Person-Centred Care Advocacy Academy: HIV in Europe – Event report

A series of interactive sessions to explore person-centred care approaches to service delivery

12 – 15 October 2025,
Paris, France

In partnership with: GILEAD

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.

Contents

Executive summary

This third Person-Centred Care Advocacy Academy, organized by IAS – the International AIDS Society – was held in Paris from 12 to 15 October 2025. We would like to warmly thank our organizing partners, AIDES, AIDS Action Europe, Coalition PLUS and the European AIDS Clinical Society for helping us organize such an important learning journey for all participants. We also thank our partner, Gilead Sciences, for its collaboration and financial support. This event convened 47 participants from 19 European countries, including 18 supported fellows. 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. Following the academy, participants had the opportunity to immediately put their new knowledge into action via their active participation in the 20th European AIDS Conference (EACS) which was held from 15 to 18 October 2025.

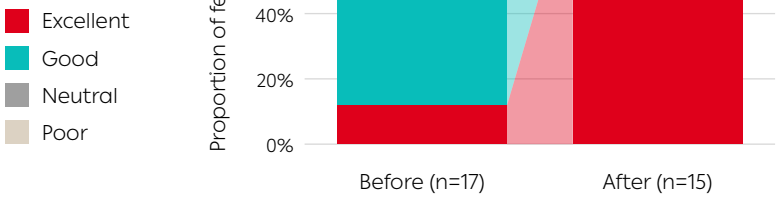
Participants of the PCC Advocacy Academy: HIV in Europe

The objectives of the advocacy academy were to:

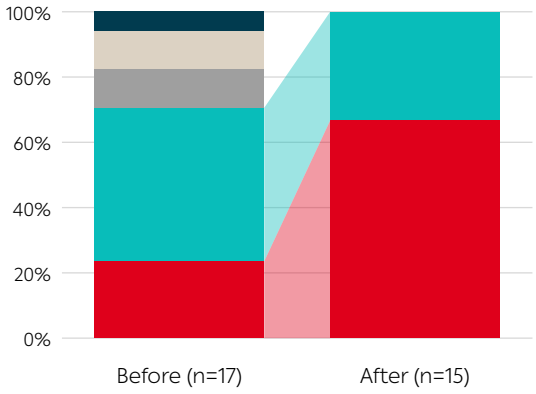
- Provide training and skills building on current person-centred care approaches to service delivery and existing barriers to their implementation.
- Develop tools to disseminate information on person-centred approaches and their importance to the wider community, including programme managers, the media 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.

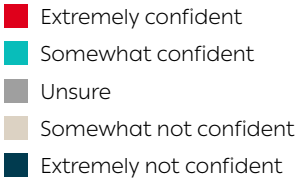
A post-event feedback survey confirmed that the academy met the expectations of the supported fellows. Of the 18 fellows who attended, 17 responded to the pre-academy survey and 15 responded to the post-event survey. Two-thirds of the survey respondents confirmed that the academy exceeded their expectations, with the remaining third having their expectations met. Nearly all of the survey respondents (93%) stated that their participation in the academy improved their ability to engage in the HIV response. After the academy, 100% of the survey respondents reported a good or excellent understanding of person-centred care approaches compared to 59% prior to the academy. Also, after the academy, 100% of the survey respondents reported feeling extremely confident about implementing a project to enhance person-centred care approaches in their setting compared with 71% before the academy.

Understanding what PCC means



Confidence to implement a PCC advocacy initiative





Two-thirds of the survey respondents confirmed that the academy exceeded their expectations, with the remaining third having their expectations met.

Exceeded expectations
Expectations met

93%

reported that their participation in the academy improved their ability to engage in the HIV response

“What I liked most about the event was the perfect balance between gaining new professional knowledge and meaningful human interaction. Each session offered something valuable - from evidence-based practices to inspiring real-world examples. But what truly made this Academy so impactful for me was the opportunity to connect with other participants, speakers, and the organizing team. The openness, support, and thoughtful atmosphere encouraged genuine exchange and collaboration. This combination of content and community made the whole experience incredibly useful and inspiring.

— PCC fellow feedback on their experience at the academy

Introduction to person-centred care

Lina Golob (IAS, France) opened the academy with a foundational presentation on person-centred care (PCC). She emphasized that while many participants may be familiar with the term, PCC is likely to carry different meanings in different contexts. Her goal was to ensure a shared understanding of the concept, especially as it applies to HIV service delivery. Lina highlighted the importance of moving beyond disease-focused models to approaches that recognize the full complexity of individuals' lives, including their social identities, lived experiences and evolving health needs.

What is person-centred care?

Person-centred care refers to 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 health[1]. 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 individual[2] as a unique[3] and whole person[4]
- 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 alone[5]
- Personalized, coordinated and enabling[6] – 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 circumstances[7].

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

Lifelong engagement with HIV treatment 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. The destigmatization of HIV prevention and testing, as well as increased access to a choice of effective HIV prevention methods, are also crucial for reducing rates of HIV acquisition.

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.
- Some of the 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.

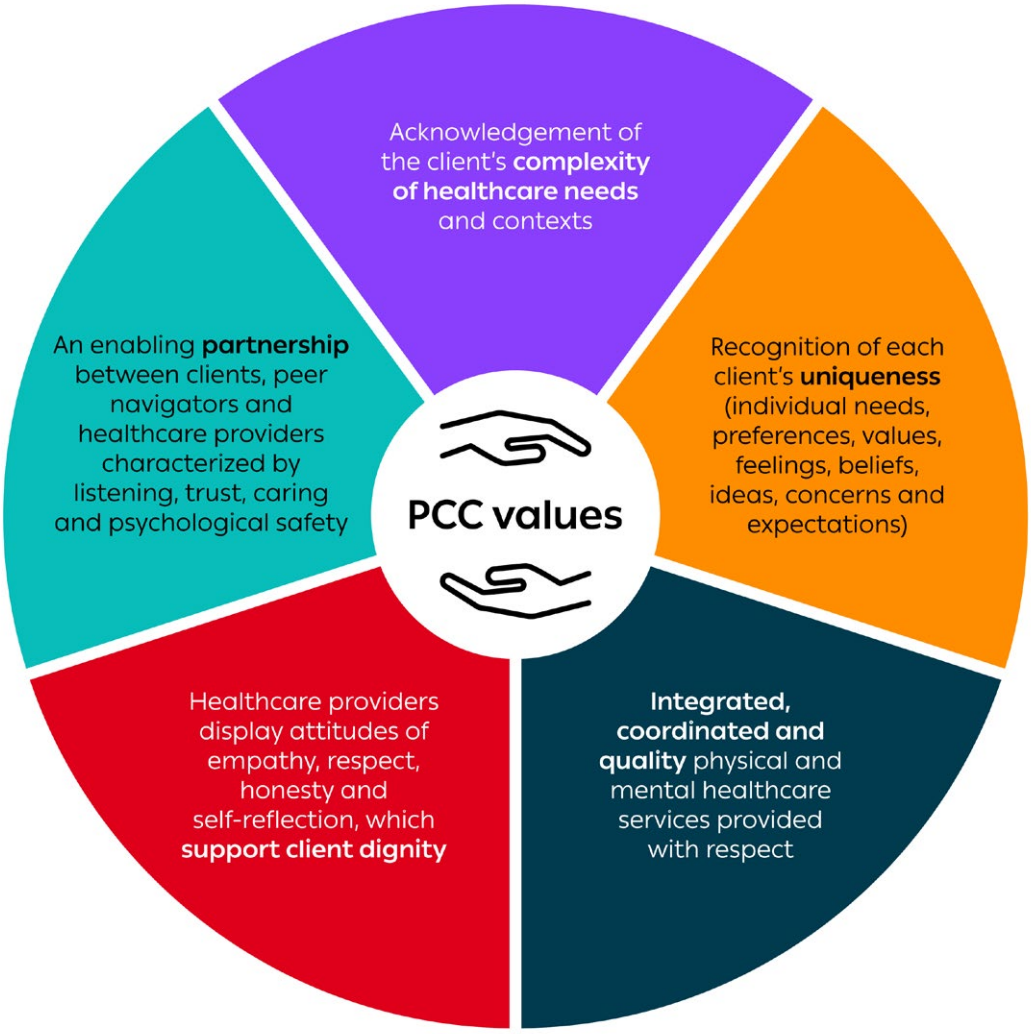
Research has shown that putting people at the centre of their care helps improve their health and reduces the burden of healthcare services and providers[8]. Engaging clients in their care can lead to improved health literacy, self-management skills and overall satisfaction with healthcare services[9].

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 PCC[10].

> **"True person-centred care puts both clients and providers at the centre of services … Lots of little changes can add up to big changes that can make the healthcare system a better place to work and to receive care.**
>
> **— Lina Golob, IAS, France**

PCC values wheel

The PCC values wheel, adapted from the Scholl[11] framework, includes key principles, such as respect for lived experience, personalized care, integrated services, client empowerment and collaborative partnerships. Lina emphasized that PCC is not just about improving clinical outcomes – it is about improving the experience of care for both clients and providers. The client and their relationship with the healthcare provider are placed at the centre of their care. PCC is not only about the mechanics of the service; it includes the relationship and care that underpins the service[12].. A key takeaway from Lina's presentation was the need to adapt PCC to local contexts and recognize that small changes can lead to systemic improvements.



PCC: Origins, evolution and application in today's HIV response

Richard Harding (King's College London, United Kingdom) traced the historical roots and modern relevance of person-centred care in HIV. He began by referencing Dame Cicely Saunders' concept of "total pain", which includes physical, emotional, social and spiritual dimensions of pain. This holistic view laid the groundwork for PCC, especially in palliative care, and has evolved to inform broader healthcare models. Richard emphasized that PCC is not a luxury – it is a core component of high-quality care. His presentation underscored the importance of shifting focus from the virus to the person.

> **"From the life of the virus to the life of the host.**
>
> **— Carla Alexander**

This quote from a colleague encapsulates the essence of PCC: centring care around the individual rather than the disease. His message was: PCC is feasible, evidence-based and essential for improving both clinical and human outcomes in HIV care.

He shared insights from his global research, including studies in Africa, Europe and the UK, demonstrating how PCC improves outcomes when implemented through tools like patient-reported outcome measures (PROMs). These tools allow clients to express what matters most to them, enabling clinicians to respond effectively and efficiently. Richard discussed the challenges often raised by healthcare providers when requested to use PROMs, such as time constraints and feeling unequipped to address complex social issues. He noted that PROMs can save time by focusing consultations and that it is important to clarify to healthcare providers that they are expected to refer or signpost issues beyond their expertise, not resolve all problems directly. Therefore, it is important to develop brief, actionable PROMs and referral systems to support implementation of PROMs.

The POSITIVE Outcomes[13,14] tool is a PROM designed to assess the holistic needs of people living with HIV. The tool is brief, clinically actionable and developed through extensive consultation with communities to ensure relevance and usability. It supports shared decision-making and helps clinicians focus on what matters most to the client, improving both care quality and engagement. The POSITIVE Outcomes tool has been successfully implemented in HIV care settings across Europe and the United States, demonstrating significant impact on both individual and service-level outcomes.

Developed through rigorous research and stakeholder consultation, the tool enables clinicians to quickly identify and address the multidimensional concerns of people living with HIV – including emotional, interpersonal, socioeconomic and physical well-being – during routine appointments. Its use has led to improved client engagement, better identification of unmet needs and enhanced quality of care. At demonstration sites, the tool has been integrated into annual quality improvement cycles, with feedback from both clients and healthcare providers informing ongoing refinement. Importantly, it has shown strong validity, reliability and responsiveness in clinical trials involving over 1,300 participants and has been linked to improved health-related quality of life and reduced symptom burden.

