







Person-Centred Care Advocacy Academy, southern United States, 2025 - Event report

An interactive workshop to explore person-centred care approaches to service delivery

6 to 8 April 2025 Atlanta, United States

In partnership with:



The Person-Centred Care programme of IAS – the International AIDS Society – is implemented with financial support from, and in collaboration with, Gilead Sciences. The IAS has full control over all the activities and decisions relating to, and forming part of, the Person-Centred Care programme.

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Executive summary

This second Person-Centred Care Advocacy Academy, organized by IAS – the International AIDS Society – was held in Atlanta from 6 to 8 April 2025. We would like to warmly thank our organizing partners, the Southern AIDS Coalition and the Community Education Group for helping us organize such an important learning journey for all participants and organizers. We also thank our collaborating partner, Gilead Sciences, for its kind support. This event convened 17 fellows and four observers from eight southern US states. Four faculty members, 17 guests and keynote speakers and three IAS staff members supported the fellows in their exploration of person-centred care approaches. Participants explored the core principles of person-centred care within the HIV response, delved into several case studies exploring implementation of person-centred care strategies, and visited local healthcare facilities to learn more about implementation in real-world settings.



The objectives of the advocacy academy were to:

- Provide training and skills building on current person-centred care approaches to service delivery and existing barriers to their implementation.
- Develop tools to disseminate information on person-centred approaches and their importance to the wider community, including programme managers, the media and policy makers.
- Create opportunities to interact with leading researchers and advocates in the field.
- Guide participants to identify service delivery gaps in their communities and develop action plans to overcome these challenges.

A post-event feedback survey confirmed that the academy met the expectations of all of the participants. Of the 17 fellows who attended, 15 responded to the pre-academy survey and 13 responded to the post-event survey. Nearly all (85%) of the survey respondents confirmed that the academy exceeded their expectations. Importantly, all of the survey respondents stated that their participation in the academy improved their ability to engage in the HIV response. After the academy, 92% of the survey respondents reported a good or excellent understanding of person-centred care approaches compared to 73% prior to the academy. After the academy, 54% of the survey respondents reported an excellent understanding of person-centred care approaches compared with 0% before the academy. Also after the academy, 69% of the survey respondents reported feeling extremely confident about implementing a project to enhance person-centred care approaches in their setting compared with 0% before the academy.

I am extremely grateful for this experience! Thank you for entrusting me with this knowledge, as well as the charge to be a change agent within my sphere for the betterment of people living with HIV.

– Academy participant

Introduction to person-centred care

What is person-centred care (PCC)?

Elvin Geng (Washington University of St. Louis, United States) introduced the concept of person-centred care as approaches and practices in which the person is seen as a whole, with many levels of needs and goals, and those needs shaped by their personal social determinants of health¹. It is an approach in which a person is placed at the centre of decisions and actively participates in their health treatment in close cooperation with healthcare providers to achieve the best outcome. For people living with and affected by HIV, this means providing a multidisciplinary, integrated and long-term-focused approach to care that is responsive to their evolving needs, priorities and preferences.

We define person-centred care in the HIV response as:

- Being respectful of, and responsive to, the needs, experiences, values and preferences of the individual² as a unique³ and whole person⁴
- Considering the complex health needs of a person (beyond only HIV treatment or prevention), their identity and the contexts in which they live, rather than focusing on the disease alone⁵
- Personalized, coordinated and enabling⁶ person-centred care empowers people on HIV treatment or people seeking HIV prevention services
- Focused on the person receiving care, the person providing the care, and the relationship between them
- Treating people living with HIV or vulnerable to HIV acquisition as equal partners in planning, developing and monitoring care

PCC approaches can be used in all settings related to client care; they allow individuals to be part of the planning, developing and monitoring of their treatment and medical care. This model of care differs from the traditional approach where healthcare providers are viewed as the experts, making decisions for their "patients" with limited input from the clients themselves. The goal of PCC is to establish cooperation between the client, healthcare providers and caregivers to ensure that care is designed to consider the individual's unique circumstances⁷.

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Why do we need person-centred care in the HIV response?

Lifelong engagement with HIV treatment for people living with HIV is crucial at this stage of the HIV pandemic to ensure sustained viral suppression and quality of life, a healthy population of people living with HIV, and a reduction in transmission. By healthcare providers focusing on kindness and connection, rather than "caring rudely", people living with HIV will feel more welcome and more comfortable engaging in HIV treatment over their life course. The destigmatization of HIV prevention and testing, as well as increased access to a choice of effective HIV prevention methods, are also crucial to reduce rates of HIV acquisitions.

By putting people at the centre of their care:

- Quality of care is improved.
- Access to care for treatment and prevention is improved.
- People become more active in managing their health and preventing illness.
- Demands on health and social services are reduced.
- HIV acquisition rates are reduced.
- Linkage to care is supported.
- Retention in care is improved.
- Viral suppression rates are improved.

Research has shown that putting people at the centre of their care helps improve their health and reduces the burden of healthcare services and providers. Engaging clients in their care can lead to improved health literacy, self-management skills and overall satisfaction with healthcare services.

Why are "good" communication skills foundational for person-centred care?

The PCC approach places the person and their caregivers at the centre of decision making regarding health conditions and treatment processes. In doing so, it enhances effective communication and minimizes misunderstandings. Practices such as active listening, displaying genuine interest, respect and collaborating with clients enhance the quality of care provided¹⁰. Open communication between healthcare providers and clients or their families is vital for improving personal health outcomes. Adherence difficulties arise when clients do not have sufficient knowledge or information about their treatment and are excluded from decision making.

Taking the physical, emotional, socioeconomic and cultural needs of the person into consideration contributes towards more comprehensive care. Involving a family member or other support person creates a supportive environment and helps make sure the client understands the information.

Challenges of integrating a PCC approach in real-world settings are recognized, but by looking at examples of where PCC has been implemented, one can start thinking of a bottom-up approach to implementation in various settings where PCC is not implemented. A PCC approach should be part of a healthcare provider's actions and their way of being if we are to advocate for change and implementation of PCC¹¹.

Global guidance to support PCC

Clarice Pinto (<u>Department of Global HIV</u>, <u>Hepatitis and STI Programmes</u>, WHO) shared WHO's global guidance on people-centred and integrated health services which outlines a strategy for quality care and provides a comprehensive overview of supporting evidence and effective practices.

World Health Organization (WHO) normative guidance

Ensuring high-quality HIV care goes beyond the clinical aspects of diagnosis and treatment – it requires a fundamental shift towards people-centred care. This approach, endorsed by WHO, prioritizes the voices, needs and preferences of individuals, families and communities. By embracing people-centred care, health systems can deliver services that are more effective, accessible and equitable, especially for those living with or affected by HIV. WHO's global guidance on people-centred and integrated health services outlines a strategy for quality care and provides a comprehensive overview of supporting evidence and effective practices.

7.4 People-centred care

Good practice statement



Health systems should invest in people-centred practices and communication, including ongoing training, mentoring, supportive supervision and monitoring health-care workers, to improve the relationships between patients and health-care providers

Good practice statement

HIV programmes should:

- provide people-centred care that is focused and organized around the health needs, preferences and expectations
 of people and communities, upholding individual dignity and respect, especially for vulnerable populations;
- engage and support people and families to play an active role in their own care by informed decision-making;
- offer safe, acceptable and appropriate clinical and non-clinical services in a timely fashion, aiming to reduce morbidity and mortality associated with HIV infection and to improve health outcomes and quality of life in general;
- · promote the efficient and effective use of resources.

Good practice statement

Health-care workers should receive appropriate recurrent training and sensitization to ensure that they have the skills and understanding to provide services for adults and adolescents from key populations based on all persons' right to health, confidentiality and non-discrimination

Source: WHO Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach - 2021, p.38

"People-centred health services are an approach to care that consciously adopts the perspectives of individuals, families and communities and sees them as participants and beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways."

- Framework on integrated, people-centred health services - 2016³²

What should high-quality health services include?

To put people-centred care into practice, it is crucial to understand how quality-improvement strategies can be applied across different levels of the health system – from national policies to individual interactions between healthcare workers and clients. The HIV Quality Interventions Pyramid highlights these multi-level approaches, ensuring that high-quality care is embedded at every step of service delivery.

High-quality HIV care services should:

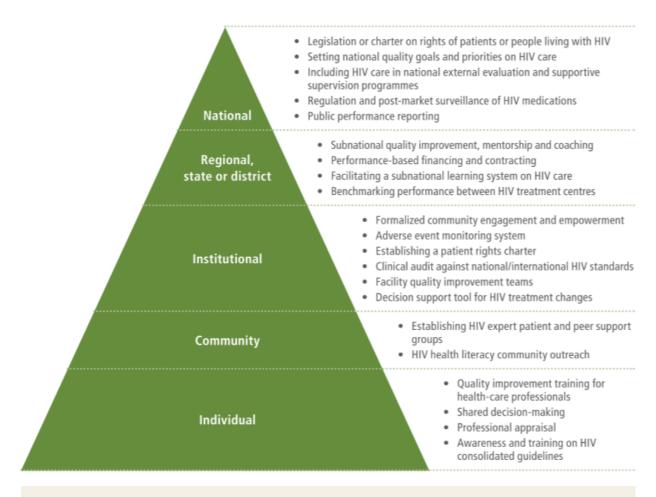
- Deliver person-centred care that focuses on the individual needs and preferences of clients.
- Provide safe, acceptable and appropriate clinical and non-clinical services, ensuring that all aspects of care meet high standards.
- Promote the efficient and effective use of resources, optimizing outcomes while minimizing waste.

