RESEARCH SNAPSHOT

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Ethical research during a crisis: Insights from the West African Ebola epidemic

Understanding diverse and context-specific influences impacting engagements with research, and clear, consistent communication are key to effective collaboration and ethical best practices during the conduct of essential research in public health emergencies.

Trust is essential for ethical research

This qualitative study examined the experiences of research participants and stakeholders during the West Africa Ebola epidemic through an ethical lens. It found that building and maintaining trust with research stakeholders is essential to advancing three practices that are core to the ethical conduct of research in public health emergencies:

1) meaningful consent;
2) clear communication to prevent harm;
3) collaborative, equitable partnership.

The study outputs provide researchers and operational partners with recommendations which can help address these three priorities in practice.

An information campaign in Guinea combines text and images to promote Ebola prevention measures. Credit: Elysée Nouvet.

Background

When the 2014-6 West African Ebola Outbreak hit, no vaccines or treatment had yet been shown to be effective against the disease. As the epidemic grew and spread, research trials assessing potential agents were rolled out. Yet the extent to which ethical research standards could be upheld in this challenging context was not clear; little evidence was available on good ethical practices in these contexts. This research study, conducted in three countries affected by the West African Ebola epidemic, draws on the perspectives of people who were directly involved in Ebola research to better understand the social and moral experiences of research participants and explore the implications for good practice.

How the research was conducted

In-depth semi-structured interviews were conducted with 108 Ebola research stakeholders. Interviewees included proxy-decision makers for relatives, researchers, research ethics board members, policy-makers and community who had been involved with various clinical trials and viral persistence or sequalae studies conducted in Guinea, Liberia, or Sierra Leone, during or after the 2014-6 outbreak.

Key findings

Meaningful consent

- A range of motivations led people to take part in research. Many believed that yet-unproven treatments would be more effective than the standard of care.
- Illness and stress in Ebola Treatment Centres contributed to imperfect consent processes. Some participants took part due to a perceived lack of choice, feeling that they would 'enter a trial or die'.

Communication

- Some Ebola survivors are unsure of what, if any, experimental treatments they received. Lack of communications about Ebola research processes and findings left some participants feeling confused, concerned, or betrayed.

Collaboration

- Ebola research strengthened health research infrastructure and up-skilled local personnel. But the rapid influx of international researchers worsened power imbalances and undermined existing capacity. Few opportunities arose for local actors to lead studies.

Implications for humanitarian practitioners and policymakers

To build trust, support free and informed consent, and avoid preventable harm to research participants, research teams working in public health emergencies should:

- Ensure all research and care personnel understand and emphasize to potential participants the voluntary nature of research participation, and the distinction between care and research.
- Partner with survivors and community leaders to identify best verbal and non-verbal communication strategies in context to support informed and voluntary research participation decision-making.
- Before in-country research approval, engage with representatives of communities from whom research participants are to be recruited: to clarify potential ethical challenges and mitigation strategies informed by community expertise
- Ensure access to care is neither contingent on research participation or perceived as such.
- Ensure that potential participants isolated in treatment units can easily communicate and consult with loved ones about research participation options and decisions. This can be facilitated by providing clear information in appropriate formats.
- Facilitate open lines of communication after research ends and make efforts to share findings of studies with research participants.
- Policymakers could maintain and build on the research and community engagement expertise built under difficult circumstances by funding research institutions and programs in Ebola-affected countries.

About the study team

The study was co-led by Elysée Nouvet (Western University) & Lisa Schwartz (McMaster University), in with the Guinea's Comité partnership National d'Éthique pour la Recherche en Santé (CNERS), and the Humanitarian Health Ethics research group.

Conducting a research study is not a right: it is a privilege. The consent of participants is essential."

-Yusuf Kabba, Sierra Leone Association of Ebola Survivors (SLAES). SLAES is advising the study team as they develop research communication tools as part of ongoing work. Photo by Yusuf.

Keywords

Public Health Emergencies; Research Ethics; Free and Informed Consent; Ebola Virus Disease; West Africa; Guinea; Liberia; Sierra Leone

Articles and resources available:

- Research report (Survivor perceptions of Ebola research)
- Literature review: ethical challenges of research during the West Africa epidemic
- Two-pager on ethical partnerships in humanitarian healthcare research

Future research:

- Drawing on the expertise and networks developed during this project, work is ongoing to build tools to support research communication for participants in low-resource settings and humanitarian crisis contexts.

For further information please visit:

- https://humanitarianhealthethics.net
- Project page on the Elrha site https://www.elrha.org/project/perceptions-research-conducted-2014-15-ebola-crisis-2/

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