The Political Life of Research Ethics Committees

And What It Means for Ethnographic Research

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Abstract

This review discusses three pieces of work, that is, a conference panel and two books, that deal with the role of research ethics committees (RECs) in regulating biomedical research and medical anthropological research. We summarise the papers and conversations of a panel we convened on this topic during the 2020 European Association for Social Anthropologists (EASA) conference. We review two relatively recent books which discuss the role of RECs in biomedical research: Adam Hedgecoe's (2020) *Trust in the System: Research Ethics Committees and the Regulation of Biomedical Research*, and Salla Sariola and Bob Simpson's (2019) *Research as Development: Biomedical Research, Ethics, and Collaboration in Sri Lanka*. Finally, we consider how the review that RECs outside academic institutions perform is inadequate for ethnographic research, including that involving prospective participants who may lack capacity to consent. We conclude that undertaking the research ethics review internally (i.e., under university RECs) would be a first step forward in reclaiming ethnographic research ethical conversations.

Keywords

Informed consent, Capacity, Research ethics, Ethics committees, Ethics review.

The premise for (re)opening the conversation on ethical concerns

What is the role of institutional ethics in ethnographic research conducted with people whose capacity to consent to participate in research is diminished or lost? In 2020 this question inspired hours-long conversations between the authors, mostly about informed consent in our individual fieldwork conducted with people living with dementia. Our current research reflects different institutional approaches to ethical review. On the one hand, in Scotland (where Cristina's research institution and fieldwork are located), research involving people with diminished or lost capacity to consent is highly regulated and requires prior mandatory approval from National Health Service Scotland A Research Ethics Committee (NHS Scotland A REC).[1] On the other hand, Barbara's research institution in Germany did not require prior approval of an ethics committee (Dilger 2017), and authorities in Italy, where she conducted fieldwork, did not have in place regulatory procedures regarding this kind of research.

In the following, we review three pieces of work that deal with the role of research ethics committees (RECs) in regulating ethnographic research involving adults lacking capacity in particular, and biomedical research in general. First, we start by presenting how the authors of this Review essay (re)opened the conversation on ethical concerns in anthropological research conducted with prospective participants living with impaired capacity to consent. We did this by organising a panel on the topic for the 2020 European Association for Social Anthropologists (EASA) conference. We then put this panel into conversation with two relatively recent books that deal with the role of RECs in biomedical research: Adam Hedgecoe's (2020) *Trust in the System: Research Ethics Committees and the Regulation of Biomedical Research*, and Salla Sariola and Bob Simpson's (2019) *Research as Development: Biomedical Research, Ethics, and Collaboration in Sri Lanka*. Both books approach how RECs and the overall ethics governance landscape in biomedical research create local cultures of research ethics by using a situated understanding, through politics of 'trust' and 'collaboration' across national borders. We conclude by arguing how biomedical models of ethics review governance are inappropriate for ethnographic research for these very reasons, and that conducting the research ethics review internally (i.e., under university RECs) would be a first step towards anthropologists' reclaiming ethics in ethnographic research, particularly in the case of research involving prospective participants who may lack capacity to consent.

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1   'A' stands for 'Adults with Incapacity (Scotland) Act 2000', which is the legal act regulating any kind of research involving people who do not have the capacity to consent to participation.

EASA panel on ethical concerns: Reopening the conversation

In 2020, we proposed a panel for the biennial EASA conference to explore our concerns about tensions in our research projects regarding various anthropological ethics codes of research. We wanted to assess whether these concerns were a product of our relative lack of professional experience (as PhD students), or whether they were shared more widely among other ethnographers. And, if they were common, we hoped to provide an impetus for further collective action.

The papers presented on our panel reflected the ethical complexities—institutional, ontological, and practical—of ethnographic research working with prospective participants with diminished or lost capacity to consent. The discussion addressed the shortcomings of external committee-managed ethical procedures, which sometimes suggested simply excluding prospective participants based on their lack of capacity for consent. But, panellists agreed, avoiding strict procedures and (especially) debate about the potential ethical challenges in ethnographic research on dementia has created problems of its own: ethnographers are left to cope almost entirely on their own with the ethical and epistemological tensions of their work.

