

ETHICAL CHALLENGES IN CONDUCTING EMBEDDED, LONG-TERM RESEARCH



Policy brief, April 2017

Introduction

Ethical practices are central to the conduct of all types of research including health systems research. In this brief we discuss the specific ethical challenges faced when health systems researchers are embedded in the institutions they study.

Researchers in Kenya have been using a novel approach to better understand the health system by working alongside health managers and facility workers and experiencing their daily routines and challenges. The research entails a long-term process of engagement, action learning and reflective practice with health workers and managers; the process of enquiry is emergent, and types of research and wider engagements are constantly developing (see box 1). There are several benefits to this approach. It provides an opportunity for researchers to develop trusting relationships with health system practitioners. Through each engagement, researchers can build on their understanding, resulting in a more profound knowledge of the health system. It also provides opportunities for researchers to support managers in their decision-making and to intervene positively in the health system – strengthening it from within.

Researchers have, however, faced several ethical dilemmas that are uncommon in other forms of biomedical research, and even in less embedded forms of health policy and systems research. Many of these issues arise from the evolving relationships between researchers and participants and the blurring of their roles. This brief outlines the ethical dilemmas faced by the researchers in their work and the solutions they devised to minimise these. Their experiences are relevant for health policy and systems researchers, as well as others conducting long-term, embedded, research.

Box 1: About the Kilifi learning site

Research in Kenya is taking place in a learning site situated in Kilifi County. Researchers and health managers have been working together to understand the implications of devolution on health system governance and health service delivery. The research areas are related to various health systems governance issues including:

- Priority setting and resource allocation in public hospitals;
- Micro-processes of accountability between health facility managers and sub-county managers;
- Health sector budgeting and planning in the context of devolution.



More information is available in the RESYST research brief on Learning sites [↗](#)

KEY MESSAGES

- Health systems research, that relies on long-term engagements with participants and 'embedded' researchers, raises significant ethical dilemmas that are not easily tested and checked by ethics committees.
- Many ethical dilemmas only emerge over the course of the fieldwork and are related to complex interactions and relationships between researchers, community members, health providers and managers.
- The blurring of roles between researcher and participant, whilst having important benefits, can create ethical challenges relating to the need to maintain trusting relationships with multiple actors, in managing expectations appropriately, and in the consent process.
- For this type of research, careful consideration and planning is needed to ensure that relationships are not harmed, and that unequal power imbalances are not exacerbated.
- All researchers have a responsibility to build ethical mindfulness in their day-to-day practice. Regular reflective practice sessions, where researchers can deliberate on ethical dilemmas faced and how these should be handled, are an invaluable way of achieving this.

Key ethical challenges

Table one sets out the main ethical challenges experienced by the researchers. These are discussed in more detail below.

Table 1: Overview of challenges experienced by researchers in the Kilifi learning site

General areas	Challenges
Consent process and participants' understanding of the research	<ol style="list-style-type: none"> 1. Use of data obtained outside the formal research environment and over a long period of time 2. Changing nature and understanding of the research
Building and maintaining respectful relationships	<ol style="list-style-type: none"> 3. Forming relationships and alliances as an 'embedded' researcher 4. Disclosing (sensitive) research findings without risking participants being identified
Managing expectations and requests from participants	<ol style="list-style-type: none"> 5. Responding appropriately to requests to act outside the researcher role

Consent process and participants' understanding of the research

1. Use of data obtained outside the formal research environment

The long-term nature of the research created an ethical challenge regarding whether the initial formal consent processes covered information gained many months later: how long a period does the consent processes cover? Further, information was often gathered during informal meetings with managers and/or practitioners outside the work environment. Researchers faced a challenge in deciding whether the information was covered by the consent process, and if so, how to use it in a way that did not compromise the trust developed with health managers.



2. Changing nature and understanding of the research

Both researchers and health managers/practitioners' understanding of the research evolved over time. For some managers/practitioners, their view of researchers also changed towards seeing them more as confidantes and problem-solvers than as objective researchers. While this process supports access to key tacit information about health system issues, it raises further questions about the initial consent processes and whether those remain relevant for the research and true to what participants initially signed up to over time.

Solutions and lessons learned

- Consent, in terms of fixed messages given formally to research participants at the outset of the study, is only one part of a wider set of interactions. Regular discussions and reflection with key actors throughout the research process was found to be essential.
- To minimise ethical challenges relating to the consent process, researchers held regular planning and feedback meetings with participants to ensure they contributed to, understood and supported the evolving research ideas and overall approach.



"Apart from the times you are doing formal interviews a lot of the information you get is told informally which significantly contributes to the research subject...how do I use that data in a way that doesn't cause harm to the people who provided that information?"

Dr Benjamin Tsofa

Building and maintaining respectful relationships

3. Forming relationships and alliances as an embedded researcher

In the Kilifi learning site, one researcher held formal roles as both a researcher and system/policy advisor. The continuous engagements with managers at national, county and sub-county level meant that he was particularly 'embedded' in the health system, with positive implications for learning and building relationships. However, a challenge of this embeddedness was the need to be careful about who he was (seen to be) aligned with, which in turn had the potential to influence others' perceptions and engagements with researchers, and how findings were listened to and taken up.

