

Research It! Women's and Girls HIV/AIDS Care in the Gulf Coast

Our Louisiana Chapter event combines our “Let’s Stop HIV Together” campaign with our “All of Us Research Program” into an impactful webinar that highlights how increasing diversity in genetic research can help support HIV researchers and healthcare workers to provide care, increase adherence to treatment, and promote prevention strategies to benefit vulnerable populations.

Featured Speakers:

Julia Garcia-Diaz, MD, MSc, FACP, FIDSA

Medical Director, Clinical Research Group, Pharmacovigilance
Infectious Disease Consultant, Ochsner Health

Josh Maticotta, PsyD, MA, CAHIMS

Assistant Dean of Assessment & Strategic Initiatives, Assistant Professor
Western University of Health Sciences

Mariana Montero, MBA

Executive Director of Golden Change, Inc.



Save the Date:

February 28th
12 to 1 p.m. CT

bit.ly/NHMALAWebinar

NHMA
National Hispanic Medical Association

Welcome



Mariana Montero, MBA

Executive Director of Golden Change, Inc

Housekeeping

- All participant microphones will be muted, but please feel free to type your question into the Q & A box for the panelists to address during our Q & A session at the end.
- Recording will be housed on NHMAmd.org and sent out one week after the event.



Julia Garcia-Diaz, MD, MSc, FACP, FIDSA
Medical Director, Clinical Research Group Pharmacovigilance
Infectious Disease Consultant, Ochsner Health



Josh Maticotta, PsyD, MA, CAHIMS

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National Hispanic Medical Association

Research It! Women's and Girls HIV/AIDS Care in the Gulf Coast

Julia Diaz-Garcia, MD, MSc, FACP, FIDSA

Medical Director, Clinical Research Group, Pharmacovigilance
Infectious Disease Consultant, Ochsner Health

Objectives

1. Epidemiology HIV in women and the Hispanic Community
2. HIV/AIDS Stigma in the Hispanic Community
3. Risk factors faced by the Hispanic Community
4. Gender Disparities in HIV/AIDS Care
 - How can we decrease the number of women with HIV/AIDS?
4. Why Research is Important to HIV Care
5. Importance of Cultural Competency Among Providers
6. Treatment & Care
 - Best strategies moving forward



**1.5
MILLION**

people were newly infected with HIV
in 2021

**38.4
MILLION**

people were living with HIV in 2021

**650
THOUSAND**

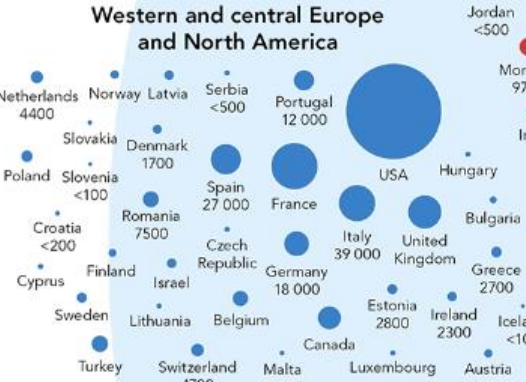
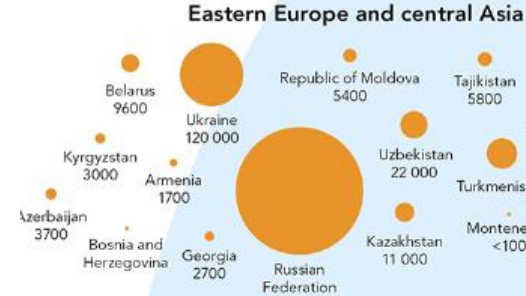
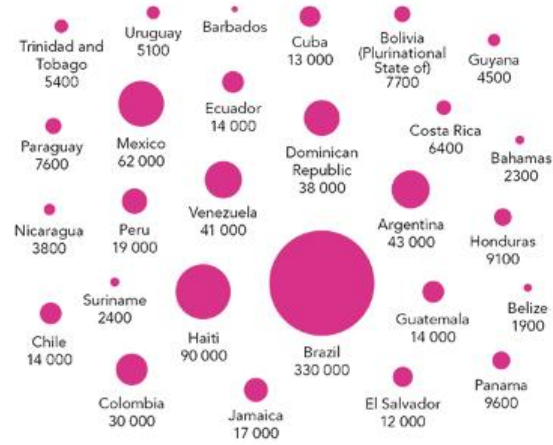
people died of AIDS-related illnesses
in 2021

20.2 MILLION GIRLS AND WOMEN LIVING WITH HIV

Girls and women make up more than half of the 38.4 million people living with HIV.

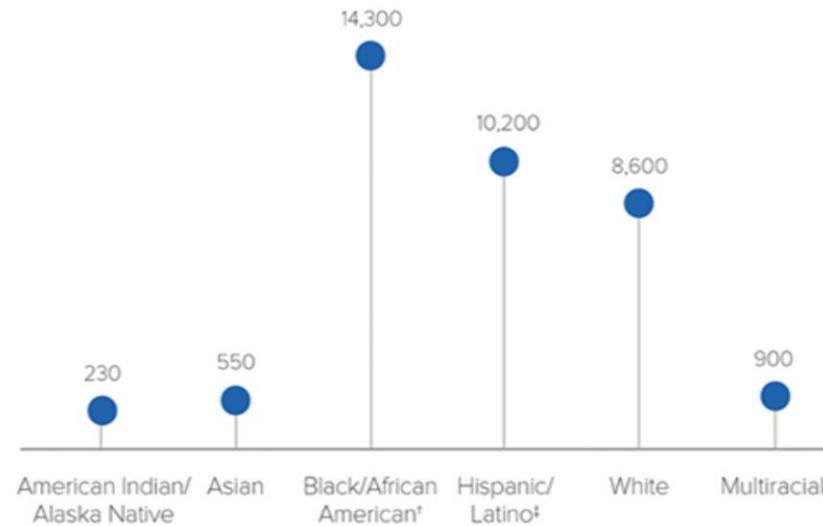
Global 20 200 000

Latin America and the Caribbean



Estimated HIV Infections in the US by Race/Ethnicity, 2019*

Overall, Black/African American people accounted for the largest number of estimated new HIV infections.



