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

June 27, 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

Roadmap and Recap

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

Session 3 Recap: Describing Self-Identified American Indian and Alaska Native (AI/AN) Participants in *All of Us* Data

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

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)

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

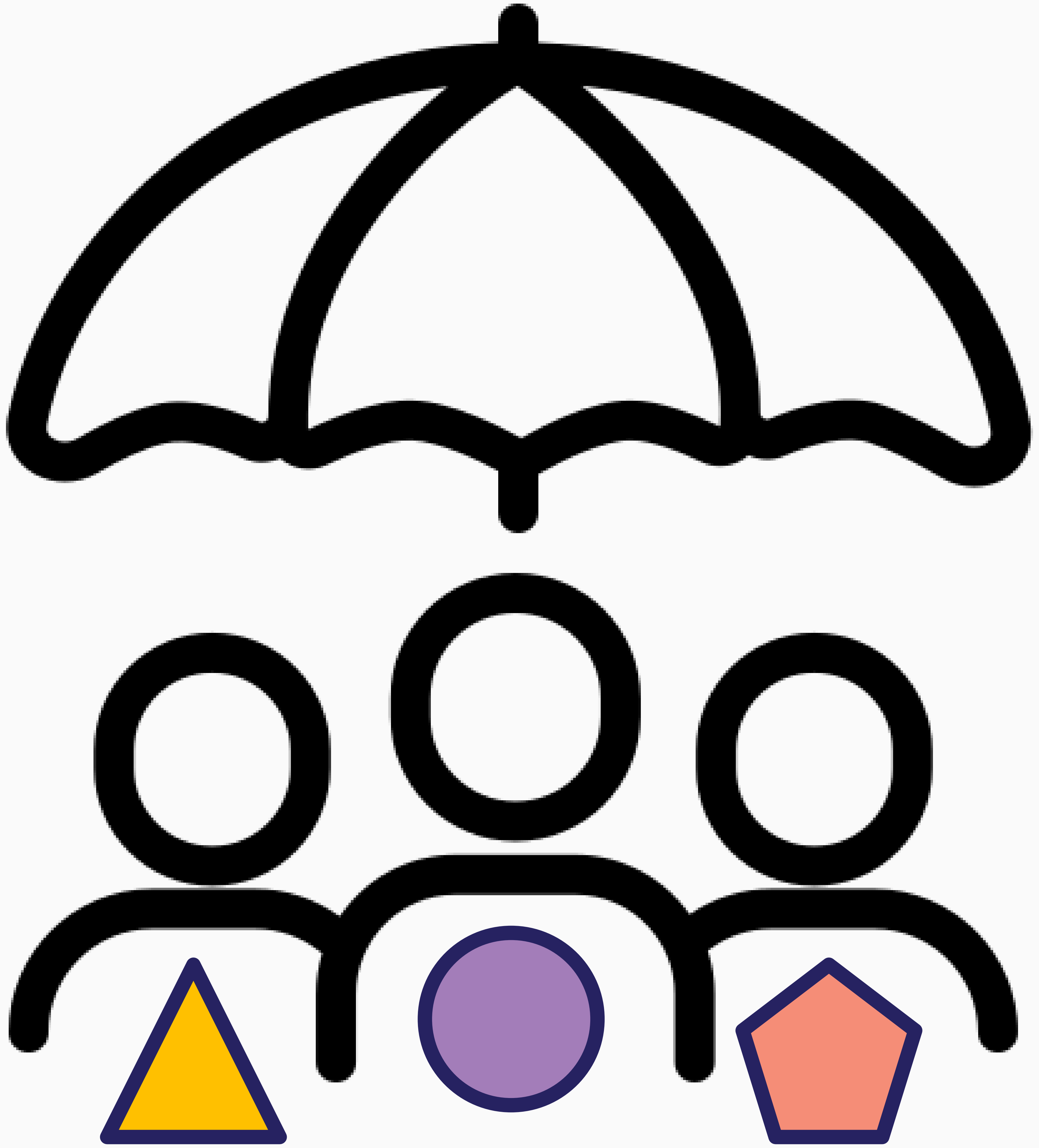
People may identify as AI/AN alone, or in combination with other races, too.

**and their descendants*

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	✓	• Likely enrolled in a Tribal Nation • Residing within their Nation's land-based jurisdiction
▲ Urban	✓	• Likely enrolled in a Tribal Nation • Residing in a setting outside of their Nation's land-based jurisdiction
● Ancestry	X	• Asserts ancestry to a Tribal Nation • Most likely to reside off of their Nation of ancestry's land
⬟ Central and South American Indian	X	• 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
- Difference between AI/AN as a population descriptor and as a political designation for sovereign Tribal Nations

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

Supplemental Information: Responsible Management and Sharing of American Indian/Alaska Native Participant Data

- Supplemental Information intended to assist researchers in developing appropriate DMS Plans when proposing research with Tribes
- Goals
  - Promote an understanding of Tribal sovereignty
  - Recognize the historic harms to Tribes in relation to inappropriate data use and misuse and participant risks
  - Provide best practices to mitigate potential risks (e.g., group harm, stigmatization, and privacy vulnerabilities) to Tribes
  - Facilitate respectful, sustained, mutually beneficial, and equitable partnerships
  - May also be useful for researchers partnering with urban AI/AN communities, non-Federally recognized Tribes (e.g., state recognized Tribes), communities (e.g., Native Hawaiians), and Indigenous peoples outside the United States

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Thank you to the Office of Science Policy for the content on this slide

Considerations for Researchers Working with Tribes

Tribal Sovereignty	Ability to govern and to protect and enhance the health, safety, and welfare of Tribal citizens within Tribal jurisdiction
Tribal Research Laws	Tribal sovereignty includes right of Tribes to establish and enforce their own laws; may go beyond Common Rule requirements
Historical Awareness	Researchers’ awareness of past research abuses perpetrated against Tribes is critical for understanding Tribes’ perspective on research
Health Disparities	Sufficient inclusion of Tribes in research remains a challenge

Thank you to the Office of Science Policy for the content on this slide

Best Practices for Responsible Management and Sharing of AI/AN Participant Data

Understand	Understand Tribal sovereignty and laws, regulations, policies, and preferences
Engage	Engage early with Tribes when developing a Data Management and Sharing Plan, before research begins, and continue throughout research
Establish	Establish mutually beneficial partnerships
Agree	Agree who will manage data (e.g., Tribe, researcher, trusted 3rd party)
Consider	Consider additional protections, as necessary

Thank you to the Office of Science Policy for the content on this slide

Building Tribal Partnerships into *All of Us*

- Respecting Sovereignty and Autonomy
- Addressing Underrepresentation
- Building Trust
- Improving Research Quality and Relevance
- Promoting Tribal Data Governance
- Improving Health

***All of Us* doesn’t currently have any active partnerships with Tribes**

A Framework for Tribal Partnerships and Data Use Agreements

- What We Mean by Data Use Agreements (DUAs)
- Why DUAs are Essential
- Legal and Regulatory Frameworks
- Benefits to AI/AN Communities

Designing Effective Data Use Agreements

Some Key Elements of Agreements

- Engagement and Enrollment Protocols
- Data Access
- Researcher Education
- Data Management
- Biospecimen Collection and Management
- IRB Representation
- Data Governance
- Reviewing Research Projects and Publications
- Withdrawal Procedures

Establishing Tribal Partnerships and Negotiating Data Use Agreements

- Partnerships center on negotiating tailored data use agreements.
- Trust and shared decision-making guide our negotiation process.
- Negotiations manifest in mutually-beneficial, community-driven outcomes.
- Agreements focus on Tribal preferences for research regulation including protocols, access, and use.

