# **All of Us** Research Hub Presented to the National Hispanic Medical Association

Presented by Ashley Green, MLIS Senior Research Analyst ashley.e.green@vumc.org



# **Key Definitions & Acknowledgement**

- **Researcher Engagement:** Intentional, bidirectional relationship and capacity building with researchers and their communities across all career stages, institution types, and demographics, emphasizing researchers underrepresented in the biomedical workforce (UBW) through ongoing information sharing, collaboration, consultation, empowerment, and support.
- **Outreach:** Unidirectional interaction, such as providing materials and information to an audience.
- **Researcher diversity:** Defined across multiple dimensions, including demographics (inclusive of self-reported race/ethnicity, sex, gender, and SGM status, and disability), career stage, and institution type.

Source: All of Us Research Program 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]

# WHO WE ARE

Established in 1994 in Washington, DC, NHMA is a nonprofit association representing 50,000 licensed Hispanic physicians in the U.S.

# **PRESIDENT & CEO**



Elena Rios, MD, MSPH, MACP

# VISION

NHMA's vision is to be the

national leader in improving

the health of Hispanic

populations.

# MISSION

NHMA's mission is to empower Hispanic physicians to lead efforts to improve the health of Hispanic and other underserved populations in collaboration with Hispanic state medical societies, residents, medical students, and other public and private sector partners. During today's presentation, we will

- Learn about the All of Us Research Program and the data we offer
- Explore the public-facing Research Hub and its tools
- Examine the steps for registration
- See how to start a research project on the Workbench

### All of Us community and provider partner network (as of November 2023)



### All of Us consortium members (beyond community partners, as of November 2023)



All of Us consortium members (Continued) (beyond community partners, as of November 2023)

### Nutrition for Precision Health (NPH)





THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL

**UNC** 

C NUTRITION RESEARCH

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

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



## 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 with a secure connection



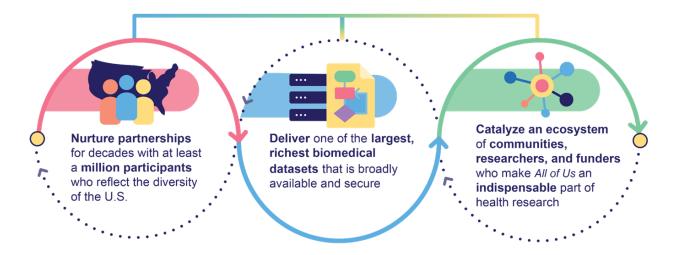
Follows participants as they move, age, and grow



## 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.

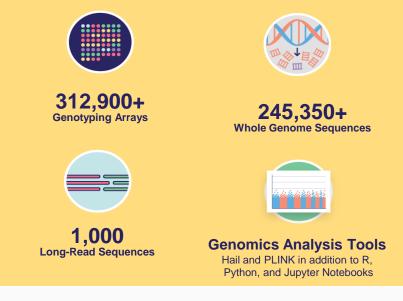
Underrepresented in Biomedical Research (UBR) Categories	<b>Curated Data</b> (% out of 413,457 participants)	
At least one UBR	74%	
Non-white race or Hispanic/Latino ethnicity	43%	
Age >= 65	24%	
Less than GED	9%	
Annual Income <=\$25k	25%	
Sexual and Gender Minorities	10%	
Disability	10%	

# Summary of Data Available in the Researcher Workbench



# Including genomic data

The whole genome sequence dataset includes variation at more than **1 billion** locations, which is nearly **one-third** of the entire human genome.



\*Only available in the Controlled Tier

### Genomic Data Is Paired With Rich Phenotypic Data



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



245,100+ Have Whole Genome Sequences + Physical Measurements + Survey Responses



206,150+ Have Whole Genome Sequences + Electronic Health Records



Have Whole Genome Sequences + Fitbit Records Fitbit data may include physical activity, step counts, heart rate, and sleep data

# **Data: Surveys**

Chiles

- 1. The Basics
  - 2. Overall Health
  - 3. Lifestyle



- 4. Health Care Access & Utilization
- 5. Personal Health History and Family Medical History (Revised)
- 6. Social Determinants of Health (SDOH)
- 7. COVID-19 Participant Experience (COPE)
- 8. COVID-19 Vaccines Minute Surveys

Visit the <u>Survey Explorer</u> on ResearchAllofUs.org for more information on survey data

