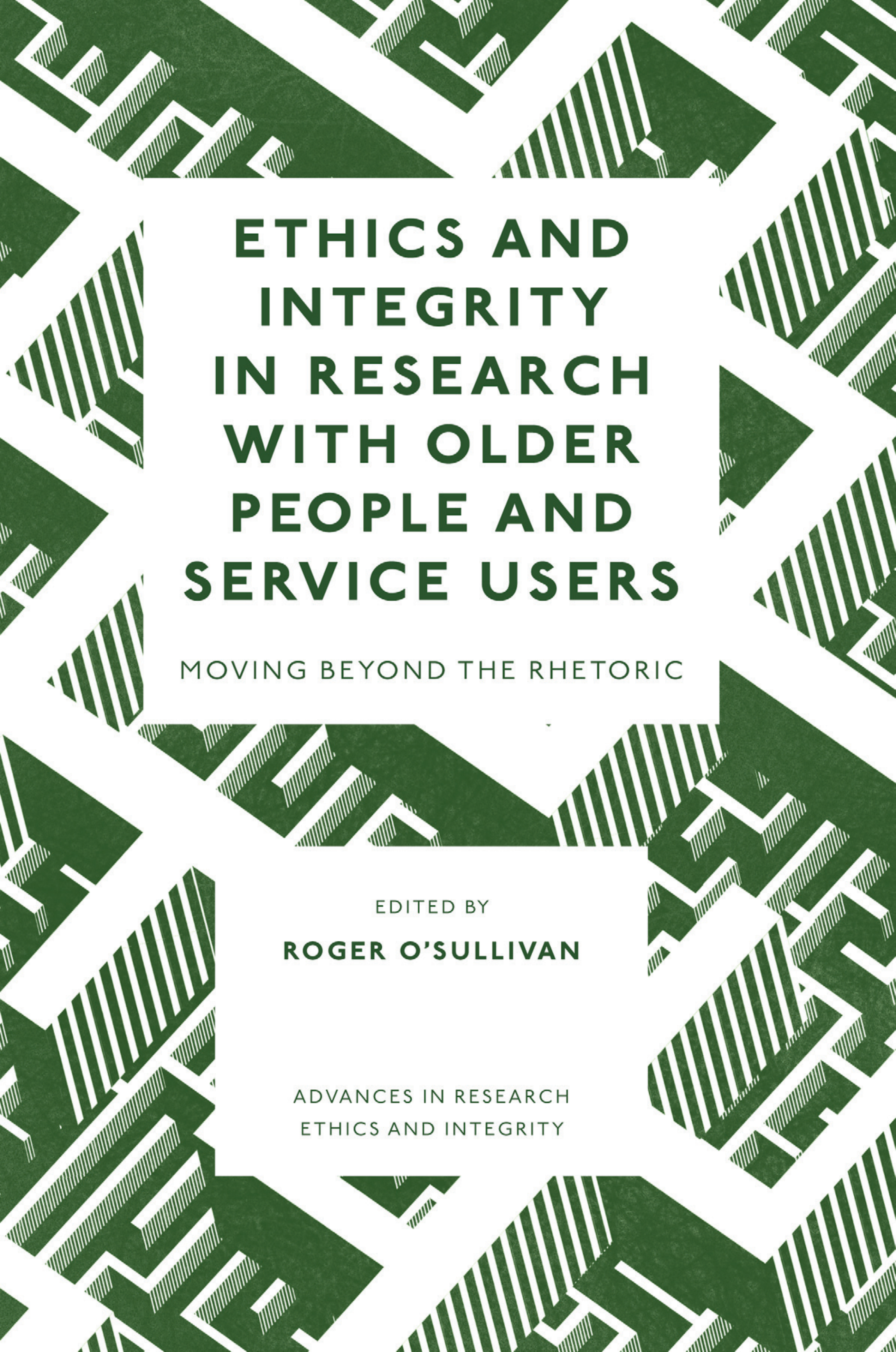

ETHICS AND INTEGRITY IN RESEARCH WITH OLDER PEOPLE AND SERVICE USERS

MOVING BEYOND THE RHETORIC

EDITED BY

ROGER O'SULLIVAN

ADVANCES IN RESEARCH ETHICS AND INTEGRITY

ETHICS AND INTEGRITY IN RESEARCH WITH OLDER PEOPLE AND SERVICE USERS

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

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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.

