Consumer Input Project Executive Summary

Findings and recommendations from interviews with people living with HIV experiencing homelessness.

Local context

Since December 2018, Hennepin and Ramsey counties have been experiencing an HIV outbreak among people experiencing homelessness (PEH) and injection drug use (IDU). This outbreak is divided into two subclusters. The first includes people who inject(ed) drugs and spent time in a known encampment; the second includes men who have sex with men (MSM) and use injection drugs, but who did not spend time in an encampment. As of May 8, 2024, there are a total of 253 cases in this outbreak, with 111 in the encampment subcluster and 142 in the MSM/IDU subcluster (Minnesota Department of Health, 2024).

The lack of access to stable housing is a key contributing factor to the outbreak, as well as IDU. Surveillance data also show that there are certain populations that are disproportionately affected by the HIV outbreak. This includes Native Americans, African Americans, and multi-racial people, making this outbreak an important health and racial equity issue (Minnesota Department of Health, 2024).

Accordingly, Hennepin County has been using a multi-sector, data-driven approach to respond to the outbreak. Housing has been central to these efforts, especially given that it is one of the most significant predictors of positive HIV-related health outcomes locally (Peterson, 2018). One part of this response is the Low Barrier Housing Technical Work Group (TWG), an interdisciplinary group that convened in September 2021 to address housing-related challenges for people living with HIV (PWH) affected by the outbreak. The workgroup aims to create a model for low-barrier housing for this population, with an emphasis on providing linkage to services and centering cultural responsiveness and harm reduction.

Project background and business need

In February 2022, the TWG sponsored the Hennepin County Ryan White HIV/AIDS Program to conduct the Consumer Input Project to better understand PWH's challenges to accessing and maintaining housing. The goal of this project is to answer two main questions to inform the workgroup's efforts: (1) What are the barriers and facilitators to housing for PWH affected by the outbreak? and (2) What does desirable housing look like for this population? The aim is to answer these questions through semi-structured interviews with outbreak cases with current or recent experiences with unsheltered

homelessness. This project addresses the TWG's business need to incorporate the perspectives of people with lived experience in program planning and service provision.

There was a total of 22 interviews completed as part of this project between July 2022 and March 2023. Participants were asked about their current and past housing experiences, barriers and facilitators to housing, decision-making processes around housing, elements of desirable housing, resource use, and key demographics. Participants were identified through Health Care for the Homeless street outreach, Red Door Clinic's Disease Investigation Services, and Ryan White programmatic data. About three-quarters of the interviews were conducted either on the street or at Avivo Village, with others conducted at individual clinic locations. The interview data were analyzed and transcribed in 2023 using established qualitative data analysis methods and software (ATLAS.ti Web version 7.9.0). These findings were then synthesized to produce a definition of desirable housing and to identify common themes across barriers and facilitators to housing access. These results are detailed in this report.

Key findings

Participant reflectiveness and resource use

Participants are reflective of the HIV outbreak, allowing for greater applicability of these results to the larger population of PWH affected by the outbreak. Over half of the participants (15) identify as Native American, with three identifying as multi-racial in addition to Native American. Three participants identify as Black, two as Hispanic, and two as White. Looking at gender identity, ten participants identify as cisgender men, nine as cisgender women, and three as transgender, nonbinary, or an additional gender identity. While most participants are straight or heterosexual (16), three identify as MSM and six in total do not identify as straight or heterosexual. The median age of participants is 36.5. Half of the participants were younger than 35 at the time of the interview, and two were older than 50.

