



**Research in global health emergencies: ethical issues short report**

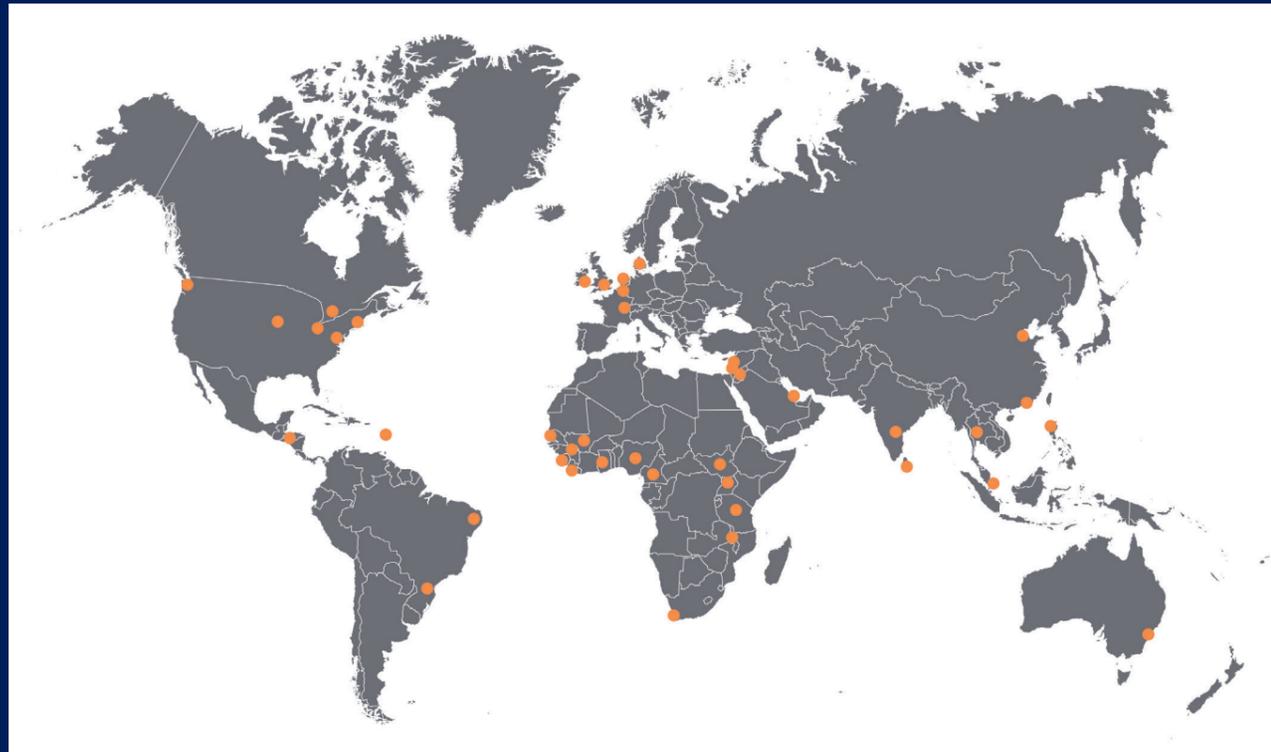
**NUFFIELD COUNCIL ON BIOETHICS**



This document outlines the main themes, findings, and recommendations from the Nuffield Council on Bioethics' report *Research in global health emergencies: ethical issues* (published January 2020).

The report follows a two-year in-depth inquiry run by an international working group, who benefited from the evidence and experience shared by many contributors across the globe (see map below for locations of contributors). Contributions were made through responses to an open call for evidence, participation in roundtable and one-to-one meetings, critique of early drafts of the report, and involvement in international workshops and events.

#### CONTRIBUTIONS TO OUR INQUIRY INTO RESEARCH IN GLOBAL HEALTH EMERGENCIES



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# Why is this report needed?

See introduction and Chapter 1 of the full report

Global health emergencies are health emergencies that are of concern to more than one country. They can have many causes, including (singly or in combination):

- epidemics of infectious diseases such as Ebola, measles, Zika virus, or Lassa fever;
- natural disasters such as earthquakes, tsunamis, floods, or hurricanes;
- human-made disasters, such as large-scale industrial accidents, conflict, and mass displacements of people.

Research conducted during global health emergencies raises particularly complex ethical challenges.

