

Community Listening Session Summary Report

Sacramento, California at Golden Rule Services, Inc. – April 26, 2018

All of Us Research Program National Sexual and Gender Minority Engagement Network

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Background

The All of Us National Sexual and Gender Minority (SGM) Engagement Network (the Network) (staffed by San Francisco General Hospital Foundation) is charged with ensuring that LGBTQ perspectives are included in the [All of Us Research Program](#) (AoURP). The Network is conducting Community Listening Sessions (CLS) around the country in order to understand what SGM people think about:

1. the health of their communities
2. participating in health research, in general
3. the best ways to get and share health information

We will use this information to help us educate SGM communities (we also use the term LGBTQ communities) about this opportunity and motivate them to participate in AoURP.

Planning and Outreach

We collaborated with Community Partner Consortium (CPC) members Golden Rules Services, Inc. and the Sacramento LGBT Community Center to conduct an in-person Community Listening Session (CLS) with LGBTQ-identified community members who reside in the greater Sacramento area and are over 18 years of age. Together, we developed a registration form and refined questions. Our partner, Golden Rule Services, offered to use their community room as a venue for April 26, 2018 from 5pm to 8pm local time and arranged for refreshments (no federal funds were used to purchase food). The session was audio recorded, but no individuals were identified by name. Nineteen (19) people were screened for eligibility via Qualtrics and invited to attend the session.

Attendees

The session was facilitated by Clarmundo Sullivan (Golden Rule Services) and Chris Packey (Sacramento LGBT Community Center). Nine individuals attended on the day of the session. Five (5) attendees identified as Black or African American, 4 as White, 3 as Hispanic. See Appendix A below for information on sexual orientation and gender identity. Forty-four percent of attendees (n=4) had participated in a health research study before.

Key Findings (attendee quotes are italicized)

The recordings were transcribed and reviewed for themes which are summarized below.

Community health concerns:

- Trans exclusion and lack of competent care: *...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 healthcare...now they’re [the federal government] trying to roll back all the healthcare provisions for trans people*
- Stigma and discrimination within healthcare settings: *...going to see a physician. They’re sometimes disrespectful to the patients because of their community, because there’s still*

discrimination out there...good professionals really understand and do their job how they're supposed to do it. The bad professionals, they do their job, but it's sloppy.

- Providers focus on HIV and/or sexual behavior instead of whole person: *...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.*
- Lack of competent care and cultural humility: *...you should be able to go to any doctor and have the service that you need...it shouldn't be like, I have to travel to X, Y, Z, to get the care that I need...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.*
- Lack of mental health care and resources: *...mental health resources are really the number one issue...that we really need to address that touches all of our health issues.*
- Unaddressed trauma: *...sometimes, you know, when you have a traumatic incident you need good healthcare for mental health...you may have a professional who thinks they're doing their job right...but they don't address it with the whole service, so that you have this traumatic event that happened to you and now you have a professional who's not addressing it properly. That adds to the stress.
 ...to kind of piggy back on that, it's kind of like you're getting half service. They're only treating the half they understand and not treating the whole person so you can be whole.*
- Substance abuse and stigma within healthcare settings: *...if you are using drugs, you are easily the most discriminated against person in any healthcare setting, anywhere in this country.*
- Lack of discussions around sexual assault and intimate partner violence: *...it's not rape when men get raped. It's just – it just happened...being able to give that therapy, that education that rape is any unwanted touch...and it's okay to report it, it's okay to speak out and speak in truth.*

Community health solutions:

- Focus on the whole person: *Health is general wellbeing, whether it's mental, physical, emotional.
 Health is a good balance between looking at like someone said ...spiritual, physical, mental health. I would add spiritual into it as well.*
- Focus on community empowerment: *I think that our community is really strong with getting the word out, whether it be gay, or bisexual, black and Latino...there's a lot of organizations trying to get information out and reach everywhere...
 I look at our community here as a very engaged community of professionals and volunteers who are very interested in issues of health with homeless people, LGBTQ youth, gay seniors...*
- Provider training on competent care and cultural humility: *I feel like they slip in these areas because they are not informed on the protocol. They're not aware of what is needed for trans care or what is needed for HIV care, or they don't want to evolve to get the information...if they're bringing healthcare, it should be more tailored to each individual's needs.*

- Offer navigation services for accessing health care: *...a big part of our job is healthcare navigating ... helping them learn how to navigate, how to go to the insurance company. I find navigation, being able to find where I need to go and how I need to go, and who I need to go to, is going to be the best thing for me...I get lost easily, so it helps.*
- Challenge health providers and systems to provide adequate care: *I think we have to take our medical professionals off the pedestal and treat them as we do anybody who works for us. You wouldn't tolerate that treatment from any contractor you hire to come in and work on your house, would you?*
- Meaningful participation of LGBTQ individuals on advisory boards/committees: *...every hospital has like a community advisory board, and I don't know how many of them have any LGBT people sitting on them. I know there's people in this room that might be good for that...joining these things might help the community at large.*

Participating in research:

- Use results for policy change/advocacy: *I think using any information obtained to affect policy, to affect laws, to affect changes in our medical system, in our advisory capacity is going to be the biggest thing. It's really [about] getting the information to who matters.*
- Address privacy concerns: *Is the information going to be protected and kept confidential...unless that's communicated to people and they feel like they can share the information and not have it spread all over the place, we're probably not going to want to share it.*
- Do not misconstrue results or use them against community: *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.*
- Be mindful of the history of LGBT exclusion and exploitation: *...they can only research the information that's put in front of them, or the questions 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.*
- Competing priorities and lack of immediate results can affect participation: *...research for a lot of people can be frustrating because there's no end, and in most cases, all of us deal with immediate issues and we want some resolution and we ain't seeing it, you know?*

Trusted information sources:

- Family and peers: *I think some of it also comes from not wanting to deal with healthcare professionals...it's a fear of, once again, not being properly serviced. So, I will go somewhere where I can at least trust the person, even if the information is wrong.*
- Trusted Community Based Organizations: *I would go to one of our LGBTQ services such as the Community Center or Golden Rule Services to see if maybe one of those organization has a specific place for me to get help.*

Conclusions

The people gathered in this session are concerned about being a “half-served” community where many individuals are dealing with the effects of unaddressed trauma from intimate partner violence, sexual assault, and need resources to address their mental and emotional health. They see treating mental health as an important first step to improving individual and community health. They identified insurance access, patient navigation, and required cultural humility training for providers as important solutions to addressing health in the LGBTQ community. Many had experience participating in health research both as participants and program staff and expressed concerns about being exploited as a community by researchers and having research results misconstrued in ways that had negative impacts on the community. They also identified strong trust in family and peers and local LGBTQ serving organizations when receiving and sharing health information.

Appendix: Attendee Sexual Orientation and Gender Identities

Table 1: Sexual Orientation Categories

What is your current sexual orientation? Select all that apply.

Sexual Orientation Categories	Number of Individuals (n=9)
Bisexual	2
Gay	6
Lesbian, Pansexual	1
Total	9

Table 2: Gender Identities

What is your current gender identity? Select all that apply

Current Gender Identity	Number of Individuals (n=9)
Another gender identity: Gender Neutral	1
Man	6
Transgender woman (male-to-female)	1
Transgender woman (male-to-female), Woman	1
Total	9