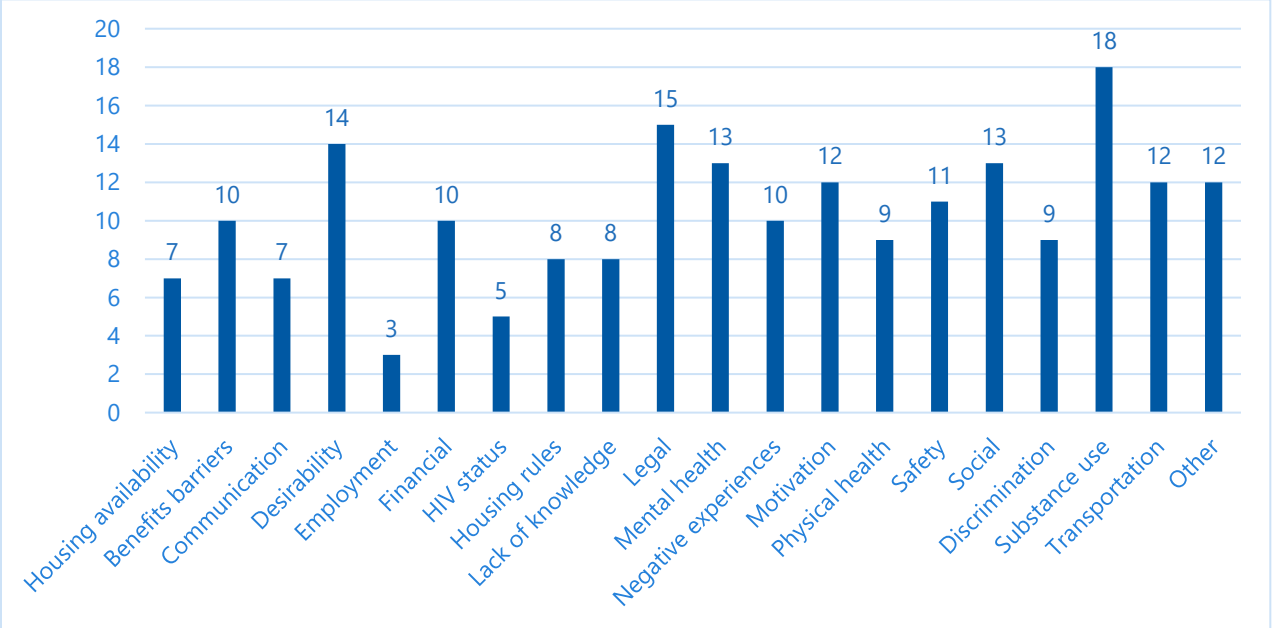
In addition, participants have a broad range of housing experiences. The majority were unhoused at the time of interview, with ten experiencing unsheltered homelessness and seven experiencing sheltered homelessness or unstable housing. Five participants were stably housed. All participants had current or past experiences with chronic homelessness, and the majority also had experiences with unsheltered homelessness (20), sheltered homelessness (15), and stable housing (18). This allowed them to speak to all aspects of the housing continuum, allowing for more complete results.

Finally, all participants were connected to at least one resource, with most participants using several. The most popular resources included Health Care for the Homeless, nutrition benefits (like Electronic Benefits Transfer), syringe service programs (SSPs), housing programs, health insurance, and General Assistance. There were 12 participants who reported current injection drug use, all of whom were using at least one SSP. The most popular SSPs were Health Care for the Homeless, Southside Harm Reduction, and Indigenous Peoples Task Force. This shows the range of facilitators participants had access to and highlights opportunities for greater coordination of care at the agencies and locations at which participants are already receiving services.

Barriers to housing

Participants' barriers to housing were organized into 20 unique categories, which are quantitatively and qualitatively described below.

