# Methodologies to Sustaining Community Engagement & Partnerships in Genomics Research

**Mitchell R. Lunn, MD, MAS, FACP, FASN (he/him)**
Associate Professor, Department of Medicine (Nephrology)
Associate Professor, Department of Epidemiology & Population Health
Co-Director, The PRIDE Study and PRIDEnet

**Sustaining Community Engagement in Genomics Research: A Workshop**
**National Academies**
**17 July 2024**

THE PRIDE STUDY PRIDEnet

Stanford MEDICINE

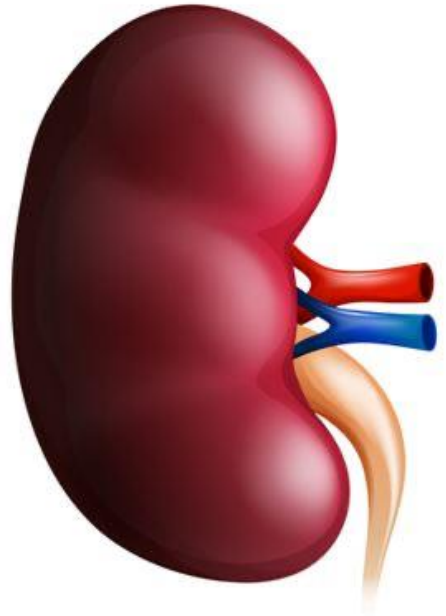
# Disclosures

**Funding**
- National Institutes of Health (T32 DK007219, OT2 OD025276, K12 DK111028, R21 MD015878, R21 CA256759, R01 DA052016, R01 CA237670)
- Patient-Centered Outcomes Research Institute (PPRN-1501-26848, PPRN-EA-00050)
- Society for Family Planning (I1, I2)
- Stanford Maternal Child Health Research Institute
- Private philanthropy

**Consulting**
- Hims, Inc. (2019 – present)
- Folx, Inc. (2019 – present)
- Otsuka Pharmaceutical Development and Commercialization, Inc. (2023)
- American Dental Association (2024)

**Software Development**
- THREAD Research

# My Identities & Pronouns




@MitchellLunn
@ThePRIDEstudy

THE PRIDE STUDY PRIDEnet

Stanford MEDICINE

# My Goal for This Talk

**Inspire thought and conversations about intentionally designing community engagement strategies to engage, welcome, and affirm minoritized and/or underrepresented communities**

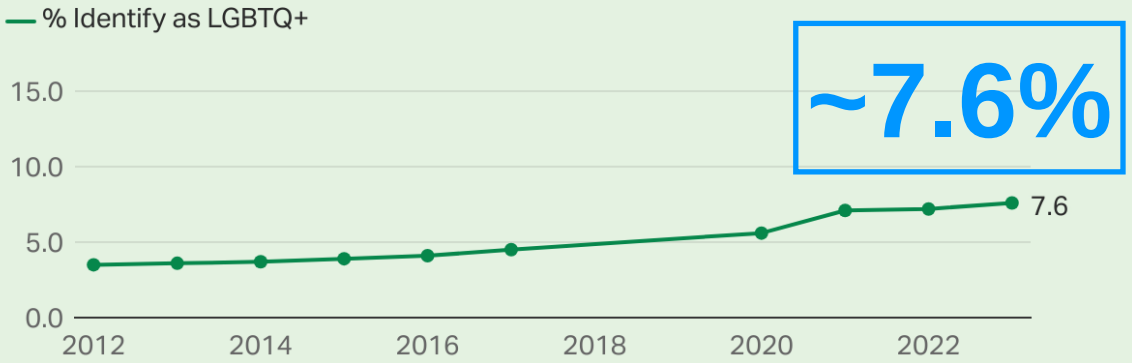
Stanford MEDICINE

# Sexual and Gender Minority Communities

# SGM Population Estimates

**Americans' Self-Identification as Lesbian, Gay, Bisexual, Transgender, or Something Other Than Heterosexual, 2012-2023**

Which of the following do you consider yourself to be? You can select as many as apply. Straight or heterosexual; Lesbian; Gay; Bisexual; Transgender




Respondents who volunteer another identity (e.g., queer; same-gender-loving; pansexual) are recorded as "Other LGBTQ+" by interviewers. These responses are included in the LGBTQ+ estimate.
Data were not collected in 2018 and 2019.
2012-2013 wording: Do you, personally, identify as lesbian, gay, bisexual or transgender?

GALLUP

**SGM (*i.e.*, LGBTQIA+) people represent ~7.6% of the US.**

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

**SGM people at all age groups.**

**SGM identity has not been collected on US Census (or ACS).**


THE PRIDE STUDY PRIDEnet

Stanford MEDICINE

# Why Community Engagement?

# Why Community Engagement? (The Problem)

- Community members have been marginalized
- Community members have been disrespected
- Community members have been “researched” and used
- Communication about results usually never happens


# Why Community Engagement?


**It’s time to start (re)building relationships.**

# PRIDEnet: A National Community Engagement Network

# PRIDEnet

CATALYZING LGBTQ HEALTH RESEARCH

## Community Engagement

- Activities that excite and involve SGM people in a research project
- Based on a set of values and principles

**Transactional** → **Transformational**

*"Do this for me."*

*"Let's create something new and better together."*

# PRIDEnet supports the meaningful engagement of LGBTQ+ people in every step of the research process.

*Helicopter researchers are doing disservice to communities. You must bring holistic perspective and service provision if you want to support not-yet-researched communities.*

Session Attendee - *Visibility is Viability: Envisioning a Black, Queer, Southern Research Agenda*

*I think it's a really important question to ask about what is the research agenda that communities need... one thing I really love about The PRIDE Study is the focus you have on building connections with communities.*

Session Attendee - *Visibility is Viability: Envisioning a Black, Queer, Southern Research Agenda*

