Data Sharing in a Public Health Emergency: The challenges of implementation

Katherine Littler, Wellcome

IMED Meeting, 6 November 2016

Data Sharing: Mandating for change

World Health Organization

centre | Publications | Countries | Programmes | Governance | About WHO

Essential medicines and health products

Developing global norms for sharing data and results during public health emergencies

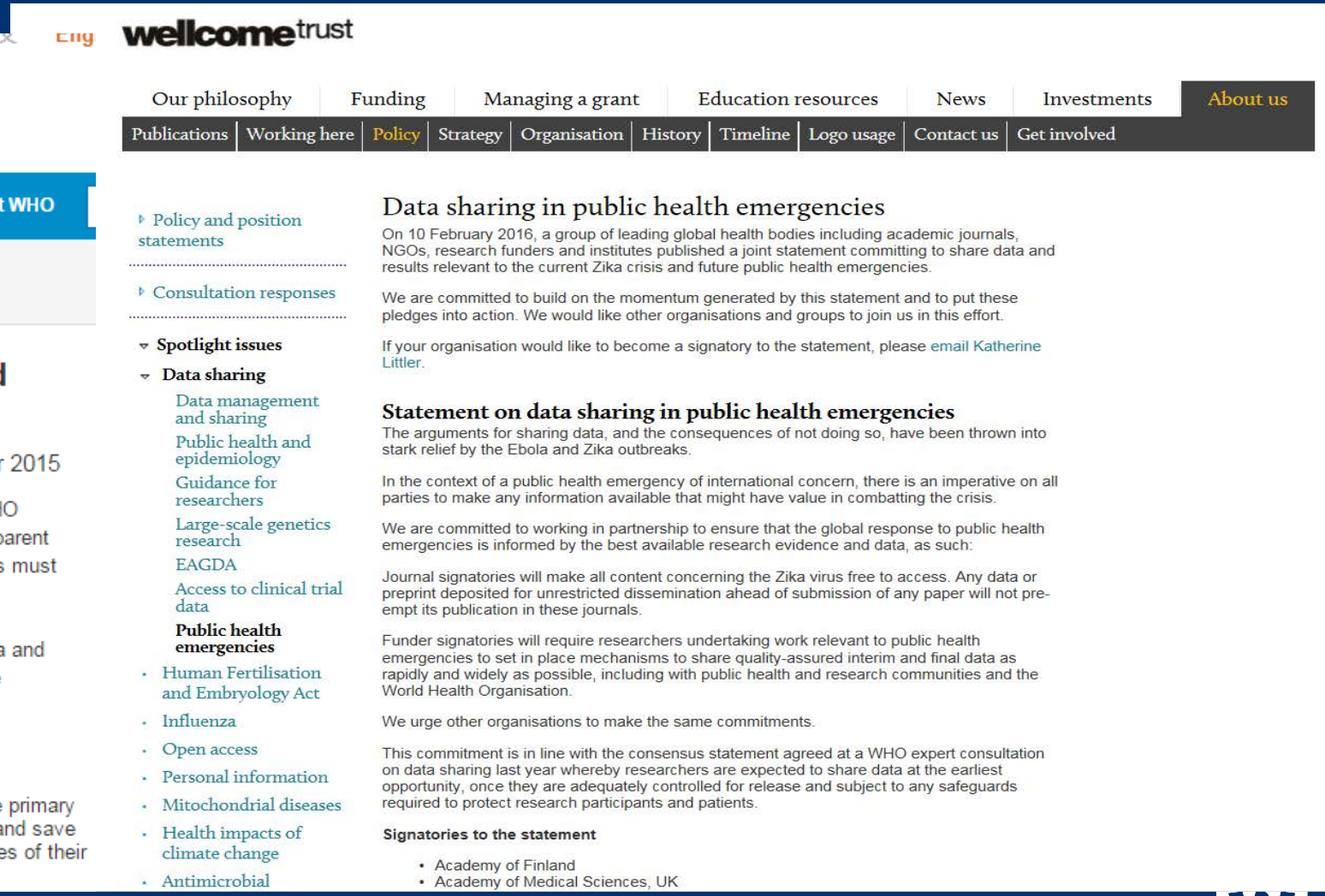
Statement arising from a WHO Consultation held on 1-2 September 2015

Leading international stakeholders from multiple sectors convened at a WHO consultation in September 2015, where they affirmed that timely and transparent pre-publication sharing of data and results during public health emergencies must become the global norm.

