



The *All of Us* Research Program

Sheri Schully, Ph.D. (she/her)
Deputy Chief Medical and Scientific Officer
All of Us Research Program

April 5, 2024



Overview of the *All of Us* Research Program

The *All of Us* Research Program is a historic, longitudinal effort to **gather data from one million or more people** living in the United States **to accelerate research and improve health**. By taking into account individual differences **in lifestyle, socioeconomics, environment, and biology**, we hope that researchers will one day uncover paths toward delivering **precision medicine – or individualized prevention, treatment, and care – for all of us**.

The *All of Us* Research Program is part of the broader Precision Medicine Initiative.

“Tonight I’m launching a new Precision Medicine Initiative to bring us closer to curing diseases like cancer and diabetes.

And to give us all access to the personalized information we need to keep ourselves and our families healthier.”

President Barack Obama
2015 State of the Union Address | January 20, 2015



Core Values Drive *All of Us*



The Precision Medicine Initiative Cohort Program – Building a Research Foundation for 21st Century Medicine

Precision Medicine Initiative (PMI) Working Group Report to the Advisory Committee to the Director, NIH

September 17, 2015



We set core values for the program at its inception. Our Core Values fuel our purpose, shape our vision, and guide the implementation of our mission.

Participation is **open** to all.

Participants have **access** to their information.

Participants reflect the rich **diversity** of the U.S.

Data will be accessed **broadly** for research purposes.

Participants are **partners**.

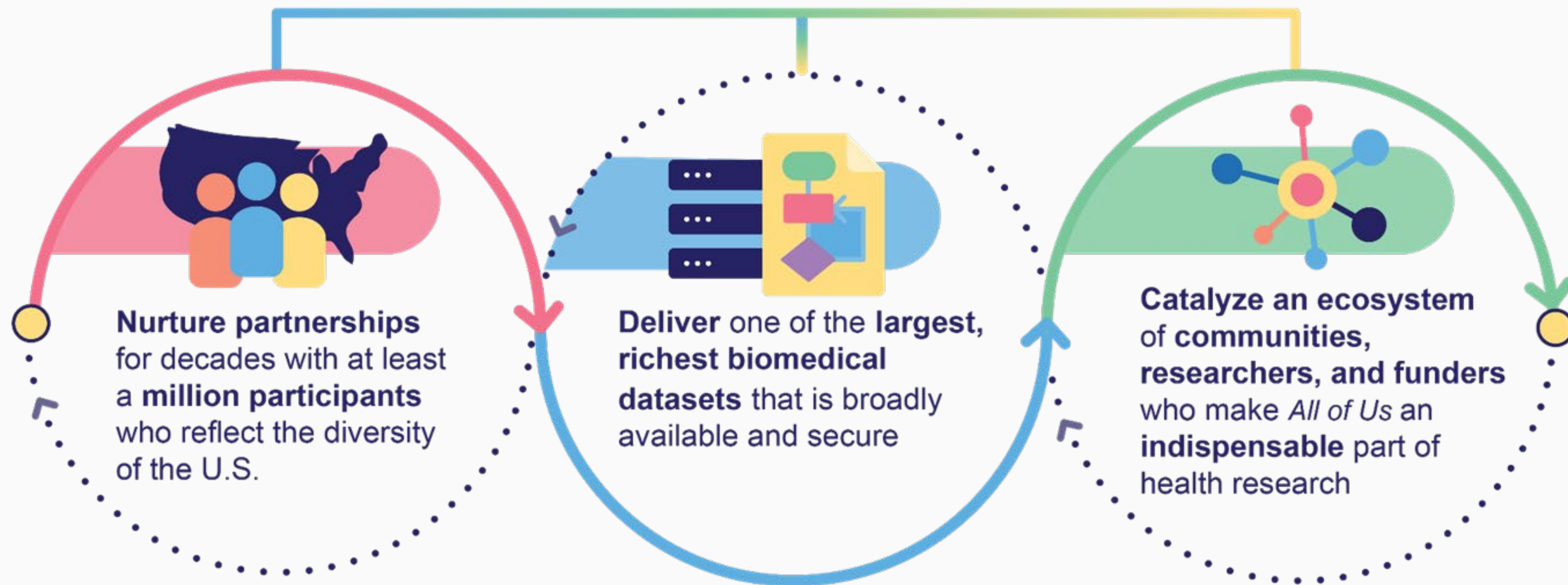
Security and privacy will be of highest importance.

Trust will be earned through **transparency**.

The program will be a catalyst for **positive change** in research.

