All of Us RESEARCH PROGRAM

All of Us Research Program: Opportunities for Clinicians Using R



Last Updated: May 2023

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NIH National Institutes of Health

All of Us Research Program
Key Definitions & Acknowledgement

- **Engagement:** A broad range of relationship-building bidirectional interactions, including information sharing, consultation, collaboration in decision making, and empowered action between the program, people, awardees, and other partners.
- **Outreach:** Unidirectional interaction, such as providing materials and information to an audience.
- **Recruitment:** Facilitating enrollment in the program.
- **Retention:** Ongoing activities with participants after enrollment.

Source: All of Us protocol

Acknowledgement: This event is funded by the Division of Engagement and Outreach, *All of Us* Research Program, National Institutes of Health. Award Number [Pyxis Partners: OD028404]

Disclosure

Dr. Dreisbach is an *All of Us* Research Ambassador through Pyxis Partners and serves on the *All of Us* Research Program Community Advisory Board. She is also a participant in *All of Us*. Her research work is funded by the National Institutes of Health (K01NR020504). She has no other conflicts of interest to disclose.

Dr. Koleck is an *All of Us* Research Ambassador through Pyxis Partners. Her research work is funded by the National Institutes of Health (R00NR017651).

Outline

- Describe the All of Us Research Program
- Discuss the workflow for accessing data
- Outline the analytic tools to support researchers

What is the *All of Us* Research Program?

One of the largest, richest, most diverse biomedical datasets of its kind

Inviting

1 Million or more people across the United States



Data available from **372,000+** participants

80%
are from communities underrepresented in biomedical research





45%
are from racial and ethnic minority groups

Data as of June 2022

Selected Data Snapshots

(Updated 5/19/23)

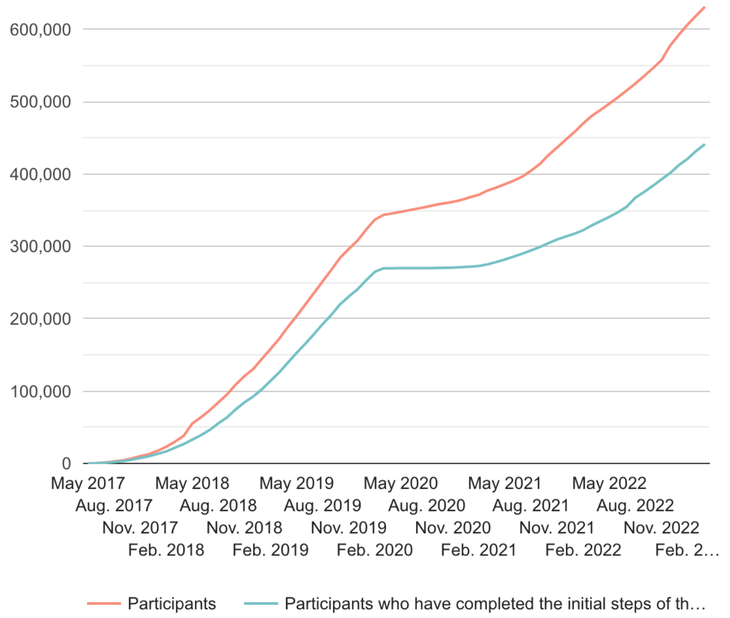
640,000+
Participants

447,000+
Participants who have completed initial steps of the program

Enrollment Numbers

This graph represents participants who have consented to join the program and those who have completed all initial steps of the program. The initial steps are consenting, agreeing to share electronic health records, completing the first three surveys, providing physical measurements, and donating at least one biospecimen to be stored at the biobank.

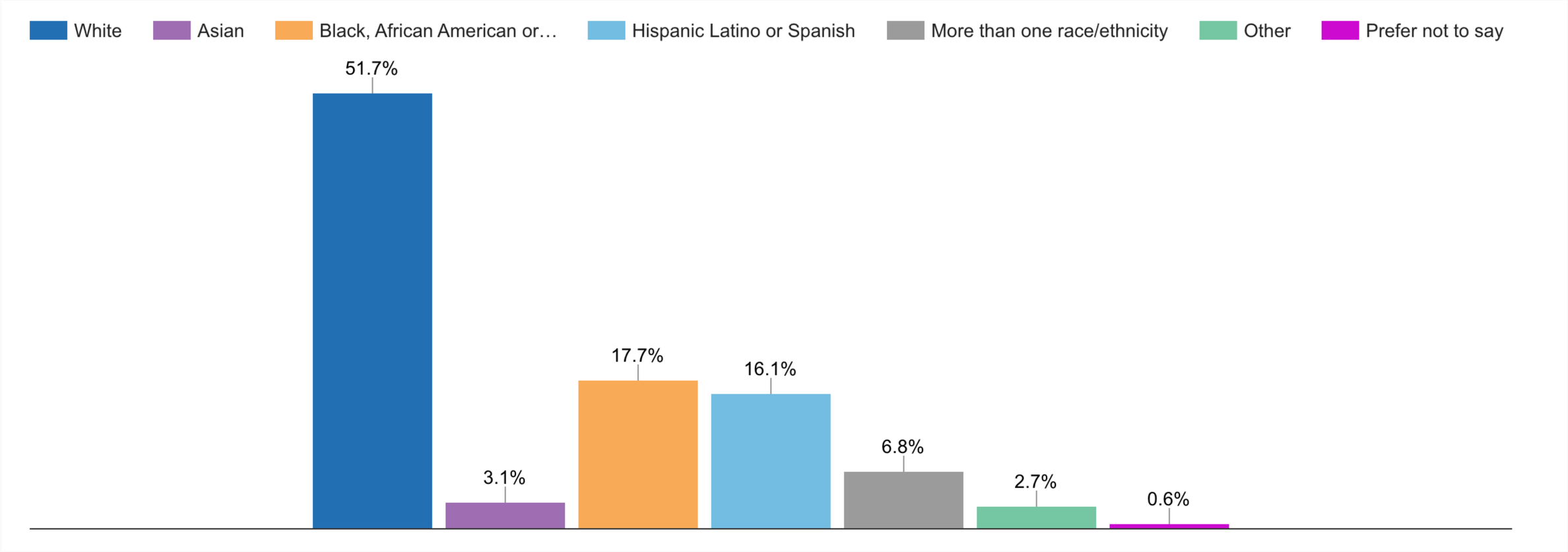
The following numbers are approximated to protect participants' privacy. Numbers are updated as of May 18, 2023.