# **Data: 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

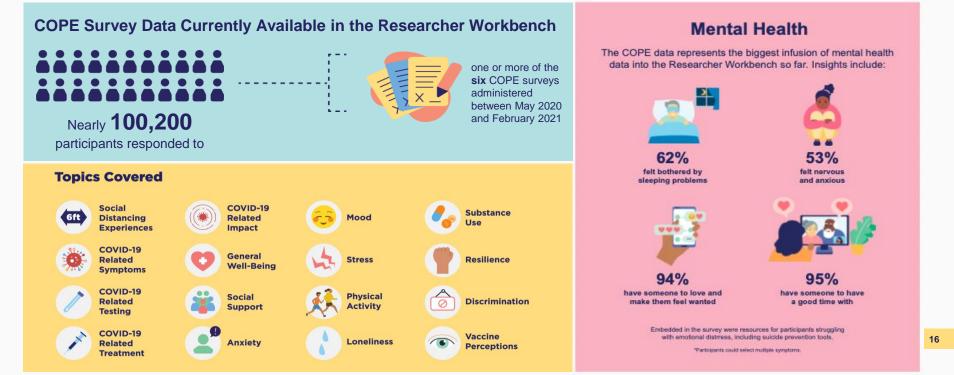
### Social Determinants of Health (SDOH) Survey data



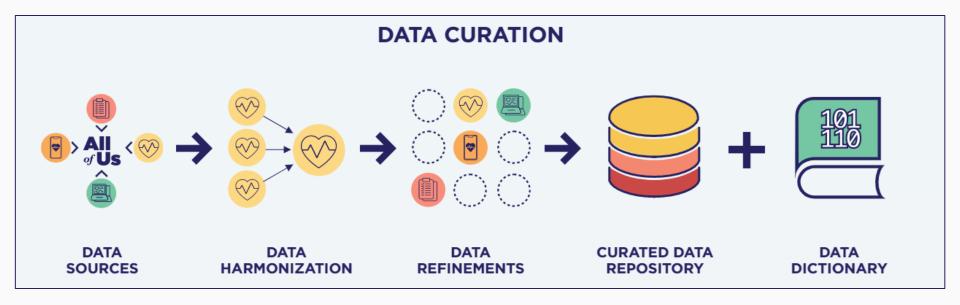
### from 117,750+ responses

## Data: Cope Survey

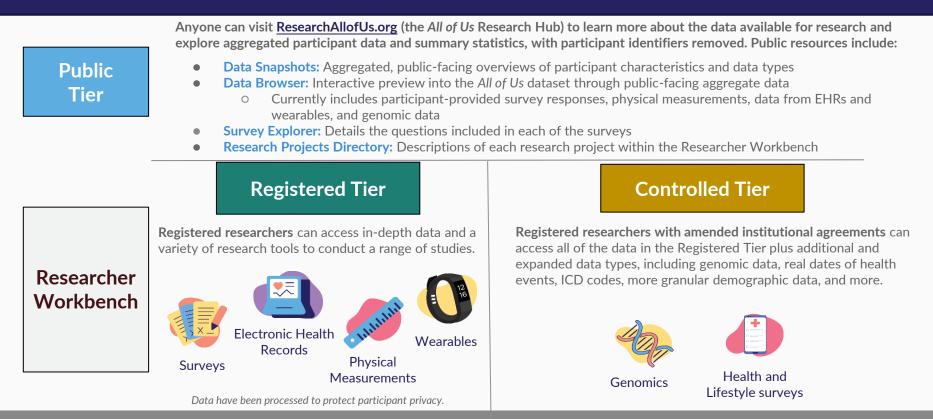
All of Us released its recurring COVID-19 Participant Experience (COPE) survey to learn more about changes in participants' daily life, health, and well-being throughout the pandemic. Registered researchers can access the data in the Researcher Workbench and use it as part of an integrated dataset to explore potential associations across a variety of factors, from genetics to geography to mental health.



# All of Us Research Data Pipeline

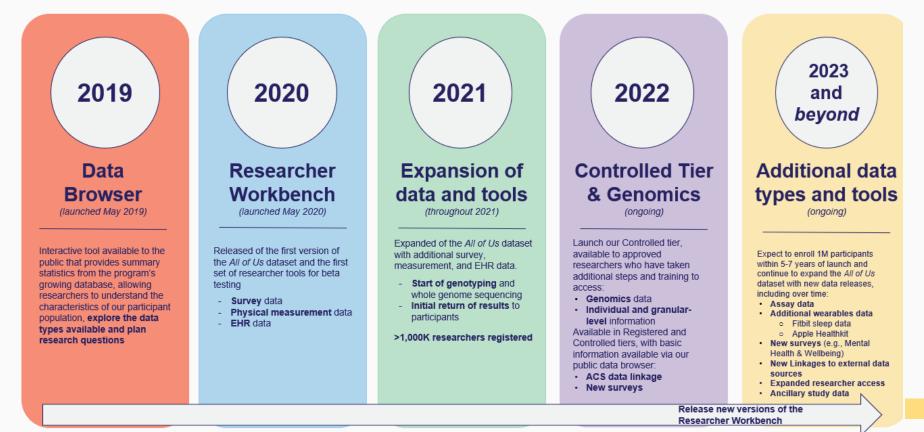


# **Data: Access Flowchart and Tools**



Counts in the Public, Registered, and Controlled Tiers may vary based on the lag time associated with the data curation process under the program's rigorous privacy protections.

