Strengthening Data Sharing for Public Health

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The Centre on Global Health Security is engaging with leading experts from around the world to develop guidance on how to create the right environment and achieve good practice for sharing public health data.

Finding and implementing solutions

Recent public health crises have demonstrated a global need for improved public health surveillance data-sharing procedures. While the barriers are well understood, solutions still have to be identified and adopted. The project seeks these solutions.
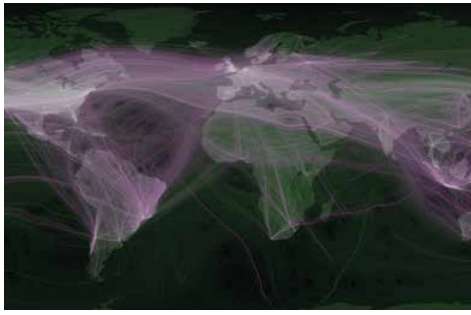
Sharing responsibilities and benefits

Surveillance networks contributed in a major way to the identification of the SARS outbreak in 2003, which led to the World Health Organization's (WHO) revision of the International Health Regulations. This revision strengthened the global public health surveillance system. However, there remains no systematic global framework for sharing data.

There is a lack of practical guidance on which public health surveillance data should be shared and how. Additionally, no global mechanism exists to ensure the benefits that result from data sharing are equally distributed. Sharing such data across country borders raises political, ethical, and legal concerns, specific to different regional contexts, and these have to be addressed before effective and efficient sharing becomes possible.

Chatham House convened a preliminary roundtable in February 2014 and a high-level strategy roundtable in April 2015. International participants were drawn from areas that covered public health, open data, commercial data, research data and big data. Both meetings identified the need for practical guidance to be made available at the earliest opportunity. They also informed the project's development of draft data-sharing principles.

How should data be shared?

Data sharing in public health is most successful when a clear need is identified, and the social, political, and cultural context is taken into account. Negotiations can be complex and time-consuming. Even when the right environment has been established, issues remain concerning how data should be shared in practice.

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What we are doing

This project will produce practical guidance to facilitate the negotiations for the sharing of public health surveillance data across borders. The guidance will target the needs and expectations of data generators, secondary data users, and those who wish to facilitate data sharing, such as multilateral organizations. The guidance will also address technical good practice to overcome obstacles to data sharing once an agreement to share has been reached. With a focus on providing actionable solutions, draft guidance will be piloted in various global contexts. It will be reviewed and revised on the basis of feedback from these pilots, before its launch towards the end of 2016.

Key questions
- When should data sharing be the expectation?
- How can data sharing be incentivized?
- What type of data need to be shared internationally?

How we are doing it

Gathering evidence for practical guidance
- **Strategic roundtables** to consider key topics and approaches and to provide high-level expert input to the project.
- **Targeted thematic and regional roundtables** to address context-specific legal, ethical, technical and political challenges.

Collaboration with leaders in global health
- **Iterative outputs** will involve senior stakeholders throughout the course of the project to achieve maximum utility and traction for the guidance.
- **The guidance** will be launched at the highest level internationally. As a global public good it will be made freely available. The WHO has an essential role to play in ensuring wide uptake of the guidance, and has been involved throughout its development.

'USAID boosts disease surveillance across borders' by Richard Nyberg on Flickr CC BY-NC 2.0

Current and planned actions

The guidance is designed to inform and support global policy and action to shift the norms towards more open and transparent data sharing. To reach this goal:

- **Data-sharing principles are being developed** by the Centre to form the basis of the guidance.
- **Regional pilot studies of the draft guidance** will take place in 2015/16.
- **Subsequent iterations of the guidance** will be the subject of further pilot studies during 2016.
- **The guidance** will be launched at the end of 2016.

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