Resources for Tribal Partnerships and Data Use Agreements

THE UNIVERSITY OF ARIZONA
NATIVE NATIONS INSTITUTE
Founded by the Udall Foundation
& the University of Arizona

Strengthening Indigenous Governance

COLLABORATIVE RESEARCH CENTER FOR AMERICAN INDIAN HEALTH
CRCAIH

NCAI Policy Research Center
Improving Outcomes for Indian Country with Research

Please note: None of the groups on this slide are affiliated with *All of Us*, but they do have great resources

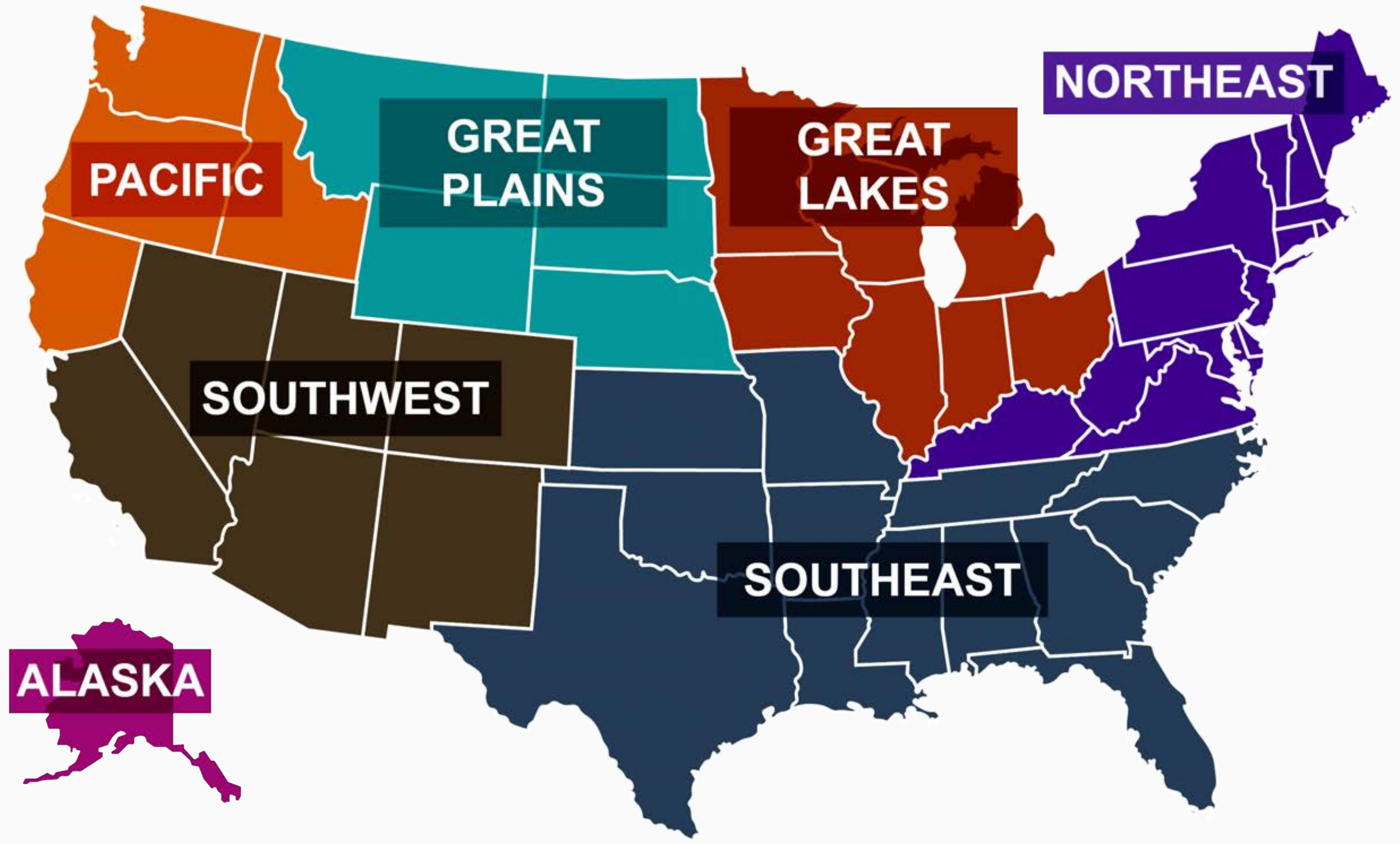
Challenges and Opportunities

- Impact of Participant Numbers
- Balancing Data Access and Protection
- Understanding Statistical Significance

What Could Tribal Partnerships Look Like?

1:1

Individual Tribes



Cultural Affiliation

National or Intertribal Organizations

Geographic or IHS Regions

Tribal Epidemiology Centers

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

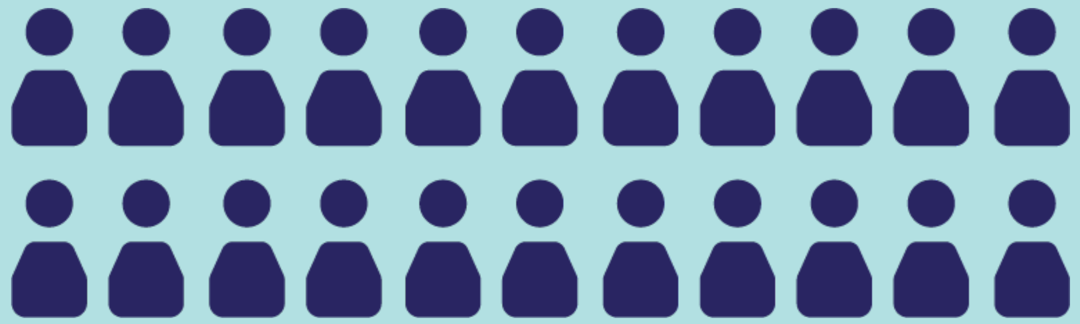
- **Outreach and engagement** to AI/AN and Indigenous communities
- **Training and career development** in research as it relates to precision medicine
- **Education and culturally appropriate resource development** for AI/AN populations and partners
- **Research infrastructure and capacity building**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

Review SAM.gov for full submission requirements

Ancillary Studies and Pediatrics

COVID-19 Participant Experience (COPE) Survey

COPE Survey Data Currently Available in the Researcher Workbench



More than **100,200** participants responded to

one or more of the **six** COPE surveys administered between May 2020 and February 2021

Topics Covered

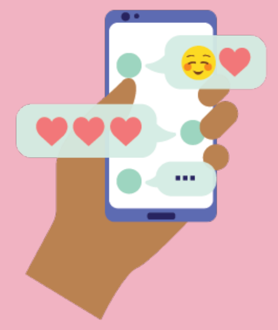
- Social Distancing Experiences
- COVID-19 Related Impact
- Mood
- Substance Use
- COVID-19 Related Symptoms
- General Well-Being
- Stress
- Resilience
- COVID-19 Related Testing
- Social Support
- Physical Activity
- Discrimination
- COVID-19 Related Treatment
- Anxiety
- Loneliness
- Vaccine Perceptions

