All of Us Research Program
May 22, 2023
The cornerstone of the larger PMI – led by the NIH.

One million or more volunteers, reflecting the broad diversity of people who live in the U.S.

Volunteers key to success as they will provide information on their own unique health an ongoing basis.

This information will benefit thousands of research studies throughout the nation.

Opportunities for communities that historically have not been represented in biomedical research studies
Who Can Participate?

❖ People 18 years old or older.
❖ People who live anywhere in the U.S.
❖ People of every race, ethnicity, sex, gender, and sexual orientation.
❖ Participants can be healthy or can have a long-term health issue.
❖ Participants don’t have to speak English to join. Enrollment materials in Spanish and advisors will help Spanish-speaking volunteers.
❖ No health insurance is required.
What might participants be asked to do?

**Enroll, Consent and Authorize EHR**
- Recruiting 18+ years old initially; plan to include children later
- Online, interactive consent
- Includes authorization to share Electronic Health Record (EHR) data
- Consent to get DNA Results

**Answering Surveys**
- Six initial surveys: The Basics, Overall Health, Lifestyle, Health Care Access & Utilization, Family Medical History, Personal Health History, Social Determinants of Health
- Additional surveys will be released on an ongoing basis.

**Physical Measurements***
- Blood pressure
- Heart rate
- Height
- Weight
- BMI
- Hip circumference
- Waist circumference

**Provide Biosamples***
- Blood (or saliva, if blood draw is unsuccessful)
- Urine specimen
- Biosamples will be stored at the program’s biobank

**Wearables and Digital Apps**
- Share data from wearable fitness devices, starting with Fitbit
- More integrations under development

*Based on diverse sampling and capacity
How to join - Roadmap

- Learn about the program.
- Have physical measurements taken
- Talk with family, friends, or health care provider about your interest in joining.
- Give blood and urine samples.
- Decide to join the All of Us Research Program, enroll, and give your consent.
- Update your health and lifestyle information from time to time.
- Agree to share your electronic health records.
- If eligible, take part in new research projects.
- Answer health-related questions.
- Participants may not, if they withdraw, have access to the data they give to the program.

Pilots in development: complete EHR data, health applications, wearable devices that track physical activity and genetic return of results.
What information will we share with you?

We expect to share information about:

- Your ancestry (where your family comes from)
- Your traits, such as why you might love or hate cilantro
- Whether you may have an increased risk of developing a particular health condition
- How your body might react to certain medications
- Other health-related information

We plan to use many different methods to check your DNA for information. You may get some DNA results sooner than others.

It will take some time to get your DNA results. Some participants may not get their DNA information for a few years.
Join Now!

All of Us
You have the power to drive health research.
Without you, it won’t be All of Us.

Scan code to access the website on your phone or visit:
joinallofus.org/juntos

Use this QR code in cities with HPO
All of Us Journey & Tour in Nebraska – Summer 2023

- **June 26-29** TBD; Looking for lead community partner
- **July 3-7** Columbus, NE (Pending)
- **July 10-13** Lincoln, NE (Lead: El Centro De Las Americas)
- **July 17-20** Grand Island, NE (Lead: Multicultural Center for Development Education and Sport)
- **July 24-27** South Omaha, NE (Lead: Latino Center of Midlands)
- **July 29** South Omaha, NE @ One World’s Vive Tu Vida / Get Up Get Moving Event
- **July 31-August 3** TBD; Possibly Kearney

OPEN Monday-Thursday from 10am-4pm
Staffed with bilingual personnel
Enabling 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

Follows participants as they move, age, and grow

Easily accessible to any researcher with a secure internet connection and data use agreement
The *All of Us* Research Program’s Data and Research Center (DRC) curates a range of different data types as part of the data collection process.

By securely capturing a range of different data types

- **413,350+** Survey Responses
- **337,500+** Physical Measurements
- **312,900+** Genotyping Arrays
- **287,000+** Electronic Health Records
- **245,350+** Whole Genome Sequences (WGS)
- **11,350+** Structural Variants
- **1,000+** Long-Read Sequences
- **15,600+** Fitbit Records

NEW! In 2023

NEW! Sleep Data

Data as of April 2023
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 and Data Browser offer more information about the unique data elements and let visitors browse aggregated participant data.
   * researchallofus.org/data-tools/survey-explorer
   * 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. Publications related to All of Us Research Program data are posted on the Publications page.
   * researchallofus.org/research-projects-directory
   * researchallofus.org/publications
Registered researchers can access in-depth data and a variety of research tools to conduct a wide range of studies.

Data have been processed to protect participant privacy.

Available to anyone

Available to registered researchers

Tiered access levels enable discovery

Public Tier

Anyone can visit ResearchAllofUs.org (the All of Us Research Hub) to learn more about the data available for research and explore aggregated participant data and summary statistics, with participant identifiers removed. Public resources include:

- **Data Snapshots**: Aggregated, public-facing overviews of participant characteristics and data types
- **Data Browser**: Interactive preview into the All of Us dataset through public-facing aggregate data
  - Currently includes participant-provided survey responses, physical measurements, data from EHRs and wearables, and genomic data
- **Survey Explorer**: Details the questions included in each of the surveys
- **Research Projects Directory**: Descriptions of each research project within the Researcher Workbench

RESEARCHER WORKBENCH

Registered Tier

Registered researchers can access in-depth data and a variety of research tools to conduct a wide range of studies.

Available to registered researchers

Controlled Tier

Registered researchers with amended institutional agreements can access all of the data in the Registered Tier plus additional and expanded data types, including genomic data, real dates of health events, ICD codes, granular demographic data, and more.

Available to registered researchers
Create an *All of Us* account

Register to be an *All of Us* Researcher

1. **Step 1**: Learn More About the Data Available
2. **Step 2**: Check for Your Institution’s Agreement
3. **Step 3**: Register as a Researcher
4. **Step 4**: Verify Your Identity
5. **Step 5**: Complete All of Us Responsible Conduct of Research Training
6. **Step 6**: Sign Data User Code of Conduct

[ResearchAllofUs.org/User](ResearchAllofUs.org/User)
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alof-us.org/RRSignup
Questions?

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