Bacon, Eggs, and Data: The Importance of SOGI Data Collection
February 14, 2018 | Webinar

Moderator: Regina R. Washington, DrPH
Program Director
LGBT HealthLink, a program of CenterLink

Guest Speaker: Mitchell R. Lunn, MD, MAS, FASN
Assistant Professor of Medicine
Co-Director, The PRIDE Study
About Us
CenterLink

✓ Nonprofit founded in 1994
✓ Helps develop strong, sustainable LGBT community centers with a national network of 190+ organizations
✓ Builds a thriving network of centers for healthy, vibrant communities
✓ Recognized by the White House as a “Champion of Change”
LGBT HealthLink

➢ Advance LGBT wellness by addressing LGBT tobacco and cancer health disparities

➢ Link people with information and promote adoption of best practices

➢ One of eight CDC-funded cancer and tobacco disparity networks

www.lgbthealthlink.org
LGBT HealthLink Promotes:

- Tobacco prevention & cessation
- Decreased second-hand smoke exposure
- Cancer prevention and screenings
- Improved quality of life for those with cancer
LGBT HealthLink Provides:

➢ Technical Assistance
➢ Trainings/Webinars/Presentations
➢ Needs Assessment Tool
➢ Sample non-discrimination policies
➢ Other resources such as educational materials
➢ Tobacco Census

➢ Cancer Assessment of Community Level of Readiness
➢ Cross-sectoral connections between health systems, providers, community centers, and departments of health
➢ Linkages for information and best and promising practices
LGBT HealthLink Team

Dr. Regina R. Washington
Program Director

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Donna Solomon-Carter
Program Specialist

Quiviya Eldridge
Program Evaluator

Lora Tucker Eldridge
CenterLink CEO
Bacon, Eggs, and Data!

The Importance of SOGI and other SGM Health-Related Data

Mitchell R. Lunn, MD, MAS, FASN
Assistant Professor, Division of Nephrology, Department of Medicine
Affiliate Faculty, Center for Vulnerable Populations
University of California, San Francisco

Co-Director, The PRIDE Study
Principal Investigator, PRIDEnet
Principal Investigator, All of Us Research Program National Sexual & Gender Minority Engagement Network

LGBT HealthLink Webinar Series
CenterLink, The Community of LGBT Centers
Fort Lauderdale, Florida

14 February 2018
Happy Valentine’s Day
My Identity & Pronouns

Gay cisgender man
I use he/him/his pronouns.
I talk fast.

@MitchellLunn
@ThePRIDESTudy
Disclosures

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

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- National Institutes of Health (T32 DK007219, OT2 OD025276)
- Patient-Centered Outcomes Research Institute (PPRN-1501-26848)

Software Development
- THREAD Research

Employer
- University of California, San Francisco
Learning Objectives

1. Describe health and health care disparities faced by sexual and gender minority (SGM) people and the historical context underlying SGM stigma and discrimination

2. Describe the current state of sexual orientation and gender identity (SOGI) data collection

3. Increase knowledge about The PRIDE Study and PRIDEnet

4. Learn why SGM research participation is important

5. Describe strategies used to engage vulnerable populations
Today’s Plan

• SGM People are Understudied, Underserved, & Vulnerable

• Collecting Sexual Orientation and Gender Identity

• The PRIDE Study & SGM Community Engagement
SGMs are Underserved, Understudied, and Vulnerable to Poor Health
People who are not heterosexual or not cisgender

- Lesbian
- Gay
- Bisexual
- Transgender
- Queer
- and many others!
Population Estimates

Massachusetts BRFSS
0.5% transgender
(131/28,662)

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


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

## U.S. Adults Identifying as LGBT, 2012-2016

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

<table>
<thead>
<tr>
<th></th>
<th>2012 %</th>
<th>2013 %</th>
<th>2014 %</th>
<th>2015 %</th>
<th>2016 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>% LGBT</td>
<td>3.5</td>
<td>3.6</td>
<td>3.7</td>
<td>3.9</td>
<td>4.1</td>
</tr>
<tr>
<td>Estimated number of LGBT</td>
<td>8.3 million</td>
<td>8.673 million</td>
<td>9.18 million</td>
<td>9.652 million</td>
<td>10.052 million</td>
</tr>
</tbody>
</table>

