



THE PRIDE STUDY

YOUR STORY. YOUR HEALTH.

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STUDY OVERVIEW

BACKGROUND

Sexual and gender minority (SGM) people – including lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals – experience health and healthcare inequities. Previous population-level studies lack sexual orientation and gender identity data, thereby restricting understanding of factors influencing the health of SGM people. Baseline demographics, disease states, and risk factor prevalence influencing SGM health remain unknown. The National Academy of Medicine's report on improving the health of LGBT people recognized these limitations noting "the relative **lack of population-based data** presents the **greatest challenge** to describing the health status and health-related needs of LGBT people." [emphasis added] As shifting sociopolitical landscapes have heightened awareness about SGM human rights, the creation of a prospective research cohort can describe and then change the health landscape for SGM people by collecting data unique to these populations.

GUIDING PRINCIPLES

Mission: Improving SGM health through rigorous research.

Vision: A world where SGM people have optimal health.

FOUNDATIONAL QUESTION

How does being a sexual and/or gender minority influence physical, mental, and social health?

SAMPLE RESEARCH QUESTIONS

- What are the primary factors influencing cardiovascular disease morbidity and mortality in the SGM population?
- Among SGM people eligible for HIV infection pre-exposure prophylaxis (PrEP), what are the barriers to starting and continuing PrEP?
- How does perceived stress (or conversely, flourishing) vary within the SGM population? What contributes to it?
- Are particular SGM groups (e.g., African-American lesbians) at differential risk for specific cancers?
- What are the differential levels and sources of stigma within the SGM population?
- What are the protective factors for mental disorders, suicide, and deliberate self-harm among SGM individuals?

STUDY PHASES

Phase I: Community listening and pilot phase (launched June 25, 2015 via a ResearchKit-powered iOS app)

Phase II: Longitudinal cohort study (planned launch for 2017)

STUDY CHARACTERISTICS

- Novel Design. Nationwide, electronic, longitudinal cohort designed to understand how being SGM influences health.
- LGBTQ Researchers. Created by SGM-identified physician-researchers who understand SGM-specific health needs.
- Diverse Experience. Designed by primary and specialty care physicians at the University of California, San Francisco, a Top 10 hospital by *U.S. News & World Report*.
- State-of-the-Art System. Rich, responsive user interfaces with robust, secure backend infrastructure to support a novel multi-channel (web, mobile app, e-mail, text message) participant recruitment, engagement, retention, and reporting system with third-party software services and devices.
- Advanced Security. Application- and network-level security combined with secure data facilities ensure participant data is safe and compliant with local, state, and federal regulations.
- Long-Term Planning. Semi-annual profile updates, automated annual questionnaire administration, frequent study updates, ancillary studies, and emerging technology pilot studies foster long-term, continued participant engagement.
- Broad Reaching. Designed to reach diverse SGM communities in their own environments with plans for multilingual support and engagement options for individuals without access to the Internet.
- Community Engagement. Active SGM engagement in all study aspects via a collaborative network (PRIDENet) with community centers, health clinics, and community-based organizations help ensure all voices will be heard.



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STUDY DESIGN

The PRIDE Study is a national, electronic, longitudinal cohort study which focuses entirely on the health of SGM people. Any SGM adult living in the United States is eligible to participate. Historically, the health experiences of SGM people have not been addressed in prospective cohorts, resulting in knowledge gaps for healthcare providers. These gaps instill distrust and feelings of invisibility amongst SGM individuals. The collection of rich participant demographic information is central to **The PRIDE Study**. Furthermore, **The PRIDE Study** will partner with participants to ensure that every aspect of the research process – from question design to results dissemination – are driven by a participatory model (PRIDENet). At the individual level, a user-maintained personal profile will be updated semi-annually providing useful information about how demographics change for SGM people over time. These profile data will contextualize annual health questionnaires sent to all participants. Taken together, demographic and health data focused on community-generated priorities will allow longitudinal measures of association to understand population-specific needs and resources. Once the cohort is mature, investigations into topics pertaining to specific medical specialties (e.g., gynecology, nephrology, dermatology), regional differences, ages, or sexual minorities can be pursued. Enhancing knowledge about SGM individuals will also help drive evidence-based health interventional studies. **The PRIDE Study** was designed by SGM-identified physician-researchers sensitive to the needs of SGM individuals with a plan to collaborate with participants throughout their lives. National recruitment will occur through marketing campaigns designed in collaboration with community partners through PRIDENet.

TECHNICAL FEATURES

Participant engagement and long-term retention is critical to all longitudinal cohort studies. **The PRIDE Study's** state-of-art participant recruitment, engagement, retention, and reporting system will feature participant self-service enrollment and streamlined automation to initiate and maintain contact with participants. Multichannel participant engagement via web, mobile app, e-mail, text message (SMS), and telephone as well as easy, online, self-service updating of contact information, demographic data, and medical history will provide a centralized research infrastructure for participants and study staff. Health questionnaires will be electronically distributed with customized, automated, completion reminders via e-mail and SMS. Study design will also allow for engagement with participants who do not regularly use the Internet or SMS. Robust cohort search tools can delineate a specific subset to enable targeted survey distribution to participants meeting specific criteria for a particular study. Novel integrations with Qualtrics (survey administration), Twilio (SMS processing), SmartyStreets (geocoding, mailing address verification), DocuSign (digital document signature), and SendGrid (e-mail infrastructure) facilitate participation and seamless information processing and verification to ensure clean data. A rich, responsive online environment engages participants to make meaningful and impactful contributions to improve population health while maintaining stringent, high-level security.

SECURITY AND DATA PRIVACY

Prior in-person studies involving disclosure of SGM status have encountered reluctance from participants to disclose their identity. Despite this, prior research has also shown an interest from SGM people to participate in research that is sensitive to their needs. Our web-based interface will allow participants to disclose information about their sexual orientation and gender identity in a safe and secure manner. Participants can be assured of confidentiality with an National Institutes of Health Certificate of Confidentiality; data will be stored in accordance with local, state and federal regulations and the UCSF Institutional Review Board. Data hosting will be performed by Amazon Web Services, which employs multiple stringent security features at the application, server, and network levels in addition to robust data storage facility security measures. All data is encrypted while in transit and at rest. These features will ensure that all participant data is secure, available only to authorized users, and used only for the intended purposes.

COMMUNITY TO IMPROVE LGBTQ HEALTH

The PRIDE Study's website will educate potential participants about the study with inviting intuitive experiences. The website will be a hub for education and recruitment of study participants as well as those interested in finding other methods to support **The PRIDE Study's** efforts to improve SGM health. Detailed study information for researchers, healthcare providers, and SGM service organizations interested in learning about the study's methods, objectives, and impact will be available. The multifaceted nature of SGM people including different ages, abilities, cultural and linguistic backgrounds, and education levels will be reflected in the purposeful design of the site. We are working to create a welcoming environment where all SGM-identified people can share their unique story, so we can stand together for health!