Research in global health emergencies: ethical issues

Considerations for researchers during COVID-19

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Rethinking ethical research in emergencies

- Aim to identify ways in which research can be conducted ethically in emergencies
  - Good quality evidence essential for effective current and future response – but …
  - … emergencies highly non-ideal circumstances in which to conduct research
- Two-year project, supported by international interdisciplinary working group
- Detailed report, policy recommendations, and ‘call for action’ to funders and others to help support ethical research
  - plus materials aimed more directly at researchers and others ‘on the ground, including an e-learning course
Breadth of contributions to our inquiry
Starting points

• Shared characteristics of emergencies (whatever the cause):
  • disruption, great health need, time pressure to act, uncertainty, distress

• ‘Global’ emergencies bring:
  • additional ethical challenges in scope for tensions over control, responsibility, and legitimacy

• ‘Ethics’ not just about ethical review:
  • crucial ‘macro’ ethical questions of power and influence, as well as ‘micro’ questions of trial design, review and recruitment
  • also involves what is owed to researchers
Ethical considerations

Developing an ‘ethical compass’
An ‘ethical compass’ to guide decision-making

- Three core values to guide conduct (at policy level and on the ground)
- No simple answers - recognition that these values can be in tension, but none can simply be overridden
- Recognition of opportunity costs / harms of not doing research
Policy implications across six broad aspects of research

• More inclusive approach to influencing research agenda and priorities
• More inclusive approach to study design and review
• Consent – and the wider ‘ethics ecosystem’
• Equitable collaborations and partnerships
• Respectful and equitable sharing of data and samples
• Better support for front-line workers
Implications for researchers(1)

- Encouraging the involvement of local communities from as early as possible in the research process
  - we recommend that ethics committees, as a minimum, should expect researchers to engage with communities in the development of appropriate communication tools and consent procedures (recommendation 6)

- Avoiding an automatic exclusion of ‘vulnerable groups’ – important to think of risks of both inclusion and exclusion
  - need for clear justification of any exclusion criteria that are set (recommendation 7)
Implications for researchers (2)

• Considering:
  • if proposed consent processes are the best and most sensitive that are possible to achieve in the circumstances;
  • whether other requirements are needed to respect participants as people of equal moral worth and agency; and
  • whether what is being asked of participants can be justified as fair (recommendation 9); and

• Communicating well throughout the full length of the research process (including at the end)
  • Ethics committees should expect to see communication plans across the lifetime of the research when asked to authorise studies (recommendation 10).
Better support for front-line researchers

- Duties of employers and others to protect welfare of front-line research workers
  - including supporting them in dealing with ethical challenges that arise
- Challenge of differential terms of employment between local and international workers
  - equal respect underpins equality of treatment but ‘levelling up’ can bring its own challenges
    - eg international salaries undermining local health economies
  - transparent justification required for any differential treatment
  - in some aspects, no justification for differential treatment—eg re safety and welfare
Role of ‘duty bearers’: our Call for Action

• Funders to work in partnership with govts and others to ensure that participants’ basic health needs being addressed through response effort – minimum requirement for research to be ethical
• Invest in community engagement mechanisms for the long-term
• Promote equitable collaborations – particularly between research partners in low and high income settings
• Support emergency planning – including robust health and research systems
Thank you!

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All materials available online at:
www.nuffieldbioethics.org/publications/research-in-global-health-emergencies

e-learning course:
https://globalhealthtrainingcentre.tghn.org/elearning/