Qualitative research ethics: an agenda for researchers and research organisations

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Abstract

New developments in methodologies, technologies, and evolving ways of conceptualising research relationships have added complexity to the existing ethical challenges faced by qualitative researchers. Although generalist rule-based ethics frameworks struggle to anticipate and respond to dynamic qualitative methodologies, reflections by researchers offer some important ways forward on these issues. We argue that qualitative researchers and research organisations should go beyond the project-based practice of research ethics review to: (1) reflect on ethical issues that qualitative researchers are encountering; (2) learn from the diversity of approaches to ethics appraisal and review; (3) embed ethics across curricula; (4) strengthen institutional resources for social research ethics; and (5) recognise that institution-wide measures to support research integrity are necessary to facilitate ethical research. While there has long been a focus on the responsibilities of individual researchers in this context, they also need a research ecosystem that will support ethical practice. We propose several ways that organisations can reconfigure structures and practices to better support ethics and integrity in diverse modes of qualitative research.

Keywords: qualitative research ethics; ethical considerations in qualitative research; Declaration of Helsinki; human research ethics; research organisations.

Introduction

There have been unescapable tensions between qualitative research and systems for overseeing research ethics for some decades. Although we can point to a consensus on the need to reform research ethics in the social sciences to take account of the distinctive features of these approaches, changes have been slow in coming (Iphofen, 2017a) and have not always been progressive. New developments in methodologies, technologies, and evolving ways of conceptualising research relationships have added further complexity to this terrain. This is evident in the contributions to this volume exploring, for example, the nuances of applying principles of informed consent when researching online spaces and communities in Helena Webb's and Rhonda Shaw's chapters, in Bree Akesson and Karen Frensch's reflections on the use of GPS technologies in new contexts, and in Fride Klykken's account of her work in a 'technologically dense classroom'.

While the qualitative researchers who contributed to this volume are interested in exploring and mitigating the ethical concerns their methodologies give rise to, they found generalist rule-based ethics frameworks largely failed to do so and had proved unable to anticipate such issues. An additional concern, in common with researchers in other fields, is that outcomes of research ethics reviews seem unpredictable. In our view, the limitations associated with applying rule-based ethics frameworks to some of these qualitative methodologies pose a challenge for research ethics committees (RECs) in reaching decisions, namely, to find a way to balance predictability with responsiveness, a matter to which we return below. At the same time, as is clear from these accounts, researchers face challenges in finding the best way to put ethical principles into practice in complex situations. Here, isolation can pose as much of a problem for researchers as do rules: such challenges call above all for support and advice.

The ways forward generated in these chapters include the following agenda for qualitative researchers and for research organisations: (1) reflect on ethical issues to strengthen research; (2) learn from the diversity of approaches to ethics appraisal and review; (3) devolve and embed ethics in the curriculum; (4) strengthen institutional resources for social research ethics; and (5) recognise that institution-wide measures to support research integrity are necessary to facilitate ethical research.

1. Reflect on ethical issues and problems as a resource for research

Concerns deemed to be ethical issues may speak to wider questions. This is illustrated by Rhonda Shaw's chapter, in which exploring vloggers' "understandings of 'public' and 'private' in relation to their intended audiences in online spaces" is seen to be important when thinking about the practices that will be appropriate for respecting their privacy. Drawing on Berlant's concept of "intimate publics" (Berlant, 2008, p.5), Shaw's chapter explores how ethical issues raised by her research methodologies articulate with wider sociological work concerned with online narratives.

It can be productive to frame such dynamic issues as an area for research, rather than only as problems to be fixed for all times and places. To take one example, what term should be used for people who take part in research? Whether we call them "research subjects" or "participants" might appear to be a matter of convention or of changing fashions, yet underlying this are more substantial questions about how we understand people's agency within particular methodologies. Love and McDonnell (2024) have reflected on how, early in their careers, their proposed work with women who had had abortions and with psychiatric patients leaving hospitals was disapproved—and so disallowed—because their RECs focussed on the vulnerability of these groups rather than also acknowledging the moral agency of these individuals. Eventually, both went on to research in these fields, and then to

propose the development of "a politics of presence in ethics [which] engages with vulnerability as a potentially positive field of force" (Love & McDonnell, 2024, p. 4–5). This points to an important dimension to considering participants' potential vulnerability, an issue that is intensely debated in research ethics, underscoring as it does the importance of researchers' presence and commitment to their participants in this context.

