Janet Hamilton, MPH

Executive Director, Council of State and Territorial Epidemiologists

Janet Hamilton, MPH, assumed the role of CSTE's Executive Director in April 2020. As Executive Director, Janet works directly with the Executive Board and senior management team to lead and shape CSTE's mission of advancing the field of applied public health epidemiology in the U.S. Janet received her Master of Public Health in Epidemiology from the University of Michigan and is a graduate of the American Medical Informatics Association (AMIA) 10 X 10 program. She was a member of CSTE's Executive Board, serving from 2011 to 2015 as the Surveillance and Informatics Steering Committee Chair and was CSTE President from 2017-2018.

Janet is an epidemiologist with over 15 years of public health work experience at the national, state, local, tribal, and territorial levels overseeing policy development and liaising with CSTE members and strategic partners. She started her career as fellow in the Florida-based Epidemic Intelligence Service with the Florida Department of Health in 2003 where she focused primarily on conducting outbreak investigations. Prior to her selection as Executive Director, Janet served as CSTE's Senior Director of Science and Policy, leading organizational efforts to strategically combine applied epidemiology science with policy efforts to advance public health and applied epidemiologic public health practice. One focus of her work at CSTE has been to lead public health surveillance data modernization through the "Data: Elemental to Health" campaign, which seeks to secure $1 billion in federal funding over 10 years to support this foundational need.

In her previous role with the Florida Department of Health, Janet played leadership roles in Florida's response to 2009 H1N1, MERS-CoV, Zika, fungal meningitis, Deep Water Horizon Gulf oil spill, 11 major hurricanes including the 2004 season where the state was impacted by four major storms, the threat of imported Ebola from West Africa in 2014 and other outbreaks and public health events. She oversaw

both the design, development and maintenance of the disease/condition surveillance systems themselves, as well as the rules and regulations to support data collection efforts. Additionally, she oversaw Meaningful Use activities for the Florida Department of Health in the areas of electronic laboratory reporting and syndromic surveillance. Her efforts developing and running the Florida Department of Health's infectious disease surveillance systems made Florida a leader in innovation in both reportable disease and syndromic surveillance.

Janet's work has been recognized in 2011 with the receipt of the Healthcare Information and Management Systems Society (HIMSS) Davies Award for positively impacting population health by optimizing health information technology. She has also been actively involved in numerous national committees to advance public health surveillance. At CSTE, she continues her work to support effective public health surveillance and sound epidemiologic practice through training, capacity development, and peer consultation.

Written Testimony
House Committee on Science, Space, and Technology
Subcommittee on Investigations and Oversight
Data for Decision-Making: Responsible Management of Data During COVID-19 and
Beyond
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Statement of Janet Hamilton, MPH
Executive Director, Council of State and Territorial Epidemiologists

Chairman Foster, Ranking Member Norman, and distinguished members of the

Subcommittee, thank you for allowing me the privilege to appear before you today. I am Janet

Hamilton, Executive Director of the Council of State and Territorial Epidemiologists (CSTE). I

am an epidemiologist with over fifteen years of experience in public health, formerly serving in

the Florida Department of Health where I oversaw disease surveillance programs, both the

epidemiologic scientific content and the surveillance systems that support them. I now head

CSTE, an organization of 56 member states and territories representing applied public health

epidemiology that serves as the professional home for 2,000 applied public health

epidemiologists or "disease detectives" nationwide. Like in other outbreaks, we are the

epidemiologists in state, territorial, local, tribal health departments on the front lines of the

COVID-19 response. CSTE and its members work tirelessly to respond to and protect the

public's health, a role that has never been more important than it is today. Thank you for the

opportunity to testify before the Subcommittee regarding "Data for Decision-Making:

Responsible Management of Data During COVID-19 and Beyond," an issue of incredible

importance to CSTE, our partners, and the American people.

COVID-19 has exposed deadly gaps in our nation's public health data infrastructure. Now more

than ever it is critical for the Centers for Disease Control and Prevention (CDC) and state and

local health departments across the country to have a strong national public health surveillance system that detects and facilitates the immediate response to and containment of emerging health threats. Unfortunately, that is not the case today. The COVID-19 pandemic demonstrates many of the issues we face are due to a *consistent failure over many years* to invest in the public health infrastructure. Whether it's influenza, measles, pertussis, Ebola, dengue, Zika, lead, hepatitis A, human papillomavirus (HPV), wildfires, tornados, hurricanes, e-cigarette or vaping product use-associated lung injury (EVALI), or now COVID-19, public health threats are persistent and constantly evolving here at home and overseas. Effective prevention and efficient, timely responses rely on an interactive network of governmental public health agencies at the federal, state, territorial, local, tribal (STLT) levels working with health care providers and the public and private sector. Every day, this cooperative network saves lives by detecting and responding to COVID-19 and other health threats.

