

Written testimony from Lisa M Lee to the U.S. House Committee on Science, Space, and Technology, Subcommittee on Investigations and Oversight, remote hearing titled *“Data for Decision-Making: Responsible Management of Data during COVID-19 and Beyond.”*

September 23, 2020 at 11:00 a.m. EDT, via Cisco WebEx.

The statements below reflect my professional opinion and do not necessarily represent the views of my current or former employers, including Virginia Tech, the Department of Health and Human Services, or the Centers for Disease Control and Prevention.

Mr. Chairman and members of the Subcommittee,

Thank you for the opportunity to give voice to the critical issue of how the nation collects, uses, and communicates the meaning of health data during this global COVID-19 crisis and beyond.

I have been asked to provide testimony about two topics:

- 1) The role of CDC epidemiologists in analyzing and validating data that is collected via the National Healthcare Safety Network (NHSN), and how hospitals, states, and researchers have traditionally interacted with the system, including the role of surveillance scientists, including local and state stakeholders, and, your opinion about the new TeleTracking system contracted by the Department of Health and Human Services to collect and host COVID-19 hospital data from around the country; and
- 2) How the federal government can invest in a long-term public health surveillance strategy beyond the COVID-19 pandemic, including a discussion of what a trustworthy data management system should look like, including how to ensure patient data is adequately protected and validated while making it readily accessible to researchers.

Together, these two questions bring three points to the fore. First, public health surveillance serves as vital health intelligence, without which we experience loss of productivity and life. Second, public health surveillance is a *set* of activities, all of which must function both during and between public health emergencies. And, third, public health surveillance requires the public’s trust; without trust, the system fails.

To address the first point, it is important to note that public health surveillance has served as the eyes and ears of the health system since 1741, when tavern keepers were required to report contagious conditions among their patrons to colonial leaders.ⁱ Public health

surveillance is the health intelligence that provides critical—and often early—warning about health threats. Contemporary public health surveillance is defined as “the ongoing, systematic collection, analysis, and interpretation of health-related data with the a priori purpose of preventing or controlling disease or injury, or of identifying unusual events of public health importance, followed by the dissemination and use of information for public health action.”ⁱⁱ

Public health surveillance is a multi-layered system that includes health care providers, local and state health departments, the Centers for Disease Control and Prevention (CDC), which employs our federal public health experts, and in our increasingly connected world, the World Health Organization (WHO), which serves as the international body to coordinate multinational public health emergencies. All of these organizations work together to keep their eyes on the horizon and their ears to the ground to anticipate and respond to health threats both during epidemics and in times of good health.

Similar to other types of intelligence, a well-functioning public health surveillance system provides health intelligence that can anticipate and contain threats before they become catastrophic. For a public health surveillance system to motivate effective public health action, it must be accurate, objective, and its findings clearly communicated. A successful system requires consistent investment in technical infrastructure as well as human resources. It is often said that the public health system is working well when nothing happens, indicating that health threats were anticipated and mitigated. To make nothing happen, however, is not cost-free. It requires a skilled and prepared workforce as well as regularly updated technology. Chronic underfunding of the U.S. public health system over the past decadeⁱⁱⁱ has led to underinvestment in the public health surveillance system at all levels.

Without consistent investment in a well-functioning public health surveillance system, governments are at risk for failing to meet their basic duty of caring for the health of their population.

The second point is that public health surveillance is a *set* of activities, not simply the collection of health data and posting of data files. Public health surveillance, especially for a highly-lethal, novel virus, is a complex system that includes numerous, interconnected activities. In addition to careful planning and efficient system design, data must be collected and collated—which includes ensuring they are valid, complete, timely, deduplicated, and reliable. Once the raw data are deemed accurate, the next steps are to analyze and interpret the data. To do this well, a surveillance scientist must know the characteristics of the data and how to use appropriate statistical methods to accurately analyze the data. In addition, the surveillance scientist must translate the findings into meaningful information for health officials, policy makers, and others who need the data to make decisions about actions. A

key characteristic of a public health surveillance system is the expectation that the data and findings are used to motivate public health *action* in the form of disease prevention, health promotion, and reduction of morbidity and mortality. Collection of health data in the absence of useful public action is not public health surveillance.

In the United States, we conduct public health surveillance on injuries, health-related behaviors, and over 70 conditions—some chronic, some infectious—as well as health events that might signal a new or unusual health threat. For each condition, we count a variety of what we call “sentinel events.” These are events that occur over the duration of an injury or illness. For example, we often count the number of positive laboratory tests for a disease; the number of clinical diagnoses of a condition; if applicable, the number of persons who have recovered or are vaccinated and are now immune to the disease; and (almost always) the number of deaths related to a condition. Each of these events tells us something different about the disease or condition in question.

