CLICK HERE FOR PART 2

CLICK HERE FOR PART 3

Los Angeles County Commission on HIV

Community Listening Sessions Report Part 1: Undocumented Individuals, Women of Color, Aging/Older Adults, and Service Planning Area 1 (Lancaster/Antelope Valley)

This report is a collaborative effort of the:
Los Angeles County Commission on HIV
Division of HIV and STD Programs, Department of Public Health
NCLR/ California State University Long Beach (CSULB) Center for Latino Community Health, Evaluation, and Leadership Training

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Overview

The NCLR/CSULB Center for Latino Community Health, Evaluation and Leadership Training staff conducted four focus groups with various target audiences (undocumented, women of color, aging/older adults, and service planning area 1) to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Methodology

Recruitment

All focus group target recruitment was coordinated by the Los Angeles County Commission on HIV. All groups were scheduled and implemented within a one-month period in Spring 2016 in different locations in Los Angeles County.

Instruments

Consent forms and demographic surveys were developed by the Los Angeles County Commission on HIV and provided to the NCLR/CSULB Center Evaluation Team to administer prior to the focus group (Appendix A). The Los Angeles County Commission on HIV Team developed the focus group guide, and survey questions. The NCLR/CSULB Center Evaluation Team provided translation of the survey into Spanish. Focus group questions were designed in order to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Focus Group Facilitation

Each focus group was moderated by experienced and trained bilingual NCLR/CSULB Center evaluation staff who are certified in the protection of research subjects' rights. Focus group participants were greeted, thanked for their participation, engaged in informed consent procedures by the moderator and note taker(s), and all provided written and verbal agreement to participate in the focus group discussions. Each focus group was digitally recorded and each session lasted approximately 90 minutes. The digital recording was sent to a transcription service, which typed up and translated the discussion when needed. The English transcriptions were provided to the NCLR/CSULB Center staff for analysis.

Analysis

The survey data was entered, cleaned and analyzed by NCLR/CSULB Center staff using Statistical Program for the Social Sciences (SPSS) (IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp.) for descriptive statistics.

The transcripts were coded in Dedoose (Version 7.0.23, web application for managing, analyzing, and presenting qualitative and mixed method research data (2016). Los Angeles, CA: SocioCultural Research Consultants, LLC, www.dedoose.com) by three independent coders. Using the questionnaire guide and the debriefing notes as base documents, the moderators and note-takers met

as a team to discuss potential codes and to create a preliminary codebook. New codes were added after periodic team meetings and transcripts subsequently re-reviewed for additional categories. The survey results are presented first, followed by the discussion findings.

Results

Demographic Characteristics

The CSULB Center facilitated four focus groups as part of the evaluation process for the Los Angeles County Commission on HIV. Table 1 displays the logistics of the focus group facilitation.

Table 1. Focus Group Description

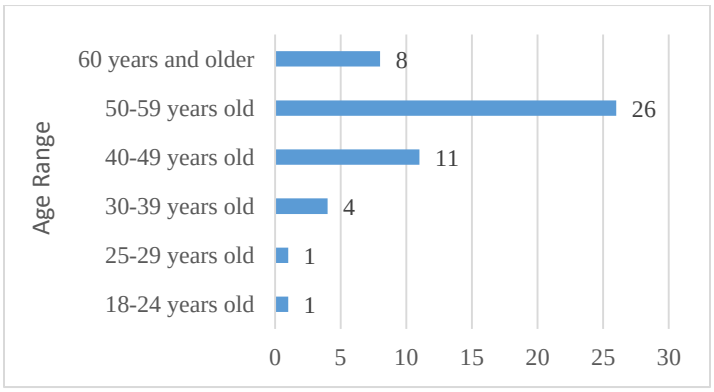
Focus Group No.	Target audience & Language of Focus Group	Date & Time of day	Location	No. of people	Moderator	Note Taker
1	Undocumented Spanish	4-Apr-16 6:00-7:30pm	Plaza de La Raza, 3540 N. Mission Rd, Los Angeles, CA 90031	14	Mara Bird, PhD	Erika Gonzalez, MA
2	Women of Color English	6-Apr-16 6:00-7:30pm	COH office, 3530 Wilshire Blvd, Suite 1140, Los Angeles, CA 90010	13	Mayra Rascon, MPH, MS	Erika Gonzalez, MA
3	Aging/Older Adults English	13-Apr-16 6:00-7:30pm	COH office, 3530 Wilshire Blvd, Suite 1140, Los Angeles, CA 90010	11	Mayra Rascon, MPH, MS	Erika Gonzalez, MA
4	Service Planning Area 1 English	2-May-16 12:30-2pm	907 West Lancaster Boulevard, Lancaster, CA 93534	17	Mara Bird, PhD	Erika Gonzalez, MA

Focus Group Demographic Results

The focus groups consisted of a total of 55 participants from Los Angeles County. Three respondents indicated that they were HIV negative and these surveys were excluded in the analysis due to the small number. However, it should be noted that a better and targeted recruitment of high-risk negatives should be considered for future projects. One person declined to answer the survey entirely; that survey was also excluded from the analysis. The results presented below therefore reflect information from 51 participants.

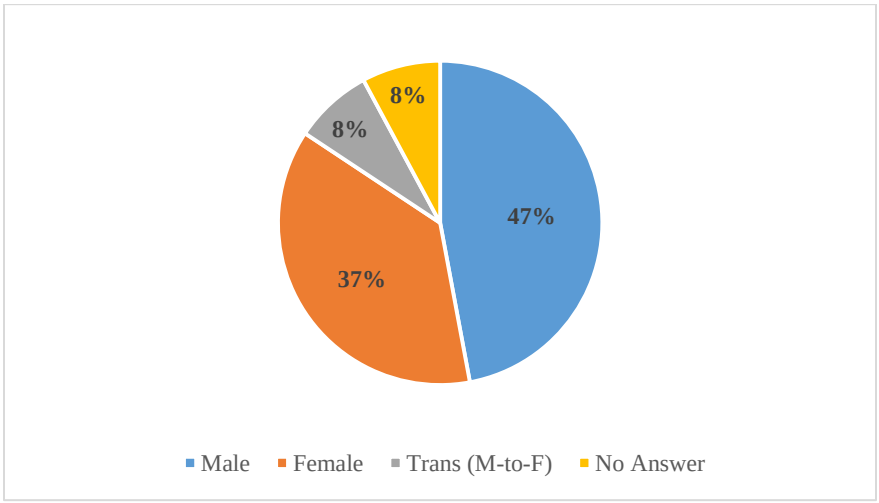
Focus group participants were primarily 50+ years old (n=34). Figure 1 displays the age range of all participants.

Figure 1: Age (n=51)



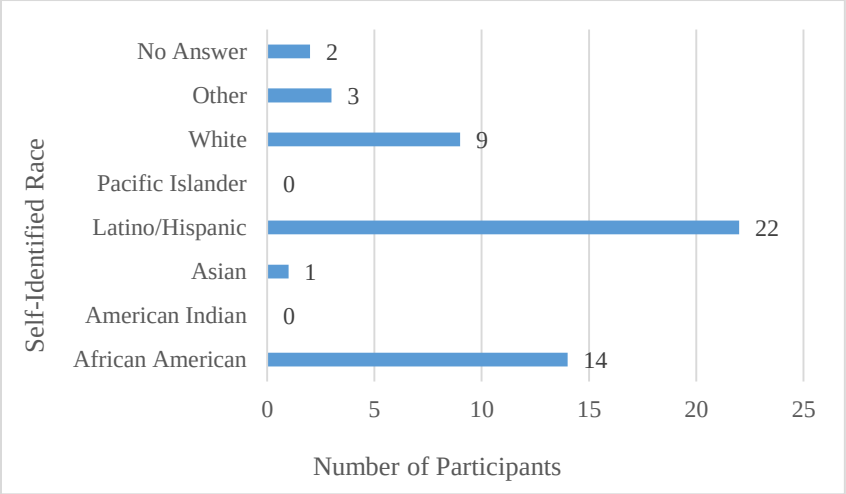
More males (47%) than females (37%) participated in the focus group. Figure 2 presents the gender of the participants.

Figure 2. Gender (n=51)



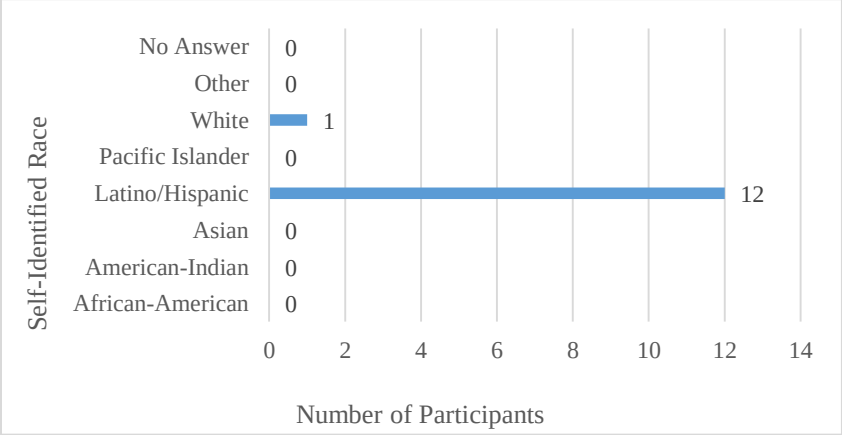
A majority of participants were Latino (n=22), followed by African-American/Black (n=14), and White (n=9). Figure 3 displays the race and/or ethnicity of all participants.

Figure 3. Race (n=51)



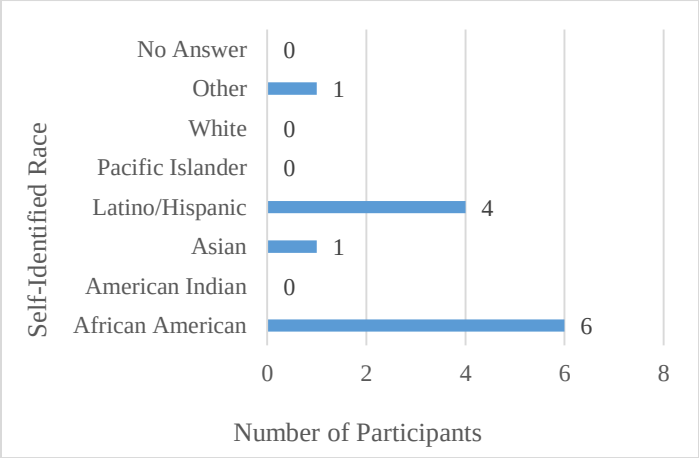
The focus group of undocumented participants (FG 1) primarily consisted of Latino/Hispanics (n=12). Figure 4 shows the breakdown of self-identification for this focus group.

Figure 4. Undocumented Focus Group Race (n=13)



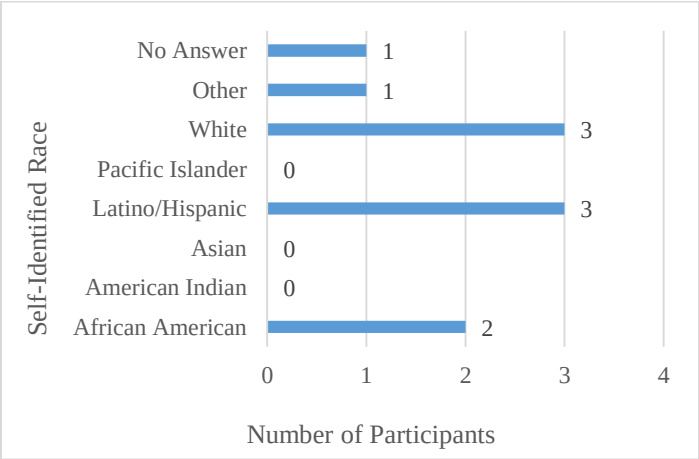
The focus group of women of color (FG 2) were primarily African-American/Black (n=6) or Latino/Hispanic (n=4). Figure 5. Displays information on all participants.

Figure 5. Woman of Color Focus Group Race (n=12)



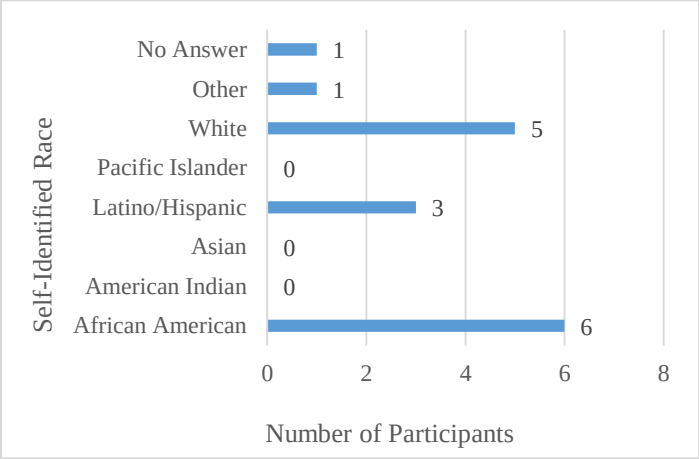
The aging/older adults focus group (FG 3) participants included those who identify as White (n=3), Latino/Hispanic (n=3), African-American/Black (n=2) and other. Figure 6 shows the complete breakdown.

Figure 6. Aging/Older Adults Focus Group (n=10)



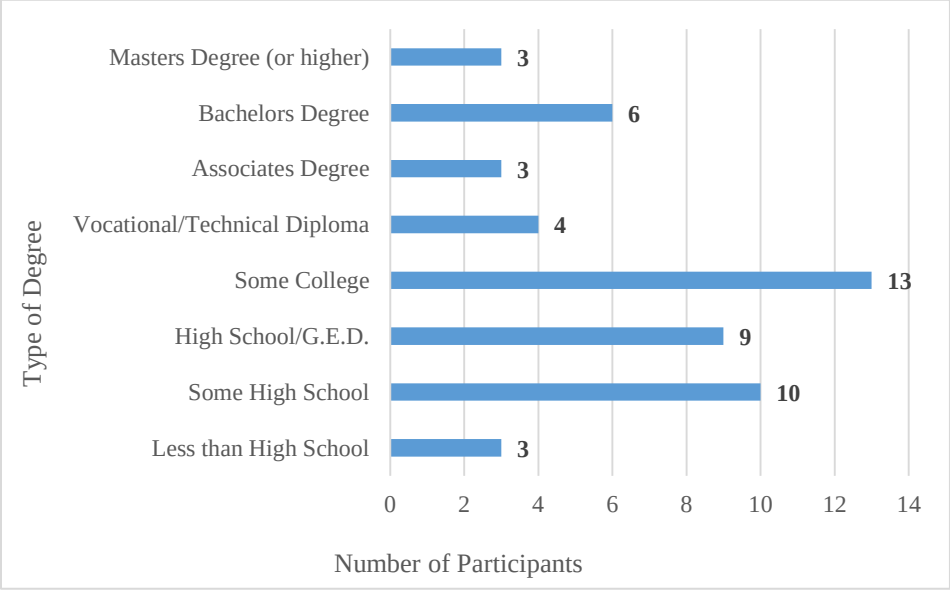
The majority of the Service Planning Area 1 focus group (FG 4) participants were African-American/Black (n=6), White (n=5), and/or Latino/Hispanic (n=3). Figure 7 displays all identifications.

Figure 7. Service Planning Focus Group (n=16)



Educational level varied with some college (n=13) being the mode, followed by some high school (n=10), and high school/GED (n=9) as the two next frequent categories. Figure 8 portrays the educational levels of the participants.

Figure 8. Participant Educational Level (n=51)

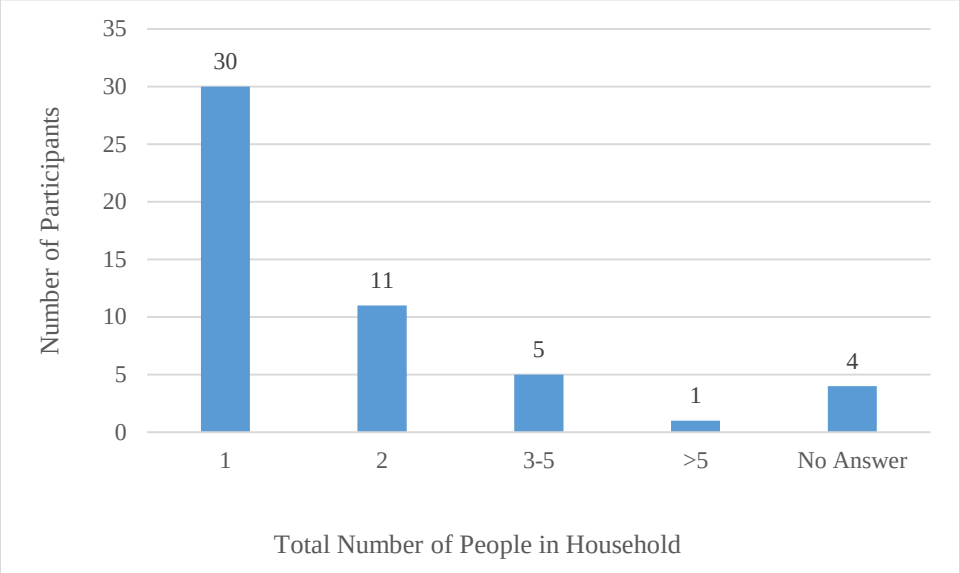


A majority of participants (n=40) earned $15,000 or less a year. Only one participant claimed that they earned more than $30,000 a year. Figure 9 displays the participant's self-reported income.

Figure 9. Participant's Income (n=51)

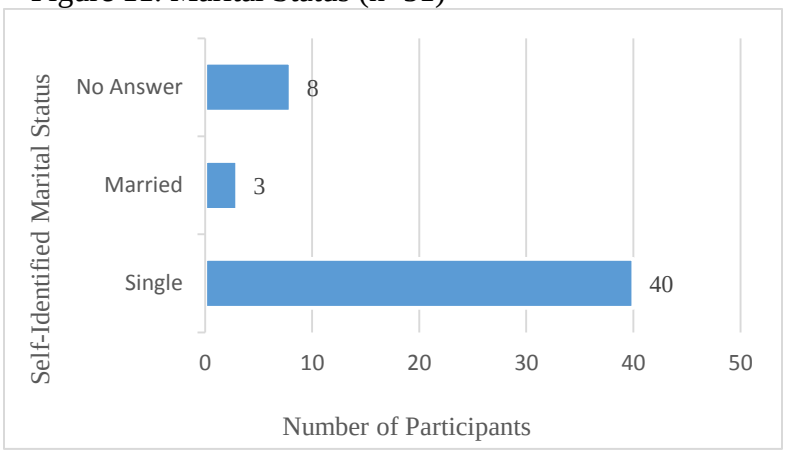
Many of the participants (n=30) lived alone. Figure 10 portrays the participants' household size.

Figure 10. Household Size (n=51)



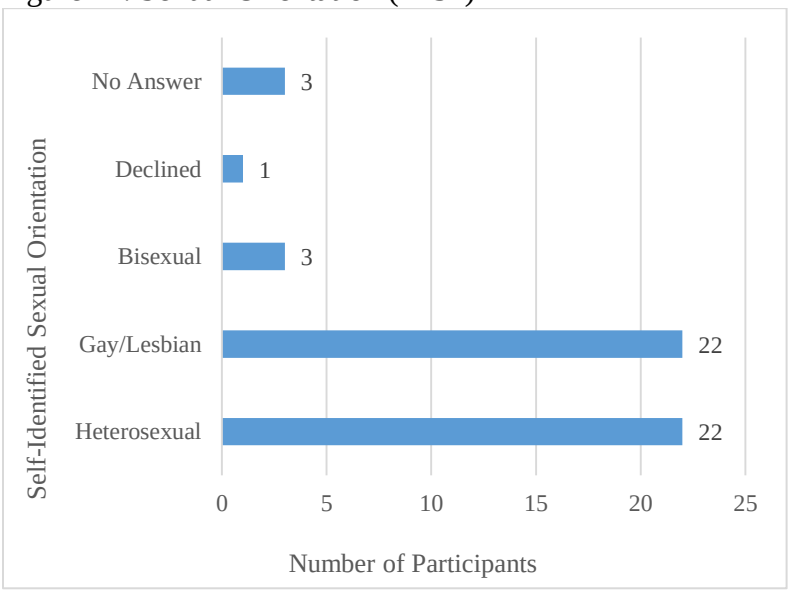
More than half of the participants were single (n=40). Figure 11 displays the marital status of the participants.

Figure 11. Marital Status (n=51)



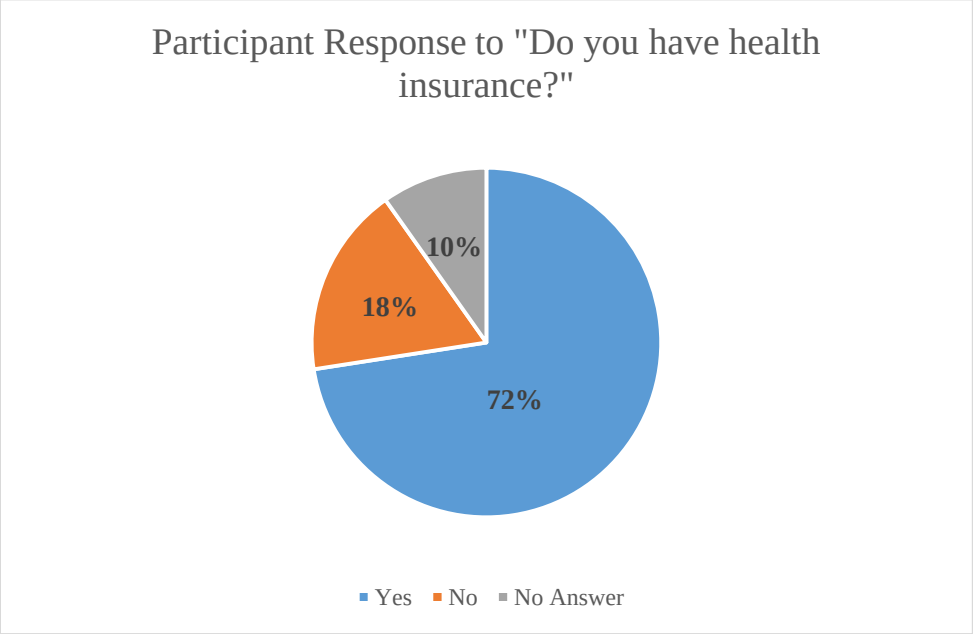
Heterosexual (n=22) and gay/lesbian (n=22) participants were both well represented. Figure 12 displays the sexual orientation categorization.

Figure 12. Sexual Orientation (n=51)



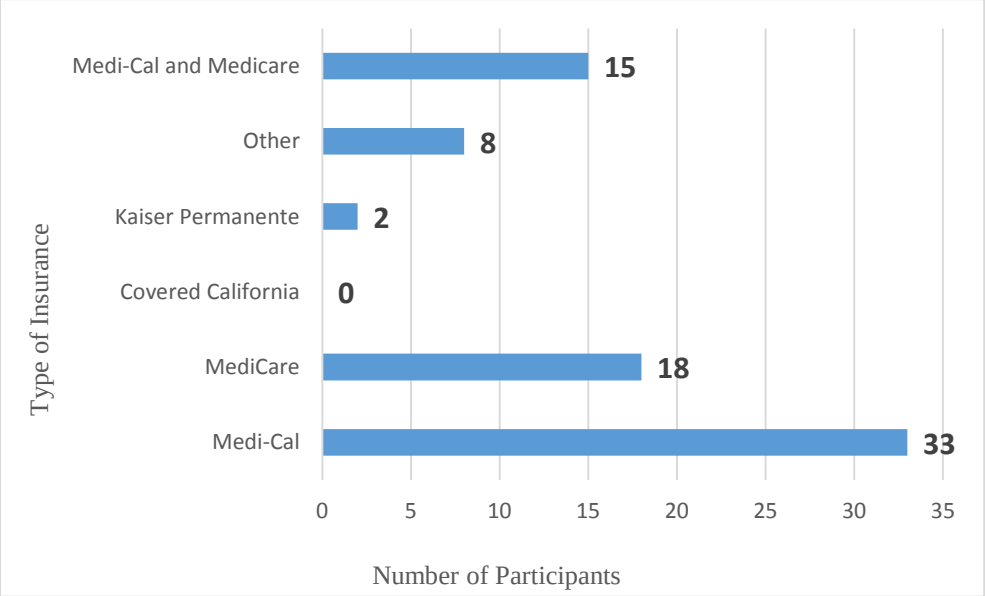
More than half of the participants (72%) have health insurance. Figure 13 portrays the health insurance status of the participants.

Figure 13. Health Insurance Status (n=51)



A majority of participants had either Medi-Cal (n=33) or MediCare (n=18). Fifteen people indicated having both Medi-Cal and MediCare. The types of insurance reported are shown in Figure 14.

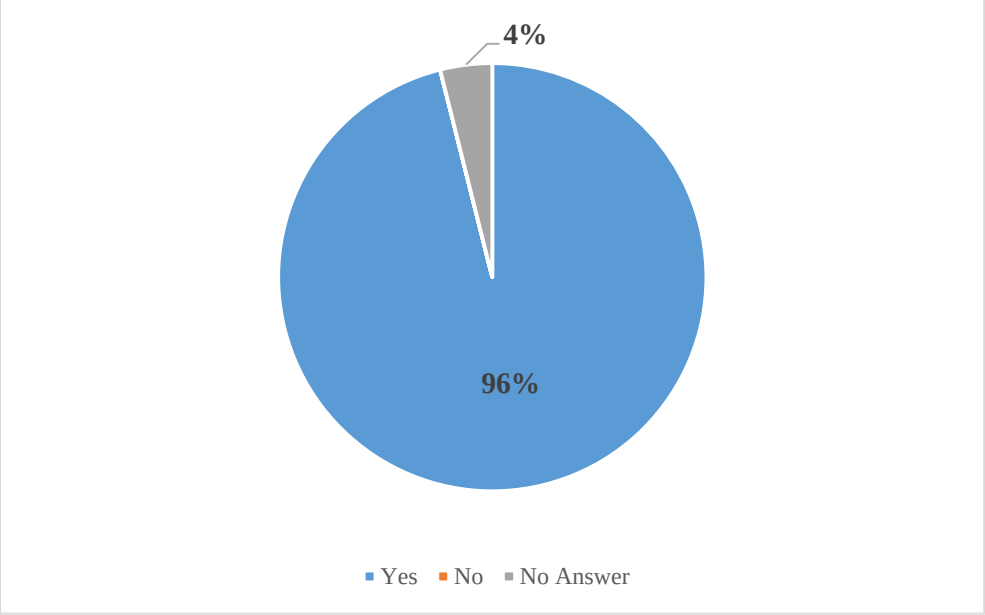
Figure 14. Types of Health Insurance (n=51)



*Note: This is a check all that apply option so total is greater than number of respondents.

Almost all (96%) participants reported having been told that they have HIV. Other respondents declined to answer. Figure 15 shows all responses for this question.

Figure 15. Participants who have been told that they have HIV (n=51)



The number of years a participant was diagnosed with HIV ranged from 41 (2%) to 2 years (2%). The average number of years living with HIV was 20.0 (SD = 10.24). Table 2 portrays the breakdown of the amount of years the participants have been diagnosed with HIV.

Table 2. Years Diagnosed with HIV (n=51)

	Frequency	Percent
2	1	2%
4	1	2%
8	3	6%
11	3	6%
12	3	6%
13	1	2%
15	2	4%
16	2	4%
17	2	4%
18	4	8%
19	2	4%
20	1	2%
22	3	6%
23	1	2%
24	3	6%
25	1	2%
26	1	2%
30	1	2%
31	1	2%
35	1	2%
36	1	2%
41	1	2%
Mean	20 (SD=10.24)	

In the undocumented focus group (FG 1), the number of years a participant was diagnosed with HIV ranged from 23 (8%) to 2 years (8%).The average number of years a participant has been diagnosed with HIV is 13.9 years (SD = 7.34). Table 3 displays the number of years a participant has been diagnosed with HIV.

Table 3. Undocumented FG – Years Diagnosed with HIV (n=13)

Years since diagnosis:	Frequency	Percent
2	1	8%
4	1	8%
8	1	8%
11	1	8%
15	1	8%
17	1	8%
18	1	8%
19	1	8%
22	1	8%
23	1	8%
No Answer	3	23%
Mean	13.9 (SD = 7.34)	

In the woman of color focus group (FG 2), the number of years a participant was diagnosed with HIV ranged from 30 years (8%) to 12 years (17%). The average number of years a participant has been diagnosed with HIV is 20.4 (SD = 6.99). Table 4 shows the number of years a participant has been diagnosed with HIV.

Table 4. Women of Color FG – Years Diagnosed with HIV (n=12)

Years since diagnosis:	Frequency	Percent
12	2	17%
16	1	8%
20	1	8%
24	2	17%
30	1	8%
No Answer	5	42%
Mean	20.4 (SD = 6.99)	

In the aging/older adults focus group (FG 3), the number of years a participant was diagnosed with HIV ranged from 35 years (10%) to 11 years (10%). The average number of years a participant has been diagnosed with HIV was 23.0 (SD = 8.14). Table 5 displays the number of years a participant has been diagnosed with HIV for that group.

Table 5. Aging/Older Adults Focus Group– Years Diagnosed with HIV (n=10)

Years since diagnosis:	Frequency	Percent
11	1	10%
18	2	20%
19	1	10%
22	1	10%
25	1	10%
31	1	10%
35	1	10%
No Answer	2	20%
Mean	23 (SD = 8.14)	

In Service Planning Area 1 focus group (FG 4), the number of years a participant was diagnosed with HIV ranged from 41 (6%) to 8 years (13%). The average number of years a participant has been diagnosed with HIV is 19.9 (SD = 9.77). Table 6 shows the number of years a participant has been diagnosed with HIV.

Table 6. Service Planning Area 1 Focus Group– Years Diagnosed with HIV (n=16)

Focus Group on 5/2/2016		
Years since diagnosis:	**Frequency**	**Percent**
8	2	13%
11	1	6%
12	1	6%
13	1	6%
15	1	6%
16	1	6%
17	1	6%
18	1	6%
22	1	6%
24	1	6%
26	1	6%
36	1	6%
41	1	6%
No Answer	2	13%
Mean	19.9 (SD = 9.77)	

The average number of services per person currently being used is 4.59. The top two services currently being used are HIV medical care (47%) and free condoms (33%). The following services tied for third place at 27% for currently usage: helping getting enrolled in health insurance, HIV prevention education, and STD prevention education.

Participant's responses to "What kind of services are you currently using now?		
Service:	**Frequency**	**Percent**
HIV medical care	24	47%
Condoms (free)	17	33%
Help getting enrolled in health insurance	14	27%
HIV prevention education	14	27%
STD prevention education	14	27%
Medical case management services	13	25%
Food bank/home-delivered meals	13	25%
HIV testing	11	22%
STD testing	11	22%
STD treatment	10	20%
Oral health services (general)	10	20%
Medical nutrition therapy	10	20%
HOPWA program services	9	18%
Mental health services (psychiatry)	7	14%
Medical transportation services	7	14%
Mental health services (psychotherapy)	6	12%
Other housing services	6	12%
Language services	5	10%
Home and community based services	4	8%
Non-medical case management (linkage case management, benefits specialty)	4	8%
Housing services (Residential Care Facility for the Chronically Ill)	4	8%
Referrals for services	4	8%
Other (Specify)	4	8%
Oral health services (specialty)	3	6%
Housing services (Transitional Residential Care Facility)	2	4%
Substance abuse treatment (residential)	2	4%
Substance abuse treatment (outpatient)	2	4%
Legal services	2	4%
PrEP (Pre-Exposure Prophylaxis)	1	2%

Outreach (linkage to and re-engagement)	1	2%
Average number of services per person		4.59
Standard deviation		4.9
Range [Min, Max]	[1, 24]	

The average number of services per person that the participants need but are having trouble accessing is 1.92. The top service that participants need but are having trouble accessing is legal services (16%). The second top two services needed (14% respectively) are medical nutrition therapy and non-medical case management (linkage case management, benefits specialty).

Participant response to "What kind of services are you currently receiving/needing but having trouble accessing/going to need soon?"	**"I need but am having trouble accessing it."**	
Service:	**Frequency**	**Percent**
Legal services	8	16%
Medical nutrition therapy	7	14%
Non-medical case management (linkage case management, benefits specialty)	7	14%
Oral health services (general)	6	12%
Medical transportation services	6	12%
HOPWA program services	6	12%
Home and community based services	5	10%
Housing services (Residential Care Facility for the Chronically Ill)	5	10%
HIV prevention education	4	8%
Oral health services (specialty)	4	8%
Mental health services (psychiatry)	4	8%
Food bank/home-delivered meals	4	8%
Other housing services	4	8%
Referrals for services	4	8%
Help getting enrolled in health insurance	3	6%
STD prevention education	3	6%
Mental health services (psychotherapy)	3	6%
Housing services (Transitional Residential Care Facility)	3	6%
PrEP (Pre-Exposure Prophylaxis)	2	4%
HIV medical care	2	4%
Medical case management services	2	4%
Substance abuse treatment (outpatient)	2	4%
Outreach (linkage to and re-engagement)	2	4%

STD testing	1	2%
Language services	1	2%
Substance abuse treatment (residential)	1	2%
Condoms (free)	0	0%
HIV testing	0	0%
STD treatment	0	0%
Other (Specify)	0	0%
Average number of services per person		1.94
Standard deviation		2.02
Range [Min, Max]	[0, 8]	

The average number of services per person that the participants will need in the next year is 0.69. The most common service that the participants reported needing in the next year is food bank/home-delivered meals (8%) followed by medical transportation services (6%).

