

# Advancing Research through Sustainable Collaborations

HBCU Engage Conference  
Nashville, TN

April 18, 2023



# Poll Questions QR Code

**Visit:**  
**<https://pollev.com/uidp>**



# Workshop Objectives

- Institutional research advancement
- Creating multisector collaborations and partnerships
- University and industry self-assessment
- Understanding the value and impact of the *All of Us* Research Program and the *All of Us* Researcher Workbench
- Opportunities to join the *All of Us* Researcher Academy as a faculty or student scholar

# Meet our Presenters



**Yvonne Ford, PhD, RN**  
*College of Health &  
Human Sciences*  
North Carolina A & T  
State University



**Kristen Rhinehardt, PhD**  
*College of Engineering*  
North Carolina A & T  
State University



**Javan Carter, PhD**  
*GenOmics, Bioinformatics &  
Translational Research Center*  
RTI International



**Sula Hood, PhD**  
*Center for Communication  
& Engagement Research*  
RTI International



**BriAnna Walker, MA**  
*University Collaboration Office*  
RTI International

delivering the promise of science  
for global good



RTI International is an independent, nonprofit research institute dedicated to improving the human condition. We combine scientific rigor and technical expertise in social and laboratory sciences, engineering, and international development to deliver solutions to the critical needs of clients worldwide.

# North Carolina Agricultural and Technical State University



**NORTH CAROLINA  
AGRICULTURAL AND TECHNICAL  
STATE UNIVERSITY**

## RANKED BY U.S. NEWS & WORLD REPORT:

**No. 1** Historical Black College and University in America (Washington Monthly & Money Magazine)

**Top 40** in Social Mobility\*

**Top 50** in Most Innovative Universities\*

\*Among the top national universities (U.S. News & World Report)



# *All of Us* Researcher Academy

# What Is the *All of Us* Researcher Academy?

The National Institutes of Health's ***All of Us* Research Program** is a historic effort to collect and study data from one million or more people living in the United States.

The goal of *All of Us* is to speed up health research discoveries, enabling new kinds of individualized health care.

The program aims to reflect the diversity of the United States and to include participants from communities that have been underrepresented in health research in the past.



The ***All of Us* Researcher Academy** is a comprehensive program that provides training and technical assistance for researchers conducting research with the ***All of Us* Researcher Workbench**, the cloud-based analytics platform where registered researchers can access participant data.

The Academy also supports peer-to-peer learning and network-building among researchers and students from communities that are underrepresented in the biomedical workforce. The first phase of the ***All of Us* Researcher Academy** is directly supporting researchers at **Historically Black Colleges and Universities**.



# All of Us Researcher Academy

## GOAL

Establish a diverse learning network of researchers who will use *All of Us* data

## PURPOSE

Promote equitable access to and use of the *All of Us* Researcher Workbench by a diverse array of researchers

## INITIAL OBJECTIVES



Engage with HBCUs to **raise awareness** and **assess needs**



**Create internships and fellowships** for HBCU students and faculty



**Curate a training curriculum** focused on the skills needed to access and conduct research using *All of Us* data



**Provide technical assistance** for HBCUs using the Researcher Workbench



**Build partnerships** with similar programs to draw insights to support scholars



Conduct **ongoing evaluation** of academy activities to ensure program success

# Institutional Champion Awards

- Support teams at HBCUs in conducting research with the *All of Us* Research Program dataset
  - Up to \$75,000 to support teams of faculty, students, and postdocs
  - Interdisciplinary teams of health and social science researchers
- First round of six Institutional Champion awardees announced in August 2022



**All of Us Researcher Academy Selects 6 HBCUs | RTI**

# RTI International's *All of Us* Researcher Academy Team



**Megan Lewis**  
*Principal Investigator*



**Jen Uhrig**  
*Principal Investigator*



**Sula Hood**  
*Co-Lead*



**Brian Southwell**  
*Co-Lead*



**Ifeoluwa Adewumi**



**Sheri Cates**



**Javan Carter**



**Heidi Guyer**



**Trey-Rashad Hawkins**



**Vincenzo Malo**



**Courtney Richardson**



**Hadyatoullaye Sow**



**Tamara Terry**



**BriAnna Walker**

**HBCU Alumni and Affiliation Ties of Howard University, Meharry Medical College, North Carolina Central University, and Winston-Salem State University**