PRIDEnet

# PRIDEnet: How We Do It

# Engagement from Beginning to End (& Beyond)

**PRIDEnet**
CATALYZING LGBTQ HEALTH RESEARCH

**Ideal State**: Identifying, recruiting, engaging, and integrating community perspectives in **ALL** stages of research

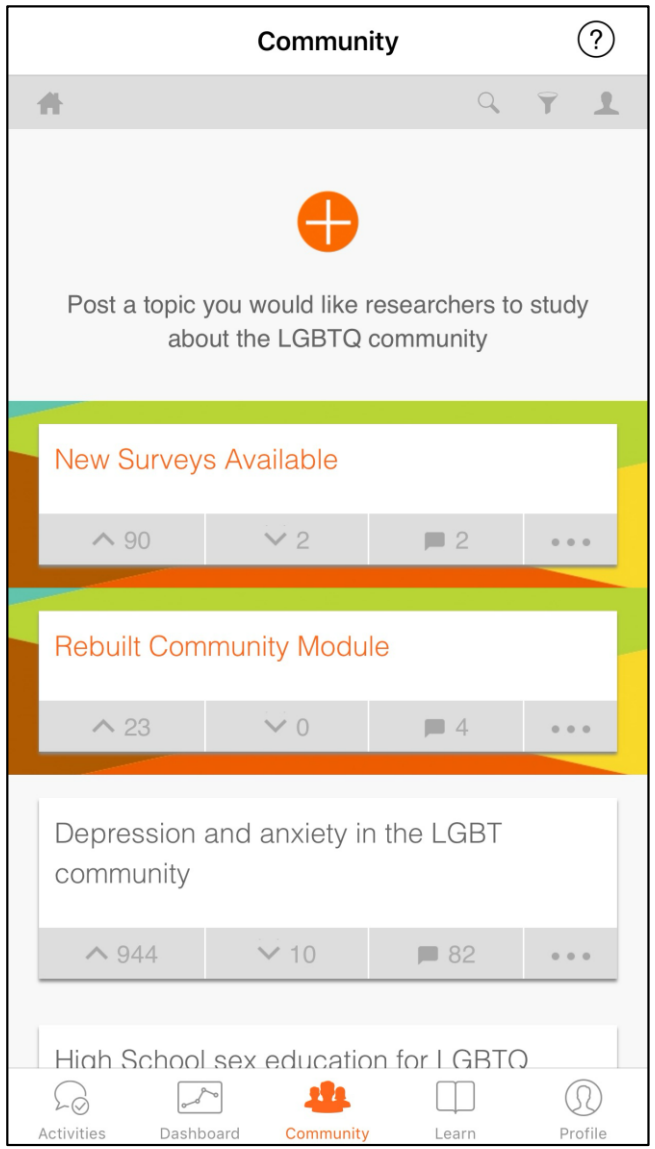
**Research Stages**

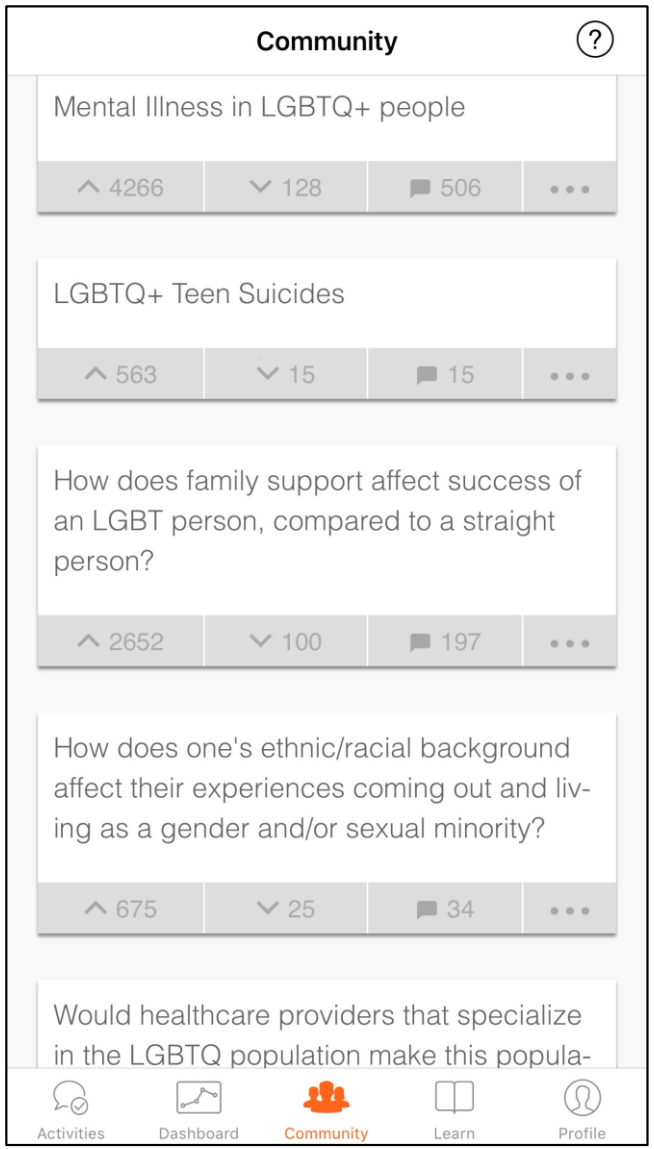
- Study Planning & Design
- Participant Recruitment
- Participation
- Data Analysis & Interpretation
- Results Dissemination [& Implementation]

