



**PRIDEnet**

CATALYZING LGBTQ HEALTH RESEARCH

# Guidance on Community Engaged Research:

A PRIMER FOR ANCILLARY STUDY APPLICANTS





# Contents

- 4**            **Overview of Ancillary Study Guidelines**  
A note about sexual and gender minority (SGM) communities
- 7**            **Community Engagement**  
What is community engaged health research?
- 10**          **Language**  
LGBTQ+ terms & definitions
- 14**          **Participants**  
Participant inclusion / exclusion
- 16**          **Dissemination**  
Examples of research dissemination plan, timeline, and materials
- 26**          **About PRIDENet and The PRIDE Study**

# Guidance for Ancillary Study Applicants: Overview

Thank you for applying to conduct an Ancillary Study!

*Guidance for Ancillary Study Applicants* explores the theory and practice of community engaged research and offers best practices to advance health research that improves care, advances policy, and positively impacts the well-being of LGBTQ+ people everywhere. Our goal is to help you build relationships, communicate your research, and disseminate the results of your study back to the communities who are at the heart of our work.

The PRIDE Study is supported by the community engagement efforts of PRIDENet, a national network of organizations and individuals that care about the experiences of sexual and gender minority (SGM) people—which includes members of the LGBTQ+ community—in health research. Made up of community partner organizations and an advisory group of health care specialists known as the Participant Advisory Committee (PAC), PRIDENet ensures SGM community members are actively involved in every stage of how health research is created, analyzed, and shared from The PRIDE Study.

**The PAC has prepared the following guidelines to ground Ancillary Study researchers in the core principles of community engaged research:**

1. Approaches to engaging our communities in your research
2. Language to use when communicating to or about our communities
3. Considerations in excluding or including groups of participants
4. Community-friendly dissemination practices

We hope these guidelines will help you maintain a consistent and comprehensive focus on historically marginalized and under-represented sub-communities in your research.

Welcome to The PRIDE Study!

—The PRIDENet PAC, April 2019

## A note about sexual and gender minority (SGM) communities

In general, our communities are sophisticated in their knowledge about health research and understand its importance to policy, advocacy, and care, as evidenced by the TPS participation numbers and overall enthusiasm for this study. However, many community members or their families have been mistreated by research institutions and are understandably wary of impressive promises.

PRIDENet is not interested in “dumbing down” or “talking down” to community members. Instead, we practice using “**people-first language**” that is sensitive and respectful to our demographically diverse communities. As an AS researcher, we encourage you to practice using “simple not simplistic” straightforward language that avoids jargon and communicates your research clearly, without over-promising results.

When in doubt, please ask us! That’s why we’re here.

### **Below are the essential principles that should guide your work as you build relationships with the SGM community:**

**1. Convey dignity and respect.** In our communities, language has historically been used to marginalize, disenfranchise, and pathologize people, causing enormous harm. This is particularly true for trans and gender non-conforming people. Later we share a list of terms we encourage you to use in your writing. but here are two things we always avoid using:

- Terms that are offensive to most and should, therefore, never be used: *she-male*, *he-she*, *it*, *tranny*, *transvestite*, “*real*” woman or “*real*” man.
- The adjective *normal* when describing a participant’s or community member’s sexual orientation, gender identity, or physical or mental disabilities.

Finally, precision with language conveys dignity and respect. For example, when you use the term *men*, make sure you clarify if you’re referring to cisgender and transgender men.

**2. Employ a strength-based approach.** While disproportionate rates of certain health conditions and negative social experiences are a reality among members of LGBTQ+ communities, we also have long histories of fostering interpersonal connection, encouraging altruism, developing impressive leadership, and mobilizing for change, among other strengths. But in research, we tend to focus exclusively on the problems and pathologies, and fail to see the full picture.

At The PRIDE Study, we want to tell a more complete health story. When possible, avoid pathologizing language and remember to describe the positives your research uncovers. Note that there are disproportionate amounts of research studies that document health disparities compared to those that document resilience or inform potential health interventions.

- 3. Ensure that words you use include rather than exclude.** We sometimes use the term “alphabet soup” to describe all of the words we have for members of our communities. There are so many! We do this because all of us have experienced some form of rejection, exclusion, or erasure in relationships or by social systems related to our sexual orientation or gender identity.

We also use these terms to build community and represent our community’s vast diversity. While there are some experiences all LGBTQ+ people have in common, we are not uniform and have many important differences. Therefore, we ask for your patience in understanding why such a wide variety of terms is critical to advancing health and aiding the communication of your findings.