Mental Health

The COPE data represents the biggest infusion of mental health data into the Researcher Workbench so far. Insights include:

62%
felt bothered by sleeping problems

53%
felt nervous and anxious



94%
have someone to love and make them feel wanted

95%
have someone to have a good time with

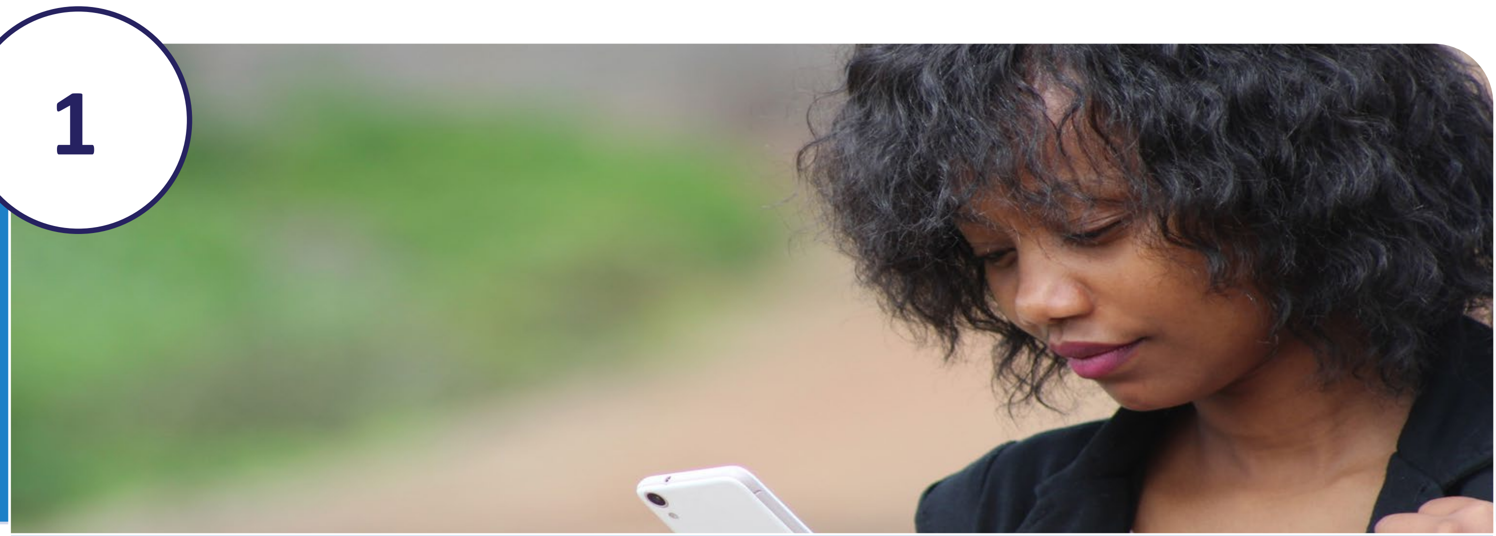
Embedded in the survey were resources for participants struggling with emotional distress, including suicide prevention tools.

Participants could select multiple symptoms.

Data as of April 2023

Nutrition for Precision Health: Overview

1



Examine baseline diet and physiological responses to nutrition by participants monitoring and reporting what they eat

10,000 *All of Us* participants

2

Examine responses to 3 short-term intervention diets in community-dwelling controlled feeding studies

1,500 Module 1 participants

3

Examine responses to 3 short-term intervention diets in live-in controlled feeding studies

500 Module 1 participants

In all 3 modules

- Collect microbiome, physiological, metabolic, behavioral, cognitive, and environmental data, and leverage existing genomic, EHR, and survey data, and conduct mixed meal challenges to model the impact of diet and dietary patterns on physiological responses
- Use machine learning and artificial intelligence to develop algorithms that predict individual responses to foods and dietary patterns

nutritionforprecisionhealth.org

Exploring the Mind: Overview

***All of Us* and the National Institute of Mental Health (NIMH) worked together to co-design the one of AoU's first ancillary studies:**

- NIMH selected research tasks that assess cognitive performance on visual attention, cognitive control, visual reward learning, reward valuation over time, and facial emotion recognition, while still being fun and engaging to participants.
- These tasks underwent pilot testing at AoU from December 2022 to May 2023.
- Evaluation of the pilot performance led the program to select four tasks to launch to all participants (estimated to become available August 2023).
- Each task is available using web or mobile devices, available in English and Spanish, and takes 2-8 minutes to complete.
- Researchers can examine this data longitudinally to understand connections between cognitive performance and health outcomes and/or events (e.g., progression of neurodegenerative disease, environmental exposures, presence of mental disorder) over the lifetime.

Four tasks will launch to all eligible participants (*estimated August 2023*)

*eligible participants are those who have completed the program's first three surveys (PPIs 1-3)

Guess the Emotion

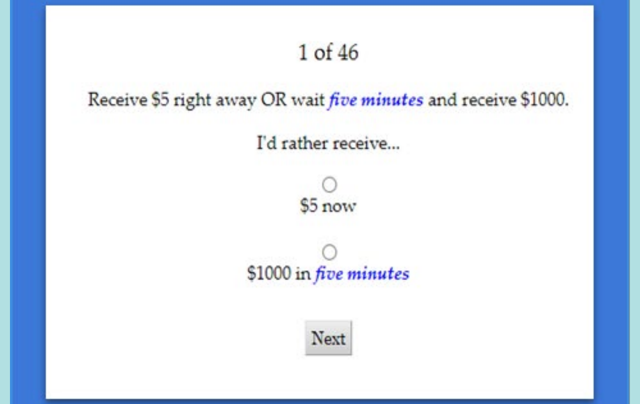
Flanker Test

<<><<

Can you ignore distractions?

City or Mountain

Flanker



1 of 46

Receive $5 right away OR wait *five minutes* and receive $1000.

I'd rather receive...

○ $5 now

○ $1000 in *five minutes*

Guess the Emotion

AOU AI/AN Demo Project

AOU Demonstration Projects will replicate known, previously published findings, and will not aim to discover new disease classifications, relationships, or risk associations – **our role is to support the community's use of data, not to make first discoveries.**

Characterization of the quality and utility of AI/AN data in AOU

- Does the AI/AN cohort in AOU reflect the rich diversity of the AI/AN population in the U.S through analysis of demographic and survey data? If not, what are the gaps to be prioritized and addressed in future recruitment for AOU?
- Descriptive statistics on demographic, anthropomorphic, laboratory, and disease status data.

Replicate known health disparities in disease in AI/AN communities in AOU to compare collected measures in other AI/AN population studies

- Diseases of focus: T2D, obesity, hyperlipidemia, hypertension, myocardial infarction, stroke, heart failure, lung cancer, colon cancer, kidney cancer, breast cancer (women), prostate cancer (men).

