AAPA- PAEA Research Fellowship



Exploring the All of Us Research Hub



August 12, 2021

Courtney Wallin, PhD
NIH's *All of Us* Research Program

Adrienne Roman, PhD

All of Us Data and Research Center



Goals of Today's Presentation

- Share the mission and objectives of the All of Us Research Program
- Offer AAPA-PAEA Research Fellows an opportunity to learn more about the All of Us Research Hub and how to access data, tools, and surveys



All of Us Research Program Overview

Thank you to our <u>participants</u> and community partners!



All of Us Community and Provider Partner Network (as of Jan 2021)



















































































Thank you to our consortium partners!

The Participant Center























PARTNERS

BOSTON!















BlueCross. BlueShield





All of Us New England

BRIGHAM HEALTH

BRIGHAM AND WOMEN'S HOSPITAL

MASSACHUSETTS

GENERAL HOSPITAL









HPO Network

(Health Care Provider Organizations)

RMCs

All of Us California

UC San Diego Health

UCI Health









All of Us Wisconsin

Illinois Precision Medicine

Consortium





















Trans America Consortium



Essentia Health

BaylorScott&White

SPECTRUM HEALTH

RELIANT

Part of OntumCare®

HealthPartners

Banner Health



New York City

Consortium



COLUMBIA UNIVERSITY

MEDICAL CENTER



All of Us Southern Network





SCHOOL OF MEDICINE

LSU Health





LSA HEALT

FQHCs (Federally Qualified Health Centers)





THE UNIVERSITY OF ALABAMA®

Cooper Green Mercy

All of Us SouthEast **Enrollment Center**

UNIVERSITY OF MIAMI MILLER SCHOOL of MEDICINE











VA Medical Centers















University of Arizona and















Froedtert



Data & Research Center (DRC)









Commun*ty

























Participant Technology Biobank **Systems Center (PTSC)** vibrent ∺

The All of Us Research Program: An Innovative Research Effort

- Diversity at the scale of 1 million people or more
- Focus on participants as partners
- Longitudinal design, ability to recontact



- Multiple data types: EHR, surveys, baseline physical measurements, biospecimens, genomics
- National, open resource for all: broadly accessible to all researchers with open-source software & tools
- Security and privacy safeguards for all participant data

The All of Us Research Program: Our Mission

Nurture relationships

with one million or more participant partners, from all walks of life, for decades



Our Mission

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



that is easy, safe, and free to access



Catalyze the robust ecosystem

of researchers and funders hungry to use and support it



Build and maintain a strong All of Us Team

capable of achieving the program's mission

Building a Diverse All of Us Researcher Cohort

• <u>Creating a demographically diverse researcher cohort</u>: promote responsible and ethical use of our data, return value to our participant communities, and accelerate research impact.

 Encouraging student assemblies and early-stage investigators: bring fresh, creative perspectives & innovative research outcomes.

 Ensuring access for researchers from various institutions/organizations: establish a truly equitable resource for all.

How will All of Us lead to discoveries?

Participants Share Data

Participants share health data online. This data includes health surveys and electronic health records. Participants also may be asked to share physical measurements and blood and urine samples.



In the future, approved researchers will use this data to conduct studies. By finding patterns in the data, they may make the next big medical breakthroughs.

Researchers Share Discoveries

Research may help in many ways. It may help find the best ways for people to stay healthy. It may also help create better tests and find the treatments that will work best for different people.



Data Is Protected

Personal information, like your name, address, and other things that easily identify participants will be removed from all data. Samples—also without any names on them—are stored in a secure biobank.

Participants Get Information

Participants will get information back about the data they provide, which may help them learn more about their health.

Current All of Us Protocol



Enroll, Consent and Authorize EHR

Recruiting 18+ years old initially; plan to include children in future

Online, interactive consent

Includes authorization to share EHR data



Answering Surveys



- The Basics
- Overall Health
- . Lifestyle
- Health Care Access & Utilization
- Family Medical History
- Personal Health History

Additional surveys will be released on an ongoing basis.



Physical Measurements*

Blood pressure

Heart rate

Height

Weight

BMI

Hip circumference

Waist circumference

*Based on diverse sampling and capacity



Provide Biosamples*

Blood (or saliva, if blood draw is unsuccessful)

Urine specimen

Biosamples will be stored at the program's biobank

*Based on diverse sampling and capacity



Wearables and Digital Apps

Share data from wearable fitness devices, starting with Fitbit

Coming soon:

Integrated apps to track mood & cardio-respiratory fitness

All of Us Scientific Framework

All of Us can enable research that will:

- Increase wellness and resilience, and promote healthy living
- Reduce health disparities and improve health equity in populations that are historically underrepresented in biomedical research (UBR)
- Develop improved risk assessment and prevention strategies to preempt disease
- Provide earlier and more accurate diagnosis to decrease illness burden
- Improve health outcomes and reduce disease impact through improved treatment and development of precision interventions

How will All of Us lead to discoveries?

