

Update on the *All of Us* Research Program's Tribal Engagement Efforts: A Message for Our American Indian and Alaska Native Participants

Table of Contents

Executive Summary	1
<i>All of Us</i> Tribal Consultation Process	1
What This Means for You.....	1
What's Next	2
Questions and Answers	2

Executive Summary

Spring 2020

Hello!

When signing up for the *All of Us* Research Program, you chose "American Indian or Alaska Native" as a category that describes you. Because of that, we thought you might want to hear about the *All of Us* conversations with Tribes and how these conversations could affect you.

All of Us Tribal Consultation Process

All of Us is committed to partnering with diverse communities across the country — especially those that have been left out of research in the past. As part of that commitment, we've been having formal conversations called Tribal consultations with American Indian and Alaska Native Tribal leaders and members. Our goals were to better understand the views and concerns of Tribal communities, respect Tribal sovereignty, and find ways to work together. We visited with Tribal leaders and organizations across the country. We also got emails with many different questions, suggestions, and requests. In the next few months, after more input from Tribal leaders and discussions with the NIH Tribal Advisory Committee, we'll release a report summarizing the feedback and our plans in response.

What This Means for You

For now, we have decided to wait to share data from American Indian and Alaska Native participants. We've taken this approach out of respect for Tribal communities and our participants, many of whom want more information about our recruitment strategies, policies, and efforts to reduce the risk of harmful research.

That means that, currently, your information is not included in our [Data Browser](#) or the [Researcher Workbench](#). The Data Browser is a tool that lets the public learn more about the health data participants have shared so far. The Researcher Workbench is a secure website where approved researchers can access participants' data for their studies.

We have also decided to wait to do genetic analyses on samples donated by American Indian and Alaska Native participants. This means that there may be a delay in giving you back your DNA information.

We will provide more information in the consultation report, which will be posted on our website later this year.

What's Next

We know you joined the program to support research, and we are so grateful. Your data is still in the system, and we hope you will stay in the program so we can share your data for research in the future. We want to give you a chance to learn more about the Tribal consultation and our plans so you can make an informed decision.

Before you decide to stay in the program or not, if you are a member of a U.S. Tribe, we encourage you to talk to your Tribal leaders to discuss your participation in *All of Us*. You may want to visit the [All of Us Tribal engagement website](#) for more details. Below are answers to some questions you may have right now.

Again, thank you for being part of *All of Us*, and please stay tuned!

Sincerely,

The *All of Us* Research Program

Questions and Answers

What did you hear from Tribal leaders during consultation?

All of Us heard questions, suggestions, and concerns on a variety of topics. Some topics included the management of samples, special training for researchers working with American Indian and Alaska Native data, and ways Tribes can be involved in research.

What can we expect from the consultation report?

The report will summarize the feedback we got and outline our plans to address the concerns we heard.

How long will my data be held back?

We don't know yet. It will probably be at least six months after the report comes out, to give you plenty of time to learn more about our plans and decide if you want to stay in the program. If you decide to stay involved, we will unlock your data for research.

What are you doing with the samples I provided?

We are keeping and storing your samples for now. We are not doing genetic analyses of your samples yet.

I want my data included. If I give permission now, will you add it to the Data Browser and the Researcher Workbench?

Before we continue, we want all self-identified American Indian and Alaska Native participants to have a chance to learn more about the report. Once the report comes out, self-identified American Indian or Alaska Native participants can choose to either stay in *All of Us* or withdraw. Those who choose to continue to participate will have their data included in the future.

What if I'm not formally a part of a U.S. Tribe, but have American Indian or Alaska Native ancestry?

We understand not everyone who identifies as American Indian or Alaska Native may have Tribal leadership with which to discuss these issues. Because U.S. Tribal members and others with American Indian and Alaska Native backgrounds are all included under the same category within the *All of Us* survey, it's important for us to give everyone the opportunity to review information from consultation before unlocking data from this group for researchers.

More questions? Email the *All of Us* Support Center at help@joinallofus.org.