Moreover, HIV services should concentrate on:

- Enhancing user experiences by valuing client feedback, ensuring that the voices of those receiving care are heard and acted upon
- Measuring and reducing stigma and discrimination, with a particular emphasis on addressing these issues within the healthcare system
- Cultivating and maintaining a culture of quality within programmes and organizations that deliver HIV services, ensuring ongoing improvement and excellence

HIV quality interventions pyramid

This framework illustrates how high-quality HIV services may be considered at different levels of the healthcare system.



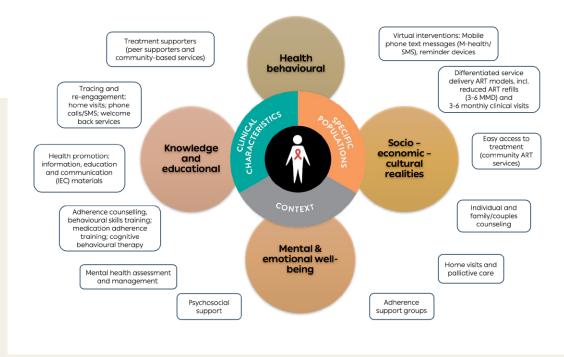
Source: WHO Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach - 2021, p.415

People at the centre

This vision of people-centred care is not only about clinical excellence, but also about recognizing a client's needs. WHO's guidance on adherence, retention and reengagement support underscores that tailoring interventions to each person's unique context is essential for achieving sustained, positive health outcomes. WHO emphasizes a person-centred care approach for HIV treatment, addressing four interconnected spheres: (1) behavioural; (2) socioeconomic; (3) educational; and (4) emotional/psychological support. This approach tailors interventions to each client's unique needs, incorporating activities like virtual reminders, differentiated service delivery, adherence education, psychosocial support and community engagement. By continuously adapting treatment plans, engaging family and community, and addressing barriers and stigma, care providers can enhance adherence and retention, promoting better long-term outcomes for clients.

Putting people first: Combination of adherence, retention, DSD and re-engagement support interventions will depend on context, clinical characteristics, specific client's needs and preferences





Source: Presentation from Clarice Pinto, WHO, at the PCC Advocacy Academy pre-meeting, 19 March 2025.

Conclusion

Ultimately, achieving high-quality, stigma-free, people-centred HIV care requires ongoing investment, collaboration across sectors and continuous quality improvement. By aligning policies, strengthening health worker capacity, fostering community participation and embedding stigma reduction into every aspect of care delivery, health systems can truly put people at the centre – improving not only health outcomes, but also the dignity, trust and experience of care for all.

Further reading:

- WHO Consolidated guidelines on HIV prevention, testing, treatment, service delivery
 and monitoring: recommendations for a public health approach 2021
- Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis,
 treatment and care for key populations 2022
- Global HIV, Hepatitis and STIs Programmes, including the Global health sector strategies 2022-2030 and the 2024 Report on progress and gaps
- WHO technical brief: Social participation for universal health coverage 2023
- Consolidated guidelines on differentiated HIV testing services 2024
- WHO technical brief: reducing HIV-related stigma and discrimination 2024
- Supporting re-engagement in HIV treatment services 2024

Priorities for PCC in the US South

Ronnie "Matt" Gravett (<u>University of Alabama at Birmingham</u>, United States) outlined the priorities for person-centred service delivery in the US South, reminding participants that person-centred care is rooted in activism and advocacy. He challenged healthcare providers to listen and respond to clients and their needs – that is, to advocate for their clients. He also called on all stakeholders in the HIV response to acknowledge and deconstruct the historical imbalances in client-provider relationships and to acknowledge the systemic determinants of the inequities inherent in the HIV pandemic in the southern United States. Matt proposed a "six Cs" framework for these priorities:

- 1. Collaboration: Client input, co-creation, community advisory boards and multidisciplinary teams of healthcare providers who "orbit" the client, rather than the other way around
- Communication: Transparency, clear policies and accessible, person-first language
- 3. Contextualization: Meeting people where they are, trauma-informed care and an approach that is broader than clinical needs, with an emphasis on wellness
- 4. Choice: Shared decision making, decentralized services and innovation
- 5. **Culture:** Healthcare worker values, affirming environments for clients and staff and a need for buy-in across all levels of the healthcare system
- 6. **Challenges:** Funding, policies that inhibit changes, lack of resources and lack of buy-in

Role of pharmacies in PCC prevention

Natalie Crawford (Rollins School of Public Health, Emory University, United States) presented on the opportunity for integrating pharmacies into the HIV prevention continuum to counter the insufficient number of PrEP clinics in the US South to meet the PrEP initiation needs of Black and Latino communities. This lack of investment in PrEP clinics has meant that there are significant race disparities among people who could benefit from PrEP: 94% of White people, 24% of Latino people and 13% of Black people who could benefit from PrEP had been prescribed PrEP in 2022 (Source: United States Centers for Disease Control and Prevention).

Natalie invited participants to review the extensive resources available at the RxEACH website, rxeach.org, and to join the advocacy efforts to expand access to HIV prevention services. RxEACH is a national coalition effort working to expand and sustain access to HIV prevention and linkage to care services in community pharmacies.

She presented data from a specific intervention, the PrEP Up Pharmacies study which demonstrated that pharmacies are viable solutions for reducing HIV and substance-related harms and that they could increase access for Black and Latino communities, especially in rural areas. She called for more investment to support sustained implementation and the development of implementation science frameworks and supportive policies to promote and sustain the integration of HIV prevention in pharmacies nationwide.

BRIDGING GAPS

Community pharmacies can play a crucial role in addressing geographic disparities in PrEP* access, particularly in underserved areas where access to HIV prevention services may be limited.

BOOSTING EQUITABLE ACCESSIBILITY

With over half of the 70,000 pharmacies in the U.S. in medically underserved areas, community pharmacies can serve as vital entry points for essential HIV prevention and linkage to care services.

EMPOWERING CHOICE

Individuals can choose to receive PrEP and other prevention services in a location that best suits their needs.

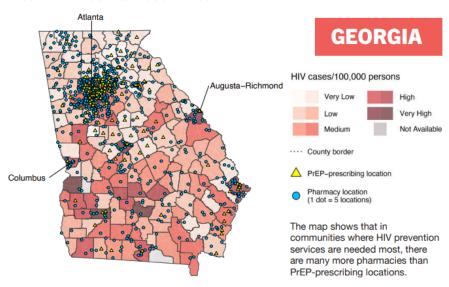
SAVES LIVES AND MONEY

Early intervention through PrEP offered by community pharmacies can significantly decrease HIV transmission rates, reducing lifetime healthcare costs.

*PrEP (Pre-Exposure Prophylaxis) is a medicine that greatly reduces the chances of getting HIV from sex or injection drug use.

LEVERAGING COMMUNITY PHARMACIES FOR HIV PREVENTION MATTERS

Pharmacies can improve access to HIV prevention services in communities that need it most.



Harrington, K. R. V., C. Chandra, D. I. Alohan, D. Cruz, H. N. Young, A. J. Siegler, and N. D. Crawford. "Examination of HIV Preexposure Prophylaxis Need, Availability, and Potential Pharmacy Integration in the Southeastern Us." JAMA Netw Open 6, no. 7 (Jul 3 2023): e2326028. https://dx.doi.org/10.1001/jamanetworkopen.2023.26028.



- 57% of the 70,000 U.S. pharmacies are in medically underserved areas.
- 85% of adults identify pharmacies as easy to access.
- 引고 Over 70% of adults support pharmacies administering HIV tests and 65% support pharmacies prescribing PrEP.

Session 1 Welcome to Atlanta



Tara Mansell (IAS, Switzerland) welcomed participants, emphasizing the importance of the event given recent changes and challenges to the HIV funding and political landscape. She encouraged open communication in this safe space for sharing opinions, feelings and experiences. Tara discussed the impact of recent US government changes on organizations and individuals, noting the gutting of institutions, attacks on science and funding cuts. Tara highlighted how these changes have affected organizations and individuals, stressing the importance of adapting to these new challenges. She emphasized the urgency of adopting person-centred care approaches to meet the needs of

people living with and affected by HIV. Tara expressed solidarity with the participants, highlighting the efforts of the IAS to advocate for the HIV response in top-tier media outlets. She encouraged participants to learn from each other and push the agenda forward, given the current climate.

