Health Data Leaders Push for Data Reporting Standardization

New legislation and efforts at HHS are looking at reporting standards for all levels of government.

Lawmakers and public health experts are pushing for greater standardization of health data to improve public health response efforts and research outcomes.
Maintaining accurate and quality data has been necessary for tracking and responding to COVID-19. Introducing more standards could improve how all levels of government provide consistent information about public health in the future, said Rep. Scott Peters during FedInsider’s webinar Tuesday. Peters, as well as representatives Lucy McBath, Anna Eshoo and Brian Fitzpatrick, introduced the Health STATISTICS Act of 2020 in response to the data-sharing issues that came up during the pandemic.

“We seemed to have a lot of data but not a lot of information,” Peters said. “It’s really hard to draw conclusions about what the impacts are across the country. So with the bill we put together, the STATISTICS Act would require [the Department of Health and Human Services and the Centers for Disease Control and Prevention] to set standards for everyone to report.”

The bill builds upon the Foundations for Evidence-Based Policymaking Act, Peters added, which tasked federal agencies to safeguard data and leverage it as a strategy asset in decision-making. The STATISTICS Act looks to standardize health data to ease data collection not only about COVID-19, but also other public health challenges and concerns by requiring the HHS secretary and CDC to designate data and technology standards and set common reporting criteria for the highest priority data elements.

The legislation would also form a grant program for state, local and tribal public health departments to modernize their public health data systems.

Although Peters’ piece of legislation is bipartisan and seeks to reinforce preexisting efforts in government to standardize data, it does not specifically point to how HHS and the CDC should standardize health data reporting. Former HHS CIO and CDO Jose Arrieta, who previously worked on building HHS’s COVID-19 reporting platform HHS Protect, explained some of the challenges and best practices in collecting and consolidating quality health data.

“When you think about collecting data, the challenges that we encountered were very specific — identity and access management, authentication,” Arrieta said. “A lot of legacy IT identity access management capabilities across the federal government and state government and being able to share data requires a flexible identity access management, authentication capability.”
Arrieta added that data quality is also a major hurdle, as the meaning of data quality is opaque with instances like COVID-19, where researchers and medical experts do not know much about the virus. Normally researchers try to identify specific data points they need to advance their work with quality data. For COVID-19, however, HHS has tried to instead maximize data collection, which makes curating quality data difficult.

“When you don’t know a bunch about the virus, you need to maximize [data] coverage, and you need to share information, and that leaves gaps,” Arrieta said. “I think you want to be flexible at the point of integration, at least, that’s what we learned in the health care sector. There’s lots of different levels of technology, whether it’s hospitals, state government, federal government, local government, so [we needed to be] flexible from a point of integration.”

While HHS has tried to overcome these data standardization challenges, Arrieta said that it is important that HHS does not re-platform its data and instead connect the data ecosystem to enable better data-sharing. He added that health data reporting standards should also include time series elements, which shows how the data was parsed, curated and shared, and should make the data shareable with the broader public.

Former Director of the National Center for Health Statistics Charlie Rothwell suggested potentially integrating other data points outside of medical data to curate quality public health data, since economic, demographic mental health and other various types of data have been critical to understanding and responding to the pandemic.

“If we would’ve had data that’d really broken out broadly and geographically and very specifically, we could have made much better appropriate decisions early on, and that’s not just with COVID-19,” Rothwell said. “That’s a variety of health outcomes. ... We’ve seen that we’re a connected society, right now, more than ever.”
Even with the STATISTICS Act, agencies are still working to coordinate better efforts to make data more usable across the federal community. Through the Federal Data Strategy, recent formation of the Federal CDO Council and focus on data usage in decision-making, standardizing health data is just a more specific effort amid the overarching theme of data standardization and usability across the government.