HHS Data Chief Dr. Mona Siddiqui on Plans to Liberate Trove of Health Data

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Margaret Flinter: Welcome to Conversations on Health Care, with Mark Masselli and Margaret Flinter, a weekly show where we speak with the top thought leaders in health innovation, health policy, care delivery, and the great minds, who are shaping the health care of the future. This week Mark and Margaret speak with Dr. Mona Siddiqui, Chief Data Officer of the U.S. Department of Health and Human Services, who's overseeing the targeted effort to create a seamless interface between all the health data stored at the various departments of HHS.

Lori Robertson also checks in, the managing editor of FactCheck.org, looks at misstatements spoken about health policy in the public domain, separating the fake from the facts. We end with a bright idea that's improving health and well being in everyday lives.

If you have comments, please email us at chcradio@chc1.com, or find us on Facebook or Twitter. We love hearing from you. You can also find us on iTunes, or Stitcher, or wherever you listen to podcasts. Please feel free to leave us a review there. Now, stay tuned for our interview with Chief Data Officer at HHS, Dr. Mona Siddiqui, on Conversations on Health Care.

Mark Masselli: We're speaking today with Dr. Mona Siddiqui, Chief Data Officer at the U.S. Department of Health and Human Services, where she's tasked with building an agency-wide data management strategy. Prior to becoming the CDO, Dr. Siddiqui served as the Health Lead for the White House Social and Behavioral Health Science team during the Obama administration. Dr. Siddiqui is on the faculty at Johns Hopkins School of Medicine, where she earned her medical degree. She earned a master's in quantitative methods from the Harvard T.H. Chan School of Public Health. Dr. Siddiqui, welcome to Conversations on Health Care.

Dr. Mona Siddiqui: Thank you so much.

Mark Masselli: Well, HHS is sitting on a treasure trove of health data that really holds the power to advanced health care and medicine as well as better informed national health policy. The liquidity of that data still presents a major challenge. HHS currently doesn't have a common practice in place for data sharing between departments at the agency. I'm wondering if you could tell our listeners about the data insights initiative and the efforts under way to allowing data sharing protocols between all of the divisions of HHS.

Dr. Mona Siddiqui: Yes. Really the underlying premise is how does an organization become more data-driven and the way in which it makes decisions around policies and resource allocation. It turns out that there really isn't a process in place right now for all the departments within HHS to share data in a

seamless way. That if an individual in one agency requests data from another agency, oftentimes it can take just as long as if that internal person was an external individual to the department. Those data use agreements can take about a year to negotiate. There isn't any transparency built into the process.

What we are really charged with is building an enterprise-wide governance model for HHS that creates a more transparent, accountable, and consistent process for sharing data across agencies to really have a more data-driven approach to decision-making. As we do that, we're also looking to see how we can begin to harmonize the legal interpretations for how we share data.

Depending on who you speak to when you're part of a data sharing negotiation process, words can be interpreted in very different ways. We want to really start to understand how are those processes getting handled right now, and how can we begin to address that variation to create a more consistent model for the department as a whole.

Then the other piece is how do we create a technical platform that can enable that data sharing to happen in a more seamless way. Harmonizing the workflow, so that somebody sitting in one agency can put in a request that can get tracked, and somebody on the other end has a defined time period within which to respond, and where we can begin to bring data together. Behind the HHS firewall understand in a more holistic way the ways in which right now agencies are seeing things in silos that we want to really bring together.

I always say this is really a 15 to 20-year journey for any department. My job is really to make sure that we lay the foundation that is strong, both on the governance side and the platform side. We can't let complexity really stop us from taking that first big leap.

Margaret Flinter: I think, Dr. Siddiqui, even harder to imagine the sheer volume of these datasets that you're trying to align. I understand you have decades of information from the Centers for Disease Control and Prevention, from the FDA, from Medicare. Talk us through processes required to manage such vast datasets, and then to build a seamless interface?

Dr. Mona Siddiqui: Well, so right now, all of those different agencies really manage their own data. Our agencies get data from states, or from hospital associations. That process is really within the purview of the agency, and that entire lifecycle of getting the data, cleaning up the data, and making sure that it's in a usable format. We know that the data stored at those agencies have the expertise and the best sense of how to manage that data.

We want to build a structure -- when we say governance, it's really about the people, processes, and the technology needed to have in place, to enable data sharing. Really our focus right now is to create those pipes and those processes

that we really need in order to be able to share the data in a more seamless way, without letting the complexity of the different architecture at each agency be the thing that stops us from making that progress.