The conversation we want to reopen is not related to the general suitability of RECs (including university RECs) regarding ethnography. Rather, our conversation about ethics in ethnography refers strictly to research that involves people who lack capacity to consent. Such research, at least in some countries, falls under the same legal and regulatory ethics frameworks as those that apply to biomedical research. By bringing into conversation how RECs operate in biomedical research and whether these same committees are appropriate for ethnographic research, as discussed in the two books we review, we want to open the conversation on how the ethics governance landscape of research involving adults who lack capacity to consent needs to better accommodate disciplines using qualitative methodologies. Given the profound and far-reaching consequences for how ethnographic knowledge of dementia is shaped by this regulatory landscape, we argue that this topic should continue to be addressed in its own right. This, we believe, requires (re)opening the conversation on what forms of ethics governance are most appropriate for ethnographic research involving people who may lack capacity to consent and what can we do as a community to move toward collective actions.

From ethical issues of consent to issues of Research Ethics Committees (RECs)

Current debates on ethics in ethnographic (and, more broadly, qualitative) research have been discussed in two main directions: either in regards to researcher-participants relations (e.g., Ludwin and Capstick 2017; Hillman 2017; Eilat 2023; Pieta and Diodati 2023; Groot et al. 2023); or in relation to researchers' critical reflections on the inadequacies of research ethics review performed by RECs or other nation correspondents arising after approval and fieldwork completion (Crabtree 2013; Tauzer, Cowdell and Nässén 2023; Balkin et al. 2023; for more theoretical discussions on the legal and regulatory frameworks, see Fletcher 2021, 2023). Some scholars specifically argue that ethnographic research regarding people living with dementia is not only a method of collecting and analysing data, but also a form of practising ethics (e.g., Ludwin and Capstick 2017; Glavind and Morgensen 2022). However, most ethnographic studies involving people living with dementia just briefly state that their study has received ethics approval, even when this appears to have been substantial in shaping the approach and the research design (e.g., Featherstone and Northcott 2020).

In ethnographic research, the first direction in the literature on ethical aspects related to ethnographic research involving people living with dementia (i.e., ethics concerns emerging in the field) can be linked to a more general disciplinary preoccupation with ethics and the development of an 'ethical self' as inscribed in professional codes of ethics (see Pels 2000). This direction contends to real-life situations in which fieldwork relations can be fraught with ethical dilemmas, concerns, or issues of social justice and care, which become even more complex given participants' cognitive impairment. The second direction, more prominent in Global North countries where ethics have been codified by regulatory apparatuses (for example, the UK, the US, Canada, Australia, and New Zealand), aligns ethics in dementia research with what Marilyn Strathern (2000) conceptualises as 'audit cultures' (285). This direction inhibits social scientists, particularly those early in their careers, undertaking research involving this category of participants (see Crabtree 2013). This avoidance of vulnerable groups that require complicated research ethics approvals, in turn, Crabtree argues, disenfranchises members of these groups from their communities and restricts their lived experience from being reflected in social research.

Adam Hedgecoe's (2020) *Trust in the System* and Salla Sariola and Bob Simpson's (2019) *Research as Development* bring detailed understandings of the political underpinnings of RECs and their work. Although both books address ethical procedures in biomedical research, we bring them into conversation because, in some countries, similar ethics bodies review ethnographic research

involving adults who lack capacity to consent for themselves. Therefore, Hedgecoe's and Sariola and Simpson's detailed accounts of how RECs are formed and operate can shed light into how ethnographic research review may follow the patterns of biomedical research. By circling back to the presentations on our EASA panel on the shortcomings of such reviews, we offer a brief critical account of the unsuitability of such bodies in reviewing ethnographic research and potential solutions given the complex legal framework of research involving adults who lack capacity to consent.

