

Engaging Sexual and Gender Minority (SGM) Communities for Health Research: Building and Sustaining PRIDENet

Juno Obedin-Maliver*, Carolyn Hunt*, Annesa Flentje, Cassie Armea-Warren, Mahri Bahati, Micah E. Lubensky, Zubin Dastur, Chloe Eastburn, Ell Hundertmark, Daniel J. Moretti, Anthony Pho, Ana Rescate, Richard E. Greene, JT Williams, Devin Hursey, Loree Cook-Daniels, and Mitchell R. Lunn

Abstract

Lesbian, gay, bisexual, transgender, queer, intersex, asexual, aromantic, and other sexual and/or gender minority (LGBTQIA+) communities are underrepresented in health research and subject to documented health disparities. In addition, LGBTQIA+ communities have experienced mistreatment, discrimination, and stigma in health care and health research settings. Effectively engaging LGBTQIA+ communities and individuals in health research is critical to developing representative data sets, improving health care provision and policy, and reducing disparities. However, little is known about what engagement approaches work well with LGBTQIA+ people. This paper describes the development of PRIDENet (pridenet.org), a national network dedicated to catalyzing LGBTQIA+ community involvement in health research and built upon well-established community-engaged research (CEnR) principles. PRIDENet's relationship building and digital communications activities engage thousands of LGBTQIA+-identified people across the country and offer multiple low-threshold ways to participate in specific studies and shape research. These activities comprise a CEnR infrastructure that engages LGBTQIA+ people on behalf of other projects, primarily The PRIDE Study (pridestudy.org) and the National Institutes of Health's *All of Us* Research Program (joinallofus.org/lgbtqia). Our impact, results, and lessons learned apply to those engaging communities underserved in biomedical research and include: the importance of building adaptable infrastructure that sustains transformational relationships long-term; implementing high-touch activities to establish trust and broad-reach activities to build large data sets; nurturing a team of diverse professionals with lived experiences that reflect those of the communities to be engaged; and maintaining CEnR mechanisms that exceed advice-giving and result in substantive research contributions from beginning to end.

Reflexivity and Positionality Statement

The authors of this manuscript include present and former PRIDENet staff across different areas of focus (research, community engagement, and communications) and members of PRIDENet's Participant Advisory Committee (PAC) and Community Partner Consortium (CPC), which are described below. The process for developing the manuscript included JOM and CH working in close collaboration with the authoring team for contributions. JOM and CH developed a full manuscript draft that all coauthors reviewed, provided feedback on, and edited on multiple occasions. All authors reviewed and approved the final submitted manuscript.

The authors represent multiple LGBTQIA+ and other identities (e.g., age, race and ethnicity, abilities, and geographic locations). They also represent many professions along the academic- to community-based spectrum. We intentionally took a community-engaged approach in developing this manuscript by assuring that the makeup of the authorship team would mirror the cross-section of identities represented within PRIDENet and its associated components (PAC, CPC, Ambassadors). All authors have played crucial roles in the community engagement activities described herein. The use of "we" within this manuscript refers to the collective of PRIDENet and its associated components.

* Co-first authors

Lesbian, gay, bisexual, transgender, queer, intersex, asexual, aromantic, and other sexual and/or gender minority (LGBTQIA+) communities experience documented health disparities and are underrepresented in health research. The term commonly used in academia—sexual and/or gender minority (SGM)—and the term LGBTQIA+ (commonly used in community settings) will be used interchangeably depending on context (*i.e.*, SGM for academic settings and LGBTQIA+ for community settings; Sexual & Gender Minority Research Office, n.d.).

Historically, LGBTQIA+ communities have faced mistreatment, stigma, and discrimination in health care and health research as they have in society broadly (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2011). Effectively engaging LGBTQIA+ communities and individuals in health research is critical to developing representative data sets, understanding LGBTQIA+ health issues, improving health care provision and policy, and reducing disparities. PRIDENet was founded in 2015 to address these problems.

PRIDENet—based at Stanford University in collaboration with the University of California, San Francisco—is a national community-engaged research (CEnR) network dedicated to catalyzing LGBTQIA+ community involvement in health research. PRIDENet facilitates opportunities for community members to provide comprehensive feedback on components of the research process such as the development of research plans, processes, products, communication strategies, data access mechanisms, and research results dissemination. Throughout its activities, PRIDENet fosters engagement and excitement about health research in general (pridenet.org). Currently, PRIDENet primarily engages LGBTQIA+ communities on behalf of two national research programs: The PRIDE Study (pridestudy.org) and the National Institutes of Health's (NIH) *All of Us* Research Program (joinallofus.org/lgbtqia).

PRIDENet's team includes full-time staff who are based at Stanford University and the University of California, San Francisco. Staff positions are funded through research and community engagement or network grants, private philanthropy, and intramural funding. PRIDENet's associated components include individual members of a Participant Advisory Committee (PAC) and Ambassadors (described below) who receive stipends (funded by PRIDENet research grants and network grants) for their work.

PRIDENet's network also includes organizational members of the Community Partner Consortium (CPC, described below) with hard costs for events/activities often funded by PRIDENet research grants, network grants, and intramural funding.

PRIDENet's leadership, staff, PAC, and Ambassadors are comprised of LGBTQIA+-identified people and allies with diverse professional skills (*e.g.*, activism, administration, community engagement and organizing, communications, data science, health care provision, policy, and research) and lived experiences across diverse ages, gender identities, sexual orientations, races, ethnicities, cultures, abilities, and regions of the country. At its inception in 2015, PRIDENet originally one person at 0.5 full-time equivalents (FTE) in addition to limited time from two principal investigators and one associate director. As of 2024, staff and faculty had grown to a total of 13.1 FTE, including staff focused on community engagement directly (community engagement lead [1 FTE], senior community engagement specialist [0.75 FTE], regional community engagement specialists [2 FTE], communications [2 FTE], operations and administration [1.25 FTE], participant engagement and experience [1 FTE], intersectional advisory group leadership [0.1 FTE], and community-engaged clinical research leadership and coordinators [5 FTE]). PRIDENet's geographic reach is national (*i.e.*, the United States and its territories). The majority of PRIDENet's staff are based in the continental West. Additional team members based in the Midwest, Northeast, and South focus on community engagement activities in their regions.

PRIDENet's CPC is composed of organizations that work nationally, regionally, and locally; roughly half of the organizations have a national scope, and half have a regional or local scope. Organizations are based across the country, with approximately 13% in the Midwest, 25% in the Northeast, 38% in the South, and 25% in the West. Individual members of PRIDENet's PAC and Ambassadors are based across the country, with roughly 14% in the Midwest, 24% in the Northeast, 29% in the South, and 33% in the West. The demographics of SGM researchers partnering with PRIDENet (also called Ancillary Study Collaborating Investigators) exemplify PRIDENet's commitment to diversity in race and ethnicity, sexual orientation, and gender identity. These researchers currently represent at least 10 states and a variety of institutional affiliations (academic/medical centers, nonprofit organizations, public/private universities, *etc.*). PRIDENet intentionally

maintains this diversity, which contributes to the effective integration of community and research perspectives in all aspects of research projects and the ability to reach LGBTQIA+ subcommunities with appropriate messages.

This paper describes PRIDEnet's development and offers lessons learned for those seeking to engage LGBTQIA+ and other communities who are underrepresented in biomedical research (Matthews et al., 2018). In so doing, this paper is intended to provide a foundational guide for the development and early maintenance of one model for operationalizing meaningful community engagement within research. Here, we discuss CEnR and how it relates to work with, by, and for LGBTQIA+ communities; describe the key components of PRIDEnet with examples of its work on the ground; and discuss impact, lessons learned, and future directions.

Community-Engaged Research (CEnR)

Since its inception, PRIDEnet has aspired to increase the long-term, meaningful engagement of LGBTQIA+ communities in health research. This aspiration has a solid foundation in the extensive history of CEnR, in which community partners work with researchers in different ways depending on the identified goals of the partnership, the expertise of the partners, and available time and resources. Balls-Berry and Acosta-Pérez (2017) referencing prior Centers for Disease Control work note “[c]ommunity-engaged research is ‘the process of working collaboratively with groups of people affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being’” (p. 2). CEnR can best be described as a continuum of community member influence that ranges from consultations about specific research/study components to participatory action research and community-based participatory research (CBPR) models characterized by shared responsibility between researchers and community members in making decisions, defining questions, implementing study designs, and equitably distributing resources (Fullerton et al., 2015; Israel et al., 2006, 2020; Rubin et al., 2012). CEnR and CBPR have become more established over the past 25 years as effective ways to learn about social and health inequities and disparities among communities underrepresented in research (Wallerstein et al., 2020).

In general, there are four widely accepted best practices for forming CEnR and CBPR projects (Wallerstein et al., 2020). First is the importance of

a shared definition of a given community—based on common interests or concerns, geographic locations, lived experiences, identities, cultural norms, or knowledge—among partners. Second is the importance of building trusting relationships through commitments to transparency, following through on promises, and ensuring mutual benefit and reciprocity (Maiter et al., 2008). Third is clearly defining and describing roles and responsibilities among partners; this happens not only through conversations but also through formal cooperative agreements (e.g., memoranda of understanding) with associated terms and timelines, bylaws, and/or operating principles. Regardless of how these roles and responsibilities are defined, nurturing a culture of collegial communication is a CEnR hallmark (Israel et al., 2020). Fourth, recruiting, hiring, and supporting staff from the communities to be reached is fundamental. Here, we note the particular importance of community members leading the research when possible since, historically, the study of marginalized and minoritized communities by outside researchers has led to confirmation of biased hypotheses and broken trust (DuBois et al., 2011).

A key dimension of sustainability for CEnR projects is the management of relationships and commitments among partners. Israel et al. identified 10 key strategies that have contributed to the success of CEnR/CBPR projects (Israel et al., 2006). These aspirational strategies—particularly developing trusting relationships, providing clear benefit to partners, and developing multiple, sequential projects to honor and leverage relationships and to build on lessons learned—describe PRIDEnet's approach. Attending to these strategies is an ethical imperative given widespread and well-grounded mistrust in medical research stemming from current and historical mistreatment, misconduct, and abuses (Jaiswal & Halkitis, 2019).

While PRIDEnet is unique in that it focuses on LGBTQIA+ community involvement across multiple studies, our research methodology is firmly rooted in CEnR, as it applies to the whole network and to each study individually. Table 1 describes how PRIDEnet has implemented 10 CEnR strategies. Examples cited will be described in the remainder of the manuscript.

