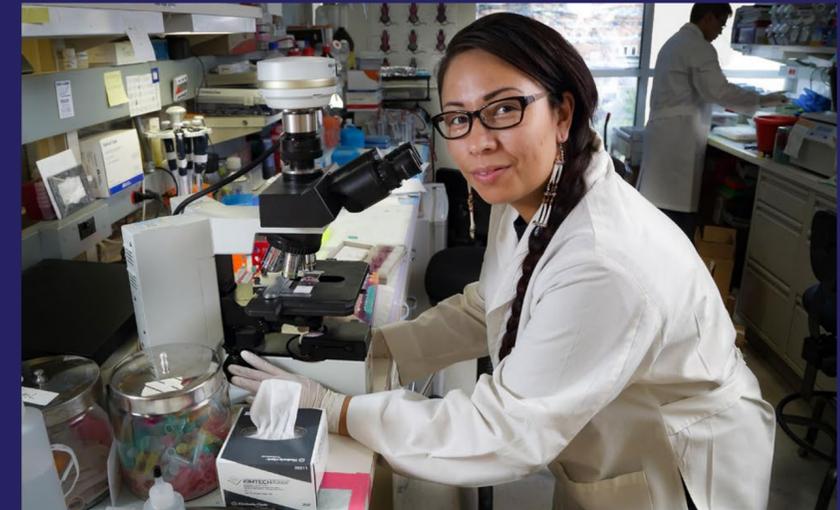


Session 3: Describing Self-Identified AI/AN Participants in *All of Us* Data

All
of **Us**
RESEARCH PROGRAM

June 20, 2023



Welcome and Introduction

Dr. Karriem Watson

Chief Engagement Officer, *All of Us*

Logistics

- **Links and resources will be posted in the chat**
- **Please pose questions in the chat**
- **Please keep yourself on mute - at the end of the program, we'll address questions in the chat and open up for live questions**
- **The Questions and Discussion section will be recorded for our notes but not posted online**
- **Slides and a recording will be posted online afterwards**
- **Contact the Tribal Engagement team at AOUTribal@nih.gov**

Describing Self-Identified AI/AN Participants in *All of Us* Data

Presentation Roadmap

1. RECAP



**2. AI/AN
PARTICIPANTS**



**3. DATA TIERS &
INFORMATION**



**4. IDENTIFIABILITY
& PRIVACY
CONTROLS**



**5. QUESTIONS &
DISCUSSION**



Brief Recap of Previous Sessions

Session 1: *All of Us* Research Program Overview and Tribal Engagement

- Precision medicine and scientific framework
- History and set-up of *All of Us*
- Milestones of *All of Us* Consultation & Tribal Engagement

Session 2: How Researchers Access and Use *All of Us* Data

- Important Considerations for Policy-Making and Data Governance Principles
- Database Compilation and Structure, Data Access Process, and Privacy and Security Measures
- Data governance policies, Education, Accountability, and Oversight

Recordings will be made available at
[Allofus.nih.gov/TribalEngagement](https://allofus.nih.gov/TribalEngagement)

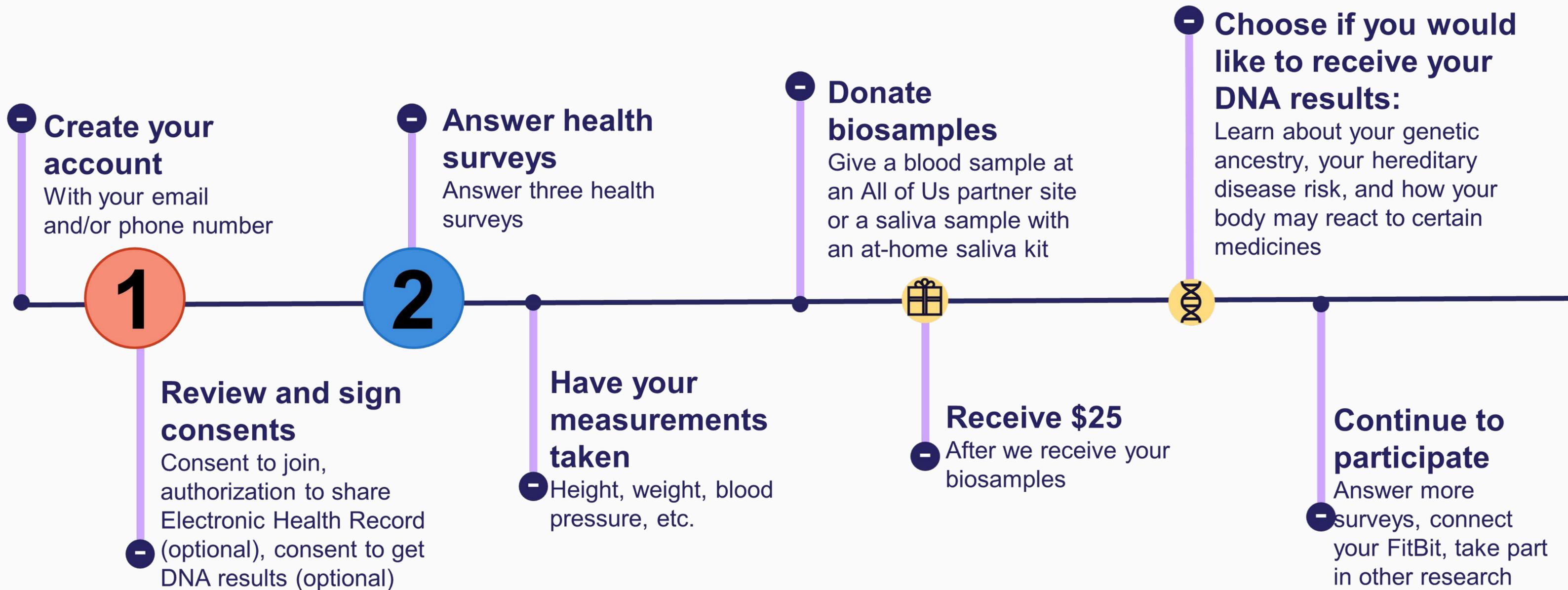
How the All of Us Research Program Protects My Information



the program has safeguards in place

Self-Identified AI/AN Participants in *All of Us*

Self-identified AI/AN Participants and *All of Us* - Consent and Surveys



1 All of Us Informed Consent

- The informed consent process for *All of Us* is completed entirely online
- There is no cost to participate other than some of your time. Most people will spend no more than a few hours a year taking part in the program's activities
- The *All of Us* Research Program's informed consent process is designed to be as transparent and understandable as possible.
- The program's website has a wealth of information about the process, and potential participants can also talk to the Support Center or a research team member if they have any questions.

The screenshot shows the website allofus.nih.gov/about/protocol/all-us-consent-process. The page is titled "The All of Us Consent Process" and is part of the "All of Us Research Program" website. The page content includes:

- A breadcrumb trail: *All of Us* > About > The All of Us Consent Process
- A main heading: **The All of Us Consent Process**
- A paragraph explaining the program's commitment to helping potential participants make informed decisions about whether to participate.
- A paragraph stating that before signing forms, participants view a series of screens with text and short videos that explain the program's goals, how it works, and what participation entails.
- A list of links to consent forms and videos:
 - [Consent to Join the All of Us Research Program \(En Español\)](#)
 - [HIPAA Authorization for Research–Electronic Health Record Supplement \(En Español\)](#)
 - [Consent to Get DNA Results \(En Español\)](#)
- A button labeled "OPEN ALL +"
- A list of sections with "OPEN +" buttons:
 - Consent Overview
 - Health Information
 - Physical Measurements and Fitness Trackers

1

Pre-Consent Screens with Information for AI/AN Participants

The screenshot displays the 'All of Us Research Program' dashboard. The left sidebar contains navigation links: Dashboard (highlighted), My Data, Notifications, Sync Apps & Devices, Agreements, Learning Center, Settings, and Support. The main content area is titled 'Primary Consent' and features a progress bar. The central text reads: 'Information for American Indians and Alaska Natives (AI/AN). All of Us seeks to partner with many different groups across the country—especially those that have been left out of research in the past. As part of those efforts, we held formal meetings called “consultations” with tribal leaders to learn more about their views. Tribal leaders gave us important input that helped us make plans for the program.' Below this is a question: 'Would you like to learn more about what this means for participants who identify as American Indian or Alaska Native (AI/AN)?' with two radio button options: 'Yes, tell me more.' and 'No, I would like to continue with the consent.' A note states: 'If you want to read more about this later, you can find this information in your All of Us account and on our website.' A right-hand callout box lists categories of AI/AN people: 'People who identify as American Indian and Alaska Native include: Members of federally-recognized tribes, Members of state-recognized tribes, Members of a tribe not recognized by either federal or state governments, Central and South American Indians, First Nations peoples (Canada), and People with AI/AN ancestry but no tribal affiliation.' A final note says: 'People may identify as AI/AN alone, or in combination with other races, too.' At the bottom, there are 'Previous' and 'Next' navigation buttons. The footer includes a chat icon and 'Copyright © 2021'.

