All of Us Research Hub

Presented to the Southern *All of Us* Network
November 4, 2020

Presented by Kelsey Mayo, PhD
Mgr, Scientific Product
kelsey.mayo@vumc.org

All of Us
DATA & RESEARCH CENTER

What is the NIH *All of Us* Research Program?

All of Us RESEARCH PROGRAM | The Future of Health Begins With You

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

"*All of Us* is among the most ambitious research efforts that our nation has undertaken!"

NIH Director Francis Collins, M.D., Ph.D.

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

Thank you to our participants and our consortium partners!

The Participant Center

America's Blood Centers; The Behavioural Insights Team; careevolution Healthcare Technology; DXC.technology; Medscape; Montage Marketing; 4waves; patientslikeme; QTC (A Leidos Company); Quest Diagnostics; Sage Bionetworks; Scripps Research Translational Institute; Sync for Science; Urban One; Walgreens; WebMD; BlueCross BlueShield; fitbit; National Blood Collaborative; PicnicHealth; San Diego Blood Bank Foundation; SENSIS

Communications & Engagement

WONDROS; The University of Utah; PYXIS Growth Partners

HPO Network (Health Care Provider Organizations)

RMCs

All of Us California: UC San Diego Health; UCI Health; UCSF; UC Davis Health; Cedars-Sinai; USC University of Southern California

Illinois Precision Medicine Consortium: Northwestern Medicine; The University of Chicago; NorthShore University HealthSystem; Rush; Cook County Health; The University of Illinois College of Medicine; UI Health

All of Us New England: Brigham Health (Brigham and Women's Hospital); Massachusetts General Hospital; Partners HealthCare; Boston Medical Center

Trans America Consortium: Henry Ford Health System; Essentia Health; BaylorScott&White Health; Spectrum Health; Reliant Medical Group (Part of OptumCare); HealthPartners

New York City Consortium: Columbia University Medical Center; NYC Health+ Hospitals; NewYork-Presbyterian; Weill Cornell Medicine

All of Us Southern Network: UAB School of Medicine (The University of Alabama at Birmingham); UAB School of Medicine (The University of Alabama at Birmingham, Selma Family Medicine); UAB School of Medicine (The University of Alabama at Birmingham, Montgomery Regional Medical Campus); The University of Mississippi Medical Center; UAB Medicine; Tulane University; LSU Health New Orleans; The University of Alabama; University Medical Center; UAB School of Medicine (The University of Alabama at Birmingham, Huntsville Regional Medical Campus); Cooper Green Mercy Health Services; USA Health; Huntsville Hospital

All of Us SouthEast Enrollment Center: University of Miami Miller School of Medicine; Emory University; Morehouse School of Medicine; University of Florida; Grady

All of Us Wisconsin: Marshfield Clinic Health System; Gundersen Health System; University of Wisconsin; Froedtert & Medical College of Wisconsin

All of Us Pennsylvania: University of Pittsburgh; Temple University

University of Arizona and Banner Health: The University of Arizona; Banner Health

FQHCs (Federally Qualified Health Centers): Cherokee Health Systems; Jackson-Hinds Comprehensive Health Center; San Ysidro Health; Community Health Center, Inc.; Cooperative Health; HRHCare Community Health

VA Medical Centers: VA; U.S. Department of Veterans Affairs

Participant Technology Systems Center (PTSC)

vibrent

All of Us Research Program

Biobank

Mayo Clinic

Data & Research Center (DRC)

Vanderbilt University Medical Center; Broad Institute; verily; Columbia University Medical Center; University of Michigan School of Public Health; Northwestern Medicine; UTHealth (The University of Texas Health Science Center at Houston)

Genomics Partners

Baylor College of Medicine; Johns Hopkins Medicine; UTHealth (The University of Texas Health Science Center at Houston); HudsonAlpha Institute for Biotechnology; Broad Institute; color; Partners HealthCare; University of Washington

Thank you Data and Research Center (DRC) and NIH teams!

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BROAD INSTITUTE

COLUMBIA UNIVERSITY MEDICAL CENTER

verily

NIH National Institutes of Health
All of Us Research Program

VANDERBILT UNIVERSITY MEDICAL CENTER

All of Us
DATA & RESEARCH CENTER

All of Us Research Program Objectives

Nurture relationships

with **one million or more** participant partners, from all walks of life, for decades

