# The Dish: Your Participant Reps—Face-to-Face with

<https://www.youtube.com/watch?v=iZLxOLkg4og>

## Title Slide: The Dish, Your Participant Reps

## Title: Face-to-Face with Karl Surkan, July 12, 2017

Logo of the All of Us Research Program

## Scene Change

Eric Dishman and Karl Surkan sitting together.

## Dr. Dishman:

Welcome back to the Director’s Corner. I’m going to start having conversations with different players in our consortiums so you can get to know people and the different perspectives they bring. I’m here with Karl today, who recently joined our Steering Committee as a participant representative to bring some different whacks on the side of the head for us and things to think about as a consortium. So I would be interested in hearing—like, how did you first hear about the program? What were your first impressions? And then, how did—you know, how have you found your way with us?

## Mr. Surkan:

I mean, really, I was watching the State of the Union Address in 2015, and President Obama was sort of talking about precision medicine, and I immediately was like, “OK, that’s something I’m really interested in.” I had, you know, already had a cancer diagnosis. I had already been established as a person with the BRCA1 mutation. I’m a transgender person. I have a son with a rare bone disease. I have so many reasons to be interested in precision medicine. It was very user-friendly to get involved through social media. So I’m one these organic—I don’t know—digital volunteers, I guess, right?—that I just started exploring the hashtag, and then I found that there were open, livestreamed meetings, and I started listening to them. Then I found that you could sign up to actually come to a meeting, which surprised me, because I didn’t think that I’d ever heard of a government initiative that just welcomed a citizen—a random citizen. My thought was, you know, “What can I do to help this along? What can I do to further this research and connect to people, you know, that I know who want answers—medical answers with this initiative?” I just kept hearing people saying, “We want to return the data to the participants,” and I was like, “Yes!” You know, “We want people to be involved and help direct the research,” and I said, “Yes!” You know, this is what we’ve been asking for! Part of the excitement of the Precision Medicine Initiative for me—and the *All of Us* Program is that it really enables you to look not only at the genetic factors but also the environmental factors and also some of the social conditions that cause or—either cause disease in the first place or, you know, are creating barriers to people to getting care. I mean, I like to think that I’m a kind of self-sufficient person, and I like to go out and do my own research and try to study, you know, things I don’t understand; but in this case, it’s a little bit more—we have to rely on each other, because it’s the mass effect that causes the out—you know, the truth to emerge.

## Dr. Dishman:

You’re fairly new to the program. As you come into it, what are you worried about? What are you—is there anything that you’re like, “I wish I could nudge this program in a direction before we get too much further down the road.” We’re not quite a one-year-old yet, right? But before we become a two-year-old, is there something you wish you could nudge us to or pay attention or shine a light on?

## Mr. Surkan:

I think that the real test will be, you know, “Can you honor the promise of returning the data in a responsible way? Can you engage the people in a way that engenders trust and, you know, enables them to feel good about participating?”

## Dr. Dishman:

Well, thanks for joining the effort, and it’s good to get to know you a little bit better, and I look forward to a long journey. We’ll have to do a time capsule and come back and have some more conversations to see how we’re doing on that front.

## Closing slide

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