Setting

Defining Communities

SGM people, as defined by the National Institutes of Health, include those who identify as

Table 1. CEnR Strategies and Example Activities Used by PRIDEnet’s Model (Strategies from Israel et al., 2006, With PRIDEnet-Specific Activities).

	Strategies	Example Activities From PRIDEnet
1	Develop and adhere to collaborative principles to build trusting relationships.	<ul style="list-style-type: none"> • Recruiting, building, and maintaining a Community Partner Consortium (CPC) • Tailored approach to partnership, ensuring partnerships are mutually beneficial • Acknowledging historical harm and implementing strategies led by partners to build trust
2	Use structure, processes, and flexibility in rules governing partnerships.	<ul style="list-style-type: none"> • Establishing, maintaining, and updating as needed PRIDEnet Participant Advisory Committee (PAC) and Ambassadors governance structures developed by those stakeholders
3	Gather the right people around the table and get organizational and individual commitments for the long-term.	<ul style="list-style-type: none"> • Ongoing work of PRIDEnet PAC, Ambassadors, and CPC organizations • PRIDEnet Summits
4	Cultivate champions who stay with the partnership through high and low points.	<ul style="list-style-type: none"> • PRIDEnet PAC members • Ambassadors • CPC organizations and contact points
5	Build new relationships (and warmly welcome and orient new people).	<ul style="list-style-type: none"> • Inviting new people and potential partners to PRIDEnet Summits • Cultivating warmth and welcome through comprehensive orientation materials, personal check-ins • Supporting basic needs and lowering the bar for participation by paying for travel, lodging, food, and entertainment • Conducting focused efforts to solicit applications for new PRIDEnet PAC members and Ambassadors where we have gaps in representation • Providing orientation and onboarding meetings and materials for new PRIDEnet PAC members and Ambassadors
6	Provide clear, tangible benefit, including attending to partners’ needs to experience personal, organizational, and community benefits to stay engaged.	<ul style="list-style-type: none"> • Establishing memoranda of understanding/ collaborative agreements with CPC organizations • Contracting with a third-party consultant to obtain, summarize, and guide incorporation of feedback from CPC into PRIDEnet stakeholder relationships and agreements • Providing training, capacity building, and funding opportunities to partners
7	Provide safe environments for self-reflection.	<ul style="list-style-type: none"> • PRIDEnet Summits • PRIDEnet Cafés
8	Build power through organizational affiliation and engaging senior leadership.	<ul style="list-style-type: none"> • Cultivating meaningful relationships with CPC organizations
9	Develop multiple, sequential projects for building on lessons learned.	<ul style="list-style-type: none"> • Community Listening Sessions • “Lunch and Learn” presentations • PRIDEnet Summits (4; 2016, 2017, 2020, 2021) built on one another and helped foster and improve activities like <ul style="list-style-type: none"> • PRIDEnet Cafés • PRIDEnet Journal Club
10	Recognize community knowledge and skills and promote them through networks.	<ul style="list-style-type: none"> • Open invitation for CPC and PRIDEnet PAC members to participate in The PRIDE Study Ancillary Study process • Dissemination of research methods and outcomes back to community members • PRIDEnet Newsletters, PRIDEnet Blog, and social media

asexual, lesbian, gay, bisexual, transgender, queer, and/or Two-Spirit; those with same-sex or same-gender attractions/behaviors; and those who are intersex and with variations of sex characteristics (Sexual & Gender Minority Research Office, n.d.). SGM people can also include people in subcommunities (described below) that are less represented in the data (e.g., people who identify as aromantic). Although population statistics on SGM people are imprecise, the group accounts for at least 7.2% of adults and 19.7% of adults aged 18–24 years old in the United States (J. M. Jones, 2023). The majority of LGBTQIA+ Americans (54.6%) identify as bisexual (J. M. Jones, 2022). Sexual minority people, defined here as having a sexual orientation other than exclusively heterosexual/straight, may be of any gender. Gender minority people, defined here as having a gender identity different from what is commonly associated with the sex assigned to them at birth (e.g., someone who identifies as a woman or a nonbinary person and was assigned male sex at birth), may be of any sexual orientation.

LGBTQIA+ people do not comprise one monolithic community but rather encompass diverse groups with both different and common experiences with stigma, discrimination, familial rejection, and resiliencies as well as interests in securing political rights and policy advancements. Dramatic differences in community members' experiences and interests stem from differences in race and ethnicity, geographical location, self-identity, socioeconomic status, disability status, age, and other factors (Chen et al., 2022; Hulko & Hovanec, 2018; Smith et al., 2022; Walubita et al., 2022). We refer to these subgroups as “subcommunities” within the larger LGBTQIA+ umbrella. These subcommunity distinctions are important because of the different lived experiences, resources, and, at times, social invisibility, stigma, and discrimination that manifest in differential health care and can influence health research. Taking an intersectional frame, LGBTQIA+ individuals' experiences can be influenced not only by belonging to one (or multiple) LGBTQIA+ subcommunities but also by other social and cultural characteristics such as age, race, ethnicity, country of origin, location of residence, religion, and income, among others (Hulko & Hovanec, 2018; Schmitz & Tyler, 2018).

LGBTQIA+ Health History

Since the 1960s, LGBTQIA+ people in the United States have worked to develop safe

spaces to provide health care and other services for themselves given absent and discriminatory support elsewhere. Those efforts have been closely linked to activism calling for social change and increased civil rights in addition to the coalescing of LGBTQIA+ community identity following the Compton's Cafeteria and Stonewall uprisings. These services evolved along with a growing scientific understanding of the physical, mental, and social health needs of these communities (Martos et al., 2017).

In 1973, following significant social and professional pressure, the American Psychiatric Association approved the removal of the diagnosis of “homosexuality” from the *Diagnostic and Statistical Manual of Mental Disorders–III* (DSM–III) published in 1980 (Drescher, 2015). The medical normalization of “homosexuality” occurred concurrently with increased visibility and pathologizing of transgender people in the DSM–III through a new diagnosis of “gender identity disorder (GID).” Some have noted that this may have facilitated the systematic distancing from and exclusion of transgender people in the advocacy, social, political, and health care provision groups that represented and served (cisgender) lesbian, gay, and bisexual people (Martos et al., 2017).

Since the mid-1980s, LGBTQIA+ political activists have worked to broaden public acknowledgment of and funding for the HIV/AIDS crisis. As part of these efforts, other topics were made visible, such as same-sex partnerships, estate planning and associated rights, housing, equitable and accessible medical care, and family building. Activists implored federal agencies such as the NIH, the Food and Drug Administration, and the Centers for Disease Control and Prevention to recognize and address gaps and community needs related to health care and social services. These activists' hard-won achievements formed the basis for funding mechanisms and the proliferation of community advisory boards at the federal level (Padamsee, 2020).

Despite progress and numerous examples of community creativity and resilience, LGBTQIA+ people experience ongoing discrimination in social, medical, legal, and health care settings; over 474 state-level anti-LGBTQIA+ bills have been introduced and are being tracked in the 2024 United States Legislative Session. (ACLU, 2024; Jones & Navarro, 2022). In addition, although risks vary by subcommunity, being an LGBTQIA+ person is generally associated with health disparities including worse physical health (e.g., diabetes,

cardiovascular disease, asthma) and mental health (e.g., depression, anxiety, substance use disorders) compared to cisgender and heterosexual/straight counterparts (Flentje et al., 2022; Frank et al., 2019). These negative health outcomes are likely related to sexual and/or gender minority stress—that is, the experience of persistent additional stress that is related to one’s minoritized status.

Outside of very focused (and often stigmatizing) work predominantly regarding people living with HIV/AIDS, comprehensive sexual orientation and gender identity (SOGI) data, as well as data on topics specifically important to or focused on the LGBTQIA+ community (e.g., social support networks, primary care access, or family building among LGBTQIA+ people), are rarely or unreliably collected. When LGBTQIA+ people are not included in meaningful ways and numbers and the differences between SGM and non-SGM people are not described, the applicability of research results to LGBTQIA+ communities is limited. With limited national-level health data, studies on the health and well-being of LGBTQIA+ communities and the development of LGBTQIA+-focused interventions are challenging to implement (Drescher, 2015; Federal Committee on Statistical Methodology, 2018).

To advance health equity and population health, in 2010, the NIH commissioned the Institute of Medicine (now National Academy of Medicine) to report on and develop a research agenda for SGM health. The report concluded that “the relative lack of population-based data presents the greatest challenge to describing the health status and health-related needs of LGBT people” (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2011). The report emphasized the need for national data collection efforts about SGM identity and experience. This report confirmed that, while in-depth information is sorely lacking, certain LGBTQIA+ communities are subject to health disparities, including higher rates of smoking, HIV incidence, certain cancers, depression, and suicide attempts when compared to the general population.

Establishing PRIDENet’s Model

The 2010s saw increased societal awareness of LGBTQIA+ issues, improved understanding of the negative impacts of excluding LGBTQIA+ people and other communities traditionally underrepresented from health research, and increased use of technology in health research.

Recognizing these trends, PRIDENet’s directors (JOM and MRL) began (in 2013–2014) to design a national online health study of LGBTQIA+ people that would eventually become The PRIDE Study (described below). Recognizing that the size and scale of the envisioned research would not be possible, real, or relevant without deep community involvement, they established PRIDENet in 2014–2015 to support the development and launch of The PRIDE Study.

PRIDENet was conceived as a patient/participant-powered research network (PPRN) designed to catalyze the involvement of LGBTQIA+ people in health research. The initial establishment of PRIDENet’s CPC happened through phone and email inquiries to SGM-serving or -focused organizations. They were invited to join in creating a PPRN to support building The PRIDE Study (see related communications, Appendix 1). In 2015, we sought and received initial funding from the University of California, San Francisco, and the Patient-Centered Outcomes Research Institute (PCORI) to support and grow PRIDENet. PRIDENet originally comprised 41 original partner organizations including 20 community centers, 13 health organizations, and eight national/international organizations (see Appendix 2). These partners responded to a survey that proposed possible ways to collaborate with PRIDENet and build The PRIDE Study. The survey queried partners to convey their interest in and potential actions related to governance, research priorities, study design and recruitment, and dissemination of study results (see Appendix 3, Appendix 4). The original and enduring structure of PRIDENet can be seen in an organizational structure diagram (see Appendix 5, Figure 1). Since its founding, PRIDENet has been the central community engagement mechanism for The PRIDE Study (established in 2015) and has provided community engagement support for other projects, including the *All of Us* Research Program (established in 2015; PRIDENet joined in 2017). These projects illustrate two different ways PRIDENet works to enhance LGBTQIA+ equity in health research.

