

Nurses Advancing Reproductive and Sexual Health Using the *All of Us* Researcher Workbench

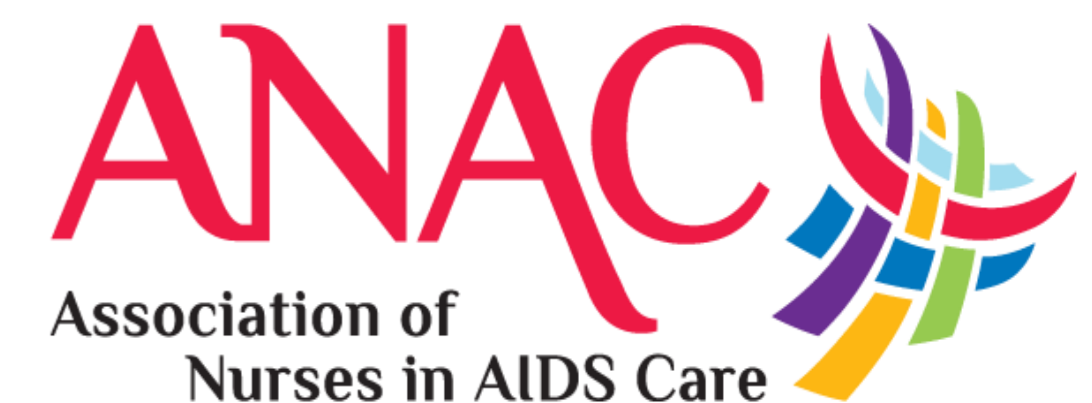
Faculty:

Caitlin Dreisbach, PhD, RN

Moderator:

Sheila Tumilty, BSN, RN, ACRN

May 9, 2024



The Association of Nurses in AIDS Care (ANAC)

Mission: ANAC fosters the professional development of nurses and others involved in the delivery of health care for persons at risk for, living with and/or affected by the human immunodeficiency virus (HIV) and its comorbidities. ANAC promotes the health, welfare and rights of people living with HIV around the world.



ANAC2024

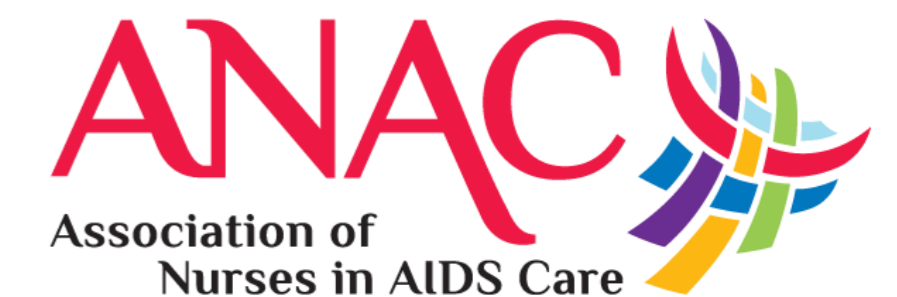
INDIANAPOLIS

NOVEMBER 14 - 16

Race for the Cure

NOVEMBER 14TH-16TH, 2024

WWW.NURSESINAIDSCARE.ORG/CONFERENCE



Housekeeping

- This webinar is being recorded
- **Please keep your lines muted during the webinar**
- Type questions in the Chat
- There will be a Q & A session at the end of the webinar



Nursing Continuing Professional Development (NCPD)

ANAC will provide one contact hour of NCPD on completion of this activity.

To receive a certificate of completion, attendees must:

- Be registered to attend
- View today's webinar presentation in its entirety
- Complete the online, post-activity evaluation. You will receive a link to the evaluation by email within the next two business days

The deadline to claim contact hours is December 31, 2024.



ANAC is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.

Questions? Email Sheila@anacnet.org



Disclosures

No one in a position to control the content for this educational activity has relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.

Learning Outcomes

At the conclusion of today's activity, participants will be able to:

- Describe the mission and goals of the *All of Us* Research Program.
- Discuss how nurse scientists are engaging with the *All of Us* Research Program to advance their programs of research.

The *All of Us* Researchers Convention

The *All of Us* Researchers Convention is organized by Pyxis Partners in collaboration with the *All of Us* Division of Engagement and Outreach. The division partners with community organizations nationwide to foster relationships with participants, researchers, and health care providers. The convention and other researcher engagement activities are central to building a diverse community of researchers.

This annual event occurred April 3-4, 2024

Find out more: <https://convention.researchallofus.org/>



The *All of Us* Research Scholars Program (RSP)

The All of Us Research Scholar Program pairs student researchers with a mentor who guides them through a research project using All of Us data. Students will also have the opportunity to participate in professional development workshops and to network with mentors and students.

Applications for the 2024-2025 cohort will open in August 2024

<https://rsp.researchallofus.org/en/scholars>



Nurses Advancing Reproductive and Sexual Health Using the *All of Us* Researcher Workbench



Last Updated: April 2024

Caitlin Dreisbach, PhD, RN

Assistant Professor, University of Rochester



All of Us Research Program

Key Definitions & Acknowledgement

- **Researcher Engagement:** Intentional, bidirectional relationship and capacity building with researchers and their communities across all career stages, institution types, and demographics, emphasizing researchers underrepresented in the biomedical workforce (UBW) through ongoing information sharing, collaboration, consultation, empowerment, and support.
- **Outreach:** Unidirectional interaction, such as providing materials and information to an audience.
- **Researcher diversity:** Defined across multiple dimensions, including demographics (inclusive of self-reported race/ethnicity, sex, gender, and SGM status, and disability), career stage, and institution type.

Source: All of Us Research Program protocol

Acknowledgement: This event is funded by the Division of Engagement and Outreach, *All of Us* Research Program, National Institutes of Health. Award Number [Pyxis Partners: OD028404]

nurses week

2024

Introduction to *All of Us*

Description of the analytic tools in the Workbench

How do I work in the Workbench?

Research exemplars

Question & answer!

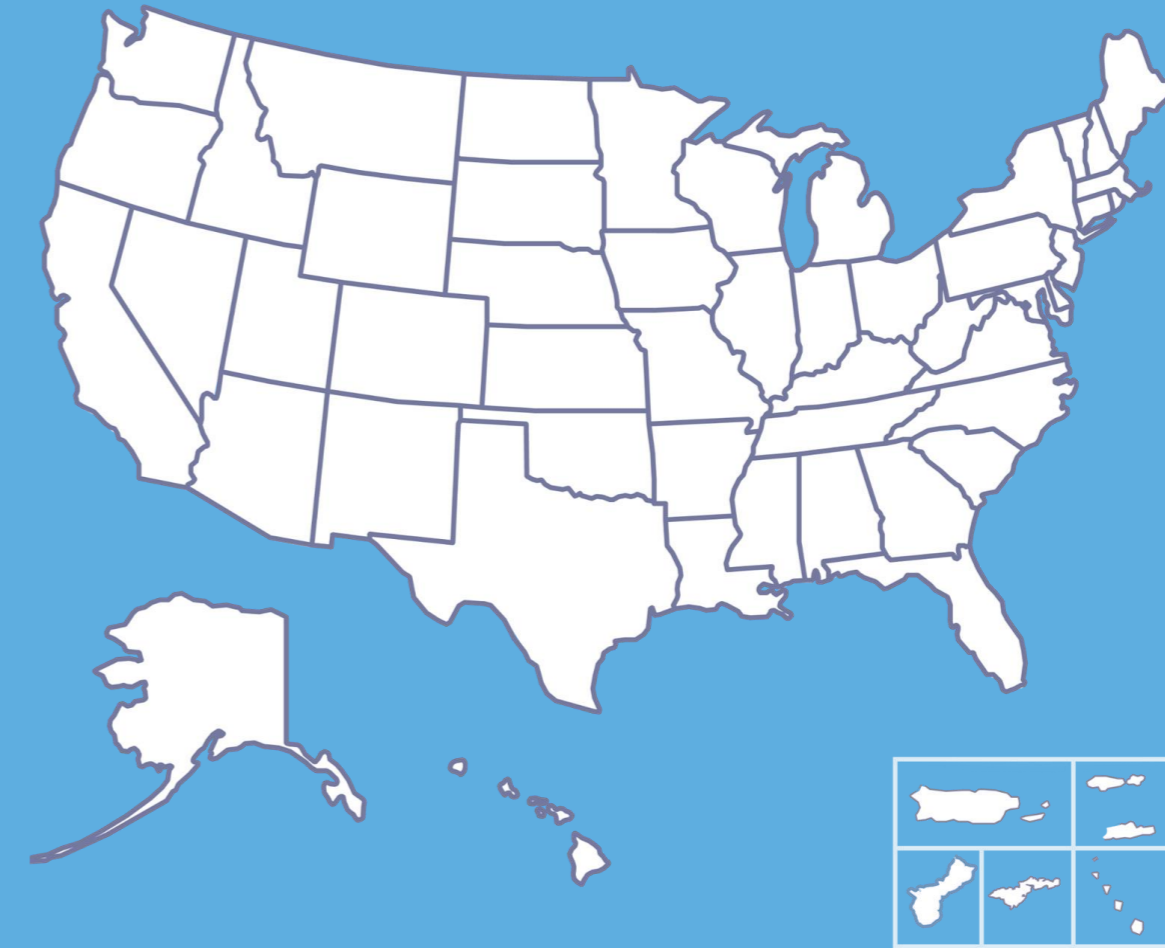
What is the *All of Us* Research Program?

