement is crucial in order to realistically assess what strategies, tactics, and techniques are successful, which are not, and why. Again, this type of research raises political questions that differ from the ethical considerations described above. We briefly illustrate how some of these issues manifested during studies in the Global South before moving on to consider political research within the context of the IRB.

Informed Consent

This first vignette contrasts the absurdity of how procedural ethic frames informed consent with what happened amidst a vibrant demonstration, in which people were looking for someone to tell their story to, and have that story shared. Informed consent was not their priority.

> On Mayday, 1992, I attended a massive rally in downtown Guadalajara, Mexico, organized by the victims of a gasoline explosion in one of the oldest neighborhoods in that city. Because of the disaster's human and property costs, and because it was a clear result of government negligence, public anger was high. Hundreds died in the explosion, which devastated a mixed-use neighborhood where families lived and worked. The government was in damage control mode, which superseded addressing the damage done. That day I observed several marches that converged in the main plazas, listened to speakers, and spoke to numerous people, disaster victims and those disgusted with national and local politics. At one point, with paper and pen in my hands and a camera around my neck, I was surrounded by a crowd of people for 40 minutes, three to six people deep throughout that time. Although I explained I was a sociologist

> repeatedly, it was clear that most people who spoke to me thought I was a member of the international press. Others didn't care, so long as I was willing to carry their story to others. The conversation was nonstop, and at times very emotional, as people shared not only their losses with me, but also their feelings of deep betrayal by a government whose neoliberal practices for a decade preceding the disaster had already leveled significant hardships on citizens. Comments ranged from history lessons on the corrupt government, to the government's claims that there was no danger despite weeks of gasoline smell preceding the disaster, to the failure of the government-owned petroleum company, to calls for a new, more open, and representative government. Throughout the event, I wrote their comments as quickly as I could, and asked questions that elicited dozens of answers. There was no time or possibility to ask for consent to quote, let alone ask for signatures on a form assuring informed consent. Instead the situation was defined by the crowd's desire to get their anger on some kind of record. When I told people I was a sociologist and not a reporter, none left the conversation.

This vignette points out other issues with informed consent in highly contentious political settings. First, obtaining consent is sometimes just not possible. Although the senior author tried to establish his researcher credentials in the face of misunderstandings about his role, there would have been no way to gather the rich data that moment provided while pursuing informed consent. Filling out forms would have interrupted a spontaneous flow of information. Second, the moment was one of high suspicion and political sensitivity, which also denied the possibility of a formal informed consent procedure. Asking for signatures at that moment would not only have diminished data availability, it would have raised suspicions that the interviewer was a police officer or an informer. The physical actions of asking questions, requesting photographs, and clearly writing notes while asking questions, with respondents staying until they were convinced they had been heard and their words recorded, implied consent. Several respondents volunteered their personal contact data, and explicit informed consent was achieved in individual follow-up interviews. Finally, people's desire to tell their stories about politically-driven issues should trump formal consent – their desire should be sufficient to satisfy researcher's and institutional concerns. Because the senior author used no names other than those with whom he conducted follow-up interviews, no norms of confidentiality or anonymity were breached.

Personal Safety

Once the ethnographer has cleared the hurdles of IRB review and issues of informed consent, additional issues accompany research in conflictual political locales. Researchers must be able to deal with personal safety issues that become more pronounced in politically contentious situations. In this section, we briefly highlight some of the challenges that ethnographers face once they are in the field and discuss the political ramifications that may arise. The second vignette focuses not on protecting the participants but on protecting the researcher from harm.

> The social movement ferment in Guadalajara continued to build throughout May of 1992. Anger at insufficient answers, and reactions from government officials that ranged from lies to paternalistic and insufficient material redress, led to further mobilizations. Throughout that period, I accompanied victims in their protests, observed visits of government officials to their tent community near their demolished homes, and interviewed them, other organizers, and as many government officials who would speak with me, including engineers in charge of demolition and rebuilding, public health officials worried about the implications of the damaged sewer system, and a variety of elected officials. Eventually, angry over the government's responses, several groups called for a miles-long silent march that would end with an encampment in the plaza directly across from the main government building. As we lined up to march, one of the organizers came to me to warn me that the police had been asking about me, at rallies and in the destroyed neighborhood. At the time, I shrugged it off.
>
> After the march, the occupation of the plaza proceeded. The disaster victims set up tents, carried large tanks of propane to the encampment, along with stoves, large caches of food, beds, blankets,

> etc. By all appearances, the protestors were preparing for a long siege in front of the state capitol. They hoped this camping out in the government's front yard would embarrass the intransigent officials, because the capitol was an old and historical building not only used for legislative purposes, but also a main tourist site (with famed murals) in the middle of the downtown area. I stayed at the tent city, talking to people and listening to them play music, until late in the night before I returned to my residence. The next morning, as I bought my usual morning paper, I found that forces soon found to be police had attacked the camp in the middle of the night, beating men, women, and children, taking their possessions, and forcing several of the organizers on a badly planned bus trip to local police headquarters. The danger my friend had warned me of proved too real.

Although the IRBs and federal regulations require that researchers protect their subjects from harm, these guidelines are notably silent when it comes to information on how to protect the researchers themselves from physical, psychological, and existential injury. Indeed, numerous ethnographers have been exposed to violence in the course of their fieldwork. Ferrell (1997) was arrested for his role as a participant observer of graffiti artists. Anner was kidnapped while working with the National Federation of Salvadoran Workers in El Salvador and was nearly killed in a bombing while working in a San Salvador union building (Anner, 2014). Moreno (1995) was sexually assaulted while working in the field. These examples illustrate, as Librett and Perrone note, 'we are not given guidelines on how to ensure our safety and wellbeing in the field' (2010: 739).

Ethnographers have to recognize the political considerations of the researched group and the potential for injury during the investigation, and consider strategies to avoid being hurt. Language barriers represent one of the most clear cut obstacles, as researchers who are not fluent in the language of their participants would be remiss to try and undertake such a study. Likewise, considerations about the researcher's race, gender, and sexual orientation should also be reflected upon before entering the field, and along the way. Horowitz (1983), for example, recognized danger and chose to leave her research on Chicano youth when she found herself increasingly sexualized by the young men in the study. Morales (1989) had to negotiate political conflict and personal danger in his study of cocaine production in the Andes, and Bourgois' (2003) extended foray into the drug economy as part of his study of New York public housing residents brought numerous moments of danger which cannot be understood outside of the political context of his study. Without proper respect for the political ramifications or dangers of the host community that are defined by the political context or conflict within that community, researchers run the risk of harming both themselves and the participants.

Different political and economic situations create different risks for the researcher. Anner's injuries and Ferrell's arrests had everything to do with their active participation in and political commitment to their field sites. Gay's (2005, 2015) work interviewing drug peddlers in Rio de Janeiro put him in similar physical risk, which increased over his time in the field due to the increasing prevalence of the drug economy. Across much of the Global South, conducting research on politically contentious issues brings risks that must be recognized. Resorting to protection by authorities may not be an option. Indeed, it may be the authorities themselves who put researchers in risk, as in the vignette above. It is often moments like these when the political commitments researchers display come back to serve them – it may be those we study who provide the best protection, or at least information about where risk may come from. Regardless of the source of danger, however, we need to recognize that the political and economic dynamics that we witness may similarly affect us. The substantial difference, of course, between our potential experiences of danger and those whose lives we research is that our exposure is temporary while theirs persists as a defining character of their political and economic struggles. Still, remaining safe in an intrinsically conflictual field site can be a challenge to researchers. Some strategies might include mapping out the different stakeholders and examining their likelihood to commit violence; assessing one's own vulnerability; making sure one's informant network is informed of what actions the researcher will attend or accompany; and, building sufficient trust with participants that when potential threats arise, those participants will apprise the researcher of that danger.

Triangulating Data

The third vignette stems from the ethics of triangulating data. At what point does validation betray confidentiality? For example, Venkatesh's triangulation leads to harm to all his informants.

> 'Hey, you know what, I could actually use the chance to tell you [JT and Ms. Bailey] what I've been finding', I said, taking out my notebooks. 'I've been meeting so many people, and I can't be sure whether they're telling me the truth about how much they earn. I suppose I want to know whether I'm really understanding what it's like to hustle around here…'. For the next three hours, I went through my notebooks and told them what I'd learned about dozens of hustlers, male and female. (2008: 200–201)

The information divulging the tenants' employment had been given to him freely because Venkatesh was a trusted person under the patronage of the two power brokers. Venkatesh had gained no informed consent, offered no confidentiality, showed little respect for persons and this resulted in the two gatekeepers using the information to seek retribution from the tenants Venkatesh named. Venkatesh's efforts to confirm his data put those he researched at a clear disadvantage.

Nonetheless, triangulation is essential. As researchers on political issues, it becomes even more crucial to provide validity to the data gathered in the field. Good politics is never a substitute for good method. Especially in politically engaged fieldwork, researchers must be able to defend themselves against charges of bias. Ethnographers owe it to both their participants and their audiences to ensure that the final narrative is an accurate representation of the naturalist settings they observe, subjected to rigorous data gathering and clear-eyed analysis. One of the most promising avenues for ensuring the accuracy, reliability, and generalizability of fieldwork is through the process of triangulation. The vignette below shows one such effort.

> In 1994, I was researching how austerity and the global economy impacted neighborhood politics, again in Guadalajara, Mexico. The area I studied lacked sewers, potable water, and electricity, among other services; these hardships became the source of the neighborhood's political grievances. At the macro-political level, I found that national debt and Mexico's high interest payments diminished the resources used by the one-party state to incorporate challengers and stifle political dissent. At the neighborhood level, I found these political and economic changes opened the door to more democratic protest and coalitional organizing alternatives. During and after my initial year-long study, which turned into a 12-year engagement with a community organization (Shefner, 2008), I interviewed community members, activists, opponents of those activists, and multiple government officials, as well as conducting extensive archival research and observing countless events from festivals to protests to planning meetings.
>
> At one point, I arrived at a community welfare office to ask about certain infrastructure projects urged by the federal government, but viewed suspiciously by the community organization as a source of patronage and graft by the corrupt local political boss. When I asked questions about that latter individual, and how he sought to use those funds, the local government official displayed discomfort, and paused to call his federal-level boss in order to assure that he could in fact answer my questions. As it turned out, I had spoken to that official just days previously, and although the local administrator told his boss, with me in earshot, about the 'hot' questions I was asking, the fact that I had already gathered such information from that government entity eased my data collection. After the conversation with his superior, the local official I was speaking with provided me with his perspective on the local struggle, which turned out to be very consistent with the views of those in the community organization. The fact that I was asking about a public figure whose actions were documented in local newspapers provided another avenue for triangulation.

This form of triangulation, data triangulation, was one of four ways suggested by Denzin (1978). Data triangulation involves the use of multiple data sources when in the field. An ethnographer may, for example, learn something from a semi-structured interview and then confirm what consulting archival sources and conducting participant observation have said. The second process is investigative triangulation, which involves using multiple researchers in a study. Several ethnographers may go into the same field and then compare and contrast the different observations. Third, researchers may utilize theory triangulation, which involves applying different theoretical lenses to the data in order to uncover overlooked insights. Fourth, and finally, ethnographers may use methodological triangulation, or the use of multiple methods in a single study. A researcher may elect to study a sample of the population using interview techniques and then attempt to gather data on the entire population using survey analysis, or by observing an event that will allow additional perspectives and data regarding the issue at hand. Through the process of triangulation, the researcher can provide a more holistic description of the situation, confirm or refute evidence, and ensure the accuracy of their findings. In a setting where one has clear political affinities in a conflictual field context, such efforts are crucial.

Several scholars have built on Denzin's four-fold typology for triangulating data. Janesick (1994) adds a fifth type, interdisciplinary triangulation, which involves incorporating the methods and theories from a variety of academic disciplines. In her research on education, for example, she argues that interdisciplinary triangulation allows her to move beyond the purview of psychology, which has traditionally dominated the discourse. Likewise scholars from the post-structuralist tradition have engaged in what they describe as crystallization (Ellingson, 2008; Richardson, 1994; Tracy, 2010). Crystallization is similar to process of triangulation in that it encourages the use of different data sources, multiple investigators, and a variety of theoretical traditions, but, unlike triangulation, does not assume that convergence around multiple data points necessarily leads the researcher to a more accurate understanding. Crystallization research acknowledges multiple truths. Relatedly, ethnographers have also stressed the need to incorporate multivocality into research designs (Lindlof & Taylor, 2002; Tillmann-Healy, 2003). Multivocal research, as the name implies, stresses the need to incorporate varied voices and multiple perspectives in nearly all aspects of the research process. This tradition also encourages the research to reflect on their own status and include perspectives that differ from their own with regard to issues of class, race, gender, and sexuality. Although the strategies described here bear different names, they all aspire to achieve a more rich, thick, and accurate product of qualitative research.

As the preceding discussion indicates, triangulation is an effective method for ensuring the accuracy and validity of data gathered in the field. This is not to suggest that the method is unproblematic or without its consequences. As Venkatesh's (2008) example illustrates, data triangulation can have the unintended consequence of violating the confidentiality of research participants. Additionally, researchers have to ensure that the different sources of information they consult are actually providing accurate accounts and not just compounding errors. As Iphofen, Krayer, and Robinson note:

> Necessarily, the major problem with triangulation is the possible overlapping of weaknesses in each method which might serve to compound any errors that might be made. We might be deceived that merely by triangulating we are overcoming errors or weaknesses, thus leading us to have more faith in our findings than is justified. Consequently triangulation has to be employed carefully and with clear methodological justification in each case. Researchers would also have to show how they could guard against compounding errors of inference. (2009: 312)

Deacon, Bryman, and Fenton (1998) similarly caution researchers against conflating accounts when differences are found through the use of triangulation. Instead of privileging one account over another, the authors recommend respecting the validity of the different sources of data and discussing why the accounts may be in tension with one another. The important point is to plan carefully how and when to use the different approaches.

In the case described above, I was able to gather information about precise infrastructure projects from the organization I worked closely with and then checked them with local journalistic accounts and government documents. I additionally was able to confirm the data I collected with government officials of different levels and proximity to the streets I worked on; these officials were often political opponents of organization members. Because these were public struggles, I was able to avoid using names of those in the community organization, and often referred to the information in newspapers. Thus, triangulation not only allowed for a data check, but also inclusion of varied perspectives that informed the larger telling of the story. Triangulation not only made the data collection more comprehensive, it freed some to share their stories in ways they would not have done had they not known I had pursued additional data sources. Politically speaking, triangulation also addresses the danger raised by Shefner and Gay (2002). Politically engaged researchers may be susceptible to uncritically accepting the perspective of those they support without exercising due diligence to confirm the biases of those perspectives. Asking political opponents may not always be possible, but some kind of data check through triangulation should be.

Triangulation also is subject to power analysis. On the one hand, the perspectives of those in positions of lower power are often doubted, or taken as less important. On the other hand, those with greater power often have greater access to media by which their perspectives may be disseminated. This latter possibility questions how useful some use of archival triangulation may be. Yet even in contentious political field sites, those with less power may have allies willing to share information that aids triangulation. In situations such as the one I researched, the fact that a community organization of the urban poor was one of the stakeholders, and that it was supported by a coalition of more powerful middle-class NGOs allowed the former organization more consistent coverage in the local media, while the latter organizations provided for greater expertise in areas of infrastructure, legal aid, and human rights. This wide political field allowed for greater access to more people and more documents, while also providing the urban poor in the community organization greater access to media. Media coverage also highlighted those government actors important to the conflict. These characteristics of the political field, which may be somewhat common, allowed for wider possibilities to triangulate data. So too do alternative and self-generated media of varied and increasingly common kinds. The nature of the wide coalition, and the public nature of the conflict, also allowed me to ask questions about community needs and perspectives, while diminishing the need to share confidential information shared by vulnerable individuals in the community.

The Relationship between the IRB and Field Research

How does one apply the scholarship that tackles the problematic relationship between the IRB and field research (Bowern, 2010; du Toit, 1980; Feeley, 2007; Librett & Perrone, 2010; Salzinger, 2006; Stark, 2007; Thorne, 1980) in the situations that have been detailed in the vignettes? A few examples illustrate the range of views that critics of the IRB process hold. Authors such as Bowern (2010) argue that, despite numerous anecdotal accounts to the contrary, IRB oversight is not as burdensome as many linguistic and ethnographic fieldworkers may believe. In her survey of a hundred linguistic fieldworkers, Bowern found that the vast majority of respondents were not required to alter their research protocols in any substantial way, and only two respondents reported that their protocols were rejected by the IRB. This leads Bowern to conclude 'the review process appears to be working, in that more than two thirds of the respondents were seeking approval, gaining it with a minimum of protocol revisions, conducting their research, and not reporting problems even when given the opportunity to do so anonymously' (2010: 901).

Other scholars are not so sanguine. Stark (2007) takes a historical look at the evolution of the IRB process and sees it as an intrusive but necessary safeguard against abuse. Stark recommends several ways that IRBs could be more accommodating to fieldwork. These changes include adding more ethnographers to the review boards and encouraging serious dialogue among board members when objections arise. Instead of making changes to the federal regulations that oversee human subjects, Stark advocates for researchers to attempt to make local changes within the context of their home institutions. Like Bowern, Stark expresses concerns about the relationship between the IRB and academic freedom, but states that the 'victim narrative' among social scientists 'does not stand up to historical scrutiny' (2007: 785).

Vocal critics of the IRB review process such as Feeley (2007), Katz (2006), and Salzinger (2006) argue that ethical review boards are a flagrant form of censorship and should be done away with. Feeley suggests that '[w]hen held up to the standards for legality, IRBs fall short in many respects' (2007: 771). He argues not only for a complete overhaul of the review system, but also encourages faculty members to subvert the review process by becoming members of the boards and helping to facilitate all research. Similarly, Katz (2006) illustrates how fieldworkers conducting participant observation simply cannot comply with the regulations specified by IRBs. He advocates for IRBs to develop a culture of legality and take seriously the 'escape routes' that would allow ethnographic research to be exempted from review (2006: 500). Finally, Salzinger (2006) describes eight complexities of IRB review that not only stifle research projects, but also that actually produces problems in the research design and implementation. Salzinger recommends 'eliminating IRB's various and sundry supervising groups' and instead simply trusting researchers to be responsible in their conduct (2006: 9).

One of the most troubling impositions that IRB's apply to ethnographic fieldwork is the issue of informed consent. Many researchers have commented that informed consent, while necessary in biomedical experiments, is ineffective, impossible in some situations, poses undue risks on research subjects participating in ethnographic studies, and can have chilling effects on the research (du Toit, 1980; Librett & Perrone, 2010; Nelson, 2004; Thorne, 1980). When greeted with a written document and a request for signature, individuals may be less willing to divulge their true feelings and intentions, directly compromising the researcher's efforts to observe natural behavior. As Librett and Perrone (2010) note, potential participants are uneasy about the signing of official documents and often mistakenly assume that informed consent statements are waivers that surrender the participant's right to anonymity. In the worst-case scenario, the IRB's requirement of informed consent may actually increase the risk of exposing the participant's true identity (Librett & Perrone, 2010; Thorne, 1980).

The vignettes above suggest a variety of contributions to this debate. First, in certain field moments, rigidly hewing to the informed consent process might not only chill data collection, it may be physically impossible. In moments like these, the physical cues of taking notes while being honest about why data is being collected serves as implied consent; when one does not take names as a process of data collection, anonymity and confidentiality cannot be breached. Additionally, hewing to IRB standards may help safeguard the wellbeing of those being researched, but the researcher may face a variety of dangers. Clear knowledge of the field and good relations with research participants may provide the researcher with some protection. Finally, IRBs often have very little to do with good data collection, which requires a commitment to triangulation that may prove difficult to achieve in politically contentious field sites.

CONCLUSION – WHY ARE POLITICS IMPORTANT?

This chapter has advocated for a more nuanced consideration of the political concerns that ethnographers face in the field. As we have demonstrated, political concerns differ from procedural ethical concerns in substantive ways. The stated goal of ethical review boards is to prevent harm to research subjects, but the regulations they impose do not require that researchers be held to a higher standard – to care for the struggles of their participants, to empower their research subjects, to fight for positive political change. This is not a call for IRBs to try and impose these standards, neither is it a call for ethnographers to pander to their research participants, nor is it an expectation that all ethnography explore politically contentious activity. Instead, it is a call for politically engaged researchers to be mindful of the implications of their work. Ethnographers should be critical, they should be honest, and they should be reflexive, but they should also be cognizant of power differentials within society and understand that, in many cases, the people or groups they study have comparatively little. Standpoint theory suggests the perspectives of the oppressed be privileged. We are sympathetic to this contribution, but recognize the need for triangulation efforts that take into account that the perspectives of the less powerful may not always be represented faithfully or at all in document and archival evidence. Here, alternative media and allies can provide data confirmation if it is not available in other ways.

Political concerns also differ from reciprocity. Ethnographers should do whatever they can to ensure that the research is mutually beneficial, and researchers should give back by working for the people they study. In the locales the senior author worked, he shared data with those studied, acted as event photographer, aided with political analysis, and participated in electoral observations. Reciprocity does not end when the study concludes, however. Researchers should continue to consider the political concerns that we have outlined. Ethnographers must contemplate the policy implications of their work, share their work in meaningful ways, and serve as an advocate for those people and organizations that they study. Perhaps it is best to remember, especially in researching politically conflictual sites, Becker's (1967) famous question: whose side are we on? To Becker's contribution, we add the following question, to which we hope we have offered some answers: How does the researcher keep good politics from obstructing good data collection? Here is where the ethics and politics of research intersect, as neither social science nor progressive politics is furthered by bad data collection.

REFERENCES

Anner, Rosemarie. 2014. 'Greenwich Mother Recalls Horror of a Son in Peril in a Dangerous Land'. Greenwich Time, October 30.

Becker, Howard S. 1967. 'Whose Side Are We On?' *Social Problems* 14(3): 239–247.

Bourgois, Philippe. 2003. In Search of Respect: Selling Crack in El Barrio 2nd ed. New York: Cambridge. University Press.

Bowern, Claire. 2010. 'Fieldwork and the IRB: A Snapshot'. *Language* 86(4): 897–905.

Collins, Patricia Hill. 1997. 'Comment on Heckman's "Truth and Method: Feminist Standpoint Theory Revisited": Where's the Power?' *Signs: Journal of Women in Culture and Society* 22(2): 375–381.

Deacon, David, Alan Bryman, and Natalie Fenton. 1998. 'Collision or Collusion? A Discussion and Case Study of the Unplanned Triangulation of Quantitative and Qualitative Research Methods'. *International Journal of Social Research Methodology* 1(1): 47–63.

Denzin, Norman K. 1978. The Research Act: A Theoretical Introduction to Sociological Methods 2nd ed. New York: McGraw-Hill.

Duncombe, Jean and Julie Jessop. 2002. '"Doing Rapport" and the Ethics of "Faking Friendship"', pp. 107–122: In Ethics in Qualitative Research, edited by Melanie Mauthner, Maxine Birch, Julie Jessop, and Tina Miller. Thousand Oaks, CA: Sage.

du Toit, Brian. 1980. 'Ethics, Informed Consent, and Fieldwork'. *Journal of Anthropological Research* 36(3): 274–286.

Ellingson, Laura L. 2008. Engaging Crystallization in Qualitative Research. Thousand Oaks, CA: Sage.

Ellis, Carolyn. 2007. 'Telling Secrets, Revealing Lives: Relational Ethics in Research With Intimate Others'. *Qualitative Inquiry* 13(1): 3–29.

Feeley, Malcom. 2007. 'Legality, Social Research, and the Challenge of Institutional Review Boards'. *Law & Society Review* 41(4): 757–776.

Ferrell, Jeff. 1997. 'Criminological *Verstehen*: Inside the Immediacy of Crime'. *Justice Quarterly* 14(1): 323.

Gay, Robert. 2005. Lucia: Testimonies of a Brazilian Drug Dealer's Woman. Philadelphia, PA: Temple University Press.

Gay, Robert. 2015. Bruno: Conversations with a Brazilian Drug Dealer. Durham, NC: Duke University Press.

González, María Cristina. 2000. 'The Four Seasons of Ethnography: A Creation-Centered Ontology for Ethnography'. *International Journal of Intercultural Relations* 24(5): 623–650.

Guillemin, Marylis and Lynn Gillam. 2004. 'Ethics, Reflexivity, and "Ethically Important Moments" in Research'. *Qualitative Inquiry* 10(2): 261–280.

Harding, Sandra, ed. 2004. The Feminist Standpoint Theory Reader: Intellectual and Political Controversies. New York: Routledge.

Hartstock, Nancy C. M. 1983. 'The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism', pp. 283–310: In Discovering Reality: Feminist Perspectives on Epistemology, Metaphysics, Methodology, and Philosophy of Science, edited by Sandra Harding and Merrill B. Hintikka. Dordrecht, The Netherlands: Kluwer Academic Publishers.

Heckman, Susan. 1997. 'Truth and Method: Feminist Standpoint Theory Revisited'. *Signs: Journal of Women in Culture and Society* 22(2): 341–365.

Horowitz, Ruth. 1983. Honor and the American Dream: Culture and Identity in a Chicano Community. New Brunswick, NJ: Rutgers University Press.

Iphofen, Ron, Anne Krayer, and Catherine Robinson. 2009. Reviewing and Reading Social Care Research: From Ideas to Findings. Bangor, UK: Bangor University.

Janesick, Valerie J. 1994. 'The Dance of Qualitative Research Design: Metaphor, Methodolatry, and Meaning' pp. 209–219: In Handbook of Qualitative Research, edited by Norman K. Denzin and Yvonna S. Lincoln. Thousand Oaks, CA: Sage.

Katz, Jack. 2006. 'Ethical Escape Routes for Underground Ethnographers'. *American Ethnologist* 33(4): 499–506.

Librett, Mitch and Dina Perrone. 2010. 'Apples and Oranges: Ethnography and the IRB'. *Qualitative Research* 10(6): 729–747.

Lindlof, Thomas R. and Brian C. Taylor. 2002. Qualitative Communication Research Methods 2nd ed. Thousand Oaks, CA: Sage.

Miles, Matthew, A. Michael Huberman, and Johnny Saldaña. 2014. Qualitative Data Analysis: A Methods Sourcebook. Thousand Oaks, CA: Sage.

Morales, Edmundo. 1989. Cocaine: White Gold Rush in Peru. Tucson, AZ: University of Arizona Press.

Moreno, Eva. 1995. 'Rape in the Field: Reflections from a Survivor', pp. 219–250: In Taboo: Sex, Identity, and Erotic Subjectivity in Anthropological Fieldwork, edited by Don Kulick and Margaret Wilson. New York: Routledge.

Nelson, Cary. 2004. 'The Brave New World of Research Surveillance'. *Qualitative Inquiry* 10(2): 207–218.

Punch, Maurice. 1994. 'Politics and Ethics in Qualitative Research', pp. 83–98: In Handbook of Qualitative Research, edited by Norman K. Denzin and Yvonna S. Lincoln. Thousand Oaks, CA: Sage.

Richardson, Laurel. 1994/2000. 'Writing: A Method of Inquiry', pp. 923–948: In Handbook of Qualitative Research 2nd ed., edited by Norman K. Denzin and Yvonna S. Lincoln. Thousand Oaks, CA: Sage.

Sales, Bruce and Susan Folkman. 2000. Ethics in Research with Human Participants. Washington, DC: American Psychological Association.

Salzinger, Kurt. 2006. 'The Institutional Review Board: A Modest Proposal'. *Journal of Social Distress and the Homeless* 15(1): 5–12.

Shefner, Jon. 2008. The Illusion of Civil Society: Democratization and Community Mobilization in Low-Income Mexico. University Park, PA: The Pennsylvania State University Press.

Shefner, Jon. 2016. 'How Community Collaboration Transformed the Research Question in a Study of Knoxville's Green Economy', pp. 147–158: In Qualitative Ethics in Practice, edited by Martin Tolich. Walnut Creek, CA: Left Coast Press.

Shefner, Jon and Robert Gay. 2002. 'The Politics of Field Research: Lessons from Brazil and Mexico'. *Canadian Journal of Latin American and Caribbean Studies* 27(54): 199–213.

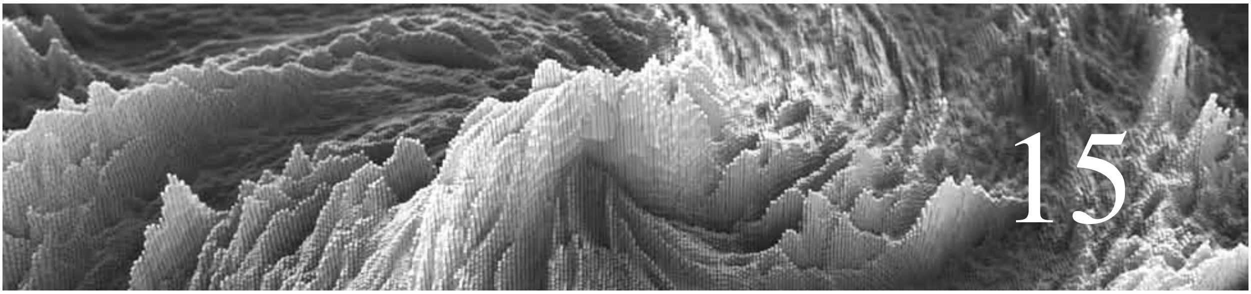
Stark, Laura. 2007. 'Victims in Our Own Minds? IRBs in Myth and Practice'. *Law & Society Review* 41(4): 777–786.

Thorne, Barrie. 1980. '"You Still Takin' Notes?" Fieldwork and the Problems of Informed Consent'. *Social Problems* 27(3): 284–297.

Tillmann-Healy, Lisa. 2003. 'Friendship as Method'. *Qualitative Inquiry* 9(5): 729–749.

Tracy, Sarah J. 2010. 'Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research'. *Qualitative Inquiry* 16(10): 837–851.

Venkatesh, Sudhir. 2008. Gang Leader for a Day: A Rouge Sociologist Crosses the Line. New York: Penguin Press.



15

Qualitative Ethics in a Positivist Frame: The Canadian Experience 1998–2014

Igor Gontcharov

Research ethics review emerged in biomedical and behavioral research following WWII, and became a mainstream practice in these areas of knowledge throughout the late 1970s to mid 1990s in both Canada and the United States. It was initially introduced as an instrument of 'risk management' following the disclosure (esp. Beecher, 1966) of, and a growing public concern over, existing ethical problems in *government-sponsored* biomedical research. The current model of prospective ethics review can be traced back to particular institutional settings, and in this sense it can be understood as an 'outgrowth of the particular organization and shifting power dynamics of the National Institutes of Health, and its parent organization, the Department of Health, Education and Welfare, in the mid-twentieth century' (Stark, 2006). The focus of new regulations, such as the *Belmont Report* (1979) in the United States, and The Medical Research Council of Canada *Guidelines on Research Involving Human Subjects* (1987) and earlier institutional guidelines (Dickens, 1979), fell largely on the risks of physical and lasting psychological harm posed to prisoners, military personnel, and psychiatric patients, who all had a limited ability to give free and informed consent for their participation in research.

Following the introduction of research ethics review in a narrow segment of government-sponsored research, the focus of ethics review started to broaden rapidly. By the late 1990s, the mandate of research ethics boards (REBs) expanded to all research, including self-funded and unfunded, and to all disciplines including the social sciences and humanities (SSH), and became applicable to all populations. Importantly, research ethics regulation has taken a global character as national research ethics regimes are borrowing from each other, uncritically transplanting the biomedical approach to the governance of all research involving humans.

The expansion of REB oversight (institutional review boards, IRBs in the USA) progressed with little respect to the principles, standards, and contexts of SSH research, and was not supported by relevant data substantiating its need and effectiveness in non-biomedical research settings. Neither was there an open forum with either social scientists or research participants regarding *their* perspectives on the principles and approaches to the governance of research involving humans. It has to be noted that prior to 'harmonization' in the disciplinary approaches to ethical governance in research involving humans in 1998, the SSH had their own set of ethics guidelines, the 1979 Social Sciences and Humanities Research Council *Ethics Guidelines for Research with Human Subjects* (1980), which was first developed by the Canada Council for the Arts in 1976 and was largely unknown with limited regulatory effects (McDonald, 2009).

The goal of this chapter is to examine how social science in general and qualitative research in particular has weathered this policy development. A case study concerning the development of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* in 1998 is featured along with its revision in 2010 and 2014. The overall thesis offered here is that research governance on the basis of the biomedical model of prospective ethics review has negatively affected the ethics and methodologies of knowledge production in the SSH, as has also been argued by van den Hoonaard in *The Seduction of Ethics* (2011).

The expansion of research ethics review to SSH research has been rationalized in such terms as *ethics creep* (Haggerty, 2004), *mission creep* (Gunsalus et al., 2007), and *ethical imperialism* (Schrag, 2010), which all imply a regulatory and methodological colonization of the SSH by the growing ethics industry. The first edition of the *Tri-Council Policy Statement* (*TCPS 1*) was adopted in 1998. The second edition (*TCPS 2*) was adopted in December 2010 and updated in 2014, reaffirming the biomedical model of research ethics review as a standard of ethical governance, thus further tightening the regulatory capture of the SSH by the institutions of prospective ethics review. The outcome has been an expansion of the procedural basis of research oversight.

Burris (2008) notes that the governance model behind the 'Common Rule' (the phrase used since 1981 for the baseline standard of ethics for human subjects research in the USA) (DHHS, 2005) is in its basic design consistent with reflexive regulation and new governance models, presumably allowing research ethics committees to take advantage of their proximity to the sites of research, local experts and broad autonomy in interpreting and applying the regulations. In practice, however, the model functioned differently than one would predict. This observation is also valid in respect to the *TCPS*. For example, the character of ethical guidance by such diverse REBs, existing in different research settings, was idiosyncratic – their review and decisions regarding the same projects, such as in multicenter studies which had to pass review at every participating site, were inconsistent and often contradictory. Accordingly, REBs restricted themselves in exercising their autonomy. They demanded more guidance from the Interagency Advisory Panel on Research Ethics, more rules rather than principles, and thus gravitated towards a decontextualized ethics review model to ensure consistency, and other ways to ensure the uniformity of expert knowledge contributing to ethics review. This has led to the processes of standardization, centralization, professionalization, and specialization in ethics review, which has been a characteristic of the ethical landscape in the governance of research involving humans since 1998. Importantly, and although these processes were generally triggered by the requirements of biomedical research, they unavoidably affected knowledge production in the SSH. These processes prompted further integration of non-biomedical research in the biomedical framework of ethics review.

Indeed, *standardization* may bring with it a number of advantages. In terms of the cost–benefit analysis, which is often used as a rationale for standardization, such advantages include lower expenditures on implementation, management, learning, adaptation, and further development. Meanwhile, standardization has its own costs related to the transition and subsequent performance of the common standard, which may be distributed unequally among the standardized fields. Thus, the adoption of the common standard in the governance of research involving humans was accompanied by an unavoidable extinction of many established practices and disciplinary research standards, especially in the SSH, which policymakers could not, or preferred not to accommodate.

For example, there are significant differences with respect to *free and informed (documented) consent* for participation in research. While it is an important standard in the biomedical sciences, this requirement may contradict certain research methodologies within SSH, and if implemented and followed, may serve as a source of harm to researchers and participants. Similarly, a number of 'default settings' in SSH research are different, and even opposite to those of biomedical research. In biographic research for example, anonymity may not be desirable or achievable; in critical policy research, an obligation to disclose research objectives and seek informed consent could compromise its objectives; in survey-based research consent is implied, unless revoked by the participant. The extension of the biomedical standard to these research environments introduced a different standard – often antagonistic to the context and applied research methodology. At times the requirement of free and informed consent was seen as merely a nuisance, contributing an element of awkwardness, such as insisting on written consent forms in a basic survey, which only wasted time and resources of all parties. On other occasions, the requirement could put researchers and participants in danger when studying such sensitive issues as corruption, use of regulated substances, or euthanasia.

Meanwhile, biomedical ethics has influenced the standard of care in the social sciences, changing their research landscape. For example, research participants may now expect and request written consent forms. Accordingly, the defaults have been reversed. Such influence has significant consequences for a number of research fields and methodologies. In some cases, written consent forms may be understood by researchers and participants as annoying legalistic requirements/interventions, a kind of disclaimer limiting institutional liability, rather than informing about research objectives, risks of harm, or communications of gratitude for participation. In other cases potential research participants may insist on written consent forms to restrict researchers' access, thus protecting organizational and personal interests. Even if an understanding of research participants as vulnerable may generally reflect the situation in biomedical research, in the SSH the context may be different: individuals and organizations are often more powerful and may pose risks to researchers.

Similar observations can be made about other biomedical requirements, such as the insistence of anonymity and generalizability of data, and the understanding of risks and benefits in terms of individuals rather than collectivities.

It is common to identify three general approaches to standardization: (1) developing a new standard from 'scratch'; (2) proceeding from a common denominator; and (3) generalizing existing standards (e.g. Pistor, 2002).

Standardization of the mid to late 1990s in the governance of research involving humans was generally rendered by policymakers in terms of *harmonization*. This is the language used in the first *TCPS*. In practice, the biomedical approach of prospective ethics review was adopted as a common standard, since the SSH lacked the mechanism of prospective ethics review altogether, even if some research was peer reviewed at the funding stage. This is why a number of academic researchers disagreed that the first *TCPS*, and their counterparts in other countries, such as the *Belmont Report* are in any sense *harmonized* policies. Rather, they argued that the process of standardization in research involving humans is an example of regulatory capture, describing what was happening in terms of biomedical ‘ethics creep’, ‘ethical imperialism’, ‘methodological colonialism’, using politically-loaded language to emphasize the disempowerment of social disciplines and the worsening of their ethical landscape. This is when ‘ethics’ acquired a derogatory meaning for many social researchers, and REBs acquired an aura of ‘the ethics police’ (Klitzman, 2015), rather than a friendly collegial space for discussing ethical challenges and dilemmas. Tolich and Smith offer to correct this trajectory by proposing the adoption of an optional consultative model of ethics review (2015).

It is important to emphasize that the first *TCPS* formally endorsed *ethical pluralism* and even allowed for alternative regulatory regimes (via a mechanism of exemptions) for certain research methodologies, but these regimes were immediately suppressed by the overall framework requiring determination of the exemption status by REBs. In the second *TCPS* (2010), the regime of non-working exemptions was dropped altogether. Furthermore, the second *TCPS* adopts the language that is, presumably, more familiar to the social sciences, such as ‘*human participant*’ instead of ‘*research subject*’, or ‘*project*’ instead of ‘*protocol*’. These changes can be better understood as formal gestures to SSH researchers, since the universality of prospective review has not been challenged in any way in the new edition of the Policy. For example, the concept of *human participants* is not necessarily representative of the whole spectrum of relationships among humans involved in knowledge production in the SSH. Furthermore, when transplanted into a positivist framework of the *TCPS*, they may not be able to ‘patch up’ such problems of human subjects as power imbalances or lack of free and informed consent in biomedical research, but they will introduce more challenges for critical research, as I argue elsewhere (Gontcharov, 2016).

The *‘colonization’* of the SSH was facilitated by the heterogeneity of their ethico-methodological landscape. A number of social disciplines use a methodological toolset that they share with biomedical disciplines, especially in research projects that unfold sequentially and adhere to an earlier established study design or protocol. In this case, the application of prospective ethics review as an instrument of risk management is at least methodologically consistent. Nevertheless, there is still a question of whether or not prospective ethics review is an adequate measure to the character of risks arising in SSH research, and if such risk justifies a system of research oversight based on prospective ethics review.

Accordingly, some social researchers would not necessarily oppose prospective ethics review from a methodological perspective, though they might still disagree on ethical grounds (Dingwall, 2008). This might explain the position of the Social Sciences and Humanities Research Council to collaborate with two other major Canadian Research Councils in developing common ethical standards in research involving humans. The social sciences reflect a broader spectrum of research methodologies, but not all of them are equal at the governance level, where preference is given to quantitative data rather than views/narratives from a unique perspective.

The majority of social researchers who participated in developing a new ‘harmonized’ approach of prospective ethics review generally represented a perspective consistent with positivist methodology. For them, the integration of the SSH in the existing biomedical framework would not be a methodologically incoherent step. Accordingly, the Social Sciences and Humanities Research Council generally adopted the biomedical approach, while making reservations and exceptions for disciplines, methodologies, or populations that did not seem to fit the framework well enough, such as qualitative, critical, public policy, educational and aboriginal/indigenous people’s research.

The minority hoped that through collaboration with their biomedically-minded colleagues it would be possible to develop a truly *common* ethics framework that could embrace the non-positivist modalities of knowledge production. However, as van den Hoonaard, one of the founding members of the Interagency Advisory Panel on Research Ethics, writes in the *Seduction of Ethics* (2011), it had become obvious very soon that the underlying conceptual and regulatory structure was tailored to the needs of biomedical sciences, which effectively suppressed any initiatives to design a consensus model of research ethics.

The 'Ethics Rupture' expert symposium was one instance of this widening rift in the ethics of the social sciences. The *Ethics Rupture: An Invitational Summit about Alternatives to Formal Research-Ethics Review* was held in Fredericton, New Brunswick in 2012 (van den Hoonaard, 2013a; van den Hoonaard, 2013b). This was the first conference – 14 years after adopting the biomedical standard – which focused on the impact of prospective ethics review on the social sciences in Canada and discussed the alternatives to prospective ethics review. In the words of its organizers:

> Many scholars in the SSH have noted the inadequacy of the current formal system of research-ethics review to fairly offer ethical consideration in light of their research needs. The formal system of ethics review has placed the social sciences (and some humanities research) in a precarious situation. The bio-medical conceptions of research on which the system relies are not up to the task to give discipline-appropriate advice to other fields.
>
> The time has come to convene an international summit to find alternative means to underscore the ethical approaches in social-science and humanities research. Alternative means would also stem the tide of the homogenization of the social sciences and the humanities and the pauperization of their methodologies brought on today by research-ethics regimes.
>
> … Because supporters of the prevailing formal research-ethics regimes are already given much airtime on official agendas, listservs, and policy conferences, the Summit provides a unique opportunity for scholars to freely exchange ideas about alternative ideas about research-ethics review. The Summit is open to all who wish to follow and learn more about these ideas. (van den Hoonaard, 2012)

One outcome of the Summit was a publication of *The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review* (2016), edited by Will van den Hoonaard and Ann Hamilton, to which I contributed chapter 13: 'The Eclipse of "Human Subjects" and the Rise of "Human Participants" in Research Involving Humans'.

It is important to note that the Social Sciences and Humanities Research Council funded the *Ethics Rupture* Summit with members of the Secretariat on Responsible Conduct of Research (SRCR) attending the event. According to the Terms of Reference, the mandate of the SRCR is to provide substantive and administrative support to the Interagency Advisory Panel on Research Ethics with respect to the *TCPS*. The Social Sciences and Humanities Research Council's support is indicative of its interest in learning more about the role of the *TCPS* in the governance of social science and humanities research. However, in the preceding seventeen years the study of the impact of prospective review on the SSH has not been one of the funding priorities for the Council. Even if this question is formulated more narrowly in terms of risk, safety and protection of human participants in SSH research and thus reflecting the approach of the *TCPS,* there is still no systematic approach to measuring the effectiveness of prospective ethics review. In this sense the process of policy development in research involving humans has not been empirically grounded and validated.

A major issue with prospective ethics review is seen to be its adoption on a *moral panic* (Cohen, 2002; van den Hoonaard, 2001) wave – that is, without a proper justification of its need and effectiveness in maintaining required ethical standards in SSH research. Another major issue is the limited interest of regulators in learning whether or not the *TCPS* was able to enhance the ethical dimension in research involving humans. It is necessary to find out why an event such as the *Ethics Rupture* Summit has not triggered a review of the conceptual and regulatory framework in research involving humans.

Now to the question of why ‘non-positivist’ researchers, that is those who represent the disciplines and methodologies inconsistent with the biomedical model of risk management, did not or could not offer a strong and persuasive alternative to prospective ethics review. A number of reasons contributed to this outcome – methodological heterogeneity, disciplinary fragmentation, and existing methodological hierarchy at the level of funding and governance.

As indicated above, some researchers counted on the evolution of the *TCPS* into a policy that will eventually embrace ethico-methodological pluralism, since the 1998 edition was still relatively open to non-positivist research. It also emphasized its flexibility and consultative character, positioning itself as a living document and soft law – flexible ethical guidelines rather than administrative law. Thus, there was a hope that the Policy would build upon and learn from the existing communities of research practice, rather than reshaping them from above.

Others counted on the exemptions mechanism and separate regulatory regimes for their disciplines, methodologies, and areas of research. Still others thought that the issue is not so much in the underlying ethical principles and prospective ethics review as a mechanism ensuring compliance, but in the composition of REBs – their methodological expertise. They argued that the presence of experts in ‘qualitative’ methodologies on ethics committees would be necessary when considering non-positivist research. Similarly, there were suggestions that a linguistic overhaul of the *TCPS*, for example, avoiding such biomedical irritants as ‘research subject’ and ‘protocols’, would facilitate the development of the Policy towards multidisciplinarity, yet social scientists were excluded from the core policymaking groups. For example, Zachary Schrag’s monograph details how social researchers were excluded from the governance of research involving humans in the USA (Schrag, 2010, 2011). Canada followed a similar trajectory, being influenced by the emerging ethics oversight regime in the USA, and borrowing heavily from the *Belmont Report* (1979), subsequently incorporated in the *Code of Federal Regulations* (2005).

The work on the second *TCPS*, updated again in 2014, presented an opportunity to respond to the recommendations and criticisms of the *Law Commission of Canada Report, 2000* (McDonald, 2000; McDonald, 2001), *Giving Voice to the Spectrum* Report (Interagency Advisory Panel on Research Ethics, 2004), as well as the feedback from criminologists (Palys, October 16, 2015; Palys & Lowman, 2016), critical submissions received during several rounds of consultations (December 2009), and contributions of the *Ethics Rupture* Summit participants. However, by and large the Interagency Advisory Panel on Research Ethics has not taken advantage of these critical contributions, since SSH researchers, non-biomedical research participants (Gontcharov, 2016) have not been sufficiently empowered as policy actors and invited to the table.

Somewhat paradoxically, despite promoting a positivist perspective of research ethics, the Panel, including the Secretariat on Responsible Conduct of Research, has not adopted an empirical standard for evaluating its own performance. Evidence-based regulation of research ethics (Beagan & McDonald, 2005) has yet to become a criterion of its effectiveness in the governance of research involving humans. Since the performance of the Panel is part of its accountability to the public as a research ethics regulator, it should not exclude itself when developing ethical standards. Meanwhile, although empirical studies of REBs were rare by the time when ethics review expanded to the social sciences, they already expressed concerns about the suitability of the mainstream biomedical approach to critical public health research and health research based non-positivist methodologies (Bell et al., 1998; McDonald, 2000).

In developing the *TCPS*, the regulators, following the unified science model, assumed that SSH research is subject to the same problems as documented in other branches of positivist research, and therefore no justification for the expansion of ethics oversight was required and provided. Although SSH researchers could not immediately produce sufficient evidence regarding the impact of the first *TCPS*, there were strong ethical and structural arguments against ethics oversight in the SSH (Dingwall, 2008; Hammersley, 2009; Schrag, 2011), which the Panel could have considered. The fact that they did not challenge the overall approach can be possibly attributed to the composition of the Panel, which is tailored to the needs of biomedical research (Gontcharov & MacDonald, 2016).

The promise of reflexive regulation has not been fulfilled since the overall positivist framework prevented the Panel from becoming a learning regulator, capable of transfiguring their approaches in response to the needs and values of *all* researchers and participants whose conduct it regulates, rather than responding to the needs of biomedical researchers exclusively. This explains how idiosyncratic decision-making could result in restricting particular research areas and methodologies in a uniform way (Meyer, 2013, 2014; Stark, 2012). Since 1998 the development of the *TCPS* proceeded in the direction of enabling positivist research and suppressing research initiatives and methodologies that deviate from it. The processes of centralization, specialization, and professionalization in the governance of research involving humans generally supports the biomedical framework, thus making it more and more difficult for REBs to attune themselves to the actual ethical requirements of SSH research.

Since the formation of 'moral regulation' and institutionalization of IRBs from 1953 to 1974 (Stark, 2006; Stark, 2012) the mandate of ethics committees has expanded beyond its original task of protecting human subjects in biomedical research. New responsibilities include the consideration of scientific merit, soundness of research methodology, institutional liability, conflict of interest, and even criminal checks of researchers. C.K. Gunsalus and co-authors, in a landmark policy paper *The Illinois White Paper: Improving the System for Protecting Human Subjects: Counteracting IRB 'Mission Creep'*, identify such critical issues in the system of research oversight as: (1) the system of reward and punishment does not correspond to the stated objectives of ethics oversight, (2) vague definitions lead to expansive interpretation, (3) prospective ethics review promotes how to appear ethical, and (4) preoccupation with irrelevant tasks, such as management of legal risks (Gunsalus et al., 2007). These are some of the issues behind IRB mission creep, which is also characteristic of ethics review in Canada.

The first issue, which Gunsalus et al. call 'rewarding the wrong behaviors', is a result of an 'inherent contradiction' in the mission of research ethics committees. This contradiction is a consequence of how the Policy understands the production of new knowledge and the role of researcher in this process. On one hand, researchers cannot be trusted, so every single initiative required research ethics review. On the other, research ethics committees have to trust researchers anyway, since they are largely unable to oversee the actual run of research, beyond the initial ethics review and periodic review based on self-reporting. Accordingly, REBs can only assess the ethics of the submitted research protocols. But can the protocol serve as an indicator of the actual research? Since the review procedure does not engage with the research itself, REBs can only *hope* that research is conducted ethically.

Currently, there is no comprehensive system of research ethics oversight, but rather a system of research protocol/project oversight. Nevertheless, the *TCPS* understands the mission of REBs as extending beyond the oversight of research projects, but can hardly engage in the oversight of the actual research projects due to financial and logistical limitations. Hence the situation is such that (a) all individual research projects require review and approval and (b) REBs can only *hope* that researchers conduct approved research ethically, since they do not entirely trust them. In part, this is a result of the *TCPS*'s understanding of research in terms of danger, rather than risk, despite using the language of *risk* management, such as, *risk of harm* to human participants. Its general operative framework is built on the 'medieval' coupling danger-hope, rather than the 'modern' trust-risk (Luhmann, 2000). Understanding research in terms of uncertain dangers forces REBs to address a wide spectrum of possible dangers associated with research activity, rather than focus on the specific risks that research poses to its participants. In this sense, REBs can only hope that ethics review averts some of the dangers. This would explain why neither the Interagency Advisory Panel on Research Ethics, nor individual REBs engaged in developing the substantive indicators of their contribution in protecting human participants on national and institutional levels, which would go beyond the procedural ones, such as the duration of ethics review or the number of projects reviewed.

Although the focus on research projects rather than research itself can be explained in terms of limited resources, the preoccupation with research protocols can be also seen as an outcome of the adopted conceptual framework, which gives priority to the scheme of research. From the procedural point of research ethics review, as in Platonism, the protocol is truer and more real than research itself. For REBs, a research design that corresponds to the ideal form is all that matters. This is a consequence of the *TCPS*'s reductionist understanding of research. This understanding is consistent with positivism, according to which research is divided into stages – rigid and sequential – in which one stage of research design always precedes other stages, such as data collection, analysis, interpretation, and dissemination of results. It is assumed that researchers will follow the approved design until research is completed. Indeed, the actual picture of science is more nuanced, paradigmatic (Feyerabend, 1993; Kuhn, 1962), subject to socio-political, and economic pressures and challenges. The role of REBs then becomes to identify and correct any undesirable deviations from the prescribed standard at the stage of research design.

A linear understanding of the research process maps poorly on other methodologies of knowledge production. Brunger and Burgess (2005) use the term 'linear model of research ethics' to articulate a similar idea. They suggest that governance on the basis of the linear model should give way to an analysis that would consider research ethics as an embedded phenomenon, thus explicitly recognizing that it is subject to complex social influences. For example, in 'qualitative' methodologies the stage of research design does not necessarily precede data collection. In fact, various stages, if we use this language, may coincide. Research design may change in the process of 'data collection'. It has to be flexible and adaptive, capable of responding seamlessly to the changes in the research situation, as required, for example, in participant observation with risk-taking populations.

Since the *TCPS* adopted the positivist understanding of research as a universal standard for all research disciplines, it is unavoidable that some research initiatives based on alternative or mixed methods experience challenges in passing ethics review. Since the format of ethics review is tailored to positivist research, 'qualitative' researchers try to fit in the framework – even if it is hardly relevant – when/thus filling out REB forms, identifying risks of harm, answering questions about anonymity and generalizability of data, or designing written consent forms. If they anticipate significant challenges in passing ethics review, they will probably decide against pursuing the project. Will van den Hoonaard's *The Seduction of Ethics* (2011) documents the ongoing methodological pauperization of the social sciences. If the projects are designed to appear consistent with the positivist standard, then how can ethics review have any favorable effect on achieving such goals of the *TCPS*, as protection of human participants, sustaining trust in science, advancing research, or ensuring highest ethical standards?

When the *TCPS* was updated in 2010 and 2014, the overall biomedical framework had not been critically and systematically reassessed. Instead, the Interagency Advisory Panel on Research Ethics preferred to better accommodate the SSH within the deficient conceptual framework through terminological changes and expanded guidance to REB members and professionals. Although some elements of the updated *TCPS* are undoubtedly important and innovative, such as the idea of group consent in aboriginal research, these elements had not resulted in questioning the universality of the biomedical approach with its focus on individuals – risk management via the assessment of the risk of harm to individuals, written individual consent, or the focus on privacy and anonymity. The concept of collectivities remained exclusive to aboriginal communities. Most of the tensions between prospective research ethics review and the actual practices of knowledge production are even more acute now than immediately after adopting the first *TCPS* in 1998 when it still had the status of ethical *guidelines*.

Since the biomedical conceptual framework remains largely intact, all initiatives at knowledge production that do not fit the required protocol format continue to be censored or modified by researchers themselves in order to resemble the standard. In this sense, prospective ethics review engendered a practice of *conspicuous compliance,* to borrow from Veblen's concept of *conspicuous consumption* (1979), rather than having contributed to the stated objectives of ethics review. This is why the bureaucratic process and paperwork remain the indicators of REBs' effectiveness in ensuring ethical standards in research involving humans.

According to *The Illinois White Paper*, vague definitions of such central concepts as *risk*, *harm*, *research*, *research subject*, and distinctions, such as *practice/research*, *confidentiality/anonymity* in the Common Rule constitute another cause of REB mission creep (Gunsalus et al., 2007). For example, 'research' comes to be understood expansively as including any kind of verbal interaction between researchers and human participants.

Zachary Schrag's *How Talking Became Human Subject Research* (2009) traces how the mission of ethics committees expanded to the SSH. *Don't Talk to the Humans* is a title of a popular article that captures how research ethics oversight transformed social science research (Shea, 2000). For researchers whose methods include 'talking' in a form of casual conversation or even more structured interviews, ethics oversight poses significant challenges since *talking* is research for which ethical clearance is required. Research ethics boards use biomedical context and definitions in reviewing social science research. Accordingly, talking can be understood as potentially dangerous to human participants. For example, it may cause an emotional distress. These dangers, if REBs find them acceptable, together with research objectives, have to be communicated to research participants, who are expected to document their consent in a tangible form, such as by signing a written consent form.

In most situations the review procedure and REB-required interventions in research situations, such as consent forms, may be a harmless nuisance, wasting time and resources, but they may also impede research, go against ethical practices in certain disciplines, and even introduce risks to researchers and participants, such as in critical policy research. It is worth noting, that after ethics review expanded to the SSH, some researchers could not see any reflection of their practices of knowledge production in the adopted definitions of research. They argued that talking to people is not research in this sense since the context is different. Others sought exemptions, or other strategies of escape from the regulated sphere, arguing that talking to people is closer to 'unregulated' creative practices than to biomedical research.

Where does the problem of vague concepts and unclear distinctions come from? When national systems of research oversight were introduced in North America in 1970s, the idea was to articulate a set of general ethical principles, leaving research institutions the task of their interpretation. This initiative can be seen as congruent with responsive law and regulation, new governance, and soft law approaches (Ayres & Braithwaite, 1992; Burris, 2008; Nonet & Selznick, 1978). Research institutions, by establishing research ethics committees within their limits and by delegating them the authority of deciding on ethical matters, would create a local and contextual approach to ensuring the safety of research involving humans. It was expected that institutional ethics committees will be flexible in interpreting and applying general ethical principles to individual research projects, building on and benefitting from their expert knowledge of available resources and researched populations in their various dimensions.

This may look like a good approach a priori, but in practice this resulted in an opaque, expensive and expansive regulatory regime with a reductionist understanding of research ethics, insensitive to the specifics of research situations and methodologies, lacking consistency in decision making, and not capable of assessing its contribution to the protection of human participants beyond procedural indicators, to name some of the critical issues with prospective ethics review.

Policymakers and REB professionals generally respond to the criticisms of ethics review by insisting that the overall conceptual and regulatory framework is good for the social sciences. For example, see my analysis of 'The Great debate: Be it resolved the Tri-Council Policy Statement is a good standard for which to review research in the social sciences and humanities' at CAREB National Conference in Calgary in April 2013 (Gontcharov & MacDonald, 2016). Policymakers and REB professionals tend to explain existing issues in terms of the limited resources available to REBs and poor understanding of their mission by researchers. Thus, what needs to be done is to allocate more financial and human resources to REBs, and to *educate* researchers about the risks of research, goals of research ethics oversight, and constitutive elements of a successful ethics application.

In other words, policymakers deflect the criticisms of the conceptual framework and its implementation and consider further expansion of ethics oversight as a solution to current problems. Since SSH researchers appear generally not to be trusted, their feedback regarding the governance of research involving humans does not receive proper consideration. Instead, policymakers assume that SSH researchers lack adequate understanding of the mission of the *TCPS* and REBs; and hence the situation can be addressed through online certification programs, such as the *TCPS 2: CORE (Course on Research Ethics),* and better training in procedural research ethics by offering REB 101 and 'best practices' workshops (Mueller, 2007).

Again, the context of the online course is largely biomedical, and it omits mentioning that prospective ethics review emerged as a way of ensuring the safety of government-initiated and sponsored studies. In terms of qualitative ethics, the purpose of the course is rather to impute a complex of shared guilt, thus legitimating the system of oversight in general. An example of this approach is a videotape series produced by the US Department of Health and Human Services in 1986, which includes an instructional film 'Evolving Concern: Protection for Human Subjects' (DHHS, 1986).

The culture of mutual distrust is one characteristic of the institution of ethics review. Ethics regulation in its current form is a product of a low trust environment. Many of the phenomena, such as (procedural) ethics avoidance by SSH researchers, as well as pseudo-educational *TCPS* 101 workshops, are a direct result of this low trust environment. Mutual distrust can generate a deviancy amplification spiral, producing more ethics regulation. Ethics regulation in its turn can further undermine ethical research practice, leading to more regulation, and also leading to greater efforts at avoidance. This issue is critical for the institutions of ethics review and was emphasized in the New Brunswick Declaration (2013), as well as in *The 2016 New Brunswick-Otago Declaration on Research Ethics,* 'Article 1 (Culture of Trust) – emphasizes trust and mutual respect as a basis of research governance. Researchers and participants should be treated equally by ethics committees and policymakers' (Gontcharov & MacDonald, 2016).

While the first *TCPS* acknowledges different approaches to research ethics, and expresses a wish to become an arena for ethical deliberation, by promoting consensus on the most challenging issues, an ethical pluralist approach to research ethics has not been sufficiently enabled at the level of policymakers and individual REBs, either structurally or procedurally. With each update of the *Tri-Council Policy Statement,* the Interagency Advisory Panel on Research Ethics and the supporting Secretariat on Responsible Conduct of Research act less and less as an agency that initially planned to draft a consensus-based set of guidelines and who represent various perspective of research ethics. Instead, they act as an agency that has a superior understanding of research ethics, and thus has to assume the task of ethics education rather than listening and learning from researchers and participants and building on the existing communities of practice, sponsoring the transfer of knowledge, creating platforms for sharing of best research practices and discussing actual ethical challenges that are relevant to particular disciplines and communities.

The following feature of the biomedical conceptual framework helps to understand why the regulators of research involving humans are conservative in revising their own assumptions. Research disciplines conceptualize research situations dissimilarly in respect to power relationships. For example, Boser, who uses a Foucauldian approach, argues that tensions between participatory researchers and REBs are caused by different operative understandings of power (2007). REB professionals rely on a hierarchically-structured concept of power, *power as dominance*, assuming that researchers have *power over* their human participants. On the other hand, participatory researchers do not operate from within this 'power over' perspective, since the context presupposes a more nuanced, multidimensional understanding of power, in which even the very distinction between researchers and participants may be blurred or even irrelevant.

When REBs insist on the universality of the *power as dominance* perspective, they may distort the ethico-methodological dimension of the research situation. This may also force researchers to act unethically (in a procedural understanding of ethics) in order to ensure their research integrity within particular fields of knowledge or research methodology. For example, researchers may promise to hand out consent forms to the participants (i.e. to seek free and informed consent), since their use is a condition of approval, but refrain from using them in actual research situations.

Researchers realize that consent forms may undermine their research situation, since research participants may experience an ethics rupture, questioning the existing relationships of trust between them and researchers, and thus refusing to participate. In critical policy and criminological research, where it may be desirable to conceal the very fact of research, seeking free and informed consent is not even a viable option.

There are known challenges concerning knowledge transfer between expert systems and 'people on the ground'. The flow of information is *funneled* (McDonald, 2000) and stripped of many details constitutive to situational research ethics. This challenge becomes more acute, if the information has to undergo conceptual conversion, such as when travelling between the frameworks with different understandings of power.

Research ethics boards as a governance node in the system of research oversight based on prior approval of research initiatives receive limited feedback from researchers *doing* research, rather than *planning* it. When researchers need to modify something in their research, the change has to be approved. Research ethics boards do not allow making changes 'on the fly', which would imply delegating ethical authority to researchers themselves. In other words, any change in research is considered to be a change in research design (protocol/scheme/form) and, hence, requires ethics approval.

Haggerty suggests that 'ethics creep' is an outcome of the expanding semantics of the key concepts of the *TCPS* (Haggerty, 2004). For example, the concept of research first narrowly formulated as a systematic way of data collection with the intent of contributing to generalizable knowledge in a medical context, gradually expands to embrace any kind of knowledge production, such as Augusto Boal's dramaturgy, as a way of learning and releasing social traumas (Boal, 1979), or any variant of community-based research. Once the new fields of knowledge production have been captured by the system of ethics oversight, REBs apply a reductionist positivist understanding of research. Accordingly, conceptual expansion and reduction go hand in hand in 'colonizing' and inscribing knowledge production in other fields in a traditional biomedical positivist framework, insisting on privacy, anonymity, generalizability, free and informed individual paper-based consent, vulnerability, personal data, or risk of harm to participants. Research ethics forms used by research ethics committees reflect this conceptual framework, thus making it difficult to propose and pursue anything that deviates from the standard.

Many REBs understand research not just in terms of academic research, that is in terms of practices intended to advance scholarship, but all research on campus and beyond. For example, exit surveys of graduates may be considered as 'research requiring approval', rather than 'audit' or 'performance review'; or student research, none of which are conducted with intent to broaden epistemic horizons (Haggerty, 2004). In the concept of 'research involving humans', the human involvement component is treated very broadly and the prerogative of determining the non-involvement of humans rests with REB professionals, who also determine whether proposed research is minimal risk of harm or above.

Originally, 'risk of harm' was understood in terms of physical or lasting psychological harm, but the principles of human dignity in the first *TCPS* suggested an emphasis on privacy thus expanding the understanding of harm in terms of social, professional, and economic standing. Since the likelihood of physical and lasting psychological harm in SSH research is remote, the emphasis shifts to possible reputational harms and/or challenges to participants' worldview and system of beliefs. In critical policy research, for example, this is a definite possibility, while the benefits of individual projects may not be immediately possible to assess at all.

The Illinois White Paper also makes an observation that research institutions are driven by 'the desire not simply to be ethical, but to appear ethical' (Gunsalus et al., 2007: 628). In other words, research institutions willingly extended the Common Rule to non-federally funded research. The extension was prompted by such consideration as demonstrating loyalty to federal sponsors, saving resources on developing new ethics codes, or through realization that the Common Rule is becoming a new standard of care. The adoption of the external standard helped to elevate the Common Rule approach to ethics oversight to its current universal and cross-disciplinary status.

Equally, the necessity to be ethical in the procedural meaning of the term, i.e. in the eyes of REBs, motivates individual researchers to adopt the standard positivist understanding of research ethics, abandoning the methodologies and themes that deviate from it, or attempting to inscribe them into the existing templates. This is one of the key reasons for the ongoing erosion of ethics in research involving humans. From a procedural standpoint of prospective review, REBs deal for the most part with the project's *ethical* appearance rather than actual research ethics. Therefore, it is important to interrogate the operative concept of ethics in the governance of research involving humans.

Regarding the impact of prospective ethics review on research ethics, it has been noted that researchers' intrinsic ethics gives way to rule-following and bureaucratic compliance, thus depleting the ethical dimension of researchers, at least in their interaction with REBs (Haggerty, 2004; Koro-Ljungberg et al., 2007). Rule-following and self-censorship to satisfy procedural criteria and to appear ethical have become the new standard of ethical conduct in research involving humans. The constitutive elements of externalized ethics include filling out prescribed ethics forms and adopting recommended language and consent forms, patiently awaiting ethics approval, and introducing recommended changes, even if they pose new risk of harm to human participants. An 'ethical researcher' acknowledges the ethical authority and superiority of REBs, completes the online certification program and attends 'best practices' workshops.

A reductionist understanding of research leads to a reductionist understanding of research ethics as expressed in the documents submitted for ethics approval by REB members and professionals. When REBs consider research prospectively, they can only review the ethics of stated research intentions. Deviation from the required procedural standard serves as a proxy for the risk of harm to human participants. Accordingly, a missing comma, an 'incorrect' font, or 'none' in the field 'risks to human participants', which REB professionals take as a personal insult, 'because there are so many things that could go wrong in research', may be taken as evidence of poor research ethics.

The monitoring of research ethics extends beyond REB oversight. Many other policy actors operate in the same regulatory space, including academic journals, funding agencies, academic and professional associations, university departments, centers and other communities of research practice, paradigmatic circles, various territorial and virtual communities, and of course, researchers and participants, all of whom influence the processes of knowledge production. These policy actors can be understood as governance nodes, which have their own resources, modes of thinking, and technologies (Burris et al., 2005).

Since the *TCPS* introduces prospective ethics review as a singular mechanism ensuring ethical standards in research involving humans without any need for coordination with other nodes, this may, willingly or not, undermine the work of other nodes. For example, it is becoming standard for academic journals to request evidence of ethics approval when accepting research articles for publication. Although this practice is still largely limited to the biomedical field, it has already begun to expand to the SSH disciplines. The downside of this process is that academic journals may start withdrawing from the regulatory space, transferring ethical issues to REBs, despite being in a better position to review the ethics of the actual research, beyond the proposal stage that is accessible to REBs. Otherwise, the trouble with journals' ethics 'review' is that it necessarily occurs after the event – all they can do is 'reject' the publication on ethical grounds – not advise, warn and/or guide. Similarly, ethics workshops, offered by REB professionals, may undermine local communities of practice, serving as an argument for administrators for limiting the place of research ethics training in the curriculum.

Since ethics review was extended to SSH research without justifying its need and effectiveness, without mapping the regulatory space and understanding the role of various nodes in research ethics, it becomes rather difficult to isolate the contribution of prospective ethics review in maintaining ethical standards in research involving humans. Accordingly, the *Interagency Advisory Panel on Research Ethics* can claim the contribution of other nodes, while ascribing the failures to other peer review mechanisms, individual researchers and research teams, since it does not oversee the actual research. The regulators can further use the 'appropriated' contribution of other nodes as a justification for an expansive regulatory regime. In fact, it may turn out that the contribution of the *TCPS* to ethics education, and other stated objectives, such as the reduction of the risk of harm to human participants is negligible or even negative (Hyman, 2007).

A view that prospective ethics review by REBs is the only necessary and sufficient instrument ensuring proper research standards, which requires no coordination with other governance nodes, is an obstacle to regulatory innovation in the governance of research involving humans.

Most of the regulatory initiatives deal with the procedural aspects of ethics review, such as proposals related to centralization, standardization and coordination between institutional ethics committees, or to required expertise, duration of review, quorum and voting procedures, criteria for expedited and full board review, presence of researchers, certification of REB professionals and accreditation of individual boards, recognition of other boards' ethical decisions via introduction of the board of record model or similar mechanisms, among others. At the same time, there is a shortage of independent empirical data about the institution of ethics review. The regulators themselves have yet to adopt an evidence-based approach themselves. Our knowledge of the impact of ethics review on SSH research, its ethics and methodology is limited. There is also no data that could shed light on the contribution of REBs vis-à-vis other actors in the regulatory space of research involving humans.

It is necessary to highlight the importance of (auto)ethnographic narratives of research ethics review (Murray, 2016), and document those aspects of research ethics review that might be lost when knowledge is reduced to systematically collected and generalizable data. 'IRB horror stories' (Kleiman, May 02, 2009) and similar first-hand encounters (Rambo, 2007) are very important for understanding the phenomenon of ethics review in the SSH. Since the criteria for evaluating REBs' performance remains exclusively procedural, it is particularly important to identify the fault lines in the research ethics terrain. Such criteria as the length of review or number of approved projects, does not give a comprehensive understanding of the boards' contribution to research ethics.

Haggerty notes that it takes an insider to expose the expansion of REB oversight. The reason for this is a deficit of transparency of the institution of ethics review (2004). Research ethics boards communicate their decisions to researchers, but the 'ethics kitchen' remains generally inaccessible. It is hard to observe directly how REBs interpret and apply the *TCPS*. Furthermore, REBs have a conflict of interest in reviewing critical policy studies on ethics review. It is hard to expect that they would be interested in facilitating research initiatives that could potentially challenge or undermine the institution of prospective ethics review. For example, Haggerty refers to a study, rejected by his REB, which intended 'to measure the participation rates of research subjects when different styles of informed consent forms were used' (2004: 406). This example shows that REBs may, perhaps inadvertently, but nonetheless effectively, filter off research initiatives that could shed light on the effectiveness of the instruments they use. In this case, consent forms for individuals are generally taken by REBs as a standard way of documenting free and informed consent, suppressing other methods of consenting to participation and documenting consent.

In sum, although the first *TCPS* expanded the biomedical approach to SSH research, there remained a possibility that subsequent editions of the Policy will address theoretical inconsistencies and growing tensions between procedural ethics and ethics in practice. However, the elements of ethico-methodological pluralism have not received further development in the second *TCPS* despite embracing the language of *research participants* instead of *human subjects, and projects* instead of *protocols*. Indeed, the second *TCPS* may have a chapter devoted to qualitative research and research on collectivities, but these regulations are (1) still framed within a wider positivist approach, and (2) research project's ethics are not reviewed by codes but by human beings who themselves embody the positivist frame that research is linear and therefore predictable as procedural ethics. Finally, (3) policymaking in the governance of research involving humans is currently driven by biomedical experts, thus suggesting that any future updates of the Policy are unlikely to resolve the tensions in REB review of qualitative and critical research.

REFERENCES

Ayres, I. and Braithwaite, J. (1992) *Responsive Regulation: Transcending the Deregulation Debate*. New York: Oxford University Press.

Beagan, B. and McDonald, M. (2005) Evidence-based practice of research ethics review? *Health Law Review* 13(2–3): 62–68.

Beecher, H.K. (1966) Ethics and clinical research. *The New England Journal of Medicine* 274(24): 1354–1360.

Bell, J., Whiton, J., and Connelly, S. (1998) *Final Report: Evaluation of NIH Implementation of Section 491 of the Public Health Service Act, Mandating a Program of Protection for Research Subjects* June 15, 1998. Prepared for The Office of Extramural Research, National Institutes of Health.

Boal, A. (1979) *Theatre of the Oppressed*. Urizen Books.

Boser, S. (2007) Power, ethics, and the IRB: Dissonance over human participant review of participatory research. *Qualitative Inquiry* 13(8): 1060–1074.

Brunger, F. and Burgess, M. (2005) A cultural understanding of research ethics governance. *Health Law Review* 13(1–2): 69–74.

Burris, S. (2008) Regulatory innovation in the governance of human subjects research: A cautionary tale and some modest proposals. *Regulation & Governance* 2(1): 65–84.

Burris, S., Drahos, P., and Shearing, C. (2005) Nodal governance. *Australian Journal of Legal Philosophy* 30: 30–58.

Cohen, S. (2002) *Folk Devils and Moral Panics: The Creation of the Mods and Rockers*. Psychology Press.

Department of Health and Human Service. (1986) Videotape Series: 'Protecting Human Subjects'. Part 1: 'Evolving Concern: Protection for Human Subjects'; Part 2: 'Balancing Society's Mandates: Criteria for Protocol Review'; and Part 3: '*The Belmont Report*: Basic Ethical Principles and Their Application'. The Office for Protection from Research Risks, Department of Health and Human Services.

Department of Health and Human Service. (2005) 45 Code of Federal Regulations, Part 46: Protection of Human Subjects.

Dickens, B. (1979) *Guidelines on the Use of Human Subjects*. Office of Research Administration, University of Toronto.

Dingwall, R. (2008) The ethical case against ethical regulation in humanities and social science research. *Twenty-First Century Society* 3(1): 1–12.

Feyerabend, P.K. (1993) *Against Method*. London: Verso.

Gontcharov, I. (2016) The Eclipse of 'Human Subjects' and the Rise of 'Human Participants' in Research Involving Humans. In: van den Hoonaard, W.C. and Hamilton, A. (eds) *Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review.* University of Toronto Press, pp. 267–282.

Gontcharov, I. and MacDonald, L. (2016) Alternative models of ethical governance: The 2016 New Brunswick-Otago Declaration on Research Ethics. *New Zealand Sociology* 31(4): 56–81.

Gunsalus, C.K., Bruner, E.M., Burbules, N.C., Dash, L., Finkin, M., Goldberg, J.P., Greenough, W.T., Miller, G.A., and Pratt, M.G. (2007) The Illinois White Paper: Improving the system for protecting human subjects: Counteracting IRB 'mission creep'. *Qualitative Inquiry* 13(5): 617–649.

Haggerty, K.D. (2004) Ethics creep: Governing social science research in the name of ethics. *Qualitative Sociology* 27(4): 391–414.

Hammersley, M. (2009) Against the ethicists: On the evils of ethical regulation. *International Journal of Social Research Methodology* 12(3): 211–225.

Hyman, D.A. (2007) Institutional Review Boards: Is this the least worst we can do? *Northwestern University Law Review* 101(2): 749–773.

Interagency Advisory Panel on Research Ethics. (2004) *Giving Voice to the Spectrum: Report of the Social Sciences and Humanities Research Ethics Special Working Committee to the Interagency Advisory Panel on Research Ethics*. Ottawa.

Interagency Advisory Panel on Research Ethics. (December 2009) *Public Comments on the Revised Draft of the TCPS 2*. Available at: http://www.ethics.gc.ca/eng/archives/participation/comments-commentaires2009/

Kleiman, M. (May 02, 2009) The IRB horror show. Available at: http://www.samefacts.com/archives/science_and_its_methods_/2009/05/the_irb_horror_show.php

Klitzman, R.L. (2015) *The Ethics Police? The Struggle to Make Human Research Safe*. Oxford University Press.

Koro-Ljungberg, M., Gemignani, M., Brodeur, C.W., and Kimiec, C. (2007) The technologies of normalization and self: Thinking about IRBs and extrinsic research ethics with Foucault. *Qualitative Inquiry* 13(8): 1075–1094.

Kuhn, T. (1962) *The Structure of Scientific Revolutions*. The University of Chicago Press.

Luhmann, N. (2000) Familiarity, Confidence, Trust: Problems and Alternatives. In: Gambetta, D. (ed) *Trust: Making and Breaking Cooperative Relations.* Oxford: Department of Sociology, University of Oxford, pp. 94–107.

McDonald, M. (2000) *The Governance of Health Research Involving Human Subjects (HRIHS)*. Ottawa: Law Commission of Canada.

McDonald, M. (2001) Canadian governance of health research involving human subjects: Is anybody minding the store? *Health Law Journal* 9: 1–21.

McDonald, M. (2009) From code to policy statement: Creating Canadian policy for ethical research involving humans. *Health Law Review* 17(2–3): 12–25.

Medical Research Council of Canada. (1987) *Guidelines on Research Involving Human Subjects*. Ottawa: Medical Research Council of Canada.

Meyer, M.N. (2013) Regulating the production of knowledge: Research risk–benefit analysis and the heterogeneity problem. *Administrative Law Review* 65(2): 237–298.

Meyer, M.N. (2014) Three Challenges for Risk-Based (Research) Regulation: Heterogeneity Among Regulated Activities, Regulator Bias, and Stakeholder Heterogeneity. In: Cohen. I.G. and Lynch, H.F. (eds) *The Future of Human Subjects Research Regulation.* Cambridge, MA: MIT Press.

Mueller, J.H. (2007) Ignorance is neither bliss nor ethical. *Northwestern University Law Review* 101(2): 809–836.

Murray, B.L. (2016) Research Ethics Boards: Are They Ready for Autoethnography? In: van den Hoonaard, W.C. and Hamilton, A. (eds) *The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review.* University of Toronto Press, pp. 153–166.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979) *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*.

Nonet, P. and Selznick, P. (1978) *Law and Society in Transition: Toward Responsive Law*. New York: Octagon Books.

Palys, T.S. (October 16, 2015) *Research Confidentiality: Researcher & Institutional Responsibilities*. Available at: https://youtu.be/xB21-3jWMQk

Palys, T.S. and Lowman, J. (2016) *List of Articles on Research Ethics*. Available at: http://www.sfu.ca/~palys/articles.htm

Pistor, K. (2002) The standardization of law and its effect on developing economies. *American Journal of Comparative Law* 50(1): 97–130.

Rambo, C. (2007) Handing IRB an unloaded gun. *Qualitative Inquiry* 13(3): 353–367.

Schrag, Z.M. (2009) How talking became human subjects research: The federal regulation of the social sciences, 1965–1991. *Journal of Policy History* 21(1): 3–37.

Schrag, Z.M. (2010) *Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965–2009*. Baltimore, MD: Johns Hopkins University Press.

Schrag, Z.M. (2011) The case against ethics review in the social sciences. *Research Ethics* 7(4): 120–131.

Shea, C. (2000) Don't talk to the humans: The crackdown on social science research. *Lingua Franca* 10(6): 27–34.

Social Sciences and Humanities Research Council. (1980) *Ethics Guidelines for Research with Human Subjects*. Ottawa: Social Sciences and Humanities Research Council of Canada.

Stark, L. (2006) *Morality in Science: How Research is Evaluated in the Age of Human Subjects Regulation*. Department of Sociology, Princeton University.

Stark, L. (2012) *Behind Closed Doors: IRBs and the Making of Ethical Research*. The University of Chicago Press.

Tolich, M. and Smith, B. (2015) *The Politicisation of Ethics Review in New Zealand*. Auckland: Dunmore Publishing Ltd.

van den Hoonaard, W.C. (2001) Is research-ethics review a moral panic? *Canadian Review of Sociology and Anthropology* 38(1): 19–36.

van den Hoonaard, W.C. (2011) *The Seduction of Ethics: Transforming the Social Sciences.* University of Toronto Press.

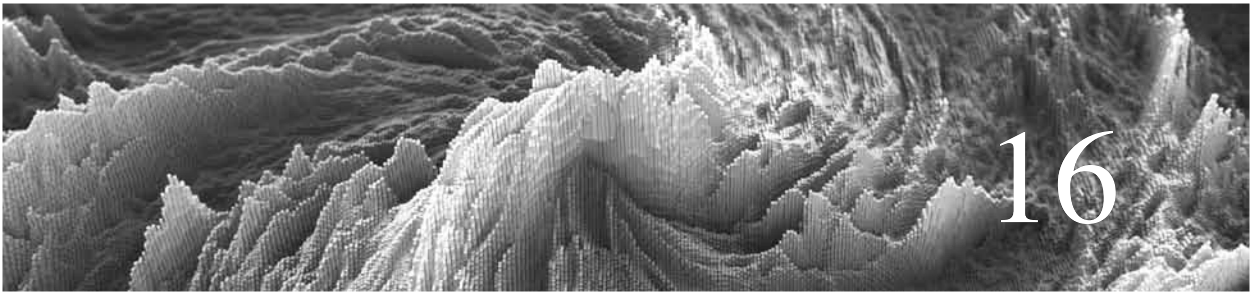
van den Hoonaard, W.C. (2012) *Ethics Rupture: An Invitational Summit about Alternatives to Research-Ethics Review in Fredericton, Introduction from the Website*. Available at: https://web.archive.org/web/20130507065940/http://wp.stu.ca/ethicsrupture/

van den Hoonaard, W.C. (2013a) The 'Ethics Rupture' Summit, Fredericton, New Brunswick, Canada, October 25–28, 2012. *Journal of Empirical Research on Human Research Ethics: An International Journal* 8(1): 3–7.

van den Hoonaard, W.C. (2013b) The social and policy contexts of the New Brunswick Declaration on Research Ethics, Integrity, and Governance: A commentary. *Journal of Empirical Research on Human Research Ethics: An International Journal* 8(2): 104–109.

van den Hoonaard, W.C. and Hamilton, A. (eds) (2016) *Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review.* University of Toronto Press.

Veblen, T. (1979) *The Theory of the Leisure Class*. New York: Penguin Books.



16

When Ethics Review Boards Get Ethnographic Research Wrong

L.L. Wynn

INTRODUCTION

By now, there is a large body of literature critical of the applicability of ethics review bureaucracies to social science research, and particularly ethnography (Fitzgerald, 2004; Gunsalus et al., 2007; Haggerty, 2004; Lederman, 2006a, 2006b, 2007; Shea, 2000; Shweder, 2005; Taylor & Patterson, 2010; Tolich & Fitzgerald, 2006). Much of this literature, however, has been based on small samples or case studies of individual ethics committees or research projects. As a result, some critics have claimed that the literature on the impact of ethics review on ethnographic research is biased toward two extremes: criticism based on bad experiences – what Laura Stark calls the ‘social science victim narrative’ of ‘anecdotal “horror stories”’ (Stark, 2007: 783) – or apologists for the ethics review system.

In an attempt to go beyond polarized case studies and small samples, in 2010 I undertook an international online survey of 315 ethnographers’ experiences of ethics review. I recruited participants through respondent-driven snowball sampling, using multiple starting points from my academic networks in the United States, Canada, Australia, New Zealand, and the United Kingdom. Reflecting this sampling strategy and the survey language (English), most of the respondents were based in those countries, with a minority of respondents from Europe, South America, Africa and Asia. Most respondents were anthropologists, but ethnographers from a range of other disciplines were represented, including political science, sociology, education, and cultural studies.

The online survey asked a mix of demographic questions about discipline and research backgrounds, including where respondents had conducted research and whether, where, and when they had gone through an ethics review process. Likert-scale questions asked people’s opinions about and experiences with ethics review. Finally, a series of questions invited open-ended accounts of respondents’ research experiences, their interactions with ethics review bureaucracies, and their opinions of ethics review.

The survey was limited in two key respects. First, it focused on the experiences of academic researchers (both PhD students and researchers with PhDs) based at universities. The survey design scarcely addressed the experiences of researchers outside of the university system, where the majority of researchers with PhDs get jobs. Therefore, this is a fertile area for future research, especially to discover whether social science research that does not undergo ethics review raises the risks to participants over that which does undergo review.

Second, despite the large number of respondents, snowball sampling is a method that inherently introduces bias. The response rate is unknown, since my invitation e-mails were forwarded to an unknown quantity of recipients. It is plausible that the academics who chose to respond to the survey invitation were those who felt strongly (whether positively or negatively) about ethics review, with a lower response rate from the indifferent (see also Wynn, 2011). While the responses probably represent a wide range of ethnographers' experiences of and opinions about ethics review, they are not representative of how those experiences are distributed. (For this reason, I do not report numbers of respondents who raised a particular issue, focusing on qualitative themes rather than quantifiable data, since the results are not representative.) In particular, there are significant geographical variations as a result of national differences in ethics codes and regulatory frameworks governing ethics review (or lack thereof).

Ethnographers' experiences of ethics oversight illuminate a great deal about contemporary neoliberal audit culture in the university, how researchers navigate the structures of bureaucracy, and what forms dissent take. While there is a well-known genre of 'horror stories' about ethics committees (Hedgecoe, 2008; Stark, 2007; Wynn, 2011), especially amongst social scientists, these are often based on particular institution-based committees. The broader objection that many ethnographers have to ethics review is more fundamental and structural than a set of complaints about a particular committee. Ethics committees typically demand that the research trajectory, participants, and research questions can be known in advance, a positivist framing of research that is antithetical to ethnography's iterative nature and which may exclude the creative, collaborative directions that many ethnographers consider to be the research ideal (Lederman, 2006a; Tolich & Fitzgerald, 2006). They also often assume a simple hierarchy between researcher and research participant, one in which the researcher is powerful and the research participant is vulnerable and in need of protection, an assumption which ill prepares them for evaluating research designs characterized by more complicated and collaborative research relationships. As a result, many ethnographers report being disillusioned with the ethics review process and engage in strategies of evasion or deception in order to limit the damage that ethics review committees might do, not only to their research, but also to their relationship with research participants and collaborators.

A summary and general analysis of the survey responses has been published (Wynn, 2011). In the following, I briefly review the themes that emerged in the survey responses, including critiques of the biomedical framing of research that precluded some ethics committees from understanding ethnographic methods; concern over the bureaucratization of relationships that ethics committees demand; fear-based fantasies of risk that drive committee decisions; the framing of research as hierarchical, not collaborative; committees' lack of respect for research participants' demands and intellectual property; committees' failure to understand the different cultural and political contexts of international research; committees' discomfort with intimacy in the relationship between researcher and research participant; 'studying up' (Nader, 1972) dilemmas when ethnographers research the powerful; and the obstruction of research on 'sensitive' topics (such as sexuality) and 'vulnerable' research participants (such as teens).

After reviewing these themes, I examine ethnographers' responses to ethics review, which range from giving up on human research or on particular areas of research to cynically telling committees 'what they want to hear' and then doing something else entirely in the field. Some decide to join ethics committees in order to educate them, engaging in acts of cooperative co-optation. Others refuse to undergo ethics review, then face dilemmas over how to train their students, who are more vulnerable to censure for not undergoing review than are well-established academics.

The fact that researchers are leaving academia, changing their research strategies, or avoiding research into certain topics as a result of ethics review is concerning. But what about those who refuse to undergo ethics review? Are they causing harm to research participants? To answer this question, I asked respondents to report any cases they knew of (whether it was themselves, a colleague, or simply a rumor they had heard) where a research participant complained of unethical research conduct. I report on those responses here.

Finally, I analyze the different epistemologies of the research relationship that underpin ethnographers' attitudes toward ethics review. A recent study has established through careful, representative sampling that in Australia, at least, ethnographers experience more conflict with ethics committees than do their colleagues who conduct clinical research (Wynn et al., 2014). But the problem is more than a matter of biomedically-oriented committees, disciplinary differences, or competing ideologies about the role of bureaucratic audit culture in the academy. Researchers' attitudes to ethics review reflect competing epistemologies about accountability and whether they conceptualize their primary relationship as being with academic peers or research participants/collaborators.

As Shore and Wright (2000) point out, the last two decades of the last millennium saw 'the rise of technologies of audit and accountability and their transfer from the financial domain to… higher education', technologies which are 'not simply innocuously neutral, legal-rational practices' but rather 'instruments for the introduction of new forms of governance and power' (p. 57). The expansion of the domain of ethics review was part of this rise of audit culture in the university. Studying researchers' responses to ethics committees, therefore, offers a lens on the evolution of these new forms of governance, power, and relations between researchers and research participants.

SURVEY RESULTS: ETHNOGRAPHERS' EXPERIENCES OF ETHICS REVIEW

Positivist, Deductive, and Clinical Understandings of Research

Many respondents argued that review committees are biased toward clinical, positivist understandings of research and therefore make inappropriate demands for the conduct of their research. More than one respondent, for example, reported an ethics committee asking them to organize control groups for research projects that used participant-observation as the primary methodology.

But for most respondents, the clinical bias of ethics committees was more subtle than demanding control groups in qualitative research. Many survey respondents complained that ethics review committees are not structured, and that the methodological assumptions in protocol forms are fundamentally ill-designed, to address the particular challenges and ethical dilemmas that inhere in ethnographic research. Review processes typically assume a field situation, research method, and set of research questions that can be planned in advance, rather than asking researchers for a more general orientation toward field ethics that could inform the unpredictable directions that ethnographic research takes. Structuring ethics review so that it is a one-off encounter before research begins is thus inherently at odds with the ethnographic method. One respondent commented,

> In the course of fieldwork I realized that the actual field situations are very different from what I anticipated and what I described in my ethics review application. There was no way I could anticipate those before getting into the field, which makes the whole exercise of filling the forms not particularly useful.

Another noted,

> One example shows that the ethnographic research process is still not well understood – we are asked to list in the application all the sites we will be working at before the research commences.

The fact that most ethics forms require information about research scenarios that are not knowable in advance, and provide amendment forms for deviations from a predetermined research plan, frames such 'deviations' as exception rather than the rule. Yet the ethnographic method is predicated on an expectation that researchers will follow unexpected paths, that their research directions will be informed by their research participants' interests, and that they will learn from their research participants what are the right questions to ask (Bosk & de Vries, 2004; Lederman, 2006a, 2007). A research trajectory that is known in advance (never mind the minutiae of details such as exact locations of meetings and the number of research participants) is the exception, rather than the rule, in ethnographic research.

Further, the idea that researchers can clearly delineate the start of a research project is also challenged by ethnography, where research questions often emerge out of everyday life and pre-existing relationships (Lederman, 2006b). As we shall see, the fact that ethnographers have pre-existing relationships with their research participants is another challenge not only to ethics committees' understandings of an ethical researcher-participant relationship but to their understandings of what constitutes valid research.

THE BUREAUCRATIZATION OF RESEARCH RELATIONSHIPS

Survey respondents reported that ethics committees demand a bureaucratization of research relationships that is incommensurate with ethnographic research and inappropriate for many cultural and political contexts. For example, many respondents complained that ethics committees demanded written consent, even when research participants were illiterate or written consent was politically inappropriate.

> A graduate student was prevented from submitting her PhD thesis because she had not gained written consent from people. The requirement was unreasonable. The researcher had demonstrably gained informed consent as the recorded and transcribed interviews included statements that clearly indicated this. There was no social scientist on the committee – the procedure was dominated by a lawyer who used spurious arguments to imply that the research was 'illegal'.

Respondents also argued that in addition to an obsession with form over substance, the bureaucratic rituals and legal frameworks implied by signed consent forms are highly culturally specific. They translate poorly into other cultural contexts and socio-economic divides, yet committees typically do not recognize the cultural specificity of bureaucratic forms and procedures, instead viewing them as culturally universal. As one respondent put it, ethics committee' interpretation of research guidelines was based on 'profoundly middle-class western conceptions that sit awkwardly at best with local realities'. Respondents to my survey described being asked to present signed informed consent forms to non-Western populations among whom the entire concept of signing a form to consent to participate in research had no cultural translation. Another commented that research participants viewed consent forms with suspicion and fear because of histories of colonial or political exploitation involving written forms: 'They have been previously duped by government officials to sign documents that resulted in their displacement'.

Other respondents reported that when they asked participants to sign documents, they were accused of being foreign spies. In short, in many of the contexts where ethnographers do their research, consent forms symbolized colonial histories, capitalist (especially mining company) land grabs, or state surveillance bureaucracies.

More generally, respondents argued that signed consent forms do not fit into the long-term, gradual approach of ethnographic research. How do you decide when research has started when research questions emerge organically out of an engagement with people's lives, often in the place where the ethnographer already lives (Lederman, 2006a)? Why focus on a one-off moment of gaining consent, when informed consent is something that must be continually revisited and negotiated over an extended period of time for ethnographic research (Wynn et al., 2009)? Why focus on the moment research begins as the time when consent must be obtained, when research participants may not then be able to grasp the full scope and implications of their participation, and when matters of representation continue to impact on research participants long after the research has concluded (Bell, 2014)?

Further, formalizing the contexts in which researchers can work would mean excluding the informal and the quotidian from the research gaze. As one respondent noted,

> Aspects of everyday life become less possible to observe because the researcher has to have this set-up, formal approach to interviewing and observation. The roles of researcher and researched become more obvious and this may mean less of the everyday is revealed.

Ethics committees were often skeptical of, and sometimes prohibited outright, researchers from doing research in private homes, often framing this as a matter of researcher safety (see also Wynn, 2016). Yet denying ethnographers from being able to enter people's homes would not only foreclose the possibility of particular research topics (such as family life, cooking and food sharing, and childrearing practices), it also would mean silencing particular groups of people who spend a majority of their time in the home, privileging the voices of research participants who more comfortably occupy public space.

Finally, respondents reported that ethics committees sometimes rejected research when there was evidence of a previous relationship between the researcher and research participants. Committees offered positivist perspectives on the research relationship when they suggested that intimacy was evidence of 'bias' or a lack of neutrality on the part of the researcher. As respondents argued, no research is ever unbiased, and it is through building relationships of trust with research participants that ethnographers conduct ethical research grounded in local norms of reciprocity and trust. 'I can't ask people to give consent to be researched unless they know me and who I am and can trust me', argued one respondent. Another said,

> I work with refugees, and my experiences with them suggest that they feel more comfortable participating in research when they know the researcher ahead of time. My current institution mandated that I was not allowed to recruit participants I already know, because they thought this would represent coercion.

One respondent described her ambivalence about an ethics committee's demands for formal consent procedures with people she had known long before research started. On the one hand, she argued, having to describe possible 'harms' that might befall them was likely exaggerated and changed her relationship with the community 'into a business and legal relationship rather than one of trust-building, honesty, cooperation, and open exchange of ideas (the latter set of guidelines I feel shape ethical relationships)'. On the other hand, the apparent informality of ethnographic research means that it can be difficult for research participants to understand that they are in fact participating in research, so formal discussion around this, she argued, is necessary in order 'to draw the boundaries and to be clear about what it means – in terms of benefits, risks, and rights – to enter into such relationships is very difficult and important to do'.

Fantasies of Risk

> What angered me most was their inability to understand ethnographic research and to treat it as equivalent to injecting teenagers with substances. Prior to attending that university, I spent 5 years doing outreach with at-risk populations and was extremely aware of the potential psychological challenges of doing research. Instead of being able to leverage this experience, I felt as though I was treated like a sadist out to harm people. (An ethnographer, doing research in the US)

Survey respondents reported that ethics committees were predisposed to seeing risk and danger in ethnographic observation. Several argued that this was evidence of clinical bias, arising as it does from a tradition of medical and psychological experimentation on research participants, as opposed to more naturalistic observational approaches to understanding people's everyday lives.

Committees, for example, often assume that research participants might be 'traumatized' by talking. Three respondents described being *required to hire psychologists* to debrief research participants or be on call in case of distress. 'We are often asked whether our participants will be 'upset' by talking to us. This medicalization/psychologization is really creepy', commented one researcher. This paradigm of research review, another argued, was based on fantasies of risk and worst-case scenarios that were not realistic but rather seem based on committee members' stereotypes about specific research populations or their indoctrination with ethical concerns from the medical-psychological clinical trial.

Hierarchies of Power in the Researcher-Participant Relationship

An ethical paradigm focused on protection and vulnerability of research participants can be inadvertently infantilizing at best, and at worst refuses to recognize participants' own wishes about how they should be respected.

> Our research governance committee refused point blank to allow us to use anyone's real names, resulting in the ridiculous situation that we have to anonymize instantly recognizable VIPs who spoke to us in full expectation that they could go on the record in their own names, and the much more troubling situation that we have had to deny participants their wishes because of the inflexibility of the ethics committee. In some of the cases, I feel that concealing someone's real name after she has repeatedly asked us to use it is actually putting us in breach of our ethical obligation to her, even though by doing so we're supposedly living up to this idiotic committee's interpretation of 'ethics'!

Multiple survey respondents reported that ethics committees had required them to keep their participants' identities anonymous, even when the participants themselves *demanded* to be identified. For example, one respondent described a graduate student's research project into elderly survivors of World War II from the Ukraine. The research participants wanted to be named in the research publications, and the ethics board refused, arguing that they were 'vulnerable' because of their age and thus not competent to make their own decisions about whether to be named or not. In the end, the World War II survivors refused to participate in the project because of that. Another respondent reported:

> Many of those I work with online are not only artists, writers and others in the creative arts, but most are online at least in part because their gender (female) and often, their sexualities and politics and age and ethnicity have been marginalized by the mainstream society, so that they don't wish to be anonymous; they've been effaced through anonymity all too often.

Several survey respondents noted that allowing research participants to make their own decisions around anonymity and identification was not only a matter of respect for their wishes and abilities to make informed decisions, but also a matter of respecting their intellectual ownership of the ideas they express to researchers and according recognition to their work as activists and public intellectuals. One corollary of the protection paradigm is that, when committees fail to see participants as intellectual equals to the researchers and committee members, they may fail to understand the possibilities for (and challenges in) collaborative relationships between researchers and research participants. One respondent noted,

> I had students involved in a participatory action research practicum with local NGOs…. The REB didn't want to approve it and called me into a special session to defend the project – because 'participatory research' did not fit the guidelines for protecting research subjects. (Go figure)

Another said,

> If I was at first enthusiastic about the existence of an ethics process at my university, I was disappointed by the lack of support it provides into building a real collaborative research framework. It is very easy to get ethics approval… [but] it does not truly involve the research participants into the making of the research. The Ethics Board still perceives the research process as a researcher-researched relationship (or observer-object of research). The ethics approval process does not make room for the 'researched' to be actively involved.

If ethics committees have difficulty recognizing equal relations between researchers and research participants, they also sometimes fail to recognize the possibility of inverted hierarchies. In an inverted hierarchy, a researcher may be vulnerable to a powerful research participant, or the researcher seeks to expose the workings of power. These 'studying up' dilemmas may be the product of inversion of ethnography's tradition of studying the vulnerable and thus identifying with, and wishing to protect, our research participants (Nader, 1972). But some respondents argued that, even when we are not studying the powerful, it is nevertheless rarely the case that the researcher is always at the top of a simple hierarchy of power. 'They assume that the ethnographer is always in a position of power and control over the research subjects, which isn't the case for most of us', said one respondent. Ironically, even as ethnographers have called for studies of elites, states, and bureaucracies, ethics committees are increasingly demanding permission from the corporations and organizations where anthropologists seek to work, which means potentially granting powerful organizations censorship rights over research. Further, one respondent argued, in the era of ethics committees there is little or no tolerance for covert research, even when it is the only way to get accurate and important research data:

> Kreager's wonderful study 'Working for Ford' would never pass now – he took a job on the factory line then wrote it up. Put another way – there is NO place for the very difficult question of POLITICS in the ethics committees – very difficult question but crucial to any form of social research (emphasis in original).

The result is that important research topics are now seen as the domain of investigative journalists but not of social scientists.

Vulnerable Populations and 'Sensitive' Topics

> I think that projects on places that are violent and sketchy need to be done, and that 'ethics' does not help with the real ethics of working in dangerous places.

Finally, the other key arena where respondents reported that ethics committees were having a negative impact on ethnographic research (particularly the research of their students) was in research on and with vulnerable populations, and on politically and culturally sensitive research topics. Many respondents described constraining their research or their students' research to exclude populations that ethics committees perceived as vulnerable, such as children, refugees, and the mentally ill, or on 'sensitive topics', such as sexuality, reproductive health, and political activism. '[The ethics committee] stopped a student from doing an honors project that might have revealed problems facing gay students', noted one respondent. Another reported a student's difficulty in getting approval for what the committee classified as a 'high risk' project: asking university students about contraceptive use.

Respondents described a mixture of committee censorship and self-censorship by researchers and research supervisors to avoid anticipated difficulties with ethics committees. Many also reported that committees seemed to conflate 'risk' and culturally or politically sensitive topics, even when they didn't fit into any classic risk categories, such as research into women who have sought legal abortions. As one respondent argued,

> Ethics committees can stifle grounded research because they reinforce what is actually political, not ethical, constraints on certain forms of research.

RESEARCHERS RESPONSES TO ETHICS REVIEW

Delays, Self-Censorship, and a Pauperization of Research Agendas

What is the overall impact of ethics review on ethnographic research? Some respondents reported losing funding when ethics review dragged on for time periods that ranged from six months to over two years. Survey respondents also reported a widespread (though difficult to quantify) practice of self-censorship amongst ethnographers, many of whom are gravitating away from ethically challenging research and toward bland, inoffensive research topics (see also Bell, 2014; Bledsoe et al., 2007; and Dehli and Taylor, 2006 for discussions of how self-censorship is changing research agendas). One respondent said,

> There were questions I didn't ask and issues I didn't pursue, not because it would have been problematic for my interlocutors in the field, but because I was afraid that they might get me into trouble with the [ethics review board].

Many also reported deliberately excluding children from their research: 'I felt that by including "children" I would be subjected to so much hassle on the part of the Ethics Committee that it might cause me a lot of unnecessary work and delay my research'. Others reported not being able to go to particular field sites, or being banned from conducting research in private homes, because of their ethics committees' concerns for researchers' safety. One respondent who served on an ethics committee noted that this concern was applied unequally, with women researchers being subjected to far greater scrutiny over their safety than their male peers. Another described how a committee's imagination of the risks attached to particular geographical areas prevented her from doing research there:

> The oversight and review process placed unnecessary limitations on where I could choose to locate my field site based on notions of protecting my own personal safety. In essence the result was that the very thing I wished to research was excluded from the possibilities left available to me according to the ethics committee assessment. They made this decision based on a profoundly naive perception that the area I wished to conduct research in was, by merit of its geographical location alone, more dangerous than other areas in the place I wished to conduct research. As such the key focus of my research was rendered inaccessible. To actually research it would require breaching ethics protocol and if something did happen I would not have been covered by institutions insurance policy which would place me at extreme risk in the event of an accident etc.

At one extreme, some respondents reported avoiding human research altogether, or leaving academia so that they could avoid the bureaucracy. 'I ended up not doing research with the most marginalized populations because of the perceived risks for the university… I realized that the university was only going to get more and more scared of research going forward and so I left', said one respondent.

Respondents often mentioned the impact on student research (see also Wynn, 2016). Many reported that students self-censored their projects in anticipation of conflict with ethics review committees:

> One student in my cohort decided to change her research topic because she decided in advance it would be too difficult to get IRB approval (her research was in sexual behavior).

Similarly, teachers who taught their students ethnographic methods reported changing their teaching practice to exclude student research from the curriculum, a finding subsequently replicated in a survey of Australian universities (Wynn, in press).

Cynicism as Usual

Many respondents described a cynical manipulation of committees to ensure that research proceeded as usual. 'I also know now to "game" the system', said one, 'which means just following the directions for the forms while understanding the reality of research can and likely will be quite different'. Another complained, 'I jumped through their hoops and then did what I needed… I was forced to act in a deviant behavior as a result of their lack of understanding of ethnography'. Researchers who were required to use signed consent forms in contexts where they felt it was inappropriate explained that they conveniently 'forgot' to bring those forms with them when conducting interviews. Several described how doctoral students and their supervisors collaborated to deceive ethics committees or manipulate forms to ensure that their research appeared to be low risk. 'I was encouraged to simply tell the ethics board what they wanted to hear and then do whatever I wanted anyway', said one. Another said,

> They have made it extremely difficult for doctoral students to be honest (and ethical!) and there has arisen a rather nasty practise of supervisors advising students to take the path of least resistance and promise whatever the ethics committee wants while continuing to do what ethnographers have done for a long time.

It is worth quoting multiple respondents to give a sense of the scope of deception, cynicism, and perceived outcomes:

> 'Most people write what the ethics committee wants to hear and then conducts the research differently if necessary. They follow their own ethics and don't exploit or harm research participants, but they do things that wouldn't necessarily pass review'.

> 'Eventually I found withholding information to deceiving the committee to the true nature of my research the most efficient form of dealing with [them]'.

> 'At present the REB is considering whether they should declare "snowball sampling" unethical and unallowable. We have found that if we just take the word out of the proposal we submit and simply describe the procedure for contacting participants, they accept it'.

> 'They say all informants must remain anonymous as a blanket rule. My informants are part of a cultural revitalisation movement that demand that their full and real names be used or they will not take part in the research. So I lie instead of engaging in a justification'.

A few reported challenging their ethics committees on what they perceived as inappropriate demands. These often reported that success came at the expense of lengthy delays, but considered it an ethical imperative to reach agreement with their ethics review institutions. Others reported joining their universities' ethics committees so that an ethnographer would be represented and could educate the committee about ethnographic research methods. As Bledsoe et al. (2007) argue, careful analysis of the interactions between researchers and ethics committees shows that this is not simply a process of researcher duplicity that is uncritically accepted by naïve committees. Rather, in many universities there is a collaborative process of deception between researchers and committees, which together engage in fictions about what research will actually look like in the field, in order to cope with the fact that the ethics review process is not designed to handle what ethnographic research actually consists of (Bledsoe et al., 2007).

Positive Responses to Ethics Review

While many respondents reported that ethics review was having a chilling effect on ethnographic research at their universities, some supported the process. Some stated that it helped them to plan their research:

> The ethics considerations was part of what helped me think about my research as part of a dialogical process with my 'informants', e.g. that they

> possibly would and probably SHOULD have access to my writing, be afforded the ability to comment to it or contribute to it or, to some extent, edit it.

Others showed sympathy to ethics review committees, particularly when they had had experience serving on one: 'It was made up of a bunch of overworked, under-compensated, under-recognized people trying their best to uphold ethical standards in the conduct of research', one commented. Still others had seen evidence of unethical practice by researchers, and believed that an ethics review process would prevent such harms:

> I was on the board of a migrant pre-school program in which a linguistics MA student sought employment as an aide. We later (after the end of the season) learned he was studying the students and the teachers, something he had not informed anyone about. We were appalled, and also concerned that we had opened the program to legal liability had any parent wished to complain. While the university IRB at that time was insensitive to ethnographic research, being geared toward more experimental medical and psychological researchers, this event made a believer out of me.

A number of respondents argued that ethics review protected universities and researchers from legal liability. While most viewed this as evidence that such bureaucracies primarily served to protect the powerful ('It's more or less commonly accepted that the process has nothing to do with ethics and everything to do with legal liability', was a representative comment), a small number of respondents described instances where ethics review had protected them from vindictive and powerful research participants who sought to use the legal system to punish researchers for publishing unfavorable research results. As one respondent noted, 'It protects the university and the researcher as well as the groups studied. It also prompts researchers to really think about the ethical aspects of work. And it (hopefully) prevents things like Tuskegee'.

Yet it is telling that Tuskegee, a case of unethical *medical* research, is, for this ethnographer, the symbol of the dangers of research. What is the risk posed by social science research, and ethnographic research more specifically, to research participants? Are the risks of different kinds of research comparable? Ethics committees are in the business of imagining, and then planning for, risk. But what is the relationship between imagined risk and actual harm caused to research participants by ethnographers? Given the evidence that a number of ethnographers engage in deception vis-à-vis ethics committees or evade bureaucratic review altogether, is there evidence of corresponding harm to research participants?

THE REAL DANGERS OF ETHNOGRAPHIC RESEARCH

To answer this question, the survey asked respondents to describe any known cases of unethical conduct by any ethnographer. Of 315 survey respondents, 25% reported that they personally obtained ethics approval for human research either seldom or never (Wynn, 2011), yet *only 5%* (17 respondents) mentioned cases where they were aware of or had heard about a research ethics violation by any social scientist or knew of a case where a participant had complained about a researcher's conduct (whether justified or not). This figure includes not only any cases that respondents were personally aware of, but also any cases they had heard of or even just read about, and respondents mentioned several cases where participants were harmed by medical, not social science, researchers. Respondents mentioned David Mosse, Oscar Lewis, Gilbert Herdt, and Jared Diamond as famous cases where a researcher had been accused of unethical behavior (whether justified or not); a couple mentioned Laud Humphreys' *Tearoom Trade* study (Humphreys, 1970), and several cited Patrick Tierney's accusations against Napoleon Chagnon (Tierney, 2000). The vast majority said they were unaware of any cases of complaints or of ethics violations by social scientists. As one respondent noted,

> The AAA [American Anthropological Association] task force on reviewing the ethics policy some years ago found that virtually all complaints under that policy were made by one anthropologist against another (either colleagues or students/supervisors) on issues that were mainly guild-related, i.e. concerned with intellectual property issues, etc. This was an important finding.

A couple of respondents mentioned the value of ethics review for researchers accused of misconduct:

> This happened to one of my colleague's PhD students. Fortunately he was able to demonstrate that his research had received ethics approval and that he had not departed in his methodology or his conduct from the approved research plan. The HREC [Human Research Ethics Committee] provided him with a great deal of support, and also mediated a resolution.

Yet most respondents argued that participants lacked the social capital and legal knowledge to make complaints against ethnographers. Even the few respondents who knew of cases where researchers had engaged in conduct that was unethical, caused harm, or at the very least was disliked by their research participants, were skeptical that participants could or would use ethics committees to seek redress (see also Iphofen, 2011). One commented, 'It is ludicrous to think that research participants would ever complain to a university. Too intimidating, too out of their world'. Another remarked, 'I don't think my informants know about IRB. Most of them are uneducated and have little knowledge about litigation or Western-styled ethics'. Yet another observed, 'Informants rarely complain, particularly when they are illiterate, ESL, no English or from developing countries'. Ironically, this last respondent argued that this was precisely why ethics review was necessary – so that researchers would reflect on their ethical responsibilities before they went into the field, since there would be no recourse for their participants once research had begun.

An observation about the ineffectiveness of ethics review bureaucracies in protecting research participants is hardly a compelling argument for perpetuating that review system. As I have argued elsewhere (Wynn, 2016), there are other mechanisms for formal reflection on research ethics that might produce better results for ethnographers and their research participants. Further, several respondents noted that research participants did not lack recourse against unethical research conduct. One argued that going to the media was easier for most research participants with a grievance, and produced more effective results:

> Members of the public probably won't complain to the university anyway, it just isn't part of their life-world.… they'll go to the papers and put you in an even worse position than the ethics committee would do if someone just complained to them. Scrutiny in the eyes of the general public is a much more effective sanction … if the worst really comes to the worst and an ethics committee finds you in breach of something, you may find it hard to get another academic job but at least you could probably still get a professional job somewhere else.… if your name comes up in a hostile Daily Mail on Google when a prospective employer searches for you, you'll be spending the next few years on benefits.

ANALYSIS: COMPETING EPISTEMOLOGIES OF THE RESEARCH RELATIONSHIP

Paul Atkinson has argued that, 'With a very small number of egregious exceptions, *ethnography is among the most ethical forms of research*' (2015: 172, emphasis in original). He maintains that this is because the method demands such a deep, personal, intellectual and 'emotional commitment to the lives of others' (p. 172). This view appeared to be shared by the majority of respondents to this survey, many of whom argued that research ethics was a matter of utmost concern to anthropologists. For these ethnographers, their own ethical orientation to research, and the collective enforcement of their peers, did more to protect research participants than ethics review bureaucracies. This respondent's comments were typical:

> Conversations about ethics are hugely important when doing ethnographic work, and my dissertation research proposal had a significant section devoted to them. But the REB [research ethics board] process was the least helpful thing I did concerning issues of ethics. (Wynn, 2011: 105)

Perhaps this is a conceit of the discipline. The ethnographic method produces an intimacy between researcher and participants that in turn may create an alliance of interests between them. As we have seen in a few famous cases of anthropologists who have fallen out with their informants (e.g. Mosse, 2005), this alliance of interests is at best partial (see also Nader, 1972). It also presupposes a unity of interests amongst research participants (cf. Ortner, 1995), an assumption which leaves the ethnographer ill prepared for dealing with research participants who are in conflict with each other or who seek different research outcomes or outputs than what the ethnographer is prepared to provide. Indeed, some respondents described working so hard to plan to protect their research participants, imagining them as a unified group of vulnerable people, that they were completely surprised and did not know what to do when they got to the field and encountered social and political factions who sought to use the ethnographer to gain an advantage over another group.

Yet this myth or reality of an alliance of interests that convinces some, but not all, ethnographers that their own conscientious reflection produces more ethical research praxis than can ever be produced by an ethics review bureaucracy, in fact reflects competing epistemologies of the research relationship. Ethnographers' attitudes toward ethics review are fundamentally shaped by whether they are oriented more toward seeing their peers or their research participants as their interlocutors and judges on matters of appropriate research conduct.

For those who consider that the relevant relationship in considering research ethics is between researcher and colleagues, ethics review is framed as peer review, and a necessary practice, *even when* ethics committees make mistakes:

> I am committed (though often disappointed) to the possibility of a critical dialogue about ethical issues between me as researcher, my colleagues in different disciplines and members of my institutions HREC. I think it is reasonable to be asked to be accountable for my research practice and for the decision-making I make around ethical issues.

For others, the relevant relationship is between researcher and research participant. As one respondent put it,

> Every time I go to the field, I am confronted with ethical dilemmas that are not even imagined by ethics review committees … my participants … often challenge me to benefit their communities in more tangible ways than the prospect of a few journal articles somewhere down the road.

For these respondents, the ethics committee is either a distraction from building that research relationship or it is a cynical mechanism for ensuring indemnification for the university and researchers. This epistemological orientation toward research participants, not academic peers, as the relevant peer reviewers of their research conduct explains why several respondents reported colluding with participants to stymie unreasonable demands by ethics committees:

> I am currently based in the UK where researchers are required to record field data in a format that makes data accessible to others … Hell will freeze over before I hand my fieldnotes over to a government body for inspection or for others to use, so my general position is that informants have spoken to me on the understanding that what they say is confidential and will not be disclosed to a third party in any way; that they have spoken to me on a condition of anonymity; and that they will not be required to sign any forms, since doing so would compromise their anonymity. I am beginning to make this part of my fieldwork preamble, i.e. encouraging informants to impose these conditions on me, particularly where these informants are friends of long standing, prior to talking to me.

But ethnographers' attitudes towards ethics committees also reflect different research subjects and relationships of power between researchers and research participants. The respondents who described the protective capacity of ethics committees were those who felt it shielded them against powerful research participants, often corporations or international non-governmental agencies, or other people with the ability to mobilize the legal apparatus of the state against the researcher. The ones who denied ethics committees' relevance in protecting their research participants tended to work in countries far removed from their institutional home base and believed that they understood that research context far better than an ethics committee ever could.

CONCLUSIONS

In this sample of ethnographers describing their experiences of and attitudes towards ethics review, many ethnographers argued that ethics committees rarely understand participant observation. This was apparent in committee requests for control groups, signed consent forms from illiterate participants or populations where contracts with foreigners are regarded as politically dangerous, and the availability of counseling for research participants who might be 'traumatized' by talking about their own lives. Respondents took issue with ethics committees' demand to anonymize research participants, even when the participants wanted recognition (see also May, 2010), and the demand that researchers never enter private homes, even though ethnographic research is premised on the documentation of everyday life, including private, family life. They described ethics committees that were perplexed by relationships of intimacy between ethnographers and their 'informants', which came up against the fact that ethnographers often consider long-term friendships an ethical ideal. They also blamed ethics committees for obstructing research with vulnerable populations, such as children and refugees, and on sensitive topics, such as abuse, criminal activity, and sexuality.

In response, ethnographers disappointed by the ethics review process have taken different tacks. Some have abandoned human research, stopped using human research in their teaching, or have self-censored the types of research they conduct. Others have engaged with ethics committees, argued with them, or sought to educate them until they could achieve mutual agreement, recognizing that ethics committees are, after all, just a group of their peers, working hard to play a thankless role in the institutional audit culture. A few respondents reported that they have continued to do research without undergoing review. (While many journals in the clinical sciences require proof of ethics review before publishing research results, most anthropology journals do not, so senior anthropologists can conduct unfunded research without review at little cost to their careers.) The most common response reported in this survey, however, was to partially engage with ethics review, giving committees selective, incomplete information about research circumstances, or agreeing to research protocols only to abandon them in the field – what Guillemin and Gillam (2004: 263) call 'ethics-committee speak': using language meant to reassure committees and avoid conflict, even when it does not accurately describe research practices in the field.

Given the number of people evading review or deliberately deviating from approved research protocols, it is surprising how few respondents were able to cite an instance of ethical misconduct by an ethnographer in the field. Even ethnographers who reject the authority of ethics review bureaucracies still position ethical research conduct at the center of their disciplines and practice. Many insisted that their own research practice was far more rigorously ethical than anything demanded by an ethics committee, and many provided examples of how they went beyond what their ethics committee required to ensure ethical research practice. These ranged from protecting participants' confidentiality in politically tricky situations that could not have been anticipated by committees, to consulting with research participants about how they wanted themselves to be represented in publications, to reciprocating for participants' time and knowledge with service to the community. (And a few, even when they reject the authority of the ethics committee, acknowledged that the review process prompted them to reflect on possible ethical dilemmas before embarking on fieldwork.)

In contexts where ethnographers know that their research participants lack access to and understanding of ethics review bureaucracies, perhaps it is not surprising that ethnographers would regard themselves as being the ones best positioned to ensure ethical research practice, rather than an oversight committee that has no legal or political authority in their field site. But this position also reflects a particular epistemology of the research relationship. Survey respondents who rejected the authority of ethics review bureaucracies argued that their primary interlocutors and critics were their research participants. For these researchers, their participants were the ones who kept them in check and enforced the norms of ethical research practice. Ethics review was a redundant, often naïvely-informed, obstacle. Other respondents were more oriented toward their academic peers as the critics who mattered; they disregarded the judgment of ethics committees but felt that colleagues within their discipline offered meaningful ethics guidance. They also had less confidence in the ability of their research participants to enforce ethical research conduct, whether because of a lack of knowledge, cultural capital (since they lacked language skills or the cultural know-how needed to report unethical conduct to ethics committees), or access to legal apparatuses to seek redress from unethical researchers.

REFERENCES

Atkinson, Paul. 2015. *For Ethnography*. London: Sage.

Bell, Kirsten. 2014. 'Resisting Commensurability: Against Informed Consent as an Anthro-pological Virtue'. *American Anthropologist* 116(3): 511–522.

Bledsoe, Caroline H., Bruce Sherin, Adam G. Galinsky, Nathalia M. Headley, Carol A. Heimer, Erik Kjeldgaard, James T. Lindgren, Jon D. Miller, Michael E. Roloff, and David H. Uttal. 2007. 'Regulating Creativity: Research and Survival in the IRB Iron Cage'. *Northwestern University Law Review* 101(2): 593–641.

Bosk, Charles L. and Raymond G. De Vries. 2004. 'Bureaucracies of Mass Deception: Institutional Review Boards and the Ethics of Ethnographic Research'. *The ANNALS of the American Academy of Political and Social Science* 595: 249–263.