# Guidance for Ancillary Study Applicants: Community Engagement

## What is community engagement?

In the context of health research, community engagement (CE) is an umbrella term that encompasses a wide variety of concepts, models, practices, and definitions refined over many decades by community organizers, advocates, public health workers, and researchers. In general, community organizers and advocates utilize confrontational strategies for systems change; public health workers facilitate community members' participation in improving individual and community health; and researchers work within models such as participatory action research (PAR) and community-based participatory research (CBPR). CE can also include collaboration, empowerment, co-learning, motivating to action, and capacity-building.

**For the purposes of The PRIDE Study, community engagement describes both an overall approach to our work and a variety of:**

1. Specific high touch relationship-building activities
2. Broad reach digital campaigns
3. Mechanisms and processes that involve participants and other LGBTQ+ people at all stages of research.

These stages include research question development, survey instrument design, participant recruitment, data collection, data analysis, and dissemination of findings.

## Ancillary Study (AS) Application

Does your study have any community engagement components?

For the purposes of submitting an AS application, it is crucial for researchers to involve members of LGBTQ+ communities whenever appropriate, in order to remain as current with language and cultural norms as possible. The PAC encourages but does not require community engagement components in developing the research question and conducting the study. However, we realize that formal community engagement is not always appropriate for every study.

**As you develop your research ideas, please consider using some or all of the following best practices:**

- Utilize participant advisory committees to inform and provide feedback on research design.
- Conduct community listening sessions or focus groups to solicit feedback as well as generate community interest in the proposed project.
- Conduct interviews or social media polls with members who represent relevant segments of the community.
- Plan for non-researchers who identify as members of the community from which participants will be recruited to review materials, survey instruments, and manuscripts.
- Hire study staff who are members of the community not only to contribute to the study's relevance but also to aid in the recruitment of participants.

If the suggested methods above have not been or cannot be employed, the PAC strongly encourages soliciting input from non-researcher community members:

- Have informal discussions with community members.
- Articulate which of the people involved in conducting research are also members of the community being studied and have relevant lived experience.
- Write a literature review that mentions community input, or other inputs (even if they're anecdotal).

How do you know that this research question is relevant or meaningful to the community being studied?

A sample response to the Ancillary Study application:

“ As members of the SGM community ourselves, we are deeply invested in promoting SGM health through our research and community involvement. We have conducted focus groups with SGM smokers about what they would like to see in a smoking cessation intervention, and using that information, we are preparing to launch a clinical trial. Through our shared research on SGM smoking, and my graduate research on social media use and well-being, we have seen how social media can be both a positive and negative force.



# Guidance for Ancillary Study Applicants: Language

When submitting a proposal to conduct an Ancillary Study, great care must be taken to use the most appropriate, empowering, and inclusive language whenever possible. Please note that language selection can be highly variable, as it is informed by different contexts and intended audiences. For example, some words that might be appropriate to use in medical contexts may be seen as offensive when used in community-based settings.

In order to standardize current naming conventions—as well as make these proposals accessible to community members beyond medicine and academia—the PAC recommends the following language guidelines:

1. **Consider how language is used with respect to the context of the data being analyzed.** For example, if a researcher is looking to examine sexual behavior, they should use language that describes participants’ behavior, like “men who have sex with men” or “women who have sex with women,” as opposed to using identifying terms like *gay* or *lesbian*.
2. **When referring to a participant’s sex assigned at birth, authors should describe it as such.** Use the phrase “sex assigned at birth” or “sex recorded on original birth certificate.” Avoid terms such as *natal sex* or *birth sex*.
3. **Please note that when referring to transgender people, *trans* is an adjective or a prefix** (*i.e.*, *trans* people/*trans* women/*trans* men is more correct than *trans* people/*trans*women/*trans*men”). Additionally, *trans* or *transgender* are not nouns and should not be used as such (*i.e.*, “transgenders”).
4. **Always refer to trans people by their current gender identity/expression.** For example, a person who identifies as a woman and was assigned male at birth is a trans woman, not a trans man.

