All of Us Research Hub

November 15, 2022

Gage Rion, ME Research Support Team Lead gage.rion@vumc.org



Objectives

During today's presentation, we will

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

Thank you to our participants and community partners!



Thank you to our consortium partners!





All of Us is building one of the largest, most diverse health databases ever



Data in the Researcher Workbench

329,000+ Participants



80%

are from underrepresented communities

50% are racial and ethnic minorities

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



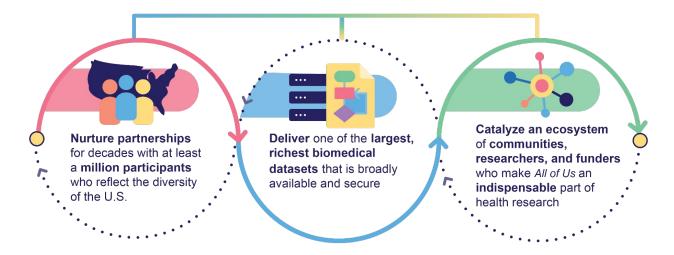
Follows participants as they move, age, and grow



All of Us Mission

Our Mission

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



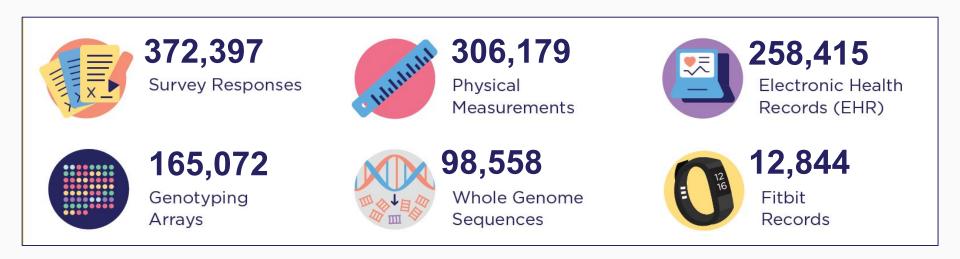
Made possible by a team that maintains a culture built around the program's core values

Participants included in All of Us research data are diverse.

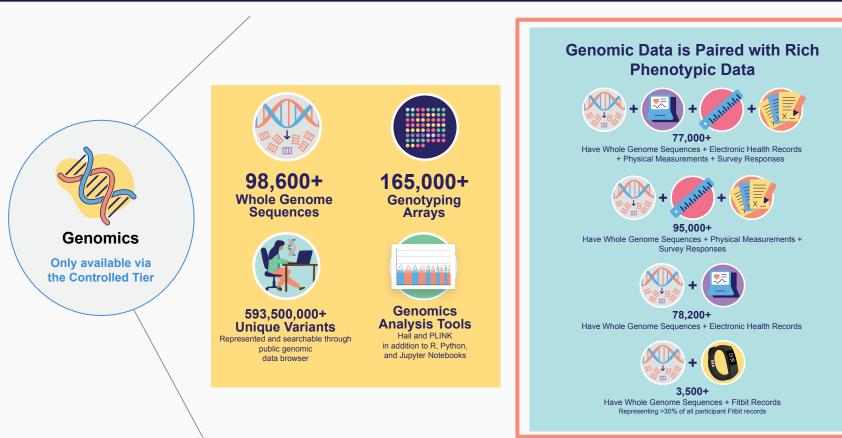
Underrepresented in Biomedical Research (UBR) Categories	Curated Data (% out of 372,380 participants)
At least one UBR	78%
Non-white race or Hispanic/Latino ethnicity	44%
Age >= 65	24%
Less than GED	9%
Annual Income <=\$25k	26%
Sexual and Gender Minorities	10%
Rural Location	7%



Key takeaways for registered users



Including the first batch of genomic data



Data Highlight: Cancer

Conditions	0	Labs & Measurements	0	Procedures
192		122		27
matching medical concepts		matching medical concepts		matching medical concepts
227,740 participants in this domain		227,280 participants in this domain		221,860 participants in this domain
/iew Conditions		View Labs & Measurements		View Procedures
rvey Questions				
	0	Family Health History	0	
Personal Medical History	0	Family Health History	0	220,000+
Personal Medical History	0	Family Health History 1 matching survey questions	0	220,000+
Personal Medical History 2 matching survey questions	0	1	0	220,000+ responses
urvey Questions Personal Medical History 2 matching survey questions 142,100 participants in this domain This survey includes information about past medical histor including medical conditions and approximate age of diag	ry,	1 matching survey questions		220,000+ responses

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

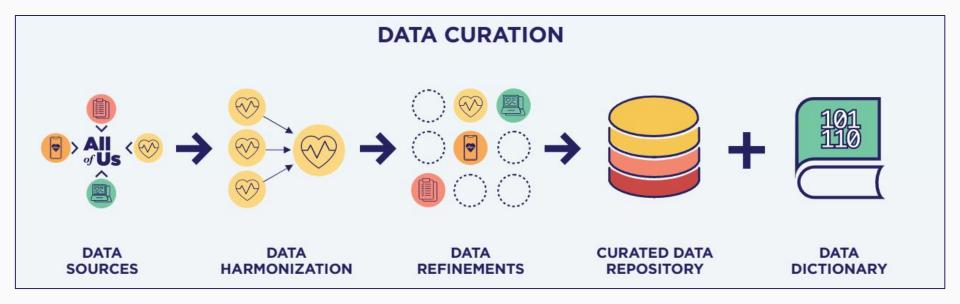
Remove unnecessary barriers to access

"keep my data safe"

