

Commentary I: Sharing and Responding to Day-to-Day Ethics Challenges in Health Research

Sassy Molyneux^{1,2} and Vicki Marsh^{1,2}

Journal of Empirical Research on Human Research Ethics
2019, Vol. 14(5) 513–515
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1556264619835709a
journals.sagepub.com/home/jre



We thank the authors of this case for giving us the opportunity to comment. We recognize that many researchers conducting scientifically and ethically approved health research are faced with daily dilemmas about what “the right thing” to do is. In this commentary, we would like to (a) support the need for us all, including social scientists, to share more of the day-to-day ethics dilemmas that arise over the course of conducting our health research; (b) highlight how potentially important the key intersecting issues of positionality and collaborations can be in shaping the nature of the ethical dilemmas faced and how they might be responded to; and (c) share some examples of strategies and approaches we have used in similar contexts to respond. In so doing, we hope to contribute to continued discussion on day-to-day ethics and prompt input and ideas from others.

We Should Share Our Day-to-Day Ethics Dilemmas and Responses

The authors of this case share a range of important day-to-day ethics dilemmas they have faced over the course of their work, and some of their responses. This is important in itself: All too often, the day-to-day ethics dilemmas we face in our studies are quietly dealt with by individual researchers or within the research team. There may be many reasons for this: It could be part of what we consider to be the normal work of being a professional researcher, or there might be a concern that sharing our issues may lead to our professionalism or morals being questioned. The ethical dilemmas that we encounter can be particularly acute when our research involves apparently vulnerable participants (whether patients, parents, community members or staff) and where we have responsibilities not only to research participants but also to research team members. We can feel torn: We are often conducting research in contexts of vulnerability and inequity precisely because we think there is an important gap or need that research can address (a social value), but what if we are inadvertently contributing to that vulnerability and causing harm? For social scientists, where positive transformation is often a key driver of conducting the research, this may be a particular tension.

The suggestion to share more of our day-to-day ethics dilemmas is far from new. Over 10 years ago, participants in a large international, interdisciplinary meeting held in Kenya highlighted the importance of giving more emphasis in ethics guidance and practice to issues of justice, and to ethics issues associated with complex power relationships between

different research stakeholders (Molyneux & Geissler, 2008). Meeting participants highlighted that the frontline researchers and field staff who often play a crucial and undersupported role in “doing ethics” in the field should be given greater voice and visibility. In “doing ethics,” Guillemin and Gillam’s (2004) work provides invaluable advice. They highlight that giving credence to those moments in the everyday practice of research where researchers are “not feeling quite right” is ethically important; a crucial part of building up our “ethical mindfulness.”

Appropriate ethical guidance and review processes should carefully consider the ethics issues and dilemmas expected to emerge in a specific context, how these issues and dilemmas will be identified and handled, and the implications for science. In some cases, anticipation of ethics dilemmas may necessitate the selection of an alternative study design, given that good science requires good ethics. Nevertheless, as researchers and reviewers, we need to be careful not to shy away from potentially transformative, ethically challenging, studies. Conducting such research, where there are no alternative approaches to gather the knowledge and achieve the associated social value, could be argued to be an ethical responsibility (Council for International Organizations of Medical Sciences, 2016). Furthermore, we must recognize that even after selecting an appropriate study design, ethics issues will almost inevitably emerge over time; sometimes in dramatic events, but more often in feelings of discomfort that reflect ethical tensions. Below we suggest some mechanisms to build into studies (and into protocols for review) that might support the identification, sharing, and discussion of ethical issues as they emerge over time, “in real time.”

How Positionality and Collaborations May Influence the Nature of the Ethical Dilemmas Faced and Potential Responses

Key issues in the science and ethics of important but potentially sensitive studies like the one shared in this case are

¹Centre for Tropical Medicine and Global Health, Nuffield Department of Medicine, University of Oxford, Oxford, UK

²Kenya Medical Research Institute (KEMRI) Wellcome Trust Research Programme, Kilifi, Kenya

Corresponding Author:

Sassy Molyneux, Kenya Medical Research Institute (KEMRI) Wellcome Trust Research Programme, P.O. Box 230, Kilifi 80108, Kenya.

