All of Us Research Hub

November 15, 2022

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All of Us
DATA & RESEARCH CENTER

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!

The Participant Center

Scripps Research Translational Institute · Medscape · patientslikeme · BlueCross BlueShield · Bloodworks Northwest · PicnicHealth · URBAN ONE · SENSIS · New York Blood Center · San Diego Blood Bank · ACHA American College Health Association · DXC.technology · Gulf Coast Regional Blood Center Commit for Life. · SYNC FOR SCIENCE · Quest Diagnostics · owaves · careevolution HEALTHCARE TECHNOLOGY · Walgreens · WebMD · Sage · NATIONAL BLOOD COLLABORATIVE · THE BEHAVIOURAL INSIGHTS TEAM · fitbit · QTC

Communications & Engagement

THE UNIVERSITY OF UTAH · RTI INTERNATIONAL · PYXIS PARTNERS · WONDROS

HPO Network

(Health Care Provider Organizations)

RMCs

All of Us California

UC San Diego Health · UCI Health · UC DAVIS HEALTH · UCSF · Cedars Sinai · USC University of Southern California

IllinoisPrecision Medicine Consortium

Northwestern Medicine · THE UNIVERSITY OF CHICAGO · NorthShore University HealthSystem · RUSH · COOK COUNTY HEALTH · THE UNIVERSITY OF ILLINOIS COLLEGE OF MEDICINE · UI Health

All of Us New England

BRIGHAM HEALTH BRIGHAM AND WOMEN'S HOSPITAL · MASSACHUSETTS GENERAL HOSPITAL · Mass General Brigham · BOSTON MEDICAL

Trans America Consortium

Henry Ford HEALTH SYSTEM · Spectrum Health · Essentia Health · UMass Chan MEDICAL SCHOOL · BaylorScott&White HEALTH · RELIANT MEDICAL GROUP Part of OptumCare · HealthPartners Institute

New York City Consortium

COLUMBIA · Weill Cornell Medicine · NYC HEALTH+ HOSPITALS | Harlem · NewYork-Presbyterian

All of Us Southern Network

UAB MEDICINE · USA HEALTH · UAB SCHOOL OF MEDICINE · Cooper Green Mercy · TUSKEGEE UNIVERSITY · MEDICAL CENTER · LSU Health NEW ORLEANS · Tulane University · HUNTSVILLE HOSPITAL

All of Us SouthEast Enrollment Center

UHealth · MILLER SCHOOL OF MEDICINE · EMORY UNIVERSITY · MOREHOUSE SCHOOL OF MEDICINE · UF UNIVERSITY of FLORIDA

HPO Lite

UTHealth · VCU Health · Washington University in St. Louis

All of Us Wisconsin

Marshfield Clinic Health System · WISCONSIN · Froedtert & Medical College of Wisconsin · GUNDERSEN HEALTH SYSTEM

All of Us Pennsylvania

University of Pittsburgh

University of Arizona and Banner Health

THE UNIVERSITY OF ARIZONA · Banner Health · MARIPOSA Health COMMUNITY HEALTH CENTERS

FQHCs (Federally Qualified Health Centers)

Cherokee · JACKSON-HINDS COMPREHENSIVE HEALTH CENTER · SAN YSIDRO HEALTH · WAIANAE COAST COMPREHENSIVE HEALTH CENTER · Community Health Center, Inc. · Cooperative Health · Sun River Health

VA Medical Centers

VA · U.S. Department of Veterans Affairs · Veterans Health Administration

Participant Technology Systems Center (PTSC)

vibrent

Biobank

MAYO CLINIC

Data & Research Center (DRC)

VANDERBILT UNIVERSITY MEDICAL CENTER · BROAD INSTITUTE · verily · COLUMBIA · SCHOOL OF PUBLIC HEALTH UNIVERSITY OF MICHIGAN · Northwestern Medicine · UTHealth The University of Texas Health Science Center at Houston

Genomics Partners

Baylor College of Medicine · JOHNS HOPKINS MEDICINE · UTHealth The University of Texas Health Science Center at Houston · HudsonAlpha INSTITUTE FOR BIOTECHNOLOGY · BROAD INSTITUTE · color · Mass General Brigham · UNIVERSITY of WASHINGTON

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

Enabling research discoveries that drive more precise approaches to care

Engages people & communities who have been left out of medical research in the past

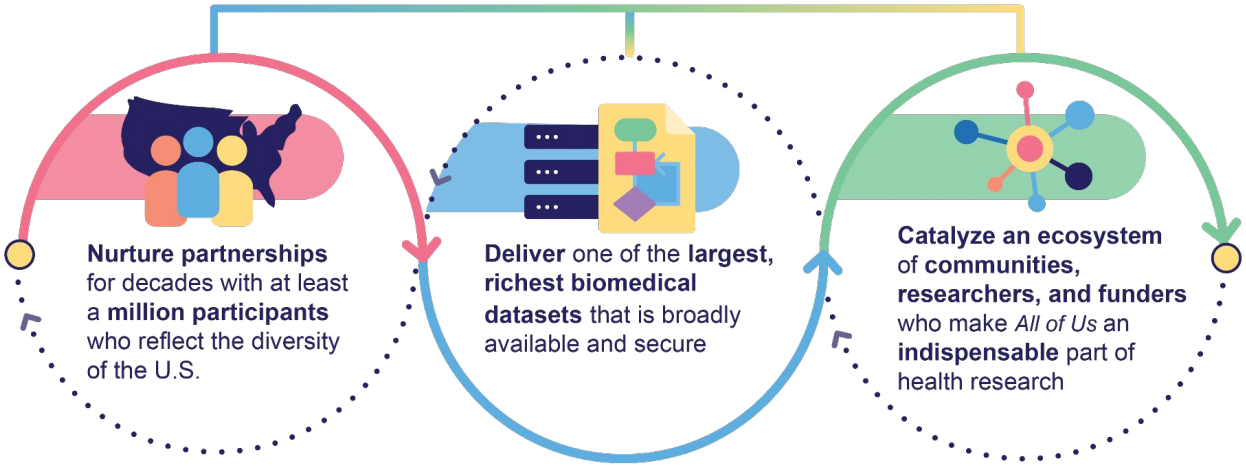
Combines biological factors and social determinants on a large, inclusive scale

Easily accessible to any researcher with a secure internet connection

Follows participants as they move, age, and grow

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

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

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
Represented and searchable through public genomic data browser

Genomics Analysis Tools
Hail and PLINK in addition to R, Python, and Jupyter Notebooks

Genomic Data is Paired with Rich Phenotypic Data

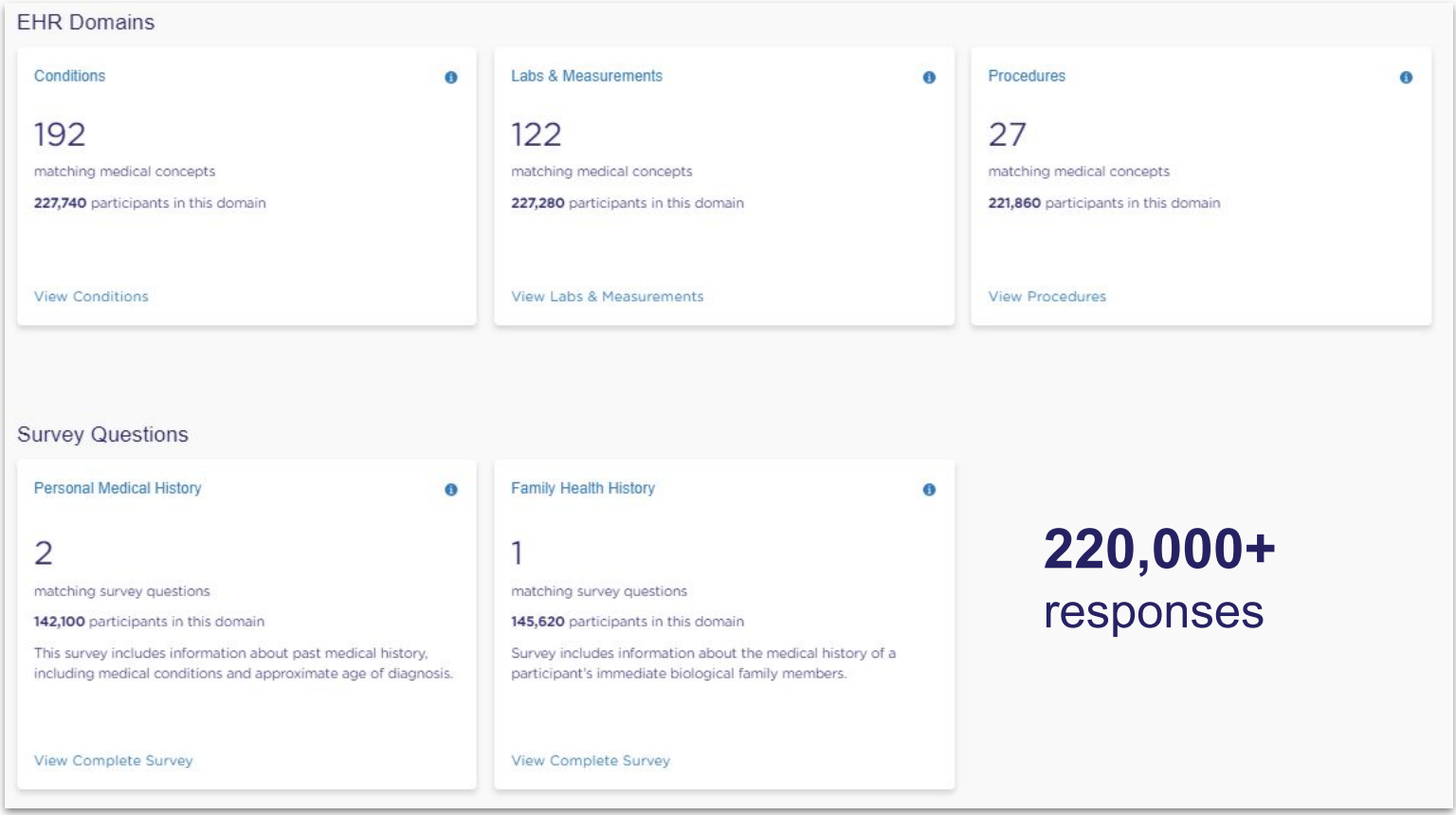
77,000+
Have Whole Genome Sequences + Electronic Health Records + Physical Measurements + Survey Responses

95,000+
Have Whole Genome Sequences + Physical Measurements + Survey Responses

78,200+
Have Whole Genome Sequences + Electronic Health Records

3,500+
Have Whole Genome Sequences + Fitbit Records
Representing >30% of all participant Fitbit records

