AAPA- PAEA Research Fellowship



Exploring the All of Us Research Hub



August 12, 2021

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National Institutes of Health

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 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



Catalyze the robust ecosystem of researchers and funders hungry to use and support it

Our Mission

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



Deliver the largest, richest biomedical dataset ever

• that is easy, safe, and free to access



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.

Researchers Study Data

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



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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

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Example Use Case: Blood Pressure



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?



Treatment & Outcomes

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

Health Equity

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



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?



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"

Broad and Open Access

Commitment to Protecting Privacy

A data resource for All of Us (Academic Researchers <u>and</u> Community Scientists)

Removal of unnecessary barriers to access



Privacy first, privacy always

Strive to build a system that participants can trust



Data and resource access is tiered.

Individual Biospecimen and Participant Data (Available in the future)

Future ancillary studies

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

Controlled Tier (Available in the future) <u>No obvious PII</u>. 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)

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.





Source: https://www.researchallofus.org/



RESEARCHER LOGIN

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FAQ

APPLY

Home > Data & Tools > Data Snapshots

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 503,000 people have registered with the program by creating online accounts at <u>JoinAllofUs.org</u>, beginning the enrollment process. The snapshots below highlight participants in the All of Us Research Program.

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





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 AP of Un Tesearch Program respond to surveys spanning a variety of topics, including demographics, heidth care, and lifetingfue.

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

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

Learn more about the All of Us Research Program survey development process







Publications

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





Source: https://www.researchallofus.org/



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 <u>AlloUs.nih.gov</u> in compliance with the 21st Century Cures Act.

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

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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

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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

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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

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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



LEARN MORE ABOUT THE 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

<u>Check that your institution has</u> <u>signed the Data Use and</u> <u>Registration Agreement</u>. If your institution is not listed, please fill out <u>the form</u> 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. STEP 6

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.







All/Us

Already have a Researcher Workbench account?



Trouble Signing In?

Don't have an 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, duit, and/or criminal penalties. Unsutherized users of this website should have no expectation of privacy regarding any communications or data processed by this website.

Ry 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 memilioring reveals possible evidence of criminal activity. Nill may provide that evidence to law enforcement. officials.









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DATA	ANALYSIS ABOUT			
				Help Tips
Cohorts		Datasets 🛛		Q Search
A cohort is a group of part specific criteria.	ticipants based on	A dataset is a table containing cohort that can be exported fo		Cohorts A "cohort" is a group group of researchers
	Participant ID 1	Participant ID 1 Participant ID 2 + R Medication ED Labs	1D1 Med 1 Later 1	cohort builder allows review cohorts and a a researcher's study
All of Us Participants	Participant ID 3 Your Cohort	Your Cohort Data About Your Cohort Your Cohort	Your Dataset	Concept Sets Concepts describe in medical record, such have, a prescription t
ow: Show All Col	horts Cohort Review	s Concept Sets Data	sets	physical measureme Subject areas such a measurements, etc. Concept sets are col from a particular do
Height Cohort Participants with physical measurement	Height Cohort Participants with physical measurement Height and Inpatient	: HeightConcepts Standing Height from EHR and PPI	Height	Datasets Datasets are analysis be exported to analy notebooks. Users can build and
Height and Inpatient EHR Height	EHR Height			

Workspaces >

= AllofUs

× t" is a group of participants that a researchers are interested in. The uilder allows you to create and phorts and annotate participants in

Synthetic Dataset v4

t Sets

s describe information in a patient's record, such as a condition they rescription they are taking or their measurements. areas such as conditions, drugs, ments, etc. are called "domains." sets are collections of concepts articular domain, that users can use to create a dataset for analysis.

are analysis-ready tables that can rted to analysis tools such as ks. n build and preview a dataset for

nding what you're looking for? User Support Hub page or contact

Cohort + Dataset Builders



Workspaces > Demonstrating All of Us





NOTEBOOKS



Workspaces > Duplicate of How to Get Started with Registered Tier Data > Notebooks > Data 101 - Data Fundamentals [Python]



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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.

STEP

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Overview of Contracting Timeline (for the Registered Tier)



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: <u>ResearchAllofUs.org/apply/</u>





Q&A, **Discussion**