## LGBTQ+ terms & definitions<sup>1</sup>

<b><u>Agender</u></b>	A person who does not self-identify as any gender.
<b><u>Asexual</u></b>	A person who does not experience sexual attraction to any gender.
<b><u>Bisexual</u></b>	A person who is emotionally, romantically, spiritually, sexually and/or relationally attracted to people whose genders are both similar and different from their own.
<b><u>Cisgender</u></b>	A term indicating that someone is not of trans experience ( <i>i.e.</i> , does not identify as transgender or any other associated identity). Often used to denote the conformity of one's self-identified gender identity, expression, or roles with their assigned sex at birth.
<b><u>Gender</u></b>	Refers to a socially constructed categorization system that assigns traits of masculinity and femininity to individuals. Not a fixed system: characteristics vary by culture and can change over time.
<b><u>Gender Dysphoria</u></b>	Term used to reflect the occurrence of clinically significant distress related to a difference (or discordance) between one's gender identity and the gender group to which others would assign the individual (Note: One's discordance in gender identity—or non-conformity—is not an inherent disorder; rather, the diagnosis is included as a means to affirm those who experience tremendous anguish related to gender identity).
<b><u>Gender Expression</u></b>	The multitude of external characteristics that we may choose to communicate our gender identities, including apparel, grooming habits, mannerisms, etc.
<b><u>Gender Binary</u></b>	The idea that there are only two gender identification options: woman and man or feminine and masculine.
<b><u>Gender Identity</u></b>	One's personal identification of being a woman, man, a combination of these genders, or another gender entirely (e.g., agender, genderqueer). Someone's gender may or may not align with the gender expectations associated with one's sex assigned at birth.
<b><u>Intersex</u></b>	A word used to describe individuals born with bodies or genetic traits that may not be clearly defined as female or male. Characteristics may include ambiguous genitalia and/or chromosomal combinations. This is sometimes also referred to as a difference in sex development (DSD) in medical literature.
<b><u>LGBTQ+</u></b>	An acronym for lesbian, gay, bisexual, transgender, queer (or questioning), intersex, asexual communities.

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<sup>1</sup> Adapted from [Person First Guidelines](#) (rev. 1/2019) from the City of Philadelphia Department of Behavioral Health and Intellectual and disAbility Services.

**Pansexual**

A person who is sexually attracted to individuals of all gender identities or expressions (*i.e.*, gender identity has no significance or relevance in determining attraction).

**Same-Gender Loving**

An alternative to the more commonly used term “same sex”. This term is used to symbolize the expression of romantic and/or sexual attraction between people of the same gender. An especially significant term, as it can reflect that two romantic partners may be of the same gender identity, but not the same sex/sexual identity.

**Sex**

Refers to a person’s biological characteristics/status assigned at birth and typically categorized as male, female, or intersex. Such characteristics include gonads, chromosomes, and internal and external organs/genitalia. Often used inaccurately as interchangeable with gender, which it is not.

**Sexual Orientation**

Refers to one’s patterns of romantic, sexual, and/or emotional attraction to and/or behaviors with another sex, as well as one’s own gender identity, the gender identity(ies) of those one is attracted to romantically/sexually and/or emotionally, and the gender identity(ies) of those that one engages in sexual activity with. The degree of attraction may vary as aspects of identity are fluid and can develop over time.

**Third Gender / Genderqueer**

Most often refers to people who identify their gender as not conforming to the binary model of gender (man/woman).

**Transgender**

One who feels as though the gender they were assigned at birth is an inaccurate or incomplete representation of their current gender identity. This is an umbrella term used to describe multiple communities whose expressions or identities transcend gender norms. These may include (but are not limited to) transsexual, third gender, people who identify themselves as being of “trans experience,” Two Spirit people, gender variant and gender non-conforming people, drag kings and queens, and sometimes people who are born intersex.

**Queer**

“Umbrella term” often used to indicate a sexual and/or gender identity that may deviate from heteronormative, gender binary standards. Appropriated within the past twenty years, this term was formerly used to malign, harass, and spread hatred and animosity toward members of these communities. While many elders may refrain from using the term due to its history, it has been reclaimed as a widely used term by younger people within the communities.

The following is a glossary of terms that may be outdated or have fallen out of favor, along with their more appropriate equivalent. Please avoid terms in the first column whenever possible.

<b>Less appropriate language</b>		<b>Preferred language</b>
<i>Homosexual</i>	-----	<i>Gay or lesbian</i>
<i>Hermaphrodite</i>	-----	<i>Intersex</i>
Sexual preference	-----	Sexual orientation
<i>Transvestite, transsexual</i>	-----	<i>Transgender</i>
Biological or natal sex	-----	Assigned sex at birth
<i>Preferred gender Pronoun</i>	-----	Pronoun
Gender reassignment surgery (GRS) or sex reassignment surgery (SRS)	-----	Gender affirming surgery or genital reconstruction, or the name of a specific procedure, <i>e.g.</i> , vaginoplasty

## Reading level and readability

1. **Please determine the readability of your research materials** by using a [Reading Level Calculator](#) and do your best to achieve a 12th grade reading level or below.<sup>2</sup>
2. **Use a readable font.** For text, this means using a 12pt sans-serif font made up of mainly straight lines. Some common sans-serif fonts include Helvetica, Arial, Tahoma, Verdana, and Helvetica.
3. **Use white space, bullets, and lists.** We understand that specific publications, manuscripts, or grants may have other requirements and these recommendations will be context-specific, but when working on general information for community dissemination, these are best practices:
  - Indent 1 inch at margins
  - Justify left margin, unjustify right margin
  - Use a wide, san-serif font for ample kerning
  - Space 1.25 between lines, especially on forms where underscores and boxes are used to provide space for writing
  - Double space (30-34pt.) between paragraphs or other bodies of text
  - Use block paragraph style, no indents
  - Use headings and subheadings

<sup>2</sup> An additional test for appropriate Reading Level and Readability can be found [here](#).



