All of Us Research Hub

Presented to AAPA
January 31, 2023

Ashley Green, MLIS
Sr. Research Projects Coordinator
ashley.e.green@vumc.org

All of Us DATA & RESEARCH CENTER

1

Objectives

During today's presentation, we will

- Learn about different the data available
- Explore the Research Hub
- Examine the steps for registration
- See how to start a research project on the Workbench

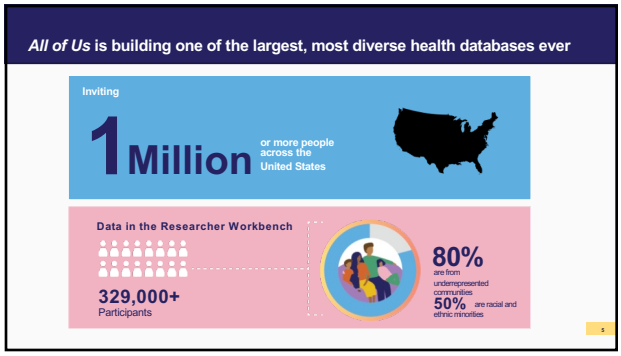
2

Thank you to our participants and community partners!

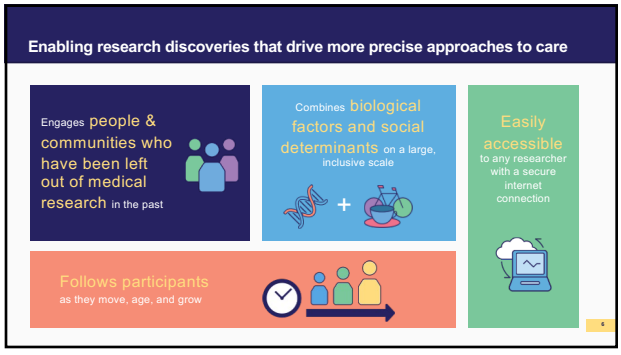
3

Thank you to our consortium partners!
The Participant Center
Communications & Engagement
WONDROS
HPO Network
RMCs
All of Us California
Illinois Precision Medicine Consortium
All of Us New England
Trans America Consortium
New York City Consortium
All of Us Southern Network
All of Us SouthEast Enrollment Center
All of Us Wisconsin
All of Us Pennsylvania
University of Arizona and Banner Health
FQHCs (Federally Qualified Health Centers)
VA Medical Centers
Participant Technology Systems Center (PTSC)
Biobank
Data & Research Center (DRC)
Genomics Partners

4


All of Us is building one of the largest, most diverse health databases ever
Inviting
1 Million
or more people across the United States
Data in the Researcher Workbench
329,000+
Participants
80%
are from underrepresented communities
50%
are racial and ethnic minorities

5

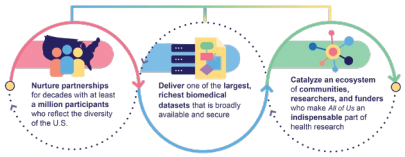

Enabling research discoveries that drive more precise approaches to care
Engages people & communities who have been left out of medical research in the past
Combines biological factors and social determinants on a large, inclusive scale
Easily accessible
to any researcher with a secure internet connection
Follows participants
as they move, age, and grow

6

All of Us Mission

Our 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

7

Participants included in All of Us research data are diverse.

Underrepresented in Biomedical Research (UBR) Categories	Curated Data (% out of 372,380 participants)
At least one UBR	78%
Non-white race or Hispanic/Latino ethnicity	44%
Age >= 65	24%
Less than GED	9%
Annual Income <=$25k	26%
Sexual and Gender Minorities	10%
Rural Location	7%

8

Key takeaways for registered users

372,397 Survey Responses

306,179 Physical Measurements

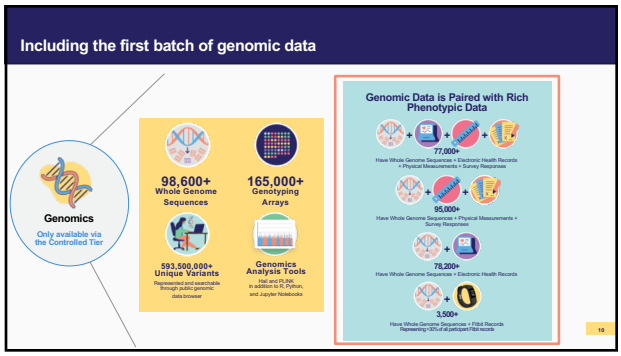
258,415 Electronic Health Records (EHR)