One of the world's largest, most diverse biomedical datasets of its kind

Inviting

1 Million

or more people
from across
the United States



Data available from **413,450+** participants

75%

identify with
communities
underrepresented in
biomedical research



45%

are from racial
and ethnic
minority groups

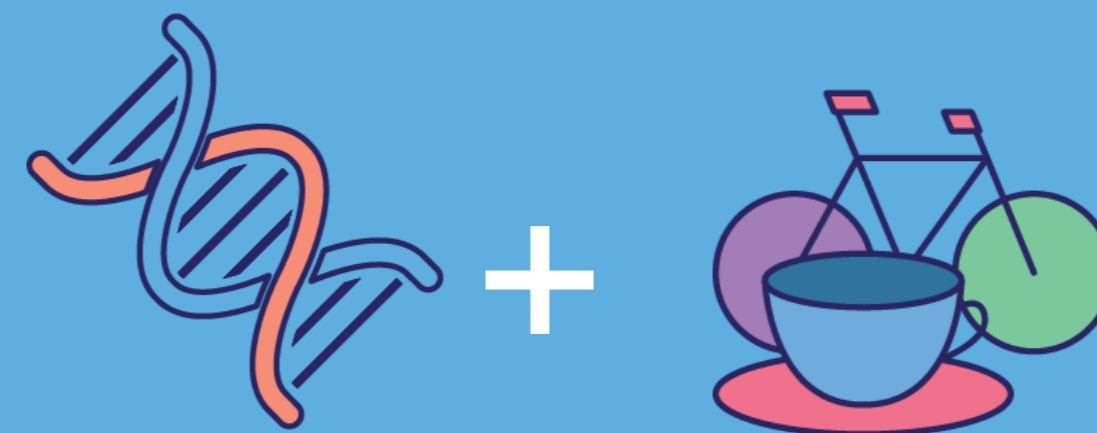
Data as of April 2023

Enabling research discoveries that drive more precise approaches to care

Engages **people & communities who have been left out of medical research** in the past



Combines **biological factors and social determinants** on a large, inclusive scale



Easily accessible to any researcher with a secure internet connection and data use agreement



Follows participants as they move, age, and grow



By securely capturing a range of different data types

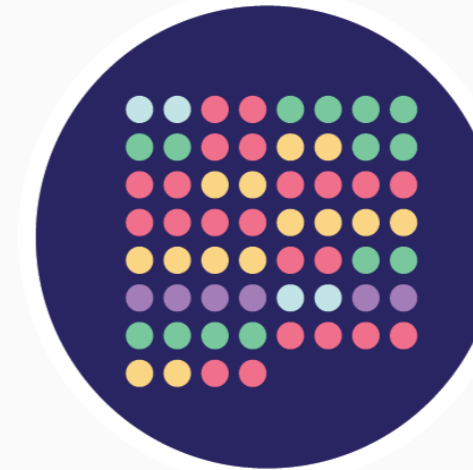
The *All of Us* Research Program's Data and Research Center (DRC) curates a range of different data types as part of the data collection process.



413,350+
Survey Responses



337,500+
Physical Measurements



312,900+
Genotyping Arrays



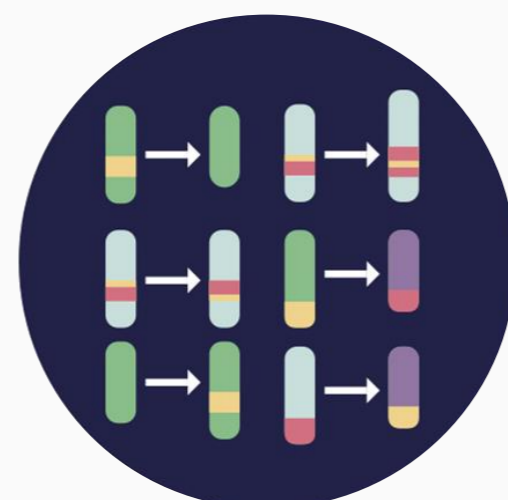
287,000+
Electronic Health Records



245,350+
Whole Genome Sequences (WGS)



15,600+
Fitbit Records
NEW! Sleep Data



11,350+
Structural Variants
NEW! In 2023



1,000+
Long-Read Sequences
NEW! In 2023

Along with the Social Determinants of Health Survey

By connecting biological and social determinants of health data on a large, inclusive scale and following participants as they move, age, and grow, the *All of Us* dataset is driving new insights into health and disease.

Social Determinants of Health (SDOH) Survey data



from 117,750+ responses

While making the data accessible to researchers across stages and settings

Our Researchers



10,100+
Registered
Researchers



450+
Academic
Institutions



130+
Not-for-Profit
Organizations



90+
Health Care
Institutions

110+

Historically Black Colleges and Universities
and Hispanic-Serving Institutions

Research Currently Underway



10,000+
Active projects



290+
Publications in
peer-reviewed
journals



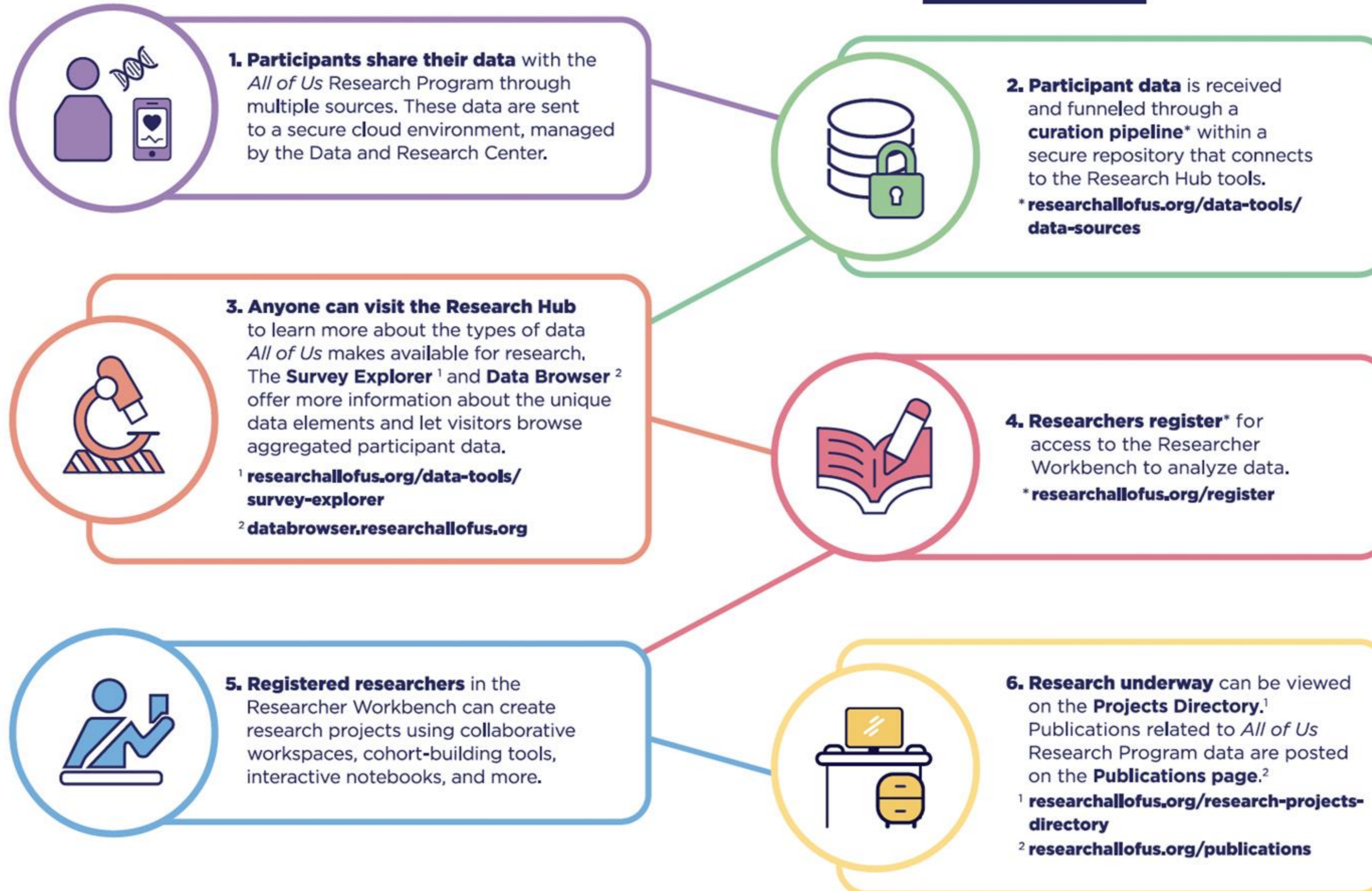
Top conditions
being studied in
the Researcher
Workbench include:

