ETHICS AND INTEGRITY IN RESEARCH WITH OLDER PEOPLE AND SERVICE USERS

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ADVANCES IN RESEARCH ETHICS AND INTEGRITY
VOLUME 9

ETHICS AND INTEGRITY IN RESEARCH WITH OLDER PEOPLE AND SERVICE USERS: MOVING BEYOND THE RHETORIC

EDITED BY

ROGER O'SULLIVAN

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INVESTOR IN PEOPLE

To my lovely mum who embraced growing older and to my dad who never got that privilege.

> ‘If you think research is expensive, try disease’.
>
> Mary Lasker (1900–1994)
> Medical philanthropist, political strategist,
> and health activist.

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SERIES PREFACE

This book series, *Advances in Research Ethics and Integrity*, grew out of foundational work with a group of Fellows of the UK Academy of Social Sciences (AcSS) who were all concerned to ensure that lessons learned from previous work were built upon and improved in the interests of the production of robust research practices of high quality. Duplication or unnecessary repetitions of earlier research and ignorance of existing work were seen as hindrances to research progress. Individual researchers, research professions and society all suffer in having to pay the costs in time, energy and money of delayed progress and superfluous repetitions. There is little excuse for failure to build on existing knowledge and practice given modern search technologies unless selfish 'domain protectionism' leads researchers to ignore existing work and seek credit for innovations already accomplished. Our concern was to aid well-motivated researchers to quickly discover existing progress made in ethical research in terms of topic, method and/or discipline and to move on with their own work more productively and to discover the best, most effective means to disseminate their own findings so that other researchers could, in turn, contribute to research progress.

It is true that there is a plethora of ethics codes and guidelines with researchers left to themselves to judge those more appropriate to their proposed activity. The same questions are repeatedly asked on discussion forums about how to proceed when similar long-standing problems in the field are being confronted afresh by novice researchers. Researchers and members of ethics review boards alike are faced with selecting the most appropriate codes or guidelines for their current purpose, eliding differences and similarities in a labyrinth of uncertainty. It is no wonder that novice researchers can despair in their search for guidance and experienced researchers may be tempted by the 'checklist mentality' that appears to characterize a meeting of formalized ethics 'requirements' and permit their conscience-free pursuit of a cherished programme of research.

If risks of harm to the public and to researchers are to be kept to a minimum and if professional standards in the conduct of scientific research are to be maintained, the more that fundamental understandings of ethical behaviour in research are shared the better. If progress is made in one sphere, all gain from it being generally acknowledged and understood. If foundational work is conducted, all gain from being able to build on and develop further that work.

Nor can it be assumed that formal ethics review committees are able to resolve the dilemmas or meet the challenges involved. Enough has been written about such review bodies to make their limitations clear. Crucially they cannot follow researchers into the field to monitor their every action; they cannot anticipate all of the emergent ethical dilemmas nor, even, follow through to the publication of findings. There is no adequate penalty for neglect through incompetence, nor worse, for conscious omissions of evidence. We have to rely upon the 'virtues' of the individual researcher alongside the skills of journal and grant reviewers. We need constantly to monitor scientific integrity at the corporate and at the individual level. These are issues of 'quality' as well as morality.

Within the research ethics field new problems, issues and concerns and new ways of collecting data continue to emerge regularly. This should not be surprising as social, economic and technological change necessitate constant reevaluation of research conduct. Standard approaches to research ethics such as valid informed consent, inclusion/exclusion criteria, vulnerable subjects and covert studies need to be reconsidered as developing social contexts and methodological innovation, interdisciplinary research and economic pressures pose new challenges to convention. Innovations in technology and method challenge our understanding of 'the public' and 'the private'. Researchers need to think even more clearly about the balance of harm and benefit to their subjects, to themselves and to society. This series proposes to address such new and continuing challenges for both ethics committees and researchers in the field as they emerge.

The concerns and interests are global and well recognized by researchers and commissioners alike around the world but with varying commitments at both the 'procedural' and the 'practical' levels. This series is designed to suggest realistic solutions to these challenges – this 'practical' angle is the USP for the series. Each volume will raise and address the key issues in the debates, but also strive to suggest ways forward that maintain the key ethical concerns of respect for human rights and dignity, while sustaining pragmatic guidance for future research developments. A series such as this aims to offer practical help and guidance in actual research engagements as well as meets the often varied and challenging demands of research ethics review. The approach will not be one of abstract moral philosophy; instead, it will seek to help researchers think through the potential harms and benefits of their work in the proposal stage and assist their reflection of the big ethical moments that they face in the field often when there may be no one to advise them in terms of their societal impact and acceptance.