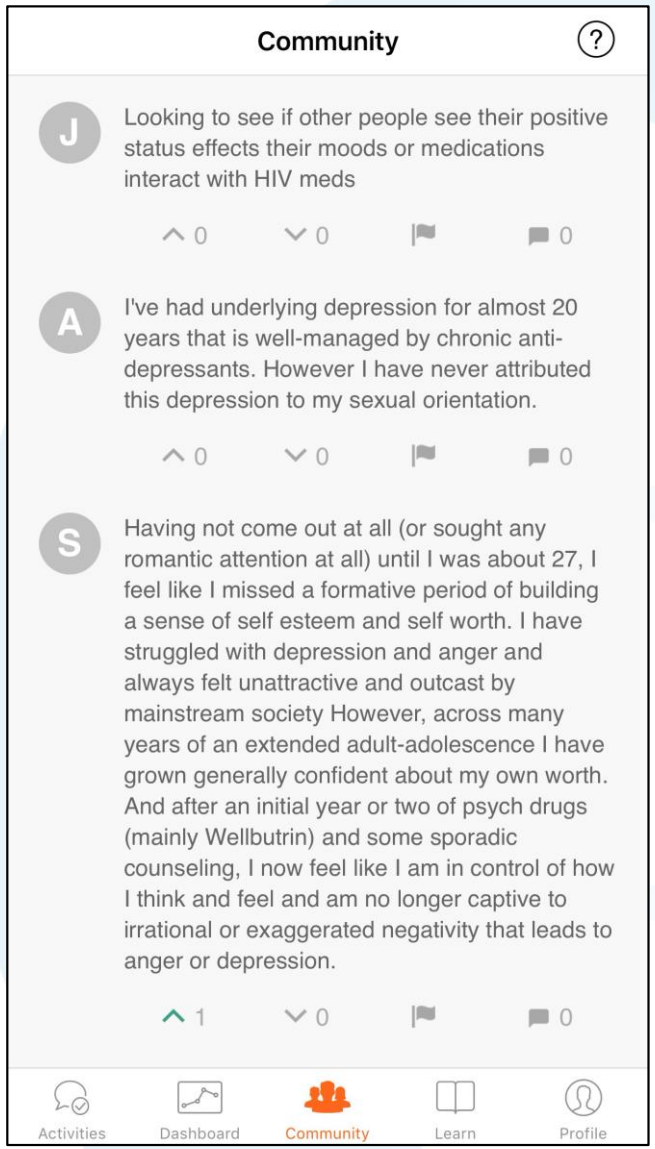
Community engagement is **not just** engaging the community for study recruitment.

To engage communities in **ALL** stages, community engagement must begin **before** designing a research study.

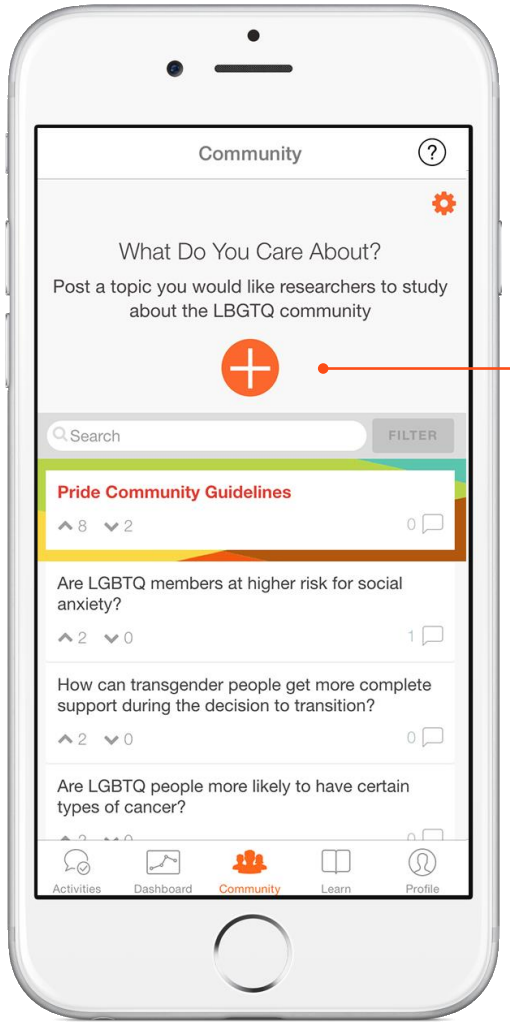
# The PRIDE Study: Community Forum (Research Agenda Setting)



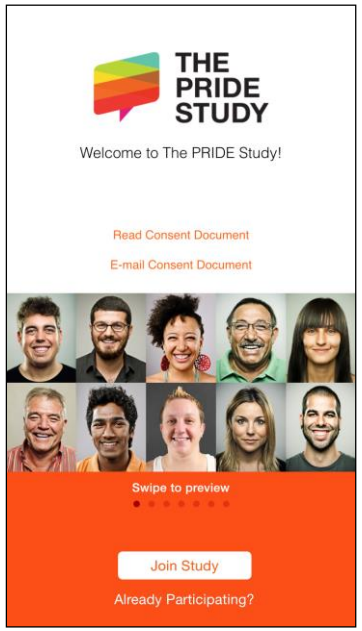



# The PRIDE Study: Community Forum (Research Agenda Setting)




Nominate research questions to the community




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

THE PRIDE STUDY PRIDEnet

Stanford MEDICINE

# Early Community Engagement

What kind(s) of community engagement do you need (or want)?

- Research agenda setting?
- Methods advisors?
- Community-based organizations trusted by communities?
- Recruitment efforts?
- Implementers?

