

ALL OF US NEW ENGLAND PARTICIPANT NEWSLETTER SPRING/SUMMER 2022

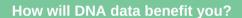
All of Us Adds DNA Data to Research Database

This spring, the *All of Us* Research Program released the first set of DNA information from participants into the *All of Us* Researcher Workbench. The information includes nearly 100,000 whole genome sequences, which involves a process that looks at participant DNA. Thanks to your participation, the dataset you are helping build will be one of the most diverse in the world.

This new data will help researchers see a more complete picture of health by looking at the genes a person was born with, their lifestyle, and what it's like where they live. Considering all these factors together could help researchers better understand why some people get sick and others stay healthy. This may lead to new discoveries that benefit everyone.



It's thanks to participants like you who contributed their DNA samples to the *All of Us* Research Program that we now have this more complete picture. Your DNA samples may provide valuable data for thousands of studies about conditions like Alzheimer's, depression, diabetes, heart disease, and others that could lead to the development of new treatments and preventions in the future.





Health-related DNA results can provide important details about your health that you might otherwise not be aware of. Knowing this information could help you and your doctor or health care provider take steps to prevent or identify a health condition early on.

One of the benefits of participating in the *All of Us* Research Program is getting your DNA information for free, if you want it. When participants provide a blood or saliva sample, *All of Us* will analyze the DNA in the sample. This DNA information could tell you whether you may have an increased risk of developing a serious health condition (your "hereditary disease risk"), such as certain cancers or heart disease and/or how your body might react to certain medicines. Hereditary means something that is, or can be, passed down from parents to their biological children. Most participants will get a report that says *All of Us* did not find an increased risk in the genes we looked at.

Help us create a community cookbook!

Speaking of information that can benefit your health...you might have read our recent newsletters that shared lots of information about nutrition and how important it is to your health. Eating well is critical to managing your health. Eating the right types of food is important, too. We want to hear from participants like you about the healthy recipes you follow to help support a healthy lifestyle.



Do you have a healthy recipe that you'd like to share with the *All of Us* New England community? Scan the QR code or visit: https://bit.ly/3vKYdDz to submit your favorite healthy recipe and we'll share it as part of our community cookbook project.

Answers to your Frequently Asked Questions about DNA Results

DNA data is now available to researchers. But what does that mean for you? Here are some answers to your Frequently Asked Ouestions about DNA results, data, and more.

Q: How will sharing DNA with *All of Us* help speed up health research?

A: There's power in numbers and diversity. When researchers study DNA information from many people, they may see small differences they couldn't see in smaller groups. Also, if a particular community of people has been left out of research before, they may have unique information to share. That information could help researchers make discoveries to improve the health of their communities.





Q: Who has access to my DNA information?

A: Only you will have access to your DNA results reports. Researchers cannot view your personal reports. The information we share with researchers does not contain your name or other information that could directly identify you.

Q: What will I learn from my DNA results?

A: You could learn important health information from your personal DNA results that could help you work with your doctor to prevent, detect, or treat disease. You could discover something that could help explain the history of a health condition among your blood relatives. Sharing your DNA results with your blood relatives can help them think about their own health.



Q: When will I get my DNA results?

A: We are working as guickly as possible to return results, and we want to do it responsibly. We need to make sure that all the right support systems and processes are in place. All of Us plans to start returning health-related DNA results to participants later this year. We're starting with blood samples and plan to return results for saliva samples as soon as we can. We are the first large population research program to offer free health-related DNA results and genetic counseling to all participants as part of being in the program. We are building things for the first time, and we want to make sure we get it right.

Q: How do I get my DNA results from *All of Us*?

A: If you decide you want your DNA results from All of Us, there are a few steps you need to take. Log in to your *All of Us* account and make sure you:

- Complete the "Consent to Join the *All of Us* Research Program" to participate in the program.
- Complete the program activities that might be available in your All of Us Dashboard. Depending on when you joined the program, this could include:
 - Agreeing to share your electronic health records (EHRs) with All of Us.
 - o Completing the "Consent to Get DNA Results" and telling us you want your DNA results.
 - Completing at least "The Basics" survey.
 - o Providing your blood, urine, and/or saliva sample when invited to do so.

For more information on DNA and All of Us, please visit: https://www.joinallofus.org/genomics

More Questions? Check out the Learning Center in your All of Us account or view our website at JoinAllofUs.org. You can also call us at (844) 842-2855 or send an email to help@joinallofus.org.



