

NLM *All of Us* Data Training and Engagement Program



Creating Interdisciplinary Interest in the *All of Us* Research Workbench Across Campus Communities

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Medical Library Association Conference



Our Team



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Agenda

- The *All of Us* Research Program
- Significance to the Academic Library
- Practical Engagement Panel Discussion
- Breakout Activity
- Engaging Campus Communities
- Toolkit Review
- Wrap Up



Today's Learning Objectives

1

Gain knowledge of the *All of Us* Research Program and Research Hub.

2

Understand how to employ the Research Hub and Research Workbench to grow research capacity including biomedical and public health data skills within your campus community.

3

Ability to apply tools and resources provided to develop tailored messaging for promoting the Workbench to both emerging and established researchers of various disciplines.

Why the *All of Us* Research Data?

The *All of Us* Research Hub and Researcher Workbench:

- Includes a variety of data to explore and share with multiple disciplines
- Ensures access for researchers from various institutions/organizations to establish a truly equitable resource for all
- Promotes responsible and ethical use of data, returns value to participant communities, and accelerates research impact
- Encourages students and early-stage investigators to bring fresh, creative perspectives & innovative research outcomes

Digital Toolkit



Access additional resources via our digital toolkit!

- Slides
- Quick Links
- Connecting with Researchers
- Website Resource Template
- Data Scavenger Hunt Template
- *All of Us* Flyers



All of Us Research Program

All of Us
RESEARCH PROGRAM

Inviting

1 Million

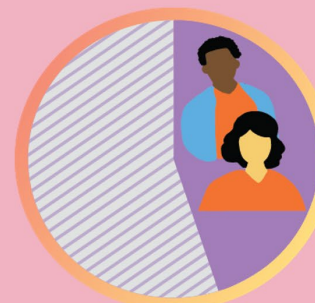
or more people
across the
United States



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

75%

identify with communities
underrepresented in
biomedical research



45%

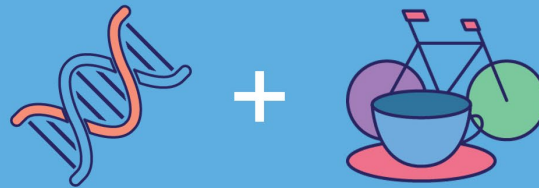
are from racial and
ethnic minority
groups

Data as of April 2023

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



Follows participants as they move, age, and grow



Participants included in *All of Us* research data are diverse.

Underrepresented in Biomedical Research (UBR) Categories	Curated Data (% out of 413,457 participants)
At least one UBR	74%
Non-white race or Hispanic/Latino ethnicity	43%
Age >= 65	24%
Less than GED	9%
Annual Income <=\$25k	25%
Sexual and Gender Minorities	10%
Disability	10%



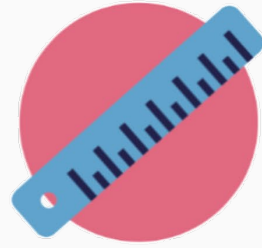
Data as of April 2023

Summary of Data Available in the Researcher Workbench



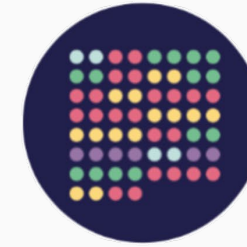
413,350+

Survey
Responses



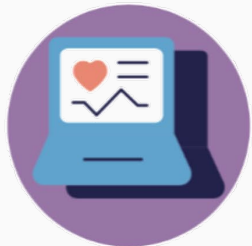
337,500+

Physical
Measurements



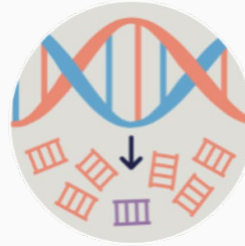
312,900+

Genotyping
Arrays



287,000+

Electronic Health
Records



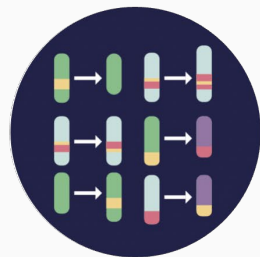
245,350+

Whole Genome
Sequences



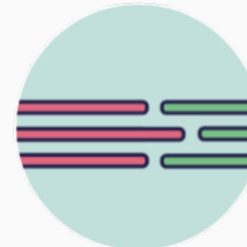
15,600+

Fitbit
Records
NEW! Sleep Data



11,350+

Structural Variants
NEW! In 2023



1,000+

Long-Read Sequences
NEW! In 2023

Data: 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

Making the data accessible to researchers across stages and settings

Our Researchers



10,600+
Registered
Researchers



450+
Academic
Institutions



140
Not-for-Profit
Organizations



100
Health Care
Institutions

110+

Historically Black Colleges and Universities and
Hispanic-Serving Institutions

Research Currently Underway



10,600+
Active projects



320+
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 May 2024

See if your institution has an agreement with us for access.

