

Conversation Cafés and Statewide Coordinated Statement of Need (SCSN) Survey *Update*

HIV Planning Group Meeting
January 22, 2026

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Presentation Outline

- Conversation Cafés
 - Update on process, outreach, and findings
- SCSN Needs Assessment Survey
 - Update on process, recruitment, and findings
- Questions, comments

Conversation Cafés

Conversation Cafés - Overview

Stakeholder Engagement Plan: Approved by the HPG in July 2024

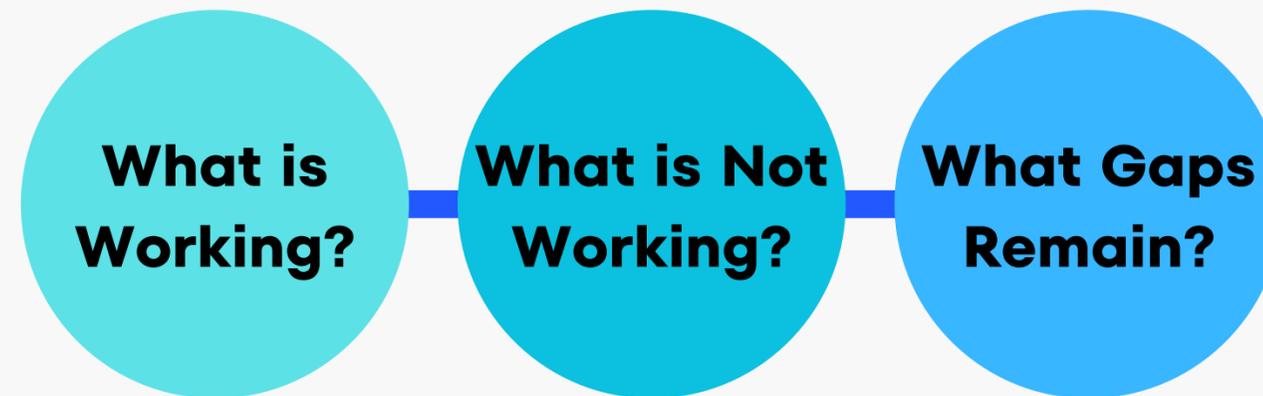
Purpose: Focus Groups were held across the state to provide participants an opportunity to voice their opinions about HIV medical care and support services.

Specific Goals:

- help identify gaps
- improve existing services
- guide future planning and priorities

Conversation Cafés - Process

- Partnered with local organizations, who:
 - Gave essential insight into their regions and clients.
 - Provided meeting space and assistance with planning.
 - Determined logistics, including whether to host sessions for Providers.
- Sessions were facilitated with a focus group guide - with three main questions:



- Post-Its were used to give participants time to brainstorm independently.
- Incentives were provided to thank participants for their time.

Conversation Cafés - Recruitment

- Primarily facilitated by partner organizations and area providers.
- Advertising flyers were provided for distribution.
- Social media advertising was also piloted for virtual sessions.

Greatest recruiting success came when providers, particularly case managers, provided direct invitations to clients.

Join us at the Conversation Café!
Share your experience with HIV care, help us better understand the needs of people living with HIV

Refreshments provided. Participants will be compensated for their time.

RSVP to Attend!
<https://tinyurl.com/HIVConvoCafe>
Thursday, October 23rd
2:30pm to 5pm
Hamilton Health Center
110 S 17th Street, Harrisburg, PA