# Community-Campus Partnerships for Health's *All of Us* Researcher Academy Team



**Alan Richmond, MSW**  
Executive Director



**Cyreeta Hannah-Boykin, MBA**  
Community Engagement  
Coordinator



**Virginia W. Hunter**  
MSI Projects Strategist

**HBCU Alumni of Livingstone College, Elizabeth City State University, and Central State University**

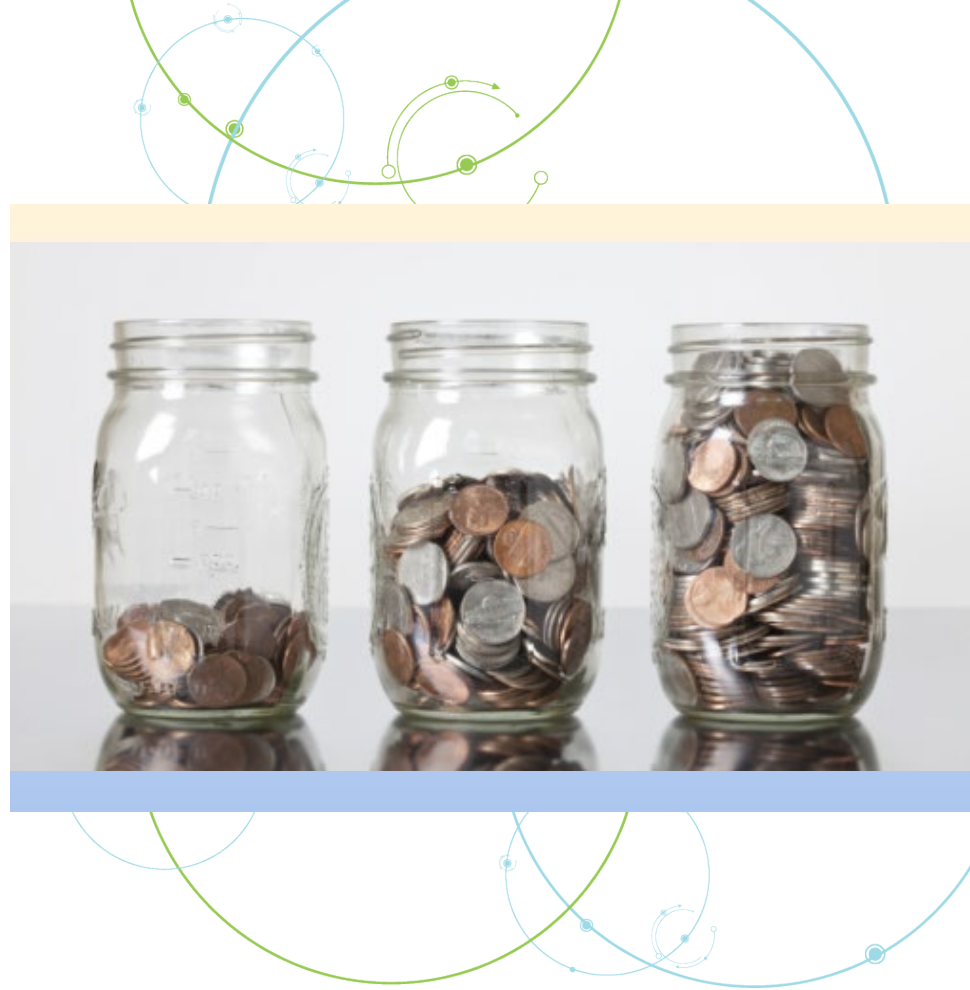
# Institutional Champions Representation in Research and Data

# Social Determinants of Health



# Economic Stability

- Socio-economic status
  - Education
  - Income
  - Occupation
- Employment status/occupation
- Debt/expenses
- Health insurance
- Access to care