The PRIDE Study: “By Us, For Us” Research

The Population Research in Identity and Disparities for Equality (PRIDE) Study was founded in 2015, in collaboration with PRIDENet’s network, to address a dearth of LGBTQIA+ health research. The PRIDE Study was and continues to be an example of “by us, for us” research in which the majority of faculty, staff, affiliated researchers, and

trainees involved identify as LGBTQIA+ persons. The PRIDE Study—a national longitudinal cohort study of the physical, mental, and social health of LGBTQIA+ adults—utilizes multiple technology-rich strategies to recruit, enroll, and retain 28,000+ participants through an online research platform; to develop a scientifically robust dataset; and to produce collaborative research on diverse topics through its Ancillary Study program. In the Ancillary Study program, researchers submit applications to answer specific research questions. The applications are reviewed by the Research Advisory Committee (RAC) and the PRIDENet PAC prior to approval and implementation.

All of Us Research Program: Inclusion Research

In 2017, PRIDENet received funding as a National Community Engagement Partner with the NIH's *All of Us* Research Program to ensure that SGM people are consulted, welcomed, and excited to participate in the *All of Us* endeavor. Designed to advance precision medicine, *All of Us* is a historical effort that aims to enroll at least 1 million participants and build one of the most diverse biomedical resources ever created. *All of Us* facilitates low-cost, publicly accessible research access via a secure cloud-based analytical environment to balance privacy and security while facilitating analyses with multiple data types (Ramirez et al., 2022). A key area of emphasis is actively engaging communities traditionally underrepresented in biomedical research (UBR), such as SGM people, people from racial and ethnic minority backgrounds, people living with disabilities, people over age 50, and others (Mapes et al., 2020). As of June 2021, *All of Us* had enrolled over 387,000 people, including approximately 75% UBR participants and approximately 13% SGM participants (Ramirez et al., 2022), an intentional oversampling of these groups compared to their numbers in the general population (Wallerstein et al., 2020).

Building and Sustaining PRIDENet's Infrastructure

PRIDENet's goal is to catalyze real, respectful, and relevant LGBTQIA+ health research by engaging LGBTQIA+ people at every step of the health research process. PRIDENet focuses LGBTQIA+ people overall with an emphasis on those LGBTQIA+ subpopulations who are the most underserved, understudied, and vulnerable to poor health. PRIDENet's focus on research is seen as catalytic to enhancing what is known

about LGBTQIA+ people as well as the capacity of researchers, community-based organizations, and community members to ultimately improve LGBTQIA+ community health and address historical injustices, underrepresentation, and inadequate service delivery and policy. Because LGBTQIA+ people's lived experiences are diverse, community engagement helps ensure that voices from LGBTQIA+ subcommunities (Doan Van et al., 2019; Morrison et al., 2021) are heard and included in the research design and implementation.

PRIDENet uses an intersectional frame (Bauer, 2014; Collins, 2019; Crenshaw, 1989) to guide its work by taking a comprehensive look at health and experiences. The current and historical injustices experienced by LGBTQIA+ people are not solely shaped by their LGBTQIA+ status and are not experienced equally among members of LGBTQIA+ communities. PRIDENet recognizes the impact of racism's long history in the United States and that race, ethnicity, and other components of culture shape the framing of LGBTQIA+ norms and concepts. For example, LGBTQIA+ people of color experience different health outcomes than LGBTQIA+ White people (Dawes et al., 2022).

While PRIDENet is deeply embedded in CENR principles, it was also built in alignment with the five principles of collective impact (*i.e.*, common agenda, shared measurement, mutually reinforcing activities, continuous communication, backbone [infrastructure] support; Center for Community Health and Development., n.d.). Additionally, rather than supporting a single study, PRIDENet is a CENR *infrastructure* that ensures significant LGBTQIA+ community involvement across several long-term projects, adapts to changing funding sources, and leverages new opportunities. The decision to create PRIDENet as a network stemmed from critiques that LGBTQIA+ studies were small, often regionally bounded, narrow in assessed health outcomes, and cross-sectional. Additionally, building relationships and mobilizing resources for individual projects rather than supporting ongoing infrastructure would lead to redundancy and lost opportunity.

PRIDENet uses bi-directional relationships and 360-degree feedback to provide value to all stakeholders in its ecosystem, including participants, advisory committee members, Ambassadors, community-based organizations, researchers, staff, and funders. Other similar research-based networks are primarily focused on serving researchers, and they are either

disease/population agnostic (e.g., PCORnet) or focused on a specific disease (e.g., HIV Prevention Trials Network, Cancer Prevention and Control Research Network, American Heart Association's Strategically Focused Research Networks). PRIDENet focuses on subject-matter expertise rooted in community experiences with broad-spanning research across many facets of health. This approach is evident from PRIDENet's involvement in a wide range of published work *via* The PRIDE Study and research projects on other physical, mental, and social health topics (60 papers as of March 2024; see Appendix 6, and for ongoing updates see pridenet.org/research and pridestudy.org/research).

PRIDENet's commitment to long-term transformational relationships ("Let's create something new and better together") rather than short-term transactional relationships ("Do this for me") sets it apart from other networks. Its focus on disseminating research results back to participants/communities is also unique; it stays true to the community-engaged principle of giving back to the community via various communications channels (*i.e.*, posting peer-reviewed scientific manuscripts on our website, emailing community summaries of findings to participants first, and sharing easy-to-read infographics on social media). PRIDENet's engagement of participants from end to end and the belief that participants know best is exemplified by the RAC collating, discussing, and incorporating participant feedback to make iterative changes in our work related to, for example, our Ancillary Study surveys, participant dashboards, website, and so on. Unlike other large longitudinal health studies, The PRIDE Study is not a data repository but a valuable collaborative partner with Ancillary Study Collaborating Investigators. Finally, PRIDENet uses innovative technologies to facilitate the participation of LGBTQIA+ communities in health research (Lunn, Capriotti, et al., 2019; Lunn, Lubensky, et al., 2019).

How PRIDENet Works

PRIDENet's methods, which are meant to mobilize and accelerate LGBTQIA+ health research, include engaging a wide variety of community members in activities, guiding interested participants to research opportunities in The PRIDE Study and *All of Us*, and facilitating substantive, low-threshold, respectful participation

in PRIDENet activities. PRIDENet's model includes the following structures and strategies common to CEnR projects:

- community advisory boards (PRIDENet PAC);
- mutually beneficial agreements with community-based organizations that comprise PRIDENet's CPC; and
- research conducted at events, conferences, and health fairs with community-specific promotional items such as keychains and pens.

PRIDENet utilizes a blend of additional strategies to foster experiences of belonging in all stages of health research:

- tiers of influence starting with structured groups (ongoing long-term relationships with individuals and organizations including the CPC, PAC, and Ambassadors) whose members provide input and guidance;
- in-person engagement activities designed to benefit long-term partners and reach new people; and
- strategic digital communications activities that reach thousands of LGBTQIA+ people.

PRIDENet developed these structures and strategies to build synergy across our efforts to catalyze real, respectful, and relevant LGBTQIA+ health research that engages LGBTQIA+ people at every step of the health research process. Each of these structures and strategies has its own set of tactics or activities that play a role in operationalizing PRIDENet's theory of change (the necessary actions and ingredients that contribute toward achieving our intended goal). PRIDENet's core activities and elements are described in detail below and highlighted in Table 2.

Structured Community Groups: Participant Advisory Committee (PAC), Ambassadors, Community Partner Consortium (CPC), and Underrepresented in Biomedical Research (UBR) Groups

PRIDENet maintains two groups—the PAC and PRIDENet Ambassadors—that meet monthly and provide input and guidance on research and engagement activities. Members receive stipends in compensation for their time and expertise. As described above, PRIDENet's CPC participates in a wide variety of activities and supports the convening of four intersectional SGM advisory groups to increase the participation of UBR groups.

Table 2. PRIDENet Core Activities and Elements Used to Foster CEnR

Activity/Element	Stakeholder Group	Example Actions
Structured Community Group: PRIDENet Participant Advisory Committee (PAC)	Research participant advisors	<ul style="list-style-type: none"> • Critically review all study proposals and select engagement materials • Develop, review, and revise research dissemination guidelines
Structured Community Group: Ambassadors	LGBTQIA+ influencers	<ul style="list-style-type: none"> • Review and guide communications messages and images • Distribute research-related messages to excite participants
Structured Community Group: Community Partner Consortium (CPC)	LGBTQIA+ organizations	<ul style="list-style-type: none"> • Relay study recruitment materials and findings to CPC constituents • Disseminate LGBTQIA+ research-related promotions items/swag (on the order of thousands annually)
“Lunch and Learn” presentations	LGBTQIA+ organizations	<ul style="list-style-type: none"> • Address individual and group questions about research-related topics, for example about privacy, security concerns
PRIDENet Cafés	LGBTQIA+ community members	<ul style="list-style-type: none"> • Address wellness concerns during the pandemic and enhance access to research findings
Outreach at LGBTQIA+ events	LGBTQIA+ community members	<ul style="list-style-type: none"> • Reach thousands of LGBTQIA+ people and allies with health research messages
Community listening sessions	LGBTQIA+ subcommunity members	<ul style="list-style-type: none"> • Give voice to LGBTQIA+ people’s lived experiences
Community review sessions	LGBTQIA+ subcommunity members	<ul style="list-style-type: none"> • Improve photos, videos, and written copy to make them relevant for community members
Data access and use sessions	LGBTQIA+ subcommunity members	<ul style="list-style-type: none"> • Inform data use and access policy development
Social media platform outreach	General public	<ul style="list-style-type: none"> • Reach thousands of LGBTQIA+ people, raising awareness of activities and health-related outcomes among non-LGBTQIA+ people
Community-friendly summary generation and distribution	LGBTQIA+ community members	<ul style="list-style-type: none"> • Improve community access to research findings and ensure dissemination of results to communities that contributed their data

The PRIDENet PAC is governed by collaboratively developed bylaws and has maintained 12–15 LGBTQIA+-identifying members since it was formed in 2015. PAC members have specific knowledge and experience working with and coming from LGBTQIA+ communities, live throughout the country, and help PRIDENet maintain a consistent and comprehensive focus on historically marginalized and underrepresented subcommunities. The PAC follows established guidelines for participation and expansion and maintains diversity by considering personal and professional characteristics in recruitment. The PAC is concerned with ensuring that community members are welcomed, respected, and offered substantive opportunities to participate and that PRIDENet stays accountable to research

participants with relevant research generation and timely dissemination of findings. To influence the proposal and conduct of respectful research within The PRIDE Study, the PAC wrote “Guidance on Community-Engaged Research: A Primer for Ancillary Study Applicants” and a document to guide community-friendly research dissemination entitled “Closing the Loop: A Plan for Disseminating The PRIDE Study Research Results Back to LGBTQIA+ Communities,” both of which are available on The PRIDE Study’s website (pridestudy.org). The PRIDENet PAC reviews applications to conduct Ancillary Studies with The PRIDE Study, overall strategies with The PRIDE Study, PRIDENet’s community engagement activities, and *All of Us* materials, surveys, and policies.