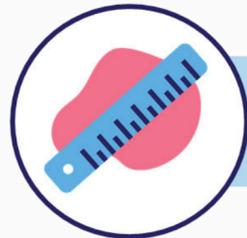
2 All of Us Demographics and Health Surveys



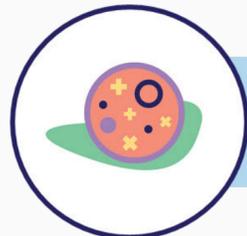
Consent and
EHR Authorization



Participant Surveys



Physical Measurements



Biosamples

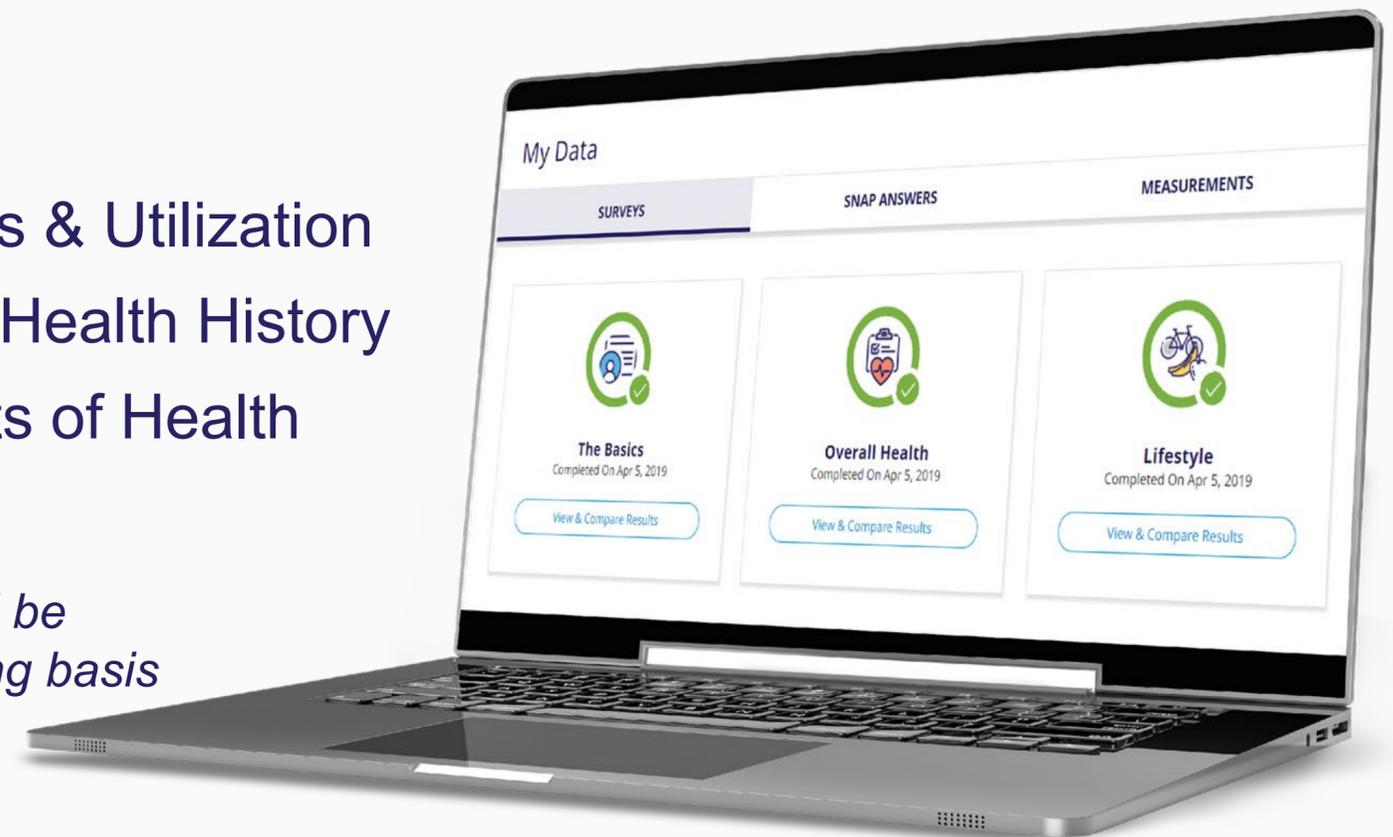


Mobile/Wearable Tech

Open Surveys:

- **The Basics**
- Overall Health
- Lifestyle
- Health Care Access & Utilization
- Personal & Family Health History
- Social Determinants of Health

*Additional surveys will be
released on an ongoing basis*



2

All of Us Surveys - The Basics

researchallofus.org/data-tools/survey-explorer/

All of Us Research Hub | NIH National Institutes of Health All of Us Research Program

Home > Data & Tools > Survey Explorer

Survey Explorer

Participants in the *All of Us* Research Program respond to surveys spanning a variety of topics. The program has tested each survey for readability and accessibility using 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, Lifestyle, and Overall Health), they may complete additional surveys on other topics.

In addition to the source material below, more detailed information is available in the [Survey Data Codebooks](#).

The Basics

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

> [View English version](#)
> [View Spanish version](#)

EXPLORE SOURCE MATERIAL

Lifestyle

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

> [View English version](#)
> [View Spanish version](#)

EXPLORE SOURCE MATERIAL

Which categories describe you? *Select all that apply.*
Note, you may select more than one group.

- American Indian or Alaska Native
(For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utqiagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)

Branching Logic: when “American Indian or Alaska Native” selected, then:

- American Indian
- Alaska Native
- Central or South American Indian
- None of these fully describe me

Branching Logic: when subcategory selected, then:

Provide the name of the tribe in which you are enrolled or affiliated or your tribal descent:

(display optional free text)

Self-Identified AI/AN Participants

People who identify as American Indian and Alaska Native (AI/AN) include:

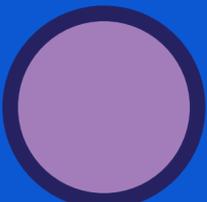
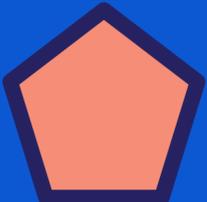
- Members of federally-recognized tribes*
- Members of state-recognized tribes*
- Members of a tribe not recognized by either federal or state governments*
- Central and South American Indians
- First Nations peoples (Canada)
- People with AI/AN ancestry but no tribal affiliation

People may identify as AI/AN alone, or in combination with other races, too.

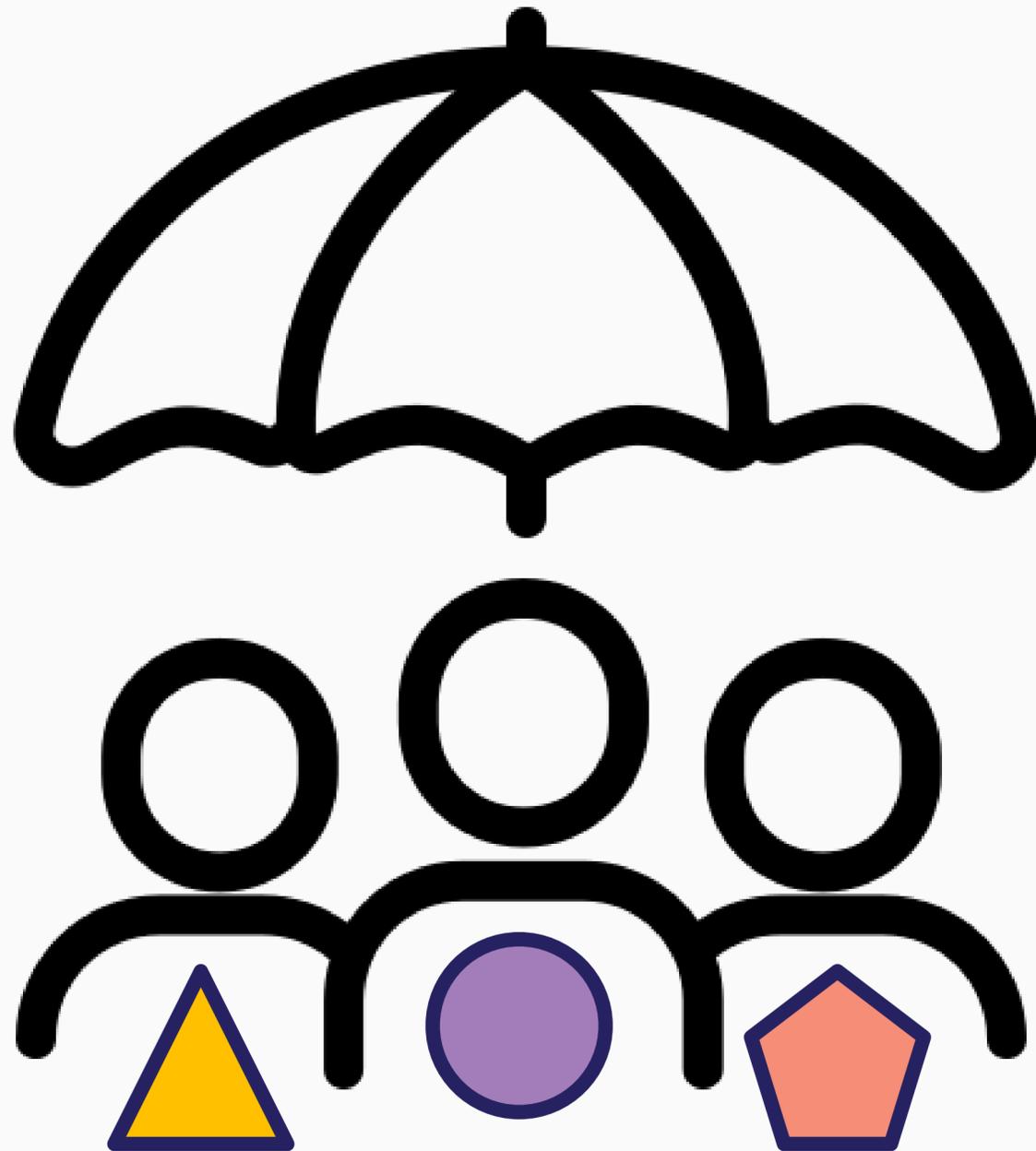
*and their descendants

The screenshot shows the NIH All of Us Research Program website. The header includes the NIH logo, the text "National Institutes of Health All of Us Research Program", a search icon, and a "Sign up today" button. The navigation menu has "HOME", "ABOUT", and "FAQS". The page title is "Information for American Indians and Alaska Natives". The main content area features a heading "Information for American Indians and Alaska Natives" and a sub-heading "Learn more about how All of Us is working with tribes across the U.S. and what that means for participants." Below this is a paragraph about the program's partnership with tribes. A yellow callout box contains a list of who is included: "People who identify as American Indian and Alaska Native (AI/AN) include:" followed by three bullet points: "Members of federally-recognized tribes", "Members of state-recognized tribes", and "Members of a tribe not recognized by either federal or state governments". The footer contains contact information: "Live chat", "(844) 842-2855", "TTY dial 711", and "help@joinallofus.org".