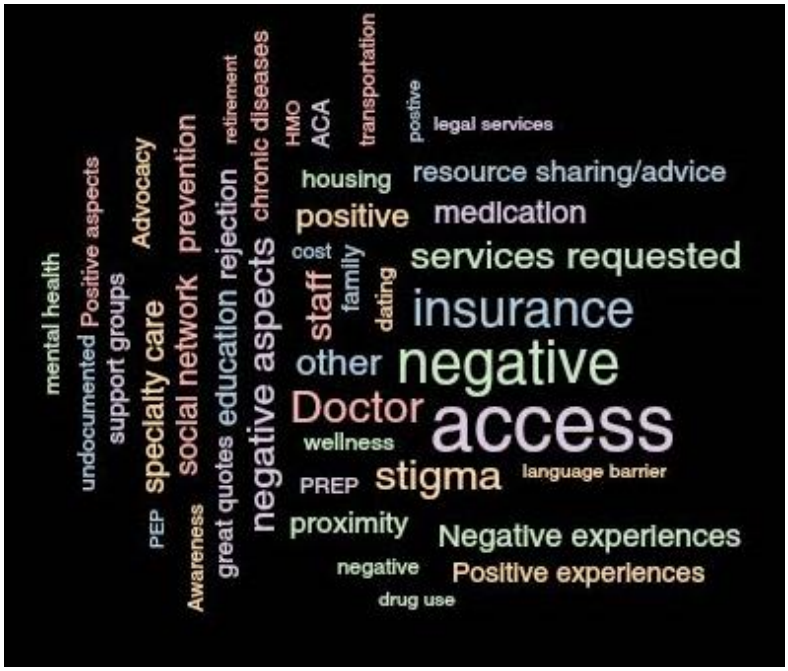
Participant response to "What kind of services are you currently receiving/needing but having trouble accessing/going to need soon?"	**"I will need in the next year."**	
Service:	**Frequency**	**Percent**
Food bank/home-delivered meals	4	8%
Medical transportation services	3	6%
PrEP (Pre-Exposure Prophylaxis)	2	4%
Oral health services (general)	2	4%
Mental health services (psychiatry)	2	4%
Housing services (Residential Care Facility for the Chronically Ill)	2	4%
Housing services (Transitional Residential Care Facility)	2	4%
HOPWA program services	2	4%
Substance abuse treatment (residential)	2	4%
Outreach (linkage to and re-engagement)	2	4%
Condoms (free)	1	2%
STD testing	1	2%
Oral health services (specialty)	1	2%
Mental health services (psychotherapy)	1	2%
Medical case management services	1	2%
Home and community based services	1	2%
Medical nutrition therapy	1	2%
Non-medical case management (linkage case management, benefits specialty)	1	2%

Other housing services	1	2%
Language services	1	2%
Substance abuse treatment (outpatient)	1	2%
Referrals for services	1	2%
Help getting enrolled in health insurance	0	0%
HIV prevention education	0	0%
STD prevention education	0	0%
HIV testing	0	0%
STD treatment	0	0%
HIV medical care	0	0%
Legal services	0	0%
Other (Specify)	0	0%
Average number of services per person		0.69
Standard deviation		0.84
Range [Min, Max]	[0, 4]	

Qualitative Findings

The two topics most central to the discussions were access to services and insurance issues, with stigma being the third theme raised most often. These are discussed in order below as well as other topics that were raised less often, but of no less import. Within each topic, the variety or range of opinions is noted.

Figure 16. Coding Frequency Word Cloud



A. Experiences Obtaining HIV Care/Services

Doctors

Participants commented frequently about their doctors, highlighting both positive and negative aspects. For many, their experiences with their doctor was a supportive one that endures over years.

> "My personal experience was excellent. I've met my doctor for 19 years and she continues to improve as a human being, really intelligent. She's studied. I'm happy with her, really." (FG1)

> "There was a doctor that lasted a long time at the clinic I go to. I felt very comfortable with her." (FG1)

For those who had negative experiences with their doctors, a chief complaint was failure to treat the whole person with all of their physical health conditions. Another common complaint was feeling treated like a lab report instead of a human being, the lack of personal connection during the visits, and the hurried pace of the visits.

> "No, he just has a note and says: "your levels are fine", but he doesn't check me up. The old doctor did check this, my mouth, this one doesn't and I don't feel comfortable with him." (FG1)

> "the doctors only want to focus on your labs. You are your labs, anything beyond that, they're not going to listen to. And so, that's my biggest issue, is they don't want to hear what it is that I have to say, how I feel with the side effects or what else is going on with me. And then that's just been a huge struggle, is just getting them to hear what I'm saying, because if it doesn't match my labs, then they're thinking I'm a liar, and that's a huge, huge problem." (FG3)

> "…when I was with my first doctor, as [name deleted] said, my first experience was snap snap snap, he wouldn't even let me explain my symptoms or how I felt; it was one patient after the other and the other. I was barely diagnosed. So that and the fact that I was getting depressed led me to stop going to him because I didn't like it." (FG1)

Doctor Turnover

Doctor turnover was an issue for some, but something seen as a normal part of life, or normal part of the medical system, for others.

> "…that depends; in my case, since they change my doctor every 2 years, out of 8 doctors I've seen, 2 are embedded in my memory because they did take the time and I felt that. They talked to me. They cared." (FG1)

Other Health Professionals

Experience with other health professionals including receptionists, social workers, emergency room staff, chronic condition specialists (non-HIV) and oral health care varied and were identified as an area for improvement.

Various participants noted that hospital and emergency room staff, professional staff who should be aware of protocols, would out the patient's status to the room at large. This was noted as a problem among participants in SPA 1 particularly because distance to specialty care requires people living with HIV to turn to emergency room services if an HIV specialty care doctor is not in the area. Nonetheless, participants from various groups mentioned it as both a historic and current issue.

> "I don't need everybody up [in my business]. You're messing with the wrong [unclear audio (U/A)] she shouldn't take you to the emergency room because I didn't come to the emergency room for you to put my business in there. I came to the emergency room for help. Next thing I know security comes." (FG4)

> "They really do do that to us. They come in and they speak on our medical issue and they ask about the viral levels, [unclear audio (U/A)] our T-Cell levels, and say you in between 2 people who you don't want to know your business. Even when you're in my hospital. They admitted you in the hospital and say get in a room with somebody. They still come in there talking loud about your medication [unclear audio (U/A)] in a hospital they don't want to touch you and don't want to breathe the same air as you." (FG1)

> "In 97, I had an opportunist disease. I got really sick. My family from Guadalajara got here; they thought I was going to die. So when I was really sick, one of my nieces asked 'Why is my uncle sick? What does he have?' the doctor said: '… he's being consumed by AIDS.' I was bedbound and didn't know what to do. But that's what he told my family; everybody found out. So I'm the one with AIDS, but I got over it in therapy. They still call me that, but it's not important anymore. I'm over it, but it was terrible to me. [U/A]. I don't have any family here, but I get support from the groups, my friends." (FG1)

Appointment Timing

Various patients mentioned the need for additional appointment time, or that the visit was too short or impersonal.

> "Going back to the original question of how can the doctor-patient relationship improve, I think they need to give us more space as patients because it's illogical that they make you wait 2 hours to see a doctor that will only see you for 20 minutes. The commute takes longer than the meeting with the doctor." (FG1)

Health Care Access

Health care access is closely linked with issues stemming from insurance company practices. Issues raised that were barriers to access included the need to go through their primary care provider first for other types of care, a diminished ability to access providers of choice (particular doctors or institutions), less services being offered (e.g. support groups or child care no longer available) or available at fewer places. Prohibitive costs for care and medications were also serious issues that often led to the inability to follow all recommended treatments.

> "I go to the Woman's House. I was going to the one that's a hospital for years and years and years. Was going to the programs there, the Wise Study, [U/A]. And now they say I can't go there no more. They won't accept me …Because once Obamacare came along, it changed everything. You can only go to your primary doctor. Because I used to go to the clinic down the street from my house and went down there. They said 'Oh no, you got to go to your primary doctor.'
> Moderator: But can't you change your primary doctor?
> …
> But I don't want to change my primary doctor, because then you got to go through the process of getting the note in, they all up in your business, just want to know what's going on, why you here and blah blah blah. So I'm staying with my doctor because they already know all this information. And I don't want my information all over, going God knows where and lost. And I don't have no problem with my doctor, I just have a problem with the receptionist, but I've got that under control. But other than that, I don't have no problem with the pharmacy." (FG2)

> "I've been in the country for a little while. It'll be 5 months, I think, so I'm just getting familiarized with the services you offer. … The only issue I've had at the services is the schedules. I know I can find other agencies that have more accessible schedules and stay open later, but why should you look for anything else instead of improving the one that's already there, nearby. I could go half across town for a meeting with a doctor, but that implies money and a ton of things. If you already have it, you should improve that service, right? So the only thing I've struggled with is that: since they close at 3:30pm, I get off at 3 and I barely make it there. But the doctor has been very accessible and cool. He waits for me and helps me. But that's the only thing that's taken some struggle." (FG1)

> "People are getting lost in care because of the fact it's strictly medical, so then who connects you to housing, I'll say [U/A], mental health, who? Social security, who tells you exactly where to go? I live in South Bay, I went all the way to West Hollywood because HIV friendly to the social security office quote-unquote 'just a place to go' but yeah, you have to just ask people that are working, some of the most old-timers have been up there for a while, you get as much information as you can from them because they're getting read, just like you said things are ready to change and I believe that county clinics are going to be the first to go." (FG2)

Accessing Health Insurance

Access to health insurance varied. Most participants had Medi-Cal or Medicare or both. Others lacked health insurance entirely, and still others had private managed care insurance or subsidized managed care health insurance through options opened after the Affordable Care Act. Participants brought up a host of positive and negative experiences with Medi-Cal and/or Medicare, but it was more positive than negative. Of note, one of the few who had private insurance (Kaiser) had a negative and stigmatizing experience.

> "I wanted to share that one of my first negative experiences when I was diagnosed 16 years ago was how they notified me that I was HIV-positive. And I don't know if the doctors have changed their procedures, but every time I go I have to, I'm employed, so I have a job and I have Kaiser Insurance. And one of the reasons I started looking for work is because I don't want to have Medi-Cal and resort to all having one doctor and when he's out of town, the treatment stops. So I got a job and I have Kaiser, but the shame and the stigma that the staff demonstrates to HIV-positive, or if you have an STD is embarrassing. Doesn't even want to make me go back to Kaiser. And I have good insurance. So I'm always complaining with the staff, you know, and those are the negative experiences that I've had in the last 16 years…. the stigma that they place on people that are HIV-positive or if you have an STD or a new STD, you know, is crazy. It doesn't make me want to go back to Kaiser, you know? …I had, because I live with syphilis as well, and so my titers were going up and they're like, 'Oh, you must have been re-infected with a new strain of syphilis.' And the nurse said: 'I don't want to see you here in this room and give you more penicillin shots. This is the bad room. And the next time I'm going to spank you.' And she was playing around, but I was like 'You don't know me to be playing around like that. You're making me feel bad that I'm having sex…'" (FG2)

Communication with providers, particularly for those participants requiring multiple providers was an issue compounded by insurance company processes. Moreover, the paperwork required by insurance companies themselves was confusing to many. Inter-provider care was a critical issue for many participants so eliminating or streamlining third party intermediaries like insurance companies might alleviate some of these problems.

> "I just need to be into one setting. I don't want to go all over town just to see about this problem that I'm having and then another problem that I'm having, and then you know what really complicates that situation? Is that either one of the doctors don't even communicate together and I can go to either of them and say 'did you get that report for the… he said he was gonna pass it over' and he says like 'What report? who is this doctor?' and then I go over to the next 'Did you pass that over to them?' 'Oh, well, what doctor was that?'" (FG3)

> "… you get a form in the mail, and says: 'L.A. Healthcare something', and you're like: 'who are they?' and then you call the number, and then they say a different name on the phone,

and you say, you ask them: 'Are you part of Medicare?', 'No, we're part of…' 'Is that part of Medi-Cal?', 'No.' 'Is that part of Care First?' which is my health insurance, 'No'. And then it's like, and then, okay, you're not part of anything that I'm part of, so where do I go from here? And that's, for me, where it gets to the point of, how do you function? How do you get anything solved when the people you're getting letters from don't even know? They don't know what letters are about, first of all, you don't know who they are, there's so many things, levels, of bureaucracy and everything, you are behind all these forms that you get, it's maddening." (FG3)

"… the paperwork is astoundingly uninformative, this piece of paper, and once… it says it's talking about A, but it's really talking about Z, and then wanting to do D, and you call to find out what's going on, and then you get someone who's an answering service to forward the call and no one has anything and I'm one of the most persistent people in… my therapist says I'm at the top of the list, and if I'm frustrated and having an issue, I can't even imagine how difficult it could be with someone dealing with this who, does not have the time, or gets tired and fed up"(FG3)

Transportation and Proximity

Transportation and proximity were two related issues that arose. In terms of location, transportation was particularly difficult for SPA 1 residents as they were farther from services, and had limited access to specialists. Many had moved to SPA 1 for availability and affordability of adequate housing. When referred to services at various locations, access to transportation coupled with the time needed to travel across town as well as office hours for services became compounded issues. The extra time required for accessing services as disparate distant locations also conflicted with work schedules for some.

"My problem is the whole transportation issue because I live off the grid, in the mountains, and I have to drive 39 miles to get medical care when I have a high desert clinic 13 minutes away from me, but they don't have a … specialist that specializes on HIV. So I have to drive 39 miles just to get care. And before I even had a car, I used to have to sit at my boyfriend's auto body shop all day because I would have to ride with him down into town just to go see the doctor in Cedar Hills and he would shop in Lancaster. And the bus, I have to call and set up an appointment and that's like 18 miles walking across the desert just to get to that bus stop where they pick me up at. So my issue is transportation and they also have a whole bunch of people who live that way in my area, and the van don't go that far. And if they don't have transportation, no family support or no outside support that can give them a ride to take them halfway to meet that van, they won't get into care." (FG4)

"right now I'm seeing like two doctors, and I really don't care for either one of them, you know. I don't know, because I need to be where I can be in one facility getting everything done, you know. Instead I'm still running to this doctor way across town, the other one back down in Georgia [U/A] you know, I'm just tired of that type of runaround." (FG3)

"but for my doctors and everything, it doesn't matter how long it takes me to go back to L.A. [from SPA 1], but I would never change that because I have everything in the same spot." (FG4)

Availability of Specialty Care

As those living with HIV age, they are faced with multiple chronic conditions. Coordinated care and treatment of all conditions becomes more critical. Therefore, there is a need not only for specialty care but coordinated specialty care. Other participants commented on the perception that the availability of HIV specialty care is declining, resulting in shorter visits, more patients per doctor, and less days/time available.

"So what I would suggest is for them to give us more time to know what other needs or concerns we have besides HIV, because it's not used HIV, but HIV-related stuff. Not only HIV affects you, but other things. For example, in my case, since you've passed this age, you need these studies. And unless you ask for those, they won't offer them to you. I noticed that because I read, I stay informed, 'hey doctor, because of my age, I think I qualify for this.' 'Oh, that's true. Yes. I'll order them.' I don't have to tell him; he needs to tell me. He's the expert, you know what I mean?" (FG1)

"being in my 50s and growing older, which is great, but I have an easier time with getting my HIV dealt with than getting a colonoscopy….then on top of that, you got other things that are either amplified with HIV or 'oh, you're more prevalent for' [U/A] things like that; teeth issues." (FG3)

Medication Coordination

Coordination of medication across specialists for different types of conditions was also mentioned. Other medication issues included side effects (short and long-term); lack of knowledge among providers, users and their social support caretakers; cost; and long-term impacts such as oral health issues.

"We just have a doctor, an HIV doctor once a week. If we get sick, we go to the emergency room. I go to emergency many times, but they just give me like a [U/A] they charge for everything we access right here, they just want us for the money. We don't have another HIV doctor, … you go to the hospital and each time they use a medication that has nothing to do with your body because you take HIV medication and there's a difference, it doesn't work with that…" (FG4)

"when you take a medicine and let's say you have a chronic disease and I'm not talking about HIV 'cause chronic can be kidney or in testicle, it will tell you on the prescription "do not take this medicine", well, why do the doctor give it to you?" (FG3)

"wondering what, okay 'I'm walking and I'm slipping, am I gonna break something?' and then it's gonna be 'is the healing going to be compounded by…Or, if that's adding you can't

take this medication because that will harm your healing'. So, doing that juggle and having someone who understands that and can explain it both to yourself and family who want to help but don't know what they're doing." (FG3)

"medication is really horrible, it really is. It gives you more problems just having HIV, you are beginning an experience other things….You should be able to take your medication without having to go through another trauma." (FG3)

Language Barriers

This issue was only brought up in the Spanish language group, but was a prevalent topic within that discussion. Many of the participants felt that they were less connected to their doctor and other health care staff when a language barrier existed. There was no specific question that asked about language barriers; however, this topic was broached in response to the question about how it has been receiving HIV related services and care. One participant mentioned the language barrier as in response to advice from a fellow participant of how to advocate for himself with a doctor.

"He doesn't speak Spanish. They always set up an interpreter for him. So, another issue, I prefer to have a doctor that speaks Spanish, but they don't have one now." (FG1)

The group also seemed to feel that having translators over the phone was not as effective as having another human being that spoke their language in the room with the doctor and during their time receiving health care.

"That's what we need sometimes at the clinics because there are some doctors that don't speak Spanish and sometimes their assistants don't either. That's what we need the most: to have interpreters next to the doctors. Sometimes there's none." (FG1)

Cost

The cost of multiple medicines was too high, leading to a forced choice between the recommended medication for some. Even with insurance, co-payments were very high, particularly for dental services.

"…When I get there they're like 'Ok, yeah, we take your insurance, but it's going to cost you like almost $2,000, $900 for this, and this for that,' and I was like why do you guys pay for, then? I thought you guys took my insurance." (FG2)

"I'm on Medicare! But I'm only allowed 6 prescriptions to be filled a month and after that they get to tell you, you got to do [U/A] and like, I'm not supposed to be without heart medication. When they told me I had to [U/A], it's when you have went over your limit on your medication and they have to get in contact with [U/A] to see if they can see if you really needed it, they are approved to get." (FG4)

B. How Affected by HIV Status

Stigma

Stigma and rejection related to HIV status continue to be very prevalent. Stigma is experienced in all settings: when accessing health care services, in the workplace, among romantic relationships, among the general public.

With respect to the health care setting, stigma was mentioned. In particular, many mentioned that the way they found out about their diagnosis and subsequent treatment was very stigmatizing. While for most the diagnosis was long ago, the comments were articulated with a pain that is still raw.

> "Just wanted to add one thing: a lot of the connections to the county hospitals, the diverse frustration of the wait time, the frustrations of how they're treating you, like they're going to put you in a contagious infectious ward, put on masks and curtains and everything. It's just a different treatment." (FG2)

Participants across groups mentioned comments from health care providers inferring denial of care due to HIV status, including oral health care, fertility treatment and kidney transplant needs.

> "it was 2014, I was going through infertility because I was diagnosed with PCOS, Polycystic Ovarian Syndrome, where it was hard for me to ovulate, so I needed assistance in getting pregnant. So my doctor referred me to the reproductive endocrinologist and they did all the workups, they did the labs, I went through all these procedures, [U/A] and all this stuff, so when they gave me the results, they went, 'oh, you know you're HIV positive?' I'm like 'yeah, I know I'm HIV positive!' … So I did all these workups for months and when it was time to do the actual insemination, because I had to do intrauterine insemination, and when it was time for my appointment to do that insemination, then people called me and said: 'we can no longer assist you because we don't have a donor [U/A] in this facility.' And I literally went, I lost it. I was in the mental hospital 5 times after that."(FG4)

Many experienced stigma from the general public, both past and present, leading many to self-isolate and also prompting participants to request general information or campaigns about HIV for the public. Stigma from the general public ranged from verbal abuse to direct interpersonal violence or attempts to evict neighbors.

> "I've been positive for 18 years and I asked this guy for a light so I could light my cigarette, it was him and his girlfriend. She said, 'No, you got AIDS!' and she spat at me! And I had to stand back. You know, because I have sciatica, because I got all these neurological problems I'm not like I used to be. Would I be able to knock her out or would she knocked me out? So I stepped back, took a deep breath and said, 'Lord, get me around this corner,' you know? And I'll be ok. That's the first time that I've ever, ever experienced that and I'm not

ashamed that I'm HIV-positive, because I was a national speaker, but this, the way it is, it was like what? This has never happened to me before, you know? And what do you do with a situation like that? This was in Lancaster. Downtown Lancaster." (FG4)

"I was discriminated so badly because [U/A] he said to me: 'no, no, no, no, that's for seniors,' he said. 'If I do your haircut, that's one more problem to us.' Meaning [U/A] It made me feel so bad." (FG4)

"We need to have more resources not just for us but for the general public. Where do you find HIV 101 course?" (FG4)

"I have to be careful even in what kind of details I use, we are in 2016, like what's going to happen if I use your plate. So what we need in here is more education, [and] more [support] groups." (FG4)

Family or Social Network

Family support for participants included the spectrum from highly supportive (e.g. providing housing, on-going care) to extremely ostracizing (e.g. taking legal action to prevent interaction with grandchildren due to HIV status). For those for whom family was supportive, the family unit was the primary source of care and needed support services for the participant. For those for whom family members were not supportive, close social or friend networks filled that role. Those without either type of social support were more likely to be homeless and have greater support needs overall.

"but worst of all is my family. My family doesn't let me come over their house. My family doesn't let me see, a couple of them, I got a couple of grandkids. I don't get to see, talk, speak, or anything with my grandkids. That's the worst of it all. That's what really cut me deep … To see your own family get in cahoots with Children Services to figure out a way to write it up to where I'm helpless to my own damn grandkids." (FG4)

"my family raped me and now it turns out I'm an HIV positive. They helped me on the first, the first time I'd been to a hospital. … because I had a severe fungus in my blood, instead of HIV. And also, they were fine with me, but after that they said, 'Okay, you need to find a place', then my brother, my older brother, he told me, 'You can consider yourself homeless, you're not going to be [U/A]', so that was the rejection from my family." (FG3)

"I've created a number of, what I call "safety nets", of, if such and such happens, then, if you don't hear for me within, if you call me, if you don't hear from me within two days, call me again, then there's a problem, or something happened, or whatever. Or with doctors, if this happens, I've created my own little domino effect, because I know if there is a problem, I live alone, I make sure friends and family… who has keys to the apartment? Who has…? Here's where I keep papers and everything that you will need. Here's that stuff. So I've

created that safety net and one time I was hospitalized and my safety nets all clicked into place and the social worker of the house was like: "Oh my god, how does this happen?", I was like, 'Yeah. It's worked. Thank God.' (FG3)

"A month after my diagnosis I had told my family; I laid my cards to see if I was accepted or rejected. Thanks to my conversation with my family, I spoke to my friends the next day. They all accepted me, just like you. I have a lot of support from my family and friends. That's what helps you grow emotionally and to work for others who can't face it."(FG1)

Dating/ Significant Others/ Social Relationships

While there were some positive stories, rejection was a prevalent fear and reality, for both the general public interaction as well as more romantic, personal or intimate relationships. Personal strategies for facing this reality varied from celibacy to isolation, to full disclosure prior via on-line social dating sites, to "don't tell if not asked."

"I'm celibate too because at this point, living in Lancaster, they have broken some of my spirit that I had before. I just can't tell people like I used to." (FG4).

"I want to meet somebody and I want to date somebody that's positive so we have that shared experience so then if we know that we decide to be in a monogamous, exclusive relationship and we both consult with our doctors and we want to make that decision to not use condoms, well then I know he's positive and I'm positive even though that's probably not, the medical community might not agree to it, but it's between two mutual consenting adults and whatever him and I want to do in the privacy of our bedroom is our business." (FG2)

"there's a website online where you can meet other positive people called PositiveSignals.com, right? And I met some boyfriends that way." (FG2)

"MODERATOR: What are the specific methods that you used to protect yourself and your wife?
MALE SPEAKER: Well, I use a condom. I mean, that's all there is. I have a drug that I know that won't get her pregnant because that's the latest, the best drug that's out today in today's market, but still, I'm not willing to go rough-ride, to say."(FG3)

"Well, you know, I was about honesty, I'm not going, if I'd be honest, [U/A]. I ain't never getting none. So, I just started saying, "Well, they ask you no questions, I take you no asks", and that's how bad that was. If you don't ask me, I'm not going to tell you. But if you ask me, I'll tell you. "But always use safe sex", but I'm not going to just put that disclosure out because of the rejection." (FG3)

Disclosure

Disclosure of status varied by participants with many preferring to keep that information to a trusted few, but other public advocates. Some mentioned fear of violence, while others were sometimes hesitant to even check off a box on a form about status, given that the form could be seen by multiple others.

> "We're afraid to be exposed to the society [U/A] people in our neighborhoods, it's very dangerous, they can do harm to us." (FG4)

> "…when you go and apply for stuff now they have that word on the form, you have to fill out an application. Like, I went to [U/A] foundation and every year I'm in the dental plan but every year I have to fill out a questionnaire and you know, they have HIV up there that's as big as day, and I'm like "Wow, I remember when you didn't see HIV on an application, you know? But since my dentist, she already knows I have it, you know, because I didn't hide it. I told her I had it and so when I had to fill the paper out I don't have a problem with it now, but in the beginning it bothered me."(FG2)

C. Overall Education and Awareness about HIV and Services Available

Education

Education for the general public, family, friends, and allied health professionals was recommended most often in efforts to reduce stigma in and outside of the health care sector. Many participants expressed their frustration about the continued lack of education, especially after years from the early cases of HIV in the 1980s and 90s. Some participants commented on their struggles to educate others and the general public's lack of understanding about how the virus is transmitted. The need for education was also referenced as a form of prevention.

> "People get sick, and like the lady said, you know, they're isolated, they don't know who's positive and then if you do tell somebody you're positive, it's the education [U/A], the people right here, they ostracize you. How can you live in a place? That happened in early 80s and 90s, people was doing that. Here it's 2016 and people still doing that because they're not educated." (FG4)

> "but the biggest thing, it's like we're in a country on an island, all here by ourselves. People have absolutely no education and it's before even medication came around. Even though this is still Los Angeles County, is like there's another country. And that education aspect, these doctors how who do DDS, do and done shit, not understanding or treating you like a plague of some sort that's airborne, they need to be educated and they need to be reprimanded for their behavior. So we do need to stick up for ourselves in that aspect. I've never experienced that but we need to start writing them up as doctors. And knowing that we have that option because it's not just here that that's happening. My ex-husband's friend was getting ready to get surgery and he told her about my status, I told him: 'Once I tell you, whoever you feel

you need to tell I don't care, because I want you to be healthy and I want you to get the support that you need. I can't give that to you because it's me.' The doctor, the surgeon told her to stay away from him because you never know how that disease is spread." (FG4)

"MODERATOR: So, going along, kind of with this topic, how do you protect yourself and others from HIV?
FEMALE SPEAKER 1: Educate them.
FEMALE SPEAKER 3: Educate them, yeah." (FG2)

"Yes, they are. I have had to explain it- I do not have AIDS. I have HIV. Then you got to sit and explain and after a while it's like, 'forget it.'" (FG2)

Advocacy

Many participants identified themselves as being their own advocates and advocating for the services they needed and wanted. However, they also referenced the importance of having other individuals, whether it be their health care provider or a relative/friend, as advocates, especially when they are not feeling well.

"I just have to advocate for that myself. I mean, seriously advocate. Kind of like, I wouldn't say demand, but show a reason why this is necessary all the way up to the director. And then the director to the other dentist in order for me to get the proper service." (FG4)

"What you just said, I'm like yourself in the sense of, you know, I rather navigate it myself. But, if you're sick, if you're not feeling good, if you have no energy or if you're having side effects, or you're dealing with anything, even if all you have to do is sign this piece of paper, and continue your medical insurance, you can't even deal with that, you know? So it sits there. And when you're at that stage, you've lost everything because you didn't even sign that piece of paper and mail it in on time, and nobody can understand that because you're the only one, you know, besides dealing with everything else, so, yeah, when I can navigate things by myself and be a voice for myself, I have no problem. But, when I have those days, that, you know, I can't even get out of bed, or I can't focus, or I can't see, or, you know, blah, blah, blah, then it's difficult, then I have to ask for help, you know? And a lot of times people don't have time to help you, you know?" (FG3)

Resource Sharing

More information about services available was recommended. Participants noted that current advertisement of services was ineffective, and that many were unfamiliar with the diversity of resources available. If patients were more familiar with services, they were more likely to access them and share the information with others. Participants were also particularly keen on sharing information about resources with each other. An example of resource sharing within the focus groups is included.

"They have them here, I think just their resources and their advertising is real bad the way they advertise their services, they don't know how to advertise their services. I just

want to talk to the supervisor and say, 'Y'all need help. Y'all don't know how to advocate and give us these resources, let us know these resources are available.'" (FG4)

"So, when I'm newly diagnosed there's always somebody that had called somebody to find out and if they can get through this, they can get through this. I don't speak Spanish but I understand a little bit and, you know, when I now know of my sisters who do speak Spanish to say 'well, wait a minute, I got somebody for you'." (FG2)

"Yes, I wanted to ask you is that Weight Watchers program free? Because I had weight loss surgery.
Female Speaker: It's free, it's free. I'll give you the resources, I'll give you the lady's number. Another thing, I want to let you guys know that they have a camp for people living with HIV, it's called '[U/A] the journey' and if you guys want to go, I can…it's in June for 5 days, it's health and wellness." (FG4)

D. Other Issues Raised

Housing

Access to housing was a critical issue raised by the participants without being asked directly about it. Some participants were homeless, and most lived in crowded housing conditions. Those with families on Section 8 housing mentioned lack of private space household members. Housing was seen as a precarious issue so if one had adequate housing, maintaining that was primary over access to near-by specialty services.

"There's something that wasn't mentioned and it's important: housing. It's terrible for those who are HIV positive and undocumented. That's where we need more support. I've been looking for an accessible place to live for years and the agencies haven't been able to help me either. When they say they do, they ask for my earnings and say I need to make more. If I earned more, I wouldn't be looking for housing assistance. It's illogical really and it's quite frustrating to be in a situation like this. I think the priority here is that HIV services have advanced a lot, there are a lot of services, housing is missing." (FG1)

"I've been on disability since '08, I've been having so many problems with housing and being able to pay for it because only get $900 [U/A] pay your insurance, your car, food, it's like if you're in social security, I think you should get housing vouchers. It should go hand in hand." (FG4)

"I came back to L.A., the center put me on medicines immediately, that was on 2007 and I was homeless. I got into Section 8. That took me, for the first available housing I could find, which was then across the board in Oregon. So, I moved to Oregon and I was there for a year and the townsfolk in Oregon eventually found out I was positive and they basically ran me out of town and I was still dealing with people down here in L.A. just asking very basic medical questions, "How are my kidneys" and the doctors up in Oregon were afraid. They

were like "we don't feel qualified enough to answer whether your kidneys are good or not" and I eventually was transferred to Hawaii and right before I was to get on the plane, the landlord reneged and I lost my Section 8. I had three days to find something else, I couldn't find it and so I moved homeless to San Francisco." (FG3)

"Even with Section 8, I have problems. I have a housing grant through Housing Assist for People with AIDS. My Section 8 is through them. And I have an 11 year old boy, they gave me a one bedroom voucher. I got a one bedroom voucher, which is why I had to come out here because I got to make sure I got a bedroom for me and my son." (FG4)

Work

Medicare/Medi-Cal insurance and other social security benefit stability like housing were sometimes more important than a job; making employment a detriment, particularly for those who can only work occasionally or part-time due to illness. For those with regular employment, the issue of having to hide their status for fear of job security or rejection was brought up.

"the moment that I was to document that I was HIV positive or AIDS or whatever, I wouldn't be hired, even though California has the laws to protect, but I know, you know, in my field, that was suicide." (FG3)

PREP and PEP

There was not a lot of discussion about neither pre-exposure prophylaxis (PreP) nor post-exposure prophylaxis (PEP). There was not a specific question nor prompt posed to the groups about either, but it was raised by participants in three groups. For two groups, the discussion surfaced when asked how they navigate their sexual health and how they protect themselves and others.

One person mentioned it in that he acts as a resource person to others:

"Well, I have different profiles online and at first I was very afraid to disclose my status. When I was going to therapy, my therapist recommended I did on at least one of my profiles to see what the result was. He said: "nothing's gonna happen. Give it a try." I was very scared. I was just starting to attend support groups, started to get more information, started seeing people, as they were saying, sharing your condition, which helps you to move forward. So, I decided to disclose it on one of my profiles. Nothing happened; in fact, I became an educator. They asked: "how did you get it? How do you deal with it?" etc. "What does undetectable mean? Or PrEP?" So that's what I do now, besides, and even if I am disclosing my status over there, I say I only do safe sex because there's still a risk to infect someone or get yourself reinfected. You can get other STDs. So I'm very open: I'm undetectable, but I only practice safe sex. As simple as that." (FG1)

A second mentioned use of PEP as a strategy, albeit an ineffective one:

> "My experience when I learned that I had HIV, I went for the PEP, which is Post Exposure Prophylaxis, and they gave me a negative and they gave me the medication. I was on my 5th or 6th pill, I think, and I got a call and tell me I needed to come over. I knew then that something wasn't right." (FG1)

After this topic was raised, the moderator asked "Does anyone use PreP or PEP?" Despite the fact that these medications are meant for HIV negative individuals, two participants indicated that they had used both PreP and PEP, with both using PreP more extensively as part of a research study.

> "So I was trying to have fun and not paying attention to the important things in life. 'This will be an era,' I said. So in order to protect myself I signed up for PrEP at UCLA because I wanted to avoid what happened. I took it for a year, before it went [U/A]. It only lasted a year because it was research. When it ended, like 6, 7 months later, I got it [HIV]." (FG1)

In the second group where the topic came up within the same context, the participant mentioned that the partner did not want to use PreP:

> "So how I protect myself and others, I'm in a [U/A] relationship where my partner is negative. So I take my medication because he don't want to take PrEP. He's like, 'If I ain't got it, I ain't taking no meds. But our treatment is prevention and you take your medication, then you keep taking yours to protect me.' So that's what I do, I protect, I take my medication to protect us both." (FG4)

The use of PreP was discussed by both male and female participants of varied sexual orientations.

In the third focus group where PreP was mentioned, it was brought up as a resource-sharing comment at the end of the group when participants were asked to highlight important issues to them.

> "The new injectable medicines, I'm not sure they're doing stage 3 this year, it'll be coming out in 2018, I'm going to be first in line to get rid of my pills. 2019, the injectable prep will be coming out, and then they've got like all this stuff that's coming out with a cure." (FG3)

E. Services Requested by Participants

Some highlighted funding for a cure as the preferred priority while others emphasized the need for addressing social determinants of health over biomedical strategies. With respect to social determinants, housing was identified in various groups as the critical issue

> " I've been positive since 1985 and I've always heard about cures coming soon, but haven't seen anything. I've seen improvements, yes, but no cure. And I want to know who's pushing

for the end of all this. This is what I want: see, there's this agency created so they can push someone to cure us." (FG1)

"The federal government is shoving more pharmaceuticals down our throat and coming up with more preventive medicines instead of finding the cure and they focus on the biomedical preventions rather than the education and the information and the social aspect, because they're not addressing the social determinants which is esteem, anxiety, depression, emotion, our spirit, our substance use, our affordable or lack of housing, child care, transportation, all of those are barriers to accessing." (FG2)

Support Groups

Support groups were one of the primary services requested and identified to be helpful. Many participants reported having had access to support groups previously, but that they were no longer available. A support group, primarily for women, was also requested. Participants mentioned that the support groups offered them a safe place to share their stories and to receive information. In addition to the support groups, participants also recommended having more social events to provide some emotional relief.