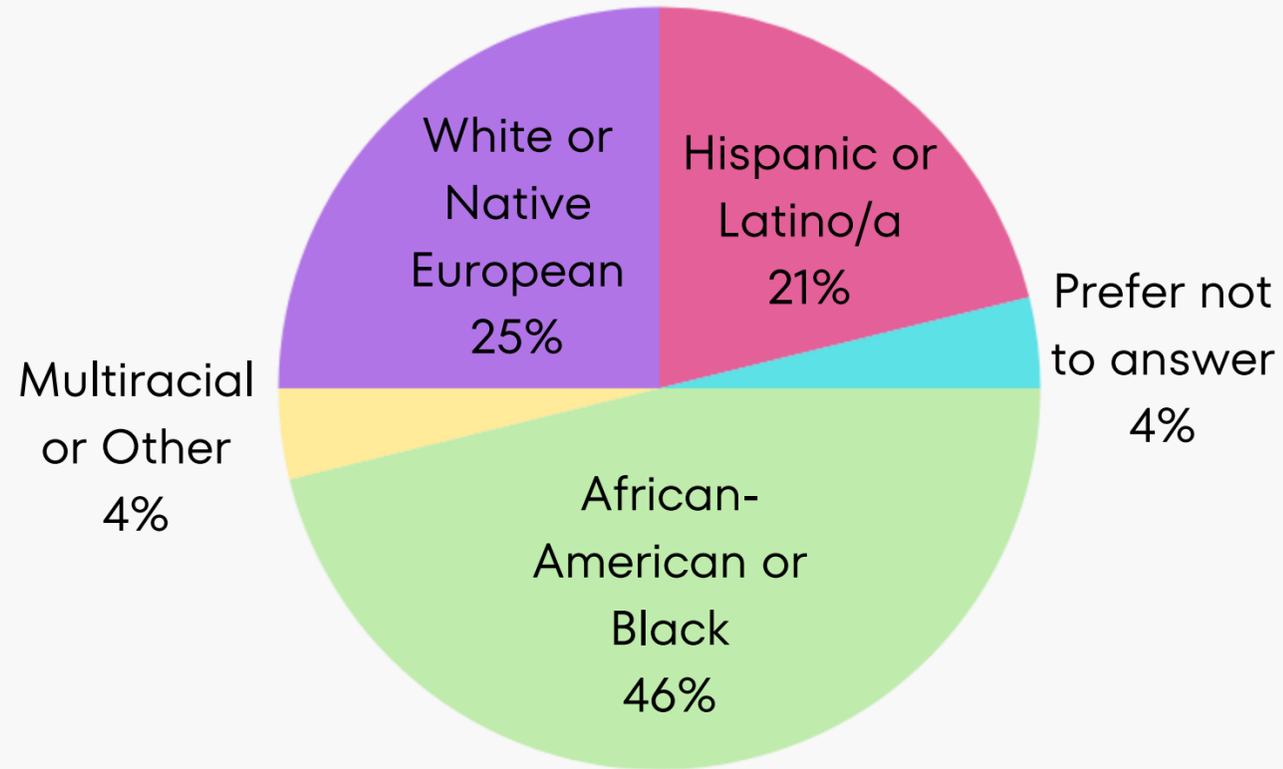
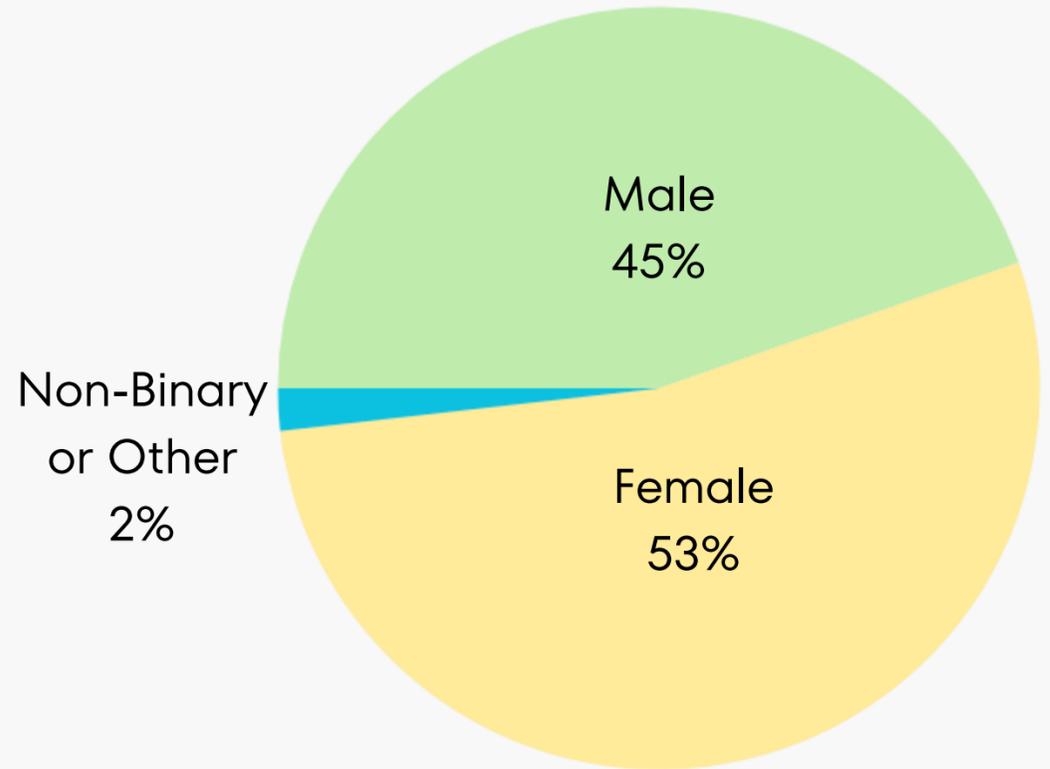
Contact Cheryl Choice with any questions: c.choice@pitt.edu

The Conversation Café will take place in both English and Spanish.