Self-Identified AI/AN Participants and Tribal Sovereignty

Type	Likely to be Enrolled in a Federally Recognized Or State Recognized Tribe	Description
 Tribal Land/ Reservation	✓	<ul style="list-style-type: none">• Likely enrolled in a Tribal Nation• Residing within their Nation's land-based jurisdiction
 Urban	✓	<ul style="list-style-type: none">• Likely enrolled in a Tribal Nation• Residing in a setting outside of their Nation's land-based jurisdiction
 Ancestry	X	<ul style="list-style-type: none">• Asserts ancestry to a Tribal Nation• Most likely to reside off of their Nation of ancestry's land
 Central and South American Indian	X	<ul style="list-style-type: none">• Asserts Central or South American Indigenous ancestry• Resides within the U.S.

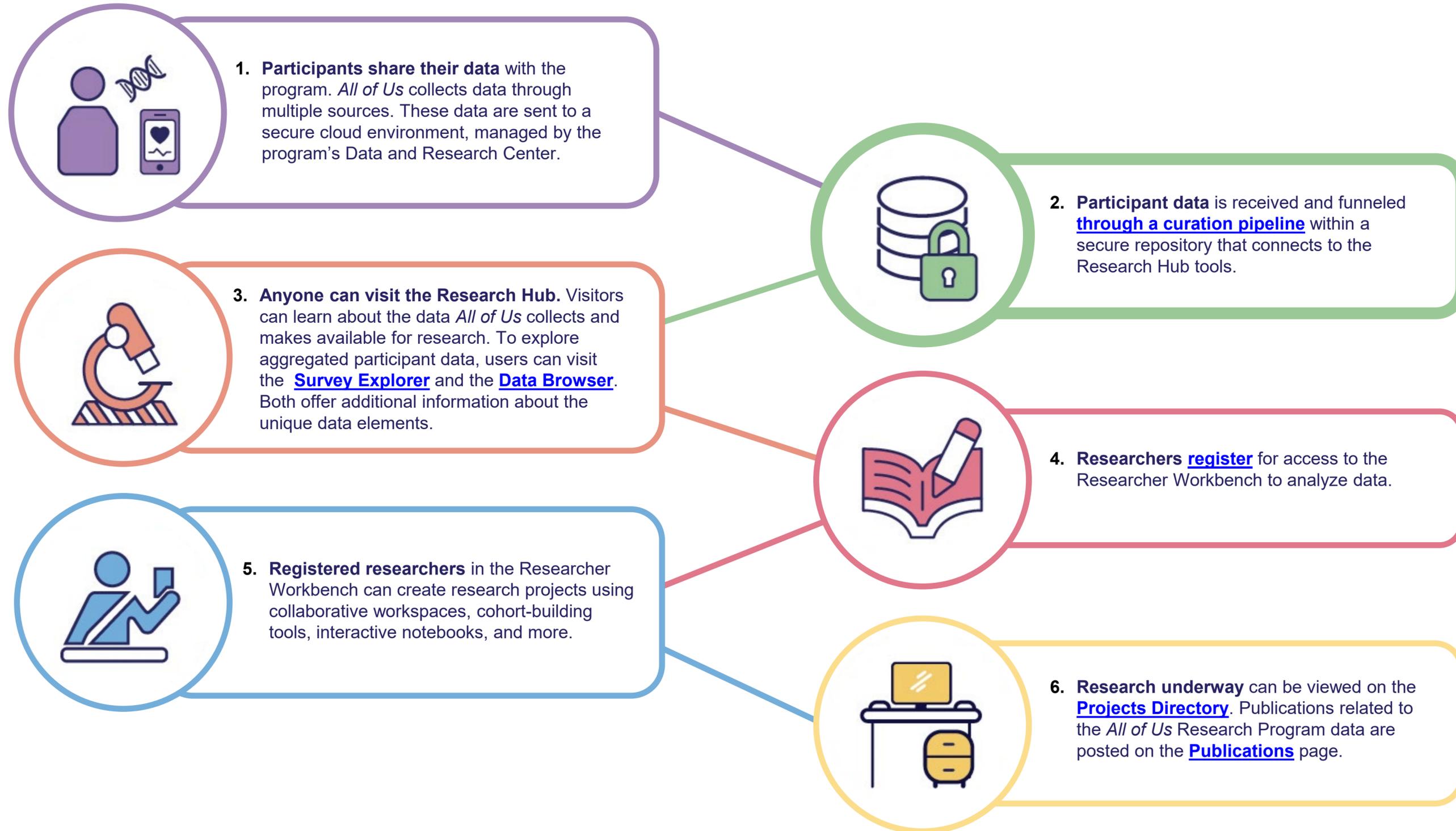
AI/AN Data: Responsibility and Representation



- *All of Us* has waited on introducing AI/AN data in the Researcher Workbench
- Participants are currently grouped dependent on if they select one or multiple race categories:
 - AI/AN only
 - More than one race
- The Responsible Conduct of Research training that researchers must take to access the Researcher Workbench includes education about the proper use of population descriptors and the potential for stigmatization

All of Us Participants and Descriptive Data

All of Us Research: How it Works



Many Different Kinds of Data and Data Sources



Participant Surveys

- The Basics
- Lifestyle
- Overall Health
- Personal & Family Medical Hx
- Health Care Access & Utilization
- Social Determinants of Health
- *Mental Health and Wellbeing*



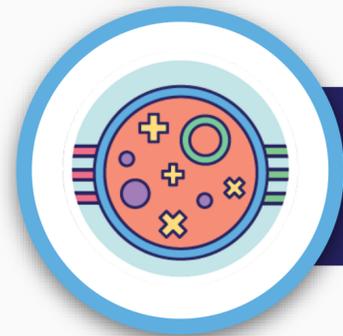
Electronic Health Records

- Medical Records
- *Claims Data*
- *Pharmacy Data*
- *Vision and Dental Records*



Physical Measurements

- Blood Pressure
- BMI
- Heart Rate
- Height
- Hip Circumference
- Waist Circumference
- Weight



Biospecimens

- Blood
- Saliva
- Urine
- DNA (from blood or *saliva*)
- *RNA*

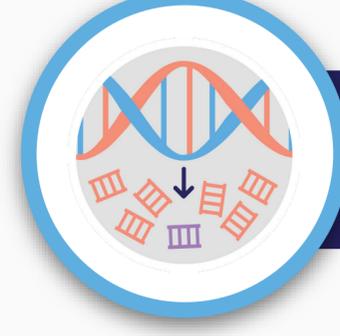


Mobile/Wearable Tech



Assays

- COVID Serology
- *HbA1c*
- *Heavy Metals*



Omics

- WGS Arrays
- *Other Omics*

For more on upcoming data types, please visit the Data Road Map at allof-us.org/Roadmap



Visit the data roadmap for more information about upcoming data types

	Available end of 2022	Early 2023 additions	2023 and beyond
Electronic Health Records (EHRs)	EHRs>	
Surveys	<ul style="list-style-type: none"> The Basics Overall Health Lifestyle Health Care Access and Utilization Personal and Family Medical History Social Determinants of Health COVID-19 Participant Experience (COPE) COVID-19 Vaccines Minute Surveys 1-3 	<ul style="list-style-type: none"> Combined Personal and Family Health History COVID-19 Vaccines Minute Survey 4 	<ul style="list-style-type: none"> Life Functioning
Physical Measurements	<ul style="list-style-type: none"> Physical Measurements >	<ul style="list-style-type: none"> Participant-reported height and weight
Genomics	<ul style="list-style-type: none"> 165k+ genotyping arrays 98K+ whole genome sequences (WGS) 	<ul style="list-style-type: none"> 245K+ WGS 312K+ Arrays CRAM files 1,000 long-read sequences 	<ul style="list-style-type: none"> 245K+ WGS CRAM files 1,000 long-read sequences
Data Linkages	<ul style="list-style-type: none"> American Community Survey (ACS) 3-digit zip code >	<ul style="list-style-type: none"> ACS 5-digit zip code
Digital Health Technologies	Fitbit: <ul style="list-style-type: none"> Heart rate by zone summary and minute-level Activity (daily summary) Activity intraday steps (minute-level) 	<ul style="list-style-type: none"> Fitbit sleep data 	<ul style="list-style-type: none"> Fitbit device data Vital measurements Apple HealthKit activity data
Assays	<ul style="list-style-type: none"> COVID-19 serology data >	
Ancillary Studies>		<ul style="list-style-type: none"> Exploring the Mind Pilot Nutrition for Precision Health (NPH) modules



<https://allof-us.org/Roadmap>

Data availability and access timelines are estimates and subject to change. Timeline accurate as of April 2023.

All of Us Data Curation and Data Dictionary



The Data Dictionary provides the following:

- A description for each data field
- Information on whether the data in each field come from participant health records or from information the participants provide themselves, like survey data
- Versioning data so you can see what has been changed, added, or removed since the previous curated dataset

Three Tiers



Public Tier

The Public Tier dataset is available at ResearchAllofUs.org. Visitors can explore aggregated overviews and interactive data previews—with participant identifiers removed—through the Data Browser. Registration is not required.