What kind(s) of community engagement can you fund?

pcori $ PRIDEnet

# Planning for Community Engagement

## Seed Grants

Stanford MEDICINE

UCSF

Smaller amounts

Sufficient for CE “start-up”

## CE-Specific Funding

All of Us LGBTQIA+

pcori

Rare (except for PCORI)

Enable rapid CE growth

## Integrating CE into “Traditional” Funding Sources

NIH

Integrate into an Aim

CE as its own Aim = risky

(but hopefully changing…)

**We do all of these!**

*(with intentionality)*

# PRIDEnet Structure

## PRIDEnet

CATALYZING LGBTQ HEALTH RESEARCH

### PRIDEnet Components

1. Participant Advisory Committee
2. Community Partner Consortium
3. Ambassadors
4. The PRIDE Study Participants

### Main Research Projects

THE PRIDE STUDY

All of Us

… and many others

### *Guiding Principles*

**Low Burden**
We make it feasible to engage with us

**Easily Accessible**
We make it easy to find us

**Community Engaged**
We employ participant input at all stages

**Participants Know Best**
We rely on feedback to make iterative changes

**Give Back to Community**
We disseminate what we learn

# PRIDEnet Participant Advisory Committee (PAC)

12-15 SGM-identified community members

Serve as advisors to our projects

Purposeful recruitment for representation

- Sexual orientation & gender identity
- Ethnoracial identity
- Geography
- Disability
- Expertise

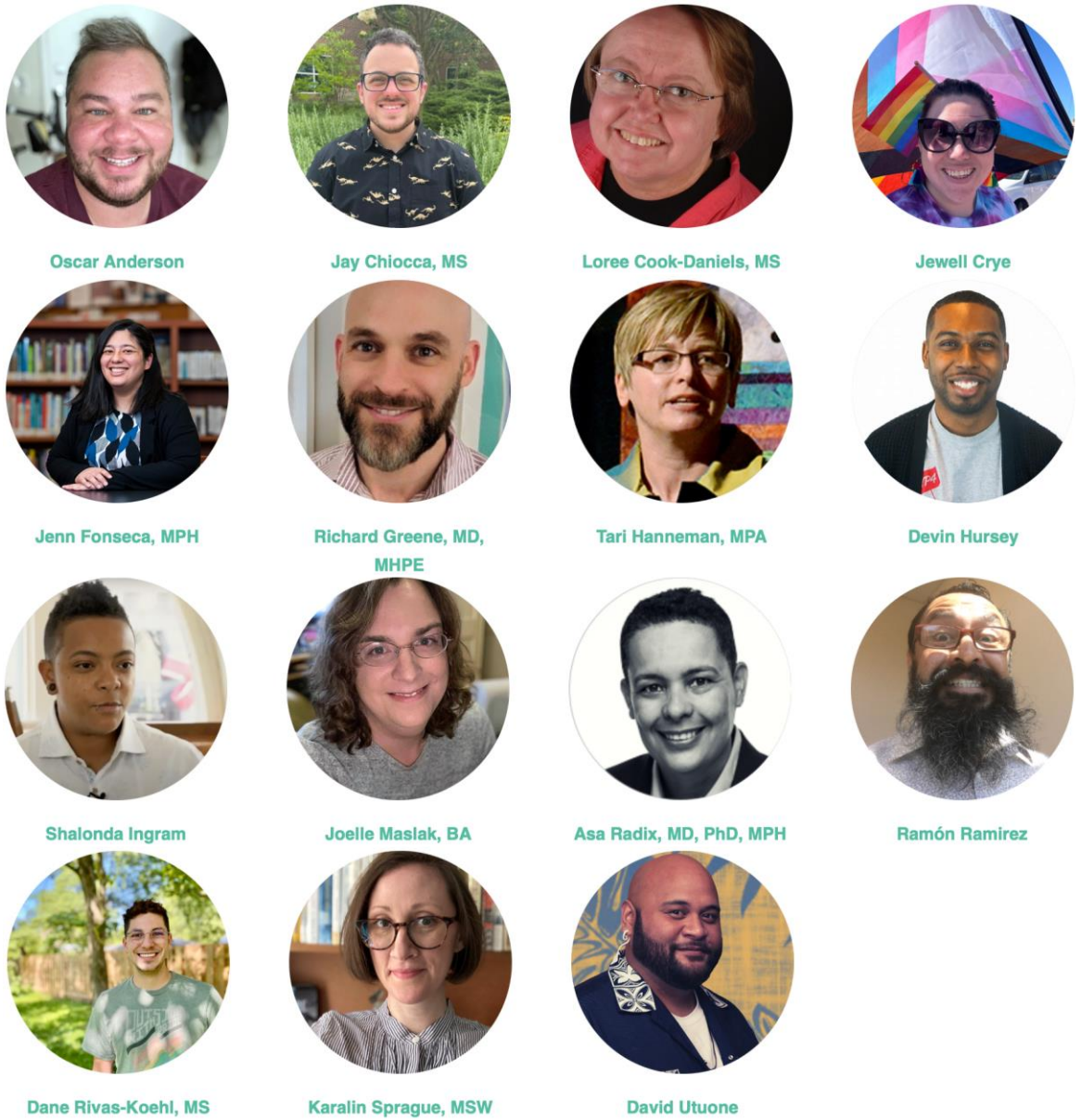
Meet monthly for ~1.5 hours

Paid ($2500/year)

Self-governing (create bylaws, elect chairs)

Creation of space for candid discussion

Bidirectional information flow



# PRIDEnet Ambassadors


Nikki Alexander-Tumblin


Donald M. Bell


Liat Feller


Ederick E. Johnson


Rosaia Shepard


Paul Vila


SaVanna Wanzer


Jeffery Worthington


Lilli Xiang

8-10 SGM-identified community members

Serve as spokespeople for and reviewers of our projects, deliverables, etc.

