

# HIV Prevention & Care Integrated Needs Assessment 2022 Final Report

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## **Needs Assessment Development**

During the early weeks of the planning phase, we conducted a thorough review of existing literature to identify qualitative data useful for the current needs assessment survey. Items reviewed include but are not limited to the current HIV Prevention & Care Integrated Plan, the previous Needs Assessment Qualitative Report, the HIV National Strategy 2015-2021, our previous needs assessment with the Trans community and the Peer Navigator programs including the Peer Specialist Lit Review compiled by WI DHS, and other peer reviewed articles published since 2017 focusing on HIV prevention and care in rural and indigenous communities.

Following the Zoom Webinar Guidance from CDC/HRSA for the new Integrated Care Plan on 10/27/21, and with information gleaned from the literature and previous needs assessments review, we drafted our initial survey instrument for target community members and distributed it internally for review by project staff. After initial changes were made, the survey was distributed to program participants through our Milwaukee Counseling, Testing & Referral program and to Vivent's HIV Prevention and Harm Reduction programming serving Outagamie and Brown counties. Vivent staff working with People Who Inject Drugs (PWID) also reviewed the survey and provided critical feedback specifically regarding the language on the questions related to intravenous drug use. One final review was conducted by Wisconsin DHS Communicable Disease Harm Reduction Section, Division of Public Health team members. The survey was then translated into Spanish by a bilingual key stakeholder with an understanding of common language used for all related issue areas of the survey.

## **Survey Overview**

The survey collected basic demographic information about participants including the following:

- Age
- County of Residence/Zip Code
- Race
- Ethnicity
- Sex at Birth
- Current Gender Identity
- Sexual Orientation
- Education
- HIV Status

We also asked respondents if they had previously or were currently working in an HIV related field. These survey respondents ultimately formed a subgroup for the analysis you will see throughout this report.

Questions followed that assessed needs and input from participants across a wide array of domains and included:

- Experience with and interest in “at-home” HIV tests
- Condom use
- Needle use
  - injecting steroids and testosterone
  - drug use
- Employment
- Housing
- Healthcare Experiences, including dental and telemedicine
- Transportation
- Stress & Emotional Well-Being (includes substance use questions to cope with stress/mental health)
- General Social Support
- Experiences of Oppression
- HIV Related Services

The surveys were created in Formstack (an online survey platform) and could be completed via computer/laptop or smartphone. Survey distribution was supported by agencies across the state including HIV Prevention & Care programs funded by DHS, Tribal Health Coordinators and Programs, Syringe Service Programs, and some Federally Qualified Health Centers. Assistance was also provided by members of the Statewide Action Planning Group (SAPG). In total, 65 contacts at local and statewide community-based organizations and 30 members of the SAPG received the community survey in English and Spanish to distribute to eligible community members via direct recruitment of their program staff. The survey was distributed in “waves” which grouped small organizations together but allowed for larger organizations to receive unique survey links making it easier for communication and follow up. The survey links were open from a Monday through Friday of the same week to minimize the sharing of the survey link outside of individuals who were recruited directly by staff. Survey respondents received \$75 incentives either directly via CashApp or a mailed gift card. In total we received 184 completed surveys. Individuals with no risk factors for HIV transmission or no individual factors targeted by federal guidance for HIV prevention programs were removed prior to survey analysis leaving 126 total surveys.

Once the survey period was completed, staff from Diverse & Resilient, including, Katie Hamm, consultant, Kofi Short, Director of HIV/STI Prevention Services, and Justin Roby, Director of HIV Care, conducted analysis of the survey data and extracted themes. Themes were further analyzed through virtual and in-person focus groups with community members and key stakeholders in central and rural Wisconsin counties. Focus group participants were serodiscordant and were white, BIPOC, cis and Trans, with participants being either current or previous consumers of harm reduction or HIV prevention services or were currently engaged in care. One focus group included individuals in various states of substance use recovery and due to stigma associated with PWID, wanted their identities to remain anonymous. This focus group

was virtual with cameras remaining off. Participants were called upon using only their initials. In total, 26 individuals participated in focus groups, including a subgroup of providers who were also either current or previous consumers of harm reduction or HIV Prevention & Care services. Focus group participants received a \$50 gift card for their participation.

Our process also included a Provider/Key Stakeholder survey. In preparation for the creation of the provider or key informant survey, we integrated what we learned in our literature review, research for the community survey, and information gleaned in our research for the development of the Peer Navigator (PN) program. Though the PN program was specific to PLWH, it was also focused on barriers to engagement in care and supportive services and highlighted elements that were also relevant to the current project that were developed from listening sessions with PLWH about their needs prior to their seroconversion and after their HIV diagnosis. Based on this knowledge, we developed a survey that included the following questions/categories:

- Age
- County/Zip Code where they provide services
- Race
- Ethnicity
- Sex at Birth
- Current Gender Identity
- Sexual Orientation
- Education
- HIV Status
- Role in HIV Prevention & Care
- Telehealth
- Populations Served
- Knowledge of population barriers to service
- Training

In total 83 providers completed the provider survey.

We used a grounded theory approach to our analysis, systematically analyzing the data for thematic patterns. Our research design allowed for (1) the exploration and discovery of concepts and themes, (2) added context and depth to the understanding of the qualitative data via focus groups, (3) provided an interpretation of the data from the point of view of the community and key stakeholders, and (4) used lived experiences of community members to make specific programmatic recommendations.

*When analyzing the results, percentage points above .5 were rounded up, below .5 were rounded down. Percentages in one category may not always equal 100%.*

**Provider Survey Respondent Demographics**

Race (Participants could check all that applied)		Ethnicity	
Native American / Alaska Native	2%	Hispanic or Latinx	7%
Asian	2%	Not Hispanic or Latinx	90%
East Asian/South Asian	1%	Decline to Answer	2%
Black / African American	13%		
Native Hawaiian / Pacific Islander	1%		
White	72%		
Indicated more than one race	4%		
Don't know	1%		
Prefer to self-describe: <ul style="list-style-type: none"><li>○ Hispanic</li><li>○ Native of Mexican descent</li></ul>	2%		
Sex at Birth		Gender Identity (Participants could check all that applied)	
Male	28%	Male	23%
Female	69%	Female	64%
Decline to answer	4%	Transgender	2%
		Non-binary	4%
		Gender Non-Conforming	2%
		Gender Fluid	1%
		Decline to Answer	2%
Sexual Orientation			
Heterosexual/Straight	57%	Providers who preferred to self-describe: <ul style="list-style-type: none"><li>○ As a woman of the trans experience I would identify as Heterosexual because I am a woman attracted to men. However, a lot of the programmatic materials don't educate clients and community on the difference between Gender Identity and Sexual Identity.</li><li>○ Non-practicing panromantic? Honestly, I try not to put a label on myself.</li><li>○ Bi-curious I'd say</li><li>○ My sexual partners are male</li></ul>	
Gay	18%		
Lesbian	8%		
Bisexual	5%		
Pansexual	4%		
Asexual (Ace)	1%		
Queer	4%		
Prefer to Self-Describe	5%		
What is the level of education that you have completed?			
Middle school, no high school			

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Some high school, but did not graduate	17%
High School Diploma or GED	
Some College, but did not graduate	
College degree (undergraduate)	40%
Associate degree	4%
Master's degree (graduate)	31%
PhD or Doctorate	6%

Provider HIV Status	
I am HIV Positive/I am living with HIV	6%
I am HIV Negative/I am not living with HIV 7	94%
If you are a person living with HIV, are you:	
Engaged in care (seeing a doctor, getting regular lab work, etc.)	6%
Previously engaged in care but not currently	
Never engaged in care	
Does not apply to me	86%
No response	8%
If you are a person living with HIV, have you ever had an AIDS diagnosis (been told by a medical professional that lab results indicate symptoms of AIDS?)	
Yes	
No	6%
No response	6%
Does not apply to me	88%

### Populations Served by Provider Respondents

Which of the populations below does your program serve? (check all that apply)	
Persons Living with HIV (PLWH)	84%
People Who Use Drugs (Including Intravenous Drugs)	88%
Black, Indigenous, and other People of Color disproportionately impacted by HIV	83%
People who engage in Sex Work	82%
Gay and Bisexual Men	87%

People at-risk of or currently experiencing Homelessness	84%
Other people who engage in behavior where threats to their sexual health occurs (see below)	31%
Another Population (see below)	20%

Other populations served by providers who engage in behavior where threats to their sexual health occurs:

- Immigrants, documented and undocumented
- Adolescents and young adults
- All populations that come to the clinic or bar HIV /Syphilis testing
- Community members who engage in sexual activities that are not considered high-risk by CDC or DHS definitions
- College age students not using protection
- PreP patients, individuals struggling with mental health
- Trans / Gender non-conforming people for sexual health and Pregnant Women via WellWomen a CDC infant mortality prevention program

Another Population:

- People with mental illness
- The partners of those living with HIV
- Women of Trans experience



**Community Survey**

Average age of community survey respondent was 47.5, with participants ranging from age 20 – 67.

Participant County of Residence			
Milwaukee	58%	Eau Claire	<1%
Lacrosse	10%	Juneau	<1%
Dane	8%	Kenosha	<1%
Douglas	3%	Racine	<1%
Brown	2%	Sawyer	<1%
Marathon	2%	Vernon	<1%
Outagamie	2%	Vilas	<1%
Ashland	2%	Waupaca	<1%
Iron	2%	West Allis	<1%
Rock	2%	Winnebago	<1%
Waukesha	2%		

Participant Zip Code of Residence	
Zip Code	# of participants
53212	6
52309	1
53110	1
53144	1
53150	2
53202	7
53204	8
53205	2
53206	12
53207	3
53208	5
53209	4
53211	3
53214	1
53215	4
53216	4
53218	2
53219	2
53220	1
53221	1
53223	1

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53225	2
53233	2
53235	1
53403	1
53545	1
53548	1
53703	1
53704	3
53711	1
53712	3
53714	1
53716	1
53944	1
54130	1
54170	1
54207	1
54302	1
54304	1
54313	1
54403	2
54476	1
54521	1
54534	2
54601	4
54603	7
54634	1
54650	1
54701	1
54806	2
54843	1
54880	4
54901	1
54914	1
54961	1