The *All of Us* Research Program Mission

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



Enrolled 775K+ Participants With Continued Growth

Participant Enrollment

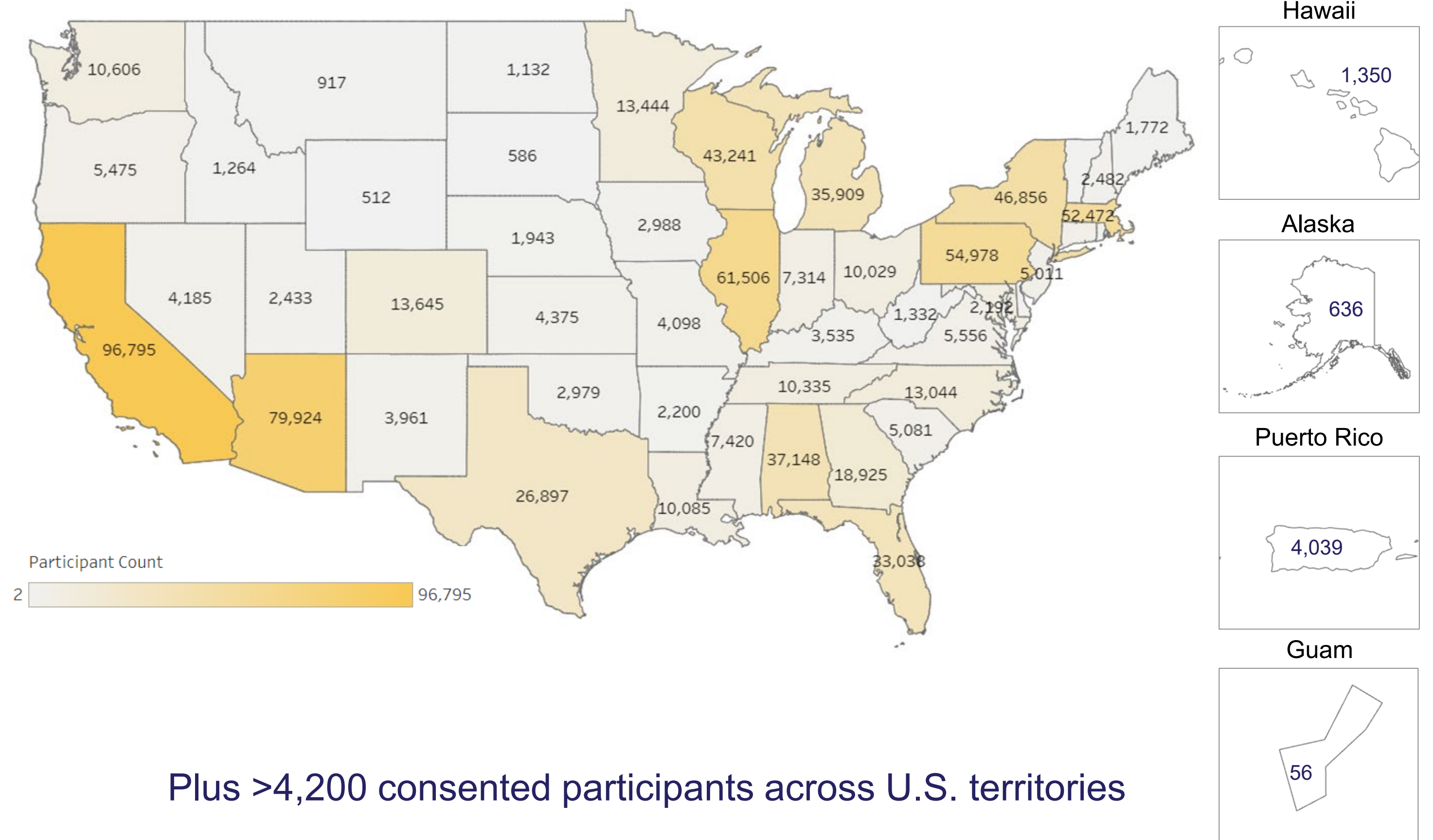
775,000+
Participants

431,000+
Electronic Health
Records

533,000+
Participants who have
completed initial steps of the
program

550,000+
Biosamples

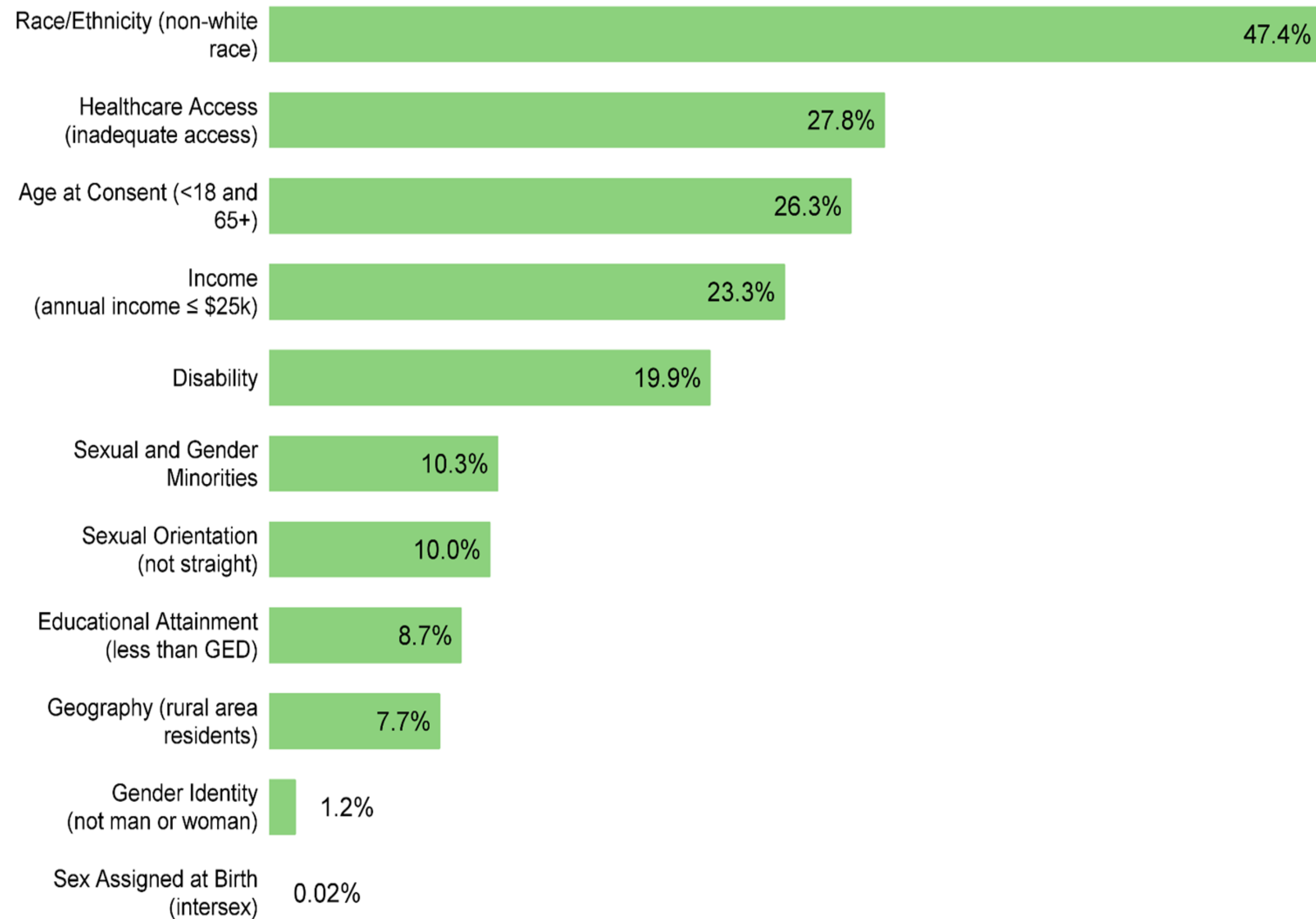
Map of Consented Participants



Numbers current as of March 11, 2024

Prioritizing Intersectionality & Social Determinants of Health

Underrepresented in Biomedical Research (UBR)

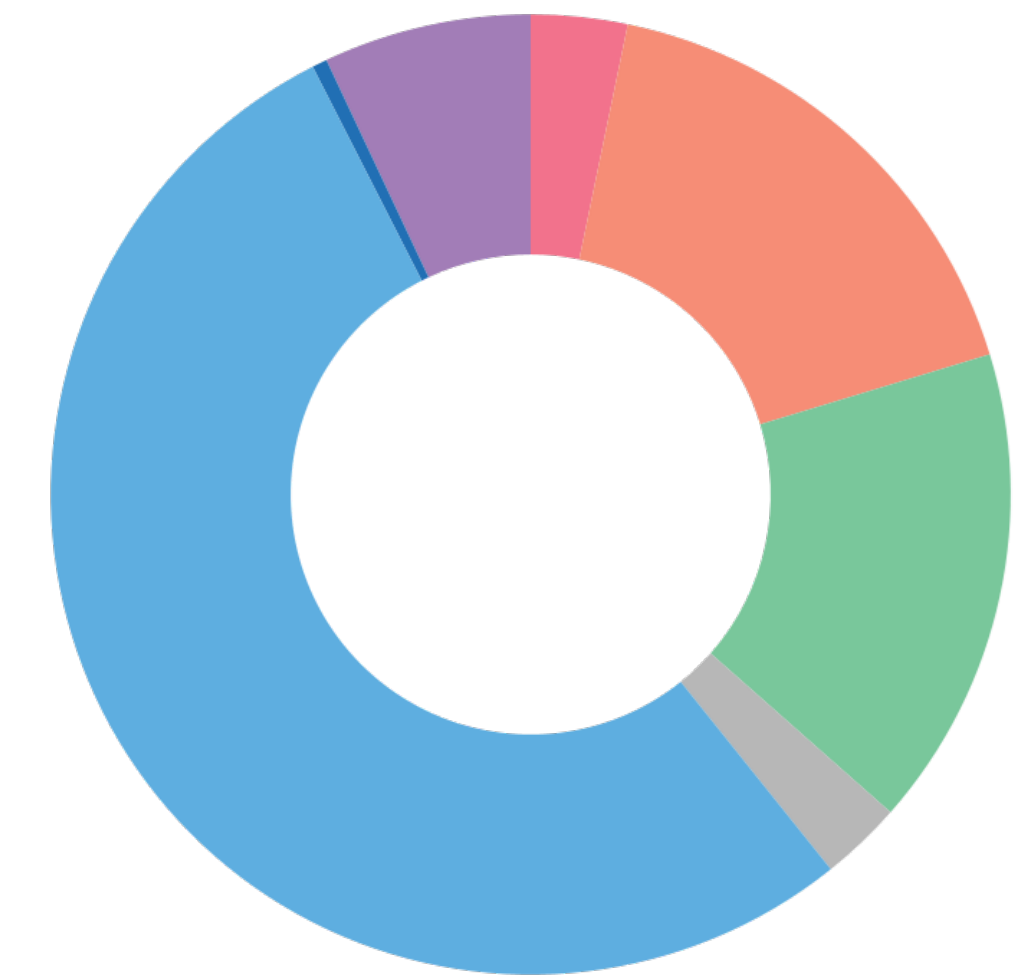


Source: [All of Us Research Program Data Snapshots](#) (Data current as of March 11, 2024)

All of Us Research Program

- Asian 3.2%
- BAA 16.8%
- H/L 16%
- MENA, NHPI, or None fully describe me 2.7%
- White 52.5%
- Prefer not to say 0.5%
- More than one race 6.9%

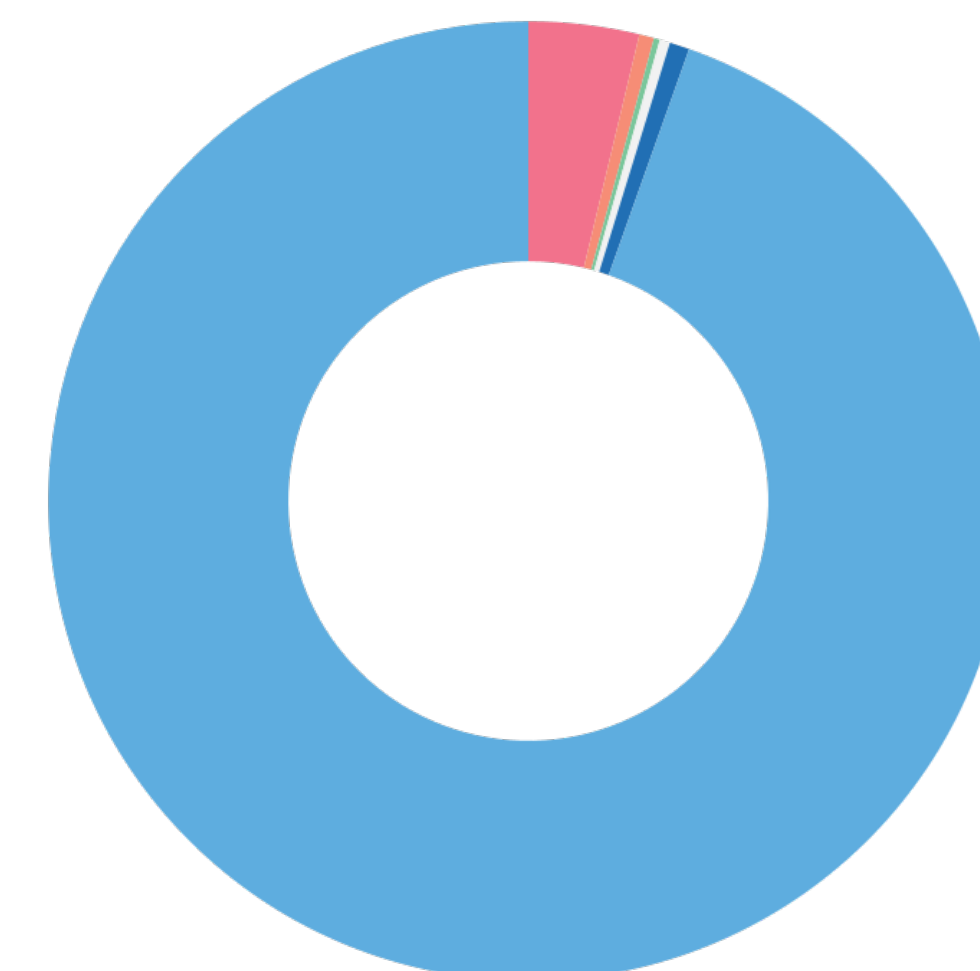
Source: [All of Us Research Program Data Snapshots, Race and Ethnicity](#) (Updated February 6, 2024)