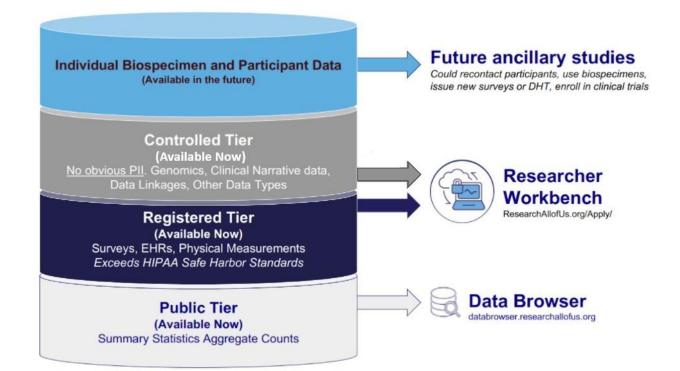
Privacy first, privacy always

Strive to build a system that participants can trust

All of Us Research Data Pipeline



Data and resource access is tiered.



Distinguishing between the Registered and Controlled Tier

Available to registered researchers

Δ

Registered Tier

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



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:

Genomics

- 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)



The Research Hub

https://www.researchallofus.org/

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



Data Snapshot provide an overview of participant data.

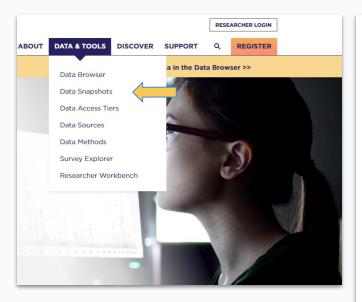
547.000+

Participants

385.000

Participants who have completed initial steps

of the program



Data Snapshots

These aggregated, public-facing data snapshots provide an overview of *All of Us* Research Program participant characteristics and the types of data that we collect from participants.

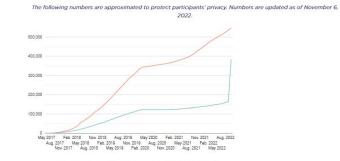
Note: There are many stages of the All of Us participant journey. More than 778,000 people have registered with the program by creating online accounts at <u>JoinAlloUs.org</u>, beginning the enrollment process. The snapshots below highlight participants in the All of Us Research Program.

The following numbers are approximated to protect participants' privacy. Numbers reflect data collected through November 6, 2022.

Participants at a Glance

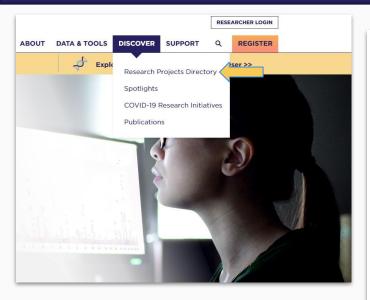
Enrollment Numbers

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.



----- Participants ----- Participants who have completed the initial steps of the program

Use the Project Directory to view all active projects.



Research Projects Directory

3,000 ACTIVE PROJECTS

This information was updated 11/14/2022

The Research Projects Directory includes information about all projects that currently exist in the Researcher Workbench to help provide transparency about how the Workbench is being used. Each project specifies whether <u>Registered Tier or Controlled Tier</u> data are used.

Note: Researcher Workbench users provide information about their research projects independently. Views expressed in the Research Projects Directory belong to the relevant users and do not necessarily represent those of the All of Us Research Program. Information in the Research Projects Directory is also cross-posted on <u>AllofUs.nih.gov</u> in compliance with the 21st Century Cures Act.

Search By: V Project title: enter keywords you are looking for

Genetics of complex diseases

Most diseases are caused by many genes and environmental factors, as well as interactions between them, i.e., they are complex diseases. Identify disease-causing genes and their interactions with environmental factors can help us understand the disease etiologies and thus novel...

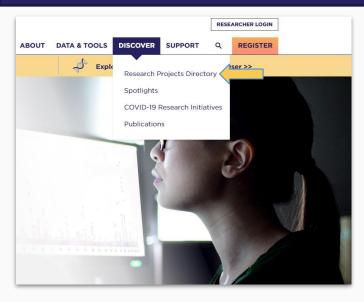
AA and rosacea

V

Q

We want to explore the systemic impacts of highly inflammatory skin pathologies on other organ systems.

Use the Project Directory to view all active projects.



Impact of Exposomics and Genomics on Prostate Cancer Outcomes

~

SCIENTIFIC QUESTIONS BEING STUDIED

How does behavior and lifestyle affect oncologic outcomes in prostate cancer? Does genetic ancestry influence
oncologic outcomes or type of therapy received in prostate cancer? One of the risk factors for aggressive prostate cancer
is a confounding social construct: racism: Identifying which societal behaviors, modifiable and non-modifiable, contribute
to the development of aggressive prostate cancer may finally replace racism with non-stigmatizing, potentially modifiable
risk factors.

