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DATASHEET

Federal Health Agencies Are Digitizing for Data

Efforts to Optimize Health Data Access Supports More Efficient Care and Better Health Outcomes

As the health sector continues on its digital transformation journey, agencies are adopting innovative technologies that analyze quality data to better inform providers and researchers, and improve overall health outcomes. These kinds of programs are contributing to cancer treatment, COVID-19 spread prevention and improved patient care.

Government and industry leaders spoke at a recent FedInsider webinar about how they're using technology-enabled data collection to produce valuable analytics for better decision making for health. The following are some of the most important aspects of their discussion.

Data Challenges in Government

Federal health agencies share a common goal of providing better health outcomes to citizens and are modernizing legacy systems to do so. However, they are facing transformation challenges around people, processes, technology and in achieving end user efficiency.

"You have the right tools; but do they have the right methods of interacting and analyzing and sharing?," noted senior vice president of strategic consulting at ICF Byron Caswell. Data distribution, collection, and ownership also raise obstacles, especially when considering the various types and formats of health data and streamlining them to generate meaningful analytics.

"The kind of consistency across data sources and across the collection entities is really required to make good inferences with it," Caswell added. "It also brings a big challenge about data governance and ownership provenance, stewardship, and data that is collected and owned and shared from local territorial to commercial entities."

Overcoming these challenges will allow health officials to make decisions regarding clinical research, healthcare delivery, and policy. The scale and breadth of the COVID-19 pandemic also brought its own set of challenges, said Alan Sim, chief data officer for the Centers for Disease Control and Prevention. The pandemic highlighted how fragile and underfunded the public health infrastructure is, especially at the state, local and tribal level.

"Their systems haven't been updated, with many still using paper and fax machines instead of electronic or cloud-based data management systems," Sim said. "We have identified the need to repair and replace the infrastructure of road highways and bridges; we need consistent and sustainable funding to ensure that our public health systems are also properly rebuilt, modernized, and managed optimally to respond to future pandemics and emergencies."

Data's Part in Digital Transformation in Healthcare

Mamatha Pancholi, chief data officer for the Agency for Healthcare Research and Quality, said that while the industry has deployed new technologies like artificial

FEATURED EXPERTS:

- **Dr. Jonas Almeida**
  Acting Chief Data Officer,
  National Cancer Institute,
  Division of Cancer
  Epidemiology & Genetics

- **Mamatha Pancholi**
  Chief Data Officer,
  Agency for Healthcare
  Research & Quality, HHS

- **Dr. Partha Bhattacharyya**
  Chief Data Officer,
  Office of Data Resources
  & Analytics, National
  Institute on Aging

- **Dr. Alan Sim**
  Chief Data Officer,
  Centers for Disease Control
  & Prevention

- **Byron Caswell**
  Senior *Vice President,*
  Strategic Consulting,
  ICF

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intelligence and telehealth medicine to help respond to the pandemic, questions remain around how well it supports or provides care in terms of quality and safety.

"We don't have enough information about the actual way in which those services are delivered in the telehealth environment," Pancholi said. "How well do the services compare to office visits? We need the data."

Understanding how critical digital health tools are for patients and clinicians requires high-quality, accurate, and validated data. "That accuracy and validation needs to go as part of a key design component, when you're building digital healthcare systems," Pancholi said.

For example, Partha Bhattacharyya, chief data officer in the Office of Data Resources and Analytics for the National Institute on Aging, said that while the work they support is conducted by external researchers, Internet of Things (IoT) health wearables are collecting daily living activity data that provides helpful information. "These are all part of research studies," Bhattacharyya said. "It will give us answers on what role these sensors will play in the long run."

Federal Data Modernization Initiatives

The Centers for Disease Control and Prevention (CDC) launched a data modernization initiative a few years ago in anticipation of public health challenges like the pandemic, and in response to data management challenges in a siloed public health system. The initiative has five major priorities centered around people, processes, technology, governance, and policy. "These are very broad priorities but they reflect the areas that need to be addressed in order to have a truly functional data modernization platform," Sim said.

Bhattacharyya said that the office in the National Institute on Aging works on cleaning the data it collects from its studies with the Centers for Medicare and Medicaid Services, and then making it available in a timely manner. This comes from a data reuse premise: once the resources are created, other people can use them, rather than reinventing the wheel. Bhattacharyya said the team is working with researchers to make data available, user-friendly, and reusable.

But Caswell said aside from the technology challenges, the policy and system development of rebuilding the public health infrastructure is difficult. Incentivizing data collection and sharing to create a feedback loop is another key to improving outcomes.

"Providing not only data but also tools that can facilitate analysis, really helps clinicians to work from a consistent sheet of music," Caswell said. "Once you can do that in more domains, you have an ability to start moving the needle on some of the public health outcomes much more readily."

Putting Data Innovation to Work in Healthcare

Jonas Almeida, chief data scientist and senior investigator for the National Cancer Institute's Intramural Research Program in the Division of Cancer Epidemiology & Genetics, provided a use case that showcases digital transformation driving better health outcomes during the pandemic.

His agency created a mortality tracker, and the way it collected the data it needed to feed the tracker evolved over time. First, the agency went after data by utilizing GitHub, as the government was initially lacking substantial COVID-19 data. Through GitHub's social network-like model of public coding, Almeida's team was able to utilize COVID-19 data being generated by the New York Times and the Johns Hopkins COVID-19 map.

The tracker is a real-time reporting model that shows final data alongside data still being generated. Today, the agency is no longer pulling data from the New York Times or Johns Hopkins. "We are pulling it from the CDC," Almeida said. "So, as time goes on, this is the impression I have, that the federal government eventually provides the highest quality data. It just takes time. And if we understand the ecosystem, we can wait for this moment to emerge."

These and other examples stressed by the panelists show how government data collection and usage is evolving, especially in the public health space. And, it demonstrates how the process of democratizing modernization can be a key to improving health outcomes that can make use of innovative data programs and accurate data models.

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