"Number of barriers experienced by participants"



Qualitative descriptions of barriers to housing (from most to least frequently experienced)
Substance use was the most significant barrier to housing. Participants' experiences with withdrawal sickness, complex substance use schedules, and lack of motivation stemming from use made it difficult for them to do basic life tasks related to housing, such as attend appointments or maintain employment. Participants also often lost or surrendered housing once their landlords were aware of their use. It was typically harder for participants to manage their use or access harm reduction supplies when unhoused, highlighting the cyclical nature of this barrier.
Legal barriers included participants not having ID documents or having a criminal or legal background. Several participants did not have ID documents due to the loss or theft of their belongings while experiencing homelessness, which made it difficult for them to access benefits, obtain employment, and get approved for housing. Having a legal background could similarly make it difficult to obtain these resources. The criminalization of homelessness and substance use made it very likely for participants to experience legal challenges, making them a significant barrier to housing.
Participants explicitly stated that they surrendered, turned down, or had difficulties maintaining past or new housing opportunities that were **undesirable**. Some of the things that could make housing undesirable included its location, lack of privacy or independence, and reputation as HIV-specific.

Mental health issues and trauma could make it difficult for participants to do basic life tasks related to housing because they negatively affected participants' motivation, executive functioning skills, and bandwidth for understanding and navigating complicated housing processes. Most participants' mental health issues were worsened by homelessness, making this another cyclical barrier to housing.
Social barriers included both a lack of social support and unstable relationships. Participants who had little to no social support had difficulties accessing or maintaining housing without any advocates on their side. In contrast, participants in unstable or negative relationships faced additional challenges from this instability (such as violence, co-dependency, or stress) that became barriers to housing.
Participants who **lacked motivation** for housing had a harder time prioritizing and working towards it. This lack of motivation could stem from their substance use or mental health issues, fears around losing housing again, or unfavorable feelings towards housing programs or shelter options.
Most participants were dependent on public transit or faced barriers to accessing other forms of transportation. These **transportation challenges** made it difficult for them to get to housing or medical appointments and could cause them to give up or not accept housing that was not transit accessible. It was also hard for participants to pick up transit passes or call for rides without phones.
Miscellaneous barriers included homelessness and systemic issues such as encampment clearings, the war on drugs, and structural racism. These led to greater instability for participants and amplified their substance use, legal issues, mental health issues, and other barriers to housing.
Safety issues on the streets or in shelters (like violence, theft, or harassment) amplified participants' mental and physical health issues and could cause them to disengage from shelter services or lose important legal documents. Safety issues in housing (like uncontrolled substance use) caused them to forfeit housing and could worsen their existing barriers or issues.
Most participants had little to no income and struggled with money management or maintaining employment. Even participants who had financial benefits often found them to be insufficient. These **financial challenges** made it difficult for participants to afford housing and other basic needs.
Bureaucratic challenges (like high paperwork burden or catch-22s) and participants' lack of access to ID documents, phones, and transportation could create **barriers to benefits**. This made it difficult for participants to get the resources they needed to access or maintain housing.
Some participants had **negative experiences** with housing programs, case managers, shelters, and other providers, which ranged from not having sufficient support from providers to discrimination to invasions of privacy. These experiences eroded trust between participants and providers, exacerbated other barriers participants faced, and made it less likely for them to engage with services.

