

Statement of Janet Hamilton, Director, Science and Policy
Council of State and Territorial Epidemiologists

Chair DeLauro, Ranking Member Cole, and other members of the subcommittee, thank you for the privilege of appearing before you today. I am Janet Hamilton, Director of Science and Policy at the Council of State and Territorial Epidemiologists (CSTE). CSTE is organization of 56 member states and territories representing applied public health epidemiology and serves as the professional home for 2,000 applied public health epidemiologists nationwide. As the subcommittee works on the fiscal year (FY) 2020 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we respectfully request that you appropriate \$100 million in FY 2020 to the Centers for Disease Control and Prevention's (CDC) Public Health Scientific Services for a new, cross-cutting initiative that will transform public health and save lives.

This initial down payment, as part of a \$1 billion investment over the next decade, would allow CDC, state, local, tribal, and territorial health departments to move from sluggish, manual, paper-based data collection to seamless, automated, interoperable, and secure data systems that yield critical health information in real-time. This funding would also support efforts to modernize the public health workforce by training, recruiting (e.g., student loan repayment and fellowships), and retaining skilled data scientists. Data systems require adept staff to use them, maintain them, interpret the data, and develop and deploy actionable public health interventions to save lives.

Whether it's Ebola, dengue, lead, wildfires, or tornados, public health threats are persistent and consistently 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, local, tribal, and territorial levels working with health care providers and the

public. Each day, this cooperative network saves lives by detecting and responding to health threats, like *E. coli* contaminated lettuce, measles, influenza, opioid overdoses, Zika, and more.

Unfortunately, the nation's public health data systems are antiquated, rely on obsolete information sharing methods, and are in dire need of security upgrades. Lack of interoperability, reporting consistency, and data standards leads to errors in quality, completeness, timeliness, and communication. Sluggish, manual processes—paper records, phone calls, spreadsheets, and faxes requiring manual data entry—*still in widespread use* have important consequences, most notably delayed detection and response to public health treats of all types: chronic, emerging, and urgent. Rapid advances in data science and evolving cybersecurity threats demand public health professionals with new skills to protect, defend privacy, and securely integrate health data.

In my experience on the front lines of public health emergency detection, prevention, and response as a Florida epidemiologist during the 2009 H1N1 influenza pandemic, locally acquired dengue outbreak, Deepwater Horizon Gulf oil spill, multistate fungal meningitis outbreak, Zika, 11 major hurricanes, the opioid epidemic, and now in my role representing state and local epidemiologists nationwide, I have seen first-hand and heard from colleagues about the challenges and frustrations with the current data infrastructure. For example:

- My colleague in Pennsylvania, working in concert with CDC and the Agency for Toxic Substances and Disease Registry (ATSDR), is responding to a manufacturing plant “bad actor” that has released lead into the air. The community understandably wants answers about their health: What are our blood levels? How many people and children have been tested? How do they compare to other communities? Does my child need to be tested? Unfortunately, those questions can't be answered with today's data, because while health care facilities have data stored in electronic medical records, data are sent on paper to the

health department and the stacks take time to enter and process. Included as an appendix are examples of the millions of hand-written, paper lab reports that I received while in Florida.

- After the hurricanes in 2017 and 2018, colleagues in North Carolina and Puerto Rico were asked by policymakers, the media, and the public about the number of hurricane related deaths—where did they occur and what populations were most vulnerable? What immediate steps could be taken to prevent more deaths based on the data? Unfortunately, because of the lag in paper-based data systems, neither the North Carolina officials nor the Puerto Rico officials could give fast, high-quality answers the public wanted, needed, and expected.
- More recently, a colleague shared a story from the frontlines of the *E. coli* lettuce outbreak, where public health professionals took pictures of their computer screens to share via text messages images of lab reports from implicated food samples identifying the linkage to human illness. Why? Because key electronic data systems storing epidemiologic and laboratory data had no way to seamlessly share the information and speed the response.

These modes of data sharing are slow and cumbersome. 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. 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.

The nation's public health infrastructure is so fragmented and antiquated that health care providers who *already have the data stored and collected in electronic health records* cannot

rapidly share these health data because public health departments cannot receive them electronically. This environment leads to an increased burden on providers to report—or delays and failures to report—and inefficiency and frustration on the part of both care providers and public health professionals. It leads to lost time, lost opportunities, and lost lives. For in any outbreak—where *E. coli* contaminated lettuce or *Listeria* contaminated ice cream must be recalled, where measles patients need to be isolated to prevent others from becoming infected, where influenza threatens the lives of pregnant mothers—time matters. Data matters.

Public health professionals, providers, policymakers, and the public will all agree that we need more, better, faster, and secure data to protect health. To date, in our quest for better data, we have taken a piecemeal, fragmented approach. When a new disease emerges, such as Zika, Congress has funded standalone data systems at CDC to support the response. But this funding approach is inconsistent and doesn't support an invested, sustainable approach in detection and prevention *before* an event, instead waiting and allowing multiple people to become ill because the *data is moving slower than the disease*. For example, during the Zika response, emergency funds came to Florida months after the initial cases were identified. While Congress's support and funding during emergencies is critical to support a response, a well-planned, long-term, optimal data collection and data system management is not 'one and done'.