RESEARCHER LOGIN

ABOUT DATA & TOOLS DISCOVER SUPPORT Q REGISTER

Genomic Data in the Data Browser >>

About the Research Hub
 Registered Institutions
 Privacy & Security Protocols
 Research Hub Updates
 FAQ

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Registered Institutions

Access to the Researcher Workbench is available only to registered researchers with an institutional Data Use and Registration Agreement (DURA). Academic, not-for-profit, and health care institutions can enter into a DURA. Search or browse the list below to confirm if your institution has a DURA in place.

685
 Institutions Have
 Agreements in
 Place

If your institution is listed below,
AND includes your preferred data tier,
AND doesn't require individual agreements

If your institution is not listed below,
OR doesn't include your preferred data tier,
OR requires individual agreements

CREATE AN ACCOUNT

SUBMIT A REQUEST

Quick search - enter your institution's name

Key: **R** Registered Tier **C** Controlled Tier **i** Individual agreements required by institution **e** eRA Commons required by institution

Institution	Access Level	Contact at Institution
A.T. Still University of Health Sciences	R C	Gayla Sublette
Abigail Wexner Research Institute at Nationwide Children's Hospital	R C	Nichole Michaels
Above and Beyond Family Recovery Center	R C	Daniel Hostetler
Access Care Anywhere	R C	Carissa Bishop
Acton-Boxborough Regional School District	R C	Deborah Bookis
Adams State University	R C	Benita Brink
AI LA Community, Inc	R C	Todd Terrazas

The Importance of the *All of Us* Research Program to the Academic Library

Why the Library?

- The library is the center of the campus community.
- Libraries provide services to early career and established researchers, faculty, and students.
- The library is already responding to the need for data-driven research.
 - Libraries provide access to datasets and promote them to researchers from various disciplines.
 - Libraries provide training materials, resources, and basic instruction.
- Libraries are well-situated to utilize training materials to assist campus communities.
 - Already provides access to coding software, such as SPSS, SAS, and GIS.
 - Already supports research.



Librarians and Research Teams

- Librarians are a part of interdisciplinary research teams.
 - Reference Services – find and accesses information and resources
 - Literature and Systematic Reviews
 - Training others in software access and providing support
 - Advise on and assist with Research Data Management
- What else can library workers do?
 - Forge connections
 - Facilitate collaboration and communication strategies
- Continued Reading: University of Miami's Laboratory for Integrative Knowledge initiative (U-LINK)
 - [Webinar](#)
 - [Libraries as research partners](#)
 - [How librarians contribute to interdisciplinary research teams](#)



Ways to Collaborate with Researchers

- Raise awareness of the *All of Us* Research Program
 - Utilize the *All of Us* [Publications](#) repository to find articles
 - Encourage use of the [Research Projects Directory](#) for research ideas and to forge connections with other researchers
 - Suggest a [virtual demonstration](#) from *All of Us* Data Resource Center for a campus group
 - Encourage engagement with the [Data Browser](#) through a scavenger hunt or other passive program
- Share [funding opportunities](#) throughout campus

Ways to Collaborate with Researchers, cont.

- Help researchers gain access to the Researcher Workbench
- Help a class with registered students use the cohort and dataset builder
- Help a class without registered users with the public data browser
- Develop resource guides and tutorials for use on your campus
- Offer in-library or recorded information sessions and trainings
- Work with faculty to incorporate *All of Us* data into the curriculum
- Include *All of Us* in your coding instruction



The NLM *All of Us* Data Training and Engagement for Academic Libraries Program

This program aims to help campus libraries with the *All of Us* Researcher Workbench platform and equip library workers with the expertise to teach others to employ it, as a means of growing institutional research capacity and enhancing skills in biomedical and public health data.