## Why is research needed in global health emergencies?

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

Global health emergencies by their nature are challenging environments in which to conduct research. They involve disruption and great health need, among multiple urgent needs, and may often be accompanied by time pressure to act, competing lines of accountability, uncertainty, and distress. All these factors add to the risks that research, however well intentioned, could cause direct harms or inadvertently add to existing injustice and exploitation. However, there are also risks in *not* conducting research – for example the risks of providing inadequate, ineffective, or even harmful care.

This report aims 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.

## DIFFERENT KINDS OF RESEARCH CAN HELP TO:

- improve understanding of the concerns of people affected by the emergency, and of how emergency responders can best prioritise needs;
- make diagnoses quicker and easier, so help can be given faster;
- develop new vaccines and treatments for diseases that cannot currently be treated, or where treatment options can be significantly improved;
- adapt existing ways of caring for people, so that the services provided are appropriate and sensitive to their needs; and
- find the best ways of providing health services in very challenging situations.

Humanitarian organisations and others may also gather data from populations affected by emergencies in order to audit or evaluate the services that they provide. This is not usually treated formally as ‘research’, but raises many of the same ethical issues.

## A NOTE ON TERMINOLOGY

This report uses the term ‘global health emergencies’ to refer to emergencies that cannot be managed effectively without help from outside the country – for example support from the World Health Organization and other United Nations bodies, from humanitarian organisations, from overseas donors, or from research teams in other countries.

Responding to a ‘global health emergency’ involves cooperation between many different organisations. There will inevitably be tensions as a result of differences in approach, and scope for disagreement over control, responsibility, and legitimacy.

Depending on the cause of the emergency, the terms ‘humanitarian crisis’ or ‘complex disaster’ are also often used, and this report does not seek to distinguish between these terms.

Ethical challenges in global health emergencies include:

- Questions of **power and influence**: how are the voices of those who are most affected by emergencies meaningfully included in deciding what research takes place, where, and how?
- Questions of **appropriate study design** and **flexible review** that are sensitive to the difficult contexts in which research is taking place.
- Achieving **meaningful consent processes** within a wider ethical system of governance, to ensure people’s interests are respected.
- The need for greater **fairness in collaborations** between researchers and research institutions in different countries.
- Consideration of when and how **data and biological samples** provided during an emergency may ethically be used by other researchers.
- How **front-line research workers can be better supported** in addressing the ethical dilemmas they face.

Ethics is not just about the behaviour of people directly involved in the research. The decisions taken at policy level – by funders, regulators, research institutions, journals, and others – are very influential in shaping and limiting the possibilities for ethical research conducted on the ground. Our recommendations are aimed at those organisations whose policies and actions could bring about real change.

## What are the ethical challenges?

‘Research ethics’ is often thought to refer only to the process of independent ethical review that all research involving human participants should receive. We make the case for a much broader approach to research ethics.



# Emergency preparedness, response, and research

See Chapters 2 and 3 of the full report

## Key people and organisations

### The role of communities

The leading role in emergency response, particularly in natural disasters, is often taken by affected communities themselves. This has important consequences for the ethical conduct of any research associated with that response – for example in terms of how external parties such as overseas research teams are accountable to those communities.

**“After the tsunami struck on 26 December 2004, a call went out in the Maldives – “Whoever can help, please come.” Each volunteer was given an age-appropriate task. Many adults stayed away. Many young people came forward. When a psychosocial counsellor was sent to concentrate on possible problems with young people, she couldn’t find anyone. “They were all working,” she said.”**

UNICEF (2007) *The participation of children and young people in emergencies*

The response to infectious disease outbreaks tends to be more institution-led and dominated by external responders. However, the central role played by local community health services is increasingly recognised. Some researchers are calling for international responders to relinquish control, and trust community responders to take the lead.

### The experiences of research participants

Understanding the experiences of those who have taken part in research during emergencies is essential in order to appreciate where misunderstandings or risks of exploitation might arise. The reason why people take part in health-related research is often the hope of getting better, while some also want to help others. The invitation to take part in research may in practice be an ‘empty choice’ with few if any apparent alternatives. Trust in the system, or in the person seeking consent, is very important in people’s decisions.

In humanitarian crises, it can be very difficult for participants to separate out research and response activities, especially when these are associated with healthcare. It may be unrealistic to expect people to trust in the good intentions of researchers if their basic needs are not being met.