University of Pittsburgh

Conversation Cafés - Who We Spoke To

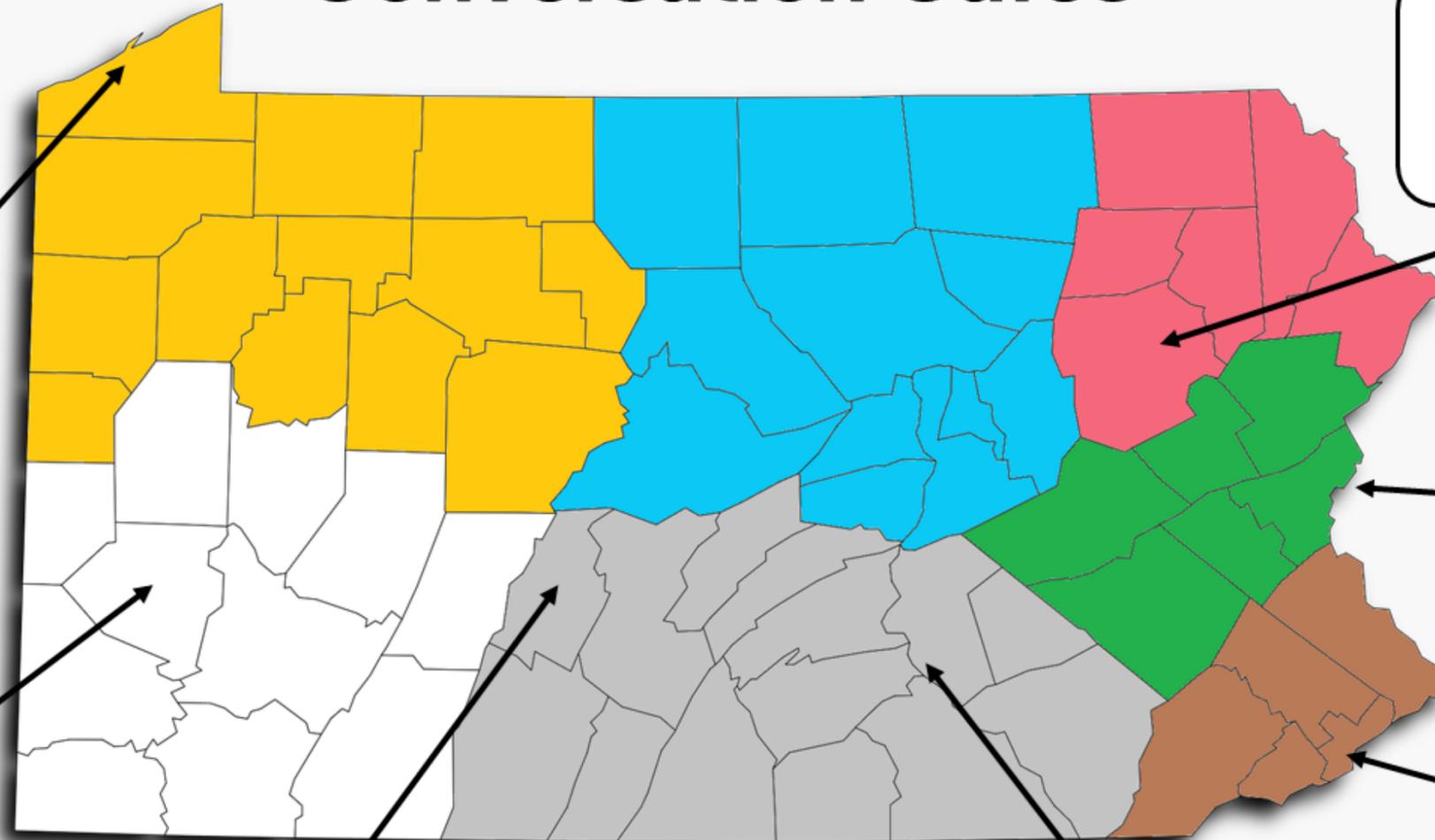
- **90 Stakeholders**
 - Including, 1 session in Spanish



*Demographic information is not available for all participants

Conversation Cafés - Who We Spoke To

Conversation Cafés



Erie
August 25, 2025
Erie County Department of Health
PA Thrive

7 Participants:
2 Clients
5 Providers

Pittsburgh
June 20, 2024
Shepherd Wellness Community

20 Participants

Altoona
November 13, 2024
Altoona Intervention Project (AIP)

15 Participants:
6 AIP Clients
5 Community Members
4 AIP Staff/Providers

Harrisburg
October 23, 2025
Hamilton Health Center

2 Participants

Wilkes-Barre
August 12, 2025
United Way

12 Participants

Mideast Virtual
November 7 & 11, 2025
Zoom

8 Participants:
7 Participated in Spanish

Philadelphia
January 29, 2025
Philadelphia Fight

26 Participants

Conversation Cafés - Major Topics

Topics Discussed in over 50% of Sessions

- Provider/Client Relationships
- Case Management
- Opportunities to Provide Community HIV Education
- Medication Quality/Undetectable Status
- One Stop Shops and Care Coordination
- Support Groups
- Community Strength
- HIV Awareness
- Support with Disclosure
- Political Climate
- Client Knowledge of Services
- Access to services
- Stigma, including from Providers
- Mental Health Services

Conversation Cafés - Awareness and Stigma

Participants expressed the need to improve:

- Mental health services,
- HIV awareness
- Anti-stigma efforts

It takes time. It definitely takes time. But I mean, having those **mental health services and that support** when you first are diagnosed--**is critical**.

It's like if you open the book that you wrote, you knew you were the author. You knew what you wrote in there. You don't have to tell anyone that. **When you hand them that book and they don't open it and look at it**, they're like, but I'm telling you, this is what it is. **Did you even read it? You didn't even read it because you're not listening to me.** That's how they make you feel.