Dehli, Kari and Alison Taylor. 2006. 'Toward New Government of Education Research: Refashioning Researchers as Entrepreneurial and Ethical Subjects'. In *Education Research and Policy: Steering the Knowledge-Based Economy*, eds. Jenny Ozga, Terri Seddon, and Thomas S. Popkewitz. New York: Routledge, pp. 105–118.

Fitzgerald, Maureen. 2004. 'Punctuated Equilibrium, Moral Panics, and the Ethics Review Process'. *Journal of Academic Ethics* 2(4): 315–338.

Guillemin, Marilys and Lynn Gillam. 2004. 'Ethics, Reflexivity, and "Ethically Important Moments" in Research'. *Qualitative Inquiry* 10(2): 261–280.

Gunsalus, C. K., Edward M. Bruner, Nicholas C. Burbules, Leon Dash, Matthew Finkin, Joseph P. Goldberg, William T. Greenough, Gregory A. Miller, and Michael G. Pratt. 2007. 'The Illinois White Paper: Improving the System for Protecting Human Subjects: Counteracting IRB "Mission Creep"'. *Qualitative Inquiry* 13(5): 617–649.

Haggerty, Kevin D. 2004. 'Ethics Creep: Governing Social Science Research in the Name of Ethics'. *Qualitative Sociology* 27(4): 391–414.

Hedgecoe, Adam. 2008. 'Research Ethics Review and the Sociological Research Relationship'. *Sociology* 42(5): 873–886.

Humphreys, Laud. 1970. *Tearoom Trade: Impersonal Sex in Public Places.* London: Duckworth Overlook.

Iphofen, Ron. 2011. *Ethical Decision-Making in Social Research: A Practical Guide*. London: Palgrave.

Lederman, Rena. 2006a. 'The Perils of Working at Home: IRB "Mission Creep" as Context and Content for an Ethnography of Disciplinary Knowledges'. *American Ethnologist* 33(4): 482–491.

Lederman, Rena. 2006b. 'Introduction: Anxious Borders Between Work and Life in a Time of Bureaucratic Ethics Regulation'. *American Ethnologist* 33(4): 477–481.

Lederman, Rena. 2007. 'Comparative "Research": A Modest Proposal Concerning the Object of Ethics Regulation'. *Political and Legal Anthropology Review* 30(2): 305–327.

May, Shannon. 2010. 'Rethinking Anonymity in Anthropology: A Question of Ethics'. *Anthropology News* 51(4): 10–13.

Mosse, David. 2005. *Cultivating Development: An Ethnography of Aid Policy and Practice.* London: Pluto Press.

Nader, Laura. 1972. 'Up the Anthropologist – Perspectives Gained from Studying Up'. In *Reinventing Anthropology*, ed. Dell H. Hymes. Ann Arbor, MI: University of Michigan Press, pp. 284–311.

Ortner, Sherry B. 1995. 'Resistance and the Problem of Ethnographic Refusal'. *Comparative Studies in Society and History* 37(1): 173–193.

Shea, Christopher. 2000. 'Don't Talk to the Humans: The Crackdown on Social Science Research'. *Lingua Franca* 10(6): 27–34.

Shore, Cris and Susan Wright. 2000. 'Coercive Accountability: The Rise of Audit Culture in Higher Education'. In *Audit Cultures: Anthropological Studies in Accountability, Ethics and the Academy*, ed. Marilyn Strathern. London: Routledge, pp. 57–89.

Shweder, Richard A. 2006. 'Protecting Human Subjects and Preserving Academic Freedom: Prospects at the University of Chicago'. *American Ethnologist* 33(4): 507–518.

Stark, Laura. 2007. 'Victims in Our Own Minds? IRBs in Myth and Practice'. *Law & Society Review* 41(4): 777–786.

Taylor, Judith and Matthew Patterson. 2010. 'Autonomy and Compliance: How Qualitative Sociologists Respond to Institutional Ethical Oversight'. *Qualitative Sociology* 33(2): 161–183.

Tierney, Patrick. 2000. *Darkness in El Dorado: How Scientists and Journalists Devastated the Amazon*. New York: W.W. Norton & Co.

Tolich, Martin and Maureen H. Fitzgerald. 2006. 'If Ethics Committees Were Designed for Ethnography'. *Journal of Empirical Research on Human Research Ethics* 1(2): 71–78.

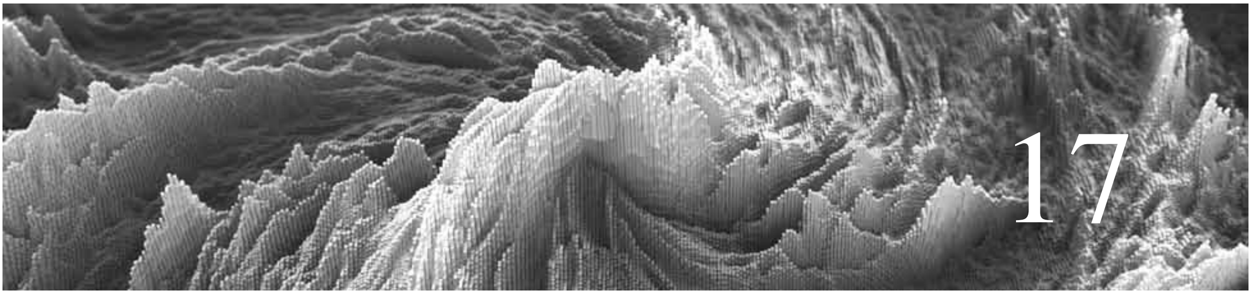
Wynn, L.L., Paul Mason, and Kristina Everett. 2009. 'Human Research Ethics for the Social Sciences and Humanities: Online Training Module'. http://www.mq.edu.au/ethics_training/

Wynn, L.L. 2011. 'Ethnographers' Experiences of Institutional Ethics Oversight: Results from a Quantitative and Qualitative Survey'. *Journal of Policy History* 23(1): 94–114.

Wynn, L.L., Mark Israel, Colin Thomson, Karolyn L. White, and Louise Carey-White. 2014. 'A National Survey of Experiences with Ethics Review'. *The Australian Journal of Anthropology* 25(3): 374–377.

Wynn, L.L. 2016. 'What Is Wrong with Ethics Review, the Impact on Teaching Anthropology, and How to Fix It: Results of an Empirical Study'. *The Australian Journal of Anthropology*, online preprint, DOI: 10.1111/taja.12187.

Wynn, L.L. In press. 'What is wrong with ethics review, the impact on teaching anthropology, and how to fix it: results of an empirical study'. *The Australian Journal of Anthropology*. Accepted 5 February 2016.



17

Reflexivity: Overcoming Mistrust between Research Ethics Committees and Researchers

Lynn Gillam and Marilys Guillemin

INTRODUCTION

Relationships between researchers and research ethics committees (RECs) have long been somewhat fraught. Recent empirical research shows that there is a persistent sense of mistrust between some researchers and REC members (Burris & Moss, 2006; Gillam et al., 2009; Guillemin et al., 2010; McCormack et al., 2012). Although researchers generally see the ethics review process as important in principle (Burris & Moss, 2006; Gillam et al., 2009), they also perceive the process as adversarial, and as creating unnecessary bureaucratic hurdles. Researchers from different disciplines and approaches, both quantitative and qualitative, feel not only frustrated, but also misunderstood and mistrusted by RECs (Gillam et al., 2009; Guillemin et al., 2010; McCormack et al., 2012). Qualitative researchers in particular tend to feel that their research is misunderstood, or not understood at all, by RECs and that a foreign biomedical paradigm is being imposed on them (Israel & Hay, 2006; van den Hoonaard & Tolich, 2014).

This phenomenon of mistrust in research ethics is not just problematic for the individuals involved, but it also represents a threat to integrity in research. It is important not to accept this mistrust as inevitable or insoluble. It is vital that we have a research ethics review process that is respected, and respectful of all involved (van den Hoonaard, 2013) and in which the integrity of both REC members and researchers is upheld. This is important for a number of reasons. First, we know that REC members and researchers, as well as broader stakeholders, value research ethics as part of sound and rigorous research practice (Guillemin et al., 2010, 2012). Researchers have a commitment to conducting ethical research, and ethics committee members have a commitment to ensuring, as far as they can, that they only approve research that will be conducted ethically. It is a matter of integrity for both; the way that the process of ethics review is conducted must not lose sight of this. We also know that a great deal of time is committed to the ethical review process. Ensuring respectful relationships between those involved ensures that the effort invested in the review process is put to best use. The second point is based on concerns that if RECs are perceived to be overly bureaucratic and intrusive, researchers may become less compliant (de Vries et al., 2006; Deslauriers et al., 2010; Keith-Spiegel et al., 2006); or worse, become demoralized and less personally invested in conducting research ethically (Israel & Hay, 2006; Pettit, 1992). This may lead to inappropriate and counterproductive practices on the part of researchers, as well as compromising their integrity. Third, the primary role of the REC is to protect participants. Having respectful REC-researcher relationships means honest, transparent and trusting interactions where the ultimate beneficiaries are research participants who take part in ethically and technically rigorous research. Finally, the benefit of respectful relationships is that both REC members and researchers can learn from one another about emerging ethical issues that arise from new research methods and innovations. In the case of qualitative research specifically, innovative research methods such as visual and sensory research, and internet-based research methods present new ethical challenges that need to be addressed. Approaching these new research areas from a position of respect rather than friction means that the potential of these methods can be explored and their benefits realized in an ethical manner.

Many suggestions and recommendations have been made about ways to improve REC review of qualitative research, including having qualitative researchers attend REC meetings in person to explain and discuss their research projects (Tolich & Fitzgerald, 2006); having RECs specifically for qualitative research (van den Hoonaard, 2013); and focusing more on the benefits of qualitative research to participants and less on the risks (Childress, 2006). We support these recommendations. It is vital that RECs, and the bodies that regulate them, respond to the legitimate concerns of researchers, and find ways to conduct ethical review that gives due attention to the substantive ethical matters that are actually relevant to qualitative studies, rather than getting side-tracked on minor and administrative matters. The problem is complex, and there is no single or simple solution. Our focus here is primarily on what qualitative researchers can do to reduce misunderstandings and improve ethics review of qualitative research; and then more briefly on what would be required in return from REC members for this approach to be fruitful. We see that both 'sides' have a part to play. We propose a way forward for qualitative researchers which involves developing a deeper understanding of what the process of research ethics review is fundamentally about, what members of RECs understand their task to be, and how they go about it.

In what follows, we will argue that research ethics is not foreign to the ideals and foundations of qualitative research. There are resources and concepts within qualitative research which can form the basis for greater understanding of the research ethics review process, and a greater sense of working together towards a shared goal. This chapter takes further the enterprise we began in 2004 (Guillemin & Gillam, 2004), of identifying connections between the procedural aspects of research ethics (that is, the formal process of research ethics review) and the ethical practice of qualitative research, focusing in particular on the idea of reflexivity. Reflexivity is a useful sensitizing concept that has some practical applications. Being reflexive and placing yourself under critical scrutiny provides a way of challenging your own practice (and that of those you are interacting with). It provides a frame to step back and objectively observe, and then to step back again to reflect on your observation. In previous work, we explored the role of reflexivity as a way for researchers to critically examine their everyday research practice. We suggest that reflexivity also provides an important conceptual and practical frame for qualitative researchers to re-imagine their relationship with RECs, and thus to enhance mutual trust and respect.

In the first section that follows, we examine research that has investigated REC-researcher relationships, to gain a better understanding of the issues at play and how they can be addressed. In particular, we unpick the possible sources of feelings of being misunderstood and mistrusted. Next we review and extend the concept of reflexivity in qualitative research. In doing so, we highlight its *similarities* with concepts in standard 'biomedical' research ethics, and unsettle the idea that the standard research ethics paradigm is fundamentally 'foreign' to qualitative research. Finally, we discuss what reflexivity would involve when applied to the context of researcher-REC relationships, and how it could be learned or enhanced. In the process, we provide specific and practical advice to qualitative researchers, as well as offering an approach to conceptual framing of the relationship.

RELATIONSHIPS BETWEEN QUALITATIVE RESEARCHERS AND RESEARCH ETHICS COMMITTEES

Studies have demonstrated that at least some researchers, including qualitative researchers, believe that the ethics review process is both important and useful (Dixon-Woods & Ashcroft, 2008; Guillemin et al., 2010). In their view, it provides researchers with the opportunity of reflecting on both methodological and ethical considerations in the design phase of the research, as well as providing legitimacy and reassurance about the research to the broader society. Despite this, a sense of mistrust in RECs lingers. Researchers tend to perceive the review process as an adversarial one, where RECs and their processes challenge their professional and personal integrity. Although this sense of frustration and mistrust has been reported across all types of researchers who deal with RECs, it seems to be particularly prominent for qualitative and social researchers. The level of feeling can be seen in the language used by researchers. For example, van den Hoonaard and Tolich (2014) refer to a 'near two-decade historical process marked by the disappointment and frustration of social science researchers' (p. 88), and Schrag describes ethics review of social research as 'ethical imperialism' (Schrag, 2010).

One of the most common criticisms of RECs by qualitative researchers is that RECs do not understand qualitative research or overstep their role in terms of providing advice or direction on particular qualitative research methods (Burris & Moss, 2006; Guillemin et al., 2012; Israel & Hay, 2006;). This has been a particular concern for certain qualitative research methodologies, for example, action research, ethnographic research and community-based participatory research (Flicker et al., 2007; Griebling et al., 2009; Ross et al., 2010; Shore, 2007). On the other hand, others have pointed to ways that RECs are working to address these concerns, particularly with regard to community-based participatory research (Guta et al., 2012; Wolf, 2010). A related criticism of RECs by qualitative researchers is the lack of qualitative research expertise on RECs. Many commentators have pointed to the dominance of quantitative researchers on RECs, who often do not have qualitative research expertise (Flicker et al., 2007; Lincoln & Tierney, 2004; McCormack et al., 2012; Parnis et al., 2005). One seemingly obvious response to this is to increase the representation of qualitative researchers on RECs. This would help, but not entirely solve the problem. The potential for RECs not understanding research methodologies would continue, because of the large range of qualitative research methodologies, and the near-impossibility of representing all of these on every committee. Although they may share an epistemological base, qualitative research methods, the contexts in which they are undertaken, and the data which they collect differ, meaning that different kinds of methodological and ethical considerations may arise.

An important finding from empirical research that has examined RECs and the REC process is concern about the 'faceless committee'. We have previously reported on findings from interviews with health researchers, including qualitative researchers, about the notion of the faceless committee (Guillemin et al., 2010). In many countries, researchers do not usually meet with the REC; an ethics application is submitted for review, then considered by the REC and a decision made without any personal interaction. Researchers report having little awareness and knowledge about the decision-making process or who the REC members are (Fitzgerald & Yule, 2003; Fitzgerald et al., 2006; Guillemin et al., 2010; Vries & Forsberg, 2002). This is a key point, which we will return to below.

We suggest that there are two main possible sources for the sense of being misunderstood or mistrusted. The first is in the domain of methodology. Qualitative researchers often feel that their methodology is misunderstood, on the basis of the questions they are asked by RECs about sample sizes, control groups, repeatability, objectivity/subjectivity, 'bias', lack of rigour and so on. This misunderstanding, when it occurs, is methodological and epistemological, and does indeed most often come from REC members trained in a biomedical or quantitative, positivist research paradigm. The concern about a foreign paradigm being imposed is well founded in these instances. However, it is important to be aware that there is nothing in the way that RECs are constituted or in the guidelines they use which stipulates positivist biomedical research paradigms as the only acceptable ones. This phenomenon represents the history of RECs, which, in the vast majority of countries, were originally set up to review clinical and biomedical research only, and have had their ambit gradually expanded over the years by the governmental bodies which govern them.

The second domain of misunderstanding or mistrust is that of ethics and integrity. Some of the reactions of qualitative researchers to RECs suggest that they feel their fundamental ethical orientation or 'ethical habitus' is disregarded or disbelieved ('ethical habitus' was a phrase coined by one of our research participants in Guillemin et al. (2012), following Bourdieu's (1977) well-known notion of habitus). In this domain, researchers of all disciplines, whether qualitative or quantitative, are potentially subject to this feeling. In general, researchers conducting research with human participants regard themselves as ethical, and are generally motivated at least partly by a desire to help others. This is the case whether they are aiming to improve survival for cancer patients by conducting clinical trials of new drugs, aiming to make life better for people with cancer by qualitative research on their experiences, or aiming to contribute to a better understanding of the experience of having cancer. If the research ethics review process causes researchers to feel that their inherent ethical stance is being doubted, it is not surprising that it would be felt as demoralizing and degrading (Burris & Moss, 2016).

This negative experience is reported by both qualitative and quantitative researchers, and suggests gaps in communication between researchers and RECs at a fundamental level, and the lack of a sense of shared purpose. However, we suspect that some qualitative researchers might be particularly prone to this sense that their integrity or ethical habitus is being impugned. These are the qualitative researchers working within research paradigms that are, in ethical terms, value-based. Specific examples of these paradigms include feminist methodologies (Creswell, 2013: 29–30), decolonizing methodologies (Smith, 1999) and participatory action research (Kindon et al., 2007; McIntyre, 2007). Such methodologies aim to promote freedom from oppression (Denzin et al., 2008: 2), and change participants' lives for the better (Johnson & Parry, 2016). Critical methodologies in general, which draw on critical theory, also have a strong value orientation, aiming at empowering people to overcome constraints placed on them by social factors (Fay, 1987). More broadly, Denzin and Lincoln argue that the goal of qualitative research is to 'be committed up front to social justice, equity, non-violence, peace and universal human rights' (Denzin & Lincoln, 2011: 11). REC members may be unaware of the values inherent in some qualitative research methodologies. While researchers working in these paradigms may think it is obvious that they are ethically motivated, concerned for their participants' interests and seeking to empower them, this will not be obvious to those who do not have considerable understanding of qualitative research. So when REC members ask their usual questions about respect for participants and possible harm to them, researchers may find this offensive. The questions may be taken as implying that researchers do not care (enough) about their participants, or have not thought about their participants.

We suggest that thinking about, and applying, the concept of reflexivity is a way to reduce this potential for counter-productive misunderstanding.

REFLEXIVITY

The concept of reflexivity has a long history in the social sciences. Many major social theorists, such as Pierre Bourdieu (Bourdieu & Wacquant, 1992) and Anthony Giddens (1991), have discussed it, particularly with respect to the relationship between individuals and society, and the ways that individuals and society have become more self-aware. Following this, reflexivity has become a core concept in qualitative research methodology. Reflexivity standardly means 'the process of reflecting critically on the self as researcher' (Lincoln et al., 2011: 124). In our earlier work, we argued for explicit recognition that the concept of reflexivity extends beyond being aware of the researcher's impact on knowledge construction, to awareness of the researcher's impact on participants (Guillemin & Gillam, 2004). Paying attention to the possible impact that the researcher has on research participants then leads to one of the key elements of standard procedural ethics, which is about minimizing potential harm to participants. Qualitative researchers who are reflexive in this extended sense are in a good position to identify possible negative effects on participants (risks and burdens) and develop approaches to minimize these. These approaches may be specific and concrete, but will often involve being in a state of preparedness to deal with whatever might arise, with the heightened awareness brought about by reflexivity.

Reflexivity in this sense requires researchers to be able to see things from a participant's point of view, to have an understanding of what matters to the people who are participating in the research, their goals and values, as well as their concerns and vulnerabilities. Researchers also need to be able to see themselves as the participants might see them – as representatives of respected organizations, as having access to knowledge and resources, and so on (Guillemin et al., 2015, 2016a).

An important point here is that reflexivity, a core tenet in qualitative research, points in the same direction as standard research ethics, even though this is not immediately obvious because the language differs. In research ethics terms, this is the process of identifying possible risk of harm to participants, while qualitative researchers approach the impact of the research interaction on participants by way of reflexivity. One way of understanding this, combining the discourses of ethics and qualitative research, is that reflexivity in relation to research participants is an ethical value. In the imperative for reflexivity lies respect for research participants and concern for their rights, interests and well being. This also resonates with the values inherent in some qualitative research methodologies, as described above, providing another fundamental connection between standard research ethics and the ethos of many qualitative researchers.

REFLEXIVITY IN QUALITATIVE RESEARCHER-REC RELATIONSHIPS

Just as qualitative researchers can be reflexive in their relationship with participants, they can also be reflexive in their interactions with RECs and their members. Just as with ethics, reflexivity needs to occur at the very outset of planning and designing research. Being reflexive with respect to RECs means researchers thinking about the impact of their ethics application on REC members. How will the research project and the researchers appear to REC members? What do REC members value, consider and worry about? For example, qualitative researchers may wish that RECs would just trust them to do the right thing, because they are ethically well motivated. But experience as a member of a REC would provide an insight into the way REC members understand their job, and how seriously they take it. REC members cannot just trust researchers; they need to look for evidence that researchers are trustworthy. Some understanding of how RECs go about their business is needed for qualitative researchers to be reflexive in relation to their dealings with RECs. The most direct way for a qualitative researcher to acquire this understanding is to become a member of a REC (indeed, apart from the more altruistic service to the profession and the community, this is one of the two major reasons why researchers should take up opportunities to join RECs). This is not possible for all qualitative researchers; but there is research evidence that this can help provide some level of understanding.

Some years ago now, we undertook a research project (the Human Research Ethics Project or HREP) to investigate the perspectives of both researchers and REC members on the research ethics review process. The methodology and findings of HREP have been reported previously in a number of publications (Gillam et al., 2009; Guillemin et al., 2010, 2012). As part of this project, we interviewed 34 Australian REC members, with a spread across all categories of membership: researchers, those involved in clinical care, and legal, religious and lay members. The HREP project provided insights into the world of REC members. The REC members who participated in that study clearly indicated that they saw their job as protecting the rights and interests of participants, a responsibility that they took very seriously. One mechanism that they used for doing this (also reported by some researchers in the study) was ‘imaginative identification’, which means imagining themselves (or their mother) in the shoes of the potential research participant, to get an idea of how the research might affect a participant. This did not mean that REC members were anti-research, or seeking to block it; but it did mean they were actively looking for potential concerns which would need to be addressed in order for the proposed research to be ethically acceptable. REC members mostly described themselves as looking for the researcher to ‘reassure’ them that they were competent at research, and willing and able to act ethically. REC members looked for this reassurance in various ways in the ethics application itself, as it was very rare for them to have the opportunity to have any personal interaction with the researcher. Opportunities for personal interactions were highly valued when they did arise.

In the HREP project, we asked REC members about their own processes of reviewing and assessing ethics applications. REC members identified a number of aspects of the ethics application which they paid particular attention to, and a number of features that they regarded as indicators of a high quality ethics application and an ethically appropriate study. There was a high level of consistency in relation to these aspects and features between the participants: many participants identified many of the same issues. There were six key features that REC members were looking for (Gillam et al., 2009):

1. Consideration of the research from the participants' perspective
2. Evidence that the ethical context for the research has been considered
3. Demonstration that the research has scientific/academic merit
4. Explicit focus on potential ethical issues
5. Use of clear and plain language
6. Demonstration that the ethics review process has been taken seriously.

Taken together, these features give a comprehensive account of what REC members are looking for in an ethics application and what they regard as ethically sound. They are set out in Box 17.1 in the form of advice to qualitative researchers. We suggest that qualitative researchers who have this understanding of REC members' perspectives and concerns are in a good starting position to become more reflexive about their interactions with RECs.

LEARNING REFLEXIVITY AS A RESEARCH SKILL

Reflexivity in our expanded sense (referring to awareness of the researcher's impact on and appearance to participants and REC members) is a research skill that can be learned. However, just like other complex professional skills which draw on experience and reflect attitudes and habits of thinking, reflexivity is learned over time, through practice, role-modelling and mentoring, as part of the progression from beginner to expert (Dreyfus & Dreyfus, 2004). There are a number of ways in which educators can facilitate novice researchers' learning of reflexivity. One approach is a structured programme involving facilitated small group discussion over a period of time, supported by written materials and specific ground rules, in which participants reflect on their experiences in practice (see, for example, Delany & Watkin, 2009). This approach is more common for health practitioners, but is readily adapted for researchers, provided that the participants have experience of conducting research. Another approach, which is suitable for those who do not yet have actual experience of doing research, is the use of real-life narratives about ethical issues and challenging situations in research practice, which tap into the experience of established researchers and make them indirectly available to beginning researchers. Through the use of 'trigger questions', this narrative approach challenges students about their responses to the situation being posed, and then extends this to other situations they could encounter in their own research practice. We have found this narrative approach successful in teaching reflexivity and ethical practice to both researchers and health care professionals (Guillemin & Heggen, 2011; Guillemin et al., 2009).

A third approach is research ethics simulation, which we have used very effectively over many years in teaching beginning qualitative researchers, most of whom have no prior experience of RECs or of conducting research of any kind. Research ethics simulation involves creating a realistic experience of being a member of a REC, reviewing ethics applications in a REC meeting, and then following up with a facilitated discussion about participants' experiences of the process. To work well, the students need a reasonable understanding of the standard principles of research ethics, and the tasks of an REC; and some understanding of qualitative research design. It is also important the simulation is realistic. The key requirements for realism are:

a. One or more complete ethics applications (two is good, one will suffice if necessary) describing a realistic qualitative research project (see TREAD [the research ethics application database] https://tread.tghn.org/ as an excellent resource) including a participant information statement, interview schedule and so on. The applications can be modified and de-identified real ethics applications, or hypothetical purpose-written ones.

Box 17.1 Approaching the research ethics application with reflexivity

1. **Show that you have thought things through from the perspective of the participants**
   Before you start your application, mentally 'walk through' your proposed research design and methodology, imagining how it would appear to a person who is approached to be involved in the research. Then plan how you will make sure that you cover the key ethical bases – giving people good information and free choice, protecting their confidentiality (even in the recruitment phase), minimising any negative impacts on them (risk, burden, discomfort, or inconvenience). In particular, consider from the point of view of the potential participants:
   a. What would they want to know – in particular, what might they worry about, or think important?
   b. How would they feel about what you are asking them to do?
   c. What would it be like for them to actually participate?
   d. What might go wrong for them – what could turn their participation into a bad experience?
2. **Before you start your application, consider the ethical context**
   Think about the role and standard concerns of REC members, and how these would apply to your particular research project. Investigate what sorts of ethical issues are common in this type and field of research – speak to colleagues, look in the literature, look at the relevant research ethics guidelines to see if there is something specific about the research methods or participants that you plan to use in this project.
3. **Show that your research project has academic/scientific merit**
   It is part of the role of REC members to assess whether your research methodology is sound and rigorous enough to be able to produce meaningful results. You need to show that you know what you are doing.
   a. Show that it is based on a good understanding of the literature, including previous studies – make sure you refer specifically to relevant published studies and appropriate literature.
   b. State the aim of the research project clearly and precisely – avoid being woolly, or grand or broad in your application.
   c. Show that the methods proposed will be able to achieve the aim.
   d. Show that you understand the methods you are planning to use – give clear explanations of the methods of sample selection, data collection and analysis.
4. **Explicitly identify and address any ethical issues or problems or sensitivities that you can see might or will arise**
   a. Show that you take ethics seriously – do not try to cover up, fudge or downplay the ethical issues.
   b. Show that you understand the nature of the ethical issues, and use the language that the ethics committee members use. Talk specifically about ethical principles such as confidentiality, consent, voluntary choice, risk/harm etc. This is a translational task to some extent – translating from the often-implicit values language and sensibilities embedded in qualitative research, to the explicit, rather hard-nosed language of research ethics.
   c. Describe the strategies you will use, or the design/methods you have adopted, to minimise the ethical problems. Explain why you have chosen these strategies (for example, that you have used them successfully in previous research).
5. **Write in clear and plain language**
   a. REC members are not experts in your particular research field – you need to make it understandable to them.
   b. REC members may well assess your ability to explain your research to the participants on the basis of how well you can explain it to them in the application form.
   c. REC members will pay particular attention to the lay summary of the project, which you give early on in the application, and to the Plain Language/Participant Information Statement.

6. **Do a professional job just as you would for a grant application**
   REC members may make an assessment of how seriously you are taking the process (and by extension, the importance of conducting research in an ethical way) on the basis of the quality of your application.
   a. Pay attention to proof-reading for spelling, typographical errors, and consistency of information.
   b. Check to see all the necessary sections are completed, and all additional documents are attached.
   c. Beware of cutting and pasting from other applications, or from one answer to another – if you do, check carefully, and make sure the pasted section makes sense in the context, directly answers the question in the application form, and does not contain information that actually refers to a different project.

The advantage of purpose-written ones is that they can be designed to have features known to be contested between RECs and qualitative researchers.

b. Applications provided to the participants at least several days before the simulated REC meeting, as would happen for a real REC.
c. A group of 6–10 participants, with one taking the role of chairperson, and another to record the REC's responses in writing (it is not necessary to assign specific roles for the other participants).
d. A reasonable amount of time to discuss the ethics applications (approx. 30 mins per application works well in our experience), in a quiet space around a table.
e. Having the task of coming to a decision about each application: to approve without changes, require changes and/or ask for more information, or reject, just as an REC would, and to provide reasons for this.

In our experience, participants take the simulation seriously, put significant effort into it, and slip into the role of being an REC member very readily, despite having no prior experience. The outcomes, and the participants' reflections, are revealing. Most participants are quite critical of the ethics applications, especially the methodology, and produce a long list of modifications and further information required from the researcher. They are very quick to pick up and criticize inconsistency or vagueness in the description of the research methods. Specifically on ethical issues, the groups identify quite a number of possible risks to participants that have not been stated in the ethics application, and some find the risk management plans inadequate. They commonly view the informed consent process as problematic, because of deficiencies in the written information, or they identify aspects of the process which do not fully allow for free choice. Overall, the participants in the simulation judge the ethics applications quite harshly, in comparison with our own experience with RECs, both as a member of a REC and as a researcher submitting an ethics application.

In the facilitated discussion after the simulation, participants are invited to reflect on how they came to decisions that they made as a group, and views that they personally formed about the research and the researcher. This reflection elicits significant insights for many participants. They report that they found themselves making judgements and assumptions about the researcher, such as being annoyed that information was missing or poorly presented, and being suspicious about the researcher's motives. Virtually every group has at least one or two members who are outraged by the typographical errors that we purposefully put into the ethics applications, and judge the researcher as not taking the process seriously, or not caring about ethics. Afterwards, some are surprised by the strength of their reaction. Overall, participants typically report that they learnt a lot about how to present their research in an ethics application, so that it will provide the REC members with the information they need in a format that is clear and understandable to them. They also gain an experience of being in the shoes of a REC member, and seeing research and researchers through their eyes. This is a powerful experience that builds reflexivity in the sense we have been describing in this chapter.

THE ROLE OF REC MEMBERS

So far, the focus has been on qualitative researchers, and what they can do to improve mutual understanding and take a more positive approach to the procedural ethics process. It is sounding very much as if it is the job of qualitative researchers to fit in with REC norms and practices. But this would be only half the story. REC members must also bear responsibility for improving relationships and fostering improved understanding. In a somewhat similar vein to Tolich and Fitzgerald's idea that RECs take an ethnographic approach of seeking to learn from qualitative researchers (Tolich & Fitzgerald, 2006), we also propose that REC members adopt the qualitative research mindset, by being consciously reflexive about their review practices. Reflexivity would be a valuable tool for REC members, in at least two ways.

The first relates to reciprocity and mutually trusting relationships. Qualitative researchers being open with RECs about the potential ethical problems or issues in their research will only be feasible if this openness is met with equal frankness by RECs. REC members would need to be open to really listen to the researcher's perspective and experience, rather than pre-judge, using their established practices or norms. This would involve REC members questioning their own assumptions and interpretations of ethical principles, being open to different ideas about how to protect and promote the rights, interests and well-being of research participants. This does not constitute abandoning ethical principles or ignoring national guidelines, but it does mean preparedness to see beyond formulaic and traditional ways of interpreting them. This would open the way for RECs and qualitative researchers to learn from each other and work together to find ways to resolve ethical challenges in research.

In addition to thinking more flexibly about participants, a reflexive REC member would also be aware of how the procedural ethics process appears to researchers, and the concerns they might have; and then communicate carefully, in a way that is informed by this awareness. One of us (LG) has previously argued that RECs should be transparent in their processes and give clear reasons for their decisions (Davies & Gillam, 2007). Seeing this as underpinned by reflexivity towards researchers rather than simply principles of good governance and procedural justice gives a better account of the ethical importance of respectful relationships between REC members and researchers. Likewise, calls for REC meetings and deliberations to be open, rather than conducted behind closed doors (e.g. Gillam, 2003), are a practical method of encouraging reflexivity by REC members. Having RECs discuss researchers and their research projects in an open environment, where they knew that others could hear (even if not the particular researchers in question) would be a powerful prompt for REC members to see themselves as others may see them, reflect on their own standpoint and assumptions, and take account of the impact on researchers of what they say and do. This in turn would promote respectful and collaborative relationships with researchers.

Some REC members have the opportunity for experiential learning of reflexivity. One opportunity occurs when members of RECs submit an ethics application themselves. This is not an uncommon situation. Many REC members are also researchers (most research ethics guidelines require RECs to have researchers as members), and some join the REC in some other membership category, but become actively involved in doing research along the way. The potential light-bulb moment arrives when the REC-member-as-researcher receives a response from the REC which reviewed their application. Taking note of what assumptions have been made by both parties, what miscommunications have occurred, and above all, how this *feels*, can prompt a level of reflexivity which will enhance that person's practice as a REC member. Another opportunity comes when a REC member is given the task of talking in person with a researcher, perhaps to gather more information, or to explain the REC's concern or reasons for their decision. Being open to hear the researcher's perspective in this interchange, rather than concentrating solely on getting across the REC's message, also provides a powerful opportunity for learning reflexivity.

CONCLUSION

We have argued here for using a conceptual resource native to qualitative research, namely reflexivity, to illuminate qualitative researchers' understanding of, and approach towards procedural research ethics. What we have suggested may involve varying degrees of change in perspective and practice. It asks qualitative researchers to treat the procedural ethics process, and the members of RECs, with respect and understanding. It also asks researchers to consciously aim to build a relationship of trust with their REC, in a similar vein to building trust with research participants (Guillemin et al., 2016b). Researchers find RECs faceless, but RECs have the same feeling about researchers. Building a trusting relationship would call for less facelessness, with researchers (re)inserting themselves into their ethics applications, perhaps by writing in the first person and in a less formulaic way, in an effort to speak directly to REC members. In turn, this openness would need to be reciprocated by REC members, who would also need to see the procedural ethics process as involving building relationships and trust. REC members would need to be willing to be reflexive about their role in the process, in just the same way as we are encouraging qualitative researchers to be.

The changes we have suggested here obviously cannot be achieved overnight, or by an individual researcher alone. A measured, incremental and systematic approach is required to bring about the trusting and respectful relationships outlined here. This involves review and revision of practices by REC members and qualitative researchers, both individually and collectively, using the resource of reflexivity as a guide.

REFERENCES

Bourdieu, P. (1977). *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.

Bourdieu, P. and Wacquant, L. (1992). *An Invitation to Reflexive Sociology*. Chicago: The University of Chicago Press.

Burris, S. and Moss, K. (2006). U.S. health researchers review their ethics review boards: A qualitative study. *Journal of Empirical Research on Human Research Ethics*, 1(2), 39–58.

Childress, H. (2006). The anthropologist and the crayons: Changing our focus from avoiding harm to doing good. *Journal of Empirical Research on Human Research Ethics*, 1(2), 79–88.

Creswell, J. (2013). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Thousand Oaks, CA: Sage.

Davies, G. and Gillam, L. (2007). Articulation and transparency of decision-making by Human Research Ethics Committees. *Monash Bioethics Review*, 26(1–2), 46–56.

Delany, C. and Watkin, D. (2009). A study of critical reflection in health professional education: 'Learning where others are coming from'. *Advances in Health Sciences Education* 14(3), 411–429.

Denzin, N. and Lincoln, Y.S. (2011). *The SAGE Handbook of Qualitative Research. 4th edition*. Thousand Oaks: Sage.

Denzin, N., Lincoln, Y.S., and Smith, L.T. (eds). (2008). *Handbook of Critical and Indigenous Methodologies*. Thousand Oaks, CA: Sage.

de Vries, R., Anderson, M.S., and Martinson, B.C. (2006). Normal misbehavior: Scientists talk about the ethics of research. *Journal of Empirical Research on Human Research Ethics*, 1(1), 43–50.

Deslauriers, C., Bell, E., Palmour, N., Pike, B., Doyon, J., and Racine, E. (2010). Perspectives of Canadian researchers on ethics review of neuroimaging research. *Journal of Empirical Research on Human Research Ethics*, 5(1), 49–66.

Dixon-Woods, M. and Ashcroft, R.E. (2008). Regulation and the social licence for medical research. *Medicine, Health Care and Philosophy*, 11(4), 381–391.

Dreyfus, H. and Dreyfus, S. (2004). The ethical implications of the five-stage-skill acquisition model. *Bulletin of Science, Technology, & Society*, 24(3), 251–264.

Fay, B. (1987). *Critical Social Science: Liberation and its Limits*. Ithaca, NY: Cornell University Press.

Fitzgerald, M. and Yule, E. (2003). The research ethical review black box. *Anthropology News*, 44(8), 64.

Fitzgerald, M.H., Phillips, Paul A., and Yule, E. (2006). The research ethics review process and ethics review narratives. *Ethics and Behavior*, 16(4), 377–395.

Flicker, S., Travers, R., Guta, A., McDonald, S., and Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*, 84(4), 478–493.

Giddens, A. (1991). *Modernity and Self-identity: Self and Society in the Late Modern Age.* Stanford, CA: Stanford University Press.

Gillam, L. (2003). Secret ethics business?: The alleged confidentiality of HREC proceedings. *Monash Bioethics Review*, 22(1), S52–S62.

Gillam, L., Guillemin, M., Bolitho, A., and Rosenthal, D. (2009). Human research ethics in practice: Deliberative strategies, processes and perceptions. *Monash Bioethics Review*, 28(1), S1–S17.

Griebling, S., Zayas, V.R., Borders, C., Moore, E., Sokol, A., Brydon-Miller, M., Gerlach, J., Norman, C., and Members of the Action Research Seminar (2009). Exploring the relationship between faculty, students, and the social and behavioral ethics review committee through action research. *Journal of Empirical Research on Human Research Ethics*, 4(2), 27–36.

Guillemin, M., Barnard, E., Walker, H., Bennell, K., Hinman, R., and Gillam, L. (2015). Participants' understanding of informed consent in a randomized controlled trial for chronic knee pain. *Journal of Empirical Research on Human Research Ethics*, 10(5), 435–443.

Guillemin, M. and Gillam, L. (2004). Ethics, reflexivity and 'ethically important moments' in research. *Qualitative Inquiry*, 10(2), 261–280.

Guillemin, M., Gillam, L., Barnard, E., Stewart, P., Walker, H., and Rosenthal, D. (2016a). 'We're checking them out': Indigenous and non-Indigenous research participants' accounts of deciding to be involved in research. *International Journal for Equity in Health*, 15(1), 8; online: doi:10.1186/s12939-016-0301-4

Guillemin, M., Gillam, L., Barnard, E., Stewart, P., Walker, H., and Rosenthal, D. (2016b). 'Doing trust': How researchers conceptualize and enact trust in their research practice. *Journal of Empirical Research on Human Research Ethics*, 11(4), 370–381.

Guillemin, M., Gillam, L., Rosenthal, D., and Bolitho, A. (2010). Resources employed by health researchers to ensure ethical research practice. *Journal of Empirical Research on Human Research Ethics*, 5(2), 21–34.

Guillemin, M., Gillam, L., Rosenthal, D., and Bolitho, A. (2012). Human research ethics committees: Examining their roles and practices. *Journal of Empirical Research on Human Research Ethics*, 7(3), 38–49.

Guillemin, M. and Heggen, K. (2011). The narrative approach as a learning strategy in the formation of novice researchers. *Qualitative Health Research*, 22(5), 700–707.

Guillemin, M., McDougall, R., and Gillam, L. (2009). Developing 'ethical mindfulness' in continuing professional development in health care: Use of a personal narrative approach. *Cambridge Quarterly of Healthcare Ethics*, 18(2), 1–12.

Guta, A., Nixon, S., Gahagan, J., and Fielden, S. (2012). 'Walking along beside the researcher': How Canadian REBs/IRBs are responding to the needs of community-based participatory research. *Journal of Empirical Research on Human Research Ethics*, 7(1), 15–25.

Israel, M. and Hay, I. (2006). *Research Ethics for Social Scientists.* London: Sage.

Johnson, C.W. and Parry, D. (2016). Fostering Social Justice through Qualitative Inquiry: A Methodological Guide. Routledge.

Keith-Spiegel, P., Koocher, G.P., and Tabachnick, B. (2006). What scientists want from their research ethics committee. *Journal of Empirical Research on Human Research Ethics*, 1(1), 67–82.

Kindon, S., Pain, R., and Kesby, M. (eds). (2007). *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. Routledge.

Lincoln, Y.S. and Tierney, W.G. (2004). Qualitative research and institutional review boards. *Qualitative Inquiry*, 10(2), 219–234.

Lincoln, Y.S., Lynham, S.A., and Guba E.G. (2011). Paradigmatic controversies, contradictions, and emerging confluences revisited. In Denzin, N. and Lincoln, Y.S. *The SAGE Handbook of Qualitative Research, 4th edition*. (pp. 97–128). Sage.

McCormack, D., Carr, T., McCloskey, R., Keeping-Burke, L., Furlong, K., and Doucet, S. (2012). Getting through ethics: The fit between research ethics board assessments and qualitative research. *Journal of Empirical Research on Human Research Ethics*, 7(5), 30–36.

McIntyre, A. (2007). *Participatory Action Research* (Qualitative Research Methods Series Vol. 52). Sage.

Parnis, D., Du Mont, J., and Gombay, B. (2005). Cooperation or co-optation?: Assessing the methodological benefits and barriers involved in conducting qualitative research through medical institutional settings. *Qualitative Health Research*, 15(5), 686–697.

Pettit, P. (1992). Instituting a research ethic: Chilling and cautionary tales. *Bioethics*, 6(2), 89–112.

Ross, L.F., Loup, A., Nelson, R.M., Botkin, J.R., Kost, R., Smith, G.R., and Gehlert, S. (2010). Human subjects protections in community-engaged research: A research ethics framework. *Journal of Empirical Research on Human Research Ethics*, 5(1), 5–18.

Schrag, Z.M. (2010). *Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965–2009.* Baltimore, MD: Johns Hopkins University Press.

Shore, N. (2007). Community-based participatory research and the ethics review process. *Journal of Empirical Research on Human Research Ethics*, 2(1), 31–41.

Smith, L.T. (1999). *Decolonising Methodologies: Research and Indigenous Peoples London.* London, UK: Zed Books Ltd.

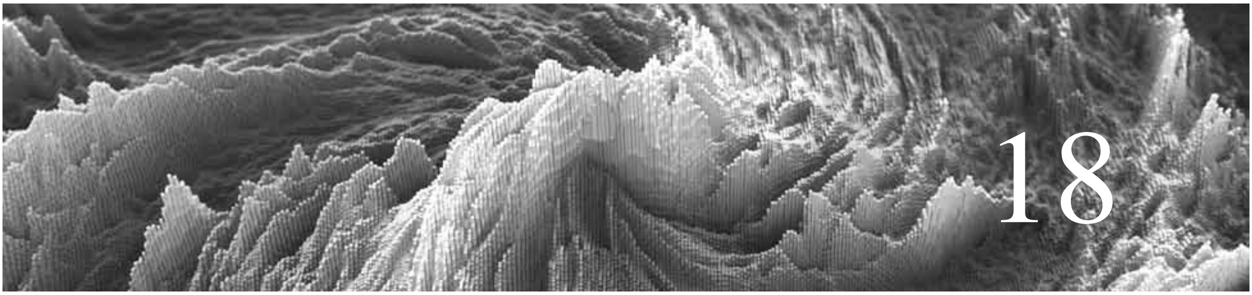
Tolich, M. and Fitzgerald, M.H. (2006). If ethics committees were designed for ethnography. *Journal of Empirical Research on Human Research Ethics*, 1(2), 71–78.

van den Hoonaard, W.C. (2013). The ‘Ethics Rupture’ Summit, Fredericton, New Brunswick, Canada, October 25–28, 2012. *Journal of Empirical Research on Human Research Ethics*, 8(1), 3–7.

van den Hoonaard, W. and Tolich, M. (2014). The New Brunswick Declaration of Research Ethics: A simple and radical perspective. *Canadian Journal of Sociology*, 39(1), 87–97.

Vries, R.D. and Forsberg, C.P. (2002). What do IRBs look like? What kind of support do they receive? *Accountability in Research: Policies and Quality Assurance*, 9(3–4), 199–216.

Wolf, L.E. (2010). The research ethics committee is not the enemy: Oversight of community-based participatory research. *Journal of Empirical Research on Human Research Ethics*, 5(4), 77–86.



18

Moving beyond Regulatory Compliance: Building Institutional Support for Ethical Reflection in Research

Gary Allen and Mark Israel

INTRODUCTION

The scope of research that now requires research ethics review can encompass a vast array of designs, methods, disciplines and sub-disciplines including qualitative investigations in the social sciences, humanities and creative arts. In some jurisdictions, ethics review also covers work with existing identified personal information and stretches to disciplines such as computer and biophysical sciences that have rarely understood their activities as involving human participants.

Unfortunately, any comfort that we might take in expanding the remit of human research review has been undercut by a cultural lag in regulatory requirements and practices. The biomedical roots of most review arrangements ossify assumptions that may be relevant to quantitative biomedical research but have proven to be less than helpful for the majority of research conducted elsewhere. This gap in relevance has two very predictable results: local review bodies attempt inappropriately to apply biomedical standards and requirements to all research (Israel, 2018, Chapter 5, this *Handbook*); and review decisions for research outside of the health sciences can be idiosyncratic and inconsistent between bodies, or even within the same review body over time (Allen et al., 2015; de Jong et al., 2012; Stark, 2012; Tolich & Smith, 2015; Vadeboncoeur et al., 2016). This presents what might appear to be an insurmountable challenge: if national research ethics review arrangements can have only fairly limited practical utility outside biomedical research, what can be done to increase the value, transparency and consistency of local research ethics arrangements?

The solution does not lie in a more comprehensive set of rules; even national ethics statements that have been tailored to meet the needs of social sciences have flaws. Indeed, the first step is perhaps recognizing that there is a conceptual flaw in the rulebook mentality. Social research can be diverse and complex, fluid and unpredictable. Rulebooks can generate an adversarial climate of resentment, avoidance and misrepresentation encouraging researchers to outsource their responsibility for the ethical design of a project to the review body (Israel et al., 2016). Directive rules might also thwart research to tackle important social problems, distorting research agendas toward approaches that are more likely to receive ethics clearance.

We argue that a better strategy is to move away from a rules-based approach focused upon enforcing compliance. Instead research ethics arrangements should be about ethical conduct and have as their primary objective resourcing the reflective practice of research. In this chapter, we discuss the elements of such an approach and explore how research institutions could re-imagine their research ethics arrangements. Such an approach is not only a more sustainable use of institutional resources, it can address the often adversarial climate between researchers and research ethics reviewers, and ultimately more effectively manage institutional risk (Israel et al., 2016).

CHALLENGING NATIONAL CODES

Israel (2015) traced a series of patterns in the regulation of social research. In many countries, ethics review strategies founded in response to biomedical malpractice are being applied to the work of social scientists. Many countries have adopted national codes, statements or guidelines set out legislatively or by major government bodies and research organizations. Within these strategies:

> debates about research ethics largely: are produced and conducted in the global North; are based on universalist claims about ethics and the primacy of the individual; exclude other belief systems; and erase colonial and neo-colonial experiences. (Israel, 2015: 46)

Not surprisingly, therefore, social scientists around the world have complained. There are examples of this in Australia (Israel et al., 2016), Brazil (Guerriero & Bosi, 2015), Canada (Bell, 2016; Gontcharov, 2016; van den Hoonaard, 2011), New Zealand (Tolich & Smith, 2015), South Africa (Posel & Ross, 2014), the United Kingdom (Dingwall, 2012; Hammersley, 2009), and the United States (Schrag, 2010).

In some jurisdictions there have been attempts to include the expertise, needs and insights of researchers from the social sciences into the process of creating national guidelines. These have had some limited success though, as the following review of regulation in Canada, Australia and the United Kingdom reveals, in many cases social scientists have still found themselves pushing against national regulation rooted in research discourses that demonstrate limited understanding of social science research methodologies.

In Canada, the 1998 *Tri-Council Policy Statement* (*TCPS*) was not supposed to impose one disciplinary perspective on others (Tri-Council, 1998: 1–2). Nevertheless, the Social Sciences and Humanities Research Ethics Special Working Committee (SSHWC) set up by the Interagency Advisory Panel on Research Ethics reported (SSHWC, 2004) that the *TCPS* did not respond well to the range of research approaches found in social and behavioral research. Will van den Hoonaard, chair of the Committee, later described 'a fourteen-year paradigmatic hiatus in the life of the *TCPS* which allowed ethics-review committees to look askance at qualitative research' (2011: 259). The revised *TCPS 2* (Tri-Council, 2010) was a marked improvement. As such, it offered hope to social scientists around the world that, where regulators allowed consultation with and showed a willingness to learn from social scientists, positive changes could occur. Nevertheless, some of the changes in *TCPS 2* were symbolic rather than fundamental, constructing social science practices as exceptions that needed to be justified in relation to a standard positivist model.

In Australia, national regulation emerged from a biomedical starting point led by the

National Health and Medical Research Council (NHMRC). Requirements were imposed without much attempt to consult or negotiate with social researchers. However, in 2004, the NHMRC invited social scientists to contribute to redrafting. The 2007 *National Statement on Ethical Conduct in Human Research* (National Health and Medical Research Council, 2007) provided social researchers with additional tools for challenging Human Research Ethics Committees with poor understanding of qualitative research. As a result, some social scientists were happier with the narrower definition of research participant, the express approval of alternative mechanisms for obtaining and documenting informed consent, and recognition in some circumstances of the value of covert research. However, social scientists still faced 'national guidelines and local review processes that frequently demonstrate[d] little understanding of the practices and traditions of social science' (Israel et al., 2016: 310).

The United Kingdom departed from the Australian and Canadian models by creating national guidelines specific to the social sciences. The Economic and Social Research Council (ESRC) released its *Research Ethics Framework* (*REF*) in 2005, and the *Framework for Research Ethics* (*FRE*) in 2010. The frameworks identified good practice for all social science research. The *REF* claimed to: preserve researchers' disciplinary affiliations; emphasize their ethical reflexivity and responsibilities; and seek a thoughtful, consistent structure for social science ethics scrutiny. However, the *REF* was criticized for fashioning prescriptive requirements more concerned with institutional risk and reputation than with fostering an ethical research culture (Dingwall, 2012; Hammersley, 2009; Hedgecoe, 2016). The 2015 *FRE* noted the ESRC's 'commitment to a process of regular review through consultation with the research community and stakeholders, to ensure ethical standards reflect changing scientific agendas and policy developments' (ESRC, 2015: 1). The 2015 version also established key principles and minimum requirements but placed more emphasis on the need for researchers to take responsibility for thinking ethically when conducting research and for considering ethical issues throughout the research lifecycle.

Mindful of the lack of progress in creating a regulatory environment sensitive to social sciences, in 2012, thirty academics from North America, Europe, Brazil and Australasia met in Canada. Following the summit, we drafted the New Brunswick Declaration (reproduced in van den Hoonaard & Hamilton, 2016). The Declaration articulated themes with which social scientists have struggled, including: 'Encouraging a variety of means of furthering ethical conduct involving a broad range of parties' (Article 4); 'Encouraging regulators and administrators to nurture a regulatory culture that grants researchers the same level of respect that researchers should offer research participants' (Article 5); and the need to 'Commit to ongoing critical analysis of new and revised ethics regulations and regimes' (Article 7) – for many of the attendees, this agenda represented business as usual.

The Declaration was intended to support constructive dialogue between groups with an interest in nurturing ethical research and appropriate regulatory practices. In particular, we hoped to provide international support for researchers seeking to influence regulatory practices in their own institutions and jurisdictions. Noting a suppression of the ethical imagination by a combination of national regulation and conservative review committees, Gontcharov (2013) described the Declaration as offering the 'possibility for restarting the conversation on the principles of ethical governance in academic research' (p. 156).

Between 2015 and 2017, we both participated in the revision of part of the Australian National Statement. The Working Party originally had responsibility for revising the sections associated with qualitative research, but this remit was expanded to discuss elements of human research across methodologies, disciplines and methods. As a result, for perhaps the first time, a working party tasked with revising a key part of the National Statement had a sizeable number of social scientists with a strong background in qualitative methods and methodologies. An important consideration for this group was ensuring that the guidelines provided helpful advice with regard to participant-directed work in the broad social sciences, humanities and fine arts.

This process of revising a national guideline is rarely easy, and can never be truly inclusive of all designs, disciplines and methods. Any resulting national framework is likely to be constrained by design factors and, where revision is done section by section, the need to ensure the consistency of the new material with the rest of the document. A practical problem in the framing of national arrangements is that the inclusion of an illustrative example in the text can sometimes be misread by reviewers, administrators and researchers as implying that a provision applies only to the stated example or, worse still, this is the only acceptable way of approaching a particular research methodology. Given that it would be impossible – or at least unwieldy – to list all possible situations where a provision might be used, this might mean that no practical examples appear in a national arrangement.

The New Brunswick Declaration also committed signatories to ‘seek to promote the social reproduction of ethical communities of practice’ (Article 6), ‘highlighting exemplary and innovative research ethics review processes’ (Article 7), and in the rest of this chapter we wish to move away from critique of regulation to consider how to resource reflective and ethical practice among researchers.

RESOURCING REFLECTIVE PRACTICE

Our starting point is that the central objective of an institution’s research ethics arrangements should be to nurture ethical conduct. If institutions are serious about this, they have to resource reflective practice among their researchers. The importance of reflective practice is well established in many professions (Schön, 1983). In the context of education, Boud and his colleagues argued that ‘Reflection is an important human activity in which people recapture their experience, think about it, mull it over and evaluate it. It is this working with experience that is important in learning’ (Boud et al., 1985: 19). Successful research institutions have encouraged reflection in developing their research culture in general (Hanover Research, 2014). We argue that the strategies outlined in the reflective practice literature in general should also shape how an institution approaches human research ethics in particular.

The foundation of such an approach is that ethical challenges and questions that arise in human research rarely produce a single answer that would be correct for every project. The specifics of the discipline, methodology, research question and research topic, the potential participant pool and contextual factors such as the location of the research and the experience of the researcher necessitate a more nuanced approach. In the face of such complexity, institutional insistence on inflexible rules reinforces an adversarial climate between researcher and ethics reviewer (Israel et al., 2016) and encourages researchers to outsource their ethical responsibilities to review structures. A resourcing reflective practice approach moves an institution away from rules and the routines of administrative processes towards using resources and processes intended to inspire and support the ethical imagination of researchers, as well as research ethics reviewers and research office professional staff.

Many institutions see a focus on research ethics review as the ‘easiest’ way of ensuring both compliance and the appearance of compliance. However, a focus on review can be counterproductive as it may reinforce the message that research ethics review is primarily about compliance with externally imposed and arcane rules that have little to do with the process of actually conducting quality research. There are many examples of researchers' war stories that identify poor practices among RECs. There are also some studies of committees' letters to health researchers. Dixon-Woods et al. (2007) reviewed 141 letters from RECs placed on the Research Ethics Database maintained by the Central Office for Research Ethics Committees in the United Kingdom. The authors concluded that these letters defined ethical practice and purported to do so authoritatively. In so doing, 'the scripting of these letters reinforces a ritualized supplicant–authority relationship between applicants and committees' (p. 799). There are few systematic analyses of the way that committees interact with social researchers and we are wary of overgeneralizing between institutions and jurisdictions. In one small Canadian study, van den Hoonaard (2011) examined five letters from Research Ethics Boards (REBs) to applicants. He traced how these REBs were able to generate an 'endless number of open-ended questions with each subsequent submission of the same application' (p. 190). These letters adopted a formal, authoritative and occasionally intimidating tone. The source of authority – either in terms of ethical principles or guidelines – was rarely identified explicitly. In addition, the committees' requests to applicants for greater clarity often themselves failed to reveal clearly what researchers were expected to do:

> This can result in mounting frustration on both sides. The REB quite genuinely seeks clarification, but the researcher has no idea what clarification the REB seeks. (p. 194)

Researchers' failure to understand and unwillingness to trust a research ethics committee can be exacerbated by the way that committees work (Fitzgerald & Yule, 2004; Gillam, 2004; Tolich et al., 2015). 'Closed' committees that regard all internal communication as confidential, communicate with researchers through depersonalized and formal letters in order to maintain a paper trail, and regard researchers as untrustworthy, are more likely to focus on compliance. Conversely, Fitzgerald and Yule argued that 'open' committees that used an open and transparent model of decision-making are more likely to support genuine engagement with ethical questions.

Ultimately, the emphasis on 'preparing good research ethics review applications' is almost certainly a mistake because attention to the ethical dimensions of a project should commence from the earliest stages of the design of a project (well before a project is submitted for review) and continue through the conduct of the work, analysis of the data, dissemination of results and beyond. Consequently, a more balanced approach to human research ethics would see professional development resourced to a greater degree than research ethics review systems. An effective approach to professional development would be focused upon practical ethical challenges, explore useful strategies and how to justify alternative approaches, and have clear disciplinary relevance to the audience. In practice this is likely to mean working with smaller audiences of researchers who share disciplinary or methodological approaches. We also suggest it entails deploying more thoughtful teaching approaches, resource materials, and building a collaborative network of researchers, reviewers, administrators, and managers.

A Collaborative Network

Research institutions need to locate research ethics within a broader research culture that recognizes the value of distributed leadership. Such leadership results from the devolution of functions and responsibilities from the top of the institutional hierarchy as well as emerging from the autonomous actions of scholars developing their own research practices (Bolden et al., 2009; Gosling et al., 2009). In such a model, research ethics becomes a key responsibility of everyone involved in research, a collaborative endeavor involving researchers, reviewers, administrators, and advisors, rather than being sequestered away behind research managers and specialists.

Researchers and reviewers should be working with rather than against each other. Information about regulatory requirements and ways of working with the review bodies should be shared well beyond the research office and committee structure and across the research community; and, the review process has to be able to hear and understand feedback from researchers. Researchers need sources of practical and non-judgmental advice so they feel safe to raise questions, concerns, and problems. Professional development needs to be provided by people respected across the institution who, collectively, can support researchers whatever their disciplines and methodologies.

Institutions can attempt to meet these needs by appointing people to chair and service research ethics committees with skills in communication and collaboration. Some institutions no longer see ethics officers as administrators, but recruit people with community development, teaching or research backgrounds. The amount of time that capacity building might consume should be recognized in job descriptions and workload arrangements.

We have also advocated for (and introduced) the use of a network of experienced researchers who can provide collegiate advice (see also Iphofen, 2011), deliver workshops and facilitate constructive communication in their disciplinary area:

> Research Ethics Advisers have been a source of education and advice on both ethical conduct and regulatory compliance to graduate students and their supervisors, early career researchers, and other researchers in their academic areas. The network represents a distributed approach to the ownership of ethics expertise as a research design, conduct, and quality concern, rather than just the purview of central research administrators and the institution's research ethics committee. Research Ethics Advisers both support an approach to research ethics by researchers focused on reflective practice and provide discipline-specific expertise to the human research ethics committee, enhancing communication among applicants, administrators, and committee members. (Israel et al., 2016: 304)

An active network of advisers can improve the quality of research ethics review applications, mitigate against review delays and frustrations, and generally improve the climate between researchers, ethics reviewers, and the research office. Institutions should formally appoint members, provide professional development, advice, support and resources through the research office, and assist and encourage communication and mutual support. In the United Kingdom, some professional bodies have been offering some of these functions to their members; examples include the Social Research Association, British Psychological Society and the British Society of Criminology – all provide expert guidance (Iphofen, 2016). We believe that there is scope to broker the provision of specialist advice on-line for those who do not have ready access within their own institutions.

Resource Material

Most national bodies responsible for human research ethics or integrity offer very little in the way of resources for researchers or reviewers. Even those that do provide training, tend to focus on more operational and technical matters. They are also jurisdictionally specific even though they are designed to be used by researchers who may be working multinationally. The consent package templates issued by the United States Department of Health and Human Services and the Human Research Ethics Application form issued by the Australian National Health and Medical Research Council are two examples. Much resource material issued by individual institutions also tends to be procedural or intended to do little more than facilitate 'good' applications for research ethics review. Sadly, these reinforce the perception that human research ethics arrangements are bureaucratic, or just about compliance, and research ethics is only the purview of research office staff and technical experts.

Training courses can turn out to be little more than tools for institutional risk management. Some United-States-based social scientists have been particularly scathing in their assessment of 'McEthics' (Freyd, 2011) material in Collaborative Institutional Training Initiative (CITI) courses, particularly when the course strays from biomedical research paradigms. Yet, leading educational institutions in the United States, like Columbia University, require their researchers to complete CITI courses once every three years. The co-chair of the Center for the History of Ethics of Public Health at Columbia University condemned the CITI program in a public hearing:

> I have to tell you, it is the most insulting experience to sit in front of a screen, to download a text and then a series of questions to which there is only one right answer, and if God forbid you think that there may be an ambiguity or an uncertainty, you get the answer wrong … there is something off when people see the entire process, not as something they feel proud about, but as something they experience … as, in a way mortifyingly stupid, and stupefying. (Beyer, 2011)

Much less common are resources intended to prompt and support the ethical reflections of researchers and/or provide suggestions on how researchers might justify a novel or innovative approach. The 'help text' and guidance material associated with an institution's human research ethics forms and processes should reference and link to relevant resource material. We argue such resource material should make it clear to applicants and reviewers that innovative approaches to research are welcome and encouraged, and provide suggestions, tools, and information to assist a researcher in justifying his or her approach to an ethical challenge. While such an approach can offer greater latitude to researchers, there is a reciprocal obligation – researchers need to reflect carefully upon the issues for the specific project, they cannot simply apply 'the rule'.

Over the last few years, we have developed a range of materials to support reflective practice. For the Australian university sector, Gary Allen has produced the *University Research Ethics Manual* (n.d.) (based on the *Griffith University Research Ethics Manual*) which has been licensed for use by 13 other institutions and provides practical advice with regard to potential participant pools (e.g. children and young people), designs (e.g. computer-mediated research), challenges (e.g. the discovery of illegal behavior) and operational matters (e.g. the ethical design of evaluative practice). In 2014, as members of the Australasian Human Research Ethics Consultancy Services (AHRECS) team, we were commissioned by the Australian government's Office for Learning and Teaching (an agency that existed within the Commonwealth Department of Education and Training) to produce freely available resources for researchers and research ethics reviewers with regard to the scholarship of teaching and learning (Allen et al., 2016).

The European Commission has a variety of programs that fund research and innovation across disciplines and jurisdictions that may have limited experience of articulating their approach to social research ethics. The Commission's Directorate-General for Research and Innovation has generated guidance notes for social scientists, including particular papers on ethnography, the use of ethics advisors, dual use of data and researching migrants (for example, European Commission, 2010; Iphofen, 2013). The European Research Council (ERC) has also attempted to render transparent its ethics screening, review and audit processes, and improve the quality of researcher reflection (for example, European Commission, 2013), running a social research ethics workshop in Brussels in 2015. Some of the activity by European agencies is not necessarily well judged in identifying and responding to social science-specific matters, some of the guidance material is not easy to uncover, and at least one chair of a review panel has cautioned against the tendency of groups of reviewers to fall into poor habits (Iphofen, 2016). Nevertheless, the intent of providing guidance to researchers should be acknowledged.

Given the heavy workload reported by some university research ethics committees, it is unsurprising committee chairs, research offices and those involved in the conduct of research ethics reviews strive to avoid difficult reviews, researcher complaints or formal complaints about the design or conduct of a project from research participants (Motil et al., 2004). However, feedback and complaints could be approached positively as providing a useful opportunity to improve practice. The process of refining items and materials based on feedback can improve their relevance and usefulness, increase a sense of ownership and support and satisfy a complainant that her views have been taken seriously and have been acted upon.

For example, the research ethics review of a proposed project with an unfamiliar design or approach can be uncomfortable for reviewers, involve multiple exchanges of correspondence between the reviewers and proponent, and take longer than a typical review. At the end of a difficult review it might seem counterintuitive, or unhelpful to add a further step to the correspondence, but there is real value in the reviewers and research office seeking feedback upon how the review process and resource materials could be improved for researchers planning similar projects in the future. There may also be value in seeking permission to use the project as a vignette for the training of research ethics reviewers, ethics advisors, and researchers. This extra step can communicate to applicants that the review was more difficult and more time-consuming than normal and that there is an intention for the reviewers to learn from the exercise and improve the review process.

Teaching Social Research Ethics

It is easier to imagine a new approach to research ethics if entrants to the research culture are already acculturated to reflecting on ethics. Yet the literature on teaching social research ethics is poorly developed. Von Unger (2016) argued for three departures from the sterility of prevalent training packages. She called for research ethics education to: draw on experiential learning; locate the learning of ethics in the context of methodology; and acknowledge multiple possible responses to ethical quandaries.

Over the last decade, we have slowly been developing a small library of hypothetical case studies of social research stories and have invited expert commentary from experienced researchers (Allen et al., 2016; Israel & Hay, 2006).[1] Our aim has been to move practice from training to education. We wanted to shift capacity building exercises away from 'spotting the problem in an application' towards helping researchers recognize ethical issues, develop analytical skills, respect the points of view of other people, take personal responsibility for decision-making, and negotiate with regulatory bodies (Hay & Israel, 2005). Some of the more interesting initiatives that we have encountered have also allowed multiple perspectives to be heard. In the United States, the University of California Center for Collaborative Research for an Equitable California (CCREC) is creating a casebook of scripts that represent the interactions that might occur in social justice-oriented collaborative community-based research and which can be used in teaching (Baloy et al., 2016). While fictitious, the scripts draw on data generated through interviews with researchers and community partners. They have also created a board game that requires participants to take and defend positions on the ethical acceptability of particular research practices.

In Australia, we can point to Macquarie University's *Online Ethics Training Module* developed by Lisa Wynn and her colleagues (Wynn et al., n.d.). In contrast to CITI, 'There are no multiple choices here, just a stark presentation of an ethical challenge a scholar might reasonably face' (Schrag, 2009). The freely available Macquarie Module outlines a series of ethical issues confronted by social scientists and, in particular, ethnographers:

> When I first started this project, I had the idea that, since I was writing for an undergraduate audience, I needed to provide concrete advice and unambiguous solutions. The more I wrote and researched

> ethics, the more I realized that not only was this impossible, but it was an intellectually barren goal to set. Instead what I ended up doing was showing how much research ethics are contested, both within and across disciplines … even as I described controversies and lack of consensus, each issue and case study raised is far more complicated than I could ever convey… even if I could, in a short training module, satisfy myself that I'd covered these issues thoroughly and with enough attention to the ethical complexities raised, I could never satisfy others. (Wynn, 2009)

There are, of course, other examples. The *Resources for Research Ethics Education* hosted by the University of California, San Diego and the *Resources for Teaching Research Ethics* produced by the Poynter Center at Indiana University also designed cases to allow participants in group discussion to practice the process of ethical decision-making rather than coming to the single correct end point (Pimple, 2007).

Change Management

Most people care about and invest in ethics. Institutional approaches to human research ethics are often built over the course of several years, can be the fruit of the labors of volunteers and committed specialists, and so be deeply entrenched in practice. This is undoubtedly one of the strengths and advantages of research ethics review compared to other areas of research governance, but it can also represent a significant weakness when an institution seeks to reform or at least consider making significant changes to its approach to matters such as research ethics review. The same professional pride, energy, and commitment to the institution's arrangements that can make it possible for the research ethics committee and research office to cope with the massive volume of work, can make the bureaucracy resistant to change. This can be especially true if it is perceived by the review committee or the research office that the agenda for change is an implied criticism of the current system or the work that has gone before.

We have seen attempted reform of research ethics review arrangements fail for reasons that we believe are relatively easy to avoid. These common and serious missteps include: looking for a magic cure by focusing heavily on the information technology/research management elements of the changes; addressing only a part of the problem by failing to treat all of the changes as a complementary suite; under-resourcing human capital by neglecting to appoint, train and support a network of research ethics advisers; squandering social capital by disregarding promised implementation dates or by providing inadequate support to champions of institutional change.

Consequently, any refinement or replacement of an institution's research ethics arrangements needs to be approached as an organizational change task. Without wishing to go at any depth into the change management literature, we can point to Kotter's model (2012) for successful organizational change: establish a sense of urgency; form a guiding coalition; create a vision; communicate the vision in order to gain buy-in; empower others to act on the vision; create short-term successes; consolidate improvements and never let up; finally, incorporate change into the institutional culture. While Kotter was insistent that all eight elements needed to take place (either consecutively or concurrently), we have already discussed our vision and now want to focus on two more elements identified by Kotter: coalition-building, and embedding change.

Coalition-Building

Change only occurs if sufficient numbers of people inside an organization support it early on and build up a broader coalition over time. There needs to be a guiding group that transcends existing structures and can identify and communicate with stakeholders, mobilizing support, building legitimacy, and creating trust. This group also needs the support of some senior staff members with line-manager responsibility who will help broker institutional endorsement. Within the university, those seeking to change research ethics culture are likely to need the early support of the senior academic responsible for research in the university, the research office, and the research ethics committees, and subsequent buy-in from discipline heads, research groups, and research higher degree students. 'Champions' for the changes should be identified within the review body and wider research community who should be invited to be involved in the implementation and to voice why they support the changes.

The guiding group needs to be aware of what stakeholders want and what change will entail for them. In some cases, stakeholders will lose or gain control of resources and it is sensible to anticipate and respond to objections to change early on. Some members of the research administration and review body may feel that any change reflects poorly on their work. Champions for change need to make it clear the institution is by no means unique in facing the difficulties, frustrations and review problems, and that the work to date of the review body and research office is appreciated and valued, and the objective of the changes is to build upon the foundation they have laid. Indeed, the changes we propose may well deliver a number of benefits for the review body and research office including better quality applications, more time to focus on the most ethically sensitive projects, less time wasted on administrative activity, and a more sustainable resourcing of human research ethics.

Embedding Change

If changes are to last within an organization, they have to be embedded within institutional culture. Stakeholders must be progressively informed and end up recognizing the degree to which changes have been responsible for any improvement in the effectiveness and the efficiency of the processes that underpin research ethics reflection and review. In particular, they need to be alerted to the ways organizational change has diminished the adversarial culture that we have found to exist around research ethics in some institutions (Israel et al., 2016). So, changes need to be evaluated periodically and the evidence provided to researchers, managers, administrators and reviewers. Given the obvious importance of research to the research community, change that finds a place in publication in reputable journals and forms part of a national or international community of practice may also gain greater legitimacy. Later on, changes need to become part of the natural order of things in the organization, finding a place in the norms and shared values of the research community. In doing so, they should transcend the vision of a small group of individuals and become 'the way we do things around here'. Nevertheless, in turn they should be open to further reform and periodic reviews will be necessary to stop the leadership concluding that the institution has 'done' ethics reform and does not need to allocate further attention or resources.

CONCLUSION

We know that social researchers are frustrated by many elements of current research ethics review arrangements. Review arrangements that are rule-based and focus on enforcing compliance do not belong in educational institutions. Where national regulations exist, social researchers have had only a little success in shaping the rollout of guidelines, codes and statements that almost always start from a positivist and biomedical model of research. Even where national arrangements have started to engage with social scientists, we have found some local review processes have been unresponsive. It is a sad and sobering fact that very few social scientists have written about the joys of working with local research ethics review. We want to change this.

We argue that there is some possibility of changing how institutions approach research ethics. Institutions need to inspire researchers, reviewers and professional staff to think imaginatively about how to engage with the significant ethical issues that their community confronts in research. An approach that resources reflective practice should yield less antagonistic relationships between researchers and reviewers, prove more sustainable and might even better manage institutional risks.

We want to move the focus away from regulatory compliance and towards supporting the ethical conduct of research. However, this requires a shift in the way we see the roles of different stakeholders, alterations in patterns of communication, the development of far more sophisticated resource materials, and greater attention to curriculum and pedagogy so that a new generation of researchers and staff seek partnership rather than conflict. This may entail organizational change but it ought to be worth it. After all, do we not wish to work in organizations where researchers, managers, and senior executives take pride in the fact that the research ethics culture supports cutting edge research?

Note

1 These can be found at http://www.ahrecs.com/resources

ACKNOWLEDGEMENTS

Earlier versions of minor parts of this chapter were published in Israel (2015) and Israel (2017). Our work in this chapter was informed by the Australian Research Council-funded Discovery Project DP130104760 ‘The expanding disciplinary scope of research ethics committees: an inquiry into need and resistance’.

REFERENCES

Allen, G., Israel, M., and Thomson, C. (2015) *Office for Learning and Teaching: Research Ethics Report*. (http://www.olt.gov.au/system/files/olt_report_ethics_2015.pdf)

Allen, G., Israel, M., and Thomson, C. (2016) *Scholarship of Teaching and Learning Human Research Ethics Resource Manual*. (http://www.ahrecs.com/previous-projects/sotl-resource-booklets)

Baloy, N.J.K., Sabati, S., and Glass, R.D. (eds) (2016) *Unsettling Research Ethics: A Collaborative Conference Report*. Santa Cruz, CA: UC Center for Collaborative Research for an Equitable California. (https://ccrec.ucsc.edu/sites/default/files/attachments/2016.06.30%20Unsettling%20Research%20Ethics%20Report_LOW%20Res.pdf)

Bell, K. (2016) ‘The more things change, the more they stay the same: *TCPS 2* and the institutional oversight of social science research in Canada’, in W. van den Hoonaard and A. Hamilton (eds) *The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review*. Toronto: Toronto University Press, pp. 189–205.

Beyer, R. (2011) *Transcript: Meeting 5, Session 4. Implementing Federal Standards – Ethics Issues.* Presidential Commission for the Study of Bioethical Issues. (https://bioethicsarchive.georgetown.edu/pcsbi/node/229.html)

Bolden, R., Petrov, G., and Gosling, J. (2009) ‘Distributed leadership in higher education: Rhetoric and reality’, *Educational Management Administration Leadership*, 37(2): 257–277.

Boud, D., Keogh, R., and Walker, D. (1985) ‘Promoting reflection in learning: A model’, in D. Boud, R. Keogh, and D. Walker (eds) *Reflection, Turning Experience into Learning*. New York: Kogan Page, pp. 18–40.

de Jong, J.P., van Zwieten, M.C.B., and Willems, D.L. (2012) ‘Ethical review from the inside: Repertoires of evaluation in Research Ethics Committee meetings’, *Sociology of Health & Illness*, 34(7): 1039–1052.

Dingwall, R. (2012) ‘How did we ever get into this mess? The rise of ethical regulation in the social sciences’, in K. Love (ed.) *Ethics in Social Research*. Bingley: Emerald, pp. 3–26.

Dixon-Woods, M., Angell, E., Ashcroft, R.E., and Bryman, A. (2007) ‘Written work: The social functions of Research Ethics Committee letters’, *Social Science & Medicine*, 65(4): 792–802.

Economic and Social Research Council (United Kingdom) (2005) *Research Ethics Framework*. Swindon: Economic and Social Research Council.

Economic and Social Research Council (United Kingdom) (2010, revised 2012) *Framework for Research Ethics*. Swindon: Economic and Social Research Council. (http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2010/)

Economic and Social Research Council (United Kingdom) (2015) *Framework for Research Ethics*. Swindon: Economic and Social Research Council. (http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015)

European Commission (2010) *European Textbook on Ethics in Research*. Luxembourg: Publications Office of the European Union. (http://ec.europa.eu/research/swafs/pdf/pub_archive/textbook-on-ethics-report_en.pdf)

European Commission (2013) *Ethics for Researchers: Facilitating Research Excellence in FP7*. Luxembourg: Publications Office of the European Union. (http://ec.europa.eu/research/participants/data/ref/fp7/89888/ethics-for-researchers_en.pdf)

Fitzgerald, M.H. and Yule, E. (2004) 'Open and closed committees', *Monash Bioethics Review*, 23(2): S35–S49.

Freyd, J.J. (2011) 'Journal vitality, intellectual integrity, and the problems of McEthics', *Journal of Trauma & Dissociation*, 12(5): 475–481.

Gillam, L. (2004) 'Secret ethics business', *Monash Bioethics Review*, 22(1): 52–62.

Gontcharov, I. (2013) 'Methodological crisis in the social sciences: *The New Brunswick Declaration* as a new paradigm in research ethics governance?' *Transnational Legal Theory* 4(1): 146–156.

Gontcharov, I. (2016) 'The eclipse of "human subjects" and the rise of "human participants" in research involving humans', in W. van den Hoonaard and A. Hamilton (eds) *The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review*. Toronto: Toronto University Press, pp. 248–266.

Gosling, J., Bolden, R., and Petrov, G. (2009) 'Distributed leadership in higher education: What does it accomplish?', *Leadership*, 5(3): 299–310.

Griffith University Research Ethics Manual (n.d.) (https://www.griffith.edu.au/research/research-services/research-ethics-integrity/human/human-research-ethics-manual)

Guerriero, I.C.Z. and Bosi, M.L.M. (2015) 'Research ethics in the dynamic of scientific field: challenges in the building of guidelines for social sciences and humanities', *Ciência & Saúde Coletiva*, 20(9): 2615–2624.

Hammersley, M. (2009) 'Against the ethicists: On the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3): 211–225.

Hanover Research (2014) *Building a Culture of Research: Recommended Practices*. Washington DC: Hanover Research. Academy Administration Practice. (http://www.hanoverresearch.com/media/Building-a-Culture-of-Research-Recommended-Practices.pdf)

Hedgecoe, A. (2016) 'Reputational risk, academic freedom and research ethics review', *Sociology*, 50(3): 486–501.

Hay, I. and Israel, M. (2005) 'A case for ethics (not conformity)', in G.A. Goodwin and M.D. Schwartz (eds) '*Professing' Humanist Sociology* (5th edition). Washington, DC: American Sociological Association.

Iphofen, R. (2011) *Ethical Decision-Making in Social Research: A Practical Guide*. Houndmills: Palgrave MacMillan.

Iphofen, R. (2013) *Research Ethics in Ethnography/Anthropology*. Brussels: DG Research and Innovation, European Commission. (http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-ethnog-anthrop_en.pdf)

Iphofen, R. (2016) 'Professional research ethics: Helping to balance individual and institutional integrity, in W. van den Hoonaard and A. Hamilton (eds) *The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review*. Toronto: Toronto University Press, pp. 391–406.

Israel, M. (2015) *Research Ethics and Integrity for Social Scientists: Beyond Regulatory Compliance*. London: Sage.

Israel, M. (2017) 'Research ethics and integrity in socio-legal and legal research', in M. McConville and W.H. Chui (eds) *Research Methods for Law* (2nd ed.). Edinburgh: Edinburgh University Press, 180–204.

Israel, M. (2018) 'Ethical Imperialism? Exporting Research Ethics to the Global South', in R. Iphofen and M. Tolich (eds) *The SAGE Handbook of Qualitative Research Ethics*. London: Sage, pp. 89–102.

Israel, M., Allen, G., and Thomson, C. (2016) 'Australian research ethics governance: Plotting the demise of the adversarial culture', in W. van den Hoonaard and A. Hamilton (eds)

The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review. Toronto: Toronto University Press, pp. 285–316.

Israel, M. and Hay, I. (2006) *Research Ethics for Social Scientists: Between Ethical Conduct and Regulatory Compliance*. London: Sage.

Kotter, J.P. (2012) *Leading Change*. Boston, MA: Harvard Business Review Press.

Motil, K.J., Allen, J., and Taylor, A. (2004) 'When a Research Subject Calls with a Complaint, What Will the Institutional Review Board Do?', *IRB: Ethics & Human Research* 26(1): 9–13.

National Health and Medical Research Council, Australia (2007, updated 2013) National Statement on Ethical Conduct in Human Research. (http://www.nhmrc.gov.au/guidelines/publications/e72)

Pimple, K. (2007) *Using Case Studies in Teaching Research Ethics*. (https://www.nationalethicscenter.org/resources/7282/download/292.pdf)

Posel, D. and Ross, F.C. (2014) 'Opening up the quandaries of research ethics: Beyond the formalities of institutional ethical review', in D. Posel and F.C. Ross, (eds) *Ethical Quandaries in Social Research*. Cape Town: HSRC Press, pp. 1–26.

Schön, D.A. (1983) *The Reflective Practitioner: How Professionals Think in Action*. New York: Basic.

Schrag, Z.M. (2009) Macquarie's Innovative Ethics Training. *Institutional Review Blog*, April 17. (http://www.institutionalreviewblog.com/2009/04/macquaries-innovative-ethics-training.html)

Schrag, Z.M. (2010) *Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965–2009*. Baltimore, MD: Johns Hopkins University Press.

Social Sciences and Humanities Research Ethics Special Working Committee (2004) Giving Voice to the Spectrum. Ottawa: Interagency Advisory Panel on Research Ethics. (http://www.pre.ethics.gc.ca/english/workgroups/sshwc/SSHWCVoiceReportJune2004.pdf)

Stark, L. (2012) *Behind Closed Doors: IRBs and the Making of Ethical Research*. Chicago: University of Chicago Press.

Tolich, M., Bathurst, R., Deckert, A., Flanagan, P., Gremillion, H., and Grimshaw, M. (2015) 'One size does not fit all: Organisational diversity in New Zealand tertiary sector ethics committees', *Kōtuitui: New Zealand Journal of Social Sciences Online*, 11(1). (http://dx.doi.org/10.1080/1177083X.2015.1035732)

Tolich, M. and Smith, B. (2015) *The Politicisation of Ethics Review in New Zealand.* Auckland: Dunmore Publishing.

Tri-Council (Medical Research Council of Canada, National Science and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada) (1998) *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Ottawa: Public Works and Government Services. (http://www.pre.ethics.gc.ca/eng/archives/tcps-eptc/Default/)

Tri-Council (Canadian Institutes of Health Research, National Science and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada) (2010) *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Ottawa: Public Works and Government Services. (http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf)

Vadeboncoeur, C., Townsend, N., Foster, C., and Sheehan, M. (2016) 'Variation in university research ethics review: Reflections following an inter-university study in England', *Research Ethics* doi:10.1177/1747016116652650, June 5.

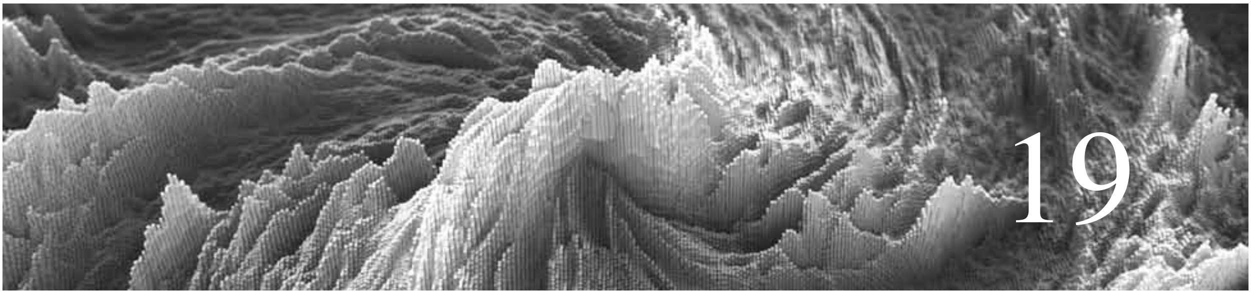
van den Hoonaard, W.C. (2011) *The Seduction of Ethics: Transforming the Social Sciences*. Toronto: University of Toronto Press.

van den Hoonaard, W. and Hamilton, A. (eds) (2016) 'Appendix: The New Brunswick Declaration', in W. van den Hoonaard and A. Hamilton (eds) *The Ethics Rupture: Exploring Alternatives to Formal Research-Ethics Review*. Toronto: University of Toronto Press, pp. 431–432.

von Unger, H. (2016) 'Reflexivity beyond regulations: Teaching research ethics and qualitative methods in Germany', *Qualitative Inquiry*, 22(2): 87–98.

Wynn, L. (2009) 'Making ethics training ethnography-friendly', *Culture Matters*, 23 April. (https://culturematters.wordpress.com/2009/04/23/making-ethics-ethnography-friendly/)

Wynn, L.L., Mason, P.H., and Everett, K. (n.d.) *Human Research Ethics for the Social Sciences and Humanities*. (http://www.mq.edu.au/ ethics_training/)



19

Research Ethics Committees – What Are They Good For?

David Hunter

There tends to be considerable angst among qualitative researchers about research ethics committees and research regulation as evidenced by the many comments, observations and concerns raised throughout this *Handbook*. The general feeling also expressed elsewhere seems to be that these processes and formal procedures: don't understand social science research in general, are focused on issues more pertinent to biomedical research, don't respect academic freedom, and are undemocratic. Authors arguing along these lines include Dingwall (2007), Dyer and Demeritt (2009), Hammersley (2009), Schrag (2010, 2011), Wynn (2011), and Dyck and Allen (2013). Hence it might be claimed that they are not well suited for the review or regulation of such research. Wynn's empirical work on the experiences of anthropologists with research ethics committees illustrates these kind of views:

> 'The ethics committee was interdisciplinary but nobody seemed to understand ethnographic research. I was even asked for my set of interview questions! I thought of the thousand or so questions I expect to ask over the year's fieldwork … [like] Hey what's for breakfast?'.
>
> 'They tend to use a medical/psych disciplinary model that doesn't work well for ethnography'.
>
> 'As I heard more and more accounts of how IRBs worked and were constituted – often of people with little experience themselves, or who wanted to impose 'one size fits all' rules across a highly textured and variable research landscape – I became very disillusioned'. (Wynn, 2011)

However, in most jurisdictions now, much human participant research has become regulated by the review of research proposals by ostensibly independent committees[1] who assess the ethical soundness of the proposed research. What research is regulated in this way depends on jurisdiction, but in many jurisdictions at least some social science research is regulated in this fashion.

To use Australia as an example:

In Australia all research involving humans is regulated via the rules laid out in *the National Statement on Ethical Conduct in*

Research Involving Humans (NMHRC, 2007). This puts responsibility for ethical review and approval on institutions conducting or hosting research, with obligations to establish Human Research Ethics Committees (HRECs) which conform to the processes and composition laid out in the *National Statement*. There are broadly three pathways of regulation in Australia: full committee approval, minimal risk and audit. Which pathway a specific project needs to take depends on that project but broadly, full committee approval is required if research poses more than minimal risk, where minimal risk is defined as really any harm greater than 'taking offence'. Who reviews the application depends both on where the researcher is located and where the research is being conducted, with approval usually being needed from all sites involved. This multicentre review is evolving with mutual recognition between HRECs, but at this stage that applies primarily to medical research and only to a limited subset of that, so not too much social science research. And as is common in a federal system what can be mutually recognised changes from state to state. This process is quite intensive and typically involves the completion of a long (20+ pages) form and substantial supplemental information. If the research is no more than minimal risk and the relevant HRECs have established procedures to regulate such applications differently (most have) then it will usually go through a fast track review process involving a much shorter form and a much quicker turn around since it will not usually be reviewed by full committee. Finally, some projects are approved of as audit – if they are aimed at assessing whether specific standards are met; such as audits of service delivery. Many committees request that audits be approved by them as well – although technically in those cases they are not approving applications to audit, they are just ensuring that they are actually audits and thus don't need to have ethical approval.

While something like this system is the current state of play in many jurisdictions, it is worth briefly discussing why these research ethics systems exist and, in particular, whether they are justified in the context of social science more generally and qualitative research specifically. In this chapter I will explore this question first by looking at general justifications of research ethics systems, then whether the criticisms raised by social scientists and qualitative researchers are fair and whether a justification for either different treatment of or an exemption for qualitative research is warranted. I will also argue inter alia that some of the problems researchers have with research ethics committees and systems are of their own making and born out of their own suspicion and misunderstanding of research ethics committees themselves (Wynn, 2011). This is not to say that research ethics committees are infallible and fault free – as with all human institutions they make mistakes, sometimes serious ones. (See, for example, Hedgecoe's (2013) discussion of the Northwick Park incident where arguably the Research Ethics Committee reviewing the application failed to seek to clarify important details of the trial that would have reduced the harm caused when it went tragically wrong.) However, a successful research ethics process requires an element of trust on both sides, a combative relationship rarely ends well for anyone and ought to be avoided (Hedgecoe, 2012). In making this case I will draw on theoretical and empirical research on research ethics committees and their interactions with social science researchers.[2]

WHY HAVE RESEARCH ETHICS SYSTEMS IN GENERAL?

While research ethics systems vary from country to country they have broadly settled on a model of regulation which requires prospective review of the researcher's planned course of action by an independent committee. These committees typically comprise lay people, experts in the area of research (broadly conceived), and other interested parties such as academics, statisticians, lawyers, ethicists, clinicians and so on. They typically function at an arms-length from the research and the researcher although their composition and how they are operationalised is jurisdiction dependent.[3]

The regulation of research by research ethics committees is controversial, because the imposition of regulation has costs both financially and in terms of time (Whitney & Schneider, 2010). Research in and of itself is good, either because of the intrinsic value of knowledge or because of the human benefit we get out of applying that knowledge. It also ought to be acknowledged that ethics committee review is a very unusual form of regulation – there are few other activities for which we require prospective review by an independent group before we consider them morally permissible (Wilson & Hunter, 2010).

There are a number of justifications offered for regulation in the literature, appealing to the potential harms of research for participants, historic abuses in research, and conflicts of interest by current researchers and so on. Each of these justifications is somewhat compelling but also doesn't tell the whole story by themselves since other human activities seem to suffer from the same deficits but we don't consider prospective regulation the appropriate response in those areas. For example, take the historic abuses that have occurred in the conduct of research (European Commission, 2010; Schüklenk, 2005). These are unquestionably horrific and disturbingly widespread – it would be rare to find any country without at least one high profile scandal in research ethics, and there are usually plenty of other troublesome historic cases which don't have the high profile of the Nazi Medical Research or Tuskegee but raise nearly as many concerns. For example in the 1950s US public health researchers investigated the ability of young children to escape from being trapped in fridges and optimal fridge door design by luring young children into wooden boxes and then slamming them closed to see how the children react to being enclosed in the dark (Bain et al., 1958). Arguably an important piece of research which has saved many lives since by showing that the more expensive magnetic strip technology was far safer, but at what moral cost?[4] Similar controversial cases can be pointed to in the history of the social sciences such as Scheper-Hughes' (1979) study of mental illness in Ireland, Laud Humphreys (1975) *Tearoom Trade*, more recently Alice Goffman's (2014) research which she details in *On The Run* has been described as unethical, exploitative of its participants and potentially illegal (Lubet, 2015).

But do these historic abuses serve as adequate justification for regulation in this fashion? The problem here is that in other similar activities there have been similar historic abuses – take medical practice for example. In 1999, the Irish Medical Council suspended a consultant obstetrician for sterilising over a hundred of his female patients via medically unnecessary hysterectomies.[5] Should we take the actions of this obstetrician as a reason to prospectively regulate all obstetric practice? The answer seems to be no, so why should we react in that way to misconduct in research?

I think that a combination of factors separates out research from medical practice and provides a justification for research ethics committee review. This largely involves recognising our own weaknesses as researchers, and reacting to them appropriately to enable us to fulfil our own ethical obligations (Wilson & Hunter, 2010).

The first factor focuses on the conflict of interests that human research presents – in essence it is an activity that is aimed at generating knowledge via using people to test hypotheses. There is a natural tension here between the interests of the researcher and those of the research participants. Indeed, if we look at many of the historical scandals – these have often occurred not because the researchers were 'evil' but instead, because they were aiming at what they perceived to be a greater good, and were willing to make sacrifices (of others…) to get there.

Hopefully, most of us no longer hold such view (the Helsinki Declaration for example puts the wellbeing of research participants above any possible knowledge gained by the research) but even if we don't hold such consequentialist attitudes towards our research participants we ought to acknowledge that it is human nature that we are likely to view our own research in too rosy a light in regards to both the potential benefits and the probability of risks occurring, we are often too close to our own research to be objective (Hedgecoe, 2008).

Second, research is fundamentally complex, unpredictable and uncertain. This complexity is compounded by the contested nature of research ethics and ethical claims more generally (Hunter, 2007a). This makes it difficult for an individual researcher to make ethically sound and defensible decisions. In essence, on this view a research ethics committee helps a researcher discover their own ethical obligations to their participants.

Finally, even if we are in a good position to make ethical decisions about our own research, given that these decisions are ethically controversial and contestable, having a publicly established and warranted committee decide ensures that as much as possible differing perspectives have been taken on board, giving the research a legitimacy it could not otherwise obtain (Stark, 2012). This is particularly important if there is public outcry about a research project – having independent scrutiny tends to reduce concerns about it. In 2008, the University of Bath conducted research where Bluetooth broadcasters in cellphones were used to track the movements of tens of thousands of people throughout the city without consent. This enabled the researchers to make various predictions and claims about the movement of people through cities, important to know for example in civil emergencies. The newspapers found out about the research and there was an initial outcry, but this soon damped down when it was revealed that the project had been through the appropriate ethics approval process, and the obvious concerns about privacy had been considered and dealt with appropriately as part of the research methodology.[6] There is also a sense that insofar as the research ethics committee is established and granted authority via the State it serves a democratic function of deciding in situations of potential ethical disagreement what is morally acceptable.

Hence, I suggest that we should think of research ethics committees not as gatekeepers (though they do fulfil that function) but instead as aids for researchers – helping them resolve the ethical complexity of determining what obligations they have towards their participants, and protecting research from public outcry (Wilson & Hunter, 2010).

This provides a general justification for the regulation of research not merely as a reaction to the past actions of researchers but instead as a means to help researchers avoid making the same mistakes in the future. Now it is of course an open and empirical question about whether specific research ethics committees do function in such a fashion, but if they do not, that is not a reason to abandon the system but instead to reform that committee or regulatory system's culture until it does. Research based on decision letters by UK Research Ethics Committees seems to show that their decision making does helpfully improve the quality of research (Angell & Dixon-Woods, 2009). Sociological research on the attitudes of research ethics committee members in the UK seems to underwrite this with Hedgecoe quoting a member of one committee stating:

> It's part of the ethics of being on a Research Committee. If you actually are obstructive of research, this is not an ethical way of doing your business. The opposite is facilitating, that's what we're taught, that facilitating the research is the job of the Committee. (Hedgecoe, 2008)

And Hedgecoe more generally noted:

> For the committees I observed, it was part of their role to support research and to offer advice that allowed it to progress (rather than place hurdles in its way). (Hedgecoe, 2008)

IS THERE A REASON TO TREAT QUALITATIVE RESEARCH DIFFERENTLY?

In some jurisdictions only certain types of research are regulated (either those conducted by representatives of specific institutions such as in the US or certain types of research such as medical research in the UK) – should social science more generally or qualitative research specifically perhaps be excluded from regulation? Failing such an extreme measure, do we need special committees or regulatory processes for such research.

It is difficult on the face of it to see what could justify treating qualitative research totally differently to other research. It is often research aimed at the public good, but much the same could be said about a lot of other research. However, several authors have argued that social science and qualitative research ought to be treated differently, so it is worth at least exploring their arguments. Before we do that though it is worth considering how social science research might be regulated or treated differently.

The most radical option is to exempt social science research from ethical review entirely. Zachary Schrag could be read as arguing for this – at least in the context of ethnographic research (Schrag, 2010, 2011). This I think would be quite difficult to justify – given that social science research can entail both physical and other ethical risks, the broad regulatory principle of proportionality would suggest that at the very least that research should be regulated the same way (Gefenas et al., 2010).

A less radical option would be to review social science via a different process – for example, it has been floated that peer review rather than committee review would solve issues of reviewers not understanding or having relevant expertise in social science (Dyck & Allen, 2013; Wynn, 2016). However, it would be difficult to see how this could be appropriately independent of the researchers – and if it is not, then the role of research regulation as a safeguard for researchers from being too close to the subject matter or methods to see the risks/harms entailed would be lost.

Finally, we might adopt specialist review of some kind. This could either comprise a specialist committee as has been set up in the UK for Social Care research with the National Social Care Research Ethics Committee,[7] or by making sure that there are some members with relevant expertise on all research ethics committees, or having some subset of committees with appropriate expertise. While this may still trigger concerns about appropriate independence it seems the most palatable proposal for 'special' treatment of social science in general or qualitative research specifically.

Qualitative Research Is Lower Risk

I suggested earlier that the classic justification of research regulation was related to the risks and harms imposed by researchers on participants. Robert Dingwall writes:

> These arguments do not apply to most empirical research in the social sciences and humanities. This work is not comparable with injecting potentially toxic green stuff that cannot be neutralized or rapidly eliminated from the body if something goes wrong. (2007: 787)

This line of argument could be run two ways – first, that qualitative research should be excluded from ethical review because it is typically low risk, and second, that it is a different type of research and the historic justification of regulation of research is a biomedical justification. Weaved into both of these arguments is the view that the paradigm, epistemology and ethical threats of social science research are significantly different from the classically positivist biomedical research. I will take these arguments in turn.

First, it might be argued that qualitative research is generally low risk and hence regulating it is too burdensome. If successful this would be a powerful argument as the costs of regulation ought not to outweigh its likely benefits (Wilson & Hunter, 2010). However, qualitative research doesn't automatically fall into any particular category of risk since the level of risk involved will depend on the nature of the specific research project. Like any other type of research, qualitative research runs the gamut of risks – qualitative research with vulnerable subjects, in war zones, with migrants could be very high risk. It is probably true that most social science and qualitative research is low risk in nature. But again this is true of many types of research that we do not exclude from all regulation. Indeed some have argued that research in general is low risk:

> The occupational hazards of the role of subject in medical research are slightly greater than those of being an office secretary, one-seventh those of window washers, and one-ninth those of miners. (Levine, 1988)

Even if the risks in qualitative research are in fact considerably lower in general than those in medical research, for example, this does necessarily warrant a differing system for handling such research, especially if it is epistemically difficult to determine beforehand which projects are likely to be low risk. Indeed another way to conceptualise the work that a Research Ethics Committee does is the epistemic task of determining the level of ethical risks present in a piece of research (Hunter, 2007b). It is also worth considering that physical harms are not the sole ethical concern regarding research – failing to respect individuals' right to autonomy, self-determination, as well as confidentiality are potentially very live concerns in much of social science or qualitative research (Hunter, 2014). Hence, while qualitative research is generally of low physical risk compared to biomedical research it can still raise significant ethical concerns.

Systems that exclude particular types, or methodologies of research from ethical review altogether, seem fundamentally flawed because types of research rarely map well onto potential risks and ethical concerns in research (Hunter, 2014). Given the complex nature of research, and the difficulty of drawing boundaries between research types and methods inevitably means some risky research will end up being unregulated if the system used allows for exclusions. Likewise, having exceptions in a system of regulation simply invites moral hazard, the attempt to redescribe what is clearly research of one sort as another sort in order to avoid regulation.

More importantly, the justification given earlier for ethics review still applies even if social science research is generally of low risk, it still helps us fulfil our professional obligations as researchers by helping to identify when our research is not ethical, and when it can be ethically improved.

Research Ethics Committees Aren't Well Suited to Reviewing Qualitative Research

It might be argued that research ethics committees as they are currently run and constituted are just not that well suited to regulating qualitative research (Murphy & Dingwall, 2007). This might be because they simply lack expertise and understanding in these areas of research. This is particularly problematic when a research ethics system originally set up for something else such as biomedical research expands to include social science research as happened in the UK research ethics system (Dawson, 2006). I recall commenting to a colleague when I sat on a NHS Research Ethics Committee in Northern Ireland at around this time, that the committee's default attitude seemed to be research giving people drugs is probably perfectly fine, but talking to them, '…now that is really risky'. But what this anecdote demonstrates is simply the committee's familiarity with that type of research – the unfamiliar is often treated with some suspicion because the committee will be less familiar with the possible risks and benefits. This, however, as Hedgecoe points out, is likely to be a temporary issue as committees transition to handling this sort of research as part of their regular business

(Hedgecoe, 2008). Once a research ethics system begins to consider a type of research as its business then typically people are brought on board with appropriate expertise, training is made available and guidance is issued. To move back to the Australian context, whilst the *National Statement on Ethical Conduct in Research Involving Humans 1999* (NMHRC, 1999) was endorsed by the Academy of the Social Sciences in Australia, it contained in total two references to qualitative research and focused largely on health research.[8] In contrast, the *National Statement on Ethical Conduct in Research Involving Humans 2007* (NMHRC, 2007) mentions qualitative research 25 times, and has a specific section devoted to ethical issues in qualitative research. And least we think this is an Australian quirk, similar trends can be observed internationally with for example the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 1999* in Canada having no mentions of qualitative research and the 2010 replacement mentioning it 69 times, including again a specific section on the ethical issues in qualitative research (Tri-council, 1999, 2010).

However, even if committees become used to dealing with such research, without appropriate methodological expertise and disciplinary knowledge they will still fail to do a good job some of the time – they will permit some qualitative research that they ought not, and prevent some that that they should allow. This is because without disciplinary knowledge and methodological expertise they will not be aware of the ethical quagmires and potential risks proposed by the relevant methodologies, nor how they are commonly mitigated, nor alternative methodologies which may achieve the same results at lower ethical risk (Hammersley, 2014).

This then provides grounds for some special treatment of social science research in general and qualitative research specifically – although in reality it is simply what is required for equally effective research regulation of social science and other research. Research ethics regulation systems ought to either provide specialist committees or ensure that non-specialist committees have sufficient expertise to appropriately review qualitative research. The HREC that I serve on in Australia can serve as an example of this – we have several members who are flagged as having expertise in various forms of social science research and if we have an application using a particular methodology we will not review it unless someone flagged as competent in that methodology is present at the meeting. So if a piece of qualitative research is to be reviewed, then the committee will have relevant expertise. This is a requirement set out in the National Statement:

> (f) at least two people with current research experience that is relevant to research proposals to be considered at the meetings they attend. These two members may be selected, according to need, from an established pool of inducted members with relevant expertise. (NMHRC, 2007)

A more significant concern along these lines is that there might be something in the nature of qualitative research that makes it not fit into the model of prospective review (Murphy & Dingwall, 2007). I suspect this is part of what objections that focus on the ‘inappropriate imposition of biomedical norms’ are appealing to. So for example:

> It is often argued that the system of REC review cannot be appropriately applied to at least some social science research such as history or qualitative work because the research questions themselves are emergent from the research and hence not amenable to prior review. (Hunter, 2014)

I think this objection though both misconstrues research in other disciplines and research ethics committees’ practices. It is true that if a committee took a very narrow proceduralist approach of requiring an exact detailed account of what would be done in a research project, then yes absolutely this would conflict with a lot of interview-based research because of its emergent nature. However, this is not a property unique to social science research nor to qualitative research. Research by its very nature is exploring the unknown and thus has emergent properties. This uncertainty is dealt with by research ethics committees by trying to predict the possible ethical consequences, and seeking expert advice and this can be done by describing in broad brush strokes the sorts of content likely to occur in the research. There seems little reason why this can be dealt with in other areas of research but not with qualitative research. Hedgecoe points out that similar issues would seem to be present in other forms of bureaucratic form filling required in academia like describing the nature of research when applying for a grant, yet it is rare to hear anyone suggest that they cannot apply for grants due to the emergent nature of their research (Hedgecoe, 2008).

Academic Freedom and Democracy

A number of authors criticise research ethics regulation on the grounds of academic freedom or a conflict with democratic values. The broad idea equates research either with exercising academic freedom or with freedom of speech and associates the importance of social science for democracies (Dingwall, 2006; Hammersley, 2009; Schrag, 2010). On these grounds it is argued that research ethics illegitimately imposes moral values on research and limits academic freedom by shaping the nature and content of research. Furthermore, there are some strong arguments that some research such as public policy research is required by our democratic system to provide adequate information to the public (Spicker, 2007).

While there is considerable debate about the exact nature, scope and limits (if any) of academic freedom, the broad idea is that the social value of academia requires a fair amount of leeway in terms of determining what we should study and how we should study it. The apparent conflict with research regulation is clear, and indeed research ethics systems can be used to interfere with academic freedom inappropriately by being captured, for example, by concerns about reputational risks to the institution if they are not situated appropriately independently (Hedgecoe, 2016).

Simply because a system can be abused doesn't mean that it is a bad system – the system of contracts and employment at universities can likewise be abused to put people under pressure to significantly limit their academic freedom but I suspect few social scientists want to do away with that. For this line of argument to work then it has to be shown that research regulation fundamentally conflicts with academic freedom in an inappropriate way.

To make this argument work you need to rely on a very libertarian version of academic freedom where any limit on research (including legal, moral etc) was considered illegitimate. This would be very difficult to justify in practice; as Adam Hedgecoe points out, there are many things that impact on the scope and type of research being done, such as the priorities of research funders, the legal framework we operate within and so on, but it is rare to hear complaints about these on academic freedom grounds (Hedgecoe, 2008). So it seems that limiting research to that which is deemed ethical is unlikely to be undemocratic or contrary to academic freedom. In many jurisdictions at least some Research Ethics Committees are either public bodies or established by legal frameworks, and thus they might instead represent a balancing act between the interests of the public in good quality academic research and minimising the exposure of the public to ethically inappropriate research. Even where this is not the case, arguably part of the obligation that a democratic institution has is to take some responsibility for research activity carried out under its auspices (Iphofen, 2011).

Distorting the Type of Research Being Done

Finally, it is sometimes objected that the imposition of research regulation changes the type of research that can and will be done. This is in one sense true since the aim of research regulation is precisely to do this by excluding unethical research. However, since it is unlikely that all research with a particular subject matter, or methodology or participants will be unethical it doesn't straightforwardly follow that the nature of the research itself changes. Instead, this sort of argument is based on the idea that some valuable social science research might be avoided because people don't want to have to deal with a more complicated approval process. This could in principle mean that certain study populations are avoided – so for example in Australia some qualitative researchers will avoid including indigenous participants because they don't want to trigger review by special committees for this purpose. Alternatively, it could mean that certain research topics are avoided – for example those dealing with the vulnerable because these will get special attention from research ethics committees. Or it might mean that particular research methodologies are used less frequently because they trigger concern from research ethics committees. Of course a good research ethics committee will challenge a researcher if particular populations seem to be unfairly excluded, but insofar as it may map onto a category perceived as vulnerable it may endorse the exclusion (Baylis & Ballantyne, 2016; Wynn, 2016).

Of course it is difficult to determine empirically what isn't done as a result of regulation – because it's hard to measure what would have been the case without that regulation (Hunter, 2015). Nonetheless it seems like that there is some truth to this, at least anecdotally you hear examples which would appear to bear out that this does sometimes happen and Dyck and Allen provide some evidence for this occurring stating:

> Researchers who are time-limited regularly report changing the nature of the research they conduct in order to increase the chance of obtaining rapid IRB approval or in order to avoid the need for IRB review. (Dyck & Allen, 2013)

The first thing to note about this is that insofar as this occurs it is a largely self-inflicted injury to the body of research. While I have seen plenty of controversial research projects face challenges getting research ethics approval, if the researcher has been willing to work at educating the committee involved and adapting the project, and they genuinely have a good project with a solid reason for the risks they want to take, I have not seen a project ultimately rejected on these grounds even if a committee might be initially hesitant about approving it. Whilst this is of course only my personal experience, given the evidence that Hedgecoe puts forward regarding the attitudes and aims of research ethics committee members seeing themselves as primarily facilitators of good quality research:

> When an application is rejected there is no sense of celebration on the part of REC members, but rather regret and disappointment that this decision had to be made. This attitude is not just about being pro biomedical research, but rather carries over into a supportive attitude towards whatever research comes before the committee, even qualitative social science. (Hedgecoe, 2008)

This seems to suggest that research ethics committees are more inclined to try and facilitate tricky proposals than they are to stonewall them. So if researchers put these supposedly difficult proposals forward, I suspect they would get approved much more often than not.

Second, this is not a harm specifically to either social science research more generally nor qualitative research specifically – it impacts on all research. So unless there is some reason to believe it is especially prevalent in qualitative research it really speaks to the broader question of whether research ethics regulation is justified at all insofar as it is one of the costs that have to be considered when evaluating the impact of such a system.

CONCLUSION

Qualitative research is vitally important to improve our understanding of people and their lived experience of their environment. Nonetheless, given that there is no morally significant difference in kind between qualitative or other social science research and other research then it needs to be regulated in the same fashion as other research. While this does present some challenges for qualitative and other social science researchers, as I have suggested above, these issues are likely to reduce over time as the regulatory system is developed and improved upon as we can see in the Australian and Canadian systems. There is clearly work to be done here, but it does not justify excluding research from appropriate regulation. It may however justify ensuring that our regulatory system does accommodate social science research in general and qualitative research specifically by ensuring either a specialist review system with appropriate expertise or by ensuring that such expertise and familiarity resides on all committees. Finally, I have argued that working with research ethics committees to resolve these issues is far more effective as a strategy than adopting an adversarial relationship. As Hedgecoe's research has shown, for the most part research ethics committees and their members do not delight in stopping research and creating roadblocks, instead they are there to help researchers navigate the ethical issues that may emerge in the course of their research (Hedgecoe, 2008).

Notes

1 (Research Ethics Committees) RECs in this article since I am discussing regulation specifically in Australia

2 In particular I will draw on empirical work from Adam Hedgecoe, Mary Dixon-Woods, Laura Stark and Lisa Wynn.

3 See Office for Human Research Protections (2017) for a listing of over 1,000 laws, regulations, and guidelines that govern human participants research in 126 countries, as well as standards from a number of international and regional organisations.

4 For discussion of this case see here: http://blogs.bmj.com/medical-ethics/2008/09/22/the-good-old-but-somewhat-cold-days/

5 See here for more details: http://www.independent.ie/opinion/analysis/the-motives-of-dr-neary-remain-to-be-unmasked-26473154.html

6 See here for details about the case: http://www.theguardian.com/uk/2008/jul/21/civilliberties.privacy

7 http://www.hra.nhs.uk/news/rec/national-social-care-research-ethics-committee/

8 And one of those references was a recommended reading on the ethics of qualitative research – in the medical context.

REFERENCES

Angell, E. and Dixon-Woods, M. 2009. Do Research Ethics Committees identify process errors in applications for ethical approval? *Journal of Medical Ethics*, 35(2): 130–132.

Bain, K., Faegre, M.L., and Wyly, R.S. 1958. Behavior of young children under conditions simulating entrapment in refrigerators. *Pediatrics*, 22(4): 628–647.

Baylis, F. and Ballantyne, A. 2016. Missed trials, future opportunities. In F. Baylis and A. Ballantyne (Eds), *Clinical Research Involving Pregnant Women* (pp. 1–13). Springer.

Dawson, A.J. 2006. A messy business: Qualitative research and ethical review. *Clinical Ethics*, 1(2): 114–116.

Dingwall, R. 2006. Confronting the anti-democrats: The unethical nature of ethical regulation in social science. Medical Sociology online, 1: 51–58.

Dingwall, R. 2007. 'Turn off the oxygen…'. *Law & Society Review*, 41(4): 787–795.

Dyck, M. and Allen, G. 2013. Is mandatory research ethics reviewing ethical? *Journal of Medical Ethics*, 39(8): 517–520.

Dyer, S. and Demeritt, D. 2009. Un-ethical review? Why it is wrong to apply the medical model of research governance to human geography. *Progress in Human Geography*, 33(1): 46–64.

European Commission. 2010. *European Textbook on Ethics in Research*. Luxembourg: Publications Office of the European Union. https://ec.europa.eu/research/science-society/document_library/pdf_06/textbook-on-ethics-report_en.pdf

Gefenas, E., Dranseika, V., Cekanauskaite, A., Hug, K., Mezinska, S., Peicius, E., Silis, V., Soosaar, A., and Strosberg, M. 2010. Non-equivalent stringency of ethical review in the Baltic States: A sign of a systematic problem in Europe? *Journal of Medical Ethics*, 36(7): 435–439.

Goffman, A. 2014. *On the Run: Fugitive Life in an American City (Fieldwork Encounters and Discoveries)*. The University of Chicago Press.

Hammersley, M. 2009. Against the ethicists: On the evils of ethical regulation. *International Journal of Social Research Methodology*, 12(3): 211–225.

Hammersley, M. 2014. On the ethics of interviewing for discourse analysis. *Qualitative Research*, 14(5): 529–541.

Hedgecoe, A. 2008. Research ethics review and the sociological research relationship. *Sociology*, 42(5): 873–886.

Hedgecoe, A. 2012. Trust and regulatory organisations: The role of local knowledge and facework in research ethics review. *Social Studies of Science*, 42(5): 662–683.

Hedgecoe, A. 2013. A deviation from standard design? Clinical trials, research ethics committees, and the regulatory co-construction of organizational deviance. *Social Studies of Science*, 44(1): 59–81.

Hedgecoe, A. 2016. Reputational risk, academic freedom and research ethics review. *Sociology*, 50(3): 486–501.

Humphreys, L. 1975. *Tearoom Trade: Impersonal Sex in Public Places.* New York: Aldine.

Hunter, D. 2007a. Proportional ethical review and the identification of ethical issues. *Journal of Medical Ethics*, 33(4): 241–245.

Hunter, D. 2007b. The roles of research ethics committees: Implications for membership. *Research Ethics Review*, 3(1): 24–26.

Hunter, D. 2014. Can significant differences in regulating medical and non-medical research be justified? *Monash Bioethics Review*, 32(3–4): 254–267.

Hunter, D. 2015. Is research ethics regulation really killing people? *Medical Journal of Australia*, 202(6): 338–339.

Iphofen, R. 2011. *Ethical Decision Making in Social Research: A Practical Guide*. Basingstoke, UK: Palgrave Macmillan.

Levine, R.J. 1988. *Ethics and Regulation of Clinical Research*. New Haven, CT: Yale University Press.

Lubet, S. 2014. Ethics on the run: Review of 'On the Run: Fugitive Life in an American City (Fieldwork Encounters and Discoveries)', by Alice Goffman, The University of Chicago Press, 2014. http://newramblerreview.com/images/files/Steven-Lubet_review-of_Alice-Goffman.pdf

Murphy, E. and Dingwall, R. 2007. Informed consent, anticipatory regulation and ethnographic practice. *Social Science and Medicine*, 65(11): 2223–2234.

NMHRC. 1999. *National Statement on Ethical Conduct in Research Involving Humans (1999)* https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e35.pdf

NMHRC. 2007. *National Statement on Ethical Conduct in Human Research* (2007) – Updated May 2015. https://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research

Office for Human Research Protections. 2017. *International Compilation of Human Research Standards 2017 Edition*. U.S. Department of Health and Human Services. https://www.hhs.gov/ohrp/sites/default/files/international-compilation-of-human-research-standards-2017.pdf

Scheper-Hughes, N. 1979. *Saints, Scholars, and Schizophrenics: Mental Illness in Rural Ireland*. University of California Press.

Schrag, Z.M. 2010. *Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965–2009*. Baltimore, MD: Johns Hopkins University Press.

Schrag, Z.M. 2011. The case against ethics review in the social sciences. *Research Ethics*, 7(4): 120–131.

Schüklenk, U. 2005. Introduction to research ethics. *Developing World Bioethics*, 5(1): 1–13.

Spicker, P. 2007. The ethics of policy research. *Evidence and Policy*, 3(1): 99–118.

Stark, L. 2012. *Behind Closed Doors: IRBs and the Making of Ethical Research*. The University of Chicago Press.

Tri-Council. 1999. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. http://www.pre.ethics.gc.ca/archives/tcps-eptc/docs/TCPS%20October%202005_E.pdf

Tri-Council. 2010. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf

Whitney, S.N. and Schneider, C.E. 2010. Viewpoint: a method to estimate the cost in lives of ethics board review of biomedical research. *Journal of Internal Medicine*, 269(4): 392–406.

Wilson, J. and Hunter, D. 2010. Research exceptionalism. *The American Journal of Bioethics*, 10(8): 45–54.

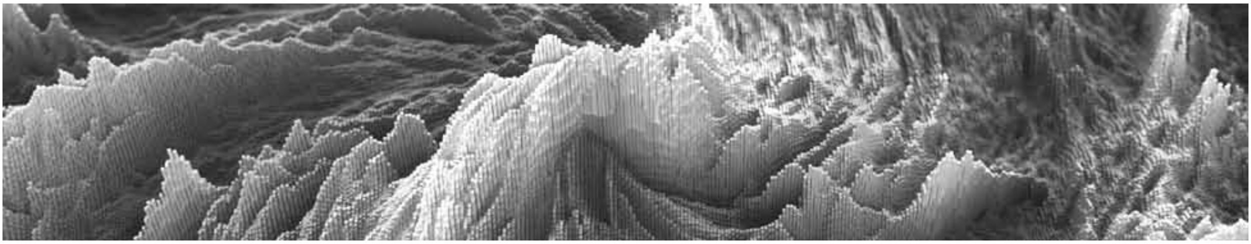
Wynn, L.L. 2011. Ethnographers' experiences of institutional ethics oversight: Results from a quantitative and qualitative survey. *Journal of Policy History*, 23(1): 94–114.

Wynn, L.L. 2016. What is wrong with ethics review, the impact on teaching anthropology, and how to fix it: Results of an empirical study. *The Australian Journal of Anthropology*. doi:10.1111/taja.12187

PART IV

Qualitative Research Ethics with Vulnerable Groups

Ron Iphofen and Martin Tolich



The chapters in Part IV all address what ethics committees and their regulatory codes classify as vulnerable groups. For example, children, the elderly, and prisoners are all traditionally regarded to be vulnerable. Yet these chapters are not the only discussion of vulnerability. Many other *Handbook* chapters overlap with vulnerability; the walking interview (Chapter 11)focused on psychiatric forensic patients; visual research in politically sensitive regions (Chapter 12); a later chapter on disaster ethics (Chapter 29) highlights a temporal form of vulnerability in the immediate aftermath of calamitous events affecting a community. Even litigants self-representing in the unfamiliar surroundings of courtroom hearings can be classed as vulnerable. Vulnerability, as **Will van den Hoonaard** claims, is ubiquitous and his chapter is as groundbreaking as it is refreshing. He takes a different tack to the static notion of vulnerability, questioning if the category of vulnerability is even a useful ethical concept. He assumes all persons should be considered vulnerable.

Chih Hoong Sin's chapter reflects on the ethical considerations that manifest themselves when conducting research with disabled people who have experienced hate crimes and makes a number of recommendations. First, he considers the impact on the 'researched', such as the potential for unwanted self-realization and the re-living of traumatic experiences. Second, he makes the reader mindful of the potential impact on researchers who can often be exposed to highly distressing accounts of hyper-violent and/or hyper-sexual attacks. Third, there are implications for the researchers' behaviours and research praxis in relation to dealing with victimhood in the context of a commitment to the 'social model' of disability; the need to resist simplistic and uncritical assumptions around vulnerability while negotiating the minefield of safeguarding requirements. Additionally, there are specific challenges around conducting research in an area where the personal is highly political and where there is a deep-rooted activism and social change culture underpinning the disability rights movement in the UK.