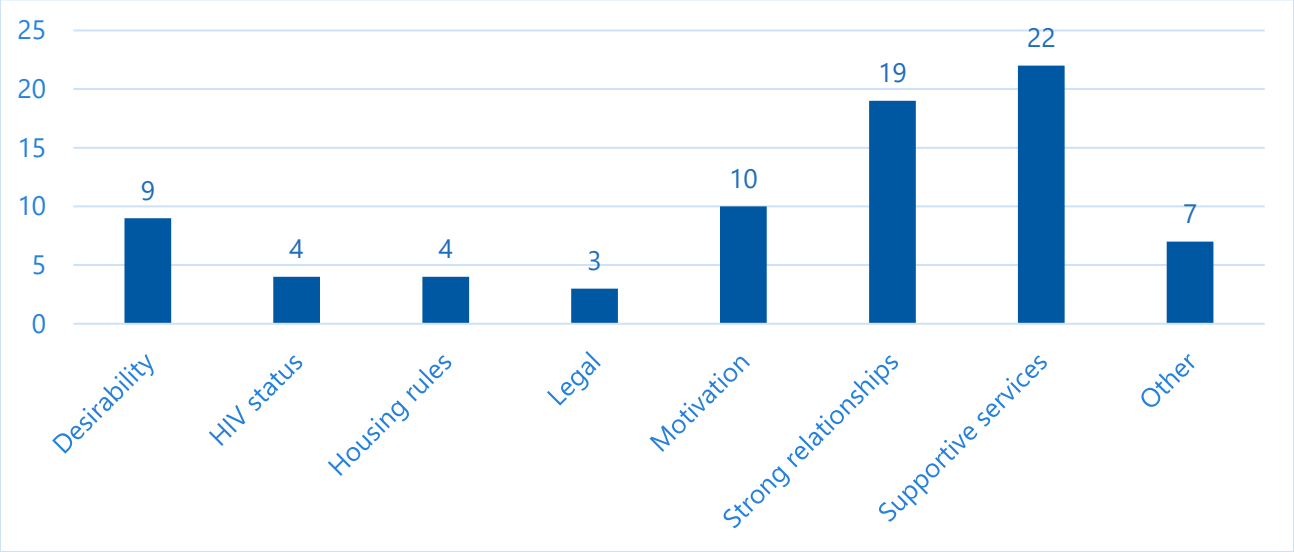
Physical health issues included physical disabilities and issues stemming from long-term drug use, chronic homelessness, or untreated HIV (like malnutrition, endocarditis, frostbite, or AIDS). They made it difficult for participants to get to appointments, maintain employment, and prioritize housing.
Stigmatization (of HIV, homelessness, drug use, or sex work) and discrimination (like racism, homophobia, transphobia) manifested in ways like increased scrutiny by law enforcement, profiling, violence, and exclusion from certain housing programs. These issues could make it challenging for participants to live in certain areas, access shelters and other resources, and maintain employment. They could also lead to legal barriers and erode trust between participants and systems of care.
Restrictive, undesirable **housing program rules** (such as check-in requirements or belonging checks) created high barriers to housing that made it difficult for participants to both access and maintain it.
Participants' **lack of knowledge** about available resources and housing processes made it difficult for them to access benefits, navigate systems, and create plans. Without any guides or roadmaps, it was hard for them to know where to start looking for housing or how to get connected to housing support.
Long waitlists and the **lack of housing** were frustrating for participants to deal with and made it hard for them to get housed. This negatively affected their motivation for housing and trust in systems.
Most participants either did not have a phone (or other communication tool) or struggled to afford or maintain one due to higher rates of theft and loss while homeless. This made it difficult for them to **communicate** with providers and thus access housing and other resources.
Stigma and medical issues related to **HIV** created mental and physical health issues for participants that negatively affected their abilities to attend appointments and engage in services, particularly HIV-specific ones. This was cyclical, as participants often struggled to manage their HIV or adhere to medications while experiencing homelessness (due to loss or theft of medications and a lack of routine) or while having internalized stigma around their status.
Most participants struggled to access or maintain **employment** because of their physical or mental health issues, substance use, legal backgrounds, and homelessness. Without stable employment, participants struggled to afford or get approved for housing.

These data show how interconnected and self-reinforcing participants' barriers to housing can be. As explored above, barriers often amplify and feed off each other, creating larger, cyclical barriers to housing. This is complicated by the fact that homelessness itself is a barrier to housing that both negatively impacts and is worsened by other barriers like substance use, legal issues, or mental illness. As a result, participants are often trapped in cycles of homelessness, which is corroborated by the fact that most participants were previously housed but lost housing due to these overlapping barriers. These data suggest that it is important to focus on disrupting these cycles to help people access and maintain housing, as it is often the intersections between these barriers that create challenges around housing.

Facilitators to housing

Participants' facilitators to housing are organized into eight unique categories, which are quantitatively and qualitatively described below.

