



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

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## The PRIDE Study as Community-Engaged Research

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

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

*People come to SAGE Bronx and ask us to participate in these different research projects, and we just often wonder what is being done with this information.*

*...With these research studies, just making sure that they get out to enough people. If you only go to a bisexual website or a bisexual Facebook group, those people are already self-selected. So, it's not really like getting out to the Bi+ people who maybe don't really know about the Bi+ community.*

*I'm in the field of research and I encourage other folks to participate, especially trans and non-binary folks, but I feel like the issue is that we have all this funding and then they support trans people throughout the study, but once they find the research findings...there's no community feedback about what the findings were...we feel uh, very disconnected from the researchers.*

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

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

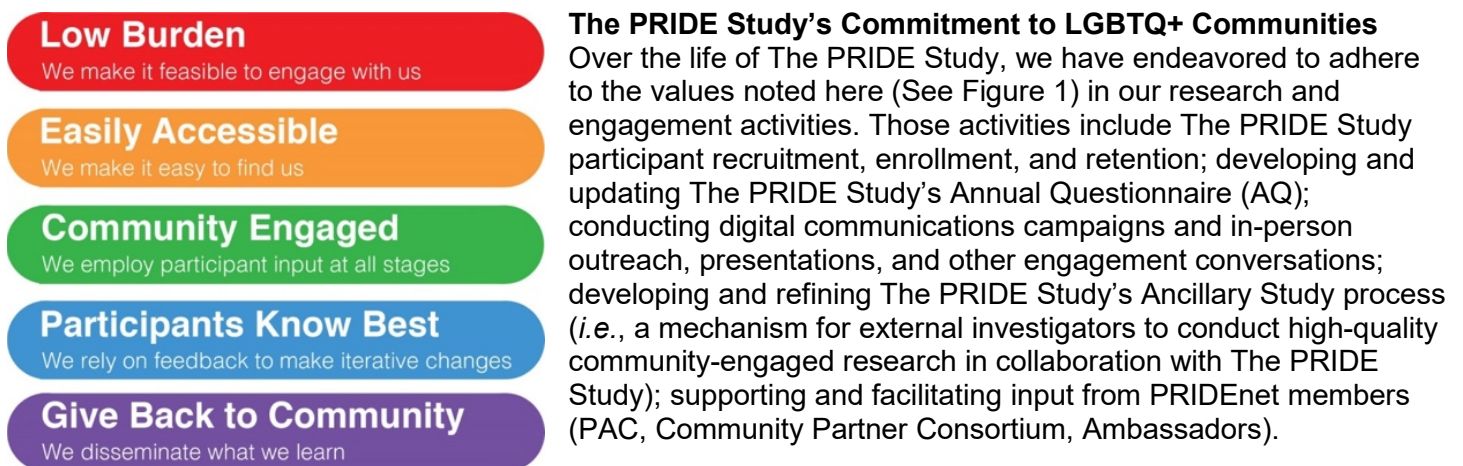


Figure 1: PRIDENet Values

The last value listed here – “Give Back to Community” – is truly “where the rubber meets the road,” is the most critical in defining The PRIDE Study as a community-engaged research project, and is the focus of this document.

### **Research Dissemination Vision**

In order to deliver on the value of “Giving Back to the Community,” the PRIDE Team commits to the following **Research Dissemination Vision**:

1. First and foremost, we hold ourselves accountable to LGBTQ+ communities when making decisions about research dissemination activities and resources.
2. Our results can be accessed by the LGBTQ+ community members who made the research possible (participants in The PRIDE Study, PRIDEnet Community Partners, PRIDEnet PAC).
3. Our research results are available and used to improve health care and develop health policy for LGBTQ+ communities (relevant advocacy organizations).
4. Our research results are available to people who are and are not digitally engaged to the best of our ability.
5. The most historically marginalized and underrepresented LGBTQ+ sub-communities receive tailored research results dissemination first (when feasible).
6. Our research results support a robust cohort in The PRIDE Study by encouraging LGBTQ+ community members to engage, enroll, and stay involved in The PRIDE Study.