## Guidance for Ancillary Study Applicants: Participants

### Participant inclusion / exclusion

We are committed to ensuring that research reflects the wide diversity of SGM communities. The PAC is charged with helping maintain a consistent and comprehensive focus on historically marginalized and underrepresented SGM sub-communities in the promotion, enrollment, research, and dissemination phases of research. Historically underrepresented SGM groups include various gender identity groups (including women or people with non-binary gender identities), transgender people, older adults, people of color, and people with disabilities, among others.

**The PAC requests for AS applicants to think carefully about the reasoning behind excluding certain participants—particularly groups that have been historically underrepresented in research—and, in cases where exclusion might be necessary, to provide a clear rationale.**

We recognize that appropriate inclusion/exclusion criteria will vary based on the research question. The following are two examples that consider approaches to inclusion of transgender sexual minority men in studies of sexual minority men.

**Example 1. The relationship between childhood gender non-conformity and adult depressive symptoms in cisgender sexual minority men**

This study may have a strong justification for excluding transgender (*i.e.*, non-cisgender) sexual minority men because social responses to children's gender expression often differ considerably based on the child's sex assigned at birth. Moreover, the gender non-conformity measure may not have been validated in a transgender sample. We would nonetheless encourage the AS applicant to briefly explain their rationale for the exclusion in their application.

**Example 2. The relationship between personal rejection sensitivity and heavy alcohol use in cisgender sexual minority men**

There is no self-evident justification for excluding transgender sexual minority men from this study. If the AS applicant believes that rejection sensitivity might affect heavy alcohol use differently in transgender and cisgender men, then we would recommend an analysis with both cisgender and transgender men. The applicant may also opt to conduct a sensitivity analysis (*i.e.*, a second analysis in which transgender men are removed and the results are compared), a stratified analysis (analyzing transgender and cisgender men separately), or formal tests for effect modification (interaction). If the exclusion of transgender men is in fact necessary, the AS applicants should provide a clear justification, including references when appropriate.

## Focusing on a subgroup of participants

We understand that many AS projects investigate the experiences of a particular subgroup, often a group that has not been well-represented in prior research (*e.g.*, sexual minority Asian-Americans). This type of focus is appropriate and encouraged. However, investigators should consider that there may be little "cost" to analyzing a broader group in an AS, particularly when only Annual Questionnaire data are used as in a secondary analysis of already collected data. For instance, rather than limiting a study to sexual minority Asian-American men, investigators may choose to include sexual minority Asian-American participants of any gender. If they hypothesize that results may differ by gender, they may conduct a stratified analysis or look for evidence of effect modification.

## Additional notes on gender minorities

With respect to the exclusion of transgender and other gender minority participants in sexual minority studies, investigators should keep in mind that many gender minority people are also sexual minorities, so gender minority sample sizes may be adequate for stratified analysis or effect modification tests, even when heterosexual gender minorities are excluded. Investigators should also keep in mind that cisgender sexual minority participants may have partners who are transgender and/or have non-binary gender identities and should plan their measures accordingly.

# Guidance for Ancillary Study Applicants: Dissemination

## Why dissemination guidance?

Health research, no matter how innovative, will never make a difference in the lives of SGM people unless it is disseminated in an appropriate and timely manner to the people and organizations that deliver healthcare and make policy on behalf of LGBTQ+ individuals. Yet, many researchers are not trained, rewarded, or supported to disseminate research findings beyond academic journals and professional conferences.

With generous permission from the University of California, San Francisco's Center for AIDS Prevention Studies and the Prevention Research Center's Community Engagement Core, the PAC has adapted [\*Community Advisory Board Recommendations for Research Dissemination\*](#) for use by researchers conducting Ancillary Studies.

### **Best practices for research dissemination:**

#### **1. Create a dissemination plan for all studies.**

- Include your dissemination plan in your AS application. If writing a grant for the study, include the plan in the grant. See below for sample grant language.
- Develop a budget that supports dissemination efforts. This may include translation, printing, mailing, webinar, and/or community forum costs. Budget for food at community forums and an honorarium or fee to be paid to a community stakeholder who helps you plan these public events.
- Develop a timeline for dissemination efforts. If your study is longitudinal, this may include annual updates. See below for guidelines for dissemination.
- Get input from study participants and community representatives on the best methods to disseminate research findings. Seeking this input may be part of your AS community engagement plan. Engage community stakeholders in the dissemination process. SGM community members are much more likely to come out for something if someone they recognize is coordinating the event or visible as a spokesperson.

communities, and policymakers. Make sure the results are also relatable and understandable to a lay reader. Convey the message in summary formats that are easily digestible.