165,072 Genotyping Arrays

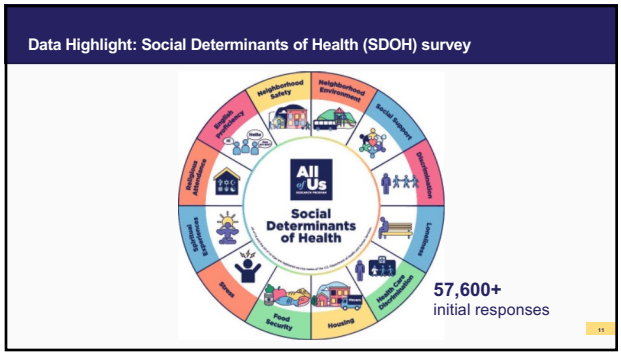
98,558 Whole Genome Sequences

12,844 Fitbit Records

9


Including the first batch of genomic data
Genomics
Only available via the Controlled Tier
98,600+
Whole Genome Sequences
165,000+
Genotyping Arrays
593,500,000+
Unique Variants
Genomics Analysis Tools
Genomic Data is Paired with Rich Phenotypic Data
77,000+
95,000+
78,200+
3,500+

10

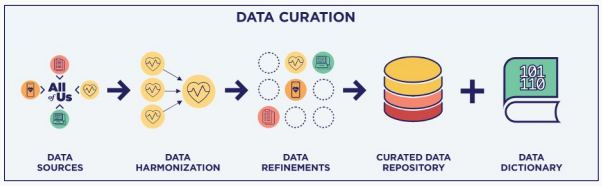

Data Highlight: Social Determinants of Health (SDOH) survey
All of Us
Social Determinants of Health
57,600+
initial responses

11

Principles of access & privacy: "Share widely and wisely."
Broad and Open Access
Commitment to Protecting Privacy
"'make my data useful"
A data resource for all of us
Remove unnecessary barriers to access
"keep my data safe"
Privacy first, privacy always
Strive to build a system that participants can trust

12

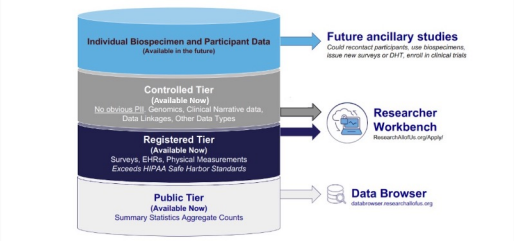
All of Us Research Data Pipeline



13

13

Data and resource access is tiered.



14

14

Distinguishing between the Registered and Controlled Tier

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.

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 and NEW data** including:

- Expanded demographics
- Responses to entire COPE Survey
- COVID-19 EHR data
- Unshifted event dates
- Genomic data derived from WGS (~100k participants) and array genotyping (>165k participants)

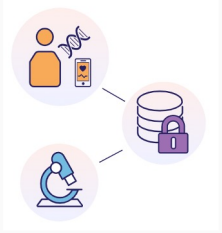
15

The Research Hub

https://www.researchallofus.org/

16

Researchallofus.org is home to *All of Us* data, research tools, & projects.

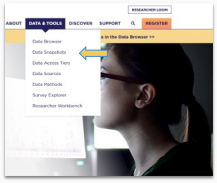


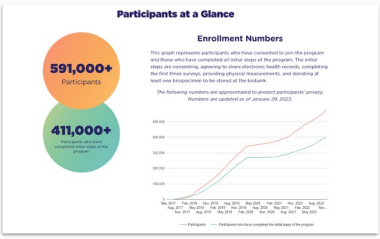
"The Public Website"

"The Workbench"

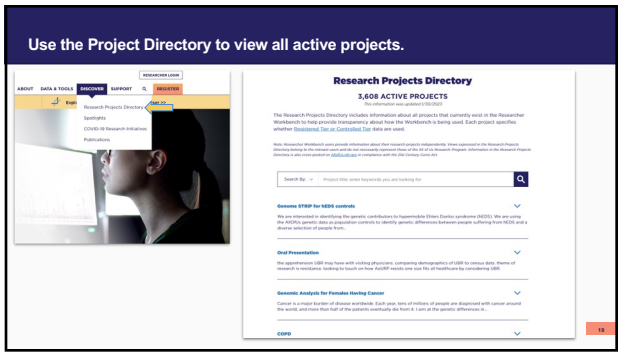
17

Data Snapshot provide an overview of participant data.