Registered Tier

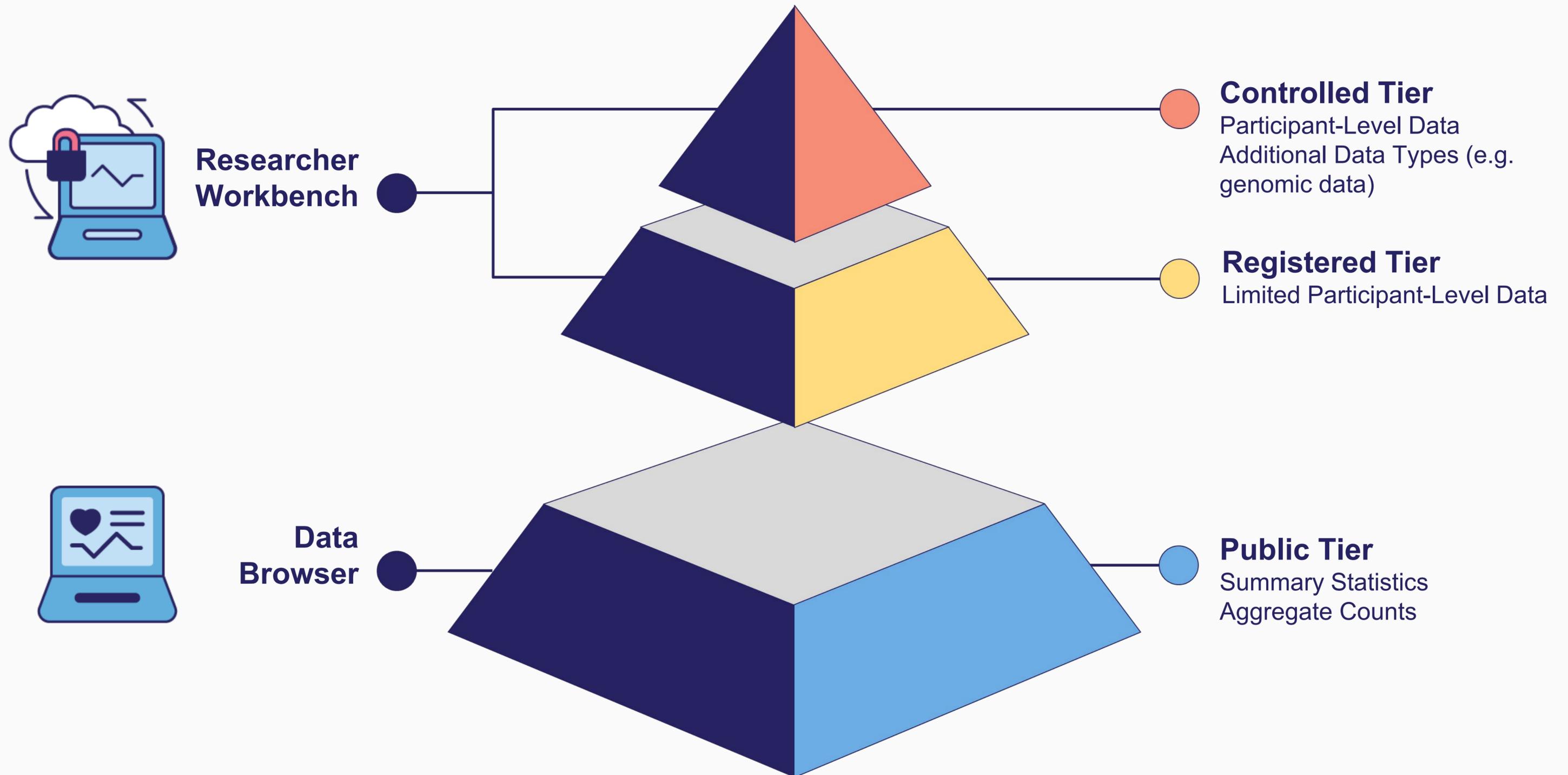
Includes individual-level data from EHRs, wearables, and surveys, as well as physical measurements taken at the time of participant enrollment. Registration and a Responsible Conduct of Research training are required for access.



Controlled Tier

Includes data available on the Registered Tier, as well as genomic data and expanded demographic, survey, and EHR data. Genomic data includes whole genome sequences, long read sequences, genotyping arrays, and structural variants. Researchers must have amended institutional agreements and complete an additional training to access this tier.

The *All of Us* Research Hub | Data Access Tiers



Aggregated overviews and interactive previews are available to everyone

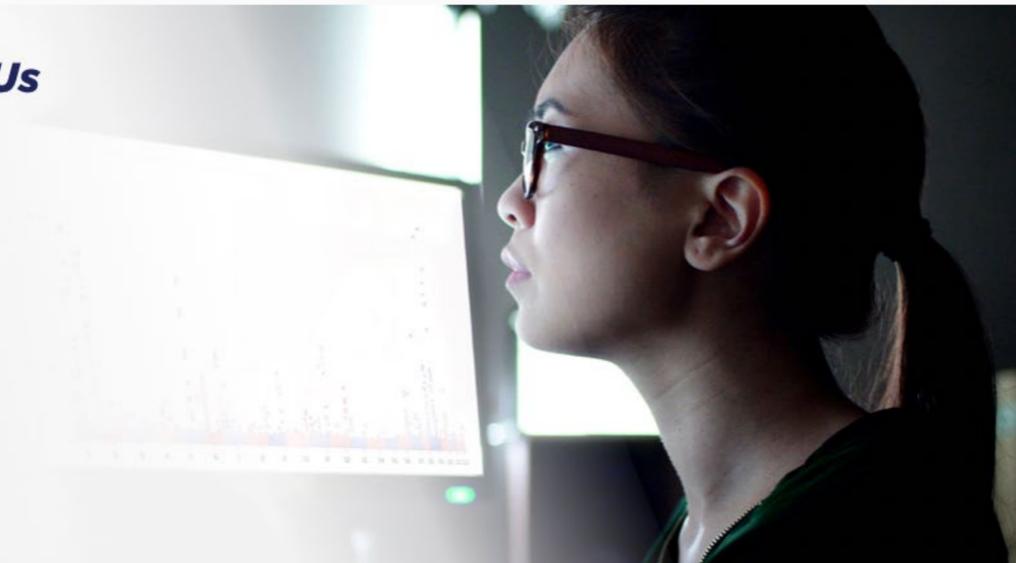
ResearchAllofUs.org

Welcome to the *All of Us* Research Hub

The *All of Us* Research Program, led by the National Institutes of Health, is building one of the largest biomedical data resources of its kind. The *All of Us* Research Hub stores health data from a diverse group of participants from across the United States.

Registered researchers can access *All of Us* data and tools to conduct studies to help improve our understanding of human health.

[REGISTER FOR ACCESS](#)



Data Snapshots

Data Snapshots showcase the scale and diversity of the *All of Us* Research Program participant cohort. The snapshots provide participant demographics, geographic distribution, and more. We update the snapshots daily.

 623,000+ Participants	 361,000+ Electronic Health Records	 449,000+ Biosamples Received
--	---	---

Search Across Data Types

Data includes 409,420 participants as of 2/15/2023.



EHR Domains

Conditions 25,638 medical concepts 254,700 participants View Conditions	Drug Exposures 29,865 medical concepts 239,740 participants View Drug Exposures	Labs & Measurements 16,216 medical concepts 252,980 participants View Labs & Measurements	Procedures 30,328 medical concepts 242,580 participants View Procedures
--	--	--	--

Genomics

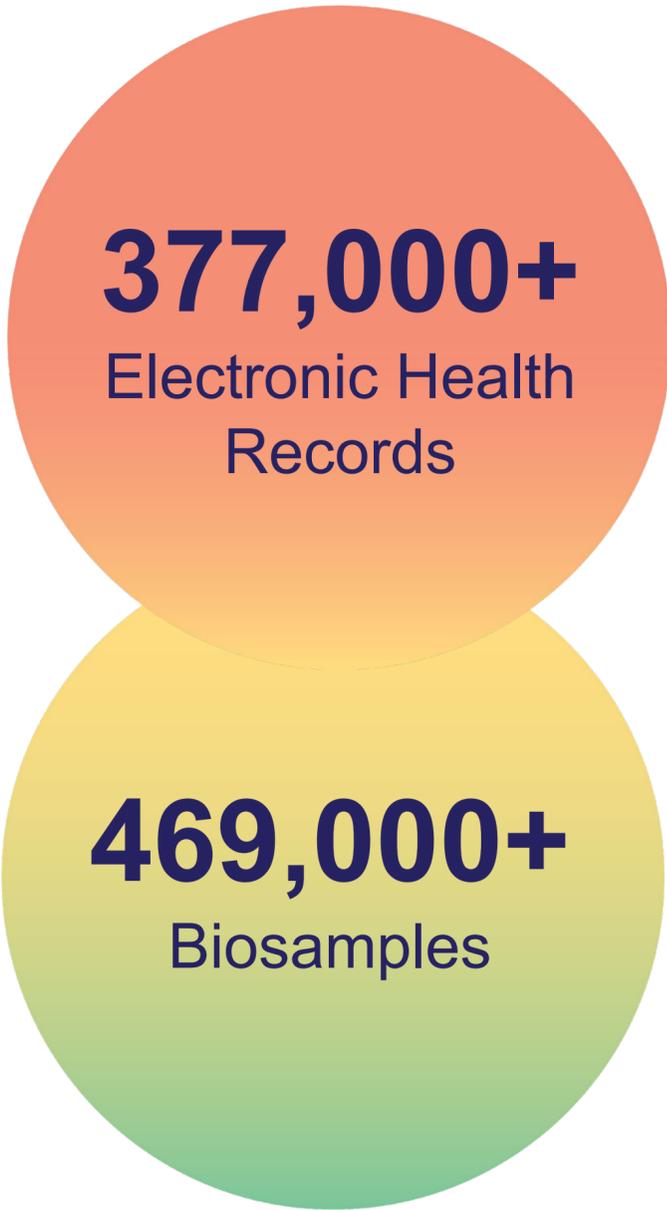
SNP/Indel Variants 245,400 Participants in Short-Read Whole Genome Sequencing (WGS) dataset 1,074,881,214 SNP/Indel Variants View SNP/Indel Variants	Genomic data only in Researcher Workbench 1,040 participants in the Long-Read WGS dataset 11,400 participants in the Short-Read WGS Structural Variants dataset 312,940 participants in the Genotyping Arrays dataset Register for access
--	--