"I don't have much to say, I just would like to see more groups, more education because I think this is kind of like, I don't know how to say it, but we cannot talk about anybody about HIV because we're going to be out the circle…" (FG 4)

"we need a woman support group and also we need a support group for everybody. We don't have it anymore. And case managers. We don't have it." (FG 4)

"we need to focus more on refocusing our government funding to prevention and education services and social activities that brings up the self-esteem, brings up the self-love, brings up all the support and the community because that's all we have at the end of the day, is we have each other. The medical and the pharmaceutical establishments, I don't really think they really care about us. We're not another statistic, we're not another number." (FG 2)

Advocate/Case Managers

Having an advocate and/or case manager in the health care sector was also important for participants. Participants want someone who can help them navigate the health care system and link them to services. They also want someone with whom they can establish a rapport and who is knowledgeable of their medical history. Some participants mentioned having case managers before financial cuts, and reported their effectiveness in advocating and linking them to services.

"Well, I still think that is crucial to have an advocate in the hospital or in the clinic or wherever it is that someone is going to help you navigate these things when you can't. And even if that means [U/A] there with your physicians so you get your questions answered, or how do I, the simplicity of how do I even get my labs?" (FG3)

"You know, there used to be, before they started cutting all the funding was [U/A]. You could go to, you know, APLA or Asia Pacific AIDS and you had a coordinator that would help you and they knew you. They had a personable relationship with you and would say if you are so frustrated then you, then they would call the facility or with their voice they would say "hi, I'm calling from this organization or from the HIV Board on behalf of this patient, we want to get him in or they're having a problem with Medi-Cal or where can they go now for housing or whatever" and you'd have that advocate. That's all they cut away, you know? Then you're just left out on the streets now. So, that was a big, big help because they were the ones who were up to date of what's going on- "they're sending treatment, they're sending funding, oh, you need a new bus pass? Oh, you need this? Oh, we're gonna have something social. This is a list for dentistry, this is a list for psychiatry and this is support group or even if you need personal counseling, we'll set you up, you need a home visit" you know, all that's gone, okay? Because HIV and AIDS doesn't get the government funding anymore, you know." (FG3)

Community/Wellness Center

A community health or wellness center was requested to access services such as exercise and nutrition classes to maintain a healthy lifestyle. Participants mentioned that services are currently provided in different locations spread throughout the city, which makes it more difficult to access those services. Therefore, having one centralized location where health and wellness services can be provided is needed.

"I feel that that's cool that we all have places where we have to go, but why should we have to drive that far to get those services? Why? You know, why we have to drive that far when we live in a city that have all these services whether they spread it out or not. Why we have to drive far? Like, they have yoga. They have yoga for us. Free. Now you guys don't even know about that, but they have health and wellness stuff. I contacted the L.A. Healthcare. Half of these people in here probably don't even know Weight Watchers have a 20 week program where they give you coupons for 20 weeks so you can go to Weight Watchers and your case manager referred you out and they give this information, they give you these tickets. Every week for 20 weeks. And also, because I'm very resourceful and I advocate; don't get me wrong, I advocate for you guys. Michelle, no. I'm a strong advocate to get these services across the 5 freeway. And they will come soon, you hear me? Soon! So APLA, L.A. Healthcare, they care for our health and wellness services like they have in L.A. where they show you how to cook your dinners, eat fresh meals, they can't do that because they don't have a community center here. And you know we can't get these services." (FG 4)

Participants brought up healthy lifestyles and self-care practices for both mental and physical health as central to the wellbeing. These included personal strategies of maintaining a positive spirit or attitude, exercising, relieving stress, and maintaining mental health through social support. A sense of gratitude was also articulated across groups.

Mental Health Services

Improved access to mental health services was mentioned throughout, however was of greater concern for participants in SPA 1. For participants in SPA 1, access to any mental health specialist was either not available at all or too far. Participants also expressed their need to see mental health specialists that are closer to them in order to maintain their treatment.

> "We don't have nowhere to go, like I need to go see a psychiatrist but we don't have one, we have to go all the way to L.A. because we don't have it in Lancaster" (FG4)

> "I'd like to see better psychiatric services, at least once or twice a month. Because it doesn't require that you go on a weekly basis. At least not having to go to LA all the time, because that is a really rough trip to go." (FG4)

Discussion

In analyzing the transcripts, the authors noted evidence of resiliency or the ability to recover from disruptive change or misfortune without being overwhelmed or acting in dysfunctional or harmful ways. It was expressed in every focus group. In the group with people living in the US without standard documentation, many had come seeking refuge for sexuality-related identity and health care related issues. Even though they lived in precarious circumstances that are often deleterious to health, on balance they were grateful for improvements in their lives due to increased acceptance and availability of services.

> "I want to say that the acceptance that we have because we're Latino, we're gay, and we live with HIV, and feeling accepted relies on the society we live in. The say that we live in this city changes all of our perspective. If we lived in the places we're from, the stigma and the way we would be treated would be totally different. I think it's a blessing for all of us to be here because we can see the progress. People care about it. A progress of the whole community, which is reflected in the treatment we all get as equals." (FG1)

> "I'm very thankful for this round table that's for feedback. I'm very thankful for the health services you provide for people with HIV and maybe you want to know its defects. These are our points of view. Thank God you want to improve. So that's it, I'm thankful for the services you provide in the county. I don't know where the funds are coming from or how this works, but I'm very thankful." (FG1)

Appendices:

Appendix 1. Demographic survey (English and Spanish)

Appendix 2. Focus Group guide (English and Spanish)

Appendix 3. NCLR/CSULB Center Background

LOS ANGELES COUNTY COMMISSION ON HIV
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Community Engagement Task Force Listening Sessions (Updated 3-20-16)

Demographic Questionnaire

Thank you for sharing your ideas and feedback on how we can improve HIV services in Los Angeles County. This questionnaire is intended to collect important information that the Commission on HIV needs in order to understand the service gaps and opportunities in our community.

I. Age

○ 13-17 years old	○ 40-49 years old
○ 18-24 years old	○ 50-59 years old
○ 25-29 years old	○ 60 years and older
○ 30-39 years old	

II. Race/Ethnicity (please check all that apply)

○ African American	○ Pacific Islander
○ American Indian/Alaskan Native	○ White/Not Hispanic
○ Asian	○ Other:_____
○ Latino/Hispanic	○ Decline to state

III. Gender

○ Male	○ Trans (Male to Female)
○ Female	○ Trans (Female to Male)

IV. Sexual Orientation: Do you consider yourself to be:

○ Heterosexual or straight	○ Queer/Questioning
○ Gay, lesbian, same gender loving	○ Other:_____
○ Bisexual	○ Decline to state

V. Educational Attainment (please check highest level completed)

○ Less than high school	○ Vocational/Technical School Diploma
○ Some high school	○ Associates degree
○ High school or GED	○ Bachelors degree
○ Some college (did not graduate)	○ Advanced degree (Masters and above)

VI. Income

○ Less than $15,000 a year	○ $25,000- $30,000 a year
○ $15,000-$20,000 a year	○ More than $30,000 a year
○ $21,000-$25,000 a year	

VII. Marital Status

○ Single	○ Married

VIII. Family Household: How many people are in your household?

○ 1, just me.	○ 3-5
○ 2	○ More than 5

IX. **Have you ever been told that you have HIV? ____Yes _____No**
a. **If so, when were you diagnosed? (month/year) _____**

X. **Do you have health insurance? ____Yes _____No**
a. If yes, what type? (please check all that apply)
_____Medi-Cal _____Covered California
_____Medicare _____Kaiser Permanente
_____Other: (specify): _____
b. Do you have difficulty paying your premium or co-pay?
____Yes ___No

XI. **What kind of services are you currently receiving? Check all that apply.**

Type of Service	I am using now	I need but am having trouble accessing it	I will need in next year
○ Help getting enrolled in health insurance			
○ PrEP (pre-exposure prophylaxis)			
○ HIV prevention education			
○ STD prevention education			
○ Condoms (free)			
○ HIV testing			
○ STD testing			
○ STD treatment			
○ HIV medical care			
○ Oral health services (general)			
○ Oral health services (specialty)			
○ Mental health services (psychiatry)			
○ Mental health services (psychotherapy)			
○ Medical case management services			
○ Home and community based services			
○ Medical nutrition therapy			
○ Non-medical case management (linkage case management, benefits specialty)			
○ Medical transportation services			
○ Food bank/home-delivered meals			
○ Housing services (Residential Care Facility for the Chronically Ill)			
○ Housing services (Transitional Residential Care Facility)			
○ HOPWA program services			
○ Other housing services			
○ Language services			
○ Substance abuse treatment (residential)			
○ Substance abuse treatment (outpatient)			
○ Outreach (linkage to and re-engagement)			
○ Referrals for services			
○ Legal services			
○ Other: (specify):_____			

COMISIÓN SOBRE EL VIH DEL CONDADO DE LOS ÁNGELES
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Sesiones de intercambio de información de grupos de trabajo de participación comunitaria (Actualizado 3-20-16)

Cuestionario demográfico

Gracias por compartir sus ideas y opiniones sobre cómo podemos mejorar los servicios de VIH en el Condado de Los Ángeles. Este cuestionario está diseñado para recopilar información importante que la Comisión sobre VIH necesita para entender las deficiencias de servicio y las oportunidades en nuestra comunidad.

I. Edad

○ De 13 a 17 años	○ De 40 a 49 años
○ De 18 a 24 años	○ De 50 a 59 años
○ De 25 a 29 años	○ 60 años o más
○ De 30 a 39 años	

II. Raza/Grupo étnico (por favor, indicar todas las que aplican)

○ Afroamericano	○ Isleño del Pacífico
○ Indígena Americano/ Nativo de Alaska	○ Blanco/no hispano
○ Asiático	○ Otro:_____
○ Latino/Hispano	○ Se niega a responder

III. Género

○ Masculino	○ Transexual (masculino a femenino)
○ Femenino	○ Transexual (femenino a masculino)

IV. Orientación sexual: Se considera:

○ Heterosexual o hétero	○ Queer (raro) /Indeciso
○ Gay, lesbiana, amantes del mismo sexo	○ Otro:_____
○ Bisexual	○ Se niega a responder

V. Nivel educativo (por favor, indicar el nivel más alto completado)

○ Menos que el secundario	○ Diploma de escuela vocacional/técnica
○ Algo de la escuela secundaria	○ Título de asociado
○ Secundario o GED (Diploma de educación general)	○ Licenciatura
○ Algo de universidad (no se graduó)	○ Título avanzado (maestría y más)

VI. Ingreso

○ Menos de $15,000 por año	○ De $25,000 a $30,000 por año
○ De $15,000 a $20,000 por año	○ Más de $30,000 por año
○ De $21,000 a $25,000 por año	

VII. Estado civil

○ Soltero	○ Casado

VIII. **Vivienda familiar ¿Cuántas personas residen en su vivienda?**

○ 1, solo yo.	○ De 3 a 5
○ 2	○ Más de 5

IX. **¿Le han dicho alguna vez que tiene VIH? ____Sí _____No**

a. **Si la respuesta es sí, ¿cuándo se lo diagnosticaron? (mes/año)**

_____

X. **¿Tiene seguro de salud? ____Sí _____No**

a. Si la respuesta es sí, ¿qué tipo? (por favor, indicar todas las que aplican)
_____Medi-Cal _____Covered California
_____Medicare _____Kaiser Permanente
_____Otro: (especifique):

b. ¿Tiene dificultades para pagar su prima o copago?
____Sí ___No

XI. **¿Qué tipo de servicios recibe actualmente? Indicar todas las que aplican.**

Tipo de servicio	Ahora uso	Necesito, pero tengo problemas para acceder	Necesitaré el próximo año
○ Ayuda para inscribirme en un seguro de salud			
○ PrEP (profilaxis previa a la exposición)			
○ Educación de prevención del VIH			
○ Educación de prevención de ETS			
○ Condones (gratis)			
○ Prueba de VIH			
○ Prueba de ETS			
○ Tratamiento de ETS			
○ Cuidado médico de VIH			
○ Servicios de salud oral (general)			
○ Servicios de salud oral (especialidad)			
○ Servicios de salud mental (psiquiatría)			
○ Servicios de salud mental (psicoterapia)			
○ Servicios de administración de casos médicos			
○ Servicios basados en el hogar y la comunidad			
○ Terapia de nutrición médica			
○ Administración de casos no médicos (administración de casos de enlace, especialidad en beneficios)			
○ Servicios de transporte médico			
○ Banco de alimentos/servicio de envío de comidas			
○ Servicios de vivienda (Centro de cuidado residencial para los enfermos crónicos)			
○ Servicios de vivienda (Centro de cuidado residencial de transición)			
○ Servicios del programa HOPWA (Programa de oportunidades de vivienda para personas que viven con SIDA)			

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Focus Group Questions and Guide (Updated 3-20-16)

Group maximum size: 15 people max per session
When: April 4, 2016 (6pm to 7:30 pm; 6 -6:30 pm check-in and answer demographic questionnaire; 6:30-7:30 pm focus group)
Target audience: Consumers of Ryan White services who are undocumented

Facilitator Duties and Expectation(s):

1. Set the stage (Cheryl Barrit or designee): Introduction of the Commission, its intention, and highlight some of the successes and opportunities for involvement and improvement in the work of the body.
2. Confidentiality: ***Set ground rules for safety and inclusion***, including the role of any commissioners in the room. Sample rules may include: cell phones on silent mode, what happens in the room stays in the room, step up step back, no cross talk, agree to disagree, and speaking from "I" statements.
3. Facilitation: Use guide to ask question provided, however, be mindful of emerging themes that may elicit more conversation or offer an opportunity for less participatory individuals to be included in the conversation.
4. Attendance (coordinated by Cheryl and staff in advance): Any Commissioner in attendance will be asked to support the process by observation and volunteerism through note taking and/or referrals; setup and clean-up facility, welcome and thank participants.

Focus Group Questions: Questions in BLUE may be eliminated for time considerations

1. Where would you go for your dream vacation? (**Facilitator note**: This is a warm up opportunity to get people thinking bigger.)
2. Describe your experience with obtaining HIV-specific medical care? Positive experience? Negative experience? Next question in blue can be used a prompt for question #2
3. What have been your experiences with obtaining HIV-specific services? (**Facilitator note**: This question includes opportunities to prompt attendees toward service types such as psychosocial, dental, transportation.) Where do you go to look for services?

4. Have you attempted to sign up for health insurance? What has been your experience? Are you receiving the service you need? If not, why?
5. How have you been affected by your HIV status? In what ways have you experienced disapproval or rejection that you believe may have been related to your status?
6. What is your relationship with your doctor? Do you talk about HIV? Sexually Transmitted Infections?
7. How do you protect yourself and others from HIV? (**Facilitator note**: This is an opportunity to learn how people are navigating their sexual health. Can incorporate abstinence, partner negotiation, condoms, treatment as prevention – counseling, testing, medication adherence, and other biomedical strategies)
8. When you try to access services, what issues or concerns come up for you? Has learning your HIV status changed the ways in which you access support? If so, how?
9. How can your doctors and other providers serve you better? (**Facilitator note**: This is an opportunity to talk about quality of care, language, and other potential barriers or tools do you think doctors and other support staff need to enhance clinical delivery.)
10. In thinking of the future, where do you want to be in five years?

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Guía y Preguntas para el Grupo de Enfoque (Actualizado 3-20-16)

Tamaño máximo del grupo: Límite de 15 personas por sesión
Cuando: Abril 4, 2016 (6pm a 7:30 pm; de 6 a 6:30 pm registración y cuestionario demográfico; de 6:30-7:30 pm grupo de enfoque)
Dirigido a: Consumidores indocumentados de los servicios de Ryan White

Expectativas y Responsabilidades de los Facilitadores:

1. Crear el ambiente (Cheryl Barrit o personal designado): Introducción de la Comisión, su intención, destacar algunos ejemplos del éxito y de las oportunidades de participación en el trabajo del organismo.
2. Confidencialidad: ***Establezca las reglas de seguridad e inclusión***, incluyendo el rol de los Comisarios presentes. Algunos ejemplos de las reglas pueden incluir: los celulares deben estar en silencio, lo que pase en el grupo se queda en el grupo, participar activamente sin acaparar la discusión, no interrumpir, estar de acuerdo en discrepar, declaraciones que empiecen con "Yo".
3. Facilitación: Use la guía para realizar las preguntas, sin embargo, tenga en cuenta los temas que se presenten que puedan provocar más conversación o brindar una oportunidad para que los participantes menos activos puedan incluirse en la conversación.
4. Asistencia (coordinada por Cheryl y personal asignado): Se le pedirá a cualquier Comisario presente apoyar el proceso mediante la observación y el voluntariado a través de toma de notas y/o referencias; instalación, organización y limpieza del lugar, además de darle la bienvenida y las gracias a los participantes.

Preguntas para el Grupo de Enfoque: Las preguntas en AZUL pueden eliminarse por falta de tiempo.

1. ¿Donde serían las vacaciones de tus sueños? (**Nota para el facilitador**: Esta es una oportunidad de calentamiento para que los participantes comiencen a pensar en grande.

2. Describe tu experiencia respecto al acceso de cuidado médico especifico al VIH. ¿Ha sido una experiencia positiva? ¿Ha sido una experiencia negativa? La siguiente pregunta en azul puede usarse como introducción para la pregunta #2 .
3. ¿Cuáles han sido tus experiencias al obtener servicios específicos al VIH? (**Nota para el Facilitador:** Con esta pregunta se pueden ofrecer ejemplos como servicios psicológicos, dentales, de transportación, etc.) ¿Dónde buscas esos servicios?
4. ¿Has intentado inscribirte a un seguro médico? ¿Cuál ha sido tu experiencia? ¿Estás recibiendo el servicio que necesitas? Si la respuesta es no, ¿por qué no?
5. ¿De que manera te ha afectado tu estatus de VIH? ¿De que maneras has experimentado rechazo o desapruebo que creas estén relacionados con el VIH?
6. ¿Cuál es tu relación con tu doctor? ¿Hablan sobre el VIH? ¿Hablan sobre enfermedades de transmisión sexual?
7. ¿Cómo te proteges a ti mismo y a los demás del VIH? (**Nota para el Facilitador**: Esta es una oportunidad para saber cómo las personas navegan su salud sexual. Puede incluirse ejemplos como la abstinencia, negociación con la pareja, condones, tratamiento como prevención – consejería, pruebas, cumplimiento con los medicamentos y otras estrategias biomédicas)
8. Al intentar tener acceso a servicios, ¿qué problemas o preocupaciones tienes? El conocer tu estado de VIH, ¿ha cambiado la manera en que buscas apoyo? Si la respuesta es sí, ¿de que manera?
9. ¿Cómo podrían tus doctores y otros proveedores servirte de mejor manera? (**Nota para el Facilitador**: Esta es una oportunidad de hablar sobre la calidad del cuidado o servicio, el idioma y otras posibles barreras o herramienta que piensen que los doctores y demás personal de apoyo necesitan para mejorar el servicio clínico)
10. Cuando piensas en el futuro, ¿dónde quieres estar dentro de 5 años?

CLICK HERE TO RETURN TO PART 1

Los Angeles County Commission on HIV

Community Listening Sessions Report Part 2:

Spanish-speaking Women of Color, Teen Youth, and Native Americans

This report is a collaborative effort of the:
Los Angeles County Commission on HIV
Division of HIV and STD Programs, Department of Public Health
NCLR/ California State University Long Beach (CSULB) Center for Latino Community Health, Evaluation, and Leadership Training

October 31, 2016

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Overview

The NCLR/CSULB Center for Latino Community Health, Evaluation and Leadership Training staff conducted three focus groups with various subgroups within the target audience (Spanish-speaking women of color, teen youth, and Native Americans) to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Methodology

Recruitment

All focus group recruitment was coordinated by the Los Angeles County Commission on HIV. All groups were scheduled and implemented within a one-month period in Fall 2016 in different locations in Los Angeles County.

Instruments

Consent forms and demographic surveys were developed by the Los Angeles County Commission on HIV and provided to the NCLR/CSULB Center Evaluation Team to administer prior to the focus group (Appendix A). The Los Angeles County Commission on HIV Team developed the focus group guide and survey questions. The NCLR/CSULB Center Evaluation Team provided translation of the revised items into Spanish. Focus group questions were designed in order to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Focus Group Facilitation

Each focus group was moderated by experienced and trained bilingual NCLR/CSULB Center evaluation staff who are certified in the protection of research subjects' rights. Focus group participants were greeted, thanked for their participation, and completed informed consent procedures with the moderator and note taker(s). The listening session process is a non-research activity exempt from IRB requirements. Nonetheless, all participants provided written and verbal agreement to participate in the focus group discussions. Moreover, while formal parental consent was not requested, parents provided tacit consent by bringing their children to the focus group location.

Each focus group was digitally recorded using two recorders and each session lasted approximately 90 minutes. The digital recording was sent to a transcription service, which typed up the discussion and translated when needed. The English transcriptions were provided to the NCLR/CSULB Center staff for analysis. Spanish transcription was also provided when applicable (these were used as reference during coding of the English translated transcripts).

Analysis

The demographic survey data was entered, cleaned and analyzed by NCLR/CSULB Center staff using Statistical Program for the Social Sciences (SPSS) Version 23.0 (IBM Corp. Released 2015, Armonk, NY) Descriptive statistics were computed.

The transcripts were coded in Dedoose (Version 7.0.23, web application for managing, analyzing, and presenting qualitative and mixed method research data (2016). Los Angeles, CA: SocioCultural Research Consultants, LLC, www.dedoose.com) by three independent coders. Using the focus group guide and the debriefing notes as base documents, the moderators and note-takers met as a team to discuss potential codes and to create a preliminary codebook. New codes were added after periodic team meetings and transcripts subsequently re-reviewed for additional categories. For translated transcripts, both Spanish and English versions were uploaded to Dedoose, but only English was coded. The Spanish version was included to clarify the interpretation of translation if necessary. This process also confirmed the accuracy of the translation by a third party. Below, the survey results are presented first, followed by the focus group discussion findings.

Results

Focus Group Characteristics

The NCLR/CSULB Center facilitated three focus groups as part of the community input process for the Los Angeles County Commission on HIV. Table 1 describes characteristics and logistic information for the focus groups.

Table 1. Focus Group Description

Focus Group No.	Target audience & Language	Date & Time	Location	# of People	Moderator	Note Taker
1	Spanish Speaking Women of Color	Monday, August 22,2016 (6:00-7:30pm)	AltaMed Health Clinic 5427 Whittier Blvd. Los Angeles CA 90022	10	Mayra Rascon, MPH, MS	Luis Cendejas, BS
2	English Speaking Youth ages 13-17y/o	Saturday, Sept 10, 2016 (1:00-2:30pm)	Children's Hospital Los Angeles 5000 Sunset Blvd. Los Angeles, CA 90027	3	Mara Bird, PhD	Luis Cendejas, BS

3	English Speaking Native American/Alaskan Native	Thursday, Sept 22, 2016 (6:00-7:30pm)	Southern California Indian Center, Inc. 3440 Wilshire Blvd. Suite 904y Los Angeles CA 90010	17	Mara Bird, PhD	Luis Cendejas, BS

Focus Group Demographic Results

The focus groups consisted of a total of 30 participants from Los Angeles County. One survey was excluded as the respondent declined to answer, indicating that they did not understand it. The results presented below therefore reflect information from 29 participants.

Overall

Focus group participants were primarily 40-59 years old (55.2%). Figure 1 displays the age range of all participants.

Figure 1. Age (n=29)

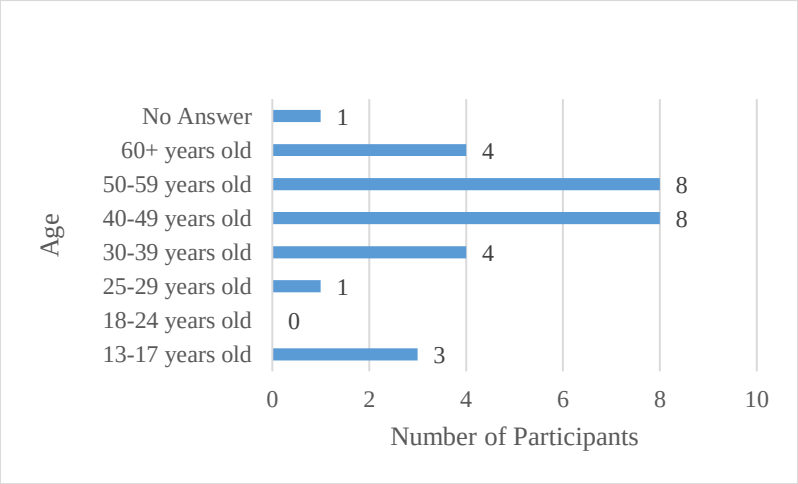
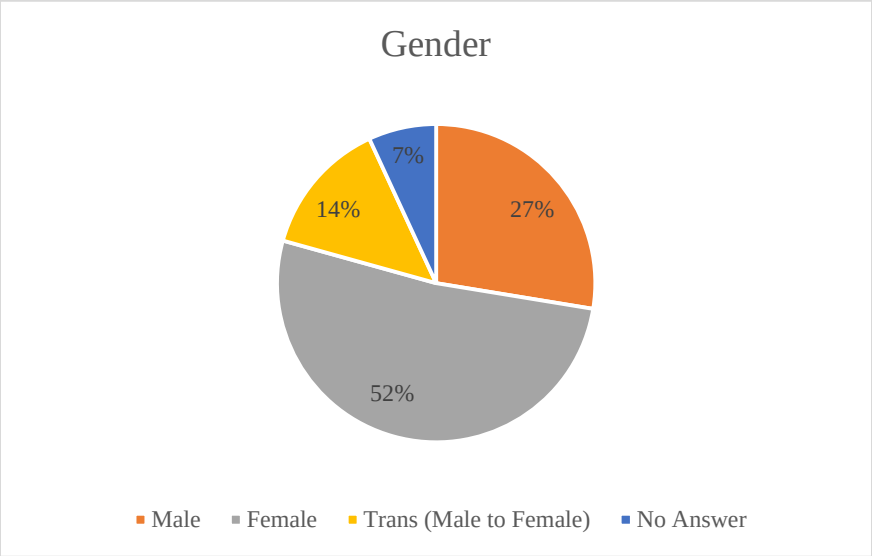


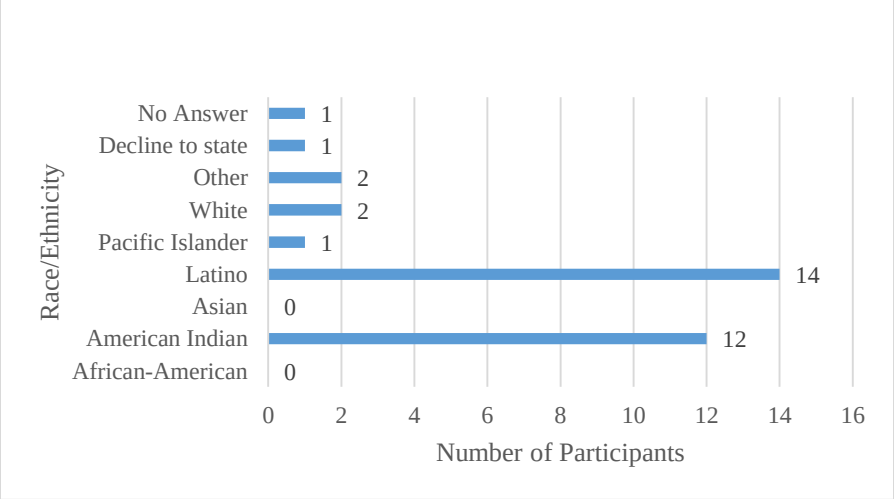
Figure 2 presents the gender of the participants. More females (n=15) than other groups.

Figure 2. Gender (n=29)



The largest proportion of participants were Latino (48.3%), followed by American Indian (41.4%), White (6.9%) and Other (6.9%). Figure 3 displays the race and/or ethnicity of focus group participants. Some participants have more than one race/ethnicity.

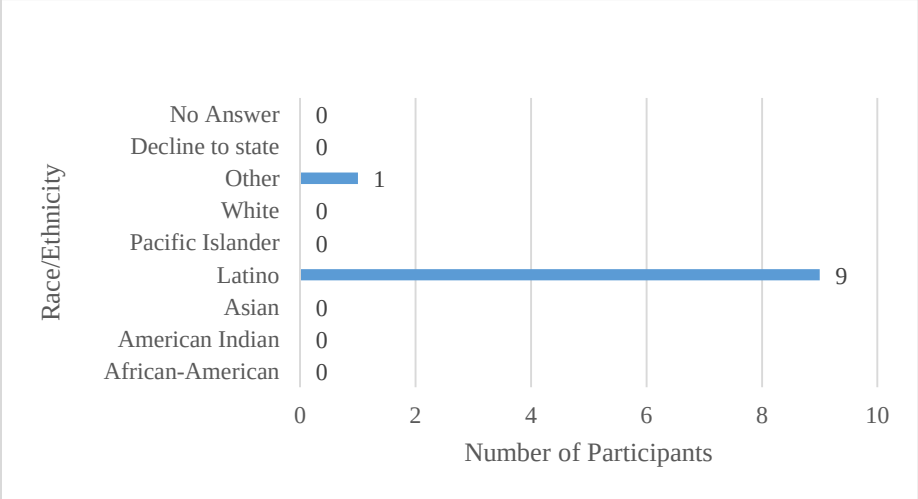
Figure 3. Race/Ethnicity (n=29)



By Focus Group

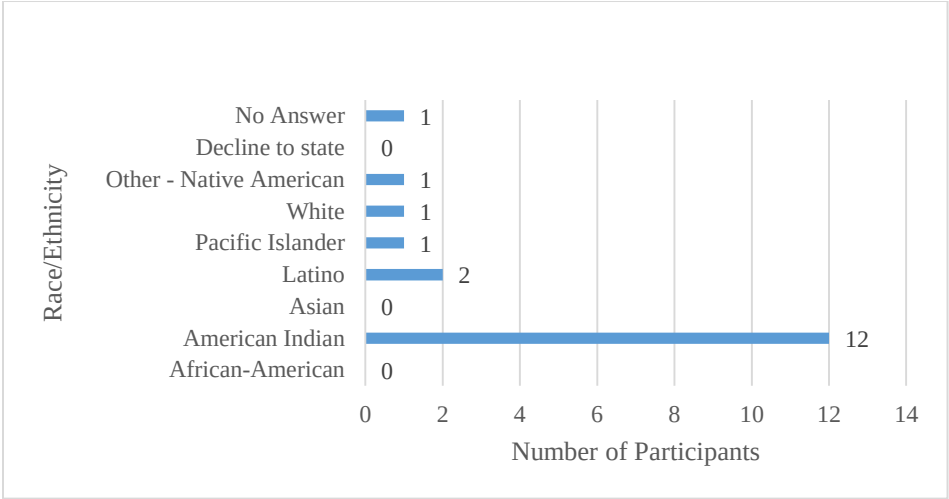
The focus group of Spanish Speaking Women of Color participants (FG 1) primarily consisted of all but one Latino/Hispanic participants (n=10). Figure 4 shows the breakdown of self-identification for this focus group.

Figure 4. Spanish Speaking Women of Color (n=10)



The focus group of Youth ages 13-17 (FG 2) were 100% Latino (n=3). The Native American focus group (FG 3) participants included those who identify as American Indian (75%), Latino (12.5%), White (6.3%), Pacific Islander (6.3%) and Other-Native Americans (6.3%). Some participants from this group identified with more than one race or ethnicity, thus the numbers listed in the figure add up to more than the total participants. Figure 5 shows the complete breakdown.

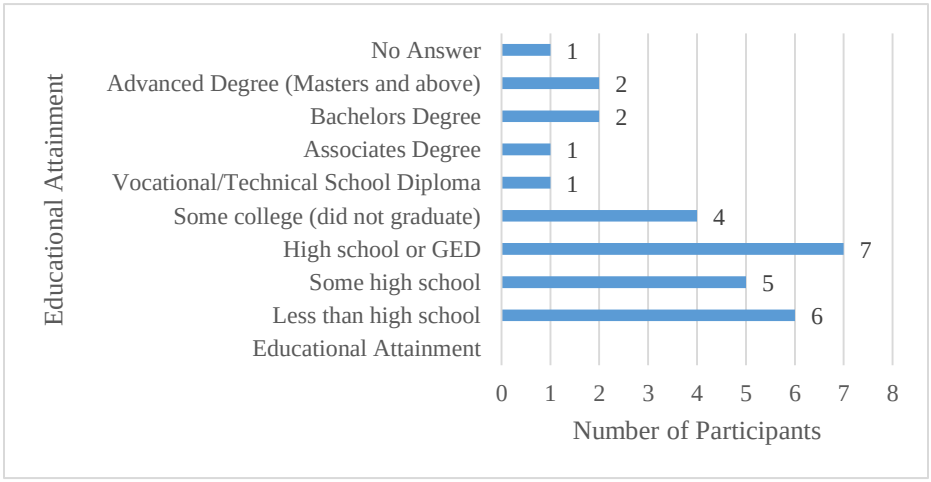
Figure 5. Native American/Alaskan Indian Focus Group (n=16)



Overall

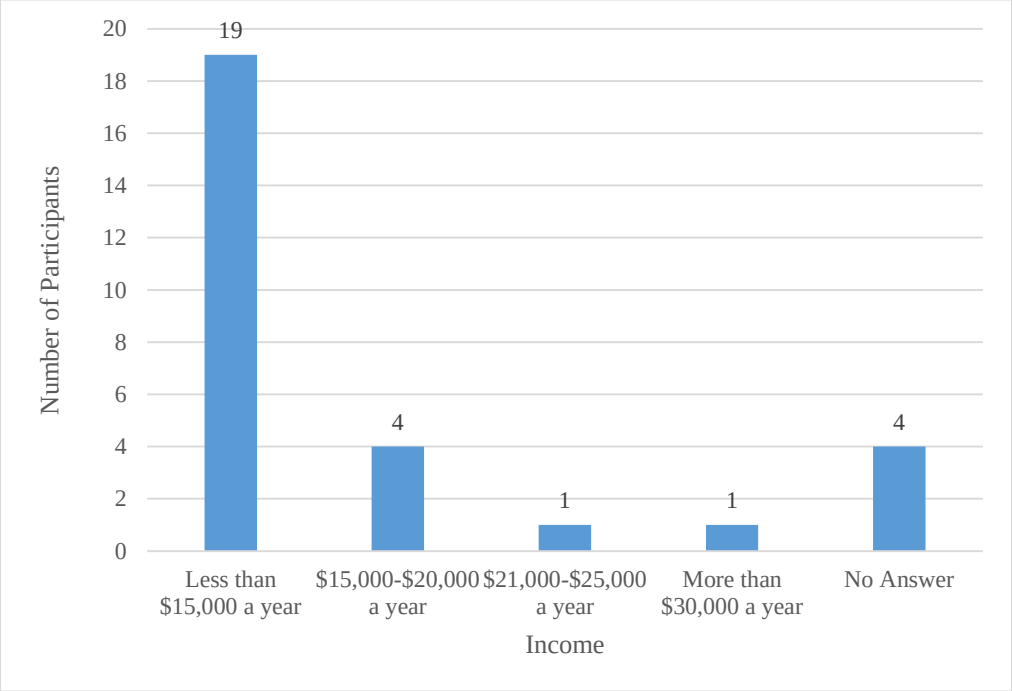
Educational level varied, with those completing High School or GED (24.1%) comprising the largest group, followed by less than high school (20.7%), and some high school (17.2%). Figure 6 displays the educational levels of all of the participants.

