Focus Groups to Inform the 2022-2026 Arizona HIV/STI/Hep C Integrated Plan

Better Understanding our Priority Populations

February – June 2022

Arizona Department of Health Services

Office of Disease Integration & Services

Contents

BACKGROUND

The Arizona Department of Health Services (ADHS) undertakes a planning process every five years, in order to develop an Integrated Plan for how the state should and will respond to the HIV epidemic. During Summer 2021, the HIV prevention and care teams at ADHS launched statewide surveys to better understand the services, needs, gaps, and barriers experienced among clients in Arizona. Although the surveys had over 1,800 responses and provided significant and impactful data for planning, the planning staff agreed that greater efforts were needed to understand the personal and unique experiences of priority populations.

Focus groups were selected in order to gather information on priority populations. These were populations who may represent only a small portion of survey respondents, who may be underrepresented in survey responses, or who have previously been identified as a priority population for HIV, STI, or hepatitis C prevention and/or care services.

Six priority populations were included in this set of focus groups, listed below. All groups focused on engaging individuals who were living with or who experienced risk for HIV, STIs, or hepatitis C.

1. Individuals aging with HIV (ages 50+)
2. Spanish monolingual clients
3. Individuals experiencing housing instability or homelessness
4. Individuals who were using or had used substances
5. Young men who have sex with men (MSM) of color (18-34 years)
6. Gender expansive clients

APPROACH

The ADHS HIV planning staff hired a contractor to facilitate each focus group, and began planning for the groups in Fall 2021. The plan was shared with internal staff (HIV, hepatitis C, and STI) and planning bodies. This plan stressed that focus group participants should be individuals who did not routinely participate in planning efforts and who were not members of planning bodies, in order to diversify the voices and experiences gathered during the groups.

Groups were conducted in phases, with two priority populations recruited at a time, in order to reduce the burden on planning staff and the contracted facilitator. Recruitment was conducted in collaboration with community partners identified as having access to the priority populations. Community partners were provided with flyers, recruitment materials, and survey links to support individuals to sign up.

The default for focus groups was a virtual setting, due to ongoing COVID-19 restrictions. However, exceptions were made for groups identified as more likely to participate in an in-person focus group.

Groups were held for 90 minutes each. All participants received a $75 gift card (Walmart or Target) for their time. All notes were collected without names or other identifying information. Recordings of virtual groups were used only for note-taking purposes.

WHO DID WE TALK TO?

Overall, 18 focus groups were held. Additionally, two participants were spoken with individually, due to mental health concerns and technological barriers, respectively. In all, 182 individuals participated, with an average of approximately 10 participants per group.

Many participants were new to planning efforts and had not previously participated in surveys, planning bodies, or community engagement efforts for HIV, hepatitis C, or STIs.

The majority of the focus groups were held virtually on Zoom.

The focus groups occurred from February 2022 to June 2022.

PRIORITY POPULATION	# GROUPS	# PARTICIPANTS
Aging with HIV (ages 50+)	2	13[+]
Spanish monolingual clients	3	27[+]
Experiencing housing instability or homelessness	4[*]	45
Using or had used substances	5[**]	83
Young MSM of color (18-34 years)	2	8
Gender expansive clients	2	6
TOTAL:	**18**	**182**

[+]Total includes an interview participant.
[*]All 4 focus groups were held in-person.
[**]2 of the 5 focus groups were held in-person.

WHAT DID WE LEARN?

Following each set of focus groups, all facilitators and note takers met to debrief the groups and identify common themes, unexpected results, and suggestions or concerns raised. Listed below are the key takeaways identified for each priority population.

Additional ideas and experiences were shared during groups and can be shared with interested individuals as needed.

Aging with HIV (ages 50+)

- Importance of support systems & support groups
    - Although many individuals aging with HIV have support systems in place, the absence of pre-COVID-19 support groups and group programming is strongly felt
- Individuals' health priorities are everything that comes with "getting older" – not just their HIV!

"We're not dying of something; we're living with something"

- Poverty and housing are major issues
    - These are getting worse instead of better
    - There is interest in financial literacy and financial planning resources
- Desire for more general awareness of HIV & risks for HIV to prevent new diagnoses
- Lack of consistency among agency staff has a direct negative impact on the quality of services and the experience of receiving them
    - Clients experience issues with communication among their various providers, particularly between primary care and specialists

Spanish Monolingual Clients

- Need for more peer support & support groups
    - Especially for newly HIV diagnosed clients
- Need for more Spanish-speaking therapists & mental health providers
    - Using interpretation & unknown interpreters causes frustration and limits the effectiveness of therapy and mental health services
- There is power in casual communication & word-of-mouth to spread information
    - Want more mechanisms to get education/information in casual or group formats

"Como minoría, el VIH no es una prioridad, trabajando es una prioridad"

Translation: "As a minority, HIV care is not a priority, work is priority."