Epidemiological dynamics, person-centred care policies and guidelines

HIV in Europe: Epidemiology and progress towards global goals

Teymur Noori (European Centre for Disease Prevention and Control, ECDC, Sweden) presented a comprehensive overview of the HIV epidemic across Europe at the academy and at the 20th European AIDS Conference[15], highlighting both progress and persistent challenges. He began by outlining the regional distribution of the estimated 2.1 million people living with HIV in the World Health Organization (WHO) European Region in 2024, with approximately 110,000 people newly diagnosed with HIV in the region in 2023. He noted that the eastern Europe region accounts for 57% of people living with HIV and 70% of people newly diagnosed with HIV. Teymur did acknowledge that there are important gaps in the reported data, leading to the underestimation of the number of people living with HIV, particularly in central Europe. He emphasized the importance of understanding transmission dynamics and the role of migration, particularly in western Europe, where an average of 56% of all new diagnoses occur among migrants.

Teymur discussed the implementation of pre-exposure prophylaxis (PrEP), showing that while 27 countries have nationally funded programmes, many still rely on out-of-pocket payments or lack access entirely. He highlighted such barriers as stigma, geographic limitations and high costs, especially for long-acting injectable PrEP formulations. Women and migrants remain under-represented among PrEP users, raising concerns about equitable access. Despite recent progress in countries like Greece, Cyprus and Lithuania, the region is still far from meeting the WHO Europe target of 500,000 people on PrEP by 2025.

Turning to the UNAIDS 95-95-95 targets, the overall European region has achieved 86-86-95, with 10 countries meeting the first 95 target, 19 countries the second 95 target and 24 countries the third 95 target. He noted that this means that only 70% of all people living with HIV in the region are virally suppressed. Sub-regional disparities are stark, with only 59% of people living with HIV virally suppressed in eastern Europe, lagging significantly behind the 85% of people living with HIV and virally suppressed

Teymur Noori responds to a question posed by the session moderator, Marlène Bras, IAS, Switzerland

in western Europe. He stressed the importance of looking beyond aggregate figures to identify who is being left behind, particularly those undiagnosed or diagnosed but not on treatment. Late diagnosis remains a major challenge in Europe, especially among older adults, heterosexual men and people who inject drugs.

Finally, Teymur addressed the issue of stigma and discrimination, presenting data from surveys of both people living with HIV[16] and healthcare workers[17]. A significant proportion of people living with HIV reported fear of discrimination and avoidance of healthcare services. Among healthcare workers, knowledge gaps about HIV prevention tools like U=U and PrEP were widespread, and many reported witnessing discriminatory behaviour in clinical settings. He concluded by showing that HIV acquisition rates and deaths from advanced HIV disease are rising in the WHO European Region instead of reducing to meet targets, underscoring the urgent need for improved surveillance, targeted interventions and policy reform.

Evidence and WHO guidance for people-centred approaches

Stela Bivol (WHO, Regional Office for Europe, Denmark) delivered a presentation focused on the strategic and normative guidance supporting PCC in the HIV response. She began by contextualizing the evolution of HIV programming, from its origins as a vertical emergency response to a more integrated, health systems-based approach. Since 2015, there has been a shift toward mainstreaming HIV into broader health services, including primary healthcare. Stela emphasized that while integration is important, it must be context sensitive, especially in regions with concentrated epidemics where key populations may face stigma in general healthcare settings.

> **“Person-centred care is an approach to care that consciously adopts the perspectives of individuals, caregivers, families and communities as participants in, and beneficiaries of, trusted health systems organized around the comprehensive needs of people rather than individual diseases, and respects social preferences.**
>
> **— WHO guideline on HIV service delivery, 2025[18]**

WHO’s definition of PCC prioritizes individuals, families and communities not only as beneficiaries, but also as active participants in care. This approach requires reorienting core health system functions – governance, financing, service delivery and human resources – to support comprehensive, coordinated and equitable services. Stela highlighted the importance of strategic change management, noting that achieving PCC is not just about reorganizing services, but also about transforming mindsets and institutional cultures.

The presentation reviewed WHO’s regional action plans and technical guidance, including frameworks for integrated service delivery and differentiated care models. These plans advocate for decentralized, partnership-based approaches involving primary care, civil society and public health institutions. Stela stressed the need for tailored services that address the unique needs of key populations, such as trans people, sex workers and people who inject drugs. She referenced WHO’s service packages and implementation tools for PrEP, HIV testing and mental health integration, noting that many of these interventions are still aspirational in parts of Europe due to systemic barriers.

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

Stigma and discrimination

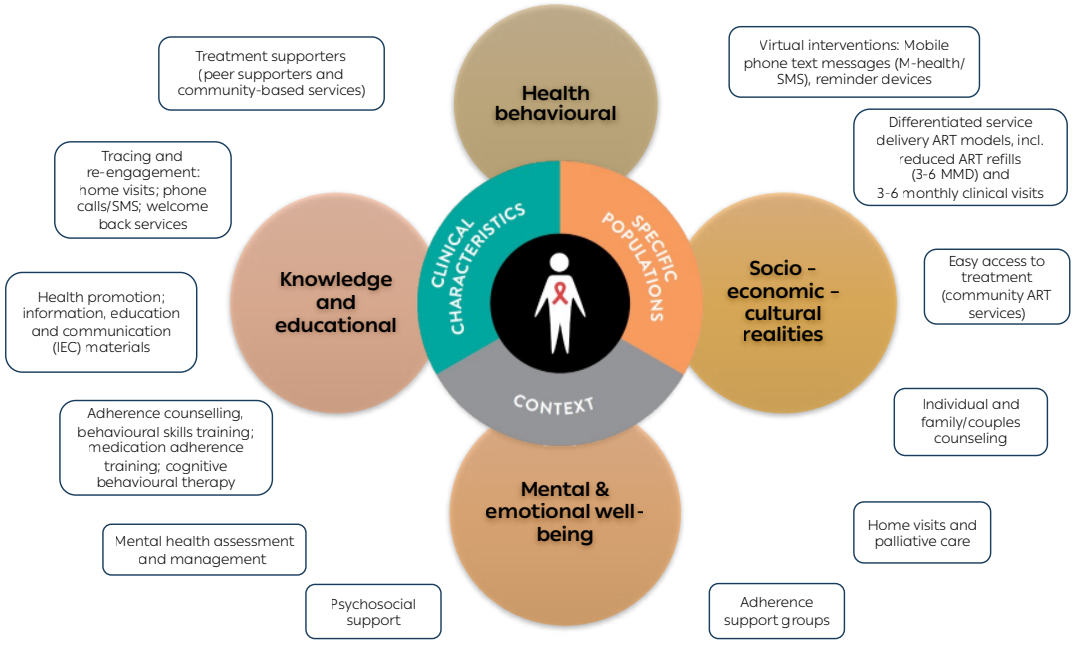
Stela addressed the role of stigma and discrimination in undermining PCC. She presented WHO's technical brief, Ensuring quality health care by reducing HIV-related stigma and discrimination[19], which includes actionable strategies for training providers and improving service quality. Stigma within healthcare settings directly affects access, uptake and retention in care. Without tackling stigma, even the most well-designed services will fail to meet the needs of those they aim to serve. WHO's technical brief emphasizes that eliminating stigma in healthcare settings is vital for delivering high-quality, person-centred care. By actively involving communities and stakeholders in developing and implementing strategies to combat discrimination, healthcare providers can create a more supportive environment. Priority actions outlined in this guidance are:

1. Ensure that people are at the centre of processes and that approaches are framed around enabling quality of life.
2. Build stigma reduction into facility-based quality improvement approaches to improve quality of healthcare services.
3. Engage structures and systems that create enabling environments for quality healthcare.

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 re-engagement 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 Stela Bivol, WHO, at PCC Advocacy Academy, Paris, 2025, 13 October 2025

Stela concluded by acknowledging the challenges posed by shifting funding landscapes and political environments, but argued that these crises also present opportunities to strengthen PCC. Integration and people centredness, she affirmed, are not luxuries; they are essential strategies for sustaining HIV services and improving health outcomes. In the context of the current funding emergency, WHO has released additional guidance[20] for countries and communities to undertake a transparent and structured prioritization process to ensure that access to essential and important services can be maintained while working on short- to long-term strategies for gradual improvement of services through the implementation of person-centred care.

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.

Case studies from advocacy groups and community-led and community-based service providers across Europe

EU migration policies: Increasing barriers in access to healthcare for undocumented migrants

Louise Bonneau (Platform for International Cooperation on Undocumented Migrants, PICUM, Belgium) presented an overview of the increasing barriers undocumented migrants face in accessing healthcare across Europe. She began by clarifying the term, "undocumented", emphasizing that it refers to individuals lacking formal authorization to reside in a country due to expired visas, rejected asylum applications or other administrative reasons. Louise highlighted that undocumented status is often fluid and can affect entire families, including children. Despite the right to health being universal, she noted that no EU member state fully meets WHO's definition of universal health coverage for undocumented populations. While some countries like Belgium, France and Portugal have historically provided access to healthcare, recent trends show a rollback of these rights, with countries like France and Finland proposing restrictive reforms and Sweden considering mandatory reporting of undocumented clients by healthcare professionals.

Louise addressed the practical barriers undocumented migrants face even where legal access exists, such as complex administrative procedures, lack of housing documentation, financial constraints and fear of deportation. She cited research estimating that there are 2.6 to 3.2 million undocumented migrants in 12 European countries, noting that this figure has remained stable since 2008, contradicting narratives of rising irregular migration. The presentation concluded with a warning about EU-level legislative developments, particularly a March 2025 deportation proposal that threatens to increase immigration detention, data sharing and reporting obligations, further undermining healthcare access. PICUM's advocacy focuses on ensuring that migration policies do not obstruct health rights and that undocumented individuals are treated with dignity and equity.

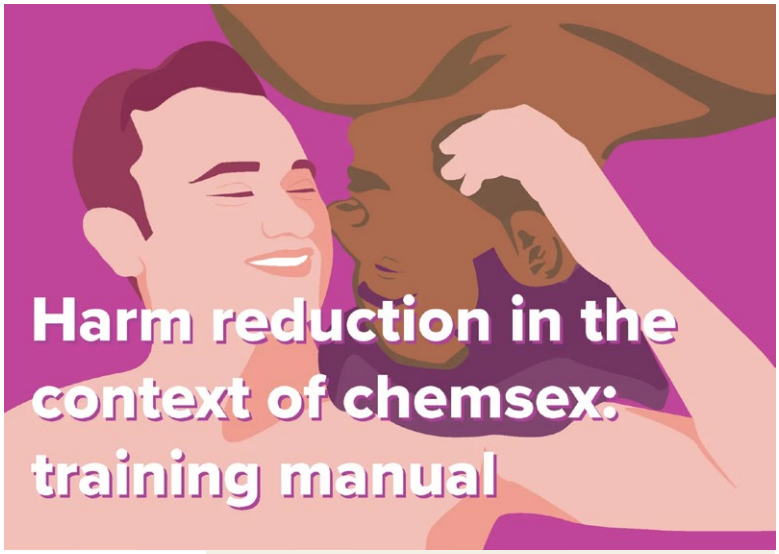
Buddy Polska: Peer support initiative for men who have sex with men recently diagnosed with HIV

Grzegorz Jezierski (Lambda Warszawa Association, Poland) presented the Buddy Polska initiative, a peer support programme designed to support men who have sex with men who are newly diagnosed with HIV. The programme, active since 2019, is built around a network of trained volunteers – currently 18 volunteers working across Poland's cities – who have lived with HIV for at least two years. These volunteers offer non-professional, experience-based support both online and in person, helping clients navigate the emotional and practical challenges following diagnosis.

The initiative emphasizes immediate support, encouragement to begin and adhere to treatment, and reducing stigma through shared lived experiences. It aims to address the lack of psychosocial support and limited opportunities for autonomy experienced by many clients in traditional, medically focused HIV treatment centres. Volunteers receive supervision from psychologists and follow strict boundaries to ensure safe and ethical interactions, leveraging the United Kingdom's National Standards for Peer Support in HIV[21], developed by Positively UK.