...**stigma**, it's still out there and it shouldn't be.

Conversation Cafés - Knowledge, Access, and Uncertainty

Gaps in knowledge of and access to services exist

Like having a navigator to help them navigate.

There are many people who don't know how to deal with— the hospital system.

...the thing that's wrong for me is **not knowing that there's programs** out here.

I explained SPBP to them and they had no idea.

And that's what got me. ...just because they're not [seeing a Ryan White specific provider] doesn't mean they can't benefit from a program like SPBP.

...so I almost got in a panic. **What the hell gunna happen with me?**

Uncertainty about the future was a common concern

Are we in trouble, or are we possibly in trouble?" Or I just don't know what to believe or what to think. I'm assuming everyone's dealing with it, and people are figuring that out for me. **So, I don't even know if it isn't working well.**

Conversation Cafés - Care Coordination

Care Coordination is Valued:

- Case Management
- One Stop Shops

...**case management, really helps a lot.** You know, whenever anything happens, my case manager, telephone, like if he doesn't pick up, he calls me right back...

It's very encouraged to reach out if you ever need anything. *And I know exactly who I can reach out to about what. I'm in a good spot right now, but I didn't have a job for a year. And they took care of me through that whole thing, let me buy groceries and stuff like that.*

...this [agency] **will follow you on other needs that you have.** And I understand that for the clients that need it, there might be housing, ...food, things like that. ...a care package to take home. And that is... because some of the clients don't have the basic needs. *And you get a good sandwich.*

Medication quality was frequently discussed as a success

...**since I've been taking them my quality of life has improved a lot, feeling better, feeling in a more comfortable state of health.** *They are always very caring with us in that clinic. I don't know if it's because it's our clinic, but they always give good treatment."*

Conversation Cafés - Relationships and Community Building



Communities are a strength:

- Provider/client relationships
- Support Groups
- Providing HIV education to the broader community

... finally, after 30-something years. I joined a group. **And they turned out to be wonderful.**

There is a lot of love and a lot of respect there. **We are a family.** We see each other, we hug each other, "Hello, how are you?", we communicate. Because what there is in that clinic is a lot of love.

[Support groups work] because **not only are we learning, but we go out there.** Like, I'll go from here and I'll talk to my family... I'll go to my friends, I'll talk to them...

... people got to tell their stories and share their testimonies of where they've been and where they've come from, where they are now. **It's just, it's a huge help.** *Because we think we're alone, but you don't ever know who you're standing by anymore.*



Conversation Cafés - Next Steps

- Topics raised during Conversation Cafés will be used to help inform the 2027-2031 Integrated HIV Prevention and Care Plan (IHPCP).
- We are busy brainstorming new Stakeholder Engagement activities and would love to hear your thoughts and ideas!

Questions?
Comments?

2025 Statewide Coordinated Statement of Need (SCSN) Survey

2025 State-Wide Coordinated Needs Assessment Survey

Overview

- **Pennsylvania (PA)-wide survey** to collect input and understand current HIV medical care and support services throughout the state. Survey information will **help identify gaps, improve existing services, and guide future planning and priorities.**
- Survey was developed by the Division and HIV Prevention and Care Project (HPCP/Pitt) with input and revisions from HPG
- Three potential survey paths where respondents selected the option that best reflected their experience with HIV medical care or support services in PA
 - a. Receive HIV medical care or support services in PA
 - b. Provide HIV medical care or support services in PA
 - c. Both receive and provide HIV medical care or support services in PA
- Survey was voluntary, anonymous, completed online, and took 15-20 minutes to complete. Survey included 15 write-in response questions to capture additional context and understanding around respondents' perspectives and experiences.

2025 State-Wide Coordinated Needs Assessment Survey

Client Survey

Respondents receive HIV medical care or support services in Pennsylvania

Participant Characteristics

Collect client background information (11 questions)

HIV Healthcare Experience

Assess experience and relationship with HIV provider and case manager (13 questions)

HIV Service Utilization

Examine use of Ryan White services and other medical/support services (5 questions)

Health and Well-Being

Assess overall health and well-being, and other factors that may impact health outcomes (7 questions)

HIV Healthcare Access

Examine factors impacting HIV healthcare access (6 questions)

HIV History and Treatment

Assess HIV treatment history and medical adherence (12 questions)

2025 State-Wide Coordinated Needs Assessment Survey

Provider Survey

Respondents provide HIV medical care or support services in Pennsylvania

Participant Characteristics

Collect provider background information (7 questions)

Organization Characteristics

Collect information on organization (5 questions)

Job Satisfaction

Explore attitudes around current position and role in HIV care and services (3 questions)

Services Currently Offered

Assess availability of comprehensive HIV care and services (5 questions)

Barriers to Providing HIV Services

Explore barriers to providing HIV medical care and services at current organization (6 questions)

Barriers to Clients Receiving HIV Services

Explore provider perspective on barriers to clients receiving HIV medical care and services at current organization (3 questions)

Changes to Current HIV Services

Explore ideas for strengthening current HIV services at organization and interest in education training or capacity-building support (2 questions)