* Data not available for Native Hawaiian and other Pacific Islander people.

† Black refers to people having origins in any of the Black racial groups of Africa. *African American* is a term often used for people of African descent with ancestry in North America.

‡ Hispanic/Latino people can be of any race.

Source: CDC. Estimated HIV incidence and prevalence in the United States 2015–2019. *HIV Surveillance Supplemental Report 2021*;26(f).

HIV in Women

Today, more than 1.1 million people living with HIV in the U.S

- 258,000 or 23% are women

In 2019, there were 36,801 new HIV Diagnosis in the U.S

- 6,999 or 19% were women

Of the 6,999 or 19% of women diagnosed with HIV

- 1,326 or 19% were Hispanic/Latino women

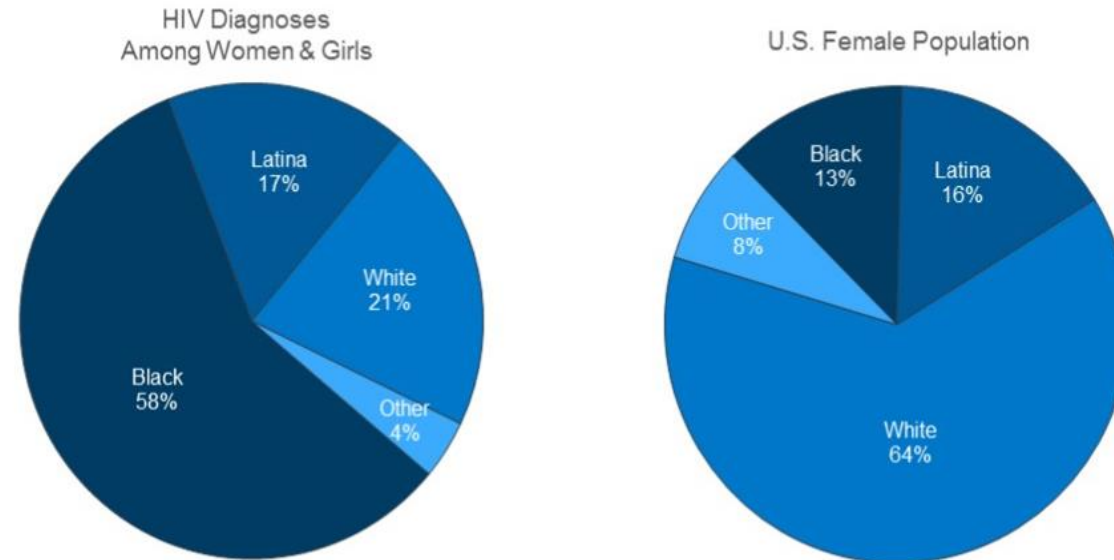
Hispanic Americans accounted for almost 30% of all HIV infection cases in 2019

Hispanic women were 4x as likely to have AIDS in 2019, compared to White women

Hispanic women are 3x as likely to die of HIV infections, compared to White women

HIV in Women

HIV Diagnoses Among Women & Girls and U.S. Female Population, by Race/Ethnicity, 2018



NOTES: Data are estimates among those ages 13 and older and includes U.S. dependent areas. Percentages may not sum to 100 due to rounding. U.S. female population data is from the U.S. Census Bureau 2010 population estimates, the most recent year available.
SOURCES: CDC. [NCHHSTP Atlas Plus](#). Accessed March 2020. U.S. Census Bureau, 2010 Population Estimates.

Figure 2: HIV Diagnoses Among Women & Girls and U.S. Female Population, by Race/Ethnicity, 2018

HIV in the Gulf Coast

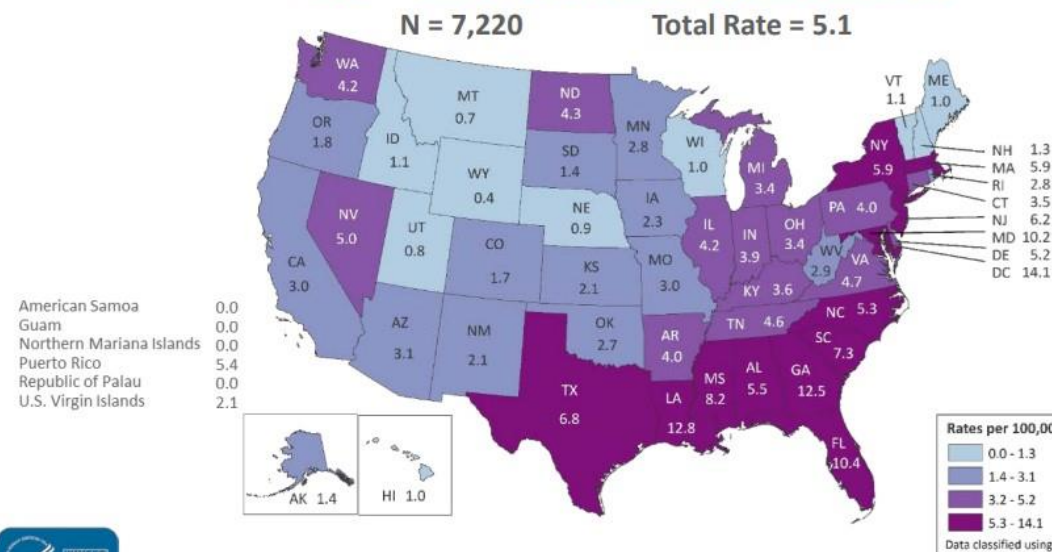
Diagnoses of HIV Infection among Female Adults and Adolescents by Region and Race/Ethnicity, 2018—United States



Note. Data for the year 2018 are considered preliminary and based on 6 months reporting delay.
^a Hispanics/Latinos can be of any race.



Rates of Diagnoses of HIV Infection among Female Adults and Adolescents 2018—United States and 6 Dependent Areas



Note. Data for the year 2018 are considered preliminary and based on 6 months reporting delay.