Race (Participants could check all that applied)		Ethnicity	
Native American / Alaska Native	2%	Hispanic or Latinx	20%
Asian		Not Hispanic or Latinx	79%
East Asian/South Asian		Don't Know	0
Black / African American	35%	Decline to Answer	1%
Native Hawaiian / Pacific Islander			
White	47%		
Indicated more than one race	4%		
<ul style="list-style-type: none"> <li>Black/African American &amp; White</li> <li>Native American/Alaska Native &amp; White</li> <li>Native American/Alaska Native &amp; Asian</li> <li>Asian &amp; Black/African American</li> <li>Native American/Alaska Native &amp; Black/African American</li> </ul>			
Not specified	3%		
Decline to answer			
Don't know	2%		
Prefer to self-describe: Puerto Rican, Latino, Hispanic, Latino, Hispano, Latino, 2 or more races, Middle Eastern, Latino, Serbian	7%		

Sex at Birth		Gender Identity (Participants could check all that applied)	
Male	78%	Male	70%
Female	19%	Female	19%
Intersex	0	Transgender	9%
Decline to answer	3%	Non-binary	2%
		Gender Non-Conforming	2%
		Gender Fluid	<1%
		Agender	0
		Another Gender	0
		Two Spirit	2%
		Discovering	0
		Decline to Answer	0
		Prefer to self-describe:	0

Sexual Orientation	
Heterosexual/Straight	22%
Gay	54%
Lesbian	2%
Bisexual	16%
Pansexual	3%
Asexual (Ace)	0%
Queer	3%
Prefer to Self-Describe:	2%
<ul style="list-style-type: none"> <li>○ My sex partners tend to be male</li> <li>○ Like men more than women</li> </ul>	

Highest level of education completed	
Middle school, no high school	2%
Some high school, but did not graduate	10%
High School Diploma or GED	22%
Some College, but did not graduate	40%
College degree (undergraduate)	14%
Associate Degree	7%
Master's degree (graduate)	5%
PhD or Doctorate	

HIV Status		In Care	
I am HIV Negative/ I am not living with HIV	47%	Engaged in care (seeing a doctor, getting regular lab work, etc.)	92%
I am HIV Positive /I am living with HIV	50%	Previously engaged in care but not currently	3%
I don't know my current HIV status	3%	Never engaged in care	2%
PLWH who have received an AIDS diagnosis			
Yes	40%		
No	60%		

Individuals who are HIV Positive and indicated they are not currently or have never been in care:

Care Status	Race/Ethnicity	Age	County	Gender Identity	Sexual Orientation	PWID	Condom Use for anal/vaginal	Shares Needles
Never in Care	Black/African American Not Hispanic	62	Milwaukee	Cis Male	Bisexual	No	Never Uses	NA
Previously Engaged	White	40	Eau Claire	Cis Male	Straight	Yes	Most of the Time	Yes, but not

	Declined to Report Ethnicity							currently sharing
Previously Engaged	Black/African American Not Hispanic	33	Milwaukee	Cis Male	Gay	No	Not currently sexually active	NA

**If you are not a person living with HIV (are HIV negative) how often do you get tested for HIV?**

Once a year	27%	Other (Specified below): 8%
Every 3 to 6 months	47%	<ul style="list-style-type: none"> <li>○ Not often enough but was not sexually active for like 6 years</li> <li>○ 2-5yrs</li> <li>○ Last tested 25 years ago</li> <li>○ I've been tested just not regularly</li> </ul>
Every month	1%	
After sexual activity with a new partner	7%	
When a partner asks me to	4%	
Never	5%	
<b>Currently or ever worked in an HIV related field</b>		
Yes	31%	Roles included: Volunteer, Harm Reduction Navigator, PrEP Navigator, Peer Navigator, Prevention, CTR, Mentor, Advocate, Case Manager, Counselor, Home Health Care, Facilitator, Educator, Outreach, Director, Coordinator
No	69%	

Throughout this report we break down survey responses by subgroup where indicated. The following subgroups were used (though not every survey question is broken down by every subgroup):

**All** – All survey participants

**Trans** - We use Trans as an umbrella term to encompass gender variants that are not cisgender yet recognize there are also gender variant people who don't fit within Transgender identifiers or language. Participants under the Trans umbrella identified as Trans, gender nonconforming, gender fluid, nonbinary, and Two Spirit.

Additional information about this subgroup:

- Age range: 21-53
- 43% Black/African American
- 35% White
- 13% Indicated more than one race
- 4% Native American/Alaska Native
- 2 participants did not specify their race

- 22% Hispanic/Latino
- 91% LGBTQ+
- 48% HIV Positive, all engaged in care
- Of those who indicated they are HIV positive, 36% have received an AIDS diagnosis at some point

***Trans Women of Color*** – Participants who were assigned male at birth and identify as female or transgender, and are members of Black, Indigenous, and other People of Color (BIPOC) communities.

Additional information about this subgroup:

- Age range: 21-50
- 10% Hispanic/Latino
- 80% LGBTQ+
- 50% HIV Positive, all engaged in care
- Of those who indicated they are HIV positive, 40% have received an AIDS diagnosis at some point

***PWID*** – People who inject drugs

Additional information about this subgroup:

- Age range: 24-61
- 74% White
- 9% Black/African American
- 9% Indicated more than one race
- 9% Native American/Alaska Native
- 3% preferred to self-describe (Middle Eastern)
- 3% checked “don’t know”
- 17% Hispanic/Latino
- 94% cisgender
- 3% non-binary
- 3% Transgender
- 40% LGBTQ+
- 11% HIV Positive (75% in care, 25% previously in care, but not currently)
- 9% do not know their status
- Of those who indicated they are HIV positive, 75% have received an AIDS diagnosis at some point

***PLWH*** – People living with HIV

Additional information about this subgroup:

- Age range: 21-67
- 74% White
- 9% Black/African American
- 9% Indicated more than one race
- 9% Native American/Alaska Native
- 3% preferred to self-describe (Middle Eastern)
- 3% checked “don’t know”
- 17% Hispanic/Latino
- 94% cisgender
- 3% non-binary
- 3% Transgender
- 40% LGBTQ+
- 75% in care, 25% previously in care, but not currently
- 44% have received an AIDS diagnosis at some point

**White Gay/Bi Men** – Gay and bisexual cis men who identify as white

Additional information about this subgroup:

- Age range: 24-67
- 56% HIV Positive (100% engaged in care)
- 4% don’t know their status
- Of the 56% who indicated they are HIV positive, 57% have received an AIDS diagnosis at some point

**Black Gay/Bi Men** – Gay and bisexual cis men who identify as Black/African American, including two respondents who identify as Black/African American and one other race.

Additional information about this subgroup:

- Age range: 20-65
- 77% HIV Positive (90% engaged in care, 5% never engaged in care, 5% were previously in care but not currently)
- 32% have received an AIDS diagnosis at some point, including the 5% who indicated they have never engaged in care

**His/Lat Gay/Bi Men** – Gay and bisexual cis men who identify as Hispanic/Latinx

Additional information about this subgroup:

- Age range: 27-54
- 30% HIV Positive (100% engaged in care)
- Of the 30% who indicated they are HIV positive 67% have received an AIDS diagnosis at some point

**Con/Pro** – Consumers who are currently or were previously providers of HIV related services, including volunteers. Based on participant responses to the following question: Are you currently or have you ever worked in an HIV related field?

Additional information about this subgroup:

- Age range: 23-65
- 62% Black/African American
- 28% White
- 8% Indicated more than one race
- 5% Native American/Alaska Native
- 21% Hispanic/Latino
- 23% Transgender
- 8% Non-Binary
- 3% Gender Fluid
- 95% LGBTQ+
- 46% HIV Positive, 90% in care, 5% previously in care, but not currently, 5% never engaged in care
- 44% have received an AIDS diagnosis at some point, including 5% who indicated they have never been engaged in care



## At-Home HIV Tests

Have you ever used an at-home HIV or STD test?								
	All	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes, at-home HIV test	11%	13%	10%	6%	20%	13%	12%	24%
Yes, at-home STD test	2%						8%	
Yes, at-home HIV & STD test	<1%				3%			3%
No	87%	87%	90%	94%	80%	84%	80%	74%

Individuals who are HIV positive are not included in the charts for the questions on HIV home tests. They were able to select “does not apply to me”.

If you have never used at home test for HIV, would you be interested in using one?								
	All	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	44%	44%	37%	41%	57%	29%	75%	41%
No	22%	39%	50%	16%	14%	29%	17%	18%
Maybe	29%	17%	13%	44%	29%	41%	8%	41%

### If yes, why would an at-home HIV test be a good option for you?

This was an open field question. There were no significant differences between subgroups. Responses were identified by key words and overall themes. The most consistent responses across all groups were the following (in order of highest number of responses):

- Private/Discrete/No shame or stigma
- Easy/easier/no travel involved
- Convenience
- Curiosity

If yes, would it be helpful to have someone walk through the process with you over the phone?								
	All	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	34%	17%	33%	27%	88%	29%	44%	29%
No	18%	25%	33%	27%	12%	21%	0	17%
Maybe	43%	58%	33%	46%		50%	56%	54%
If yes, would you be comfortable taking the test by yourself (reading instructions, collecting sample, etc.)?								
	All	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	84%	91%	80%	91%	76%	57%	100%	87%
No	5%	9%	20%		12%	14%		9%
Maybe	11%			9%	12%	29%		4%

**If you answered no, why would an at-home HIV test *not* be a good option for you?**

This was an open field question. Across all groups, the one consistent theme was:

- Prefer test to be conducted by professionals out of fear of doing it wrong.

**If you answered “maybe”, what makes you on the fence about it? (What concerns you?)**

This was an open field question. Across all groups, the only consistent theme was:

- Accuracy, fear of an inaccurate result due to an error on the consumer’s part.

