

Making strides in US health through All of Us Research Program

Surveys track experiences during pandemic

All of Us Research Program advancing COVID-19 science

WITH LIMITED TESTING in the early days of the COVID-19 outbreak, it was hard to pinpoint exactly when and where the virus first began infecting people in America. But with help from the All of Us Research Program — which is on its way toward building one of the nation's largest health databases — scientists are getting closer.

Using specimens from All of Us participants, researchers identified evidence of possible COVID-19 infections in a handful of states weeks before they were officially confirmed there. The research, published in June in *Clinical Infectious Diseases*, suggests COVID-19 was present early on in places that were not considered likely entry points.

The information could help officials better prepare for future disease threats, said study co-author Keri Althoff, PhD, MPH, an associate professor of epidemiology at the Johns Hopkins Bloomberg School of Public Health.

“These epidemics start somewhere, and knowing where they start is really helpful in getting ready for the next one,” Althoff told *The Nation's Health*. “All of Us is such a large, highly diverse study. We knew there was a unique contribution that could be made here.”

The study is one of many ways the All of Us Research Program, led by the National Institutes of Health, is contributing to

the science on COVID-19.

Since 2018, more than 400,000 people nationwide have signed up to participate in All of Us, which aims to enroll and follow 1 million people over many years to capture new insights on health and medicine.

When the pandemic began, it quickly became clear the program's diverse cohort and collection of biological specimens could not only contribute to COVID-19 research, but also help fill in gaps, said Andrea Ramirez, MD, MS, senior advisor to the CEO of the All of Us Research Program.

For example, in the months before the outbreak was declared a national emergency in the U.S., All of Us collected

more than 24,000 blood samples from participants. It was those samples that Althoff and colleagues tested for SARS-CoV-2 antibodies to reveal that the



Data from All of Us participants is being used by scientists.

See **SCIENCE**,
Page 12



Photo by RichVintage, courtesy iStockphoto

People can learn how to find trustworthy health information online with a suite of tools from library groups and All of Us.

Partnerships supporting US health Libraries working with All of Us to advance digital health literacy

THE ALL OF US Research Program is partnering with libraries across the country to help people hone their digital health literacy skills.

Last year, All of Us — a National Institutes of Health program to build one of the most diverse health datasets in history — along with the National Network of Libraries of Medicine and Public Library Association, released a new suite of digital literacy tools that libraries can use to teach



Libraries can help people learn vital health literacy skills.

residents how to find trustworthy health information online. The tools run the gamut, from basic internet competencies such as getting a free email address and creating a strong password, to tips for teasing out the good health information from the bad.

Healthy People 2030, which guides the nation's health objectives, defines personal health literacy as the ability to find, understand and use

information for health-related decisions. The skill — the importance of which became even more evident during the COVID-19 pandemic and vaccination campaign — is considered a key social determinant of health. Research has found considerable disparities

on the issue, with low health literacy

See **LIBRARY PARTNERS**,
Page 14

**All of Us
program
benefiting
public health**

INSIDE THIS SECTION

- Caring for communities Page 13
- Learn about the app Page 13
- Participants learn about DNA Page 14



Photo by Kate_sept2004, courtesy iStockphoto

The All of Us Research Program calls on Americans to voluntarily share their health information to advance and expand science. Data from the 400,000 participants is already providing insights.

All of Us finds new ways to stay connected during pandemic

RECRUITING people for health research is more important than ever. But with face-to-face activities limited during the COVID-19 pandemic, the All of Us Research Program turned to virtual tools to bring new participants on board.

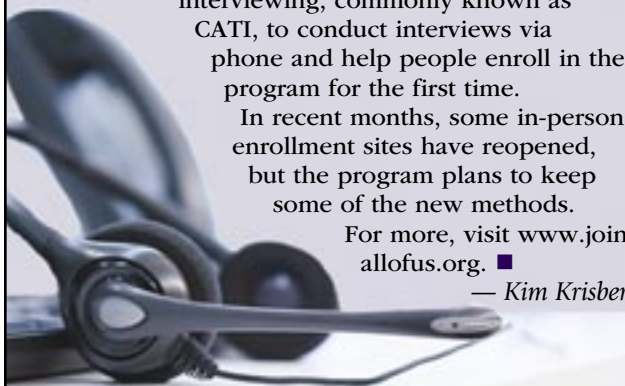
Like the rest of the nation, All of Us — a National Institutes of Health program that is working to collect health data on 1 million people in the U.S. — paused its in-person activities in March 2020. The program turned online to keep recruiting and connecting with its hundreds of thousands of participants. The traveling All of Us Journey Exhibit switched to virtual presentations, for example, while All of Us partner organizations shifted to virtual cooking demos, dance parties and games.