The chapter by **Linda Liebenberg** and colleagues is one of two chapters that feature participatory action research – how its emergent research design can be compromised by unequal power relationships between researcher and researched. What comes first the chicken or the egg – in this case ethics approval or research collaboration? Liebenberg addresses this inequality, explaining the lengths they as academic researchers went to in order to ensure that the research question resulted from the collaborative involvement of both parties in the co-creation of the research problem. Power relationships are further complicated, first by the research taking place among indigenous communities and second by the community of interest being young persons. A feature of this story is the *getting in* to the research site as well as *getting along*. Ethical assurances take distinctive features, highlighting the four Rs of respect, relevance, reciprocity, and responsibility that coalesce under a fifth R, reflexivity.

A second chapter using a participatory action research design examines role conflict in sexual health research by asking if the community researchers and the academic researchers co-opted to collect the data are placed in a vulnerable situation. Here explored are the ethics of employing hired-hand researchers (Seiber & Tolich, 2013). **Julie Mooney-Somers and Anna Olsen** present three scenarios in which community researchers inadvertently create big ethical moments. In the first, a research assistant discloses information collected in the research setting to a member of the community who is an interested party. The second example involves a disclosure about a member of the community to a research informant. The third example documents an attempt at advocacy by a research assistant who coaches an informant in presenting information that would lead to a beneficial outcome for the community. These scenarios are examined in detail but so too is the question of the downside of co-opting community researchers. Co-opting community researchers as research assistants ensures better access and buy-in from the community but does this lead to a decline in scientific rigour?

Angel García and Gary Alan Fine's chapter builds a continuum around the notion of many childhoods – from the preschool to the adolescent. The requirement to gain parental consent prior to gaining assent from younger children is established. Older children's consent is more contextual. So too is gaining consent from children in non-traditional contexts; i.e. street kids who exist without parental oversight are seen as special cases in this continuum. Any attempt to put an age restriction on them opens up a claim of being patronizing.

Fiona Poland and Linda Birt's chapter presents research involving older people dispelling negative stereotypes of the vulnerable, isolated persons individually or as a hidden population collectively. The authors present an array of challenges that present themselves to any person researching the elderly. These include cognitive impairment, the necessity to use ongoing consent, the ability to secure co-researchers and navigate around gatekeepers. While other chapters discuss ongoing consent or process consent this chapter's interest in ongoing consent is periodically asking 'in-the-moment' ethical questions such as: does the participant know what the researcher's job is and what they are there for?

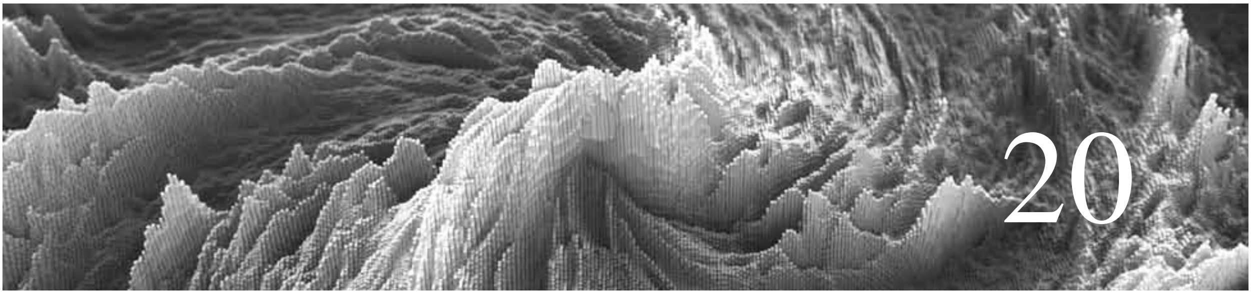
Emma Tumilty and colleagues extend our understanding of vulnerability in novel ways. They reveal the invisible rights of animals who find themselves co-opted to take part in qualitative research. The focus of this type of research is not the animal itself; dogs in prison or the calming effect of a walking-a-dog programme are two examples. Rather, the authors ask or insist that these animals have rights and that research ethics committees should write code that recognizes these rights.

Static or standing categories of vulnerable person generate an oversupply of paternalism. Some are acute. Tolich (2016) claims studies involving death or bereavement are a third rail that research ethics committees are reluctant to touch. Research involving people who use drugs are also categorized on the extreme end of the vulnerability continuum. **Lucy Pickering** asks should researchers compensate drug users for taking part in their project? Does this compensation further enhance the drug users' diminished autonomy? Does it condone drug use? The chapter takes the reader through various perspectives that justify the compensation and mitigate the diminishing of autonomy. The chapter also turns its attention to the researcher's drug use; can an intoxicated researcher continue to collect data? Overall the concept of vulnerability remains a complex one to apply – allowing participant autonomy while protecting their interests, even if no one fully understands what those might be.

REFERENCES

Sieber, Joan and Martin Tolich (2013) *Planning Ethically Responsible Research*. Thousand Oaks, CA: Sage.

Tolich, Martin (ed.) (2016) *Qualitative Ethics in Practice*. Walnut Creek, CA: Left Coast Press.



20

The Vulnerability of Vulnerability: Why Social Science Researchers Should Abandon the Doctrine of Vulnerability

Will C. van den Hoonaard

INTRODUCTION

The fixed, bio-medically driven character of the concept of vulnerability is undermining research in the social sciences. Whereas in medical research researchers must pay attention to such matters as power imbalances, capacity to consent, and increased potential for harm (this category stereotypically includes prisoners, pregnant women, or children), the social sciences see 'vulnerability' as a relational concept. More often than not, researchers in the social sciences believe that medical ethics codes see vulnerability as an imaginary label because many research participants are not as vulnerable as we imagine them to be. There are, to be sure, certain bona fide categories of vulnerability, but the ethics review process has stretched the idea of vulnerability to such an unprecedented degree that it has hampered research in the social sciences. This chapter champions the idea that the social sciences should challenge the centrality of vulnerability as an ethical concept. The concept is an invention that does not always match the lived experience of most research participants deemed vulnerable by ethics committees. The four-part chapter starts with an overview of the emergence of the doctrine of vulnerability and examines the underlying problems that arose when the doctrine migrated from the medical framework to the ethics of social science research. The result was lost in translation. The second part sketches the broader, changing cultural context that stimulated the incorporation of vulnerability in core ethics codes in Canada, USA, UK, and Australia as it has manifested itself in a creaking, research governance-focused ethics review system. The third part makes the claim that the concept of vulnerability can be safely abandoned altogether. The medical concept of vulnerability is a fixed, yet vague, unmovable concept that has little utility in the social sciences. The fourth part goes beyond ethics codes in offering practical solutions that circumvent imagined problems.

The doctrine of vulnerability has, according to Kenneth Kipnis (2001: 1) become part of 'the lexicon, lore, and literature of research ethics'. The concept of vulnerability has been the keystone test in medical research when researchers had to know whether a research subject had the capacity to understand and give consent to being researched. Because many researchers had difficulty determining the nature of vulnerability, Kipnis eventually felt obliged to configure the criteria that would signal to medical researchers the six conditions of vulnerability. The incipient period (from 1979) of ethics regimes clearly articulated the medical-research perspective on vulnerability with the concept's link to research participants' ability to give informed consent, and the social sciences had little option but to accept that definition. Most recently, however, we are seeing that social researchers have become critical of the medical ethics notion of vulnerability. Nonetheless, ethics committees still call upon researchers in the social sciences to assess the vulnerability of their research participants and accommodate their research actions to that supposed vulnerability. What is more, researchers in the social sciences are now challenging the idea of vulnerability itself, sometimes claiming that the concept is an invention that does not correspond to the lived experience of most research participants deemed vulnerable by over-zealous ethics committees.

Ethics regimes which review research in the social sciences are currently muddling through a stage of guessing which individuals or groups should be considered 'vulnerable' – a concept that hovers like a shadow from the time when ethics was tied to medical research and the concept was simply reduced to a categorical list that included children, prisoners, pregnant women, and people with mental disabilities, and so on, to name a few obvious examples. Even some biomedical ethics reviewers might not regard those in the category of 'patient' as necessarily vulnerable. While medical sociologists would be more likely to see patients as necessarily vulnerable in terms of their illness or diseased condition and/or the imbalance in the power relationship between practitioner and client.

Ethics review committees have come to define 'vulnerable' groups as the new 'untouchables' for whom researchers often require a special permit to research. According to Joan Sieber (1992: 93), there are about 50 categories of vulnerable people. The threshold to research these groups is high. The list of groups identified as vulnerable is, in some respects, quite arbitrary; so much so that members of some groups may be surprised to see themselves categorized as 'vulnerable'. It is hard, even undesirable, to arrive at an objective definition. Unmoored from its original design, the concept of vulnerability has become an anachronism in contemporary research ethics in the social sciences.

As long as vulnerability has been a doctrine in formal research ethics review, research ethics regimes speculated that vulnerability could be applied as a fixed characteristic of particular people and groups selected for research. Ethics regimes still link the notion of vulnerability to the consent process, but now see vulnerability as a significant, stand-alone component that researchers in the social sciences must also consider. More recently, there has been a growing recognition that vulnerability is an amorphous concept and perhaps quite meaningless in relation to how research participants see themselves. This chapter calls into question what once seemed so incontrovertible in research ethics. 'Ethical enthusiasts' who treat 'ethicality as the pre-eminent requirement, demanding that researchers exemplify ethical ideals' (Hammersley, 2009: 213–214) assign prominence to vulnerability in research on humans. Indeed, with the involvement of the social sciences in the research ethics review process, there is a growing awareness of the limitations of formal review, leading social researchers to question the usefulness of the doctrine of vulnerability.

The need to research 'vulnerable' groups is ever-present, but contemporary research ethics regimes create significant barriers in fulfilling that need. As a consequence, vulnerable groups receive less attention from researchers and there is no reason, however, why they should be excluded from any research. 'Ethical concerns arise', as Ron Iphofen (2009: 109) shows, 'when routine exclusion [in research] perpetuates or exacerbates an individual's or group's lowered status in society'. While there is an intrinsic value in doing research on vulnerable groups, there are stumbling blocks, in addition to it being hard to categorically define who constitutes a vulnerable group.

For Ron Iphofen (2009), like other researchers in the social sciences, the only point that should be of concern to researchers (and to ethics committees) is that research does not make people vulnerable. In this framework, vulnerability (as conceived in medical research) is not attached to whether someone is unable to give consent to research, but is something that a researcher must consider as a potential impact of his or her research. Iphofen proffers the idea that 'we should not be asking: 'Are these subjects vulnerable?' Instead the question should be: 'Are these subjects made more vulnerable than they might ordinarily be in their daily lives as a result of their participation in this research?' (2009: 108). Implicit in these questions is the idea that ethics codes should, with very few exceptions, get out of the business of defining what populations are vulnerable.

INSTITUTIONAL DOCTRINE

We can trace the origins of the concept of vulnerability – and indeed to the founding of research ethics review committees – to a time when research like the Tuskegee Study might typically involve:

> a programme of controlled genocide (whites against blacks); as a violation of basic human rights; as a study by the US government's Public Health Service in which effective treatment for a fatal disease was withheld from a poor, uneducated, vulnerable minority group in disregard of their health and safety; as a callous scientific pursuit that ignored human values and was "almost beyond belief and human compassion"; as "an outrage to our commitment to integrity and equality for all our citizens"'. (Shweder, 2004: 1)

In the Tuskegee investigation the researchers selected poor Black men with syphilis and studied them to learn the course of the disease offering them free health care, but without direct treatment of their condition, when they came to participate in the research. These (and other) experiments in America provided 'a compelling example of why we need[ed] the system of ethical surveillance and control for research with human subjects' (Shweder, 2004: 1). These various concerns led to the eventual creation of the *Belmont Report* that would later constitute the basis for ethics codes for research. Suspicion of scientific, social scientific associations, and academic institutions became a pervasive phenomenon in ethics review procedures. These procedures were 'swept along in … [the] 20th-century overreaction to its own sins – an overreaction now, ironically, being moderated in medicine itself' (Boyd, 2013: 21). Eventually, the establishment in other parts of the world of similar systems of control of research followed the American pattern. What interests us is the migration of this form of surveillance and control of medical research to the social sciences.

We have already alluded to the dilemma of the impossibility of knowing or ascertaining which individuals or groups are vulnerable. One knows from experience that the social contexts that make people vulnerable alter over time. LBGTQs[1] today in Canada (2016) are less likely to be socially vulnerable than twenty years ago. Thus, the number and kind of people who are socially vulnerable fluctuates. Originally, the doctrine of vulnerability was intended to deal with the 'asymmetrical power relationship' between the medical researcher and the research subject. However, this power relationship 'is often [not] as stark in the social sciences as it is in biomedical research' (Academy of Social Sciences, 2013: 30). Matthew Sleat (quoted by Emmerich, 2013: 30) proclaims that, 'whilst the participant in biomedical research was always more vulnerable, in the social sciences the researcher might be the more vulnerable party', such as in the case of studying motorcycle gangs (see, for example, Wolf, 2000).

Chapter 10 (on Qualitative Research) in Canada's *Tri-Council Policy Statement on Research Involving Humans* (known as the *TCPS*) acknowledges 'qualitative research approaches are inherently dynamic and may be grounded in different assumptions than those that shape quantitative research approaches'. Sometimes we look towards studies involving 'mixed methods', but such studies are still overwhelmingly quantitative. Creswell and Plano Clark (2007) point out that three out of four 'mixed methods' studies have a quantitative emphasis. One of the references to vulnerability offers this insight:

> Studies may involve participants who are in highly vulnerable circumstances because of the social and/or legal stigmatization that is associated with their activity or identity, and who may have little trust in the law, social agencies or institutional authorities. (CIHR et al., 2014: 141)

Most of the references in ethics codes point to not only the usual vulnerability 'suspects', but also to the elderly, people with diminished self-determination, and people in vulnerable circumstances. The *TCPS* (second version, *TCPS 2*) (CIHR et al., 2014: Glossary) defines Vulnerability as:

> A diminished ability to fully safeguard one's own interests in the context of a specific research project. This may be caused by limited decision-making capacity or limited access to social goods, such as rights, opportunities and power. Individuals or groups may experience vulnerability to different degrees and at different times, depending on their circumstances.

As a doctrine, it cautioned researchers to approach these populations with an eye of self-restraint and not to overwhelm them with a gratuitous sense of power that comes with being medical researchers. At the same time medical researchers were urged to include these groups in their studies as a matter of justice: why should they be excluded from the benefits of medical research? The term 'justice' in medical research ethics codes, moreover, devolves upon the idea of not only distributing the benefits of research, but also the burdens (see, for example, Barber's contribution to the *Belmont Report,* 1978). Canada's *Tri-Council Policy Statement on Research Involving Humans* (CIHR et al., 2014), in the section, 'Concern for Welfare', asserts that '[r]esearchers and REBs must attempt to minimize the risks associated with answering any given research question. They should attempt to achieve the most favourable balance of risks and potential benefits in a research proposal'. In the Glossary, it declares:

> Justice … refers to the obligation to treat people fairly and equitably. Fairness entails treating all people with equal respect and concern. Equity requires distributing the benefits and burdens of research participation in such a way that no segment of the population is unduly burdened by the harms of research or denied the benefits of the knowledge generated from it.

Finally, the World Health Organization Ethics and Health Unit (WHO, 2013: 32) asserts that '[a]ny type of research must be preceded by a scrupulous evaluation of the relationship between the risks and the potential benefits for the participants and/or their communities'.

One cannot ignore the warrants on vulnerability as determined by ethics committees. These warrants are a firmer predictor of the disposition of applications for ethics clearance than even those stipulated by ethics codes. It is a matter of researchers navigating through ethics committees (Wilson, 2005: 9).

The Canadian *TCPS 2* (2014), contains 42 references to 'vulnerability' and further extends the notion of vulnerability in asking research participants about their 'feelings regarding participation and/or for their assent'. It suggests that 'vulnerability is often caused by limited decision-making capacity, or limited access to social goods, such as rights, opportunities and power' (p. 8). The categories of people deemed vulnerable include 'children, the elderly, women, prisoners, those with mental health issues and those with diminished capacity for self-determination … [and] … ethnocultural minorities and those who are institutionalized' (p. 8).

The United Kingdom's guidelines (*ESRC Framework for Research Ethics*, updated January 2015) have 20 such references and consider 'children, young people, those with a learning disability or cognitive impairment, or … those in a dependent or unequal relationship' as potentially vulnerable. Lynne Roberts and David Indermaur (2003: 4) inform us that the British Society of Criminology Code of Ethics obligates researchers

> to ensure that the physical, social and psychological well-being of an individual participating in research is not adversely affected by participation in the research. Researchers should strive to protect their rights, their interests, sensitivities and privacy. Researchers should consider carefully the possibility that the research experience may be a disturbing one, particularly for those who are vulnerable by virtue of factors such as age, social status, or powerlessness and should seek to minimize such disturbances. Researchers should also consider whether or not it is appropriate to offer information about support services (e.g. leaflets about relevant self-help groups). (Article 4.i)

It is this spirit, however, that has created a needless chill on research.

The Australian 2007 *National Statement on Ethical Conduct in Human Research* has 19 references to vulnerability (NHMRC, 2007). It includes 'young people', children, those in neonatal intensive care, people in terminal care, and 'people with a cognitive impairment, an intellectual disability, or a mental illness' fall under the rubric of vulnerability in the Australian guidelines. What is more, the *National Statement* makes the point that if researchers discover the research participants' illegal activity, that discovery makes the participants vulnerable.

The United States *Code of Federal Regulations* (Title 45) (DHHS, 2009) adumbrates children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons as vulnerable groups. The *Code* also established supplementary regulations for research on fetuses and neonates (Hamburger, 2005: 291). *The Belmont Report,* the source of these concerns, specifically emphasizes the protection of vulnerable subjects, such as persons who are likely to have compromised autonomy 'to a degree that demands extra protection' related to decisions about research participation (Amdur & Bankert, 2011: 21). Researchers must consider six 'distinct domains of vulnerability' (the so-called 'C.A.B.L.E.S.', i.e. cognitive, affective, biological, legal, economic, and social/cultural) which powerfully drives home the idea that vulnerability can pervade all of a research participant's life.

We trust that the United States *Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences* (National Research Council, 2014) augur in a new era that will redefine vulnerability to make more sense for the social sciences. It is unlikely though that these *Revisions* will make a misplaced attention to vulnerability disappear. The term has been so thoroughly implanted in the minds of the upholders of research ethics regimes that its disappearance is quite unlikely.

These conceptual developments recognize that, as Cosmin Munteanu et al. affirm, contemporary research involving vulnerable participants 'has its own unique ethical challenges [and these] are becoming more prominent and do not fit the ethical templates to which we are accustomed' (2014: 52).

It is too easy for ethics committees and researchers to misread who constitutes a vulnerable person or group. For example, since 1979 with the onset of an Islamicist clerical regime in Iran, more than 200 Bahá'ís have been executed, others have been barred from getting an education (from primary school to including university), are no longer entitled to receive any pensions, are forbidden to operate a business in most occupational categories, and are daily subject to public vilification. One would think that imprisoned Bahá'ís would be the most vulnerable of all, with many carrying 10-to-20-year sentences without as much as a trial or any constitutional protections. Without any protections, one could argue that the imprisoned Bahá'ís are the most vulnerable of any despised group in Iran. Recent developments (in 2016), however, prove how fallacious such a perspective would be. Journalists, film makers, lawyers, and politicians (who are not Bahá'ís)[2] have been thrown in as cellmates of the imprisoned Bahá'ís, but have emerged after their release from prison as powerful defenders of the Bahá'í Community. The Bahá'í prisoners, despite their apolitical and non-violent stance, have transmuted the attitude of imprisoned journalists, filmmakers, and politicians, into a weighty concern that is achieving wholesale national and international public attention.[3]

Before we discuss the specific problems with the concept of vulnerability, we need to take a closer look at the broader cultural context that explains the rise of the issue because the concept of vulnerability derives its strength from the wider culture.

THE BROADER CULTURAL CONTEXT

As a society, we have invested a lot in maintaining the notion of 'vulnerability'. The contemporary discourse on 'triggers' in university classes simply underscores our overwhelming sense that almost all people are vulnerable, in large or small measure. This is the 'risk society', says Michael Rustin (2010: Item 2.4), 'in which the more vulnerable and fragile individuals feel, the more intrusive the measures of surveillance and regulation that can legitimately be adopted to protect them'. Vulnerability is now an inescapable part of our language. It has become such a contested arena among those laying claim to be the legitimate protectors of the vulnerable that these 'protectors' restrict access to their clients who might wish to study them. They have become the gatekeepers (Luxardo et al., 2011: 988). Institutions and programs run by professionals, for example, would give no allowance to others outside their respective professional circles to conduct research in those venues (2011: 989).

The growing pre-occupation with privacy and individual rights has led many to consider the protection of individual autonomy. Political and societal trends enter into the debate as well with a 'growing concern for individual rights, including those of research participants, and for the rights of social groups who may be affected by research' (Lee & Renzetti, 1990: 513–514). According to Bronwyn Davies (cited by Linda Eyre, 2007: 92), ethics codes have clearly moved the debate about vulnerability into a political and ideological discourse about individualism. The 'individual', says Linda Eyre (2007: 92), 'is cut loose from the social; from morality to moralistic audit-driven surveillance; from critique to mindless criticism in terms of rules and regulations combined with individual vulnerability to those new rules and regulations'. And yet, the nagging questions remain: in our efforts to protect vulnerable human subjects through anonymity, should we not argue that research participants (such as Internet users, for example) 'deserve credit for their creative and intellectual work' (Bruckman, 2002: 217)? Shall we hide vulnerable people behind the veil of pseudonymity and anonymity, robbing 'them of a legitimate claim to credit' for their contributions (p. 228)?

'It is no accident', says Linda Eyre (2007: 92), 'that the [Canadian] Tri-Council rules are being imposed in neoliberal regimes'. We can make similar claims about such control in other contemporary national jurisdictions. This notion is wrapped around the 'ideology of empowering the weaker party. It has become a formalistic ritual that weakens the researcher's control over his or her research' (Juritzen et al., 2011: 644). Virtually all of the formal, prescriptive ethics concerns thus center around the notion of autonomy, which turns on the role of acquiring consent from these researched, vulnerable populations. Voluntary and informed consent, affirms Juritzen et al. (2011: 643), is the basis for all research with humans to counterbalance the asymmetry of power.

With the rising dependence on external financial support for universities, there is a growing sensitivity on the part of universities to how local elites view their operations, teaching, and research. The new institutional context of universities includes the fear of offending these elites (Lee & Renzetti, 1990: 514). Such fears can be a significant element to doing research on vulnerable people: local elites may find research on vulnerable people not worth the attention or resulting in challenging the status quo. What is more, according to White (2007) the doctrine of vulnerability is

> not really aimed at protecting vulnerable research subjects from dangerous research, but at protecting vulnerable institutions from potential lawsuits and public-relations fiascos hastened by a growing cultural obsession with zero-risk lifestyles, an ever-drifting concept of harm, and growing regulatory tentacles. (p. 558)

Yan and Munir (2004) furthermore add that, 'IRBs also may inadvertently prioritize institutional precautions and legal concerns'.

OPERATIONAL CONUNDRA

Going well beyond the age of innocence and enthusiasm for ethics, we are increasingly recognizing that our understanding about the use of the concept of vulnerability should either be more profound or be abandoned altogether. The problem is now part of a creaking ethics regime. The ethics guidelines 'shaped from "above" embodies a protectionist attitude which does not serve the needs of respondents' (Helgeland, 2005: 549). Lee and Renzetti (1990: 512) stated that 'a study seen as threatening by one group will be thought innocuous by another' and vice versa.

When there is a vast power discrepancy between research participants and researchers, such as the case of studying the homeless, Paul Cloke and his colleagues (2000: 133–134) realized that before starting their research, they had to consider the ethics and danger of researching 'the other'. They realized that their research could quickly become the equivalent of mere voyeurism, tourism, or colonialism. This is akin to walking through a landscape that seems exotic to researchers, gawking as visitors, and being ready to colonize the landscape with social remedies. Individuals who are cognitively impaired or who are mentally ill will, however, be relieved not to be 'treated' or be befriended for research purposes. There is, too, another source of ethical turbulence, namely the mismatch between standard ethics advice, 'expectations from research funders, and academic evaluators' (Cloke et al., 2000: 134). Each of these promotes a different conception of vulnerability and the aim of research. Researchers are ill prepared when they must rely on these expectations as an instrument that would permit them to understand what constitutes vulnerability.

The following sections highlight the problematic nature of vulnerability in the context of social research and should cast doubt on the usefulness of vulnerability as a research concept. We suggest that in its current use, vulnerability is a fixed, unmovable, yet vague concept. There is a rich reservoir of research that indicates that research on vulnerable people has not led to despair or further disabling the research participant. In fact, there is much research to indicate the beneficial aspects of the interactions between research participant and researcher. Gary Allen (private communication, 14 January, 2017) explains 'in the case of populations such as the residents of nursing homes, interaction with researchers can be perceived very positively' because of the opportunity to speak to someone new, and 'exclusion because of perceived vulnerability can cause confusion/dismay/humiliation'. We now turn to some of these elements.

1. Vulnerability is a Fixed and Unmovable Concept

Since the incorporation of reviewing the social sciences for ethical propriety, ethics review committees have latched on to the idea that vulnerability is a fixed and unmovable concept, and researchers may be legally mandated to follow this fixed notion. Research practice in the social sciences, however, sees vulnerability as a more fluid, a more nuanced, and as a less stable concept. The notion of 'vulnerability' as a concrete reality also enters into the deeply-held beliefs that one does not violate sanctuaries, including moments of bereavement and privacy (Lee & Renzetti, 1990: 522). For some like Cherry Russell (1999: 403), 'the construction of vulnerability suffuses … [all] … research', and there is a fear on the part of ethics committees that researchers will mine 'the minds of disempowered people', potentially creating a 'hit and run' scenario. What is more, research might intrude into the private self/deeply personal experience, touching on issues of deviance and social control, and, as mentioned before, impinging on vested interests (Lee & Renzetti, 1990: 512).

Researchers, too (like ethics committees), run into the pitfall of seeing vulnerability as an overarching issue in research. So much so, according to Russell (1999) that researchers 'approach subjects with preformed ideas' and can, as a result, heighten the lack of self-worth of research participants. In this connection, Lee and Renzetti (1990: 512) claim 'the research act itself disempowers vulnerable people'. The typical list of vulnerable populations produces near-insurmountable consequences. They act as a sort of 'megaphone' that magnifies even minor vulnerabilities in the eyes of ethics committees, researchers, and research participants.[4] There is a heightened sense of sensitivity towards vulnerable research participants, perhaps unnecessarily so. Ethics committees overestimate the importance of risks (Buckle et al., 2010: 113). The Proposed Revisions to the Common Rule in the United States, significantly, urge us to 'avoid subjective overestimations of potential research harms', and recommend that Human and Health Services 'eliminate current regulatory language at 45 C.F.R. § 46.111b. [that identifies] certain populations as "vulnerable to coercion or undue influence"' (National Research Council, 2014: 4).

Once we recognize that vulnerability is not anchored in a fixed, doctrinal perspective, we also need to realize that the disciplinary background of the researcher will lead to a different understanding of how to approach, or abandon the idea of vulnerability. A researcher in nursing is more likely to contextualize vulnerability in terms of setting out a therapeutic approach, while a social anthropologist will more likely correlate vulnerability as a variable cultural attribute. Regardless of the conceptual or methodological approach of the researcher, *TCPS 2* adds another concern when studying vulnerable research participants, namely that

> researchers who question social structures, or deal with the disempowered, may face pressures from authority figures. Research may also involve participants, such as business executives or government officials, who may be more powerful than the researchers. (CIHR et al., 2014: 141)

Even if the vulnerability of research participants is an obdurate reality, the particular gender of the researcher may well lessen the idea that vulnerability is at stake in research. Lee and Renzetti (1990: 520), for example, cite research at a drug rehabilitation center involving highly sensitive information in file drawers. The staff at the center was male and ignored the access gained by female researchers to those files because the males believed staff had more important work to do. We thus affirm its ambiguity and demonstrate that the term is fluid, unstable, changeable, malleable, and even dispensable.

2. Vagueness of the Concept

The vagueness of the concept makes it troublesome to operationalize. The terms 'vulnerability', 'sensitivity', and 'marginality' have in the present-day discourse become coterminous – indistinguishable one from the other. In a study on family violence and adolescent young women in Buenos Aires, for example, vulnerability and marginality are mentioned equally and interchangeably (Luxardo et al., 2011). The heightened purview of sensitivity spills over into deliberations on ethics review committees where the definition of 'sensitive' is akin to 'controversial' (Lee & Renzetti, 1990: 510). There are also variations among researched groups as to what constitutes research on sensitive topics. Not uncommonly, research on vulnerable populations, is referred to as research on *sensitive* topics.

Buckle et al. (2010: 112) note that ethics committees are more likely to reject proposals in the area of 'grief, death and trauma' than proposals about other dimensions of human experience. They also note that the 'concern of REBs appears to run counter to the experience of bereaved research participants who frequently comment on the personal benefits they derived from the process of sharing their perspective in a detailed manner with an interested and engaged researcher'. As Hollway and Jefferson (2000) note: 'the ethical touchstone should be to ensure that the level of harm that might be predicted is no greater than that to which they (*the participants*) have anyway been exposed' [italics inserted] (2000: 92).

3. Implications for Consent Procedures

The doctrine of vulnerability employs, according to Juritzen et al. (2011: 640), formal, voluntary, and informed consent, which, in turn, is 'based on an intention to protect participants from an evil – unacceptable research practices'. Researchers must translate their ethical obligations to vulnerable people into 'special procedures to promote and protect their interests'. These considerations often boil down to devising special 'consent materials'.

In many cases researchers in the social sciences do not link the doctrine of vulnerability with the need to acquire consent from a research participant, but competition in the field of medical research privileges consent procedures and drives researchers to offer the most 'complete' (written) procedures. As Mark Wilson makes clear (2005: 10), the statutory-defined vulnerability occurs in 'a research milieu where competition to recruit research subjects is fierce and can involve lucrative financial interests'. In both the United States and Canada, ethics committees, despite their desire to have the most complete consent procedures and presumably under the pressure of satisfying commercial interests, approved research that 'clashed with the Helsinki Declaration' (Wilson, 2005: 10). Even so, researchers in the social sciences might be caught up in creating elaborate and 'complete' consent procedures, just to echo the desires of their ethics committees.

Qualitative researchers, despite the pressure by ethics committees to use signed consent forms, are likely to prefer 'information sheets'. Researchers use these sheets as a necessary courtesy to explain to the research participant(s) the purpose of the research, what method the researcher will use to discover data, and how long the research will take, whether or not it relates to a particular method (e.g. interviewing) or something long-term. The inductive nature of empirical research makes it hard to predict those things, and qualitative researchers are even reluctant to explain their anticipated research in detail. Quite commonly, even researchers themselves cannot be fully aware of the beneficial aspects or outcome of their research and the particular path of scientific inquiry.

In contrast to the social sciences, medical researchers may have an easier time pointing to the potential benefits of their research (and thereby make a convincing case for including particular vulnerable groups). Researchers in the social sciences, by virtue of their broader research interests, have a more difficult time to pinpoint particular benefits of their research. It is also often difficult for research participants to be made aware of the full implications of the research (Juritzen et al., 2011: 644). We do tend to give little consideration to what the research participants themselves think about their being considered vulnerable, even rejecting the idea that they are vulnerable. Hollway and Jefferson (2000) argue at length that 'giving voice' to vulnerable participants can be a significant benefit, but something more is needed.

The case of doing research on children, however, accentuates the difficulties with formal consent procedures. There are countless niches of potential vulnerabilities in the lives of children and one wonders if it is appropriate for consent procedures involving children to fall under the same rubric as a vulnerable group. Lumping children with the elderly, people with disabilities, and prisoners is bizarre. What can we expect children to know about research? And is consent by parents or guardians a perfunctory procedure in that the wishes of the child are ignored (with or without their assent) or that the maturity of the child does not come to the fore in deciding whether or not research can be undertaken? How do we estimate the maturity of children? And does it really matter in the face of stringent ethics codes?

Morrow and Richards (1999) offer new insights about ethical issues related to social research with children. They explore the extent to which children should be regarded as similar to, or different from, adults in social research, given the fact that ethics committees position children as vulnerable, incompetent, and relatively powerless in society in general, and how this conceptualization of children needs to be taken into account in social research.

'Heinous discovery', i.e. when a researcher finds children in harmful situations, whether they involve abuse or issues in research on child-laborers, is a concern that chiefly affects research on children. In some jurisdictions, researchers are obliged to follow strict procedures in reporting abuse despite the fact that such reporting might have unintended, even more negative, consequences for the child and family. The profound dismay that accompanies research on children in truly intolerable conditions cannot be easily offset by a convenient set of consent procedures. The implications, however, are far too important to ignore morally, or to categorize all children as vulnerable. Researchers have to 'balance the maintenance of confidentiality with care for the rights of the child…' (Iphofen, 2009: 111–113):

> On top of this layer about research on children, one would be unable to conclusively answer a key question: Just how much do children comprehend what is being asked of them and what the research may be for? Hence it remains difficult to assess just what 'capacity' for consent children do actually possess (p. 113).

4. Poor-Quality Research

Ironically, the doctrine of vulnerability makes it more difficult to do research on particular groups (Juritzen et al., 2011: 643). This exclusion, according to Juritzen et al. (2011: 640), 'opens the gate for other evils – continued concealment of unacceptable healthcare practices or exclusion from participation in the progress and development that research could have provided'. These unintended (and potentially negative) consequences are the opposite of what ethics codes of research 'have been meant to protect: vulnerable and exposed participants' (Juritzen et al., 2011: 640).

Vulnerability can encapsulate a wide spectrum of people and situations, with ethics review boards and researchers each casting their own (mis)understanding of what it means to be vulnerable. The undue focus on the 'protection' of vulnerable research participants may well lead to poor quality research (Roberts & Indermauer, 2003) that also overlooks particular groups. The doctrine of vulnerability leads researchers to carefully weigh the 'acceptable threshold of minimal risk', to 'maximize potential benefits', and to think concretely about 'the welfare of recipients', and the need to keep copies of field materials in ‘secure locations’. Throughout the process, the researcher ought to make sure that he or she does not include vulnerable people in research ‘in ways that may be unfair and inequitable’. These obstacles alone may force a researcher to select research participants without those anticipated impediments in research.

5. Other Instances Involving Vulnerable People

There are still genuine, inescapable instances where research participants are truly vulnerable and perhaps subject to special considerations. For example, one thinks of students as a potentially vulnerable population. Subject to the demands and requirements of their academic programs, students now must submit themselves to the insistent, often unyielding demands of ethics committees. These precarious conditions make them vulnerable and cause them great worry about their work, missing deadlines for research or thesis. At the same time, vulnerability is a social construction applied nonchalantly to any group that happens to be under the purview of ethics committees.[5] What researchers do need to manage, in addition to their keen sense about what vulnerability entails, is to be ‘sensitive to emergent vulnerabilities and manage undue stress to participants’ (Iphofen, 2009: 108).

Significantly, Ingeborg Marie Helgeland (2005: 550) adds that ‘this heightened concern with this type of privacy first and foremost reflects middle-class values and is contributing to a “catch 22” of ethics’. When researchers followed the instructions of an ethics committee and requested, by mail, women and men for an interview, and found that the reply to the mailed request was too low, the researchers ‘decided to pay a personal visit to the potential participants and discovered that 60 of the 85 participants were willing to participate in the research’ (Helgeland, 2005: 551). The ethics committee had thought they would be more vulnerable if contacted directly. As in so many cases, it became clear to the researchers that ‘research ethics guidelines do not correspond to the reality of the situation’ and that, ‘nearly without exception, the interviewees answered that they had no problems with being contacted [directly]’ (Helgeland, 2005: 552, 557). Respondents,

> liked getting chances to speak their minds and that someone was interested in listening to their experiences. They felt their participation in the study had been a good thing. If they had been protected against being brought into the study, their voices as independent actors would never have been heard. (Helgeland, 2005: 563)

There are numerous cases across all disciplines in which participation in research brought a measure of joy and willingness to share with research participants. In her study on widows (D. van den Hoonaard, 2001), it became clear to the author that the opportunity to share their stories of bereavement dissipated the clouds of apprehension about being interviewed. No less similar are stories about research with older people: the researcher is often the only one who has taken the time to hear and record their stories. Misconceptions about vulnerability abound.

Cherry Russell (1999: 2) suggests that while conventional advice about interviewing elderly research participants suggests that the old are ‘vulnerable’, the reality of researching them (including the frail and the lonely) is quite different. She makes it clear that we tend to ‘imagine’ subjects and that our concern with the vulnerability of these isolated and lonely people only tended to heighten their vulnerability, disempowering them even more (p. 5). In her research, as well as in those of others, research participants were reluctant to end the session (p. 9). When I was interviewing an old Bahá’í for my research on the history of the Bahá’í Community of Canada (W. van den Hoonaard, 1996), I learned she had had a stroke and the whole left side of her body was paralyzed. I had assumed she was very weary and needed a break. When she learned of my plan to take a break in the middle of the interview, she asked if I were tired while at the same time saying she did not need any breaks.

We researchers, who have invested so much of our time, education, and resources into our work often forget the minimal perception research participants have of us. Prisoners sometimes welcome us because we promise a break from the monotony of life in a human cage. Sometimes even after the 'best' interview, a research participant may forget that she was interviewed, as was the case when I was doing interviews for my book on women cartographers (W. van den Hoonaard, 2014).

That research can benefit vulnerable research participants is quite a contrasting view to how ethics review committees view research participants.

6. The 'Dangerous' Researcher

Ethics committees see the researcher as 'powerful, potentially uncontrolled and dangerous' (Juritzen et al., 2011: 641) while others aver that the researchers may become 'manipulative and deceitful' (Lee & Renzetti, 1990: 523). In the United Kingdom, the *Safeguarding Vulnerable Groups Act 2006* requires that the criminal record of researchers must be checked so that there is no history that would make researchers 'unsuitable for work involving children and vulnerable adults'. In the aftermath of their research, researchers in the United Kingdom must manage 'unforeseen or adverse events'.

Despite the tone set by ethics committees to see researchers as potentially 'dangerous', researchers in the social sciences are more likely to see themselves as endangered. Lee and Renzetti (1990: 512) write about the role of researchers in vulnerable contexts, and make it abundantly clear that the researcher's personal security may be jeopardized. In some cases (and this is increasingly the case in ethics committees), there is a deepening concern with the researcher's jeopardy when researching violent social settings (Lee & Renzetti, 1990: 521). It remains to be seen whether such concern has grown out of an authentic worry about such matters or whether such a worry was fostered by legal liability (as perceived by the research ethics reviewers). One might assert that the focus on protecting researchers has led to a more rigorous use of consent forms in, for example, criminological research. Still others warn that 'researchers themselves need to be mindful of having their data related to criminal acts subpoenaed' (Lee & Renzetti, 1990: 518). The recent attempts by authorities to inspect interview data related to fighters in Northern Ireland are a case in point (see for example, Lawler, 2016).

GOING BEYOND ETHICS CODES: SOME PRACTICAL SUGGESTIONS

It is not hard to imagine researchers' returning from their stint in researching vulnerable people being moved or impressed by the resilience of their research participants. Imagining a person as vulnerable can evoke images of pity or misplaced sympathy.

There are those who aver that with a seemingly debilitating disease, such as ankylosing spondylitis (an extreme inflammatory disease that can cause some parts of the spine to fuse together), a person would become physically very vulnerable. However, the disability and the vulnerability now allow that person to draw on unsuspecting sources of strength hitherto unrecognized or unavailable. A friend of our family remarked to us about a friend with 'ankos' that the illness had brought out her strengths. Indeed, she is a celebrated writer, travelling far and wide well beyond her perceived physical capacities. And early in my own career, I supervised a graduate student who, while researching the social contexts of forest fires in Canada's boreal forests, contracted skin cancer. As the skin cancer advanced, however, her family, her newly married husband, and friends (and her supervisor) noticed a significant growth of her perceptual and emotional powers that seemed to have exceeded her original capacity. To approach her (and others) as a vulnerable person would have been a grave, and insulting, misreading of her condition. Both women mentioned in this paragraph became an inspiration to many others.

Cohorts of potential participants should not be excluded from research because they are perceived as vulnerable. If called upon, researchers should be prepared to explain why the chosen cohort should not be classified as vulnerable. The following strategies could be used to either minimize or negate the vulnerability, or to mitigate the potential consequences of the vulnerability.

We are not offering earth-shaking proposals on how to research vulnerable people. It will become immediately clear to the reader that the proposals are not different from those applied in normal considerations of ethics in research. The following suggestions will circumvent these imagined problems.

a. Promote the idea among non-research professionals to allow fieldwork and joint action among different professionals in their venue, including the researchers, and to visualize the long-term aspects of the research (Luxardo et al., 2011: 989). Perhaps for too long, professionals have seen people with vulnerabilities as their exclusive preserve, creating social barriers insofar as research is concerned. At the same time, it is important that researchers do not over-research a group in ways that might create or enhance a potential 'vulnerability' (Iphofen, 2009: 114);
b. The phrasing of the overall research question and questions within the interview setting is critical when trying to understand the context of vulnerability. Instead of directly asking about violence, the interviewer would let the research participant speak freely, to avoid generating situations of high emotional impact on the research participant (Luxardo et al., 2011: 990). Even after the research has started, Ron Iphofen reminds us that 'the choice of phrasing in interviews and in questionnaires is anything but methodologically and ethically trivial' (Iphofen, 2009: 110). An inductive approach in interviews generates more insight and allows the interview participant to convey what is meaningful in his or her life. In this regard Hollway and Jefferson (2000) advocate free association 'induced' via the respondent's self-constructed narrative as a way for participants to, in essence, authentically 'answer their own questions'. Researchers need to be mindful of the way they phrase their research questions which artificially create a vulnerable person, such as 'Why do battered women stay?' rather than 'Why do men batter?' Faulty social conceptions of the problem create 'vulnerability' (Lee & Renzetti, 1990: 515);
c. Researchers should encourage themselves to engage in participant observation and other, more subtle, nuanced, and suitable methods of data collection (Luxardo et al., 2011: 993). They should revisit the idea of covert research, for it has a special place among data-collection strategies while researching sensitive topics, especially in public spaces (Lee & Renzetti, 1990: 523). Even when not conducting covert research, researchers will need to take extra care with anonymity, privacy, and confidentiality (Iphofen, 2009: 116). Researchers will need to go to great lengths to hide the identity of anyone who by physical appearance would be easily spotted in a study, such as, for example, an especially tall or short soccer player in a particular school district;
d. As 'normals' researchers have cultural blind spots in understanding 'vulnerability'. Do not rule out the idea of getting to know a vulnerable group long before you start your research, and talk with them, and get to know how they relate to others so as to avoid stereotypes (equivalent to a point made by Iphofen, 2009: 114). 'Hanging out' with the people before formally starting the research is one way to become aware of the social and cultural baggage researchers bring into their research, whether they deal with prejudices or uncovering our taken-for-granted knowledge about genuinely vulnerable groups. Increasing these opportunities for 'reflexive and dialogic research' with research participants brings out 'interesting complexities in the understanding and application of standard ethical approaches' (Cloke et al., 2000: 150). And as Helgeland (2005: 554) avows:

> Discursive ethics assumes a different perspective. Conflicts are solved through dialogic processes between implicated parties.... It is only through dialogues between participants that agreement may be reached.

e. It might be useful to organize community advisory boards comprised of vulnerable groups to consider, plan, or veto research (in the event 'that it might compromise the safety of group members' (DePalma, 2010: 95). As researchers, we should resist the 'assumption of homogeneity' (Iphofen, 2009: 109) but anticipate to see diversity in any group we study (p. 114). Disability awareness training might be useful in avoiding insensitivities (p. 115), but associating with people with disabilities before starting the research is key;

f. Many agencies have explicitly recognized that written informed consent may not always be appropriate. The standard consent process is transactional at a moment in time, and research 'subjects' agree to participate only after being apprised of the predetermined and fixed 'treatment' they will undergo. Researchers in the social sciences have a different vision altogether. They value 'an ongoing, negotiated, and collaborative relationship between researchers and community partners who co-develop the inquiry goals and process – and who may be both researcher and research subject'. Additionally, the emergent nature of the research process may make it impossible, in some cases, to delineate at the outset the experiences a research participant might have (Newman & Glass, 2014: 287). The European Research Council's draft guidance for social science researchers acknowledged,

> that certain groups may be more vulnerable to harm from having information they provided be linked to them (illegal immigrants, victims of home violence, prostitutes, HIV-positive employees, etc.). In these cases, standard procedures for obtaining written informed consent may be harmful to the subjects instead of offering protection and therefore need to be replaced. (European Research Council, 2010: 10)

g. Obtaining written, informed consent is a bedrock medical ethical requirement. In this connection, a researcher can develop, instead, an 'Information Sheet', rather than a 'signed consent form', fitting it appropriately to the needs of the research participant, even whether to create a text in large font or Braille? (Iphofen, 2009: 113). Regarding the participation of 'captive' populations, i.e. populations who have been instructed by their supervisors, without exception, to participate in the research, we as researchers can privately tell these research participants that they do not have to participate in the research (see, for example, Iphofen, 2009: 119). Researchers need to be aware of gatekeepers and proxies (Iphofen, 2009: 116) who often 'take charge' of people with vulnerabilities;

h. Children, as a category of vulnerable research participants, are deserving of special attention, and should not be necessarily included in any lists of vulnerable participants.

CONCLUSION

The doctrine of vulnerability evolved out of a deep concern that medical researchers ought to be prevented from taking advantage of research subjects who were seen as 'weak', whether from the perspective of social location or personal circumstances. In this connection, one of the primary ethical concerns of researchers in the social sciences, however, is the hope that research participants do not become vulnerable after the research. This chapter suggests that, with very few exceptions, we are better off disowning the term 'vulnerability'. For most purposes it is better to send the term to the dustbin of unworkable and imaginary concepts. Research participants are loathed to use the concept. It is time to follow their lead.

Notes

1 Lesbian, Gay, Bisexual, Trans, Queer or Questioning.

2 Such as Maziar Bahari, Faezeh Hashemi, Nasrin Soutudeh, and Muhammad Nourizad.

3 *The Huffington Post* (see, e.g. http://www.huffingtonpost.com/payam-akhavan/irans-bahai-problem_b_10100320.html) and other media have carried numerous reports of the attention given by the formerly imprisoned journalists, lawyers, etc. to the plight of the Bahá'í s. To claim that the imprisoned Bahá'í s are vulnerable is an unrealistic assessment in light of their power to redirect public concern about the Bahá'í community in Iran. The prisoners are experiencing the vulnerable context imposed by prison, but they are not "vulnerable." See also http://iranpresswatch.org/post/14705/.

4 In this connection, one might consider the current rise of interest in "resilience" as a counter concept to vulnerability.

5 Finding the impact of ethics review directives to students in terms of opportunities and time lost, will be an important contribution to the scholarly literature on ethics in research.

REFERENCES

Academy of Social Sciences (2013). *Generic Ethics Principles in Social Science Research. Professional Briefings.* October. Issue 3.

Amdur Robert and Elizabeth A. Bankert (2011). *The Institutional Review Board Member Handbook* (3rd edition). Sudbury, MA: Jones and Bartlett Publishers.

Barber, Bernard (1978). 'Some Perspectives on the Role of Assessment of Risk/Benefit Criteria in the Determination of the Appropriateness of Research Involving Human Subjects'. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research: Appendix Volume II*: 320.

Boyd, Kenneth (2013). 'Response (2) to "Responsible to Whom? Obligations to Participants and Society in Social Science Research"', in Academy of Social Sciences, *Generic Ethics Principles in Social Science Research. Professional Briefings.* October. Issue 3: 21–22.

Bruckman, Amy (2002). 'Studying the amateur artist: A perspective on disguising data collected in human subjects research on the Internet'. *Ethics and Information Technology*, 4 (3): 217–231.

Buckle, Jennifer L., Sonya Corbin Dwyer, and Marlene Jackson (2010). 'Qualitative Bereavement Research: Incongruity between the Perspectives of Participants and Research Ethics Boards'. *International Journal of Social Research Methodology*, 13 (2): 111–125.

CIHR et al. (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada) (2014). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (2nd revised edition). Ottawa: Interagency Advisory Panel on Research Ethics.

Cloke, Paul, Phil Cooke, Jenny Cursons, Paul Milbourne, and Rebekah Widdowfield (2000). 'Ethics, Reflexivity and Research: Encounters with Homeless People', *Ethics, Place & Environment*, 3 (2): 133–154.

Creswell, John W. and Vicki L. Plano Clark (2007). *Designing and Conducting Mixed Methods Research.* Thousand Oaks, CA: Sage.

DePalma, Renée and E. Atkinson (eds) (2010). *Undoing Homophobia in Primary Schools.* Stoke-on-Trent, UK: Trentham Books.

DHHS (US Department of Health and Human Services) (2009). *Code of Federal Regulations Title 45 Public Welfare Part 46 Protection of Human Subjects.* Rockville, MD: Office for Human Research Protections. http://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html

Dingwall, Robert (2012). 'How Did We Ever Get into This Mess? The Rise of Ethical Regulation in the Social Sciences'. *Studies in Qualitative Methodology*, 12: 3–25.

ESRC (The Economic and Social Research Council) (2015). *ESRC Framework for Research Ethics.* (Updated January 2015). http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/

European Research Council (2010). 'Guidance Note for Researchers and Evaluators of Social Sciences and Humanities Research'. http://ec.europa.eu/research/participants/data/ref/fp7/89867/social-sciences-humanities_en.pdf

Eyre, Linda (2007). 'Whose Ethics? Whose Interests? The Tri-Council Policy and Feminist Research'. *Journal of Curriculum Theorizing*, Summer: 91–102.

Hamburger, Philip (2005). 'The New Censorship: Institutional Review Boards'. *Public Law and Legal Theory Working Paper* No. 95. The Law School at the University of Chicago, 17 May.

Hammersley Martin (2009). 'Against the Ethicists: On the Evils of Ethical Regulation'. *International Journal of Social Research Methodology*, 12 (3): 211–225.

Helgeland, Ingeborg Marie (2005). '"Catch 22" of Research Ethics: Ethical Dilemmas in Follow-up Studies of Marginal Groups'. *Qualitative Inquiry*, 11 (4): 549–569.

Hollway, Wendy and Jefferson, Tony (2000). *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method*. London: Sage.

Iphofen, Ron (2009). *Ethical Decision-Making in Social Research: A Practical Guide.* Basingstoke: Palgrave Macmillan.

Juritzen, Truls I., Harald Grimen, and Kristin Heggen (2011). 'Protecting Vulnerable Research Participants: A Foucault-Inspired Analysis of Ethics Committees'. *Nursing Ethics*, 18 (5): 640–650.

Kipnis, Kenneth (2001). In: *National Bioethics Advisory Commission* [NBAC]. *Ethical and Policy Issues in Research Involving Human Participants. Volume II: Commissioned Papers and Analysis* (G1–G13). Rockville, MD: National Bioethics Advisory Commission. http://hdl.handle.net/10822/941754

Lawler, David (2016). 'US court orders Boston College to hand IRA tapes to police in Northern Ireland.' *The Telegraph* online, 24 April. http://www.telegraph.co.uk/news/2016/04/26/us-court-orders-boston-college-to-hand-ira-tapes-to-police-in-no/

Lee, Raymond M. and Claire M. Renzetti (1990). 'The Problems of Researching Sensitive Topics: An Overview and Introduction'. *American Behavioral Scientist*, 33 (5): 510–528.

Luxardo, Natalia, Graciela Colombo, and Gabriela Iglesias (2011). 'Methodological and Ethical Dilemmas Encountered During Field Research of Family Violence Experienced by Adolescent Women in Buenos Aires'. *The Qualitative Report*,16 (4): 984–1000.

Morrow, V. and M. Richards (1999). 'The Ethics of Social Research with Children: An Overview'. *Children & Society*, 10 (2): 90–105.

Munteanu, Cosmin, Heather Molyneaux, and Susan O'Donnell (2014). 'Fieldwork with Vulnerable Populations Ethical Implications for Human Computer Interaction Research'. *Interactions*, 21(1) (Jan–Feb): 51–53.

National Research Council (2014). *Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences.* Committee on Revisions to the Common Rule for the Protection of Human Subjects in Research in the Behavioral and Social Sciences; Board on Behavioral, Cognitive, and Sensory Sciences; Committee on National Statistics; Division of Behavioral and Social Sciences and Education; Board on Health Sciences Policy, Institute of Medicine. Washington, DC: The National Academies Press.

Newman, Anne and Ronald David Glass (2014). 'Comparing Ethical and Epistemic Standards for Investigative Journalists and Equity-Oriented Collaborative Community-Based Researchers: Why Working for a University Matters'. *The Journal of Higher Education*, 85 (3) (May/June): 283–311.

NHMRC (National Health and Medical Research Council) (2007). *National Statement on Ethical Conduct in Research Involving Humans.* Canberra, Australia.

Roberts, Lynne and David Indermaur (2003). 'Signed Consent Forms in Criminological Research: Protection for Researchers and Ethics Committees but a Threat to Research Participants?' Paper presented at the *Evaluation in Crime and Justice: Trends and Methods*. Conference convened by the Australian Institute of Criminology in conjunction with the Australian Bureau of Statistics, Canberra, 24–25 March.

Russell, Cherry (1999). 'Interviewing Vulnerable Old People: Ethical and Methodological Implications of Imagining our Subjects'. *Journal of Aging Studies*, 13 (4): 403–419.

Rustin, Michael (2010). 'The Risks of Assessing Ethical Risks'. *Sociological Research Online.* 15 (4): 18. <http://www.socresonline.org.uk/15/4/18.html> 10.5153/sro.2266

Shweder, Richard A. (2004). 'Tuskegee reexamined'. http://www.spiked-online.com/newsite/article/14972#.WYBO0Lz5wUE

Sieber, Joan E. (1992). *Planning Ethically Responsible Research: A Guide for Students and Internal Review Boards* (Applied Social Research Methods Series). Thousand Oaks, CA: Sage. http://www.spiked-online.com/newsite/article/14972#.WYBO0Lz5wUE

Sleat, Matt (2013). 'Responsible to Whom? Obligations to Participants and Society in Social Science Research', *Academy of Social Sciences' Professional Briefing*, October. 3: 15–18.

van den Hoonaard, Deborah K. (2001). *The Widowed Self: The Older Woman's Journey Through Widowhood.* Waterloo, ON: Wilfrid Laurier University Press.

van den Hoonaard, Will C. (1996). *The Origins of the Bahá'í Community of Canada,* *1899–1948.* Waterloo, ON: Wilfrid Laurier University Press.

van den Hoonaard, Will C. (2014). *Map Worlds: A History of Women in Cartography.* Waterloo, ON: Wilfrid Laurier University Press, 2nd edition.

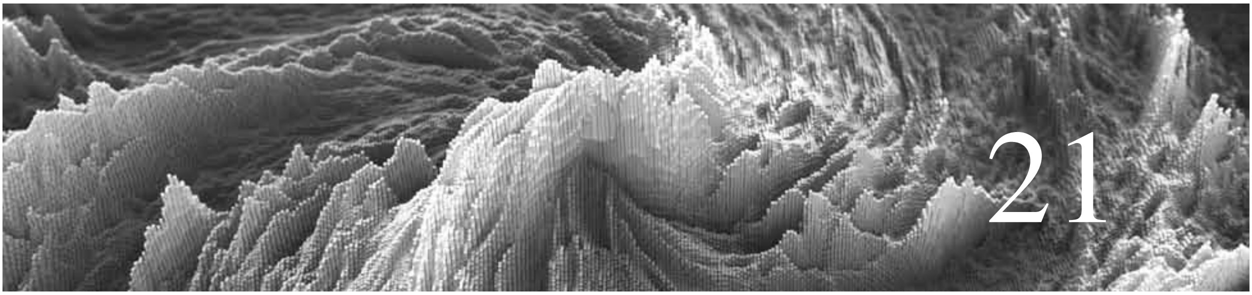
White, R. F. (2007). 'Institutional Review Board Mission Creep: The Common Rule, Social Science, and the Nanny State'. *The Independent Review*, 11 (4): 547–564.

WHO (World Health Organization) Ethics and Health Unit (2013). *Research Ethics Committees: Basic Concepts for Capacity-building –* 'Evaluation of risks and benefits'. Geneva: WHO Document Production Services.

Wilson, Mark (2005). 'Vulnerable Subjects and Canadian Research Governance'. *IRB: Ethics & Human Research*, 27 (6): 9–11.

Wolf, Daniel R. (2000). *The Rebels: A Brotherhood of Outlaw Bikers.* Toronto: University of Toronto Press.

Yan, E. G. and K. M. Munir (2004). 'Regulatory and Ethical Principles in Research Involving Children and Individuals with Developmental Disabilities.' *Ethics and Behavior*, 14: 31–49.



21

Researching Hate Crime Against Disabled People – Working through Ethical Considerations When the ‘Personal Is Political’

Chih Hoong Sin

INTRODUCTION

The following extract is taken from the UK Equality and Human Rights Commission’s (EHRC) Formal Inquiry into disability-related harassment (EHRC, 2011: 41–42). Read it, then take a moment to let it sink in.

How did it make you feel?

When Katherine Quarmby first started documenting hate crime against disabled people in 2007, she reported widespread ignorance of such crime, or disbelief that these things happened or were prevalent (Quarmby, 2008). Until very recently, there has been a woeful lack of systematic recording and centralized

Box 21.1 The murder of Laura Milne

On 12 December, 2007, Laura Milne, a young woman with learning disabilities, was at a flat in Aberdeen with three people, Stuart Jack, Debbie Buchan and Leigh Mackinnon. Buchan had previously bullied Laura when they were at school together. She had also been present on another occasion in 2006 when Laura had been assaulted with a golf club.

That night all four had been drinking alcohol when an argument ensued. Laura was punched, kicked and stamped on and forced to drink a glass of urine. Mackinnon and Buchan are said to have demanded that Jack ‘Finish her off’. Jack repeatedly slashed Laura’s throat with a kitchen knife. He later said that he enjoyed cutting her throat and that he had murdered her because she was ‘worthless’.

On 16 December, Jack and Buchan returned to the flat and attempted unsuccessfully to dismember Laura’s body by hacking at her neck and legs. They then hid her body in a cupboard beneath the kitchen sink. The following day Laura was reported as a missing person to Grampian Police by staff at the Stopover project, where she lived. Her body was found at the flat two days later.

collation of disablist hate crime statistics. One of the consequences of this is the invisibility of hate crime against disabled people (Sin et al., 2009). Coupled with the entrenched 'charity model' of disability where disabled people are depicted as victims of circumstance and deserving of pity (Sin, 2014a), there can be doubt as to whether there really is such a thing as 'disablist hate crime' (Adams-Spink, 2008). After all, who would do such 'nasty things' to 'those poor people'? Hate crime against disabled people has thus been characterized as being 'hidden in plain sight' (EHRC, 2011) due to a culture of disbelief that exists around the issue (Sherry, 2010).

Partly as a result of high profile scandals and the concerted activism of the disability rights lobby, much of the 'disbelief and ignorance has fallen away' by the time Quarmby wrote about the subject in 2010. The hate crime scholarship relating to disability has exploded (e.g. Emerson & Roulstone, 2014; Roulstone & Mason-Bish, 2012; Sheikh et al., 2011; Sin et al., 2009) so that the scholarship relating to hate crime against disabled people is approaching a critical crossroad. Petersilia, writing in 2001, observed the severe paucity of research in this area and lamented that what existed lacked rigour. In the span of 16 years since Petersilia's observation, the coverage and quality of scholarship in this field is unrecognizable from the state of affairs in 2001.

Despite these welcome transformations, there remains a curious absence of explicit discussion of the ethical dimension of conducting such research. Instead, the evidence base is characterized, first, by a growing focus on empiricism, which has come about as a response to the criticism that earlier works were predominantly 'anecdotal' and 'non-scientific' (see Petersilia, 2001: 658). Second, and as a continuation of previous currents, much of what is written in this area retains a strong political dimension concerned with social movements for positive change. This is largely due to the strength and thrust of the disability rights movement in the UK. However, much of this literature is not research (although it often draws on research), but is of a journalistic and/or lobbying nature.

It is my contention that a more explicit consideration of ethics, at this timely juncture when the scholarship is starting to mature, surfaces important implications for the thrust of the research to come. This chapter is evocative and is intended to be so as it demonstrates how a number of the issues discussed here run parallel to similar arguments in other fields such as indigenous research (Chilisa, 2011; Denzin et al., 2008), deviance (Ferrell & Hamm, 1998), ageing (Baars et al., 2014; Sin, 2005) and more.

These considerations relate to, first, being mindful of the impact on the 'researched', such as the potential for unwanted self-realization and the re-living of traumatic experiences. As many have noted, hate crime against disabled people can be qualitatively different from hate crime based on other characteristics and from crime in general. They can often be hyper-violent and/or hyper-sexual attacks. Recognizing the potential for such harms to research participants heightens the need for clarity with regards to the purpose of further research in this area. This is consistent with arguments advanced in other research fields dealing with trauma (e.g. Seedat et al., 2004).

Second, as researchers who listen to these highly distressing accounts from victims, we should also be mindful of the potential impact on the researchers in terms of their wellbeing. This is also something reported by those working in other fields of research (e.g. Woodby et al., 2011, coding interviews with the kin of deceased US veterans). Recognizing this potential for researcher distress points to the fact that ethical research requires the individual to engage in constant reflection and continuous professional development with regards to ethical practice – what Iphofen (2011) has called 'ethical awareness' – as well as collective endeavours at supporting, mentoring and developing those working in this field; and to create 'safe spaces' for discussion and debate that surfaces the practice, decision-making and strategies in what is an extremely demanding aspect of research praxis.

Third, and perhaps more uniquely, we must be aware that the emotional response, coupled with the often implicit 'framing narratives' through which individual researchers comprehend and make sense of disability and disablism, can pose certain risks to research praxis. There are implications in relation to dealing with victimhood in the context of a commitment to the 'social model' of disability. Much as researchers may be affected by the distressing accounts from victims, we need to resist simplistic and uncritical assumptions around 'vulnerability' that can unwittingly reproduce disabling attitudes. Recognizing this requires us to locate and make explicit our personal practice and values against the wider structural and hegemonic discourses that surround disability and disablism. There are specific challenges around conducting research in an area where the personal is highly political and where there is a deep-rooted activism and social change culture underpinning the disability rights movement such as in the UK.

A FEW POINTS OF CLARIFICATION

Before going any further, it may be useful to provide a degree of definitional clarity for some of the terminology used here, particularly for readers who may not be familiar with the disability and/or hate crime literature. In addition, I will attempt to draw out features underpinning disablist hate crime that I think introduces important nuances in the way ethical considerations play out that can be different from similar research and practice with other 'minoritized' groups and/or with those experiencing crime or trauma.

What Is Disability?

In the UK, the 'social model' of disability makes a clear distinction between 'impairment' and 'disability'. The 'social model' of disability is a way of thinking about disability developed by the Union of the Physically Impaired Against Segregation (UPIAS) in the 1970s that makes the crucial distinction between the biological and the social. They defined disability as something that is 'imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society' (UPIAS, 1976: 3–4). It attempts to shift the emphasis away from individual impairments towards the ways in which physical, cultural and social environments exclude and disadvantage, thereby 'disabling', people (Oliver, 1983).

This way of thinking about disability can have concrete impacts on policy and practice, as well as on the thrust of research conducted in different social milieu. For example, Sherry (2012) argued that the 'social model' underpinning the use of the term 'disabled people' rather than 'people with disabilities' in the UK focuses attention on the collective experience of oppression and requires large-scale social change. The policy and practice response has increasingly been on dismantling disabling barriers, while scholars have increasingly been working to shift the emphasis away from uncritical assumptions around the inherent 'vulnerability' of disabled people, and using this assumed 'vulnerability' to explain why hate crimes happen to disabled people (Crown Prosecution Service, 2010; Roulstone & Sadique, 2012; Sin, 2014a).

At the same time, it is important to recognize that the social model of disability has not been without its critics. Shakespeare and Watson (2002), for instance, argued that while the social model has been an excellent basis for a political movement in the UK, it is now an inadequate grounding for a social theory. These authors, and others, have argued that the denial of the experience of impairment and the construction of disability purely as a form of social oppression is unhelpful. Likewise, the continued adherence to the impairment/disability dichotomy fails to recognize what Shakespeare (1994) called the essential connection between impairment and embodiment. Certainly, in the evidence base relating to disabled people who experience hate crime, it is clear that different impairments can influence the nature of hate crime as well as the degree of response to it (e.g. Barclay & Mulligan, 2009; Sheikh et al., 2011). At the same time Sin et al. (2009) have also demonstrated how these experiences are not determined by impairment alone, but are manifestations of complex interactions with sex, age, ethnicity, sexual orientation, socio-economic status, geography and many other variables; while simultaneously framed by meta-narratives of disablism that permeate large parts of society.

What Is (Disablist) Hate Crime?

The UK Association of Chief Police Officers (ACPO) and the Crown Prosecution Service (CPS) define hate crime as

> [a]ny criminal offence which is perceived by the victim or any other person, to be motivated by hostility or prejudice, based on a person's disability or perceived disability; race or perceived race; or religion or perceived religion; or sexual orientation or perceived sexual orientation or a person who is transgender or perceived to be transgender. (CPS, 2016: 2)

Just as the definition of disability has to be understood in the context of the specific political and social milieu from which it originates, likewise Ray and Smith (2001: 211) argued that 'the definition of hate crime is subject to a process of contestation and negotiation rather than being pre-given'. In the UK, the definition of hate crime is intentionally victim-centred (Perry, 2009). This is aimed at shifting the power to identify 'what happened' from criminal justice agencies to victims and witnesses, and fundamentally shaped the way criminal justice agencies prioritize and respond to hate crime, and more towards a focus on victims and witnesses generally (cf. Foster et al., 2005). This definition of hate crime in the UK, therefore, recognizes that 'hate crime is about the assertion of the offender's own identity and belongingness over and above others – in short it is about power' (Perry, 2001: 125).

In relation to disability, the growing use of the term 'disablist hate crime' in preference over 'disability hate crime' in the UK combines a 'social model of disability' approach with the recognition of the power imbalance underpinning identity-based hate crime. 'Disablist' hate crime is often used by those who embrace the social model of disability, as: 'This term more clearly shows that the problem is with the perpetrator, and how disablist hate crime … comes from … prejudice against groups' (Strengthening Disabled People's User-led Organisations Programme, 2012: 5).

Why Is Hate Crime Different?

In the UK, Iganski (2008) conducted fresh analyses of data from the British Crime Survey and demonstrated compellingly that hate crimes caused more harm than the same offence without the bias motivation. This has also been demonstrated in the evidence from the USA (Herek et al., 1999). In relation to disabled victims, even so-called 'low level' non-criminal incidents have been shown to have high impact (Sin et al., 2009).

Previously, Iganski (2001) had also eloquently argued that 'hate crimes hurt more' because they generate 'waves of harm' that ripple far beyond the negative impact on direct victims. Hate crimes are 'signal crimes' and have powerful symbolic and concrete impacts that extend far beyond the physical and emotional harm experienced by victims. Family members of disabled hate crime victims, who may not be disabled themselves, can similarly be victimized. Other people who share the identity labels that have been targeted through hostility and prejudice, who may not have experienced hate crime directly, also restructure their lives to avoid putting themselves at risk. Hate crimes degrade the communities in which they occur, members of which often feel a sense of shame and anger, thereby striking at wider social cohesion, citizenship, and belonging.

Why Is Disablist Hate Crime Different from Other Forms of Hate Crime?

Levin (2012: 98) observed 'attacks against people with disabilities tend to be committed less by strangers and more by family members, neighbours, employees, and friends who may also be caregivers'. While the 'stranger danger' narrative has similarly been challenged in the literature pertaining to other forms of hate crimes (Roberts et al., 2013), notable differences remain in the composition of perpetrators who are 'known to' the victim. Clements et al. (2011), for example, argued that hate crime against disabled people are different from other forms of hate crime in that carers feature more prominently in the former. Human Rights First (2007) similarly noted the preponderance of cases that occur in the 'private sphere' including institutional settings where perpetrators can be professionals and staff from statutory agencies.

These features of hate crime against disabled people, coupled with the entrenched 'charity model' and 'personal tragedy' lenses through which disabled people still tend to be viewed, mean that individual-, organizational- and systemic-level responses can often be orientated towards protection or the minimization of risk rather than towards providing access to justice and effective redress (Sin et al., 2011).

I argue, in this chapter, that this urge to protect is ever-present when conducting research with disabled people who have experienced hate crime. It is easy, when listening to often appalling accounts from disabled research participants, to locate them unquestioning through an amplified 'personal tragedy' lens and to uncritically attribute their experiences to their 'vulnerability'.

Unfortunately, however well-intended we may be, these often implicit undercurrents of emotions and prejudices that condition our responses can reinforce endemic low aspirations for disabled people, leading to fatalistic acceptance that disabled people cannot expect anything different because they are inherently vulnerable. The best that may be done for them is to 'protect'. This 'urge to protect' or 'urge to rescue' can actually serve to reinforce an entrenched 'charity model' of disability. This does not challenge fundamentally the structures that reproduce vulnerability and the contexts in which disabled people experience hate crime.

FROM 'I FELT I DESERVED IT' TO 'I DON'T IDENTIFY AS A VICTIM' – THE COMPLEXITY OF RESPONSE IN A RESEARCH SITUATION

Data from the USA (Harrell, 2011), Australia (Sherry, 2000) and the UK (Sin et al., 2009) suggest strongly that people who are known to the victim perpetrate a significant proportion of hate crime against disabled people. This feature of hate crime against disabled people has implications for the potential impact on

Box 21.2 This is not me

'[My ex-husband] would be out drinking most nights and when he got home it would start. He'd begin with telling me I was fat and ugly. And then he would begin hitting me and throwing me around.'

'It's embarrassing [talking about it]. I was always quite an outgoing person before I got married. I was embarrassed about the situation I had ended up in where I was being abused. When I look back on it, it doesn't feel like it was even me'. (Woman in her 30s with a mental health condition, Sin et al., 2009) research participants. As I have written elsewhere (Sin, 2005: 279), 'the experience of participating in research may cause some participants to feel disturbed and anxious. It may also give rise to uncalled for self-knowledge with adverse psychological implications'. The experience of crime, in general, is distressing. This is more so when the perpetrator of that crime has a close relationship with the victim.

When I was conducting research for the Equality and Human Rights Commission (EHRC) in 2008 on targeted violence and hostility against disabled people in Great Britain, a significant number of the 30 interviewees we worked with as part of the wider research struggled to articulate their experiences (Sin et al., 2009). Many were hesitant and found it difficult and/or traumatic to verbalize their experiences. For example, one interviewee indicated that:

> I find it difficult to speak about these things. I get worked up and can't express my feelings.

Many used the expression of having kept it 'bottled up inside' for a long time, and of finding it difficult to initiate or engage in a conversation with someone else about it. This was particularly so for those who had experienced violence and abuse from family members. As is apparent from the vignette at the start of this section, there can be a deep sense of embarrassment in disclosing such experiences as the interviewee's sense of self can feel compromised through a perceived 'failure' to 'take care of oneself' and/or to maintain perceived normative relationships (e.g. as a wife). Often, this perceived 'failure' could compound the feeling of inadequacy that internalizes wider discourses around disablism that characterizes disability as 'lacking' or being 'incomplete' (Oliver, 1983).

Regardless of whether the perpetrator is a family member or someone known to the disabled person, there is evidence more generally that the experience of hate crime itself causes victims to feel embarrassed or humiliated (DRC and Capability Scotland, 2004). The act of articulating these past experiences to a stranger (the researcher, in this instance) not only makes the research participant relive the encounters but also to experience further potential for embarrassment in disclosure.

Research participants often admitted that they felt others (such as witnesses of the hate crime, and also the researcher) may perceive them differently, or may affix a label to them, which they did not identify with. For example, a male interviewee with a mental health condition indicated that his sense of embarrassment was rooted in perceived conflict with gendered norms of behaviour:

> I was too shamed and embarrassed to tell anyone. Because I'm a bloke, I'm expected to handle it. I still get upset and cry but it's not acceptable for a man to do so. (Black male in his 40s with a mental health condition)

The fact that this interviewee is a black man introduced further complexity to his emotional response, as does the fact that he has a mental health condition. The complex interplay of men's gendered identities with 'race', ethnicity and culture in the context of the black men having disproportionately high rates of mental ill health has been discussed elsewhere (see Robinson et al., 2011).

Disabled victims of hate crime often ignore their experiences as a means of coping, and are also commonly advised by others to ignore perpetrators. Sustained harassment and abuse is seen to be, and accepted as, a 'part of everyday life':

> My auntie tells me to ignore it if people say bad things to me. When I ignore them, she says I have done the right thing. (Woman in her 20s with learning disabilities)

This demonstrates the pernicious effect of wider conditioning leading to acceptance that disabled people cannot and should not expect to lead fulfilling lives. Indeed, when they do experience hate crime, many victims often feel that they 'deserved it' or that this was something 'to be expected' (Richardson et al., 2016).

It has to be said that not all research participants displayed resigned acceptance or negative self-image during the research process. In a few instances, participants actively resist 'victimhood' and, during the research process, crafted alternative self-empowering identities. In other instances, the resistance of victimhood can result in participants challenging the researcher's conscious as well as sub-conscious acts of locating them as such:

> I hate the word victim – it's not me, I don't identify as a victim … I don't want to be afraid. I want to live my life. (Focus group participant, woman with visual impairment, age 31–59, quoted in Sykes et al., 2011: 25)

To be labelled a 'victim', and hence the subject of research interest, can be seen as an attempt by the Other (in this case, the researcher) to assign an identity to the research participant that they do not agree with, and that they see as a sign of further 'marginalization'. That this happened in the context of a research setting usually underpinned by unequal power dynamics that privilege the researcher is also instructive.

Recognizing the impact of research on participants requires greater clarity about the purpose of research. This is especially pertinent at a time when there has been, and continues to be, an explosion of scholarship in this area particularly in the UK. Sherry (2010: xv) commented 'there have been probably more publications about disability hate crimes in the UK over the last five years than the rest of the world combined'. Whose purpose does this research serve and why should disabled people be involved in this type of research when the potential for harm is ever present? This same challenge has been posed in many other forms of research with populations framed as 'vulnerable'. Certainly, in private conversations, I am aware of the suspicions among some disabled people and disability rights advocates that the eagerness of academics to enter this burgeoning area of research may have more to do with personal and professional advancement in an emergent area that has been attracting more political and popular attention, than about improving the lives of disabled people.

Disabled people have cause for concern as this invokes the ghosts of past experiences with research and researchers. They can be critical of research and can see it as part of the problem contributing to their marginalization (Barnes, 2001; Oliver, 1992). This is exemplified in the case of the disabled residents in Le Court Cheshire Home, which has since been identified as a watershed moment in the history of the disabled people's movement in the UK. These residents had asked 'experts' in 'group dynamics' to support their struggle against local managers and professionals for greater control over their everyday lives. Two social researchers from the Tavistock Institute were funded to undertake a three-year in-depth study. As Barnes and Mercer (1997) described, the residents were soon alienated by the way in which 'unbiased social scientists' failed to listen to residents' accounts and experiences; recommending that traditional practice should largely continue in the Home even though they themselves categorized institutional life for the residents as 'living death' (Miller & Gwynne, 1972).

Hunt (1981), in a trenchant critique, argued that early research processes were largely non-reciprocal, self-servicing and exploitative. In fact, he used the word 'parasite' to describe researchers. Researchers had failed to examine the power dynamics operating within the research relationship, and subsequently contributed to disabled people's classification as 'other' (Barnes, 2003). In the Le Court example described above, the research actually contributed to practices that reduced disabled people's wellbeing and reinforced their segregation from society. Disabled people often complain that the voluminous research conducted into every imaginable aspect of their lives has not necessarily translated into positive changes for them. Research can therefore be seen as a continuing 'ask' by researchers, with outcomes that accrue to them but not to the disabled research participants or disabled people more generally (Barnes & Mercer, 1997).

Iphofen's (2011: 4) caution is of relevance here when he questioned whether

> when seeking to advance social scientific knowledge we can treat human beings as exploitatively as we wish to since they are our vital data source – and we would only be doing so in the interests of, say, advancing knowledge, producing the commissioned deliverables for our funders and so on.

While I believe, and would hope, that no researcher in the field of hate crime against disabled people sets out to deliberately cause harm; a refusal to recognize the potential for harm by the mere fact that we are asking participants to relive distressing experiences is to fail to take ethical research practice seriously.

I have, personally, questioned whether there is point in always doing 'more research'. Certainly, there are still gaps in the scholarship, but many issues and experiences are well documented by now, with compelling consistency within the UK and also internationally (see Sin, 2016 for precis). How much more do we need to know before we start doing something about it? There is a risk that research may unwittingly reproduce the structures that perpetrate violence against disabled people rather than help challenge and dismantle them.

To date, my own research activities in this area have all been commissioned by organizations with explicit aims to bring about social change through evidence. For example, the research for the EHRC (as a regulator for equalities and human rights in Great Britain) triggered a Formal Inquiry (EHRC, 2011), with a manifesto for change issued (EHRC, 2012) and a progress report published in 2013 (EHRC, 2013). The research for Mencap (Sheikh et al., 2011) informed their 'Stand By Me' campaign which drew a significant number of police forces to sign up to a 10-point list of promises, including more support for crime victims with learning disabilities, an end to discriminatory language and attitudes among officers, and efforts not to write offences off as 'just' anti-social behaviour or 'low level' incidents.

On a personal level, I cannot guarantee change as a result of my research, and it would have been irresponsible to assert this guarantee to the research participants. Nonetheless, there is a responsibility on me to work closely with the commissioning bodies to ensure that the evidence is understood properly; that the implications for action are understood; and that progressing on these actions continues to benefit from an evidence-based approach. In addition, I firmly believe in the value and necessity of working with disabled people to frame the research questions; to steer the research; and to play an active role in determining methods, analysis, reporting and dissemination.

Before interviewing research participants, my research teams always researched and pulled together leaflets containing information on the range of local and national services and support that may be relevant to research participants in different parts of the country. These often included not only victim support services, but also mental health support services, advocacy, counselling, third party reporting services, and more.

Beyond the completion of research projects, I endeavour to support different organizations to take action. For example, I have worked with numerous local authorities, community safety partnerships, and police services on the formulation of hate crime strategies and action plans; community engagement; training of front line professionals in relation to tackling hate crime, and more. Most recently, I worked with Leicestershire Partnership NHS Trust and their local authority and voluntary and community sector organization partners to design and implement a hate crime care pathway (Sin, 2014b, 2015). This was the direct result of a specific recommendation in my 2009 research for the EHRC urging other agencies to step forward and to stop seeing hate crime as merely a criminal justice issue (Sin et al., 2009: 89). In these, and other, ways, I have attempted to go beyond the conventional role of the 'detached' researcher and address the key ethical concerns. This has been influenced and inspired by proponents of participatory, emancipatory, and action research etc. working across very diverse fields of scholarship (Truman et al., 2000).

REVERSING THE GAZE

There is no intention here of sensationalizing or encouraging voyeuristic tendencies that 'objectify' disabled people and portray their experiences as either 'personal tragedy' (as opposed to shining a light on the oppression and exclusion that has led to this) or, for survivors, to be characterized as 'heroic victims'. At the same time, I have to acknowledge the impact that such research has had on me. Sherry (2010: xiii) had similarly talked about how being immersed in this field of research and writing about it has 'burned my soul with pain … Sometimes, it has been hard to continue because I've been overwhelmed by the violence, anger, abuse and pain'.

I have been working in the field of hate crime for around ten years, and at various points during those ten years, I have questioned my faith in humanity. This may come across as sensationalist, and I can only hope the following narrative helps explain my emotional responses.

One of my earliest 'crisis of faith' happened during the research conducted for the EHRC when I realized that every single one of the women with learning disabilities we interviewed across England, Wales and Scotland for the research had experienced sexual attacks. In addition, someone they knew had sexually abused the majority of these women:

> After dinner, when my dad and step-mum were watching TV or playing on the PlayStation downstairs, my step-uncle used to tell them he was going to the toilet and come into my bedroom and touch me and things.

> A couple of months ago I was asked by a friend [here the interviewee made a gesture like masturbating a penis] … I told him 'no'. I know him from the pub – he had his willy hanging out there as well.

I often struggle to understand how some segments of our society can be represented as 'less than human', with such dehumanization then facilitating abuse and violence. Disabled women in particular are more vulnerable to sexual violence (Marley & Buila, 2001) and disability can exacerbate or alter the nature of domestic violence (Barclay & Mulligan, 2009). Yet disabled women experience significant barriers in seeking help (Hague et al., 2008). Furthermore, cases of sexual assault or rape against women and girls with learning difficulties or mental health conditions are less likely to result in convictions in cases of sexual assault and rape (HM Crown Prosecution Service Inspectorate and HM Inspectorate of Constabulary, 2007).

It is, however, easy to think that hate crimes against disabled people are perpetrated by rogue 'villains' – by 'awful' people who 'should have known better'. Yet this conveniently absolves us from our role, however indirect, in potentially sustaining wider disabling attitudes and behaviours. Every time we turn a blind eye to a disabled person being subjected to verbal abuse, taunts, bullying, and violence; we are condoning such behaviours. Disabled people unsurprisingly feel that these acts are 'to be expected', while perpetrators feel that they can (sometimes literally) 'get away with murder' (Quarmby, 2008). This feature of disablist hate crime sets it apart from much other (hate) crime. After all, one of Brent Martin's murderers told friends: 'I am not going down for a muppet' (EHRC, 2011: 50). Brent Martin had learning difficulties and a mental health condition, and was 23 years old when three young people whom he had previously considered to be his friends killed him. His assailants had a bet on who could inflict the most damage. Brent Martin died from a massive head injury and had suffered at least 18 separate blows to his head and neck.

I cannot be blind to how wider attitudes towards disability and disabled people have conspired to sustain the structures that reproduce violence. Pejorative attitudes towards disabled people sustain endemic low aspirations and fatalistic acceptance that disabled people should not expect to live fulfilling lives. The pernicious devaluing of disabled people indicates a disdain for their equality as human beings. This lends itself easily to the devaluation of the residents in Winterbourne View hospital in the UK whom the staff had stopped seeing as complete people. (Local social services and the English national regulator the Care Quality Commission had received various warnings but the mistreatment continued.) This also lends itself to the ease with which Fiona Pilkington's repeated and desperate pleas for help fell on deaf ears as the police and the council dismissed her experience and those of her disabled daughter Francecca Hardwick as 'trivial' (see details below). This lends itself to the countless instances when we look away as a disabled person is subjected to verbal abuse and ridicule in the streets or on public transport.

I have been one of those people. I had lacked the civic courage to intervene. While I no longer just stand by and do nothing, the guilt I continue to feel about past inaction has been deeply disconcerting. I have sometimes felt like a 'fraud' when conducting research with disabled people who have experienced hate crime.

While hate crime against disabled people is often hyper-violent and hyper-sexual, it has to be said that the so-called 'low level incidents' can be equally shocking and depressing. David Askew, a 64-year-old man with learning disabilities, who collapsed and died of a heart attack in his garden in 2010, was found to have reported incidents of harassment by at least 26 different people to the police 88 times in six years, to no avail. On 23 October 2007, the charred remains of Fiona Pilkington and her daughter Francecca Hardwick were found in their burnt-out car in a lay-by. Fiona, out of sheer despair and hopelessness, had killed herself and her daughter (who had a learning disability), having endured seven years of persistent harassment. The police and the local authority had repeatedly ignored her cries for help, believing that 'there was no indication … that this was anything other than low level nuisance behaviour' (Leicestershire and Rutland Safeguarding Adults Board, 2008). This overlooked the fact that the persistent and corrosive effect of prolonged exposure to this so-called 'low level nuisance' can be devastating (Sin, 2012).

These accounts of persistent hate incidents that have almost always been ignored by statutory agencies are certainly common fare in my own hate crime research with disabled people. Indeed, the hopelessness that comes from being ignored and the expectation to just 'get on with it' over long periods of time, has compelled numerous research participants to literally get down on their knees and beg me and other members of my research teams to 'help them' and to 'please do something about it'. It is difficult to overstate the emotional impact that these accounts and the utter despair of research participants have had, and continue to have, on colleagues and myself.

Iphofen (2011: 3) has argued that 'ethical practice in social research is about being a "good" researcher at the same time as being a "good" human being'. I have found it incredibly challenging to enact these aspirations in practice. In striving to be a 'good' researcher and 'good' human being, I simultaneously resist lapsing into attitudes and behaviours that risk disempowering the participants in my research. I am reminded of how entrenched the 'tragedy' or 'charity' model of disability continues to be, and how easy it is to construct disabled people as victims of circumstance, deserving of pity. In situations when disabled people have been victimized through hate crime, this tendency to represent and understand their experiences through such a perspective is compounded.

Reflecting upon the 'ableist gaze and the politics of rescue', Razack (1998: 130–131) acknowledged uneasily that 'I am the imperial gazer, rather than the gazed upon, the one who engages in a politics of saving other[s]'.

This can be patronizing, and also self-serving. It lends itself to the imposition of an 'expert' or 'professional' model where an authoritarian, over-active and self-fashioned 'expert' prescribes and acts for a 'passive beneficiary'. However well-intentioned this 'act of saving' may have been, it can be fundamentally disabling and disempowering – reproducing the unequal power relationships within the research relationship and within wider societal structures.

In locating myself as researcher in this context, I acknowledge that my perspective is necessarily a conflation of my personal, political and professional experiences. On a personal level, as a minority ethnic, gay and first-generation immigrant to the UK; I have always been acutely aware of identity politics and the struggles in relation to equality, diversity and human rights within the UK context and also more widely. The personal has always been political to me. My research and professional career has revolved around equality issues including 'race'/'ethnicity', age and ageing, sexual orientation, religion and faith, and disability. My research has almost always been in the applied policy and practice context, which has always led me to work in organizations with an explicit commitment to improving social outcomes.

As former Head of Information and Research at the UK Disability Rights Commission, I am knowledgeable about the politics, philosophies and evidence base in relation to disability and disablism. As a researcher who is committed to ethical practice, I am also deeply aware of the debates around ethical research praxis and have written about researcher-researched relationships, informed consent, and more. As a professional who works closely with public services to improve outcomes, I am also aware of the institutional disablism that underpins much of public service commissioning, design and delivery; and the fight for disability equality and meaningful involvement of disabled people. The interplay between these various worlds has also made me acutely aware of specific ethical challenges when research is conducted by non-disabled researchers with disabled participants (see Marks, 1996), against the wider backdrop of the long-standing disability rights movement in the UK and the strength of the disabled user-led movement underpinned by the commitment to 'research *by* disabled people *for* disabled people'. I am very aware that things do not 'stand still' and that ethical practice needs constant reflection and renewal.

RESEARCH AS POLITICS

In the UK, the 'social model' of disability makes a clear distinction between 'impairment' and 'disability'. As I explained earlier, this shifts the emphasis away from individual impairments towards the disabling physical, cultural and social environments. This is not for pedantic purposes, but are expressions of the 'personal is political' thrust of the disability rights movement, and have concrete impacts on research praxis within such a socio-political milieu.

The implications of a social model approach to research are profound. For far too long the academic and popular discourse around hate crime against disabled people has revolved around the characteristics of disabled people themselves: in particular those that render disabled people 'vulnerable'. The hate crime scholarship has therefore, until very recently, demonstrated an obsession with understanding what types of hate crime happen to what types of disabled people; the prevalence and experience of such crime; how disabled victims respond and seek help; etc. There is a real risk of thinking that we can tackle disablist hate crime by finding out more about disabled people and what makes them 'at risk'. This risk has similarly been noted for research with a number of other groups.

It is easy to think that disabled people experience hate crime *because* they have various impairments; and that these impairments mean that they are inherently vulnerable; and this vulnerability is therefore a fixed condition. This lazy and flawed logic sustains fatalism, with little real commitment to change. The best that may be done for disabled people, to follow this logic to its conclusion, is to 'protect'. This does not challenge fundamentally the structures that reproduce vulnerability and risks, and the contexts in which disabled people experience hate crime. This approach will never prevent hate crimes from happening, and only serves to locate disabled people in a way that enables them to be managed. To me, ethical research plays a vital role in helping to shift this deeply entrenched mindset that large segments of society, unfortunately, still have about disabled people.

Ethical research in this area should therefore not reproduce the 'inventory' approach of cataloguing every feature of disabled people and their experiences, but should instead shift the gaze onto the disabling barriers that position disabled people as being more at risk of victimization.

It is instructive that Iganski et al. (2011) and Roberts et al. (2013) have observed that there is a real paucity of data on perpetrators of hate crime against disabled people in the UK and internationally. Instead, the overwhelming weight of the scholarship has been on disabled people. While the scholarship in this area has gradually moved to critique the representation of vulnerability (e.g. Sin et al., 2009; Roulstone & Sadique, 2012; Sin, 2014a), there is still a severe paucity of research on perpetrators and the disabling structures that reproduce violence against disabled people in different contexts.

Certainly, in my own research, I have adapted the theories of Dahlgren and Whitehead (1991), originally applied in the arena of public health interventions, in order to develop a model that explains the complex interactions between hate crime victims, agencies and other actors from different social spheres (Sin, 2014a). This 'layers of influence' model can best be understood as a series of concentric circles (representing social 'layers'), with the disabled person in the centre of them. The layer immediately outside the centre is occupied by carers and families, and the one after that organizations and institutions, while the outer layer hosts society and attitudes.

As Garland (2015: 6) noted,

> these layers are interdependent, interacting with each other in complex ways contingent on time and place. Sin argues that too often in the past academics and practitioners have concentrated on the centre of these circles – and in particular the supposedly 'vulnerable' characteristics of the disabled person being targeted – without examining how the structures and contexts surrounding them – the outer layers – have impacted upon their situation.

In putting forward this model, I acknowledge not only the influence of wider 'layers of influence' on the experiences and expectations of disabled people, but also the role of personal characteristics and identities. It is never one or the other, but it is always about the complex interactions between the two.

MANAGING RISK

> 'Risk' in one form or another underpins almost every area of disadvantage in disabled people's lives, with serious ramifications for independence and equality … 'Risk' is used to discriminate. (DRC, 2006)

Representations of disability as presenting risks to oneself and to others have had a pernicious effect on attitudes and behaviours towards disabled people in all spheres of life (Grewal et al., 2002). For disabled people, the sensible management can sometimes turn into disproportionate steps to attempt to completely eliminate risk, leading to diminished opportunities across life (DRC, 2006). Instincts to protect are heightened in the context of disabled people as victims of hate crime. Individual-, organizational-, and systemic-level responses can often be orientated towards protection and/or the minimization of risk rather than towards providing access to justice and effective redress.

The issues relating to disabled people's experiences of hate crime have sometimes been underpinned by a protectionist paradigm focusing on disabled people's perceived vulnerability as opposed to a rights paradigm; a situation disabled people and others have expressed frustration about (see Sin et al., 2009). Disabled people and other stakeholders working in this field argue that the issue should be approached through a lens of rights and entitlements for disabled people to have the same experience of safety and security as well as access to justice as non-disabled people (EHRC, 2011; Sin et al., 2009).

There are, however, inherent tensions within a rights based approach, and rights may at times be competing or contradictory. This is especially the case when hate crime is perpetrated by those known to disabled people. For example, the need to balance a person's right to a private life with the right for protection if that private life is harmful. A rights based approach can therefore be conceived as a balancing act between different rights. Disabled people must be empowered themselves to be involved meaningfully to get the balance right.

Risk assessment and risk management have become de rigueur in many of the professions that have high levels of contact with disabled people. Indeed, when it comes to working with disabled people, safeguarding requirements can often be at the fore. I have written, elsewhere (Sin et al., 2011) about how adult protection and safeguarding legislation can sometimes contradict the tenets of disability equality. Similarly, in the research contact, this issue rears its head and is usually managed through the system of ethical review, informed consent, and other orthodoxies associated with ethical research practice. While risk is distinct from vulnerability, the two can often be conflated particularly by those in caring professions and also amongst ethical researchers who are motivated by a 'do no harm' ethos (Sin & Fong, 2008). The conflation of risk with perceived vulnerability of disabled people as a result of their impairment can be at odds with the social model of disability (Sin, 2014a).

As Iphofen (2011: 5) argued, while there is certainly

> a need for an ethical system of ethical review, no system can guarantee ethical practice throughout. Unnecessarily cumbersome systems of ethical review can be a hindrance, and institutional caution has taken precedence over ethical concerns and ethical review has been confused with risk aversion, damage limitation and managerial line accountability (so-called research governance).

If we are not careful, the formalistic practice of ethical research can be self-serving – aimed at 'protecting' the 'system' from negative outcomes. This is especially so when the interplay between ethics in research and wider safeguarding legislation combine into a heady mix of formalistic requirements that run the risk of 'placing' and infantalizing research respondents within the structures designed to 'manage' them.

Ethical practice must be reflexive (Sin, 2005). In addition, disabled people must be involved meaningfully in the process of ethical research. The clarion call issued by the disability rights movement: '*Nothing about us without us*', serves as a reminder of the need for disabled people to have a say in every stage of the process. This principle should thread through research praxis (Farmer & Macleod, 2011). Many disabled academics have argued that emancipatory research is vital to research relationships (Barnes, 2001). The principle of co-production is increasingly being advocated by those in the disability rights movement, and has become a popular concept in public policy in Britain more generally (Morris, 2011). These developments place emphasis on flexibility, power sharing and empowerment of the disabled person. For ethical research, it means genuine co-creation of process and meaning. It challenges us to fundamentally re-examine how we design, conduct, and report research; and the social and interpersonal underpinnings of these.

CONCLUSION

It has sometimes been said that reflective pieces, such as this, may be more about the researchers undergoing public soul-searching resulting in catharsis. It can come across as self-serving, as the researchers rationalize their own practice and decisions, and demonstrate how they have wrestled heroically with ethical dilemmas. I think this challenge is particularly acute in the context of qualitative research, where the researcher often has direct encounters with research participants with attendant emotional investment into the process of research. In addition, the imperative to be not only a 'good researcher' but also a 'good human being', particularly in the eyes of the wider community of scholars and practitioners, can be all-consuming.

I have no easy response to this, and can only point to the deep-seated challenges in conducting research when the personal is always political, not only from the perspective of research respondents but also from my own values and positioning as a researcher and as a person. Being so acutely aware of this fact comes with benefits (e.g. resisting naïve notions of 'vulnerability'), but also presents unique dilemmas and risks (e.g. the urge to 'rescue'). Perhaps the point is not about holding ourselves to absolute standards of 'getting it right', but to recognize that these standards are not simply set by ourselves as researchers but are co-created through our interaction with others in specific contexts.

REFERENCES

Adams-Spink, G. (2008) Does disability hate crime exist? 19 August. Available at: http://news.bbc.co.uk/1/hi/magazine/7570305.stm (Accessed on 24 February 2017).

Baars, J., Dohmen, J., Grenier, A., and Phillipson, C. (eds) (2014) *Ageing, Meaning and Social Structure: Connecting Critical and Humanistic Gerontology*, Bristol, UK: Policy Press.

Barclay, H. and Mulligan, D. (2009) Tackling violence against women – lessons for efforts to tackle other forms of targeted violence, *Safer Communities*, 8(4), 43–50.

Barnes, C. (2001) 'Emancipatory' disability research: project or process? Public Lecture at City Chambers, Glasgow, on 24 October 2001. Available at: http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/glasgow%20lecture.pdf (Accessed on 24 July 2016).

Barnes, C. (2003) What a difference a decade makes: reflections on doing 'emancipatory' disability research, *Disability & Society*, 18(1), 3–17.

Barnes, C. and Mercer, G. (eds) (1997) *Doing Disability Research*, Leeds: The Disability Press.

Chilisa, B. (2011) *Indigenous Research Methodologies*, London: Sage.

Clement, S., Brohan, E., Sayce, L., Pool, J. and Thornicroft, G. (2011) Disability hate crime and targeted violence and hostility: A mental health and discrimination perspective, *Journal of Mental Health*, 20(3), 219–225.

Crown Prosecution Service (CPS) (2010) Disability Hate Crime – Guidance on the Distinction between Vulnerability and Hostility in the Context of Crimes Committed Against Disabled People, London: CPS.

Crown Prosecution Service (CPS) (2016) *Hate Crime: What It Is and How to Support Victims and Witnesses,* London: CPS. Available at: http://www.cps.gov.uk/publications/docs/hate_crime_leaflet_support.pdf (Accessed on 27 February 2017).

Dahlgren, G. and Whitehead, M. (1991) *Policies and Strategies to Promote Social Equity in Health,* Stockholm: Institute for Future Studies.

Denzin, N.K., Lincoln, Y.S., and Smith, L.T. (eds) (2008) *Handbook of Critical and Indigenous Methodologies*, Thousand Oaks, CA: Sage.

Disability Rights Commission (2006) *Whose Risk Is It Anyway?* Discussion Paper. London: DRC.

Disability Rights Commission and Capability Scotland (2004) *Hate Crime Against Disabled People in Scotland: A Survey Report*. Edinburgh: DRC and Capability Scotland.

Emerson, E. and Roulstone, A. (2014) Developing an evidence base for violent and disablist hate crime in Britain: findings from the Life Opportunities Survey, *Journal of Interpersonal Violence*, 29(17), 3086–3104.

Equality and Human Rights Commission (EHRC) (2011) *Hidden in Plain Sight: Inquiry into Disability-related Harassment,* Manchester: EHRC.

Equality and Human Rights Commission (EHRC) (2012) Out in the Open – Tackling Disability-related Harassment: A Manifesto for Change, Manchester: EHRC.

Equality and Human Rights Commission (EHRC) (2013) *Manifesto for Change – Progress Report 2013*, Manchester: EHRC.

Farmer, M. and Macleod, F. (2011) Involving Disabled People in Social Research. Guidance by the Office for Disability Issues, London: ODI.

Ferrell, J. and Hamm, M.S. (ed.) (1998) *Ethnography at the Edge: Crime, Deviance and Field Research,* Boston, MA: Northeastern University Press.

Foster, J.A., Newburn, T., and Souhami, A. (2005) *Assessing the Impact of the Stephen Lawrence Inquiry*. Home Office Research Study 294. London: Home Office.

Garland, J. (2015) One step forwards, two steps backwards? Difficulties and dilemmas with connecting hate crime policy and research, *Criminal Justice Policy Review,* forthcoming, doi: 10.1177/0887403415601474.

Grewal, I., Joy, S., Lewis, J., Swales, K., and Woodfield, K. (2002) *Disabled for Life? Attitudes Towards, and Experiences of, Disability in Britain*. *Research Report No. 173,* London: NatCen for the Department for Work and Pensions.

Hague, G., Magowan, P., Thiara, R.K., and Mullender, A. (2008) *Making the Links: Disabled Women and Domestic Violence*, Bristol, UK: Women's Aid.

Harrell, E. (2011) Crimes Against Persons with Disabilities, 2008-2010 - Statistical Tables, *Department of Justice National Crime Victimization Survey*, Washington, DC, USA: Bureau of Justice Statistics, U.S. Department of Justice.

Herek, G.M., Gillis, J.R., and Cogan, J.C. (1999) Psychological sequelae of hate-crime victimization among lesbian, gay and bisexual adults, *Journal of Consulting and Clinical Psychology,* 67(6), 945–951.

HM Crown Prosecution Service Inspectorate (HMCPSI) and HM Inspectorate of Constabulary (HMIC) (2007) *Without Consent: A Report on the Joint Review of the Investigation and Prosecution of Rape Offences*, London: HMIC.

Human Rights First (2007) *Hate Crimes: 2007 Survey*, New York: Human Rights First.

Hunt, P. (1981) Settling accounts with the parasite people, *Disability Challenge*, 1, 37–50.

Iganski, P. (2001) Hate crimes hurt more, *American Behavioural Scientist*, 45(4), 626–638.

Iganski, P. (2008) *Hate Crime and the City*, Bristol, UK: Policy Press.

Iphofen, R. (2011) Ethical Decision Making in Social Research: A Practical Guide, London: Palgrave Macmillan.

Leicestershire and Rutland Safeguarding Adults Board (2008) *Executive Summary of Serious Case Review in Relation to A and B*, Leicester: Leicestershire and Rutland Safeguarding Adults Board.

Levin, J. (2012) Disablist violence in the US: unacknowledged hate crime, in Roulstone, A. and Mason-Bish, H. (eds) *Disability, Hate Crime and Violence*, pp. 95–105, London: Routledge.

Marks, D. (1996) Able-bodied dilemmas in teaching disability studies, in Wilkinson, S. and Kitzinger, C. (eds) *Representing the Other*, pp. 64–67, London: Sage.

Marley, J.A. and Buila, S. (2001) Crimes against people with mental illness: Types, perpetrators and influencing factors, *Social Work*, 46(2), 115–124.

Miller, E.J. and Gwynne, G.V. (1972) *A Life Apart,* London: Tavistock.

Morris, J. (2011) *Rethinking Disability Policy*, York, UK: Joseph Rowntree Foundation.

Oliver, M. (1983) *Social Work with Disabled People*, London: Macmillan.

Oliver, M. (1992) Changing the social relations of research production, *Disability, Handicap & Society*, 7(2), 101–114.

Perry, B. (2001) In the Name of Hate: Understanding Hate Crimes, New York: Routledge.

Perry, J. (2009) At the intersection: hate crime policy and practice in England and Wales, *Safer Communities*, 8(4), 9–18.

Petersilia, J.R. (2001) Crime victims with developmental disabilities: a review essay, *Criminal Justice and Behavior*, 28(6), 655–694.

Quarmby, K. (2008) *Getting Away with Murder: Disabled People's Experiences of Hate Crime in the UK*, London: Scope, Disability Now, UK Disabled People Council.

Quarmby, K. (2010) From disbelief and ignorance to anger and action, The Huffington Post, 8 February 2010. Available at: http://www.huffingtonpost.com/katharine-quarmby/from-disbelief-and-ignora_b_453088.html (Accessed on 24 June 2016).

Ray, L. and Smith, D. (2001) Racist offenders and the politics of 'hate crime', *Law and Critique*, 12(3), 203–221.

Razack, S.H. (1998) Looking White People in the Eye: Gender, Race and Culture in Courtrooms and Classrooms, Toronto, ON: University of Toronto Press.

Richardson, L., Beadle-Brown, J., Bradshaw, J., Guest, C., Malovic, A., and Himmerich, J. (2016) 'I felt that I deserved it' – experiences and implications of disability hate crime, *Tizard Learning Disability Review,* 21(2), 80–88.

Roberts, C., Innes, M., Williams, M., Tregidga, J., and Gadd, D. (2013) *Understanding Who Commits Hate Crime and Why They Do It*, Merthyr Tydfil: Local Government and Communities, Welsh Government.

Robinson, M., Keating, F., and Robertson, S. (2011) Ethnicity, gender and mental health, *Diversity and Equality in Health and Care,* 8(2), 81–92.

Roulstone, A. and Mason-Bish, H. (eds) (2012) *Disability, Hate Crime and Violence*, London: Routledge.

Roulstone, A. and Sadique, K. (2012) Vulnerable to misinterpretation: disabled people, 'vulnerability', hate crime and the fight for legal recognition, in Roulstone, A. and Mason-Bish, H. (eds) *Disability, Hate Crime and Violence*, pp. 25–39, London: Routledge.

Seedat, S., Pienaar, W.P., Williams, D., and Stein, D.J. (2004) Ethics of research on survivors of trauma, *Current Psychiatry Reports*, 6(4), 262–267.

Shakespeare, T.W. (1994) Cultural representations of disabled people: dustbins for disavowal?, *Disability and Society*, 9(3), 283–299.

Shakespeare, T.W. and Watson, N. (2002) The social model of disability: an outdated ideology?, in Barnartt, S.N. and Altman, B.M. (eds) *Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go (Research in Social Science and Disability, Volume 2),* pp. 9–28, London: Emerald Group Publishing Limited.

Sheikh, S., Khanna, M., Pralat, R., Reed, C., and Sin, C.H. (2011) *Hate Crime Research for Stand By Me Campaign*, London: OPM for Mencap.

Sherry, M. (2000) *Hate Crimes Against People With Disabilities*, Paper published by School of Social Work, University of Queensland, January 2000. Available at: http://www.wwda.org.au/hate.htm (Accessed on 23 June 2016).

Sherry, M. (2010) Disability Hate Crimes: Does Anyone Really Hate Disabled People?, Surrey, UK: Ashgate.

Sherry, M. (2012) International perspectives on disability hate crime, in Roulstone, A. and Mason-Bish, H. (eds) *Disability, Hate Crime and Violence*, pp. 80–91, London: Routledge.

Sin, C.H. (2005) Seeking informed consent: Reflections on research practice, *Sociology*, 39(2), 277–294.

Sin, C.H. (2012) Making disablist hate crime visible: addressing the challenges of improving reporting, in Roulstone, A. and Mason-Bish, H. (eds) *Disability, Hate Crime and Violence*, pp. 147–165, London: Routledge.

Sin, C.H. (2014a) Using a 'layers of influence' model to understand the interaction of research, policy and practice in relation to disablist hate crime, in Chakraborti, N.A. and Garland, J. (eds) *Responding to Hate Crime: The Case for Connecting Policy and Research*, pp. 99–112, Bristol, UK: Policy Press.

Sin, C.H. (2014b) Why we should bring a 'hate crime' perspective to abuse in care settings, *Community Care,* 28 May. Available at: http://www.communitycare.co.uk/2014/05/28/bring-hate-crime-perspective-abuse-care-settings/ (Accessed on 21 June 2016).

Sin, C.H. (2015) Social care has a role in preventing hate crime – it's not just a criminal justice issue, *Community Care,* 5 February. Available at: http://www.communitycare.co.uk/2015/02/05/social-care-role-preventing-hate-crime-just-criminal-justice-issue/ (Accessed on 21 June 2016).

Sin, C.H. (2016) Commentary on 'I felt I deserved it' – experiences and implications of disability hate crime, *Tizard Learning Disability Review*, 21(2), 89–94.

Sin, C.H. and Fong, J. (2008) 'Do no harm'? Professional regulation and disabled nursing students and professionals in Great Britain, *Journal of Advanced Nursing,* 62(6), 642–652.

Sin, C.H., Hedges, A., Cook, C., Mguni, N., and Comber, N. (2009) *Disabled People's Experiences Of Targeted Violence And Hostility*, London: OPM for EHRC.

Sin, C.H., Hedges, A., Cook, C., Mguni, N., and Comber, N. (2011) Adult protection and effective action in tackling violence and hostility against disabled people: some tensions and challenges, *The Journal of Adult Protection,* 13(2), 63–75.

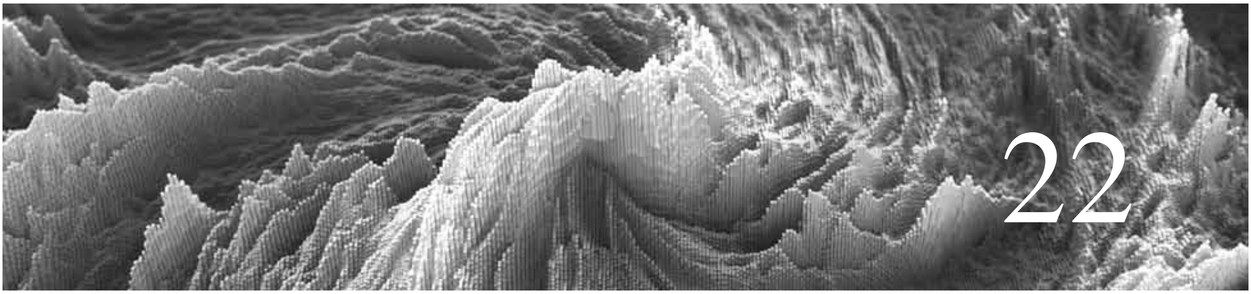
Strengthening Disabled People's User-led Organisations Programme (2012) *Disabled People's User-led Organisations Making a Difference. Disability Hate Crime*, London: Office for Disability Issues. Available at: http://odi.dwp.gov.uk/docs/dpulo/disability-hate-crime-rtf.rtf. (Accessed on 24 June 2016).

Sykes, W., Groom, C., and Desai, P. (2011) *Disability-related Harassment: The Role of Public Bodies. A Qualitative Research Report*, Manchester, UK: Equality and Human Rights Commission.

Truman, C., Mertens, D.M., and Humphries, B. (2000) *Research and Inequality*, London: UCL Press.

Union of the Physically Impaired Against Segregation (UPIAS) (1976) *Fundamental Principles of Disability*, London: UPIAS.

Woodby, L.L., Williams, B.R., Wittich, A.R., and Burgio, K.L. (2011) Expanding the notion of researcher distress: the cumulative effects of coding, *Qualitative Health Research*, 21(6), 830–838.



22

Participatory Action Research with Indigenous Youth and their Communities

Linda Liebenberg, Michele Wood
and Darlene Wall

INTRODUCTION

Recent decades have seen a growing movement to rethink the way we conduct research with Indigenous communities. This is reflected in Fals-Borda's (1995) now seminal request that we rethink, in its entirety, the research process; from theoretical frameworks, through data collection and analysis techniques, to dissemination of findings. He urged for an all-encompassing move away from academic-style colonialism and expertise to a knowledge base that is truly co-created and shared between communities and researchers. This call for a renewed approach to the research process is reflective of both a social justice agenda as well as Indigenous approaches to research.

Reflecting this move is the steady increase in requirements from Indigenous communities to conduct research in ways that honor and respect Indigenous cultures and knowledge (see for example Brunger & Bull, 2011; Castleden et al., 2012), alongside a growing number of Indigenous academic frameworks asserting the legitimacy of Indigenous ways of knowing (Chilisa, 2012; Kovach, 2009; Smith, 1999). Simultaneously we see significant challenges to entrenched understandings of ethical research practice in the increased use of Participatory Action Research (PAR) and engagement of children and young people (CYP) as co-researchers and knowledge mobilizers. Collectively, these various developments are forcing us to rethink much of the taken-for-granted in research ethics. What is also becoming apparent however, is that a one-size-fits-all framework to research, including participatory research, will not suffice and indeed is even challenged as ethical in and of itself (Battiste, 2008; Bull, 2016). Rather than finding ways of fitting Indigenous and PAR approaches into institutional frameworks rooted in so-called Westernized or Euro-American knowledge systems, we should rather ensure that these former approaches frame and drive research (Bull, 2010). This chapter will review proposed approaches to ethical research with Indigenous youth and their communities within a PAR and Indigenous framework drawing on examples from the *Spaces & Places* study.

INDIGENOUS ETHICAL FRAMEWORKS

Most contemporary institutional review boards are embedded in Euro-American culture and are therefore often contradictory to Indigenous worldviews (Blackstock, 2007; Chilisa, 2012; Kovach, 2009; Smith, 2005; Wilson, 2008). Consequently, standardized institutional guidelines do not necessarily ensure that research is aligned with the cultural practices and belief systems of many culturally and socioeconomically disenfranchised groups (Gallagher et al., 2010). Without careful consideration of the enactment of these dominant principles, we may inadvertently engage in research that is counter to the intent of research ethics guidelines (Christians, 2007; Swauger, 2009; Wynn, 2011).

There are significant differences between Euro-American and Indigenous epistemological assumptions (Blackstock, 2007; Smith, 2005), including how we understand the positioning of individuals in relation to the collective; the importance of land and place; and the role of ancestral knowledge, values, and beliefs (Chilisa, 2012; Kovach, 2009; Smith, 2005). Wilson (2008) illuminates the relational foundation of Indigenous methodology, highlighting the way in which self-in-relation-to-wholistic context shapes Indigenous meaning making and interactions. While Western frameworks such as constructivism acknowledge that people make sense of their context and experiences through interaction with others (i.e. co-construction), such frameworks are predominantly driven by notions of individuality rather than notions of the collective. They consequently fail to account for *interdependence* and responsibility within relationships, including research relationships. As Smith (2005: 97) explains, 'For indigenous … communities, research ethics is … about establishing, maintaining, and nurturing reciprocal and respectful relationships, not just among people as individuals but … as collectives, and as members of communities'. Wilson (2008) frames this process as 'relational accountability'. Furthermore, Brunger and Burgess (2005) argue that research ethics board (REB) processes fail to account for the fact that research is ordinarily taking place in complex social environments that are constantly changing and evolving; what Smith (2005: 85) calls 'tricky ground'. Static, linear ethical processes cannot always keep pace with or accommodate these realities and the demands they place on the research process (Brunger et al., 2014).

The move towards culturally aligned Indigenous Ethical Principles (IEPs) that encapsulate relational accountability is reflected in frameworks for Indigenous research. The OCAP™ principles (Schnarch, 2004; Ownership, Control, Access and Possession of Indigenous data in Canada) and Kirkness and Barnhardt's (1991) Four Rs (respect, relevance, reciprocity and responsibility) exemplify this. Drawn together, these two frameworks are informed by *relational accountability*. They simultaneously shape research that is accountable through its relationships, prioritizing the 'betterment' of the community rather than the researcher or participants through multiple means, including capacity development (Brunger & Russell, 2015; Brunger & Wall, 2016; Wilson, 2008). This is important, as IEPs emphasize community capacity development through both research processes and dissemination of findings (Ball & Janyst, 2008; Weber-Pillwax, 2001; Wilson, 2008).

Briefly, OCAP™ principles assert that Indigenous communities (referring to First Nations, Inuit and Métis peoples in Canada) *own* their cultural knowledge, including data, collectively. Within this understanding, stewardship is awarded to an individual or institution that is responsible for the safekeeping of the knowledge, and as such is accountable to the community. Additionally, Indigenous communities have the right to *control* all components of the research, including intellectual knowledge and dissemination products, as components of their heritage. As part of ownership and control, communities should have full *access* to information about themselves and their communities, including their own data. Communities also have the right to determine who else has access to this data (for example secondary data analysis). *Possession* relates to stewardship of data and knowledge – the physical control of data and is the mechanism through which ownership is enacted and maintained.

While the OCAP^{TM} principles reflect the rights of Indigenous peoples and their relationship to their cultural knowledge, the Four Rs provide a guideline to conducting research with Indigenous communities. McCubbin and Moniz (2015), applying the Four Rs' framework to Indigenous resilience research, explain that *respect* is concerned with Indigenous ways of knowing and adapting research methods to be culturally relevant. *Relevance* pertains to both culturally and contextually sensitive understanding of the data, but also to conducting research and producing findings that are relevant to the community itself. *Reciprocity* is focused on bi-directional interactions between researchers and communities, manifested in 'shared understandings of the purpose, legitimacy and process of the research' (p. 219) with mutual benefit. Finally, *responsibility* is related to the alignment of research with the values, beliefs, and practices of the community.

In many ways, PAR echoes the principles of Indigenous research frameworks. As a *guiding* philosophy, PAR promotes research partnerships that are able to challenge social oppression through more nuanced understandings of the conditions that establish and maintain it. This is achieved through the understanding of lived experience as it relates to social concerns, and the establishment of infrastructure to challenge oppressive structures (Bradbury & Reason, 2003).

Chevalier and Buckles (2013) explain the underlying principles of PAR ethics. First, notions of *partnership* (rather than participation), necessitate flexible frameworks of agreement developed collaboratively, rather than a narrow acceptance of the research conveyed through consent. Additionally, agreement is expressed in ways that are contextually congruent, for example through verbal agreement rather than enforced through conventional signatures (Bull, 2010). Second, ethical practice respects *community welfare* as a component of social justice agendas, rather than only the welfare of the individual. Assessments of risk stemming from the research include therefore a consideration of both those directly engaged, and the broader community. Third, ethical practice requires agreement regarding expectations and responsibility of all partners to the project (Brunger & Bull, 2011). Tied to this is the need to be recognized and heard; a consideration that supersedes concerns of privacy and confidentiality. How, and the extent to which, people wish to be heard needs to be respected in the processes of dissemination.

To summarize, both PAR and IEP position respectful relationships at the center of the research process. These respectful relationships call for an understanding of the local socioeconomic and cultural context of the research as well as the positioning of the local context in the macro socioeconomic and cultural setting, with the expectation that such understanding will shape decisions made about ethics protocols. This facilitates a culturally sensitive research focus, approach, and design, accounting for the positioning of community research partners. Just as the relevance of research to communities and capacity development is emphasized in IEP, so are the goals of social justice and empowerment central to PAR. These foci ensure that local concerns are addressed, and moreover that local capacity to address concerns is developed. Finally, the emphasis in PAR on both the inclusion and amplification of voice aligns with the IEP emphasis on community betterment, importantly ensuring that youth voice is respectfully accounted for within the immediate and broader community. Within these discursive and reciprocal relationships, ethical research practice guidelines are negotiated, better accounting for the prevention of harm, and the promotion of respect and justice as understood locally.

A key difference between IEP and PAR with youth should however be noted. In research settings dominated by Euro-American culture, PAR with youth emphasizes the ways in which CYP (often to the exclusion of their community) are included in the research. IEP approaches to research challenge these assumptions, and redirect our attention to the ways in which communities *and* CYP are included.

PAR AND THE INCLUSION OF CHILDREN AND YOUTH IN RESEARCH

Included in the concerns voiced regarding ethics and research with marginalized populations is the focus on CYP specifically (Abebe, 2009; Morrow, 2013; Prout & James, 1997). Here arguments are based on the uniqueness of children's experiences together with their agency and capacity to contribute meaningfully to their communities (Prout, 2005). Consequently, it is argued that research should not be conducted *on* or *about* childhood; but rather *for* and *with* children (Cairns, 2001; Christensen & Prout, 2002; Mayall, 2002; Punch, 2002). Moreover, CYP should be engaged as *participants* in the research process, if not as *researchers* (Cairns, 2001; Kellett et al., 2004). Various authors therefore advocate the use of PAR as means of increasing the ethical nature of our research with young people (Grover, 2004; Powell et al., 2012; Sime, 2008).

The inclusion of CYP in social research raises important ethical questions and challenges, which are shaped in large part by the power imbalance underlying research. Euro-American adult constructs and understandings of childhood and the capacity of CYP to participate in research, ordinarily shape understandings of related risks and/or related benefits of such participation (see for example Kennan & Dolan, 2017). These perceptions inform the ways in which CYP are included in participatory research. The broad spectrum within which CYP are included in research has been outlined by Hart (1992). While this spectrum provides a useful framework for understanding the ways in which CYP are, or are not, included in the research process, authors such as Gallacher and Gallagher (2008) have noted the need to better operationalize what 'participatory research' actually means. We add to this concern, the need for critical reflection when applying the term across cultural settings, and specifically within Indigenous contexts.

Ethical principles promoted in the prevailing discussions within the 'new social studies of childhood' include the importance of relationships with all parties connected to studies (Grover, 2004; Morrow, 2013; Schenk & Williamson, 2005). It is only through understanding the social, cultural, and economic context in which children find themselves, that ethically appropriate actions can be taken (Alderson, 2005; Morrow, 2013; Powell et al., 2012). Furthermore, assessment of ethical concerns, including agreement regarding what participation looks like and who should be included in that participation, should be continuous and revisited throughout the project (Morrow, 2013; Sime, 2008). Again, these principles echo those of PAR and in particular IEP, lending support to our understanding of ethical research approaches to PAR with Indigenous youth and their communities.