Figure 6. Participant Educational Level (n=29)



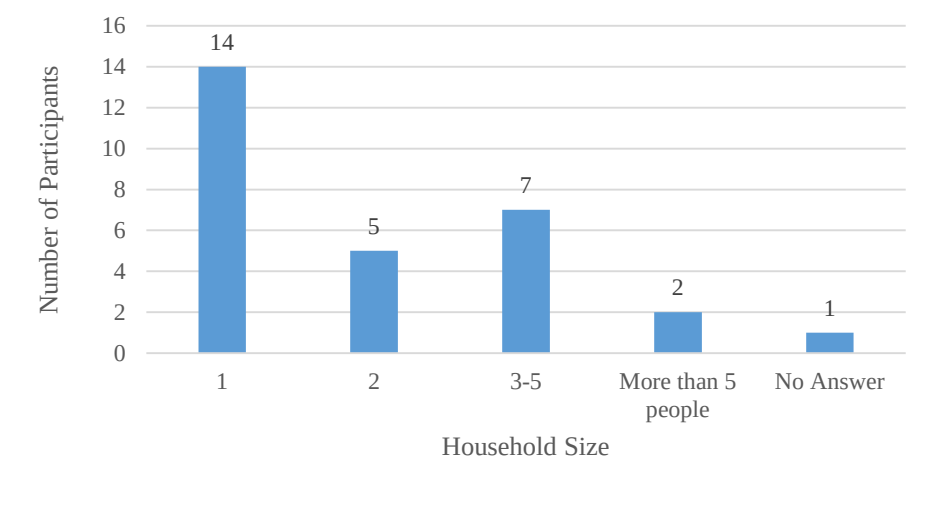
A majority of participants (65.5%) earned $15,000 or less a year. Only one participant indicated that they earned more than $30,000 a year. Figure 7 displays the participant's self-reported income.

Figure 7. Participant's Income (n=29)



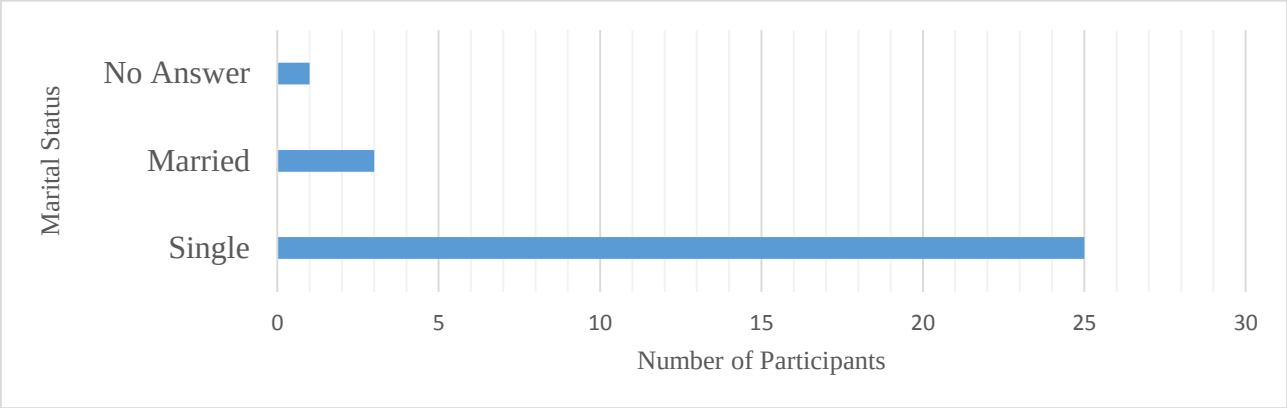
Many of the participants (48.3%) lived alone. Figure 8 portrays the participants' household size.

Figure 8. Household Size (n=29)



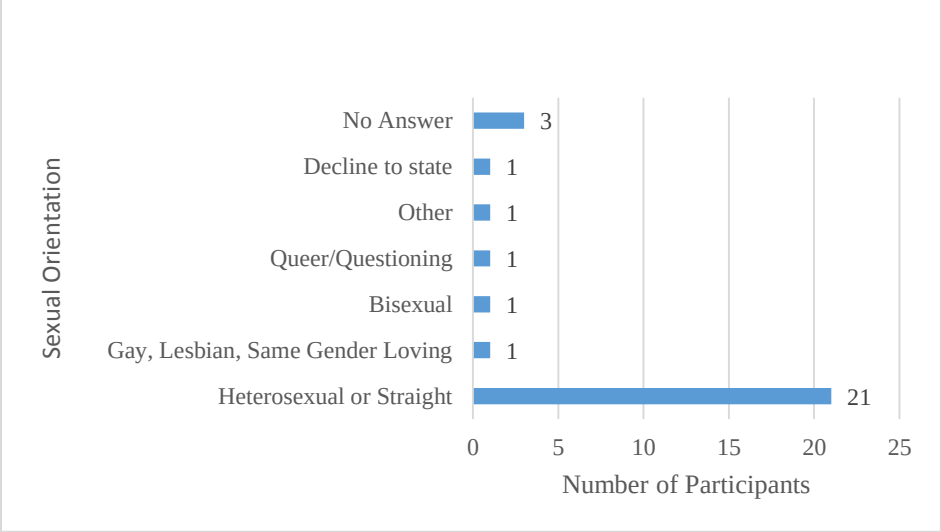
The large majority of the participants were single (86.2%). Figure 9 displays the marital status of the participants.

Figure 9. Marital Status (n=29)



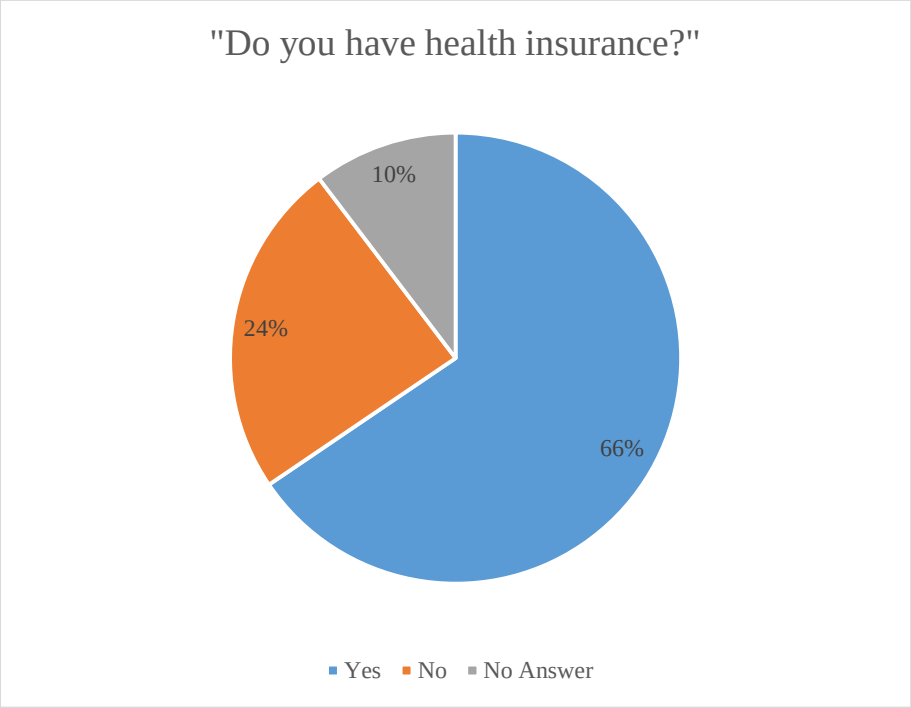
Those who self-reported being heterosexual (n=21) made up the majority of focus group participants. Figure 10 displays the sexual orientation categorization.

Figure 10. Sexual Orientation (n=29)



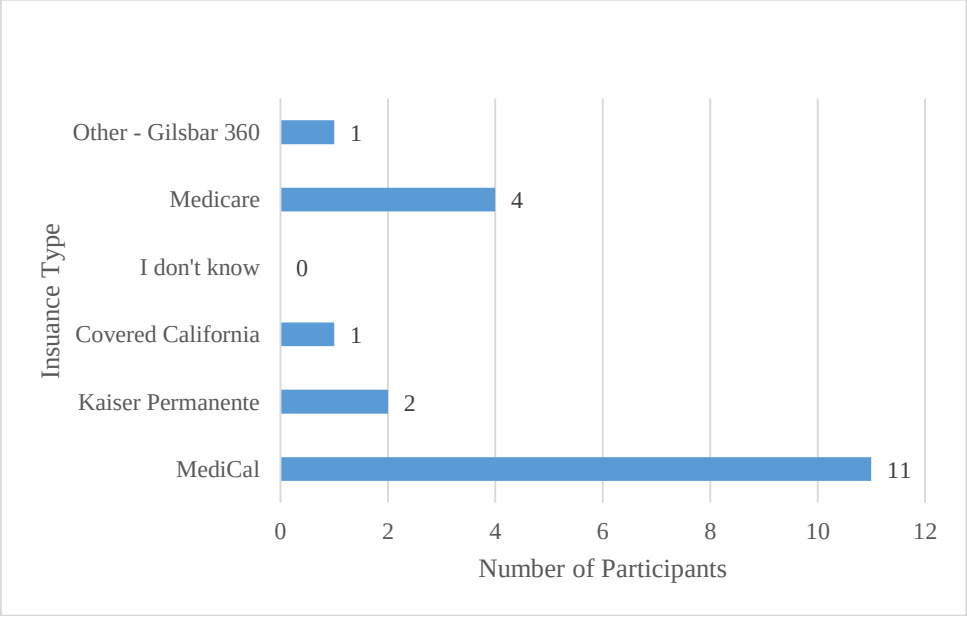
More than half of the participants (n=19) had health insurance. Figure 11 portrays the health insurance status of the participants.

Figure 11. Health Insurance Status (n=29)



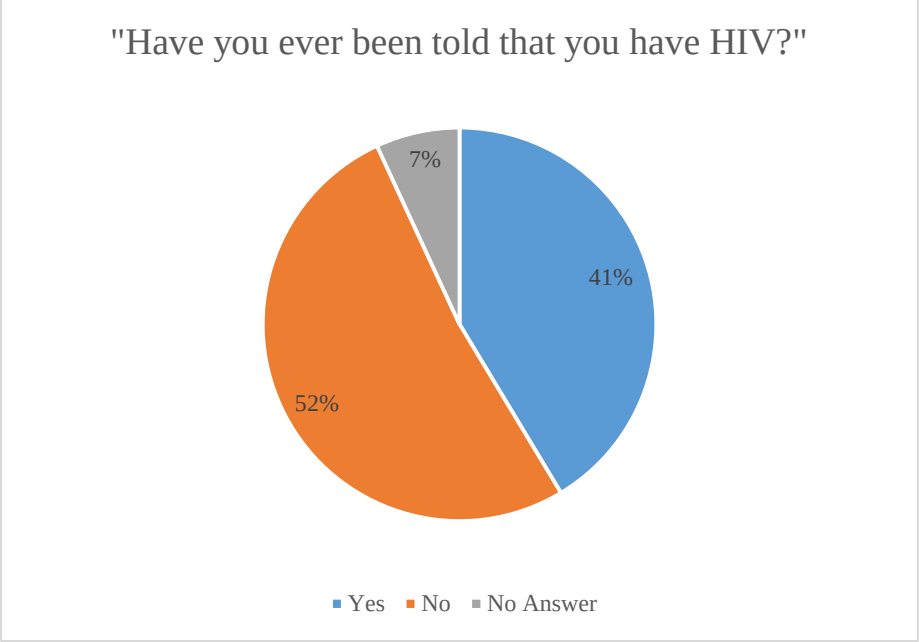
Those that had Medi-Cal (n=11) or Medicare (n= 4) comprised the largest proportion of participants. The types of insurance reported are shown in Figure 12.

Figure 12. Types of Health Insurance (n=19)



Less than half (n=12) of participants reported having been told that they have HIV. Two respondents declined to answer. Figure 13 shows all responses for this question.

Figure 13. Participants who have been told that they have HIV (n=29)



Overall

For those that reported being diagnosed with HIV, the average number of years living with HIV was 13.75 (SD = 9.85). The number of years since a participant was diagnosed with HIV ranged from 2 (n=1) to 29 years (n=1). Table 2 portrays the breakdown of the number of years since the participants had been diagnosed with HIV.

Table 2. Years Diagnosed with HIV (n=29)

Years Since Diagnosis	Frequency	Percent
29	1	3%
28	1	3%
17	1	3%
15	1	3%
10	1	3%
6	1	3%
3	1	3%
2	1	3%
Not Applicable	15	52%
No Answer	6	21%

By Focus Group

In the Spanish Speaking Women of Color focus group (FG 1), seven participants reported being diagnosed. Among them, the number of years since a participant was diagnosed with HIV ranged from 2 to 29 years (1%). Table 3 displays the number of years since a participant had been diagnosed with HIV.

Table 3. Spanish Speaking Women of Color – Years Diagnosed with HIV (n=10)

Years Since Diagnosis	Frequency	Percent
29	1	1%
17	1	1%
15	1	1%
10	1	1%
6	1	1%
3	1	1%
2	1	1%
Not Applicable	0	0%
No Answer	3	3%

In the youth ages 13-17 years old focus group (FG 2) none had ever been diagnosed with HIV.

For the Native American/Alaskan Indian focus group (FG 3), only one of the focus group members had ever been diagnosed (28 years ago).

Overall

The average number of services per person currently being used is 6.60. The top service currently being used are free condoms (45%). HIV Testing (38%) and general oral health (38%) tied for second place and the following services tied for third place at 34% for currently usage: STD testing, HIV medical care, mental health services (psychiatry) and medical case management services.

Table 4. Types of services participants are currently accessing

What kind of services are you currently receiving? I am using now	n	Percent
Condoms (free)	13	45%
HIV testing	11	38%
Oral health services (general)	11	38%
STD testing	10	34%
HIV medical care	10	34%
Mental health services (psychiatry)	10	34%
Medical case management services	10	34%
Help getting health insurance	9	31%
HIV prevention education	8	28%
Non-medical case management	8	28%
STD prevention education	7	24%
Mental health services (psychotherapy)	7	24%
Housing services	7	24%
Outreach	7	24%
Referrals for services	7	24%
PrEP (Pre-Exposure Prophylaxis)	6	21%
STD treatment	6	21%
Home and community based services	6	21%
Medical nutrition therapy	6	21%
Language services	5	17%
Oral health services (specialty)	4	14%
Medical transportation services	4	14%
Food bank/home-delivered meals	4	14%
HOPWA program services	4	14%
Substance abuse treatment (outpatient)	3	10%
Legal services	1	3%
Other - Hormone Therapy	1	3%
Condoms (free)	13	45%

The average number of services per person that the participants need but are having trouble accessing is 3.82. The top service that participants need but are having trouble accessing is housing (28%). The second top two services needed (24%) are general oral health services and HOPWA program services.

Table 5. Types of services participants have barriers accessing

What kind of services are you currently receiving? I need but am having trouble accessing it	Frequency	Percent
Housing services	8	28%
Oral health services (general)	7	24%
HOPWA program services	7	24%
Oral health services (specialty)	6	21%
Food bank/home-delivered meals	6	21%
Legal services	6	21%
Mental health services (psychiatry)	5	17%
Mental health services (psychotherapy)	5	17%
Home and community based services	5	17%
Medical nutrition therapy	5	17%
Medical transportation services	5	17%
Outreach	5	17%
Help getting health insurance	4	14%
Referrals for services	4	14%
PrEP (Pre-Exposure Prophylaxis)	3	10%
Condoms (free)	3	10%
Non-medical case management	3	10%
Language services	3	10%
Substance abuse treatment (residential)	3	10%
HIV prevention education	2	7%
STD prevention education	2	7%
HIV testing	2	7%
STD testing	2	7%
STD treatment	2	7%
Medical case management services	2	7%
HIV medical care	1	3%
Substance abuse treatment (outpatient)	1	3%
Other - Hormone Therapy	0	0%

The average number of services per person that the participants will need in the next year is 0.92. The most common service that the participants reported needing in the next year is medical transportation services (14%) followed by the following services each at (7%): HIV Testing, STD testing, mental health services (psychotherapy), medical case management, non-medical case management and food bank/home-delivery meals.

Table 6. Types of services participants will need in the next year

What kind of services are you currently receiving? I will need in the next year	Frequency	Percent
Medical transportation services	4	14%
HIV testing	2	7%
STD testing	2	7%
Mental health services (psychotherapy)	2	7%
Medical case management services	2	7%
Non-medical case management	2	7%
Food bank/home-delivered meals	2	7%
HIV prevention education	1	3%
STD prevention education	1	3%
STD treatment	1	3%
Oral health services (general)	1	3%
Oral health services (specialty)	1	3%
Medical nutrition therapy	1	3%
Housing services	1	3%
Substance abuse treatment (outpatient)	1	3%
Outreach	1	3%
Other - Hormone Therapy	1	3%
Help getting health insurance	0	0%
PrEP (Pre-Exposure Prophylaxis)	0	0%
Condoms (free)	0	0%
HIV medical care	0	0%
Mental health services (psychiatry)	0	0%
Home and community based services	0	0%
HOPWA program services	0	0%
Language services	0	0%
Substance abuse treatment (residential)	0	0%
Referrals for services	0	0%
Legal services	0	0%

Qualitative Findings

The topics most central to the discussions were prevention, awareness and education services. Access to services and housing were also prominent concerns. These are discussed below as well as other topics that were raised less often, but which does not signify that they are less important. Within each topic, the variety or range of opinions is noted.

Figure 14. Coding Frequency Word Cloud

A. Experiences Obtaining HIV Care or Services

Specialty Care

Participants mentioned a variety of specific service providers of specialty care for people living with HIV and or AIDS. Participants seemed to prefer places that specialized in HIV and many found that utilizing these specialty clinics increased their awareness about HIV and prevention. One participant mentioned that he/she did not like working with volunteers and instead wanted knowledgeable professionals to help him with his illness.

"I tried going to an agency, but, with my experiences … they weren't helpful enough. At the time, it takes a specialist, people that I was speaking to, they were volunteers, so, I didn't… I felt like my time was wasted there, so, with the health services through other agencies and it's been more of a positive experience."(FG3)

"I went to the clinic, at U.A.I.I. and I found out that, if you either do a [U/A] a [U/A] is where you just prick your finger, and then, I found out, you know, that they could draw blood, find out that way. So, I didn't know that." (FG3)

"My experience with HIV services… initially I [U/A] there's a clinic there [U/A], that specializes in HIV and other special… I forgot the name on what type of clinic that is, but, HIV is one of the specialties that they treat, so, receiving services through an agency and, at the time, living in this community downtown L.A., I had an option to see an HIV specialist with an agency, and through that doctor and the nurses there, I was able to link with other services in the community that offer workshops on HIV education, and through that, it's been really helpful." (FG3)

"I haven't had any bad experiences with dentists so far, on the contrary, the receptionist, the dentist assistant, everyone has taken good care of me and I haven't had any problems myself, as far as I'm concerned. Everything is fine." (FG1)

The participants further discussed where they went for medical care, what services were offered at these clinics, and their experiences with care. Multiple participants mentioned that the clinics they attended for medical services were also able to help them with other needs. Respondent indicated that more HIV prevention services like the one he/she attended are needed, especially those that are culturally specific. All groups requested services that were tailored to them, be it a Native culture or a youth-oriented service. If this is not possible the requests were to make it clear that the services are for them/all and to treat them respectfully. The youth in particular were hesitant to access services where they were not sure they would be welcomed. Based on participant feedback, it appears that medical clinics could be the first line of service and information for people living with HIV and people looking for more information about prevention and testing.

"I went to a treatment [U/A] and they gave us HIV classes and stuff like that, on STD and HIV, and then we could volunteer if we wanted to be tested. And so, I was tested and I'm negative. There's a lot to check on mine because I've got my I.V. user and then [U/A] always try to check it every six months, or every year now." (FG3)

"Yeah, they had the specialty clinic, and with someone dealing with the HIV, you know, with me dealing with depression, and, you know, substance abuse, they had other services and individuals that I was able to link with." (FG3)

"I think there needs to be more HIV prevention. There is only one that I know of, and I think the only one that exists for L.A. county that specifically targets Native Americans and L.A.

county is huge and there's a lot of Natives all throughout L.A. county and given the number of Natives or the rate of Natives being diagnosed with HIV, I think there needs to be more money allocated to prevention services and education for Natives." (FG3)

"I think that there should be more funding for HIV-A.I.D.S. education and prevention for the, I want to say the Native American community, but generally, the entire population."(FG3)

"E: I think they should have, like, information geared towards young people, rather than, like, adults.
Moderator: So, what would that look like? Information geared towards young people?
E: Since most of us get our information on the internet, like, maybe, a social media account of some type?
A: I feel like, it should specifically say that it's for young people, like teenagers, because, I know that there's a planned parenthood clinic near my house, but I've always wondered if, like, like, how old do you have to be to get services there or actually go there, or, like, kind of, like, what are the requirements?
E: Like, [U/A], oh, that's where young people [U/A]. Something like that.
Moderator: Okay. Okay. Alright. So, things that you can clearly say, okay, that's meant for people my age.
E: Like, you'd feel more comfortable knowing that, if you go there, they're not going to be, like, 'why are you here?"(FG2)

B. Accessing Health Services: Insurance-related Issues

Affordable Care Act (ACA)

The Affordable Care Act was not mentioned in detail. When it was, participants seemed to have negative experiences with changes in their health care providers and disorganization within the system.

"I was on Covered California for a while and, that was a pain. I didn't like that at all …. maybe because it was very [disorganized]. It just seemed like a lot of …disorganization." (FG3)

"They take too long, now. It didn't use to be like this, but now, with that Obama, everything changed."(FG1)

Medicare/Medi-Cal

Of those with health insurance coverage, a large portion of participants were covered by Medicare, and a few by Medi-Cal (see Figure 12, p. 9). The principal barrier to accessing care for these participants was denial due to missing paperwork to prove insurance status. Lack of

paperwork stemmed from precarious housing/homelessness, moving, drug use, and having paperwork stolen. Access to electronic insurance records might mitigate this issue.

> "They asked me if I had medical insurance and what it covered. I told them I had both Medicare and Medi-Cal, but all my papers were stolen. I have my Medicare right now, but I wasn't carrying it then. They said they were going to send it to my home, but, since I don't live there anymore, I don't know if they sent it or not." (FG1)

> "I had medical but my purse was stolen [U/A], they stole my Medi-Cal, so, I went to Martin Luther King because I had a procedure done here. I had something like an abscess." (FG1)

A second barrier to access to care associated with Medi-Cal was the lack of knowledge about the application process. Participants indicated appreciation for clinic staff who helped them to enroll with Medi-Cal.

> "I've been told I need emergency Medi-Cal, but I don't know where to get it." (FG1)

> "I was assisted very well. They accepted my medical insurance immediately, and today, I went to get it renewed because it had been suspended, but they took care of it quickly, too." (FG1)

> "With an agency, they weren't able to assist me with the financial side of billing, so now I have Medi-Cal." (FG3)

> "I currently have Medi-Cal, and, in addition, I have [U/A] my employer, so, until I do not qualify for Medi-Cal, Medi-Cal is still picking up the billing for my medication and doctor, health services. When that happens, [no longer eligible for Medi-Cal because employed] I'm going to have to look for a new doctor, but, I guess I have to get used to paying co-pay."(FG3)

Indian Health Services (IHS)

Access and utilization of health services through IHS was mentioned, as well. This type of insurance and medical services, however, is unique to Native Americans/Alaskan Natives. A participant mentioned having services from IHS in tandem with other public health providers.

> "Hey, okay. I have I.H.S. and I also have [U/A] insurance [U/A] medical, and, I.H.S. picks up on copayments when combined with [U/A] clinic, which is a good program, it's like an H.M.O. program, but for my H.S.E. [U/A] if I have surgery, you know, they cover that, it's like a coverage plan." (FG3)

<u>Private Insurance</u>

When dealing with private health insurance, the main barrier to accessing services is the difficulty of navigating the insurance company's and provider's rules and coverage limits. These

included geographic rules, types of services covered and cost. Participants did seem to obtain most of the services they needed, but they did have to spend time working out issues with their insurance. One participant highlighted a very positive experience with an agency and their family-like treatment that she experienced through that provider. The positive experience with this agency was echoed within the group.

> "From Pacific Northwest in Seattle, it's a private carrier for my insurance, and here, they won't take it. They want the full coverage. They want the full package. I had a hip replacement, … years ago, but they helped pay for [U/A]. You think this place would help me? No, darling. So, I don't go…" [Even with insurance care denied] (FG3).

> "I get a lot of runaround from [U/A] insurance representatives on the phone and, it's just a lot of miscommunication and misunderstanding, but I'm trying to get as much as I can from the insurance company that sells but, I do understand that they're the ones ultimately paying [U/A] So, sometimes [U/A] [it is] difficult talking to people…"(FG3)

> "…everyone here at an agency, nurses, doctors, receptionists have supported us as if they were family." (FG1)

C. Services Requested by Participants

Sexual Health Education

The need for sexual health education was mentioned often throughout the groups. There is an alarming disconnect between the overwhelming opinion of participants that this information is needed starting at the middle school and high school levels, with the severe lack of provision of this education. The youth group mentioned their physical education (PE) class as one of the main places where they received information about sex, HIV, STDs and prevention. The youth conveyed that the six-week healthy lifestyle curriculum was integrated into the PE class during their freshmen year. Each class was one hour and sexual health was addressed once. Of note, the healthy lifestyles curriculum was provided by staff from a local university as part of a special project. The curriculum did not appear to have been integrated into the regular schedule to be offered yearly, so most students may not even receive one hour of sexual health education. Health as a high school class is an elective or optional course that is not required to be offered. Finally, the youth participants indicated that few people talked to them about sexual health, that it was not discussed between friends, and that they were uninformed.

> "Moderator: What about other STDs? Who has talked to you about other STDs?
> A: I feel like school is the main place where they've taught us everything.
> …
> Moderator: So, school is the main place, but, from what I'm hearing, you had one 1-hour class on STDs?
> E: Yeah.
> Interviewer: Did you ever have any other information in any other class?
> E: No.

A: Nope.
Moderator: Nope? Even when you were younger?
E: No.
Moderator: Do they have classes later? That was it?
A: That was it.
E: That was it."(FG2)

Moderator: So, what about your friends? Do your friends give you information about [sex]?
A: No.
Interviewer: Okay. So, it's not really a topic of conversation?
A: It's not."(FG2)

"Moderator: [Referring to parental advice] Do they tell you how to be careful? How to go about being careful?
A: No.
L: No.
E: No.
..
L: Just to be careful."(FG2)

"A: HIV is an STD. You can sexually transmit it from penetration, and it's not... you don't get it from, like bodily fluids. I think.
…
A: Like, saliva.
E: Yes, that's what I was going to say. I think it's like, one of them is a virus, and one of them is a disease. Or something like that.
Interviewer: Okay. Anything else about HIV that you can think of?
A: There's no cure yet.
E: And, then, I think they cured somebody in Germany?"(FG2)

Many adult participants also mentioned sexual health education and stated that they wished there had been more of these classes when they were younger. They also stated their beliefs that there is a need for more sexual education classes to inform youth about HIV prevention and safe sex.

"To start educating kids at a younger age, even though it's a hard subject to talk about, they need to know this before they start junior high, middle school, because that's when they start having sex and start experimenting with drugs. Would they even really know, you know, what those habits are? Know that it can be prevented?"(FG3)

"What I say is to spend more education in public and private schools in Los Angeles County regarding HIV and AIDS prevention."(FG3)

"What I would like to see is, you know, all these young people today, you know, they're not being careful with their lives, you know? …What I feel that should be done to prevent HIV in the first place is that I think HIV should be taught in school, HIV prevention should be taught in high schools, you know, that way they can be tested on HIV prevention and stuff

and what have you learned from HIV prevention class and stuff like that. That should be a curriculum in high school; that way the younger generation will know what HIV is and how it would affect people in their everyday lives."(FG3)

Support groups

Many participants talked about going to support groups and workshops. One participant mentioned how she learned to cope with her HIV diagnosis through attending a support group. Another participant indicated that he/she would like more support groups and workshops to be available.

"No... oh, yes, I had an experience, well, at the beginning, I didn't know how to cope with the disease, but with the help from the support group, I don't feel like that anymore, I feel very well." (FG1)

"We have a women's group here on Thursdays, and that's when we talk about everything." (FG1)

"More knowledge on support and volunteer work that could be done. More knowledge on the basis support groups for mental [U/A] things like that, and, after care, I don't know, a lot of voluntary things that could be done. I would like to go to those" (FG3)

Mental health

Many aspects of mental health were discussed by participants. The majority of responses indicated the importance of having quality mental health services and maintaining good mental health. Some participants commented on their mental health practitioners in a positive and helpful light, one mentioned learning to stay busy to stay mentally healthy, and one is currently worried about his mental health. Some participants did not like turnover of therapists and some discussed their journey from depression to acceptance of their HIV diagnosis, which has made them a stronger person.

"Yes, mostly. Well, I had an amazing psychiatrist, she was always willing to help with everything. I used to live in the streets, and she would send the nurse to look for me, knowing where to find me, because they didn't believe I was living in the streets, because I never looked homeless." (FG1)

Either way, you can control them, especially mentally, because if you're constantly thinking 'I have this', 'I tested positive', 'I'm...'. No, you can't do that. It's better to keep yourself busy, active, doing something, like therapy." (FG1)

"Like me, I changed medication, I'm concerned that I'm falling asleep in my car and it's very uncomfortable to be driving around like that, I've been feeling very depressed, I'm a bit ashamed to say it here but, I don't feel well. (FG1)

For me, it's been or it was a positive experience, up until they changed my therapist. They changed my therapist and I didn't feel comfortable with the new one. (FG1)

So much human emotions are involved with that and finally coming to terms with depression. I wasn't so worried about the acceptance of others because I figured there are millions, billions of people on this planet; if one person doesn't like me or doesn't accept me, you know, move on. So, that was just the thought that was going through my mind, but internally I was just beating myself up, being accountable for my irresponsible behavior, so there was a lot going on over the years and, you know, I mean, I'm 41 years young, I wish I knew what I know now back then, so it was difficult. I come across certain individuals who deal with it, who are dealing with it that maybe seem to not, either they're not comfortable with it, they're taking it a little bit more… they're being reckless with their lives and that was something that I saw in myself, so whether you're, you know, gay, straight, white, black, if you're rich or poor, you know, I've come across numerous people who deal with it. It's tough, but after a while it's just, mentally, for me, and spiritually, I became stronger. That's my response. (FG3)

Housing

Housing was discussed in many different ways with a strong call for help with finding housing options resounding, with information about starting the process from homelessness to housing a particularly grave need. One participant did not know that there were options if she were to leave her current precarious housing situation.

"We need support and we need housing, I don't know about the others but, personally, I do need help with that and I said to myself I was going to mention this to you before I left."(FG1)

"R: About housing. They can't help us with that here?
Moderator: About housing?
R: Yes.
Moderator: So, that's... well, we can talk about that one, but, for example, now, is that a service you need, you're having trouble with it, or?
R: Yes, because I need housing.
Moderator: Okay, and, for example, what are the needs for housing you have, or is it access to...?
R: Well, one, because I don't have a job, and right now, I have a friend who pays my rent but [U/A] get angry, if I had my own place, if he wants to leave, he can [U/A] [O/V] he's a young boy [U/A], he leaves and he's going to leave me hanging with no job or anything.
Z: Well, they can help you, for example, well, I know they do help you out, but it doesn't happen overnight. It's a process. And then, they send you to a shelter, then they move you around and you have to be patient [U/A] for them to -
R: I'm sorry, what's a 'shelter'?" (FG1)

D. Other Issues Raised

PrEP and PEP

Although six participants indicated that they are currently accessing PrEP and three anticipated needing it within the next year, there was little discussion on the use of either PrEP or PEP within the focus group. One participant pointed out that as it only protects against one type of STD, it is not an efficient tool.

> "I will. Usually when, you know, coming out of this experience, I usually let my partner know about my HIV status and the guys, men, they don't seem to really be bothered by the HIV status. I can go in depth, dialogue about that, but I think, nowadays, there just seems to be this thing about this, it's just not a really… it's not a big concern as it used to be, like it was in the 80s or early 90s, I mean, there's medications and there's a PrEP, but, still, you can always get an STD. That's just my take. Being sexually active, you know, just being sexually active, just being honest, but, usually, guys are not willing to use protection at all, but I have to be, you know, I need to be careful, so, usually I am safe when I'm sexually active and that's just the truth, that's all I care about: my experience."(FG3)

Youth Services – No Cost

For youth to access sexual health services, even though participants had health insurance, their first point of recourse would be to look up free testing and free service providers. This was due to the preference for privacy from parents. They also indicated they would ask another trusted adult to take or accompany them, but not their parents.

> "L: Like, just knowing that you have HIV, they would know that you're sexually active, and, then, that would be a problem.
> A: So, confidentiality is the problem. …I think most kids or teenagers would not want their parents to know that they're sexually active.
> Moderator: So, if they didn't want their parents to know, and they wanted to access services, how would they go about it?
> L: Ask someone we trust.
> E: To take them.
> L: Mm-hm, yeah.
> A: Yeah.
> E: Make up a fake name."(FG2)

Addressing Health Disparities where they Happen

When asked what was the most important thing they would want the LAC Commission on HIV to know, a few participants discussed providing more HIV testing and services in the highest need areas and populations of the city.

> "I think they should be a little more proactive in testing people that are in the streets and testing people that come in to shelters just to know their status, and other places. I know there's a lot of places, like, for homeless people, for the transgender, like, the transgender

people on the streets, they go to the places, shelters and they don't have a lot of information; I think they should have information there, too, and also testing there." (FG3)

"I think marketing, promotion of the preventions taken and the drugs targeted and transportation. I think there's probably about [U/A] going downtown in L.A. and target a whole bunch of drug addicts that are in the prime of their addiction and are probably in a time of their lives that they're probably not very prompt to take that action to really want to get tested or, you know, I think you should probably not putting that off, it should always be awkward, but the way that it's… maybe if there's some incentive for people that are in those areas, [U/A], today there's a bit of an incentive to be here, which is really a huge… it's a big deal, because, not only are you getting this education but you're also taking something [U/A] that they can take back and maybe spread the word with these things. They're not going to be easily adopted by people with substance abuse issues, but, I think, also with, I've been in several recovery homes in Los Angeles and there's several [U/A] but I believe people in transitions are more active or, more receptive to receive services and I think that [U/A] public houses, the recovery homes available whether they're high end or low, and education [U/A]."(FG3)

"Yes, I'm [U/A] of the county, Los Angeles County. They need to be more knowledgeable of these practices of the HIV people that are doing this, you know? Such as the ones who are using drugs. You know? I would say that when they get to the level [high], they have sex or whatever, and they use condoms or something it gets so nasty, you know. [U/A] There's a high percentage of people that's infected with this. … I just think the County could help us prevent with programs or something. Preventions, yes."(FG3)

HIV Perception

Some participants living with HIV viewed their diagnosis as manageable and not as life threatening as other chronic diseases such as diabetes or cardiovascular disease. They expressed being more concerned about their treatment and health outcomes related to a chronic disease diagnosis rather than their HIV status.