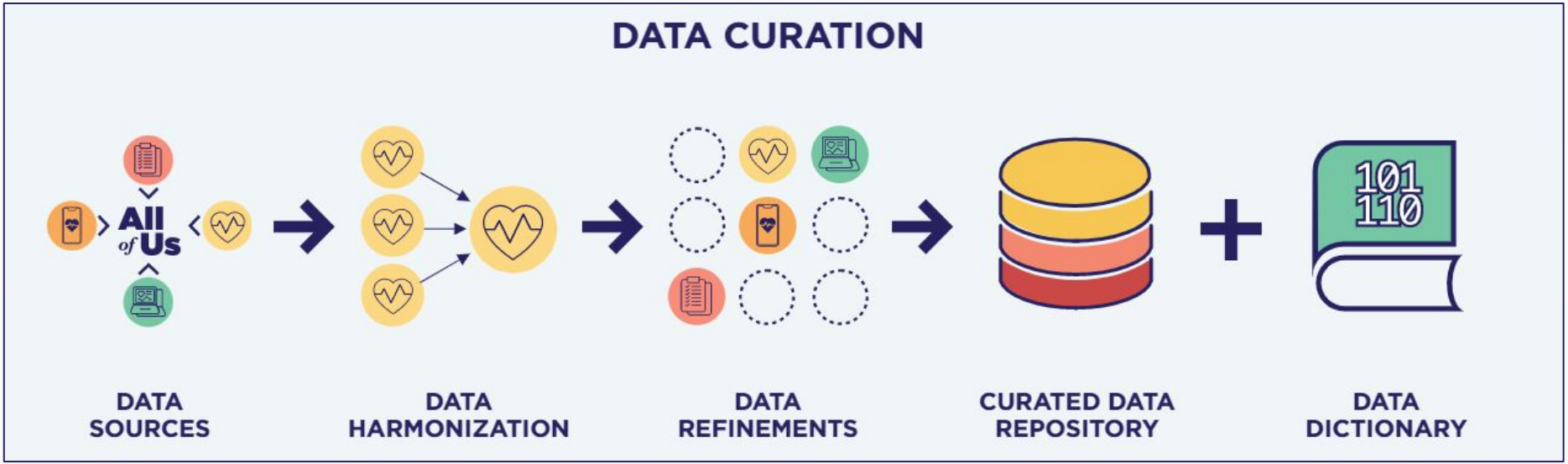
Data Highlight: Cancer



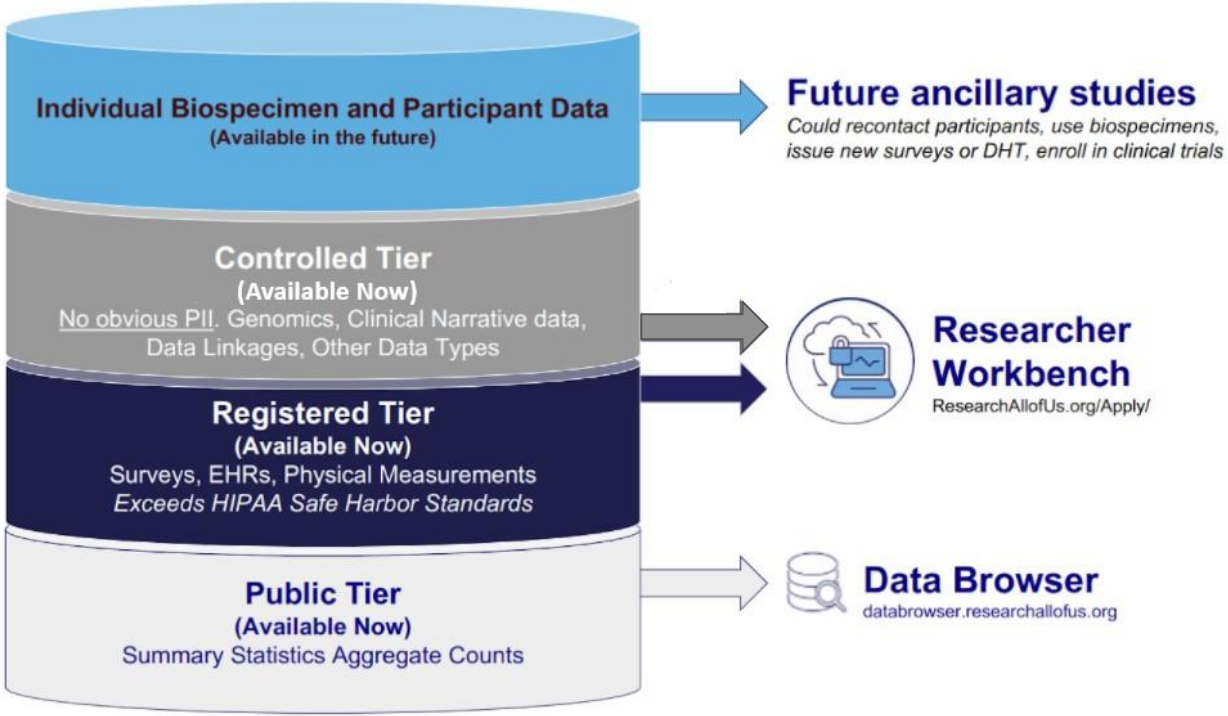
220,000+
responses

Principles of access & privacy: “Share widely and wisely.”

All of Us Research Data Pipeline



Data and resource access is tiered.

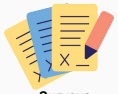


Distinguishing between the Registered and Controlled Tier

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.


Surveys

Electronic Health Records

Physical Measurements

Wearables

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

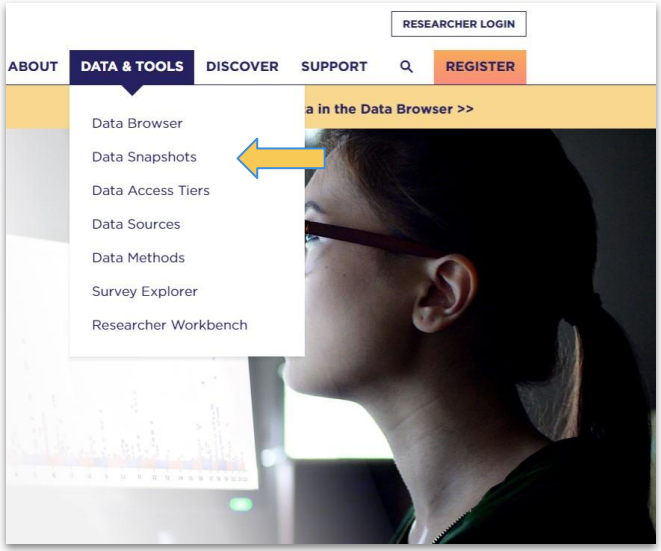
- Expanded demographics
- Responses to entire COPE Survey
- COVID-19 EHR data
- Unshifted event dates
- Genomic data derived from WGS (~100k participants) and array genotyping (>165k participants)

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.



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 JoinAllofUs.org, 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

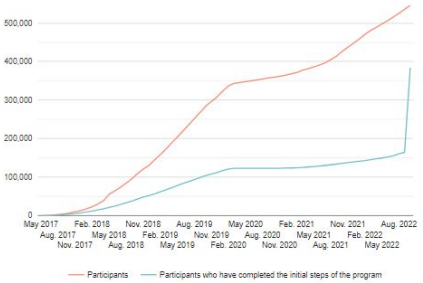
547,000+
Participants

385,000+
Participants who have completed initial steps of the program

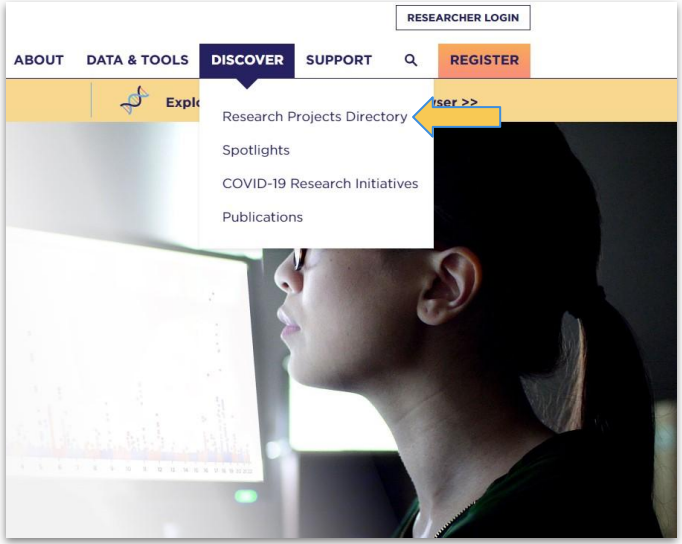
Enrollment Numbers

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 November 6, 2022.



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 Registered Tier or Controlled Tier 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 AllofUs.nih.gov in compliance with the 21st Century Cures Act.

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

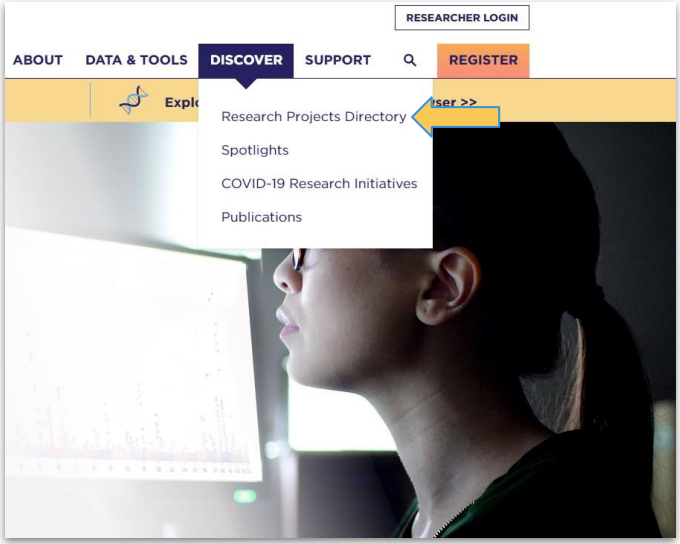
Genetics of complex diseases

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

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 evidence-based standard of care)? Identifying real-world practice patterns based on SDOH can reveal where efforts can be directed to improve oncologic outcomes.

PROJECT PURPOSE(S)

- Disease Focused Research (prostate cancer)
- Social / Behavioral
- Control Set
- 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 treatment), 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

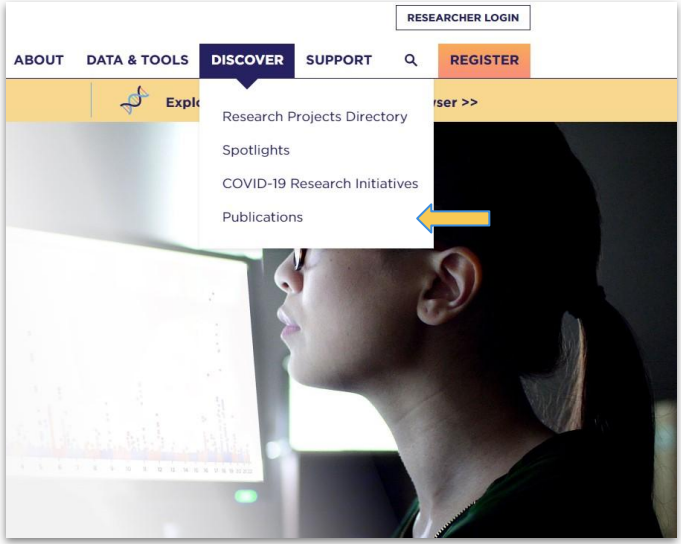
- Race / Ethnicity
- Geography
- Access to Care
- Education Level
- Income Level

DATA SET USED
Controlled Tier

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

SORT BY: DATE ↓ | TITLE ↑

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.

