PRIDEnet
CATALYZING LGBTQ HEALTH RESEARCH

Guidance for Ancillary Study Applicants: Overview
PRIDEnet's Participant Advisory Committee (PAC)

Welcome to PRIDEnet and The PRIDE Study (TPS)!

Thank you for applying to conduct an Ancillary Study (AS). We want to help you work closely with and communicate your plans and results to the communities who are the heart of our work. As you know, we are an LGBTQ community-engaged research project and are committed to including community perspectives throughout all stages of research. We are also committed to disseminating useable results widely. We want you to succeed and we think the information here will help you do just that.

The PRIDEnet Participant Advisory Committee (PAC)

The PAC is composed of Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ) SGM-identified people [we use the term Sexual and Gender Minority (SGM) people to mean the same communities] from around the country who care about advancing LGBTQ health research. Please see photos and bios here. The PAC's mission is the following:

The PRIDEnet Participant Advisory Committee (PAC) is a group of mentors who have specific knowledge and experience with Sexual and Gender Minority (SGM) people and communities. In addition to this expertise and experience they are either active participants with a PRIDEnet research project or a community member or both. The PAC brings their expertise at a high level to PRIDEnet, increases credibility with potential partners and participants, and helps maintain a consistent and comprehensive focus on historically marginalized and under-represented sub-communities.

Guidance

Here you will find guidance on the following:

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

About Sexual and Gender Minority (SGM) Communities

In general, our communities are sophisticated 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.

We are not interested in "dumbing down" or "talking down" to community members, but rather, in using "simple not simplistic" straightforward language that avoids jargon and communicates your impressive results clearly without over-promising. We encourage "People-first language" that is sensitive to our demographically diverse communities. In this way, you will help convey the respect and dignity for our participants we know you intend.

Below are the principles we encourage you to adhere to as you work with SGM people:

1. Convey dignity and respect

In our communities, language has historically been used to marginalize, disenfranchise, and pathologize people, and has caused enormous harm. This is particularly true for people who are gender non-conforming. Later in this document (See: LGBTQIA+ Terms & Definitions) we share a list of terms we would like you to use in your writing. In addition to using those terms, please avoid the following terms which are offensive to most and should, therefore, never be used: she-male, he-she, it, tranny, transvestite, "real" woman or "real" man. Please also avoid using 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 that you mean cisgender and transgender men. When in doubt, please ask us! That's why we're here.

2. Employ a strength-based approach

While disproportionate rates of certain health conditions and negative social experiences are a reality among members of our communities, LGBTQ communities have long histories of fostering interpersonal connection, encouraging altruism, developing impressive leadership, and mobilizing for change, among other strengths. 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*

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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 gender identity or sexual orientation. 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. Ask us if you're confused about the meaning or appropriateness of any particular word.

We are delighted to partner with you in advancing LGBTQ health research in ways that improve care, advance policy, and positively impact the health of LGBTQ people everywhere. Thank you for your contribution.

Welcome to PRIDEnet and The PRIDE Study!

The PRIDEnet Participant Advisory Committee (PAC), January, 2019

Guidance for Ancillary Study Applicants on Community Engagement
PRIDEnet's Participant Advisory Committee (PAC)

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). Community engagement 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, and
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 Application

For the purposes of submitting an Ancillary Study application, it is crucial for researchers to involve members of LGBTQ communities whenever the study design allows in order to remain as current with language and cultural norms as possible.

The Ancillary Study application asks researchers to address the following question:
Does your study have any community engagement components?

The Participant Advisory Committee (PAC) encourages, but does not require, some community engagement components in developing the research question and conducting the study. However, the PAC realizes that formal community engagement is not always appropriate for every study.

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In general, though, please consider using some or all of the following as you develop your ideas:

- 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 part 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 aid in recruitment of participants.

If these formal methods have not been or cannot be employed, the PAC wants to see some attention paid to soliciting input from non-researcher community members. The underlying question that the PAC wants considered is: *how do you know that this research question is relevant or meaningful to the community being studied?*

Some responses might be:
- Informal discussions with community members.
- Articulating which of the people involved in conducting research are also members of the community being studied and have relevant lived experience.
- A review of literature that mentions community input, or other inputs (even if they're anecdotal).