All of Us also launched a few pilot initiatives to help people safely engage, such as one that lets program participants share saliva samples via mail rather than visiting a medical site. To reach people with limited access to computers or the internet, All of Us used computer-assisted telephone interviewing, commonly known as CATI, to conduct interviews via phone and help people enroll in the program for the first time.

In recent months, some in-person enrollment sites have reopened, but the program plans to keep some of the new methods.

For more, visit www.joinallofus.org. ■

— Kim Krisberg



All of Us boosts science about pandemic



Photo by Nensuria, courtesy iStockphoto

All of Us participants have been surveyed on mental health, physical activity and other issues during the COVID-19 pandemic.

SCIENCE,
Continued from Page 11

novel coronavirus was likely in some states earlier than reported.

After the antibody study made headlines, Ramirez reported that the All of Us program experienced a spike in enrollment.

“It was definitely an early and large win for the program in terms of meeting an unmet research need,” she told *The Nation’s Health*.

In addition to antibody testing, All of Us is also collecting a range of information from participants on how the COVID-19 pandemic is impacting their lives. First deployed in May 2020, the COVID-19 Participant Experience Survey — or COPE Survey — has engaged nearly 63,000 All of Us participants. It covers topics such as COVID-19 symptoms, social distancing experiences, financial struggles, resilience, discrimination and mental well-being.

For example, in a survey conducted in July and August 2020, 29% of nearly 30,000 respondents answered “sometimes” when asked how often they felt nervous and stressed in the last month. Thirty percent answered “almost never,” 12% said “fairly often” and 7% said “very often.” Participants also answer questions about social support, physical activity, substance use and loneliness.

This year, Ramirez said the survey added questions about COVID-19 vaccination, which could yield helpful insights on Americans’ attitudes toward vaccines.

“We’re building a dataset that will be useful for years to come,” Ramirez said. “The survey will be a great environment for researchers to come in and replicate what we’re seeing,

but also discover how the pandemic is affecting people around the country.”

Another COVID-19-related project through All of Us involves electronic

health records, as more than 200,000 participants have shared their records with the research program. Ramirez said the work involves standardizing record data to make it easier for researchers to study COVID-19, related health problems and treatment.

“We want to make sure the data already being collected can be repurposed and reused for research,”



Photo courtesy Busracavus, iStockphoto

Blood samples from program participants provided insights on COVID-19 antibodies.

she said.

An expert on longitudinal study design, Althoff was already working with All of Us when the pandemic hit. It was clear right away that the research program — which had just collected tens of thousands of blood samples — could make a unique contribution to understanding the outbreak, she said.

“That’s one of the great benefits of these long studies — they become highly versatile,” Althoff said. “And we needed to use everything we could at the time to learn about this virus.”

To conduct the *Clinical Infectious Diseases* study, Althoff and colleagues developed a plan to test more than 24,000 All of Us specimens, sending them to the lab in batches of 5,000. Among the specimens tested, which were all collected between Jan. 2 and March 18, 2020, researchers found SARS-CoV-2 antibodies in nine specimens using two different serology tests. Positive samples were detected as early as Jan. 7, 2020, for people in Illinois, Massachusetts, Mississippi, Pennsylvania and Wisconsin.

Althoff said the findings help corroborate other research based on blood bank donations that also show COVID-19 likely arrived in the U.S. earlier than previously thought.

“It’s an incredible national resource,” Althoff said of All of Us. “There’s still no hard and fast conclusions about when exactly the virus came here, but trying to uncover that is important work to do as we prepare for the next pandemic.”

For more on All of Us and COVID-19 research, visit www.joinallofus.org/coronavirus. ■

— Kim Krisberg



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Photo by Chainarong Prasertthai, courtesy iStockphoto



Session 3152.3:

The All of Us Research Program and the Research so Far

MONDAY, OCT. 25, 4-5:30 P.M. MT

Make plans to attend the virtual session during APHA’s Annual Meeting and Expo



Diversity among investigators, scientists part of All of Us program

Q&A with investigator Cheryl Clark: Caring for communities, not just conducting research



Photo by SDI Productions, courtesy iStockphoto

Among the data All of Us is collecting on diverse groups is how the pandemic is impacting people's health and daily lives.