The programme also measures its impact using the WHO Quality of Life Questionnaire, administered at the start and three months into the support relationship. Preliminary results show improvements in psychological well-being and social relationships, though limitations exist due to the lack of a control group and reliance on self-reported data.

Harm reduction in the context of chemsex: An AIDS Action Europe training manual



Source: AIDS Action Europe

Antonis Poulios (AIDS Action Europe/ University of Crete, Greece) presented a comprehensive training manual[22], developed by AIDS Action Europe, focused on harm reduction in the context of chemsex. It aims to encourage service providers to continuously engage with the topic and use their analytical, critical and creative skills to better serve their communities using culturally competent and community-led approaches. The manual, available in 14 languages[a], offers a comprehensive framework for understanding chemsex not merely as a set of behaviours, but as a complex intersection of pleasure, identity and marginalization. It promotes a harm reduction philosophy that spans before, during and after substance use, integrating psychological first aid, crisis intervention and community empowerment. Antonis emphasized the importance of building chemsex-friendly services rooted in cultural humility, affirmative care and systemic awareness, advocating for a shift from traditional clinical paradigms towards inclusive, community-centred models.

The training manual outlines practical recommendations for service providers, including the need to relinquish hierarchical power dynamics and engage in continuous self-reflection and supervision. Antonis advocated for healthcare providers to acknowledge the limits of their expertise and learn from the lived experiences of the communities they serve. He highlighted the value of embedding services in spaces that affirm LGBTQI+ identities rather than mainstream harm reduction services, which often lack cultural relevance. His presentation concluded with a call to recognize the existing knowledge in communities, particularly among sex workers and people who engage in chemsex, and to support their leadership in harm reduction efforts.

[a] The manual was originally published in English and has since been translated into 13 languages: Czech, Finnish, French, Greek, Hungarian, Italian, Polish, Portuguese, Romanian, Russian, Slovenian, Turkish and Ukrainian

Community-led advocacy for sex workers' rights

Lisa Philippo (European Sex Workers' Rights Alliance, ESWA, France) outlined ESWA's role as a network of sex worker-led organizations across Europe. It has advocated since 2004 for the recognition of sex work as legitimate labour and for the protection of sex workers from violence, coercion, discrimination and exploitation. Lisa emphasized the diversity of the sex worker community and the multiple layers of marginalization sex workers face, including structural, institutional, interpersonal and internal stigma. She highlighted how legal frameworks, ranging from full or partial criminalization to client criminalization (the Nordic model) to legalization, create access barriers to healthcare, housing and justice, and often exacerbate vulnerability and precarity.

Lisa advocated for full decriminalization as the most effective legal framework to advance sex workers' health and rights, citing examples from New Zealand and Belgium. She stressed the importance of community-led responses, such as peer education, legal support and mutual aid, particularly during crises like the COVID-19 pandemic. Her presentation called for meaningful inclusion of sex workers in decision-making spaces, urging stakeholders to avoid speaking for sex workers and instead elevate their voices as experts of their own lived experiences.

For effective advocacy, it is essential to avoid language and imagery that perpetuates stigma or gendered stereotypes, as these reinforce harmful narratives and discrimination. Advocacy efforts should also prioritize the needs of the most marginalized communities rather than adopting a one-size-fits-all model, ensuring that interventions are tailored and equitable. Recognizing sex work as legitimate work is fundamental alongside supporting the unionization of sex workers. Furthermore, advocates must hold governments and donors accountable by challenging punitive laws and addressing institutional biases that perpetuate inequality, especially in the face of threats to these hard-won rights.

Lisa Philippo presenting on behalf of the European Sex Workers' Rights Alliance

Integrated services for men who have sex with men and people who use drugs

Ricardo Fernandes (GAT, Portugal) presented an overview of the organization's integrated, person-centred HIV services for screening, linkage to care, medical services, combination prevention and social interventions across eight centres. These centres are supported by services focused on anti-discrimination, housing, peer support and condom distribution. One of these centres, CheckpointLX, is a sexual health clinic tailored for men who have sex with men, offering a comprehensive package that includes STI screening, anonymous partner notifications, PrEP consultations, vaccinations and peer-led support. Another centre, IN-Mouraria, serves people who use drugs, providing supervised drug consumption facilities, medical and mental health services, social support and peer navigation. Both centres operate with multidisciplinary teams and are deeply rooted in community engagement, prioritize the use of rapid testing and provide strong linkage-to-care pathways.

Despite the success and impact of these services, Ricardo highlighted several pressing challenges. Political barriers continue to hinder access for undocumented migrants, and the lack of sustainable funding models threatens the continuity of care. Moreover, community-based services like those offered by GAT often struggle for recognition in the national health system, despite their proven effectiveness. Ricardo emphasized the importance of empowering communities not only to design and deliver services, but also to advocate for policy change, ensuring that marginalized populations are actively involved in shaping public health responses.

Humanizing and optimizing HIV healthcare for refugees

Krystyna Rivera (100% LIFE, Ukraine/Germany) highlighted the ongoing need to humanize and optimize HIV healthcare for refugees, particularly Ukrainians living with HIV in Germany displaced by the war in Ukraine, by addressing structural, linguistic and psychological barriers. Acting as a bridge between Ukraine and Germany, 100% LIFE, a well-established Ukrainian community-based organization and its German chapter, work to ensure continuity of care for migrants by combining advocacy with practical service delivery. The presentation highlighted how unfamiliar health systems, language barriers, legal uncertainty and trauma from forced displacement create layered vulnerabilities that prevent refugees from accessing timely HIV treatment, prevention and social support, despite formal entitlements in host countries.

To overcome these challenges, Krystyna is leading the development and pilot testing of DATACHECK Connect, a multi-component digital ecosystem project supported by the Elton John AIDS Foundation, designed to reduce these barriers in a user-friendly way. The vision is that by building on the trusted DATACHECK Ukraine platform, DATACHECK Connect will guide users in Germany to relevant medical, social and legal services while offering assisted telephone translation during doctor visits to overcome language obstacles. Complementing this, the project integrates mental health support through cooperation with Ukraine's National HIV Hotline, enabling refugees to receive culturally sensitive psychological counselling in their native language. A legal chatbot forms the third pillar, providing clear, reliable answers on German HIV-related legislation, human rights and infectious disease regulations.

Together, these tools demonstrate how digital solutions, when grounded in community trust and rights-based approaches, can significantly improve access, dignity and continuity of HIV care for refugees navigating complex host-country systems.

Integrated services for trans people

Mimi Chuichai, Christine Mingo and Giovanna Rincon (Acceptess-T, France) shared the history and mission of Acceptess-T, a trans-led organization founded in 2010. It delivers integrated, community-based services for trans people, combining medical, social, legal and community approaches. Led by a largely trans staff, the organization supported nearly 3,900 trans people in 2024, most of whom face multiple layers of precarity, including migration and/or undocumented status, lack of employment, reliance on sex work and heightened HIV vulnerability.

Acceptess-T's model is built on close collaboration with hospitals and research institutions, through peer-led PrEP and ART provision in hospitals and reciprocal medical follow up at community sites. Its work responds directly to intersecting structural barriers, such as the lack of legal documents, health coverage, language, criminalization of sex work and HIV-related stigma that can leave trans communities vulnerable to disrupted care, isolation and even treatment abandonment.

Their presentation emphasized that effective HIV prevention and treatment adherence cannot be separated from material living conditions. Acceptess-T provides housing as a priority health intervention through its community housing project, Maison des Orchidées, and via emergency hotel stays. It leverages the evidence that stable and safe accommodation enables medication storage, continuity of care, psychological stability and dignity. In 2024, 83% of the 23 individuals that Acceptess-T supported with housing needs were able to access PrEP or ART according to their needs. The community houses go beyond the provision of shelter; they enable therapeutic continuity, the reduction of stress and mental health challenges linked to precarity, access to information about social and medical rights, health mediation, community follow up and the support to rebuild self-esteem and agency.

Acceptess-T adds its voice to a call for a "fourth 95" global UNAIDS target, that is, ensuring that 95% of people living with HIV have a stable and dignified quality of life explaining that this fourth pillar could reframe housing, safety and social recognition as infrastructures of care, which are essential to end HIV as a threat to public health and personal well-being.

Integrated harm reduction for women who use drugs

Aura Roig Forteza (Metzineres, Spain) highlighted the urgent need to rethink harm reduction for women and gender-diverse people who use drugs by centring dignity, community and lived experience rather than medical control. She explained that mainstream harm reduction and consumption services in Catalonia, despite being longstanding and well resourced, have historically been designed around men. They are often highly medicalized, surveillance-heavy and unsafe or unwelcoming for women, trans and non-binary people.

As a result, these populations are under-represented in services and face compounded stigma linked to drug use, gender, poverty, violence, criminalization and migration status. Metzineres was created in response: it is a feminist, anti-prohibitionist, community-led space built with women who use drugs, recognizing them as experts in their own lives and prioritizing relationships, trust and safety over rules, diagnosis or abstinence.

Ismar Hačam , AIDS Action Europe, Germany poses a question to a guest speaker

Metzineres' integrated model reframes harm reduction as a holistic practice rooted in care, housing, legal support, pleasure and collective belonging, rather than solely overdose prevention or infection control. The centre operates as a low-threshold community space, which is open, non-judgemental and flexible, and where women can rest, eat, wash clothes, use drugs more safely, receive legal accompaniment, avoid incarceration and access peer support. Aura emphasized the political dimension of this work: harm reduction cannot be separated from struggles against criminalization, the war on drugs, gender-based violence and social exclusion.

Metzineres produces community-generated evidence, demonstrating that meaningful data can emerge through long-term relationships rather than extractive research methods. The core takeaway was that effective harm reduction for women who use drugs must be feminist, resist incarceration, be community-designed and grounded in love, autonomy and social justice because survival alone is not enough; people deserve to live with dignity.

Introduction to an evidence-to-action framework

Emma Williams (IAS, Switzerland), introduced the structure and elements of the Glasgow Evidence Integration Triangle (EIT) framework. Evidence-to-action (E2A) frameworks, such as the EIT framework, are used in public health to encourage a structured approach that helps translate research findings, data and proven interventions into practical policies, programmes and practices that improve population health outcomes in a few important ways:

1. Bridging the research-practice gap

Public health often generates strong evidence from research and surveillance, but these findings do not automatically influence real-world programmes or policies. An E2A framework provides a step-by-step pathway for turning knowledge into practical solutions, ensuring that evidence does not remain in journals, but informs health systems, policies and community actions.

2. Guiding decision making

E2A frameworks help policy makers and practitioners prioritize interventions by showing which actions are most effective, feasible and cost efficient. They also help identify when evidence is strong enough to act and when more research is needed.

3. Ensuring contextual adaptation

Evidence from one setting may not directly apply to another due to cultural, social or economic differences. E2A frameworks emphasize adaptation of best practices to local contexts, making them relevant and acceptable for communities.

4. Strengthening accountability and monitoring

These frameworks encourage continuous monitoring, evaluation and feedback loops, so that actions based on evidence can be assessed for impact and adjusted over time.