Measurements and Wearables

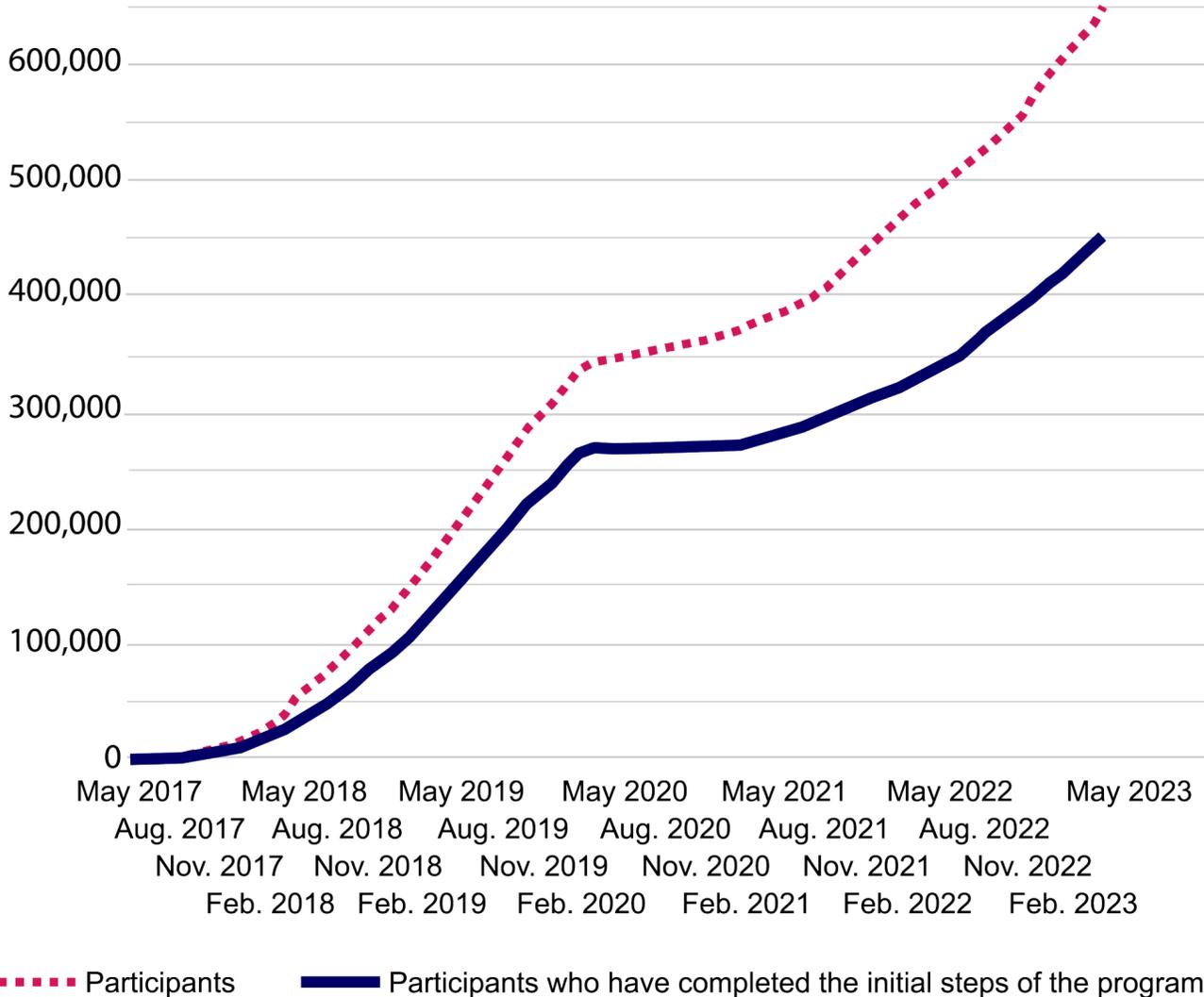
Physical Measurements 8 Physical Measurements 342,840 participants Participants have the option to provide a standard set of physical measurements. View Physical Measurements	Fitbit 6 Fitbit Measurements 15,620 participants Fitbit data includes heart rate and activity summaries. View Fitbit
--	--

Enrollment data snapshot

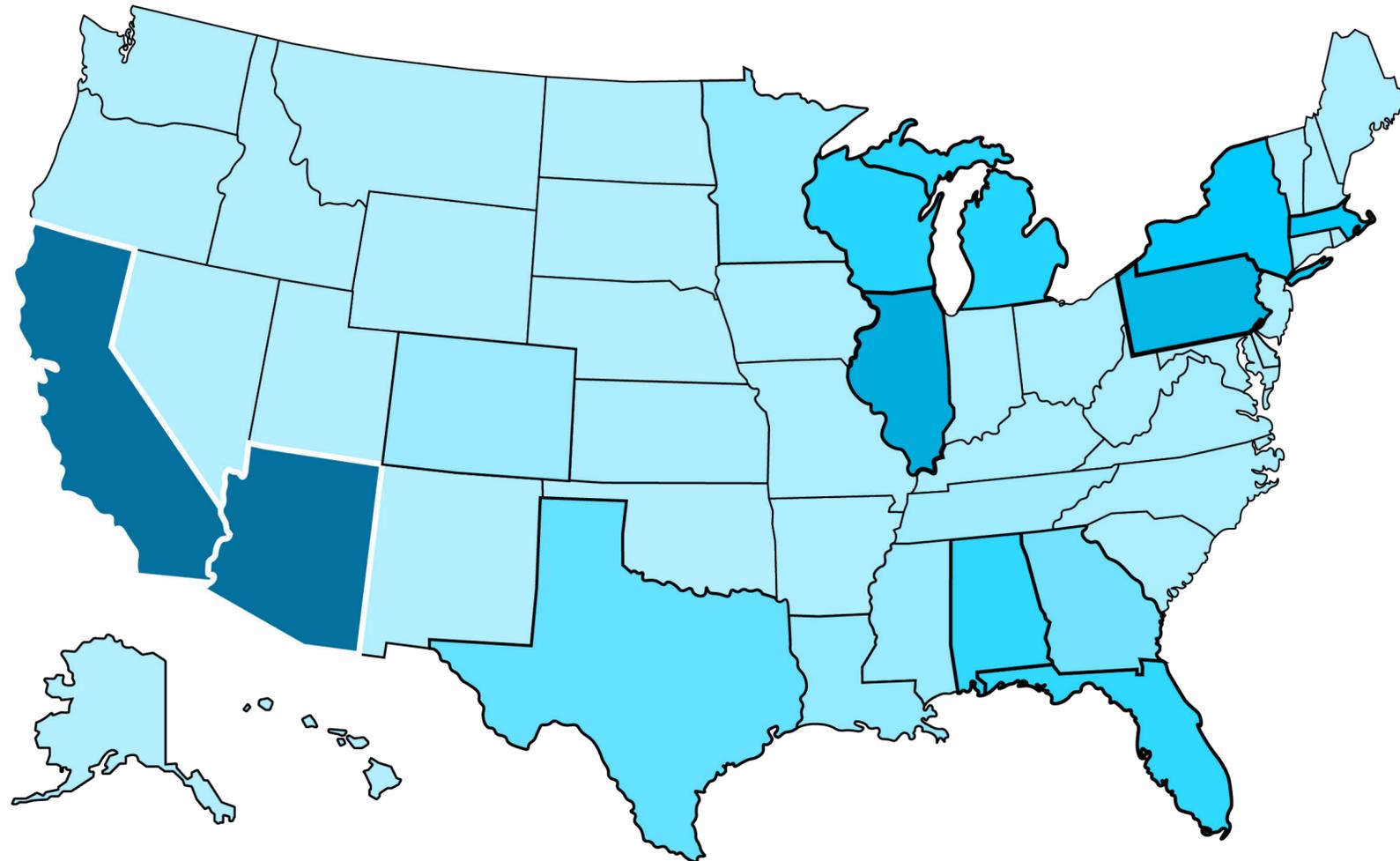
(Updated 6/8/23)