"Number of facilitators experienced by participants"



Qualitative descriptions of facilitators to housing (from most to least frequently experienced)
Supportive services were a significant facilitator and included both transactional services (like financial benefits or health insurance) and intensive services (like case management or substance use treatment). These services reduced participants' barriers to housing and provided them with material support around accessing and maintaining housing.
Strong relationships that participants had with providers and their friends or family members were not only a source of material support but also offered participants emotional support around navigating housing. While many of these relationships occurred organically, specific care models (such as street outreach) helped foster these relationships between providers and participants.
The **availability of housing**, particularly programs that were low-barrier and specific to participants' needs, was a major deciding factor for participants. Participants often chose their housing because it was the first available option that they liked.
Participants noted that they were more likely to work towards housing if they were **motivated** to do so. Several things could affect participants' readiness for housing, but generally included factors such as wanting to do better for themselves or others, sobriety, and access to desirable housing.
Participants were more likely to access and maintain housing that they found **desirable**. Some things that could make housing desirable included location, flexible rules, and supportive services on site.

Miscellaneous facilitators included having access to transportation, money, or benefits, which made it easier for participants to get to appointments, afford housing, and have resources. Some participants also did not have communication or other barriers, which enabled them to get housed faster.
Some participants were able to access housing faster because of their **HIV status** and the availability of HIV-specific housing services. Participants also typically found it easier to manage their HIV and consistently take their medications when housed because of the sense of stability housing provided.
Participants who did not have any **legal** record or evictions, or who were able to access or recover their ID documents, were able to access housing and other benefits more easily. Most of them had support from providers in mitigating their legal barriers.

This analysis reveals how interconnected facilitators can be, with certain facilitators leading to or resulting from others. As explored above, this synergistic relationship between facilitators allows participants to both address their barriers as a whole and benefit from several facilitators at once. Furthermore, many of these facilitators are not necessarily things or programs, but rather participants' feelings and attitudes towards themselves and their providers. Here, trust arises as an important factor in cultivating these feelings and relationships, with participants emphasizing that they were connected to care because they trusted their providers, who then helped them build their motivation for housing. The data suggest that this combination of trust and synergy ultimately allows participants to access and maintain housing.

Desirable housing

An important aspect of this project is the emphasis on desirability. Looking at specific elements, most participants want housing in the Twin Cities, especially south Minneapolis, that is at least one-bedroom and allows them to either live alone or with family. It is important for housing to be accessible by and well-connected to public transit, affordable and subsidized (with no extra fees or deposits), and flexible around people's legal or criminal backgrounds. It is also important for housing to safeguard against evictions and discrimination, and it should include on-site amenities like laundry, storage, private bathrooms, kitchens, and parks or green spaces. Participants overwhelmingly want housing to allow visitors and pets and to be in a safe neighborhood with low crime or violence, friendly, welcoming neighbors, and even gated or secure entrances. Participants also want housing that offers ample independence and privacy but in conjunction with on-site supportive services, such as case management or homemaker services. For those with specific accessibility needs, it is important for housing to be on a lower floor, have elevator access, and be wheelchair accessible.

Participants' needs and desires related to harm reduction elements, HIV-specific housing, and culturally specific housing are less consistent. However, to synthesize, most participants are not in favor of sobriety requirements and want flexibility around the types of substance use support and rules present in housing depending on where they are in their use or recovery journey. Just over half are in favor of harm reduction-based housing, with supplies nearby or on-site, but the rest are opposed to this as it would be unsafe for their recovery. Regarding HIV-specific housing, participants are not opposed to increased housing resources dedicated for PWH but are opposed to housing options or resources that are

recognizable as HIV-specific, as this is stigmatizing. Similarly, most participants either do not strongly favor culturally specific housing or are opposed to it because they find it unnecessary or exclusionary.