**Focus Group Recommendations for Increasing Use of At-Home HIV Tests**

Focus group participants explored what would increase their comfort in taking an at-home HIV test. Their suggestions included:

- A YouTube video link that could demonstrate how to use the test.
  - Different videos for different populations
  - By providers who are known in the community or other community gatekeeper or stakeholder. The “model” is important.
- On participant stated:
 

“I prefer an at home test, I don’t like the stomach twisting nervous feeling right before you get the results, and I would rather go through that on my own rather than in front of other people. I would feel comfortable calling in the results if it’s to someone I know.”
- The instructions can be intimidating, therefore someone to talk the consumer through the process over the phone would be welcomed and helpful to many

- A professional who could come to the house and conduct the test in the comfort and privacy of the person's home
- The language of the instructions need to be in clear, non-scientific language
- A positive result could have an initial telehealth follow up prior to an in-person visit

### Condom Use

How often do you use condoms for oral sex?	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Every time	5%	2%	4%	10%		10%	6%	4%	8%
Most of the time	13%	14%	22%	40%	9%	20%	23%	4%	18%
When I remember	2%	4%	4%	10%	3%		3%		3%
Only when my partner(s) asks to	8%	12%	17%		3%	10%	10%		11%
With new partners only	8%	7%	13%	30%	9%		6%	8%	8%
Never	52%	47%	35%	10%	66%	50%	39%	76%	45%
I'm not currently sexually active	10%	14%	4%		9%	10%	13%	8%	11%
How often do you use condoms for anal or vaginal sex?	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Every time	12%	11%	14%	10%	3%	30%	10%	16%	18%
Most of the time	24%	21%	32%	50%	23%	40%	32%	4%	21%
When I remember	2%	2%	5%	10%	2%				3%
Only when my partner(s) asks to	9%	9%	14%		11%		10%	12%	10%
With new partners only	13%	14%	5%	10%	9%		19%	20%	15%
Never	25%	26%	18%	10%	40%	20%	19%	28%	21%
I'm not currently sexually active	14%	17%	14%	10%	9%	10%	10%	20%	13%

The responses across all groups indicating no condom use during anal or vaginal sex provides an opportunity for programs to conduct subgroup specific focus groups in order to better understand an appropriate program level response. Specifically, focus groups are needed with PLWH, PWID, and white gay & bisexual men. Hispanic/Latinx gay & bisexual men have the most consistent condom use for anal/vaginal sex. 70% indicate they use condoms most of the time to every time with 30% of this group indicating they are HIV positive. Trans women of color, 50%

of whom are HIV positive, have the second most consistent use of condoms across all groups indicating that 60% use condoms most of the time to every time for anal/vaginal sex.

Do you have easy access to condoms when you need them?		Where do you usually get condoms? (Check all that apply)							
Yes	95%	Grocery store		17%					
No	5%	Gas station		6%					
If you checked "I get them somewhere else". please tell us where you get condoms (my brother, friends, school, etc.)		Community agency/non-profit (Not related to HIV)		52%					
		HIV Prevention program or testing service		59%					
		Online (Amazon or other site)		4%					
<ul style="list-style-type: none"> <li>○ Local Bars/Clubs</li> <li>○ Pharmacy</li> <li>○ My doctor's office</li> <li>○ Friends/Family</li> <li>○ Adult Store</li> </ul>		I get them somewhere else		11%					
How comfortable are you in telling your partner/s you want to use a condom before or during sex? (We are referring to any kind of sexual activity: oral, anal or vaginal)	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Not comfortable	8%	14%			11%	20%	6%	16%	
A little comfortable	12%	12%	9%	20%	11%	10%	3%	8%	15%
Moderately comfortable	12%	9%	4%	10%	14%		13%	12%	10%
Quite comfortable	25%	28%	7%	20%	23%	40%	26% <sup>1</sup>	24%	28%
Extremely comfortable	44%	37%	57%	50%	40%	30%	42%	40%	46%

## Use of Needles for Hormones

In open field survey responses, participants indicated that there is a need for programs to provide sterile equipment services to participants who use needles for hormone injections, but these programs should not be confused with programs providing services to PWID. 48% of Trans respondents and 50% of Trans women of color indicated they are HIV positive. 48% of Trans respondents and 50% of Trans women of color indicated they are unemployed, with 69% of Trans respondents and 60% of Trans women of color stating that their income was not enough to cover their regular expenses from not at all to only sometimes.

Because 29% of respondents indicate they share needles sometimes, having sterile equipment available through programs and other services would reduce risk of HIV transmission in this subgroup, particularly for those participants who would otherwise purchase their equipment but struggle with having enough income to pay their regular expenses.

Do you use syringes (needles) to inject testosterone, estrogen, or steroids?		Have you ever shared syringes (needles) with someone?
Yes	11%	21%
No	89%	79%
How often do you use sterile (new) equipment?		How often do you share?
Every time	77%	
Most of the time	15%	
Every other time or so	7%	
Sometimes		29%
Rarely or never		71%

## Use of Needles to Inject Drugs

Do you use syringes (needles) for injecting drugs to get high?		Have you ever shared syringes (needles) with someone?
Yes	28%	18%
No	72%	82%
How often do you use sterile (new) equipment?		How often do you share?
Every time	44%	
Most of the time	47%	14%
Every other time or so	6%	

Sometimes	3%	43%
Rarely or never		43%

57% of PWID share needles sometimes to most of the time. 11% of PWID respondents are HIV positive, 25% of whom are not currently in care. 9% do not know their status.

## Employment

<b>Do you have a job right now?</b>	<b>All</b>	<b>PLWH</b>	<b>Trans</b>	<b>Trans Women of Color</b>	<b>PWID</b>	<b>His/Lat Gay/Bi Men</b>	<b>Black Gay/Bi Men</b>	<b>White Gay/Bi Men</b>	<b>Con/Pro</b>
Yes	56%	53%	52%	50%	43%	60%	55%	84%	77%
No	44%	47%	48%	50%	57%	40%	45%	16%	23%
<b>If yes, how many?</b>	<b>All</b>	<b>PLWH</b>	<b>Trans</b>	<b>Trans Women of Color</b>	<b>PWID</b>	<b>His/Lat Gay/Bi Men</b>	<b>Black Gay/Bi Men</b>	<b>White Gay/Bi Men</b>	<b>Con/Pro</b>
1	41%	77%	67%	80%	93%	50%	82%	76%	67%
2	12%	23%	25%		7%	33%	18%	19%	27%
3	2%		8%	20%		17%		5%	6%
More than 3	<1%								
<b>Does your job provide you with time off/sick time?</b>	<b>All</b>	<b>PLWH</b>	<b>Trans</b>	<b>Trans Women of Color</b>	<b>PWID</b>	<b>His/Lat Gay/Bi Men</b>	<b>Black Gay/Bi Men</b>	<b>White Gay/Bi Men</b>	<b>Con/Pro</b>
Yes	78%	79%	100%	100%	44%	75%	60%	90%	85%
No	22%	21%			56%	25%	40%	10%	15%
<b>If your job provides you with time off/sick time, is it paid time off?</b>	<b>All</b>	<b>PLWH</b>	<b>Trans</b>	<b>Trans Women of Color</b>	<b>PWID</b>	<b>His/Lat Gay/Bi Men</b>	<b>Black Gay/Bi Men</b>	<b>White Gay/Bi Men</b>	<b>Con/Pro</b>
Yes	60%	58%	45%	100%	25%	50%	73%	55%	80%
No	40%	42%	55%		75%	50%	27%	45%	20%
<b>Does your job provide you with paid holidays?</b>	<b>All</b>	<b>PLWH</b>	<b>Trans</b>	<b>Trans Women of Color</b>	<b>PWID</b>	<b>His/Lat Gay/Bi Men</b>	<b>Black Gay/Bi Men</b>	<b>White Gay/Bi Men</b>	<b>Con/Pro</b>
Yes	60%	52%	67%	60%	31%	64%	70%	62%	70%
No	40%	48%	33%	40%	69%	36%	30%	38%	30%
<b>Are you able to get time off when needed to make appointments or take care of personal needs?</b>	<b>All</b>	<b>PLWH</b>	<b>Trans</b>	<b>Trans Women of Color</b>	<b>PWID</b>	<b>His/Lat Gay/Bi Men</b>	<b>Black Gay/Bi Men</b>	<b>White Gay/Bi Men</b>	<b>Con/Pro</b>
Yes	83%	82%	83%	100%	75%	88%	79%	90%	82%
No	17%	18%	17%		25%	12%	21%	10%	18%

Have you ever had to miss a medical appointment because you were unable to get off of work?	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	37%	23%	17%	20%	61%	25%	37%	37%	34%
No	63%	77%	83%	80%	39%	75%	63%	63%	66%

Is your pay enough to cover your regular expenses? (housing, utilities, phone, food, transportation, etc.)	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	49%	30%	31%	17%	22%	50%	47%	60%	44%
No	26%	43%	31%	50%	61%	25%	27%	25%	33%
Sometimes	25%	27%	38%	33%	17%	25%	27%	15%	22%
Are you now, or have you ever been a sex worker?	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	22%	26%	52%	70%	11%	10%	10%	15%	28%
No	78%	74%	48%	30%	89%	90%	90%	85%	72%

51% of respondents indicate that their income is not enough to consistently cover their regular expenses, with 25% indicating it covers expenses only sometimes, while 26% of participants stated that their pay is never enough. PWID, Trans women of color and PLWH have the highest income instability with 61% of PWID indicating their pay is not enough to cover their regular expenses.

Of participants who *do not have a job* currently, 63% are receiving other sources of income or benefits. The most listed benefits or sources of income are reflected below in order of frequency with which they appeared in the open field question:

- SSI or SSDI
- Social Security
- Unemployment
- SNAP/Foodshare
- Undocumented work, Housing Assistance
- Side gigs/under the table jobs
- VA Educational Benefits
- Friends/Partner
- Student loans/family assistance

Respondents indicated high levels of employment instability.

### Provider Responses Related to Employment Barriers

Providers recognize this with 87% of providers indicating that employment instability is a barrier to healthcare for the consumers served by their programs. Providers indicated an understanding that many of the barriers to service are economic in nature.

Many providers indicated that they observe other providers forgetting about the impact of social determinants of health, and if barriers to care are addressed, they are often addressed in separate parts, not comprehensively, resulting in disjointed efforts that don't ultimately improve access to care for patients.

In the Provider Survey, respondents indicated that clinic hours can be a barrier for consumers who are employed and can't get time off to make their appointments. For PLWH this can include physician appointments twice a year (in addition to any specialty or other health related appointments) and lab appointments. One missed appointment can result in an individual waiting months for the rescheduled appointment, and prescriptions can go unfilled in the meantime.

Employment instability impacts all other areas of an individual's life including access to reliable transportation, housing, opportunities for socialization and coping, mental health, etc. One provider stated the following:

"Our clients lead chaotic lives. The existing healthcare system is very rigid - there is very little flexibility to meet people where they're at or when they're available. Many times, clients get penalized for missing appointments, and they miss appointments because of a) mental health challenges; b) transportation issues; c) emergencies; d) other things outside of their control."

However, providers do not always agree. One provider stated:

"We are looking for a commitment to care in the form of keeping appointments from patients. Too often, time and /or materials are wasted when they could have been valuable to others."

The comment above indicates a potential lack of understanding regarding the nature of client's lives, if a missed appointment is presumed to be an indicator of a lack of care about their health, and blame is cast on participants for wasting resources.

Focus group participants were asked about *housing* barriers, but in those discussions issues regarding the link between employment barriers and housing barriers was made many times. Specifically:



- Work time missed often means missed pay, which can mean missed rent payments. This should not be viewed as a lack of care for their health. A missed appointment can often mean the patient had to choose between multiple basic needs and rent money will trump a medical appointment most of the time.
- Late night appointments after 5:00, weekend appointments, etc. would be a potential solution for this issue. This was a theme across all focus groups and all participant demographic groups.