 Are current prostate cancer treatments disproportionately administered to patients with specific social determinants of health? If so, are patients with worse social determinants of health (SDOH) receiving inferior treatments (per evidencebased standard of care)? Identifying real-world practice patterns based on SDOH can reveal where efforts can be directed to improve encologic outcomes.

PROJECT PURPOSE(S)

- · Disease Focused Research (prostate cancer)
- Social / Behavioral
 Control Set
- Ancestry
- Ancestry

SCIENTIFIC APPROACHES

- Patients with a diagnosis of prostate cancer.

Main Cohorts: by treatments received (prostatectomy or radiation or androgen deprivation therapy (ADT)
 Sub-cohorts: by race, by ethnicity, by inferred genetic ancestry, by waist circumference, by body mass index, by activity

level (Fitbit data), by highest education, by income, by median income per zip code.

 - Outcomes: descriptive statistics, ADT sequencing, progression (requiring a different modality of troatment), survival.
 - Evaluate actuarial outcomes with Kaplan-meier statistics and binary logistic regression for correlation of univariates followed by multivariable logistic regression for variables that are statistically significant (p<0.05).

ANTICIPATED FINDINGS

- Inferred genetic ancestry will not impact any outcomes.

Higher waist circumference, less activity and worse SDOH will be associated with worse outcomes.
 These findings would corroborate that race and ethnicity are social constructs derived from a complex system of shared.

behaviors rather than a genetic determinant for higher risk disease.

DEMOGRAPHIC CATEGORIES OF INTEREST

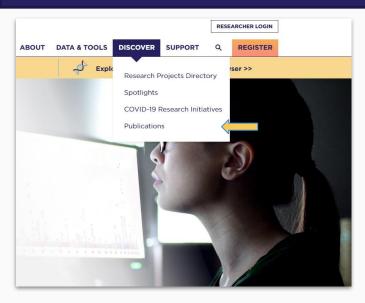
- Race / Ethnicity
- Geography
 Access to Care
- Education Level
- Income Level

DATA SET USED

RESEARCH TEAM Owner:

· William Jin - Research Fellow, University of Miami

Read researchers' peer-reviewed All of Us publications



All of Us Publications

There are currently 66 publications and counting

Inclusion on this list does not constitute endorsement by All of Us

Last updated June 2022

Featured Publications



Hypertension prevalence in the All of Us Research Program among groups traditionally underrepresented in medical research

Hypertension prevalence in the All of Us Research Program among groups traditionally underrepresented in medical research.

Chandler PD, Clark CR, Zhou G, Noel NL, Achilike C, Mendez L, Ramirez AH, Loperena-Cortes R, Mayo K, Cohn E, Ohno-Machado L, Boerwinkle E, Cicek M,

Qian J, Schully S, Ratsimbazafy F, Mockrin S, Gebo K, Dedier JJ, Murphy SN, Smoller JW, Karlson EW; All of Us Research Program Investigators.

Sci Rep. 2021 Jun 22;11(1):12849. doi: 10.1038/s41598-021-92143-w. PMID: 34158555; PMCID: PMC8219813.

Browse or Search all Publications

SEARCH by TITLE	SEARCH
	10.00

SORT BY: DATE 1 TITLE 1

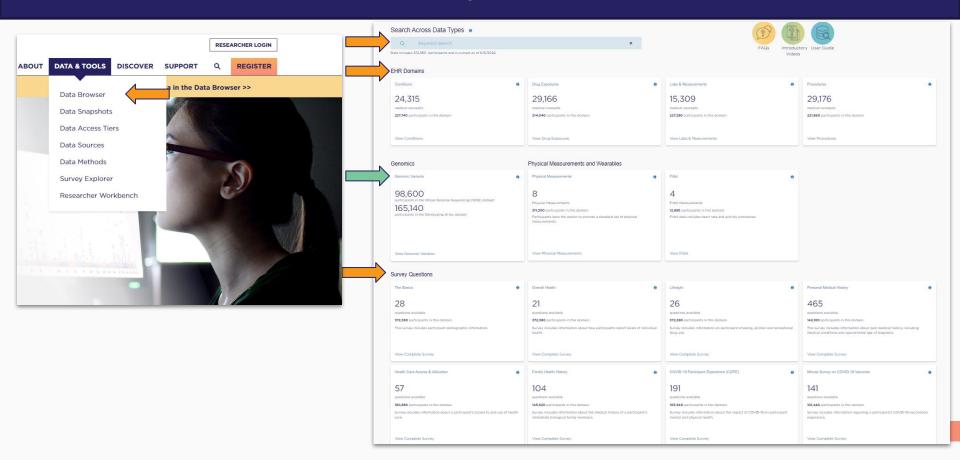
Keeping synthetic patients on track: feedback mechanisms to mitigate performance drift in longitudinal health data simulation.

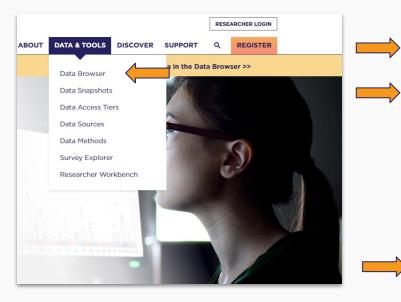
Keeping synthetic patients on track: feedback mechanisms to mitigate performance drift in longitudinal health data simulation,

Zhang Z, Yan C, Malin BA. J Am Med Inform Assoc. 2022 Aug 4:ocac131. doi: 10.1093/jamia/ocac131. Epub ahead of print. PMID: 35927974.