THE UNIVERSITY OF ARIZONA

Inclusion of American Indian and Alaska Native Children in *All of Us*

Thank you for the opportunity to discuss pediatrics with you today

Hometown

- Winona, MN

Training

- Undergrad at University of Minnesota
- M.D./Ph.D. at Mayo Clinic
- Residency, Chief Residency & Clinical Pharmacology Fellowship at Vanderbilt (mentor, Dan Roden)

Early Career

- Physician-scientist studying pharmacogenetics and precision medicine for children
- Clinical practice in general pediatrics and genomics & therapeutics clinics

Now

- Director of Pediatrics for *All of Us* Research Program since October 23, 2022

Sara Van Driest, Director of Pediatrics
All of Us Research Program

What We Hope to Accomplish Today

SHARE

- Background on Inclusion of Children into *All of Us*
- Pediatric Vision for *All of Us*

DESCRIBE

- *All of Us* Mission for Infants, Children, and Adolescents

DISCUSS

- Future inclusion of AI/AN children in the *All of Us* Research Program

Inclusion of Children in the *All of Us* Research Program

Background on Inclusion of Children

- Inclusion of children in research is an important advancement and has been an important goal of the program since its inception
- Pediatric work was started and paused to ensure the program first scale up our diverse adult enrollment successfully.
- The program approach to inclusion will be a phased approach with intentional engagement with Tribal Nations and communities.

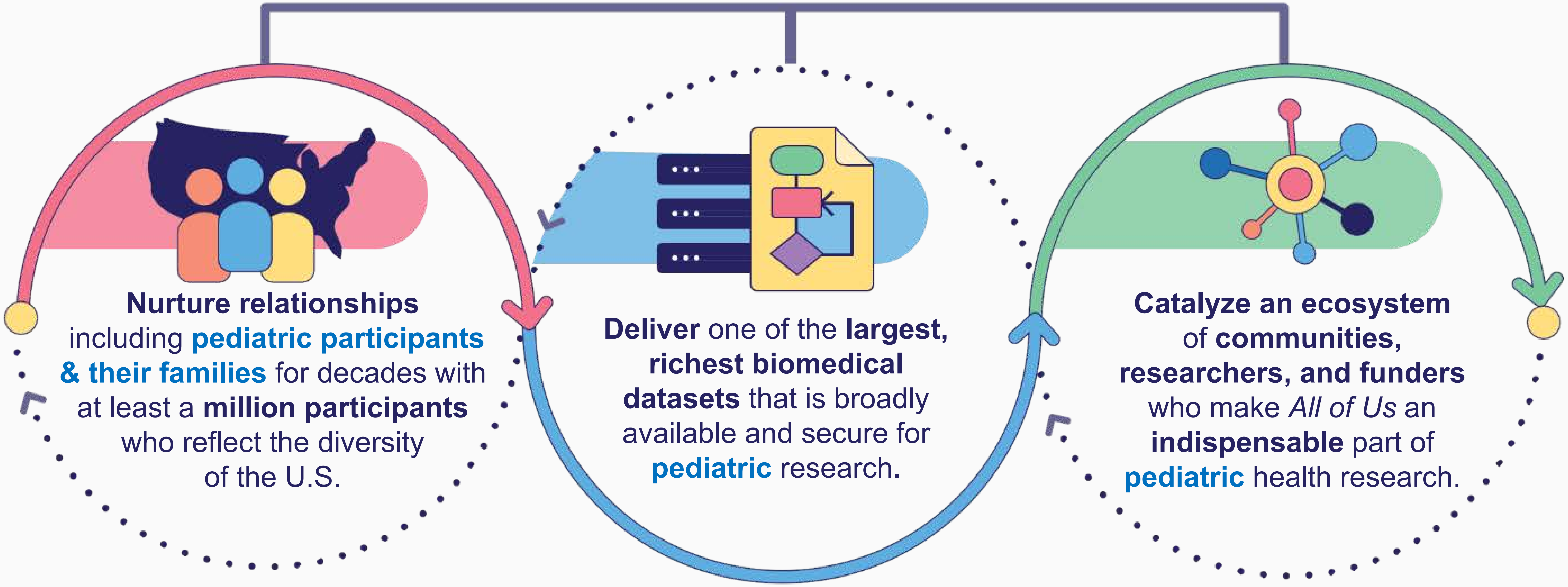
Pediatric Vision for *All of Us*

- Plans are to use primarily a family-based approach
- Have a supplemental protocol that incorporates the pediatric populations unique characteristics
- Develop outreach strategies to incorporate youth and AI/AN voices into our governance and advisory bodies

Long term goal: Achieve the ***All of Us* Mission** for infants, children, and adolescents

Our Mission

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



Nurture relationships including **pediatric participants & their families** for decades with at least a **million participants** who reflect the diversity of the U.S.

Deliver one of the **largest, richest biomedical datasets** that is broadly available and secure for **pediatric** research**.**

Catalyze an ecosystem of **communities, researchers, and funders** who make *All of Us* an **indispensable** part of **pediatric** health research.

Made possible by a team that maintains a culture built around the program’s core values

Long term goal: Fulfill the *All of Us* Core Values for infants, children, and adolescents

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.**

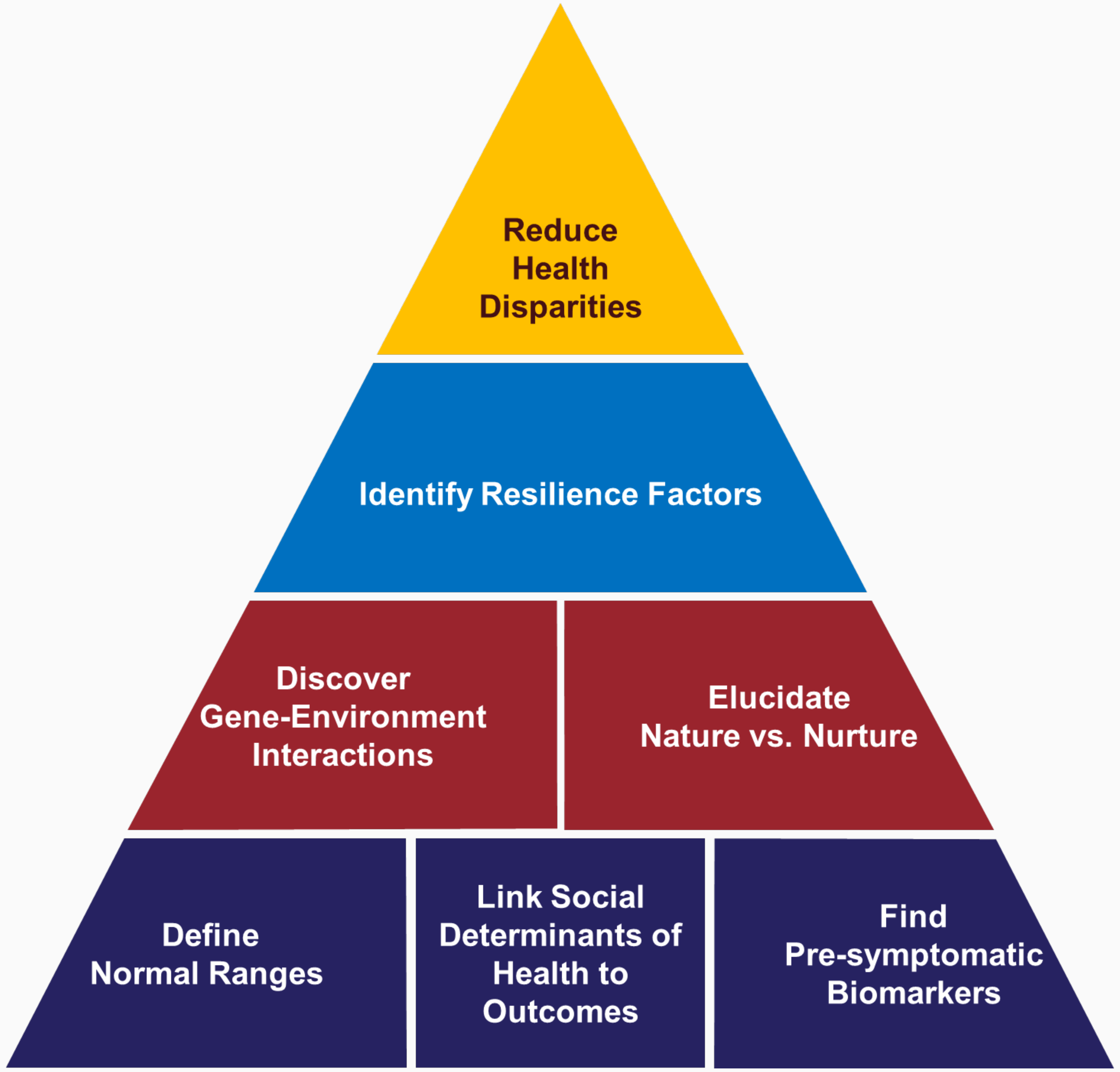
Security and privacy will be of highest importance.