Is your income or other benefits you receive stable and consistent?		Do you currently have health insurance?	
Yes	70%	Yes	92%
No	30%	No	8%
If you answered “yes” I have insurance, can you afford your co-pays for office visits, medications, lab work or tests?		If you answered "yes" I have insurance, is your insurance through your job/employer?	
Yes	79%	Yes	30%
No	21%	No	70%

### Housing: Stability

What best describes your current housing?	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
I own my own home	10%	5%	9%	10%		10%	13%	24%	21%
I pay rent for my place	48%	61%	57%	40%	20%	80%	55%	52%	54%
I live in government subsidized housing (Section 8, My Home, or other program)	5%	9%			6%		3%	8%	5%
I live with friends or family and <i>do not</i> pay rent	10%	4%	9%	10%	17%		6%	8%	5%
I live with friends or family and pay rent	10%	5%	17%	20%	17%		13%		13%
I am couch hopping right now	6%	9%			9%	10%	10%	4%	3%
I am in a shelter, in my car, or on the street	11%	7%	9%	20%	31%			4%	
How would you describe the stability of your housing?								All participants	

<b>(Check all that apply)</b>	
I am able to pay my rent regularly (either on my own or with assistance)	54%
I am welcome in my home (either because I live alone or my friends and family are accepting of me)	52%
I have my own room for sleeping	40%
I have a lease or I am able to stay in my current place as long as I need to	29%
I have what I need to cook and store food	46%
My home is mostly clean (other than general clutter) with no bugs or mold	48%
My home is mostly in good condition (little to no peeling paint or loose plaster)	40%
To my knowledge, my home meets all building codes and is safe for me to live in	45%
My home has a bathroom with a tub or shower	42%
My home has hot and cold water	44%
My home has heat in winter	44%

**Indicator Rule (6 out of 11 = Moderately Stable)**

Number of housing stability indicators	% of individuals meeting indicators
11	13%
10	11%
9	7%
8	8%
7	2%
6	4%
<b>Participants below this line do not meet the indicator rule for moderate housing stability</b>	
5	2%
4	5%
3	2%
2	3%
1	44%

The number of individuals meeting the indicator rule (6 or more indicators) which indicates moderate to complete housing stability is 58 or 46%. Therefore, 54% of total participants are experiencing housing instability, including 17% who are currently experiencing homelessness.

Breakdowns by subgroup:

# of Indicators	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
11	9%	13%		3%	30%	6%	28%	10%
10	12%	9%	10%			6%	28%	10%
9	9%	4%		9%		6%	4%	10%

8	10%	9%		6%	10%	16%	4%	18%
7	2%	9%	10%			3%		5%
6	5%	13%	10%	3%		3%	4%	8%
<b>Participants below this line do not meet the indicator rule for moderate housing stability</b>								
5	9%			3%	10%			3%
4		9%	10%	11%			4%	3%
3						3%		
2				6%				
1	44%	34%	60%	59%	50%	55%	28%	33%
<b>% Unstably Housed</b>	53%	43%	70%	79%	60%	58%	32%	39%

<b>The <i>cost</i> of my housing is about this percentage of my income: (check one/it's okay to guess or estimate)</b>	
I don't currently pay for my housing	21%
Less than 30%	13%
30%	20%
50%	12%
70%	6%
More than 70%	5%
I don't know/Not sure	22%

### Housing: *Safety*

<b>How would you describe the safety of your housing? (Check all that apply)</b>	
I am able to walk around freely in my home	78%
I am able to have friends over	52%
I am treated with respect by other tenants or neighbors	49%
I don't have to worry about being harmed by people I live with or who live near me	55%
I am able to be myself in my home	57%
I am not asked to do things I don't want to do in return for living there	44%

When I'm home, I can let my guard down	49%
When I'm home I feel relaxed	45%

**Indicator Rule (5 of 8 = Moderately Safe)**

The number of individuals meeting the indicator rule (5 or more indicators) which indicates moderate to complete housing safety is 50%, therefore 50% are not safe in their homes.

Number of safety indicators	% of individuals meeting indicators
8	31%
7	10%
6	3%
5	6%
<b>Participants below this line do not meet the indicator rule for moderate housing safety</b>	
4	3%
3	5%
2	2%
1	40%

# of Indicators	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
8	32%	26%		26%	30%	26%	44%	26%
7	12%	22%	20%	5%	10%	10%	12%	20%
6	5%	4%		3%			8%	3%
5	7%	4%		3%		16%	4%	5%
<b>Participants below this line do not meet the indicator rule for moderate housing safety</b>								
4	2%		10%		10%	6%		3%
3	5%	9%		3%	10%	3%	4%	12%
2	4%	9%	20%					5%
1	33%	26%	50%	60%	40%	39%	28%	26%
<b>% Unsafe in their housing</b>	<b>44%</b>	<b>44%</b>	<b>80%</b>	<b>63%</b>	<b>60%</b>	<b>48%</b>	<b>32%</b>	<b>46%</b>

Of all participants, 36% stated that their housing situation had caused them stress or anxiety, a lack of sleep, or other things that sometimes resulted in not being able to go to work or keep appointments. Of those, 88% reported that it happened occasionally to always.

## Provider Responses Related to Housing Barriers

90% of providers indicated that housing instability is a barrier to healthcare and in the comments explaining their responses most demonstrated an understanding of this issue. Specifically:

- “Many of the clients I see have limited housing, transportation, or phone/internet services. This impacts their ability to make and keep appointments, particularly when they can't foresee what each day will bring and what they will have to do to cover their most basic needs.”
- “Many clients I see do not have consistent access to safe housing. They do not prioritize healthcare or seeing a doctor when they don't know where they'll be staying or if they'll be safe that night.”

## Focus Group Findings & Recommendations for Housing Related Barriers

In focus groups, participants were asked what providers could do to address housing issues so fewer people missed health-related appointments. The following themes emerged across all groups regarding a provider's need to understand the community they are serving:

- There is more to housing than having a roof over your head. Your home may be unsafe, violent, or unstable.
- Housing can also impact whether a person has access to other things such as a place to refrigerate their meds, store food, and destress.
- Unsafe and unstable housing situations contribute to a decline in an individual's mental health and a lack of motivation to prioritize higher level needs.
- Participants felt that providers have a general lack of knowledge/understanding regarding the nature and reality of homelessness. There may be an academic knowledge that a provider holds but it doesn't translate into how services are delivered. Individuals experiencing homelessness are still expected to participate in the system in the same ways that housed patients do. This is especially true of individuals experiencing homelessness who are also PWID. One participant stated:
  - “When I'm actively using, I don't care about appointments. There's zero chance that I will go to that physical. If I'm not using, then I want to focus on my health and I will follow through. You have to be patient, understanding, and non-judgmental to work with people in my situation, but they're (providers) not usually like that.”

- Providers sometimes know the housing situation for their patients but can show a lack of empathy, or a lack of understanding by sending the patient “on their way” without connecting them to resources. Participants stated:
  - There is stigma associated with HIV and active addiction, and when you share with your provider that you’re also homeless it would be helpful for them to be able to connect you with resources instead of sending you on your way. They don’t ask “what do you need” or “what would work for you”.
  - “If you’re not completely upfront with your provider, you can come across as shady. But if you disclose what’s happening in your life you often get judgment. If you don’t have that trust in your provider, the empathy and non-judgment, then you can’t be forthcoming about your health behaviors and the barriers you face, and they can’t really help you.”
- When providers reach out to the individual who has dropped out of care, it matters.
- Housing barriers should not be seen as siloed from other areas of the clients’ lives. Issues with employment and financial resources, mental health, transportation, etc., all impact a client’s housing situation and vice versa.

To combat housing barriers at the program/provider level, participants across all groups agreed that the following are needed:

- A phone call to check in on an individual can make the difference between someone dropping out or staying engaged in care, particularly when the individual may be struggling to prioritize their care. One individual stated:
  - “When they reached out to say ‘We miss you, are you okay?’, that helped me stay connected.”
- Phone calls from provider offices the day prior to an appointment as a reminder, help and can also be a problem-solving opportunity.
  - Callers can ask if the patient has transportation and offer support and solutions (see section on Transportation barriers for details on this)
  - If a patient indicates they will not be able to make the appointment, alternatives could be offered such as telehealth, a home visit that can be scheduled sooner than a rescheduled office visit, mobile medical vans with lab techs, physician assistants, or outreach nurses
- Emergency appointments should be available for urgent needs but could also be used to reschedule missed appointments quickly
- Off hour appointments. Many individuals experiencing housing instability also have financial and other related barriers such as transportation. The ability to see a provider outside of what are considered “normal” clinic hours is long overdue.
- Programs often offer supportive resources specific to housing related barriers, but these services are often siloed, and patients may not be aware of them. All provider offices should have housing navigators at hand that can be pulled in to offer support to patients

“in the moment” without there having to be a need to call at another time or schedule an appointment to meet with someone *when the client is there right now*.

- Information regarding resources should always be available, client friendly, and eligibility requirements clear.
- Providers should assess for eligibility before making any referral to avoid participants attempting to access a referral only to be told they don’t meet eligibility requirements. This contributes to the breakdown of trust with the provider.
- Resources are needed that provide legal support to participants regarding prior evictions, legal histories that are a barrier to housing eligibility, outstanding energy payments, etc.
- Programs need funds available to assist individuals with “other” housing needs such as the purchase of appliances, energy bills, cleaning products, and other items not available through food pantries. Too many individuals try to make do without these things, impacting their overall well-being and health behaviors.