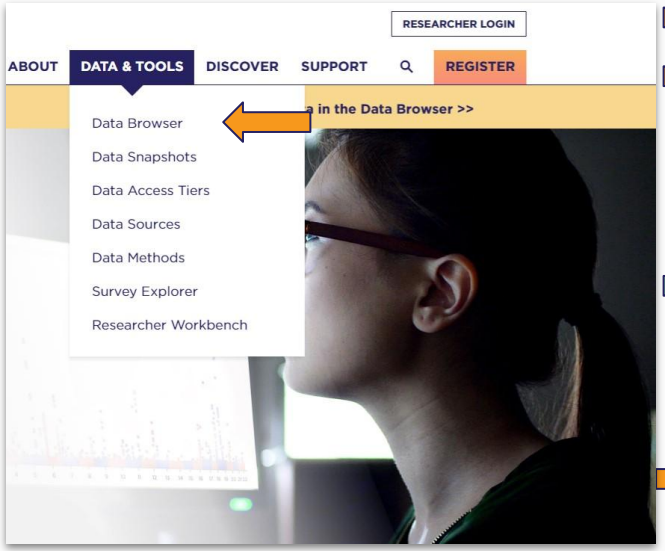
Zhang Z, Yan C, Malin BA. J Am Med Inform Assoc. 2022 Aug 4:ocac131. doi: 10.1093/jamia/ocac131. Epub ahead of print. PMID: 35927974.

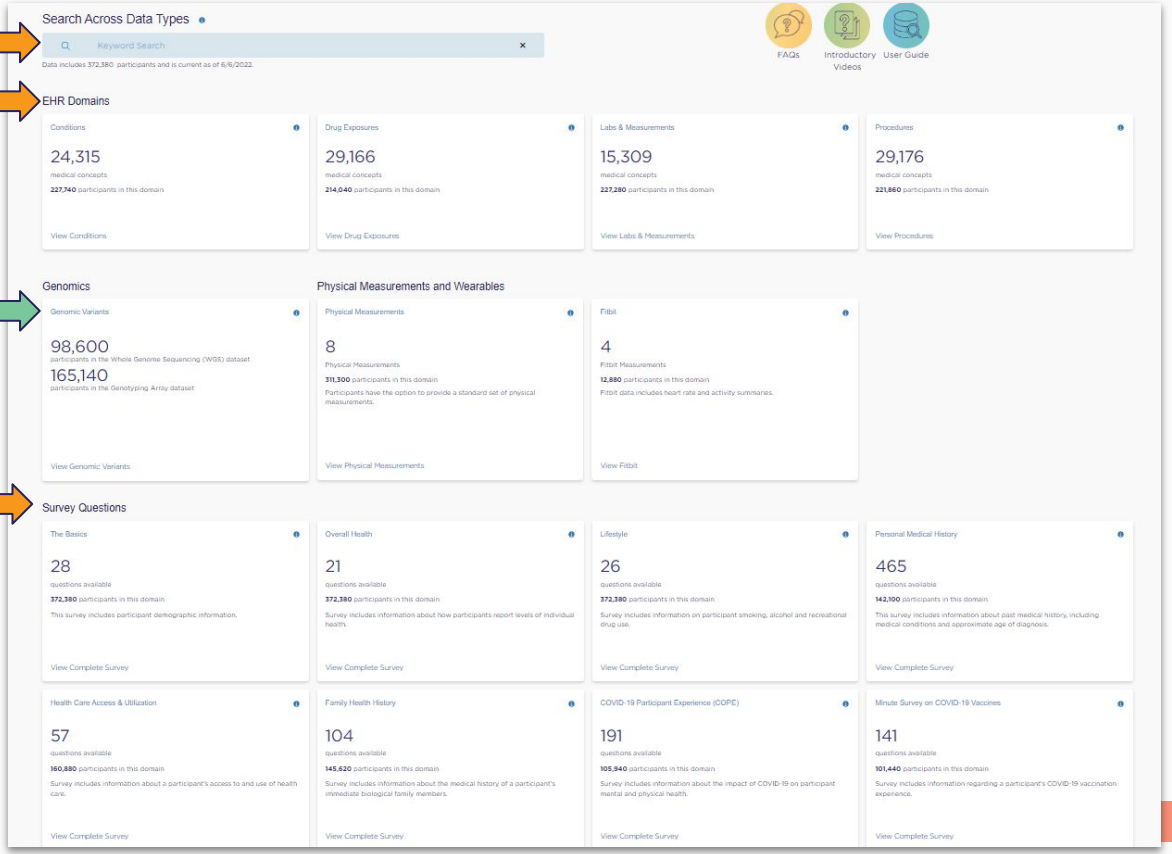
August 4, 2022

All of Us RESEARCH PROGRAM

Exploring the Data - The Data Browser & Survey Explorer

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





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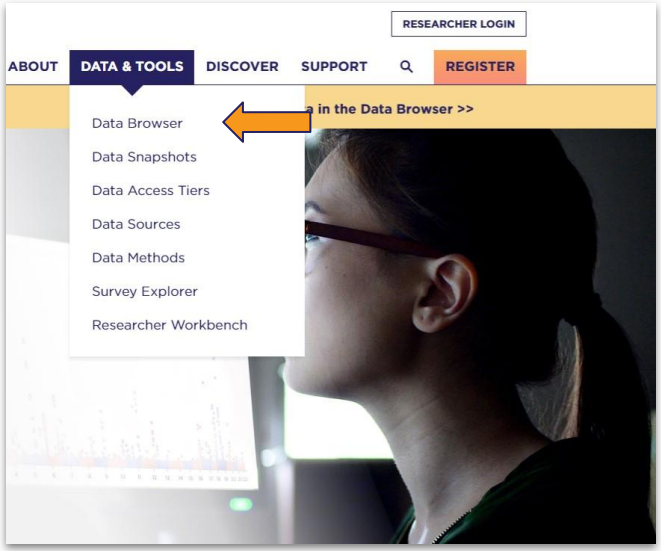

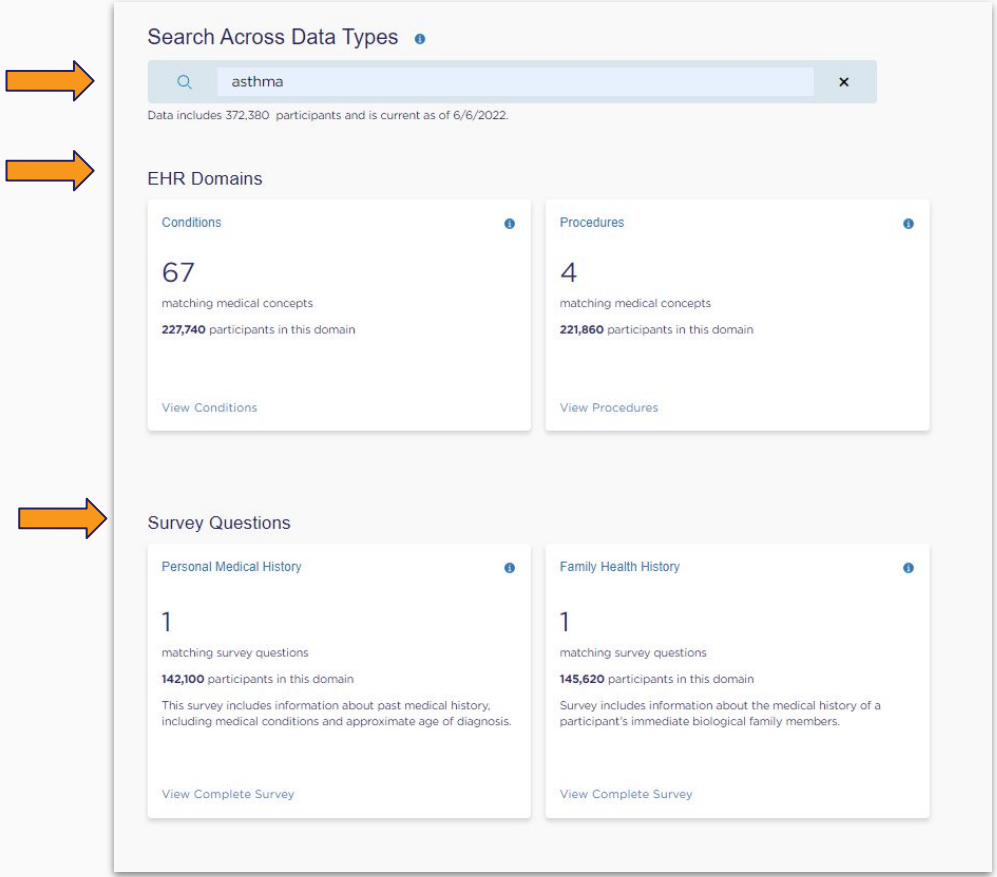

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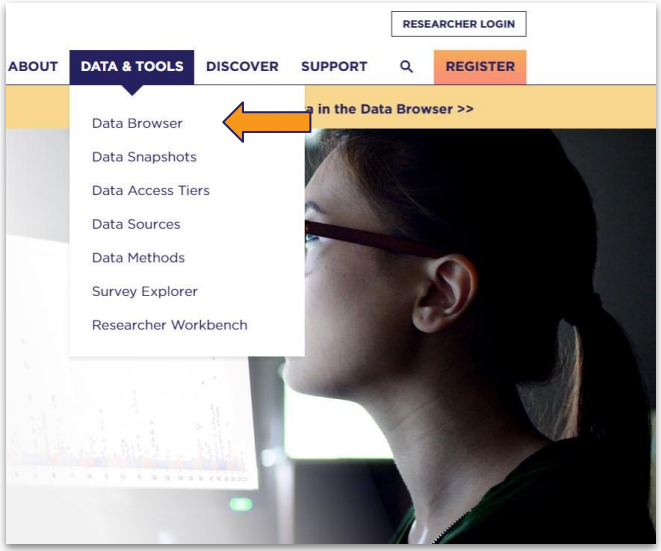

