

REFRAMING QUALITATIVE RESEARCH ETHICS

ADVANCES IN RESEARCH ETHICS AND INTEGRITY

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ADVANCES IN RESEARCH ETHICS AND
INTEGRITY VOLUME 12

REFRAMING QUALITATIVE RESEARCH ETHICS

EDITED BY

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Independent Research Ethics Consultant, UK



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INVESTOR IN PEOPLE

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ABOUT THE EDITOR

Helen Busby is an independent research ethics consultant, advising on the management of complex ethical issues in research involving fieldwork in multiple countries.

After studying Medical Anthropology and Sociology at the Universities of Brunel and Nottingham (UK) and holding Postdoc Fellowships at the latter, she led multidisciplinary research at the Universities of Nottingham and Leicester. Having particular interests in qualitative approaches, and building on her earlier involvement in research on public health and primary care, she was a Principal Investigator for research projects about blood donation, stem cell banking, and social frameworks of altruism. She was a member of two local National Health Service research ethics committees during this time.

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Her research is published in *Sociology of Health and Illness*, *Clinical Ethics*, *Health: An Interdisciplinary Journal for the Social Study of Health Illness and Medicine*, *European Law Review*, and other journals in these fields. She has also contributed chapters to edited books – engaging with fellow researchers, writers, and practitioners along the way. Her most recent book chapter is: ‘Modes of Influence: What Can We Learn from International Codes of Ethics for Health-Related Research?’ In R. Iphofen and D. O’Mathúna (Eds.), 2022, *Ethical Evidence and Policymaking: Interdisciplinary and International Research* (Policy Press).

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Anke Erdmann is professor for Chronic Illness and Long-Term Care at Kiel University of Applied Sciences. She is also affiliated to the Medical Ethics Working Group, Kiel University, Germany. She studied sociology, philosophy, nursing science, and social work and received her doctorate in 2015 with a qualitative evaluation study on integrative validation therapy, a particularly appreciative form of communication and care for people with dementia. During her postdoc, she focussed on ethical issues related to chronic illness: end-of-life-decision-making in amyotrophic lateral sclerosis (ALS), collecting lifestyle data with mobile health technologies from people with inflammatory bowel diseases (IBD), body image, disclosure of illness, stigma and self-perception in chronic inflammatory diseases, and deception in dementia care. She works predominantly with qualitative methods, and research ethics issues are a further focus of her work.

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Margaret Sleeboom-Faulkner is Professor of Social and Medical Anthropology at the University of Sussex, UK, with a regional focus of China and Japan. For nearly two decades, her research has engaged with developments in the life sciences and biotechnologies in Asian societies, as well as their role in the global dynamics of research collaborations and regulation. The concerns discussed in her chapter – clashes of formalised research ethics and with ethics as experience

in daily lives – emerged in her long-term field research, some of which is published in *Global Morality and Life Science Practices in Asia: Assemblages of Life* (Palgrave MacMillan, 2014) and *Regulatory Violence: The Global Dynamics of Regulatory Experimentation in Biomedicine and Health* (CUP, 2025). The formative impact of formalised ethics on communication and conversations in field research has been a main theme in her engagement with ethics review in anthropology. An example of this is the EthNav.

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Lloy Wylie (PhD) is an interdisciplinary specialist in implementing equity, diversity, and inclusion in health professional education, policy, and practice. She is an advisor on accreditation standards in medical education for Indigenous health in Canada and internationally. She provides expert advice on ethics for health and medical research with underserved populations. Her main areas of research are in health systems and health services, with a focus on equity and improvement of health services and access through community-based participatory research. As the lead of the Health Equity Action Research Team, her research focusses on Indigenous, immigrant, and refugee health, drawing on cultural safety as a framework for health system improvements to advance equity in health care. She is an Associate Professor in the Schulich Interfaculty Programme in Public Health at Western University in Canada. As an award-winning educator, she develops innovative programmes in community-engaged learning in public health.

