

How the *All of Us* Research Program Handles Your DNA

What is DNA?

DNA is short for deoxyribonucleic acid. It is the material that makes up the genes that pass from parents to their kids. Half of your DNA came from your biological mom and half came from your biological dad. Your DNA determines traits like your hair color, eye color, and risk for developing some diseases. Your DNA is more than 99% the same as everyone else's DNA. The tiny amount that is different is what makes each of us unique.



How do I pronounce deoxyribonucleic?

"dee-ox-see-rye-boh-noo-clay-ic"

Why is the *All of Us* Research Program studying DNA?

We know that certain changes in DNA can affect our health, but there is still a lot to learn. By studying DNA from *All of Us* participants, researchers could:

- Learn more about what keeps us healthy or makes us sick
- Identify which treatments work best for different types of people
- Create medications to treat or prevent common conditions, such as chronic pain or diabetes

How will *All of Us* study my DNA?

We will use the most current technology to analyze your DNA in different ways. Two ways we will do this are by:

- Genotyping, which looks at a small amount of DNA that gives us information about many of the common DNA changes among us
- Whole genome sequencing, which looks at almost all of your DNA

Researchers will be able to study your de-identified DNA information through our Research Hub. They can also request to study your de-identified DNA directly. Before they can do either, they will have to go through special training and submit a request that states what they plan to study.

What can I learn from my DNA?

If you want to learn about your DNA, we can give your DNA results to you. We plan to check your DNA for a variety of information. We expect this will include information about your genetic ancestry, your traits, your risks for developing certain serious health conditions (such as cancer or heart disease), and how your body might react to certain medications. Knowing this information could help you take steps to prevent or identify a health condition early on.

One of the goals of *All of Us* is to learn more about DNA. As researchers learn more, we may go back and look at your DNA again in a new way. We will tell you if we find anything new.

What if I don't want to know my DNA results?

That's okay. You can share your DNA for researchers to use and learn from but choose not to see your results. You can also change your mind later.



(844) 842-2855



help@joinallofus.org



JoinAllOfUs.org

How will you protect my DNA information?

Your privacy and data security are very important to us. We will protect your DNA information in the same way we protect the other information you share with *All of Us*.

- We follow all federal, state, and local laws and regulations for keeping information safe.
- We have Certificates of Confidentiality from the U.S. government. They will help us fight legal demands to give out information that could identify you.
- We have strict internal policies and procedures to make sure your data is not misused. Researchers who want to study your DNA must promise not to try to identify you.
- We store information on protected computers. We limit and keep track of who can see it.
- We have security experts who have done and will keep doing thorough security testing.
- We will tell you if there is a breach that is a risk to your privacy.

Your DNA information is also de-identified, which means that researchers studying your DNA will not know your personal details like your name or where you live.

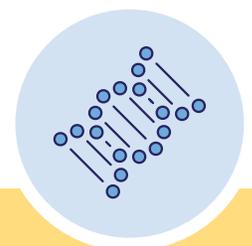
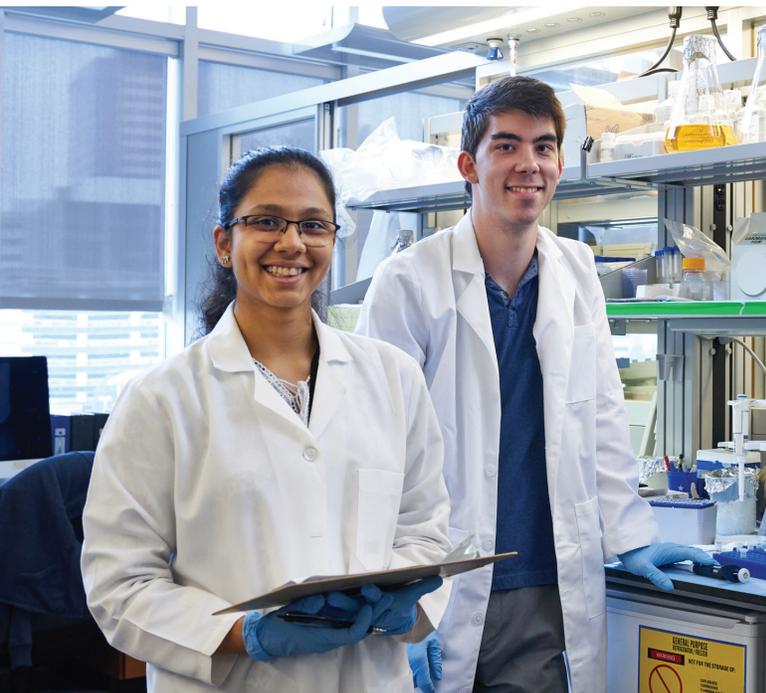


Can my DNA information be used against me?

All of Us is designed to protect the security of our participants' data. There are laws that help prevent your DNA information from being used against you, but it could happen.

- The Genetic Information Nondiscrimination Act (GINA) says employers can't treat you differently because of your DNA or require a DNA test to get or keep your job. This doesn't apply to uniformed military and employers with less than 15 employees.
- GINA also says health insurers can't use DNA information to change your coverage, drop you, or charge you more. GINA does not apply to disability, life, and long-term care insurance.
- The Americans with Disabilities Act says employers can't discriminate based on disability status.
- The Patient Protection and Affordable Care Act says health insurers can't use your health information to decide whether to cover you. Go to healthcare.gov for more information.

The National Human Genome Research Institute has information about these and other laws. It also has information about exceptions to the laws. Go to genome.gov/about-genomics/policy-issues/Genetic-Discrimination for more details.



More Questions?

This fact sheet is an overview. For more details, check your *All of Us* account or our website at JoinAllofUs.org. You can also call us at (844) 842-2855 or send an email to help@joinallofus.org.