### Successful collaborative research

**“Key success factors were / are: strong leadership, effective communications & logistics planning, team of African consultants who knew the terrain and cultures/customs, strong community engagement, building and harnessing the survivor network, including a humanitarian approach in addition to clinical research by partnering with World Food Program and other governmental and non-profit organizations.”**

Respondent to our call for evidence

## PATIENT AND SURVIVOR-LED ACTION IN SIERRA LEONE DURING THE 2014-16 EBOLA OUTBREAK

During our inquiry we heard about these examples of survivor-led actions:

- Organising improvised theatre and talent competitions in Ebola Treatment Units (ETUs) to help maintain hope among patients (described as “these talented friends”).

- Coaxing fellow patients in ETUs to eat, to improve their chance of recovery.
- Once recovered, volunteering as staff members in ETUs and acting as community mobilisers.
- Acting as advocates for the needs of other survivors.

We recommend:

- People should not be asked to take part in health research when their basic health needs are not being met.
- Research funders should require research teams to include clear partnership plans with relevant service-providers, such as humanitarian organisations and national health departments, when seeking funding for research during emergencies.

- the tension between doing research and the immediate emergency response, especially in the face of great need.

## Role of technology and surveillance in supporting preparedness

Technological developments play a valuable role in helping to provide information to guide the actions and decisions of all those involved in emergency preparedness, response, and research. These include:

- developing early-warning tools and monitoring systems;
- creating predictive models to help guide the way health services are provided; and
- developing and improving ‘near-patient’ diagnostic tests.

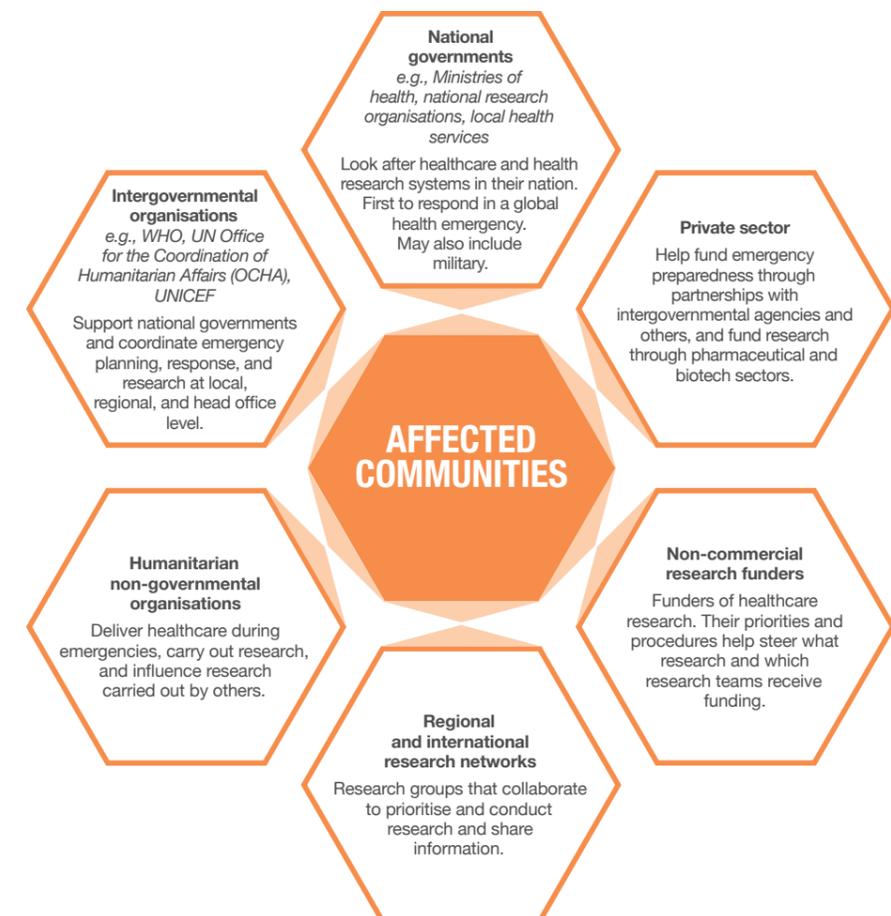
These technologies complement the important role of local communities and health services in being alert to the early signs of emergencies, and initiating local action plans.