HIV Planning and Coordination

Explore awareness and involvement in state HIV planning and coordination and use of IHPCP (7 questions)

2025 State-Wide Coordinated Needs Assessment Survey

Recruitment and Implementation

- Outreach and recruitment led by DOH and HPCP
 - Involved a variety of approaches, including SPBP client account messages, emails, in-person at other stakeholder outreach events, on hivhealthpa.com website
 - Access to survey via link, QR codes, flyers (electronic, printed)
- Survey was available to complete for three months (June 25 to September 30, 2025)
- Resource guide available upon survey completion



Flyers distributed via emails and in-person

2025 State-Wide Coordinated Needs Assessment Survey

Summary of Respondents

Participant Demographics, total sample		Client (n=90) n (%)	Provider (n=116) n (%)
Age, years	Mean (range)	60.4 (26 - 79)	44.7 (23 - 71)
Race*			
	Asian	2 (2.30)	3 (2.97)
	Black or African American	15 (17.2)	8 (7.92)
	White	61 (70.1)	74 (73.3)
	Multiracial	3 (3.45)	4 (3.96)
	Other [ex: Hispanic, South Asian, American]	3 (3.45)	7 (6.93)
Ethnicity			
	Hispanic or Latino/a	9 (10.3)	10 (9.90)
	Not Hispanic or Latino/a	76 (87.4)	86 (85.2)

Total numbers may not add up to 100 due to missing values or prefer not to say response selected

** Respondents could select more than one option*

2025 State-Wide Coordinated Needs Assessment Survey

Summary of Respondents

Participant Demographics, total sample		
	Client (n=90) n (%)	Provider (n=116) n (%)
PA Region of HIV Medical Care		
Northwest	2 (2.30)	5 (4.76)
Southwest	24 (27.6)	17 (16.2)
Northcentral	5 (5.75)	9 (8.57)
Southcentral	19 (21.8)	27 (25.7)
Northeast	1 (1.15)	7 (6.67)
Mideast	7 (8.05)	14 (13.3)
Southeast	29 (33.3)	26 (24.8)

Total numbers may not add up to 100 due to missing values or prefer not to say response selected

2025 State-Wide Coordinated Needs Assessment Survey

Gaps, Needs, and Priorities among Clients (N=90)

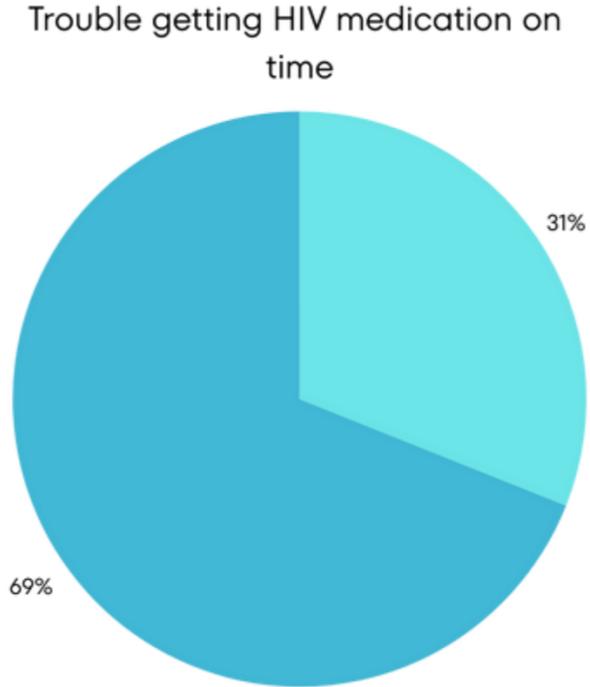
Barriers faced when seeking HIV healthcare (n=36)*	n (%)
Co-pay/co-insurance costs	14 (38.9)
Inconvenient appointment times	9 (25.0)
Transportation issues	8 (22.2)
Lack of personal time off	8 (22.2)
Finding provider covered by insurance	7 (19.4)
Confidentiality concerns	7 (19.4)
Finding provider nearby	5 (13.9)
Finding a provider or accessing health services, generally	3 (8.33)
Long wait times	3 (8.33)
Finding provider knowledgeable about HIV treatment	2 (5.56)
Translation services needed	1 (2.78)
Other [ex: coordinating with provider and specialty pharmacies, dental care, rude and dishonest provider terrible to work with, miscommunication with health system, not able to get health insurance, lack of case management, lack of trauma-informed care, provider not offering Cabenuva]	11 (30.5)

* Respondents could select more than one response

2025 State-Wide Coordinated Needs Assessment Survey

Gaps, Needs, and Priorities among Clients (N=90)

In the past 12 months...