- Strongly consider publishing in open access journals and using institutional repositories or subject-based repositories for wider dissemination beyond proprietary peer reviewed academic journals.

## **2. Disseminate research progress and findings to study participants.**

- When possible (i.e., for projects collecting original data), ask study participants how they would like to be informed of findings.
- Set and advertise a time (say, six months after close of study) when participants can access a website, webinar, or other type of update on the study findings.
- Activities might include:
  - In consultation with PRIDENet, draft content for the PRIDENet Blog, The PRIDE Study social media accounts, and/or PRIDENet email newsletters
- A live (e.g., webinar) or asynchronous (e.g., message board) Q&A where researchers discuss the results with participants. Involve a community stakeholder in the dissemination process. Ask those key community stakeholders to help with the dissemination process.

## **3. Disseminate research progress and findings to community organizations and service providers.**

- Prioritize dissemination of results for community organizations that assisted with study development and/or that serve targeted population(s).
- Emphasize the practical implications of the study results and how they might inform health promotion or healthcare efforts for LGBTQ+ communities.
- Activities might include:
  - Writing articles about the study in newsletters or websites frequently used by service providers
  - Presenting at conferences or taking part in webinars that target service providers and/or community organization staff

## **4. Disseminate research findings to the community.**

- Use dissemination venues appropriate to the targeted community(ies).
- Be sure to avoid technical jargon that a non-researcher audience will not understand.
- Consider how you will reach both LGBTQ+ communities generally as well as sub communities relevant to your study topic (e.g., LGBTQ+ women, LGBTQ+ older adults, LGBTQ+ people living with HIV).

- Also, consider activities that target key community members who are not part of the study population (e.g., non-LGBTQ+ parents and caregivers of LGBTQ+ youth).
- Activities might include:
  - Writing articles about the study results for a community organization newsletter or blog
  - Live or asynchronous online Q&A, as described above
  - Articles in traditional media (e.g., newspapers, magazines), either LGBTQ+-specific or general
  - Social media posts by the research team, or by the institution, organization, or center your research study is based at. Social media content might include text summaries, infographics, video interviews with the research team, etc.
  - Hosting a community forum, which could offer a live-stream for those unable to attend in person
  - Presenting at community-oriented conferences

## 5. Disseminate research findings to policymakers.

- Many research findings will have implications for policy, so consider disseminating results to relevant LGBTQ+ health policy groups and/or directly to lawmakers. This includes data about the characteristics and needs of SGM populations, program evaluation data, and data about measurement of SGM status.
  - Leverage relationships with policy advocates to find channels for dissemination of your findings. For example, take part in a lobby day for a local chapter of the [Human Rights Campaign](#), [PFLAG](#), or [GLSEN](#), or for a [state Equality Federation organization](#).
  - Connect with professional organizations in your field that have government affairs or public interest staff. These institutions often regularly interface with both advocates and policymakers.
  - Share findings with the National Institutes of Health [Sexual and Gender Minority Research Office \(NIH-SGMRO\)](#).
- Consider policy relevance at the local, state, and federal levels.
  - Prepare one-page summaries of research methods and findings for these policymakers and tie to on-going policy debate or proposed policy solution (e.g., *The Equality Act*, *Health Equity and Accountability Act*, *LGBT Data Inclusion Act*).
  - Request meetings with Congressional staff, state administrators, county officials, and city leaders to share findings and support relevant policy proposals.

- Request meetings with Congressional staff, state administrators, county officials, and city leaders to share findings and support relevant policy proposals.
- Share findings with local health departments and related agencies that can make administrative and regulatory changes. Many health departments have LGBTQ+ liaisons or offices of health equity. Those are good places to start.
- Consider implications of your findings to change policies in education.
  - Share findings with universities and school systems to support LGBTQ+-inclusive administrative policies.
  - Find outlets for influencing medical education and health training programs through accreditation programs and other educational advocacy.



### Sample proposal language:

*Our dissemination efforts will be aimed at study participants and community representatives as well as researchers, policymakers, and community based organizations. Dissemination strategies will include:*

1. *Making the results available through PRIDEnet by summarizing them for the PRIDEnet blog, social media accounts, and email updates.*
2. *Reporting the results at conferences that target researchers or clinicians and conferences that are more community-based.*
3. *Writing an academic journal article and including one or more community members as co-author(s).*
4. *Writing an article for a local magazine or newsletter in English or Spanish.*
5. *Disseminating study results via social media and/or a webinar.*

## Guidelines for research dissemination plan / timeline

Sufficient resources must be budgeted to ensure a successful dissemination plan. Suggested below are minimum requirements for when submitting your proposal.

