# The Dish | Update on *All of Us*’s Genomics Plan

<https://allofus.nih.gov/news-events-and-media/videos/dish-update-all-uss-genomics-plan>

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

Eric Dishman on Camera.

## Mr. Dishman:

Well, it’s good to do a video blog. Haven’t done one in a while. We’ve all been heads down, just focusing on preparing for national launch, executing this beta phase that we’re in, and really deciding key parts of the program. And that’s the topic I want to cover today because we’ve actually made some really good progress on genomics. In fact, we’ve just released a notice of intent on the NIH Guide—just search for “NIH Guide” on your favorite search engine on the internet and you’ll find it—for genome centers. These will be the centers that process a million people’s genotypes and whole genome sequences.

So it’s a good opportunity for me to both update you on the genomics plan, but also to thank everybody who’s given input to it. Especially, we had a great workshop last year on the return of genetic information to participants, from participants and experts and genetic counselors and others involved in that. Thanks to our advisory panel working group on genomics, who gave us a great report that’s on our website to help us think through these challenges, and now, especially, our consortium Omics Committee, who’s now tasked with executing all of this. So these are the elements of our plan.

For those of you that work in the genomics space, you probably know this, but it’s important for me to reiterate the three big challenges that we’re trying to overcome here to do this right, and the first is just the cost and capacity of sequencing. You know, genotyping is rather common now; the costs have come down. But whole genome sequencing is still very expensive, and there’s just not enough capacity in the country to serve our needs as a program. So we’ve got to build out that infrastructure. The second is the capacity and availability of genetic counseling. If we’re going to do the responsible return of information, which we’re committed to as a program, then we’re going to need to tap into genetic counseling, and we know that that’s a scarce resource in many parts of the country. And then a third of this is, okay, once we’ve got the genomic data—both the whole genome sequences and the genotyping data—how do we de-identify that, secure that, store that, and curate and clean that data and make it really easy for researchers to be able to use this? So those are the challenges that we’ve actually been working on.

So, you know, I should say, genomics has been a part of our plan and program from the beginning. It’s just not the only part. People get hung up and think that precision medicine equals genomics only. And it’s like, no, we need electronic health record data, and behavioral data, and environmental data, but it is a key part of the program, and we’ve waited until we can get lots of public input, as well as participant input. I mean, now we’ve got more than 30,000 participants during this beta phase who are giving us input on lots of different aspects of the program. Now we’re ready and think, you know, okay, we’re headed in a direction and know how to do this right.

The first thing, I’ve already mentioned it, is we’re going to conduct both genotyping and whole genome sequencing analysis for all 1 million participants, and we want to do that as quickly as we possibly can, depending on both funding and infrastructure costs. So we’ll start processing both kinds of samples this year. That’s the goal in 2018. Given the core value is to return information and data to participants, we’re going to also start piloting. Before we scale out to all million, we’ll pilot a responsible return of information strategy and different approaches to that with 20,000 people. So 10,000 with genotyping data and 10,000 with both genotyping and whole genome sequencing data. So that’ll really help us learn before we’re ready to scale up that challenge of returning information to a million or more people from across the country. And then the third key piece of this, in addition to just getting the sequencing going and piloting the return of information, is the infrastructure buildout. So we’re going to need partners who have a clear path to scale to the unprecedented volumes that we need. You know, we want two to three genome centers. They need to be reaching 100,000 participants per year by the end of 2019 so that we come into 2020 as a program with at least 200,000 people per year or samples per year that can be processed for whole genome sequencing and genotyping. So that’s a big challenge to those of you that live and breathe this ecosystem and know that it’s like, okay, yeah, that’s some capacity that has to be built out.

So we’re working on the genomics consent now and integrating it into our general consent. It’ll be in place very soon, in April, and certainly it’ll be in place with national launch. We’ll be processing its samples and doing our responsible return of information pilot, certainly by the fall of this year if not sooner, and then we’re aiming to include this de-identified genomic data in the launch of the researcher portal, which will take place sometime in the first half of 2019. We want the launch of that portal to include for participants their de-identified survey data, genomic data, EHR data, so that we’ve got a pretty round or complete data set as we come out of the gate with that. So we’re looking forward to it, and we look forward to many of you applying, hopefully soon, to a funding announcement coming soon. Thanks!

## Closing slide

Logo of the All of Us Research Program

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