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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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Lyn M. Holley, PhD, is the inaugural Dr Chuck Powell Professor in the Department of Gerontology at University of Nebraska Omaha (UNO), the inaugural (2015) UNO Service Learning Academy Faculty Fellow, and has served twice as Vice President of the UNO Faculty Senate. Dr Holley's research helps improve services for elders – in general and for minority elders, and helps improve intergenerational relationships. She has published articles in several journals, including 'The Gerontologist', 'Educational Gerontology', 'Gerontology and Geriatrics Education', 'Quality in Ageing and Older Adults' and 'Public Performance Management Review'. She earned her BA in Psychology from American University (1964). After working in Federal (including service in the US Army Reserve) and International public service (in the United Nations International Civil Service Commission), she earned an MPA (UNO, 1995) and PhD (UNO, 1999). Following gerontology research at the University of Kansas and University Wisconsin-Milwaukee, she joined UNO's gerontology faculty in 2004.

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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Robin Webster is an Adjunct Lecturer, Irish Centre for Social Gerontology, National University of Ireland, Galway. He is a social science graduate, with postgraduate qualifications in education, social work and gerontology. His previous positions include CEO of Age Action, Ireland, Director of AONTAS, the National Association of Adult Education in Ireland, Director of Age Concern Scotland, National Development Officer, Society of St Vincent de Paul in Ireland, Lecturer in Social Work, Trinity College, Dublin, Lecturer in Gerontology, the Open University in Ireland and HM Inspector of Schools (Further Education) in the Scottish Education Department.

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
Institute of Lifecourse and Society
National University of Ireland Galway

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

SECTION 1

‘VIEWS FROM THE *RESEARCHERS*’

CHAPTER 1

THEORY AND PRACTICE OF USER-INVOLVED RESEARCH

Erin McGaffigan, Dani Skenadore Foster,
Sophia Webber and Missy Destrampe

ABSTRACT

The application of user involvement in the design and implementation of research has progressed through various frameworks and is an increasingly recognized and expected as a key element of ethical research methodologies. The practice of engaging users (the public, patients, service recipients, etc.) beyond the traditional scope of subject, and elevating their role as partner or co-designer of the research process, is theoretically rooted in civil rights and social justice ideologies. The success of these types of models are influenced by various factors including the people involved, their capacities and values; the physical and funding environment in which the research occurs and the approaches used to engage. In theory, user involved research is most successful when the people, approaches and environment are genuinely interested and centralized around inclusive methods that posit that populations researched have the right to contribute to research done and researchers have the ethical responsibility to engage them using measurable strategies. User involved research frameworks have the potential to create a space that both values and uplifts historically marginalized voices, while touting the demonstrated advantage of improved effectiveness in research outcomes and implications. Yet there exists a dissonance between theory and practice in the field, due to a lack of consistent understanding, practices and standards tied to the approach.

Keywords: User involvement; theory; participation; frameworks; rights; practice

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INTRODUCTION

The application of user involvement in the design and implementation of research has evolved over recent decades and is an increasingly recognized and expected element of ethical research methodologies. This is largely because user involvement offers a strategy to bridge the disconnect between researchers and the communities they study, informing the application of more responsible and equitable research methods. Historically and contemporarily, researchers have not effectively or uniformly dismantled the power structures that alienate communities from research institutions and the research processes. In fact, communities have often failed to mutually benefit from, or have actively been harmed by, traditional research models and methods (Hacker, 2013). This has led to distrust in research, particularly among marginalized communities who have borne the brunt of traditional research's discriminatory approaches (Hacker, 2013). Ultimately, these broken relationships prevent communities from accessing research of benefit to them and deny researchers the important input those communities may offer. User involvement seeks to disrupt this cycle by acting outside of the researcher-subject dynamic, and instead, commits to equitable co-design research models that involve users of services in the planning, implementation and dissemination of research.

While some researchers apply user involvement strategies in nearly every research project developed, other researchers have never heard the term, 'user involvement', before. There also are researchers who have attempted user involvement in research, either because it was required by an external influencer or simply because it felt like the right thing to do. These researchers may have left the process confused or frustrated, either by the time required, the conflict that resulted, or the minimal impact it had on their overall methods or findings.

This chapter defines user involvement and provides a closer look at nationally recognized frameworks to guide how one thinks about user involvement in research. We attempt to cover what is often missing within the literature – a thorough review of the concrete factors that play into one's success with this unique, yet bold, approach to research. We also review examples of user involvement in action to provide the reader with insight on how user involvement can improve, and maybe even simplify, the research process. We believe this review will provide readers a foundation in which to make informed decisions about when and how to apply user involvement in their research design, implementation, analysis and dissemination strategies.

