

Building resilient health systems in Global Health Emergencies: Role of research and Innovation

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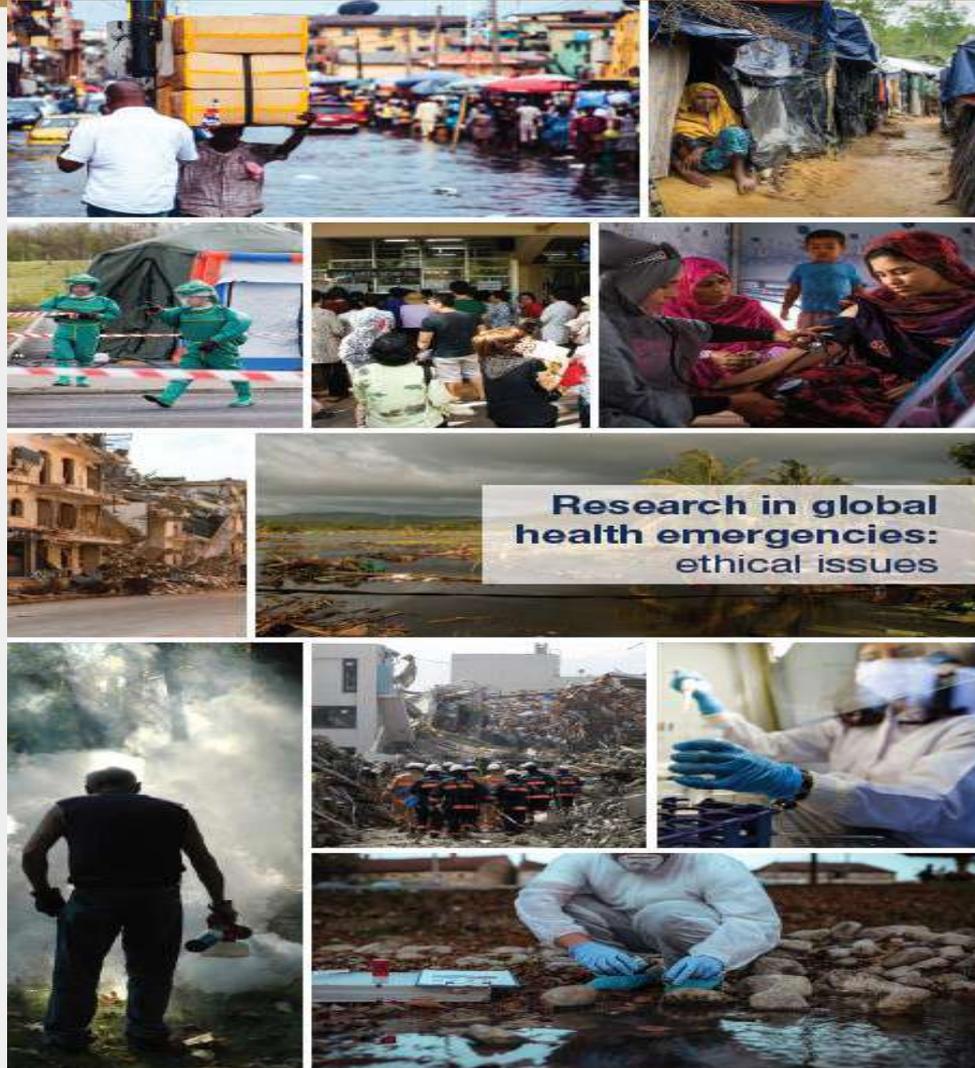
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Outline

- Introduction
- Role of research in global health emergencies
- Ghana's response: Research and Innovation
- Harnessing local research capacity
- Key recommendations



Research in global health emergencies: ethical issues



**Nuffield
Council Report
2020**

**NUFFIELD
COUNCIL ON
BIOETHICS**

Introduction

- Health emergencies/crisis' are characterised by
 - Uncertainty
 - Disruption
 - Great health need
 - Time pressure to act
 - Distress at different levels and sectors
- The ethical imperative of **preparedness**
- Historically, limited role of research in response



Research in Health emergencies

- Many different forms of research are intrinsic to effective response to health emergencies i.e COVID-19:
 - Understanding the **nature** of the health threat
 - Understanding **concerns** and needs of those affected by the emergency (social sciences)
 - Making **diagnoses** quicker and easier
 - Developing **new vaccines and treatments**
 - **Adapting existing forms** of service provision to meet needs in extreme circumstances



Particular challenges in emergencies?