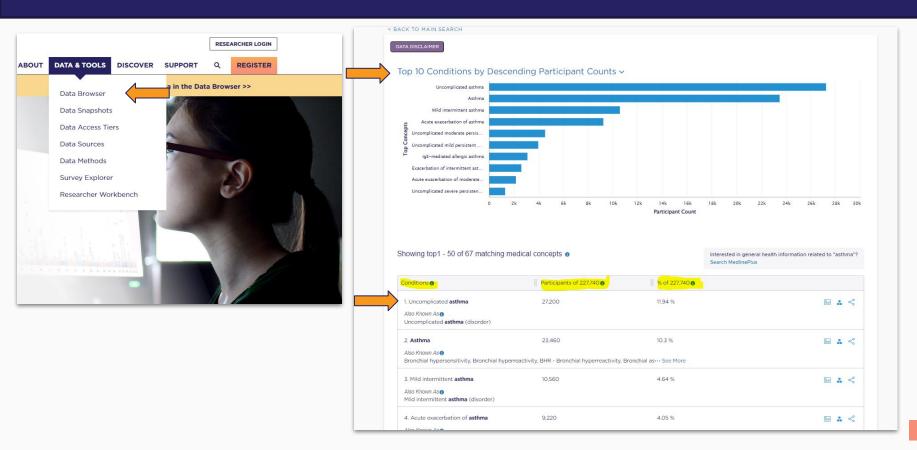


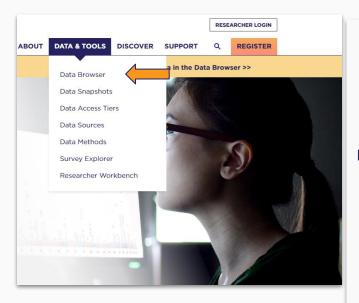
Exploring the Data - The Data Browser & Survey Explorer

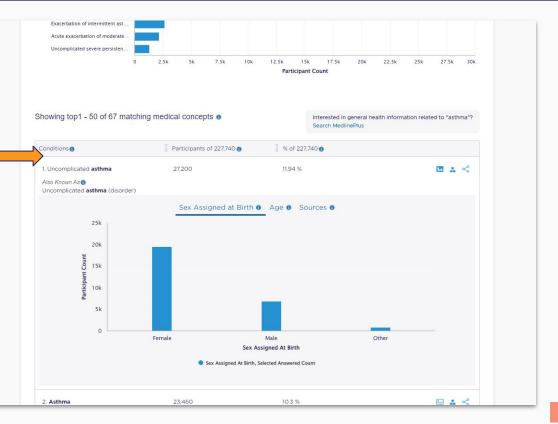




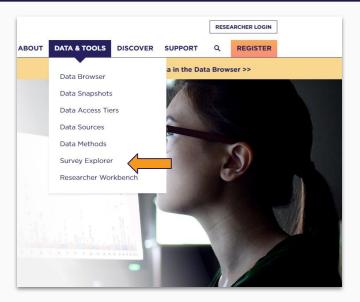
Q	asthma		×	
ata inclu	des 372,380 participants and is current as of 6/6	/2022.		
EHR D	omains			
Conditio	ins	0	Procedures	0
67			4	
matchin	g medical concepts		matching medical concepts	
227,740	participants in this domain		221,860 participants in this domain	
View Co	onditions		View Procedures	
Survey	Questions I Medical History	0	View Procedures	8
Survey	Questions	0		0
Survey Persona 1	Questions	0		0
Survey Persona 1 matchin	Questions al Medical History	0	Family Health History	0
Persona Persona 1 matchin 142,100 This sur	Questions Il Medical History g survey questions	ory,	Family Health History 1 matching survey questions	0







The Survey Explorer hosts all surveys available to participants.



This core survey asks basic demographic questions, including questions about a participant's work and home. Participants must complete this survey before responding to additional surveys.	This survey asks about a participant's use of tobacco, alcohol, and recreational drugs.
View English version EXPLORE SOURCE NATERIAL	> View English version > View Spanish version EXPLORE SOURCE MATERIAL
Overall Health	Personal Medical History
This survey collects information about a participant's overall health including general health, daily activities, and women's health topics.	This survey collects information about past medical history, including medical conditions and approximate age of diagnosis.
> View English version View Spanish version EXPLORE SOURCE NATERIAL	View English version View Spanish version
Health Care Access & Utilization	Family Health History
This survey asks questions about a participant's access to and use of health care.	This survey asks about the medical history of a participant's immediate biological family members.
View English version EXPLORE SOURCE MATERIAL	> View English version > View Spanish version
COVID-19 Participant Experience	Minute Survey on COVID-19
(COPE) Survey	Vaccines
This survey asks about the impact of COVID-79 on a participant's mental health, well-being, and everyday life. This survey was administered to participants multiple times from May 2020 to March 2021.	This survey collects information regarding a participant's COVID-19 vaccination experience. This survey was administered to participants multiple times from June 2021 to March 2022.
View English version EXPLORE SOURCE NATERIAL	> View English version > View Spanish version EXPLORE SOURCE MATERIAL
Social Determinants of Health	
This survey asks about the social determinants of health.	

