Leveraging the AoU Research Program for HIV and Behavioral Health Research
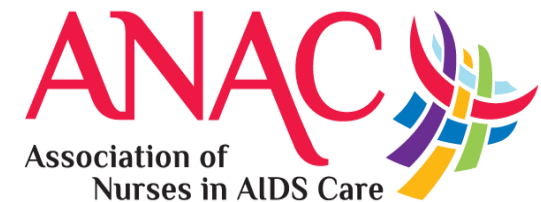
Faculty:
Josh Matacotta, Psy.D., MA, CAHIMS

Moderator:
Sheila Tumilty, BSN, RN, ACRN

April 2nd, 2024

ANAC
Association of
Nurses in AIDS Care

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

ANAC
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Nurses in AIDS Care

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 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 Objectives

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

- Describe the All of Us Research Program, including the types of data available for research

- Identify ways to leverage the All of Us Research Program data for health and behavioral health research

The All of Us Researchers Convention

The All of Us Researchers Convention will take place April 3-4. This free, virtual event is open to researchers across all disciplines and career stages. The Researchers Convention provides an opportunity for researchers who use All of Us data to showcase their work to others who share their interests in precision medicine. You can register for the convention at ResearchAllofUs.org/2024Convention.

Leveraging the AoU Research Program for HIV and Behavioral Health Research

Josh Matacotta, Psy.D., MA, CAHIMS
Western University of Health Sciences
AoU Researcher Ambassador

Objectives

- Describe the All of Us Research Program, including the types of data available for research

- Identify ways to leverage the All of Us Research Program data for health and behavioral health research
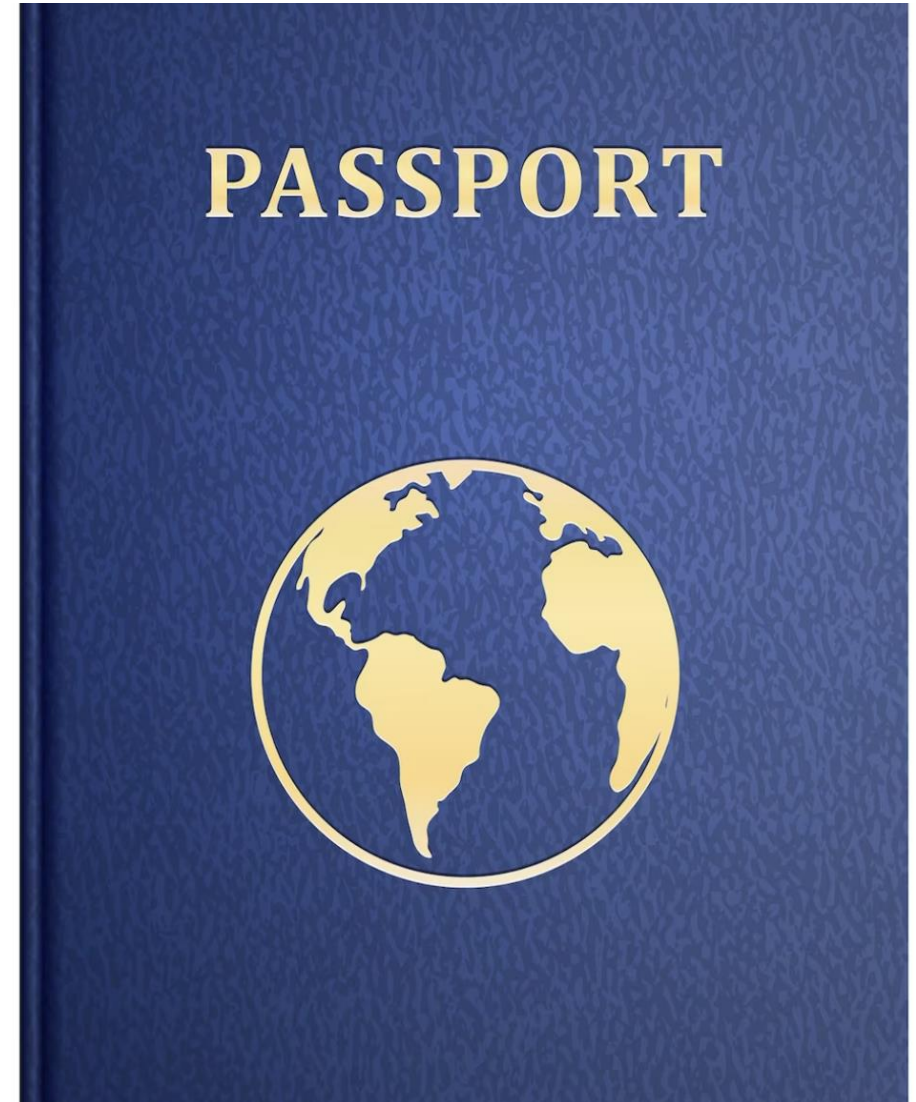
Overarching Goals