Enrollment Numbers



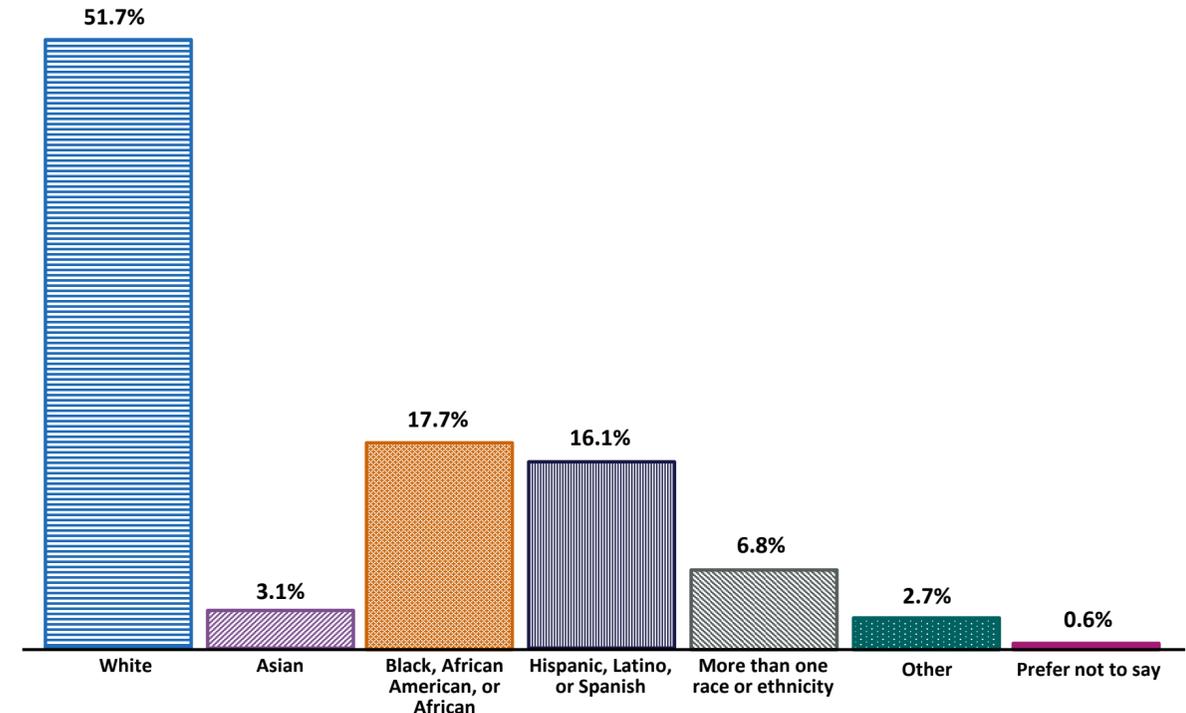
A bit about *All of Us* participants



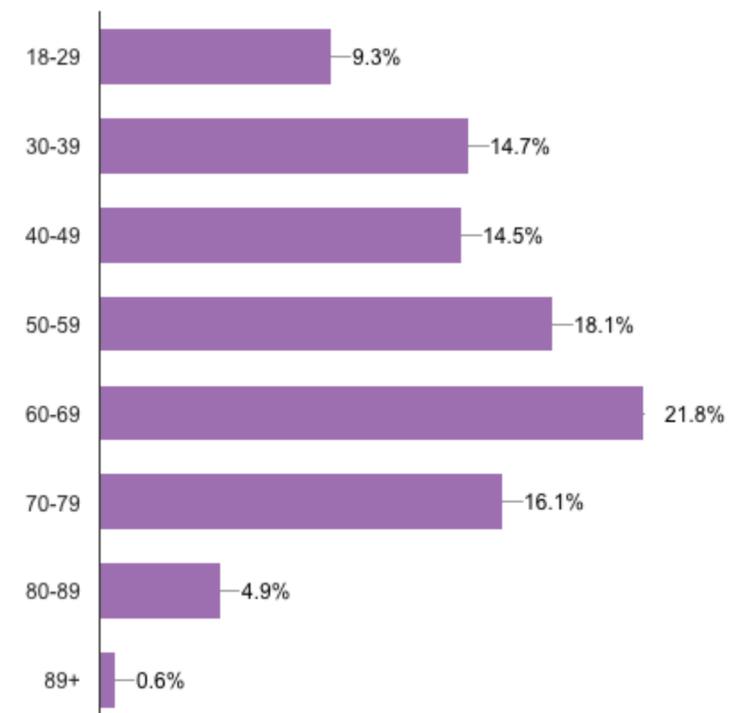
0 61,640

80% of *All of Us* participants are underrepresented in biomedical research

Race and Ethnicity



Age



About the *All of Us* Data Browser

DataBrowser.ResearchAllOfUs.org

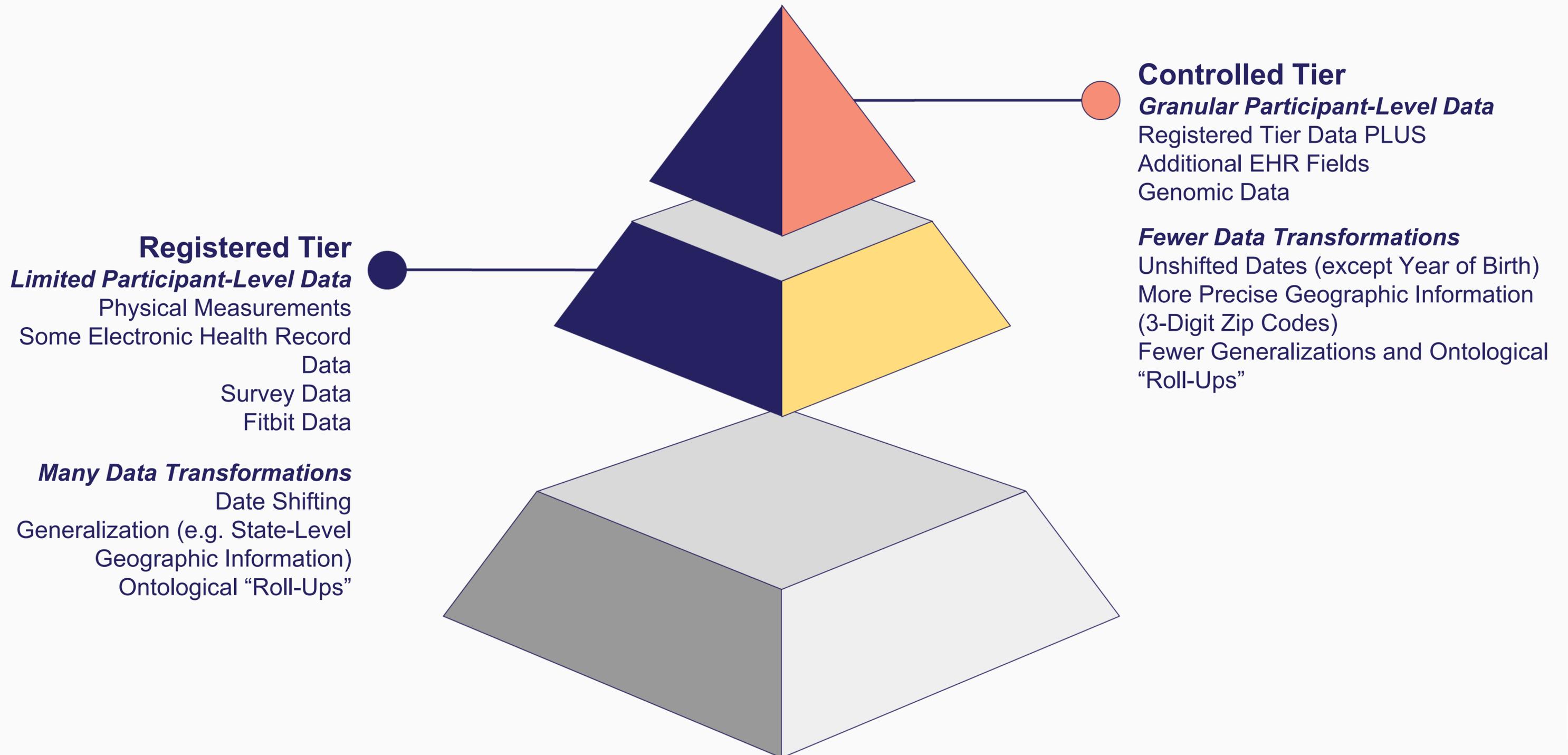
- Provides **summary statistics** from the program's growing database
- **Open to everyone** – no login!
- Allows participants to **understand the makeup of the cohort**
- Allows researchers to understand the **characteristics of our participant population, explore the data types available, and plan research questions**

Interactive tool launched in May 2019

The screenshot displays the All of Us Data Browser interface. At the top, there is a search bar labeled "Search Across Data Types" with a "Keyword Search" input field and a search icon. To the right of the search bar are three circular icons: a question mark in a speech bubble labeled "FAQs", a question mark in a document labeled "Introductory Videos", and a question mark in a database cylinder labeled "User Guide". Below the search bar, it states "Data includes 409,420 participants as of 2/15/2023." The main content is organized into several sections:

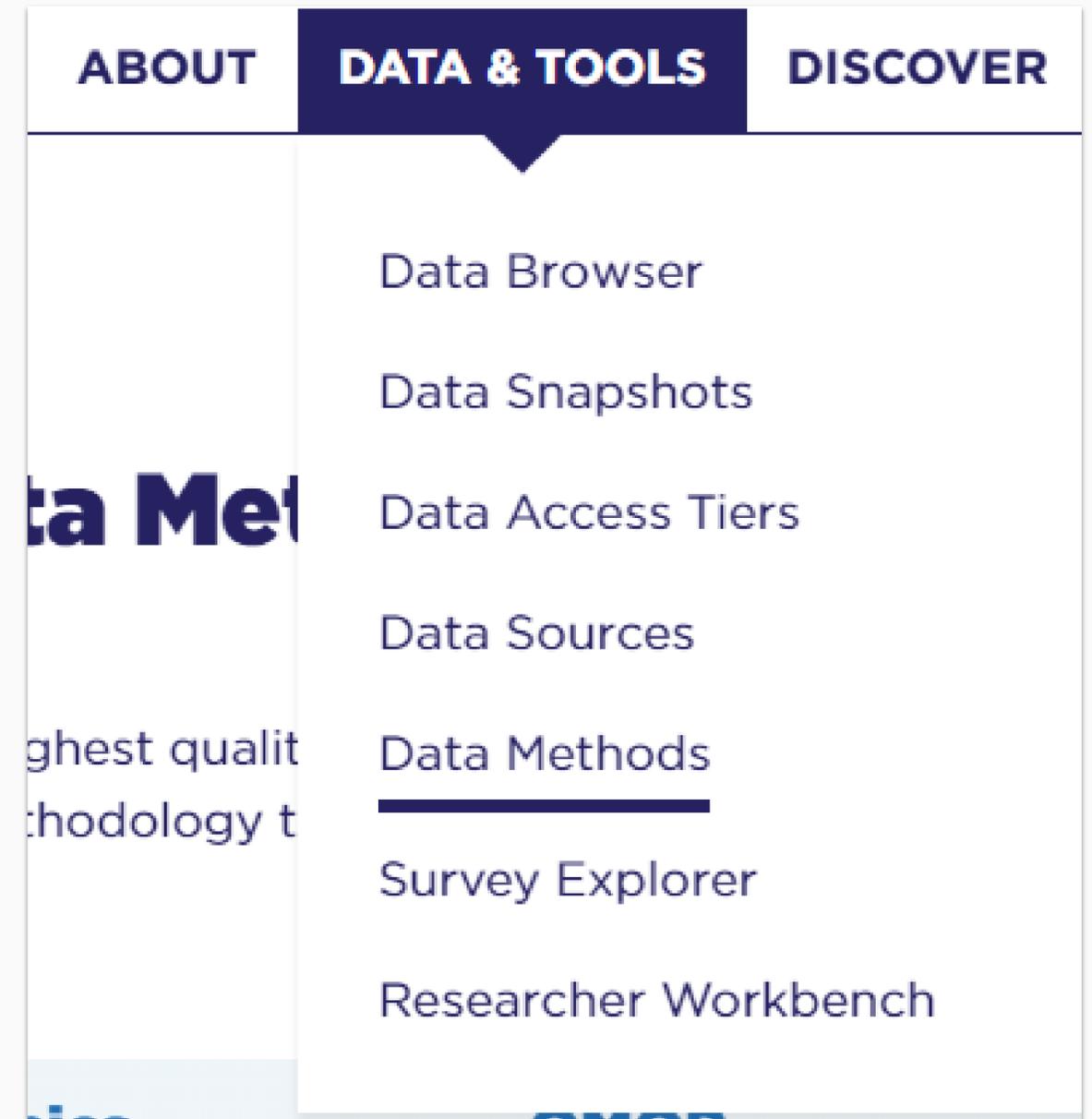
- EHR Domains:** Four cards showing medical concepts and participant counts: Conditions (25,638 concepts, 254,700 participants), Drug Exposures (29,865 concepts, 239,740 participants), Labs & Measurements (16,216 concepts, 252,980 participants), and Procedures (30,328 concepts, 242,580 participants).
- Genomics:** Three cards: SNP/Indel Variants (245,400 participants in Short-Read WGS dataset, 1,074,881,214 variants), Genomic data only in Researcher Workbench (1,040 participants in Long-Read WGS dataset, 11,400 in Short-Read WGS Structural Variants dataset, 312,940 in Genotyping Arrays dataset), and Physical Measurements (8 concepts, 342,840 participants).
- Measurements and Wearables:** Two cards: Physical Measurements (8 concepts, 342,840 participants) and Fitbit (6 concepts, 15,620 participants).
- Survey Questions:** Four cards: The Basics (28 questions, 409,420 participants), Overall Health (21 questions, 400,760 participants), Lifestyle (26 questions, 398,200 participants), and Health Care Access & Utilization (57 questions, 190,220 participants).
- Personal and Family Health History:** Four cards: Personal and Family Health History (614 questions, 185,240 participants), COVID-19 Participant Experience (COPE) (191 questions, 100,220 participants), COPE Minute Survey (141 questions, 127,240 participants), and Social Determinants of Health (80 questions, 117,800 participants).