## Data release timeline





# **The Research Hub**

### The All of Us Research Hub

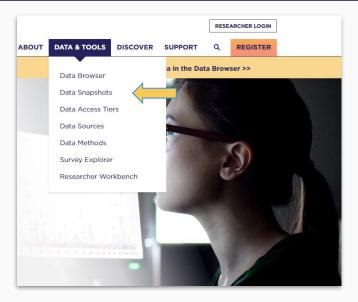


# https://www.ResearchAllOfUs.org/

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



# Data Snapshot provide an overview of participant data.



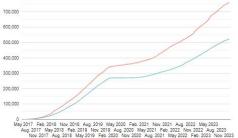


### **Participants at a Glance**

### **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.

The following numbers are approximated to protect participants' privacy. Numbers are updated as of February 4, 2024.



Outreach

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

### Funded Partner Organizations

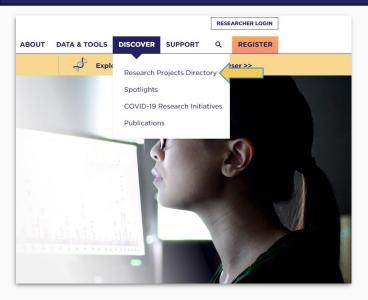
100+

860+

Sites Collecting Samples and Measurements

These counts represent the number of program partner awardees and enrollment sites launched. These numbers are updated on an as-need basis.

### Use the Project Directory to view all active projects.



### **Research Projects Directory**

### 8,984 ACTIVE PROJECTS

This information was updated 2/5/2024

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 ningov</u> in compliance with the 21st Century Cures Act.

Search By: V Project title: hispanic



### 49 projects have 'hispanic' in the project title

< Go back to All Projects View or enter a new search query

### Interdisciplinary approach to understanding obesity in Hispanic populations

We plan to explore the data to formalize a research question about the correlations between obesity and the gut microbiome in Hispanic populations. I also want to formalize a research question about the correlations between obesity, polycystic ovarian syndrome, and...

### Asthma genetics in Hispanic and Latino individuals

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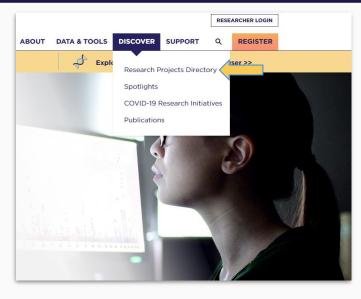
 $\sim$ 

We will apply population genetics methods such as admixture and IBD mapping to identify genomic regions, and ultimately, genetic variants, that are associated with asthma in Hispanic and Latino individuals in the U.S. Hispanic and Latino individuals are admixed, and...

#### Hispanic/AMR Workspace

24

### Use the Project Directory to view all active projects.



### Asthma and Social Stressors 2

~

### SCIENTIFIC QUESTIONS BEING STUDIED

I hope to explore associations between asthma severity (categorized as intermittent or persistent) and exposure to environmental and psychosocial stressors, such as community violence, discrimination, and perceived stress. An understanding of this can aid in health promotion for marginalized populations who are often exposed to these stressors, and assist in assessing appropriate interventions (mental health-focused or otherwise).

### PROJECT PURPOSE(S)

- Disease Focused Research (asthma)
- Population Health
- Social / Behavioral

### SCIENTIFIC APPROACHES

We hope to analyze data from the Social Determinants of Health survey as they relate to the condition of interest (asthma; in the Conditions domain), while potentially controlling for certain demographic variables.

### ANTICIPATED FINDINGS

We hope to assess whether there is an association between these adverse social/environmental exposures and experiences with asthma. This will support an understanding of how environmental factors may influence the severity of this disease.

#### DEMOGRAPHIC CATEGORIES OF INTEREST

This study will not center on underrepresented populations.

### DATA SET USED

Registered Tier

### **RESEARCH TEAM**

Owner:

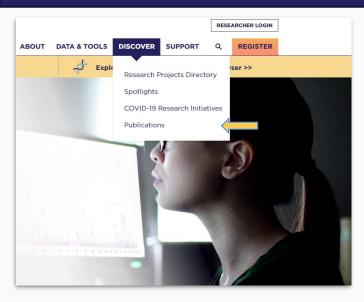
· Prudny Bonnaire Fils - Undergraduate Student, University of Florida

#### Collaborators:

· Ruina He - Project Personnel, University of Florida

### Request a Review of this Research Project

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



### **All of Us Publications**

There are currently 221 publications and counting

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

### **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	

### Reconstruction of private genomes through reference-based genotype imputation

Reconstruction of private genomes through reference-based genotype imputation

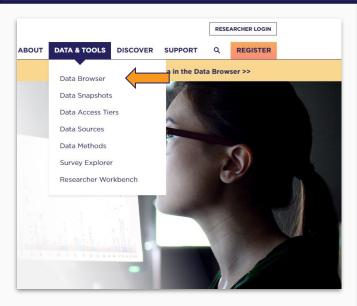
Mosca MJ, Cho H. Genome Biol. 2023 Dec 6;24(1):271. doi: 10.1186/s13059-023-03105-6. PMID: 38053191; PMCID: PMC10698978.