Other Genomic Studies

- Asian 3.72%
- African American or Afro-Caribbean 0.5%
- African 0.2%
- H/L 0.35%
- Other/More than one 0.67%
- White/European Descent 94.56%

Source: [Global Genome Wide Association Studies \(GWAS\)](#) (Updated January 2024)



Data Types Collected from *All of Us* Participants



Electronic Health Records

Data types collected from EHR include:

- Demographics
- Vital signs
- Diagnoses
- Procedures
- Medications
- Doctor and Laboratory Visits



Participant Surveys

The Basics
Overall Health
Lifestyle

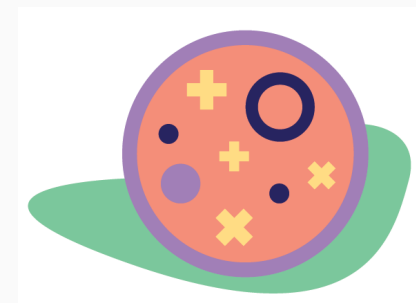
Health Care Access & Utilization
Personal and Family Medical History
Social Determinants of Health

Mental Health and Well-Being



Physical Measurements

- Blood pressure
- Heart rate
- Height
- Weight
- BMI
- Hip circumference
- Waist circumference



Biosamples

- Blood
- Saliva
- Urine



Wearable Data

Fitbit data, including:

- Heart Rate
- Activity (Daily Summary)
- Activity Intraday Steps
- Sleep data

Data Collected and Return of Value to *All of Us* Participants



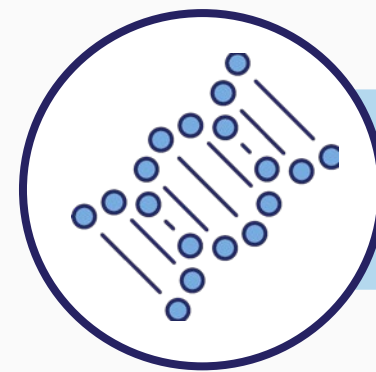
Consent and Electronic Health Records



Participant Surveys



Physical Measurements



Biosamples

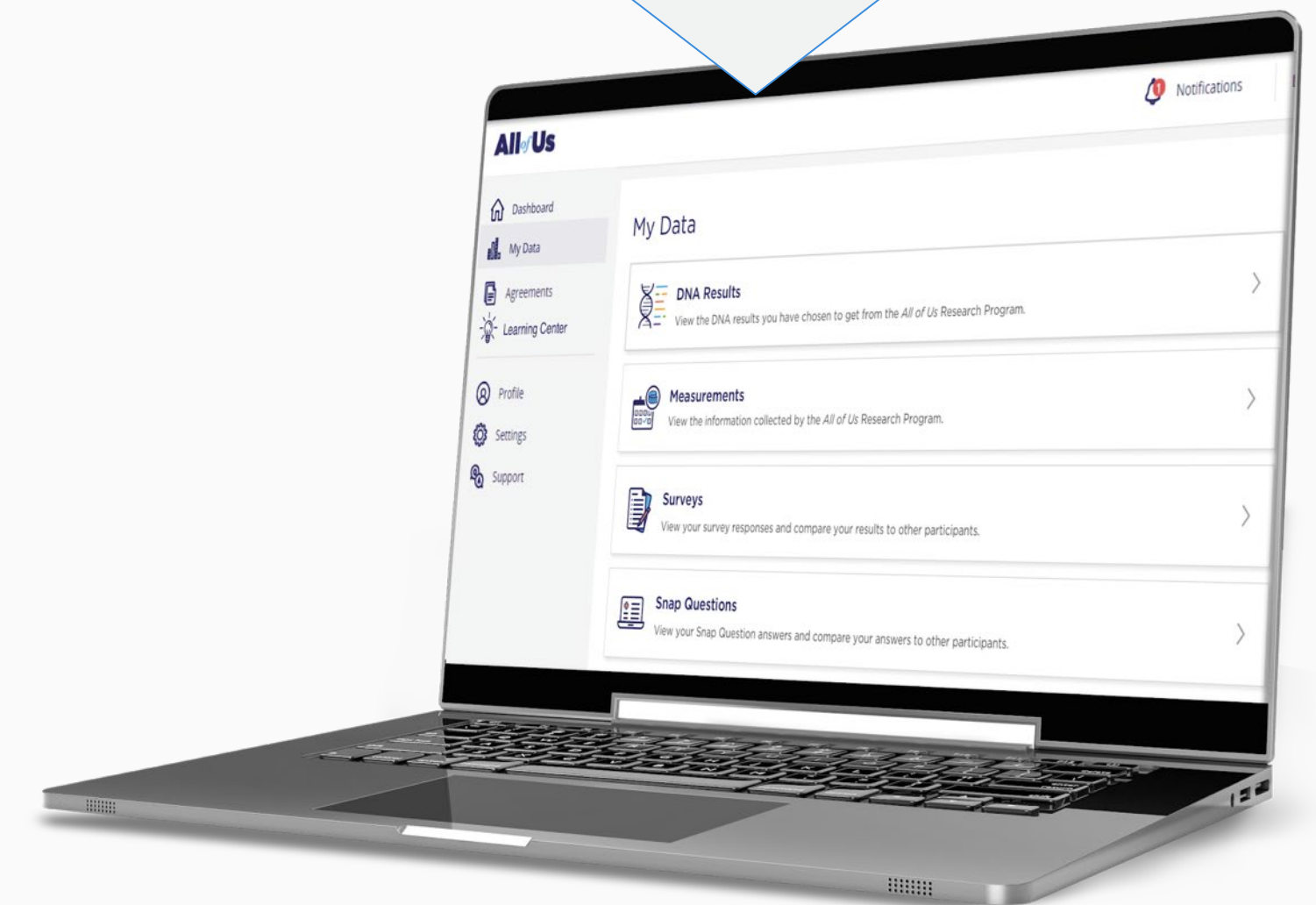
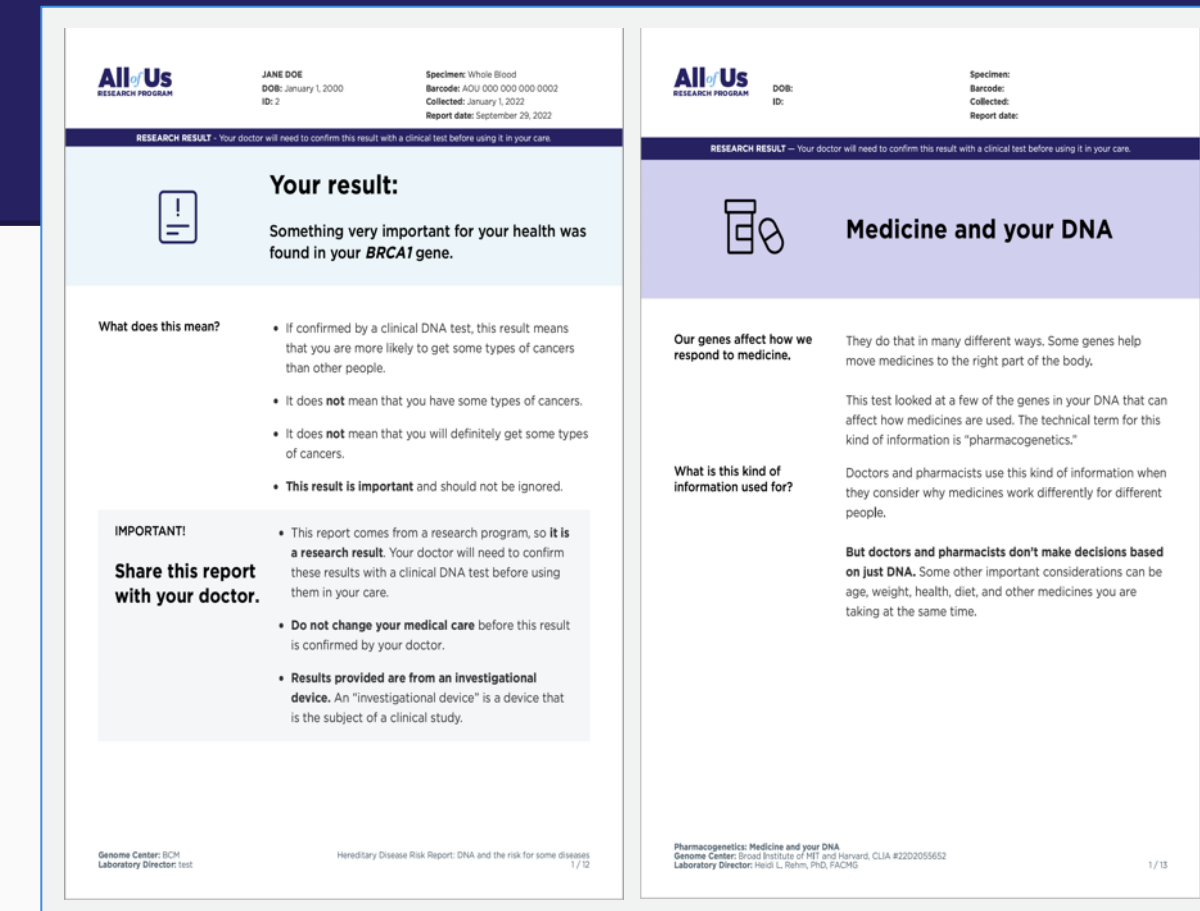


