

# Strengthening Global Public Health Surveillance through Data and Benefit Sharing

## Technical Appendix

### Public Health Surveillance: A Call to Share Data

#### IANPHI US Office

Disease outbreaks such as Ebola, and increasing concerns about the impact of Zika virus, point to the urgent need for sharing public health surveillance data, including that collected by governments, researchers, donors and international organizations. Convened by Chatham House, over 40 international public health leaders, including IANPHI Founding President Dr. Jeff Koplan, Vice President Dr. Mwele Malecela and Executive Board member Dr. Ilesh Jani participated in the discussion and development of the statement.

“Sharing routine public health surveillance data is crucial to understanding what is going on in our countries, regions and the world as a whole,” said Dr. Malecela, who is the director of the National Institute of Medical Research, Tanzania. “We commend Chatham House for its important work in bringing together thought leaders to develop strategies for the future.” Dr. Jani noted that public health institutes such as Mozambique’s National Institute of Health play a major role in analyzing surveillance data and developing policy recommendations. “To do so we need access to all types of data, including that from those working in our countries.” Dr. Koplan noted that the new Child Health and Mortality Prevention Surveillance network (CHAMPS), in which IANPHI is a partner, will result in substantial new data on the causes of childhood death. “This data, in line with our discussions at Chatham House, will be widely available in a way that will help parents, communities, nations and the world,” he said. IANPHI members interested in signing the document may do so by emailing us at [communications@ianphi.org](mailto:communications@ianphi.org).

The beginning of the 21st century has seen several global disease outbreaks including SARS, H1N1, Ebola and Zika. These outbreaks differ in many ways, but they all have one

important characteristic in common: timely sharing of public health surveillance data as the outbreaks unfolded led to more coordinated and effective risk management and improved the public health response. Conversely, as the MERS outbreak has illustrated, a failure to share can have very real health consequences at the individual and population levels.

### **Sharing Data Saves Lives**

The benefits are not restricted to outbreaks. Sharing routine public health surveillance data enables regional collaborations, capacity strengthening, insight into public health system performance and ultimately better control of infectious diseases. For example, timely and accurate sharing of polio surveillance data has clearly contributed to the reduction in circulation of wild polio virus on the way to eradication. In addition, the global sharing of antimicrobial resistance data enables the tracking and mitigation of what is considered one of the biggest health threats of the 21<sup>st</sup> century.

### **Data Sharing will be Essential for the Achievement of the Sustainable Development Goals**

Successful control of infectious diseases benefits individuals and communities globally and can be considered a global public good. Public health surveillance is a critical tool that helps achieve this. Nevertheless, despite examples of success, sharing public health surveillance data beyond national borders is still not the norm. There are understandable technical, political, ethical, legal and economic reasons why there may be reluctance to share. However, restricting access can harm the health of populations and denies health benefits to individuals entitled to them. Thoughtful deliberate policies that protect legitimate interests without restricting access are urgently needed.

Since 2014, the Centre on Global Health Security at Chatham House has worked to overcome the obstacles by developing guidance on how to create the right environment and achieve good practice for sharing data for public health action. The 'Strengthening Data Sharing for Public Health project' has been an iterative process involving a wide range of leading experts and targeted thematic and regional roundtables.

Those who have engaged in the Chatham House project recognize that public health surveillance data benefit not only those to whom the data directly relate, but also the wider community. Sharing these data helps to inform local and global decision making to achieve better health outcomes. Noting the recent calls for the sharing of data for research and during

emergencies, we now call for all public health surveillance data to be shared as necessary to improve and protect public health. We also consider it unacceptable for organizations to claim ownership of, and restrict access to, public health surveillance data when that would decrease potential health benefits derived from these data. The norm should be for these data to be accessible in a timely manner for public health action while taking appropriate steps to safeguard the privacy of individuals and other legitimate public interests.

The consequences of making a decision to withhold data can be critical, and those considering such a decision must be ready to justify their actions. In accordance with the recent Statement on Data Sharing in Public Health Emergencies, the sharing of data in advance of publication in peer-reviewed journals should not be penalized.

We call on stakeholders to commit to the following:

- To share public health surveillance data by default where a public health need is identified, in a timeframe necessary for public health decision-making and to the highest standards they can achieve.
- To use public health surveillance data responsibly, with the intention of protecting and improving the health of the population and in accordance with the agreed terms.
- To articulate the value proposition for sharing in an explicit, clear, and accessible way - the benefits should be evident to all.
- To ensure that public health surveillance data are shared with as few restrictions as possible, and with a commitment to principles of social beneficence, respect, justice and transparency.

We believe strongly that real and perceived obstacles to sharing can be overcome by working together, and that establishing sharing as the new norm will bring great benefit in improving and protecting public health.

#### **Signatories to the Statement**

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<sup>1</sup>The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Center for Disease Control and Prevention.

<sup>2</sup>The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of Médecins Sans Frontières.