Our mission

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

Deliver the largest, richest biomedical dataset

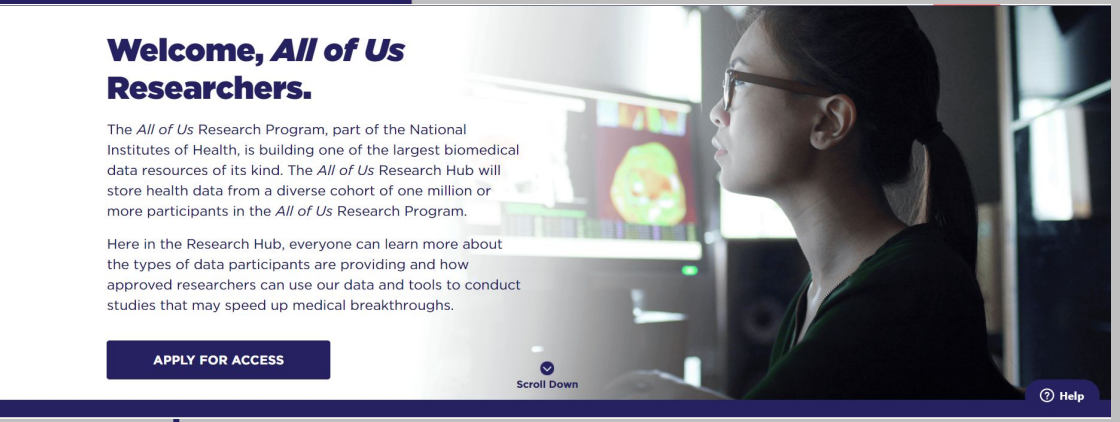
that is easy, safe, and free to access

Catalyze a robust ecosystem

of researchers and funders hungry to use and support it

All of Us DATA & RESEARCH CENTER

All of Us Research Hub

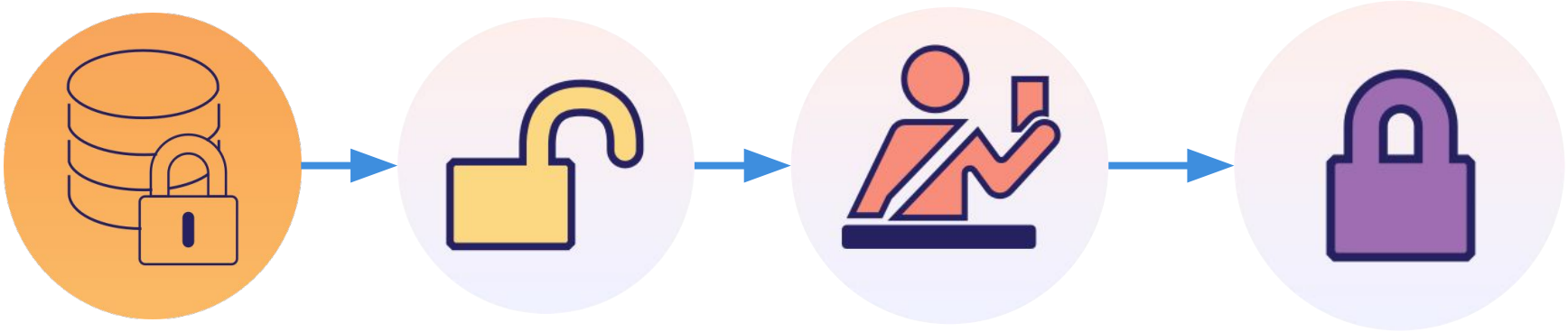


All of Us RESEARCHER WORKBENCH

Launched Beta in May 2020!

Outline for Today

1. **Data Overview**



2. **Live demo of researchallofus.org & Researcher Workbench**

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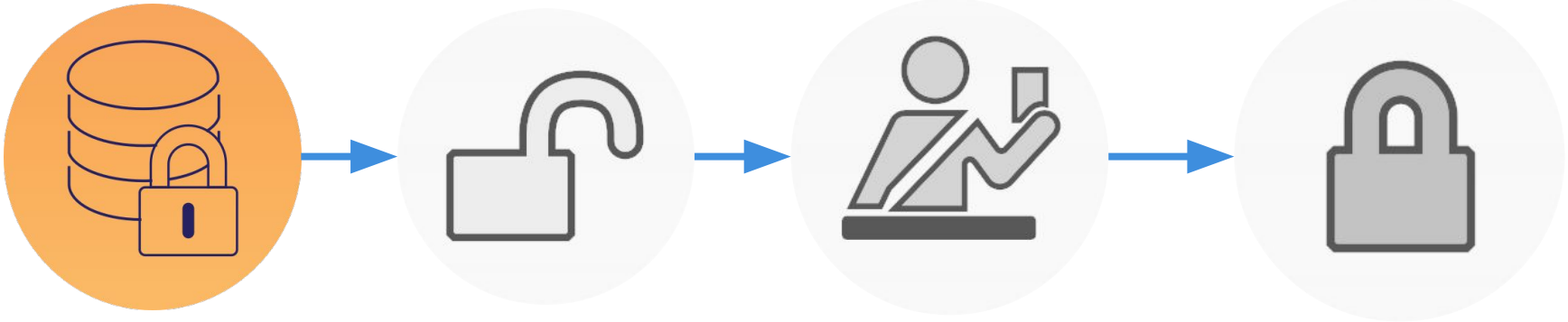

2. Live demo of researchallofus.org & Researcher Workbench

All of Us DATA & RESEARCH CENTER

Our Data are Growing. Here are the Current Data Types

Enroll, Consent and Authorize EHR

- Recruiting 18+ years old initially; plan to include children in future
- Online, interactive consent
- Includes authorization to share Electronic Health Record (EHR) data

Answering Surveys

- Initial surveys: The Basics, Overall Health, Lifestyle, Health Care Access & Utilization, Family Medical History, Personal Health History
- Additional surveys will be released on an ongoing basis.

Physical Measurements*

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

Provide Biosamples*

- Blood (or saliva, if blood draw is unsuccessful)
- Urine specimen
- Biosamples will be stored at the program's biobank

Wearables and Digital Apps

- Share data from wearable fitness devices, starting with Fitbit
- More integrations to come. E.g., integrated apps to track mood & cardio-respiratory fitness

Available in the Current Dataset

*Based on diverse sampling and capacity

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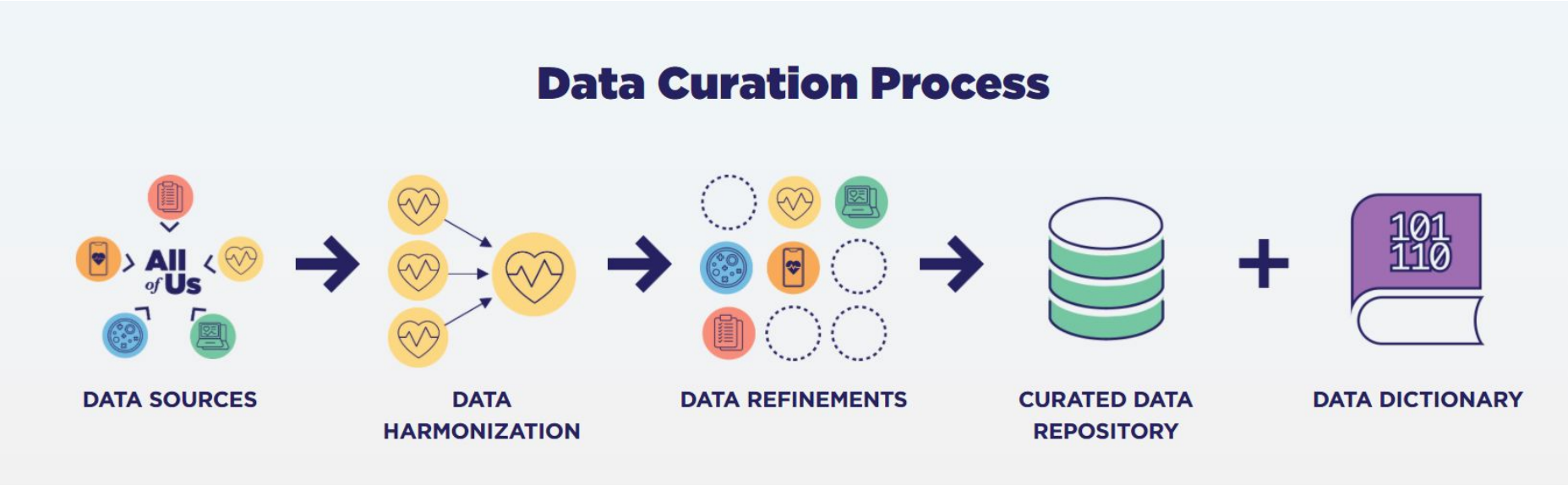
Data are harmonized and standardized to a common data model