5. Promoting multisectoral collaboration

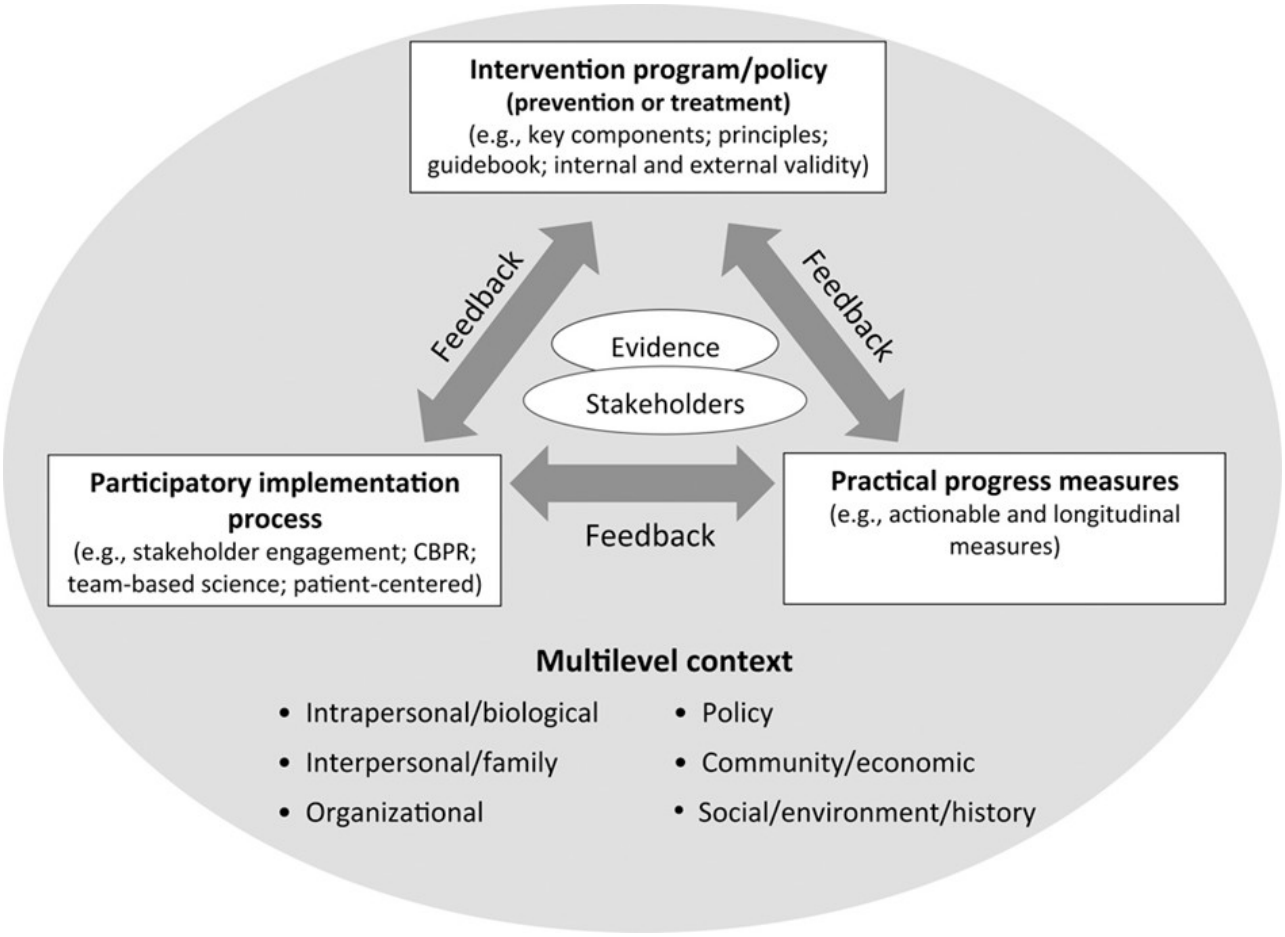
Public health challenges, like the HIV response, often require coordinated action across health, education and policy sectors. E2A frameworks facilitate communication between researchers, policy makers, healthcare workers and communities.

6. Accelerating scale up of effective interventions

Many small-scale pilot programmes show success but fail to expand nationally. By providing structured pathways, E2A frameworks help scale up proven interventions more systematically.

In conclusion, E2A frameworks serve as a bridge between science and practice, ensuring that reliable knowledge drives effective public health interventions and policy decisions and improved population outcomes.

The Evidence Integration Triangle (EIT) framework depicts the complex multilevel contextual factors affecting the integration of scientific knowledge into practical applications. As shown in the diagram below, bringing together evidence and relevant stakeholders is central.



Source: Glasgow et al. (2012). An Evidence Integration Triangle for Aligning Science with Policy and Practice, Am J Prev Med. 42 (6): 646-54

Interactions among the three main evidence-based components – intervention programme or policy, participatory implementation processes and measures of progress – empower these stakeholders to use scientific evidence to maximize positive health impact and value and encourage development and sharing of new knowledge to inform future interactions.

Context is pivotal to the EIT. The multilevel context (that is, the conditions surrounding health problems and intervention opportunities in a particular place with a particular population) is a key starting point. Context also changes over time, giving a temporal and recursive aspect to the EIT, with context continually informing the other key components. Keeping an eye on contextual factors allows evidence to be made and kept relevant.

Applying the E2A framework to advance PCC approaches: Discussion group report backs

Participants were allocated one of the five themes from the PCC values wheel. As a group, they were then challenged to prioritize one specific question related to that theme and to then apply the following EIT framework checklist to explore the relevant evidence to support targeted interventions related to this theme.

Step A: Define and select practical, evidence-based interventions

What you do: Identify interventions with a strong evidence base that are feasible to deliver in the local context (not just ideal trial conditions). Prioritize interventions where effect sizes are meaningful for the target population.

Practical tip: Instead of asking "Is this efficacious?", ask "Can this be delivered with existing staff, supplies and workflows?" and document any required adaptations.

Why this matters: EIT emphasizes interventions that are both evidence-based and practicable so implementation can begin quickly and be scaled.

Step B: Co-design participatory implementation processes

What you do: Convene and sustain active partnerships among stakeholders including people with lived experience, community organizations, frontline providers, healthcare system managers, funders and policymakers to co-design how the intervention will be delivered.

Practical tip: Use rapid cycles of feedback (short Plan-Do-Study-Act loops) and intentionally design for equity and to reach the most vulnerable populations.

Why this matters: EIT stresses that stakeholder engagement and iterative adaptation are core and not optional when the goal is real-world uptake.

Step C: Choose pragmatic, actionable measures of progress

What you do: Select a small set of meaningful, low-burden indicators that stakeholders care about and that can be measured frequently (weekly/monthly), with data fed back rapidly for decision-making.

Practical tip: Prioritize measures already collected in routine systems (logs, registers) and supplement with short rapid-feedback surveys (for example, brief client experience questions).

Why this matters: Rapid, pragmatic measurement creates the feedback loop that lets teams adjust implementation quickly.

Step D: Create rapid feedback loops and align incentives

What you do: Operationalize processes to share measurement results with stakeholders quickly and visibly (dashboards, short meetings, community briefs) and align incentives/roles so data leads to action (e.g., clinics get implementation coaching if uptake lags).

Practical tip: Keep feedback short, focused on decisions ("what will we change this week?") and track whether changes move the needle.

Why this matters: Without rapid cycles that link measurement to adaptation, good interventions may still fail in practice.

Step E: Document context, adaptations, and sustainability strategies

What you do: Systematically record contextual factors and adaptations (who, what, when, why) and plan for long-term funding, workforce and policy supports to sustain effective delivery

Practical tip: Use an "adaptation log" and build sustainability milestones into the implementation plan (e.g., policy change or budget line within 12 months).

Why this matters: EIT emphasizes context as dynamic; capturing adaptations is needed both for local improvement and for others who might replicate the programme.

Step F: Iterate – use evidence, implementation experience, and measurement together

What you do: Repeat the cycle. Review evidence and local data, co-design adjustments with stakeholders, implement changes, measure again. Scale what works and stop what doesn't work.

Practical tip: Build decision thresholds (e.g., if 3-month retention < X% after 6 months, change model) so iterations are explicit and time-bounded.

Why this matters: The EIT framework is intentionally iterative; it's designed for ongoing system learning and scale.

Participants discuss the application of the EIT framework to different themes

Language and communication: What are some successful approaches in Europe for reducing stigma, including self-stigma, in healthcare settings?

- Any intervention must include all clinical and non-clinical staff that a client may interact with during a visit to a healthcare setting and must include the meaningful participation of clients with lived experience in the co-design process.
- For clinical healthcare providers, it can be helpful to bring their awareness to the communication barriers that can arise due to the use of overly medicalized terminology or from their unconscious biases.
- Storytelling approaches can be a helpful way to illustrate how stigma can be experienced during these clinical conversations and other interactions in healthcare settings.

Client empowerment: What is needed in practice to enable this to happen consistently?

- Communities themselves are the experts, and meaningful programmes must be co-designed with them, involving community members in implementation, monitoring and evaluation.
- Creating safe, trusted spaces is critical so people feel a sense of belonging and can share their real lived experiences without fear or stigma.
- Data collection should be community-led and relevant, prioritizing timely, meaningful and context-specific data rather than outdated reports or top-down metrics.
- Stigma should be addressed through training and awareness, shifting from labels and simplistic messaging toward deeper understanding of why people make the choices they do.

Healthcare provider and community healthcare worker well-being and support: What are good practice models in which community healthcare workers are implementing HIV prevention and treatment services in Europe?

- In Europe, a priority is to develop approaches that can reach people living with HIV, especially from key populations, who are diagnosed late with contributing factors, including poor living conditions and multiple vulnerabilities.
- Good practice models are those that are geographically proximate, community-based, friendly and accessible and provide comprehensive and integrated medical care with social support, including housing, food and community activities.
- To be effective, strong emphasis must be placed on multi-pronged outreach, including mobile services and on-foot engagement to reach people who are hardest to connect to care.
- Good practice models also prioritize co-design and collaboration with healthcare providers, community leaders, NGOs, social workers, public health authorities and policy makers.
- Monitoring and adaptability are central, combining clinical data with outreach and satisfaction metrics, regular community feedback and a shared culture aimed at reducing hierarchy across medical, social and community teams.

Integrated care models: Can integrated care packages for people living with HIV or vulnerable to HIV acquisition in Europe be delivered effectively through primary healthcare?

- Primary healthcare often excludes HIV services, leaving many populations underserved, especially key populations, migrants, undocumented migrants, refugees and internally displaced persons, meaning that "everyone is missing out" to some degree depending on the country context.
- Major access barriers include geographic distance to a limited number of HIV treatment centres, financial constraints, lack of information and restricted mobility during crises (for example, the war in Ukraine), where people may only be able to reach local primary healthcare providers.
- Stigma, discrimination and language barriers in healthcare settings are widespread, compounded by insufficient psychological support for people facing displacement, stress and new HIV diagnoses.
- Integrated HIV care in primary healthcare is feasible, but requires capacity building, particularly training and educating general practitioners and primary healthcare providers on the needs of people living with HIV and of key populations.
- Effective implementation must be co-designed, involving public health institutions, governments, communities and private healthcare providers while accounting for high mobility among migrant populations (for example, Ukrainians refugees).

Healthcare systems and governance: What are good practice models for ensuring that healthcare governance processes meaningfully incorporate the voices of community representatives?

- The discussion focused on identifying good practice models for healthcare governance that genuinely include community representatives in decision making.
- The group centred their reflections on Black African populations while noting strong relevance to other migrant populations and other diverse key populations.
- A key concern was that current healthcare data collection and evaluation frameworks are not person centred and fail to reflect people's lived experiences or priorities.
- Existing indicators of "success" in healthcare services are often defined without meaningful community input, leading to misaligned outcomes.
- The proposed intervention was to train Black African peer supporters to co-design success indicators, including mapping the diversity within key populations relating to gender and other intersecting identities.

Effective communication and ethical storytelling

Tara Mansell (IAS, Switzerland) facilitated a group discussion on the traits of effective communicators, including active listening, clarity, sincerity and the ability to adapt language to the audience. She also introduced the importance of challenging singular narratives in advocacy by providing multiple voices and perspectives, and demonstrated techniques for positive framing and solution-oriented communication.

Example of re-framing

Don't say: "People living with HIV don't stay in care."

Do say: "Health systems need to meet people where they are, so care is easier to stay in."

