ETHICS AND INTEGRITY IN RESEARCH WITH CHILDREN AND YOUNG PEOPLE

EDITED BY
GRACE SPENCER

ADVANCES IN RESEARCH
ETHICS AND INTEGRITY

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ADVANCES IN RESEARCH ETHICS AND INTEGRITY

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INVESTOR IN PEOPLE

For Harry, Emily and Oliver, and all the incredible children and young people that have inspired the chapters in this volume and my broader programme of work.

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SERIES/VOLUME EDITORS' BIOGRAPHIES

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Grace Spencer is a Ruskin Fellow at the Faculty of Health, Education, Medicine and Social Care, Anglia Ruskin University, Cambridge, UK. Her research focusses on children and young people's health and their health-related practices with reference to concepts of risk, agency and empowerment theory in health promotion. She is the author of *Empowerment, Health Promotion and Young People: A Critical Approach*. She is recognised globally for her expertise in qualitative research methods and the ethics of childhood and youth-centred research, and has published widely on the ethical aspects of research with children and young people.

Series Editor, *Advances in Research Ethics in Integrity*

Ron Iphofen, FAcSS, is Executive Editor for this Emerald book series. He is an Independent Consultant, a Fellow of the UK Academy of Social Sciences, 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, his major activity has been as an adviser to the European Commission (EC) and its executive agencies, and the European Research Council (ERC) on both the seventh 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 (SRA), updated their ethics guidelines and now convenes the SRA's Research Ethics Forum. He has acted as scientific and ethics advisor for several EC Projects and has advised the UK Research Integrity Office, the National Disability Authority of the Irish Ministry of Justice, the UK Parliamentary Office of Science and Technology, the Scottish Executive, the Food Standards Agency, the Ministry of Justice, Agence Nationale de la Recherche (the French research funding agency), the Social Science Research Council Canada amongst many others. He was founding Executive Editor of the Emerald gerontology journal *Quality in Ageing and Older Adults*, published *Ethical Decision Making in Social Research: A Practical Guide* (Palgrave Macmillan, 2009/2011), coedited with Martin Tolich *The SAGE Handbook of Qualitative Research Ethics* (2018) and edited the *Handbook of Research Ethics and Scientific Integrity* for Springer Nature (2020). He is currently leading a European Commission-funded project (PRO-RES) that aims at promoting ethics and integrity in all non-medical research.

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SERIES PREFACE

By

Ron Iphofen (Series Editor)

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 longstanding 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 characterise a meeting of formalised 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 everyone gains from it being generally acknowledged and understood. If foundational work is conducted everyone gains 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 reviewers and funding agency evaluators. 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 re-evaluation 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 funders, research managers, research ethics committees and researchers in the field as they emerge. The concerns and interests are global and well recognised 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 *unique selling proposition* (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 meeting 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 judgment 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 localised 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 multi-national 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 instances 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, 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 recognise 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.

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ACKNOWLEDGEMENTS

There are a number of people that have made this volume possible and I am grateful for their support and ongoing commitment to the book. First, I would like to thank Ron Iphofen, Series Editor for Advances in Research Ethics and Integrity, for inviting me to be Editor for this important volume on ethics and integrity in research with children and young people. I am immensely grateful for Ron's timely guidance and support throughout the process of preparing the manuscript and its final publication. I would like to thank the full team at Emerald Publishing for their assistance and meticulous work on preparing the final volume. I am especially thankful to all the authors of the book for their considered and critical engagement with the volume and ethical issues. Their contributions and hard work have resulted in an exciting addition to the field of research ethics with children and young people. I am also hugely appreciative to all of those who participated in the peer review process. I am grateful to all my colleagues at Anglia Ruskin University in Cambridge, particularly Roxana Anghel, and Jill Thompson from the University of Sheffield, for their ongoing support and review of the final manuscript. Finally, warm appreciation goes to my close friends and family who have supported me unreservedly from afar during the preparation of the volume and at the exceptional time of the COVID-19 pandemic.