### **The AS dissemination plan must clearly state the following:**

#### **Who will receive the research findings?**

- Study participants (to include opportunities for Q&A with researchers)
- Community organizations, particularly any organizations that took part in study design or community engagement activities
- Service providers, including administrative and front-line staff (outreach workers, peer counselors, etc.)
- Affected communities
- Policymakers
- Funders

#### **When will they receive them?**

- At the beginning of each research project, set a specific and firm timeline for releasing research findings to participants. It is suggested this be no more than two years after the final data are collected, whether the findings are positive, negative, or null.
- If the study lasts for more than two years, participants must be provided with at least yearly updates on the progress of the study.

**What will they receive?** See examples of dissemination materials below.

#### **How they will receive them?**

- Research findings, whether positive, negative, or null, should be disseminated through multiple methods, including but not limited to peer reviewed journals. Other dissemination methods may include: websites, conferences, agency in-services, town halls, social media, newsletters, emails, phone calls, mailings, press releases, community forums, various media (including print, radio, television, online), and presentations to various government bodies and policymakers, when appropriate.
- Dissemination of research findings must be available in the language/s in which the study is conducted, and must be accessible to the specific audience.

## What kinds of research data should be disseminated?

We want to be clear that when we talk about dissemination, we are not asking for confidential, unanalyzed, or proprietary data to be released to the public. We're also not asking that you "prove that it worked" (although if you can, that would be great). In general, community audiences appreciate being informed about ongoing studies in many ways.

Dissemination is for any information about the research study. For an Ancillary Study, this may include:

- Basic study description
- Inclusion/exclusion criteria
- Baseline demographic data on those recruited
- Research instruments
- Follow-up data (retention, etc.)
- Data analysis
- Final research findings (whether positive, negative, or null)
- Implications of the research, including recommendations for policy or practice

In addition, materials that are disseminated through traditional research venues should also be made available to lay audiences:

- Posters presented at conferences
- Slides presented at conferences
- Talks given to peers
- Reports to funders (perhaps with some editing)
- Journal articles
- A one page summary with bullet points and/or key findings conveyed in an infographic format

## Examples

The following pages are examples of common dissemination materials from our Community Partners at [Callen-Lorde Community Health Center](#), [Equitas Health Institute](#), and UCSF's [Center for AIDS Prevention Studies](#). For an example of online dissemination, see the LGBTQ+ National Aging Research Center's [Aging with Pride Study](#) website.

**Newsletter** for The LITE Study (2018)  
Callen-Lorde Community Health Center  
PRIDEnet Community Partner



# THE LITE STUDY NEWSLETTER

November 2018

## 562 TRANS WOMEN HAVE PARTICIPATED!

562 people have participated in the LITE study in Atlanta, GA (68), Baltimore, MD (97), Boston, MA (111), Miami, FL (82), New York City, NY (119) and Washington, DC (85)! Our sample is racially and ethnically diverse with 60% of our sample identifying as Black, Latinx and/or multiracial.



## PRIDE AND RESILIENCE



About 80% of LITE participants expressed high levels of pride in their gender identity. Almost half of participants indicated they they were comfortable or very comfortable with their body. 57% agreed or strongly agreed with the statement "My family is accepting and supportive of my gender identity".

## VIOLENCE AND DISCRIMINATION

50% of all participants have experienced intimate partner violence that was related specifically to their gender identity (i.e. a partner hid or damaged hormones, used the wrong name or pronoun intentionally to hurt someone, etc.)



## FOOD SECURITY

65% of LITE participants experienced at least some degree of food insecurity (i.e. running out of food or money to purchase food at the end of the month occasionally or more). Among participants who reported receiving food stamps (SNAP or EBT), 77% still experienced food insecurity pointing to complex socioeconomic challenges and mixed ability to access adequate social supports

**THE LITE STUDY**  
LEADING INNOVATION FOR TRANS  
WOMEN'S HEALTH AND EMPOWERMENT

Read more at  
[litestudy.org](http://litestudy.org).