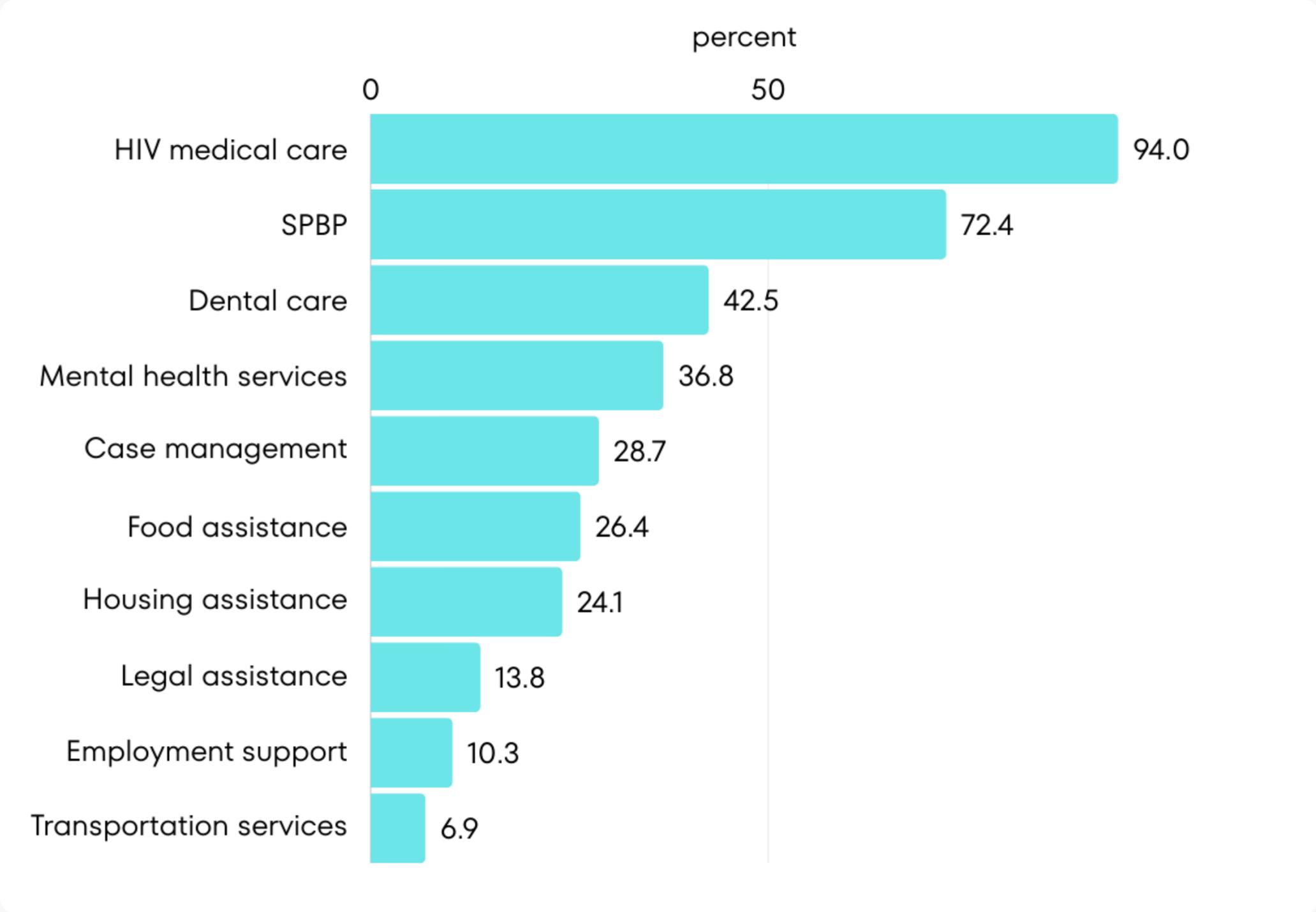
Barriers faced when getting HIV medication on time (n=29)*	n (%)
Pharmacy delays	11 (37.9)
Insurance issues	10 (34.5)
Multiple pharmacies required	5 (17.2)
Cost	2 (6.89)
Other [in hospital]	1 (3.45)

* Respondents could select more than one response

2025 State-Wide Coordinated Needs Assessment Survey

Gaps, Needs, and Priorities among Clients (N=90)

Top priorities for health and well-being*



* respondents were able to select up to 5 options



“What is the most immediate HIV care need for PLWH in PA?”

80 participant responses

Access to HIV Medications

Need for access to HIV medications, which may include availability of current/most effective medication, affordability, and other things related to access or ability to obtain medications (e.g., expensive pharmaceutical, prescriptions are expensive)

Comprehensive Health Insurance

Need for medical care and prescription insurance or financial assistance and concerns of losing access due to federal changes

HIV Medical Care

Need for HIV medical care broadly as an immediate HIV care need, including a need for improved access in underserved rural settings

2025 State-Wide Coordinated Needs Assessment Survey



Access to HIV Medications

“The most immediate HIV care need is access to **affordable drug treatment.**” (Client, age 68)

Comprehensive Health Insurance

“Easy access to insurance, full coverage, stop red tape of denials/declines in approvals.” (Client, age 63)

“**Gaps in coverage** delay ART [antiretroviral therapy] initiation; SPBP has eligibility thresholds.” (Client, age 46)

“The most immediate need for HIV care would be **insurance** to help cover the cost of frequent doctor visits, procedures, labs, etc. Also, there needs to be a **way to link the other issues** that HIV patients experience to the virus.” (Client, age 37)