Trust in the System (Hedgecoe 2020) discusses exactly explores how NHS RECs make decisions when reviewing biomedical research in the UK. All biomedical research taking place in the UK has to be approved by a designated REC (a similar system to which is in place in many other countries). As such, RECs play a major role in terms of what research is considered ethical and allowed to take place. Hedgecoe's book is one of few attempts at an ethnographic account of this decision-making process. His approach aligns with similar efforts, such as Laura Stark's (2011) archival research into understanding research ethics decisions taken by Institutional Review Boards (IRBs) in the US, or, more recently, the ethnographic study of Edward Dove (2020) on NHS RECs in the UK.

Hedgecoe (2020) shows how a particular way of assessing *trust* lies at the core of NHS RECs' decisions. At the time of Hedgecoe's fieldwork, RECs had no power of auditing the research projects they approved nor any oversight in being audited themselves. He explains that assessing trust is a strategic decision: on the one hand, once approved, researchers are trusted they will do what they state in their protocol; on the other, RECs must be trusted to perform unbiased reviews. As Hedgecoe points out, trust assessment practices by NHS RECs takes a very particular form. They examine research documents (application forms, participant information sheets, informed consent forms) for clues that might reveal researchers' ethical character. First, RECs might interpret an inconsistency between various documents as evidence not only of a lack of scientific robustness of a given study, but also of the applicant's attitude toward the participants, rendered in a dismissal toward the REC's own robust review process. This attitude could signal to REC a sloppiness that could. hinder relation with participants—and, therefore, of a potential (un)ethical behaviour. Second, Hedgecoe suggests, NHS RECs base their trust decisions on local knowledge. This local knowledge might be formed through a REC's historical affiliation with a local hospital trust or research institution, and the REC's trust in these institutions to have the knowledge, infrastructural capacity and ethical integrity to conduct research. Equally, as certain researchers might submit numerous applications, a REC might develop a certain knowledge of these applicants in terms of their scientific record,

consistency and robustness of ethics application, and willingness to comply with the committee's recommendations.

A third—and probably most important—way for an REC to assess trust in a research application, Hedgecoe asserts, is through face-to-face encounters with applicants. As part of the NHS REC's review procedure, an applicant can attend the REC's meeting to answer questions and clarify issues that might arise when the committee reviews the application. The face-to-face encounter (or, for that matter, the absence of one) carries such weight in generating trust, Hedgecoe argues, that in some cases it can alter a committee's decision even after they have reviewed the application documents. Trust, in this case, is generated based not just on how the applicant who attends the meeting answers the committee's questions (Do they show satisfactory scientific and practical understanding? Do they take the committee's concerns seriously, and address them with respect?), but also on the personal and professional impression they make (Do they discuss their research with confidence? Do they seem genuine in their commitment to ethical research?)

In contrast with this close locality of NHS RECs, the newly-formed RECs in Sri Lanka discussed in *Research as Development* (Sariola and Simpson 2019) make their ethics review decisions in the particular context of multi-site biomedical research, that is, research taking place across nations (most often, nations with imbalanced research capacities). On the one hand, the 'developed' nations and large pharmaceutical companies bring the potential for greater infrastructure and development; on the other, Sri Lanka offers a pool of research-naive subjects, attractive in the context of overly-researched populations internationally. This offers Sri Lankan researchers the opportunity to build capacity for future autonomy when collaborating with international partners. In these partnerships, the authors argue, collaboration might balance itself, but it might also raise worries as its connotation can be linked to historical instances of medical researchers and doctors collaborating with the political system (as with the Nazi regime). Interestingly, Sri Lankan RECs insist on operating their own approval systems and generally resist Sri Lankan research relying on the approval of sponsors' home RECs. Local Sri Lankan RECs tend not to emulate the NHS REC model of bioethical review (which attempts to apply universal principles of ethical research to each case). Rather, Sariola and Simpson suggest, they perform a fresh review which assesses the character of an international collaboration in terms of local benefit and development, and of the national importance of the research in question. As such, ethics reviews in international collaboration become circumscribed to politics of development.

