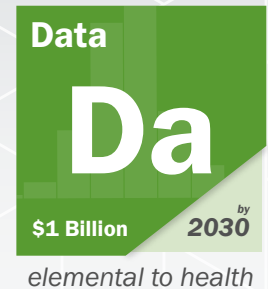


Data: *Elemental to Health*

By committing \$1 billion over 10 years to modernize the public health surveillance enterprise, we can transform disease surveillance and save lives. More, better, faster data yielded by secure, interoperable systems will allow public health professionals and policymakers to make better decisions and get ahead of chronic, emerging, and urgent threats.



Problem: Public Health Surveillance Struggling to Catch Up

“Public health surveillance” is the interactive system of government public health agencies at the federal, state, local, tribal, and territorial levels working with health care providers and the public to detect, report, and prevent illness and death. Each day, public health surveillance saves lives by detecting and facilitating the response to health threats, such as *E. coli* contaminated lettuce, measles, influenza, opioid overdoses, Zika, and more. But the nation’s public health data systems are antiquated, in dire need of security upgrades and rely on obsolete surveillance methods leading to delayed detection and response to public health threats of all types.

Solution: Robust, Sustained Funding for Data Science

The development of 21st century data systems and the public health workforce needed to operate and maintain them have been woefully underfunded. Degree programs and early- and mid-career workforce development overhauls are needed for epidemiologists, vital registrars, laboratorians, and other public health professionals. A **\$1 billion investment** over the next decade at the Centers for Disease Control and Prevention (CDC)—and through it, funding to directly support state, local, tribal, and territorial health departments—would transform today’s public health surveillance into a state of the art, secure, and fully interoperable system.

Approach: Invest in and Implement Leading Edge Data Systems

As health threats continue to evolve, so too must public health’s methods. There are **five core data systems** that support the public health surveillance enterprise. These systems need modernization now to protect the health security of all Americans:



National Notifiable Disease Surveillance System (NNDSS)

The secure national disease reporting system and infrastructure collects vital individual case investigation data at state, local, tribal, and territorial public health agencies from hospitals, physicians, and labs. Jurisdictions then send case investigation data to CDC to create a national snapshot of health, used to respond to public health outbreaks and act as the first line of health security defense.

Funding for NNDSS would improve **(1)** data security across the infrastructure, **(2)** automated electronic receipt of data (existing and new data sources), **(3)** integrated, real-time analysis of data from multiple sources (clinical, lab, epidemiologic), and **(4)** seamless, efficient communication of robust data to and from health care providers to public health agencies and onto CDC.



Electronic Case Reporting (eCR)

eCR is the automatic submission of disease reports directly from electronic health records at clinical care organizations (e.g., hospitals, health systems, community health centers) to state, local, tribal, and territorial public health departments. eCR reduces physician burden in fulfilling their legal responsibility to report, and dramatically improves disease/condition reporting, which leads to early implementation of public health interventions and limits further spread of infectious agents.

Funding for eCR would **(1)** initiate broad-scale, secure reporting from electronic health records in clinical care organizations to public health agencies from a handful of sites to across all jurisdictions, **(2)** support interoperable and intelligent real-time reporting from multiple sources and; **(3)** eliminate paper-based provider reporting.



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, such as the impact of natural disasters, including hurricanes, flu pandemics, and opioid overdoses. It provides public health professionals the ability to monitor the pulse of the community, and identify health threats as they emerge.

Funding for syndromic surveillance would **(1)** expand the number of hospitals participating, **(2)** expand reporting to other health system entry points such as urgent care centers **(3)** add predictive analytics and artificial intelligence to uncover changes in the occurrence of illnesses and injuries.



Electronic Vital Records System

The electronic vital records system 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 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.

Funding for the electronic vital records system would **(1)** expand broad scale, secure vital record systems implementation across jurisdictions, **(2)** support interoperable and intelligent real-time reporting of data from multiple sources, including electronic health records and medical examiner/coroner systems and **(3)** deliver rapid, seamless exchange of birth and death data with CDC.



Laboratory Information Systems

Laboratory Information Management Systems (LIMS) 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 and 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.

Funding for laboratory information systems would **(1)** expand public health laboratories' data capacity, exchange, and analytics as they implement next generation bioinformatics tools, including advanced molecular detection (AMD), **(2)** enhance LIMS to interface with laboratory instruments to eliminate hand data entry of results, **(3)** build robust electronic test order and result (ETOR) systems that rapidly share sample status and results, and **(4)** ensure secure, instantaneous communication of results from the public and private sector to disease detectives.



Public Health Data Science Workforce

New technology and enhanced cybersecurity to facilitate more, better, faster public health data is paramount. Technology's potential can only be realized, however, if public health professionals are equipped to harness it. Developing this newly skilled, public health data scientist will require direct hiring authority for CDC, an increase in salary caps to recruit and retain optimal staff, new job creation in the public and private sector across jurisdictions, new curricula, professional development, post-graduate fellowships, and on-the-job training.

Funding would help the public health workforce acquire new skills to understand and securely integrate health data to: **(1)** Provide more complete, accurate, and timely population-level monitoring; **(2)** Ensure optimal health security through robust public health surveillance to prevent death and disease; **(3)** Move data to action by driving policy and practice to accelerate health improvement; **(4)** Reduce provider reporting burden; and **(5)** Bolster and maintain cybersecurity.