## Percentage of U.S. Adults Identifying as LGBT by Birth Cohort, 2012-2016

<table>
<thead>
<tr>
<th>Birth Cohort</th>
<th>2012 %</th>
<th>2013 %</th>
<th>2014 %</th>
<th>2015 %</th>
<th>2016 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Millennials (1980-1998)</td>
<td>5.8</td>
<td>6.0</td>
<td>6.3</td>
<td>6.7</td>
<td>7.3</td>
</tr>
<tr>
<td>Generation X (1965-1979)</td>
<td>3.2</td>
<td>3.3</td>
<td>3.4</td>
<td>3.3</td>
<td>3.2</td>
</tr>
<tr>
<td>Baby boomers (1946-1964)</td>
<td>2.7</td>
<td>2.7</td>
<td>2.7</td>
<td>2.6</td>
<td>2.4</td>
</tr>
<tr>
<td>Traditionalists (1913-1945)</td>
<td>1.8</td>
<td>1.8</td>
<td>1.9</td>
<td>1.5</td>
<td>1.4</td>
</tr>
</tbody>
</table>
Homosexuality as Pathology

“Homosexuality” was included in the Diagnostic and Statistical Manual of Mental Disorders (DSM) until 1973 (removed in DSM-III)

Hunt for the ‘gay gene’ or other causes in order to fix/repair

Conversion (reparative) therapy
The HIV Epidemic

THE NEW YORK TIMES,
FRIDAY, JULY 3, 1981

RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men in New York and California — 8 Died Inside 2 Years

By LAWRENCE H. GROSS

Doctors in New York City have diagnosed among gay men in the last two years 41 cases of a rare and deadly form of cancer. Eight of these patients died within less than 24 months after the diagnosis was made.

The cause of the outbreak is unknown, but it has been suggested that the patients may have had some kind of sexual contact that brought them into contact with the cancer.

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THE PRIDE STUDY

PRIDEnet

UCSF
University of California
San Francisco
Neglected by Government and Medicine

A.I.D.S.: WE NEED RESEARCH, NOT HYSTERIA!
Neglected by Government and Medicine
SMOKING IS THE LGBT COMMUNITY’S BIGGEST HEALTH BURDEN

$7.9 billion
Estimated annual LGBT money spent on cigarettes

20% U.S. Population

33% LGBT 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

References upon request.
SGM Health Disparities

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

5% GENERAL YOUTH POPULATION
40% HOMELESS YOUTH POPULATION

GAY, LESBIAN, BISEXUAL, TRANSGENDER
STRAIGHT

References upon request.
It’s More than Just (Health) Disparities

- Documented health disparities… but…
  - In some cases, limited by scope and study design

- Most SGM health-related topics remain unstudied
  - Do exogenous hormones affect heart disease? Cancer?
  - What breast cancer screening protocols are optimal?
  - How do social interactions improve well-being of bisexual cisgender men?

- Various barriers remain.
Persistent Discrimination: Employment
SGM Designation as Health Disparity Pop’n

National Institute on Minority Health and Health Disparities

October 2016

Director’s Message
October 6, 2016

Sexual and Gender Minorities Formally Designated as a Health Disparity Population for Research Purposes

On behalf of many colleagues who have worked together to make today possible, I am proud to announce the formal designation of sexual and gender minorities (SGMs) as a health disparity population for NIH research. The term SGM encompasses lesbian, gay, bisexual, and transgender populations, as well as those whose sexual orientation, gender identity and expressions, or reproductive development varies from traditional, societal, cultural, or physiological norms.

Mounting evidence indicates that SGM populations have less access to health care and higher burdens of certain diseases, such as depression, cancer, and HIV/AIDS. But the extent and causes of health disparities are not fully understood, and research on how to close these gaps is lacking.

In addition, SGM populations have unique health challenges. More research is needed to understand these challenges, such as transgender people taking exogenous hormones.

