The ethics of health systems research:

Selected guidelines and studies

May 2015

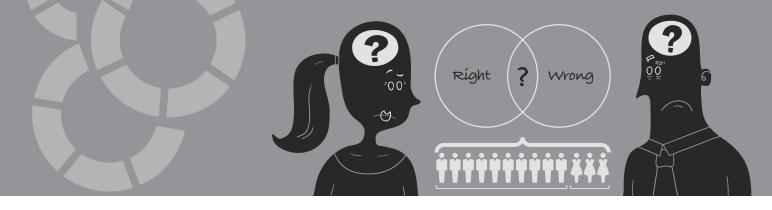Right ? Wrong

Contents

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
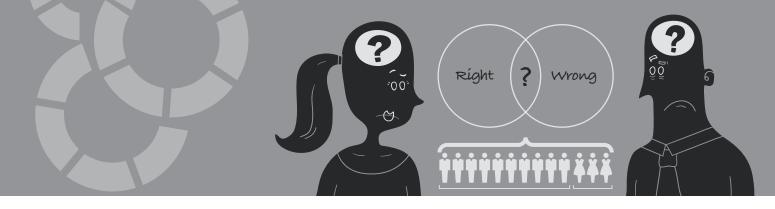3. How to strengthen health system performance over time.

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

- Sheikh, K., George, A., & Gilson, L., 2014. People-centred science: strengthening the practice of health policy and systems research. Health Research Policy and Systems. 12:19.
- Hyder, A.A. et al. 2014: Ethical review of health systems research in low and middle income countries: a conceptual exploration. American Journal of Bioethics. 14(2): 28-37. See also commentaries in the same issue.

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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.
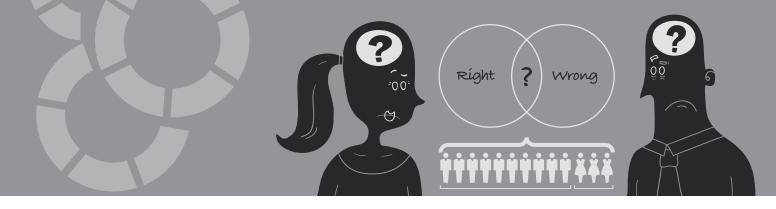
Recommended reading

- Carrel, M. & Rennie, S. 2008. Demographic and health surveillance: longitudinal ethical considerations. Bulletin of the World Health Organization. 86(8): 612-616.
- Faden, R. et al. 2013. An Ethics Framework for a Learning Health Care System: A Departure from Traditional Research Ethics and Clinical Ethics. Hastings Centre Report. 43(s1): S16-S27.
- Kass, N. 2001. An Ethics Framework for Public Health. American Journal of Public Health. 91(11): 1776-1782.

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

- Council for International Organizations of Medical Sciences (CIOMS). 2002. International ethical guidelines for biomedical research involving human subjects (PDF). Geneva: CIOMS.
- Emanuel, E. et al. 2004. What Makes Clinical Research in Developing Countries Ethical? The Benchmarks of Ethical Research. Journal of Infectious Diseases. 189(5): 930-937.

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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

- Edwards, R. & Mauthner, M. 2002. Ethics and feminist research: theory and practice. In Mauthner et al. (eds). Ethics in Qualitative Research. SAGE Publications Ltd: London.
- ESRC (Economic and Social Research Council), 2005. Research ethics framework. (PDF).
- Hoeyer, K., Dahlager, L., & Lynoe, N. 2005. Conflicting notions of research ethics. The mutually challenging traditions of social scientists and medical researchers. Social Science & Medicine. 61(8): 1741–1749.
- Khanlou, N. & Peter, E. 2005. Participatory action research: considerations for ethical review. Social Science & Medicine. 60(10): 2333–2340.
- Sherwin, S. 2008. Whither bioethics? How feminism can help reorient bioethics, in International Journal of Feminist Approaches to Bioethics. International Journal of Feminist Approaches to Bioethics. 1(1): 7-27.
- Wassenaar, D.R. & Mamotte, N. 2012. Ethical issues and ethics reviews in social science research. In M. Leach, M. Stevens, G. Lindsay, A. Ferrero, & Y. Korkut (Eds.) The Oxford handbook of international psychological ethics (pp. 268- 282). New York: Oxford.

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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.
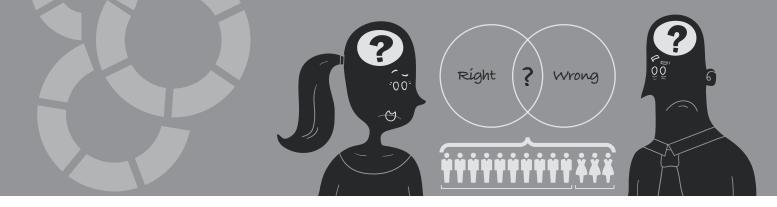
Recommended reading

- Hill, P. 2004. Ethics and health systems research in 'post'-conflict situations. Developing World Bioethics. 4(2): 139-153.
- Hutton, J., Eccles, M., & Grimshaw, J. 2008. Ethical issues in implementation research: a discussion of the problems in achieving informed consent. Implementation Science. 3:52.
- Macklin, R. 2014. Ethical Challenges in Implementation Research. Public Health Ethics. 1:8
- Weijer, C. et al., 2012. The Ottawa Statement on the Ethical Design and Conduct of Cluster Randomized Trials. PLOS Medicine. 9(11): e1001346. doi:10.1371/journal.pmed.1001346.