All of Us can enable research that will:

- Increase wellness and resilience, and promote healthy living
- Reduce health disparities and improve health equity in populations that are historically underrepresented in biomedical research (UBR)
- Develop improved risk assessment and prevention strategies to preempt disease
- Provide earlier and more accurate diagnosis to decrease illness burden
- Improve health outcomes and reduce disease impact through improved treatment and development of precision interventions

Example Use Case: Blood Pressure



Health Equity

What is the impact of economic stability on rates of screening, likelihood of receiving treatment, and blood pressure levels?



Risk & Prevention

How do age-related changes in blood pressure in children and young adults impact the development of hypertension and hypertension-related conditions in adulthood?



Diagnosis

Does ambulatory blood pressure monitoring (ABPM) or home blood pressure monitoring (HBPM) provide a more accurate estimate of cardiovascular risk?



Wellness & Resilience

What genomic, environmental, and lifestyle factors underlie the different patterns in age-related trajectories of blood pressure, thereby increasing or reducing the risk of high blood pressure?



Treatment & Outcomes What are effective and scale

What are effective and scalable community-based interventions to improve blood pressure levels, medication prescription and medication fill rates?



All of Us Research Hub

The All of Us Research Hub



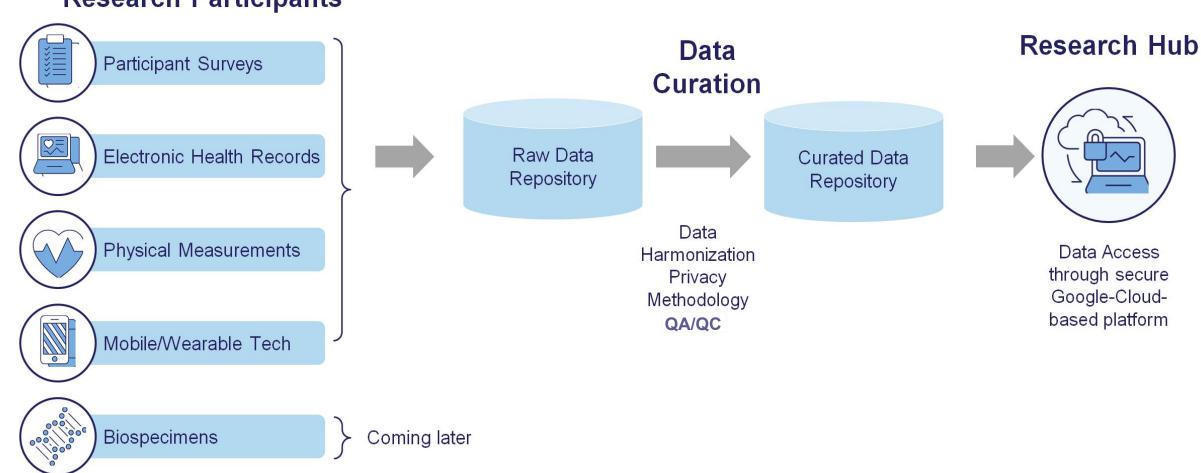
Learn. Discover. Connect.

https://www.researchallofus.org/



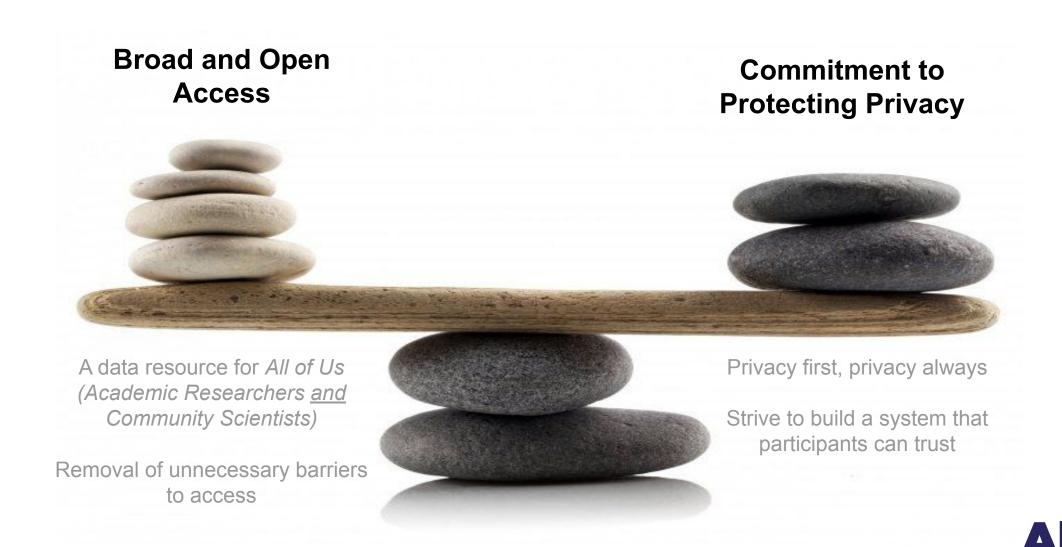
All of Us Research Data Pipeline

Data Collection from Consented Research Participants

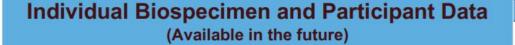




Principles of Access & Privacy: "Share Widely and Wisely"



Data and resource access is tiered.