Trust will be earned through **transparency**.

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

This scientific program will support advancement across multiple areas of opportunity

Selected scientific areas of opportunity*


Reduce Health Disparities

Identify Resilience Factors

Discover Gene-Environment Interactions

Elucidate Nature vs. Nurture

Define Normal Ranges

Link Social Determinants of Health to Outcomes

Find Pre-symptomatic Biomarkers

*Adapted from Child Enrollment Scientific Vision Working Group Report, December 2017

Example research questions

What is associated with optimal outcomes for children at risk for common conditions? Rare diseases?

How do genetic predictors differ across ancestry groups for monogenic and polygenic diseases?

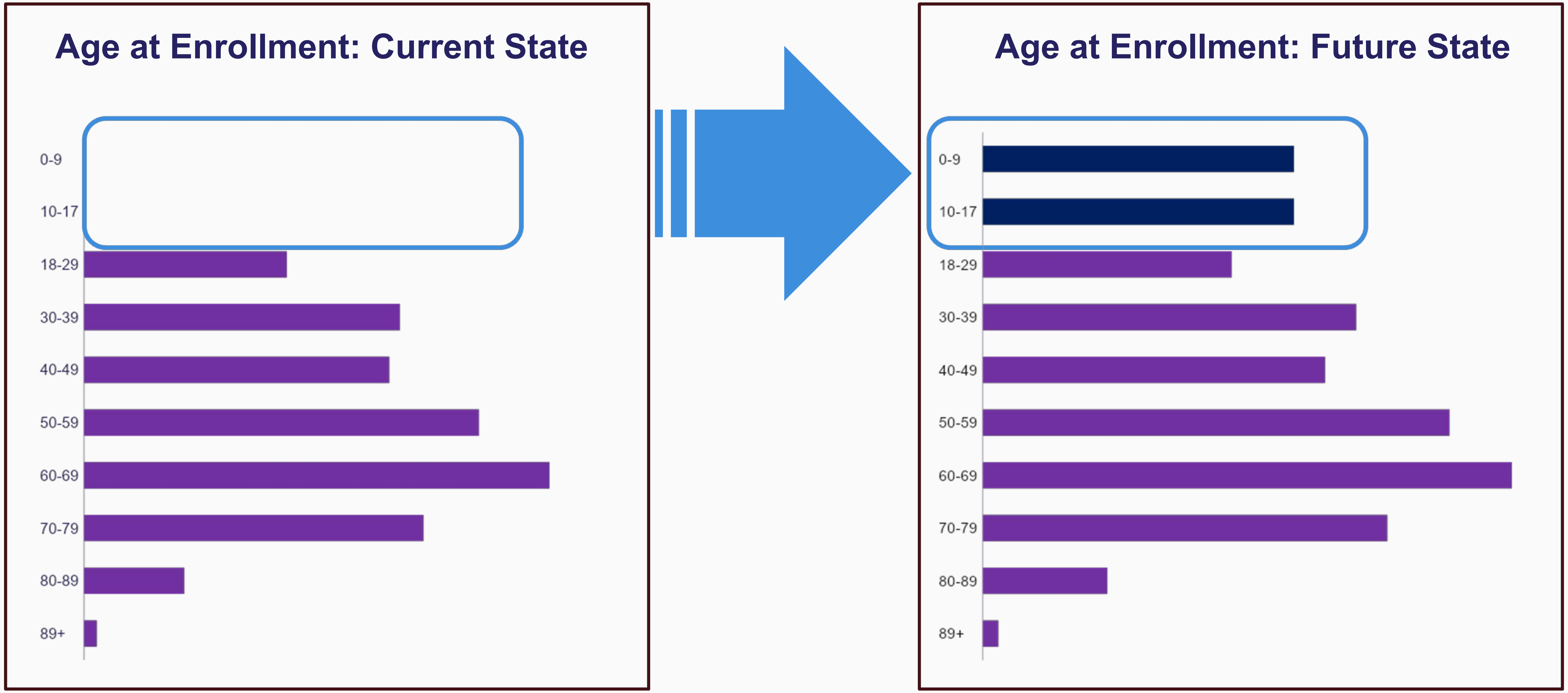
What exposures in childhood (or before birth) are associated with risk for or resilience to later onset conditions?

What biomarkers predict therapeutic (or adverse) drug outcomes?

What is the prevalence and impact of health inequities experienced by families, infants, children, and adolescents?