Purposeful recruitment for representation

- Sexual orientation & gender identity
- Ethnoracial identity
- Geography
- Disability
- Expertise

Meet monthly for ~1.5 hours

Paid ($2500/year)

Well-connected to local/digital SGM communities

Identify new opportunities for engagement

# PRIDEnet Community Partner Consortium

SGM-serving community-based organizations (CBOs)

Formal bilateral agreements signed with Stanford University

PRIDEnet helps CBOs fulfill their health-related missions

CBOs…

- Participant in listening sessions
- Publicize PRIDEnet projects
- Recruit research participants, advisors
- Provide subject-matter expertise

Funding for events/projects available via application



















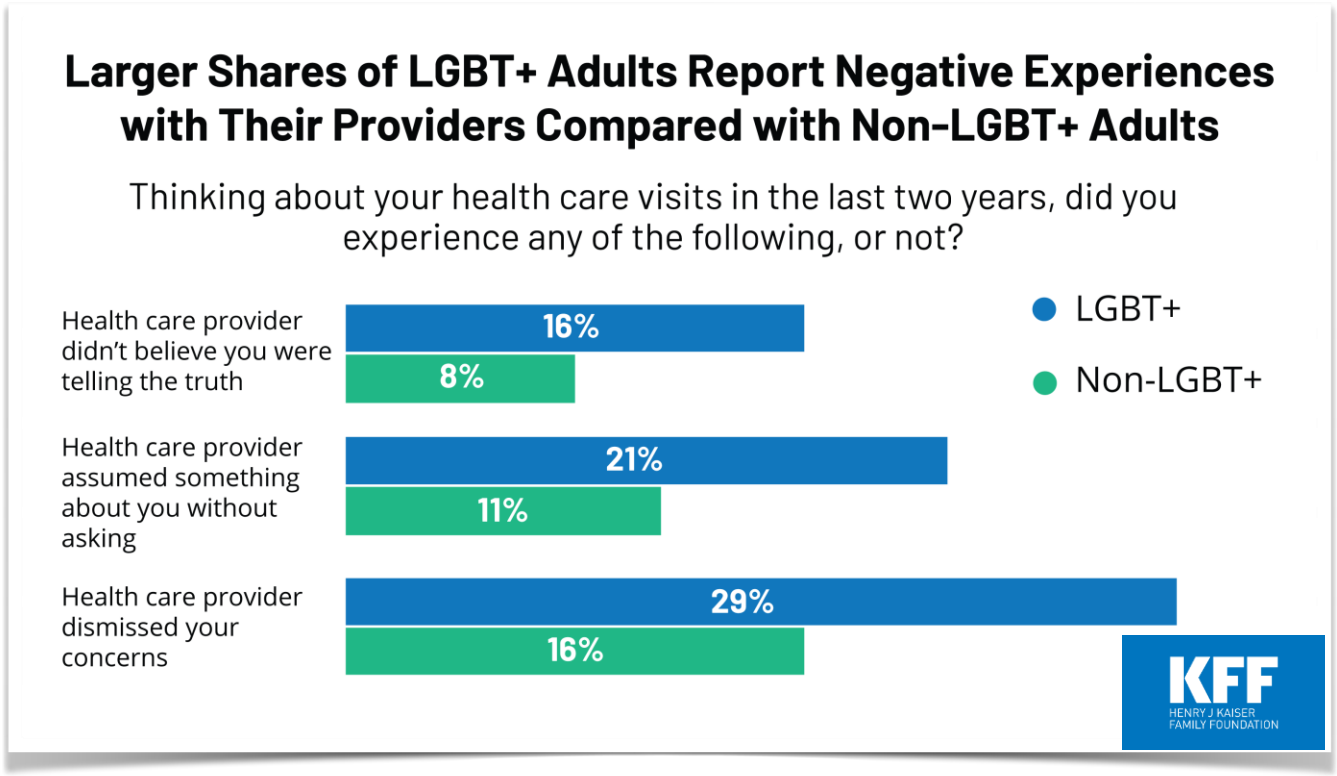


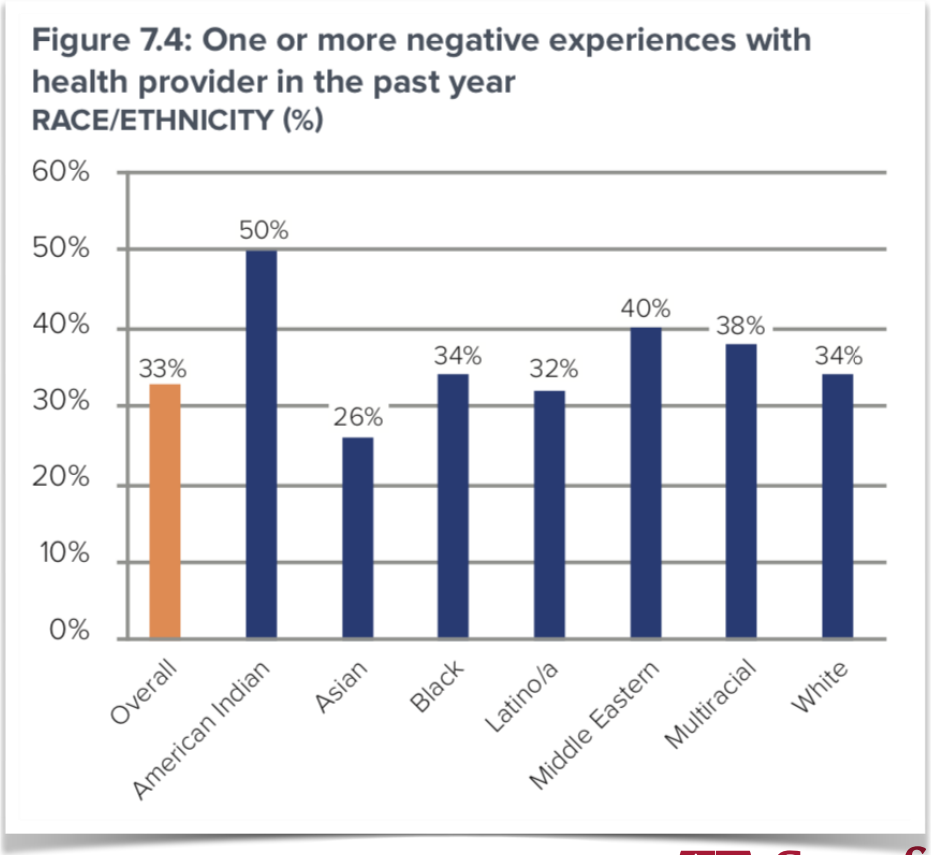
# Community-Engaged Activities to Build Trust

# Meeting Participants Where They Are

SGM people have experienced transgressions, stigma, and discrimination from the medical & research communities.