- Desire to hear more about HIV prevention, not just HIV care
    - More interest in status-neutral (mixed-status) groups and activities
    - Want greater awareness around prevention instead of "waiting" for people to be diagnosed with HIV
- Immigration and visas DO negatively impact willingness to utilize available services
- Clients have experienced issues with HIV medications while traveling internationally

Clients Experiencing Housing Instability & Homelessness

- Housing is getting worse, not better
    - There is an extreme impact from the rising rent costs
- For clients on AHCCCS, access to medical care is pretty good!
    - However, most individuals still access services through the hospital or emergency department (ED)
    - Individuals typically only seek medical care for urgent needs
    - Breakdowns exist for "ongoing" care and/or follow-up and connection to other services, including substance use treatment and mental health services

"Homeless folks don't go to the doctor for much - they don't want to know [what's wrong]"

- Loneliness is a HUGE issue when you are homeless and living on the streets
    - There is a lack of trust among homeless individuals
    - It is difficult to maintain and build friendships when you are homeless
- Major day-to-day concerns include:
    - Lost/stolen documentation & medications
    - Limited charging stations for phones
    - Limited access to therapy and mental health services

- Perception that housing systems are set up to reward those who act or appear to be "worthy" of help
    - Individuals who are homeless and use drugs are often deemed "unworthy"
- Housing programs are not always the best or preferred option for homeless individuals
    - Programs may not consider the location of the housing unit in relation to an individual's existing services and social networks
    - Programs may set strict or unreasonable expectations and rules

"Systems don't talk to each other. It feels like we're running around in circles to get any kind of help"

- This group is NOT homogenous!
    - Example: people experiencing acute homelessness and living on the street reported that free meals and food were readily available to them through homeless service providers, but people with housing who experienced housing instability reported issues obtaining groceries to eat/cook at their own housing

Clients Who Use or Have Used Substances

- People who use are the same people who are helping their communities
    - These communities often have norms about how members can/should use
    - Strong community networks exist despite concerns about trust
- Use often begins as social and fun, before becoming more isolated and "necessary"
- Client experiences and perceptions of use vary by the substance they use
- AHCCCS clients report decent access to services through the emergency departments
    - Fewer clients report seeking out preventive or ongoing care options
- There is a strong perception of internalized stigma and shame due to substance use

"Nine times out of ten, I talk myself out of going [to the doctor] so I don't have to deal with the stigma [in the medical setting]."

- SSPs (syringe services programs) ARE working!
    - Decreased reported sharing and re-use of syringes and works
    - High interest in receiving wraparound services through an SSP entry point
    - Individuals reported on the value of having SSP staff with lived experience
    - BUT: people are still re-using and sharing supplies, and we need more SSPs in more places
- Substance use disorder treatment is often not available when, how, and where it is needed

- Clients have a general awareness of the hepatitis C cure, but need additional information on the details and availability
    - Clients report getting tested for hepatitis C, but want more testing opportunities
- Individuals shared an optimism that things are getting better for those who use

"If you want to see a world free from the harm of addiction, you first need to create a world free of harm towards addicts."

Young Men Who Have Sex with Men (MSM) of Color (ages 18-34)

- Importance of financial self-sufficiency and employment as a form of support
- Short-term hookups and long-term dating/relationships are not the same
    - Apps are used for hookups more than they are used for dating
- Empowerment and accountability for STI testing, sexual health protection, and HIV is at a personal level instead of at the community level
    - Someone who regularly tests and protects their sexual health is seen as attractive and desirable

"It's like in the airplane – you have to put the mask on yourself before you can help anyone else!"

- Need to move away from white cis gay males as the "PrEP message demographic"
- Need to message PrEP as one piece of the sexual health puzzle, not the ONLY thing
- Perception that disparities in HIV/STI rates among YMSM of color are due to the lack of access to medical facilities and services among people of color
    - People of color reported experiencing racism and discrimination from all facets of the health care system

"It's accessibility. Men of color do not have access to these facilities, [which are] in metropolitan place white spaces that are not accessible to people of color."

- There is a need for a greater focus on general preventive health if we want to improve sexual health
- YMSM of color who are first- or second-generation immigrants reported strong cultural values and norms around sex, often leading to stigma, shame, and hiding of behaviors
    - HIV and STIs are taboo, and people do not want to test for or talk about them
- Individuals shared a desire for factual, to-the-point messages about sex, HIV, and STIs
    - Interest in "boots on the ground" messaging and education from their own community members

