Dr. Esteban González Burchard
All of Us
Oral History

The All of Us Research Program is an ambitious effort to gather health data from one million or more people living in the United States to accelerate research that may improve health. All of Us is working with participants across the country, collecting many types of information over time, and building a database that many researchers can use. This new model could shape how people do research in the future. All of Us will share lessons about what works well with other research programs around the world. The program is supported and overseen by the National Institutes of Health (NIH) and is the result of NIH's Precision Medicine Initiative Working Group of the Advisory Committee to the Director, which concluded its work in 2015.

Condon: I'm Aaron Condon. It's Friday, November 3, 2023, and I'm joined by Dr. Esteban González Burchard, Professor of Pharmacy and Medicine at the University of California, San Francisco, who was also a member of the Precision Medicine Initiative Working Group, which advised then [NIH] Director Francis Collins as well as [President] Barack Obama prior to the creation of the All of Us Research Program. Today, I'm going to conduct an interview to explore the origin of the All of Us [program] and document it as part of an oral history series for the Office of NIH History and Stetten Museum.

How are you today?

Burchard: I'm doing well. Thank you.

Condon: Would you prefer me to call you Esteban or Dr. Burchard?

Burchard: Esteban.

Condon: Perfect. Can you tell us first a little bit about your background and how you came to be a part of the working group?

Burchard: What kind of background do you want to know?

Condon: What led you into being interested in an Advisor of the Precision Medicine Initiative?

Burchard: So why did I want to waste my time doing this for free? I live and breathe health in minority populations, and I'm trained in pulmonary critical care medicine. I'm trained in genetics. I run a clinical pharmacology fellowship, so I know a lot about drugs. I am a key opinion leader in medicine, race, and genetic ancestry and how that influences risk of disease and response to medications. When I was invited to participate in this program. I saw it as an opportunity to have a much larger impact on U.S. minority populations. A much larger impact than what my lab does. So that that's really the impetus of why I joined.

Condon: Okay, and so obviously, the precision medicine, in general, has been discussed in scientific circles for decades. How did you first become aware of precision medicine?

Burchard: I don't think precision medicine has been discussed for decades. I think that it really came about probably around 2005. In 1997, I started studying the genetics of asthma between African Americans and Whites and we identified a gene that was associated with asthma severity and is 40% more common in African Americans than Whites, and to me that was the first evidence, biologic evidence, that might help explain why African Americans have a higher prevalence in morbidity and mortality compared to Whites. Because up to that point, everybody was saying it's all socioeconomic, social discrimination. But I trained as a geneticist [and] knew that there are genetic differences between populations. That was my “Aha” moment. Then in 1998, as my mentors and I started a study called the Genetics of Asthma and Latino Americans to look at Puerto Ricans, who have one of the highest prevalence of asthma in the world, and Mexicans, who have one of the lowest prevalence. But they are two Hispanic groups, and I, I'm Mexican, grew up in California, U.S., studying in Boston, at Harvard, where they, in the East Coast, have a lot of Puerto Ricans, Cubans, Dominicans, and my mom looked very African. I knew that Puerto Ricans had a higher mix of African ancestry. We started the study to recruit children with asthma. We measured their lung function and gave them asthma medications. And we found that the strongest predictor response to the medication was genetic ancestry. That's how I got interested in precision medicine. Here, we're seeing different population-specific differences in response to medications, and that was never shown before. That's how I got interested in it.

Condon: Generally, at this point I’d ask what your role was during the early years, but I understand that as part of the Working Group you were involved, as you said, until the program launched, and that's where your involvement ended, or your knowledge base ends regarding the running and the administration of the program. Can you describe your role for me, within the working group, and how it evolved to come to some of the more popular goals that we have today of one million participants and sharing of data?

Burchard: All of Us was different, but we all had the same role. First of all, it was awesome because obviously, this was a top priority for the NIH, and President Obama. Why that's important is I've been on other working groups with the NIH, and it has kind of been like a fumble, where this was smooth as silk. We were given instructions by Francis Collins at the beginning of what we needed to do, just global instruction about what they wanted. Then it was left up to us to decide the science and who we should include. Those were the instructions,

and we met in person almost every three weeks for a year. Every meeting was at a different location. We had meetings in Nashville, [Washington] DC, I think in Chicago. There are 13 of us, and we would, at each meeting, invite different key opinion leaders to come speak to inform the Working Group on their particular topic of interest and expertise. My role kind of evolved. I took a leadership role in making sure that All of Us would reach racial and ethnic minorities. My role, in addition to other people's roles, was to make sure that we had broad coverage of the United States by including race, ethnicity, and socioeconomic class. We didn't want what happened to 23andme, where you had a bunch of rich people, mostly White, that could afford $100 or $200 to take a test. Because that's obviously biased. We wanted to have—we specifically said this—low-income people from Appalachia to be able to be part of this. Then we want all racial groups to be included as well.