This turns people away… sometimes ***forever***.

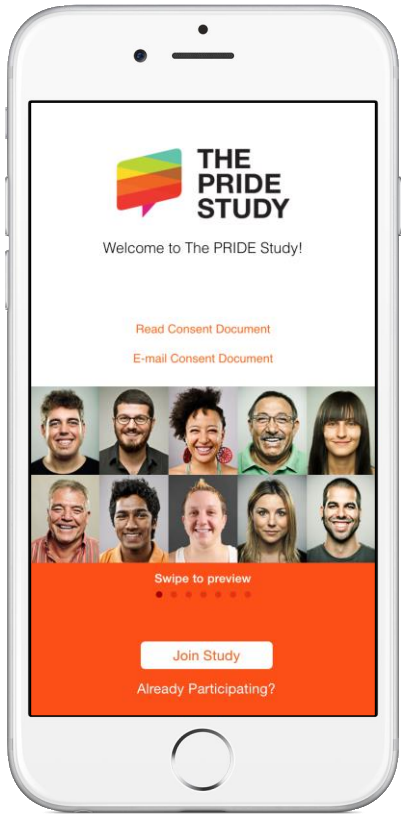


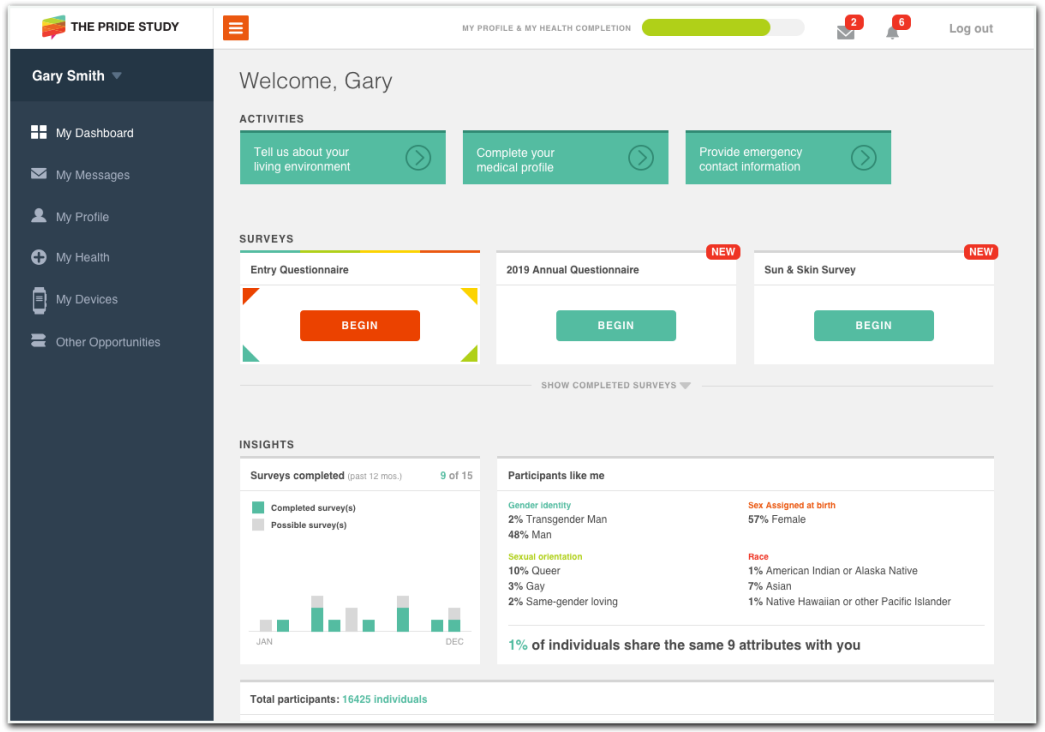




Kaiser Family Foundation, "LGBT+ People's Health and Experiences Accessing Care," 2021.
National Center for Transgender Equality, "The Report of the 2015 US Transgender Survey," 2017.

# Meeting Participants Where They Are

Online experience provides ease, convenience, and safety.




Do we ***really*** need participants to participate in-person?

<u>Considerations</u>

- Taking time off work
- Child care
- Transportation
- Parking
- Discrimination

# Community Listening Sessions

- Conduct community listening sessions with SGM people from across the country
- We listen to **opinions** and **experiences** of SGM people:
  - Importance of health research
  - Health issues facing the community and possible solutions to these problems
  - Barriers to research participation
  - Sources of health information

**Impact**

- Provides us with on-the-ground insights from LGBTQIA+ community members
- Enables us to adjust our engagement approaches
- Helps us understand barriers that we need to counter

# Hire Staff from the Community




# Hire Staff from the Community

**While you cannot explicitly ask a candidate about certain identity characteristics (*e.g.*, sexual orientation, gender identity), you can assess experience working with specific underserved communities.**

# Closing The Loop

**Most research participants are never told the results of their participation!**

This is **disrespectful** and **antithetical** to improving the health of communities.

**PRIDEnet's Approach to "Closing the Loop"**

1. Participants notified of results first!
2. Variety of Dissemination Products
   - Manuscript
   - Plain language summary of key points
   - Plain language summary in PowerPoint
   - Infographics
3. New "Impact" section [coming soon]

Providing research results is **returning value** to participants!

