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Appropriations Committee
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
In Support of FY 2023 Funding for CDC's Data Modernization Initiative

Chair DeLauro, Ranking Member Cole, and members of the Subcommittee, thank you for the opportunity to submit this testimony in support of at least $250 million in Fiscal Year (FY) 2023 funding for the Data Modernization Initiative (DMI) and the Center for Forecasting and Outbreak Analytics (CFA) at the Centers for Disease Control and Prevention (CDC). I am Janet Hamilton, the Executive Director of the Council of State and Territorial Epidemiologists (CSTE). CSTE represents public health epidemiologists nationwide working on the front lines to respond to emerging public health threats—including, recognizing and identifying the very first introductions of COVID-19, and then responding daily during the COVID-19 pandemic.

As you know, COVID-19 exposed deadly gaps in our nation's public health data infrastructure. After years of neglect, our antiquated public health data systems were not prepared to handle the onslaught of a pandemic caused by a highly infectious virus. Instead, paper-based systems, phone calls, spreadsheets, and faxes requiring data entry by hand remain in widespread use and left us ill-equipped to combat the spread of the virus as it emerged and surged. Delayed detection and response had dire consequences. And, while COVID-19 is the most recent—and ongoing—threat that requires a robust public health response, it is not the only threat we face nor last public health threat we will face. As we submit this, an outbreak of Monkeypox in the US and other non-endemic countries is occurring and a new emerging threat leading to unexplained hepatitis in children is emerging – illnesses (potentially due to adenovirus) can be severe, associated with hospitalization and liver transplants in some children. Led by the CDC, state and local health departments across the country need a nationwide public health surveillance system to detect emerging threats and facilitate immediate response to keep our population safe.

Prior to the COVID-19 pandemic, CSTE initiated the call for improved public health surveillance systems. The pandemic only made it clear that this goal cannot wait. With our partners at the Data: Elemental to Health Campaign we called on Congress to provide the first ever dedicated funding for public health data systems and to build a 21st century public health data superhighway. Thanks to the work of this Subcommittee, Congress answered the call and has provided more than $1 billion to date in annual funding as well as critical injections of supplemental funding through the CARES Act and the American Rescue Plan for CDC's public health DMI.

The DMI is a commitment to building the world-class data workforce and data systems that support daily operations and are 'response-ready' for the next public health emergency with capacity to surge and scale. We need far more resources to meet our nation's current and long-term public health surveillance needs, which Data: Elemental to Health estimates will cost at least $7.84 billion over five years. In the immediate term, we need robust, sustained, annual funding for DMI to ensure we are providing resources for public health systems and infrastructure, including at state and local health departments, to keep pace with evolving technology.

DMI is an enterprise approach and there are five key interconnected pillars essential for public health data modernization. They are: Electronic Case Reporting, the National Notifiable Disease Surveillance System, the Electronic Vital Records System, Syndromic Surveillance, and Laboratory Information Systems.

We need electronic Case Reporting (eCR) to give health care providers a means to seamlessly communicate with public health. eCR will help guarantee that when providers see patients—in any setting—patient demographics, clinical information, and test results for reportable conditions (including, but by no means limited to COVID-19) are rapidly shared with state and local public health and then able to be seamlessly incorporated into CDC's National Notifiable Disease Surveillance System (NNDSS). eCR also assists with data completeness and rapidly understanding health inequities. DMI investments in eCR are already paying off. For example, race and ethnicity

data received on case reports in pilot jurisdictions are over 90% complete which will support a more robust ability to appropriately address health disparities. All 50 states, DC, and Puerto Rico, as well as 13 jurisdictions have received initial electronic case reports for COVID-19 ad more than 18 million COVID-19 case reports have been sent electronically to public health agencies.