Controlled Tier

(Available in the future)

No obvious PII. Genomics, Clinical Narrative data,

Data Linkages, Other Data Types

Registered Tier

(Available Now)

Surveys, EHRs, Physical Measurements

Exceeds HIPAA Safe Harbor Standards

Public Tier

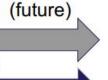
(Available Now)

Summary Statistics Aggregate Counts



Future ancillary studies

Could recontact participants, use biospecimens, issue new surveys or DHT, enroll in clinical trials





Researcher Workbench ResearchAllofUs.org/Apply/





The Research Hub

The Research Hub is home to *All of Us* data, research tools, and research projects.

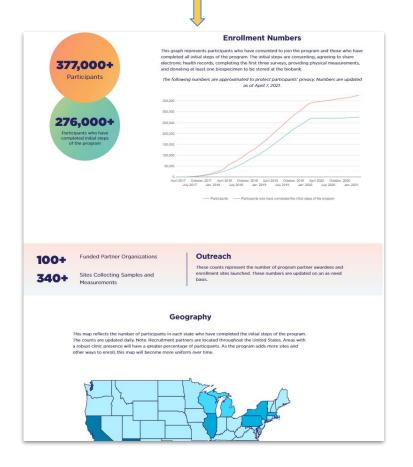




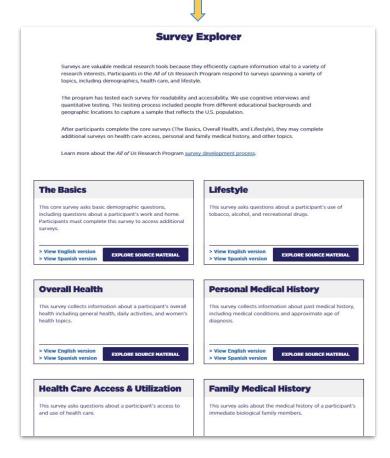


Public tools enable researchers to learn about data.

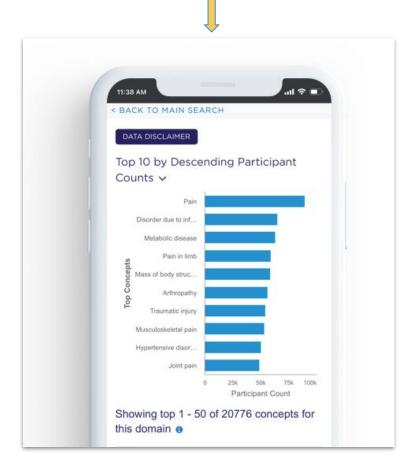
Data Snapshots



Survey Explorer

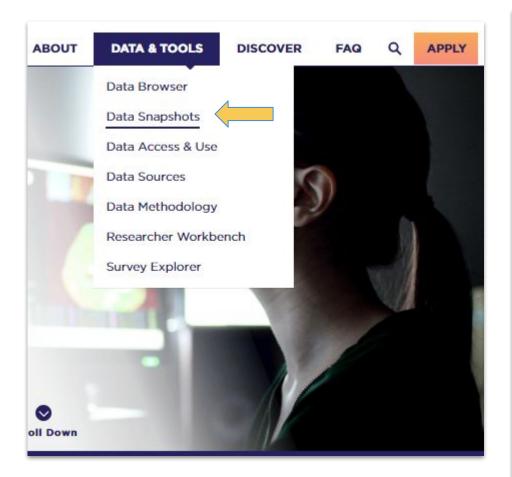


Data Browser









AllyUs Research Hub



DATA & TOOLS

DISCOVER

FAQ a

RESEARCHER LOGIN

APPLY

Home > Data & Tools > Data Snapshots

Data Snapshots

ABOUT

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 503,000 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 August 8, 2021.

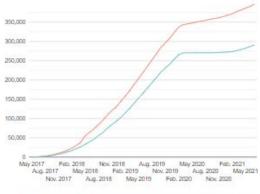
Participants at a Glance



Enrollment Numbers

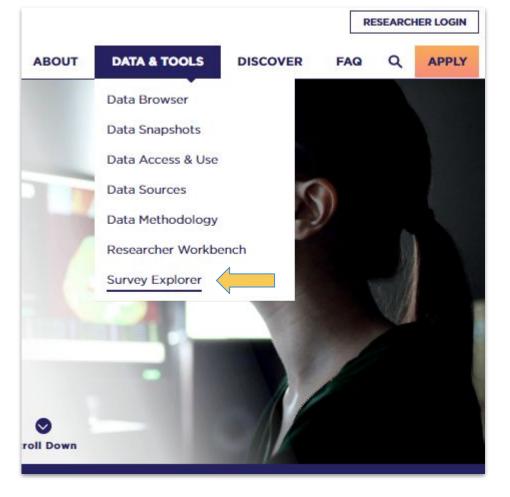
This graph represents participants who have consented to join the program and those who have completed all initial steps of the program. The initial steps are consenting, agreeing to share electronic health records, completing the first three surveys, providing physical measurements, and donating at least one biospecimen to be stored at the biobank.

The following numbers are approximated to protect participants' privacy. Numbers are updated as of August 8, 2021.





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



For more information about our survey development process, please read "Development of the Initial Surveys for the All of Us Research Program" (Cronin et al., 2019)

Survey Explorer

Surveys are valuable medical research tools because they efficiently capture information vital to a variety of research interests. Participants in the AF of £5 Research Program respond to surveys spanning a variety of topics, including demographics, health care, and liferatyle.