"Well, I've accepted the HIV virus because I know it won't kill me, diabetes, on the other hand, can, because it's a disease that even if you're having medical check-ups, diabetes is a disease that slowly and silently kills you, because, if you're happy, or if you feel a strong emotion, everything can turn your sugar levels upside down. Either it goes way up, or way down." (FG1)

"Well, let me tell you, I came here before I had my heart surgery because I wasn't feel well. My arms and back hurt, and I came here to get it checked by the doctor. He told me 'don't worry, it's just the flu'. The next day, I felt as if I were choking, and my daughter took me to the E.R. So, what happened was, the heart valve wasn't functioning properly, so, instead of pumping blood to the heart, it was pumping it to the lungs, so my lungs filled with fluids and I felt as if I were choking. They rushed me to the hospital and I had to have emergency open

heart surgery and they put a new valve. So, that's the problem I have now, of which I'm more mindful of than the HIV" (FG1)

Limitations

The low number of participants in the youth group coupled with the fact that they were from the same school and same social circle limit the representativeness of this information. Furthermore, the youth found the recruitment information at their local library, which may suggest that they are somewhat more informed than others their age because they access library services. All youth participants were also from the same cultural and ethnic group, which further limits the representativeness of their experiences to the diverse Angelino geography. The authors suggest replicating this focus group to confirm/disconfirm results, with targeted recruitment via high schools. While recruiting through one high school will also have some similar limitations, a large urban entity may reflect the diversity of the ideal participant population.

A fourth focus group with young adults 18-24 was scheduled but cancelled due to lack of participants. It will be re-scheduled. Potential recruitment for this age range could be completed at a community college or public university.

To address the reality that health disparities exist by zip code, the two groups mentioned above could be held in different areas in Los Angeles where high disparities currently exist or have existed historically. If there is an area that has made marked health improvements, it could be a potential site.

Participants in the focus group held at an agency provided positive feedback about their experiences at this agency. This could be a social desirability limitation in that participants might have indicated this sentiment as the focus groups and other services are held there, and they felt the need to be thankful for or appreciative of those services to maintain positive relationships with providers.

Discussion

At the end of two of the focus groups each participant was asked to provide 1 to 3 points that they considered the most important message for the LA Commission on HIV to address.

A key message heard across groups was the need for prevention services in the form of early education, awareness and prevalent HIV testing. With respect to prevention education services, there was a strong preference for culturally responsive services for Native Americans as well as youth-oriented and women-oriented services. If tailored services were not possible to serve all, respect and dignity was the expected standard. To reach this level of expected service the information needed to be clearer and visually welcome all groups (e.g. Native Americans, youth, substance users).

Several groups also emphasized the need for education, awareness and follow-through with standard protocols among providers. A key issue was the outing or disclosure of status by health professionals.

Appendices:

Appendix 1. Demographic survey

English

Spanish

Appendix 2. Focus Group guide

English, Adult

Spanish, Adult

English, Youth

Appendix 3. NCLR/CSULB Center Background

_____ID

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Community Listening Sessions Discussion Questions, Tier 2

Demographic Questionnaire

Thank you for sharing your ideas and feedback on how we can improve HIV services in Los Angeles County. This questionnaire is intended to collect important information that the Commission on HIV needs in order to understand the service gaps and opportunities in our community.

I. Age

- ○ 13-17 years old
- ○ 18-24 years old
- ○ 25-29 years old
- ○ 30-39 years old
- ○ 40-49 years old
- ○ 50-59 years old
- ○ 60 years and older

II. Race/Ethnicity (please check all that apply)

- ○ African American
- ○ American Indian/Alaskan Native
- ○ Asian
- ○ Latino/Hispanic
- ○ Pacific Islander
- ○ White/Not Hispanic
- ○ Other:_____
- ○ Decline to state

III. Gender

- ○ Male
- ○ Female
- ○ Trans (Male to Female)
- ○ Trans (Female to Male)

IV. Sexual Orientation: Do you consider yourself to be:

- ○ Heterosexual or straight
- ○ Gay, lesbian, same gender loving
- ○ Bisexual
- ○ Queer/Questioning
- ○ Other:_____
- ○ Decline to state

V. Educational Attainment (please check highest level completed)

- ○ Less than high school
- ○ Some high school
- ○ High school or GED
- ○ Some college (did not graduate)
- ○ Vocational/Technical School Diploma
- ○ Associates degree
- ○ Bachelor's degree
- ○ Advanced degree (Masters and above)

VI. Income

- ○ Less than $15,000 a year
- ○ $15,000-$20,000 a year
- ○ $21,000-$25,000 a year
- ○ $25,000- $30,000 a year
- ○ More than $30,000 a year

VII. Marital Status

- ○ Single
- ○ Married

VIII. Family Household: How many people are in your household?

- ○ 1, just me.
- ○ 2
- ○ 3-5
- ○ More than 5

IX. Have you ever been told that you have HIV?

- ○ Yes
- ○ No

a. If so, when were you diagnosed? (month/year) _____

X. Do you have health insurance?

- ○ Yes
- ○ No

a. If yes, what type? (please check all that apply)

- ○ Medi-Cal
- ○ Covered California
- ○ Medicare
- ○ Kaiser Permanente
- ○ I don't know.
- ○ Other: please specify: _____

b. Do you have difficulty paying your premium, co-pay, or medications?

- ○ Yes
- ○ No

XI. What kind of services are you currently receiving? Check all that apply.

Type of Service	I am using now	I need but am having trouble accessing it	I will need in next year	I don't need it right now.
Help getting enrolled in health insurance				
PrEP (pre-exposure prophylaxis; for people who are at very high risk for HIV take HIV medicines daily to lower their chances of getting infected)				
HIV prevention education (classes, workshops, presentations)				
STD prevention education (classes, workshops, presentations)				
Condoms (free)				
HIV testing				
STD testing				
STD treatment				
HIV medical care				
General oral health services (regular check-up, cleaning, root canals, braces)				

Type of Service	I am using now	I need but am having trouble accessing it	I will need in next year	I don't need it right now.
Specialty oral health services (surgery, more complex procedures)				
Psychiatry mental health services (focused on the diagnosis, treatment and prevention of mental, emotional and behavioral disorders)				
Psychotherapy mental health services (treating mental health problems by talking with a psychiatrist, psychologist or other mental health provider; helps you learn how to take control of your life and respond to challenging situations with healthy coping skills).				
Medical case management services				
Home and community based services				
Medical nutrition therapy				
Non-medical case management (assistance in accessing medical, social, community, legal, financial, and other needed services)				
Medical transportation services				
Food bank/home-delivered meals				
Housing services				
Housing Opportunities for People with AIDS (HOPWA) program services				
Language services (interpretation, translation)				
Residential substance abuse treatment (Long-term residential treatment provides care 24 hours a day, generally in non-hospital settings)				
Outpatient substance abuse treatment (group counseling; treatment for patients with medical or other mental health problems in addition to their drug disorders.)				
Outreach (basic education; get people into needed services)				
Referrals for services				
Legal services				
Other: (specify):_____				

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Sesiones de intercambio de información de grupos de trabajo de participación comunitaria , T2

Cuestionario demográfico

Gracias por compartir sus ideas y opiniones sobre cómo podemos mejorar los servicios de VIH en el Condado de Los Ángeles. Este cuestionario está diseñado para recopilar información importante que la Comisión sobre VIH necesita para entender las deficiencias de servicio y las oportunidades en nuestra comunidad.

I. Edad

○ De 13 a 17 años	○ De 40 a 49 años
○ De 18 a 24 años	○ De 50 a 59 años
○ De 25 a 29 años	○ 60 años o más
○ De 30 a 39 años	

II. Raza/Grupo étnico (por favor, indicar todas las que aplican)

○ Afroamericano	○ Isleño del Pacífico
○ Indígena Americano/ Nativo de Alaska	○ Blanco/no hispano
○ Asiático	○ Otro:_____
○ Latino/Hispano	○ Se niega a responder

III. Género

○ Masculino	○ Transexual (masculino a femenino)
○ Femenino	○ Transexual (femenino a masculino)

IV. Orientación sexual: Se considera:

○ Heterosexual o hétero	○ Queer (raro) /Indeciso
○ Gay, lesbiana, amantes del mismo sexo	○ Otro:_____
○ Bisexual	○ Se niega a responder

V. Nivel educativo (por favor, indicar el nivel más alto completado)

○ Menos que el secundario	○ Diploma de escuela vocacional/técnica
○ Algo de la escuela secundaria	○ Título de asociado
○ Secundario o GED (Diploma de educación general)	○ Licenciatura
○ Algo de universidad (no se graduó)	○ Título avanzado (maestría y más)

VI. Ingreso

○ Menos de $15,000 por año	○ De $25,000 a $30,000 por año
○ De $15,000 a $20,000 por año	○ Más de $30,000 por año
○ De $21,000 a $25,000 por año	

VII. Estado civil

○ Soltero	○ Casado

VIII. Vivienda familiar ¿Cuántas personas residen en su vivienda?

○ 1, solo yo.	○ De 3 a 5
○ 2	○ Más de 5

IX. ¿Le han dicho alguna vez que tiene VIH? ____Sí _____No

a. Si la respuesta es sí, ¿cuándo se lo diagnosticaron? (mes/año)

_____

X. ¿Tiene seguro de salud? ____Sí _____No

a. Si la respuesta es sí, ¿qué tipo? (por favor, indicar todas las que aplican)

_____Medi-Cal _____Covered California
_____Medicare _____Kaiser Permanente

_____Otro: (especifique):

b. ¿Tiene dificultades para pagar su prima o copago?
____Sí ___No

XI. ¿Qué tipo de servicios recibe actualmente? Indicar todas las que aplican.

Tipo de servicio	Ahora uso	Necesito, pero tengo problemas para acceder	Necesitaré el próximo año
○ Ayuda para inscribirme en un seguro de salud			
○ PrEP (profilaxis previa a la exposición)			
○ Educación de prevención del VIH			
○ Educación de prevención de ETS			
○ Condones (gratis)			
○ Prueba de VIH			
○ Prueba de ETS			
○ Tratamiento de ETS			
○ Cuidado médico de VIH			
○ Servicios de salud oral (general)			

○ Servicios de salud oral (especialidad)			
○ Servicios de salud mental (psiquiatría)			
○ Servicios de salud mental (psicoterapia)			
○ Servicios de administración de casos médicos			
○ Servicios basados en el hogar y la comunidad			
○ Terapia de nutrición médica			
○ Administración de casos no médicos (administración de casos de enlace, especialidad en beneficios)			
○ Servicios de transporte médico			
○ Banco de alimentos/servicio de envío de comidas			
○ Servicios de vivienda (Centro de cuidado residencial para los enfermos crónicos)			
○ Servicios de vivienda (Centro de cuidado residencial de transición)			
○ Servicios del programa HOPWA (Programa de oportunidades de vivienda para personas que viven con SIDA)			
○ Otros servicios de vivienda			
○ Servicios de idiomas			
○ Tratamiento por abuso de sustancias (residencial)			
○ Tratamiento por abuso de sustancias (ambulatorio)			
○ Participación de la comunidad (vínculo y nuevo compromiso)			
○ Derivaciones para servicios			
○ Servicios legales			
○ Otro: (especificar):_____			

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Focus Group/Listening Sessions Questions and Guide

TIER 2 MASTER FILE (Updated 7-26-16)

Group maximum size: 15 people max per session

When: Varies (6pm to 7:30 pm; 6 -6:30 pm check-in and answer demographic questionnaire; 6:30-7:30 pm focus group)

Target audience: High-risk HIV negative and HIV-positive individuals

Facilitator Duties and Expectation(s):

1. Set the stage (Cheryl Barrit or designee): Introduction of the Commission, its intention, and highlight some of the successes and opportunities for involvement and improvement in the work of the body.
2. Confidentiality: ***Set ground rules for safety and inclusion***, including the role of any commissioners/planning council members in the room. Sample rules may include: cell phones on silent mode, what happens in the room stays in the room, step up step back, no cross talk, agree to disagree, and speaking from "I" statements.
3. Facilitation: Use guide to ask question provided, however, be mindful of emerging themes that may elicit more conversation or offer an opportunity for less participatory individuals to be included in the conversation.
4. Attendance (coordinated by Cheryl and staff in advance): Any Commissioner in attendance will be asked to support the process by observation and volunteerism through note taking and/or referrals; setup and clean-up facility, welcome and thank participants.

Focus Group Questions:

1. Where would you go for your dream vacation? (**Facilitator note**: This is a warm up opportunity to get people thinking bigger.)
2. Describe your experience with obtaining HIV-specific medical care? Positive experience? Negative experience?
3. What have been your experiences with obtaining HIV-specific services? (**Facilitator note**: This question includes opportunities to prompt attendees toward service types such as HIV/STD testing, prevention education, psychosocial, dental, transportation.) Where do you go to look for services?
4. Have you attempted to sign up for health insurance? What has been your experience? Are you receiving the service you need? If not, why?
5. How have you been affected by your HIV status? In what ways have you experienced disapproval or rejection that you believe may have been related to your status?
6. What is your relationship with your doctor? Do you talk about HIV? Sexually Transmitted Infections?
7. How do you protect yourself and others from HIV? (**Facilitator note**: This is an opportunity to learn how people are navigating their sexual health. Can incorporate abstinence, partner negotiation, condoms, treatment as prevention – counseling, testing, medication adherence, and other biomedical strategies)
8. When you try to access services, what issues or concerns come up for you? Has learning your HIV status changed the ways in which you access support? If so, how?
9. How can your doctors and other providers serve you better? (**Facilitator note**: This is an opportunity to talk about quality of care, language, and other potential barriers or tools do you think doctors and other support staff need to enhance prevention and clinical services delivery.)
10. In thinking of the future, where do you want to be in five years?

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Guía y Preguntas para el Grupo de Enfoque , T2

Tamaño máximo del grupo: Límite de 15 personas por sesión

Cuando: varia (6pm a 7:30 pm; de 6 a 6:30 pm registración y cuestionario demográfico; de 6:30-7:30 pm grupo de enfoque)

Dirigido a: Personas quienes viven con VIH o que tengan alto riesgo de contraer a VIH

Expectativas y Responsabilidades de los Facilitadores:

1. Crear el ambiente (Cheryl Barrit o personal designado): Introducción de la Comisión, su intención, destacar algunos ejemplos del éxito y de las oportunidades de participación en el trabajo del organismo.
2. Confidencialidad: ***Establezca las reglas de seguridad e inclusión***, incluyendo el rol de los Comisarios presentes. Algunos ejemplos de las reglas pueden incluir: los celulares deben estar en silencio, lo que pase en el grupo se queda en el grupo, participar activamente sin acaparar la discusión, no interrumpir, estar de acuerdo en discrepar, declaraciones que empiecen con "Yo".
3. Facilitación: Use la guía para realizar las preguntas, sin embargo, tenga en cuenta los temas que se presenten que puedan provocar más conversación o brindar una oportunidad para que los participantes menos activos puedan incluirse en la conversación.
4. Asistencia (coordinada por Cheryl y personal asignado): Se le pedirá a cualquier Comisario presente apoyar el proceso mediante la observación y el voluntariado a través de toma de notas y/o referencias; instalación, organización y limpieza del lugar, además de darle la bienvenida y las gracias a los participantes.

Focus Group Questions (SPANISH):

1. **¿En dónde serían las vacaciones de sus sueños?** (Nota del Moderador: esta es una oportunidad para que los participantes piensen en grande.)
2. **¿Describa cómo ha sido su experiencia al obtener atención médica relacionada con el VIH? ¿Fue una experiencia positiva? ¿Fue una experiencia negativa**?
3. **¿Cuáles han sido sus experiencias al obtener servicios específicos para el VIH?** (Nota del Moderador: esta pregunta incluye oportunidades para enfocar en los tipos de servicios como: prueba de VIH/SIDA, educación para la prevención de enfermedades, psicológica, dental y transporte.)
   ¿En dónde busca servicios?
4. **¿Ha intentado inscribirse en algún seguro médico? ¿Cuál ha sido su experiencia? ¿Está recibiendo el servicio que necesita? Si no, ¿por qué no?**
5. **¿Cómo ha sido afectado su estado de VIH? ¿De qué manera ha experimentado desaprobación o rechazo, que crea haya sido a causa de su estado?**
6. **¿Cómo es su relación con su médico? ¿Hablan sobre el VIH? ¿Hablan sobre las infecciones de transmisión sexual?**
7. **¿Cómo se protege a sí mismo y a otras personas en contra del VIH**? (Nota del moderador: esta es una oportunidad para aprender cómo las personas están manejando su salud sexual. Puede incorporar abstinencia, dialogando con su(s) pareja(s), preservativos, tratamiento como prevención - consejería, pruebas, cumplimiento con la medicina y otras estrategias biomédicas)
8. **Cuando usted intenta acceder a los servicios, ¿qué dudas o preocupaciones surgen? ¿Al conocer su estado de VIH, cambió la forma en que usted obtiene apoyo? Si es así, ¿cómo?**
9. **¿Cómo pueden los médicos y otros proveedores dar mejor servicio**? (Nota del Moderador: esta es una oportunidad para hablar de calidad de atención, lenguaje y otras barreras potenciales o herramientas que cree que los médicos y otro personal de apoyo necesitan para mejorar la prevención y prestación de servicios clínicos.)
10. **Pensando en el futuro, ¿dónde quiere estar en cinco años?**

LOS ANGELES COUNTY COMMISSION ON HIV

3530 Wilshire Boulevard, Suite 1140 • Los Angeles, CA 90010 • TEL (213) 738-2816 • FAX (213) 637-4748
www.hivcommission-la.info

Focus Group/Listening Sessions Questions and Guide

Youth 13-17 years old

TIER 2 MASTER FILE (Updated 7-26-16)

Group maximum size: 15 people max per session

When: September 10, 2016 12 noon to 4 pm @ CHLA DAM Conference Room 4th Floor Large; DAM Conference Room 4th Floor Small; DAM Conference Room 5th Floor

(1pm to 2:30 pm; 1:00-1:30 pm check-in and answer demographic questionnaire; 1:30-2:30 pm focus group)

Target audience: Youth 13-17 Years Old

Facilitator Duties and Expectation(s):

5. Set the stage (Cheryl Barrit or designee): Introduction of the Commission, its intention, and highlight some of the successes and opportunities for involvement and improvement in the work of the body.
6. Confidentiality: ***Set ground rules for safety and inclusion***, including the role of any commissioners/planning council members in the room. Sample rules may include: cell phones on silent mode, what happens in the room stays in the room, step up step back, no cross talk, agree to disagree, and speaking from "I" statements.
7. Facilitation: Use guide to ask question provided, however, be mindful of emerging themes that may elicit more conversation or offer an opportunity for less participatory individuals to be included in the conversation.
8. Attendance (coordinated by Cheryl and staff in advance): Any Commissioner in attendance will be asked to support the process by observation and volunteerism through note taking and/or referrals; setup and clean-up facility, welcome and thank participants.

Focus Group Questions:

11. Where would you go for your dream vacation? (**Facilitator note**: This is a warm up opportunity to get people thinking bigger.)
12. Have you heard of HIV? How about STDs or STIs? What do you know about HIV? What do you know about STDs? (probe for prevention knowledge)
13. Who has talked to you about HIV? Who has talked to you about STDs?
14. Where do you get your information on sex? Where do your friends get their information about sex? When you and your friends talk about sex, what do you talk about?
15. Where do you go for HIV/STD services? Where do your friends go for HIV/STD services? What have been your experiences with obtaining HIV/STD services?
16. How do you protect yourself and others from HIV and STDs? (**Facilitator note**: This is an opportunity to learn how people are navigating their sexual health. Can incorporate abstinence, partner negotiation, condoms, testing)
17. When you try to access services, what issues or concerns come up for you?
18. How can your doctors and other providers serve you better? (**Facilitator note**: This is an opportunity to talk about quality of care, language, and other potential barriers or tools do you think doctors and other support staff need to enhance prevention and clinical services delivery.)
19. In thinking of the future, where do you want to be in five years?

NCLR/CSULB Center for Latino Community Health, Evaluation, and Leadership Training

Established in 2005, the NCLR/CSULB Center for Latino Community Health, Evaluation, and Leadership Training is a collaborative between CSULB and the largest Latino advocacy and civil rights organization in the U.S., NCLR. In 2013, the NCLR/CSULB Center staff opened a community-based participatory research site in a densely-populated, Latino dominant area of downtown Long Beach, the *Centro Salud es Cultura*. The shared mission of the NCLR/CSULB Center and of the *Centro* is to improve, promote, and advocate for the health, culture, and well-being of diverse Latino communities. The NCLR/CSULB Center has experience in developing, implementing, and evaluating health interventions aimed to address HIV/AIDS, STIs, maternal and child health, obesity prevention, youth leadership, and student academic achievement. In addition, the NCLR/CSULB Center provides technical assistance to the NCLR Institute of Hispanic Health, NCLR affiliates, other Latino-focused community based organizations and health care providers to inform research and develop program evaluation tools and effectiveness measures. The NCLR/CSULB Center also works to increase the number of Latinos in health and human services professions, and provide evidence to bolster health and education policy processes at the local, state, and national levels.

CLICK HERE TO RETURN TO PART 1

Los Angeles County Commission on HIV

Community Listening Sessions Report Part 3:

Asians and Pacific Islanders, Trans-Masculine Individuals, Recently Post-Incarcerated Individuals, 25-25 Year Olds, HIV Workforce

This report is a collaborative effort of the:
Los Angeles County Commission on HIV
Division of HIV and STD Programs, Department of Public Health
NCLR/ California State University Long Beach (CSULB) Center for Latino Community Health, Evaluation, and Leadership Training

July 3, 2017

Special acknowledgements: This report was prepared by the following individuals from NCLR/ California State University Long Beach (CSULB) Center for Latino Community Health, Evaluation, and Leadership Training: Mara Bird, Ph.D., Katharine Shiota, MSW, Natalia Guerrero, BA, Maryan Santa Cruz, Denisse Nereida Valdez, BS, Luis Cendejas, BS, Mayra Rascon, M.P.H, Erika Bonilla, MPH, Melawhy Garcia, Ph.D.

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Overview

The NCLR/CSULB Center for Latino Community Health, Evaluation and Leadership Training staff conducted four focus groups with consumers of various subgroups in the Los Angeles community: Asian/Pacific Islanders, Trans-Masculine People, Recently Post-Incarcerated People, and 25-29 Year-Olds. Additionally, two focus groups with members of the LA County HIV workforce were implemented to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Methodology

Recruitment

All focus group recruitment was coordinated by the Los Angeles County Commission on HIV. All groups were scheduled and implemented within a one-month period in Spring 2017 (January 25-February 28, 2017) in different locations in Los Angeles County.

Instruments

Consent forms and demographic surveys were developed by the Los Angeles County Commission on HIV and provided to the NCLR/CSULB Center Evaluation Team to administer prior to the focus group (Appendix A). The Los Angeles County Commission on HIV Team developed the focus group guide and survey questions. The NCLR/CSULB Center Evaluation Team provided translation of the revised items into Spanish. Focus group questions were designed in order to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Focus Group Facilitation

Each focus group was moderated by experienced and trained bilingual NCLR/CSULB Center evaluation staff who are certified in the protection of research subjects' rights. Focus group participants were greeted, thanked for their participation, and completed informed consent procedures with the moderator and note taker(s). The listening session process is a non-research activity exempt from IRB requirements. Nonetheless, all participants provided written and verbal agreement to participate in the focus group discussions.

Each focus group was digitally recorded using two recorders and each session lasted approximately 90 minutes. The digital recording was sent to a transcription service, which typed up the discussion. The transcriptions were provided to the NCLR/CSULB Center staff for analysis.

Analysis

The demographic survey data was entered, cleaned and analyzed by NCLR/CSULB Center staff using Statistical Program for the Social Sciences (SPSS) Version 23.0 (IBM Corp. Released 2015, Armonk, NY) Descriptive statistics were computed.

The transcripts were coded in Dedoose (Version 7.5.16, web application for managing, analyzing, and presenting qualitative and mixed method research data (2016). Los Angeles, CA: SocioCultural Research Consultants, LLC, www.dedoose.com) by four independent coders. Using the focus group guide and the debriefing notes as base documents, the moderators and note-takers met as a team to discuss potential codes and to create a preliminary codebook. New codes were added after periodic team meetings and transcripts subsequently re-reviewed for additional categories. Below, the survey results are presented first, followed by the focus group discussion findings.

RESULTS

Focus Group Characteristics

The NCLR/CSULB Center facilitated six focus group events as part of the community input process for the Los Angeles County Commission on HIV. Table 1 below describes characteristics and logistic information for the focus groups.

Table 1., Characteristics, Timing and Location of Listening Sessions

Focus Group No.	Target audience	Date & Time	Location	# of People	Moderator	Note Taker
1	Asian/Pacific Islander	January 25, 2017; 6-7:30pm	APAIT Building 1730 W Olympic Blvd #300	16	Mara Bird, PhD	Luis Cendejas, BS
2	Trans-Masculine	January 30, 2017; 6-7:30pm	APAIT Building 1730 W Olympic Blvd #300	2	Mara Bird, PhD	Luis Cendejas, BS
3	Recently Post-Incarcerated	February 14, 2017: 5:30-7pm	Commission on HIV 3530 Wilshire Blvd Ste. 1140	1	Mayra Rascón, MPH	Maryan Santa Cruz
4	25-29 Year Olds	February 16, 2017; 12-1:30pm	Reach LA 1400 E Olympic Blvd # 240	4	Luis Cendejas, BS	Mara Bird, PhD

5	HIV Workforce #1	February 24, 2017; 12-1:30pm	The California Endowment 1000 North Alameda St.	13	Mara Bird, PhD	Maryan Santa Cruz
6	HIV Workforce #2	February 28, 2017; 12-1:30pm	Building Healthy Communities Long Beach 920 Atlantic Ave. Suite 102	11	Mara Bird, PhD	Luis Cendejas, BS

Focus Group Demographic Results -Consumers

The four focus groups were the following: (1) Asian and Pacific Islander (n=16); (2) Trans-Masculine (n=2); (3) 25-29 year-olds (n=4); and (4) Recently Incarcerated (n=1). In total, the focus groups consisted of 23 participants from Los Angeles County.

Overall

Focus group participants were primarily 30-39 year-olds (30.4%) and 50-59 year-olds (30.4%). Figure 1 displays the age range of all participants.

Figure 1. Age (n=23)

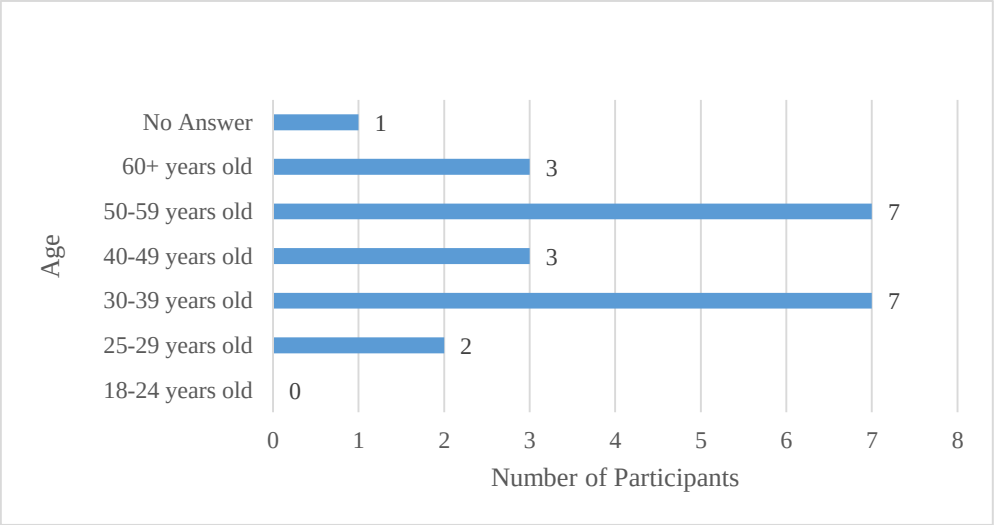
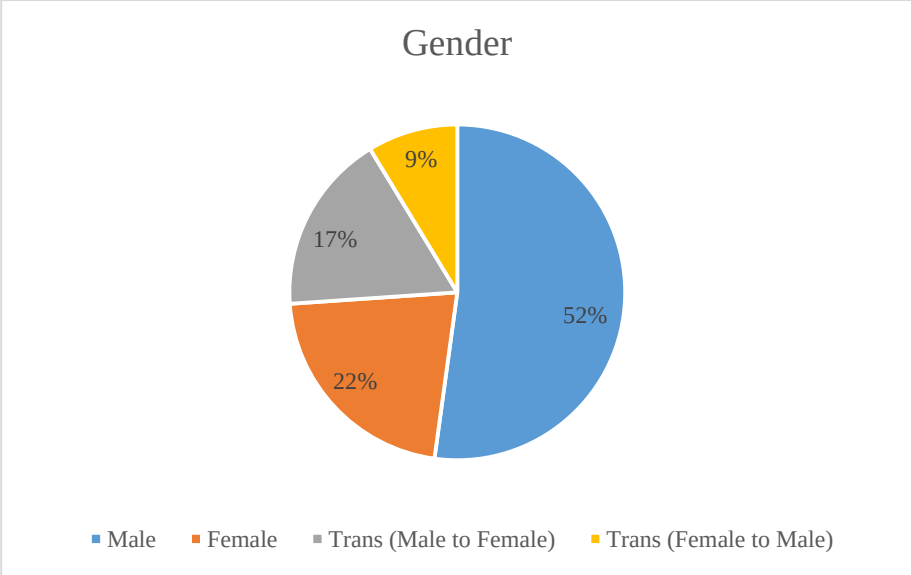


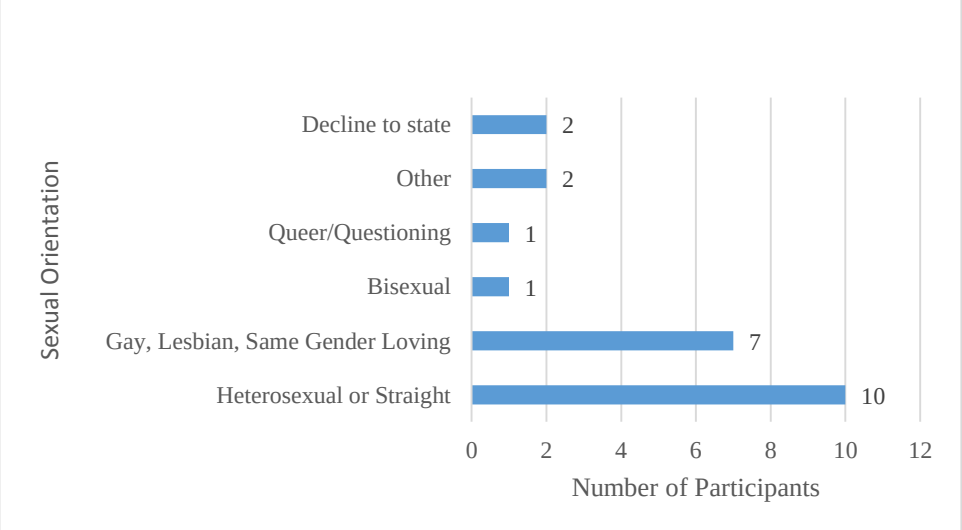
Figure 2 shows that there were more male participants than other groups.

Figure 2. Gender (n=23)



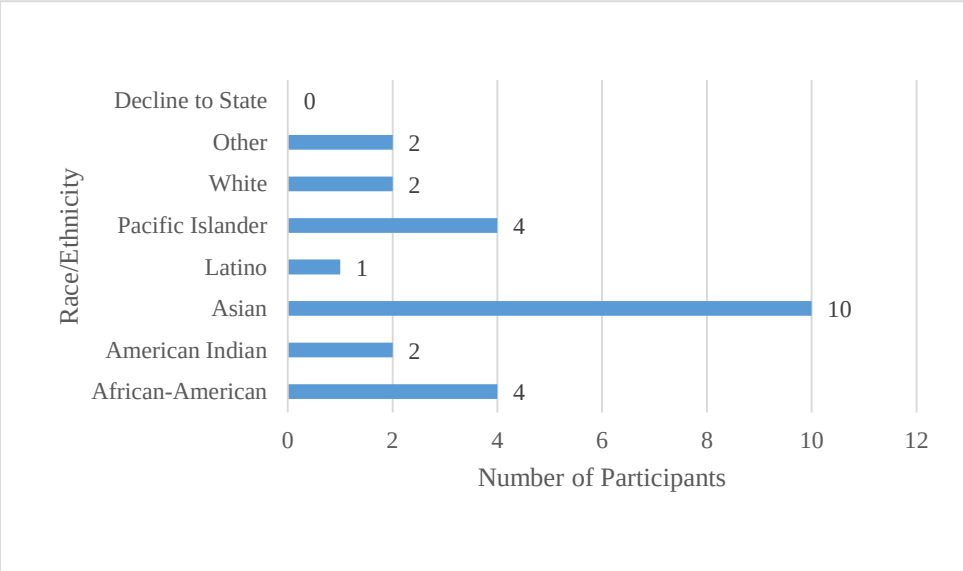
Those who self-reported being heterosexual (43.5%) made up slightly less than half of focus group participants, with those with more fluid sexual orientations also represented among participants. Figure 3 displays the sexual orientation categorization.