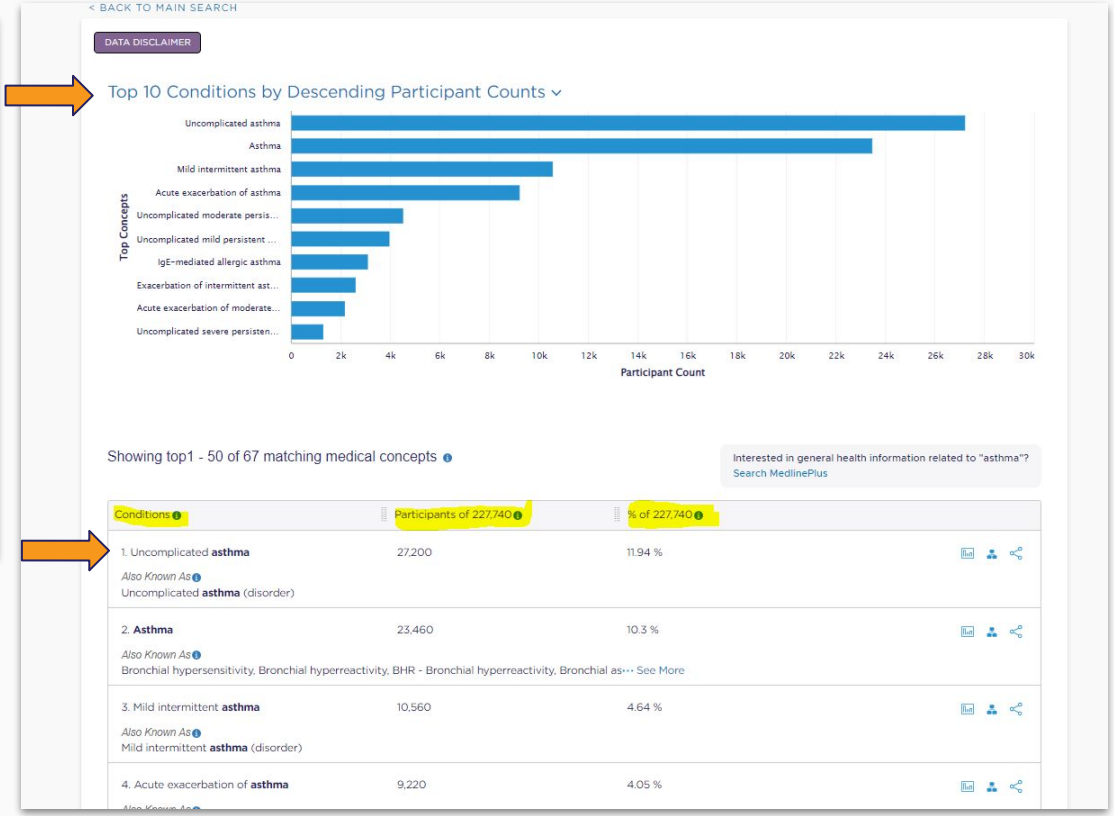

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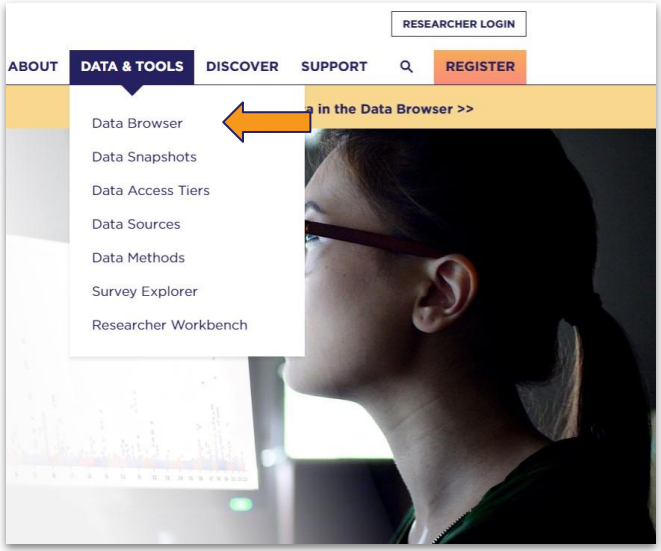
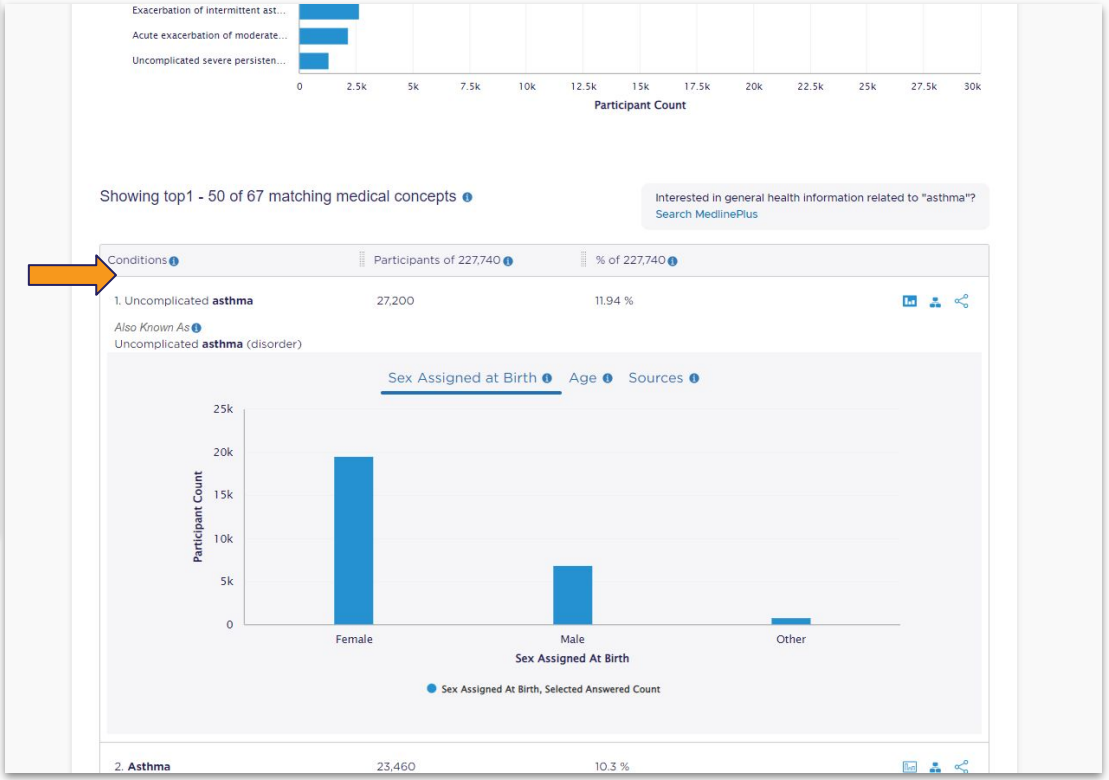
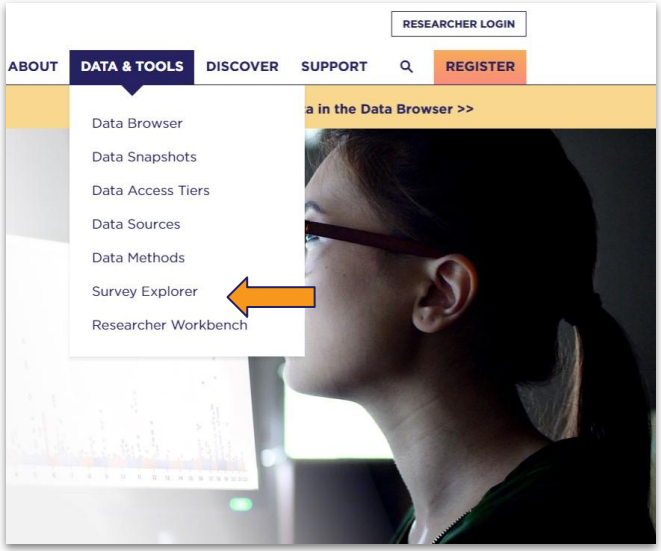
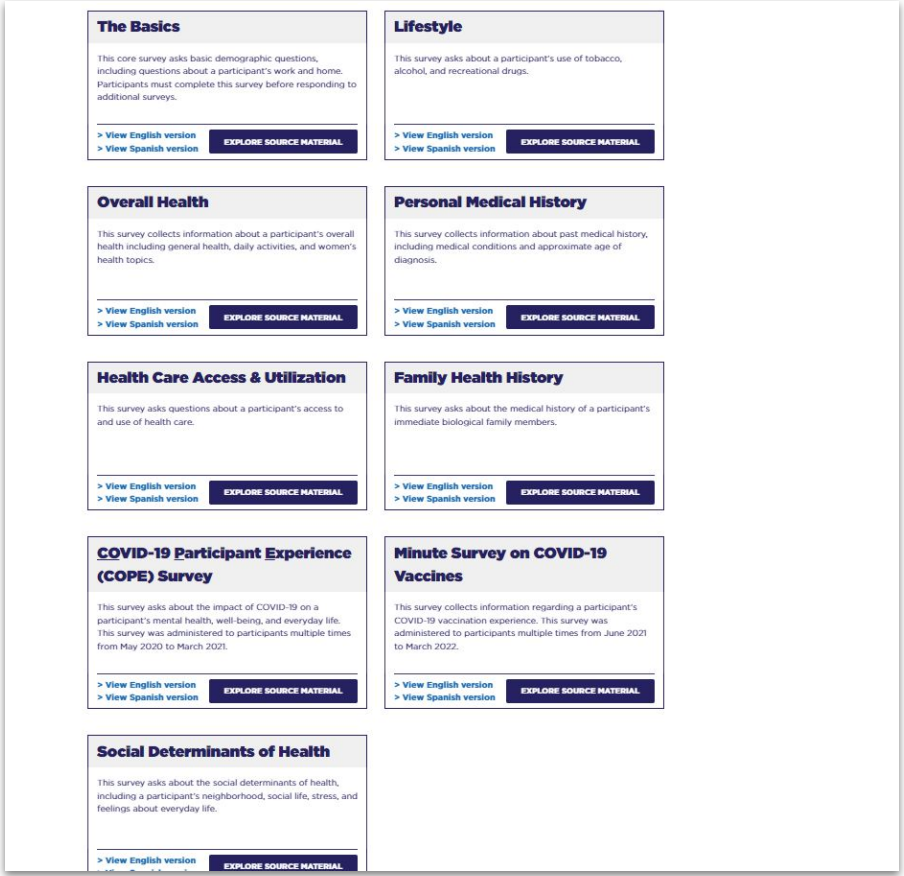




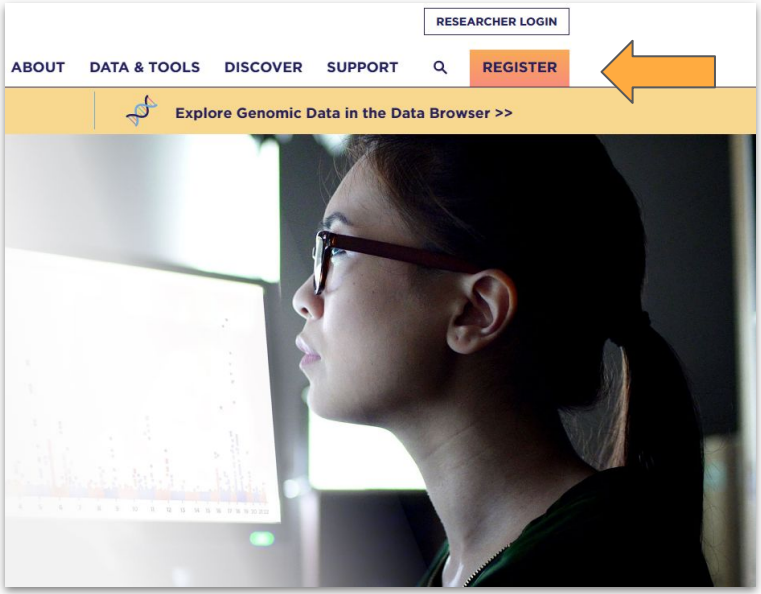
The Survey Explorer hosts all surveys available to participants.





How to Register

Registration is easy!



How to Register

STEP 1

LEARN MORE ABOUT THE DATA AVAILABLE

Explore the data available through the Data Browser, which provides interactive views of aggregate-level participant data. Learn about individual-level data access tiers and the Researcher Workbench tools.

STEP 2

CHECK FOR YOUR INSTITUTION'S AGREEMENT

Before you can register, your institution must have a Data Use and Registration Agreement in place with *All of Us* to ensure data security.

STEP 3

CREATE A RESEARCHER WORKBENCH ACCOUNT

Complete your researcher profile, sign the Terms of Service, and agree to the Privacy Policy.

STEP 4

VERIFY YOUR IDENTITY USING LOGIN.GOV

Verify your identity using Login.gov. You may need to provide an SSN and a state-issued ID. Your institution may also require you to use an eRA Commons account. If so, contact your institution directly. Read more about Login.gov.

STEP 5

COMPLETE *ALL OF US* RESEARCH TRAINING

The mandatory training provides education on conducting responsible and ethical research with data from *All of Us* participants. Please allow at least one hour to complete.