The program has helded each survey for readfability and accessibility. We use cognitive interviews and quantitative testing. This testing process included people from different educational backgrounds and geographic locations to capture a sample that reflects the U.S. population.

After participants complete the core surveys (The Basics, Overall Health, and Lifestyle), they may complete additional surveys on health care access, personal and family medical history, and other topics.

Learn more about the Alf of Un Research Program survey development process

The Basics

This core survey asks basic demographic questions, including questions about a participant's work and home. Participants must complete this survey to access additional surveys.

- > View English version
- View Spanish version

Lifestyle

This survey asks questions about a participant's use of tobacco, alcohol, and recreational drugs.

- > View English version
- View Spanish version

EXPLORE SOURCE MATERIAL

Overall Health

This survey collects information about a participant's overall health including general health, daily activities, and women's health topics.

- > View English version
- > View Spenish version

EXPLORE SOURCE MATERIAL

Personal Medical History

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

- > View English version
- > View Spanish version

EXPLORE SOURCE HATERIAL

Health Care Access & Utilization

This survey asks questions about a participant's access to and use of health care.

- > View English version
- > View Spanish version
- EXPLORE SOURCE MATERIAL

Family Medical History

This survey asks about the medical history of a participant's immediate biological family members.

- > View English version
- > View Spanish version

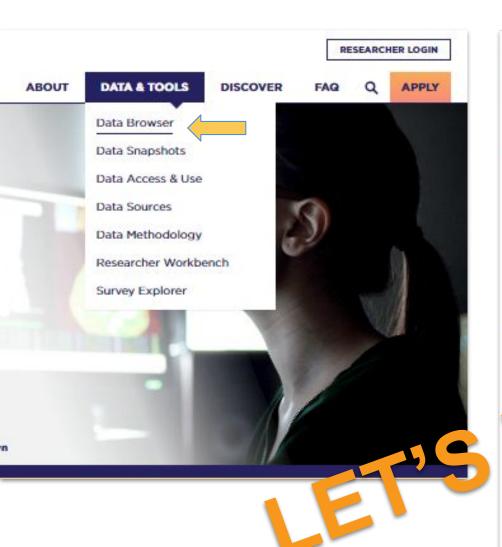
EXPLORE SOURCE HATERIAL

COVID-19 Participant Experience (COPE) Survey

This survey asks questions about the impact of CCVID-19 on a participant's mental health, well-being, and everyday life. This survey was deployed to participants multiple times, beginning in May 2020.

- > View English version
- View Spanish versio

EXPLORE SOURCE MATERIA



Search Across Data Types o

Q Keyword Search

Data includes 316,760 participants and is current as of 10/1/2020.







FAQs

Introductory User Guide Videos

EHR Domains: 0

Conditions 6

24,770

medical concept

192,000 participants in this domain

View Top Conditions

Drug Exposures ()

27,311

medical concepts

174,660 participants in this domain

View Top Drug Exposures

Labs & Measurements 6

13,631

medical concer

182,000 partic hts in s domain

V. To Leasure lents

Procedures 6

27,702

medical concepts

182,000 participants in this (

View Top Procedures

Survey Questions:

The Basics

28

ns av

60 par par this main

for tion

View Complete Survey

Ov

21

uestions available

316,760 participants in this domain

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

View Complete Survey

Lifestyle 6

26 questions available

note that the same of the same of

316,760 participants in this domain

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

View Complete Survey

Personal Medical History

465

questions available

89,640 participants in this d

This survey includes informa medical history, including me and approximate age of dias

View Complete Survey

Health Care Access & Utilization 6

57

questions available

98,940 participants in this domain

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

View Complete Survey

Family Health History 6

186

questions available

92,080 participants in this domain

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

View Complete Survey

COVID-19 Participant Experience (COPE) 6

151

questions available

62,920 participants in this domain

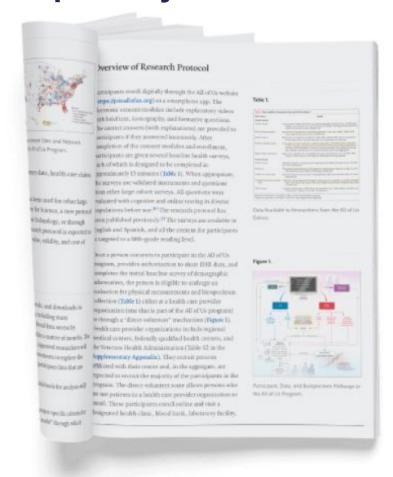
Survey includes information about the impact of COVID-19 on participant mental and physical health.

