



Report on 13 Health Research Community Listening Sessions (CLS) with Sexual and Gender Minority (SGM) People Across the Country

PRIDEnet for the
All of Us Research Program
at Stanford University

Final Version: March 30, 2020

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**All
of Us**
RESEARCH PROGRAM



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PRIDENet

The Stanford University's PRIDENet for the *All of Us* Research Program [formerly the San Francisco General Hospital Foundation's (SFGHF) the *All of Us* Research Program National Sexual and Gender Minority (SGM) Engagement Network] conducted 13 CLS with Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ+) [also referred to as Sexual and Gender Minority (SGM)] communities across the country.

PRIDENet is a network of individuals, community groups, and service organizations dedicated to ensuring that SGM people are included in existing health research and catalyzing new SGM health research.

PRIDENet for the *All of Us* Research Program engaged Community Partner Consortium (CPC) members to coordinate these sessions. These CLS were initiated at SFGHF and continued when PRIDENet moved to Stanford University early in 2019. Sessions were conducted both in-person and online. CLS conversations focused on health care concerns, research participation, and communication preferences. The voices captured here will help the *All of Us* Research Program (AoURP) better understand common experiences and perspectives, as well as unique issues within specific sub-communities as we continue to build the warm, welcoming, and respectful research program we all envision for our underrepresented communities.

We are pleased to present themes from these sessions (highlighting, in particular, the voices of the attendees by using numerous quotes) for use in communications, planning, engagement, and enrollment activities throughout the Consortium.





Introduction

PRIDEnet is based in California but our network extends across the country and includes community partner organizations, participant advisors, and ambassadors. The network engages SGM individuals in specific research programs, such as the *All of Us* Research Program (AoURP), and provides input into the design, conduct, and dissemination of health research.

Many SGM people have experienced political disenfranchisement, social stigma, familial rejection, discrimination in health care, and exclusion from clinical trials. As a result, they may be reluctant to participate in research, particularly research conducted by institutions with which they are unfamiliar. In an effort to overcome these barriers, PRIDEnet established a Community Partner Consortium (CPC) composed of LGBTQ+-serving clinics, community centers, and advocacy organizations known and trusted by SGM individuals.

PRIDEnet's CPC currently consists of 31 organizations around the country. We work with these organizations to support their health-related missions and activities and to advance our engagement and dissemination goals. We share information, materials, promotional opportunities, influential contacts, and presentation opportunities in order to expand opportunities for SGM health research and dissemination.

We initiated the CLS process in close collaboration with select CPC members [primarily those based in AoURP Direct Volunteer (DV) cities] in order to hear from a variety of geographical regions and from sub-communities who are less represented in research in general.

We greatly appreciate the willingness of the NIH and the AoURP to begin by listening to the real concerns and ideas of our SGM communities as together we aspire to developing an approach to research participation that is warm, welcoming, and respectful.

Glossary of Key Terms Used in SGM Health Research

When working with our communities, great care must be taken to use the most appropriate, empowering, and inclusive language whenever possible. Please note that appropriate language can vary, as it is informed by different contexts as well as intended audiences. In general, the PRIDEnet Participant Advisory Committee (PAC) recommends the following definitions:

- 1. Agender:** A person who does not self-identify as any gender.
- 2. Asexual:** A person who does not experience sexual attraction to any gender.
- 3. Bisexual:** A person who is emotionally, romantically, spiritually, sexually and/or relationally attracted to people whose genders are both similar and different from their own.
- 4. Cisgender:** A term indicating that someone is not of trans experience (i.e. does not identify as transgender or any other associated identity). Often used to denote the conformity of one's self-identity with the socially constructed gender expression and roles associated with their assigned sex.
- 5. Gender:** Refers to a socially constructed categorization system which assigns traits of masculinity and femininity to individuals. Not a fixed system: characteristics vary by culture and can change over time.
- 6. Gender Dysphoria:** A term used to reflect the incidence of clinically significant distress related to a disparity between one's gender identity and the gender group to which others would assign the individual (Note: One's deviation in gender identity—or nonconformity—is not an inherent disorder rather the diagnosis is included as means to affirm those who experience tremendous anguish related to gender identity; perceived versus self-identified
- 7. Gender Expression:** The multitude of external characteristics that we may choose to communicate our gender identities, including apparel, grooming habits, mannerisms, etc.
- 8. Gender Binary:** The idea that there are only two gender identification options—masculine and feminine.
- 9. Gender Identity:** One's personal identification of being masculine, feminine, a combination of the two, or neither. May or may not align with the gender expectations associated with one's assigned sex.
- 10. Intersex:** A word used to describe individuals born with bodies that may not be clearly defined as female or male. Characteristics may include ambiguous genitalia and/or chromosomal combinations.
- 11. LGBTQ+:** An acronym for Lesbian, Gay, Bisexual, Transgender, Queer (or Questioning), Intersex, Asexual communities (Note: The plus sign is used to further abbreviate the acronym and reflect that a greater number of additional identities exist within the greater community beyond what is specified).
- 12. Pansexual:** A person who is sexually attracted to individuals of all gender identities or expressions (i.e. gender identity has no significance or relevance in determining attraction).

