Ethics reflection questions as the research is developed

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Community perspectives and concerns,as well as cultural context and norms, should be considered in all categories, not just those explicitly mentioned.

Why?

Why are you doing this research?
What is the question you are trying to address?
What evidence are you seeking?
Why does this research need to be done in a humanitarian crisis and not in a non-crisis context?
How was the local community, including relevant subgroups, consulted to determine their interest in engaging with this research?

How?

What methodology best addresses the question in your research?
What ethical issues does your methodology raise in the context of your research?
How has the feasibility of the proposed research been evaluated for your setting?
Might any part of the research be perceived as coercive by the participants or their community, and how will this be addressed?
What competencies are required by all those involved in different phases of the research?
What partnerships or collaborations are needed for the research?
Have various types of resources been secured for all stages of the research and do any of these raise challenges for the local community?

Benefits

What are the scientific/evidence generation benefits from doing this research?
What are the key benefits that will realistically derive from this research for participants and their community?
Are there any benefits in regards to people's rights or legal protections from this research?
What benefits beyond the physical might arise from this research, such as emotional, psychosocial, spiritual or other benefits?
Are there different benefits for individual participants compared to their communities?
What benefits may arise immediately compared to those potentially arising in the future?
What are the benefits for individuals or organisations conducting this research?
How will the benefits of this research be shared with participants and their communities?

Risks

What are all the risks that participants are likely to be exposed to? Consider the physical, environmental, emotional, psychosocial, spiritual and other holistic risks.
Are anyone's rights being put at risk through this research? How will the views on this issue of participants and their communities be determined?
Are there different risks for individuals or various sub-groups compared to larger communities?
How do issues of vulnerability impact on the potential risks? What sub-groups are particularly vulnerable in the context of this research and what mitigation strategies are in place?
What are the short-term and the long-term risks?
What safeguards, referral mechanisms, security factors, exit strategies and other mitigation factors need to be introduced? e.g. for you, your research team or participants in a deteriorating local situation
What steps have been taken to explore differences in the risks identified by participants compared to researchers?
What are the risks for researchers or organisations conducting this research?
Are there risks attached to sourcing or availability of any required resources?

Balancing benefits against risks

How will the various risks and benefits be balanced against one another?
How have local priorities been considered and do they differ from those of the researchers? How will any differences be reconciled?
How will risks or benefits to one sub-group be balanced against risks or benefits to another sub-group?

Confidentiality, privacy, data protection

How will risks to confidentiality or privacy be identified? By whom?
How will confidentiality and privacy be protected at each stage of the research? Different strategies may be needed at different phases, e.g. during data collection in the midst of acrisis versus later during data analysis.
Will participants be expected to maintain confidentiality towards other participants? How will this be addressed if they can identity one another?
Will any situations arise where confidentiality may be violated? What legal basis might lead to this? How will this be justified and communicated to all involved?
How will data, samples, images, etc. be collected, stored, distributed and protected?
How will the identities of individuals, communities, sub-groups, organisations, regions, etc. be protected?
Could alternative sampling strategies provide better protection of data, privacy or confidentiality?

Informed Consent

How will informed consent be protected?
How will participant information be developed and checked for understanding? e.g. How will translation be undertaken to ensure consent is truly informed?
Will oral, written or presumed procedures be used? Why?
Will individual, group, or proxy strategies be accepted?
How will gatekeepers be involved, if at all?
Will consent be taken once or on a number of occasions, and why is this approach being taken?

What approvals should be obtained?

Research ethics committee?
Own institution or organisation? Regulatory body?
Government agency or Ministry of Health? Local community leaders?
Others?

2

Ethics reflection questions as the research is conducted

Fieldwork

How will unanticipated ethical issues be identified and addressed during the research?
If human rights violations are identified in the research, how will this be addressed? Will researchers be assumed to take the role of advocate or neutral observer?
How will ethical issues arising during participant recruitment or retention be identified and responded to?
How will protocol changes and deviations be determined and approved to mitigate any ethical problems or concerns?
How will ethical concerns and conflicts be managed during the research (for example, within the team or with stakeholders, with the community, over withdrawal of consent or ethical approvals, etc.)?
How will ethical problems within partnerships or collaborations be addressed?

Engagement

How will safety concerns be monitored during the research? How will all stakeholders be engaged with to identify safety concerns?
Who will have responsibility to introduce new safeguards if required?
How will ethical issues regarding exit strategies after the research be monitored and addressed?

3

Ethics reflection questions after the research is completed

Dissemination

How will gratitude be expressed to participants and their community for their contribution to the research?
How will feedback be provided to participants and their community about the research and its findings?
How will feedback be obtained from participants and their community about how the research was conducted and disseminated?
Will all findings be disseminated in open access outlets? If not, why is this justified?
Who are all the people who will have access to data after the research is completed?
How will the research findings lead to change in practice, policy or participants’ lives?
What steps will be taken to ensure the research findings are used to enact change? For example, having researchers act as a voice for participants, or exerting influence with other stakeholders.

Sustainability

How will the research and its findings help build and sustain specific local capacities?
Do all stakeholders and local communities continue to express buy-in to the research and its aims? If not, how will the reasons for this be determined and responded to?
Has funding been arranged so that benefits identified in the research will be continued after the research ends?
How well have the partnerships and collaborations worked together? What ethical strengths and weaknesses exist within these partnerships?

Post-research ethics and project reflection

What is the plan for post-research evaluation of its design, methods and implementation?
What is the plan to evaluate how well ethical issues were identified and addressed during the research, with special attention given to any unanticipated ethical issues that arose?
What is the plan to evaluate the research’s actual impact, short-term and long-term?