CSTE and our partners in this effort—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 80 other institutions representing patients and consumers, public health professionals, health care providers, and health systems believe the time has come to step up and take a coordinated, comprehensive, strategic approach to building a public health data super

highway of the 21st Century. 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 where required to be reported nationally, share that data seamlessly and securely with CDC. Once built, you can put any “car” or data you want on this interstate, whether a “car” for opioid, Zika, or gun violence.

And while our proposed *approach to funding* this IT modernization is new, what we’re proposing isn’t. The data systems that feed this public health information superhighway already exist, have demonstrated value, and are used to varying degrees in all state and local public health departments. What we need is to bring all jurisdictions online with all of these systems, and to modernize receiving, sharing, and connecting data that exists in silos. In addition, CDC needs its own secure data platform to receive data electronically from the states via the National Notifiable Disease Surveillance System.

CSTE hopes in your ongoing deliberations on FY 2020 and beyond you will consider the need for a modernized, electronic, interoperable public health data system and a new generation of skilled public health data scientists. **Data and workforce are the lifeblood of public health action.** We recognize the need for lawmakers to raise discretionary the caps to avoid devastating spending cuts to public health and all domestic programs. We also recognize this effort must be funded with *new* money, rather than cut already underfunded public health programs. A robust, sustained commitment to transform today’s public health data system will ultimately improve Americans’ health. We look forward to working with the subcommittee in these endeavors and hope you will turn to the CSTE as a resource in the future. Thank you very much for the opportunity to testify before you today.

ADDENDUM

Example: Lead test results received by the Florida Department of Health as submitted by a private provider to fulfill required lead test result reporting, August 2018, January 2019.

Patient information, test results, and reporting provider information difficult to read and creates delays in identifying the patient as well as recording the data in the health departments data system necessary to identify any community increases in blood lead, respond and implement control measures. While these examples are lead data, **data across all diseases and conditions** are regularly submitted and received via paper by private providers to public health.

P 2/2

specimen type: capillary

Reporting physician office name and address

8/13/2018

Instructions: Please provide complete information for each patient. Do not use cursives; information must be legible for data entry purposes. This information where the information cannot be obtained. All blood lead levels $\geq 10 \mu\text{g/dL}$ must also be reported to your local county health department. Fax the completed form daily to Florida CHAD (Childhood Lead Poisoning Prevention Program): 880-245-4204 / 850-922-8473

Specimen Type: Capillary

Address: 5266 Office Park Blvd, Suite 207, Bradenton, FL 34203

Telephone Number: 941-755-7000

Facsimile Number: 941-755-7088

Collection/Result Date: 8/13/2018

Report Date: 8/13/2018

Health Care Provider/Physician: Dr. Farias / Dr. Roman / Laura (Nurse) / Sandra (Nurse)

NAME (Last Name, First Name)	MIDDLE INITIAL	STREET ADDRESS	PHONE #	DOB	SEX (M or F)	RACE	HISPANIC (YES/NO)	SSN	TEST RESULT ($\mu\text{g/dL}$)
[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	13.3 <i>u/dl</i>
[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	13.3 <i>u/dl</i>

Pediatrics 64 9412097685 >> EPI FAX

BUR
EPIDE
COM

Patient information redacted here to protect confidentiality, information here as seen in other places difficult to read

Patient blood lead test results

FLORIDA LEADCARE II LEAD TESTING INTERIM REPORTING FORM
DAILY SCREENING INFORMATION

Instructions: Please provide complete information for each patient. Do not use cursives; information must be legible for data entry purposes. Place "U" (unknown) where the information cannot be obtained. All blood lead levels $\geq 10 \mu\text{g/dL}$ must also be reported to your local county health department. Fax the completed form daily to Florida CHAD (Childhood Lead Poisoning Prevention Program): 880-245-4204 / 850-922-8473

Specimen Type: Capillary

Reporting Physician Office Name and Address: APC Pediatrics, 5266 Office Park Blvd., Suite 207, Bradenton, FL 34203, Phone: 941-755-7000, Fax: 941-755-7088

Collection/Result Date: 11/15/18

Report Date: 11/15/18

Health Care Provider/Physician: [REDACTED]

Race: W = White, B = Black, I = Indian, A = Asian, O = Other, U = Unknown

BUREAU OF EPIDEMIOLOGY
JAN 16 2019
RECEIVED
AMP 210
L7973597

NAME (Last Name, First Name)	MIDDLE INITIAL	STREET ADDRESS	PHONE #	DOB	SEX (M or F)	RACE	HISPANIC (YES/NO)	SSN	TEST RESULT ($\mu\text{g/dL}$)
[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	[REDACTED]	13.3 <i>u/dl</i>