Considerations for **ALL** Researchers: Opportunities & Challenges Using Sexual Orientation, Gender Identity, and Sex Assigned at Birth in the *All of Us* Controlled Tier Data

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***All of Us* Researcher Workbench Staff Presentation**
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- THREAD Research

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Our Identities & Pronouns

Hello Address me as **Juno** Please Use: **She, Her, Hers**

Hello Address me as **Mitch** Please Use: **He, Him, His**

@ThePRIDEStudy

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Today's Talk

1. Introduction to sexual orientation, gender identity, and sex assigned at birth

2. Health disparities experienced by sexual and gender minority (SGM) people

3. Brief research history with SGM people with some context of our work outside of *All of Us*

4. Discussion of example questions that could be tackled with *All of Us* controlled tier data
   - Elucidating health of SGM people
   - Caution / Opportunity: Why understanding of SOGI variables is critical for accuracy in **ALL** *All of Us* projects

5. Q&A

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Today's Objectives

1. Provide tools for understanding how to accurately use sexual orientation, gender identity, and sex assigned at birth variables in the *All of Us* controlled tier data

2. Provide a foundational understanding of sexual and/or gender minority (SGM) people and their health disparities

3. Discuss how *All of Us* controlled tier data presents a unique opportunity to understand the health and health care needs of SGM people

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Sexual Orientation, Gender Identity, & Sex Assigned at Birth

The Population: Sexual and Gender Minority People

People who are not exclusive heterosexual or not cisgender

- **L**esbian
- **G**ay
- **B**isexual
- **T**ransgender
- **Q**ueer
- and many others!

We use the terms "LGBT," "LGBTQ," "LGBTQ+," and "SGM" interchangeably throughout this presentation.

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Sex (assigned at birth) *versus* Gender

Sex (assigned at birth):
>   The biologic, anatomic, and physiological characteristics that define <u>males and females and people with differences of sex development</u>.

Gender:
>   The socially constructed roles, behaviors, activities, and attributes that a given society considers appropriate for <u>men and women or people of other genders</u>. This is further broken down in *gender identity and gender expression.*

As an example: "<u>female</u>", "<u>intersex</u>" & "<u>male</u>" are sex categories, while "<u>agender</u>", "<u>genderqueer</u>", "<u>girl / woman</u>", "<u>boy</u>" / "<u>man</u>" are gender categories.

Putting It Together
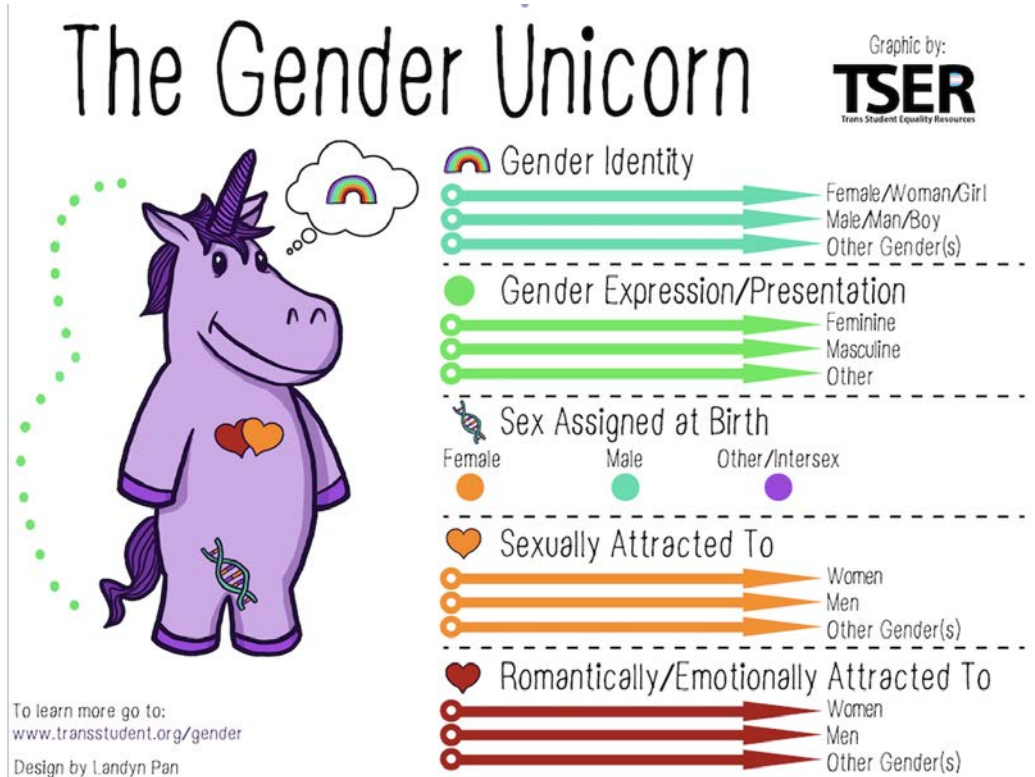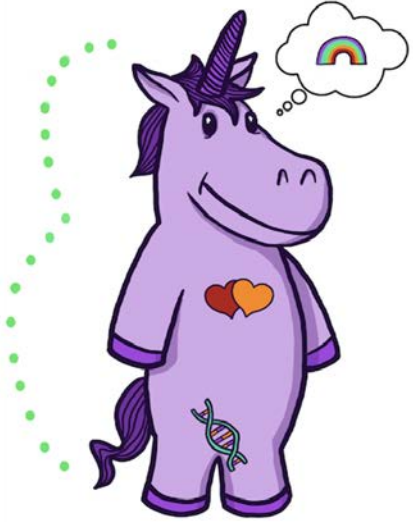
"Sex is what's in your genes/jeans.
Gender identity is what's between your ears."
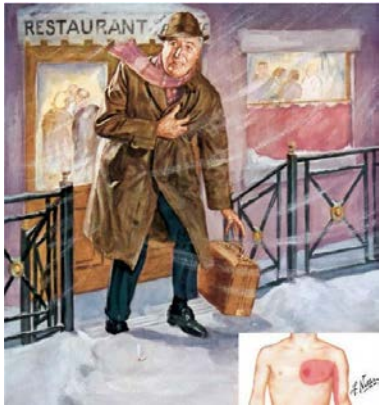
Putting It Together

