

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 researcher's 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.

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.ⁱ

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.ⁱⁱ

Discussions explicitly addressing ethical issues in the social sciences were published from the 1960s and 70s 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 introduction, 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. Whilst 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 2nd world war and set out in the Declaration of Helsinki in 1964.ⁱⁱⁱ 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.^{iv} In this clause lies the origins of RECs and IRBs, as they subsequently became known.^{v, vi}

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 (notably the US, Canada, the UK, Ireland, Australia and New Zealand), which have largely mandated research ethics review for social research, and the directions taken elsewhere.^{vii} 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 the 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). Whilst 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 US 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 Organisation and Médecins Sans Frontières established their own influential research ethics committees (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 many 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.^{viii} Van den Hoonard (2018) sees in ‘vulnerability’ a concept that is, in general, wrongly applied to 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 Organisations 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 a detailed 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; given that 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, research ethics committees 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 this method 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 the sensitising themes in the course of the 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 pre-determined 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.^{ix} 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 (p. 5-6).

This, they continue, means that the role of an ethics committee member for such research should be less like a judge and more like a “critical reader” (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 multi-disciplinary 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 that mandating ethics committees to apply a conventional ethics rubric to social science research may impact on the kind of work that researchers choose to do. Indeed, some researchers have described how, based on their experiences of research ethics reviews, they came to avoid working with certain populations and using certain methodologies knowing that such research would be scrutinised more intensively (Bledsoe et al., 2007, p. 619). Some deem research ethics review to be disproportionate to the extent that they consider this form of scrutiny to be ‘anti-democratic’, in that it prevents social scientists from freely deciding their research priorities and so adversely impacts upon academic freedom (Dingwall, 2016, p. 30-31). According to van den Hoonaard (2011), whose analysis focusses on RECs and IRBs in the UK, US and Canada, there are substantial economic costs associated with research ethics reviews and associated infrastructures. Added to this, social costs arise from the barriers that ethics reviews pose to innovative research being freely conducted; furthermore, ethics review systems in some Universities have come to embed a ‘command and control’ mechanism through which otherwise disorderly academic agendas are managed (Dingwall, 2016, p. 31-32). A related concern is that RECs in effect act as a mechanism for reputation management and risk mitigation in this context. These critiques are as much to do with the wider shift to an audit culture in Universities, where we have seen an expansion of other kinds of monitoring such as institutional ‘pre-reviews’, internal and external peer reviews and quality checks, as with ethics reviews specifically. Nonetheless, these analyses point to the possibility that research ethics review can be deployed, even weaponised, by powerful individuals and units in organisations, both within and beyond the University sector and, as researchers may be unwilling to speak about this, we do not necessarily know the full story.

Although the claim that research ethics review is anti-democratic is a serious one, taken to its logical conclusion it appears to dismiss the legitimacy of anyone other than the responsible investigators having a role in considering ethical issues entailed in their research. There seems to be an assumption at play in some of these critiques that social scientists are ‘more ethical’ than other researchers, which may not stand the test of evidence. Those of us who have been involved in ethics assessment and review panels have occasionally encountered proposals in the social science field that are characterised by a strong ethos of entitlement to undertake research that may be extremely intrusive, accompanied by a lack of due regard for its impact on participants. Do we really want to accept that the investigators responsible for such proposals are the only people who should consider whether some limits or modifications are advisable for such projects? Added to this, the claim that scrutiny by a REC or IRB will inevitably impede good social research and undermine innovation is contested. Some counter that requiring a discussion about ethics can be conducive for innovation, compared to encouraging individual researchers to make fully autonomous decisions about research. For example, Carniel et al. (2022) have described how in their own institution, research ethics reviews at their institution are informed by an in-depth understanding of, and dialogue about, specific methodologies. From this point of view, we are reminded that sharing proposals with colleagues for ethics review can be reciprocated with generous advice which, rather than hindering research activity, “holds the capacity for enhancing understandings of the research process” (Carniel et al., 2022, p.150).

To sum up, although each of the key critiques of ethics review for social science research referred to above is important, the extent to which they offset the case for research ethics review in this field is debatable. Many of the problems that have been identified lie not with research ethics review in principle, but in the overlaying of such discussions with excessive bureaucracy, and in expecting RECs and IRBs to act as regulators without giving them the

tools and sophisticated remit expected of a modern regulator. It is paradoxical that for many researchers, ‘ethics’ has become synonymous with getting approval via institutional procedures, seen as simply another hurdle to be cleared. Far from entailing a process of moral reasoning that is intrinsically part of research, the lens through which ethical issues are viewed then becomes focussed on the tasks that must be undertaken prior to the review: following a series of questions and prompts associated with preparing a submission for ethics review may well result in a thinned-out account of such issues.

