

Disaggregating gender from sex in sexual dysfunction epidemiology.

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Learning Objectives

1. Introduce the sexual and gender minority (SGM) population.
2. Understand The PRIDE Study design
3. Draft results using The PRIDE Study to disaggregate gender from sex in sexual dysfunction epidemiology.

Disclosures

I have no financial or professional conflicts of interest related to this presentation.

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- Stanford MCHRI
- Private philanthropy

Consulting

- Hims Inc. (2019– present)
- Folx Inc. (2019 - present)
- Ibis Reproductive Health (2017 – 2019)

Sexual and Gender Minority (SGM) People



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The Population: Sexual & Gender Minorities

People who are not heterosexual or not cisgender

- **Lesbian**
- **Gay**
- **Bisexual**
- **Transgender**
- **Queer**
- and many others!



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SGM Population Estimates

U.S. Adults Identifying as LGBT, 2012-2017

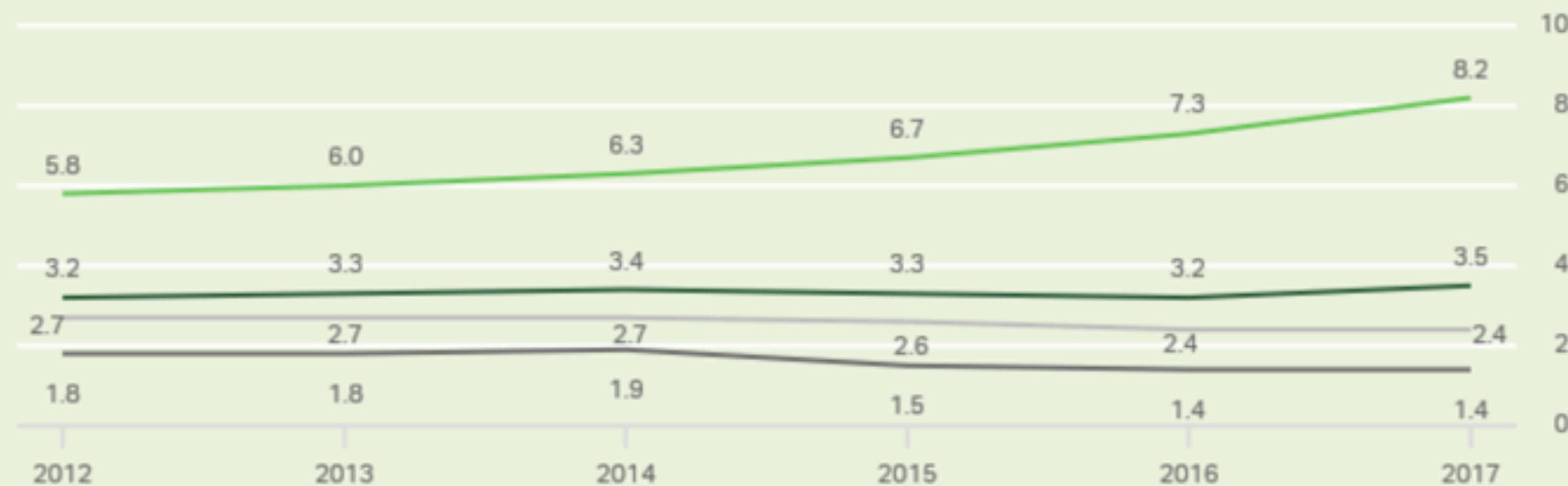
Do you, personally, identify as lesbian, gay, bisexual or transgender?

	2012	2013	2014	2015	2016	2017
	%	%	%	%	%	%
% LGBT	3.5	3.6	3.7	3.9	4.1	4.5

GALLUP DAILY TRACKING

Percentage of Americans Identifying as LGBT, by Birth Cohort

■ % Millennials (1980-1999) ■ % Generation X (1965-1979) ■ % Baby boomers (1946-1964)
■ % Traditionalists (1913-1945)



GALLUP DAILY TRACKING

SGM people at all age groups.



