



# Research in global health emergencies: ethical issues

A Working Group

Michael Parker  
Katharine Wright

NUFFIELD  
COUNCIL ON  
BIOETHICS

## How have we got to this point?

- Established an expert **working group** – wide range of experience (including geographical reach)
- Open **call for evidence**
- **Evidence-gathering** of various forms, including:
  - review of literature
  - roundtable meetings
  - international workshops (Dakar, Beirut, Beijing)
- Approaching an **external review** process
- Aim to publish **December 2019**

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Aim – publish our findings, analysis and recommendations as a report



## Scope of project (1)

### What counts as 'global health emergency'?

- Triggered by 2014-2016 Ebola outbreak – highlighting tension between value of research but real unease about what is ethically acceptable
- Broadened out to include other forms of disaster/humanitarian crisis
- Not seeking firm 'definition' but rather looking at common factors: disruption, pressure of time, extent of impact on affected populations, uncertainty...
- 'Global' in sense of need for solidarity-based support from outside the country – *not* perceived threat to other countries

## Scope of project (2)

- **What counts as ‘research’?**
  - Difficulty in creating clean boundaries with public health surveillance, with evaluation, and in ‘hybrid’ activities
    - Thinking about ‘evidence creation’?
- **What counts as ‘ethical’?**
  - Not just about ethical review...!
  - Thinking about ‘macro’ ethical questions, in particular about power and influence as well as the micro questions
  - Also concerns what is owed to researchers

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Sketching out an ethical approach (1)

**Three aims:**

- **To help find a common language**
  - Recognising the diversity of disciplines & professions involved, and the different ethical traditions and codes to which they may be working
- **To use this common language to help explore what is ‘ethically at stake’ in standard research principles and processes**
  - What if it’s not possible, or potentially harmful, to follow standard principles and processes?
  - On what basis can we justify variation?
- **To underpin concrete recommendations**
  - Ethical force to practical suggestions for change

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Sketching out an ethical approach (2)

- Based on **three values**:
  - **Respect** (equal or mutual)
  - **Alleviating suffering**
  - **Fairness** (distributive justice)
- Emerged from the evidence and from the working group's discussions
- Very familiar!

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Sketching out an ethical approach (3)

- Identifying **duty-bearers**:
  - Funders, governments, journals...
- Thinking about different ways in which such duties might be grounded:
  - '**Capacity**' – response based on ability to help achieve change
  - **Social role/responsibility** arising through relationships (eg employers)

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Emerging themes (1)

### Community / stakeholder engagement

- Issue of **power** and **influence** absolutely central to consideration of what is 'ethical'
- **Engagement** with affected communities essential – not a 'nice to have' (recognition of agency of those directly affected)
- Recognition that this is hard – particularly because of diversity and inequities within communities
- Some very practical recommendations to be made on how to facilitate and embed engagement

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Emerging themes (2)

### Study design, review, and recruitment

- Not about taking shortcuts or lack of rigour – but about looking at what is appropriate for the context (even '**heightened**' ethics)
- Important links with **community engagement**
  - is this the right study for this location / population?
  - Is this the right design for this location / population?
- '**Beyond consent**'? – recognising that consent for any intervention is essential, but may not be enough.
  - Role of the rest of the 'ethical ecosystem'

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Emerging themes (3)

### Role of front-line staff

- Hierarchies and disparities in treatment of staff members – raises very strong feelings, and suggests real underlying problems with many international partnerships
- How to support front-line staff better in dealing with ethical challenges – recognition that ethical review doesn't answer all issues.



NUFFIELD  
COUNCIL ON  
BIOETHICS

## Emerging themes (4)

### Fair collaborations

- **More equitable approaches now**
  - Influence on the research agenda (genuine 'partners' or using others as data collectors / translators? – moving away from parachute research)
  - Recognition – eg through publication
  - Role of research institutions, funders, journals...
- **Capacity strengthening for the future**
  - Role of funders, governments and others
  - Social science capacity strengthening emerged as a particular need
  - Institutional as well as individual

NUFFIELD  
COUNCIL ON  
BIOETHICS

## Emerging themes (5)

### Data and sample 'sharing'

What needs to be in place to enable data and samples to be shared equitably and responsibly?

- From perspective of sources of data and samples (community engagement / involvement, governance arrangements that secure local trust)
- From perspective of those using and sharing – is there prospect of mutual benefit or is it all one-way?  
Development of local capacity and labs?



NUFFIELD  
COUNCIL ON  
BIOETHICS

## Cutting across everything

- The ethical imperative of **preparedness**
  - Some things will always be difficult in emergencies – others can be planned and prepared for (with political will)
    - resilient health systems
    - capacity strengthening in research – rooted in local infrastructure and with community involvement
    - but also in terms of foreseeing ethical challenges – and planning how to support those having to deal with difficult ethical decisions on the ground

NUFFIELD  
COUNCIL ON  
BIOETHICS