Progress has been made in recent years, with gains in legal rights and changing social attitudes. However, stigmatization, hate-violence, and discrimination are still major barriers to the health and well-beings of SGM populations. Research shows that sexual
Collecting Sexual Orientation and Gender Identity (SOGI)
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.”
Sexual orientation and gender identity are **not** collected

**SOGI removed** from “Subjects Planned” document

SO will remain in “Census Barriers, Attitudes and Motivators Survey”
SO in NHIS and NHANES

**National Health Interview Survey (2013-)**
Which of the following best represents how you think of yourself?
- Lesbian or gay
- Straight, that is, not lesbian or gay
- Bisexual
- Something else
- I don’t know the answer

**National Health and Nutrition Examination Survey (2001-)**
Do you think of yourself as…?
- Heterosexual or straight (attracted to ___)
- Homosexual or gay (attracted to ___)
- Bisexual (attracted to men and women)
- Something else
- You’re not sure
SO in Large Cohort Studies

Nurses’ Health Study (1995, 2009)
Whether or not you are currently sexually active, what is your sexual orientation or identity? (Please choose one answer).
- Heterosexual
- Lesbian, gay, or homosexual
- Bisexual
- None of these
- Prefer not to answer

Framingham Heart Study
A Project of the National Heart, Lung, and Blood Institute and Boston University

None
Youth Risk Behavior Surveillance System (2015-)

Which of the following best describes you?
• Heterosexual (straight)
• Gay or lesbian
• Bisexual
• Not sure

During your life, with whom have you had sexual contact?
• I have never had sexual contact
• Females
• Males
• Females and males
SOGI in BRFSS

Behavioral Risk Factor Surveillance System (2013-)

Do you consider yourself to be:
• Straight
• Lesbian or gay
• Bisexual
• Other
• Don’t know/Not sure
• Refused

Do you consider yourself to be transgender?
• Yes, Transgender, male-to-female
• Yes, Transgender, female-to-male
• Yes, Transgender, gender non-conforming
• No
• Don’t know/not sure
• Refused
SOGI in BRFSS

Sexual orientation and gender identity data collection on the 2015 BRFSS

- No SOGI data collection
- Used the SOGI module to collect SOGI data
- Did not use the module to collect SOGI data
- Used the SOGI module in 2014 but discontinued it in 2015

Note: Micronesia and Samoa do not currently field BRFSS. Palau did not respond to inquiries and is excluded from this analysis.
All of Us Research Program

- Research cohort with >1 million people
- Diverse
- Everyone will be asked SOGI
- Participants will…
  - Answer surveys
  - Provide consent to access EHR
  - Be measured (height, weight, BP, etc.)
  - Provide biological specimens (blood, urine)

- First time SGM people are involved in design of a large national, research study from the beginning

joinallofus.org/lgbt
The Cycle

SGM Health Disparities Persist

Lack of SGM Health Data

Health Workers Don’t Ask about SO/GI

SGM Health Disparities Unknown
Poor Provider Education

Discussing STIs: doctors are from Mars, patients from Venus

V Verhoeven, K Bovijn, A Helder, L Peremans, I Hermann, P Van Royen, J Denekens and D Avonts

Reasons for Not Taking a Sexual History

• Fear of being intrusive
• Lack of genital complaints
• Ignorance regarding clinical relevance
• Lack of knowledge about what/how to ask
• Unsure how to respond
• Time
• Cultural differences
• Age of patient / Age of provider
• Sex of patient / Sex of provider (F ask more than M)
• Presence of third party in exam room / home
How to Ask

1. Remember SGM history of stigma/discrimination
2. Determine purpose of SOGI data collection (clinical care, research, etc.)
3. Create welcoming physical environment
4. Create welcoming interpersonal environment
5. Practice!