### Healthcare: *Barriers*

How would you describe your experiences in healthcare settings? (Service, how people treat you, easy to make appointments, etc.)			
Great		45%	
Generally good		29%	
Okay, not bad but not great		21%	
Generally bad		5%	
Terrible		<1%	
Have you ever avoided seeing a doctor due to fear of stigma around your HIV status?		Have you ever avoided seeing a doctor due to fear of discrimination in general?	
Yes	19%	Yes	27%
No	81%	No	73%

If yes, was the fear about being discriminated against due to any of the following? (Check all that apply)		“Other” ways respondents feared being discriminated against/	
Sexual orientation	35%	<ul style="list-style-type: none"> <li>○ My skin condition or my weight</li> <li>○ Patronizing treatment/Microaggressions</li> <li>○ Immigrant status</li> <li>○ Because of being an addict</li> </ul>	
Gender identity	20%		
Race or ethnicity	18%		
Age	12%		
Physical or mental ability	20%		
Sexual behavior questions	22%		
Drug or alcohol related questions	45%		

HIV Stigma	20%	
Previous bad experiences	31%	
Other (please tell us in the space below)	2%	
Have any of the reasons from the previous question ever caused you to avoid seeking care when you needed it?		
Yes	34%	
No	66%	
Have you ever avoided seeing a doctor due to fear of judgment about any of the following? (check all that apply)		
General health condition	59%	
Weight	25%	
Mental health	37%	
Have you ever avoided seeing a doctor due to fear of being scolded or shamed about past missed appointments?		
Yes	29%	
No	71%	
Have you ever avoided going to the doctor due to concerns about confidentiality?		
Yes	23%	
No	77%	
Is cost a factor when deciding to seek medical care?		
Yes	25%	
No	75%	
Is lack of insurance a factor when deciding to seek medical care?		
Yes	21%	
No	79%	

### Provider responses regarding barriers to healthcare

<b>Based on your knowledge of the population your program serves, what barriers to healthcare do your clients/patients experience? (Check all that apply)</b>	
Employment Instability	86%
Housing Instability	90%
Lack of Insurance	72%
No Primary Care Provider	60%
Transportation Issues	94%
Inconsistent Phone Service	83%
Child Care Issues	53%



Mental Health (Stress, Depression & Anxiety, other general mental health issues)	95%
Substance Use Disorder	88%
General lack of support	82%
Fear of stigma	88%
Experiences of Oppression (racist, homophobic or transphobic harm from a provider or healthcare staff)	80%
Other Barrier(s) (Please describe in the space provided): 13	16%

72% of providers believed lack of insurance was a barrier faced by their clients, while 88% believed fear of stigma was a barrier to healthcare. 80% believed barriers could be attributed to experiences of oppression. It should be noted that the greatest barrier to healthcare that providers observe is mental health, with 95% of providers indicating their clients experience this.

In addition to their response to the survey question, in open fields providers stated:

#### Regarding Stigma Related Barriers

- “I work with People Who Inject Drugs (PWID). Stigma and transportation are two huge barriers along with mental health that almost all my clients express.”
- “Stigma is a large barrier to healthcare in the PWID population. Clients are often reluctant to seek medical help because of the looks, comments, and judgement they have received in the past. My clients are generally reluctant to be open and honest regarding their risk factors until they have gained trust and dependability with a service provider, which is harder to achieve when they do not have a regular supportive provider already established and are reluctant to seek out health services due to past experiences.”
- “People who use drugs continue to be stigmatized. I wouldn't say many have an "active fear" of being stigmatized, rather they know they will not be taken seriously, or asked to become sober before doctors will treat any of their health concerns.”
- “Drug use also carries a lot of stigma and it is often correlated to crime and other illegal activities. In many cases this may not be true but eventually due to systemic and societal stigma and isolation, PWIDs end up with no support therefore with no access to resources to survive or deal with their addictions. The individuals we serve in prevention and PLWH who live and socialize in our service areas live in poverty and face other social determinants of health that hinder their ability to thrive.”
- “Barriers related to immigration status.”

- “Stigma is still big when it comes to disclosing HIV status, sexual orientation, gender identity and even civil status for those who are married to or in a relationship with same sex partners.”

### Regarding Insurance Related Barriers

- “Many of the patients receiving services at our agency do not have insurance or are underinsured, they also face isolation, lack of knowledge about their rights and benefits.”
- “Patients have insurance but the cost of using their insurance is prohibitively high. Folks are still getting huge bills for PrEP despite federal changes. Whether it's our health care system's problem to fix or insurance companies' problem to fix, I'm not sure. But it's driving people away from care.”
- “Healthcare in this country is extremely expensive, even those who are adequately insured will avoid care due to copays.”
- “Need more clinics to serve the undocumented population without insurance.”

### Additional Barriers to Healthcare Noted by Providers

- “Environments can be culturally insensitive”
- “Trauma history, developmental and cognitive delays, criminal history, eviction history, credit history, classism, and ableism”
- “Healthcare while incarcerated - our jails do not want to test for HIV because they don't want to pay for treatment”
- “Many of my clients have mental health issues and have experienced trauma. Many are distrustful of institutions such as the medical system due to feelings of powerlessness and negative past experiences. Many of my clients struggle to navigate health care due to mental health (e.g. anxiety about seeing doctors or inability to effectively communicate needs due to fear). I serve many rural clients who struggle with transportation. We do not have an adequate public transportation system so unless clients are lucky enough to have their own car and license, transportation is a huge barrier. Homelessness and the general instability that comes along with it is a growing issue for many of my clients given the current lack of affordable housing. Clients are often unable to make and keep appointments when they are just trying to survive.”
  - “Mental health and substance use challenges interfere with time management and attendance.”
- “Contacting clients via phone can be a challenge as sometimes their phone is off, or their numbers often change. We need to explore other options.”
- “Trust (lack of) in health systems also impacts engagement”

- “Lack of health literacy”
- \*\*\*It is important to note that one provider stated they do not see any barriers to clients accessing healthcare.

## Focus Group Findings & Recommendations for Healthcare Related Barriers

### Regarding Stigma Related Barriers

- Across all groups, participants indicated they downplay their substance use to providers due to stigma associated with addiction and alcohol or drug use.
  - “When I was in active addiction and ended up in the hospital, they weren’t the nicest people to me, because I have the label of “addict” associated with all my paperwork and that impacted how people saw me and treated me.”
- Individuals often won’t go back to a provider after one visit if that provider showed any indication of judgment. There was a general consensus that this happens more with newer or less experienced providers. PAs were consistently identified by many participants as being judgmental and/or less experienced.
  - “When I found out I had Hep C I didn’t know where to go. I ended up having to go back to my old primary because I knew he wouldn’t judge me. The last time I went to a new primary I felt judged and couldn’t open up to them and never went back.”
- Participants who were PWID were particularly vulnerable to provider judgment and bias and often felt a lack of empathy from their provider.
  - “I have heard providers say, ‘can’t you figure it out?’ or ‘why can’t you do this?’. Instead of saying, ‘How can we work on this together? Let’s problem solve.’ We have to stop saying stand up on your own two feet, because some people just can’t in that moment. And never will if they are shamed about it.”
  - “Stop the scolding, the finger pointing. What can we do to help them do better?”
  - “Doctors should do role plays so they have the opportunity to experience what we experience. We can’t mandate that doctors do anything, they have to want to be better, and make effort.”
- Providers who are non-judgmental, empathetic, and unbiased can greatly increase a patient’s engagement in care and positively benefit their health behaviors.
  - “My primary was very kind and welcoming. On our first visit he said, ‘Thank you for choosing me to help you get healthy’. He was nonbiased, non-judgmental. And it was because of that that I stayed with him and got my health under control.”

- Participants indicated that having a provider who shares their identity and experience would be helpful in increasing their comfort with the provider, but identity can't be seen as equivalent to training and education.
  - "Providers need to have the same background. Black, LGBTQ+, HIV +, whatever."
  - "You may be a professional, but it doesn't mean you can relate to my experience, but you should try, and make that effort visible."
  - "It's the environment, too, not just the doctor. I can go to a clinic that only has Black folks, but I will still feel discrimination based on which doctor I'm seeing because the stigma within the community about HIV is deep."
- Participants need to know their providers know more than they do, but they often find themselves in the position of having to educate their doctors about their health, identity, and the barriers they face.
  - "I feel most comfortable with a doctor that is educated about me, my needs, my issues. You want your doctor to know more than you."
  - "I feel more comfortable when I don't have to educate my doctor."
- Black focus group participants indicated that it can still be difficult to discuss their pain levels with a provider due to medical bias regarding opioid addiction.
  - "They treat people like they're bad, when you're the one that started this by overprescribing to white people. But when Black people are in pain, it's too bad. They treat you like you're bad, when they're the drug pusher, they're the one that created the issue in the first place."
  - "People are just dealing with the pain so as to avoid conversations with their provider about pain."

### Regarding General Healthcare Related Barriers

- Too often patients are discriminated against by providers and denied access to care when they miss appointments due to barriers they are experiencing including substance use, housing, transportation, employment, mental health, and others. One provider and focus group participant noted in working with a client who is PWID:
  - "Met with a client today, good person, really working hard. Concerns about his liver function, Hep C, and the need to get tested, to see a primary. He told me he was booted from his primary because he missed two appointments and they won't see him anymore. People have to jump from provider to provider. At the policy level, people shouldn't be booted from a provider. That provider should say "what are we doing wrong here?", "how can we help you keep your appointments?", "what do you need?", "what could help?"."
- When a patient identifies a barrier to care, the provider often doesn't accept that barrier as real. One participant stated:

- “My barriers shouldn’t have to be seen as barriers by the provider in order for them to be acknowledged. If a person says it is a barrier it is a barrier to them. Period. You don’t walk in my shoes. How would you even know?”
- Some participants are in the “middle”, not fully eligible for supportive services, but are not able to do things on their own. There needs to be a tiered category for supportive services, not simply eligible/ineligible.
- Participants stated they have to self-advocate heavily to get the care they need, even with nurses, who they observed have a lot of power. However, individuals have to have the energy and resources to be able to advocate for themselves, and even then it can be overwhelming.
  - “Navigating systems is exhausting, and every barrier requires navigation of another system to address. It burns people out, even when they have a case manager.”
  - “We have to be our own advocates and sometimes with multiple doctors. So, if one doctor doesn’t work for you but you have transportation issues, and you have housing issues, you stay with the doctor you don’t like because it’s too hard to try to change providers.”
  - “Physicians can exert power through withholding meds and prescriptions when you don’t do what they want you to do. They also overstep and comment on areas of your life that aren’t any of their business.”
- Patients often don’t understand the provider grievance process, and experience has taught them that it frequently won’t matter if they do complain.
  - “I complained to the nurse, and she said, ‘you are not the only person who has complained’. But at no point did she tell me how to file an actual complaint, and at the time I thought it wouldn’t matter anyway since they apparently, already know he was a problem. My question became, then why is no one doing anything about it? All I came to was it was because we are the ones suffering. And ultimately it just feels like no one cares.”
- Trans participants expressed frustration and anger that they continue to be outed in waiting room areas, though they have advocated and spoken out about this for years.
- Cultural Competency trainings often don’t include “peripheral” providers like receptionists, maintenance staff, assistants, or technical staff. Yet all members of an organization interact with the community and should receive the same trainings that primary providers do. A bad experience with a receptionist can prevent an individual from returning for care that is critical to their well-being.