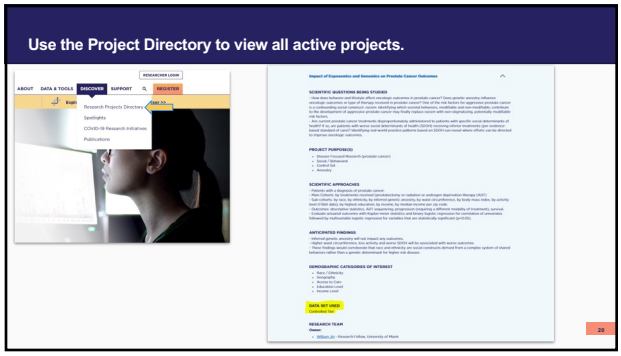




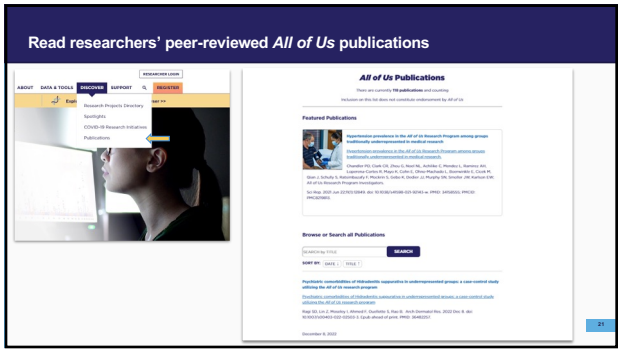
18


Use the Project Directory to view all active projects.
Research Projects Directory
3,608 ACTIVE PROJECTS

19


Use the Project Directory to view all active projects.

20


Read researchers' peer-reviewed All of Us publications
All of Us Publications

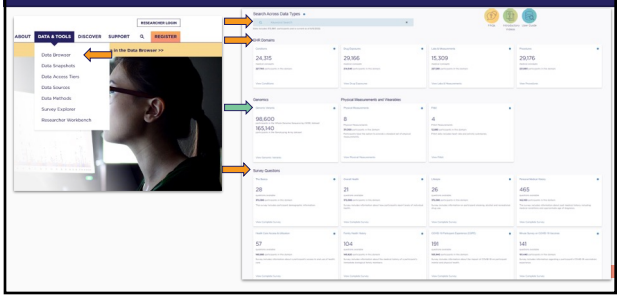
21

All of Us RESEARCH PROGRAM

Exploring the Data - The Data Browser & Survey Explorer

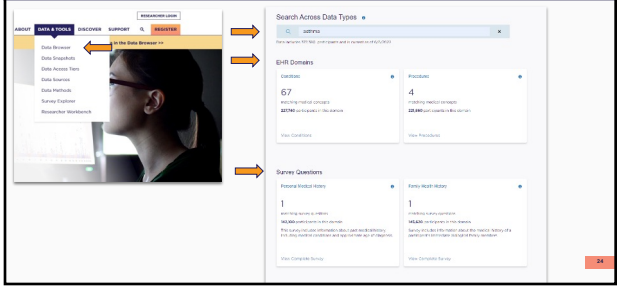
22

The Data Browser is an interactive way to view the data.

