Data: Elemental to Health

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Modernize Public Health Data: A Call to Congress

Invest at least $7.84 billion over five years to modernize public health data

Our COVID-19 response was hampered by a fractured, outdated, and underfunded state and local public health data infrastructure. **We need a robust, modern, and secure public health information ecosystem capable of sustainment and surge that delivers real-time, accurate, and useful data to public health and policymakers at the local, state, and federal levels.**

Public health agencies at the federal, state, local, tribal, and territorial levels work together to detect threats and to prevent and reduce illness and death. **But right now, across the country, state and local public health departments operate a mismatched network of siloed public health information systems, most of which do not talk to each other nor to the health care delivery sector, and all of which are in urgent need of upgrade.**

The *Data: Elemental to Health Campaign* was founded in 2019—before COVID-19—with the goal of raising $1 billion over ten years to modernize public health data systems. Then COVID-19 happened. It showed us that things are worse than we realized and this work is needed more than ever. Faster and more complete data is the foundation for preventing illness and saving lives, but also for systemically addressing health equity. **We do not have ten years. We must act now.**

Improvements are underway. An investment of $50 million in Fiscal Year (FY) 2020 marked the start of the Data Modernization Initiative (DMI) at CDC. With $50 million in FY 2021, $500 million in the CARES Act, and approximately $300 million in the American Rescue Plan Act, DMI is beginning to build a standards-based, interoperable public health information ecosystem ready to confront any emerging threat. We are grateful to Congress and the Administration for recognizing this need and supporting these early investments. While improvements are being made with these dollars, to really build a modern public health data infrastructure, significant and sustained funding is needed so jurisdictions can confidently invest in the systems and workforce they need to bring their data systems into the 21st century. It will take time and continued funding to support the critical investments made to date and to ensure data delivery and collection address health equity.

The initial investments have already begun to improve systems at the federal level. While those investments in federal systems must be maintained, we cannot realize the potential of data modernization without also modernizing foundational state and local public health data systems. We urge Congress to provide at least **$1.57 billion per year to fully modernize our public health data infrastructure at the state and local levels**. This funding is essential to invest seriously in new technology in every jurisdiction and to attract, train, and retain the diverse workforce needed at the state, local, tribal, and territorial levels to build, implement, and sustain a modern public health data infrastructure across the U.S.

The foundation of the DMI is built on a set of guiding principles: an **enterprise approach** to data exchange, **interoperability** between public health and health care systems, **security** to protect patient data, a **workforce** empowered to build and maintain the systems, and **public private partnership** to drive innovation.

Five pillars of DMI require investment across each public health jurisdiction along with support for local implementation and state-level management.

1. **ELECTRONIC CASE REPORTING:** eCR is the automatic submission of disease reports directly from electronic health records (EHR) at clinical care sites to state, territorial, local, and tribal health departments. eCR connects clinical and public health data to improve data completeness—ensuring that public health has the race and ethnicity data that is critical for achieving equity in our response.
   Hiring epidemiologists and building systems to manage eCR requires at least $656 million over 5 years, of which $336 million are human costs and $320 million are for systems.

2. **LABORATORY INFORMATION MANAGEMENT SYSTEMS:** LIMS form the backbone for laboratory data collection, analysis, management and sharing. Electronic Laboratory Reporting (ELR) and Electronic Test Ordering and Reporting (ETOR) support automated electronic transmission of laboratory results from commercial and hospital laboratories to public health departments. ETOR facilitates the collection of complete demographic information so that laboratories can report complete data and results to public health.
   Putting LIMS, ELR, and ETOR in place requires $1.032 billion over 5 years, of which $392 million are human costs and $640 million are for systems.

3. **SYNDROMIC SURVEILLANCE:** Syndromic surveillance uses near real-time data collection from hospital emergency department visits and other data sources such as urgent care centers, poison center calls, or emergency medical service runs for continuous monitoring of community health. Data from both inpatient encounters and intensive care unit admissions are also needed for public health.
   Implementing syndromic surveillance systems requires $310.4 million over five years, of which $86.4 million are human costs and $224 million are for systems.

4. **ELECTRONIC VITAL RECORDS:** The electronic vital records system provides secure electronic collection of birth and death data from hospitals, funeral homes, health care providers, and medical examiners. Electronic death registration systems (EDRS) provide timely mortality data. Our vital records systems are in dire need of upgrades to be interoperable with public health and EHR data systems.
   Modernizing vital records systems requires $688 million over 5 years, of which $336 million are human costs and $352 million are for systems.

5. **NATIONAL NOTIFIABLE DISEASE SURVEILLANCE SYSTEM:** NNDSS collects, aggregates, and analyzes—at the national level—deidentified data from all individual cases of reportable diseases and conditions from state, territorial, local, and tribal public health agencies reported by hospitals, health care providers, and laboratories. NNDSS requires rapid electronic data streams from health departments to aggregate national data for decision-making, and is a critical component of public health response.
   Bringing NNDSS into the 21st century requires $1.24 billion over 5 years, of which $280 million are human costs and $960 million are for systems.

LOCAL WORKFORCE AND SYSTEMS COMPATIBILITY: Local, county, and city health departments play a critical role in our public health infrastructure. A skilled workforce and compatible data systems at the local level are necessary to ensure that data can flow seamlessly into state and federal systems and that all communities can use that information to provide efficient and effective public health practice.
Supporting local health departments' data infrastructure needs requires $3 billion over five years split evenly between system and human costs.

LEADERSHIP, MANAGEMENT, AND INTEGRATION: To best use taxpayer resources and ensure value and efficiency, public health leadership at the state level is needed to coordinate, implement, and provide leadership for the development of the DMI.
Leadership, project management, coordination, and implementation require $814 million over 5 years, of which $379 million are human costs and $435 million are for systems.