- Cancer
- Cardiovascular disease
- Diabetes
- Mental health
- COVID-19

Figures accurate as of April 2024

Data Access and Analytical Tools

All of Us Research: How It Works



Tiered access levels enable discovery



Available to anyone

Public Tier

Anyone can visit ResearchAllofUs.org (the *All of Us* Research Hub) to learn more about the data available for research and explore aggregated participant data and summary statistics, with participant identifiers removed. 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

Data have been processed to protect participant privacy

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

Making aggregated overviews and interactive previews available to everyone

ResearchAllOfUs.org

Welcome to the *All of Us* Research Hub

The National Institutes of Health's *All of Us* Research Program 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.

Register for the Researcher Workbench to access data and tools to conduct health research and improve understanding of health and disease.

[REGISTER FOR ACCESS](#)

Data Snapshots

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


783,000+
Participants


432,000+
Electronic Health Records


555,000+
Biosamples Received

[VIEW MORE DATA SNAPSHOTS](#)

Search Across Data Types

Keyword Search

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



FAQs



Introductory Videos



User Guide

EHR Domains

Conditions	Drug Exposures	Labs & Measurements	Procedures
25,638 medical concepts	29,865 medical concepts	16,618 medical concepts	30,328 medical concepts
254,700 participants	239,740 participants	255,640 participants	242,580 participants
View Conditions	View Drug Exposures	View Labs & Measurements	View Procedures

Genomics

SNV/Indel Variants	Genomic data only in Researcher Workbench	Physical Measurements	Fitbit
245,400 Participants in Short-Read Whole Genome Sequencing (WGS) dataset	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	8 Physical Measurements 337,540 participants Participants have the option to provide a standard set of physical measurements.	6 Fitbit Measurements 15,620 participants Fitbit data includes heart rate and activity summaries.
1,074,881,214 SNV/Indel Variants			
View SNV/Indel Variants	Register for access	View Physical Measurements	View Fitbit

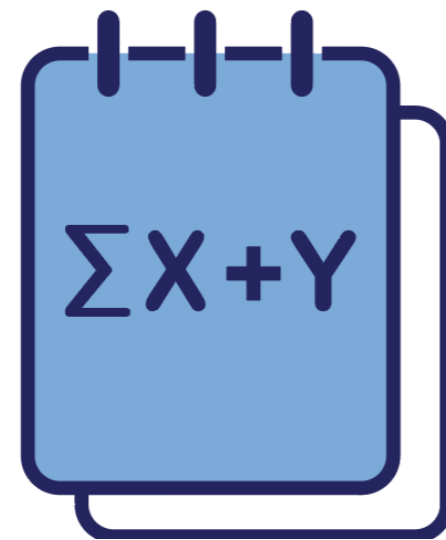
Supported by Workbench tools and resources



WORKSPACES

USES:

- Organizing research projects
- Collaboration
- Transparency

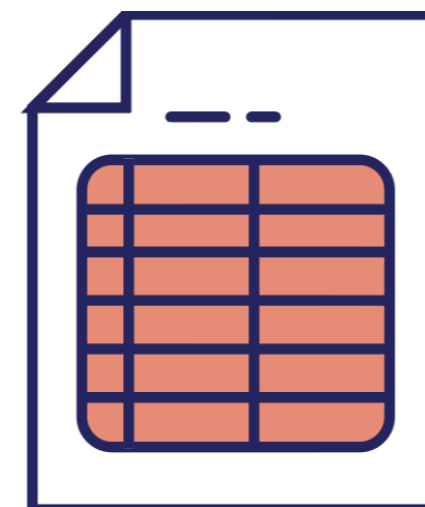


ANALYSIS TOOLS

USES:

- Analyses
- Queries

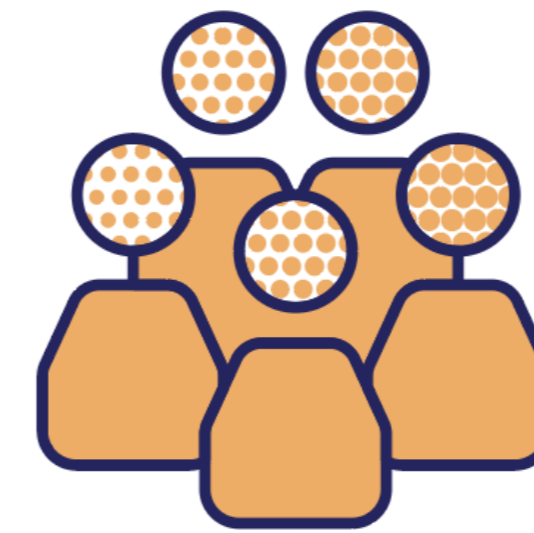
Conduct analyses with R, Python, or SAS using our integrated, cloud-based analysis tools, including Jupyter Notebooks, RStudio, and SAS Studio.



DATASET BUILDER

USES:

- Pre-populated analyses
- Dataset previews



COHORT BUILDER

USES:

- Cohort creation



USER SUPPORT HUB

USES:

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

With answers to common questions on the User Support Hub

No Login Required! Visit the Support Hub to learn more about becoming a registered researcher and using the *All of Us* dataset.



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

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

Search 300+ 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



researchallofus.org/support

*Source: Figure as of April 2024

And this is just the beginning

In the coming years, *All of Us* expects to enroll one (1) million or more people from across the United States and continue adding new data to the dataset, including:



**More Wearables
Data**



**More
Surveys**



**New Linkages to
External Data
Sources**



**Ancillary
Study Data**

Visit the data roadmap for more information

	Available end of 2022	Early 2023 additions	2023 and beyond
Electronic Health Records (EHRs)	<ul style="list-style-type: none"> 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 >
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.