In undertaking their analyses, qualitative researchers can inform thinking about ethics in other fields, and so contribute to evolving understandings of what it means to be engaged in research in an ethical way. To continue with the example above, the question of terminology is of significance well beyond the field of qualitative research. Indeed, this is an instance where medical ethics can learn from social research ethics: while "participants" has long been the term preferred by many social scientists, it was common to refer to "human subjects" in clinical research. However, there has been a shift in understanding in the medical research community, and accordingly, the most recent revision of the Declaration of Helsinki has replaced the term "subjects" with "participants" throughout because it was considered more respectful of the rights, agency, and importance of those individuals (World Medical Association, 2024).[i] This misses the point; there are occasions when researchers deliberately seek not to offer agency to the researched – for example those who perpetrate abusive or exploitative practices – and participant seems an odd choice of word, in those situations. A more sophisticated recognition of power relations suggests it would be appropriate to have a plurality of terms for people being researched, depending on the nature of their involvement, given a spectrum from passive to active roles.

2. <u>Learn from the diversity of approaches to ethics appraisal and review across different systems</u>

Although many publications about research ethics in the social sciences have focussed on problems encountered with RECs, this is a particular preoccupation of social scientists in selected, notably Anglophone, countries in the Global North. At times the debate takes on a binary form—arguing in favour of, or against, abolishing RECs—yet there is sometimes too a quiet acknowledgement that these committees undertake an important role. As Michael Herzfeld has written: "We do need some means of perpetually reminding ourselves that our actions affect our interlocutors, a concern not negated by horror stories about bureaucratic overreach. We need informed advice" (Herzfeld, 2023, p. 3). Notwithstanding this, developing the view from anthropology, Herzfeld suggests in his chapter in this volume that "static forms of bureaucratic oversight, well-intended though they may (in part) have been, do a disservice to the very concept of ethics. They not only posit a universal ethics; they posit an unchanging ethics". Like Herzfeld, we argue research ethics regimes should be anchored in greater contextual specificity and historical awareness. One response to this position may be to say that some universal or generic ethics principles and standards can and should be agreed upon, especially given the growing number of multinational and interdisciplinary research endeavours. Certainly, it is important to have contributions to the development of ethical guidance and policy that go beyond disciplinary and national contexts. However, although we see more international exchange and a wider range of stakeholders invited to comment in consultations about such codes than in the past, these processes are rarely broadly inclusive. It remains an open debate whether some universal ethics approaches could be agreed upon if a sufficiently rigorous and inclusive process were to be put in place.

As we consider how ethics oversight can be re-configured, there is much to learn from approaches taken beyond Anglophone institutional research ethics. Most countries in the Global South and many in the Global North do not require review of the ethics of social research. Although this can limit collective engagement with the ethical challenges of a

particular context and discipline, some researchers working within such regimes have described how having the flexibility to improvise has generated good solutions to ethical and methodological problems. For instance, faced with methodological challenges in their work on the study of Muslims in Western Thrace (Greece) and Tamil immigration in France, Dequirez and Hersant (2013) have written about how they found it necessary to re-orientate their project, revisit the field, increase the number of field sites, organise access to some key informants informally, and undertake a more extended analysis of the local political context. Some of these strategies would have been impracticable if they had been bound by a predefined protocol as is typically required by RECs (Dequirez & Hersant, 2013). An alternative proposition would be to take a fine-tuned, nuanced approach to ethics review for social science research rooted in a range of closely related disciplines, as some universities in the Netherlands have done (Elfenbein & Hoffman, 2024). Institutions and jurisdictions that mandate RECs can learn from models such as these to explore a continuum of approaches for supporting ethical research.

Other approaches that could be adopted to allow for evolving methodologies are staged reviews that do not require projects to commit to particular responses in later stages, or more flexible and responsive forms of oversight such as the use of expert research ethics advisors or ethics advisory boards to support the development of ethical practice in context, an approach used by the EU research agencies to provide additional support to and oversight of projects with complex ethical issues (European Commission, 2023).

3. Devolve and embed ethics in the curriculum

Qualitative researchers are concerned that research ethics reviews often fail to allow the reflection needed to explore important issues that arise in their research and may not even help to foreshadow the multitude of small but ethically resonant decisions to be made upon

entering the field. Amongst other things, these decisions relate to introducing oneself, seeking consent or, where appropriate, assent, thinking about how people's initial questions will be addressed, considering how the benefits and harms likely to flow from a research project are likely to be balanced and distributed, anticipating how research outputs can be made informative for those who took part, and considering how researchers can contribute to the participants or community that welcomes or hosts them.