One sample response to the community engagement question on the AS 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 on Language
PRIDEnet's Participant Advisory Committee (PAC)

When submitting proposals for ancillary studies of The PRIDE Study (TPS) data, 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, as well as 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 language conventions, as well as make these proposals as accessible as possible to community members beyond academia, TPS recommends the following guidelines:

1. Consider how language is used with respect to the context of what data are 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," "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, either using 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/transwomen/transmen"). 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.

LGBTQIA+ Terms & Definitions

[Adapted from *Person First Guidelines*, from the City of Philadelphia Department of Behavioral Health and Intellectual and DisAbility Services]

Agender: A person who does not self-identify as any gender.

Asexual: A person who does not experience sexual attraction to any gender.

Bisexual: A person who is emotionally, romantically, spiritually, sexually and/or relationally attracted to people whose genders are both similar and different from their own.

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Cisgender: A term indicating that someone is not of trans experience (*i.e.,* 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.

Gender: 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.

Gender Dysphoria: A 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 nonconformity—is not an inherent disorder; rather, the diagnosis is included as a means to affirm those who experience tremendous anguish related to gender identity).

Gender Expression: The multitude of external characteristics that we may choose to communicate our gender identities, including apparel, grooming habits, mannerisms, etc.

Gender Binary: The idea that there are only two gender identification options: woman and man or feminine and masculine.

Gender Identity: 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.

Intersex: 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.

LGBTQIA+: An acronym for Lesbian, Gay, Bisexual, Transgender, Queer (or Questioning), Intersex, Asexual communities (Note: The plus sign is used to further abbreviate the acronym and reflect that a greater number of additional identities exist within the greater community beyond what is specified).

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).

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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 identitiy(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.

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Less Appropriate Language	Preferred Language
Homosexual	Gay or Lesbian
Hermaphrodite	Intersex
Sexual Preference	Sexual Orientation
Transvestite, transsexual	Transgender
Biological or Natal Sex	Assigned sex at birth
Preferred Gender Pronoun	Pronoun
Gender Reassignment Surgery (GRS) or Sex Reassignment Surgery (SRS)	Gender Affirming Surgery or Genital Reconstruction or the name of a specific procedure, *e.g.,* vaginoplasty

Reading Level and Readability

Please use a reading level calculator and do your best to achieve 12th grade or below (based primarily on length of sentences but also on length of words. In research, it can be difficult or impossible to eliminate long words): http://www.readabilityformulas.com/free-readability-calculators.php

An additional test for appropriate Reading Level and Readability can be found here: http://www.aph.org/research/design-guidelines/

Readable Font

Use a readable font: For text, a readable typeface means a sans-serif (/san-ser-if/) typeface (or font) made up of mainly straight lines. A serif is a short stroke that projects from the ends of the main strokes that make up a character. Although serif typefaces often work well in headings and personal stationery, they can be difficult to read in continuous text. Among the better san-serifed typefaces are APHont, Antique Olive, Tahoma, Verdana, and Helvetica. The minimum size of any typeface to be used on documents should be 12 points.

Use White Space, Bullets, and Lists

- 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 (30-34 pt) between paragraphs or other bodies of text

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- Use block paragraph style, no indents
- Use Headings and Sub-Headings

Note: 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.

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Guidance for Ancillary Study Applicants on Participant Inclusion/Exclusion
PRIDEnet's Participant Advisory Committee (PAC)

The PRIDE Study and PRIDEnet are committed to ensuring that research reflects the wide diversity of sexual and gender minority (SGM) communities. The PRIDEnet Participant Advisory Committee (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. Historically underrepresented SGM groups include various gender identity groups (women or people with non-binary gender identities), transgender people, older adults, people of color, and people with disabilities, among others. We therefore ask that Ancillary Study (AS) applicants think carefully about the rationale of 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. Below are two examples, considering approaches to inclusion of transgender sexual minority men in studies of sexual minority men.