- 13. Same-gender loving:** An alternative to the more common usage of same sex, used to symbolize the expression of romantic and/or sexual attraction between people of the same gender. An especially significant term, as it can reflect that two romantic partners may be of the same gender identity, but not the same sex/sexual identity.
- 14. Sex:** Refers to a person’s biological characteristics/status assigned at birth and typically categorized as male, female or intersex. Such characteristics include gonads, chromosomes, and internal and external organs/genitalia. Often used inaccurately and interchangeably with gender.
- 15. Sexual orientation:** Represents one’s romantic, sexual and/or emotional attraction to another sex: the degree of attraction may vary as aspects of identity are fluid and can develop over time.
- 16. Third Gender/Genderqueer:** Most often refers to people who identify their gender as not conforming to the binary model of gender (male/female).
- 17. Transgender:** One who feels as though the gender they were assigned at birth is an inaccurate or incomplete representation of their current gender identity. This is an umbrella term used to describe multiple communities whose expressions or identities transcend gender norms. These may include (but are not limited to) transsexual, third gender, people who identify themselves as being of “trans experience,” Two Spirit people, gender variant and gender non-conforming people, drag kings and queens, and sometimes people who are born intersex.
- 18. Two Spirit:** Most often used by Indigenous (Native), Aboriginal, and First Nations people from Canada; and chosen to distinctly reflect associated traits; characterized by their masculine and feminine attributes (in tandem), combined with the designation and distinct gender and social roles.
- 19. Queer:** “Umbrella term” often used to indicate a sexual and/or gender identity that may deviate from heteronormative, gender binary standards. Appropriated within the past 20 years, this term was formerly used to malign, harass and spread hatred and animosity toward members of these communities. While many elders may refrain from using the term due to its history, it has been reclaimed as a widely used term by younger people within the communities.

Why Community Listening Sessions?

SGM are an identity-based population that includes sexual minorities (individuals with a sexual orientation that is not heterosexual) and gender minorities (individuals with a gender identity that is not congruent with their sex assigned at birth). Because sexual orientation and gender identity data are not collected for the US Census, the precise number of SGM people in the US (as well as their age, geographic, linguistic, race, ethnic, income, and regional distributions) is unknown. However, despite limited data, SGM people are believed to live in nearly all counties in the US, be a part of other underrepresented minority groups, come from every socioeconomic group, and speak a wide variety of languages.

Many SGM people experience mistreatment or discrimination in clinical settings and likely deter participation in health research as a result. Health care providers receive inadequate training in caring for SGM patients. Inconsistent collection of sexual orientation and gender identity data in clinical settings makes conducting SGM-specific studies challenging.

Further, we know that medical advancements don't always benefit socially marginalized communities and do not necessarily translate into improved access or better health outcomes for LGBTQ+ people. For example, men who have sex with men (MSM) of color still experience significant health inequities when it comes to HIV prevention, care, and treatment. Stigma, shame, homophobia, racism, discrimination, inaccurate sexual health education continue to impede better access and positive outcomes for this community.

In 2010, the NIH commissioned the Institute of Medicine (now the National Academy of Medicine) to study SGM health and inform the nation's SGM health research agenda. In addition to recommending research in nearly all aspects of health, the consensus committee stated that "the relative lack of population-based data presents the greatest challenge to describing the health status and health-related needs of LGBTQ+ people" and emphasized the need for national efforts, such as the AoURP, to explicitly include data measures or questions about SGM identity.

Given the paucity of data on SGM health, the likely prevalence of negative experiences in health care settings for SGM people, and the fact that AoURP is one of the first federal programs to actively engage SGM communities, we dedicated our first phase to listening to a variety of communities in order to build the AoURP's capacity to engage and retain SGM participants.

Our CLS were conducted both in-person and online and addressed the following topics:

1. The health of communities
2. Participating in health research in general
3. The best ways to get and share health information.

SGM-identified people over the age of 18 who completed an online registration form could participate. Partners promoted the session on social media and in organizational newsletters and emails. Sessions were audio recorded.

Summary reports were sent to coordinators and attendees after each session. Coordinators had opportunities to review and comment on each report and on the compilation reports (versions 1 and 2). PRIDEnet also hosted a live discussion with coordinators that resulted in edits and additions to those compilation reports.

Please note: Below we use the term "bisexual plus" to convey inclusion of all non-monosexual identities. As stated by the co-facilitator of these sessions: "If you are attracted to more than one gender [including agender, fluid, non-binary and transgender (people)], you are under the bisexual umbrella. We share the same issues and disparities. Our shared non-monosexuality is important when collecting data and reporting on us."