SPACES & PLACES: AN EXEMPLAR

Relevance: Responding to Community Needs

A growing body of Indigenous resilience research is demonstrating the importance of relational resources, including relationships to land, in promoting positive psychosocial outcomes (Fleming & Ledogar, 2008; McGuire, 2010). Research exploring how children who experience significant adversity thrive in spite of hardships, is demonstrating that increased cultural engagement by Indigenous youth is linked to improved psychosocial outcomes (Kirmayer et al., 2003; Liebenberg et al., 2015a; Mignone, 2003) and significantly reduced rates of suicide (Caldwell, 2008; Chandler & Lalonde, 2008; Mignone & O'Neil, 2005; Wilson & Rosenberg, 2002). The effects of cultural engagement are particularly important given the high rates of suicide and poor psychosocial outcomes amongst Indigenous youth (Fleming & Ledogar, 2008; Mignone, 2003; Mignone & O'Neil, 2005), stemming from the legacy of cultural genocide (Adelson, 2005; Lalonde, 2003; Loppie Reading & Wien, 2009) and continuing socioeconomic marginalization of Indigenous peoples in Canada (Galabuzi, 2004; Loppie Reading & Wien, 2009; Reading et al., 2007). What we understand less well however is how communities can better facilitate this engagement.

Spaces & Places responds to this gap in understanding, exploring the physical and relational spaces that facilitate a sense of civic engagement and related cultural continuity for youth (aged 12–18) in three Indigenous communities of Atlantic Canada (www.youthspacesandplaces.org), two of which are remote and one of which is rural. Importantly, this PAR project is based on a community service provider-youth-academic partnership, which uses reflective video and photography elicitation methods, engaging youth and their communities in data gathering, analysis and dissemination of findings. The goal of this longitudinal study, with two data gathering points over approximately 12 months, is to explore the contextually embedded processes that bolster cultural engagement and related positive psychosocial outcomes for youth. Such an understanding is critical as mental health supports are extremely limited and strained in rural and remote Indigenous communities of Canada (Boksa et al., 2015; Gaye Hanson & Smylie, 2006; Loppie Reading & Wien, 2009). Services are significantly underfunded (Assembly of First Nations, 2007a; 2007b), a situation which is exacerbated through the largely project-based and time limited approach to service funding (Boksa et al., 2015; Liebenberg & Hutt-MacLeod, 2017), limited access to trained workers, high staff turnover and a preponderance of service provision models that are culturally misaligned (Assembly of First Nations, 2007a; 2007b).

Respect: Partnerships, Ownership and Control

The research partnership undertaking this study emerged from existing relationships between Liebenberg and each of the three communities. Liebenberg as the academic researcher is not Indigenous; she is a white South African immigrant to Canada, now living in the largest urban area of Atlantic Canada. She has a long history of working in contexts where she has crossed boundaries (Giroux, 1992) relating to race, ethnicity, language, culture, age, and working from a position of socioeconomic privilege. This work has consistently been characterized by an awareness of related power and control. Despite years of experience, she continues to recognize that the complexities of working with any community that has experienced pervasive intergenerational trauma and marginalization cannot be fully understood, and that her position in relation to the communities continues to be characterized by boundary challenges and related power imbalances. As such, she works in partnership with communities recognizing the wisdom and experience of community members.

The project was designed collaboratively with the mental health service representatives of the two original partnering communities: Wall, a member of the NunatuKavut Community Council (southern Inuit), and Wood, a beneficiary of the Labrador Inuit

Land Claims Agreement for the Nunatsiavut region of Labrador. This collaboration aligned with the IEP of control. Importantly, the focus of the study emerged from a series of previous research projects, which highlighted the relevance of the research question to youth, their communities, and local service providers. Collaboration regarding the project design included a three-day face-to-face meeting, attended by Wall, Wood, and Liebenberg; one member from each of the two participating communities (one of whom was a youth) who had experience conducting research with local youth; and, a project manager who had extensive experience working in communities.

The meeting shaped the data gathering and dissemination of findings, how best to situate the research within each community, and ensure that youth remained at the center of the process, reflecting the *respect* component of the Four Rs. While youth were not present at this meeting, the IEP ethic of relational accountability and the embeddedness of individuals within their community ensured they were honored through the community representatives that did attend.

During the planning meeting, a memorandum of agreement (MoA) and an intellectual property agreement (IPA) was established with Wall and Wood, as representatives of their communities. These agreements outline ownership, storage and sharing of or *access* to the data as well as guidelines for dissemination of findings. For example, the MoA stipulates where consent forms and raw data would be stored in each community until they could be transported (in person by a member of the research team) back to the host university research office where they would be security-stored electronically. The MoA also states that each community will own their data. Once data collection was complete, full data sets would be returned to each site. Data would also be shared between the project co-applicants (i.e. community partners) on password protected hard drives which would be security-stored at all times under double lock. The IPA included guiding principles promoting the dissemination of findings as well as terms of access to the data that protected participants and their communities. To this end, for example, we agreed that:

> To avoid improper disclosure of Intellectual Property and/or Confidential Information, each party will furnish all other parties with copies of any proposed publication or presentation within a reasonable amount of time.... Each party shall have the right to request that Information be deleted from the materials submitted, or that portions thereof be rewritten so as to protect each party's interests.

Following the planning meeting, funding applications were submitted jointly, with community representatives as co-applicants, again reflecting the IEP of ownership. Funding was located at the host university, with the institution positioned as a central hub supporting the work of the various communities rather than as a central site of academic authority. Similarly, Liebenberg was informally positioned as an extension of community-based research in health administration departments, forming a link between each of the three sites. Within each organization, Wall and Wood as co-applicants to the grant, were positioned as site lead investigators. At two of the sites one person was hired as a local site researcher. At the third site, five existing frontline staff were incorporated into their project as local site researchers, resulting in a total of seven site researchers. Finally, two Master's level students worked in succession as project managers, collaborating with the local site researchers to conduct the fieldwork. Both project managers and site researchers received training in the fieldwork approaches from the project lead.

Responsibility: Negotiating Ethics Approval

Each of the remote communities was represented by their own research approval board, from which research approval was obtained.

Additionally, ethics approval within the province where the communities are located is legislated and governed by the Health Ethics Research Board (of the province). Ethics approval was therefore obtained from both the host academic institution and this provincial board. In the rural community, located in a different province, the review was conducted by a university-based review board – Mi'kmaw Ethics Watch – specifically established to protect the integrity and cultural knowledge of the Mi'kmaw people. The university at which this board is located is separate from the university hosting the research itself. Each of these review boards upholds the OCAP™ principles and function as representatives of the respective communities.

The ethics protocol submitted to the host academic institution was shaped by the principles of these community research review boards and clearly articulated the wishes of participating communities. In line with both community guidelines (for example the Inuit Holistic Lifelong Learning Model: http://katiqsugat.itk.ca/items/show/13), and the research team's MoAs and IPAs, the host university protocol acknowledged that 'The data will be owned by each community it was collected in and dissemination products developed by youth will be owned by the youth themselves'. Permission would be sought from youth and their guardians for the research team to continue with analysis and dissemination following the study. Detailed discussions of data management and storage during and following data collection, as originally determined in the MoA, honored this ownership. Finally, the protocol outlined the role of the lead applicant and the mental health service providers within each community as stewards of the data.

Where our process differed from conventional ethical procedures, we provided detailed descriptions of what would be done and why this approach was preferred. Through the revision process, we were able to engage in a dialogue with the REB, responding to their questions in ways that allowed for a negotiated agreement. For example, in their review of the application, the REB asked 'Why offer the child the opportunity to use their real name or show their face? Why is this necessary?'. In response, we explained that:

> We have chosen this approach … because in previous research we have conducted … youth … have informed us that they feel empowered by giving voice to their opinions and experiences. … they do not want their identities to be concealed with pseudonyms or by having their faces blurred because they want credit for their thoughts and ideas. Furthermore, transformatory, indigenous-based approaches to research require that researchers honor the contributions of participants. As stated in the 2010 ethics guidelines of the Tri-Council 'In First Nations communities, privacy and confidentiality of identifiable personal and community information may be affected by the application of the principles of ownership, control, access and possession […] in some social sciences and humanities research, the significance of information is tied to the identity of the source. In these cases individual attribution, with consent, is appropriate […] Communities partnering in research may wish to be acknowledged (e.g. in the research report) for their contribution to the research effort […] Privacy protections in research are evolving. Respect for, and accommodation of, First Nations, Inuit and Métis priorities on joint ownership of the products of research and maintaining access to data for community use should guide research practices – with appropriate deference to applicable federal, provincial and territorial privacy legislation'.

Respect: Inviting Youth Participants

The seven local site researchers worked with participating mental health service providers in each community to identify and recruit youth participants. Service providers were positioned as gatekeepers to youth (Morrow & Richards, 1996; Powell et al., 2012). Acting as advisors to the study, service providers drew on their understanding of the local contexts and of youth living there (see Liebenberg et al., 2017) to identify potential participants. Site researchers, people who were largely respected and more importantly trusted by parents and youth in the communities, invited identified youth to the study. The knowledge that service providers held of the community and youth, together with the trust youth and their families had of site researchers, meant that the combination of service providers and site researchers provided the best insight into the social positioning of youth, and our ability to engage people who would have something important to say about how community spaces and places impacted youths' sense of belonging.

Once youth indicated an interest in participating, a two-phase consent process was engaged in. In the first phase, consent to participate was obtained from guardians of the youth. Importantly, 'guardians' did not refer to parents or *legal* guardians, but rather the adult(s) who predominantly assumed responsibility for care of the participant. As such, culturally embedded, informal, and extended kinship care arrangements were accounted for and we were able to ensure that youth would not be prevented from participating should they be unable or unwilling to obtain consent from someone who had a Euro-American legal standing as their guardian. Furthermore, the consent guardians provided established the parameters for each youth's participation: First, by consenting, guardians agreed that the youth could personally make decisions regarding sharing of data as well as their anonymity. For example, the consent form stated, 'I understand that the identity of my child need never be known outside of the research team, though anonymity cannot be guaranteed. If my child wishes that his/her face be shown on videos outside the research team, he/she must sign a video release form; otherwise the tapes will be edited to conceal his/her identity' (followed by 'yes, I agree' and 'no, I do not agree' option boxes). Second, guardians indicated aspects of the project that they did or did not want youth participating in. For example, guardians were given the option of allowing youth to participate in dissemination of findings such as traveling out of town to conferences. Once guardian parameters were established, youth could then decide what phases of the study they wanted to participate in and how.

The project was designed to work flexibly with youth, ensuring their participation in data gathering, analysis, and dissemination. Youth could have as much or as little control of the research process as they were comfortable with and could engage in ways that they wanted to and that their own schedules would allow. This engagement and flexibility began with consent. After obtaining consent from guardians, we asked youth themselves for active consent, the second phase of the consent process. As stated in the ethics protocol 'youth participants will also be assured that only they can consent to their participation; even though their parents/guardians may agree to their participation in the study, ultimately it is up to the youth to decide whether they want to take part and to what extent'. Additionally, the protocol reads 'Should a youth decline to participate in phase 2 [i.e. the analysis and mobilization phase] of the research of the project, the youth will have the final say over if and how their data can be used in the youth led analysis and dissemination activities'. And:

> youth are able to portray as much or as little of themselves as they wish. … Guidance provided by local site investigators, site researchers and advisory committees will also ensure safeguards are in place for youth safety in dissemination activities. … Furthermore, once products have been created, individual youth can decide to what extent they wish to participate in the public presentation of these products. In instances where they choose not to participate, the larger team can continue with the dissemination activities.

These points are reflected in the consent form, which states for example, 'You will determine the extent of your participation in these activities', and 'you can portray as much or as little as you want of yourself in these [dissemination] projects'. Giving youth the option to actively consent and reveal their identity as participants was important for several reasons. First, we foregrounded youth agency

(Morrow & Boyden, 2013) and aligned with both PAR principles regarding the inclusion of youth voice and the United Nations Convention of the Rights of the Child (Articles 12 and 13), working to ensure that certain voices and perspectives were not excluded from the process and as such silenced. Furthermore, Indigenous principles of relational accountability between researcher, participant, and community are muted through anonymity (Wilson, 2008), undermining key components of IEP. Similarly, anonymity stands to prevent youth from developing a sense of ownership in PAR over the research through publicly claiming ownership over their data (Bray & Gooskens, 2006).

Additionally, we engaged in ongoing consent with youth. As the research progressed, if youth changed their minds about initial decisions they had made with regards to various aspects of the research, we were able to revisit what they had indicated in the consent form. Where changes did occur, these all related to youth initially not wanting to participate in a particular component of the study and then later choosing to engage. We also asked youth to re-consent before the second year of data gathering and again allowed for ongoing consent throughout the process.

Reciprocity: Encouraging Youth Ownership and Control

Continuing with the spirit of collaboration established during the initial consent process, we ensured that during the fieldwork and dissemination youth could participate in ways that they were comfortable with. For example, rather than being filmed for as much of a day as possible by the research team who were attempting to be as invisible, some youth decided to adapt the research design and took site researchers and the project manager on a ‘guided tour’ of their community. While challenges were encountered in terms of finding availability in youth schedules to conduct fieldwork, being amenable to their priorities and accommodating their availability, contributed to effective collaboration.

Following data gathering, youth participated in a two-day data analysis workshop (Liebenberg et al., 2013a; Liebenberg et al., 2015b; Liebenberg et al., 2015c). Here, youth worked collaboratively with the project manager, site researchers, and Liebenberg to analyse the data. An adapted approach to thematic analysis that integrates youth friendly coding and theme development activities was used. At each site, identified themes have created an analysis framework that supports continued data analysis, ensuring that we accurately reflect youth experiences. These frameworks also extend the relevance of the research and youth/community ownership of the project.

Youth then selected ways in which to share findings with their community. In one community, youth decided at the start of the project to disseminate findings by painting a mural in the community. By contrast, youth in another site struggled to select from ideas presented to them by the site researcher (including posters, a mural, a play, and a video). It was only once this suggestion list was significantly reduced that they were comfortable making a decision, and created posters reflecting themes from the data. Similarly, while in some communities youth had a strong idea of how they wanted final products or outputs to look, in other sites youth preferred working within much greater structure. Here again, the youth who made posters selected photographs they had made as part of the fieldwork and paired images up with ‘theme cards’ produced by the project manager following the data analysis. In another community, youth generated ideas about what they wanted to include in a mural, but allowed the research team (project lead, project manager and site researchers) to produce an initial design that youth could then draw on to paint the actual mural. Interestingly, youth have been less interested in creating, or for some, even reviewing written documents (see also Reich et al., 2017). These experiences underscore questions regarding researcher understanding of what participation means and highlight the need for critical consideration of what respectful collaboration looks like (see also Sanders & Munford, 2017).

Finally, community-based dissemination of findings presented in these outputs was prioritized in the study. Once youth products had been returned to communities, for example through community events, ways of reaching additional knowledge users (such as other service providers and federal agencies) were explored. For example, where community murals had been painted, videos were made that could be shared with broader audiences by youth, other members of the research team, and communities (for all dissemination projects discussed, see http://youthspacesandplaces.org/findings/). Similarly, where youth had created themed posters, multiple approaches were taken to dissemination. Each youth received copies of their own posters (ranging in size from 18x24in to 24x30in depending on image resolution) and community service providers received multiple copies for distribution both within the community and to relevant federal departments. Postcard size versions were printed allowing for even greater dissemination by youth and service providers (for example by attaching them to memos and other communications). Video slide shows were created, again facilitating e-dissemination by youth and community service providers. Finally, a photobook discussing the project at all three research sites, was produced and distributed as a speaker's gift at an international youth resilience conference. Speakers included academic leaders in their respective fields (for example Ann Masten in Resilience) as well as leading advocates for Indigenous youth rights (for example Cindy Blackstock with the First Nations Child & Family Caring Society of Canada).

In addition to youth-driven products, co-authored reports of findings were returned to communities where site researchers worked with local and regional organizations in dissemination. These reports were used as the basis for publications of relevance to communities and their cultural neighbors (see for example Ikeda et al., 2014). Publications are being produced with youth around both the process (see for example Reich et al., 2017) and findings (Liebenberg et al., in progress). Finally, youth have presented the findings in both paper presentations and posters at numerous national and international conferences.

Honoring youth agency, dissemination products produced by youth are owned by the participants. In this regard, youth (all of whom had the permission of their parents/guardians) were able to engage in this process as much or as little as they wanted, and were able to reveal their identity if they chose. Because of this, youth were able to use photographs they had created of themselves in their community as part of dissemination posters, and could participate in the production of dissemination videos.

DISCUSSION

Through a respectful community service provider-youth-academic partnership, we have been able to construct an ethical project framework that has successfully supported youth participation. Drawing on their existing relationships with youth, community-partners were able to ensure the study's relevance to community and that methods used would resonate with youth. Through dialogue, we then attained REB approval of processes informed by IEP and PAR principles. Using IEP and PAR principles we ensured a flexible approach to *Spaces & Places*, providing structure and support as youth required it, ensuring meaningful participation and engagement of all youth in a safe and respectful environment. In some ways, youth moved along a continuum of participation: a collaborative academic-community partnership established an initial framework for the study. As the project unfolded, youth were able to increasingly assume ownership of the process. In some instances this concerned how the data was gathered but pertained mostly to findings and how these were disseminated. Consequently, youth were able to confidently share their knowledge regarding civic engagement and cultural continuity with their communities, larger audiences of national and international service providers, and national policy makers within relevant government departments overseeing resource allocation, using multiple approaches (reports, themed posters, murals and videos, as well as conference presentations). The success of the project in terms of engaging youth is reflected in the suggestion from youth at one site to repeat some of the research components as well as youth engagement in dissemination activities outside of their communities (see for example Liebenberg et al., 2013b). This capacity may very well have been curtailed by more conventional approaches to ethics. Respecting young people's capacity for example to make informed and responsible decisions from the outset regarding their participation, created the foundation for meaningful engagement throughout. Indeed, adhering to dominant norms regarding anonymity would most certainly have prevented this level of engagement. Similarly, accounting for the priorities and capacity of youth, and collaborating with them in ways that were flexible and respected their lived realities resulted in strong and positive working relationships.

Alternatively, this process may seem overly restrictive when viewed purely with a PAR lens (for example youth were not engaged in the initial design of the study framework). When viewed with an IEP lens however, it respected the context and experiences of participants and their communities. The consent process and research design ensured that multiple voices, lived experiences, and perspectives were included in the study. Additionally, youth had the capacity to engage in a meaningfully reflective and analytic process that produced accurate accounts of youth experiences and needs in relation to community supports of cultural continuity. Consequently, youth voice was amplified through dissemination products that spoke with authority to their intended audiences. Put simply, what youth were saying and the ways in which they were saying this, was taken seriously. In this way, the project not only made a space for youth voice, but also helped ensure that this voice was heard. These experiences respond to Gallacher and Gallagher's (2008) interrogation of what 'participatory research' actively means, and suggests cautions around overly prescriptive and/or narrow definitions of participation.

As a core component of this project arc, and again reflecting both IEP and PAR principles, we integrated a process of continuous consent from youth. As youth became more familiar with the project process they could adapt (i.e. increase or decrease) their levels of participation accordingly. Interestingly, all youth who stayed in their communities for the duration of the project continued their participation. Perhaps more interesting was the way in which some youth who had originally opted out of revealing their identity through the dissemination process, changed their minds and later opted in.

The collaborative structure of the project also meant that the skillset of the local site researchers (all of whom had previous research experience) was expanded to include PAR approaches to qualitative image-based elicitation methods and workshop facilitation. Similarly, youth were exposed to research processes, as well as civic engagement and awareness raising. Service providers and communities have greater insight into supporting the cultural continuity of youth as components of mental health outcomes. In this way, community capacity has been enhanced.

CONCLUSION

If we consider ethical behavior to be 'the sum of human aspiration or honor in interpersonal life, for respect in face-to-face encounters, and fairness in the collective treatment of people' (Stake & Rizvi, 2008: 526) then the need to situate our work within the specific cultural and contextual frameworks in which our research is taking place becomes apparent, as does the need for flexibility in our approaches (Kennan & Dolan, 2017). In this spirit, using dialogue to establish what ethical research practice looks like would better ensure truly ethical research. However, when our institutional approach is driven by a biomedical model framed in a dominant and one-size-fits-all model, we lose these opportunities for discussion (Bray & Gooskens, 2006; Blee & Currier, 2011; Swauger, 2009; Wynn, 2011).

Perhaps through the efforts of Indigenous and other marginalized groups to 'disrupt the "history of exploitation" and develop methodologies … that privilege indigenous knowledges, voices, [and] experiences' (Smith, 2005: 87, citing Rigney, 1999), researchers and the institutions within which they are embedded, have an opportunity to similarly disrupt entrenched research structures and approaches. In doing so, we can join communities on the collective 'tricky ground' (Smith, 2005) of change, growth, and transition, to establish something more relational, respectful, reciprocal, and indeed, relevant (Kirkness & Barnhardt, 1991), honoring Fals-Borda's (1995) insightful request.

REFERENCES

Abebe, T. (2009). Multiple methods, complex dilemmas: Negotiating socio-ethical spaces in participatory research with disadvantaged children. *Children's Geographies*, *7*(4), 451–465. doi: 10.1080/14733280903234519

Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health*, *96*(Supplement 2), S45–S61.

Alderson, P. (2005). Designing ethical research with children. In A. Farrell (Ed.), *Ethical Research with Children* (pp. 27–36). Berkshire, UK: Open University Press.

Assembly of First Nations (2007a). *Leadership Action Plan on First Nations Child Welfare*. Ottawa, ON: Assembly of First Nations.

Assembly of First Nations (2007b). *Reclaiming Our Nationhood; Strengthening Our Heritage: Report to the Royal Commission on Aboriginal Peoples*. Ottawa, ON: Assembly of First Nations.

Ball, J. and Janyst, P. (2008). Enacting research ethics in partnerships with Indigenous communities in Canada: 'Do it in a good way'. *Journal of Empirical Research on Human Research Ethics*, *3*(2), 33–51. doi: 10.1525/jer.2008.3.2.33

Battiste, M. (2008). Research ethics for protecting indigenous knowledge and heritage: Institutional and researcher responsibilities. In N.K. Denzin, Y.S. Lincoln, and L.T. Smith (Eds.), *Handbook of Critical and Indigenous Methodologies* (pp. 497–509). Thousand Oaks, CA: Sage.

Blackstock, C. (2007). The breath of life versus the embodiment of life: Indigenous knowledge and western social work. *World Indigenous Nations Higher Education Consortium Journal*, *4*(1), 67–79.

Blee, K.M. and Currier, A. (2011). Ethics beyond the IRB: An introductory essay. *Qualitative Sociology*, *34*(3), 401–413. doi: 10.1007/s11133-011-9195-z

Boksa, P., Joober, R., and Kirmayer, L. (2015). Mental wellness in Canada's Aboriginal communities: Striving toward reconciliation. *Journal of Psychiatry and Neuroscience*, *40*(6), 363–365. doi: 10.1503/jpn.150309

Bradbury, H. and Reason, P. (2003). Action research: An opportunity for revitalising research propose and practices. *Qualitative Social Work*, *2*(2), 155–175. doi: 10.1177/1473325003002002003

Bray, R. and Gooskens, I. (2006). Ethics and the everyday: Reconsidering approaches to research involving children and young people. *Anthropology Southern Africa*, *29*(1–2), 45–55.

Brunger, F. and Bull, J. (2011). Whose agenda is it? Regulating health research ethics in Labrador. *Études/Inuit/Studies*, *35*(1–2), 127–142. doi: 10.7202/1012838ar

Brunger, F. and Burgess, M. (2005). A cultural understanding of research ethics governance. *Health Law Review*, *13*(2–3), 69–74.

Brunger, F. and Russell, T. (2015). Risk and Representation in Research Ethics: The NunatuKavut experience. *Journal of Empirical Research on Human Research Ethics*, *10*(4), 368–379. doi: 10.1177/1556264615599687

Brunger, F., Schiff, R., Bull, J., and Morton-Ninomiya, M. (2014). Animating the Concept of Ethical Space: The Labrador Aboriginal Health Research Committee Ethics Workshop. *International Journal of Indigenous Health*, *10*(1), 3–15.

Brunger, F. and Wall, D. (2016). 'What do they really mean by partnerships?' Questioning the unquestionable good in ethics guidelines promoting community engagement in Indigenous health research. *Qualitative Health Research*, *26*(13), 1862–1877. doi: 10.1177/1049732316649158

Bull, J. (2016). A Two-eyed seeing approach to research ethics review: An Indigenous perspective. In W.C. Van den Hoonaard and A. Hamilton (Eds.), *The Ethics Rupture: Exploring Alternatives to Formal Research Ethics Review* (pp. 167–188). Toronto, ON: University of Toronto Press.

Bull, J.R. (2010). Research with Aboriginal Peoples: Authentic Relationships as a Precursor to Ethical Research. *Journal of Empirical Research on Human Research Ethics*, *5*(4), 13–22. doi: 10.1525/jer.2010.5.4.13

Cairns, L. (2001). Investing in children: Learning how to promote the rights of all children. *Children & Society*, *15*(5), 347–360. doi: 10.1002/CHI.665

Caldwell, D. (2008). The suicide prevention continuum. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, *6*(2), 145–153.

Castleden, H., Sloan-Morgan, V., and Lamb, C. (2012). 'I spent the first year drinking tea': Exploring Canadian university researchers' perspectives on community-based participatory research involving Indigenous peoples. *Canadian Geographer*, *56*(2), 160–179. doi: 10.1111/j.1541-0064.2012.00432.x

Chandler, M. and Lalonde, C. (2008). Cultural continuity as a moderator of suicide risk among Canada's First Nations. In L.J. Kirmayer and G. Valaskakis (Eds.), *Healing Traditions: The Mental Health of Aboriginal Peoples in Canada* (pp. 221–248). Vancouver, BC: University of British Columbia Press.

Chevalier, J.M. and Buckles, D.J. (2013). *Participatory Action Research: Theory and Methods for Engaged Enquiry*. New York: Routledge.

Chilisa, B. (2012). *Indigenous Research Methodologies*. Thousand Oaks, CA: Sage.

Christensen, P. and Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood*, *9*(4), 477–497. doi: 10.1177/0907568202009004007

Christians, C. (2007). Cultural continuity as an ethical imperative. *Qualitative Inquiry*, *13*(1), 437–444. doi: 10.1177/1077800406297664

Fals-Borda, O. (1995). *Research for Social Justice: Some North-South Convergences*, Plenary Address at the Southern Sociological Society Meeting, Atlanta, April 8.

Fleming, J. and Ledogar, R.J. (2008). Resilience, an evolving concept: A review of the literature relevant to Aboriginal research. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, *6*(2), 7–23.

Galabuzi, G.-E. (2004). Social exclusion. In D. Raphael (Ed.), *Social Determinants of Health: Canadian Perspectives* (pp. 235–251). Toronto, ON: Canadian Scholars' Press.

Gallacher, L.-A. and Gallagher, M. (2008). Methodological immaturity in childhood research? Thinking through 'participatory methods'. *Childhood*, *15*(4), 499–516.

Gallagher, M., Haywood, S.L., Jones, M.W., and Milne, S. (2010). Negotiating informed consent with children in school-based research: A critical review. *Children & Society*, *24*(6), 471–482. doi: 10.1111/j.1099-0860.2009.00240.x

Gaye Hanson, P. and Smylie, J. (2006). *Knowledge Translation for Indigenous Communities: Policy Making Toolkit*. Regina, SK: Indigenous KT Summit Steering Committee.

Giroux, H. A. (1992). *Border Crossings: Cultural Workers and the Politics of Education*. New York: Routledge.

Grover, S. (2004). Why won't they listen to us? On giving power and voice to children participating in social research. *Childhood*, *11*(1), 81–93. doi: 10.1177/0907568204040186

Hart, R. (1992). *Children's Participation: From Tokenism to Citizenship*. Florence: UNICEF International Child Development Centre.

Ikeda, J., Liebenberg, L., and Wood, M. (2014). Spaces and Places. *Northern Public Affairs (2), Special Issue: Revitalizing education in Inuit Nunangat*, 85.

Kellett, M., Forrest, R., Dent, N., and Ward, S. (2004). 'Just teach us the skills please, we'll do the rest': Empowering ten-year-olds as researchers. *Children & Society*, *18*(5), 329–343. doi: 10.1002/CHI.807

Kennan, D. and Dolan, P. (2017). Justifying the involvement of children and young people in social research: Assessing harm and benefit. *Irish Journal of Sociology*. doi: https://doi.org/10.1177/0791603517711860

Kirkness, V.J. and Barnhardt, R. (1991). First Nations and higher education: The four R's – Respect, relevance, reciprocity, responsibility. *Journal of American Indian Education*, *30*(3), 1–15.

Kirmayer, L.J., Simpson, C., and Cargo, M. (2003). Healing traditions: Culture, community and mental health promotion with Canadian Aboriginal peoples. *Australasian Psychiatry*, *11*(S1), S15–S23.

Kovach, M. (2009). *Indigenous Methodologies: Characteristics, Conversations, and Contexts*. Toronto, ON: University of Toronto Press.

Lalonde, C.E. (2003). Counting the costs of failures of personal and cultural continuity. *Human Development*, *46*(2–3), 137–144.

Liebenberg, L., Ikeda, J., Penny, D., and Wall, D. (in progress). Understanding community, culture and recreation as resilience resources for Indigenous youth. In L. Moran, K. Reilly, and B. Brady (Eds.), *Narrating Childhoods across Contexts: Knowledge, Environment, and Relationships*. Basingstoke, UK: Palgrave.

Liebenberg, L. and Hutt-MacLeod, D. (2017). Aboriginal community development approaches in response to neoliberal policy: The example of Eskasoni Mental Health Services. In P. Dolan and N. Frost (Eds.), *The Routledge Handbook of Global Child Welfare* (pp. 47–58). London: Routledge.

Liebenberg, L., Ikeda, J., Penney, D., Wall, D., and Participants of the *Spaces & Places* project. (2013a). Spaces & Places*: Port Hope Simpson Mural Recap* [video file]. Retrieved from https://www.youtube.com/watch?v=_79rivJIGQw

Liebenberg, L., Ikeda, J., Penney, D., Wall, D., and Participants of the *Spaces & Places* project. (2013b). Spaces & Places*: Youth Help Share the Research at the CYC Conference* [video file]. Retrieved from https://www.youtube.com/watch?v=bKRszmKyqE0

Liebenberg, L., Ikeda, J., and Wood, M. (2015a). 'It's just part of my culture': Understanding language and land in the resilience processes of Aboriginal youth. In L. Theron, L. Liebenberg, and M. Ungar (Eds.), *Youth Resilience and Culture: Commonalities and Complexities* (pp. 105–116). New York: Springer.

Liebenberg, L., Jamal, A., and Ikeda, J. (2015b). *Analysing Data with Youth: A Guide to Conducting Thematic Analysis*. Retrieved from: http://youthspacesandplaces.org/wp-content/uploads/2015/09/Spaces-and-Places-Data-Analysis-Manual.pdf

Liebenberg, L., Jamal, A., Reich, J., Mott, B., and Participants of the *Spaces & Places* project. (2015c). *Participatory Data Analysis with Youth: Lessons from Spaces and Places* [video file]. Retrieved from https://www.youtube.com/watch?v=K27jwK2_OIQ

Liebenberg, L., Sylliboy, A., Davis-Ward, D., and Vincent, A. (2017). Meaningful engagement of Indigenous youth in PAR: The role of community partnerships. *International Journal of Qualitative Methods*. *16*, 1–16. doi: 10.1177/1609406917704095

Loppie Reading, C. and Wien, F. (2009). *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*. Prince George, BC: National Collaborating Centre for Aboriginal Health.

Mayall, B. (2002). *Towards a Sociology for Childhood: Thinking from Children's Lives*. Buckingham, UK: Open University Press.

McCubbin, L.D. and Moniz, J. (2015). Ethical principles in resilience research: Respect, relevance, reciprocity and responsibility. In L. Theron, L. Liebenberg, and M. Ungar (Eds.), *Youth Resilience and Culture – Commonalities and Complexities* (pp. 217–229). New York: Springer.

McGuire, P.D. (2010). Exploring resilience and indigenous ways of knowing. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, *8*(2), 117–131.

Mignone, J. (2003). *Measuring Social Capital: A Guide for First Nations Communities*. Ottawa, ON: Canadian Institute for Health Information.

Mignone, J. and O'Neil, J. (2005). Social capital and youth suicide risk factors in First Nations communities. *Canadian Journal of Public Health*, *96*(1), S51–S54.

Morrow, V. (2013). Practical ethics in social research with children and families in young lives: A longitudinal study of childhood poverty in Ethiopia, Andhra Pradesh (India), Peru and Vietnam. *Methodological Innovations* Online, *8*(2), 21–35. doi: 10.4256/mio.2013.011

Morrow, V. and Boyden, J. (2013). Ethics of researching children's well-being. In A. Ben-Arieh, F. Casas, I. Frønes, and J.E. Korbin (Eds.), *Handbook of Child Well-Being* (pp. 2895–2981). Amsterdam: Springer.

Morrow, V. and Richards, M. (1996). The ethics of social research with children: An overview. *Children & Society*, *10*(2), 90–105. doi: 10.1111/j.1099-0860.1996.tb00461.x

Powell, M., Fitzgerald, R., Taylor, N., and Graham, A. (2012). International Literature Review: *Ethical Issues in Undertaking Research with Children and Young People*. Childwatch International Research Network. Retrieved from: http://epubs.scu.edu.au/cgi/viewcontent.cgi?article=1041&context=ccyp_pubs

Prout, A. (2005). *The Future of Childhood*. London: Routledge Falmer.

Prout, A. and & James, A. (1997). A new paradigm for the sociology and childhood? Provenance, promise and problems. In A. James and A. Prout (Eds.), *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* (pp. 7–34). London: Routledge Falmer.

Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood*, *9*(3), 321–341. doi: 10.1177/0907568202009003005

Reading, J.L., Kmetic, A., and Gideon, V. (2007). *First Nations Wholistic Policy And Planning Model.* Assembly of First Nations: Discussion Paper for the World Health Organization Commission on Social Determinants of Health. Ottawa, ON: Assembly of First Nations.

Reich, J., Liebenberg, J., Denny, M., and Youth Participates from the *Spaces & Places* Study (2017). In this together: Relational accountability and meaningful research and dissemination with youth. *International Journal of Qualitative Methods*, *16*, 1–12. doi: 10.1177/1609406917717345

Rigney, L.-I. (1999). Internationalization of an indigenous anticolonial cultural critique of research methodologies: a guide to indigenist research methodology and its principles. *Wicazo Sa Review: Journal of Native American Studies*, *14*(2), 109–121.

Sanders, J. and Munford, R. (2017). Hidden in Plain View: Finding and Enhancing the Participation of Marginalized Young People in Research. *International Journal of Qualitative Methods*, *16*(1), 1–12. doi: 10.1177/1609406917704765

Schenk, K. and Williamson, J. (2005). *Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources.* Washington, DC: Population Council.

Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, *1*(1), 80–95.

Sime, D. (2008). Ethical and methodological issues in engaging young people living in poverty with participatory research methods. *Children's Geographies*, *6*(1), 63–78. doi: 10.1080/14733280701791926

Smith, L.T. (1999). *Decolonising Methodologies: Research and Indigenous Peoples*. London: Zed Books.

Smith, L.T. (2005). On tricky ground: Researching the native in the age of uncertainty. In N.K. Denzin and Y.S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (3rd Edn, pp. 85–107). Thousand Oaks, CA: Sage.

Stake, R. and Rizvi, F. (2008). Research ethics in transnational spaces. In D.M. Mertens and P.E. Ginsberg (Eds.), *The Handbook of Social Research Ethics* (pp. 521–536). Thousand Oaks, CA: Sage.

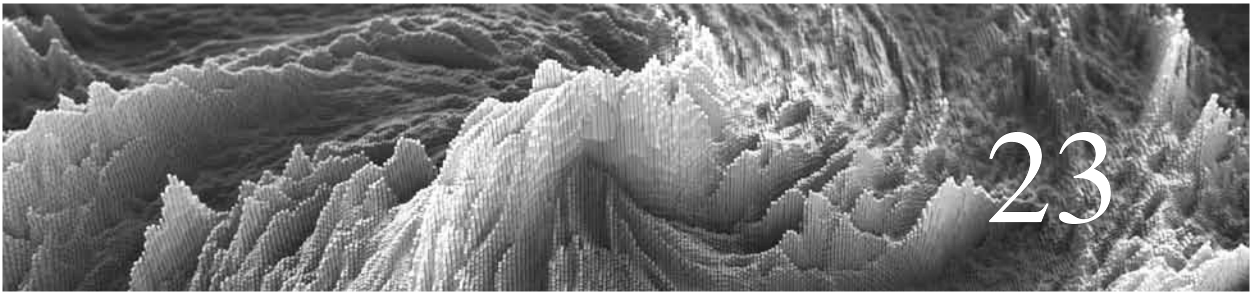
Swauger, M. (2009). No kids allowed!!! How IRB ethics undermine qualitative researchers from achieving socially responsible ethical standards. *Race, Gender, & Class*, *16*(1–2), 63–81.

Weber-Pillwax, C. (2001). What is Indigenous research? *Canadian Journal of Native Education*, *25*(2), 166–174.

Wilson, K. and Rosenberg, M.W. (2002). Exploring the determinants of health for First Nations peoples in Canada: Can existing frameworks accommodate traditional activities? *Social Sciences and Medicine*, *55*(11), 2017–2031.

Wilson, S. (2008). *Research Is Ceremony: Indigenous Research Methods*. Black Point, NS: Fernwood Publishing.

Wynn, L. (2011). Ethnographers' experience of institutional ethics oversight: Results from a quantitative and qualitative survey. *Journal of Policy History*, *23*(1), 94–114. doi: 10.1017/S0898030610000333



23

Role Conflict and Questions of Rigour: Working with Community Researchers in Sexual Health

Julie Mooney-Somers and Anna Olsen

PARTICIPATORY RESEARCH: ‘NOTHING ABOUT US, WITHOUT US’

This chapter draws on our experiences as university researchers using participatory research (PR) to work with community researchers in the field of sexual health. PR methodologies (action research, experience-based co-design, participatory action research and community-based participatory action research) involve ‘a collaborative approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process’ (Israel, 1998: 177). PR challenges researchers to share influence and control over the research agenda, research questions and design, research processes, data collection, interpretation, dissemination and translation. It focuses on community priorities, community knowledge and pursuing knowledge oriented to action (Campbell & Vanderhoven, 2016; Durham Community Research Team, 2011). Instead of seeing ‘experts’ (e.g. university researchers) as the only legitimate source of knowledge, PR recognises and values the knowledge of ‘ordinary’ people (members of affected communities). While the technical knowledge of researchers is valuable, it is not the only legitimate way of knowing about the world (Brydon-Miller, 2003).

Participatory research is popular in research with marginalised communities or communities affected by stigmatised health conditions. For example, in terms of Indigenous communities, PR offers the promise of addressing the ‘colonising-effects’ (Baum et al., 2006) of classical research *on* Indigenous peoples and the potential to avoid the misrepresentation of ‘Indigenous societies, culture and persons by non-Indigenous academics and professionals’ (2006: 855). Directly involving the people affected by the research topic in research was once seen as a radical move, but PR has become increasingly mainstreamed (Guta et al., 2013). This is unsurprising given arguments that PR enables ‘greater opportunities to explore and test knowledge in the context where the application is required and where implementation will take place' (Campbell & Vanderhoven, 2016: 12). That is, prioritising community members' knowledge increases the likelihood of any policy or intervention outcomes having beneficial outcomes for the affected community (Viswanathan et al., 2004).

Equitable involvement and meaningful engagement of community members demands the establishment of new ways of working together, building trusting relationships, developing methods for shared decision making and thoughtful consideration of research methods. It demands methods that are 'useful and useable to all of those participating in the process' (Brydon-Miller, 2003: 190). Qualitative and arts-based methods are popular, as their narrative and creative aspects often resonate with the knowledge making and sharing practices already employed by many cultures. For many projects, PR also means engaging people who are members of the community affected by the topic under investigation as researchers (community researchers, co-researchers, peer researchers) (Guta et al., 2013).

Participatory research can address a number of ethical issues troubling modern research including the dis-empowerment of participants and communities, researchers stigmatising communities with thoughtless publication of sensitive findings, and communities providing access and resources to research but receiving no benefit. Sensitivity to rights, desires and vulnerabilities of partners and participants are often claimed to be implicit in PR, and PR can be unproblematically presented as a 'good thing'. However, PR is not inherently ethical (Flicker et al., 2007). In challenging research norms and disturbing traditional power dynamics and lines of accountability, PR is also messy and unpredictable. New (and old) ethical issues can and do emerge.

Research ethics review committees fulfil a central role in the protection and safety of all research participants from abuse, exploitation and manipulation. The common processes of ethics approval encourage researchers to develop the skills to respond ethically, be more aware of ethical principles in the field and preconceive of ways suggestion to respond to real-world research. However, there has been much criticism of procedural ethics by non-positivist, non-medical researchers who feel restricted and harassed by various institutional research ethics review committees. It is commonly argued in the literature (and the halls of academic institutions) that the increased bureaucratisation of research governance is 'paternalistic and unfit' for non-positivist study designs (Allbutt & Masters, 2010: 210).

We agree that ethics review processes only defined within the medical tradition are not always well suited to the broad church of qualitative research approaches and note the unreasonable hurdles some ethics review committees put in front of PR and other qualitative approaches. We also note the tensions between standard ethics principles and principles of participation for those conducting PR. In creating opportunities for a more communal ethical approach, PR researchers are required to meet principles of participation as well as more traditional ethical research principles. PR demands shared control, emerging and responsive design, and inclusion of local needs and priorities and, as a consequence, current procedural ethics processes can pose significant problems. For example, ethics review committees commonly require detailed research plans prior to any engagement with communities. However, applying for ethics approval before a community is engaged can be considered a 'breach of trust' by the community (DiStefano et al., 2013); co-design is a core intent of PR.

Flicker et al. (2007) argue that ethics review committees have been slow to adapt to PR methodologies and describe some of the common tensions between PR and procedural ethics:

- Standard ethics principles are primarily focused on addressing risk to individuals and not to communities.
- What constitutes 'risk' to an outsider may be part of everyday experience in a community.

- As a methodology focused on process, it can be difficult to address upfront all steps in the PR process and details of all expected methods, tools, recruitment activities and outcomes.
- Standard ethics principles rely on the notion of academic researchers as 'experts' and participants as 'subjects'.
- PR generally relies on an advisory group and/or community research partners who are not always 'representative' of an entire community; this process can inadvertently cause conflict between community members.
- Confidentiality is not always possible when it is known who is involved in the project.
- Handling, storage and ownership of the data will often occur in the community (rather than the academic institution).
- Payment issues arise when some community members are employed or compensated for their time, while others are expected to volunteer as participants.
- Concepts of bias, objectivity and staying true to the data are complicated by relationships and can cloud the process of analysis and dissemination.

Furthermore, we note that the ethical implications of community researchers have largely been ignored by research ethics scholarship in general and by ethical review processes specifically (Flicker et al., 2007). While ethics review committees ask researchers to address risks for participants, and sometimes for the research team, they rarely (in our experience) ask about risks to community researchers. Community researchers are neither just participants nor simply researchers; their specific roles in research projects are rarely made explicit in procedural ethics review. Their invisibility means that the unique ethical issues they face as researchers *and* as members of the 'affected population' (as cultural mediators and collaborators) are not recognised and addressed in procedural ethics. We will discuss the specific issue of community researchers again later in this chapter.

It is clear that there is a need for the processes of ethics review to better adapt to participatory research and community researchers. Yet, it is also the case that procedural ethics requires researchers to pre-empt ethical issues. The iterative and fluid nature of PR means that the complications and dilemmas of a particular research project often only emerge in the field (Walls et al., 2010). Many ethical issues in PR are what Guillemin and Gillam (2004) call 'ethically important moments'. These are ethical dilemmas that do not fit the neat guidelines, with their medical framing, articulated in formal procedural ethics. Unlike positivist and linear procedural ethics where the researcher has plenty of time to consider future scenarios and develop ethical responses, ethically important moments require the researcher to react immediately; the PR researcher must decide how to respond ethically to the participant and the broader community as well as within their collaborative team. This means invoking the research team's values as well as the ethical framework articulated in the institutional guidelines governing the research.

The 'messiness' of PR involving community researchers provokes questions about modern ethical practice in research including the blurred roles of 'insiders' and 'outsiders', and empirical rigour. While contemporary procedural ethical guidelines deal with these complex issues in part, they are often found wanting when put into practice in the field. This is particularly the case when dealing with sensitive topics such as health and sexuality, topics that already raise poignant ethical and moral dilemmas during fieldwork (Dickson-Swift et al., 2007; Lazarus, 2013; McCosker et al., 2001; Seal et al., 2000; Zago & Holmes, 2015).

In this chapter we will explore the specific ethical issues faced by PR with community researchers by highlighting two key issues: blurred roles of 'insiders' and 'outsiders', and challenges to rigour. We use several case studies here – taken from our work around sexual health (with details significantly changed to ensure the anonymity of the communities and projects involved) or developed for research training in order to begin to address some of the wonders and hazards of ethical practice in PR. The case studies can be used to promote scenario-based training of community researchers.

ROLE CONFLICT: INSIDERS AND OUTSIDERS

It is not uncommon for both university and community researchers to hold multiple roles as researchers, clinicians/practitioners, advocates and/or community members. University researchers often have prior relationships with community members and collaborators which, in many ways, strengthen the project by saving time in setting up agreements, helping to engage community members and generally supporting the development of more inclusive research. Yet, team members can also experience particularly complex ethical tensions when they have multiple roles (de Laine, 2000).

Researcher-practitioners are common in PR dealing with health. Many of the issues facing researcher-practitioners can be anticipated and are dealt with in traditional ethics guidelines. For example, safeguards around practitioners directly recruiting clients and health practitioners clearly defining their clinical responsibilities when engaged in research. Still, these issues can be particularly challenging in relation to differing legal and regulatory approaches to confidentiality (Marshall et al., 2012). Practitioner-researchers need to be aware of professional and institutional guidelines that may affect their participation in research and their obligations to disclose personal information revealed by a participant. Practitioner-researchers in medicine, nursing, education, social work and psychology must abide by mandatory reporting laws (for example, being required to report risk of harm to a child).

The tensions produced by community researchers' multiple roles are less visible in the ethics review process because the specific risks and vulnerabilities related to their involvement are rarely formally addressed, in part because these processes are focused on the institution's research governance (Iphofen, 2011). Nor does the ethics review process easily provide room for a PR project engaging with a community's cultural norms and expectations around confidentiality, protection of vulnerable community members and how 'dangerous' information should be handled.

Case One: Confidentiality

A collaborative project was established between university researchers and a government health service to evaluate young people's sexual health service needs. Several young people from one urban community were trained in ethnographic methods. One of these young community researchers (Rob) is hanging out at the local shopping centre with a group of young men. Rob gets into a conversation with James about a friend's experience receiving treatment for a sexually transmitted infection (STI) at the local community health service. James says the health worker who treated his friend was great and told him how to protect himself against STIs in the future. When James mentions the friend's name, Rob is pretty certain he knows who James is referring to – the young man currently involved with his sister.

Does Rob have any professional or ethical obligations in this situation? This is a superficially straightforward case. Rob is there as a researcher and he is having the conversation for the purposes of a research project (regardless of whether it is a formal interview or an informal conversation with an informant). He has clear obligations to maintain the confidentiality of his informant (and anyone whose private information is implicated in the account). The institutional ethics committee overseeing the research would have asked how the researchers would protect participants' information and the researchers would likely have stated they would keep it strictly confidential. A Participant Information Sheet would likely have made a similar promise to the participants. There is no hint of any legal reason why Rob should disclose what he has heard to anyone outside the research team.

The principles of confidentiality are integral to procedural ethics and are based on the concept of individuals' rights to privacy. Ethics committees are especially concerned by issues of confidentiality when sensitive or stigmatising personal data, such as STI status, are sought overtly or could be uncovered in the process of the project. Yet, upholding this right is far from straightforward in any research (Wiles et al., 2008).

When we discuss this case in training sessions with community researchers (Julie also uses this case in postgraduate teaching about qualitative research ethics), a more complex situation emerges. Community researchers and students imagining themselves to be researching their own community raise the interests of their 'sister'. The case provokes passionate debate about whether James's friend had disclosed his STI infection to her so that she could also get checked and treated. Many feel their 'sister' has a right to know that her partner has potentially been unfaithful. Despite knowing that, as researchers, the promise of confidentiality to research participants is explicit, they canvas what they could do to get their 'sister' to have an STI check. In moderating the discussion, we talk about what confidentiality means in research context and reiterate that anyone involved in the project is obliged not to disclose any of the information collected in an identifying way. We also challenge the assumptions students have made in responding to the scenario: perhaps their 'sister' already knows; perhaps their 'sister' was the source of the infection; perhaps it was the 'sister' who 'cheated'; perhaps the story is about someone else; perhaps the participant was telling his own story under the guise of 'a friend'. However, we also hear the struggle to do the right thing by family and community. We suggest an alternative ethical approach – educate and enable positive health behaviours by supplying family, friends and community with information about STIs, give them condoms, encourage them to be tested regularly and have explicit discussions with their sexual partners about preventing STI transmission.

When working on any PR project involving community researchers we provide research ethics training. We also use case studies that are salient to the research topic and highlight ethical responsibilities and tensions for people in different roles. The above scenario is especially potent for exposing the different loyalties made salient in research involving community researchers: loyalties to community, to family, to friends as well as to research participants and research teams. Training is integral to the PR process and success of the project, we use it to seek a consensus about how we, as a group of people motivated to improve the lives of a community, will act in each situation. These discussions reference the framework provided by the *National Statement on Ethical Conduct in Human Research* (National Health and Medical Research Council, 2007, revised 2015). An example of this framing can be seen in one of our training manuals where we highlight the four values underpinning research ethics (respect, justice, beneficence, and research merit and integrity) and define important concepts such as consent and confidentiality (Mooney-Somers et al., 2007). But such conversations must also make space to talk about the community's cultural norms and expectations around confidentiality and looking after family and community – and potential tensions between them. Following the ethos of PR, these discussions provide education for the university researchers; community researchers provide context and interpret situations for the university research team. These interactions create mutual understanding, empathy for one another, and ongoing learning for all team members. Such a 'culturally anchored approach to participatory research' (Mohatt et al., 2004) means not just shared responsibility for research questions, but a project design and process that reflects the values and priorities of the affected community. It also means shared responsibility for what constitutes ethical research practice and recognition that ethics is always culturally grounded.

Practising PR can be challenging. There can be a significant emotional toll for community researchers who are researching the lives and experiences of their family members, friends, colleagues and communities. Community researchers can be left feeling helpless and hopeless that they cannot directly help community members (Simon & Mosavel, 2010)[1]. The burden of living with and not sharing (keeping confidential) information obtained 'in the field' can produce fraught situations. Unlike university researchers who often fly in from distant urban centres, 'the field' is of course a community researcher's usual social world, one in which they have a history and a future. The burden can persist long after the research is completed and the university researchers have left. It is vital to be upfront about these issues early on through training sessions. The following real-life case emerged in one of our projects and is an example of how complex data collection can be for community researchers.

Case Two: Unexpected Disclosures

A university research team is conducting a PR project with a local health service about rural young people's sexual health. The university researcher (Carol) is visiting the community, far from her home institution and the ethics committee that approved the project. She has worked with the local health service to train several young members of the community and health workers (community researchers) to conduct individual interviews. One young community researcher (Angela) is conducting an interview when a 20-year-old participant discloses that she is having a sexual relationship with her uncle.

How should Angela respond? Angela's first ethical obligation is to the participant. Rather than guess at what the participant wants or needs, Angela should pause the interview and ask what she'd like to do next. The participant is free to continue the interview now or at another time, or decide to abandon it all together (and ask for the recording to be retained or deleted). The participant may be upset about her disclosure; she may have meant to make it, or made it accidentally; she may feel embarrassed. Or the participant may not be concerned about the incident she has just described. Angela may wonder why the participant disclosed – was she looking for Angela to take some action, or to help her take action? Angela should respect the participant's autonomy and follow her lead, continuing the interview or not, providing referrals to support services or not. If the interview does continue then Angela should check in at the end: is the participant feeling OK, does she need referrals for counselling, legal or health support service?

'Sensitive' disclosures like the one above are not unique to PR as big ethical moments like this can occur in any research project. For PR, the case raises three important questions about the setup of the PR projects and implications for ethical practice:

First, the need to discuss in every research project how participant and researcher safety is protected by ethical practice. In the real-life case above, Angela stopped the interview, and clarified if the sex was consensual (the mention of an uncle may have triggered her concern about consent; she was not aware that in many jurisdictions incest is a criminal activity and consent can be immaterial). In a research project on sexual health it is not unlikely that a participant would make a disclosure about sexual abuse, a non-consensual sexual experience or some other traumatic experience. It is also not unlikely that a participant may disclose a sexual practice or experience that makes the interviewer uncomfortable.

The Participant Information Sheet (as approved by an ethics committee) informed participants they did not have to answer questions, and that they could stop the interview at any time. But in hindsight, there were omissions. It should have made explicit that some of the topics covered in the interview may trigger memories or feelings about unpleasant experiences. It should also have included details about counselling, health and legal support services that are appropriate and equipped to deal with issues that may arise. Equally, the ethics review process should have addressed the community researcher's wellbeing. For example, the project could have had more detailed protocols to deal with such situations and ensure Angela had support for her own distress (e.g. access to independent counselling or supervision). In hindsight, any ethical review committee overseeing this project should have asked what strategies were being employed to mitigate these anticipatable risks.

Second, we need to consider any legal issues that may relate to this scenario. Most Participant Information Sheets in Australia include a variation of a statement promising confidentiality 'except as is required by law'. It should never be assumed that participants understand what this phrase means. It is a researcher's responsibility to make themselves aware of the legal limits of confidentiality (in the jurisdiction in which they are researching) so they understand their obligations and can explain them to a participant. Apart from mandatory reporting requirements, the research team had not discussed the researchers' legal responsibilities during training. Most researchers are not mandatory reporters and community researchers rarely are; but both are subject to the same responsibilities as any citizen. In the jurisdiction where this research took place, for example, citizens are legally obliged to report to police if they have material information that could assist prosecution of a serious indictable offence (i.e. subject to a penalty of 5 years or more). Neither Angela nor the research team sought legal advice about whether incest is a serious indictable offence, so no further action was taken. We have used this case study to highlight the complex issues that emerge and the *potential* for legal implications. While institutions offer assistance to university researchers should a legal issue arise, the protection and assistance for community researchers is much less clear.

The third issue stemming from this scenario relates to training. Community researchers are usually research-inexperienced people being trained to engage with participants and collect data about social problems in their own communities. Angela had received a week of formal training and subsequent mentoring from an experienced researcher. The training had included discussion of respectful communication and how to handle participant distress during interviews. This was reflected in her response during the interview – she paused the interview, checked in with the participant and followed her lead. In our experience of sitting on ethics review committees, researcher qualifications and expertise for qualitative research are rarely discussed (Mooney-Somers & Olsen, 2016). As researchers, ethics review committees have never asked us about community researcher training. Sexual health is a complex research area and training of community researchers should address what to do if trauma comes up in an interview or a participant reveals they may be at risk. Our training did this to a degree; real-life experiences such as that outlined above exposed some areas of deficit. We could have role-played scenarios and then discussed a range of responses. Although, in reality, we could never fully cover all (or even preconceive of all) potential tricky scenarios. As such, an important aspect of this training is to discuss the boundary between being a researcher and being a counsellor/social worker/etc. Angela is a researcher (likely a very inexperienced one) and not a trained counsellor or social worker. It is important to remember that Angela may also know the young woman she interviewed, the young woman's uncle or their family; or their paths may cross in the future. Angela needs to feel confident that she does not have to take *sole* responsibility for this situation – even if the participant indicates they would like help. The project leader(s) must ensure that the project has protocols to deal with expected and unexpected scenarios and ensure that researchers like Angela have someone to discuss options for action. Again, any ethics review committee overseeing this project should have asked what strategies were in place to provide professional and ethical support to the research team.

BALANCING SCIENTIFIC RIGOUR WITH COMMUNITY INTERESTS IN THE FIELD

Doing social research with rigour is an ethical issue. A number of published criteria are available to assist researchers and others assess the rigour of qualitative research (Cutcliffe & McKenna, 1999; Olsen et al., 2015; Tracy, 2010; Walsh & Downe, 2006), however, they rarely address the specific desired processes or outcomes in PR. Smith, Monaghan and Broad (2002) suggest that in seeking to promote acceptance of participatory approaches, proponents may have ‘glossed over’ questions of methodology and rigour and ‘may have created an impression that these issues are unimportant’ (Smith et al., 2002: 194). If we are to use the knowledge produced by PR as evidence for action to improve the wellbeing of affected communities – the whole justification for PR approaches – then we need to attend to data quality issues.

The concept of rigour in research ‘deals with correct method’ (Ezzy, 2002: 51), which implicitly valorises the researchers’ perspective about what is ‘correct’. Indeed, discussion of rigour in PR often evokes notions of control; as experts in method, researchers experience many pressures to exercise ‘control over the conditions affecting the research’ (Allison & Rootman, 1996: 333). However, such dominance creates significant tensions for PR where researchers are explicitly seeking to share control over the research process.

Conflicts between the researchers and the community about what counts as correct research methods – or what matters – may arise at several stages of investigation. Community interests may clash with scientific interests during the development phase of the project (Resnik & Kennedy, 2010). University researchers may suggest study designs driven by scientific rationale (such as randomised control studies) or funder preferences while the community partners are more interested in inclusive, exploratory methods (Mohatt et al., 2004). We have also had the opposite occur when community partners were influenced by positivist ideals of rigour in a project where randomisation and a control group were not possible. Mohatt et al. (2004) provide an example of such complex tensions and negotiations in their paper about university researchers and Alaskan Natives coming together to conduct research on alcohol use. How the research topic was conceptualised – and the language used – was a crucial first step in recognising community experiences and priorities. Explicit discussion of the funder’s needs and how that would influence methodological choices helped the community and the researchers develop a pragmatic research design to meet everyone’s needs. At the same time, creative thinking around data collection allowed everyone who wanted to, to share their experiences while meeting sampling needs.

For researchers, one of the most significant tensions in co-design and data collection is rigour; the concept and practice of ‘rigour’ looms large and shapes the research in complex ways. In the spirit of PR, community researchers enhance rigour (completeness) through their capacity to recruit participants, their in-depth knowledge of the culture, the different questions they pose, the trust they bring for participants and the level of community interest they generate in the project (Tyler et al., 2006). However, working with inexperienced researchers can also lead to poor quality data. In one of our studies, community researchers made written notes of interviews they conducted (written notes are common in field research especially with marginalised communities where recording may be seen as threatening). The cultural expertise that the researchers brought to the interviews was clear but their novice interviewing and note-taking skills meant the data did not contain the same detail, breadth and accuracy that may have been produced by expert researchers. Several artefacts in the data underscored these issues. There were moments of slippage where interviewers shifted between writing in the first person (recording the participant’s own words), and writing in the third person (often summaries of participant's words). The interviewer's voice – the questions they asked, prompts they used, or their responses – was also inconsistently recorded in the data. The following extract – exactly as it was written by the community researcher – is an extreme example of these artefacts. The interviewer's question is marked with brackets, the participant's words are then recorded possibly verbatim (*It can give you diseases*), then there is a third person summary (*knows about HIV*), followed by a verbatim recording with quotation marks, and a third person summary (*School is the only place she has learnt about STI)*:

> *[What do you know about STI] It can give you diseases, knows about HIV. 'I was the clumsy one in school and didn't pay attention'. School is the only place she has learnt about STI.* (Field note written by community researcher)

While some of this slippage is expected when using field notes rather than audio recordings, it does point to important issues relating to rigour and PR. Smith et al. (2002: 198) talk about PR producing a 'more open and sensitive, but also more uneven approach'. This 'unevenness' can be acknowledged and incorporated. The community researchers on the project that produced the above field note, for example, developed confidence and skill while conducting the research that meant that the data collected toward the end of the project contained a depth and clarity that was missing in the very early interviews. We acknowledged this point in the final project report, in a section explicitly dealing with the status of the data (Mooney-Somers et al., 2009).

Skill is not the only challenge to data quality in PR. Community researchers have a variety of motivations for participating in research about their community. They may be looking to become involved in their community in order to enhance community wellbeing. They may be motivated by the promise of social change, wanting to raise awareness or increase health service usage, or to influence social policy. They may be using the research to enact changes in their own lives (Fenge et al., 2009). Unrecognised in procedural ethics, community researchers carry a burden: the reputation of their community. This is obvious in the following case:

Case Three: Protecting Your Community (and Undermining Rigour)

> A partnership project about enhancing HIV prevention practices was established between university researchers and a community development organisation. Young members of a marginalised community were trained to conduct interviews with peers. During transcription of the interviews it became clear that one community researcher repeatedly paused the audio recorder during interviews. The university researchers wondered if he was posing the questions as per the interview schedule and then stopping to further explain the questions (i.e. the project needed to rework the questions), or if participants were getting upset and the project team needed to reconsider duty of care? It transpired that the community researcher was pausing the recording to discuss 'better', more complete answers; he was concerned that the participants (his friends and family) should not be perceived to be stupid if they provided 'incorrect' or incomplete answers. He was not aware this was the 'wrong' thing to do in a research interview.

We hesitate to merely characterise this case as simply a matter of insufficient training. Many communities tell stories of researchers taking community knowledge to advance academic careers with little community benefit, or stigmatising community by focusing on deficits, attributing problems to community characteristics, or thoughtlessly publishing damaging findings. Given this history, it is not only understandable but perhaps even sensible for community researchers to be cognisant of how their family and community may look to or be represented by outside 'experts'. Or how their information or experiences may/might be used. We encountered such mistrust on a project with a community-based health service; staff marked medical records as not to be used for research when the study design called for interviews with participants recruited outside the service (Mooney-Somers & Maher, 2009).

Participatory research seeks to take advantage of community researchers' relationships, shared experience, and identity (Guta et al., 2013). Expecting communities to simply trust university researchers to 'do good' is naïve. We are not arguing that the community researcher coaching participants is acceptable; we are arguing that it reminds us of the importance of establishing trusting relationships and genuine co-ownership of the research process and product (knowledge). This case then highlights the ethical imperative in PR to develop mutual trust and credibility (DiStefano et al., 2013). The key here is for university researchers to take time to find out the history of research in a particular community, to acknowledge how academic knowledge has sometimes been used to harm (or at least, not necessarily to benefit) communities, and to appreciate that this history has very real consequences for the present. It is also imperative for research teams to make sure that all researchers know why the data is being collected and how that data will be used in order to avoid misunderstandings or reduce fears about how the community will be represented and presented.

Qualitative research data are produced through social interactions. A particular researcher will always shape a data generating interaction in ways particular to them, be they a community researcher or a university researcher, and this challenges mainstream 'scientific' criteria assessing rigour. Participatory research further challenges traditional concepts of rigour as the production of knowledge in PR comes from personal and social relationships, and working together to produce positive change and practical solutions to local problems (Oliver, 1992). As such, the quality or success of PR is often judged by whether a project achieves a 'true "community driven" agenda' (Minkler, 2004). By placing the affected community at its heart and seeking to involve them in all aspects of the research process, PR inherently strives for local completeness. We find this alternative conceptualisation of rigour, as the completeness of data collection, analysis and interpretation (Yardley, 2000), more productive and relevant for PR.

Participatory research is a very resource intensive approach to producing knowledge. We agree with Tyler et al. (2006) that always prioritising the quality of the research (in the traditional sense) means that academics may as well undertake the research themselves. Furthermore, in considering rigour in PR, academics need to balance when to intervene and when to let things go (Tyler et al., 2006). However, this does not mean that data quality should be ignored. University researchers need to be unafraid as *expert* researchers to address issues within the scope of the project. That means regularly reviewing data during data collection, having debriefing sessions around the experience of data collection and holding training updates. As a PR team is comprised of researchers and community members with 'different yet complementary types of experience' (Mohatt et al., 2004: 272), roles should be assigned based on skills (assessed via a role play, an interview or a test). Not everyone needs to be involved directly in data collection; in one of our projects, for example, we assigned one community researcher responsibility for tracking data collection in the field and making sure interviewers had the materials they needed.

This brings us back to the importance of appropriate ethics and methods training for all team members. Community researchers need more than just didactic training; they need to see examples of good and bad interviewing practice, to practice, to role play, to have constructive feedback, to hear how experienced interviewers (or focus group facilitators or participant observers) respond to the variety of scenarios that crop up during data collection. As discussed earlier, the team also needs to openly discuss difficult scenarios and decide on ethical responses. Indeed, working in a team provides the scaffolding for community researchers to learn about and practice integrity and for monitoring of data quality to persist throughout a project.

CONCLUSION: RESPONDING TO 'MESSINESS' WITH ETHICAL REFLEXIVITY

In this chapter, we uphold the tradition of reviewing and renewing our ethical approaches to research. We have discussed many of the ways in which PR teams need to balance scientific and community interests and how this impacts on ethical practice. Procedural ethics alone cannot provide coverage for dealing with all ethically important moments in research and thus we must take a reflexive decision-making approach towards our research (Guillemin & Gillam, 2004). Researchers must 'assume responsibility for the big ethical moments they are likely to routinely discover' (Tolich, 2016: 194). For our part, that means drawing on our experiences to highlight in this chapter issues that PR may produce. There is a growing body of literature reporting honest accounts of the difficulties and dilemmas encountered when conducting research (James & Platzer, 1999). 'Being transparent about research difficulties', write Bowtell et al. (2013: 653), 'helps to create an invaluable pool of awareness and experience for researchers'. PR is a challenging endeavour for researchers and for communities. Rather than idealise it we seek realistic and grounded understandings of PR as a process not an outcome.

Rather than simply considering these ethical moments in the field as occasions when procedural ethical rules may be in danger of being infringed, we suggest that researchers engage in constant negotiation of the ethical issues that lie across a spectrum from every day interactions to highly difficult decisions. This way of constructing ethical practice as reflexive practice defines researchers not just as 'impartial deliberators', but also as embedded moral agents with 'relationships, responsibilities, values and commitments that frame and constrain ways of seeing, judging and acting in particular situations' (Banks et al., 2013: 266). Community researchers should be equal partners in these reflective discussions.

Training, especially working through case studies such as those above, is crucial to preparing researchers (university and community) for ethically important moments. But this is not simply a matter of educating naïve researchers in the correct ways to conduct research or the precise definitions of ethical concepts. Training allows all involved to develop shared understandings of the research community's *and the affected community's* values, to discuss how these values shape ethical research practice in a specific cultural context, and to reach consensus on research protocols. This co-learning is the key to achieving a culturally anchored ethical practice in PR[2].

Notes

1 Simon et al. (2010) discuss several strategies for helping community researchers manage this emotional burden.

2 We are building here on Mohatt et al.'s (2004) discussion of a culturally anchored approach to participatory research.

REFERENCES

Allbutt, H. and Masters, H. (2010). Ethnography and the ethics of undertaking research in different mental healthcare settings. *Journal of Psychiatric and Mental Health Nursing*, *17*(3), 210–215. doi: 10.1111/j.1365-2850.2009.01493.x

Allison, K. and Rootman, I. (1996). Scientific rigor and community participation in health promotion research: are they compatible? *Health Promotion International*, *11*(4), 333–340.

Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., McNulty, A., Moore, N., Nayling, N., Stokoe, A., and Strachan, A. (2013). Everyday ethics in community-based participatory research. *Contemporary Social Science*, *8*(3), 263–277. doi: 10.1080/21582041.2013.769618

Baum, F., MacDougall, C., and Smith, D. (2006). Glossary: Participatory action research. *Journal of Epidemiology and Community Health*, *60*(10), 854–857.

Bowtell, E. C., Sawyer, S. M., Aroni, R. A., Green, J. B., and Duncan, R. E. (2013). 'Should I send a condolence card?': Promoting emotional safety in qualitative health research through reflexivity and ethical mindfulness. *Qualitative Inquiry*. doi: 10.1177/1077800413500927

Brydon-Miller, M. (2003). Using participatory action research to address community health issues. In M. Murray (Ed.), *Critical Health Psychology* (pp. 187–202). London: Palgrave.

Campbell, H. and Vanderhoven, D. (2016). *Knowledge That Matters: Realising the Potential of Co-Production*. Retrieved from N8 Research Partnership, Manchester, UK: http://www.n8research.org.uk/view/5163/Final-Report-Co-Production-2016-01-20.pdf

Cutcliffe, J. R. and McKenna, H. P. (1999). Establishing the credibility of qualitative research findings: the plot thickens. *Journal of Advanced Nursing*, *30*(2), 374–380.

de Laine, M. (2000). *Fieldwork and Dilemmas in Qualitative Research*. London: Sage.

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research*, *7*(3), 327–353. doi :10.1177/1468794107078515

DiStefano, A., Quitugua, L., Hui, B., Barrera-Ng, A., Peters, R., Vunileva, I., Dimaculangan, J., Tui'one, V., Takahashi, L., and Tanjasiri, S. P. (2013). A community-based participatory research study of HIV and HPV vulnerabilities and prevention in two Pacific Islander communities: Ethical challenges and solutions. *Journal of Empirical Research on Human Research Ethics*, *8*(1), 68–78. doi: 10.1525/jer.2013.8.1.68

Durham Community Research Team. (2011). *Community-based Participatory Research: Ethical Challenges*. Retrieved from www.ahrc.ac.uk/documents/project-reports-and-reviews/connected-communities/community-based-participatory-research-ethical-challenges

Ezzy, D. (2002). *Qualitative Analysis: Practice and Innovation*. Crows Nest, NSW: Routledge.

Fenge, L.-A., Fannin, A., Armstrong, A., Hicks, C., and Taylor, V. (2009). Lifting the lid on sexuality and ageing: the experiences of volunteer researchers. *Qualitative Social Work*, *8*(4), 509–524.

Flicker, S., Travers, R., Guta, A., McDonald, S., and Meagher, A. (2007). Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, *84*(4), 478–493.

Guillemin, M. and Gillam, L. (2004). Ethics, reflexivity, and 'ethically important moments' in research. *Qualitative Inquiry*, *10*(2), 261–280. doi: 10.1177/1077800403262360

Guta, A., Flicker, S., and Roche, B. (2013). Governing through community allegiance: a qualitative examination of peer research in community-based participatory research. *Critical Public Health*, *23*(4), 432–451. doi: 10.1080/09581596.2012.761675

Iphofen, R. (2011). Systems of ethical approval and formal ethical scrutiny. In R. Iphofen, *Ethical Decision Making in Social Research* (Chapter 13). London: Palgrave.

Israel, B. A., Schulz, A. J., Parker, E. A. and Becke, A. B. (1998) Review of community-based research: Assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173–202.

James, T. and Platzer, H. (1999). Ethical considerations in qualitative research with vulnerable groups: exploring lesbians' and gay men's experiences of health care – a personal perspective. *Nursing Ethics*, *6*(1), 73–81.

Lazarus, L. (2013). Working with marginalized and 'hidden' populations: researchers' anxieties and strategies for doing less harmful research. *Caribbean Review of Gender Studies*, *7*, 1–22.

Marshall, Z., Nixon, S., Nepveux, D., Vo, T., Wilson, C., Flicker, S., McLelland, A., and Proudfoot, D. (2012). Navigating risks and professional roles: research with lesbian, gay, bisexual, trans, and queer young people with intellectual disabilities. *Journal of Empirical Research on Human Research Ethics*, *7*(4), 20–33. doi: 10.1525/jer.2012.7.4.20

McCosker, H., Barnard, A., and Gerber, R. (2001). Undertaking sensitive research: issues and strategies for meeting the safety needs of all participants. *Forum: Qualitative Social Research*, *2*(1).

Minkler, M. (2004). Ethical challenges for the 'outside' researcher in community-based participatory research. *Health Education &*

Behavior, *31*(6), 684–697. doi: 10.1177/1090198104269566

Mohatt, G., Hazel, K. L., Allen, J., Stachelrodt, M., Hensel, C., and Fath, R. (2004). Unheard Alaska: culturally anchored participatory action research on sobriety with Alaska Natives. *American Journal of Community Psychology*, *33*(3–4), 263–273.

Mooney-Somers, J., Brockman, D., and Maher, L. (2007). *Sexual Health Through the Eyes of Indigenous Youth: Participatory Action Research Training Manual*. Distributed by UNSW for workshops run in 2008.

Mooney-Somers, J. and Maher, L. (2009). The Indigenous Resiliency Project: a worked example of community-based participatory research. *NSW Public Health Bulletin*, *20*(7–8), 112–118. doi: 10.1071/NB09007

Mooney-Somers, J. and Olsen, A. (2016). Ethical review and qualitative research competence: guidance for reviewers and applicants. *Research Ethics*. doi: 10.1177/1747016116677636

Mooney-Somers, J., Olsen, A., Erick, W., Scott, R., Akee, A., and Maher, L. (2009). Sexual Health through the Eyes of Indigenous Youth: Community-based Participatory Research with Indigenous Young People in Townsville. Retrieved from http://hdl.handle.net/2123/11477

National Health and Medical Research Council. (2007 (revised 2015)). *National Statement on Ethical Conduct in Human Research*. Retrieved from https://www.nhmrc.gov.au/guidelines-publications/e72

Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, *7*(2), 101–114.

Olsen, A., Higgs, P., and Maher, L. (2015). A review of qualitative research in *Drug and Alcohol Review. Drug and Alcohol Review*, *34*(5), 474–476. doi: 10.1111/dar.12307

Resnik, D. B. and Kennedy, C. E. (2010). Balancing scientific and community interests in community-based participatory research. *Accountability in Research*, *17*(4), 198–210. doi: 10.1080/08989621.2010.493095

Seal, D. W., Bloom, F. R., and Somlai, A. M. (2000). Dilemmas in conducting qualitative sex research in applied field settings. *Health Education & Behavior*, *27*(1), 10–23. doi: 10.1177/109019810002700102

Simon, C. and Mosavel, M. (2010). Community members as recruiters of human subjects: ethical considerations. *The American Journal of Bioethics*, *10*(3), 3–11. doi: 10.1080/15265160903585578

Smith, R., Monaghan, M., and Broad, B. (2002). Involving young people as co-researchers: facing up to the methodological issues. *Qualitative Social Work*, *1*(2), 191–207.

Tolich, M. (2016). *Qualitative Ethics in Practice*. Walnut Creek, CA: Left Coast Press.

Tracy, S. J. (2010). Qualitative quality: eight ‘big-tent’ criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837–851. doi: 10.1177/1077800410383121

Tyler, P., Turner, C., and Mills, H. (2006). *Involving Young People in Research: Want to Know What Young People Think about Bullying*. Retrieved from http://www.barnardos.org.uk/involving_young_people_in_research_pdf.pdf

Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K. N., Griffith, D., Rhodes, S., Samuel-Hodge, C., Maty, S., Lux, L., Webb, L., Sutton, S. F., Swinson, T., Jackman, A., and Whitener, L. (2004). *Community-based Participatory Research: Assessing the Evidence*. Retrieved from https://archive.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf.

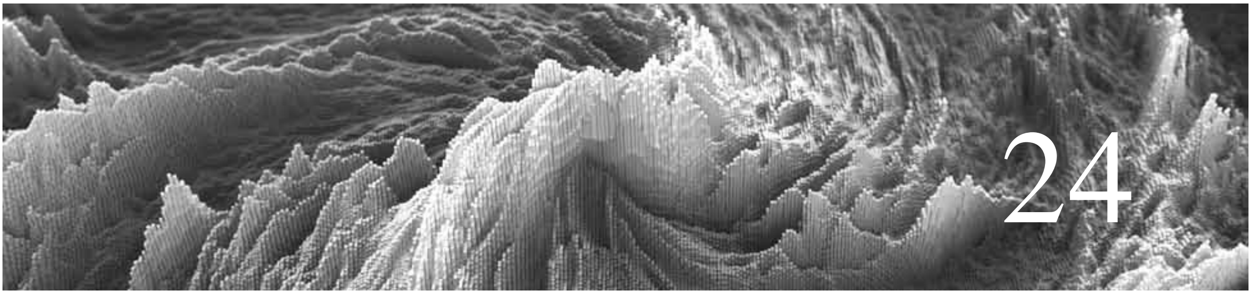
Walls, P., Parahoo, K., Fleming, P., and McCaughan, E. (2010). Issues and considerations when researching sensitive issues with men: examples from a study of men and sexual health. *Nurse Researcher*, *18*(1), 26–34. doi: 10.7748/nr2010.10.18.1.26.c8045

Walsh, D. and Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, *22*(2), 108–119. doi: 10.1016/j.midw.2005.05.004

Wiles, R., Crow, G., Heath, S., and Charles, V. (2008). The Management of Confidentiality and Anonymity in Social Research. *International Journal of Social Research Methodology*, *11*(5), 417–428. doi:10.1080/13645570701622231

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. doi: 10.1080/08870440008400302

Zago, L. F. and Holmes, D. (2015). The ethical tightrope: politics of intimacy and *consensual* method in sexuality research. *Nursing Inquiry*, *22*(2), 147–156. doi: 10.1111/nin.12068



24

Fair Warnings: The Ethics of Ethnography with Children

Angel A. Escamilla García and Gary Alan Fine

INTRODUCTION

Every researcher who conducts any project that involves human subjects must take into consideration the varieties of potential harm to subjects that may possibly result. Research ethics are central to the systematic analysis of human behavior, whether through qualitative or quantitative methodology. Ethics in research, as one author has put it, addresses 'the application of a system of moral principles to prevent harming or wronging others, to promote the good, to be respectful, and to be fair' (Morrow & Richards, 1996, citing Sieber, 1993: 14).

Within this focus on research ethics, certain groups of participants are considered more vulnerable than others and, as a result, the considerations of the responsibility of researcher to researched are more intense. Such populations are especially vulnerable to pressures to participate in research against their will, and less likely to be fully informed about the implications of the research in which they are participating (Iphofen, 2009: 109). Therefore, at times, special forms of ethical intervention or oversight are viewed as warranted. The cognitively impaired, the institutionalized, subjects being studied by those in positions of power, the elderly, and children – both under control of adults and not fully mature – are given special attention.

In this chapter we focus on the last of these groups, and, given the topic of this *Handbook*, ask how ethical issues are conceptualized and put into practice in qualitative field research. Across disciplines, all researchers working with child subjects[1] must think carefully about how children may be harmed even without the researcher's intention. Given that researchers may be blinded by their own self-interest in conducting research, many institutions assign their institutional review boards (IRBs) or research ethics committees (RECs) the task of reviewing applications for research with particular care, reminding the researcher that children are especially vulnerable and require heightened protection.

Like all forms of social science research, participant observation was used by ethnographers to study children and adolescents long before ethical considerations became a common concern. Perhaps the classic study, revealing profound cultural differences in childhood, was that of anthropologist Margaret Mead (1928). Her book *Coming of Age in Samoa* remains an iconic, and now heavily criticized, ethnographic work. The book investigated the way of life of Samoan youth, revealing that American standards of sexuality were not necessarily shared globally. However, Mead's book devotes no space to discussing the ethical concerns that today's ethnographers typically fret about. Given the standards of early-twentieth-century anthropology, it is unlikely that Mead had the formal assent of her research subjects to observe and write about them, that her research subjects ever learned the outcome of her study, or that the children were even fully aware they were being studied for eventual publication. Certainly, these young Samoans were aware that she was a stranger, writing notes, and asking questions. Whether her conclusions were empirically justified, it is unlikely that any particular Samoan child suffered harm, although the research certainly typified Samoan society in a way that inscribed its otherness (whether romantic or immoral, depending on the reader). Still, Mead's work has now been thoroughly criticized, in part for these ethical and methodological concerns (Freeman, 1983). These are errors that we aim to help modern ethnographers avoid.

Our goal in this chapter is to lay out a set of significant ethical concerns that ethnographers must consider when carrying out field research. The first section of the chapter highlights core ethical issues that pervade the literature on ethnography with children. Then, using these issues as a guide, we consider ethical issues as they pertain to children of specific age groups: preschoolers, preadolescents, and adolescents. While we generally use the term children, age categories and age cohorts matter greatly in the relationships between researchers, their young informants, and the familial and organizational guardians of children. A toddler and a teen must necessarily be treated with different forms of respect.

We then briefly address specific concerns when working with child subjects, such as working with children in non-traditional contexts, working with children with disabilities, and the implications of a researcher's gender, race, and ethnicity in the research. In conclusion, we offer ideas that may further enhance the discussion surrounding ethical ethnography with children. Our overarching aim is to illustrate the challenges that ethnographers face when working with minors. It is well to remember that while some ethnographies have children as their focal population, many others have children as present but peripheral, such as studies of neighborhoods, gangs, or the occupational world of teachers. Even if children are not central, ethical engagement and informed consent must take into account the age of each informant.

ASSESSING THE ETHNOGRAPHIC LITERATURE

The literature surrounding the ethics of ethnography with children, though not extensive, has grown and evolved over the last few decades. This literature can be found in a variety of sources: in volumes compiling chapters on research and ethics (Farrell, 2005; Greene & Hogan, 2005), in peer-reviewed journal articles (Christensen, 2004; Levey, 2009; Skånfors, 2009), and in methodological texts (Fine & Sandstrom, 1988; Pellegrini, 1996; Holmes, 1998; Murphy & Dingwall, 2001). Further, some ethnographers discuss ethical issues and dilemmas directly in the ethnographies themselves or in a methodological appendix (Fine, 1987; Pascoe, 2007; Bertran, 2014).

The discussion of ethics in ethnography with children, generally maps onto a broader ongoing conversation within child studies and the social sciences. Researchers originally viewed children as research objects, but in recent decades increasing emphasis has been placed on children's agency and children's ability to participate in and be part of the research process (James, 2001; Christensen & Prout, 2002; Einarsdóttir, 2007).[2] Accordingly, where 'in the past, researchers sometimes assumed that they had the right to study children as they pleased, today there are more safeguards protecting the rights of participants, especially children' (Eder & Corsaro, 1999: 526).

Among these safeguards, a few pervade the literature. One recurrent ethical issue is whether a researcher has obtained consent and/or assent for a child to participate in a study. Another involves the ethnographer's position as a witness, and whether an ethnographer should intervene in potentially dangerous or harmful situations. A wide array of other ethical issues has also appeared in the literature, from giving gifts, to privacy, to the role that ethics boards play in the discipline.

Consent and assent are the preeminent ethical concerns in ethnographies with children (Grisso, 1992; Gallagher et al., 2010; Alderson and Morrow, 2011). Consent refers to a conscious and deliberate agreement for an individual to participate in a study when that individual has reached the legal age of consent. For example, an adolescent or a child's parent may consent for her child to participate in an ethnography. Although parental consent 'is clearly an area where there is a wide range of views, especially in relation to older children and adolescents' (Cashmore, 2006: 971), researchers should still provide a consent form before beginning research.[3] Generally, a consent form for gatekeepers should include a section explaining the purpose of the study; an explanation of the minor's role in the research; and a description of how the information obtained through the study will be handled and protected. The document should also explain any direct benefit that will be obtained from the research, either directly benefitting the subject or otherwise.

Assent, in contrast, 'is the agreement of someone not able to give legal consent to participate in the activity' ('Consent and Assent'). Assent, in this context, may consist of a child agreeing to participate without recognizing the full implications of that approval, at least as defined in institutional terms. It is generally accepted that researchers must receive a child's assent in order to include the child as an informant in an ethnographic study. In gaining assent, the researcher must explain the research to a child subject, and the child must have an opportunity to understand the research objectives to the extent of her or his cognitive abilities (Grisso, 1992: 109; Hill, 2005: 61). This is often done through an assent form, which for minors should be a shorter and simpler version of the consent form, providing the minor with enough information to fully understand the research and decide whether or not to participate (Chambliss & Schutt, 2013: 51). Depending on the reading abilities of the minor, the researcher may also give a verbal explanation of the information on any written materials. Further, many authors now suggest that children's assent should be considered not just at the beginning of the study but throughout the course of a research project (Graue & Walsh, 1998; Lewis & Lindsay, 2000; Gallagher, 2009).[4] In other words, assent is an evolving agreement, and this is particularly the case as children may be less aware of the contours of research when they are first asked to agree to participate.[5] Due to the nature of ethnography, it is important to provide information to both gatekeepers and minor subjects regarding the nature of our presence in their daily lives, the measures that will be taken to ensure confidentiality, and the fact that subjects have the control of the collected information at all times. At any moment, they may choose not to participate.

However, in most cases assent alone is typically insufficient. The researcher must also obtain the consent of 'gatekeepers', like the child's parents, a school, or a hospital (Pellegrini, 1996: 47), and there may be more than one gatekeeper.[6] For Stanley and Sieber (1992: 188), deciding who these gatekeepers are depends on the norms within the institution where the ethnography is taking place, and whether the setting is public or private.

Another ethical concern is that the ethnographer is in a position to witness potentially harmful behaviors or situations. Some of these involve physical danger and others involve children acting in morally unacceptable ways (as defined by adults). And, if the researcher does observe some type of harm, what rules or ethical requirements determine how to respond? Fine and Sandstrom (1988: 27) note the ethical tension embedded in this question because, as an adult, the researcher may be expected by other adults and by children to intervene in case of any bad behavior, but participant observers rarely want to intervene or shape those scenes that they are observing. These authors caution that

> participant observers should be careful about being placed in a position in which they are responsible for policing the behavior of children and, as a consequence, see their positive relations become truncated. Still, intentionally standing by while a child injures him- or herself or others is surely the devil's bargain. (p. 75)

Confidentiality is yet another prominent ethical issue in ethnography. Fine and Sandstrom (1988) preserve the identities of children, even when a child gives assent to include her name in the study, or, in some cases, actively desires to be named. In contrast, Haggerty (2004: 409) argues that the censorship of names in research, as often required by ethics, can reduce the 'political weight and critical edge' of the research. Beyond identity, ethnographers' work may also result in the collection of knowledge or personal information that might be used against the child subjects (Barberin, 2003). For example, in the case of research in schools, an ethnographer revealing information about children's behavior and practices might lead to a school using that information to attempt to control the children (Burgess, 1985). As a measure to prevent such issues, ethnographers can eliminate any information from their data that might contain identifiable information 'by using pseudonymous and altering non-relevant details' at the time of the research (Murphy & Dingwall, 2001: 341).

Several other important ethical questions surrounding the power relationship of researcher to child are highlighted in the literature. One example is whether the ethnographer should give gifts or rewards, like candy or gum, to children as a means of encouraging participation (Fine, 1987: 25). As a rule, ethnographers should refrain from using gifts to get information or gain access to groups of children on a regular basis because of the expectations that it sets up for further research and because it could lead to false information from the desire to please. One possible solution is for the researcher to give no gifts directly to study subjects, but instead to give gifts to the hosting institution, where gifts can be distributed evenly and without the direct involvement of the researcher (Holmes, 1998).

The issues raised above, like consent and confidentiality, have been present throughout the literature on ethics in ethnography with children. As researchers' views on how to conduct research with children have changed, so have the ethical concerns involved. At one time, researchers considered children to be a distinct group with its own culture. However, Morrow and Richards (1996) suggest that children are best viewed within broader social and cultural contexts that include adults, institutions, and children of various ages. Today, James (2001: 250) expounds upon this view, explaining that, 'through their social interaction and engagement with their peer and adult care-takers, ethnographic accounts have shown how children contribute to the shape and form which their own childhood takes'.

In addition, gender, race, and immigration status, as well as being situated in national contexts can segment the world of children. In recent research, authors increasingly view children as 'social actors' and as active participants in participant observation (Boyden & Ennew, 1997: 10; Einarsdóttir, 2007: 198; Mason & Hood, 2011: 491). With this shift in children's position in the research process, new ethical questions have arisen, and authors have introduced fresh terminology to discuss contemporary ethical issues. For example, new terms like 'ethical radar' appear in contemporary literature. Skånfors' (2009: 11) 'ethical radar' refers to a position in which the researcher has 'to be observant of children's actions and understand these not only in terms of the collection of data, but also in the context of the impact of the research process on their worlds, rather than just relying on children's initial verbal acceptance or consent given by parents'. As such, Skånfors (2009: 16) suggests that ethics require the researcher to think beyond the consent and assent from gatekeeper and child and instead to think constantly about how the research process can impact subjects. Pia Christensen and Alan Prout (2002: 478) offer their own term, 'ethical symmetry', which they envision as calling for an equal relationship between the researcher and the child. In this view, the researcher should consider the child in his or her social and cultural context and should respect the child's rights, feelings, and interests throughout the research process (2002: 493). Contributions like that of Skånfors and of Christensen and Prout emphasize the individual responsibility and skills of researchers to develop a reflexive and dynamic approach to their research practices.

These works reflect a broader shift toward considering children as more than a distinct cultural group. Instead, scholarly literature in the last two decades – what has been labeled the 'new sociology of childhood' – has increasingly viewed children as actors with agency and the capability to make decisions on their own terms (James, 2001). If this model holds, it might suggest that the ethical requirements of researchers should be little different for children than for adults.

RESEARCH ETHICS COMMITTEES AND REVIEW BOARDS

The *Guidelines for Research with Children and Young People* (Shaw et al., 2011: 30) offer a series of ethical recommendations for use when conducting research involving the observation of minors. In particular, the document provides a series of ethical standards regarding the consent of the minor, parental consent, and describing those conditions when parental consent might be exempt.

In general, a shift toward giving children agency over their involvement in the research process is now being felt across the social sciences (Morrow & Richards, 1996: 97; Farrell, 2005: 6; Wall, 2013: 68). But, this change has occurred at the same time that researchers are recognizing the increasing burden of complying with international ethical guidelines set by regulating bodies (O'Kane, 2000; Shea, 2000; van den Hoonaard, 2002; Haggerty 2004). The global trend toward institutionally formulated rules, codes, and regulations that researchers must follow affects most researchers, and it cuts against the flexible ways of thinking that authors like Pia Christensen and Alan Prout (2002) endorse.

One of the first hurdles that any researcher working with children must face is obtaining the approval of the study by an ethical review committee, regardless of the researcher's discipline. Many universities have ethical review boards or research ethics committees that act as filters for research proposals. These review panels can require changes to research plans, ask for additional information, and ultimately approve a research project if it is to be endorsed by a college or university. The purpose of these boards is to ensure that all research involving human subjects is ethically conducted, at least according to the standards of the reviewing board.

Ethnography is not ideally suited for such institutional oversight (Scarce, 1994; Shea, 2000; Haggerty, 2004; Katz, 2006; Librett & Perrone, 2010). Tolich and Fitzgerald (2006) suggest that ethnography and other inductive methods of research struggle to fit the positivist requirements of ethics boards, which favor tightly controlled research environments and strong hypotheses. Researchers are asked to know what they are attempting to test before they enter the field, challenging the possibility of inductive research. Additionally, Haggerty (2004: 408) worries that one possible consequence of an overall emphasis on externally imposed ethical rules might be that academics simply ignore such protocols, a disturbing unintended consequence. Despite the challenges by faculty members, worried about losing their professional autonomy, such review committees are not vanishing. Instead, researchers continue to obey such protocols, which are, after all, intended to reduce potential harm to research subjects.

Authors have suggested that, in order to make research ethics committees more effective for methods like participant observation, at the very least such boards need staff that understand the research methodologies of the social sciences, versus those of the natural sciences (Allen, 2005; Tolich & Fitzgerald, 2006; Librett & Perrone, 2010). Moreover, literature suggests that research ethics committees should receive specific training in identifying and understanding what is involved in research with children, in child ethnography, and in the developments that have taken place over time in conducting ethical research with children (Reeves et al., 2007).

This brief review of the way in which ethical rules are developed and how they speak to the ethnography of children reminds us that researchers are constantly confronted with ethical questions. The power relationship between researcher and child should be a continuing concern, as is a determination of the proper role of the researcher.

ETHICAL CONSIDERATIONS OF THE 'MANY CHILDHOODS'

Encompassing individuals from infancy to their late teens, the term 'child' includes a wide range of mental, physical, and social development levels. Childhood has long been seen to be a construction (Ariès, 1962), and perhaps the term is too broad to be useful. Ethnographers frequently note distinct ethical issues when working with children depending on a child's age (Thompson, 1992: 26; Pascoe, 2007: 191). In order to address the ethical concerns of ethnography with children, the term 'child' must therefore be specified for any given research project.

It is common in the literature to divide 'children' into three age-based groups. Fine and Sandstrom (1988: 11) categorize children as preschoolers, preadolescents, and adolescents. Fraser et al. (2004: 147, 161, 175) similarly divide children into early childhood, middle childhood, and young people (2004: 147, 161, 175). Of course, these are not the only ways to conceptualize subgroups of children. For example, anthropologists Grove and Lancy (2004: 47–55) offer six different stages of childhood based on 'ethnographic accounts of childhood from nearly 1,000 societies': birth and the external womb, joining the community, separation, getting noticed, youth in limbo, and adulthood. Such classifications may be particularly useful for researchers conducting ethnographies with children in non-western societies. Others challenge the very idea of classifying children by age or development level. Christensen and Prout (2002: 483) argue that such categorical approaches may inappropriately place children into rigid categories regardless of individual children's competence and capacity.

While this is surely true for particular children, in general, these divisions make empirical sense, and, to date, the three-group approach has remained dominant. Therefore, in this chapter, recognizing hazy boundary ages and the gaps in these categories, we will group children into the three stages of childhood described by Fine and Sandstrom (1988: 11): '(1) preschoolers (4- to 6-year-olds), (2) preadolescents (10- to 12-year-olds), and (3) middle adolescents (14- to 16-year-olds)'. These represent the core ages of these stages, each part of the cultural construction of childhood and recognizing the uncertain boundary ages in between. Although we appreciate the concerns of authors like Christensen and Prout, we still believe that certain categorization is useful for ethnographers, as it serves as a guideline that helps researchers generally focus on the types of ethical challenges they may face during the course of their research.

Preschoolers

Regardless of the label we assign to very young children, researchers agree that conducting participant observation with this group requires special ethical considerations. As explained by Thompson (1992: 40):

> The younger the children who participate, the more vulnerable they are in research because of the enhanced limitations in cognition and reasoning, experience, social power and other features that limit their capacity to protect their rights as research participants. Consequently, research protocols involving younger populations typically receive stricter scrutiny.

As a practical matter, we ask how toddlers should give assent in a research study? Even if an adult or guardian has consented to a child's participation, the child should give approval as well (Grisso, 1992: 110). Getting such agreement in a meaningful way can be difficult, ambiguous, and time-consuming, especially because the researcher must ensure that the young child understands the purpose of the research (Grisso, 1992; Holmes, 1998; Hill, 2005). As explained by Fine and Sandstrom (1988: 46), children must receive an 'explanation for [the presence of] this strange person at the early stages of the research', and children should be informed 'as much as possible, even if some of them cannot understand the full explanation. Their age should not diminish their rights'.

In very young children, one technique for obtaining assent is to observe the child's behaviors during an interaction and to detect if the child is uncomfortable or is rejecting interaction with the researcher (Bertran, 2014: 191). However, reading young children's behaviors can be difficult and it provides the researcher who wishes to have the child assent in the position of operating out of self-interest. Skånfors' (2009: 11) 'ethical radar' is useful here, where emphasis on respecting boundaries and understanding the context of children's assent encourages researchers to be especially observant of continuing assent throughout the research process.

Several other ethical concerns arise in the context of research with very young children. During interactions with all children, including the very young, an ethical concern regarding physical contact arises. At this stage 'unobtrusive participant observation, where the researcher remains apart from but carefully observes the behaviors of interest, is particularly suitable' (McKechnie, 2000: 65). However, Holmes (1998: 25–26) notes the difficulties of maintaining physical distance from young children, especially when a child seeks contact like hugs. Holmes explains that researchers should be careful about physical contact to avoid misinterpretations by adults who have the responsibility to protect children.

Another recurrent problem noted in the literature is that very young children may have trouble distinguishing researchers from other adults. Ethnographers, therefore, must explain the researcher's role and ensure that children understand this role. Bertran (2014: 191) for example, explained to preschool children that she was a researcher and not a teacher; the preschool teacher reinforced this message. Further, each time a child mistakenly called Bertran 'teacher', she would explain that she was not. One wonders whether correcting such a minor error did more harm than good in creating a barrier between the child and the researcher, or in creating a methodological concern whereby a child reacts differently to a researcher than she might to a teacher. In balancing ethics with methodological standards, it might be better to note the error, rather than challenging the child.

Privacy can be yet another point of ethical tension if the child discloses what might be taken as some kind of abuse or psychiatric trouble. In England, Australia, and most states in the United States, adults in positions of authority have a mandatory requirement to report abuse or neglect, and researchers often fall into this category of mandatory reporter. But it is not only abuse that is at issue. Holmes (1998: 25) in her research with young children writes that 'one day when [a child] and I were playing alone in the sandbox, he said, "Can I tell you something? I hate my life. I just want to kill myself"'. Her response to this disclosure was to communicate her concerns to the teacher with the request that the teacher not disclose that Holmes had been the source of this knowledge; still, on some level, the child's confidential communication was being violated. The researcher must always be prepared to deal with these types of traumatic and consequential situations; often there may be no easy ethical response. If the researcher attempts to respond directly to the comment, they may be 'stepping outside' their researcher role into that of 'counselor'. That decision can have methodological consequences. If the research does not respond to the comment directly, the child may feel ignored and perhaps that such disclosure is inappropriate. To retain a researcher role, one could ask the child if they would like to talk to someone and act accordingly.

These constitute a few examples of the ethical concerns that a researcher must consider when working with very young children. As these children may not be able to communicate fully or may not understand the situation as adults do, the ethnographer must be flexible, consider potential ethical issues in advance, and use forms of communication beyond verbal communication. Despite an admirable desire to give children agentic responsibility, this is not so clear in cases of preschoolers.

Middle Childhood/Preadolescence

During middle childhood (Williams & Stith, 1980) or preadolescence, a somewhat undefined period, children 'have increased mobility, increased privacy, and increasing knowledge of previously taboo subjects [that] pose ethical problems for researchers that were less evident with younger children' (Fine & Sandstrom, 1988: 55).

In addition, children at this age develop behaviors that may challenge researchers. For example, children may become increasingly mischievous, make racial slurs, or engage in physical altercations in the presence of researchers. Fine and Sandstrom (1988: 55–56) note the ethical concerns involved in simply observing children and intervening in their behaviors that are 'outside the rules set by adults'. In fact, in the case of ethnography, sometimes the researcher is the only adult present.

Researchers typically prefer not to intervene, or to intervene in a way so that trust is not lost with the group or that behaviors do not change as a result. Yet, intervention is sometimes ethically necessary. Fine and Sandstrom (1988: 27) explain that 'the judgment as to whether intervention is appropriate should depend at least somewhat on the situation', adding that, 'if a possibility of serious physical injury exists, an adult participant observer may need to intervene, even though he or she will thereby alter the behavior of the group'. For example, should boys begin to fight amongst themselves, a sense of morality may demand intervention.

Of the three categories, middle childhood is perhaps least explored. The middle childhood ethnographic studies are usually focused on children in elementary school (Gallo, 2014) and so are structured by institutional pressures on both the children and the researcher. Those pressures include many of those discussed in this chapter, including the need to acquire consent from multiple gatekeepers, the need to maintain confidentiality, and the potential for children and other adults in a school setting to expect a researcher to help regulate children's behavior (Burgess, 1985; Murphy & Dingwall, 2001). More generally, preadolescents have developed their own distinctive (and oppositional) cultures, but these cultures are harder to gain access to outside of the eyes of authorities. While young children lack such deeply embedded cultures, and adolescents have more control of their spaces, permitting researchers to join them, preadolescents occupy a middle ground requiring researchers to be especially aware of questions of access and vulnerability.

Adolescents

As children draw closer to the age of maturity, they become adolescents or young people. France (2004: 179–180) notes the historical marginalization of adolescents' opinions in research and the necessity to 'listen to their voices' in order to understand 'what it means to be young'. However, this near-maturity also comes with its own ethical challenges.

Obtaining consent for participation in an ethnographic study is slightly different with this oldest group of 'children'. According to France (2004: 181), adolescents have a great degree of agency in deciding whether or not to participate in a study, independent of their parents. As young people, they can review written information about the research, and they can better comprehend to what they may be assenting and/or consenting. However, determining whether a child is old enough or mature enough to decide is a matter of judging the child's competence and therefore can be highly subjective. Despite adolescents' developmental maturity, France notes that they still have parents and institutional authorities in their lives that need to be asked for consent. One possible solution to this challenge is to ask for 'passive consent' from gatekeepers by, for example, sending 'a letter that requires a response if the parents wish to object' (France, 2004: 183).

Another challenge for researchers is that adolescents have begun to explore sexuality; 'themes of sexuality and orientation to the adult world that are first grappled with by preadolescents become central for adolescents' (Fine & Sandstrom, 1988: 59–60). Pascoe (2007), in her study of gender and sexuality among high school boys, offers a methodological approach to dealing with some of the inherent ethical issues in working with these older children by refusing to police their behavior. She notes that ethnographers studying topics like sexuality are always at risk of being involved in misunderstandings and having problems with authorities at schools where they are conducting fieldwork. In order to avoid problems as a woman researching sexual topics with young men, Pascoe built on Mandel's (1988) concept of 'least adult' to create the concept of the 'least-gendered' role (Pascoe, 2007: 175). This least-gendered approach helped her 'maintain rapport while simultaneously enforcing a professional distance (and maintaining [her] own dignity)'. Sexuality research with adolescents presents unique ethical challenges that may require the researcher to find innovative solutions.

In summary, the grouping of children by age or development level can be blurry and can vary across disciplines (Williams & Stith, 1980). Still, categorizing children by age or development level reminds researchers that children of vastly different ages pose distinct ethical challenges that argue against any single set of rules for dealing with 'children'.

CHILDREN IN NON-TRADITIONAL CONTEXTS

Ethnographers often work with children that live in non-familial contexts, and these contexts require special ethical considerations. For example, ethnographers have discussed the ethics of participant observation with homeless children (Kovats-Benat, 2006: 10), children at war (Boyden, 2004: 250), detained migrant children (Heidbrink, 2014: 25), and child-aged sex workers (Montgomery, 2001: 9). Such varied contexts require researchers to employ different strategies to ensure that their research is ethical, and power relations and consent/assent are constant concerns.

Heidbrink's (2014) ethnography of Central American migrant youth offers insights into the ethical difficulties of working with undocumented children (pp. 25–26). Heidbrink notes the imbalanced power dynamic between herself and her research subjects, many of whom were undocumented migrant children in federally-funded detention centers. This led her to take special measures, like asking for the consent of a child initially while the child was in detention but also consistently throughout different points of her research, including once the child had been released from detention. Similar ethical issues may arise when working with children in other non-traditional contexts.

Ethical considerations also require that researchers take into account the possibility of misrepresenting and patronizing populations of children. Boyden (2004: 249–250) points out that researchers are 'at risk of infantilizing childhood as a life phase that is unfettered by awareness or responsibility, thereby denying political realities that war-effected populations live with'. Boyden notes, however, that 'children are often more aware and active politically, and more developed morally and socially, than adults generally assume' (2004: 250). This agency means that, while ethical research does, for example, require researchers to go through the proper channels for assent and consent, children may also be their own decision makers. Those decisions should not be undervalued, and researchers must therefore balance ethical 'protections' and respect for a young person's autonomy.

In sum, conducting ethical ethnography with children from non-traditional and non-familial environments requires a deep understanding of children's particular vulnerabilities as minors, while also respecting their capacities to reason and act independently.

GENDER, RACE, AND ETHNICITY

Ethnographers are not only observers, but they are also observed. As Fine and Sandstrom write (1988: 66), 'the characteristics of the researcher do make a difference … The race and sex of the researcher are critical'. Holmes (1998: 27) notes that in Western societies, female ethnographers often have easier access to children as a research population than do males because it is more socially common for females to be around children. Friedl's (2004: 657) research in southwestern Iran similarly notes that,

> [t]o observe girls one has to be in many different people's houses for hours on end, which is difficult for a woman and next to impossible for a man. Observing boys is easier for a male researcher but next to impossible for a female one because she has to cross the strong gender boundaries of 'outdoors' and 'being with males'.

Ethnographers must keep gender in mind when considering the ethics of seeking consent and access to certain populations.

While Holmes (1998: 29) did not find that her ethnicity impacted her ability to conduct research with very young children, other authors argue that race and ethnicity of the researcher do matter. The appendix to Pascoe's analysis is filled with examples of the challenges a researcher faces when working with adolescents, including the ways gender, race, and age affect interactions with youth (2007: 168–175). For example, while observing an extracurricular activity comprised primarily of African American girls, Pascoe, a white researcher, recounts:

> [One girl] ran up [to Pascoe] from the other side yelling, 'She's my nigga!'. I laughed and hugged them both back, happy to be included in such an intimate way, indeed in a way that crossed racial lines. However, I found that because of my own racial and class status I couldn't reciprocate in kind, since for me using the word nigga would be laden with racist history.

This example illustrates that the race and ethnicity of a researcher can impact the ethical decisions that a researcher must make. Thus, gender and race, as well as other characteristics like age and class, introduce additional ethical challenges that researchers must take into account. Additional discussion on this topic by ethnographers would benefit the discipline.

CHILDREN WITH DISABILITIES

In recent decades, social scientists doing research with children have turned their attention to the ethics of research when working with children with disabilities, and sometimes this research poses problems, given assumptions of to what disabled children can assent. As Lewis and Kellett (2004: 199) explain:

> Children and young people are a vulnerable population group, easily exploited by researchers. When disability is added into the equation, the level of vulnerability increases and issues of power relation become more acute. Greater ethical sensitivity and increasing layers of gatekeeping have done much to protect disabled children from becoming easy prey to unscrupulous researchers.

However, researchers today recognize that those with disabilities, including children, form a heterogeneous group with a broad range of capacities and capabilities, placed in a variety of social and cultural contexts (Alderson & Goodey, 1996; Costley, 2000; Detheridge, 2000; Lewis & Kellett, in Fraser et al., 2004; Kellett, 2010; Kliewer et al., 2004). In this short chapter, we cannot address the many ethical concerns that arise when conducting ethnographies with children with disabilities. Instead, we briefly raise the issue of assent.

Communication presents some of the main challenges for researchers in this area. Regarding access, Tina Detheridge (2000: 116) explains that children with severe communication difficulties rarely are able to give assent to participate in research. As a consequence, it is necessary to engage parents or guardians for consent. However, researchers must be careful not to consider such children incapable of making decisions related to their own preferences. Thus, ethnographers must listen to the way the child is able to communicate, seeking alternatives to those abilities with which these children struggle. As explained by Lewis and Kellett (2004: 198), 'if disability research is to become ethically purer and more socially inclusive, then methodological design has to become flexible and creative'.

FINAL THOUGHTS

Ethnographers must deal with ethical issues not only at the beginning of their research, but consistently as challenges arise (Davis et al., 2000: 219). We have provided a brief overview of a set of major ethical concerns that ethnographers of childhood may encounter and have presented examples of how researchers have handled these issues, but we recognize that there are multiple ways to address ethical concerns. After all, quoting Alan France (2004: 181), 'what is unethical to one person may be ethical to another and different situations will require different responses'. Further, because of the nature of ethnography, researchers will not always have a fixed ethical rule to follow in every situation. Instead, ethics serve as a framework of principles that guide the researcher during the research process, rather than as 'laws'.

Throughout this chapter, we have highlighted consent and assent as major ethical concerns of all researchers studying children. However, ethnographers must also keep in mind other issues, such as surveillance, discipline, intervention, and the guidelines of institutional review boards and research ethics committees. While these issues can be extrapolated to research with adults, the literature on children reflects an especially deep concern with power relations and competence.

In closing, we offer four observations to contribute to this critical dialogue. First, faculty members should promote ethical training of students, engaging with the foundational texts on ethics in ethnography with children. Second, researchers should seek feedback on their methods beyond ethics board reviews. This means seeking out the opinions of colleagues before, during, and after the completion of research as well as other adults in the field, and even the children observed. Such feedback can help illuminate potential harms and address ethical puzzles. Third, ethnographers must write about the ethical dilemmas they face in the field, including how they faced and attempted to resolve ethical challenges. This allows researchers to learn from the experiences of others, sensitizing researchers to possible outcomes. Finally, the different social science disciplines must be in dialogue regarding different approaches to ethics and different standards of methodology. If we wish to develop credible perspectives and best practices, such a wide-ranging discussion is essential.

Notes

1 Scholars have used a variety of different terms to refer to children involved in or participating in research, such as 'participant', 'respondent', or 'subject'. However, Ron Iphofen argues that the term 'subject" can be used as a generic label when the kind of 'engagement of those being studied is not known and/or is not central to the discussion" (Iphofen, 2009: 210). Therefore, throughout this paper we will use the term 'subject'.

2 This paper focuses on participant observation and not participatory research. Participant observation is a research method that implies an immersion of the researcher into the subjects' world in order to understand their culture, society, or point of view. Through this method, researchers are interested in observing their subjects in their natural environment. The participation aspect of participant observation usually means that the researcher is the one participating in the subjects' activities. In contrast, participatory research is a style of research that involves subjects in creating and designing research projects, as well as shaping and participating in the different stages of research. Through participatory research, researchers can still conduct interviews, use participant observation, or use other research methods. For more information on participatory research, see *Children in Focus: A Manual for Participatory Research with Children* (Boyden & Ennew, 1997) and *Participant Observation versus Participatory Research: Voices from the Field* (Heinonen, 2013).

3 There are exceptions to this rule. For more information, see 'Giving Information and Seeking Consent' in Iphofen (2009: 66–84).

4 Ron Iphofen describes this approach to consent as 'fluidity' in consenting (2009: 67).

5 The National Centre for Social Research (NatCen) in England has a series of points outlining the information researchers need to offer to children in order to obtain proper consent (Reeves et al., 2007).

6 Carroll-Lind et al. (2006) developed a three-stage consent process for their national survey project involving children in schools. The three stages were asking for consent from the schools, the parents, and the children.

REFERENCES

Alderson, Priscilla and Christopher Goodey. 1996. 'Research with Disabled Children: How Useful is Child-Centered Ethics?'. *Children & Society* 10(2): 106–117.

Alderson, Priscilla and Virginia Morrow. 2011. The Ethics of Research with Children and Young People: A Practical Handbook. London: Sage.

Allen, Gary. 2005. 'Research Ethics in a Culture of Risk', pp.15–26 in *Ethical Research with Children*. Edited by Ann Farrell. Maidenhead, UK: Open University Press.

Ariès, Philippe. 1962. Centuries of Childhood: A Social History of Family Life. New York: Vintage.

Barberin, Gill. 2003. '"To Tell or Not to Tell?": Ethics and Secrecy in Anthropology and Childbearing in Rural Malawi', pp. 133–154 in *The Ethics of Anthropology: Debates and Dilemmas*. Edited by Patricia Caplan. London: Routledge.

Bertran, Marta. 2014. 'Factors That Influence Friendship Choices in Children under 3 in Two Schools: An Approach towards Child Culture in Formal Settings in Barcelona'. *Childhood* 22(2): 187–200.

Boyden, Jo. 2004. 'Anthropology Under Fire: Ethics, Researchers and Children', pp. 237–261 in *Children and Youth on the Front Line: Ethnography, Armed Conflict and Displacement*. Edited by Jo Boyden and Joanna De Berry. New York: Berghahn.

Boyden, Jo and Judith Ennew. 1997. Children in Focus: A Manual for Participatory Research with Children. Stockholm: Rädda Barnen.

Burgess, Robert. 1985. 'The Whole Truth? Some Ethical Problems of Research in a Comprehensive School', pp. 141–162 in *Strategies of Educational Research: Qualitative Methods.* Edited by Robert Burgess. Lewes, UK: Falmer Press.

Carroll-Lind, Janis, James Chapman, Janet Gregory, and Gabrielle Maxwell. 2006. 'The Key to the Gatekeepers: Passive Consent and Other Ethical Issues Surrounding the Rights of Children to Speak on Issues that Concern Them'. *Child Abuse & Neglect* 30(9): 979–989.

Cashmore, Judy. 2006. 'Ethical Issues Concerning Consent in Obtaining Children's Reports on Their Experience of Violence'. *Child Abuse & Neglect* 30(9): 969–977.

Chambliss, Daniel F. and Russell K. Schutt. 2013. *Making Sense of the Social World: Methods of Investigation*. Thousand Oaks, CA: Sage.

Christensen, Pia. 2004. 'Children's Participation in Ethnographic Research: Issues of Power and Representation'. *Children & Society* 18(2): 165–176.

Christensen, Pia and Alan Prout. 2002. 'Working with Ethical Symmetry in Social Research with Children'. *Childhood* 9(4): 477–497.

Costley, Debra. 2000. 'Collecting the Views of Young People with Moderate Learning Difficulties', pp. 163–172 in *Researching Children's Perspectives*. Edited by Ann Lewis and Geoff Lindsay. Buckingham, UK: Open University Press.

Davis John, Nicholas Watson, and Sarah Cunningham-Burley. 2000. 'Learning the Lives of Disabled Children: Developing a Reflexive Approach', pp. 201–224 in *Research with Children: Perspectives and Practices*. Edited by Pia Christensen and Allison James. London: Falmer Press.

Detheridge, Tina. 2000. 'Research Involving Children with Severe Learning Difficulties', pp. 112–121 in *Researching Children's Perspectives*. Edited by Ann Lewis and Geoff Lindsay. Buckingham, UK: Open University Press.

Eder, Donna and William Corsaro. 1999. 'Ethnographic Studies of Children and Youth: Theoretical and Ethical Issues'. *Journal of Contemporary Ethnography* 28(5): 520–531.

Einarsdóttir, Jóhanna. 2007. 'Research with Children: Methodological and Ethical Challenges'. *European Early Childhood Education Research Journal* 15(2): 197–211.

Farrell, Ann (ed.). 2005. *Ethical Research with Children.* Maidenhead, UK: Open University Press.

Fine, Gary Alan. 1987. With the Boys: Little League Baseball and Preadolescent Culture. Chicago: The University of Chicago Press.

Fine, Gary Alan and Kent L. Sandstrom. 1988. *Knowing Children: Participant Observation with Minors.* Newbury Park, CA: Sage.

France, Alan. 2004. 'Young People', pp. 175–190 in *Doing Research with Children and Young People*. Edited by Sandy Fraser, Vicky Lewis, Sharon Ding, Mary Kellett, and Chris Robinson. London: Sage.

Fraser, Sandy, Vicky Lewis, Sharon Ding, Mary Kellett, and Chris Robinson (eds). 2004. *Doing Research with Children and Young People.* London: Sage.

Freeman, Derek. 1983. Margaret Mead and Samoa: The Making and Unmaking of an Anthropological Myth. Cambridge, MA: Harvard University Press.

Friedl, Erika. 2004. 'The Ethnography of Children'. *Iranian Studies* 37(4): 655–663.

Gallagher, Michael. 2009. 'Ethics', pp. 11–64 in *Researching with Children and Young People: Research Design, Method and Analysis.* Edited by E. Kay Tisdall, John M. Davis, and Michael Gallagher. London: Sage.

Gallagher, Michael, Sarah Haywood, Manon Jones, and Sue Milne. 2010. 'Negotiating Informed Consent with Children in School-Based Research: A Critical Review'. *Children & Society* 24(6): 471–482.

Gallo, Sarah. 2014. 'The Effects of Gendered Immigration Enforcement on Middle Childhood and Schooling'. *American Educational Research Journal* 51(3): 473–504.

Graue, M. Elizabeth and Daniel J. Walsh. 1998. *Studying Children in Context: Theories, Methods, and Ethics*. Newbury Park, CA: Sage.

Greene, Sheila and Diane Hogan. 2005. Researching Children's Experience: Methods and Approaches. London: Sage.

Grisso, Thomas. 1992 'Minor's Assent to Behavioral Research Without Parental Consent', pp. 109–127 in *Social Research on Children and Adolescents: Ethical Issues*. Edited by Barbara Stanley and Joan E. Sieber. Newbury Park, CA: Sage.

Grove, M. Annette and David F. Lancy. 2004 'Cultural Models of Stages in Child Development', pp. 47–62 in *Childhood and Adolescence: Cross-cultural Perspectives and Applications*. Edited by Uwe P. Gielen and Jaipaul Roopnarine. Westport, CT: Praeger.

Haggerty, Kevin D. 2004. 'Ethics Creep: Governing Social Science Research in the Name of Ethics'. *Qualitative Sociology* 27(4): 391–414.

Heidbrink, Lauren. 2014. Migrant Youth, Transnational Families, and the State: Care and Contested Interests. Philadelphia, PA: University of Pennsylvania Press.

Heinonen, Paula. 2013. Participant Observation versus Participatory Research: Voices from the Field. June. Rivista di Antropologia Post-Globale.

Hill, Malcolm. 2005. 'Ethical Considerations in Researching Children's Experiences', pp. 61–85 in *Researching Children's Experience: Approaches and Methods*. Edited by Sheila Greene and Diane Hogan. London: Sage.

Holmes, Robyn M. 1998. *Fieldwork with Children*. Thousand Oaks, CA: Sage.

Iphofen, Ron. 2009. Ethical Decision Making in Social Research: A Practical Guide. Basingstoke, UK: Palgrave Macmillan.

James, Allison. 2001. 'Ethnography in the Study of Children and Childhood', pp. 246–257 in *Handbook of Ethnography.* Edited by Paul Atkinson, Amanda Coffey, Sara Delamont, John Lofland, and Lyn Lofland. London: Sage.

Katz, Jack. 2006. 'Ethical Escape Routes for Underground Ethnographers'. *American Ethnologist* 33(4): 499–506.

Kellett, Mary. 2010. Rethinking Children and Research: Attitudes in Contemporary Society. New York: Continuum International.

Kliewer, Christopher, Linda May Fitzgerald, Jodi Meyer-Mork, Patresa Hartman, Pat English-Sand, and Donna Raschke. 2004. 'Citizenship for All in the Literate Community: An Ethnography of Young Children with Significant Disabilities in Inclusive Early Childhood Settings'. *Harvard Educational Review* 74(4): 373–403.

Kovats-Bernat, J. Christopher. 2006. Sleeping Rough in Port-au-Prince: An Ethnography of Street Children and Violence in Haiti. Gainesville, FL: University Press of Florida.

Levey, Hilary. 2009. '"Which One Is Yours?": Children and Ethnography'. *Qualitative Sociology* 32(3): 311–331.

Lewis, Ann and Geoff Lindsay (eds). 2000. *Researching Children's Perspectives*. Buckingham, UK: Open University Press.

Lewis Vicky and Mary Kellett. 2004 'Disability', pp. 191–205 in *Doing Research with Children and Young People.* Edited by Sandy Fraser, Vicky Lewis, Sharon Ding, Mary Kellett, and Chris Robinson. London: Sage.

