

The *All of Us* Research Program

SGMRO Regional Meeting
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One of the world's largest, most diverse biomedical datasets of its kind

Inviting


1 Million

or more people from across the United States




Data available from **413,450+** participants

75% identify with communities underrepresented in biomedical research



45% are from racial and ethnic minority groups



Data as of April 2023

Enables research discoveries that drive more precise approaches to care

Engages **people & communities who have been left out of medical research** in the past



Combines **biological factors and social determinants** on a large, inclusive scale



Easily accessible to any researcher with a secure internet connection



Follows participants as they move, age, and grow



All of Us Research: How It Works



1. Participants share their data with the *All of Us* Research Program through multiple sources. These data are sent to a secure cloud environment, managed by the Data and Research Center.



2. Participant data is received and funneled through a **curation pipeline*** within a secure repository that connects to the Research Hub tools.
*** researchallofus.org/data-tools/data-sources**



3. Anyone can visit the Research Hub to learn more about the types of data *All of Us* makes available for research. The **Survey Explorer**¹ and **Data Browser**² offer more information about the unique data elements and let visitors browse aggregated participant data.

¹ researchallofus.org/data-tools/survey-explorer

² databrowser.researchallofus.org



4. Researchers register* for access to the Researcher Workbench to analyze data.
*** researchallofus.org/register**



5. Registered researchers in the Researcher Workbench can create research projects using collaborative workspaces, cohort-building tools, interactive notebooks, and more.



6. Research underway can be viewed on the **Projects Directory**.¹ Publications related to *All of Us* Research Program data are posted on the **Publications page**.²

¹ researchallofus.org/research-projects-directory

² researchallofus.org/publications

Current protocol



Enroll, Consent and Authorize EHR

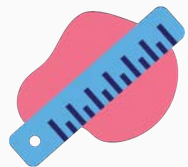
Recruiting 18+ years old initially; launched phased approach to recruiting children
Online, interactive consent
Includes authorization to share EHR data



Answer Surveys

The Basics	Health Care Access & Utilization
Overall Health	Personal and Family Medical History
Lifestyle	Social Determinants of Health

Additional surveys will be released on an ongoing basis



Provide Physical Measurements

Blood pressure	Height	BMI
Heart rate	Weight	Hip circumference
		Waist circumference

Based on diverse sampling and capacity



Provide Biosamples

Blood (or saliva)
Urine specimen
Biosamples will be stored at the program's biobank

Based on diverse sampling and capacity



Share data from Wearables/Digital Apps

Share data from wearable fitness devices, starting with Fitbit

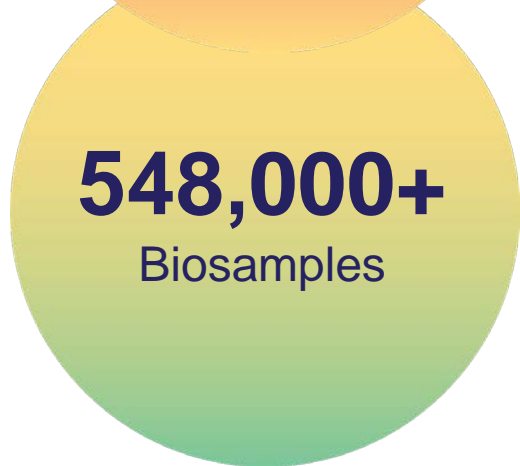
Fitbit data may include physical activity, step counts, heart rate, and sleep data