The PRIDENet Ambassador program started in 2018 to expand PRIDENet’s ability to educate, excite, and motivate LGBTQIA+ people to participate in health research and to extend the community voices providing input into PRIDENet’s activities. Approximately 8–10 Ambassadors serve at any one time and represent a variety of identities and lived experiences, including multiple racial and ethnic groups, gender minority people, ages, and professional areas including storytelling, the arts, community organizing, and social media influencers. Ambassadors support PRIDENet’s mission in the following ways:

- incorporating PRIDENet messages into their professional or volunteer activities;
- presenting at conferences;
- speaking at community events;
- amplifying messages on their social media accounts;
- reviewing print and digital materials for appropriate and respectful messages/images; and
- supporting dedicated PRIDENet-produced events like PRIDENet Cafés (an ongoing online forum for presentations and discussions of LGBTQIA+ health issues, see more details below).

The PRIDENet CPC currently includes approximately 33 community-based organizations from around the United States, including LGBTQIA+ health clinics, community centers, service agencies, and professional and advocacy organizations (see Appendix 7). To bring flexibility to the arrangements, CPC participation is tailored to the specific mission and capacity of each organization. These organizations sign collaborative agreements with Stanford University that detail bidirectional expectations of the collaborating organization and PRIDENet as well as the collaborating organization’s responsibilities. Organizations may perform the following tasks:

- attending meetings and summits;
- amplifying social media posts;
- linking to PRIDENet websites from organizational websites;
- reviewing materials and proposals;
- distributing project promotional items;
- hanging project posters in their physical spaces;
- conducting outreach at organizational conferences and events; and
- hosting community listening sessions (see below).

The collaborative agreements are signed by CPC organizational leadership and PRIDENet to ensure high-level buy-in and accountability. PRIDENet continues to update the collaborative agreements to be responsive to feedback from CPC organizations and to build multiple pathways for collaboration, breaking out of a “one-size-fits-all” approach.

In constructing collaborative agreements, PRIDENet recognizes that successful CEnR projects invest in reciprocal relationships and are obligated to articulate clear benefits (*i.e.*, a value proposition) to CPC member organizations and their representatives, including personal, organizational, and community benefits (Maiter et al., 2008). Financial benefits to community-based organizations can result from these partnerships, particularly *via* CBPR projects (Wallerstein et al., 2020).

The value proposition for CPC organizations working with PRIDENet includes these benefits (where appropriate):

- free or subsidized participation in The PRIDE Study Ancillary Program as investigators;
- cohosting and/or supportive production of topical webinars and presentations;
- dissemination and visibility of partner activities through PRIDENet’s digital and social media reach;
- capacity building and coaching;
- technical assistance consultations in research-related topics;
- opportunities to enhance the organization’s network, national, regional, and local positioning in the field of LGBTQIA+ health research through joint projects;
- use of PRIDENet’s work and platform to enhance community-partner consortium member mission-driven activities; and
- attendance at in-person summit activities.

PRIDENet convenes diverse voices in other ways. For example, PRIDENet recently collaborated with other *All of Us* National Community Engagement Partners to convene four intersectional SGM advisory groups: African American SGM advisory group, Asian American Native Hawaiian Pacific Islander SGM advisory group, Hispanic/Latinx SGM advisory group, and People Living with a Disability SGM advisory group. The goal in convening these groups was to gather feedback and recommendations related to these UBR groups within the broader LGBTQIA+ community.

Live Engagement Activities

Since its founding, PRIDENet has hosted in-person and virtual events to enhance relationship building, address questions and concerns among LGBTQIA+ people about research participation, and partner with subcommunity influencers. PRIDENet's community engagement activities are primarily carried out by four full-time staff members (including one staff member based in the Midwest and one based in the South), but, for many years, it was 1.5 FTE of two staff members. While PRIDENet's staff are responsible for this work, activities are implemented with contributions from others.

PRIDENet conducts outreach at LGBTQIA+ health conferences, annual Pride Month events, and smaller gatherings for subcommunities, particularly those that serve transgender people, bisexual people, and people of color within any LGBTQIA+ subcommunity. Outreach and relationship building are supported by the distribution of promotional items, including palm cards, posters, lip balm, stickers, pens, lapel pins, hand sanitizer, and first-aid kits. These promotional items direct people to websites for continued education and information sharing. As part of a comprehensive strategy of supporting LGBTQIA+ people, when possible PRIDENet partners with LGBTQIA+-identified artists for these promotional items.

PRIDENet uses different types of events produced and hosted by either PRIDENet or its partners to educate and engage. Some example event types (described below and in Table 2) are "Lunch and Learns," PRIDENet Cafés, PRIDENet Journal Clubs, PRIDENet Summits, and PRIDENet Community Listening Sessions.

PRIDENet Lunch and Learns. "Lunch and Learn" presentations educate CPC organizations and others about PRIDENet's work while PRIDENet staff learn about the CPC organizations and how to meaningfully continue collaborating. "Lunch and Learns" are usually in-person events held on location with a current or potential CPC organization site with food provided. These sessions are led by a PRIDENet team member and are meant to facilitate information sharing and rapport building. During the COVID-19 pandemic, the format transitioned to virtual settings, and in-person events restarted in mid-2022.

PRIDENet Cafés. PRIDENet Cafés are a series of online events held every quarter and focused on LGBTQIA+ well-being, community building, research, and health broadly. These events started

in 2020 with the COVID-19 pandemic and are held every 1–3 months. PRIDENet Cafés have previously covered the following topics:

- human papillomavirus vaccination among transgender and gender-expansive people;
- how to ask about sexual orientation and gender identity in research;
- racial disparities in breast cancer care among sexual minority women;
- awareness of various political and legal challenges threatening the health of LGBTQIA+ community members and what to do about them; and
- facilitating personal and community support spaces to provide opportunities for self-knowledge building and creative expression (such as creative writing) and more.

PRIDENet Journal Club. In December 2020, to support continued capacity building and connection despite the ongoing COVID-19 pandemic, we designed and hosted the PRIDENet Journal Club to increase community members' skills and comfort with reviewing and interpreting academic articles. The club met three times for 75 minutes each time, and meetings were attended by various stakeholders. The club's success led to a more intensive "Researcher Basecamp Training" that was held in March 2023.

PRIDENet Community Listening and Review Sessions. Since 2017, PRIDENet has designed and conducted "community listening/review sessions" in-person and virtually across the country. The goals of these sessions are to understand common barriers to, facilitators for, and concerns with research participation among LGBTQIA+ people, with an emphasis on topics relevant to subcommunities most underrepresented in health research supported by PRIDENet. These sessions are co-coordinated with CPC organizations. PAC members and Ambassadors often provide input into the questions asked as well as the structure, goals, and outlines of each session. So far, sessions have focused on the following content areas or structural considerations within research:

- acceptability of images and messages used in digital campaigns;
- ensuring that LGBTQIA+-focused community-based organizations and community-based researchers will be able to access and use *All of Us* and The PRIDE Study data;
- privacy and security concerns of particular interest to LGBTQIA+ communities; and

- encouraging meaningful participation and representation in research by less visible stakeholders, such as those who identify as intersex or who have a variation of sex development (VSD, sometimes called difference of sex development or DSD).

Participants in these sessions are compensated. Sessions are recorded, and the content of the sessions is analyzed and compiled into reports that are brought back to PRIDENet for review and, where applicable, project integration. Results of the findings are shared back with the wider community, including those who participated in the sessions and more broadly across social media and through PRIDENet’s PAC, CPC, and Ambassadors.

In 2017 and 2018, PRIDENet held 13 in-person (in eight states) and five online community listening sessions with 186 LGBTQIA+-identified attendees on behalf of *All of Us* and in collaboration with CPC organizations. In these sessions, PRIDENet learned that LGBTQIA+ people value health research participation in solving community health problems but did not always feel reflected by or welcomed into studies. They were concerned about data privacy and security and emphasized the overarching need for culturally competent health care in all regions of the country. Attendees wanted to ensure that any findings from research studies in which LGBTQIA+ people participate are shared back with participants. Bisexual and transgender subcommunities expressed specific concerns, including the importance of being seen, respected, and served by health care providers and researchers. They noted that online platforms may include these communities “in name only” and that many people did not feel safe publicly disclosing their sexual orientation, gender identity, or experience as a transgender or gender minority person.

To continue these important dialogues and develop products that reflect community input, PRIDENet conducted three community review sessions in collaboration with CPC organizations. The purpose of these sessions was to develop more acceptable communication messages and images to facilitate positive experiences with *All of Us*. A total of 41 attendees participated in these in-person sessions (in Houston, TX; Sacramento, CA; and San Francisco, CA); reviewed flyers, photos, and videos; and provided candid insights into engagement messages and strategies. The primary recommendation throughout these sessions was to include visual symbols of LGBTQIA+ communities to catch attention quickly. Additionally, attendees

especially wanted to see images of gender nonbinary people—people who do not conform to typical expressions of femininity and masculinity. In addition, photos should depict diversity within the community—varying abilities, ages, skin tones, body types—and show community settings, such as LGBTQIA+ events. Attendees recommended that videos be upbeat and positive, include good music, have an engaging voiceover, and quickly get to the point.

PRIDENet conducted two community listening/review sessions with LGBTQIA+ community members to teach them how to use *All of Us* data as well as answer any questions and concerns about accessing and conducting research with the data. CPC member organizations and representative staff attended these sessions. The sessions included basics about how to access data through the *All of Us* Researcher Workbench (researchallofus.org) as well as advanced topics, such as how to structure analyses and potential challenges to using these data. Attendees expressed a need for data that could be used for population estimation purposes, needs assessments, program planning, and policy change. Attendees emphasized that organizations would appreciate being trained on research terminology and basic research skills. Lastly, small CPC organizations expressed a need for support in conducting literature reviews and funding to conduct local needs assessments.