Librett, Mitch and Dina Perrone. 2010. 'Apples and Oranges: Ethnography and the IRB'. *Qualitative Research* 10(6): 729–747.

Mandel, Nancy. 1988. 'The Least-Adult Role in Studying Children'. *Journal of Contemporary Ethnography* 16(4): 433–467.

Mason, Jan and Suzanne Hood. 2011. 'Exploring Issues of Children as Actors in Social Research'. *Children and Youth Services Review* 33(4): 490–495.

McKechnie, Lynne. 2000. 'Ethnographic Observation of Preschool Children'. *Library & Information Science Research* 22(1): 61–76.

Mead, Margaret. 1928. Coming of Age in Samoa: A Psychological Study of Primitive Youth for Western Civilization. New York: Morrow.

Montgomery, Heather. 2001. Modern Babylon? Prostituting Children in Thailand. Oxford: Berghahn.

Morrow, Virginia and Martin Richards. 1996. 'The Ethics of Social Research with Children: An Overview'. *Children & Society* 10(2): 90–105.

Murphy, Elizabeth and Robert Dingwall. 2001. 'The Ethics of Ethnography', pp. 339–351 in *Handbook of Ethnography.* Edited by Paul Atkinson, Amanda Coffey, Sara Delamont, John Lofland, and Lyn Lofland. London: Sage.

O'Kane, Claire. 2000. 'The Development of Participatory Techniques – Facilitating Children's Views about Decisions which Affect Them', pp. 136–159 in *Research with Children: Perspectives and Practices*. Edited by Pia Christensen and Allison James. London: Falmer Press.

Pascoe, C. J. 2007. *Dude, You're a Fag: Masculinity and Sexuality in High School*. Berkeley: University of California Press.

Pellegrini, Anthony D. 1996. *Observing Children in Their Natural Worlds: A Methodological Primer*. Mahwah, NJ: Lawrence Erlbaum Associates.

Reeves, Alice, Caroline Bryson, Rachel Ormston, and Clarissa White. 2007. *Children's Perspectives on Participating in Survey Research*. London: National Centre for Social Research.

Scarce, Rik. 1994. '(No) Trial (But) Tribulations: When Courts and Ethnography Conflict'.

Journal of Contemporary Ethnography 23(2): 123–149.

Shaw, Catherine, Louca-Mai Brady, and Ciara Davey. 2011. *Guidelines for Research with Children and Young People*. London: NCB Research Centre.

Shea, Christopher. 2000. 'Don't Talk to the Humans: The Crackdown on Social Science'. *Lingua Franca* 10(6). http://www.linguafranca.com/print/0009/humans.html (Retrieved August 17, 2016).

Sieber, Joan. 1993. 'The ethics and politics of sensitive research'. pp. 9–14 *in Researching Sensitive Topics.* Edited by Renzetti, Claire M. and Lee, Raymond M. London: Sage.

Skånfors, Lovisa. 2009. 'Ethics in Child Research: Children's Agency and Researchers' "Ethical Radar"'. C*hildhoods Today* 3(1): 1–22. http://www.childhoodstoday.org/download.php?id=40 (Retrieved August 17, 2016).

Stanley, Barbara and Joan E. Sieber. 1992. *Social Research on Children and Adolescents: Ethical Issues*. Newbury Park, CA: Sage.

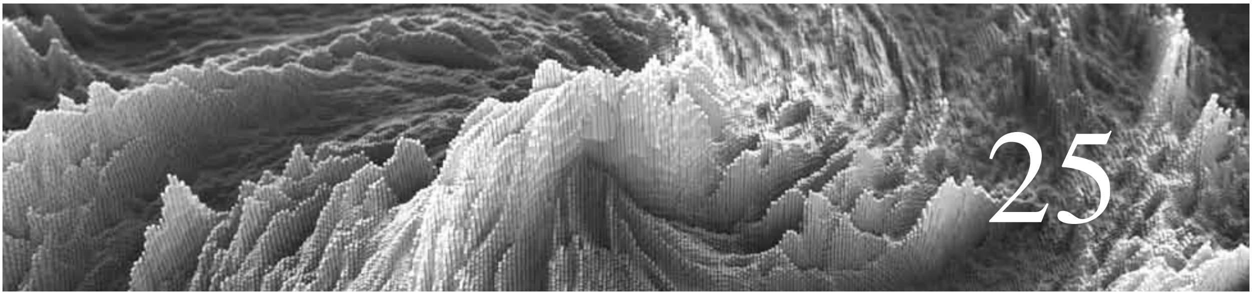
Thompson, Ross A. 1992. 'Developmental Changes in Research Risk and Benefit: A Changing Calculus of Concerns', pp. 31–64 in *Social Research on Children and Adolescents: Ethical Issues*. Edited by Barbara Stanley and Joan E. Sieber. Newbury Park, CA: Sage.

Tolich, Martin and Maureen Fitzgerald. 2006. 'If Ethics Committees Were Designed for Ethnography'. *Journal of Empirical Research on Human Research Ethics* 1(2): 71–78.

van den Hoonaard, Will C. 2002. *Walking the Tightrope: Ethical Issues for Qualitative Researchers*. Toronto: University of Toronto Press.

Wall, John. 2013. 'Childism: The Challenge of Childhood to Ethics and the Humanities', pp. 68–84 in *The Children's Table: Childhood Studies and the Humanities.* Edited by A. M. Duane. Athens, GA: The University of Georgia Press.

Williams, Joyce and Marjorie Stith. 1980. *Middle Childhood: Behavior and Development*. New York: Macmillan.



25

Protecting and Empowering Research with the Vulnerable Older Person

Fiona Poland and Linda Birt

INTRODUCTION

The process of biological ageing is an inevitability of old age, however being socially positioned as a vulnerable, frail older person does not have to be. Recognizing and challenging stereotypes and the stigmatizing attitudes and actions that risk defining an older person as vulnerable, merely because of their chronological age, are not only political actions but ethical imperatives. In challenging stereotypes it becomes possible to make apparent that chronological age alone is not a reliable marker of vulnerability. A person may be positioned, or be perceived to be positioned, as vulnerable by limitations in their physical and cognitive capabilities, by poverty, by contracting social networks, and by dependence on others to fulfil activities of daily living (Age UK, 2014). Environmental and cultural differences will also impact on an older person's vulnerability (Schröder-Butterfill & Marianti, 2006). Being positioned as a vulnerable older person can lead to other people enacting stereotypical and stigmatizing behaviours; for example excluding the person from decisions which affect them, or restricting their access to activities which others deem may be harmful or distressing (Carstensen & Hartel, 2006). Nonetheless, some older people may be vulnerable due to impaired cognition or restricted communication, meaning they need assistance to participate in research activities; they may be at risk of exclusion from research, or of coercion to take part in research.

In this chapter we draw on case examples of recruiting older people with cognitive impairment, using a process of ongoing consent with vulnerable people, and working with older people as co-researchers. These case studies illustrate an imperative to balance the scales of ethical research concerns so that protection is balanced against empowerment. Ethical research with older people should not therefore assume vulnerability and thereby restrict opportunities for involvement in research; rather the ethical researcher needs to remain alert to and responsive to the agentic older person (Poland & Birt, 2016) and take actions to enhance rather than reduce opportunities to support the autonomy of the older person. First, we explore the gerontological discourse, which may position older people as vulnerable, and we provide examples to counteract this position, thereby defining a theoretical space in which to consider research examples.

SOCIALLY POSITIONING OLDER PEOPLE

Simply using the phrase 'older people' is problematic, because alongside the measurable biological changes of ageing, old age is also socially constructed. Perceptions of when someone is classed as 'old' differ. For example, people aged 50–64 have reported old age as starting at 60 years, whereas people aged over 80 have asserted old age as having started at 68 years (Sweiry & Willitts, 2012). Cultural and social attitudes shape when a society names someone as 'old'. Within western developed countries, an increasingly healthy and wealthy older population has political influence; they are consumers of leisure and the mainstay of volunteering activity (Gilleard & Higgs, 2000; Joloza, 2013). Societal expectations of old age can differ in developing countries where the visible markers of old age such as illness and loss of economic activity may be seen much earlier in life. For example being 60 years of age in Africa marks one out as having a long life as less than five per cent of the population reach this age. Yet, in Europe almost a quarter of the population are aged 60 years or over (United Nations, 2013: 91). In applying ethical principles, we would therefore need to consider the situation of an individual older person within the standing of the older population of their country.

The social standing of the older person will also impact on others' perceptions of their vulnerability. Social imaginaries linking old age with vulnerability have been reinforced by the theories of the fourth age. A social imaginary is a set of values, beliefs and expectations that are held within society about a particular group of people and informs a 'background consensus' of what life for that group may be like (Habermas, 1996). The fourth age is a sociological construct and a social imaginary which focuses on the losses associated with ageing, foregrounding others' expectations of old age as a time of increasing frailty, diminishing personal and social resources. It has been defined as a period of 'decrepitude and dependency' (Kertzer & Laslett, 1995), when older people are 'stripped of social and cultural capital' (Gilleard & Higgs, 2010: 123). However, it is perhaps an imaginary that is imposed on the older person by institutions, health care professionals and family rather than one accepted or internalized by the older person themselves (Lloyd et al., 2014). The social imaginary of older people frail and perhaps cognitively impaired can position them as socially vulnerable and so at risk of discrimination and exclusion from research (IIgili et al., 2014). Attending to the potential vulnerabilities of older people can enable researchers to consider ways to enable older people to be autonomous in sometimes subtle ways.

AUTONOMY IN OLDER PEOPLE

Having autonomy means that an individual has free will, can exercise choice and take responsibility for their own actions (Agich, 2004) and so they should have capacity to voluntarily enter into a research study; this is one of the key principles of ethical practice (Beauchamp & Childress, 2009). The *International Ethical Guidelines for Health-Related Research Involving Humans* (2016) reinforces the importance of respecting autonomy while also recognizing the need to protect people whose autonomy is diminished. Guideline 15 and 16 highlight diverse reasons why older people may be regarded as vulnerable including: living within institutional settings such as care homes or prisons, living with a diagnosis of dementia, being in receipt of welfare benefits, lacking political power, experiencing an acute medical emergency, being an immigrant or refugee, or belonging to some ethnic and racial groups (CIOMS, 2016).

Different types of vulnerability can compromise autonomy and therefore also voluntary choice about being, or not being, a research participant. Thus, older people who have mental capacity might still be denied opportunities for voluntary involvement in research. Kipnis (2001) defines six types of vulnerability (cognitive, juridic, deferential, medical, allocation and infrastructural). The older person's susceptibility to any of these will vary in different settings and at different times. For example an acute infection may lead to hallucinations and confusion, which may render the person cognitively vulnerable; yet this is short term and effective treatment will remove this vulnerability. For a person living with dementia, their cognitive ability to make autonomous decisions is likely to decline over time and the researcher may need to look for signs of assent rather than fully informed consent. The concept of assent is applied to a person having sufficient capacity to decide if they want to take part, even if they cannot give full consent. When there is cognitive impairment, a friend or family member may be asked to act as a consultee. Although they cannot legally give consent, they can review the study information and advise the researcher whether they think the person would want to take part in the study.

Autonomous decision-making may be diminished when there is deferential vulnerability. Older people living in institutional care or who rely on others to provide care either in hospital or home setting may experience an internal constraint about acting on their own wishes for fear of conflicting with the wishes of others (Rodgers & Neville, 2007). In these situations they may either be excluded from opportunities for joining research or may experience either internal or external pressure to consent or abstain from studies.

The starting point for inclusive ethical research rests within robust research designs that acknowledge the rights of the individual as well as the processes to protect people. We now draw on examples from research to explore ethical challenges at each stage of the research process.

RECRUITING OLDER PEOPLE: A HIDDEN POPULATION

Older people, and particularly older people with complex needs, are likely to be under-represented in clinical trials as researchers are apprehensive that older people are vulnerable and that co-morbidities may increase risk of 'drop out' (McMurdo et al., 2011; IIgili et al., 2014). While qualitative studies may not place such physical restrictions on recruitment, for recruitment to be inclusive of diversity it needs to avoid over-relying on participants from groups with ready access to community spaces – such as healthy older people living independently – who are able to directly access recruitment material. Restricted access to written material due to cultural norms or literacy differences can also limit peoples' opportunity to interact with written study material (George et al., 2014). To maximize recruitment of older people into any type of research one needs to consider the intersectionality of people's lives and how interconnected social categories such as gender, sexuality, race, religion and class can all either empower or can restrict an older person's access to research opportunities. While recruiting can be challenging, it is vital in health and social care research as older people are the most likely to experience the impact of 'evidence based practice'.

Family, friends and care staff may act as gatekeepers filtering the research information which is made available to the older person (Holloway, 2002; Godwin & Poland, 2015). Gatekeepers monitor information, deciding what to share and what to withhold from the potential research participant. Case study 1 (see Box 25.1) provides an example of gatekeepers' involvement in recruiting people living with dementia. An ethical tension for many gatekeepers is the desire to balance the choice of the older person against safeguarding a vulnerable person from physical, emotional or social harm (Iphofen, 2011). Hughes-Morley et al. (2015) reviewing international literature on recruitment to depression trials illustrated that decisions about the risks versus benefits of taking part in the trial were often subjective. Gatekeepers, such as clinicians, were judging the capacity of depressed patients to give informed consent and whether patients were 'too depressed' to take part (p. 278). Hinton et al. (2000) reported that family and practitioner gatekeepers hindered the recruitment of people with dementia within a Chinese-American community. They were concerned that taking part in research would increase worry in the person with dementia and that the research was intrusive and of no direct benefit to the person. Alongside these concerns for the wellbeing of the vulnerable person were the cultural norms limiting some gatekeepers' recognition of dementia as an illness, viewing it instead as a 'normal' part of ageing. Furthermore, the social stigma linked with dementia leads to families avoiding diagnosis, treatment and research (Hinton et al., 2000), bringing to the fore issues researchers may need to address in order to successfully create opportunities for vulnerable older people to participate in research.

In the United Kingdom the National Institute for Health Research (NIHR) have commissioned a database of care homes where staff are interested in research. The Enabling Research in Care Homes (ENRICH) project provides guidance on research in care home environments for all stakeholders, residents, family, care home staff and researchers (NIHR, 2016); however, access to information about potential research may still be controlled by the care home manager. The ENRICH initiative has the potential to specifically increase access to research for people with dementia as approximately 80% of people living within care homes are living with dementia (Alzheimer's Society, 2014). An ethical tension is that gatekeeper decisions about whether a study is in the 'best interest' of participants may be conditioned by thoughts on whether it is in the 'best interest' of home or care staff. A review on the feasibility and impact of care home research groups highlighted that care home managers were most interested in research which would provide staff support, be of benefit to the residents and cause minimal disruption (Davies et al., 2014). Nonetheless, gatekeepers are essential in recruiting this group of people and also in alerting researchers to forms of language which may be a threat to the older person's sense of self.

Socially isolated older people are potentially vulnerable to coercion or deferential vulnerability (Kipnis, 2001), during recruitment, and data collection. Gatekeepers can create barriers to access but may also over-encourage a person to take part in research. The researcher needs to remain alert to the risk of coercion, as the desire to recruit 'hard to reach' older people to ensure their experiences are heard, may lead to situations which test their ethical right to refuse to participate. Russell (1999), in reflecting on an interview study with social isolated older people, provides an example of an interaction between researcher and an older man: 'When I rang he said "No" he would prefer not to see me. I told him I would only stay 15 minutes and promised not to mention any services' (p. 405). Although no further context is offered in this research note, the statement raises questions over the point when the researcher accepts the 'no' or when they should try to provide further information or make concessions about data collection and so 'capture' the 'hard to reach' person.

Box 25.1 Case study 1: Recruitment of older people with dementia

Older people living with dementia often need informal care from family and friends to help them meet their daily needs. This relationship may be unequal, with the carers undertaking the majority of household and daily living activities. As such, carers can experience stress, burden and loss of opportunities to fulfill their own needs. During recruitment to the 'Talking about memory' study, part of the Promoting Independence in Dementia (PRIDE) programme[1], researchers were surprised by the reticence of some carers to engage with research, as it was not intended to explore their caregiving experiences or evaluate services for carers. It was said by a few people that the research money would be better spent on supporting carers' needs, as without them the vulnerable person would flounder. Some carers restricted access to the person with dementia, stating they and their relative were only interested in drug trials, which might provide a potential cure. This challenged the researcher to consider ways of engaging carers while not promising outcomes that the study may not be able to deliver.

This case study highlights ethical issues to be considered when recruiting potentially vulnerable older people:

- Who benefits from the study, does the information sheet make this clear;
- should incentives, financial or otherwise, be used to encourage engagement;
- how can conflicting expectations between researchers, gatekeepers and participants be addressed; and
- is it ethical to by-pass gatekeepers and provide information directly to potentially vulnerable older people?

In this situation we explained that improvement in the independence and mood of the person with dementia may relieve some stress for the caregiver and we reinforced their vital role in supporting their relative. We also used an online database 'Join Dementia Research' (Alzheimer's Research UK, 2016) to directly recruit people with dementia who lived alone.

THE PROCESS OF INFORMED CONSENT

In ethical research, participants are fully informed of what will happen during the research, what will happen with their data during and after the study, and their right to withdraw from the research without it having consequences. Most research-active countries require research involving human subjects to be overviewed and agreed by an independent research ethics review board; one aspect they typically focus on is informed consent. Ethics review boards are guided by the laws of the land and will often refer to guidance from international organizations supporting people with dementia (Alzheimer Europe, 2010). Legislation such as the UK Mental Capacity Act (2005) in many ways empowers the vulnerable older person because its first principle is that a person is presumed to have capacity unless it is established otherwise. It also serves a protective function as principle 6 states that a person must consider if there is another way of undertaking an action, which will not affect the person's rights.

While legislation and international guidelines provide structure for best practice research, ethical review ethics committees generally make approval for research at local levels. A review of 45 letters sent from English and Welsh Research Ethics Committees (RECs)[2] in response to reviews of studies including people who might lack capacity to give consent (who predominantly will be older people), found that consent and assent forms from third parties were advocated by some RECs even though neither are legally valid (Dixon-Woods & Angell, 2009). Consent or assent can only come from the participant and the third party; usually a relative or friend acts as a consultee, advising whether they feel the person would want to participate in the research. Although Dixon-Woods' study captured data within 18 months of the UK Mental Capacity Act's enactment, researchers must still ensure meeting the need to protect vulnerable people does not forestall such peoples' empowerment and inclusion in research.

Box 25.2 Case study 2: Negotiating consent during data collection

The principles of ongoing consent require the researcher to remain aware of signals that the participant no longer understands their role in the research or wishes to withdraw from the research. Focused ethnographic observation (Knoblauch, 2005) was used to collect data in the 'Talking about memory' study[3]. The researcher accompanied the person with dementia in a variety of social events recording how they interacted with others, the ways in which they were included or excluded from social groups. Prior to starting the observation the participant's capacity to give consent was confirmed and written consent obtained.

The researcher and participant (pseudonym 'Mary'), were at a memory club where guided activities included paired discussions. The researcher was in a participatory role, sitting alongside Mary and joining in on activities. Informed consent had been achieved prior to going to the group. Mary actively took part in the group and frequently told the researcher how much she enjoyed the group and the activities. About an hour into the observation, Mary and the researcher were talking about Mary's holiday and what they enjoyed, when Mary casually asked the researcher 'What is your job then, what do you do?'.

This question generated a number of 'in-the-moment' ethical questions:

- if the participant did not know what the researcher's job was, could they still be giving informed consent;
- what relationship did the participant think she had with the researcher;
- if there was not informed consent, how could the data collection be stopped in ways which did not disrupt the group activity?

On this occasion, the researcher observed that Mary was not distressed or anxious. Following a brief explanation that Mary was involved in a research study and therefore that the role of the researcher was namely to find out what she did during the morning and what she enjoyed about the activity, Mary said: 'Oh I see, I love it here', before continuing to talk about her holiday. The researcher continued to monitor Mary's behavior for any signs that she wanted to withdraw from the research event. On this occasion data collection continued, as following the brief explanation Mary appeared to remember who the researcher was. At the end of the meeting, Mary's husband joined them and the researcher asked Mary if she was happy for notes on the activity to be written up and used in the research. At this point, Mary replied that she was always happy to help others. Mary's husband confirmed this statement and in his role as consultee, commented that Mary liked to take part in research.

The principles of informed autonomous choice to participate in research are procedurally confirmed and recorded through written consent most usually taken before the data collection starts. However Guillemin and Gillam suggest that 'ethics in practice' must accompany procedural ethics (2004: 264). Throughout the research encounter, the researcher's reflexivity enables them to consider their role and the impact of their actions and relationships with participants (Guillemin & Gillam, 2004; Ellis 2007, Iphofen, 2011). A situation which can occur in any interview is where the person 'goes off script', disclosing information or talking of topics not directly within the formal study remit. With people who may be vulnerable due to cognitive impairment or deferential vulnerability, the researcher has to explicitly consider the ethical response in the moment: whether to stop the data collection, how to respond to a disclosure in ways that support the person without leading to further distress. Neither procedural ethics, nor a textbook can provide answers to every possible ethical scenario but reflexivity enables the researcher to remain alert to and learn from potential ethical moments (Guillemin & Gillam, 2004). Case Study 2 (Box 25.2) provides an example of the researcher enacting 'ethics in practice' where their pre-fieldwork preparation had flagged the relevance of 'process consent' (Dewing, 2002, 2007) during research with people with dementia. Dewing suggests that participatory research will involve processes of consent and assent that are sensitive to the person's capabilities and competences rather than narrowing focus and procedures on the basis of diminished verbal or cognitive functions. In process consent, the researcher remains alert to signs of assent and dissent during the data collection.

Even if the older person does not have a diagnosed sensory or cognitive impairment, giving consent at the beginning of a research event may fail to anticipate that data collection can unfold in ways which require the researcher to renegotiate informing the person of their role and responsibilities in the study and the opportunity to exercise their right to withdraw.

CRITIQUING THE ETHICAL IMPLICATIONS OF QUALITATIVE DATA COLLECTION METHODS

Qualitative research can help identify and attune the reader to the detail of ethical issues relevant to different individuals, groups, settings and life course stages and how these may influence research activities and relationships. The processes and approaches used in qualitative research to examine topics, interactions and situations, enable older peoples' experiences to be understood from their perspective and be actively revisited, allowing unexpected issues to come to the fore and to be responded to (Robertson & Hale, 2011). This can be valuable as older people often live in physically and socially complex situations that can impinge on how they can take part in research and on the nature of their relationship with the researcher.

Managing data collection in ethical ways will include taking steps to redress power differentials with those who may have little agency in their daily lives. Therefore, the researcher needs to remain alert to risks of coercion and unrealistic expectations raised by specific features of data collection design and implementation (Iphofen, 2011). Socially-isolated older people may welcome the opportunity to talk to someone who has the time to really listen to them; nonetheless researchers have a responsibility to remain alert to how the desire for social contact can lead to coercion. Wenger (2002), when reporting on methods to interview older people, suggests that lonely older people are likely to respond to a friendly researcher voice on the telephone and therefore will willingly take part and respond to questions (p. 263). While 'rapport' may be encouraged in some aspects of regular research practice, such findings raise important and ethical concerns about research relationships.

An inherent ethical tension in any qualitative research is that the methods used specifically aim to break down barriers between the researcher and participant; some methods are often described as mediating a power relationship (Robertson & Hale, 2011; Lundgren, 2013). In this situation the potentially vulnerable person may come to see the event as a social (friendship) interaction rather than as the 'work' of research (Dickson-Swift et al., 2006). Such 'friendship' requires ethical ways of withdrawing from the research environment and ensuring that the participant is left in a 'safe' place not feeling that they have been tricked into the relationship (Iphofen, 2011). Some researchers keep contact for several years through Christmas cards (Dixon-Swift et al., 2006). Others seem to step out of the researcher role. Russell (1999) reported that in a study exploring social isolation in older people the researcher after hearing of the participant's wish to go to the beach returned a few days later to take the person out for the day. While this may have been a once only act of kindness it raises questions about the 'professional' role of the researcher and the boundaries of research relationships. The author does not report on how this was managed within a predefined ethical framework that usually sets out researcher/participant boundaries.

Complex communication difficulties, due to stroke or cognitive impairment, often mean the ubiquitous one-off, semi-structured interview will be too clumsy a tool for data collection. Yet, there is an ethical imperative to hear the 'voice' of these groups particularly as caregivers' opinions of situations and experiences often differ from those of the person living with dementia (McKeown et al., 2010) and carers are often easier to access. Empirical work within the field of dementia studies provides examples of innovative ways of collecting data which can meet both the need for data which is relevant to the specific views and circumstances of these research participants, and enables them to remain agentic in the research iteration (Nygård, 2006).

There is an imperative to understand not only the narrative of the older person's life but also the emotional dimensions of their life. Vulnerable older people, who have language and cognitive difficulties, may more readily express how they feel in the moment rather than recalling information about past or future events. Godwin, when conducting research with people with moderate to severe dementia (Godwin & Poland, 2015), specifically designed data collection conversations to base them firmly on the participant's abilities to express their feelings, supplementing this with her detailed observations of actions and interactions, rather than relying on their recall of factual events. This approach enabled a nuanced understanding of the agency these highly dependent people were still able to generate and that the 'delusions' they articulated could be seen as creating comfort and fulfilment for themselves rather than simply pathological manifestations.

Collecting data while the participant, like Mary mentioned above, is engaged in their everyday activities provides a non-threatening data collection environment, although to interact ethically the researcher needs to repeatedly check the participant's continuing awareness of the interaction as a research event (see Case study 2, Box 25.2). A 'walking interview' may take place within the home, or in the neighbourhood, or in a public building such as an art gallery (Nygård, 2006; Clark & Emmel, 2010). As with any research, guidance will be provided about the purpose and length of data collection but the participant takes the lead in where to walk or take the researcher, and can build in every-day events such as visits to the shop. While the method has predominantly been used to gather information about how people conceptualize and articulate their neighbourhoods and their social networks (Clark & Emmel, 2010; Evans & Jones, 2011), it could be adapted for older people who may have restricted mobility. For example, a walking interview around the care home enables the person to show the researcher their favourite spaces or those areas where they feel less at ease. The method provides the opportunity for participants to show, rather than merely to rely on recall and language to describe emotions and events, prompting more discussion than might happen in the interview room. If verbal communication is severely impaired perhaps use of storyboards, talking mats, art and drama may provide opportunities for sharing lived experiences, thereby increasing opportunities for inclusion.

Most qualitative data collection methods are designed to encourage the participant to feel comfortable to share often sensitive experiences and this can create spaces where people feel 'safe' to disclose issues of concern, presenting the researcher with ethical challenges (Guillemin & Gillam, 2004). Many vulnerable older people are dependent on others to provide care and support (Weicht, 2015). These care relationships may be grounded within behaviours which to the outsider appear abusive but which are constructed by the carer and the older person and which are mutually beneficial. Locher et al. (2006) report on the ethical challenges faced when working with a vulnerable group of homebound older people. In one example, an older blind lady was mistaking hydrocortisone cream for toothpaste. When the researcher spoke with her about this, the lady requested that other services were not brought in as she wished to remain at home and needed the help of her family to do that (p. 163). In this case the researcher decided not to report the incident. In each research event, the researcher will need to appropriately translate ethical principles into the specific circumstances of any particular interview and any particular relationship with the interviewee.

While guidance on ethical procedure will be available, ultimately the researcher will need to balance concerns about the safety and wellbeing of the person against the risk of too quickly excluding them from research due to vulnerability. In each case of ‘ethics in practice’, the researcher will need to be able to explain and justify their decision. While in some situations legislation will enforce practice, on other occasions the ‘correct’ action will depend on a variety of factors. These will include: the likelihood and consequences of the perceived risk, the professional code of practice of the researcher, and the ability the older person has to understand the consequence of their disclosure or actions. Tolich (2016) provides real-life examples of how researchers have addressed a range of ‘ethics in practice’ situations, which enable researchers to think beyond procedural ethics.

WORKING WITH OLDER PEOPLE AS CO-REASERCHERS

Older people can and should be involved in research that has a potential impact on their lives. Before the 1980s, it was assumed that older people with cognitive impairment could not take part in research; it is now more usual to include these groups as participants in research (McKeown et al., 2010). A recent drive has been to include older people as ‘experts’ advising on research objectives, service evaluations and providing specific insights into research processes, including study information and dissemination (St Clair Tullo et al., 2015; Backhouse et al., 2016). While many argue that patient and public involvement (PPI) is empowering for the layperson and respects their status as experts, others question its impact. Carey (2010) provides a robust critique on whether PPI can shift inequitable researcher-participant relationships, arguing that practices can be oppressive and disempowering. Such criticisms have not dampened enthusiasm for public involvement in research, with opportunities for those living with dementia to be agentic in developing research agendas and raising the profile of research in the field (Litherland, 2015). The trajectory of patient involvement now encompasses the methodology of co-research.

In co-research, there is a partnership between the researcher and the layperson, who is usually an expert by experience, with each bringing their own skills and experiences to the data collection and analysis phase of the study (Clough et al., 2006). However, often the most vulnerable in any group of people are excluded from participatory approaches. Littlechild, Tanner and Hall (2014) report on the processes and outcomes of a study, which sought to redress exclusionary practices, highlighting the advantages, disadvantages and ethical concerns of such an approach. Their study included older people with dementia and those from minority ethnic groups as co-researchers on a project exploring care transitions in four sites in England in the UK (Tanner, 2012; Littlechild et al., 2014). A particular ethical challenge arising from their work was the need to make transparent at the beginning of the research process that while the research results could inform an understanding of health and social care practice, the research may not be instrumental in changing policy or practice (Littlechild et al., 2014).

WAYS FORWARD AND CONCLUSIONS

The term ‘*vulnerable older people*’ brings to mind stereotypical images of frail older people either sitting alone at home isolated from communities, or lining the walls of the care home, where they pass time uncommunicatively until death takes them. These are the social imaginaries within discourses of the fourth age. Here we have sought to dispel such negative stereotypes by identifying issues and illustrating ways to include vulnerable older

Box 25.3 Case study 3: Working with older people as co-researchers

The PERFECTED study (Peri-operative Enhanced Recovery hip FracturE Care of paTiEnts with Dementia) study[4] aimed to address the experiences of people with dementia and their carers when being treated for hip fractures in hospitals. An active service user and carer panel supported the research team in developing and implementing the research in practice. Co-researchers were recruited to work with the researchers on interview and observational data collection and analysis. Involving older people as co-researchers presented distinct ethical challenges. In this UK-based study, co-researchers, although not of employed status and always working with a member of the university research team, were required to undergo formal checks of their suitability including health status checks and review of any previous criminal offences. This level of scrutiny led some people who expressed an interest in the role to withdraw from what they perceived as an intrusive legal procedure. Some withdrew due to time delays between expressing an interest and starting the study. The final remaining group of three co-researchers were older adults but they did not have the characteristics one might attribute to vulnerable older people – all were well educated with few physical difficulties and were previously employed in the care professions. The co-researchers undertook observations of hospital care of people with dementia immediately before and after their operations and interviewed carers. The ethical challenges here were:

- Conflicting expectations of what counted as data and what should be recorded, where some co-researchers wanted to add personal judgemental reflections to their observation report;
- The need to protect the co-researcher from physical and emotional distress in encountering challenging environments such as hospital wards delivering acute care to patients in trauma;
- Ensuring the co-researcher remains aware that their role is voluntary.

The researcher provided emotional support before and after the observation to ensure that the co-researcher was minimally distressed. There were some distressing incidents as when, for example, during a telephone interview, a participant became tearful and upset. The co-researcher with direct lived experience was able to support the participant in ways the researcher would have found difficult. However, following data collection, the researcher was then able to reciprocate by debriefing and emotionally supporting the co-researcher. Follow-up information on the co-researchers' experience of the role was not available on this study.

people in qualitative research so as to promote their agency and protect their ethical right to informed choice. It is clearly a challenge to include vulnerable older people, but simply to exclude so as to reduce potential risk to them or to ease ethical review approval reproduces the negative social imaginary and increases exclusion of older people from studies which directly impact on their lives (Iphofen, 2011).

During recruitment, the researcher needs to share the potential benefits and risks of the study in ways relevant to the gatekeeper and older people. Such discussion may give the gatekeeper confidence that the older person will be protected and that this may produce better quality research which can inform practice, encouraging them to share study information with the older person. Information technology (IT) is increasing ways to involve vulnerable older people in research. Despite the remaining age gap in access to information technology (Milligan & Passey, 2011), older people are increasingly using computers and the Internet, and as they become the oldest-old they are likely to continue to use IT. The development of online recruitment databases and research-studies advertising makes detailed information about studies available without the need to leave their homes. Direct access to information reduces the scope for the gatekeeper role, although this may risk older people being inundated with research information. To manage this risk, researchers will have to ensure effective means of communication which respect participant confidentiality while also minimizing risks of people being swamped by 'phishing' emails about studies they 'might' be interested in. More direct involvement of older people in research through online sources therefore raises fresh ethical questions.

Vulnerable older people living in care homes may need to negotiate the permission of home staff to take part in research. However, the ENRICH programme, supporting research in care homes, while still in its infancy, suggests that more care homes are actively interested in promoting research, which can include their older residents. This is essential, for results may directly influence the older person's physical, emotional or medical care. Again, researchers involving frail, older people dependent on others for care need to be extra-aware of the potential for deferential vulnerability and coercion.

Fully informed consent is the bedrock of ethical research, but when working with vulnerable people, is rarely straightforward and the standard written consent at the beginning of a study does not acknowledge the ways in which research questions may develop through the research or how consent may be ongoing (Tolich, 2016). A process consent approach can ensure understanding and consent are renegotiated throughout the study and confirmed at the end. Other ethical challenges around role boundaries may arise if participants are more likely to construct data collection events as opportunities for friendship (Iphofen, 2011). The researcher makes ethical decisions about whether to continue the research, based not only on the signed consent form but also on the participant's actions.

Wider use of innovative participatory data collection methods can enable the most vulnerable, including those with communication difficulties, to have a 'voice' within the research community. Research using the arts and participatory methods, creates novel ways of recording and understanding the experiences of those with cognitive or communication difficulties. By relying less on the semi-structured interview, the qualitative researcher may be more inclusive of those without standard spoken and written language. Nonetheless, including the most vulnerable people can raise challenges in ending the research relationship where decisions about mitigating harm and distress must sensitively reflect the nature and circumstances of the researcher-participant relationship.

Co-research is a natural development from the patient and public involvement agenda of the 1980s, perhaps marking some shift of power away from academic institutions towards a research future led by and co-constructed with older people.

The desire to include and empower the older person will need to be balanced against ethical and often, now, legal requirements to protect vulnerable older people who may need support to make fully informed decisions. This discussion of ethical issues in recruitment, consent, data collection and co-research provides a starting point for asking questions and finding answers specifically applicable to each research event and each researcher-participant interaction. Qualitative research with older people, and to include the most vulnerable, will therefore always pose ethical challenges for the researcher, but the reflexive ethical researcher will make decisions in practice to 'ensure no harm'.

Notes

1 The PRIDE study is a five-year program (2014–2019) that explores social independence for people with dementia. The study recruits people with mild to moderate dementia. Forthcoming publications can be accessed at http://www.institutemh.org.uk/x-research-/pride

2 Ethical review committees ensure that research studies comply with international and local ethical practices. They can suggest amendments to the study and have a surveillance role. They can approve, amend or stop a study. Further details on the role of ethical review committees can be found at http://www.who.int/ethics/Ethics_basic_concepts_ENG.pdf

3 'Talking about memory' is part of the PRIDE study, see Note 1.

4 The PERFECTED study is a five-year program (2014–2019) aiming to develop an improved pathway of care for people with dementia admitted to hospital with hip fracture. Researchers work with lay colleagues to undertake data collection and analysis. Further information at www.perfected.ac.uk

REFERENCES

Age UK (2014) *Improving later life. Vulnerability and resilience in older people*. London: Age UK. http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Final_Improving_Later_Life_4-Vulnerability.pdf?dtrk=true

Agich, G.J. (2004) *Autonomy and long-term care*. Oxford: Oxford University Press.

Alzheimer Europe (2010) *Legal capacity and proxy decision making.* http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2010-Legal-capacity-and-proxy-decision-making

Alzheimer's Research UK (2016) *Getting patients involved in dementia research*. http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/ARUK-Getting-patients-involved-in-dementia-research-Policy-Statement-Jan16.pdf

Alzheimer's Society (2014) *Dementia 2014 report statistics*. https://www.alzheimers.org.uk/statistics

Backhouse, T., Kenkmann, A., Lane, K., Penhale, B., Poland, F., and Killett, A. (2016) 'Older care-home residents as collaborators or advisors in research; a systematic review', *Age and Ageing*, 1–9. doi: 10.1093/ageing/afv201

Beauchamp, T.L. and Childress, J.F. (2009) *Principles of biomedical ethics* (6th Edn). Oxford: Oxford University Press.

Carey, M. (2010) 'Should I stay or should I go? Practical, ethical and political challenges to 'service user' participation within social work research', *Qualitative Social Work*, 10(2): 224–243. doi: 10.1177/1473325010362000

Carstensen, L.L. and Hartel, C.R. (2006) 'Opportunities lost: the impact of stereotypes on self and others'. In L.L. Carsten and R.C. Hartel (eds) *When I'm 64* (Chapter 6). National Research Council. doi: 10.17226/11474

Clark, A. and Emmel, N. (2010) *Using walking interviews.* http://eprints.ncrm.ac.uk/1323/1/13-toolkit-walking-interviews.pdf

Clough, R., Green, B., Hawkes, B., Raymond, G., and Bright, L. (2006) *Older people as researchers: evaluating a participative project*. York, UK: Joseph Rowntree Foundation.

Council for International Organizations of Medical Sciences (CIOMS) (2016) *International ethical guidelines for health-related research involving humans.* Geneva. https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf

Davies, S.L., Goodman, G., Manthorpe, J., Smith, A., Carrick, N., and Iliffe, S. (2014) 'Enabling research in care homes: an evaluation of a national network of research ready care homes', *BMC Medical Research Methodology*, 14: 47. doi: 10.1186/1471-2288-1447

Dewing, J. (2002) 'From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have dementia', *Dementia*, 1(2): 157–171. doi: 10.1177/147130120200100204

Dewing, J. (2007) 'Participatory research: a method for process consent with persons who have dementia', *Dementia*, 6(1): 14–25. doi: 10.1177/1471301207075625

Dickson-Swift, V., James, E.L., Kippen, S., and Liamputtong, P. (2006) 'Blurring boundaries in qualitative health research on sensitive topics', *Qualitative Health Research*, 16(6): 853–871. doi: 10.1177/1049732306287526

Dixon-Woods, M. and Angell, E.L. (2009) 'Research involving adults who lack capacity: how have research ethics committees interpreted the requirements?', *Journal of Medical Ethics*, 35(6) 377–381. doi: 10.1136/jme.2008.027094

Ellis, C. (2007) 'Telling secrets, revealing lies: relational ethics in research with intimate others', *Qualitative Inquiry*, 13(1): 3–29. doi: 10.1177/1077800406294947

Evans, J. and Jones, P. (2011) 'The walking interview: methodology, mobility and place', *Applied Geography*, 31(2): 849–858. doi: 10.1016/j.apgeog.2010.09.005

George, S., Duran, N., and Norris, K. (2014) 'A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders', *American Journal of Public Health*, 104(2): e16–e31. doi: 10.2105/AJPH.2013.3017061

Gilleard, C. and Higgs, P. (2000) *Cultures of ageing: self, citizen and the body*. Harlow, UK: Pearson Education Limited.

Gilleard, C. and Higgs, P. (2010) 'Aging without agency: theorizing the fourth age', *Aging & Mental Health*, 14(2): 121–128. doi: 10.1080/13607860903228762

Godwin, B. and Poland, F. (2015) 'Bedlam or bliss? Recognising the emotional self-experience of people with moderate to advanced dementia in residential and nursing care', *Quality in Ageing and Older Adults*, 16(4): 235–248. doi: 10.1108/QAOA-08-2015-0038

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "ethically important moments" in research', *Qualitative Inquiry*, 10(2): 261–280. doi: 10.1177/1077800403262360

Habermas, J. (1996) *Between facts and norms: contributions to a discourse theory of law and democracy* (translated W. Rehg). Cambridge: Polity Press.

Hinton, l., Guo, Z., Hillygus, J., and Levkoff, S. (2000) 'Working with culture: a qualitative analysis of barriers to the recruitment of Chinese-American family caregivers for dementias research', *Journal of Cross-Cultural Gerontology*, 15(2): 119–137.

Holloway, I. (ed.) (2002) *Qualitative research in health care*. Maidenhead: Open University Press.

Hughes-Morley, A., Young, B., Waheed, W., Small, N., and Bower, P. (2015) 'Factors affecting recruitment into depression trials: systematic review, meta-synthesis and conceptual framework', *Journal of Affective Disorders,* 172: 274–290. doi: 10.1016/j.jad.2014.10.005

Ilgili, O., Arda, B., and Munir, K. (2014) 'Ethics in geriatric medicine research', *Turki Geriatri Derg,* 17(2): 188–195. Online at PubMed Central (PMC) January 1, 2015. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4257472/pdf/nihms611678.pdf

Iphofen, R. (2011) *Ethical decision-making in social research: a practical guide*. Basingstoke, UK: Palgrave Macmillan.

Joloza, T. (2013) *Measuring national wellbeing: older people's leisure time and volunteering*. London: Office of National Statistics. http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171766_305915.pdf

Kertzer, D.I. and Laslett, P. (eds) (1995) *Aging in the past: demography, society, and old age*. California: University of California Press.

Kipnis, K. (2001) Vulnerability in research subjects: a bioethical taxonomy. In *Ethical policy and issues in research involving human participants: Volume II: Commissioned papers and staff analysis*, G1–G13. Bethesda, MD: National Bioethics Advisory Commission. https://bioethicsarchive.georgetown.edu/nbac/pubs.html

Knoblauch, H. (2005) 'Focused ethnography', *Forum: Qualitative Social Research*, 6(3): 1–10. http://www.qualitative-research.net/index.php/fqs/article/view/20/43

Litherland, R. (2015) *Developing a national user movement of people with dementia*. York, UK: Joseph Rowntree Foundation. https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia

Littlechild, R., Tanner, D., and Hall, K. (2014) 'Co-research with older people: perspectives on impact', *Qualitative Social Work*, 14(1): 18–35. doi: 10.1177/1473325014556791

Lloyd, L., Calnan, M., Camerson, A., Seymour J., and Smith, R. (2014) 'Identity in the fourth age: perseverance, adaptation and maintaining dignity', *Ageing & Society*, 34(1): 1–19. doi: 10.1017/S0144686X12000761

Locher, J.L., Bronstein, J., Robinson, C.O., Williams, C., and Ritchie, C.S. (2006) 'Ethical issues involving research conducted with homebound older adults', *The Gerontologist*, 46(2): 160–164. doi: 10.1093/geront/46.2.160

Lundgren, A.S. (2013) 'Doing age: methodological reflections on interviewing', *Qualitative Research*, 13(6): 668–684. doi: 10.1177/1468794112459670

McKeown, J., Clarke, A., Ingleton, C., and Repper, J. (2010) 'Actively involving people with dementia in qualitative research', *Journal of Clinical Nursing*, 19(13–14): 1935–1943. doi: 10.1111/j.1365-2702.2009.03136.x

McMurdo, M.E.T., Roberts, H., Parker, S., Wyatt, N., May, H., Goodman, C., Jackson, S., Gladman, J., O'Mahony, S., Ali, K., Dickinson, E., Edison, P., and Dyer, C. (2011) 'Improving recruitment of older people to research through good practice', *Age and Ageing*, 40(6): 1–7. doi: 10.1093/ageing/afr115

Mental Capacity Act 2005 (Chapter 9) London: HMSO.

Milligan, C. and Passey, D. (2011) *Ageing and the use of the internet: current engagement and future needs*. Oxford: Nominet Trust. https://www.nominettrust.org.uk/sites/default/files/NT%20SoA%20-%20Ageing%20and%20the%20use%20of%20the%20internet_0.pdf

National Institute for Health Research (2016) *The ENRICH toolkit: Enabling research in care home*; a simple guide for researchers, care home staff and residents. http://www.enrich.nihr.ac.uk

Nygård, L. (2006) 'How can we get access to the experiences of people with dementia? Suggestions and reflections', *Scandinavian Journal of Occupational Therapy*, 13(2): 101–112. doi: 10.1080/11038120600723190

Poland, F. and Birt, L. (2016) 'The agentic person: shifting the focus of care', *Aging & Mental Health'*, 20(8): 771–772. doi: 10.1080/13607863.2016.1146873

Robertson, L. and Hale, B. (2011) 'Interviewing older people: relationships in qualitative research', *The Internet Journal of Allied Health Sciences and Practice*, 9(3): 1–8.

Rodgers, V. and Neville, S. (2007) Personal autonomy for older people living in residential care: an overview, *Nursing Praxis in New Zealand*, 23(17): 29–36.

Russell, C. (1999) 'Interviewing vulnerable old people: ethical and methodological implications of imagining our subjects', *Journal of Aging Studies*, 13(4): 403–417.

Schröder-Butterfill, E. and Marianti, R. (2006) 'A framework for understanding old-age vulnerabilities', *Ageing & Society*, 26(1): 9–35. doi: 10.1017/S0144686X05004423

St Clair Tullo, E., Robinson, L., and Newton, J. (2015) 'Comparing the perceptions of academics and members of the public about patient and public involvement in ageing research', *Age and Ageing*, 44(3): 533–536. doi: 10.1093/ageing/afu193

Sweiry, D. and Willitts, M. (2012) *Attitudes to age in Britain 2010/11*. London: Department for Work and Pensions. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214361/ihr7.pdf

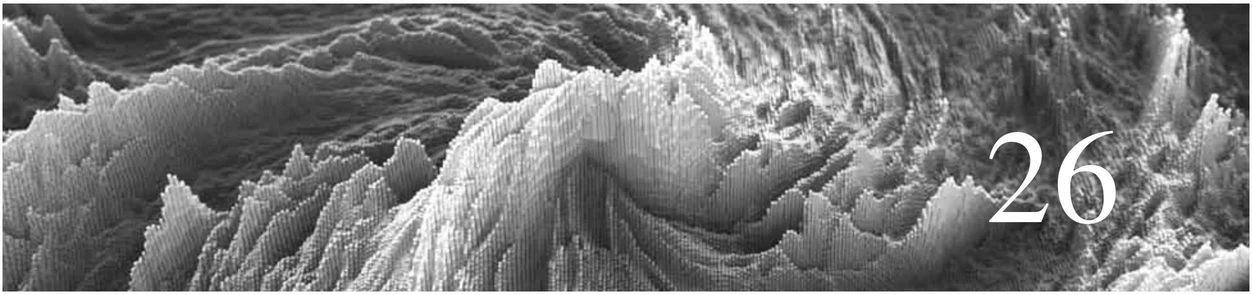
Tanner, D. (2012) 'Co-research with older people with dementia: experiences and reflections', *Journal of Mental Health*, 21(3): 296–306. doi: 10.3109/09638237.2011.651658

Tolich, M. (ed.) (2016) *Qualitative ethics in practice.* Walnut Creek, CA: Left Coast Press.

United Nations, Department of Economic and Social Affairs, Population Division (2013). *World Population Ageing 2013.* ST/ESA/SER.A/348.

Weicht, B. (2015) *The meaning of care: the social construction of care for elderly people*. London: Palgrave Macmillan.

Wenger, G.C. (2002) 'Interviewing older people'. In J. F. Gubrium and J. A. Holstein (eds) *Handbook of interview research: context and method*. Thousand Oaks, CA: Sage. pp. 259–278.



26

Ethics Unleashed: Developing Responsive Ethical Practice and Review for the Inclusion of Non-Human Animal Participants in Qualitative Research

Emma Tumilty, Catherine M. Smith,
Peter Walker and Gareth Treharne

INTRODUCTION

Traditionally, animal ethics committees evaluate situations in which non-human animals will be 'experimented on'. In this process, the risks of harm to the non-human animal are weighed against the benefits to humans. Human research ethics committees are also human-centric. Our relationships with non-human animals are changing, and consequently, these changes are being investigated via an increasing body of research. Service animals (animals used to support people with physical or mental impairment either through therapy or assistance) are more prevalent in society and social service provision, and the therapeutic benefits of companion animals are increasingly recognized (see, for example, Marr et al., 2000; Nimer & Lundahl, 2007; Fine, 2011; Bernabei et al., 2013; Kamioka et al., 2014). Rather than 'experimenting on' animals, this body of research investigates the therapeutic relationship between human and non-human animals in the organizational or home setting (see selection: Benda et al., 2003; Berns, 2013; Nagasawa et al., 2015; Barker et al., 2016; Campbell et al., 2016; Burgon et al., 2017). Included in this body of research are qualitative inquiries exploring the human experience with companion and service animals. Therapeutic human-animal interaction studies call for a revision of our conception of the non-human animal in research. Such studies require the application of new thinking both for researchers and ethics committee members in supporting ethical research practice. In this chapter, we provide background on the shifts in thinking regarding non-human animals in the service and companion animal setting. We also propose an ethical framework for considering animals in service and research settings. We then outline how we think traditional ethical principles in research can be applied to non-human animals in a responsive manner recognizing their sentience and capacities for awareness of their own wellbeing. We conclude with suggestions for further work in this area.

THE CHANGE IN THE LANDSCAPE

The 'Animal Turn' has led to recognition of the nature and inner lives of non-human animals; their relationships to us, as well as our obligations to them (Weil, 2010). This shift in paradigm has compelled human recognition of non-human animal sentience, for which animal rights' activists and theorists had been arguing for some time (Regan, 1987; Singer, 1995). As these notions take hold, work to advocate for non-human animal personhood (Seps, 2010; Francione, 2010; also see: https://www.nonhumanrightsproject.org/) is taking place; there are arguments for animal citizenship (Donaldson & Kymlicka, 2011); and work exploring the extent of our relationships (Serpell, 1996; Grandgeorge & Hausberger, 2011) is occurring. Global societal changes are somewhat inconsistent in response to this recognition. More countries are moving away from cosmetic animal testing ('Worldwide Progress', NVAS website). Some universities are exploring other options for animal testing in medical research: Johns Hopkins University for example, has the dedicated Center for Alternatives to Animal Testing (http://caat.jhsph.edu/). Vegan and vegetarian diets are also on the rise with an increase in plant-based meat and milk substitutes, and more dedicated food blogs and restaurants appearing all the time (Cormack, 2016; Quinn, 2016). In some countries, a growing desire for humans to provide an enriched life for companion animals has seen unprecedented economic growth in the companion animal industry, supplying toys, bedding, clothing and even a TV channel (DogTV https://www.dogtv.com/) (Hoorspool, 2013). Conversely, many animals (both wild and domesticated) are still subject to cruelty, abuse, neglect and death at the hands of humans.

Along with this, we have also seen a rise in the use of Animal-Assisted Interventions and Activities (AAI & AAA – terms defined by the International Association of Human Animal Interaction Organizations (IHAIO); IAHAIO, 2014) stories from stress pigs at airports (Meltzer, 2016) to horseback riding for spasticity (Cherng et al., 2004) appear in the media and the research literature. As these complex activities increase in popularity, research concurrently aims to investigate perceptions, feasibility, acceptability, effectiveness and efficacy (Medical Research Council, 2006). These research objectives frame the non-human animal's role as that of an 'intervention'. Conversely, organizations providing governance for AAI and AAA frame the non-human animal as an equal (an active) partner in the intervention (along with the patient, the human therapist and the animal trainer/owner) (Animal Assisted Intervention International, 2015). The relationship between a human and their companion dog can also be considered therapeutic and (often) mutually beneficial. These benefits are seen both in healthy adults and adults with long-term health conditions where the non-human animal can be seen as an active therapeutic partner. For example, in one study by Smith et al. (2017) a human participant discussed their experience, how they and their dog helped each other to recover from coinciding surgery:

> The walks are just as beneficial for him [participant's dog] and his dodgy legs as they are for me and my back … sometimes I think that like, because we've both got, you know, we've both been through challenging surgeries and long recoveries and we've both got bits of metal and stuff in us, so we are sort of like a pair now.

For some AAI/AAA and companion animal settings, relationships and interventions could be said to be mutually beneficial or therapeutic. There are of course times, both in the service setting and companion animal setting where relationships are not mutually beneficial (see, for example, Hunt et al., 2012), but this idea of mutuality both for benefit and harm needs to be explicitly considered. Research ethics theory and practice does not currently recognize let alone accommodate the non-human animal in review beyond traditional animal testing; nor does it recognize or consider the potential for mutually therapeutic relationships between two sentient but different beings which requires redress.

As stated, the service animal literature describes the non-human animal as an active participant, i.e. one that through actions evokes responses (Animal Assisted Intervention International, 2015). These actions are sometimes brought about by extensive training (a mobility assistance dog for example) and/or are an inherent non-human animal characteristic, including benign predispositions to humans (such as a companion dog). This theorizing of animal as therapeutic partner however moves them beyond the 'non-human animal to be experimented on' or 'passive intervention' to the 'non-human animal to experiment/conduct research with'. In some respects this parallels the 'preceding' change in depiction of humans as research 'subjects' to the increasing concern that they be seen as 'participants' and so less implicitly 'passive' in their relationship to research. Whilst the nature of these non-human animal roles are recognized by organizations, individual researchers, and humans with companion animals, there is currently no explicit ethical framework for research practices in this area. In New Zealand, animal ethics committees and human ethics committees adapt to these trends in an ad hoc manner. This absence prompted us to explore what such an ethical framework for qualitative research could look like.

What we are describing is the changing relationships between human and non-human animals, moving from the left of Figure 26.1 towards the right – essentially a shift in the balance of power in the relationship. What occurs in contemporary society is that rather than all animals moving from left to right on this spectrum of power relationships, different species of animals sit in different places.

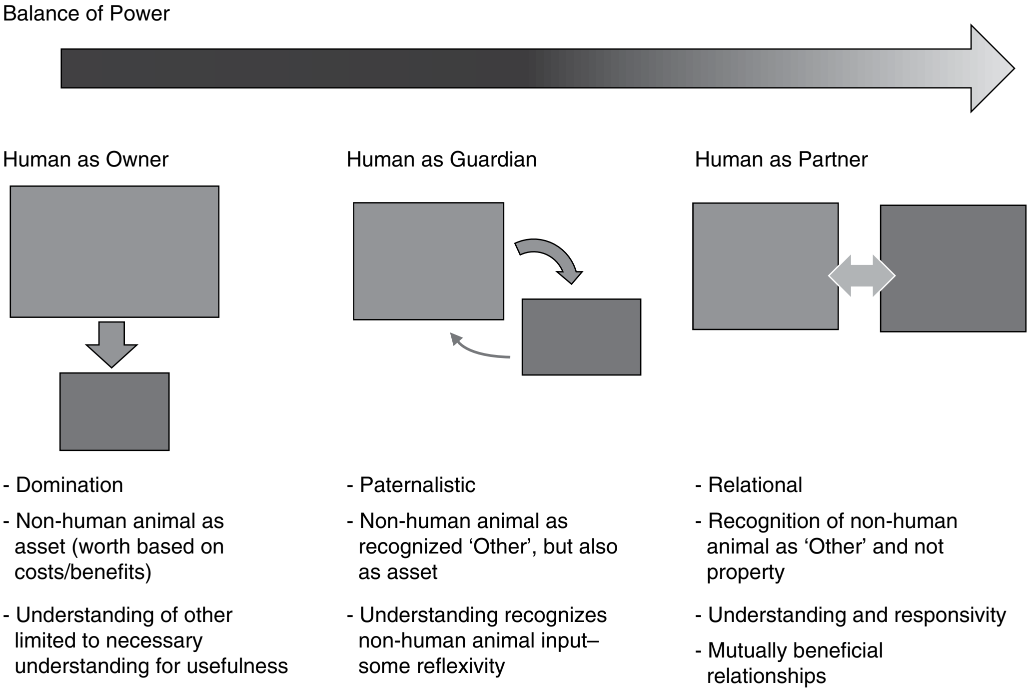


Figure 26.1 Power relationship between human and non-human animals as a spectrum

Furthermore, different members of the same species can be located on different points of this balance of power spectrum in different settings. So for instance, food animals would still be located to the left of the power spectrum, while guide dogs, might arguably be on the right or at least much closer to the right. Horses used in the military or police maybe closer to the right but other horses, especially those who have become old or lame, are often located to the left and used for meat (often for pet food). Guide dog training and police dog training are extremely different in their conception of the dog as tool or partner (using positive versus negative behavioural techniques for example (Walker & Tumilty, forthcoming), showing that within species differentiation can also occur.

It is worth noting, however, that legislation currently perceives the non-human animal as property and 'property cannot acquire personhood' (Ryan, 2011: 114). In addition, an offence against the animal by a non-owner is a property violation, but an offence against an animal by an 'owner' is an offence under law and therefore the Crown in New Zealand.

In our previous work we made two suggestions that we hope to be useful in guiding this thinking. In the first, Walker and Tumilty (2015) suggest that the type of roles that non-human animals have in these situations can be quite different and these need to be categorized in order for practices to be responsive to the degree to which a non-human animal is employed. Second, Smith, Tumilty, Treharne & Walker (forthcoming) propose that ethical principles traditionally used for humans can meaningfully be adapted to accommodate animals when we recognize them as sentient beings with whom we have meaningful interactions.

ETHICAL FRAMEWORK FOR AA INTERVENTIONS AND ACTIVITIES

There is currently little in the way of regulation for service animals. Private organizations have voluntary guidelines and training manuals and, there are some animal welfare provisions within legislation (these vary internationally). As mentioned earlier, the IAHAIO White Paper (2014) provides some guidance and limits for the service setting (on types of animals, length of activities, etc.), but little else exists that focuses on the non-human animal. Walker and Tumilty (2015) have suggested that service animal regulation should take account of three levels of service, which are stratified based on risk, training and time in service: primary, secondary and tertiary. Primary denotes services that require little to no training, risk is minimal and service animals spend the majority of their time not in service (i.e. the most freedom within their setting). The secondary level denotes service where non-human animals receive training, risk is somewhat increased, but time in service would still only be a portion of the non-human animal's day. Tertiary level services are those activities that include extensive training and often breeding for purpose. These are settings where the animals spend the majority of their time in service and risk of harm/injury or fatigue is higher (i.e. the least freedom). The framework seeks to ensure ethical practice across these levels of service by asking those creating and managing services to be responsive to not only the basic animal welfare needs set out in current legislation, but also to take account of animal safety within the service setting, be prescriptive about downtime and post-service arrangements (i.e. retirement), and acknowledge and describe the roles and responsibilities of those in a given non-human animal's life (Table 26.1). In addition, non-human animals employed in service may have multiple humans that care for their needs whether these are training or work needs, recreational needs or other health and welfare needs. All of these roles need to be described and covered for non-human animals to be cared for properly while in the service of humans. Walker and Tumilty (2015) also suggest that changing language to help support a shift in thinking is likely to be effective. Using words such as 'guardian'

Table 26.1 Elements of an ethical framework for service animals (Walker & Tumilty, 2015)

Ethical framework elements	*Example 1:* *Eldercare visiting dog* *(Primary level)* *- little or no training* *- small risk*	*Example 2:* *Police dog* *(Tertiary level)* *- high level of training* *- high risk*
Provision of the basic necessities of life: food, water, shelter, acknowledging animals preferences	Appropriate housing and diet	Appropriate housing and diet
Provision of security from cruelty, harm and pain	In the service setting, need to protect dog from injury or harm through oversight, etc.	In the service setting, need to protect dog from injury or harm, through appropriate training and health and safety
Provision of freedom for natural behaviour and/or exercise and play (inter-/intra-species)	Service time is limited and small part of dog's day	Down time provided outside of 'service'
Recognition of guardianship versus ownership	Recognition of dog's feelings towards service on any given day	Appropriate training for tasks required, respect for animals 'instincts' and skills
Establishment of authentic, stable, and reciprocal relationships either within or adjunct to the service setting	Need for relationship outside of the eldercare setting	Relationship provided with 'partner'/ handler
Reward/recognition for labour and skill	Post visit rest/play, treats and affection as appropriate to animal	Recognition as colleague, provision of annual leave, post-trauma or stress downtime, incorporation into partner's life/family, etc.

rather than 'owner' or 'working with' rather than 'using' helps signal to people the moral status of the non-human animal 'Other' and our relationship to them. Last, this work requires an ongoing commitment to staying abreast with animal behaviour research in order to ensure that practices are evidence-based and appropriate.

As can be seen in Table 26.1, while the elements under evaluation for service animals remain stable the response required for different service animals differs based on the skill requirements, risk exposure in the service setting, and restriction of freedom. This framework aims to recognize that our relationships with animals should be moving to the right on the continuum mapping the status of each party within the relationship (Figure 26.1). This framework builds upon Martha Nussbaum's *Capabilities Approach* as applied to non-human animals (Nussbaum, 2009). A capabilities approach combines an Aristotelian principle of flourishing with a Kantian deontological principle to treat lives (in this case non-human animal lives) as ends in themselves (Nussbaum, 2011). It states that animals deserve justice based on their capacities and that justice entails being able to lead a flourishing life (Nussbaum, 2009). Of note, there is no hierarchy of capacities as such, i.e. apes with greater capacities than frogs, given current evidence, do not deserve greater justice, but require different capabilities to flourish, these capabilities may require a greater commitment, but the principle of justice does not apply to different degrees between the two species. Certain capabilities are required to flourish, and in taking on responsibilities for lives we have responsibilities to provide those capabilities. The tiers suggested in Table 26.1 do not create a hierarchy of justice; animals in the primary setting do not deserve less justice than those in the tertiary, but rather a hierarchy of capabilities that need to be addressed with the increased demands of the service setting. The choice of a Nussbaum-based framework is purposeful for this animal welfarist approach, as Nussbaum defends certain 'uses' of animals that an animal rights approach would not allow. We see an animal welfarist approach as necessary on the path to animal rights achievement, especially in the domain of companion and service animals, where harms are not as easily defined (in contrast to food animals) and people make cases for mutual benefits. Our approach inevitably means that it eventually becomes unnecessary, i.e. when animal rights have been achieved, a temporary welfarism will no longer be required, and some of the practices it applies to will no longer exist. This is in contrast to Francione (2010) who has argued that animal welfarism undermines animal rights efforts. We believe pragmatically, that both welfarism and rights advocacy have to occur in parallel for the benefit of not only future non-human animals but those currently in various relationships and contexts with humans, given the urgency of some settings (experimentation, food production, etc.) over others (companion animals and service animals). Mellor has argued that the traditional five freedoms used in animal welfare codes are not specific enough to provide appropriate care to animals based on their complex needs (Mellor, 2016), which we agree with. However, we depart from Mellor (2016) in that he accepts an animal welfare approach (with evolving modifications) as an end goal, where we argue for an animal welfare approach as a means to an end. Our framework guides humans to attend to these capabilities and, to recognize and respond to these capabilities as they are altered in the service setting. As animal behaviour research evolves and our understanding grows, providing these capabilities will require a greater commitment. In some settings, the capabilities required and the way in which we might wish to employ the non-human animal may be at odds and will mean that we cannot continue.

This proposed ethical framework describes what we consider acceptable for non-human animals employed in service to humans given current information. Growing acknowledgement of non-human animals as beings with feelings, relationships, intelligence and desired states of wellbeing, also challenges us to consider qualitative research ethics. What should we consider when designing or approving research that includes non-human animals as active agents in an intervention, assistance activity or process? While the above describes how a service could be considered ethical, undertaking qualitative research with non-human animals to understand the efficacy of a particular service/intervention or the various factors involved in human-non-human animal relationships requires additional thought.

QUALITATIVE RESEARCH ETHICS

The capabilities approach asks us to recognize non-human animals as beings worthy of respect, and as such, they should not be treated solely as means to our own (human) end (Nussbaum, 2009, 2011). That being said, humans need to be cognizant that different human-animal relationships demand different responsibilities in order to provide non-human animals with the capabilities to flourish. These differing relationships could be said to evoke positive and negative responsibilities, i.e. those that actively provide the capabilities to flourish, and those that do not infringe on a non-human animal's capability to flourish. This distinction is most clearly seen between the companion and wild animal. For one, by breeding and bringing an animal into our homes, our responsibilities to that animal differ greatly from those we have to wild animals in not encroaching or removing their capabilities to flourish, through habitat encroachment for example. These distinctions can be blurry, i.e. sometimes we may feel a responsibility to actively provide capabilities to wild animals where we are aware of potential suffering or starvation. Bush fires would be an example of this.

In a research setting, to date animal research ethics has focused on the three 'Rs', that is 'Replace, Reduce, Refine' (Russell & Burch, 1959). The three 'Rs' set out that where possible we should use alternatives (replace); we should minimize the numbers of animals needed as far as possible (reduce); and use techniques that cause as little suffering as possible (refine) (Russell & Burch, 1959). This guidance provides no help to those undertaking research with companion or service animals outside of the lab setting, premised on the idea that human-animal interactions are (mutually) beneficial. Nevertheless, ethical issues arise in these settings and require guidance. In considering a proposed research project, ethics committee reviewers or researchers must first agree that a particular AAT or AAI is in and of itself appropriate and ethical as described in the standards above. In addition to this however, we can also apply broader ethical principles to non-human animal participant research design.

Principles of research ethics are often described as those set by Beauchamp and Childress (1982), that is:

a. Autonomy
b. Beneficence
c. Non-Maleficence
d. Justice

These principles are the foundations of many ethical review guidelines and practice guides, but have also been debated and expanded (for example: Holm, 1995; Takala, 2001; Rendtorff, 2002; Guillemin & Gillam, 2004). These principles originated in biomedical practice and, as such, over time required adaptation with input from those in health research and the social sciences undertaking research with different perspectives. Interestingly, part of this evolution has been a move away from 'subject' to 'participant' in recognition of the researcher 'researching with' rather than 'researching on' those taking part; similar to the move we are suggesting here for non-human animals. It has also involved researchers and ethicists creating and defining practices and principles that recognize partnership roles and co-design processes for example (Goodyear-Smith et al., 2015). We propose a further shift in perspective is required to apply existing ethical principles to non-human animal participants. Below we set out what we believe are the beginnings of ethical principles applied to non-human animals in research, where the animal is not being 'experimented on', but rather 'experimented with'.

Dignity and Respect

All non-human animals deserve dignity and respect – this has been argued by many and is grounded on a recognition of their sentience and/or capacities (Regan, 1987; Singer, 1995; Nussbaum, 2009; Donaldson & Kymlicka, 2011). Their ability to feel pain and pleasure as minimum for ethical consideration was first described by Jeremy Bentham in 1789 in justifying how we should treat non-human animals. This is constantly supplemented by new studies showing a much broader range of capacities from tool use, problem solving, planning, relationship building, etc. (Clayton et al., 2003; Galef & Laland, 2005). Sandoe, Corr and Palmer (2016) stated, 'the lives and experiences of sentient animals should count for something in our ethical decision-making' (p. 3). This requires that we pay attention to their lives and enable them to flourish. Lori Gruen has described our ideal interactions with non-human animals as an *entangled empathy* – a relational response that rather than anthropomorphizing the animal asks us to recognize their otherness and respond to it as otherness with compassion (Gruen, 2015). What does this mean for ethics? It means that we must be well-researched on non-human animals' normal behaviours, their capacities, needs, forms of communication, etc. As an ethics committee, one would want to see that the researcher proposing work with a non-human animal had provided ample justification and explanations both for why the animal is suitable for the research proposed, or if researching an already existing service or relationship, how the researcher will monitor the non-human animal's wellbeing during the research.

Autonomy

Informed consent is the normal process by which autonomy is affirmed in research. This process is meant to ensure that a participant freely chooses to take part in research that they fully understand and support. We propose that a non-human animal can give dynamic assent throughout a research project, while their guardian or the organization that manages the non-human animal can give the more formal consent generally accepted for participation in research on their behalf. This is in part an extension of recognizing a non-human animals' inherent right to dignity and respect. It means, when planning research, having a clear understanding of a participating non-human animal's normal routine or incorporating sufficient flexibility in the research process so as to be able to respond to the non-human animal's preferences is required. It also demands a good understanding of non-human animal signs of distress or discomfort or having someone to hand that does. The signs will need to be specific to the species in question; in some instances to the specific animal within the species, where they may have particular idiosyncrasies (in the case of companion animals for example).

Consent/assent paradigms were originally proposed for humans in situations where the full elements of informed consent could not be guaranteed. These elements are capacity to consent, ability to comprehend, provision of information and voluntariness (Faden & Beauchamp, 1986). Within the traditional consent/assent paradigm, children or those who lack capacity to consent can assent to research where they understand what will occur and agree to take part, as long as their guardian has also provided informed consent (Leikin, 1993). While we are not arguing that non-human animals have the same capacity to understand a research process and assent to it, or at least we do not believe we are capable of communicating sufficiently to a non-human animal a research process, we do believe a form of monitored dynamic assent can be ascertained. This can be established through a non-human animal's willingness to undertake tasks associated with the research and an ongoing responsiveness to their distress/discomfort. In dogs, certain behaviours such as low posture, restlessness, oral behaviour, etc. have been shown as possible indicators of moderate to severe stress (Beerda et al., 1998). Ear and neck positioning can indicate excitability or anxiety in horses (Musters et al., 2012). For each type of non-human animal there will be different signs and in some cases researchers may know the best indicators, but in others cases, this might be the animal handler or their 'owner' if a companion animal. For example, in a dog walking study with a human participant, the researcher could discuss beforehand the ways in which they recognize that their dog is unhappy, frightened, or unwilling. The researcher notes and adds to the human consent form, e.g.:

- I understand that should my dog demonstrate the following behaviours [list] I am free to stop the interview and ask the researcher to leave the dog-walk.

Beneficence

Applying the principle of beneficence to non-human animals in research requires a new perspective from those normally taken in ethics review and research. While traditionally the benefits to humans are weighed in ethical review, it is our suggestion that research undertaken with non-human animals should also be of benefit to the non-human animals taking part. This benefit can be short or long term, but must be demonstrable. It can involve the provision of reward or play (short term) or might be the change in the non-human animal's position. For example, research exploring the benefits of prison inmates training shelter dogs (Zimmer, 2014) provides the dogs with attention and stimulation that they would not necessarily otherwise receive due to the resource constraints within these kinds of organizations. It also opens the possibility of them becoming more capable of adoption, ultimately saving them from destruction at the pound. Therefore, while such a project may have been conceived for the benefit of humans, it also benefits the non-human animals.

Maleficence

As with human participants, the principle of maleficence is fundamental and to some extent precedes all other considerations. All projects must have fully considered the potential for harm and have addressed it. We suggest this is no different for non-human animal participants. The shift from 'experimented on' to 'experimenting/researching with' means that we must attend to the potential for animal harm or suffering when designing research and reviewing it. For example, most animal behaviourists will stress the importance for dogs of regular routines (McMullen, 2015). In previous work, Smith et al. observed (with an untrained eye) behavioural changes associated with their dog-walking routine being interrupted by a third party human. Sometimes owners became distressed and/or grumpy when this happened which further confused their dog (Smith et al., 2017). One way to minimize this would be to forewarn human participants that this might happen and to discuss beforehand what steps could be taken. This could be accomplished via a participant information sheet; e.g. the researcher would stop asking questions if the dog was interacting with other humans or dogs so that the owner could respond/intervene without distraction in order to guide their dog away from trouble.

If we accept a capabilities approach to animal service and research ethics and, therefore, the fundamental assumption of dignity and respect, then no suffering is tolerable for human benefit. The idea of animal suffering for human benefit does not hold, as we can make no strong case for the weighing of one group's rights against another's. When we take the fundamental shift from a morally relativistic view of non-human animals (i.e. their worth is determined by their relation to us) to a morally individualistic view (their worth is independent of us) (Ryan, 2011; May, 2014), then we can no longer make robust arguments regarding our supremacy when considering outcomes. This mimics the move from an animal welfarist approach to an animal rights' approach – it asks that we recognize non-human animals as morally relevant individuals separate from our own interests (May, 2014). In our model, this requires that we adequately consider their capacities, their flourishing, and the requisite capabilities to ensure that flourishing.

Justice

The principle of justice normally concerns the benefits to a group on a macro- rather than micro-level. Where beneficence asks us to pay attention to the individual taking part in a research project and the benefits they will incur by taking part, justice asks us to pay attention to the benefits (or risks) that will accrue to the group that the individual is part of. What does this mean when considering non-human animals? First, injustice would be anything that either undermined or jeopardized a species or specific group of non-human animals. By undermined, we mean something that may make their perception in society less stable or less positive, or their situation

Box 26.1 Example: The Dog's Tale: ethical considerations from a dog-walking study

Smith and Treharne lead a dog-walking research progamme that uses dog-walk-along interviews (DWAs) to explore how dog-walking influences the health and wellbeing of the dog-walker (Cameron et al., 2014; Campbell et al., 2016; Smith et al., 2017). An early study explored the acceptability and feasibility of DWAs and identified unique ethical issues that guided subsequent ethical applications and research methods (Cameron et al., 2014). Initially, these considerations were directed towards the safety of the human participant; however, as the study programme progressed Smith and Treharne became more aware of dog-centred ethical issues: physical safety, changes in routine, loss of pleasure from walking, being told off for play-mauling the researcher, etc. In addition, we learned more about the bond between human and dog and were mindful that it was important to human participants for researchers to be friendly, polite, non-judgemental and respectful towards their dog and their (sometimes unappreciated) behaviours. Participants would for example, engage in conversations with their dog about a particular topic, or draw the researcher's eye to the dog and their behaviours during the DWA interview. Furthermore, we contributed our research results to local government submission processes regarding dog control (and dog-walking access), an act that could be considered as upholding justice for dog-walkers and their dogs. Subsequently, Smith and Treharne proposed a study that looked at how dog walking might influence the health and wellbeing of humans other than owners. We were advised that this proposal would need to be submitted through both a human ethics committee and an animal ethics committee, neither of which adequately catered for the ethical issues we had identified in our previous studies.

precarious. By jeopardize, we mean a research project that may cause that particular group of animals or species to be more at risk of some predictable danger. Justice on the other hand would be something that promoted species wellbeing or more broadly non-human animal wellbeing. By undertaking research with non-human animal participants we expand the evidence-base on human-animal interactions whether professional (AAT/AAI) or personal (companion animals). This allows future decision-making to be better informed, whether the indications for a particular AAT/AAI for example are negative or positive.

An example of how research might promote justice occurred during a study that explored how dog-walking influenced the health and wellbeing of people with long-term health conditions (Smith et al., 2017). The local council initiated a review of the district's dog control policy. One of the proposed changes was that dogs should be leashed at all times around sports fields. Through DWAs, Smith and Treharne learned that sports fields were often the only areas that participants were able to access in order to walk their dogs off-leash. This knowledge resulted in a written and oral submission by Smith to the submissions hearing panel. This submission was one of approximately sixty that lobbied for dogs to be allowed off-leash in these areas. Subsequently the proposed change was amended to dogs only being required to be leashed when sports were being played on the fields.

Conflicts of Interest

In suggesting that a Code of Ethics is required for service animals in general, Walker and Tumilty suggested that some form of regulatory body be established to monitor research evidence relating to animal behaviour (2015). This was suggested for two reasons. First, many of the organizations that undertake service animal work are charities with limited resources and therefore face barriers in being able to stay abreast and evaluate large volumes of evidence regarding the species they might be working with. Second, having organizations that want to work with animals in certain specific ways filter and evaluate evidence that may in some cases contradict their goals, creates a conflict of interest. It sets the 'poacher up as a gamekeeper' so to speak. Having an independent body that monitors and evaluates new evidence that relates to service animal activity in a given country allows a degree of detachment from the work.

As the creation of such a body is neither agreed nor foreseeable, researchers and ethics committees must consider what is informing decisions and whether that information is free from bias or distortion when designing or evaluating a research project. The co-opting of a specific expert to the review of certain projects as required would be recommended for those committees whose Terms of Reference allow this.

Further principles of ethics could be developed overtime. Much will depend on the external regulatory environment as it relates to service and companion animals in general, although impetus to change or create regulation in this regard does not currently appear evident. In the meantime, researchers and ethics committees need to consider proceeding with some ethical foundations when doing their work. The idea of a framework using the capabilities approach, stipulating non-human animal's moral individualism (rather than relationism), as well as the ability to adapt current ethical principles to non-human animals, seems a good start.

CONSIDERATIONS

At least two points of contention can be raised about the thinking presented in this chapter so far. Both relate to the implications this work has on other settings.

Other Animals

If we embed a more sophisticated ethical framework for animals in service and companion settings, where we ask people to see non-human animals as moral individuals (i.e. that is individuals with moral status, although no moral agency), what are the implications for animals in other settings? It becomes harder to argue that animals in food or vivisection settings, for instance, are not moral individuals in the same way that non-human animal Others are in the companion or service setting. If in the one case we recognize their rights to be seen as ends rather than means, how can we then ignore these rights in other situations? The authors of this chapter are a mix of animal rights thinkers (humans and animals are equal) and animal welfarists (animals are not equal, but we should treat them well). As such we have mixed or contradictory views, on such things as animal consumption, vivisection, and companion animals. What has been outlined in this chapter should push us towards better treatment of animals. This is a good thing. If this also pushes people to examine their relationship with animals, then this is also a good thing. Whether such work has the power to change human dominance of animals is highly questionable and we point to the fact that currently there are contradictory views of animal status already present as described earlier when discussing Figure 26.1 (i.e. consider food versus companion animals). Therefore, reforming ethical review of non-human animal research projects that work 'with' animals rather than 'on', is a good thing in and of itself, in that it makes our practice more considered and robust in this specific setting at least. A precedent for this stance is how indigenous research has moved away from extractive research on persons to inclusive research with people – much more needs to be accomplished here, too, but such beginnings lay the foundation for the future.

Other Moral Individuals

The other implication of such work is what it might say about how we treat other individuals in research processes. The consent/assent model with parents and young persons can be distorted, i.e. a young person's dissent being ignored because of parental wishes (Rossi et al., 2003). This distortion implies something about our thinking about parents and young people, but may also indicate that this model in practice is potentially a performance without meaning. By that we mean, if guardians can override assent, is it effective? It is also the case of course that non-human animals, much like young people, are required to do some things that are for their overall benefit despite their potential rejection of them. Examples such as young people going to school or non-human animals going to the vet spring to mind. What we saw in the nineteenth century, however, was that legislation about non-human animals and their welfare had a positive effect for young people and their welfare (LeBow & Cherney, 2015).

CONCLUSION

The way we think about non-human animals and our relationships to them have changed. There has been a corresponding change in the types of activities we undertake with animals and the qualitative research that studies these activities. Previous research with animals historically fell into two categories – either animal (behavioural) research (in Zoology, Agriculture, etc.) or biomedical research where animals were used to test agents or investigate physiological or biochemical processes, for example. New research examines human-animal interactions and as such sees animals as participating in interactions. We suggest such research requires new guidance in ethics. Previously, human ethics committees and animal ethics committees weigh risk/benefit ratios largely in relation to humans. These models may aim to minimize animal suffering, but human wellbeing is prioritized. We have suggested that a model building off already established ethical principles in research can be adapted to recognize non-human animals as participants in research – 'researching with' non-human animals, rather than 'researching on' them. This model requires both researchers and ethics committees to consider:

1 In the service setting, whether the service is appropriate and ethical. This includes:
   - Is a non-human animal intervention/activity/therapy justified?
   - Is the non-human animal chosen appropriate, and why?
   - Does the service meet the demands of the ethical framework set out in Table 26.1, considering in addition the roles and responsibilities of various actors in the non-human animal's life?
   - Is animal safety within the service informed by current best evidence? How is this shown (through expert involvement, etc.)?
   - Does the use of language recognize the non-human animal's inherent right to dignity and respect?

2 For research:
   - Does the project recognize the non-human animal's inherent right to dignity and respect?
   - Does the project promote the non-human animal's autonomy through an assent/consent model including specific information recognizing dynamic assent through the project?
   - Is there a benefit to the non-human animal in taking part?
   - Is there sufficient information and justification to exclude harm? Or is harm of such a nature that it is minimal and balanced against non-human animal benefit (such as vaccination for example)?
   - Is the project just? In what ways does it benefit non-human animals?
   - Have researchers provided justification for the non-human animals' employment or study in the research that is in line with animal behavioural research and is this information free from conflicts of interest?

We imagine over time that these suggestions will evolve with greater activity in this area and practice.

REFERENCES

Animal Assisted Intervention International. (2015). *Standards of practice for animal assisted intervention: Animal assisted therapy*. http://www.aai-int.org/wp-content/uploads/2016/02/AAT-Standards-final.pdf

Barker, S. B., Barker, R. T., McCain, N. L., and Schubert, C. M. (2016). A randomized crossover exploratory study of the effect of visiting therapy dogs on college student stress before final exams. *Anthrozoös*, 29(1), 35–46.

Beauchamp, T. L. and Childress, J. F. (1982). *Principles of biomedical ethics.* Oxford and New York: Oxford University Press.

Beerda, B., Schilder, M. B., van Hooff, J. A., de Vries, H. W., and Mol, J. A. (1998). Behavioural, saliva cortisol and heart rate responses to different types of stimuli in dogs. *Applied Animal Behaviour Science*, 58(3), 365–381.

Benda, W., McGibbon, N. H., and Grant, K. L. (2003). Improvements in muscle symmetry in children with cerebral palsy after equine-assisted therapy (hippotherapy). *The Journal of Alternative and Complementary Medicine*, 9(6), 817–825.

Bernabei, V., De Ronchi, D., La Ferla, T., Moretti, F., Tonelli, L., Ferrari, B., Forlani, M., and Atti, A. R. (2013). Animal-assisted interventions for elderly patients affected by dementia or psychiatric disorders: A review. *Journal of Psychiatric Research*, 47(6), 762–773.

Berns, G. (2013). How dogs love us: A neuroscientist and his adopted dog decode the canine brain. New York: Houghton Mifflin Harcourt.

Burgon, H., Gammage, D., and Hebden, J. (2017). Hoofbeats and heartbeats: Equine-assisted therapy and learning with young people with psychosocial issues – theory and practice. *Journal of Social Work Practice*, 1–15.

Cameron C, Smith C. M., Tumilty, S. and Treharne, G. J. (2014). The feasibility and acceptability of using Mobile Methods for capturing and analysing data about dog-walking and human health. *The New Zealand Journal of Physiotherapy*, 42(2), 163–169.

Campbell, K., Smith, C. M., Tumilty, S., Cameron, C., and Treharne, G. J. (2016). How does dog-walking influence perceptions of health and wellbeing in healthy adults? A qualitative dog-walk-along study. *Anthrozoös*, 29(2), 181–192.

Cherng, R.-J., Liao, H.-F., Leung, H. W. C., and Hwang, A.-W. (2004). The effectiveness of therapeutic horseback riding in children with spastic cerebral palsy. *Adapted Physical Activity Quarterly*, 21(2), 103–121.

Clayton, N. S., Bussey, T. J., and Dickinson, A. (2003). Can animals recall the past and plan for the future? *Nature Reviews Neuroscience*, 4(8), 685–691.

Cormack, L. (2016). 'Australia is the third-fastest growing vegan market in the world', Retrieved 3rd April 2017, from: http://www.smh.com.au/business/consumer-affairs/australia-is-the-thirdfastest-growing-vegan-market-in-the-world-20160601-gp972u.html

Donaldson, S. and Kymlicka, W. (2011). *Zoopolis: A political theory of animal rights*. Oxford and New York: Oxford University Press.

Faden, R. R. and Beauchamp, T. L. (1986). *A history and theory of informed consent*. Oxford and New York: Oxford University Press.

Fine, A. H. (Ed.). (2010). *Handbook on animal-assisted therapy: Theoretical foundations and guidelines for practice*. London: Academic Press.

Francione, G. (2010). *Rain without thunder: The ideology of the animal rights movement*. Philadelphia, PA: Temple University Press.

Galef Jr, B. G. and Laland, K. N. (2005). Social learning in animals: Empirical studies and theoretical models. *Bioscience*, 55(6), 489–499.

Goodyear-Smith, F., Jackson, C., and Greenhalgh, T. (2015). Co-design and implementation research: Challenges and solutions for ethics committees. *BMC Medical Ethics*, 16(1), 78.

Grandgeorge, M. and Hausberger, M. (2011). Human-animal relationships: From daily life to animal-assisted therapies. *Annali dell'Istituto Superiore di Sanità*, 47(4), 397–408.

Gruen, L. (2015). *Entangled empathy: An alternative ethic for our relationships with animals*. Brooklyn, New York: Lantern Books.

Guillemin, M. and Gillam, L. (2004). Ethics, reflexivity, and 'ethically important moments' in research. *Qualitative Inquiry*, 10(2), 261–280.

Holm, S. (1995). Not just autonomy – the principles of American biomedical ethics. *Journal of Medical Ethics*, 21(6), 332–338.

Horspool, L. J. (2013). Animal health markets and opportunities: Companion animal landscape, in Rathbone, M. J. and McDowell, A. (eds.) *Long Acting Animal Health Drug Products: Fundamentals and Applications*. US: Springer. pp 15–46.

Hunt, M., Otto, C. M., Serpell, J. A., and Alvarez, J. (2012). Interactions between handler well-being and canine health and behavior in search and rescue teams. *Anthrozoös*, *25*(3), 323–335.

Jegatheesan, B., Beetz, A., Ormerod, E., Johnson, R., Fine, A., Yamazaki, K., and Choi, G. (2014). International Association of Animal-Human Interactions Organizations (IAHAIO) White Paper: Definitions for Animal Assisted Intervention and Animal Assisted Activity and Guidelines for Wellness of Animals Involved. Columbia, MO: IAHAIO.

Kamioka, H., Okada, S., Tsutani, K., Park, H., Okuizumi, H., Handa, S., Oshio, T., Park, S.-J., Kitayuguchi, J., Abe, T., Honda, T., and Mutoh, Y. (2014). Effectiveness of animal-assisted therapy: A systematic review of randomized controlled trials. *Complementary Therapies in Medicine*, 22(2), 371–390.

LeBow, E. W. and Cherney, D. J. (2015). The role of animal welfare legislation in shaping child protection in the United States. *International Journal of Education and Social Science*, 2(6), 35–44.

Leikin, S. (1993). Minors' assent, consent, or dissent to medical research. *IRB: Ethics & Human Research*, 15(2), 1–7.

Marr, C. A., French, L., Thompson, D., Drum, L., Greening, G., Mormon, J., Henderson, I., and Hughes, C. W. (2000). Animal-assisted therapy in psychiatric rehabilitation. *Anthrozoös*, 13(1), 43–47.

May, T. (2014). Moral individualism, moral relationalism, and obligations to non-human animals. *Journal of Applied Philosophy*, 31(2), 155–168.

McMullen, D. (2015). 'He never does that!'. Victoria Stilwell (blog) Positively: The future of dog-training. Retrieved 3rd April, 2017, from: https://positively.com/contributors/he-never-does-that/

Medical Research Council. (2006). *Developing and evaluating complex interventions: New guidance*. https://www.mrc.ac.uk/documents/pdf/complex-interventions-guidance/

Mellor, D. J. (2016). Updating animal welfare thinking: Moving beyond the 'Five Freedoms' towards 'a Life Worth Living'. *Animals*, 6(3), 21.

Meltzer, H. (2016). 'San Francisco Airport recruits therapy pig to calm stressed passengers'. Retrieved 3rd April 2017, from: http://www.telegraph.co.uk/travel/news/san-francisco-airport-lilou-therapy-pig/

Munsters, C. C., Visser, K. E., van den Broek, J., and Sloet van Oldruitenborgh-Oosterbaan, M. M. (2012). The influence of challenging objects and horse-rider matching on heart rate, heart rate variability and behavioural score in riding horses. *The Veterinary Journal*, 192(1), 75–80.

Nagasawa, M., Mitsui, S., En, S., Ohtani, N., Ohta, M., Sakuma, Y., Onaka, T., Mogi, K., and Kikusui, T. (2015). Oxytocin-gaze positive loop and the coevolution of human-dog bonds. *Science*, 348(6232), 333–336.

Nimer, J. and Lundahl, B. (2007). Animal-assisted therapy: A meta-analysis. *Anthrozoös*, 20(3), 225–238.

Nussbaum, M. C. (2009). *Frontiers of justice: Disability, nationality, species membership*. Cambridge, MA: Harvard University Press.

Nussbaum, M. (2011). The capabilities approach and animal entitlements, in Beauchamp, T. L. and Frey, R. G. (Eds), *The Oxford handbook of animal ethics* (pp. 228–252). Oxford and New York: Oxford University Press.

NVAS 'Worldwide Progress'. Retrieved 3rd April 2017, from: http://www.navs.org/what-we-do/keep-you-informed/legal-arena/product-testing/worldwide-progress/#.WOZWd0Xyu70

Quinn, S. (2016). 'Number of vegans rises 360% in ten years'. Retrieved on 3rd April 2017, from http://www.telegraph.co.uk/food-and-drink/news/number-of-vegans-in-britain-rises-by-360-in-10-years/

Regan, T. (2004). *The case for animal rights.* University of California Press.

Rendtorff, J. D. (2002). Basic ethical principles in European bioethics and biolaw: Autonomy, dignity, integrity and vulnerability – towards a foundation of bioethics and biolaw. *Medicine, Health Care and Philosophy*, 5(3), 235–244.

Rossi, W. C., Reynolds, W., and Nelson, R. M. (2003). Child assent and parental permission in pediatric research. *Theoretical Medicine and Bioethics*, 24(2), 131–148.

Russell, W. M. S. and Burch, R. L. (1959). *The principles of humane experimental technique*. Retrieved 12th October, 2016, from: http://altweb.jhsph.edu/pubs/books/humane_exp/het-toc

Ryan, T. (2011). *Animals and social work: A moral introduction*. Springer.

Sandøe, P., Palmer, C., and Corr, S. (2016). Human attachment to dogs and cats and its ethical implications. In 22. FECAVA Eurocongress. pp. 11–14).

Seps, C. D. (2010). Animal law evolution: Treating pets as persons in tort and custody disputes. *University of Illinois Law Review*, 1339.

Serpell, J. (1996). *In the company of animals: A study of human–animal relationships*. Cambridge, MA: Cambridge University Press.

Singer, P. (1995). *Animal liberation*. New York: Random House.

Smith, C. M., Treharne, G. J., and Tumilty S. (2017). 'All those ingredients of the walk': The therapeutic spaces of dog-walking for people with long-term health conditions. *Anthrozoös*, 30(2), 327–340.

Smith, C., Tumilty, E., Treharne, G., and Walker, P. (2018). Non-human animals as co-workers and research participants: Ethical practice in animal-assisted interventions and research in Aotearoa/New Zealand, in McLeod, C. Marx, J., Mnyaka, P. and Treharne, G. (Eds), *The Palgrave handbook of ethics in critical research.* London: Palgrave-MacMillan.

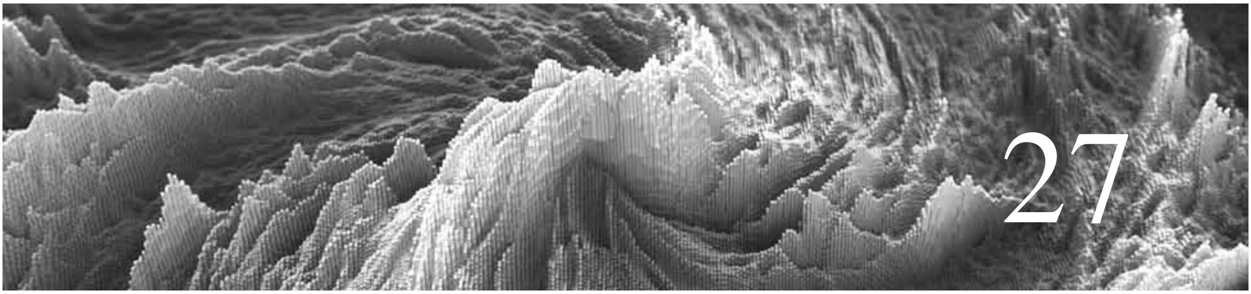
Takala, T. (2001). What is wrong with global bioethics? On the limitations of the four principles approach. *Cambridge Quarterly of Healthcare Ethics*, 10(1), 72–77.

Walker, P. and Tumilty, E. (2015). *Developing codes of ethics for therapeutic interventions with animals*. Ethics in Practice Conference (22–24 May), Dunedin, New Zealand.

Walker, P. and Tumilty, E. (forthcoming). Developing ethical frameworks in animal assisted social service delivery in New Zealand.

Weil, K. (2010). A report on the animal turn. *Differences: A Journal of Feminist Cultural Studies*, 21(2), 1–23.

Zimmer, R. M. (2014). *Partnering shelter dogs with prison inmates: an alternative strategy to reduce recidivism and teach social therapy*. Master's Capstone Theses. 13. Available from: http://digitalcommons.apus.edu/theses/13



27

Paternalism and the Ethics of Researching with People Who Use Drugs

Lucy Pickering

INTRODUCTION

Eddie was an active heroin user who I first met when recruiting recovering heroin users for a study. During interviews, he would ask if I had a budget for snacks, what it was, take me to a cafe and spend up to the limit. Eddie was a willing and eager participant in research, keen to get as much from the research process as he possibly could. I also used to often see him as I walked home from work, sitting on the benches frequented by street drinkers close to where I lived. He would sometimes stop me as I walked home to ask if I had any more research he could take part in.

Recruiting Eddie and other such 'vulnerable' persons was difficult, but not as difficult as securing ethical approval can be. Research Ethics Committees (RECs) and Institutional Review Boards (IRBs) tend to see habitual drug users as highly vulnerable – particularly to the inducement of monetary payment. Such a view is often based on assumptions about people who use drugs (PWUD) (rather than the growing body of empirical research), and has been discussed by drugs researchers as paternalistic. Efforts to protect PWUD from exploitation can inadvertently reinforce inaccurate stereotypes and exclude marginalized groups from representation through research.

This chapter examines this process in three sections. First, it reviews bioethicists' perspectives toward researching the intoxicated. They argue that PWUD may not be in a position to give informed consent because of the influence of substances or payment, which have been the foci of recent ethical debate in this field. This is contrasted with drug researchers' work, as they address the conflicts of interest inherent in participant agency and apparent diminished autonomy in recruitment. Second, I discuss the ethics of payment, in particular differences between payments in cash and vouchers. Finally, I bring in the voices of PWUD who have taken part in research to explore how their priorities relates to those of RECs and researchers.

RESEARCHING THE INTOXICATED

Heroin Assisted Treatment Trials and the Construction of Addiction

Heroin assisted treatment (HAT) trials have been the focus of intense debate between bioethicists and drugs researchers. This first section gives an overview of bioethicists' arguments about addiction and intoxication, exposing the assumptions and stereotypes that so often inform how RECs think about PWUD. For example, the bioethicist Louis Charland (2002) characterizes heroin addiction as a totalizing, compulsive condition, in which addicts' entire orientation is towards accessing and using the drug. This assumption is critiqued by the drugs researchers Foddy and Savulescu (2006) who argue that heroin use is not most usefully characterized this way, but rather that people who use heroin desire it, and that it is a difference of degree, rather than kind, from other sorts of appetitive desires. By comparing HAT trials with other types of trials in which participants are given access to substances they desire strongly (for example HIV antiretroviral trials), they show that most trials do not generate cases of totalizing consumption, arguing, rather, that the strength with which prospective participants desire an intervention by definition should exclude them; this is not the case for Charland and HAT trials. By reframing addiction not as totalizing compulsion but appetitive desire, Foddy and Savulescu challenge Charland's characterization of addiction and argue against his paternalistic stance that heroin users should be excluded from research that gives them access to heroin.

In turn, bioethicist Neil Levy (2006) has argued that Foddy and Savulescu (2006) go too far in their analysis. Like them, he notes that there is much to suggest that PWUD can and do make choices around their drug use, for example changing patterns of use in response to changes in price, abstaining in order to reduce tolerance to decrease the dose required in future, or going into recovery. However, he suggests that researchers cannot argue on the basis of this that addicts consequently suffer no impairment to independent decision-making. For Levy addiction is characterized by 'ego depletion', in which it is relatively easy to exercise self-control in the short term, but that to do so depletes future reserves of self-control. This makes heroin difficult to resist in the long term, but that in relation to other decisions – such as the decision to take part in research – 'addicts are as autonomous as you and me' (2006: 20).

These two positions rest on very different notions of addiction (see Singer, 2012; Weinberg, 2011 on this range of notions). Both Levy and Foddy and Savulescu reject Charland's totalizing characterization of addiction and highlight its contingent nature. This matters for Foddy and Savulescu because they see dependent heroin users as constantly moving between being high, being in withdrawal, and a state between the two (where heroin users spend most of their time) called 'sober'. They argue that capacity to give consent to take part in a research project may be compromised when a heroin user is high or in withdrawal because their focus is – albeit in different ways – on the drug, but that when 'sober', heroin users are able to attend to other aspects of their life, and to make autonomous, rational decisions.

For bioethicists Henden and Bærøe (2015), what limits heroin addicts' capacity to give informed consent to participate in HAT trials is not about compulsion, strength, of desire or ego depletion, but rather the social circumstances of use. For them, the 'badness of their lives' impacts on individuals' capacity to see themselves as a person with options. Their concern is that despite having alternatives to trial participation (abstinence), the attraction of 'free heroin' in HAT trials is so strong that prospective participations will see themselves as without options. And where a person perceives himself or herself as lacking alternatives (even if they do in fact have multiple options), then their consent cannot be said to have been freely and voluntarily given.

In their critique of Henden and Bærøe (2015), Uusitalo and Broers (2016) draw attention to the fact that prospective trial participants' desires are framed by Henden and Bærøe solely in terms of their desire for continued heroin use; however, their very willingness to participate in such a trial could be indicative of a desire to improve or at least change their current life condition (2016: 766). Further, they note that the options are presented solely in terms of abstinence and accessing so-called 'free heroin', when in fact HAT trials generally offer the control group 'best available treatment' (in this case often forms of opiate substitution therapies) thereby complicating the simple 'free heroin'/abstinence binary. Finally, they see Henden's definition of voluntariness – whereby multiple available options that promote wellbeing must be available for a truly voluntary choice to be possible – as overly onerous. By comparing HAT with other clinical trials such as end-of-life cancer trials in which participants will not benefit from their trial participation but future cancer sufferers may, they highlight that not all trials necessarily require all options to promote the participant's individual wellbeing, and that this expectation that all options in HAT trials equally work towards individual wellbeing (as viewed from the outside) reflects paternalistic concerns predicated on an assumption of PWUD's lack of capacity to make autonomous decisions in the interest of their own wellbeing.

This decision-making is important because, as Foddy and Savulescu point out, 'imprudent desires do not render a person non-autonomous' (2006: 14). Charland (2002) appears to invalidate the choices to participate made by heroin users on the grounds that they lack the autonomy to make such decisions, or to make decisions that benefit their wellbeing. Either approach is paternalistic in operating from an assumption that PWUD qua PWUD lack capacity to engage in meaningful decision-making, and consequently placing the onus of decision-making responsibility around what is best for PWUD on researchers, medical practitioner-gatekeepers and ethicists, rather than PWUD themselves.

Research Participation and Intoxication

While the theoreticians discussed have wrangled with questions of whether people who use heroin are inherently and at all times unable to consent to take part in research which potentially includes access to heroin, drug researchers have been more concerned with the question of intoxication, and in particular when and how to ensure the inclusion of drug-dependent individuals into research.

As discussed earlier, Foddy and Savulescu (2006) characterize dependent heroin use as a sort of wave, with peaks of intoxication and troughs of withdrawal and a state in between (where they argue PWUD spend most of their time) called 'sober'. They argue that PWUD can give meaningful consent when 'sober' but not intoxicated or in withdrawal (see also Fisher, 2011: 730; Carter & Hall, 2013). But how do researchers *know* what condition a given individual is in? Some advocate for the use of standardized scales to measure intoxication and exclusion of impaired individuals (Carter & Hall, 2013, see also Goldim et al., 2011: 181). The use of such scales, however, works to exclude on the paternalistic grounds of protecting intoxicated persons from making potentially uninformed decisions about research participation – a view that is contested within the field of nightlife studies.

In their paper on the ethics of informed consent and intoxication in nightlife research, which examines the social worlds of pubs, bars, nightclubs, and parties, where alcohol and party drugs are often consumed, Aldridge and Charles (2008) problematize the knowability of intoxication as a state. They point out that biochemical markers can have limited utility, using the example of the same blood alcohol concentrate affecting different people differently and even the same person differently under different circumstances. Behavioral measures of intoxication, they uncover, are no less inconsistent. What Aldridge and Charles do identify diverse biochemical and behavioral measures as having in common (beyond their unreliability), is that they are researcher-led. The question is not: does a prospective research participant understand themselves to be intoxicated, or too intoxicated to take part in research, but does the researcher consider them to be intoxicated, or too intoxicated to take part (see also Home Office (2003) for researcher-led assessment of intoxication).

Within nightlife research – in which prospective participants are frequently intoxicated, but to differing extents and in differing ways – there has been some discussion of the limitations of finding absolute measures of intoxication, and the utility of including the intoxicated in research. These concerns about pre-emptory exclusion of the intoxicated are mirrored in Sandberg and Copes' 2013 exploration of the views and experiences of ethnographers of drug dealers on intoxication. They found that, in general, these ethnographers did not see their subjects being intoxicated ('high') as an inherent barrier to research. Rather, these ethnographers explained their choices to collect data when participants were high in terms of an ethical drive to record life as it is lived. To quote one of the ethnographers interviewed, '[Dealers] were so accustomed to being high that it was just their normal state of being anyway' (2013: 9).

The idea of intoxication as a 'normal state' stands in sharp contrast to Foddy and Savulescu's characterization of dependent heroin use as an oscillation between three states where the 'normal' (i.e. most commonly experienced) one is 'sober'. This may be explainable in terms of the substances used by these dealers (not consistently disclosed in Sandberg and Copes, 2013), but may perhaps more usefully be explained in terms of method. Ethnography allows researchers to spend time with participants as they move between 'sober' and intoxicated, or 'sober', intoxicated, and withdrawal. Researchers and participants are then able to collaboratively identify what is 'normal' for a given individual, and ensure that consent is sought and given in that state.

This is very different to research settings where consent is necessarily given in the context of a single encounter. In these settings, the collaborative process of finding 'normal' is not possible and researcher must rely on other strategies to make decisions about inclusion. These include advocating for the blanket exclusion of all people experiencing addiction from research entailing potential access to the object of their addiction, using behavioral or biochemical markers to assess intoxication and excluding those deemed too intoxicated, or assessing whether potentially intoxicated individuals are 'informable' (Goldim et al., 2011) and excluding those deemed uninformable. All these forms of exclusion operate from a position of protection – all seek to protect prospective research participants from exploitation by excluding them. Such a position is paternalistic: decisions about who gets to participate in research, whose voices are heard, whose needs are brought to light (and thus potentially alleviated) are made *for* PWUD, without their needs or desires being taken into account. By moving towards the framing of consent as a process, rather than an event, research could – and indeed many drugs researchers do – work towards and ethics of *inclusion* rather than protection by, for example, taking inclusion as the default option in nightlife and related research, and giving participants multiple opportunities to withdraw/reaffirm consent as they move between states.

THE ETHICS OF PAYMENT

Payment as Reimbursement

It has been and continues to be common practice for researchers to pay PWUD to take part in research (Fry et al., 2005). However, despite the at least anecdotally reported ubiquity of this practice, it continues to generate debate. This debate has focused primarily on whether to pay participants, how much to pay them, what to pay them for, and what to pay them with.

The use of payment to PWUD who take part in research has been questioned on the grounds that it raises ethical concerns about undue influence, relapse potential, and appearing to 'reward' illegal behavior (Fry et al., 2005; Ritter et al., 2003; Seddon, 2005). For most researchers, however, the ethical questions turn less on whether or not to offer payment than on how much is an appropriate amount, the role of payment as incentive or reimbursement, and whether participants should be paid in cash or non-cash forms.

In contrast to the assumption that PWUD are universally paid to take part in research, when Fry et al. (2005) surveyed research reimbursement practices across a range of settings in Australia, they found that PWUD are not always paid to take part in research, although they and other 'vulnerable' groups (Aborigines and Torres Strait Islanders) did tend to be reimbursed more frequently, however at consistently lower rates than other populations such as patients, young people, and 'the general public'. Reasons research organizations gave for not reimbursing (across PWUD and other populations) included that they were unnecessary, fears that they may operate as an inducement, and fears that study participants may consequently not adequately consider risks and benefits of participation. These concerns prompted lower payments to PWUD, which can be read as an effort to protect PWUD from the excessive appeal that larger amounts may produce, and thus an effort to protect them from undue influence.

One consequence of this can be low retention rates in longitudinal research. Festinger et al. (2005, 2008) have noted that low retention rates compromise statistical validity. Operating from a position of justice ethics, in which robust data are needed to represent the most socially and economically marginalized accurately, they experimentally explored the effects of payments at different levels, and in the form of cash and gift cards on study retention, levels of follow-up tracking, and new drug use. They compared payments between $10 and $160 across two studies and found that higher rates of payment produced higher levels of follow up with lower levels of follow-up tracking required. In addition, they found that those paid in cash had higher rates of follow up than those paid in gift cards, and that levels of new drug use remained low across all payment levels and payment type. From this, they argue that higher rates of reimbursement do not prompt relapse, and are a cost-effective way to ensure high retention rates and thus statistically robust data. This suggests that concerns about payment as a relapse trigger is misplaced (see also Dempsey et al., 2008).

One approach taken to managing the ethical tensions around payment has been to research what PWUD spend reimbursements on. Festinger and Dugosh (2012) note that across several studies undertaken by the team, those paid in cash primarily reported spending the money on household items, bills and transport, and those given gift cards primarily reported spending them on household items and non-essential items for themselves or as gifts; only extremely small numbers reported spending the reimbursement on drugs. These findings resemble those of Topp et al. (2013) who found intentions to spend cash on transport and intentions to spend vouchers on groceries, with only small numbers in either group reporting intent to buy alcohol or illicit drugs. For Festinger and Dugosh this means that 'we have found, as expected, that participants generally use both baseline and follow-up payments in a responsible and safe manner' (2012: 46).

By contrast, Thurstone et al. (2010) found that around one-third of participants in an ADHD (attention deficit/hyperactivity disorder) clinical trial with substance using young people reported spending at least one of the 14 available payments on tobacco and around the same proportion on alcohol or non-tobacco drugs (all cannabis). However, Thurstone et al. conclude that 'these findings do not necessarily mean that adolescents with substance use disorder should not receive cash reimbursement [rather than gift cards or vouchers]' (2010: 264) because (a) they were already using cash to buy these substances prior to entry into the study and (b) use of tobacco and non-tobacco drugs declined for both those who did and did not use payments to buy them over the study. This suggests to these researchers that cash payments – even when spent on tobacco, alcohol, and other drugs – do not contribute to an increase in the use of these substances. And, more implicitly, perhaps the view that young people have the right to spend their income as they wish.

Some others have gone even further and explicitly argued that discussion of what PWUD spend reimbursement on is overly paternalistic: that it should not matter what drug users spend research remuneration on, just as it does not matter for members of any other researched community, and that efforts to constrain how PWUD spend research remuneration is 'patronizing, offensive and misguided' (Oransky et al., 2009: 1653), further stigmatizes PWUD, undermines the principle of participant autonomy, implies that PWUD are untrustworthy and irresponsible, and devalues the information they provide (AIVL, 2003; Marsh & Loxley, 1992; Murdoch & Caulfield, 2016; Ritter et al., 2003).

A final question for ethical debate is what PWUD are understood to be being paid *for*. In clinical research ethics, concerns revolve around offers of payment acting as an inducement to participate in research that potentially compromise prospective participants' capacity to assess risk. However, empirical research suggests that while payment is often a significant motivator for participation in clinical trials, it is not necessarily the only one, and does not override prospective participants' assessments of risk and benefit – even among those of lower socioeconomic standing who may be particularly vulnerable to the inducement of payment for research participation (Beckford & Broome, 2007; Bentley & Thacker, 2004; Russell et al., 2000). The same pattern emerges in empirical research with PWUD.

However, ethical discussion about what PWUD who take part in research are being paid for can be hampered by the lack of consistency of language: sometimes participants are 'reimbursed' (Fry & Dwyer, 2001; Thurstone et al., 2010), sometimes given 'compensation' (Collins et al., 2017; Fisher, 2011), and sometimes 'paid' (Slomka et al., 2007) for their time; occasionally they are given a cash 'incentive' (Singer et al., 2008). These terms appear to be used largely interchangeably to refer to fair remuneration for the time and transportation costs, and inconvenience of research participation, and this diversity of language may reflect the ethical frameworks and accepted nomenclature within a given jurisdiction. Davidson and Page (2012), by contrast, discuss explicitly choosing 'payment' over 'reimbursement' to reflect the work-like nature of research participation (at least in terms of how their study participants discuss it). Others, however, have talked of payment as 'incentivization', which entails a different set of considerations, addressed below.

Payment as Incentivization

In qualitative research with PWUD, the use of payment as incentivization is understood as doing something different to simply reimbursing for time and transport costs, compensating for inconvenience, or respecting expertise: it entails the use of payments specifically to attract people into a research project. Incentivization is used more broadly in qualitative research to attract participants, potentially increasingly so (Head, 2009), however debates within drugs research focus on the particular complexities which surround respondent-driven sampling and related recruitment methods.

Respondent-driven sampling (RDS) has become increasingly popular in recent years to access 'hard-to-reach' groups such as PWUD

(Heckathorn, 1997), by giving a small number of participants ('seeds') a finite number of coupons to pass onto peers who fulfill the study criteria. When those peers complete data collection, they are provided with payment for the data collection, plus coupons to pass out in turn and the recruiter receives a small payment for successfully recruiting the participant.

Recently, debate has emerged about the ethical limitations of RDS. One aspect of this revolves around the number of coupons distributed: in order to minimize the risk of the emergence of 'semi-professional recruiters' (Mosher et al., 2015: 838) who may use coercive recruitment techniques, participant-recruiters are often given only a fixed and small number of coupons; however, given that these finite coupons are distributed through personal networks, these small numbers potentially compromise confidentiality, particularly in the light of the persistent recruitment methods often employed by recruiters in the field.

While confidentiality remains a concern, and more recent RDS recommendations and guidelines have worked to manage this (Mosher et al., 2015), a significant ethical issue remains the role of financial incentives in RDS. Fry (2010) notes that it is the role of payment in RDS, which makes it 'controversial', and Scott (2008) has candidly explored the unanticipated harms that can emerge from the 'coupon economy' (2008: 44) of RDS recruitment in a drug-using community. While extensively critiqued, this text nonetheless provides a candid insight into the harms and risks of an RDS coupon economy. Scott (2008) found that the coupons became part of the local economy, with individuals often exploiting RDS for personal gain: first, in contrast with the aim of RDS that coupons would be given to peers (as occurred in Mosher et al.'s 2015 account of RDS in practice), coupons were 'sold', with recruiters often accompanying recruits to the research site to ensure recruits handed over their fee after having received their participation reimbursement. Scott notes that this advantaged the already advantaged, for example those with cars, those running 'shooting galleries', or those with lower levels of addiction and higher levels of organization.

Mosher et al. (2015) undertook a similar analysis of RDS recruiters, but found somewhat different results. Some recruiters described gaining valuable self-knowledge and an opportunity for non-judgmental listening in research participation, and carefully chose coupon recipients in terms of who they felt would benefit from this experience, as well as those they saw more frequently or whom it would be easy to follow up to ensure they had attended the research site. While much less persistent than Scott's participants, nonetheless, 25% of interviewees reported using persistent recruitment strategies to ensure recruits' attendance at the research site. By contrast with Scott (2008), who reported high levels of threatened and actual violence accompanying persistent recruitment, recruits interviewed by Mosher et al. (2015) seemed to locate the persistent recruitment strategies used with acceptable 'norms' of their relationships. What may have appeared to be unacceptable levels of pressure from the outside, when viewed from inside were seen to be on a par with everyday relationships, leaving recruits seeing themselves as free to decide whether or not to participate despite these persistent recruitment practices.

When taken together, Mosher et al. (2015) and Scott (2008) highlight the heterogeneity of PWUD: some were more 'successful' recruiters than others, some were more persistent, and different recruits experienced that persistence differently. Their communities are similarly heterogeneous, with different levels of violence, persistent recruitment strategies, and selection of peers on different criteria in different communities. The nature of the study may also be relevant: many participants in Mosher et al. (2015) described the survey as an opportunity to 'reflect on their lives … and to have the opportunity to tell their stories' (p. 839). Not all study designs can create the space for these reflexive encounters, so different study designs may impact differently on RDS practice.

This latter point highlights a key but often underexamined difference between 'payment' and 'incentive'. In a study of incentives in youth research in Australia, Seymour (2012) distinguishes between financial and non-financial incentives, noting the importance of recognizing forms of incentive such as altruism and recognition. In highlighting the importance of altruism, Seymour draws out the ways in which this can be emphasized as an incentive through study design, recruitment material and how studies are explained to participants. Similarly, she emphasizes the importance of expressing gratitude to participants in recognition of their contributions, and the role this plays in incentivizing research participation. Mosher et al. (2015) and others show that within drugs research, an opportunity to tell one's story in a non-judgmental space can operate as an incentive. Thus, while payment as a form of incentive requires heightened ethical sensitivity, the ethical challenges around payment may be quite different to those around what motivates PWUD to take part in research, to which we now turn.

STUDY PARTICIPANT PERSPECTIVES

There is a small but growing body of research on study participants' perspectives on the research process. In relation to research with PWUD, this work has been both qualitative and quantitative and explored primarily motives for taking part in research, risks and benefits of research participation, and perspectives on payment.

Payment and the Assessment of Risk

Economic gain is a key motive for research participation, cited by almost half (46%) of respondents to an Australian survey on motives for taking part in qualitative and quantitative drug research (Fry & Dwyer, 2001). However, further qualitative research has unpacked this figure to highlight the complex and multiple ways in which PWUD make sense of, and are motivated by or attracted to payment to take part in drugs research. Research with PWUD who engage with research reveals the profound heterogeneity of PWUD. Davidson and Page (2012) described study participants who carefully curated a program of research activities to ensure weekly research-related income, but also others who only assented to procedures once they discovered they would be paid for it. Slomka et al. (2007) asked participants about the price for their participation in different sorts of, primarily clinical, drugs research. Some participants said they would take part if the price was right; others stated that no amount of money would entice them to overlook what they saw as the risks of participating in some hypothetical studies. Some women weigh up the risks of research participation against the risks entailed in alternative available revenue-generating strategies such as sex work (Bell & Salmon, 2011), and PWUD assess research risks in relation to the risks of street life or the risks attendant on alternative-generating strategies (Singer et al., 2008; Slomka et al., 2007). However, while these assessments of risk may produce very different results, and PWUD are assessing risk against highly personal criteria, what is significant is that research demonstrates that PWUD *do* assess risk. As Slomka et al. (2008) conclude:

> None of our participants fit the stereotypical image of drug users as challenged in their ability to perceive and evaluate risks of research and willing to ignore those risks because of their drug use or desire for money. (2008: 1650)

As a result, and in contrast to the bioethicists discussed above, researchers see their participants as rational actors making informed choices – because this is how study participants see themselves.

When discussing the remunerative aspects of research participation, they located research participation within their universe of revenue-generating strategies. For some, research was 'better than getting money the old-fashioned way [sex work]' (Bell & Salmon, 2011: 89–90). They saw research participation as a safe – and therefore attractive – way to make money. As Davidson and Page note, 'economically marginalized drug users often, even if not exclusively, understand time spent answering questions as "work"' (2012: 1257; see also Collins, 2017; Slomka et al., 2007). Such an orientation shifts the ethical parameters. As Davidson and Page see it, this requires a shift from RECs' consideration of whether a given sum constitutes an undue inducement or not, to whether a given payment is 'just' or not from the perspective of economically marginalized PWUD. It also requires a shift in perspective from research participation 'risk' being assessed in a vacuum, to risk being assessed in the context of the available economic strategies of PWUD.

This idea of research participation as a *transaction* comes out particularly clearly in Collins et al. (2017). They draw on Canadian focus groups with PWUD living with HIV to argue that to develop ethical approaches towards remuneration for research participation it is most useful to address research as their participants see it – as an income-generating option, as a form of work, and as a transaction between two sets of experts (people who use drugs and people who research drugs). This notion of seeing oneself as an expert with something to give (and thus resentment when that expertise is 'taken' without due respect for the giver) is echoed in Bell and Salmon (2011) and Slomka et al. (2007), and in large part underpins the notion of research participation as transaction, as work, and as worthy of recompense.

Across these studies, PWUD frequently noted that researchers needed to pay participants in order to get them to undertake research (supported by Festinger et al., 2005), and that they needed to be paid a fair rate. For some, this was a rate equivalent to unskilled labor (Dickert & Grady, 1999; Slomka et al., 2007); others felt that PWUD themselves should be consulted on what constitutes a fair rate (Collins et al., 2017; Davidson & Page, 2012), all located of course within the context of the prevailing remunerative norms of the local drugs research 'market'.

People who use drugs had strong views on forms of payment and generally rejected the idea that cash payments would prompt drug use, drawing attention to the fact that they can adequately source drugs without cash payments from research (Slomka et al., 2007; Bell & Salmon, 2011). However, they also almost universally regard non-cash forms of payment as untrusting and paternalistic. The participants in Slomka et al. (2007) felt that while they might spend cash remuneration on drugs, they would be more likely to spend it on fast food or groceries, but more importantly, they had the autonomy to make those choices for themselves.

This same sentiment was expressed in Bell and Salmon (2011). These women further argued that 'It is disrespectful to decide for me what my money should be spent on' (2011: 90) and that non-cash payment was judgmental – particularly given that this level of scrutiny is not given to other groups, members of whom may also choose to spend research money on drugs. Further, they, like the participants in Collins et al. (2017), emphasized the impracticalities of non-cash payments, usually in the form of gift cards. Such forms of payment could be inappropriate (such as a gift card for an electronics shop when the participant's fridge is empty) (Bell & Salmon, 2011), or unusable (because the study participant has been barred from the gift card store), or cost-ineffective (for a store where basic goods are more expensive than can be purchased elsewhere) (Collins et al., 2017).

In unpacking financial motives for taking part in research, it becomes clear that there is more to accepting – or indeed seeking out – payment than simply 'economic gain'. People who use drugs tend to evaluate research participation in terms of risks related to research participation – and for many there are clinical research risks they will not engage with for any money – but also the risks of 'life on the street' and the constellation of alternative revenue-generating strategies open to them. As a result, many PWUD understand research participation as a form of 'work', a revenue-generating option that necessarily entails opportunity costs. By placing PWUD' perspectives front and center a new approach to risk and payment emerges – one in which payment is an ethical good, not only in recognition of their expertise, or compensation for time costs but as a transaction which recognizes research participation as a form of work.

Motives, Risks and Rewards of Research

While money is a key motivator for research participation it is rarely the only one, and research into motives for taking part in research and perceptions of the risks and rewards of participation highlight a multiplicity of motives and their simultaneous self- and other-oriented nature.