## Healthcare: General

Do you have a primary care doctor?	
Yes	73%
No	22%
Don't know/Not sure	5%
How often do you go to the doctor?	
Every few weeks	6%
Every few months	39%
Twice a year	16%
Once a year	10%
Only when I'm sick	10%
Rarely	15%
Other (please explain below)	6%
<ul style="list-style-type: none"> <li>○ Yearly physical when I had insurance, have not had insurance for a year and a half so have not gone</li> <li>○ I only go when I'm sick or when I have an ailment that isn't bad enough to warrant a trip to the ER. However, when I see my Infectious Disease specialist semi-annually, she mostly fills the role of a PCP.</li> <li>○ I haven't been to a Dr in 7yrs due to having issues with drs in general</li> <li>○ When not feeling well or the conditions of streets would push me to get checked out</li> <li>○ My feet swell up</li> </ul>	

## Telehealth

If you were able to see a doctor virtually via telemedicine (sometimes called telehealth, this is a virtual appointment on a smart phone or computer) would this be a good option for you?		If yes, what is the main reason this would work for you?	If no, why would this not work for you?
Yes	48%	Transportation Saves time Easier Convenience Disability COVID	Prefer in person (most) Unstable internet or phone service Have to go in for labs anyway
No	17%		
Maybe	35%		

## Provider Responses Related to Telehealth

Does your program offer any form of tele-health?	
Yes	73%
No	27%

Providers who indicated their program offers telehealth are located in the following counties:

Adams, Ashland, Brown, Burnett, Calumet, Columbia, Crawford, Dane, Dodge, Door, Douglas, Fond du Lac, Grant, Green, Iron, Jefferson, Juneau, Kewaunee, La Crosse, Lafayette, Manitowoc, Marinette, Milwaukee, Oconto, Outagamie, Ozaukee, Racine, Richland, Rock, Sauk, Sawyer, Shawano, Sheboygan, Stockbridge Munsee Community, Walworth, Washburn, Washington, Waukesha, Waushara, and Winnebago.

## Focus Group Findings & Recommendations for Telehealth

In focus group discussions, telehealth had wide consensus as being a game changer when there are healthcare related barriers that limit access to care.

- Experiences with telehealth were generally good.
- COVID provided an opportunity for increased access to care due to increased use of telehealth that participants widely want continued post-COVID.
  - “When I thought I had COVID I called my doctor and they got me into a virtual visit within an hour. I loved it. It was immediate and a time saver on both sides.”
  - A provider noted: “Once COVID happened I just told everyone this is an option now. Now that we’re coming out of the pandemic, I have folks asking me if they can still be virtual if they have transportation or childcare issues. This helps us continue to work with clients ‘where they’re at’. Just because we’ve historically prioritized in person, doesn’t mean that we have to continue to do that.”
  - Another provider stated: “I’ve become a better listener because of telehealth. It breaks barriers, and I have more patients these days that call and ask for a 15-minute virtual visit, and that is possible in ways now that weren’t before.”
- Telehealth opened up avenues in terms of flexibility for participants with no childcare or transportation. They maintained appointments that they might not have been able to otherwise.
  - “For me it was not the same as in person but much better than missing appointments and the repercussions.”

- All participants agreed that even though telehealth appointments might not be for everyone, or available for every type of appointment, they were good and increased the general likelihood of keeping their appointments.
- If a participant needed to miss an in-person appointment, fewer individuals experienced rescheduling problems when telehealth was available.
- However, confidentiality becomes critical when using telehealth. Treatment and recovery groups may not be well suited for virtual sessions, unless there are guidelines in place that protect client confidentiality. The host of any meeting can use session settings so that cameras aren't turned on, for example.
  - "The treatment center that I recently graduated from was virtual, and I didn't like it for that, but it was better than nothing. Other people keep coming into other people's spaces while we were in session, so it didn't feel private like it was supposed to be."
- Internet service costs money making telehealth tricky for people without sufficient income.
- Having private spaces for virtual visits for those who use shelters or have community living circumstances can present challenges that need to be resolved through community partnerships with the organizations providing shelter services, and a system that coordinates care.

Specific telehealth recommendations across all focus groups:

- With the accessibility of technology, all clinics and programs can be offering telehealth.
- Telehealth options should be discussed at every in-person appointment to increase patient awareness
- Provider offices and waiting areas should include posters, stickers, brochures, etc. saying "ask your provider about telehealth"
- When scheduling appointments, telehealth should be offered as an option
- If a patient calls to cancel an appointment, telehealth should be offered as a way to potentially maintain the appointment
- When calling to remind patients of an upcoming appointment, telehealth should be offered as an alternative to canceling if a patient is expressing difficulty in keeping the appointment
- Programs should have computer labs that clients can use who don't have computers at home.
  - "There is an assumption that everyone has computers now, but that's not the case."



## Dental Care

<b>Do you have a dentist?</b>	
Yes	61%
No	37%
Don't know/Not sure	2%
<b>How often do you go to the dentist?</b>	
Every six months	33%
Once a year	21%
Every other year or so	10%
Only if I have tooth pain or other issues	23%
Never	14%
<b>If you do not see a dentist, what best describes the reason? (Check all that apply)</b>	
Cost	46%
Being reprimanded or shamed about my dental care in the past	20%
Fear of the procedures	25%
No provider I like in my area	14%
Transportation	20%
Other (please explain below)	20%
<ul style="list-style-type: none"> <li>○ Insurance issues (x 4)</li> <li>○ Badgercare rarely accepted/when they do the waitlist is long (x 3)</li> <li>○ Because honestly I don't like pain and I'm just really scared</li> <li>○ No teeth/dentures (x 3)</li> <li>○ I have dentures that don't really fit and still haven't went and got them fixed. Transportation is probably part of the reason and I guess I don't really care that much</li> <li>○ No money and because of drugs</li> </ul>	

## Transportation

<b>Is transportation an issue in getting to work or meeting other needs?</b>	
Yes	39%
No	61%
<b>Do you have your own car or do you have a car available to you when you need it?</b>	
Yes	60%
No	40%
<b>Do you rely frequently on public transportation (bus, train, van pool)?</b>	
Yes	33%
No	67%
<b>Do you rely frequently on ride shares such as Uber or Lyft for transportation?</b>	
Yes	32%
No	68%
<b>Do you have friends or family who can help get you places when you need to?</b>	
Yes	65%
No	35%
<b>Has a lack of reliable transportation ever caused you to miss work or appointments (healthcare or any other type of appointment)?</b>	
Yes	46%
No	54%

## Provider Responses Related to Transportation

94% of providers indicated that transportation is a barrier to healthcare for their clients/patients. In focus groups with participants, transportation was the most mentioned barrier to health-related activities. Participants feedback regarding transportation barriers was specific and insightful, and yielded a rich discussion that included many things providers can do to reduce transportation related barriers and increase access to care.

Provider survey responses specific to transportation included the following:

- Some patients rely on friends and family for rides and have no control over what that looks like. Patients sometimes arrive 1-2 hours early for an appointment and stay late before someone is able to pick them up.
- Rural Wisconsin does not have public transportation. Our clients with low incomes do not have reliable transportation of their own and don't have friends or family they can reliably count on for rides. There is a fear of being outed in small towns which can make people reluctant to get health care.
- Proximity to care is an issue in rural areas, especially when clients don't have reliable transportation. This is a systemic issue rather than an individual issue, yet we expect the individual to solve the problem.
- Transportation is a major barrier for those who do not have a car/funds to take the bus. The medical transportation service offered through BC+ is terribly inconsistent and unreliable.
- Medical rides are not reliable.

## Focus Group Findings & Recommendations Related to Transportation Barriers

- Bus tickets should have enough transfers to completely cover the ride to and from the provider and wherever the client needs to go.
- Community members and providers recognize that medical transports are not always reliable, can be late, etc. which can lead to rescheduling issues outside of an individual's control.
- Participants who rely on others for transportation are vulnerable to their friend/family member's schedule changing. Medical transportation needs to be booked in advance and isn't a solution if the participant finds out on the day before or day of the appointment.
  - "Sometimes appointments have to be scheduled around friends and family members schedules and we rely on them to keep the appointment. If something changes for the person who is driving me, I have no control over that, but I suffer the consequences with the provider as if I am somehow bad or at fault for missing the appointment."
- Even when medical transportation is available, needing to book it far in advance can be a barrier to accessing the service, making it available but not accessible given the unpredictability of many client's lives and is an indicator that the system of medical transportation was not set up with the most vulnerable in mind.
  - Participants often have to pay friends/family for gas when they rely on them for transportation.
  - "Getting places depends on whether I have money to give to friends or family so they can drive me."

- Weather considerations are necessary for people who take public transportation. Excessive heat in summer and cold/snow/freezing conditions in winter can prevent participants from keeping appointments.
- Bus tickets given in advance are sometimes needed for other things, then when the appointment comes around that ticket is gone.
- Late public transportation can lead to missed appts, and a refusal to see the patient.
- Public transportation, in general, isn't safe for Trans people.
- Asking friends or family for a ride can strain relationships if that person also has to make sacrifices. In addition, depending on the location of the provider, the client may be outing themselves, and they may not be out as HIV+ to friends or family.
- Participants may have their own vehicle, but due to other issues related to employment and housing, they may not always have the resources to keep gas in their car.
- Many participants noted that in rural parts of the state, they are traveling sometimes 40+ miles to get to their provider. This raises issues related to cost, time away from employment and strained relationships with friends/family members who have the same issues.
  - "Healthcare should look different now. You do not have to leave your home to speak to a provider. Your meds can be mailed to you. The patient shouldn't have to do so much work."

### Specific Recommendations Related to Transportation Barriers

- In communities where it makes sense to do so, funds should be allocated for Uber and Lyft in the form of gift cards, Uber/Lyft contracts for services, etc.
- Where relevant, taxi vouchers can also be utilized.
  - "After an accident when I was actively using, the hospital gave me a taxi voucher to get home, and to return the next day. That was an example of help. I was homeless at the time and didn't have anyone in my life I could depend on. That cab voucher really helped me."
- Gas cards are needed. Many participants have cars, but no funds for gas.
- Providers should be proactive regarding transportation to appointments with questions specific to transportation asked when the appointment is scheduled and again when calling to remind the patient of the appointment.
  - Participants indicated that transportation services are sometimes covered by insurance, but providers need to assist with the process
- Peer Specialists/Navigators/Case Managers can pick up participants for appointments and serve as their advocates throughout the process. This can be extremely supportive for our most vulnerable clients and is a relationship that can impact other areas of their lives.

