

Answers to patients' top 5 questions on All of Us Research Program

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With the goal of enrolling 1 million or more participants, the *All of Us* Research Program is among the most ambitious data-gathering efforts in medical history. Unlike a single research study focused on a specific disease or population, *All of Us* will serve as a national research resource, covering a wide variety of health conditions.

Participants in the program—which is open to the healthy and the sick—will contribute to an effort to advance the health of generations to come. The success of *All of Us* requires informed patients and health care providers. To that end, the AMA and NIH have worked in tandem to help you answer these top five questions that patients are likely to have about participating in this emerging initiative.

What is precision medicine?

Precision medicine is an innovative approach to disease prevention and treatment that takes into account individual differences in people's environments, lifestyles and genes. Precision medicine gives clinicians resources to get a more well-rounded picture of a person's health and can help inform decisions on prevention strategies and treatments that may be the safest and most effective.

All of Us is part of the federal government's Precision Medicine Initiative, which aims to enable a new era of medicine through research, technology, and policies that empower patients, researchers, and providers to work together toward development of individualized care.

Who is eligible to participate in *All of Us*?

Participants must live in the United States and be 18 or older, with the ability to provide consent on their own. (Enrollment is expected to expand to include children and additional special populations in the future.) Those participating in the research will be asked to complete surveys over time and share access to their electronic health records; participants may also be invited to visit a partner center to provide physical measurements and blood and urine samples for analysis.

If my patient decides to participate, will they be required to change physicians?

They will not. *All of Us* is not a clinical care program, so patients who opt to participate may keep their current health care teams.

What happens if my patient finds out they have a previously undetected disease?

The *All of Us* Research Program is a research effort, so it cannot provide any health care.

Right now, the program doesn't know what tests it may do on blood and urine samples. It also doesn't know when testing will occur. It may be months, or even several years, until certain tests on samples are conducted.

The program will share the numbers they get back from the tests and may provide educational materials to help participants learn more about the tests. The program always recommends that participants talk to their doctor about their health care needs and concerns.

How will the privacy and security of participants' data be ensured?

The protection of this data is a top priority of the project. Here are a few of the steps the *All of Us* Research Program will take:

- Information about participants will be stored on protected computers. The program will limit and keep track of who see the information.
- The program will remove participant names and other direct identifiers (such as patients' date of birth) from participant information and replace them with a code. There will be a

- master list linking the codes to names, but the program will keep it separate and secure.
- In order to work with participant health information, researchers must promise not to try to find out who participants are.
 - The program will tell participants if there is a data breach.
 - The program has Certificates of Confidentiality from the U.S. government. This will help the program fight legal demands (such as a court order) to give out information that could identify participants.

The AMA recently held a webinar providing more information about *All of Us*. It is available for viewing on demand. The AMA offers online CME on a series of precision medicine education courses to expand your knowledge. Explore precision medicine CME.

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