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HEALTH AND LIFE SCIENCES  
RESEARCH

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ADVANCES IN RESEARCH ETHICS AND INTEGRITY  
VOLUME 4

# ETHICS AND INTEGRITY IN HEALTH AND LIFE SCIENCES RESEARCH

EDITED BY

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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 program 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 behavior 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 the 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 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 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 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 fulfill 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 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 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 behavior” 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 favors 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 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)



## ABOUT THE SERIES EDITOR

**Ron Iphofen**, FAcSS, is Executive Editor of the Emerald book series *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). He is an Independent Research 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 agencies, the European Research Council (ERC), and the Research Executive Agency (REA) 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, updated their Ethics Guidelines and now convenes the SRA's Research Ethics Forum. He was scientific consultant on the EC RESPECT project – establishing pan-European standards in the social sciences and chaired the Ethics and Societal Impact Advisory Group for another EC-funded European Demonstration Project on mass transit security (SECUR-ED). He has advised the UK Research Integrity Office; the National Disability Authority (NDA) of the Irish Ministry of Justice; the UK Parliamentary Office of Science and Technology; the Scottish Executive; UK Government Social Research; National Centre for Social Research; the Audit Commission; the Food Standards Agency; the Ministry of Justice; the BIG Lottery; a UK Local Authorities' Consortium; Skills Development Scotland; Agence Nationale de la Recherche (ANR the French Research Funding agency) among many others. Ron was founding Executive Editor of the Emerald gerontology journal *Quality in Ageing and Older Adults*. He published *Ethical Decision Making in Social Research: A Practical Guide* (Palgrave Macmillan, 2009 and 2011) and coedited with Martin Tolich *The SAGE Handbook of Qualitative Research Ethics* (Sage, 2018). He is currently leading a new €2.8M European Commission-funded project (PRO-RES) that aims at promoting ethics and integrity in all non-medical research (2018–2021).

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## ABOUT THE EDITOR

**Zvonimir Koporc** has international recognition for expertise on research in life sciences (immunology) and professional standards in research ethics. His primary consultative activity in ethics and life sciences at present is for the European Commission (EC) Ethics Unit, Directorate General for Science and Innovation, the Research Executive Agency (REA), and the European Research Council (ERC). He has acted as Consultant, Adviser, and/or delivered training on research ethics at the European and national level. He has worked in several life science teams in Europe, and his PhD in Chemistry was awarded by the Technical University of Vienna, Austria. At the beginning of 2007 he returned to his home country through the national program called “Return of the scientists,” which was announced from the Croatian Ministry of Science. As a scientist he took up a position at the prominent Croatian scientific institution – Institute Rudjer Boskovic, Zagreb. Receiving his university tenured track position, he moved then to the Department of Biotechnology, University of Rijeka, where he stayed until 2015. From that year on, he joined Catholic University of Croatia Zagreb where he currently holds a position of University Associate Professor in Physiology where he is also a member of the Ethics Review Board. He has published extensively on immunology. Over and above the life sciences, his current professional interests are in research ethics and scientific integrity. Developing a fruitful cooperation with the Croatian Data Protection Agency in October of 2017, he organized a symposium on “Data protection in research – an insight in to the EU General Data Protection Regulation (GDPR) 25/5/2018” where he acted as a president of the organizing committee. Another fruitful cooperation has been developed with the Croatian National Agency for Mobility and EU Programmes funds where Dr Koporc regularly holds guidance workshops on ethics and research integrity for scientists and research professionals intending to apply for EU funds.





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