- There was incredible agreement across all groups that the Peer Specialists are an invaluable asset to the community
- Telehealth was widely agreed upon to be a proactive measure for many participants in accessing appointments that don't require lab work or tests.
- When labs are required, participants across all groups discussed the use of mobile medical units/vans that could offer in person medical exams, blood draws or other specimen collection and medication delivery.
  - This is particularly needed in rural parts of the state
  - Vans would need to be “unmarked”, without markings that inadvertently “out” the person who is using it
  - In-home appointments
    - Pharmacies already utilize home delivery services, with staff who are trained in packaging and explaining meds to patients
    - Providers could provide rotated in-home care that allows for patients with transportation issues to schedule medical visits in their homes
    - This would be useful for individuals with other barriers that make it difficult for them to leave their homes

### Stress & Avoidant Coping

How often do you experience feelings of stress or anxiety?	
Every day	36%
Every couple of days	14%
Weekly	13%
Every couple of weeks	10%
Monthly	5%
A couple of times a year	6%
Rarely	16%
Have you ever used alcohol to help you cope with stress or feelings of anxiety?	
Yes	50%
No	50%
Do you currently use alcohol to help you cope with stress or feelings of anxiety?	
Yes	23%
No	77%
How frequently do you use alcohol to cope with stress or anxiety?	
Every day	5%
Every couple of days	2%

A couple of times a week	11%
Once a week	2%
Only on weekends	2%
Every couple of weeks	5%
Once or twice a month	7%
Almost never	23%
Never	43%
<b>Have you ever used drugs or medication (that was <u>not</u> prescribed to you) to help you cope with stress or feelings of anxiety?</b>	
Yes	59%
No	41%
<b>If yes, please check the <u>one</u> you use/used the most)</b>	
Synthetic opioids (fentanyl, methadone, meperidine, tramadol)	22%
Heroin	34%
Prescription opioids (codeine, oxycontin, morphine, Percocet, Vicodin)	24%
Cocaine	27%
Methamphetamine	32%
Prescription Stimulants (Adderall, Vyvanse)	11%
Marijuana	68%
Something else (described below) <ul style="list-style-type: none"> <li>○ CBD (x 3)</li> <li>○ BENZIES (mushrooms)</li> </ul>	4%
<b>Have you used drugs (including meds <u>not</u> prescribed to you) in the last 7 days to help you cope with stress or feelings of anxiety?</b>	
Yes	40%
No	60%
<b>How often do you use drugs (including meds not prescribed to you) to cope with stress or anxiety?</b>	
Every day	33%
Every couple of days	8%
Once a week	<1%
A couple of times a week	2%
Only on weekends	2%
Every couple of weeks	2%
Once or twice a month	5%
Almost never	11%

Never	37%
<b>Has your alcohol or drug use ever impacted your ability to complete your daily activities (work, childcare, family or social responsibilities)?</b>	
Yes	32%
No	68%
<b>If yes, how often?</b>	
Every day	35%
Every couple of days	5%
Once a week	
Only on weekends	
A couple of times a week	15%
Every couple of weeks	5%
Once or twice a month	15%
Almost never	25%

<b>Do you currently have <u>a prescription</u> for medication to help you with feelings of stress, anxiety or depression?</b>	
Yes	37%
No	63%
<b>If yes, have you ever taken more than the prescribed dose to help you cope with those feelings? (stress, anxiety, depression)</b>	
Yes	34%
No	66%

<b>Have you ever felt down, depressed, or hopeless for more than two weeks in a row?</b>	
Yes	53%
No	47%
<b>Have you ever had thoughts of suicide or self-harm?</b>	
Yes	37%
No	63%
<b>If yes, did you have a plan for how you would hurt yourself?</b>	
Yes	60%
No	40%
<b>Have you ever attempted suicide?</b>	

Yes	25%
No	75%
<b>Were you ever hospitalized because of a suicide attempt?</b>	
Yes	59%
No	41%
<b>Have you ever been hospitalized due to depression or other mental health concerns?</b>	
Yes	20%
No	80%
<b>If you experience feelings of depression or self-harm do you know someone you can go to for support?</b>	
Yes	65%
No	35%

<b>Do you have people in your life who support you? (check as many as apply)</b>	
I have friends who support me	76%
I have family who support me	58%
I have people in community organizations who support me (AA groups, Church, etc.)	33%
I don't have anyone in my life who supports me	9%

### Experiences of Oppression – General

<b>Have you experienced harm directed at you personally due to your race?</b>	
Yes	25%
No	75%
<b>Have you experienced harm directed at you personally due to your gender identity/expression?</b>	
Yes	32%
No	68%
<b>Have you experienced harm directed at you personally due to your sexual orientation?</b>	
Yes	40%
No	60%



<b>Have you experienced harm directed at you personally due to your HIV status, or perceived HIV status?</b>	
Yes	21%
No	79%
<b>If you answered "yes" to any of the questions regarding experiences of oppression, who harmed you? (check all that apply)</b>	
Friend or acquaintance	37%
Family member	37%
Employer/Supervisor	22%
Coworker	27%
Landlord	8%
Other tenant or neighbor	10%
Health care provider (doctor, nurse, assistant)	14%
Stranger	76%
Someone Else: (Please describe in the space below)	7%
<ul style="list-style-type: none"> <li>○ Classmates (x 2)</li> <li>○ internet trolls</li> <li>○ Sex partners</li> <li>○ Men</li> </ul>	

## PrEP

<b>Have you heard of PrEP? (PrEP or pre-exposure prophylaxis: A medication prescribed to individuals at higher risk of acquiring HIV which prevents the transmission of the virus)</b>									
	<b>All</b>	<b>PLWH</b>	<b>Trans</b>	<b>Trans Women of Color</b>	<b>PWID</b>	<b>His/Lat Gay/Bi Men</b>	<b>Black Gay/Bi Men</b>	<b>White Gay/Bi Men</b>	<b>Con/Pro</b>
Yes	85%	95%	96%	100%	59%	100%	97%	92%	100%
No	15%	5%	4%		41%		3%	8%	
<b>Are you currently taking PrEP?</b>									
Yes	12%		22%	30%		40%	10%	12%	23%
No	60%		52%	50%	71%	40%	71%	48%	54%
Does not apply to me	29%	100%	6%	20%	29%	20%	19%	40%	23%

**If you are HIV negative/not living with HIV, has anyone ever talked to you about HIV, what it is, and how it is transmitted?**

	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	86%	NA	100%	100%	86%	75%	69%	100%	87%
No	14%				14%	25%	31%		13%

**If you are HIV negative/not living with HIV, and feel that you are at risk of getting HIV, would you be interested in taking PrEP?**

Yes	64%	NA	67%	60%	58%	88%	43%	67%	69%
No	36%		33%	40%	42%	12%	57%	33%	31%

Below are open field responses broken down by subgroup:

***If you answered "yes" I am interested in taking PrEP, please tell us what motivates you to want this medication?***

#### **Trans**

- Recently, my partner and I want to explore sexual partners outside our relationship
- Safety

#### **Trans Women of Color**

- More safety and prevention

#### **PWID**

- Because I'm high-risk
- Because I'm high-risk due to sex work and needles
- Because I want to not get it and be as safe as possible
- If I had to take it I know it would help
- Personal safety
- Because I want to stay HIV/negative and if I'm single then it would keep me safe

#### **His/Lat Gay/Bi Men**

- For more protection
- Extra protection in general

#### **Black Gay/Bi Men**

- So I can stay healthy
- To prevent the potential of contracting HIV
- To protect myself and my partners

### **White Gay/Bi Men**

- I generally don't use condoms but would like the extra layer of protection
- It is another means of prevention and has been proven safe and effective. I am not on it currently, but it could be a possibility
- As a precaution
- Because I want to stay HIV/negative

### **Con/Pro**

- Do not want to deal with other HIV related diseases
- I'm still in the contemplation stage
- Not very sexually active
- As a precaution, would allow me to have more sex which I am hesitant about
- Precaution of contracting HIV and feeling I've become a stereotype
- Recently, my partner and I want to explore sexual partners outside our relationship
- It's an all-around great medication and as someone who works in the field and in an at-risk community, I feel I should be on it
- I was on it and need to get back on it but am not sexually active

***If you answered "no" I am not interested in taking PrEP, please let us know why this isn't something you're interested in.***

### **Trans**

- I guess I wouldn't because I don't know really how effective it would be. I don't share needles when I get high, and don't have many sexual partners so far. Sometimes I think I should tell them to use condom but then I push that thought out of my head.
- I don't have time/\$ for appointments every 3/6 months while starting the medication (PCP is a 1.5 hr drive away)

### **Trans Women of Color**

- I'm with one person
- I practice safe sex/ having low sex

### **PWID**

- I don't need it
- I don't have the virus.
- The only way I could be exposed to HIV is iv drug use and my friends don't have HIV and I use new tools every time or I use a tool that I know(marked) as mine
- I don't trust it

- I guess I wouldn't because I don't know really how effective it would be. I don't share needles when I get high, and don't have many sexual partners so far. Sometimes I think I should tell them to use condom but then I push that thought out of my head.
- I'm not sexually active at this time and I'm negative
- The most part I've been absent from sex so I should be good
- I don't believe I need this
- Because I'm with same person and use extreme clean self-care and condoms

### **His/Lat Gay/Bi Men**

No responses, except for a provider whose response is captured in the Consumer/Provider subgroup.

### **Black Gay/Bi Men**

No responses, except for those who were also providers. Those responses are captured in the Consumer/Provider subgroup.

### **White Gay/Bi Men**

- It's been over 2,162 days since I have had any type of sex
- I don't want to take a pill to be careful -I prefer my judgement and/or abstaining from sex

### **Con/Pro**

- No sex
- I'm with one person
- Because most of my life I've used condoms during sex, and I do stay updated with my health status and so far I've tested HIV negative. Currently I haven't been sexually active or engaging in any sexual activity

## PEP

<b>Have you heard of PEP? (PEP, or post-exposure prophylaxis, is a dose of HIV medicine taken very soon after a possible exposure to HIV to prevent the virus from taking hold in your body. You must start it within 72 hours (3 days) after a possible exposure to HIV, or it won't work. This med is used in emergency situations)</b>									
	All	PLWH	Trans	Trans Women of Color	PWID	His/Lat Gay/Bi Men	Black Gay/Bi Men	White Gay/Bi Men	Con/Pro
Yes	75%				49%	90%	84%	80%	100%
No	25%				51%	10%	16%	20%	
<b>If you were exposed to HIV, would you know how to obtain a dose of PEP?</b>									
Yes	68%				42%	89%	81%	79%	75%
No	32%				58%	11%	19%	21%	25%
<b>How likely, if exposed to HIV, would you ask for PEP in an emergency room or other healthcare facility?</b>									
Not likely	13%				9%	11%	19%		14%
Somewhat likely	14%				23%	11%	6%	9%	14%
Moderately likely	14%				4%		19%		4%
Strongly likely	13%				14%	44%	6%	18%	14%
Extremely likely	45%				50%	33%	31%	72%	54%

## Syringe Services

<b>For individuals who use syringes (needles) to inject drugs, do you know where to get sterile (new) equipment or supplies in your area?</b>	
Yes	89%
No	11%
<b>For individuals who use syringes to inject hormones (testosterone, steroids, estrogen), do you know where to get sterile (new) equipment or supplies in your area?</b>	
Yes	71%
No	29%

<b>Are you comfortable going to a syringe services program (needle exchange) if one is available?</b>	
Not comfortable	8%
A little comfortable	4%
Moderately comfortable	15%
Quite comfortable	13%
Extremely comfortable	60%

**If you are comfortable going to a syringe services program, what helps you feel comfortable?**

Responses are listed in order of the frequency with which they appeared.