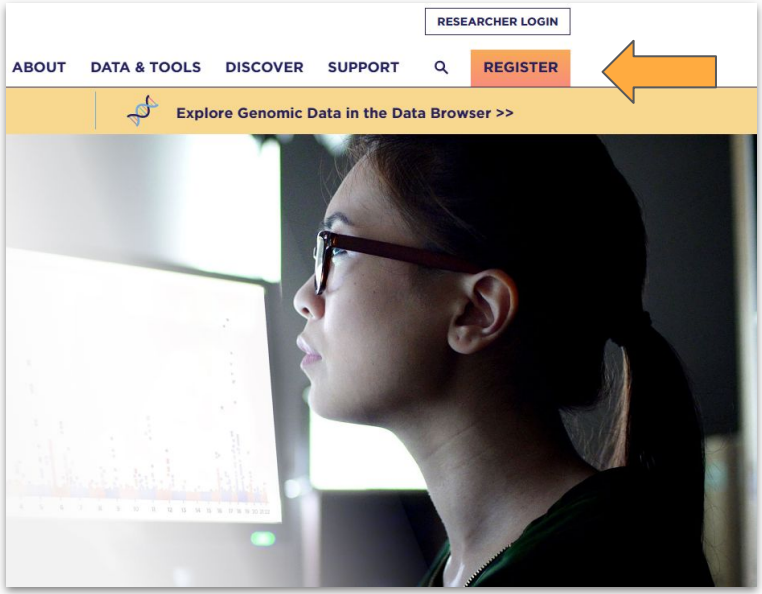
STEP 6

SIGN THE DATA USER CODE OF CONDUCT

The Data User Code of Conduct is an agreement that outlines the program's expectations for researchers.

REGISTER

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



Institutional Agreements

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, submit a request.

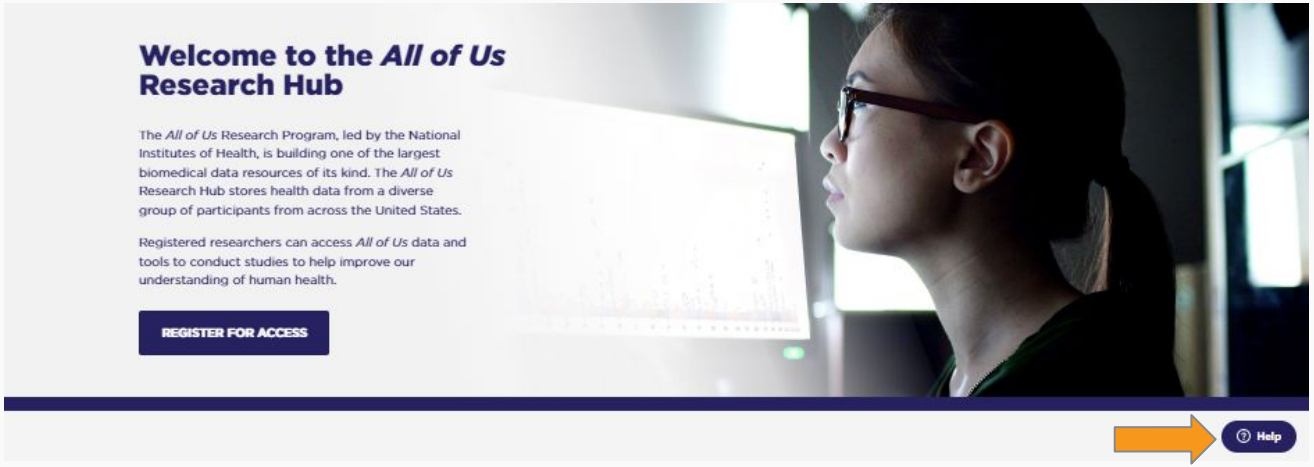
428
Institutions Have Agreements in Place

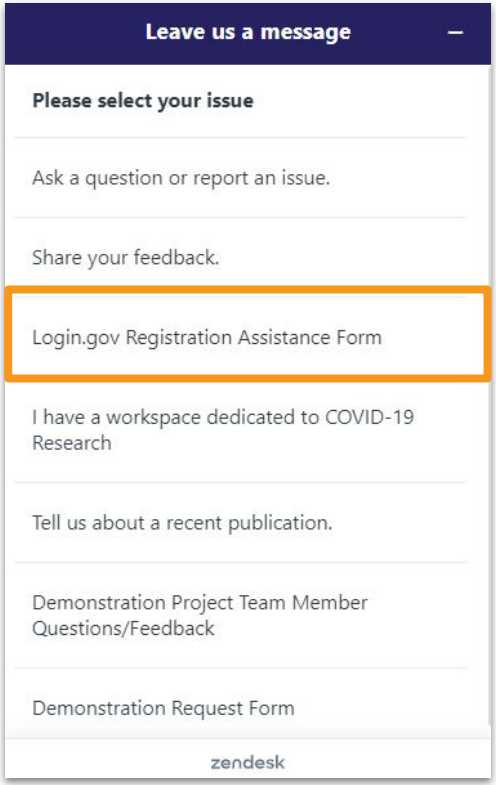
Quick search - enter your institution's name

Key: R Registered Tier · C Controlled Tier · i Individual agreements required by institution · e eRA Commons required by institution

Institution	Access Level	*Contact at Institution*
A.T. Still University of Health Sciences	R C	*Gayla Sublette*
AI LA Community, Inc	R C	*Todd Terrazas*
Alabama Agriculture and Mechanical University	R	*Damian Clarke*
Alabama College of Osteopathic Medicine	R C	*Carmen Lewis*
Albany State University	R C	*Louise Wrensford*
Albert Einstein College of Medicine	R C	*John M. Greally*
All of Us Researcher Academy/RTI International	R C	*Julie Durway*

Assistance with Registration





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.**

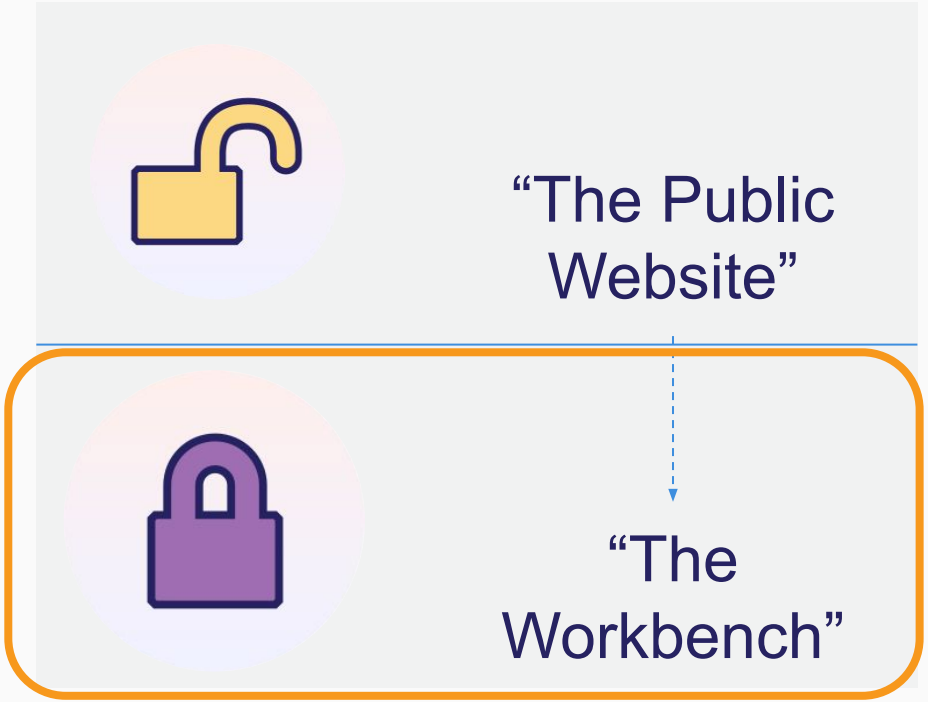
- Team science
- Dissertation
- Thesis
- Poster presentations
- Class projects
- Self-practice (especially data science)

All of Us RESEARCH PROGRAM

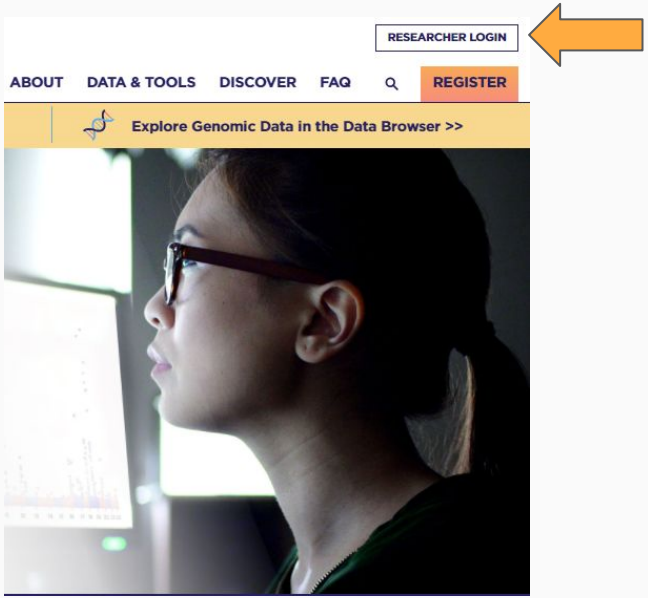
The Researcher Workbench and how to start a research project

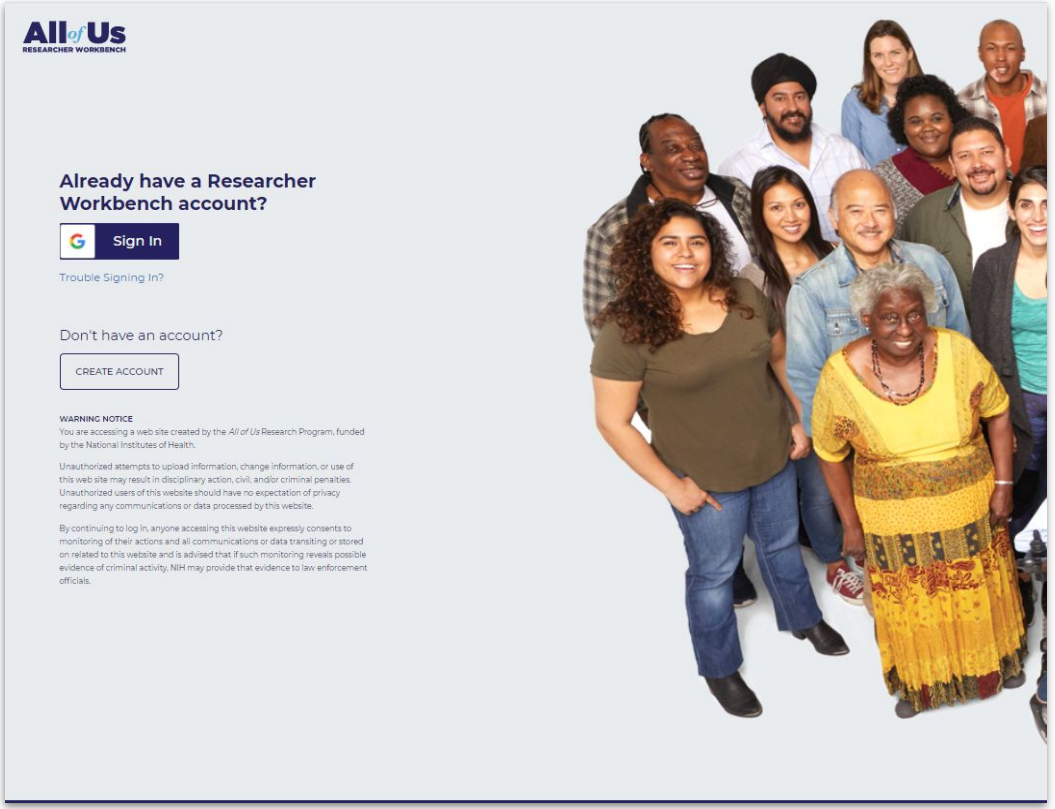
The Researcher Workbench

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



Login from the Hub to access your Workspaces.