# Education

- Literacy
- Health literacy
- Language
- Early childhood education
- Higher education





# Neighborhood and Physical Environment

- Safety
- Housing
- Transportation
- Neighborhood walkability
- Zip code/geography
- Green areas/parks
- Playgrounds
- Crime rate



# Food

- Hunger
- Nutritional knowledge
- Access to healthy food
- Affordability



# Social and Community Context

- Social support
- Social integration
- Community engagement
- Social networks/media
- Racial/ethnic discrimination
- Racism
- Stress



# Healthcare System

- Health insurance coverage and type
- Use of preventive/primary care services
- Provider availability
- Cost of medication
- Implicit bias in clinical decision-making
- Quality of care
- Timeliness of care



# Establishing Sustainable Partnerships

# NCAT Needs Assessment Reflection

- What type of relationship are you seeking?
- What are your expectations?
- What assets are you leveraging?
- To complete your vision what are you missing?



# Express Expectations

- **Resources**

- What are you sharing? What is being leveraged?

- **Timeline**

- Milestones, outcomes, duration and long-term goals

- **Visibility**

- What is your sharing methods and policy?
- Social media, journals, papers...

- **Impact**

- What community are you serving
- What is your reach?
- Is your relationship mutually beneficial? (If not, reassess)



# Managing Your Communication

- **Perception of language**

- Deficit models: The cultural deficit model is the perspective that minority group members are **different because their culture is deficient in important ways from the dominant majority group.**

- **Establish an infrastructure**

- Who is meeting, when the meetings occur, clear goals and milestones

- **Educate yourself** on your environment

- **Be transparent** in your purpose and aware of changes in the relationship

- Respect, Succession





# Assets Management

- Do you openly show assets or what work you do?
- What are your methods of partnership?
  - Internships, visiting scholars, train the trainer
- Do you have a clear updated list of your assets?
  - Research, resources, personnel, contacts
- People matter
  - Who do you need to contact? Is there a head of engagement?
  - <https://www.ncat.edu/give/advancement/contact-us.php>



**Kenneth E. Sigmon, Jr.**

*Vice Chancellor for University Advancement*

[kesigmon@ncat.edu](mailto:kesigmon@ncat.edu)



**Tamera Ziglar**

*Director of Development*

*College of Engineering*

[ttziglar@ncat.edu](mailto:ttziglar@ncat.edu)



**Eric Muth, PhD**

*Vice Chancellor for Research*

*Division of Research and Economic Development*

[ermuth@ncat.edu](mailto:ermuth@ncat.edu)

# Workflow



**Needs Assessment to Identify Potential Partners**

- Personnel
- Resources
- Intellectual Knowledge

**Determine Possible Partners**

- Assets
- Networking

**Establish Contact and Relationship Type**

- Partnership, Collaboration
- Business Officer

**Name your Expectations and Potential Impact**

- Intellectual Property
- Research Progress
- Student Matriculation
- Training Platforms

**Establish your Infrastructure**

- Communication Methods
- Fiscal Details
- Visibility

# Industry and University Partner Lessons Learned

- Eliminating deficit model
- Trust network
- Multilayer engagement
- Operational meetings
  - Milestone celebrations
  - Conferences and other events
- Respect for the academic and industry calendars
- Collaborations that impact students, faculty, and administrators
- HBCU as the PI and industry the Co-PI



# Poll Questions QR Code

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**<https://pollev.com/uidp>**



## Select the challenge that aligns with your institution.



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# *All of Us* Researcher Workbench

# Data Use and Registration Agreement (DURA)

A completed DURA allows researchers to access the *All of Us* Researcher Workbench with institutional sign-off.

**Follow Step 2 | How to Register to search for  
your institution's agreement**

*Always use your institutional email address.*



# Signing Up for the *All of Us* Researcher Workbench

When you sign up, it is important to acknowledge that you are a **Researcher Academy participant** by clicking “*All of Us* Researcher Academy/RTI International” on the “Who gave this activity, event, or presentation.”

