NUFFIELD COUNCIL ON BIOETHICS

Research in global health emergencies: ethical issues

Published 28 January 2020

The Nuffield Council on Bioethics has published the findings of an in-depth inquiry on ethical issues relating to research in global health emergencies. The inquiry was run by an international working group which gathered evidence from contributors across the globe.

The report of our inquiry identifies ways that research can be undertaken ethically during emergencies. It presents an ethical compass to guide research conduct at policy level and on the ground, with three guiding values: fairness, equal respect, and helping reduce suffering. A diagram of the ethical compass (overleaf) provides prompts that those involved in the wider research ecosystem should think through.

Several of our recommendations are directed to ethics committees. We suggest that changes in line with these recommendations would align committees' policies and practices more closely with our three guiding values. The recommendations include:

- Encouraging the involvement of local communities and, as a minimum, expecting researchers to engage with those communities in the development of appropriate communication tools and consent procedures (recommendation 6);
- Avoiding an automatic exclusion of 'vulnerable groups' such as children or pregnant women, and requiring the clear justification of any exclusion criteria that are set (recommendation 7);
- 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
- Looking for communication plans across the lifetime of the research when asked to authorise studies (recommendation 10).

The full list of our recommendations is published in the long report and executive summary, both available at www.nuffieldbioethics.org. We have summarised these in the following call for action to research funders, governments, and others.

A call for action

We want to maximise the contribution that scientifically robust, ethical research can make to improving the health of people affected by emergencies.

We are issuing a call for action to research funders, governments, and others to:

[a] Ensure that research is not supported unless the basic health needs of research participants are being addressed through the response effort. Research funders will need to work in partnerships with humanitarian organisations and health ministries to ensure this.

[a] Invest in putting community engagement mechanisms into emergency research to make them a reality. In the longer term, engagement must be a central part of local healthcare systems to ensure sustainability and preparedness.

[a] Promote fair and equitable collaborations between research organisations, particularly between external research institutions and their local partners in high- and low-income settings.

[a] Support emergency planning – including securing robust health and health research systems – given the vital importance of properly resourced preparedness between emergencies.

Considering…

Whose needs are being met by this research?

Who has defined these needs?

Are these the most important needs?

Thinking about how best to…

Distribute the benefits/burdens of research equitably.

Make the entire process inclusive and transparent.

Make collaborations between researchers fair for all.

HELPING REDUCE SUFFERING

FAIRNESS

EQUAL RESPECT

Demonstrating respect for others as moral equals…

How will communities be involved in planning the research?
How will the research design be sensitive to local values?
What can be done to ensure participants are treated respectfully
throughout the research lifecycle,
including feedback on study findings?