Dafina Ward (Southern AIDS Coalition, United States) emphasized the importance of centring and caring for people in the South facing barriers related to HIV care and prevention. Dafina discussed the myriad of barriers faced by individuals in the South, including systemic and long-standing challenges that impact HIV care and prevention efforts.

A. Toni Young (Community Education Group, United States) discussed the need to reimagine a world without federal resources, emphasizing the importance of adapting to the current climate where traditional support may no longer be available. She also highlighted the need to act in concert with clients and adapt to changing community needs.

David Wyley Long (Southern AIDS Coalition, United States) facilitated a session where participants shared their current challenges and experiences. Participants highlighted various challenges, including funding cuts, access to care, the impact of government changes and the need for better education about, and resources for, person-centred care and addressing systemic challenges.

Keynote address Client advocate

Daniel Driffin (Project Manger, External Relations, HIV Vaccines Trial Nework, Fred Hutch, United States) addressed the significant disparities in HIV services across the Atlanta Metropolitan area, emphasizing the need for equitable care regardless of socioeconomic or geographic background. He explained that most specialized HIV healthcare providers are concentrated in central Atlanta; however, many clients who need these services reside in outlying areas with limited public transit, where transportation challenges severely limit access. This reliance on systems like the Metropolitan Atlanta Rapid Transit Authority (MARTA) correlates with lower viral suppression rates, highlighting the structural issues that disproportionately affect marginalized communities.



Daniel also pointed to the housing crisis as a major determinant of HIV health outcomes. The rapid loss of affordable housing in Atlanta has pushed vulnerable populations further from healthcare services, contributing to worsening outcomes - particularly for Black and Hispanic communities facing economic inequities. Median income gaps and systemic racism exacerbate difficulties in accessing consistent, quality care. Clinics often lack culturally competent staff and materials, eroding trust and reducing engagement. As a result, viral suppression rates in Black communities remain below 55%, signalling a profound systemic failure that must be addressed through tailored, inclusive care models.

To move forward, Daniel emphasized the importance of community engagement, mental health support and policy advocacy. He called for outreach in genuine community spaces, like bars and local gathering spots, and the inclusion of non-traditional partners and community foundations. Such issues as mental health and substance use, often neglected in southern HIV care, require urgent attention. Daniel also stressed the need for education around the roles of city versus county governments in shaping housing and health policy.

He issued a call to action: if traditional funding mechanisms won't support integrated, community-led solutions, then the community itself must lead the way.

Session 2

Case studies from local providers in Atlanta, Georgia

The implementation and scale up of person-centred care approaches looks different in different settings and contexts. We invited leaders from various implementation projects in Atlanta to share their experiences, challenges and lessons learnt regarding implementing person-centred care approaches in their advocacy, service delivery and/or research settings.

A Vision 4 Hope, Inc. – Importance of routine syphilis screening in rapid-start ART for newly diagnosed individuals

Brianna Harper (Lead Medical Case Manager, <u>Vision for Hope, Inc.</u>) emphasized the critical importance of integrating routine STI screening, especially for syphilis, into HIV care for individuals newly diagnosed with HIV. She shared the story of a client, a 23-year-old Black gay man, whose syphilis co-infection likely delayed his HIV viral suppression despite receiving rapid start antiretroviral therapy (ART). This illustrates how early detection and treatment of sexually transmitted infections (STIs) can significantly accelerate viral suppression and improve health outcomes. Brianna advocated for person-centred, holistic care that addresses all coexisting conditions from the moment of diagnosis, highlighting the need for coordinated, timely and integrated healthcare practices to reduce transmission and improve client engagement and outcomes.

Project RED Paint, Inc. - Advocacy centred on respect, equity and diversity

Latonia Wilkins (Co-Executive Director, Project Red Paint, Inc.) shared the mission, vision and strategy of Project Red Paint which was founded in 2018 by Darriyhan Edmond to address the lack of support faced by many people in his community. "RED" stands for "respect, equity and diversity". Project RED Paint aims to empower individuals through peer support, capacity building and community engagement. Its work includes creating safe, stigma-free spaces, facilitating panels and listening sessions to amplify community voices, and collaborating

David Wyley Long, from Southern AIDS Coalition, handing the microphone to Latonia Wilikins, Co-Executive Director from Project Red Paint.



with local organizations to improve health and wellness systems. Project RED Paint has hosted events like a National Black HIV/AIDS Awareness Gala and a World AIDS Day award ceremony. It aims to expand peer training, publish advocacy models and enhance youth leadership, all rooted in dignity and collaboration.

Game Changing Men - Real talk and research

Quinton Reynolds (Founder and Executive Director, Game Changing Men) highlighted the importance of visibility in HIV prevention for transmasculine individuals, emphasizing that representation in care, research and policy is essential to improving health outcomes. Quinton shared outcomes from "Real Talk on the Road", a community-led initiative, which conducted a four-month, 11-stop tour across the southeastern United States to engage over 270 trans men, primarily Black and Latino, in conversations about sexual and reproductive health. The project revealed critical gaps in healthcare provider knowledge, access barriers (especially in rural areas) and the lack of inclusive environments. Lessons learnt stressed the need for gender-affirming care, better healthcare provider training and structural inclusion of trans men in public health responses, particularly around HIV. Recommendations include adopting status-neutral approaches, fostering genuine inclusivity and reallocating resources to ensure person-centred care for trans men.

Trans Women of Color Healing Project - Healing Through Highways: "Eliminating rural barriers to care for Black trans women in the South"

Toi Washington-Reynolds (Founder and Executive Director, Trans Women of Color Healing Project) shared a passionate message about creating environments where marginalized communities, especially Black trans women, can thrive. Toi highlighted the organization's efforts to combat harmful narratives and ensure visibility, healing and community support for trans women of colour. Based in rural Georgia, the organization operates in underserved areas outside Atlanta, where healthcare, housing and transportation barriers leave many Black trans women without access to vital resources. Through initiatives like Healing Through Highways, Toi described how the organization meets people where they are - literally and figuratively - by providing such services as transportation assistance, outreach at local colleges and holistic wellness care.

Personal stories of participants illustrated the profound impact of services like mental health support, reiki, yoga and massage, which help clients regain control of their lives from a place of healing rather than trauma. These stories underscored the organization's belief in intentional care and community-led health interventions as a pathway to long-term well-being. Toi called for continued advocacy, partnership and resource allocation to address the systemic neglect faced by trans communities outside Atlanta's resource-rich centre.

Grady Ponce de Leon Center - The Ponce G.O.A.L. clinic

Bruce Aldred (Medical Director, <u>Grady Ponce de Leon Center</u>) and Syraja Minnis (Patient Navigator, Grady Ponce de Leon Center) presented their G.O.A.L. (Get Out and Live) clinic approach. G.O.A.L. is a low-barrier care model designed to serve people living with HIV who face significant obstacles in accessing traditional healthcare. The G.O.A.L. clinic was created in 2022 to accommodate clients with flexible walk-in access to multidisciplinary care teams, including healthcare providers, mental health specialists and case managers. The aim is to remove systemic barriers, like transportation, unstable housing, mental health and address substance use.

Bruce and Syraja detailed how the clinic supports clients with services like MARTA cards, Lyft rides, fresh food access, housing assistance and medical supplies. Clients qualify if they have a history of missed appointments and struggle to achieve viral suppression under standard care. G.O.A.L. staff meet weekly to monitor progress and adapt support as needed. Since it was established, the clinic has improved viral suppression rates from 4% to 56% among its 123 enrolled clients. The team hopes to expand the G.O.A.L. clinic's availability and reach, especially in underserved regions with high HIV prevalence.



Bruce Aldred, Medical Director, and Syraja Minnis, Patient Navigator, present on their work at the Grady Ponce de Leon Center.

Status: Home - Housing, healthcare and the power of person-centred care

Maryum Phillips (President and CEO, Status: Home) and Kenneth Gantt (Case Manager, Status: Home) highlighted the organization's central belief that housing is healthcare, particularly for people living with HIV. Kenneth explained how unstable housing is directly linked to poor HIV health outcomes, citing such barriers as stigma, discrimination and lack of supportive services. He emphasized that people living with HIV who are provided with stable housing show significantly improved ART adherence and viral suppression rates, as well as reduced reliance on costly emergency care, hospitals, shelters and jails. This demonstrates both improved health and cost savings to the broader community.

Maryum explained that Status: Home, formerly known as Jerusalem House, began in 1988 with a single home for five people dying from AIDS-related causes and has grown into the largest provider of permanent supportive housing for people living with HIV in Atlanta. It now operates four tiers of housing combined with case management: a high-support facility for 23 people with advanced HIV disease; five multi-family apartment complexes; master lease management for over 100 individuals and families; and a voucher-based Tenant-Based Rental Assistance Programme where clients pay 30% of their income toward rent and utilities. In the past year, Status: Home served 477 people, including 120 children and 84 seniors. Looking ahead, Status: Home plans to expand into senior housing, advocate for state-level funding for HIV housing (which currently has zero investment in Georgia) and build partnerships to create paths to home ownership, thereby offering long-term stability and dignity for people living with HIV.