Create an *All of Us* account

Get started today

STEP
1

CONFIRM YOUR INSTITUTION'S
AGREEMENT

STEP
2

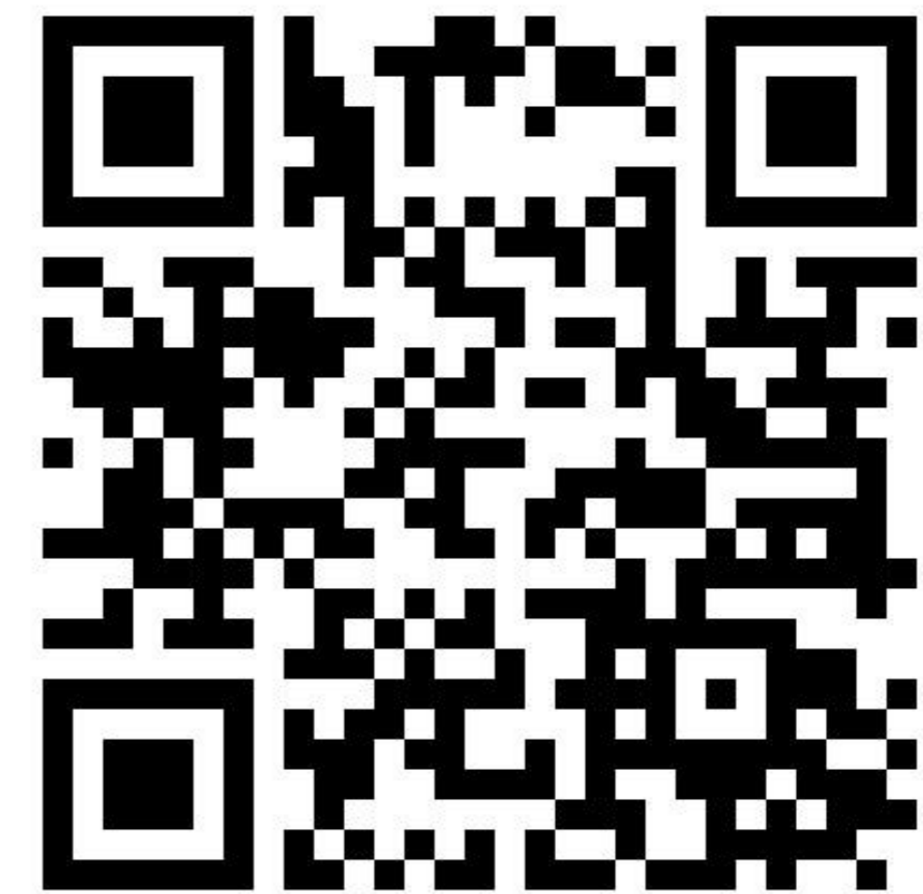
CREATE AN ACCOUNT AND
VERIFY YOUR IDENTITY

STEP
3

COMPLETE THE MANDATORY
TRAINING

STEP
4

SIGN THE DATA USER CODE OF
CONDUCT (DUCC)



allof-us.org/Register

How do I work in the Workbench?

Collaboration is key!

If you have programming skills (R, Python, or SAS)...

- Amazing, you are at a head start!
- Familiarize yourself with data (e.g., surveys, EHR, etc)
- Identify an appropriate research question considering the data

If you don't feel comfortable programming...

- Don't be discouraged!
- Reach out
- Extend your network

Research Exemplars



Emma Dickerson



Tyler Walton



Shiya Xiao



Dr. Theresa Koleck



Hamidah Shaik



Xintong (Carol) Li



Dr. Chen Zhang

Mapping sequences of contraceptive prescriptions

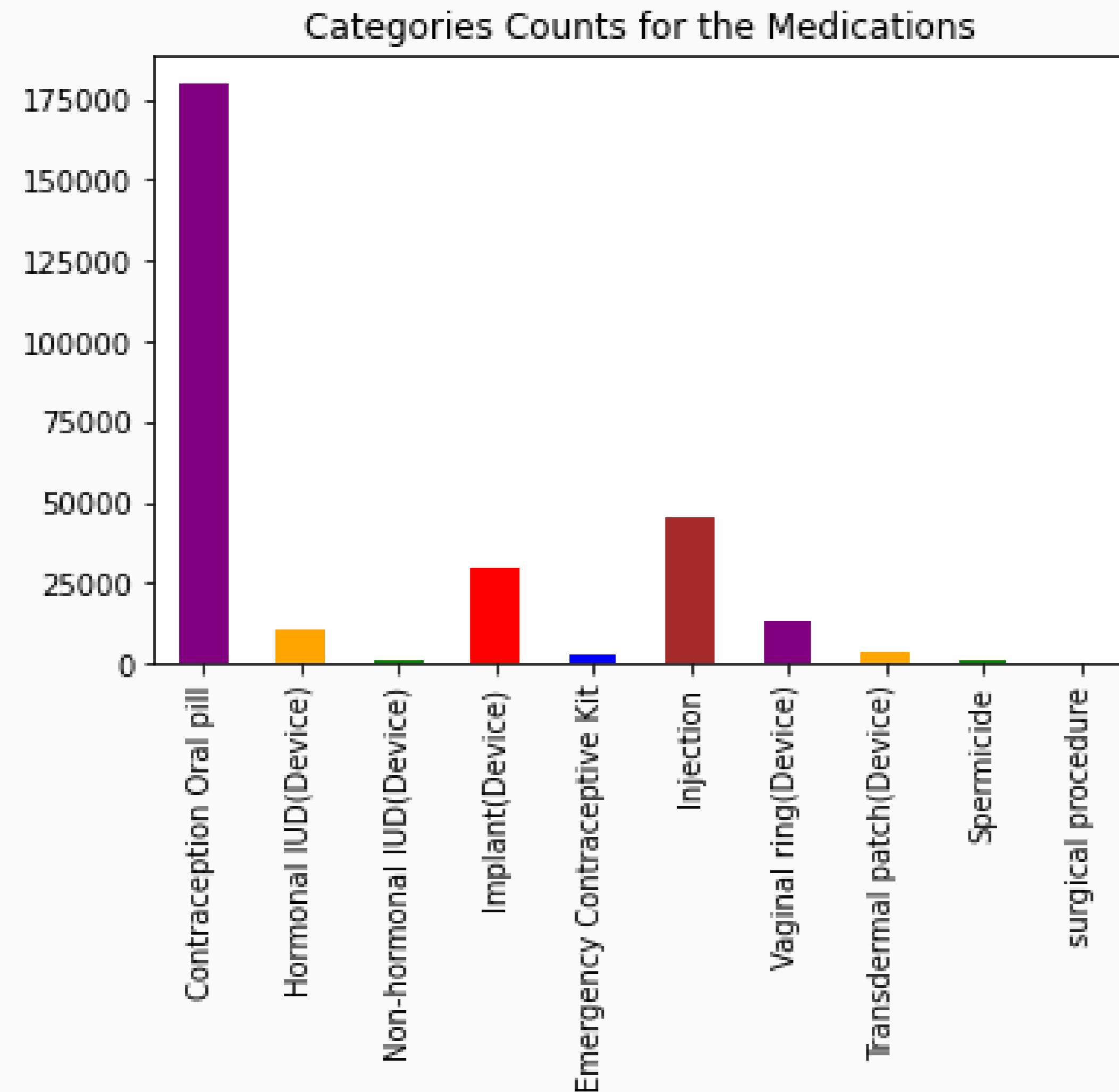


Background

- In the United States, over 88% of individuals with a uterus aged 15-44 have been prescribed birth control methods at some point in their reproductive life (Britton et al., 2020).
- However, determining the most suitable method for an individual can be challenging.
- Because there is a wide range of available options and many personal considerations, up to 45% of individuals end up switching or discontinuing their contraception within 12 months (Simmons et al., 2019).
- Previous studies have been able to map variations in medication administration and treatment decisions in conditions like Type 2 Diabetes and substance abuse disorder (Peterson et al., 2021; Fujita et al., 2023).