The *All of Us* community listening and review sessions resulted in the following outcomes:

- photo and video shoots of LGBTQIA+ people for communications assets;
- toolkits for CPC organizations to amplify messages;
- reports to *All of Us* staff and steering committees recommending messages for materials specific to engaging LGBTQIA+ people;
- an *All of Us* data privacy and security infographic;
- the launch of a community journal club; and
- plans for future researcher-focused trainings on conducting research with *All of Us* data (implemented in March 2023).

PRIDENet Summits. PRIDENet hosted three in-person summits for the PAC, Ambassadors, and CPC organizations in 2016, 2017, and 2020, as well one virtual summit for these groups (and open to a larger audience) in 2021. These gatherings were designed to provide updates (on activities, challenges, and plans), globally increase awareness of The PRIDE Study and *All of Us*, gather input

into research and activities, and generate and strengthen connections among partners and researchers. Summit 2016 had 38 attendees from 10 states and 20 community-based organizations (CBOs); Summit 2017 had 50 attendees from 15 states and 25 CPC organizations; and Summit 2020 had 46 people from 21 states and 25 CPC organizations. Summit 2021 was digital to balance COVID-19 pandemic restrictions with a desire to convene our stakeholder groups. We had 238 participants, including members of the public, for the 4-day online event. The gathering featured 24 sessions across four tracks: the Community Track, Research Track, Intersectional Conversations Track, and Networking/Network Building Track. To measure the impact of each summit, pre and post surveys assessed changes in attendees' levels of understanding, excitement, and comfort in engaging with PRIDENet and evaluated how relationships were strengthened. In general, attendees were very satisfied with their experience and appreciated the opportunity to meet so many people dedicated to the same vision. PRIDENet will host its next in-person summit in March 2024 (details here: pridenet.org/summit).

Each gathering involved a mixture of project presentations, community building and networking activities, arts and culture performances, and community input sessions. Following are some examples of outcomes achieved:

- a funded proposal submitted by two CPC organizations;
- new Ancillary Study applications to The PRIDE Study;
- input on *All of Us* study processes, procedures, and promotional materials; and
- input on financial sustainability, building the network, and improving The PRIDE Study Ancillary Study program via stakeholder suggestions.

Strategic Digital Communications. Current studies supported by PRIDENet aim to engage and enroll large numbers of people in large cohorts, something that only can be accomplished through activities that have a broad reach. Since 2017, PRIDENet has invested in digital communications for outreach, engagement, recruitment, enrollment, retention, and dissemination of materials back to the community via the following mechanisms:

- social media posting;
- focused internet-based advertisement campaigns on six channels—two each on Facebook, Instagram, and X (formerly Twitter);

- active use of reports on social media “engagement,” “likes,” and “shares” and other feedback from Google Analytics about website visits;
- original artwork and images;
- community partner–focused newsletters;
- novel content such as infographics, videos, and posters featuring LGBTQIA+ community members for use in digital communications as one-off and bundled “toolkits”;
- use of constituent relationship management software to collect and organize email addresses and conduct focused campaigns;
- dynamic websites; and
- a blog with posts by community members focused on LGBTQIA+ health research topics.

PRIDENet also conducts outreach to media outlets (earned media) when there is a newsworthy development such as the launch of a new platform version or timely new research findings.

Since 2022, PRIDENet has had two full-time staff positions focused on communications (it had one full-time staff prior). While PRIDENet's communications staff are responsible for strategic communication work, activities are implemented with contributions from additional staff and PRIDENet's PAC, Ambassadors, and CPC, all of whom serve as trusted community messengers and amplify communications across their networks.

These mechanisms have helped PRIDENet steadily build an email list, increase social media engagement (e.g., “likes” and “shares”), and conduct targeted advertising (paying to increase exposure to likely participants by identifying social media users who fit geographic, behavioral, demographic, or other profiles). PRIDENet regularly uses email campaigns—a series of emails strategically crafted and timed to achieve a specific outcome—to motivate community members to visit websites, disseminate findings broadly, encourage enrollment, retain research participants, and more.

The numbers of people who follow PRIDENet's social media platforms have increased substantially since the beginning of our expanded social media efforts in 2017. Therefore PRIDENet had two aims in using social media: (1) developing our Facebook, Instagram, and X (formerly Twitter) presence, each of which has unique requirements for posting text and graphics, (2) identifying prospective research participants. We have continued to refine our strategies to attract different audiences and

achieve different purposes. There has also been a need to manage and counter the presence of hostile people who post publicly demeaning or aggressive comments. This dynamic space requires continuous attention and staff time, skills enhancement, and expertise in digital communication.

In another communications effort, PRIDENet worked with *All of Us* communications personnel to conduct a photoshoot and generate original, respectful, and representative LGBTQIA+ images after hearing consistently from PAC members and Ambassadors that stock photo images were minimally engaging. To maintain engagement with the broadest constituent group—including PRIDENet members, researchers, and those who visit our websites and sign up at in-person activities—PRIDENet publishes a newsletter with updates, opportunities for input, research findings, and information on PRIDENet partner events and activities. PRIDENet also produces an annual Pride Month (mostly held in June) Digital Toolkit with LGBTQIA+-themed social media messages, images, and video and maintains three websites: pridenet.org, pridestudy.org, and joinallofus.org/lgbtqia.

Research Participant Engagement and Retention Activities. In general, community and research participant engagement have different purposes, audiences, and goals. Community engagement and CEnR focus on mutually beneficial partnerships and opportunities for substantive input into the entire research endeavor, while research participant engagement focuses on the nuts and bolts of recruitment, consent, enrollment, and retention for a study. Though study enrollment is one intended outcome for most CEnR projects, maintaining the distinction between community member and research participant engagement is important to avoid reducing community engagement to a series of recruitment transactions (Dempsey, 2010). Both efforts are based on similar principles—ensuring the community member’s positive experience, respecting their input, and sustaining reciprocity—and should be connected.

The PRIDE Study participant engagement and retention strategy involves a participant portal with engaging features, robust customer service, thoughtful email campaigns, and community-friendly research dissemination to “close the loop” to participants about the impact of their participation. The PRIDE Study currently has one full-time staff member dedicated to participant engagement. In June 2023, PRIDENet began to

conduct enrollment and enrolled participant engagement for *All of Us*, which are currently managed by four full-time staff.

Some features of The PRIDE Study participant journey (*i.e.*, the individual experience of enrolling and participating in a study) are designed to keep participant engagement and experience at the forefront. The participant portal was custom-built to respond to participant preferences and needs. Participants who prefer email or text messages automatically receive brief, friendly messages and automated notifications (Lunn, Lubensky, et al., 2019). Digital engagement of The PRIDE Study participants includes month-long campaigns to encourage survey and profile completion in which each participant who has completed either their survey or profile is entered into a random drawing to win a prize, such as a gift card (to Amazon.com or Target) or Fitbit physical activity tracker. These campaigns increase completion rates 2–9 times that of no campaign conducted.

Recognizing the history of marginalization and exploitation of communities underrepresented in health research requires that participant engagement utilize a strong customer service approach to convey warmth and appreciation. For The PRIDE Study, this includes a support request management system (Zendesk; zendesk.com) for logging and responding to all participant inquiries and comments. PRIDENet sends The PRIDE Study participants a “Community-Friendly Summary of Findings” (one-page summaries written at an 8th–12th grade reading level) as soon as possible after research is published and ensures that participants are notified before the public is. This PRIDENet-initiated practice in The PRIDE Study is now being adopted by *All of Us*, speaking to how PRIDENet’s action in one study can inform work in another.

Impact

As The PRIDE Study and the group of SGM-identified participants in *All of Us* are both larger than prior longitudinal studies of SGM communities, they represent a leap in researchers’ and community members’ capacity to address questions about LGBTQIA+ health and to do work that delineates various SGM subcommunities. The PRIDE Study currently has over 28,000 consented participants, all of whom identify as a SGM person. Furthermore, roughly 13% (>387,000 total enrolled participants) of the *All of Us* cohort (total ~50,300) can be classified as SGM persons (Ramirez et al., 2022). The full impact of the data collected from these large numbers of participants has yet to be

realized, but it represents a potential for knowledge generation and health improvement via CEnR that PRIDENet has helped catalyze.

Since January 2017, PRIDENet's network has received 68 Ancillary Study applications for The PRIDE Study, of which 47 were approved, seven were withdrawn by the collaborating investigators, and eight were rejected by the RAC and/or PAC. Six are currently under review. Among those accepted, ~86% were unfunded or funded by small institutional funds, and ~18% were supported by sponsored awards. PRIDENet has worked through The PRIDE Study with 46 Ancillary Study Collaborating Investigators and has published 48 manuscripts since June 2019. All published papers are presented with their Community-Friendly Summaries at pridestudy.org/research. Additionally, PRIDENet has contributed to at least 25 awarded grants (8% institutional, 12% foundation, 20% training awards, 56% NIH, and 16% PCORI). However, not all impact can be quantified, and as community engagement is often more qualitative in nature, it is hard to measure impact in the traditional ways that research and academia consider valuable. The PRIDENet network has benefited its associated research projects in the following ways:

- PRIDENet has improved the research methodology of associated studies thanks to the PAC's work raising community concerns while vetting Ancillary Study applications. For example, when reviewing an Ancillary Study researching intimate partner violence committed by one romantic partner against another, PAC members offered invaluable insights to the Ancillary Study Collaborating Investigators on how to refine the project's community engagement plan. Here, PRIDENet provided guidance on how to make study materials accessible to impacted communities, defined and clarified scientific and academic terms with examples of affirming language, suggested using easy-to-comprehend infographics for dissemination, and collaborated with community organizations focusing on intimate partner violence to determine the most critical policy and advocacy applications of the study data.
- PRIDENet has impacted health policy. Partially resulting from our work on self-managed abortion experiences among transgender and nonbinary people in the United States, an Ancillary Study Collaborating Investigator was approached

to help draft a resolution for the U.S. House of Representatives and U.S. Senate that was introduced on the anniversary of the *Dobbs v. Jackson Women's Health Organization* (2022) decision. This is an example of our research translating to text in a federal resolution opposing the criminalization of essential sexual and reproductive health care, including self-managed abortion and gender-affirming care, and imploring policymakers to follow such a growing body of research and science.