SisterLove - Healthy loving is healthy living

Krystal Stewart (Program Director, SisterLove, Inc.) shared the mission and work of the organization. It was founded in 1989 by Dázon Dixon Diallo to address the lack of HIV services for Black women during the height of the HIV epidemic. Krystal emphasized the organization's holistic, personcentred approaches, which include STI and HIV testing, counselling, mobile outreach, communitybased research, sexual and reproductive health justice legislative advocacy. Rooted in the principle of "healthy loving is healthy living", SisterLove, Inc. provides not only care, but also respect, empowerment and advocacy, particularly for underserved and stigmatized communities. Its services extend from metropolitan Atlanta to rural areas in the southern United States and even to South Africa, reflecting its global commitment to sexual reproductive health justice.



Krystal Stewart, Program Director at SisterLove, shares her insights with the fellows.

Latino Commission on AIDS - El Camino to equity for Latinos in the South

Edric Figueroa (Zero Campaign Director, <u>Latino Commission on AIDS</u>) shared the mission and work of the organization, particularly through the Latinos in the South Program, which was established to address the unique challenges faced by Latino communities in the southern United States. He highlighted alarming HIV disparities: Latinos make up 29% of new diagnoses despite making up only 19% of the population. He spoke about the compounded barriers caused by limited language access, undocumented status, restrictive immigration policies and anti-LGBTQ+ legislation in the South.

The commission tackles these issues through a multi-level prevention approach, community-based programmes, national and regional advocacy efforts and dedicated support networks, aiming to uplift and protect Latino communities amid growing political and health-related challenges. The commission engages in community outreach, offers online support groups for LGBTQ+ Latinos and their families, hosts an annual conference focused on LGBTQ+ Latino health, organizes advocacy days and rallies, and maintains a clinic in New York that informs southern programmes. It also facilitates national and regional policy discussions, like its recent convening of 120 Latino leaders in Washington, D.C., to shape a national health agenda, and is preparing a southern-specific strategy through upcoming regional calls to strengthen local advocacy efforts and build a more connected base. Edric emphasized the need for culturally competent care, regional policy advocacy and strong community partnerships.

Positive Impact Health Centers - Access to injectable therapies as person-centred care

John Stanton (Nurse Practitioner, Positive Impact Health Centers) introduced their organization, a community-based HIV care provider with four locations serving 20 counties in the Atlanta region. Its mission is to offer client-centred care for the HIV community to have a life worth loving and to reach 15,000 clients by 2026. The organization integrates care teams, including medical and behavioural healthcare providers, recovery professionals, pharmacists, social workers and community advocates, to care for each client in an affirming and supportive environment. It offers a range of services, including HIV treatment, primary care, addiction recovery, mental health counselling, case management and, soon, housing support.

John highlighted a case study of a client with advanced HIV disease and active injection drug use who had not sustained oral ART, but achieved viral suppression and improved health through off-label use of long-acting injectable ART combined with intensive case management. This underscored the need for flexible, client-centred approaches that challenge traditional treatment protocols to save lives.

Keynote address Advancing cultural competence in HIV prevention and care

Leandro Antonio Mena (Professor, School of Medicine, Emory University School of Medicine) shared a powerful and personal journey through his career in public health, beginning with his upbringing and medical training in the Dominican Republic, which instilled in him a deep respect for clients and the meaning of care. After moving to the United States, he trained at Cook County Hospital in Chicago, where he first encountered the devastating impact of HIV on isolated clients. That experience became his calling, driving him to specialize in HIV care. His career took him to New Orleans and eventually to Mississippi, where he served as medical director at a public STI clinic and began deeply engaging in HIV prevention, treatment and research, particularly focused on young Black men.

In Mississippi, Leandro became increasingly aware of the systemic barriers to care in the Deep South: persistent poverty, food insecurity, lack of Medicaid expansion, inadequate insurance coverage and deeply entrenched stigma. He spoke of the staggering HIV burden among young Black men in rural areas and the urgent need for open-access, gender-affirming care. His work led to the creation of innovative, lowbarrier clinics, like Open Arms Healthcare and Express STI Clinics, which provided fast, respectful and inclusive care. He also helped launch volunteer-based comprehensive clinics for trans people, bringing together multiple specialties in a single visit.

Leandro emphasized the importance of culturally competent, low-barrier, personcentred models that prioritize empathy, case management, peer support and telehealth, especially in underserved, rural areas. He advocated for systemic changes, including Medicaid expansion, investment in housing and transportation infrastructure, and the integration of HIV and STI services in primary healthcare. His approach is deeply community-based, drawing on partnerships with non-traditional allies, such as child healthcare programmes, grocery stores and transportation departments, to meet people where they are.

Leandro called for continued advocacy and solidarity in the face of growing political and structural challenges. He urged health professionals to combat stigma, structural racism and systemic inequities with action, empathy and partnership. He reminded participants that health equity requires not only good medicine, but courageous, inclusive leadership and collective resistance to injustice, echoing the belief that the triumph of injustice only happens when good people do nothing.

Session 3

Cultural humility, awareness & navigating political realities

Participants explored the following skills that healthcare providers need to implement PCC effectively:

1. Effective communication:

- Listen to the person and their families. Acknowledge and value their input.
- Provide sufficient information on healthcare, conditions and treatment or prevention options in a way that the client understands.
- Ask open-ended questions to obtain information about the client's needs.
- Ask clients if they are connected to other peer clients and if they engaged between clinical visits in their own self-care.
- Engage in active listening with opportunities to reflect with the client on what they've shared and what strategies may work for them.
- Get to know the person they are caring for so that they can ask the right questions.
- Provide reflective comments, making accurate summaries of what the client has shared.
- Allow enough time for client visits and don't have rushed visits.
- Allow clients to feel that they are a part of their care team.

2. Empathy and compassion:

- Show understanding of a person's emotional, socioeconomic and psychological needs.
- Create a supportive and non-judgemental environment where a person feels safe to express concerns or preferences.
- Treat a person with dignity and respect.
- Use awareness days to showcase and uplift unique populations.
- Be aware of what might be going on before or after a clinical visit.
- Respect lived experiences.
- Do not dismiss the hardships faced by individuals, giving time, even briefly, to process how difficult a client's situation may be.

3. Cultural humility:

- Consider and respect that the person's cultural background may affect their healthcare preferences.
- Ensure that healthcare approaches are inclusive and responsive to each person's cultural needs.
- If there is a misunderstanding, acknowledge the mistake.
- o Don't assume, ask.
- Acknowledge diverse experiences.
- Know that we all come from different life experiences that shape us into the people we are.
- Consider how to incorporate the client's traditions or rituals.

4. Coordinated care and collaboration (engagement and relationship):

- Collaborate with other disciplines for a multidisciplinary approach, ensuring that the client's perspective is always represented.
- Involve clients and families in their healthcare planning and decision making.
- Work across organizations to get people to appointments. As an example, a community healthcare worker can meet a client at the Uber pick up and/or clinic for a warm hand over.
- Make time to allow for sharing of resources and referrals.
- Create referral services with other community-based organizations that provide extra services, like counselling, therapy and other resources.
- Identify collaboration networks and fostering opportunities to build connections between organizations across different sectors: community, academia and private.
- A lot of times, there are waitlists for services. Ensure that not just referrals are placed, but also that organizations have capacity to deliver the services.

5. Flexibility:

- Tailor care strategies to the individual needs of the person, rather than following a standardized approach.
- Be flexible and adapt to unexpected challenges in the care of the individual. Adjust their care plans and schedule accordingly.
- Work within a client's limitations and circumstances, not against them.
- For HIV testing, provide expanded walk-in hours outside of regular business hours.
- Simplify the administrative burden. Have someone answer the phone, if possible.
- Use multiple pathways and creative solutions to address diverse needs and priorities.

6. Advocacy:

- Professionals can show up at advocacy events and elevate advocate voices on social media as a demonstration of solidarity, ensuring that they de-centre themselves to let grassroots folk do the talking.
- Speak on behalf of the individual, but only when necessary, ensuring that their rights, preferences and best interests are prioritized.
- Help the person navigate the healthcare system, connect with their case manager and access necessary services.
- Be politically active, engaged and informed.

By acting on, sharing and training others on these skills, healthcare providers can advocate for and implement person-centred care in everyday practice.

What is client journey mapping?

Client journey mapping¹⁶ is a strategic tool used to understand and visually present the experiences, interactions, emotions and pain points that clients or customers experience as they navigate the healthcare system. It helps organizations identify areas for improvement.