In this volume, the aim is to draw on qualitative traditions to give context and meaning to accounts of qualitative research ethics, which will in turn inform proposals for reframing how institutions can best support ethical qualitative research. Particularly relevant here is the concept of thick description, a term which became widely known through Geertz’s writing (1973), and was then elaborated by Denzin, who noted that “A thick description [...] presents detail, context, emotion, and the webs of social relationships that join persons to one another [and] inserts history into experience” (Denzin, 1989, p. 83, brackets added). This calls for narratives that are “meaningful, interpretative, relational, authentic, contextualised, and linked” (Younas et al., 2023, p. 4). Whilst this volume does not pretend to offer an in-depth ethnographic account of research ethics, the contributors take inspiration from this tradition.

Qualitative Research Ethics in Practice

The extent to which shifts in context have radically changed the nature of qualitative research has been elaborated in depth in a number of recent publications (Thambinathan & Kinsella, 2021; Denzin et al., 2023). Yet we can identify some core tenets that consistently buttress the wider qualitative project (Iphofen & Tolich, 2018). Notable amongst these is the importance of positionality: it is acknowledged that “researchers have multiple identities that are fluid, context situated, and inform the positions from which they engage with and make meaning of

the world” (Bayeck, 2022, p.1). This means that, rather than seeking to eliminate or control for this aspect, the researcher’s relationships are seen as a part and parcel of the research. For this reason, an explicit concern with the relational aspects of their research and elaboration of these is common to the narratives of research in this volume. This dynamic, different from fields of research which aim to eliminate the researcher’s influence from the analysis—or at least to control it— shapes how ethical issues are to be addressed. For example, reflection on the process of obtaining informed consent can become part of the research, which will then inform the approach taken to an issue which is all too often viewed in generic terms. As Frida Klykken explores in this volume, care about the ethics of undertaking research continues into the recruitment and informed consent processes: using examples from an ethnographic study of an upper secondary school classroom, she argues that this “entails a continuous relational negotiation that needs attention throughout the research process”. Similarly, Hildah Mokgolodi’s account of her experience of researching the perspectives of retired educators in Botswana skilfully deploys empathy to unpack the ethical issues she encountered, going beyond those anticipated by her REC. Increasingly, community engagement is seen as an important precursor to undertaking research, so that important conversations about aligning research priorities with those of communities can take place earlier. As Lloy Wylie et al. underline in their chapter, researchers may already have worked (or have lived) in their study communities for years and have highly relevant knowledge of them. Despite this experience, however, there can be a marked dissonance between an ethics committee’s bird’s eye view of what is ethical and an experienced, engaged researcher’s view, as Metro (2014) has explored in a paper about her fieldwork with Burmese teachers in Thailand.

Even before considering the experience that participants may have of research, it is apt to begin with the question about whether a particular research project should be undertaken at all: if it involves collection of ‘primary data’ from participants, it is worthwhile carefully

considering the reasons for doing so, and whether this is likely to be acceptable to those participants, before the question of research ethics review arises. Hildah Mokgolodi's chapter elaborates a restraint that has led her to sometimes prefer using data that has already been collected, rather than initiating data collection anew herself: at a time when it is well documented that some participant groups face multiple demands from researchers, the question of whether to revisit groups or populations that are at risk of being over-researched is an important and under-explored issue in qualitative research.

Staying with the early stages of setting up a project, a raised awareness of ethical issues broadly conceived can be discerned in the recent development of deploying peer researchers to assist with engaging and recruiting participants. These approaches, although reminiscent of the tradition of using key informants in ethnography, embody a more contemporary aim of explicitly de-centering the researcher-participant divide. Yet translating the principle of participation by people with lived experience into practice raises challenges which are deserving of further reflection. Nienke Boesveldt offers a granular account of how the involvement of peer researchers subtly altered the kinds of questions that were asked in interviews and how participants responded: here, methodological and ethical issues are shown to be interpenetrated. Katz