The *All of Us* Research Hub | The Researcher Workbench



All of Us Data Dictionary

- The All of Us Data Dictionary describes the row-level data and what modifications the program makes to protect participant privacy.
- Located on the researchallofus.org website under Data and Tools → Data Methods.



Re-identifiability and Privacy controls

- Removal and monitoring for explicit identifiers and minimize re-identification risks
- Data available does not include:
 - free-text fields, geolocation data smaller than U.S. state level, living situations, race and ethnicity subcategories, active duty military status, cause of death, and diagnosis codes subject to public knowledge



Registered vs Controlled Tier

Data Fields	Registered	Controlled
Direct Identifiers, e.g. name, address	Unavailable	Unavailable
Dates of events, e.g. visit to doctor	Random shift	As collected
Date of birth	Random shift	Year only
Date of death	Random shift	As collected
Location	US State	3 digit zip code
Marital Status	As collected	As collected
Annual household income	As collected	As collected
Education	Generalize	As collected
Employment Status	Generalize	As collected
Race and ethnicity	Generalize	As collected
Race and Ethnicity Subcategories	Unavailable	Unavailable
Sex assigned at birth	Generalize	As collected
Gender identity	Generalize	As collected
Sexual orientation	Generalize	As collected
Genomic data	Unavailable	As collected

- White
- Black
- Asian
- None of these
- Another single population
- More than one population
- Prefer not to answer
- No answer
- Hispanic, Latino, or Spanish

- White
- Black
- Asian
- Native Hawaiian or Other Pacific Islander
- Middle Eastern or North African
- Any combination of categories
- Prefer not to Answer
- No answer
- Hispanic, Latino, or Spanish

**Self-identified American Indian and Alaska Native individuals do not currently appear in the dataset.

Tribal Affiliation

From the 2019 Consultation Report:

- *All of Us* understands that tribal affiliation and membership are determined by tribes themselves and cannot be determined by the program.
- *All of Us* recognizes that this information is highly sensitive and that verifying tribal affiliation is currently beyond the capabilities of the program.
- Tribal affiliation will never be made available to researchers unless the program enters into a partnership with that specific tribe.
 - Participants currently enrolled in the program will need to re-enroll under that agreement in order to have their tribal affiliation listed.

Questions for the Program:

- Should the program continue to collect tribal affiliation as part of the Basics survey?
- What is the risk v. benefit of retaining this data element?
- What other data elements should the program scrutinize to protect the privacy of tribal affiliation?

Geographic information

Protecting Participant Privacy

- Geographic locations for participants are only shown at the state level or 3-digit zip code
- Research may provide more information about health outcomes if linked with more specific location data

Preventing Accidental Outreach on Tribal Land

- Generated a list of zip codes that overlap with Tribal land and are excluded from marketing efforts
- This approach excludes large areas of land - especially in the West - where there is any overlap at all between the two
- How should the program guide engagement and outreach efforts where zip codes overlap with Tribal land?

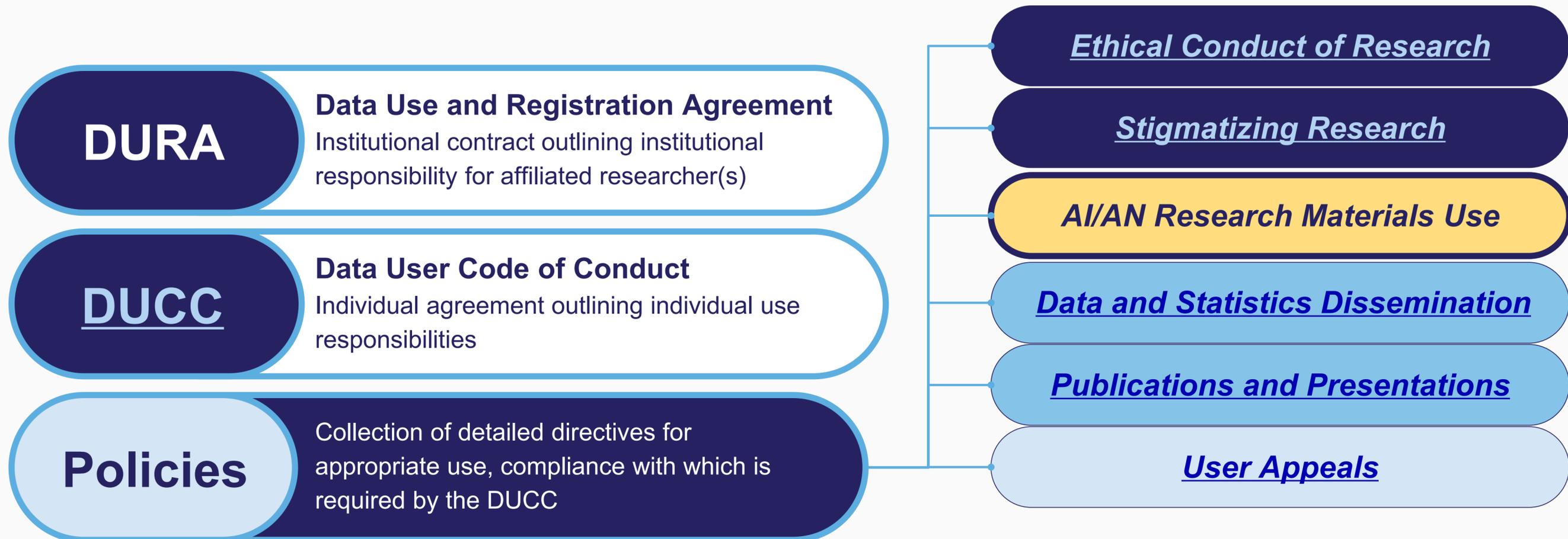
All of Us Data Passports



The *All of Us* Research Workbench uses a "data passport" model to give registered researchers broad access to the Research Workbench rather than granting data access on a **project-by-project** or **question-by-question** basis.

- Once they complete the requisite steps, researchers can create workspaces in the tier or tiers to which they have access —no pre-approval required
- When researchers set up their workspaces, they are required to provide publicly-facing project descriptions on the platform
- Researchers must ensure that their research complies with the program's data use policies

Accountability | Data Use Contracts and Policies (continued)



For more on data use policies, visit
www.researchallofus.org/data-tools/data-access

Accountability | AI/AN Research Materials Use Policy (Overview)

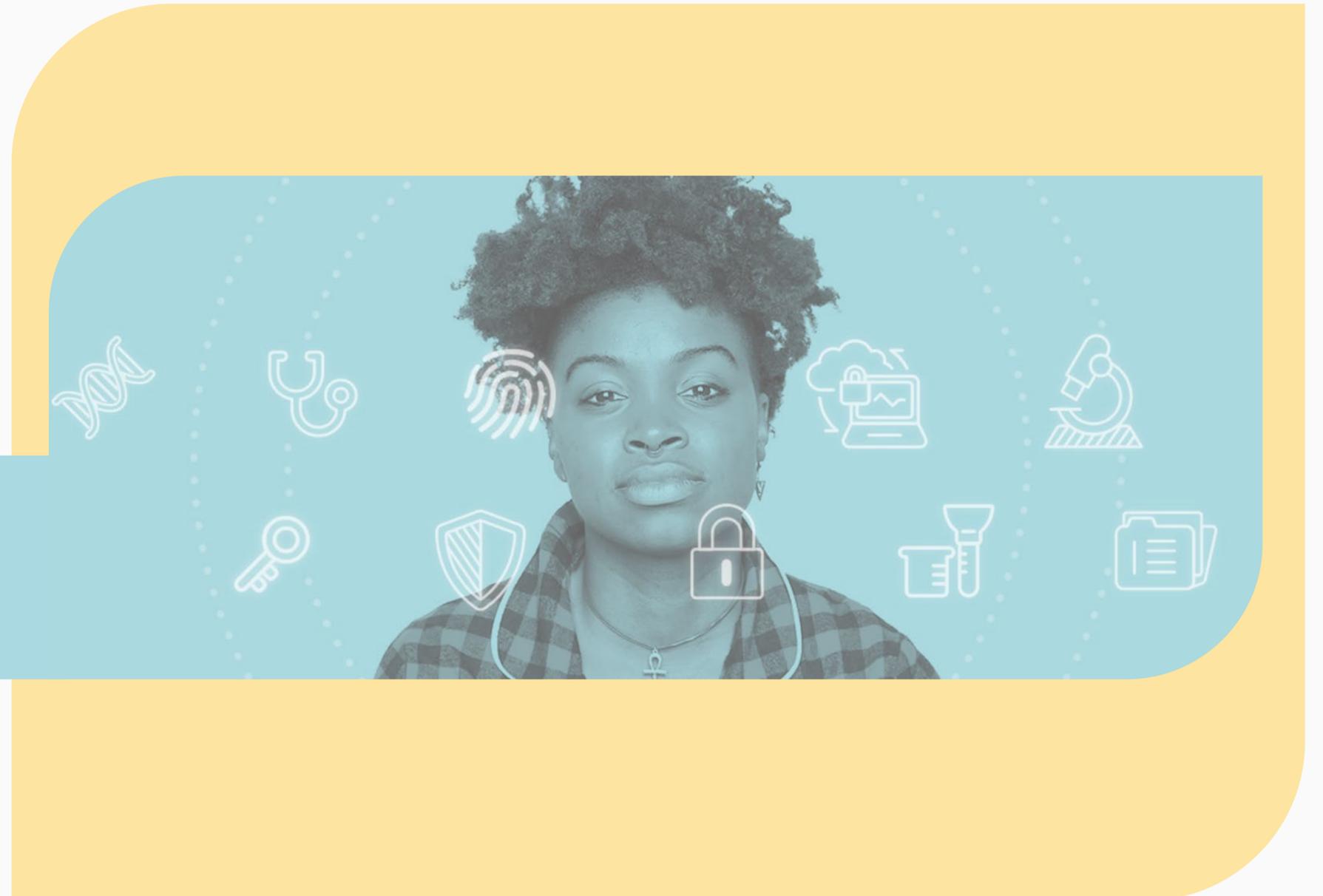
- Take actions that acknowledge and protect against **historical (and contemporary) sources of harm:**
 - **MUST** review and agree to abide by the DUCC, Policy on Stigmatizing Research, and Policy on the Ethical Conduct of Research
 - **MUST NOT** attempt to reidentify AI/AN individuals, the region(s) from which they originate, or the tribe(s) to which they belong
 - **MUST** fulfill all technical and logistical requirements for authorized usership, including annual RCR training comprised of the basic modules and any future modules specific to the use of data from AI/AN individuals, as appropriate
 - **MUST** use respectful and appropriate language and preferred terminology, as dictated by the forthcoming guidance
- Comply with all applicable **federal, state, and local laws**
- Abide by all applicable **program policies and procedures** for access to data and non-data resources originating from participants who self-identify as AI/AN
- Agree to **additional scrutiny** of research focusing on AI/AN populations that is conducted using All of Us research resources