Early exploratory research into PWUD' experiences of research participation addressed motives for participation. Fry and Dwyer (2001) found that their Australian participants (described as injecting drug users (IDUs)) discussed taking part in research for a range of reasons, which Fry and Dwyer grouped into economic gains (cited by 46% of interviewees), citizenship (37%), altruism (19%), personal satisfaction (i.e. curiosity) (17%), drug user activism (16%), and seeking information or treatment (5%). They distinguished these six themes into two orientations: self-oriented and other-oriented motives. While 22% cited economic gain as their only reason, most cited multiple motives, both self- and other-oriented. This is in significant contrast to the characterization of PWUD as interested only in securing access to heroin, as proposed by Charland (2002), or the 'prevailing stereotypes that depict drug users as selfish, irresponsible and unable to make sound judgements' (Bell & Salmon, 2011: 85; see also Slomka et al., 2007), which are seen to inform RECs' constructions of drug users.

Subsequent research has shifted away from motives towards a focus on PWUD study-participants' perceptions of risk and benefit in research participation, and this body of work continues to support these key findings that research participation by PWUD is often driven by multiple motives, and that these motives are often both self- and other-oriented. This self and other focus is maintained in relation to risk as well as benefit.

Risks or harms identified across multiple such studies include the inconvenience of research participation, noted as a negative of research participation by Slomka et al. (2007) in response to a series of hypothetical drug research scenarios presented to PWUD in the USA, and by Australian IDUs in survey research into 'the positives and negatives' of qualitative and quantitative drug research participation undertaken by Barratt et al. (2008). These inconveniences related to such things as the time research participation took, time and financial costs of travel to and from research sites, and level of financial reimbursement relative to time costs.

A second key harm identified in this body of research into PWUD' engagement with research related to confidentiality. This emerged more strongly in research into past and future hypothetical participation in clinical rather than qualitative or quantitative research, suggesting that the key concerns of biomedical research – which can often shape RECs' approaches to risk – may place undue emphasis on risks which are not priorities for participants in qualitative research at the expense of those (such as the risk of exclusion from research or research not impacting policy) which are.

In their exploration of the risks and benefits of research participation among Hispanic drug users in the USA, undertaken in the context of a wider study into participant perspectives on drug use and HIV research ethics, Singer et al. (2008) identified confidentiality as the key risk of research associated with participation in clinical HIV research. Critically, these concerns about confidentiality took a particular form: that friends or family members might discover (or make assumptions about) one's HIV status as a result of research participation. Linked to this, Oransky et al. (2009) identified confidentiality as a key risk of research participation in relation to their qualitative research into recruitment in public spaces in the USA. However, they discovered that those risks diminished when researchers explained and emphasized the confidential nature of the study, and were seen by participants to be honest and respectful.

Confidentiality, then, is always contextual: how confidentiality is managed in recruitment is different to concerns about being outed as HIV-positive as a result of walking into a clinical research setting. Clinical research is seen to pose greater risks of outing an individual as HIV-positive or a PWUD than participation in qualitative research, and only one identified qualitative study addressed confidentiality as a potential risk. In their analysis of the risks and benefits of participation in an ongoing series of epidemiological studies out of a single drop-in research site for young homeless IDUs in the USA, Davidson and Page (2012) flagged up privacy and confidentiality as important risks to their participants. However, they emphasize that a far more urgent concern to these young, homeless IDUs was the question 'am I going to get ripped off?', linked to ideas of fair recompense discussed above. This again emphasizes the (often substantial) gap that can exist between the priorities of PWUD, RECs, and researchers in terms of what the risks of research participation are and how to manage them.

A risk which emerged across several studies in relation to participation in both qualitative and (hypothetical) clinical research was that of being 'treated like a guinea pig' (Slomka et al., 2007; Bell & Salmon, 2011). In their focus group research with women who use drugs in Canada, Bell and Salmon were able to unpack this further, and found that their participants criticized researchers who they saw as 'acting superior' or 'talking down and being condescending' (2011: 88). These focus group participants recommended that researchers, 'Be approachable. Don't be judgmental. Hear what we have to say. Honestly listen to it' (2011: 88). As noted previously, some participants cited a positive, non-judgmental space to speak as a positive of research participation, and thus while the possibility of research as non-judgmental listening can operate as an incentive to or benefit of research participation when successful, it can pose a risk to future research participation when not.

Consistent with Fry and Dwyer's early findings, participants in research into the experience of taking part in drugs research identify a range of benefits. These are primarily financial, discussed in detail above, but also accessing information and having an opportunity to be listened to and to tell one's story in a non-judgmental space (Bell & Salmon, 2011; Mosher et al., 2015; Barratt et al., 2008). However, as Barratt et al. (2008) reveal, it is essential to go beyond the risk and benefits of research participation in solely individual terms, as advocated by biomedical models of ethics, and to ground our ethics in how PWUD understand them: in fundamentally social terms.

Barratt et al. (2008) asked IDUs in Australia what were the 'best' and 'worst' things about taking part in qualitative or quantitative non-treatment research. Only 19% cited any form of self-oriented benefit; however, 85% said the best things about research participation were such other-oriented factors as being able to provide researchers with 'real' or 'true' information, contributing to policy improvement or helping the drug using community. Few of their participants identified risks associated with qualitative or quantitative drugs research, but among the small minority who did these included both self-oriented factors such as the inconvenience of research participation and personal discomfort (too personal, repetitive, researcher flaws etc.) and other-oriented ones, which centered on limited impact on policy, and the non-implementation of findings. Strikingly, as many participants cited the limited impact of research on policy as a harm of research participation as personal discomfort.

Thus, neither the benefits accrued from research participation nor its harms focused primarily on impact on the self, and the 'best thing' about taking part in research were overwhelmingly other-oriented. On the basis of this Barratt et al. (2008) recommend that informed consent information could emphasize community level benefits of research participation in place of the current biomedical model focus on individual benefits, supporting Seymour's argument that incentives entail more than simply access to payment, and minor changes to recruitment materials and approaches could enhance altruistic incentives for research participation (Seymour, 2012).

PATERNALISM AND THE ETHICS OF RESEARCHING WITH PWUD

Paternalism continues to characterize bioethical discourse on the ethics of research with PWUD. Both Charland (2002) and Henden and Bærøe (2015) advocate for the exclusion of heroin dependent individuals from research designed to identify new and potentially effective strategies for engaging with entrenched heroin users. Such a protectionist stance focuses on questions of consent, at the expense of other ethical concerns such as inclusion or representation. Because they cannot be certain that heroin dependent individuals are sufficiently free from the influence of heroin (or its co-occurring psychological and social harms), the safest course of action is to not include them in such research at all.

Drugs researchers, by contrast, emphasize other ethical goals. Festinger et al. (2005, 2008) advocate for justice ethics based on maximizing inclusion to ensure that the most marginalized are included – and thus represented – in research findings, to increase the likelihood that any intervention development accounts for their needs. This emphasis on representation is shared between both researchers and PWUD, as illustrated by the women in Bell and Salmon's (2011) focus groups. These women emphasized their right to be represented as fundamental to research. When asked, these women argued that exclusion from research is 'always harmful' and that those who wish to participate in research should be welcome to do so, for some even if intoxicated. This stands in stark contrast to the forms of protection offered by bioethics and can be understood by situating both discourse (paternalistic exclusion and the right to representation) within the discourses and power structures within which they occur. Bioethicists operate out of a biomedical framework that prioritizes the minimization of physical, individual harms over other forms of (social) harm and benefits (Simpson, 2011). These female drug user focus group participants, by contrast, are multiply marginalized because of substance use, sex work, maternity, and histories of physical and sexual abuse (Thom, 2010). This is a group familiar with being marginalized and excluded – and it is perhaps not surprising that when asked, their key ethical concerns turned not around consent, or even confidentiality, but around the question of inclusion. They were not concerned that they were being inadequately protected from risk by research, but rather that they were being refused their 'right' to be heard (see also Small et al., 2014).

Researchers and PWUD alike saw non-cash payment for research participation as paternalistic. Efforts to protect them from the potentially undue influence of payment resulted in lower levels of payment for PWUD and other vulnerable groups compared to other members of society invited to participate in similar research (Fry et al., 2005).

Efforts to protect PWUD from converting payment into drugs by disproportionately offering them payment in the form of vouchers rather than cash (despite the fact that, as some of Bell and Salmon's (2011) participants noted, people involved in non-PWUD research may choose to spend research payments on drugs) were similarly felt by PWUD – and most researchers – to be unnecessarily paternalistic. For PWUD, such decisions were not only paternalistic, but also patronizing and impractical. All expressed strong but consistent views that it was their right to spend research payment as they wished – even on illicit drugs.

People who use drugs tend to approach payment and risk assessment from a radically different perspective to how drugs researchers saw RECs making those assessments. They and the researchers who work with them reject the stereotype of PWUD as always high, or always focused on accessing drugs, or so out of control that they cannot assess risk. They strongly assert a right to self-determination, to make and be responsible for their decisions both to participate in research and spend any remuneration. They have shown through various studies that money is a key motivator for research participation but that this still entails an assessment of risk – and that this assessment of research-related risk does not occur in a vacuum: risks of research participation are evaluated against the costs and benefits of a range of alternative revenue-generating strategies and activities undertaken 'on the street'. By advocating for a narrow definition of risk, which falsely assumes that study participants make decisions about research participation solely in terms of the risks as presented on a Participant Information Sheet, is to ignore the complex and multifaceted nature of human risk assessment and decision-making. An ethics of inclusion must necessarily work towards an understanding of the contexts in which PWUD and others evaluate research risks and make decisions about participation.

CONCLUSION

Thus, in summary, paternalism continues to inform bioethical debate about the ethics of research with PWUD, and consequently REC decision-making processes. This paternalism is built on a series of stereotypes of PWUD as out-of-control 'addicts' who cannot – and should not – be trusted to take part in well-remunerated research because of fears that such remuneration will undermine their capacity to assess risk. As the research discussed here shows, PWUD can and do assess risk. But they do so in different ways, and not necessarily those articulated in Participant Information Sheets. By asking PWUD about why they take part in research, and giving adequate weight to the discourses of transaction and inclusion that shape their responses, an ethics of inclusion, rather than protection, becomes possible.

REFERENCES

Aldridge, J. and Charles, V. (2008). Researching the intoxicated: informed consent implications for alcohol and drug research. *Drug and Alcohol Dependence*, 93(3), 191–196.

Australian Injecting and Illicit Drug Users League (AIVL) (2003). *National Statement on ethical issues for research involving injecting/illicit drug users*. Canberra: Australian Injecting and Illicit Drug Users League.

Barratt, M.J., Norman, S.J., and Fry, C. (2008). Positive and negative aspects of participation in illicit drug research: implications for recruitment and ethical conduct. *International Journal of Drug Policy*, 18(3), 235–238.

Beckford, L. and Broome, M.R. (2007). Ethics and the payment of research subjects. *Psychiatry*, 6(2), 83–85.

Bell, K. and Salmon, A. (2011). What women who use drugs have to say about ethical research: findings of an exploratory qualitative study. *Journal of Empirical Research on Human Research Ethics*, 6(4), 84–98.

Bentley, J.P. and Thacker, P.G. (2004). The influence of risk and monetary payment on the research participation decision making process. *Journal of Medical Ethics,* 30(3), 293–298.

Carter, A. and Hall, W. (2013). Ethical implications of research on craving. *Addictive Behaviors*, 38(2), 1593–1599.

Charland, L.C. (2002). Cynthia's dilemma: consenting to heroin prescription. *The American Journal of Bioethics*, 2(2), 37–47.

Collins, A.B., Strike, C., Guta, A., Turje, R.B., McDougall, P., Parashar, S., and McNeil, R. (2017). 'We're giving you something so we get something in return': perspectives on research participation and compensation among people living with HIV who use drugs. *International Journal of Drug Policy*, 39, 92–98.

Davidson, P. and Page, K. (2012). Research participation as work: comparing the perspectives of researchers and economically marginalized populations. *American Journal of Public Health*, 102(7), 1254–1259.

Dempsey, J.P., Back, S.E., Waldrop, A.E., Jenkins, L., and Brady, K.T. (2008). The influence of monetary compensation on relapse among addicted participants: empirical vs. anecdotal evidence. *The American Journal on Addictions*, 17(6), 488–490.

Dickert, N. and Grady, C. (1999). What's the price of a research subject? Approaches to payment for research participation. *The New England Journal of Medicine,* 341(3), 198–203.

Festinger, D.S. and Dugosh, K.L. (2012). Paying substance abusers in research studies: where does the money go? *The American Journal of Drug and Alcohol Abuse*, 38(1), 43–48.

Festinger, D.S., Marlowe, D.B., Croft, J.R., Dugosh, K.L., Mastro, N.K., Lee, P.A., Dematteo, D.S., and Patapis, N.S. (2005). Do research payments precipitate drug use or coerce participation? *Drug and Alcohol Dependence*, 78(3), 275–281.

Festinger, D.S., Marlowe, D.B., Dugosh, K.L., Croft, J.R., and Arabia, P.L. (2008). Higher magnitude cash payments improve research follow-up rates without increasing drug use or perceived coercion. *Drug and Alcohol Dependence*, 96(1–2), 128–135.

Fisher, C.B. (2011). Addiction research ethics and the Belmont Principles: do drug users have a different moral voice? *Substance Use & Misuse*, 46(6), 728–741.

Foddy, B. and Savulescu, J. (2006). Addiction and autonomy: can addicted people consent to the prescription of their drug of addiction? *Bioethics*, 20(1), 1–15.

Fry, C. (2010). Ethical implications of peer-driven recruitment: guidelines from public health research. *The American Journal of Bioethics*, 10(3), 16–17.

Fry, C. and Dwyer, R. (2001). For love or money? An exploratory study of why injecting drug users participate in research. *Addiction*, 96(9), 1319–1325.

Fry, C.L., Ritter, A., Baldwin, S., Bowen, K.J., Gardiner, P., Holt, T., Jenkinson, R., and Johnston, J. (2005). Paying research participants: a study of current practices in Australia. *Journal of Medical Ethics,* 31(9), 542–547.

Goldim, J.R., Fernandes, M.S., and Pechansky, F. (2011). Ethical, legal and social issues related to alcohol and drug research. *Current Opinion in Psychiatry*, 24(3), 181–185.

Head, E. (2009). The ethics and implications of paying participants in qualitative research. *International Journal of Social Research Methodology*, 12(4), 335–344.

Heckathorn, D.D. (1997). Respondent-driven sampling: a new approach to the study of hidden populations. *Social Problems*, 44(2), 174–199.

Henden, D. and Bærøe, K. (2015). Providing free heroin to addicts participating in research: ethical concerns and the question of voluntariness. *BJPsych Bulletin,* 39(1), 28–31.

Home Office (2003). *Home Office Findings 208: Recreational drug use among clubbers in the South East of England*. London: HMSO.

Levy, N. (2006). Addiction, autonomy and ego-depletion: a response to Bennett Foddy and Julian Savulescu. *Bioethics*, 20(1), 16–20.

Marsh, A. and Loxley, W. (1992). Coffee shops and clinics: the give and take of doing HIV/AIDS research with injecting drug users. *Australian Journal of Public Health*, 16(2), 182–187.

Mosher, H.I., Moorthi, G., Li, J., and Weeks, M.R. (2015). A qualitative analysis of peer recruitment pressures in respondent driven sampling: are risks above the ethical limit? *International Journal of Drug Policy*, 26(9), 832–842.

Murdoch, B. and Caulfield, T. (2016). Doing research with vulnerable populations: the case of intravenous drug users. *Bioéthique-Online,* 5(32), 1–11.

Oransky, M., Fisher, C.B., Mahadevan, M., and Singer, M. (2009). Barriers and opportunities for recruitment for nonintervention studies on HIV risk: perspectives of street drug users. *Substance Use & Misuse*, 44(1), 1642–1659.

Ritter, A., Fry, C., and Swan, A. (2003). The ethics of reimbursing injecting drug users for public health research interviews: what price are we prepared to pay? *International Journal of Drug Policy*, 14(1), 1–3.

Russell, M.L., Moralejo, D.G., and Burgess, E.D. (2000). Paying research subjects: participants' perspectives. *Journal of Medical Ethics*, 26(2), 126–130.

Sandberg, S. and Copes, H. (2013). Speaking with ethnographers: the challenges of researching drug dealers and offenders. *Journal of Drug Issues*, 43(2), 176–197.

Scott, G. (2008). 'They got their program, and I got mine': a cautionary tale concerning the ethical implications of using respondent-driven sampling to study injection drug users. *International Journal of Drug Policy*, 19(1), 42–51.

Seddon, T. (2005). Paying drug users to take part in research: justice, human rights and business perspectives on the use of incentive payments. *Addiction Research & Theory*, 13(2), 101–109.

Seymour, K. (2012). Using incentives: encouraging and recognising participation in youth research. *Youth Studies Australia*, 31(3), 51–59.

Simpson, B. (2011). Ethical moments: future directions for ethical review and ethnography. *Journal of the Royal Anthropological Institute*, 17(2), 377–393.

Singer, M. (2012). Anthropology and addiction: an historical review. *Addiction,* 107(10), 1747–1755.

Singer, M., Mirhej, G., Hodge, D., Saleheen, H., Fisher, C.B., and Mahadevan, M. (2008). Ethical issues in research with Hispanic drug users: participant perspectives on risks and benefits. *Journal of Drug Issues*, 38(1), 351–372.

Slomka, J., McCurdy, S., Ratliff, E.A., Timpson, S., and Williams, M.L. (2007). Perceptions of financial payment for research participation among African-American drug users in HIV studies. *Journal of General Internal Medicine*, 22(10), 1403–1409.

Slomka, J., Ratliff, E.A., McCurdy, S., Timpson, S., and Williams, M.L. (2008). Perceptions of risk in research participation among underserved minority drug users. *Substance Use & Misuse*, 43(11), 1643–1655.

Small, W., Maher, L., and Kerr, T. (2014). Institutional ethical review and ethnographic research involving injecting drug users: a case study. *Social Science & Medicine*, 104, 157–162.

Thom, B. (2010). Women in recovery. In R. Yates and M.S. Malloch (eds) *Tackling Addiction: Pathways to Recovery*. London: Jessica Kingsley Publishers, pp. 52–69.

Thurstone, C., Salomensen-Sautel, S., and Riggs, P.D. (2010). How adolescents with substance use disorder spend research payments. *Drug and Alcohol Dependence*, 111(3), 262–264.

Topp, L., Islam, M.M., and Day, C.A. (2013). Relative efficacy of cash versus vouchers in engaging opioid substitution treatment clients in survey-based research. *Journal of Medical Ethics*, 39(4), 253–256.

Uusitalo, S. and Broers, B. (2016). Addiction, heroin-assisted treatment and the idea of abstinence: a reply to Henden. *Bioethics*, 30(9), 776–780.

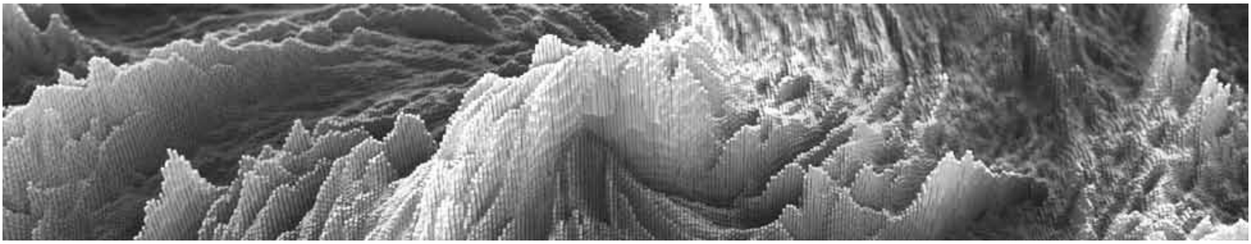
Weinberg, D. (2011). Sociological perspectives on addiction. *Sociology Compass*, 5(4), 298–310.

This page intentionally left blank

PART V

Relational Research Ethics

Ron Iphofen and Martin Tolich



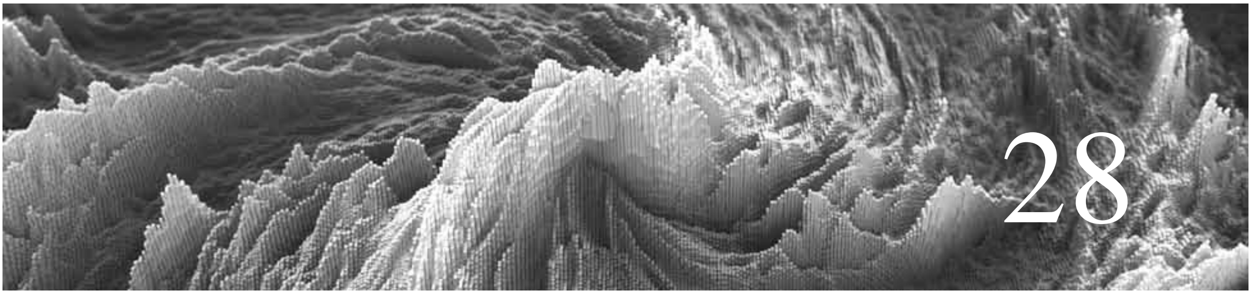
Many authors in this *Handbook* take issue with the time delays that ethics review involves and this is acute for research conducted by journalists. Thus **Donald Matheson** claims differences in research conducted by journalists stem less from the research techniques but from a timescale. An unfolding news story cannot wait 2 to 4 weeks for their research questions to be reviewed and approved. Opportunism as practised by journalists does not match ethics review. This does not mean that journalists operate without ethical codes. The first duty of a journalist, Matheson explains, is public disclosure making journalists' research an exception to the 'common' rule.

There is nothing unusual about the ethics of research conducted following a disaster (earthquake, flood, hurricane, chemical spill) as they all rely on core ethical issues. Again, like the ethics journalists practice, what is unique is the timeframe. Researchers do not choose these sites, the serendipity of disasters provide the researchers' opportunities – today. **Dónal O'Mathúna** hones in on the root of the vulnerability of these people, not a category of person (children, the elderly) but the vulnerability that stems from experiencing a collective calamity. A fundamental ethical issue featured in the chapter addresses a dual imperative in research: first, involvement of the local community ensures its needs are accurately identified and, second, participants see how the findings will be furthered.

The positioning of the researcher vis-a-vis the research subjects is complex in insider/outsider research sites, forcing the researcher to constantly address a set of role conflicts unanticipated in the formal research ethics committee application. In **Bridgette Toy-Cronin's** chapter, she takes off her lawyer's wig when recruiting nonlawyers (laypersons) who seek to self-represent in formal legal proceedings. The researcher's role conflict is manifest as attempting to distance herself from a place (courtrooms) where all professionals recognize her as an insider, rather than an outsider researcher. The researcher as outsider faces distinctive ethical moments when she observes the nonlawyers she is researching making basic yet remedial errors in court procedures. Does she intervene? If she does not, where is the reciprocity?

David Calvey unpacks the controversy surrounding conducting research covertly, recognizing this type of data collection has sizeable ethical luggage. Before describing his own research as a nightclub bouncer in Manchester, UK, he details a rich history of previous examples of data collection using deception. He doesn't argue that all research should be covert but he does build a case that these historical exemplars provide ways to make private issues public debates. Deception research overlaps with insider and outsider research, as in deception the insider does not disclose their double identity.

Karin Olson's chapter on grounded theory provides an overview of the history of the technique as well as the general overview of core ethical issues that arise generating the research question and sampling. These ethical issues revolve around autonomy, risks and benefits, and justice. Like the authors of other chapters in the *Handbook* who spotlight ethical issue as power relationships, this grounded theory author takes as realistic the position that the researcher remains the person who frames the study, defines the questions and conducts the analysis.



28

An Exception to the Rule: Journalism and Research Ethics

Donald Matheson

INTRODUCTION

In mid 2015, the *Süddeutsche Zeitung* in Munich was contacted by an anonymous person wishing to give it a large amount of personal banking data and legal correspondence taken from the Panamanian law firm, Mossack Fonseca. After some negotiations with the leaker, the newspaper, working with investigative journalists from media outlets in 80 countries, received a hard drive containing four large databases, about 4.8 million emails and much more: in total about 11.5 million documents. The Panama Papers constitute by far the largest journalistic leak of data in history and they led to news stories of public significance alleging globalized tax-dodging by leading politicians, sportspeople, celebrities and businesspeople – the likes of Argentine footballer Lionel Messi, Sarah Ferguson, Duchess of York and the associates of Russian president Vladimir Putin. *The Guardian*'s editors wrote that the data showed that,

> normal rules do not apply to the global elite. In a new gilded age, taxes would – once again – appear to be for the little people … No longer is this about faceless corporations and financiers, but about leading politicians and their circles, sometimes the same politicians who have been asking for all the sacrifices. (*The Guardian,* 4 April, 2016)

Yet the leak – and much of the reporting – also traded off against this public interest justification the principle of lawyer-client privilege, the privacy rights of the law firm and those involved with the 216,000 companies whose data were leaked, as well as the risk of harm to the prominent individuals exposed. The leaker broke laws and – we can assume – the terms of his or her employment, on a story where most of the clients of Mossack Fonseca were not themselves breaking any tax laws.

The outcomes in my own country, Aotearoa New Zealand, were significant. After initially denying that the country was a tax haven, the Prime Minister succumbed to pressure from a leading investigative journalist, Nicky Hager, and others, and launched an inquiry into aspects of the tax system. Significant changes were later made to New Zealand tax laws.

Without going further into the ethics of the Mossack Fonseca case, it is clear that journalism, particularly at moments when it is making its grandest claims to value, collides with legal and ethical structures elsewhere in society. Indeed, western journalism has developed its own broad consensus on ethical practice, in which freedom of expression, the public good and the interests of the disempowered are given the highest prominence. The New Zealand Press Council, for example, begins its statement of principles with the assertion that: 'There is no more important principle in a democracy than freedom of expression'. Consequently its judgments give freedom – and the public interest it sees as flowing from that – primary consideration (NZPC, n.d.). US journalism scholar Dale Jacquette draws on the same set of ideas: 'it is not only morally permissible but morally obligatory for journalists in possession of the facts [about a matter of public importance] to make that information known' (2010: 220). The first duty of the press, to use the 1861 words of *Times* editor John Thaddeus Delane, is disclosure (cited in Briggs & Burke, 2009: 189).

The classic liberalism at the heart of this kind of journalism contrasts starkly with research ethics governance frameworks within universities. Freedom of speech and the public good do not feature prominently in the latter's guidelines. Indeed the UK's Economic and Social Research Council (ESRC) Framework for Research Ethics (FRE, 2015) does not mention the terms at all. Moreover, while the ESRC's second principle, that research must be worthwhile 'and provide value that outweighs any risk of harm' (p. 4), gives some scope for a public good defence of the breaches above, its first principle does not:

> Research participants should take part voluntarily, free from any coercion or undue influence, and their rights, dignity and (when possible) autonomy should be respected and appropriately protected. (FRE, 2015)

The principle also requires that research funded by the ESRC comply with relevant laws and with data privacy standards. The *Süddeutsche Zeitung*, which colluded with a leaker who breached the rights of the world's superrich, would probably not get its investigation funded. Yet journalism academics would join their professional colleagues in seeing that investigation as exemplary – one Cardiff academic calling it 'a remarkable feat' with a clear public interest (Sambrook, 2016) – and would teach it as such.

Seiber and Tolich (2013: 77–81) note that journalists have well-established freedom of speech rights which form the ethical heart of their practice, while researchers begin not with rights but instead with ethical constraints. This difference in ethical grounding would not be of much concern to readers of this *Handbook* except for three trends. First, research ethics committees and similar bodies at universities are increasingly being tasked – whether through the requirements of national research ethics frameworks, the concerns from risk-averse management or decisions driven by scholars themselves – with overseeing journalism conducted by academic staff and students at their institutions. At some universities, an ethics subcommittee must approve all teaching that uses interviews in its assessment or where work will be published (including journalism). Second, it is becoming more common for journalism to be published by academics as part of their research output or community engagement. Third, the weakening of in-depth journalism in a number of western countries, as newspapers lose circulation and advertising and so lay off staff, has led to calls for universities to take a leadership role in public-good, in-depth journalism, both in training investigative reporters and in producing it themselves. Nolan writes that there are 'significant opportunities for forms of university education to act as an important check on some of the more deleterious effects engendered by the increased commercialization and deregulation of the media sector that has occurred in recent times' (Nolan, 2008: 747; cited in Richards and Josephi, 2013: 203).

This chapter argues that dealing with this collision of perspectives requires some accommodation from all sides. It also provides an opportunity for learning on all sides. On one level, academic journalism is just one academic practice among many that have been affected by the general 'mission creep' (Gunsalus et al., 2007) of ethical review processes in a number of countries. But, on another level, there is a sharper problem about how universities recognize the ethics systems particular to practices, like journalism, which set out to serve the public good and which produce knowledge in ways distinctive to that practice. Underneath this problem is the more fundamental question of how to establish the boundaries between research and other activities that take place in the university. The chapter proposes, in the same way as Spicker (2007) has argued in relation to policy studies, that distinctive ethical criteria must be recognized in different areas of university activity where claims to be producing research are being made. Yet it must also be noted that exceptionalism risks leaving university-based journalists with a weak ethical system. To take the lead that Nolan advocates, they must engage with a wide range of ethical frameworks to take ethical critique much further than journalists outside the university – and the often highly commercialized media outlets who employ them – tend to.

JOURNALISM AS KNOWLEDGE

Bell and Nutt (2002) write that there will be divided loyalties in any professional field taught in universities: a social work academic working in the field, for example, will need to balance research goals with the needs of clients taking part in that research, the research participants and any students involved. Yet the problem we are considering in this chapter is not one of finding ways to balance those interests through reflexive professional practice: it is a matter of competing ethical frameworks and jurisdictions, brought into tension as formerly secure boundaries between journalism and research are blurred by journalism academics and by research ethics committees alike. To take one example, Vine et al. (2016) point out a fundamental tension for journalism academics who sign up to professional or journalist union codes of practice. The major US code calls on journalists to act independently, including 'to resist internal and external pressure to influence coverage' (SPJ, 2014). To cede editorial judgement to an ethics committee operating under the ambit of non-journalists and ultimately to guidelines set by state-controlled research bodies is prima facie, Vine et al. argue (2016: 241), unethical for a journalist.

These differences are at heart epistemological. Journalism tells timely stories about the real in public. It often constitutes a direct intervention in the social, and it is often a critical and disputative one. Without seeking to caricature either practice, it is possible to describe a systematic set of differences between journalistic knowledge and typical qualitative social science research (Table 28.1).

Table 28.1 Contrasting journalistic knowledge and social science knowledge

Journalism	*Social science*
story	analysis
provisional	enduring
public space	reflective space
actual	conceptual
practical	theoretical
challenging	interpretive

The left-hand category (Table 28.1) is, of course, devalued in scholarly terms and must justify itself. As Park (1999[1940]) wrote in an early scholarly account of news as knowledge, news is related to other kinds of unsystematized, commonsensical knowledge that come 'with use and wont rather than through any sort of formal or systematic investigation' (p. 670), and that become embedded in habits and tacit knowledge. It is also embedded in its object of scrutiny: 'The function of news is to orient man and society in an actual world' (p. 685).

Without an explicit methodology of analysis, journalism's implicit methodology has tended to draw upon the notion of the independent observer and to prioritize freedom of speech, as ways of creating some distance between its knowledge claims and those of powerful social actors. The senior Canadian journalism ethicist Stephen Ward, for example, has restated the centrality of independence in the face of arguments that the convergence of journalism with other forms of public communication in blogs and social media make transparency and reflexivity more useful terms. 'Independence insists that journalists not let allegiances and sources weaken their commitment to journalism in the public interest. On my view, independence, not transparency, distinguishes journalism from propaganda, journalism from narrow advocacy' (Ward, 2013). In much of journalism's self-understanding, truth telling is understood in agonistic terms as a never-completed action, a matter of pushing back against those who cloak self-interest in the language of public interest. 'Every society', German journalism professor Michael Kunczik (2000) writes, 'has experienced that the powerful in politics and business don't want their affairs critically observed by the media and so find themselves under public scrutiny. Corruption and abuse of power happen everywhere, all the time, and fighting them is a task central to democratic journalism.' For Bourdieu (2005), journalism is paradigmatic of a field of practice because of its pursuit of autonomy from state and market forces (as well as the weakness of that in actuality).

In these formulations of the status and role of journalistic knowledge in the world, ethical principles such as the preservation of individual human dignity are necessarily subordinated to the collective project of open public life. This is because journalism assumes that people are participants in society as well as private individuals. Hence, privacy is not simply paramount. Privacy ethics entails deciding whether there is a 'more compelling moral good' (Meyers, 2010: 200) than individual privacy, which requires information about that person to be made public. To ask journalists to do otherwise would be to reduce some of their claim to be telling the real story, that is, the claim of their texts to be connected to public realities. Zelizer goes as far as to argue that journalism is so instrumental and pragmatic a practice that ethical codes have little purchase:

> Its variable standards of action patched together largely on a case-by-case basis and often via improvisory responses to unpredictable and emergency-like situations, journalism's capacity to repair to an aspired to but largely abstract ethics code remains a sideshow, supporting a more general journalistic disregard for abstractions that is exacerbated by 'a busy newsroom … impatient of any form of reflection that doesn't contribute to a result or which may slow things down'. (Zelizer, 2013: 274; citing Brock, 2010)

Scholars of journalism practice often take a softer position. Formal ethical codes are not so much ignored but backgrounded in daily decision-making, where decisions about the news belong to the 'now' in which that news is situated and where longer-term thinking is pushed aside in the pursuit of capturing the truth of that moment (see Schlesinger, 1979). In these moments, ethics is implicit in action, an exercise in practical wisdom (Glasser and Ettema, 1989). Learning gleaned from past practice combines with appreciation of specific situations and an orientation towards doing the job well.

Langlois (2011) makes a similar epistemological claim for some political studies research and argues that research ethics frameworks make little allowance for these kinds of knowledge. Research is assumed to be 'premeditated, time delimited, discrete and external to the researcher' (p. 144), with little connection to political life, and researchers to be distinct from advocates or political actors. Yet for him, 'Political research is in the public fray, and to play its legitimate and crucial role in the public fray it must be allowed to proceed in accord with the pulse of public life' (p. 146). Instead, he complains, ethical committees demand long lead times and an alignment with the interests of research participants as private individuals; they forget that participants may set out to coerce or deceive the researcher. He argues that doing harm to such a research participant – an industrial baron seeking to influence public policy or those guilty of human rights abuses – may be a social good: 'The 'harm' that is done to the individuals and corporate entities in question here – 'harm' done by undertaking research – is very much in the public interest' (p. 150).

There is a risk that such critiques of ethics frameworks are mistaking the practicalities of public life for the pursuit of good work. It is better to begin from the position that research should not set out to do harm and should consider other ways of achieving a good with no or minimal harm, and should justify any harm done. The problem for university research on journalism – and related fields such as political studies and public policy research – is that research ethics rarely validates those practices' own approaches to the good. As Romano (2016) notes in relation to journalism, an ethics review language is needed that draws on the practical reason of the media industries, so that it can bridge the two.

INSTITUTIONAL RESPONSES TO THE ETHICS OF JOURNALISM RESEARCH

That language is not yet well developed, as is clear when we consider the variation and ambiguity in how journalism is treated within academic institutional review processes. In the United States, journalism done for professional education or as professional practice does not meet federal definitions of research, which require systematic investigation and the generation of generalizable knowledge (OHRP, 2009), although there are exceptions and differences of view. Journalism at the University of North Carolina was judged to be research when it involved opinion polling (UNC, 2000). Elliott (2013) by contrast argued that journalism was not research when it was intended for a lay audience. In Australia, academic journalism is generally counted as research. Davies (2014) found that two out of 28 university committees she surveyed had particular criteria for journalism. All required academic staff – and all but one required postgraduates students – to submit journalism practice research projects to committees, and a third required it of undergraduates. Distinctions were made between journalism intended for publication and learning exercises, as well as between professional practice and activity that involves what one called 'academic credentialing' (2014: 106). In Aotearoa New Zealand, journalism is generally exempted from university guidelines, except when it is 'a major study' (AUT, 2016).

Institutions rarely specify the grounds on which these criteria are applied, tending instead to divide activities into research, teaching and professional, and leaving the grounds implicit in those pragmatic institutional distinctions. When reasons for these divisions of work are given, they are problematic and it is difficult to judge why institutions differ. Why, for example, should journalism done as a substantial investigation require ethical approval in some universities when – potentially quicker and dirtier – daily practice does not require that? Gunsalus et al. (2007: 634) talk of 'gossamer distinctions' for which it is hard to find principled grounds. In its simplest terms, the problem is that rules designed with other kinds of activity in mind do not apply well to journalism done within the university. Ethics frameworks lack sensitivity to the ways that they might constrain practice that journalists see as good. Richards and

Josephi (2013: 204) point out that procedures that require researcher-journalists to prepare questions weeks in advance are 'antithetical to investigative journalism'. Similarly, requirements that researchers gain informed consent, grant anonymity when requested and accord respect for persons (if respect is interpreted narrowly as not challenging or intruding upon people's self-understanding), all cut across common journalism practices (Richards, 2009). Gunsalus et al. (2007: 634) comment that these kinds of strictures not only conflict with journalists' ethical codes but put journalism students and researchers in the 'intolerable position' where they are forced to violate the ethical consensus of their discipline. Davies (2014) reports that one ethics chair told her:

> We also acknowledge that journalism is 'opportunistic' and therefore under extenuating circumstances have allowed journalism researchers to seize an opportunity to conduct an interview prior to formal approval. Only if the research is, without question, low risk and only when the researcher follows standard ethical practices of informed consent. However, this is only considered under extenuating circumstances and is rare. The responsibility lies with the researcher to demonstrate that there was no possibility that the circumstances were foreseeable and ethics approval could have been sought prior to the interview. (p.114)

Davies wonders whether 'only a certain kind of tame and agreeable kind of journalism is deemed to be possible in HREC [human research ethics committee] contexts' (p. 114). Clearly, a journalist in the field with the opportunity to confront a person suspected of wrongdoing, in a way that carried risk but also promised public benefit, would not be able to carry out that accountability journalism. Similarly, it is impossible for journalists, whose story ideas often arise from constant contact with a wide range of sources, to seek prior ethical approval before talking to the sources they will use. Journalistic and research ethics frameworks are at odds here. What appears 'tame' in one language is 'low risk' in the other; interviewing permeates all aspects of one process but is regarded as a distinct stage in the other. The point here is not that journalism provides the better ethical framework but that research ethics overrules journalistic ethical norms that have evolved alongside practice. For example, for a journalist the norms of public life entail that, once the journalist has introduced herself to a public individual as a journalist, everything that person says is 'on the record' without explicit need for consent. Yet an academic doing journalism in this way would in many universities be deemed to be acting unethically.

Partly because of this sidelining of journalistic ethical practices, practitioners often regard review processes as external forms of pressures and therefore a form of censorship. In this, they – and some of those who manage the processes – conflate the distinction Iphofen (2011: 163) draws between ethical review of research (what are the harms and benefits of a project for researchers and participants?) and the governance of research (what are the harms and benefits of the research for this institution?). Arguments about managerial interference are a separate matter to the ethics of the work. But that conflation is perhaps more likely when the reviewing is controlled by people outside the field of journalism and the academic department. One widely discussed case concerns a young graduate of the University of Canberra's journalism programme who reported (Ingram, 2012) that she was pressured by a deputy dean to withdraw a request, made under federal freedom of information laws, about her university's plans to close parts of the journalism programme. As well as being told that refusing to withdraw the request could result in a breach of student conduct rules (with expulsion or exclusion as ultimate possible sanctions), she said she was told that the university had received a legal opinion that the request for information – part of an investigative journalism course – required ethics clearance. Ingram wrote that the university had not required ethics clearance of previous journalism student work: 'I believe this was just another attempt to frighten me off investigating a potentially negative story on UC [University of Canberra] by accessing documents through FOI [Freedom of Information]' (Ingram, 2012.). These cases where university-wide ethical review processes are deployed in ways that can be readily perceived by journalists as censorship that suppresses truth telling in the public interest are certainly rare. On the other hand, journalist academics approached for this chapter were unwilling to speak publicly about their institutional structures because of concerns about how institutional power over ethics review processes might be used. Journalism is a cultural practice that has developed historically in the face of attempts to suppress it and whose practitioners, researchers and teachers therefore often push back against constraints on its practice.

This tells us as much about journalistic ideology as about bad university management. Universities typically share with journalism a historical commitment to critical or disruptive thinking. While the former has tended to formalize and systematize that commitment at the level of methodology, the latter is institutionally wary of formalizations. Journalism culture's valorization of freedom may cause journalists to forget how much they form powerful institutions that have communicative obligations beyond their individual freedoms (O'Neill, 2013). But on the other hand they remain sensitive to important structural conditions for healthy public debate and to the value of robust and critical interventions in public life that the more risk-averse culture of institutional review processes may lose sight of.

REFLEXIVITY

If journalism is understood to overlap with research in the contemporary university, and yet is understood also as a distinct form of knowledge, it becomes difficult to demand that journalism simply fit into a standard model of research ethics. University-based journalists produce texts that intervene in political and cultural debate and therefore cannot always be treated as planned, discrete moments of research, or as congenial and consensual. Journalism-as-research, like policy research (Spicker, 2007), may at times legitimately research its subjects without their consent. Spicker (2007: 6) describes the sometimes 'astonishing restrictions' imposed by review bodies on some research, restrictions which fail to recognize that action in the public domain 'is neither confidential nor subject to consent before it can be reported'. Not all research ethics can be forced into ethical frameworks for research on private individuals. For this reason, Gunsalus et al. (2007: 627) would want to leave journalism ethics to the professionals: 'Trying to make them fit a biomedical research … misunderstands and threatens the distinct values and purposes to which such work is dedicated, threatening, for example, the fundamental principle of freedom of the press'.

Yet the many weaknesses in professional journalism's ethical structures make this position just as inadequate. To take just one aspect, journalism's professional claims to independence cannot be taken at face value, for journalism that is detached from community standards is at risk of being unethical – as is clear from the case of the *News of the World*, where a 'predatory culture' of getting the story at all costs led to the endemic use of deception, bribery and hacking before an unprecedented backlash forced the newspaper's closure (White, 2011: 61). The traditional journalistic claims to independence or impartiality are unsustainable when commercial pressures are strong (indeed, it could be argued that journalism's practices are ineluctably commodified) and when news organizations are large and powerful. The 'public journalism' movement that arose in the United States in the 1990s represents one attempt among many to rework that claim to public value into a responsibility to the community's best interests. Journalism ethics frameworks are often contradictory, incomplete and riven with compromise and they are the subjects of vigorous debate in journalism scholarship and trade journals. Journalists disagree, for example, on whether sources should be allowed to see stories before publication or withdraw 'on the record' comments. They disagree on whether social media material that is in the public domain but intended as private may be reproduced. Journalistic practice requires and undergoes continual rethinking. A key question is therefore what role do university ethics committees play as a leading focal point for that discussion.

For one journalist who made a documentary on the experiences of a group of female sex workers in Rwanda for a public service broadcaster in 2014 (that also formed the empirical component of a PhD thesis in journalism), filling in a research ethics application forced her to confront some significant weaknesses in journalism practice. The university's processes gave rigour to the preparation for the fieldwork she did – including challenging her to show that she understood the culture she was going into and requiring her to plan for various risks. She reflected afterwards that it made her constantly aware of people around her and her impact on them, including the highly vulnerable women she was working with and her fixer (personal interview, 2016). Most importantly, these are forms of reflective practice that are weakly developed in journalism, requiring her to draw on postcolonial and other theory. She was working with a highly vulnerable group – women sex workers, in a community where there had recently been 18 violent deaths and in a country where they could not rely on police or other authorities, and all against Rwanda's legacy of extreme violence. In her view, journalism practice provided her few tools to balance the public interest in telling the story and giving these women some agency in their own representations. The risk of good intentions leading to paternalistic and exploitative coverage was high, she said.

> I still wanted to tell the stories because I could see the value in telling people's stories. But I had this internal conflict because at the same time I felt I was exploiting and yet at the same time I would have story subjects want to tell their stories and really value that process. (personal interview, 2016)

In this kind of human-interest documentary journalism, where the journalist was working more slowly (she had to pitch the story to a broadcaster and then plan her trip) and where the focus was on an exploited group, an ethics review process was valuable in providing a framework within which to develop a reflective practice. The journalist proceeded by flipping the usual journalistic question – what can I get from these sources? – so as to prioritize the interests of the sex workers themselves, making them feel as much in control of the story as was possible, to show solidarity with them and to do no further harm to them. She also gave the interviewees confidentiality, used a pseudonym in Rwanda (which is why she is not named here) and did not pursue leads on who had murdered their colleagues. In doing so, she sought to position herself outside a tradition of journalism in which Africans are often viewed by westerners without adequate sensitivity to what they might want or think. She noted in particular the risk of western journalists operating by double standards, and referred to the practice of US photojournalist Lynsey Addario as an example. Addario, she said, photographed, at different times, the dying moments of a US soldier in a combat situation and of a young Sierra Leonean woman in childbirth. The images of the soldier were never published because his father refused consent. The images of the young woman were not put through the same permissions process. Such examples raise questions not so much about a journalist's intentions to document others, but about longstanding and deeply embedded ways of thinking. Thus, Campbell and Power (2010) describe a 'scopic regime' in which Africa has been remarkably consistently infantilized, homogenized and feminized in the west.

Ethical review of a journalistic project can deepen its author's engagement with the power of journalism, and in particular the power of the privileged in reporting on others. In this kind of reporting, when journalism is consciously slowed down so as to disembed it from the moment of the news and so as to enable more explicit ethical knowledge than Zelizer describes above, the university models some practices that the profession can draw from in daily work. In this case, it led to a trade-off between a more abstract public interest and solidaristic engagement with members of a particularly disadvantaged part of the public. In another case, cited by three authors (von Dietze, 2012; Davies, 2014; Romano, 2016), a student using journalistic methodology who had initially intended to interview East Timorese freedom fighters, produced instead an oral history project after four months of negotiation with a university review body over risks to participants. For Romano (2016) that process was constructive, allowing the student to rehearse the impact of research on participants. For Davies (2014) it was significant time and effort, which could have been better devoted to the research itself under processes more attuned to the practicalities of journalistic fieldwork. Reflexivity should not be romanticized as an easy process or one that invariably improves practice. But these moments are often valuable, and especially so today given the flux and permeability of most current western journalisms, because they allow questions to be asked about what a good relationship might look like between journalism and communities and between journalists and other participants in civil society.

CONCLUSION

In the East Timor case, von Dietze (2012) argued that university bodies should trust and work in a more consultative way with academic journalists. That suggests that tensions over journalism's place in the academy are central to the question of how to connect journalism to institutional research ethics processes. The arguments discussed above may be partly understood as journalism establishing its academic legitimacy. But they can also be understood as a challenge to the dominant institutional structures around ethical research practice within the university. A case can be made that journalism is so distinct as a form of knowledge that it does not make sense to subsume journalism in the university under the term research, a point reviewers raised with the author. Alternatively, a case can be made that journalism – and the many other activities within the university that make an impact on social and cultural life, from artistic production to public policy – need be governed by institutional review practices that acknowledge they straddle the boundary of research in sometimes awkward ways. This chapter ends with two points of challenge that seek to accommodate that awkwardness.

First, journalism's pursuit of what Bourdieu (2005) terms autonomy, in a context of considerable pressure on it, places it on a collision course with more rigid review structures. Scrutiny of the ethics of research journalism is more likely to be welcomed by journalism scholars when there is some autonomy from institutional power and when it begins from a position of respect for the kind of knowledge that journalists set out to produce. This does not mean ceding authority to professional codes of ethics for, as Zelizer (2013) points out, these are often weakly connected to practice. Making journalism an exception to the predominant rule does not have to mean exempting journalism from critical scrutiny or, as Iphofen (2017) notes, allowing one practice to operate by vastly different standards and much less scrutiny. To do that would risk undermining the very claims to value that journalists are making for themselves within the university. Spicker (2007) provides an alternative way of framing the differences in terms of ethical reference points: different academic practices need different rules, because the human subjects they study are located differently in society. In order to do that, a close connection with journalism culture, and with the lively debates amongst journalists about what they should be aspiring to, can be achieved through the development of practices of self-review within university-based journalism.

Second, it may be that other, more suitable structures than ethics review boards can prompt reflection (and compliance) for journalism within the university setting. If we follow Park (1999[1940]), the practical knowledge of journalism can be better understood using Aristotelian notions such as phronesis (which can be glossed as practical wisdom). Svenaeus (2003), writing about clinical medicine, argues that praxis cannot be approached through principle-based ethics because it is a meeting of doctor, patient and the particular conditions of that moment in which the good practitioner comes to know the good thing to do. Ethics in this way of thinking is iterative, a process of reflection that guides future practice in cycles of deepening knowledge that are embedded in action. The university's responsibility here would be in fostering the practical wisdom of its senior journalism educators so that they might guide good practice, drawing on discussion, peer review, self-evaluation and other tools. Boeyink and Borden (2010) propose the use of case-based reasoning, focused on paradigm cases that crystallize ethical breaches or norms. Such tools need to be implemented in ways that demand reflection by slowing down and challenging journalism, rather than relying on the journalist's own immediate response to a situation. However, these questions are resolved, this chapter suggests that the broader issue of how journalism fits within the university prompts wider questions still about how to accommodate a diversity of ways of doing ethical reflection on research.

REFERENCES

AUT (Auckland University of Technology) (2016) Exemptions to activities requiring AUTEC approval. AUT University research ethics guidelines and procedures, 6. Available at: http://www.aut.ac.nz/researchethics/guidelines-and-procedures/exceptions-to-activities-requiring-autec-approval-6

Bell, L. and Nutt, L. (2002) Divided loyalties, Divided expectations: Research ethics, professional and occupational responsibilities. In M. Mauthner, M. Birch, J. Jessop, and T. Miller (eds) *Ethics in qualitative research*, pp. 70–90. London: Sage.

Boeyink, D.E. and Borden, S.L. (2010) *Making hard choices in journalism ethics: Cases and practice*. New York: Routledge.

Briggs, A. and Burke, P. (2009) *A social history of the media: From Gutenberg to the internet*. Cambridge: Polity Press.

Brock, G. (2010) Road to regaining the high ground. *British Journalism Review* 21(4): 19.

Bourdieu, P. (2005) The political field, the sociological field and the journalistic field. In R. Benson and E. Neveu (eds) *Bourdieu and the journalistic field*, pp. 29–47. Cambridge: Polity Press.

Campbell, D. and Power, M. (2010) The scopic regime of Africa. In F. MacDonald, R. Hughes, and K. Dodds (eds) *Observant states: Geopolitics and visual culture*, pp. 167–198. London: I.B. Tauris.

Davies, K. (2014) HRECs and journalism research: The uneven playing field. *Pacific Journalism Review* 20(1): 99–116.

Elliott, D. (2013) When is media studies research…research? *Media Ethics* 25(1). Available at: http://www.mediaethicsmagazine.com/index.php/browse-back-issues/179-fall-2013-vol-25-no-1/3998996-when-is-media-studies-research-research

FRE (2015) ESRC Framework for Research Ethics. Economic and Social Research Council, updated January. Available at: http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/

Glasser, T.L. and Ettema, J.S. (1989) Common sense and education of young journalists. *The Journalism Educator* 44(2): 18–75.

Guardian (2016) The Guardian view on the Panama Papers: secret riches and public rage (editorial). *The Guardian*, 4 April. Available at: https://www.theguardian.com/commentisfree/2016/apr/04/the-guardian-view-on-the-panama-papers-secret-riches-and-public-rage

Gunsalus, C.K., Bruner, E.M., Burbules, N.C., Dash, L., Finkin, M., Goldberg, J.P., Greenough, W.T., Miller, G.A., Pratt, M.G., Iriye, M., and Aronson, D. (2007) The Illinois white paper: Improving the system for protecting human subjects: Counteracting IRB 'Mission creep'. *Qualitative Inquiry* 13(5): 617–649.

Ingram, L. (2012) Uni of Canberra 'restructure' … and how students were warned off the story. *Crikey*, 10 April. Available at: http://www.crikey.com.au/2012/04/10/uni-of-canberra-restructure-and-how-students-were-warned-off-the-story/

Iphofen, R. (2011) *Ethical decision making in social research: A practical guide*. New York: Palgrave Macmillan.

Iphofen, R. (2017) Achieving consensus in research ethics: An interim conclusion and some recommendations. In R. Iphofen (ed.) *Finding common ground: Consensus in research ethics across the social sciences*, Chapter 17/pp. 213–227. Bingley: Emerald Group Publishing.

Jacquette, D. (2010) Journalism ethics as truth-telling in the public interest. In S. Allan (ed.) *The Routledge Companion to News and Journalism*, pp. 213–222. London: Routledge.

Kunczik, M. (2000) Introduction: Freedom of the press, Where to draw the line? In M. Kunczik (ed.) *Ethics in journalism: A reader on their perception in the Third World*, pp. 5–30. Bonn: FES Library. http://www.fes.de/fulltext/iez/00710a.htm#E9E1

Langlois, A.J. (2011) Political research and Human Research Ethics Committees. *Australian Journal of Political Science* 46(1): 141–156.

Meyers, C. (ed.) (2010) *Journalism ethics: A philosophical approach*. New York: Oxford University Press.

NZPC (New Zealand Press Council) (n.d.) Statement of principles. Available at: http://www.presscouncil.org.nz/principles

Nolan, D. (2008) Journalism, education and the formation of 'public subjects'. *Journalism* 9(6): 733–749.

OHRP (2009) Protection of human subjects. Code of Federal Regulations 45(46). Office of Human Research Subjects, 15 January. http://www.hhs.gov/ohrp/policy/ohrpregulations.pdf

O'Neill, O. (2013) Media freedoms and media standards. In N. Couldry, M. Madianou & A. Pinchevski (eds) *Ethics of media,* pp. 21–38. London: Palgrave Macmillan.

Park, R.E. (1999 [1940]) News as a form of knowledge. In H. Tumber (ed.) *News: A reader*, pp.11–15. Oxford: Oxford University Press.

Richards, I. (2009) Managing the margins: How journalism reports the vulnerable. *Asia Pacific Media Educator* 19(1): 15–22.

Richards, I. and Josephi, B. (2013) Investigative journalism on campus: The Australian experience. *Journalism Practice* 7(2): 199–211.

Romano, A. (2016) Ethical review as a tool for enhancing postgraduate supervision and research outcomes in the creative arts. *Educational Philosophy and Theory*. http://dx.doi.org/10.1080/00131857.2015.1111130

Sambrook, R. (2016) Panama Papers: The nuts and bolts of a massive international investigation. *The Conversation*, 4 April. Available at: https://theconversation.com/panama-papers-the-nuts-and-bolts-of-a-massive-international-investigation-57197

Schlesinger, P. (1987) *Putting 'reality' together: BBC News*. London: Methuen.

Seiber, J.E. and Tolich, M.B. (2013) *Planning ethically responsible research*. London: Sage.

Spicker, P. (2007) The ethics of policy research. *Evidence & Policy: A Journal of Research, Debate and Practice* 3(1): 99–118.

SPJ (Society of Professional Journalists) (2014) SPJ code of ethics, 6 September. Available at: https://www.spj.org/ethicscode.asp

Svenaeus, F. (2003) Hermeneutics of medicine in the wake of Gadamer: The issue of *phronesis*. *Theoretical Medicine* 24(5): 407–431.

UNC (University of North Carolina) (2000) Academic Affairs-IRB guidelines for the School of Journalism and Mass Communication. University of North Carolina at Chapel Hill.

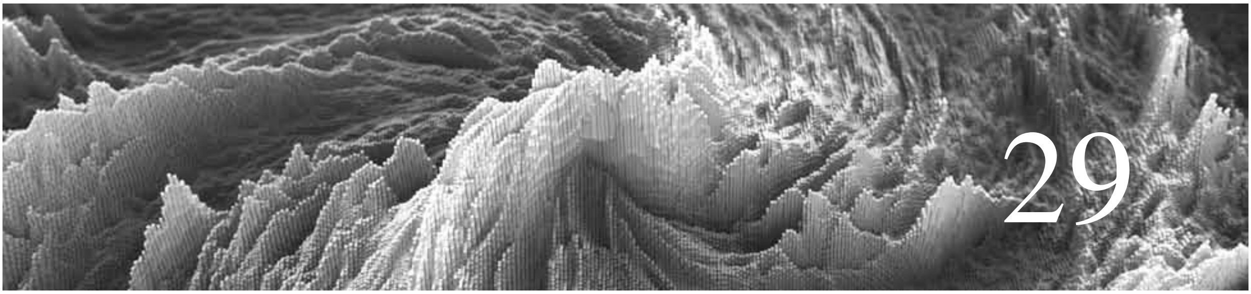
Vine, J. Batty, C., and Muir, R. (2016) A question of ethics: The challenges for journalism practice as a mode of research. *Journal of Media Practice* 17(2–3): 232–249. DOI: 10.1080/14682753.2016.1248193

von Dietze, E. (2012) A story behind the story: Journalism, research and ethics. Paper presented at Australasian Ethics Network Conference, Brisbane, Australia, 16 February.

Ward, S.J.A. (2013) Why hyping transparency distorts journalism ethics. *MediaShift*, 4 November. Available at: http://mediashift.org/2013/11/why-hyping-transparency-distorts-journalism-ethics/

White, A. (2011) Ethical journalism and human rights. In Council of Europe, *Human rights for a changing media landscape*, pp. 47–76. Strasbourg: Council of Europe Publishing.

Zelizer, B. (2013) When practice is undercut by ethics. In N. Couldry, M. Madianou, and Z. Pinchevski (eds) *Ethics of Media*, pp. 271–285. London: Palgrave Macmillan.



29

The Dual Imperative in Disaster Research Ethics

Dónal O’Mathúna

INTRODUCTION

Disaster research began a century ago. In 1917, two ships collided in the harbor at Halifax, Nova Scotia (Scanlon, 2014). Initially a maritime fender-bender, one of the ships, the *Mont Blanc*, caught fire. The crew jumped into lifeboats and rowed hard. Reaching the shore, they started running and shouting at the crowd. But no one understood their French, so curious onlookers wandered towards the waterfront. Only the crew knew the *Mont Blanc* was loaded with ammunition bound for the war in Europe. Suddenly, it exploded, reportedly sending a sheet of fire a mile in every direction, and a black ball of smoke hundreds of feet into the air. Almost 2,000 people died, and another 9,000 were injured. Whole neighborhoods disappeared, including a community of First Nations people drowned in the ensuing tsunami. The detonation was the largest human-caused explosion until nuclear weapons were developed. Survivors, later joined by trainloads of helpers from across the region, provided rescue and aid immediately. Boston, Massachusetts, continues to receive its official Christmas tree every year as a gift in gratitude for the help sent to Halifax. Disaster research was another legacy.

Samuel Prince was an Anglican priest in Halifax who studied the social change resulting from the explosion (Scanlon, 1988). His sociological study of the recovery earned him a PhD and produced one of the first pieces of disaster research. Another forty years passed before disaster research began in a systematic way. Prince’s research asked, ‘what does the explosion tell us about the way communities react to devastating events and what lessons can we learn from the explosion that might make us better prepared today?’ (Scanlon, 2014: 12–13). Replace ‘explosion’ with ‘disaster’ and you have the key research questions for many disaster research projects.

DISASTER RESEARCH

The term disaster is plagued by multiple definitions. The *Handbook of Disaster Research* devotes a chapter to discussing its meaning

(Perry, 2007). Over three dozen definitions were collected from disaster research literature, and from these Perry identified three traditions. The first focuses on *disruption to social order* from the devastation, resulting in changes to 'normal' behavior. The second looks more at the *environmental events* that trigger disasters and their social consequences. The third focuses on *social phenomena*, with an emphasis on social vulnerabilities and resilience. This emphasis on the social impact of disasters explains why much disaster research makes use of qualitative research methods.

Other definitions have emphasized the sudden onset of disasters, the large-scale destruction and suffering, and the overwhelming of local resources for responses (O'Mathúna, 2015a). Incidents involving conflict and war are sometimes viewed as disasters, as are protracted situations involving famine, poverty, disease, and migration crises. Some prominent disaster researchers prefer to exclude situations involving these additional complexities from the category of disasters (Quarantelli, 2006). However, the terminology is becoming more complex, with disasters typically viewed in the broadest way.

While some view 'disaster research' as a distinct field, other fields of inquiry are now conducting research on and in disasters. Healthcare research into the resulting death and injuries uses the term 'emergency' to cover natural disasters, conflict situations, and refugee situations. As humanitarian organizations generate evidence for their practice, research into humanitarian crises has developed. Natural disasters are sometimes distinguished from technological disasters (or industrial accidents), although the human and environmental roles are difficult to separate. The term 'complex emergency' can be applied to disasters involving natural and conflict-related actions. Since conflicts and disasters often produce refugees, disaster research now includes studies of refugee camps and forced migration. Given all of these overlapping fields, it is difficult to see a clear and concise definition of disaster research being widely accepted soon.

DISASTER RESEARCH ETHICS

For this chapter, disaster research will be viewed broadly to include research conducted on natural disasters, industrial accidents, conflict situations, and protracted humanitarian crises. While clear distinctions cannot be made between these events, some similar ethical issues arise with research in all these settings. The common features include vulnerable participants, dangerous research sites, major social disruption, shortages of resources, and significant cultural, social and economic differences between participants, researchers, and other stakeholders. Including military operations in a disaster site, or mixing disaster responders with different perspectives on research will add to the complexities of negotiating entrée for research and conducting projects.

Ethical issues in disaster research received relatively little explicit attention until the twenty-first century. Before this, ethical issues were usually addressed in informal ways 'on the assumption that [disaster] research has very little potential for injuring the people and organizations that are studied and on the hope that it may ultimately actually do some good' (Tierney, 1998: 6). More recent events like the 9/11 terrorist attacks and the 2004 Indian Ocean tsunami led to calls for more research to guide disaster planning and responding, and also identified the need to address disaster research ethics (O'Mathúna, 2010). Evidence has been collected of 'unethical and potentially exploitative research' conducted in humanitarian settings (Mackenzie et al., 2007: 300). Most reports are anecdotal, and cannot be taken to show if the problems are extensive or not. Regardless, researchers, nongovernmental organizations (NGOs) and international organizations have begun addressing disaster research ethics (O'Mathúna et al., 2014).

Ethical guidelines now are being developed for some disaster research. For example, the Council for International Organizations of Medical Sciences (CIOMS), with the

World Health Organization, has produced ethics guidelines for biomedical research for sixty years. For the first time, the 2016 revision included research ethics guidelines for disasters – defined broadly as in this chapter (CIOMS, 2016). Ethics guidelines for qualitative disaster research are less common. 'Ethics writings over disaster research have surfaced only fairly recently and primarily in the aftermath of terrorist events' (Phillips, 2014: 38). However, with a broader view of disasters, some relevant publications exist on the ethics of conducting qualitative research in conflict zones, humanitarian crises and with refugees. Even here, much remains to be done. 'Despite the humanitarian community's recent focus on ethics and humanitarianism, the emerging literature on war zone research makes scant mention of ethical challenges' (Goodhand, 2000: 12).

This chapter will explore some ethical issues relevant to qualitative research in disasters. Many of these issues arise in other contexts, and are addressed throughout this book. For this reason, Stallings, in his chapter in the *Handbook of Disaster Research* claims 'the ethics of disaster research are no different from those associated with the social sciences in general' (2010: 77). Certainly, each ethical issue can arise in other settings. Yet the combination of multiple vulnerabilities, physical and psychological dangers, risks to participants and researchers, resource shortages, cross-cultural issues, political considerations, and narrow windows of opportunity for research create unique combinations of ethical issues. Research in disasters sets up the perfect ethical storm of intense magnitude. As with other storms, careful planning and preparation are required, leading to numerous calls for focused attention on disaster research ethics. These have come from both researchers (Allden et al., 2009; O'Mathúna & Siriwardhana, 2017) and international agencies like the United Nations International Strategy for Disaster Reduction (Aitsi-Selma et al., 2016). This chapter makes a contribution towards those ethical issues that are distinct in their combination and intensification during qualitative disaster research. The discussions here will not be exhaustive, and in many places will point to the need for further reflection, discussion and research.

QUALITATIVE DISASTER RESEARCH ETHICS

Ideally, all research seeks to generate knowledge that improves our understanding of a topic. Disaster research seeks to understand many different aspects of disasters, including how the initial response went, how people and communities were impacted, how they coped with required changes, how resilience develops, and many other issues. Qualitative research engages with people through interviews, focus groups, observation or document analysis – including diaries and personal communications. Such methods can lead to researchers building relationships with participants, especially if the project continues for extended periods of time. Even with short-term engagement, interpersonal connections can develop quickly depending on the topic (especially if particularly sensitive) or the setting (immediately after traumatic events). Part of the distinct ethos of qualitative research is that closeness in interpersonal relationships is needed 'if people's perspectives are to be understood adequately, and perhaps also if the full relevant range of their activities is to be documented' (Hammersley & Traianou, 2012: 1).

This distinctive strength of qualitative research can also lead to ethical challenges. 'The often prolonged and personal interactions with those in the setting during field research create the possibility of myriad ethical questions, none of which are accompanied by easy solutions' (Bailey, 2007: 15). Conducting an interview in the midst of destruction, or asking someone to recall details about a disaster, can impact the participant deeply and this needs to be taken into account to ensure the research is ethically justified.

Such issues can be heightened by the vulnerabilities of participants. A systematic review of disaster research ethics guidelines found that vulnerability was one of the two core themes emerging from fourteen guidelines identified (Mezinska et al., 2016). Vulnerability arises for many reasons, including the trauma of the disaster, bereavement, loss, violence and conflict, social hierarchies, chronic injustice, fear of reprisal, and others. People may be living in dangerous situations due to the natural environment or social conflict or both. When asked to participate in research, such vulnerabilities are compounded by additional risks. People may feel they must participate in research to receive aid, to have a better chance of 'getting out', or to avoid problems with authorities. An extensive search of diverse literature on research in emergency settings found that participants are exposed to risks of stigmatization, recrimination, sexual exploitation or abuse, discrimination, targeting for reprisals, becoming scapegoats, breaches of confidentiality, dashed expectations, retraumatization, loss of time, and many others (Allden et al., 2009). Such factors vary with each research project, but must be considered carefully as the project is designed.

THE DUAL IMPERATIVE

Since disaster research has many risks, the potential benefits must be sufficient to justify the study. Qualitative disaster research, like other humanitarian research, has a dual imperative. 'Many of us want to believe that research and teaching will contribute to the theoretical understanding of the world while actually helping the millions of people caught up in humanitarian disasters and complex emergencies' (Jacobsen & Landau, 2003: 185). This creates an ethical tension between methodological rigor and relevance to people's lives, both directly and through advocacy and policy change.

Within qualitative disaster research, an emphasis was placed first on objectivity and the scientific nature of qualitative methods (Phillips, 2014). As early as the 1960s, concerns were expressed about this. 'That the social scientist … can achieve olympian detachment and objectivity is a myth which is fortunately not as widespread as it was thirty or more years ago' (van den Berghe, 1967: 183). From the 1980s onwards, qualitative research came to be seen more as a means of advocacy through exposing and challenging social injustice and human rights abuses (Hammersley & Traianou, 2012). Researchers' political views became enmeshed in their research. An anti-apartheid researcher entering South Africa during apartheid stated, 'I decided that I should have no scruples in deceiving the government' (van den Berghe, 1967: 183). Understandably with apartheid, this raises ethical questions about where and when deception is acceptable within research.

This type of 'advocacy research' led to other concerns that well-meaning researchers 'already know what they want to see and say, and come away from the research having "proved" it' (Jacobsen & Landau, 2003: 187). Such studies undermine the trustworthiness and credibility of qualitative disaster research since 'humanitarian studies in general, reveal a paucity of good social science, rooted in a lack of rigorous conceptualization and research design, weak methods and a general failure to address the ethical problems of researching vulnerable communities' (Jacobsen & Landau, 2003: 187).

In spite of these types of challenges, qualitative disaster research is seen by many as an 'ethical opportunity' to overcome devastation, injustice, violence, deprivation or other suffering (Ganiel, 2013, 167). Many disaster researchers agree with David Turton's statement, 'I cannot see any justification for conducting research into situations of extreme human suffering if one does not have the alleviation of suffering as an explicit objective of one's research' (1996: 96). A tension exists between academic rigor and practical relevance, giving rise to some of the ethical challenges in qualitative disaster research. Careful and appropriate study design is thus an ethical issue, not just a methodological one.

STUDY DESIGN

'Ethical considerations permeate every aspect of the field research process, from selecting the research topic to disseminating the results' (Bailey, 2007: 15). Ethics starts when the project is being conceptualized, with the first question in disaster qualitative research – as it should with all research – being: 'Should the study be done at all?' (Phillips, 2014: 31). This question is uniquely critical for disaster research. As noted already, and to be elaborated below, research exposes participants to risks of many serious harms. Researchers often enter dangerous settings where potential participants may already be traumatized. Disaster research will consume resources and time that could be used otherwise for life-saving efforts, such as for search and rescue, or providing medical, nutritional and security needs. Thorough consideration must be given to whether the research question can be answered elsewhere, at another time, or through other means. However, some research does need to be done in disaster settings, sometimes even in the immediate aftermath, to provide knowledge relevant to that phase of disasters.

Qualitative disaster research typically involves engagement with people and developing relationships. Some projects are more objective, with researchers remaining more detached. Collecting data on logistical issues, observing how policies, procedures, or equipment work, and even interviewing about these issues, can happen with minimal interpersonal engagement. At the same time, decisions made about who to engage with, and how, are crucial to the success of the study. Careful attention must be paid to obtaining proper permits for entrée into disaster settings (Phillips, 2014). Research in another country may require authorization or support from one's own institution, organization or Department of Foreign Affairs, from political or governmental authorities at the disaster, from international or humanitarian organizations in the field, from local communities, and others. All of these require time for negotiation and trust building.

Increasingly, qualitative disaster research will engage with participants at a deeper level and raise many additional ethical issues. These should be considered carefully as the project is designed, not just upon implementation. 'The most appropriate decisions are likely to be made when ethical issues are thought about prior to starting research. Researchers are most likely to "do harm" when they do not anticipate likely ethical challenges' (Goodhand, 2000: 13). Many of these ethical issues are best addressed with input from others, particularly from participant communities, and especially when conducted cross-culturally.

Participant Selection and Recruitment

Participants are central to qualitative research. Research ethics aims 'to safeguard the rights and experiences of those who choose to participate' (Phillips, 2014: 31). As noted, participants in disaster research are usually vulnerable, so great care is required during their selection and recruitment. Probability sampling techniques reduce the researcher's role in selecting participants and can reduce bias, but for practical reasons are often difficult in disaster settings. Qualitative disaster researchers use non-probability sampling more frequently (Phillips, 2014). Various methods of recruiting participants can be used, and can be grouped into researcher-driven, key informant-driven, or participant-driven (Peek & Fothergill, 2009). In the first, the researcher uses flyers, posters, websites, mail and other methods to ask participants to contact the researcher; in the second, an organization or individual (sometimes clearly acting as a gatekeeper) agrees to support the research and help recruit participants through their contacts; in the third, which includes snowball sampling, participants propose or encourage others to participate.

Each has practical strengths and limitations, and in disaster settings raises different ethical issues. When using any non-random method, consideration must be given to its fairness, and how this is perceived. In a humanitarian study of the impact of illness on household livelihoods in resource-poor African countries, households not selected to participate later expressed dissatisfaction about the research (Molyneux et al., 2009). While this was explained to the whole community beforehand, the researchers and the community perceived the fairness of the process differently. This is particularly important when participation is associated with real or perceived benefits, especially when resources are scarce.

Key informants and/or gatekeepers, are often used in disaster settings, but this can create ethical challenges due to existing hierarchies and when the research topics address questionable, unethical or illegal behavior. For example, researchers were told by refugees that other research projects had recruited participants through community leaders. The result was that researchers '"come in and just talk to the leaders and their wives – they never hear what it is really like in the camps"…; "We get no justice from the leaders, but they are the ones that UNHCR listen to"' (Mackenzie et al., 2007: 304). In this way, some recruitment methods increase the risk of making the findings unreliable. Similar risks apply with participant-driven recruitment methods. To address these, knowledge of the local context, particularly the actual power dynamics, and involvement of local representatives in designing studies are important.

Informed Consent

Engagement with the local community when planning disaster research helps identify and address ethical issues at many stages of research, including with informed consent. Obtaining informed consent is an ethical prerequisite for disaster research, as it is for most other research. When ignored, this can put participants at great risk. One researcher interviewed and photographed a human rights activist who was also a refugee as part of a research project. The participant heard nothing further from the researcher until eighteen months later someone gave her an international magazine containing her story and photograph (Mackenzie et al., 2007). She had not consented to this, which placed her in extreme danger because it revealed her political activity and illegal movements across borders situated within a war zone.

Many of the practical challenges with informed consent are the same as those faced in other settings, especially in low and middle-income countries (LMIC), and with cross-cultural research. For example, when translators and interpreters are required, additional checks should be added to ensure information is being translated accurately (Temple & Edwards, 2002). Even when bilingual researchers translate project information, they may have different educational or socio-economic backgrounds to the participants, which can lead to misunderstandings and misinterpretations (Allden et al., 2009). In disaster settings these challenges can be more intense. One researcher stated: 'When I go into a horrendous camp situation as a white researcher, the people are so desperate for any form of assistance they would agree to anything just on the off-chance that I might be able to assist. It makes asking for permission to interview them or take photographs a farce' (Pittaway et al., 2010: 234). As with qualitative research involving other marginalized or deprived participants, disaster research can further heighten expectations of aid or advocacy due to the interpersonal connections that develop during projects.

Informed consent is complicated by the growing consensus that research in disasters and conflicts should provide benefits to the participants and their communities. Some go so far as to state that, 'If the research is determined to be of *no* benefit to the local population, then it should not be carried out' (Allden et al., 2009: s221). This upholds one side of the dual imperative: to make a difference in participants' lives. However, it opens up other ethical challenges, particularly where benefits might become inducements to accept risks if people believe they have no alternative other than to participate. Benefit sharing with research participants, particularly those in LMIC, is increasingly seen as ethically important, especially since its inclusion in the Universal Declaration on Bioethics and Human Rights (UNESCO, 2005). Although the concept of 'benefit sharing' has been defined in various ways, it includes providing material benefits and achieving justice (Schroeder, 2007). The latter fits directly with the aims of much qualitative disaster research.

Engagement and consultation with participants and their communities is another way to respond to ethical challenges like these. The current model where researchers' first engagement with participant communities is to explain predesigned research and seek participants has many limitations. More extensive changes to research methodologies have been proposed to better address the ethical challenges in disaster qualitative research. One example is participatory action research.

Participatory Action Research

Participatory action research (PAR) takes engagement with communities very seriously. This method starts with ethics and makes reciprocity a central ethical value (Zwi et al., 2006). In disaster settings, participants are vulnerable to many risks, and these can be heightened by research participation. The principle of reciprocity means that individuals and their communities should be provided tangible benefits in return for accepting research risks. Determining what risks and benefits are acceptable can be challenging. Researchers in one longitudinal study provided one day's food allowance each time they visited a participating family to compensate for their lost earning time (Molyneux et al., 2009). What they didn't anticipate was the envy this generated among other families not involved in the study.

Participatory action research involves engaging with participant communities about all phases of the research, from design to dissemination. 'Negotiating reciprocity is rarely simple, and in conflict and disaster affected settings it has proved especially difficult' (Zwi et al., 2006: 268). For example, the aims and limitations of the project are discussed, and negotiations are held about how to recruit participants, obtain informed consent, disseminate findings, and conduct other parts of the project. During this time, participants can reveal their fears and concerns about risks, and describe the benefits they hope to achieve. Researchers can take steps to mitigate the risks, and clarify the feasibility of what the research can provide.

Participatory action research involves extensive discussions, which can take significant amounts of time. The research is shaped to better address the needs of the community and respect their concerns and values. For example, rather than a once-off approach to consent, PAR uses an iterative model aiming to avoid misunderstandings and ethical problems. At the same time, PAR provides a mechanism by which unanticipated issues can be addressed to the satisfaction of both researchers and the community. As findings develop, they are discussed with participants to ensure they are trustworthy and acceptable. The method has 'an explicit aim of building trust and giving voice to the views of the powerless and voiceless' (Mackenzie et al., 2007: 312).

Another aim of PAR is to improve the trustworthiness of the resulting data. Research in refugee camps is notoriously difficult yet important for disaster responses because camps are used after natural disasters, conflicts, and humanitarian crises. Short-term arrangements can turn into long-term situations. For example, after the 2010 earthquake in Haiti, 1.5 million people were housed in temporary camps, with nearly 150,000 remaining in these tent cities four years later (International Organization for Migration, 2014). These camps continue to house tens of thousands of Haitians in 2017.

Sexual abuse and rape are a major concern within these camps, yet conflicting research accounts are available. For example, during formal interviews with refugee camp staff, researchers were told that claims of rape were fabricated by refugees to accelerate their immigration applications (Mackenzie et al., 2007). Yet when the same staff spoke *informally* to the researchers, they disclosed that rape and sexual abuse were frequent in the camp. A senior administrator commented informally, 'I will give you a prize if you can find a woman in this camp who has not been raped' (p. 308). When pressed further, the staff stated they formally gave 'the official line', but informally would 'tell the truth, but don't ever quote me' (p. 308). Other qualitative researchers have found a general problem with the trustworthiness of interview data because it can be compromised when participants have fears about how the data will be used. In such situations, 'the underlying reasoning seems to follow considerations like: "What will happen if I give the 'wrong' answer?" or "What will happen if I tell the truth and this angers officials?"' (Belousov et al., 2007: 163).

Participatory action research addresses such problems through negotiation and relationship-building. As these lead to trust, then openness and transparency can develop. For example, after four years using this methodology, researchers reported:

> There is a conventional wisdom that 'women do not talk about sexual abuse'. However, in camps and urban settings in five countries the researchers have found that by using this methodology, once trust is established and they have been involved in negotiating the process, the women are desperate to tell their stories and to share their experience. (Mackenzie et al., 2007: 314)

Participatory action research addresses both aspects of the dual imperative. Involvement of the local community ensures its needs are accurately identified, and participants see how the findings may have an impact. At the same time, the openness and trust ensures the findings are trustworthy and credibly present the participants' experiences. 'From an ethical point of view such a process gives real content to the principle of *respect for persons*' (Mackenzie et al., 2007: 307).

The PAR methodology has limitations, particularly the extensive time commitment required for everyone involved, and for researchers to be in the field for extended periods. This method does not fit well into current models of research funding and ethics approval that can be slow and bureaucratic. It is not well suited to the acute phase of a disaster, but aspects of the methodology could be applied. For research into the long-term social impact of disasters and people's experiences during recovery and rebuilding, PAR has many advantages. It addresses several prominent ethical challenges with qualitative disaster research and uses ethics to shape its methodology.

RESEARCHER TRAINING AND SUPPORT

'Qualitative research is not intrinsically more ethical or of better quality; an interview can be as unethical and poorly conceived as a bad questionnaire' (Mackenzie et al., 2007: 315). In quantitative research, the precision and accuracy of the findings are impacted greatly by the instrument and how well it has been validated. In qualitative research, the main 'research tool' is the person interacting with the participants. The trustworthiness of qualitative data depends heavily on those conducting the interview or focus group, and those doing the analysis. Assessing these can be challenging, especially in disaster contexts.

Attention must be given to the training and support of researchers and fieldworkers. Disaster research can recruit local people to do fieldwork like conducting interviews, to help resolve language issues, or to contribute to building research capacity in the region. Training and assessment should be put in place before researchers and fieldworkers go into the field, especially if they are new to disaster research. When conflict is involved, some hold that ‘it is unethical to involve researchers who are inexperienced and unfamiliar with working in areas of conflict’ (Goodhand, 2000: 13).

Ongoing field support is vital, as unexpected questions and concerns may arise. For example, research into how people provide medical and food needs during scarcities included debriefing sessions with fieldworkers (Molyneux et al., 2009). One fieldworker reported that a wife and mother revealed sleeping with another man in her community to provide for her children. The fieldworker did not record this out of concern for confidentiality, but also because it seemed to be ‘gossip’, not relevant information. This led the whole research team into discussions that clarified what was to be reported. Without this planned support, important data could have been missed. Innovative approaches to providing this support are needed, and are starting to become available for disaster research.

Personal risks to researchers must also be evaluated and re-assessed regularly. Disaster research includes an ethical responsibility to consider the safety of researchers, not just participants. A plan should be developed so that researchers know how to respond if risks increase. Depending on the setting, additional precautions may be required, such as limiting research to certain times, travel precautions, and securing special permits. In some settings, ‘researchers may have little protection other than their wits against parties wishing to prevent certain issues being researched and reported’ (Belousov et al., 2007: 161). Sometimes, the risks to researchers, fieldworkers, or participants may be so high that it is unethical to conduct the research in that place at this time.

The interpersonal nature of qualitative research can also lead to interpersonal challenges for researchers. Interviewers have bad days, get tired or afraid, read situations incorrectly, and may be intimidated by participants, clash with them, or get emotionally involved. Such issues should be raised in training, but also require ongoing support in the field and debriefing. People need to be aware of their own strengths and limitations, and to be humble enough to postpone or stop an interview because of their own disposition.

Some ethical dilemmas can be anticipated and prepared for. However,

> as is often the case in research, many of the ethical dilemmas and challenges were unexpected and faced only once the fieldwork had begun. The challenges we faced reveal significant ethical dilemmas for household studies in poverty settings, and show that ‘solutions’ often lead to new challenges and complications. (Molyneux et al., 2009: 313–314)

Disaster sites are typically chaotic. Local infrastructure may be disrupted if not destroyed. Projects may not be able to proceed as planned, requiring flexibility. Normal communication mechanisms may be down, preventing fieldworkers from communicating with the team. Some ethical issues may require immediate responses.

At times like this, researchers may only have their personal integrity to lean on. Ethical virtues are those personal character traits (habits of the heart) that lead people to do what they believe is right. The virtues have long been seen as central to ethics, but are only recently getting attention in research ethics (O’Mathúna, 2015b). Increasingly, they are included in research integrity initiatives and linked to research training, mentoring, and supervision. Engagement with such issues puts an ethical responsibility on research teams to ensure experienced researchers spend regular time supporting fieldworkers and less experienced researchers.

FEEDBACK AND DISSEMINATION

For research to make an impact, its results must be disseminated. This helps justify the risks taken by participants (and researchers) and the use of resources that could have been employed otherwise in the disaster. This makes the right forms of dissemination an ethical imperative, and makes it important that findings get to the right audiences. Impact requires dissemination in the right way at the right time. Publication in academic journals may satisfy one side of the dual imperative, but may not address the other side. To make a difference in participants' lives, the dissemination plan may need to be broader and focused on formats that reach policy-makers, international organizations, the general public, or other relevant audiences. This may require researchers to 'be able to communicate with integrity in several languages: as a specialist, as a generalist, as an academic, as a populist, as a public speaker, and as a journalist' (Smyth & Robinson, quoted in Ganiel, 2013: 176).

Feedback to participants is also important to express respect and gratitude. Not doing so may have a lasting impact on the participants' view of researchers, as some participants have revealed. '"They get their PhDs and funding from our stories and they cannot even be bothered to send us a report and a thank you letter"; "Do they think that because we cannot read English we do not care?"; "We give up our time and share our pain and they cannot give the time to write us a letter"' (Mackenzie et al., 2007: 305).

The head of a community-based organization stated, 'In the past year I have spoken to eleven people who are doing their PhD and not one of them has even sent me a report' (Mackenzie et al., 2007: 306). Women who had been raped and gave interviews to researchers who never contacted them again, subsequently said the researchers 'stole our stories' (Pittaway et al., 2010: 236).

In contrast, fieldworkers in a longitudinal study prepared a one page summary of their project and returned to discuss it with participants. 'We felt it would be an important sign of respect and gratitude for their assistance, clarify again what our work was about, and symbolise the end of the research relationship with the households we had come to know so well' (Molyneux et al., 2009: 321–322). The participants enjoyed seeing the fieldworkers again, appreciated being remembered, felt they had made a contribution, and were pleased to hear that the full report had been forwarded to authorities and policy-makers.

Various approaches are taken regarding when and how much material to discuss with participants. Different communication strategies can be used, adapting each to the particular participants. However, asking participants to review findings can raise additional ethical dilemmas. After one researcher did so, some participants were fully supportive, saying her 'conclusions were brilliant', while others found them 'inappropriate' and asked her to stop publishing (Ganiel, 2013: 177–178). The researcher used this dilemma as an opportunity to reflect on her own research skills. She concluded that she needed to communicate better in future projects, both about disseminating findings and addressing participants' expectations for the research. This exemplifies how reflection and learning from unexpected ethical dilemmas can lead to improved research practice, or to the realization that nothing further could have been done to avoid participants' differing perspectives.

Another ethical challenge here is confidentiality. This should always be protected. People's lives, well-being or careers can be at risk if their identities are revealed, such as happened with the human rights activist mentioned earlier. Confidentiality can be particularly difficult to protect in disaster research, especially if the disaster has received media coverage. Careful attention should be taken during dissemination to ensure that identities are not inadvertently disclosed because 'participants' safety and right to confidentiality are always more important than the findings of a particular project or the advancement of one's career' (Ganiel, 2013: 180).

At the same time, some participants may want their identities revealed as a way to bring attention to their concerns and causes. And in certain situations, confidentiality should be broken, as when another person's life is at risk, or to protect a child. However, such decisions are highly complex and sensitive, especially in cross-cultural settings, and require careful planning and consultation. Discussions during research planning and recruitment should make explicit where both risks and limits to confidentiality exist.

ETHICS COMMITTEES

In the systematic review of disaster research ethics guidelines noted earlier, the role of research ethics committees (RECs) was the second core theme identified (Mezinska et al., 2016). Many RECs, also called Institutional Review Boards (IRBs), do not have experience with disaster research (Allden et al., 2009), and even less with qualitative disaster research (Mackenzie et al., 2007; Siriwardhana, 2015). Increasingly, ethics approval is required for qualitative disaster research (Phillips, 2014).

As with much qualitative research, debates occur over the procedures and adequacy of research ethics governance (Hammersley & Traianou, 2012). Some of the challenges have led to proposals for changes in how RECs review disaster research (Mezinska et al., 2016). Mechanisms exist by which projects can receive preliminary approval for a general research plan, then once a disaster strikes, the research is tailored to the specific setting and the final proposal submitted for rapid review (Tansey et al., 2010). Another adaptation is to have a centralized REC review all research applications for a particular disaster, assuming the necessary infrastructure remains in place. The large medical NGO, Médecins Sans Frontières, has an independent REC that reviews all disaster research projects conducted within the organization (Schopper et al., 2009). While such procedures will not work in all settings, they show the need and willingness to adapt existing REC procedures to the distinct requirements of disaster research (CIOMS, 2016).

For universities or organizations where qualitative disaster research is regularly conducted, established RECs will need to become familiar with its ethical issues. Depending on the number of projects, this could involve training for the whole committee, establishing a specialized sub-committee, or having a qualitative disaster researcher on the committee. For RECs that infrequently review qualitative disaster research, input from an independent advisor could be sought, as with other topics where expertise is needed.

Projects involving participatory action research involve more substantial changes. A one-time submission of an ethics approval form may not suffice. Just as researchers develop the projects through negotiation and trust-building with participants, something similar may be needed with RECs. The flexibility and adaptability characteristic of this and other qualitative research methods require flexibility on the part of RECs, but also put requirements on researchers to demonstrate clearly how changes will be negotiated and implemented. An ethics framework could be used to demonstrate the researchers' accountability to the participants and to their own institution or organization (Mackenzie et al., 2007). A mechanism for identifying and responding to unanticipated ethical dilemmas should be available, which may require regular communication with the REC. Alternatively, the research team could engage an ethics consultant, in agreement with the REC, to help guide ethics decisions as needed.

Research ethics committee approval and oversight, based on negotiation and regular communication, will have resource implications. Assessment of REC procedures is also vital. With communication and trust building, the researchers could debrief the REC and assess how ethical issues were addressed, and what unexpected ones arose. Issues with researcher safety and institutional reputation could also be examined. Projects could be evaluated in light of the dual imperative: to produce highly credible research results and improve the lives of participants while promoting the highest ethical standards.

LOOKING TO THE FUTURE

Qualitative disaster research ethics is a new field. As it develops, practical ways of evaluating the issues are needed. A Post-Research Ethics Analysis mechanism has been proposed to develop evidence for disaster research ethics (Siriwardhana, 2015). Sitting outside of REC procedures, this mechanism would facilitate researchers discussing openly with other researchers and stakeholders (including RECs) the ethical challenges encountered during humanitarian and disaster research. The proposal aims to encourage learning from past experiences and sharing of best practice. Qualitative disaster researchers could contribute much here.

As disaster responses change, new ethical challenges will be created for qualitative disaster research ethics, while existing issues will require continued reflection. New technology will bring new ethical issues. Smart phones, photographs, videos and images are prevalent in disasters, as elsewhere, and researchers will want to analyze these. Social media is increasingly used in disasters (Lindsay, 2011). Research into its impact will raise new and challenging ethical questions regarding privacy, confidentiality, and ownership. Machine translation is increasingly used for communication in disasters, raising ethical questions about its reliability and human impact. Unmanned search and rescue vehicles are used, raising ethical questions about human-machine interfaces. All these developments will ensure that ethical issues in qualitative disaster research will require careful consideration and cross-cultural dialogue.

CONCLUSION

In all areas of research ethics, codes and guidelines have their limitations, as do informed consent forms and ethics committees. A 1966 review of medical research found that most ethical problems arose from ‘thoughtlessness and carelessness’, and that informed consent was less reliable in ensuring ethical research than ‘the presence of an intelligent, informed, conscientious, compassionate, responsible investigator’ (Beecher, quoted in O’Mathúna, 2015b: 34). Likewise, social scientists have long noted the limitations of ethics codes and guidelines as they can undercut the ‘sense of personal accountability and, hence, of the importance of personal integrity’ (Payne et al., 1981: 249).

Individual researchers and research teams need to develop the capacity to identify and reflect on ethical issues, and reach decisions based on ethical principles and virtues that can be defended. Training and assessment in such areas are challenging, partly because they are so personal. Yet when researchers are tempted in some less than ethical direction, all they may have is their conscience and their virtues. Developing ethical researchers with the highest standards of personal and research integrity is the major challenge ahead.

REFERENCES

Aitsi-Selmi, Amina, Murray, Virginia, Wannous, Chadia, Dickinson, Chloe, Johnston, David, Kawasaki, Akiyuki, Stevance, Anne-Sophie, and Yeung, Tiffany (2016) ‘Reflections on a science and technology agenda for 21st century disaster risk reduction. Based on the scientific content of the 2016 UNISDR Science and Technology Conference on the Implementation of the Sendai Framework for Disaster Risk Reduction 2015–2030’, *International Journal of Disaster Risk Science*, 7(1): 1–29.

Allden, Kathleen, Jones, Lynne, Weissbecker, Inka, Wessells, Michael, Bolton, Paul, Betancourt, Theresa S., Hijazi, Zeinab, Galappatti, Ananda, Yamout, Rouham, Patel, P., and Sumathipala, Athula (2009) 'Mental health and psychosocial support in crisis and conflict: Report of the Mental Health Working Group', *Prehospital and Disaster Medicine*, 24(Suppl 2): s217–s227.

Bailey, Carol A. (2007) *A Guide to Qualitative Field Research*, 2nd edn. Thousand Oaks, CA: Pine Forge Press.

Belousov, Konstantin, Horlick-Jones, Tom, Bloor, Michael, Gilinskiy, Yakov, Golbert, Valentin, Kostikovsky, Yakov, Levi, Michael, and Pentsov Dmitri (2007) 'Any port in a storm: Fieldwork difficulties in dangerous and crisis-ridden settings', *Qualitative Research*, 7(2): 155–175.

CIOMS (2016) *International Ethical Guidelines for Health-related Research Involving Humans*. https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf

Ganiel, Gladys (2013) 'Research ethics in divided and violent societies: Seizing the ethical opportunity', in Cathriona Russell, Linda Hogan, and Maureen Junker-Kenny (eds), *Ethics for Graduate Researchers: A Cross-disciplinary Approach*. London: Elsevier. pp. 167–181.

Goodhand, Jonathan (2000) 'Research in conflict zones: Ethics and accountability', *Forced Migration Review,* 8: 12–15.

Hammersley, Martyn and Traianou, Anna (2012) *Ethics in Qualitative Research: Controversies and Contexts*. London: Sage.

International Organization for Migration (2014) *Supporting Durable Solutions to Urban, Post-disaster Displacement: Challenges and Opportunities in Haiti*. http://publications.iom.int/books/supporting-durable-solutions-urban-post-disaster-displacement

Jacobsen, Karen and Landau, Loren B. (2003) 'The dual imperative in refugee research: Some methodological and ethical considerations in social science research on forced migration', *Disasters,* 27(3): 185–206.

Lindsay, Bruce R. (2011) 'Social media and disasters: Current uses, future options, and policy considerations', *CRS Report No. R41987*. https://www.fas.org/sgp/crs/homesec/R41987.pdf

Mackenzie, Catriona, McDowell, Christopher, and Pittaway, Eileen (2007) 'Beyond "do no harm": The challenge of constructing ethical relationships in refugee research', *Journal of Refugee Studies*, 20(2): 299–319.

Mezinska, Signe, Kakuk, Péter, Mijaljica, Goran, Waligóra, Marcin, and O'Mathúna, Dónal (2016) 'Research in disaster settings: A systematic qualitative review of ethical guidelines', *BMC Medical Ethics*, 17(6): 1–11.

Molyneux, Catherine, Goudge, Jane, Russell, Steve, Chuma, Jane, Gumede, Tebogo, and Gilson, Lucy (2009) 'Conducting health-related social science research in low income settings: Ethical dilemmas faced in Kenya and South Africa', *Journal of International Development*, 21(2): 309–326.

O'Mathúna, Dónal P. (2010) 'Conducting research in the aftermath of disasters: Ethical considerations', *Journal of Evidence-Based Medicine*, 3(2): 65–75.

O'Mathúna, Dónal P. (2015a) 'Disasters', in Henk A. M. J. ten Have (ed.), *Encyclopedia of Global Bioethics*. Dordrecht: Springer. pp. 1–13.

O'Mathúna, Dónal P. (2015b) 'Research ethics in the context of humanitarian emergencies', *Journal of Evidence-Based Medicine*, 8(1): 31–35.

O'Mathúna, Dónal P., Gordijn, Bert, and Clarke, Mike (eds) (2014) *Disaster Bioethics: Normative Issues When Nothing is Normal*. Dordrecht: Springer.

O'Mathúna, Dónal, and Siriwardhana, Chesmal (2017) 'Research ethics and evidence for humanitarian health,' *The Lancet*, 9 June. doi: 10.1016/S0140-6736(17)31276-X

Payne, Geoff, Dingwall, Robert, Payne, Judy, and Carter, Mick (1981) *Sociology and Social Research*. London: Routledge.

Peek, Lori and Fothergill, Alice (2009) 'Using focus groups: Lessons from studying daycare centers, 9/11, and Hurricane Katrina', *Qualitative Research*, 9(1): 31–59.

Perry, Ronald W. (2007) 'What is a disaster?', in Havidán Rodríguez, Enrico L. Quarantelli, and Russell R. Dynes (eds), *Handbook of Disaster Research*. New York: Springer, pp. 1–15.

Phillips, Brenda D. (2014) *Qualitative Disaster Research: Understanding Qualitative Research*. Oxford: Oxford University Press.

Pittaway, Eileen, Bartolomei, Linda, and Hugman, Richard (2010) '"Stop stealing our stories": The ethics of research with vulnerable groups', *Journal of Human Rights Practice*, 2(2): 229–251.

Quarantelli, Enrico L. (11 June, 2006) 'Catastrophes are different from disasters: Some implications for crisis planning and managing drawn from Katrina'. Social Science Research Council. http://understandingkatrina.ssrc.org/Quarantelli/

Scanlon, T. Joseph (1988) 'Disaster's little known pioneer: Canada's Samuel Henry Prince', *International Journal of Mass Emergencies and Disasters,* 6(3): 213–232.

Scanlon, Joe (2014) 'The Halifax explosion', Canadian Risks & Hazards Network. http://www.crhnet.ca/sites/default/files/library/HazNet_Special_Edition_2014-01-15.pdf

Schopper, Doris, Upshur, Ross, Matthys, Francine, Singh, Jerome Amir, Bandewar, Sunita Sheel, Ahmad, Aasim, and van Dongen, Els (2009) 'Research ethics review in humanitarian contexts: The experience of the independent Ethics Review Board of Médecins Sans Frontières', *PLoS Medicine*, 6(7): e1000115.

Schroeder, Doris (2007) 'Benefit sharing: It's time for a definition', *Journal of Medical Ethics* 33(4): 205–209.

Siriwardhana, Chesmal (2015) 'Rethinking vulnerability and research: Defining the need for a post-research ethics audit', *Asian Bioethics Review*, 7(2): 188–200.

Stallings, Robert A. (2007) 'Methodological issues', in Havidán Rodríguez, Enrico L. Quarantelli, and Russell R. Dynes (eds), *Handbook of Disaster Research*. New York: Springer. pp. 55–82.

Tansey, Catherine M., Herridge, Margaret S., Heslegrave, Ronald J., and Lavery, James V. (2010) 'A framework for research ethics review during public emergencies', *CMAJ*, 182(14): 1533–1537.

Temple, Bogusia and Edwards, Rosalind (2002) 'Interpreters/translators and cross-language research: Reflexivity and border crossings', *International Journal of Qualitative Methods*, 1(2): 1–12.

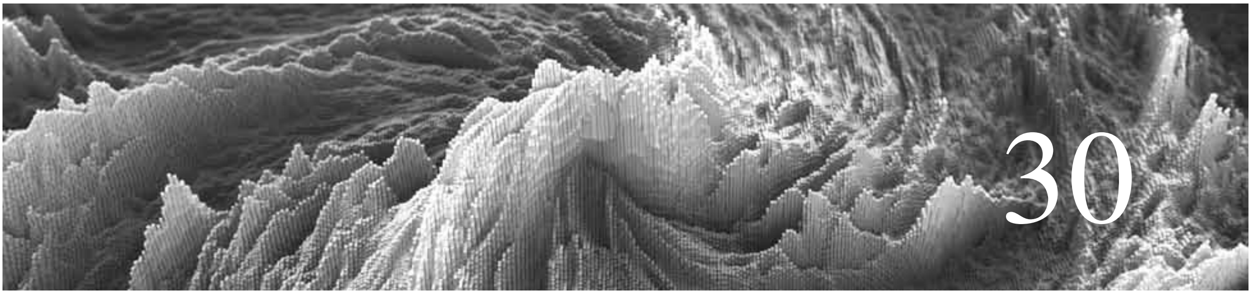
Tierney, Kathleen J. (1998) 'The field turns fifty: Social change and the practice of disaster field work', *Disaster Research Center.* http://udspace.udel.edu/handle/19716/287

Turton, David (1996) 'Migrants and refugees: A Mursi case study', in Tim Allen (ed.), *In Search of Cool Ground: War, Flight, and Homecoming in Northeast Africa*. Trenton, NJ: Africa World Press. pp. 96–110.

UNESCO (2005) Universal Declaration on Bioethics and Human Rights. http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/

van den Berghe, Pierre L. (1967) 'Research in South Africa: The story of my experiences with tyranny', in Gideon Sjoberg (ed.), *Ethics, Politics and Social Research*. Cambridge, MA: Schenkman. pp. 183–197.

Zwi, Anthony B., Grove, Natalie J., Mackenzie, Charlie, Pittaway, Eileen, Zion, Deborah, Silove, Derrick, and Tarantola, Daniel (2006). 'Placing ethics in the centre: Negotiating new spaces for ethical research in conflict situations', *Global Public Health*, 1(3): 264–277.



30

Ethical Issues in Insider-Outsider Research

Bridgette Toy-Cronin

INTRODUCTION

A substantial literature has developed within the humanities and social sciences about 'insider research'. This body of work looks at the advantages (including greater access, understanding and rapport) and disadvantages (lack of critical distance, subjectivity and bias) of conducting insider research. A large variety of insider roles have been considered, including researching one's own racial or ethnic group (Beoku-Betts, 1994; Song & Parker, 1995), family (Chavez, 2008), queer community (Taylor, 2011) and religious community (Heilman, 1980). It also includes professionals recruiting colleagues as participants and using their work places as research settings, including a particularly rich literature on teachers (Hammersley, 1993; Thomson & Gunter, 2011), nurses (Bonner & Tolhurst, 2002; McDermid et al., 2014) and social workers (Bell & Nutt, 2002; van Heugten, 2004), as well as some literature on librarians (Hannabuss, 2000), academics (Floyd & Arthur, 2012; Mercer, 2007) and lawyers (Toy-Cronin, 2016). Some of the literature also concerns being an insider to an experience, rather than a group, for example the grief process (Breen, 2007) and adoptive parenting (Corbin Dwyer & Buckle, 2009). Labaree (2002) provides further citations of 'insider' studies conducted across many disciplines including anthropology, education, ethnic studies, family research, feminist studies, folklore research, geography, nursing, social work and sociology.

While ethical issues are often mentioned in this literature, much more emphasis has been given to methodological issues, although there are notable exceptions such as Floyd and Arthur (2012) and Labaree (2002). The purpose of this chapter is to examine the ethical issues that can arise when an insider of any type conducts a qualitative study. Through a review of the literature and by reflecting on my own experience as an insider researcher, I develop a discussion of the major ethical issues that commonly arise. One of the most significant of these is role conflict between the group role and researcher role, which in turn gives rise to a host of ethical issues including consent, managing pre-existing and ongoing relationships, and the use of insider knowledge. The other major issue is the challenge of maintaining confidentiality, both during and after the research, and the possibility of a duty to disclose confidential research data.

Before examining these ethical challenges, I briefly introduce my own insider research experience and consider the definition and limitations of the commonly used terminology: 'inside-outside research' or 'insider research'. The chapter concludes by reflecting on methods to identify the ethical issues before they arise and encouraging more consideration of the ethical framework the researcher is applying, ideally before embarking on the research and continuing throughout the project.

RESEARCHING FROM THE INSIDE OUT

My own research experience of being an 'insider' was my doctoral research about self-represented litigants (people who go to court without a lawyer representing them). My research employed multiple qualitative methods and was a phenomenological study about the experience of being a self-represented litigant (Toy-Cronin, 2015). I began by examining the perspective of self-represented litigants, who participated either by way of a case study (n=10) involving observation, interview and document review, or by way of an interview only (n=24). While the observations for this part of the study were focused on the self-represented litigant, I was also examining how the lawyers and judges interacted with them both in court and through documents (letters and court documents). Once this aspect of the study was completed, I moved on to conducting semi-structured interviews with 8 court staff, 16 lawyers, and 13 judges.

My insider status arose from the fact that, before beginning my doctorate, I had been a courtroom lawyer, so I had pre-existing collegial relationships and membership of the legal profession. While I did not previously know any of the self-represented litigants who participated in my study, I was accustomed to interacting with people with legal problems in a lawyer-client relationship. I also had pre-existing relationships with many judges: my first job after law school was as a Judges' Clerk (a research assistant to the judges) and once I began practising as a lawyer, I had appeared on behalf of clients in their courtrooms.

I therefore had a range of relationships to the different participants and was neither truly 'inside' nor 'outside' in relation to any group. I also related differently to various members of each group depending on a range of factors such as the extent and nature of our pre-existing relationship and their level of involvement in the research.

USEFULNESS OF THE INSIDER/ OUTSIDER DISTINCTION

My experience was another illustration of the oft-made point that the 'inside-outside' dichotomy is not, by itself, particularly useful: researchers are never completely inside or outside (e.g. Mercer, 2007; Merton, 1972; Thomson & Gunter, 2011). The descriptions that resonated with my experience were those that acknowledged the complexity, fluidity and multidimensional nature of positioning relative to participants. Several authors have argued that being inside or outside is not a static place of being, but is fluid and unstable (Banks, 1998; Corbin Dwyer & Buckle, 2009; Mercer, 2007; Song & Parker, 1995; Thomson & Gunter, 2011). It is also multidimensional in that belonging to a group in one dimension (e.g. a shared race or shared profession) does not necessarily equate to 'inside' status with the group if the researcher's other characteristics mean they are also 'outside' the group (Beoku-Betts, 1994; Chavez, 2008; Labaree, 2002). The inside or outside position can also be manipulated and interpreted by both the researcher and participant (Floyd & Arthur, 2012; Labaree, 2002; Song & Parker, 1995; Thomson & Gunter, 2011).

Given the fluidity and multiple positions that a researcher can take, I share other researchers' reservations about the usefulness of the terms 'insider' and 'outsider'. The term is, however, widely used in the literature and the English language does not seem to offer a good alternative. I therefore use the term in the sense described, that being an insider researcher is not a stable, one dimensional position, but is reactive and unstable, moving depending on time, place, topic and participants.

ROLE CONFLICT

One of the core ethical issues of insider research is role conflict. As a member of a social or professional group, the insider is expected to conduct themselves in accordance with the norms of the group. This is because a role within that social or professional group comes with its own cluster of 'rights and duties, powers and permissions' (Dare, 2013: 31). For example, within a family or group of friends there will be duties and expectations around 'honesty, empathy, loyalty, affection, esteem, altruism and love' (Taylor, 2011: 13). Collegial relationships have duties of trust, respect, confidence and loyalty to the organization. Professional service relationships might include duties to clients but also duties to wider society. For example, New Zealand academics are to act as critic and conscience of society, and New Zealand lawyers are tasked with upholding the rule of law and the administration of justice (Education Act 1989; Lawyers and Conveyancers Act 2008). The researcher role also comes with its own rights and duties. Those duties might include to do no harm, to protect privacy and dignity, to respect autonomy, to report findings accurately and in some research paradigms, to promote the interests of the participants. The researcher in return is allowed to ask questions that might otherwise violate the insider role.

The research role norms may, however, be different and may even be in direct conflict with the role obligations as a member of the professional or social group. Heilman gives a pithy example of this sort of conflict when researching his Jewish Orthodox synagogue: 'Was, for example, the Sabbath to be a rich source of data or a day of rest?' (Heilman, 1980: 104). This issue of role conflicts, and the ethical decisions flowing from them, arose continually through the research. This should have come as no surprise, as other researchers have identified that researching one's own professional practice can lead to serious ethical conflicts. In various situations throughout the research, and potentially after the research has concluded, the researcher has to decide which role's norms take primacy (Iphofen, 2011; Sapsford, 1999).

Lawyer or Researcher?

I anticipated my role obligations as a lawyer could clash with my role obligations as a researcher and took steps to address this conflict. I cancelled my practising certificate so that, legally speaking (my prime mode of analysis at the time), I was no longer a lawyer. This made it clear that no lawyer-client relationship could arise and I owed no professional duties to the litigants or to the court. This was to avoid the most stark type of role obligation clash, when a code of professional ethics (to which I would otherwise be bound) clashed with my research principles (Socio-Legal Studies Association, January 2009).

Despite not being a lawyer anymore (although with no decision made about whether I would return to lawyering after the research or not), I expected that self-represented litigants would ask me for advice because I had the very thing they were likely lacking: intimate knowledge of the legal system and the law. I therefore made clear statements in the consent documents that I would not give legal advice. While I expected this to be an issue in the research, it was not particularly difficult to address. Occasionally litigants did ask for advice and I simply restated my position that I could not provide advice. I sometimes chose to redirect them to sources of advice if they pressed me for help, as this was a minimal intervention to ensure the relationship was not exploitative.

This was not the most complex issue, however. While I thought that cancelling my practising certificate ended my role as lawyer, I found that it was not as simple as this. The lawyer role turned out to be more deeply engrained than a formal legal role. When I listened to self-represented litigants' stories it was initially difficult to hear them as a social researcher rather than searching for the legal meaning of the stories, although with practice this became easier.

One aspect of the interactions that made it hard to separate the lawyer from the researcher role was that the self-represented litigants knew I was a former lawyer and they expected that I would understand the court procedure they were discussing. They often checked their use of terminology with me during discussions or asked 'is that normal?' after describing a courtroom experience. This precluded one strategy that is available to an insider researcher, to 'play dumb' or stage *naiveté*. That strategy can assist in making the roles clearer, as well as from a methodological standpoint, to make the familiar strange (Hockey, 1993: 209). I chose not to employ this strategy however as I felt it would have undermined my credibility. Bell and Nutt discuss this issue in the context of practitioner-researcher in the social work setting. They wonder whether Nutt's staged naïvety may have undermined the participants' confidence in her as a foster care expert and whether feigning non-comprehension is an unethical form of deception (Bell and Nutt, 2002: 78). I avoided this issue where possible by deflecting direct questions where I could, for example replying to the question 'is that normal?' with questions such as, 'had that happened to you before?'. Where I was asked questions about terminology, I usually simply gave the correct term or definition.

More complex issues arose when I perceived that the litigant needed advice, and I had the expertise to give it. This was not advice at the litigant's request, as they were sometimes over-confident and lacked the knowledge to see the problems ahead. Instead this occurred when I anticipated a problem and wanted to assist. I tried to resist the urge to give this advice, as it would clearly overstep the boundary of the research role: the litigants would no longer be self-represented and I would potentially create a lawyer-client relationship.

I came to realize, however, that 'advice' could potentially be much more subtle. There was the potential to either intentionally or unintentionally influence their litigation decisions by my body language or a leading question. For example, I could ask, 'are you going to make an application for *x*?' (knowing *x* would be a good strategy) but not knowing if they knew doing *x* was a possibility. It was relevant to the research, as I wanted to know how much they knew and how they were making decisions, but could also lead them to a new line of inquiry or strategy of which they were previously unaware. I tried to keep from such temptations and remain firmly in the observational, researcher role. There were probably times where I did unwittingly send them off on new lines of inquiry but I justified this on the basis that I was doing no harm, and simply took this into account when analyzing the data. I acknowledged that the litigants may have made more informed choices because of their conversations with me than what another similarly situated litigant may have made, but I did not want to step beyond this unintentional redirection as I was specifically trying to avoid intervention.

My lack of intervention generally, was something I justified on consequentialist grounds: if I had intervened I would have undermined the whole research project as the litigants were no longer strictly self-represented. It also risked creating a lawyer-client relationship, which is something I was careful to avoid, as this would mean I was required to adhere to a lawyer's professional responsibilities. Even if I did not go as far as creating a lawyer-client relationship, I worried that the litigant, who was already in the difficult position of navigating a complex system, would blame me if the litigant believed any suggestion or help had a negative consequence. For all these reasons, I chose to position myself firmly as an observer.

As other insider researchers have found, choosing such a stance does have costs. My personal ethical commitments, and my lawyer-role commitments, are for the pursuit of truth and justice. To watch a case be mishandled, potentially undermining the ability of the court (through no fault of its own) to reach a result that is fair and just, was morally and psychologically taxing. To manage this conflict, I focused on the larger benefits I hoped would come from a research project such as the one I was conducting (knowledge production that will guide future policy and practice); that a greater good for more people would arise if I stayed in the research role.

I did however make some minimal interventions in the setting that I considered necessary to maintain an ethical research relationship. For example, on one occasion I met a self-represented litigant in the courtroom and she was waiting in an area of the court where I knew it was not possible to hear the loudspeaker announcing the case. I therefore suggested we move closer to the courtroom. I gave another self-represented litigant a ride to the courthouse as she had no transport, and once there, directed her around the maze of corridors. It was this aspect of her court experience – getting to the courtroom – she was most concerned about. In both instances I interfered with the setting, getting the litigants to court when they may or may not have done so without me. I justified this on the basis that it was minimal intervention necessary to maintain a non-exploitative relationship with a measure of reciprocity (Adler & Adler, 1987; Skolnick, 1975: 38).

Pre-existing and Ongoing Relationships – Judges and Lawyers

The role conflict did not only arise in relation to the litigants, however, but also in relation to the lawyers and judges. I did not know most of these participants before the research began, but some I did know and all belonged to a group to which I had previously been a member. Though cancelling my practising certificate meant I was no longer legally part of the group, this did not immediately change how I related to the group or felt about my membership. Throughout the research process, my sense of belonging did however diminish. This occurred gradually as I read literature critical of the legal profession (a body of literature that had not been part of my legal training), talked to litigants who had negative experiences with lawyers, and then watched court proceedings from an ethnographic standpoint, trying to make the familiar strange (Hammersley & Atkinson, 2007: 81–82). By the time I interviewed lawyers and judges, my sense of belonging and even desire to belong had been reduced. This is not an uncommon experience for an insider researcher and has been termed 'going observational' (Adler & Adler, 1987; Heilman, 1980). In contrast with 'going native' (where the researcher adopts the outlook and behaviour of the participants), 'going observational' refers to the insider becoming alienated from their group because their research role disrupts their previous relationships and group membership. This may be, as it was in my case, due to the researcher's own perceptions.

It can also, however be due to the research participants repositioning the researcher, questioning their belonging. For example, research participants may directly question the 'native status' of the researcher (Heilman, 1980: 103), make reference to guarding information from the researcher that would otherwise have been freely shared in the insider role ('oops, I'd better be careful or that will turn up in her next papers') (Taylor, 2011:18), or viewing the researcher as having 'sold out' to the mainstream by becoming an academic (Banks, 1998: 15). It was unclear how judges and lawyers regarded my position and the extent to which they saw me as an insider or otherwise. There is not a very strong divide between practising and academic lawyers in New Zealand and there is a close relationship between the academy and judiciary so they may have seen me as still belonging.

While I have limited insight about how participants viewed my membership, I became aware that I could use tactics to influence how they positioned me and by doing so, potentially alter the responses elicited. For example, I could make small talk about shared professional experiences or reference shared professional norms through jokes and asides. In doing so, I would position myself as 'one of them' and elicit responses that might only be shared with a group member. These answers would not of course be 'more correct', they had to be analysed in the context, they were given (Atkinson & Coffey, 2001; Hammersley & Atkinson, 2007). From an ethical perspective however, such positioning ran the risk of being disingenuous and a manipulation or 'doing rapport' (Duncombe & Jessop, 2002). Corbin Dwyer and Buckle, citing Glesne, suggest that a qualitative researcher must not 'hide behind the mask of rapport or the wall of professional distancing … we must be fully authentic in our interactions with our participants and "honour the consequences of acting with genuineness"' (2009: 60). This admonishment was difficult to put into practice, however, as while I felt a degree of disaffection; I still felt a degree of belonging and also longing. I was, and remain, ambivalent about whether to become a total outsider or keep one foot in the door. When I present to legal audiences, I find myself often talking about 'we' and 'us'. Perhaps this is a rhetorical mechanism, asking them to consider the changes I suggest by positioning it as an appeal from the inside, but it may be equally because I genuinely want to remain part of the group. Simply being 'genuine' is therefore not a simple remedy to a complex problem.

As with the self-represented litigants, my insider status also created dilemmas about how to question the judges and lawyers. When interviewing judges – my previous bosses – should I continue in my role as 'junior' and try to impress them with my knowledge and mastery of the subjects at hand, or adopt a naïve researcher role to get the best answers for my questions? If I behaved in a naïve way, would this undermine my credibility with them and would it be unethically disingenuous? When I reviewed the interview transcripts I could see evidence of my attempts to navigate this complexity. For example, in an interview with someone I knew quite well, I pressed them on a difficult issue but then moved to protect my own position as 'insider' in the following passage:

> Author: I'm playing devil's advocate with you by the way, not expressing a view.
>
> Respondent: I know (laughing)
>
> Author: Just in case you were feeling alarmed (laughing)
>
> Respondent: no, no (laughing).

Questions also arise about whether it is ethical to use knowledge the researcher has gathered outside the research role to elicit other information from the interviewee or contradict the interviewee (Floyd & Arthur, 2012; McDermid et al., 2014). For example, as a Judges' Clerk I had access to the 'bench book', a manual for judges. This manual is not publicly available and my access to it was only granted in my role as Judges' Clerk and therefore with duties of confidence. It has a section on how judges should interact with self-represented litigants. Could I use that information to ask questions about how judges should interact with self-represented litigants, or ask why their reported or observed behaviour contravened what was suggested in the bench book? Fortunately, my memory of the bench book is sufficiently poor that the issue was not a live one in my research, but it illustrates the difficulty of possession of knowledge in one context and whether it is ethical to use that in the research context.

Consent

The transition from group role to research role can also create issues with consent to participate. The participants may still see the researcher in their group role and feel constrained or unable to deny the request to participate in the research. It is possible that, even with the best intentions, the researcher may be 'exploiting [their] position in the power hierarchy' to encourage subordinates to participate (Hannabuss, 2000; McDermid et al., 2014). Clear statements about voluntary consent do not necessarily cure the implicit power of the researcher's position in relation to the participants (Bell & Nutt, 2002; Sapsford, 1999). Even peers may be reluctant to refuse requests if they feel doing so would compromise their collegial relationship or their position at work (McDermid et al., 2014). This may be a difficult issue to overcome. The researcher would need to emphasize the research role, providing clear signals of the separation from the group role and face-saving means for participants to turn down requests to participate. For example, a researcher studying their own workplace or colleagues could establish a separate email account for research-based communications and conduct interviews off-site and, if possible, outside work hours.

CONFIDENTIALITY

Insider research creates particularly significant risks to confidentiality. Commonly social science researchers disguise the site of the research to protect the identity of the institution or the site of the research, as well as minimize the risk of individuals being identified. With insider research, this is likely to be futile as once the author of the research is known, then the institution or group they belong to is easily discovered, whether it be a place of employment, a family or a group of friends. This will often make it simple for those who are not participants to identify members of the group, threatening what Tolich (2004) calls 'external confidentiality'. As participants will usually belong to the same group, e.g. a staff at an institution or a church group, difficulty will also arise in preventing the 'research subjects involved in the study to identify each other in the final publication of the research', what Tolich calls 'internal confidentiality'.

The protection of the site of research, and external and internal confidentiality were all difficult issues within my research. I chose not to try to conceal the site of my research, as any attempt to do so was likely to be unsuccessful. When I entered a court to observe, most people knew who I was and why I was there. This is of course a well-recognized problem with ethnographic research (see for example Brettell, 1993). It is a problem that is becoming more pronounced in a digital age where a Google search allows any reader to locate the author (for example from their university website) and therefore the likely site of the research (Floyd & Arthur, 2012). Any pretence that I could successfully shield the site of the research might create a false sense of security. I therefore concentrated on protecting the identity of individuals.