Email: smolyneux@kemri-wellcome.org

positionality and collaborations: who's involved in the research, what are our various identities, backgrounds and experience, and what are our interests and perspectives? These factors interact with what can be complex socio-political contexts and team dynamics to influence the ethical issues encountered and the responses.

In this case, in our view, key strengths to support the quality of the science and appropriate handling of ethics issues are: firstly, the social science team including a senior Kenyan social scientist with long experience of working collaboratively with mid-level health system managers in the country; and secondly, the social scientists being part of a broader research collaboration involving experienced clinical researchers as well as senior hospital and wider Ministry of Health staff and policy makers. The team are uncovering major and diverse challenges for nurses with potentially important implications for patient care, and the findings are likely to point to actions and interventions to support positive transformation of the health system. The social scientists' debriefs and regular feedback meetings with their research colleagues and hospital collaborators have the potential to further strengthen the science and ethics through:

- Reminding everybody about the roles of the research team and seeking advice on the appropriate distance to maintain (strengthening understanding of the research and demonstrating respect);
- Supporting learning about any challenges or burdens being imposed on the staff and more widely by the research team (facilitating agreements on less burdensome research practices);
- Allowing careful sharing of what is being learned and seeking additional information from those with tacit knowledge of the system (supporting the social value of the work); and
- Building interest in and support for the quality and relevance of the work, in turn hopefully promoting positive action in response to research findings (supporting individual-, community-, and system-level benefits from the work).

Our own experience elsewhere in Kenya suggests that such mechanisms are important to establish, but will face their own practical and ethical dilemmas. They require—and are an approach to building—strong and productive relationships between collaborators. However, researchers will need to operate within what are often complex health systems imbued with unequal and shifting power relations. There may well be other researchers working in the setting with different approaches and institutional requirements. Developing close and trusting relationships is difficult in these situations and, as relationships develop, researchers will inevitably become part of those contexts, potentially influencing power dynamics in both intended and unintended or unexpected ways. Dilemmas can result. For

example, in this case the identity of the nurse who left her post might be inadvertently revealed to her managers, adding to her challenges. Or—as a result of sharing findings that are considered to be inappropriately accusatory of poor practice—there may be a distancing between hospital managers and researchers, with a negative impact on further learning and positive action. The longer and stronger the links and relationships between researchers and health managers, with the positive gains mentioned above, the greater the potential risk that “Researchers come to see questionable practices as normal and acceptable, possibly because they become so acclimated to study settings, or because they feel uncomfortable about ‘betraying’ the staff who allowed them access, p. 267” (Dixon-Woods & Bosk, 2011). Fundamentally, there could be a dilemma that in trying to build and maintain relationships, a transformative agenda to raise awareness about and reduce damaging power imbalances is undermined.

Despite such concerns, our experience suggests that such feedback mechanisms are valuable in building mutual understanding and trust, and are central to good quality science; that careful reflection of the positionality of different members of the research team, and of the evolving relationships and their implications, can help to mitigate some of the biggest potential challenges and dilemmas.

Some Examples of Strategies and Approaches to Raise and Respond to Day-to-Day Ethics Dilemmas

Recognizing that it is usually the frontline researchers and field staff who face the most challenging issues in “doing ethics” in the field, and that there may be pressures and power dynamics within a research team and among collaborators that discourage frontline staff from sharing their dilemmas with others, we share some examples of strategies and approaches we have begun to develop for similar studies in Kenya.

One strategy is *building in specific ethics reflection meetings into studies*. We initiated such approaches in our health systems studies (Molyneux et al., 2016; Molyneux & Geissler, 2008) and have continued to evolve them over time. In brief, special sessions lasting 2 to 4 hours each and involving all social science team members are organized, with the specific aim of creating a relaxed and judgment-free setting to share experiences of feeling “not quite right” about professional and personal roles, and where the right thing to do is unclear. These sessions allow team members with different experiences and expertise to share worries, carefully identify and explore any related ethical issues and researcher responsibilities, and agree upon any appropriate action. For studies where social science teams are part of wider collaborations, we have found these sessions invaluable in reflecting upon which issues need to be shared with the wider team/collaborators, and how. These sessions might well be valuable for the social scientists working on

this case, essentially as expanded versions of their regular debriefs. We recognize that clinical research team members and non-research clinical staff in this and other similar interdisciplinary studies may themselves face numerous day-to-day ethical dilemmas. In one such study, we ran ethics reflection sessions for both the social science team and the wider research team. Across both sets of ethics reflection sessions, we valued access to diverse forms of expertise: local field assistants with deep local knowledge; as well as social scientists, clinicians, and ethicists. Accordingly, we recognize that for the NBU case we are discussing, and for other similar research teams, it is key to carefully consider the range of expertise and experience needed and available to support the science and ethics of research in practice.