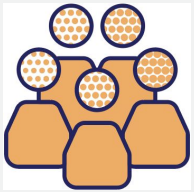




The Researcher Workbench = secure cloud analysis platform

WORKSPACES

DATASET BUILDER



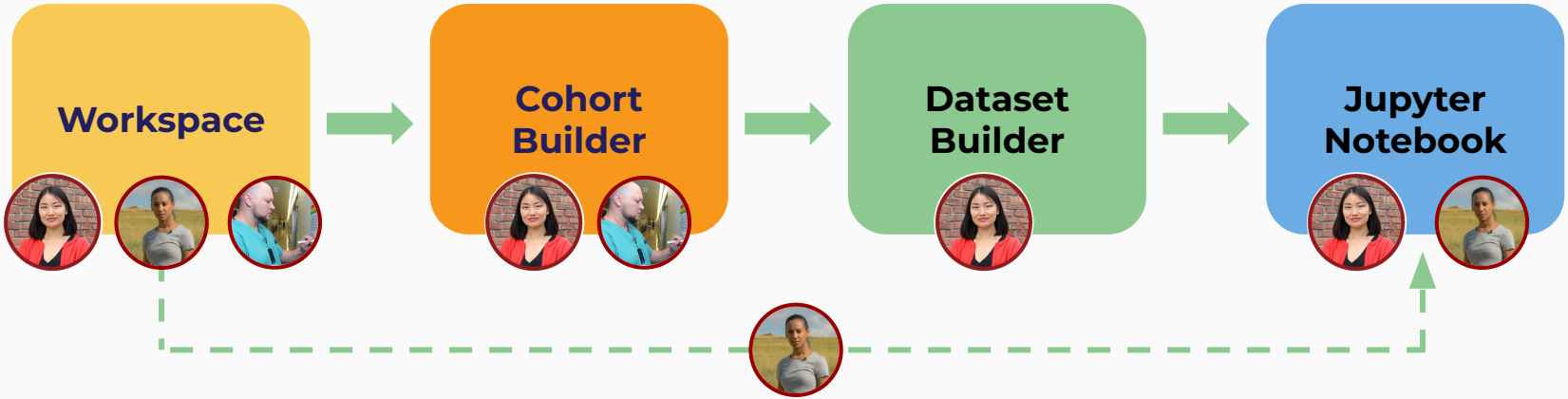
COHORT BUILDER

NOTEBOOKS

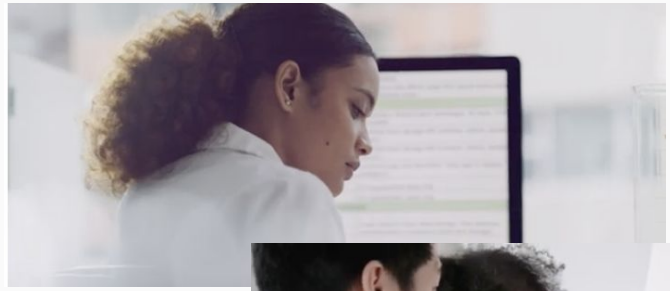
WORKBENCH USER SUPPORT HUB

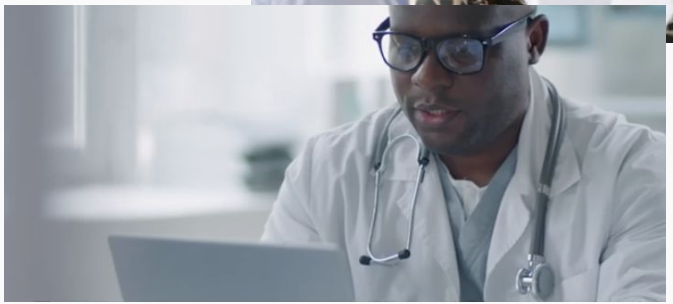
The Workbench is Collaborative

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



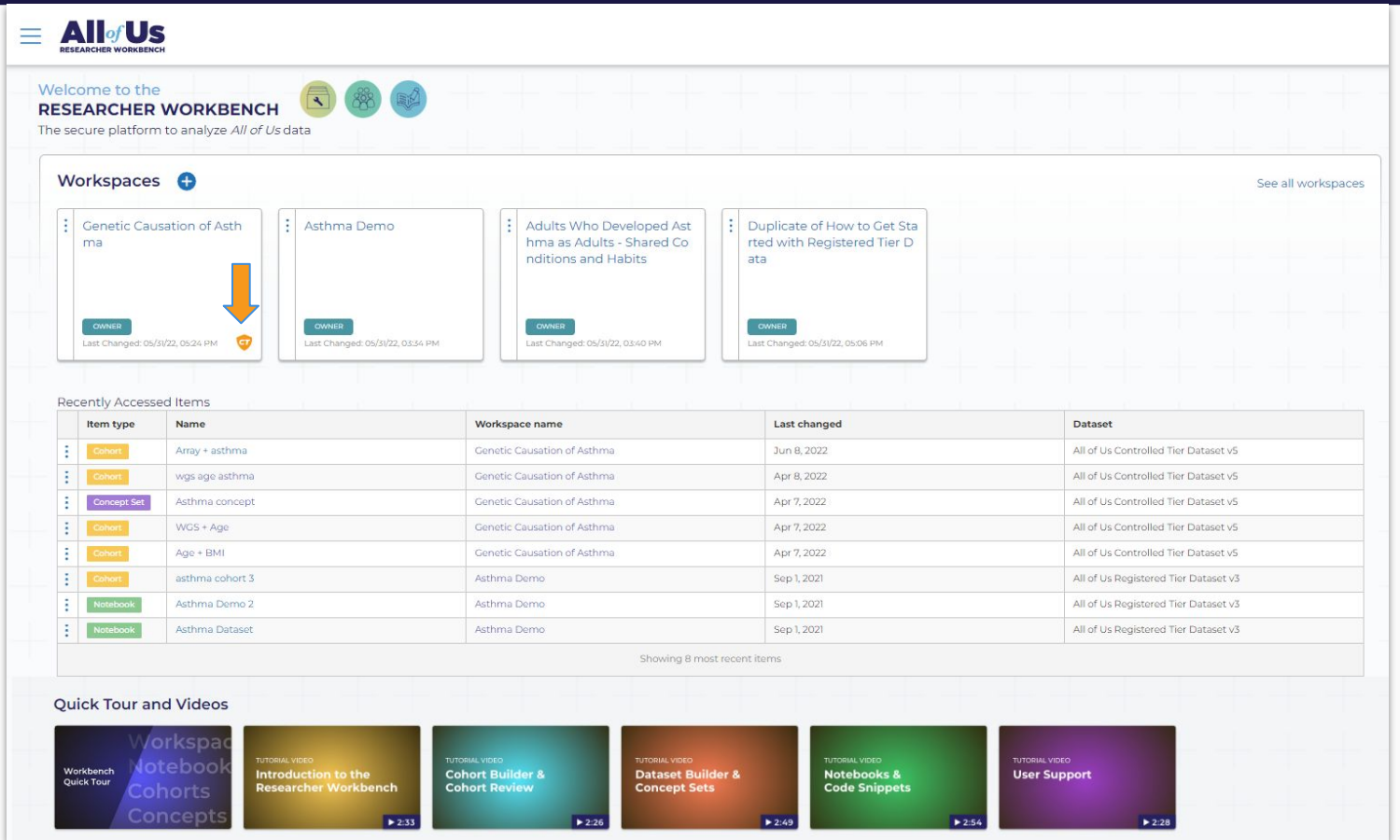
No IRB approval needed.



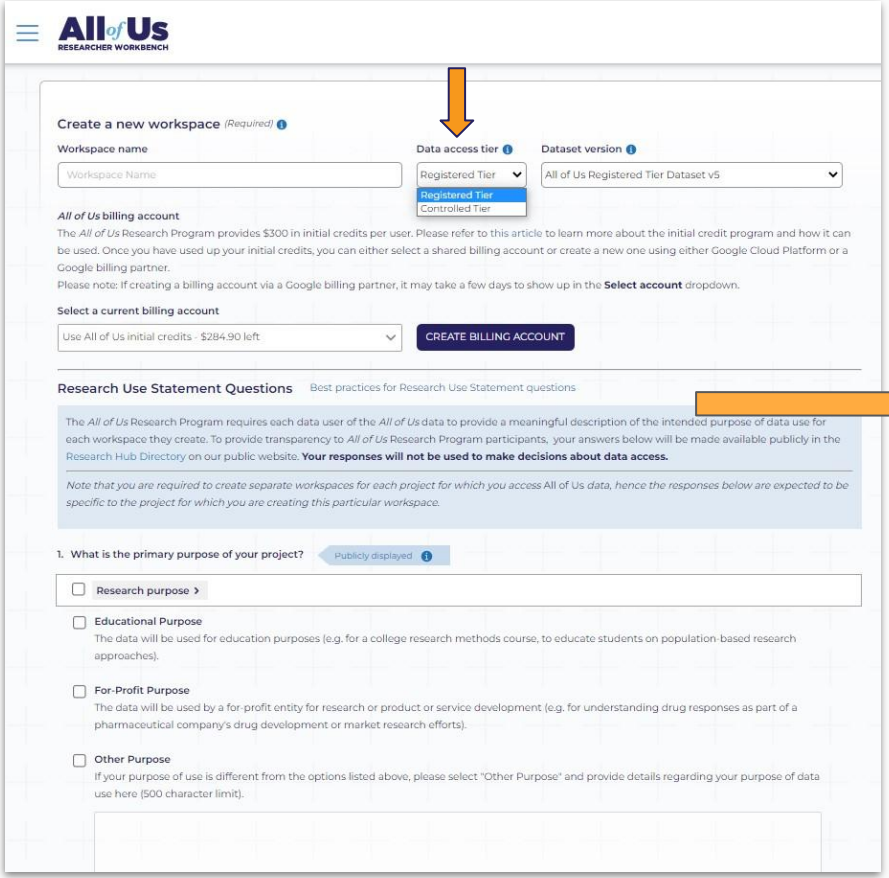


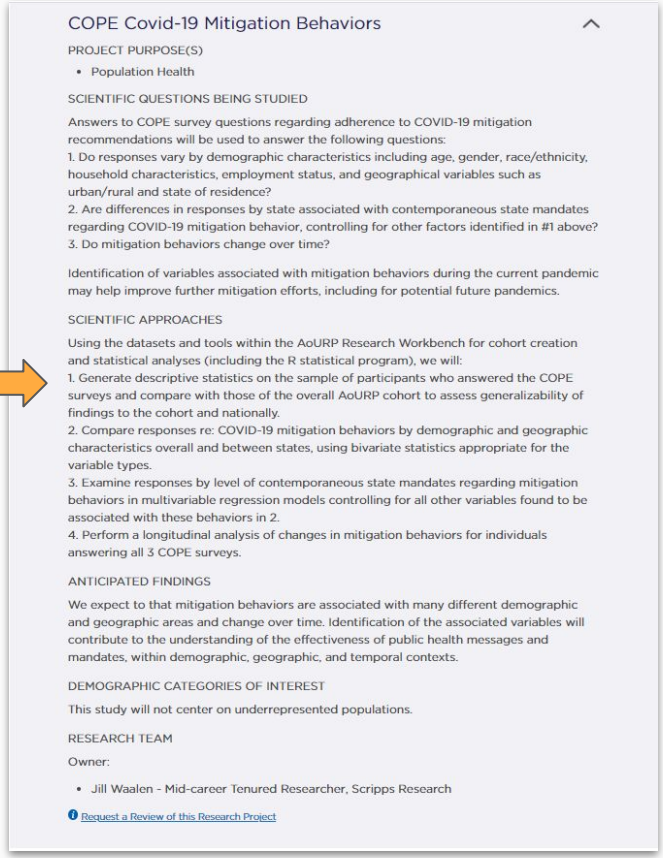
We use a passport model and approve the researcher