- National effort to build the largest, most diverse health information resource

- Participants are partners

- NIH AoU Research Program has begun returning personalized health-related DNA results to participants

- Biological factors and social determinants

Enabling Discoveries Through Broad Access to Data

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

413,350+
Survey Responses

337,500+
Physical Measurements

312,900+
Genotyping Arrays

287,000+
Electronic Health Records
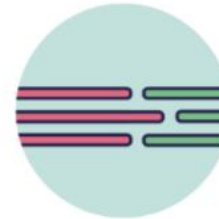
245,350+
Whole Genome Sequences

15,600+
Fitbit Records
NEW! Sleep Data

11,350+
Structural Variants
NEW! In 2023

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

Data as of April 2023

Data: Types and Sources

SDOH Survey data

COPE Survey Data

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

Diversity of Research and Researchers

Stephanie Cook, DrPH, MPH
Assistant Professor
NYU School of Global Public Health

Josh Matacotta, Psy.D., CAHIMS
Assistant Dean of Assessment & Strategic Initiatives
Western University of Health Sciences

Sally Baxter, MD, MSC
Assistant Professor, Shiley Eye Institute
University of California, San Diego

Raúl Montañez-Valverde, MD
Resident, Internal Medicine
Jackson Memorial Hospital at U. of Miami

Elizabeth Burnside, MD, MPH, MS, FACR
Associate Dean, School of Medicine and Public Health
University of Wisconsin, Madison

Studying cardiovascular risk among sexual and gender minorities

Studying the behavioral health needs of people with HIV

Studying predictive analytics for glaucoma

Studying the Latino Epidemiological Paradox in the U.S.

Studying a more personalized approach to breast cancer screening

HIV & Behavioral Health

- Changing demographics of the HIV epidemic

- Community-wide trauma

- Strengths-based approach

- Add *quality* life years

Aging Well with HIV

- Are there correlational relationships between SOC, proactive coping, health-related quality of life in gay-identified men over the age of 50?

- How do HIV health characteristics like CD4 count and the presence of comorbidities influence health-related quality of life?

SOC and Proactive Coping Improves HRQoL

	1	2	3
1. SOC	--	.29**	.52**
2. Physical Functioning	.29**	--	.38**
3. Mental Health	.52**	.38**	--

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Intercorrelations Among Variables

	1	2	3	4	5	6	7	8
1. Age	--	-.01	-.04	.15	.18	.02	.01	-.06
2. Income	-.01	--	.08	.07	-.17	.21*	.15	.01
3. CD4 count	-.04	.08	--	.16	.03	.13	.02	.15
4. ARV treatment	.15	.07	.16	--	-.03	-.10	.21*	.08
5. Comorbidity	.18	-.17	.03	-.03	--	-.10	.07	-.08
6. HRQoL	.02	.21*	.13	.10	-.10	--	.35**	.41**
7. SOC	.01	.15	.02	.21*	.07	.35**	--	.23*
8. Proactive coping	-.06	.01	.15	.08	-.08	.41**	.23*	--

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

PROJECT PURPOSE(S)

- Disease Focused Research (HIV)
- Social / Behavioral

SCIENTIFIC APPROACHES

This is an exploratory study using the AoU data of participants with HIV. Using the exploratory methodology, results will help inform future research and treatment approaches. We will use demographic data, EHR data, physical measurements, and survey data.

ANTICIPATED FINDINGS

We hope that using the AoU data can help identify risk factors and protective factors for HIV, as well as the social, environmental, and behavioral factors that influence HIV prevention and treatment.