***All of Us*: a rich resource for SGM health researchers**

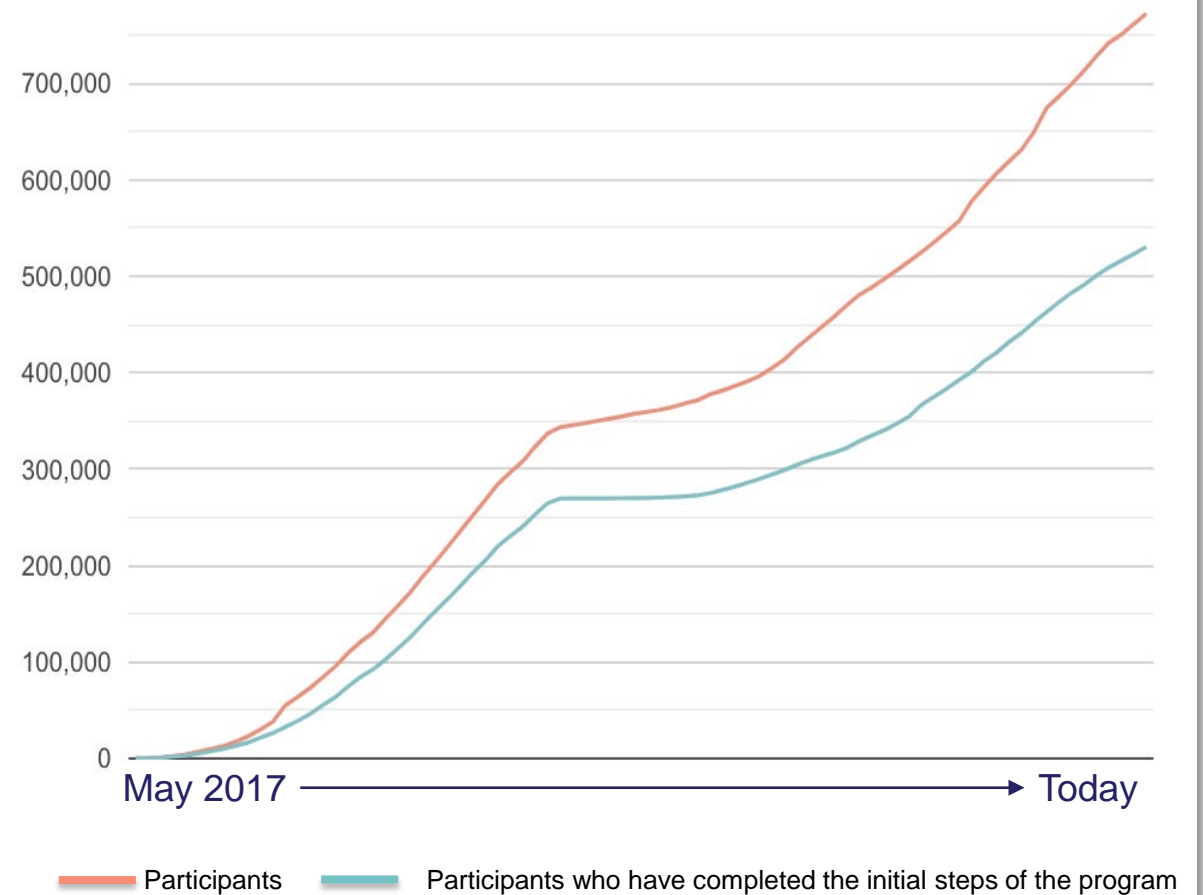
- From **Day 1** *All of Us* has engaged sexual and gender minority (SGM) communities.
- Comprehensively collects sexual orientation, gender identity, and sex assigned at birth from all participants (1+ million people).
- Previously invisible SGM subgroups (e.g., asexual, gender-fluid) will likely be explicitly included.
- Rich demographics enable studies of intersecting identities among UBR communities.
- Electronic health record (EHR) data enables SGM-specific analyses based on diagnoses, procedures, laboratory tests, imaging studies, medications, etc.