Existing gaps include:
- A lack of seamless interoperable data sharing to public health from health care and across public health;
- Absence of a robust process to order COVID-19 laboratory tests electronically that supports 'at the time of test order' collection of even the *minimal* information needed to initiate a rapid public health response;
- Laboratories are unfamiliar with electronic laboratory reporting and are faxing paper results instead of sending files in electronic machine-readable formats or are changing formats multiple times without communicating with the health department—leading to unusable files and test results;

- Nearly absent electronic case reporting to share data between health care and public health at the STLT;

- Emergency departments not participating in public health syndromic surveillance systems; and

- Death certificates not being filed electronically.

Months into this response, these gaps lead to slow, cumbersome and incomplete data exchanges, resulting in sluggish efforts to respond effectively with the speed and intensity the COVID-19 pandemic demands. The absence of information is a very dangerous thing. It leaves public health officials blind to the pandemic.

To respond successfully to COVID-19—or a future pandemic—we need a vastly improved data infrastructure that ensures information moves to public health at pace with the spread of disease. In a time when many industries have transitioned quickly to working digitally, the United States is operating an antiquated public health system that relies on *sluggish* paper records, phone calls, faxes, and spreadsheets that often require manual data entry. All of this has allowed the disease to outpace our response—the disease is moving faster than the data.

A robust, interoperable public health data system is the key to responding to any public health emergency, particularly a pandemic of the magnitude of COVID-19. State laws governing and requiring disease reporting and receipt of these data during a pandemic like COVID-19 is how state public health officials know where the virus is surging and who is most impacted and most at risk. Public health officials in your home states are asking the same questions you and your

constituents are asking. How many cases of COVID-19 are there in my area? Where will the next hotspot be? When can we open schools safely? Are there cases in my children's school? Are hospitalizations in children or pregnant women increasing? As some schools re-open, are there also increases in Multisystem Inflammatory Syndrome in Children (MIS-C)? Where are the types of places that people most likely to be exposed and then become infected? Are we starting to see cases of re-infection? Are there so many infections occurring in my community that activities are no longer safe? Your state public health officials need access to data to understand how the virus is progressing and to make the decisions necessary to contain it. In order for these questions to be answered, the data must flow from the health care setting (doctor's offices, laboratories, and outbreak settings) into public health at the STLT level. Disease detectives conduct interviews to learn detailed information about when and how people became infected and identify their contacts. Additionally, the reports are aggregated from *all* these settings, de-duplicated, de-identified and then passed onto CDC and federal partners for national policy setting. Data security is paramount to the infrastructure.

Tragically, many reports are missing valuable information, delayed or in many instances never made. For example, many jurisdictions indicate laboratory reports have three major problems:

1. Illegible, hand-written results—these often come from point of care testing locations using rapid tests. These tests have no infrastructure deployed with them to ensure the results can be reported electronically; some health departments report hiring more than 50 staff just to handle incoming data entry and decipher records, yet still have lags handling tens of thousands of reports daily.

2. Thousands of results that don't have enough information for the state/local health department to act upon—a name and a positive/negative result and that is all—no street address, county of residence, zip code, phone number, race or ethnicity.

3. Thousands of results from laboratories unfamiliar with reporting through structured electronic reporting formats, and changing and updating file types without communicating with public health, structures creating data mis-matchings and they can't be read or processed. (This is like putting the bank routing number in a different place, or reversing it with the account number—the machine cannot process the info and it errors out). Mismatched and duplicative data must be rapidly identified and corrected by public health. All of these facilities need support and training from the health department staff, and staff time to consult with facilities providing information to correct file submissions and mitigate further errors.

Jurisdictions report missing street address and phone number as much as 50% of the time, and data for race and ethnicity are missing as much as 80-85% of the time—despite state laws that require providers to report these data and require them to be stored in electronic health records. Because the nation's public health infrastructure is so fragmented and antiquated, even when health care providers already have the data stored and collected in electronic health records they cannot rapidly share these health data with public health. This environment leads to increased challenges on fatigued, exhausted providers to report—or delays and failures to report—and inefficiency and frustration on the part of patients, care providers and public health professionals.