This report covers CLS with the following groups:

1. The Equi Institute in Oregon (January 6, 2018): 15 attendees
2. The Montrose Center in Texas (#1) (January 13, 2018): 20 attendees
3. The Montrose Center in Texas (#2) (January 13, 2018) for gender minority people only: 12 attendees
4. MPower in New Mexico (January 25, 2018) for gay and bisexual men and transgender people: 11 attendees
5. The Windsor and Bronx SAGE Centers in New York (January 22, 2018) for LGBT elders: 21 attendees
6. Bisexual Plus Community (#1) (March 22, 2018): 20 attendees
7. Bisexual Plus Community (#2) (April 25, 2018): 12 attendees
8. Golden Rule Services, Inc. in California (April 26, 2018): 9 attendees
9. Saving Ourselves Conference in Alabama (June 7, 2018): 10 attendees
10. My House Nashville in Tennessee (June 27, 2018): 14 attendees
11. The Haven Memphis in Tennessee (October 6, 2018): 16 attendees
12. Transgender and Gender Non-Conforming (TGNC) community (October 17, 2018): 15 attendees
13. Zami NOBLA in Georgia (April 30, 2019): 11 attendees

Total attendees: 186

Common Themes

We Need Culturally Competent Health Care

Concerns about accessing and receiving care from providers who are sensitive to, knowledgeable about, and humble in their approach toward working with members of LGBTQ+ communities were prominent in every single CLS we conducted. We believe these insights have profound resonance with, and implications for, research participation. The reluctance with which people perceive health care likely mirrors attitudes toward health research participation.

New Mexico:

You know, gay people and trans people, you don't go into doctors in general, because you know that there's going to be a significant chance that the doctor is not going to treat them or respect them. I think that is a very big issue.

California:

...Doctors need to be informed on the type of care that is tailored for these [LGBTQ+] people... yet when you're a trans person... the first time you go to a doctor, your first hour visit is educating your doctor on everything. And believe me, some of the questions [they ask] are traumatizing themselves.

Texas #2:

I want to know that when I make the phone call that the person on the other end of the phone is going to be good to me. That the receptionist is going to be good to me. That the nurse is going to be good to me. That the doctor is going to be good, and that the financial person, or whoever the check-out person will be good. Because any one of those steps that doesn't go, right? We might not continue in that care...

Tennessee:

...It's shocking when you see transgender or homosexual males come into the hospital and the slurs that they're called. Or how they're talked about by the health care professionals themselves. And [then you see] the quality of health care that they're denied because of their sexuality.

Tennessee:

...In my eyes, you know, me as a trans woman, I did experience discrimination and things of that nature... access to health care is very limited. And then when you do access it, I feel like a lot of the times you have doctors not respecting our community or pronouns.

Transgender and Gender Non-Conforming:

...So, I absolutely do not, flat out, never disclose with employers... if you go to this specific clinic and it's the only one in town that like is catered towards queer people in general then that could open you up to potential risks like losing a job or other- or like losing your housing, things like that.

Transgender and Gender Non-Conforming:

My doctor can't even get my pronouns right so I don't trust them on trans health advice, but I pay them. Shrug. [laughs]

Our Health Should be Seen Holistically

One attendee from the Sacramento session summarized the health care situation for his community by stating “our communities have been ‘half-served.’” Patients and communities need both culturally competent care and to be treated for issues that are not specific to a patient’s sexual orientation or gender identity. In addition, attendees of these sessions wanted to be able to access care for their physical, social, and mental health issues, ideally in one location where they feel welcome.

New Mexico:

They focus on the transgender part, but they don't focus on the main issue.

California:

One thing that bothers me as a gay black male is that the only thing people think about when it comes to health is HIV... I can have mental health, spiritual issues, glaucoma, diabetes... but when it comes to gay men... all that people give attention to is HIV and AIDS... it's very frustrating and it's demonizing, and it's vilifying.

Bisexual Plus #2:

Health includes eating disorders as well as access to food or living in food deserts... One of the biggest health issues in the community is sexual assault and sexual abuse and sexual harassment.

Texas #2:

A combination of multiple factors, including mental health, physical well-being, environment, and support social networks... for one to be whole and [of] sound mind, body and spirit, they have to tend all parts of themselves...

Mental and Behavioral Health Care is Often Deficient for our Communities

Tennessee:

I think [that] a lot of gay black men suffer from depression and it's not treated correctly... it's not looked at correctly... it's not diagnosed correctly... it's hard once you get older and you start realizing, "Oh my gosh, I've gone all these years and I was really clinically depressed and never treated". And you know, it could've been treated earlier.

Tennessee:

I think, um, mental health is big in the gay community. And people kind of sweep it under the rug because they're like, it's either two guys or two women. They can figure it out.

We Need to be Represented in Research, but We're Worried

The community members we listened to conveyed a remarkable enthusiasm for health research participation and a sophisticated understanding of the value of research. People want to see themselves in the campaigns that encourage research participation. At the same time, there are equally strong, deep, and specific anxieties about the potential harm unsecured or unethically used data could have on our communities. These anxieties are based on past experiences with research, high profile data breaches in the news, and the current political environment in which LGBTQ+ civil rights are perceived to be rolling back and transgender communities, in particular, are being negatively targeted. In addition, some attendees worried that LGBTQ+ research participation

may be insufficient to illuminate what we need to know about our precision medicine issues. One prominent fear relates to the use of precision medicine data to “fix the gay gene.” Another is that the information will be used to further restrict civil and political rights. Some people fear that participation will cause a social backlash against LGBTQ+ people. Some are concerned that health data will be used to abuse us, for example to hurt, control, or change us in undesired ways.