- PRIDENet has affected medical and scientific guidelines to improve the health of LGBTQIA+ people. For example, PRIDENet members were part of an international group of experts working to revise and update the World Professional Association for Transgender Health (WPATH) Standard of Care (SOC) guidelines (published in October 2022). SOC not only impacts direct clinical care but also encourages governments and policy makers to improve access to gender-affirming care. PRIDENet-affiliated publications are now cited in the following guidance documents: *WPATH Standard of Care 8 Guidelines* (Coleman et al., 2022), *The Society for Maternal-Fetal Medicine Special Statement: Commitment to Excellence in Obstetrical Care, Research, and Education for People with Diverse Sexual and Gender Identities* (Brandt et al., 2022), and the National Academies of Science, Engineering, and Medicine's Consensus Study Report *Measuring Sex, Gender Identity, and Sexual Orientation* (National Academies of Sciences, Engineering, and Medicine, 2022).
- PRIDENet has strengthened recruitment for study participation, especially among members of LGBTQIA+ subcommunities. For example, CPC members and intersectional SGM advisory groups successfully recruited participants for community listening sessions for research focused on LGBTQIA+ parents and those interested in parenthood, specifically cisgender sexual minority men, transgender women, and nonbinary people assigned male at birth.
- PRIDENet has provided evidence for the need or use of particular studies. For example, PRIDENet was able to activate its CPC members to sign on to a letter of support for one researcher's successful grant application to conduct a study on

post-traumatic stress disorder treatments designed for LGBTQIA+ communities.

- PRIDENet has widened the dissemination of research findings with the potential to influence programs, practice, and policy and thus create better health outcomes for LGBTQIA+ people. For example, a PRIDE Study paper was referenced in a motion approved by the Sherman Oaks Neighborhood Council to adopt gender-inclusive language in their correspondence regarding Los Angeles City's effort to preserve abortion care (Imber, 2022).
- PRIDENet is training the next generation of SGM researchers. PRIDENet facilitates the training of ~25 undergraduate, postbaccalaureate, graduate, medical, postdoctoral, early career faculty, and other trainees and learners to grow a pipeline of skilled and competent researchers in CEnR. Collectively, they work together (and are called The PRIDE Lab) to provide each other with a supportive, rich environment to learn new methods and develop their careers, proving to be a resource with a positive future impact.

PRIDENet has received feedback from partners and community members that its model, strategies, activities, and approaches for community engagement have resulted in LGBTQIA+ community members, especially those from often underrepresented subcommunities, feeling seen, heard, and valued in research. For example, at an event co-produced by PRIDENet and CPC organization ZAMI NOBLA (zaminobla.org), attendees reported feeling celebrated and centered as Black lesbians. Many participants in a community listening session with people who identify as aromantic reported that being in a safe space with so many other aromantic people was a positive, affirming experience. Many people stayed after the 2-hour conversation to share social media contact information to remain in touch.

The *All of Us* Research Program has benefited from the PRIDENet network in the following ways:

- PRIDENet has facilitated culturally sensitive and appropriate community engagement activities focused on raising awareness of *All of Us* within LGBTQIA+ communities. For example, PRIDENet's staff and an Ambassador co-produced multiple events in Chicago, IL, focused on engaging and enrolling on-site residents of an LGBTQIA+ older adult housing center where the Ambassador lived.

- PRIDENet has provided access to subject-matter experts who help guide the work of *All of Us*. For example, PRIDENet encouraged one of its Ambassadors to apply for (and successfully join, ultimately) the *All of Us* Participant Advisory Board.
- PRIDENet has offered tangible recommendations for community engagement and research strategies to be LGBTQIA+-inclusive. For example, the four intersectional SGM advisory groups are each developing summaries of recommendations for responsive community engagement within their specific subcommunities.
- PRIDENet has provided scientific expertise related to SGM research. For example, PRIDENet's research staff have trained other researchers working with *All of Us* data on proper usage of variables around sexual orientation, gender identity, and sex assigned at birth.

The *All of Us* team acknowledges that the above activities have contributed to the roughly 13% (>387,000 total enrolled participants) of the *All of Us* cohort (total ~50,300) who can be classified as SGM persons (Ramirez et al., 2022).

Lessons Learned

This paper intends to offer one model of community engagement in health research. The components of our work can be tailored and adapted for projects that differ in their aims, impacted communities, and methodologies. Community engagement is an ongoing process that, ideally, utilizes robust information loops for continuous improvement and refinement and helps ensure ethical, accurate, inclusive, and high-impact research. The following lessons learned from building and sustaining PRIDENet may inform other community engagement efforts:

- Hire and cultivate a diverse team from the communities to be reached.
- Build and maintain an infrastructure that adapts to multiple projects and sustains long-term relationships.
- Implement a blend of high-touch activities (to establish trust) and broad-reach activities (to build large LGBTQIA+ cohorts).
- Build and maintain trusting reciprocal relationships.
- Build and maintain a recognizable and continuous loop of community engagement.
- Clarify the audience for each activity by project (e.g., who is included as study

participants in *All of Us* or The PRIDE Study, who is invited to join Summits, who are PRIDENet CPC members; discussed above).

- Articulate the roles and responsibilities of partner organizations and stakeholders (*i.e.*, CPC, PAC members) and PRIDENet staff.

Below, we discuss lessons learned from PRIDENet's community engagement model that we have so far not discussed elsewhere.

Hire and Cultivate a Diverse Team

Traditional research projects tend to silo individuals and efforts into either "community engagement" or "research." In contrast, an aspiration of many CEnR projects is the continuous and harmonious flow of different perspectives, concerns, and approaches across these two areas. We have found that building a team of people with diverse professional skills and lived experiences (across age, race, ethnicity, ability, and LGBTQIA+ subcommunity) that reflect the communities to be engaged has helped PRIDENet address problems and implement activities from an integrated perspective. Additionally, employing people with diverse skills and diverse lived experiences with whom LGBTQIA+ community members can relate and connect is the most important way we build trust with key subcommunity members.

Build and Maintain an Adaptable Infrastructure

PRIDENet's extensive and multi-faceted CEnR infrastructure can adapt to different projects and new funding sources while maintaining valuable long-term relationships with LGBTQIA+ community members and LGBTQIA+-serving clinics, community centers, and professional and advocacy organizations. This infrastructure includes:

- structured groups (*i.e.*, PRIDENet PAC, Ambassadors, CPC) with clear purpose and guidelines (*e.g.*, bylaws and collaborative agreements);
- honoraria (for PAC and Ambassadors); and
- opportunities for substantive input.

In-person engagement activities respond to community needs and concerns and include respectful and appropriate images and messages. Strategic digital communications help PRIDENet stay in touch with large numbers of people. PRIDENet keeps in contact *via* well-maintained websites, social media channels, and constituent relationship management software to organize

email addresses and design and launch campaigns. Our well-developed digital communications and virtual platforms, which existed prior to the COVID-19 pandemic, helped us maintain and modify existing activities and create new ones to be responsive to the pandemic.

Blend High-Touch and Broad-Reach Activities

PRIDENet uses a blend of informal and formal methods in maintaining relationships, including scheduling regular phone calls and emails with partner organizations, conducting personal check-ins to start webinars and meetings, updating key stakeholders (*i.e.*, ambassadors, PAC members, CPC, and study participants) about PRIDENet activities, as well as discussing, maintaining, and modifying collaborative agreements and bylaws. This blend facilitates personal belonging and high-level buy-in and has helped PRIDENet grow with its partners, adapt to their needs, and ensure reciprocity.

Investing in and developing individual relationships and activities that reach many people, such as digital communications and community event outreach, has helped PRIDENet grow with integrity while ensuring that larger numbers of people have access to research participation opportunities. Investing in digital communications is no longer optional for health research efforts (Whitaker et al., 2017). PRIDENet learned from community listening sessions that engaging *via* social media in a strategic and community-responsive way is critical to reaching people in their preferred modes of communication, particularly for stigmatized communities and those that are geographically isolated, such as rural communities. Approaches need to utilize consistent connections such as regular newsletters as well as targeted campaigns to certain subcommunities to reach all intended audiences.

Build Trusting Reciprocal Relationships

Reciprocal relationships undergird all activities. Concerning lessons learned, this has been most challenging when things are deemed "off" or "inappropriate" by community members. For example, at one PRIDENet Summit, an attendee raised questions about the transparency of Ancillary Study applications and their status in the process of research dissemination. At that same summit, another attendee raised questions about data privacy and security. These difficult conversations led to improvements in The PRIDE Study: the development of publicly accessible

dashboards (pridestudy.tools) offered more visibility into Ancillary Study processes (goto.stanford.edu/PrideStudyAS), and the community/listening and review sessions described above were organized to better understand and address privacy and security concerns. We know, though, that to substantively engage communities that have been negatively impacted by health research and mistreated in health care settings, the most important factor is to consistently “walk the talk” by bringing warmth and welcome to each interaction, decision, and activity and building integrity, accountability, and transparency into the DNA of the project.

Establish a Recognizable and Continuous Loop of Community Engagement

Building CEnR mechanisms that are identifiable and recognized by community members ensures a continuous loop of community engagement in the research and allows community members and research participants to see the impact of their participation. It also reinforces trust and strengthens relationships when each cycle of the loop of engagement turns. Each year, The PRIDE Study participants and PAC members are invited to and spontaneously make suggestions to surveys, and the RAC reviews each one for needed survey modifications. PAC members review every Ancillary Study program application to ensure inclusion of robust community engagement components and to educate researchers about the importance of integrating community engagement and dissemination into their work. Holding frequent PRIDENet Summits allows partners to provide input into key areas of *All of Us*, including the Researcher Workbench and survey modules. These mechanisms encourage helpful reflection and lead to community-initiated improvements in all stages of the research. Every publication is then disseminated back to all stakeholder groups with next steps and actions.