Figure 3. Sexual Orientation (n=23)



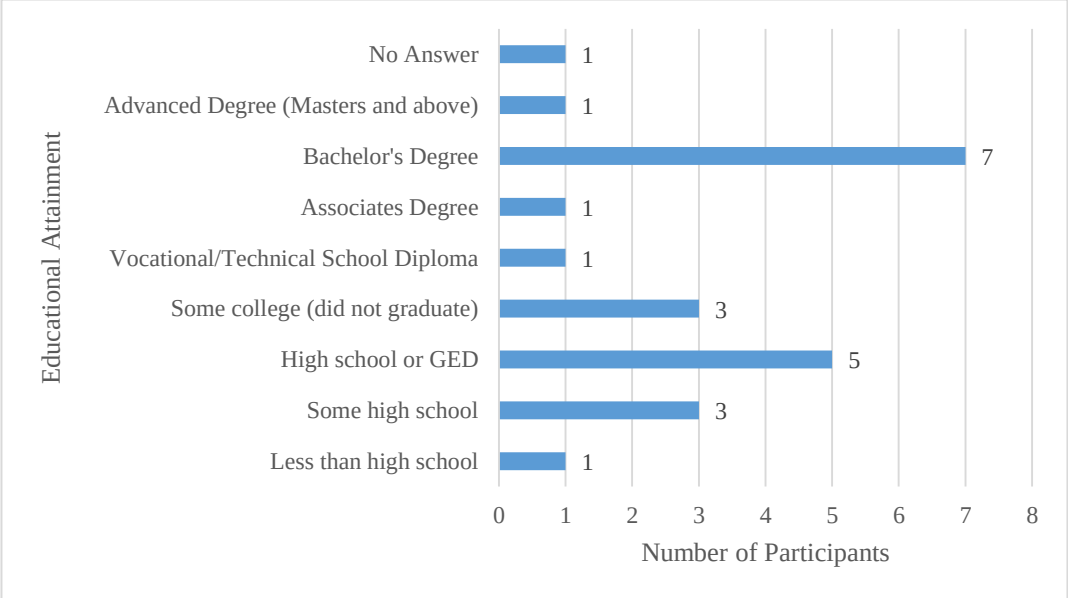
The majority of the participants were Asian (43.5%), followed by Pacific Islander (17.4%) and African American (17.4%). The figure below shows the racial/ethnic background of all participants. Some participants have more than one race/ethnicity.

Figure 4. Race/Ethnicity (n=23)



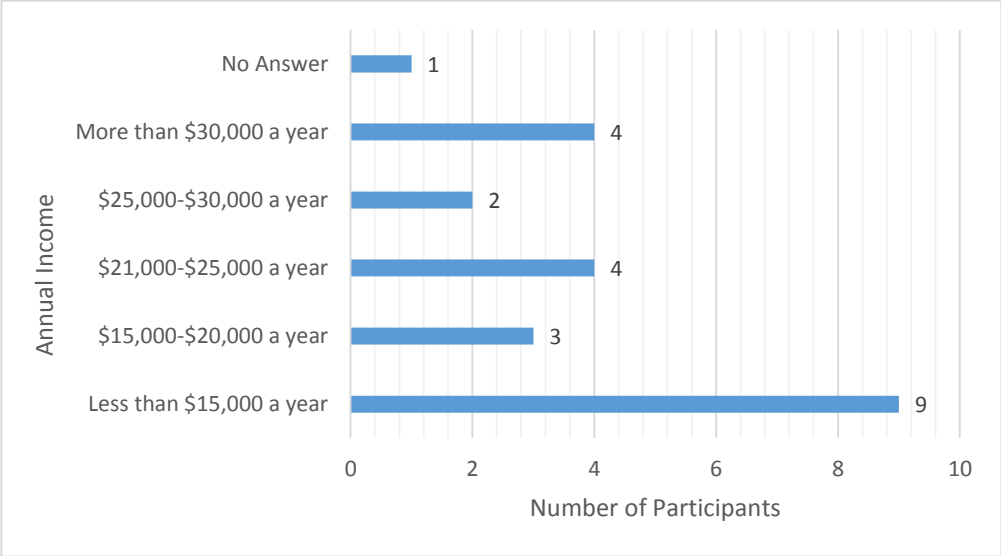
Educational level varied, with those completing a Bachelor's Degree (30.4%) comprising the largest group, followed by High School or GED (20.7%). Figure 5 displays the educational levels of all of the participants.

Figure 5. Participant Education Level (n=23)



The largest proportion of participants (39.1%) earn $15,000 or less annually. Figure 6 displays the participant's self-reported income.

Figure 6. Annual Income (n=23)



Out of the 23 participants, most (56.5%) live alone, and self-reported being single (87.0%). One person noted that they were widowed. The figures below portray household size and marital status of all the participants.

Figure 7. Household Size (n=23)

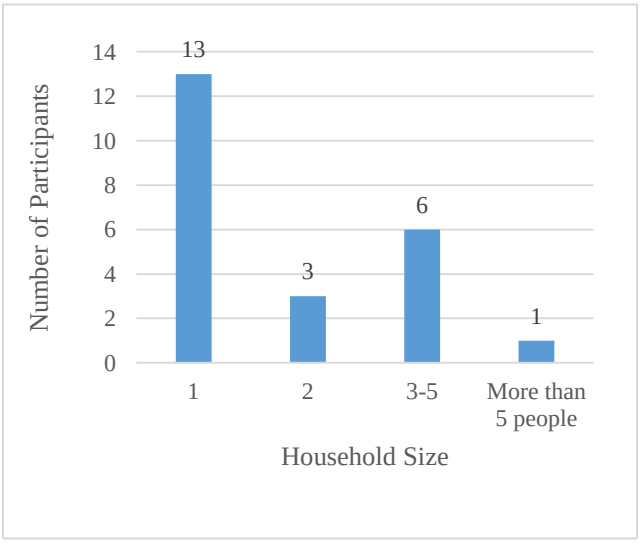
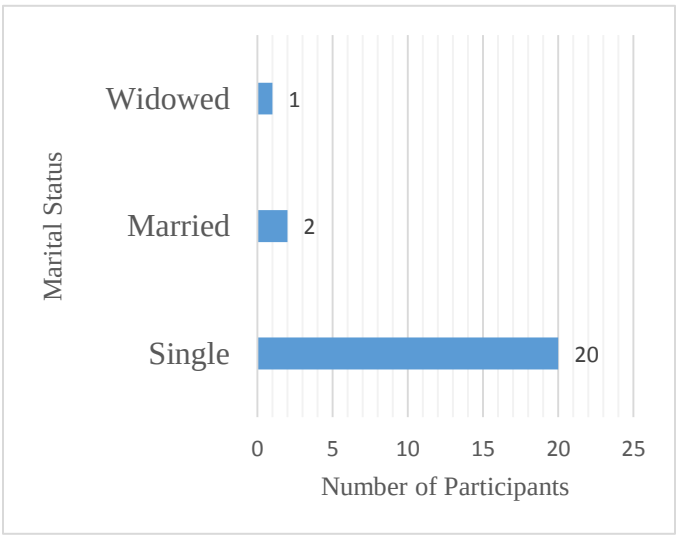


Figure 8. Marital Status (n=23)



More than half of the participants (n=21) have health insurance; Medi-Cal (56.5%) being the most common. The figures below illustrate the health insurance status and types of health insurance of all participants.

Figure 9. Health Insurance Status (n=23)

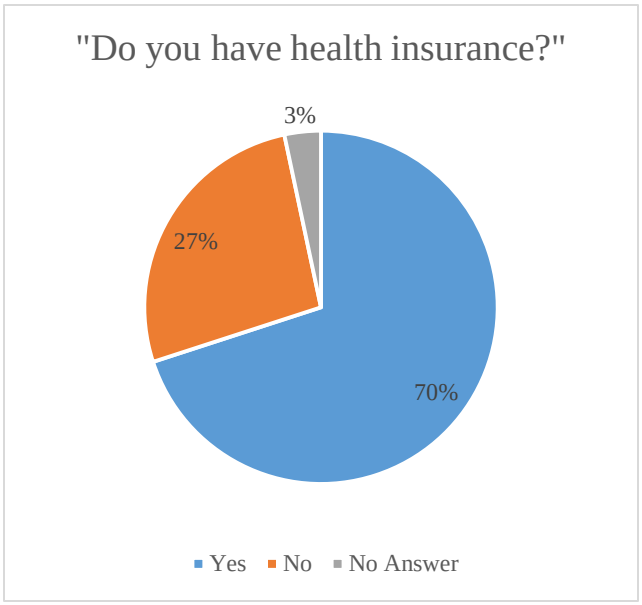
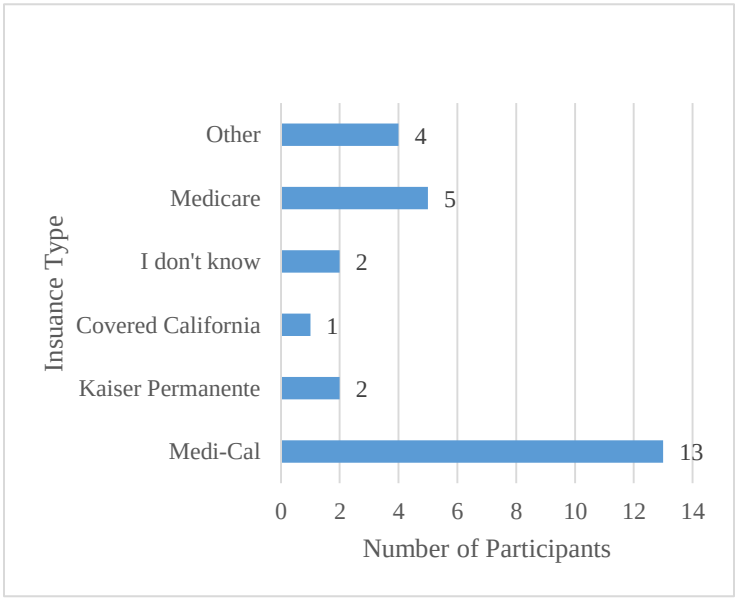
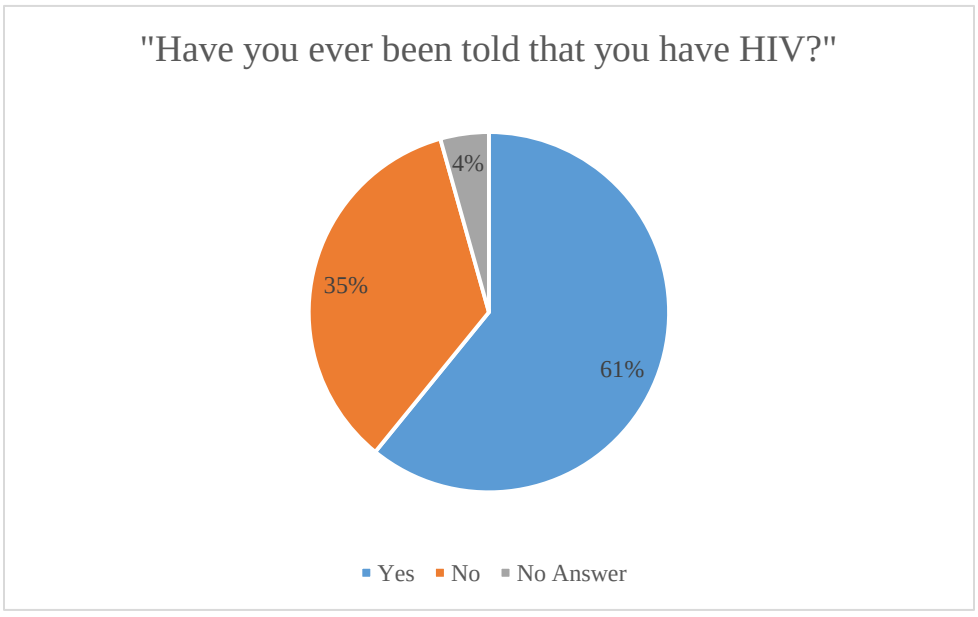


Figure 10. Types of Health Insurance (n=23)



Among the 23 participants, more than half of the participants (n=14) reported being diagnosed with HIV, and one participant declined to answer. The figure below illustrates all responses.

Figure 11. Participants Diagnosed with HIV (n=23)



Those that had been diagnosed with HIV averaged 17.2 years living with HIV (SD = 9.06). The years since their diagnosis ranged from 2 to 33 years. Four participants reported having HIV without providing the date of diagnosis. Table 2 provides an aggregate list of reported years living with HIV.

Table 2. Years living with HIV (n=23)

Years Since Diagnosis	Frequency	Percent
33	1	4%
30	1	4%
20	1	4%
18	2	9%
17	1	4%
16	1	4%
13	1	4%
5	1	4%
2	1	4%
Not Applicable	8	35%
No Answer	5	22%

The number of services used per participant averaged 5.11, with the majority using free condoms (48%), followed by psychiatry/mental health services (48%), and HIV medical care (39%). The services not in use currently are residential substance abuse treatment, and outpatient substance abuse treatment. The average number of services per person that the participants need but have trouble accessing is 1.57. The most commonly reported needed services are general oral health services (30%), specialty oral health services (17%), and medical nutrition therapy (17%). The table below provides more details of these services in demand. The average number of services per person that the participants anticipate needing in the next year is 0.75. The majority of the participants reported the expected need for outpatient substance abuse treatment (13%), Pre-Exposure Prophylaxis (9%), general oral health services (9%), medical transportation services (9%), and home-delivered meals (9%). Note that while no one responded that they currently receiving outpatient substance abuse treat, this is the top services expected to be needed in the next year.

Table 3. Use of services

"What kind of services are you currently receiving?"	I am using now		I need but am having trouble accessing it		I will need in the next year		I don't need it right now	
	n	Percent	n	Percent	n	Percent	n	Percent
Condoms (free)	11	48%	0	0%	0	0%	10	44%
Psychiatry mental health services	11	48%	3	13%	0	0%	8	35%
HIV medical care	9	41%	1	5%	0	0%	8	36%
STD prevention education	8	35%	0	0%	0	0%	11	48%
Psychotherapy mental health services	8	36%	3	14%	1	5%	7	32%
Referrals for services	8	42%	0	0%	1	5%	9	47%
Help getting enrolled in health insurance	7	32%	2	9%	0	0%	10	46%
HIV prevention education	7	30%	1	4%	1	4%	10	48%
HIV testing	7	30%	0	0%	0	0%	13	57%
Medical case management services	7	37%	1	5%	0	0%	9	47%
Non-medical case management	7	39%	3	17%	0	0%	6	33%
STD testing	6	26%	0	0%	1	4%	13	57%
Specialty oral health services	5	22%	4	17%	0	0%	10	44%
Food bank/home-delivered meals	5	28%	0	0%	2	11%	10	56%
HOPWA program services (housing assistance for PLWHA)	5	26%	1	5%	1	5%	10	53%
STD treatment	4	18%	0	0%	0	0%	14	64%
Home and community based services	4	21%	3	16%	1	5%	9	47%
Medical nutrition therapy	4	22%	4	22%	0	0%	8	45%
Housing services	4	22%	3	17%	1	6%	8	44%
Legal services	4	21%	2	11%	1	5%	10	53%
PreP (Pre-Exposure Prophylaxis)	3	13%	0	0%	2	9%	14	61%
General oral health services	3	13%	7	30%	2	9%	7	30%
Medical transportation services	2	11%	2	11%	2	11%	12	63%
Outreach	2	11%	3	16%	1	5%	11	58%
Language services (interpretation, translation)	1	6%	1	6%	0	0%	14	78%
Other	7	37%	0	0%	0	0%	0	0%
Residential substance abuse treatment	0	0%	0	0%	1	5%	16	84%
Outpatient substance abuse treatment	0	0%	0	0%	3	16%	14	74%
Total (N)	23							

Focus Group Demographic Results –HIV Workforce

The two focus groups consisted of a total of 24 participants from Los Angeles County who currently work in the HIV field.

Overall

Focus group participants were primarily 50-59 years old (50%). Figure 12 displays the age range of all participants

Figure 12. Age (n=24)

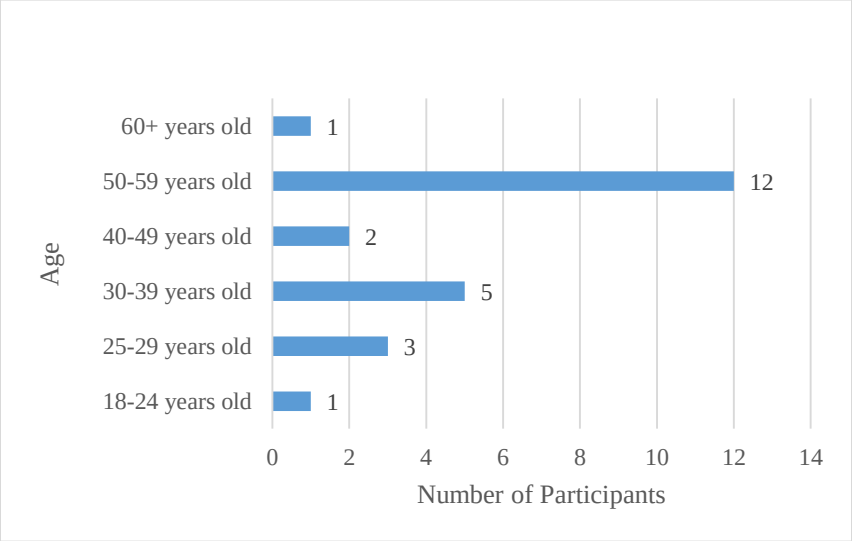
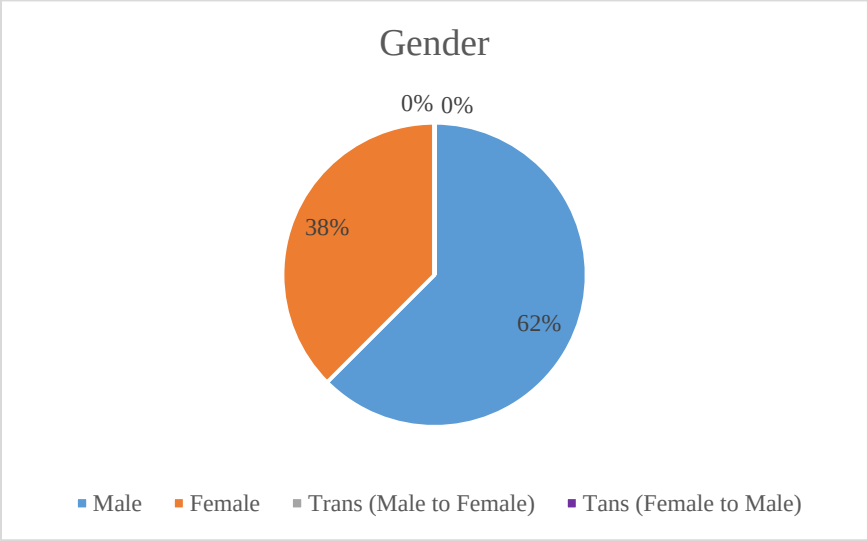


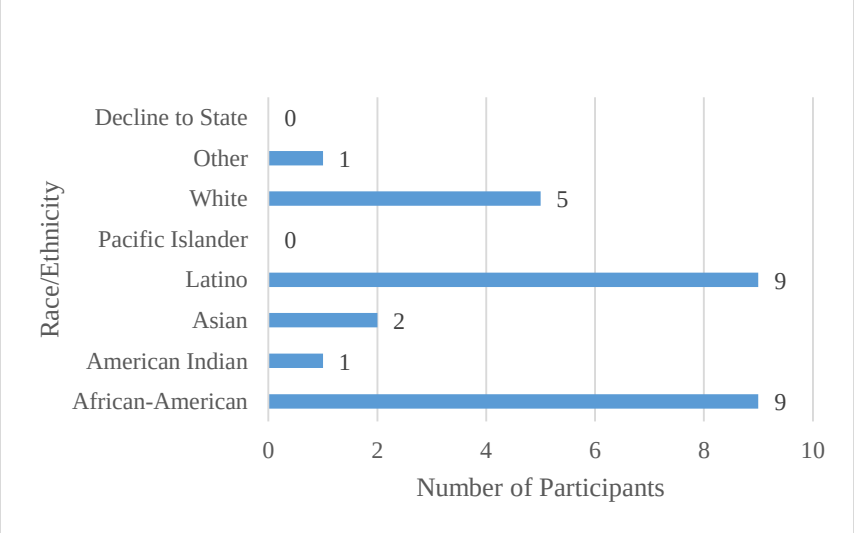
Figure 13 presents the gender of the participants. More males (n=15) participated than in consumer groups; two genders were represented.

Figure 13. Gender (n=24)



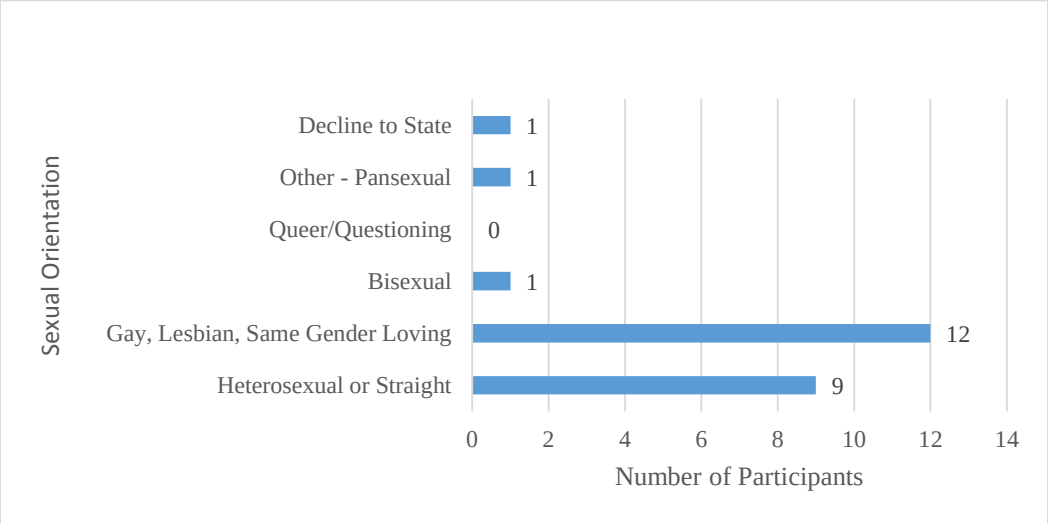
The largest proportion of participants were Latino (37.5%) and African American (37.5%), followed by White (20.8%), and Asian (6.9%). Figure 14 displays the race and/or ethnicity of focus group participants. Some participants have more than one race/ethnicity.

Figure 14. Race/Ethnicity (n=24)



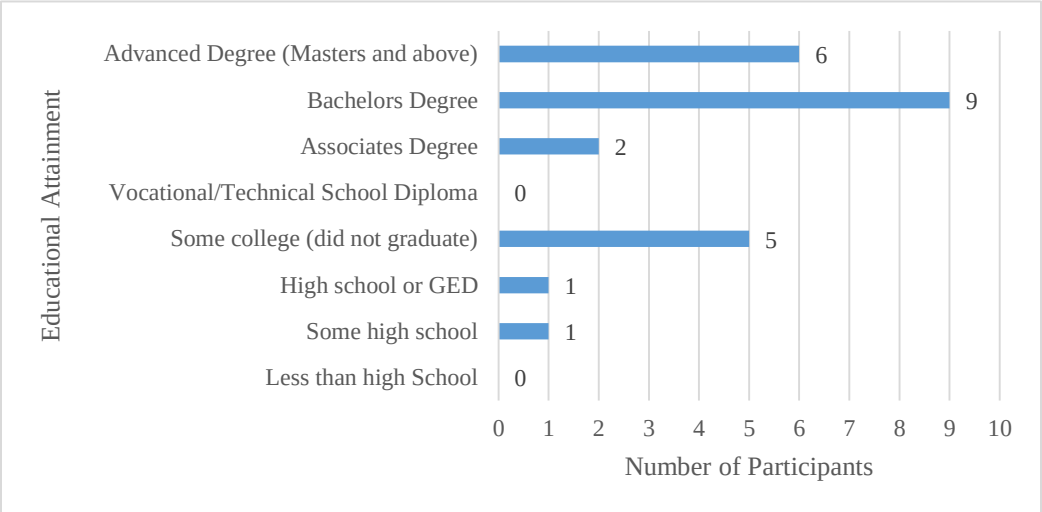
Those who self-reported being Gay, Lesbian, Same Gender Loving (52.2%) made up the majority of focus group participants. Figure 15 displays the sexual orientation categorization.

Figure 15. Sexual Orientation (n=23)



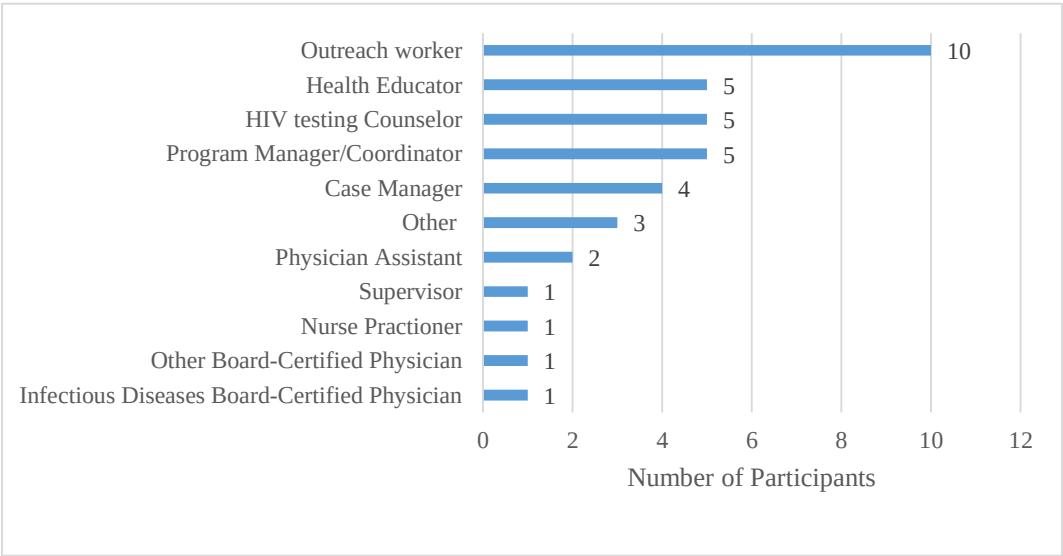
Educational level varied, with those completing a Bachelor's Degree (37.5%) comprising the largest group, followed by Advanced Degree (25.0%), and some college (20.8%). Figure 16 displays the educational levels of all of the participants.

Figure 16. Educational Attainment (n=24)



The types of HIV professions also varied, with 41.7% of the participants being outreach workers, followed by equal representation of program managers/coordinators, HIV testing counselors, and health educators (20.8% each). Figure 17 displays an aggregate list of HIV professions among the participants.

Figure 17. Type of HIV Profession (n=24)



Other types of professions: harm reduction counselor, peer educator, PrEP navigation

Figure 18 illustrates the working experience of these participants, with the largest groups having less than five years (33.3%), and between 20 to 25 years (25.0%) in the HIV field. This diversity suggests that perspectives from employee from all experience levels were represented.

Figure 18. Working Experience in HIV Field (n=24)

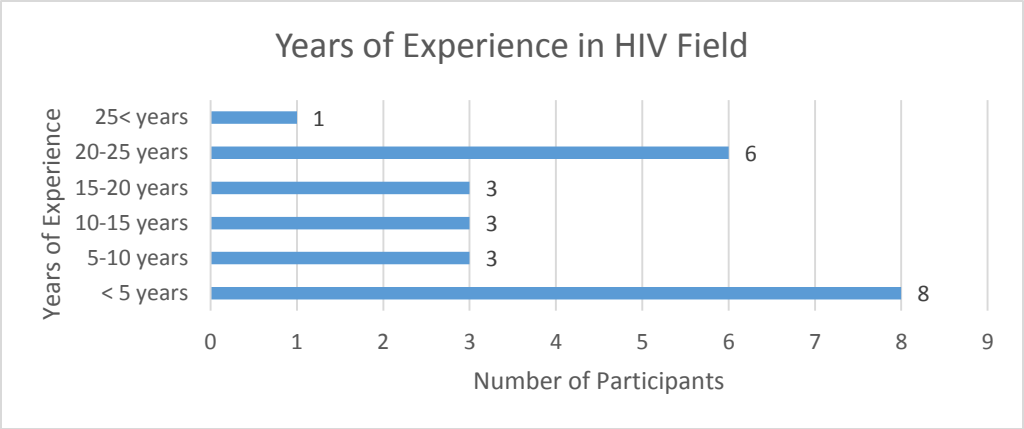
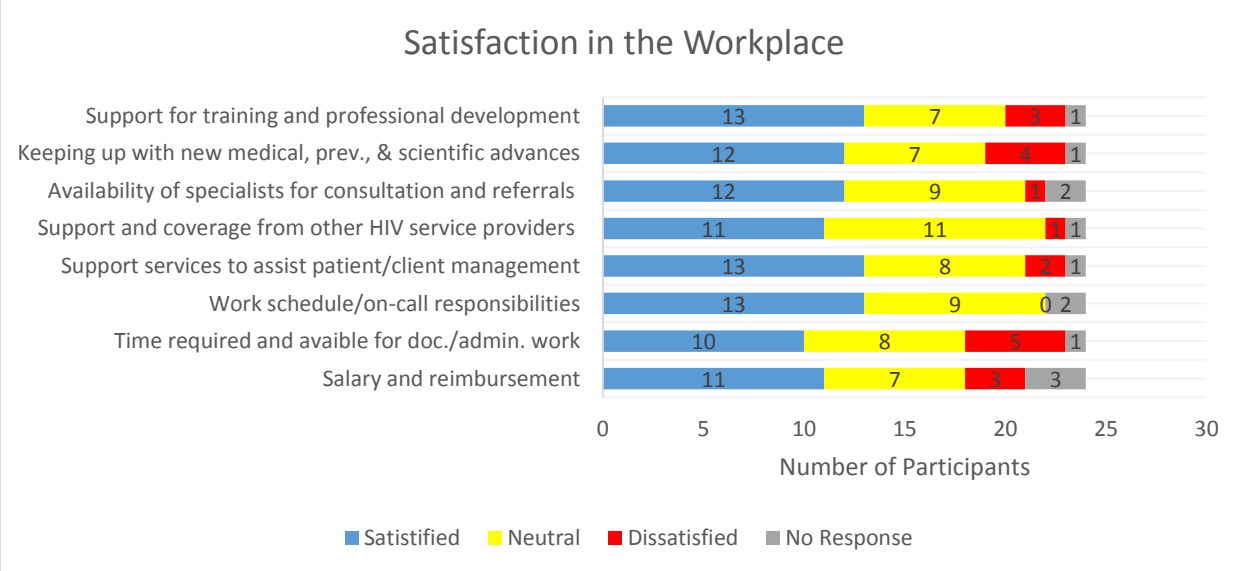


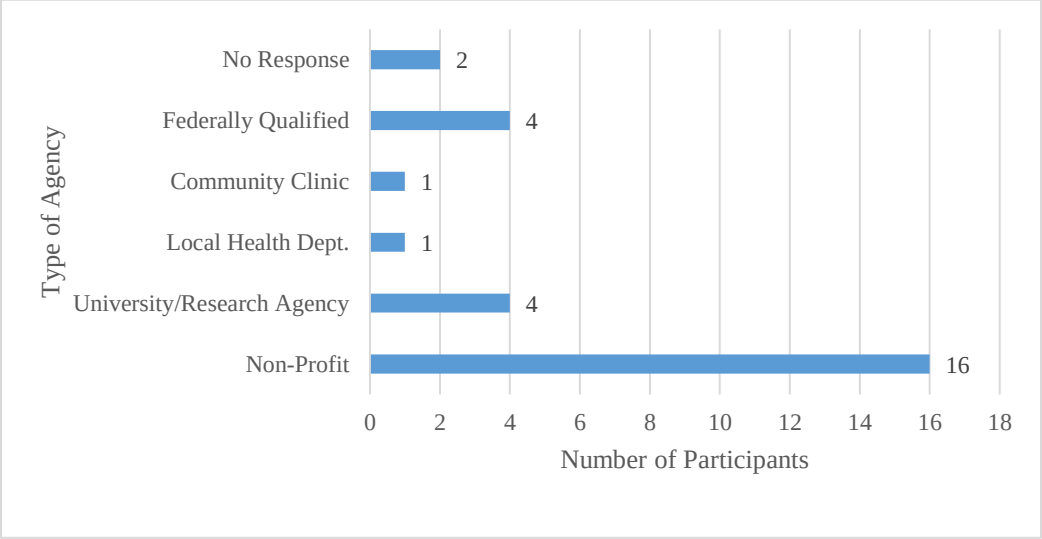
Figure 19 shows the participant's personal satisfaction in the workplace. Interestingly, all participants reported personal satisfaction with their work schedule and on-call responsibilities. The most stressful area of the participant's profession noted is the lack of time required for documentation and administrative work.

Figure 19. Satisfaction in the Workplace (n=24)



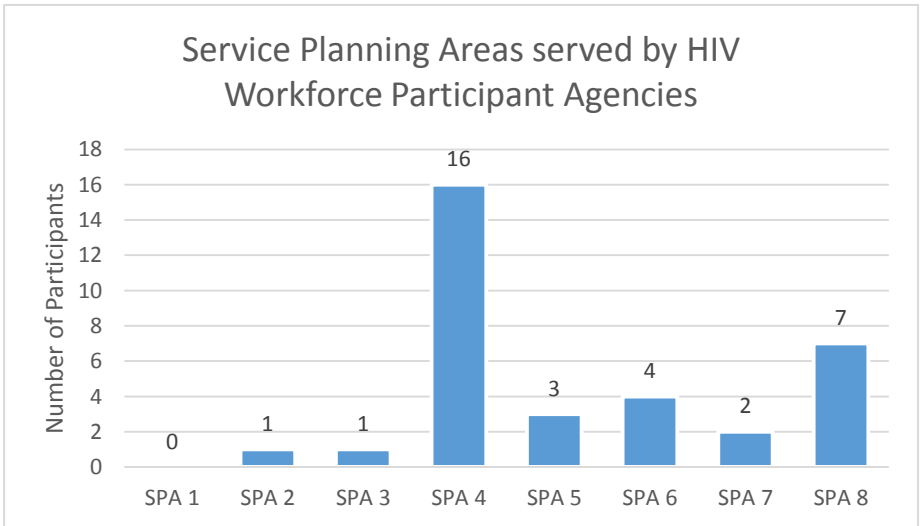
Among those who responded, most participants provide HIV services to non-profit organizations (72.7%), followed by University/Research agencies (18.2%) and federally qualified health centers (18.2%). The following figure below displays the types of agencies in which the participants provide HIV services.

Figure 20. Type of Agency (n=22)



The region in which these services are provided are mostly in the Metro area (66.7%), followed by the South Bay area (29.2%), and South area (16.7%). The figure below displays all service planning areas (SPAs). These results relate to the location of the focus groups --which were held in SPA 4 (Metro) and SPA 8 (South Bay).

