HHS is in a Data Marathon, Not a Sprint

The department is embarking on an enterprisewide data strategy initiative. 

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The Health and Human Services Department is determined to use data to save lives and improve government operations, and is developing an enterprisewide data strategy to do so.
Over the past years, HHS’ Office of the Chief Technology Officer released more than 1,500 data sets on HealthData.gov, held a cross-sector code-a-thon to fight the opioid epidemic and participated in conversations like the annual Health Datapalooza to connect with the health community. The department is working toward an open, transparent government, allowing researchers, academics and entrepreneurs to develop solutions the government otherwise wouldn’t be able to.

“We've actually reconvened to help data stewards from across all the HHS agencies, and are very proactively talking about our strategy for understanding what the demand is for data from our outside users, and how we can best address that demand,” HHS Chief Data Officer Mona Siddiqui told GovernmentCIO Media. This process is being referred to as the Data Insights Initiative.

Let’s Start from the Beginning

The department’s 24-hour code-a-thon in December provided participating coding teams with 70 public data sets from government, states and one private entity to develop solutions to fight the opioid epidemic. One if its significant impacts was showing how data can lead to tangible solutions.

The process of putting all that data together also helped HHS understand what some of the technical, legal and cultural challenges are with data sharing, within the department and with outside entities. That’s what set the stage for building an HHS enterprisewide data strategy and a governance structure for how HHS shares data internally to make evidence-based decisions.

Making Rounds

“The governance takes a lot of different approaches,” Siddiqui said. “Our focus here is not to boil the ocean, but really to understand how data is shared internally.”

The goal is to create a more transparent and accountable process that enables HHS agencies to share data across agency boundaries to advance evidence-based policy. The initiative has four areas: governance, legal framing, analytics, and partnerships and open data.

The strategy itself and its implementation are still in the works, but the Office of the
CTO is making its way around the department to understand what the current state of data sharing is at each division.

Siddiqui said they’ve spent eight to 10 hours at each HHS division taking a comprehensive look at how data sharing practices differ, what practices work, how to translate them to other parts of HHS, and which processes the Office of the CTO needs to create from scratch.

The department will also have to overcome data-sharing challenges.

Each division operates within its own statutory authority, so every data set has regulations around accessibility and use. The Office of the CTO will consider those, as it’s an important part of developing a departmentwide governance structure. It’ll mean harmonizing how divisions share data and form data use agreements, and addressing the cultural lift to sharing data (because of traditional practices, legal framings or a lack of resources and staff capacity to meet data sharing demands).

Depending on these findings, the Office of the CTO will draw a roadmap for data sharing and governance and test it against two use cases.

“The process we’re creating would be meaningless if we can't enable the analytics piece of it to help change how we run our programs [and] make decisions,” Siddiqui said.

**Use Cases?**

One of the use cases will likely relate to the opioid crisis, and the other is still being determined, but it has to be a focus area HHS has data for and requires at least two different divisions to bring together their data. The use case will be a priority for leadership, for agencies running programs that have real questions they need answered, and for the greater health community.

“There are things that naturally rise to consensus even without us trying, and so when we go to agencies and we ask what they’re working on, what they really care about, we are again listening to that and we’ll synthesize all of that feedback,” Siddiqui said. They’ll engage with stakeholders to understand where the community as a whole wants to focus, and where HHS can facilitate and bring the data.

Siddiqui said she has an internal timeline of when those next use cases will be
decided by, and hopes to announce them after this spring.

**Post-Development**

Once complete, the strategy, data portfolio, assessment learnings, roadmap developed and the use cases will all be publicly available to keep the process transparent and elicit feedback.

Siddiqui also hopes that creating a better process internally will lead to a more accountable, transparent process for how HHS makes data publicly available.

“We think of data as an essential part of how an organization should run, and I think that’s really the fundamental premise that we’re working on — that data should be inseparable from an organization’s larger strategy,” she said.

It’s a journey to get a massive organization like HHS to ingest data into the way it operates, but it’s a transformation the department is starting to become more efficient and solution-oriented in the long run.