Who gave this activity, presentation, or event?

- American Association on Health and Disability (AAHD)
- Asian Health Coalition
- Baylor College of Medicine
- Delta Research and Educational Foundation (DREF)
- Hunter College - CUNY
- National Alliance for Hispanic Health (NAHH)
- Network of the National Library of Medicine (NNLM)
- Pyxis Partners
- All of Us Researcher Academy/RTI International
- FiftyForward (Senior Citizens, Inc.)
- PRIDeNet - Stanford University
- Other

Sign up here:

[https://www.researchallofus.org/academy\\_ev](https://www.researchallofus.org/academy_ev)

*Always use your institutional email address.*



# What Is the *All of Us* Researcher Workbench?

The ***All of Us* Researcher Workbench** is a secure, cloud-based platform that houses participant data and tools and support resources. These include an integrated help desk, regular office hours, sample datasets, and more.

This centralized database hosts three tiers of data:

- **Public Tier**
- **Registered Tier**
- **Controlled Tier**

# All of Us Researcher Workbench Tiers

## Public Tier

Data Browser Access that only shows visuals of aggregate data with identifiers removed (**Free for general public**)

- **Physical measurements** 8 measurements with 311,300 participants in this domain
- **Survey responses** 9 different survey questionnaires with 101,000-375,000 participants
- **Electronic health records** 24,315 Conditions, 29,166 Drug Exposures, Labs & measurements, Procedures and from more than 258,000 participants.
- **Wearable data** 4 Fitbit measurements and from more than 12,800 participants with Fitbit® devices, including physical activity and heart rate.
- **Genomic data** a variant search to explore allele frequencies for a gene or genomic region.

# All of Us Researcher Workbench Tiers

## Registered and Controlled Tiers

Complete access to raw data described below (**restricted**)

- **Physical measurements**, including blood pressure, heart rate, and body mass index, from more than 306,000 participants.
- **Survey responses** from more than 372,000 participants that include lifestyle, access to care, and medical history.
- **Electronic health records** from more than 258,000 participants.
- **Wearable data** from more than 12,800 participants with Fitbit® devices, including physical activity and heart rate.



## Additional Controlled Tier Data

- **Genomic data** with large sample sizes that are appropriate for precision medicine research (nearly 100,000 whole genome sequences and more than 165,000 genotyping arrays).

# How to Navigate the *All of Us* Researcher Workbench



## **WORKSPACES**

In order to conduct various research studies, *All of Us* researchers will be able to create project specific workspaces and add collaborators to them. Each workspace will feature a description of the project and act as a home to save cohorts and analysis notebooks



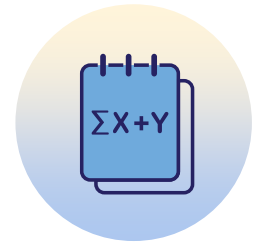
## **COHORT BUILDER**

The Cohort Builder is a custom tool that gives researchers the autonomy to create, review, and annotate cohorts of the *All of Us* research dataset



## **DATASET BUILDER**

The Dataset Builder allows researchers to search and save collections of health information about cohorts, called concept sets.



## **NOTEBOOKS**

For more tech-savvy *All of Us* Researchers, the Workbench has an integrated, web-based Jupyter Notebook environment to allow for high-powered query and analysis of the *All of Us* research dataset



# Workspaces

**The Workspace is designed to present research to the world and to promote collaboration between researchers. Each main project needs to be in a workspace.**



- You can have unlimited workspaces.
- You can add other researchers to your workspace if you are using the same tier and tier versions.
- Each workspace does have a public-facing title, project description, and researcher's name. You can request to reach out to a researcher from within the platform (no personal contact info is publicly available).

# Cohort Builder

The **Cohort Builder** is your first exposure to the different patient datasets. This is your first opportunity to build several cohorts that can later be combined to form datasets.