### Researcher experiences

Researchers in global health emergencies work in complex, rapidly changing, and often uncoordinated environments. Challenges include:

- the many organisations and lines of accountability involved;
- the rapid turnover of workers and their different motivations;
- the inherent dangers of the emergency setting; and

## KEY STAKEHOLDERS IN RESEARCH IN GLOBAL HEALTH EMERGENCIES



# Developing an ethical compass

See Chapter 4 of the full report

Research in global health emergencies presents difficult ethical challenges for a number of reasons – for example:

- because decisions made at policy level can make it difficult to act ethically on the ground;
- because of uncertainty about how and whether ‘standard’ ethical frameworks still apply in these uniquely challenging circumstances; and
- because practitioners from different disciplines are guided by different (and at times competing) ethical frameworks.

## QUESTIONS RAISED BY CONFLICTING OBLIGATIONS AND GUIDELINES

- How should studies of new treatments balance the interests of individuals (who may want the chance to access experimental forms of care straight away) and the wider interests of communities (who may benefit more in the long term from rapid and decisive research results about effectiveness)?
- Should individuals be given a choice of opting out of research that is concerned with public good, such as using routine patient data to improve health systems?
- How do research organisations negotiate the interests of their workers, and those of research participants, for example, in health and safety requirements in inherently dangerous situations?
- How do researchers manage conflicting lines of accountability – e.g., to the communities they are working with, national governments, their funders and employers, and their own professional standards?

There is no simple answer to any of these questions. We propose an **‘ethical compass’** of three widely shared values, to help guide policy approaches, and provide a common language for thinking through ethical dilemmas arising on the ground. The ethical compass was developed in the light of the experiences and evidence shared by those who contributed to our inquiry.

## Using the compass

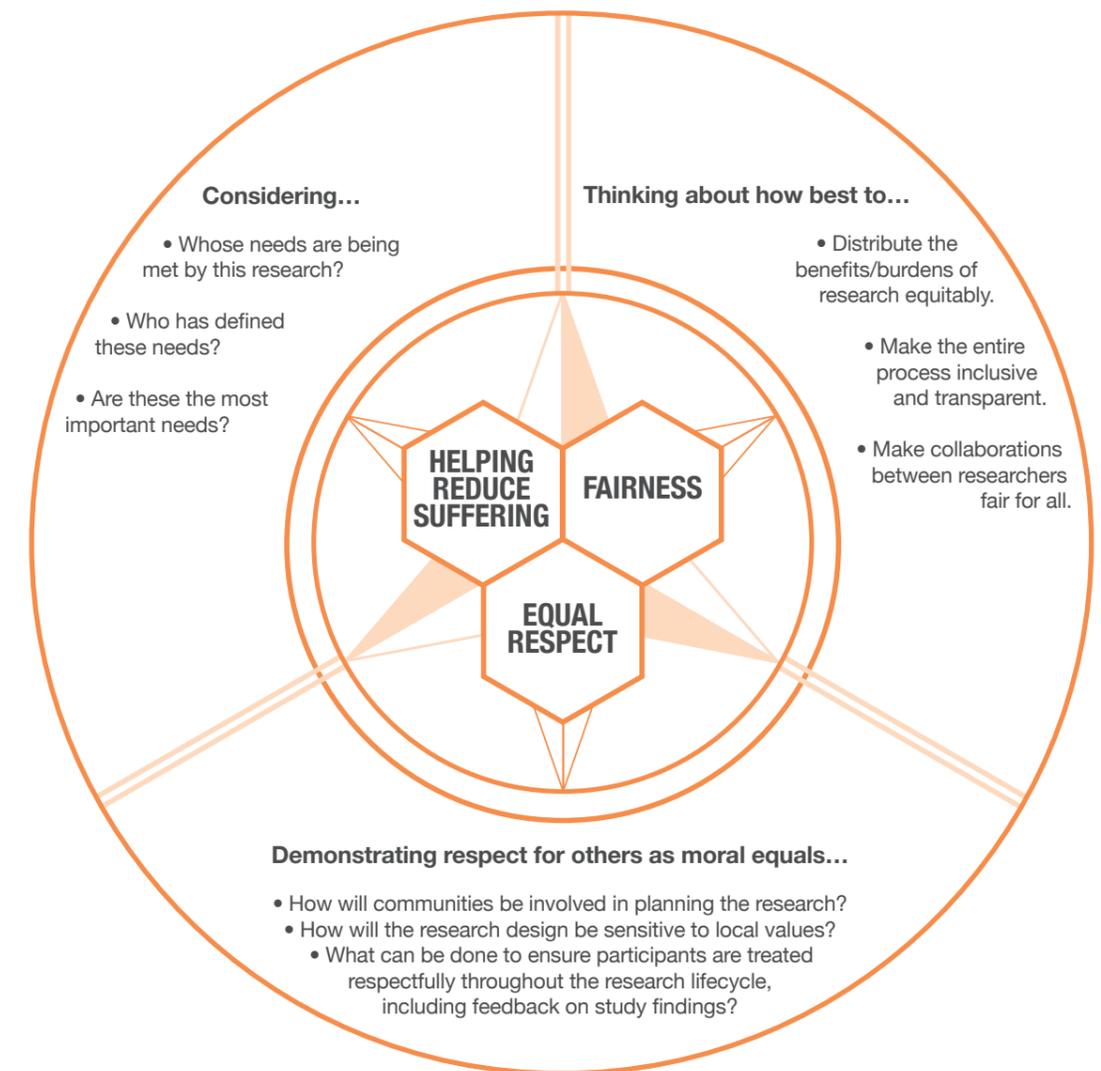
In many cases the three values of equal respect, fairness, and helping reduce suffering will point in the same direction, leading to a clear course of action. Where this is not the case, a decision about whether to proceed with research will need a careful, inclusive, and transparent decision-making process, and independent review. The question *‘What best helps reduce suffering?’* will always be important. However, considerations of what is fair, and what shows equal respect, must also influence the way research is conducted.