Challenges for Women

Women with (and at risk) for HIV face several challenges to getting the services and information they need, including socio-economic and structural barriers

- Poverty
- Cultural inequities, and
- Intimate partner violence (IPV)

In addition, women may place the needs of their families above own.

Additional Factors:

- Knowledge of HIV Status
- Sex partner's risk factors
- Knowledge of PrEP
- Other sexually transmitted diseases (STDs)
- Mental Health

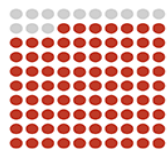


In 2019, an estimated **1.2 million PEOPLE** had HIV. Of those, **263,900** were women.



In 2019, an estimated **1.2 MILLION PEOPLE** had HIV. Of those, **294,200** were Hispanic/Latino people.

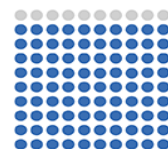
For every 100 people with HIV



87

knew their HIV status.

For every 100 women with HIV



90

knew their HIV status.

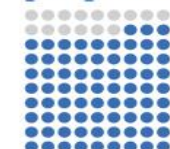
For every 100 people with HIV



87

knew their HIV status.

For every 100 Hispanic/Latino people with HIV



84

knew their HIV status.

Challenges in the Hispanic community

There are several risk factors that directly impact Hispanic community when it comes to HIV.

- Poverty
- Racial discrimination
- Lack of access to health care
- Language barriers
- Immigration status
- Mistrust of the healthcare system

That is why effective health education and bilingual health resources are so important to end the transmission of HIV in the United States.

Prevention for Hispanic Women

HIV prevention opportunities may not be reaching women effectively. Pre-exposure prophylaxis (PrEP), a highly effective medication, prevents acquisition of HIV but uptake has been slow among women in the US

PrEP Coverage Among Women in the US, 2019*†

PrEP is highly effective for preventing HIV from sex or injection drug use.

ONLY



of women who could benefit from PrEP were prescribed PrEP in the US in 2019.

* Based on sex assigned at birth.
† Among people aged 16 and older.

Source: CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2019. *HIV Surveillance Supplemental Report 2021;26(2)*.

PrEP Coverage Among Hispanic/Latino People in the US, 2019*†

PrEP is highly effective for preventing HIV from sex or injection drug use.



of Hispanic/Latino people who could benefit from PrEP were prescribed PrEP in 2019.

* Hispanic/Latino people can be of any race.
† Among Hispanic/Latino people aged 16 and older.

Source: CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2019. *HIV Surveillance Supplemental Report 2021;26(2)*.

HIV Stigma in Hispanics

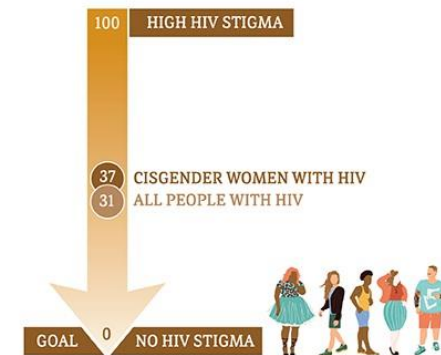
HIV Stigma is higher among Hispanic women than Hispanic men

The most common HIV stigma among Hispanic persons with HIV are

- Concern about disclosure of HIV status
- Health care discrimination - Clinician was not listening to them

Median HIV Stigma Score Among Women with Diagnosed HIV in the US, 2019*†

Women with diagnosed HIV experienced HIV stigma.



Data for transgender women are not included because the numbers are too small to report.

Median HIV stigma scores are presented based on a ten-item scale ranging from 0 (no stigma) to 100 (high stigma) that measures personalized stigma, disclosure concerns, negative self-image, and perceived public attitudes about people with HIV.

* Based on current gender identity.
† Among people aged 18 and older.

Source: CDC, Medical Monitoring Project.

Addressing HIV Stigma in Hispanics

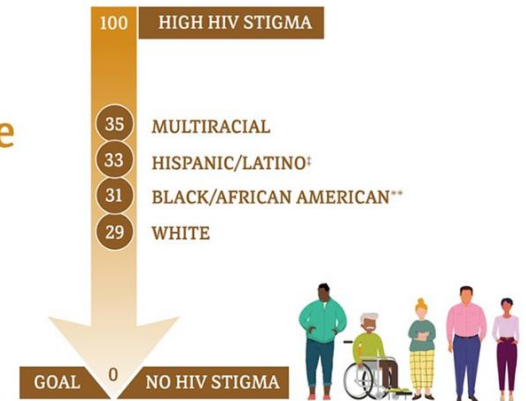
Hispanic persons with HIV are highly diverse. Efforts to reduce HIV stigma and discrimination should consider the varied and unique experiences of this population.

What is needed:

- HIV stigma reduction in Hispanic/Latino communities.
- The development of behavioral interventions tailored to Hispanic/Latino populations.
- The engagement of Hispanic/Latino community leaders.

Median HIV Stigma Score Among People with Diagnosed HIV in the US by Race/Ethnicity, 2019*†

People with HIV experience stigma. The median HIV stigma score among all people with HIV was 31.



Median HIV stigma scores are presented based on a ten-item scale ranging from 0 (no stigma) to 100 (high stigma) that measures personalized stigma, disclosure concerns, negative self-image, and perceived public attitudes about people with HIV.

* Among people with HIV aged 18 and older.

† Data not available for Asian, American Indian/Alaska Native, and Native Hawaiian and other Pacific Islander people.

‡ Hispanic/Latino people can be of any race.

** Black refers to people having origins in any of the Black racial groups of Africa. African American is a term often used for people of African descent with ancestry in North America.

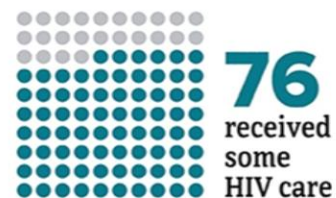
Source: CDC, Medical Monitoring Project.

HIV Treatment and Care

Looking across the spectrum of access to care, from HIV diagnosis to viral suppression, reveals missed opportunities for reaching women. Among women living with HIV in the U.S., 9 in 10 (89%) were aware of their HIV status; however, many were tested late, many years after acquiring HIV, suggesting missed prevention opportunities.