Mark Masselli: Dr. Siddiqui, a lot of tech enthusiasts have been at HHS to help liberate the data. We've been honored to have a number of them on our show, Farzad Mostashari, Bryan Sivak, Todd Park, and Susannah Fox. It takes a lot more time than some had hoped to get that data liberated. The HHS IDEA Lab was created back in 2013 to accelerate that pace of transformation. I'm wondering if you could share a little more about the Ignite Accelerator. Tell us about some of the innovative strategies that have been developed through that process.

Dr. Mona Siddiqui: Yes. The Ignite Accelerator really was a program that was put in place by Bryan to spur innovation at the frontlines of HHS. The idea being that our frontline staff are seeing problems in really the most fully formed way and have pain points that sometimes just aren't getting addressed by a department as a whole. Since we want to be able to enable and empower those frontline staff to be able to address those, those pain points, and the Ignite Accelerator has really had transformed the culture of the department to embed innovation, and every agency that we've worked with [inaudible 00:07:20] we have had projects in the Ignite Accelerator from across all the different agencies at HHS.

Thinking about all of those individuals who then go back to their agencies after working on these projects through mentorship at the IDEA lab, they go back and they become champions for this way of approaching problems of collaboration, of thinking outside the box, and of working with the private sector in a really meaningful way. Again, I think it's that culture of innovation, and I don't use that word lightly, I think it's that culture that has led us to where we are today, on a journey to a fairly massive undertaking for the department and becoming more data-driven.

A lot of the individuals, who've gone through the idea of lab accelerator actually have raised their hands to come and work on this data portfolio now, which I think is really a testament to the strength of the program over the years and the feeling of empowerment that these individuals have had, and wanting to make sure that they are part of this journey moving forward.

Margaret Flinter: Well, Dr. Siddiqui, your outgoing Chief Technology Officer, Bruce Greenstein, has said that he's particularly proud of the initiative to accelerate strategies for battling the opioid crisis. I know earlier this year your agency hosted an Opioid Code-a-Thon to bring together experts from technology and data science, and government sectors, all seeking to develop better tools for public health officials, and HHS to access data that's related to this deadly epidemic.

Can you talk with us about what you think you might be able to achieve here and if you have any promising early results or outcomes to date?

Dr. Mona Siddiqui: Yeah, of course. We were privileged to host the Opioid Code-a-Thon at the department in December. Really the genesis of it was the call to action for the entire department to take part and doing its part to help address the opioid epidemic. Just because our office focuses on technology and data, doesn't mean that we don't have an important role to play in all the department priorities, especially a public health emergency, like the opioid epidemic. I'm also a physician. From that perspective, I will just say that this is -- speaking from the frontlines, this is one of the worst public health crises that our country has seen and we all need to do our part.

Our office really said that we can, through our work on the open data side, really create an opportunity to open the doors of HHS to the private sector to come and help us in addressing this crisis through data. We compiled about 70 data assets from across HHS, from the Department of Justice, from the Department of Transportation, the Department of Education, Census Bureau. We had about seven states that participated in broad data for the first time and one private entity as well. 70 data assets for one event and we had about 250 people come from across the country to participate, and really the range of participants was fantastic to see.

We had academics, we had industry, we had startups. About 60% of the people who participated did not identify health care as their primary domain of expertise, which in my mind really says that people are looking for an opportunity to help the federal government in this journey. Data really can be the way in which we all work together and the thing we convene around. We had a solution, so we requested solutions around three specific areas. One was around opioid prevention. One was on solutions for treatment. The third was an understanding opioid usage. We had a winner in each of those tracks. Each of those winners are actually continuing to build their solutions, which to me is a testament that this wasn't just a one and done event, but really a continuing movement forward.

We are in constant communications with those companies to see how we can continue to support their work moving forward. As they develop their solutions further, we hope to continue to partner in helping facilitate connections for testing and scaling.

Mark Masselli: We're speaking today with Dr. Mona Siddiqui, Chief Data Officer at the U.S. Department of Health and Human Services. Dr. Siddiqui, one of the important goals of all these initiatives and you're talking about it in a specific area, but is to really make all of this streamline data available to the outside world for research, spark citizens, scientists. HealthData.gov is the portal through which developers and entrepreneurs can access data for research and

development. How do you see this portal ultimately accelerating the pace of research, both within the agency, but more broadly in the research community?

