

The *All of Us* Research Program

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About *All of Us*

What is the NIH *All of Us* Research Program?

The *All of Us* Research Program is a historic, longitudinal effort to **gather data from at least one million people** living in the United States **to accelerate research and improve health**. By taking into account individual differences in **lifestyle, socioeconomic, environment, and biology**, we hope that researchers will one day uncover paths toward delivering **precision medicine – or health care that is based on an individual**.

The *All of Us* Research Program is part of the broader
Precision Medicine Initiative.

Core Values

- Participation is **open** to all.
- Participants reflect the rich **diversity** of the U.S.
- Participants are **partners**.
- Trust will be earned through **transparency**.
- Participants have **access** to their information.
- Data is accessed **broadly** for research purposes.
- **Security and privacy** are of highest importance.
- The program may be a catalyst for **positive change** in research.

Why do We Even Need the *All of Us* Research Program?



People/Patients

- Patients may not be served well by treatments designed for the “average” patient. We hope in the future that *All of Us* will help advance precision medicine.
- Many people and populations have been left out of biomedical research, and thus, often left out of health care solutions.
- Health problems can take years to unravel and require much trial-and-error.
- Patients may not have access to, or make use of, their own health data.



Health Care Providers

- Precision medicine research is still in the early days, so providers do not have enough information available to provide precision care for many conditions.
- Developing individualized approaches to care often requires time.
- It can be difficult to coordinate care between many different providers, especially with medical records and key data scattered in different silos.

Why do We Even Need the *All of Us* Research Program?



Biomedical Researchers

- Researchers spend a lot of time and resources creating new IT systems, databases, and analytic tools.
- They also face enormous costs and time just to recruit participants.
- Data collection is often not standardized, and data can be siloed and difficult to integrate.
- A single lab's resources may not be sufficient to answer the research questions that matter.

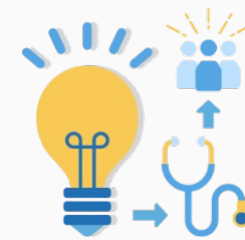
Current Protocol for Participant Enrollment

- 1. Enroll, Consent and Authorize HER**
- 2. Answer Surveys**
- 3. Provide Physical Measurements**
- 4. Provide Biosamples**
- 5. Share Data from Wearables/Digital Apps**

How Will *All of Us* Lead to Discoveries?

Participants Share Data

Participants share health data online. This data includes health surveys and electronic health records. Participants also may be asked to share physical measurements, and blood and urine samples. We also want to know if you will want information about your DNA.



Researchers Study Data

Researchers use the data to conduct studies. By finding patterns in the data, they may learn more about what affects people's health.

Researchers Share Discoveries

Research may help in many ways. It may help find the best ways for people to stay healthy. It may also help create better tests that will work best for different people.