- There are two ways to develop your studies cohorts: the **Cohort Builder** and the **Analysis Notebook**. Using the Cohort Builder is the free and user-friendly method.
- You can create multiple cohorts that vary in size: Independent variable cohort, dependent variable cohort, etc.
- You can create different cohorts from patients' physical measurements, survey responses, electronic health records, wearable data, demographic info, and whether or not they have WGS data.

# Dataset Builder

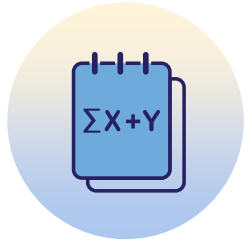
**The Dataset Builder allows you to take several cohorts and combined them to form datasets**



- Again, you can use this tool or use the Jupyter Notebook to create your datasets. Using the dataset builder is the free and user-friendly method.
- You can create multiple datasets that vary in size that has several different cohorts within it.
- You do have a limit on the amount of WGS dataset data you can move and analyze in the jupyter notebook so be mindful of that.

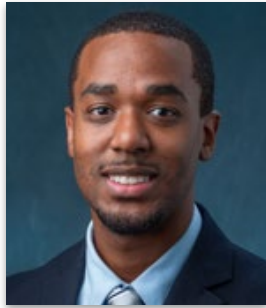
# Notebooks

**The Notebook is a fee-based Jupyter Notebook platform where you conduct your analyses.**



- You can use the analysis notebook to create cohorts or manipulate them more thoroughly. Do as much as you can in the cohort builder prior to manipulating anything in the notebook because of the cost.
- Intermediate to advanced understanding of R or python is needed to at least conduct analyses in the notebook. To be fully comfortable with the notebook, general understanding of SQL, bash, R, and python is need, especially when doing genomic analyses.
- Genomic data can be analyzed with either PLINK or HAIL software

# RTI International's *All of Us* Researcher Academy Coaching Team



Javan Carter, PhD



Trey-Rashad Hawkins, MS



Vincenzo Malo, MS

## **Working with the Researcher Academy's HBCU Institutional Champions:**

- Howard University
- Morgan State University
- North Carolina A&T
- North Carolina Central University
- Southern University at New Orleans
- Tuskegee University

# Roles We Fulfill with Our HBCU IC Partners

- Administrative assistance on how to navigate the Researcher Workbench
- Project consultation on public health, epidemiology, biostatistics, and genomic research
- Coding troubleshooting during analysis phase of projects
- Co-investigating during project development phase

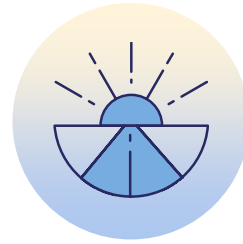
## How We Are Using *All of Us*

- What are the effect of social determinants of health (SDOH) on cardiovascular health (CVH) and 10-year risk of ASCVD?
- What is the incidence of heart failure or adverse cardiac events in Black/ African American women who are long-term (5 years or more) survivors of breast cancer?
- How can consideration of SDOH and biomarkers of cardiovascular risk help predict adverse cardiac events?

# How You Can Use *All of Us*



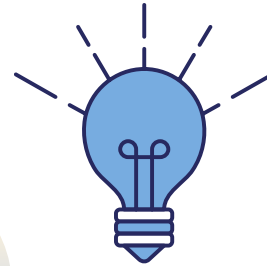
**Mentorship**



**PI Career  
Development**



**Research  
Infrastructure**



**Student  
Engagement**



**Grant  
Applications**



# HBCU Outreach and Engagement

# Tuition-Free Short Courses for Academy Scholars



**We are offering a suite of tuition-free course offerings and learning resources:**

- Accessing and Using the Researcher Workbench
- Research Study Design
- Data Analysis and Management
- Research Dissemination
- Securing External Research Funding
- Self-Care for Researchers
- Research Partnership Considerations
- Guidance for Educators
- Library Science Resources for Research

# Course Highlights: Summer 2023

- **Topics in Publishing Health Data: Promoting Your Publications:** May 4, 11, and 25, 2023
- **Ethical, Legal, and Social Implications of Genetic Research for *All of Us*:** June 12-July14, 2023
- **Health Introduction to Literature Searching to Support *All of Us* Data Analysis:** August 30, 2023