We use the OHDSI collaborative's OMOP Common Data Model (more info here)

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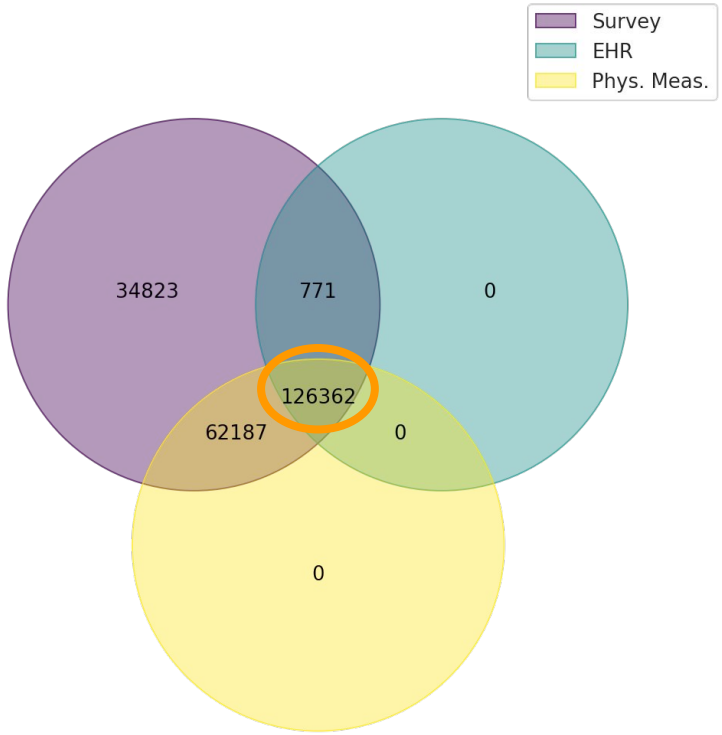
Research Data Available Now

Data Type	Participant Count
Survey	>224,000
Physical Measurement	>188,000
Electronic Health Record	>127,000

*Counts reflect unique participants with ANY of data of the specified type.

Count of participants with multiple data types



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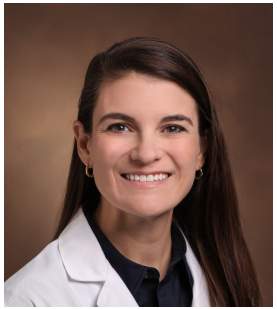
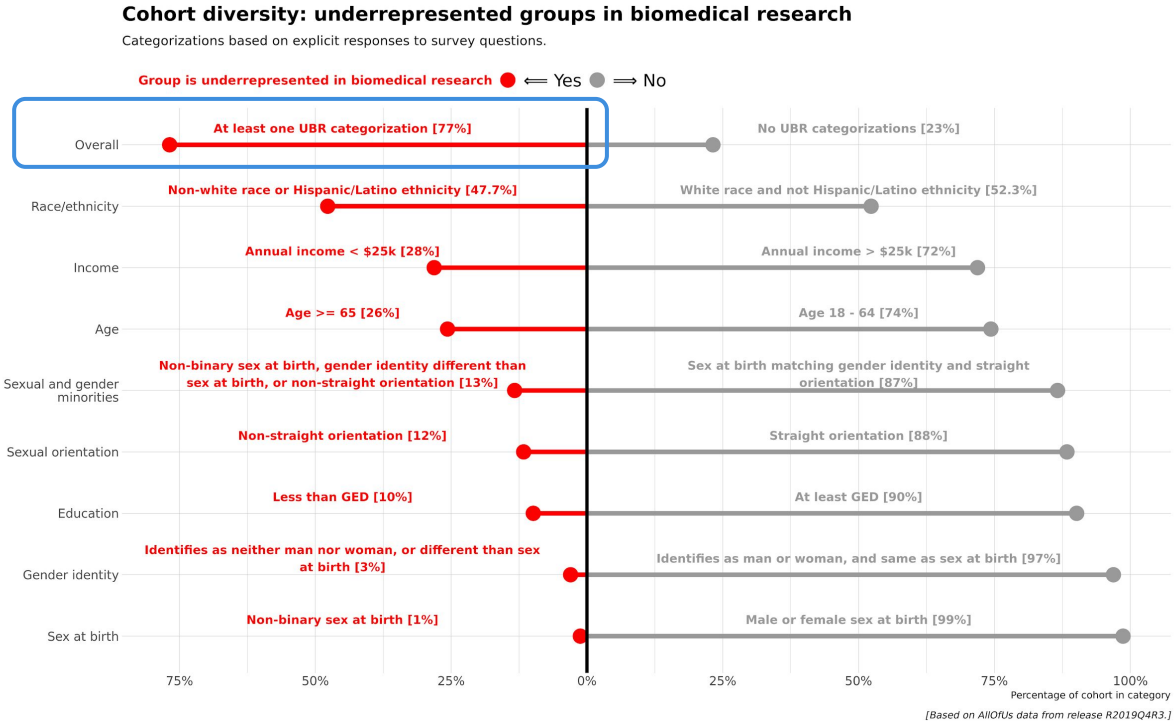
Participants included in this dataset are diverse.