Women with Diagnosed HIV in 44 States and the District of Columbia, 2019*

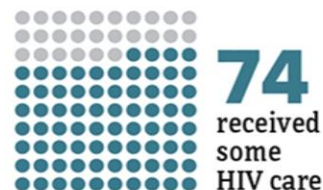
Compared to all people with diagnosed HIV, women have lower viral suppression rates. **For every 100 women with diagnosed HIV in 2019:**



For comparison, for every **100 people overall** with diagnosed HIV, **76 received some care**, **58 were retained in care**, and **66 were virally suppressed**.

Hispanic/Latino People with Diagnosed HIV in 44 States and the District of Columbia, 2019*

Compared to all people with diagnosed HIV, Hispanic/Latino people have about the same viral suppression rates. **For every 100 Hispanic/Latino people with diagnosed HIV in 2019:**



For comparison, for every **100 people overall** with diagnosed HIV, **76 received some care**, **58 were retained in care**, and **66 were virally suppressed**.

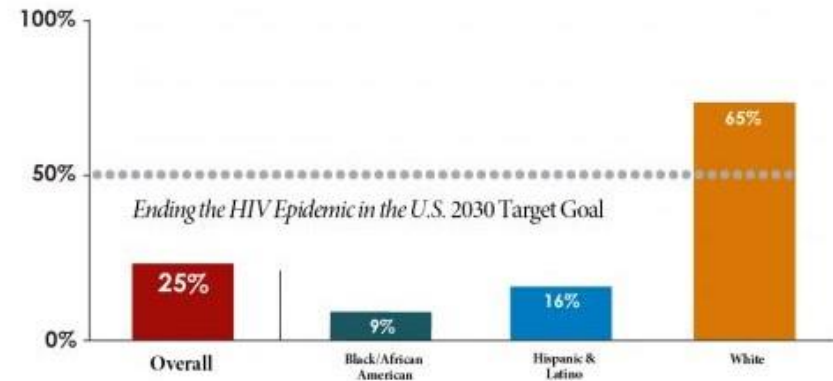
Improving HIV Treatment and Care

Treatment and Care begins at Prevention

To combat the HIV epidemic, the nation must scale up HIV testing, link people with HIV to care and treatment, and ensure equitable access to HIV prevention—including PrEP—for everyone who could benefit.

JUST 16% OF HISPANIC & LATINO PEOPLE IN THE U.S. WHO WERE ELIGIBLE FOR PREP IN 2020 WERE PRESCRIBED IT, SHOWING THAT UNEQUAL COVERAGE PERSISTS

PREP COVERAGE IN THE U.S. BY RACE/ETHNICITY, 2020



For more information, visit
cdc.gov/nchstp/newsroom



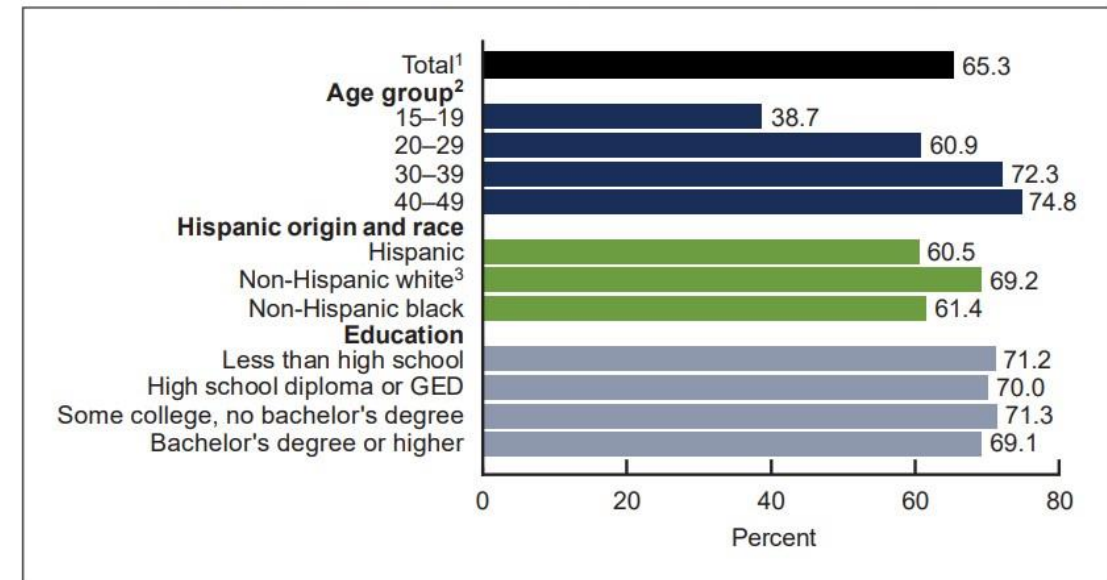
Improving HIV Treatment and Care

Understanding the Gender Dynamic in Hispanic Communities

Latinas may be less likely to suggest condom use than their White or African American counterparts. This is possibly due to culturally constructed gender role constraints, female modesty, male dominance in sexual behavior, and/or misconceptions about the use and efficacy of condoms

Latinos are reported to have negative attitudes about condoms and are less likely than other ethnic groups to believe that condoms protect against HIV

Figure 1. Percentage of women currently using any contraceptive method among all women aged 15–49 and by age group, Hispanic origin and race, and education: United States, 2017–2019



¹Includes persons of other and multiple race and origin groups, not shown separately.

²Significant linear trend across all four age groups.

³Significantly different from non-Hispanic black women and Hispanic women.

NOTES: The population size referenced for women aged 15–49 is 72.7 million. Analyses of education are limited to women aged 22–49 at the time of interview. Less than high school is no high school diploma or GED. Access data table for Figure 1 at:

<https://www.cdc.gov/nchs/data/databriefs/db388-tables-508.pdf#1>.

SOURCE: National Center for Health Statistics, National Survey of Family Growth, 2017–2019.

Culturally Appropriate Interventions



Innovation is key. A total-person approach to care integrates HIV prevention and treatment into health services that people are already seeking.

