



All of Us
RESEARCH PROGRAM



NLM *All of Us* Data Training and Engagement for Academic Libraries Program

Sample *All of Us* Resource Guide

What Is the *All of Us* Research Program?



All of Us
RESEARCH PROGRAM

The National Institutes of Health's (NIH's) *All of Us* Research Program is a historic effort to speed up health research discoveries, enabling new kinds of individualized health care (known as precision medicine). To make this possible, the program is building one of the world's largest and most diverse databases for health research. The program seeks for its participant cohort to reflect the diversity of the U.S. population.

All of Us participants contribute to the program in many ways, such as by responding to surveys, sharing electronic health records, and providing biosamples. The *All of Us* Data and Research Center [curates](#) and validates data derived from these sources. All direct identifiers are removed before the data are made available for research.

Data sources include:

- Electronic health records (EHR) standardized using the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM)
- Biosamples and bioassays from blood, saliva, and/or urine samples
- Survey responses about identities and backgrounds, overall health, lifestyles, medical histories, healthcare access, experiences with COVID-19, and more
- Physical measurements from enrollment and EHR data
- Heart rate, physical activity, and sleep as tracked by Fitbit devices¹

¹ (Data Sources, 2023)

Data Now Available in the Researcher Workbench



413,350+
Survey
Responses



337,500+
Physical
Measurements



312,900+
Genotyping
Arrays



287,000+
Electronic
Health Records



245,350+
Whole
Genome
Sequences



15,600+
Fitbit
Records



1,000+
Long-Read
Sequences

The diverse database, which is a part of the [Precision Medicine Initiative](#), is intended to inform studies on a multitude of health conditions.²

What Is Precision Medicine?



Precision medicine is a growing area of medical research and practice. The goal of precision medicine research is individualized care that treats patients as individuals by considering factors like the environment, lifestyle, family health history, and a person's genetics. Researchers working on precision medicine acknowledge that some treatments may work differently depending on one's background. They are hopeful that advances in precision medicine care may reduce health care costs by more quickly matching patients to the appropriate treatment.³

Learn more about precision medicine in [this video](#).

² (Health, 2021)

³ (Health, 2021)

The Researcher Workbench



Visit ResearchAllofUs.org to learn more.

All of Us and the All of Us logo are registered service marks of the U.S. Department of Health and Human Services.

The Researcher Workbench is a cloud-based platform where registered researchers can access Registered and Controlled Tier data.

Learn more about the Researcher Workbench in the [Introduction to the Researcher Workbench video](#).

The Research Hub



The *All of Us* Research Hub is available at ResearchAllofUs.org. Researchers can visit the site to learn more about the data available and how researchers are using it. It also includes details about how the data are curated and processed.

Research Projects Directory

The [Research Projects Directory](#) includes information about projects that are underway in the Researcher Workbench to help provide transparency about how the *All of Us* data are being used.

Publications

Researchers have already started publishing studies using *All of Us* data. You can explore these [publications](#) under the discover tab on the Research Hub.

Access Tiers

There are three tiers of data. The **public tier** is available to anyone. You must register for the Researcher Workbench to access the **Registered** and **Controlled Tiers**.

Your access to these tiers depends on the Data Use Registration Agreement (DURA) your institution has with the *All of Us* Research Program. You can check your institution's access level [online](#).

Learn more about the tiers in [this video](#).

The Public Tier

The Public Tier dataset includes aggregate data contributed by *All of Us* participants. To protect participant privacy, *All of Us* has removed personal identifiers, rounded aggregate data to counts of 20, and included only summary demographic information. Individual-level data are available for analysis in the **Researcher Workbench**.

Visit the [Data Browser](#) to preview available data, including survey responses, physical measurements, data from electronic health records and wearables, and genomic data.

The [Data Snapshots](#) provide an overview of the *All of Us* participant cohort, including overall enrollment numbers and demographic data. Note that data from participants must be securely processed before it is made available. Therefore, the overall enrollment number is higher than the number of participants with data available.

The Registered Tier

The Researcher Workbench's **Registered Tier** dataset contains individual level data from EHRs, wearables, and surveys, as well as physical measurements taken at the time of participant enrollment. Registration and a Responsible Conduct of Research training are required for access.