# Exploring the Data - The Data Browser & Survey Explorer

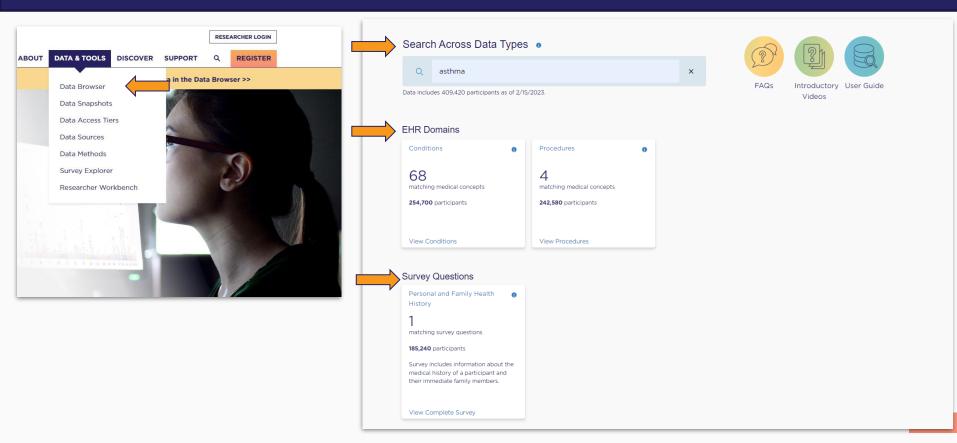
Follow along: https://DataBrowser.ResearchAllOfUs.org

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

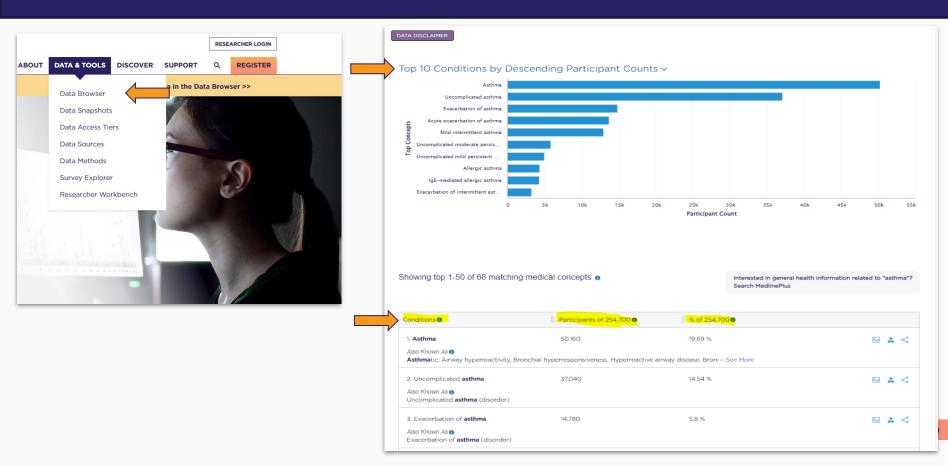


Search Across Data Types				
Q Keyword Search				×
Data includes 409,420 participants as of 2/15/	/2023.			FAQs Introductory User Videos
EHR Domains				
Conditions	Drug Exposures 0	Labs & Measurements	Procedures 0	
25,638	29,865	16,216	30,328	
254,700 participants	239,740 participants	252,980 participants	242,580 participants	
View Conditions	View Drug Exposures	View Labs & Measurements	View Procedures	
	View Drug Explorers	1		
Genomics SNP/Indel Variants		Measurements and Wearables		
SNP/Indel Variants	Genomic data only in Researcher Workbench	Physical Measurements 0	Fitbit 0	
245,400 Participants in Short-Read	1,040 participants in the Long-Read WGS dataset	8 Physical Measurements	6 Fitbit Measurements	
Whole Genome Sequencing (WGS) dataset	11,400 participants in the Short-Read WGS Structural	342,840 participants	15,620 participants	
1,074,881,214 SNP/Indel Variants	Variants dataset 312,940 participants in the Genotyping Arrays dataset	Participants have the option to provide a standard set of physical measurements.	Fitbit data includes heart rate and activity summaries.	
View SNP/Indel Variants	Register for access	View Physical Measurements	View Fitbit	
		View Physical Measurements	View Fitbit	
Survey Questions	Register for access	]		
		View Physical Measurements	View Fithit Health Care Access & Utilization @	
Survey Questions	Register for access	]		
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Survey Questions The Basics  28 questions available  499,499 participants The survey inclusions participant demographic information.	Register for access  Verail Health  2  Guidenne svatable  3  Druge Incluses  4  Druge Inc	Lifestyle   26 Guestos participation  39,000 participates  Surpsy Includes information on participant sineking, acceleration	Health Care Access & Utilization 57 custion available 190.20 participants Survey includes information about a participant's access to and use of health care.	
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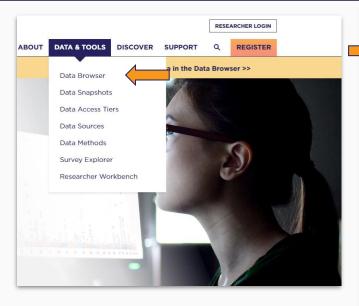
### **Explore the Data: The Data Browser**

