Data: *Elemental* to Health

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$1 Billion by 2030

September 23, 2019

The Honorable Richard Shelby
Chairman
Committee on Appropriations
U.S. Senate

The Honorable Patrick Leahy
Vice Chairman
Committee on Appropriations
U.S. Senate

The Honorable Nita Lowey
Chairwoman
Committee on Appropriations
U.S. House of Representatives

The Honorable Kay Granger
Ranking Member
Committee on Appropriations
U.S. House of Representatives

Dear Chairman Shelby, Vice Chairman Leahy, Chairwoman Lowey, and Ranking Member Granger:

As you work to finalize the Labor, Health and Human Services, Education and Related Agencies appropriations legislation for fiscal year (FY) 2020, the Association of Public Health Laboratories, Council of State and Territorial Epidemiologists, Healthcare Information and Management Systems Society, and National Association for Public Health Statistics and Information Systems—together with 90 other organizations representing patients and consumers, public health professionals, health information technology (IT) developers, health care providers, and scientists—urge you to appropriate at least **$100 million to the Centers for Disease Control and Prevention (CDC) in FY 2020 for a new, multiyear 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.

The current respiratory illness outbreak associated with electronic cigarettes is just the latest in a long line of emerging health threats—*Candida auris*, Zika virus, acute flaccid myelitis, opioid misuse, maternal mortality, and more—where the public health enterprise is unprepared. Now two months into the e-cigarette outbreak there is still no national surveillance in place. We have no idea about the pace of this outbreak, how many new cases are occurring daily, where they are occurring, what the major risk behaviors are, and most concerning, no aggregated national data to drive public health action.
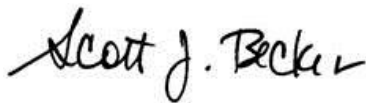
Public health is caught flatfooted once again because of the nation's antiquated, siloed, and fragmented surveillance infrastructure. Sluggish, manual processes—paper records, manual data entry, spreadsheets, faxes, and phone calls— are still in widespread use and hinder our basic understanding about the underlying causes of outbreaks and epidemics, who's at greatest risk, and how to develop an appropriate response. The lack of interoperability, reporting consistency, and data standards plaguing

the data infrastructure leads to errors in quality, timeliness, and communication. As in most public health responses, the data about e-cigarette illnesses are moving more slowly than the disease, leading to lost time, lost opportunities, and lost lives.
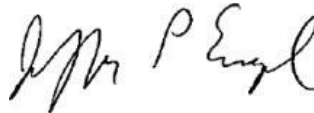
The implementation of interoperable data systems and the public health workforce needed to operate and maintain them have been woefully underfunded to date. Federal investments in surveillance have typically been disease and condition-specific, perpetuating fragmentation. As a result, public health data remains stuck on a series of disease and condition-specific dirt roads that are disconnected and disjointed and don't give a complete picture of health at the national level. Our nation requires a robust, sustained commitment to build a 21st Century data superhighway to speed the seamless exchange of data for *all* diseases and conditions, to predict and prevent public health threats before they occur, and to ultimately improve and protect Americans' health. We strongly urge you to prioritize $100 million for CDC and health departments nationwide to build a public health surveillance enterprise that will speed the data collection and response for current and future public health threats.

If you have questions, please contact Celia Hagan at chagan@dc-crd.com.

Sincerely,

Scott J. Becker, MS
Executive Director
Association of Public Health Laboratories

Jeffrey P. Engel, MD
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Council of State and Territorial Epidemiologists

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Harold F. Wolf III, FHIMSS
President & CEO
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CC: The Honorable Roy Blunt
        The Honorable Patty Murray
        The Honorable Rosa DeLauro
        The Honorable Tom Cole