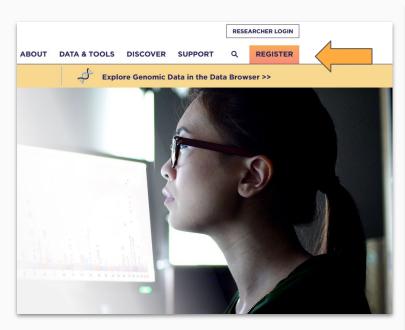
> View English version

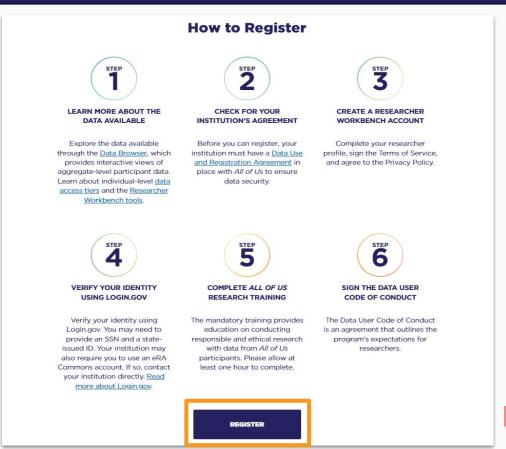
EXPLORE SOURCE MATERIAL



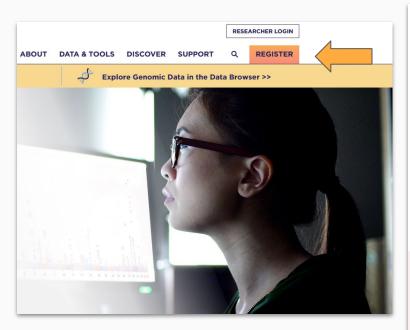
How to Register

Registration is easy!





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



Institutional Agreements

428

Institutions Have

Agreements in

Place

Access to the *All of Us* Researcher Workbench Controlled and Registered Tier data is available to researchers with an institutional agreement in place. Any U.S.-based academic, nonprofit, or health care institution can enter into our Data Use and Registration Agreement. Below is the growing list of institutions that have already signed agreements.

If your institution currently has an agreement that includes access to your preferred data tier, create an account.

If your institution does not have an agreement that includes access to your preferred data tier or requires individual agreements, <u>submit a request</u>.

Q	Quick search	- enter y	our	institution's name	
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Key: 🛛 Registered Tier 🕝 Controlled Tier	 Individual agreements required by institution 	eRA Commons required by institution
Institution	Access Level	Contact at Institution
A.T. Still University of Health Sciences	0 0	Gayla Sublette
AI LA Community, Inc	B G	Todd Terrazas
Alabama Agriculture and Mechanical University	B	Damian Clarke
Alabama College of Osteopathic Medicine	B C	Carmen Lewis
Albany State University	® ©	Louise Wrensford
Albert Einstein College of Medicine	0 0	John M. Greally
All of Us Researcher Academy/RTI International	0 0	Julie Durway

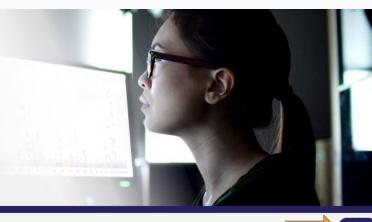
Assistance with Registration

Welcome to the All of Us Research Hub

The All of Us Research Program, led by the National Institutes of Health, is building one of the largest biomedical data resources of its kind. The All of Us Research Hub stores health data from a diverse group of participants from across the United States.

Registered researchers can access All of Us data and tools to conduct studies to help improve our understanding of human health.

REGISTER FOR ACCESS



() Help

Leave us a message	-
Please select your issue	
Ask a question or report an issue.	
Share your feedback.	
Login.gov Registration Assistance Form	
I have a workspace dedicated to COVID-19 Research	
Tell us about a recent publication.	
Demonstration Project Team Member Questions/Feedback	
Demonstration Request Form	
zendesk	

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.

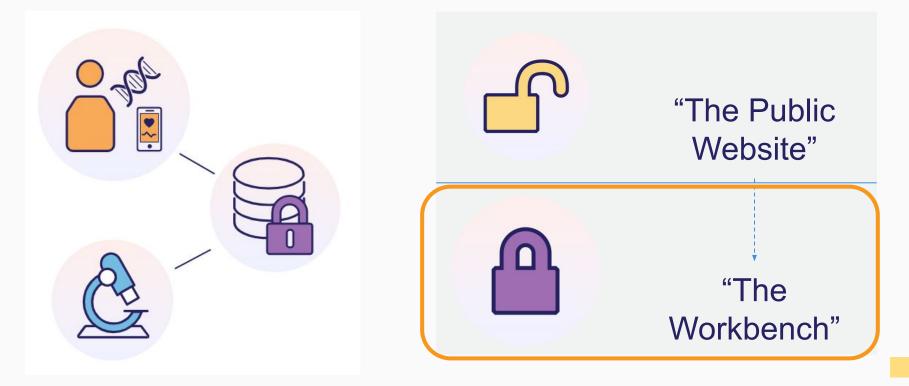
- Team science
- Dissertation
- Thesis
- Poster presentations
- Class projects
- Self-practice (especially data science)



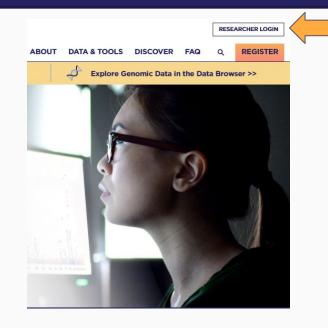
The Researcher Workbench and how to start a research project

The Researcher Workbench

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



Login from the Hub to access your Workspaces.



		e a Research account?
G	Sign In	

ner



Don't have an account?