Tennessee:

I don't feel the white coats. I mean, I think you should just show average people doing average things. But if you show the white coats, it's just going to- it's going to make people feel like you're going to make them a lab rat or something. There needs to be somebody with dreads. And there needs to be somebody black. Somebody white. Somebody old. And somebody with glasses. And somebody bald. And different nationalities to show that—everybody—all of us should be a part of the study.

Tennessee:

When you read research articles, you'll [see] a percentage of males, percentage of females. But it's not just a male and female anymore. There's a gay, black male. There's a transgender male. There's all this variety... if we did get into this research, then there could be some diversity.

Transgender and Gender Non-Conforming:

I'm just quite frankly really tired of hearing we don't know from doctors... I think being part of answering a lot of those questions, and being part of the trans brain trust, that will be a huge benefit. I'll give you all my information if it helps the next person that comes along... There's all these questions that everybody asks um, as far as what happens to your body that nobody's done any research on and nobody has any idea you know what happens when you're 60, 70 years old.

Transgender and Gender Non-Conforming:

At the most basic level our humanity will be recognized and legitimized by being counted... numbers equal funding for future research and for intervention-based programs to address the health disparities in our community. It can help us address the epidemics of HIV, suicide, substance abuse, and other barriers that people experience like homelessness.

Texas #2:

There are people dying in the streets right now, because of a lack of research. Because of that lack of research, health care professionals and community outreach organizations have a lack of knowledge in how to even help these people. So that the research is vital for them to understand who needs the help and how they can help them.

Texas #2:

Black trans women are dying. People are finding them and they're killing them just for who they are. There are still people out there that will try to hurt you, just for who you are. That's really concerning... being in Texas over the last year and listening

to our elected officials berate us and call us nasty names had a direct effect on my health care... Whether it's the health care provider, the insurance company, a walk-in Urgent Care center, one of the first things they ask is 'Male/Female.' Well, I'm a transwoman; I'm not female... But then it's going to cause issues, because now the doctor who I thought was OK is now 'Oh, I don't believe in transwomen.'

Texas #2:

There's hardly any info about gender non-binary resources. My mental health providers seem to somewhat understand, but you don't see that in physical health spaces. There's a lack of training, lack of education... we have no idea what HIV rates are in gender non-binary or even transgender communities. Because the CDC forces everyone to identify as male or female. Their data is based off of binary genders.

Tennessee:

...Medication now is like, oh well, if you're a black male, we know that it will affect you this way. But if you're a black gay male, then we know it's going to affect you this way. No, we don't. Because we didn't have any black gay males that we know of in this study.

Bisexual Plus #2:

We've seen a lot of issues with data being released... it seems as though nothing is secure, even secure sites... there's a lot of concern for getting your personally identifiable information out there... and I have children. I have a friend who's in a polyamorous relationship, and they have no protections. While sexual orientation may be protected, relationship styles are not protected. Having that information leak out... or shared without my knowledge, those sorts of things can be really scary.

New York:

People come to SAGE Bronx and ask us to participate in these different research projects, and we just often wonder what is being done with this information. You know the horror stories that have happened from research studies. And let's not forget the Tuskegee syphilis study, where the government recently paid those who were still surviving.

California:

Using our numbers and our data for unjustified and unreasonable needs is a concern... Is the information going to be reported in the spirit it was given?... Don't tell me that you're asking me this question for this, and then when we get the information back you used it for this.

Transgender and Gender Non-Conforming:

History has proven that it's not safe for trans folks to be part of federally funded research studies um, even if they're locally or regionally driven by proven organizations. I'm scared of being treated by able cis people who don't know what they're doing and harm me in the process.

We Need Access to Health Care in Order to Effectively Participate in Health Research

Attendees in these sessions articulated the connection between access to health care and capacity to participate effectively in health research studies. They described concerns about the impact of poverty and structural discrimination in limiting health care access for SGM people and worried that our sample would lack representation as a result.

Bisexual Plus #1:

The cost of health care and not having insurance is a barrier to care...

New York:

Because I know of several people that can't afford to buy these supplies. Some people can't even afford it. I received—from Social Security—that they were taking me down to \$775 a month. Consider my income from seasonal unemployment is \$265 a week.

New Mexico:

If you don't have money, you don't buy good food. If you don't have money to get yourself in decent housing conditions. And if you don't have money to get insurance to go to the doctor, things like that. I mean, it'll (expletive) your health up.

Oregon:

What I'm seeing a lot as a problem—especially in the queer community—is access to health insurance... some people just give up. In order for someone to get a life-saving and life-altering surgery, they might have to go through years of dealing with insurance and trying to find insurance, so if you just... made it a simple informed consent process, you could take like years of trauma off of people's lives.