All of Us Research Program Privacy and Security Measures

Partner organizations must meet strict data security standards before they may collect, transfer, or store information from participants

All participant data is encrypted, and obvious identifiers are removed from data used for research

Independent reviewers to check plans and test systems on an ongoing basis to ensure the program has effective security controls in place





Research and Opportunities with *All of Us*

All of Us Research Hub | Who is using the data now?

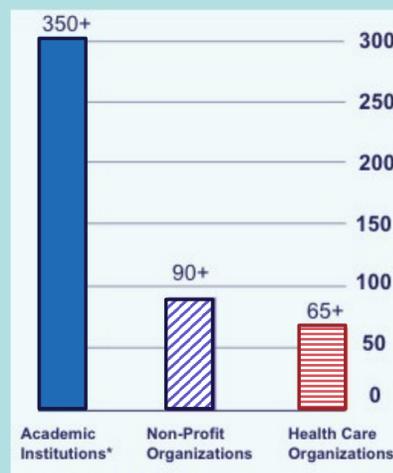


5,700+
Registered
Researchers

Comparing registered researchers	2/2022	6/2023
Total Registered Researchers	1,015	5,705
Researchers from UBW communities SGM, race/ethnicity, disability status, & career stage	56%	72%
Researchers from UBW communities By race/ethnicity alone	14.3%	28%



530
Institutions



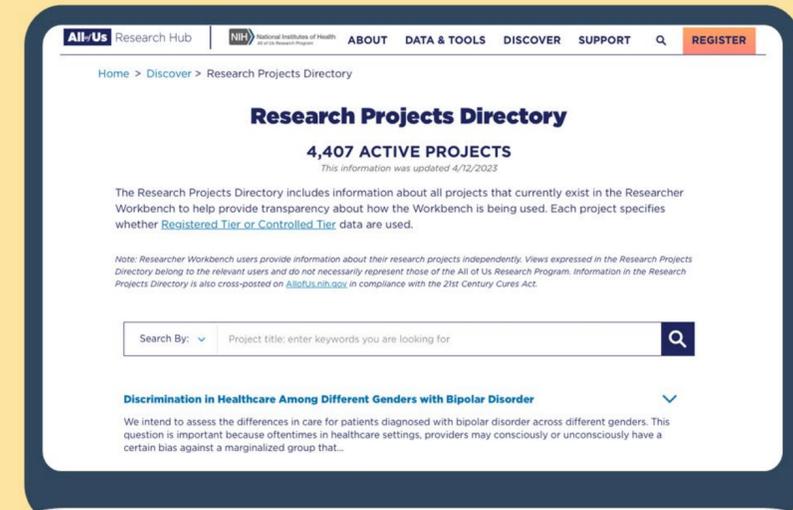
5,300+
Active projects



160
Publications in
peer-reviewed
journals

**Top conditions
being studied**

- Cardiovascular disease
- Hypertension
- Mental Health
- Cancer
- Diabetes



See the research currently underway by visiting
researchallofus.org/research-projects-directory

Stay in touch to learn more

Sign up for our bimonthly newsletter

Subscribe to Research Roundup

Stay up-to-date on the latest news and insights from the *All of Us* Research Hub through our bimonthly email newsletter.



allof-us.org/RRSignup

Create an *All of Us* account

Register to be an *All of Us* Researcher

STEP
1

LEARN MORE ABOUT THE
DATA AVAILABLE

STEP
2

CHECK FOR YOUR
INSTITUTION'S AGREEMENT

STEP
3

REGISTER AS A RESEARCHER

STEP
4

VERIFY YOUR IDENTITY

STEP
5

COMPLETE *ALL OF US*
RESPONSIBLE CONDUCT OF
RESEARCH TRAINING

STEP
6

SIGN DATA USER CODE OF
CONDUCT



[Allof-us.org/Register](https://allof-us.org/Register)

Assistance | Researcher Support Hub

Visit the Support Hub to find answers to common questions about becoming a registered researcher, using the *All of Us* dataset, and more. **NO LOGIN REQUIRED**



Find instructional materials about the *All of Us* Researcher Workbench

- Includes video tutorials, educational resources, release notes, and more

Search 280+ articles

- Find information about data dictionaries, the Controlled Tier directory, how WGS and Array data are organized, and more

Connect with experts during weekly live office hours

- Explore our calendar of dedicated office hours where researchers can talk about data types and tools with experts

Purpose of the ROA

Area of Interest 1: Participant Engagement and Enrollment

- Task 1:** Participant outreach and engagement
- Task 2:** Enrollment and retention
- Task 3:** Pediatric outreach and engagement
- Task 4:** Computer access
- Task 5:** Healthcare provider outreach and engagement

Area of Interest 2: Researcher Engagement

- Task 1:** Researcher Hub awareness and researcher engagement
- Task 2:** Building research capacity
- Task 3:** Promote team science

Area of Interest 3: Tribal Nations, American Indian and Alaska Native populations, and Indigenous Communities

- Task 1:** Outreach and engagement
- Task 2:** Training and career development
- Task 3:** Education and culturally appropriate resource development
- Task 4:** Research infrastructure and capacity building

Area of Interest 4: Participant as Partners

- Task 1:** Oversight of consortium participant partner related activities
- Task 2:** Full integration of participants and advocates
- Task 3:** Facilitation of ongoing input from participant representatives
- Task 4:** Assess the impact of participant engagement

Area of Interest 3: Engagement with Tribal Nations, American Indian and Alaska Native Populations, and Indigenous Communities

The *All of Us* Research Program initiated **tribal consultation in 2019** to engage Tribal Nations about the inclusion of AI/AN populations in this research program. The information received during consultation has been used to guide our work with AI/AN communities and Tribes.

Technical Objectives

- **Outreach and engagement** to AI/AN and Indigenous communities
- **Training and career development** in research as it relates to precision medicine
- **Education and culturally appropriate resource development** for AI/AN populations and partners
- **Research infrastructure and capacity building** within AI/AN and Indigenous communities ensuring sustainability of precision medicine research



[Review SAM.gov for full submission requirements](#)

Informational Presentation and Discussion Schedule

Session 1: *All of Us* Research Program Overview and Tribal Engagement

Tuesday, June 6, 2023, 1:00 - 3:00 pm ET

Session 2: How Researchers Access and Use *All of Us* Data

Tuesday, June 13, 2023, 1:00 - 3:00 pm ET

Session 3: Describing Self-Identified AI/AN Participants in *All of Us* Data

Tuesday, June 20, 2023, 1:00 - 3:00 pm ET

Session 4: Data and Partnerships in *All of Us*

Tuesday, June 27, 2023, 1:00 - 3:00 pm ET

***All of Us* Tribal Consultation**

Thursday, September 28, 2023, 1:00 - 3:00 pm ET

Thank You to Our Partners

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



All of Us Community and Provider Partner Network (as of April 2023)



Note: These are not approved lockups and should not be repurposed on assets.

All of Us Consortium Members (as of April 2023)

The Participant Center



Communications & Engagement



HPO Network

(Health Care Provider Organizations)

HPO Lite



RMCs

All of Us California



Illinois Precision Medicine Consortium



All of Us New England



Trans America Consortium



New York City Consortium



All of Us Southern Network



All of Us Southeast Enrollment Center



All of Us Wisconsin



All of Us Pennsylvania



University of Arizona and Banner Health



FQHCs (Federally Qualified Health Centers)



VA Medical Centers



Nutrition for Precision health (NPH)



All of Us Puerto Rico



Participant Technology Systems Center (PTSC)



Biobank



Data & Research Center (DRC)



Genomics Partners



Questions and Discussion

Naomi Aspaas

Tribal Engagement Specialist

Dr. Karriem Watson

Chief Engagement Officer, *All of Us*

Thank You!



National Institutes
of Health

AllofUs.nih.gov/TribalEngagement

AllofUs.nih.gov



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