In any outbreak, time matters—whether the issue is vaccine and prophylactic treatment following meningococcal exposure, which needs to be rapidly disseminated, or measles and COVID-19 cases who 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, or where COVID-19 which threatens the lives of minorities in greater proportion and highlights longstanding racial health disparities—time matters—and data needs to be at the fingertips of public health. Further 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 the transmission of data from health care to public health in the form of an electronic case report. Electronic case reporting, or eCR generates information directly from the patient's electronic health record and with no additional clicks by providers, sends that information to public health with test results. Since EHRs include complete patient information entered by providers, it includes information not only about race and ethnicity, but pregnancy status, treatments, co-morbidities, and vaccination status—all critical information state/local public health departments need to gather when conducting case investigations to pass data onto CDC. Electronic case reporting is the transformation public health needs—and has been requesting for years.

Death certificates were one of the first sources of public health surveillance data. When we look at COVID-19 mortality data, every death certificate tells a story. COVID-19 mortality data when viewed collectively, uncover health disparities, inform policy and funding decisions, and improve outbreak and disaster response efforts. Sadly, in some states, death certificates are still filed on paper, and nationally it still takes as much as 1 – 8 weeks or more for death certificates

to be submitted to CDC for national aggregation. The estimated number of excess deaths alone, now over 200,000, tragically tells the story of the devastating impact of COVID-19 (https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm). But it can take weeks to uncover and link the death information with case data, laboratory data or medical examiner information in order to communicate meaningful information to policymakers, the media, the public, and providers who need answers to questions—where did the deaths occur and what populations are most vulnerable? What immediate steps can be taken to prevent more deaths based on today's data? Unfortunately, because of the lag in paper-based data systems and lags caused by the non-integration of key public health data systems, public health officials are hampered to provide fast, high-quality answers the public wants, needs, and expects in our technologically capable world.

As the nation's leading public health agency, CDC is charged with protecting the nation's health. CDC has been at the forefront of responding to every major public health crisis since its founding—including COVID-19. CDC's experience with data collection, analysis, and dissemination is an essential part of our nation's effective response to COVID-19. CSTE supports CDC's coordinated 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 ensuring there is an actionable public health reason for collecting the data. The sudden change in hospital capacity reporting announced earlier this summer did not adhere to our guiding principle to coordinate across the response and to strengthen our public health infrastructure at all levels – STLT, CDC and data needs within HHS. Any further changes should be adequately vetted with STLT input to avoid confusion in

responding to a public health emergency that is managed in many aspects at the state level. It is not about the technology we are using; it is about the process and we must ensure that process includes public health rather than ignoring them. If we are going to implement new technology and new IT platforms, we should include public health and ensure the transition is done with input from STLT and CDC.

In our response to COVID-19 we have seen an unfortunate lack of engagement between federal and state officials. State and local public health officials have been key parts of every public health response to date serving on key task forces and work groups, in pre-decisional capacities, and most importantly, as part of the planning for future responses. Different levels of data are needed at different levels of government in this response. At the STLT, personally identifiable information is needed for accurate counting and de-duplication prior to passing this information onto the federal government. For example, in the case of point-of-care COVID-19 test results STLT public health need access to the identifiable results – to conduct case counting and de-duplication, case interviews, contact tracing etc., to identify where the tests were performed and if they were part of an outbreak, assess health disparities; the federal-level needs de-identified data in aggregate. State public health officials must have direct and regular access to federal officials to help effectively contain the virus in their regions and ensure that decisions to collect necessary data are informed by those who will use it across all levels of the response. We cannot (or should not) make essential policy decisions without input from experts on the ground to fully understand the data collection, aggregation and analyses gaps, challenges, or strengths.

An essential part of communication in a public health emergency are data and data transmission. Before COVID-19 public health data was a little known and little thought about challenge outside of the public health world. As evidenced by the topic of this hearing, data is finally being recognized outside public health as a keystone for public health, but unfortunately, our years of neglect for this essential infrastructure have left us debilitated during the COVID-19 pandemic.

Finally, our focus today is on COVID-19 data challenges, but as a public health professional who works across disciplines, I must reflect these public health data challenges are broad and systemic and hamper our public health responses beyond COVID-19 to other critical but non-infectious disease threats. When I reflect upon some of the recent public health emergencies, such as Zika, fungal meningitis, the opioid epidemic, and EVALI, one of the common critical stumbling blocks to rapid response has centered on data collection, data management, and data sharing. I fear that this will continue and worsen, unless investment in data infrastructure occurs across all of public health. Data sharing with public health is slow and cumbersome but they are also vulnerable. With sophisticated cybersecurity threats, it is critical that public health systems are 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 frequently the target of hackers.

Fortunately, there are solutions and we can (and have) started to implement them, but this will take a coordinated, sustained approach between state and local public health, the CDC, Congress

and the federal government. We need to move now, we need to move fast, and most importantly, we need to do all of this with public health in the lead.