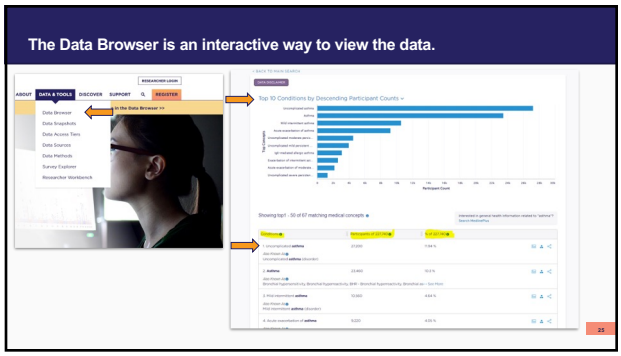


23

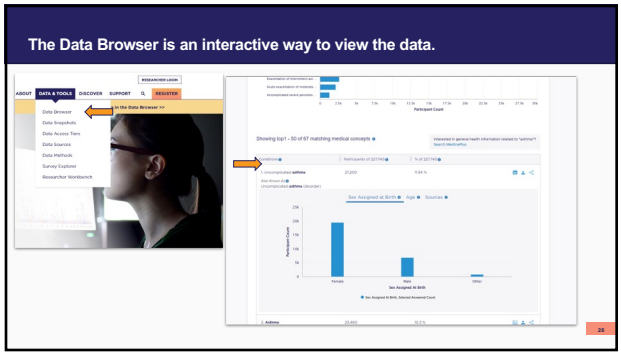
The Data Browser is an interactive way to view the data.



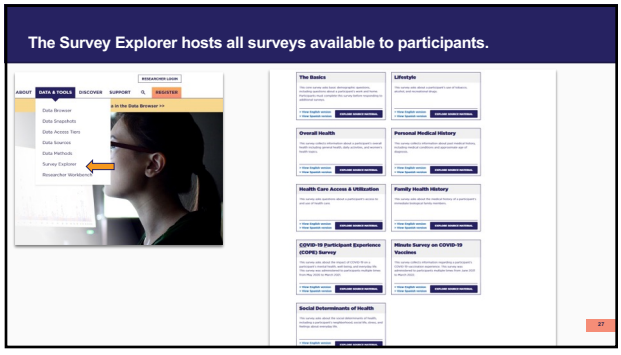
24


The Data Browser is an interactive way to view the data.

25


The Data Browser is an interactive way to view the data.

26

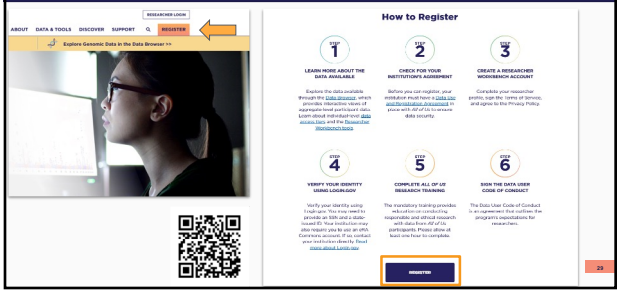

The Survey Explorer hosts all surveys available to participants.

27

How to Register

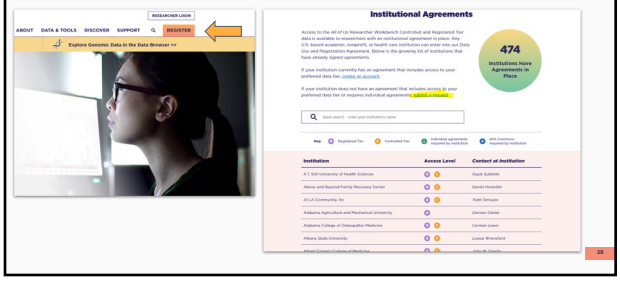
28

Registration is easy!



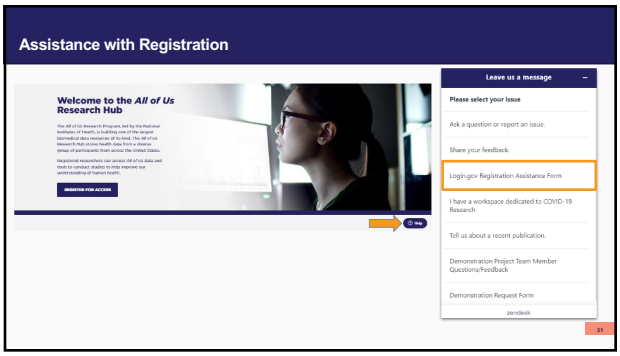
29

See if your institution has an agreement with us for access.



30

Assistance with Registration



31

Benefits of Registration

Available to all registered users

Resources

***All of Us* offers data and more.**

Registered users have access to:

- Platform and tools
- $300 in initial credit
- User support materials and staff
- Opportunities to showcase work

Platform Uses

***All of Us* is for publishing and more.**

- Team science
- Dissertation
- Thesis
- Poster presentations
- Class projects
- Self-practice (especially data science)

32

All of Us RESEARCH PROGRAM

The Researcher Workbench and how to start a research project

33

The Researcher Workbench

A secure enclave where researchers access & analyze All of Us data.