Condon: Thank you. President Obama highlighted the Precision Medicine Initiative or PMI, in his 2015 State of the Union address. How did the Obama Administration, from your perspective, and the US Congress come to support precision medicine?

Burchard: My opinion, it was a President Obama's idea. I only got to meet him at the end. But looking back, I knew that he was very, very, very, very smart, very intelligent, very knowledgeable about precision medicine, and what it could do. I don't know where he got that influence, but I'm positive that President Biden, Vice President Biden at the time, influenced him. And then Francis Collins, obviously, he was brilliant. Brilliant in a particular area, like genetics, but clueless when we wanted to talk about racial differences. I respected him on his expertise, and I'll just say I didn't respect him on his knowledge of minorities. But I knew that he was receptive to learning, and I thought it was my responsibility to educate him and educate the group on minorities.

Condon: Okay, yeah, that's really interesting. Is this something—and I mean obviously we're not talking about any particular administration here at this point in this question, or this follow up rather—but is it something that you've experienced before in working with specific working groups with specific agencies, we don't have to name any of them, that groups have been unreceptive to learning about minority populations?

Burchard: Yes. Not only people at the NIH, but scientists in general, and the public in general. I think there are two elements of this. I think people were clueless about different racial groups. The majority of scientists are White, and they tend to be males and are clueless about different racial groups. I think that there was a thought back then, and I know now that there's a strong element of racism embedded in science and in medicine. What I say is Jim Crow never went away. He just went underground.

Condon: Thank you. So precision medicine. We've talked about it. We probably said it a few times since we began this discussion, but what does precision medicine mean to you?

Burchard: It's very fascinating. I'll use an example. If I had a tumor in my lungs, I would get a biopsy, they would do genetic testing on it, then they would look at the genetics and see which drugs would work and which drugs wouldn't, and they would come up with a specific combination of drugs for me. So that, to me, is precision medicine. I call it having a smart bomb. So instead of carpet bombing a patient who has cancer with chemo[therapy] that will get to every cell in your body, from your toes to your lungs to your brain, we have the ability to have drugs that will only go to the cancer and not touch any other cells. That is precision medicine to me. That's what's happening today.

Condon: Great. The current enrollment goal of 1 million participants in 10 years is very ambitious. The Working Group of which you are a member, determined that the program will reach this goal of 1 million participants in four years. Why do you think the goal changed and what do you think of it?

Burchard: I think the goal changed because we knew how difficult it would be. I've recruited patients before, and so had other people, not everybody, but other people on the committee have recruited patients before and we knew how difficult it is to recruit, especially non-Whites. That difficulty is due to couple factors: historical misuse of medicines, like Tuskegee; mistrust of the government, especially by Native Americans; and a lack of cultural sensitivity to different racial groups [such as] Asians, Native Americans, African Americans, and Latinos. We knew that it would take longer to recruit.

Condon: Sounds reasonable. Another goal of the program, one that does not get quite as much attention as enrolling one million participants, is a sharing of data to research institutions. Personally, I love this goal and I try to highlight it when I talk with colleagues or folks that don't work at the NIH when I talk about my job. Essentially, the availability of data that All of Us collects enables researchers to skip participant recruitments for their own studies. How did the data sharing element begin?

Burchard: There are other groups that were doing a large patient collection. The group that comes to mind is Kaiser of Northern California. They did a fantastic job of recruiting patients, but they didn't share the data, and so, they have this wealth of data. It's untapped. Whereas we thought, if we had a wealth of data, we should distribute it to all the brilliant minds in the United States. That's how we came to that.

Condon: Did you pattern that sharing on a different model, or is that something that was concepted during the working group?

Burchard: In was concepted during the Working Group.

Condon: Great. It's clear to me, from my work within the program as well as my review of historical material, that inclusivity has always been paramount in both the enrollment of participants and workforce composition. We've been talking about reaching minorities in previously underrepresented communities so far, a bit in our discussion. But let's expand on that a little bit. Why is it important that we gain more participants from previously underrepresented communities? What is the value there added to the research?

Burchard: I'm not clear. Are you asking why it's important to have different racial groups included or personnel?

Condon: Yes, I'm asking why it's important to have different racial and ethnic groups included in study as participants.