- Implementing effective linkage and retention strategies for clients with HIV and substance use disorders.
- Coordinating community level interventions using educational talks, social network testing, and social.
- Marketing campaigns to decrease HIV stigma and encourage HIV testing and treatment.
- Improving authenticity and effectiveness by developing culturally tailored communications.
- Working with syringe services programs to identify and support clients with HIV who also have opioid use disorders.

Benefits of Research in HIV Care

- The impact of HIV care research has it possible for people to live, healthy and full lives with HIV.
- The research has also contributed to the prevention, diagnosis, and treatment of other health conditions affecting many more millions of people like Hep C, Leukemia, cardiovascular and hematologic disorders.

Why Don't Latinos Join Clinical Trials?

There are many reasons:

- Lack of information
- Disparities in access to health care
- Not being fluent in English
- Cultural fears, such as fear of being a guinea pig



10
PERCENT
OF CLINICAL TRIAL
PARTICIPANTS ARE LATINOS

Thank You

About the *All of Us* Research Program and the Researcher Workbench



Last Updated: February 2023

Josh Maticotta, PsyD, CAHIMS

Assistant Professor/Assistant Dean
Western University of Health Sciences
College of Health Sciences

All of Us Research Program Key Definitions & Acknowledgement

- ⦿ **Engagement:** A broad range of relationship-building bidirectional interactions, including information sharing, consultation, collaboration in decision making, and empowered action between the program, people, awardees, and other partners.
- ⦿ **Outreach:** Unidirectional interaction, such as providing materials and information to an audience.
- ⦿ **Recruitment:** Facilitating enrollment in the program.
- ⦿ **Retention:** Ongoing activities with participants after enrollment.

Source: All of Us protocol

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

One of the largest, richest, most diverse biomedical datasets of its kind

Inviting

1 Million

or more people
across the
United States



80.9%

are from communities
underrepresented in
biomedical research



45%

are from racial and
ethnic minority
groups

Enables 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



With aggregated overviews and interactive previews available to everyone

 [Learn How to Join as a Participant >>](#)

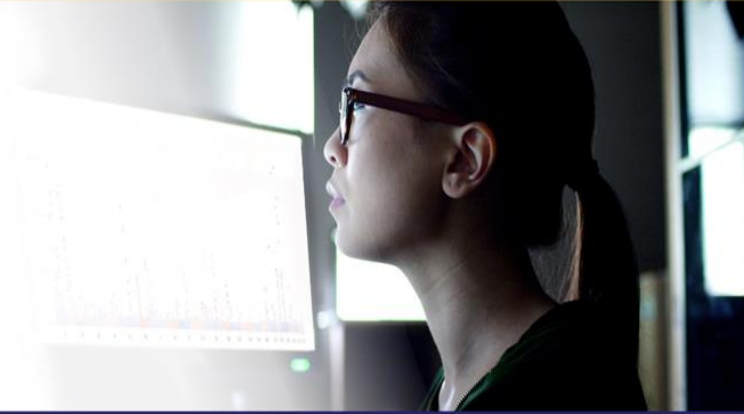
 [Explore Genomic Data in the Data Browser >>](#)

Welcome to the *All of Us* Research Hub

The *All of Us* Research Program, led by the National Institutes of Health, 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.

Registered researchers can access *All of Us* data and tools to conduct studies to help improve our understanding of human health.

[REGISTER FOR ACCESS](#)



ResearchAll of Us .org

Data Snapshots

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


603,000+
Participants


353,000+
Electronic Health Records


434,000+
Biosamples Received

[VIEW MORE DATA SNAPSHOTS](#)

Search Across Data Types



Keyword Search



Data includes 372,380 participants and is current as of 6/6/2022.



FAQs



Introductory
Videos



User Guide

EHR Domains

Conditions

24,315

medical concepts

227,740 participants in this domain

[View Conditions](#)

Drug Exposures

29,166

medical concepts

214,040 participants in this domain

[View Drug Exposures](#)

Labs & Measurements

15,309

medical concepts

227,280 participants in this domain

[View Labs & Measurements](#)

Procedures

29,176

medical concepts

221,860 participants in this domain

[View Procedures](#)

Genomics

Genomic Variants

98,560

participants in the Whole Genome Sequencing (WGS) dataset

165,080

participants in the Genotyping Array dataset

[View Genomic Variants](#)

Physical Measurements and Wearables

Physical Measurements

8

Physical Measurements

311,300 participants in this domain

Participants have the option to provide a standard set of physical measurements.

[View Physical Measurements](#)

Fitbit

4

Fitbit Measurements

12,880 participants in this domain

Fitbit data includes heart rate and activity summaries.

[View Fitbit](#)

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 identifiers removed. Public resources include:

- **Data Snapshots:** Aggregated, public-facing overviews of participant characteristics and data types
- **Data Browser:** Interactive preview into the larger *All of Us* dataset through public-facing aggregate data
 - Currently includes participant-provided information such as surveys and physical measurements taken at the time of participant enrollment as well as electronic health record (EHR) data
- **Survey Explorer:** Collection of participant survey questions and source information
- **Research Projects Directory:** Information about each research project within the Researcher Workbench

RESEARCHER WORKBENCH

Registered Tier

Registered users can access curated, individual-level data and a variety of research tools to conduct a wide range of studies **and NEW data** including:

- Initial Social Determinants of Health (SDOH) data
- Additional COVID-19 EHR data



Surveys



Electronic Health Records



Physical Measurements



Wearables

Data have been processed to protect participant privacy

Controlled Tier

Registered users with amended institutional agreements can access **all of the data in the registered tier plus**