E-mail me for role play scenarios!
SGM-Inclusive Policies and Programs

Inclusive non-discrimination policies

Inclusive patient visitation policies

Same-sex partner benefits

SGM visibility program
Two-Step Method to Assess Gender Identity

The “Two-Step” Method (*in this order*)
1. Assess current gender identity (allow multiple selections)
2. Assess sex assigned at birth on original birth certificate

then…
• Assess sexual orientation (allow multiple selections)

Assessing GI and sex assigned at birth permits identification of non-cisgender people
Two-Step Method to Assess Gender Identity

Assessing GI and sex assigned at birth permits identification of non-cisgender people

I am a (non-cisgender) woman

How would you describe your current gender identity? (Select all that apply.)
- Genderqueer
- Man
- Transgender Man (Female-to-Male)
- Woman
- Transgender Woman (Male-to-Female)
- Another Gender Identity [text box]

What sex were you assigned (on your birth certificate)?
- Female
- Male
Use SGM-Competent Forms

What is your current gender identity? (Please check all that apply.)
• Female
• Male
• TransFemale / Transwoman
• TransMale / Transman
• Genderqueer
• Another gender identity (please specify) ___________
• Decline to state

What sex were you assigned at birth?
• Female
• Male
• Decline to state

Consider using fill-in for GI, sex, and SO (depending on your needs)
Specific Interview Tips

• Use language **free of assumptions**
  Don’t start with: “Are you married?” or “What form of birth control do you use?”

• Ask about **specific sexual activities** in a direct, non-judgmental manner to assess for high-risk behavior.
  **Remember asexuality and pansexuality.**

• Normalize discussion of often **stigmatized** content
  *(e.g., “atypical” sex practices, gender identity and expression)*

• Encourage patients to obtain legal documents that **specify who can make medical and/or legal decisions** for them in accordance with state laws
The PRIDE Study & SGM Community Engagement (PRIDEnet)
The PRIDE Study

THE PRIDE STUDY
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?

pridestudy.org
The PRIDE Study: Guiding Principles

- Low Burden
- Participants Know Best
- Easily Accessible
- Give Back to SGM Community
- Engaged from End-to-End
The PRIDE Study: Overview

THE PRIDE STUDY
YOUR STORY. YOUR HEALTH.

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
• Comfortable reading/writing in English
The PRIDE Study: Phases

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

~10,400 participants
The PRIDE Study: Overview

THE PRIDE STUDY
YOUR STORY. YOUR HEALTH.

Recruitment
• Electronic
  • Social media
  • Mobile apps
  • Online advertisements
• Community SGM- and health-focused organizations (PRIDEnet)
• Health care providers
Community Engagement Arm - operationalize how to engage people at every step of the process

• The PRIDE Study
• *All of Us* Research Program

We do this through…

• Community Partner Consortium
• Participant Advisory Board (PAC)
• Engagement activities and communications
Community Partners
The PRIDE Study: Phase I

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
Safety of the Internet

“On the Internet, nobody knows you’re a dog.”
Nominate research questions to the community

3,544 Conversations
5,063 Replies
60,522 Votes
Community Forum

**Top Health Concerns / Topics**

- Depression and anxiety
- Teen suicide
- Role of family support
- Violence among trans* women of color
- Role of race/ethnicity in coming out
- Specific LGBTQ-competent training for healthcare providers
- High school sex education for LGBTQ students
How would you describe your current gender identity? (Select all that apply.)
- Genderqueer
- Man
- Transgender Man (Female-to-Male)
- Woman
- Transgender Woman (Male-to-Female)
- Another Gender Identity [text box]

What sex were you assigned (on your birth certificate)?
- Female
- Male

15.4% were gender minorities (i.e., not cisgender)

Among gender minorities…
- 79.1% selected something other than exclusively trans*, woman, man
- 16.5% selected “another GI” exclusively
- 38.1% selected more than one GI

N=16073; unpublished data
How would you describe your current sexual orientation? (Select all that apply.)
- Asexual
- Bisexual
- Gay
- Lesbian
- Queer
- Questioning
- Straight/Heterosexual
- Another Sexual Orientation [text box]

98.1% were sexual minorities (i.e., not straight)

Among sexual minorities...
- 28.8% selected something other than exclusively bisexual, gay, lesbian
- 4.3% selected “another SO” exclusively
- 17.1% selected more than one SO

N=16073; unpublished data

Juno Obedin-Maliver, MD, MPH, MAS
Every gender identity and sexual orientation was selected by every race and ethnicity except AI/AN.

Racial minorities were more likely than white participants to select less common sexual orientations and gender identities (p<0.001).