DEFINING USER INVOLVEMENT

What do we mean by user involvement in research? What do we even mean by user? User involvement indicates that there are individuals who use the services or substance of our older adult research and these individuals, groups and/or communities have a stake in what is prioritized for research, how research is implemented, how data is interpreted and how and where findings are disseminated. Often a diverse range of users have a stake in a research topic; however, user involvement is most often interested in elevating the voices of those who commonly go unheard in research. In the context of this book, the specific users of interest are older adults. User involvement should not be conflated with engaging users as research subjects. Of course, many researchers engage older adults in their research as subjects by way of surveys, focus groups, interviews, observations, trials and more, but this is not what is meant by user involvement in research. Instead, it starts much earlier. *User involvement in research is the involvement of older adults through various modalities to inform the design of research aims, methods and dissemination strategies well before data collection even occurs.*

Some of the questions asked when deploying user involvement in research include:

- What do older adults want to learn from research? What do they feel is broken?
- Who is often left out of research, whether as research subjects or in the research design and data collection? Why? What can be done about it?
- Why are there obstacles to outreach and inclusion of many older adults in research, and what can be done about it?
- What communities are impacted by research, but are rarely informed of the findings?

As evidenced by the questions above, user involvement in research is an applied research model. Applied research implies that we believe what we study should influence the improvement of programs and the quality of life of older adults. While some academic researchers may feel research is not always applied, we would like to push the boundaries of this notion. We must consider the implications of what it means to conduct research generally, particularly research involving people, and how the research process might impact the lives of research subjects, even when the researcher is not actively pursuing that research for applied purposes. How will the triumphs or failures of the design, implementation, and later, dissemination of findings, affect the subjects and the communities to which they belong? Moreover, researchers must consider that somehow they concluded that a research topic was important and should be studied. Why is it important? To whom is it important? One might argue that all research starts with some perception of what is important to learn; therefore, older adult research, whether the researcher considers it academic or applied, is influenced by someone and most likely, someone who is not personally impacted by the findings. Who is making assumptions of study importance, and why are these assumptions more important than those of the older adults, or subjects, being studied?

In discussions of user involvement, researchers are frequently concerned that introducing users of services will create bias; however, researchers must recognize the bias that already exists within research. See Table 1.1 for examples of potential bias. For instance, research colleagues come to the design table with

Table 1.1. Potential Biases by Lens.

Lens	Potential Bias
Department chair	• 'Is this type of work publishable?' • 'While this benefits the community, it does not benefit your progress towards tenure, the department's strategic priorities, nor will it generate future funding for the department'.
Co-investigator/colleague	• 'A peer-reviewed journal is interested in rigorous research design, not user involvement'. • 'Engaging users of service will not bring enough value to offset the amount of work needed to involve them in the process'.
Research funder	• 'Your proposal needs to align with one of our strategic priority areas, as outlined on our website'. • 'Your proposal is accepted pending a modification to your research design, which aligns more closely with the breadth of research and methodologies we traditionally fund'.
Organizational/provider-based research sites	• 'Older adults do not have the capacity to inform research design, but our staff can represent our priorities and their needs'. • 'You will get better insight from caregiver involvement than older adult involvement'.
Older adult	• 'This survey doesn't get to the real root of the problem because it does not ask the right questions. Let me tell you about the real issue'. • 'Research subjects will have a hard time getting to that focus group location because the nearest bus stop is three blocks away'.

Source: Collective Insight, LLC (2022).

their own assumptions about what is important to research and how to do it. Funders also have a stake in the research focus areas, methods, data analysis plans and dissemination strategies. Researchers and funders, among others, influence research; we like to think their voices are neutral, but individual biases and institutional interests are commonly present. With a closer look, we realize many professional lenses can influence our research just as involving users might.

As the examples above highlight, all those involved in research have their own lived experience and motivations that influence their topics of interest, desired methods and use of the data. We propose here, and throughout this chapter that user involvement in research can actually minimize bias simply by opening the discussion and broadening the decision-making to people who think differently.