### **Research Dissemination Guidelines**

In order to operationalize the values and vision above within the context of The PRIDE Study’s Ancillary Study program, the PRIDE Team commits to the following **Research Dissemination Guidelines**:

1. Research results are published in appropriate peer-reviewed journals before they can be disseminated more widely. However, there may be some high-level descriptive results and information about study methods that can be disseminated to community groups before publication.
2. Top-level research results can be shared at community presentations or conferences before they are published. Getting initial feedback from those working in communities can improve manuscripts.
3. Upon publication of a manuscript, participants are notified first whenever possible. Members of PRIDEnet (PRIDEnet PAC, Community Partners, and Ambassadors) are notified second.
4. Ancillary Study investigators must develop a community-level description of the research (“Community Summary of Research Plan”) they plan to conduct prior to conducting the research.
5. Ancillary Study investigators must develop community-level summaries that describe their research results (“Community Summary of Findings”). Ideally, these summaries should strive to replace reading the published paper and be approximately one page in length, written at an 8<sup>th</sup>-12<sup>th</sup> grade reading level, and written in 12-point sans-serif font. Authors are encouraged to use white space, bullets/lists, and headings/subheadings as possible and appropriate.
  - a. Community summaries of findings should be:
    - i. created for all published papers
    - ii. required from all Ancillary Study investigators (including PRIDE Team members)
    - iii. released as close as possible to the paper publication date
    - iv. posted on ‘The Research’ page at [pridestudy.org](http://pridestudy.org)
  - b. Community summaries of findings should include the following sections:
    - Why did we do this study?

- What did we do?
  - What was innovative?
  - What did we learn?
  - Why does it matter to our communities?
  - What's next?
6. Ancillary Study investigators can receive the following support from the PRIDE Team in conducting their research dissemination:
    - a. dissemination on The PRIDE Study/PRIDENet communication channels (e.g., social media, monthly newsletter, PRIDENet blog, direct-to-participant e-mails)
    - b. access to communications templates and guidance in developing additional dissemination materials
    - c. opportunity to receive feedback from the PRIDENet PAC about their community summaries of findings
    - d. posting of community summaries of findings and published papers on 'The Research' page of [pridestudy.org](http://pridestudy.org)
    - e. introduction to PRIDENet Community Partner Consortium organizations for tailored dissemination (when applicable and requested)
  7. The PAC will review this dissemination plan (i.e., this document) annually to see which changes they might offer after more experience with its implementation.
  8. In research dissemination products (e.g., "Community Summary of Findings") and communications (e.g., press releases, blog posts, newsletters), papers authored by The PRIDE Study researchers are referred to as being authored by "The PRIDE Study Team." Ancillary Study papers are referred to as being authored by the lead researcher (e.g., "Dr. Smith and colleagues").
  9. Finally, we are committed to [Open Access](#) of publications from The PRIDE Study and PRIDENet.
    - a. For research projects led by PRIDE team members (i.e., not mentee projects):
      - PRIDE will publish in a journal that is either 100% OA or has an OA option.
      - PRIDE will fund OA publishing charges if funding is not available from the project lead or other sources.
    - b. For research projects with a PRIDE team mentor (i.e., mentee projects):
      - Research results should be published in a journal that is either 100% OA or has an OA option.
      - The PRIDE mentor should fund OA publishing charges.
      - In event that the PRIDE mentor cannot (fully) fund OA publishing charges, PRIDE will fund partial or full OA publishing charges.
    - c. For research projects led by Ancillary Study investigators:
      - Research results should be published in a journal that is either 100% OA or has an OA option.
      - PRIDE will *highly recommend* all Ancillary Study investigators to publish OA.
      - Therefore, we encourage investigators to investigate OA funding early in the project in the spirit of comprehensive and accessible community dissemination.
      - The Ancillary Study investigator must notify PRIDE if they are or are not going to publish OA at the time of manuscript submission to a journal for peer review. If they are not publishing OA, they should specify if it was because of limited OA funding.
      - For projects that are not being published OA, the PAC will receive a copy of the submitted manuscript in order to decide if PRIDE should (wholly or partially) fund OA publishing. (Assistance from the RAC is available if desired and funding is currently available.)

### **How The PRIDE Study Research is Conducted**

The primary mechanism to conduct collaborative research with external investigators is called The PRIDE Study Ancillary Study program. Community- or academic institution-based researchers can apply to access The PRIDE Study's current data or collect new data by surveying The PRIDE Study participants. Ancillary

Study proposals are reviewed by The PRIDE Study’s Research Advisory Committee (RAC), which evaluates the research question, the rigor of the research methods, the appropriateness of the proposed Ancillary Study, and the feasibility to conduct the Ancillary Study. When approved by The PRIDE Study’s RAC, the proposal is reviewed by the PRIDENet PAC. The PRIDENet PAC reviews the rigor of community engagement components in developing the research question and project direction, relevance of the project to the LGBTQ+ community, and quality of a community dissemination plan. When the application is approved by both RAC and PAC, the Ancillary Study proposal is accepted, and the collaborating researcher(s) works with the PRIDE Team to implement the Ancillary Study.

