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# The future of health begins with you.

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The *All of Us* Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.

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Interested in learning more about the *All of Us* Research Program?

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Diversity, transparency, and accessibility are core values that guide *All of Us*.

**Funding and Partners** 

See our Core Values

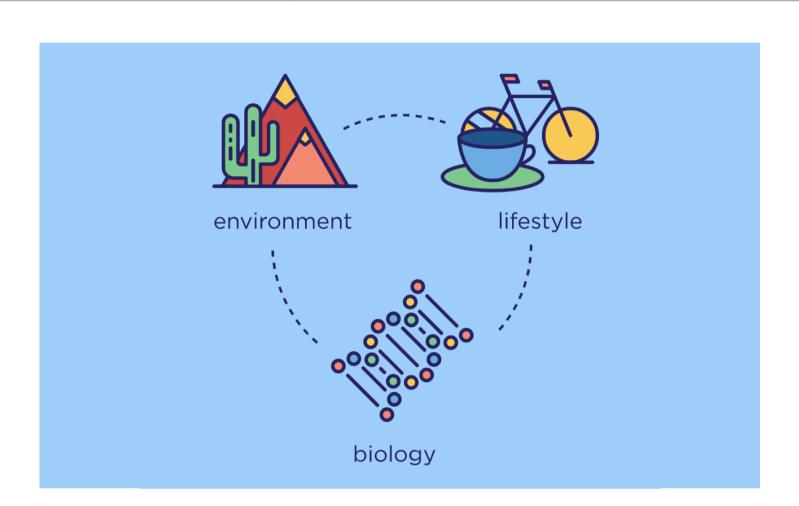
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# We're building a research program of 1,000,000+ people.

The mission of the *All of Us* Research Program is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us.

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We are actively partnering with others to create a groundbreaking national research resource platform.

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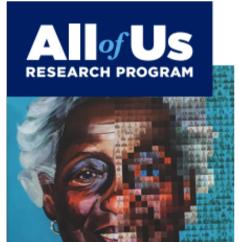


# Oklahoma City, OK Listening Session

Location: Oklahoma City, OK

Event Time: 1:00-4:00 pm CT

Oct 22, 2019



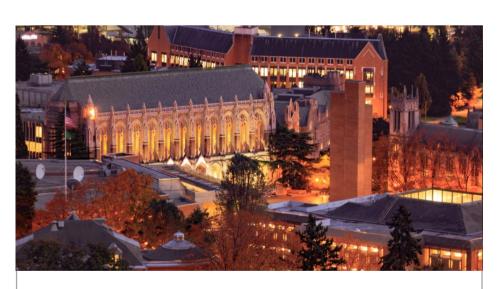


Cohort Diversity and Data Diversity - American Society of Human Genetics (ASHG) Annual Conference

Location: Houston, TX

Event Time: 10:45 a.m.-12:45 p.m. CDT

Oct 15, 2019



Advisory Panel Meeting -Northwest Genomics Center at the University of Washington

Location: Seattle, WA

Sept 25, 2019

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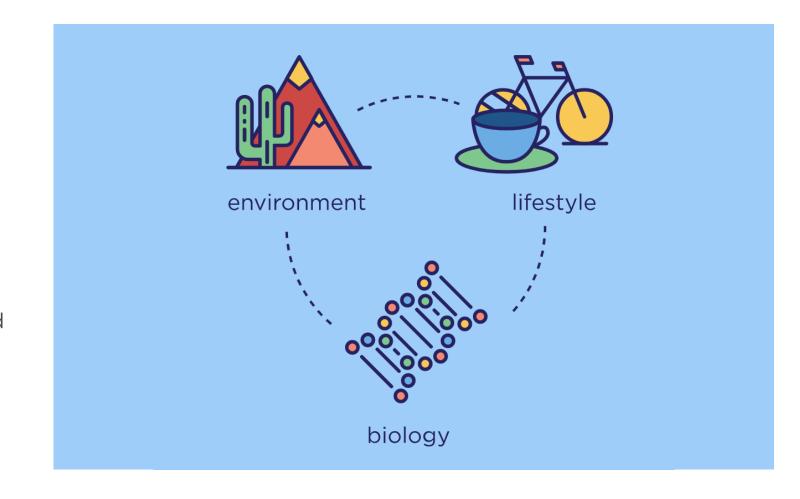
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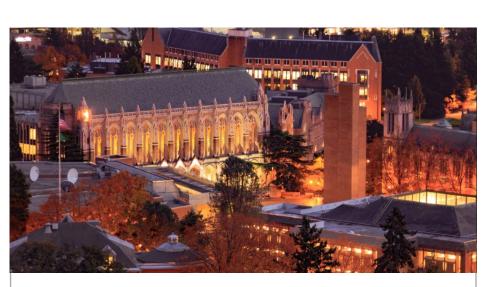