Use Privilege and Social Capital to Help Those Who Don't Have It

Georgia:

Um, you know, I, I can't stress that enough. I also think that people who have privilege, uh, should share it... sometimes if they are invited to do something, they can say no, and they can certainly recommend somebody else who might be in a marginalized community to take their place and to speak for themselves as opposed to them speaking for the other person. I think that's really important.

When It Comes to Research Results: Share, Share, Share!

Due to historically being studied and failing to receive even the most basic information about results, implications, or program and policy improvements that result from research, attendees in most of these sessions conveyed skepticism about receiving benefit from

participating in something like AoURP. Some individuals had been involved in numerous studies and others resisted participating in research in the past. Past experience with research and researchers left some attendees feeling vulnerable, exploited, and angry.

Bisexual Plus #1:

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

New Mexico:

When I see people collecting data, I want to know that you didn't just collect that. I want to know what you're going to do about high STI rates.

Oregon:

...To have information available, so that, like, we feel included. And like knowing... where is this taking us or where is this research being presented.

California:

...They can only research the information that's put in front of them... very few people ask our opinions about anything. And so, when we're vulnerable and when we come and share our personal experiences, we never hear from them again. They got what they wanted, they disappeared and we never heard anything back.

New York:

We've had too much studies. Studies, studies, studies. No cures. Just studies. It's getting boring. And when you're 69 years old, it's ridiculous.

Tennessee:

Transparency. Being very transparent with the process. Knowing what the data is going through [and] how stuff will be used... Every time you take a collection, [remind] people. [Keep] it transparent throughout the entire process so people feel comfortable. They have something to go back and reference [and] they have a number to call.

Tennessee:

I know something that one of my coworkers does... where [each year] she sends a survey, you know? She gives no incentives [for taking the survey]. But the thing is, at the end of the year, you have a product, a booklet, that, again, gives tons of individuals a guide to places, to everything from gyms to doctors to spas that are welcoming...

Transgender and Gender Non-Conforming:

I'm in the field of research and I encourage other folks to participate, especially trans and non-binary folks, but I feel like the issue is that we have all this

funding and then they support trans people throughout the study, but once they find the research findings... there's no community feedback about what the findings were... we feel uh, very disconnected from the researchers.

Georgia:

I would say also storytelling, um, people, um, coming out of the closet about for instance, their mental health issues, and giving people a chance and an opportunity to relate and then to express their own concerns and needs.

Georgia:

It's multi-tiered, but I think it starts with us telling our stories and not filling in that persona of the strong black woman who is fearless and is infallible and can withstand anything, that we really are vulnerable beings and... need support... that we have those stories to tell.

Georgia:

...Get our voices and perspectives in early and not just at the beginning, but be consistent and sustainable along the way. I think oftentimes when things are developed and implemented, they are without the voices of people who are most affected, affected and impacted.

Georgia:

Let me just offer this. One of the things that- I've been in some conversation with some, some black lesbians in Atlanta... not necessarily delivering, uh, these findings in the same usual dry, scientific way, but maybe to use, uh, song and poetry and use- and, and use plays to deliver this research, you know? I think it would add a whole new dimension to research and to research delivery as well.

Family and Friends are Trusted Sources of Information but Providers are Still Important

Tennessee:

I trust a lot in my family... I trust a lot in people who have been through or gone through similar instances. [Whether] that be friends, co-workers, or my family. I don't really trust doctors because I feel like they're pushing for medication. I'm not really a 100% medication person... and I self-diagnose a lot of times.

Tennessee:

...Even when I go to the internet, I still have to hear it from the doctor. Like, I still have to hear it from the most knowledgeable person. Sometimes the internet isn't the best source... doctors are my connection but- but even before I get to the point of trusting, or believing whatever that information that's given to me by them, I have to form a relationship. I have to build a bond and feel comfortable with that- that physician, even to trust in what they're telling me.

Tennessee:

I'm not just talking about medical. I'm talking about just, you know, the people who the information's going through. You know, it's great that they want to hear the issues that we're having. You have people of color who should be, you know, in the position, like hiring more trans women, trans women of color... getting basically people that look and represent us and, you know, understand us well, because some of these things, you can't do [through] trainings...

Tennessee:

I would actually partner with an already established organization instead of doing the groundwork... that way we can help each other instead of getting in the way.

Georgia:

One of the things that we've been doing recently has been going to black LGBTQ+ churches, uh, to recruit and sitting through the service, and not knowing any of those folks, and then having them come into a room afterwards.

Georgia:

So, in rural areas, um, you know, you sort of have to know a gatekeeper or, you know, Ms. Jane introduces you... or Ms. Anne's sister's daughter's niece's cousin's in-law. [laughs] You know, you have to have some kind of, uh, introduction or some kind of entrée into these communities.