All of Us Data and Research

All of Us Data At-a-Glance

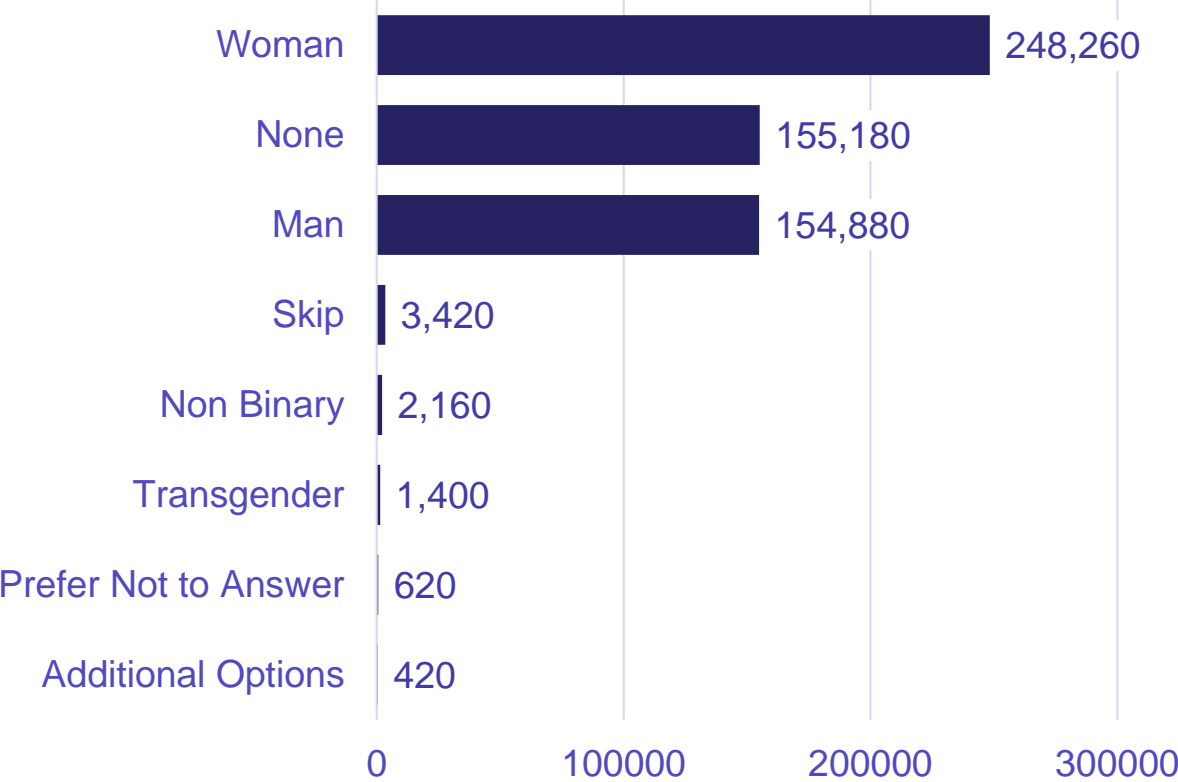


Enrollment Numbers

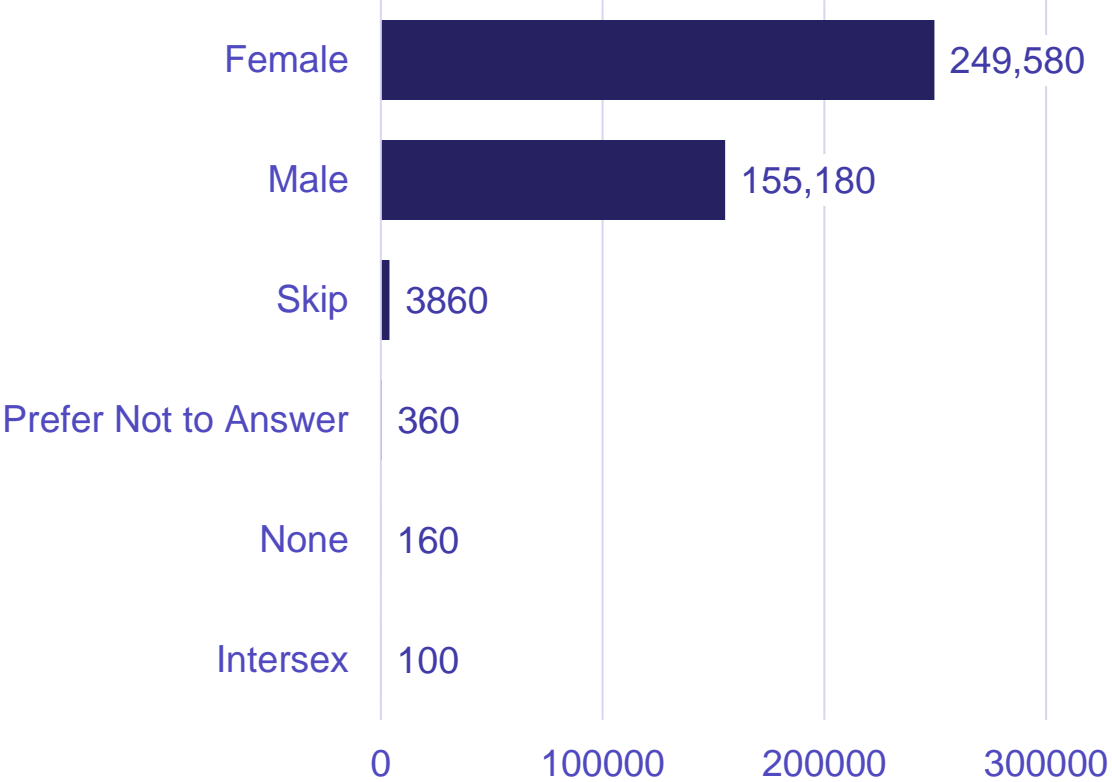


SGM participants in *All of Us*

What terms best express how you describe your gender identity? (Check all that apply)