Among her tips for reframing language were:

1. Shifting from blame (hard to reach) to support (marginalized)
2. Shifting from gaps (people fall out of care) to opportunities (we can build flexible pathways back to care)
3. Shifting from deficit (clients don't adhere to treatment) to agency (people stay in care when care fits with the reality of their lives)

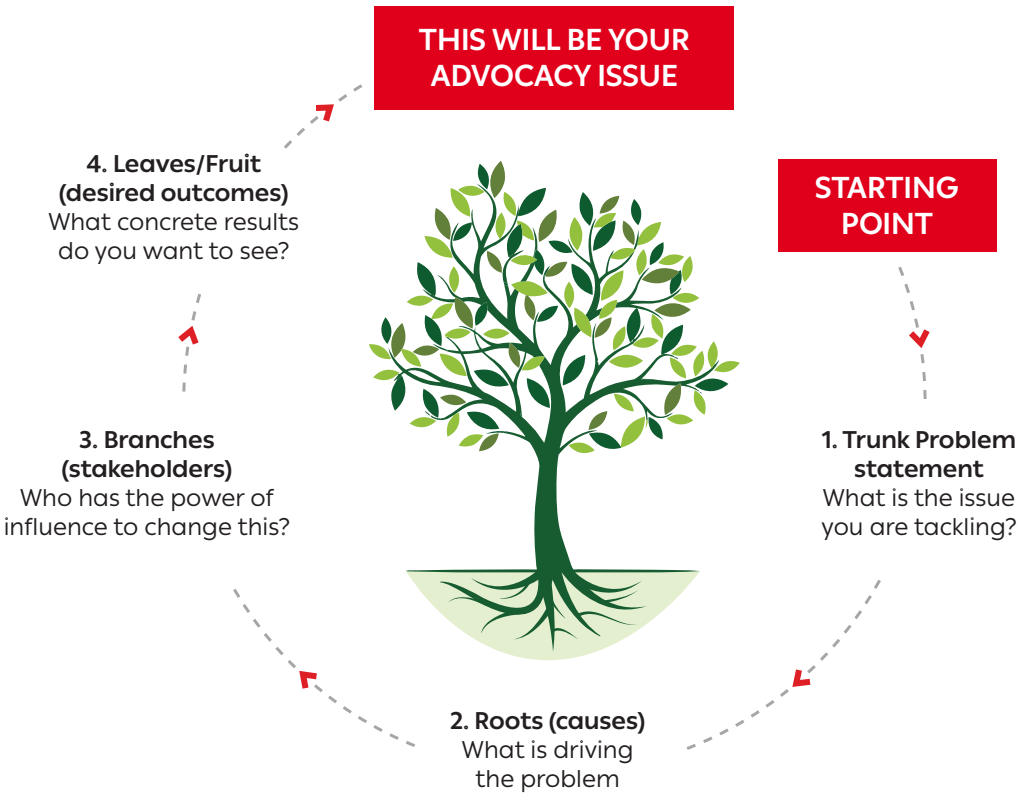
Tara Mansell facilitates a discussion on effective communication and ethical storytelling

Tara introduced the principles of ethical storytelling, such as prioritizing the voices of people with lived experience, respecting dignity, obtaining consent, avoiding stereotypes and ensuring accuracy without sensationalism. Participants discussed the ethical implications of using images in advocacy, including the potential for overexposure to negative imagery, the risk of reinforcing stereotypes and the importance of consulting with community representatives to ensure respectful representation. The conversation also addressed the need to adapt storytelling approaches to different cultural contexts, recognizing that language, imagery and narrative strategies may have varying effects depending on the audience and local norms.

Participants reviewed examples of person-first language, discussing the importance of placing the person before their condition and avoiding terms that attribute blame or reinforce stigma, such as "infected" or "risky behaviour". The group explored the challenges of translating person-first language into different languages, noting that some concepts do not have direct equivalents and that cultural adaptation is necessary to ensure that messages are effective and respectful. Tara highlighted the risks of overusing acronyms and technical terms, which can depersonalize communication and exclude non-specialist audiences, and instead encouraged the use of concise, clear language tailored to the context.

Structuring advocacy messaging using the "advocacy tree" framework

Tara Mansell introduced the "advocacy tree" framework for structuring advocacy messaging for more effective communication with stakeholders, illustrated below:



Using an example to illustrate the "advocacy tree" framework:

Trunk (problem statement): People living with HIV are not receiving person-centred care because health workers are not trained in PCC approaches.

Roots (causes): Stigma among healthcare providers caused by lack of training and persisting myths about HIV

Branches (stakeholders): Ministry of Health (training programmes), hospital directors (staff policies), donors (funding training), media (translating science to media)

Leaves/Fruit (desired outcomes): Inclusion of PCC training in national guidelines; funded programmes to retrain staff; reduction in reports of stigma in health facilities

Exercise: Pitching to priority stakeholders

Fellows pitch tailored advocacy messages for each priority stakeholder group

Each group used the "advocacy tree" framework to prepare a pitch for priority actions for each group of stakeholders.

Clients

Clients need to be supported to learn which HIV services, rights and standards of care they are entitled to, and to be able to clearly articulate gaps or barriers they experience in accessing these. Equipped with this knowledge and clarity, clients can demand appropriate, respectful and inclusive care and actively engage with healthcare providers, healthcare systems and HIV advocates to influence how services are designed and delivered.

Community-based organizations

Community organizations and people living with HIV hold critical lived experience knowledge that is being undervalued and excluded from national and global HIV policy and decision making, despite the long-standing principle of "nothing about us without us". Community-based organizations must be meaningfully embedded in HIV policy, funding and healthcare service delivery processes because they embody the lived expertise, trust and reach that drive equitable, inclusive and effective outcomes. A truly effective HIV response requires sustained funding and genuine partnership between governments and community-based organizations to ensure that healthcare services are inclusive and fit for purpose.

Clients

Healthcare workers must be supported and encouraged to recognize and eliminate stigmatizing behaviours toward people living with HIV by applying proper knowledge, standard precautions and the ethical principle of "do no harm". They are also encouraged to partner with community members to co-design evidence-based training that addresses bias and improves trust, safety and quality of care.av

Healthcare system administrators

Healthcare administrators should invest in continuous professional education for healthcare workers, focusing on empathetic, stigma-free care, psychosocial support and harm reduction approaches. Healthcare administrators should expand and decentralize HIV and PrEP services by integrating HIV prevention, PrEP counselling and chemsex support into existing clinics outside major cities to improve equitable access. Healthcare administrators should also embed age-appropriate screening for co-morbidities into routine HIV care to support healthy ageing and treatment adherence.

Policy makers

Researchers should move beyond narrow clinical- and adherence-focused frameworks by centring the lived experiences, priorities and realities of communities affected by HIV. Meaningful community involvement at every stage of a research project can make findings more relevant, ethically grounded and impactful while strengthening arguments to funders for future research projects. Building equal, sustained partnerships with communities restores trust and autonomy and ultimately produces better and more socially responsive science.

Funders

Funders should prioritize targeted capacity building for local NGOs working in prisons, enabling them to deliver quality peer support, HIV and TB services and digital or distance education for people in, or recently released from, prisons and other closed settings. Investments should support integration of prison-based interventions into national health systems, recognizing prisons as high-impact settings where early prevention and care can reduce long-term healthcare costs and save lives.

Media

Priority actions for media are to humanize HIV by amplifying authentic voices from stigmatized communities through short-form and long-form digital storytelling that challenges moral judgments and stereotypes. Media should use relatable, life-affirming narratives and multidisciplinary formats (social media videos, interviews, animation, print) to foster public empathy and awareness. This visibility should also be strategically used to influence policy makers and healthcare providers toward more inclusive, rights-based responses to HIV, migration status and access to care.

Recommended further reading:

A multi-phase process led by the IAS in 2022-2024 was used to develop a roadmap with roles and actions for different stakeholders to realize the full potential of PCC. It concluded that there is a joint need to foster a culture that hears all voices in the care team, including clients and their caregivers, the community and all HCW cadres. At a systems level, it will be crucial to strengthen HIV and primary health care integration and align with the universal health coverage agenda for increased investment in inclusive, responsive and sustainable healthcare for all.

Access the full article: Golob L, Williams EL, Bras M, Clifton B, Ford N, Geng EH, Green KE, Janamnuaysook R, Katz IT, Mworeko L, Olete RA, Pinto C, Rajasuriar R, Sikombe K, Tan DHS, Grinsztejn B. A roadmap to scale up person-centred care in the HIV response: recommendations from a global consensus-building process. J Int AIDS Soc. 2025 Dec;28(12):e70071.

Good practice models of PCC in France

Current advocacy priorities in France and the AIDES experience

Fabrice Pilorgé (AIDES, France) presented the history of AIDES. This is a long-standing, community-based HIV organization whose advocacy is built by and for people affected by HIV and grounded in lived experience rather than institutional or professional viewpoints. He emphasized that this positioning gives AIDES greater freedom and legitimacy in advocacy, allowing it to challenge policies and practices directly from a community-needs perspective. Advocacy at AIDES pursues two core objectives: defending the rights and health of people affected by HIV; and shaping public policies to improve prevention, care and health democracy. This work is carried out by a multidisciplinary advocacy team that, while having areas of specialization, works collectively across issues as they emerge.

Fabrice highlighted several current advocacy priorities in France, including access to HIV treatment and PrEP (notably the complex debates around injectable PrEP), defending harm reduction and ending punitive drug policies, and combating growing discrimination against people living with HIV. A major concern is migrants' health rights, particularly threats to state medical assistance and the rollback of protections allowing seriously ill migrants to remain in France for treatment – changes that AIDES argue will increase suffering and long-term costs. He also stressed AIDES' strong engagement in global advocacy and its role in promoting "health democracy", ensuring that affected communities are involved in decision making.

Finally, he illustrated how AIDES uses bold, strategic communications and high-profile allies to amplify messages, reminding both professionals and the public that the HIV epidemic is not over and that solidarity remains essential.

Ikambere

Founded in 1997 in Saint-Denis, Ikambere ("the Welcoming House" in Kinyarwanda) supports women living with chronic illnesses, particularly those facing socioeconomic insecurity. It initially focused on women living with HIV and, since 2022, women with diabetes, obesity and hypertension. Through a holistic and compassionate methodology combining individualized social and therapeutic support, peer aid, group workshops (for example, nutrition, physical activity, sewing and digital literacy) and emergency assistance, Ikambere empowers over 500 women annually toward autonomy.

Academy participants and Ikambere staff pictured inside the "Welcoming House"

The association also offers respite stays ("Maison reposante"), affordable transitional housing ("appartements passerelles") and actions to reduce isolation among older women ("Femmes Roseaux") and mothers ("Mères et Enfants"). Additionally, Ikambere leads health mediation in hospitals and communities, including training professionals and using creative tools like the "Réponses pour elles" cards to promote sexual health and reduce stigma while expanding its impact across Île-de-France and overseas territories.

Le 190

Le 190 is a pioneering sexual health centre in Paris, one of very few of its kind in France. It was created in 2010 and is currently located in the 11th arrondissement. The centre offers a comprehensive, stigma-free approach to sexual health, including information, testing, prevention, diagnosis, treatment and follow up for HIV, hepatitis and other STIs, alongside vaccination and contraception services. It caters primarily for gay and bisexual men who have sex with men, though open to all. It provides multidisciplinary care through a team comprising doctors, nurses, psychologists, psychiatrists, sexologists, dermatologists and addiction specialists. Le 190 is also a leading provider of PrEP in France – ranking among the top two centres for PrEP prescriptions – and addresses broader needs like mental health, chemsex-related support and psycho-sexual care.

Checkpoint Paris

Checkpoint Paris offers a comprehensive, inclusive and free health service focused on sexual health, HIV and STI prevention and community well-being. It provides rapid testing for HIV, hepatitis and STIs with on-site treatment when needed, as well as access to PrEP, PEP, contraception and vaccinations. Specialized consultations are available in sexology, gynaecology, mental health and social support, all tailored for LGBTQIA+ and marginalized communities. The centre also offers harm reduction and counselling for substance use and chemsex, wound care for injection complications and holistic support for trans health and hormone treatments – ensuring respectful, confidential and non-judgemental care.