**Print assets (2018)**  
 Equitas Health Institute  
 PRIDENet Community Partner



**EquitasHealth Institute** FOR LGBTQ+ HEALTH EQUITY

**PUBLICATIONS**

**OHIO'S MARK OF SHAME**

**KINDNESS AND COURAGE**

**WITHIN REACH**

**PROVIDING CULTURALLY COMPETENT CARE**

**28%** Nationally

**3.4%** of LGBTQ+ people

**50%** of LGBTQ+ people

**2x** more likely to be hospitalized

**95 OHIO'S GROWING LGBTQ+ COMMUNITY**

9575 Huntington Park Dr., #200  
 Columbus OH 43230  
 (614) 929-8884 | [equitas@equitashealth.com](mailto:equitas@equitashealth.com)

EquitasHealthInstitute.com

**SELECT PUBLICATIONS**

**2 YEARS OF SERVICE REPORT**

**EARNED MEDIA**

HARVEY Local Historian PRISM CU 614

**CONFERENCE IMPACT** 1400+

**COMMUNITY ENGAGEMENT** OVER 1,000 PEOPLE REACHED

**CULTURAL HUMILITY TRAININGS**

**6,427 TOTAL INDIVIDUALS TRAINED**

**151 TOTAL TRAININGS**

**REGIONAL AND NATIONAL CONFERENCE PRESENTATIONS**

**2,666 PEOPLE REACHED**

**6 NATIONAL RESEARCH RELATIONSHIPS**

**GRANTS CONTRACTS**

**PROVIDED**

Training Settings:  
 17% Conferences  
 18% Community  
 12% Health Equity  
 15% Hospital  
 15% Local History  
 4% Research  
 25% Professional Association  
 2% Provider Care  
 1% Other

# How does stigma affect HIV prevention and treatment?



Community Engagement (CE) Core

Prepared by Pamela DeCarlo and Maria Ekstrand PhD, CAPS

Date prepared: October 2016

## What is HIV stigma?

HIV-related stigma is a significant problem globally. HIV stigma inflicts hardship and suffering on people living with HIV and interferes with research, prevention, treatment, care and support efforts.

**HIV-related stigma** refers to negative beliefs, feelings and attitudes towards people living with HIV, their families and people who work with them. HIV stigma often reinforces existing social inequalities based on gender, race, ethnicity, class, sexuality and culture. Stigma against many vulnerable populations who are disproportionately affected by HIV (such as the stigma of homosexuality, drug use, poverty, migration, transgender status, mental illness, sex work and racial, ethnic and tribal minority status) predates the epidemic and intersects with HIV stigma, which compounds the stigma and discrimination experienced by people living with HIV (PLWH) who belong to such groups.<sup>1</sup>

**HIV-related discrimination**, also known as enacted HIV stigma, refers to the unfair and unjust treatment of someone based on their real or perceived HIV status. Discrimination also affects family members and friends, caregivers, healthcare and lab staff who care for PLWH. The drivers of HIV-related discrimination usually include misconceptions regarding casual transmission of HIV and pre-existing prejudices against certain populations, behaviors, sex, drug use, illness and death. Discrimination can be institutionalized through laws, policies and practices that unjustly affect PLWH and marginalized groups.<sup>1</sup>

## How do people cope with stigma?

Several factors help individuals cope with HIV-related stigma, and respond to feelings of worthlessness, depression, and anger associated with their diagnosis. Many people learn to manage or cope with stigma quite well and have very positive relationships not impacted greatly by stigma, especially if they have supportive family and friends.

**Social support.** For many PLWH, social support can help buffer the impact of any stigma. A study of African American PLWH found many had experienced stigma and discrimination, but the impact was softened by having non-PLWH in their social networks express interest and take the initiative to offer help. Connection with other PLWH gave them an opportunity to share their feelings and to fight for their rights.<sup>2</sup> A study of young African American men who have sex with men (MSM) found that stigma of racism and homophobia was associated with delayed HIV testing, but that men with peer support tested earlier.<sup>3</sup>

**Adapting and coping.** Although it can be difficult for persons in already stigmatized communities to identify as HIV-positive, many PLWH do accept their HIV status and successfully form an identity of being pro-active and choosing to live. Adequate treatment for depression and anxiety, along with acceptance of one's diagnosis, provide a protective buffer against stigma and promote acceptance of lifelong HIV treatment.<sup>4</sup>

## How is HIV stigma harmful?

Stigma and discrimination add barriers which weaken the ability of people and communities to protect themselves from HIV and to stay healthy if they are living with HIV.

**To persons living with HIV.** Fear of stigma, discrimination and potential violence, may keep people from disclosing their status to family, friends and sexual partners. This can increase isolation and undermine their ability to access and adhere to treatment, and undermine prevention efforts such as using condoms and not sharing drug equipment. Enacted stigma can result in losing housing and jobs, being ostracized by family, and being treated badly in healthcare facilities, among other effects.

**To vulnerable populations.** The way people experience stigma varies across countries and communities. Stigma discourages people from seeking information and programs, for fear it will make others think they have HIV, are promiscuous or unfaithful, or are members of populations associated with HIV, like people who inject drugs, sex workers and gay men. It can make people less likely to get tested for HIV, use condoms, ask their partners about their status, use clean needles and injection equipment, or access biomedical prevention options such as male circumcision and pre-exposure prophylaxis (PrEP).