Finally, there are some elements that participants want related to transitional housing and encampments. Participants want more transitional housing options with greater safety, independence, privacy, and hands-on support around finding permanent housing. They also highlighted that encampments often provide a sense of community, independence, and safety that they want reflected in housing.

While these data point to general trends in what participants want from housing, it is also important to note that they can want specific elements in housing that are unique to their individual backgrounds and needs. These elements can sometimes conflict with what others want from housing. In this context, housing programs and processes should not only be generally desirable but also as flexible and accommodating as possible around people's unique needs given how central desirability is to housing.

Discussion and recommendations

The cyclical relationship between barriers and the synergistic relationship between facilitators indicate that it may be most effective to address barriers simultaneously and connect clients to multiple facilitators at once. In other words, there needs to be a holistic, coordinated approach to addressing barriers and uplifting facilitators while centering desirability.

Holistically addressing barriers will require dismantling structural barriers to care, such as the war on drugs, criminalization of homelessness, and structural racism. While participants did not explicitly speak to these structural factors as barriers, it is clear from their interviews that their individual barriers are heavily impacted and even directly caused by these structural factors. Addressing these structural issues will require incremental, sustained changes in all areas across long periods of time, and it is important for a low-barrier housing model to proactively consider and address these barriers.

While addressing barriers, it is also equally important to improve the accessibility of facilitators. As explored above, participants often need to be connected to multiple facilitators at once to move along the housing continuum. Here, improving systemwide coordination of care and streamlining processes can make facilitators more accessible to participants and thus make them more likely and able to engage with them. From the data, improving coordination of care can be done by using low-barrier models, improving collaboration between agencies, and prioritizing consistent long-term engagement with clients. With regards to streamlining processes, capitalizing on the synergistic relationship between facilitators and reducing bureaucratic burdens on participants can help speed up the housing timeline.

Underscoring these recommendations is trust. Participants reiterated that their engagement with services was predicated on whether they trusted providers. Accordingly, it is important to focus on (re)building trust with this population, which can be done by allowing clients to be leaders in their care, providing them with the information they need to make informed decisions, meeting them where they are, and adopting a harm reduction approach at all levels. It is often more important to first focus on building trust than it is to focus on immediately connecting people to services, as having trust creates a solid foundation for participants to engage in services and eventually get connected to housing.

Finally, the last recommendation is to center desirability. As established previously, participants are less likely to access or maintain housing that they find undesirable, and more likely to access and maintain housing that they do find desirable. This shows that desirability is a key barrier and facilitator to housing and must be incorporated in a low-barrier housing model. While there are general trends in what participants consider desirable, it is also important to note that participants have unique, sometimes conflicting needs that affect what they want from housing. It is thus important to not only make housing generally desirable for clients, but also flexible around and tailored to their individual needs.

Limitations

These data and results primarily apply to the research questions and populations included in this project. While many of these results may apply to other populations or research questions, generalization is not recommended; use caution if doing so. Additionally, the inclusion criteria for this project were established before the HIV outbreak subclusters were created, which limits the possibility of stratifying results. There are also small counts for some of the subgroups in this sample, which limits generalizability. Furthermore, due to the recruitment methodology, all participants were engaged in care in some capacity, which creates an inherent bias. Finally, the findings are based on participants' self-reported experiences, which may affect the completeness of results.

Conclusion

The data show that the final low-barrier housing model should address common barriers to care by simultaneously targeting barriers, disrupting the cyclical relationship between barriers, and connecting clients to multiple facilitators at once. It should also invest in and increase the accessibility of facilitators by improving coordination of care, streamlining processes, and fostering trust between clients and systems. Above all, the model should center desirability; it should include elements that are generally considered desirable and adopt a flexible, client-centered approach. The findings from this project affirm that housing is not only central to the Hennepin and Ramsey counties HIV outbreak but also a human right. Incorporating the voices of PWH in these efforts is an important step in both the housing-first response to the HIV outbreak and the push for greater health equity for PWH in Hennepin County.

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