

ALL OF US NEW ENGLAND PARTICIPANT NEWSLETTER SPRING 2023

Celebrating Five Years of All of Us

In May 2018, the *All of Us* Research Program began an exciting journey toward creating a healthier future for everyone. We have accomplished so much over these past five years, both nationally and locally. So far, more than **32,500 participants** have joined *All of Us* in New England. Of these participants, **73% are a part of groups traditionally underrepresented in biomedical research.** This includes racial and ethnic minorities as well as sexual and gender minorities, people with low income or limited education, and other groups.

All of Us aims to build one of the largest and most diverse health resources for researchers to use to conduct thousands of studies on health and disease.

There are **161 researchers** at Mass General Brigham and **29** at Boston Medical Center who are approved to use *All of Us* data to make important health discoveries. These local researchers have published multiple studies that cover topics such as mental health during the pandemic, reproductive health issues that disproportionately affect Black women, and hypertension prevalence in diverse populations. Local researchers also used *All of Us* data in a study that confirmed COVID-19 infections in five states weeks earlier than had first been reported. As more data comes in, we hope this will support new studies that could lead to new insights, treatments, and strategies for disease prevention that are tailored to individuals.

In November 2022, we started returning health-related DNA results to participants. So far, **more than 2,000 participants** in New England have been notified that their results are ready. This is a big milestone for *All of Us*. As an *All of Us* participant, you are our partner in research. Offering health-related DNA results is one way we are returning information to you that can help you learn more about your health.

We are so grateful for our community partners. In the past five years, we've partnered with **more than 30 community organizations**, including the American Cancer Society, Asian Women for Health, The Lupus Foundation, The Delta Research and Educational Foundation, MGH Chelsea Community Research Program, La Alianza Hispana, New England Regional Black Nurses Association, BCYF Grove Hall,

Mission Hill Health Movement, and so many more. We've participated in **125+ community events** and met thousands of people who want to learn more about how they could help make the world a healthier place to live. We look forward to growing these relationships and collaborating with more groups in the future.



These accomplishments wouldn't be possible without your help. Thank you for all you've done and continue to do for *All of Us*!

Spread the Word About All of Us!

Did you know that you can invite your friends and family to join the *All of Us* Research Program? You can send referrals through email or link right from your participant portal. Scan the QR code or log in to your participant portal and find "Invite Family & Friends" on your dashboard to get started!

You can also refer your family and friends by giving them our phone number: Mass General Brigham: (617) 768-8300 Boston Medical Center: (617) 414-3300







National DNA Day: The History of Genomics and Your DNA Results Updates

National DNA Day celebrates the completion of the Human Genome Project in 2003 and the discovery of DNA's double helix in 1953. Every year on April 25, students, teachers, and the public come together to learn about the latest advances in genomic research and how it impacts their lives.

What is genomic research? Genomics refers to the study of a person's DNA, including all their genes and how they interact with each other and the environment. This is different from genetic research, which looks at a limited number of specific genes.

In October of 1990, scientists launched the Human Genome Project to study all the DNA (genome) of a select set of organisms. The project was completed in 2003 and developed the first sequence of the human genome, which provides important information needed to build and maintain your body. This helped speed up the study of human biology and improve the practice of medicine.

Researchers can study DNA and other information from *All of Us* to understand how environment, lifestyle, and genes can impact your health. This information may help identify which treatments work best for different people and create medications to treat or prevent common conditions, such as chronic pain or diabetes.

How to Receive Your DNA Results from All of Us

Did you complete the Consent to Get DNA Results? Take a minute to log into your *All of Us* account and confirm if you said "Yes" to this consent form. Receiving these results is your choice. You may have other steps to complete to get your results when they're ready.

There are two reports participants can get: **Hereditary Disease Risk report** and **Medicine and Your DNA report.** The Hereditary Disease Risk report focuses on increased risk for some diseases that can be passed down from parents to their biological children through their DNA. For the Medicine and Your DNA report, *All of Us* will look at seven genes that can affect how our bodies process certain medicines. It also includes more than 50 medicines that are affected by those genes.

To stay up to date on the return of health-related DNA results, please visit <u>https://www.joinallofus.org/genomics-and-your-dna-updates</u>.

How All of Us Protects Your Information

When you joined *All of Us*, we promised to do everything we can to protect your privacy and keep your information safe. We use the latest technology to help keep your data private and safe. Before we share any data with researchers, we remove information that can directly identify individuals, including names, addresses, and more. Only approved researchers can access *All of Us* participant data.



To learn more about how we protect your information, watch our video on privacy and security by scanning the QR code or visiting <u>https://tinyurl.com/yft3jcvb.</u>





All of Us Research Highlights

Approved researchers from across the country are using *All of Us* data to better understand health and disease. More than 4,300 research projects are already underway, exploring health conditions such as mental health, diabetes, cancer, and many more. Below are a few highlights of the research powered by data provided by participants like you.

Steps to Better Health with All of Us



Walking every day can help prevent diseases. Exactly how many steps protect against which diseases is harder to understand. A new study linked *All of Us* participant Fitbit data with health records. The study found that participants who took at least 8,200 steps a day had lower risks for certain health conditions. These included chronic diseases like high blood pressure, obesity, and diabetes. The study also uncovered new links between steps and lower risk for sleep apnea, depression, and acid reflux.

Read the full study: https://tinyurl.com/2p8edza8

Study Links Birthplace and Cancer Risk Among Hispanic All of Us Participants

Scientists used *All of Us* data to study cancer risk in participants who self-report as Hispanic, Latino, or Spanish. Liver cancer rates were nearly twice as high in Hispanic participants born outside of the United States, showing that place of birth is an important consideration for understanding cancer risk.

Read the full study: https://tinyurl.com/34n2333b

These studies wouldn't be possible without your participation. By completing program activities such as the Social Determinants of Health Survey and sharing your health history, you are helping researchers understand more about what affects people's health. This information may help improve health for everyone. Log in to your participant portal today to check for any new surveys or program opportunities.

Interested in reading more research highlights? Please visit <u>https://allofus.nih.gov/news-events/research-highlights</u> or scan the QR code.



WE HEARD YOU!

Thanks to your responses to our recent surveys, we learned about topics that you want to see in our newsletter. 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 in future issues by scanning the QR code on the left, visiting <u>https://bit.ly/3hECh6k</u>, leaving a message at (617) 638-4471, or sending an email to <u>AllofUsNEcommunity@bmc.org</u>.



You may be eligible to complete a new All of Us survey.

The *All of Us* Research Program Life Functioning Survey is a brief survey about your life functioning, including disabilities you may have. The survey has six questions and only takes about two minutes to complete. Your input is valuable and has the power to help drive health research forward.

Log in to your account to see if the Life Functioning Survey is available in your participant portal.

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 information from people 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 App Store 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 any time at one of the locations below.

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



