Introducing the Nuffield Council on Bioethics

– contributing to the debate on the ethical conduct of research in global health emergencies

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Who are we?

• UK-based independent body, established in 1991
  – not government sponsored (not a ‘National Ethics Commission’ as such)
  – appoint our own members, set our own agenda – influence depends on quality

• Remit
  – to explore ethical issues raised by developments in biology and medicine
  – engage with relevant stakeholders
  – make policy recommendations
How do we work?

Details will vary from project to project but will include:

– Establishing an expert working group – wide range of experience (including geographical reach where appropriate)

– Open consultative/deliberative activities

– Evidence-gathering of various forms, including review of literature and meetings with experts

– External review process
Publication of findings, analysis and recommendations: as a report
... and in many other forms

- Booklets, magazines
- One-page for MPs
- Animation, films
- Teaching resources
Research in global health emergencies: ethical issues

• Triggered by experiences of Ebola outbreak 2014-16:
  – Essential to improve evidence base
  – But real unease and uncertainty about what was ethically acceptable in such non-ideal circumstances

• Similar challenges in other types of health-related emergency / crisis
Progress to date

- Exploratory workshop Dec 2016
- Established international working group
  - six meetings so far
- Issued ‘call for evidence’ (nuffieldbioethics.org)
  - around 50 detailed responses with wide geographical reach
- Held series of roundtable meetings
  - frontline responders; funders; data and samples
  - Beirut, Dakar
- Final report – end of the year
Questions of scope

• What counts as a ‘global health emergency’?
  – Broad approach; ‘global’ in sense of need for solidarity-based support – not perceived threat

• What counts as ‘ethical’
  – Not just about ethical review …!

• What counts as ‘research’?
  – Uncertain boundaries with public health surveillance, with evaluation, and in ‘hybrid’ activities
Emerging themes (1)

• Community/stakeholder engagement and fair collaborations
  – Issue of power and influence absolutely central to consideration of what is ‘ethical’
  – Engagement with affected communities essential – not a ‘nice to have’
  – Fair partnerships with researchers, institutions and governments in affected countries – real problem of ‘parachute’ research and lack of long-term capacity building
Emerging themes (2)

• Study design, review & 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 stakeholder engagement
    • is this the right study for this location/population?
    • Is this the right design for this location/population?
  – ‘Consent plus’? – recognising that consent for any intervention is essential, but may not be enough
• 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 frontline staff better in dealing with ethical challenges – recognition that ethical review doesn’t answer all issues!
Emerging themes (4)

• Data and sample ‘sharing’
  – What does ‘sharing’ mean in this context? How level is the playing field?
    • How much control do local populations / participants have over the use of their data and samples?
    • Sharing data and samples can help advance science – but may also further disadvantage researchers in low income environments without the resources to act quickly. How can this be avoided?
Thank you!

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