

ALL OF US NEW ENGLAND PARTICIPANT NEWSLETTER FALL 2022

All of Us Reaches Another Milestone in its Goal to Gather Health Data for its Groundbreaking Research Platform

You're in good company! We're excited to share that over 500,000 participants have started their journey with the *All of Us* Research Program. This represents significant progress towards our goal of one million participant partners.



We've accomplished so much over the past four years. As of September 2022, more than **3,000**

researchers have registered to use our data and there are over 2,400 research projects underway! Data contributed by more than 320,000 participants are lending insights on lifestyle, access to care, medical history, COVID-19 experiences, and more. Nearly 50% of this data comes from participants who identify with a racial or ethnic minority group and 80% are from communities underrepresented in biomedical research overall.

We wouldn't be celebrating these accomplishments without you. We are making a good start on closing the age, gender, and racial gaps in health research. Thank you for being our partner and helping us transform the future of health research and care.

All of Us Research: Paving the Way for Medical Discoveries

In prior issues, we've shared how our New England researchers are using information shared by *All of Us* participants to solve health problems. The *All of Us* Research Hub stores de-identified health information from a diverse group of participants nationwide. Thanks to your continued participation, approved researchers can access *All of Us* data to conduct studies improving our understanding of human health. These are just a few research projects that *All of Us* researchers are studying:

African American Health

Gastrointestinal Disorders Among Black/African American Patients

Taylor Boyd, Casey Silvernale, Kyle Staller; Mass General Brigham

Asian American & Pacific Islander Health

Type 2 Diabetes Risk Among Asian Americans

Helen Lam and Fornessa Randal; Asian Health Coalition

LGBTQ+ Health

Characterizing Transgender Health Conditions

Sarah Jackson, National Institutes of Health

Persons with Disabilities

Focusing on the Intersection of Race, Disability, & Cancer Diagnosis

Chandra Char; Oregon State University

Hispanic/Latino Health

Prevalence of Tobacco/Nicotine
Use in the Hispanic/Latino
Community

Coralia Vazquez-Otero & Alan Meca; University of Texas, San Antonio

You can explore the growing list of research projects that may impact you and your community by visiting www.ResearchAllofUs.org/research-projects-directory

Researcher Spotlight: Dr. Dean Xerras and the City of Chelsea



Dr. Dean Xerras is a Co-Investigator for *All of Us* New England, Medical Director of the MGH Chelsea HealthCare Center, and Assistant Professor of Medicine at Harvard Medical School.

"When *All of Us* approached us in Chelsea, it was one of the first times that we were allowed the opportunity to become part of the process and help to develop a research program from the ground locally and make sure the patients' interests and concerns were addressed from the beginning," said Dr. Dean Xerras when he was approached to become a Co-Investigator for the *All of Us* Research Program.

Dr. Xerras has served the Chelsea community for over 12 years and was on the front lines of the pandemic in Chelsea during the surge in 2020. Chelsea is the



Source: Zaslow, Joelle. "Researchers Aim to Gather Data Reflecting Diversity." *Mass General Hopsital Giving*. 28 June 2018.

smallest city in Massachusetts in terms of total area and the second most densely populated city in Massachusetts. The city also has the second-highest percentage of Latino residents.

The tightly knit, diverse area was hit harder than any other community in Massachusetts. To help contain the virus, city officials from Chelsea and Revere developed an isolation center, giving patients a safe environment to isolate and keep their household members protected. Dr. Xerras provided clinical oversight for the isolation center, putting in countless hours to make sure things ran smoothly for the community.

Dr. Xerras hopes that the research being conducted using *All of Us* data can help prevent situations such as the COVID-19 crisis in Chelsea from happening again. Through community participation, Dr. Xerras believes the program can help reduce inequalities in health research and improve treatment and prevention strategies for future generations.

Researchers Aid Chelsea, Epicenter of MA COVID-19 Outbreak.

Source: BU Today, April 28, 2020



Help Us Create a Community Cookbook!

Do you have a comfort-food 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 recipe and we'll share it as part of our community cookbook project.

Representing Local Voices: All of Us Community Advisory Panel

All of Us New England has a Community Advisory Panel (CAP) composed of representatives from our local neighborhoods. CAP members are considered the "heart" and the "local voice" of the program. They provide valuable feedback on all aspects of our strategies in New England such as how we talk about the program so that our efforts to enroll and retain participants are respectful and beneficial. Their perspectives and feedback are key to our decision-making processes.

Meet Michelle Anderson

Michelle Anderson is a "nursepreneur," speaker, educator and consultant with over 30 years experience in the health care industry. She is fond of time spent as a surgical trauma nurse and mentor, and is known for her profound wisdom and upbeat spirit. She enjoys gardening, traveling, and live music.

As a CAP member, Michelle is a champion for those whose voices are often unheard. Through the CAP, Michelle is able to share her passion for equity and equality for all, sharing the benefits of being involved with *All of Us*. Her mantra is "Who can best represent you but you?"

"It's imperative to have a seat at the table, and being a Participant Ambassador via the CAP allows me to do just that. Having a stake in your future in health and wellness is what *All of Us* is all about. It is also an opportunity to meet others with the same desires from a different experience. With a diverse think tank of minds from across the spectrum, ALL voices are heard, valued, and respected," said Michelle.

As an advocate, CAP member, and Participant Ambassador for *All of Us*, Michelle is able to encourage all to be involved, participate in research, and learn what exciting breakthroughs are evolving.



WE HEARD YOU!



Thanks to your responses to our recent surveys, we learned about topics that you want to hear. 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 https://bit.ly/3hECh6k, leaving a message at (617) 638-4471, or sending an email to AllofUsNEcommunity@bmc.org.

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