While the research community can be highly imaginative both in the fields of study and methodological innovation, the structures of management and funding and the pressure to publish to fulfil league table quotas can pressure researchers into errors of judgement that have personal and professional consequences. The series aims to adopt an approach that promotes good practice and sets principles, values and standards that serve as models to aid successful research outcomes. There is clear international appeal as commissioners and researchers alike share a vested interest in the global promotion of professional virtues that lead to the public acceptability of good research. In an increasingly global world in research terms, there is little point in applying too localized a morality, nor one that implies a solely Western hegemony of values. If standards 'matter', it seems evident that they should 'matter' to and for all. Only then can the growth of interdisciplinary and multinational projects be accomplished effectively and with a shared concern for potential harms and benefits. While a diversity of experience and local interests is acknowledged, there are existing, proven models of good practice which can help research practitioners in emergent nations build their policies and processes to suit their own circumstances. We need to see that consensus positions effectively guide the work of scientists across the globe and secure minimal participant harm and maximum societal benefit and, additionally, that instance of fraudulence, corruption and dishonesty in science decrease as a consequence.

Perhaps some forms of truly independent formal ethics scrutiny can help maintain the integrity of research professions in an era of enhanced concerns over data security, privacy and human rights legislation. But it is essential to guard against rigid conformity to what can become administrative procedures. The consistency we seek to assist researchers in understanding what constitutes ‘proper behaviour’ does not imply uniformity. Having principles does not lead inexorably to an adherence to principlism. Indeed, sincerely held principles can be in conflict in differing contexts. No one practice is necessarily the best approach in all circumstances. But if researchers are aware of the range of possible ways in which their work can be accomplished ethically and with integrity, they can be free to apply the approach that works or is necessary in their setting. Guides to ‘good’ ways of doing things should not be taken as the ‘only’ way of proceeding. A rigidity in outlook does no favours to methodological innovation, nor to the research subjects or participants that they are supposed to ‘protect’. If there were to be any principles that should be rigidly adhered to they should include flexibility, open-mindedness and the recognition of the range of challenging situations to be met in the field – principles that in essence amount to a sense of proportionality. And these principles should apply equally to researchers and ethics reviewers alike. To accomplish that requires ethics reviewers to think afresh about each new research proposal, to detach from pre-formed opinions and prejudices, while still learning from and applying the lessons of the past. Principles such as these must also apply to funding and commissioning agencies, to research institutions and to professional associations and their learned societies. Our integrity as researchers demands that we recognize that the rights of our funders and research participants and/or ‘subjects’ are to be valued alongside our cherished research goals and seek to embody such principles in the research process from the outset. This series will strive to seek just how that might be accomplished in the best interests of all.

By
Ron Iphofen (Series Editor)

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LIST OF ABBREVIATIONS

(AS)—Alzheimer's Society
(BIPOC)—Black, Indigenous, and People of Color
(CDC)—Centers for Disease Control and Prevention
(CRANE)—Clinical Research Data Warehouse Environment
(CRN)—Clinical Research Network
(CBPR)—Community-Based Participatory Research
(CER)—Comparative Effectiveness Research
(DPIA)—Data Protection Impact Assessment
(EU)—European Union
(EC)—European Commission
(ERC)—European Research Council
(GDPR)—General Data Protection Regulation
(GAO)—Government Accountability Office
(HIPAA)—Health Insurance Portability and Accountability Act
(HRS)—Health Research Authority
(ICEnR)—Indigenous Community Engaged Research Method
(IRB)—Institutional Review Board
(IAP)—International Association for Public Participation
(ISPOR)—International Society for Pharmacoeconomics and Outcomes Research
(LEAP)—Lived Experience Advisory Panel
(LTSS)—Long-term Services and Supports
(MeSH)—Medical Subject Headings
(NIA)—National Institute on Aging
(NHS)—National Health Service
(NICE)—National Institute for Health and Care Excellence
(NIHR)—National Institute of Health Research
(NIH)—National Institutes of Health
(OPERAT)—Older Peoples External Residential Tool
(PAC)—Patient Advisory Council
(PPI)—Patient and Public Involvement/Public Patient Involvement/Personal and Public Involvement
(PCOR)—Patient-Centered Outcomes Research
(PCORI)—Patient-Centered Outcomes Research Institute
(PWD)—People with Dementia
(PiiAF)—Public Involvement Impact Assessment Framework
(RDS)—Research Design Service