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) from the Seventh Framework Programme (FP7) to the current Horizon Europe. His consultancy work has covered a range of research agencies (in government and independent) globally. 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); the Social Sciences and Humanities Research Council (SSHRC) in Canada; and in Ireland the National Disability Authority (NDA) of the Ministry of Justice and the Institute of Public Health, among many others. He 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), coedited with Martin Tolich *The SAGE Handbook of Qualitative Research Ethics* (Sage, 2018) and edited the SPRINGER Nature *Handbook of Scientific Research and Integrity* (2020). Between 2018 and 2021, he was Principal Investigator (PI) on a €2.8M European Commission-funded project (PRO-RES) aimed at promoting ethics and integrity in all non-medical research. He co-edited three open access publications for the PRO-RES Project: *Ethical Issues in Covert, Security and Surveillance Research*, Emerald Publishing (2022); *Ethical Evidence and Policymaking: Interdisciplinary and International Research*, Bristol University Press (2022); and *Ethics, Integrity and Policymaking: The Value of the Case Study*, Springer (2022) (<https://roniphofen.com/>).

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SERIES PREFACE

Advances in Research Ethics and Integrity grew out of the foundational work of a group of Fellows of the UK Academy of Social Sciences (AcSS) who were all concerned to ensure that lessons learned from previous work in the research ethics field were built upon and improved. Unnecessary duplications of or ignorance of earlier work were seen as hindrances to 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. 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.

Given the plethora of ethics codes and guidelines, it can be difficult for researchers to judge those most relevant to their proposed activity. Long-standing issues in the field are confronted afresh by novice researchers so that it is no wonder they can despair in their search for guidance. Even experienced researchers may be tempted by the 'checklist mentality' that can characterise the meeting of formalised ethics review requirements.

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.

It should not 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. They cannot follow researchers into the field to monitor what goes on, nor can they anticipate all emergent ethical dilemmas or dissemination risks. There is no adequate penalty for neglect through incompetence, or 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. Scientific integrity must be constantly monitored at the corporate and at the individual levels.

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. Developments in social media blur the distinction between ‘the public’ and the ‘private’.

This series proposed to address such new and continuing challenges for funders, research managers, research ethics committees and researchers in the field. The concerns and interests are well recognised globally but with varying commitments at both the procedural and the practical levels. This series is designed to suggest realistic solutions to these challenges, and this practical angle is the unique selling proposition 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.

We 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. 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 research world, 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 multinational projects be accomplished effectively and with a shared concern for potential harms and benefits.

While the diversity of experience and unique 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.

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 and corporate protectionism. Consistency in ‘proper behaviour’ does not imply uniformity. Having principles does not lead inexorably to an adherence to principlism. 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.

Such principles should apply equally to researchers and ethics reviewers alike. Reviewers need 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 strives to seek just how that might be accomplished in the best interests of all.

Ron Iphofen, Series Editor

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Helen Busby, Editor

INTRODUCTION

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CHAPTER 1

QUALITATIVE RESEARCH ETHICS: CHANGING CONTEXTS AND NEW METHODOLOGIES

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ABSTRACT

Practitioners of social science research have long reflected on ethical and moral aspects of conducting research in this field, and mandatory research ethics review was introduced for social science research in some countries from the 1990s. Moving to qualitative research, recent years have seen the emergence of a range of innovative methodologies and approaches – including visual methods, novel technologies, autoethnography, involvement of peer researchers, and analysis of user-generated online data – which bring new ethical challenges. This chapter situates the emergence of research ethics review for social science research in a broad historical trajectory, considers the critiques of such processes by social scientists, and analyses the implications of changing contexts and new methodologies for qualitative research ethics. I argue that generic models of research ethics review are undermined by the complexity of qualitative research methodologies and draw on researchers' experience in these fields to rethink and reframe ethics oversight of qualitative research.