Selected Data Snapshots

(Updated 5/19/23)

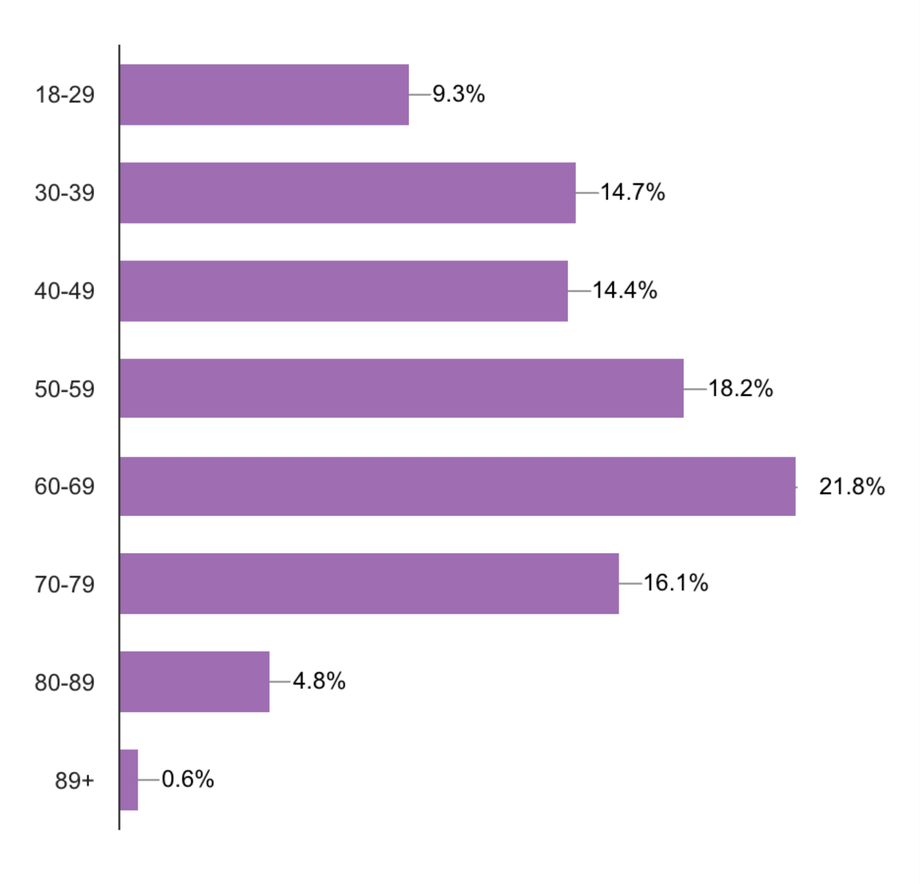
Race & Ethnicity



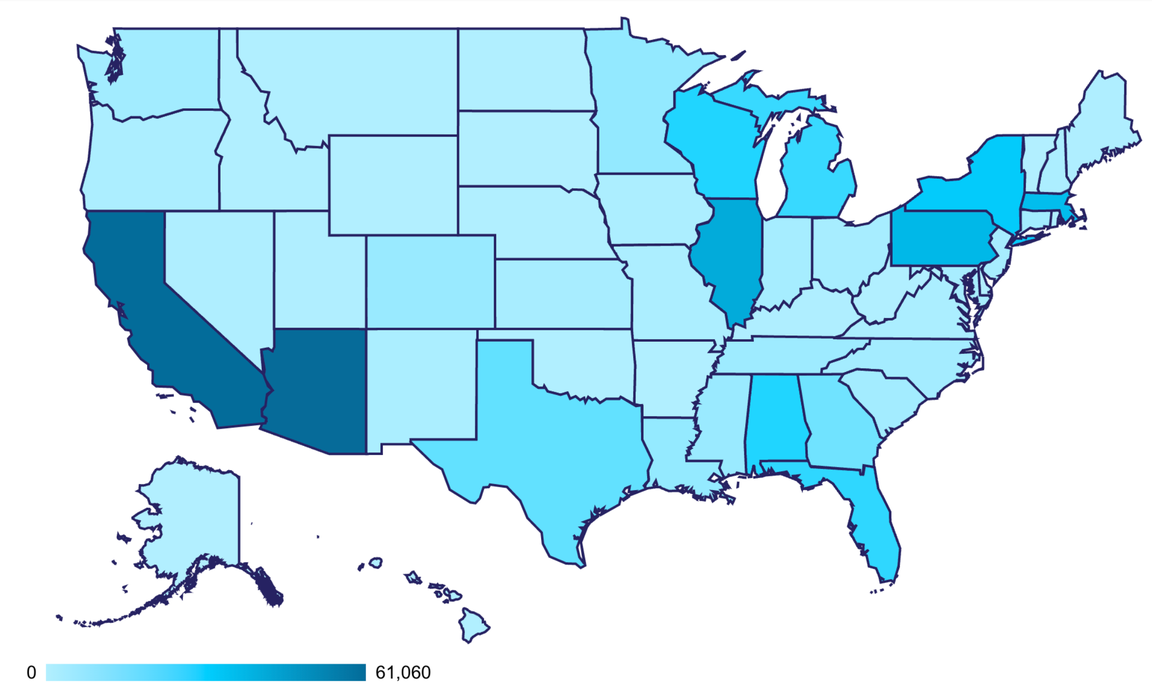
Selected Data Snapshots

(Updated 5/19/23)

Age



Geography



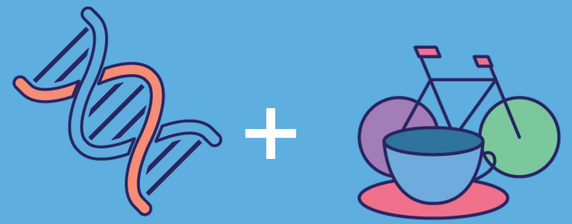
All 50 states
Bilingual enrollment
Interactive mobile exhibits

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



Follows participants as they move, age, and grow



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



By securely capturing a range of different data types



Surveys

(from 372,000+ participants)
Including lifestyle, access to care, medical history, and **data from nearly 100,000 participants on their experiences during the COVID-19 Pandemic**



Wearables

(from 12,800+ participants)
Physical activity and heart rate from participants who have connected their Fitbit devices



Electronic Health Records

(from 258,000+ participants)
Standardized to OMOP common data model



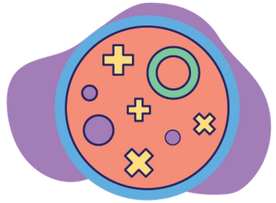
Genomics

(Nearly 100,000 whole genome sequences) and 165,200 shorter DNA samples known as genotyping arrays
Only available via the Controlled Tier



Physical Measurements

(from 306,000+ participants)
Blood pressure, heart rate, BMI and more



Biosamples

Additional data from biosamples to come

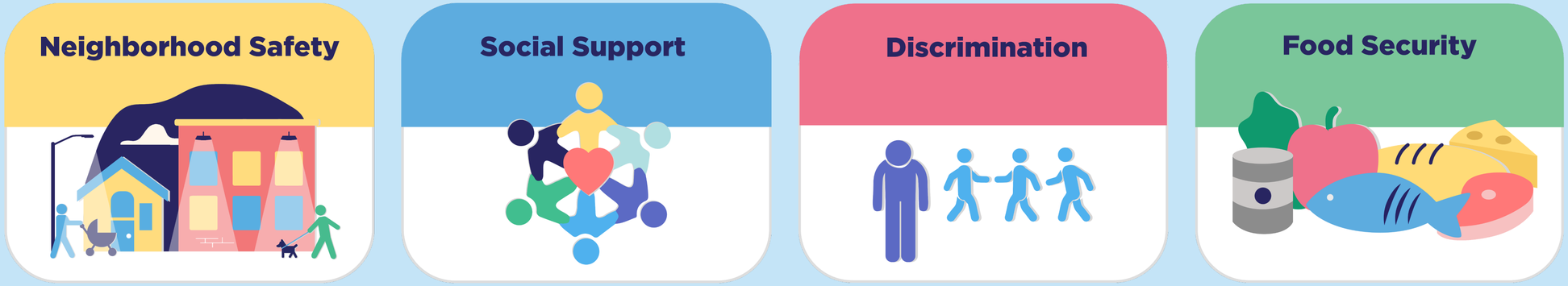
Data as of June 2022

Linked to drive new insights

