Written Statement of Kathryn A. Turner PhD MPH
Council of State and Territorial Epidemiologists
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Ready or Not: U.S. Public Health Infrastructure | February 24, 2021

Chair DeLauro, Ranking Member Cole, and distinguished members of the Subcommittee, thank you for allowing me the privilege to appear before you today. My name is Kathy Turner, I am a public health epidemiologist—or disease detective—with twenty years of experience in state-level public health. Currently, I serve as Idaho's Deputy State Epidemiologist and oversee the Bureau of Communicable Disease Prevention, including programs focused on epidemiology, immunization, health care associated infections, food safety, communicable disease surveillance, and refugee health. I am also the Secretary/Treasurer of the Council of State and Territorial Epidemiologists and today I am here representing CSTE.

CSTE is an organization of member states and territories representing applied public health epidemiologists. "Epidemiologist" has become a common household word during the COVID-19 pandemic. In short, our job is to investigate diseases and conditions of public health significance including outbreaks—no matter how large or small—and identify the cause of the disease, the people at risk, and how we can control the spread to stop more people from being exposed or becoming infected. CSTE's members are epidemiologists on the front lines of the COVID-19 response and all potential future public health crises. Our nation's public health infrastructure is made up of a network of state and local public health departments that understand and respond to the needs of their individual populations while also supporting and implementing national requirements, policies, and goals. CSTE members have surveillance and epidemiology expertise across all domains including occupational health, infectious diseases, environmental health, chronic diseases, injury, maternal and child health, and more.

A Modern Public Health Data Infrastructure Protects the Most Vulnerable

We are now in the second year of a grave public health crisis that has exposed deadly gaps in our public health data infrastructure. However, COVID-19 is just the latest threat demonstrating that critical upgrades to our public health data systems are needed. This is not the last public health threat we will face. It is critical for the nation to have a strong public health infrastructure. Led by the Centers for Disease Control and Prevention (CDC), state and local health departments across the country need a nationwide public health surveillance system to detect emerging health threats, and facilitate the immediate and ongoing response to containment. Public health threats are persistent and constantly evolving, here at home and overseas, be it influenza, measles, pertussis, Ebola, dengue, Zika, lead, hepatitis A, human papillomavirus (HPV), wildfires, tornados, hurricanes, e-cigarettes or vaping product use-associated lung injury (EVALI), or COVID-19.

Effective prevention and efficient, timely intervention rely on an interactive network of governmental public health agencies at the federal, state, territorial, local, and tribal (STLT) level working with health care providers and the public and private sector. Every day, this cooperative network saves lives by detecting and responding to health threats like COVID-19. Yet broad and systemic data challenges hamper our public health responses. Some recent public health emergencies, such as Zika, fungal meningitis, the opioid epidemic, and EVALI, have each shared common obstacles to rapid response, which have centered on rapid data collection, data management, and data sharing. These barriers will likely get worse unless regular, sustained investments in data infrastructure occur across all of public health.

The Data Pipeline: From Providers, to State and Local Public Health, to CDC

State and local public health officials are the foundation of every public health response—they conduct the frontline response, serve on key task forces and work groups and in pre-decisional capacities and, importantly, as part of the planning for future responses. Different levels of data are needed at different levels of government. Using the COVID-19 response as an example, let's examine the data pipeline to better understand how data gets to the people who need it and what we can do to improve this infrastructure. It is *state* law that governs disease and condition reporting and the collection of personally identifiable information. At the STLT levels, personally identifiable information is needed for case investigation and contact tracing as well as patient matching from multiple data sources. When you visit your doctor's office because you suspect you might have COVID-19, your doctor likely orders a laboratory test to confirm your diagnosis. Remember, your doctor has important information about you as a patient—your age, race, ethnicity, sex, if you are pregnant, vaccination status, other health conditions, and they also have essential demographic information including your address and phone number. After you are tested for COVID-19, the results are sent back to your doctor, and because COVID-19 is a reportable disease for public health surveillance, your doctor and the laboratory must report the information and test results (positive or negative) to the state health department. Unfortunately, while the results are typically returned to the provider electronically, they are often reported to the health department by fax or phone and they are almost never come accompanied by the crucial demographic, racial, and ethnicity data—even though your doctor has your personal data. Without that information reaching public health, contact tracing and case investigation are delayed, more time consuming, and sometimes impossible for state public health departments to do. Sadly, this impedes the public health response in the very communities public health is trying

to protect—more illness, hospitalizations, and deaths result. State laws govern the reporting of these data by providers—all states have a requirement for health care providers to report certain conditions to state and local public health departments. When data are missing, public health staff search for the missing data, but public health resources are limited and sometimes inadequate to perform this time-consuming work. In today's digital world, these data, already collected during the health care visit, can and should be provided to public health at the time of initial report. We already see that attempting to collect these data (such as race and ethnicity) after the fact, is inefficient, can be delayed, is error prone and impedes our ability to optimize policies to protect those most at risk. Policy levers, similar to those implemented by the Centers for Medicare and Medicaid Services (CMS) to encourage providers to use electronic health records are needed now to incentivize timely and complete transmission of data from health care to public health in the form of an electronic case report (eCR).