- Tensions between policy-level decisions and what happens (or is possible) on the ground
- Competing / incompatible frameworks and guidelines – e.g between different professional disciplines, organisations, cultures
- Uncertainty whether emergency contexts permit variation from ‘standard’ approaches
- With limited local research funding, how do research institutions support response?



Making it happen: who has a duty to take action?

- Solidarity and reciprocity
- Those with the **greatest ability to act** (for example **research institutions**, research funders and governments)
- Those who have a **particular relationship** with others (e.g. employers)
- Those whose actions or failings mean they have a **degree of culpability** in connection with the emergency (e.g. negligent failure to prevent it, or mitigate effects)



Ghana National Health Policy 2020

3.1.10 Strengthen research to inform policy and management decision making

- Health research to provide evidence is paramount to the continuous learning and development of any health system.
- Little focus on strengthening the research to evidence and practice framework in the health sector.
- Issues about research funding
- Integrated national research agenda and capacity are suboptimal.



Ghana's response: Research and Innovation

- Harnessing local **research capacity** to support COVID-19 response
- Early leading role of **research institutions** in Ghana: UG(NMIMR/WACCBIP)KNUST(KCCR)/UHAS
- Utilising expertise of Ghana Health Service research institutions (Navrongo, Kintampo, Dodowa)
- Using existing research capacities; **laboratory infrastructure** for testing, **genome sequencing facilities**,



Streamlining the research ethics and regulatory review system

- Developing **specific guidelines** for research during COVID-19
- Facilitating **joint reviews** for clinical trials with FDA and others under AVAREF
- Introducing **online submissions** of research protocols
- Moving to **virtual review meetings** (introducing more review meetings, often involving several hours)



Public engagement: Science in the media space

- Scientists/researchers actively engaged in public engagement and science communication on COVID-19
- Media houses and journalists giving greater attention to the science of COVID-19
- Changing narrative from experiences with clinical trials on Ebola
- Political will (focus on science and research in the President's speech)
- Also, mixed messages as well
- Expert opinion vs. personal/public opinion
- (Mis) Trust in science
- Vaccine hesitancy



What COVID-19 taught us

- Need for multisectoral collaborative partnerships in response
- Importance of capacity strengthening in research – rooted in local infrastructure and with community involvement
- Need resilient health systems (integration of research in response)
- Need to be self-reliant (Moving from externally driven research to research that is responsive to local health needs)
- Effect of lockdowns/closure of borders
- Importance of community and public engagement in science to build public trust

