

Mental Health Data in the *All of Us* Research Program: Opportunities for Participants and Researchers



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April 17, 2023

Agenda

1. Introduction to *All of Us*
2. Mental health data collection in *All of Us*
3. Researchers using mental health data
4. Returning value to participants
5. Opportunities for partnership with *All of Us*



[Register as a participant](#)



[Register as a researcher](#)

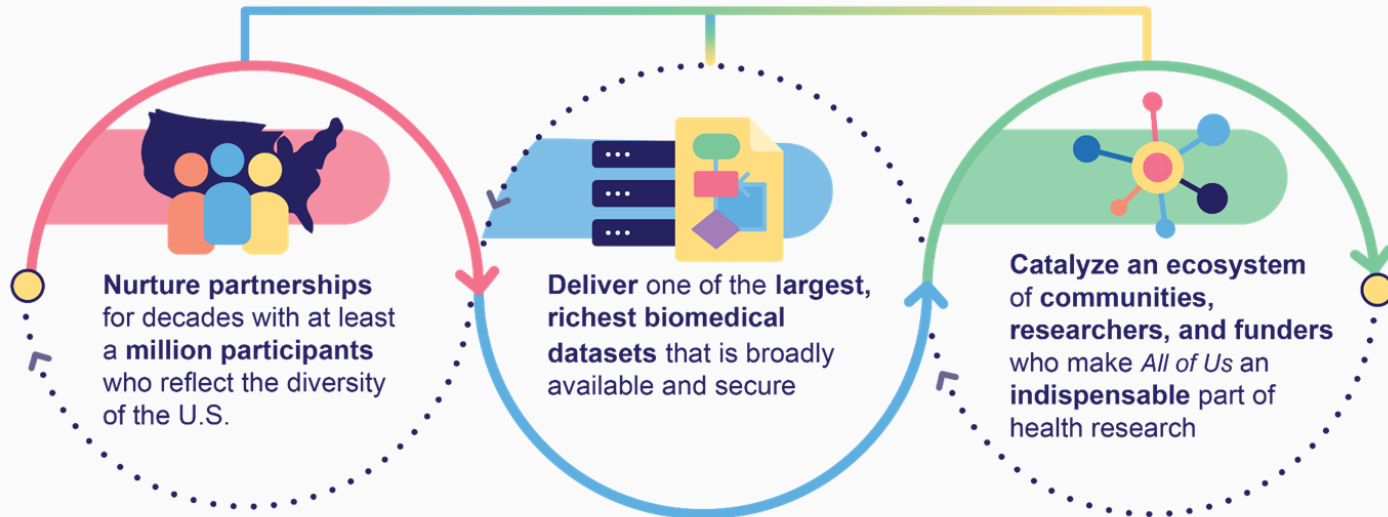
Our goals today:

- Provide the Friends of NIMH with insight into how the *All of Us* Research Program is working to advance mental health research
- Discuss opportunities for partnership between the Friends of NIMH and the *All of Us* Research Program

What is the *All of Us* Research Program?

The *All of Us* Research Program mission

Accelerate health research and medical breakthroughs,
enabling individualized prevention, treatment, and care for all of us



Made possible by a team that maintains a culture built around the program's core values

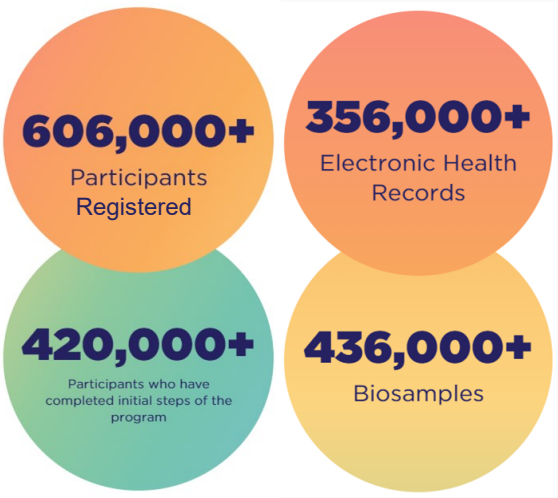
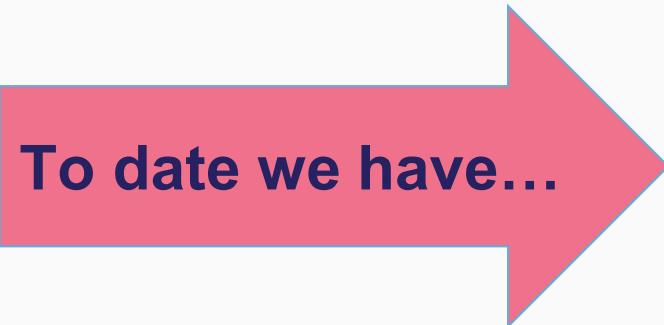
Enrolled 420K+ participants with promise for growth

Inviting

1 Million

or more people
across the United
States

to partner
long-term with
the program.