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Gallup Daily Tracking



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SGM Population Estimates

Percentage of U.S. Adults Identifying as LGBT by Gender and Race/Ethnicity, 2012-2017

	2012	2013	2014	2015	2016	2017
	%	%	%	%	%	%
Gender						
Male	3.4	3.5	3.6	3.7	3.7	3.9
Female	3.5	3.6	3.9	4.1	4.4	5.1
Race/Ethnicity						
White, non-Hispanic	3.2	3.3	3.4	3.5	3.6	4.0
Black, non-Hispanic	4.4	4.0	4.6	4.5	4.6	5.0
Hispanic	4.3	4.7	4.9	5.1	5.4	6.1
Asian, non-Hispanic	3.5	3.3	4.2	4.9	4.9	4.9

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SGM status is not unique to a particular race/ethnicity.



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SGM Population Estimates

Percentage of U.S. Adults Identifying as LGBT by Annual Household Income and Educational Attainment, 2012-2017

	2012	2013	2014	2015	2016	2017
	%	%	%	%	%	%
Less than \$36,000	4.7	4.5	4.9	5.1	5.5	6.2
\$36,000 to <\$90,000	3.1	3.4	3.5	3.9	4.0	4.7
\$90,000 or more	3.0	3.5	3.6	3.6	3.7	3.9
High school or less	3.5	3.5	3.9	4.1	4.1	4.5
Some college	3.8	3.9	3.9	3.9	4.1	4.7
College graduate	2.9	3.3	3.5	3.6	4.1	4.4
Postgraduate	3.3	3.6	3.7	3.9	3.9	4.3

GALLUP DAILY TRACKING

SGM people in all income brackets and educational levels.



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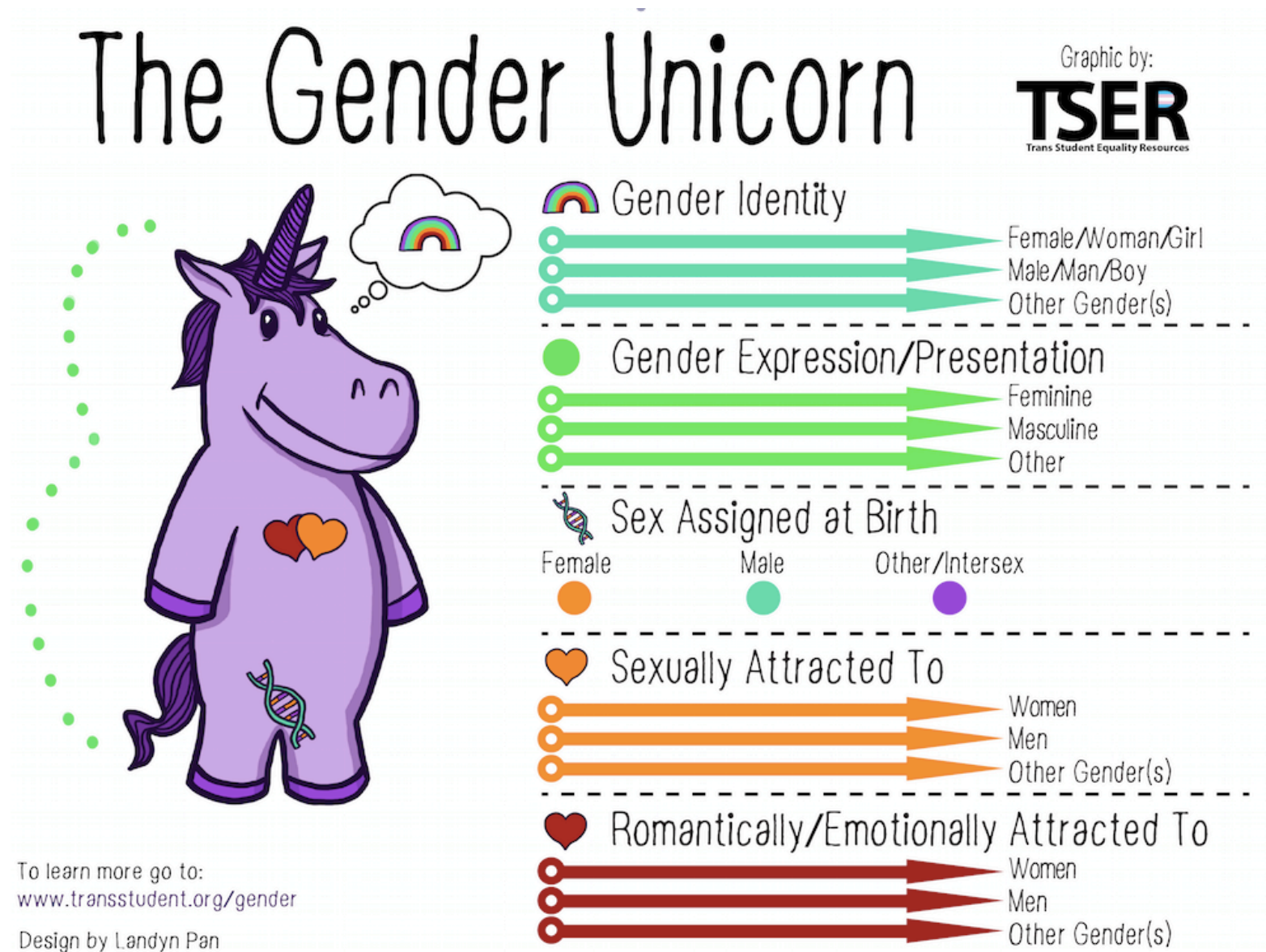
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Gallup Daily Tracking