Client journey mapping essentially involves creating a detailed, step-by-step representation of a client's journey from their initial identification of a need to seek help through to their contact with a healthcare service, the conclusion of their treatment and beyond. It covers various stages, such as:

- Need: Recognizing the need to seek medical advice or assistance
- Finding a service: Searching for and selecting a care provider or service
- Accessing a service: Making appointments and initial consultations
- o Receiving care or treatment: The actual medical or therapeutic intervention or service
- Ongoing or follow-up care: Post-treatment support and follow up or appointments

By mapping out these stages, healthcare providers can highlight key touchpoints and interactions with healthcare providers, systems and processes. The primary goal is to gain insights into the client's experience, identify pain points and discover opportunities for improvement. Client journey maps also enable healthcare teams to see the client's experience from their perspective, fostering empathy and a deeper understanding of their emotions, motivations and challenges.

What does a client journey map include?

While client journey mapping isn't a one-size-fits-all approach, in health, a modern journey map typically captures both "front-of-house" and "back-of-house" elements, represented as separate rows or "swim lanes":

Front-of-house elements: These are parts of the journey that clients directly interact with or are impacted by, including:

- o Goals: The outcomes that matter to the client at each stage
- o Client actions: The activities the client is doing at each stage
- **Emotional status:** The emotions the client is experiencing, helping healthcare providers understand how to better support a client's emotional journey

Back-of-house elements: These refer to the behind-the-scenes processes and systems that support the client journey, such as:

- o Touchpoints: The different people, systems and processes the client interacts with
- o Friction or pain points: Challenges, frustrations or friction points the client faces
- o **Opportunities:** Potential solutions to improve the client experience
- Success metrics: How to track success for clients, through measures like client-reported measures and loyalty or client satisfaction scores

Exercise: "How might we ..." meet these needs in a person-centred way?

A client has just tested positive for HIV and needs to start treatment as soon as possible.

- Try to understand the client's fears or concerns prior to coming in. Ask open-ended questions to assess what their journey has been and to ascertain if they face any language barriers.
- Streamline the referral process and introduce clients to no more than two healthcare providers at a given time to avoid overwhelming the client.
- Clinicians need to establish trust. They can do this by sharing their own story.
- Assess the person's mental state, sleep habits and mental health condition to be able to better support their HIV treatment adherence.

2_{\circ} $\,$ An adolescent approaches a clinic for PrEP, but has underlying social and psychological concerns.

- Open a dialogue and let the adolescent lead the conversation to identify their needs and motivations for wanting PrEP and any other support needs they may have.
- o Consider the contexts of adolescents. For example, are they linked to their parents' health insurance policy? Will this lead to unintended or problematic disclosures? Do they have the knowledge and confidence to make informed decisions? What would help to empower them?

A trans woman has decided to explore her HIV prevention options.

- Provide peer navigation and outreach at community events.
- Have trans people on staff to ensure commitment is deeper than displaying a flag.

Keynote address Community healthcare advocate



A. Toni Young (Community Education Group, CEG, United States) outlined the evolution of CEG from its urban-focused Community HIV/AIDS Mobilization Prevention Services (CHAMPS) programme in Washington, D.C., to its expanded outreach in rural Appalachia. Initially designed for city settings, CHAMPS trained over 150 community health workers, linked 90% of engaged clients to care, screened more than 10,000 people for HIV and 5,000 people for hepatitis C virus annually and distributed over 1 million condoms. The programme's success in Washington, D.C., prompted its adaptation to West Virginia, the third most rural state in the United States, requiring a shift in training formats to include virtual synchronous sessions and blended models that accommodate rural access needs.

The transition to Appalachia included a significant focus on culturally responsive care through initiatives like "Healing Appalachia", which delivers confidential HIV self-testing, low-barrier service access and peer education in trusted, community-based environments. The programme aims to support the whole person, prioritizing empowerment and follow-up care. Through these efforts, CEG emphasizes equity, trust building and person-centred approaches to public health in both urban and rural settings. Additionally, CEG provide technical assistance and capacity-building to organizations that work within communities to ensure they are equipped with the knowledge, skills and ability to receive grant funding, evaluate their services and programme outcomes and evolve to meet the community where they are.

Session 4

Person-centred design in action

Participants prepared mind maps to explore specific approaches to person-centred care. These included:

Client and healthcare provider experience measures

It is essential to hear from clients themselves about their experience at the service delivery site. This can be done via various means, such as suggestion boxes, digital tools like SMS surveys, and also in-depth evaluation interviews directly organized with clients. However, the group emphasized that these evaluations should not be used to single out healthcare providers with low scores or assign blame, but instead to highlight and strengthen practices that are effective across the entire team. The group also discussed the importance of measuring healthcare providers' experiences, too, noting that enhancing their experience at the point of care ultimately leads to better experiences for clients, as well. Finally, whether assessing client or provider satisfaction, the group agreed that the key is to ensure that these evaluations lead to meaningful actions, rather than becoming unused data points.

Motivational interviewing

This group discussed the concept of motivational interviewing, a counselling technique that focuses on behaviours and aims to meet people where they are. This means understanding whether they are ready for change or not yet ready for change, and exploring this readiness and the possible next steps in collaboration with the client. To achieve this requires asking open-ended questions, listening without judgement, active listening and reflecting back to the client what they are saying. It is also important to acknowledge that moving between different stages of readiness for change is often not a linear process. Motivational interviewing can empower clients and create rapport with clients to try to determine the real, underlying issues with the goal of evoking a response from the client to set clear goals and a step-by-step plan to achieve them. Implementing this approach requires training, practice and patience. It is important not to push for change before a client is ready.

Supporting effective communication

This group discussion centred on the need for creating safe, inclusive and effective communication in healthcare and community settings. Emphasis was placed on active listening, ensuring that spaces are welcoming and emotionally safe, and using person-first, affirming language. This group highlighted the need for adaptive communication strategies, especially given recent restrictions on digital platforms, by promoting alternatives like newsletters, town halls and secure clinical apps to maintain connection with clients. They also underscored the value of community partnerships (such as food banks) to disseminate health

information discreetly and meaningfully. Finally, attention to non-verbal cues, such as open body language and warm smiles, was stressed as a powerful way to reduce fear and foster trust in healthcare environments.

Empowering community healthcare workers (CHWs)

This group discussion focused on the importance of giving CHWs the autonomy and resources to do their work. This means training and certifying them so that they have the knowledge and confidence to support their clients' challenges. It also means paying them a living wage and not compensating them only with candy! This group also explored the role of biases, particularly racial bias, and what that can mean for the acceptance and placement of specific CHWs in certain settings. This group also highlighted the importance of supporting the mental health and prioritizing burnout prevention for CHWs and simply making sure that CHWs feel seen and appreciated by their colleagues in other parts of the healthcare system.

Safeguarding of participants, creating inclusive and safe spaces

The key themes of this group's mind map centred on building inclusive, safe and community-rooted spaces, represented metaphorically as a tree. At its foundation is the principle that "all are welcome here", supported by essential elements like inclusive and accessible locations, community leadership and evidence-based practices. Surrounding the tree is "grassroots" support – symbolizing leadership's role in securing funding and enacting supportive policies. The tree's branches represent core operational areas: communication (emphasizing multilingual, culturally competent resources); trust (grounded in accountability, confidentiality and retention); staffing (focused on capacity and representation); and services (responsive to community needs). Cutting across all branches are principles of trauma-informed care, cultural humility and continuous learning.

Role of "upstanders" who call out stigma and discrimination and take voluntary actions

The group discussed persistent stigma and discrimination in the southern United States – not only towards people living with HIV, but also affecting specific communities, such as Black people, Latinx populations and trans people. To provide stigma-free services rooted in respect for human rights, the group emphasized three key priorities: compassionate care; culturally sensitive approaches; and care that promotes client empowerment and respects individual agency. At the heart of this model are the individuals who have raised their voices to make prevention, care and treatment truly effective and inclusive for everyone. The group then reflected on the challenges of being the "upstander" and explored ways to protect and support oneself while advocating for change.

Session 5 Advocacy and storytelling workshop

1. Advocacy and storytelling 101

Maxx Boykin (Campaign Manager, <u>#SaveHIVFunding</u>, United States) emphasized the power of personal storytelling as a central tool in advocacy work. Maxx shared his own background, including his family's civil rights history and personal experiences with HIV-related loss, to illustrate how stories can humanize policy issues and move people to action. He encouraged participants to reflect on their own motivations, values and personal connections to the work as a foundation for crafting impactful stories. The "story of self", he said, is not just about where you come from, but also why you do this work and what change you seek.

A core part of effective storytelling, Maxx stressed, is clarity of purpose. Before crafting a narrative, advocates should ask: What is the goal of this story? Who is the audience? And what outcome do I want to achieve? Tailoring stories to specific audiences – be they legislators, media or community members – is key. He recommended stakeholder power mapping to identify and assess the influence of stakeholders in advance. Additionally, storytelling should engage multiple senses and include both emotional and logical elements, integrating lived experience with factual context to resonate more deeply.

2. Tips for media engagement

Rebecca Grapevine (Journalist, <u>Healthbeat</u>) focused on practical strategies for effective media interaction. She emphasized that advocates should always respond to media with a sense of urgency. Journalists often work on tight deadlines, so a rapid response – whether with a quote, an interview or a simple acknowledgement of their email – is crucial. Clear, concise soundbites and repeated messaging help ensure that your key points are heard and remembered, especially in fast-paced or high-stakes settings.