To register for course,  
scan QR code or access:  
[https://bit.ly/RA\\_Course](https://bit.ly/RA_Course)



# Course Highlight: Partnering with H.W. Odum Institute

- **Big Data—Big Deal or Bigger Deal Breaker: Using the *All of Us* Dataset**
- **Two session options:**
  - June 6 & 9, 2023
  - June 13 & 16, 2023

To register for course,  
scan QR code or access:  
[https://bit.ly/Odum\\_Course](https://bit.ly/Odum_Course)



# Researcher Academy Internship

- **Internships to facilitate experiential learning through mentored research projects**
  - Students are paired with mentors who have active projects in the *All of Us* Researcher Workbench
  - Internships are hosted virtually or in person
  - 3-month commitment
  - Students submit an abstract to the *All of Us* Research Program Researchers Convention or other scientific meeting
- **Internship completion recognition**
  - Certificate acknowledging Academy Internship Program completion
  - Feature in Researcher Academy Connections newsletter
- **Internships will begin in May 2023!**



# All of Us Researcher Academy Newsletter

- Quarterly distribution
- Features
  - Researcher Spotlight
  - Career Corner
  - Academy Announcements
  - Upcoming Courses and Events

**Spring issue coming in May!**

To read the Fall issue,  
scan QR code or access  
<https://bit.ly/3kqo5U2>



**All of Us** Researcher Academy **Connections**

Issue 2 | Winter 2023

**IN THIS ISSUE**

- **Researcher Outlook:** Building New Resources
- **Academy Announcements**
- **Upcoming Academy Courses**
- **Spotlight**  
Southern University at New Orleans (SUNO) Grad Students Use Researcher Workbench in Capstone Projects
- **Career Corner:** Perfecting your Elevator Pitch

**Researcher Outlook:**  
**Building New Resources**

Welcome to another edition of the *Connections* newsletter. The *All of Us* Researcher Academy began in summer 2022 as a resource to facilitate researcher engagement with the National Institutes of Health's *All of Us* Research Program.

It has been a pleasure to build the *All of Us* Researcher Academy as a resource hub for faculty and student researchers. We both spent part of our careers as university faculty members and understand the myriad challenges that university-based researchers face. Because of that, we have carefully assembled a teaching team for our short courses to develop researcher-centered content ranging from programming skills to publication strategies to self-care and wellbeing for academic professionals.

The process of scientific discovery doesn't happen quickly or magically. Science requires thoughtful decision-making and hard work, and mentors play a vital role in teaching new scholars how to contribute. HBCUs have a long history of offering mentorship to new scholars, and the *All of Us* Researcher Academy is proud to support mentors who are helping to continue that tradition. See [Academy Announcements](#) to learn how you can become a Researcher Academy mentor this year.

We welcome your feedback on what we have been offering and your ideas for the future, including topics for future issues of *Connections*.

