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NIH Seeks Americans’ Health Info to Advance Precision Medicine

The All of Us Research Program aims to collect data from 1 million people.

May 15, 2018 By Liz Highleyman

On May 6, the National Institutes of Health (NIH) opened enrollment for its All of Us Research Program, a new initiative to gather health information from a diverse group of Americans in order to accelerate research and improve health.

The effort aims to advance precision medicine, in which a massive amount of data from a population is used to uncover patterns than can help customize treatment for individuals. For example, targeted therapies for cancer are based on an understanding of the genetic characteristics of different types of cancer.

The NIH plans to provide data collected through the program to qualified researchers, and participants will be able to access their own information, summary data about all participants and the resulting study findings.

“All of Us is an ambitious project that has the potential to revolutionize how we study disease and medicine. NIH’s unprecedented effort will lay the scientific foundation for a new era of personalized, highly effective health care. We look forward to working with people of all backgrounds to take this major step forward for our nation’s health,” Health and Human Services Secretary Alex Azar said in a press statement.

“The All of Us Research Program is an opportunity for individuals from all walks of life to be represented in research and pioneer the next era of medicine,” added NIH director Francis Collins, MD, PhD. “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.”

All of Us aims to enroll at least 1 million people, starting with adults and adding children next year. More than 25,000 participants have already joined as part of a yearlong pilot test to prepare for the national launch.

The program encourages the participation of people of every race, ethnicity, sex, gender and sexual orientation and intends to “oversample” communities that have previously been underrepresented in medical research, especially people of color. Healthy people and those with long-term health issues are welcome. Representation of the full diversity of the population is important to ensure that study findings are complete and relevant to everyone.

Participants can share their health data online or at a participating health center, including electronic health records and responses to surveys about diet, exercise, environmental exposures and other lifestyle factors. They may also be asked to share physical measurements such as height and weight and provide blood and urine samples; genetic testing will be included in the future.

Participants will remain anonymous. Identifying information will be removed from health records and samples will be stored without names in a biobank. The NIH said it would prohibit disclosure of the data to law enforcement.

Spanish-speaking advisers are now available and more languages will be added. No health insurance is required and data collection appointments are free, though the program does not provide medical care. It is not necessary to have a computer or smartphone, though these will make data collection and communication with the program easier.

“All of us are unique, but today we live mostly in an era of ’one-size-fits-all’ medicine,” said All of Us Research Program director Eric Dishman, a survivor of a rare from of kidney cancer. “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.”

Click here to learn more and enroll in the All of Us Research Program.

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