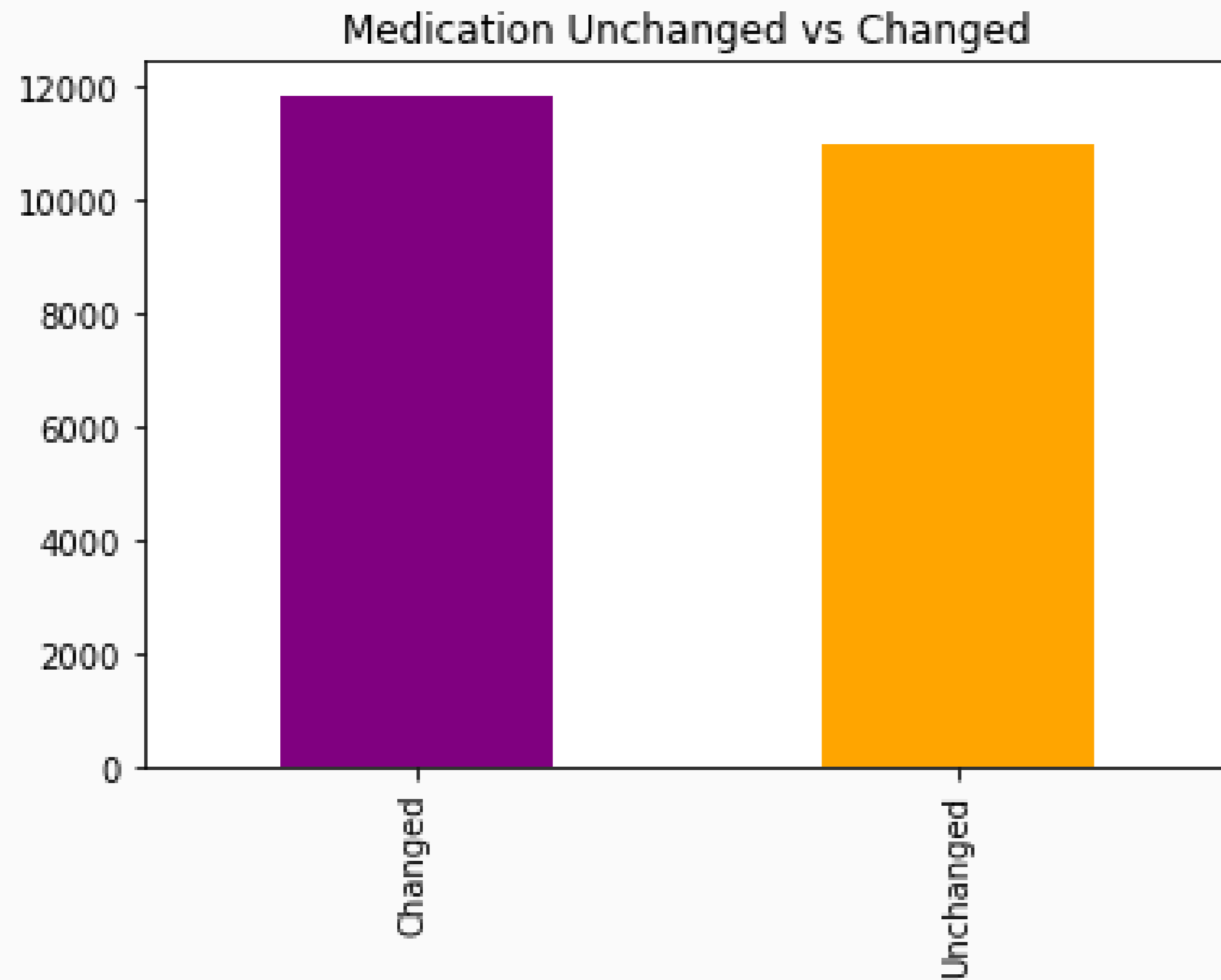
No currently published work has mapped the contraception decisions of an individual over time.

Description of Prescribed Contraceptives and Procedures



	category	count	%
0	Contraception Oral pill	180000	62.684353
1	Injection	45447	15.826754
2	Implant(Device)	29650	10.325506
3	Vaginal ring(Device)	13463	4.688441
4	Hormonal IUD(Device)	10838	3.774295
5	Transdermal patch(Device)	3475	1.210156
6	Emergency Contraceptive Kit	2419	0.842408
7	Spermicide	1046	0.364266
8	Non-hormonal IUD(Device)	628	0.218699
9	surgical procedure	187	0.065122

Changes in Prescriptions



Type	Begin	End	Change in %
Contraception Oral Pills	12627	11217	-11.17%
Injection	3637	3062	-15.81%
Implant	2571	3388	31.78%
Hormonal IUD	2018	3094	53.32%
Vaginal Ring	792	807	1.89%
Emergency Contraceptive Kit	361	276	-23.55%
Transdermal patch	291	399	37.11%
Non-hormonal IUD	208	336	61.54%
Surgical Procedure	155	155	0.00%
Spermicide	99	25	-74.75%

Identifying pregnancy episodes in *All of Us*



Identifying Pregnancy Episodes in *All of Us*

We wanted to enhance research in reproductive health by identifying and validating pregnancy episodes using the *All of Us* dataset.

- Pregnancy episodes include medical diagnosis codes that indicate a pregnancy occurred in the electronic health record (EHR).
- Challenges of this research include the sparsity of EHR data and variability in how pregnancy-related information is documented.
- Accurate and uniform identification of pregnancy episodes is crucial for advancing research in reproductive health.

Goal: To replicate and extend previous research (Jones et. al, 2023)

- Previous algorithm development was conducted in different dataset, the National COVID Cohort Collaborative (N3C), that is structured similarly to *All of Us*.

Previous Research (Jones et al, 2023)

- Created HIPPS, a combination of the following algorithms:
 - **Hierarchy-based Inference of Pregnancy (HIP) Algorithm**
 - A rule-based algorithm that is an extension of a previously published pregnancy episode algorithm (Matcho et al, 2018)
 - **Pregnancy Progression Signature (PPS) Algorithm**
 - Uses temporal sequence analysis for detecting gestational age-specific signatures of a progressing pregnancy for further episode support
 - **Estimated Start Date (ESD) Algorithm**
 - Estimates pregnancy episode start dates and their precision level

Example of why this is important

25 pregnancy-related visits from 2016-2022

Visits by category:

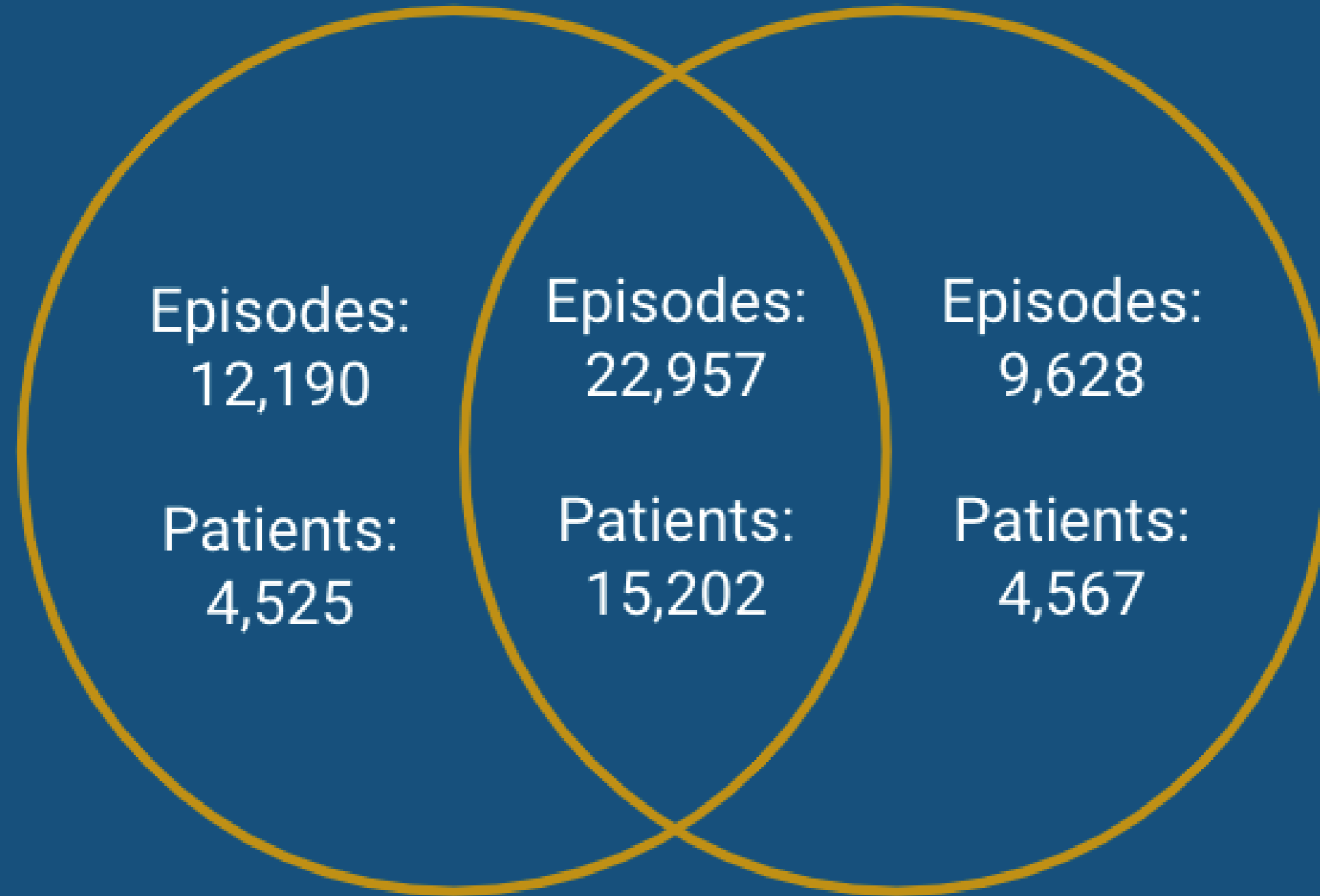
- 3 live birth visits - All distinct episodes
- 1 spontaneous abortion visit - Unrelated to LB episodes
- 21 gestation-related visits - 5 distinct episodes
 - 4 map gestational timing to previous episodes
 - 1 new episode
- End result: 5 distinct pregnancy episodes

GEST	OUTCOME
✓	LB
✓	LB
✓	LB
✓	SA
✓	?