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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.
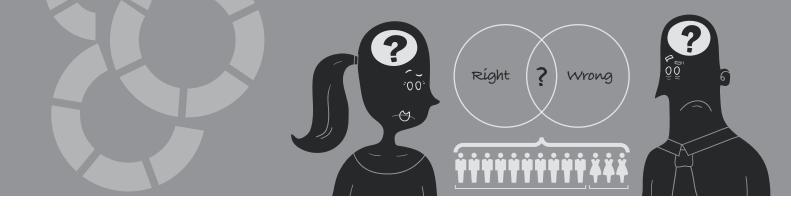
Recommended reading

- Heimer, C. 2013. 'Wicked' ethics: Compliance work and the practice of ethics in HIV research. Social Science & Medicine. 98: 371-378.
- Kingori, P., de Vries, R., & Orfali, K. 2013. Special issue introduction: Bioethics in the field. Social Science & Medicine. 98: 260-263.
- Molyneux, C.S. & Geissler, W. 2008. Editorial: Ethics and ethnography in medical research in Africa. Social Science & Medicine. 67(5): 685-695.
- Molyneux, C.S. et al. 2009. Conducting health-related social science research in low income settings: ethical dilemmas faced in Kenya and South Africa. Journal of International Development. 21(2): 309–326.

Recognising and responding to local and global differences and inequities

- Azetsop, J. 2011. New direction in African bioethics: ways of including public health concerns in the bioethics agenda. Developing World Bioethics. 11(1:) 4–15.271 4
- Bhutta, Z.A. 2002. Ethics in international health research: a perspective from the developing world. (PDF) Bulletin of the World Health Organization. 80 (2): 114-120.
- Chukwuneke, F., Umeora, O., Maduabuchi, J. & Egbunike, N, 2014. Global Bioethics and Culture in a Pluralistic World: How does Culture influence Bioethics in Africa? Annals of Medical and Health Sciences Research. 4(5): 672-675.
- Hyder, A.A. et al. 2014. The ethics of health systems research in low and middle-income countries: A call to action. Global Public Health. 9(9): 1008-1022.
- Lange. M.M., Rogers, W.A. & Dodds, S. 2013. Vulnerability in Research Ethics: a Way Forward. Bioethics. 27(6): 333-340.
- Rogers, W. & Lange, M.M. 2013. Rethinking the vulnerability of minority populations in research. American Journal of Public Health. 103(12): 2141-2146.
- Pratt, B. & Hyder, A.A. 2015. Global justice and health systems research in low and middle-income countries. Journal of Law, Medicine, & Ethics (in press, Spring 2015 issue).
- Pratt, B. & Hyder, A.A. 2015. Applying a global justice lens to health systems research ethics: An initial exploration. Kennedy Institute of Ethics Journal (in press, June 2015 issue).

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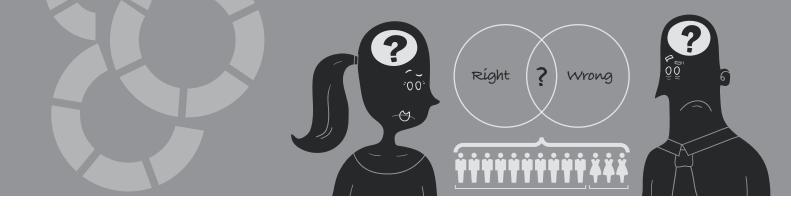## Thinking about the researcher and his/her relationships with others

- Dixon-Woods, M. & Bosk, C.L. 2011. Defending Rights or Defending Privileges? Public Management Review. 13(2): 257-272.
- Guillemin, M. & Gillam, L., 2004. Ethics, Reflexivity, and "Ethically Important Moments" in Research. Qualitative Inquiry. 10(2): 261-280
- Guillemin, M. & Heggen, K. 2009. Rapport and Respect: Negotiating Ethical Relations between Researcher and Participant. Medicine, Health Care & Philosophy. 12(3): 291–299.
- Meriam, S. et al. 2001. Power and positionality: negotiating insider/outsider status within and across cultures. International Journal of Lifelong Education. 20(5): 405-416.
- Moore, J., Engel, J., & Prentice, D. 2014. Relational ethics in everyday practice. Canadian Oncology Nursing Journal. 24(1): 31-39.
- Simon, C. & Mosavel, M. 2011. Getting personal: ethics and identity in global health research. Developing World Bioethics. 11(2): 82-92.

Recognising and supporting volunteers or staff who assist with research

- Angwenyi, V. et al. 2013. Working with Community Health Workers as 'volunteers' in a vaccine trial: practical and ethical experiences and implications. Developing World Bioethics. 13(1): 38-47.
- 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.
- Kingori, P. 2013. Experiencing everyday ethics in context: frontline data collectors perspectives and practices of bioethics. Social Science & Medicine. 98: 361-370.
- Molyneux, S. et al. 2013. Field workers at the interface. Developing World Bioethics. 13(1): ii-iv.
- Mosavel, M. et al. 2011. Community researchers conducting health disparities research: Ethical and other insights from fieldwork journaling. Social Science & Medicine. 73(1): 145-152.

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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

- Baylis, F., Kenny, N. & Sherwin, S. 2008. A Relational Account of Public Health Ethics. Public Health Ethics. 1(3): 196-209.
- Kenny, N., Sherwin, S. & Baylis, F. 2010. Re-visioning Public Health Ethics: A Relational Perspective. Canadian Journal of Public Health-Revue Canadienne De Sante Publique. 101(1): 9-11.
- Research Ethics: Women, Sex, and Gender in Biomedical Research. 2008. International Journal of Feminist Approaches to Bioethics. Volume 1(2).

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