Keywords: Ethics in qualitative research; qualitative methodologies; research ethics; Declaration of Helsinki; innovative qualitative methodologies

INTRODUCTION

Questions of norms have been integral to social research since the advocates of anthropology, sociology, and social policy first began to articulate these disciplines and their methods.¹ Added to this, reflection on the moral aspects of conducting sociological and anthropological research – although not yet formulated in terms of research ethics – emerged in some of the pioneer university departments for these disciplines earlier than is generally recognised.² Discussions explicitly addressing ethical issues in the social sciences were published from the 1960s and 1970s onwards, after which time debates on researchers' responsibilities from an ethical perspective proliferated across diverse countries and regions, with codes of ethics being initiated, debated, expanded, and overhauled during the 1980s and 1990s (Fluehr-Lobban, 2002). Notwithstanding these emerging reflections on ethics within the academy, external pressures brought mandatory research ethics review to the table for social scientists in some countries from the 1990s, opening up a new and challenging phase in the relationship between social scientists and research ethics.

Over the intervening years, much has been written about research ethics in the social sciences, and new contexts have emerged that could hardly have been imagined just a few decades ago. These shifts have been brought about in part by the growth of qualitative research and by the influence of its practitioners, who have drawn on their own research to problematise tenacious assumptions about research ethics. We have now arrived at a point where qualitative researchers have extensive experience of ethics review of social science research, many have been members of research ethics committees (RECs) and institutional review boards (IRBs), and some have contributed to policies and guidance that influences research ethics oversight at local, national, and international levels. Given the experience of today's qualitative research practitioners, it is timely to explore the current state of play in this field. Just as Guillemin and Gillam (2004, p. 262) differentiated between 'ethics in practice' and 'procedural ethics', it is useful here to distinguish between the nuances of reflection on ethical issues during fieldwork and the formalities of institutional research ethics procedures: the brief for contributors to this volume was to draw on their own experience of fieldwork to inform suggestions for change and so to begin to reimagine how institutional support for qualitative research ethics should look.

In the first section of this chapter, I briefly situate the emergence of ethics review processes for social science research in a historical trajectory. In the second, I look to balance an acknowledgement of the scholarly literature that is critical of research ethics review in the social sciences with a counterchallenge: I argue that, notwithstanding the importance of these critiques and their significance in pointing to how things should be done differently, ethics review still has the potential to support innovative qualitative research in today's landscape.

RECs aim to provide guidance in an environment where new ideas and methodologies abound. In the third part of the chapter, I explore the significance of some of these changes: not only have qualitative methodologies evolved considerably, even since the turn of the century, there are also contemporary social phenomena

that either did not exist then or were not recognised or articulated at that time. While a short introduction cannot comprehensively encompass all such changes, I will describe selected changes thematically, because this volume is as much about the authors grappling with their significance as it is about how procedural ethics can do justice to them.

RESEARCH ETHICS REVIEW AND QUALITATIVE RESEARCH: HISTORICAL PERSPECTIVES

Formal rules for international research ethics for clinical research were first codified in the years after the Second World War and set out in the Declaration of Helsinki in 1964.³ Only later, during its first revision, was a recommendation added that clinical investigators should seek review of their protocol by an independent committee of peers prior to undertaking their research.⁴ In this clause lies the origins of RECs and IRBs, as they subsequently became known.^{5,6}

The story of how the remit of research ethics review for interventional clinical research changed from being advisory to mandatory in character, was then extended to broader health-related research and finally, in some jurisdictions, came to encompass research across other disciplines is deserving of its own in-depth historical account. That account would need to distinguish between the distinctive trajectory in some Anglophone countries in the Global North (including the United States, Canada, the United Kingdom, Ireland, Australia, and New Zealand), which have largely mandated research ethics review for social research, and the directions taken elsewhere.⁷ To tell it succinctly, the expansion of research ethics review from health research into other fields had a great deal to do with the expansion of the state into funding and steering research and with the perceived need for control and accountability of research conducted in universities. In many cases, the initial steps towards the inclusion of the social sciences in research ethics review came via the expansion of the remit of RECs and IRBs in the health sector to include scrutiny of social research involving patients: the steady growth of qualitative research applied to health offered a significant opening for such bodies to become involved with qualitative methodologies. Later, qualitative research gained increasing recognition in the expanding field of multidisciplinary global health research, which has brought more of its practitioners into the ambit of RECs that are primarily clinically orientated ([Liamputtong & Rice, 2020](#)).