A notable shift in the way in which qualitative research is undertaken has been the move from a disciplinary to a 'transdisciplinary' landscape for many fields of study (Leavy, 2020). In more pragmatic terms, there has been an expansion of qualitative research embedded in multi-method projects. Qualitative researchers working in larger global health research projects, for example, have testified to the difficulties of raising their ethical concerns, especially those which involve questioning the policies of organisations that are gatekeepers, funders, and stakeholders: at times, it seems that 'ethics' can become part of a defensive dynamic in this context, with objections to the asking of such questions being framed as an

“ethical discourse” (Parker & Allen, 2015, p.36). At the same time, qualitative research in health settings has raised particular challenges, as Sarah Potthoff and Anke Erdmann acknowledge in their chapter, which includes proposals for more in-depth engagement between REC members, researchers, and participants in this context. They remind us that ethics committees should have appropriate qualitative expertise when reviewing such projects, and go further to propose representation of patients and/or representatives of participant groups in the discussion to improve the contextual information available in these deliberations. One size does not fit all, however, in qualitative research, and therefore continuous ethical awareness and reflexivity are needed to address ethical issues on a case-by-case basis (Taquette & da Matta Souza, 2022). We have seen in multi-disciplinary projects beyond the health field that qualitative researchers have deployed technologies in novel ways, raising new questions that have not so far been well explored in accounts of qualitative research ethics. Being interested in the experience of war-affected families, Bree Akesson and Karen Frensch describe how they deployed GPS data within their multi-method project, arguing that this can be used as an important tool within an overall qualitative approach, and exploring how the ethical concerns that arose from these uses of this technology were addressed, in part, by enabling their participants to lead on its use.

The writings of auto-ethnographers, in which researchers narrate and draw directly on their own experience as data for analysis, have generated intense interest and some controversy in recent years (Tolich, 2010). Such accounts inevitably entangle others, and questions arise about the others’ potential vulnerability and their rights to consent or decline to be involved and/or included. It is worth remembering that autobiographical elements have been included in ethnographic writing from over 100 years ago, even though the term autoethnography did not come into use until more recently (Adams & Holman Jones, 2024). However, there is a sense in which auto-ethnography (AE) is between a rock and a hard place, as researchers

proposing to write in this genre are criticised for not following ethical standards, yet they may find it difficult to obtain an ethics review. Nevertheless, there is an emerging body of work pointing to appropriate ethical practices for AE studies (Gibbs, 2018; Tolich, 2010). In this volume, Nicole Brown underscores the value of ethics reviews in providing iterative feedback and advice for university-based researchers who plan to undertake this kind of writing.

Historically, the handling of written texts—especially field notes and interview transcripts—have been central to the discussion of qualitative research ethics. Ethical concerns here go beyond the considerations of privacy and practices of anonymisation that dominate many a discussion about ethics, given that validity and ethics are interpenetrated in qualitative research. For Sanjek, writing before digitisation, field-note evidence is seen as one of the canons of validity for ethnography alongside theoretical candour about the choices made in fieldwork and the provision of a level of detailed description about ‘the ethnographer’s path’ (Sanjek, 1990, p.395). At that point, ethnographers relied primarily on detailed hand-written notes written in the field, and the extent to which people might be identifiable from these varied according to individual fieldworkers’ ways of making these. Notes and recordings of qualitative investigations were seen as a valuable in-depth record of an encounter that belonged to the researcher, although they might sometimes be shared with the interviewee or informant. In recent years, as the digitisation of data has progressed apace, the relationship that researchers have with these kinds of data has become complicated by an expectation that others should be able to access these data in the future. Having had an early impetus as an activist movement, ‘Open Science’ has become associated with institutional requirements relating to access to data and research outputs. Even though evaluating data management was not traditionally considered to be within the remit of a REC or IRB, these committees increasingly find themselves expected to mediate institutional expectations for data archiving.

In this volume, Margaret Sleeboom-Faulkner documents how, in many universities, archiving requirements have been redefined as ethical issues, and explores the consequences of this entangling of research ethics and data storage.

New questions about the social lives of data are not confined to the handling of written materials: dilemmas have also arisen about the handling of visual materials as their use has become more common in qualitative research, and user generated data such as social media posts and blogs may also test the boundaries of research ethics policies. As we see in Helena Webb's account, researchers with experience of working with these modalities may be well-placed to offer input to REC policies addressing these and to wider discussions about what ethical practice should look like in this context.