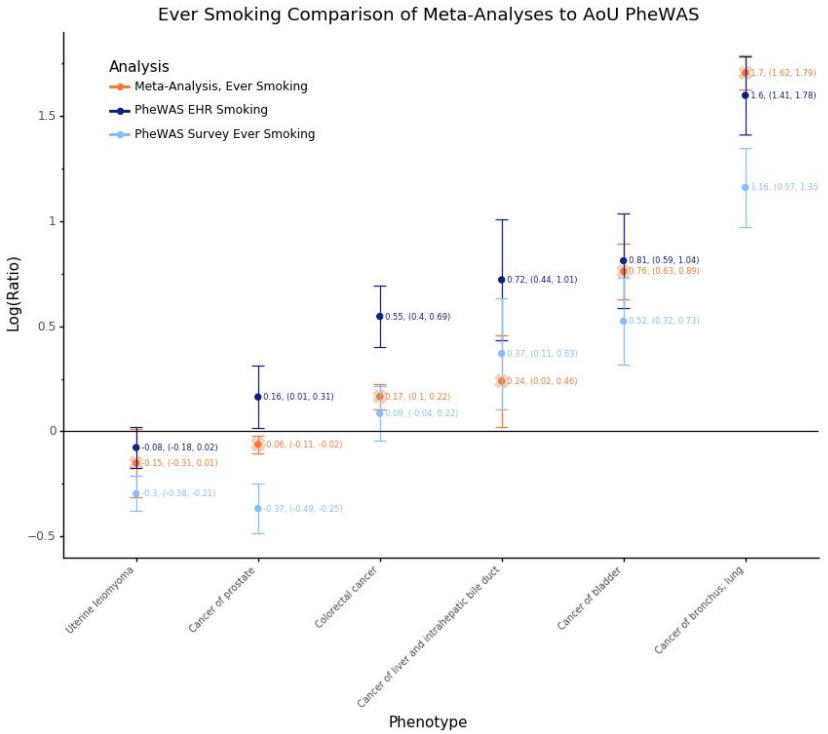




A. Ramirez, L. Suleiman, D. Schlueter, et al., *The All of Us Research Program: data quality, utility, and diversity*, medRxiv 2020.05.29.20116905; doi: https://doi.org/10.1101/2020.05.29.20116905

This dataset reproduces known associations.

Description	EHR Ever Smoking OR (95% CI)	Survey Ever Smoking OR (95% CI)
Top 3 Increased risk effects		
Cancer of the bronchus; lung	4.94 (4.11, 5.95)	3.19 (2.65, 3.84)
Cancer within the respiratory system	4.94 (4.12, 5.92)	3.15 (2.62, 3.78)
Malignant neoplasm of bladder	2.36 (1.87, 2.98)	1.76 (1.42, 2.18)
Top 3 Decreased risk effects		
Vascular hamartomas and non-neoplastic nevi	0.51 (0.42, 0.62)	0.55 (0.48, 0.64)
Nevus, non-neoplastic	0.52 (0.43, 0.64)	0.57 (0.49, 0.66)
Benign neoplasm of skin	0.53 (0.49, 0.58)	0.62 (0.58, 0.66)



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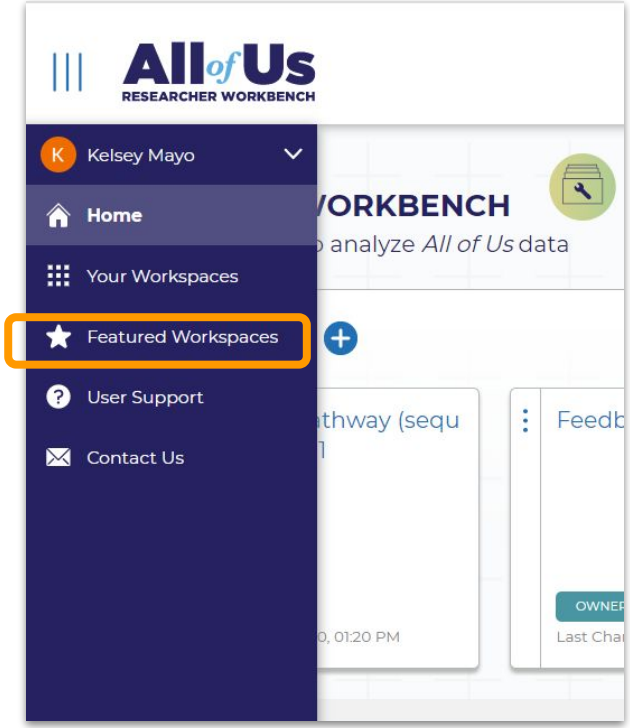
Want to learn more?



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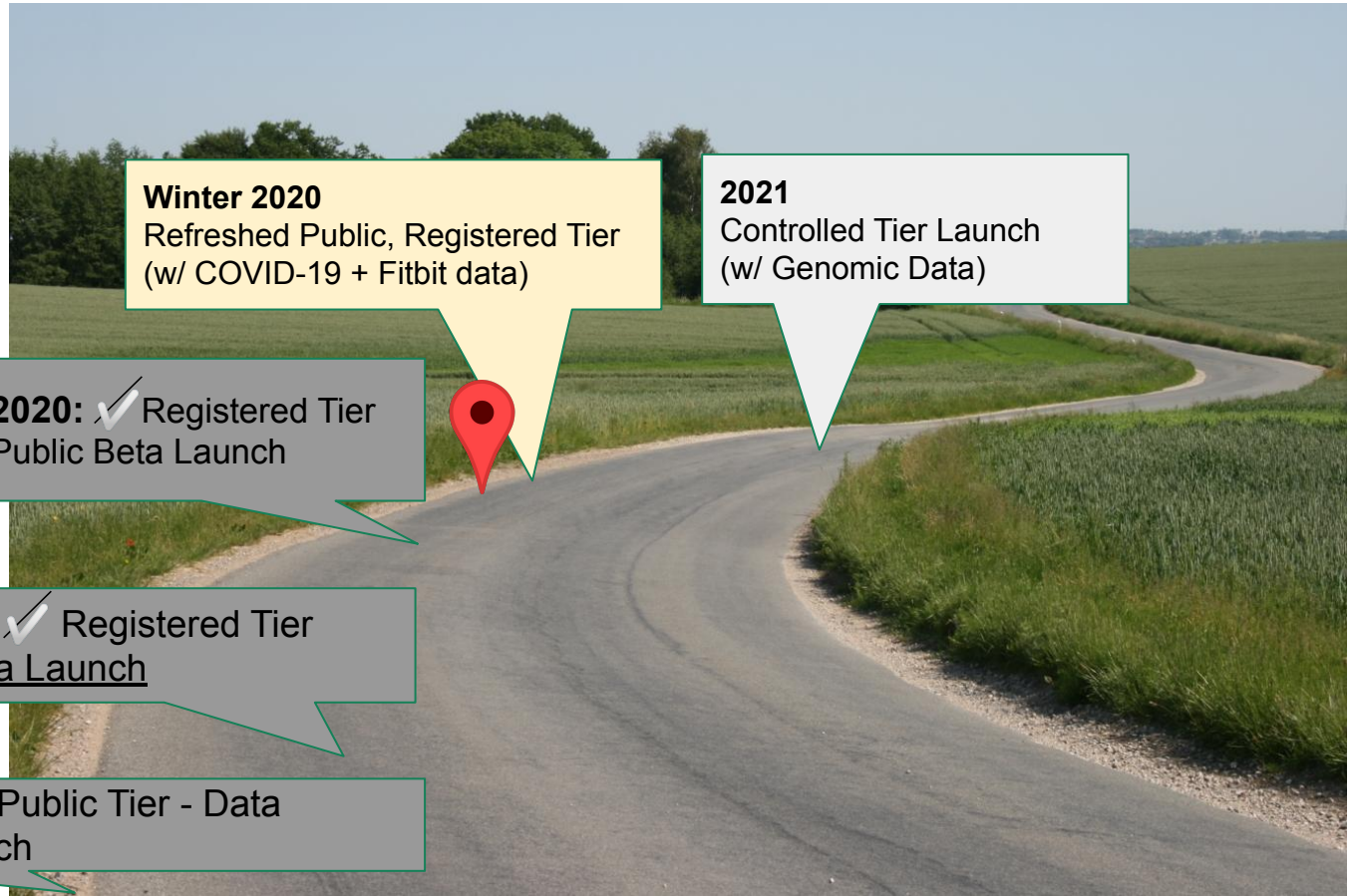
Coming Soon...