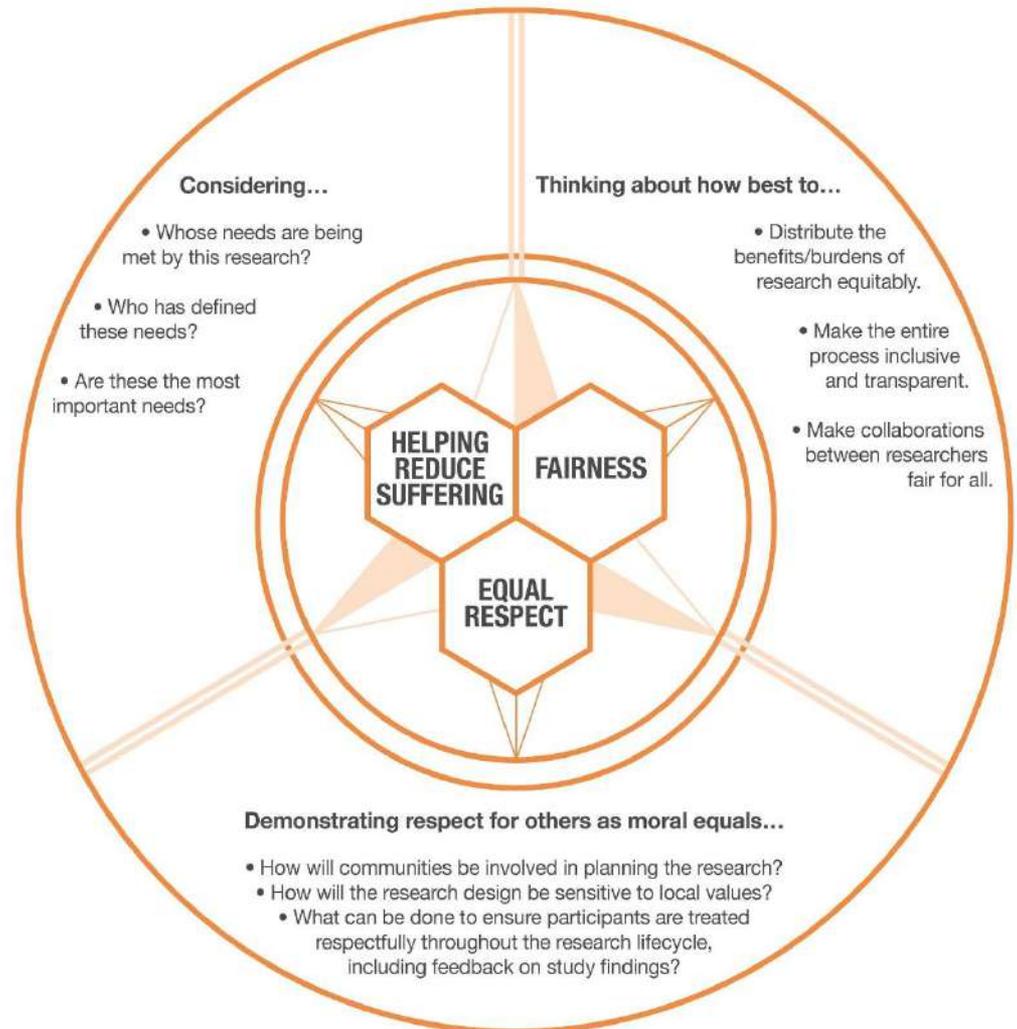


“Research and Innovation: what changes do we need to make after COVID-19 to build and sustain a resilient health system”.



