

Your privacy and security questions answered



Top facts

- We take great care to protect your privacy.
- Your personal information will be stored securely.
- The *All of Us* Research Program will not sell your information to anyone.

What kind of personal information is the *All of Us* Research Program collecting?

If you join the *All of Us* Research Program, we will collect basic facts, such as your name, birthday, and email address. We will ask about your ancestry, gender, and education. We may also ask if you want to give us your physical measurements or blood and urine samples. If you have an electronic health record, we may ask for access to it. Everything will be stored securely.

Where is my information stored?

Your information will be stored in several places.

These include:

- The place where you sign up (if you enroll at a clinic or through your health care provider organization).
- The place where you give your physical measurements and samples (if you choose to).
- The *All of Us* Data and Research Center.
- The *All of Us* Participant Technology Systems Center.

How will the *All of Us* Research Program protect my privacy and keep my information safe?

The *All of Us* Research Program follows privacy and data security rules. The rules lay out the best ways to keep your information private and safe. They also guide how we collect data and work with participants.

Will my information be made public?

Your personal information will be kept private. We will create a database that everyone can use to make discoveries. The information that is public will be about the group of participants. For example, it might show the number of *All of Us* participants in your state or the average age of people who have joined. No one will be able to use this information to identify you.

Will you ever give out my name or other information that identifies me?

There may be times when we will have to give someone your information. This may include information that identifies you, like your name. We may do this to obey U.S. laws and regulations. Most often, this information is given to protect your health or the health of others. For example, we might do this if we learn that you have a disease that is a risk to public health, like measles.

If we have to give out your information, we will try to give out as little as possible and still obey the law. We will also do our best to tell you if we had to give out your information.

Who will use my information?

The *All of Us* Research Program will take great care in deciding who can use your information. To use your information, researchers must explain what they plan to do, what they hope to learn, and why their study would be useful.

Only researchers approved by the *All of Us* Research Program will be allowed to see data from individual participants. Researchers who can see individual participant data will not be able to see names or other information that could identify someone directly. These researchers will have to go through training. They must sign a code of conduct agreeing to respect the *All of Us* Research Program values and rules. They will have to promise not to try to find out who any of the people participating in the *All of Us* Research Program are.

What happens if a researcher breaks the *All of Us* Research Program's rules for accessing data?

Researchers must agree to follow certain rules before they can access *All of Us* Research Program data that is not public. Researchers who break those rules will be punished. The *All of Us* Resource Access Board will review what happened and decide on a punishment. Punishments could range from blocked data access to criminal penalties.

Will you sell my information to drug companies?

No. *All of Us* will not sell your information to anyone. But because we are a research program, we will share the data that participants give us to help researchers. The researchers who use this data may study many topics. They may come from universities, school groups, drug companies, and other places. Before using your information, researchers must share why and how they will use the information.

We hope that researchers will use this information to make discoveries. If their research leads to new tests, drugs, or other commercial products, you will not get any profits. These inventions will be the property of the researchers or the places where they work.

What will the *All of Us* Research Program do to help me if my information gets hacked, stolen, or tampered with?

The *All of Us* Research Program works to keep your information safe. However, there is a chance of a security breach in any information-sharing setting. If a breach is a risk to your privacy, we will tell you. We will tell you about the information that was exposed and share steps you can take to protect your privacy in the future.

What will happen to my information if I decide to stop participating in the *All of Us* Research Program?

If you decide to leave the program, you will have two choices. You can let the *All of Us* Research Program keep using your samples and information for new studies, or you can make them unavailable.

If you choose the first option, researchers can still use the information you have already contributed.

If you choose the second option, your information will not be used for new studies. We will destroy your samples. We will remove your information the next time we update the database. Once that happens, researchers who get *All of Us* data cannot get your data. If researchers already have your information, we at *All of Us* cannot get it back.

Also, we will let researchers check the results of past studies. If they need your old data to do this work, we will give it to them.

In both cases, we will keep your name and contact information. We keep this information so we can follow U.S. research laws and regulations.

After you submit your change, you will receive a message that confirms your decision.

Where can I learn more about the *All of Us* Research Program?

You can learn more about the program at JoinallofUs.org. Also, the *All of Us* Research Program's Support Center is open every day (except public holidays) to answer your questions. You can call toll free at (844) 842-2855 or email help@joinallofus.org.

Your privacy is very important. Here are some specific ways we protect your privacy:

- We follow all federal, state, and local laws and regulations for keeping information safe.
- We have strict internal policies and procedures to prevent misuse of data. You can read our **Privacy and Trust Principles** and our **Data Security Policy Principles and Framework** at www.allofus.nih.gov.
- Experts continue to test the security of our databases.
- We store information on protected computers. This limits and keeps track of who can see it.
- To work with your health data, researchers must agree to a number of rules. This includes promising they will not try to find out who you are.
- We will tell you if there is a risk to your privacy because of a data breach.
- The *All of Us* Research Program has Certificates of Confidentiality from the U.S. government. This will help us fight legal demands (such as a court order) to give out information that could identify you.

For more information, visit JoinallofUs.org

All of Us, the *All of Us* logo, and "The Future of Health Begins with You" are service marks of the U.S. Department of Health and Human Services.