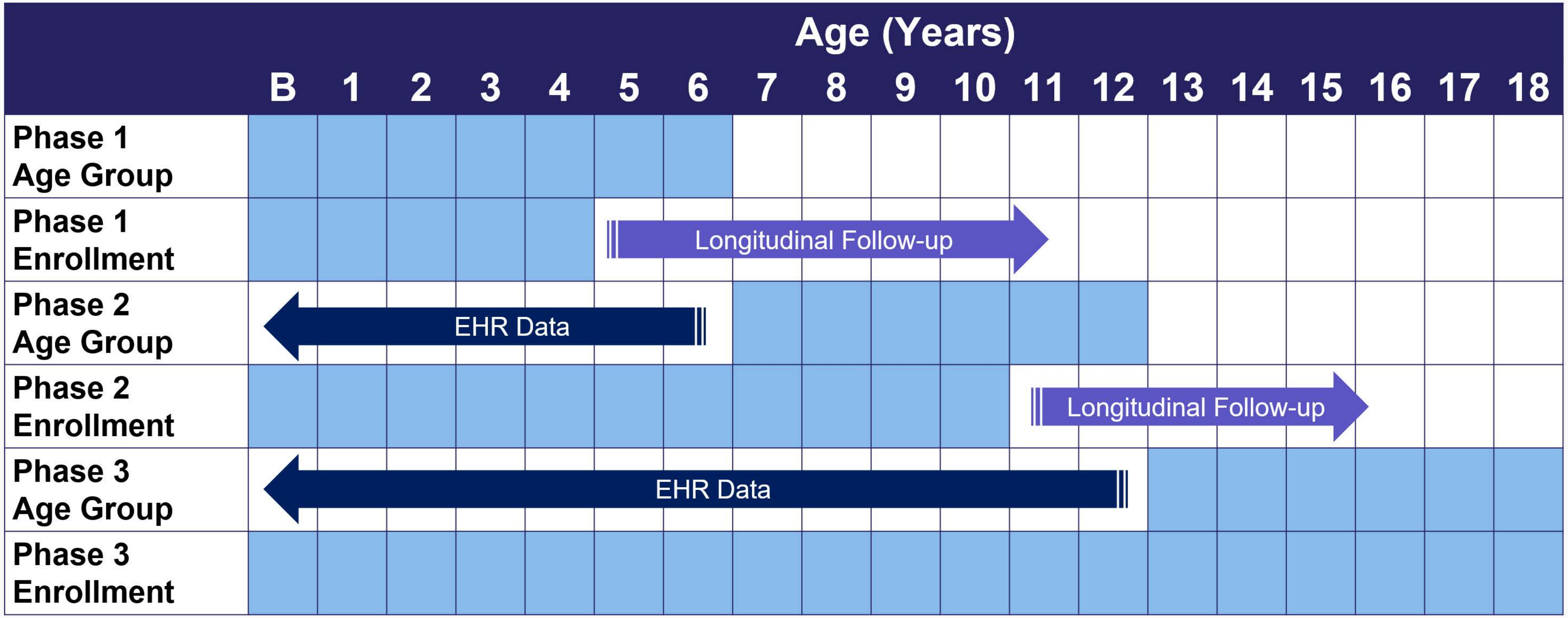
How can pediatric researchers build cohorts that reflect and serve our diverse patients?

A current focus of *All of Us* is to close the age gap, enabling participation at all ages (birth through adulthood)



https://www.researchallofus.org/data-tools/data-snapshots

Expected design approach: Phased launch, beginning with the youngest age group, enrolling children of current participants



	Age (Years)																		
	B	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Phase 1 Age Group	▨	▨	▨	▨	▨	▨	▨												
Phase 1 Enrollment	▨	▨	▨	▨	▨														
Phase 2 Age Group								▨	▨	▨	▨	▨	▨						
Phase 2 Enrollment	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨								
Phase 3 Age Group														▨	▨	▨	▨	▨	▨
Phase 3 Enrollment	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨

LINKAGE of data from parent of participant will extend exposure data to prenatal and preconception time frames

Design principle: Carefully examine the entire current protocol and adapt to support pediatric and family participation

Area	**Matches Current**	**Planned Peds Adaptation**
Participant Portal	Each participants has an account	Peds accounts are linked to adult accounts
Consent	Overall framework for experience	Parent provides permission; age 7 years and older provide assent
Participant Provided Information	Survey format (for now)	Revised questions
EHR Data	Requested for each participant	Parent provides authorization
Biospecimens	Blood preferred; saliva optional	Smaller volume for blood
Return of DNA Results	CONSIDERING return of traits, ancestry, health-related results	Pediatric participant assent to DNA results is required for return
Physical Measurements	Height & weight/length required with additional measurements	Revisions based on age
Compensation	At enrollment for time and travel to parent	Add small gifts of appreciation based on age

Tribal Engagement (Pediatric Planning) Activities

2023

June

Listening Sessions
Introducing the program's plans for AI/AN Pediatric Inclusion

July

National Community Engagement Partners
Working with new ROA awardee to include pediatric milestones

August

Reaching Out to Pediatric SMEs
Including AI/AN and Indigenous experts on the program's advisory panel on pediatrics; incorporating lessons from other agencies in the program's plans.

September

Tribal Consultation
Including questions about Pediatric inclusion in the program for Tribal leaders to weigh in.

October

Incorporating Feedback From Consultation

Creating FAQs, Fact Sheets with AI/AN and Indigenous Community Considerations

Future Inclusion of AI/AN Children in the *All of Us* Research Program

Upcoming Tribal Consultation on September 28, 2023

- **Future inclusion of children in the *All of Us* Research Program**
  - What unique considerations are there for the future inclusion of AI/AN infants, children, and adolescents as participants in the program, given that a child’s parent or legal guardian must be a current participant?
  - What unique considerations are there for family-based enrollment in the research program (e.g., parent or legal guardian participating with their child)?
  - What specific factors should be taken into account when enrolling families in the research program, considering the possibility of kinship caregivers or non-traditional child care arrangements for the child?