Algorithm Overlap

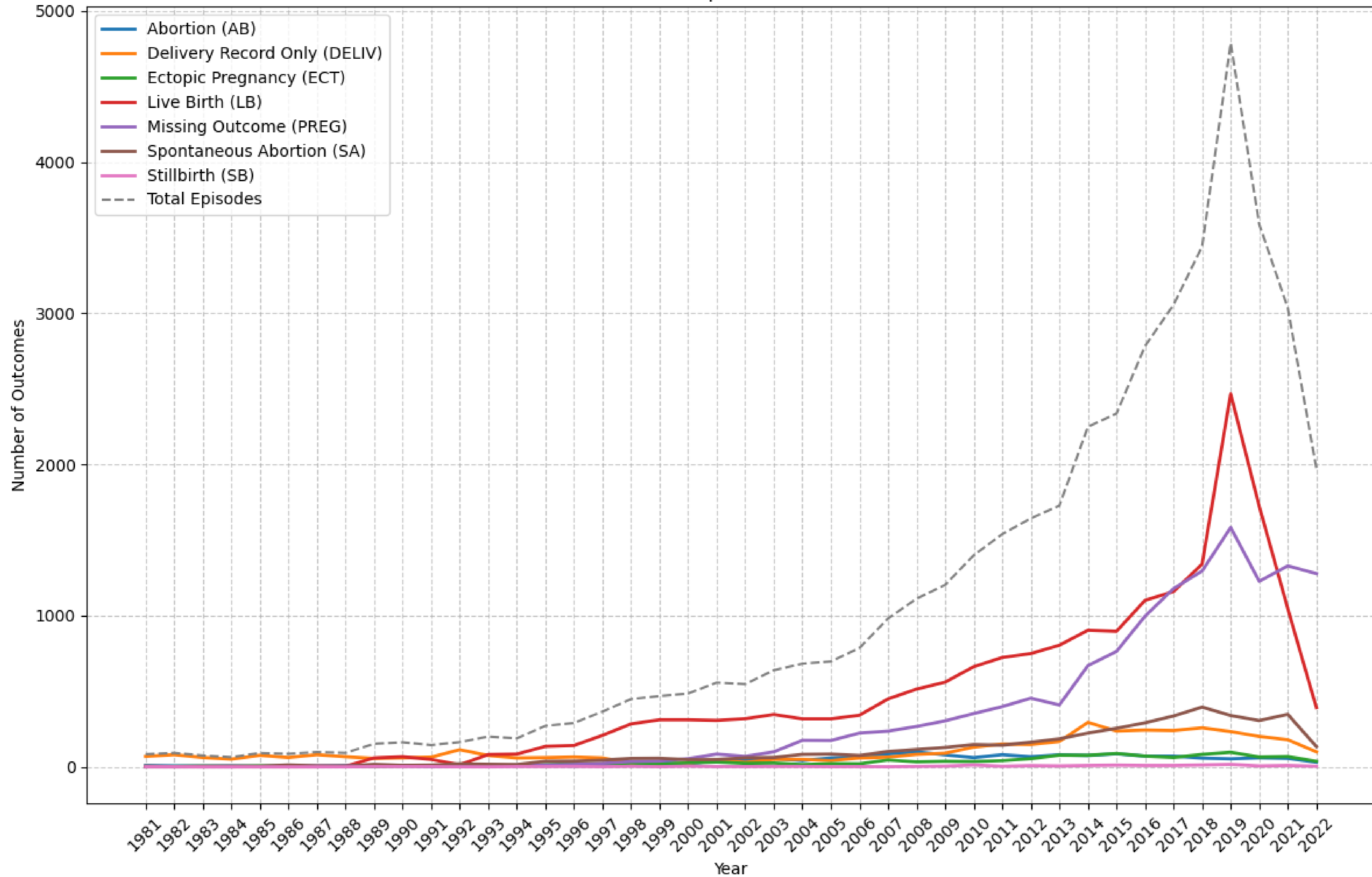
Totals: Episodes: 44,775 Patients: 24,294

HIP
Algorithm



PPS
Algorithm

Outcomes and Total Episodes Over Time (FINAL)



Experiences of discrimination and pregnancy outcomes



Along with the Social Determinants of Health Survey

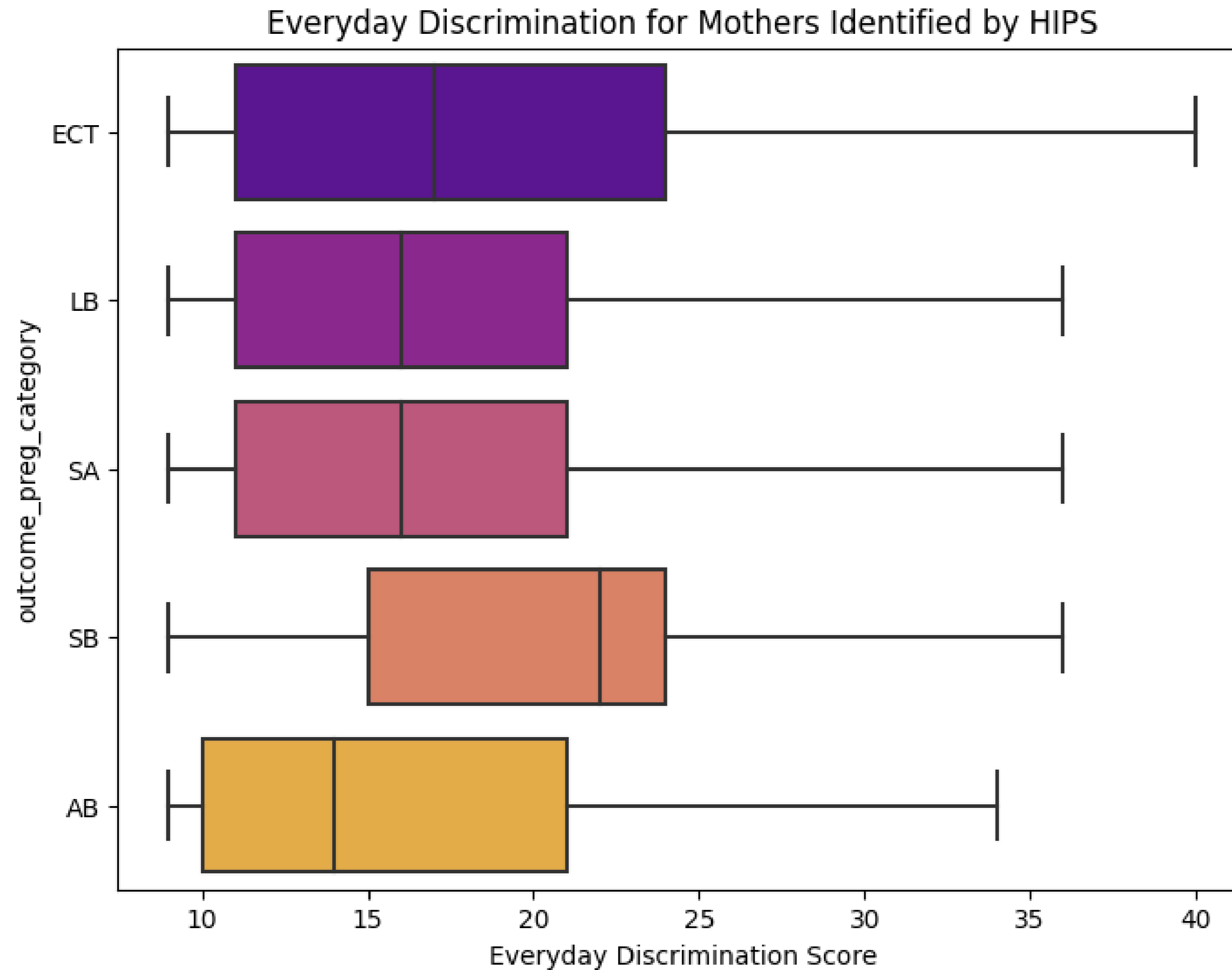
By connecting biological and social determinants of health data on a large, inclusive scale and following participants as they move, age, and grow, the *All of Us* dataset is driving new insights into health and disease.

