United States Senate
WASHINGTON, DC 20510

September 26, 2019

The Honorable Richard Shelby
Chairman
Committee on Appropriations
U.S. Senate
Washington, D.C. 20510

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

The Honorable Patrick Leahy
Vice Chairman
Committee on Appropriations
U.S. Senate
Washington, D.C. 20510

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

Dear Chairman Shelby, Vice Chairman Leahy, Chairman Blunt, and Ranking Member Murray,

As you continue to work to come to a final, bipartisan appropriations agreement on the Labor, Health and Human Services, Education and Related Agencies appropriations bill for Fiscal Year (FY) 2020, we urge you to include $100 million for public health data modernization at the Centers for Disease Control and Prevention (CDC). We were pleased that the House of Representatives included this critical investment in their bill and we ask that your committee do the same.

The multistate outbreak of lung illnesses linked to the use of e-cigarette products is the latest of many examples clearly illustrating that our response to health threats can only be as strong as the data systems, processes, and workforce we have in place to address them. Reporting indicates[1] that state health officials have struggled with the lack of a seamless, interoperable data system through which states could share information about cases with one another and the CDC. The absence of an enterprise approach to address this threat underscores the need for improved public health data infrastructure that would support responses to threats of all types—acute, chronic, and emerging. We have also heard from CDC officials that fully implemented data modernization would have permitted timely, interoperable, and more complete information exchange between states and the CDC, expediting the investigation and response to this outbreak.
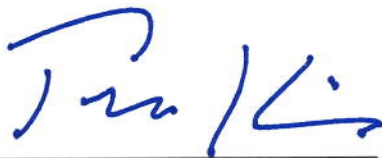
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[1] Politico, "Mystery Youth Vaping Disease Reveals Gaping Holes in Regulation," August, 28, 2019, https://www.politico.com/story/2019/08/27/vaping-lung-disease-regulation-1686396.

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Unfortunately, the public health data systems we rely on for our health and safety are antiquated and fragmented. Systems lack the interoperability needed to facilitate timely and secure information sharing. Too often, public health departments are forced to rely on systems with manual processes that are time consuming and error prone, such as paper records, faxes, and phone calls. Despite a nationally agreed upon standard,[2] to date only two health care providers—Houston Methodist and Intermountain Healthcare—have implemented interoperable systems to exchange electronic case reports directly from health records, and only for the small number of diseases and conditions states require to be reported to public health authorities.

Our bipartisan legislation, the Saving Lives Through Better Data Act, would improve the nation's public health data systems to ensure high quality, timely, and accurate information sharing. Our legislation would help public health departments improve data collection and analysis, simplify provider reporting, and support earlier disease detection and response. It would improve interoperability of data systems utilized by public health departments at the federal, state, territorial, tribal, and local levels, develop public-private partnerships to support expansion and modernization of electronic case reporting, and facilitate the development of a strategy to improve data systems at all levels of government. Our bill authorizes $100 million per year for the CDC in fiscal years 2020 through 2024, and we were pleased to see provisions of our bill advance through the HELP Committee as part of the bipartisan Lower Health Care Costs Act of 2019.

We urgently need an interoperable, public health surveillance enterprise that will speed up data exchange and response for all present and future health threats—known or unknown. In light of the e-cigarette-related respiratory illness outbreak and other serious health threats our nation is facing, including opioid overdoses, maternal deaths, and rising suicide rates, we urge you to make the necessary investment that will help us better identify and respond to such threats so we can save more lives.
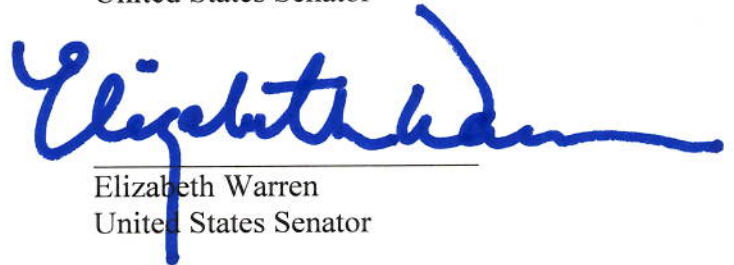
Sincerely,

Tim Kaine
United States Senator

Richard Blumenthal
United States Senator

Sheldon Whitehouse
United States Senator

Elizabeth Warren
United States Senator

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[2] Balloted standard developed through a consensus based standards development organization (Health Level Seven International (HL7), https://www.hl7.org/implement/standards/product_brief.cfm?product_id=436.

Mazie K. Hirono
United States Senator

Margaret Wood Hassan
United States Senator