Hispanic participants were more likely than non-Hispanics to select less common gender identities (p<0.001) but not sexual orientations.

N=16073; unpublished data

Juno Obedin-Maliver, MD, MPH, MAS
Reaching Diverse Populations

@mitchelllunn says @ThePRIDESTudy is building a web version b/c reach of the iPhone isn't "diverse enough" fastcompany.com/3058125/its...

In Its First Year, Has Apple's ResearchKit Revolutionized Medical Research?
100,000 people have participated in studies powered by the service.
fastcompany.com
The PRIDE Study: Phases

PHASE 2

Longitudinal Data Collection

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

~10,400 participants
Web-Based Enrollment

ELIGIBILITY

Do you live in the United States?  
Yes  No

Do you identify as lesbian, gay, bisexual, transgender, queer (LGBTQ), or another sexual and/or gender minority? ☑

What is your date of birth? (MM/DD/YYYY)

Are you able to read and understand English?  
Yes  No

CONTINUE
Web-Based Enrollment

You are eligible to join The PRIDE Study!

OUR PLEDGE

We promise to:
- Keep your information private and secure
- Respect your time
- Make things easy
- Keep you up-to-date
- Take your interests to heart

You promise to:
- Check in as often as you can
- Tell us about your life and what you like
- Participate!

Learn more about how we keep your information safe
Click here

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: The Population Research in Identity and Disparities (PRIDE) Study

Research Project Directors:
Mitchell R. Lunn, MD
Real-Time Stats

Participants like me

<table>
<thead>
<tr>
<th>Gender Identity</th>
<th>Sexual Orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>28% Male</td>
<td>28% Gay</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>78% White</td>
<td></td>
</tr>
</tbody>
</table>

21% of individuals share the same 3 attributes with you

Total participants

6885 individuals

Timeframe
- Last 3 Months

Gender Identity
- All

Sex Assigned at Birth
- All

Sexual Orientation
- All

Age Range
- All

Race
- All

State
- All

Health Condition
- All
SOGI in The PRIDE Study

**Current Gender Identity (Check all that apply):**
- Genderqueer
- Transgender Woman
- Transgender Man
- Man
- Woman
- Another gender identity

**Current Sexual Orientation (Check all that apply):**
- Asexual
- Lesbian
- Questioning
- Another sexual orientation
- Bisexual
- Pansexual
- Same-gender loving
- Gay
- Queer
- Straight/Heterosexual
SOGI in The PRIDE Study

Currently unchanged
Evaluating write-in responses

Added 2 new responses
We will study health differences between identities
Opening the Front Door

ANCILLARY STUDIES

• Collaborative spirit to support academic researchers
• Research Advisory Committee and Participant Advisory Committee ensure appropriateness
• Types of Ancillary Studies
  • Manuscript (existing/planned data collection)
  • New elements (survey, biospecimen, intervention)
• Proposal form available now
Pending Ancillary Studies

- Sun protection behaviors
- Association of trauma and migraine
- Body dysmorphia and disordered eating
- Breast cancer screening experiences
- Physical and mental health of LGBT elders
- PrEP knowledge, experiences, stigma
- Employment discrimination

We want you
Take Away Messages

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

2. Collecting data, especially SOGI, will help us understand the health and health-related needs of SGM people. We must advocate for/do this wherever and whenever possible.

3. The PRIDE Study uses community engagement to improve SGM health research for our diverse communities.

4. *All of Us* Research Program will collect SOGI on all participants and serve as a national research resource.

5. The PRIDE Study and PRIDEnet are using technology to engage researchers and SGM communities in partnership.
Acknowledgements

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Leslie Suen, MD
THANKS!
mitchell.lunn@ucsf.edu
pridestudy.org
joinallofus.org/lgbt

Join the Study!
Sign-up for our Mailing List!
JOIN THE MOVEMENT TO ACHIEVE LGBT HEALTH EQUITY!

www.mylgbthealthlink.org

HealthLink members have access to:

• Weekly LGBT Health News Roundup
• Scholarships to help support and promote leadership in LGBT health
• Members-only online networking groups
• Exclusive webinars and resources available for download
• Co-branding opportunities