The Controlled Tier

the Researcher Workbench's **Controlled Tier** dataset includes data available on the Registered Tier, as well as genomic data and expanded demographic, survey, and electronic health record data. Genomic data includes whole genome sequences, long-read sequences, and genotyping arrays. Researchers must have amended institutional agreements and complete an additional training to access this tier.

Researcher Workbench Tools

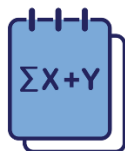
Powerful tools in the Researcher Workbench support data analysis and collaboration.



WORKSPACES

USES:

- Organizing research projects
- Collaboration
- Transparency



ANALYSIS TOOLS

USES:

- Analyses
- Queries

Conduct analyses with R and Python using our integrated, cloud-based analysis tools, including Jupyter Notebooks and RStudio.



DATASET BUILDER

USES:

- Pre-populated analyses
- Dataset previews



COHORT BUILDER

USES:

- Cohort creation



USER SUPPORT HUB

USES:

- Workbench training and resources
- Articles on Data and Tools
- Live office hours

These tools include:

- Shared **Workspaces** to access, store, and analyze data
- **Analysis tools** capable of high-powered queries using R, Python, or SAS
- A **Dataset Builder** to search and save collections of health information about cohorts
- A **Cohort Builder** to create, review, and annotate cohorts within the Researcher Workbench
- A publicly available **User Support Hub** with support articles, tutorials, and videos

Data Curation

Details on the [data curation processes](#) are detailed in the Research Hub.



How to Gain Access

To access the Researcher Workbench, you must register and create an [account](#) online.

Step 1: Confirm institutional agreement

Confirm that your institution has a **Data Use and Registration Agreement (DURA)** in place.

If your institution **has** a DURA, you can create an account using your **institutional email** (e.g., yourname@youruniversity.edu).

If your institution does **not** have a DURA, you will need to [submit a request](#) for one before you can register.

Step 2: Create an account and verify your identity

Agree to the terms of use and privacy policy. Then, create an account using your **institutional email** (e.g., yourname@youruniversity.edu). Finally, sign in to complete registration and verify your identity.

You must verify your identity using **Login.gov** or **ID.me**. These are secure services used by participating government agencies. You may need to provide a social security number (SSN) and a state-issued ID during this process.

Researchers who live in the United States, have an SSN, and have a valid U.S. government-issued ID (e.g., U.S. territory- or state-issued ID) can use login.gov for identity verification. Otherwise, you must use ID.me.

This [article](#) provides more information on how to verify your identity.

Step 3: Complete training and sign our code of conduct

The [Responsible Conduct of Research Training](#) raises awareness of the potential for community and group harm and the need for cultural humility in the research process. It also provides guidance on topics like using population descriptors, protecting participant privacy, and communicating science responsibly.

The [Data User Code of Conduct \(DUCC\)](#) outlines the program's expectations for researchers. In the DUCC, researchers agree to adhere to [core values](#), comply with laws and regulations, respect participant privacy, and use the data solely for biomedical or health research. The DUCC also emphasizes responsible handling of external data, prohibits discriminatory research, and sets restrictions on sharing participant-level data. When researchers sign the DUCC, they also agree to abide by accompanying data use policies, including the program's policies on stigmatizing research and ethical conduct of research.

Step 4: Explore support resources

Before starting research on the Researcher Workbench, explore the User Support Hub for tips or attend a [new user orientation](#). You can view a list of recommended resources [here](#).

Step 5: Use the Researcher Workbench

Start your first project on the Researcher Workbench. Your project description will be publicly available in the [Research Project Directory](#). Read [this article](#) for guidance on how to write a description of your research project.

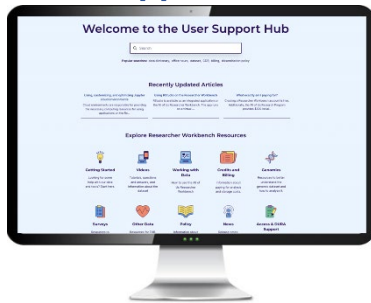
Step 6: Publish and present findings

When you're ready to publish or present your findings, review the [All of Us publication, presentation, and poster checklist](#) to confirm that your research is in compliance with the program's policies. Researchers must submit the mandatory [All of Us Publication and Presentation Reporting Form](#) **at least two weeks** before the publication or presentation date.