Challenges to PRIDENet

In general, funding for community engagement, CEnR, and CBPR is more limited than it is for traditional health research projects (Israel et al., 2006). Building and sustaining a network like PRIDENet involves time, effort, and resources. Additional time, effort, and resources are needed to pursue CEnR with a sensitivity to and focus on the differential experiences of LGBTQIA+ groups, especially by race and ethnicity and LGBTQIA+ subcommunity experience. For example, it takes

time, effort, and understanding to procure funding for participant incentives, connect with community consultants, and create materials and events to address specific subcommunities in ways that are responsive to their needs and perspectives (e.g., engaging with lesbian transgender women of color in the South differently than cisgender bisexual white men in the Northeast). Supportive funders, institutional stakeholders (e.g., informed, nimble, and responsive institutional review boards, who are responsible for assessing and mitigating harmful impact to research participants), and journal editors who understand the demands and benefits of CEnR are needed to sustain and build these approaches. Toward these aims, PRIDENet was able to build infrastructure, implement professional digital engagement, hire exceptionally skilled and diverse staff members, and invest in mechanisms for substantive community involvement because of strong working partnerships with supportive funders (PCORI, NIH), supportive institutions, and philanthropists who understand the importance of CEnR. The primary challenge faced by PRIDENet and others who seek to replicate this model is funding availability. Although policy needs for LGBTQIA+ issues have been changing and diversifying with multiple competing demands since some substantive wins (e.g., the repeal of the Defense of Marriage Act) and broad threats (the 2022 *Dobbs* decision signaling potential challenges and rights reversals), funder opportunities have also diversified, with the potential for comprehensive health to be a keystone issue (Brown & Maulbeck, 2015). Additional challenges PRIDENet has faced include a reliance on specific social media platforms whose rapidly changing policies can impede progress for LGBTQIA+ work. For example, certain LGBTQIA+-themed posts have been seen as political rather than social and were delayed or prevented from being posted. In addition, fielding negative or hate-filled comments from the public can be draining and demoralizing for communications personnel and can threaten to undermine the validity of PRIDENet activities and products.

Limitations

A major limitation PRIDENet encounters is the lack of ability to demonstrate direct impact of many activities. For example, while it is assumed that the high levels of support and SGM participation in *All of Us* are, at least in part, due to PRIDENet's efforts, currently there are no mechanisms in place by which to measure this impact (Ramirez et al., 2022). Although mechanisms to track engagement in *All*

of Us, for example, are actively being developed, community standards and understanding about what meaningful impact is and what generates it are still lacking. In addition, systematic evaluation of PRIDENet activities, including relationship building, is critical to demonstrate success but requires significant additional resources and a new framework, as many traditional rubrics used for key performance indicators do not fully capture this type of impact.

Future Considerations

PRIDENet will maintain and expand its structured groups, in-person activities, and strategic digital communications activities to engage LGBTQIA+ individuals, communities, and organizations and enhance LGBTQIA+ participation in research broadly and on behalf of The PRIDE Study and the *All of Us* Research Program, specifically. The funding to support these activities will come from research and engagement grants as well as other avenues of revenue, such as The PRIDE Study's Ancillary Study program for the costs associated with application reviews and community-friendly research dissemination. Other avenues for ensuring sustainability include building coalitions with other UBR groups for joint projects such as pursuing foundation grants and connecting with major donors who are increasingly interested in LGBTQIA+ health and the importance of CEnR (Brown & Maulbeck, 2015). PRIDENet's next step in development, however, is to evolve and diversify a network for leveraging PRIDENet connections to develop collaborative projects that advance LGBTQIA+ health research and LGBTQIA+ health equity.

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The PRIDE Study is a community-engaged research project that serves and is made possible by LGBTQIA+ community involvement at multiple points in the research process, including the dissemination of findings. We acknowledge the courage and dedication of The PRIDE Study participants for sharing their stories, the careful attention of PRIDENet Participant Advisory Committee members for reviewing and improving every study application, and the enthusiastic engagement of PRIDENet Ambassadors and Community Partner Consortium organizations for bringing thoughtful perspectives as well as promoting enrollment and disseminating findings. For more information, please visit pridenet.org.

Disclosures

MRL consulted for Hims, Incorporated (2019–present), Folx, Incorporated (2019–2020) Otsuka Pharmaceutical Development and Commercialization, Incorporated (2023), and the American Dental Association (2024). JOM has consulted for Sage Therapeutics (2017), Ibis Reproductive Health (2017–2018, 2020–present), Hims, Incorporated (2019–present), Folx, Incorporated (2019–present) and Upstream, Incorporated (2024). None of these engagements influenced or are pertinent to the work described in this manuscript. The other authors have no conflicts of interest to disclose.

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Appendix 1. PRIDENet Initializing Partner Engagement: Phone Call and Email Follow-up (2015)

Phone Call Follow-up (January 2015)

Hi <<name>>,

I'm following up on a phone call I just left for you from **The PRIDE (Population Research in Identity and Disparities for Equality) Study**.

In early January, we contacted you to see if <<ORG>> would be interested in partnering with The PRIDE Study in our plans to create a Participant-Powered Research Network (PPRN) of sexual and gender minorities through an application to The Patient Centered Outcomes Research Institute (PCORI). We were thrilled to have you express your interest as a potential partner!

Now, we are working to submit the full application to PCORI for grant funding on this large national effort, and **we need your help!**

As we move forward with the application, we want to assess the potential ways that <<ORG>>, its staff, and members, may be interested in participating in the PPRN. Please follow this link to a **very brief survey** where you can describe some ways <<ORG>> and The PRIDE Study could collaborate. None of your responses are binding, they just give us groundwork for future conversations.

Please fill out this link now, it should take less than 5 minutes.

<<personalized Qualtrics survey link>>

As the grant is due soon and we don't want <<ORG>> left out, we will follow-up in a couple of days if we have not received a response!

If you would like to discuss or have questions/comments, please do not hesitate to contact Juno Obedin-Maliver, M.D., M.P.H. or Mitchell Lunn, M.D. at pridestudy@ucsf.edu or 855-421-9991 (toll-free). We look forward to hearing from you about this exciting opportunity soon.

With best regards
Mitchell R. Lunn, MD, Co-Director
Juno Obedin-Maliver, MD, MPH, Co-Director

Email Follow-up (February 2015)

<<Name>>

<<Organization>>

<<City>> <<State>>

<<Date>>

Dear <<Name>>:

In early January, we contacted you to see if you would be interested in partnering with The PRIDE (Population Research in Identity and Disparities for Equality) Study in our plans to create a Patient-Powered Research Network (PPRN) of sexual and gender minorities. We were preparing to submit a Letter of Intent to the Patient-Centered Outcomes Research Institute (PCORI) to support PPRN development. You voiced interest in your organization becoming a partner in the PPRN. Our Letter of Intent was submitted to PCORI, and we are happy to announce that we have been invited to submit a full application!

As we move forward with the full application, we want to assess the potential ways that your organization may be interested in participating in the PPRN. There are a variety of ways for organizations to be involved, which include:

PPRN GOVERNANCE

[Exact details will be decided by PPRN community members/patients – likely monthly two-hour call. Financial compensation for time likely will be provided.]

- Recruiting an staff member to play a role in PPRN governance (e.g., serving on a committee)
- Recruiting a community member/patient to play a role in PPRN governance (e.g., serving on a committee)
- Participating in PPRN engagement evaluations and providing feedback about optimal ways for continued engagement and meaningful contributions to the PPRN

RESEARCH PRIORITIES

[Because the voices of our diverse communities are important in the planning and conduction of research, we will solicit annually for research questions and other current topics of health interest.]

- Distributing and/or contributing to The PRIDE Study's annual Request for Research Questions (RFQ)
- Holding a local community listening forum to determine current LGBTQ health-related priorities
- Participating in the annual PRIDE-PPRN summit in San Francisco to help plan research questions and priorities for current and future studies (travel support likely will be provided)

STUDY DESIGN AND RECRUITMENT

- Providing expertise (from either within or external to your organization) in particular topic areas (e.g., depression, cancer screening, minority stress) to assist with question design, data analysis, and manuscript writing
- Recruiting participants to The PRIDE Study through your networks including e-mail distribution lists, websites, social media, and physical materials, and/or local events.

DISSEMINATING STUDY RESULTS

- Sharing The PRIDE Study results via networks including US mail, e-mail distribution lists, websites, social media, physical materials (posters, postcards), and/or local events
- Co-authoring manuscripts and/or co-presenting study results at scientific conferences (travel support likely will be provided)

Please indicate, by March 9th, your organization's likely involvement by visiting the following link:

<<link>>

[This link is unique to your organization. You may visit it more than once.]

Please note that your selections are not final or binding. They provide a rough expectation of the desired level of involvement by our Partners for planning and PCORI grant application purposes.

If you have colleagues at other organizations may be interested in becoming a partner in this PPRN, please have them contact us at pridestudy@ucsf.edu.

If you would like to discuss or have questions/comments, please do not hesitate to contact Mitchell R. Lunn, M.D. at pridestudy@ucsf.edu or 855-421-9991 (toll-free). We look forward to hearing from you about this exciting opportunity soon.

With best regards,

Mitchell R. Lunn, MD
Co-Director

Juno Obedin-Maliver, MD, MPH
Co-Director

~UCSF PRIDE Study Advisory Team~
Kirstin Bibbins-Domingo, PhD, MD, MAS
Mark Pletcher, MD, MPH
Jae Sevelius, PhD

Appendix 2. PRIDENet Original PCORI Grant (2015) Supportive Partners (41)

Organization	City	State
COMMUNITY CENTERS (20)		
Billy DeFrank LGBT Community Center of Silicon Valley	San Jose	CA
Center on Halsted	Chicago	IL
The Center Project	Columbia	MO
The Center: 7 Rivers LGBTQ Connection	La Crosse	WI
The Diversity Center	Santa Cruz	CA
Gay Alliance	Rochester	NY
Gay & Lesbian Community Center of the Ozarks	Springfield	MO
Hudson Pride Connections Center	Jersey City	NJ
Kaleidoscope Youth Center	Columbus	OH
LGBT Community Center of Greater Cleveland	Cleveland	OH
LGBT Community Center of the Desert	Palm Springs	CA
LGBTQ Center of Southern Nevada	Las Vegas	NV
The Montrose Center	Houston	TX
Oasis Youth Center	Tacoma	WA
Pasadena Pride Center	Pasadena	CA
The Pride Center of Vermont	Burlington	VT
Resource Center	Dallas	TX
San Diego LGBT Community Center	San Diego	CA
The San Francisco LGBT Center	San Francisco	CA
The Spectrum Center	Hattiesburg	MS
HEALTH ORGANIZATIONS (13)		
Callen-Lorde Community Health Center	New York	NY
Center for Gender, Sexuality and HIV Prevention at Lurie Children’s Hospital	Chicago	IL
Howard Brown Health Center	Chicago	IL
Johns Hopkins Bayview Medical Center	Baltimore	MD
Lesbian Health Initiative	Houston	TX
Lyon-Martin Health Services	San Francisco	CA
Mazzoni Center	Philadelphia	PA
Pittsburgh AIDS Task Force	Pittsburgh	PA
Penn Medicine Program for LGBT Health	Philadelphia	PA
The PRIDE Clinic at MetroHealth Medical Center	Cleveland	OH
San Francisco Department of Public Health, Transgender Health Services	San Francisco	CA
University of Minnesota Program in Human Sexuality	Minneapolis	MN
Whitman-Walker Health	Washington	DC
NATIONAL/INTERNATIONAL ORGANIZATIONS (8)		
Center for American Progress	Washington	DC
CenterLink: The Community of LGBT Centers	Ft. Lauderdale	FL
Gay Men’s Health Crisis	New York	NY
GLMA: Health Professionals Advancing LGBT Equality	Washington	DC
National Center for Lesbian Rights	San Francisco	CA
National LGBT Cancer Network	New York	NY
Services & Advocacy to GLBT Elders	New York	NY
World Professional Association for Transgender Health	Minneapolis	MN

Appendix 3: Partner Engagement Questionnaire

The PRIDE (Population Research in Identity and Disparities for Equality) Study, is a groundbreaking national longitudinal cohort study that will examine the health of sexual and gender minorities for decades. To ensure that LGBTQ people are involved in every step of the research process, The PRIDE Study is applying for a Patient-Centered Outcomes Research Institute (PCORI) grant to create a Patient-Powered Research Network (PPRN) of sexual and gender minorities.