"Gender identity is who you go to bed **as**.
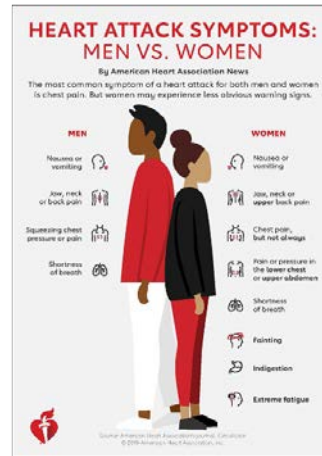Sexual orientation is who you go to bed **with**."
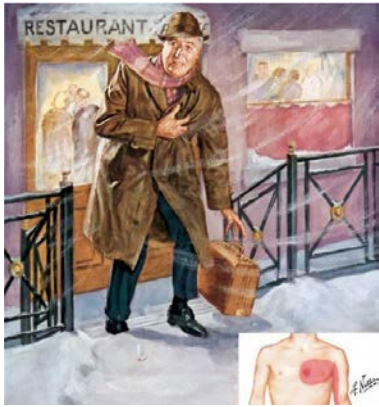
Where we are starting from in medicine

What does someone having a heart attack look like?

Where We Are Starting From in Medicine

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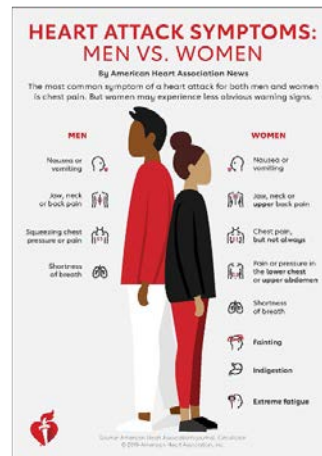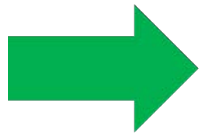
Where We Are Starting From in Medicine

What does someone having a heart attack look like?

Where We Are Starting From in Medicine

What does someone having a heart attack look like?

**Differences in sex (hormones/physiology/anatomy)
and gender, race can influence…**

**Risk factors?
Diagnosis?
Treatment?
Prevention?
Outcomes?**

Where We Are Starting From in Medicine

What does someone having a red heart attack look like?

HEART ATTACK SYMPTOMS: MEN VS. WOMEN

Differences in **sex** (hormones/physiology/anatomy)
and **gender**, race can influence…

Risk factors?
Diagnosis?
Treatment?
Prevention?
Outcomes?

What does a pregnant person (and support people) look like?

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Where We Are Starting From in Medicine

What does someone having a heart attack look like?

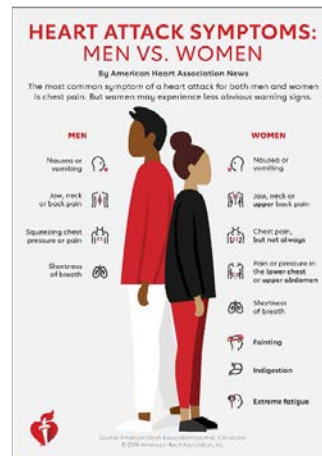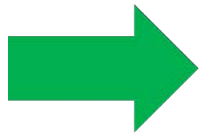Differences in **sex** (hormones/physiology/anatomy)
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Where We Are Starting From in Medicine