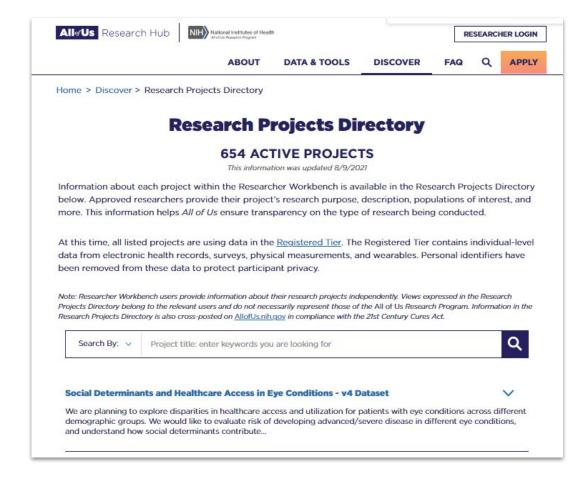
View Complete Survey

croomar wicarcar motory

Publications

The stories, projects, & publications made possible by *All of Us* are shared **publicly** & transparently.

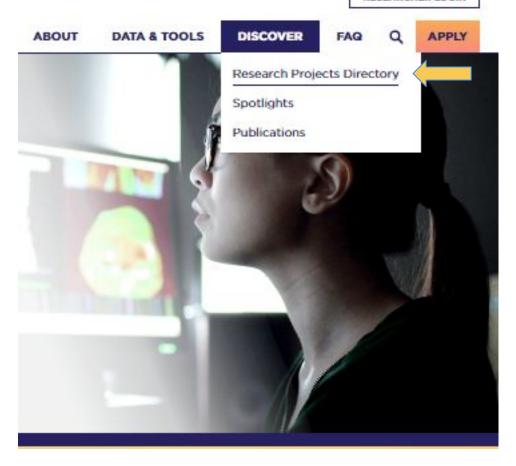








RESEARCHER LOGIN



Home > Discover > Research Projects Directory

Research Projects Directory

654 ACTIVE PROJECTS

This information was updated 8/9/2021

Information about each project within the Researcher Workbench is available in the Research Projects Directory below. Approved researchers provide their project's research purpose, description, populations of interest, and more. This information helps All of Us ensure transparency on the type of research being conducted.

At this time, all listed projects are using data in the <u>Registered Tier</u>. The Registered Tier contains individual-level data from electronic health records, surveys, physical measurements, and wearables. Personal identifiers have been removed from these data to protect participant privacy.

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



Social Determinants and Healthcare Access in Eye Conditions - v4 Dataset



We are planning to explore disparities in healthcare access and utilization for patients with eye conditions across different demographic groups. We would like to evaluate risk of developing advanced/severe disease in different eye conditions, and understand how social determinants contribute...

Stroke risk factors



Stroke is the second leading cause of death and the leading cause of adult disability in the world, but relatively little is known about the underlying mechanisms that lead to stroke. No mechanism-based treatment or established prevention for hemorrhagic stroke...

Thyroid nodule and cancer

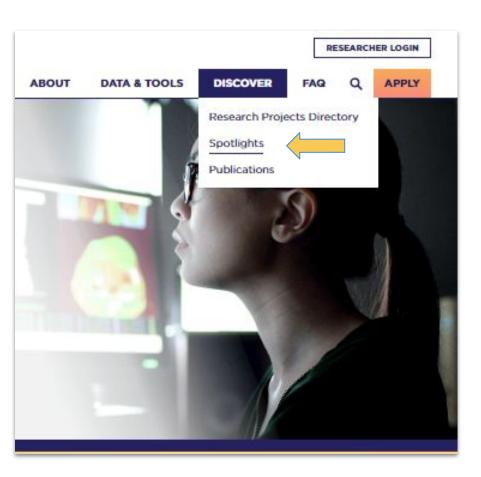


Thyroid cancer is one of the fastest increasing cancer over the last 40 years. From 1974 to 2013 the incidence increased 3.6% per year. With increased use of radiology studies throughout all facets of medicine, the incidental identification of thyroid...

Determinants of neurovascular diseases



Neurovascular disease is responsible for a substantial proportion of the morbidity and mortality observed in the general population. Mounting evidence indicates that this impact disproportionately affects minority populations. This disproportionate effect is not only present in minorities defined by race/ethnicity,...



Spotlights



Meet the Researchers

A new study to better understand the health outcomes of sexual and gender minority people

January 19, 2021

Meet Dr. Mitch Lunn. He's on a mission to better understand and support the health needs of sexual and gender minority people.

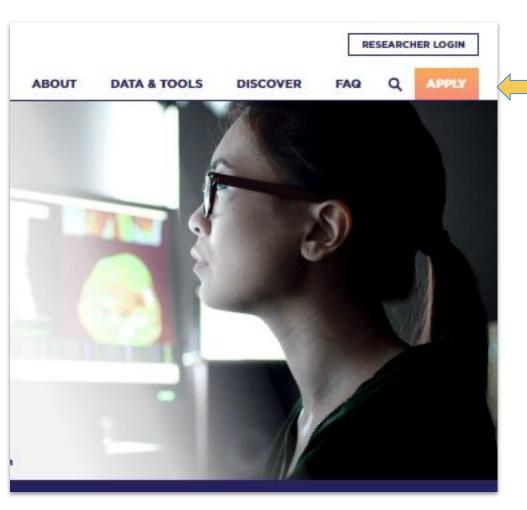


Meet the Researchers

An exploration of reproductive health issues that disproportionately affect Black women

January 19, 2021

Dr. Nyia Noel, an OBGYN at a Boston hospital, is leveraging the *All of Us* Research Program dataset to study hypertensive disorders in pregnancy and uterine fibroids.