State and local public health departments also share essential data with the federal government. This information is de-identified prior to being passed on to the federal government, where it is used to develop national polices to reduce morbidity and mortality and protect those most vulnerable. Data help identify hot spots, new strains, or other emerging threats based on changes to the virus such as transmissibility or ability to cause more severe disease. We cannot (and should not) make essential policy decisions without timely and accurate data, but more importantly, we cannot develop policy without input from the experts on the ground—applied public health epidemiologists—to fully understand the data collection, aggregation and analyses gaps, challenges, or strengths.

We will need a vastly improved data infrastructure to ensure information moves faster than the spread of disease, but we must not create parallel or duplicative systems that circumvent

CDC and STLT departments where the data are needed for immediate action. CSTE supports CDC's coordinated interoperable approach incorporating data providers and public health. It is adaptable and can accommodate new data elements that meet important criteria including being assessed for feasibility and burden and ensures there is an actionable public health reason for collecting the data.

Five Pillars of Public Health Data Infrastructure

CSTE and our partners initiated the call for improved public health data systems before COVID-19, and it is now critical that we transform our existing public health data infrastructure system to live beyond this pandemic. To streamline the process outlined above, we need to focus on five pillars necessary to effectively upgrade the nation's public health surveillance system. Each of the five pillars will play a role in moving the United States from an outdated and burdensome system to a 21st Century public health data system that provides accurate, instantaneous data. The five pillars are:

1. **Electronic Case Reporting (eCR):** In an outbreak, time matters—whether the issue is vaccine and prophylactic treatment following meningococcal exposure that needs to be rapidly disseminated, measles and COVID-19 cases that need to be isolated to prevent others from becoming infected, or where vaccine effectiveness to prevent pertussis needs to be evaluated for both children and adults—time matters—and data need to be at the fingertips of public health. eCR is the automatic, seamless submission of disease reports directly from electronic health records at clinical care organizations to state, local, tribal, and territorial health departments. eCR dramatically improves disease and condition reporting and, once implemented, requires no additional work at the time of patient encounter. eCR reduces physician delays and burden in fulfilling their legal responsibility

to report, and leads to early implementation of public health interventions and limits further spread of infectious agents. eCR implementation is currently in progress with over 6,800 facilities sending electronic initial case reports to public health.[1] While still in relative infancy, eCR has the potential to dramatically transform data exchange between health care providers and public health departments. However, without widespread adoption of eCR, health departments at every level will continue to be hamstrung by outdated and slow data systems that cannot communicate with one another and put the public at risk.

2. **Syndromic Surveillance:** Syndromic surveillance provides near real-time data on every hospital emergency department visit for hourly detection and continuous monitoring of community health incidents plus the impact of natural disasters (including hurricanes), flu pandemics, and opioid overdoses. It gives public health professionals the ability to monitor the pulse of the community and identify health threats as they emerge. Most recently, syndromic surveillance has been an important mechanism for identification of vaccine adverse events. Unfortunately, approximately 30 percent of emergency departments still do not participate in public health syndromic surveillance systems.

3. **The Electronic Vital Records System:** The national system of 57 vital records jurisdictions provides secure electronic collection of birth and death data from hospitals, funeral homes, physicians, and medical examiners. It allows for timely and accurate reporting of birth outcomes and causes of death, which serve to monitor and respond to public health crises as they arise in communities, including reducing preventable deaths and infant and maternal mortality rates. Sadly, in some states, death certificates are still

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[1] https://www.cdc.gov/coronavirus/2019-ncov/hcp/electronic-case-reporting/hcfacilities-map.html

filed on paper, and nationally it still takes as much as eight weeks for death certificates to be submitted to CDC for national aggregation. It can take weeks to uncover and link the death information with case data, laboratory data, or medical examiner information. This delays the communication of meaningful information to policymakers, the media, the public, and providers who need answers. For instance, Idaho easily matches electronic death records to electronic laboratory reports and electronic case reports to determine whether the decedent is a known COVID-19 case without manual processes but not all jurisdictions have this benefit. Crucially, electronic vital records systems are also used to match against HIV registries to ensure client information is updated and accurate. This is important for monitoring whether people are in care or outreach is needed. Electronic vital records systems need to be improved across the country.