(REC)—Research Ethics Committee
(SAIL) databank—Secure Anonymised Information Linkage
(The Bureau)—The Bureau of Sages
(Brexit)—United Kingdom's withdrawal from the EU
(UN)—United Nations
(VSC)—Virtual Senior Center
(WHO)—World Health Organization

ABOUT THE EDITOR

Professor Roger O'Sullivan is the Director of the Ageing Research and Development Division within the Institute of Public Health in Ireland and visiting Professor at The Bamford Centre for Mental Health and Wellbeing, Ulster University. He was the Director of the Centre for Ageing Research and Development from 2007 to 2015 and prior to that Research Coordinator with the Rural Community Network in Northern Ireland (1999–2007). Professor O'Sullivan has extensive experience of undertaking research as well as commissioning, managing and administering research programmes with particular expertise on public policy and services relating to ageing and older people. He was awarded membership through distinction of the Faculty of Public Health, UK in 2017 and in 2020 he was made Fellow of the Gerontological Society of America.

ABOUT THE CONTRIBUTORS

Katherine M. Abbott, PhD, is Professor of Gerontology and the Executive Director of the Scripps Gerontology Center at Miami University in Oxford, Ohio. Her research and teaching focuses on preference-based person-centred care and the social networks and health of older adults receiving long-term services and supports. She is the co-founder of Preference Based Living, whose mission is to conduct studies that build understanding of individual preferences and test innovative methods to honour preferences for people receiving long-term services and supports.

Peter Bates has provided consultancy support through the National Development Team for Inclusion since 1999. He previously worked in social services, the NHS and audit. Project work has been undertaken for a range of national bodies including the NHS Confederation, Department of Health and the Scottish Government. In his work with over 150 local service providers, Peter has combined a detailed knowledge of what needs to be done to make a difference, with an understanding of frontline work in hard-pressed services. He has published in the areas of employment, disability, empowerment and inclusion. Peter has also been supporting public involvement in academic and NHS infrastructure organizations since 2011 and contributed to research projects valued at £7m. As well as convening patient and public advisory groups, he has developed over 30 'How To' guides addressing the practicalities of research co-production.

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Ron Iphofen, FAcSS (British), is an Independent Consultant with international recognition for expertise on research ethics and professional standards in research. He is a Fellow of the Academy of Social Sciences and the Royal Society of Medicine. Since retiring in 2008 from his post as the Director of Postgraduate Studies in the School of Healthcare Sciences, Bangor University, Wales, he has presented at over 250 national and international events for universities, government, research institutes and the European Commission (EC) and European Research Council (ERC). He has served in the Universities Sector of the Association for Research Ethics, UK. He has acted as consultant, adviser and/or delivered training on research ethics for the Scottish Executive, UK Government Social Research, National Disability Authority (Ireland), National Centre for Social Research, Social Research Association, Audit Commission, UK Research Integrity Office, Ofsted, ANR (French Research Funding agency), SSRC (Canada) among many others. His primary consultative activity at present is for agencies of the European Commission and European Union-funded research projects.

Dr Erin McGaffigan, PhD, started Collective Insight in 2014 to demonstrate how effective engagement is possible and a powerful system improvement strategy. Dr McGaffigan, as the founder and leader for a certified woman-owned business comprised of engagement experts, has extensive experience in the area of community-based long-term services and supports for elders and people with diverse disabilities. Dr McGaffigan received a Master of Science in Public Policy from the University of Massachusetts, Boston and a Master of Social Work with a concentration in Community Organization, Public Policy and Administration from Boston College. She received her PhD from the University of Massachusetts, Boston, where she focused her dissertation research on the complex factors and related outcomes of community engagement practices.

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Andy Willis is a History graduate, lifelong Chelsea FC supporter, proud socialist, former Secondary School Teacher and trade unionist – NUT Division Secretary for Peterborough 2007–2011, married with two daughters and a son; with the recent addition of a Grandson. It has been a life well lived alongside six episodes of severe mental illness which has amounted to eight years of his life. His dual diagnosis is recurrent depression and emotionally unstable personality disorder with each episode having significant periods of crisis and suicide risk. Since discharge from psychiatric care in 2017, he is a member of the Lived Experience Advisory Panel (LEAP) within the local Personality Disorder Hub as well as joining the LEAP for a national study of depression. He has been privileged to make many Co-Production 'lived experience' contributions all with the intention of working collaboratively to improve recovery outcomes and patient experience for others. He is also a national Suicide Prevention Influencer.

FOREWORD

I am delighted to introduce this book that explores the intersection of research ethics, research integrity, the well-being and voices of older people and service users.

Through a collection of fascinating contributions, this volume shares insights on the ethical and practical aspects as well as the challenges of researching older people and service users.