The three values provide a tool for thinking through whether it is acceptable to adapt standard ethical principles in any way. Possible approaches include:

- **Interpreting principles in the light of the features of the emergency** – for example aiming to develop community engagement processes as the research develops, when the situation is too urgent to build up processes before the start;
- **Recognising additional principles from partners’ ethical traditions** or in response to local needs – for example including a tier of community consent to research, as well as individual consent, and taking account of local traditions; and
- **Taking action to strengthen other parts of the ethics ‘ecosystem’** in cases where standard principles alone cannot provide the degree of protection required – for example, thinking about how participants’ interests can be protected in circumstances where people might feel they have no choice but to consent to research participation.

These decisions will need to be taken on a case-by-case basis depending on the features of each emergency, but should always be guided by consideration of the three values.

## AN ETHICAL COMPASS TO GUIDE DECISION-MAKING



## Who has a duty to take action?

People and organisations may have an ethical duty to take action:

- if they have the **greatest ability** to act;
- if their **relationship with others** (for example as an employer) gives them special responsibilities; or
- if their actions or failings mean that they have a **degree of culpability** for the effects of the emergency (for example through negligent failure to prevent it or mitigate the effects).

‘Duty-bearers’ include governments, intergovernmental organisations, humanitarian organisations, research funders, employers of researchers, and journals. The three values of fairness, equal respect, and helping reduce suffering should underpin the approach that these duty-bearers take at policy level, so that they are able to support ethical research during emergencies. Many of these duty-bearers also have duties to plan for the future, to minimise or prevent the impact of future emergencies through strengthening health and health research systems.

# Whose voices should be heard? – An inclusive approach to influencing research

See Chapter 5 of the full report

Those planning to undertake research in an emergency need to engage seriously and respectfully with those whose interests are fundamentally affected by the emergency. These include:

- national governments and research institutions;
- local health services, voluntary organisations, and research institutions in the affected area; and
- members of affected communities.

Communities themselves are complex and diverse. It is essential for researchers to identify those with informal influence within the many different subgroups that make up a community, as well as those with more formal leadership roles.

## FINDING WHO CAN SPEAK FOR, OR FACILITATE ACCESS TO, DIFFERENT PARTS OF A COMMUNITY

Examples frequently cited in responses to our inquiry include:

- women’s associations;
- youth groups;
- church communities;
- traditional healers and birth attendants; and
- associations associated with people’s jobs, such as market traders or bicycle couriers / chauffeurs.

## Influencing decisions about prioritisation and funding

Action is needed first to create a more collaborative approach between funders, and then to ensure that a wider range of voices is heard in determining the kind of research that should get funded.

*We recommend:*

- *Research funders, relevant governments, national research institutions, and UN bodies should collaborate at the start of an emergency, to agree research priorities.*
- *Funders should encourage and incentivise researchers to include affected communities directly in grant applications – for example through small flexible grants for rapid scoping work.*

## Influencing how research is conducted on the ground

The development of trustworthy relationships is at the heart of meaningful and respectful engagement between researchers and diverse parts of affected communities. At its best, engagement takes the form of ongoing dialogue between community members and researchers throughout the research process, contributing to the design of the study, the way it is carried out, and the way the results are used.