By readily connecting biological and social determinants of health data on a large, inclusive scale and following participants as they move, age, and grow, the *All of Us* dataset is driving new insights into health and disease.

Initial Social Determinants of Health (SDOH) Survey Data

Including:



From 57,600+ responses to SDOH surveys

Figure accurate as of June 2022

QR CODE

To access the publicly available data, scan this QR code and explore the Data Browser and Data Snapshot!

Including the first batch of genomic data



Genomics

Only available via the Controlled Tier



98,600
Whole Genome Sequences



165,200
Genotyping Arrays



593,500,000+
Unique Variants
Represented and searchable through public genomic data browser



Genomics Analysis Tools
Hail and PLINK
in addition to R, Python, and Jupyter Notebooks

Genomic Data is Paired with Rich Phenotypic Data



81,000+
Have Whole Genome Sequences + Electronic Health Records + Physical Measurements + Survey Responses



98,000+
Have Whole Genome Sequences + Physical Measurements + Survey Responses



81,000+
Have Whole Genome Sequences + Electronic Health Records



3,300+
Have Whole Genome Sequences + Fitbit Records
Representing >25% of all participant Fitbit records

And data from the recurring COVID-19 Participant Experience (COPE) survey

COPE Survey Data Currently Available in the Researcher Workbench

More than **100,300** participants responded to

6 one or more of the **six** COPE surveys administered between May 2020 and March 2021



*45,547 participants responded to three or more surveys.