Even as they struggle to facilitate reflection on such issues, RECs are increasingly charged with new tasks to be undertaken on behalf of the institutions they serve. In the UK and in some European countries, one such addition is the funnelling of requirements for data management, data protection and data archiving from the centre to individual investigators. Margaret Sleeboom–Faulker argues in this volume that these developments in the UK have adversely affected research relying on ethnographic fieldwork to the point where the integrity of such research is under threat. While this is a well-reasoned critique of the way some University RECs in the UK interpret and implement legislation on data protection, other bodies, such as the UK Research Councils, lead policy on data archiving for funded research. Another way of looking at this situation is to see it as symptomatic of a tendency for organisations to freight these committees with responsibilities over and above reviewing research protocols, which may extend to aspects of research governance such as data protection, checking administrative and gatekeeper approvals, as well as scientific merit, researcher safety, protection of institutional reputation, and so on. This means RECs are perceived as 'moral bureaucracies' (Molina & Borgatti, 2021, p. 13), rather than as offering 'genuine' ethics advice. It may be necessary to de-couple many of the administrative, resource allocation, managerial and political tasks from the work of RECs, in order to allow the capacity for effective approaches to research ethics to flourish.

As the introduction to this volume argued, it is helpful to understand the history of RECs: originally, proposals for ethics review of clinical research were framed in terms of advice and guidance from peers (World Medical Association, 1975, p. 2). Today's RECs operate within complex organisations and systems, and it would be naïve to suggest a neat boundary can be drawn between research ethics advice and governance. Nevertheless, it will still be useful to maintain a distinction between research ethics review—an independent process of reflection concerned with acting in the best interests of those who will be researched— and research governance, concerned with regulatory compliance, standards of good practice, and corporate oversight (Iphofen, 2017b, p.1). With this in mind, RECs should focus on supporting researchers with thinking about their responsibilities towards those being researched, rather than being distracted and perhaps subverted by questions of corporate interests and reputation. Research organisations, being learning institutions, may need to think beyond committees for this process of reflection: if they are to develop cutting edge approaches to research, researchers and reviewers need to keep pace and address the ethical issues posed by new methodologies, topics, collaborations, participants and contexts.

Professional development opportunities should support a reflective approach to research ethics, yet ethics training can be counterproductive if an unduly didactic approach is taken (Allen & Israel, 2018). Indeed, the language of 'training' does not pay much respect to the quality of thought required to make ethical decisions. Many researchers and reviewers grudgingly turn up to institutionally-mandated training expecting to be told the requirements for completing a form or the rules for passing the committee hurdle. Such sessions can be stultifying dull and do little to prepare researchers to engage with new challenges that they encounter in their research or enable reviewers to build a community of ethical practice with stakeholders. Significant players in the research management ecology would do better to reimagine training as professional development and design opportunities for researchers and

reviewers to build and practice their skills in ethical decision making in authentic contexts. These opportunities should also be built into the curricula of research programs so that ethics is embedded in research practice from the beginning of researchers' careers. Such opportunities should be constructed in terms of a shared endeavour rather than simply a 'dissemination' of polices, not least because many among the current cohort of active researchers are already actively engaged with research ethics (Taylor & Patterson, 2010) and may be well ahead of the ethics bureaucracy in understanding the ethical challenges of new research contexts.

We now turn to the theme of wider measures for developing and strengthening institutional capacity for social research ethics.

4. Develop and strengthen institutional capacity for handling social research ethics

We propose several preconditions for effective ethics review in this field: expertise; proportionality; predictability; principle-based decision making, and appropriate resourcing. In combination, most of these are quite rare even when mandated by national policy.

Firstly, we need better recognition of ethics review as a scholarly process that requires deep understanding of what a research project is trying to do and reflection on how it might be achieved ethically. This requires a range of knowledge, skills and experience to be brought into the decision-making process. No committee will have expertise in all methodologies, which means that ongoing dialogue and exchange of views between RECs and researchers are needed, with the aim of developing shared understandings (Mustajoki & Mustajoki, 2017). In general, we would argue RECs should be constituted at a level of granularity that allows for multiple perspectives, and so a multidisciplinary committee—with access to appropriate specialist expertise—is a good option, especially as larger projects increasingly require multidisciplinary responses. While a committee may seek additional external advice,

it might also recruit a pool of researchers to draw on as members for particular kinds of research, rotating them to reflect the most significant projects that are being reviewed at a particular session. In addition, 'lay' representation is being reconceived as enabling research ethics review to draw on multiple community perspectives. Lloy Wylie et al.'s chapter describing their experience of developing research and health service partnerships with Indigenous people in Ontario speaks to the challenges of establishing and sustaining community partnerships that go beyond tokenist consultations. Such a broader engagement with stakeholder communities should include linguistically and culturally diverse communities and any vulnerable groups likely to be overrepresented among research participants. A Community Stakeholder Reference Group comprising advocacy, community, cultural and overarching interest groups may be an effective way of drawing on advice about distinctive ethical issues associated with researching in the region or the community.