—Sula Hood and Brian Southwell,  
*All of Us* Researcher Academy co-leaders

**Sula Hood, PhD**  
Senior Research Scientist  
RTI International

**Brian Southwell, PhD**  
Senior Research Scientist  
RTI International

Learn more about the Researcher Workbench

Visit the All of Us Research Program website

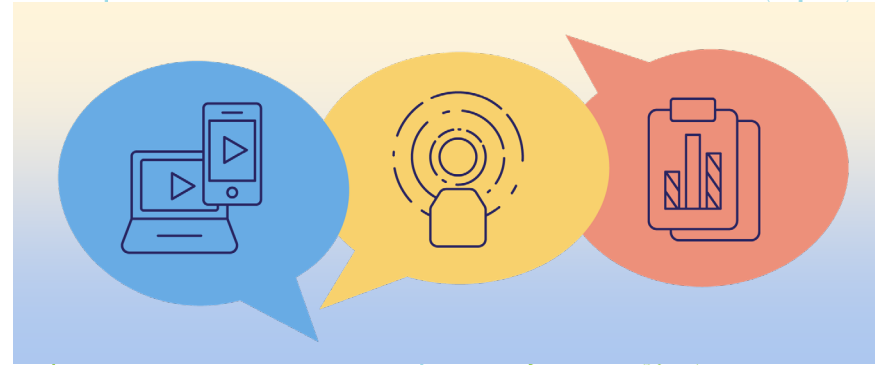
Subscribe to stay connected

Read past issues

All of Us Researcher Academy | Connections, Issue 2 | 1

# All of Us Researcher Academy HBCU Road Tour

- HBCU campus events to engage with attendees about the academy, build recognition for Institutional Champion awardees, and introduce researchers to the *All of Us* Researcher Workbench
  - **Howard University**, January 2023
  - **Tuskegee University**, April 2023
  - **Winston-Salem State University**, April 2023
- New destinations and dates coming soon!



# Stay Connected with Us

- Submit your email address to receive All of Us Researcher Academy updates or to connect with today's presenters.







# Thank you

Contact: [AllOfUs\\_Academy@rti.org](mailto:AllOfUs_Academy@rti.org)

# How to Register for the *All of Us* Researcher Workbench

Go to [researchallofus.org/academy\\_ev](https://researchallofus.org/academy_ev) and follow these steps:



1. Learn more about the data available at [databrowser.researchallofus.org](https://databrowser.researchallofus.org)



2. Check for your institution's Data Use and Registration Agreement



3. Create a Researcher Workbench account



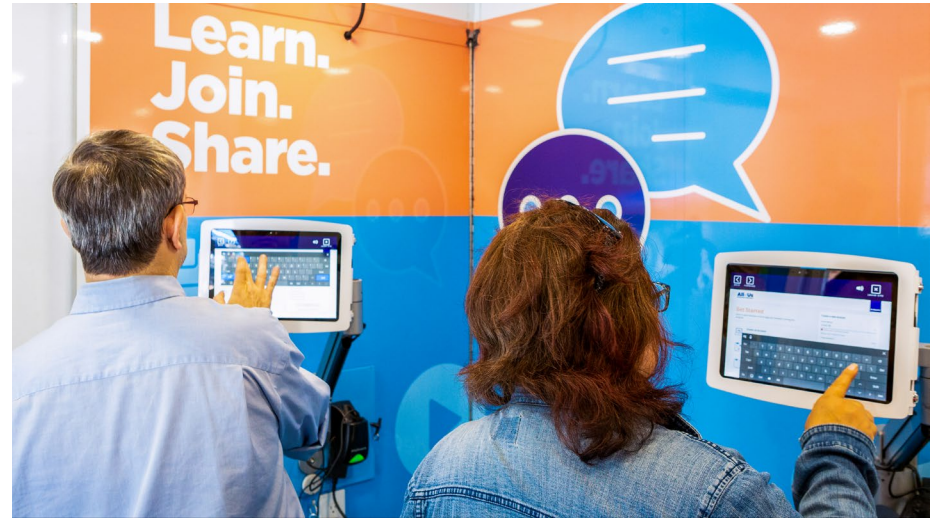
4. Verify your identity using Login.gov



5. Complete All of Us Research Training



6. Sign the Data User Code of Conduct



**Register here.**

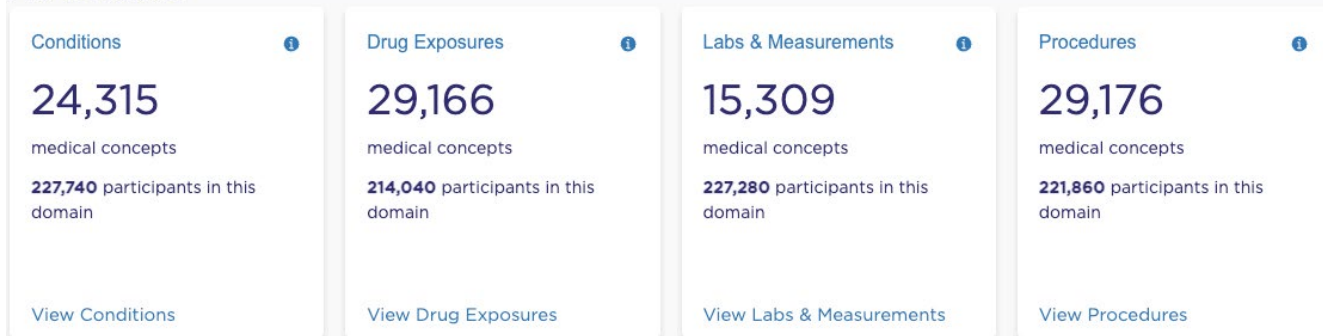
*Always use your institutional email address.*