Internal processes

Support Tools and Resources

User Support Hub



The [User Support Hub](#) is a repository of articles and videos about how to use the Researcher Workbench.

Support desk

The *All of Us* Support Desk can assist help with technical questions and other issues. Email support@researchallofus.org or click the “help” button on the [User Support Hub](#).

Live event calendar

Friday office hours, new user orientations, and other events can be found in the [Live Event Calendar](#).

Some events are open to registered researchers only. Invitations for those events are sent directly to registered researchers. You can also email support@researchallofus.org for questions about events.

Selected resources

- [New user orientation video recording \(May 2023\)](#)
- [Getting started with the *All of Us* dataset](#)
- [New to the Researcher Workbench? Start here!](#) (A resource map)
- [Featured workspaces](#) (Tutorials within the Researcher Workbench)

Coding resources

R

- [Using R in the Researcher Workbench \(Office hours recording\)](#)
- [Using RStudio in the Researcher Workbench](#)
- [Using RStudio in the Researcher Workbench](#) (Office hours recording)

Additional resources

- [R for Data Science website](#)
- [Teacups, Giraffes, & Statistics](#)
- [Data Analysis with R Specialization \(Coursera\)](#)
- [Data Science Specialization \(Coursera\)](#)

Python

- [Jupyter Notebooks and programming](#)
- [Code snippets catalog \(Python\)](#)
- [How to use workspace buckets using Python \(Office hours recording\)](#)

Additional resources

- [A Whirlwind Tour of Python by Jake VanderPlas](#)
- [Practice Python](#)
- [Python for Everybody Specialization \(Coursera\)](#)
- [Data Analysis with Python \(Coursera\)](#)

SAS

- [Overview of SAS in the Researcher Workbench \(Office hours recording\)](#)
- [How to run SAS in the Researcher Workbench](#)
- [Exploring *All of Us* data using SAS Studio](#)
- [SAS demonstration projects \(Office hours recording\)](#)
- [SAS analytics guide: How to perform logistic regression](#)
- [SAS analytics guide: How to estimate frequency](#)
- [SAS analytics guide: How to perform binary logistic regression](#)

Institutional Support Resources

Interactive Apps

- [All of Us Activities](#)
 - [Hearing](#)
 - [Vision](#)
 - [Your Unique Combination](#)

Further Reading

- [All of Us Research Hub](#)
- [National Institute of Health All of Us Research Program](#)
- [User Support Hub Video Directory](#)
- [All of Us Research Program YouTube Channel](#)

Other Ideas

- Feature existing researchers working in the Researcher Workbench (see testimonials below).
- Create your own tutorial videos.
- Include bibliography of relevant resources.
- Link to relevant databases, research guides, etc.
- Highlight NIH [funding opportunities](#)
- Include subject-specific resources.
- Offer a gallery of data visualizations.
 - Feature a calendar of upcoming trainings or events related to *All of Us* at your institution.
- Include a directory of institutional contacts.
- Offer designated computer availability, location, and access instructions.
- *All of Us* Research Testimonials
 - [Expanding Genetics Research and Discovery at Historically Black Colleges and Universities](#)
 - [Team Science and the All of Us Researcher Workbench](#)
 - [Building a Transparent and Inclusive Research Community](#)
 - [Meaningful Inclusion of LGBTQ+ People in Research](#)
 - [Understanding the Behavioral Health Needs of People with HIV](#)
 - [Advancing Women's Health Research](#)
 - [Advancing Research in Underrepresented Communities](#)
 - [The *All of Us* Research Program advances medical genetics](#)
 - [Predictive Analytics for Glaucoma: A project powered by the *All of Us* Research Program](#)
 - [How diverse data can power more impactful research](#)
 - [Studying health care access and utilization among adult cancer survivors](#)