OVERVIEW OF REPORT

Research in global health emergencies: ethical issues

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

Better evidence about what helps or doesn’t help during an emergency is needed in order to improve the response to global health emergencies. Research conducted during an emergency itself plays a crucial role in obtaining this evidence, and helps support the immediate response, as well as learning for the future.

The aim of this report is to identify ways in which research can be undertaken ethically during emergencies, in order to promote the contribution that ethically-conducted research can make to improving current and future emergency preparedness and response.

We have devised 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) includes a number of prompts that all those involved in the wider research ecosystem should think through.

We have made a number of recommendations to ‘duty bearers’ such as research funders, research organisations, governments, and researchers. We suggest changes that would align their policies and practices more closely to the values of fairness, equal respect, and helping reducing suffering, as set out in the ethical compass.

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:

• 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.

• 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.

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

• 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?