

Medical research hasn't always seen you. We're changing that.

People from all walks of life will share their health information. Health data from diverse people will help fill gaps in knowledge about why people get sick or stay healthy. The information we gather from one million or more people will create the largest health data resource ever.

Why is diversity important to the All of Us Research Program?

All of Us is asking lots of people to join. Participants are from different races and ethnicities, age groups, and regions of the country. They are also diverse in gender identity, sexual orientation, and health status.

Diversity in a research program is important for several reasons. First, where we live, how we live, and our background can all affect our health. Second, many groups of people have been left out of research in the past. This means we know less about their health.

By studying data from a diverse group of people, researchers can learn more about what makes people sick or keeps them healthy.

Data from All of Us could someday help researchers:

- Identify what makes people more likely to develop a disease.
- Find out how environment, lifestyle, and genes can impact health.
- Build better tools for detecting a health condition and encouraging healthy habits.

Why have some communities not been part of research?

There are different reasons. For example, some communities have not been invited to take part in research. Or, they were invited but were not told what was involved. For these reasons, we know very little about them.



The All of Us Research Program has learned from this history. We want to be sure we do things right, so many different groups of people can join. We will tell you what we are doing. We will share results. And we will protect your data.

Why are the Hispanic/Latino communities important to All of Us?

Hispanics/Latinos, like many other groups, have often been left out of research. As a result, we know less about their health and ways to provide them with the best care. The All of Us Research Program wants to change this. By joining All of Us, Hispanics/Latinos can help ensure their communities are included in health studies. These studies could help researchers understand health conditions that are more common in the Hispanic/Latino communities. What they learn may lead to more tailored health care in the future.

All of Us is working with community partners to educate Hispanics/Latinos about the program and how research has potential benefits for their families and future generations.

All of Us Core Values

- Participation is open to all.
- Participants reflect the rich diversity of the United States.
- Participants are partners.
- Trust will be earned through transparency.
- Participants have access to their information.
- Data will be accessed broadly for research purposes.
- Security and privacy will be of highest importance.
- The program will be a catalyst for positive change in research.



How is *All of Us* addressing concerns about taking part in research?

Here are some of the ways *All of Us* is addressing these concerns:

Becoming a participant

All of Us wants people to make an informed decision about whether to join.

We have worked hard to make the process for joining *All of Us* clear and detailed. Before you decide if you want to join, we will tell you the purpose of the research program. We will also share the risks and benefits of taking part, what to expect in the program, and how to withdraw if you choose to leave. People must agree that they understand the program and their rights as participants before they can join. We have a Support Center and other staff who help answer questions about being a participant.

Ensuring privacy and data security

All of Us is committed to making sure data is kept private. We also want to make sure that data is not misused. The *All of Us* Research Program:

- Follows all federal, state, and local laws and rules for keeping data safe.
- Has strict policies and procedures to prevent misuse of data.
- Has Certificates of Confidentiality from the U.S. government. These will help the program fight legal demands (such as a court order) to give out information that could identify a participant.
- Continues to test the security of our databases.
- Will tell participants if there is a risk to their privacy because of a data breach.
- Stores data on protected computers. This limits and keeps track of who can see it.
- Removes personal details that could identify participants from the data.
- Requires researchers to agree to follow data use rules, including promising they will not try to identify participants.

Giving information back to participants

The *All of Us* Research Program will give information back to participants. People who join can choose to see their own health information, such as results from DNA tests. In the future, this might include information from health records. *All of Us* will post information on its website about the research being done with the data. General demographic information about all participants will be publicly available.



Is the program working with participants and their communities?

Yes. *All of Us* participant representatives shape the program at all levels. Participant representatives are part of local advisory boards and *All of Us* working groups, where they share ideas and help decide what the program does.

All of Us also funds community organizations. They reach groups that have historically been underrepresented in research to tell them about the research and answer questions. They also help spread awareness of the *All of Us* Research Program.

Why should someone consider joining *All of Us*?

People join for many reasons. Some people join because they can:

- Learn more about their health.
- Help improve the health of their communities and future generations.
- Help researchers find the best ways for people to stay healthy.

The *All of Us* Research Program will last for 10 years or more. This will allow researchers to study health over time. If you decide to join the *All of Us* Research Program, you will be contributing to an effort to improve the health of generations to come.



National Hispanic Medical Association