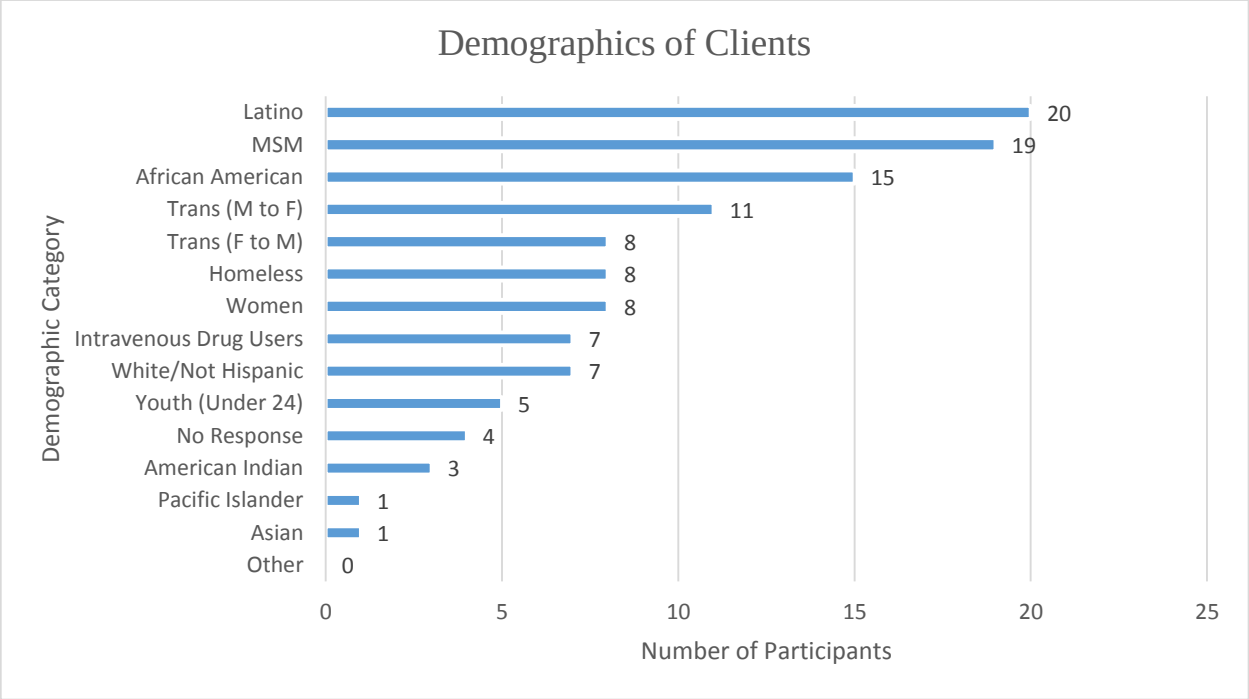
Figure 21. Service Planning Areas (SPA) Served by Workforce Participant Agencies (n=24)



SPA 1 = Antelope Valley
SPA 2 = San Fernando Valley
SPA 3 = San Gabriel Valley
SPA 4 = Metro
SPA 5 = West
SPA 6 = South
SPA 7 = East
SPA 8 = South Bay

To capture information about the demographic characteristics of clients served, HIV Workforce participants were asked to indicate if 50% or greater of their clients fit the demographic categories listed in Figure 22. Clients receiving HIV services are frequently Latinos (90.9%), followed by men who have sex with men (MSM, 86.4%), and African Americans (68.2%). Figure 22 below displays the demographics of the majority of clients served by the agencies represented.

Figure 22. Demographic Characteristics of Clients Served (n=22)



The average number of types of services provided per agency is 12.33. Among these services, the majority offer free condoms (88%), whereas the majority lack residential substance abuse treatment (8%), and specialty oral health services (8%). The following table displays an aggregate list of services provided by the participant's agency.

Table 4. Type of Service Provided (n=24)

Service Currently Provided by Agency	Frequency	Per. (%)
Condoms (free)	21	88%
HIV testing	19	79%
HIV medical care	19	79%
PrEP (Pre-Exposure Prophylaxis)	18	75%
Medical case management services	18	75%
Help getting enrolled in health insurance	17	71%
HIV prevention education	17	71%
Housing services	17	71%
Referrals for services	17	71%
STD prevention education	16	67%
STD testing	16	67%
STD treatment	16	67%
Comprehensive prevention with HIV-positive individuals.	16	67%
Psychotherapy mental health services	16	67%
HOPWA program services (housing assistance for PLWHA)	16	67%
Outreach	16	67%
Non-medical case management	14	58%
Psychiatry mental health services	12	50%
Partner Services	11	46%
General oral health services	11	46%
Food bank/home-delivered meals	11	46%
Evidence-based interventions for high-risk population	10	42%
Home and community based services	10	42%
Social marketing, media, and community mobilization	9	38%
Medical nutrition therapy	9	38%
Capacity building and technical assistance	8	33%
Outpatient substance abuse treatment	7	29%
Medical transportation services	6	25%
Language services (interpretation, translation)	5	21%
Legal services	5	21%
Specialty oral health services	2	8%
Residential substance abuse treatment	2	8%
Other	0	0%

Qualitative Results

The topics most central to the discussions were prevention, awareness and education services, as well as social determinants of health such as housing and cultural norms. Access to mental health and biomedical interventions (medication) were also prominent concerns. These are discussed below as well as other topics that were raised less often, but which does not signify that they are less important. Within each topic, the variety or range of opinions is noted. Quotes are cited as health worker (HW) or community member (CM) followed by the number of the first character of the quote in the transcript. Un-audible portions of recordings were indicated as "[U/A]".

Figure 23. Coding Frequency Word Cloud

A. Experiences Obtaining HIV Prevention Services

Many participants discussed difficulty accessing various services as well as concerns over losing access to services they were currently receiving. Several mentioned that they would not know where to receive testing for sexually transmitted infections (STI) even though they were insured. Many felt that primary care providers should take more responsibility in promoting and making STI testing accessible to their patients.

> "From experience I remember three clients who it took long for them to be diagnosed with HIV and they spent large amount of money on vitamins and shots of who knows what, because they didn't receive the testing right away. So, [it's] very important … that

the medical providers at those small clinics know what to do in case they identified someone who was at a high risk for HIV" (HW: 35888).

"I don't even know where [provider name deleted] I would go to get tested, maybe just primary care. But yeah, they don't make that widely known to you" (CM: 6837).

"S: [name deleted]. I just wanted to mention I cannot tell you how many women who are between the ages of 40 and 60 that come to me newly diagnosed. They're educated, heterosexual, divorced, widow whatever and it's sad. They end up in the ER with pneumocystis pneumonia or MAC or whatever and it's because their primary care physicians or their OB-GYN just looked at them like that. And I agree, I think with S[name] that, we get these letters from the LA County Health Department, 'I need to give a rebate on meningitis vaccine,' and the same thing should be for the [STI] testing" (HW:22967).

Outreach and education was also mentioned to increase knowledge about where resources exist, specifically testing resources as prevention, as well as the need for comprehensive prevention efforts.

"It feels like HIV transmission is a big balloon and it will cross on one area. It just squeezes out into another area and I think whatever we do, it can't be one factor. It has to be everything. It has to be comprehensive, medical, biomedical, education, peer, staff, all across the board" (HW:8573).

"even with my family, I have brothers, I have a little brother, I have an older brother and I give them all the education I know even when I go to like agencies or get tested, I take my brothers with me and my brother is not even gay, but I take him with me because he still needs to know and if he just stay inside a box he won't ever know. So I just try to educate all the people in my family, everybody, because to them HIV is, 'Oh, you gay. Of course, you're going to get it. Let me make sure what you're eating out of. I need to wash it. Keep that away from my kids.' So, my family has come a long way like now, it's nothing to them like they're really cool with it but that's only one family" (CM:26556).

"From experience I remember three clients who it took long for them to be diagnosed with HIV and they spent large amount of money on vitamins and shots of who knows what, because they didn't receive the testing right away, you know. So, very important and so that the medical providers at those small clinics know what to do in case they identified someone who was at a high risk for HIV, you know" (HW:35888).

Participants across subpopulations also mentioned the importance of prevention through creating a safe dialogue about sex and sexual health in various aspects of the public. This safe dialogue could be used to inform, empower, and educate both HIV positive and others about how to protect their health and the health of their partners and loved ones.

"A: Okay, again, I think it is still is a variety of things. I think doing what we can do to reduce stigma around HIV, STDs and sex, and kind of help bring sex as a normal way of life for people could be the beginning, you know, or at least conversations to have that will have people maybe shift their thoughts a little bit, which could help with prevention as well" (HW:9840).

"I feel like a lot of young people are not aware about certain information….not because they are dumb, but because the information that is given to them is taboo topic. It's not talked at homes, at schools. I definitely want to be a peer and provide information in a way they are comfortable and in a way they are able to talk about the topic openly" (HW:3716).

"But, the testing that I just do is at [name deleted], that's where my producer she does her testing too, and then we just work with other performers that are OK with us just having the negative HIV test. And we don't even show it to each other, we don't even really explicitly talk about it, like, even when I got gonorrhea I didn't talk to any of the other people about it" (CM:10501).

"And then finally is making sure is more positive in public health I understand the importance of like, we want to reduce infections and things like that, at the same time, I think we need to also sell it from more empowering perspective, because I feel like most of the time is consequence driven. Like, if you don't do this, then you will get this as a result" (HW: 9215).

Barriers to Accessing Medication including PrEP and PEP

Another common theme concerning prevention services included immediate access to HIV medication, PrEP and PEP when requested. The latter medications lower the risk of HIV transmission and can prevent new infections. Some of the barriers to "on demand" access to HIV medication and PrEP discussed were cost, awareness/knowledge (among both users and physicians) and insurance bureaucracy.

"Biomedical prevention certainly includes PrEP and PEP and also importantly, includes having people who are HIV positive on treatment and that being on treatment prevents HIV infections and then it is very [un]likely that you will transmit HIV when your viral load is undetectable, in essence. So that's an important prevention … Getting people who are HIV positive on treatments quickly is very important. So that's the other side of biomedical prevention" (HW:36672).

"Well I was just thinking like, if I ever needed to get [PEP], I would probably go to the ER urgent care with [name of hospital deleted], but then that's a 100 dollars' copay right there to go, so I was thinking if I ever needed [PEP] that would be automatic like, "Oh, do I have 100 bucks?" I mean they always bill it to me, but that's what I was just thinking right now, so I would have access to the cares of, I mean, it's still, I think it is still considered preventative even though it's post exposure" (CM:12393).

"T: Yeah, and having that access to immediate on demand HIV treatments, PrEP, PEP is hugely important to be able to help people do well and retain the people in care. Also, you know, in terms of just prevention in the community, you know, the quicker you get people on meds or on PrEP, you know, the less chance they're going to be transmitting out there in the community so I mean it's a win-win and it seems like a… Yeah, so that would be. I think that's great. Be able to really provide on demand services. And there's also other resources behind that too though, you know, in terms that we have to have

enough staff and we have to have enough manpower, you know, we have to be able to have the resources to give on demand whatever if they need to, so" (HW:59331).

"And what I had found is everyone like friends with benefits that it's a really long process to get somebody on PrEP and I'm just talking about doing this as a friend is that there is…they go through like the stages of change. And so, they're not really thinking about it and then your kind of give them a little education and then later on then they come back with some questions and then they talk to their doctor, their doctor has never heard of it. And so it's just back and forth and for the few guys that I've known who've gotten on PrEP that I've talked to it's taken about a year and that's just what having their own health insurance and talking with their private doctor" (HW: 41801).

"A: A. One of the things [name deleted] said, lack of resource for the people that are HIV negative and at risk because if you're positive, we can probably find you a bed within two days. If you're a gay male engaging in high risk behavior because of your substance use and you're not positive and there's really no bed or resources to send you to get assistance to address that issue, that maybe somewhere down the road you became clean and sober and will prevent you from engaging in high risk behavior" (HW: 51951).

HIV workforce participants indicated the need to educate non-physician health care staff in hospitals and large clinics, as well are "front line" physicians and staff at small, community clinics.

"Also at big clinics as well, people who don't work in HIV aren't health care professionals. They don't seem to be well educated on, first what PrEP actually is. So, I think sometimes that's is kind of where it starts. For example, I've also had a client that when he had risky behavior and just saw a doctor at [name of hospital deleted] that was in an emergency room and they wind up having to educate the doctor on what PrEP was" (HW:36364).

"Well, one of the things that I do know about that is that, it's not the information, it's not being received where it needs to be received, like for example, at the very small clinics that are in our communities. Those clinics were normally someone who just arrived in the country, or someone who has no health insurance or maybe works the night shift, goes in, just because they are not feeling well. And many times the medical staff doesn't have the information or they don't even know what PrEP and PEP is, or other biomedical products that are out there. So, I think we need to provide education, all of those who work there, specifically you know, for outreach workers to go in those little clinics and introduce themselves, provide information to the staff, it's very important" (HW: 35103).

The location of entities offering PrEP and PEP was also noted.

"One of the things is that there's not enough providers that are providing the PrEP and PEP. It's like we continue to keep to promoting it, but it's not accessible in all communities. …You have one in Metro area, but I work in the inner city South LA and there is very few in our area. So, I think you know, we're promoting it, but it needs to be accessible, so if people are ready for it, they don't have to go all across town to get something that could possibly save their lives" (HW: 31638).

Condom Usage

Participants mentioned that oftentimes there is a lack of use or resistance to the use of condoms for a variety of reasons. Some participants felt that individuals on PrEP felt that condoms were less important for them, and others either disliked condoms or felt that they were either ineffectual for their lifestyle or type of sexual activity.

> "I have noticed like, even when I have been with men, mostly straight men, they wouldn't even know, I wouldn't disclose myself, but they wouldn't even want to even think about using condoms and when the subject came up, it would almost like kill the sexual moment because it was either, like, the person who didn't have HIV would feel uncomfortable with doing anything because the other person is going to feel that they're better because they don't have HIV, but, they are going to be more [U/A] condom on, because, they're going to be afraid of anything so it ruins the sexual moment" (CM:5795).

> "You know I was encouraged by somebody at the Las Vegas LGBT center to use female condoms. But, like as lame as it is, it's in my head that like that's incredibly not sexy. I'm still just trying to navigate being masculine, but like receiving penetration. So, this is a whole new world to me" (CM: 41205).

> "And for me the kind of sex that I'd like to have would be when I'm like you know what you would consider topping and so, you know the sex I'm having it's like involving like you know me penetrating a partner with my clitoris and like, there is like fluids and stuff going on but that's like there is not condoms. I guess you could put a dental dam in there but it's like I don't, so here I am like you know topping. I don't know what kind of, I guess I could talk to my doctor more about that, about what kind of transference can happen in that kind of sex. Because like people don't even conceive that that kind of sex is like happening, you know" (CM: 44691).

> "It's like people don't care. They want to put no condoms on so they don't care" (HW: 13047).

> "What I hear with some of the guys that I talk to is some people are just very aware of what they're doing and sometimes there's condom burn-out with some of the guys that are above 30, I would say where people have been used to kind of using them regularly and it just kind of get like, 'You know what? Okay, I did it without a condom. I'm not going to freak out too much'"(HW: 18092).

> "A lot of people are using PrEP, but are still refusing to use condoms. A lot of things people aren't talking about is the high rates of syphilis in LA County right now too. Again PrEP is great, but we are still missing those other components. Now, we have somebody who is HIV positive. Or somebody who is negative and yet they are facing other, you know, health issues as well. So now you have somebody who is at risk for HIV as well other communicable diseases" (HW: 36916).

Unaware/Uninformed/Underinformed

A prominent theme regarding the prevention of HIV infection was that many people are still widely under-informed about sex education, HIV, and AIDS and that thus there is great for general education and outreach. Among both the Trans-Masculine and Asian-Pacific Islander groups, participants mentioned that when they do not see messages or illustrations targeting these aspects of their identities, they do not receive the information. Note that the request for general education and messaging to all has been emphasized in previous listening sessions by other sub-populations as well, and is thus a recurrent, prominent theme.

> "A few months ago, I was on my lunch break, I still had my ID on me, my little badge, I went to the mall down the street and I walked into a store and I was shopping and I purchased something and the person at the front said, "Oh, you work for AIDS Project Los Angeles. That's so cool." He kept on talking now. At the end of it he's like, "Nice to meet you. I've never met someone with AIDS before." He's like, "My friends have gotten gonorrhea before but I've never met someone with AIDS." There's people behind me waiting in line. And that moment I was just like, 'wow,' like, I can feel what people are walking into the clinic and not, you know, just getting it tested can feel, but, just to be out there and he just saw my badge and automatically assumed that I had AIDS. It was really like 'wow,' like so much education needs to be in the community, you know" (HW:26742).

> "But, we talked about me doing those two things because I'm a performer in the adult industry and I only do condom…hard core oral condom penetration, but I do like oral sex without condoms. And, I just started having sex with transwomen this past year, and doing that personally without condoms and so I talked to her about just the possibility of me getting pregnant. Or me getting AIDS, HIV, I don't really know much about AIDS or HIV to be honest" (CM:1998).

> "I think that I learned about, you know, STIs and HIV on my own and it was because I was in a community that was exposed to it. You know? But, I think that a lot of like young youth are not really aware of you know, what's out there and nowadays youth is starting to explore into the sex a lot earlier. And so, I think you know, education for younger people to know what is out there is very important" (HW:9931).

B. Experiences Obtaining HIV-Specific Care

A number of respondents described discordance between clinic offerings and the services they need. Participants reported having to utilize more than one clinic to receive the breadth of services they needed.

> "it's lacking somewhere where something…another one has it, but you're getting great services now, and it's really difficult to kind of access the other clinic because you're with another clinic and it's just kind of becomes a struggle because, not everybody, not every clinic has all the services in one and so, that's posing a challenge for me because I'm like, okay, you are accessing services here but they are also becoming a restriction" (CM:21135).

> "They're forgetting to understand that one clinic may not have services of the other clinic and that's where the restriction on accessing two clinics is becoming restrictive and actually detrimental because you cannot access it. And, I think that needs to be addressed in terms of a case watch, that's so important, because you have to understand not every clinic has the same [services] at every clinic" (CM:24231).

Transportation as a barrier to accessing HIV care services was mentioned by some participants. Many participants also cited time as an issue in accessing HIV care services; often patients' schedules made it difficult to attend appointments.

> "Another challenge is transportation, being able to get to the agency for services. Yes, transportation sometimes is provided by buses, but you need to meet the medical qualifications which is being HIV positive asymptomatic. You don't qualify for an MTA disabled ID and so therefore, [transport] becomes another obstacle. We provide tokens but those will go by real fast so maybe making a change as far as the requirement or the eligibility for transportation assistance that you have to be symptomatic or anything like that having it more accessible would probably work" (CM: 29296).

> "…as far as the times, some people work because they have to work really hard because, you know, jobs are challenging and people aren't making that much money so 'I have to work 12 hours a day and then the clinic is closed by the time I get there, the one that's closest to me or whatever so I can't go or when I get there it's closed'" (HW:24598).

Several participants described issues with their care providers, such as their doctor changing or unpleasant interactions with their providers.

> "T: The one thing I don't like about [provider name deleted], too. I've been going like every other year, my doctor changed; I'm having a new doctor. And that's one thing I don't like about there because like a year ago, I had [doctor name deleted] and all of a sudden, they gave me some new doctor and I never knew nothing about him, never told me anything, that's one thing I don't like about [provider name deleted], but as far as that, everything is good" (CM:12321).

Others describe negative relationships with providers, particularly for treating the whole person instead of just HIV.

> "When you get up in certain age group and stuff like that, what kind of testing you need to take so you can avoid getting cancer or getting this [U/A]. They don't do that. It's just like, you go in there and it's just very 'how are you doing today?' and 'you've got all…you're taking all your meds?' and 'okay, I'll make your next appointment', and, you know, it's just, like…it's, like, there's no concern" (CM:38369).

> "This was through [provider name deleted] and then they wanted me to see their endocrinologist, at [provider name deleted]. This guy was like super creepy. He sexually assaulted like one of my friends who was a patient of his. I didn't like the interaction I had with him, and then through that time I had, he wouldn't let me get my testosterone for like a month. Just terrible, so hated that situation. Came back to the center now I have doctor [name deleted]. I really like him. He is trans specific" (CM:33865).

"I think they need to have more awareness groups on tolerance, like on transgender people because, last time, when I went to different clinics, and hospital emergency rooms and stuff like that, when they learn that you are transgender, they are very disrespectful. Like I have gone to [provider name deleted], and I'm always watching the commercial [for provider name deleted], how they treat you with kindness and all that, I said to myself, "that's a crock of shit", because, when I came up in there, as soon as they learned that I was transgender, I've seen all the nurses out in the middle of the nurse station, [U/A] that's a man up in there [U/A]". That's just disrespectful, you know, and that was one of my concerns; that they need to have more groups on how you treat people" (CM:2539).

C. <u>Mental Health Services</u>

While mental health services are part of HIV-specific medical care, it is being noted separately in this report to draw attention to the fact that the need or demand for services greatly outweighs the accessibility and availability of appropriate services. Several respondents described having precarious relationships with receiving mental health services. Many participants feared losing access to their psychiatrist and/or therapist, and described their dissatisfaction in having access to a finite number of sessions. There are long waits and only those with gravest situations (e.g. suicidal, assault) receive services. This can lead to a negative feedback loop wherein patients self-harm to be eligible for care.

"I have tremendous fear that I'm going to run out of the number of sessions I'm allowed to have or that I'm going to all of a sudden stop having care. Because like for my mental care, like, that's happened already, like I had so many therapy sessions and then I ran out of how many I could use. And then the person that was supposed to help me access more mental services just handed me like a list and was like, 'Call these numbers' and like you know sliding scale. Stop. I just didn't do it. And then what happened was, I had like traumatic event where I like you know self-harmed, and I…because it was an emergency, they got me back into one-on-one counseling. And then like because I got sexually assaulted […], then I got to have the EMDR therapy. So, it's like I've had access to stuff that's really great, but it's being contingent on traumatic events happening." (CM:18069).

"Otherwise, you are on a waiting list. Like I was before I got into the one-on-one therapy, the first time which was like 2015 I was on a wait list for like a year and three months, and they just tell you call back every month, call back every month. So, I'm like super scared like that I'm going to get like kicked off my therapy." (CM:19122)

"Like if I wanted to do something like therapy or psychiatrist or something like that. It is provided at the [provider name deleted]. It's available but it's very general. I mean like timeslots what we can do what we can" (CM: 11881).

Some participants also had tenuous experiences with receiving their medications, which they noted as creating anxiety and negatively impacting mental health. One participant noted that doctors split the HIV medication belonging to one person to purportedly share with other inmates.

"Right now, I'm having that problem right now by getting my medications filled. I've missed out on my doctor's appointment, my lab appointment last week. I wanted to

reschedule it because, mentally, I didn't want to be in that clinic; I kind of run into a burnout stage. But I requested for the doctor to refill my medication and within over the last three months, four months, I haven't got no refills and I'm pretty close to running out. My next doctor visit is not till April, so, that's kind of getting me upset right there."(CM:9493).

"M: I'm like pins and needles am I going to get my testosterone (T).

P: And that's an issue, yeah getting testosterone I think is very, I think it's very politicized too. I think it's controlled and the access is restricted, I think sometimes intentionally, sometimes unintentionally. When I was, way before I ever worked for [name of agency deleted], I was uninsured and I accessed hormones and trans care there, initially that's how I first transitioned actually. And then the last couple of years I've had insurance through employers, but getting T has always been an issue. I've had several lapses where I've been out of testosterone long enough to get my period back. That was a couple of times, because of the center. For sure, so, I've had that exact same feeling M--- as you at the window, not really sure until I have it in my hand that I'm going to get it. And then also with [name of provider deleted], they're still charging me full price for testosterone, when it's like I am full on F t M. I have all of the letters from the shrink and everything is good to go, like why isn't like or…I don't know, I don't…like, that's like a medically necessary item at this point for me. And yet it's not subsidized at all, it's not covered at all. And then also yeah it's like instead of just having refills that you can request, you have to put a full on new prescription in every time, which I also feel is ridiculous" (CM: 21367).

"The doctors are quacks, and, they write all this good stuff that they're going to do for you, and I had brought medication there with me, and, if there's other HIV positive people there, they have separated my medication with the other guys just to claim that they're doing something. So, that's wrong right there. I didn't like that." (CM:16470)

D. How Culture Influences HIV Prevention and Care

These listening sessions also included questions regarding to culture, such as: "Are there cultural (broadly defined) or linguistic issues that are unique to your community that affect HIV prevention and awareness? What are those issues? What about unique cultural/linguistic factors that affect HIV care?" Note that these questions were not asked of the HIV workforce participants.

The main cultural foci that emerged were: Asian Pacific Islanders, gay men, gay women, transgender men, transgender women. Other cultural identities noted were related to religion, being African-American, and age. Participants across all groups agreed that difficult challenges and self-imposed barriers often stem from cultural norms and beliefs. These were seen to influence disclosure of status; access to services; emotional support; stigma; prevention; quality of care; and sexual health education. Through their comments participants provided evidence of the importance of culturally competent care, and the diversity of cultures or subcultures that exist.

"K: I would say cultural competence is probably one of the most important things that you need to consider when targeting different [U/A] and communities because,

> understanding the different multicultural needs of communities, makes the biggest difference as far as the quality of care that they get, so, you know, I feel like this funding would be really important for the community because, …one size does not fit all. You need to kind of tailor it to the community and be culturally competent" (CM: 56772).

Among Asian Pacific Islanders one of the key factors influencing the decision to disclose is a desire to protect the family from shame. The fear of bringing dishonor to the family has made the discussion of sexual orientation and HIV or other sexually transmitted disease (STD) status taboo subjects.

> "W: I was raised by a Japanese mother, I was adopted, and their culture was very…you don't say nothing. You don't express your feelings. You don't let nobody public know nothing…everything is supposed to be honorable" (CM:9787).

> "In the Asian community, we don't really talk about sex in general, much less STDs, so I think that it needs…I mean, I don't know what the solution is but, I mean, I think that just with more discussion, with more awareness, putting it out there, more in specific to that community, would that maybe raise some awareness and hopefully discussions will be had, because …we don't talk about that" (CM:48983).

Among lesbians and transgender men preventative services and education were not easily accessible or they felt excluded, even if they are engaged in high-risk activities.

> "P: …We do come from that demographic that's just forgotten, it's like, 'Oh, no we don't need to worry about them, they're STD free.' Yeah like, jokingly 'the chosen people' but it's, I mean I don't think that's really based on data, I think that's based on just assumptions and…it's just like pervasive and it's carried on" (CM:27868).

> "P: I also was living most of my life, up until 28 as a butch lesbian. And I just noticed that as a butch lesbian there wasn't any pointed or focus on advertising or promotion regarding safe sex, HIV, awareness, anything" (CM: 4574).

Stigma is present across all cultures. However, participants perceived it to be more prevalent in certain cultures or communities. Notably they would name their own culture as being more stigmatizing. This perception appears to be based on personal negative in-group experiences and superficial interaction with other cultures/out-groups.

> "A: The barriers I think is still stigma and I think that's probably going to outshine a lot of stuff with people in certain communities. Certain communities still don't trust their health care system at all. They have some historical trauma that they're dealing with so they're not going. A lot of people don't go for regular health care. A lot of people have gotten insurance but they still don't go" (HW:23946).

> "K: There is so many different sub-communities within the community… some people have a stronger stigma than another." (CM:49677).

> "Sp: And then over extra alpha male being gangster black, all that shit, like all those ideas of what that is, I'm like how you're supposed to be, how you're supposed to act, how you're supposed to sit, how you're supposed to talk, what you like, all that shit is frustrating within itself and it's like even if it's not being projected to me like, 'Oh, my

gosh, you're gay' or 'you're too feminine.' Even if I'm not getting thrown at, like, you still feel it" (CM:30855).

"I grew up in like catholic school so I've just kind of had that background of just not even talking about it, so yeah, like going off what she said, it was pretty common about, you know, not knowing much about HIV prevention, or STDs, or things like that, because we were always taught to go for abstinence, all of that, so, even when, you know, even when my [U/A] appears, it's…there's this strong stigma attached to it, so it wouldn't really be talked about, so no one really would know how to get the resources as far as getting tested and things like that" (CM:7480).

Participants from the workforce acknowledge that gay men and adolescents are increasingly at risk for HIV and STI/STDs due to lack of culturally relevant education for them as well as high risk behavior. High risk behavior is fueled by the "app culture". However, they believe that preventative care and education should be available to all cultural groups.

"Sh: I think that one of the trends I see in the gay community is behind PrEP. You know, I think that PrEP was targeted for the gay community initially. It was, you know, one of the main focus groups. And I think the gay community has been waiting for this, for such a long time, that it created a permission to have condom less or bareback sex. And you know, I think that the STI increase is huge and we're thinking about a quick fix like, you know, I'll go get treated, but we are not looking at the long effects of some of these STIs that they could have on us. So, I think, you know, the misconception that PrEP has about allowing you to stop using the condom and taking care of other things is something that is very popular in the gay community" (HW:16790)

"St: I'm finding in the population I work with, is still stigma and I think because there is the app culture, the hooking-up and that's sort of stigmatizing within itself, so you kind of do is open the door again. It's almost like you are fearful and you feel like you might, or you're bound to get it and so you kind of just want to hope and pray that you just maybe dodge it" (HW: 21618)

"Sa: And in the past, we've seen certain communities like one that's more prevalent among straight people or among gay people but it's really kind of across the board and that's frightening" (HW: 15144)

E. <u>Accessing Health Services: Insurance related Issues</u>

Participants critiqued the Medi-Cal system for lacking consistency and transparency. One respondent commented that they were unable to see the same doctor more than once and that they were forced to wait an undetermined amount of time to receive requested services.

"S: I'm trying to get some repeaters that I would get just being able to like go here and get this done or have somebody that I see consistently. I just feel like it's been a little uncertain or I just haven't been able to have things happen in a timely manner, like I'm not even going to see the same doctor if I go to this place again because I don't know for whatever reason, that's just generalized Medi-Cal. So, I don't think I got any like the most of what I can get" (CM:11239).

Providers of health services describe similar obstacles when dealing with Medi-Cal. In particular they described difficulty communicating with Medi-Cal representatives and that they often feel they are sending clients into a "lion's den" of bureaucracy when they are forced to interact with Medi-Cal representatives.

> "And I would say it's just kind of related in a way to what [name deleted] was saying about the benefits or insurance problems. I think living, especially in Los Angeles County, it's very difficult for us to interact or interface with Medi-Cal in our county and our patients have a lot of barriers that come up around Medi-Cal being discontinued and things like that. Then we have to send them sort of into the lion's den of the, you know, of the county, Medi-Cal bureaucracy. ..Years ago, it was easier … you kind of have that person, that somebody who could get things done for you in Medi-Cal if you had a patient who needed something to get fixed or done right away. A lot of times we don't know at all what's happening in the Medi-Cal, but what happens in Medi-Cal and LA County really affects what we do. So, any tool or any way that we could interface, more efficiently, if we had a person. Because if it's another HIV agency, we can pick up the phone and we can talk to that person and, 'Hey, you can help when it's dealing with the county or specifically Medi-Cal .' We don't have those kinds of relationships. It's just a wall and that really affects patient care. So whatever we could do to increase that kind of communication between Medi-Cal and our services" (HW:48818).

One workforce participant suggested a grace period as potential solution to barriers created by insurance issues for those newly diagnosed with HIV.

> "Having a grace period of how…being able to access services whether insured or uninsured. You know, figuring all that, you know, bureaucracy out and getting you the direct services as needed because you walk in the door, you need the services. Just recently, there was a gentleman who was referred to our agency, newly diagnosed the day before, started doing the enrollment process, started explaining the whole process we're going to go through as far as making some changes because he's got Medi-Cal with an HMO that's not contracted within our agency. So if he wanted to come here, this is what we do doing the footwork to finding out who his medical provider is who he's never seen because he never really uses Medi-Cal benefit and to go there to expedite, you know, services and so having that grace period would be perfect because now, we can start to write services while we're navigating and, you know, looking at all, you know, making the proper changes so that they can continue having the access…." (HW: 57910).

Another issue that came up with insurance was gender markers on medical forms. One participant felt that gender markers on medical forms could be detrimental to accessing services for those whose gender may not conform to a binary gender system.

> "Moderator: Would it be helpful if there were more categories on that medical form, than just two genders?
>
> M: I think so, because then you get more specific care than right, if I developed ovarian cancer and they were like, 'Oh, but he is female to male, check that box, OK, that's a particular case,' … all of the insurance coding is gendered. And thus gendered options are blind to the body, a lot of bodies that are there" (CM:40215).

F. Issues Relating to HIV Status

All participants agree that the advancement in medicine has led to great improvement in the health and life expectancy of people living with HIV. However, despite these advances, there has been little change in the way the public perceives people who are HIV positive. Thus, stigma and discrimination remains one of the biggest barriers people living with HIV face. The belief that HIV/AIDS is a "death sentence" has not diminished among people who are not educated on HIV/AIDS.

> "…I think everybody automatically jumps to AIDS, like 'Oh, my gosh. I'm going to die' like it's over" (CM:38092).

> "Well, I have to say, people shouldn't give up on, you know, by speaking more about the HIV or…publicizing more… I want to let people know that it's not a death sentence. [U/A]…It's nothing to be ashamed of. So, just live your life right, make some wise choices. I think a positive message like that needs to be more [A/U]" (CM:15549).

> "I think it's like that frame of mind of thinking like, 'Oh my goodness, my life is completely over,' when actually it's not really over, but you do have to take medications to insure that you know your life isn't over" (HW:23461).

The stigma of HIV contributes to many difficulties and barriers people living with HIV deal with frequently. These issues range from access to care, disclosure of status (their decision to disclose their status, to whom, when and how), housing, personal relationships, low self-esteem, and discrimination. Stigma diminishes the ability of individuals to protect themselves from HIV and to live a healthy lifestyle, if they are living with HIV.

> "… I had some backs turned on me. I had some rejections. I had some hateful calls. I mean, I've been ignored. I've been pictured as a poisoned person. I have been turned away because of my status. If it was like getting your hair cut or going to a dentist or even a restaurant, especially when I look ill. It was very frightening" (CM:6671).

> "D: People are not educated because…I told my family I was positive. I was close with my family. It's like now, they turned their back on me and I've been thinking like I wish I could have kept it to myself, you know, but, they not educated. They say stupid stuff and it hurts me because now, I'm isolating myself. I don't call my family. I just stay at home and watch sports, you know, just watch TV all day by myself. It hurts because I cry, you know, and stuff but they're not educated, you know. And I want to be close with my family but there's no contact there" (CM:27472).

> "You do have to worry about your self-esteem also, because most of them have low self-esteem, about themselves. They don't really care no more. You know? 'Somebody gave it to me, I'm going to give it to somebody else'" (HW:17583)

Largely due to stigma, people who are positive sometimes live in fear of disclosing their status, while those who are negative are discouraged from accessing preventative care in fear of being associated with HIV.