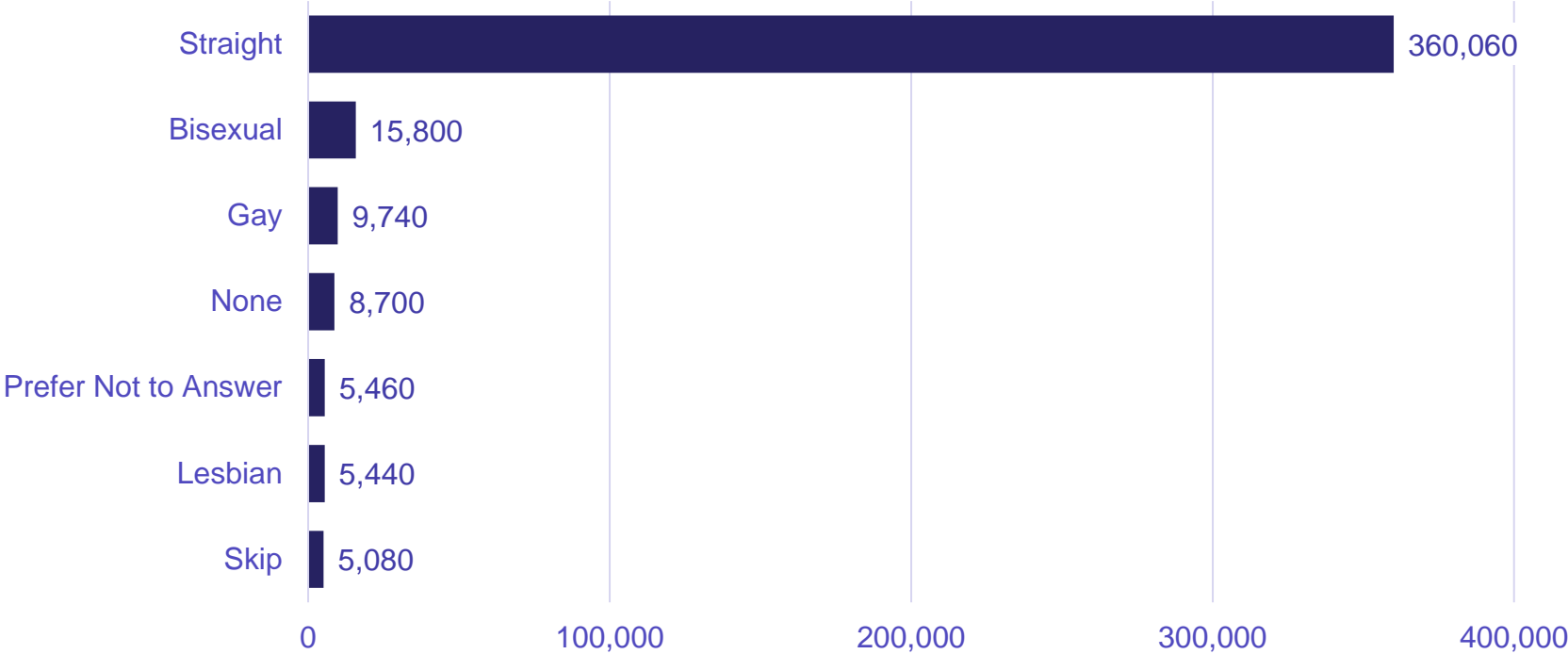


What was your biological sex assigned at birth?



SGM participants in *All of Us*

Which of the following best represents how you think of yourself.



About the *All of Us* Data Browser

DataBrowser.ResearchAllOfUs.org

- Provides **summary statistics** from the program's growing database
- **Open to everyone** – no login!
- Allows participants to **understand the makeup of the cohort**
- Allows researchers to understand the **characteristics of our participant population, explore the data types available, and plan research questions**