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Research Data Available Soon (Winter 2020)

Data Type	Participant Count*	
Survey	>315,000	~40% increase
COPE Survey	>63,000	New!
Physical Measurement	>260,000	~38% increase
Electronic Health Record	>204,000	~60% increase!
FitBit	<8,000	New!

*Counts reflect unique participants with ANY of data of the specified
Counts are approximate and subject to change upon final release of the dataset.

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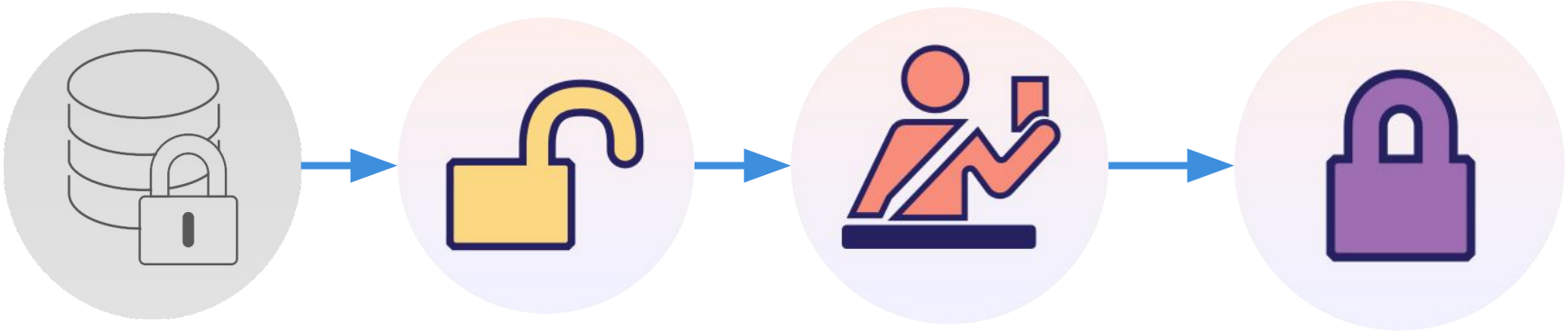
Outline for Today

1. Data Overview



2. Live demo of researchallofus.org & Researcher Workbench

All of Us DATA & RESEARCH CENTER

Research Hub

- Data Browser
- Apply Page

Researcher Workbench

- Support Hub
- Ex. Workspace

RESEARCHER LOGIN

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

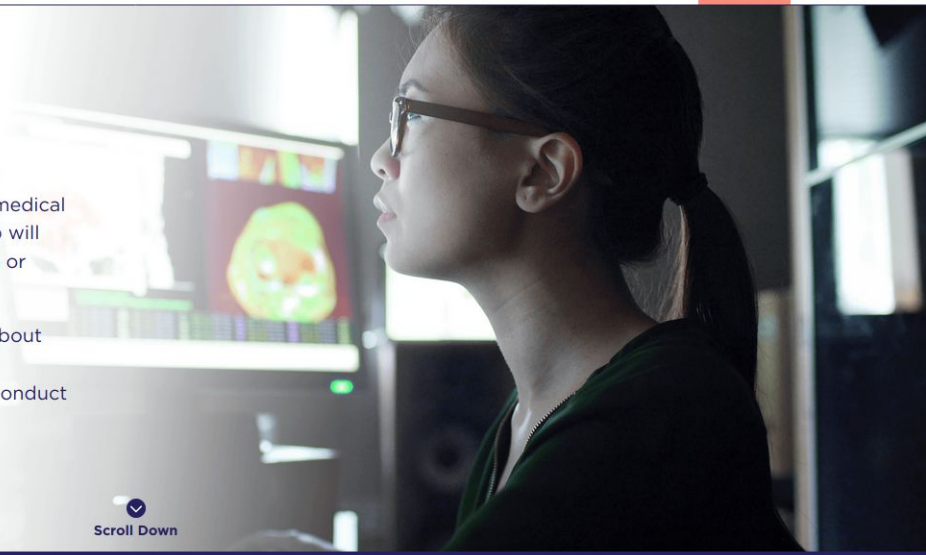
ABOUT DATA TOOLS DISCOVER FAQ APPLY

Welcome, *All of Us* Researchers.

The *All of Us* Research Program, part of the National Institutes of Health, is building one of the largest biomedical data resources of its kind. The *All of Us* Research Hub will store health data from a diverse cohort of one million or more participants in the *All of Us* Research Program.

Here in the Research Hub, everyone can learn more about the types of data participants are providing and how approved researchers can use our data and tools to conduct studies that may speed up medical breakthroughs.

APPLY FOR ACCESS



Scroll Down

Data Snapshots

Our Data Snapshots are the fastest way to view the diversity of the *All of Us* Research Program participant data. These snapshots provide visualizations of participant demographics, geographic distribution, and more.

