The ethics of health systems research: Selected guidelines and studies

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Contents

Who is this resource for? .....................................................................................................................................1
Contribute to the resource and discussions ............................................................................................1
An overview of ethics in health systems research. ..................................................................................2
Frameworks focused on public health, longitudinal surveillance, or learning health systems ..................3
Challenges of work in low- and middle-income settings .......................................................................3
Social science and feminist frameworks and approaches .........................................................................4
Frameworks for other more specific health systems research approaches ........................................5
Integrating ethics into our everyday practice as health system researchers ........................................6
A focus on relationships and power ............................................................................................................8

Who is this resource for?

If you are doing health systems research you have probably grappled with ethical questions related to your work. Most studies are subject to ethical review before they even begin. But ethical principles and practice are something that should concern academics throughout the research process. To help you navigate the expanding world of ethics relevant to health systems research, Research in Gender and Ethics (RinGs): Building Stronger Health Systems has put together this resource that gathers together a selection of some of the most useful and interesting frameworks and papers that we have come across.

Contribute to the resource and discussions

We hope you find this preliminary list of resources useful and that you will help to build it up and strengthen it by sharing your own resources, papers, and thinking with us.
Join a growing community of practice that is interested in ethics in health policy and systems research!
Email us and be kept up to date with our work (rings.rpc@gmail.com).
An overview of ethics in health systems research

Health systems research is a hybrid, or ‘trans-disciplinary’ field. It draws on different disciplinary traditions and methodological approaches, with an overall aim to influence policy and wider action to improve health system performance.

Health systems research is a broad field which focuses on:
1. The performance of health systems and their sub components (resources, organizations, and services);
2. How links between the sub components shape performance, and what forces influence those links; and
3. How to strengthen health system performance over time.

There is a growing interest in the ethics of health systems research, and some debate about whether a specific ethical framework or set of guidance is needed. Hyder and his colleagues provide an excellent framework to begin to think about this, organised around eight considerations: (1) the nature of intervention; (2) types of research subjects; (3) units of intervention and observation; (4) informed consent; (5) controls and comparisons; (6) risk assessment; (7) inclusion of vulnerable groups within different contexts, and; (8) benefits of research. This is an invaluable starting place for any researchers interested in health systems research ethics. The authors note several challenges to thinking about the ethics of health systems research, including the diverse range of studies and disciplines involved, the grey zone between research and non-research, and the many overlaps of issues with other types of health research. They call for more conceptual work and empirical research aimed at better understanding this topic.

Recommended reading
Frameworks focused on public health, longitudinal surveillance, or learning health systems

These frameworks might be particularly valuable where the distinction between research and practice or audit is blurred.

**Recommended reading**


Challenges of work in low- and middle-income settings

These frameworks focus on biomedical and clinical research, rather than on health systems research, but many of the principles and issues covered are relevant to all research in low- and middle-income countries. There is a particular interest in recognising and minimising the potential of exploitation in multinational research.

**Recommended reading**

Social science and feminist frameworks and approaches

Health systems are often understood as social and political constructs which provide vital opportunities for tackling social injustice. Social science and feminist approaches to research ethics tend to have a strong emphasis on the relational elements of ethical practice, and of producing quality data. They stress the need to be aware of and pay attention to conflicting interpersonal relationships and the power imbalances inherent in many research relationships, and there is interest in the political implications of the research endeavour. In feminist ethics specifically, exposure and elimination of oppression for women and other disadvantaged groups, including women in general, racial and ethnic minorities, the elderly, children, the poor, and the disabled is often a key goal. Research is often viewed in relation to its effect on the quality of relationships among people with an emphasis on considerations of justice and the concept of caring.

Recommended reading

Frameworks for other more specific health systems research approaches

Depending on where you work, and what type of health systems research you are conducting, the following frameworks and papers may be valuable.

**Recommended reading**

Integrating ethics into our everyday practice as health system researchers

Relatively few papers describe the ethical issues that arise during health systems research from a ground-up perspective, particularly in low- and middle-income countries. An understanding of the everyday practice of our research in diverse social, economic, and political contexts can help us to move closer towards a more ‘situated ethics’ of research, in which the relevance and application of ethical principles and guidelines for different studies and contexts, is considered. A particular issue highlighted in several of the papers below is the ethical dilemma facing those who are requested by researchers to conduct research ‘in the field’, working as employees or volunteers at the interface between research systems and communities. The complexity of this role is often under-recognised and under-supported by researchers.

Recommended reading


Recognising and responding to local and global differences and inequities

Thinking about the researcher and his/her relationships with others


Recognising and supporting volunteers or staff who assist with research

- Kamuya, D.K. et al. 2014. “When they see us, it’s like they have seen the benefits!” experiences of study benefits negotiations in community-based studies on the Kenyan Coast. BMC Medical Ethics. 15:90.
A focus on relationships and power

Together, many of the above papers show that in practice it is often the social relationships – many of which involve complex imbalances of power – that are established in research teams, between researchers and health staff and managers, and between field-teams and community members, that are often critical to fulfilling the moral (as opposed to the legal) aspects of ethics practice. These essential elements of ethical practice, and of producing quality data, are not easily tested and checked by ethics committees, particularly where health systems research is reviewed by institutional and national science and ethics committees most familiar with reviewing biomedical studies. In fact, many are not easily tested and checked by ethics committees at all. Rather, they are linked to the insight and integrity of all involved in the research endeavour. Relational elements can also unfold over the course of research in ways that can be difficult or impossible to predict in advance, and require recognition and appropriate response as they arise. These require further documentation, analysis, and careful reflection on the implications for policy and practice for different types of health systems research.

Recommended reading