The following summary points represent WHO's position with regard to data and results sharing in public health emergencies, having taken into account the perspectives of those who attended the meeting.

Summary Points

1. Research is essential in the context of public health emergencies. The primary purpose of such research is to advance public health, prevent illness and save lives. Researchers should always weigh the public health consequences of their actions in withholding and sharing results.



wellcome trust

Our philosophy | Funding | Managing a grant | Education resources | News | Investments | About us

Publications | Working here | Policy | Strategy | Organisation | History | Timeline | Logo usage | Contact us | Get involved

- Policy and position statements
- Consultation responses
- Spotlight issues
- Data sharing
  - Data management and sharing
  - Public health and epidemiology
  - Guidance for researchers
  - Large-scale genetics research
  - EAGDA
  - Access to clinical trial data
  - **Public health emergencies**
- Human Fertilisation and Embryology Act
- Influenza
- Open access
- Personal information
- Mitochondrial diseases
- Health impacts of climate change
- Antimicrobial

Data sharing in public health emergencies

On 10 February 2016, a group of leading global health bodies including academic journals, NGOs, research funders and institutes published a joint statement committing to share data and results relevant to the current Zika crisis and future public health emergencies.

We are committed to build on the momentum generated by this statement and to put these pledges into action. We would like other organisations and groups to join us in this effort.

If your organisation would like to become a signatory to the statement, please email Katherine Littler.

Statement on data sharing in public health emergencies

The arguments for sharing data, and the consequences of not doing so, have been thrown into stark relief by the Ebola and Zika outbreaks.

In the context of a public health emergency of international concern, there is an imperative on all parties to make any information available that might have value in combatting the crisis.

We are committed to working in partnership to ensure that the global response to public health emergencies is informed by the best available research evidence and data, as such:

Journal signatories will make all content concerning the Zika virus free to access. Any data or preprint deposited for unrestricted dissemination ahead of submission of any paper will not pre-empt its publication in these journals.

Funder signatories will require researchers undertaking work relevant to public health emergencies to set in place mechanisms to share quality-assured interim and final data as rapidly and widely as possible, including with public health and research communities and the World Health Organisation.

We urge other organisations to make the same commitments.

This commitment is in line with the consensus statement agreed at a WHO expert consultation on data sharing last year whereby researchers are expected to share data at the earliest opportunity, once they are adequately controlled for release and subject to any safeguards required to protect research participants and patients.

Signatories to the statement

- Academy of Finland
- Academy of Medical Sciences, UK

Funders working together: GloPID-R

WHAT IT IS:

- Global Research Collaboration for Infectious Disease Preparedness
- Network of research funders with WHO as an observer
- Established working groups, including one on data sharing

AIM:

- to facilitate an effective research response **within 48 hours** of a significant outbreak of a new or re-emerging infectious disease with pandemic potential

The GLoPID-R Action Plan

Aim: Design a system for data sharing in public health emergencies (PHE) to support the research response

Key Areas:

- Define the data we are talking about & 'public health emergency'
- Map the environment
- Develop policy and a framework for data sharing for PHE
- Focus on implementation of data sharing policy and practice
- Roadmap for collaboration – wider than the community we fund

Examples of projects

1. Decision Tree - ascertaining the data you will need to share, when & with whom
   - Creating an interactive tool to manage real time sharing
   - What key questions need to be addressed at what stage
2. Case Studies
   - Retrospective – learn from past PHEs
   - Current – learn in real time
   - Prospective – test on potential future PHEs
3. Developing Principles for Data Sharing

Developing a framework for responsible data sharing

Key Principles for Data Sharing in a Public Health Emergency

Implementation: Challenges to overcome

1. Incentives & Recognition
   - Develop mechanisms to promote data sharing
   - Censure those who misuse data
2. Infrastructure & Tools Development
   - Develop norms for repositories & promoting best practice
   - Develop tools to enable pre-publication data sharing
3. Ethical, legal & Governance Issues
   - Addressing issues of benefit sharing & reciprocity
   - Safeguarding participants, communities
   - Building trustworthiness, building confidence

Further issues to consider

Preparedness is key – systems, standards, principles need to be in place in advance of a PHE

Speed is critical but not at the expense of justice?

Acceptable risk may be different in a PHE – are individuals/communities willing to take on greater risk given what is at stake?

Relationships of trust often key to research, public health response and data sharing, given the nature of a PHE, these might not always be possible to build – as a minimum, we need to aim for ‘confidence’ in our data sharing system

Our focus should not be on ‘ownership’ but on an underpinning system that creates a fair or just system for data sharing