Protecting individuals' identity was challenging. It is common to assign participants pseudonyms to protect their identity (Guenther, 2009; Hopkins, 1996) but this was unlikely to be successful in the context of my research. Participation in the case studies was not completely confidential because the methods followed inevitably meant that everyone else involved in the case knew that the self-represented litigant was a research participant. Furthermore, New Zealand is a small country, with a small legal community and a small number of cases reaching trial each year. Take for example observing cases in the High Court. In 2013, 143 civil cases went to trial in the High Court nationwide (High Court of New Zealand, 2013). Of those, we do not know how many involved a self-represented litigant, but if we take a rough estimate of 10–20% and estimate that half of those would have been conducted in the area I carried out my study, we get to a total of 7–14 cases. Many trials receive some media coverage, or are discussed informally among legal professionals. If I included in my description of a case study the cause of action (such as it being an action in tort or contract), some general information about the parties involved (e.g. it involved a company or individual, or the litigant's approximate age, educational background, or previous experience of the courts), it might be possible to narrow the range to just one or two possible cases. This problem is not unique to the legal world. Tolich and Davidson have discussed the problems of protecting confidentiality in any research setting in a small place, where just a few descriptive details can make the possible sites of research or participants so narrow as to make them identifiable (Tolich & Davidson, 1999: 77–80). Where smallness of the community is a factor, as it was in my research, careful attention has to be paid to protecting confidentiality, as the usual practice of using pseudonyms to protect participants' identity is unlikely to be effective.

Confidentiality among Participants

While the use of pseudonyms was insufficient to protect confidentiality vis-à-vis the audience at large, it was a problem that was compounded by trying to protect the confidentiality of participants within the group. Ensuring confidentiality in research involving small groups is always difficult, as the data has to be presented in such a way as to make a participant to whom the data relates unidentifiable to the other participants. The ability of participants within any group to identify (or mis-identify) each other – as the source, for instance, of a certain quote – has the potential to harm participants and the researcher (Tolich, 2004: 101).

This takes on further implications where a legal case is ongoing as there was a possibility that what a self-represented litigant disclosed to me, but not to their opponent, was either legally privileged or information that was strategically useful to the other side. It was unlikely, but not impossible, that the opposing party would try to compel disclosure to the court of my research notes. To date, no one has made such an attempt. The possibility did not terminate with the publication of my research, however, and in fact, publication may exacerbate the threat. What if participants recognize themselves and therefore recognize the opposing party? If the opposing party has said something the participant thinks might be useful to an appeal or their ongoing case, then perhaps they will attempt to compel production of my notes. Protecting internal confidentiality therefore took on an extra element of importance: I needed to ensure that I did not write something that the other party can use as 'ammunition'. While there was nothing in my notes that was obviously useful, I was not intimately acquainted with all the facts and legal issues in the cases studied. In fact, I deliberately avoided becoming so acquainted to assist in distinguishing the line between lawyer and researcher. I could not therefore be certain that seemingly innocuous information was not useful to another party.

Methods to Protect Confidentiality of Case Study Participants

To protect internal confidentiality, I needed to break the link between a description of something I observed and the self-represented litigant's commentary on the relevant events. As discussed, the usual method of assigning participants pseudonyms, where the case is otherwise described in full, was insufficient to maintain confidentiality in my research. But if the cases were too heavily disguised then there was the different risk that I would not be able to convey the most coherent account possible of the events.

An approach, which I did not consider, but which is sometimes discussed as a solution, is to limit the audience for the research to exclude the participants. Mercer studied two Higher Education Institutes in the Middle East at which she was employed. She explains that she promised informants that her findings would not be reported to senior management and that 'a number' of her informants referred to the fact that they were giving her information in the 'strictest confidence' and one believed she would be fired if she was identified as having provided the data (Mercer, 2007). Worryingly, Mercer seems to suggest that this obligation has an endpoint. She goes on to explain that while she still believes that presenting her findings to the institutions researched would cause harm to her and the participants,

> now that [she has] moved thousands of miles from both institutions, [she is] a little less anxious about allowing the wider research community to critique [her] findings. Were [she] still working at either of the two institutions in questions, [she] would have kept certain aspects of [her] research under wraps for a little while longer.

Even leaving aside the implication that the promise to the participants might have expired, making an undertaking of this kind is difficult in a globalized world where all publications are accessible regardless of location. It is also practically difficult when most researchers have an obligation to prove to their funders, governments or institutions that they have 'outputs' and their research has 'impact'. Even if research findings are kept close and presented only to select groups, there is no way to prevent an audience member spreading the findings, for example by the common practice of posting a photo of a PowerPoint slide on Twitter.

Another method to protect confidentiality is writing about all the data in very general ways, not giving any detail that could lead to identification, and discussing only themes. The obvious difficulty with this approach is that it would fail to provide the evidence upon which the themes were based and would therefore lack the rigour that could reasonably be expected. It would also omit all the detail that would make it compelling to the reader (Hockey, 1993: 219–220). I had to do this to some extent, in that I could not use all the documentary data I had available. Many legal documents are publicly available, so using direct quotes from them could reveal the identity of the participants. For example, it is a simple matter to enter a quote from a judgment into a legal database and retrieve the whole judgment and therefore learn the names of the parties. There was other detail, including examples which would be excellent for this chapter, that are simply too specific to include as the risks of identifying the participants are too high. In general, however, losing too much detail from the research undermines the methodological commitment to a phenomenological study.

An alternative is to take the writing back to participants who could be identified by a certain passage and ask for their informed consent to its publication. This approach was for example in a friend-researcher relationship when the information was given when in 'friend' not 'researcher' role (Taylor, 2011: 14). Floyd and Arthur (2012) also report that when Floyd interviewed his academic colleagues about their career trajectories he emailed them copies of the transcripts for comments and clarifications. They do not state whether this was using workplace email addresses but if it was, this could give rise to confidentiality issues as employers often have a right to access employee email accounts. This approach assumes the participant is able to fully assess the risks of any disclosure or elements of such. In the context of my own research, participants were unable to make that assessment. Neither they nor I were necessarily fully aware of the implications for their case if the information involved was disclosed. Informed consent may not therefore be possible without independent legal advice, which of course is not available for a self-represented litigant.

Instead, I decided to use direct quotes from individual self-represented litigant participants in the text, but with no pseudonyms attached. This was so the quotes could not be aggregated, by reference to such pseudonyms, to construct a composite picture that might be used to identify particular participants. I also altered gender, where necessary, or other identifying details to protect confidentiality. Some quotes simply identified the person by reference to the name of the court in which their case was filed, calling them for example 'Family Court Litigant', unless providing even the name of the court would threaten confidentiality.

In addition, I chose to present more detailed accounts of the data on self-represented litigants via construction of composite cases. This is an accepted method of presenting qualitative research findings in the health sciences, particularly psychiatry and counselling, as well as having precedent in other disciplines (Duffy, 2010; Piper & Sikes, 2010; Wertz et al., 2011). The composites blended of a number of cases, so that the person reported was fictional but the details, and sometimes dialogue, were taken from a number of real cases. This avoided the difficulties associated with trying to disguise a single case: there is either too little disguising detail (failing to protect participant identities), or so much disguising detail that it distorts the case. It is therefore more 'honest to develop a composite case instead' (Duffy, 2010: 147). The disadvantage of such an approach is that it departs from the basic commitments of social *science* research, with fact becoming secondary to maintaining confidentiality, though it is probably better than not being able to present such data at all.

This approach was used in Piper and Sikes's research on teacher-pupil sexual relationships because of the considerable harm that could be caused through identification of the participants (2010). They conclude that the 'storying approach' offered the best protection for their participants:

> Taking such an approach requires that readers trust writers not to have invented and fabricated data to fit their purpose. We would argue, however, that such trust has to be there regardless of the writing forms, styles, genre that researches adopt or, for that matter, whatever paradigm they espouse.

An advantage of the storying approach is that it helps to make lived experience vivid for the reader. As an aim of my research was to investigate the experience of litigating in person, using fictionalized accounts could help to achieve this goal. Presenting fictionalized composites was the best way to maintain both confidentiality and to fulfil one of the primary aims of the research – to elucidate the experience of self-represented litigants.

Continuing Risks

The ongoing nature of relationships between the insider and the group creates a continuing risk for confidentiality. Bell and Nutt (2002), citing Brannen, suggest 'that it is safer for participants if they never again meet the researcher as this minimizes any gossip and maximizes the chance of secrecy and anonymity'. It is highly unlikely that this can be achieved when an insider researcher is conducting the research. Like Hockey, who discusses invitations to gossip about data (1993: 220), lawyers often ask me which of the infamous frequent self-represented litigants participated in my study. The appeal is to the shared professional norms, where gossip about litigants is common but as a researcher, of course I have to refuse to participate. There is also the potential for awkward interactions at professional events where participants and I meet. Having reverted to a member role, or at least concluded the research, the participant and I nevertheless both know that they took part and I have to stay alert to not referencing any information learned from them when we interacted as researcher-participant.

This is particularly important because participants make disclosures to the researcher in the research role, information they might not have otherwise shared. Once the researcher returns to the previous role in the group the researcher cannot 'unknow' what they have learned. Floyd and Arthur (2012), for example, discuss the problem of having come into possession of information in their research role that they have to decide whether they can act on in later situations, or need to conceal and possibly even tell covering 'white lies'. They comment that the researcher may have to 'rein themselves in from replying' to queries from colleagues that they could answer with reference to material they learned in the research interview.

Duty to Disclose

While maintaining confidentiality is one of the core duties of ethical research practice, an ethical question that can be equally pressing but is less discussed, is the duty to disclose information given in a research context (Guillemin & Gillam, 2004). Recall that one of the issues in my research was the possibility that a party to litigation would attempt to compel disclosure of my research notes in court. I dealt with this by seeking expert opinion on the likely risk, which was assessed as remote but still possible. I therefore made a statement on the information sheet which set out the terms of participation, stating that it was possible disclosure could be ordered by a court. Fortunately, no one has so far attempted to compel my research notes.

The duty to disclose can arise in insider research in other ways however, most likely where the insider owes a professional duty to disclose information and a conflicting research duty to maintain confidentiality. Bell and Nutt give a memorable and stark example of the conflicting duties. Linda Nutt was practising as a social worker when she conducted research investigating 'how foster carers make sense of their everyday lives in relation to their own families and to the "extra" children for whom they care' (Bell & Nutt, 2002). On leaving the home of a carer she had interviewed she 'noticed an unambiguously sexually explicit picture in the hallway'. This was an issue because carers are told to assume the children in their care have been sexually abused, unless specifically told otherwise. 'It is thus always considered essential not to give fostered children messages that could be interpreted as in any way sexual'. As a researcher Nutt had an obligation to maintain confidentiality but as a social worker, employed by the National Foster Care Association, she had a 'statutory responsibility to disregard confidentiality where children are at risk'. She decided the duty to inform outweighed the research duty to maintain confidentiality and informed the local authority. Sapsford gives the example of a prison officer interviewing a prisoner and promising confidentiality. At the time of writing a report on the fitness of that prisoner for release however, the prison officer's professional responsibility would take precedence (Sapsford, 1999). Similarly ethical codes for nurses make it clear that the nursing ethics take precedence over research ethics. If a 'researcher' was discovered to have contravened this requirement their licence to practice could be revoked.

PREPARING TO ENTER THE FIELD

The literature, and my own experience, suggests that insider researchers often fail to anticipate the ethical issues that arise. This is, of course, not uncommon in any form of qualitative research 'where often ethical challenges and dilemmas are unexpected and emerge as research unfolds' (Wiles, 2012: 16).

Recognition of the nature of insider research may limit this surprise. As, Thompson and Gunter (2011) argue, if researchers escape from the idea of the binary 'inside-outside' position they can recognize the fluidity of roles and relationships with each group of participants. This frees researchers to think nimbly about the sorts of ethical, as well as methodological issues that might arise when they are in the field.

Chavez (and other researchers) have suggested that preparation should include reflective exercises examining the researcher's role:

> They need to get into their own heads first before getting into those of participants'; they need to know in which ways they are like their participants and in which ways they are unlike them; they need to know which of their social identities can advantage and/or complicate the process. (Chavez, 2008: 491)

I would add to this that researchers should think about how the research might change the current relationships, how the participants might position the researcher, how the researcher will resume their group role at the conclusion of the research, and what complications might arise in doing so.

Undertaking this exercise could take the form of regular reflexive writing (e.g. through a project diary), a self-interview, or testing the research instruments on oneself. It is a process to be undertaken before the research begins and continuing throughout, to assist the researcher in recognizing and examining the unstable, fluid and multidimensional relationships to the participants so informed ethical decisions are made.

Part of this process would be considering what ethical framework the researcher is working within and how this relates to the research methodology. This process seems underdeveloped in some of the inside-researcher literature. For example, Taylor suggests:

> As researchers, we have no handbook or manual to follow, no precise way of orchestrating such engagements to ensure a mutually beneficial outcome. To guide us in our research, we must equally value and rely upon our strength of character, goodwill, our gut instincts and emotional intelligence as we do our formal training. (2011: 18)

I would suggest that researchers can make more conscious and considered decisions than Taylor suggests, as there are a number of 'handbooks' and 'manuals' (this *Handbook* included) that consider these issues. Researchers can consider what ethical framework they intend to work within, for example consequentialist, non-consequentialist, principlist, or ethic of care approaches (Wiles, 2012). Considering the possible ethical positions does not give automatic answers but provides a framework for making conscious, considered decisions when issues do arise, rather than rely on 'gut instinct'.

Some of these frameworks minimize (although they do not eliminate) some of the ethical tensions that are produced by insider research. For example, some researchers adopt a strong ethic of care or critical ethics framework:

> Ethical decisions are made on the basis of care, compassion and a desire to act in ways that benefit the individual or group who are the focus of research, recognising the relationality and interdependency of researchers and research participants. (Wiles, 2012)

Some epistemological positions and research perspectives, particularly 'constructionism, feminism, critical theory, and postmodernism', meld well with an ethic of care, as they allow the researcher to conduct research 'with' rather than 'on' the group (Breen, 2007: 164; see also Corbin Dwyer & Buckle, 2009). As decisions are guided by what is in the best interests of the individuals researched, this framework is well suited to insiders of minority social groups, who see their role is to bring social justice to that group (see for example Banks, 1998; Chavez, 2008).

This does not meant that using ethic of care and participatory research frameworks will make insider research 'more "ethically acceptable"' (Bell & Nutt, 2002). A researcher might equally decide the most ethical approach is to conduct the research using a randomized, controlled trial as this is widely accepted as the most robust evidence. This type of research would have a very different ethical framework but would not, on the face of it, be more or less ethical. Similarly, my ethical decisions were influenced by the pragmatic research paradigm I was working within (Creswell, 2013). I wanted access to all the participants' perspectives (lawyers, judges, litigants and court staff) so I needed to maintain a neutral standpoint. An ethic of care towards the self-represented litigants would not have melded well with this approach to the research. It would have meant I should intervene to assist the litigants in more situations than I did, undermining the neutrality I was trying to foster to retain access to the other participant groups. Instead, I adopted a consequentialist position, examining ethical decisions from the standpoint of whether my action (or inaction) would produce research that would be beneficial for a larger group of people than only the participants in the research. Other researchers with the same research questions may have taken a different approach, both to the methodology and the ethical framework. The point is not to be 'more ethical' but to have initial and then ongoing attention to ethical considerations and how these relate the research methodology and purpose.

CONCLUSION

Recognition of the complexity of what it means to be an insider, whether to a social group or professional group, will assist researchers in navigating the ethical complexity of qualitative research projects. While it is not possible to anticipate all ethical issues at the outset of a project, it is possible to anticipate and consider how relationships might change, how the identity of participants can be protected and how the complexity of the group role versus the research role might be navigated. Continuing to reflect on these matters throughout the research, with reference to an ethical framework, will help researchers make consistent, ethical decisions so the advantages of insider research can be realized without compromising ethical practice.

REFERENCES

Education Act 1989. [New Zealand]

Adler, P. A. and Adler, P. (1987). *Qualitative Research Methods: Membership Roles in Field Research,* Sage.

Atkinson, P. and Coffey, A. (2001). Revisiting the Relationship Between Participant Observation and Interviewing. In: Gubrium, J. and Holstein, J. (eds) *Handbook of Interview Research*, Thousand Oaks, CA: Sage. pp. 801–814.

Banks, J. A. (1998). The Lives and Values of Researchers: Implications for Educating Citizens in a Multicultural Society. *Educational Researcher*, 27(7), 4–17.

Bell, L. and Nutt, L. (2002). Divided Loyalties, Divided Expectations: Research Ethics, Professional and Occupational Responsibilities. In: Mauthner, M., Birch, M., Jessop, J., and Miller, T. (eds) *Ethics in Qualitative Research*. London: Sage. pp. 70–90.

Beoku-Betts, J. (1994). When Black is not Enough: Doing Field Research among Gullah Women. *NWSA Journal*, 6(3) (Fall), 413–433.

Bonner, A. and Tolhurst, G. (2002). Insider-Outsider Perspectives of Participant Observation. *Nurse Researcher*, 9(4), 7–19.

Breen, L. J. (2007). The Researcher 'in the Middle': Negotiating the Insider/Outsider Dichotomy. *The Australian Community Psychologist*, 19(1), 163–174.

Brettell, C. B. (ed.) (1993). *When They Read What We Write: The Politics of Ethnography,* Westport, CN: Bergin & Garvey.

Chavez, C. (2008). Conceptualizing from the Inside: Advantages, Complications, and Demands on Insider Positionality. *The Qualitative Report*, 13(3), 474–494.

Corbin Dwyer, S. and Buckle, J. L. (2009). The Space Between: On Being an Insider-Outsider in Qualitative Research. *International Journal of Qualitative Methods*, 8(1), 54–63.

Creswell, J. W. (2013). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches,* Thousand Oaks, CA, Sage.

Dare, T. (2013). *Counsel of Rogues? A Defence of the Standard Conception of the Lawyer's Role,* Abingdon, Ashgate Publishing.

Duffy, M. (2010). Writing About Clients: Developing Composite Case Material and its Rationale. *Counseling and Values*, 54(2), 135–153.

Duncombe, J. and Jessop, J. (2002). 'Doing Rapport' and the Ethics of 'Faking Friendship'. In: Mauthner, M., Birch, M., Jessop, J., and Miller, T. (eds) *Ethics in Qualitative Research*. London: Sage. pp. 107–122.

Education Act 1989. [New Zealand]

Floyd, A. and Arthur, L. (2012). Researching from Within: External and Internal Ethical Engagement. *International Journal of Research and Method in Education*, 35(2), 171–180.

Guenther, K. (2009). The Politics of Names: Rethinking the Methodological and Ethical Significance of Naming People, Organizations, and Places. *Qualitative Research*, 9(4), 411–421.

Guillemin, M. and Gillam, L. (2004). Ethics, Reflexivity, and 'Ethically Important Moments' in Research. *Qualitative Inquiry*, 10(2), 261–280.

Hammersley, M. (1993). On the Teacher as Researcher. *Educational Action Research*, 1(3), 425–455.

Hammersley, M. and Atkinson, P. (2007). *Ethnography: Principles in Practice,* London and New York, Routledge.

Hannabuss, S. (2000). Being There: Ethnographic Research and Autobiography. *Library Management*, 21(2), 99–107.

Heilman, S. (1980). Jewish Sociologist: Native-as-Stranger. *The American Sociologist*, 15(2), 100–108.

High Court of New Zealand (2013). *Report from the High Court 2013: The Year in Review*. High Court of New Zealand – Te Kōti Matua o Aotearoa.

Hockey, J. (1993). Research Methods – Researching Peers and Familiar Settings. *Research Papers in Education*, 8(2), 199–225.

Hopkins, M. (1996). Is Anonymity Possible? Writing about Refugees in the United States. In: Brettell, C. (ed.) *When They Read What We Write: The Politics of Ethnography*, Westport, CN, Bergin & Garvey. pp. 121–130.

Iphofen, R. (2011). *Ethical Decision-Making in Social Research: A Practical Guide,* Basingstoke, UK and New York, Palgrave Macmillan.

Labaree, R. V. (2002). The Risk of 'Going Observationalist': Negotiating the Hidden Dilemmas of Being an Insider Participant Observer. *Qualitative Research*, 2(1), 97–122.

Lawyers and Conveyancers Act (Lawyers: Conduct and Client Care) Rules 2008. [New Zealand]

McDermid, F., Peters, K., Jackson, D., and Daly, J. (2014). Conducting Qualitative Research in the Context of Pre-existing Peer and Collegial Relationships. *Nurse Researcher*, 21(5), 28–33.

Mercer, J. (2007). The Challenges of Insider Research in Educational Institutions: Wielding a Double-edged Sword and Resolving Delicate Dilemmas. *Oxford Review of Education*, 33(1), 1–17.

Merton, R. K. (1972). Insiders and Outsiders: A Chapter in the Sociology of Knowledge. *American Journal of Sociology*, 78(1), 9–47.

Piper, H. and Sikes, P. (2010). All Teachers Are Vulnerable but Especially Gay Teachers: Using Composite Fictions to Protect Research Participants in Pupil-Teacher Sex-Related Research. *Qualitative Inquiry*, 16(7), 566–574.

Sapsford, R. (1999). *Survey Research*, London, Sage.

Skolnick, J. H. (1975). *Justice without Trial: Law Enforcement in Democratic Society,* New York, John Wiley & Sons.

Socio-Legal Studies Association. (January 2009). Statement of Principles of Ethical Research Practice [Online]. Available: http://www.slsa.ac.uk/ (Accessed 3 October 2014).

Song, M. and Parker, D. (1995). Commonality, Difference and the Dynamics of Disclosure in In-Depth Interviewing. *Sociology*, 29(2), 241–256.

Taylor, J. (2011). The Intimate Insider: Negotiating the Ethics of Friendship when Doing Insider Research. *Qualitative Research*, 11(1), 3–22.

Thomson, P. and Gunter, H. (2011). Inside, Outside, Upside Down: The Fluidity of Academic Researcher 'Identity' in Working with/in School. *International Journal of Research & Method in Education*, 34(1), 17–30.

Tolich, M. (2004). Internal Confidentiality: When Confidentiality Assurances Fail Relational Informants. *Qualitative Sociology*, 27(1), 101–106.

Tolich, M. and Davidson, C. (1999). *Starting Fieldwork: An Introduction to Qualitiative Fieldwork in New Zealand,* Melbourne, Oxford University Press.

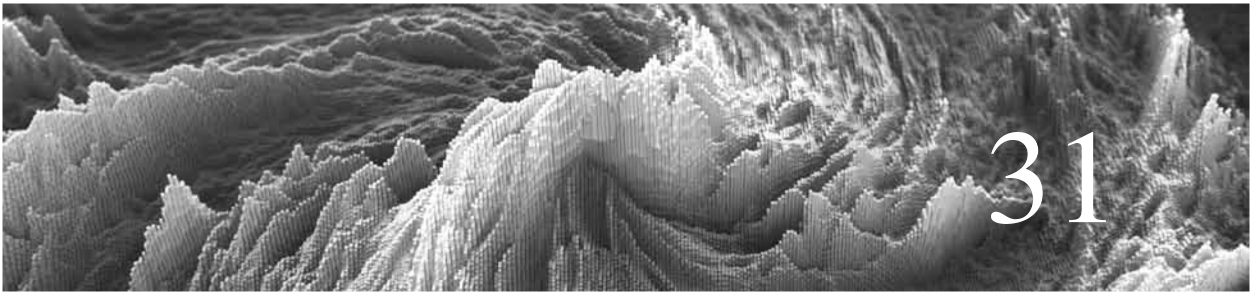
Toy-Cronin, B. (2015). *Keeping Up Appearances: Accessing New Zealand's Civil Courts as a Litigant in Person*, PhD Thesis, University of Otago.

Toy-Cronin, B. (2016). From Litigator to Researcher: The Burdens and Benefits of Moving Between the Profession and the Academy. *International Journal of the Legal Profession*, forthcoming.

van Heugten, K. (2004). Managing Insider Research Learning from Experience. *Qualitative Social Work*, 3(2), 203–219.

Wertz, M. S., Noske, M., McNiesh, S., and Marlow, E. (2011). The Composite First Person Narrative: Texture, Structure, and Meaning in Writing Phenomenological Descriptions. *International Journal of Qualitative Studies on Health and Well-being*, 6(2), 1–10.

Wiles, R. (2012). *What are Qualitative Research Ethics?,* London, Bloomsbury.



31

Covert: The Fear and Fascination of a Methodological Pariah

David Calvey

INTRODUCTION

This chapter has several goals. First, to recognize the controversy surrounding deception in social research, which covert research is squarely associated with. Second, to explore some classic and contemporary exemplar case studies in covert research. Third, to offer some critical reflections on 'ethical moments' from the field, based on a covert ethnography of bouncers in the night-time economy of Manchester by the author. Fourth, to speculate on the futures of covert research and particularly its potential revival from various different sources. Finally, to offer some concluding sentiments around the future uses of covert research. Namely, a recognition and appreciation of the depth and diversity of covert research, both historically and currently, which could lead to a type of rehabilitation of covert research in the social science research community. Covert research, due to the obvious ethical luggage it carries, is likely to remain a specialized and niche tool in social research but hopefully a less maligned and stigmatized one. A related sentiment is to move away from a belligerent, cavalier, and heroic picture of covert research to a more reasoned and balanced one where covert research could be appropriate in some, but certainly not all, research settings.

DECEPTION IN SOCIAL RESEARCH

Covert research is firmly and clearly equated with deception. It is morally and politically frowned upon and stigmatized as a 'last resort methodology' (Calvey, 2008). Put another way, the minute one does any covert research, or indeed thinks about doing some, you enter an ethical minefield and a maze plagued with myriad dilemmas, guilt syndromes and deviant knowledge. The use of covert research then violates the mantra of informed consent that we are, as academics, institutionally socialized into and brings with it complex issues of harm and risk to both the researcher and the researched.

Covert research thus becomes treated as necessarily methodologically invasive, which betrays trust, privacy and confidentiality. It comes as no surprise then that for most professional bodies, associations and codes in the social science community[1] regard covert research with suspicion and disdain, which in the longer term effectively stifles the growth of this maligned yet creative tradition (Calvey, 2013). It is effectively a methodological pariah.

Covert research has a type of index and footnote status in various social science fields, where you have to dig for a more discursive, nuanced and detailed understanding of it. This somewhat stifled understanding of covert research gives readers a rather crude and simplistic understanding of the complex issues involved and a limited knowledge of the rich corpus of covert work across the social sciences. Deception has a familiar place in popular culture and the public imagination. As Iphofen cogently argues:

> In research terms deception is routinely employed in a mundane fashion in the blind randomised control trial in biomedicine now seen as almost 'ethically secure'. That is, participants are told of the form of deception to be employed beforehand. This is done regularly in market research when mystery shoppers are employed to test the service skills and systems of employees. More importantly various forms of deception are routinely, again mundanely, employed by several agencies with little public retribution and may even attract enthusiastic moral approbation – the police employ it for undercover operations and legalised 'entrapment' of suspects. Well-respected sociological research has shown how television news is inherently deceptive … There could be nothing more deceptive than most forms of advertising. But the public are not ignorant of this. Indeed it is culturally endemic to the human condition, embedded in folk tales and myths. The entertainment, fashion and art industries depend for their survival upon our collusion in the suspension of disbelief. (2011b: 80)

Moreover, many of the assumptions about, and images of, covert research are somewhat evocative ones drawn from populist investigative journalism and not from academia. It is probably reasonable to claim then that if we conducted a straw poll with the public, most people would be more familiar with the televised undercover exploits of Irish investigative journalist Donal MacIntyre[2], or the USA TV show *Undercover Boss*, or indeed when celebrity figures hit the news headlines when stung for wrongdoing and indiscretions by undercover journalists. There are clear and significant issues here about justifications, breaches and boundaries. Iphofen again sums up the thorny and complex issue in his provocative question: 'Is it ever ethically acceptable to investigate unethical behavior by employing unethical means? For example, in a study of how human beings lie or deceive each other, is it permissible for researchers to lie and deceive in order to find out more about lying and deceiving?' (2011b: 6). This is the classic means/end question. Put another way: can the potential gains and insights from deception be valuable in certain cases and hence be sanctioned? For me, there are cases where covert research can go the extra analytic mile, but there are clear restrictions with regard to vulnerable groups and sensitive topics.

The big screen film adaptations of real undercover police agent's biographical memoirs such as *Serpico* (1973), *Prince of the City* (1981), *Donnie Brasco* (1997), *ID* (1995), *Gommorah* (2008), *The Infiltrator* (2016) and *Imperium* (2016), to name the most familiar ones, add to this glamorized, romanticized and heroic pictures of undercover work. Some of the covert work from investigative journalism is robust and fascinating but it is playing a different game to the academic one and within a different genre in terms of logic, imperatives, success criteria and outcomes. Much of the work done by investigative journalism is legally bounded and justified by arguments around public interest.

Van den Hoonaard makes an interesting comment when stating that 'ethnographic fieldwork is fleeing into the hands of journalists who have largely remained free of the ethics review constraints that researchers commonly face' (2011: 288). Thus, types of 'quick and dirty' covert ethnography for the news media are turned over at a much more rapid pace than academic ones. Hence, although covert investigative journalism is playing in a different genre, we can learn lessons from this discipline rather than ignoring it and treating it as the intellectual poor cousin.

Lugosi usefully defines covert research as 'an investigative strategy in which the researcher's professional identity and academic intentions are hidden either partially or fully from those involved in the study. Research is therefore conducted without the knowledge or consent of those being studied' (2008: 133). Lugosi also makes an interesting distinction between active and passive types of covert research, with the former being part of a deliberate strategy to deceive and the latter being more to do with the concealment of some part of the research. This distinction becomes useful, as a large amount of covert research, on closer scrutiny and granulation, is not 'purist' but realistically semi-covert with gatekeeping arrangements and/or collaborations with key informants. Hence, what becomes vital to such distinctions is intention. Thus, whether the covert research has come about by drift or design is an important distinction to ascertain and attribute.

Spicker provocatively argues:

> Covert research is research that is not declared to the research participants or subjects. This is often muddled with deception, and condemned as intrinsically unethical. The basis of that condemnation is a legitimate concern with the rights of research subjects. It is, however, over-generalized. Research subjects do have rights, but they are not the only people with rights. They may have some say about the use of information, but not all information is under their control. They are entitled to privacy, but not everything is private. Undeclared, undisclosed research in informal settings has to be accepted as a normal part of academic enquiry. (2011: 1)

The problem of 'over generalization' is a significant one given the need for gatekeeping arrangements. The alarmist hyper-reaction to covert research is then based on extremity. The other important issue raised here is one about the dispersal of information, which a crude absolutist notion of informed consent seems to neglect or, at best, underplay. Put another way, does, should and can everyone have the same information about a project in a research setting?

There is a standard established literature on informed consent as well as a more dissident literature which broadly views the process in a more dynamic manner as well as variably critiquing the increasing ethical regimentation in research (Denscombe, 2005; Dingwall, 2008; Fistein & Quilligan, 2011; Haggerty, 2004; Hammersley, 2010; Hammersley & Traianou, 2012; Hedgecoe, 2016; Katz, 2006; Lawton, 2001; Librett & Perrone, 2010; Murphy & Dingwall, 2007; Reed, 2005; Whitaker, 2005). What Corrigan (2003) elegantly describes as 'empty ethics'.

Clearly ethical decision making must be sensibly regarded as a more complex process (Iphofen, 2011a) rather than a blanket application of crude 'one size fits all' logic. Despite this more realistic and instructive dissident literature on the disconnect between ethical theory and field reality, a rather absolutist version of informed consent is still very pervasive and recursive in the social community. Within such a model, covert research does not fair very well.

The philosophical driver then of covert research is centred on types of naturalism and realism, and more particularly with obviating artificiality in research settings. Put another way, covert research attempts to neutralize the Hawthorne Effect, which is where research participants can change their behaviour in a setting because of the presence of the researcher. It is very problematic to estimate the extent of the Hawthorne Effect in any accurate way but it is a constant thorn in the side of social researchers who creatively try to manage this in different contexts.

EXEMPLARS IN COVERT RESEARCH

I will draw upon what I loosely describe as the 'usual suspects' of classic covert research that are popularly quoted in the field (Calvey, 2017). These are namely, Erving Goffman, Laud Humphreys and Stanley Milgram. They collectively represent the conventional wisdom on covert research, and have had a seminal impact on much academic theorizing on research ethics. There are dedicated and specialized literatures on these figures, that have been massively influential across the social sciences and have left seminal legacies that are still being worked out. Our consideration here is with their particular covert journeys. In addition, I will then consider some more contemporary and very instructive exemplars of covert research in Buckingham et al. (1976), Pearson (2009) and Scheper-Hughes (2004).

As expected, there is a large scholarship on Goffman (1922–1982). He is rightly regarded as an iconic figure in the social science community, whose influence extended beyond sociology. *Asylums: Essays on the Situation of Mental Patients and Other Inmates* (1961) is one of his most well-known books within a wide corpus, which has had a particular influence on healthcare fields and the anti-psychiatry movement (Sedgwick, 1974).

The book centred on the process of mortification in total institutions. His year long sponsored ethnographic study in the mid 1950s was of St Elizabeth's Hospital, Washington, DC in the US, which was a very large federal institution. His role was a covert one as an 'an assistant to the athletic director' (Goffman, 1961: ix), with gatekeeping with senior medical staff.

From the outset for Goffman, 'a chief concern is to develop a sociological version of the self' (1961: xiii). The humanism of Goffman is poetically clear as he concludes 'mental patients can find themselves crushed by the weight of a service ideal that eases life for the rest of us' (p. 386).

The Laud Humphreys (1930–1988) saga is a legendary one of challenge and redemption in the social sciences, which resulted in his initial suspension from his academic post to his eventual celebration as an innovative and pioneering activist. The goal of his doctoral study, *Tearoom Trade: Impersonal Sex in Public Places* (1970), was based in the Sociology Department at Washington University in St. Louis in the US, was 'to describe for the reader the social structure of impersonal sex, the mechanisms that make it possible' (p. 14).

Contrary to popular belief, his study was semi-covert as it involved extensive interview data with his 'intensive dozen' of key informants. Humphreys is also keen to point out that this is a study centred on the subculture of those involved in public sexuality and not exclusively homosexuality, although a large number of the participants were gay men. Such activity was seen at the time as sexual deviance and illegal.

Humphreys' method was voyeuristic in that he acted as a passive participant observer in his role as a 'watch queen' or look out for the police vice squad, which for him was the 'real methodological breakthrough of the research' (1970: 27). Much of the controversy centred on the latter phases of the research, which he later regretted (Humphreys, 1975), where he traced license plates of cars that tearoom participants drove followed by fake health surveys at their personal homes, which was seen by many as hugely invasive and intrusive. Namely, seen by many as a step too far in ethical terms.

Humphreys, who was a gay man himself trapped in a heterosexual marriage, and founded a network to support academics with alternative sexual orientations in later life, was partly motivated to counter the stigma attached to tearoom trade and vigorously question public policy and police activity around it. The activism of Humphreys ultimately related to his own biography and is clearly evident throughout his study. Humphreys had a huge impact on future studies of the 'erotic oasis' (Tewksbury, 2010) within sexuality studies. In praise of his legacy Galliher et al. (2004) refer to him as the 'prophet of homosexuality and sociology'.

One of the most famous exemplars, in that it has crossed disciplinary boundaries, is Stanley Milgram's (1933–1984) *Obedience to Authority: An Experimental View* (1974). His experiments in social psychology have also been popularly referred to as 'pain and torture' experiments but were really about the nature of obedience to authority. As with the other exemplars there is a recognized scholarship on Milgram who was clearly influenced by the work of Arendt (1963) on the banality of evil. The initial experiments were conducted at the Department of Psychology at Yale University between 1961 and 1963, and published in the early 1960s in various psychology journals before being collected in the 1974 book. The experiments were repeated over the years to involve around 663 participants.

Milgram also conducted a series of experimental variations with similar results, which have not been as intensively discussed as the main one. The results of the experiments, where participants were duped into thinking they were giving electric shocks to people, basically endorse the belief in conformity to authority in society.

At the outset Milgram outlines the centrality of the topic under study:

> Obedience, because of its very ubiquitousness, is easily overlooked as a subject of inquiry in social psychology. But without an appreciation of its role in shaping human action, a wide range of significant behaviour cannot be understood…What the present study does is to give the dilemma contemporary form by treating it as subject matter for experimental inquiry, and with the aim of understanding rather than judging it from a moral standpoint. (1974: xi)

Clearly, Nazi war crimes and atrocities provided the clear context for his specific worldview. Despite the dissident literature, which casts serious doubt on the reliability of his data (Brannigan, 2004, 2009; Perry, 2013), Thomas Blass, an influential Milgram scholar, sums up the wider reactions to Milgram's work as an unexpected and extreme type of research involving clear elements of dupery, in the title of his 2004 book *The Man Who Shocked The World*. Milgram is still widely cited in psychology and, indeed 'poached' by other social scientists as part of their tropes on flawed ethicality as Tolich (2014) elegantly argues.

Milgram was also to have a direct influence on the controversial Stanford Prison Experiment by Zimbardo and his colleagues (Haney et al., 1973; Zimbardo, 1973), which although not covert, is commonly regarded as an infamous example of extreme ethical transgression. This was a larger scale study of institutional conformity, rule following and cruelty, that very much saw Milgram and his experiments as a pioneering forerunner. Tolich (2014) poses the interesting question in his journal paper of the same title: 'What can Milgram and Zimbardo teach ethics committees and qualitative researchers about minimizing harm?'. As Tolich rightly argues both cases are highly instructive yet are still routinely demonized.

Other exemplars from different areas are also highly instructive and remind us that covert research still offers a robust more contemporary contribution. For example, within a pseudo-patient tradition, Buckingham et al.'s (1976) 'Living with the Dying' is a very controversial and greatly under-utilized covert study. The study was conducted by medical anthropologists who used covert participation observation to explore the culture of care for terminal cancer patients in a hospital in Montreal, Canada. Such were the serious medical risks of life threatening infection that senior medical staff were part of the necessary gatekeeping arrangements. The staff were told there was to be a study but importantly not what form it would take. Buckingham, the lead researcher from a team of four, passionately committed himself to an embedded covert role as he assumed the role of a patient with terminal pancreatic cancer, with a second researcher acting as his cousin who visited regularly, and who was his key contact during the hospitalization period.

Buckingham and colleagues describe his detailed and somewhat extreme passing as:

> Puncture sites from intravenous infusion needles on the hands and arms, a 10-kg weight loss induced by a six-month diet, patchy beard alopecia related to the stress of preparation, and abstinence of several days from washing or shaving completed the picture. (1976: 1211–1212)

Buckingham spent a total of nine days in the hospital. Despite the time frame being brief it was a very intense field setting. Buckingham stressed the emotional angst over his disguised role as: ‘he identified closely with these sick people and became weaker and more exhausted. He was anorexic and routinely refused food. He felt ill’ (1976: 1212).

Their results showed that, although staff do not neglect the needs of the dying and their families, the patient perspective still needs more centering. Healthcare staff, the dying and their families display coping and adjustment mechanisms, but this can result in inappropriate distancing by staff, which can result in feelings of isolation and abandonment by the dying. They argued that support for dying patients came from other patients, patients’ own families and adopted families, volunteers and student nurses, as much as from professional nursing staff or physicians.

Buckingham et al. humanely conclude:

> There is a need for comfort, both physical and mental, for others to see them as individuals rather than as hosts for their disease, and for someone to breach the loneliness and help them come to terms with the end. (1976: 1215)

As expected, initially, there was a strong belligerent reaction and response to this controversial study from several medical professionals, yet it would later be seen by many as a landmark study in medical anthropology and sociology. In discussing the history of hospice research, Kovacs stresses that the Buckingham et al. study ‘helped substantiate the need for hospice care’ (Kovacs, 1998: 296). So, the policy implications could be seen as part of the positive consequences of this study, despite its controversial and intrusive methodology.

Many would zealously view this study as a step too far in ethical terms because of the vulnerable groups involved and the clear topic sensitivity, yet it compassionately reveals issues about a subject still saturated in taboo. The interesting question here is do the means, albeit controversial, justify the ends? For me it does and ultimately it was worth doing the study. It would be very difficult to imagine such a covert study funded in the present climate.

Scheper-Hughes, a professor of medical anthropology, conducted a controversial study of organ trafficking, another taboo subject, which was to have a significant impact on policy and resulted in a considerable amount of media coverage. Her collaborative study directly influenced wider debates about medical human rights and played a part in setting up an innovative organ watch project. For her the topic is ‘as forbidden a topic as witchcraft, incest or paedophilia’ (Scheper-Hughes, 2004: 31).

She took on several important faked roles in what she describes as an ‘undercover ethnography’ to access and collect delicate information; she briefly posed as a kidney buyer in a suitcase market in Istanbul, and as a relative of a patient looking to purchase or broker a kidney in person and over telephones. Observationally, she sometimes visited transplant units and hospital wards unannounced, posing, if anyone inquired, as a confused friend or family member. The project was given exceptional dispensation and the project findings were made public, including handing over information to government officials, criminal investigators and agencies across the world. Such moves resulted in her collaboration with the South African Police in criminal prosecutions of organ traffickers.

Geoff Pearson has researched the sensitive issue of football hooliganism covertly for some time. Indeed, a journal article was provocatively titled ‘The Researcher as Hooligan: Where “Participant Observation” Means Breaking the Law’ (2009), which involved the researcher in pitch invasions and being regarded and treated as a fellow hooligan by the participants.

Part of the reason for adopting covert methodology, for Pearson, centred upon the problems of gathering accurate interview data from fans that either exaggerated or downplayed their involvement in violence, both of which are equally problematic. Pearson stresses: ‘If you are genuinely interested in “who did what to whom and when”, there is still no substitute for getting out there into the field and being a bit naughty’ (2011: 14). Pearson, like my own study of bouncers discussed below, walked a risky legal tightrope throughout his study.

MANAGING ETHICAL MOMENTS ON THE DOOR: THE CONFESSIONS OF A NOMADIC BOUNCER

A whole range of ethical moments (Guillemin & Gillam, 2004) was encountered in my own covert study of bouncers in the night-time economy of Manchester (UK) over a six-month period. I had sought and gained informal support and encouragement from various colleagues but not formal ethical approval from the Sociology Department at Manchester University, where I was employed as a temporary lecturer at the time. The research then was covert – to the institution. It must be stressed that this was at a time when the regimentation of ethics and the associated boards and committees was much lower key and less oppressive and bureaucratically stifling than the current state. If the project was starting now, I have serious doubts that it would be approved. I had not got formal funding for the project but opportunistically went ahead with the project, as it was a small-scale achievable one. I had trained in martial arts for several years and knew working doormen from martial arts clubs I had trained at. This was not gatekeeping, as I never revealed I was a sociologist at any stage of the fieldwork. My martial arts training and general body image and cultural capital aided my credible passing as a bouncer in the setting. I have previously characterized these particular field dynamics as ‘getting on the door and staying there’ (Calvey, 2000). The characterization as ‘moments’ is useful as they do occur in a certain time frame in the field but also, profoundly for me, various ethical dilemmas typically become a matter of situated judgements (Calvey, 2008) in the doing of fieldwork rather than abstracted matters of good and best practice. Namely, a sort of ‘here and now’ logic.

This characterization also importantly points toward the types of ethical self-regulation that covert researchers can apply rather than being necessarily unethical and belligerent. What I hope to debunk here is the entrenched heroic picture of the covert researcher, which is a heavily romanticized and sensationalist one.

Bouncers are a highly stigmatized occupational group who do the dirty work (Ashforth & Kreiner, 1999; Hughes, 1951) associated with the burgeoning night-time economy. They are strongly associated with entrenched and stereotypical assumptions about criminality, violence and hypermasculinity. For example, there are assumptions about the collusion between door people and drug dealers in the supply of recreational drugs in dance nightclubs, but this has been shown to involve only a small minority of door people with the vast majority tolerating and keeping their distance from such criminal activities (Sanders, 2005). There is a small but established literature on bouncers and bouncing (Calvey, 2000, 2008, 2013, 2017; Hobbs et al., 2000, 2002, 2003, 2005, 2007; Lister, 2002; Lister et al., 2000, 2001; Monaghan, 2002, 2003, 2004, 2006; O’Brien, 2009; O’Brien et al., 2008; Rigakos, 2002, 2008; Sanders, 2005; Silverstone, 2008; Winlow, 2001; Winlow et al., 2001).

I wanted to critically investigate this occupation by, simply put, becoming one of them. I wanted to build a faithful (Bittner, 1973) picture of their mundane realities. My bodily capital (Wacquant, 2000) and cultural capital (Bourdieu, 1984) assisted me in blending into the setting as just ‘one of the lads’ with no one questioning my suitability for the role. Connected to this, I had to deliberately and artfully fake a credible door career in the early days of the fieldwork. Building rapport with the door team typically centred on credibility and status issues such as who I knew in the door community, what doors I had worked on previously and for how long.

Despite the typical urban demonization surrounding bouncers, I wanted to avoid turning the bouncers into sociological exotica, namely a stereotyped caricature with which to apply standard academic moral correctives. Building on the cogent early metaphor of Gouldner (1968), I did not want to turn bouncers into another zookeeping study. I was applying a sort of 'criminological *verstehen*' (Ferrell, 1998), to trade on Weber's empathetic sociology of 'the inside'. My nomadic ethnography was clearly a type of edgework (Lyng, 2005), although in saying that I want to resist painting an overly glamorized picture of covert fieldwork, with somewhat inflated ideas of risk and danger. Lee-Treweek and Linkogle (2000) cogently put 'danger in the frame' by problematizing danger as having emotional, physical, ethical and professional dimensions. They also stress that the myriad risks and dangers are typically concealed or ignored. There is now more literature on researcher well-being and harm but it is still an under-explored field and a significant one for fieldworkers. Lee-Treweek and Linkogle usefully remind us of the limitations of our research roles, no matter how immersive, as they state that 'the researcher can never completely share the experience of participants' (2000: 199). Such a caveat is worth bearing in mind, particularly if our brief interactions do cause any harm, which is very difficult to estimate or indeed plan for. These are ethical checks and balances that must be individually and robustly assessed when we think about doing covert research. Clearly there is no blueprint but instructive scenarios we can collect and reflect on. Some ethnographic vignettes might help to articulate some 'ethical moments' in the field:

Witnessing Violence

Violence happened early in the fieldwork period when I witnessed the assault of a fellow bouncer, a young male who was local to Manchester. I was standing on the door with him at a busy city centre pub when the assault occurred. This bouncer became a victim of group violence when he was called over to chat with a group of bouncers from another door. They had collected on the opposite side of the road and next to a canal. From a distance, I could hear shouting and aggressive remonstrations and finger pointing, when he was punched in the face, his nose broken, and he was thrown into the canal directly behind them. Such 'turf fueds' are rare and not common. Such an episode is clearly a rich ethical moment to reflect on but this does not reflect the mundane and ordinary reality of bouncing. I approached the group and had deliberately got closer to them to act as a witness to try and stop them possibly further assaulting him on the ground. On approaching them I was aggressively told to 'piss off' and that it had 'nothing to fucking do with me'.

I switched my tape recorder off, although still taking mental notes, and put my jacket to one side in order to help get my fellow bouncer safely out of the canal. An alarmed member of the public phoned the police and they quickly attended to interview any witnesses and take statements. Before they arrived I asked him if he wanted to press charges and that I would act as a witness in that process. He defiantly replied 'no way' and informed me that I had 'seen now't'. He made it quite clear that I should not provide the police with any information, adding that, if I did, we would 'fall out'. When the police asked if I had witnessed anything, I said that the important issue was whether my colleague wanted to press charges or not, knowing that he clearly was not going to press charges. One police officer replied to me with a glare 'OK, smart Alec', as they left.

Being Recognized

On another occasion, I was hanging around a different door, which was a busy dance night club in the city centre of Manchester known to have a high use of recreational drug taking and criminal gang activity. I was not actually working the door but was chatting to the head doorman (in an attempt to get some work in order to shift from my current door) when a female student I had previously taught sociology to at University recognized me whilst she was queuing to get into the night club. After a period of exclamations from her, which nearly blew my cover, I had to assertively deny all knowledge of her, saying 'you must be pissed'. She was then refused entry into the club and wandered off with her friends in a confused state. After I finished my rapport-building with the doormen, I tried to find her and explain the situation but with no success. I felt guilty about this situation and the consequences of it for some time.

These two different ethnographic episodes raise interesting questions about 'taking a side' (Becker, 1967) in a situated sense and of the ethical self-regulation that researchers can practice. Within the constraints of an embedded covert insider role, I geared into the ethical milieu of the bouncers and suspended my own personal version of ethics. I had surrendered to the setting (Forrest, 1986) and managed guilt syndromes and deviant knowledge (Polsky, 1967) as best I could. Not every researcher would surrender or, if they did, not in the same way. These episodes display the problems with what some have traditionally described as 'going native' and what I term as the conditions of 'marginal membership' (Calvey, 2017). Covert fieldwork can then be a complex set of shifting circumstances that you cannot plan for in any exact way but is played out in the doing.

THE FUTURES OF COVERT RESEARCH: A REVIVAL OF SORTS

For me there has been a revival in covert research for a host of different reasons. Ultimately, this does not equate to a paradigm shift, as it is still likely to remain a niche field and take a minority stance in the social sciences. Having said that, there is an increased appetite for and interest in covert research in the social sciences. Two of the key reasons, amongst several, for this revival has been the rise of autoethnography and cyber-ethnography as increasingly popular ways to explore a range of phenomena in the social science community and I will briefly explore these in turn.

Autoethnography

The autoethnographic genre, although relatively new, has been well documented (Anderson, 2006; Denshire, 2014; Ellis, 1995, 1998, 1999, 2000, 2004, 2007, 2009; Ellis & Bochner, 2000, 2006; Ellis et al., 2011; Ellis & Rawicki, 2013; Jewkes, 2011; Hayano, 1979; Holman Jones et al., 2013; Humphreys, 2005; Reed-Danahay, 1997, 2001). Clearly such a genre is diverse and can, and no doubt will in some quarters, become a convenient gloss on a number of different approaches. Autoethnography is on the rise in the social science community and, as a consequence, introduces aspects of covert work into the methodological landscape.

A controversial figure within autoethnography is Carol Rambo whose work on childhood sexual abuse is graphic and frank (2005). Her multi-layered approach, which has emotion at its centre, is worth further investigation. The pioneering insider accounts of the British police by Holdaway (1993) and Young (1991) are notable autoethnographies, although they were not classified as such at the time of their publication. The same might be said of the somewhat neglected covert work of Dalton's (1959) study of administration and bureaucracy, a longitudinal epic spanning around ten years, which used an extended network of acquaintances.

The philosophic driver for much autoethnography is, then, the primacy of biography in the research and writing process. Typically, experiential accounts of a range of phenomena are offered. Clearly, the typical routes for informed consent are obviated, compounded by some of the retrospective elements of the genre. It is not to say that all autoethnographic research is covert but that the typical features of much of the genre have covert implications.

Despite the interesting dissident literature on autoethnography, which partly centres on the narcissistic tendencies of this turn (Atkinson, 1997, 2006; Buzard, 2003; Delamont, 2009; Forber-Pratt, 2015; Sparkes, 2002; Tolich, 2010), for me, autoethnography is a vibrant methodological work in progress (Calvey, 2017) that can form an invigorating part of the covert researcher's toolkit. Tolich (2010) raises a range of useful issues related to the complex problem of retrospective informed consent, which, for me, is a common position that many autoethnographers find themselves trading on for ethical legitimation. One of the key endemic problems here is that of implicating others into your account, which is compounded when done without their knowledge.

Cyber-Ethnography

In the cyberworld, which is very different from traditional fieldwork locations, a wide range of online locales, communities, populations and spaces are research 'fair game'. Various researchers have pointed to the significant growth and rapid developments in cyber-ethnography (Hallet & Barber, 2014; Hine, 2000, 2005; Kozinets, 2010). Murthy argues that 'the rise of digital ethnographies has the potential to open new directions in ethnography' (2008: 837) and these developments can no longer be sidestepped or ignored. Moreover, for Murthy many of the new directions are of a covert nature.

The issue of informed consent has not gone away in the cyberworld but has radically changed shape and is clearly more difficult to regulate in this diffuse and fragmented environment. Consequently, various researchers have become concerned with ethical protocols for Internet methodology (Denscombe, 2005; Flicker et al., 2004; Rosenberg, 2010) and in particular the ethical dilemmas, moves and tactics involved in 'lurking' online.

Carusi and Jirotka (2009) elegantly describe the field of Internet and online ethics as an 'ethical labyrinth'. It is not to say that virtual research is implicitly ethically belligerent or cavalier, as various researchers use online informed consent forms and are explicit about their research role. Cyber-ethnography is diverse, but the particular nature of this field opens up, wittingly and unwittingly, many more spaces and opportunities for covert research. What Robinson describes as 'the creation of cyber personas' (2007: 98), can involve blurred and deceptive narratives. Cyberspace then becomes a space to act out various real and imagined scenarios in an era of 'transformed digital self-representation' (Yee et al., 2009: 30).

The typical researcher fudge here then, which legitimates types of lurking, takes several forms. First, the research domain is a public one; hence the researcher lurking is not invasive or intrusive, although some might be so accepting of such a rationale. As long as the anonymity of participants is sustained throughout the research project, which for many is a standard part of their research practice, cyber life becomes fairer research game. Second, it is regularly stated that little or no harm was done to the participants due to the distance, remoteness and absence of intrusion between the researchers and researched. The end result of this is that a range of sensitive topics like extreme dieting, cancer support, sexual deviance, to name a few, can be explored with the standard ethical protocol of informed consent being obviated. If such topics were to be explored covertly by more traditional participation observation methods, it would likely be a much more restricted and bounded investigation, if indeed allowed at all.

CONCLUSIONS

For me, although we must continually be both sensible and sensitive in the use of covert research, the social science community is missing a trick. Covert research, although clearly not to everyone's analytic taste, should become a more standard part of the sociological imagination and analytic toolkit for both students and professional researchers and academics. We have different attitudes and expectations of research into the public and private realms, with much more protection of the latter. As Iphofen (personal communication, 2016) points out covert research could be one way to move a private trouble into the public sphere. The decision to undertake covert research is not to be taken frivolously, but neither should it be treated with over-apprehension and hypermorality. Like ethical decision making in real world settings, it is a complex and shifting business. Some covert research can occur by drift rather than by deliberate design and is therefore difficult to plan for.

There is a limited dedicated literature on covert research (Bulmer, 1982; Calvey, 2000, 2008, 2013, 2017; Denzin, 1968; Goode, 1996; Herrera, 1993, 1997, 1999; Hilbert, 1980; Homan, 1980; Lugosi, 2006; Miller, 1995; Mitchell, 1993; Spicker, 2011). For me, much more rehabilitation work needs to be done in this area to uncover instructive covert gems and for researchers to engage with methodological debates in the social science community rather than hide away in the intellectual closet as a horror and pariah.

I am not suggesting that covert research is a new panacea as clearly its use has costs and implications, but I am appealing for a fairer reading and more democratic understanding of this still controversial tradition. Much of the fear around risk and harm with covert work is, for me, inflated and exaggerated. The paradox of fear and fascination surrounding it has not gone away and no doubt shall persist.

Notes

1 If we examine the ethical codes of various professional associations and bodies in the social science community they take a similar line on covert research. For more information consult: Association of Social Anthropologists of the UK and the Commonwealth (ASA, www.theasa.org) *Ethical Guidelines for Good Research Practice* (1999); *Statement of Ethical Practice for the British Sociological Association* (2002, www.britsoc.co.uk); *Social Research Association Ethical Guidelines* (2003, www.the-sra.org.uk); *Social Policy Association Guidelines on Research Ethics* (2009, www.social-policy.org.uk). This is clearly not a definitive list but on examination you can discern the standard received view on covert research.

2 Donal MacIntyre is a popular Irish investigative journalist who came to fame with the televised *MacIntyre Investigates*, screened by the BBC. Other investigative programmes by him, like *World's Toughest Towns* followed it. He has also directed a controversial and award winning film titled *A Very British Gangster* about the Noonans, an infamous criminal family based in Manchester. He is currently fronting *Unsolved*, a televised criminal documentary series on CBS Reality.

REFERENCES

Anderson, L. (2006) 'Analytic autoethnography', *Journal of Contemporary Ethnography*, 35(4): 373–395.

Arendt, H. (1963) *Eichmann in Jerusalem: A Report on the Banality of Evil*. New York: Penguin.

Ashforth, B. E. and Kreiner, G. E. (1999) 'How can you do it?': Dirty work and the challenge of constructing a positive identity', *The Academy of Management Review*, 24(3): 413–434.

Atkinson, P. A. (1997) 'Narrative turn or blind alley?', *Qualitative Health Research*, 7(3): 325–344.

Atkinson, P. A. (2006) 'Rescuing autoethnography', *Journal of Contemporary Ethnography*, 35(4): 400–404.

Becker, H. S. (1967) 'Whose side are we on?', *Social Problems*, 14(3): 239–247.

Bittner, E. (1973) 'Objectivity and realism in sociology', in G. Psathas (ed.), *Phenomenological Sociology*. New York: Wiley. pp. 109–125.

Blass, T. (2004) *The Man who Shocked the World: The Life and Legacy of Stanley Milgram.* London: Basic Books.

Bourdieu, P. (1984) *Distinction: A Social Critique of the Judgement of Taste*. London: Routledge.

Brannigan, A. (2004) *The Rise and Fall of Social Psychology: The Use and Misuse of the*

Experimental Method. New York: Aldine de Gruyter.

Brannigan, A. (2009) 'The defense of situationalism in the age of Abu Ghraib', *Theory & Psychology*, 19(5): 698–704.

Buckingham, R. W., Lack, S. A., Mount, B. M., MacLean, L. D., and Collins, J. T. (1976) 'Living with the dying: Use of the technique of participant observation', *Canadian Medical Association Journal*, 115(12) (18th December): 1211–1215.

Bulmer, M. (ed.) (1982) *Social Research Ethics: An Examination of the Merits of Covert Participant Observation*. London: Macmillan Press.

Buzard, J. (2003) 'On auto-ethnographic authority', *The Yale Journal of Criticism*, 16(1): 61–91.

Calvey, D. (2000) 'Getting on the door and staying there: A covert participant observational study of bouncers', in G. Lee-Treweek and S. Linkogle (eds.), *Danger in the Field: Risk and Ethics in Social Research*. London: Routledge. pp. 43–60.

Calvey, D. (2008) 'The art and politics of covert research: Doing 'situated ethics' in the field', *Sociology*, 42(5): 905–918.

Calvey, D. (2013) 'Covert ethnography in criminology: A submerged yet creative tradition in criminology', *Current Issues in Criminal Justice*, 25(1): 541–550.

Calvey, D. (2017) *Covert Research: The Art, Ethics and Politics of Undercover Fieldwork*. London: Sage.

Carusi, A. and Jirotka, M. (2009) 'From data archive to ethical labyrinth', *Qualitative Research*, 9(3): 285–298.

Corrigan, O. (2003) 'Empty ethics: The problem with informed consent', *Sociology of Health & Illness*, 25(7): 768–792.

Dalton, M. (1959) *Men Who Manage: Fusions of Feeling and Theory in Administration.* New York: John Wiley.

Delamont, S. (2009) 'The only honest thing: Autoethnography, reflexivity and small crises in fieldwork', *Ethnography and Education*, 4(1): 51–63.

Denscombe, M. (2005) 'Research ethics and the governance of research projects: the Potential of internet home pages', *Sociological Research Online*, 10(3).

Denshire, S. (2014) 'On auto-ethnography', *Current Sociology Review*, 62(6): 831–850.

Denzin, N. K. (1968) 'On the ethics of disguised observation', *Social Problems*, 15(4): 502–504.

Dingwall, R. (2008) 'The ethical case against ethical regulation in humanities and social science research', *Twenty-First Century Society*, 3(1): 1–12.

Ellis, C. (1995) *Final Negotiations: A Story of Love, Loss, and Chronic Illness*. Philadelphia, PA: Temple Press.

Ellis, C. (1998) 'Exploring loss through auto ethnographic inquiry: Autoethnographic stories, co-constructed narratives, and interpretive interviews', in J. H. Harvey (ed.) *Perspectives on Loss: A Sourcebook.* Philadelphia, PA: Taylor and Francis. pp. 49–62.

Ellis, C. (1999) 'Heartfelt autoethnography', *Qualitative Health Research*, 9(5): 669–683.

Ellis, C. (2000) 'Creating criteria: An ethnographic story', *Qualitative Inquiry*, 6(2): 273–277.

Ellis, C. (2004) *The Ethnographic I: A Methodological Novel about Autoethnography.* Walnut Creek, CA: AltaMira Press.

Ellis, C. (2007) 'Telling secrets, revealing lives: Relational ethics in research with intimate others', *Qualitative Inquiry*, 13(1): 3–29.

Ellis, C. (2009) *Revision: Autoethnographic Reflections on Life and Work*. Walnut Creek, CA: Left Coast Press.

Ellis, C., Adams, T. E. and Bochner, A. P. (2011) 'Autoethnography: An overview', *Forum: Qualitative Social Research*, 12(1), Article 10.

Ellis, C. and Bochner, A. (2000) 'Autoethnography, personal narrative, reflexivity: Researcher as subject', in N. K. Denzin and Y. S. Lincoln (eds.), *Handbook of Qualitative Research*. 2nd edn. Thousand Oaks, CA: Sage. pp. 733–768.

Ellis, C. S. and Bochner, A. P. (2006) 'Analyzing analytic autoethnography: An autopsy', *Journal of Contemporary Ethnography*, 35(4): 429–449.

Ellis, C. and Rawicki, J. (2013) 'Collaborative witnessing of survival during the holocaust: An examplar of relational autoethnography', *Qualitative Inquiry*, 19(5): 366–380.

Ferrell, J. (1998) 'Criminological *verstehen*: Inside the immediacy of crime', in J. Ferrell and M. S. Hamm (eds.), *Ethnography at the Edge: Crime, Deviance, and Field Research*. Boston, MA: Northeastern University Press. pp. 20–43.

Fistein, E. and Quilligan, M. (2011) 'In the lion's den? Experiences of interaction with research ethics committees', *Journal of Medical Ethics*, 38(4): 224–227.

Flicker, S., Haans, D., and Skinner, H. (2004) 'Ethical dilemmas in research on Internet communities', *Qualitative Health Research*, 14(1): 124–134.

Forber-Pratt, A. J. (2015) '"You're going to do what?" Challenges of autoethnography in the academy', *Qualitative Inquiry*, 21(9): 821–835.

Forrest, B. (1986) 'Apprentice-participation: Methodology and the study of subjective reality', *Journal of Contemporary Ethnography*, 14(4): 431–453.

Galliher, J. F., Brekhus, W. H., and Keys, D. P. (2004) *Laud Humphreys: Prophet of Homosexuality and Sociology*. Madison, WI: University of Wisconsin Press.

Goffman, E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* New York: Doubleday.

Goode, E. (1996) 'The ethics of deception in social research: A case study', *Qualitative Sociology*, 19(1): 11–33.

Gouldner, A. W. (1968) 'The sociologist as partisan: Sociology and the welfare state', *American Sociologist*, 3(2): 103–116.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity and "ethically important moments in research"', *Qualitative Inquiry*, 10(2): 261–280.

Haggerty, K. D. (2004) 'Ethics creep: Governing social science research in the name of ethics', *Qualitative Sociology*, 27(4): 391–414.

Hallett, R. E. and Barber, K. (2014) 'Ethnographic research in a cyber era', *Journal of Contemporary Ethnography*, 43(3): 306–330.

Hammersley, M. (2010) 'Creeping ethical regulation and the strangling of research', *Sociological Research Online*, 15(4): 16.

Hammersley, M. and Traianou, A. (2012) *Ethics in Qualitative Research: Controversies and Contexts.* London: Sage.

Haney, C., Banks, C., and Zimbardo, P. (1973) 'Interpersonal dynamics in a simulated prison', *International Journal of Criminology and Penology*, 1: 69–97.

Hayano, D. M. (1979) 'Auto-ethnography: Paradigms, problems and prospects', *Human Organization,* 38(1): 99–104.

Hedgecoe, A. (2016) 'Reputational risk, academic freedom and research ethics review', *Sociology*, 50(3): 486–501.

Herrera, C. D. (1993) 'A clash of methodology and ethics in "undercover" social science', *Philosophy of the Social Sciences*, 33(3): 351–362.

Herrera, C. D. (1997) 'A historical interpretation of deceptive experiments in American psychology', *History of the Human Sciences*, 10(1): 23–36.

Herrera, C. D. (1999) 'Two arguments for "covert methods" in social research', *The British Journal of Sociology*, 50(2): 331–343.

Hilbert, R. A. (1980) 'Covert participant observation: On its nature and practice', *Urban Life*, 9(1): 51–78.

Hine, C. (2000) *Virtual Ethnography*. London: Sage.

Hine, C. (ed.) (2005) *Virtual Methods: Issues in Social Research on the Internet*. Oxford: Berg.

Hobbs, D., Hadfield, P., Lister, S., and Winlow, S. (2002) 'Door lore: The art and economics of intimidation', *The British Journal of Criminology*, 42(2): 352–370.

Hobbs, D., Hadfield, P., Lister, S., and Winlow, S. (2003) *Bouncers: Violence and Governance in the Night-Time Economy*. Oxford: Oxford University Press.

Hobbs, D., Lister, S., Hadfield, P., Winlow, S., and Hall, S. (2000) 'Receiving shadows: Governance and liminality in the night-time economy', *The British Journal of Sociology,* 51(4): 701–717.

Hobbs, D., O'Brien, K., and Westmarland, L. (2007) 'Connecting the gendered door: Women, violence and door work', *The British Journal of Sociology*, 58(1): 21–38.

Hobbs, D., Winlow, S., Hadfield, P., and Lister, S. (2005) 'Violent hypocrisy: Governance and the night-time economy', *European Journal of Criminology*, 2(2): 161–183.

Holdaway, S. (1982) 'An inside job': a case study of covert research on the police', in M. Bulmer (ed.), *Social Research Ethics: An Examination of the Merits of Covert Participant Observation*. London: Macmillan Press. pp. 59–79.

Holman Jones, S., Adams, T. E., and Ellis, C. (2013) *Handbook of Autoethnography.* Walnut Creek, CA: Left Coast Press.

Homan, R. (1980) 'The ethics of covert methods', *The British Journal of Sociology*, 31(1): 46–59.

Hughes, E. C. (1951) 'Work and the self', in J. H. Rohrer and M. Sherif (eds.), *Social Psychology at the Crossroads*. New York: Harper & Brothers. pp. 313–323.

Humphreys, Laud. (1970) *Tearoom Trade: Impersonal Sex in Public Places*. Chicago: Aldine Publishing Company.

Humphreys, Laud. (1975) *Tearoom Trade: Impersonal Sex in Public Places*. Chicago: Aldine Publishing Company. (Enlarged edition).

Humphreys, M. (2005) 'Getting personal: Reflexivity and autoethnographic vignettes', *Qualitative Inquiry*, 11(6): 840–860.

Iphofen, R. (2011a) 'Ethical decision making in qualitative research', *Qualitative Sociology*, 11(4): 443–446.

Iphofen, R. (2011b) *Ethical Decision Making in Social Research*. London: Palgrave Macmillan.

Jewkes, Y. (2011) 'Autoethnography and emotion as intellectual resources: Doing prison research differently', *Qualitative Inquiry*, 18(1): 63–75.

Katz, J. (2006) 'Ethical escape routes for underground ethnographers', *American Ethnologist*, 33(4): 499–506.

Kovacs, P. J. (1998) 'Hospice research: Challenges, opportunities and rewards', *American Journal of Hospice and Palliative Medicine*, 15(5): 295–300.

Kozinets, R. V. (2010) *Netnography. Doing Ethnographic Research Online.* Thousand Oaks, CA: Sage.

Lawton, J. (2001) 'Gaining and maintaining consent: Ethical concerns raised in a study of dying patients', *Qualitative Health Research*, 11(5): 693–705.

Lee-Treweek, G. and Linkogle, S. (2000) *Danger in the Field: Risk and Ethics in Social Research*. London: Routledge.

Librett, M. and Perrone, D. (2010) 'Apples and oranges: ethnography and the IRB', *Qualitative Research*, 10(6): 729–747.

Lister, S. (2002) 'Violence as a commercial resource: Situating bouncers and the use of force in context', *The Journal of Forensic Psychiatry*, 13(2): 245–249.

Lister, S., Hadfield, P., Hobbs, D., and Winlow, S. (2001) 'Accounting for bouncers: Occupational licensing as a mechanism for regulation', *Criminology & Criminal Justice*, 1(4): 363–384.

Lister, S., Hobbs, D., Hall, S., and Winlow, S. (2000) 'Violence in the night-time economy; bouncers: The reporting, recording and prosecution of assault', *Policing and Society*, 10(4): 383–402.

Lugosi, P. (2006) 'Between overt and covert research: Concealment and disclosure in an ethnographic study of commercial hospitality', *Qualitative Inquiry*, 12(3): 541–561.

Lugosi, P. (2008) 'Covert research', in L. M. Given (ed.), *The SAGE Encyclopedia of Qualitative Research Methods*, Volume 2. Thousand Oaks, CA: Sage, pp. 133–136.

Lyng, S. (ed.) (2005) *Edgework: The Sociology of Risk-Taking.* New York, CA: Sage.

Milgram, S. (1974) *Obedience to Authority: An Experimental View.* London: Tavistock Publications.

Miller, M. (1995) 'Covert participant observation: Reconsidering the least used method', *Journal of Contemporary Criminal Justice*, 11(2): 97–105.

Mitchell, R. G. Jr. (1993) *Secrecy and Fieldwork.* London: Sage.

Monaghan, L. F. (2002) 'Regulating "unruly" bodies: Work tasks, conflict and violence in Britain's night-time economy', *The British Journal of Sociology*, 53(3): 403–429.

Monaghan, L. F. (2003) 'Danger on the doors: Bodily risk in a demonised occupation', *Health, Risk & Society*, 5(1): 11–31.

Monaghan, L. F. (2004) 'Doorwork and legal risk: Observations from an embodied ethnography', *Social & Legal Studies*, 13(4): 453–480.

Monaghan, L. F. (2006) 'Fieldwork and the body: Reflections on an embodied ethnography', in D. Hobbs and R. Wright (eds.), *The SAGE Handbook of Fieldwork.* London: Sage. pp. 225–241.

Murphy, E. and Dingwall, R. (2007) 'Informed consent, anticipatory regulation and ethnographic practice', *Social Science & Medicine*, 65(11): 2223–2234.

Murthy, D. (2008) 'Digital ethnography: An examination of the use of new technologies for social research', *Sociology*, 42(5): 837–855.

O'Brien, K. (2009) 'Inside "doorwork": Gendering the security gaze', in R. Ryan-Flood and R. Gill (eds.), *Silence and Secrecy in the Research Process: Feminist Reflections.* London: Routledge. pp. 117–132.

O'Brien, K., Hobbs, D., and Westmarland, L. (2008) 'Negotiating violence and gender: Security and the night time economy in the UK', in S. Gendrot and P. Spierenburg (eds.), *Violence in Europe: Historical and Contemporary Perspectives*. New York: Springer. pp. 161–173.

Pearson, G. (2009) 'The researcher as hooligan: Where "participant" observation means breaking the law', *International Journal of Social Research Methodology*, 12(3): 243–255.

Pearson, G. (2011) 'A commentary on "Little Hooliganz: The Inside Story of Glamorous Lads, Football Hooligans and Post-Subculturalism"', *Entertainment and Sports Law Journal*, 9(1): 1–14.

Perry, G. (2013) *Behind the Shock Machine: Untold Story of the Notorious Milgram Psychology Experiments*. New York: The New Press.

Polsky, N. (1967) *Hustlers, Beats, and Others.* Chicago: Aldine.

Rambo, C. (2005) 'Impressions of grandmother: An autoethnographic portrait', *Journal of Contemporary Ethnography*, 34(5): 560–585.

Reed, K. (2007) 'Bureaucracy and beyond: The impact of ethics and governance procedures on health research in the social sciences', *Sociological Research Online*, 12(5) 18.

Reed-Danahay, D. E. (ed.) (1997) *Auto/Ethnography: Rewriting the Self and the Social*. Oxford: Berg.

Reed-Danahay, D. (2001) 'Autobiography, intimacy and ethnography', in P. Atkinson, A. Coffey, S. Delamont, J. Lofland, and L. Lofland (eds.), *The Handbook of Ethnography.* London: Sage. pp. 407–425.

Rigakos, G. S. (2002) *The New Parapolice: Risk Markets and Commodified Social Control.* Buffalo, Canada: University of Toronto Press.

Rigakos, G. S. (2008) *Nightclub: Bouncers, Risk, and the Spectacle of Consumption.* Montreal, Canada: McGill-Queen's University Press.

Robinson, L. (2007) 'The cyber self: the self-ing project goes online, symbolic interaction in the digital age', *New Media & Society*, 9(1): 93–110.

Rosenberg, A. (2010) 'Virtual world research ethics and the private/public distinction', *International Journal of Internet Research Ethics*, 3(1): 23–37.

Sanders, B. (2005) 'In the club: Ecstasy use and supply in a London nightclub', *Sociology*, 39(2): 241–258.

Scheper-Hughes, N. (2004) 'Parts unknown: Undercover ethnography of the organs-trafficking underworld', *Ethnography*, 5(1): 29–73.

Sedgwick, P. (1974) 'Goffman's anti-psychiatry', *Salmagundi*, 26(Spring): 26–51.

Silverstone, D. (2006) 'Pub space, rave space, urban space: Three different night-time economies', in B. Sanders (ed.), *Drugs, Clubs and Young People*. Ashgate: Hampshire. pp. 141–153.

Sparkes, A. C. (2002) 'Autoethnography: Self-indulgence or something more?', in A. P. Bocher and C. Ellis (eds.), *Ethnographically Speaking: Autoethnography, Literature and Aesthetic*. Walnut Creek, CA: AltaMira Press. pp. 209–232.

Spicker, P. (2011) 'Ethical covert research', *Sociology*, 45(1): 118–133.

Tewksbury, R. (2010) 'Men and erotic oases', *Sociology Compass*, 4(12): 1011–1019.

Tolich, M. (2010) 'A critique of current practice: Ten foundational guidelines for autoethnogaphers', *Qualitative Health Research*, 20(12): 1599–1610.

Tolich, M. (2014) 'What can Milgram and Zimbardo teach ethics committees and qualitative researchers about minimizing harm?'. *Research Ethics*: 1747016114523771.

van den Hoonaard, W. C. (2011) *The Seduction of Ethics: Transforming the Social Sciences.* Toronto, ON: University of Toronto Press.

Wacquant, L. (2000) *Body and Soul: Notebooks of an Apprentice Boxer*. New York: Oxford University Press.

Whitaker, E. (2005) 'Adjudicating entitlements: The emerging discourses of research ethics boards', *Health*, 9(4): 513–535.

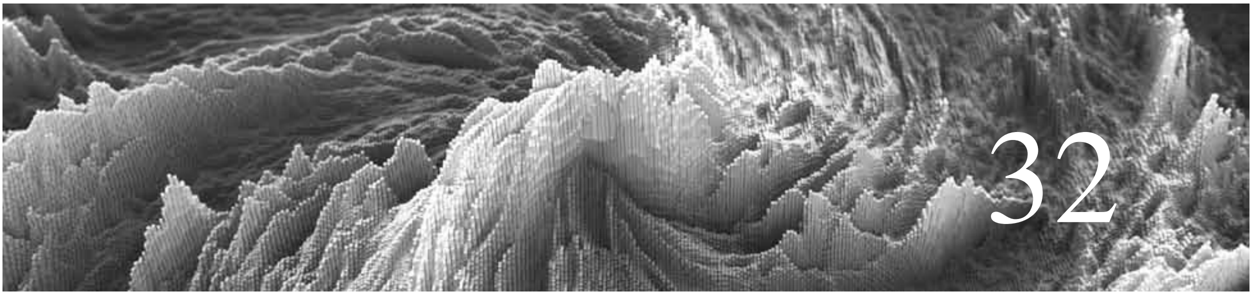
Winlow, S. (2001) *Badfellas: Crime, Tradition and New Masculinities*. Oxford: Berg.

Winlow, S., Hobbs, D., Lister, S. C., and Hadfield, P. (2001) 'Get ready to duck: Bouncers and the realities of ethnographic research on violent groups', *The British Journal of Criminology,* 41(3): 536–548.

Yee, N., Bailenson, J. N., and Ducheneaut, N. (2009) 'The Proteus effect: implications of transformed digital self-representation on online and offline behaviour', *Communication Research*, 36(2): 285–312.

Young, M. (1991) *An Inside Job: Policing and Police Culture in Britain.* Oxford: Clarendon Press.

Zimbardo, P. (1973) 'On the ethics of intervention in human psychological research: With special reference to the Stanford prison experiment', *Cognition*, 2(2): 243–256.



32

Ethical Issues in Grounded Theory

Karin Olson

INTRODUCTION

Although many qualitative designs have evolved over time, these changes are sometimes hard to trace. The developments in grounded theory are easier to see, however, and can be followed by examining the work of Glaser and Strauss, Strauss and Corbin, Charmaz, and Clarke. In this chapter I begin by briefly describing the philosophical roots of grounded theory, and the four approaches developed by Glaser and Strauss, Strauss and Corbin, Charmaz, and Clarke, and then use the distinction between external and internal contexts of research, as developed by van den Hoonaard (2002), to identify ethical issues in grounded theory. Ethical issues arising from external context are related to the core ethics principles of autonomy, potential risks and benefits, and justice. Issues arising from the internal context are related to the study design itself, including the nature of the research question, sampling, and epistemology, but I will link them to the core ethics principles. A fundamental ethical issue raised by grounded theory is that although there is a general-purpose statement for any given study, it is not possible to know ahead of time what direction the study will take, and so it is not possible to ensure that participants are fully informed about the nature of the study when the consent is first signed.

THE ROOTS OF GROUNDED THEORY

Symbolic interactionism and pragmatism are generally understood as significant philosophic underpinnings of grounded theory; Glaser or Strauss, developers of grounded theory, discussed neither extensively (Bryant, 2009). Most of the writing linking symbolic interactionism, pragmatism and grounded theory has been written instead by scholars interested in further developing grounded theory and who recognized some key features of symbolic interactionism and pragmatism to be found in grounded theory.

The symbolic interactionist author most closely associated with grounded theory is Blumer (1969). His classic text on symbolic interactionism opens with a discussion of its three core premises. The first is that any given action directed toward something is based on the meaning that it has for the actor. The second premise is that this meaning arises out of interactions the actor has with other people; meaning is not inherent in an object and therefore not an objective 'given'. This is important because it challenged prevailing positivistic notions in behavioral science about deterministic and observable causes of behavior, which is considered a type of action. The second premise implies therefore that an action is not mechanistically caused by some set of factors and therefore predictable. Rather, it arises dynamically out of the meanings that actors construct for themselves based on their interactions with others. The third premise is that people modify these meanings through an active, interpretive process and transform these meanings in the light of the situation in which they find themselves. This interpretive process, known within grounded theory as the basic social process or basic psychological process, will be discussed in further detail later in this chapter.

Pragmatism in grounded theory is generally linked to the work of Dewey (1917) and Mead (1934). Dewey and Mead both stressed the importance of reflective thought in the development of knowledge. They took the view that people are not born knowing things, and nor do they acquire knowledge simply by being in a nurturing environment. Rather, knowledge and hence meaning, comes about by reflecting on their own experience. Pragmatists such as Dewey and Mead rejected the idea that knowledge existed independently of peoples' activity and was simply awaiting discovery, offering, instead, the idea of knowledge as provisional, always evolving, and thus neither certain nor static. Pragmatists stressed the evaluation of knowledge by those who generated it, testing its utility within the empirical world. Methodology itself therefore had to be more than a set of steps to be followed. It encompassed the whole process of inquiry, from the identification of the research question, through to the interpretation of the results and their integration into existing knowledge. Both Dewey and Blumer argued that knowledge should be judged by how useful it was. Rorty (1980) extended their work by arguing against the idea that knowledge should also be judged by how well it approximated reality, thus linking usefulness to contexts of use.

APPROACHES TO GROUNDED THEORY

The core ideas of symbolic interactionism and pragmatism run through all four of the main approaches to grounded theory. All four approaches focus on ways to generate knowledge about the interpretive processes, and to test these processes in the empirical world. All four approaches share a common ontological position, rooted in symbolic interactionism and pragmatism concerning the nature of truth – that the empirical world exists but that knowledge of it may vary. This position gives rise to the tenet that runs across all qualitative designs regarding the variability of knowledge. Two individuals may be present at the same event but experience it differently, and hence generate different knowledge about it. The main difference in the four approaches to grounded theory is rooted in the epistemological positions proposed by their developers. In the next section I will discuss these four approaches, and highlight the differences in their epistemological consequences.

Classic Grounded Theory

Barney Glaser and Anselm Strauss developed the fundamentals of classic grounded theory (1967) with the goal of discovering theory from data, using a strategy called constant comparison. Students beginning their first grounded theory study are often initially perplexed by the lack of information in early writings about grounded theory regarding how to do it, particularly if their initial research training has centered upon quantitative designs. Glaser and Strauss did not articulate a step-by-step guide for conducting a study with a grounded theory design, which is not surprising given the emphasis on variability emphasized in its philosophic roots described earlier. Pragmatism stressed the importance of scientific inquiry of the empirical world, and so focusing on the whole process of inquiry, from research question through to findings integration. This broad view encouraged the exposition of their early work in books such as *The Awareness of Dying* (Glaser & Strauss, 1965), *Anguish* (Strauss & Glaser, 1970) and *Chronic Illness and the Quality of Life* (Glaser & Strauss, 1975), rather than in articles.

In general terms, a grounded theory study begins with the identification of a purposive sample, the collection of data via unstructured interviews and sometimes observations. Glaser (1978) termed the researcher's ability to attend to data and to see 'what is actually happening', theoretical sensitivity. He stated that theoretical sensitivity required the researcher to enter a study without prior hypotheses so that their interpretation of data was not 'filtered through and squared with pre-existing hypotheses and biases' (Glaser, 1978: 3). He added that while the researcher, of course, brings general knowledge related to the study, perhaps based on previous work, which will increase theoretical sensitivity.

The goals of data collection are to hear the participant's own story, not simply as answers to the researcher's questions. Soon after the work on constructivist grounded theory was published by Charmaz in 2006, I had the opportunity to discuss Glaser's ideas about epistemology and grounded theory directly with him, and to ask what he thought about the idea of the constructivist stance proposed by Charmaz. His response was that because the goal in grounded theory was to hear the participant's story, the impact of the investigator would be negligible. When I questioned whether he thought an investigator's own experience would influence what he or she 'heard', he pointed out that this was exactly why we worked from transcripts – the participant's own words. The point here was to learn about how the participant viewed his or her experience and created meaning from them. He added that two researchers who had the patience to hear the participant's whole account would essentially obtain the same result. Two elements are critical here: the participant's ability to articulate their experience, and enough time within the context of the research study to hear the participant's whole account. The importance of time needs to be clear in the consenting process so that participants are not surprised when the researcher begins the interview by saying, 'Please tell me about xx' or 'Please describe a time when …', rather than a question the researcher would like the participant to answer. The goal of the interviewer should be on getting detailed descriptions of the participant's experience, rather than on their analysis of it. A second, and maybe even a third interview will often be needed to obtain a complete account. This is why interviews should be transcribed and analyzed, as they are collected. The analysis helps the researcher see areas of the account that require further elaboration, and so helps to frame the direction of subsequent interviews. If the participants are purposively selected and the accounts of experience are complete, the required sample size is likely to be smaller than if a convenience or random sample is used and only single interviews not interlinked by a theory-testing logic, are collected.

Analysis in grounded theory begins with open coding. Open coding involves line-by-line analysis of data, to identify ideas that link meaning and action. Common ideas are grouped together to form categories and, as the study progresses, it becomes clear that some of the categories are more central to the participants' experiences than others. These categories generally include data from all interviews and become the prime focus of data collection for the remainder of the study. As the researcher collects more data, the characteristics of the categories become clearer, possible links between categories can be proposed, key concepts within the categories can be identified, and relationships between concepts can be proposed. At this point, the researcher switches to theoretical sampling, a sampling approach in which additional participants are recruited to test and elaborate the proposed relationships. It is at this stage that the researcher actively seeks negative cases to further test the proposed links. Once the process has been verified using data from theoretical sampling, the study is finished. The result is the basic social or basic psychological process. This process provides a theoretical explanation of how participants create meaning through interactions about the topic under investigation – it is the interpretive part of the third premise of symbolic interactionism described by Blumer (1969) above.

Straussian Grounded Theory

Anselm Strauss published his first text on grounded theory in 1987, which was followed shortly by a book written with Corbin in 1990 (Strauss & Corbin, 1990), with a second (Strauss & Corbin, 1998) edition and a third (Corbin & Strauss, 2008) edition. The epistemological positions of Glaser, Strauss, and Corbin were very similar in the early days of grounded theory, and were rooted in the writing of Blumer (1969) on social interactionism, but with some subtle differences also apparent. Strauss and Corbin proposed that, ‘by the end of the inquiry, the researcher is shaped by the data, just as the data are shaped by the researcher’ (1990: 42). They went on, however, to discuss the importance of remaining both objective and sensitive to the data, noting that, ‘objectivity is necessary to arrive at an impartial and accurate interpretation of events’ (1990: 42), followed by an entire section on: ‘Maintaining an Objective Stance’. When I had an opportunity to discuss with Corbin, Strauss and Corbin’s epistemological position work, shortly after Charmaz’s work on constructivist grounded theory was published, Corbin defined her epistemological position now as much closer to that of Charmaz. This shift is reflected in her more recent writing (Corbin, 2009).

The goal of Strauss and Corbin in 1990 was to provide a more detailed description of how to analyze data in studies that used a grounded theory design. Although each edition of their work became less and less prescriptive, Glaser argued that they had essentially developed a new design because their analytic approach ran counter to the emergent approach that was one of the hallmarks of grounded theory (Glaser, 1992).

Constructivist Grounded Theory

Charmaz’s work on constructivist grounded theory provided an approach to grounded theory with explicitly different epistemological roots than those held by Glaser and Strauss. Charmaz (2000) viewed her work as a revision to classical grounded theory. Its unique new features were an assertion that knowledge was influenced by multiple standpoints of both the participants and the researcher, and by the researcher’s reflexive approach (Charmaz, 2006, 2009). In her approach, reflexivity was seen as a strategy for helping the researcher be transparent about his or her own perspectives, so that their influences on the contexts studied, questions asked, the voices included, and the interpretations provided could be seen by the reader. Reflexivity and other strategies that uncovered the researcher’s perspectives were critical in this approach because the researcher was the one who heard and who (re)presented the participant’s story. The main point here is that contrary to the previous approaches to grounded theory, Charmaz argued that the data do not ‘speak’ for themselves. Rather, consistent with the writing of Blumer (1969) noted above, the meaning of the data came from interactions among all those, including the researcher, who were part of the research process. Part of the researcher's responsibility was to track these interactions.

Situational Analysis

Adele Clarke developed situational analysis in an effort to (re-)ground grounded theory and to disentangle it from the remaining vestiges of positivism (2005; Clarke et al., 2015). Rather than construct a basic social process to explain how meaning arises from interactions, Clarke sought to derive this meaning by mapping out three groups of influences, which she called situational maps, social worlds/arenas maps, and positional maps. She noted that the idea for these maps came from earlier conversations with Strauss (Clarke, 2009). As a result, the epistemological position of this approach moved beyond constructivism to make the influences of the three maps on the research participant and the researcher explicit (Clarke et al., 2015).

Summary

My goal in the first part of this chapter was to briefly describe four main approaches to grounded theory. All four groups of developers explicitly linked their work to philosophical worldviews based in symbolic interactionism and pragmatism, and held similar ontological positions about the nature of truth. The features that distinguished their approaches were rooted in their epistemological positions. These four approaches to grounded theory were deliberately elaborated by their developers to explore different ways to inductively build theory about how meaning gets attached to social interactions. Each approach provides a slightly different answer to a given research question. The point here is not to argue about which approach is 'right', but rather to set the stage for a discussion of key ethical issues that flow from these approaches.

ETHICAL ISSUES IN GROUNDED THEORY

I searched MEDLINE and CINAHL between 2010 and 2016 and found many examples of ethical issues identified within the results of grounded theory studies, but no examples of ethical issues related to methodological features of grounded theory. Hence, to identify both types of issues in this section I have adopted a broad approach and will discuss ethical issues related to both external and internal contexts of research, as developed by van den Hoonaard (2002). Ethical issues arising from the external context of a study are related to the core ethics principles of autonomy, potential risks and benefits, and justice, while issues arising from the internal context are related to the study design itself, including the nature of the research question, sampling, and epistemology.

Ethical Issues Arising from the External Context of Research

The external context of research is described by van den Hoonaard (2002) as the rules that surround all research. These rules address such topics as processes for ensuring anonymity and confidentiality, for obtaining consent, and for preventing harm.

Autonomy

Autonomy refers to the right of the research participant to choose whether to participate in research, based on the information provided. Because the goals and research questions for studies that use a grounded theory design evolve over the course of the study, it is difficult to provide participants with a comprehensive description of what involvement in the study will entail, and thus one could argue that it is difficult to obtain fully informed consent. This issue can be addressed through the use of a process consent, whereby progress in a study is shared with participants as the study unfolds, and they are explicitly asked whether they consent to continue in the study.

Risks and benefits

The topics that grounded theorists choose to study often result in the telling of experiences that have been missing in the literature to date. These experiences are sometimes difficult to describe and the experience of doing so may be emotional and distressing for participants, particularly when the study is focused on a sensitive subject. On the other hand, it is also possible that participants may enjoy telling their story, as there are, ideally, no researcher interruptions or requests to reflect upon their story. In the risks and benefits section of the consent form, participants must be advised of these two possibilities and how the researcher will address distress if it occurs. The ethics committee that reviews my proposals typically asks that I pre-arrange support for participants who request it, which is usually organized through the psychosocial unit of our health care system. I include information about the availability of this support but have never been asked by participants for assistance in obtaining it.

Justice

It is important to remember that while the focus of the grounded theory study is on the participant's story, researchers using constructivist grounded theory or situational analysis must also make their own perspective clear prior to analysis and show the steps they will take to make sure that they don't simply obtain the results they are expecting. One approach is for the researcher to write a statement of what he or she thinks the answer to the research question will be, prior to conducting the study. This approach provides an opportunity for the researcher to make their assumptions more explicit and hence facilitates the tracking of these assumptions in the analysis.

A second ethical issue related to the principle of justice has to do with the limits of language as they relate to describing the story of a participant. Language is the primary symbol system through which meaning is conveyed across all cultures, but some words available in one culture are not necessarily available in other cultures. Participants should always be given the opportunity to be interviewed in their own language, and someone who is fluent in that language should analyze the data. Translating interview data into a language known by the research team prior to analysis may inadvertently result in the loss of important information, viewed here as a violation of the principle of justice. Given the limits of language, a growing number of qualitative researchers, including grounded theorists, are searching for other ways to (re)present their results using arts-based approaches such as theatre, painting, and poetry.

Ethical Issues Arising from the Internal Context of Research

The internal context of research is described by van den Hoonaard (2002) as the elements related to the construction of a study – things like choosing the research question, sampling, and how to manage the issue of 'voice'. In this section I describe these issues in more detail and briefly discuss links to the core ethical issues noted above.

Constructing the study

Comprehensive descriptions of experience are of critical importance in grounded theory studies, but consents must advise participants that they are free to choose how completely they want to describe their experience, with the understanding that there may be some key aspects of the experience that the participants do not wish to provide. The withholding of descriptions may result in some 'thin' spots where little data is available. These spots can be gently re-approached in subsequent interviews, recognizing, however, that the participant may have deliberately excluded them. If this is the case, it is harmful to the participant to attempt further follow-up in this area.

A related issue concerns anonymity and confidentiality. These relate to the core principles of risks and benefit. Analytic decisions in grounded theory studies must be supported with quotes *verbatim* from interview text or evidence from other data sources. For this reason, participants must be told that although all identifiers will be removed from their data to help provide some degree of anonymity, confidentiality cannot be provided. There are occasions, especially when working with small groups of participants, that the nature of the quotes used to support analysis make it difficult to ensure anonymity. The researcher must consider this point carefully. In one of my student's studies, we deliberately collected data in two cities that were far from each other to make it more difficult to identify participants.

Sampling and consent

It is sometimes difficult to find and recruit participants who are able to fully describe their experience. As a result, the researcher may need to recruit more participants than originally planned because each participant is only able to contribute part of the data required. If additional recruitment is required, some ethics committees require that an amendment to the ethics application be submitted.

In the nature of grounded theory studies, the sample could be quite heterogeneous, given theoretical sampling and the search for negative cases, and thus require multiple consent options in one study. Sometimes the most appropriate participants are unable to read or sign their own name, and so other consent processes are required. For example, in my own studies with palliative care patients, I have been permitted to record consent for those who wish to participate but who cannot read or sign their own name due to their illness. In Canada, separate guidelines for obtaining consent are available for studies in cultural settings where written consent may be inappropriate. The important point here from the standpoint of the principle of autonomy is that the grounded theorist is obliged to look for ways to include individuals who want to participate.

The intersection between sampling and 'voice'

Grounded theory studies require participants who are articulate and who have experience with respect to the topic under investigation so as to gain descriptions that are as full as possible. In the early days of qualitative research, we were proud of movement away from calling the people in our studies 'subjects' and thought use of the term 'participant' was more suitable for individuals who now had a chance to tell their own story in their own words. We somehow thought that by changing our language we would create a more level playing field and remove power differentials. While the intentions were understandable, we failed to recognize that regardless of how friendly and enthusiastic we as researchers tried to be, we were still the people who framed the study, defined the research questions, and collected the data and conducted the analysis. The power differential was still present, and hence the potential for the voice of the researcher to be heard over the voice of the participant was still present. This point has been articulated in more detail by Duncombe and Jessop (2012) who drew on their own research experiences and those of others to highlight the violations to the principle of justice associated with trying to build trust in order to get 'good' data and inadvertently crossing the boundary between researcher and new friend or perhaps even therapist. It is important for grounded theorists, particularly those who take a constructivist or situational analysis approach, to recognize that threats to the principle of justice (whose voice? whose story?) could ensue if they fail to recognize the power differential inherent in the research endeavor.

Epistemology

Epistemological considerations center on the relationship between the researcher and the data. A discussion of participant 'voice' will help to underscore the connections between epistemology, voice, and the principle of justice. In classical and Straussian grounded theory, the epistemological position is essentially objectivist and so voice is not a major concern. But in constructivist grounded theory and situational analysis, the issue of voice is critical. The danger in the constructivist and situational analysis approaches is that the voice of the researcher and the voice of the participant become blurred. Blurring occurs when the researcher fails to keep track of the data used to identify key concepts during the analytic process, which is problematic because it may shift the analysis away from the participants' stories and toward the researcher's own perspective. Thus, it is important for the researcher to maintain a meticulous memoing process that carefully provides supporting data for the analysis. This approach helps the researcher to see when his or her own voice is in danger of overshadowing the voice of the participants.

CONCLUSION

In this chapter I have presented an overview of the four main approaches to grounded theory and identified key similarities and differences. While the ontological roots of the four approaches to grounded theory are similar, the epistemological assumptions are significantly different. Glaser and Strauss as well as Strauss and Corbin (in their early work), based their work on an objectivist epistemology, while Charmaz and Clarke used a constructivist epistemology. These variations in philosophical underpinnings were used as the foundation for a discussion of potential ethical challenges related to the external and internal research context. Issues around the difficulty of fully informing individuals about the nature of a study designed using grounded theory, and of including those who want to participate, underscore challenges related to the principle of autonomy. The potential for harm if data collection evokes distressing emotion and the difficulties of obtaining an articulate and experienced sample highlight issues related to the core principles of risks versus benefits. Finally, the challenges of honestly and authentically hearing and analyzing the story of participants, with all its challenges related to language, show the potential for violating the principle of justice. The breadth of the approaches that fall under the grounded theory umbrella indicate the value of this design for the development of knowledge in many disciplines. An appreciation of the ethical issues associated with these approaches will help to strengthen the quality of the knowledge generated using grounded theory.

REFERENCES

Blumer, H. (1969) *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice Hall.

Bryant, A. (2009) Grounded theory and pragmatism: The curious case of Anselm Strauss. *Forum: Qualitative Social Research*, 10(3): 2. Available at: <http://www.qualitative-research.net/index.php/fqs/article/view/1358/2850>. Date accessed: 17 August, 2016.

Charmaz, K. (2000) Constructivist and objectivist grounded theory. In N.K. Denzin and Y.S. Lincoln (eds), *Handbook of Qualitative Research,* 2nd edn. Thousand Oaks, CA: Sage, pp. 509–535.

Charmaz, K. (2006) *Constructing Grounded Theory*. Thousand Oaks, CA: Sage.

Charmaz, K. (2009) Shifting the grounds. In J. Morse, P. Noerager Stern, J. Corbin, B. Bowers, C. Charmaz, and A.E. Clarke. (eds), *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA: Left Coast Press, pp. 127–154.

Clarke, A.E. (2005) *Situational Analysis: Grounded Theory After the Postmodern Turn*. Thousand Oaks, CA: Sage.

Clarke, A. (2009) From grounded theory to situational analysis: What's new? Why? How?. In J. Morse, P. Noerager Stern, J. Corbin, B. Bowers, C. Charmaz, and A.E. Clarke. (eds), *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA: Left Coast Press. pp. 194–233.

Clarke, A., Friese, C., and Washburn, R. (eds) (2015) *Situational Analysis in Practice: Mapping Research with Grounded Theory*. Walnut Creek, CA: Left Coast Press.

Corbin, J. (2009) Taking an analytic journey. In J. Morse, P. Noerager Stern, J. Corbin, B. Bowers, C. Charmaz, and A.E. Clarke. (eds), *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA: Left Coast Press, pp. 35–53.

Corbin, J. and Strauss, A. (2008) *Basics of Qualitative Research: Techniques and Procedures For Developing Grounded Theory* (3rd edn). Thousand Oaks, CA: Sage.

Dewey, John (1917/1998) The need for a recovery of philosophy. In L.A. Hickman and T.M. Alexander (eds), *The Essential Dewey, Volume 1: Pragmatism, Education, Democracy.* Bloomington, IN: Indiana University Press, pp. 46–70.

Duncombe, J. and Jessop, J. (2012) 'Doing rapport' and the ethics of 'faking friendship.' In T. Miller, M. Birch, M. Mauthner, and J. Jessop (eds), *Ethics in Qualitative Research* (2nd edn). Los Angeles, CA: Sage, pp. 108–121.

Glaser, B. (1978) *Theoretical Sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. (1992) *Basics of Grounded Theory Analysis: Emergence vs. Forcing*. Mill Valley, CA: Sociology Press.

Glaser, B. and Strauss, A.L. (1965) *The Awareness of Dying*. New York: Aldine Publishing Company.

Glaser, B. and Strauss, A.L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine Publishing Company.

Glaser, B. and Strauss, A. (1975) *Chronic Illness and the Quality of Life*. Mill Valley, CA: The Sociology Press.

Mead, G.H. (1934) *Mind, Self and Society*. Chicago, IL: University of Chicago Press.

Rorty, R. (1980) *Philosophy and the Mirror of Nature*. Princeton, NJ: Princeton University Press.

Strauss, A.L. (1987) *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.

Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage.

Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (2nd edn). Thousand Oaks, CA: Sage.

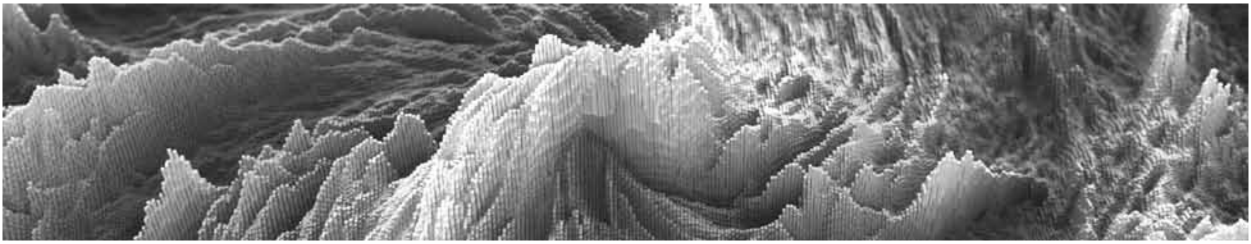
Strauss, A. and Glaser, B. (1970) *Anguish*. Mill Valley, CA: The Sociology Press.

van den Hoonaard, W.C. (ed.) (2002) *Walking the Tightrope*. Toronto, ON: University of Toronto Press.

PART VI

Researching Digitally

Elizabeth Buchanan



We could think of none better than Elizabeth Buchanan to introduce this last section of the *Handbook*. She is well known for her work in the field of digital/online research and the ethics of working in this area. She is Endowed Chair in Ethics and Director of the Center for Applied Ethics as well as Acting Director for the Office of Research and Sponsored Programs University of Wisconsin-Stout, Menomonie, Wisconsin, USA. She provides us with the groundwork for understanding the kinds of ethical concerns raised by qualitative research online and outlining the challenging issues raised by these three, thought-provoking closing chapters.

ETHICS ONLINE: AN INTRODUCTION

'Online research', often used interchangeably with 'Internet-based research', has become an umbrella term to capture a strikingly large array of methods and methodologies, employed by disparate disciplines. Internet research, in the mid 1990s, was a now seemingly simplistic phrase that included the uses of online tools, databases, search engines. The second prong of the definition included the application of such methods as observation or interviews, surveys or questionnaires, in online spaces, domains, communities, games and other locales, some with a corresponding physical location, some with only an online presence. Nursing, communications, and information sciences were some of the earliest employers of qualitative methods in online spaces; Sherry Turkle's important publication, *Life on the Screen*, was published in 1995, with Annette Markham's *Life Online* following in 1998. Early ethical concerns in online research revolved around the representation of the researcher (Markham lying about her age, for example), studying (or lurking) around participants who are unaware of the researcher presence, difficulties in obtaining consent from participants, and ultimately, knowing where, how and when a researcher engages with participants. Researchers have been innovative with their approaches in engaging participants, including the use of avatars donning 'researcher' hats or t-shirts in virtual worlds, handing out 'tokens' that are consent documents for participants to review, sending targeted communications to specific community members to recruit a subset of the group, and, establishing fake personae to get 'unbiased' results.

Those early online studies not only presented opportunities and challenges to researchers, who were developing a new field of enquiry, Internet Studies, noting the Association of Internet Researchers' (AOIR) inception in 2000; but, also ethicists, research ethics boards, and research regulators. While Markham described her internal turmoil over the research ethics of her work in her 1998 book, she to this day writes cogently on the ways in which ethics differ from regulations, how ethics must be discipline specific, and how traditional models of research and research ethics are unsuited to much qualitative research in general and online qualitative research in particular. For example, to protect the identities of online participants, Markham promoted the use of 'fabrication' a term and practice that raises eyebrows in research ethics and regulatory circles.

> It seemed innocuous enough, my mentioning that 'I have fabricated data before'. Dead silence in the room compelled me to immediately add the explanation: 'I interviewed someone online who really didn't want their words traced, and so I invented a dialogue that would represent but not duplicate our conversation'. Responses were extreme: For some, the idea of my 'faking' or 'falsifying' data was shocking and disappointing, to say the least, prompting one to blurt: 'How could you do such a thing!?' For others, the idea that I had pulled back the facade of objective reporting of facts to reveal some of the inventive practices available was a relief. Some were excited to talk about their own struggle to balance the need to present examples of lived experience in research reports with the need to protect the privacy of their participants. (Markham, 2011)

This is but one example of the large-scale challenges facing online researchers from the early days of the Internet as a popular social tool and space. With the emergence of social media – Facebook, Twitter, Instagram, and countless others – the era of social computing and sharing took hold, and researchers had more participants, more data, and data from their participants' social networks than ever in documented history: in a very short time, the research domain created in and by social media exploded and information about individuals, their relations, their data trails, patterns, and habits were easily accessible and ready to be studied. Simultaneously, however, the use of algorithmic processing and data analyses was also growing, and researchers could study these same things in the absence of direct interaction or intervention with an individual. By 2016, researchers would have access to data through any number of channels, especially those that did not involve what we have now come to define as 'human subjects research'. Jaffe, quoting Tanzeem Choudhury, reported in 2014:

> researchers [could] get to a point where they can collect behavioral information without sampling human participants at all …Technology such as smartphones and wearable sensors can gather information on physical activity, social interactions, geographic location, and so on. The upshot of this type of data collection is that it's effectively invisible to users; it doesn't require their time or energy, and it drastically reduces self-report errors. We can continuously get measurements of behavior without bugging people to fill out surveys. We can potentially get continuous measurement without actually having to engage users all the time and rely on their self-input. (Jaffe, 2014)

Researchers have come a very long way in a short period of time vis-à-vis online research, what it means, how regulations may apply to it, what the ethics may be, and indeed, how they engage with their participants. The chapters presented in this final section of the

Handbook demonstrate the great complexity involved in, first, qualitative research (QR), and second, online research. Both, QR and online research, have been challenged in finding an 'appropriate' balance between regulatory models and disciplinary norms. In the US, as with other countries, research regulations grew out of biomedical research and its ethical challenges and complexities. Social-behavioral-educational research, where we see many qualitative methods employed, has awkwardly adapted the models of consent, respect for persons, and beneficence, as outlined in, for example, *The Belmont Report* (United States, 1978).

Research ethics boards (REBs) or institutional review boards (IRBs), as many in QR have lamented, seem to start their deliberations from a regulatory discourse, only to squeeze ethics in afterwards. Common criticism over the years has been consistent: 'Checklists do not fit my research'. 'Flow charts don't provide me options'. 'I cannot reduce my work to an interaction or an intervention'. 'Asking questions doesn't present risk or harm'. And so on. REB/IRBs are concerned with protecting 'human subjects'. In the US, the definition of human subjects includes:

A human subject is defined by the United States Department of Health and Human Services (DHHS) as 'a living individual about whom a research investigator (whether professional or student) conducting research obtains (1) Data through *intervention* or *interaction* with the individual, or (2) *Identifiable private* information'. [45 CFR 46.102(f)]

- **'Intervention'** as defined by DHHS regulations means 'both physical procedures by which data are gathered (for example, venipuncture) and manipulations of the subject or the subject's environment that are performed for research purposes'. [45 CFR 46.102(f)]
- **'Interaction'** as defined by DHHS regulations means 'communication or interpersonal contact between investigator and subject'. [45 CFR 46.102(f)]
- **'Private information'** as defined by DHHS regulations means 'information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record)'. [45 CFR 46.102(f)]
- **'Identifiable information'** as defined by DHHS means information that is 'individually identifiable (i.e. the identity of the subject is or may readily be ascertained by the investigator or associated with the information)'. [45 CFR 46.102(f)]

REB/IRBs have debated the terms and conditions of 'interaction' 'private information' and 'Identifiable information' and they have taken on greater complexities in Internet/online spaces. They have been debated, and contested by QR in significant ways. These areas push REB/IRBs to consider the risk and benefit to the research, both for the individual participants and for society at large. Issues such as group or community harms have been raised, and particularly, in the space of online research, where boundaries slip and slide more readily; the roles of 'research bystanders' or 'collateral subjects' have become commonplace, as researchers question how and how much of a core research participant's friends, relations, connections are within the bounds of research. For QR in particular, our research questions may be fluid; we may not realize the extent to which a bystander will serve as critical to our study – Granholm and Svedmark in Chapter 33 refer to 'fickleness'. And, the original research participant may have a different standard of private information than those around her. These are all reinvented challenges to QR in online spaces. They are not necessarily new ethical challenges, as QR has long been invested in the social networks and communities around a participant. In online QR, can there be an n of 1?

And, what does risk and harm look like in online spaces? QR is attuned to sensitive topics, conditions, emotions, actions. QR addresses the personal in studies involving the most sensitive of topics, illegal or hurtful topics. From violence in homes to gangs to street drug epidemics, online QR is there, studying the most challenging of social issues.

The chapters in this section push many boundaries. As Granholm and Svedmark state abruptly: 'Online research exposes both the subject and the researcher to harm. Research hurts'. Many REB/IRBs hesitate when presented with studies that examine death, bereavement, loss. In our social media age, the loss of a loved one takes on different meanings. Studies of bereavement and how they occur across Facebook, with its 'year in review' showing a child who died that year, or its algorithmically generated 'happy anniversary' to the loved one left behind after a spouse's death, generate different harms; they are not the fault of the researcher, to be clear; they are highlighted and brought out for examination by researchers, who are now, fortunately studying the ethics of algorithms and how researchers use those data.

The chapters we present here allow us into the world of the researcher and the challenges they face. The Internet itself is called into question as a discursively male space: McDonald, Laidler and Dean confront the ways in which meaning is made in online spaces. The gendered dynamics of Internet technologies call on 'researchers to understand their participants' (and their own) moral and ethical views from a novel perspective'.

Pushing further, Natasha Whiteman forces us to 'focus … on the nature of the exchange between the ethics of the researcher and researched, specifically how the visioning of subjects (as both 'ethical' and 'unethical') is established and used to warrant certain research practices and shape ethical practice'. Thus, we move from the larger discussion of the Internet as discursive space to research practices, both of which contain immense ethical implications.

Further, the presence of 'vulnerable' populations or individuals online has been a point of interest and concern for years, and yet, we, on REB/IRBs, are still vexed when a survey includes questions about rape, incest, abuse, or when we review an observational study of grief online. None of these research ethics concerns present as more vexing than those presented by Granholm and Svedmark, who study vulnerable populations online. In the regulatory language, 'vulnerable' has a specific meaning and requires researchers to go above the 'minimal risk' standards and address the vulnerabilities in research design, conduct and dissemination of research. But, what prepares researchers, or their REB/IRBs for the situation Svedmark encountered?

> Eva had for example one girl who committed suicide in the middle of her study. The girl had a blog, which Eva had studied for three years. One morning when logging in at the computer the girl's sister had added a post revealing the fact that the blog owner had hung herself the day before. [The reader may have a similar response to this incident]. As a researcher Eva chose to remove all data from this girl in her study as there was several ethical aspects that could not be met after her passing. In this case it was no longer a question of protecting the girl from harm but to protect her close relatives from exposure and unwanted attention. As a private person, Eva was devastated, grieving a young woman she had never met or spoken to but had followed online very closely every day for the last three years. Is it OK to grieve an informant? Where do you cry as researcher? (Chapter 33, this *Handbook)*

Every qualitative researcher should have the privilege of crying during their work; that is how important it is; emotion and raw feelings emerge. Online or on-ground, or somewhere in-between, research is meant to move us; whether socially, politically, or ideologically, QR pushes us and furthers us to understand and, maybe, take action.

The online spaces once so simple and easy to navigate have become, in the face of social media and big data, crowded, noisy spaces. They are hard to navigate with research questions, but more so, these data allow us to find answers to research questions before we even have those questions. I contend that qualitative research is more important now than ever in a time when correlations are king and causations are secondary. I value a time and a methodological ethos where the 'human subject' was more than a 'data subject'. I want to take on the bastards, as Whiteman describes, and, I want research that will push me to cry.

REFERENCES

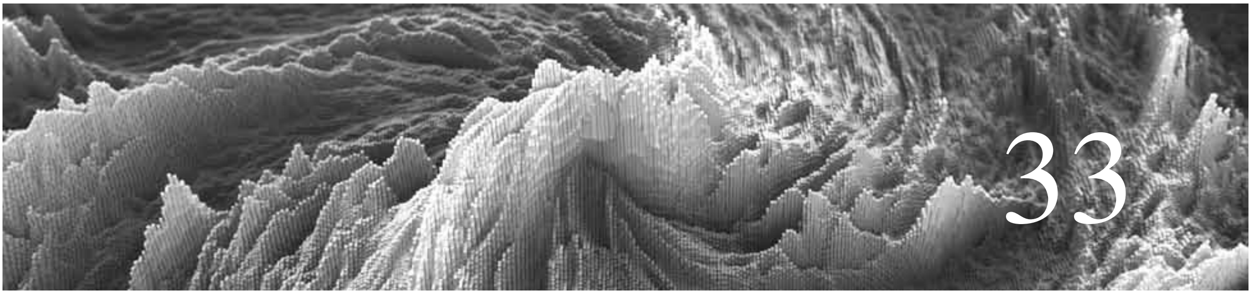
Jaffe, E. (2014) What big data means for psychological science. Retrieved from https://www.psychologicalscience.org/observer/what-big-data-means-for-psychological-science#.WQnxjRPyvcs

Markham, A. N. (1998) *Life online: Researching real experience in virtual space*, Walnut Creek, CA: Altamira Press.

Markham, A. (2011) Fabrication as ethical importance. 5 March. http://annettemarkham.com/2011/03/fabrication1/

Turkle, S. (1995) *Life on the screen: Identity in the age of the internet*, New York: Touchstone.

United States (1978) *The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research*, Bethesda, MD: The Commission.



33

Research That Hurts: Ethical Considerations When Studying Vulnerable Populations Online

Camilla Granholm and Eva Svedmark

INTRODUCTION

> ‘I have problems with my self-esteem. Even writing here feels a bit scary. I have been following this group for some time and even read the archives with discussions from previous years and wanted to contribute by writing’. (Loneliness discussion group)

> ‘I am happy that this group is in action again. It is a relief to read about other people’s thoughts and experiences. Many of them are very familiar and it is easy to identify with them’. (Loneliness discussion group)

> ‘Where do you turn as a researcher when the person you are studying chooses to die? Do I call my supervisor? Where can I cry? Am I allowed to cry? Do I even have the right to feel so close to my informants that if they go off and die I am entitled to grief? How ethical is it really to study people who are balancing on the edge of life? I should have backed off long ago. I should have realized that I already had enough material to fill this thesis. I didn’t need to walk with these people all the way to the grave. But how do I leave them? HOW?’ (From Epilog, Svedmark, 2016)

The first two quotations above are excerpts (translated from Finnish) from an online discussion group on the topic of loneliness and serve here as examples of sensitive online material published by potentially vulnerable people. The third is from our own field notes. Online research exposes both the subject and the researcher to harm. Research hurts.

In online discussion and counselling groups, people facing similar difficulties are invited to share their experiences and support each other. The problems and difficulties they discuss are vast and may concern health related issues as well as emotional distress. Non-governmental organizations (NGOs) and nonprofit organizations have acknowledged the opportunities that online tools can provide for people in difficult situations, and many now offer help and support on the Internet. Organizations such as Alcoholics Anonymous (http://aa-intergroup.org) and Parents, Family & Friends of Suicides (www.pos-ffos.com) provide their clients with online support groups. Social networking sites such as Facebook also contain groups where people in similar challenging situations may discuss their thoughts and experiences. There are also commercial sites (e.g. yahoo.com) offering space for discussions. The discussions on commercial sites are more varied and contain threads with everything from people commenting on current political events to people asking for practical advice in childcare or when buying a new car. These sites also contain more sensitive discussions for example regarding illnesses, both physical and mental.

As researchers we represent different academic disciplines (social work and informatics), but what we have in common is that we are interested in online environments and how people experiencing difficulties in life use the Internet to share their stories but also to seek help and support. The difficult situations the people we have studied are in could be interpreted as situations in which people are considered vulnerable. Another common interest for us is research ethics, and we have been engaged in discussions considering Internet research ethics since we met at the Internet Research conference in Gothenburg in 2010. In both of our doctoral dissertations (Granholm, 2016; Svedmark, 2016) Internet research ethics is given an important role and therefore most of the things we write about here are based on our dissertation research and the experiences we have had during the research and writing process.

Our studies have mostly dealt with written texts published in online discussion groups or on blogs, but published pictures, video clips (vlogs) and voice recordings had also to be considered. The material we have used in our studies is all openly published and available online to any user. Using openly published material means that we as researchers have an even greater responsibility to consider the ethics of how we refer to and use quotes from the data we have collected. Referring directly to blogs or discussion groups, or using the nicknames people use when they participate in discussions or write blogs, when reporting on the research, may make the person behind the posts recognizable, which might cause the person harm. Therefore, we have chosen different ways of presenting the data without revealing information about the people who occur in the material we have studied. For example, the empirical cases involved in Svedmark's studies (2016) are all based on conjoint stories, empirical material mashed and mixed together, creating personas that are articulating the studied phenomena not mirroring it. This way, no single person is in risk of being exposed since there are many voices in every articulated case. There are cases that cannot be conjoint since they are unique in their nature or extraordinary enough to bring media attention to them. In the latter case the harm is already done by others through the media exposure to the public eye. Even so, as researchers we must treat public cases like this with respect, and by including them in our research we might be able to shed new light on what has been happening rather than the focus of attention brought by media. This said, we must be careful not to alter facts or provide unnecessary details to the reader. It is of great importance to keep the respect of the vulnerable.

There are problems inherent in this type of data collection. Using data published anonymously online makes it difficult for the researcher to check if the person writing really is what he or she purports to be. It is impossible to ensure facts such as age or gender. Additionally, the amount of inappropriate messages is often related to the openness of the forum. In online discussion groups there are always people who, for some reason, pretend to be something other than they really are. If a discussion group is open to everybody, as the commercial forums often are, they are likely to have more trolls participating in the discussion. Forums and groups that are administered by NGOs and address people with common interests are more controlled, and participating in the discussion might require membership in an association or that the identity of the person is in other ways verified.

This chapter is organized in four parts. First, we ask what makes Internet research different from offline research? Second, we examine vulnerability, asking: Who is vulnerable? Who can judge? Is virtual vulnerability different from offline vulnerability? Third, we discuss basic ethical assurances used in online research suggesting formal ethics approval is not a 'green card'. Fourth, we turn the focus away from others' vulnerability and question the ethics related to our own vulnerability. Studying vulnerable populations online can harm the researcher. The third quote above highlights the emotionalities of research online: What do researchers do when strong emotions hit you in the guts before you can turn it into any kind of knowledge? We close the chapter concluding some of the most common ideas presented as suggestions to be considered when doing Internet research with vulnerable populations.

INTERNET RESEARCH FROM AN ETHICS PERSPECTIVE

When conducting research on sensitive topics with vulnerable participants in virtual environments there is often a need for careful ethical deliberation. The discussion considering Internet research ethics has been going on for more than two decades. In 2006, Kuula (pp. 192–195) raised the difficulties involved in defining concepts like place and reality, and the private and the public in online environments. These difficulties are still relevant and may challenge the ethical decision-making which takes place in this type of research. The Internet is global and people regard and interpret the information available on it from their own cultural perspectives. The use and contents of the Internet are constantly changing, especially since the Internet has become portable and with the entrance of social media, and these developments affect issues of research ethics (Markham & Buchanan, 2012). When conducting research in new and developing online environments, it is likely that unforeseen ethical issues may occur during the research process (Roberts, 2015). The Association of Internet Researchers (AoIR) is an interdisciplinary organization bringing together researchers mostly from the social sciences and humanities. The Association has developed a set of ethical guidelines for Internet research. The current version of the guidelines was compiled in 2012 (Markham & Buchanan, 2012) and they advocate a reflexive, case-based approach, providing researchers with a set of considerations to use when making decisions about the planned research.