CREATE ACCOUNT

WARNING NOTICE

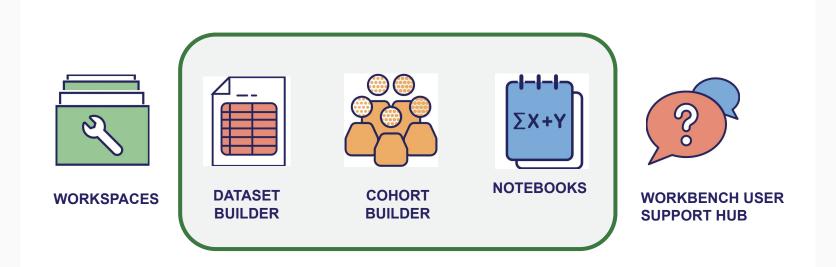
You are accessing a web site created by the All of Us Research Program, funded by the National Institutes of Health.

Unauthorized attempts to upload information, change information, or use of this web site may result in disciplinary action, civil, and/or criminal penalties. Unauthorized users of this website should have no expectation of privacy regarding any communications or data processed by this website.

By continuing to log in, anyone accessing this website expressly consents to monitoring of their actions and all communications or data transiting or stored on related to this website and is advised that if such monitoring reveals possible evidence of criminal activity, NIH may provide that evidence to law enforcement. officials.

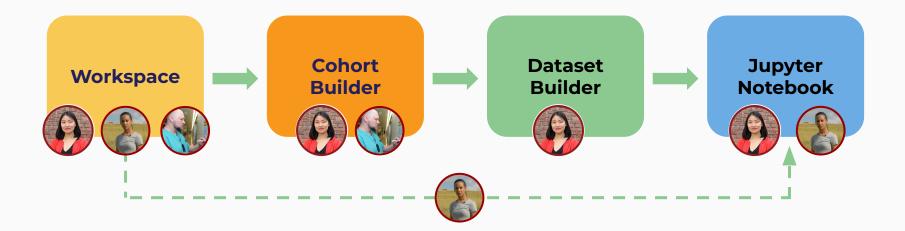


The Researcher Workbench = secure cloud analysis platform

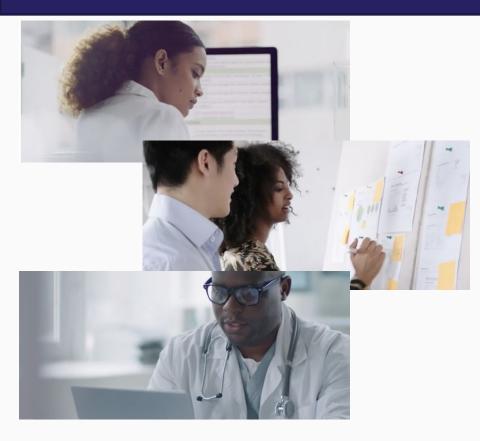


The Workbench is Collaborative

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

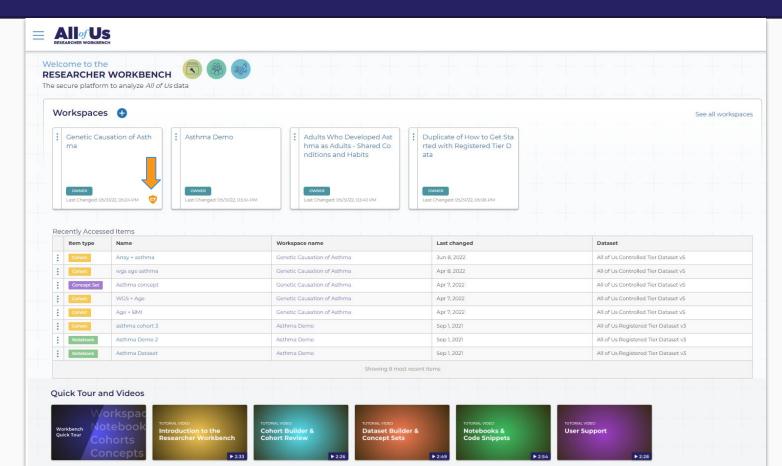


No IRB approval needed.