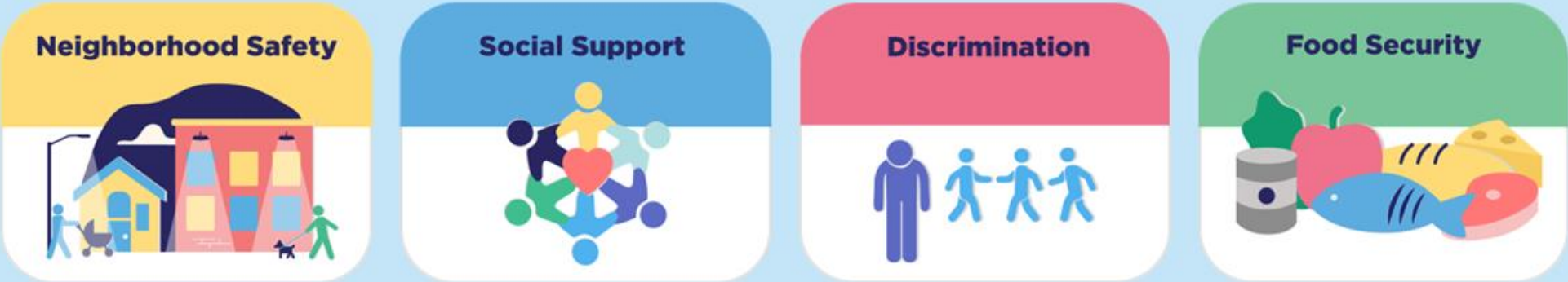
- Expanded demographics
- Unshifted event dates
- Genomic data derived from WGS (~100k participants) and array genotyping (165,200 participants)
- CRAM files which complement the genomic variant calls and enable capabilities such as custom variant evaluation and visualization
- intensity files (iDat) for custom array analyses beyond variants

Linked to drive new insights

By readily 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.

Initial Social Determinants of Health (SDOH) Survey Data

Including:



From 57,600+ responses to SDOH surveys

Figure accurate as of June 2022

All of Us - HIV Research (Aims)

Multimorbidity vs Comorbidity

Identify the behavioral health needs of PWH and multimorbidity and how those needs are being met

Identify approaches to implement integrated behavioral health and linkage to services that support psychosocial needs

All of Us - HIV Research (Demographics)

Age	Total (% of Cohort)
18-44	982 (21%)
45-64	2,670 (58%)
>65	979 (21%)

N=4,631

Ethnicity	Total (% of Cohort)
Hispanic or Latino	897 (19%)
Not Hispanic or Latino	3,499 (76%)
Prefer Not to Answer	54(1%)
None of these	49 (1%)
Skip	132 (3%)

All of Us - HIV Research (Demographics)

Race	Total (% of Cohort)
Asian	27 (<1%)
Black or African American	2,444 (53%)
I prefer not to answer	54 (1%)
Middle Eastern or North African	9 (<1%)
More than one population	94 (2%)
Native Hawaiian or Other Pacific Islander	8 (<1%)
None Indicated	772 (17%)
None of these	49 (1%)
Skip	132 (3%)
White	1,042 (23%)

All of Us - HIV Research (Demographics)

Gender	Total (% of Cohort)
Female	1,526 (33%)
Gender Identity: Additional Options	12 (<1%)
Gender Identity: Non Binary	9 (<1%)
Gender Identity: Transgender	43 (<1%)
I prefer not to answer	13 (<1%)
Male	2,910 (63%)
Not man only, not woman only	12 (<1%)
Skip	106 (2%)

Sex At Birth	Total (% of Cohort)
Female	1,519 (33%)
I prefer not to answer	14 (<1%)
Intersex	4 (<1%)
Male	2,948 (64%)
None	9 (<1%)
Skip	78 (2%)
Unknown	59 (1%)

Top 10 Conditions

• Essential hypertension	2,483	54%	
• Chest pain		1,833	40%
• Hyperlipidemia	1,646	36%	
• Dyspnea		1538	33%
• Abdominal pain	1519		33%
• MD, single episode	1512	33%	
• Lower back pain	1412		30%

685 with Recurrent Major Depression/Depressive Disorder

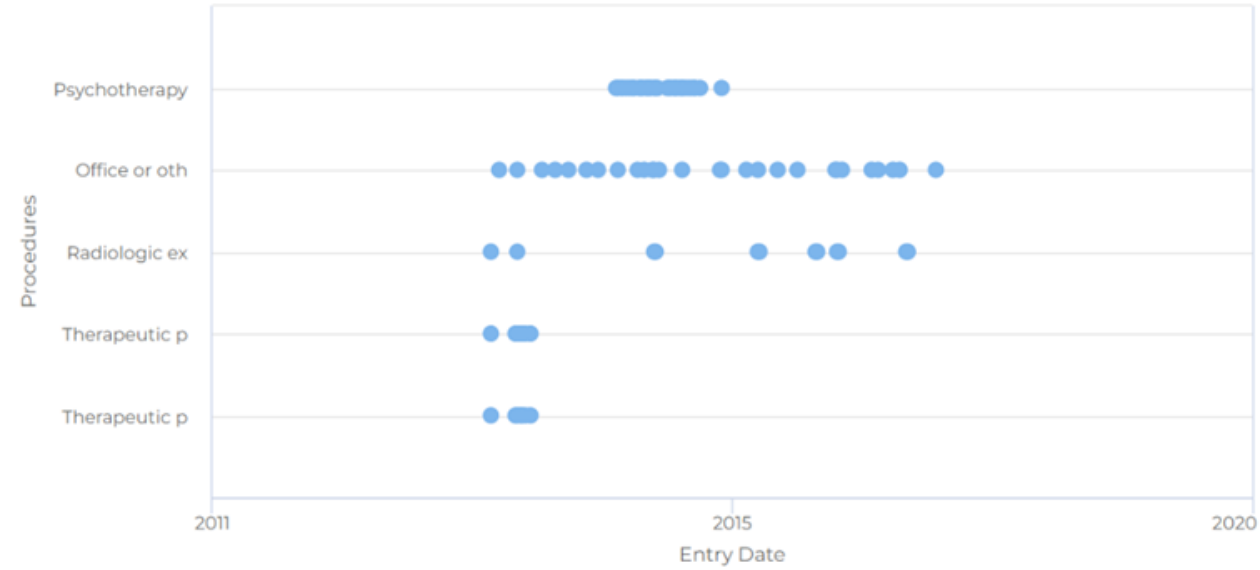
- 25% (244) Hispanic or Latino
- 37% (364) Female-identified [375 or 38% Female Sex at Birth]