Academy participants pictured outside Checkpoint Paris

Community-based participatory research principles

Bruno Spire (INSERM/AIDES, France) and Nicolas Lorente (Coalition PLUS, Spain) provided an overview of community-based participatory research (CBPR) principles and methodologies[24] that put people at the centre in HIV-related research, namely:

1. Communities are acknowledged as the expert knowledge holders

CBPR in HIV-related research must begin from the principle that people most affected by HIV are not merely subjects of research, but holders of essential knowledge. Lived experience, lay knowledge and community expertise must be positioned as equally valuable to academic or clinical expertise. Rather than conducting research on communities, CBPR insists on doing research with communities, recognizing that those living with or most exposed to HIV are best placed to identify relevant questions, priorities and meaning within the data.

2. Shared governance is actively and continually addressed

A central tenet is that CBPR must actively acknowledge and address power imbalances between researchers and communities. Even with participatory intentions, academic institutions often retain structural power through funding control, technical expertise and publication norms. Bruno and Nicolas stressed that equality should be understood as a goal rather than an assumption, requiring constant reflexivity, trust building and shared governance mechanisms. True participation involves task shifting, such as involving community members in study design, recruitment, tool development, interpretation and dissemination, rather than limiting their role to advisory or symbolic participation.

3. The goal of CBPR is social transformation

Research should not be seen as an end, but rather as a means to achieve important social changes. Community-based research is a strategic tool to influence policy, improve service access and challenge exclusionary systems. Examples from HIV testing, PrEP access and trans-led research in France were used to illustrate how data generated collaboratively can be leveraged in advocacy to change laws, funding priorities and care models. In this framing, research, advocacy and service delivery are deeply interconnected rather than separate domains.

4. Scientific credibility and community priorities are higher priorities than publication

Publishing scientific papers should not be the primary goal of CBPR. Instead, publications are one of the strategic tools that can help legitimize community knowledge, gain access to academic and policy spaces, and secure sustainable funding. However, prioritizing publication too early or too narrowly can distort research processes and suppress important findings. The key message is that publication should serve community goals, not override them.

Bruno Spire and Nicolas Lorente lead a discussion with participants on CBPR principles

5. Trust is based on capacity-building and fair compensation

Trust is the foundation of effective community-based research. Trust is built through long-term relationships, informal collaboration, transparency and mutual respect for different forms of expertise. Capacity building is most effective when it occurs through "learning by doing", with communities leading or co-leading research while being supported technically where needed. Sustainable CBPR relies on funding models that fairly compensate community organizations and recognize research as part of their core work, not an add-on. Without this, participation risks becoming extractive rather than empowering.

Bruno shared two emblematic examples to illustrate the value of CBPR approaches. First, community-led HIV testing studies[25,26] demonstrated the feasibility and public health impact of non-medicalized screening, directly contributing to rapid regulatory change authorizing community testing in France. Second, the IPERGAY PrEP trial[27] showed how participatory trial design – through community recruitment, counselling, peer support and governance – achieved a dramatic reduction in HIV incidence and accelerated PrEP rollout and policy adoption.

Nicolas indicated that CBPR has now been expanded to many communities, including migrant sex workers and trans women living with HIV, and responses to emerging epidemics, such as mpox. Studies like the Trans&VIH[28] survey demonstrate how community-based methods improve recruitment, data quality and relevance while revealing intersecting vulnerabilities related to migration status, income insecurity, violence and healthcare access. Overall, these and many more global examples, which were shared, underscore CBPR as a win-win partnership – producing impactful science, strengthening advocacy and improving the quality and equity of HIV responses.

PCC implementation, monitoring and evaluation considerations

Person-centred HIV strategic information

Brian Rice (University of Sheffield, United Kingdom) outlined why truly person-centred HIV care depends on person-centred data and explained several important ways that current data systems often fail to reflect real human behaviour. Brian's presentation drew on research that informed WHO's Consolidated guidelines on person-centred HIV strategic information[29], and specifically on Chapter 5, "Harnessing the strength of routine data for HIV surveillance", which he co-chaired with Shona Dalal (WHO, Switzerland).

Brian explained why new recommendations were necessary to improve how HIV data are collected, linked and interpreted. A core problem is the reliance on aggregated, facility-based data, which assume linear and stable care pathways. In reality, people move between clinics, test multiple times, disengage and re-engage with care or appear under slightly different identifiers. Using a simple example of one individual attending two clinics in a single reporting period, he shows how this can lead to major overestimation of new HIV diagnoses when systems cannot link records across time and place.

Brian Rice presents the evidence underpinning the WHO Consolidated guidelines on person-centred HIV strategic information

Brian illustrated these issues with research findings from the Western Cape, South Africa[30,31], in which clients recorded as "newly diagnosed" were examined in detail after paper records were digitized. Nearly half were found to be repeat testers rather than new diagnoses, and over 40% of people classified as "lost to care" were still receiving treatment at neighbouring facilities, most through undocumented transfers driven by everyday factors like work changes or seasonal access issues, such as impassable roads during the rainy season. These insights emerged only once individual-level records were linked across clinics.

The same person-centred approach underpinned work in the United Kingdom[32], where a minimal but secure national HIV dataset enabled monitoring of late diagnosis, quality of care and mortality, and strengthened advocacy for targeted funding and prevention.

Brian articulated a non-linear, cyclical care cascade[33–35] that reflects disengagement and re-engagement at multiple points, providing clinicians with more realistic insights into client pathways. He further showed why CD4 data remains critical, not only for identifying instances of late diagnosis[36], but for estimating incidence and correcting flawed clinical assumptions. For example, CD4-based modelling revealed that many migrants in the United Kingdom had acquired HIV after arrival, contradicting clinicians' assumptions that HIV acquisition occurred in their countries of birth and enabling advocacy for expanded prevention services for migrant populations[37].

Brian concluded by emphasizing that stronger case-based surveillance systems and community-generated data are feasible and essential if HIV programmes are to be both accurate and genuinely person centred[38–42].

Advocating for access to healthcare for migrant populations

Denis Onyango (Africa Advocacy Foundation, United Kingdom) outlined the significant health inequities faced by migrants across Europe, particularly regarding HIV, NCDs and maternal health. Although migrants contribute to Europe's social and economic fabric, they face persistent legal, structural and social barriers to accessing healthcare. Denis highlighted stark examples of situations in which undocumented migrants can receive an HIV diagnosis, but remain ineligible for treatment, resulting in preventable illness and, in some cases, unaffordable medical bills when care is available only under "emergency" provisions.

Denis highlighted the fragmentation and contradictions in the European policy landscape. While the EU promotes a rights-based healthcare framework aligned with the European Charter, the reality on the ground is that the EU Pact on Migration and Asylum reinforces strict border management and enforcement that can undermine access to health services.

He explained that healthcare across EU Member States varies widely because health systems are nationally governed, resulting in inconsistent entitlements, patchy insurance eligibility and differing rules on service provision. For example, some countries still restrict who is allowed to conduct HIV testing, limiting community-based models. In the Netherlands, community-based organizations are not legally allowed to perform HIV tests, forcing them to bring in public health officials, which contrasts with the more flexible and effective models of community-led testing operating in the United Kingdom.

Denis emphasized solutions grounded in community engagement, cultural competence and universal access to healthcare. Drawing on the Africa Advocacy Foundation's work, he highlighted the success of its efforts to train, support and empower community champions, trusted individuals within migrant communities who help navigate social networks, build trust and increase uptake of HIV testing and PrEP.

The Mi-Health HIV partnership tested 1,882 people in nine months in 2024, demonstrating a 1.6% HIV prevalence. Previous phases of the partnership (2022-23) demonstrated a 6.4% HIV prevalence overall and much higher rates (17-25%) among sex workers, people who inject drugs, men who have sex with men and trans people. Major gaps in HIV prevention services persist, as demonstrated by the Mi-Health PrEP & Migrants Study 2025, with only 29% of surveyed migrants having an accurate understanding of PrEP and just 9% being active PrEP users. Denis concluded that Europe cannot reach its public health goals unless healthcare is decoupled from immigration enforcement, migrant-inclusive data systems are developed, and community-based services receive sustained investment because "health for all is only possible if no one is left outside". Denis finished with a comprehensive call to action for stakeholders, as outlined in the table below::

Stakeholder group	Priority roles
Healthcare providers	Deliver non-discriminatory, culturally competent care. Challenge policies that create barriers. Advocate for your clients' rights regardless of status.
Policy makers	Align migration and health policies with human rights obligations. Support inclusive health programmes in national HIV action plans.
Researchers and academics	Partner meaningfully with migrant communities. Ensure that research includes migrant populations and addresses their specific needs.
NGOs and civil society	Collaborate with migrant-led organizations. Share best practices. Amplify community voices in policy spaces.
Funders	Prioritize community-led interventions. Support long-term capacity building, not just short-term projects.

Stakeholder engagement: Civil society and public sector partnership models

Liudmyla Legkostup (Public Health Centre of the Ministry of Health of Ukraine, Ukraine) emphasized that Ukraine's HIV prevention, treatment and care system has remained resilient despite years of conflict, including annexation in 2014 and a full-scale invasion in 2022. She described how ongoing attacks on healthcare facilities and disruptions to infrastructure have placed enormous pressure on service delivery, and yet, the partnership between the Ministry of Health and more than 50 non-government organizations (NGOs) has ensured continuity of prevention, testing and care. For example, she noted that HIV prevention and support services have largely stayed at pre-war levels, with more than 320,000 people receiving prevention services and over 33,000 people receiving care and support, with only some temporary suspensions in frontline areas.

She highlighted Ukraine's long-term transition toward state-funded HIV services. Beginning in 2018 and fully achieved by 2021, the country shifted financing for key NGO-led services from international donors to the national budget, guided by national HIV strategies, operational plans and WHO recommendations. Liudmyla explained that the state-funded service package includes harm reduction, HIV testing, TB screening, distribution of condoms and lubricants, and referral pathways for opioid substitution therapy and psychosocial support. She also pointed to several updates of national service standards since 2019, noting an ongoing revision by the Ministry of Health to further strengthen quality and alignment with community needs.

Liudmyla underscored the importance of innovation and data systems in sustaining person-centred HIV services. She described the rollout of a new national information system, launched in 2023 to help NGOs record services and monitor clients in real time, with plans for integration into the national medical information system. She illustrated progress in PrEP scale up, noting the increase from just four clients in 2017 to more than 13,000 on oral PrEP and 150 on cabotegravir, achievements she attributed to close coordination between NGOs and the Ministry of Health. Annual coordination meetings between government institutions and NGOs ensure that services remain adaptive, community focused and resilient even in emergency conditions, offering a model of effective collaboration in crisis settings.

Presentation of advocacy action plans from the fellows at the post-academy virtual convening

This virtual convening, held a few weeks after the academy in Paris, brought together fellows from across Europe with alumni from past academies to reflect on how they will apply lessons from the PCC Advocacy Academy to advance person-centred HIV care in their own contexts. Fellows described how the academy strengthened their understanding of person-centred principles, such as co-design, community leadership, cultural humility and the importance of lived experience in shaping health systems, and renewed their motivation to adapt these approaches in diverse health, policy and funding environments. Many referenced the academy's emphasis on listening before leading, the power of storytelling and the importance of translating evidence into action.

Several fellows shared concrete plans to shift their national HIV services toward models that place people and communities at the centre. In Sweden, one fellow emphasized redesigning outreach and programme development based on lived experiences, co-creation and community-led evidence to strengthen equity and shared ownership. In Ireland, a fellow is using the academy's tools to draft a policy brief advocating for more integrated, community-centred PrEP delivery, including expanding provision beyond hospital-based clinics and embedding well-being assessments into routine care. Likewise, a representative from Serbia outlined plans to expand national access to PrEP by training counsellors and coordinating with public health institutions in preparation for a forthcoming Global Fund-supported rollout.