The Workbench landing page

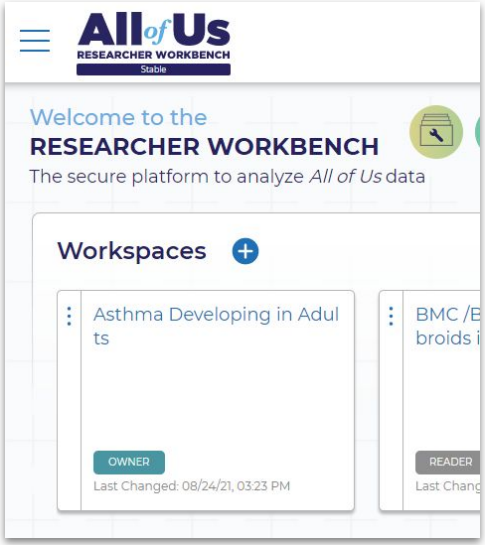


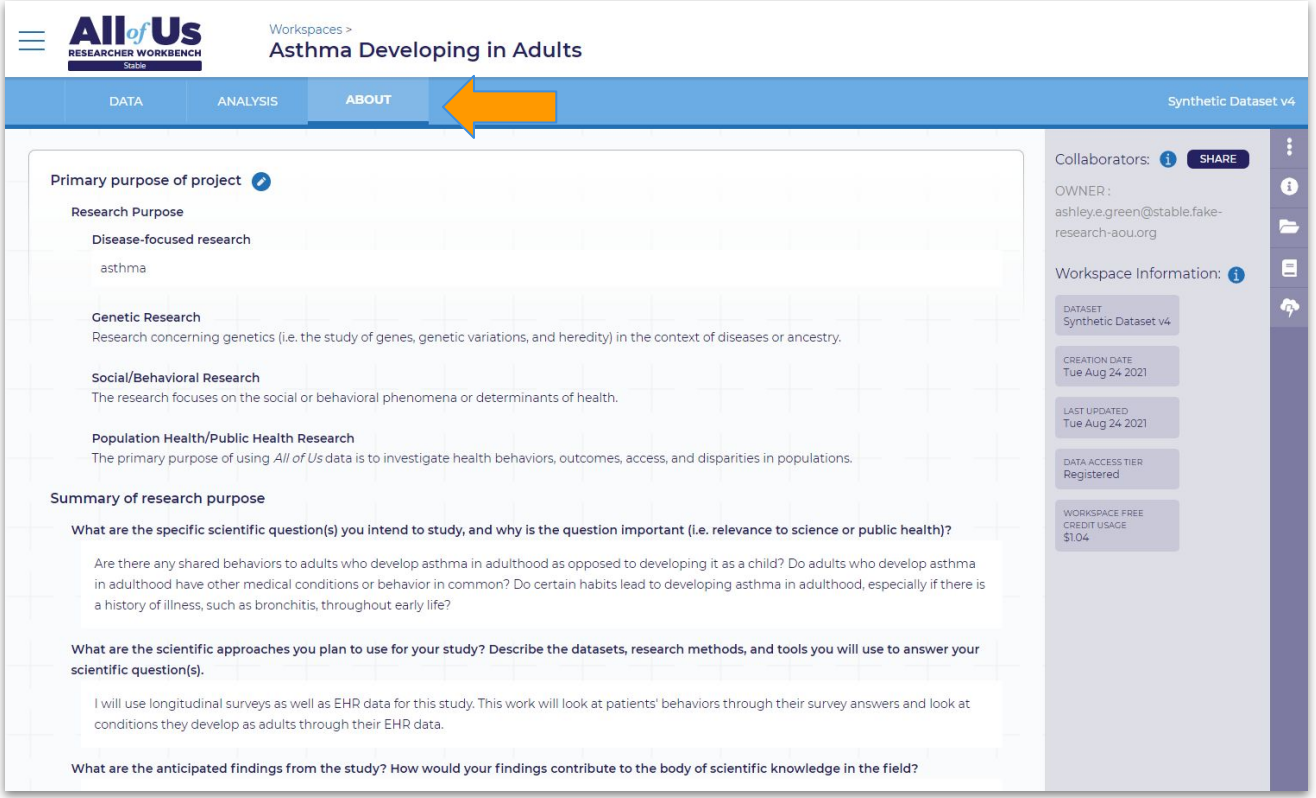
Answer questions about your Workspace.





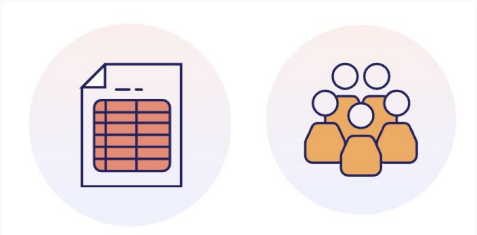
The About tab provides information about your Workspace.



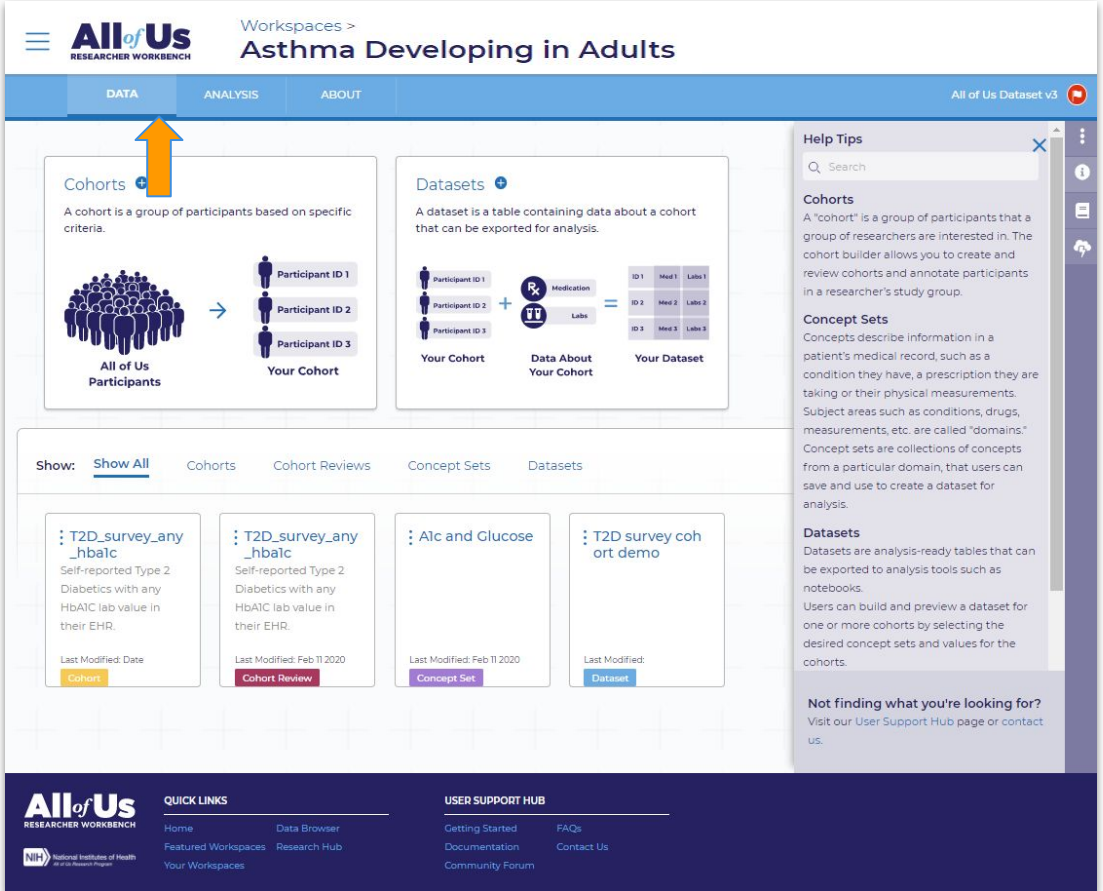


WORKSPACES

The Data tab is where you begin building your research.

