

The Health STATISTICS Act of 2021

Congressman Scott Peters (CA-52), Congressman Brian Fitzpatrick (PA-1), Congresswoman Anna Eshoo (CA-18), Congresswoman Lucy McBath (GA-6)

Problem:

The Coronavirus Aid, Relief, and Economic Security (CARES) Act, and the recently enacted COVID-19 Economic Relief Bill make large-scale investments in the modernization of our national public health data infrastructure. These investments will undoubtedly improve our country's preparedness for future public health emergencies. However, as new SARS-CoV2 variants emerge around the world and death rates spike, Congress must act quickly to streamline ad hoc data sharing agreements between local health departments, states and the federal government; remove certain data siloes across multiple Federal agencies; and fix the patchwork of data systems responsible for recording and reporting vital statistics.

According to a recent National Academies of Sciences report, "Genomic Epidemiology Data Infrastructure Needs for SARS-CoV-2: Modernizing Pandemic Response Strategies," ad hoc data sharing agreements and data siloes between the federal government and states make it difficult for researchers to combine different data sources, such as high-quality genome sequences of SARS-CoV-2, clinical data, and epidemiological data that would improve our ability to track the spread of the virus in near real-time. While states are required to share their data with some federal data collection systems, and voluntarily do so with systems like the National Vital Statistics System, these arrangements are inefficient and antiquated. For example, government and non-government researchers must broker these individual data sharing agreements with each state, which determines the granularity of data and other conditions. The practical effect of these data gaps is that in the early months of COVID-19, missing data on race masked the disease's disproportionate effect on communities of color.

Even basic mortality and morbidity data reporting protocols are patchwork. Almost one year after the first reported COVID case, the federal government still does not know the true number of deaths attributed directly and indirectly COVID-19. As death rates began to soar, our antiquated systems to track cause-of-death information couldn't keep pace. Lags in mortality data reporting to the CDC, and incomplete death records often missing important details such as underlying health conditions and information about hospitalizations. As a result, experts estimate that the true number of COVID-related deaths is likely much higher.

Solution:

COVID-19 might have exposed the weaknesses of our public health surveillance system and the data infrastructure that supports it, but it affords an opportunity to use the existing data infrastructure that supports the Federal Statistical System to quickly stand-up a unified national data strategy. The Federal Statistical System is comprised of thirteen Principal Statistical overseen by the Chief Statistician of the US, a non-political appointee at OMB. The mission of the Statistical System is to turn data into "useful, objective information; and make that information readily and equitably accessible to government decision makers and the public."¹ The National Center for Health Statistics (NCHS) at CDC is one of the most trusted stewards of public health data. NCHS's preeminent, but underfunded, data linkage program is well-equipped to rapidly assemble existing, decentralized data systems from multiple data sources at the state, local, and federal levels.

¹ https://www.whitehouse.gov/wp-content/uploads/2018/02/ap_15_statistics-fy2019.pdf

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The American people need to have confidence that their data is protected in the middle of a pandemic. It is more important than ever that the government is transparent about how health data from the states, other federal agencies, and across HHS units are used; how it provides secure access to researchers; the rules governing inter-agency data sharing protocols; and, making data available to the public while still protecting privacy.

In 2016, Congress passed the bipartisan Evidence-Based Policymaking Commission Act, which gave 15 experts, appointed by the President and congressional leaders, the charge to carry out a comprehensive study of data-sharing practices, including statistical protocols, related to federal policymaking. On January 14th, 2019, H.R. 4174, Foundations for Evidence-Based Policymaking Act, was signed into law. Known as the “Evidence Act,” it codified most of the Committee’s recommendations, including recommendations for “modernizing privacy protections for evidence building and using the infrastructure and expertise already developed in government to ensure that data linkages and access to confidential data are conducted in the most secure manner possible.”²

The Health Standards to Advance Transparency, Integrity, Science, Technology Infrastructure, and Confidential Statistics Act of 2020 or The Health STATISTICS Act of 2021 builds on the Evidence Act to rapidly assemble decentralized data systems that can inform our nation's real-time response to COVID-19, as well as future public health emergencies.

Specifically, the bill:

- Establishes a Committee with diverse, relevant expertise to oversee and advise on a national data strategy for public health emergencies, including recommending and establishing common standards to allow for the linkage of genomic data, clinical data, epidemiological data, and other relevant data, in such a way that is not overly burdensome to laboratories that collect data regularly and obtained from individuals with diverse demographic and socioeconomic backgrounds.
- Requires the Secretary of HHS to share timely, accurate, and actionable public health information collected by the Department of Health and Human Services with the Centers for Disease Control and Prevention, other public health agencies, and the public, to the extent possible while preserving individual privacy.
- Clarifies CDC’s authority to require the reporting of race and ethnicity information for cases, hospitalizations, and deaths necessary for ensuring more complete data and consistent collection of demographic data.
- Creates a pilot demonstration project, allowing for the temporary linkage of genomic data, clinical data, epidemiological data, and other relevant data.
- Provides financial assistance to support researchers and policy makers at the state and local level to match for developing data linkage and IT infrastructure services for public health researchers.
- Implements key recommendations pursuant to the National Academies of Sciences 2020 report “Genomic Epidemiology Data Infrastructure Needs for SARS-CoV-2.”

² <https://www.cep.gov/report/cep-final-report.pdf>

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- Implements key recommendations pursuant to the National Academies of Sciences 2020 report “A Framework for Assessing Mortality and Morbidity after Large-Scale Disasters.” This report was mandated by Congress after it came to light that mortality rates following Hurricane Maria in Puerto Rico in 2017 were significantly higher than reported.
- Authorizes \$100 million authorized for the pilot project to sustain the ongoing effort through fiscal year 2024.
- Authorizes \$450 million for each fiscal year until 2024 that would support researchers and policymakers at the state and local levels to use linked health data files

Goals of the legislation:

1. To allow statistical uses of public health survey, administrative data and other relevant data for evidence building
2. To optimize existing efforts to modernize the nation’s public health surveillance system
3. To pilot a public health data linkages program within the National Center for Health Statistics to meet immediate surveillance, reporting and other outbreak management needs.

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