Turning to the question of ethics review of qualitative research per se, the situation is extremely diverse: just as not all ethics committees encompass social science research, so too ‘presumed isomorphism’ about ethics committees’ approach to handling social science research is problematic ([Hedgecoe, 2012](#), p. 79). While some countries require ethics review for all social science research, most do not ([Tapscott & Machón, 2024](#), p. 5). However, other levers, notably the policies of major research funders – and later of academic journals – have resulted in a de facto requirement for research ethics review for sweeping parts of the research

portfolio across many regions. Diverse kinds of institutions and organisations now have committees whose remit includes the review of social science research. As with the establishment of IRBs in research organisations in the United States from the 1990s, RECs became widespread in clinical research establishments in numerous other countries during this period. In a second phase of development, these committees gradually extended and consolidated their mandates from the early 2000s, although the chronology for these developments varies. University ethics committees, in particular, vary enormously, as does the way in which they handle social science research (Carniel et al., 2022; Dove & Douglas, 2023; Elfenbein & Hoffman, 2024). As non-governmental organisations became more involved in partnerships with researchers, some set up ethics committees to review research proposals within their organisations. Finally, international bodies including the World Health Organization and Médecins Sans Frontières established their own influential RECs (Schopper et al., 2009). Given their involvement in a wide range of fields, social scientists may interact with any of these types of ethics review bodies. Although this volume cannot document the range of policies and practices in research ethics review across different organisations and sectors, the following chapters raise some common themes which transcend the specificities of institutional contexts.

THE CRITIQUE FROM THE SOCIAL SCIENCES

There are multiple grounds for questioning the legitimacy of, and necessity for, research ethics reviews in the social sciences. At the heart of this challenge is a critique of the way that the nature of potential risks for participants tends to be blurred across the medical and social sciences: biomedical ethics frameworks have only limited applicability to the terrain of social science research, it is argued, and this gives further strength to concerns about the impact of ethics reviews on our research.

I begin with the objection to the appropriateness of predicating ethics review for social science research on a biomedical paradigm, which still appears to underpin some such reviews. Fundamental to this objection is the concern that ethics reviews of qualitative research draw on ‘imaginings of risk’ that are rooted in clinical research ethics (Bell & Wynn, 2023, p. 537). A central tenet in biomedical ethics is the avoidance of unnecessary harm, and consequently, committees in this tradition will typically expend considerable effort evaluating the physiological risks as well as other kinds of harm that may arise from a research intervention or, more precisely, with weighing up the possibility of harm against the potential benefits to participants. Although participating in social research does not usually entail physical hazards (Dingwall, 2008), other kinds of harm should be considered (Hammersley & Traianou, 2015). Perhaps the most well-recognised risk of social harm relates to the divulging of information considered to be confidential during research, in that negative consequences may follow if such information came to be known more widely. Beyond the consequences of wider disclosure, the processes of reflection and interpretation entailed in qualitative research

may in themselves cause problems or challenges for participants, although this is not always predictable or calculable (Bringedal Houge, 2023; Kostovicova & Knott, 2022).

Related to this critique is a questioning of the relevance of the concept of vulnerability in relation to non-clinical research.⁸ Van den Hoonaard (2018) sees in ‘vulnerability’ a concept that is, in general, wrongly applied to research ethics review in the field of social sciences. However, this argument tends to overlook the way that discussions about vulnerability have evolved in the clinical research ethics community, where there has been a move away from labelling groups or sub-populations as vulnerable (Council for International Organizations of Medical Sciences, 2016). For example, Luna conceives the concept of vulnerability ‘via the notion of layers’ considering that:

We do not face ‘a solid and unique vulnerability’ that exhausts the category [...]. These layers may overlap: some may be related to problems with informed consent, others to violations of human rights, to social circumstances, or to the characteristics of the person involved. (Luna, 2019, p. 88)

This approach opens up nuanced ways of applying the concept of vulnerability that are arguably more relevant to qualitative research. The problem seems to be that the concept of vulnerability ossifies once incorporated into pre-review processes prior to ethics review, and once proposals reach a review committee, its members need to have a sophisticated understanding of the dimensions of vulnerability *and* the expertise to apply it if this concept is to be useful in this context.