Others are applying person-centred care principles to marginalized or structurally excluded populations. Fellows working on migration and displacement in Germany and Poland described plans for workshops, storytelling initiatives and participatory research to ensure that migrant communities can articulate their needs directly to health providers and policy makers. A team from Ukraine presented a pilot model to transition HIV services in prisons from donor-funded to state-funded provision, emphasizing peer-led support, capacity building for prison health staff and sustained continuity of care, even during the ongoing war.

The academy's impact was also visible in new advocacy approaches spanning law enforcement, academia and public communication. In the United Kingdom, one participant is developing training for police custody officers on stigma-free, trauma-informed, person-centred HIV care while proposing a conference plenary on how language shapes access and equity. A Turkish participant is launching a podcast series on person-centred care to bridge the gap between community stories and academic or clinical discourse. Another fellow is creating animated video stories featuring trans people, sex workers and people who use drugs in Berlin to communicate lived realities and challenge stigma within health systems.

Finally, fellows working in challenging political environments – such as Georgia and Ukraine – shared strategies for advancing person-centred care despite shrinking civic space, restrictive legislation or conflict. In Georgia, advocacy is shifting toward influencing technical bodies like national disease control centres and UN partners, integrating PCC into guidelines, operational research and programme planning without triggering political risk. Across contexts, fellows emphasized that person-centred care is not a discrete project but a mindset: a commitment to dignity, empathy, co-creation and shared power that can strengthen HIV responses even amid funding cuts and systemic instability.

Academy programme

Sunday, 12 October 2025

Time	Session
18:00 – 20:00	Welcome apéro dinatoire

Monday, 13 October 2025

Time	Session
08:30 – 08:45	Opening remarks
08:45 – 10:00	Session 1 – Epidemiological dynamics, PCC policies and guidelines
10:00 – 10:30	Refreshments break
10:30 – 12:00	Session 2 – Case studies from advocacy groups and community-led and community-based service providers across Europe (part 1)
12:00 – 13:30	Networking lunch
13:30 – 15:00	Session 3 – Case studies from advocacy groups and community-led and community-based service providers across Europe (part 2)
15:00 – 15:30	Refreshments break
15:30 – 17:00	Session 4 – PCC design in action (breakout groups)

Tuesday, 14 October 2025

Time	Session
08:30 – 08:45	Reflections on day one sessions
08:45 – 10:00	Session 5 – Advocacy in action & storytelling workshop (part 1)
10:00 – 10:30	Refreshments break
10:30 – 11:15	Session 5 – Advocacy in action & storytelling workshop (part 2)
11:15 – 12:00	Session 6 – Good practice models in France (part 1)
12:00 – 13:00	Lunch
13:00 – 18:00	Session 6 – Good practice models in France (part 2): site visits in Paris

Wednesday, 15 October 2025

Time	Session
08:30 – 08:45	Reflections on day two sessions
08:45 – 10:00	Session 7 – Putting people at the centre in HIV-related research: Community-based participatory research principles
10:00 – 10:30	Refreshments break
10:30 – 11:30	Session 8 – PCC implementation, monitoring and evaluation considerations
11:30 – 12:00	Closing remarks

Post-academy virtual convening

Wednesday, 12 November 2025

Time	Session
10:00 – 10:45	Presentation of advocacy action plans from the fellows
10:55 – 11:05	Break
11:05 – 12:00	Presentation of advocacy action plans from the fellows (continued)

About the IAS Person-Centred Care programme

The Person-Centred Care (PCC) programme, initiated by the IAS in 2021, aims to improve 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 person-centred 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
- 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

The PCC Advocacy Academies aim to be catalysts for follow-up pilot projects, ongoing good practice sharing and the development of policy recommendations. The objectives are 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 policy makers, the media and programme managers.
- 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.

Many advocacy academy alumni stay engaged with the IAS, and many have participated in IAS-organized international conferences. Each academy has a specific regional focus. The inaugural PCC Advocacy Academy took place in November 2024 in Lusaka, Zambia, with participants attending from 11 African countries. The second PCC Advocacy Academy took place in April 2025 in Atlanta, United States, with participants from 12 southern states. This event, the PCC Advocacy Academy: HIV in Europe, welcomed participants from 19 countries across Europe.

About our organizing partners

About AIDES and Coalition PLUS

AIDES is the leading HIV and AIDS organization in France, with drop-in centres and premises in over 54 cities in France and partnerships with organizations abroad. AIDES is a founding member, major funder and provides the governance framework for Coalition PLUS (CP), an international union of community-based NGOs founded in 2008, which brings together around 100 organizations operating in 51 countries. CP campaigns for people living with, affected by or particularly vulnerable to HIV to be systematically placed at the heart of decision-making processes and implementation and evaluation of health programmes that concern them. CP contributes to improving the response to HIV and viral hepatitis and social transformation through direct services (such as HIV and hepatitis screening or the distribution of antiretroviral treatment), implementation research (with communities having a dominant role in its development) and advocacy (to advance people's rights).

About AIDS Action Europe

AIDS Action Europe (AAE) is a regional network of more than 270 diverse NGOs, national networks and community-based groups, most of which are AIDS service organizations, in 47 countries spanning the WHO European Region. Its mission is to strengthen civil society to work towards a more effective response to the HIV and AIDS, tuberculosis and viral hepatitis epidemics in Europe and central Asia. AAE strives for the best standards of human rights protection and universal access to prevention, treatment, care and support, tackling health inequalities and focusing on key and affected populations. AAE is governed by a Steering Committee of seven members. Its office is hosted by Deutsche Aidshilfe e.V. and based in Berlin, Germany.

About the European AIDS Clinical Society

The European AIDS Clinical Society (EACS) promotes excellence in prevention, care, research and education for HIV and related conditions across Europe. EACS advocates for equitable access to healthcare and aims to improve quality for those vulnerable to or affected by HIV while shaping public health policies. The aim is to reduce the burden of HIV across Europe. It is Europe's largest society of healthcare professionals working in the field of HIV and AIDS.

List of participants

Speakers

Name	Organization	State
Stela Bivol	WHO Europe	Denmark
Louise Bonneau	Platform for International Cooperation on Undocumented Migrants (PICUM)	Belgium
Paulie "Amanita" Calderón-Cifuentes	Trans Europe and Central Asia	Germany
Ricardo Fernandes	GAT Portugal	Portugal
Richard Harding	King's College London	United Kingdom
Grzegorz Jezierski	Lambda Warszawa Association	Poland
Liudmyla Legkostup	Public Health Center of the Ministry of Health of Ukraine	Ukraine
Nicolas Lorente	Coalition PLUS	Spain
Chuichai Mimi	AcceptessT	France
Christine Mingo	AcceptessT	France
Teymur Noori	European CDC	Sweden
Denis Onyango	Africa Advocacy Foundation	United Kingdom
Lisa Phillipo	European Sex Workers Alliance	France
Fabrice Pilorgé	AIDES	France
Antonis Poulios	AIDS Action Europe / University of Crete	Greece
Brian Rice	University of Sheffield	United Kingdom
Krystyna Rivera	100% LIFE gGmbH	Germany / Ukraine
Aura Roig Forteza	Metzineres	Spain
Bruno Spire	INSERM	France

Fellows

Name	Organization	Country
Oluwakemi Agunbiade	National AIDS Trust	United Kingdom
Abimbola Ajomale	Noaks Ark Mosaik	Sweden
Olha Chyzhykovska	Charitable organization "FREE ZONE"	Ukraine
David Comer	University of Galway	Ireland
Tomer Einav	Charité and BezirksApotheke	Germany
Olimbi Hoxhaj	Albanian Association of PLWHA	Albania
Esma Imerlishvili	Real People Real Vision	Georgia
Liudmyla Legkostup	State institutions Public Health Center of the MOH of Ukraine	Ukraine
Rafał Majka	Association for Preventive Healthcare "Jeden Świat"	Poland
Oguzhan Latif Nuh	Our Community Action for Research and Empowerment (OurCARE)	Turkey / Switzerland
Isabella Pepe Razzolini	Erasmus Medical Center	Netherlands
Milos Peric	Asocijacija DUGA/Association RAINBOW	Serbia
Brian Rice	University of Sheffield	United Kingdom
Krystyna Rivera	100% LIFE gGmbH	Germany / Ukraine
Pank Sethi	Positive East	United Kingdom
Anna Shapoval	I-TECH and Svoja NGO	Ukraine
Tiago Teixeira	OPUS DIVERSIDADES	Portugal
Nino Tsereteli	Center for Information and Counseling on Reproductive Health – Tanadgoma	Georgia
Raymond Van Huizen	SESSTIM (Inserm, IRD, Aix-Marseille University)	France

Organizers

Name	Organization	State
Ferenc Bagyinszky	AIDS Action Europe	Germany
Teddy Bourgeonnier	IAS – the International AIDS Society	Switzerland
Marlène Bras	IAS – the International AIDS Society	Switzerland
Lina Golob	IAS – the International AIDS Society	France
Ismar Hačam	AIDS Action Europe	Germany
Loena Le Goff-Gestin	IAS – the International AIDS Society	Switzerland
Tara Mansell	IAS – the International AIDS Society	Switzerland
Fabrice Pilorgé	AIDES	France
Radka Serak	IAS – the International AIDS Society	Switzerland
Bruno Spire	INSERM	France
Stephan Vernhes	AIDES	France
Emma Williams	IAS – the International AIDS Society	Switzerland

Observers

First name	Organization	State
Rhiannon Bid	Gilead Sciences	United Kingdom
Larkin Callaghan	Gilead Sciences	United States
Christian Ramers	Gilead Sciences	United States
Giovanna Rincon	AcceptessT	France
Annette Triebel	Gilead Sciences	United Kingdom

Definitions of key PCC terms

Burnout: This term includes a combination of emotional exhaustion, cynicism, depersonalization and low personal accomplishment caused by chronic stress[43,44].

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 decisions[45].

Decentralization of services: This refers to the provision of healthcare services outside of health facilities to enhance access .[46].

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 system[47].

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 identity[48]. 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 course[49].

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 services[50].

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 services[51].

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 health[52].

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[53,54]. 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 communities[55].

Psychological first aid (PFA): This refers to a humane and supportive approach to providing psychosocial support to individuals based on human resilience, including the provision of information, comfort, practical assistance and referral to a specialist as needed[56,57].

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 system[58].

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 system[59].

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 systems[40].

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 care[60].

Key global guidance documents

- Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach – 2021
  Note: see Chapter 7.4
- Consolidated guidelines for key populations – 2022
- Global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022-2030 - 2022
- Primary health care and HIV: convergent actions: policy considerations for decision-makers – 2023
- 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
- Implementing the global health sector strategies on HIV, viral hepatitis and sexually transmitted infections, 2022–2030: Report on progress and gaps 2024, second edition - 2024
- WHO guideline on HIV service delivery: updated guidance on the integration of diabetes, hypertension and mental health services, and interventions to support adherence to antiretroviral therapy – 2025
- The Global AIDS Strategy for 2026–2031: Towards Ending AIDS – 2026
- HIV Prevention 2030 Global Access Framework – 2026

References

[1] World Health Organization, UNICEF. Operational framework for primary health care: transforming vision into action. Geneva: 2020.

[2] Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001.

[3] Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness - a systematic review and concept analysis. PLoS One. 2014 Sep 17;9(9):e107828.

[4] Stewart M. Towards a global definition of patient centred care. BMJ. 2001 Feb 24;322(7284):444-5.

[5] IAS – the International AIDS Society. Person-centred care stakeholder consultations - What are the core elements and mechanisms of person-centred care within the HIV response? IAS; 2023.

[6] The Health Foundation. Person-centred care made simple: What everyone should know about person-centred care. 2016.