An 'ethical compass' to guide decision-making

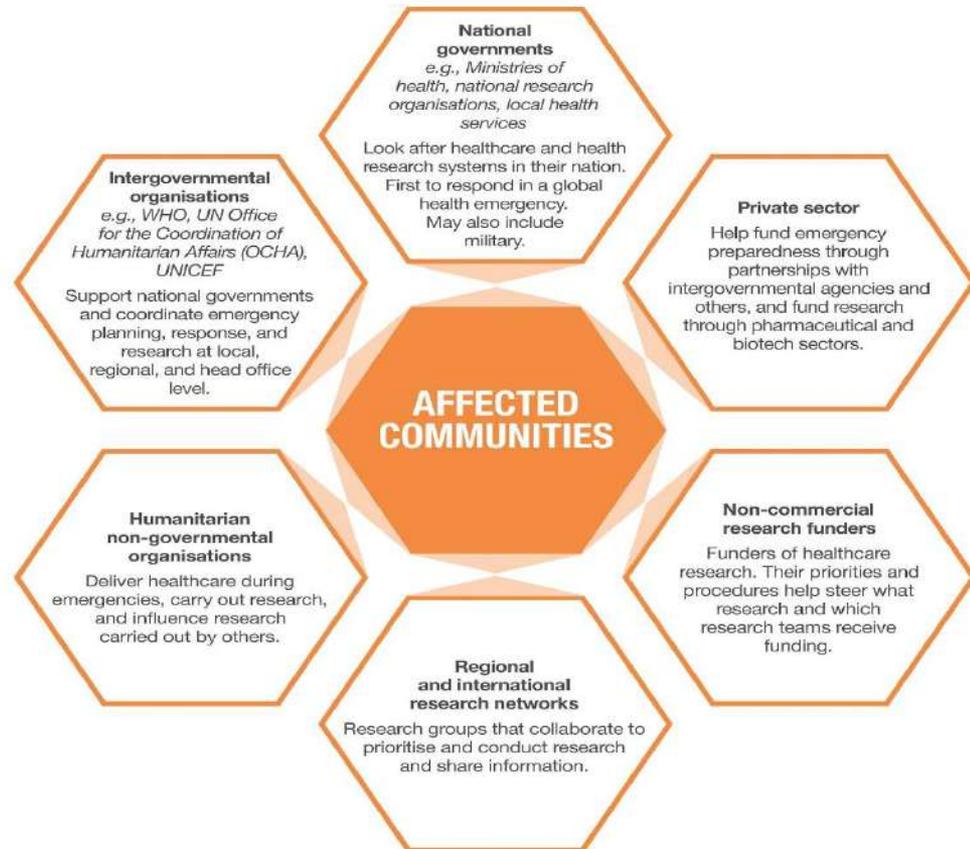
- Three core values to guide conduct (at policy level and on the ground)
- Recognition that these values can be in tension – but none can simply be overridden
- Recognition of opportunity costs / harms of *not* doing research



Key stakeholders

Implications for accountability between researchers and ...

- affected communities
- national governments and others with legitimate authority in the jurisdiction (eg national ethics bodies)
- other parts of the research sector
- other key elements in the emergency response, including intergovernmental agencies, the humanitarian sector, and private sector actors
- their own employers and funders



Policy Implications across six broad aspects of research

1. More inclusive approach to influencing research agenda and priorities
2. More inclusive approach to study design and review
3. Consent – and the wider ‘ethics ecosystem’
4. Equitable collaborations and partnerships
5. Respectful and equitable sharing of data and samples
6. Better support for front-line workers (researchers)



1. An inclusive approach to influencing research

- ‘Equal respect’ – requires serious engagement with those whose interests are fundamentally affected by the emergency
- Implications for:
 - more collaborative approach at level of major funders
 - with each other and with governments / research leaders in affected countries
 - meaningful engagement between researchers and affected populations – throughout the research process, and across diverse parts of communities
- Recognition that this is difficult – but not optional



Policy recommendations:

- Better mapping of future research plans between major funders (greater openness)
- Need for clear mechanisms, involving relevant national and international stakeholders, to prioritise research at start of emergency (facilitative role of WHO)
- Embedding research in response needs / end to 'parachute research'



2. An inclusive approach to study design and review

Study design

- Unethical to ask people to take part in research that is unlikely to produce useful results
 - importance of scientific rigour
 - importance of local acceptability: is this the right study for this location / population – and is it the right design?

Policy recommendations

- Study protocols should be developed with input of local communities
- Any exclusion criteria (eg 'children') should be clearly justified by reference to risk and benefits of the group in question



Study design and review continued ...

Independent ethical review

- Key safeguard of ethical conduct
 - **standard** of review cannot be compromised
 - **processes** used can (and should) be adapted for speed and flexibility
- Input by those with local expertise crucial in understanding the context-dependent risks

Policy recommendations

- As part of emergency preparedness, development of collaborative ethical review systems at national / regional level to support rapid and responsive review
- foreseeable harms)



3. Consent and beyond – the wider ‘ethics ecosystem’

- Central role of culturally-appropriate and respectful consent processes
 - many examples of good practice outside the emergency context

HOWEVER

- Consent alone is never the only requirement for research to be ethically acceptable
 - Other parts of ‘ethics ecosystem’ include responsibilities of researchers and ethics committees, and inclusive and collaborative engagement with communities