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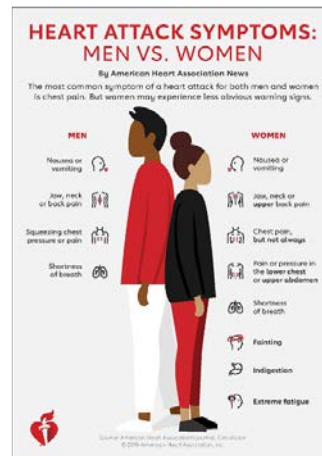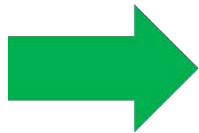and **gender**, race can influence…
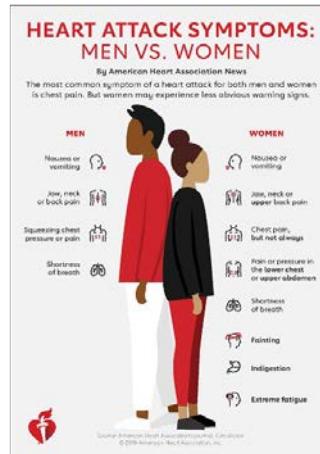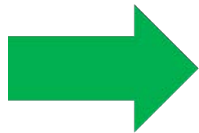
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What does someone having a heart attack look like?

Differences in sex (hormones/physiology/anatomy) and gender, race can influence…

Risk factors?
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SGM Data Disparities

LGBTQ+ Health Disparities Unknown/Poorly Characterized

LGBTQ+ Health Disparities Persist

Providers and Researchers Don't Ask about Sexual Orientation /Gender Identity

Lack of LGBTQ+ Health Data

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Putting It Together

Currently Asked Questions [Questions appear in this order in "The Basics" PPI module.]

Gender identity	What terms best express how you describe your gender identity? (Check all that apply)
	• Man
	• Woman
	• Non-binary*
	• Transgender*
	• None of these describe me, and I'd like to consider additional options*
	• Prefer not to answer
	*[The following question is shown if any answer choices marked by * are selected]*
	Are any of these a closer description to your gender identity? (Check all that apply)
	• Trans man/Transgender Man/FTM
	• Trans woman/Transgender Woman/MTF
	• Genderqueer
	• Genderfluid
	• Gender variant
	• Two-spirit
	• Questioning or unsure of your gender identity
	• None of these describe me, and I want to specify (optional free text with "Please specify.")
Sex assigned at birth	What was your biological sex assigned at birth?
	• Female
	• Male
	• Intersex
	• None of these describe me (optional free text with "Please specify.")
	• Prefer not to answer
Sexual orientation	Which of the following best represents how you think of yourself? (Check all that apply)
	• Gay
	• Lesbian
	• Straight; that is, not gay or lesbian, etc.
	• Bisexual
	• None of these describe me, and I'd like to see additional options*
	• Prefer not to answer
	*[The following question is shown if the answer choice marked by * is selected]*
	Are any of these a closer description of how you think of yourself? (Check all that apply)
	• Queer
	• Polysexual, omnisexual, sapiosexual or pansexual
	• Asexual
	• Two-spirit
	• Have not figured out or are in the process of figuring out your sexuality
	• Mostly straight, but sometimes attracted to people of your own sex
	• Do not think of yourself as having sexuality
	• Do not use labels to identity yourself
	• Don't know the answer
	• No, I mean something else (optional free text with "Please specify.")

All of Us LGBTQ

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Sexual and Gender Minority (SGM) People & Health Disparities

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SGM Population Estimates

Americans' Self-Identification as LGBT, by Generation

	LGBT %	Straight/Heterosexual %	No response %
Generation Z (born 1997-2003)	20.8	75.7	3.5
Millennials (born 1981-1996)	10.5	82.5	7.1
Generation X (born 1965-1980)	4.2	89.3	6.5
Baby boomers (born 1946-1964)	2.6	90.7	6.8
Traditionalists (born before 1946)	0.8	92.2	7.1

GALLUP, 2021

Americans' Self-Identified Sexual Orientation and Gender Identity, by Generation and Gender

	Bisexual %	Gay %	Lesbian %	Transgender %	Other %
Generation					
Generation Z	15.0	2.5	2.0	2.1	1.2
Millennials	6.0	2.2	1.3	1.0	0.4
Generation X	1.7	1.1	0.8	0.6	<0.05
Baby boomers	0.7	1.0	0.7	0.1	0.1
Traditionalists	0.2	0.4	0.1	0.2	0.1
Gender					
Women	6.0	0.4	1.9	0.8	0.4
Men	2.0	2.5	0.1	0.6	0.2