> "C: So, I agree on what [name deleted] said about having the AIDS Project Los Angeles, AIDS on our building, you know, they changed the name but I've never been like stigmatized for being positive. But there was a few months ago, I was on my lunch break,

I still had my ID on me, my little badge, I went to the mall down the street and I walked into a store and I was shopping and I purchased something and the person at the front said, 'Oh, you work for AIDS Project Los Angeles. That's so cool.' He kept on talking now. At the end of it he's like, 'Nice to meet you. I've never met someone with AIDS before.' He's like, 'My friends have gotten gonorrhea before but I've never met someone with AIDS.' There's people behind me waiting in line. And that moment I was just like, 'wow,' like, I can feel what people are walking into the clinic and not, you know, just getting it tested can feel, but, just to be out there and he just saw my badge and automatically assumed that I had AIDS. It was really like 'wow,' like so much education needs to be in the community, you know. It was just something that was just so random. I was just shopping just with my badge and I didn't even think about it, just walking around with my badge on, you know. And he just, "I've never met someone with AIDS before." And I was just like, I couldn't even say anything. I was just like, 'alright', you know, I kind of had to breathe and just like, 'alright, you know what, just move on,' you know, like 'don't acknowledge it' but I was just even feeling in that moment. I was just like, 'Wow,' like, 'you just automatically assumed it,' you know. So, that's one thing that kind of goes with what I do" (HW:26742)

"D: Yeah. Taking our clothes off and then I tell him that…I should tell him before I'm going to have sex with him. That's my…because I'd be scared to death. You know, I'm not…I'd be scared somebody turned…I don't like people turning me down, you know. I think that's part of the reason" (CM:14771).

"I've found out that, it's not always wise to mention that you're HIV positive. I was segregated. I was, you know, I'm pretty much clowned, I was like a little object where they could just, you know, just treating me like dirt."(CM:16209)

Some respondents recant interactions where they were treated differently due to their HIV status.

"My uncle was dealing with his complications with AIDS before he passed away. I just briefly remember hearing like some of the doctors or nurses that was dealing with him was like ridiculous, just rude and nasty about it. I mean treating him as if the AIDS swipe past his arm like they'll get it like the nurse and stuff. So, that would probably be my closest to experiencing that. I mean that was traumatizing to me because I'm like, 'Oh my gosh, like, this is what can happen. This is what can come about.' Yeah" (CM:3967).

"I felt like I didn't get the proper dental care that I should have when I will go to another dentist, you know, just to do the, you know, just the general check. The other dentist would tell me, "Somebody did a sloppy job on your mouth, on your teeth." Kind of makes me wonder, "did they just rush at it, you know, just because I was HIV positive?" (CM:7893).

"They would come […] with gowns on, and masks on, and give me plastic plates and spoons. They were so afraid, and a lot of them, they're in rural areas, […] they're so backwoods and they're not hip on this new education on all about that. So, their minds are already set-up. And, when it came to medication, it was good. It was good to a certain degree but, they dealt with my HIV, as far as me being mentally ill, as well. So, that was another thing that I had to deal with, the mental illness and the health issue, too. So, roll it all up into one, you know, it wasn't a pretty picture." (CM:17179)

In spite of the barriers people living with HIV face, participants also expressed hope and thankfulness for treatments that now exist.

> "We get to live, you know, and have a good the rest of our lives because we are never going to really die…it's more than great, it's just, you know, there's hope" (CM:18132).

> "I just find it so exciting that in the course of, you know, 10 or 15 years, drugs were invented. And you know, were developed, lives were being saved and it just was remarkable to me to be able to see people leave and thrive and, not just survive, but thrive" (HW:12252).

G. Housing as a Social Determinant of Health and HIV

Many participants brought up homelessness as an issue that creates barriers to accessing HIV care services as well as heightening risk for contracting HIV. Furthermore, homelessness increases risk for drug use, which again increases risk for HIV. Several healthcare workers articulated that their patients cannot prioritize their HIV treatment if they do not know where they are going to sleep or what they are going to eat. The examples they provide illustrate the gravity of the housing crisis in Los Angeles: one speaks of their female clients who use meth to stay awake and vigilant at night because they feel unsafe sleeping outdoors, another noted that patients sell their HIV medications to survive.

> "it's hard for me, like, me, I've gotten to the streets. I don't know what I'm going to do. I have all of my family here [in LA]. They're doctors, they're nurses, they have big houses, but I cannot go with them because one of my auntie told me that, 'you go with us, we are going to have AIDS' and I cannot even tell them that I have got AIDS" (CM:13415).

> "You're giving them their HIV medication and you find that their virals are really still high and you say, 'Hey, what's really going on?' Sometimes you find out they are selling their medications because that's how they're surviving. And you just you want, you know, you're not going to necessarily cut them off, but 'hey, I need to know what's really going on.' And the patient just needs to know that you hear them. And you understand what's going on with them and that they're trying, their survival is their priority at this time. So, it's just meeting them where they are" (HW: 30674).

> "Housing I mean I just want to say it's getting really challenging for my patients that live in Long Beach that are being evicted and having to leave because the section 8 housing is just disappearing. I mean it's just becoming nonexistent and one thing I didn't know until I started working at the [name deleted]clinic was all of my female patients are using meth because they don't want to be asleep at night somewhere in a park, you know? They need to be awake, constantly moving. And I've seen a difference when these women do have some kind of safe housing. Then they stop using the meth and then they could take their medications and for me that's the biggest" (HW: 28594).

> "Poverty and homelessness and, you know, people don't have always a choice, choices to make, you know, to make safer decisions or better decisions if they're, you know, if they're needing a place to stay and, you know, they're kind of in a network of people who are using or whatever, doing, you know, unsafe behaviors but they don't have… the economic or rather freedom … to get out of that situation. They need a roof over their

heads and their friends, you know, their friends use and stuff is happening, you know, so I see that interrelated stuff" (HW:15623).

H. Suggestions to Improve Healthcare Related to HIV/STDs

Consistency in Physicians

Another theme related to HIV healthcare services requested that was brought up in the young adults focus group was the consistency, or lack thereof, of their doctors. They requested being informed if there doctor was leaving the practice.

> "C: Like the same doctor about every time you go for your check-up, so you get to bond with them and make a demand too and they know exactly what to look for because you all then had the previous conversation of what you have" (CM: 20342).

> "I've said to let me know when they inform me they're going to change my doctor. That will be helpful to let me know because I'm thinking about leaving them but I like some people that worked in there. I don't want to leave because there's some nice people working there. I don't be wanting to leave but it's on my head, but they keep changing your doctor, you keep, you know, without me saying something makes me want to leave" (CM: 18898)

> "T: I think they can just be like overly concerned, like don't only go off what you're saying, look further. I mean like, really, you know, look into your body that can tell you with records to your history and tell you something that might be wrong that you don't think it is. And I definitely agree with him when he says stay consistent with the same doctor because you get to know a doctor, you tell them your history, you get in a bond with them, and then you meet somebody else and you got to start all over again. So, it could get a little hectic" (CM: 19657)

Mental Health Services

Mental health services were requested in general, as well as specific to the Asian Pacific Islander culture aspects. A wider range of availability to access mental health services was also highlighted as a needed service. This matches the survey data which put psychiatric services as the number one service currently being used, psychotherapy being third, and both listed in the top three of services needed but which patients are having difficulty accessing.

> "I was thinking that add more support groups for Pacific Islanders. More support groups. Financing for support groups" (CM: 50140).

> "A lot of different psych diagnosis and just having more access to supportive care psychologically could be just a bridge to, you know, link people to care, regardless of whether it's previous abuse or you know, issues with their self-esteem, but just the way that, you know, my thought is, who couldn't use therapy, so maybe that's a way that we could link all of the groups regardless of their backgrounds" (HW: 20791).

> "Being an API is really hard, and I think what we need is advocacy work, and pure mental counseling because, I think that, because, we don't open to people so, advocacy work and pure mentoring, is very important for our community because, we need a

helping hand. We need that one person to just say, 'hey how are you doing? It's okay.' That is the most, because…we are very private as API, and, so, one person makes a lot of difference" (CM: 50491).

Transgender Services

Participants from various sessions requested services more supportive of the transgender population including sexual health education, practitioner awareness, and funding for non-traditional sexual relationships.

> "So, a lot of the PrEP, like grants and PrEP programs are focused on of course trans women, yeah, and then MSM of color, men who have sex with men who are you know, another primary color, but we are forgotten. None of the moneys are like, 'Oh, let's get trans men educated about PrEP,' because trans men have MSM sex" (CM: 29432).

> "And so are there like you know who, are we going to talk about using mini condoms and then there is still liquid that's all happening all over. Like what kind of transference happens in those instances? That's not talked about, that's hardly even mentioned whenever you even talk to a sex educator" (CM: 46188).

> "I think they need to have more awareness groups on tolerance, like on transgender people" (CM: 25398).

Comprehensive Clinical Services

One issue regarding services that emerged from the Asian Pacific Islander population was the need for clinics to have all resources in one place. There were several comments centered on the inconvenience of needing to visit several different clinics to meet all of one's health care needs and the potential insurance problems this could initiate.

> "You want to streamline everything, but, then, you want to expand your accessibility to all the different services. But you are also finding out that, when you go to the clinic and sign up, when they find out, especially when you are signing up with the Ryan White Case Management, in the system, they are showing that you're going here and going there, and it's like, 'oh, you've got to pick and choose.' It's just, like, 'oh, my gosh!' like, it becomes more like a stress factor because you're, like, 'okay, I can't access this one, but they have something here, but I have to choose' and it becomes limiting and you are like…you're torn, and, because you know that they have great care in some aspect that you need and in the current clinic at you're not, it doesn't have it, but you're so torn, and that's where streamlining and being a restrictive is adding stress because they're starting to limit you, because of the Ryan White in the computer system, Case Management Watch, I think it's Case Management Watch. They are showing where you are going, especially if you're with Medi-Cal or if you signed up for…every time you go to the clinic and you get social services or at that clinic, there's a Ryan White or Case Watch. Case Watch now goes on a computer database and they'll know where you are going and if you're asking to see too many…you know, going through too many …they're going to be sat down and say, you know, 'well, you're accessing here, you cannot access here,'

and so, that's what I'm finding because now, they are watching where you are going and how many clinics you are accessing because they don't want … doubling up, but they don't understand that another clinic has something that the other clinic doesn't have" (CM: 22353).

"The meeting that we need is advocacy and we have to look out for ourselves, because, from my experience, when I found out I was HIV positive, I didn't know anything and what happens is, I had to go to different organizations because one organization cannot give you everything that you need" (CM: 27411).

"You know, they don't have dental, and then, you have other clinics that have access to dental and ophthalmology, optometry, but, you've been with their services for so long, and then they have other specialty, but the other clinic has optometry and dentistry, but they don't have…they're limited in their specialty" (CM: 22036).

I. Suggestions to Improve Services to Prevent HIV

Due to the low levels of awareness, focus group participants mentioned the high need for outreach and education as prevention to occur in many locations, utilizing multiple and wide reaching communication methods.

"T: I would say just educate like just expand to every spot from South Central to Beverly Hills to everywhere because at the end of the day, everybody is going through something. No matter what income they are, no matter which tax bracket they're in, like everybody is dealing with, and then the person that's dealing with the most is the one that's hiding behind the door that nobody sees. And I feel like that's the person that needs to be reached so I just feel like educating and keep doing what you guys are doing because you're doing a good job but there's always more to be done" (CM:34161).

"D: I agree with [name deleted]. I think they should be educated. I believe they should go to the church, school, even on the internet, you know, obligated to it because I feel like a lot of people don't know about HIV and stuff that's why they put that stigma with HIV. I feel like it should be taught in school, in churches and stuff, and on the internet, like on Facebook and stuff. I think it will help people, educate people more" (CM:36132).

"A: I think it's critical to continue with some of the programs that we have, prevention programs, getting social messages out to folks, media messages out to people which helps to bring in to their forefront and so that they can come to a space and get tested and get some information and hopefully, use that information to navigate through their sexual world using the tools that they need to so that they don't become infected with an STD or HIV" (HW:7708).

Prevention within schools was specifically mentioned as an ideal place to spread awareness and information on the topic of HIV.

"I think that education, it should start from high school on, where they have…the high schooler can know what number to call, where they can get help while they are still young. And, also, they have access in the school, the universities, or wherever they are studying, so they can go direct, without having to maybe uncomfortable telling to parents?"(CM:63177).

"I think that certainly schools would be, you know, introducing getting it into education, introducing it, including it in educational programs. I think young people who are newly diagnosed that are just shocked. They have no idea how they contracted it. They think they are informed, they were told that you could only get it through certain ways and so they think they have been practicing safe sex and they can't just be positive, it's just not possible" (HW:11054).

Testing

One service requested was increased testing frequency among the general population for both HIV and STDs. There were different ways suggested to implement this, which ranged from inclusion in routine primary care in any access point, to informed doctors, to the availability of mobile testing vans.

"I think that definitely [provider name deleted] could serve, I think all of their patients better by just making it a little more, like general knowledge, instead of you have to seek it out to find out where to go to get tested for STIs. I think that it should be separate from primary care, you shouldn't have to make an appointment to see your primary care doctor just to go test for STIs" (CM: 36491).

"The county or the city does not have too many, not enough mobile vans to go to locations, to places where people congregate" (HW: 24250).

"Especially with the Affordable Care Act, we should have folks have more opportunities to access the health care system and I think at all those points where they're accessing it. HIV testing should be routinized. I think if the…like the public health officer for the county just sent a letter to all the private physicians and said, you know, 'this is covered under the Affordable Care Act. You should be testing people once a year. You need to be doing this' and that kind of authority through a letter to all the providers I think would increase testing substantially. Just reminding physicians that they should be doing this on a regular basis and we could catch a lot of people that way" (HW: 22207).

"I'm insured through [provider name deleted] through my work and [provider name deleted] is interesting because I know that they are really into preventative care so if I asked for PrEP I would probably get it. But, they don't offer up like easy access, 'hey, come get tested for STIs. Just come on in, every three months, every six months…' I feel like that is not as open and welcoming and encouraging for preventative such as, example, where I work, at the [LGBT focused provider name deleted]" (CM: 6171).

"HIV prevention and care has never once been mentioned to me by [insurance provider name] and even as when I was uninsured getting care at the [LGBT focused provider name deleted] as a trans man, none of that was targeted to me" (CM: 23641).

"but also with providers, not everyone sees a provider regularly but many do and I think providers, primary care providers especially as more people get Medical and get it. They don't perceive their patients to be at risk and they don't test and that's really a missed opportunity. I feel like anyone who sees that, you know, who's sexually active and sees a primary care provider should get an HIV test or an STI testing done regularly but I don't see that happening. So, that's it, that's an issue" (HW:21386).

Continued Relevance of Print Sources

Two sources of printed material were brought up as important resources without prompting: flyers and the Rainbow manual. While this information may be available on-line, community members may not know what reputable sources exist on-line, so print sources are needed to at minimum inform of their continued existence.

> "… flyers have been really effective because they're everywhere, and you just kind of see it, and, you know, it's surprising that it's not word of mouth through friends, but, I get my information through flyers" (CM: 4103).
>
> "W: I used to be…when I first started out, I would go to [name of provider deleted], and they have a manual. And the manual has all the different organizations and stuff like that, but they've stopped handing that manual out.
>
> N: The rainbow.
>
> W: Yeah." (CM: 33709).

Limitations

There were various limitations relating to the number and characteristics of the participants within the listening sessions.

The Asian-Pacific Islander group included participants who did not self-identify as such. This group included some individuals with limited English. Another group member who spoke the same language provided a succinct synopsis of their views and assisted with accurate completion of the demographic surveys. While not ideal, it was determined more important for their perspectives to be included than for these circumstances to exclude their insights. As the Asian-Pacific Islander group is culturally and linguistically diverse, there were multiple language preferences within the group (e.g. Korean, Tagalog). As these groups represent a minority within a minority, separately there is not a wide enough pool to recruit for an effective listening session. For these reasons, despite the limitations, all were included. Another alternative would be to conduct key informant interviews, which would require translation and increased resources to conduct, synthesize and analyze the results. Although the size of this group was somewhat larger than ideal, due to the language limitations and related silence of various members, the number of full participants in the session was within desired range (8-12).

Other groups had low numbers, in particular the transmasculine and recently post-incarcerated sessions (see Table 1 for all group information). Again the potential insight provided by these participants was deemed more important than missing their perspectives entirely. In both the transmasculine and 25-29 year-old groups, some of the participants also are part of the HIV workforce. Their comments reflected their experiences as individuals, not as organizational or workforce representatives.

Toward the end of the listening sessions participants were asked if there were any cultural issues unique to their community that affect HIV prevention and awareness. This item sparked novel reflections among all groups. For future iterations, moving this question to the beginning

or middle of the session may allow time for further useful details to emerge, as some participants answer questions further along in the discussion than when they are initially posed.

Discussion

These listening sessions reiterated recommendations from past rounds of listening sessions for continuing to include HIV and STD/STI education for the general public. They also affirmed that this information needs to be presented and marketed as applicable to all, that is, for different sub-cultures to identify with the images and messaging so that it reaches them. Rather than having a single brochure or image the information needs to be presented to each culture or subculture.

Discussion surrounding PrEP and PEP indicated that more training is needed among general health staff in large clinics and hospitals, as well as to staff in small community clinics. It is also still needed for prospective consumers to move them along the stages of readiness for change. Accessibility continues to be an issue in terms of who prescribes, those to whom it is offered, and cost. A final word is concern that use of these prescriptions are decreasing use of condoms with detrimental overall health impacts.

Finally two services that stood out for their gravitas were the demand versus supply of accessible, culturally relevant mental health services, and stable housing to support both prevention and care.

Appendices:

Appendix 1a. Demographic survey

Consumers

HIV Workforce

Appendix 2. Focus Group guide

Consumers

HIV Workforce

Appendix 3. NCLR/CSULB Center Background

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Community Listening Sessions
Discussion Questions
Tier 3 MASTER FILE (1.18.17)

Demographic Questionnaire

Thank you for sharing your ideas and feedback on how we can improve HIV services in Los Angeles County. This questionnaire is intended to collect important information that the Commission on HIV needs in order to understand the service gaps and opportunities in our community.

I. Age

- ○ 18-24 years old
- ○ 25-29 years old
- ○ 30-39 years old
- ○ 40-49 years old
- ○ 50-59 years old
- ○ 60 years and older

II. Race/Ethnicity (please check all that apply)

- ○ African American
- ○ American Indian/Alaskan Native
- ○ Asian
- ○ Latino/Hispanic
- ○ Pacific Islander
- ○ White/Not Hispanic
- ○ Other:_____
- ○ Decline to state

III. Gender

- ○ Male
- ○ Female
- ○ Trans (Male to Female)
- ○ Trans (Female to Male)

IV. Sexual Orientation: Do you consider yourself to be:

- ○ Heterosexual or straight
- ○ Gay, lesbian, same gender loving
- ○ Bisexual
- ○ Queer/Questioning
- ○ Other:_____
- ○ Decline to state

V. Educational Attainment (please check highest level completed)

- ○ Less than high school
- ○ Some high school
- ○ High school or GED
- ○ Some college (did not graduate)
- ○ Vocational/Technical School Diploma
- ○ Associates degree
- ○ Bachelor's degree
- ○ Advanced degree (Masters and above)

VI. Income

- ○ Less than $15,000 a year
- ○ $15,000-$20,000 a year
- ○ $21,000-$25,000 a year
- ○ $25,000- $30,000 a year
- ○ More than $30,000 a year

VII. Marital Status

- ○ Single
- ○ Married

VIII. Family Household: How many people are in your household?

- ○ 1, just me.
- ○ 2
- ○ 3-5
- ○ More than 5

IX. Have you ever been told that you have HIV?

- ○ Yes
- ○ No

a. If so, when were you diagnosed? (month/year)

X. Do you have health insurance?

- ○ Yes
- ○ No

a. If yes, what type? (please check all that apply)

- ○ Medi-Cal
- ○ Covered California
- ○ Medicare
- ○ Kaiser Permanente
- ○ I don't know.
- ○ Other: please specify: _____

b. Do you have difficulty paying your premium, co-pay, or medications?

- ○ Yes
- ○ No

XI. What kind of services are you currently receiving? Check all that apply.

Type of Service	I am using now	I need but am having trouble accessing it	I will need in next year	I don't need it right now.
1. Help getting enrolled in health insurance				
2. PrEP (pre-exposure prophylaxis; for people who are at very high risk for HIV take HIV medicines daily to lower their chances of getting infected)				
3. HIV prevention education (classes, workshops, presentations)				
4. STD prevention education (classes, workshops, presentations)				
5. Condoms (free)				
6. HIV testing				
7. STD testing				
8. STD treatment				
9. HIV medical care				
10. General oral health services (regular check-up, cleaning, root canals, braces)				
11. Specialty oral health services (surgery, more complex procedures)				

Type of Service	I am using now	I need but am having trouble accessing it	I will need in next year	I don't need it right now.
12. Psychiatry mental health services (diagnosis, treatment and prevention of mental, emotional and behavioral disorders)				
13. Psychotherapy mental health services (treating mental health problems by talking with a psychiatrist, psychologist or other mental health provider; helps you learn how to take control of your life and respond to challenging situations with healthy coping skills).				
14. Medical case management services				
15. Home and community based services				
16. Medical nutrition therapy				
17. Non-medical case management (assistance in accessing medical, social, community, legal, financial, and other needed services)				
18. Medical transportation services				
19. Food bank/home-delivered meals				
20. Housing services				
21. Housing Opportunities for People with AIDS (HOPWA) program services (housing assistance for PLWHA)				
22. Language services (interpretation, translation)				
23. Residential substance abuse treatment (Long-term residential treatment provides care 24 hours a day, generally in non-hospital settings)				
24. Outpatient substance abuse treatment (group counseling; treatment for patients with medical or other mental health problems in addition to their drug disorders.)				
25. Outreach (basic education; get people into needed services)				
26. Referrals for services				
27. Legal services				
28. Other: (specify):_____				

LOS ANGELES COUNTY COMMISSION ON HIV

3530 Wilshire Boulevard, Suite 1140 • Los Angeles, CA 90010 • TEL (213) 738-2816 • FAX (213) 637-4748

Community Listening Sessions
HIV Workforce Demographic Questionnaire
Tier 3 MASTER FILE HIV WORKFORCE ONLY (1.31.17)

Thank you for sharing your ideas and feedback on HIV workforce issues and opportunities in Los Angeles County. This questionnaire is intended to collect important information regarding the general demographic characteristics of participants in the HIV workforce listening sessions.

I. Age

- ○ 18-24 years old
- ○ 25-29 years old
- ○ 30-39 years old
- ○ 40-49 years old
- ○ 50-59 years old
- ○ 60 years and older

II. Race/Ethnicity (please check all that apply)

- ○ African American
- ○ American Indian/Alaskan Native
- ○ Asian
- ○ Latino/Hispanic
- ○ Pacific Islander
- ○ White/Not Hispanic
- ○ Other:_____
- ○ Decline to state

III. Gender

- ○ Male
- ○ Female
- ○ Trans (Male to Female)
- ○ Trans (Female to Male)

IV. Sexual Orientation: Do you consider yourself to be:

- ○ Heterosexual or straight
- ○ Gay, lesbian, same gender loving
- ○ Bisexual
- ○ Queer/Questioning
- ○ Other:_____
- ○ Decline to state

V. Educational Attainment (please check highest level completed)

- ○ Less than high school
- ○ Some high school
- ○ High school or GED
- ○ Some college (did not graduate)
- ○ Vocational/Technical School Diploma
- ○ Associates degree
- ○ Bachelor's degree
- ○ Advanced degree (Masters and above)

VI. Type of Agency (check all that apply)

- ○ Non-Profit
- ○ University/Research Agency
- ○ Local Health Department
- ○ Community Clinic
- ○ Federally Qualified Health Center

VII. Type of HIV Health Profession

- ○ Infectious diseases board-certified physician
- ○ Other board-certified physician
- ○ Nurse practitioner
- ○ Physician assistant
- ○ Program Manager/Coordinator
- ○ Other: (please specify):

  _____

- ○ HIV testing counselor
- ○ Outreach worker
- ○ Health Educator
- ○ Case Manager
- ○ Supervisor

VIII. Which Service Planning Area (SPA) do you currently provider HIV services (check all that apply)?

- ○ SPA 1 (Antelope Valley: Acton, Agua Dulce, Gorman, Lake Hughes, Lake Los Angeles, Lancaster, Littlerock, Palmdale, Quartz Hill, and others)
- ○ SPA 2 (San Fernando Valley: Burbank, Calabasas, Canoga Park, Canyon Country, Encino, Glendale, La Cañada-Flintridge, San Fernando, Sherman Oaks, Sun Valley, Van Nuys, Woodland Hills, and others)
- ○ SPA 3 (San Gabriel Valley: Alhambra, Altadena, Arcadia, Azusa, Baldwin Park, Claremont, Covina, Diamond Bar, Duarte, El Monte, Glendora, Irwindale, Monrovia, Monterey Park, Pasadena, Pomona, San Dimas, San Gabriel, San Marino, Temple City, Walnut, West Covina, and others)
- ○ SPA 4 (Metro: Boyle Heights, Central City, Downtown LA, Echo Park, El Sereno, Hollywood, Mid-City Wilshire, Monterey Hills, Mount Washington, Silver Lake, West Hollywood, and Westlake)
- ○ SPA 5 (West: Beverly Hills, Brentwood, Culver City, Malibu, Pacific Palisades, Playa del Rey, Santa Monica, and Venice)
- ○ SPA 6 (South: Athens, Compton, Crenshaw, Florence, Hyde Park, Lynwood, Paramount, and Watts)
- ○ SPA 7 (East: Artesia, Bell, Bellflower, Bell Gardens, Cerritos, City of Commerce, City Terrace, Cudahy, Downey, East Los Angeles, Hawaiian Gardens, Huntington Park, La Habra Heights, Lakewood, La Mirada, Los Nietos, Maywood, Montebello, Norwalk, Pico Rivera, Santa Fe Springs, Signal Hill, South Gate, Vernon, Walnut Park, Whittier, and others)
- ○ SPA 8 (South Bay: Athens, Avalon, Carson, Catalina Island, El Segundo, Gardena, Harbor City, Hawthorne, Inglewood, Lawndale, Lennox, Long Beach*, Hermosa Beach, Manhattan Beach, Palos Verdes Estates, Rancho Dominguez, Rancho Palos Verdes, Redondo Beach, Rolling Hills, Rolling Hills Estates, San Pedro, Wilmington, and others)

IX. Tell us about the demographics of the clients you serve. Over 50% (over half) of the clients my agency serves are: (check all the apply):

○ African American	○ Women
○ American Indian/Alaskan Native	○ Men who have sex with men
○ Latino/Hispanic	○ Youth (under age 24)
○ Asian	○ People who inject drugs
○ Pacific Islander	○ Homeless
○ White/Not Hispanic	○ Transgender (male to female)
○ Other (please specify):	○ Transgender (female to male)

X. How many years of experience do you have working in the HIV field?

- ○ Less than 5 years
- ○ 5 to 10 years
- ○ 10 to 15 years
- ○ 15 to 20 years
- ○ 20 to 25 years
- ○ Over 25 years

XI. Professional Satisfaction: Please rate the following with your current employment experience.

	Please circle one:				
Salary and reimbursement	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied
Amount of time required and available for documentation/administrative work.	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied
Work schedule/on-call responsibilities.	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied
Support services to assist patient/client management.	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied
Support and coverage from other HIV service providers (care and prevention)	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied
Availability of specialists for consultation and referrals.	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied
Effort required to keep up with the new medical, prevention, and scientific advances.	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied
Support for training and professional development.	Very satisfied	Satisfied	OK	Dissatisfied	Very dissatisfied

XII. What kind of services does your agency currently provide? Check all that apply.

Type of Service	**Check if your agency provides the service**
Help getting enrolled in health insurance	
PrEP (pre-exposure prophylaxis; for people who are at very high risk for HIV take HIV medicines daily to lower their chances of getting infected; biomedical interventions)	
HIV prevention education (classes, workshops, presentations)	
STD prevention education (classes, workshops, presentations)	
Condoms (free)/condom distribution	
HIV testing	
STD testing	
STD treatment	
Partner services	

Social marketing, media and community mobilization	
Comprehensive prevention with HIV-positive individuals	
Evidence-based interventions for high-risk population. Please name of evidence-based intervention:	
Capacity building and technical assistance	
HIV medical care	
General oral health services (regular check-up, cleaning, root canals, braces)	
Specialty oral health services (surgery, more complex procedures)	
Psychiatry mental health services (diagnosis, treatment and prevention of mental, emotional and behavioral disorders)	
Psychotherapy mental health services (treating mental health problems by talking with a psychiatrist, psychologist or other mental health provider; helps you learn how to take control of your life and respond to challenging situations with healthy coping skills).	
Medical case management services	
Home and community based services	
Medical nutrition therapy	
Non-medical case management (assistance in accessing medical, social, community, legal, financial, and other needed services)	
Medical transportation services	
Food bank/home-delivered meals	
Housing services	
Housing Opportunities for People with AIDS (HOPWA) program services (housing assistance for PLWHA)	
Language services (interpretation, translation)	
Residential substance abuse treatment (Long-term residential treatment provides care 24 hours a day, generally in non-hospital settings)	
Outpatient substance abuse treatment (group counseling; treatment for patients with medical or other mental health problems in addition to their drug disorders.)	
Outreach (basic education; get people into needed services)	
Referrals for services	
Legal services	
Other: (specify):	

Focus Group/Listening Sessions Questions and Guide
TIER 3 MASTER FILE (Updated 1-22-17)

Group maximum size: 15 people max per session

When: Varies (see flyer for schedule and location)

Procedures: 1) check-in/sign-in; 2) get food; 3) fill out demographic questionnaire; 4) thank participants and give Commission on HIV overview and purpose of the focus group. Ensure no providers are in the room; 5) yield floor to CSULB staff to facilitate focus group.

Target audience: High-risk HIV negative and HIV-positive individuals

Facilitator Duties and Expectation(s):

1. Set the stage (Cheryl Barrit or designee): Introduction of the Commission, its intention, and highlight some of the successes and opportunities for involvement and improvement in the work of the body.

2. Confidentiality: ***Set ground rules for safety and inclusion***, including the role of any commissioners/planning council members in the room. Sample rules may include: cell phones on silent mode, what happens in the room stays in the room, step up step back, no cross talk, agree to disagree, and speaking from "I" statements.

3. Facilitation: Use guide to ask question provided, however, be mindful of emerging themes that may elicit more conversation or offer an opportunity for less participatory individuals to be included in the conversation.

4. Attendance (coordinated by Cheryl and staff in advance): Any Commissioner in attendance will be asked to support the process by observation and volunteerism through note taking and/or referrals; setup and clean-up facility, welcome and thank participants.

Focus Group Questions:

1. Where would you go for your dream vacation? (**Facilitator note**: This is a warm up opportunity to get people thinking bigger.)

2. Describe your experience with obtaining **HIV/STD prevention services**? (Examples of prevention services are health education workshops, condom use demonstration, information and access to PrEP and PEP, HIV/STD testing, prevention education, psychosocial, dental, and transportation).
3. Describe your experience with obtaining **HIV-specific medical care**? Positive experience? Negative experience?
4. Where do you go to look for HIV/STD services?
5. When you try to access services, what issues or concerns come up for you? If so, how? Would learning that you were HIV positive change the way you access services and support?
6. Have you attempted to sign up for health insurance?
    a. What has been your experience?
    b. Are you receiving the service you need? If not, why?
7. There are three types of HIV status – positive, negative or unknown. With this in mind, how have you been affected by your HIV status? In what ways have you experienced disapproval or rejection that you believe may have been related to your status?
8. What is your relationship with your doctor? Do you talk about HIV? Do you talk about sexually transmitted infections?
9. How can your doctors and other providers serve you better? (**Facilitator note**: This is an opportunity to talk about quality of care, language, and other potential barriers or tools do you think doctors and other support staff need to enhance prevention and clinical services delivery.)
10. How do you protect yourself and others from HIV? (**Facilitator note**: This is an opportunity to learn how people are navigating their sexual health. Can incorporate abstinence, partner negotiation, condoms, treatment as prevention – counseling, testing, medication adherence, and other biomedical strategies)
11. Are there cultural (broadly defined) or linguistic issues that are unique to your community that affect HIV prevention and awareness? What are those issues? What about unique cultural/linguistic factors that affect HIV care? What are those issues?
12. In thinking of the future, where do you want to be in five years?

Los Angeles County Commission on
HIV HIV Workforce Focus Group
Questions Final (1-22-17)

PrEP: Pre-exposure prophylaxis
PEP: Post-exposure prophylaxis

REMIND PARTICIPANTS WE WANT THEIR PERSPECTIVE AS AN HIV WORKER (a person who provides HIV/STD prevention and care services)

1. Why are you working in this field? **[Probe for motivators and values.]**
   a. What do you find rewarding about working in this field?

2. What do you think is the most important factor in decreasing HIV and STD infections?

3. What are trends in the risk activities, behaviors or conditions for HIV acquisition and transmission that you are seeing in the community?

4. What are barriers to getting people to test in the community you work in?
   a. What are the key challenges you face in providing services to PLWHA?

5. How do you retain clients in care?
   a. How do you keep clients connected to other resources?

6. What do you know about biomedical interventions to prevent HIV? **[Probe for knowledge of PrEP/PEP.]**

7. What types of clients do you offer PrEP to?
   a. How do you talk to clients about PrEP or PEP?
   b. How do you refer clients to PrEP or PEP?

8. Please describe the training you have received for your job. What tools and resources do you have to do your job?

9. What tools and resources do you need in order to perform your job well?

10. What do you know about other social services in the community? What social services are lacking in the community?

11. How can we improve customer service?
    a. What can be done to better serve PLWHA?
    b. What can be done to better serve high risk negatives?

12. If funding wasn't an obstacle for you organization/agency, what would you do to better serve PLWHA? How about HIV-negative individuals?

NCLR/CSULB Center for Latino Community Health, Evaluation, and Leadership Training

Established in 2005, the NCLR/CSULB Center for Latino Community Health, Evaluation, and Leadership Training is a collaborative between CSULB and the largest Latino advocacy and civil rights organization in the U.S., NCLR. In 2013, the NCLR/CSULB Center staff opened a community-based participatory research site in a densely-populated, Latino dominant area of downtown Long Beach, the *Centro Salud es Cultura*. The shared mission of the NCLR/CSULB Center and of the *Centro* is to improve, promote, and advocate for the health, culture, and well-being of diverse Latino communities. The NCLR/CSULB Center has experience in developing, implementing, and evaluating health interventions aimed to address HIV/AIDS, STIs, maternal and child health, obesity prevention, youth leadership, and student academic achievement. In addition, the NCLR/CSULB Center provides technical assistance to the NCLR Institute of Hispanic Health, NCLR affiliates, other Latino-focused community based organizations and health care providers to inform research and develop program evaluation tools and effectiveness measures. The NCLR/CSULB Center also works to increase the number of Latinos in health and human services professions, and provide evidence to bolster health and education policy processes at the local, state, and national levels.