

## OPERATIONAL CHALLENGES IN HUMANITARIAN HEALTH RESEARCH

# ETHICAL CHALLENGES

### EXAMPLES OF CHALLENGES:

- Study community/participant perceptions of research or intervention:
  - community participation, cultural challenges, use of local actors
  - ethical issues related to trust, choice, autonomy, educational levels, consent
  - ethical issues related to feelings, sentiments, attitudes, rumours about research
- Participants are 'over-researched'
- Data collection causes distress to participants or researchers
- Ethical issues related to study methods and debates over different study designs and scientific rigour
- Data accuracy, data ownership, protection and transparency
- Difficulty ensuring interview privacy
- Balance between humanitarian needs and participating in research

### IMPACT OF CHALLENGES ON A STUDY

- Loss of community trust harms ability to collect data
- Ethical breach leads to data being unusable/unpublishable
- Data collection needs to be undertaken again
- Delays in data collection whilst humanitarian response is prioritised
- Not all study team members adhere to study protocol or IRB/ERB requirements

### MITIGATING ACTIONS

- Develop a communication plan to address safe and ethical transfer of data
- Spend time communicating purpose of research to participants/communities
- Plan for restitution of findings with participants/communities
- Work with local actors to help develop community trust and understanding
- Determine referral pathways and/or debriefing for distressed research participants
- Translate research materials into local dialects/languages
- Pilot data collection tools to ensure appropriateness
- Share summary of IRB/ERB requirements with study team/partners
- Coordinate/combine research efforts to reduce community burden
- Consider celebratory events to recognise data collection efforts
- Support data collectors to communicate between themselves (eg WhatsApp group)

The challenges identified in this document are partly drawn from work undertaken by Mathuna, D. et al. *Post Research Ethical Reflection* study: <http://www.preaportal.org/>

For further details of Operational Challenges faced in R2HC-funded humanitarian research studies, please see the full report: [Mitigating Operational Challenges in Humanitarian Health Research: the R2HC Experience \(2020\)](#)