International AIDS Society

Person-Centred Care Advocacy Academy, Zambia, 2024 – Event report

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

25 – 28 November 2024
Lusaka Legacy Resort & Conference Centre, Zambia

In partnership with:

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

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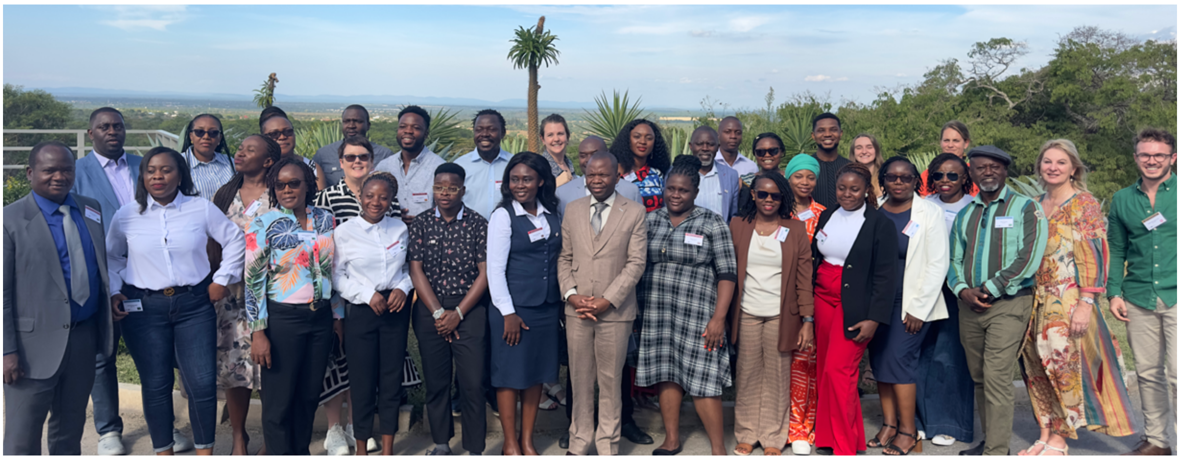
Executive summary



The inaugural Person-Centred Care Advocacy Academy, organized by IAS – the International AIDS Society – and CIDRZ – the Centre for Infectious Disease Research in Zambia – in partnership with Gilead Sciences, was held at the Lusaka Legacy Resort & Conference Centre, Zambia, from 25 to 28 November 2024. The event convened 19 fellows and three observers from 12 countries; seven faculty members, eight guest speakers and four IAS staff members supported the fellows in their learning of person-centred care approaches. Over three-and-a-half days, participants explored the core principles of person-centred care within the HIV response, delved into a number of case studies exploring implementation of person-centred care strategies and visited local healthcare facilities to learn more about implementation.

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.

> **“The Academy taught me the theory of PCC and I had an opportunity to learn the practicality of it through group work breakout discussions and the site visits”**
>
> **– Academy participant**

The objectives of the academy were clearly met. A post-event feedback survey confirmed that expectations were met by all of the participants. Almost two-thirds (62%) of the participants confirmed that the academy exceeded their expectations. Importantly, all of the participants stated that their participation in the academy improved their ability to engage in the HIV response with nearly all (95%) of the participants reported being very satisfied with the applicability of the PCC Academy to their work. After the academy, 71% of the fellows reported an excellent understanding of person-centred care approaches compared with 16% prior to the academy. Also after the academy, 90% of participants reported feeling extremely confident about implementing a project to enhance person-centred care approaches in their setting compared with 10% prior to the academy.

> **"Participating in the academy not only equipped me with the knowledge, but also the confidence, to start implementation of and advocate for PCC inclusion across all services"**
>
> **– Academy participant**

Welcome session

Lloyd Mulenga, Director of Infectious Diseases for the Ministry of Health in Zambia, welcomed the academy participants to Zambia. He commented that in addition to ensuring financial sustainability of HIV programmes, retention in care is a major challenge that is common across the 12 African countries the fellows represent. He explained that while countries have demonstrated success in testing and initiating people living with HIV on antiretroviral therapy (ART), they face challenges around retaining people in care and on treatment. Although important progress has been made due to the scale up of differentiated service delivery (DSD) and increased service integration, he encouraged the fellows to take the learnings from the academy to go a step further and to advocate for investment in person-centred care to prevent dis-engagement and facilitate re-engagement.