Numbers current
as of March 1,
2023

Our commitment to participant diversity at *All of Us*

Of the 1 million participants,

75%

will be from communities that are Underrepresented in Biomedical Research (UBR)

and

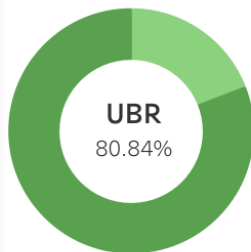
50%

will be UBR by race/ethnicity

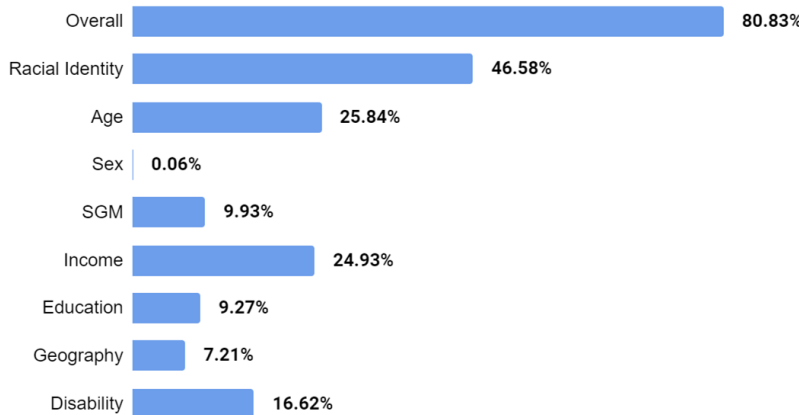


As of April 2023...

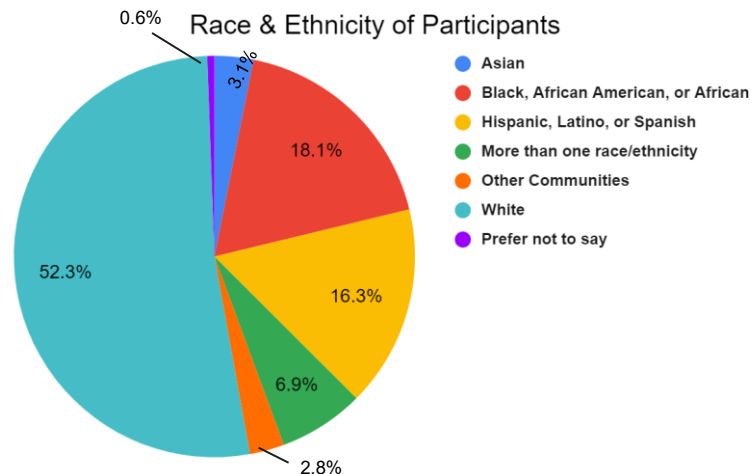
Overall UBR %



Participant Diversity by Category



Race & Ethnicity of Participants



All of Us has set out to be one of the largest, richest, most diverse biomedical datasets of its kind

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 March 2023

NEWS FLASH

The April 2023 Researcher Workbench data refresh will increase the program's collection of whole genome sequencing data to *nearly a quarter million whole genome sequences*, making the *All of Us* dataset the world's largest, most diverse genomic dataset of its kind available for wide use. The expanded dataset will include *information from more than 413,450 participants*, also including data from surveys, electronic health records, DNA, physical measurements, and Fitbit devices.

A wide array of data types available in the Researcher Workbench enables unique opportunities for layered inquiry across diverse participant populations



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 358,000+ participant)
Standardized to OMOP common data model



Genomics

(Nearly 100,000 whole genome sequences) and 165,200 shorter DNA samples known as genotyping arrays



Physical Measurements

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



Biosamples

(from 442,000+ participants)

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

What kind of research can *All of Us* support?

Example studies in *All of Us*

- Associations between diseases, medications, behaviors, SDOH, genomics
- Health disparities
- Historically underrepresented populations
- Genomics and PGx (soon)
- Drug target discovery
- Early disease detection
- Geospatial linkages (future)
- ***Insert your topic here***

Modalities of research *All of Us* supports

- AI/ML
- Risk stratification
- Predictive analytics
- Phenotype algorithms & cohort development
- Novel method development
- Basic EHR investigations
- Validation of other studies

All of Us is not

- A representative US sample
- A study with uniform follow-up of all variables for all participants

What mental health data does the *All of Us* Research Program collect?