Topics Covered

- Social Distancing Experiences
- COVID-19 Related Impact
- Mood
- Substance Use
- COVID-19 Related Symptoms
- General Well-Being
- Stress
- Resilience
- COVID-19 Related Testing
- Social Support
- Physical Activity
- Discrimination
- COVID-19 Related Treatment
- Anxiety
- Loneliness
- Vaccine Perceptions

Mental Health

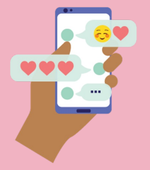
The COPE data represents the biggest infusion of mental health data into the Researcher Workbench so far. Insights include:



62% felt bothered by sleeping problems



53% felt nervous and anxious



94% have someone to love and make them feel wanted



95% have someone to have a good time with

Embedded in the survey were resources for participants struggling with emotional distrress, including suicide prevention tools.

*Participants could select multiple symptoms.

And making them accessible to researchers across stages and settings

Our Researchers



3,930+

Registered Researchers

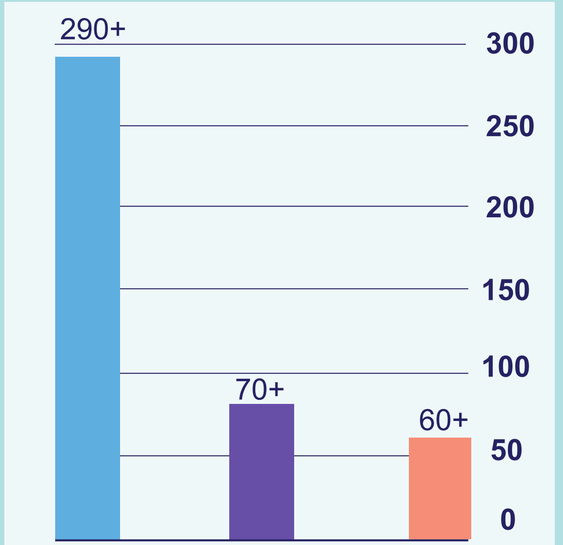
across a range of institutional roles and career stages



450+

Institutions





***Includes 60+ Historically Black Colleges and Universities and Hispanic-Serving Institutions.**

Figures accurate as of January 2023

Figures accurate as of September 2022

Research Currently Underway



3,310+

Active projects



115+

Publications in peer-reviewed journals



Top conditions being studied

In the Researcher Workbench include:

- Cardiovascular disease
- Hypertension
- Mental Health
- Cancer
- Diabetes

Figures accurate as of January 2023

2023 Goals: Pediatric Data

NIH's *All of Us* Research Program Selects First Director of Pediatrics

October 5, 2022

Sara Van Driest, M.D., Ph.D., tapped to lead pediatric enrollment for the program

The National Institutes of Health's *All of Us* Research Program has selected Sara Van Driest, M.D., Ph.D., to serve as the program's first director of pediatrics. In this position, she will help set the foundation for how people under the age of 18 can participate in this landmark precision medicine effort.

"Dr. Van Driest's expertise as a pediatrician and researcher is matched by her vision for the future of pediatric precision medicine," said Holly Garriock, Ph.D., chief cohort development officer. "Including children and adolescents in *All of Us* will provide researchers the tools to better understand how various factors influence health across the lifespan, as well as advance our knowledge of children's health and health care."



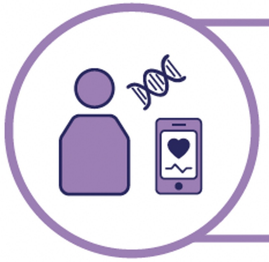
Sara Van Driest, M.D., Ph.D

All of Us RESEARCH PROGRAM

Data Access and Analytical Tools

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 identifiers removed. Public resources include:

- **Data Snapshots:** Aggregated, public-facing overviews of participant characteristics and data types
- **Data Browser:** Interactive preview into the larger *All of Us* dataset through public-facing aggregate data
  - Currently includes participant-provided information such as surveys and physical measurements taken at the time of participant enrollment as well as electronic health record (EHR) data
- **Survey Explorer:** Collection of participant survey questions and source information
- **Research Projects Directory:** Information about each research project within the Researcher Workbench

RESEARCHER WORKBENCH

Available to registered researchers

Registered Tier

Registered users can access curated, individual-level data and a variety of research tools to conduct a wide range of studies **and NEW data** including:

- Initial Social Determinants of Health (SDOH) data
- Additional COVID-19 EHR data



Surveys | Electronic Health Records | Physical Measurements | Wearables

Data have been processed to protect participant privacy

Controlled Tier

Registered users with amended institutional agreements can access **all of the data in the registered tier plus**

- Expanded demographics
- Unshifted event dates
- Genomic data derived from WGS (~100k participants) and array genotyping (165,200 participants)
- CRAM files which complement the genomic variant calls and enable capabilities such as custom variant evaluation and visualization
- intensity files (iDat) for custom array analyses beyond variants