Given that prospective ethics review inevitably involves providing an explanation of what is to be done in a research project, the tension between this anticipatory mode and the need for qualitative projects to maintain space to evolve has also preoccupied critics of RECs and IRBs. This dynamic has caused particular difficulties for anthropologists undertaking participant observation; when, as in anthropology, research questions are typically broadly defined, it may be both impracticable and epistemologically incorrect to closely anticipate the path that such fieldwork will take. In some institutions, RECs have come to expect detailed plans for such research, an expectation which arguably constrains, and may even prevent, the possibility of carrying out ethnographic fieldwork in future (Herzfeld, 2023).

At first glance, it may seem that interview-based studies are more predictable and so would fit better into a framework of anticipatory review: qualitative interview methods may appear to be similar to a questionnaire study, and RECs have become more accustomed to these approaches over time (Dingwall, 2016, p. 33). However, this perception of similarity masks important differences, given the extent to which qualitative interviewers may improvise questions for each interviewee and develop sensitising themes in the course of their research: if RECs work with an implicit model of a questionnaire-like study, qualitative researchers are obliged to present a definitive list of questions that will be asked in interviews, whereas from a methodological perspective it is good practice to keep open the possibility of changing these questions as a project develops. Hence, qualitative researchers may find themselves colluding with a REC’s notion of fixed methods

and predetermined ethical issues, despite knowing that it is by no means unusual for significant ethical dilemmas to arise once qualitative research is underway (Taquette & da Matta Souza, 2022).

The tendency for RECs to formulate risk in biomedical terms and to impose default requirements accordingly has been seen in terms of a kind of ‘ethical imperialism’ (Schrag, 2010), as international bioethics capacity-building initiatives have had a considerable influence on policies in the Global South (Israel, 2018). From this perspective, a twin dynamic of colonisation and colonialism is reflected in such initiatives, and it is argued that the unthinking adoption of procedures for clinical research into the governance of social science projects has resulted in ethically problematic procedures. A notable example is the expectation that informed consent processes for social science research should follow a template designed with clinical research in mind: researchers have testified to the inhibiting effect of asking people to sign informed consent forms (ICFs) prior to taking part in social research, questioned the morality and cultural appropriateness of asking people to do so, and traced the way that tenacious assumptions derived from biomedical research are embedded in ICFs for research in the humanities and social sciences.⁹ The expectation of a detailed focus on risk management may be even more problematic when research funded elsewhere is to take place in a low- or middle-income country, as international ethics reviews are commonly freighted with additional precautions rooted in the aim of avoiding exploitation. Even in international health research, there is now a degree of acknowledgement that this dynamic has some negative consequences, and the way forward is actively debated (Wright et al., 2023).

The arguments levelled at anticipatory ethics reviews of social science research are substantial, but it does not necessarily follow that ethical issues arising from qualitative research should be managed by the responsible researchers alone. An alternative position is to argue that processes for a proportionate iterative review should be in place (Hickey et al., 2022). In a similar vein, Stevenson et al. (2015) make a useful distinction between research traditions where a predictive approach may be appropriate and those that follow a more reflexive approach where it will be less so, setting out different approaches for the ethics review process accordingly:

The predictive nature of ethical problems means that the role of ethics boards in the first tradition is to evaluate the extent to which researchers have been able to effectively foresee ethical problems, and to design an ethically appropriate research protocol. In iterative approaches, because ethics are not ‘pre-conceived’ their role is facilitative, aiming to help researchers to think through possible problems. (pp. 5–6)

This, they continue, means that the role of an ethics committee member for such research should be framed in terms of being a ‘critical reader’ rather than a judge (Stevenson et al., 2015, p. 6). Working in the iterative mode, an ethics committee may be able to offer more appropriate advice and support to researchers, especially bearing in mind the challenges facing new researchers and the complexities entailed in working on large multidisciplinary projects.

A third key area of criticism of research ethics reviews for the social sciences centres on the social and economic costs of implementing them. It is suggested