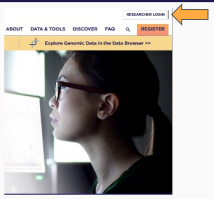
"The Public Website"

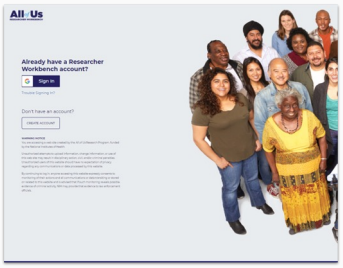
"The Workbench"

34

34

Login from the Hub to access your Workspaces.

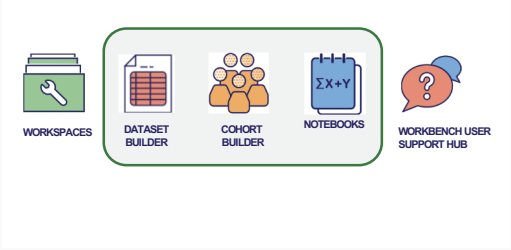




35

35

The Researcher Workbench = secure cloud analysis platform

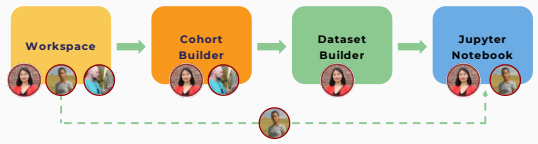


36

36

The Workbench is Collaborative

Within the Researcher Workbench, a researcher (and their research team) collaborate in "workspaces." The workflow is flexible & collaborative.



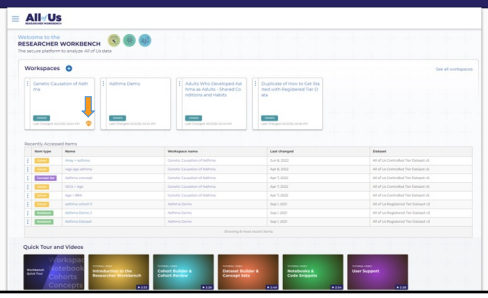
37

No IRB approval needed.

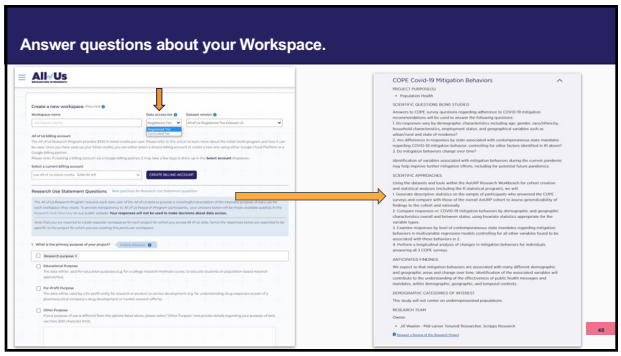
We use a passport model and approve the researcher

38

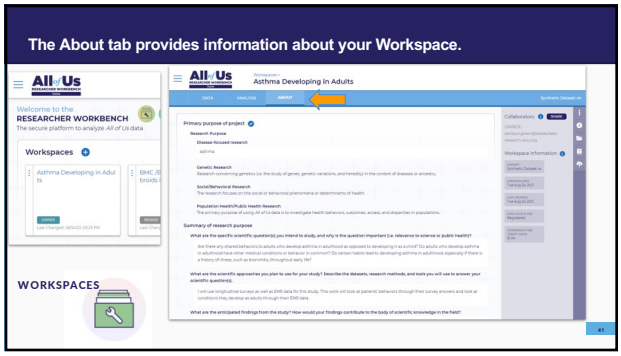
The Workbench landing page



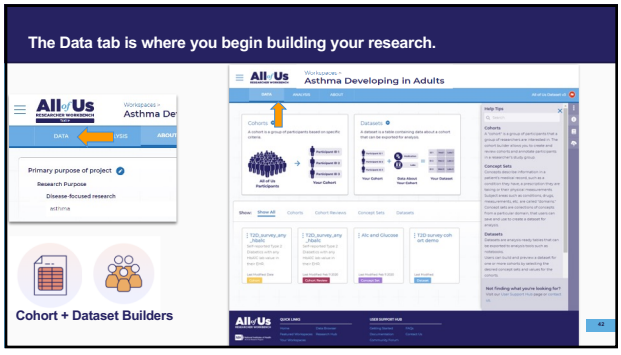
39


Answer questions about your Workspace.