Access and Security

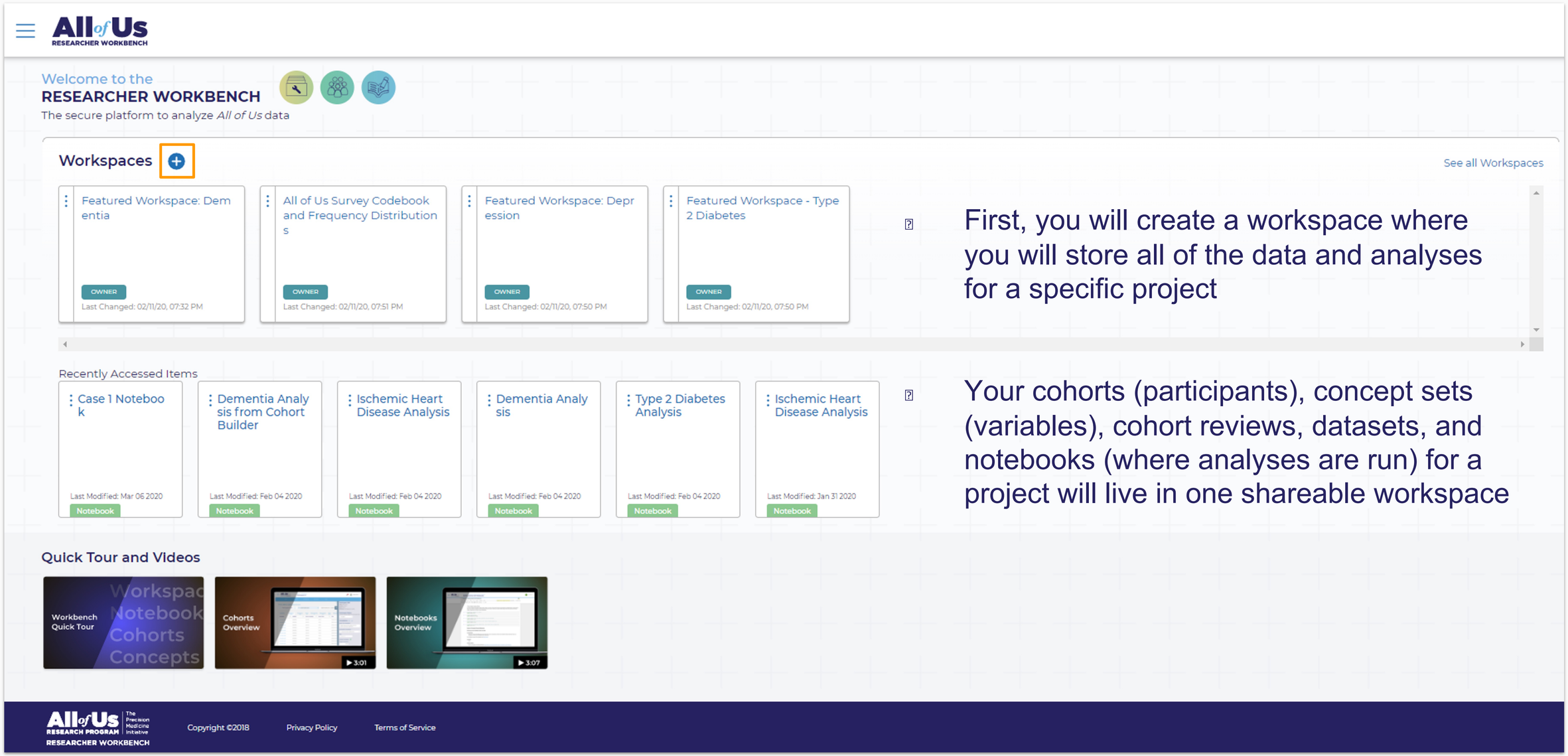
- *All of Us* employs a “data passport” model for this access tier, to grant researchers broad permission to explore the data for a wide range of studies

- Beta testing access is available to researchers with eRA Commons accounts *if* their institutions have signed a data use agreement. In the future, we’ll open the platform more broadly.

- To facilitate collaboration and keep participant data secure, the Researcher Workbench is hosted in a Cloud-based system
  - All tools and data are in one place
  - Data downloads onto your local machine are not allowed
  - During the Beta testing phase, researchers will receive free credits to cover computing and storage costs



Workspace



First, you will create a workspace where you will store all of the data and analyses for a specific project

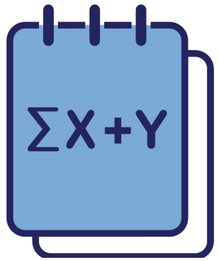
Your cohorts (participants), concept sets (variables), cohort reviews, datasets, and notebooks (where analyses are run) for a project will live in one shareable workspace

Powerful analytical tools & user support



WORKSPACES

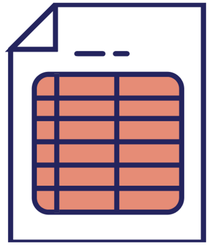
USES:
- Organizing research projects
- Collaboration
- Transparency