--Figures represent the percentage of all adult members of each demographic group who have that sexual orientation or gender identity.
--Some respondents identify with multiple sexual orientations or gender identities.
--Generation definitions are as follows: Generation Z, born 1997 to 2003; millennials, born 1981 to 1996; Generation X, born 1965 to 1980; baby boomers, born 1946 to 1964; traditionalists, born before 1946.
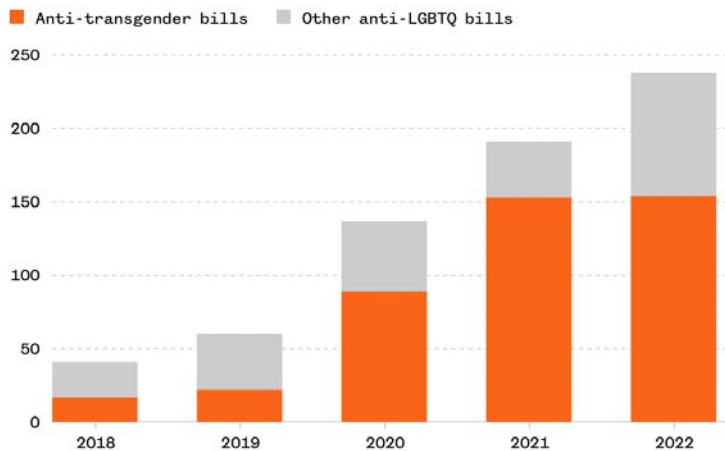
GALLUP, 2021

2021: 7.1% of US adults are LGBT (~1 in 14)

1 in 5 are LGBT (Gen Z)

1 in 48 are T (Gen Z) 0.7% or 1.8 Million Total

SGM status is not unique to a particular race/ethnicity, income bracket, or education level.

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https://news.gallup.com/poll/389792/lgbt-identification-ticks-up.aspx

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SGM Health and Politics are Intertwined

March 2022, current figures >300 not including
SCOTUS Dobbs ruling

SGM Health Disparities

"Homosexuality" in the Diagnostic and Statistical Manual of Mental Disorders (DSM) until 1973 (removed in DSM-III)

"Gender dysphoria" remains in the DSM-V

Hunt for the 'gay gene' or 'trans gene' in order to fix

Conversion (reparative) therapy

I Questioned Homosexuality. Change *is* Possible. Discover how. WWW.EXODUS.TO

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SGM Health Disparities

2015 U.S. TRANSGENDER SURVEY

Figure 7.4: One or more negative experiences with health provider in the past year
RACE/ETHNICITY (%)

Overall 33%, American Indian 50%, Asian 26%, Black 34%, Latino/a 32%, Middle Eastern 40%, Multiracial 38%, White 34%
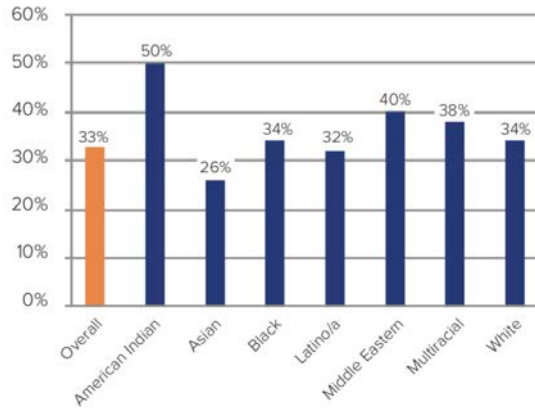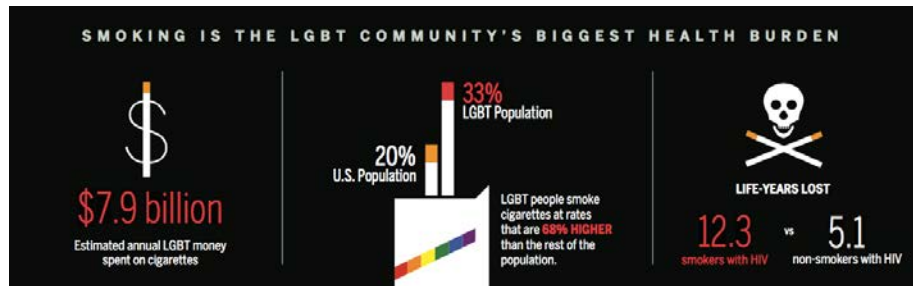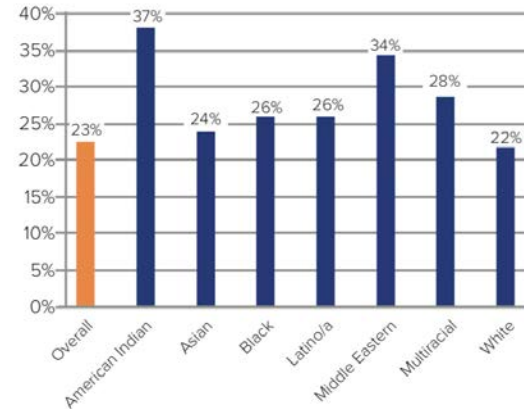
Figure 7.6: Did not see health provider due to fear of mistreatment in the past year
RACE/ETHNICITY (%)

Overall 23%, American Indian 37%, Asian 24%, Black 26%, Latino/a 26%, Middle Eastern 34%, Multiracial 28%, White 22%

Discrimination limits access

SMOKING IS THE LGBT COMMUNITY'S BIGGEST HEALTH BURDEN

$7.9 billion — Estimated annual LGBT money spent on cigarettes

33% LGBT Population
20% U.S. Population

LGBT people smoke cigarettes at rates that are 68% HIGHER than the rest of the population.