Primary sources of mental health data for *All of Us*

“Exploring the Mind”

- Game-like ‘tasks’ for participants to complete
- Objective, behavioral assessments
- Aligned with NIMH’s RDoC initiatives
 - Spans 3 constructs
- In pilot phase currently



Self-Report Surveys

- Personal and Family Health History
- COVID-19 Participant Experience (COPE)
- Social Determinants of Health (SDOH)
- Two new mental health surveys coming soon!



Electronic Health Records

- OMOP Common Data Model used to standardize data
- 4 searchable EHR domains: conditions, drug exposures, labs and measurements, procedures



Exploring the Mind

What is Exploring the Mind?

- Exploring the Mind (EtM) is one of *All of Us*' first ancillary studies and is a strategic partnership with the National Institute of Mental Health's Research Domain Criteria (RDoC) Unit. NIMH and *All of Us* have co-designed this effort.
- The goal of this project is to allow participants to complete behavioral tasks in the Participant Portal. These tasks measure aspects of behavior like reward, social processing, and attention.
- This data will be useful for mental health, behavioral health, and cognition research.

Demo tasks: [here](#)

The strength of *All of Us* is that our hundreds of thousands of participants reflect the deep diversity of people living in the U.S. These people live in different circumstances and different environments and are at different life stages. Data from EtM may help researchers find patterns about how our minds work across these differences.

Exploring the Mind: Current Status

- Exploring the Mind launched 4 tasks on **December 15, 2022** to a representative cohort of 10K participants. Phased communications were sent until we reached our goal of 400 unique completions per task for quality analysis.
- A 5th task was added for another round of communications which invited an additional 5K participants.
- Following quality analysis, 4 tasks will be made available to all participants. The Probabilistic Reward task did not show expected scientific effects, and will be removed.

Flanker

Flanker Test



Can you ignore distractions?

[Click here for instructions](#)

Delay Discounting

1 of 46

Receive \$5 right away OR wait *five minutes* and receive \$1000.

I'd rather receive...



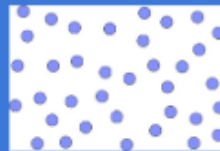
\$5 now



\$1000 in *five minutes*

[Next](#)

Probabilistic Reward



Were there more or less than 24 dots?

LESS

MORE

Face Emotion Recognition



Gradual Onset Continuous Performance



Exploring the Mind Task Information

Task	RDoC Construct	Completions (As of 4/10/23)
Facial Emotion Recognition Task	Social Processes /Social Communication/ <i>Reception of Facial Communication</i>	935
Probabilistic Reward Task*	Positive Valence /Reward Learning/ <i>Probabilistic and Reinforcement Learning</i>	689
Gradual Onset Continuous Performance Task	Cognitive Systems /Attention; Cognitive Systems /Cognitive Control/ <i>Probabilistic and Reinforcement Learning</i>	802
Delay Discounting Task	Temporal discounting, monetary decision making, reward valuation	767
Flanker Task	Attention, cognitive control	690

*Probabilistic Reward task did not show expected scientific effects, and will be removed

Participant Provided Information Surveys

Personal and Family Health History Survey: data from >300k participants

Have you or anyone in your family ever been diagnosed with the following mental health or substance use conditions?

- Alcohol use disorder
- Anxiety /panic disorder
- Attention-deficit/hyperactivity disorder (ADHD)
- Autism spectrum disorder
- Bipolar disorder
- Depression
- Drug use disorder
- Eating disorder
- Personality disorder
- Post-traumatic stress disorder (PTSD)
- Schizophrenia
- Social phobia
- Other mental or substance use condition

Branching questions

- Family members (parents, grandparents, brothers, sisters, children)
- Actively seeing a doctor for disorder
- Age of onset
- Currently prescribed medications or receiving treatment



Covid-19 Participant Experience (COPE) Survey: data from >104k participants

- May 7, 2020 through March 5, 2021

6 surveys (program's first longitudinal survey collection)

16 domains (including GAD-7, PHQ-9)