- Non-judgmental staff, an affirming, friendly environment
- I feel like I'm helping others
- Confidentiality/Anonymity
- Staying safe
- Other helpful information about staying safe
- These services are needed for folks who use needles for their hormones, too

**If you are not comfortable going to a syringe services program, what would help?**

- Someone willing to help me, a 1:1 with someone
- A drive thru exchange
- Privacy issues
- Home delivery or mobile services

## Participant End of Survey Responses

At the end of the survey, participants were invited to share with us anything else they wanted us to know. These are some of the responses we received:

- I tried to use my HIV as a way to commit suicide. I did everything I could to help it's progression and well, despite my best efforts, I am still here.
- I would like to say that I'm happy with the care and services I receive.
- Nope! Thanks for creating this survey!
- I thank you for the survey and for your goal in reaching out to those in need. After my other half passed away in 2001 I have been celibate, but I know many young people who are in the wholeness of life and hope this survey helps folks be aware of their responsibilities toward themselves and their friends and future partners.
- Thank you for asking these important questions!
- I got a lot of support from a needle exchange that help me get back into recovery

- I have been an IV user of meth since 1995. I appreciate the exchange and appreciate all of you that care. Thank you all.
- I just wish I could do this on my own :( I miss my mommy and I hope I can make the money to get clean and not be homeless. Thank you for listening.
- I hope my misery of addiction with these answers could help out with some data or helping in some way. It's not often I get to feel like I did something good. So, thank you.
- es todo !! buena encuesta:) English translation -That all!! Good survey.

## Provider Responses Related to Population/Topic Specific Trainings

How would you describe your training on the populations you serve?	
Formal (part of a certificate or degree program)	35%
Conferences or Workshops	84%
Internal Trainings offered at my workplace	87%
On-the-job experience	87%
Personal knowledge & experience (family, social networks, personal knowledge due to shared identity)	61%
I have received no training on the population I serve	1%
In your experience, is the kind of training you have received sufficient for you to appropriately serve the population you work with?	
No	24%
Yes	76%

Based on the responses we received to the follow up question “*What else should we know about population-focused trainings in the field of HIV Prevention & Care based on your experience?*” it is clear that the providers “yes” in response to the training question was an “in general, yes, but...”. Their contributions to the open field question provide valuable insight into existing gaps and future training opportunities. In total 67% of survey respondents contributed their thoughts on what was lacking or needed in order to better serve the population they work with. The themes from those responses are included below. Responses are organized by frequency. The first categories represent topics/themes that received the most comments from respondents.

### **Specific subgroup focused trainings**

Respondents widely agreed that deeper dives into specific subgroup topics were needed. Frequently, these topics were listed with a statement such as “we need inclusive trainings on X, led by members of the community itself”. Due to the volume of comments about the impact of trainers with lived experience, we have included that as its own category later in this section.

Subgroups below (in the order of the frequency with which they appeared) were specifically identified by providers.

- Specific knowledge and competency trainings are needed for working with immigrant communities, both documented and undocumented since they each present with unique issues and barriers.
- Information is needed regarding working with both currently and formerly incarcerated individuals
- More is needed on the Trans community in general
- Nonbinary terminology and competencies, in addition to increasing understanding of gender expression and identity as separate from sexual orientation which are too frequently confused or conflated
- Topics related to issues faced by BIPOC women
- Topics specific to homelessness
- Sex workers, their unique barriers, risks, and specific skills for providers in working with this population
- Burmese and Hmong cultures
- Specific subgroup trainings for working with MSM who are also PWID

### **Training Frequency, Scheduling, and Modalities**

- Trainings should be immediate upon hire, ongoing, and regular. Regular trainings that allow for going deeper on topics as you progress are critical for actually increasing competency in core areas.
- Trainings should include real case examples, with a focus on the consumer/participant experience. One of the community focus group participants stated that they thought providers should do role plays so they have a chance to experience some of the statements, etc. that are often experienced by patients. This provider comment aligns with that observation.
- Trainings need to be offered at times that make it possible for staff to attend them. One provider stated:
  - “Trainings are offered by my company; however, they are right in the middle of my work day and no options to help cover are offered. It makes it difficult for someone working in patient care to attend. Always makes me feel like they are for management so they can “check a box” that they had training, but will never actually care for the populations discussed, so the training is wasted.”



- There is a need for trainings for those first entering the field and then those who have been in the field for some time.
- Trainings need to be offered in-person statewide, (not just virtual or in Madison). One provider stated:
  - “Do a training multiple times in multiple locations so there isn’t as much pressure on an agency to send staff long distances, which limits the number of staff who can take advantage.”
- Continuing education that is mandatory for all staff would be useful and would ensure everyone has up-to-date knowledge and education.
  - “I had most of my HIV-specific training while I was being onboarded for my position and have not had as much later on”

### **Real Lived Experience**

Providers stated over and over that having trainings that are facilitated or co-facilitated by members of the community with real-lived experience was critical yet infrequent. Providers stated strongly that this increases their competency in ways that are immediate and tangible and tend to be trainings they remember long after they are over, so their impact is also long-lasting. Some specific comments from providers included:

- “It would be helpful if trainings had trainers that have lived experience. For example, I think PWID voices are commonly forgot about and would be helpful for them to lead some trainings.”
- “Lived experience has been invaluable to me. I think that more voices need to be included from the populations we work with/for in what THEY need, would like to see, and how they think they could best be supported. I see a huge disconnect in what program and policy creators envision with what our populations actually see and deal with on a day-to-day basis.”
- “The most beneficial trainings I have had, have included live voices of the specific populations and how service delivery can improve, direct from their experiences.”

### **Cultural Competence**

Providers recognized a need for population specific trainings that include objectives for increasing cultural competence, but that in general, cultural competence is an almost unmeasurable “low bar”. Specific needs and suggestions from providers include:

- Cultural intelligence and unlearning of socially or systemic imposed knowledge should be included in all trainings regarding services to all systemically oppressed communities
- Continued trainings on how to effectively communicate with systemically oppressed groups without being offensive. Providers stated:

- “Words matter and the way in which we say things matter and can directly affect patient care and outcomes.”
- “I am aware that I need to be culturally sensitive, but I have to admit, I don't always know exactly how to be culturally sensitive.”
- Providers acknowledged that too often community-based organizations are treated like on-the-job training programs. There is an observation by providers that many organizations believe if they hire individuals with lived experience they do not need additional training. Members of the LGBTQ+ community, for example, by nature of their membership are not experts on issues that don't impact them directly. Being LGBTQ does not mean you understand Trans issues.
- Providers also believed that administrators need more policy and administrative practice level training. Not just front-line staff. Administrators need to examine their hiring, training, and promotion practices to better understand changes that need to occur in order to recruit and promote more members of the communities the program serves. There was a desire to have more leadership that is reflective of the community served, but the practices that will lead us there are often left out of what is widely considered to be necessary training.

### **Trauma**

Providers indicated a need for more trauma-focused trainings. In response to the survey question, many respondents simply wrote “trauma” in the field. The following was the most common of the more detailed responses.

- A deeper understanding of how experiences of trauma impacts client health behaviors
- Providers indicated a need to understand trauma histories in order to support a practice of empathy and non-judgment

### **Social Determinants of Health and their Impacts**

There is a need expressed by providers to better understand the holistic impact of social determinants of health, specifically as it relates to the following. The trainings should include specific strategies and resources that providers can use/offer when needed. Therefore, trainings should also include local resources and staff from other agencies/community-based organizations in the areas served.

- AODA issues
- Housing
- Transportation barriers
- Food and Nutrition
- Mental Health

## **Mental Health**

Though included above, many providers indicated a dearth of trainings on mental health as a stand-alone topic. 95% of providers recognize mental health issues as a barrier to their client/patients' access to healthcare. Providers stated:

- “Mental illness often impacts every single area of their life and can be a barrier to receiving care and ART adherence. It's also often coupled with homelessness, drug use, legal issues and other challenges our clients face.”
- “Some of the people we treat are mentally ill and I've heard of some concerning experiences other employees have had where they weren't sure how to respond to a distressed client. In this way, I feel ill-prepared.”

## **HIV Topics**

Providers indicated that ongoing trainings on HIV specific topics are needed beyond onboarding and annual one-off trainings. Those trainings may also need to include non-funded providers or be open to the community. Those trainings should include:

- Barriers and cultural issues specific to rural HIV care
  - “Besides the usual transportation issues, we have medical professionals who don't have a basic understanding of HIV - my staff have been asked by their own doctors if they want an HIV test because they work with PLWH, doctors who ask case managers how to prescribe PrEP. Our rural clients often lack a community of people where they can be fully open - whether that is about their HIV status, gender identity, sexuality, or culture. Our case managers may be the only people who clients feel comfortable being their authentic self around”.
- Specific training on medications, labs, and co-occurring opportunistic diseases
- Annual refresher trainings on various aspects of care providing the latest updates as care and our understanding of HIV care continues to evolve

## **Harm Reduction**

Providers stated that harm reduction is key to HIV Prevention, and they need a comprehensive understanding of what that means in order to be effective in their roles. A provider stated:

- “Harm reduction is more than naloxone.”

## **Job/Role Specific**

Providers stated there is a need for role specific trainings. Outreach teams need to learn with other outreach teams, nurses need to learn with other nurses, etc. Their comments reflected a

need to learn with other people in their role due to the oftentimes unique nature of those roles.

Providers also indicated that there is often a lack of understanding within agencies or organizations. Often, providers in one department don't know what providers in other departments do or the actual services they provide. Having in-house learning days where departments/teams lead trainings about what they do would decrease silo-ing and increase the impact of service provision internally.

### **Empathy**

Lastly, providers desire more trainings on empathic care and de-escalation.