NOTEBOOKS

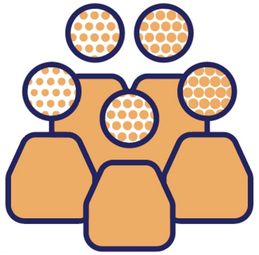
USES:
- Analyses
- Queries

Uses programming languages R and Python



DATASET BUILDER

USES:
- Pre-populated analyses
- Dataset previews



COHORT BUILDER

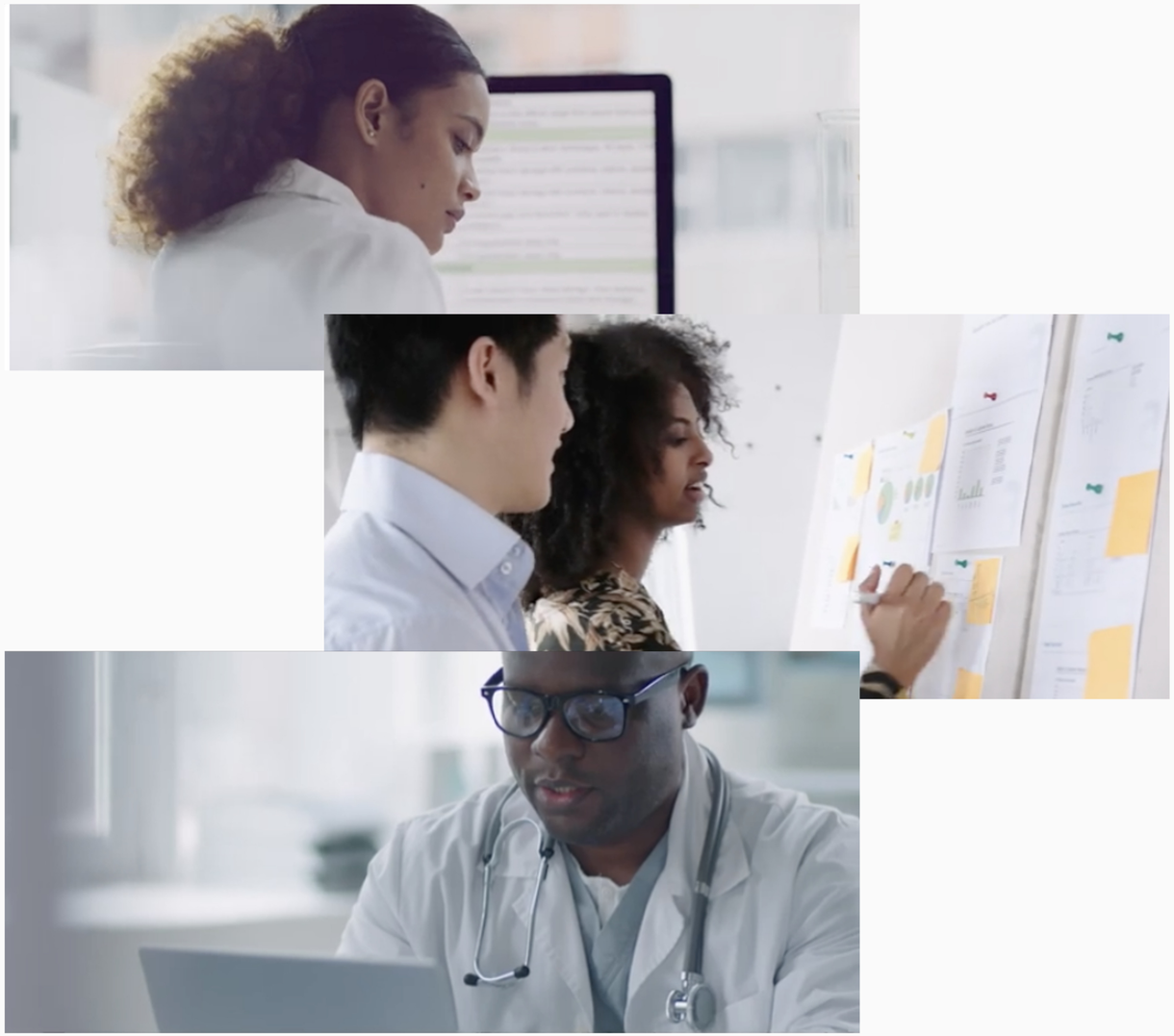
USES:
- Cohort creation



USER SUPPORT HUB

USES:
- Workbench training and resources
- Articles on Data and Tools
- Live office hours

Building a diverse researcher cohort



- **Creating a demographically diverse researcher cohort** that promotes responsible and ethical use of data, returns value to participant communities, and accelerates research impact.
- **Encouraging student assemblies 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.