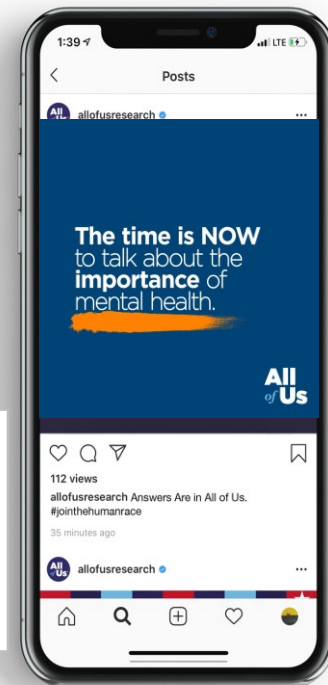
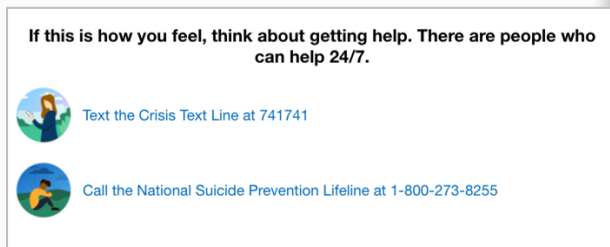
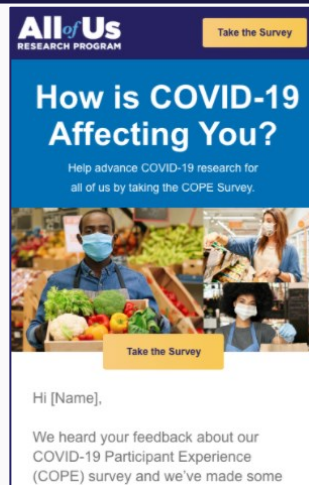
104,910 (30.7%) participants who completed 1 or more COPE surveys

- 2 Stakeholder toolkits
- 3 Stakeholder trainings
- 893,016 Social media impressions

207,839 Engagements

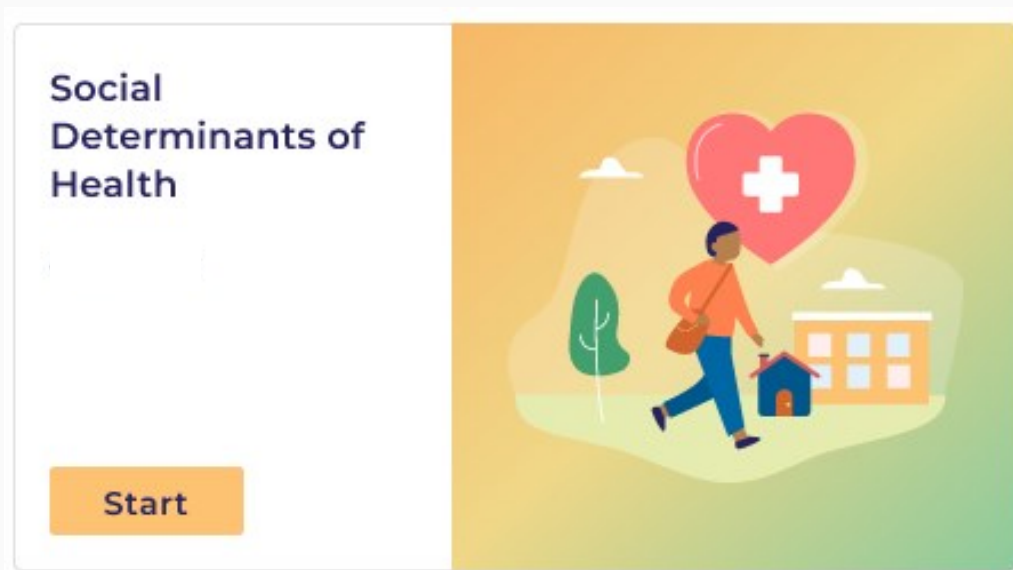
454,413 Video views

Popups with crisis resources were provided to participants that responded to PHQ-9-9 indicating any risk of suicide. In all, they were displayed 15,571 times across all survey versions (average of 5.5% of respondents were shown the popup in any month).



Social Determinants of Health: data from >57K* participants

Domain
Neighborhood Safety
Built Environment-Walkability
Social Support
Loneliness
Perceived Discrimination
Health Care Discrimination
Food Insecurity
Housing Insecurity
Perceived Stress
Daily Spiritual Experiences
Religious Service Attendance
English Proficiency

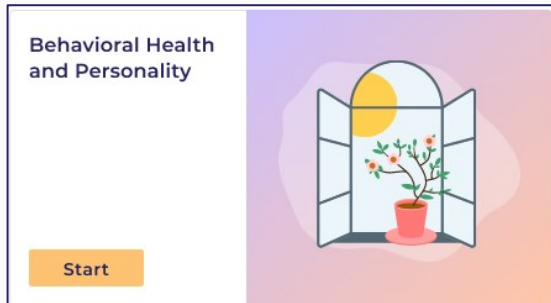


81 questions across 12 subject matter domains; time to completion is 12 minutes in English and Spanish

*In next release data will significantly increase to 117,750+

Coming soon: surveys on mental health and well-being

Two 10-minute mental health surveys are planned for release in June 2023.