Because an estimated 75 percent of emerging pathogens that cause disease in humans are spread from animals, it is increasingly important to include disease surveillance in animals as part of a fulsome public health surveillance system. This approach, called One Health,^{iv} is a resource that we have yet to meaningfully incorporate into the human public health surveillance system. If we did, however, our health intelligence would be greatly improved. We would see potential health threats much earlier and be poised to act to prevent them long before a large scale loss of human health and life.

Developing a useful public health surveillance system that measures the right sentinel events requires careful thought, planning, and coordination. In addition, it requires an understanding of the science and epidemiology of a condition, as well as what specific data will be needed for decision making.

For COVID-19, for example, we have made efforts to collect data on a number of sentinel events, or signals. We monitor the number of SARS-CoV-2 tests done because it is an important measure of how well we are *assessing the impact* of the disease in a community. We use the number or proportion of *positive* tests to measure the current spread of infection in a community, as an indicator of the completeness of our testing program, and to predict the number of additional cases we are likely to see in the coming weeks. We use the number of COVID-19 hospitalizations to tell us something about the number and characteristics of severe cases, and to estimate current and future care needs. We use the number of recovered cases, plus the number of antibody tests, to tell us about spread of disease from weeks or months before. And we collect information on the number of deaths as an indicator of delayed care seeking behavior, severity of infection, and effectiveness and equitable distribution of treatment.

Decisions about which events to include in a surveillance system are crucial because they help us describe what is happening with the particular condition; this, in turn, helps us decide how to appropriate and allocate resources, when and where to deliver which public health interventions, and to evaluate the success of the public health interventions we have used in combatting outbreaks. These important decisions about the design of the surveillance system should be made by public health surveillance scientists with training and experience with data, epidemiology, statistical analysis and interpretation, communicating complex data, and public health programming.

Since public health management is under the jurisdiction of the states in our country, a strong partnership between state and federal surveillance experts is critical. CDC has been cultivating partnerships with and among states since its founding in 1946. These partnerships, driven in large part by a long-standing partnership with the Council of State and Territorial Epidemiologists, have facilitated a national system of notifiable diseases that is the basis of the majority of public health intervention carried out by state public health professionals.

In my experience as a surveillance scientist who has worked over 30 years at the state, federal, and international levels, surveillance scientists in state health departments and at CDC are the most experienced and best positioned to think through these issues and design a system that will guide an effective, evidence-based response. This is not a task for administrators, or persons with a political agenda.

The third point is about trust. Trust is the foundation of all public health practice; it is public health's currency. The public has to trust that their government leaders are acting in its best interest. Trust is especially important for the kind of data that public health surveillance collects—data about people's health. The top two types of information people most want to keep private are financial data and health data.

The public must trust that their data are being used to improve their health and for nothing else—not for the profit of a private company; not for law enforcement; and not to cause them social, reputational, or financial harm. The public must also trust that the conclusions drawn from the analysis of the data they provide to the system are accurate, objective, and will result in benefits for them and their community. Without the public's trust, the public health system cannot function.

Each year, when asked about which government agencies Americans trust most, CDC consistently ranks near or at the top. One source of this trust is the U.S. public health system's exceptional track record of protecting privacy and confidentiality of patient data. To date, the U.S. public health surveillance system has proven to be especially trustworthy, with virtually no harm to individuals resulting from a breach of surveillance data. Even with a

highly stigmatized infectious disease like HIV, Americans trust the public health surveillance enterprise to collect, store, and use their data to benefit the public's health. Public health professionals are both ethically^v and legally^{vi} bound to protect identifying information about individuals to whom they provide essential services. One of the foundational principles of ethical data public health data collection is that data are used only for the purpose for which they are collected.^{vii} Public health surveillance scientists have been protecting and making data useful for researchers for decades. There is no reason to doubt that they will continue to do so in the future.

In the case of moving COVID-19 surveillance from CDC to the Office of the Secretary at HHS headquarters, trust is being tested in a number of critical ways.

First, the removal of public health surveillance science experts from CDC, who together have hundreds of combined years of experience and expertise in the complex process of public health surveillance, reflects the removal of the world's experts in this field. There is no equivalent of this expertise in the private sector. CDC's public health surveillance experts work closely with state, local, tribal, and territorial health department personnel to coordinate public health surveillance for over 70 conditions. They have established trusted, collaborative relationships with state and local partners over decades. Their surveillance expertise is sought after by countries and multilateral health agencies across the globe. Removing CDC public health surveillance scientists from this process is like removing trusted NASA engineers from sending a rocket to Mars.