Dr. Mona Siddiqui: Well, I think it's a testament to Todd, and Bryan, and Susannah that over the course of many years, 2,000 datasets were released for public use through HealthData.gov. I think that's really a phenomenal testament to the leadership at the department for a long time and being incredible proponents of data as the way to make government more open and as the way in which we can continue to collaborate with entrepreneurs and researchers, who have a different and unique perspective to be able to bring to some of the most complex problems that the country is facing today.

I really want to make sure that we continue those efforts that HealthData.gov is the place for accessing, not just data from the federal government from the health care side, but more and more we have states and counties that have put data on HealthData.gov. We hope to be able to bring more of that granular data to HealthData.gov, so that it can continue to be a place for people from all different backgrounds to be able to get access to data that they otherwise would not be able to.

We also want to make sure that we understand what the demand is from our stakeholders, and what data should be made publicly available. In the coming months, we're going to be reaching out more to that community to get a better understanding of what they would like to see from HealthData.gov, both in terms of the datasets that are publicly available, but also additional tools that might help in actually working with the data. We also want to make sure that we continue to make that data more usable.

Margaret Flinter: Well, Dr Siddiqui, I know you've joined with your predecessors in this quest to liberate the data, but also data that is timely. We had Harvard's Dr. Shah recently joined us in and he was saying he's just perplexed by the fact that, one, he has to pay money for Medicare datasets, but two, he just has to wait a long time to get them in three when he gets them, they're already several years old. I think you acknowledged at the recent Health Datapalooza appearance could take 15 or 20 years to get all the data moving the way everybody would like it to. Tell us a little more about the long-term expectations for the robust sharing of the HHS health data. What's it going to take to get there?

Dr. Mona Siddiqui: As we've taken a deep dive into our agencies and our team has really found across HHS over the last several months and spent sometimes between 10, 12 hours at every agency talking to leadership and in talking to data stewards of some of the most high valued data assets across HHS, this is a multilayered issue, one of which is each of our agencies are governed by different statutory requirements. Sometimes, each of our data assets have very different regulations that govern that data collection activity.

When we talk about the sharing of data, right now, we're just talking about how do we create a more seamless process for internal data sharing to happen, so we can start to use our data as an asset. Well, part of that is going to involve questions around legal interpretations, within the context of the different statutes and regulations that we are all governed by, and harmonization of that. This is an incremental process.

We are budding [PH] our work around business use cases for the department. Our first use case is the opioid epidemic. Our initial look is what are the data assets that are high value for this specific use case? How could we begin to do some data linkage and analysis, and show value from that data? As we do that, we will work to look at the legal agreements that govern that process and harmonize it to the extent possible, and then take it to the next use case.

Rather than spending time doing a complete landscape analysis, which would take another 10 years, we really do think that it is our job to show value from data and value from the process in order to really change the culture and show, not just to our leadership, but to our agencies, and the staff that there is value in being a part of this process.

Mark Masselli: Dr. Siddiqui, Margaret brought up Health Datapalooza. I'm reminded of a conversation we just had with the Co-Chair of that event, Dr. Rasu Shrestha, Chief Innovation Officer at University of Pittsburgh's Medical Center, who noted that we're going to see an acceleration of health data sharing in the coming years as the move towards precision medicine and artificial intelligence begin to take hold in the marketplace. HHS' Chief Technology Officer launched a program, called HHS Startup Day, where entrepreneurs can sell their innovative ideas to HHS. Tell our listeners a little more about that program.

Dr. Mona Siddiqui: We want to demystify the ways in which the federal government operates. We want to create a level of a playing field for those small startups that have some really big ideas and really innovative solutions. We want insight into what is happening in the market. A lot of times the folks that may get meetings are the big corporations. That is the culture that we would like to change.

HHS Startup Day is really our attempt to bring together that community with the leadership by HHS. The first event in Washington, D.C., we had representatives from FDA and from CMS, from our acquisitions folks at HHS, along with NIH, and others. It was a great way to provide feedback to the startup community about what we are looking for, and for us to hear the pain points from that community, and to understand how can we help smooth that pathway for them.

The next one was in Boston. We've had one in Nashville. We'll be having additional events around the country, both this year and next year, and hope that this is the start and a more meaningful way to engage with that community.

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Margaret Flinter: We've been speaking today with Dr. Mona Siddiqui, Chief Data Officer at the Department of Health and Human Services. You can learn more about their work by going to hhs.gov/idealab, and you can follow her on Twitter, @MonaSiddiquiMD. Dr. Siddiqui, thank you so much for joining us on Conversations on Health Care today.

Dr. Mona Siddiqui: Thank you.