Rebecca and Maxx emphasized that media interactions are strategic opportunities, not casual conversations. Interviewees should anticipate tough or leading questions and be ready to pivot with prepared responses. For example, if caught off guard, one tactic is to thank the interviewer and steer the conversation back to your core message. Participants were encouraged to consider anonymized contributions or seek help from supportive national organizations, especially when working with media outlets that may not share your values or when organizational politics limit what can be shared. Consistent follow up and staying message-focused were presented as essential for maximizing impact and minimizing misrepresentation.

Educational site visits



Participants had the opportunity to each visit one of four different HIV healthcare providers in Atlanta: the Grady Ponce de Leon Center; AID Atlanta; SisterLove and Status:Home. The group was able to gain insights into the range of services available to people living with or affected by HIV in the Atlanta metropolitan area, from a medicalized HIV service structure to housing facilities for individuals with advanced HIV disease. These visits provided a valuable opportunity for fellows to observe person-centred care in action and to engage with on-site staff, inspiring their own ideas and strategies for advancing person-centred care in their own states.







Keynote address Trauma-informed care

Jessica Sales (Rollins School of Public Health, Emory University, United States) shared her implementation science research focused on the importance of integrating trauma-informed and healing-centred approaches into HIV healthcare services, particularly in Ryan White clinics across the southeastern US. Drawing on her background in developmental psychology and decades of work in resilience and trauma, Jessica emphasized how adverse childhood experiences and trauma – both individual and collective – significantly impact the mental, emotional and physical health of individuals, especially those living with or affected by HIV. She also noted the prevalence of vicarious trauma among healthcare providers, which contributes to burnout and high turnover in the HIV healthcare workforce.

To address these challenges, Jessica and her collaborators developed a trauma-informed care training programme designed not just to educate, but to embed practices into clinic culture through coaching, assessments and leadership engagement. The training, structured into six one-hour sessions, includes modules on team care, self-care, understanding trauma's impact on clients and improving the clinic environment to prevent re-traumatization. The goal is to move beyond check-the-box trainings and create sustainable, practical change supported by leadership and tailored to each clinic's needs.

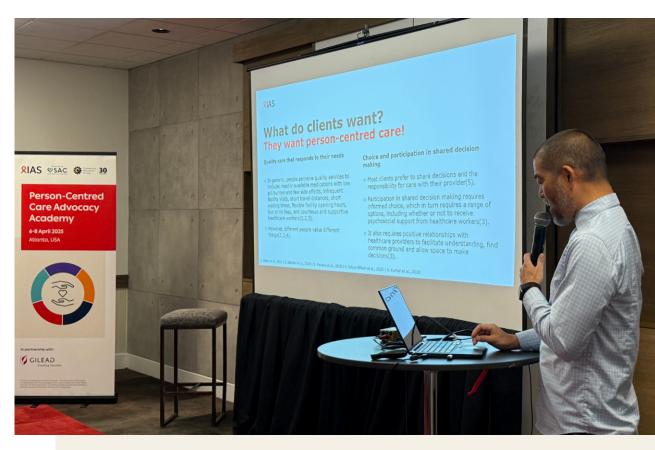
A key innovation in her approach is the shift from a traditional trauma-informed model to a "healing-centred" one. While trauma-informed care often focuses on identifying and treating trauma, the healing-centred approach emphasizes empowerment, resilience and collaborative recovery, centring clients and providers alike as active participants in their own wellness. This model is more holistic and aligns closely with the principles of person-centred care, particularly in environments serving marginalized communities.

Jessica also highlighted the need for institutional support to normalize conversations about trauma and wellness, particularly for peer navigators and staff with lived experiences of trauma. Critical components for sustaining trauma-aware, healing-centred care practices were identified: encouraging self- and team-care strategies; embedding peer-generated solutions into clinic culture; and fostering emotionally supportive environments.

Session 6 PCC implementation tools

Elvin Geng (Washington University in St. Louis, United States) provided an overview of strategies for creating meaningful change within healthcare systems. He emphasized the need to integrate whole-person care by rethinking service structures, enhancing provider competencies, collecting and using client experience data and fostering supportive interpersonal interactions. Drawing on global examples, particularly from his collaborative research in Zambia, he illustrated how innovations like differentiated service delivery and participatory design with frontline healthcare workers can empower clinics to adopt more person-centred approaches.

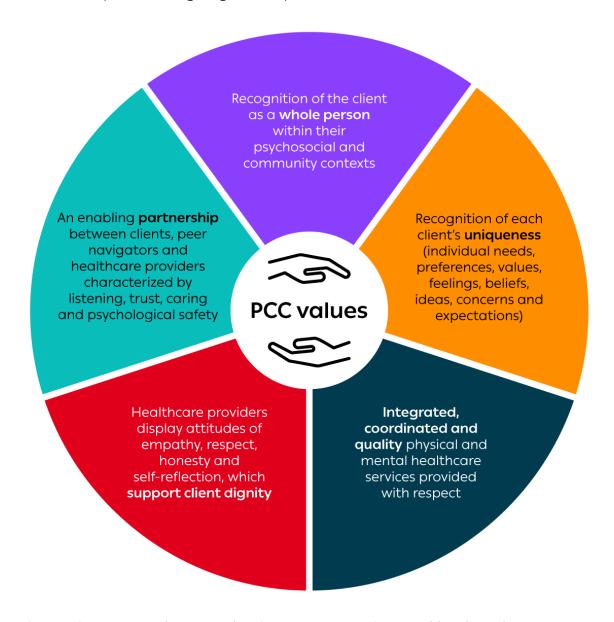
Elvin stressed that person-centredness requires more than just good intentions – it must be embedded in systems through actionable changes, like adjusting clinic workflows and providing real-time client feedback. Provider behaviours, especially interpersonal communication and discretion, play a pivotal role in shaping client experiences. Elvin also highlighted the importance of leadership and governance in sustaining these practices, advocating for systems that prioritize clients over rigid processes.



Elvin Geng, from the Washington University in St. Louis, United States, shares his perspective on person-centred care.

Framework for the operationalization of person-centred approaches

The client and their relationship with the healthcare provider are placed at the centre of their care while helping people manage their health. It is not only about the mechanics of the service; it also includes the relationship and care that underpins the service¹⁵, as illustrated by the following diagram adapted from the Scholl¹⁶ framework.



Source: IAS, Approaches to implementation of person-centred care for people living with HIV in low-resource settings, 13 June 2024.

PCC approaches are operationalized through the activities that are put in place to turn these concepts into care that is person centred. These activities fall under different categories, for example, activities that involve changing the structure or organization of the services themselves or involve supporting healthcare providers to provide care that is person centred¹⁷. The successful inclusion of PCC into existing services is not without challenges, especially in settings with limited resources and diverse client needs. Healthcare providers may question the extent of client involvement in the decision-making process and the practicality of shifting between standardized care and individualized treatment approaches¹⁹. The framework²⁰ on the next page provides a practical way of thinking about implementation.



Activities

- 1. Service structure and organization
- 2. Healthcare provider competencies and support
- 3. Data collection, feedback and utilization
- 4. Client-healthcare provider interactions
- 5. Governance and leadership commitment







Source: IAS, Approaches to implementation of person-centred care for people living with HIV in low-resource settings, 13 June 2024.

Communication and interaction underpin everything. They start with planning and continue through implementation. Evaluation and monitoring allow for flexibility to make the changes needed to ensure that services continue to be person centred. Being person centred is about recognizing the client's ability to improve their health and working with clients to meet their needs ²¹, ²².

Group discussions explored these activities within the context of the southern United States:

1. Service structure and organization

- Exercise a flexible work schedule and resource distribution of healthcare services that are accessible to clients. This means more integrated services provided at after-hours clinics or via outreach services.
- Provide clients with a single-time reimbursement for transportation to the clinic or outreach services and increase service provision directly in the community.
- Foster an inclusive environment that emphasizes a welcoming and respectful atmosphere.
- Ensure that marginalized communities, including people experiencing homelessness, are not criminalized.
- Prioritize investment in community-led, grassroots healthcare service provision.



When you feel supported, you go the extra mile.

- Fellow

2. Healthcare provider competencies and support

- Assessing where healthcare providers are at, not to blame or to shame, but to
 precisely define what support and training are needed to enhance person-centred
 care approaches in the facility.
- Provide training and on-site mentoring on communication skills, persisting biases and stigma-free care (see Session 3), as well as on assessing client experience.
- Provide training and on-site mentoring on work culture, teamwork and power dynamics, and stress management for providers.
- Train and mentor healthcare providers to enhance their skills in assessing and managing re-engaging clients through these five insights: welcome the client back to care (using the "welcome handshake" model, for example); normalize the challenges they face to demonstrate that they are not alone; acknowledge and celebrate the client's effort to return; provide the support needed to re-engage; and empower them to take ownership of their treatment and care.
- Provide specific training for adherence counsellors to enhance their psychosocial support for re-engaging clients.
- Conduct focus group discussions among healthcare workers of different practising areas to assess client-provider interactions and service delivery.
- Encourage providers involved in adopting person-centred care approaches and explore incentives to promote positive changes.