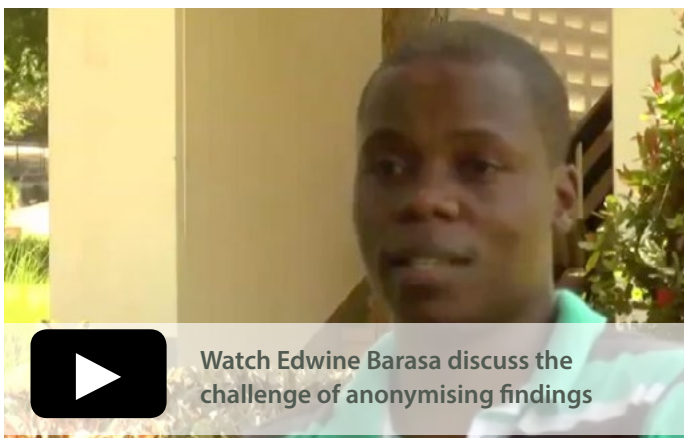


Watch Benjamin Tsafa describe how he navigates his multi-level roles

4. Disclosing sensitive research findings anonymously

Some of the information that researchers came across during their investigations was sensitive and put managers at risk if shared with others, such as accusations of corruption by managers, or evidence of unfair charging practices at health facilities. This raised several ethical challenges including if and how to make a judgement (from an outsider's perspective) on whether what was being reported was accurate or unethical and, relatedly, what if any action would be appropriate.

Further, researchers faced challenges regarding how to share research findings anonymously, especially in relation to studies with detailed descriptions of the subject. Here the dilemma was how much information could be shared without risking participants being identified, and thereby undermining respect.



Watch Edwine Barasa discuss the challenge of anonymising findings

Solutions and lessons learned

- Careful consideration and planning was needed to ensure that relationships with participants were not harmed and power imbalances between participants were not exacerbated.
- It was considered important to feedback findings in a way that did not undermine confidentiality arrangements with participants. At feedback meetings, researchers avoided discussing individual situations and provided instead broader, more generalisable lessons, and highlighted, wherever possible, positive practices to learn from and build upon.
- Another approach they adopted was to work with individuals to support them to develop their own solutions, in the hope that this would have a longer term positive impact.

Managing expectations of participants

5. Responding appropriately to requests from health managers

During the study period, researchers were presented with numerous requests from health managers and providers. Requests ranged from researchers being asked to assist with small roles in busy facilities through to requests for extra allowances. Senior health managers sometimes also requested researchers to provide 'scientific' support for decisions they had already made.



Watch Mary Nyikuri discuss managing expectations of participants

Requests introduced dilemmas for researchers. Acting on resource requests had potentially important positive implications for learning about health system realities and for building relationships. However, would acting on such requests change what researchers were observing? Researchers were also concerned about how sustainable any support would be, and whether intervening in the short-term might undermine the possibility of longer-term solutions and raise expectations of what researchers could do in the future.

"Working with managers has led me to develop relationships, they see me as part of the system."

Dr Mary Nyikuri

Solutions and lessons learned

- Requests for information from participants provided an opportunity to carefully feedback research lessons at a time and in a form most needed by senior managers.
- Often feedback required informal interaction, and being able to engage with participants positively and clearly, with very short notice.

Conclusion and policy recommendations

Many of the ethical issues that emerged in the Kilifi learning site unfolded over the course of the research in ways that were difficult or impossible to predict in advance. Many were related to the social relationships within and between research teams, health staff and managers and community members. These relational elements of the research are critical to ethics practice and to conducting quality science, but are not easily tested and checked by ethics committees in advance.

Regular, honest, reflective practice sessions among the research team provided an invaluable space for researchers to deliberate on the dilemmas as they arose, and discuss how they should be handled. Researchers also received support from external collaborators conducting similar work in other settings, and aimed to incorporate more independent voices into their reflections through submitting detailed annual reports to funders and the national ethics committee.



About the brief

This brief is based on the publication:

Sassy Molyneux, Benjamin Tsofa, Edwine Barasa, Mary Nyikuri, Evelyn Wanjiku Waweru, Catherine Goodman, Lucy Gilson
Research involving health providers and managers: ethical issues faced by researchers conducting diverse health policy and systems research in Kenya, 2016, *Developing World Bioethics*, doi: 10.1111/dewb.12130

Sassy Molyneux is a steering committee member of RinGs, which is a DFID funded initiative bringing together three health systems focused Research Programme Consortia: Future Health Systems, ReBUILD and RESYST, in a partnership to galvanise gender and ethics analysis in health systems. It is working to understand and encourage a gendered approach to the study of care-seeking, financing and contracting, governance, and human resources.

About RinGs



RinGs supports embedded approaches and analysis that is relevant and owned by local actors. Intersectionality is central to RinGs' work, given that gender intersects with other axes of inequality, such as age, ethnicity, class, poverty, geography, (dis)ability and sexuality, to influence health access and outcomes. In addressing power relations and social exclusion RinGs also calls attention to ethics in health systems research, policy and practice. More information: <http://resyst.lshtm.ac.uk/rings>

RinGs has produced a resource list of publications that members have found most relevant for Health Policy and Systems Researchers and would value additional suggestions to be posted to the website.



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