



# Person-centred care stakeholder consultation meeting series, 2022-2023

## Meeting report

### Background

IAS – the International AIDS Society – recognizes that quality healthcare for people living with and affected by HIV must integrate other health issues and be responsive to the evolving needs, priorities and preferences of each individual. Established by the IAS in 2021, the [Person-Centred Care programme](#) promotes care that responds to people's complex health needs and is sensitive to identities and contexts. The IAS conducted a stakeholder consultation meeting on 30 July 2022 in conjunction with AIDS 2022, the 24th International AIDS Conference, titled "Person-Centred Care approaches to improve quality of life for people living with and affected by HIV".

### About the consultation series

The stakeholder consultation series aims to provide a platform for exchange on the concept of person-centred care in the HIV response. The discussions, learnings and recommendations from the series will form the basis of a joint publication to build common cause around the concept of person-centred care. In particular, it will provide recommendations for different groups of stakeholders as they work towards realizing the full potential of person-centred care for the HIV response.



## Setting the scene: Consultation meeting I, 30 July 2022, Montréal, Canada

*"How can I prevent my mother-in-law from learning my HIV status? How will it affect my relationship with her, my child and my partner if she finds out?"*

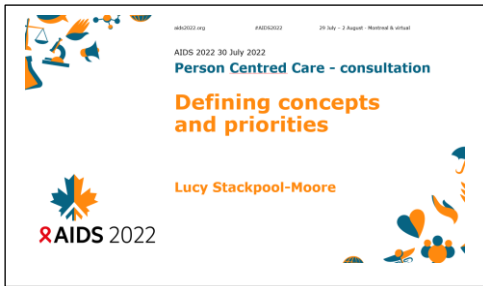
– Maximina Jokonya reflecting on her experience of being a postpartum mother living with HIV in Zimbabwe, contemplating the HIV-positive label clearly marked above her hospital bed and preparing to greet her mother-in-law as she arrives for a visit to meet the baby

### Meeting overview

Forty-three participants from a variety of disciplines in HIV science, advocacy and service implementation attended the first consultation meeting of the series. The objective of the meeting was to set the scene for the upcoming conversations – describing the key concepts around person-centred care approaches and outlining healthcare and support system experiences of various groups of people living with and affected by HIV.

In addition, participants from global normative agencies, donors, implementing partners, people living with and affected by HIV and industry provided their perspectives on person-centred care. Rapid-fire statements from this diverse group of stakeholders, followed by breakout group discussions, helped in the conducting of a first assessment of priorities and preferences. Participants from the consultation series were asked to self-nominate to be included in an IAS-facilitated person-centred care steering committee to guide the programme, objectives and output of the ongoing consultation series.

### Presentations and statements

| Presentation 1: Defining concepts and priorities of person-centred care             |  |
|---|--|
|  | <p>Meeting facilitator <b>Lucy Stackpool-Moore (IAS, Switzerland)</b> explained the aim of the consultation series and outlined the objectives of the first meeting. Lucy acknowledged that there are many different terms for the concept of person-centred care and asked if there is a need for a common definition. Lucy highlighted the importance of acknowledging intersectionality, using the example that services designed for a population group, such as "mothers", ignore the heterogeneity of that group. In addition, she emphasized that health is to be understood as dynamic and that healthfulness is not necessarily to be considered as the baseline.</p> |



## Presentation 2: Realizing the full potential of person-centred HIV care – global imperative and commitment to ending the AIDS epidemic and ensuring health and well-being for all



In her pre-recorded presentation, **Ani Shakarishvili (UNAIDS, Switzerland)** spoke about the necessity of scaling up individual, needs-responsive, gender-sensitive and local context-specific services for people living with HIV, key populations and other priority groups, such as adolescents, migrants and people in humanitarian settings. [Watch the full recording](#)

### Rapid-fire statements

**José M Zuniga (IAPAC and Fast-Track Cities Institute, United States)** outlined the steps deemed necessary to foster transition from disease-oriented to person-centred HIV care. These include: increased support for and augmentation of the healthcare workforce; measuring client satisfaction and client involvement in decision-making about their care; and prioritizing community-led engagement, planning and monitoring of HIV services. On a societal level, he calls for a shift from dominant or malignant narratives about race, gender identity and sexual orientation and, instead, to centre care on lived experience without reinforcing labels, objectification, stigmatization and marginalization.