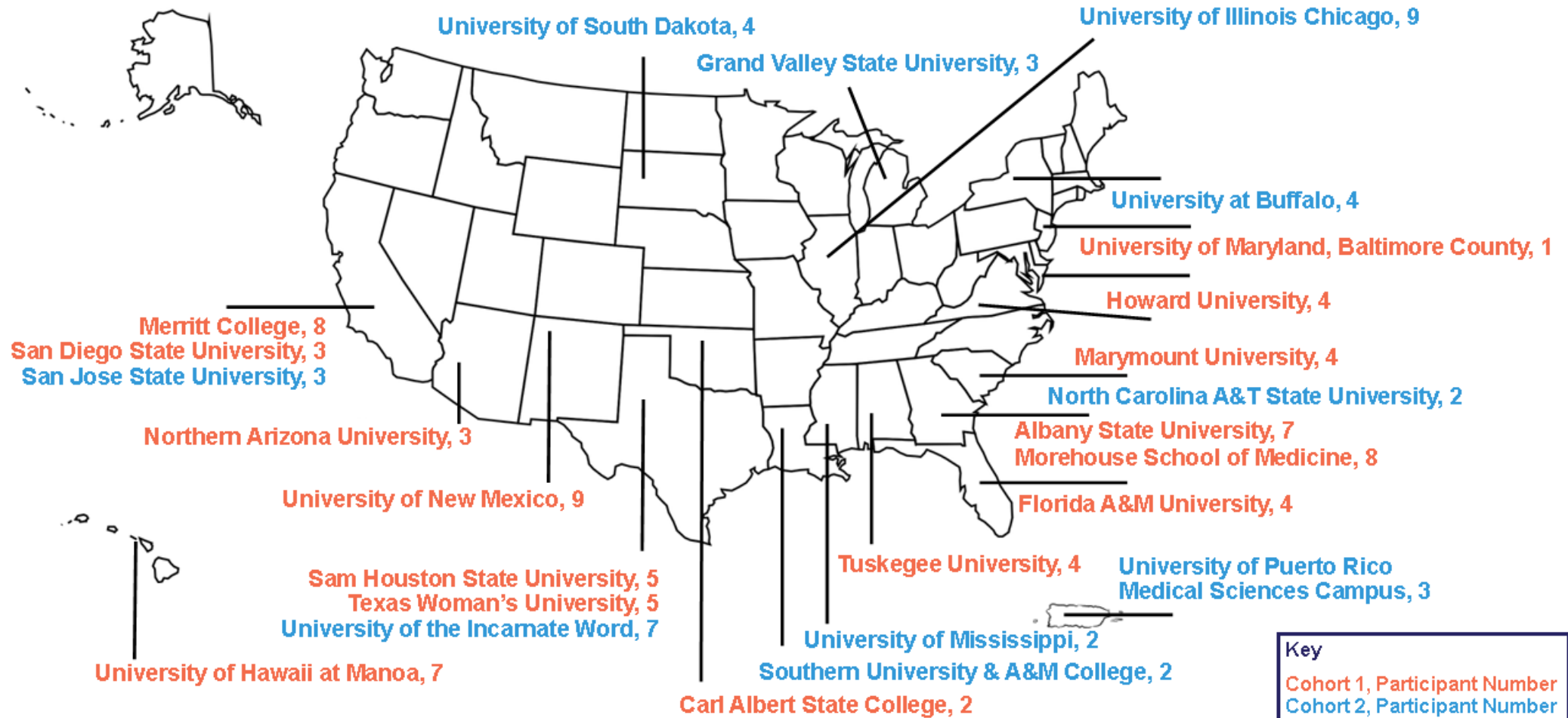
- Supported by NLM and NIH *All of Us*
- 25 Participating Institutions
- Multi-Phased Program
- Capacity Building Award



More info at <https://orau.org/alofus/academic-libraries.html>

NLM All of Us Data Training and Engagement for Academic Libraries Program

Cohort 1 & 2 Institutions and Participant Counts



Practical Engagement with the *All of Us* Research Workbench: A Panel Discussion

Panelists



Pamela Buzzard

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Health Sciences Librarian
Northern Arizona University



Brianna K. Chatmon

bchatmon@marymount.edu

Instruction & Scholarly
Communication
Librarian, Assistant Professor
Marymount University