LIFE-YEARS LOST
12.3 smokers with HIV vs 5.1 non-smokers with HIV

SGM people were specifically targeted by tobacco companies.

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LGBT HealthLink. LGBT Smoking Infographic.
www.lgbthealthlink.org/Projects/LGBT-Tobacco-Surgeon-General-Infographic

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SGM Health Disparities

41% of transgender people report having attempted suicide compared to 1.6 percent of the general population.

41%

1.6%
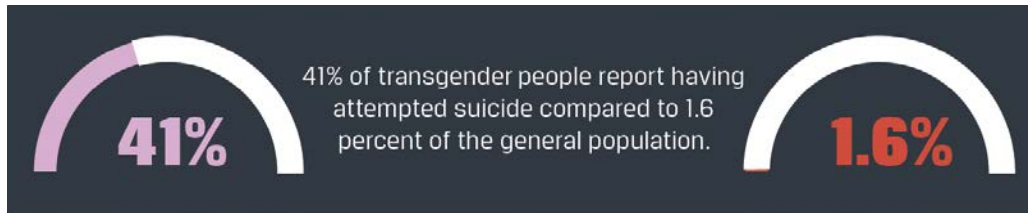
Societal stigma and discrimination lead to poor mental health outcomes for SGM people, especially among gender minorities.

Youth experience homeless because they are kicked out of their home or leave for their safety.

UP TO
40%
HOMELESS YOUTH POPULATION

UP TO
7%
GENERAL YOUTH POPULATION

LGBT   NOT LGBT

TRUECOLORSFUND

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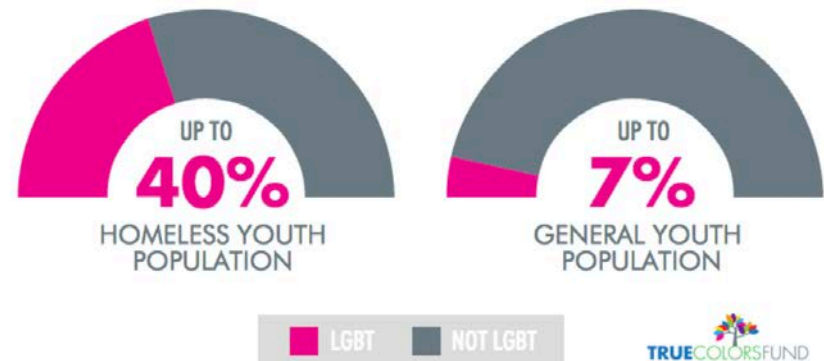
SGM Health Disparities

COVID Disproportionate Impacts LGBTQ+ People

- Barriers to health care
- More housing, job, food instability
- Higher tobacco use
- Higher cancer rates
- Higher HIV rates

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SOGI Data Collection in Census and ACS

United States™ Census Bureau

Sexual orientation and gender identity are/were **not** collected

SOGI **removed** from "Subjects Planned for 2020 Census"

Subjects Planned for the 2020 Census and American Community Survey
Federal Legislative and Program Uses

Issued March 2017
Revised

United States™ Census Bureau
U.S. Department of Commerce
Economics and Statistics Administration
U.S. CENSUS BUREAU
census.gov

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SGM Communities: Health Disparity Population for Research

SGM Health Disparities

PRIDEnet: Working to Catalyze LGBTQ+ Health Research

PRIDEnet: a network of LGBTQ+-serving clinics, community centers, and advocacy and professional organizations that:

- Represents major communities and regions

- Built from reciprocal, low burden relationships

- Uses digital & non-digital engagement to increase inclusion, reach out to these populations underrepresented in biomedical research (in *AoU* and The PRIDE Study)

- Participate in and improve research….
  ◦ Community Engagement Partner with *AoU*
  ◦ Demonstration Projects with *AoU*

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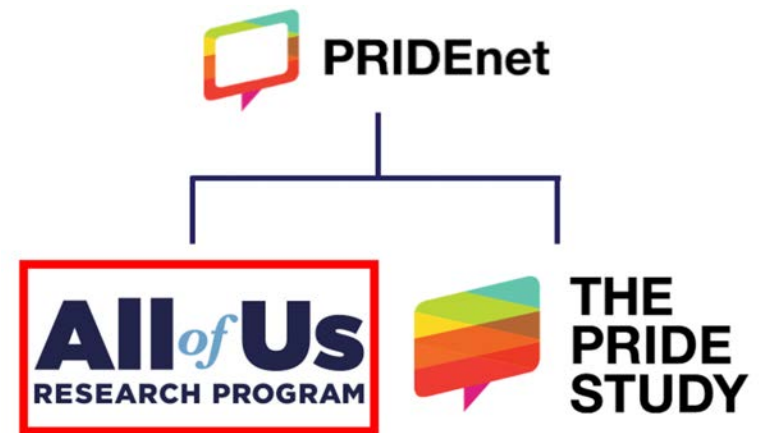
PRIDEnet in The *All of Us* Research Program