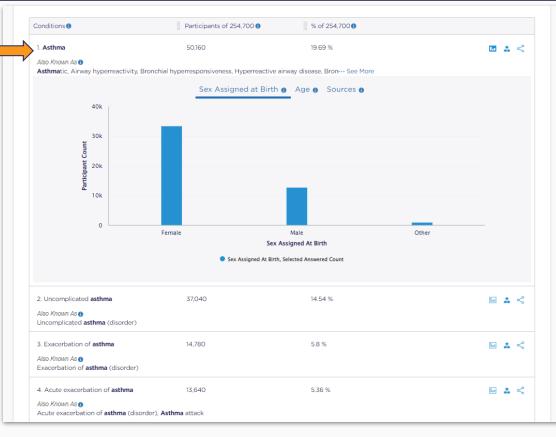


### **Explore the Data: The Data Browser**

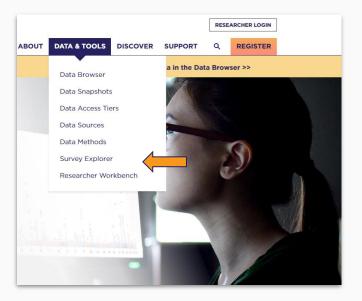


### **Explore the Data: The Data Browser**



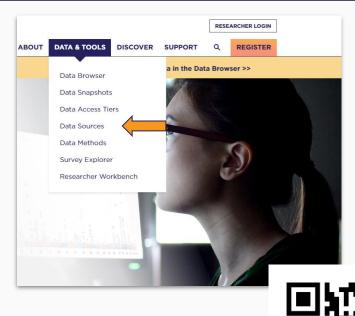


## The Survey Explorer hosts all surveys available to participants.



The Basics	Lifestyle
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 > View Spanish version	> View English version > View Spanish version
Overall Health	Personal/Family Health 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 a of diagnosis.
> View English version > View Spanish EXPLORE SOURCE MATERIAL version	> View English version > View Spanish version
Health Care Access & Utilization	Social Determinants of Health
This survey asks questions about a participant's access to and use of health care.	This survey asks about the social determinants of health including a participant's neighborhood, social life, stress and feelings about everyday life.
View English version     View Spanish     EXPLORE SOURCE MATERIAL version	> View English version > View Spanish version
<u>CO</u> VID-19 <u>P</u> articipant	Minute Survey on COVID-19
Experience (COPE) Survey	Vaccines
This survey asks about the impact of COVID-19 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 > View Spanish EXPLORE SOURCE MATERIAL version	> View English version > View Spanish version

# Visit the data roadmap for more information about upcoming data types



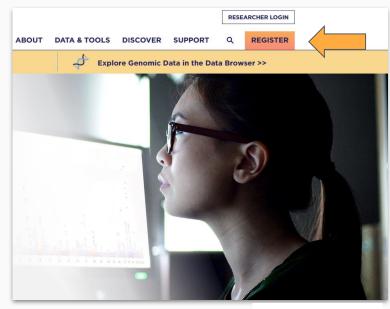
https://allof-	
us.org/Roadmap	
<u></u>	

	Available end of 2022	Early 2023 additions	2023 and beyond
Electronic Health Records (EHRs)	• EHRs		
Surveys	The Basics     Overall Health     Lifestyle     Health Care Access and     Utilization     Personal and Family     Medical History     Social Determinants of     Health     COVID-19 Participant     Experience (COPE)     COVID-19 Vaccines     Minute Surveys 1-3	Combined Personal and Family Health History COVID-19 Vaccines Minute Survey 4	• Life Functioning
Physical Measurements	Physical Measurements		Participant-reported height     and weight
Genomics	<ul> <li>165K+ genotyping arrays</li> <li>98K+ whole genome sequences (WGS)</li> </ul>	245K+ WGS     312K+ Arrays     CRAM files     1,000 long-read     sequences	
Data Linkages	American Community Survey (ACS) 3-digit zip code		ACS 5-digit zip code
Digital Health Technologies	Fitbit: • Heart rate by zone summary and minute-level • Activity (daily summary) • Activity (intraday steps (minute-level)	• Fitbit sleep data	<ul> <li>Fitbit device data</li> <li>Vital measurements</li> <li>Apple HealthKit activity data</li> </ul>
Assays	COVID-19 serology data		
Ancillary Studies		•••••	<ul> <li>Exploring the Mind Pilot</li> <li>Nutrition for Precision Health (NPH) modules</li> </ul>