# Research Dissemination Plan

THE PRIDE STUDY PRIDEnet

**Closing the Loop: A Plan for Disseminating The PRIDE Study Research Results Back to LGBTQ+ Communities**

*[December 6, 2019]*

**The PRIDE Study as Community-Engaged Research**

For community engagement to be successful with diverse LGBTQ+ people – most of whom have experienced rejection and discrimination in their personal lives and in healthcare, *how* we do our work is very important. We convey respect and engender trust when we listen carefully, provide transparency, and follow-through with promises. Because of negative experiences in the past, when it comes to research dissemination, we know that LGBTQ+ community members tend to be skeptical. Many LGBTQ+ community members doubt that research teams will "close the loop" about their research project by telling them what has been learned at the end of a long process of organizing and analyzing the information they collect.

Selected comments from PRIDEnet Community Listening Session attendees support this perspective:

> *People come to SAGE Bronx and ask us to participate in these different research projects, and we just often wonder what is being done with this information.*
>
> *…With these research studies, just making sure that they get out to enough people. If you only go to a bisexual website or a bisexual Facebook group, those people are already self-selected. So, it's not really like getting out to the Bi+ people who maybe don't really know about the Bi+ community.*
>
> *I'm in the field of research and I encourage other folks to participate, especially trans and non-binary folks, but I feel like the issue is that we have all this funding and then they support trans people throughout the study, but once they find the research findings...there's no community feedback about what the findings were…we feel uh, very disconnected from the researchers.*

We know that we have to do better than what many research teams have done in the past. We know that we have to be consistent and innovative in how we communicate what we are learning. Transparency is vital: we want participants and partners to be informed about what we do, how we do it, and what we learn.

This plan articulates The PRIDE Study's and PRIDEnet's commitment to LGBTQ+ communities including our participants. It provides details about how all members of the PRIDE Team will contribute to getting research results to the people who made the research possible, want to learn about findings, and can use research findings to improve health care and create policy. It also provides accountability to the PRIDEnet Participant Advisory Committee (PAC), whose top priority is to ensure appropriate and impactful LGBTQ+ health research.


Figure 1: PRIDEnet Values

**The PRIDE Study's Commitment to LGBTQ+ Communities**

Over the life of The PRIDE Study, we have endeavored to adhere to the values noted here (See Figure 1) in our research and engagement activities. Those activities include The PRIDE Study participant recruitment, enrollment, and retention; developing and updating The PRIDE Study's Annual Questionnaire (AQ); conducting digital communications campaigns and in-person outreach, presentations, and other engagement conversations; developing and refining The PRIDE Study's Ancillary Study process (*i.e.*, a mechanism for external investigators to conduct high-quality community-engaged research in collaboration with The PRIDE Study); supporting and facilitating input from PRIDEnet members (PAC, Community Partner Consortium, Ambassadors).


- Public (**transparent!**) plan that articulates your commitment to community members
- Details <u>how</u> you communicate research results, <u>why</u> you do it that way, and <u>who</u> does it

THE PRIDE STUDY PRIDEnet

Stanford MEDICINE

# Social Media Dissemination


# Community-Friendly Summary of Findings

## THE PRIDE STUDY

YOUR STORY. YOUR HEALTH.

Hello Ambassadors,

We hope this update finds you well. The journal *Andrology* just published the latest findings from The PRIDE Study. This study is important because it is the largest study in research literature focused on chronic pelvic pain among transgender and gender diverse adults who were assigned female at birth. The findings can help providers have a more complex understanding of chronic pelvic pain in connection to testosterone.

**Publication Title:**

Chronic Pelvic Pain among Transgender Men and Gender Diverse Adults Assigned Female at Birth

**Community Title:**

Chronic Pelvic Pain among Transgender Men and Gender Diverse Adults Assigned Female at Birth

**What Did We Do?**

Chronic pelvic pain describes pain in the lower abdomen, pelvis, or genitals that lasts 3 months or more. In our study, we looked at how common chronic pelvic pain was among transgender men and gender diverse people assigned female at birth (AFAB). We also wanted to understand how testosterone use may or may not impact chronic pelvic pain. To do this, we used 3 years of data from The PRIDE Study participants (Annual Questionnaires from 2020, 2021, and 2022). We looked at patterns of chronic pelvic pain overall. We also looked at how starting testosterone therapy impacted chronic pelvic pain over time.

**What Was New, Innovative, or Notable?**

This is the largest published study conducted on chronic pelvic pain among transgender and

- What did we do?
- What was new, innovative, or notable?
- What did we learn?
- What does this mean for our communities?
- What's next?

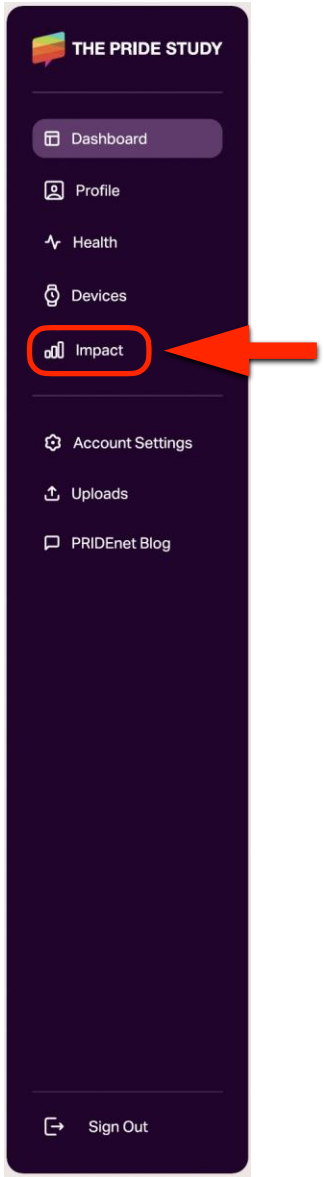
Plain language, 12th grade reading level
PPT slides for partners, PAC, etc.

**pridestudy.org/research**

Stanford MEDICINE

# The PRIDE Study: “Impact” Section [coming soon]

Valuing participants enables them to serve as study recruiters




## Make an Impact & Gain Rewards

Invite friends to The PRIDE Study and earn points with each successful referral. These points unlock exclusive perks, amplifying our quest for inclusive health research. Share your link, earn rewards, and contribute to a brighter future for LGBTQIA+ health.