- Advise *All of Us* on research processes from SGM participant perspective
- Train *All of Us* Consortium on SGM cultural competency & humility
- Conduct with SGM participant engagement, education, and recruitment
- Conduct education with SGM-serving organization
- Develop engagement approaches and communications materials
- Educate researchers about *All of Us* Researcher Workbench and its potential for health disparities research
- Conduct SGM-related research projects to demonstrate utility and diversity of *All of Us* data

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The Added Value of *All of Us* to SGM Populations

1. Gap-Filling Data
   - Gender identity, sexual orientation, sex assigned at birth are asked of *all* participants
   - All studies can use these data
   - Meaningful comparisons

2. SGM People Involved at All Phases
   - Active participation *with* UBR people
   - Broad UBR definition
   - Welcoming environment for SGM people

3. Self-Reported, Clinical, and Genomic Data
   - Many different data types and sources
   - Returning data to participants

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See more at: https://www.joinallofus.org/lgbt

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The *All of Us* Research Program

Enroll, Consent and Authorize EHR

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

Answering Surveys

- Six 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

Based on diverse sampling and capacity
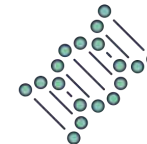
Provide Biosamples*

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

Based on diverse sampling and capacity

Wearables and Digital Apps

- Share data from wearable fitness devices, starting with Fitbit
- More integrations under development

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The *All of Us* Research Program

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.

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Examples for Consideration:
All of Us Controlled Tier (CT) Data

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Sexual Orientation, Gender Identity, Sex (Assigned) in *AoU*

Individual Biospecimen and Participant Data
(Available in the future)

Future ancillary studies
Could recontact participants, use biospecimens, issue new surveys or DHT, enroll in clinical trials

Controlled Tier
(Available Now)
No obvious PII. Genomics, Clinical Narrative data, Data Linkages, Other Data Types

Registered Tier
(Available Now)
Surveys, EHRs, Physical Measurements
Exceeds HIPAA Safe Harbor Standards

Researcher Workbench
ResearchAllofUs.org/Apply/

Public Tier
(Available Now)
Summary Statistics Aggregate Counts

Data Browser
databrowser.researchallofus.org

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Sexual Orientation, Gender Identity, Sex (Assigned) in *AoU*

Currently Asked Questions [Questions appear in this order in "The Basics" PPI module.]

Gender identity	What terms best express how you describe your gender identity? (Check all that apply) • Man • Woman • Non-binary* • Transgender* • None of these describe me, and I'd like to consider additional options* • Prefer not to answer *[The following question is shown if any answer choices marked by * are selected]* Are any of these a closer description to your gender identity? (Check all that apply) • Trans man/Transgender Man/FTM • Trans woman/Transgender Woman/MTF • Genderqueer • Genderfluid • Gender variant • Two-spirit • Questioning or unsure of your gender identity • None of these describe me, and I want to specify (optional free text with "Please specify.")
Sex assigned at birth	What was your biological sex assigned at birth? • Female • Male • Intersex • None of these describe me (optional free text with "Please specify.") • Prefer not to answer
Sexual orientation	Which of the following best represents how you think of yourself? (Check all that apply) • Gay • Lesbian • Straight; that is, not gay or lesbian, etc. • Bisexual • None of these describe me, and I'd like to see additional options* • Prefer not to answer *[The following question is shown if the answer choice marked by * is selected]* Are any of these a closer description of how you think of yourself? (Check all that apply) • Queer • Polysexual, omnisexual, sapiosexual or pansexual • Asexual • Two-spirit • Have not figured out or are in the process of figuring out your sexuality • Mostly straight, but sometimes attracted to people of your own sex • Do not think of yourself as having sexuality • Do not use labels to identity yourself • Don't know the answer • No, I mean something else (optional free text with "Please specify.")

1. **What kind of sexual orientation and gender identity (SOGI) data are collected by *All of Us*?**

2. **How can we identify cisgender and transgender populations in *All of Us*?**

3. **What should I think about when working with *All of Us* and SOGI measures?**

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Classifying Participants using *All of Us* Data Elements