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

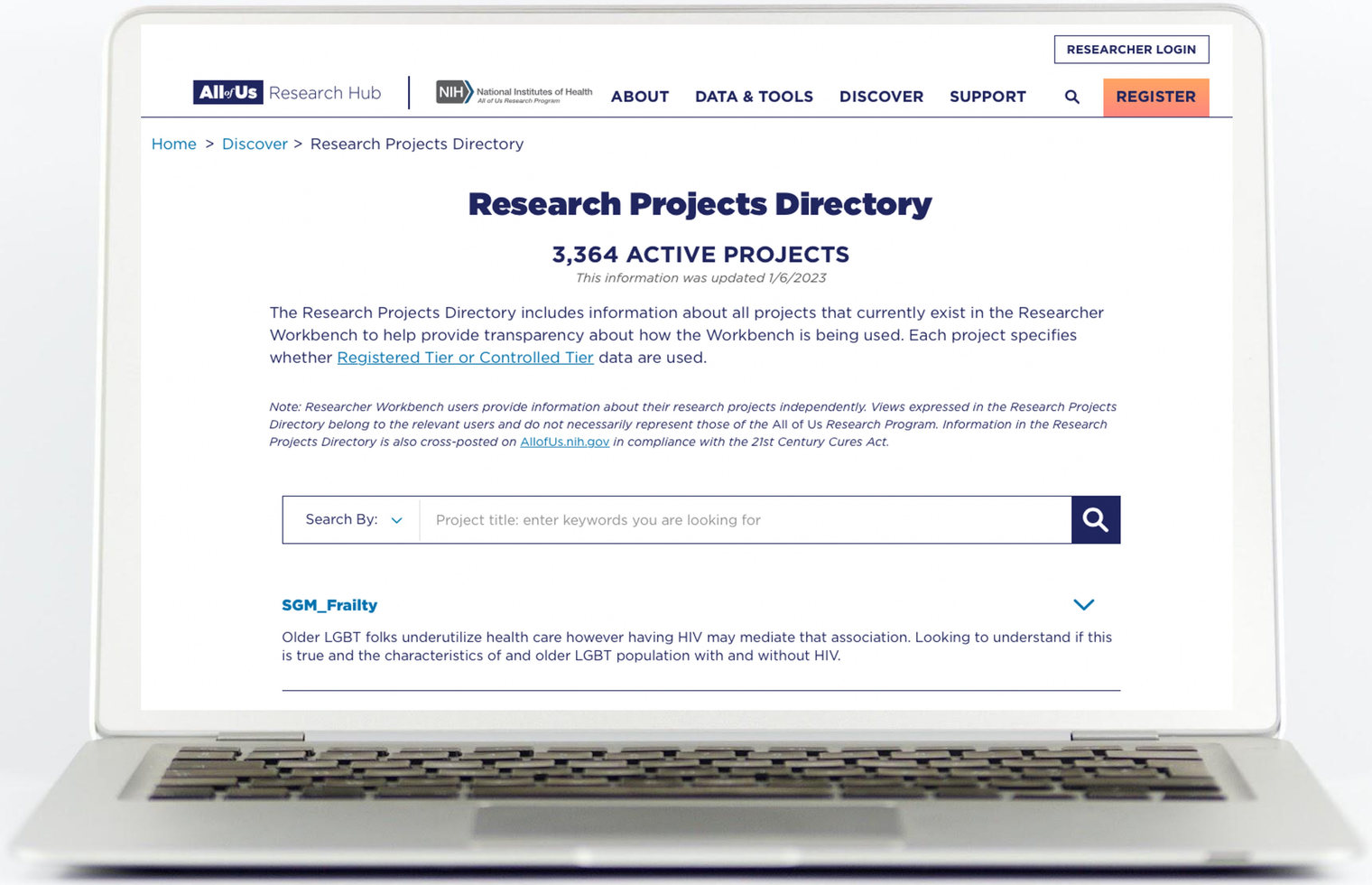
STEP 6

SIGN DATA USER CODE OF CONDUCT

allof-us.org/Register

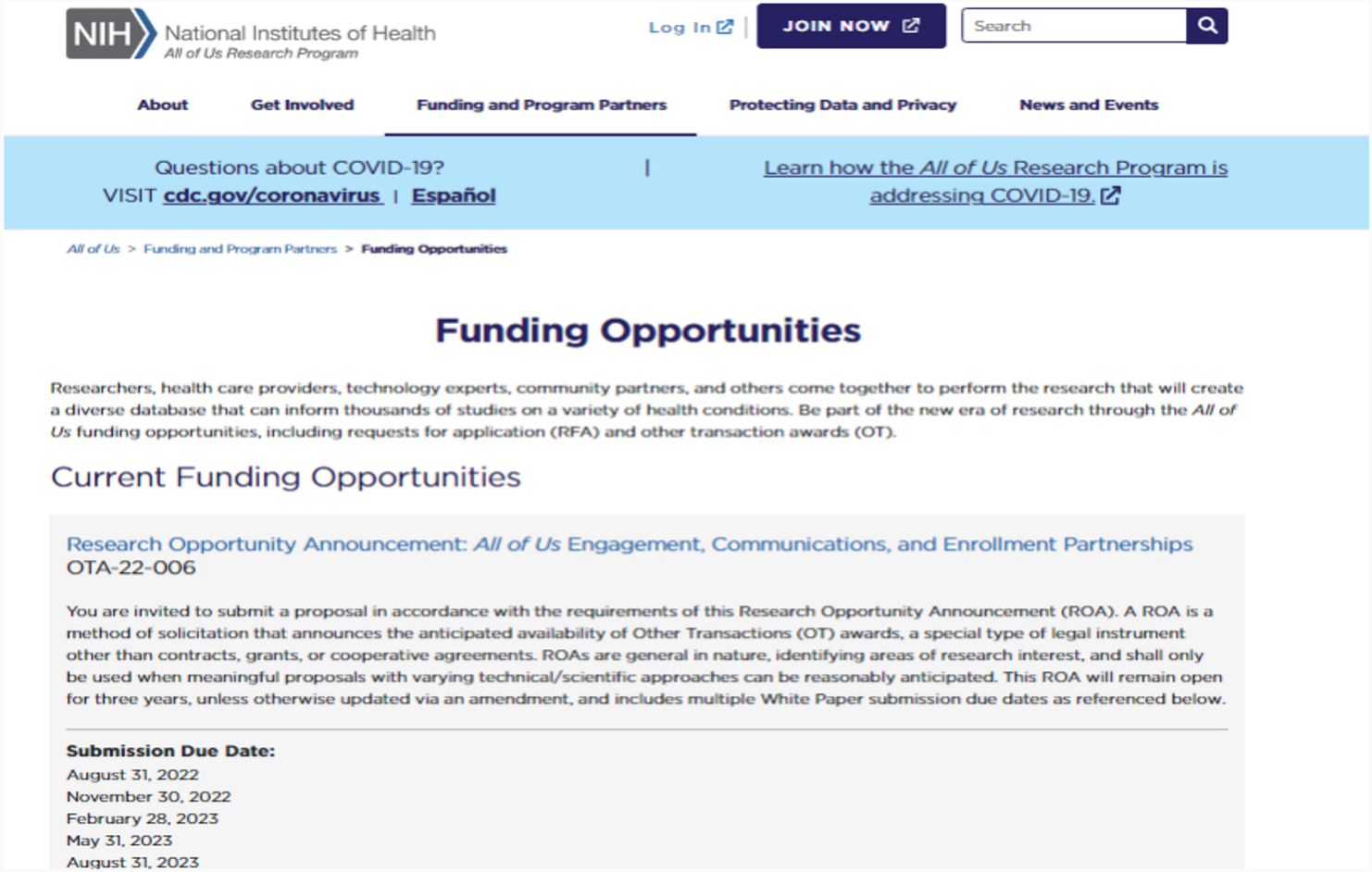
Projects

Explore how other researchers are using the data



researchallofus.org/research-projects-directory

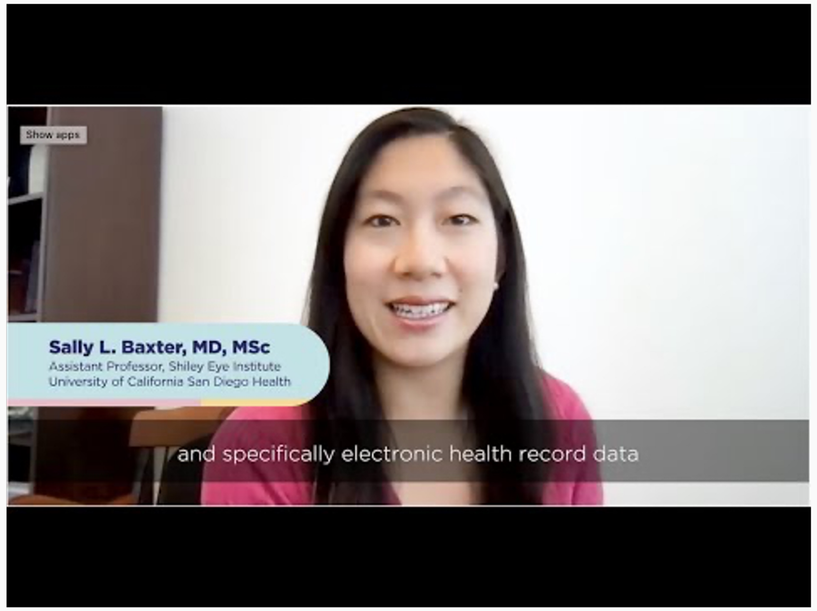
NIH Grants available



https://allofus.nih.gov/funding-and-program-partners/funding-opportunities

Testimonials from registered researchers

Predictive analytics for glaucoma



Sally Baxter, MD, MSc
Assistant Professor, Shiley Eye Institute
University of California San Diego Health

How diverse data can power more impactful research



Jason Karnes, PharmD, PhD, BCPS, FAHA
Director of Scientific Programs
University of Arizona/Banner Health

Studying health care access and utilization among adult cancer survivors



Jie Chen, PhD
Professor and Division Chief,
Biostatistics and Data Science
Medical College of Georgia, Augusta University

All of Us Community and Provider Partner Network *(as of August 2022)*



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

All of Us Consortium Members *(as of August 2022)*

The Participant Center

Scripps Research Translational Institute · BlueCross BlueShield · SENSIS · SageBionetworks · owaves · Walgreens · MAYO CLINIC · Dedalus · Medscape · Bloodworks Northwest · CVS Health · Blood Assurance · Gulf Coast Regional Blood Center *Commit for Life.* · careevolution · WebMD · active minds · patientslikeme · South Texas Blood & Tissue · Cascade Regional Blood Services · ACHA American College Health Association · SYNC FOR SCIENCE · Quest Diagnostics · San Diego Blood Bank · National Blood Collaborative · fitbit · Mary's Center

Communications & Engagement

WONDROS · PYXISPARTNERS · RTI INTERNATIONAL · THE UNIVERSITY OF UTAH