Unique Experiences and Concerns

Social stigma, familial rejection, and civil rights-based discrimination (in housing, employment, and accommodations) impact different sub-communities (people who identify as gay, lesbian, bisexual, transgender and/or gender non-conforming, people of racial minority groups, and people of different ages) disproportionately. We emphasize our similar experiences and concerns when we use the term LGBTQ+ as an umbrella for some advocacy efforts. However, in health care and health research, we also need to recognize the unique experiences and concerns of those who are members of sub-communities. For example, members of bisexual communities experience invisibility and lack of acceptance in established LGBTQ+ organizations and events. People who identify as transgender or gender-non-conforming face greater risk of violence than members of other sub-communities. And, elder LGBTQ+ people need more intensive in-person relationship-building and information-sharing to feel comfortable participating in research at all. Here, we found significant unique experiences, perspectives, and concerns within bisexual plus, gender minority, and elder communities in the following groups:

1. The Montrose Center in Texas (January 13, 2018) for gender minority people only: 12 attendees
2. The Windsor and Bronx SAGE Centers in New York (January 22, 2018) for LGBT elders: 21 attendees

3. Bisexual Plus Community (March 22, 2018): 20 attendees
4. Bisexual Plus Community (April 25, 2018): 12 attendees
5. The Haven Memphis in Tennessee (October 6, 2018): 16 attendees
6. Transgender and Gender Non-Conforming (TGNC) community (October 17, 2018): 15 attendees
7. Zami NOBLA in Georgia (April 30, 2019): 11 attendees

Texas #1:

...Trans women have issues. Trans men have issues. Lesbian women have issues. Gay men have issues... If you haven't gone out and solicited people in these different subsets, you're just not going to get a representative sample.

See Us, Respect Us, Serve Us

In all of these groups, attendees talked about the importance of visibility, both within general society, but more significantly, within the larger LGBTQ+ social and political umbrella. The bisexual plus, elder, and gender minority people in these sessions described experiences of intense invisibility even in those service organizations and institutions designed to serve LGBTQ+ people. They emphasized the need to organize and socialize, particularly online for bisexual plus people, within their sub-communities as well as the desire to receive care and participate in research that recognizes their unique needs.

Bisexual Plus #2:

Visibility has got to be the biggest thing. We're just not on anybody's radar. Us participating in this shows them that we exist, that we are a huge number of people [within] the LGBT community. We represent the largest sample size of the population in the LGBT community but we're the least addressed and have the worst outcomes of LGB people at least. We're seeing that the bi population was experiencing much higher rates of everything... but... we have to see what those numbers are.

Bisexual Plus #1:

...Culturally competent care is a barrier to health care, and prevents people from seeking what they need. Biphobia, erasure, and stigma are factors in health care here. Not being seen, heard, or understood. Providers may not differentiate between gay and lesbian issues and bi and pan issues... Finding health care providers, including therapists that are bi-identified or at least bi-friendly, is a barrier.

Texas #2:

There are damned few qualified mental health care professionals in the greater Houston area that even have any idea about trans issues. And we have to go through them in order to obtain a letter, so we can obtain hormone therapy. The greater Houston community is very ignorant about the LGBT+ community, and it prevents us from having access to health care. [For example] the Transmasculine community has trouble accessing OB/GYN services... My primary health care provider that provides my hormones has this much education, my

dermatologist has this much education. And although they are happy to talk to each other, they don't know how to talk to each other and communicate effectively.

California:

Up until the last couple of years, the trans community has been completely left out of any health conversation unless they had enough money... or were strong enough to walk in and make them give you the health care... now they're [the federal government] trying to roll back all the health care provisions for trans people.

Transgender and Gender Non-Conforming:

A thing I see a lot is I go on a lot of different social media, like specific trans specific groups, and forums and whatnot, and oftentimes I'll see a lot of people asking very specific medical questions on these pages, like stuff that they should ask a doctor. They usually have a reason to be asking it there because their doctor either doesn't know or they're not comfortable asking their doctor... I think it would be good to bring medical people into these kinds of spaces where people are already going to be gathering because these are really easy and accessible spaces for most people.

Georgia:

Black women's symptoms are often not taken seriously: I think being taken seriously about health matters is an issue. Just from my own person experience, um, being presented, uh, at a hospital with some serious conditions and being told that a psych consult was needed.

Georgia:

Reproductive concerns are not attended to by lesbians who are masculine presenting: And then as far as physical health, um, I think sometimes the reproductive, um, issues of lesbians who are more masculine presenting, butch, stud, whatever term, not always being, um, heard or taken seriously.

Our Issues Need to be Recognized (and Not Subsumed Under the LGBTQ+ Umbrella)

Texas #2 (page 3)

The LGBTQ+ community, as a whole, and the transgender community in particular, is woefully underemployed. When a person doesn't have a job, health insurance is prohibitive. For the few health facilities [that can take you]... the wait time is long. And you may not have 8 weeks to wait... There was a severe lack of transgender people who were willing to take the Affordable Care Act's coverage simply because there were no plans that were trans-inclusive. Not only is there just a lack of coverage in plans across the board, there's also a lack of information. You could, hypothetically, call any insurance provider 'Do you cover X, Y, Z?' And they have no idea. And you have to pull up that 132-page explanation of benefits document, which causes some [additional] issues. And there's a lot of trans people who are like, 'You know, why bother? This is what I really need so why bother getting insurance?'