Mobile/Wearable Tech

Return of Value for Participants

Participants may receive:

- **Genetic information**
- Survey data (comparative)
- EHR and claims data
- Ongoing study updates
- Aggregate results
- Scientific findings
- Opportunities to be contacted for other research opportunities



Participants Can Receive Four Types of Genetic Research Results

Engaging insights

Genetic ancestry and traits results



7 regions (20 subregions) and 4 traits

- Sub-Saharan Africa
- Europe
- Oceania
- Southern Asia
- Eastern and northern Asia
- The Middle East and North Africa
- The Americas
- Ear wax
- Bitter taste perception
- Cilantro preference
- Lactose intolerance

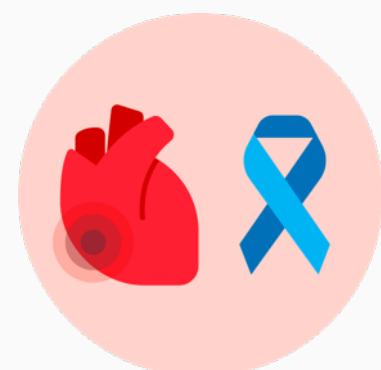
Medicine and your DNA Report



7 pharmacogenomics (PGx) genes and 50+ medications

- *CYP2C19*
- *DPYD*
- *G6PD*
- *SLCO1B1*
- *NUDT15*
- *TPMT*
- *UGT1A1*

Hereditary Disease Risk (HDR) Report



59 genes (SNVs + indels, e.g. no SVs)

- Breast cancer
- Ovarian cancer
- Uterine cancer
- Colorectal cancer
- Prostate cancer
- Melanoma
- Brain cancer
- Pancreatic cancer
- Stomach cancer
- Familial hypercholesterolemia
- Cardiomyopathies
- Arrhythmias
- Arteriopathies

Health results

Genomic Health-Related Return of Results (as of March 20, 2024)

Hereditary Disease Risk

All of Us currently looks for genetic variants in 59 genes associated with serious health conditions.



JANE DOE
DOB: January 1, 2000
ID: 2

Specimen: Whole Blood
Barcode: AOU 000 000 000 0002
Collected: January 1, 2022
Report date: September 29, 2022

RESEARCH RESULT - Your doctor will need to confirm this result with a clinical test before using it in your care.



Your result:

Something very important for your health was found in your **BRCA1** gene.

What does this mean?

- If confirmed by a clinical DNA test, this result means that you are more likely to get some types of cancers than other people.
- It does **not** mean that you have some types of cancers.
- It does **not** mean that you will definitely get some types of cancers.
- **This result is important** and should not be ignored.

IMPORTANT!

Share this report with your doctor.

- This report comes from a research program, so **it is a research result**. Your doctor will need to confirm these results with a clinical DNA test before using them in your care.
- **Do not change your medical care** before this result is confirmed by your doctor.
- **Results provided are from an investigational**

222k+ offered choice
122.5k+ (53%) said "yes"
99.5k+ viewed results
2.9% with actionable result

Medicine and Your DNA

All of Us analyzes seven genes that can affect how bodies metabolize medicines.



DOB: ID:

Specimen: Barcode: Collected: Report date:

RESEARCH RESULT - Your doctor will need to confirm this result with a clinical test before using it in your care.



Medicine and your DNA

Our genes affect how we respond to medicine.

They do that in many different ways. Some genes help move medicines to the right part of the body.

This test looked at a few of the genes in your DNA that can affect how medicines are used. The technical term for this kind of information is "pharmacogenetics."

What is this kind of information used for?

Doctors and pharmacists use this kind of information when they consider why medicines work differently for different people.

But doctors and pharmacists don't make decisions based on just DNA. Some other important considerations can be age, weight, health, diet, and other medicines you are taking at the same time.

222k+ offered choice
116k+ (52%) said "yes"
95.4k+ viewed results
>96% with actionable result

Genetic Ancestry and Traits

All of Us provides genetic ancestry details for 7 regions, and information on four genetic traits.

DNA Results

You'll see all of your DNA results here when they're ready. See [options for your DNA results](#).

Genetic ancestry and trait results

5 results



Genetic ancestry

Genetic ancestry can be very interesting, but you may also learn information you didn't expect.

[View Results](#)



Bitter taste

Learn what you



Cilantro pre

Your genes pla



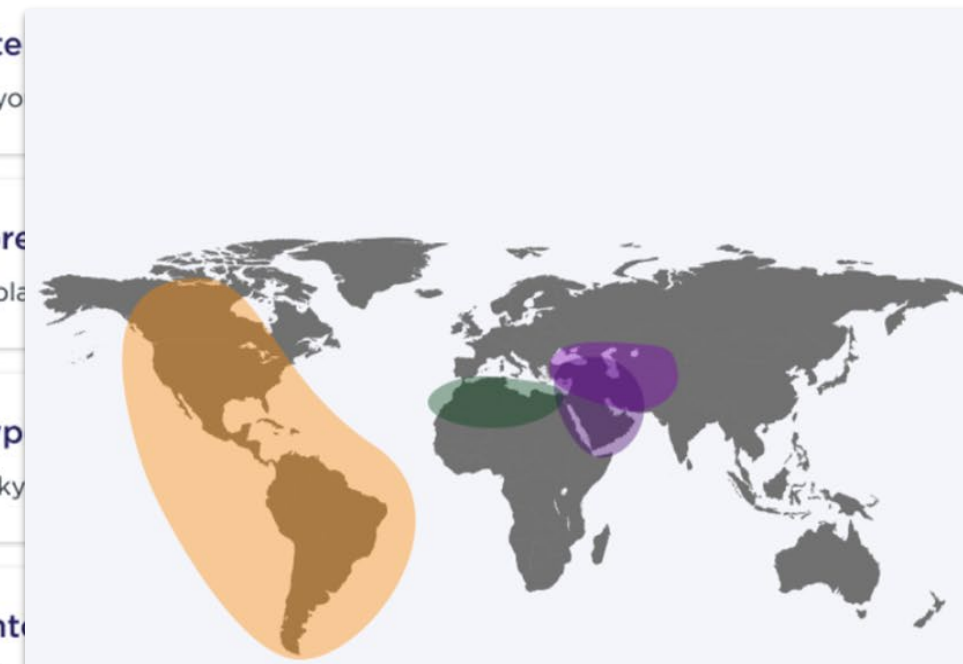
Earwax typ

Flaky or sticky



Lactose int

Your genes ha



The Americas	50%
The Americas	100%
Such as North, Central, and South America	
The Middle East and North Africa	50%
Northern Africa	10%
Such as Morocco, Algeria, and Egypt	
The Middle East	40%
Such as the Arabian Peninsula and Egypt	
Western Asia and the Caucasus	50%
Such as Turkey, Iran, Syria, Iraq, and the Caucasus	

[See Other Ancestry Groups Tested](#)

290k+ offered choice
171k+ (63%) said "yes"
168k+ viewed results

Leveraging the *All of Us* Data

Data Tiered Access Levels Enable Discovery



Available to
Anyone

PUBLIC TIER

Public resources include:

- **Data Snapshots:** Aggregated, public-facing overviews of participant characteristics and data types
- **Data Browser:** Interactive preview into the *All of Us* dataset through public-facing aggregate data
 - Currently includes participant-provided survey responses, physical measurements, data from EHRs and wearables, and genomic data
- **Survey Explorer:** Details the questions included in each of the surveys
- **Research Projects Directory:** Descriptions of each research project within the Researcher Workbench

RESEARCHER WORKBENCH

REGISTERED TIER

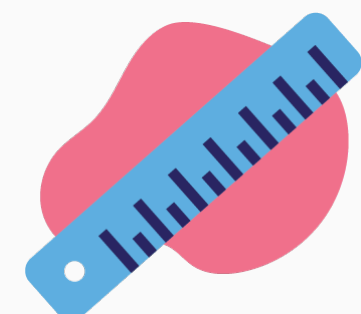
Registered researchers can access in-depth data and a variety of research tools to conduct a wide range of studies.



Surveys



Electronic
Health Records



Physical
Measurements



Wearables

CONTROLLED TIER

Registered researchers with amended institutional agreements can access all of the data in the Registered Tier plus additional and expanded data types, including genomic data, real dates of health events, ICD codes, granular demographic data, and more.



Genomics



Health and
Lifestyle surveys

Available to
Registered
Researchers

Data have been processed to protect participant privacy

Nearly 250,000 Whole Genome Sequences Available to Advance Precision Medicine

The *All of Us* Research Workbench contains the one of the largest sets of whole genome sequences widely available for research.



