

Key ethical issues in humanitarian research

Research carried out in humanitarian settings generates a host of ethical considerations which are not yet all wellevidenced or understood. This study represents an early step in categorizing and identifying key ethical issues to inform resources and tools under development.

Going beyond ethics approval

Researchers, and others leading evidence generation projects in humanitarian health, encounter many ethical issues at all phases of research, not only during the 'ethics approval' stage. Humanitarian health researchers, and their partners, reported a desire to have ethics training, support and tools to help address ethical issues and ensure research is conducted ethically and respectfully. Findings of this study have informed research ethics training and publications. An online tool to help identify ethical issues and guide researchers towards relevant resources is under development.

Background

Research and other data generating projects provide crucial insights and evidence to guide humanitarian responses. Ethical issues can arise when projects are being designed, while they are being conducted, and during dissemination of their findings. Research ethics tends to focus on ethics approval procedures, but ethical decisions are made throughout the research process. Researchers often have little support and guidance in addressing these ethical issues.

This research, carried out as part of the Post-Research Ethics Analysis (PREA) project, seeks to identify the nature of these ethical issues, how they are usually addressed, and what ethics support researchers would like to have available.

How the research was conducted

This research involved both a systematic literature review of published articles and reports addressing ethical issues in humanitarian health research, and 67 individual interviews with research stakeholders in Afghanistan, Ethiopia, Nepal and South Sudan.

ETHICAL THEMES Literature Qualitative Review (13) Interviews (10) Philosophical principles Specific ethical issues Data management Dissemination Improving ethical practice Participants' roles Ethics approval Relevance of research Addressing ethics process Communication Ethical issues with Ethics training Perceptions research methods Learning lessons Clinical research ethics Stakeholders' roles Practical issues Improving ethics approval process Professional ethics

Figure 1: Ethics Themes from the preliminary analysis of the identified literature and PREA interviews.



- The systematic review found over 700 documents in academic and non-academic sources that addressed ethical issues in humanitarian health research.
- Analysis of this literature identified 13 main themes, each with numerous sub-themes.
- The analysis of interviews in the four countries identified 10 main themes, again with multiple sub-themes.
- Figure 1 shows the main themes, with clear areas of overlap between the two analyses.
- However, much more overlap occurred than the figure suggests because the literature tended to focus on specific issues, while the interviews focused on practicalities.
- Participants provided many useful ideas about ways to address and improve how ethics is addressed in humanitarian research.

Implications for humanitarian practitioners and policymakers

- Ethics in humanitarian health research involves many more ethical issues than those that come up during the ethics approval process. Some of these ethical issues leave researchers distressed and questioning their involvement in research.
- Humanitarian researchers need and want training and support for the ethical challenges they face at all stages of research and evidence generation. This could be addressed through further attention to the development of ethics tools, training and guidance materials.
- Policies should encourage attention to and training in ethical decision-making skills so that researchers are better prepared to address ethics and ethical issues in their projects.
- Commissioners and funders of research should promote research that holds to the highest ethical standards, thereby respecting participant communities, researchers, and others. This will also help projects run efficiently and effectively by avoiding delays due to ethical challenges.

Recommendations for future research

Future research should identify evidence-based ways to address ethics in humanitarian research. Research is needed into the ethical issues themselves and how different communities address them. Key questions remain around the skills and competencies required to address ethical issues in humanitarian research, and how these can be evaluated, as well as on the effectiveness of ethical training tools for stakeholders.

About the study team

The team was Ivan Komproe & Nawaraj Upadhaya (HealthNetTPO), Tine Van Bortel & Ainul Hanafiah (Universities of Cambridge and East London), and Shannon Doherty, Steven Martin & Sapfo Lignou (Anglia Ruskin University). The interviewers were Abdul Majeed Siddiqi, Gasim Abd-Elfarag, Damodar Rimal & Yimtubezinash Mulate. The study was envisioned by Chesmal Siriwardhana (ARU), and after his death in 2017, the PI was Dónal O'Mathúna (Dublin City University & The Ohio State University).

Keywords

ethics; humanitarian health research; research ethics; ethics training; ethics support

Articles and further reading

Project page on Elrha site:

https://www.elrha.org/project/post-researchethics-analysis-humanitarian-crises-prea/

PREA website: http://www.preaportal.org/

R2HC Research Ethics Tool:

https://www.elrha.org/researchdatabase/r2hc-research-ethics-tool/

"Why research ethics should add retrospective review," *BMC Medical Ethics*

https://doi.org/10.1186/s12910-019-0399-1

"Research ethics and evidence for humanitarian health," *Lancet*

https://www.thelancet.com/journals/lancet/article/ PIIS0140-6736(17)31276-X



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