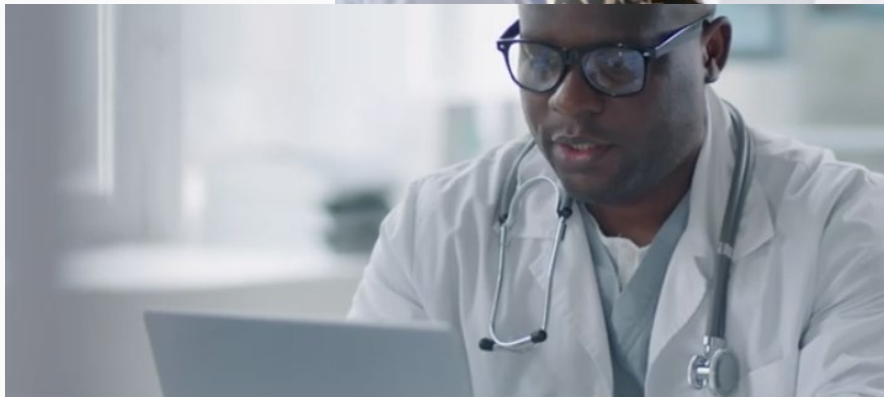
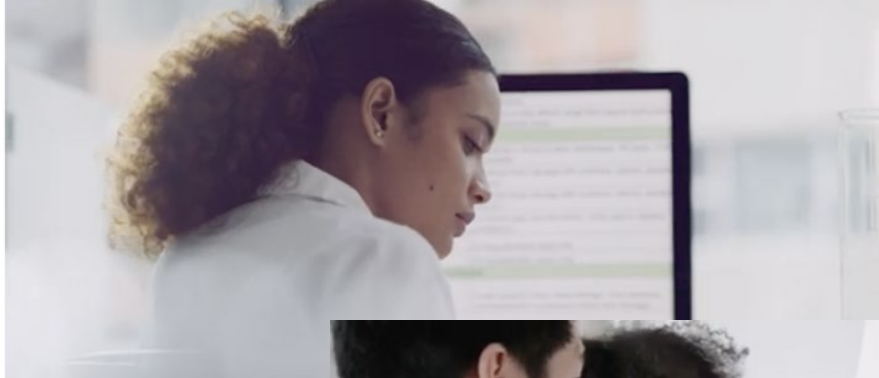
Interactive tool launched in May 2019

The screenshot displays the All of Us Data Browser interface. At the top, there is a search bar labeled "Search Across Data Types" with a "Keyword Search" input field. Below the search bar, it states "Data includes 409,420 participants as of 2/15/2023." To the right of the search bar are three icons: a question mark for "FAQs", a person with a question mark for "Introductory Videos", and a database icon for "User Guide Videos".