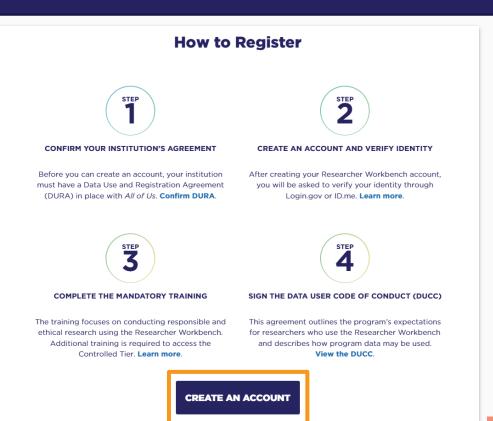
# How to Register

# **Registration is easy!**

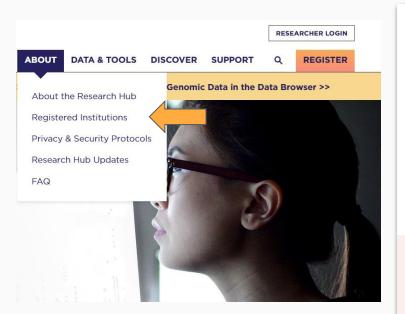


allof-us.org/Register





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



### **Registered Institutions** Access to the Researcher Workbench is available only to registered researchers with an institutional Data Use and Registration Agreement (DURA). Academic, not-for-profit, and health care institutions can enter into a DURA. Search or 685 browse the list below to confirm if your institution has a DURA in place. Institutions Have If your institution is listed below. If your institution is not listed below. AND includes your preferred data tier. OR doesn't include your preferred data tier. Agreements in AND doesn't require individual agreements **OR** requires individual agreements Place CREATE AN ACCOUNT SUBMIT A REQUEST Q Quick search - enter your institution's name eRA Commons Individual agreements R Registered Tier Controlled Tier e Key: required by institution required by institution Institution Access Level **Contact at Institution** R C A.T. Still University of Health Sciences Gayla Sublette Abigail Wexner Research Institute at Nationwide Children's Nichole Michaels Hospital Above and Beyond Family Recovery Center Daniel Hostetler Access Care Anywhere R C Carissa Bishop R C Acton-Boxborough Regional School District Deborah Bookis Adams State University Benita Brink **R C** AI LA Community, Inc Todd Terrazas

### **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**

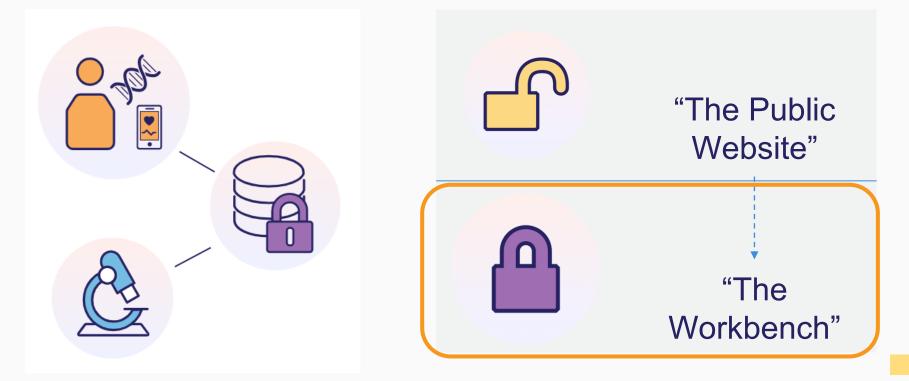
#### All of Us is for publishing and more.

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

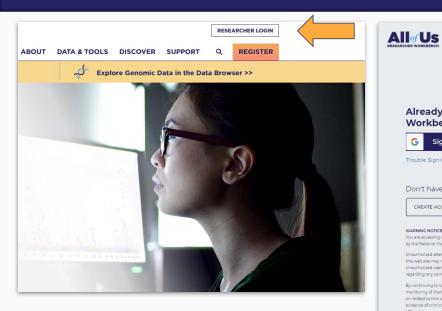


# The Researcher Workbench and how to start a research project

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



### Login from the Hub to access your Workspaces.



#### Already have a Researcher Workbench account?



Trouble Signing In?