Bisexual Plus #1

While the studies themselves may be extremely inclusive and respectful of the members of the Bi+ community, other people reporting on these studies and anything to do with them might erase us in favor of statistics regarding the lesbian and gay community, which has happened before.

Bisexual Plus #2:

I come from a mental health background... in terms of significant health concerns I've seen in the bi community is high rates of suicidality. And so, in particular, we tend to see it be higher in the bi community than in lesbian and gay communities in a lot of recent studies, as well as high rates of interpersonal violence.

Transgender and Gender Non-Conforming:

[In my state] We have a lack of physicians who can actually give HRT and we only have one health insurance that actually covers and has a program in place regarding gender reassignment... there's a lack of support services particularly around mental health services for folks who might be struggling with how the transitional med changes have impacted them... it would be nice to have more providers for uh, mental health... there just is a gaping hole it seems like.

Transgender and Gender Non-Conforming:

We belong in multiple communities and so we need representation in- in every way. I'd really love to see more info and resources for other Muslims like myself. Trans Muslims specifically. Again, highlighting, you know, the importance that, you know, we belong to multiple communities.

Georgia:

Even the nonprofits, I've worked for one, and we are not even competent in addressing the, the needs of the LGBTQ+ community or people of color... and that is leaving a lot of people out of the equation, and they're not getting the services and access to services that are necessary for their well-being.

Recognize Regional Differences

Tennessee:

When it comes to solutions, I don't like people who try to come up with just one thing and try to commit to everywhere... maybe you can tweak stuff, but at the same time, you can't rely on just a single solution, you know?... You don't understand that we're in the South. You don't understand that we have a different culture.

Memphis:

Unfortunately... it's a religious-based organization. So, in the client paperwork, they include, prayer requests and certain things like that. All the physicians ask if you want them to pray with you. Like, I mean I, of course, am religious, so that's fine with me. But not everybody is religious... being that we're in the Bible Belt and you are dealing with LGBT clients, um, not all the time is a religion a comfortable thing.

Social Media is Huge

For bisexual plus and gender minority communities, we heard that communicating, socializing, and organizing online is enormously important for social and emotional well-being.

Bisexual Plus #2:

...For a lot of us, it's because of that social isolation where... for some of us the only community that we can find and the only real ways that some of us can access other bi+ folks is through the internet and through Facebook and Twitter... and then on top of that, disabilities that keep you from being able to leave the house, physically or mentally, and it kind of amplifies the social isolation that we experience. It's really difficult in my area to even find a community, you know, people who are willing to get together and even acknowledge how we identify... there's so many different meanings to "bi".

Tennessee:

Social media, because nowadays people can say, 'I'm looking for a doctor, like, who does, like, treatments for these things.'... people will go online. So, friends from all over can just comment, like, share, or, like, retweet things.

Tennessee:

I mean there's three. There's, like, Grindr, Jack'd, and, like, Scruff. But granted, out of the three of those, they're like, in a way, like, based on racial demographics. Scruff is, like, your older, white, hairy men. Um, Grindr is, like, your, like, Millennials from all over. Then, like, Jack'd is just predominantly African American men.

Transgender and Gender Non-Conforming:

Facebook Live... it allows you to connect with people and share your experiences real time. I use Facebook for almost all friendships. Even for friends I live by. Being disabled limits how much I can do and where I can go. I use Facebook and join community groups. I use it for my personal and professional network, but I also look for trans-affirming events around me. I will say all the trans youths I work with don't do Facebook at all. And they're on Snapchat, which I can't figure out because I am already too old for Snapchat, but I'll just put that out there. The ones I use most are Reddit, Facebook, and YouTube. I also have a lot of hate for these spaces. Reddit is one of the most active ones and I read a lot and one I read a lot. There's a lot of hostility with the trans women on the general trans subreddit such as

r/asktransgender. Um, I've seen trans women on subreddit behave with hostility with trans men and non-binary people... and the moderators don't have the capacity to fully police it.

Positive Human Interactions Are Necessary for Research Participation

On the other hand, for the LGBTQ+ elders we heard from, there was virtually unanimous support for developing in-person relationships with researchers and research representatives and communicating directly.

New York:

Talk to the human being. All this research, all the money that's put into all this kind of stuff. Millions and millions of dollars a year. It's a waste. You got to sit down with each other and you got to fight it.

New York:

I just wanted to piggyback on the loneliness as a senior. Especially when you in an apartment on the South and you don't qualify for any kind of services other than what you purchase. That's a great concern of mine. I mean I was with my partner for 54 years. So now I'm by myself.

Transgender and Gender Non-Conforming:

Come out to our marches. Come out to our community forums. Get to know us. Build a relationship and build a trust with us because a lot of us don't trust y'all... really um, form relationships because some people have never met a trans person before, ever before, until we are their patients or their clients. So, come out and meet us where we're at.

Georgia:

Um, and also, not to, like, go back and be nostalgic, but I miss the days when we used to have retreats and, um, there were, like, white parties and stuff like that. And, and maybe I'm just old. Do those things still exist?