Data are Protected

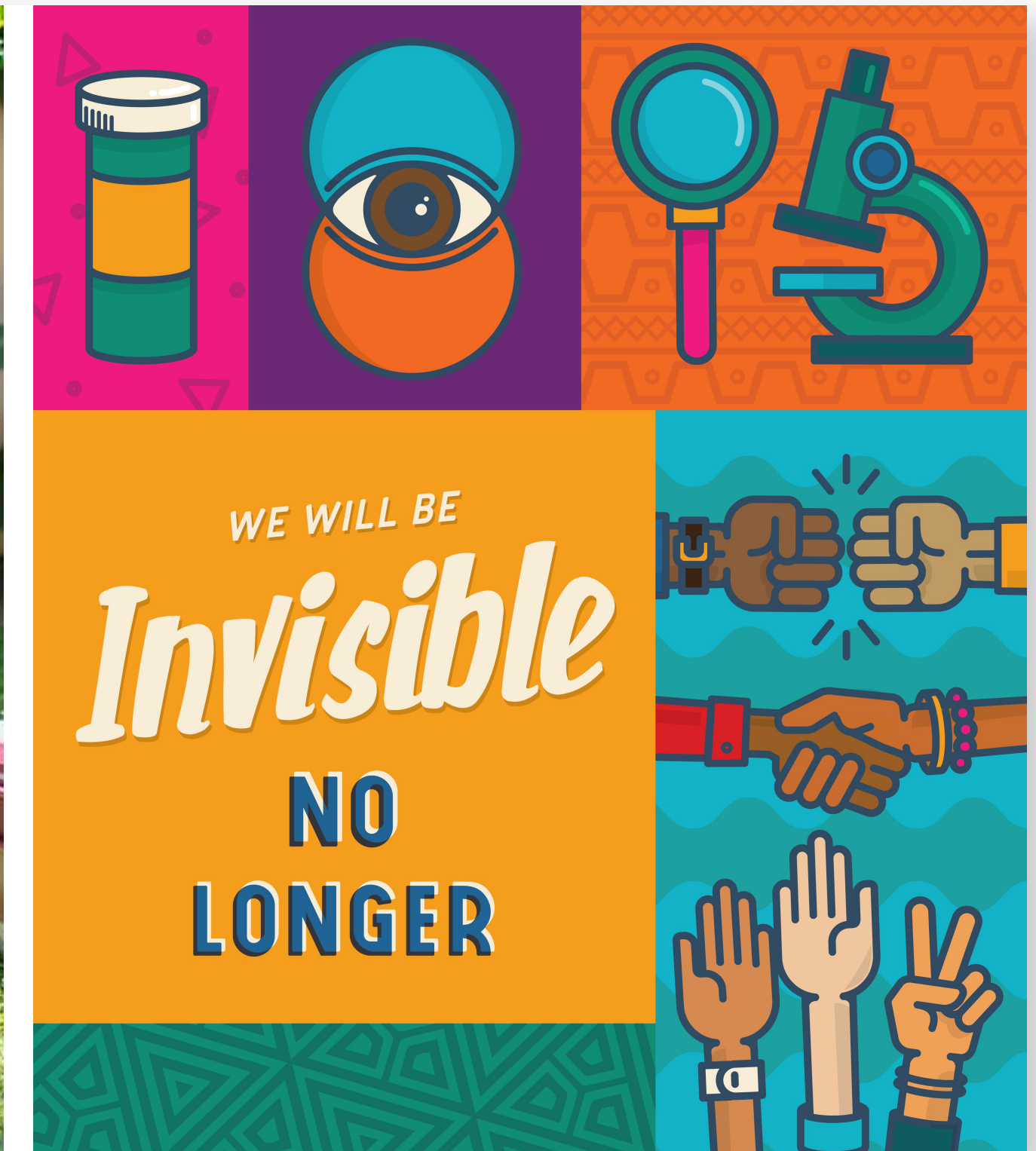
Personal information, like your name, address, and other things that easily identify participants will be removed from all data. Samples—also without any names on them—are stored in a secure biobank.

Participants Get Information

Participants will get information back about the data they provide, which may help them learn more about their health.

What is the Promise for Participants?

- An opportunity to **improve the health** of future generations.
- A chance to **learn about your own health**.
- The ability and choice to **access your own data**, including genetic results and increasingly rich health records.
- An opportunity to **ensure that your community is included** in the studies that lead to new understandings of what affects people's health.
- A chance to **learn about additional research opportunities** that may interest you.
- The choice to **meet others like you**, perhaps even joining some of them to propose and do research.



This is a long-term relationship and the value to participants (and researchers) will grow over time.

Thank You!



[JoinAllofUs.org](https://www.allofus.org)



American Association
on Health and Disability
[Joinallofus.org/disability](https://www.allofus.org/disability)



National Institutes
of Health

[Allofus.nih.gov](https://allofus.nih.gov)



No Research About Us Without Us- Letting NIH Know What's Important to Us

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What AAHD Does For *All of Us*

- Outreach & Engagement
- Education
- Hold *All of Us* Accountable
- Inclusion Statement [<https://aahd.us/inclusion-for-all-of-us/>]
- Objective of the Discussion:
 - Send a Message to NIH About Your Views on Health!
 - Help Improve Health Research Moving Forward!
 - Help Researchers Understand What Individualized Health Care Means to You!

Discussion Topic 1. Disability

- *All of Us* Research Program Disability Definitions:
- Hearing: Deaf or having serious difficulty hearing
- Vision: blind or having serious difficulty seeing, even when wearing glasses.
- Cognitive: Because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions.
- Ambulatory: Having serious difficulty walking or climbing stairs.
- Self-care Difficulty : Having difficulty bathing or dressing.
- Independent Living: Because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping.
- Do You See Yourself in These Definitions?

Discussion Topic 2. Health

- What Does Good Health Mean to You?
- What Barriers Do You Face to Good Health?

Discussion Topic 3. Health Research

- Have You Been Part of Participatory Action Research Project?
- What Type of Research Would Help Improve Your Health?

Discussion Topic 4. Knowledge & Communication

- What do Health Care Providers Need to Know to Provide Better Care for You?
 - What Type of Knowledge About Your Disability Does Your Health Care Provider Need to Know?
 - How Should Your Health Care Provider Share Information With You?

For More Information

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