Social Determinants of Health (SDOH) Survey data



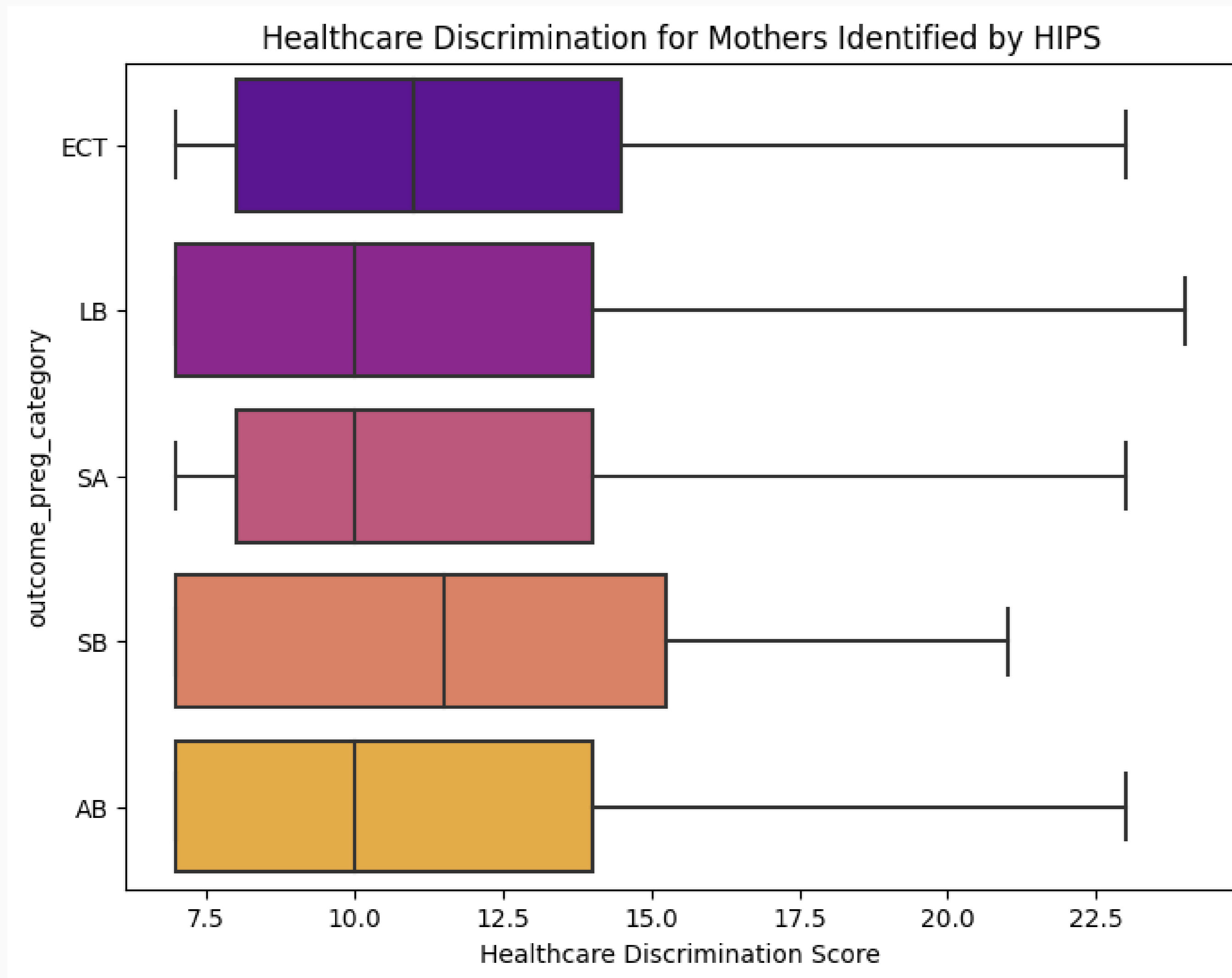
from 117,750+ responses

Experiences of Everyday Discrimination



ECT = Ectopic Pregnancy
LB = Live Birth
SA = Spontaneous Abortion
SB = Stillbirth
AB = Abortion

Experiences of Discrimination in Healthcare

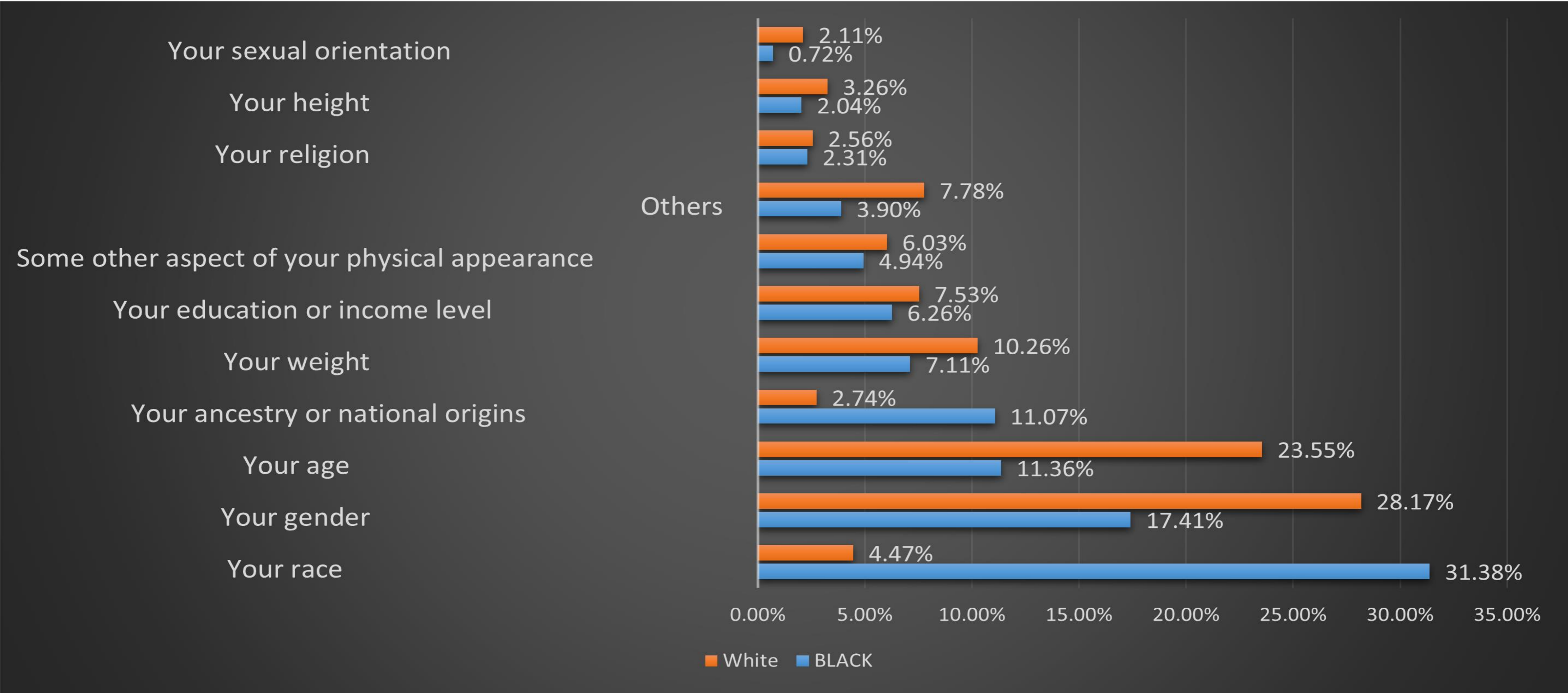


ECT = Ectopic Pregnancy
LB = Live Birth
SA = Spontaneous Abortion
SB = Stillbirth
AB = Abortion