CHERYL CLARK, MD, ScD, is principal investigator of community and participant engagement for the New England hub of the All of Us Research Program. Clark is an associate physician at Brigham and Women's Hospital and assistant professor of medicine at Harvard Medical School. She joined All of Us in its pre-launch stages to help design strategies for meaningful relationships with program participants.

How does the All of Us program benefit people and communities of color in particular?

I have not seen a program that has had this scale and scope of work around precision medicine that also has an equity focus. It's that commitment to diverse populations that made me want to participate.

We're now coming up on two years of the COVID-19 pandemic and very public murders of African Americans that have raised awareness of the way that science, health and public health don't have the information that we need to understand how both disease processes as well as prevention happen in diverse groups.

We have enrolled more than 400,000 out of a million participants in the program. Fifty percent of those come from a race or ethnic category that traditionally hasn't been included in health research. Being able to have the information — to have a deep investment in collecting the data that we need in diverse populations — is an important

stepping stone to being able to ask the kinds of questions that matter to diverse groups.

In addition to having participants who are from all walks of life, we also prioritize investigators and scientists who are from all walks of life. We have seen how important it is to have a diverse group of scientists who are asking questions from their own lived experiences and perspective. If we are hoping to move forward and advance

health equity research, we have to have diverse investigators as well as diverse participants. And it's been exciting to see the strategies All of Us is using to do that.

How does the All of Us benefit people who live in New England?

When you're doing research with people and with communities, it's important to make sure that those communities benefit from the work that you're doing. We just published a paper in the journal *Ethnicity and Disease* that talked

about our outreach during COVID. It's hard to remember this, but back in March 2020, none of us knew anything. It was a confusing time. There was a lot of disinformation, the country had just shut down, and a lot of people were hungry and they didn't know what's going on. At that point in New England, we had enrolled 20,000 people.

We called all 20,000 of them to check in and make sure that they were doing OK and to provide them with information about COVID-19 from the CDC, with information on local resources so that they could find their local food pantries if they were hungry, and other information about social services.

Why is it important for the program to be embedded in communities?

We have to make sure that as we conduct research, we also care about the communities in which we are conducting research.

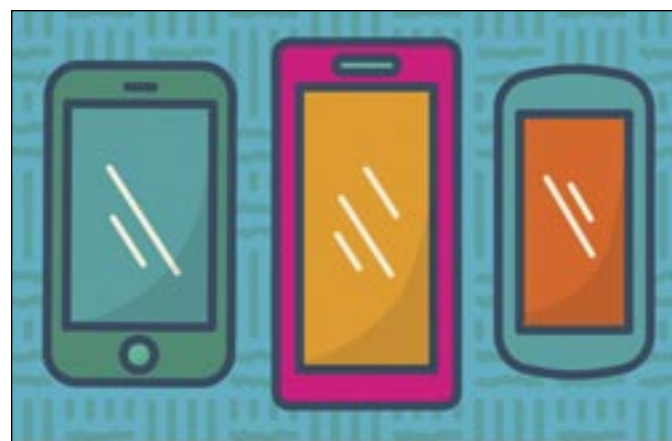
That is why All of Us doesn't talk about research participants, we talk about our partners. And that's the kind of values that we try to put forward in the way we work.

What would you tell someone who wants to join All of Us?

Zora Neale Hurston once said that "Research is formalized curiosity. It is poking and prying with a purpose." And I don't think that we get very far unless we have full participation, we need everyone's good thinking. We need everyone to be curious about what can make our health better, what can make our society better.

We really need everyone to step forward and to contribute their thinking contribute their information so that we can make sense of this and move health and public health forward. And I can't think of a more critical time than now for us to come together and do that. ■

— Interview conducted, condensed and edited by Aaron Warnick



#DYK there is a free All of Us Research Program app?

You can use the free app to:

- Enroll
- Complete self-assessments
- Answer follow-up questions
- Track your health
- Get updates

Download today from the Apple App Store or Google Play.



All of Us

RESEARCH PROGRAM

JoinAllofUs.org | help@joinallofus.org

Program gives back to its volunteers

All of Us participants learning about their genetic makeup

GIVING BACK has always been a priority for the All of Us Research Program. And in recent months, participants who had donated biological samples for research and opted to receive insights have begun getting results of their genetic tests — typically not an option for study participants.