“**Help navigating the complicated health care and insurance systems**, as well as knowledge of what help is available and what benefits we're entitled to.” (Client, age 39)

HIV Medical Care

“**Access to good HIV medical care in the middle portion** (outside of Pittsburgh and Philadelphia) of the Commonwealth.” (Client, age 64)

“Unfortunately, with what fears that the Trump administration cause because of his lack of compassion, and need to cut services, along with his degrading of the LGBTQ population, to **be able to receive immediate HIV care** seems to be nearly as concerning in itself.” (Client, age 63)



2025 State-Wide Coordinated Needs Assessment Survey

Gaps, Needs, and Priorities among Providers (N=116)

	<u>n (%)</u>
Top priorities with greatest impact on providing best HIV care (selected up to 5)	
Housing assistance	74 (69.8)
Case management support	54 (50.9)
Medical insurance	50 (47.2)
Mental health support	50 (47.2)
Financial assistance	44 (41.5)
Transportation	43 (40.6)
Trauma-informed care	40 (37.7)
Social services	30 (28.3)
Access to medications	30 (28.3)
Food services	27 (25.5)
Employment services	21 (19.8)
Substance use services	18 (16.9)
Other [ex: immigration assistance, reentry/legal support, flexible funding]	7 (6.60)

** Respondents could select more than one option, and total numbers do not add up to 100*

2025 State-Wide Coordinated Needs Assessment Survey

Gaps, Needs, and Priorities among Providers (N=116)

	<u>n (%)</u>
Barriers to clients accessing HIV care*	
Mental health challenges	80 (76.9)
Housing instability or homelessness	80 (76.9)
Stigma or fear of disclosure	69 (66.4)
Substance use	61 (58.7)
Transportation difficulties	61 (58.7)
Difficulty navigating the healthcare system	56 (53.9)
Distrust of healthcare providers or medical system	47 (45.2)
Language barriers or low health literacy	45 (43.3)
Lack of health insurance or coverage issues	39 (37.5)
High cost of medication or healthcare services	26 (25.0)
Employment services	25 (24.0)
Other [ex: intimate partner violence, waitlist, immigration support]	8 (7.69)

** Respondents could select more than one option, and total numbers do not add up to 100*

2025 State-Wide Coordinated Needs Assessment Survey

Gaps, Needs, and Priorities among Providers (N=116)

	<u>n (%)</u>
Challenges to providing HIV care*	
Lack of funding	57 (55.3)
Lack of staff	33 (32.0)
Complicated insurance process	33 (32.0)
Insufficient clinic resources	29 (28.2)
Minimal clinic / administrative support	23 (22.3)
Insufficient appointment time	16 (5.5)
Non-standardized process	10 (9.71)
Limited HIV training	8(7.77)
Provider bias and misconception	7 (6.80)
Lack of provider comfort	6 (5.83)
Limited provider knowledge	3 (2.91)
Other [ex: lack of flexibility in funding, lack of clinic infrastructure to better integrate services, complex patient needs that extend beyond medical, lack of designated space to provide services]	19 (18.5)

** Respondents could select more than one option, and total numbers do not add up to 100*



“What do you believe is the greatest unmet need(s) of your patients/clients ?”

69 participant responses

Key Structural Factors

Key structural factors of housing security, economic stability, adequate medical insurance, transportation, and food security as the greatest unmet need impacting HIV care of their clients.

Complexity and Separation of Current Systems

Complex and separate insurance, medical, pharmacy, and support service systems directly impact client treatment continuity, adherence, health outcomes.

Whole Person Comprehensive Care Approach

Need for a whole person comprehensive care approach since other factors impact HIV care and the importance of case managers and peer support in HIV.

2025 State-Wide Coordinated Needs Assessment Survey



Key Structural Factors

“The greatest unmet need of my clients—by far—is **stable, affordable housing**. Without a safe and consistent place to live, everything else becomes secondary: medical appointments are missed, medications go unfilled, and mental health deteriorates. For many of my clients living with HIV, housing instability is the single biggest barrier to maintaining viral suppression and overall well-being.” (Case manager, provider-client)

“Even when clients are housed and medically stable, they often struggle with **chronic poverty**. There is a huge unmet need for job training, education, and employment support tailored to people living with HIV—especially for those with a history of incarceration or limited work history. Without these supports, many remain stuck in cycles of dependence and instability.” (Case manager, provider-client)

Complexity and Separation of Current Systems

“**Complex systems** lead to delays in linking new diagnoses to care without strong case management. Fear of discrimination deters testing and continuing care, especially in non-urban areas.” (Case manager, provider-client)

Whole Person Comprehensive Care Approach

“We need more staff to meet the diverse needs of our clients. Client needs are different, complex, and ever-evolving (especially with changes in government currently). **The more social services/case management/social work staff we have to support clients in navigating these issues, the better of clients will be.**” (Case manager)

“Case management....agencies are understaffed and unable to meet the demand and when you do get a case manager assigned it is near impossible to reach/access them.” (Health programming, provider-client)



2025 State-Wide Coordinated Needs Assessment Survey

Next Steps

- Findings will be integrated into the 2027-2031 IHPCP
- Unable to share all analyses and findings today, but aim for this to be an ongoing conversation with an opportunity to share additional information, including specific areas as requested

Questions?
Comments?