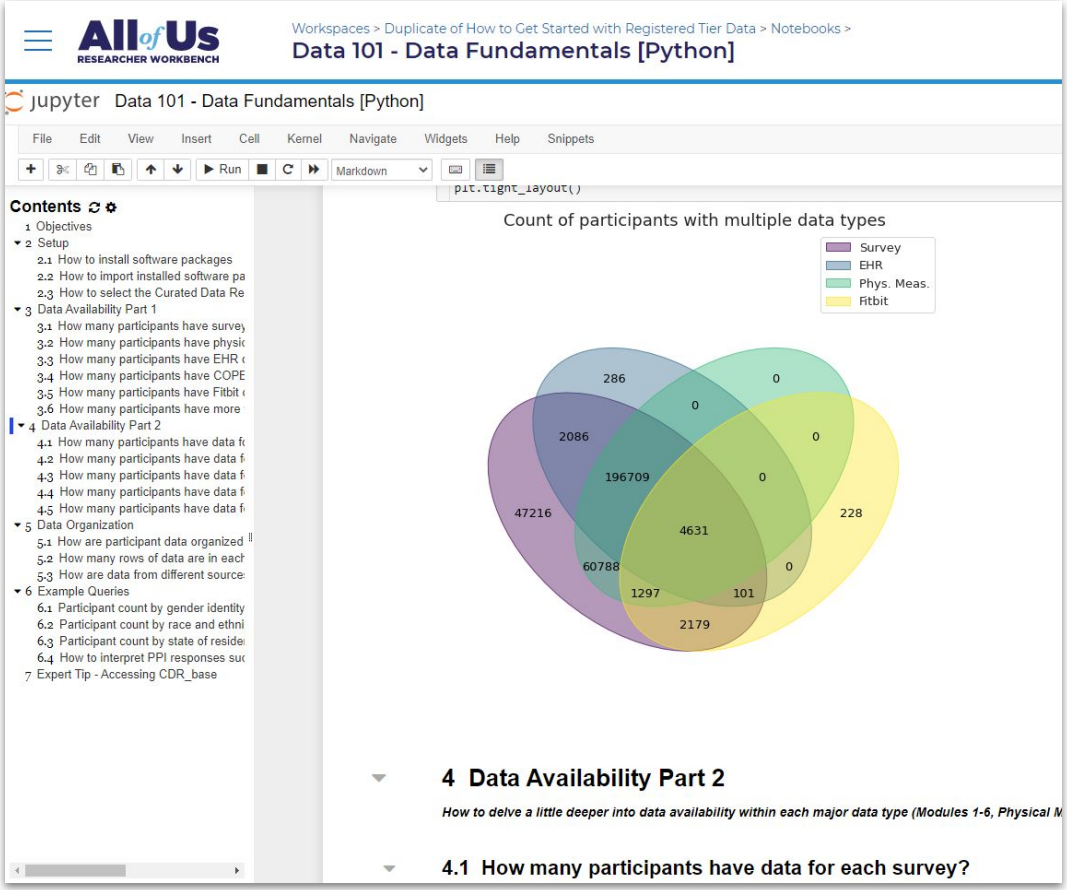


Cohort + Dataset Builders



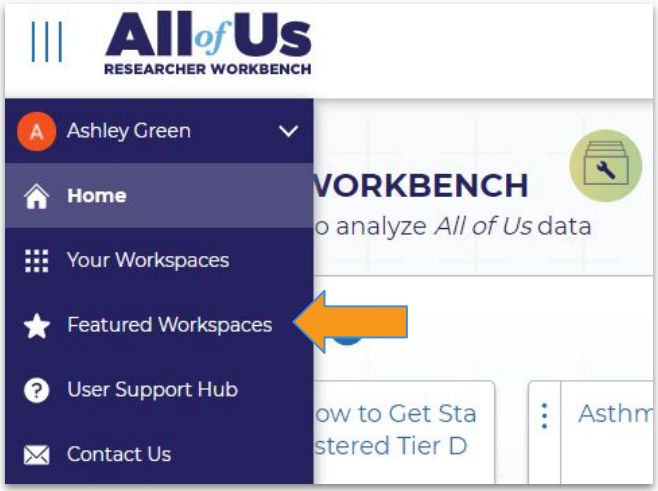
The Jupyter Notebook is where you will run your analysis.

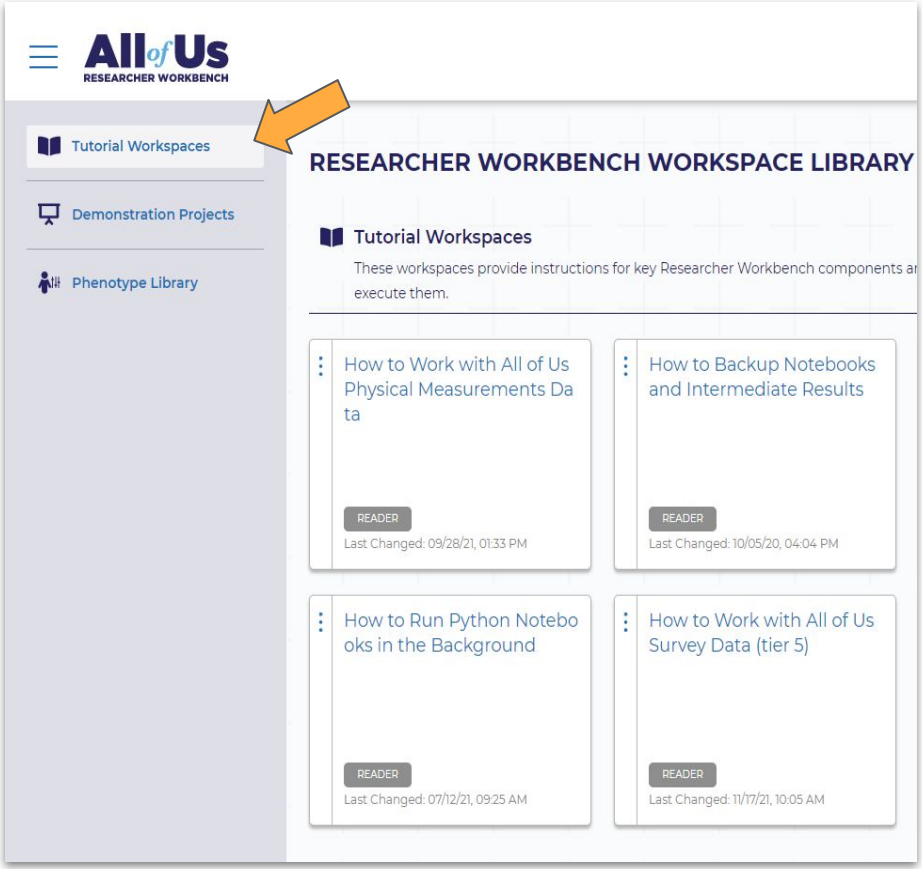
Notebooks for analysis



Support Resources

The Featured Workspaces can help you during your research.





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

Monthly
link emailed to all registered users

Office Hours

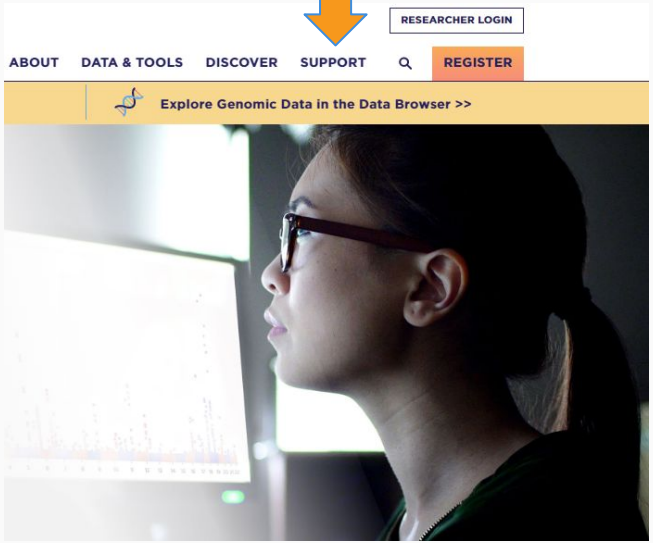
Get live, virtual help with questions.

Ask your questions live:

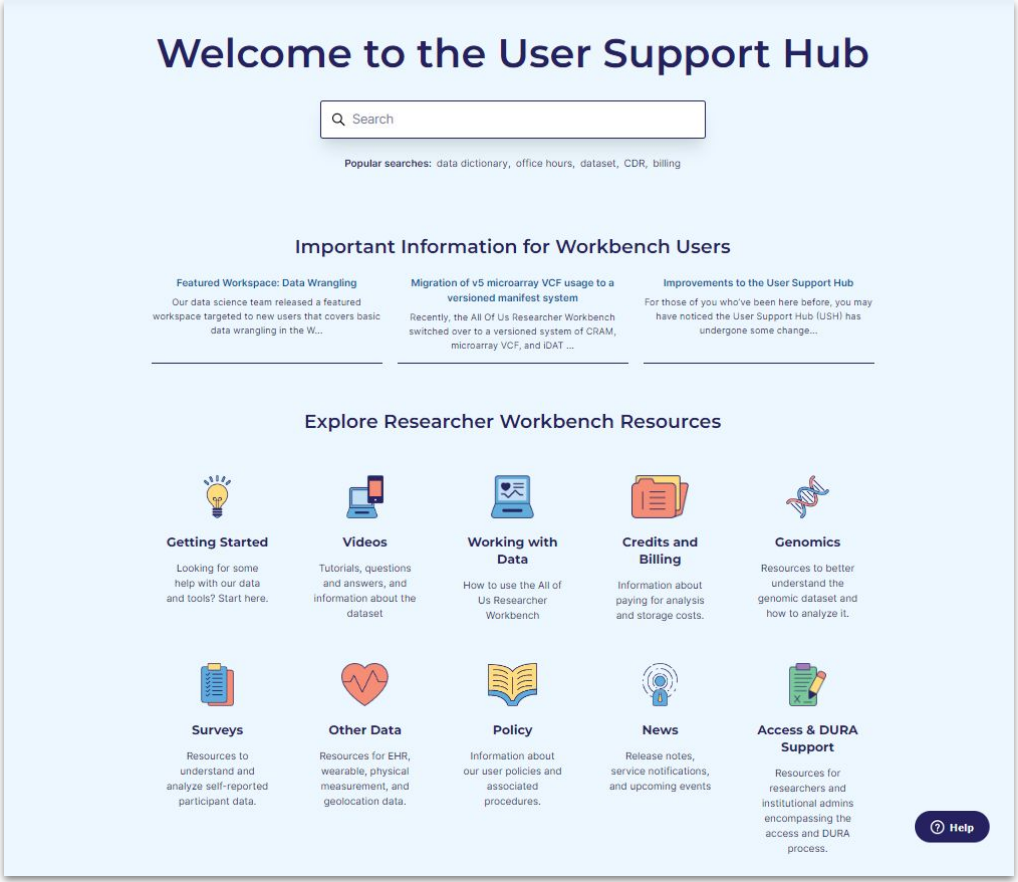
- Workflow implementation questions
- Data refreshers and updates
- Billing questions
- and more…

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

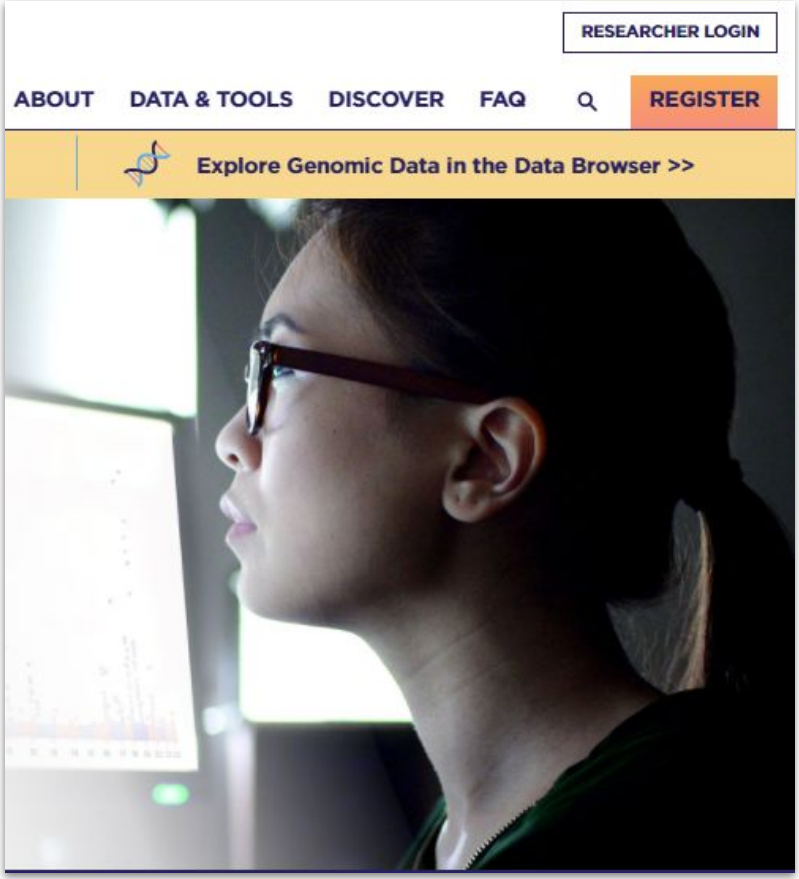
The Support Hub and Team are here to help you!



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



Join our community of researchers!



Help us connect with other researchers!

Email **ashley.e.green@vumc.org** if you know of others interested in demos or training sessions

@AllofUsResearch
#JoinAllofUs