For more information, please contact Emily Holubowich at eholubowich@dc-crd.com



March 25, 2019

The Honorable Roy Blunt
Chairman
U.S. Senate
Appropriations Subcommittee on Labor,
Health and Human Services, Education
and Related Agencies
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
U.S. Senate
Appropriations Subcommittee on Labor,
Health and Human Services, Education
and Related Agencies
Washington, DC 20510

Dear Chairman Blunt and Ranking Member Murray,

As you develop appropriations legislation for fiscal year (FY) 2020, the 80 undersigned organizations representing patients and consumers, public health professionals, health information technology (IT) developers, health care providers, and scientists urge you to appropriate \$1 billion over 10 years—\$100 million in FY 2020—to the Centers for Disease Control and Prevention (CDC) for a new initiative that will transform the public health surveillance enterprise and save lives. Specifically, this funding would allow CDC, state, local, tribal, and territorial health departments to move from sluggish, manual, paper-based data collection to seamless, automated IT systems and to recruit and retain skilled data scientists to use them. More, better, faster data yielded by secure, interoperable, integrated systems will allow public health professionals and policymakers to make better decisions and get ahead of chronic, emerging, and urgent threats.

“Public health surveillance” is the interactive system of government public health agencies at the federal, state, local, tribal, and territorial levels working with health care providers and the public at-large to detect, report, respond to, and prevent illness and death. Every day—often unbeknownst to most Americans—public health surveillance is saving lives by detecting and facilitating the response to health threats including *E. coli* contaminated lettuce, measles, antibiotic resistance, lead poisoning, influenza, health care associated infections, opioid overdoses, Zika, and many more.

Unfortunately, the nation’s public health data systems are antiquated, rely on obsolete surveillance methods, and are in dire need of security upgrades. Sluggish, manual processes—paper records, spreadsheets, faxes, and phone calls— are still in widespread use. Lack of interoperability, reporting consistency, and data standards leads to errors in quality, timeliness, and communication. In addition, public health professionals are faced with rapid advances in data science and evolving cybersecurity threats, and many do not yet have the necessary 21st century skills to understand and securely integrate health data.

There are five core data systems of the U.S. public health surveillance enterprise that require modernization now to protect the health security of all Americans:

1. The ***National Notifiable Disease Surveillance System (NNDSS)*** 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)** is the automatic, seamless submission of disease reports directly from electronic health records at clinical care organizations to state, local, tribal, and territorial public 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** provides near real-time data on every hospital emergency department visit for hourly detection and continuous monitoring of community health incidents such as 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. **Electronic Vital Records System** 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** 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.

To varying degrees, these systems lack the proper electronic automation, data security infrastructure, interoperability, and integration. Investment in these systems will facilitate accelerated, secure, and seamless detection to improve prevention and response efforts.

Additionally, the public health workforce of today and tomorrow must acquire new skills to understand and securely integrate health data and bolster and maintain cybersecurity. Developing a new generation of skilled public health data scientists will require new curricula, professional development, post-graduate fellowships, and on-the-job training.

The development of 21st century data systems and the public health workforce needed to operate and maintain these systems have been woefully underfunded to date. A robust, sustained commitment to transform today's public health surveillance will ultimately improve Americans' health. If you have questions, please contact Emily Holubowich at eholubowich@dc-crd.com.

Sincerely,

Academy of Nutrition and Dietetics
AcademyHealth
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American Association on Health and Disability
American Brain Coalition
American College of Obstetricians and Gynecologists

American Medical Informatics Association (AMIA)
American Medical Women's Association
American Organization of Nurse Executives
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Green & Healthy Homes Initiative
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Hep B United
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Hepatitis Education Project
HLN Consulting, LLC
Infectious Diseases Society of America
Intermountain Healthcare
International Society for Disease Surveillance
Inter-university Consortium for Political and Social Research
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Lakeshore Foundation
Liver Health Connection
March of Dimes
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National Association of State Emergency Medical Services Officials
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National Blood Clot Alliance
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National Environmental Health Association
National Healthy Start Association
National Multiple Sclerosis Society
National Network of Public Health Institutes
National Safety Council
National Viral Hepatitis Roundtable
NTT DATA Services Federal
Philadelphia Department of Public Health
Prevent Blindness
Public Health Institute
Research!America
Ruvos
SAP
SAP Public Services
SAS Institute
Spina Bifida Association
Teratology Society
Testability, Inc.
The Academy for Radiology & Biomedical Imaging Research
The Immunization Partnership
The Joint Commission
The Michael J. Fox Foundation for Parkinson's Research
The Society for Healthcare Epidemiology of America
Trisomy 18 Foundation
Trust for America's Health
United Spinal Association
Washington State Department of Health

March 25, 2019

The Honorable Rosa DeLauro
Chair
U.S. House of Representatives
Appropriations Subcommittee on Labor,
Health and Human Services, Education
and Related Agencies
Washington, DC 20515

The Honorable Tom Cole
Ranking Member
U.S. House of Representatives
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Health and Human Services, Education
and Related Agencies
Washington, DC 20515

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