Extra Slides

2025 State-Wide Coordinated Needs Assessment Survey

Advertisement and Recruitment Approach for SCSN Survey Completion

Approach	Description
SPBP	<ul style="list-style-type: none">• Distributed to SPBP email listserv (7/14) with a reminder notification (8/4)
Emails	<ul style="list-style-type: none">• Regional grantee email list (6/26) with several reminder emails, as well as announcements DOH-hosted listening sessions and other virtual meetings• HPG member list (6/26) with several reminder emails and inclusion in July meeting announcements• PPA email list (7/24)• Ryan White Part B email list (8/5) with a reminder email (9/4)• HPCP Capacity-Building participants (8/21) with a reminder email (9/4)
In-person	<ul style="list-style-type: none">• Printed flyers distributed at in-person conversation Cafes (Wilkes-Barre, 8/12; Erie, 8/26) and folks were encouraged to take several to distribute• Flyers were included as PDFs in all emails where recipients were encouraged to print and post in organization or share with colleagues and clients who voices are also critical to this work
Website	<ul style="list-style-type: none">• HPCP monitored website, hivhealthpa.com

2025 State-Wide Coordinated Needs Assessment Survey

Client Characteristics

Client Characteristics (N=90)		n(%)
Primary health insurance*		
SPBP		43 (49.4)
Medicare		41 (47.1)
Through employer		29 (33.3)
Medicaid or Medical Assistance		21 (24.1)
Other [Medigap, purchased on own]		6 (6.90)
Purchased through Marketplace (healthcare.gov)		4 (4.60)
Through other's employer		2 (2.30)
Employment Status		
Employed full-time (40 hrs./week)		30 (34.5)
Employed part-time (less than 40 hrs./week)		12 (13.8)
Unemployed, looking for work		3 (3.45)
Unemployed, not looking for work		2 (2.30)
Unable to work due to disability		9 (10.3)
Retired		30 (34.5)
Yearly Income		
Less than \$10,000 per year		5 (5.75)
\$10,000 - \$29,999 per year		27 (31.0)
\$30,000 - \$49,999 per year		20 (22.9)
\$50,000 - \$69,999 per year		11 (12.6)
\$70,000 or more per year		11 (12.6)
Not sure		1 (1.15)
Education Status		
Some high school but did not graduate		1 (1.15)
High school graduate or GED completion		15 (17.2)
Some college, 2-year degree or technical school		26 (29.9)
4-year college graduate		16 (18.4)
More than 4-year college degree		27 (31.0)
Housing Status		
Stable housing		77 (88.5)
Temporary housing		2 (2.30)
Unstably housed or unhoused		3 (3.45)
Other [ex: currently moving]		2 (2.30)

In the past 12 months ...

Mental health stress experienced

A lot of stress	28 (32.2)
A moderate amount of stress	29 (33.3)
Relatively little stress	19 (21.8)
Almost no stress at all	11 (12.6)

Had trouble paying for* (n=44)

Loan or other debts	26 (59.1)
Utilities	23 (52.3)
Food	22 (50.0)
Housing	16 (36.4)
Medication or other medical needs	11 (25.0)
Transportation	7 (15.9)
Other [ex: daily living costs]	2 (4.55)

Total numbers may not add up to 100 due to missing values

** Respondents could select more than one option*

2025 State-Wide Coordinated Needs Assessment Survey

Provider Characteristics

Provider Characteristics (N=116)		n(%)
Primary Role		
	Nurse Practitioner	10 (9.26)
	Doctor	7 (6.48)
	Case manager	36 (33.3)
	Navigator	3 (2.78)
	Other health care specialist (dietician, mental health specialist)	9 (8.33)
	Programming (educator, testing, prevention, outreach)	11 (10.2)
	Administration (front desk, fiscal, leadership)	32 (29.6)
Type of organization		
	Hospital	26 (23.8)
	Private clinic	10 (9.17)
	Public health department	7 (6.42)
	Community health center	16 (14.7)
	Community-based organization (CBO)	40 (36.7)
	Other [ex: allocator of funding, RW Part B, university]	10 (9.17)
No. of Years in Current Role		
	Less than 1 year	10 (9.26)
	1 to 3 years	33 (30.6)
	4 to 6 years	16 (14.8)
	7 to 10 years	11 (10.2)
	More than 10 years	38 (35.2)
No. of Years Working in HIV Field		
	Less than 1 year	6 (5.83)
	1 to 3 years	26 (25.2)
	4 to 6 years	18 (17.5)
	7 to 10 years	8 (7.77)
	More than 10 years	45 (43.7)
Percent of Time in Direct Client Service/Engagement		
	None of the time	17 (15.6)
	About 25% of time	29 (26.6)
	About 50% of time	17 (15.6)
	About 75% of time	30 (27.5)
	All of my time	16 (14.7)

Total numbers may not add up to 100 due to missing values

* Respondents could select more than one option