The authors explore topics such as people living with dementia, family conflict in caregiving, mental health, public patient involvement and the insights of patients and nursing home residents. This volume also covers the history and cultural context of our methods of involving users in research.

I found this collection of chapters informative as well as challenging but overall illustrative of the importance and value of collaboration and dialogue among researchers, service providers, policymakers, as well as older people and service users themselves.

Working with older people has been a major part of my life both professionally and as a volunteer starting in school. Recently, I became a great grandfather in a family spread over six countries and this experience has convinced me of the value of understanding ageing through the life course approach for individuals, families, communities and countries. We need to recognize that growing older starts in the womb not in a hospice or nursing home and therefore work in an inclusive manner to understand the different experiences of ageing – both positive and negative.

This volume has also reinforced my view that the highest standards of research, research ethics and research integrity can be best achieved by widening the voices that we hear, to avoid ‘group think’, which unfortunately too often guides decision-making.

I hope that the greater knowledge and understanding generated through this volume and this series will have a positive impact on the lives of service users of all ages by recording and celebrating their lives and valuing their contribution as partners rather than only objects of research.

I commend the contributors and the editor of this book for their dedication. Their collective experience, knowledge and insights will serve as a valuable resource for researchers, students, practitioners, older people and all those engaged in the field of research, policy, service delivery as well as the fields of social and health sciences, ageing, user involvement, public patient involvement, community-based participatory action research and of course research ethics and research integrity.

I hope this book fosters discussion, encourages reflection and inspires action to enhance the quality and practice of research in this field.

Robin Webster
Irish Centre for Social Gerontology
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PREFACE

With the ever increasing, competing, contrasting and sometimes conflicting views on society today, we need, now more than ever, robust research to generate valid knowledge, improve and deepen our understanding, identify or solve problems and help inform evidence-based decision-making.

This volume in the Advances series works on the premise that there is much to be gained from utilizing the knowledge, expertise and insights from older people and service users. However, at the same time, there is much to be learned, addressed and developed if we are to move beyond rhetoric and tokenism.

This volume is aimed at those who want to understand the theoretical, philosophical and, in particular, the practical aspects of research with older adults and service users, not simply as 'the subjects of research' but also as those who have views, knowledge and experiences that can help advance research to inform services, policy, practice and indeed society as a whole.

It brings together contributors from the US, Europe and the UK to share insights from their work or personal experience in a bid to both educate and also challenge.

The volume is organized into three sections – 'Views From the *Researchers*', 'Views From the *Researched*' and 'Views From Those Who Fall *In Between*' such narrow categorizations. It is important to critically approach and reflect upon traditional constructs in research – not only recognizing the limitations with some concepts, language and terms in research as applied to our field but also wider considerations about how we can help advance research beyond traditional boundaries and embed collaboration and dialogue as a foundation.

The diversity and the expertise of older people as patients, consumers, carers, volunteers, workers and increasingly as researchers is an underlying theme within this book.

Likewise, the contents also reinforce that we must recognize we have a much more highly educated older population and groups of service users who, more than ever before, understand their rights and can articulate these rights more easily than previous generations.

During the planning and production of this book, the COVID-19 pandemic struck and the related public health social measures were set in place. The challenge for society as a whole was immense and so too for the research community in the drive to produce valid and timely knowledge – not just on COVID-19 issues but wider issues as well.

As we move to a post COVID-19 era it is clear that social participatory research becomes even more crucial in understanding the everyday challenges, changing dynamics, contexts and needs of individuals, communities and organizations.

This book highlights the value of defining and agreeing clear research goals and roles; focusing on quality, relevance and overall impact, addressing dynamics, cultural contexts and especially the importance of fostering an inclusive environment that encourages the active involvement of those outside the research community in planning research, data collection, analysis and interpretation.

I would like to take this opportunity to thank the series editor, Dr Ron Iphofen, for his invaluable support and wisdom, for the time and excellent contributions of all the authors who so generously shared their insights and expertise. I would also like to thank the team at Emerald especially Katy Mathers, Lauren Kammerdiener, Jo Sharrocks and Joshi Monica.

Finally, what is clear from the collective voice of this book is that flexibility, inclusivity and a commitment to collaborative decision-making and addressing power relationships will be key in planning and conducting meaningful and impactful research as we move forward. We must recognize and accept it is no longer a question of *should* older people and service users be involved in research or if they have valid knowledge or relevant experiences, but, rather to what extent they will or want to be involved in the research process and to assign tokenism within research as a legacy of the past.

Roger O'Sullivan