4. **Laboratory Information Systems:** Laboratory Information Systems are the backbone of how laboratory data is collected, managed, and shared to inform public health decision-making. The Laboratory Response Network (LRN) is comprised of specialized laboratories that can respond to biological/chemical threats and other public health emergencies with advanced testing capabilities. Electronic Laboratory Reporting (ELR) is the electronic reporting of laboratory results from *private* and public health laboratories to disease detectives and investigators in state, local, tribal, and territorial public health departments. In the effort to ensure timely communication of disease spread, ELR and eCR go hand in hand. The only way to ensure timely communication is to create a system in which both are fully integrated. Finally, laboratory orders to public health laboratories are still nearly all paper-based and, as a result, orders can be delayed and can be missing complete information.

5. **The National Notifiable Disease Surveillance System (NNDSS):** The NNDSS is a system that collect vital individual case investigation data at state, local, tribal, and territorial public health agencies from hospitals, physicians, and labs, then sends deidentified data to CDC to create a national understanding of disease burden. This information is used to respond to public health threats of all kinds (both infectious and non-infectious) and is the first line of health security defense.

Without a modern public health data infrastructure in place, we will continue to face obstacles to optimally respond to any and every emerging public health threat. Right now, we continue to face challenges to addressing COVID-19. For instance, Multi-System Inflammatory Syndrome in Children (MIS-C) is not diagnosed in a laboratory. As a syndrome, it is provider reported and demonstrates the importance of eCR. The status quo of phone calls and multiple paged faxed medical records are difficult to manage and result in delayed discovery of this dangerous complication. As we roll out COVID-19 vaccines, interoperability between disease surveillance systems and vaccine registries needs to be in place as well to allow for rapid identification of vaccine breakthrough cases. And, as non-traditional point-of-care tests or at home tests come into widespread use, there is often no electronic way for these data to be reported to public health.

Today, data sharing with public health is slow and cumbersome but data are also vulnerable. With sophisticated cybersecurity threats, it is critical that public health systems are continuously equipped to prevent and respond to cyberattacks. Health care providers are required to report diseases and conditions to public health departments at STLT. These health records contain sensitive personal information—required to be reported and protected by state laws—and they demand significant care in handling to protect the privacy and safety of patients, particularly

since such systems are increasingly the target of hackers. To get data faster, investments must be made to build the public health data superhighway to enable any type of public health data to be electronically shared securely, quickly and efficiently. This is the only way to establish a system that supports detailed monitoring of the spread of infectious disease, including how the disease impacts different and disparate populations. A modernized data system with interoperability between public health and health care would also allow more complete collection and tracking of demographic data, enabling us to pinpoint populations who are disproportionately impacted by an emerging infection and target them for testing and treatment.

Public Health Workforce

Disease surveillance and data collection require a combination of data scientists, informaticians, and epidemiologists with enhanced data skills. Thus, another essential component of public health data modernization is a competent public health workforce with adequate capacity to respond to threats. CSTE's Epidemiological Capacity Assessment (ECA) workforce report (last published in 2017) serves as a guideline for epidemiological capacity and is released every few years. The 2017 ECA recommended an additional 1,200 epidemiologists be added to the state epidemiology workforce—an increase of 36 percent. Additional epidemiologists are needed at the local, tribal and territorial public health levels. The next ECA report is scheduled to be conducted this year and will be an important resource in continued efforts to keep our country safe from future outbreaks.

Public health data workforce needs are not limited to epidemiologists. Experts, including public health informaticists, and data scientists help ensure that the public health surveillance system meets the needs when the next pandemic occurs. A robust and successful epidemiological workforce requires sustained investment by the federal government; we need to support public

health data modernization, and put in place a workforce that is capable of maintaining and growing this system as needed.

Conclusion

We do not have a science problem; we have a resource problem. With proper, sustained resources, all jurisdictions could come online with the core public health data systems and CDC could build its own secure platform to receive electronic data from the states. We are not out to reinvent the wheel. The core data systems for a national infrastructure already exist, have demonstrated value, and are used to varying degrees in state and local health departments. To achieve a modernized public health data infrastructure requires significant federal investment and a commitment by Congress to see the project through in the near and long term. For years, CSTE and our partners have been advocating for funding for the five pillars of data modernization. We need regular, sustained annual funding at the CDC *and* supplemental funding to help us move more quickly during the COVID-19 response.

We applaud Congress' investment to date ($600 million through Fiscal Year 2020 and 2021 funding and the CARES Act) and the inclusion of language authorizing activities to improve the public health data systems at the CDC in the Consolidated Appropriations Act for Fiscal Year 2021. This provision will ensure that timely investments in our nation's public health infrastructure go toward the most necessary updates. These are critical investments, but to truly transform our public health data system and ensure it is prepared to respond to all future threats we need robust, sustained annual funding for the public health Data Modernization Initiative at the CDC. We respectfully request the Subcommittee continue to provide sustained annual funding of *at least* $100 million for the public health Data Modernization Initiative at CDC. Thank you.