We use a passport model and approve the researcher

The Workbench landing page



Answer questions about your Workspace.

ea	a new workspace (Required) ()	Ļ		
orks	ace name	Data access tier ()	Dataset version ()	
Worl	pace Name	Registered Tier 🗸	All of Us Registered Tier Dataset v5	~
		Registered Tier		
of	s billing account	Controlled Tier]	
Al	of Us Research Program provides \$300 in initial credits p	er user. Please refer to this art	ticle to learn more about the initial credit program	h and how it can
use	. Once you have used up your initial credits, you can eith	er select a shared billing acco	ount or create a new one using either Google Clou	ud Platform or a
gl	billing partner.			
ase	ote: If creating a billing account via a Google billing par	tner, it may take a few days to	show up in the Select account dropdown.	
ect	current billing account			
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ie A	of Us initial credits - \$284.90 left	CREATE BILLING AG	COUNT	
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COPE Covid-19 Mitigation Behaviors

PROJECT PURPOSE(S)

Population Health

SCIENTIFIC QUESTIONS BEING STUDIED

Answers to COPE survey questions regarding adherence to COVID-19 mitigation recommendations will be used to answer the following questions:

 Do responses vary by demographic characteristics including age, gender, race/ethnicity, household characteristics, employment status, and geographical variables such as urban/rural and state of residence?

 Are differences in responses by state associated with contemporaneous state mandates regarding COVID-19 mitigation behavior, controlling for other factors identified in #1 above?
 Do mitigation behaviors change over time?

Identification of variables associated with mitigation behaviors during the current pandemic may help improve further mitigation efforts, including for potential future pandemics.

SCIENTIFIC APPROACHES

Using the datasets and tools within the AoURP Research Workbench for cohort creation and statistical analyses (including the R statistical program), we will:

 Generate descriptive statistics on the sample of participants who answered the COPE surveys and compare with those of the overall AoURP cohort to assess generalizability of findings to the cohort and nationally.

 Compare responses re: COVID-19 mitigation behaviors by demographic and geographic characteristics overall and between states, using bivariate statistics appropriate for the variable types.

3. Examine responses by level of contemporaneous state mandates regarding mitigation behaviors in multivariable regression models controlling for all other variables found to be associated with these behaviors in 2.

 Perform a longitudinal analysis of changes in mitigation behaviors for individuals answering all 3 COPE surveys.

ANTICIPATED FINDINGS

We expect to that mitigation behaviors are associated with many different demographic and geographic areas and change over time. Identification of the associated variables will contribute to the understanding of the effectiveness of public health messages and mandates, within demographic, geographic, and temporal contexts.

DEMOGRAPHIC CATEGORIES OF INTEREST

This study will not center on underrepresented populations.

RESEARCH TEAM

Owner:

· Jill Waalen - Mid-career Tenured Researcher, Scripps Research

Request a Review of this Research Project

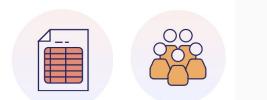
~

The About tab provides information about your Workspace.

	Workspaces > Asthma Developing in Adults	
Stable	DATA ANALYSIS ABOUT	
Welcome to the RESEARCHER WORKBENCH The secure platform to analyze All of Us data Workspaces 🔶	Primary purpose of project Research Purpose Disease-focused research asthma	Collaborators: () SHARE () OWNER: ashleye.green@stable.fake- research-aou.org () Workspace Information: ()
Asthma Developing in Adul Is BMC /E broids i	Genetic Research Research concerning genetics (i.e. the study of genes, genetic variations, and heredity) in the context of diseases or ancestry. Social/Behavioral Research The research focuses on the social or behavioral phenomena or determinants of health. Population Health/Public Health Research The primary purpose of using All of Us data is to investigate health behaviors, outcomes, access, and disparities in populations. Summary of research purpose What are the specific scientific question(s) you intend to study, and why is the question important (i.e. relevance to science or public health)?	DATASET * Synthetic Dataset v4 * CREATION DATE * Tue Aug 24 2021 * Data Access TIER * Registered * WORKSPACE FREE CREDT USAGE *
WORKSPACES	Are there any shared behaviors to adults who develop asthma in adulthood as opposed to developing it as a child? Do adults who develop asthma in adulthood have other medical conditions or behavior in common? Do certain habits lead to developing asthma in adulthood, especially if there is a history of illness, such as bronchitis, throughout early life? What are the scientific approaches you plan to use for your study? Describe the datasets, research methods, and tools you will use to answer your scientific question(s). I will use longitudinal surveys as well as EHR data for this study. This work will look at patients' behaviors through their survey answers and look at conditions they develop as adults through their EHR data. What are the anticipated findings from the study? How would your findings contribute to the body of scientific knowledge in the field?	

The Data tab is where you begin building your research.