How to Apply



DATA AVAILABLE

Explore what data are currently available with the <u>Data Browser</u>, and view the amount of information available with the <u>Data Snapshots</u>. Then, learn about the <u>Data Access & Use</u> <u>Policies</u> and our workbench.



CHECK FOR YOUR INSTITUTION'S AGREEMENT

Check that your institution has signed the Data Use and Registration Agreement. If your institution is not listed, please fill out the form to initiate the process.



REGISTER AS A RESEARCHER

Complete your researcher profile, sign the Terms of Service, and agree to the the Privacy Policy. Please note: a Data Use and Registration Agreement must be in place, and you must have an eRA Commons account.



CONNECT ERA COMMONS

Connect to your eRA Commons account upon applying to the Researcher Workbench.



COMPLETE ALL OF US RESPONSIBLE CONDUCT OF RESEARCHER TRAINING

Understand more about our privacy safeguards and the ethics surrounding the use of participant data.



SIGN DATA USER CODE OF CONDUCT

Sign the Data User Code of Conduct.

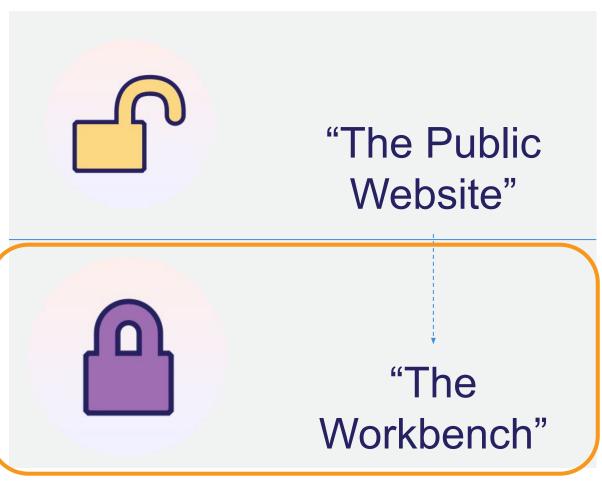
APPLY NOW



The Researcher Workbench

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







The Workbench offers analysis tools & resources.



WORKSPACES

USES: Organizing research projects, collaboration, transparency



NOTEBOOKS

USES: Analysis, queries



DATASET BUILDER

USES: Pre-populated analysis, dataset previews



COHORT BUILDER

USES: Cohort creation



WORKBENCH USER SUPPORT HUB

USES: Learning, support, guides



RESEARCHER LOGIN





Already have a Researcher Workbench account?



G Sign In

Trouble Signing In?

Don't have an account?

CREATE ACCOUNT

WARNING NOTICE

You are accessing a web site created by the AV of Lie Research Program, funded by the National Institutes of Feeth.

Unauthorized attempts to upload information, change information, or use of this was site may result in disciplinary action, divil, 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 velocite and is advised that if such maniforing reveals possible evidence of criminal activity. NRI may provide that evidence to law enforcement.





Welcome to the

RESEARCHER WORKBENCH







The secure platform to analyze All of Us data





HbAlc Distributions of Type 2 Diabetics

Last Changed: 03/26/20, 02:01 PM

Original - How to Get Starte d with Registered Tier Data

Last Changed: 03/25/20, 09:45 AM

R2019Q4R3 - How to Get St arted with Registered Tier Data

READER

Last Changed: 12/08/20, 01:25 PM

See all workspaces

: How to Work with All of Us Survey Data

READER

Last Changed: 01/15/21, 01:39 PM

Decently Accessed Items

| Item type | Name | Workspace name | Last changed | Dataset |
|-----------|---------------------------|---|--------------|----------------------|
| Cohort | T2D_survey_any_hbalc | HbAlc Distributions of Type 2 Diabetics | May 14 2020 | All of Us Dataset v3 |
| Cohort | test | Type 2 diabetes Test with Lou | Apr 28 2020 | All of Us Dataset v3 |
| Notebook | Medication Sequences Code | Medications pathway (sequences) - Phase 1 | Apr 27 2020 | All of Us Dataset v3 |
| Notebook | test | Feedback | Apr 23 2020 | All of Us Dataset v3 |
| Notebook | Concept Longitudinality | CDR Characterization | Apr 23 2020 | All of Us Dataset v3 |

