

## **Policy Brief #1: Modeling Pandemic Potential for Disease Surveillance**

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### **Introduction**

Robust disease surveillance remains the cornerstone of epidemic and pandemic preparedness. Over the course of a public health emergency, data obtained from both traditional sources (e.g., clinical data via hospital systems) and nontraditional sources (e.g., digital data via social media) can be used to inform modeling strategies designed to forecast the impact of a disease outbreak as well as mitigate its effects on a population level. The COVID-19 pandemic illustrated existing data gaps that often hamper response efforts. The purpose of this workshop was to discuss best practices related to novel data integration into disease surveillance and standardization of reproduction number estimation for disease modeling. From this discussion, several policy measures were proposed to address consensus issues identified during past public health emergencies to better inform response efforts during future epidemics and pandemics.

### **Data Communication**

Effective communication with the public is a critical step for risk management during health emergencies. As the COVID-19 pandemic has demonstrated however, many gaps remain in formulating and promoting appropriate communication strategies from relevant public health, medical, and political entities to the public. One potential solution, as discussed by workshop participants from the United States perspective, would be to create “communications corps” at the federal, regional, and local levels to direct communications support during health crises. Such an effort could function similarly to how the US National Guard has been used to help support COVID-19 vaccination efforts. This communications corps would conduct training for relevant stakeholders, such as the news media, on how to effectively and accurately convey evidence-based health information and recommendations to the general public. Developing an appropriate strategy in the interepidemic or pre-pandemic period is critical in order to activate such a corps when needed. Workshop participants also discussed the importance of building trust with the public prior to the onset of a health crisis, as most successful health campaigns are ultimately long term endeavors.

Once an outbreak has begun, ongoing communication of salient and evolving data is also important to mitigate public concern and provide appropriate public health reduction strategies. Engaging local epidemiologists and risk communicators early on to partner with medical directors at the hospital or clinic level offers an opportunity to promote evidence-based data in an effective manner that will engender local trust.

### **Data Standardization and Access**

Workshop participants reflected on barriers to data access and the lack of data standardization in certain contexts during prior outbreaks. For example, wastewater sampling came to the forefront as a valuable tool for disease surveillance during the COVID-19 pandemic; however, the lack of standardization among certain parameters, poor integration across existing systems,

and lack of longer term funding commitments may have hampered its potential as a novel tool for ongoing disease surveillance.

The National Institute of Standards and Technology creates standards and measurement assurance for science and technology; using similar rubrics to standardize infectious disease data collection and reporting would create greater ease of tracking and analysis across larger geographic areas, particularly in emergency situations.<sup>1</sup> Well-accepted global standards would be helpful for similar reasons and consensus through international regulatory bodies should be promoted to achieve this prior to the next pandemic. Use of common reporting templates may additionally limit uncertainty in data collection and analysis in the future.

### **Ethics of Data Sharing and Collection**

Workshop participants discussed the need for greater global transparency and improved privacy standards related to online data collection and regulation. Digital data collected from different countries may incur variable regulatory protections depending on where the data originated from. For example, while the European Union has implemented the General Data Protection Regulation (GDPR) to impose strict privacy and security standards for data,<sup>2</sup> there is no equivalent in the United States. Given the increasing availability of digital data and its potential applications in research, individual autonomy over the use of personal data is paramount and local regulatory bodies should ensure their protection.

Social media research has introduced new potential ethical challenges that are not yet well understood. Workshop participants agreed that there is a generalized lack of understanding, even among institutional review boards, of the potential harm that can come from the misuse of this type of data. Greater inclusion of individuals with diverse academic backgrounds and content expertise on local ethics committees may help mitigate some of these challenges. While the Association of Internet Research Guidelines for ethics of social media data collection and use can be referenced by researchers, it remains underutilized<sup>3</sup>.

Finally, workshop participants discussed the ethical implications of data collection without local capacity building. Mining data from a particular region without supporting structural change to ensure that data collection can continue at the local level poses several ethical dilemmas. Similarly, findings that come from any data should be shared with the communities where the data originates from. While Institutional Review Board approval for data collected during emergencies is usually not required, any scholarly work that comes thereafter should undergo review. Workshop participants proposed supporting local approvals for data collection at the onset of health emergencies that can be extended to research at a later point in time.

### **References**

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