

# About the *All of Us* Research Program and the Researcher Workbench



Last Updated: AUGUST 2023
Name, Job Title



# 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: Pyxis Partners is funded by the Division of Engagement and Outreach, *All of Us* Research Program, National Institutes of Health, Award Number: OD028404



# What is the All of Us Research Program?



### One of the world's largest, most diverse biomedical datasets of its kind





75% identify with communities underrepresented in biomedical research





45% are from racial and ethnic minority groups

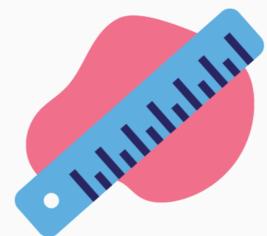


### By securely capturing a range of different data types

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



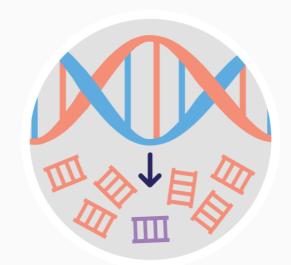
337,500+ **Physical Measurements** 



312,900+ Genotyping Arrays



287,000+ **Electronic Health** Records



245,350+ **Whole Genome** Sequences (WGS)



15,600+ **Fitbit** Records **NEW! Sleep Data** 









# And data from the COVID-19 Participant Experience (COPE) Survey

# **COPE Survey Data Currently Available** in the Researcher Workbench More than 100,200+ participants responded to one or more of the six COPE surveys administered between May 2020 and February 2021

#### **Topics Covered**



**Social Distancing Experiences** 

**COVID-19 Related** 

**Symptoms** 

COVID-19

**Related Testing** 

**COVID-19 Related** 

**Treatment** 



**COVID-19 Related** 

**General Well-Being** 

**Social Support** 

**Anxiety** 



Mood



Substance



**Stress** 

**Physical Activity** 

Loneliness



Resilience

**Discrimination** 

Vaccine

**Perceptions** 



94%

### **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



felt nervous and anxious





have someone to love and make them feel wanted

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



Data as of April 2023

# Along with the Social Determinants of Health Survey

By 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.

#### Social Determinants of Health (SDOH) Survey data













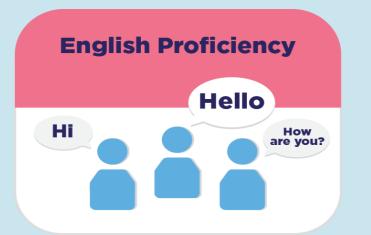














from 117,750+ responses

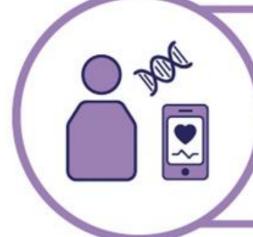


# Data Access and Analytical Tools



# 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.

- researchallofus.org/data-tools/ survey-explorer
- <sup>2</sup> databrowser.researchallofus.org



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



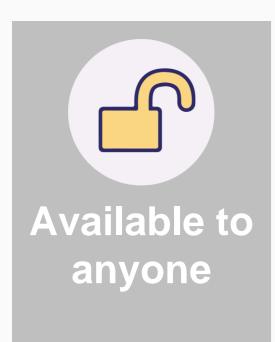
5. Registered researchers in the Researcher Workbench can create research projects using collaborative workspaces, cohort-building tools, interactive notebooks, and more.



- 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**.<sup>2</sup>
- researchallofus.org/research-projectsdirectory
- <sup>2</sup> researchallofus.org/publications



### 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:

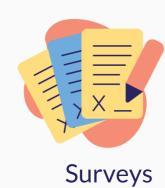
- Data Snapshots: Aggregated, public-facing overviews of participant characteristics and data types
- Data Browser: Interactive preview into the *All of Us* dataset through public-facing aggregate data
  - Currently includes participant-provided survey responses, physical measurements, data from EHRs 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



Reseacher 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.







Wearables

Physical Measurements

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.





# All of Us Community and Provider Partner Network (as of April 2023)

















































































































# Subscribe to the Researcher Newsletter

Sign up to receive our email newsletter with the latest news and insights from the All of Us Research Hub.

# allof-us.org/RRSignup



# Thank You!













@AllofUsResearch #JoinAllofUs