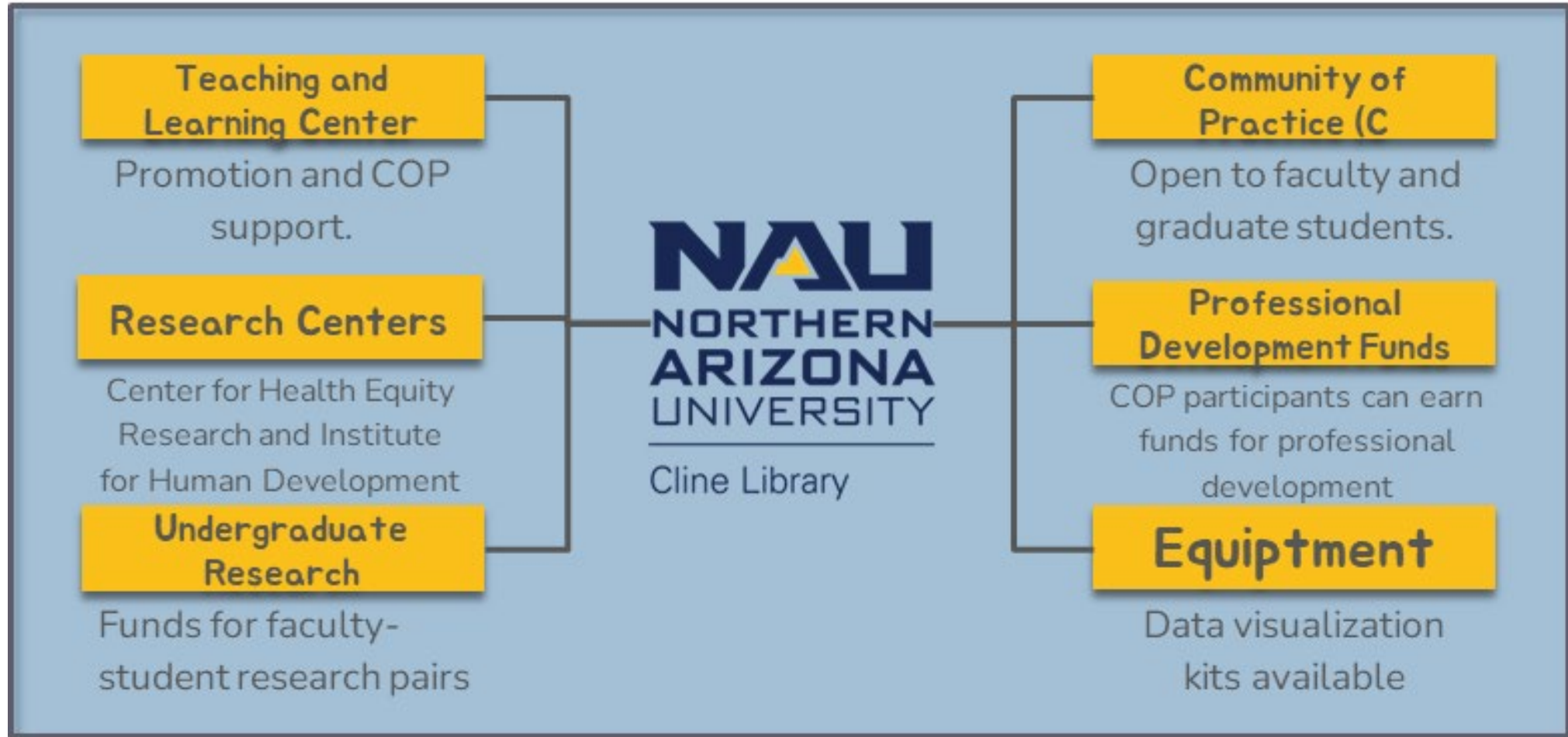


Sarah Joseph

josepsar@gvsu.edu

Health Research & Data
Librarian
Grand Valley State University

Pamela Buzzard – Northern Arizona University



Brianna Chatmon – Marymount University

Mission:

“A student-centered learning community that values diversity and focuses on the education of the whole person, Marymount guides the intellectual, ethical, and spiritual development of each individual.”

Student Population:

4,000+

Hispanic- Serving Institution (HSI)

#1 Diverse campus in VA and #15

nationally for Campus Ethnic Diversity and
#35 for Most International students by the
U.S News & World Report



“A giving hand is a
learning hand”



Sarah Joseph – Grand Valley State University



Showcase Presentation • Occurred April 12, 2024. Our initial communication about our plans to engage faculty and students with the *All of Us* dataset and Researcher Workbench on the Grand Valley State University (GVSU) campus.

Faculty Learning Community • Planned for fall 2024. Our learning community is a space where co-learning and exploration of the dataset and related resources can occur. Our way to connect with GVSU faculty more deeply around *All of Us*.

