



Tribal Health Research Office

Division of Program Coordination, Planning, & Strategic Initiatives
Office of the Director, National Institutes of Health (NIH)

NIH *All of Us* Research Program

What is precision medicine and why is it important?

- Precision medicine is health care that is based on you as an individual. It takes into account factors like where you live, what you do, and your family health history: it is medicine tailored to you.
- Researchers are learning more and more about resilience and how both common, chronic diseases – as well as those that are rare – may be prevented and treated with strategies that will work best for individuals.
- The more people that are included in a study, the more powerful the study is to identify and understand the causes of health and illness. This kind of power cannot be achieved unless individuals decide to share their data for research.

What is the *All of Us* Research Program?

- *All of Us* is a national research resource funded by NIH that will be open to all kinds of researchers. Instead of focusing on just one disease or condition, it will support research on a wide variety of health conditions.
- *All of Us* aims to engage a community of 1 million or more participants that reflects the diversity of America, including many people who haven't taken part in medical research before. They will share different kinds of information over time that will help researchers learn what prevention and treatments work for different individuals and communities.
- *All of Us* is intended to last for decades, so researchers may better understand what causes changes in health over time.
- Research using *All of Us* participant data has not yet begun; the research database may be open as soon as Winter 2019.

What does participation in the *All of Us* Research program entail?

- Participants will be asked to share information about their health, family, home, and work; access to electronic health records; basic physical measurements; and biological samples, like blood and urine. The program will ask participants periodically to provide additional information.
- Participants' information may be accessed for many different studies. At this time, there is no option for participants to opt out of specific research studies (e.g. a specific study proposed by a researchers) nor is there a way to specify that their data be used only in specific kinds of research (e.g. environmental research only).

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- Participants may withdraw from the program at any time. If they withdraw, their data will not be used for any future research but cannot be removed from research that is ongoing or has already taken place.

How does *All of Us* protect participant data?

- *All of Us* removes participants' names and other direct identifiers (like Social Security number) from their information and replaces them with a code.
- Access to data is tiered according to sensitivity. Researchers seeking access will be required to register, verify their identity, take *All of Us*' training in ethical research, and sign a data use agreement, promising not to identify participants. Researchers also must provide a description of their research project for the program to post publicly.
- While no data platform can guarantee a security breach will not occur, *All of Us* partners with top-tier security experts to help constantly improve its systems to mitigate those risks.
- At this time, the *All of Us* public data browser does not include racial/ethnic identity or Tribal affiliation; AI/AN-specific information will be visible only after consultation and using feedback received through this process.

How can Tribal Nations work with *All of Us*?

- *All of Us* is engaged in a Tribal consultation process and seeking input from Tribal leaders on the best way to work with Tribal Nations. Dates for consultation events and listening sessions may be accessed at: <https://allofus.nih.gov/about/all-us-tribal-engagement>
- The *All of Us* Research Program's consultation efforts and questions are being guided by the report of the *All of Us* Tribal Collaboration Working Group, which may be accessed at <https://allofus.nih.gov/about/who-we-are/tribal-collaboration-working-group-all-us-research-program-advisory-panel>.
- Feedback received through the Tribal consultation and other public engagement efforts will result in a plan for working with Tribal Nations. Feedback may be provided in person at events, as well as through email, call/text, or mail. Contact information for the *All of Us* Research Program Tribal Engagement team may be found at <https://allofus.nih.gov/about/all-us-tribal-engagement>.

***All of Us* Resources**

- *All of Us* Tribal Engagement website: <https://allofus.nih.gov/about/all-us-tribal-engagement>
- 2018 Tribal Collaboration Working Group report: <https://allofus.nih.gov/about/who-we-are/tribal-collaboration-working-group-all-us-research-program-advisory-panel>
- *All of Us* Research Program study protocol and lay summary: <https://allofus.nih.gov/about/all-us-research-program-protocol>
- *All of Us* website for potential participants: <https://www.joinallofus.org>
- *All of Us* Research Hub, including the Data Browser: <https://www.researchallofus.org/>