



All of Us Research Program

LGBTQ+ Data Privacy and Security

LGBTQ+ people, like many other groups, have often been left out of medical research. As a result, we know less about your health and ways to provide you with the best care. The *All of Us* Research Program wants to change this. By joining *All of Us*, LGBTQ+ people can help ensure your community is included in health studies. These studies could help researchers understand health conditions that are more common among LGBTQ+ people. What they learn could lead to more tailored approaches for preventing and treating those conditions.

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.

All of Us Privacy and Security Practices

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. See the Privacy, Trust Principles, Data Security Policy Principles, and Framework.
- 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.

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.

For more information, please visit: JoinAllOfUs.org