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Mark Masselli: At Conversations on Health Care, we want our audience to be truly in the know when it comes to the facts about health care reform and policy, Lori Robertson is an award-winning journalist and Managing Editor of FactCheck.org, a nonpartisan, nonprofit consumer advocate for voters that aim to reduce the level of deception in U.S. politics. Lori, what have you got for us this week?

Lori Robertson: With Supreme Court Justice, Anthony Kennedy's, retirement, President Trump can nominate another justice to the court that has sparked concern among democratic politicians. The court's landmark decision in Roe v. Wade, making abortion legal nationwide, could be overturned. For instance, the Senate Minority Leader, Chuck Schumer, wrote in an Op-Ed in The New York Times that there were "at least 20 states poised to ban abortion immediately if the 1973 decision is overturned." What would happen if Roe v. Wade went away? Jurisdiction would go back to the states, which then would be able to decide whether or not to allow abortion or what restrictions to impose.

The Guttmacher Institute, a reproductive health research organization, says that 17 states have laws that could restrict abortion, while nine states have laws that protect abortion rights. Among the first group, four of them have laws calling for abortion to be banned automatically if Roe v. Wade were overturned. Those four are Louisiana, Mississippi, North Dakota, and South Dakota. 10 states have bans on abortion that have been on the books since before the 1973 Supreme Court decision. Some states may reconsider those old laws, should Roe be eliminated. Massachusetts, for instance, is one of those states. Seven states have passed laws expressing an intent to put restrictions on abortion as permitted by the High Court if Roe were overturned.

As for the nine states that have laws calling for the protection of abortion rights, those are California, Connecticut, Delaware, Hawaii, Maine, Maryland, Nevada, Oregon, and Washington. The Center for Reproductive Rights says that if Roe is overturned, 23 states could ban the procedure and 19 other states could protect abortion rights. That's my fact check for this week. I'm Lori Robertson, Managing Editor of FactCheck.org.

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Margaret Flinter: FactCheck.org is committed to factual accuracy from the country's major political players and is a project of the Annenberg Public Policy Center at the University of Pennsylvania. If you have a fact that you'd like checked, email us at chcradio.com. We'll have FactCheck.org's Lori Robertson check it out for you here on Conversations on Health Care.

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Mark Masselli: Each week conversations highlight a bright idea about how to make wellness a part of our communities into everyday lives. Diabetes affects 30 million Americans and management of the chronic illness can often prove challenging for patients who must keep vigilant about things, such as diet and exercise to stay healthy. When the patient population is part of an ethnic minority, language and cultural barriers prove an additional challenge for clinicians seeking to improve the health of their diabetic patients. Researchers at the NYU School of Medicine, Department of Population Health decided to target their efforts on the city's Bangladeshi community, who suffer from high rates of diabetes.

Nadia Islam: The community health worker model, I'd like to use the metaphor of a bridge. CHWs really serve as a bridge between communities and between systems of care. Because CHWs are respected and trusted individuals in their own communities, they're able to connect people to care and connect people to resources and information in ways that's understandable and relevant for them.

Mark Masselli: Nadia Islam trained a group of community health workers to meet the participants in their home and communities to help the test group better manage their condition.

Nadia Islam: There's thousands of diabetes management curriculum out there. They are often not culturally tailored for specific communities. We worked with our coalition to completely culturally tailor a curriculum by our community health workers in group settings with some one-on-one follow-up as well.

Mark Masselli: Islam says community health workers gained the trust of patients they were assigned to, helping them and their families adhere to important diet and exercise regimes.

Nadia Islam: We found early on that female participants in particular expressed hesitations and barriers to finding what they perceived as appropriate places for physical activity. We actually created an at-home culturally tailored physical activity in language at home DVD for participants.

Mark Masselli: The results were significant. Islam says in six months, 55% of the test group, who worked with community health workers managed to keep their blood sugar levels at or below 7%, a dramatic improvement over the participants in the control group, who did not have the community health worker intervention. A targeted culturally relevant community health worker approach to helping patients better manage their diabetes that has yielded significant improvement in diabetes control, yielding better health outcomes, and lower health expenditures. Now, that's a bright idea.

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Mark Masselli: You've been listening to Conversations on Health Care. I'm Mark Masselli.

Margaret Flinter: I'm Margaret Flinter:

Mark Masselli: Peace and health.

Female: Conversations on Health Care is recorded at WESU at Wesleyan University, streaming live at chcradio.com, iTunes, or wherever you listen to podcasts. If you have comments, please email us at chcradio@chc1.com, or find us on Facebook or Twitter. We love hearing from you. This show is brought to you by the Community Health Center.