Your Referral Link:

https://www.thepridestudy.org/invite?ref=FhJ9sx

Users who joined because of you: 4

Copy Link | Share

## Participation Highlights

| Study Title | Summary of Research | Published in | |
|---|---|---|---|
| A digital health research platform for community engagement, recruitment,... | The PRIDE Study is an online study of LGBTQIA+ physical, mental, and social health. In 2015, our team built a secure online website... | Journal of the American Medical Informatics Association — JAMIA | More Details Share |
| Using mobile technology to engage sexual and gender minorities in clinica... | The PRIDE Study is an online study of LGBTQIA+ physical, mental, and social health. Our team recruited 18,099 participants for a pil... | PLOS ONE | More Details Share |
| Community norms for the Eating Disorder Examination Questionnaire a... | Many researchers who study health use a survey to ask about eating disorder attitudes and behaviors. We asked gay cisgender... | Beat Eating Disorders | More Details Share |

Listing of specific studies in which the participant’s data were used

Participants can share their contributions publicly

THE PRIDE STUDY PRIDEnet

Stanford MEDICINE

# Take Home Points

1. Developing a community engagement philosophy with guiding principles provides a framework to ensure the communities are always centered in the research.
2. Community engagement at ALL stages of the research process helps counter historical and ongoing mistreatment and oppression and builds trust.
3. Community engagement requires intentional, dedicated efforts to include marginalized and underrepresented communities.
4. Meeting participants where they are, ensuring participants can “see themselves” in the research, and disseminating results to communities in an accessible way all help build positive community-researcher relationships and trustworthiness.

*wrap-up*

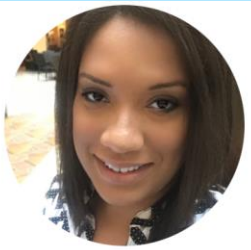
# Acknowledgements

**Cassie Armea-Warren, MSc**

LGBTQ+ REGIONAL ENGAGEMENT COORDINATOR (MIDWEST)

**Alex Armira**

LGBTQ+ COMMUNICATIONS COORDINATOR
The PRIDE Study/PRIDEnet

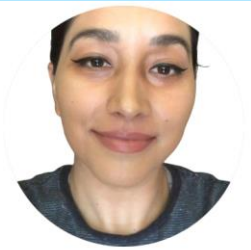


**Mahri Bahati, MPH**

SENIOR LGBTQ+ COMMUNITY ENGAGEMENT SPECIALIST
PRIDEnet

**Sage Calderon**

LGBTQ+ CLINICAL RESEARCH COORDINATOR
Los Angeles LGBT Center/PRIDEnet



**Alexis Ceja**

ASSISTANT CLINICAL RESEARCH COORDINATOR
The PRIDE Study

**Chloe Eastburn**

LGBTQIA+ CLINICAL RESEARCH COORDINATOR
Los Angeles LGBT Center/PRIDEnet

**Orlando O. Harris, PhD, RN, FNP, MPH**

SGM INTERSECTIONAL ADVISORY COUNCIL LEAD
PRIDEnet

**Astrid Herrera**

LGBTQ+ CLINICAL RESEARCH COORDINATOR ASSOCIATE
The PRIDE Study/PRIDEnet

**Eli Hundertmark**

LGBTQ+ CLINICAL RESEARCH COORDINATOR ASSOCIATE
The PRIDE Study/PRIDEnet

**David J. Kinitz, PhD, MSW**

POST-DOCTORAL SCHOLAR
The PRIDE Study

**Nadra E. Lisha, PhD, MA**

BIOSTATISTICIAN
The PRIDE Study

**Micah Lubensky, PhD**

PARTICIPANT ENGAGEMENT DIRECTOR
The PRIDE Study/PRIDEnet

**Daniel Moretti, MSc**

COMMUNITY ENGAGEMENT LEAD
The PRIDE Study/PRIDEnet

**Ari Pefley**

LGBTQ+ OPERATIONS/ADMINISTRATIVE SPECIALIST
The PRIDE Study/PRIDEnet

**Ana Rescate, MBA**

LGBTQ+ COMMUNICATIONS SPECIALIST
The PRIDE Study/PRIDEnet

**Gowri Sunder, MDes**

RESEARCH ASSISTANT
The PRIDE Study

**Diana M. Tordoff, PhD, MPH**

POST-DOCTORAL SCHOLAR
The PRIDE Study

**Nguyen Tran, PhD, MPH**

BIOSTATISTICIAN
The PRIDE Study

**JT Williams**

LGBTQ+ REGIONAL ENGAGEMENT COORDINATOR (SOUTH)
PRIDEnet

**Mitchell R. Lunn, MD, MAS**

CO-DIRECTOR
The PRIDE Study

CO-DIRECTOR
PRIDEnet

**Juno Obedin-Maliver, MD, MPH, MAS**

CO-DIRECTOR
The PRIDE Study

CO-DIRECTOR
PRIDEnet

**Annesa Flentje, PhD**

ASSOCIATE DIRECTOR
The PRIDE Study

UCSF SITE DIRECTOR
The PRIDE Study

NIH

pcori

UCSF

Stanford MEDICINE


THANKS!
Mitchell R. Lunn, MD, MAS
Stanford University
lunn@stanford.edu
pridestudy.org
pridenet.org

# Activities to Increase Representation & Visibility

## Selected PRIDEnet Activities

- **Advise** studies on research process changes from SGM participant perspectives
- **Develop** SGM-customized engagement approaches & communications materials
- **Train** groups on SGM cultural competency & humility
- **Conduct** with SGM participant engagement & education in SGM community spaces nationally
- **Convene** Researcher Basecamp to educate early-stage researchers about the *All of Us* Researcher Workbench


# END