How can we as researchers ensure that the people who produced online content, which may later be collected and used for research purposes, are aware of the fact that it may be used in this way? This question has been frequently discussed among Internet researchers (e.g. McKee & Porter, 2009; Sveningsson Elm, 2009; Markham & Buchanan, 2012). According to a tool developed by McKee and Porter (2009: 88) the need for signed consent is more likely if the online environments where the research is undertaken are private, the research topic is sensitive, and the level of interaction and subject vulnerability is high. The tool gives a result that can be used only for illustrative purposes, and gives the researcher an implication, which may be taken under consideration when deciding whether or not to ask for informed consent. In a wider sense, this tool could be used as an indicator of how serious research ethical considerations might generally be in a certain research context. But how do researchers address the vulnerability of those online?

VULNERABILITY

Is online vulnerability different from offline vulnerability? We begin with a set of questions.

Who has the right to study vulnerable populations? Who sets the rules? Should researchers who study vulnerable populations have a degree/knowledge in psychology or a therapeutic profession? Does the purpose of the study matter? What is the aim of the study? Is it merely social scientific 'voyeurism' or a worthy understanding of a phenomenon which might make the situation more bearable for the vulnerable population? Does academic discipline matter? (Such as social science in general vs. social and health care science.) Do, for example, social and health care researchers have an automatic right to explore vulnerable populations online? Is it easier for social and health care researchers to justify their research interest? If so, what ethical concerns and challenges might this imply? These questions are important but the most fundamental question is 'what is it you want to create knowledge about?'. These questions go hand in hand with the method and the interaction one chooses with the potentially vulnerable population one studies.

In her chapter in *SAGE Internet Research Methods*, Susannah R. Stern (2012) discusses the encountering of a distressing disclosure in the course of her online research. By 'distressing' disclosure she refers to information that indicates that 'an online communicant is considering harming him/herself or another/others' (Stern, 2012). In the chapter, Stern gives some examples of people who disclose distressing things about themselves such as online users' announcements of suicide intentions and/or threats to kill another person. Children and youth talking in online environments about being bullied, feeling depressed or starving themselves could also be considered making distressing disclosures. Collecting and analyzing distressing disclosure is not pleasant for the researcher, but does distressing disclosure make people who disclose thoughts about wanting to cause harm to themselves or others vulnerable individuals? These are core ethical issues.

Researchers are powerful professional experts and may be regarded as influential and knowledgeable people (Hardwick & Worsley, 2011). This power becomes even more evident when we deal with people who are experiencing some kind of difficulty or distress, and are therefore in a vulnerable position. With power comes responsibility. As researchers we are responsible for protecting the individuals that are involved in the studies we carry out. But as professional and influential experts we are also responsible for doing high quality research, and sharing the results of our studies in a way that is true and respectful towards the group of people studied.

Internet researchers have the opportunity to create knowledge about online phenomena that are emerging and growing in step with society's and individuals' increasing use of the Internet. For a long time, concerns over research ethics have contributed to a lively debate in the field as it has been repeatedly shown that national and international ethical guidelines and legislation are not always applicable in a virtual context (see, for example, Buchanan & Ess, 2008; Ess, 2009; Markham, 2006). Children are often considered a vulnerable group and usually studying children requires parental consent. In online environments checking the age of the people writing blogs or participating in discussion groups can be difficult, as it is easy to create online profiles using false information, such as where one lives, physical attributes and age. In the case of discussion groups the difficulty is also the amount of participants, which can be massive in some online groups, and the fact that some of the postings might have been written many years ago, by a person who at that point was underage, but now is an adult. (In this case it could be possible to ask the person him-/herself for consent retroactively, such as in offline research where for example child protection cases are studied retrospectively.) However, there may be a general principle that all people, including children and other vulnerable groups, should be able to participate in research and have their lived experiences heard and understood (Earls Larrison & Korr, 2013).

When research is performed on or with potentially vulnerable populations it is especially important to adjust any methods available for not causing harm to research participants. That said method becomes the means for doing ethical research as well as the ethics that form the method for knowledge construction. This means that the research questions must be in line both with the research method as well as the research ethics. In other words it should go without saying that it is not enough to adjust the research ethics just in order to gain approval from an ethics review board such as an institutional review board (IRB) or equivalent. Ethics must be both a compass as well as a guide. When dealing with human subjects, unanticipated things will happen. It is impossible to know all the different actions humans may take during a research study, even when in an online environment. Therefore, ethics can never be static assessment. Rather, ethics must be as flexible as possible, allowing all methods to alter and change as the study progresses. Doing this can be difficult since the method should, properly, be aligned with the research questions. Careful attention must be paid toward how and why the 'path' might have to be changed while making sure that the planned direction is being maintained. Qualitative method can be fickle; in fact it must be fickle in order to address an emergent research question. When using ethics as a study's compass, the researcher should be open to the fact that sometimes the method envisaged during the planning stage of the research project might in the end not fit due to ethical considerations. This means that the researcher should be able to switch to a more ethically suitable method, for example using alternative ways of presenting the results and avoiding the use of direct quotes from the material that could reveal the identity of the informants.

In some professions, such as social work, professionals and researchers routinely deal with vulnerable people; people who often live and work under totally different conditions than the academically educated professionals. Social workers face human suffering and misery every day, and working under such conditions requires compassionate empathy and a solid ethical foundation. There are many other professions, such as medical doctors, nurses and police officers, in which the professionals meet vulnerable people as a part of their everyday practice. Social work education aims to develop the students' professional self and the ability to make use of who they are; in other words, use themselves and their personalities as tools in practice (Earls Larrison & Korr, 2013). This development requires more than learning to technically apply formal knowledge and includes the ability to be context-sensitive, flexible and thoughtfully apply knowledge and practical judgement when reflecting on how to engage in social work practice. This kind of flexibility and a sensitivity for practical situations might be an advantage when engaging in qualitative research involving vulnerable populations, which also requires a flexible and sensitive approach.

At times, we have seen researchers dwelling in other people's misery for no other reason than to get attention for their own sake. This we find troublesome. There is no value of its own to do research on vulnerable populations if the goal is not to create knowledge that in the extension of itself will help people or make technology more ethical. We always need to be responsible for the knowledge we produce as scientists in general and when it comes to vulnerable populations in particular. But what does the researcher's responsibility involve? And where does the researcher's responsibility end?

Attempting to explore the ethical relations between the researcher and a vulnerable population online has raised constant questions and challenges in relation to research ethics. Who are we, as researchers, to intrude? Doing research on difficult aspects of life is highly important; we must not simply hide in the darkness, since we have the greatest need to elucidate such aspects to improve our chances of helping people who for one reason or another are vulnerable. As researchers, we are not only asked to take responsibility for ethical considerations; we also have to be able to respond to the knowledge we bring to the world. We need to dare to venture into and deeply engage in the most uncomfortable areas of life to illuminate them but, with this in mind, it is important to get the balance right in terms of the most important fundamental tenet of research ethics: to avoid exposing anyone to harm. This has proved to be easier said than done, and sometimes actions have been reminiscent of the maxim 'fools rush in where angels fear to tread' by Alexander Pope (1713).

ETHICS APPROVAL IS NOT A GREEN CARD

The most important basic rules of research ethics in general could be summarized as (1) respect for autonomy, (2) non-maleficene, i.e. causing no harm, (3) beneficence, meaning that the research must benefit both the people involved in the research and the society, and (4) justice, as in the research being fair and just for and to the wider community (Beauchamp & Childress, 2012). These four principles of research ethics originally developed and applied in biomedical research, but have been largely adopted by social care and nursing research (e.g. Hardwick & Worsley, 2011). Among social scientists, critical voices have been raised against these principles, and especially against ethics committees and academic review boards who are often said to apply these rules too strictly, without considering the differences between qualitative and quantitative research nor the particular characteristics of qualitative research (van den Hoonaard, 2013). In general, the aim of ethics is keeping us aware and continuously reflecting on what is right and what is wrong. Simple models or rules do not work very well as they tend to simplify what is complex. Instead, as Haraway (2016) suggests, we should stay with the trouble and not rush into solving problems or finding 'the right way', as there might be many paths to wander. In qualitative research, where the number of those posting might be quite small, researchers should take extra precaution to ensure the safety of the people involved in the research. But again, the ability to respond and the need for responsibility as researcher is great and important. Care and ethics is at times best practiced when we actively break pre-set narrow norm systems in order to embrace differences from within (Svedmark, 2016). Performing this kind of research is about being brave and able. It is about being able to rise to the challenge of studying the vulnerable no matter if it hurts you as researcher in the process.

Performing qualitative research online is in many aspects different from doing similar studies offline. The Internet provides us with a possibility to meet without physical presence, a factor that opens up new arenas for doing qualitative research on sensitive matters without having to expose the vulnerable person's identity even for the researcher involved. There are great opportunities to be a 'fly on the wall' as a covert researcher, being present but not visible, collecting information and data in a silent presence (Svedmark, 2016), doing non-participatory observations with no known research bias. This is sometimes called 'lurking' (see for example Nonnecke & Preece, 2001; Walther & Boyd, 2002), but we argue that the non-participatory presence is to be seen as a unique and important research method when dealing with vulnerable populations online. These examples of altering and using Internet features for new and other methods of gathering data must be discussed from ethical perspectives, making room for new ways of protecting people from harm. We feel there is a growing body of ethically questionable researchers, lacking a clear aim, using material from potentially vulnerable subjects in order to get attention rather than to improve knowledge about a phenomenon. This is in some ways problematic and we need to address research ethics in connection to this, not only in order to protect the people involved from harm but also in the light of why we do research in the first place. The aims and objectives of research should always be knowledge production not attention seeking.

The sensitivity and/or vulnerability of this research location makes the ethical responsibility of the researcher even greater. Ethical decisions are often considered in the beginning of the research process, when applying for grants and in order to gain the approval of a research ethics board. We take a different perspective arguing that, when dealing with sensitive data and vulnerable populations, this is not enough. Ethics should run as a red line through the entire research, being an integrated part of your entire method as a process – *ethics is not a green card*. Research ethics are there to protect the people involved in our studies. Usually 'the people involved in the study' are considered to be the informants, the people who are studied, but we see a need to widen the perspective here, and acknowledge that we as researchers are also involved, and thereby the responsibility to protect the ones involved also includes us as researchers. We are responsible for safeguarding our own wellbeing. This is a perspective that most review boards unfortunately, ignore when evaluating research propositions. Given both the nature of online communication and research, those who study Internet users and communities may find themselves particularly likely to come across distressing information in their research (Stern, 2012).

THE VULNERABLE ONLINE RESEARCHER

Maintaining professional distance is difficult when what you are studying contains such strong emotions that it is sometimes difficult to avoid crying. Studying people who find themselves in a difficult life situation may arouse discomfort, and feelings of intrusion into their privacy. A constant balancing act is required between getting close enough for understanding while keeping a distance and respecting people's integrity, even in moments they themselves are offering an intimate story. I [Eva] have found support for this in the work of the anthropologist Ruth Behar (1996) who challenges the traditions of academia by demanding a more personal approach in qualitative studies – studies where the boundary between researcher and research subject is not easy to draw and the researcher is not always present just to build academic knowledge but also to influence and allow herself to be influenced by the study subjects. Behar emphasizes that although the researcher seldom has any direct power to instigate change, as researchers, we should remain emotionally close to the study subjects in order ultimately to create knowledge that can provide the basis of important changes.

For professionals working with vulnerable people and crisis situations (e.g. social workers, nurses, medical doctors and police officers) there are internal procedures to safeguard the emotional coping of the professionals. Such procedures might include debriefing, professional mentoring and guidance. But who worries about and protects the researchers' vulnerability? Graduate and PhD students may have their supervisors (advisors) they can talk to, but what about the experienced researchers, who work more independently with their projects. Who can they turn to if they are struggling with overwhelming emotions caused by the encounter with human suffering? In the academic community there are no safeguarding procedures for researchers working with vulnerable populations, therefore the responsibility lies with the researcher themselves to get the help and support they need from colleagues or professionals at the occupational healthcare services. The most important thing is to be aware of the fact that doing research with vulnerable populations is emotionally challenging and often affects the mood of the researcher. For a researcher to be able to do compassionate and ethically sound research (s)he needs to start by treating her-/himself with compassion.

As the third quote at the start of this chapter shows, there are times when studying vulnerable populations is strongly emotionally upsetting and does harm to the researcher. For example, Eva had one girl who committed suicide in the middle of her study. The girl had a blog, which Eva had studied for three years. One morning when logging in at the computer, Eva saw that the girl's sister had added a post revealing the fact that the blog owner had hung herself the day before. As a researcher Eva chose to remove all data from this girl in her study as there was several ethical aspects that could not be met after her passing. In this case it was no longer a question of protecting the girl from harm but to protect her close relatives from exposure and unwanted attention. As a private person, Eva was devastated, grieving a young woman she had never met or spoken to but had followed online very closely every day for the last three years. The reader may have a similar response to this incident. Is it OK to grieve an informant? Where do you cry as researcher? At your supervisor's office?

Dealing with vulnerable populations and human suffering in a helping profession or as a researcher involves emotions and emotional engagement is necessary and perhaps unavoidable. Here, the 'airplane safety rule' can be applied: 'If you are travelling with a child or someone who requires assistance, secure your own mask first, and then assist the other person'. In other words, to be able to help others you need to secure your own wellbeing first (e.g. Granfelt, 1998; Laitinen, 2004). Another way of taking care of your emotional distress is to search for other researchers who are dealing with emotionally dense material, not necessarily within online contexts. This relation is a mutual support where the researchers are using each other as professional listeners without judgement and without trying to advise on how to solve the problem. Instead this professional friend is holding space for the other, making room for distress, grief and anger.

Even though doing online research – where you are not meeting with the people involved in the research eye to eye – is assumed to be less emotionally draining, on the contrary, we claim this is not always the case. Day after day, visiting blogs and forums populated by people whose lives are hanging by a thin thread does something to you. Their words and their pictures speak so directly and give insight and knowledge that go beyond academic or intellectual knowledge. They grab much more than the researcher's eye and do not let go. The knowledge of how bad many people feel induces responses that feel sometimes like a knot in the stomach, refusing to loosen when leaving the office at the end of the workday. Knowledge of a field of study often begins as something purely physical before it makes its way to the intellect. All of these feelings are valuable assets, as the emotional part of the material can provide profound indications of aspects that are essentially human and fundamentally existential (Ikonomidis Svedmark, 2011; Svedmark, 2016).

CONCLUSION

Our research with vulnerable populations online has brought a wealth of new insight but has also given us awareness of a unique set of ethical considerations. We end with a few suggestions and advice for researchers who study or consider studying vulnerable populations online. First, we want to underline the importance of thoroughly considering the purpose for the research. Is it just about seeking self-promotion for the researcher and the study, or is the aim to somehow highlight or improve the situation of the population studied? We also strongly disapprove of research which seems to have no other purpose than to dwell on other people's misery. Second, we highlight the need for flexibility and continuity of ethical considerations during research processes considering vulnerable populations online. Ethics approval is not a 'green card' but as Haraway (2016) suggests we should be alert to the troubles that are inherent in online research. Third, we stress the importance for researchers to be aware of that doing online research with vulnerable populations can be emotionally challenging, and prepare a strategy for coping in situations of emotional distress. Fourth, we urge ethics review boards, those evaluating the ethicality of research projects, to be observant on how the researchers plan to safeguard their own wellbeing when doing emotionally consuming research work. Online research can hurt those posting *and* those researching.

REFERENCES

Beauchamp, Tom L. and Childress, James F. (2012) *Principles of Biomedical Ethics.* 7th edition. Oxford: Oxford University Press.

Behar, Ruth (1996) *The Vulnerable Observer: Anthropology That Breaks Your Heart*. Boston, MA: Beacon Press.

Buchanan, Elizabeth and Ess, Charles (2008) Internet research ethics: The field and its critical issues. In Kenneth Einar Himma and Herman T. Tavani (eds) *The Handbook of Information and Computer Ethics*. Hoboken, NJ: John Wiley & Sons. doi: 10.1002/9780470281819.ch11

Earls Larrison, Tara and Korr, Wynne S. (2013) Does social work have a signature pedagogy? *Journal of Social Work Education*, 49(2): 194–206.

Ess, Charles (2009) *Digital Media Ethics*. Cambridge, UK: Polity Press.

Granfelt, Riitta (1998) *Kertomuksia naisten kodittomuudesta.* [Stories about female homelessness.] Helsinki: Suomalaisen Kirjallisuuden Seura.

Granholm, Camilla (2016) *Social work in digital transfer – blending services for the next generation*. Helsinki: Mathilda Wrede-institutets forskningsserie 1/2016.

Haraway, Donna (2016) *Staying with the Trouble: Making Kin in the Chthulucene*. Durham, NC and London: Duke University Press.

Hardwick, Louise and Worsley, Aidan (2011) *Doing Social Work Research*. London: Sage.

Ikonomidis Svedmark, Eva (2011) Med nätet som fält: urvalstankar, känslostormar och etikproblem. *Kulturella Perspektiv – Svensk Etnologisk Tidskrift*, 2: 11–21.

Kuula, Arja (2006) *Tutkimusetiikka:. Aineistojen hankinta, käyttö ja säilytys.* [Research ethics: Finding, using and storing the data]. Tampere: Vastapaino.

Laitinen, Merja (2004) *Häväistyt ruumiit, rikotut mielet.* [The spoiled bodies and the broken minds]. Tampere: Vastapaino.

Markham, Annette N. (2006) Ethic as method, method as ethic: A case for reflexivity in qualitative ICT research. *Journal of Information Ethics*, 15(2): 37–54.

Markham, Annette and Buchanan, Elizabeth (2012) *Ethical Decision-Making and Internet Research. Recommendations from the AoIR Ethics Working Committee* (Version 2.0). http://www.aoir.org/reports/ethics2.pdf retrieved on 22.01.2015

McKee, Heidi A. and Porter, James E. (2009) *The Ethics of Internet Research: A Rhetorical, Case-based Process*. New York: Peter Lang.

Nonnecke, Blair and Preece, Jenny (2000) Lurker demographics: counting the silent. Paper presented at the *ACM CHI 2000 Conference on Human Factors in Computing Systems*, The Hague, 1–6 April.

Pope, A. (1713) *An Essay on Criticism*. (Second edition). London: Printed for W. Lewis in Russell-Street Covent-Garden.

Roberts, Lynne D. (2015) Ethical issues in conducting qualitative research in online communities. *Qualitative Research in Psychology*, 12(3): 314–325, doi: 10.1080/14780887.2015.1008909

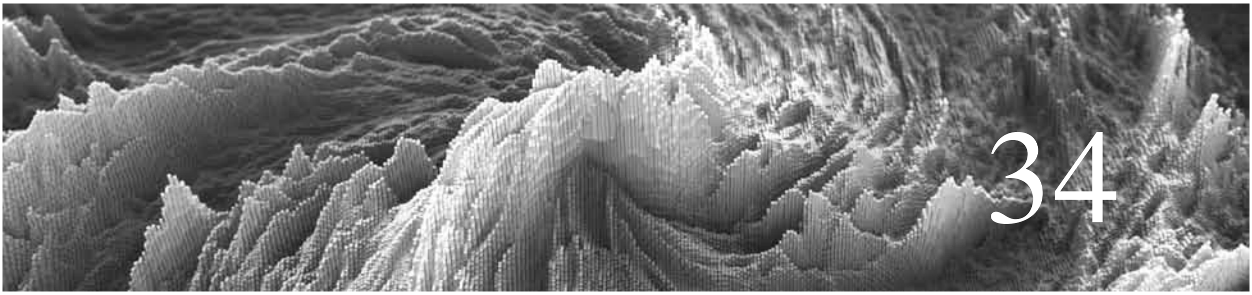
Svedmark, Eva (2016) *Becoming Together and Apart: Technoemotions and other Posthuman Entanglements*. Umeå: University of Umeå.

Sveningsson Elm, Malin (2009) How do various notions of privacy influence decisions in qualitative Internet research? In Annette N. Markham and Nancy K. Baym (eds) *Internet Inquiry: Conversations about Method* (pp. 69–87). Sage.

Stern, Susannah R. (2012) Encountering distressing information in online research: A consideration of legal and ethical responsibilities. In Jason Hughes (ed.) *SAGE Internet Research Methods. Volume 1: Core Issues, Debates and Controversies in Internet Research* (pp. 233–250). Sage.

van den Hoonaard, Will C. (2013) The 'Ethics Rupture' Summit, Frederiction, New Brunswick, Canada, October 25–28, 2012. *Journal of Empirical Research on Human Research Ethics*, 8(1): 3–7.

Walther, Joseph B. and Boyd, Shawn (2002) Attraction to computer-mediated social support. In Carolyn A. Lin and David J. Atkin (eds), *Communication Technology and Society: Audience Adoption and Use* (pp. 153–188). Cresskill, NJ: Hampton Press.



34

‘What If They’re Bastards?’: Ethics and the Imagining of the Other in the Study of Online Fan Cultures

Natasha Whiteman

INTRODUCTION

In recent years, scholars have called for those interested in contemporary audiences to pay more attention to persons and practices that do not fit the communitarian model that has sometimes been celebrated in audience research. In 2012, for example, the videogame scholar Mia Consalvo noted that ‘the ugliness of gamer culture’ is increasingly ‘being put on display for the wider world to see’, citing misogynistic abuse and harassment of female producers, journalists, gamers and researchers. Consalvo called for (in her case, feminist) projects to ‘seek out and investigate those who engage in such practices, to see how and why they do so. Without a better understanding of their own beliefs, we can’t adequately theorize their activities’ (2012: n.p.). A clear challenge was set down to explore ‘toxic gamer culture’ from the perspective of participants, one that researchers have perhaps been slow to take up.

To date, limited moves into the empirical study of the most ethically challenging elements of audience behaviour have been made (although, as I will discuss, there are exceptions). Yet it is notable that such calls, and researchers’ responses to them, have drawn attention to what is going on in online environments. During this time, a vision of the Internet as a particularly threatening and barbaric environment has taken grip. This imaginary has been escalated by media coverage of large-scale online misogyny, trolling and racism on social media platforms and websites such as 4chan and Reddit. An August 2016 cover line in *Time* magazine, for instance, proclaims that we may be: ‘[…] losing the Internet to the culture of hate’ (Stein, 2016). Online trolls are here blamed for ‘turning the web into a cesspool of aggression and violence’ (Stein, 2016) with attacks on female videogame scholars during 2014’s *#Gamergate* and on the actress Leslie Jones in relation to the 2016 remake of the film *Ghostbusters* highlighted. Hostile online practices are not new (see for example Williams, 2000; Lea et al., 1992; Reid, 1999) and, as historical studies have demonstrated so vividly, audiences have always misbehaved (see Butsch, 2000). Yet the visibility of recent events and way that media texts and fandoms have become caught up in these practices is clearly unsettling for those who celebrate more positive dimensions of audience creativity and participation.

Given these calls to scholarly action and the attention currently placed upon the fractious nature of online communication, this seems like a particularly apt moment to consider ethical issues relating to audience research with online subjects whose interests or behaviours might be regarded as 'unethical.' Whilst my starting point is an interest in academic responses to troubling forms of online activity, I am not concerned here with the search for best practice when dealing with certain groups, or with debating the moral status of specific audience practices. My focus in this chapter is instead on the nature of the exchange between the ethics of the researcher and researched. Specifically, how are research subjects objectified as ethical or unethical in accounts of research, and what forces do such objectifications exert on the warranting of methodological practice? This moves away from the more common consideration of role-related ethical choices relating to disclosure, participation, visibility and intrusion (de Laine, 2000: 102–109). In contrast, the consideration of the research regard presented in this chapter is concerned with the *visioning* of the other in research and, in particular, in exploring notions of contiguity/discontiguity between the ethics of the researcher and researched. This involves making a broader methodological point; that the others that we orient in relation to are always the product of a recontextualizing gaze – an important idea that sometimes gets lost.

These considerations have significant implications for online research. One central question explored in this context is whether we should treat online material as published text or as the utterances of individuals (see Whiteman, 2012). The latter – and how we might address the rights of the online subject – has increasingly become the focus of ethical reflection. Buchanan and Zimmer note that 'as the Internet has evolved into a more social and communicative tool and venue, the ethical issues have shifted from purely data driven to more human-centered' (2016: n.p.). Yet the ways that ethical values are attributed or denied in the objectification of online subjects, and how this might inform the production of ethical stances, remains under-examined. Instead, the general referential point '[human] subject' is typically regarded as an unproblematic entity in terms of its ethical status. This has focused attention on the protection and rights of individuals, but neglects the potential disruption to the researcher that subjects might provoke. It also leaves unchallenged the reification and mythologizing of ethical others in online research.

There is thus scope for innovation in moving beyond naïve humanism in Internet-based research. Yet, as the move between examples of offline and online studies throughout this chapter demonstrates, my concern is not just with the ethics of online inquiry. Whilst looking at accounts of offline research draws attention to complexities that need to be considered in the study of digital environments and activities, thinking about how we bring online subjects into being *as research* provides a useful distancing move that may also lead us to ask questions of the manifestation of offline subjects. Exploring this issue may also provoke a questioning of the allegiances and oppositions that are formed in the conduct of research and how these may become entrenched in ways that sometimes go unnoticed.

The particular area of scholarship that I am interested in is the field of fan studies: specifically, the study of media fandoms (communities and individuals devoted to media products and persons, such as television programmes, music, videogames and celebrities). In this area of research considerable attention has been paid to the identity of fan scholars in respect of the relationship between researchers and those they study. To date, however, considerations of the scholar/fan relationship have tended to assume that the fannish subject does not present a challenge in terms of potential ethical identification. This is partly because fan scholars have often focused on those with whom they share personal enthusiasms. This is not unique to fan studies research of course. As Pole notes: 'Many social researchers locate their work in the context of their own biographies where their studies spring out of a set of experiences integral to their own lives and careers' (2010: 163). Yet it means that discussions of the relationship between the researcher/researched in fan studies have commonly been underpinned by an expectation that the ethical sensibility of the researcher – in respect of their values and inclinations – is inherently, at some level, like, or *could be like*, that of the fan.

The limited consideration of how researchers might relate to 'problematic' others marks research on media fans as different from related bodies of scholarship. Studies of football fandom, for instance, have confronted discomfort with the other, and the ethical demands and risks of research in the context of violent and illegal activities in a more sustained manner (Spaaij & Geilenkirchen, 2011; Pearson, 2009; Giulianotti, 1995). As scholars of media fandom take steps towards the exploration of audience practices that may challenge our sensibilities and indeed safety, we now face similar problems. When the fan becomes strongly marked as *other* to our sympathies, the question becomes *how/do* we engage with *them*? As I have suggested, responding to this question might lead us to consider how we relate to apparently more unproblematic others.

FROM THE ETHICS OF STUDYING 'DEVIANT' COMMUNITIES TO THE FORMATION OF ETHICAL SUBJECTIVITY IN ACCOUNTS OF RESEARCH

The literature on qualitative inquiry offers a plenitude of guidance for those researching subjects who are marked as different from the 'norm' through their vulnerable, marginalized, deviant or elite status. Lasagna (1969) for instance, considers the inclusion of 'special groups' in experimental research, including prisoners, children, and the physically or mentally ill. As Blee suggests, orientations in ethical concerns and methodological approaches often depend on *who* we are dealing with:

> Traditionally, oral historians have emphasized caution, distance, and objectivity in interviews with members of elites and egalitarianism, reciprocity, and authenticity in interviews with people outside elites. However, this epistemological dichotomy reflects implicit romantic assumptions about the subjects of history from the bottom up – assumptions that are difficult to defend when studying ordinary people who are active in the politics of intolerance, bigotry, or hatred. (1993: 597)

Such objectifications may also explain why certain groups receive more academic attention than others. Given inequalities in society, the 'reticence to study the elite and powerful remains a scholarly anomaly' (Aguiar, 2012: 1).

The development of specialist guidance relating to the study of 'deviant' groups draws on a long history of fieldwork in fields like sociology (Klockars & O'Connor, 1979; Becker, 1963), criminology (Johnstone, 2005) and anthropology (Freilich et al., 1991). Such studies have seen researchers working in proximity to dangerous, deceptive, challenging and taboo practices and entities (including cults, criminals and 'deviants'). More recently, the move to the Internet has focused attention on online practices such as trolling (Philips, 2015) and abuse and victimization in gaming communities (Salter & Blodgett, 2012; Downing, 2010). 'Special' online communities have also become the focus of scholarly attention. These include cryptomarkets (Barratt & Maddox, 2016; Martin & Chirstin, 2016; Martin, 2016), pro-anorexia communities (Brotsky & Giles, 2007), sites devoted to pathologized and/or illegal forms of sexual behavior (Maratea, 2011; Durkin et al., 2006) and extremist groups (Ekman, 2014; De Koster & Hautman, 2008; Lauder, 2003). Such work has explored established methodological issues such as the value of covert observation (Brotsky & Giles, 2007; Lauder, 2003) and direct participation (Barratt & Maddox, 2006), as well as apparently newer problems such as the technological challenges of researching the 'dark web' (ibid.) and the analytical challenges of working in an increasingly 'nonymous' Internet (see Hughey & Daniels (2013) on how this drives racist discourse towards less visible, coded and private formations).

In some cases, researchers have assessed the ethical status of 'deviant' online activities in a way that reflects 'correctionalist' approaches to criminology (see Johnstone, 2005). In others, the concern has been with obtaining an emic perspective on practice, valorizing stigmatized groups by exploring their production of ethical stances (see Whiteman (2015) on ethical 'competence' and 'performance' in academic work on filesharing communities). As evident in the contrast between the labels 'deviant' and 'stigmatized', researchers can thus be seen to take different 'sides' (Becker, 1967).

TOWARDS THE ETHICS OF THE OTHER?

The idea of the researcher as an authority imposing their ethical practice upon the researched, who is constituted as an entity with little autonomy, has been dismantled by recent waves of qualitative research. Accounts of fieldwork and reflections on ethical practice have emphasized that in doing research, scholars are presented with competing values and need to negotiate 'diverse ethical practices' (Christensen & Prout, 2002: 492). Issues such as the 'clash of identities between researchers and their informants' and the need to 'reconcile personal differences and similarities with these respondents' (Hertz, 1997: viii) become salient.

Alongside this recognition of competing ethical principles and values, the idea that researchers' ethics should be *strongly* informed by those of the researched has also become increasingly influential. The suggestion here is that the ethics of the researcher – in respect of the design and conduct of research, for instance – should be shaped by the expectations and understandings of what constitutes ethical practice in the context of the researched setting. This move challenges traditional approaches that might seek to impose a constraining research gaze onto subjects of inquiry. In contrast, the aim is to move towards dialogue or indeed collaboration, where the nature of *our* practices is informed by *theirs*.

The idea that research should involve an aligning move with the ethics of the researched can be seen in many of the aspirations promoted in qualitative research ethics writing: the valuing of participation, reciprocity and egalitarian relationships (Herman & Mattingly, 1999); the idea that scholars working with children should take as their starting point the notion of ethical symmetry between child and adult subjects (Christensen & Prout, 2002); and moves towards compassionate, communitarian and indigenous ethics (see Denzin & Giardina, 2007; Christians, 2005). Denzin and Giardina (2007), for example, call for a methodology 'of the heart' that embraces an 'ethics of truth grounded in love, care, hope, and forgiveness' (p. 12) and promote models of ethics in which

> subjects and researchers develop collaborative, public, pedagogical relationships. The walls between subjects and observers are deliberately broken down. Confidentiality disappears, for there is nothing to hide or protect. Participation is entirely voluntary, hence there is no need for subjects to sign forms indicating that their consent is 'informed'. The activities that make up the research are participatory; that is, they are performative, collaborative, and action and praxis based. Hence, participants are not asked to submit to specific procedures or treatment conditions. Instead, acting together researchers and subjects work to produce change in the world. (p. 20)

The researcher/researched relationship is thus configured as involving a dialogic exchange based on equal relations, or in more extreme forms tilts in its weighting towards identification with the ethics of the researched. A stark alternative to such thinking is presented; one of an institutionalized exploitation, oppression, colonization, and research 'on' rather than 'with' other human beings (Denzin & Giardina, 2007: 25).

Qualitative researchers and those they study have thus become marked as needing to be entwined in a particularly intimate relationship. Yet notes of caution and criticism in respect of such thinking *have* been voiced. Whilst we might regard the ethics of the researched as one important domain of ethics, the danger of anchoring too strongly has been discussed (Whiteman, 2016, 2012). Others have argued for the need for distance in the localized negotiation of an ethics of care (see Hammersley, 2015) and challenged the utopian basis of approaches to ethics that appear to rest upon; 'the establishment of a communal or solidaristic form of social relation between researcher and researched' (Hammersley & Traianou, 2014). Hammersley and Traianou argue that such approaches can be totalizing in their 'envisioning' of the researched (2014) and probe the limits of such thinking:

> Is it being suggested that this new ethical approach should be adopted whichever group of people is being researched, so that for example it would be appropriate in study of investment bankers or Right-Wing terrorists? [..] Or is the implication that researchers should only study those groups with whom they share a sense of political or ethical solidarity? (Hammersley & Traianou, 2014)

Despite such criticisms, researchers are increasingly encouraged to move towards the subjects of research in respect of the handling of ethical issues. Working out how we might present our ethics as being informed by the other can be challenging in the face of competing codifications of ethics and informal sensibilities that may provoke confrontations. Or it may seem to involve more comfortable relations when drawing together with those who appear familiar or share certain sympathies. We might presume that 'being ethical' would be easier if we share interests with, or *are like*, *them*. Yet this would be to underestimate the complexity and instability of our 'imaginative construction' of the other (Geertz, 1977: 799). Looking to accounts of the shifting nature of identification in research reveals this complexity and undermines the notion of 'similarity' or 'difference' between 'us' and 'them' as an anchor.

UNSETTLING ETHICAL 'SIMILARITY' AND 'DIFFERENCE'

The assertion of likeness between researcher and researched is often valued from a methodological perspective. As Keenan (2012) has described, 'similarity of experience' has been configured 'as key to accessing information' in research on sensitive topics:

> Similarity is seen to enable connection, to suggest understanding and to allow for the greater flow of information. (p. 94)

In this way shared experience becomes valued in respect of the production of authentic knowledge. Yet, as Keenan notes, the idea of commonality as an anchor has been challenged by the acknowledgement of the complexity of relations and interactions in social research (Keenan, 2012: 95). The notion of similarity between researcher/researched is also linked to the valuing of empathy in qualitative inquiry. This suggests that researchers are able to connect with the other – 'the power of projecting one's personality into (and so fully comprehending) the object of contemplation' (Oxford English Dictionary) – an idea that has taken different forms in the history of social research (see Outhwaite, 1975).

Yet this idea has also been critiqued. In defending his right to conduct research with groups who are not 'like' him, Pole presents a strong challenge to 'assumptions of certainty and truth which might lie behind calls for methodological symmetry [between researcher/researched]' (p. 166). He suggests that:

> the intention of empathy could be seen as akin to attempts by quantitative researchers to ensure that the best structural conditions apply to issuing and administering a questionnaire. Moreover [..] in suggesting an automatic or inevitable empathy between women researchers and their research participants, or between researcher and researched of similar ethnic backgrounds, would surely be to engage in a form of essentialism that privileges one social or cultural characteristic or set of characteristics over another. (p. 165)

Accounts of revelations when those who appear to share interests reveal themselves as *other* also unsettle the notion of similarity between researcher/researched. In a study of young British migrants, Bott (2010) reflects on how the valuing of research relationships may change over time. She describes her surprise at experiencing racist activity in the context of groups who she had not deemed to be 'deviant' when she began her project, asking:

> [W]hat happens when research subjects, whose 'difference' from the investigator had initially seemed relatively insignificant, become increasingly 'other' to her through the very data collected? [...] How should we handle the process of sensing and experiencing growing differences and their potential to instigate or exaggerate our 'othering' of participants, when that process rests partly upon our political reactions to data we find offensive because it does not bed well with our own beliefs and standpoints? (pp. 160–161)

Not all researchers present themselves as seeking to align with the ethics of the researched. 'Compassion' and 'empathy' may not always be possible or desirable. Blee (1993) notes her hesitancy in doing research with women who were members of the Ku Klux Klan in the 1920s and asks whether '[it is] possible to fully reconcile a scholarly approach to understanding racist groups and their members with a politically progressive interest in seeing these groups as the enemy?' (Blee, 1993: 20). This provides a nice account of *not aligning*:

> In my interviews with former Klan members [...] I made few efforts to establish such rapport or to shy away from controversial topics. Indeed, I was prepared to hate and fear my informants, to find them repellent and, more important, strange. I expected no rapport, no shared assumptions, no commonality of thought or experience. (1993: 604)

It is worth noting that seeking to extract ourselves from notions of empathy may drive research into a positive/normative dichotomy that is unsustainable. As Geertz notes, 'We can apprehend [another people's or another period's imagination] well enough, at least as well as we apprehend anything else not properly ours; but we do so not by looking *behind* the interfering glosses which connect us to it but *through* them' (1977: 799, emphasis in original). Asserting a 'neutral' research gaze can be regarded as just as colonizing as a 'valued' one when it asserts 'what is really happening' within the empirical but potentially leaves the glossing principles of the research gaze unchallenged. Blee's account also demonstrates how those we may think we could never identify with might be revealed as likeable, an inversion of the experience described by Bott. She describes how: 'Although it might be comforting if we could find no commonality of thought or experience with those who are drawn into far-right politics, my interviews suggest a more complicated and disturbing reality' (Blee, 2003, 1993: 604–605).

These examples demonstrate how, in the negotiation of the ethics of the other, both similarity and difference cannot be held as static, stable or reliable states but as constructions; empathy cannot be regarded as a necessary mode of engagement or warrant for research; and, where empathy *is* claimed, questions need to be asked about how the other is being constituted. In the writing that I have cited, the primary focus is on the subjectivity of the researcher as a site of reflexivity and ethics (and as herself objectified and othered by participants (Bott, 2010: 168)). In contrast, my interest in what follows is how the subjectivity of the other is discursively imagined and recruited. This picks up on the idea of the 'envisioning' of research communities in Hammersley and Trianiou's criticism of new ethical frameworks, but extends it into a more sustained consideration of how we might understand the role that the attribution of ethical status to the researched plays in shaping methodological practice. The key point that needs to be made here is that – whether they are marked as similar or different, friend or foe – the ethics of the researched is the product of a recontextualizing gaze, rather than a graspable point of security. I will expand on this in what follows.

OBJECTIFYING THE OTHER: THINGS AND PERSONS

Fuchs's discussion of how complex systems become formulated into persons or things in *Against Essentialism* (2009) is a useful point of reference for considering the role that the attribution of moral value plays in the objectification of others. Fuchs marks out different continuums against which the observed of social research might be positioned. These include two oppositions that operate in relation to knowledge. First, 'understanding' versus 'explanation', and second, the moral closeness versus distance of the observed system from the observer. He suggests that in relation to these, systems may become more person-like or more thing-like:

> Ideological observing moves the observed close to the thing-pole of the continuum. The opponent is caused by social forces without being aware of them. If 'they' are stuck in ideology, they are unwilling or unable to see through their maze of deception and need to be explained from the outside. Then 'they' become a target for 'our' science and explanation, not equal hermeneutic partners in conversation. (p. 105)

This is contrasted with how we approach those with whom we are engaged in socially close and intimate relations. Whilst distance pushes the observational gaze towards explanation, closeness presents the promise of *verstehen* (p. 104):

> Here 'individuals' occur, and each is supposed to appreciate and understand the other as 'special'; not 'just' as a particular configuration and outcome of empirical forces and causes. In intimacy, agency terms are more expected and appropriate [...]. As an intimate relationship breaks up, of course, mutual explanations and attributions may change, moving once again close to the thing-pole. (p. 106)

One of the productive things about Fuchs's use of 'system' and person-versus-thing distinction is that it helps to force a break from common sense or romantic notions of the world and the subjects that frequent it. From this perspective, the move towards the ethics of care and love discussed earlier can be seen to attribute a sense of personhood to the subjects of research; configuring the negotiation of ethical issues as an apparent exchange between equals based on the possibility of 'deep' understanding of the other (in contrast to models that would reduce this possibility and impose object status).

The question that might then be asked is not how we should approach *x* or *y* type of group or individual, but how sensitive we are to attributions of personhood and thingness in research writing and how these are achieved in relation to moral values. Whilst my focus is primarily on the attribution/denial of ethical status to those who are marked as pathological, this can also be extended to consider the familiar and intimate. By configuring both 'understanding' and 'explanation' in the uncomfortable terms of objectification, Fuchs also serves to challenge the notion of empathy as offering authentic shared experience with something that 'is'. This suggests that we pay attention to the observational gaze and moral distance/contiguity that is established in constituting the other as the focus of research, and how this relates to how their ethics 'speak' to ours. Holding onto these ideas, I now want to turn to think about how fan studies scholars orient in relation to an objectified vision of dis/contiguity between the ethics of the researcher and researched, and how this may form fan subjects into person or thing-like entities.

FAN STUDIES AND THE ETHICS OF RESEARCHER/RESEARCHED

Assuming Contiguity

As I suggested in the introduction, fan studies is a field of scholarship in which research is often marked by an intensity of personal enthusiasm for the object of study. The result of this is that fans tend to be presented in a favourable light. As Gilbert notes:

> The concept of fans as powerful, as a positive force subverting the domination of mainstream popular culture, has pervaded scholarship and is evident in the consistently positive perspective from which fans are described. (2012/2016: 167)

This emphasis is one of taste but also politics, with early fan studies having been in part a response to negative characterizations of fans as feminized and obsessive. In 1992, Joli Jenson wrote that 'The literature on fandom is haunted by images of deviance' (p. 9) and a concern with notions of pathology can be seen to persist today. This is evident in scholarly interest in the representation of fandom in the media (Bennett & Booth, 2016; Gilbert, 2015; Duits et al., 2014) and inter and intra-fandom stereotyping and the negotiation of the 'good fan' (van de Goor, 2015; Stanfill, 2013). In writing on fans, the possibility that tensions might exist between the ethics of researcher and researched has gone largely unexamined. In contrast, we see a general presumption of contiguity between the ethical subjectivity of researcher and researched.

One location where this is evident is in discussion of the relationship between scholars and those they study. The way that fan studies research tends to be rooted in personal enthusiasms for fannish objects and practices has led to lengthy reflections on the nature and status of academic fans. As Matt Hills (2012) notes, the 'scholar fan' (or 'acafan') – the 'hybrid identity of the scholar who is also a fan' (p. 12) – has become an established figure in media studies. Writing on the need for 'proper distance' in the positioning of fan scholars, Hills presents a critique of two dominant responses to this figure:

> the 'valorising' approach where scholar-fans are superior to scholars without fan passion/knowledge, and the 'levelling' or dismissive approach, where scholarship and fandom can co-exist without any difficulty or tension and where the need for 'acafandom' as a term is contested. (p. 17)

Each of these responses can be seen to be underpinned by a sense of connection between the fan and academic in terms of the sharing of ethical sensibilities. In expressions of the former: 'scholar and fan identities are rendered contiguous, or brought closely together' (p. 15). Expressions of the latter suggest that 'fan and academic identities can be experienced as unified, integrated and continuous' (p. 16), and that 'fandom and scholarship can be smoothly aligned' (p. 16).

Recruiting Silverstone's conceptualization of 'proper distance', Hills challenges these two positions, arguing for the need for researchers to be not too close to – or distant from – both fan and scholarly positions. Hills goes on to consider the multiplicity of fan/academic moral economies, and in doing so challenges the poles ('fan' and 'academic') in relation to which this positioning is established. His analysis seeks to problematize both the identity of the fan and scholar, and draws attention to the visions of fandom that are produced in fan studies. It suggests that whilst 'they' might be diverse, there are absences in those being represented by fan scholars (something that contemporary scholars are endeavouring to address in the study of marginalized fandoms/texts: see for example, Pande, 2016).

Yet it is notable that the examples of fandom presented by Hills are not really troubling ones. One example of a fan response that seems unsettling *is* introduced, but this involves fans failing to critically engage with racial stereotypes in an episode of *Doctor Who* (see Hills, 2012: 24) and hence appearing to forgive racism within a text (but not being racist themselves). Whilst drawing attention to important issues of representation in fan studies, Hills seems to assume that what is typically being negotiated in this field is a relationship with an ethically unproblematic other.

Writing on the idea of 'fans first' (Busse, in press; Busse & Hellekson, 2012; Hellekson & Busse, 2009) presents a similar presumption of contiguity between researcher and researched. In this guidance for doing ethical research in fan studies the emphasis is on fans as a key point of authority in the constitution of scholars' ethical stances. This perspective can be linked to fans' suspicion and hostility towards 'drive-by' researchers who might exploit fan communities. In contrast to those who might disrespect or undermine fan cultures, this work suggests that those studying fans should take their lead from the ethical expectations of fan communities. As Busse (in press) notes, doing so can be difficult in practice. Yet these aspirations lead '*fans first*' to promote a certain type of emic research – one that is informed by an insider perspective and, where possible, involves active participation that is overt and sanctioned by the community. The ethics of the researcher are here configured as strongly aligned with those of the researched context, and a particular type of imagined – and, again, ethical – fan subject is invoked (see Whiteman, 2016).

But what if the fan object or practice inspires disgust or hatred? The challenge would then be how to achieve 'proper closeness' rather than proper distance, and to work out how one might put such fans 'first'.

'Unethical' Fans

The 'unethical' status of fans may be attributed to their behaviour or to the objects of fandom that are celebrated. Nash (1999) provides an early consideration of the former in a case study of hostility in an online community devoted to the MTV series *Beavis and Butt-Head*. Her account describes how fans on the 'predominantly homosocial' (Nash, p. 16) newsgroup alt.tv.beavis-n-butthead aggressively worked to close down postings 'written in the persona of a self-identified gay man suggesting a gay reading of the show or its future development' (p. 16). The posts she introduces offer an extreme case of fan disagreements as flaming: insults (p. 17), threats of physical violence, and group members adopting the mannerisms of characters' voices 'through which to speak homophobia' (p. 17). Elsewhere, scholars have explored practices that are attributed deviant status by others, such as how certain fan practices become othered and marked as shameful within fan communities (see Larsen & Zubernis, 2012). Studies of antifandom and intra-fandom tensions and flaming have similarly led to the suggestion that scholarship that 'valorizes the community, agency, and empowerment in audience activity […] can be challenging to reconcile with the contentious and fragmented landscape of the actual audience' (Gilbert, 2012/2016: 167).

In Nash's study, whilst the behaviour of fans is marked as problematic, the series *Beavis and Butt-Head* is also presented as being denied external legitimacy due to its 'stupidity, anti-political correctness, or offensive crudity' (1999: 9). Other scholars have explored fans' orientations in relation to objects that may become problematic for other reasons. How, for example, fans of the wrestler Chris Benoit negotiated the aftermath of Benoit's murder of his wife and son and subsequent suicide (Phillips, 2015). Similarly, how fans of the band Lostprophets dealt with their fan identity following the lead singer's sentencing to 29 years in prison for sexual offences against children (Jones, 2016).

Kingsepp's (2006) interview-based study with 'WWII Fanatics' explores the appropriateness and potential discomfort of using the term 'fan' to think about relations to the Second World War. Here, the object of fannish interest is again presented as problematic – with the author describing how the members of this community work to differentiate themselves from Neo-Nazis. The author emphasizes the role that (fannish) critical reason plays in this community. She notes that 'Neo-Nazis are, I would say, not welcome, as they seem to be considered stupid and violent – qualities that are not in high esteem within the community' (p. 232), and describes how 'it is not considered suitable to role-play a SS Strafgruppe or a KZKommandant (even though this had been explored in the earlier years)' (p. 236). The possible danger of the group is closed off in this emphasis that 'the threat of Neo-Nazism is in fact avoided by them putting their [historical] interest and knowledge into practice within a non-political frame […]' (p. 238).

Approaching 'Unethical' Fans

In the studies above by Philips, Jones, and Kingsepp, fans are presented as dealing with difficult events and morally questionable objects, but their inherently ethical status is not questioned by the scholar (although fans may be questioning this themselves, and may be the target of pathologization by the tabloid press as Jones describes). A sense of closeness between the researcher and researched is preserved. In Kingsepp's study, whilst the author's relationship to the researched is not explicitly discussed, the fact that these potential fans are presented as NOT being Neo-Nazis seems to alleviate possible discomfort in carrying out this reception study. Instead, these individuals are objectified as ethical entities interested in a problematic and complex object. Nash's *Beavis and Butt-Head* article establishes a different stance. Whilst this piece includes speculations about why posters might assume character's voices (potentially to distance them from the utterances they are making, for instance (p. 17)) such conclusions are not based on direct engagement with the researched. The site's participants are constituted by their usernames and online utterances and Nash's explanations of their actions – explanations that are underpinned by a critical and distanced stance that marks them as an (unethical) other.

We can see comparable moves in Bury's (2008) more recent study of explicitly homophobic statements in a public HBO online fan forum for the television series *Six Feet Under*. This adopts a similar arms-length stance to that established by Nash and has a similar focus: how fans' articulation of interpretive responses to storylines and episodes promote a heterosexist logic whilst pathologizing gay sex and desire. Bury positions the study in relation to the premise that typically fans engage in 'good' practices; 'the reworking fans do is undertaken to accommodate progressive interests, and that fan practices are ultimately bound up with larger democratizing social and cultural forces' (p. 59). She then notes her surprise at coming across fan responses that do not meet this expectation:

> As a fan and a fan scholar, I naively assumed that part of the appeal of a series like SFU would be the queer characters and storylines. I also assumed that homophobes would position themselves as 'anti-fans' and either trawl the Internet forums to cause trouble or stay clear. (p. 61)

Distance from these unexpected fan responses is then established in the author's unobtrusive focus on posting activity, her approach to anonymizing participants by '[identifying] them by the episode number for the thread and the sequence in which they posted to that thread' (2008: 78), and the decision not to collect personal data about them (ibid.). Her account establishes an explicitly critical external stance towards participants who make homophobic utterances. Responding to one post, she notes that 'This claim is, of course, not only clearly inaccurate but clearly heterosexist' (p. 65), and she describes how those members who challenged explicitly homophobic statements 'themselves functioned to erase gay desire and re-inscribe normative sexualities and identities' (p. 76). These expressions of fandom are presented as anomalous, uncomfortable and unexpected, with the researched pushed towards the status of things as existing in an other domain. The 'ideological' objectifying gaze here can be seen to be rooted in an alliance with ‘progressive interests,’ one that presents a rupture of possible identification with the fan subjects that are being confronted.

This positioning is very different from Bury’s earlier ethnographic work in women-centred online fan cultures (2005). Here, objectification serves to attribute personhood and establishes contiguity between the researcher/researched. This is achieved in different ways in the study’s focus and use of methods: the interest in friendship relations between community members; the use of participant observation and questionnaires; asking members’ permission for using contributions from these closed lists and setting up a research list when permission was not granted; using pseudonyms chosen by subjects rather than numbered pseudonyms (Bury here notes, ‘I believe that maintaining ownership over one’s name is a discursive strategy that is linked to autonomy of “voice”’ (p. 29)); including her own participation in the data cited; and sharing her research with her informants. Bury describes how: ‘By putting my practices “on the line” in the ways described above, I was in the end able to develop relationships with the participants based on trust and respect’ (p. 30).

In drawing this comparison between these two studies I am not criticizing the use of covert observation. I am instead interested in the moral dimension of methodological shifts in relation to the objectification of fans as <things to be explained> versus <persons to be understood>. In this example we see how one scholar approaches fan practices in ways that constitute very different types of subjects. Looking at different studies of the same fan phenomena also provides a way of contrasting valued objectifications of the other.

Here, my focus is on studies of school-shooting fan communities (Daggett, 2015; Rico, 2015; Oksanen et al., 2014; Paton, 2012). Paton (2012), deploys the term ‘deviant’ as a commonsense term in the study of *YouTube* networks relating to school shootings. This report of an ethnographic study – one concerned with understanding ‘fans’ interest in school shootings and determin[ing] if participation could lead to deadly outcomes’ (p. 206) – includes the presentation of screenshots from videos posted by school shooters as well as fan postings and interactions. This serves to hold school shooters up alongside fans as related groups, with the observational gaze configured in the terms of ‘monitoring’ and ‘scrutiny’ (p. 207). In outlining the methodology, Paton describes how:

> Investigating deviant groups and pursuing online ethnography requires tackling ethical issues, which in turn orient methodological outcomes. We decided to keep a low profile by neither stating our status as a researcher, nor creating a fake identity to partake in the online activities. [...] Deep immersion was nonetheless conducted during three years of fieldwork via active monitoring, including strategic phases of increased attention (during periods of one to three months). (p. 207)

Paton’s (2012) account explores the practices of this ‘deviant group’ as constituted in the content of their productions and interactions (‘The style of the deviant group is blatantly revealed in self-produced videos and personal pages’ (p. 219)). This includes the tensions and justifications for fannish interest as voiced by group members within the sites (including explicit assertions of non-identification with violent practices (p. 224)). The focus is on what this ‘peer group’ as a ‘they’ are doing, with the conclusion suggesting that the community’s primary motivation is *not* the promotion of violence ‘but support for aspirations of individuality and defence of reversed roles on society’s side lines’ (p. 225). Whilst this problematizes simplistic characterizations of such groups as cheerleaders for the violent actions of school shooters, Paton’s acceptance of the ‘deviant’ status of the researched appears linked to a denial of emic understanding/closeness and the establishing of a distanced approach that emphasizes explanation rather than the promise of more ‘empathetic’ ‘understanding’.

In her interview-based study with members of a Tumblr community devoted to the Columbine shootings, Daggett (2015) establishes a different orientation, one that shifts towards an emic perspective that more intensely challenges the pathologizing of such groups as deviant. She draws attention to the pathologized terms by which such groups have been described (p. 45), critiques earlier studies for 'conflating sympathy or empathy' with school shooters 'with admiration or glamorization' (p. 51), and directly challenges Paton's study for being informed by an effects logic of media influence and for implying 'that these social media participants in some way validate shooters' (p. 52). Daggett's account, in contrast, seeks to

> challenge the assumptions that have so far grounded academic understandings of these communities as deviant by highlighting the incongruity between these assumptions and this community's 'lived' experience. Instead, this study reveals the value of these individuals' passionate interest despite the largely unquestioned stigma they face. (p. 46)

Here, these groups can be seen to be presented as rationalizing or re-principling the actions that they comment upon, just as the researcher works to strongly re-principle their actions away from a deviant status.

CONCLUSION

> Whatever is far outside the moral boundaries separating 'us' from 'them' acquires a more thing-like character, implying that 'they' cannot participate as equals in 'our' constructions of 'their' behaviors. The reason we are not sure what bats feel is that bats are not pets, while dogs are – and so Searle (1992: 74) is ready to grant consciousness to dogs, but not 'fleas, grasshoppers, crabs, or snails'. But Searle may change his mind. (Fuchs, 2009: 105)

This chapter's focus on the relationship between the ethics of researcher and researched was inspired in part by an in-class discussion where my students argued that a methodological action (the taking on of a false identity by a researcher within an online community) was acceptable in one online context (the racist English Defence League (EDL) group), but not in another (a self-help group). This distinction appeared to be unsettled when the students considered the case of an EDL parent whose daughter had recently disappeared and might be seeking online support; should they also be denied the rights that the students would give to others? The students were suddenly unsure. This example draws attention to the ways that valued judgements about social categories and groupings may be used as the basis for the justification of ethical decision-making in online research. However, it also demonstrates – as I have explored in this chapter – how naturalized or common-sense distinctions can come undone when they are put under pressure.

So what if they (appear to be) bastards? I have suggested that the answer to this question is that it makes no difference in terms of the production of ethical stances. Whether we deny ethical status or attribute ethical authority, in establishing ethical positions we are engaged in the same objectifying practice. From this perspective, *any* judgement as to the status of the researched is a rationalization that must be interrogated. Fuchs states that 'it does not matter whether the system is a person or a thing, since "personhood" and "thingness" are the outcomes, not causes, of observations, attributions, and cultural work' (p. 107). The same can be said in respect of the moral status of others. Given this, moves to ontologize and naturalize the basis of ethical distinctions need to be placed under scrutiny. Whilst studies of 'deviant' groups often focus on the management and negotiation of 'unethical' others, I have suggested that attending to how we approach such others may also encourage a consideration of the values that are brought to bear in the study of those with whom we think we can more easily identify. Looking at how we deal with those that challenge us may therefore not just lead us to question how our sympathies inform our practice. More broadly, it may lead researchers to question the nature of the observational gaze involved in the production of ethical stances across different groups and settings, and across both online and offline domains.

This chapter has drawn attention to two dimensions that might be taken into account when questioning this gaze: whether we are positioning from an etic or emic perspective, and our propensity to *know* the other (which I have discussed in the terms of 'understanding' or 'explanation'). These dimensions can be seen to configure the researched in valued terms as more or less like a person or thing, and this may have significant implications in respect of the research design decisions that we make. When we deny the legitimacy of the other in online research, are we perhaps more inclined to move towards text approaches drawing on the public domain status of content? Does the notion of ethical contiguity become 'naturally' tied to the use of participant observation, whilst a priori etic stances that might define groups as 'this' or 'that,' become aligned with unobtrusive observational methods? Such potentially discomforting questions have not yet been confronted by Internet researchers head on.

There are also important implications here for specific fields of scholarship. Henry Jenkins (2007, n.p.) has suggested that

> […] if fan studies is going to remain a viable area of research, we necessarily need to broaden the range of theoretical and methodological perspectives which get brought to bear upon it. We need to expand the range of fan cultures we study and the kinds of fan productivity we talk about.

In the terms of fan studies, the issues discussed above might lead us to problematize what we mean by the 'visibility' of fans (and in a broader sense, media audiences) in the project of disciplinary reflection: when they are 'present' in front of the gaze but configured as things, for instance? It might also lead us to extend considerations of the diversity of academic representations of fans in the terms of ethics; specifically, are we neglecting the study of those who we do not like? More broadly, to what extent is the marginalization of apparently deviant voices regarded as a problem across other fields of online research? In our ongoing reflections on ethical and methodological approaches to the study of online subjects, there is therefore a great deal of value in considering whether, and how, 'we' treat 'them' as 'dogs' or 'bats'.

ACKNOWLEDGEMENTS

Many thanks to Russell Dudley-Smith, Alison Harvey and Tom Phillips for their comments on earlier versions of this chapter. Thanks also to Lucy Bennett for pointing me towards a number of readings in the literature on 'deviant' fans.

REFERENCES

Aguiar, Luis L. M. (2012) 'Redirecting the Academic Gaze Upward', in Luis L.M. Aguiar and Christopher Schneider (eds) *Researching Amongst Elites: Challenges and Opportunities in Studying Up*, Abingdon, Oxon: Routledge, pp. 1–26.

Barratt, Monica J. and Alexia Maddox (2016) 'Active Engagement with Stigmatised Communities through Digital Ethnography', *Qualitative Research*, 16(6), 701–719.

Becker, Howard S. (1963) *Outsiders: Studies in the Sociology of Deviance*, New York: The Free Press of Glencoe.

Becker, Howard S. (1967) 'Whose Side Are We On?', *Social Problems,* 14(3), 239–247.

Bennett, Lucy and Paul Booth (eds) (2016) *Seeing Fans: Representations of Fandom in Media and Popular Culture*, Bloomsbury.

Blee, Kathleen M. (1993) 'Evidence, Empathy, and Ethics: Lessons from Oral Histories of the Klan', *The Journal of American History*, 80(2), 596–606.

Blee, Kathleen M. (2003) 'Studying the Enemy', in Barry Glassner and Rosanna Hertz (eds) *Our Studies, Ourselves: Sociologists' Lives and Work*, Cary, NC: Oxford University Press, pp. 13–23.

Bott, Esther (2010) 'Favourites and Others: Reflexivity and the Shaping of Subjectivities and Data in Qualitative Research', *Qualitative Research*, 10(2), 159–173.

Brotsky, Sarah and David Giles (2007) 'Inside the "Pro-Ana" Community: A Covert Online Participant Observation', *Eating Disorders: The Journal of Treatment & Prevention*, 15(2), 93–109.

Buchanan, Elizabeth and Michael Zimmer (2016) 'Internet Research Ethics', *Stanford Encyclopedia of Philosophy*, http://plato.stanford.edu/entries/ethics-internet-research/ (last accessed 25 August 2016).

Bury, Rhiannon (2005) *Cyberspaces of their Own: Female Fandoms Online,* New York and Washington: Peter Lang.

Bury, Rhiannon (2008) 'Setting David Fisher Straight: Homophobia and Heterosexism in *Six Feet Under* Online Fan Culture', *Critical Studies in Television: The International Journal of Television Studies*, 3(2), 59–79.

Busse, Kristina (in press) 'The Ethics of Studying Online Fandom', in Suzanne Scott and Melissa A. Click (eds) *The Routledge Companion to Media Fandom*, Routledge.

Busse, Kristina and Karen Hellekson (2012) 'Identity, Ethics, and Fan Privacy', in Katherine Larsen and Lynn Zubernis (eds) *Fan Culture: Theory/Practice*, Newcastle, UK: Cambridge Scholars Publishing, pp. 38–56.

Butsch, R. (2000) *The Making of American Audiences: From Stage to Television, 1970–1990*, Cambridge: Cambridge University Press.

Christensen, Pia and Alan Prout (2002) 'Working with Ethical Symmetry in Social Research with Children', *Childhood*, 9(4), 477–497.

Christians, Clifford G. (2005) 'Ethics and Politics in Qualitative Research', in Norman K. Denzin and Yvonna S. Lincoln (eds) *Handbook of Qualitative Research*, 3rd edn, Thousand Oaks, CA: Sage, pp. 139–164.

Consalvo, Mia (2012) 'Confronting Toxic Gamer Culture: A Challenge for Feminist Game Studies Scholars', *Ada: Journal of Gender, New Media and Technology*, 11(1). http://adanewmedia.org/2012/11/issue1-consalvo/ (last accessed 26 August 2016).

Daggett, Chelsea (2015) 'Eric Harris and Dylan Klebold: Antiheroes for Outcasts', *Participations: Journal of Audience and Reception Studies*, 12(2). Available online: http://www.participations.org/Volume%2012/Issue%202/4.pdf (last accessed 26 August 2016).

De Koster, Willem and Dick Houtman (2008) '"STORMFRONT IS LIKE A SECOND HOME TO ME": On Virtual Community Formation by Right-Wing Extremists', *Information, Communication & Society*, 11(8), 1155–1176.

de Laine, M. (2000) *Fieldwork, Participation and Practice: Ethics and Dilemmas in Qualitative Research*, London and Thousand Oaks, CA: Sage.

Denzin, Norman K. and Michael D. Giardina (2007) 'Introduction: Ethical Futures in Qualitative Research', in Norman K. Denzin and Michael D. Giardina (eds) *Ethical Futures in Qualitative Research: Decolonizing the Politics of Knowledge.* Walnut Creek, CA: Left Coast Press, pp. 9–43.

Downing, Steven (2010) 'Online Gaming and the Social Construction of Virtual Victimization', *Eludamos: Journal for Computer Game Culture,* 4(2), 287–301.

Duits, Linda, Koos Zwaan, and Stijn Reijnders (eds) (2014) *The Ashgate Research Companion to Fan Cultures,* Routledge.

Durkin, Keith, Craig J. Forsyth, and James F. Quinn (2006) 'Pathological Internet Communities: A New Direction for Sexual Deviance Research in a Post Modern Era', *Sociological Spectrum*, 26(6), 595–606.

Ekman, Mattias (2014) 'The Dark Side of Online Activism: Swedish Right-Wing Extremist Video Activism on YouTube', *MedieKultur: Journal of Media and Communication*, 30(56).

Freilich, Morris, Douglas Raybeck, and Joel Savishinsky (1991) *Deviance: Anthropological Perspectives*, New York: Bergin & Garvin.

Fuchs, Stephan (2009) *Against Essentialism*, Cambridge, MA: Harvard University Press.

Geertz, Clifford (1977) 'Found in Translation: On the Social History of the Moral Imagination', *The Georgia Review*, 31(4), 788–810.

Gilbert, Anne (2012/2016) 'Between Twi-Hards and Twi-Haters: The Complicated Terrain of Online "Twilight" Audience Communities', in Anne Morey (ed.) *Genre, Reception and Adaptation in the 'Twilight' Series*, Farnham, UK: Routledge, pp. 163–180.

Gilbert, Anne (2015) 'What We Talk about When We Talk about Bronies', *Transformative Works and Cultures*, 20. Available online:

http://journal.transformative works.org/index.php/twc/article/view/666/549

Giulianotti, Richard (1995) 'Participant Observation and Research into Football Hooliganism: Reflections on the Problems of Entrée and Everyday Risks', *Sociology of Sport Journal*, 12(1), 1–20.

Hammersley, Martin (2015) 'On Ethical Principles for Social Research', *International Journal of Social Research Methodology*, 18(4), 433–449.

Hammersley, Martin and Anna Traianou (2014) 'An Alternative Ethics? Justice and Care as Guiding Principles for Qualitative Research', *Sociological Research Online,* 19(3), 24. Available online: http://www.socresonline.org.uk/19/3/24.html

Hellekson, Karen and Kristina Busse (2009) Fan Privacy and TWC's Editorial Philosophy, http://www.transformativeworks.org/twac/twc-citation/ (last accessed 14th June 2016).

Herman, Thomas and Doreen J. Mattingly (2009) 'Community, Justice and the Ethics of Research: Negotiating Reciprocal Research Relations', in James D. Proctor and David M. Smith (eds) *Geography and Ethics: Journeys in a Moral Terrain*, London: Routledge, pp. 209–222.

Hertz, Rosanna (1997) 'Introduction: Reflexivity and Voice', in Rosanna Hertz (ed.) *Reflexivity & Voice*. Thousand Oaks, London and New Dehli: Sage, pp. vii–xviii.

Hills, Matt (2012) '"Proper Distance" in the Ethical Positioning of Scholar-Fandoms: Between Academics' and Fans' Moral Economies?', in Katherine Larsen & Lynn Zubernis (eds) *Fan Culture: Theory/Practice*. Newcastle, UK: Cambridge Scholars Publishing, pp. 14–37.

Hughey, Matthew W. and Jessie Daniels (2013) 'Racist Comments at Online News Sites: A Methodological Dilemma for Discourse Analysis', *Media, Culture & Society*, 35(3), 332–347.

Jenkins, Henry (2007) 'When Fan Boys and Fan Girls Meet…' Available online: http://henryjenkins.org/2007/05/when_fan_boys_and_fan_girls_me.html (last accessed 2 December 2016).

Jenson, Joli (1992) 'Fandom as Pathology: The Consequences of Characterization', in Lisa A. Lewis (ed.) *The Adoring Audience: Fan Culture and Popular Media*, London: Routledge, pp. 9–29.

Johnstone, Gerry (2005) 'Research Ethics in Criminology', *Research Ethics Review*, 1(2), 60–66.

Jones, Bethan (2016) '"By listening to their music am I celebrating a paedophile?" – Moral Crusades, the Media and the Creation of an Appropriate Audience', paper presented at Society for Cinema & Media Studies (SCMS), Atlanta, 30 March–3 April.

Keenan, Michael (2012) 'The Politics of Telling: Beyond Similarity and Difference in the Interview Relationship', in Kevin Love (ed.) *Studies in Qualitative Methodology Volume 12: Ethics in Social Research*, pp. 91–109.

Kingsepp, Eva (2006) '"Nazi Fans" But Not Neo-Nazis The Cultural Community of "WWII Fanatics"', in Stefan Herbrechter and Michael Higgins (eds) *Returning (to) Communities: Theory, Culture and Political Practice of the Communal*, Brill, pp. 223–240.

Klockars, Carl B. and Finbarr W. O'Connor (1979) *Deviance and Decency: The Ethics of Research with Human Subjects, SAGE Annual Reviews of Studies in Deviance, Volume 3*. Beverly Hills, CA and London: Sage.

Larsen, Katherine and Lynn Zubernis (eds) (2012) 'Introduction', in *Fan Culture: Theory/Practice*, Newcastle, UK: Cambridge Scholars Publishing, pp. 1–13.

Lasagna, Louis (1969) 'Special Subjects in Human Experimentation', *Daedalus*, 98(2), Special Issue: *Ethical Aspects of Experimentation with Human Subjects*, 449–462.

Lauder, Matthew A. (2003) 'Covert Participant Observation of a Deviant Community: Justifying the Use of Deception', *Journal of Contemporary Religion*, 18(2), 185–196.

Lea, Martin, T. O'Shea, P. Fung, and Russell Spears (1992) 'Flaming in Computer-Mediated Communication: Observations, Explanations, Implications', in Martin Lea (ed.) *Contexts of Computer-Mediated Communication*, New York: Harvester Wheatsheaf, pp. 89–112.

Maratea, R. J. (2011) 'Screwing the Pooch: Legitimizing Accounts in a Zoophilia On-Line Community', *Deviant Behavior,* 31(10), 918–943.

Martin, James (2016) 'Illuminating the Dark Net: The Ethics and Methods of Cryptomarket Research', in Michael Adorjan and Rose Ricciardelli (eds) *Engaging With Ethics in International Criminological Research*, Routledge UK, pp. 192–211.

Martin, James and Nicholas Christin (2016) 'Ethics in Cryptomarket Research', *International Journal of Drug Policy*, 35, 84–91.

Nash, Melanie (1999) '"Beavis is Just Confused": Ideologies, Intertexts, Audiences', *The Velvet Light Trap*, 43, 4–22.

Oksanen, Atte, James Hawden, and Pekka Räsänen (2014) 'Glamorizing Rampage Online: School Shooting Fan Communities on YouTube', *Technology in Society*, 39, 55–67.

Outhwaite, William (1975) *Understanding Social Life: The Method Called Verstehen*, London: George Allen and Unwin.

Pande, Rukmini (2016) 'Squee from the Margins: Racial/Cultural/Ethnic Identity in Global Media Fandom', in Lucy Bennett and Paul Booth (eds) *Seeing Fans: Representations of Fandom in Media and Popular Culture*, Bloomsbury, pp. 209–220.

Paton, Nathalie E. (2012) 'Media Participation of School Shooters and their Fans: Navigating between Self-Distinction and Imitation to Achieve Individuation', in Glenn W. Muschert and Johanna Sumiala (eds) *School Shootings: Mediatized Violence in a Global Age, Studies in Media and Communications*, 7, pp. 205–234.

Pearson, Geoff (2009) 'The Researcher as Hooligan: Where "Participant" Observation Means Breaking the Law', *International Journal of Social Research Methodology*, 12(3), 243–255.

Philips, Whitney (2015) *This Is Why We Can't Have Nice Things: Mapping the Relationship between Online Trolling and Mainstream Culture,* MIT Press.

Phillips, Tom (2015) 'Wrestling with Grief: Fan Negotiation of Professional/Private Personas in Responses to the Chris Benoit Double Murder-Suicide', *Celebrity Studies*, 6(1), 69–84.

Pole, Chris (2010) 'How Could You Possibly Know Anything about That? Methodological Congruence in the Conduct of Life History Research', in Sam Hillyard (ed.) *Studies in Qualitative Methodology, Volume 11: New Frontiers in Ethnography*, pp. 161–176.

Reid, Elizabeth (1999) 'Hierarchy and Power: Social Control in Cyberspace', in Marc A. Smith and Peter Kollock (eds) *Communities in Cyberspace*. London: University of California Press, pp. 107–133.

Rico, Andrew Ryan (2015) 'Fans of Columbine Shooters Eric Harris and Dylan Klebold', *Transformative Works and Cultures*, 20. Available online: http://journal.transformativeworks.org/index.php/twc/article/view/671/545

Salter, Anastasia and Bridget Blodgett (2012) 'Hypermasculinity & Dickwolves: The Contentious Role of Women in the New Gaming Public', *Journal of Broadcasting and Electronic Media*, 56(3), 401–416.

Searle, John R. (1992) *The Rediscovery of the Mind*. Cambridge, MA: MIT Press.

Spaaij, Ramón and Matthijs Geilenkirchen (2011) 'Ta(l)king Sides: Ethical and Methodological Challenges in Comparative Fieldwork on Avid Football Rivalries', *Soccer and Society*, 12(5), 633–651.

Stanfill, Mel (2013) 'They're Losers, but I know Better': Intra-Fandom Stereotyping and the Normalization of the Fan Subject', *Critical Studies in Media Communication*, 30(2), 117–134.

Stein, Joel (2016) 'How Trolls Are Ruining the Internet', *Time Magazine*, August 18.

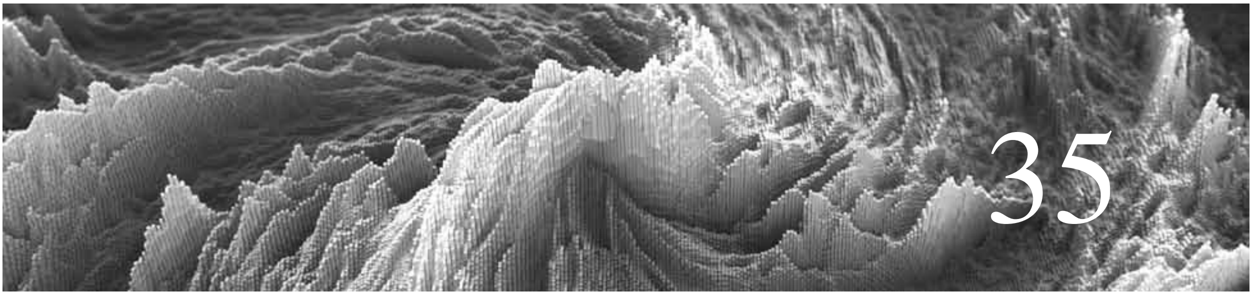
van de Goor, Sophie Charlotte (2015) '"You Must Be New Here": Reinforcing the Good Fan', *Participations: Journal of Audience & Reception Studies* 12 (2) http://www.participations.org/Volume%2012/Issue%202/16.pdf

Whiteman, Natasha (2012) *Undoing Ethics: Rethinking Practice in Online Research*, New York: Springer.

Whiteman, Natasha (2015) 'Intellectual Property and the Construction of Un/Ethical Audiences', in D. Halbert and M. David (eds) *SAGE Handbook of Intellectual Property,* Sage, pp. 470–489.

Whiteman, Natasha (2016) 'Unsettling Relations: Disrupting the Ethical Subject in Fan Studies Research', *Journal of Fandom Studies*, 4(3), 307–323.

Williams, Matthew (2000) 'Virtually Criminal: Discourse, Deviance and Anxiety Within Virtual Communities', *International Review of Law, Computers & Technology*, 14(1), 95–104.



35

Negotiating the Ethics of Gendered Online Spaces in Mainland China and Hong Kong

Tom McDonald, Karen Joe Laidler and Marissa Dean

INTRODUCTION

This chapter draws on our sociological and anthropological studies of social media use in metropolitan Hong Kong and rural China to consider how ethical concerns regarding gender become articulated in digital contexts. Despite significant differences in the communication ecologies of these two locales, we have found similarities in both cases. Specifically, both areas reveal the presence of a similar dominant discourse of social media as male dominated spaces. While reflecting traditional notions of patriarchy and space in Chinese culture, this also resonates with global assumptions about gender and the Internet. Thus, this chapter starts from the simple, but still widespread assumption – that the Internet is primarily a male space – and examines how this prevailing discourse shapes and influences the ethical concerns and practices possessed by our research participants, and how we as researchers interact with our participants around this topic. This chapter argues that researchers must recognize the dialectical process in which our own ethical considerations are inextricably tied into those of the persons we study. Indeed, we must acknowledge our own assumptions and the institutional framework within which we operate – being an 'entirely objective observer' of participants and their encounters with ethical dilemmas online creates a particular ethical lens through which we 'see' them. Yet the researcher's ethical lens undergoes continued negotiation with those held by participants. This process of negotiation can, in fact, become the grounding for establishing an understanding of the ethical dimensions of Internet use.

The evidence presented in this chapter demonstrates how this negotiated approach to understanding ethics can be particularly revealing when applied to the issue of internet use and gender, giving scope for researchers to think of digital ethics as more than being a simple set of concerns regarding the appropriateness of use (and non-use) of specific technologies in relation to gender. By including accounts of how users actively create their own spaces online in order to carve out niches within which new ethical forms of conduct might be established, it becomes possible to see how users utilize such spaces to align with, reflect upon, or even challenge existing moral frameworks.

This chapter first reviews the literature on the gendering of Internet use, before turning to consider the nature of ethics in China more broadly and how contemporary technology use may fit against this moral backdrop. We then draw on two case studies on social media use: the first from McDonald's research in rural Mainland China,[1] the second from Dean and Laidler's work in Hong Kong. In both contexts, it will be shown that females work to overcome various normative ethical constraints in order to craft their own online spaces. The chapter closes by discussing the relevance of this finding in relation to the ethics of qualitative research, warning against assuming that moral and ethical impacts of technologies implicitly reside in either technologies themselves, or in innate gendered characteristics. Instead, it is proposed that users of any particular technology always make sense of what constitutes ethical, moral and appropriate use in relation to the broader moral frameworks of their own lives. For this reason, examining the moral issues surrounding particular technologies can become a valuable resource for researchers to understand their participants' (and their own) moral and ethical views from a novel perspective. This negotiated experience can thus provide valuable space for the researcher to reflect on the ethics of their own method of research and the role that technology plays within it.

LITERATURE REVIEW

To understand the ethics of conducting research on gender and social media in China, we first examine the reasons as to why the Internet is frequently considered as a male-dominated space, discussing how this discourse has shaped the focus of many studies of internet use in Greater China[2], ultimately leading to a skewed understanding of the gendered use of its Internet(s). We then consider the frames of reference in discussions of ethics within studies of the region, before highlighting how recent calls for increased attention to the way in which 'everyday ethics' operates within the Chinese context provides an especially useful framework for understanding how ethics actually play out with regard to gender and internet use within both China and Hong Kong. Such a focus may provide a route into understanding gender and the Internet which can break free from dominant normative frames.

Gender and Technology

It would not be overstating the case to claim that, globally, 'being online' has become a central and integral part of people's everyday life today. Within Asia, particularly in much of the Greater China region, Internet usage has become commonplace. Of Hong Kong's 7 million inhabitants, 80% of them use the Internet. In Mainland China, 52% of its 1.3 billion residents are similarly online (China Internet Network Information Center, 2016). As we have noted elsewhere, despite the rapid growth of the use of computers for video gaming and staying connected to peers, popular preconceptions persist that regard technology – and the Internet in particular – as not being 'a female thing' (Dean & Laidler, 2014). Accordingly, this widespread discourse relates to beliefs that females primarily restrict their use of computers and the Internet to task-oriented activities such as sending instant messages and updating Facebook profiles. Dean and Laidler (2014) argue that this perceived 'impoverished' use of ICTs by females is often attributed to unfounded beliefs that females lack interest, or relevant abilities needed to make appropriate use of such technologies.

In contrast to such popular assumptions, recent research suggests that the supposed gender gap in the use of computers and being online has narrowed considerably. Since 2009, females now represent a greater proportion of all social networking users as compared to their male counterparts (Perrin, 2015). Yet it is open to debate as to how females (and males) engage with life online. On the one hand, one body of work finds that females engage in more interpersonal and response-oriented tasks while males are information-oriented. This finding is related to the inherent nature of the Internet and technology as a masculine one – a reflection and embodiment of larger social structures (Haferkamp et al., 2012). On the other hand, other research suggests that the increasing presence of females online is evidence that the Internet is becoming a site for them to transcend the borders of public and private spaces, and to create distinct social spaces (Takayoshi, 1999; Dean and Laidler, 2013; Dobson, 2015). From this vantage point, social media is a site for expressions of cultural production – creativity, empowerment, and resistance (Harris, 2005; McRobbie, 2009). But recently, a growing number of feminist scholars are also interrogating the very idea that girls and young women are empowered in their online lives. While young women's online practices of highly sexualized self-representations are popularly characterized as 'problematic' and risky self-indulgence, or as new expressions of freedom, these feminist observers caution to 'slow down', question our own assumptions about postfeminist girlhood, and turn on the 'ethics of seeing' (Dobson, 2015). In doing so, we may overcome the tendency to 'evaluate their media practices against pre-existing theoretical criteria or ideals' and appreciate the gendered subjectivities articulated online (Dobson, 2015: 8). For example, if one adopts an ambivalent stance towards the notion of empowerment, then this opens the possibility of alternative ways of 'seeing' – with social media practices for many girls and young women being seen less as resistance and more as a means to 'cope' and 'survive' (see Dobson, 2015: 2). Appropriately framing such efforts to understand motives and expectations surrounding the use of particular technologies makes it especially important that researchers be aware of, and attuned to, the local social context.

The Greater China Context

Studies of Internet use in Hong Kong and Mainland China have also frequently emphasized its gendered character, often pointing out those examples where great contrasts exist. This is particularly the case in examining youth engagement with the Internet. Chu (2010) found Hong Kong teenaged males generally spending more time on the Internet, though females were more likely to own a blog. Peng and Zhu (2010) found a greater proportion of young women in the territory preferred instant messaging and browsing the web, while male youth were more likely to engage in online gaming.

In China, Qiu's (2009: 22) description of Internet cafes frequented by migrant workers pointed out inherent gender disparities at play. The owners of such cafes, he notes, are typically well-educated males, while the employees charged with serving the customers are typically female. Separately, Qiu and Zhou (2005) note that Internet cafes in working-class communities almost always feature more male customers than females. Qiu (2009) also remarks upon the gendered activities of internet café customers, noting that males tend to play online games while females predominantly use QQ (a social media platform which is especially popular in rural China) or chatrooms to converse with others.

While noting instances of marked differences in gendered use of such spaces certainly constitutes important and illuminating information for understanding broader patterns of use, it is the authors' belief that such reporting may also have contributed to sustaining a wider discourse that assumes gendered use in other areas, resulting in, for instance, a shaping of the focus of studies of internet use in China so that female users are frequently overlooked. For example, Qiu and Bu's (2013) review of scholarly research on the Chinese Internet found that women are a vastly under-represented group in research surrounding Internet use in China, being the explicit focus of only 0.5% of studies in their sample. The same study notes that gender is only mentioned in 6.8% of publications on the Chinese Internet, reasoning that males are barely mentioned because they are probably 'perceived as the default gender for Chinese Internet users' (Qiu and Bu, 2013: 140). By contrast, national figures from China's Internet regulatory body in July 2016 assert that females comprise 47% of all internet users (China Internet Network Information Center, 2016).[3]

There is, however, growing interest in the ways young women in China are engaging with mobile technology, particularly with China's expansive and rapid engagement with global capitalism. Wallis's (2013) study documents migrant women's use of mobile phones to examine the 'virtual mini world' they create in the midst of having to move from their rural homes in search of work and new life possibilities in urban areas. Although they may have access to current mobile technology, their family and friends in the rural areas do not always have the same degree of access. As such, their phone becomes a 'virtual mini world' – an expressive device to capture and create through photographs of their lived and imaginary environment. The photographic capabilities of the mobile phone are a source through which they can construct and fashion the self as a modern Chinese woman – makeup, dress and hairstyles are in line with normative notions (2013: 132).

An alternative approach to focusing on gendered differences in use may instead come from examining moments in the lives of users where ethics and morals surrounding internet use happen to strongly intersect with issues of gender. Such a focus offers the possibility of understanding why such differences exist in the first place. A useful example of how ethics often features strongly in issues of gender and ICT adoption comes from boyd's[4] (2014) work on social media use by American teenagers, in which she describes how, for some, social media platforms form a key venue for exploring their own sexuality. She discusses how lesbian, gay, bisexual, and transgender (LGBT) teens from religious and conservative families are often extremely worried about the possibility that the parts of their online lives in which such experimentation occurs might inadvertently be revealed to conservative friends or family members. boyd refers to instances of collision of two otherwise separate social spheres as 'context collapse' (boyd, 2014: 31). boyd's example is useful in highlighting how the ethical dimensions of gendered technology use emerge in connection with particular social relationships: while an individual may feel comfortable acting in a particular way within one social context, if the same individual finds themselves amongst a different group of people, they may be anxious that the same actions would be met with disdain or criticism by this group because they do not view people to be acting in a way appropriate to their gender. boyd's example makes particularly clear how, 'doing gender' online is permeated with (and shaped by) specific ethical challenges and concerns.

Ethics in Chinese Contexts

If, as the above literature suggests, paying attention to the ethical dimensions of gender promises to illuminate how concepts of gender become socially constructed and operate within a range of different contexts, then it becomes important to more clearly define appropriate frameworks for understanding ethics. In this connection, China scholars have often noted that the region's people appear to be particularly concerned with issues of ethics and morality. This trend appears especially pronounced amongst studies of Mainland China, where the drastic economic and social transformations in recent decades have attracted several scholars to investigate the changing moral and ethical values present in China's reform era (Liu, 2000; Yan, 2003; Oxfeld, 2010). Such accounts generally emphasize how the transition towards a market economy interacts with the growing importance of consumerism to engender a perception amongst Chinese people that the moral principles in society are collapsing. Scholars have typically attributed such moral crises to growing individualism, or the absence of a clearly defined moral economy.

However, several researchers (Kleinman, 2011; Stafford, 2013; Steinmüller, 2013) have argued for approaches to ethics in China, which provide alternatives to the dominant focus on ethical decline. Steinmüller (2013) notes that despite considerable social change, individuals nonetheless still possess a moral code on which they are willing to base 'strong' moral judgements. Steinmüller calls for scholars to acknowledge that rather than gradually disappearing, these moral codes simply differ from those of the past. Drawing on the work of Taylor (1989), he argues that instead of assuming the existence of a specific set of 'Chinese ethics' that act in a normative and universal way (and thus subject to decline), it is essential to understand how 'moral frameworks emerge in action' (Steinmüller, 2013: 9). Steinmüller highlights how the study of ethics is often based on the assumption that ethics emerges from moments of moral crisis – where ethics become a 'second level reflection of morality' – and advocates understanding these moral frameworks by paying attention to the 'everyday ethics' of contemporary life in rural China. This view of ethics is particularly relevant in relation to framing discussions of internet use in China, where the Internet has become an embodied and mundane part of people's lives[5], while nonetheless still giving rise to ethical concerns.

Scholarly discussions of Internet use in China have often been framed in explicitly ethical terms. Some scholars have questioned whether the Internet can be compatible with Confucian ethics (Wang, 2002), others have examined in greater detail instances of moral panic surrounding the rapid growth of Internet use (Szablewicz, 2010). In response, several scholars have highlighted the importance of considering more grounded approaches to the way the Internet technologies are domesticated within everyday life (Wallis, 2013; McDonald, 2015).

These more grounded approaches tend to chime with the above arguments for everyday ethics, and are particularly relevant when it comes to considering the ethical dimensions of the interaction between gender and technology. This will be illustrated in the next two sections of the chapter that examine how women appropriate social media in each of our field sites in order to craft a particular form of gendered space. In the cases of both rural Mainland China and urban Hong Kong, we will see that the way in which this occurs changes depending on the social context – and quotidian ethical concerns – of each locale.

CASE STUDY: RURAL CHINESE WOMEN AND SOCIAL MEDIA USE

During McDonald's 15 months of ethnographic fieldwork on social media use in rural north China, he was struck by two opposing trends. The first was the moral concern around social media's potential threat to relationships and marriage where online encounters with strangers held differential meaning and practices for young men and women. The second trend was that, despite these dominant ethical discourses, young women persisted in finding ways to access these platforms and carve out their own spaces and networks online. The first trend involves the impact of location-based stranger-finding services built into social media platforms, while the second concerns new mothers' appropriation of social media as a coping and survival strategy for navigating in and around the normative path of Chinese motherhood. But the connection between these seemingly opposed trends is their awareness of the situational context and intersection of their gendered on- and offline presence.

Strangers, Romance and Morality

Two popular social media platforms in China – WeChat and QQ – contained features for connecting with and chatting to strangers. These platforms were a source for moral concern within families because (amongst other things) they could be used to pursue romantic relations. Although participants' main use of these platforms was largely for direct and group messaging between peers, the thought of using apps to connect with strangers certainly captured the popular imagination. During McDonald's fieldwork, a wide range of people shared their experiences of connecting with strangers online – from middle school children through to middle-aged and elderly users. People shared a variety of reasons for wanting to reach out to strangers over social media: relief from boredom, increase the number of online friends, search for romantic partners, or a receptive and patient ear to share the frustrations of everyday life in a small town (for a full description of such uses see McDonald, 2016). Our focus here is on the use of social media in romantic and sexual relations, simply because this issue caused the most overt moral concern in the town, and was relatively clearly differentiated by gender.

There was an apparent disparity in the use of location-based stranger-finding services[6] between male and female users within the town. Few females were visibly using these online services, while use amongst their male counterparts was far more common. This situation differed in comparison to nearby urban areas, where usage on such platforms appeared to be more gender balanced. The gendered use of this particular social media function reflected different ideas about the visibility and moral sensibility of those using this media function. Males from the town confided about using these social media platforms to find potential partners. Many were male university students from the town, but mainly used these platforms when visiting nearby urban areas. A few married men from the town also described how they used these online services to organize romantic relations outside of marriage.

In contrast to men, young unmarried women from the town tended to respond quite differently to online encounters with strangers, largely because of the moral boundaries and stigma associated with such platforms. Generally, female participants expressed greater caution in such interactions, or developed strategies to avoid, defer or manage such potentially morally problematic situations. Long Qing[7] – a single woman in her early 20s who worked part-time as a waitress in a small local hotel – described how although instant messaging on social media may make discussing romantic matters easier than in face-to-face communication, one nonetheless had to filter out and avoid interacting with undesirable male strangers:

> I only started using them [stranger-finding functions] recently. … I have [added some men I don't know]. But, if they are people I don't know, and … if it displays online that they are quite old, then I will refuse their friend request.

Other young women were more cynical about such exchanges, especially when it came to romantic relationships. Gao Li, in her mid 20s and single, held such a view. Although she grew up in the town, she had left to study dentistry in a nearby city, but unable to find employment, she returned home to take up a modestly paid nurse's position whilst preparing for advanced examinations. Gao Li finds her work in the local hospital unchallenging, and is studying in the hope of gaining extra qualifications to facilitate her return to the city. When not working or studying, she uses her smartphone to message her friends on social media. Gao Li limits her visibility on social media platforms, claiming that whenever she is visible 'online' she tends to get more 'annoying' (fan) messages from men. Gao Li is dismissive about finding partners online, believing social media creates uncertainties about strangers online, and is not an 'appropriate' way to meet, talk or date someone.

Wang Miao, a 30-year-old female pharmacist in the local hospital, and the mother of a young child, spoke similarly of her own concerns surrounding advances from strangers online, but in the broader context of fears and anxieties about interacting with strangers on the Internet.

> I always refuse strangers' [friend requests] … Let's say I am online every day, then in one month I will receive between 50 and 60 friend requests. Most of them are all cheats, or people who are idle and have nothing to do. I am also quite worried, like if in the future my son wants to go to the Internet cafe, I will be unable to look after him, he could turn into anything, I don't know.

These accounts portray the significant concerns surrounding interacting with strangers online, including how such activities may impinge upon their personal safety. However, far from these concerns simply resting on the authenticity of people one meets online, an equally important element for young women is one's sexual reputation. As Gao Li expresses, it matters to her what other townsfolk may think of someone who makes themselves too visible on such social media sites. The intertwining of new media, normative gender identities and modern cultures of desirability and sex create an irony for those in rural China. In an environment where perpetual societal expectations mean that females are disproportionately expected 'to uphold the monogamous marriage, through sexual fidelity and marital service' (Evans, 1992: 160), social media is increasingly allowing for romantic relationships to be conducted in secrecy, without having to inevitably result in marriage. Yet it appears that young women from rural areas, even some of those who have had an urban experience, remain steadfast in their commitment to local moral sensibilities and expectations.

Crafting Female Spaces within Moral Boundaries

Despite these young women's consternation over online stranger exchanges, females do find ways to craft their own spaces online that seek to overcome normative constraints of femininity as in the case of new mothers' use of social media. Visual analysis of social media postings indicate that mothers appeared keen to post images of their newborn children on their social media profiles. This is especially significant considering that while men usually return to work almost immediately following the birth of a child, mothers and their newly born babies observe a period of confinement – known as 'sitting the month' (*du manyue*) – for an entire lunar month commencing as soon as they return home from the hospital. During this time, mother and baby are to remain inside the groom's family home, with visitors to be kept to a minimum. The practice is often attributed to traditional Chinese physiological understandings of childbirth, which maintain that mother and child occupy dangerously weakened bodies following birth, necessitating a period of convalescence. Conversations with young mothers made it clear that ensuring new mothers adhered to this confinement was often a concern for the extended family, in addition to a means for young women themselves to demonstrate their motherly abilities. A 25-year-old mother who worked as a hotel waitress in a small hotel in the town explained:

> Because China is very traditional, the time of the first month is very important. You can't do anything in the first month. You can't watch TV; you cannot go outside. It's only once the month has finished that you are allowed to play on your

> phone. Yes, if you want to play on the phone, it's against the wish of old people. Old people control this; they won't even let you make a phone call.

Another mother, a 25-year-old teacher, provided a similar account of the reasons for confinement, including the pressures and expectations of family elders:

> During the month of confinement, your body is extremely weak, if you read books, watch the TV, or look at your phone for long periods of time it will be really bad for your eyes … this is all the older generation's way of seeing things, but no-one's tested it. Anyway, that's what old people say, so it's just what we hear.

The pressure placed on young mothers to conform to normative expectations of motherly confinement results in feelings of isolation and exclusion from 'normal' life – both online and offline. One new mother, aged 22, aptly captures the feelings in her post on her QZone (another social media platform linked to QQ): 'Look forward to the end of confinement soon! It will be good to go out for a walk'. This individual's post also provides a good example of how QZone appears to have become an important way for new mothers to interact with friends despite their cultural confinement, thus mitigating some of the effects of this isolation. Importantly, however, as these two new mothers remind us, they took steps to appear 'compliant'.

> My mother-in-law and my mother didn't let me use [my smartphone], but I used it [life] secretly, because it was too boring.

> I played on the phone secretly. Whenever the child's [paternal] grandmother came I would hide the phone, when she left I would take it out.

Despite the restrictions, several women acknowledge that the conditions they live in today are far better than those their mothers or grandmothers had endured. Nonetheless, the case of parental restrictions on the use of electronic devices by new mothers, often under what were ostensibly health reasons, underscores how traditional notions of gender and motherhood are enacted with new ICTs within the domestic sphere. In this context, one can also observe the creative ways that mothers find to use ICTs within these situations, and how for them social media offers a way to cope with normative expectations and to 'escape' during the confinement.

Several women emphasized that, in addition to relieving boredom and isolation, social media was a source for rallying support and empathy from their personal networks. For instance, young mothers often posted messages about their new motherly duties, including the adjustment to a newborn's routines. One mother posted, in the middle of the night:

> Finally sleeping. Half an hour earlier [his] vigour was unbelievable, in the end I fell asleep and he was left playing on his own. Finally, a sound woke me up, [my] falling from the bed onto the ground [i.e. due to falling asleep from exhaustion].

Such posts, as 'you're really great' and 'I've also experienced the same', are examples of the encouragement and reassurance of others who recognize the cultural constraints of early motherhood.

Posting of their newborns' photos also featured prominently for new mothers, as a means for sharing with friends, exchanging notes on child development, and for self-affirmation of their new motherly roles and of their emotional connection to their newborns. As one mother, who works as a teacher, explains:

> Because you have lots of time, in the first month the child is basically always sleeping, when he woke I took photos of him, when he slept I took photos of him too, when he was sleeping I would upload the photos, chat [with other friends online] for a while. The photos from the first month are the most.

Many young mothers also used their newborns' photos as their own QQ profile pictures, especially on instant messaging. Most QQ users in the town preferred to use an avatar profile picture rather than a real photo of themselves. However, some mothers implied that using their baby's picture would signal their marital and motherly status and ward off romantic approaches from strangers. In these instances, we see a continuation of the desire to limit visibility for moral concerns. Not all gave this account – a different 27-year-old office worker in a small factory claimed that using her child's photo as her avatar was more for her own purposes rather than for keeping people away. The image also served as a kind of memento she could look at, like a small child's photograph that may be kept in a wallet.

> In this way whenever I log onto QQ I can see her [picture]. As soon as I get to work I log onto QQ, in this way as soon as I start working I can see her.

The period of mother-and-baby confinement that comprises the first month of the child's life is thus especially important. This section has shown how new mothers often choose to use QZone and mobile technologies despite prohibitions laid out by their parents and concerns relating to its impact on new mothers' health. At the same time, its use helps to ease the boredom and loneliness from the confinement through helping mothers stay in contact with their friends and share the challenges and delights of motherhood. Finally, the practice of photographing and posting about the newborn baby emerged as an important way in which young mothers feel that they are able to create bonds with their newborn baby, but also sharing these images on social media solicits the generally appreciative comments of other women, helping the mother to cement her social bonds with others, mostly similarly aged young women.

CASE STUDY: HONG KONG'S DIGITAL GAMING DIVIDE AND GENDER

From the case study on young women in rural China, it becomes clear that there are implicit, and sometimes, explicit, moral strictures and codes governing on- and offline life. Social media can, simultaneously be empowering and controlling, and with a mix of blurred ethical emotions. Despite the contrast of rural China, similar paradoxes are apparent among Hong Kong's urban girls and young women's online engagement. In the Hong Kong studies (Dean, 2006; Dean & Laidler, 2013), the aim was to examine the nature of the gender divide in young people's online gaming and exchanges. Elsewhere, we have explored the ways in which young women are as active as their male counterparts in online play (Dean & Laidler, 2013, 2014). Females, who find 'packaged games' boring and monotonous, create their own playscapes on social media platforms, like Facebook. Males seemed less drawn to online exchanges, particularly instant messaging, but like their female counterparts, admitted that such platforms were much more socially flexible than face-to-face interactions. The discussion here draws from in-depth interviews with 27 young women's online experiences – use, social and emotional benefits, and expressions of self and identity. These young women were full-time students, aged between 12 and 25, lived in Hong Kong, and were predominantly ethnic Chinese. All reported using Facebook on an average of five days a week. All respondents and parents signed a consent form prior to the interview.

Girls and Young Women's Moral Code – Be Real

As with rural women in China, young women in Hong Kong describe moral codes that govern their real and virtual lives. The virtual life is a saviour, helping to overcome the 'boredom' of the everyday real world – a way to survive the tedium of school life and the nagging pressures from parents. For them, the perceived benefits of social media platforms are embedded in a sense of empowerment. They uniformly agreed that social media platforms, like Facebook, provided them with a sense of freedom, as the number one (implicit) rule of online social exchange is to ‘be real’. While ‘saving face’ plays a critical rule in offline exchanges, this cultural code has less relevance online, because as they see it, there is no face-to-face interaction. There is no ‘reading’, ‘interpreting’, or ‘misunderstanding’ of the face-to-face interaction. Facebook eliminates the need to follow ‘Chinese manners’, as they put it. Moreover, they perceive freedom from the constraints of conventional femininity as they can ‘air’ and express their opinions and feelings without direct face-to-face judgement or censure. They simply don’t have to worry about others’ expectations. Stella, a European aged 16, reflects, ‘I don’t have to worry about swearing or doing something unfeminine … I don’t have to worry about how I look’ (Dean & Laidler, 2013: 6). Dianne, aged 20 and Chinese, similarly expresses:

> On Facebook, you just have to remember to be yourself. Not what others think you are and what is expected. You can really just express how you’re feeling at that time… It’s all you and its okay. No one thinks you’re schizophrenic. You can be sexy, tough and kind as long as you are real. (Dean & Laidler, 2013: 6)

The freedom resulting from ‘being real’ and ‘true to the self’ allows girls to also develop an emotional understanding and intimacy with their female peers. While they sometimes find face-to-face exchanges difficult, especially with potential conflict, social media is seen as a way to navigate emotions indirectly (as with likes, emojis and photos) and directly. As Bonnie, aged 23 and Chinese, reflects on the difference:

> In a face-to-face conversation, you can’t hesitate … you need to carry on … and sometimes you might agree with something you don’t really want or if you blush … the other person can see you. It interrupts what you really want to say … You can think about what you want to say and this can have more real meaning. (Dean & Laidler, 2013: 5)

This intimacy is largely with their female peers. Young women are fully aware of their ‘general audience’ on platforms like Facebook, so will use access restrictions to control who can be part of their intimate dialogues. Most females report feeling constrained in expressing themselves when males joined in on instant messaging discussions, and responded by ending the conversation or texting in code undecipherable to males. Nicole, aged 16, reasons:

> When I use ICQ, I only like to talk to my girlfriends … It is easy to talk to your girlfriends if you are having a problem. You cannot be as honest if there is a boy in the conversation … you can’t trust that they will understand. You have to change the whole way you talk. (Dean, 2006: 120)

Freedom to ‘be real’ has other forms as well, but paradoxically, sometimes, it returns them to the strictures of conventional femininity. Many young women described social media as a way to also ‘play and pretend’ and to ‘test out the future’, especially in relation to potential and idealized romance. This has much salience given that these young women typically found social media platforms for blogging as a ‘safe experimental way’ in navigating their shyness and desire to interact with males. As Dianna, aged 21 and Chinese, tells us, ‘I can be playful but it is hard to do this when you are outside in a group. I can use [this platform] to be another kind of girl… one that boys will like’ (Dean, 2006: 121). They acknowledge that their presentation of self online (photos and postings) may sometimes appear ‘fake’, but this is simply an attempt to exaggerate attitudes and postures that would not be negatively judged by others, and would not do in real life. It is, what several describe, as a drama to ‘test drive the future’.

FROM PARTICIPANT TO RESEARCHER ETHICS

Looking back on the above data, it is clear that this understanding of how ethics worked within the social life of the field site was only possible because of a particular ethical approach taken by McDonald to conducting research in that locale. Indeed, the ethical considerations from the Mainland China site were much more complex and nuanced than the Hong Kong site, as the Mainland China research entailed ethnography over a relatively long period of time, and required the negotiation of presence in the site. For this reason, we shall largely concentrate our closing discussion on the issues raised by the Mainland China field site. While this ethics of fieldwork is informed by the broader ideals of the ethnographic tradition, which emphasize an empathetic and engaged approach to one's research participants, this necessarily also entails a certain ethical adaptiveness extending beyond the often frustratingly narrow and legalistic ethical frameworks enacted by academic institutions. So, although the project had to fulfil the ethical requirements of both McDonald's university and the project's funding body in terms of collecting completed informed consent forms, agreements for image releases, and approval from ethical committees, in many ways he attempted to go beyond these prescriptive demands. A sensitivity to local ethical modes of behaviour, and a willingness to tailor one's approach to these demands was vital for the success of the project.

Gaining access to the field site and demonstrating one's legitimacy was a major challenge in establishing the researcher as an 'ethical' actor. McDonald gained access to life in this rural town by way of a number of institutional and personal networks, which afforded him authenticity as a researcher. During the time of fieldwork, he held a visiting researcher position at a large university in Beijing. Being attached to a domestic institution acted to confirm his credentials, and somewhat mitigated his 'foreignness'. His supervisor at the university used her network of contacts in the province who were affiliated with the provincial level Communist Party (CPC) to help McDonald locate a suitable field site. These contacts kindly introduced McDonald to the town's local Government officials. McDonald's ability to conduct long-term research in this relatively closed area of China was thus greatly assisted by utilizing the 'correct channels' in the early stages of fieldwork.

Although (tacitly) permitting McDonald to conduct research, the town's officials, likely driven by a desire to limit exposure to a potentially disruptive foreign researcher, remained distant and non-committal during his time there. Despite their coolness, the authorities allowed McDonald to work largely unsupervised throughout the duration of his study, wandering the town freely, and speaking to whomever he desired. However, towards the final weeks of fieldwork, McDonald glimpsed the local government's anxiety regarding his presence. One of McDonald's closest participants told him how he was repeatedly interviewed by the local police who were trying to document the exact nature of his activities in the town. Ultimately, a Chinese-language article detailing the research project that McDonald had published in a Shanghai magazine helped to convince the local police of the legitimacy of his research.

In contrast to the local government, the townspeople were incredibly welcoming, showing an intense interest in McDonald's activities, and eagerness to share their views regarding social media (and life in general), complete questionnaires and participate in recorded interviews. Townspeople often found it difficult to understand the purpose of ethnographic research and why a foreigner would forsake the relative comfort of the UK to live in rural China for 15 months. McDonald discovered that conducting questionnaire surveys early in the fieldwork period helped to allay such anxieties, as participants were more familiar with this research method, and it seemed to confirm to them McDonald's legitimacy as a researcher investigating social media use. Participants were recruited for the initial questionnaire largely through visiting local businesses and workplaces. These questionnaires were a good way to meet many people very quickly, many of whom ended up becoming McDonald's regular interlocutors throughout his fieldwork.

Another key issue in the ethics of conducting fieldwork was managing the relations between the researcher and the participants, which was of added importance given the prolonged duration of the fieldwork. McDonald had to think of creative ways of ensuring that his respondents gained from their participation, as giving financial compensation could be viewed as undermining the friendship that he had built with them. As McDonald's main research methods involved participant observation, he spent longer amounts of time sitting and talking with his participants, engaging in their lives, and assisting them wherever he could. For example, his research topic meant his participants often (and incorrectly) thought of him as a computer expert, calling upon him for help in this regard, tackling problems such as uploading photos, shopping online or updating social media profiles. Providing such assistance helped to cement his friendship with participants, and he was able to learn much about their own ICT needs in this way.

Anonymity was also an important ethical consideration during fieldwork and beyond. In order to protect research participants' identities, and in line with the conventions of ethnographic writing, all names were altered – personal, business and place (below the provincial level). Occasionally, it was also necessary to change certain particulars regarding individuals' circumstances, particularly because in such a small town people are still relatively identifiable by age, family structure and occupation. Wherever such changes have occurred, care has been taken to avoid omitting details that would impact upon the overall argument of particular publications. One key area where the ethics of conducting research was considered at length emerged from McDonald's desire to present his research findings in ways beyond solely textual descriptions of use through more immediate forms of representation such as photography, documentary film and reproduction of social media postings.[8] The use of such visual media requires careful consideration, as it can undermine efforts to conceal participants' identities outlined above. In each instance, permission to use the images was negotiated with the owner and/or subject of the image. This being said, McDonald found most individuals approached were extremely happy to contribute their imagery in order that a wider audience might understand their life and town. However, ensuring participants were fully aware of all the possible implications of sharing their images proved challenging, especially given participants often limited understanding of the tenets and aims of anthropological research. Therefore, we as authors feel that ethical considerations ought not merely to be confined to a researcher's role to safeguard their participants, but also that it should be made clear to the final audiences of such research that they also have a role to play in interpreting and utilizing the data presented in publications in an appropriate way. McDonald has attempted to begin such conversations in his own publications (McDonald, 2016: 33).

SUMMARY

The above discussion of researcher ethics has shown how a fieldworker's sensitivity to the ethical and moral frameworks of their participants can potentially support a more adaptive approach to research ethics. Such an approach would not only aim to implement research in a way that is responsive to participants' specific concerns and needs, but also ideally would produce research outputs that respondents feel are representative of – or even useful to – themselves. Such considerations seem to be possible in very different fieldwork settings, although prolonged and deepened exposure with one's research participants arguably increases both the possibility for achieving such a goal, and the researcher's impetus to subscribe to such objectives. A key argument of this chapter is thus that research ethics should be viewed as an ongoing negotiation between researchers, their participants, and the audience of such research. As such, a key aim of the authors' future research is to incorporate such discussions into every stage of the research process in order to better navigate the differing needs and viewpoints of all those involved, so as to create research that is judged to be not only ethical in nature, but also able to ameliorate some of the social distance between these different parties.

Notes

1 McDonald's research was funded by the European Research Council (Grant number: ERC Project 2011-AdG-295486 SocNet) as part of a broader comparative study. See http://www.ucl.ac.uk/why-we-post

2 The term, Greater China region, is frequently used to refer to mainland China, Hong Kong, Macau, and Taiwan.

3 Females are 48.8% of the Chinese population overall.

4 boyd deliberately chooses not to capitalize her name.

5 For a discussion on the embodied nature of the Internet, see Hine, 2015.

6 Location-based stranger-finding services use the phone's GPS receiver to display a list of nearby users.

7 To preserve the anonymity of participants, all names have been altered. A discussion of the ethics surrounding anonymity is provided later in the chapter.

8 This material can be viewed at http://www.ucl.ac.uk/why-we-post

REFERENCES

boyd, d. (2014) *it's complicated: the social lives of networked teens,* New Haven, CT and London: Yale University Press.

China Internet Network Information Center. (2016) 38th Statistical Report on Internet Development in China. https://cnnic.com.cn/IDR/ReportDownloads/201611/P020161114573409551742.pdf

Chu, D. (2010) In search of prosumption: youth and the new media in Hong Kong, *First Monday* 15(2): 1–14.

Dean, M.T. (2006) *Leveling the Playing Field: Reassessing Gender and Socio-economic Disparities in Online Spaces* (PhD Thesis), The University of Hong Kong, Hong Kong.

Dean, M. and Laidler, K. (2013) A new girl in town: exploring girlhood identities through Facebook, *First Monday* 18(2–4): 1–9.

Dean, M. and Laidler, K.A.J. (2014) Leveling the playing field through Facebook: how females construct online playspaces, *Journal of Youth Studies* 17(1): 113–129.

Dobson, A.S. (2015) *Postfeminist Digital Cultures: Femininity, Social Media, and Self-Representation*, Springer.

Evans, H. (1992) Monogamy and female sexuality in the People's Republic of China. In S. Rai, H. Pilkington, and A. Phizacklea (eds) *Women in the Face of Change: Soviet Union, Eastern Europe, and China*, New York: Routledge, pp. 147–163.

Haferkamp, N., Eimler, S. Papadakis, A.M., and Kruck, J.V. (2012) Men are from Mars, Women are from Venus? Examining gender differences in self presentation on social networking sites, *Cyberpsychology, Behavior and Social Networking* 15(2): 91–98.

Harris, A. (2005) Discourses of desire as governmentality: Young women, sexuality and the significance of safe spaces, *Feminism and Psychology* 15(1): 39–43.

Hine, C. (2015) *Ethnography for the Internet: Embedded, Embodied and Everyday*, London and New York: Bloomsbury.

Kleinman, A. (2011) *Deep China: The Moral Life of the Person: What Anthropology and Psychiatry Tell Us about China Today,* Berkeley, CA: University of California Press.

Liu, X. (2000) *In One's Own Shadow: An Ethnographic Account of the Condition of Post-Reform Rural China,* Berkeley, CA and London: University of California Press.

McDonald, T. (2015) Affecting relations: domesticating the internet in a south-western Chinese town, *Information, Communication & Society* 18(1): 17–31.

McDonald, T. (2016) *Social Media in Rural China,* London: UCL Press.

McRobbie, A. (2009) *The Aftermath of Feminism: Gender, Culture and Social Change*, London: Sage.

Oxfeld, E. (2010) *Drink Water, But Remember the Source: Moral Discourse in a Chinese Village,* Berkeley, CA: University of California Press.

Peng, T.Q. and Zhu, J.H. (2010) Youth and the Internet in East Asia, *Journal of Youth Studies* 13(2): 13–30. http://eds.a.ebscohost.com/abstract?site=eds&scope=site&jrnl=10297847&AN=54311687&h=5AmN8o%2b8G8ode0l9Kh6HXuDauhBMOMpC7IT5coNBWwBwyNYRFGhmXGwOeiHgAgBIwdneNTR5%2faliX%2bScfsTZsA%3d%3d&crl=c&resultLocal=ErrCrlNoResults&resultNs=Ehost&crlhashurl=login.aspx%3fdirect%3dtrue%26profile%3dehost%26scope%3dsite%26authtype%3dcrawler%26jrnl%3d10297847%26AN%3d54311687

Perrin, A. (2015) Social media usage: 2005–2015. Pew Research Center. Downloaded on 22 December 2016 at: http:www.pewinternet.org/2015/10/08/2015/Social-Networking-Usage-2005-2015/

Qiu, J.L. (2009) *Working-Class Network Society: Communication Technology and the Information Have-Less in Urban China,* Cambridge, MA: The MIT Press.

Qiu, J.L. and Bu, W. (2013) China ICT studies: A review of the field, 1989–2012, *China Review* 13(2): 123–152.

Qiu, J.-L. and Zhou, L. (2005) Through the prism of the internet cafe: managing access in an ecology of games, *China Information* 19(2): 261–297.

Stafford, C. (ed.) (2013) *Ordinary Ethics in China*, London: Bloomsbury.

Steinmüller, H. (2013) *Communities of Complicity: Everyday Ethics in Rural China,* New York: Berghahn Books.

Szablewicz, M. (2010) The ill effects of 'opium for the spirit': a critical cultural analysis of China's Internet addiction moral panic, *Chinese Journal of Communication* 3(4): 453–470.

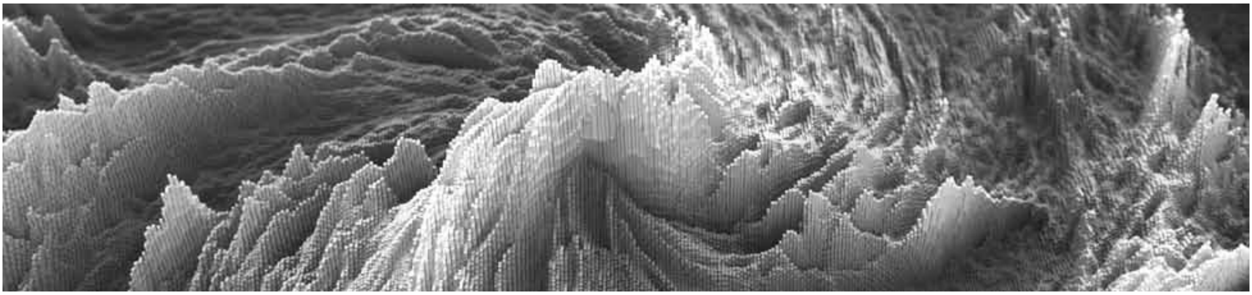
Takayoshi, P. (1999) 'No boys allowed': The World Wide Web as a clubhouse for girls, *Computers and Composition* 16(1): 89–106.

Taylor, C. (1989) *Sources of the Self: The Making of Modern Identity,* Cambridge: Cambridge University Press.

Wallis, C. (2013) *Technomobility in China: Young Migrant Women and Mobile Phones,* New York: New York University Press.

Wang, R.R. (2002) Globalizing the heart of the dragon: the impact of technology on confucian ethical values, *Journal of Chinese Philosophy* 29(4): 553–569.

Yan, Y. (2003) *Private Life under Socialism: Love, Intimacy, and Family Change in a Chinese Village 1949–1999,* Stanford, CA: Stanford University Press.



Concluding Thoughts: The Virtues of a Reflexive Qualitative Researcher

Ron Iphofen and Martin Tolich

While espousing a range of overlapping principles, values and standards, all of our authors, whatever the specifics of their 'case', are clear about one thing – as David Carpenter stated early on in this collection: 'The qualitative researcher cannot be an objective bystander'. Disinterestedness can never be an instrument in the qualitative researcher's toolbox, no matter how 'scientific' such a claimed objective stance is held to be. Varying levels of immersion are required, and emotional, political and personal responsiveness inevitable. Applying a neutral-sounding term such as 'reflexivity' does little justice to how powerful these responses might be. Nonetheless, a reflexive researcher is one who is well aware of the consequences of the impact of their mere presence, as well as the consequences of how they report their research engagement.

The 'subjects' of qualitative research are increasingly participants, collaborators and, even, co-researchers. As a consequence, researchers are in a relationship that is imbued with meaning for both researcher and researched(-with). This range of demands on researchers is as intensive and subtle as the demands that might be visited upon those who are the focus of the research. Mutual respect is a *sine qua non,* and attention must be paid to the balance of power in the relationship. Autonomy is a value for the researcher as it must be to the researched.

As we read through the contributions to this *Handbook*, we see how in addition to understanding the values, principles and standards to be observed by the qualitative researcher, we become more aware of the dispositions required. These have come to be seen as the Aristotelian *virtues* of the 'good researcher' in the act and actions of gathering qualitative data. They need to be committed to their research in an honest and transparent way. They need to be amiable in a non-trivial manner – not assuming, seeking or (worse?) feigning enduring friendship – but being friendly in a way that secures and sustains the trust of those being 'worked with'. But that social responsibility may also require that those being ‘worked with’ are also being ‘worked for’. The seeking and sustaining of a valid relationship might require the researcher to actively pursue social justice on behalf of those whose agreement to participate would have been vital to completing the research engagement. The overarching virtue required of such a researcher is courage: the courage to allow this range of virtues to become part of what it means to be a qualitative researcher. To see these virtues as key to who they are as a person and what they are as a researcher – the ‘good’ person who is also the ‘courageous’ researcher.

Having an overview of the range of views offered by our authors for this *Handbook* has given us the opportunity for reflection on the ethics of qualitative research in general, on the specific methods (focus groups, ethnography in all its forms, visual-, auto-, walking interviews etc.) and topics covered here and, also, more broadly on research ethics in social science and, indeed, all fields of science. Most of the authors have written on the specific needs and concerns of their fields of research and the specific characteristics of their related methods. Many have also made comparisons with approaches of their co-contributors to the *Handbook*. This means that both similarities and differences have been commented on, but it gives rise to one of the major concerns of all science, social science included, and that is the idiographic/nomothetic ‘balance’ – the difference between the unique and the general. Science proceeds through a combination of pattern recognition, categorizations, classifications at a general level and the ‘reductionist’ necessity of drilling down to specifics of distinct methods, specific circumstances (in the field) and unique events in time, space and place. This is as true of qualitative research as of all other ways of making sense of the world.

What does this mean in terms of the primary concern of this *Handbook*? What does this reflection offer us in terms of qualitative research ethics? It means that regardless of the commonalities of method and setting, of context and purpose, of the useful categorizations and distinctions we apply in qualitative research, we must remain aware that each research engagement we encounter, each site we enter and each person we meet is unique. It is, and they are, ‘special’ in being the only one in its time, place and space. If we forget that and fall into routinized ethical practices – no matter how ‘good’ or ‘sound’ they appear to be – we will not remain adequately aware of the unique qualities of the current situation we, and they, are in. So in addition to all the ‘learnings’ offered in this *Handbook* there is this essential extra – be alert for something different, something challenging and something special about every research encounter. Avoid the convenient assumption of even minimal homogeneity of case, place and method; expect heterogeneity. Be ready to think things through afresh in an ever-changing world of unique research experiences.

And taking heterogeneity one step further: our goal in compiling this *Handbook* was to define and refine qualitative research ethics. Rather than offering a pithy single sentence, the chapters show researchers being regularly confronted by many ethical issues and how they address them. The definition of qualitative research ethics suggests they draw from the same ethics well as biomedical researchers, but how these considerations are made manifest, recognized and resolved makes them essentially unique. While procedural research ethics review processes may offer useful anticipatory considerations, what these chapters demonstrate time and again is how this emergent epistemology makes the researcher not only the research instrument but the person responsible for ethics and the protection of those that volunteer to take part in research.

Index

Page numbers in **bold** indicate tables and in *italic* indicate figures.

- ethical habitus, 266
- ethical imperialism, 89–99, 232, 234, 265
- ethical radar, 371, 373
- ethical symmetry, 371
- ethical values, 28–33
- ethical virtues, 449
  - *see also* virtue ethics
- ethico-onto-epistemology, 53, 55, 63, 82
- Ethics Application Repository, The (TEAR), 212
- ethics capacity-building programs, 96–7