The main content area is organized into several sections, each with a grid of data cards:

- EHR Domains:** Contains four cards for "Conditions" (25,638 medical concepts, 254,700 participants), "Drug Exposures" (29,865 medical concepts, 239,740 participants), "Labs & Measurements" (16,216 medical concepts, 252,990 participants), and "Procedures" (30,328 medical concepts, 242,590 participants).
- Genomics:** Contains two cards. The first is "SNP/Indel Variants" (245,400 participants in Short-Read Whole Genome Sequencing (WGS) dataset, 1,074,881,214 SNP/Indel Variants). The second is "Genomic data only in Researcher Workbench" (1,040 participants in the Long-Read WGS dataset, 11,400 participants in the Short-Read WGS Structural Variants dataset, 212,940 participants in the Genotyping Arrays dataset).
- Measurements and Wearables:** Contains two cards. "Physical Measurements" (8 Physical Measurements, 342,840 participants). "Fitbit" (6 Fitbit Measurements, 15,620 participants).
- Survey Questions:** Contains four cards: "The Basics" (28 questions available, 409,420 participants), "Overall Health" (21 questions available, 400,760 participants), "Lifestyle" (26 questions available, 398,200 participants), and "Health Care Access & Utilization" (57 questions available, 190,220 participants).
- Personal and Family Health History:** Contains one card: "Personal and Family Health History" (614 questions available, 185,240 participants).
- COVID-19 Participant Experience (COPE):** Contains two cards: "COVID-19 Participant Experience (COPE)" (191 questions available, 100,220 participants) and "COPE Minute Survey" (141 questions available, 127,240 participants).
- Social Determinants of Health:** Contains one card: "Social Determinants of Health" (80 questions available, 117,800 participants).

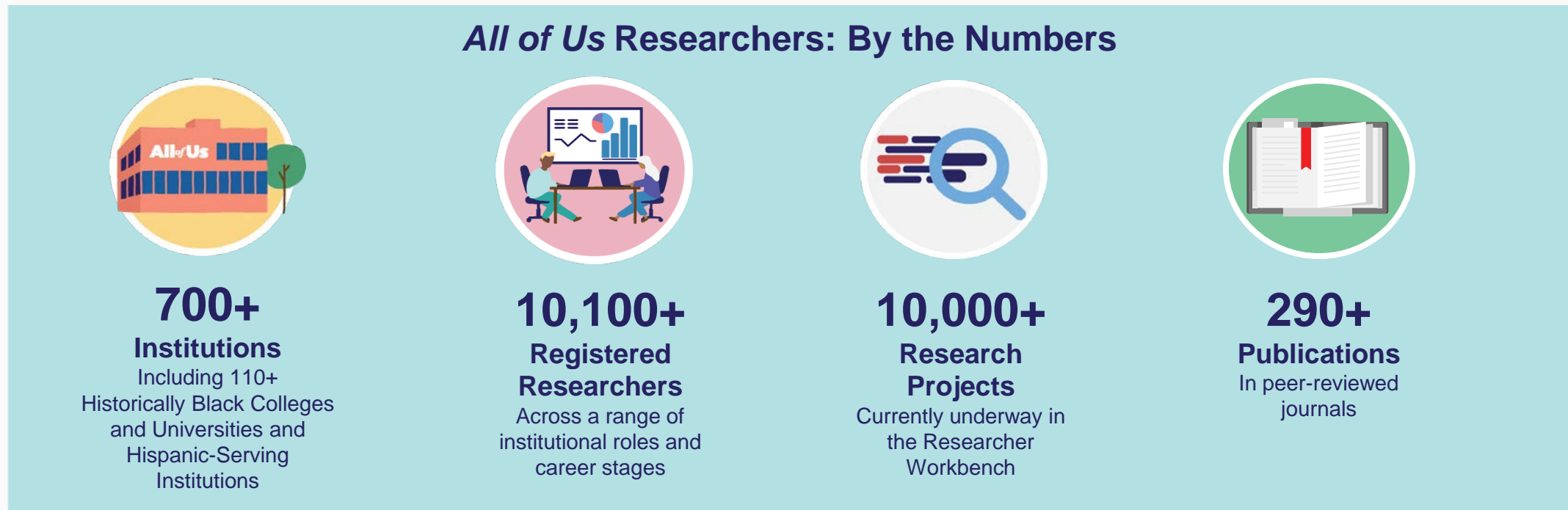
All of Us is building a diverse researcher cohort