3. Data collection, feedback and utilization

- Make sure staff at all levels understand the importance of data collection and clients' feedback to ensure collective engagement and support, from onboarding, if possible, and repeated regularly at staff meetings.
- Conduct pre- and post-evaluations of person-centred interventions and clients' clinical outcomes using routinely collected health data.
- Conduct programme evaluations, including client feedback and healthcare provider experiences of service delivery, ensuring that both quantitative and qualitative methods are used.
- Use all client and clinical data available, including adherence, drug refills and laboratory test results, to identify and address potential client challenges to adherence.
- Consider using digital and Al tools to facilitate data collection, such as systematic coding and analysis of client-provider conversations, including using audio recording assessments with medical officers, clinical officers, nurses and lay providers, to encourage positive changes in communication.

4. Client-healthcare provider interactions

- Emphasize the importance of greetings in client-provider interactions. Encourage healthcare providers to introduce themselves at the outset of a consultation by revealing their names and positions in the health facility and to invite clients to introduce themselves, as well. Use these introductory comments to demonstrate that clients will be respected and heard and to invite clients to feel free to share their opinions.
- Move beyond just creating a welcoming atmosphere to actively empowering clients to participate in care decisions: ask them questions; encourage health literacy and self-advocacy; and encourage them to share their individual challenges and reasons for disengaging from care to help them identify what they may need to remain engaged.
- Integrate a five-step counselling approach: emphasize the importance of ART adherence; explore client motivation for ART adherence; ask clients to describe "good" and "bad" days with ART; work with clients to identify adherence challenges; and identify solutions. This fosters a trusting environment between healthcare providers and an individual's treatment regimen.
- Encourage discretionary power practices, such as narrowing the hierarchical distance between client-provider interactions, active engagement, using collaborative language for equal care, and emphasizing flexible work processes.
- Encourage healthcare providers to acknowledge their own mistakes (for example, when misgendering a client), as well as acknowledge service shortcomings and apologize to clients where appropriate.
- Establish personal rapport between clients and a clinic by introducing all clients after HIV testing to clinical staff, regardless of HIV status.

5. Governance and leadership commitment

- Provide training and mentorship for management teams' buy-in to adopt and promote a work culture that prioritizes person-centred values and ensures that these principles are embedded in every aspect of care and interaction.
- Person-centred values concern not only clients but healthcare providers, too.
 Stress management and burnout prevention should be recognized as priorities for management teams.
- Encourage a team-based approach to managing power dynamics among healthcare providers in different roles and positions in the healthcare setting, promoting collaboration and mutual respect among staff members.

Approaches to implementation of person-centred care for people living with HIV in low-resource settings

Publication date: 13 June 2025

Source: IAS

Available at: https://plus.iasociety.org/webcasts/approaches-implementation-person-centred-care-people-

living-hiv-low-resource-settings

This training resource provides guidance for healthcare providers based on evidence drawn from published literature and case studies where person-centred care has been employed. It includes a brief background on person-centred care: what it is; why we need it; and what impact it has. It then provides an overview of the theoretical principles of person-centred care based on several well-researched and tested frameworks.

Implementation Readiness Assessment Tool

Publication date: August 2024

Source: JSI

Available at: https://snapetap.org/resources/implementation-readiness-assessment-tool

This tool is intended to assess readiness to implement various activities that support a whole-person approach to care and service delivery and help identify gaps and areas of improvement. The activities are aligned with, and organized by, the six domains of JSI's Person-Centred Care framework:

- 1. Service design and delivery
- 2. Policy and financing
- 3. Monitoring, learning and accountability
- 4. Workforce environment and development
- 5. Point-of-care access and experience (client level)
- 6. Leadership and governance

Baseline Needs Assessment Landscape Analysis

Publication date: 13 June 2025

Source: August 2024

Available at: https://snapetap.org/resources/baseline-needs-assessment-landscape-analysis

This serves as an example of a completed landscape analysis. It is intended to provide guidance and clarity on the structure, content and level of detail of each landscape analysis. Please note that this example is for reference purposes only and should not be replicated directly.

Future plans

At the end of the programme in Atlanta, fellows made personal pledges, which reiterated their shared commitment to advancing person-centred and trauma-informed care, particularly for people living with or affected by HIV. Fellows pledged to integrate new skills into policy development, medical and public health education and organizational practices, ensuring that healthcare remains responsive, inclusive and empowering. They shared their intention to disseminate knowledge across agencies and communities – especially in rural and underserved areas – support staff well-being and engage young people and students in meaningful ways. These future priorities emphasize the importance of proactive, evidence-based approaches and community-driven strategies in healthcare and education.



Presentation of advocacy action plans

At a follow-up virtual meeting on 7 May 2025, fellows shared diverse and innovative advocacy action plans centred around advancing PCC, HIV prevention and health equity across various communities.. Several proposed initiatives focus on supporting vulnerable populations, such as justice-involved individuals, by leveraging social networks and peer support to improve access to HIV, harm reduction and mental healthcare services. Others are working on publishing research that explores the mental health experiences of people living with HIV, particularly in the context of a shifting resource landscape.

Community-based interventions are also central to the future plans of the PCC fellows, including the creation of health equity toolkits for the ballroom community and the implementation of motivational interviewing techniques in PrEP adherence counselling. Programmes are being developed to support people ageing with HIV through Al-assisted tools, while grassroots advocacy continues through regional coalitions. Additionally, expanded use of PCC principles in training for healthcare providers, outreach materials and fitness-based client empowerment initiatives aims to improve healthcare delivery and retention across a broad range of service settings. Collectively, these initiatives reflect a strong commitment to integrating PCC into policy, practice, research and education to better serve marginalized communities.

Academy programme in Atlanta

Sunday, 6 April, 2:00pm - 9:00pm

Time	Session
2:00pm - 3:00pm	Opening - welcome and introductions
3:00pm - 4:00pm	Session 1 - Setting your goals for the academy
4:30pm - 4:30pm	Refreshments break
4:30pm - 4:50pm	Keynote address - Client advocate
4:50pm - 6:00pm	Session 2 - Case studies from local service providers
6:00pm - 7:00pm	Free time
7:00pm - 9:00pm	Networking dinner

Monday, 7 April, 8:30am - 5:00pm

Time	Session
8:30am - 8:50am	Keynote address - Healthcare provider advocate
8:50am - 10:00am	Session 3 – Cultural humility, awareness & navigating political realities
10:00am - 10:30am	Refreshments break
10:30am - 10:50am	Keynote address - Community healthcare advocate
10:50am - 11:10am	Keynote address - Researcher advocate
11:10am - 12:00pm	Session 4 - Person-centred care design in action
12:00pm - 1:00pm	Lunch
1:00pm - 2:00pm	Session 5 - Advocacy in action and storytelling workshop
2:00pm - 2:30pm	Free time
2:30pm - 5:00pm	Site visits

Time	Session
8:30am - 8:50am	Opening - welcome and introductions
8:50am - 10:00am	Session 1 - Setting your goals for the academy
10:00am - 10:30am	Refreshments break
10:30am - 12:00pm	Closing

Post-academy virtual convening

Wednesday, 7 May, 10:00am - 12:00pm (Eastern daylight time) - Teams meeting

Time	Session
10:00am - 10:55am	Presentation of advocacy action plans
10:55am - 11:05am	Break
11:05am - 12:00pm	Presentation of advocacy action plans

Presentations from individual fellows on their action plans to advocate for person-centred healthcare/HIV service access and delivery models in their settings

About the IAS Person-Centred Care programme

The <u>Person-Centred Care programme</u>, initiated by the IAS in 2021, improves health services by prioritizing the integration of health concerns and the responsiveness of healthcare services. This is to meet the changing needs, priorities and preferences of each person living with or affected by HIV. It emphasizes healthcare that empowers clients and is shaped by the many aspects of people's intersectional identities, such as gender, age, sexuality and socioeconomic status.

The IAS Person-Centred Care programme:

- Builds consensus around the concept of person-centred care to support personcentred approaches; specific focus areas include harm reduction, ageing with HIV, sexually transmitted infections and tuberculosis
- Empowers people living with and affected by HIV to demonstrate improved ability to demand person-centred care, including treatment and prevention services
- Equips healthcare providers with the skills and motivation to provide services that respond to the complex health needs and preferences of their clients
- o Documents and disseminates good practice models of person-centred care
- Strengthens the evidence base to inform delivery of integrated high-quality, person-centred healthcare services

About IAS Advocacy Academies

Since 2018, the IAS has organized seven HIV Cure Advocacy Academies in Uganda, Botswana, South Africa, Zambia and Rwanda, with training provided to 107 fellows from 21 countries across Africa, Asia-Pacific, Europe and Latin America. Follow-on grant programmes have initiated 13 high-impact projects in eight countries. Since 2023, 27 researchers and 15 advocates and peer educators from 14 countries across the African continent have been trained through the HIV Vaccine Science and Advocacy Academies; these were held in Zambia, Rwanda and Namibia. Many alumni stay engaged with the IAS, and many have participated in IAS-organized international conferences.

