All of Us RESEARCH PROGRAM | The Precision Medicine Initiative

All of Us Research Program

May 22, 2023

NIH National Institutes of Health

National Alliance for Hispanic Health

UNIVERSITY OF NEBRASKA MEDICAL CENTER COLLEGE OF PUBLIC HEALTH

The *All of Us* Research Program

- 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

**Based on diverse sampling and capacity*

Provide Biosamples*

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

**Based on diverse sampling and capacity*

Wearables and Digital Apps

- Share data from wearable fitness devices, starting with Fitbit
- More integrations under development

How to join - Roadmap

Learn about the program.

Talk with family, friends, or health care provider about your interest in joining.

Decide to join the *All of Us* Research Program, enroll, and give your consent.

Agree to share your electronic health records.

Answer health-related questions.

Have physical measurements taken

Give blood and urine samples.

Update your health and lifestyle information from time to time.

If eligible, take part in new research projects.

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?

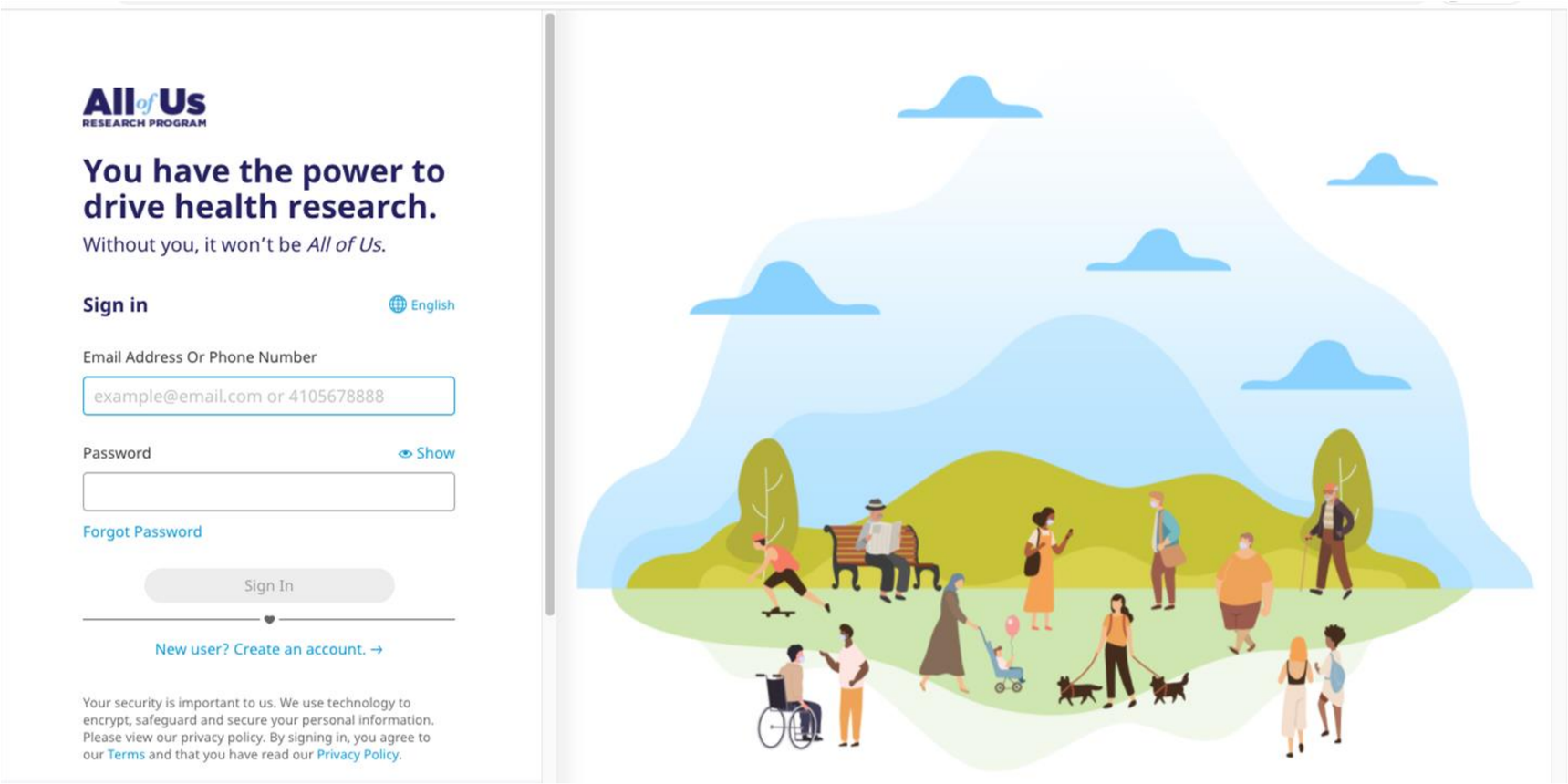
We expect to share information about:

- 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!



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

Easily accessible to any researcher with a secure internet connection and data use agreement

Follows participants as they move, age, and grow

By securely capturing a range of different data types

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.