DEMOGRAPHIC CATEGORIES OF INTEREST

- Race / Ethnicity
- Gender Identity
- Sexual Orientation

DATA SET USED

Controlled Tier

RESEARCH TEAM

Owner:

- Josh Matacotta - Early Career Tenure-track Researcher, Western University of Health Sciences

Collaborators:

Behavioral Health Needs of PWH

HIV & Behavioral Health

Study Aims

Prevalence of Depression in *All of Us* Research Program Participants with HIV

Research Question

Are participants with HIV disproportionately affected by depression?

Method: Cohort Characteristics

Demographic Data of AoU (N=412,211), PWH (N=5,193) and PWHD (N=2,238) Cohorts

Demographic	All AoU Participants		PWH Cohort		PWHD Cohort	
	n	%	n	%	n	%
Age						
18-44	150,964		1,052	20	431	19
45-64	152,648		2,917	56	1,313	59
>65	97,966		1,224	24	494	22
Unknown/No Data	10,633		-	-	-	-
Gender				<1		
Female	247,533		1,700	33	765	34
Male	154,453		3,284	63	1,383	62
Transgender	1,389		51	<1	<20	<1
Non-Binary	1,632		<20	<1	<20	<1
Additional, Skip	8,360		133	3	<20	<1

Demographic	All AoU Participants		PWH Cohort		PWHD Cohort	
	n	%	n	%	n	%
Race						
Asian	17,011	4.3	30	<1	<20	<1
Black	79,391	19.3	2,747	53	1,075	48
MENA	4,319	1.0	<20	<1	<20	<1
More than one	16,280	3.9	101	2	39	2
Native Hawaiian/OPI	1,111	0.3	<20	<1	<205	<1
White	235,340	57.1	1,199	23	583	26
None, PTNA, Skip	58,759	14.3	138	5	57	23
Sexual Orientation						
Straight/Heterosexual	360,060	87.9	2,793	54	1,174	52
Gay	9,740	2.4	1,523	29	689	31
Lesbian	5,440	1.3	30	1	<20	1
Bisexual	15,800	3.86	425	8	184	8
Other, Skip, PTNA	21,171	5.1	422	8	174	8

Ethnicity	All AoU	PWH Cohort	PWHD Cohort
Hispanic or Latino	73,710 (18%)	981 (19%)	472 (21%)
Not Hispanic/Latino	320,475 (78%)	3,965 (76%)	1,655 (74%)
PNTA	2,514 (<1%)	55 (1%)	29 (1%)
None or Skip	15,512 (~4%)	192 (4%)	82 (4%)

Findings

All of Us Research Participants with EHR Data with and without HIV

Condition, race*	Count (N=287,012)	Count with Condition	P value	Rate of diagnosis, % (95% CI)	OR (95% CI)
HIV			.001		
Asian	8,294	30		0.362 (0.360-0.363)	0.19 (0.13-0.28)
Black	58,264	2,747		4.715 (4.713-4.716)	4.58 (4.33-4.84)
MENA	1,710	<20		0.585 (0.581-0.588)	0.32 (0.17-0.59)
More than 1	5,000	101		2.020 (2.016-2.024)	1.12 (0.92-1.37)
White	154,678	11,999		0.775 (0.775-0.776)	0.25 (0.24-0.27)
Other/NA	59,066	1,106		1.872 (1.871-1.874)	1.05 (0.98-1.12)

