The American Association on Health and Disability (AAHD) joins NIH in launching the All of Us Research Program to advance precision medicine

Enrollment set to open nationwide for historic research effort

On May 6, the National Institutes of Health will open national enrollment for the All of Us Research Program—a momentous effort to advance individualized prevention, treatment and care for people of all backgrounds—in collaboration with the American Association on Health and Disability (AAHD) and other partners. People ages 18 and older, regardless of health status, will be able to enroll. The official launch date will be marked by community events in cities across the country as well as an online event.

Volunteers will join more than 25,000 participants across the United States who have already enrolled in All of Us as part of a year-long beta test to prepare for the program's national launch. The overall aim is to enroll 1 million or more volunteers and oversample communities that have been underrepresented in research to make the program the largest, most diverse resource of its kind.

"The time is now to transform how we conduct research—with participants as partners—to shed new light on how to stay healthy and manage disease in more personalized ways. This is what we can accomplish through All of Us," said NIH Director Francis S. Collins, M.D., Ph.D.

Precision medicine is an emerging approach to disease treatment and prevention that considers differences in people's lifestyles, environments and biological makeup, including genes. By partnering with 1 million diverse people who share information about themselves over many years, the All of Us Research Program will enable research to more precisely prevent and treat a variety of health conditions.

"All of us are unique, but today we live mostly in an era of 'one-size-fits-all' medicine," said Eric Dishman, director of the All of Us Research Program. "I'm alive today because of precision medicine and I think everyone deserves that same opportunity no matter the color of your skin, your economic status, your age or your sex or gender. In other words, it will truly take *all* of us."

All of Us seeks to transform the relationship between researchers and participants, bringing them together as partners to inform the program's directions, goals and responsible return of research information. Participants will be able to access their own health information, summary data about the entire participant community and information about studies and findings that come from All of Us.

"AAHD is proud to be part of this initiative that will improve the health status of people with disabilities across the nation," said Roberta S. Carlin, MS, JD, AAHD Executive Director.

Participants are asked to share different types of health and lifestyle information, including through online surveys and electronic health records (EHRs), which will continue to be collected over the course of the program. At different times over the coming months and years, some participants will be asked to visit a local partner site to provide blood and urine samples and to have basic physical measurements taken, such as height and weight. To ensure that the program gathers information from all types of people, especially those who have been underrepresented in research, not everyone will be asked to give physical measures and samples. In the future, participants may be invited to share data through wearable devices and to join follow-up research studies, including clinical trials.

Also, in future phases of the program, children will be able to enroll, and the program will add more data types, such as genetic data. In addition, data from the program will be broadly accessible for research purposes. Ultimately, the All of Us Research program will be a rich and open data resource for traditional academic researchers as well as citizen scientists—and everyone in between.

NIH has funded more than <u>100 organizations</u> throughout the U.S. to be partners in the program, AAHD is providing support by raising public awareness All of Us among people with disabilities throughout the United States. AAHD will work with partners in three states to conduct local outreach within the disability community: Center for Independence of the Disabled, NY in New York, Lakeshore Foundation in Alabama and the University of Montana Rural Institute in Montana.

On the program's May 6 launch date, the All of Us Research Program will host <u>special events</u> in diverse communities around the country. AAHD and its partners will be live tweeting throughout the afternoon, and the Lakeshore Foundation will be exhibiting at the live event in Birmingham.

People also may take part in social media activities (#JoinAllofUs) or tune in at https://Launch.JoinAllofUs.org to watch speakers across the country talk about precision medicine and the power of volunteering for research.

To learn more about the program and how to join, please visit https://www.JoinAllofUs.org.

"All of Us" is a registered service mark of the U.S. Department of Health & Human Services (HHS).