**Maximina Jokonya (HER Voice Fund Coordinator, Y+ Global, Zimbabwe)** shared her experiences of challenges related to being a young mother living with HIV. She mentioned the lack of information available to her during her pregnancy and postpartum period and related issues around involuntary disclosure of her HIV status to relatives. To overcome these challenges, Maximina recommends strengthening integration of services, especially for young mothers living with HIV, and empowering them to be at the centre of every decision being made for their own and their infants' health. Considerations should include service components related to contraception, partner protection and the mental health of the young mother, including postpartum trauma, stress and depression.

**Joel Gallant (Gilead Sciences, United States)** highlighted the promotion of health equity as a key to achieving person-centred care. The delivery of person-centred care is dependent on specific measures and targets being in place, which address inequities related to the interaction between race/ethnicity, sexual orientation, gender identity and expression, social conditions and legal status of HIV. Innovation in both HIV clinical care delivery and therapeutics that benefit clients – alongside the accompanying policy to support uptake of that innovation – should be a key component of person-centred care. People living with HIV or at risk of acquiring HIV are often seen as homogenous groups rather than individuals with their own needs and preferences. Treatment decisions should be clinically tailored for each individual and rooted in person-centred approaches to care. Long-acting treatments can also support person-centred care approaches, especially for those who have not responded to other treatments or wish to avoid daily oral therapy due to the fear of stigma.



#### Additional statements

- **Sharonann Lynch (Global Health Policy and Politics Initiative, O'Neill Institute for National and Global Health Law, United States)** pointed out that talking about equity should include talking about actual barriers, such as clinical treatments being priced out of reach for many people. With the mortality rate of people with HIV and cryptococcal co-infections at 74% in 2020 and pricing of hepatitis treatments also limiting access, we cannot talk about achieving person-centred care without actual life-saving care.
- **Kenneth H Mayer (Fenway Institute and JIAS Editor in Chief, United States)** spoke about the importance of provider training to overcome personal and institutional barriers. He also encouraged meeting participants to submit person-centred care-focused articles to the *Journal of the International AIDS Society* to share opinions and stimulate the global discussion on person-centred care.
- **Kimberly Green (PATH, Vietnam)** spoke about the importance of addressing people's primary healthcare experiences as the vast majority of healthcare system interaction takes place at that level. Considering the limited resources, the "where" and "how" of primary healthcare investments should be addressed. On integration of services, it will be important to determine how to work with the limits set by donors on how budgets should be spent.

#### Group work

Four groups discussed two sets of questions:

1. Define key concepts
  - What's in a name?
  - Should we focus on defining person-centred care?
  - And/or should we focus on bringing together all relevant concepts?
2. Outline healthcare and support system experiences
  - Who do we need to be thinking about?
  - What are the axes of difference to consider?
  - When is it useful to consider commonalities and universalities?

#### Group discussion report-back: Key themes

##### On defining the concept of person-centred care ...

There is no single agreed definition of person-centred care and different terms are used interchangeably. The group acknowledged that defining person-centred care might not be essential because different definitions already exist. A bigger challenge is to overcome the disease-oriented care approach that has developed within the HIV response and consider the complex health needs of a person and the contexts in which they live, rather than focusing on a single element of their health. If the group was to work on a definition, it would have to be clear what purpose that definition should serve and who the target audience of this definition is. To make the concept a useful tool for the HIV response, work on defining the concept should be informed by different groups of stakeholders, including people living with and affected by HIV, healthcare providers and policy makers. The group acknowledged that partnership is essential and such a process cannot be led solely by clients, nor by clinicians.