Such an assessment reveals the political and historical embeddedness of RECs both in more recently independent countries and in countries where they have a longstanding presence in histories of colonisation. As Hedgecoe stresses, NHS RECs enter into a relation of asymmetry when they assess researchers' trust (that is, that researchers will do what they say they will do): RECs do not need to be trusted by researchers in order to give their approval and, if their trust appears to have been misplaced, there is no accountability for RECs. However, in the context of collaboration that Sariola and Simpson present, local Sri Lankan RECs enter into a different power asymmetry: they have the power to decline to trust NHS RECs by performing their own reviews and recognising the implicit politics of research *and* of their ethics review.

Concerns over NHS RECs' assessment of trust in ethnographic research review

How are the discussions in these books on biomedical NHS RECs in the UK and newly formed RECs in Sri Lanka carry for ethnographic research involving people who lack capacity to consent? In terms of institutional local knowledge, if a specific NHS REC has a historical affiliation with a research institution, as Hedgecoe argues, this will be a biomedical one (for example, a hospital or a university medical department). In that case, it is very unlikely that these committees will also have a previous working relationship with a social science or anthropology department, which would put any applicant from such a department at a disadvantage.

This leads to the second point of trust discussed by Hedgecoe: trust in the researcher. As Hedgecoe shows, this usually develops through repeated applications. Those carrying out biomedical studies or clinical trials submit applications more often, allowing a committee to get to know the work they do. Comparatively, a researcher using ethnographic methods is less likely to submit applications as often, since the timeframe for ethnographic research and writing are longer. As such, it is much less likely that an ethnographer, in contrast even to other social and qualitative methodologies such as interviewing, will become a familiar face to NHS RECs given the very nature of ethnographic research. The additional aspects of NHS RECs' trust assessment suggested by Hedgecoe also seem to put ethnographic research and researcher at disadvantage. For instance, the in-person performance of a researcher during the REC interview is itself problematic, as it is highly situational and based on one single encounter—unless, of course, the researcher is already known to the committee. However, this may be highly unlikely in the case of a PhD student, for instance, especially if this would be their first research project they lead. Finally, pertaining to the 'nature' of ethnographic research, which was Bell and Wynn's (2020) biggest concern regarding RECs' reviews, NHS RECs focus on research documentation, such as

informed consent forms. Such focus has been highly contested by anthropologists, who highlight the contractual (rather than ethical) nature of relations established with participants through informed consent (e.g., Simpson 2011).

It has become more a *de facto* rather than *de jure* matter that NHS RECs are considered the appropriate body to review research applications involving prospective participants who may lack capacity to consent, regardless of the disciplinary approach. This means that there is scope for this review to be moved under university ethics committees. However, this should be done cautiously, as Fletcher (2021) argues, to avoid a replication of the problems of NHS RECs at university committees.

Given the labyrinthine legal, logistical and ethical issues raised by involving people who may lack capacity to consent, we do not advocate for an ethnographic exemption from ethics review altogether. Moving research involving adults who may lack capacity to consent under university RECs comes, of course, with its own issues, since university RECs have their own shortcomings (an unclear delineation between research and ethics governance; clunky operating systems; REC members' work overload) and inhabit a relatively diverse and inconsistent landscape of ethics governance (see Dove and Douglas 2023). However, such a move can be a first step toward acknowledging the unique and significant contribution that ethnographic research can make, as set apart from—and at times in critical tension with—biomedical research. Additionally, such a move can offer universities the opportunity to become more formally recognised in their capacity to self-govern their own research, rather than relying on external governing bodies for ethics reviews of research that is conducted in universities. This, we believe, would allow a more equitable and socially just representation of experiential aspects of what it means to live with a cognitively impairing condition.

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The first author has contributed by conceiving the format, reviewing the books, writing the drafts and addressing the editors' comments. The second author has contributed by making suggestions and drafting the panel section.

Ethics statement

This review did not require ethics approval.

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