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# **About**

The All of Us Research Program is a historic effort to collect and study data over many years from one million or more people living in the United States. The goal of the program is to speed up health research breakthroughs, enabling new kinds of individualized health care. The program began national enrollment in 2018 and is expected to last at least 10 years.

# **Program Overview**

Read an introduction to the All of Us Research Program and precision medicine.

#### What Makes All of Us Different

Read about factors that make All of Us a unique research program.

#### **Core Values**

Learn about the program's core values, such as transparency and keeping participant information secure.

# **Diversity and Inclusion**

Learn how All of Us embraces diversity and why health care is more effective when people from all backgrounds are included in health research.

# **Protocol**

See details for how the program is being carried out, including who can join, what data will be collected and how it will be protected.

Who We Are - Find information on staff members, scientific experts, participant partners, and advisory groups that support the program.

**FAQ** - Find answers to frequently asked questions about *All of Us*.

Find out how to contact All of Us.

**Contact Us** 



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All of Us Research Program Overview

#### All of Us and Precision Medicine

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The National Institutes of Health formed the <u>Precision Medicine Initiative Working Group of the Advisory</u>

<u>Committee to the Director</u> in March 2015. The group concluded its work in September 2015 with a <u>detailed report</u>

(PDF | 1.05 MB). The report provided a framework for setting up the *All of Us* Research Program.

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#### Precision medicine:

- Is based on you as an individual
- Takes into account your environment (where you live), lifestyle (what you do), and your family health history and genetic makeup
- Gives health care providers the information they need to make customized recommendations for people of different backgrounds, ages, and regions
- Helps you get better information about how to be healthier

All of Us is part of a new era in which researchers, health care providers, technology experts, community partners, and the public work together to develop individualized health care. Learn more about who is involved.

#### How Can All of Us Make a Difference?

Too often, health care is one size fits all. Treatments meant for the "average" patient may not work well for individual people. Health care providers may find it difficult to coordinate care among specialists or to access all of a patient's health information. Researchers may spend lots of time and resources creating new databases for every study.

All of Us is working to improve health care through research. Unlike research studies that focus on one disease or group of people, All of Us is building a diverse database that can inform thousands of studies on a variety of health conditions. This creates more opportunities to:

- Know the risk factors for certain diseases.
- Figure out which treatments work best for people of different backgrounds.
- Connect people with the right clinical studies for their needs.
- Learn how technologies can help us take steps to be healthier.

Learn about what makes All of Us Research Program Different.

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All of Us > About > What Makes All of Us Different

# What Makes All of Us Different

Several factors combine to make the All of Us Research Program unique:

**Breadth.** With a goal of enrolling one million or more participants in the United States, *All of Us* is building one of the largest health databases of its kind. As the amount of data grows, patterns will emerge that wouldn't be visible at a smaller scale.

**Diversity.** The program is enrolling a large group of people that reflects the <u>diversity</u> of the United States. This includes people who haven't taken part in or have been left out of health research before. *All of Us* welcomes participants of all backgrounds and walks of life, from all regions of the country, whether they are healthy or sick.