Although ethics reflection sessions, including acting on agreements made, can help to alleviate the huge moral distress that so many research staff face at the frontline, it is only one strategy. Two complementary strategies are *participatory training in communication and emotional management*, and facilitating access, where necessary, to *professional individual counseling*. We have supported the development of a series of participatory courses in communication and emotional management—for researchers, health workers and managers—to build awareness and skills of our own communication styles and emotions, and those of others, and their impacts (Mwangi, 2015). Our experience is that these courses can assist us to better understand our own and others' needs and challenges, even in the context of structural difficulties and complex power relations. Such courses can therefore inspire and support stronger relationships with other team members, collaborators, and participants/patients, and could be seen as an ethical responsibility in contexts of hierarchy and vulnerability. These courses have also assisted us to recognize that we all have limits on what we can handle ourselves; that we need to share some of our experiences with team members, and sometimes with individual professional counselors. We are delighted that the authors of the case have already participated in such a course and that together with collaborators are developing related courses to support neonatal nurses. Ensuring that such training and support is built into research proposals, training and support processes may well be valuable for other studies.

The above strategies, and others, can be considered more centrally in proposal development and institutional review processes through ensuring *that those who best understand the research context*, including the types of ethical issues likely to arise and appropriate responses, are *given a formal advisory role*. In our institution, we have tried to do this through setting up processes to ensure staff from local communities review all proposals, including development of consent and other communication processes (Boga et al., 2011). They also provide advice on ethics issues and dilemmas that arise over the course of a study and on its

completion. Regular sharing of ethics issues and responses across different studies is aimed at ensuring learning feeds back into new proposals, training and support processes.

Wrapping Up

The authors of the NBU case share a range of day-to-day ethics issues in conducting important but potentially sensitive studies, including issues of fairness to co-researchers and participants (and negotiating appropriate distance), and maintaining research integrity. In response, we have emphasized the importance of sharing such dilemmas, and of setting up approaches to identify and discuss day-to-day ethics issues across a research team and with collaborators. We have also shared some ideas from our own practice. We would value feedback and ideas from others, recognizing that “ethical mindfulness” requires having the courage to be receptive to new ways of thinking about research ethics and in some cases, being ready to critically challenge established practice.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

- Boga M, Davies A, Kamuya D, Kinyanjui SM, Kivaya E, Kombe F, et al. (2011) Strengthening the Informed Consent Process in International Health Research through Community Engagement: The KEMRI-Wellcome Trust Research Programme Experience. *PLoS Med* 8(9): e1001089. <https://doi.org/10.1371/journal.pmed.1001089>
- Council for International Organizations of Medical Sciences (CIOMS); 2016. *International Ethical Guidelines for Health-related Research Involving Humans, Fourth Edition*. Geneva.
- Dixon-Woods, M., & Bosk, C. L. (2011). Defending rights or defending privileges? Rethinking the ethics of research in public service organizations. *Public Management Review*, 13, 257-272.
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, 10, 261-280.
- Molyneux, S., & Geissler, P. W. (2008). Ethics and the ethnography of medical research in Africa. *Social Science & Medicine*, 67, 685-695.
- Molyneux, S., Tsofa, B., Barasa, E., Nyikuri, M. M., Waweru, E. W., Goodman, C., & Gilson, L. (2016). Research involving health providers and managers: Ethical issues faced by researchers conducting diverse health policy and systems research in Kenya. *Developing World Bioethics*, 16, 168-177.
- Mwangi, T. (2015). *Nursing: Nurturing a caring heart*. Retrieved from <https://healthkenya.co.ke/nursing-nurturing-caring-heart/>