A successful PPRN relies on organizations, like yours, and their community members to form the foundation for research that is *designed, conducted, and communicated* with the involvement of engaged sexual and gender minority individuals.

We are currently in partnership discussions with leaders (like you!) from more than 40 LGBTQ-focused organizations, health centers, and community centers around the country. These entities will provide the ‘patient power’ that makes a PPRN successful. This is not simply about study recruitment, but also identifying leaders to serve on steering committees, to help design the PPRN organization and governance structure, and to determine the research priorities. We hope you will join us!

Please indicate your organization’s likely involvement by selecting items below with which your organization can assist. There is also a space for you to indicate additional methods.

Note: Your selections are not final or binding. They provide a rough expectation of the desired level of involvement by our Partners for planning and PCORI grant application purposes.

Deadline: We kindly ask that you complete this form as soon as possible.

Please provide contact information for your organization’s contact person here.

Name	<input type="text"/>
Title	<input type="text"/>
Organization	<input type="text"/>
Address	<input type="text"/>
City	<input type="text"/>
State	<input type="text"/>
Postal Code	<input type="text"/>
E-mail	<input type="text"/>
Telephone	<input type="text"/>

PPRN GOVERNANCE

Exact details will be decided by PPRN community members/patients – likely monthly two-hour call. Financial compensation for time likely will be provided.

- Recruiting a staff member to play a role in PPRN governance (e.g., serving on a committee)
- Recruiting a community member/patient to play a role in PPRN governance (e.g., serving on a committee)
- Participating in PPRN engagement evaluations by providing feedback about optimal ways for continued engagement and meaningful contributions to the PPRN

RESEARCH PRIORITIES

Because the voices of our diverse communities are important in the planning and conduction of research, we will solicit annually for research questions and other current topics of health interest.

- Distributing and/or contributing to The PRIDE Study’s annual Request for Research Questions (RFQ)
- Holding a local community listening forum to determine current LGBTQ health-related priorities
- Participating in the annual PRIDE-PPRN summit in San Francisco to help plan research questions and priorities for current and future studies (travel support likely will be provided)

STUDY DESIGN AND RECRUITMENT

- Providing expertise (from either within or external to your organization) in particular topic areas (e.g., depression, cancer screening, minority stress) to assist with question design, data analysis, and manuscript writing
- Recruiting participants to The PRIDE Study through your networks including e-mail distribution lists, websites, social media, and physical materials, and/or local events.

DISSEMINATING STUDY RESULTS

- Sharing The PRIDE Study results via networks including US mail, e-mail distribution lists, websites, social media, physical materials (posters, postcards), and/or local events
- Co-authoring manuscripts and/or co-presenting study results at scientific conferences (travel support likely will be provided)

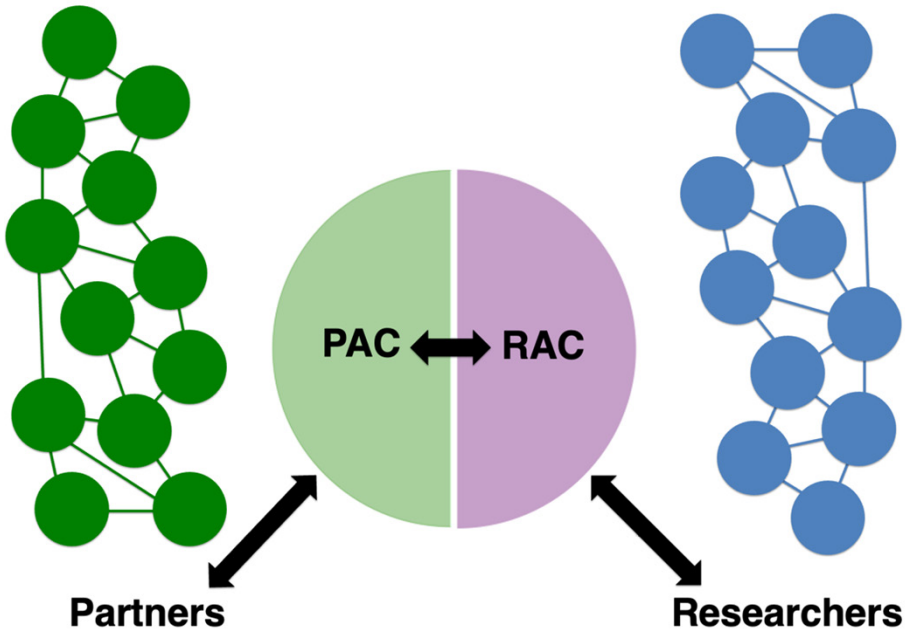
Please list any additional ways that your organization can assist in supporting a community member/patient-centered focus in this research network.

Appendix 4. PRIDENet Partner Engagement Questionnaire Results (2015)

Engagement Option	Percent Response
<i>PPRN Governance</i>	
Recruiting a staff member to play a role in PPRN governance (e.g., serving on a committee)	63%
Recruiting a community member/patient to play a role in PPRN governance (e.g., serving on a committee)	43%
Participating in PPRN engagement evaluations by providing feedback about optimal ways for continued engagement and meaningful contributions to the PPRN	70%
<i>Research Priorities</i>	
Distributing and/or contributing to The PRIDE Study's annual Request for Research Questions (RFQ)	80%
Holding a local community listening forum to determine current LGBTQ health-related priorities	60%
Participating in the annual PRIDE-PPRN summit in San Francisco to help plan research questions and priorities for current and future studies (travel support likely will be provided)	65%
<i>Study Design and Recruitment</i>	
Providing expertise (from either within or external to your organization) in particular topic areas (e.g., depression, cancer screening, minority stress) to assist with question design, data analysis, and manuscript writing	53%
Recruiting participants to The PRIDE Study through your networks including email distribution lists, websites, social media, and physical materials, and/or local events	88%
<i>Disseminating Study Results</i>	
Sharing The PRIDE Study results via networks including U.S. mail, email distribution lists, websites, social media, physical materials (posters, postcards), and/or local events	90%
Coauthoring manuscripts and/or copresenting study results at scientific conferences (travel support likely will be provided)	45%

Appendix 5, Figure 1. PRIDENet Structure.

PRIDENet has two central bodies: PRIDENet Advisory Committee (PAC) and PRIDENet / PRIDE Study Research Advisory Committee (RAC). The PAC with PRIDENet staff engages PRIDENet Community Partner Consortium Members (here "Partners") and are in close collaboration with the RAC. The RAC and PRIDENet staff are primarily responsible for engagement with SGM health researchers and compliance with research guidelines and regulations. The PAC and RAC have open communication channels bridged by PRIDENet staff. Communication and collaboration among Partners and Researchers will be encouraged and facilitated. Please note, as with any model there are limitations in representation and there are for example individuals who represent "Partners" who are researchers and "Researchers" among partners.



[For ongoing updated content about emerging research please see: <https://pridenet.org/research> and <https://pridestudy.org/research>]

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Appendix 7. PRIDENet Community Partner Organizations as of 2023 (33)

Organization	City	State
COMMUNITY CENTERS (2)		
Montrose Center	Houston	TX
Pride Center of Vermont	Burlington	VT
HEALTH ORGANIZATIONS (14)		
Allies for Health + Wellbeing	Pittsburgh	PA
Bay Area Physicians for Human Rights (BAPHR)	San Francisco	CA
Boston Medical Center	Boston	MA
Callen-Lorde	New York	NY
Equi Institute	Portland	OR
Equitas Health	Columbus	OH
Fenway Health	Boston	MA
Gender Health SF	San Francisco	CA
Golden Rule Services	Sacramento	CA
Howard Brown Health	Chicago	IL
Institute for Sexual and Gender Health at the University of Minnesota Medical School	Minneapolis	MN
San Francisco Department of Public Health	San Francisco	CA
University of California, San Francisco Alliance Health Project	San Francisco	CA
Whitman-Walker	Washington	DC
STATE-BASED ORGANIZATIONS (3)		
Arkansas Transgender Equality Coalition	Little Rock	AK
FreeState Justice	Baltimore	MD
TransFORWARD: Texas Transgender Health	Austin	TX
NATIONAL/INTERNATIONAL ORGANIZATIONS (14)		
Bisexual Resource Center	Boston	MA
Center for Black Equity	Washington	DC
Center for American Progress	Washington	DC
CenterLink: The Community of LGBTQ Centers	Remote / National	
FORGE	Milwaukee	WI
GLMA: Health Professionals Advancing LGBTQ Equality	Washington	DC
Human Rights Campaign	Washington	DC
Intersex & Genderqueer Recognition Project (IGRP)	Remote / National	
Modern Military Association of America	Washington	DC
NAESM, Inc.	Atlanta	GA
National LGBT Cancer Network	New York	NY
SAGE: Advocacy & Services for LGBTQ+ Elders	New York	NY
World Professional Association for Transgender Health (WPATH)	Union City	CA
ZAMI NOBLA (National Organization of Black Lesbians on Aging)	Atlanta	GA