413,350+
Survey Responses

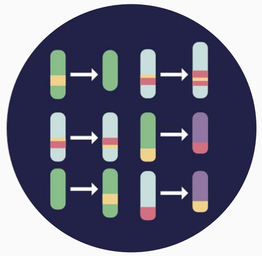
337,500+
Physical Measurements

312,900+
Genotyping Arrays

287,000+
Electronic Health Records

245,350+
Whole Genome Sequences (WGS)

15,600+
Fitbit Records
NEW! Sleep Data



11,350+
Structural Variants
NEW! In 2023

1,000+
Long-Read Sequences
NEW! In 2023

Data as of April 2023

All of Us Research: How It Works

All of Us RESEARCH PROGRAM

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**

Tiered access levels enable discovery

Available to anyone

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

Available to registered researchers

Registered Tier

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


Surveys


Electronic Health Records


Physical Measurements

Wearables

Data have been processed to protect participant privacy

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.


Genomics


Health and Lifestyle surveys

Create an *All of Us* account

Register to be an *All of Us* Researcher

STEP 1
LEARN MORE ABOUT THE DATA AVAILABLE

STEP 2
CHECK FOR YOUR INSTITUTION'S AGREEMENT

STEP 3
REGISTER AS A RESEARCHER

STEP 4
VERIFY YOUR IDENTITY

STEP 5
COMPLETE *ALL OF US* RESPONSIBLE CONDUCT OF RESEARCH TRAINING

STEP 6
SIGN DATA USER CODE OF CONDUCT

ResearchAllofUs.org/User

And stay in touch to learn more

Subscribe to Research Roundup

Stay up to date on the latest news and insights from the *All of Us* Research Hub through our **bimonthly email newsletter.**

allof-us.org/RRSignup

All of Us Consortium Members *(beyond community partners, as of April 2023)*

The Participant Center

Scripps Research Translational Institute
BlueCross BlueShield
SENSIS
SageBionetworks
waves
DENVER HEALTH
MAYO CLINIC
Bloodworks
OurCEL
careevolution
WebMD
South Texas Blood & Tissue
SunCoast Blood Centers
SYNC FOR SCIENCE
Quest Diagnostics
San Diego Blood Bank
fitbit
Mary's Center

Communications & Engagement

WONDROS
PYXIS PARTNERS
RTI INTERNATIONAL
THE UNIVERSITY OF UTAH

HPO Network

(Health Care Provider Organizations)

HPO Lite

UT Tyler
VCU Health
Washington University in St. Louis

RMCs

All of Us California

UC San Diego Health
UCI Health
UC DAVIS HEALTH
UCSF
ECRMC
Cedars Sinai
Keck School of Medicine of USC

Illinois Precision Medicine Consortium

Northwestern Medicine
THE UNIVERSITY OF CHICAGO
NorthShore
RUSH
THE UNIVERSITY OF ILLINOIS COLLEGE OF MEDICINE
UI Health
COOK COUNTY HEALTH

All of Us New England

Mass General Brigham
BOSTON MEDICAL CENTER

Trans America Consortium

Henry Ford Health System
Spectrum Health
Essentia Health
BaylorScott&White Health
RELIANT MEDICAL GROUP
HealthPartners Institute

New York City Consortium

COLUMBIA
Weill Cornell Medicine
NYC HEALTH+ HOSPITALS | Harlem
NewYork-Presbyterian

All of Us Southern Network

UAB MEDICINE
UAB HEERSINK
Cooper Green Mercy
The University of Alabama Medical Center
Tulane University
USA HEALTH
TUSKEGEE UNIVERSITY
LSU Health New Orleans

All of Us Southeast Enrollment Center

UJ Health
EMORY UNIVERSITY
MOREHOUSE SCHOOL OF MEDICINE
UF UNIVERSITY of FLORIDA
THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL

All of Us Wisconsin

Marshfield Clinic Health System
WISCONSIN
Froedtert & Medical College of Wisconsin
GUNDERSEN HEALTH SYSTEM

All of Us Pennsylvania

University of Pittsburgh

University of Arizona and Banner Health

THE UNIVERSITY OF ARIZONA
Banner Health
MARIPOSA Health COMMUNITY HEALTH CENTER

FQHCs (Federally Qualified Health Centers)

Cherokee
SAN YSIDRO HEALTH
WILLIAMS COAST COMPREHENSIVE HEALTH CENTER
Community Health Center, Inc.
Sun River Health

VA Medical Centers

VA
U.S. Department of Veterans Affairs
Veterans Health Administration

Nutrition for Precision Health (NPH)

THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL
UNC NUTRITION RESEARCH INSTITUTE
Mass General Brigham

All of Us Puerto Rico

cossma
CENTRO COMPRENSIVO DE CÁNCER

Participant Technology Systems Center (PTSC)

vibrent

Biobank

MAYO CLINIC

Data & Research Center (DRC)

VANDERBILT UNIVERSITY MEDICAL CENTER
BROAD INSTITUTE
verily
COLUMBIA
SCHOOL OF PUBLIC HEALTH UNIVERSITY of MICHIGAN
Northwestern Medicine
UTHealth The University of Texas Health Science Center at Houston

Genomics Partners

Baylor College of Medicine GENETICS
JOHNS HOPKINS MEDICINE
UTHealth The University of Texas Health Science Center at Houston
HUDSONALPHA INSTITUTE FOR BIOTECHNOLOGY
BROAD INSTITUTE
color
Mass General Brigham
UNIVERSITY of WASHINGTON

Note: These are not approved lockups and should not be repurposed on assets.

Questions?

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