Research and Opportunities with *All of Us*

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

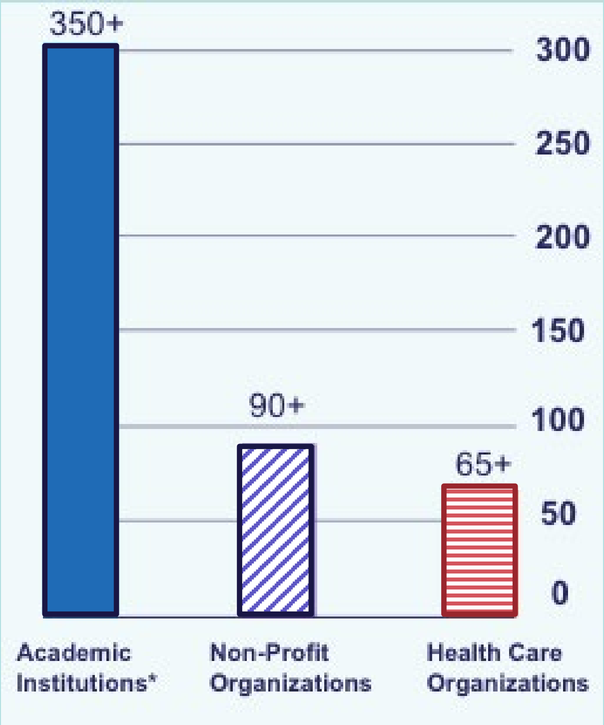
5,700+

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+

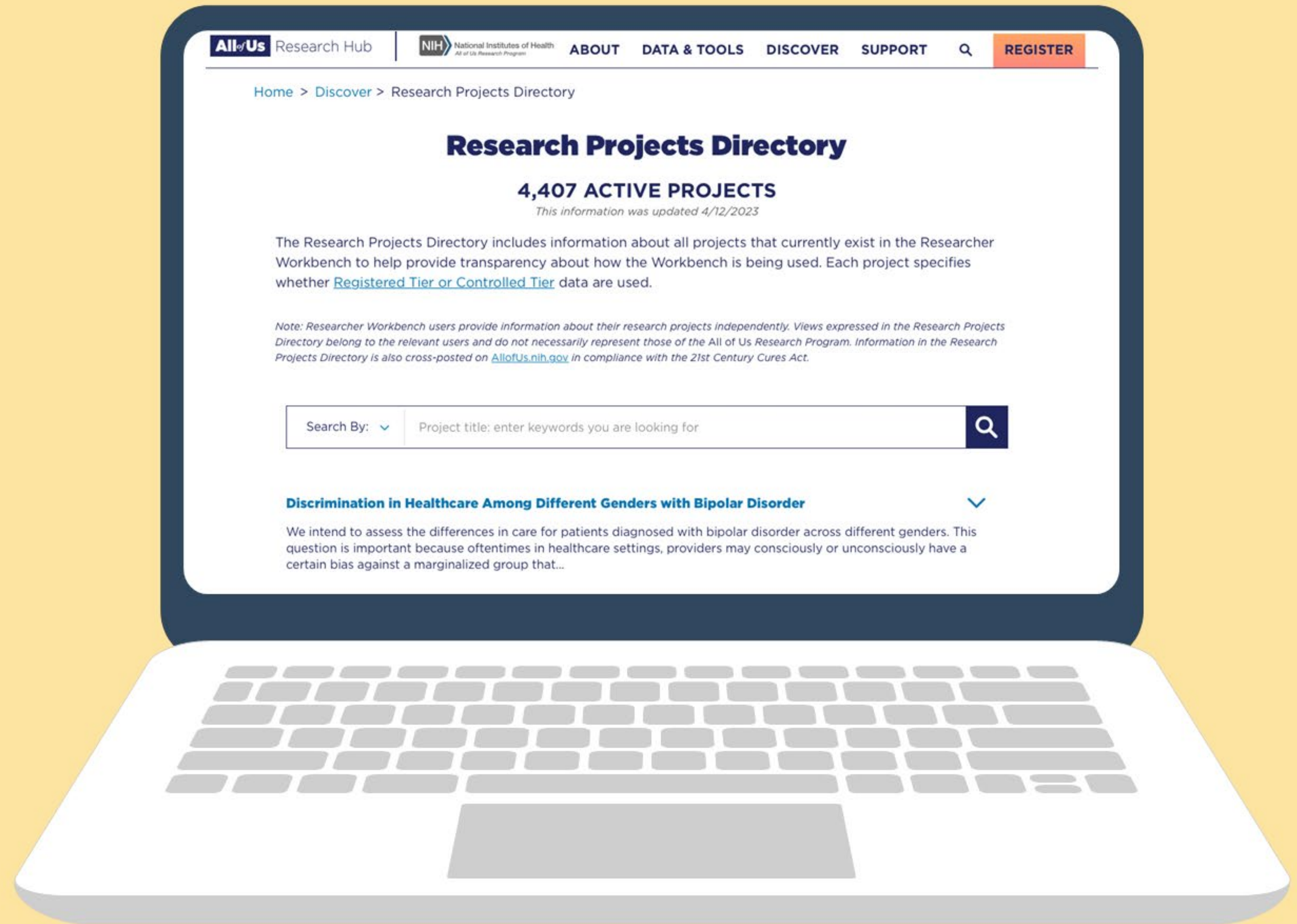
Active projects

160

Publications in peer-reviewed journals

Top conditions being studied

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



Home > Discover > Research Projects Directory

Research Projects Directory

4,407 ACTIVE PROJECTS

This information was updated 4/12/2023

The Research Projects Directory includes information about all projects that currently exist in the Researcher Workbench to help provide transparency about how the Workbench is being used. Each project specifies whether Registered Tier or Controlled Tier data are used.

Note: Researcher Workbench users provide information about their research projects independently. Views expressed in the Research Projects Directory belong to the relevant users and do not necessarily represent those of the All of Us *Research Program. Information in the Research Projects Directory is also cross-posted on* AllofUs.nih.gov *in compliance with the 21st Century Cures Act.*

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

Discrimination in Healthcare Among Different Genders with Bipolar Disorder

We intend to assess the differences in care for patients diagnosed with bipolar disorder across different genders. This question is important because oftentimes in healthcare settings, providers may consciously or unconsciously have a certain bias against a marginalized group that...

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

Stay in touch to learn more

All of Us RESEARCH PROGRAM

Research Roundup

June 2021

In this issue: Lead Story | Graphics | Spotlight | Featured Publication | *All of Us* News

Researchers Guide and Drive the Workbench's First Year

May 27 marked the first anniversary of the *All of Us* Researcher Workbench beta launch. The Workbench, part of the Research Hub, houses data from over 315,000 participants. More than 800 researchers now have access to valuable data from sources including physical measurements, electronic health records, and surveys.

(Credit: iStock)

Read about the Researcher Workbench's first year.

READ THE STORY

Researcher Workbench

Year One: By The Numbers

The *All of Us* Researcher Workbench is one year old! Since it opened to registered researchers in May 2020, participation in the program and its dataset has expanded substantially and continues to grow.

Our Researchers

Data as of May 24, 2021

826 Registered Researchers across a range of institutional roles and career stages.

209 Institutions

Researchers nationwide are using the Researcher Workbench

141 Academic Institutions*

26 Non-Profit Organizations

42 Health Care Organizations

*Includes 23 Historically Black Colleges and Universities and Hispanic-Serving Institutions.

Spotlight: Meet the Researchers

Mitch Lunn, M.D., is an *All of Us* researcher and community engagement partner whose research focuses on the health needs of sexual and gender minority (SGM) people. His Stanford University group, PRIDEnet, is examining how SGM people may be at greater risk for health conditions due to different socioeconomic factors.

(Credit: NIH)

Learn more about Dr. Lunn and his *All of Us* research.

READ THE SPOTLIGHT

Featured Publication: "Precision Medicine in 2030—Seven Ways to Transform Healthcare"

In Cell's March issue, *All of Us* CEO Joshua Denny, M.D., M.S., and NIH Director Francis S. Collins, M.D., Ph.D., discuss how cohorts, artificial intelligence, routine clinical genomics, and returning value across diverse populations can guide the future of precision medicine.

Also of note: In a new JAMA Viewpoint, leaders from across the *All of Us* consortium emphasize the scale and diversity of the *All of Us* participant cohort. They also discuss the Researcher Workbench, its rich dataset, and the ever-growing community of researchers using its powerful platform.

See more publications about *All of Us*.

***All of Us* News**

Check out the latest news:

- An *All of Us* study that tested blood samples for antibodies against SARS-CoV-2 found evidence of infections in five states earlier than had initially been reported. Read the complete study in *Clinical Infectious Diseases*. This data is now available in the Researcher Workbench.
- Watch the *All of Us* Research Trainee webinar, airing on Thursday, June 24, 2021, 2-5 p.m. ET. Hear from *All of Us* program staff and current Workbench users and learn why the beta phase of this platform is an ideal environment for trainees.

(Credit: NIH)

BACK TO TOP

Stay Up To Date

Connect with us on Facebook, Twitter, Instagram, and YouTube

You are receiving this quarterly newsletter because you expressed interest in the *All of Us* Research Program. Please CLICK HERE to opt out.
If you received this from a colleague, you can SUBSCRIBE HERE.

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

Thank You to Our Participants and Partners

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

AAFP
AMERICAN ACADEMY OF FAMILY PHYSICIANS

AAHD
American Association on Health & Disability

AAPA
American Academy of Physician Associates

ACCESS

AHEC WW
AREA HEALTH EDUCATION CENTER

AMERICAN ACADEMY OF HIV MEDICINE

American Association of Colleges of Nursing

ANAC
Association of Nurses in AIDS Care

Black Greek Letter Consortium
BGLC

National Pan-Hellenic Council

APHA
AMERICAN PUBLIC HEALTH ASSOCIATION
For science. For action. For health.

centerlink
THE COMMUNITY OF LGBTQ CENTERS

Asian Health Coalition

BLACK WOMEN'S HEALTH IMPERATIVE

Community Council
Moving families forward, leaving poverty behind.

