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 disputes 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 (e.g., 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)