

## The Day the President of the United States Said “That Data is Mine”

Sharon F. Terry

ON THURSDAY, FEBRUARY 25, 2015, the White House held a Precision Medicine Initiative Summit. I had the honor to attend since I was announcing a commitment to that effort. My commitment, made on behalf of PCORnet,<sup>1</sup> the National Clinical Research Network, was to rally the troops, the millions of individuals who are part of PCORnet, to electronically ask for, and receive, their electronic health record data. The patient powered research networks of PCORnet are designed to empower people to become active partners in the research process. This is directly in our sweet spot since we are the mothers and fathers, the people themselves, in need of interventions to alleviate suffering.

What was more remarkable than the many commitments we heard that day<sup>2</sup> were the words of President Obama. He said:

With respect to being able to map out what’s happening with these different diseases and what are the genetic similarities, what are the differences, why are some people doing okay with it, why are people not, the more samples we have, the more data we have, the more we’re going to be able to learn. Part of the problem with have right now is, is that every patient’s data is solid—it’s in a hospital here, a hospital there, a doctor here, a lab there. And so the goal here is if we can pool and create a common database of ultimately a million people that’s diverse so that they have a lot of genetic variation, we can now take a disease that may be relatively rare, but because we have a pretty large sample size and start seeing patterns that we might not have seen before.

But a couple things that requires—it requires, first of all, us understanding who owns the data. And I would like to think that if somebody does a test on me or my genes, that that’s mine. (Applause.) But that’s not always how we define these issues, right? So there’s some legal issues involved.

Harlan Krumholz, a regular rabble rouser on the side of the people, Tweeted that “It’s about empowering patients to use their data for common good.”<sup>3</sup> Dr. Krumholz committed to developing tools for patients to access their full health record,

review it, and share it with another clinician or donate it for research.<sup>4</sup> Obama agreed and went on to say,

So if I am sick and voluntarily I want to join with other people who have a similar disease to mine and donate our data to help accelerate cures, I’ve got to be able to work with the electronic health record companies to make sure that I can do that easily.

Right now, what happens is the best researchers and the best universities, oftentimes they’re kind of hoarding their samples, essentially for fear of losing their grants if they do not keep control of them.

I have had the good fortune of being invited to the White House several times during this administration. I never before heard words from the President that so echoed what we have been striving for all these years. It felt like someone heard us, and not someone, but a whole system! I was quoted in the New York Times the next day saying, “I had chills and a few tears, because I had not heard this before from the president or anyone high-up at the White House.”<sup>5</sup> However, I also said, “This is a really, really, hard issue.”

Obama hit the nail on the head when he said that researchers and their institutions are “kind of hoarding their samples.” I described one of my many experiences with this in a recent article.<sup>6</sup> There is an enormous lack of alignment around incentives to understand health and disease. They are too many to detail in one short perspectives piece. But just the issue of data sharing should be an easy one, and it is not. Data, especially from individuals, should be readily shareable. The President was not without nuance when he also talked about the costs to universities, companies, and researchers to get these data, and so this is not simple. It seems to me, however, that we cannot allow the current economy, built in an age of materials and scarcity of those materials, to thwart what is possible today.

<sup>1</sup>PCORnet: The National Patient-Centered Clinical Research Network. Available at <http://pcornet.org/>, accessed on February 25, 2016.

<sup>2</sup>Fact Sheet: Obama Administration Announces Key Actions to Accelerate Precision Medicine Initiative. Available at [www.whitehouse.gov/the-press-office/2016/02/25/fact-sheet-obama-administration-announces-key-actions-accelerate](http://www.whitehouse.gov/the-press-office/2016/02/25/fact-sheet-obama-administration-announces-key-actions-accelerate), accessed on February 26, 2016.

<sup>3</sup>Tweet from Harlan Krimholz @hmyale 10:51 AM, February 25, 2015.

<sup>4</sup>Fact Sheet: Obama Administration Announces Key Actions to Accelerate Precision Medicine Initiative. Available at [www.whitehouse.gov/the-press-office/2016/02/25/fact-sheet-obama-administration-announces-key-actions-accelerate](http://www.whitehouse.gov/the-press-office/2016/02/25/fact-sheet-obama-administration-announces-key-actions-accelerate), accessed on February 26, 2016.

<sup>5</sup>Davis, Julie Hirschfield. President Weighs In on Data from Genes. New York Times. February 25, 2016.

<sup>6</sup>Terry SF. Life as a numerator: putting the person in personal genomics. *Appl Transl Genet* [Epub ahead of print]; DOI: 10.1016/j.atg.2016.01.007

When economies were built on steel and paper, they were built with finite materials. Today, in the information age, we are overwhelmed with an abundance of new currency: data. Sure information and knowledge are still finite, and expensive to create and maintain, but data are abundant. What does an economy of abundance look like? How should we behave in an era when we have more data than we can process? Should not these data be freely shared? We have seen a revolution in music and publishing, both industries that decried “open” sharing because their business models would collapse.

At Genetic Alliance, together with Private Access, an innovative company in southern California, we are trying a bold experiment. So far it is going very well. We have put the levers for sharing in the hands of people, the people from whom the data comes. We have been greatly aided by the right to access and receive a copy of health information afforded us by HIPAA. These have been explained and made more accessible recently by Jocelyn Samuels, Director of the Office for Civil Rights.<sup>7</sup> Our tool, the Platform for Engaging Everyone Responsibly (PEER), starts from a core premise that if these systems that are striving to accelerate health and medical research started with the person, with the citizen, with the patient, then they would fly. It is our mission to equip

ordinary people with the tools to make choices and to share their health information.

It gets very sticky when the world is viewed through a clinical or a research lens. For us, individuals lying on the “stage” (the place where the specimen goes for us lay folks), the lens matters not, seeing matters. We want to be seen. We want to go even further than the President did, and say: “These data are everyone’s.” What if we go fearlessly into this new age, the age of precision medicine, in which all eyes are suddenly on the potential of big data, little data, my data? What if we try “our data”? There is enough to go around. These data are everyone’s data.

#### **Author Disclosure Statement**

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<sup>7</sup>Blog by Jocelyn Samuels. Facts sheets and FAQs. Available at [www.hhs.gov/blog/authors/jocelyn-samuels#](http://www.hhs.gov/blog/authors/jocelyn-samuels#), accessed on February 29, 2016.