Research Hub

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Search Across Data Types

Keyword Search

Data includes 225,140 participants and is current as of 2/11/2020.

FAQs

Introductory Videos

User Guide

EHR Domains:

Conditions
20,776
medical concepts
113,200 participants in this domain
View Top Conditions

Drug Exposures
20,951
medical concepts
104,500 participants in this domain
View Top Drug Exposures

Labs & Measurements
10,049
medical concepts
109,100 participants in this domain
View Top Labs & Measurements

Procedures
20,546
medical concepts
102,140 participants in this domain
View Top Procedures

Survey Questions:

The Basics
16
questions available
225,140 participants in this domain
This survey includes participant demographic information.
View Complete Survey

Overall Health
21
questions available
219,800 participants in this domain
Survey includes information about how participants report levels of individual health.
View Complete Survey

Lifestyle
26
questions available
218,500 participants in this domain
Survey includes information on participant smoking, alcohol, and recreational drug use.
View Complete Survey

Personal Medical History
465
questions available
39,320 participants in this domain
This survey includes information about past medical history, including medical conditions and approximate age of diagnosis.
View Complete Survey

Health Care Access & Utilization
57
questions available
45,820 participants in this domain
Survey includes information about a participant's access to and use of health

Family Medical History
1
questions available
41,600 participants in this domain
Survey includes information about the medical history of a participant's

Research Hub

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Apply to be an *All of Us* Researcher

The Researcher Workbench is open to researchers whose institutions have signed a Data Use and Registration Agreement with the *All of Us* Research Program. Researchers at this time must also have an eRA Commons account and complete the *All of Us* Research Program data access process before they can access the Researcher Workbench and Registered Tier data. For more information, please visit the Data Use Policies page. If you are a researcher who does not have an eRA Commons account, please work with your institution to create one. Once your account is established, you may apply for access to the Researcher Workbench. For more information, visit the eRA Commons website.

About the Beta Researcher Workbench

Currently, an institutional agreement & eRA Commons account must be in place.

Feedback is welcome.

The tools will continue to evolve.

The program cohort is actively growing, and so is our data.

The goal is to be a true game changer for understanding health.

How the Application Process Works

STEP 1

K FOR YOUR INSTITUTION'S AGREEMENT

STEP 2

REGISTER AS A RESEARCHER

STEP 3

CONNECT eRA COMMONS

Research Hub

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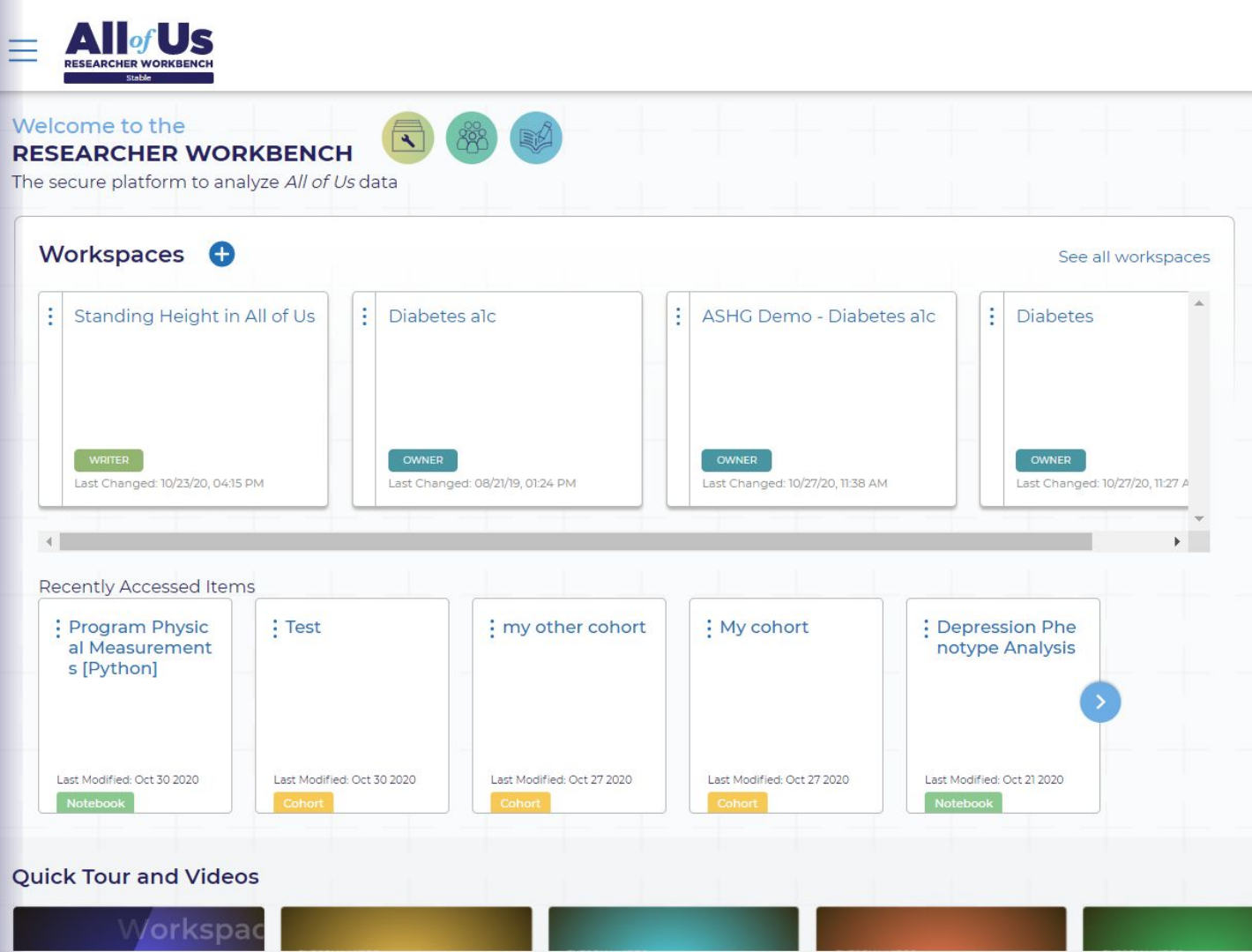
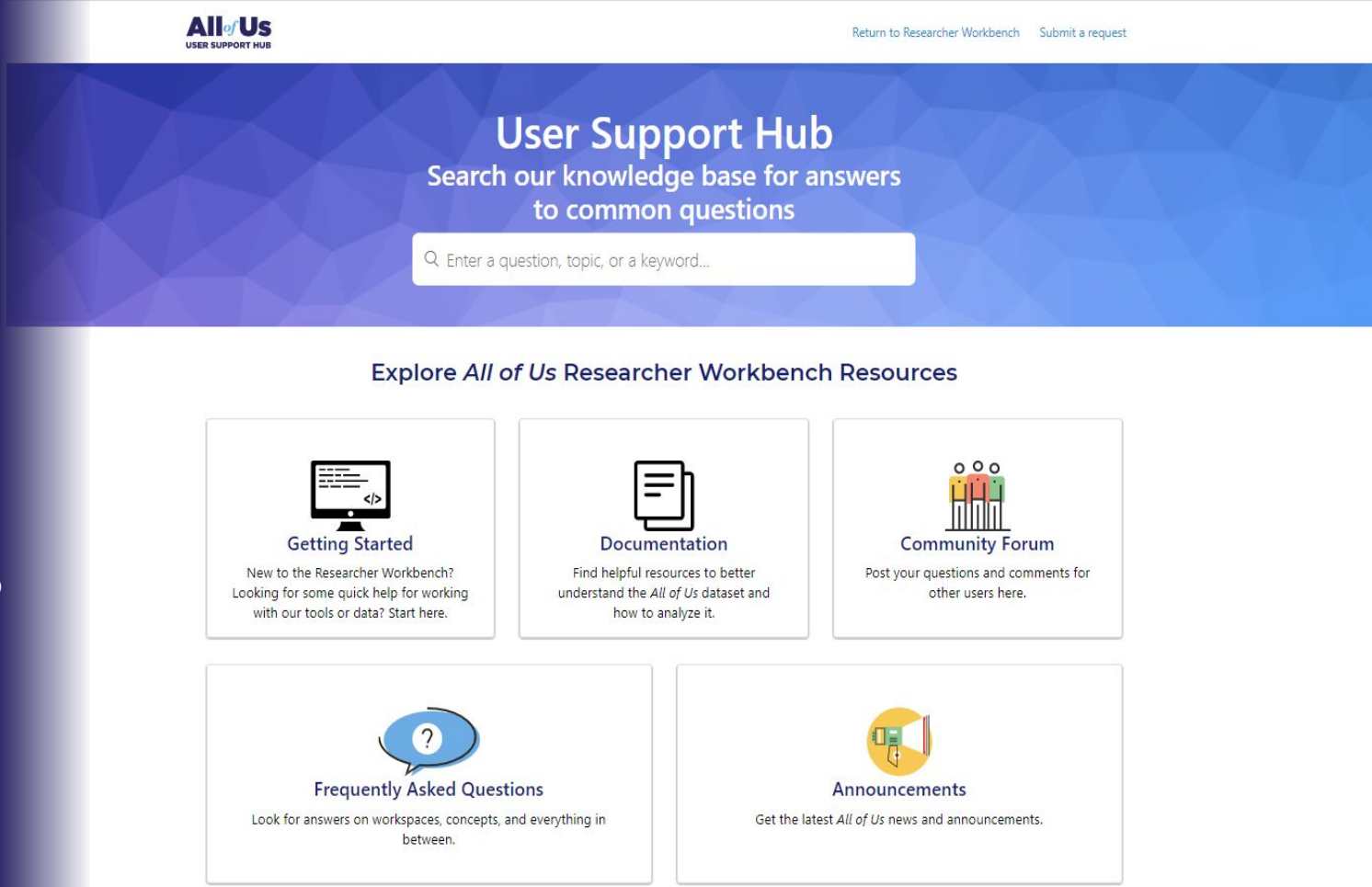
Ex. Workspace