Policy recommendations

- Key considerations for research ethics committees should include:
 - whether proposed consent processes are the most appropriate and sensitive in the context
 - whether other requirements are needed to show respect for participants as people of equal moral worth
 - whether, in all the circumstances, what is being asked of potential participants is **fair**



4. Equitable collaborations and partnerships

Cooperation between research and response

- Crucial to ensure research aligned with response
 - Strong link with what is fair to ask of participants given the extremely difficult situations in which they find themselves

Policy implications

- Duty on researchers and funders to be confident that adequate response services are being put in place, before approaching people to take part in research
- Research plans should include contingency arrangements, for exceptional cases where partners are not able to deliver agreed services



Meaningful collaborations within the research sector

- Involve shared aims, and opportunities for all to shape research and influence objectives
 - equal respect between researchers and institutions with different degrees of power and influence
 - fairness with respect to crediting contributions

Policy implications

- Duties on research institutions to take active steps to support fair collaborations with other institutions (who shapes the work? who gets credit?)
- Duties on funders
 - (in emergencies) to connect potential collaborators – and encourage fair arrangements
 - (in the longer term) to support long-term fair collaborations, including sustainable funding models that enable institutions in low income settings to apply directly for grants
- Duties on governments
 - to strengthen academic capacity, including in social science and bioethics, to support the development of local expertise



5. Respectful and equitable sharing of data and samples

- Sharing can help maximise benefit – but can also be a source of concern regarding risks of harm / exploitation
 - need to identify conditions for **equitable, respectful and responsible sharing**
 - may differ between data and samples
 - two important elements – community perspectives and researcher/institution perspectives

From community perspective

- Developing local systems of governance that people can trust
 - including
 - culturally appropriate approaches to consent for future uses
 - access committees able to prioritise locally relevant research
 - regular community feedback



Data and samples continued

...

Policy recommendations

- Need for more research in different [settings] about stakeholder concerns – to provide basis for national / regional guidance
- Future use of existing samples held without clear consent should be based on discussion with key stakeholders (governments, research leaders, community leaders, survivors' groups)
- In any future collaborative research in emergencies – the existence and scope of sample collections should be registered in a public database



6. Better support for front-line workers in research

- Duties of employers and others to protect welfare of front-line research workers
 - including supporting them in dealing with ethical challenges that arise
- Challenge of differential terms of employment between local and international workers
 - equal respect underpins equality of treatment but hard to realise in practice (e.g risk of ‘international’ salaries undermining local health economy)



Policy implications

- Importance of **transparency** in how terms and conditions are set; involving ministries of health
 - Differential treatment in some aspects of terms and conditions (such as personal security) very hard to justify
- Duty of research institutions to ensure ethics support routinely available
 - eg through training, de-briefs, clear lines of accountability, priority given to worker safety
- Need for flexible platform to provide timely ethics advice
 - welcome launch of WHO's pilot 'Public Health Emergency Ethics Preparedness and Response Network'



Research Integrity?

In a health emergency/crisis,
we need trustworthy
institutions

‘Active adherence to ethical
principles and professional
standards essential for the
responsible practice of
research’

*Stanley G Korenman: Responsible conduct of
research*

INTEGRITY
IS DOING THE
RIGHT THING.
EVEN WHEN
NO ONE IS
WATCHING.

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Research Integrity

- **Honesty** in all aspects of research
- **Accountability** in the conduct of research
- **Professional courtesy** and **fairness** in working with others
- **Good stewardship** of research on behalf of others

Singapore statement on research integrity 2010



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Wright, K., Parker, M., Bhattacharya, S. Blanchet, K., Caney, S., Chan, E., Thome, B., Guerin, P., Hughes, J., Kingori, P., Larson, H., Moses, S., Sekalala, S., Sheather, J., **Tindana, P.** In emergencies, health research must go beyond public engagement toward a true partnership with those affected. *Nat Med (2020)*.

- Department of Health Policy, Planning and Management, School of Public Health, University of Ghana
- Ghana Health Service Ethics Review Committee