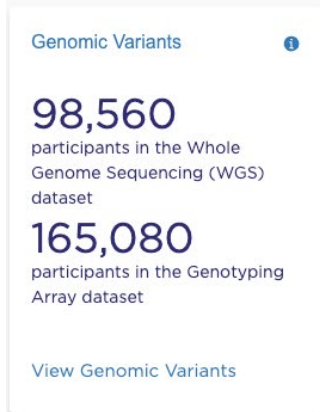
Bonus material beyond this point

# EHR & Physical Measurements

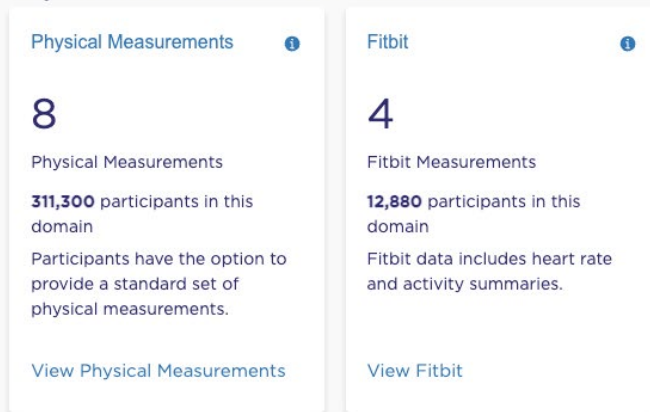
## EHR Domains



## Genomics



## Physical Measurements and Wearables



# Survey Questionnaires

## Survey Questions

The Basics



28

questions available

**372,380** participants in this domain

This survey includes participant demographic information.

[View Complete Survey](#)

Overall Health



21

questions available

**372,380** participants in this domain

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

[View Complete Survey](#)

Lifestyle



26

questions available

**372,380** participants in this domain

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

[View Complete Survey](#)

Personal Medical History



465

questions available

**142,100** participants in this domain

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

[View Complete Survey](#)

Health Care Access & Utilization



57

questions available

**160,880** participants in this domain

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

[View Complete Survey](#)

Family Health History



104

questions available

**145,620** 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)



191

questions available

**100,320** participants in this domain

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

[View Complete Survey](#)

COPE Minute Survey



141

questions available

**101,440** participants in this domain

Survey includes information regarding a participant's COVID-19 vaccination experience.

[View Complete Survey](#)

# All of Us Researcher Workbench Tiers

## Registered and Controlled Tiers

- **Physical measurements**, including blood pressure, heart rate, and body mass index, from more than 306,000 participants.
- **Survey responses** from more than 372,000 participants that include lifestyle, access to care, and medical history; survey data from nearly 132,600 participants on their experiences with COVID-19 during the pandemic; and survey data from more than 57,600 initial responses to the program's new social determinants of health survey with questions about neighborhood safety, food and housing security, and experiences with discrimination and stress.
- **Electronic health records** from more than 258,000 participants who have been standardized to the Observational Medical Outcomes Partnership Common Data Model.
- **Wearable data** from more than 12,800 participants with Fitbit® devices, including physical activity and heart rate.

## Additional Controlled Tier Data

- **Genomic data** with large sample sizes that are appropriate for precision medicine research (nearly 100,000 whole genome sequences and more than 165,000 genotyping arrays).