**The PRIDE Study Research to Community Dissemination by Stage of Research Process**

There are key points in the research process that serve as opportunities to communicate with our constituents including The PRIDE Study participants, PRIDENet members (PAC, Community Partner Consortium, Ambassadors), research colleagues, funders, and the general LGBTQ+ community. Below, we describe these key points, the appropriate audience for dissemination, and the PRIDE Team member(s) responsible for specific tasks. When possible, we will batch research dissemination communications to participants to prevent overwhelming them with notifications.

<b>Stage 1: Proposed Study</b>	<b>Ancillary Study “Community-Friendly Summary of the Proposed Study”</b> (e.g., description of research that <u>will be</u> conducted)
<i>Audience(s):</i>	<ul style="list-style-type: none"> <li>• The PRIDE Study Participants</li> <li>• PRIDENet members (PAC, Community Partner Consortium, Ambassadors)</li> <li>• General Interest (email and social media)</li> <li>• Website (pridestudy.org) visitors</li> </ul>
<i>Lead:</i>	Research Manager: <ul style="list-style-type: none"> <li>• gathers and formats summary</li> <li>• posts on the website Research page</li> </ul>

<b>Stage 2: Study Launch</b>	<b>Announcement of Ancillary Study Launch</b> (i.e., for Ancillary Studies that require a new survey data collection)
<i>Audience(s):</i>	<ul style="list-style-type: none"> <li>• The PRIDE Study Participants</li> <li>• PRIDENet members (PAC, Community Partner Consortium, Ambassadors)</li> </ul>
<i>Lead:</i>	Co-Director Mitchell R. Lunn: <ul style="list-style-type: none"> <li>• launches survey in Portal</li> </ul>

<b>Stage 3: Study Generates Early Results</b>	<b>Ancillary Study High-Level Pre-Publication Descriptive Results (“Results Teaser”) or Study Methods Information</b> (e.g., “thousands of gender minority people have participated in a study on reproductive health”) <b>Note:</b> Caution is advised as sharing results can jeopardize publication.
<i>Audience(s):</i>	<ul style="list-style-type: none"> <li>• The PRIDE Study Participants</li> <li>• PRIDENet members (PAC, Community Partner Consortium, Ambassadors)</li> <li>• General Interest (email and social media)</li> <li>• Website (pridestudy.org) visitors</li> </ul>
<i>Lead:</i>	Lead Author: <ul style="list-style-type: none"> <li>• writes shareable descriptive results</li> </ul>

<b>Stage 4: Study Publication</b>	<b>Ancillary Study Publication Announcement</b> (e.g., announcement about publication and a link to the paper)
<i>Audience(s):</i>	<ul style="list-style-type: none"> <li>• Funders</li> <li>• Colleagues / other Researchers</li> <li>• The PRIDE Study Participants</li> </ul>

	<ul style="list-style-type: none"> <li>• PRIDENet members (PAC, Community Partner Consortium, Ambassadors)</li> <li>• General Interest (email and social media)</li> </ul> <p>Optional Audiences, depending on AS topic:</p> <ul style="list-style-type: none"> <li>• LGBTQ media outlets (for example, The Advocate)</li> <li>• General media outlets (reporters with whom we have relationships)</li> <li>• Website (pridestudy.org) visitors (posting on Research page)</li> </ul>
<i>Implementer:</i>	<p>Lead Author:</p> <ul style="list-style-type: none"> <li>• communicates with The PRIDE Study team about paper acceptance</li> <li>• provides anticipated citation and key result(s) to support writing of announcement</li> </ul>
<i>Lead:</i>	<p>Communications Specialist:</p> <ul style="list-style-type: none"> <li>• liaises with lead author</li> <li>• writes announcement</li> <li>• puts in social media schedule</li> <li>• formats in monthly newsletter</li> <li>• sends to media outlets (see above), when appropriate and possible</li> </ul>

<b>Stage 5: Study Summary</b>	<b>Ancillary Study “Community-Friendly Summary of Findings”</b> (e.g., description of what the research team <u>learned</u> )
<i>Audience(s):</i>	<ul style="list-style-type: none"> <li>• The PRIDE Study Participants</li> <li>• PRIDENet members (PAC, Community Partner Consortium, Ambassadors)</li> <li>• General Interest (email and social media)</li> <li>• Website (pridestudy.org) visitors</li> </ul>
<i>Lead:</i>	<p>Research Manager:</p> <ul style="list-style-type: none"> <li>• liaises with lead author</li> <li>• gathers, reviews, and edits (as needed) summary</li> </ul>