- Developing community engagement networks in advance to foster such relationships is an important part of emergency preparedness – for example as part of regional research initiatives or community health structures. National governments should make systems of engagement a normal part of local health systems to ensure sustainability.
- In the absence of such preparedness, during an emergency, a pragmatic approach would include scope for learning and adapting in response to feedback as the research progresses. The values of equal respect and fairness, alongside the importance of helping reduce suffering through the research, should help guide consideration as to how much ‘adaptation’ of ideal processes is acceptable.

*We recommend that research funders should require inclusive community engagement plans in funding proposals, and ensure they are properly funded.*

# An inclusive approach to study design and review

See Chapter 6 of the full report

The time pressures, disruption from normal life, and distress associated with global health emergencies can create challenges for both the design of research studies, and the procedures used to review them. It is important that researchers are alert to the heightened vulnerability of those affected by the emergency, and respond flexibly to the particular emergency context. The ethical compass provides a guide when considering how and when standard procedures might need to be adapted.

## Study design

It is unethical to ask people to take part in research that is unlikely to produce useful results, and hence will not help reduce suffering. This highlights the importance of scientific rigour. It also emphasises the importance of study designs that are locally acceptable. Designs that cannot recruit sufficient participants, for example because of unaddressed local concerns, will not be feasible. Key questions to ask are:

- **Is this the right study** for this location and this population / subpopulation? Who has been involved in identifying the problem that the research seeks to answer? Will local populations benefit from any positive findings?
- **Is this the right design** for this location and this population? How have local needs, concerns, or preferences been taken into account?

*We recommend:*

- *Study protocols should be developed with the input of local communities, in order to ensure that proposed procedures are acceptable. Even in multisite trials, there will be elements that can, and should, be implemented differently in each site in response to engagement and feedback, without prejudice to study rigour.*
- *Any exclusion criteria from studies should be clearly justified with reference to the risks and benefits for the group in question. There should not be an automatic exclusion of ‘vulnerable groups’ such as children, pregnant women, or older people. In practice, exclusion may make those groups more vulnerable.*

## Independent ethical review

Independent ethical review (both in the country affected and, where relevant, in other countries) provides an important safeguard for research participants, and provides reassurance to everyone concerned that proper scrutiny has taken place. In an emergency, the *standard* of review should not be compromised in any way. However, the review *processes* can, and should, be adapted as necessary to the context. Examples include fast-tracking genuinely urgent applications, and using flexible means to communicate with researchers, and discuss the proposal. Access to local expertise from affected populations to understand the possible risks of the research, and also the wider risks to which people are exposed through the emergency, is essential.

Support for strengthening ethical review structures in areas that are currently underserved is an important part of emergency preparedness. It is also essential to recognise that independent ethical review is only one part of the ‘ethics ecosystem’ and does not absolve researchers from their own ethical responsibilities. Evidence-gathering activities such as assessing needs and evaluating humanitarian response can also have ethical implications, even though they are not formally classed as ‘research’.

*We recommend:*

- *the development of collaborative systems, at national and international level (for example within WHO regions), to support rapid and responsive review in emergencies, including access to additional ethical expertise where needed; and*
- *the inclusion of an explicit step of ethical consideration in plans for needs assessment or evaluation that raise similar ethical concerns to more formal research projects.*

# Consent and beyond – the wider ethics ecosystem

See Chapter 7 of the full report

Even in non-emergency situations, there are well-recognised difficulties in seeking genuinely informed and voluntary consent to research – for example in providing clear explanations of a complex study, and making sure people feel genuinely free to refuse. In global health emergencies, factors such as disruption, family separation, lack of access to basic resources and services, and the fear, distress, and powerlessness associated with these experiences, add to these challenges. High levels of uncertainty and heightened risks for participants, both related and unrelated to the research, complicate things further. Sometimes people may feel that agreeing to take part in research is their only option.

Culturally appropriate and respectful consent processes that demonstrate equal respect for participants are as important in emergencies as in any other context. There are many existing examples of imaginative ways to present complex information, check understanding, and avoid stigma.

## EXAMPLES OF GOOD CONSENT PRACTICE

- Asking participants to paraphrase what they understand
- Using verbal consent procedures where written consent procedures create a risk of stigma
- Using traditional games to explain randomisation
- Using participatory drama to share information

However, **consent alone is never the only requirement for research to be ethically acceptable. Good consent practices are one part of the wider ‘ethics ecosystem’ that supports ethical research conduct.** This ecosystem includes the responsibilities of researchers and ethics committees to be confident that they have carefully scrutinised benefits and risks, justified those risks, and considered wider questions of social justice and social value. It also includes demonstrating equal respect for communities and community members by developing collaborative and inclusive processes across the lifetime of the research (as described on pages 8-9).