413,350+
Survey Responses



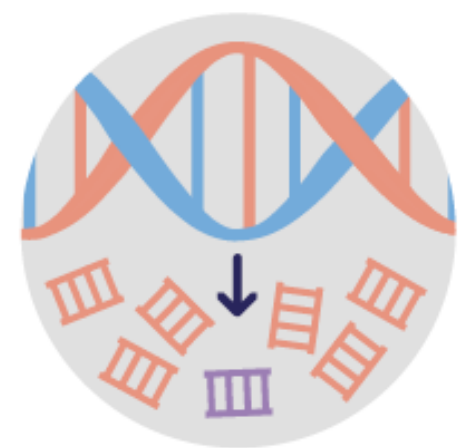
337,500+
Physical Measurements



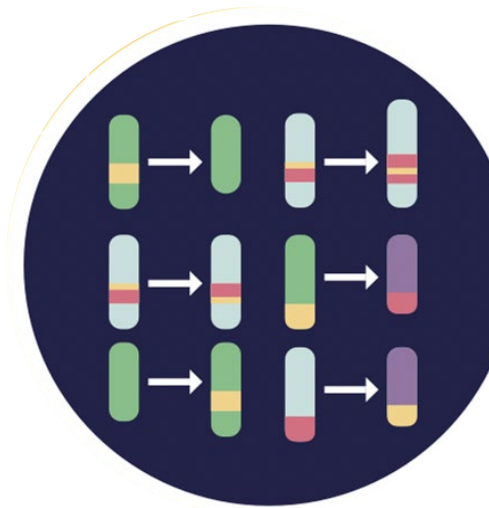
312,900+
Genotyping Arrays



287,000+
Electronic Health Records

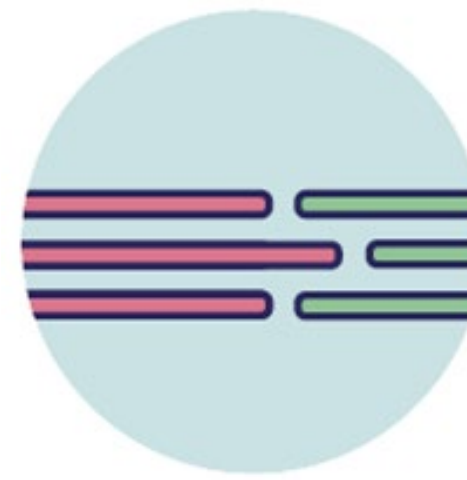


245,350+
Whole Genome Sequences



11,350+
Structural Variants

NEW! In 2023



1,000+
Long-Read Sequences

NEW! In 2023



15,600+
Fitbit Records

NEW! Sleep Data

The whole genome sequence dataset includes variation at more than **1 billion** locations, which is nearly **one-third** of the entire human genome

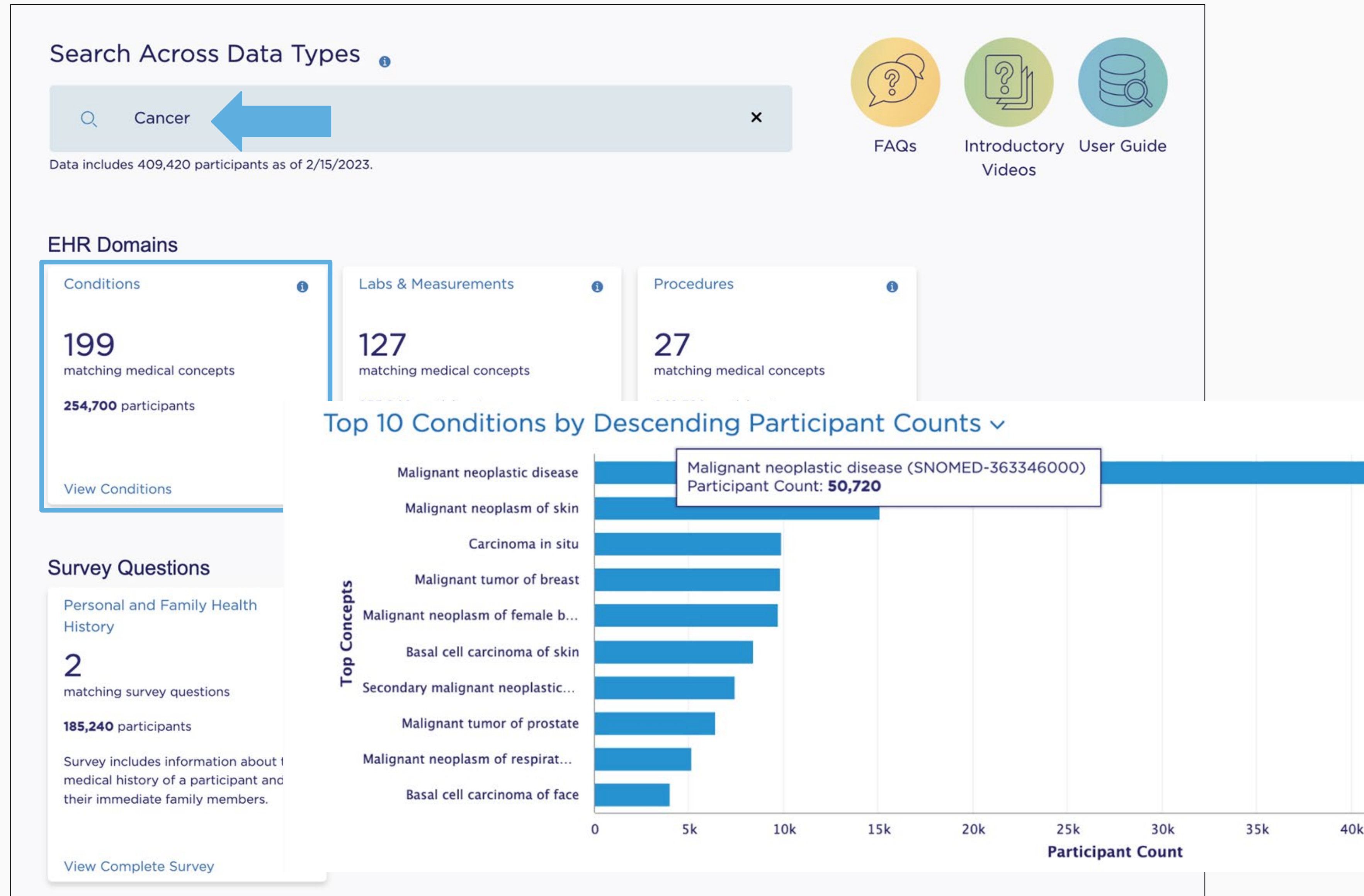


All of Us Research Hub: Public Data Browser

Summary statistics of:

- EHR Data (Conditions, Drug Exposures, Lab & Measurements, Procedures)
- Genomic Variants
- Survey Questions (including COVID-19 surveys)
- Physical Measurements
- **Open Access (no login required)**

Data Browser



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Data Browser



Have you or anyone in your family ever been diagnosed with the following cancer conditions? Think only of the people you are related to by blood. Select all that apply.

[See Answers](#) v

Answer	Concept Code ⁱ	Participant Count ⁱ	% Answered out of 185240	
Have you or anyone in your family ever been diagnosed with the following cancer conditions? Think only of the people you are related to by blood. - Breast cancer	43528499	19,300	10.42%	>
Have you or anyone in your family ever been diagnosed with the following cancer conditions? Think only of the people you are related to by blood. - Skin cancer	43529816	15,700	8.48%	>
Have you or anyone in your family ever been diagnosed with the following cancer conditions? Think only of the people you are related to by blood. - Lung cancer	43529183	11,600	6.26%	>
Have you or anyone in your family ever been diagnosed with the following cancer conditions? Think only of the people you are related to by blood. - Colon cancer/Rectal cancer	43528564	11,460	6.19%	>
Have you or anyone in your family ever been diagnosed with the following cancer conditions? Think only of the people you are related to by blood. - Prostate cancer	43529732	10,260	5.54%	>

All of Us Researcher Workbench: Access to Row-Level Data for Analysis

Researcher Workbench

- Cloud-based central resource for broad data accessibility
- Graphical tools for cohort selection and data set building
- R and Python in Jupyter notebooks; SAS available soon
- **Passport access model for approved researchers - just create, describe your workspace, and get to work! No separate IRB approval needed.**
- Currently open to academic, health care and not-for-profit organizations

All of Us
RESEARCHER WORKBENCH

Welcome to the
RESEARCHER WORKBENCH
The secure platform to analyze *All of Us* data

Workspaces +

- Featured Workspace: Dementia
OWNER
Last Changed: 02/11/20, 07:32 PM
- All of Us Survey Codebook and Frequency Distributions
OWNER
Last Changed: 02/11/20, 07:51 PM
- Featured Workspace: Depression
OWNER
Last Changed: 02/11/20, 07:50 PM
- Featured Workspace - Type 2 Diabetes
OWNER
Last Changed: 02/11/20, 07:50 PM

Recently Accessed Items

- Case 1 Notebook
Last Modified: Mar 06 2020
Notebook
- Dementia Analysis from Cohort Builder
Last Modified: Feb 04 2020
Notebook
- Ischemic Heart Disease Analysis
Last Modified: Feb 04 2020
Notebook
- Dementia Analysis
Last Modified: Feb 04 2020
Notebook
- Type 2 Diabetes Analysis
Last Modified: Feb 04 2020
Notebook
- Ischemic Heart Disease Analysis
Last Modified: Feb 04 2020
Notebook