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Sex vs. Gender



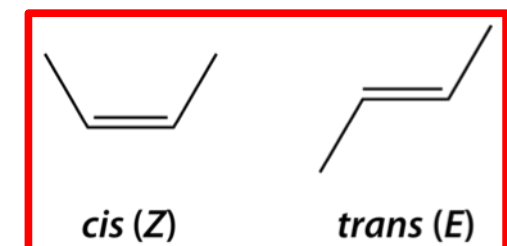
Transgender (Trans*) is an umbrella term...

For persons whose gender identity, gender expression, or behavior does not conform...to that *typically associated* with the sex to which they were assigned at birth.

Contrast to cisgender....
(where gender and sex assigned at birth do conform....)

**“Sex (AAB) is what’s in your genes/ jeans.
Gender identity is what’s between your ears.”**

**“Gender identity is who you go to bed as.
Sexual orientation is who you go to bed with.”**



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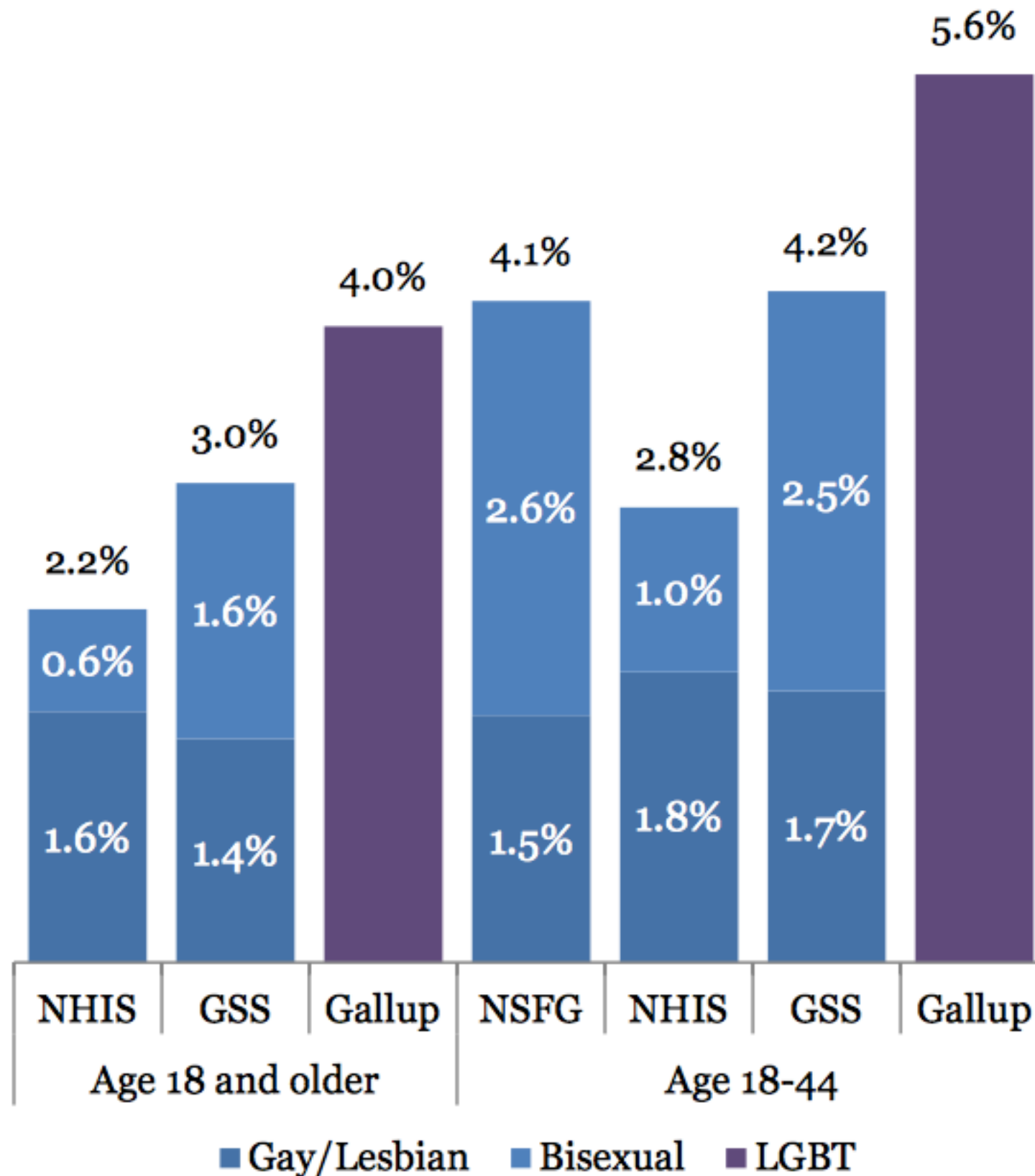


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Population Estimates



Massachusetts BRFSS
0.5% transgender

Estimated Totals
LGB ~ 6-19 Million
T ~ 1.5 Million

Conron KJ et al. Transgender health in Massachusetts: results from a household probability sample of adults. *Am J Pub Health*, 2012.

Gates GJ. LGBT Demographics: Comparisons among population-based surveys? The Williams Institute, UCLA School of Law, 2014.