Racial and ethnic disparity in social support and everyday discrimination among cisgender women

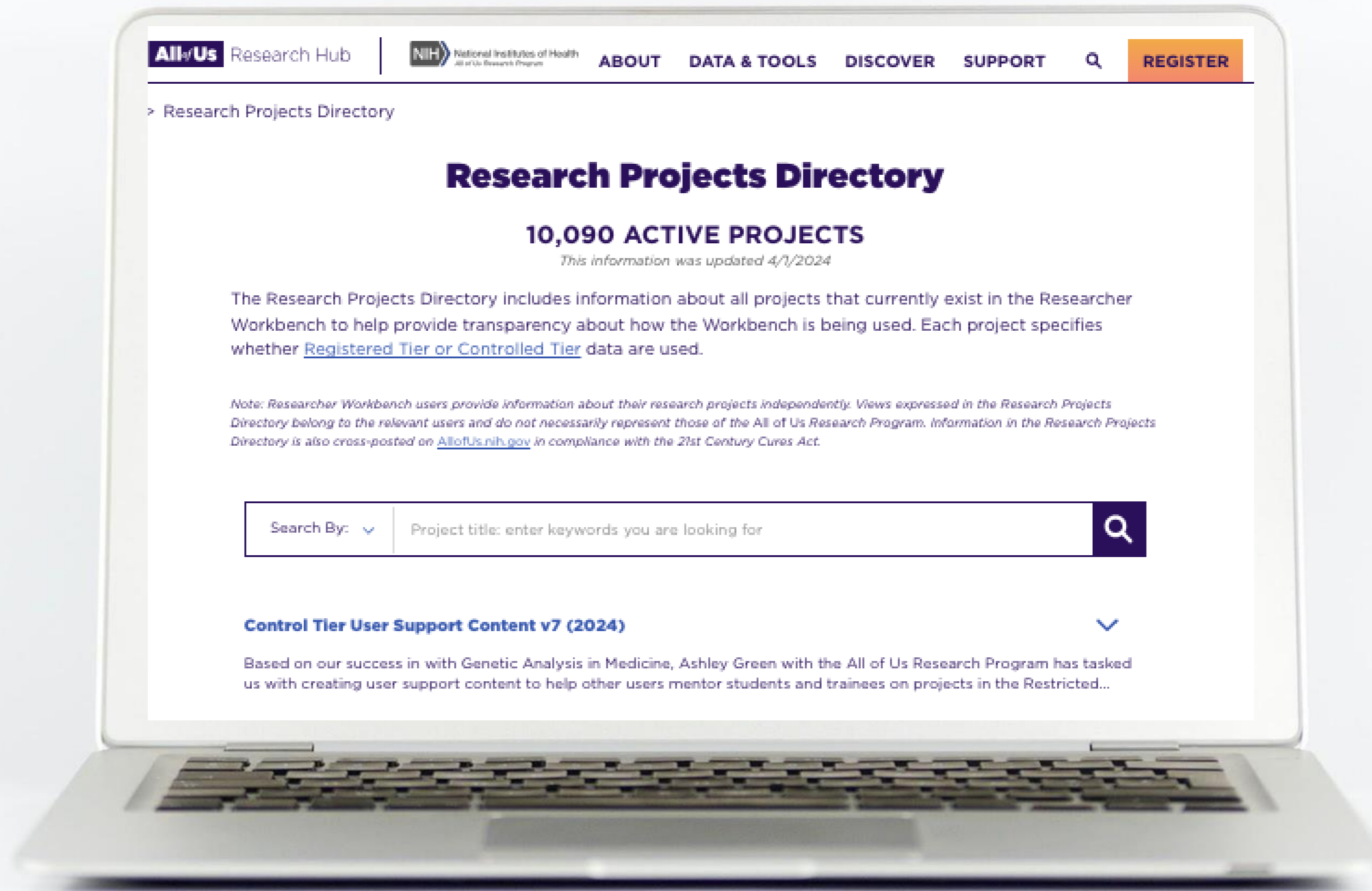


Main Reasons for Everyday Discrimination



Now is the time for advancing reproductive and sexual health using the *All of Us* Research Program dataset.

Explore how other researchers are using the data



researchallofus.org/research-projects-directory

And stay in touch to learn more

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

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 November 2023)



All of Us consortium members *(beyond community partners, as of November 2023)*

The Participant Center



Communications & Engagement



HPO Network

(Health Care Provider Organizations)

All of Us New England

Mass General Brigham



All of Us California

UC San Diego Health

UCI Health

UC DAVIS HEALTH



Cedars Sinai

USC University of Southern California

Yale *12-month supplement

Illinois Precision Medicine Consortium



Northwestern Medicine

NorthShore University HealthSystem

RUSH

THE UNIVERSITY OF ILLINOIS COLLEGE OF MEDICINE

UI Health

Trans America Consortium

HENRY FORD HEALTH Corewell Health

Essentia Health

Baylor Scott & White HEALTH SAINT LOUIS UNIVERSITY

UMass Chan MEDICAL SCHOOL RELIANT MEDICAL GROUP

HealthPartners Institute

New York City Consortium

COLUMBIA

Well Cornell Medicine

NYC HEALTH + HOSPITALS Harlem

NewYork-Presbyterian

All of Us Southern Network

UAB MEDICINE

UAB HEERSINK The University of Alabama at Birmingham

Cooper Green-McCook HEALTH SERVICES UNIVERSITY

THE UNIVERSITY OF TEXAS MEDICAL CENTER

Tulane University

USA HEALTH

University of Alabama at Birmingham

TUSKEGEE UNIVERSITY

LSU Health NEW ORLEANS

All of Us Southeast Enrollment Center

UHealth UNIVERSITY OF ALABAMA MILLER SCHOOL OF MEDICINE

EMORY UNIVERSITY

MOREHOUSE SCHOOL OF MEDICINE

UF UNIVERSITY OF FLORIDA

All of Us Wisconsin

Marshfield Clinic Health System

WISCONSIN

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 HEALTH SERVICES

FQHCs (Federally Qualified Health Centers)

Cherokee HEALTH SERVICES

SAN YSIDRO HEALTH

WAILANAI COAST COMMUNITY HEALTH CENTER

Community Health Center, Inc.

Sun River Health

VA Medical Centers

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

Participant Technology Systems Center (PTSC)

vibrent

Biobank



Data & Research Center (DRC)

VANDERBILT UNIVERSITY MEDICAL CENTER

BROAD INSTITUTE

Duke UNIVERSITY verily

COLUMBIA

Northwestern Medicine

THE OHIO STATE UNIVERSITY WEXNER MEDICAL CENTER

Yale

Genomics Partners

Baylor College of Medicine DEPARTMENT OF MEDICAL GENETICS

JOHNS HOPKINS MEDICINE

UTHealth The University of Texas Health Science Center at Houston

HUDSONALPHA INSTITUTE FOR AUTISM RESEARCH

BROAD INSTITUTE

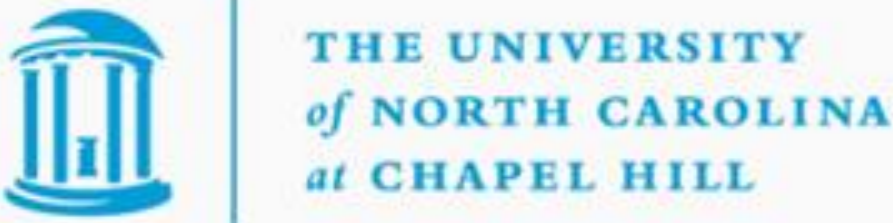
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Mass General Brigham

UNIVERSITY OF WASHINGTON

All of Us consortium members (Continued) *(beyond community partners, as of November 2023)*

Nutrition for Precision Health (NPH)



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