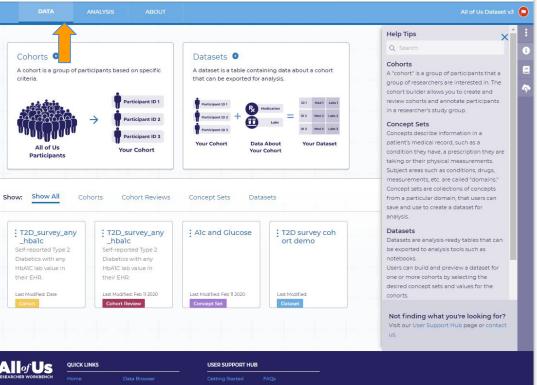


Cohort + Dataset Builders

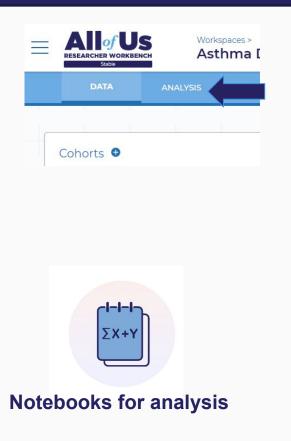


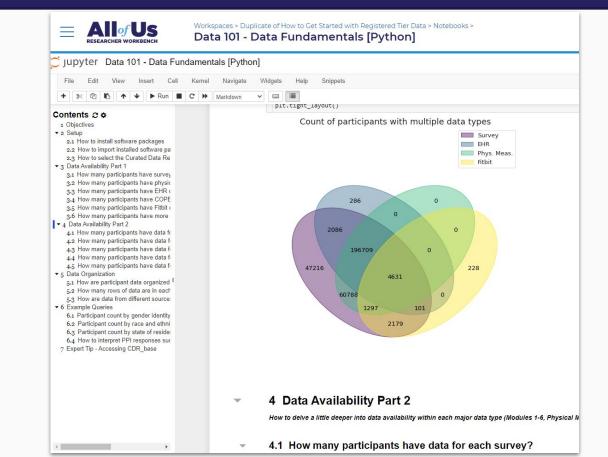
NIH National Institutes of Health

Workspaces > Asthma Developing in Adults



The Jupyter Notebook is where you will run your analysis.

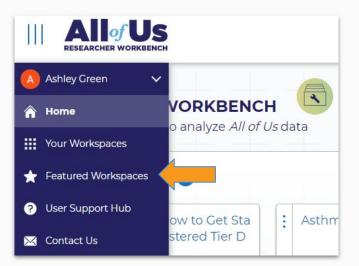






Support Resources

The Featured Workspaces can help you during your research.



Tutorial Workspaces	RESEARCHER WORKBENCH WORKSPACE LIBRAR
Demonstration Projects	Tutorial Workspaces
HH Phenotype Library	These workspaces provide instructions for key Researcher Workbench components execute them.
	How to Work with All of Us Physical Measurements Da ta
	READER Last Changed: 09/28/21, 01:33 PM Last Changed: 10/05/20, 04:04 PM
	How to Run Python Notebo oks in the Background How to Work with All of Us Survey Data (tier 5)
	READER Last Changed: 07/12/21, 09:25 AM Last Changed: 11/17/21, 10:05 AM

We also provide regular office hours & webinars.

Support Desk

Send us your 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...

Response in 1-2 business days. support@researchallofus.org

New User Orientation

Zoom in for a live orientation.

Webinar objectives:

- Understand data & data organization
- Learn how to get started on Researcher Workbench
- Learn how to utilize the User Support Hub

Office Hours

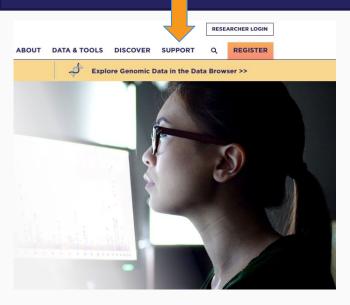
Get live, virtual help with questions.

Ask your questions live:

- Workflow implementation
 questions
- Data refreshers and updates
- Billing questions
- and more...

Monthly link emailed to all registered users **Bi-Weekly (Tues., Fri. 1-2pm CST)** link emailed to all registered users (recordings are also available)

The Support Hub and Team are here to help you!



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

Q Search Popular searches: data dictionary, office hours, dataset, CDR, billing Important Information for Workbench Users Featured Workspace: Data Wrangling Migration of v5 microarray VCF usage to a Improvements to the User Support Hub versioned manifest system Our data science team released a featured For those of you who've been here before, you may workspace targeted to new users that covers basic Recently, the All Of Us Researcher Workbench have noticed the User Support Hub (USH) has data wrangling in the W... switched over to a versioned system of CRAM, undergone some change... microarray VCF, and iDAT . **Explore Researcher Workbench Resources** 111, . Working with **Getting Started** Videos Credits and Genomics Billing Data Looking for some Tutorials, questions Resources to better help with our data and answers, and How to use the All of Information about understand the and tools? Start here. information about the genomic dataset and Us Researcher paying for analysis dataset how to analyze it. Workbench and storage costs. Surveys **Other Data** Policy Access & DURA News Support

Information about

our user policies and

associated

procedures.

Release notes,

service notifications,

and upcoming events

Resources to

understand and

analyze self-reported

participant data.

Resources for EHR.

wearable, physical

measurement, and

geolocation data.

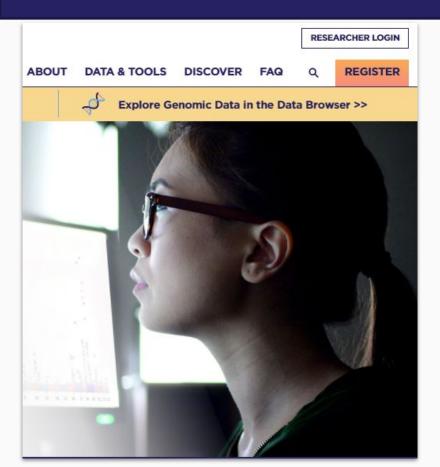
Welcome to the User Support Hub

Resources for researchers and institutional admins encompassing the access and DURA process.

⑦ Help

47

Join our community of researchers!



Help us connect with other researchers!

Email <u>ashley.e.green@vumc.org</u> if you know of others interested in demos or training sessions