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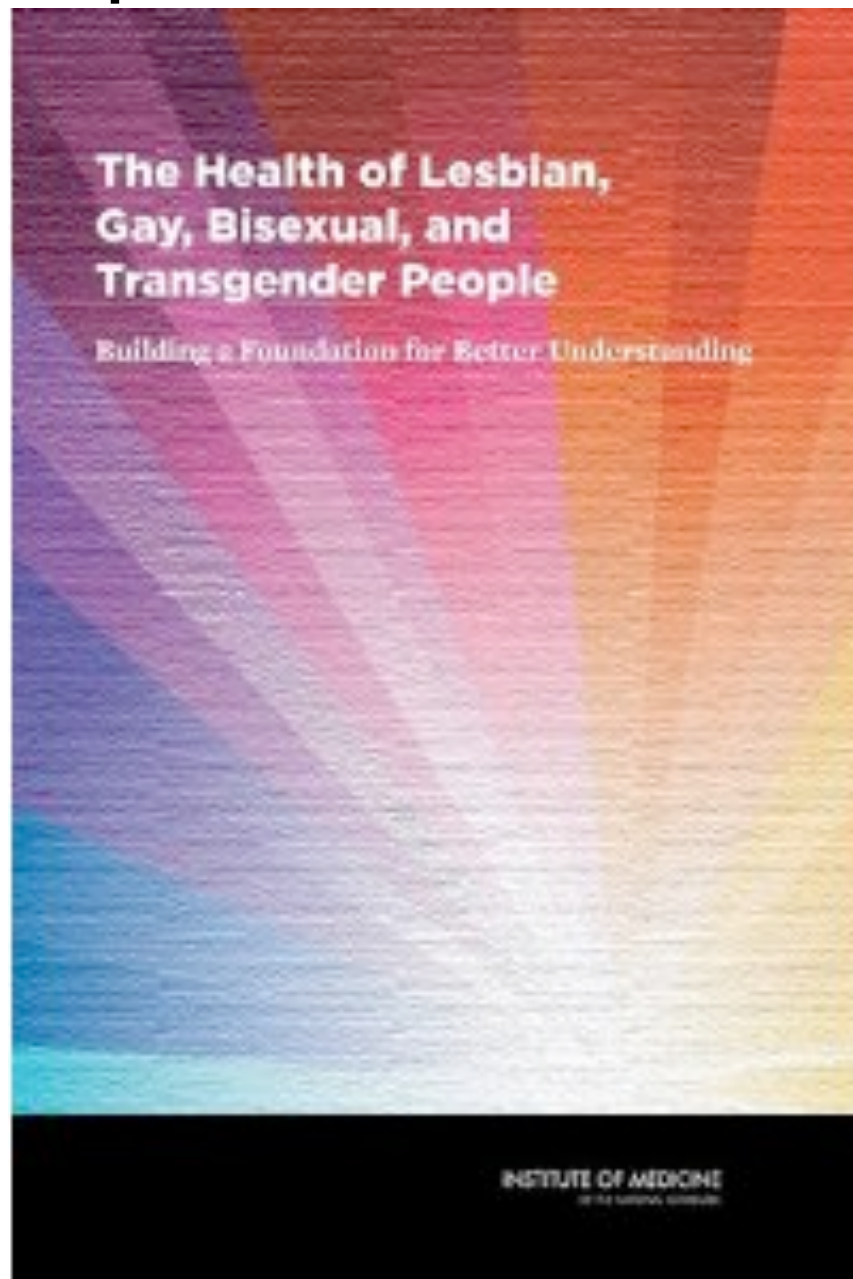
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SGM Health Disparities

In 2011, The National Institutes of Health requested the Institute of Medicine conduct a report on the health of LGBT people



“The relative **lack of population-based data** presents the greatest challenge to describing the health status and health-related needs of LGBT people.”



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The PRIDE Study & PRIDEnet: Community-Engaged Research



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The PRIDE Study



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YOUR STORY. YOUR HEALTH.

**Population
Research in
