

WPF Statement to the Civil Society Consultation on Sustainable Health Security Preparedness and Response, C20, 2021

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The World Privacy Forum is pleased to submit our statement to the Civil Society Consultation on Sustainable Health Security Preparedness. WPF is a member of the Global Health Working Group, and is an NGO that focuses on digital health, data governance, and data protection and privacy. See <u>www.worldprivacyforum.org</u> for additional information and more of our work.

In response to the question of what is required at global, regional and national levels to ensure effective multilateral, multi-sectoral co-operation to prevent, prepare for and respond to global health crises, we have learned that one of the deep lessons of this pandemic is that in a global public health crisis, knowledge is power. Usable public health knowledge requires many systemic building blocks, particularly global cooperation regarding public health data ecosystems that function robustly, interoperatively, and fairly across all jurisdictions.

To ensure equal development of a genuinely sustainable, effective, and fair global public health data ecosystem it will be essential to accomplish baseline capacities in three areas:

- Ensure presence of baseline health data ecosystem capacity in all jurisdictions, inclusive of public health data and global collaboration regarding equitable distribution of health data systems. Many Low and Middle Income Country (LMIC) jurisdictions will need assistance to bring digital health systems online and fully up to speed. Note the findings and interviews in our 2020 multi-jurisdiction / multi-stakeholder research regarding LMICs and the COVID-19 response, *Governing Data for Development: Trends, challenges, and opportunities* <u>https://www.worldprivacyforum.org/2020/11/</u> <u>governing-data-for-development-trends-challenges-and-opportunities/</u> Michael Pisa, Pam Dixon, Benno Ndulu et al, Center for Global Development, World Privacy Forum.
- 2. Ensure trust in health data ecosystems by ensuring that robust data governance, privacy protections, and human rights protections are in place in all public health data collections, exchanges, and uses. As of this year, 145 jurisdictions globally have passed comprehensive data protection legislation. However, public health data governance is still fragmented, for a number of reasons. These challenges can be solved with well-understood governance, protections, and granular implementation guidance specific to national, regional, and global public health data ecosystems.
- 3. Ensure interoperability of public health data by encouraging the use of agreed-upon, international standards for data that are achievable by *all jurisdictions* including LMICs. In the past, LMICs have not always been represented robustly in standards making processes, something which now can and must be corrected.

To summarize, for an effective and high functioning public health data ecosystem, fair, and human-centered governance inclusive of privacy, interoperability, and equitably distributed access to such systems across all jurisdictions, are among the key components that build sustainability of public health data ecosystems. Thank you for holding this civil society consultation.

Pam Dixon, Executive Director World Privacy Forum