Throughout the discussion, a picture emerged of the important elements of person-centred care. In recognizing the many factors that constitute a person's evolving health needs, person-centred care seeks to provide sustainable support and empowerment of the client. Seeking care is often a moment of vulnerability that can be enhanced by peer support and providers who are able to meet the person's needs in an empowering and sustainable way. Person-centred care acknowledges context and identity, as well as complex clinical needs – and the fact that these elements can evolve over time:

- Contexts can relate to the setting in which someone lives, their family, culture, religion or spirituality, the laws and policies governing their way of life, their access to healthcare, education and work opportunities and many other aspects.
- Identity exists in interaction with these contexts, as well as with aspects of race/ethnicity, sexual orientation, age, roles, gender identity and expression.
- Clinical manifestations of illness and related needs include mental health and psychosocial support. When people seek care, they want all of their health needs addressed coherently.

### **On healthcare and support system experiences ...**

A significant portion of the discussion focused on the range of barriers to achieving person-centred care that are situated at different levels. This could be at the individual level, in relationships with providers or at the macro level, namely the healthcare system and broader economic, political, educational and societal systems. Based on this discussion, we can start to identify a set of key enablers for achieving person-centred care at these different levels:

---

#### **Client experiences and needs inform healthcare provision**

- Define ways to ensure that clients' experiences are shared and inform their care and the care of their peers.
- Welcome people within all of their contexts, respecting their choices and preferences.

---

#### **Providers receive training and are supported by peer navigators**

- Provide the resources and continuous education opportunities needed to empower healthcare providers.
- Empower peers to support the relationships between clients and healthcare providers.

---

#### **Community-led and community-based care prioritized**

- Prioritize community-led engagement, planning and monitoring of HIV services.

---

#### **An integrated and universal healthcare system**

- Ensure equitable access to services and treatments, irrespective of personal wealth.
- Support the integration of tuberculosis, hepatitis, sexual and reproductive health, non-communicable diseases, particularly cardiovascular disease, cancer and diabetes, as well as mental health and other health needs, into HIV prevention, testing and treatment services, especially within primary healthcare settings.

---

#### **Supportive economic, political, educational and societal systems**

- Advocate for political reform to strengthen the rights and improve protection of marginalized groups in order to overcome criminalization, stigma and discrimination.
-



## Actions to enhance person-centred care

*"We know the limitation of disease-oriented care; it is the antithesis of person-centred care. The shift we need is like shifting from continuing medical education points to quality improvement measures. It requires moving away from outcomes to acknowledgement that person-centred care is a constant process."* – Group 2 representative

*"So when we train healthcare providers to actually be more accepting, less afraid of HIV and people living with and affected by HIV, to listen and identify additional needs, we then need there to be responsive funding to support the additional services to respond to those needs."* – Group 4 representative

Several specific actions across different domains were proposed throughout the discussion, including:

- **Political reform:** Advocating for decriminalization of sex workers and LGBTIQ+ communities
- **Training:** For government, advocates, funders and providers, which empowers, acknowledges and addresses the complete needs of people living with and affected by HIV within their contexts
- **Integration of care:** Expansion of HIV prevention, testing and treatment services to include mental health, tuberculosis, viral hepatitis, sexual and reproductive health, cervical cancer, cardiovascular health and diabetes – and particularly at primary health care
- **Access to technology:** Leaving no one behind, including in access to PrEP (oral and/or long-lasting), self-testing, multiplex testing (such as dual HIV/syphilis), cervical cancer screening and treatment and telehealth
- **Funding:** Addressing public financing of primary healthcare, reducing the price of medications and prioritizing funding of integrated approaches
- **Targets:** Expansion from 95-95-95 and 10-10-10 to include measures such as integration and enhancement of quality of life (for example, mental health, social isolation). Examples of measures to consider are PAM-13 (client empowerment), PROQOL-HIV (quality of life) and FRAIL (frailty).

## Next steps for the consultation series

- We are seeking feedback on the session, ideas on the format for the consultation series output and for future virtual consultation sessions throughout 2023. Please complete this quick survey to tell us what you think by 9 December 2022:  
<https://forms.office.com/r/8tSBNBHx6v>.
- Results of the survey will be analysed and discussed at the first advisory committee meeting, planned to be held in January 2023.