Identity and
Disparities for
Equality**

Primary Question

How does being a sexual or gender minority influence physical, mental, and social health?



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The PRIDE Study: Overview



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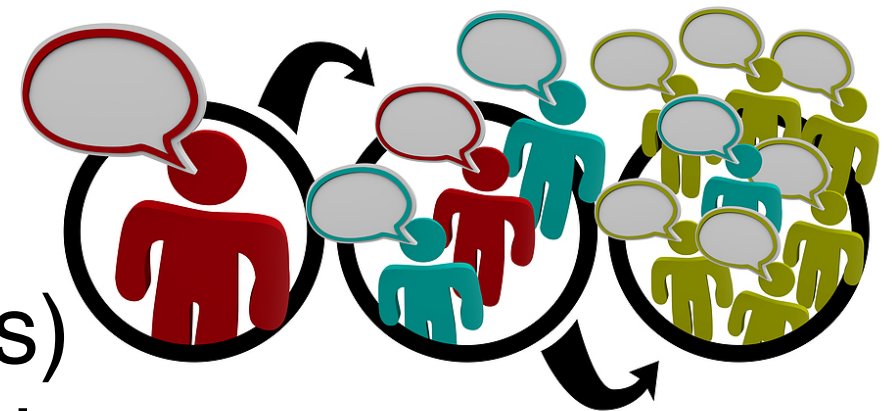
Design

- National
- Online
- Prospective
- Longitudinal dynamic cohort study



Inclusion

- Be a sexual and/or gender minority
- Be at least 18 years of age
- Live in the United States (& territories)
- Comfortable reading/writing in English



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The PRIDE Study: Phases



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YOUR STORY. YOUR HEALTH.