Emotional Health History and Well-Being	Behavioral Health and Personality
1. Generalized and lifetime anxiety <i>(Feelings of general anxiety and worry)</i>	1. Adult ADHD <i>(Attention and focus)</i>
2. Present and past depression <i>(Mood and sadness)</i>	2. Bipolar disorder <i>(Shifts in mood, energy and activity)</i>
3. Suicidal behavior <i>(Self-harm)</i>	4. Psychosis <i>(Unusual experiences and perceptions)</i>
4. Childhood and adult adversity/trauma <i>(Experiences with trauma)</i>	3. Panic disorder <i>(Experiences of panic and anxiety)</i>
5. General well-being <i>(General well-being)</i>	5. Obsessive compulsive disorder <i>(Recurring thoughts and behavior)</i>
<i>Italicized section headers are the participant-facing descriptors.</i>	6. Social phobia and agoraphobia <i>(Feeling of fear in certain situations)</i>
	7. Personality <i>(Personality traits)</i>
Total questions (no branching): 46 Total questions (fully branched): 93	Total questions (no branching): 35 Total questions (fully branched): 55

NIMH and their Friends have supported us along the way

NIMH and partner organizations have been integral to the mental health efforts at *All of Us* from the beginning:

Exploring the Mind

- The NIMH RDoC team has been a partner in the Exploring the Mind effort
- Attend monthly touch-base meetings and weekly IPT meetings
- Co-designed our EtM pilot structure
- Provided feedback on draft protocol and participant materials
- Continue to provide guidance and subject matter expertise as we move through the pilot

Surveys on Mental Health and Well-Being

- NIMH colleagues actively participated in the survey-writing task force
- Provided insights into appropriate language to use regarding mental illnesses and conditions
- Reviewed and provided input into communications materials
- Attend weekly project team meetings (ongoing)
- *All of Us* PI, Survey Task Force co-chair, and distinguished psychiatrist Jordan Smoller will be participating in a NAMI 'Ask the Expert' panel on June 15th, 2023



How are researchers using the *All of Us* mental health data?

Data on the Researcher Workbench is Diverse and Longitudinal



329,000+ Participants



267,600+ Physical Measurements



214,200+ EHRs



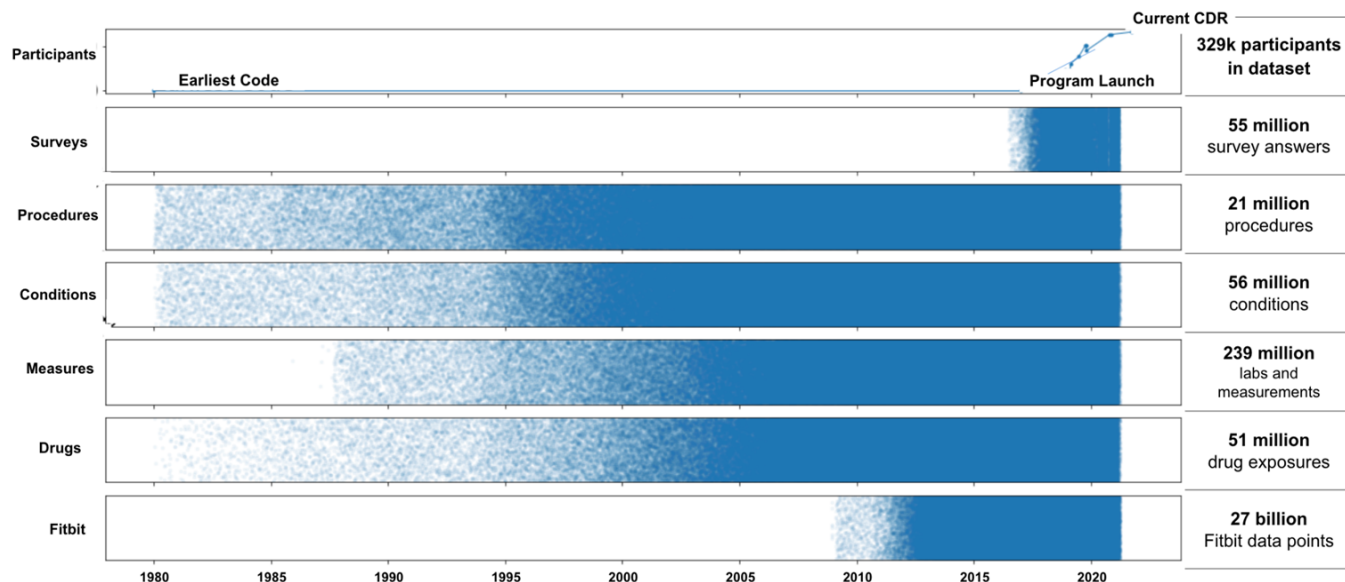
329,000+ Surveys



11,600+ Fitbit Records



98,600+ Whole Genome Sequences



Reminder: these are the data types that are available for researchers to use.