Implications and Recommendations

As discussed earlier, AoURP is one of the first (if not the first) national efforts to intentionally and explicitly seek participation from SGM communities. Our overall objective in conducting these CLS was to thoughtfully and carefully listen to concerns and perspectives from communities who, historically, have been excluded or marginalized from significant health research efforts as a step toward effective inclusion. SGM communities are relatively new to the table. There is much to learn, build, and test in paving the way forward.

The attendees in these sessions beautifully articulated suspected concerns (such as fears of misusing data) and illuminated new perspectives for consideration (such as the importance of crafting online messages that specifically reach bisexual people). While some of the discussion summarized above did not pertain directly to attendees' involvement in health research, the conversations emphasized important contextual factors that likely will have enormous impact, ultimately, on the participation of members of these communities (such as lack of access to culturally competent health care providers).

Based on the above common themes, we see the following implications for AoURP and our work as an AoURP Community Partner:

SGM Cultural Competency

Train all front-line personnel in overall LGBTQ+ cultural competency, with specific emphasis on:

1. The bisexual, gender minority, and elderly sub-communities
2. Scenarios of common interactions in health care settings, including how to recover from mis-steps
3. Ways to empower and validate SGM identities
4. Common contextual problems and perceptions that could be barriers to research participation (lack of health insurance and lack of provider competency)
5. Use people's own language by deploying the quotes above (the actual words of community members) to illustrate key points
6. Understanding the context of SGM participation in research, including significant negative historical milestones such as the early days of the AIDS epidemic and the prevalence of anti-LGBTQ+ theories (for example, the "gay gene")

Communications

1. Invest in developing new assets that represent SGM community members (rather than generic stock images), specifically including images and words from bisexual and gender minority people in videos for use online
2. Conduct communications campaigns that demonstrate how SGM people are involved in every level of AoURP
3. Conduct communications campaigns that explicitly state that the goal of AoURP is not to change SGM people or investigate the "gay gene"
4. Conduct communications campaigns for LGBTQ+ elders that focus on the listening to stories and the legacy we all want to leave to the next generations of LGBTQ+ people

5. Conduct communications campaigns for LGBTQ+ elders that focus on making a significant contribution and being part of something that matters
6. Conduct a communication campaign for bisexual plus people acknowledging and addressing that bisexual plus people live in “multiple closets”
7. Conduct communications campaigns that directly address both enthusiasm for data collection and ambivalence about data collection in LGBTQ+ communities
8. Conduct communications campaigns centered on concepts of respect and dignity
9. Develop robust data and information sharing system where LGBTQ+ communities (and possibly participants) are notified and informed of research as it is completed
10. Disseminate, in particular, how research is being distributed to health care clinics and used to improve the SGM cultural competency of providers
11. Utilize Facebook (one attended commented, “we all use Facebook”) and trusted service agencies to engage and educate SGM communities
12. Be cautious about only using “white coat” images which can turn certain people in our communities away
13. Support altruistic messaging with messaging that recognizes historical injustices and legitimate fears and concerns
14. Provide clear information about the kinds of questions AoURP will likely be able to address and not be able to address

Journey

1. Given the desire for in-person interactions, focus primarily or exclusively on organizations that serve LGBTQ+ elders to coordinate these visits. Other SGM groups have not been and will likely continue to be less interested.

PPI Modules

1. Ensure review of sexual orientation and gender identity language (SOGI) language at every step of development
2. Ensure periodic review of sexual orientation and gender identity language (SOGI) language since language norms change rapidly
3. Ensure that future research results are broken down by gender identity and sexuality and not only lumped into “LGBTQ+” findings as this minimizes the disparities seen in the bisexual community.

Engagement and Recruitment

1. Utilize messaging that emphasizes (extra) identity protections for SGM people
2. Utilize messaging that emphasizes ethical protection for SGM people (that the goal is not to change people)
3. When eliciting disclosure, be extra affirming for bisexual plus people
4. Provide resources for people, particularly mental health services, during the enrollment encounter
5. Prioritize transparency in all encounters
6. Keep in touch with people who participate:
 - a. Consider the different experience and mindset between participating in research vs. providing data and the generational differences. Be aware of differences in resiliency and optimism from younger generations compared to older ones.

Conclusion

We are honored that members of SGM communities around the country and from various sub-communities were willing to gather and share their opinions and perspectives so openly and honestly with us. Ultimately, we hope that our work serves them and helps bring their issues into sharper focus within health research communities. Going forward, we will use the suggestions and quotes here to develop broad reach digital campaigns as well as for messaging during one on one outreach and relationship-building. We look forward to working with our CPC clinics and service organizations in the coming year.

As one attendee from Sacramento stated, “...it’s kind of like you’re getting half-served. They’re only treating the half they understand and not treating the whole person.”

Together, we can ensure that from education to engagement to enrollment to participation and, ultimately, to research dissemination and health care service delivery, LGBTQ+ people are seen and served as whole people by the *All of Us* Research Program.