PHASE 1

Community Listening/Pilot

- Began June 25, 2015
- iPhone app
- SGM-generated research questions & health priorities
- Health surveys
- Develop Phase 2 with participant input

~18,000 participants

PHASE 2

Longitudinal Data Collection

- Launched May 2017
- Custom web platform
- Detailed **participant profile**
 - Demographics
 - Medical/surgical history
 - Medications
- **Annual health questionnaire**
- **Ancillary studies**

~ 21,000 participants



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The PRIDE Study Research Platform

The screenshot shows the PRIDE Study Research Platform dashboard for user Gary Smith. The interface includes a sidebar with navigation options: My Dashboard, My Messages, My Profile, My Health, My Devices, and Other Opportunities. The main content area is divided into several sections:

- WELCOME, Gary**: A personalized greeting at the top of the main content area.
- ACTIVITIES**: A section with three green buttons: "Tell us about your living environment", "Complete your medical profile", and "Provide emergency contact information".
- SURVEYS**: A section with three survey cards: "Entry Questionnaire", "2019 Annual Questionnaire" (marked as NEW), and "Sun & Skin Survey" (marked as NEW). Each card has a "BEGIN" button.
- INSIGHTS**: A section with two main components:
 - Surveys completed (past 12 mos.)**: A bar chart showing 9 of 15 surveys completed. The legend indicates "Completed survey(s)" in green and "Possible survey(s)" in grey. The x-axis shows months from JAN to DEC.
 - Participants like me**: A section showing demographic data for participants with similar attributes to the user. It includes categories like Gender Identity, Sex Assigned at birth, Sexual orientation, and Race.
- Total participants: 16428 individuals**: A summary statistic at the bottom of the dashboard.



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Lunn *et al.*, JAMIA, 2019.



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Sexual Function and Dysfunction



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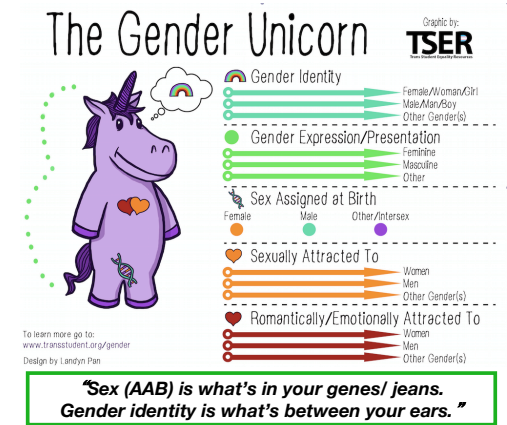
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Sexual Dysfunction in SGM people

SD: Multidimensional challenges to sexual function or pleasure

- Multiple assessment tools

- Usually assume gender and sex assigned at birth



Draft methods and results redacted - please see:
<https://pridestudy.org/research>
for future publications

Assessing Sexual Function

Table 1: Characteristics, PRIDE respondents with a vagina

Draft methods and results redacted - please see:
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for future publications



Draft Assessment of Sexual Function

Draft methods and results redacted - please see:
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for future publications



Take Away Messages

1. SGMs are an understudied and vulnerable population for whom much research does not apply.
2. The PRIDE Study and PRIDEnet are using technology to engage researchers and SGM communities in partnership.
3. Some measures might work well for SGM people but concepts will still need to be re-imagined.



THANKS!

**Join the study!
Sign-up for our mailing list!
Contact us to get involved!
pridestudy.org**

junoom@stanford.edu



Check us out on social media!