- **Encouraging students and early-stage investigators** to bring fresh, creative perspectives & innovative research outcomes.
- **Ensuring access for researchers from various institutions/organizations** to establish a truly equitable resource for all.
- **Supporting a researcher cohort** that promotes responsible and ethical use of data, returns value to participant communities, and accelerates research impact.

Tools for precision medicine research

Over 10k researchers have made *All of Us* a part of their work!



Researchers can access the User Support Hub, *All of Us* Office Hours, and regular trainings and webinars for support.

Featured publication

> J Psychosoc Oncol. 2023;41(6):661-672. doi: 10.1080/07347332.2023.2210548. Epub 2023 May 15.

Disparities in health-related quality of life among lesbian, gay, and bisexual cancer survivors

Michael A Hoyt¹, Katie Darabos², Karen Llave¹

Gay, lesbian, and bisexual identifying cancer survivors showed lower mental and social health than heterosexual survivors.



Lesbian, gay, and bisexual cancer survivors have lower social and mental quality of life than heterosexual survivors.*

*Research made possible thanks to the many LGB participants who have shared their stories with *All of Us*.

Reference: Hoyt, M. A., Darabos, K., & Llave, K. (2023). Disparities in health-related quality of life among lesbian, gay, and bisexual cancer survivors. *Journal of Psychosocial Oncology*.



Los sobrevivientes de cáncer que se identifican como lesbianas, gays y bisexuales tienen una calidad de vida social y mental más baja que los sobrevivientes heterosexuales.*

*La investigación fue posible gracias a los muchos participantes que se identifican como lesbianas, gays y bisexuales que compartieron sus historias con *All of Us*.

Referencia: Hoyt, M. A., Darabos, K., & Llave, K. (2023). Disparities in health-related quality of life among lesbian, gay, and bisexual cancer survivors. *Journal of Psychosocial Oncology*.

Other resources

The All of Us Research Program's mission is to speed up health research breakthroughs.

People from all walks of life will share their health information. Health data from diverse people will help fill gaps in knowledge about why people get sick or stay healthy. The data could help researchers develop new and better treatments that benefit all of us.

Why is diversity important to the All of Us Research Program?

All of Us is asking lots of people to join. Participants are from different races and ethnicities, age groups, and regions of the country. They are also diverse in gender identity, sexual orientation, and health status.

Diversity in a research program is important for several reasons. First, where we live, how we live, and our background can all affect our health. Second, many groups of people have been left out of research in the past. This means we know less about their health.

By studying data from a diverse group of people, researchers can learn more about what makes people sick or keeps them healthy. What researchers learn could lead to better treatment and disease prevention for all of us.

Data from All of Us could someday help researchers:

- Identify what makes people more likely to develop a disease.
- Find out how environment, lifestyle, and genes can impact health.
- Build better tools for detecting a health condition and encouraging healthy habits.

Why have some communities not been part of research?

There are different reasons. For example, some communities have not been invited to take part in research. Or, they were invited but were not told what was involved. For these reasons, we know very little about them.



The All of Us Research Program has learned from this history. We want to be sure we do things right, so many different groups of people can join. We will tell you what we are doing. We will share results. And we will protect your data.