Types of data available to researchers

Search Across Data Types



Keyword Search



FAQs



Introductory
Videos



User Guide

Data includes 372,380 participants and is current as of 6/6/2022.

EHR Domains

Conditions

24,315

medical concepts

227,740 participants in this domain

[View Conditions](#)

Drug Exposures

29,166

medical concepts

214,040 participants in this domain

[View Drug Exposures](#)

Labs & Measurements

15,309

medical concepts

227,280 participants in this domain

[View Labs & Measurements](#)

Procedures

29,176

medical concepts

221,860 participants in this domain

[View Procedures](#)

Survey Questions

The Basics

28

questions available

372,380 participants in this domain

This survey includes participant demographic information.

[View Complete Survey](#)

Overall Health

21

questions available

372,380 participants in this domain

Survey includes information about how participants report levels of individual health.

[View Complete Survey](#)

Lifestyle

26

questions available

372,380 participants in this domain

Survey includes information on participant smoking, alcohol and recreational drug use.

[View Complete Survey](#)

Personal Medical History

465

questions available

142,100 participants in this domain

This survey includes information about past medical history, including medical conditions and approximate age of diagnosis.

[View Complete Survey](#)

Genomics

Genomic Variants

98,560

participants in the Whole Genome Sequencing (WGS) dataset

165,080

participants in the Genotyping Array dataset

[View Genomic Variants](#)

Physical Measurements and Wearables

Physical Measurements

8

Physical Measurements

311,300 participants in this domain

Participants have the option to provide a standard set of physical measurements.

[View Physical Measurements](#)

Fitbit

4

Fitbit Measurements

12,880 participants in this domain

Fitbit data includes heart rate and activity summaries.

[View Fitbit](#)

Health Care Access & Utilization

57

questions available

160,880 participants in this domain

Survey includes information about a participant's access to and use of health care.

[View Complete Survey](#)

Family Health History

104

questions available

145,620 participants in this domain

Survey includes information about the medical history of a participant's immediate biological family members.

[View Complete Survey](#)

COVID-19 Participant Experience (COPE)

191

questions available

100,320 participants in this domain

Survey includes information about the impact of COVID-19 on participant mental and physical health.

[View Complete Survey](#)

COPE Minute Survey

141

questions available

101,440 participants in this domain

Survey includes information regarding a participant's COVID-19 vaccination experience.

[View Complete Survey](#)

Social Determinants of Health

80

questions available

57,620 participants in this domain

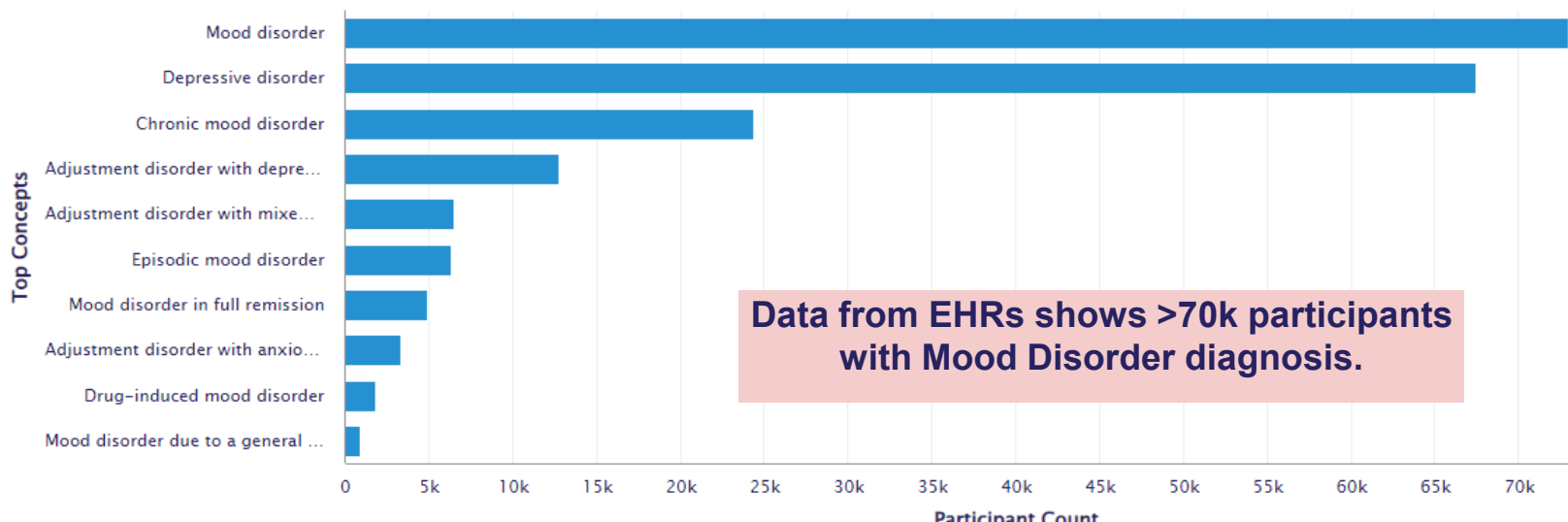
Mental health research by the numbers

3 primary sources of mental health data: surveys, tasks, and EHRs.