- Research Hub
  - Data Browser
  - Apply Page
- Researcher Workbench
  - **User Support Hub**
  - Ex. Workspace



All of Us DATA & RESEARCH CENTER

- Research Hub
  - Data Browser
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  - Support Hub
  - **Ex. Workspace**

All of Us RESEARCHER WORKBENCH Stable

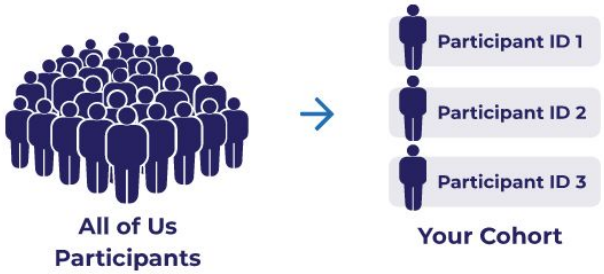
Workspaces >

Demonstrating All of Us Anthropomorphic Data Qualit

DATA | ANALYSIS | ABOUT

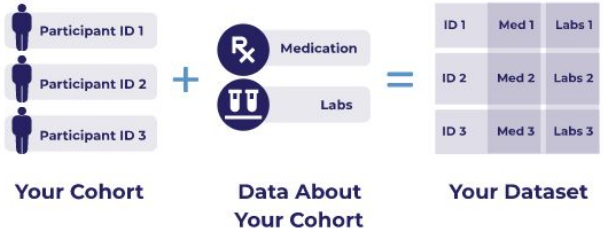
Cohorts

A cohort is a group of participants based on specific criteria.



Datasets

A dataset is a table containing data about a cohort that can be exported for analysis.



Show: Show All | Cohorts | Cohort Reviews | Concept Sets | Datasets

- Physical Measurements Concept Set 2
- Physical Measurements Concept Set 2
- Height
- PPI height

Live Demo on **Synthetic Data***

“Demonstrating *All of Us* Anthropomorphic Data Quality”

Primary Investigator

Kelsey Mayo, Ph.D.

Co-Investigator

Adrienne Roman, Ph.D.

Data Scientist

Francis Ratsimbazafy, Ph.D.

Graduate Student

Michael Holmes, B.S.