Delgado
COMMUNITY COLLEGE

DELTA RESEARCH AND EDUCATIONAL FOUNDATION
CREATING POSSIBILITIES ... IMPROVING LIVES

DILLARD UNIVERSITY

Faith-based Genetic Research Institute

Fifty Forward
Love life at 50+

GOLDEN CHANGE

HACU

HUNTER
The City University of New York

ISMW

LULAC

NACCHO
National Association of County & City Health Officials

NAHN
National Association of Hispanic Nurses

National Alliance for Hispanic Health

NIH National Library of Medicine
Network of the National Library of Medicine

National Minority Quality Forum

NBNA
National Black Nurses Association, Inc.

BLACK CHAMBER OF COMMERCE

NHCOA
NATIONAL HISPANIC COUNCIL ON AGING

NHMA
National Hispanic Medical Association

National Rural Health Association

PEARLS
Humanity Foundation

PRIDEnet

PROJECTseek

sci port
DISCOVERY CENTER

Seven Star Academy Inc.

SUNO
SOUTHERN UNIVERSITY at NEW ORLEANS

SU Ag Center
Southern University AGRICULTURAL Research & Extension CENTER

SUSLA

TEXAS AHEC EAST
WACO REGION

UNIDOSUS
STRONGER COMMUNITIES. STRONGER AMERICA.

W. MONTAGUE Cobb NMA HEALTH Institute

XAVIER UNIVERSITY OF LOUISIANA

the Y
YMCA

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

Scripps Research Translational Institute
BlueCross BlueShield
SENSIS
Sage Bionetworks
waves
MAYO CLINIC
DENVER HEALTH est. 1860 FOR LIFE'S JOURNEY
BLOOD ASSURANCE
OurCEL SOLUTIONS
careevolution HEALTHCARE TECHNOLOGY
WebMD
Bloodworks Northwest
CASCADE REGIONAL BLOOD SERVICES YOUR COMMUNITY BLOOD CENTER
South Texas Blood & Tissue A SUBSIDIARY OF BIOBRIDGE GLOBAL
MONTAGE MARKETING
SunCoast Blood Centers
SYNC FOR SCIENCE
Quest Diagnostics
San Diego Blood Bank
fitbit
Mary's Center

Communications & Engagement

WONDROS
PYXIS PARTNERS
RTI INTERNATIONAL
THE UNIVERSITY OF UTAH

HPO Network

(Health Care Provider Organizations)

HPO Lite

UTHealth The University of Texas Health Science Center at Tyler
VCU Health
Washington University in St. Louis

RMCs

All of Us California

UC San Diego Health
UCI Health
UC DAVIS HEALTH
UCSF University of California San Francisco
ECRMC
Cedars Sinai
Keck School of Medicine of USC

Illinois Precision Medicine Consortium

Northwestern Medicine
THE UNIVERSITY OF CHICAGO
NorthShore University HealthSystem
RUSH
THE UNIVERSITY OF ILLINOIS COLLEGE OF MEDICINE PEORIA CHICAGO ROCKFORD URBANA
UI Health
COOK COUNTY HEALTH

All of Us New England

Mass General Brigham
BOSTON MEDICAL CENTER

Trans America Consortium

Henry Ford HEALTH SYSTEM
Spectrum Health
Essentia Health
BaylorScott&White HEALTH
RELIANT MEDICAL GROUP Part of OptumCare
HealthPartners Institute

New York City Consortium

COLUMBIA
Weill Cornell Medicine
NYC HEALTH+ HOSPITALS | Harlem
NewYork-Presbyterian

All of Us Southern Network

UAB SCHOOL OF MEDICINE The University of Alabama at Birmingham
UAB HEERSINK SCHOOL OF MEDICINE The University of Alabama at Birmingham
Cooper Green Mercy HEALTH SERVICES AUTHORITY AFFILIATE OF UAB HEALTH SYSTEM
THE UNIVERSITY OF MISSISSIPPI MEDICAL CENTER
Tulane University
USA HEALTH
University Medical Center
THE UNIVERSITY OF ALABAMA College of Community Health Sciences
TUSKEGEE UNIVERSITY
LSU Health NEW ORLEANS

All of Us Southeast Enrollment Center

UHealth UNIVERSITY OF MIAMI HEALTH SYSTEM | UNIVERSITY OF MIAMI MILLER SCHOOL of MEDICINE
EMORY UNIVERSITY
MOREHOUSE SCHOOL OF MEDICINE
UF UNIVERSITY of FLORIDA
THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL

All of Us Wisconsin

Marshfield Clinic Health System
WISCONSIN UNIVERSITY OF WISCONSIN–MADISON
Froedtert & MEDICAL COLLEGE of WISCONSIN
GUNDERSEN HEALTH SYSTEM

All of Us Pennsylvania

University of Pittsburgh

University of Arizona and Banner Health

THE UNIVERSITY OF ARIZONA
Banner Health
MARIPOSA Your COMMUNITY HEALTH CENTER

FQHCs (Federally Qualified Health Centers)

Cherokee HEALTH SYSTEMS
SAN YSIDRO HEALTH
WAIANAE COAST COMPREHENSIVE HEALTH CENTER www.wcchc.com
Community Health Center, Inc.
Cooperative Health
Sun River Health

VA Medical Centers

VA U.S. Department of Veterans Affairs Veterans Health Administration

Nutrition for Precision health (NPH)

UNC NUTRITION RESEARCH INSTITUTE
THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL

All of Us Puerto Rico

cossma ...somos servicio, somos salud
CENTRO COMPRENSIVO DE CÁNCER universidad de puerto rico

Participant Technology Systems Center (PTSC)

vibrent

Biobank

MAYO CLINIC

Data & Research Center (DRC)

VANDERBILT UNIVERSITY MEDICAL CENTER
BROAD INSTITUTE
verily
COLUMBIA UNIVERSITY MEDICAL CENTER
SCHOOL OF PUBLIC HEALTH UNIVERSITY OF MICHIGAN
Northwestern Medicine
UTHealth The University of Texas Health Science Center at Houston

Genomics Partners

Baylor College of Medicine DEPARTMENT OF MOLECULAR & HUMAN GENETICS
JOHNS HOPKINS MEDICINE
UTHealth The University of Texas Health Science Center at Houston
HUDSONALPHA INSTITUTE FOR BIOTECHNOLOGY
BROAD INSTITUTE
color
Mass General Brigham
UNIVERSITY of WASHINGTON

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

Questions and Discussion

Carolina Cerrone

Health Science Policy Analyst

Dr. Karriem Watson

Chief Engagement Officer, *All of Us*

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, 1:00 - 3:00 pm ET

Recordings will be made available at Allofus.nih.gov/TribalEngagement

All of Us
RESEARCH PROGRAM

Thank you!

Social media:
@AllofUsResearch
@AllofUsCEO
#JoinAllofUs

Websites:
AllofUs.NIH.gov
JoinAllofUs.org
ResearchAllofUs.org

Thank you to our 628,000+ participants!