More than 120 research projects underway to study “depression” and 85 to study “anxiety.”

More than 14 peer-reviewed publications used *All of Us* Data to explore mental health topics.

Top 10 Conditions by Descending Participant Counts ▾



Data from EHRs shows >70k participants with Mood Disorder diagnosis.

How does *All of Us* return value to participants?

Participant-first, plain language summaries of new *All of Us* publications

All of Us
RESEARCH PROGRAM

Taking at least **8,200 steps a day** may **lower risk for:**

- Depression*
- Sleep Apnea
- Acid Reflux
- Obesity
- Diabetes
- High Blood Pressure

8,200 Steps

*Thanks to the data that *All of Us* participants share, this study found new links between steps and a lower risk for depression, sleep apnea, and acid reflux.

Reference: Master, H., Annis, J., Huang, S. et al. Association of step counts over time with the risk of chronic disease in the *All of Us* Research Program. *Nat Med* (2022).

Explain how data contributed by participants led to the research finding

"This study also used electronic health records (EHRs)."

Thank participants for their contributions

*"Previous research has studied this link for diabetes, high blood pressure, and obesity. Thanks to the variety of data available from All of Us participants, though, this study found new links to lowering risk for acid reflux, **depression**, and sleep apnea."*

Highlight "what's next", invite continued involvement

"The researchers plan to use genomic data from All of Us in their next study. This data will help answer questions about how genes, behavior, and environment can affect health outcomes."

Demonstrate value of diversity and representation

"This study highlights the importance of diversity in health research within underrepresented groups. Including Hispanic, Latino, and Spanish people in research can help us better understand health disparities in these communities."

Reflecting participant-provided insights back to participants

The pandemic brought challenges

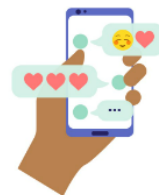


62%
felt bothered
by sleeping problems
(89,429 responses)



60%
felt nervous
and anxious
(129,911 responses)

People found ways to manage through hard times



93%
have someone to love
and make them feel wanted
(87,339 responses)



94%
have someone to
have a good time with
(90,685 responses)

Additional resources

For more information on mental health topics and research: <https://www.nimh.nih.gov/health/index.shtml>
If you or someone you care about needs help,
NIMH Getting Help page: <https://www.nimh.nih.gov/health/find-help/index.shtml>
National Suicide Prevention Lifeline: <https://suicidepreventionlifeline.org/talk-to-someone-now/>

Notes

Survey responses from May 2020 - July 2020
"Sleeping problems" includes trouble falling or staying asleep or sleeping too much.
Percentages include respondents who selected "several days", "more than half of the days", or "nearly every day" within two weeks of responding to the survey

Providing mental health resources at key moments

Where can I find help if I, or someone I love, am in distress or crisis?

If you or someone you know is experiencing emotional distress or a mental health crisis, talk to someone now. [Call or text 988](#).

The 988 Suicide & Crisis Lifeline gives free and confidential emotional support 24 hours a day, 7 days a week. For TTY Users, use your preferred relay service or dial 711 then 988.

The [988 Suicide & Crisis Lifeline](#) also can help you:

- Find a therapist and support group
- Learn how to build and use a support network
- Make a safety plan

For more mental health resources, visit the following:

- 988 Suicide & Crisis Lifeline: <https://988lifeline.org/help-yourself/>
- National Institute of Mental Health: <https://www.nimh.nih.gov/health/find-help>
- Centers for Disease Control and Prevention: <https://www.cdc.gov/populationhealth/well-being/features/how-right-now.htm>
- Substance Abuse and Mental Health Services Administration: <https://www.samhsa.gov/find-treatment>
- Veterans Crisis Line: <https://www.veteranscrisisline.net/>
- MentalHealth.gov: <https://www.mentalhealth.gov/get-help>
- National Domestic Violence Hotline: <https://www.thehotline.org/>
- Rape, Abuse & Incest National Network (RAINN): <https://www.rainn.org/>
- Eating Disorders Helpline: <https://www.nationaleatingdisorders.org/help-support/contact-helpline>

- Following the completion of certain surveys, participants receive an email/SMS thank you message with resources and educational content related to mental health.
- Long term, participants will also have the opportunity to learn more about mental health topics and access additional resources through their Participant Portals.