There are also recognised exceptions outside the emergency context where individual consent is impossible, for example if a person is unconscious. In some such cases, ethics committees may approve research with high social value on the basis of other protections that promote respect for participants – for example with prior community consultation about the research, and then permission from relatives. Any proposed waivers of consent in a global health emergency must be particularly closely scrutinised regarding the question of how equal respect for participants is to be secured.

*We recommend that in emergencies ethics committees should consider:*

- *whether the proposed consent processes are the most appropriate and sensitive that they can be in the circumstances;*
- *what other actions might be needed to ensure the research shows respect for participants as people of equal moral worth; and*
- *whether, in all the circumstances, what is being asked of participants can be justified as fair.*

Once research has been concluded, providing information in accessible ways about what the research has found is an important part of respectful relationships between research teams and participants.

*We recommend that funders should routinely require feedback to participants and wider communities about what a study has learned, with ringfenced funding for this purpose.*



# Collaborations and partnerships

See Chapter 8 of the full report

## Cooperation between research and response

Effective cooperation with the many other organisations operating on the ground is essential to ensure that research is well aligned with the emergency response needs. From the very beginning, research funders should promote close working relationships between researchers and those directly responsible for emergency response, at strategic level and on the ground.

- **When planning research in a global health emergency, researchers and funders need to be confident that adequate response services will be in place before prospective participants are approached.**
- **Research plans must include contingency arrangements, recognising that partners may not always be in a position to deliver agreed services (whether for financial or other reasons).**

## Collaborations within the research sector

**Is there an ethical obligation to work collaboratively?**

**“Hell yes. It is limited by the practical constraints of the current system and their potential impact on researchers’ livelihoods so should not be underplayed, but a grown-up system should aspire to address these issues. If grant awarding bodies were to strongly support collaboration and if academic institutions were to accept contribution as sign of output rather than just money won and papers authored then the rest should follow.”**

Respondent to our call for evidence

Good research relies on bringing together partners with different kinds of expertise, working together collaboratively to ensure that methods and approaches are coherent across the partnership. Meaningful research collaborations involve shared aims, and opportunities for all parties involved to shape the research and influence objectives and outcomes.

The importance of fair collaborations is underpinned by the ethical imperative to treat others, colleagues as well as research participants, with equal respect.

Promoting fairness in collaborations between research partners – particularly between external research institutions and their local partners in high- and low-income settings – is important both during an emergency, and over the longer-term.

*We recommend that during an emergency:*

- *Research institutions need to take active steps to ensure that their relationships with researchers from other institutions are as fair as possible in the circumstances. This includes establishing collaboration agreements early; making sure people are fairly credited for their work; and making sure partners working in low-income settings have access to essential resources such as libraries and training.*
- *Funders should take active steps to connect potential collaborators, and to encourage fair arrangements within collaborations.*

*We recommend that over the long-term:*

- *Funders should support long-term fair collaborations as an essential part of research capacity development and strengthening. They should also prioritise sustainable funding models that support institutions in low and middle income countries to apply for grants directly.*
- *National governments need to strengthen their academic capacity, including in social science and bioethics, to support the development of local expertise.*

## Data and samples

See Chapter 9 of the full report

The sharing of data and samples are often discussed together – and some of the issues raised may be the same. However the management and use of biological samples raise distinctive issues from those related to data alone – particularly because samples are a depletable resource, which raises questions of prioritisation of access. Regulatory approaches may differ substantially.

Sharing data and samples between research groups, or for further research purposes, can help maximise the benefits of research and in doing so, help reduce suffering. However, it may also raise concerns about possible harms and exploitation. The systems used for sharing data and samples need to be fair and trustworthy.

### The role of individuals and communities regarding future use of data and samples

We identify a number of conditions that would help promote equitable and responsible sharing – in particular the development of local systems of governance that people can trust. These include:

- developing locally and culturally appropriate approaches to consent for future uses;
- establishing ‘access committees’ to decide what kinds of research can be done, and which researchers should have priority (this is particularly important for samples); and
- regular feedback and information for local communities about the research being done.

Action is needed over the longer term to develop such systems. Researchers also need support on what to do in the short term before these systems are fully developed.