Gender Expansive (GE) Clients

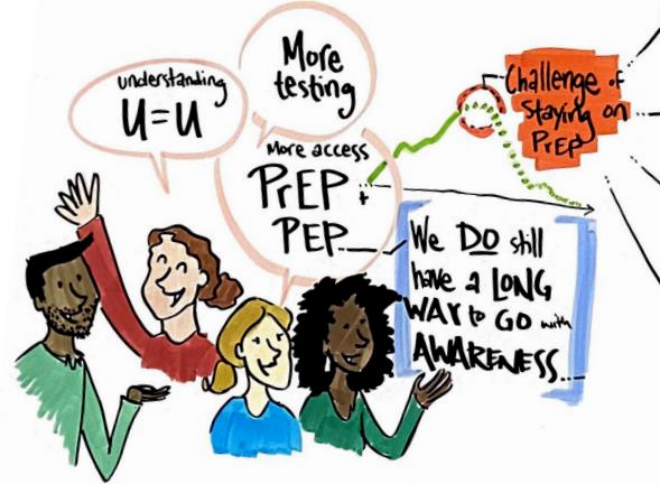
- The term "gender expansive" and being gender expansive are both perceived as affirming
    - Individuals do not like to be labeled, but they appreciate having words to apply to their self-identity
    - Being gender expansive is just one portion of complex identities and lives

"I use an analogy of trying to find the shoes that fit best. Try on different things to find the right fit. . . everyone deserves to have the shoes that are the right fit."

- The journey to gender identity is NOT linear!
- Employment and financial stability are perceived as a support system
- GE individuals are engaging in sex work, and they need more judgement-free education about what sex work is and how sex workers can protect their sexual health
- Sexual health and sexual expression are widely varied
    - There are a limited number of sexual health providers and OB-GYNs who understand the GE experience and GE clients' needs
- Access to gender-affirming (GA) medical care is low, especially in rural areas of Arizona
    - In general, there is not enough LGBTQIA+ care across the state
    - GE clients must be their own medical advocate and do their own research

"I know more than the doctor does [about GA care] and that's scary"

- GE individuals report that they need easier ways to find out what resources ARE available across the state
- Online/internet is a place for connections, friendships, and meeting people



LESSONS LEARNED & LIMITATIONS

The focus groups demonstrated that community members and service recipients are incredibly willing and eager to share their experiences and suggestions. There was a consistent interest from participants in additional ways to provide their feedback, and in future opportunities to join educational sessions or events.

Despite success with the six populations included in this report, there were two other priority populations that we were unable to reach. In the original focus group plan, we had proposed holding groups with tribal communities and individuals living on reservations. The ongoing burden of COVID-19 and our lack of previously established partnerships made these groups difficult to plan. There is a clear need to develop and strengthen partnerships with our tribal communities for planning efforts.

We also proposed speaking to people who had a recent history of incarceration. Due to privacy restrictions and limited staff, we did not host a group exclusively for these individuals. However, individuals in other focus groups self-identified a history of incarceration and provided input on how that piece of their identity influenced their current situation.

Additionally, we were able to hold in-person focus groups for individuals who used substances and individuals experiencing housing instability and homelessness. However, these in-person groups were restricted to Maricopa County. In comparison, the virtual focus groups included participants from both urban and rural areas of the state. Future focus group efforts should strive to hold in-person groups in other counties, to increase the diversity of responses and voices.

NEXT STEPS

The takeaways from the focus groups are being used to inform the development of the 2022-2026 Arizona Integrated HIV/STI/Hep C Plan. High-level takeaways from the focus groups will be included in the Needs Assessment section of the plan submission, which will be submitted to federal funders in late 2022.

The ADHS Integrated Planning Team presented these findings in July 2022, and this report will be shared with individuals involved in integrated planning efforts, planning bodies, and other related activities.

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Facilitators: Rocko Cook, Eduardo Moreira

ADHS Note Takers: Isabel Evans, Leo Fulwider, Deborah Reardon-Maynard, Joana Mendez, Macy Richardson

Additional ADHS Contributors: Christopher Garcia, Ricardo Fernandez, Arlis Jenkins, Becca Scranton, Yanitza Soto

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Recruiters:

- Aging with HIV (ages 50+):
    - Mel Benedetto, Elizabeth Markona, Catherine Moutray, Miss Jai Smith, Erika Solis, Erica TeKampe
- Spanish monolingual clients:
    - AJ Dominguez, Daniel Iniguez, Duvia Lozano, Catherine Moutray, Martha Rodriguez, Miss Jai Smith, Erika Solis, Erica TeKampe
- Individuals experiencing housing instability or homelessness:
    - Steven Lundy, James Menezes, Edward Pulley, Dave Watt
- Individuals who were using or had used substances:
    - Missy Downer, Sandi Kuhns, Arlene Mahoney, Catherine Moutray, Sebastian Thomas, Dusti Yamaguchi
- Young men who have sex with men (MSM) of color (18-34 years):
    - Jeremy Bright, Alethea Do, AJ Dominguez, Jeremy Hyvarinen, Javier Marquez, Kate Thomas
- Gender expansive clients:
    - Jeremy Bright, AJ Dominguez, Jericho Galindo, Haze Jackson

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