Showing 5 most recent items

Quick Tour and Videos

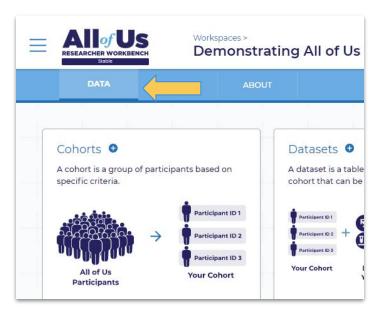






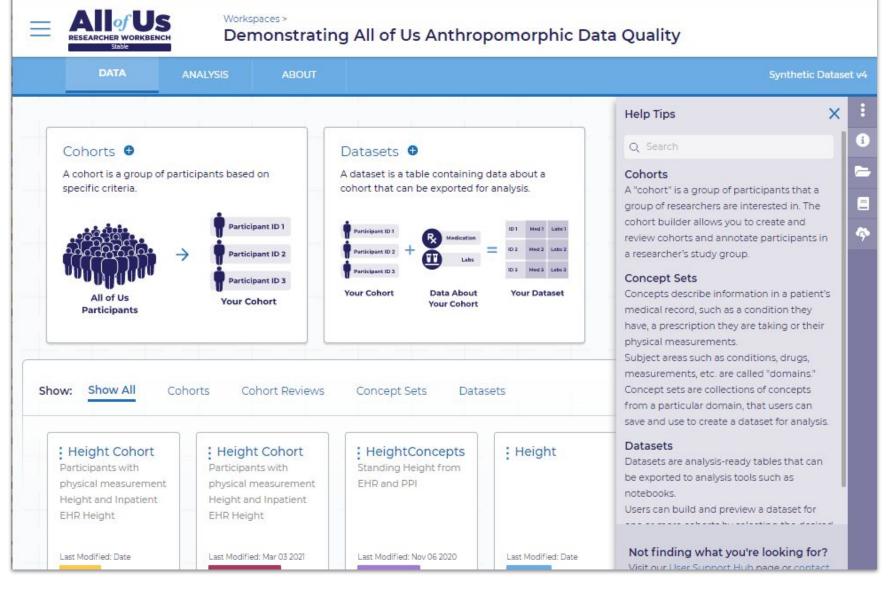


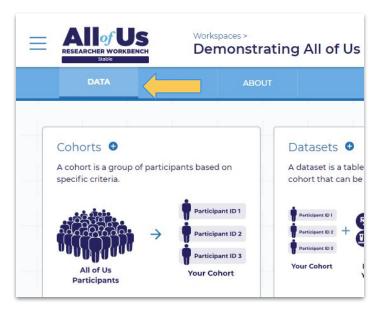






Cohort + Dataset Builders





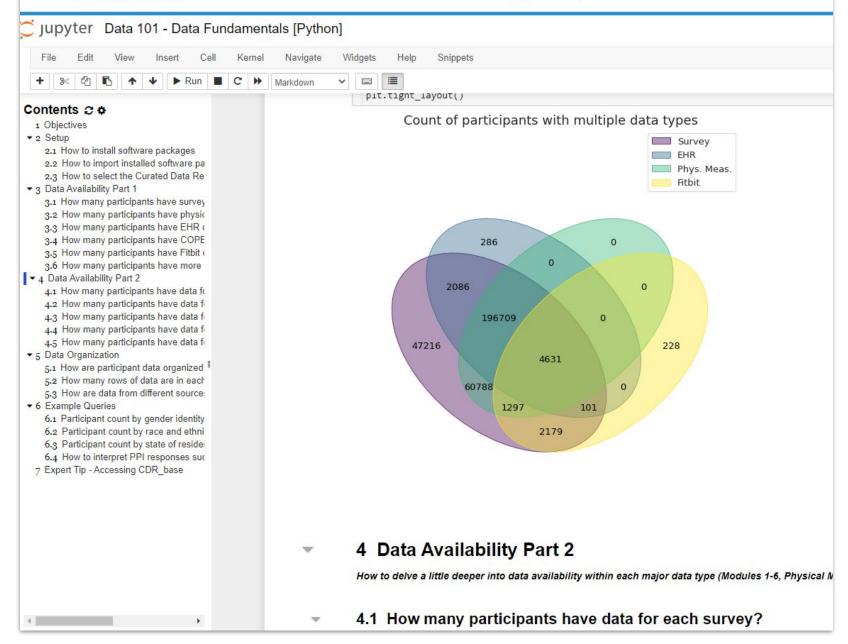


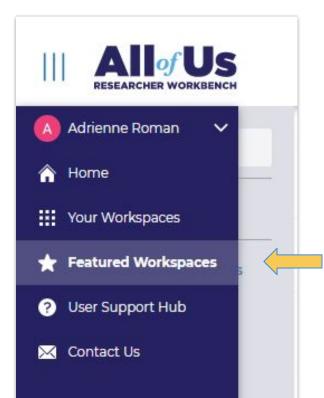
NOTEBOOKS



Workspaces > Duplicate of How to Get Started with Registered Tier Data > Notebooks >