## How is HIV stigma addressed?

Stigma exists, and should be targeted at multiple levels: individual, interpersonal (family, friends, social networks), organizational, community and public policy.<sup>5</sup> Involving PLWH in the design, creation, implementation and evaluation of stigma reduction programs is critical to success.

### Individual level

Increasing individual knowledge about HIV transmission, prevention and care, as well as access to services and legal rights is important. One study in South Africa found that while some PLWH experienced stigma through insults and arguments with family members during conflict, they knew that disclosing someone's status without their consent was a crime. In these instances, threatening to go to the police, or sometimes actually calling the police, allowed PLWH to fight back and maintain their self-esteem.<sup>6</sup>

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What is the most effective way for lesbian, gay, bisexual, and transgender (LGBT) smokers to quit? By participating in a tailored stop-smoking class where they can speak freely about their issues in quitting? If so, how well does an LGBT approach serve the needs of diverse subgroups of this population? These and other questions inspired Queer\* Tobacco Intervention Project (QueerTIP), funded by the California Tobacco-Related Disease Research Program.

*\*Queer is a term reclaimed by the LGBT community and is intended to include all LGBT persons.*

## Background

Rates of smoking among lesbian, gay, and bisexual adolescents and adults appear to be higher than rates for the general population (Gruskin, et al., 2001; Ryan, et al., 2001; Stall, et al., 1999). Smoking is also likely problematic among transgender people, many of whom face poverty, homelessness, stressful living and work environments, and depression in their daily lives. Despite the fact that smoking negatively impacts or complicates health issues of particular importance to LGBT persons (e.g., hormone therapy for transgender people, HIV/AIDS), tobacco companies target these communities. Yet, there is little research on smoking cessation by and for LGBT persons.

Community activists in San Francisco started working more than a decade ago to address these problems. In the early 1990's, Lyon-Martin Women's Health Services initiated "The Last Drag," the first stop-smoking group for LGBT and HIV positive smokers. The California Lavender Smokefree Project (CLSP), funded by the state in the mid-90's, counteracted tobacco industry targeting of LGBT communities. In 1996, the Coalition of Lavender Americans on Smoking and Health (CLASH), with the help of Progressive Research and Training for Action (PRTA), (a community-based organization specializing in LGBT technical assistance), held Alive with Pleasure! the first federally funded conference on tobacco use among California's

LGBT population. In 1998, at the urging of CLASH members, the Center for AIDS Prevention Studies (CAPS) launched its first tobacco study with gay/bisexual men.

## History of QueerTIP

With funding from the state of California, CAPS and PRTA identified the importance of smoking cessation research among LGBT people as a high priority. QueerTIP's aims were to:

- Strengthen collaboration and build capacity among members;
- Develop smoking cessation services specifically designed for LGBT smokers;
- Pilot-test services at three organizations serving diverse sub-segments of LGBT communities (Lyon-Martin, New Leaf, and LYRIC).

QueerTIP was run by CAPS and PRTA community research staff with the participation of and direction defined by a larger collaborative group. Project staff were responsible for preparation and facilitation of meetings, follow-up on the collaborative group's decisions, information gathering and dissemination, survey development, and overall project implementation. QueerTIP collaborative group members refined the research questions, provided direction and input, and implemented activities. A few members also served as paid consultants when their specialized services were required.

## The Collaborative Process

The collaborative group met once a month for two hours from September 2000 to July 2001. Prior to each meeting, members received a packet with an agenda, feedback forms to prepare them for discussions, and materials. Members requested that CAPS host the meetings because of its central location and proximity to public transportation. Refreshments and compensation for travel and parking were provided. Members received a quarterly stipend for their participation and completed quarterly feedback forms on the collaborative process and project progress.

## About PRIDEnet

**PRIDEnet** is a national network of individuals and organizations that actively involve the LGBTQ+ community in health research. Through our Participant Advisory Committee (PAC) and Community Partners, PRIDEnet builds on decades of work by activists, health advocates, service providers, and researchers to improve the health and well-being of LGBTQ+ communities.

## Participant Advisory Committee (PAC)

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## About The PRIDE Study

**The PRIDE Study** is the first large-scale, long-term national health study of people who identify as LGBTQ+ or another sexual or gender minority. The PRIDE Study aims to develop a better understanding of factors that influence the physical, mental, and social health of LGBTQ+ people in order to improve health disparities within these communities.

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**PRIDEnet**

CATALYZING LGBTQ HEALTH RESEARCH

**PRIDEnet** is a national network of individuals and organizations that actively involve the LGBTQ+ community in health research.

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