The inaugural Person-Centred Care Advocacy Academy took place in November 2024 in Lusaka, Zambia. Access the detailed <u>meeting report</u> and <u>event video</u> to learn more about this event. The PCC Advocacy Academies will be a catalyst for follow-up pilot projects, ongoing good practice sharing and the development of policy recommendations across the African continent and in the United States.

About the Southern AIDS Coalition

Since 2001, the <u>Southern AIDS Coalition</u> (SAC) has worked in partnership with government, community and health leaders, bringing to the centre the experiences of people living with and affected by HIV to transform policies and perceptions to address the HIV epidemic in the South. With a mission to end the disproportionate impact of HIV and STI epidemics in the South, SAC promotes accessible and high-quality systems of prevention, treatment, care, housing and essential support services. Working across 16 southern states and the District of Columbia, SAC engages a range of stakeholders in policy advocacy, capacity-building trainings, convenings, awareness campaigns, research and strategic grant making. SAC is a bridge and megaphone in the region, helping build relationships across southern states and amplifying the critical work and opportunities across the region to end the HIV epidemic.

About the Community Education Group

The <u>Community Education Group</u>'s work includes providing access to healthcare, public education and job training, plus securing financial investments to underserved rural communities and community-based organizations in West Virginia and Appalachia. Its focus is to improve access by providing leadership and advocacy to scale resources and funding to respond to the syndemic cluster of widespread disease and public health crises, including HIV and AIDS, viral hepatitis, opioid addiction and drug dependence. Its vision is that no matter where you live, what you do or who you are, everyone deserves and should have access to life-affirming resources for themselves and their families.

List of participants

Fellows



From left to right, top row:

Name	Organization	State
Robin Webb	We the Positive Southern Network	Mississippi
Kevin Aloysius	Legacy Community Health	Texas
DeKeitra Griffin	Louisiana State University	Louisiana
J. Christopher Johnson	Mobilizing Millennials	Louisiana
Juan Alberto Esquivel Mendoza	Center for HIV and Research in Mental Health - University of Miami	Florida
Dave Wessner	Davidson College	North Carolina

From left to right, bottom row:

Takeisha Nunez	University of Kentucky	Kentucky
Eugenia Rogers	Community Collaborative Council (D3C)	North Carolina
Lacey Despres	Miller School of Medicine - University of Miami	Florida
Annie Potts	Mercer University & Coalition for Collaboration on HIV/AIDS Research and Intervention in Middle Georgia	Georgia
Reema Chande	Mercer University & Coalition for Collaboration on HIV/AIDS Research and Intervention in Middle Georgia	Georgia
Princess Jauan Durbin	Meharry Medical College	Georgia
Yvonne Spencer-Lewis	Comprehensive Care Center of Southwest Louisiana	Louisiana
Daniel D'Antonio	RAO Community Health	North Carolina
Ryan Alvey	Positive Change Movement	Kentucky

Not appearing in the photo:

Antoine Ghoston	Arkansas Black Gay Men's Forum	Arkansas
Malcolm Reid	Unity Arc Advocacy Group	Georgia

Faculty

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Name	Organization	State
Elvin Geng	Washington University in St. Louis	Missouri
Dafina Ward	Southern AIDS Coalition	South Carolina
David Wyley Long	Southern AIDS Coalition	Tennessee
A. Toni Young	Community Education Group	West Virginia

Guest speakers & keynote speakers



From left to right:

Name	Organization	State
Krystal Stewart	SisterLove	Georgia
Toi Washington - Reynolds	Trans Women of Color Healing Project	Georgia
Daniel Driffin	HIV Vaccine Trials Network	Georgia
Maryum Phillips	Status: Home	Georgia
Kenneth Gantt	Status: Home	Georgia
Edric Figueroa	Latino Commission on AIDS	Georgia
Latonia Wilkins	Project RED Paint	Georgia
Brianna Harper	A Vision 4 Hope	Georgia
Bruce Aldred	Grady Ponce De Leon Center	Georgia
Quinton Reynolds	Game Changing Men	Georgia
Syraja Minnis	Grady Ponce De Leon Center	Georgia
John Stanton	Positive Impact Health Centers	Georgia

Not appearing in the photo:

Samira Ali	University of Houston	Texas
Maxx Boykin	PrEP4AII	Georgia
Rebecca Grapevine	Healthbeat	Georgia
Leandro Antonio Mena	Emory University	Georgia
Jessica Sales	Emory University	Georgia

44 **Observers**

First name	Organization	State
April Houston	Washington University in St Louis	Missouri
DeShawn Stevenson	Gilead Sciences	Georgia
Marcus Wilson	Gilead Sciences	Florida
LaMar Yarborough	H.Y.P.E to Empower	Georgia

IAS staff

First name	Organization	Country
Loena Le Goff - Gestin	IAS - the International AIDS Society	Switzerland
Tara Mansell	IAS - the International AIDS Society	Switzerland
Emma Williams	IAS – the International AIDS Society	Switzerland

Definitions of key PCC terms

Burnout: This term includes a combination of emotional exhaustion, cynicism, depersonalization and low personal accomplishment caused by chronic stress^{24,25}.

Client: This term refers to a person engaging with healthcare services in order to prevent illness or maintain health that respects their intrinsic autonomy irrespective of who is paying for the service. Related terms include "patient" and "recipient of care"; however, some people interpret these terms as disempowering.

Cultural humility: This process of self-reflection and self-critique for healthcare providers considers power imbalances and differences they may have with their clients, such as the diversity of background and opportunity, language, culture and way of life, which may impact their perspectives of their client's health, healthcare-seeking behaviours and decisions²⁶.

Differentiated service delivery (DSD): Previously referred to as differentiated care, DSD is a client-centred approach that simplifies and adapts HIV services across the cascade to reflect the preferences, expectations and needs of people living with and affected by HIV while reducing unnecessary burdens on the health system²⁷.

Digital technology/telehealth: This describes a wide range of remote communication tools to enable interaction between clients and providers without requiring an in-person exchange. Examples are WhatsApp, Zoom, SMS and email consultations.

Gender-affirming care: Gender-affirming care encompasses a range of social, psychological, behavioural and medical (including hormonal treatment and surgery) interventions designed to support and affirm an individual's gender identity²⁸. These interventions aim to help trans and gender non-binary people align various aspects of their lives – emotional, interpersonal and biological – with their gender identity.

Harm reduction: This is a non-judgemental approach to policies, programmes and practices that aim to minimize the adverse health, social and legal impacts of drug use, drug policies and drug laws.

Healthcare provider: This includes lay healthcare workers, such as peer supporters providing adherence counselling, as well as clinicians and administrative personnel interacting with clients.

Integrated healthcare services: These healthcare services are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector and according to their needs throughout the life course²⁹.

Peer support: Through peer support, services are provided by a peer with client experience who is trained to navigate, refer and connect people to health and social services³⁰.

People-centred care: This approach to care consciously adopts the perspectives of individuals, caregivers, families and communities as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases and respect social preferences. People-centred care is broader than person-centred care, encompassing not only clinical encounters, but also paying attention to the health of people in their communities and their crucial role in shaping health policy and health services³¹.

Person-centred care: This describes care approaches and practices in which the person is seen as a whole, with many levels of needs and goals, and with the needs shaped by their personal social determinants of health³².

Person-first language: Person-first language simply puts people before their condition, recognizing that people are people and not defined by their condition. In HIV care, for example, we should avoid labels like "HIV-infected people" and instead use "people living with HIV". Person-first language empowers rather than stigmatizes^{33,34}. Words have power: they bestow or remove dignity, build or break stigma, and promote or hinder inclusivity, dialogue and equality.

Primary healthcare (PHC): This whole-of-society approach to health aims to maximize the level and distribution of health and well-being through three components: (a) primary care and essential public health functions as the core of integrated health services; (b) multisectoral policy and action; and (c) empowered people and communities³⁵.

Social participation: This approach empowers people, communities and civil society through inclusive participation in decision-making processes that affect health across the policy cycle and at all levels of the system. It is core to primary healthcare and promotes equitable progress towards universal health coverage, producing more responsive health policies and programmes, and fostering population trust with the health system³⁶.

Structural barriers: These barriers relate to the role of the structures (laws, policies, institutional practices and entrenched norms) that provide the scaffolding for whole systems, such as the healthcare system³⁷.

Systemic barriers: These barriers relate to the involvement of whole systems and often all systems – for example, political, legal, economic, healthcare, school and criminal justice systems – including the structures that uphold the systems⁴⁰.

Universal health coverage (UHC): UHC means that all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. UHC covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation and palliative care³⁸.

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