All of Us DATA & RESEARCH CENTER

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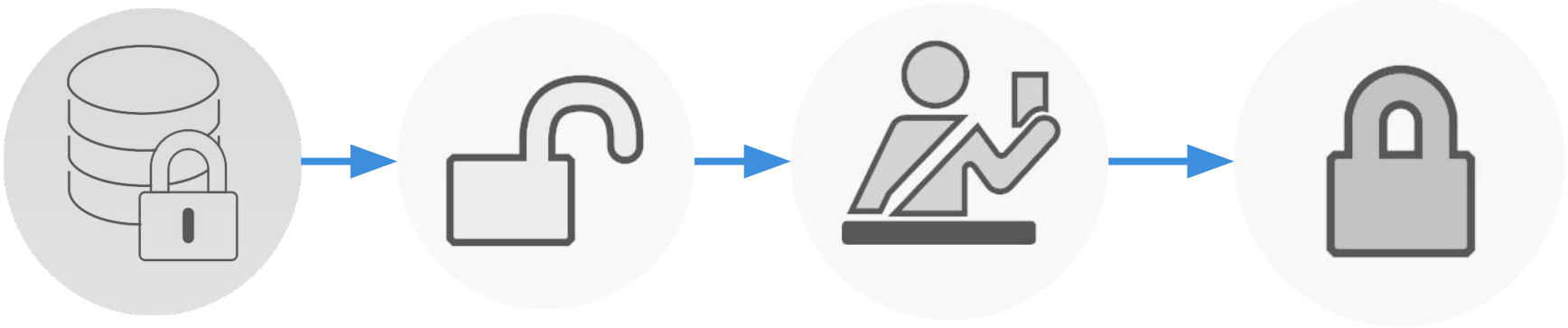

2. Live demo of researchallofus.org & Researcher Workbench

3. Thank you! & Wrap Up

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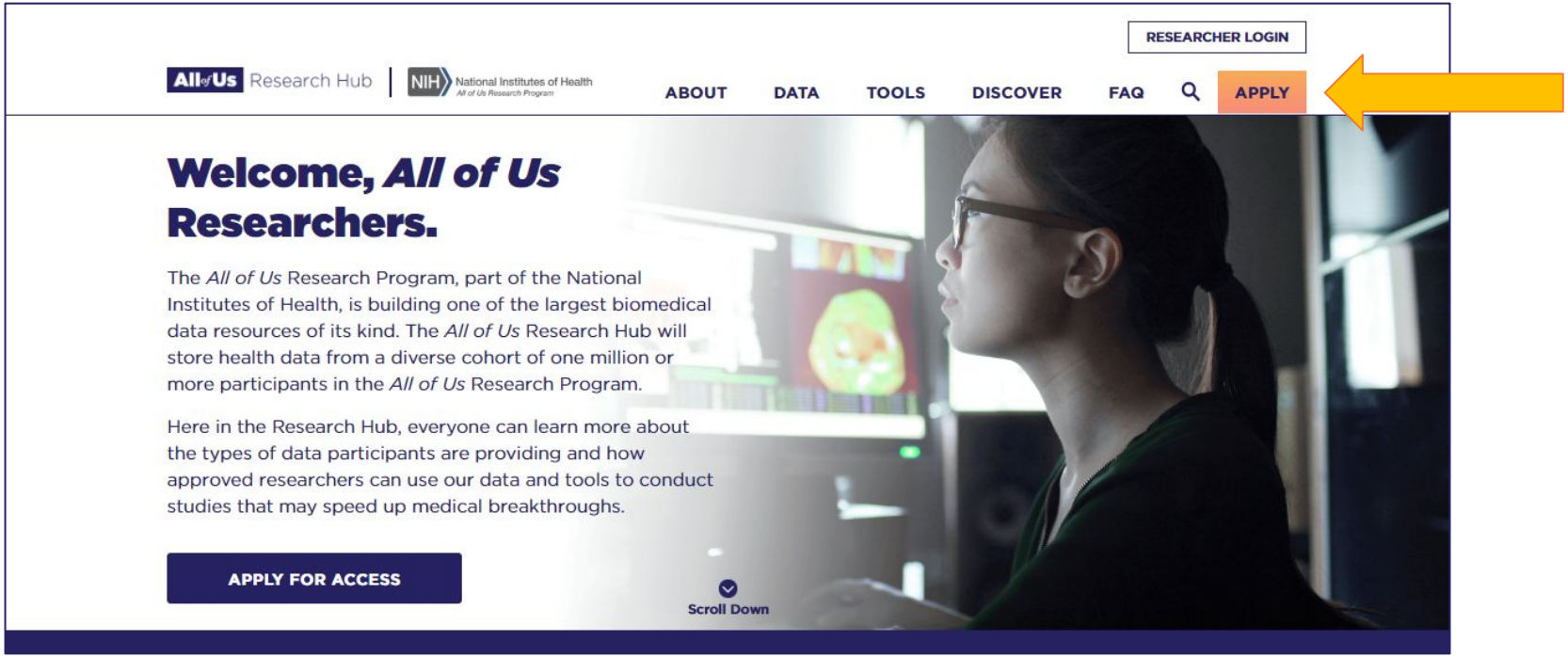
Interested in becoming a Beta Researcher?

Visit researchallofus.org to apply!



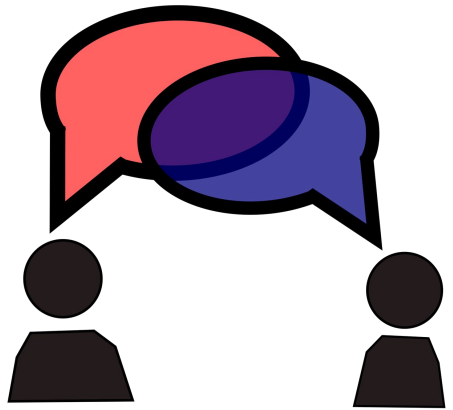
All of Us DATA & RESEARCH CENTER

Thank you for Listening!

Can you help us reach out to other early stage investigators, trainees, bioinformaticians, and data science researchers?

We'd love to connect with your community.
We are happy to arrange additional webinars and trainings.

Please email adrienne.s.roman@vumc.org



SAVE THE DATE!

All of Us Researcher Onramp

November 12 | 11 AM - 3 PM EST

Researchers interested in learning more about the *All of Us* Researcher Workbench are invited to tune into a virtual gathering on November 12th to:

- **Learn about the program's vision**
- **Experience a demonstration of the workbench**
- **Hear directly from users**
- **Learn how to register, access, and analyze data**

All of Us RESEARCHER WORKBENCH

https://allofus.nih.gov/news-events-and-media/announcements/all-us-researcher-onramp-event