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# Research in global health emergencies: ethical issues

# Call for evidence

# Response form and questions

Please complete and return to **ghe@nuffieldbioethics.org** by **17 August 2018**. We will **not** publish your name without your express permission.

**Your details**

Name:

Organisation (if applicable):

Email:

*You do not have to provide an email address, but it would be helpful to be able to contact you should we have any queries about your response. Your email address will not be shared or published in the report.*

**About your response**

**Are you responding personally (on your own behalf) or on behalf of your organisation?**

 Personal Organisation

**May we include your name / your organisation’s name in the list of respondents that will be published in the final report?**

 Yes No, I/we would prefer to be anonymous

**If you have answered ‘yes’, please give your name or your organisation’s name as it should appear in print (this is the name that we will use in the list of respondents in the report):**

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**May we quote your response in the report and make it available on the Council’s website when the report is published?**

 Yes, attributed to myself or my organisation No

 Yes, anonymously\*

*\*If you select this option, please note that your response will be published in full (but excluding this form), and if you wish to be anonymous you should ensure that your name, and any other identifying information, does not appear in the main text of your response. The Nuffield Council on Bioethics cannot take responsibility for anonymising responses in which the individual or organisation is identifiable from the content of their response.*

***Obtaining consent to publish a response does not commit the Council to publishing it. We will also not publish any response where it appears to us that to do so might result in detriment to the Council’s reputation or render it liable to legal proceedings****.*

**Why are you interested in this call for evidence? (Tick as many as apply.)**

 Researcher

 Healthcare professional

 Policy-maker

 Front-line worker

 Funder

 Work for an NGO or charity

 Work for the private sector

 Work for government

 Work for intergovernmental agency

 Academic interest

 Legal / regulatory interest

 General interest

 Other (please state):

We would like to send you a link to the report when it is published and keep you informed about activities related to this project. If you would like us to do so, please tick here:

If you would like to receive our newsletter on all the Council’s activities, please visit our [website](https://nuffieldbioethics.us1.list-manage.com/subscribe?u=8511c645b9d4da10c7b9b3d53&id=2bdce242dc), or tick here:

*We will use your data only to send you the newsletter, project updates, and for our internal reviews of our impact. We will not share your data with any third parties. You may unsubscribe from our newsletter at any time by clicking the unsubscribe link in any newsletter email or by emailing* *bioethics@nuffieldbioethics.org**.*

*For more details of our principles when dealing with personal data, see our Privacy Policy at:* [*http://nuffieldbioethics.org/legal*](http://nuffieldbioethics.org/legal)*.*

## Questions

*Please use these pages to provide your responses to our questions. Feel free to answer as few or as many questions as you wish.*

1. **Please comment on this working definition of a global health emergency.**
2. **What might be the ethical implications of defining global health emergencies in this (or other) ways?**
3. **Please provide examples of how, despite the urgency and pressure of other aspects of immediate humanitarian response, national governments, local researchers, and affected populations have genuinely been ‘at the table’ in setting research priorities in a global health emergency.**
4. **Please comment on what you believe are the essential aspects of community engagement in an emergency, their ethical justification, and how these can they be achieved.**
5. **Are there *any* circumstances in which research might be so important, and time so short, that this could outweigh the need for local voices to be heard?**
6. **In your view, in what ways, if at all, should decisions about study design and acceptable risk be affected by the fact that the research will be taking place in a global health emergency? On what basis would you justify any variation?**
7. **In what ways, if at all, could it be morally justifiable to change the ‘standard’ ethical and regulatory review processes to respond to the time pressures inherent in a global health emergency?**
8. **If any differences in approach to study design or review can be justified because of the features of a global health emergency, would safeguards, such as an independent declaration that ‘emergency’ criteria have been met, be necessary?**
9. **When choosing a study design, is it ever justifiable to prioritise a design that will maximise knowledge and hence scope for benefit for future generations, over a design that maximises the possibility of benefit for people affected by the current emergency; or could this never be justified? On what ethical basis would you justify such a choice?**
10. **Are there any specific kinds of research or innovation that, in your view, raise distinct ethical questions and / or might demand differential ethical treatment?**
11. **Are you aware of any examples of when an emergency seemed to demand a different approach to making decisions about research participation? If so, please explain how any derogation from standard approaches might be ethically justified, and the relevance of the kind of research concerned (for example research involving physical intervention as opposed to research involving data only).**
12. **If we consider the giving of valid consent as one element in the ‘ethical ecosystem’ around research in emergencies, and recognise too that consent is often imperfect, what are the other essential elements of the ecosystem necessary for such decision-making to be considered legitimate?**
13. **Are there any circumstances in which participation in research should not be optional?**
14. **What, in your experience, are the main ethical challenges that arise as a result of uncertainties in the boundaries between treatment, research, evaluation, and public health? To what extent are these associated with logistical or resource constraints?**
15. **Is it possible to create a meaningful distinction between the collection of personal data for public health purposes, and for research purposes? What does this mean for consent and for data-sharing?**
16. **How could a more coherent approach to the complex relationships between research and other essential services in a global health emergency be developed, so that front line workers are supported by ethical guidance that reflects the realities they face?**
17. **In the alternative, do you think that there are ethical justifications for maintaining clear distinctions between the activities of ‘research’, ‘health care’ and ‘public health interventions’ in a global health emergency? If so, what are they?**
18. **Do the exigencies of global health emergencies (for example levels of risk, security requirements, extremity of humanitarian need, rapidity of response) change the obligations on, and expectations of, front-line research staff in any way?**
19. **What constitutes fair treatment of both local and expatriate front-line research staff, and who is responsible for ensuring that they receive such treatment? Can differential treatment ever be justified?**
20. **What mechanisms are there, or should there be, to help ensure that obligations to front-line research staff are honoured?**
21. **What ethical responsibilities do front-line research staff in emergencies themselves hold?**
22. **Can you provide examples of where collaboration has worked well in enabling valuable research to take place in global health emergencies? What were the key success factors?**
23. **Can you give any practical examples of ways in which ethical concerns have impeded successful collaboration in research? What would have helped resolve them?**
24. **Can there be said to be an ethical obligation to work collaboratively rather than competitively in the context of global health emergencies? What might such an obligation entail and what are its limits?**
25. **What are the obligations of funders to promote collaboration in a global health emergency?**
26. **What are the key requirements for good ethical practice in sharing (a) data and (b) samples in a global health emergency?**
27. **Are there any other ethical issues arising in the context of research in global health emergencies that you would like to draw to the working group’s attention?**