Resources are needed to make improvements in NNDSS and rapid data submission from states to CDC. For example, state, territorial, local, and tribal health department staff serve as disease detectives contacting and interviewing cases gathering detailed information to learn how and where they may have become infected—are they part of a cluster or outbreak, or what co-factors may have led to a more severe illness? For example, during the Zika response, case investigations conducted by the local health department identified persons working on elevators were at increased risk of infection as standing water often collected in the bottoms of open-air elevator shafts serving as breeding location for mosquitos. After case investigations and interviews are conducted, resources are needed to provide those details to the CDC through NNDSS. Numerous similar examples exist for COVID-19 where health department staff conduct outbreak investigations or identify clusters from genomic sequencing but are unable to electronically share those data with CDC's NNDSS due to agency infrastructure shortages. Additionally, right now, there are multiple jurisdictions who have the desire to provide more detailed COVID-19 case information to CDC, but don't have the data work force and resources to update file structures and data processes to submit those data.

We need an electronic lab test ordering and result process that supports the collection of information to launch a rapid public health response. Seamless electronic communication is critical—a health department forced to sort through mailed or faxed lab reports will not be able to respond promptly or adequately to an emerging threat. Investments here have also shown early success. Electronic laboratory reporting (ELR), which has been expanded to have implementions across the country, formed the backbone of our case surveillance for COVID-19, enabling states, localities, territories, tribes and the federal government to have timely information to identify

potential cases, where those cases lived, and basic information about their age. Without ELR we would never have been able to conduct control measures and know what was happening in virtually every jurisdiction. While we still have many laboratories to incorporate into ELR, in many jurisdictions this information is automatically uploaded and ready for analysis within a day of the result. These digital roads must be maintained as new tests or test types are added and performed in the laboratory.

We need improvements to our electronic vital records systems to ensure real-time transmission of birth and death data for statistical and—critically during a pandemic—surveillance purposes. We must make sure systems are interoperable so physicians, coroners, medical examiners, and funeral directors can seamlessly report deaths through their existing electronic records systems—eliminating delays and reducing errors.

Standards-based interoperability will also help identify threats as they emerge. As it stands, nearly one third of all emergency department visits are not reported to the National Syndromic Surveillance Program, which helps detect, monitor, control and prevent emerging diseases.

These five pillars are interwoven, and each plays a key role in moving the United States from an outdated and burdensome patchwork of systems to a 21st Century public health data infrastructure that provides complete, accurate, and instantaneous data. Again, DMI is an enterprise-wide approach, which will support widespread and rapid access to public health data for all public health programs at all levels of government for all diseases and conditions. Currently, CDC has many siloed public health surveillance systems, many of which are not interoperable, which results in duplicated and redundant data entry or data submission. DMI will help break down those siloes and ensure all systems are integrated and interoperable.

Equally important is a skilled workforce that includes epidemiologists, public health informaticists, data scientists, and other experts—all of whom work together so that the public health surveillance system can detect and monitor current threats and ready for the next pandemic.

The Administration has committed to strengthening our nation's public health workforce, including epidemiologists and data scientists and we urge the committee to continue to provide resources towards this goal, an important step forward to grow and build the next-generation public health workforce and we hope to see the committee support continued funding to sustain this progress.

Working hand-in-hand with DMI, CDC's newly established CFA will facilitate the use of data, modeling, and analytics to improve pandemic preparedness and response. The CFA is already doing critical work, including helping to inform government response to the spread of the Omicron variant of COVID-19 in late 2021.

We do not have a science problem; we have a resource problem. The core data systems for a national infrastructure already exist they must be modernized and maintained so they can keep pace with new technology.

CSTE applauds President Biden for proposing an unprecedented investment in CDC through his discretionary budget request. The President requested $10.675 billion for CDC. As part of this significant and well-warranted proposed increase, the President "prioritizes investments that will modernize public health data collection, increase capacity to forecast and analyze future outbreaks, and operationalize lessons learned from the COVID-19 response." We also support the President's proposal to invest $81.7 billion in mandatory funding toward pandemic preparedness efforts, including $28 billion for CDC to invest in critical efforts, including public health infrastructure and DMI. We encourage Congress to make this proposal a reality.

To make our public health systems work now, and in the future, we need regular, sustained annual funding for our public health surveillance. We respectfully request the Subcommittee provide funding of *at least* $250 million for DMI and $50 million for CFA at CDC in Fiscal Year 2023.

Thank you.