Comparison Group	Gender Identity Participant Survey Response	Sex Assigned at Birth[1] Survey Response	Sexual Orientation Participant Survey Response
Cisgender sexual minority women	"Woman" only	Female	Anyone who answered the sexual orientation item (*i.e.*, not skipped, not missing) and answered anything <u>other than</u> the following answer choices alone or in any combination with each other: • "Straight; that is not gay or lesbian, etc." • "Have not figured out or are in the process of figuring out your sexuality" • "Do not use labels to identify yourself" • "Don't know the answer" • "Prefer not to answer"
Cisgender sexual minority men	"Man" only	Male	Anyone who answered the sexual orientation item (*i.e.*, not skipped, not missing) and answered anything <u>other than</u> the following answer choices alone or in any combination with each other: • "Straight; that is not gay or lesbian, etc." • "Have not figured out or are in the process of figuring out your sexuality" • "Do not use labels to identify yourself" • "Don't know the answer" • "Prefer not to answer"
Transgender women (of any sexual orientation)	• "Woman" only • "Transgender" only • "Trans woman/Transgender Woman/MTF" only • Any combination of the 3 selections above	Male	Any
Transgender men (of any sexual orientation)	• "Man" only • "Transgender" only • "Trans man/Transgender Man/FTM" only • Any combination of the 3 selections above	Female	Any
Gender-expansive people assigned female sex at birth (of any sexual orientation)	• Anyone who answered the gender identity item (*i.e.*, not skipped, not missing) and did **not** select "prefer not to answer" only and does **not** fit into any of the other groups	Female	Any
Gender-expansive people assigned male sex at birth (of any sexual orientation)	• Anyone who answered the gender identity item (*i.e.*, not skipped, not missing) and did **not** select "prefer not to answer" only and does **not** fit into any of the other groups	Male	Any
Cisgender heterosexual women	"Woman" only	Female	"Straight; that is not gay or lesbian, etc." only
Cisgender heterosexual men	"Man" only	Male	"Straight; that is not gay or lesbian, etc." only

Study Example 1: Uterine Cancer & Smoking

Question: What is the relationship between smoking and endometrial cancer?

Inclusion Criteria (beyond criteria for *AoU* participation): having had a uterus

Considerations:

- Smoking prevalence varies among people of different genders.

- *All of Us* collects <u>gender identity</u> and <u>sex assigned at birth</u> and <u>smoking data</u> and <u>cancer data</u>.

- <u>Endometrial cancer</u> can only occur in people who currently have or who had a <u>uterus</u>.

- People who were <u>assigned female sex at birth</u> are *likely* to have been <u>born with a uterus</u>.

- People of <u>different genders</u> (*e.g.,* cisgender women, transgender men, non-binary people) may have been <u>assigned female sex at birth</u>, <u>have a uterus</u>, can get <u>endometrial cancer</u>, and <u>may have different risk factors, outcomes, etc.</u>

- Given available data in AoU <u>"biological sex assigned at birth" NOT "gender identity"</u> should be used

- <u>Gender identity</u> SHOULD also be used to understand differences in risk factors, treatment and outcomes.

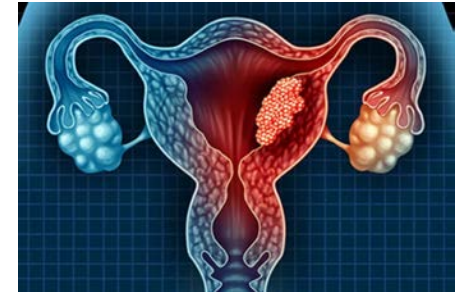THE PRIDE STUDY   PRIDEnet

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Study Example 1: Uterine Cancer & Smoking

Research Question: What is the relationship between smoking and endometrial cancer?

Inclusion Criteria: having had a uterus (in AoU sex assigned at birth == female or intersex)

Example Table 1. Sample characteristics using AoU Data in understanding the link between smoking and endometrial cancer.

	Cisgender women	Transgender men	Gender expansive people assigned female at birth
Age (median, IQR)			
Race (n, %)			
…			
Ethnicity (n, %)			
…			
Education (n, %)			
…			
Smoked at least 100 cigarettes (n, %)			
Current smoker (n, %)			
Sexual Orientation (n, %) *			
Asexual			
Bisexual			
Gay			
Lesbian			
Queer			
Straight, that is not gay or lesbian			
Two-Spirit			
Have not figure out or are in the process of figuring out your sexuality			
Mostly straight, but sometimes attracted to people of your own sex			
Do not think of yourself as having sexuality			
Do not use labels to identify yourself			
Don't know the answer			
No, I mean something else			
Sex Assigned at Birth (n, %)			
Female			
Intersex			
Gravidity (median, IQR)			
Parity (median, IQR)			
BMI (kg/m2) (median, IQR)			
Diabetes (EVER diagnosed) (n, %)			
Hysterectomy (n, %)			
Bilateral salpingoophorectomy (n, %)			
Exogenous hormones: Contraceptives (n, %)			
Exogenous hormones: post-menopausal hormone replacement therapy (estrogen/progestin - any use) (n, %)			
Exogenous hormones: Testosterone (low libido, not gender affirming) (n, %)			
Exogenous hormones: Testosterone (gender affirming) (n, %)			
Up-to-date on cervical cancer screening (n, %)			