Subset of Cohort - With Depressive Disorders

Top Conditions over Time



Top Procedures over Time



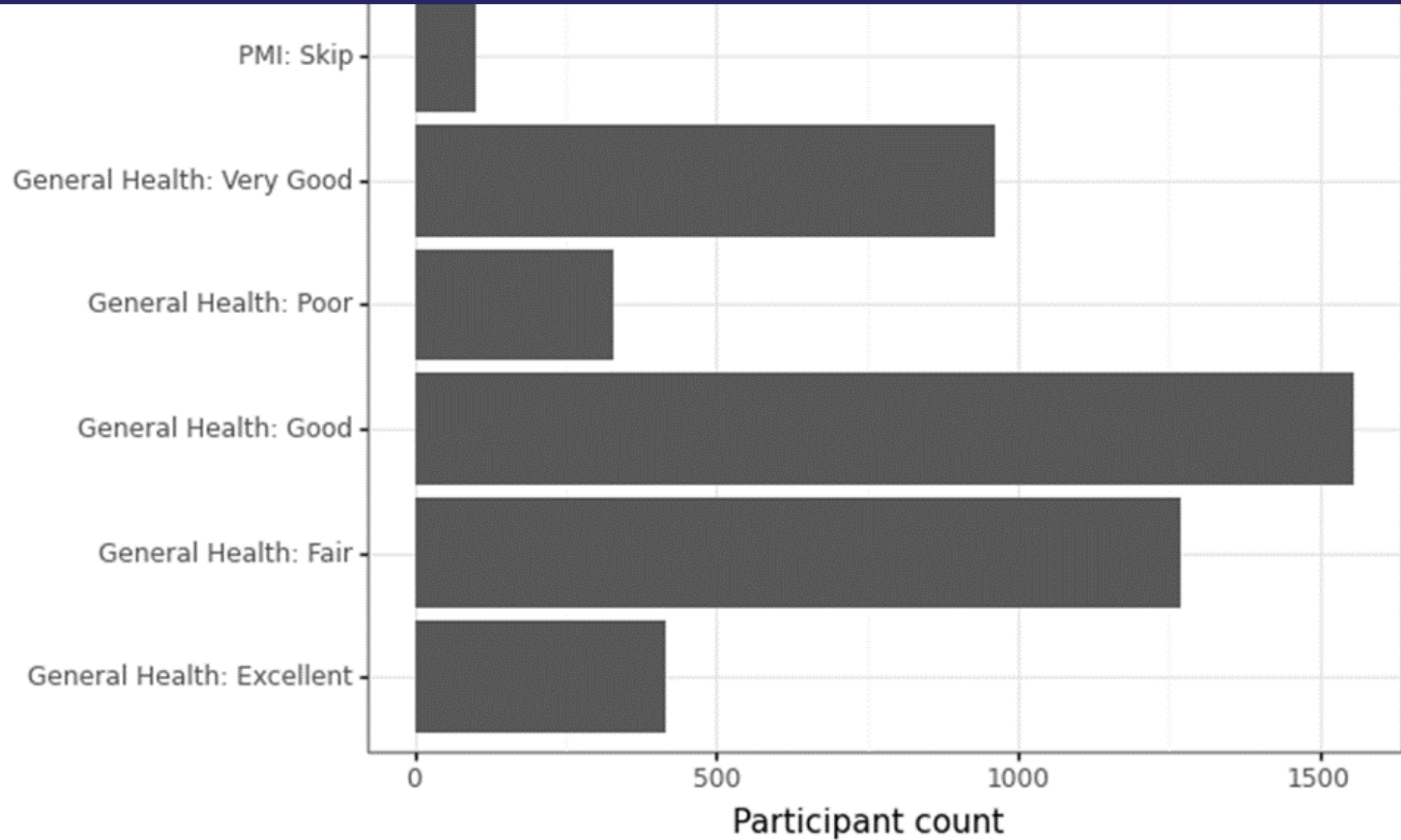
Top Conditions over Time



Top Procedures over Time



Overall Health - Cohort



Overall Mental Health - Cohort

1413 (30.5%) "Good"

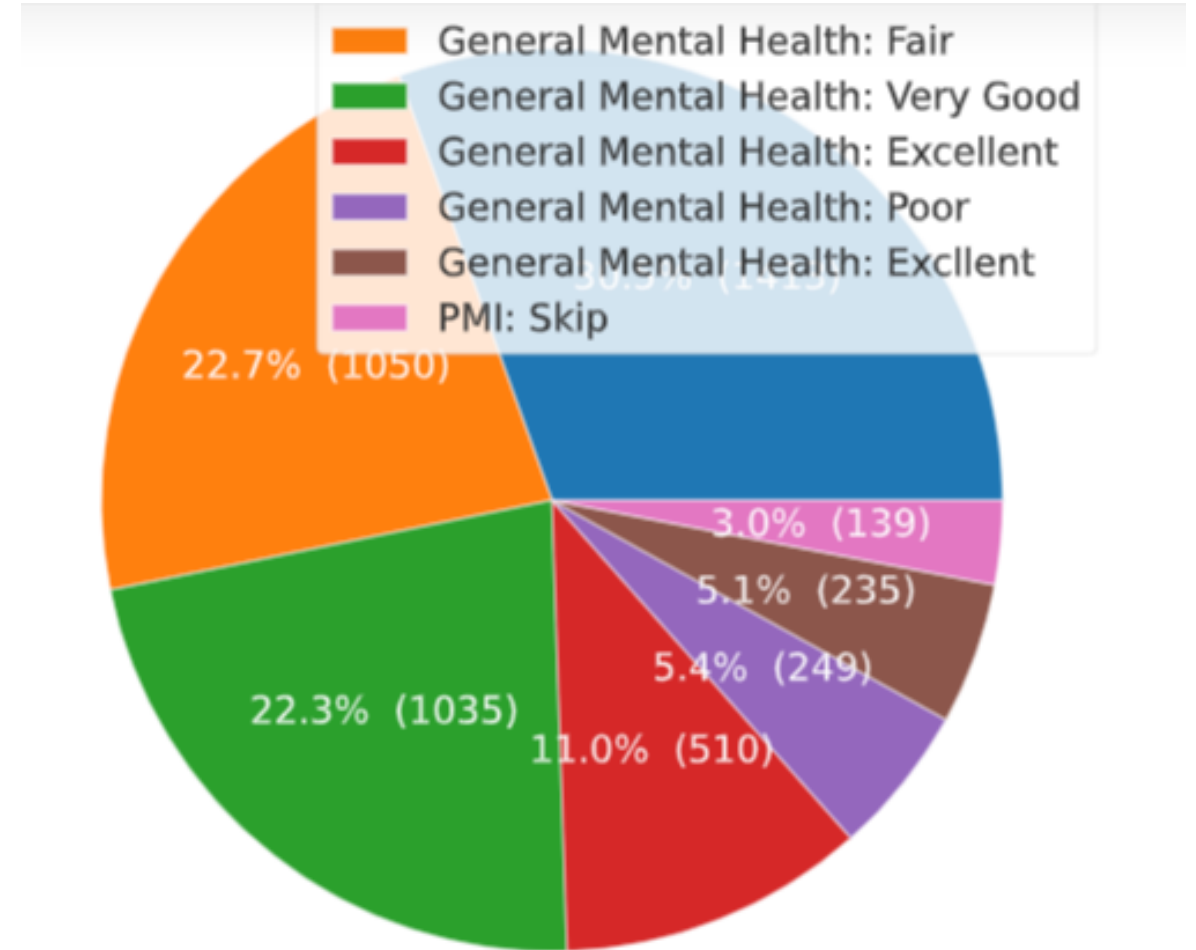
1050 (22.7%) "Fair"