*Chi-Square 3814.40, df=5

Findings
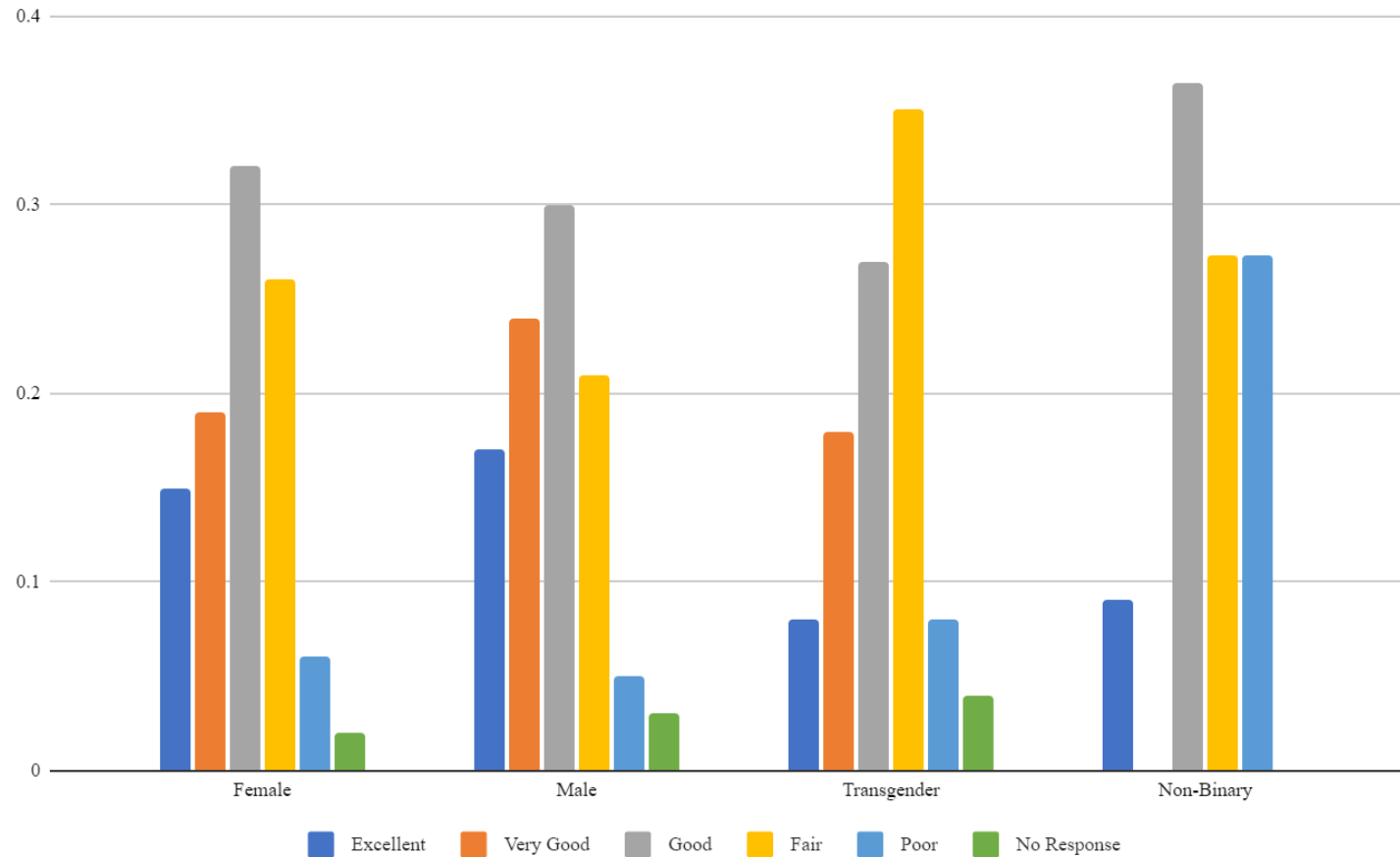
MDD Comorbidity in PWH

Comorbidity	HIV (n=5,193)%	No HIV (n=281,819)	P value	Rate of diagnosis, % (95% CI)	OR (95% CI), P
MDD	2,238 (0.43)	60,924 (0.22)	.001	43.1 (43.08-43.11)	2.75 (2.60-2.90) <.001

**Chi Square 1369.24, *df*=1

Overall Mental Health - PWH

PWH
19% Fair
4% Poor
54% EVGG

PWHD
22% Fair
5% Poor
44% EVGG

Presence of PTSD in PWH/PWHD

PWH + PTSD: **677**	
• Age	• Highest in Males (352 or 52%)
• 18-44 130 (19%)	• Highest in Black or African American (317 / 47%)
• 45-64 418 (62%)	
• 65+ 129 (19%)	

PWHD + PTSD: **560**	
• Age	• Highest in Males (290 / 52%)
• 18-44 107 (19%)	• Highest in Black or African American (269 / 48%)
• 45-64 347 (62%)	
• 65+ 106(19%)	

Implications of Findings

- Health disparities

- Ongoing MH assessment is critical

- Geographic evaluation of prevention and anti-stigma services

- Systemic barriers

- SDOH

Research Projects Directory

10,022 ACTIVE PROJECTS

This information was updated 3/28/2024

Re-engaging Registered Researchers

- New data are regularly added to the Workbench
- Explore what other researchers are studying within the dataset

Get Involved as a Researcher

For general information about the All of Us Research Hub

- www.researchallofus.org/ambassadors

How to apply to be an approved researcher on the workbench

- www.researchallofus.org/signup

Acknowledgements

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.

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