<b>Stage 6: Execution of Dissemination Plan</b>	<b>Lead Author’s Community Dissemination Plan from Ancillary Study Application</b>
<i>Audience(s):</i>	<ul style="list-style-type: none"> <li>• Groups to which the lead author committed disseminating findings in their original Ancillary Study proposal</li> </ul>
<i>Lead:</i>	Lead Author

In order to provide a different perspective on how research dissemination works, The PRIDE Study Research to Community Dissemination is described below by **Type of Dissemination** (in order of increasing effort) and includes brief descriptions of audiences and team responsibilities:

<b>Traditional Dissemination Products</b>	
<i>Dissemination Product:</i>	<i>Audience(s):</i>
<ul style="list-style-type: none"> <li>• Lectures</li> </ul>	<ul style="list-style-type: none"> <li>• Professional colleagues</li> </ul>
<ul style="list-style-type: none"> <li>• Presentations</li> </ul>	<ul style="list-style-type: none"> <li>• Conference attendees</li> </ul>
<ul style="list-style-type: none"> <li>• Abstracts</li> </ul>	<ul style="list-style-type: none"> <li>• Conference attendees</li> </ul>
<ul style="list-style-type: none"> <li>• Papers</li> </ul>	<ul style="list-style-type: none"> <li>• Peer-reviewed journal reviewers &amp; professional researchers</li> </ul>
<i>Lead:</i>	Lead Author
<i>Implementer:</i>	Research Manager

**PRIDENet Communication Channels**

<i>Communications Channel:</i>	<i>Audience(s):</i>
<ul style="list-style-type: none"> <li>The PRIDE Study portal</li> </ul>	<ul style="list-style-type: none"> <li>The PRIDE Study participants</li> </ul>
<ul style="list-style-type: none"> <li>EveryAction emails</li> </ul>	<ul style="list-style-type: none"> <li>The PRIDE Study participants</li> </ul>
<ul style="list-style-type: none"> <li>Emails to PRIDENet members</li> </ul>	<ul style="list-style-type: none"> <li>PRIDENet PAC, Community Partner Consortium, &amp; Ambassadors</li> </ul>
<ul style="list-style-type: none"> <li>Monthly PRIDENet newsletter</li> </ul>	<ul style="list-style-type: none"> <li>General interest mailing list (PRIDENet, sign-ups from outreach and pridestudy.org)</li> </ul>
<ul style="list-style-type: none"> <li>Social media posts (Facebook, Instagram, and Twitter)</li> </ul>	<ul style="list-style-type: none"> <li>Followers of The PRIDE Study</li> </ul>
<ul style="list-style-type: none"> <li>Community Partner social media managers</li> </ul>	<ul style="list-style-type: none"> <li>Community Partner constituents</li> </ul>
<ul style="list-style-type: none"> <li>The “Research” page</li> </ul>	<ul style="list-style-type: none"> <li>pridestudy.org visitors</li> </ul>
<i>Lead:</i>	Community Engagement Director
<i>Implementer:</i>	Participant Engagement Director
<i>Implementer:</i>	Communications Specialist

<b>Lead Author-Generated Community Dissemination</b>	
<i>Dissemination Product:</i>	<i>Audience(s):</i>
<ul style="list-style-type: none"> <li>Dissemination products committed to by lead author on Ancillary Study accepted proposal</li> </ul>	<ul style="list-style-type: none"> <li>[variable]</li> </ul>
<i>Lead:</i>	Lead Author
<i>Consulted:</i>	PRIDENet Participant Advisory Committee

<b>Earned Media (including Stanford News Office involvement for newsworthy findings)</b>	
<i>Dissemination Product:</i>	<i>Audience(s):</i>
<ul style="list-style-type: none"> <li>Earned media coverage</li> </ul>	<ul style="list-style-type: none"> <li>General public</li> </ul>
<ul style="list-style-type: none"> <li>Stanford University press release/news story and AS investigator’s home institution press release/news story</li> </ul>	<ul style="list-style-type: none"> <li>General public &amp; other news outlets</li> </ul>
<i>Lead:</i>	Communications Specialist
<i>Consulted:</i>	Principal Investigators

The PRIDE Team thanks the Participant Advisory Committee (PAC) members for keeping community-engaged research dissemination at the forefront of multiple conversations and the Ancillary Study investigators for committing to implement community-engaged research dissemination.