**Depth.** All of Us collects many types of data, including data from surveys, electronic health records, and blood and urine tests. Over time, participants may share data in new ways, using wearable fitness trackers and other technologies. This will help researchers get a more complete picture of factors that affect health and disease.

**Duration.** The initial plan for the program spans 10 years, but it may last even longer. Working with participants over the long term means the program can gather more information that will help researchers find out how health and disease change over time.

**Innovation.** All of Us is working to take research to a new level. The program is working with participants across the country, collecting many types of information over time, and building a <u>data platform</u> that many researchers can use. This new model could shape how people do research in the future. All of Us will share lessons about what works well with other research programs around the world.

**Accessibility.** All of Us aims to make it easy for a variety of researchers—from university professors to citizen scientists—to make discoveries using the program's data. Multiple systems and processes keep data secure and participants' personal information private.

**Engagement.** Participants are partners in All of Us. Participant input is welcome on every aspect of the program to make it better. Participants have full access to data they share and information about all research projects that use All of Us data.

Find out how you can get involved.

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# **Core Values**

The All of Us Research Program is guided by a set of core values:

Participation is open to all. Enrollment is open to all eligible adults who live in the United States. People of every race, ethnicity, sex, gender, and sexual orientation are welcome. No health insurance is required. You can be healthy or have health issues. You can sign up directly through JoinAllofUs.org or through participating health care provider organizations. Children will be able to join in the future.

Participants reflect the rich <u>diversity</u> of the United States. To develop individualized plans for disease prevention and treatment, researchers need more data about the differences that make each of us unique. Having a diverse group of participants can lead to important breakthroughs. These discoveries may help make health care better for everyone.

Participants are partners. Participants shape the program with their input and contribute to a project that may improve the health of future generations. They may also learn about their own health.

**Transparency earns trust.** We inform participants about how their data are used, accessed, and shared. Participants can choose how much information to share.

Participants can access their information. All of Us lets participants see their own information and records.

Data are broadly accessible for research purposes. All of Us makes information about participants as a group available in a <u>public database</u>. Everyone can explore the database or use it to make discoveries. Data from individual participants are also available, but only for researchers who apply and are approved. Any personal information that identifies a participant, such as name or address, is removed from data that researchers can access.

Security and privacy are of highest importance. Data are stored in a secure, cloud-based database. All systems meet the requirements of the Federal Information Security Management Act. Ongoing security tests help protect participant data. Learn more about how the All of Us Research Program protects data and privacy.

The program will be a catalyst for positive change in research. Working together, All of Us researchers, partners, and participants can build a better future for health research and care.

> Find in-depth information on how the program works in the All of Us Research Program Protocol.

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# All of Us Research Program Protocol

The *All of Us* Research Program Protocol provides a detailed look at the program's plans for building a robust research resource of data from one million or more participants reflecting the diversity of the United States.

A protocol is a scientific document with in-depth plans for a specific research effort. It can help researchers explain what they want to learn and how they'll carry out their work.

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Although the *All of Us* Protocol is written for researchers, it may be of interest to others. It has a wealth of information about the program, from who can join and what data *All of Us* will collect to how the program will protect that data and who will be able to access it.

The All of Us Protocol is revised periodically as the program makes updates and adds new features.

#### **Downloads**

The protocol was reviewed by the Institutional Review Board (IRB) of the *All of Us* Research Program. The *All of Us* IRB follows the regulations and guidance of the NIH Office for Human Research Protections for all studies, ensuring that the rights and welfare of research participants are overseen and protected uniformly.



All of Us Research Program Operational Protocol pdf | 1.43 mb (Updated 3/28/2018)



Summary of the Operational Protocol pdf | 203.32 kb

# Learn more about the All of Us Research Program

All of Us Consent Process

All of Us Surveys

**Data Security Policy and Framework** 

**Privacy and Trust Principles** 

Have questions? See our program FAQ.

FAQ



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# **Get Involved**

Join us in working to speed up medical breakthroughs that help treat all of us as individuals. Whether you are contributing health information, engaging in research, or supporting the *All of Us* Research Program as a partner, your part in this historic program will help us build a better future for health research and care. It is easy to get involved with the *All of Us* Research Program as a researcher or participant, and you can always choose what information you share and how much you engage with us.