Secondly**,** it will be necessary to differentiate between the kinds of reviews that are appropriate for various kinds of research. A proportional research ethics review matches the review process, timeframe, evidential burden and monitoring, to the risks and ethical sensitivity of a proposed project. A central element of such oversight should be a risk assessment tool directing projects to review pathways where the level of scrutiny is proportionate to risk. Such a tool might distinguish between projects that are: exempt from review; have been subjected to prior review; or require review by professional staff, a low-risk panel, the executive of the REC, or by the full committee.

Thirdly, we face a situation in which outcomes for research ethics review of qualitative research are perceived to be unpredictable. If, historically, some RECs were like clubs — reflecting a framework of professional self-regulation (Wilson, 2014, p.24)[ii]— diversity and accountability are now expected: decision-making processes should be agreed, transparent to stakeholders both inside and outside the host institution, independent of capture whether by

groups of researchers, management or special interests, and accountable with clear appeal and complaints processes.

However, predictability needs to be balanced with responsiveness, which brings us to our fourth point: moving towards principle-based decision making can contribute to finding this balance. While some institutions have adopted rules or a set of precedents that advise what will (and what will not) be seen as acceptable, the use of rules risks ossification of what is allowable and may not be responsive to changes in practice and context. This is particularly awkward when rule-makers cannot change the rules, either because of a lack of resources or will at institutional level or because the rules have been embedded in legislation. Guidance based on principles should offer greater possibility of adapting to new situations. For example, an anticipatory model of review predicated on a positivist, hypothetico-deductive, approach to research may be poorly suited to many evolving approaches applied in social research such as those explored in this volume, as well as for participatory models which are increasingly used in diverse fields of research.

Finally, effective reviewing requires sufficient institutional capacity and resourcing. Research ethics review can occur against a backdrop of limited, overstretched and sometimes even non-existent administrative support and inadequate institutional recognition of the work of reviewers. This can be compounded by the need to work around research management systems that are poorly configured for research ethics, poor access to expert advice, and a lack of funding both for professional development for researchers and reviewers and for guidance material relevant to the social sciences. Research institutions must therefore commit to resourcing research ethics at a level commensurate with the opportunities and risks associated with promoting ethical research and ensuring regulatory compliance. A balanced approach to research ethics would see investment in building the capacity of researchers and reviewers to make informed decisions. Although clinical research ethics has often received

the lion's share of time and investment, support for social research ethics is imperative for qualitative research to flourish.

5. Embrace "virtue ethics for organisations"[iii]

Ethical research is linked to the cultures of the institutions within which it is produced: the measures required to achieve research integrity go well beyond the remit of ethics reviews. As Nina Persak argues, an agenda for tackling research integrity should include addressing workplace culture and negative impacts of hierarchies of power on practices of research production. In her chapter, Persak indicates some specific ways this can be done, including inserting codes of conduct into professional contracts, and providing confidential counselling and advice for researchers faced with difficult, inequitable, or unethical dynamics in their research. Despite the evident importance of these issues, it seems that a renewed focus on research integrity may currently be biased towards quantitative modes of research, according to a recent report by the UK Committee on Research Integrity (2024, p.5), and the application of this agenda to qualitative modes of research should be explored in more depth.

This is consistent with the findings of Sørensen et al.'s study exploring what researchers and others working in research organisations think about research integrity (RI): despite finding important differences in the perspectives between disciplines, they note the research environment was considered to be key by all the groups of researchers and stakeholders taking part in the study. The environment includes "the norms and values of an institution, its handling of appointments, incentive structures, competition, diversity issues and so on" and in this context, the "responsibilisation of RI is unevenly targeted at the individual researcher rather than linked to institutions […]" (Sørensen et al., 2021, p. 12-12). Similarly with research ethics, there has been a focus on *individual* responsibilities, with the cultivation of

researcher virtues having a prominent place on this agenda. Still, it remains timely to continue to shift the emphasis to how organisations such as universities, ethics and governance secretariats and funding bodies can reconfigure structures and practices to better support ethics in diverse modes of qualitative research.

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[i] This reasoning was made clear by the World Medical Association during its Public Consultation on the Draft Revised Version of the Declaration of Helsinki, which was conducted online in 2024 but is no longer publicly accessible at the time of writing.

[ii] Characterising clinical RECs in Britain as being historically rooted in a framework of professional self-regulation, Wilson deploys Moran's concept of 'club regulation' (Wilson, 2014, p. 24; Moran, 2003, pp. 38–66).

[iii] We borrow this term from an editorial by Bernacchio et al. (2023).