Burchard: We know—let's see, I should take back “we”. A few of us knew there were genetic differences by race. I say that a few of us knew that because the Human Genome Project, which was completed in 2000, [under] Francis Collins, [President] Bill Clinton, and [Prime Minister of the United Kingdom] Tony Blair, specifically said that there are no genetic differences between populations, and therefore there is no genetic basis for race. First of all, I knew differently, based on my research in 1997, that there are genetic differences by race, and if you didn't include all racial groups, you'd miss genetic risk factors in some populations. We also knew that the majority of genetic studies were done in Whites. I knew that Whites are just a subset of Africa; all populations are a subset of Africa. If you want to capture all the genetic variations, we should have started with Africa. That would be a top-down approach, but the world started with a bottom-up approach of just getting Whites. So I, in particular, pushed really hard to make sure that we had diversity. I essentially disagreed with Francis Collins, saying that there are biologic differences between populations, and therefore, genetics correlates with race.

Condon: Okay, great. What are some of the methodologies that you championed to really get participants from these communities?

Burchard: I think it's imperative, and it's been well documented now [that] racial concordance between physicians and patients improves health outcomes. I recruited Latinos all over the United States, and by necessity, I needed to have Latino-serving providers, from physicians, to nurses, to recruiters, for a couple of reasons, cultural reasons and language reasons. That's why it's important to have diversity not only in who you recruit, but in your personnel. You need diversity in the scientists that are analyzing the data.

Condon: Why is that? I'm trying to very hard to speculate as to what that means for you, to put words in your mouth. But I imagine that would have some familiarity for the participants that we hope to reach and make them feel probably a little bit more comfortable. Is that the case?

Burchard: Yeah, yeah.

Condon: Great. Okay, so I'm sorry, go ahead.

Burchard: I mean, there are a lot of things that come along with racial concordance, and it's been proven over and over again, you have better health outcomes when you have racial concordance.

Condon: Okay. Great, thank you. Privacy is always a concern when gathering and storing and studying participant health data. From your perspective, what are the main ethical challenges you see with collecting, storing, and reporting data to participants?

Burchard: Two reasons. One, we don't want, say, for example, insurance companies getting this data and essentially discriminating against a patient. Okay, that's one important one. We didn't want anyone misusing the genetic data in a eugenics fashion. Eugenics has been done since the 1920s. In Europe, and during World War II with the Jews, and Gypsies, and gays. We wanted to make sure that we had tight regulations on the genetics, and it was not misused. Fast forward eight years to 2023. We now know that White supremacists are looking at our publications and our genetics and using that to justify discrimination. For example, the 2022 shooting in Buffalo, New York, the White supremacist that killed everybody justified killing African Americans based on a publication that came out in Nature Genetics. That looked at the genetics of educational attainment across different populations. And they, those scientists thought they were doing something just scientifically, but it turns out that people are watching them, grab their data, and manipulate it and just use it for justifying killing people. I have the manifesto from the Buffalo shooter and their direct quotes from the paper that were just used and twisted, and that is scary.

Condon: Yeah, it's quite scary, and you mentioned eugenics, [which is] historically relevant also in this country as well, I'll say, with the Native Americans and Native American remains that there are still many of which held by institutions like museums that are yet to been repatriated. That is an issue that is systemic and definitely here. From your perspective, what is the greatest challenge that the All of Us program has or will have in reaching its goals?

Burchard: The biggest challenge is, and I knew it was going to be—remember, first of all, there was a firewall between the 13 advisors and the rollout. I knew the challenge was going to be who was selected, or which clinical sites were selected, to recruit patients. Traditionally, it's been the big monsters like Harvard for example, because they would put together a great team, but then the Meharrys [Meharry Medical College, a historically Black college in Nashville] of the world would not be competitive. We wanted to make sure that there's broad distribution in the clinical sites. And [it] wasn't my idea but someone else brought it up, probably the NIH thought okay, we should also include federally qualified health centers (FQHCs) because by nature, they serve low income and often racial minority groups. So, that was a brilliant idea to include federally qualified health centers in addition to universities.

Condon: Great, well Esteban, that's the end of my list of questions for you. Is there anything else that you'd like to get documented as part of this series?

Burchard: Okay, again, I think because this came from Obama, everything was smooth, everyone was behaved. It is like the trains ran on time, the trains are clean, it was perfect. As the year progressed, we knew that the new Administration that was coming in was going to firebomb and tear down everything that Obama did. And this wasn't initially planned in at the start, but it was talked about very much at the end: let's get the money out there so no one can come in and retract it. So that made everybody speed up. And that was awesome to see because I don't think it would happen if Obama was behind it.

Condon: It's amazing and all of you were invested. That's amazing as well, and I think it's very important work. With that, we'll conclude. I'm going to stop the recording. Thank you so much.