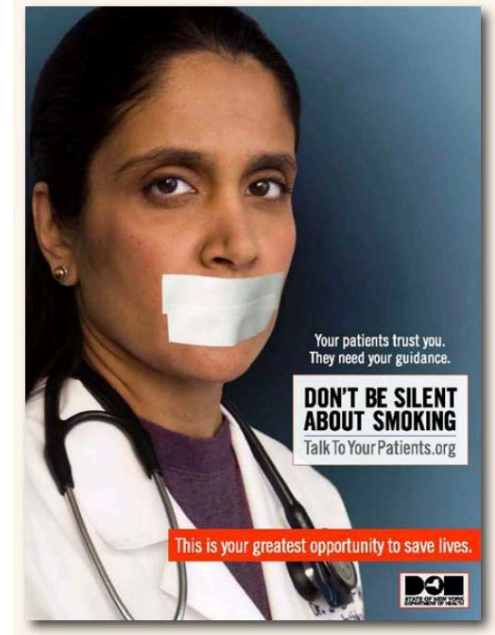THE PRIDE STUDY   PRIDEnet

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Study Example 2: Smoking & Clinic Visits

Question: What is the relationship between being a smoker and frequency of clinical encounters?

Inclusion Criteria (beyond criteria for *AoU* participation): none

Considerations:

- Typically, cisgender men and cisgender women have different patterns of smoking.

- Cisgender men and cisgender women have different patterns clinical encounters.

- Differences previously identified by gender may be driven by differences in sex assigned at birth (*e.g.*, preventative care that people who were assigned female sex would receive - cervical cancer screening, birth control, pregnancy care, *etc.*).

- Cisgender women may identify as women (gender identity) and were assigned female sex at birth.

- People of other genders (*e.g.,* transgender men, non-binary people) may also have been assigned female at birth.

- Women (a gender identity) may have been assigned male sex at birth (*i.e.,* transgender women).

- *All of Us* gathers data on both "gender identity" and "biological sex assigned at birth."

- To study this outcome, it is necessary to consider both gender and sex assigned at birth.

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Study Example 2: Smoking & Clinic Visits

Research Question: What is the relationship between being a smoker and frequency of clinical encounters?

Inclusion Criteria: none

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Example Table 2: Sample characteristics using AoU Data in understanding the link between smoking and number of clinical encounters.

	Men (cisgender, AMAB)	Men (transgender, AFAB)	Non-binary (AFAB)	Non-binary (AMAB)	Women (cisgender, AFAB)	Women (transgender, AMAB)
Age (median, IQR)						
Race (n, %)						
…						
Ethnicity (n, %)						
…						
Sex Assigned at Birth (n, %)						
Female						
Intersex						
Male						
Sexual Orientation (n, %) *						
Asexual						
Bisexual						
Gay						
Lesbian						
Queer						
Straight, that is not gay or lesbian						
Two-Spirit						
Have not figured out or are in the process of figuring out your sexuality						
Mostly straight, but sometimes attracted to people of your own sex						
Do not think of yourself as having sexuality						
Do not use labels to identify yourself						
Don't know the answer						
No, I mean something else						
Education (n, %)						
…						
Smoked 100 cigs lifetime (n, %)						
Current smoker (n, %)						
BMI (kg/m2)						
Hypertension						
Sexually Transmitted Infection, non-HIV (ever) (n, %)						
HIV positive (n, %)						
Diabetes (n, %)						
Gravidity (median, IQR)						
Parity (median, IQR)						
Exogenous hormones: Testosterone or Estrogen (Gender affirming) (n, %)						
Primary care provider seen in the last 12 months (n, %)						
Up to date on cervical cancer screening (n, %)						

AFAB: assigned female sex at birth
AMAB: assigned male sex at birth

General Principles for Research Considering SOGI

1. Make sure the group selected and the data elements make sense together.

2. Make sure to consider whether and how gender *versus* sex (assigned at birth) are important variables in the analysis.

3. Determine *a priori* how groups will be compared and grouped together.

4. There is a difference between self-identification and classification by researchers.

5. Using electronic health record (EHR) data in describing SGM people and/or health experiences may be inaccurate and/or pathologizing.

6. Sexual identity is distinct from sexual behavior. These two components of sexual orientation do not necessary overlap. (We didn't cover this much)

7. Consider how results are presented.

8. SGM people have multiple other identities and experiences.

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Q&A

Take Home Points

1. SGM people are an underserved, understudied, and vulnerable population with notable health and healthcare inequities.

2. PRIDEnet works with the *All of Us* Research Program to ensure national SGM community engagement throughout *All of Us*.

3. Sexual orientation, gender identity, and sex assigned at birth are important variables for understanding SGM health and must be considered in **ALL** research.

4. Ensuring LGBTQ+ visibility and health equity means including LGBTQ+ people & their experiences in **ALL** research going forward. You can help make that happen!

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THANKS!

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Evaluation

https://tinyurl.com/dze8w2f

Check us out on social media!

END