# **Scientific Opportunities**

Learn how the *All of Us* Research
Program benefits researchers and how
you can access program data online
through the Research Hub.

# **Participation**

Find out how you can contribute to *All of Us* as a participant and how to sign up.

#### **Partners**

Learn about funding opportunities with the *All of Us* Research Program and see examples of program partnerships.

Sign up at JoinAllofUs.org.

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# **Scientific Opportunities**

The *All of Us* Research Program will enable traditional and nontraditional researchers to learn from a community of one million or more participants, including many who haven't taken part in health research before. The program's large, diverse, and broadly accessible data resource can help answer many questions to help create a healthier future for all of us.

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#### **Benefits for Researchers**

All of Us offers researchers opportunities to:

- Save time and resources and accelerate research breakthroughs by accessing:
  - A rich data resource, including biospecimens and increasingly robust electronic health records
    - A longitudinal dataset that will follow participants as they move, age, develop relationships, get sick,
       and try treatments
    - A diverse cohort of participants
    - Raw data and data that are already cleaned and curated
    - Robust computing and analytic tools to support complex data analyses in a secure data environment
  - A group of engaged participants who may be interested in participating in ancillary studies
- Share workspaces and analyses with research partners and reviewers.
- Learn from the program's pilots and experiments.
- Leverage innovations of other studies and cohorts.

# **About the Research Hub**

The All of Us Research Hub is your gateway to participant data. Visit the Research Hub to:

- Use the interactive <u>Data Browser</u>. The *All of Us* Research Program announced the beta release of the Data Browser in May 2019 to provide a first look at the data that participants are sharing for health research.
- View <u>Data Snapshots</u>. Updated regularly, these snapshots provide visualizations of participant demographics, geographic distribution, and more.
- Read about All of Us data sources and methods of data curation.
- Find information about <u>privacy and security processes</u> that help keep participant data safe.

The Research Hub will also house the <u>Workbench</u> platform and its suite of custom tools. The Workbench will offer access to additional levels of data, workspaces, a cohort builder, and an interactive notebook environment. These tools will be available in late 2019 to authorized and approved *All of Us* researchers.

Possible areas of inquiry for researchers who register to use the Workbench include:

- Developing ways to measure risk for diseases based on environmental exposures, genetic factors, and interactions between the two
- Identifying genetic causes of individual differences in response to commonly used drugs (i.e., pharmacogenomics)
- Discovering biological markers that indicate risk of developing common diseases
- Using mobile health technologies to correlate activity, physiological measures, and environmental exposures with health outcomes
- Developing new disease classifications
- Creating a platform to enable trials of targeted therapies

Learn more about what the *All of Us* Research Program is doing to work with researchers as partners.

Learn More



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# **Participation**

Anyone over the age of 18 who is living in the United States can join the All of Us Research Program, either directly through the <u>JoinAllofUs.org</u> website or through participating health care provider organizations. Children will be able to join in the future, potentially within the next 1-2 years.

After completing the <u>consent process</u>, participants will be asked to contribute information about their medical history and lifestyle. Participants may also be asked to have their physical measurements (blood pressure, height and weight, etc.) taken at a local enrollment center, or donate a blood and urine sample. Participants will have access to their study results, along with summarized data from across the program.

Learn more at JoinAllofUs.org.

Learn More

The All of Us Research Program is a highly interactive research model, with participants as partners in the development and implementation of the research and with significant representation in program governance and oversight. Through this dynamic community, researchers will be able to advance the information derived from the program into new knowledge, approaches, and treatments.

To be most effective, the All of Us Research Program is engaging a wide variety of partners across many different communities. NIH and its partners will launch a communications campaign when enrollment begins so that people across America know the time has come to join. To stay up to date on program developments and news, sign up for email updates on this website.

> The All of Us Research Program offers free downloadable materials to help community members spread the word about the program.

**See Community Resources** 



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