[7] Cloninger CR. Person-centred integrative care. J Eval Clin Pract. 2011 Apr;17(2):371-2.

[8] Collins A. Measuring what really matters. Towards a coherent measurement system to support person-centred care. London: The Health Foundation; 2014.

[9] World Health Organization. Preparing a health care workforce for the 21st century: the challenge of chronic conditions. World Health Organization; 2005.

[10] Lood Q, Carlström E, Klinga C, et al. A collaborative endeavour to integrate leadership and person-centred ethics: a focus group study on experiences from developing and realising an educational programme to support the transition towards person-centred care. BMC Health Serv Res. 2024; 24, 395.

[11] Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness - a systematic review and concept analysis. PLoS One. 2014 Sep 17;9(9):e107828.

[12] D. Shaller. Patient-Centered Care: What Does It Take? The Commonwealth Fund. October 2007.

[13] Harding R, Jones CI, Bremner S, Bristowe K, West B, Siegert RJ, O'Brien KK, Whetham J; EMERGE Consortium, Horizon 2020. Positive Outcomes: Validity, reliability and responsiveness of a novel person-centred outcome measure for people with HIV. HIV Med. 2022 Jul;23(6):673-683.

[14] Positive Outcomes: HIV PROM

[15] Cairns G, aidsmap, More Europeans are dying from HIV now than 15 years ago, 21 October 2025.

[16] European Centre for Disease Prevention and Control. Stigma: survey of people living with HIV. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2022 progress report. Stockholm: ECDC; 2023.

[17] European Centre for Disease Prevention and Control. HIV stigma in the healthcare setting. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia. Stockholm: ECDC; 2024.

[18] World Health Organization. WHO guideline on HIV service delivery: updated guidance on the integration of diabetes, hypertension and mental health services, and interventions to support adherence to antiretroviral therapy. WHO; 2025.

[19] World Health Organization. WHO technical brief: reducing HIV-related stigma and discrimination. WHO; 2024.

[20] World Health Organization. WHO publication that can support this piece: Sustaining priority services for HIV, viral hepatitis and sexually transmitted infections in a changing funding landscape: operational guidance. Geneva; 2025.

[21] Positively UK. National Standards for Peer Support in HIV.

[22] Poulios, A. (2022). Harm reduction in the context of chemsex: training manual. Berlin: AIDS Action Europe

[23] Glasgow et al. (2012). An Evidence Integration Triangle for Aligning Science with Policy and Practice, Am J Prev Med. 42 (6): 646-54

[24] E. Demange, E. Henry, Marie Préau. De la recherche en collaboration à la recherche communautaire. Un guide méthodologique (From collaborative research to community-based research. A methodological toolkit). 2012, pp.214.

[25] Champenois K, Le Gall JM, Jacquemin C, Jean S, Martin C, Rios L, Benoit O, Vermoesen S, Lert F, Spire B, Yazdanpanah Y. ANRS-COM'TEST: description of a community-based HIV testing intervention in non-medical settings for men who have sex with men. BMJ Open. 2012 Apr 1;2(2):e000693.

[26] Lorente N, Preau M, Vernay-Vaisse C, Mora M, Blanche J, Otis J, Passeron A, Le Gall JM, Dhotte P, Carrieri MP, Suzan-Monti M, Spire B; ANRS-DRAG Study Group. Expanding access to non-medicalized community-based rapid testing to men who have sex with men: an urgent HIV prevention intervention (the ANRS-DRAG study). PLoS One. 2013 Apr 16;8(4):e61225. doi: 10.1371/journal.pone.0061225. Erratum in: PLoS One. 2013;8(6).

[27] Chaix ML, Leturque N, Gabassi A, Charreau I, Minier M, Pialoux G, Cua É, Chidiac C, Raffi F, Tremblay C, Meyer L, Molina JM, Delaugerre C; ANRS IPERGAY study group. Prevalence and incidence of HEV among men using HIV pre-exposure prophylaxis: A sub-study of the ANRS IPERGAY trial. J Clin Virol. 2023 Mar;160:105380.

[28] Mora M, Rincon G, Bourrelly M, Maradan G, Freire Maresca A, Michard F, Rouveix E, Pannetier J, Leriche D, Alain T, Yazdanpanah Y, Michels D, Spire B. Living conditions, HIV and gender affirmation care pathways of transgender people living with HIV in France: a nationwide, comprehensive, cross-sectional, community-based research protocol (ANRS Trans&HIV). BMJ Open. 2021 Dec 16;11(12):e052691.

[29] World Health Organization. Consolidated guidelines on person-centred HIV strategic information: strengthening routine data for impact. Geneva: WHO; 2022. Licence: CC BY-NC-SA 3.0 IGO.

[30] Jacob N, Rice B, Kalk E, Heekes A, Morgan J, Hargreaves J, Boulle A. Utility of digitising point of care HIV test results to accurately measure, and improve performance towards, the UNAIDS 90-90-90 targets. PLoS One. 2020 Jun 30;15(6):e0235471.

[31] Jacob N, Rice B, Kalk E, Heekes A, Morgan J, Brinkmann S, Hargreaves J, Orgill M, Boulle A. Consolidating strategic information to monitor progress against the UNAIDS 90-90-90 targets: evaluating the operational feasibility of an electronic HIV testing register in Cape Town, South Africa. BMC Health Serv Res. 2020 Aug 6;20(1):720.

[32] Rice BD, Yin Z, Brown AE, Croxford S, Conti S, De Angelis D, Delpech VC. Monitoring of the HIV Epidemic Using Routinely Collected Data: The Case of the United Kingdom. AIDS Behav. 2017 Jul;21(Suppl 1):83-90.

[33] Mugglin C, Kläger D, Gueler A, Vanobberghen F, Rice B, Egger M; International epidemiology Databases to Evaluate AIDS in Southern Africa. The HIV care cascade in sub-Saharan Africa: systematic review of published criteria and definitions. J Int AIDS Soc. 2021 Jul;24(7):e25761.

[34] Ehrenkranz P, Rosen S, Boulle A, Eaton JW, Ford N, Fox MP, Grimsrud A, Rice BD, Sikazwe I, Holmes CB. The revolving door of HIV care: Revising the service delivery cascade to achieve the UNAIDS 95-95-95 goals. PLoS Med. 2021 May 24;18(5):e1003651.

[35] Euvrard J, Timmerman V, Keene CM, Phelanyane F, Heekes A, Rice BD, Grimsrud A, Ehrenkranz P, Boulle A. The cyclical cascade of HIV care: Temporal care engagement trends within a population-wide cohort. PLoS Med. 2024 May 10;21(5):e1004407.

[36] Ammi Shah, Neil Mackay, Hannah Kitt, Catriona Harrison, Kedeen Okumu-Camerra, Natasha Ratna, Victoria Schoemig, Cuong Chau, Veronique Martin, Alison Brown, Tamara Đuretić. HIV testing, PrEP, new HIV diagnoses and care outcomes for people accessing HIV services: 2025 report. The annual official statistics data release (data to end of December 2024). October 2025, UK Health Security Agency, London

[37] Rice BD, Elford J, Yin Z, Delpech VC. A new method to assign country of HIV infection among heterosexuals born abroad and diagnosed with HIV. AIDS. 2012 Sep 24;26(15):1961-6.

[38] MeSH Consortium. Protocol for the Situational Assessment of HIV Case Reporting.

[39] Harklerode R, Schwarcz S, Hargreaves J, Boulle A, Todd J, Xueref S, Rice B. Feasibility of Establishing HIV Case-Based Surveillance to Measure Progress Along the Health Sector Cascade: Situational Assessments in Tanzania, South Africa, and Kenya. JMIR Public Health Surveill. 2017 Jul 10;3(3):e44.

[40] Rice B, Boulle A, Baral S, Egger M, Mee P, Fearon E, Reniers G, Todd J, Schwarcz S, Weir S, Rutherford G, Hargreaves J. Strengthening Routine Data Systems to Track the HIV Epidemic and Guide the Response in Sub-Saharan Africa. JMIR Public Health Surveill. 2018 Apr 3;4(2):e36.

[41] Jacob N, Rice B, Heekes A, Johnson LF, Brinkmann S, Kufa T, Puren A, Boulle A. Exploring the validity of routine individuated service data for antenatal HIV surveillance in the Western Cape. BMC Infect Dis. 2025 Mar 4;25(1):309.

[42] Jacob N, Rice B, Heekes A, Johnson LF, Brinkmann S, Kufa T, Boulle A. Can routine antenatal data be used to assess HIV antiretroviral therapy coverage among pregnant women? Evaluating the validity of different data sources in the Western Cape, South Africa. PLoS One. 2024 Apr 18;19(4):e0291844.

[43] De Hert S. Burnout in Healthcare Workers: Prevalence, Impact and Preventative Strategies. Local Reg Anesth. 2020 Oct 28;13:171-183.

[44] Steinhaus MC, Nicholson TJ, Pliakas T, Harper A, Lilleston P, Mainga T, Milimo D, Jennings K, Grobbelaar N, Louis F, Liebenberg H, Hayes RJ, Fidler S, Ayles H, Bock P, Hoddinott G, Hargreaves JR, Bond V, Stangl AL; HPTN 071 (PopART) study team. Prevalence and risk of burnout among HIV service providers in South Africa and Zambia: findings from the HPTN 071 (PopART) trial. Hum Resour Health. 2024 Jul 8;22(1):50.

[45] Prasad SJ, Nair P, Gadhvi K, Barai I, Danish HS, Philip AB. Cultural humility: treating the patient, not the illness. Med Educ Online. 2016 Feb 3;21:30908.

[46] Reidy WJ, Sheriff M, Wang C, Hawken M, Koech E, Elul B, Kimanga D, Abrams EJ; Identifying Optimal Models of HIV Care in Africa: Kenya Consortium. Decentralization of HIV care and treatment services in Central Province, Kenya. J Acquir Immune Defic Syndr. 2014 Sep 1;67(1):e34-40.

[47] IAS. Differentiated service delivery.

[48] World Health Organization. Gender incongruence and transgender health in the ICD.

[49] World Health Organization. Executive Board. Framework on integrated, people-centred health services: report by the Secretariat. Geneva: 2016.

[50] National Association of People with HIV Australia (NAPWHA). HIV Peer Support.

[51] World Health Organization. Executive Board. Framework on integrated, people-centred health services: report by the Secretariat. Geneva: 2016.

[52] World Health Organization, UNICEF. Operational framework for primary health care: transforming vision into action. Geneva: 2020.

[53] People First Charter. HIV Language, Person First Language.

[54] Dilmitis S, Edwards O, Hull B, Margolese S, Mason N, Namiba A, Nyambe M, Paxton S, Petretti S, Ross GV, Welbourn A, Zakowics A. Language, identity and HIV: why do we keep talking about the responsible and responsive use of language? Language matters. J Int AIDS Soc. 2012 Jul 11;15(Suppl 2).

[55] World Health Organization, UNICEF. Operational framework for primary health care: transforming vision into action. Geneva: 2020.

[56] Wang L, Norman I, Edleston V, Oyo C, Leamy M. The Effectiveness and Implementation of Psychological First Aid as a Therapeutic Intervention After Trauma: An Integrative Review. Trauma Violence Abuse. 2024 Oct;25(4):2638-2656.

[57] World Health Organization, War Trauma Foundation and World Vision International (2011). Psychological first aid: Guide for field workers. WHO: Geneva.

[58] World Health Organization. Social participation for universal health coverage: technical paper. Geneva: 2023.[53] People First Charter. HIV Language, Person First Language.

[59] Braveman PA, Arkin E, Proctor D, Kauh T, Holm N. Systemic And Structural Racism: Definitions, Examples, Health Damages, And Approaches To Dismantling. Health Aff (Millwood). 2022 Feb;41(2):171-178.

[60] World Health Organization. Universal Health Coverage.