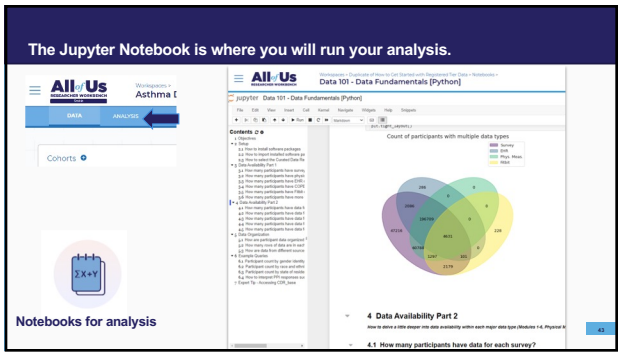
40


The About tab provides information about your Workspace.
WORKSPACES

41


The Data tab is where you begin building your research.
Cohort + Dataset Builders

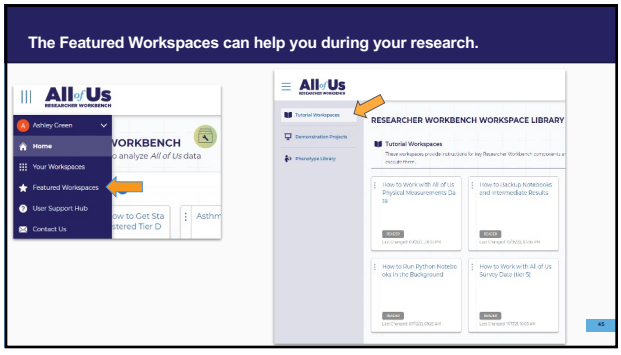
42


The Jupyter Notebook is where you will run your analysis.
Cohorts
Notebooks for analysis
Data 101 - Data Fundamentals [Python]
Count of participants with multiple data types
4 Data Availability Part 2
4.1 How many participants have data for each survey?

43

Support Resources

44


The Featured Workspaces can help you during your research.
Ashley Green
Home
Your Workspaces
Featured Workspaces
User Support Hub
Contact Us
RESEARCHER WORKBENCH WORKSPACE LIBRARY
Tutorial Workspaces
Demonstration Projects
Phenotype Library

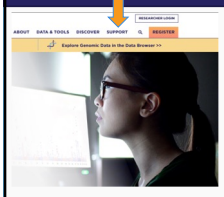
45

We also provide regular office hours & webinars.

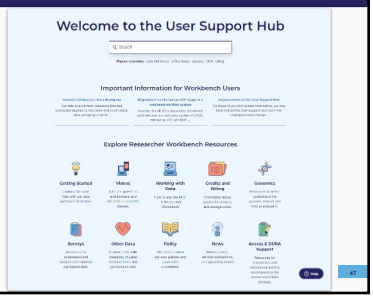
Support Desk	New User Orientation	Office Hours
Send us your questions.	**Zoom in for a live orientation.**	**Get live, virtual help with questions.**
Email us or use our "Help" icon to: • Resolve technical issues • Ask questions about our data or the research program • Give us feedback or make suggestions • and more…	Webinar objectives: • Understand data & data organization • Learn how to get started on Researcher Workbench • Learn how to utilize the User Support Hub	Ask your questions live: • Workflow implementation questions • Data refreshers and updates • Billing questions • and more…
Response in 1-2 business days. support@researchallofus.org	**Monthly** *link emailed to all registered users*	**Weekly (Tues) & Bi-Weekly (Fri)** *link emailed to all **registered users***

46

The Support Hub and Team are here to help you!



https://aousupporthelp.zendesk.com/hc/en-us



47

Stay in touch to learn more

Sign up for our bimonthly newsletter

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

48

Join our community of researchers!
Sign up for our newsletter! allof-us.org/RRSignup
Spread the word about All of Us! Visit our social media platforms!
@AllofUsResearch
#JoinAllofUs
Support@ResearchAllOfUs.org

49