#### We recommend:

- *Funders and leading research institutions should prioritise further research with stakeholders in order to understand people’s concerns about the sharing of data and of samples for research use. Such research would provide a sound basis for the development of national or regional guidance, compatible with relevant national laws, to give a clear steer to researchers. National governments and intergovernmental agencies should support such initiatives as an essential part of emergency planning.*
- *When emergencies arise where there are no such systems in place, National Research Ethics Committees should take a leading role in deciding whether data and samples can be stored for possible future sharing; and how to involve communities appropriately in these decisions.*

- *Any future use of samples collected in past emergencies that are held without clear records of consent should be based on discussions with key stakeholders such as national governments, research leaders, and community representatives or survivors’ groups.*
- *In any future international collaborative research in emergencies, the existence and nature of sample collections should routinely be registered in a publicly accessible database.*

The African Academy of Sciences launched a project in 2019 to develop the continent’s first cross-disciplinary guidelines for collecting, storing, and sharing data and samples.

### Exploring professional and institutional barriers to sharing

**Equitable sharing** requires systems that give researchers in low-income environments the same opportunities as those in high-income environments to benefit from the data and samples that they have acquired themselves, and also from open sharing arrangements.

**Responsible sharing** includes ensuring that data and samples, once shared, are used to optimum effect to help reduce suffering.

#### We recommend:

- *Journals should explore innovative ways of crediting significant input into research short of direct involvement in writing; and should consider publication policies that promote the inclusion of primary researchers in later re-analysis of their data.*
- *Funders should take a more active role in supporting the effective use of data and samples shared in repositories – for example finding ways to incentivise secondary analysis in response to identified needs.*
- *Funders should also find ways to require, and support, their grantees to share their research findings in accessible and timely ways with key policy stakeholders – not just through academic articles.*

## Ethical issues faced by front-line workers

See Chapter 10 of the full report

People working on the front-line of research in global health emergencies can face particularly challenging, often dangerous, working conditions. There is an increasing awareness of the need to support front-line workers better in dealing with ethical challenges that emerge during their involvement with a study.

### Welfare and fair treatment of front-line workers

The role of front-line workers may be inherently risky, and there can be a tension between respect for the welfare of research workers, and effective conduct of the planned research. **Funders, employers, and research ethics committees all have a duty to consider the welfare of workers, alongside the welfare of participants and the value of the research, and to ensure action is taken to mitigate foreseeable risks.** Local knowledge will be crucial in recognising such risks, and in identifying how to prevent or mitigate them.

Differential terms of employment between local and international workers, or between different staff groups (such as those with or without professional qualifications), can be exploitative. They are a source of concern to many in the field, and may undermine scope for respectful collaboration. While the value of ‘equal respect’ underpins equality of treatment, how this is realised in practice is not straightforward. In lower-income settings it can create other sources of inequality – for example, paying all workers international rates could seriously undermine local health systems and economies.

*We recommend that employers should be completely transparent about the basis for any differential treatment of local and international workers, and have an inclusive approach, involving domestic ministries of health for example, in determining relevant terms and conditions. For some aspects of employment, such as responsibility for personal security, it is hard to see how any differential treatment could be justified.*

### Ethical support for front-line workers

While careful review processes and collaborative work with local communities to understand local needs and sensitivities can play a part in reducing ethical dilemmas facing front-line workers, such dilemmas are still an inevitable part of working in an emergency.

#### We recommend:

- *People working on the front-line (who are often the least well-supported) need to have access to timely, high quality ethics support in a variety of forms.*
- *There is also a need for a flexible platform to provide timely ethics advice and support for those involved in all aspects of research in emergencies, including those funding, planning, and carrying out research. We welcome the launch by WHO of the Public Health Emergency Ethics Preparedness and Response (PHEEPR) Network.*

### EXAMPLE FROM LEBANON OF ETHICAL SUPPORT FOR WORKERS

Support for workers involved in mental health studies with Syrian refugee children included:

- providing training for workers on ethical research practices;
- creating space to raise ethical issues, including through regular debriefs and clinical supervision;
- establishing clear lines of responsibility for making difficult decisions on the ground;
- adapting study designs in consultation with local experts and Syrian refugees, thereby reducing risks of insensitive design; and
- prioritising worker safety over data collection.

#### Credit:

Queen Mary University of London  
IDRAAC / St George Hospital University Medical Center  
Médecins du Monde (France)  
American University of Beirut

**This short report and the full report are available on the Council's website:**  
[www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)

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