Mini Grant Cycle • Planned for the 2024-25 academic year. Our grant funding from the *All of Us Data Training and Engagement for Academic Libraries Program* will support a round of mini grant funding for GVSU faculty to engage with research using *All of Us*.

Questions?



Breakout Activity

Developing a Message

Breakout Activity - Directions

Pick one Breakout Area and join your Facilitator:

- a. Biomedical Sciences (Nursing, Medicine, Pharmacy, etc.)
- b. Social Sciences (Psychology, Social Work, Sociology, etc.)
- c. Public Health (Health Policy, Epidemiology, etc.)
- d. Data and Computer Sciences

Once in your breakout group, capture the following on your white board:

1. Select your message audience: students or faculty
2. Identify *All of Us* features that may interest your audience
3. Develop an example message for your audience to promote the dataset



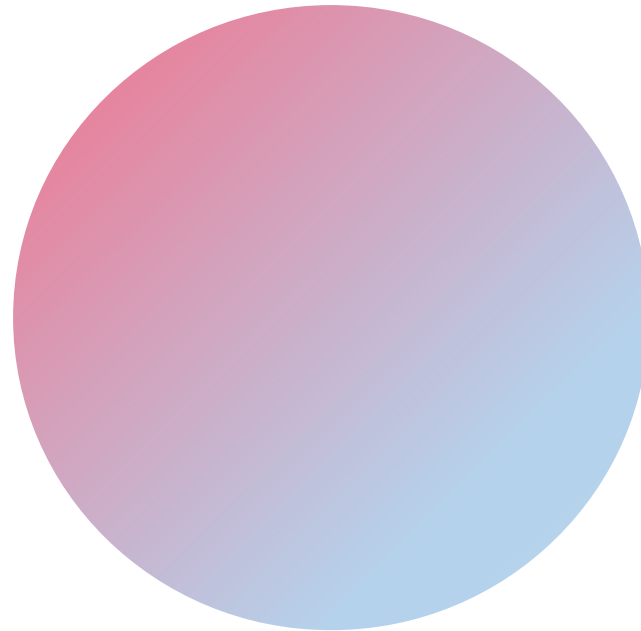
Time Remaining

Finish your
Messaging Example

2.5 Minutes Left

Start your
Messaging Example

10 Minutes Left



Decide on Audience
Student vs. Faculty

7.5 Minutes Left

Work on *All of Us*
Features to Highlight

5 Minutes Left



Engaging Campus Communities with Biomedical and Public Health Data

Who's Using the *All of Us* Researcher Workbench Now?

- **Bioinformaticians/biostatisticians**
Well-versed in the OMOP common data model, able to apply informatics and bioinformatics to support translational research, comfortable with the tools and coding languages needed to parse through initial dataset
- **Data scientists**
Able to transform a sea of data into actionable health insights by asking the right questions
- **Early-career researchers and students**
Removing the barriers to data access that typically exist for researchers at this stage of their careers
- **Epidemiologists**
Use the data to identify and study patterns of frequency and the causes and effects of diseases in *All of Us* participant populations
- **Geneticists/genomicists**
Making new associations through the integrated dataset, with the inclusion of WGS, LRS, SVs, and genotyping data
- **Health equity and health disparities researchers**
May benefit from the quality and diversity of the data currently available in the *All of Us* Researcher Workbench to identify patterns that could offer a clearer picture of health needs based on demographics, environment, experiences in society, and other factors

Departments and Specialties

Allied Health	Biology	Biochemistry	Bioinformatics	Biological Engineering	Biomedical Sciences
Computer Science	Data Science	Economics	Epidemiology	Forensic Science	Health Policy
Health Sciences	Histology	Microscopy	Medicine	Neuroscience	Nursing
Pharmacy	Psychology	Public Health	Social Work	Sociology	Speech and Hearing Sciences

Reviewing the Toolkit

What is in the Toolkit

- Presentation Slides
- Quick Links
- Getting Started Connecting with Researchers
- Resource Guide Template
- Data Scavenger Hunt
- DURA Process Infographic
- Research Hub How It Works Infographic
- Researcher Workbench Factsheet

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<https://orau.org/allofus/toolkit.html>

Next Steps

- Introduce the dataset to your campus
- Download the Toolkit
- Develop a Resource Guide for your library website

Contact Us

- NLMAIlofUs@orau.org

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<https://orau.org/allofus/toolkit.html>

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