Second, the public's trust is challenged by moving the data collection to an office that is much more vulnerable to political pressure (direct or indirect) from the White House during the most volatile and important election year we have witnessed most certainly in my lifetime. Moving data collection (though, as I mentioned, data collection is not equal to implementing a carefully planned, effective public health surveillance system), to the HHS Secretary's office is seen by many to put the data in great jeopardy. Not only is there the dire loss of expertise, as I discussed above, but there is also an infusion of what many people worry will be a lack of objectivity driven by political pressure in the face of a national disaster in the midst of this volatile election year. Most Americans (68% in a recent poll^{viii}) do not trust what the president says about the pandemic. The number of cases and deaths continue to rise with no coordinated federal response in sight. In a number of published news reports, the president has suggested that the best way to reduce case numbers is to stop testing. Given these and other comments, many people find it hard to imagine that there is a great deal of support to be sure that COVID-19 data under the control of the HHS Office of the Secretary are complete and well-suited to direct public health intervention. This increased political pressure raises serious concerns about reduced objectivity in both the collection and reporting of the data.

Finally, the data collection contract awarded to a private, for-profit company raises concerns. During the early 2000s, the Bush administration talked a great deal about whether federal employees were engaging in “inherently governmental” activities and, if not, there was a move to contract the activity out of federal agencies, from federal employees to contracts with private entities.

While the White House has moved COVID-19 hospital reporting activities from CDC to a private entity, specifically TeleTracking Technologies, it is abundantly clear that public health surveillance is as “inherently governmental” as one can imagine. It is not a good that responds to market forces. It creates a number of positive externalities (and reduces negative externalities); and a good with these characteristics is not responsive to what drives markets.^{ix}

When a private company, such as TeleTracking Technologies, takes on an inherently governmental activity like public health surveillance, there is a clear mismatch in mission. TeleTracking Technologies is driven to succeed in order to meet its obligation to ensure profits, as are all for-profit entities. Public health surveillance, however, is not a profit-driven activity. This mismatch creates a great deal of mistrust.^x

The American people have trusted the public health system to protect their communities from infectious diseases since before we were a country. The foundation of that system, the eyes and ears of public health, is public health surveillance. Without a well-functioning public health surveillance system, we will be unable to meet our fundamental duty to care for the health of our nation. And if we cannot care for the health of our nation, we cannot care for our country’s prosperity. We cannot afford to fail.

ⁱ Thacker SB. Chapter 1: Historical development. In: Lee LM, Teutsch SM, Thacker SB, St Louis ME, eds. *Principles and Practice of Public Health Surveillance*. 3d edition. New York: Oxford University Press; 2010.

ⁱⁱ Lee LM, Thacker SB. Public health surveillance and knowing about health in the context of growing sources of health data. *Am J Prev Med*. 2011;41(6):636-640.

ⁱⁱⁱ Trust for America’s Health. *The Impact of Chronic Underfunding on America’s Public Health System: Trends, Risks, and Recommendations, 2019*. Washington DC: Trust for America’s Health; 2019. https://www.tfah.org/wp-content/uploads/2020/03/TFAH_2019_PublicHealthFunding_07.pdf

^{iv} Ravinowitz PM, Kock R, Kachani M., et al. Toward proof of concept of a One Health approach to disease prediction and control. *Emerg Infect Dis*. 2013;19(12): e130265.

^v American Public Health Association. *Public Health Code of Ethics*. Washington, DC: American Public Health Association; 2019.

^{vi} National Conference of State Legislatures. Data security laws: State government. February 4, 2020. <https://www.ncsl.org/research/telecommunications-and-information-technology/data-security-laws-state-government.aspx>.

^{vii} Lee LM, Gostin LO. Ethical collection, storage, and use of public health data: a proposal for national privacy protection. *JAMA*. 2009;302:82-84.

^{viii} ABC News/Ipsos poll conducted September 2020: <https://www.ipsos.com/en-us/news-polls/abc-too-slow-on-pandemic>

^{ix} Rein DB. Chapter 3: Economic and policy justification for public health surveillance. In: Lee LM, Teutsch SM, Thacker SB, St Louis ME, eds. *Principles and Practice of Public Health Surveillance*. 3d edition. New York: Oxford University Press; 2010.

^x Marks JH. *The Perils of Partnership: Industry Influence, Institutional Integrity, and Public Health*. New York: Oxford University Press; 2019.