CSTE and our partners—the Association for Public Health Laboratories (APHL), the National Association for Public Health Statistics and Information System (NAPHSIS), and the Healthcare Information and Management Systems Society (HIMSS)—together with more than 90 other institutions representing patients and consumers, public health professionals, health care providers, and health systems have been working to increase funding to build a public health data super highway of the 21st Century to speed the seamless exchange of data for all diseases and conditions, to *predict* and *prevent* public health threats before they occur and to allow rapid response when they do occur. This interstate system of systems will seamlessly and securely collect sensitive data about diseases and conditions from health care providers and report it automatically to public health departments, link it to other key data—including birth and death records and immunization registries—and where required to be reported nationally, share that data seamlessly and securely with CDC.

We started our work *before* COVID-19, and the system we build must live beyond COVID-19, but we are faced with an emergency to which we must respond now. For COVID-19 and beyond it is critical that we transform our existing public health data infrastructure. There are five key pillars necessary to transform the nation's public health surveillance system—some of them are already under way, some of them are already showing progress, each of them builds on existing systems and platforms, but ALL of them are essential to a completely interoperable public health data system. Each of these pillars will play a key 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 key pillars are:

1. ***The National Notifiable Disease Surveillance System (NNDSS)***, which collects vital individual case investigation data at state, local, tribal, and territorial public health agencies from hospitals, physicians, and labs, then sends this data to CDC to create a national understanding of disease burden. This information is used to respond to public health outbreaks and is the first line of health security defense.

2. ***Electronic Case Reporting (eCR)***, which 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/condition reporting and reduces physician burden in fulfilling their legal responsibility to report, which leads to early implementation of public health interventions and limits further spread of infectious agents.

3. ***Syndromic Surveillance***, which 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.

4. ***The Electronic Vital Records System***, which is a national system of 57 vital records jurisdictions that provide 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.

5. *Laboratory Information Systems*, which 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 labs to disease detectives and investigators in

state, local, tribal, and territorial public health departments.

For further information about the need to modernize the public health data systems and

workforce, please see CSTE's report, "Driving Public Health in the Fast Lane: The Urgent Need

for a 21st Century Data Superhighway" at http://resources.cste.org/data-

superhighway/mobile/index.html.

We are not out to reinvent the wheel. The core data systems for this infrastructure already exist,

have demonstrated value, and are used to varying degrees in state and local health departments.

We do not have a science problem; we have a resource problem. With the proper, sustained

resources all jurisdictions could come online with the core systems and CDC could build its own

secure platform to receive electronic data from the states.

To achieve a modernized public health data infrastructure requires significant federal investment

and a commitment by Congress to see the project through in the long term. CSTE and our

partners have been advocating for several years now for funding for these pillars—both for regular, sustained annual funding at the CDC as well as supplemental funding to help us move more quickly during the COVID-19 response.

Between Fiscal Year 2020 funding and the Coronavirus Aid Relief and Economic Security (CARES) Act, Congress has provided $550 million for the Data Modernization Initiative (DMI) at the CDC. We are grateful for this foundational investment that will allow the agency to begin to allocate funding towards the five pillars and to states and local health departments to make initial upgrades to their systems. This existing funding is critical, but I must emphasize that it cannot be a one-time investment. States will simply not be able to adopt fully upgraded public health data systems with just one injection of federal funds. For the current system to truly evolve, the federal government must commit to long-term funding to complete essential system upgrades both federally and at the state and local level and to maintain these upgrades annually as technology improves. The Data: Elemental to Health campaign commits to continued advocacy for robust, sustained funding to complete and sustain the DMI well into the future and Congress must do the same.

Equally important: we must ensure that federal funding allocated to DMI is spent on DMI. While it is true that certain improvements are urgent and some funds must be spent on issues related to COVID-19, we understand Congress' intent in providing $550 million was to support long-term public health data improvements. CDC must use this money both to make immediate investments to upgrade the systems necessary to bring the pandemic to an end **and** to deliver the

necessary funding to the five pillars and facilitate a true transformation of America's public health data system.

Both chambers of Congress have recognized the importance of completing the DMI and, separately, have passed legislation authorizing the project. Language included in the House-passed Health and Economic Recover Omnibus Emergency Solutions (HEROES) Act would authorize the essential comprehensive improvements to our public health data systems that I have discussed today. The Senate passed similar language as part of the Lower Health Care Costs Act in 2019.

Over the past six months we have witnessed the failures of an outdated public health data infrastructure. We need to act now to make changes that will help us emerge from the ongoing COVID-19 pandemic and we need to make certain that we prepared for the next threat we face. COVID-19 will not be our last public health crisis.

Again, thank you for the opportunity to testify before the Subcommittee today.