1035 (22.3%) "Very Good"

745 (16.1%) "Excellent"*

249 (5.4%) "Poor"

N=4,631



Overall Mental Health - All of Us

2919 (29.2%) “Good”

2653 (26.5%) “Very Good”

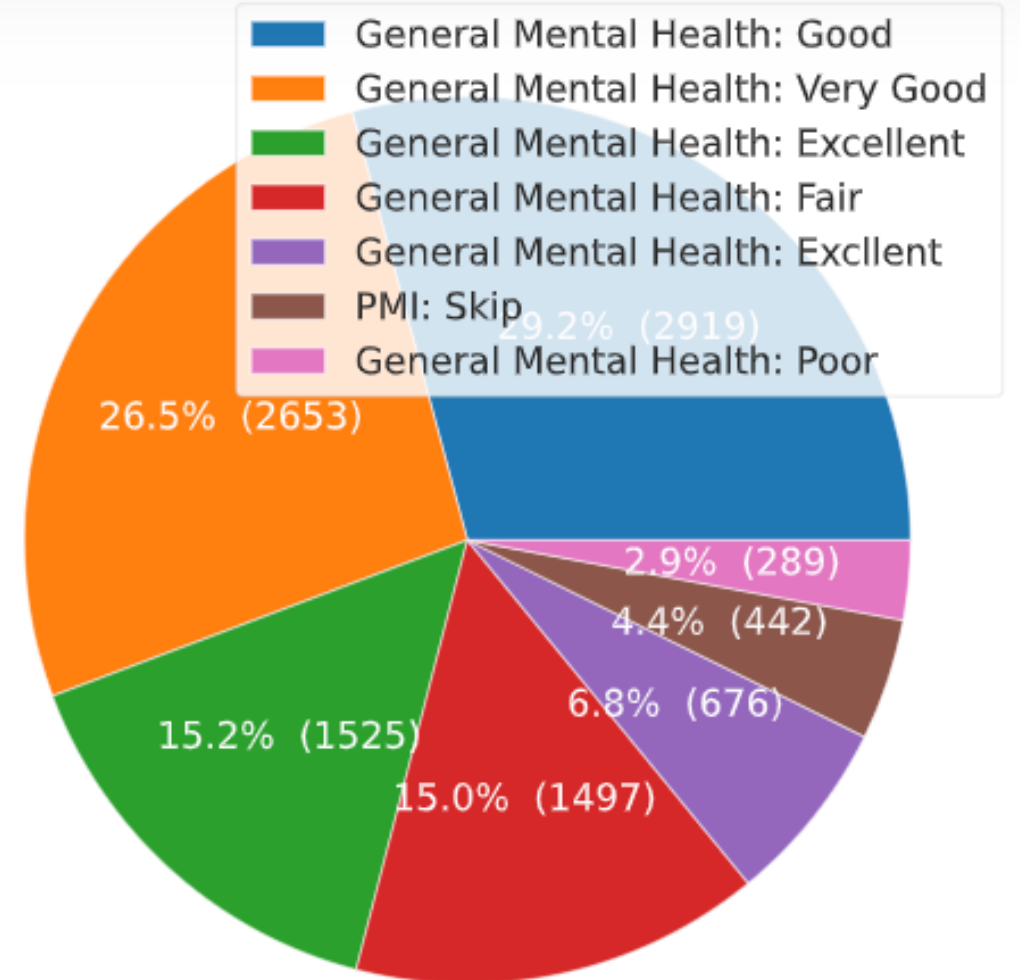
2201 (22%) “Excellent”*

1497 (15.0%) “Fair”

289 (2.9%) “Poor”

Remaining: Skip, No Data

N=372,063 / 10,001 responses



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

Join the *All of Us* Research Program!



To Learn More Visit

<https://bit.ly/3CAtwGn>



Thank you

Q and A



- Please participate in the discussion by asking questions using the Q and A box during this time.

NHMA Upcoming Events



- **National Women and Girls HIV/AIDS Awareness Day Twitter Chat:** March 10, 2023 at 1pm
- **HIV Next Steps: An Overview of the Current Epidemiology and Treatment of HIV:** March 15, 2023 from 1:00 – 2:00 PM ET via Zoom
- **NHMA Virtual Briefing Series Session #21 "Hindsight 2020: 3 Years of Public Health Emergencies":** March 29, 2023 from 7-8:15 PM ET

○ Register here



- **NHMA 26th Annual Conference:** Chicago, IL – April 27 – April 30th, 2023: Hyatt Regency Chicago

If you have any questions about our programs or events, please email us at nhma@nhmamd.org.

Thank You



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