#### Don't have an account?

CREATE ACCOUNT

#### WARNING NOTICE

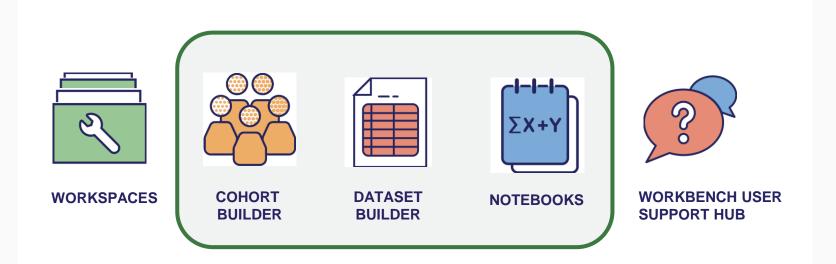
You are accessing a web site created by the All of Us Research Program, funded by the National Institutes of Health.

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.

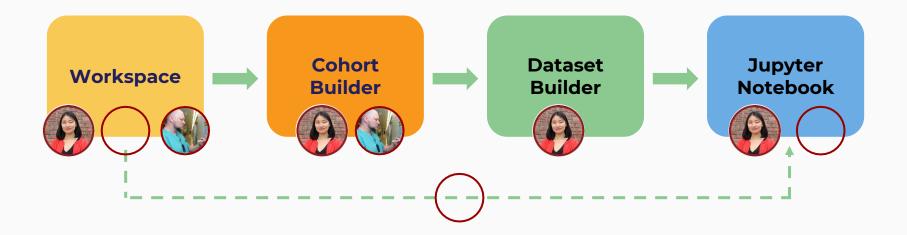


### The Researcher Workbench = secure cloud analysis platform



### The Workbench is Collaborative

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

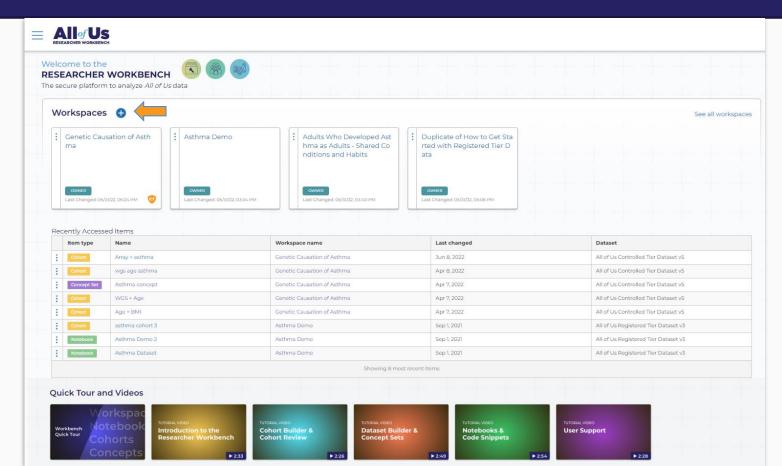


### No IRB approval needed.



### We use a passport model and approve the researcher

### The Workbench landing page



### Answer questions about your Workspace.

Create a new workspace (Required) ()			
Workspace name	Data access tier 🚯	Dataset version ()	
Workspace Name	Registered Tier 🗸	All of Us Registered Tier Dataset v5	~
	Registered Tier		
All of Us billing account	Controlled Tier	]	
The All of Us Research Program provides \$300 in initial			
be used. Once you have used up your initial credits, you Google billing partner.	a can either select a shared billing acco	ount or create a new one using either Google Clo	oud Platform or a
Please note: If creating a billing account via a Google b	illing partner, it may take a few days to	show up in the Select account dropdown	
	in g poster i con g torre a terr ange te		
Select a current billing account			
Use All of Us initial credits - \$284.90 left	CREATE BILLING AG	COUNT	
each workspace they create. To provide transparency Research Hub Directory on our public website. <b>Your</b> n 	esponses will not be used to make d	ecisions about data access.	
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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?

2. Are differences in responses by state associated with contemporaneous state mandates regarding COVID-19 mitigation behavior, controlling for other factors identified in #1 above? 3. 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

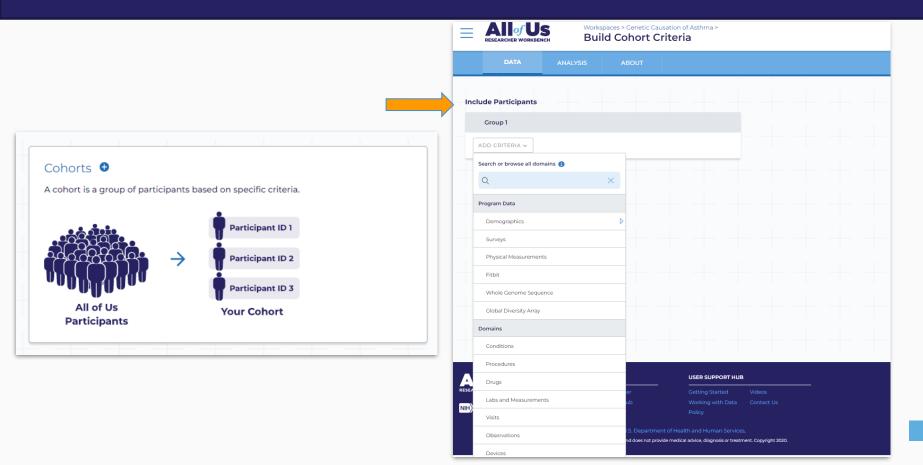
Owner:

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

Request a Review of this Research Project

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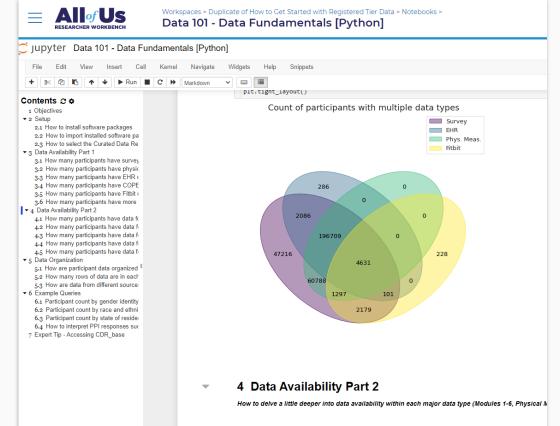
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### The Jupyter Notebook is where you will run your analysis.



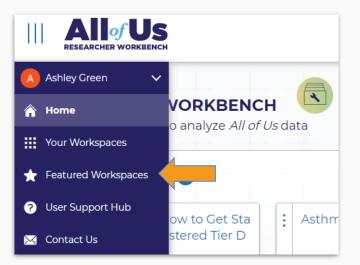


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## **Support Resources**

### The Featured Workspaces can help you during your research.

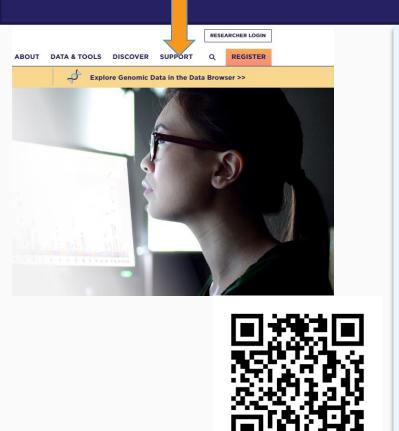


Tutorial Workspaces	RESEARCHER WORKBENCH WORKSPACE LIBRARY
Demonstration Projects	Tutorial Workspaces
♣I# Phenotype Library	These workspaces provide instructions for key Researcher Workbench components ar execute them.
	How to Work with All of Us Physical Measurements Da ta
	READER         READER           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

### **Our Support Tools**

Email us questions anytime at support@researchallofus.org.	Zoom in for our live New User Orientation or Office Hours.	User Support Hub
<ul> <li>Email us or use our "Help" icon to</li> <li>Resolve technical issues</li> <li>Ask questions about our data or the research program</li> <li>Give us feedback or make suggestions</li> <li>and more</li> </ul>	<ul> <li>Webinar objectives:</li> <li>Understand data &amp; data organization</li> <li>Learn how to get started on Researcher Workbench</li> <li>Learn how to utilize the User Support Hub</li> <li>Technical Assistance</li> </ul>	<ul> <li>Our User Support Hub provides:</li> <li>Articles, videos and tutorials about the Researcher Workbench and All of Us dataset</li> <li>Updates on product offerings and new features</li> <li>Events calendar</li> </ul>
Support@ResearchAllOfUs.org	Office Hours - Weekly on Tuesdays; bi-weekly on Fridays New User Orientation - monthly	

### The Support Hub and Team are here to help you!



### Welcome to the User Support Hub

Q Search

Popular searches: data dictionary, office hours, dataset, CDR, billing

#### Important Information for Workbench Users Migration of v5 microarray VCF usage to a

Featured Workspace: Data Wrangling Our data science team released a featured workspace targeted to new users that covers basic data wrangling in the W...

versioned manifest system Recently, the All Of Us Researcher Workbench switched over to a versioned system of CRAM, microarray VCF, and iDAT .

Improvements to the User Support Hub

For those of you who've been here before, you may have noticed the User Support Hub (USH) has undergone some change...

#### **Explore Researcher Workbench Resources**



Genomics

Resources to better understand the genomic dataset and how to analyze it.



Access & DURA Support

Resources for researchers and institutional admins encompassing the access and DURA

process.

⑦ Help

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### Stay in touch to learn more



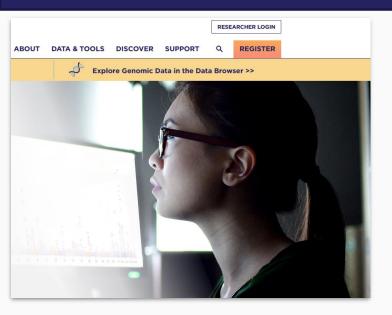
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allof-us.org/RRSignup

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