ResearchAllofUs.org/Data-Tools/Workbench/



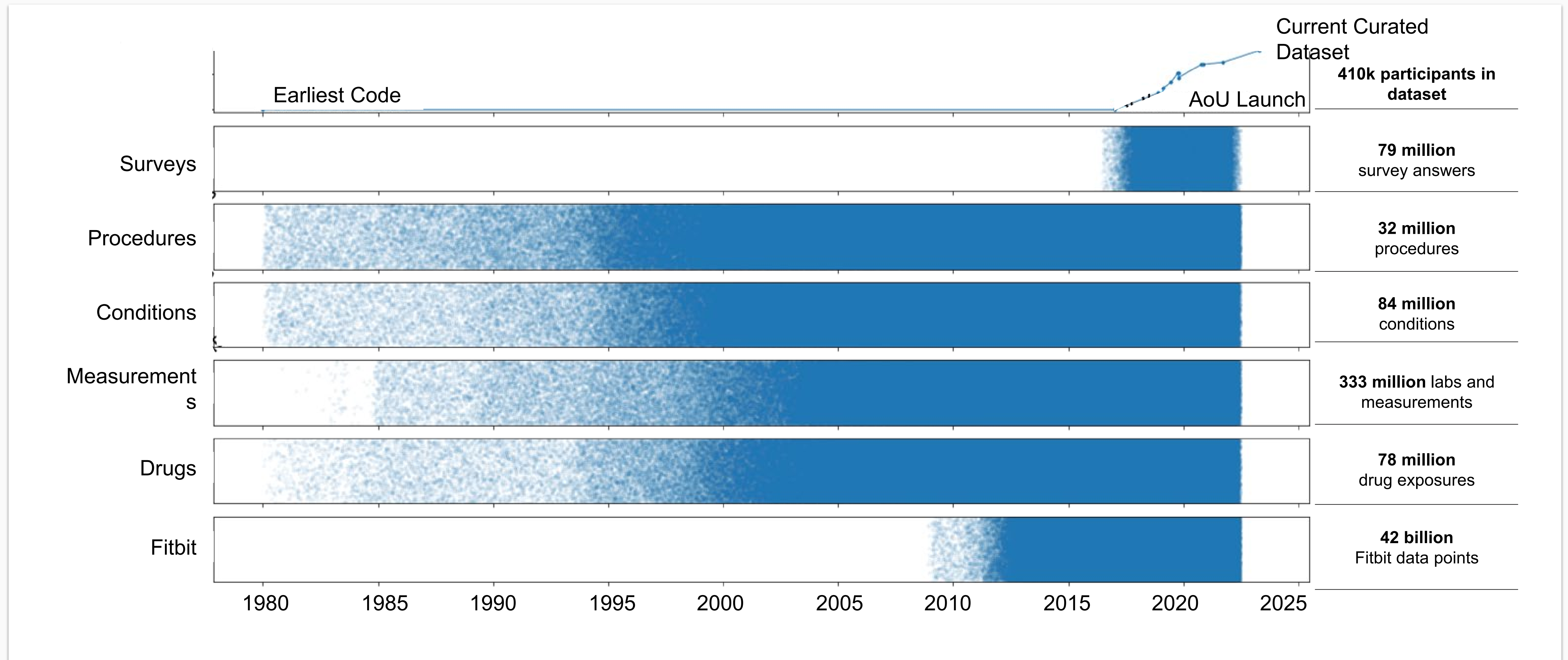
All of Us Data Includes Range of Diseases

Conditions	Domain	Participants
Heart Disease	Heart	89,180
Obesity	Endocrine	80,980
Type 1 Diabetes	Endocrine	6,740
Type 2 Diabetes	Endocrine	56,340
Any cancer	Cancer	50,720
Asthma	Pulmonary	50,160
Chronic Obstructive Pulmonary Disorder	Pulmonary	24,940
Epilepsy	Neuro	9,320
Stroke	Neuro	940
Rheumatoid Arthritis	Autoimmune	8,660
Osteoarthritis	Autoimmune	99,880

Conditions	Domain	Participants
Depressive Disorder	Mental Health	82,660
Bipolar Disorder	Mental Health	16,200
Dementia	Mental Health	6,020
Human Immunodeficiency Virus	Infectious Disease	5,500
COVID-19*	Infectious Disease	58,000*
Alcoholism	Abuse	20,380
Opioid Usage	Medication	155,000
Age-Related Macular Degeneration	Eye	4,740
Hearing loss	Hearing	30,400
Falls	Aging/Nursing	4,860

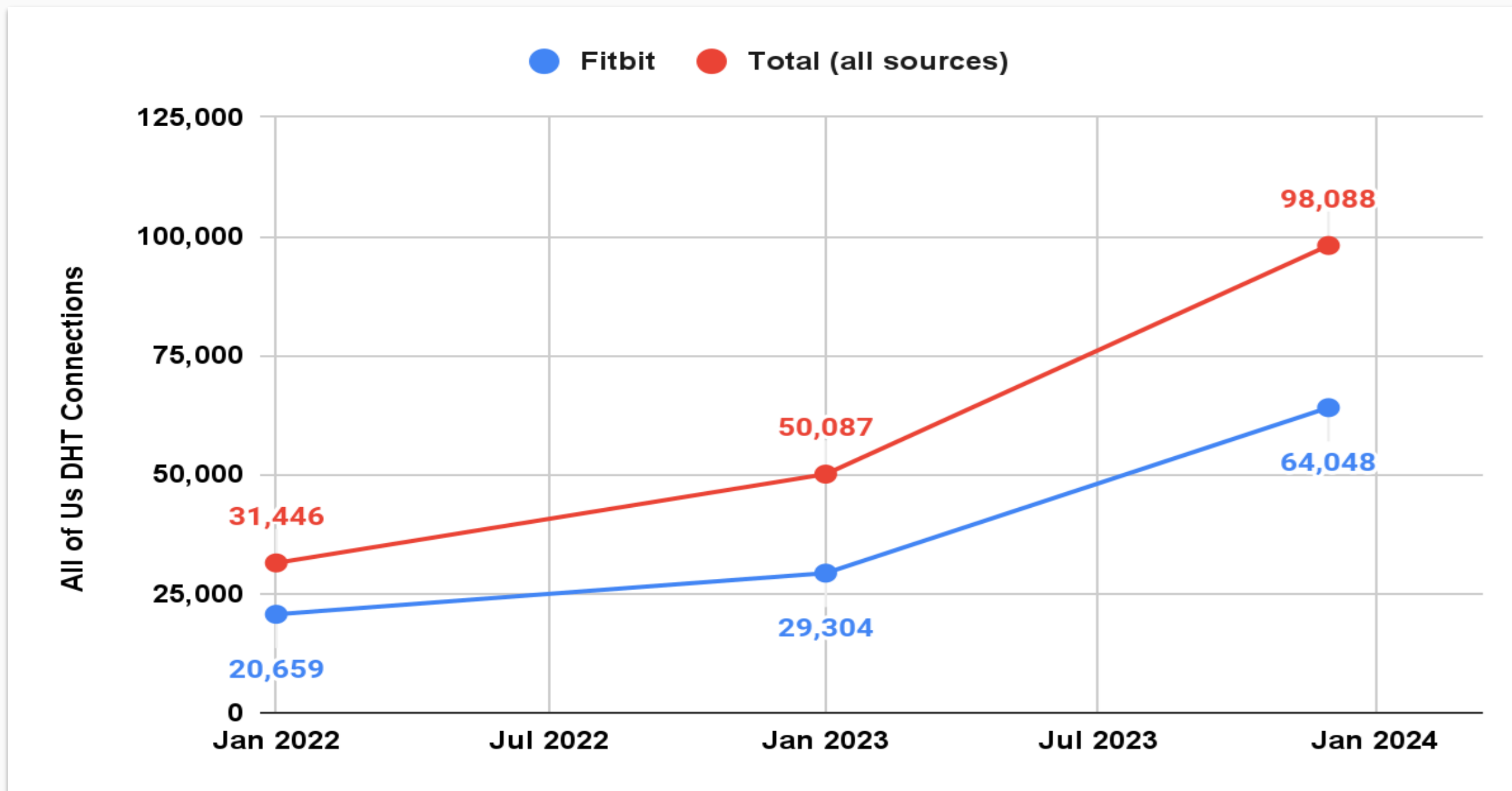
*using combination of diagnosis code, lab test, and COVID survey answers