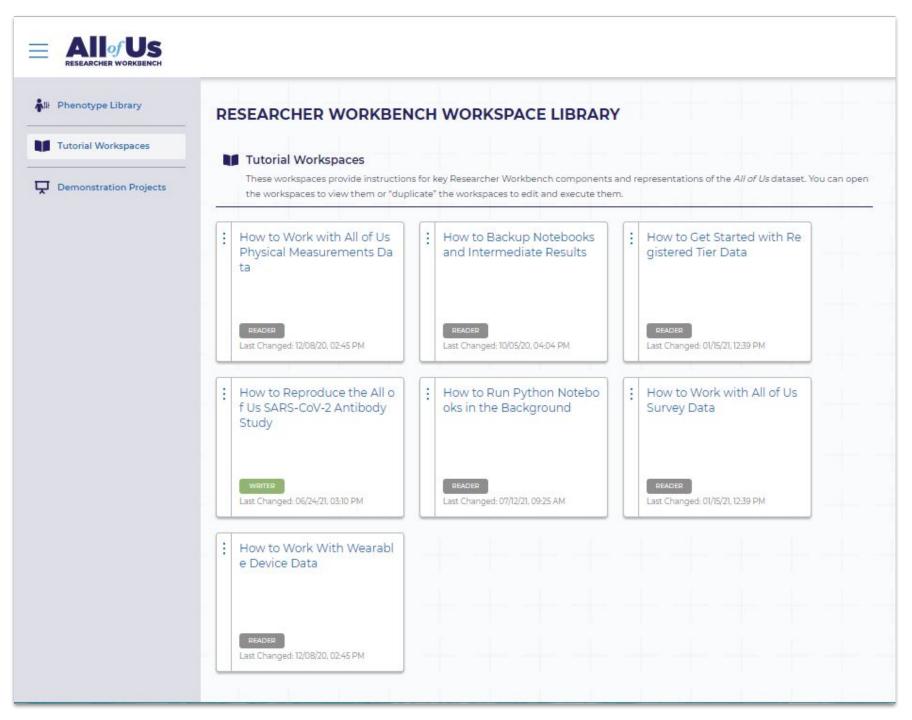
Data 101 - Data Fundamentals [Python]







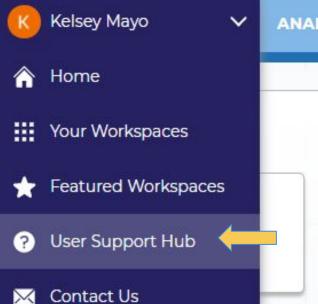
NOTEBOOKS





Workspaces >

How to Get S



ANALYSIS

ABOUT

Data 101 - Data Fundamentals [Python]

User Support Hub

Search our knowledge base for answers to common questions

Q Enter a question, topic, or a keyword...

Explore All of Us Researcher Workbench Resources



New to the Researcher Workbench? Looking for some quick help for working with our tools or data? Start here.



Find helpful resources to better understand the *All of Us* dataset and how to analyze it.



Post your questions and comments for other users here.



Frequently Asked Questions

Look for answers on workspaces, concepts, and everything in hetween.



Announcements

Get the latest All of Us news and announcements.

Have a question or would like to make a request?

Send us specific questions or requests.

SUBMIT A REQUEST





What's Next?

What to Expect in Researcher Workbench Beta Phase

- Data: The cohort is actively growing, and so are the data.
- Analytical Tools: R & Python programming; continuing to evolve.
- Access: Data passport model
 - At this time, an institutional agreement & eRA Commons account is required.
- © Credits: \$300 in compute credits upon registration.

We welcome input from researchers during the beta testing phase to help make the Workbench more robust over time.



DATA AVAILABLE

Explore what data are currently available with the <u>Data Browser</u>, and view the amount of information available with the <u>Data Snapshots</u>. Then, learn about the <u>Data Access & Use</u> Policies and our workbench.



CHECK FOR YOUR INSTITUTION'S AGREEMENT

Check that your institution has signed the Data Use and Registration Agreement. If your institution is not listed, please fill out the form to initiate the process.



REGISTER AS A RESEARCHER

Complete your researcher profile, sign the Terms of Service, and agree to the the Privacy Policy. Please note: a Data Use and Registration Agreement must be in place, and you must have an eRA Commons account.



CONNECT ERA COMMONS

Connect to your eRA Commons account upon applying to the Researcher Workbench.



COMPLETE ALL OF US RESPONSIBLE CONDUCT OF RESEARCHER TRAINING

Understand more about our privacy safeguards and the ethics surrounding the use of participant data.



SIGN DATA USER CODE OF CONDUCT

Sign the Data User Code of Conduct.

Overview of Contracting Timeline (for the Registered Tier)

1-2 days following request

1-2 days following processing

1-2 days following Timeline determined receiving partially executed **DURA**

1-2 days following executed DURA



Researcher submits Institutional **Agreement Request**

 The researcher does this by completing the Step 2 request survey available on the Research Hub

Internal processing

• DRC team pulls down requests daily and logs via internal process

Contracting Contact outreach

 DRC contracting official reaches out to the contracting contact listed on the requester's form to provide background information, agreement template, and next steps.

Communication with Contracting Contact

by institution

 Until the DRC contracting official receives the partially executed contract. the contracting official follows up with each researcher provided contact every 2 weeks.

Execution of agreement and completion of domains form

• The contracting contact sends the partially executed contract and email domains form to the DRC contracting official who will fully execute the contract.

Institutional Access Granted!

 Upon executing the contract, the DRC team configures access to the user institution and alerts the initial requestor to the access granted

Tips and Tricks in the Contracting Process

- A contracting contact is anyone who can get the All of Us Contracting team to the institutional signing authority for the respective institution or organization
- Go to your direct supervisor to confirm who your contracting contact is at your institution if you are unsure
- Contact your contracting contact ahead of time and brief them on the All of Us
 Research program before completing the access request form.
- Follow up periodically with your contracting contact to receive updates in the contracting process

Learn More and Help Us Spread the Word!

- Visit <u>ResearchAllofUs.org</u> and <u>JoinAllofUs.org</u>
- Subscribe to Research Hub Newsletter to receive updates
- Enroll in the Workbench: ResearchAllofUs.org/apply/





Q&A, Discussion