- **Example 1**: The relationship between childhood gender nonconformity 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 nonconformity measure may not have been validated in a transgender sample. We would nonetheless encourage AS applicants 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 applicants believe 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 and investigators may wish 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, AS applicants should provide a clear

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justification, including references as 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 on Dissemination
PRIDEnet's Participant Advisory Committee (PAC)

The PRIDEnet Participant Advisory Committee (PAC) has, with the generous permission of the University of California San Francisco, Center for AIDS Prevention Studies and Prevention Research Center Community Engagement Core, adapted their "Community Advisory Board Recommendations for Research Dissemination"[1] (Revised November 2017) for use by researchers conducting Ancillary Studies in partnership with The PRIDE Study.

Why Dissemination Recommendations?

Health research, no matter how innovative, will never make a difference in the lives of sexual and gender minority 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.

General Recommendations for Research Dissemination:

1) **Create a dissemination plan for all studies.**
   - Include your dissemination plan in your Ancillary Study (AS) application. If writing a grant for the study, include the plan in the grant, too. See sample grant language, below.
   - 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 guidelines for dissemination timeline, below.
   - 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

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[1] https://prevention.ucsf.edu/sites/prevention.ucsf.edu/files/uploads/2016/12/Recommendations-for-Research-Dissemination-FULL-TEXT-2013.pdf

out for something if someone they recognize is coordinating the event or visible as a spokesperson.

- Make research results accessible to various audiences, which should include study participants, community organizations, service providers, LGBTQ 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 digestable.
- 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:
     ° Drafting content—in consultation with the PRIDE Study/PRIDEnet team—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:
     o Writing articles about the study in newsletters or websites frequently used by service providers
     o 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:
  o Writing articles about the study results for a community organization newsletter or blog
  o Live or asynchronous online Q&A, as described above
  o Articles in traditional media (*e.g.,* newspapers, magazines), either LGBTQ-specific or general
  o Social media posts by the study team, the center or research organization (if applicable), or your institution. Social media content might include text summaries, infographics, video interviews with the study team, etc.
  o Hosting a community forum, which could offer a live-stream for those unable to attend in person
  o 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. Take part in a lobby day for an organization you support, for example, for a local chapter of the Human Rights Campaign, PFLAG, GLSEN, a state Equality organization (i.e. Equality Ohio, Equality Michigan), etc.
  - 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, https://dpcpsi.nih.gov/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, The Health Equity and Accountability Act, the LGBT Data Inclusion Act).

- 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 LGBT 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 collaborators as author(s).*
4. *Writing an article for a local magazine or newsletter in English or Spanish.*
5. *Disseminating study results via social media accounts (PIs' personal accounts and the research center's accounts) and/or a webinar.*

Guidelines for Dissemination Plan/Timeline

Suggested minimum requirements for each dissemination plan are below.

The 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

- Policy makers
- Funders

When they will 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 they will receive. See what kinds of research data should be disseminated, 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 policy makers, 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.

Sufficient resources must be budgeted to ensure a successful dissemination plan.

What Kinds of Research Data Should be Disseminated?

We'd like to make it 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

Here is an example of a dissemination website from the LGBT+ National Aging Research Center: http://age-pride.org/

Examples of dissemination products on the following pages include:

1. Infographic from our Community Partner Callen-Lorde Community Health Center (The LITE Study)
2. Infographic from our Community Partner Equitas Health
3. Fact Sheet from the Center for AIDS Prevention Studies, UCSF
4. (Excerpt from) Science to Community Report from the Center for AIDS Prevention Studies, UCSF

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.

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Print assets created:

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How does stigma affect HIV prevention and treatment?

UCSF Center for AIDS Prevention Studies
Prevention Research Center
Division of Prevention Sciences

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.[1]

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.[1]

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 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 PLHIV found many had experienced stigma and discrimination, but the impact was softened by having non-PLHIV in their social networks express interest and take the initiative to offer help. Connection with other PLHIV gave them an opportunity to share their feelings and to fight for their rights.[2] 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.[3]

Adapting and coping. Although it can be difficult for persons in already stigmatized communities to identify as HIV-positive, many PLHIV 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.[4]

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.[5] Involving PLHIV 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 PLHIV 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 PLHIV to fight back and maintain their self-esteem.[6]

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PRIDEnet
CATALYZING LGBTQ HEALTH RESEARCH

Science to Community

Smoking Cessation Interventions in San Francisco's Queer* Communities

Prevention #11

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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.