EHR Data on the Researcher Workbench is Diverse and Longitudinal

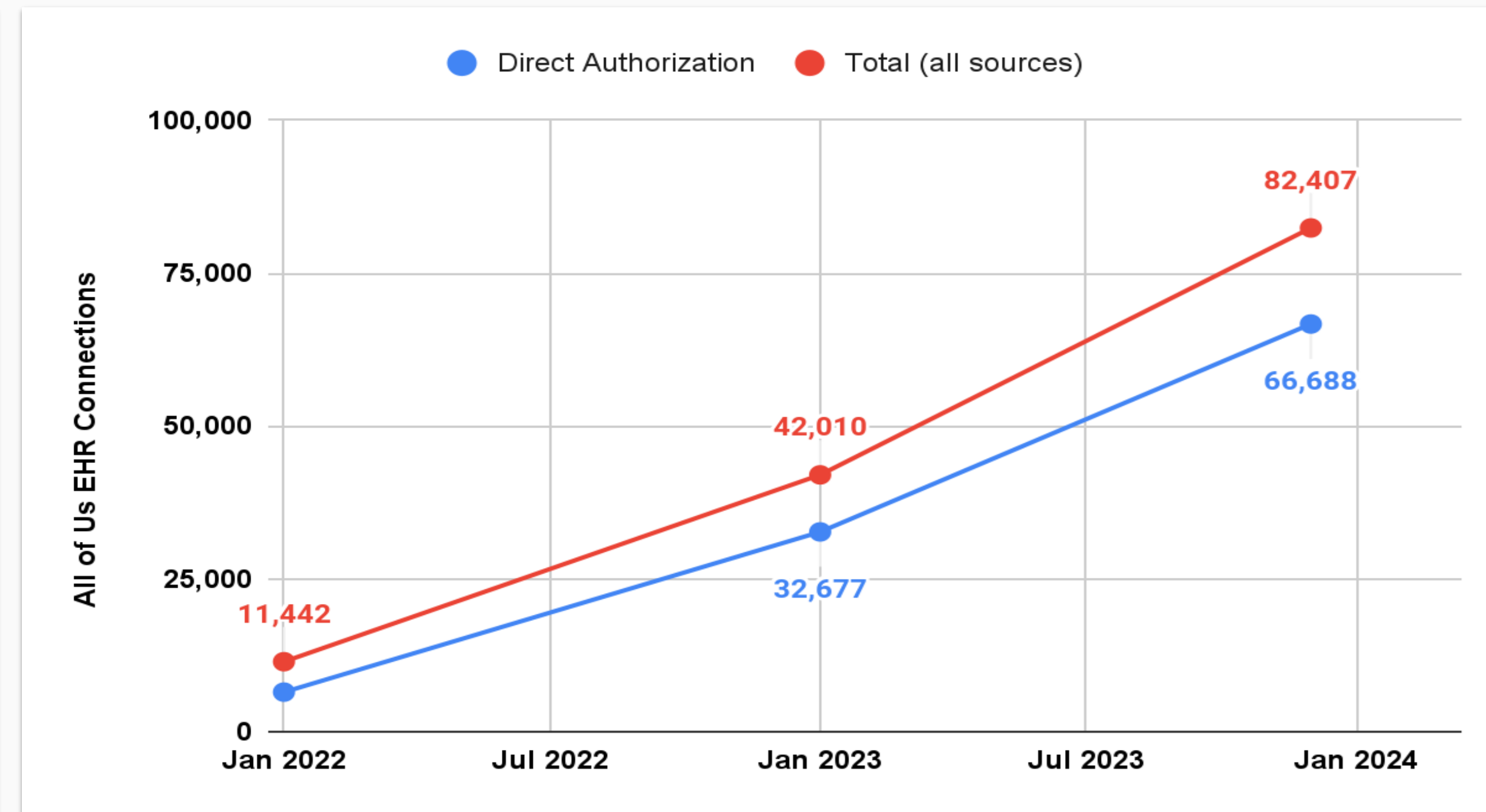


Doubled DHT and EHR Connections in 2023

DHT Device & App Connections Over Time



Participant EHR Connections Over Time



as of 12/11/2023

What Kind of Research Can *All of Us* Support?

Example studies in *All of Us*

- Associations between diseases, medications, behaviors, SDOH, genomics
- Health disparities
- Historically underrepresented populations
- Genomics and PGx
- Drug target discovery
- Early disease detection
- Geospatial linkages (future)
- ***Insert your topic here***

Modalities of research *All of Us* supports

- AI/ML
- Risk stratification
- Predictive analytics
- Phenotype algorithms & cohort development
- Novel method development
- Basic EHR investigations
- Validation of other studies

All of Us is **not**

- A representative US sample
- A study with uniform follow-up of all variables

All of Us Researcher Workbench: Access to Row-Level Data for Analysis



CONFIRM YOUR INSTITUTION'S AGREEMENT

Before you can create an account, your institution must have a Data Use and Registration Agreement (DURA) in place with *All of Us*. [Confirm DURA](#).



COMPLETE THE MANDATORY TRAINING

The training focuses on conducting responsible and ethical research using the Researcher Workbench. Additional training is required to access the Controlled Tier. [Learn more](#).



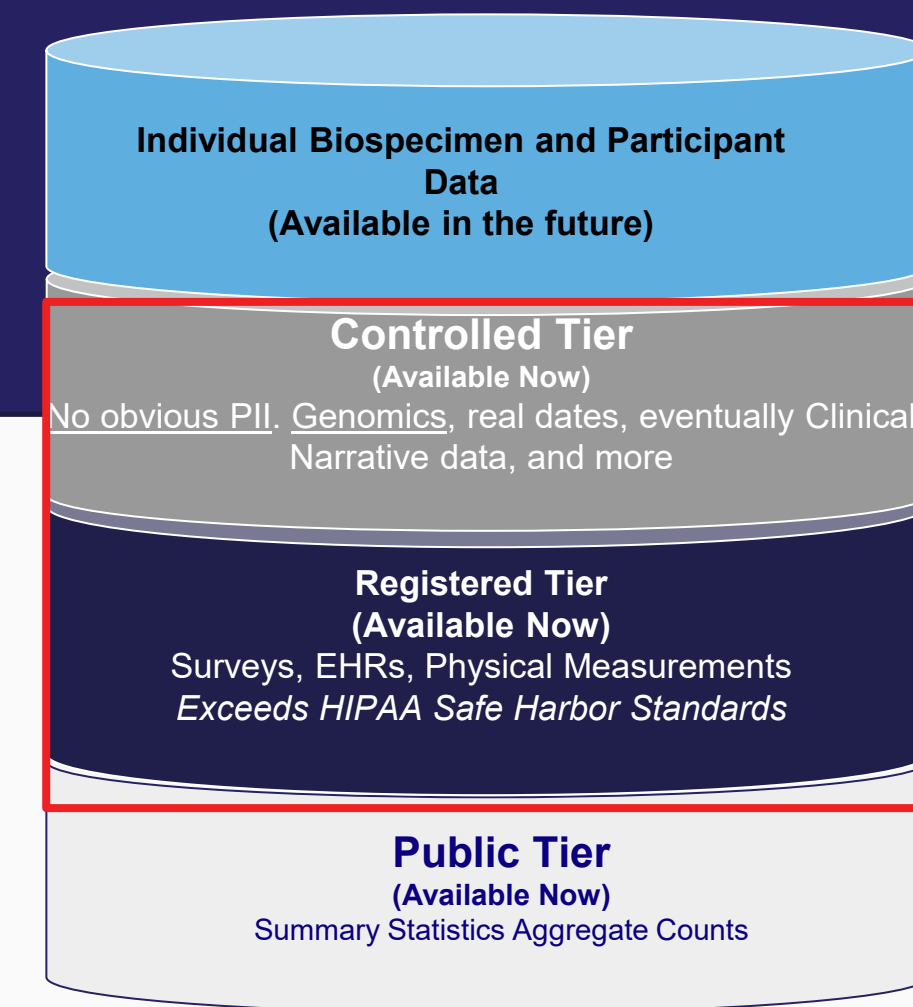
CREATE AN ACCOUNT AND VERIFY IDENTITY

After creating your Researcher Workbench account, you will be asked to verify your identity through [login.gov](#). [Learn more](#).



SIGN THE DATA USER CODE OF CONDUCT (DUCC)

This agreement outlines the program's expectations for researchers who use the Researcher Workbench and describes how program data may be used. [View the DUCC](#).



Researcher Workbench

All of Us Research Program's Commitment to Researcher Diversity (data as of March 1, 2024)



9,500+
Registered
Researchers



9,490+ Active
Projects



350+
Publications
using *All of Us*
data



700+
Organizations

42 Historically Black
Colleges &
Universities

67 Hispanic Serving
Institutions



51
International
Institutions



Top
Conditions
Studied

Cardiovascular
disease,
Hypertension,
Mental Health,
Cancer, Diabetes

- **Creating a diverse researcher cohort** that promotes responsible and ethical use of data, returns value to participant communities, and accelerates research impact.
- **Encouraging student assemblies and early-stage investigators** to bring fresh, creative perspectives & innovative research outcomes.
- **Ensuring access for researchers from various institutions/ organizations** to establish a truly equitable resource for all.