Why is the LGBTQ community important to All of Us?

LGBTQ people, like many other groups, have often been left out of research. As a result, we know less about their health and ways to provide them with the best care. The All of Us Research Program wants to change this. By joining All of Us, LGBTQ people can help ensure their community is included in health studies. These studies could help researchers understand health conditions that are more common among LGBTQ people. What they learn could lead to more tailored approaches for preventing and treating those conditions.

All of Us is working with community partners to educate LGBTQ people about the program and how research has potential benefits for their families and future generations.

All of Us Core Values

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

How is All of Us addressing concerns about taking part in research?

Here are some of the ways All of Us is addressing these concerns:

Becoming a participant

All of Us wants people to make an informed decision about whether to join.

We have worked hard to make the process for joining All of Us clear and detailed. Before you decide if you want to join, we will tell you the purpose of the research program. We will also share the risks and benefits of taking part, what to expect in the program, and how to withdraw if you choose to leave. People must agree that they understand the program and their rights as participants before they can join. We have a Support Center and other staff who help answer questions about being a participant.

Ensuring privacy and data security

All of Us is committed to making sure data is kept private. We also want to make sure that data is not misused. The All of Us Research Program:

- Follows all federal, state, and local laws and rules for keeping data safe.
- Has strict policies and procedures to prevent misuse of data. See the [Privacy and Trust Principles](#) and [Data Security Policy Principles and Framework](#).
- Has [Certificates of Confidentiality](#) from the U.S. government. These will help the program fight legal demands (such as a court order) to give out information that could identify a participant.
- Continues to test the security of our databases.
- Will tell participants if there is a risk to their privacy because of a data breach.
- Stores data on protected computers. This limits and keeps track of who can see it.
- Removes personal details that could identify participants from the data.
- Requires researchers to agree to follow data use rules, including promising they will not try to identify participants.

Giving information back to participants

The All of Us Research Program will give information back to participants. People who join can choose to see their own health information. In the future, this might include information from DNA tests and health records. All of Us will post information on its website about the research being done with the data. General demographic information about all participants will be publicly available.



Is the program working with participants and their communities?

Yes. All of Us participant representatives shape the program at all levels. Participant representatives are part of local advisory boards and All of Us working groups, where they share ideas and help decide what the program does.

All of Us also funds [community organizations](#). They reach groups that have historically been underrepresented in research to tell them about the research and answer questions. They also help spread awareness of the All of Us Research Program.

Why should someone consider joining All of Us?

People join for many reasons. Some people join because they can:

- Learn more about their health.
- Help improve the health of their communities and future generations.
- Help researchers find the best ways for people to stay healthy.
- Help researchers one day create better tests and treatments.

The longer a person stays involved with All of Us, the more they can learn about themselves and help speed up health research and medical breakthroughs.

Where can someone learn more about the All of Us Research Program?

Visit [JoinAllofUs.org](#) to learn more about the program, its privacy safeguards, benefits of joining, and how data will be used. The All of Us Support Center is open every day (except public holidays) to answer questions. Contact the Support Center at **(844) 842-2855** or [help@joinallofus.org](#).

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Research Roundup

Stay up to date on the latest
news and insights from the
All of Us Research Hub.



allof-us.org/RRSignup

Create an *All of Us* account

Get started today



CONFIRM YOUR INSTITUTION'S
AGREEMENT



CREATE AN ACCOUNT AND
VERIFY YOUR IDENTITY



COMPLETE THE MANDATORY
TRAINING



SIGN THE DATA USER CODE OF
CONDUCT (DUCC)



allof-us.org/Register

Resources

Web: <https://www.joinallofus.org/>

Community Resources: <https://www.joinallofus.org/en/community/community-resources>

Researcher Workbench: <https://workbench.researchallofus.org/login>

Newsletters: <https://www.joinallofus.org/en/newsletters>

Events: <https://www.joinallofus.org/en/events>

Email: Erica Landis, erica.landis@nih.gov

Thank You!



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