Reflections on the Way Forward

As the contributions in this volume will show, qualitative research may entail several methodological innovations that intersect with each other and these in turn shape the possibilities for respectful decisions about the use of data provided by participants. For instance, Lore Van Praag and her co-authors point to a more participatory approach to research ethics in which decisions about the use of visual images generated in their research are not seen as owned by researchers, nor by ethics committees, but rather as something which participants may help to shape. This approach is consistent with a recognition of the moral reasoning that participants, patients and other non-specialists engage in when making decisions about research, which has been eloquently advocated by Arthur Kleinman (1999).

Space precludes an extended discussion of the wider ethical implications of the developments discussed above, but it should be clear that the complexity of this terrain undermines the notion that fixed rules on how research must be conducted are credible in this landscape.

Many RECs will be unfamiliar with methods such as autoethnography, involvement of peer researchers, methods such as fictionalising accounts, or the analysis of user generated online content. Hence pleas made some years ago for such committees to deploy humility when reviewing methodologies with which they are less familiar, adopt the role of the learner and ask open questions, remain relevant (Tolich & Fitzgerald, 2006).

It would be damaging to see a situation evolve where researchers cannot communicate effectively with their RECs or IRBs, as has been reported by some researchers who have devised 'escape routes', doing what they believe is right in contradiction to the expectations of their IRBs (Katz, 2006, p.499). Beyond having an opportunity to explain their own proposals to ethics committees, it is important for researchers to be able to explore meaningful solutions to ethical challenges and to write freely about the implications of these. I hope that the following narratives by researchers of their experiences in the field, and their proposals for change, will be fruitful for a much-needed reframing of institutional research ethics to better serve the commitment of researchers in the social sciences and the interests of their participants.

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End notes

ⁱ The interest in moral aspects is of course not exclusive to qualitative traditions: Durkheim's work on moral statistics (Durkheim & Simons, 1992 [1897] and Titmuss' analyses of social statistics (Oakley and Ashton, 1997) are representative of the interest in social norms in quantitative sociology and social policy.

ⁱⁱ An early example can be found in Vivien Palmer's *Field Studies in Sociology* (1928), which codified advice to students doing fieldwork in the Chicago school of sociology and addressed such issues as perceptions of researchers' competence and professionalism, the imperative to avoid overstepping into an informant's private thoughts, and noted that the informant "must also be made to feel that any statements which he desires to have treated confidentially will be guarded, and he should be told what disposition is to be made of the data which he contributes. The current mores and situations in a group always dictate additional principles which must be observed" (p.173). Studer and Chubin's paper (1977) also offers interesting reflections on sociologists' professional responsibilities which seem to anticipate the coming of ethics governance as we now know it. For authoritative analyses of the history of anthropology's engagements with ethics, see Mills (2003) and MacClancy and Fuentes (2015).

ⁱⁱⁱ For valuable historical accounts of the development of research ethics in clinical research, see: Schmidt et al. (2020) and Hazelgrove (2002).

^{iv} Clause 2, Section 1 of the Declaration of Helsinki as revised in 1975 introduces for the first time the principle of a research protocol being considered by a committee of peers, who would offer advice to the responsible physician-researcher (World Medical Association, 1975).

^v I consider the terms research ethics committee, institutional review board, and ethics review board to be interchangeable in the context of this discussion. Although each has its own distinct context and framework in different jurisdictions, they have broadly the same functions in terms of being mandated by policy or law to formally review research protocols for their ethical soundness. Whilst there is considerable variation in the mandate, remit and constitution of such committees/boards, our interests in this volume lie primarily with their *processes* of formal ethics review of qualitative research.

^{vi} While the US was one of the prime movers of the Declaration of Helsinki, disagreements over subsequent versions later led to a divergence between the FDA and the World Medical Association (Moreno, 2020). It is clear that the regulatory frameworks in the US had a significant impact on research ethics practices elsewhere—notably through their influence on NIH funded research conducted in other countries—but it is beyond the scope of this chapter to analyse the shape and extent of this impact.

^{vii} See, for example, Nortjé et al. (2019) and Davies (2020) for critical overviews of the development of RECs in Low- and Middle-Income Countries.

^{viii} There is a parallel argument that in health research ethics too, the concept of vulnerability risks being deployed so broadly as to cloud rather than illuminate ethical judgement (Schroeder & Gefenas, 2009).

^{ix} Comments on the imposition of inappropriate expectations for the informed consent process are so ubiquitous as to make it impracticable to provide an overview of the literature on this point here. However, see Halkias (2024) for a searing account of how institutional handling of informed consent requirements can, at worst, seriously compromise the integrity of research. For discussion of cultural competence as it applies to research ethics more broadly, see George et al. (2020).