New England Researchers Use All of Us Data to Advance Health Research

These local researchers are using *All of Us* data to better understand reproductive health issues and the impact of COVID-19 on mental health.

All of Us is exploring reproductive health issues in Black women



Dr. Nyia Noel is an obstetrician-gynecologist at Boston Medical Center, Co-Investigator for *All of Us* New England and Assistant Professor of Medicine at Boston University School of Medicine. Dr. Noel is using *All of Us* data to study hypertensive disorders in pregnancy and uterine fibroids. These studies will help us better understand reproductive health issues that disproportionately affect Black women. Hypertensive (or high blood pressure) disorders in pregnancy include preeclampsia, eclampsia, gestational hypertension, and HELLP syndrome (Hemolysis, Elevated Liver enzymes, Low Platelets). They are some of the most common complications of pregnancy and are caused when high blood pressure develops. Uterine fibroids are benign tumors of the uterine muscles and can cause heavy periods, pains, and issues with fertility. Dr. Noel hopes to use *All of Us* data to help prevent and treat uterine fibroids in patients with specific demographic, clinical, and social characteristics and better understand how race and social determinants of health impact disease.

To learn more about Dr. Noel's work, please visit: https://bit.ly/3M7xurM

All of Us study highlights the impact of COVID-19 on mental health

Dr. Karmel Choi is a Co-Investigator for *All of Us* New England, Clinical Psychologist and Assistant Professor at Massachusetts General Hospital (MGH) and Harvard Medical School, and Director of the Precision Prevention Program in the MGH Center for Precision Psychiatry. Dr. Choi uses *All of Us* data to explore mental health risk and resilience. In Dr. Choi's most recent study, she and her team used participant data from the COVID-19 Participant Experience (COPE) survey to examine how social support impacts the risk of having depression during the pandemic. Social support can come in different forms, such as emotional support, social interaction, or tangible support (for example, having someone take you to the doctor if you need it). The study found that having more social support lowered depression risk, especially through forms of emotional support and positive social interactions. Dr. Choi hopes that this data can help tailor depression prevention strategies for those who may benefit from having different forms of social support.



To learn more about Dr. Choi's research, please visit: https://bit.ly/3wGg3bv

We heard you!

Thanks to your responses to our recent surveys, we learned about topics that you want to read about. Your suggestions included mental health, research successes, and details about results available to participants. We will continue to cover these topics and more in upcoming newsletters.



Tell us what you want to see by scanning the QR code on the right or visiting: https://bit.ly/3hECh6k

Have you completed the *All of Us* Social Determinants of Health (SDOH) survey?



Log in to your *All of Us* account to complete the survey today.

- Not all medical treatments and medicines work the same for everyone. That's
 because our genes, lifestyle, and environment each affect our health in different ways.
 How these things are linked is complicated. Researchers need all three pieces to put
 the picture together. That's why we're asking you to take the SDOH survey today.
- This survey asks about your everyday experiences and what it's like where you live.
- The survey will take about 10 minutes to complete.

You May Help Future Generations by Completing All of Us Surveys Today

Your survey answers are important for two big reasons: They tell us about your health experiences, and they may help researchers understand more about why people get sick or stay healthy.

- Please go online at JoinAllofUs.org or use the All of Us Research Program app on your mobile device.
- Log in to your account by entering the email or mobile phone number and the password you used to create your account.
- All surveys are available in both English and Spanish, and as always, your answers are secure and confidential.
- You can view your program information, including previous survey answers, and compare them to people like you from all over the country.

Log in to your *All of Us* account to complete surveys today.

Did you know there is a free All of Us Research Program app?

Download the app today:

- Open the camera app on your smartphone.
- Hold the device's camera up to the QR code on the right.
- No need to hit the shutter button, your smartphone will automatically recognize the QR code and provide you with an on-screen notification.
- Tap the notification to be taken to the Apple AppStore or Google Play.

Can't log in? No worries! Our team can help. We are happy to help reset your password with our new tool that allows us to assist you over the phone.



Need help in person? We can schedule an appointment with you to help complete your surveys. Surveys can be completed at one of our hospitals or health centers in person or over the phone. Contact us anytime at one of the locations below.

Mass General Brigham (617) 768-8300 allofus@partners.org Boston Medical Center (617) 414-3300 allofus@bmc.org