THEORETICAL UNDERPINNINGS OF USER INVOLVEMENT IN RESEARCH

The practice of involving users (the public, patients, service recipients, etc.) beyond the traditional scope of subject, and elevating their role to partner or co-designer in the research process, is theoretically rooted in civil rights and social justice ideologies. Thought leaders, such as Brazilian educator, Paulo Freire, laid the theoretical groundwork for elevating lived experience as expertise. In his critical 1970 work, ‘Pedagogy of the Oppressed’, Freire emphasized the need for disenfranchised peoples to understand their position within the world through ‘empowering education’, a theory which centres dialogue and participation (Wallerstein et al., 2017). Freire’s writings are the basis for many of the methodologies championed in the spectrum of community-engaged research, in which user involvement is situated (Wallerstein et al., 2017). Moreover, the Independent Living Movement plays a major role in the philosophical underpinnings of user involvement (McGaffigan, 2011). Ed Roberts and his peers are partially credited for sparking this movement when they fought for integration at the University of California, Berkeley (Shapiro, 1994). These advocates fought for themselves and other wheelchair users to be recognized as citizens who have a right to choose where they live, to receive an education and to be gainfully employed (Shapiro, 1994). Following the civil rights movements in the 1960s, many people with disabilities and older adults gained freedom from institutionalization, but paternalism and continued segregation of people with disabilities and older adults prevented them from accessing the right to full citizenship as fought for by Ed Roberts and other California advocates (About Independent Living, 2019). Accessing full citizenship, specifically the right to choose one’s own living situation, reflects a commitment to self-determination that advocates today describe as a focal point in the Disabilities Rights and Independent Living movements (Shapiro, 1994). Self-determination operates from the understanding that traditional definitions of disability and age are overly medicalized and reductive. Rather than being framed as problems that need to be cured, people with disabilities and older adults must be recognized as full persons and experts in their own needs and care (About Independent Living, 2019).

The Disabilities Rights Movement and older adult advocacy intersect with the emergence of supported decision-making models within long-term care, which advocate that all people receive the supports and services necessary to make decisions about their own lives, including decisions about health care, living situations, voting and finances. Moreover, as people with disabilities age, they endure the dual oppressions of ableism and ageism, both of which challenge their right to independence. For this reason, intergenerational leadership has been critical to the Disabilities Rights Movement and its immense contributions to the right to independent living among all older adults, including those with functional limitations who may not have identified with the disability community prior to ageing.

Arnstein’s Ladder of Participation

The fight for full citizenship is exemplified by Sherry Arnstein’s ‘Ladder of Participation (Arnstein, 1969)’. Arnstein’s ladder recognizes that not all involvement is the same and remains, to this day, to be an important measurement stick for user involvement in research. In the Ladder, Arnstein describes the nonparticipatory nature of many citizen involvement initiatives in which the public is brought into a policy or programme proposal largely for the sake of rubber stamping the decisions of those in power (the rung of manipulation) or to 'fix' the individual involved (the rung of therapy). The next three levels, informing, consultation and placation, describe practices that apply elements critical to meaningful involvement, such as information sharing. Unfortunately, they lack the transparency, support and reciprocity that are required to make involvement effective. Levels six and seven of Arnstein's Ladder, partnership and delegation, provide glimpses into meaningful involvement, including in research. Arnstein describes partnership as the redistribution of power through negotiation; however, citizens involved through partnership strategies still navigate disadvantaging power structures to collaborate with power holders. The next rung, delegation, attempts to create more leverage for citizens within the decision-making process by ensuring they are in the majority. Finally, Arnstein places citizen control at the top of the ladder. In this final rung of the Ladder, citizens conduct all planning and managing and there are no barriers between the citizens and their funding source. While Arnstein's Ladder (Fig. 1.1) was originally published in the *Journal of American Planning* and was written with community organizing in mind, researchers should not disregard its relevance to involving older adults in research. Arnstein's Ladder offers a concise understanding of user involvement, how it is often co-opted, and its potential to protect and elevate full citizenship in research. Moreover, it highlights how user involvement can look differently from one research project to the next and is influenced by existing power structures. If researchers are truly committed to elevating the voices of marginalized and often excluded users within their work,

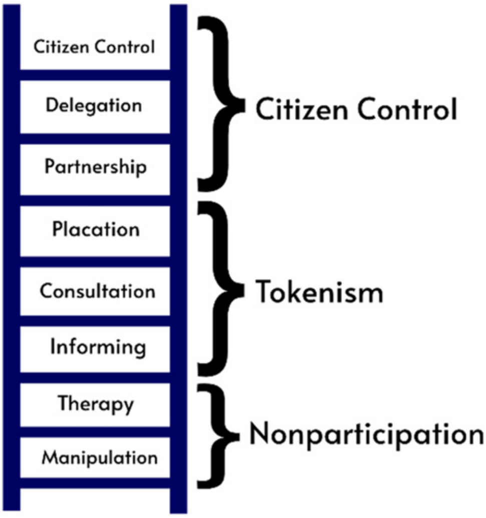

Fig. 1.1. Arnstein's Ladder (1969).