The move not only allows people to learn important things about their health; it also helps them feel engaged and a valuable part of the All of Us work.

“Participants are our most important partners in this effort, and we know many of them are eager to get their genetic results and learn about the science they’re making possible,” Josh Denny, MD, the program’s chief executive officer, said in a news release.

Launched in 2018 by the National Institutes of Health, the All of Us Research Program is calling on Americans to voluntarily share their health data to advance science, with a goal of enrolling 1 million people.

All of Us researchers are performing in-depth genetic analyses that include both whole genome sequencing and genotyping, Sheri Schully, PhD, acting chief medical and scientific officer of the program, told *The Nation’s Health*.

Among the possibilities for research

are determining how genetics affect chronic illnesses for diverse groups.

Because of the program’s informed consent process, participants can choose to receive their genetic results. Genetic counselors are available to help answer questions from participants and their health care providers.

The program has taken a phased approach to returning DNA results. In Phase 2, participants will have an opportunity to discover how genetics may affect their response to medicines, and how genetic variants might affect their risk for certain diseases.

All of Us has been collecting data during the COVID-19 pandemic through participant blood samples and surveys. The information can be used to learn more about the disease’s health and social impact, especially on minority and disadvantaged populations.

The ultimate goal of All of Us is to speed up research and improve health, in part by making timely data on a diverse range of people available to researchers. The program places a special emphasis on enrolling populations that are often left out of scientific research, such as people with disabilities, older adults and people of color. People from under-represented groups account for about 80% of All of Us participants.

All of Us embraces precision medicine, which aims to treat individuals based on their unique diversity and medical history. It uses advances in genomics, state-of-the-art methods to manage and analyze large datasets, and health information technology to improve biomedical discoveries for all people. APHA is a partner in the program, providing information and helping recruit participants.

To learn more about All of Us and sign up, visit www.joinallofus.org. ■
— Mark Barna

Libraries partnering on literacy, science

LIBRARY PARTNERS,
Continued from Page 11

more prevalent among older adults, men, racial and ethnic minorities, and people with low incomes.

Scott Allen, MS, deputy director of the Public Library Association, said libraries are especially well-suited to help close those gaps.

“Public libraries are great places to educate people on just about everything,” Allen told *The Nation’s Health*, noting public libraries are both trusted members of their communities and accessible. “Interest in health information is definitely rising, especially this year.”

Among the free tools is a curriculum guide to help librarians teach digital literacy by using health topics and a series of modules that cover basic competencies such as establishing an email address, picking good passwords, keeping personal information safe and avoiding online scams.

“Public libraries are very trusted spaces in the community, so they’re perfect partners for this kind of work.”

— Brittney Thomas

The modules, available in English and Spanish, also offer tips on how and where to find reliable health information online and explain how to use MedlinePlus, a hub of reliable information produced by the National Library of Medicine. As a tie-in to All of Us, one of the modules discusses how the program protects the personal information



Photo by Tigercat_LPG, courtesy iStockphoto

When people have high levels of health literacy, they are better able to follow instructions related to their personal health.

of its participants.

“Libraries have a big equity mission, as does All of Us, so it’s a natural partnership,” Allen said.

Libraries are also working with All of Us and other partners to promote “citizen science” activities,

which aim to engage the public in scientific research, from monitoring air and water quality to tracking and identifying wildlife.

Resources include free citizen science guides and an online tutorial. “The Library and Community Guide to Citizen Science,” available online, highlights local citizen science initiatives, provides detailed tips for planning virtual events and shares ideas.

“Citizen science is a really useful strategy for making connections

between digital literacy and health literacy,” said Brittney Thomas, MLAS, associate director of the All of Us Community Engagement Center at the University of Iowa. “It builds on what libraries are already doing on digital literacy and connects back to teaching people how to use scientific information online.”

Thomas said that in surveys of people who take the “Foundations of Citizen Science” online tutorial, a majority said it increased their awareness and interest in citizen science. Such activities can also open the door to broader conversations about what scientific research entails and how All of Us works, she said.

“Public libraries are very trusted spaces in the community, so they’re perfect partners for this kind of work,” Thomas told *The Nation’s Health*.

For more information, visit <https://allofus.nlm.nih.gov/digital-health-literacy>. ■

— Kim Krisberg



Libraries are working with All of Us and other partners to promote ‘citizen science’ activities.