HPO Network

(Health Care Provider Organizations)

HPO Lite

UTHealth · 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 University HealthSystem · RUSH · The University of Illinois College of Medicine · UI Health · Cook County Health

All of Us New England

Brigham and Women's Hospital (Founding Member, Mass General Brigham) · Massachusetts General Hospital (Founding Member, Mass General Brigham) · Mass General Brigham · Boston Medical Center

Trans America Consortium

Henry Ford Health System · Spectrum Health · Essentia Health · BaylorScott&White Health · RELIANT MEDICAL GROUP (Part of OptumCare®) · HealthPartners Institute

New York City Consortium

COLUMBIA · Weill Cornell Medicine · NYC Health+ Hospitals | Harlem · NewYork-Presbyterian

All of Us Southern Network

UAB Medicine · USA Health · UAB Heersink School of Medicine · Cooper Green Mercy Health Services Authority · Tuskegee University · The University of Mississippi Medical Center · LSU Health New Orleans · Tulane University

All of Us Southeast Enrollment Center

UHealth University of Miami Miller School of Medicine · Emory University · Morehouse School of Medicine · 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 Community Health Center

FQHCs (Federally Qualified Health Centers)

Cherokee · Jackson-Hinds Comprehensive Health Center · San Ysidro Health · Waianae Coast Comprehensive Health Center · Community Health Center, Inc. · Sun River Health

VA Medical Centers

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

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 Department of Molecular & Human 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

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allof-us.org/RRSignup

Thank You!

All of Us RESEARCH PROGRAM

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