The screenshot displays the 'All of Us RESEARCH PROGRAM' interface. On the left is a navigation menu with options: Dashboard, My Data, Notifications, Share My Data, Insights, Agreements, Learning Center (highlighted), Settings, and Support. The main content area is titled 'Learning Center > Mental Health and Well-Being'. It features a header for 'Mental Health and Well-Being' with a sub-header 'Support and Advocacy for Mental Health'. Below this, there is a section titled 'What is mental health?' which includes a brief definition and a link to 'Learn more about caring for your mental health' from the National Institute of Mental Health (NIMH). At the bottom of the content area is a 'View More' button. A 'Log out' link is visible in the top right corner.

Returning personalized information of interest to participants via the Big 5 Personality Inventory report

coming soon

- Return of information related to personality
 - The Behavioral Health and Personality Survey will be the first survey to provide a personalized return of information to participants who would like this information
 - The questions and associated report are from a validated survey instrument (BFI-2-XS)
 - Interested participants will receive a Personality Traits Report
- Each trait will be accompanied by an illustration, a description, and a visual of where the participant falls on the scale.

What do your responses say about your personality?

Each of these five traits is a range between two opposing traits. Most people fit somewhere in the middle.

These results report on only five personality traits, so they do not fully reflect who you are. Your traits indicate how you may respond in different situations. How you actually respond will depend on more than just your traits.



Openness

This is how someone feels about new experiences and ideas.

Your answers show that you **sometimes** enjoy new ideas and experiences, but **sometimes** prefer familiar ones.



How can you partner with *All of Us*?

Help us enrich the dataset!

This dataset wouldn't be possible without the generous contributions of our participants. Help us reach our goal of partnering with one million diverse participants in one of three easy ways!

1

Donate your data! Sign up as a participant at JoinAllofUs.org - and encourage your family & friends to join as well!

2

Ask your organization to share information about *All of Us* or link to JoinAllofUs.org from your institutional website.

3

Send an email to employees at your institution letting them know that they can sign up as an *All of Us* participant.



[Register as a participant](#)

We can provide sample text and images and any other resources you may need. Email daozhong.jin@nih.gov to discuss how you can support *All of Us*!



All of Us
RESEARCH PROGRAM

Medical research hasn't always seen you. We're changing that.

Learn more at:
JoinAllofUs.org/fiftyforward
(615) 743-3431

Connect with us!   

All of Us and the *All of Us* logo are service marks of the U.S. Department of Health and Human Services.


Fifty Forward
50+ Years of Progress

Partnership highlight: NRHA continues to expand its work with All of Us Research Program

Author: Lea Hain | Wednesday, Dec. 14, 2022



Since 2018, the National Rural Health Association (NRHA) has been a proud partner of the National Institute of Health's *All of Us* Research Program. From



LULAC Participates in All of Us Program to Diversify Clinical Research

As part of its mission to advance the economic, educational, political, ethnic, housing, health and overall quality of life of the Hispanic population, the Hispanic Leadership and Advocacy Center (LULAC) has been selected to participate in the All of Us Research Program. LULAC will help recruit and engage Hispanic and Latin American individuals in the study. LULAC will also help with the recruitment and retention of participants in the study.

The Hispanic Leadership and Advocacy Center (LULAC) is a national organization that provides leadership and advocacy for the Hispanic and Latin American community. LULAC is committed to promoting the health and well-being of the Hispanic and Latin American community through research, education, and advocacy.

One of the most important factors of the All of Us Research Program is recruiting a diverse group of participants. The program's goal is to have 100,000 participants from communities that have been historically underserved in biomedical research. LULAC will help with the recruitment and retention of participants in the study. LULAC will also help with the recruitment and retention of participants in the study.

Example materials from organizations that have partnered with All of Us. 32
Our team is happy to design customized materials for your organization.

Create an *All of Us* account

Register to be an *All of Us* Researcher



LEARN MORE ABOUT THE DATA AVAILABLE



CHECK FOR YOUR INSTITUTION'S AGREEMENT



REGISTER AS A RESEARCHER



VERIFY YOUR IDENTITY



COMPLETE *ALL OF US* RESPONSIBLE CONDUCT OF RESEARCH TRAINING



SIGN DATA USER CODE OF CONDUCT



allof-us.org/Register

Stay in touch to learn more



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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

Discussion & Questions

Thank You!



National Institutes
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@AllofUsResearch
#JoinAllofUs

Appendix slides