Baylor's UBR Faculty Summit

Over 85% of our researchers are underrepresented in the biomedical workforce - including over 30% diverse by race and ethnicity

Growing Scientific Impact

JOURNAL ARTICLE

The association of anxiety with granuloma annulare: a case–control study of the National Institutes of Health ‘All of Us’ research programme [Get access >](#)

Annika Belzer, Audrey C Lea

Health disparities in the treatment of bipolar disorder



Vladimir Tchikrizov^a, Mark E. Ladner^a, Felicia V. Caples^b, Mitzi Morris^c, Hailey Spillers^c, Christina D. Jordan^c, Joyce E. Balls-Berry^d, Monica J. Taylor-Desir^e, Mark A. Frye^e, Eric J. Vallender^{a,*}



Perspective

All of Us and the Promise of Precision Medicine: Achieving Equitable Access for Federally Qualified Health Center Patients

Carolyn P. Neuhaus^{1,*}, Danielle M. Pacia¹, Johanna T. Crane², Karen J. Maschke¹ and Nancy Berlinger¹

Available online 15 March 2023

In Press, Corrected Proof [What's this? ↗](#)



Evaluating Discrepancies in Self-Reported Glaucoma and Electronic Health Records in the National Institutes of Health All of Us Database

March 20, 2023



Megan E. Paul BA¹, Victoria L. Tseng MD, Fei Yu PhD^{2,4}, Anne L. Coleman MD, PhD

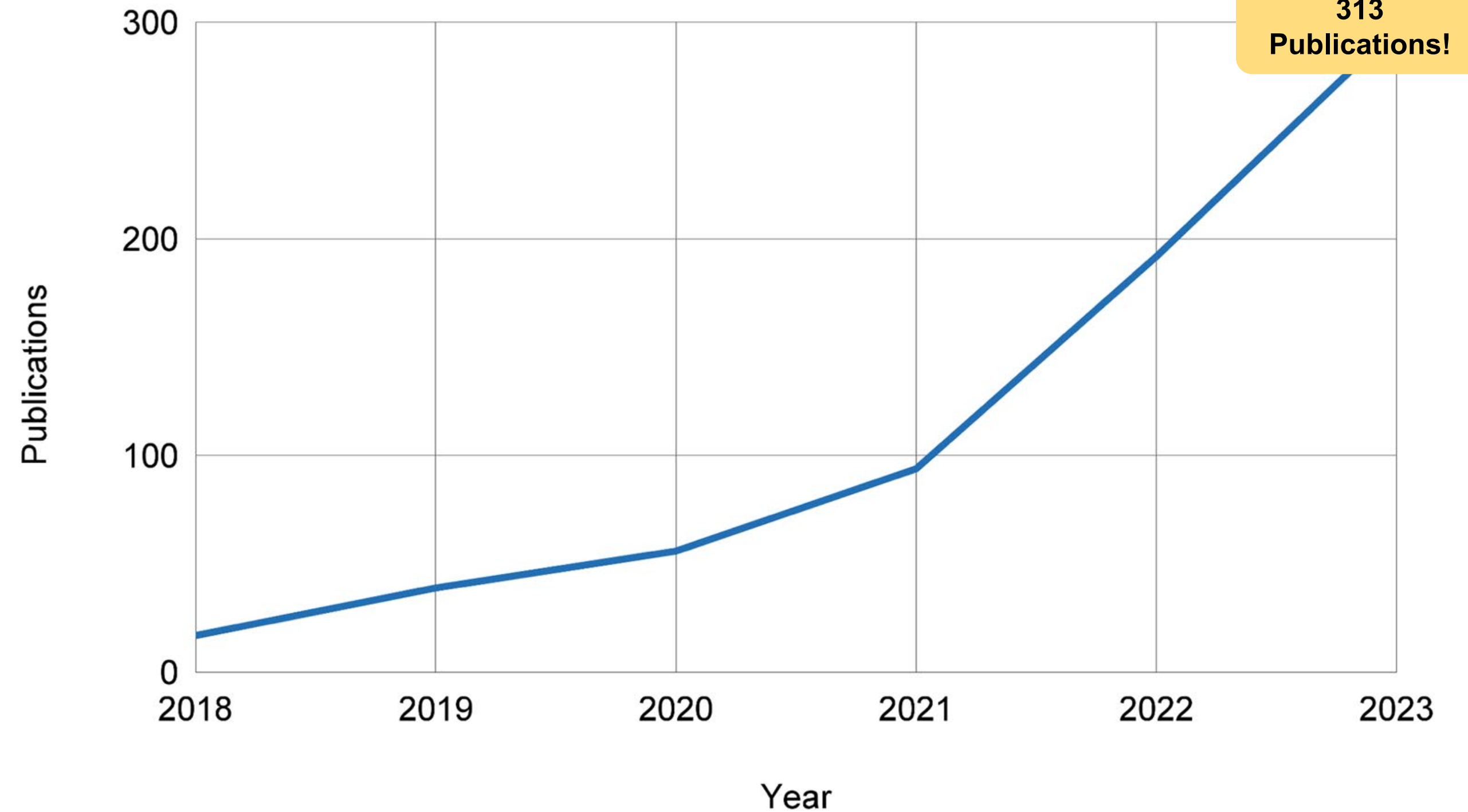
Daily Step Counts Before and After the COVID-19 Pandemic Among All of Us Research Participants

Stacy Desine, MSc¹; Hiral Master, PhD, MPTH, MPH²; Jeffrey Annis, PhD²; et al

[Author Affiliations](#) | [Article Information](#)

JAMA Netw Open. 2023;6(3):e233526. doi:10.1001/jamanetworkopen.2023.3526

Cumulative Publications Using All of Us Data



researchallofus.org/publications/



The Future and Opportunities for Researchers



Pediatrics



More Genomics in late 2024

About 400,000 whole genome sequences
About 1,500 long read whole genome sequences



More Digital Health Technology

Wearable data from diverse participants

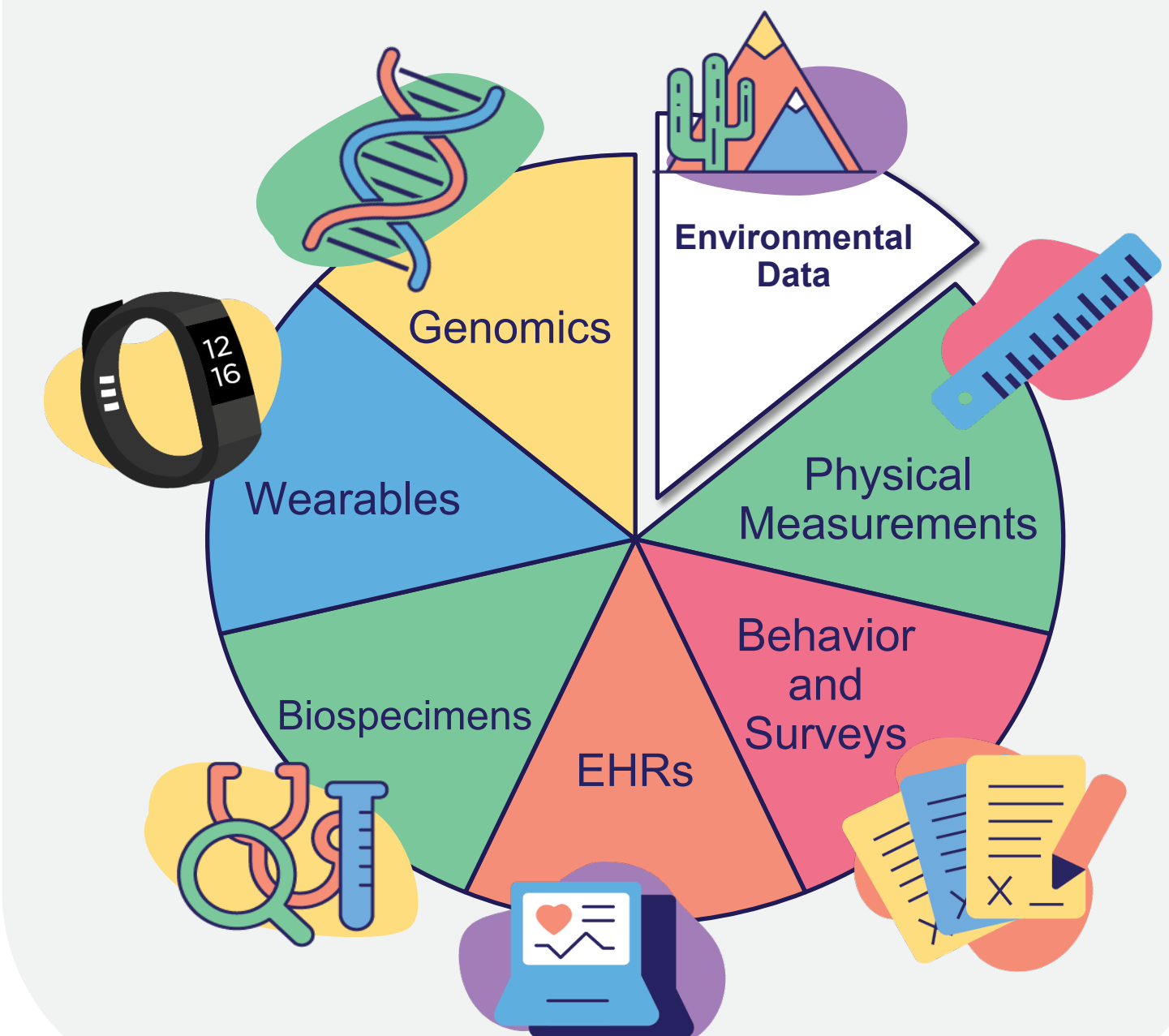


Collecting New Data

Linkages to additional data sources: Environmental data, Claims, Cancer Registries and more

Ancillary Studies

Incorporating complex questions about how genomic, environmental, and social interactions influence human health



Making Health Discoveries Possible

The *All of Us* Program wouldn't be possible without the generosity of our participants and the dedication of our researchers to enable health discoveries.



@AllofUsResearch
@AllofUsCEO
#JoinAllofUs





Thank You!

[Allofus.nih.gov](https://allofus.nih.gov)

<https://www.researchallofus.org/explore>



@AllofusResearch | #JoinAllofus