> **"Person-centred care has been the central missing piece and is what we need to truly attain HIV epidemic control"**
>
> **– Lloyd Mulenga**

He also stressed the importance of HIV prevention and providing care that considers each individual differently as each person has different needs. He noted the importance of taking a status neutral approach as a mechanism to maintain people in care or link them to prevention services, as is appropriate. He concluded by encouraging the fellows to be champions for PCC when they returned to their home countries.

Session 1: Setting your goals for the academy

The faculty were invited to share their motivations and experiences related to person-centred care, and why they are now advocates for person-centred care. They shared their experiences of:

- Entering a registry at a health facility and being faced with a large pile of files, each representing a client lost to follow up from HIV services, and starting on the journey of finding them all and working out how to keep them engaged in services
- Engaging in medical research only to feel overwhelmed at how medicalized it was, including consent forms that included medical jargon and technical terms that the participants did not always understand
- Learning about an educated mother whose child had died from advanced HIV disease after she withdrew them from care because she did not like how the healthcare provider had spoken to her, using stigmatizing language

Participants then engaged in a series of one-on-one networking conversations, which proved extremely popular, and set goals for the academy.

> **"Since there is less intrinsic motivation for prevention clients to attend healthcare services regularly compared to people living with HIV accessing treatment services…HIV prevention services need to be top-notch quality and to be reassuring. Person-centred care for HIV prevention is therefore crucial. Healthcare providers play a major role in achieving this, so it's also crucial that they don't view prevention services as added workload, they need to embrace the important role of HIV prevention services."**
>
> **– Academy participant**

Session 2: Foundations needed for PCC

What is person-centred care?

Person-centred care (PCC) describes 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 partnership 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 for people living with HIV is crucial at this stage of the HIV pandemic to ensure sustained viral suppression and quality of life, a healthy population of people living with HIV, and a reduction in transmission. By healthcare providers focusing on kindness and connection, rather than "caring rudely"[8], people living with HIV will feel more welcome and more comfortable engaging in HIV treatment over their life course. The destigmatization of HIV prevention and testing, as well as increased access to a choice of effective HIV prevention methods, are also crucial to reduce rates of HIV acquisitions.

By putting people at the centre of their care:

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

Research has shown that putting people at the centre of their care helps improve their health and reduces the burden of healthcare services and providers[9]. Engaging clients in their care can lead to improved health literacy, self-management skills and overall satisfaction with healthcare services[10].

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

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

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

The essentials of “good” communication

Njekwa Mukamba (CIDRZ, Zambia) provided an interactive workshop, introducing the PEARLS mnemonic and four essentials of “good” communication. These are:

- Building rapport
    - Building a comfortable connection so that people can share information
    - Creating a relationship based on trust and respect
    - Avoid stigmatizing or judgemental language
    - Based on verbal (choice of words or language) and nonverbal actions
- Active listening – remember to “listen to hear, not to tell”, defer judgement and involve the client in the development of their treatment plan
- Asking good questions, which are open-ended. For example, start with:
    - What … How … In what way …
    - Where … From where … Who … From whom …
    - Please give an example … Please say something more about this …
    - What do you think we can do to overcome this barrier you are facing?
- Giving good information
    - Details of diagnosis and treatment plan
    - How to take any medication prescribed
    - How to maintain health and quality of life
    - What to expect now and when to return to the healthcare clinic

P **Partnership**
"Let's work together on this"

E **Emotion**
"I can imagine how frustrating this is for you"

A **Apology**
"I'm sorry to hear how difficult this is"

R **Respect**
"I give you a lot of credit for getting through this as you have"

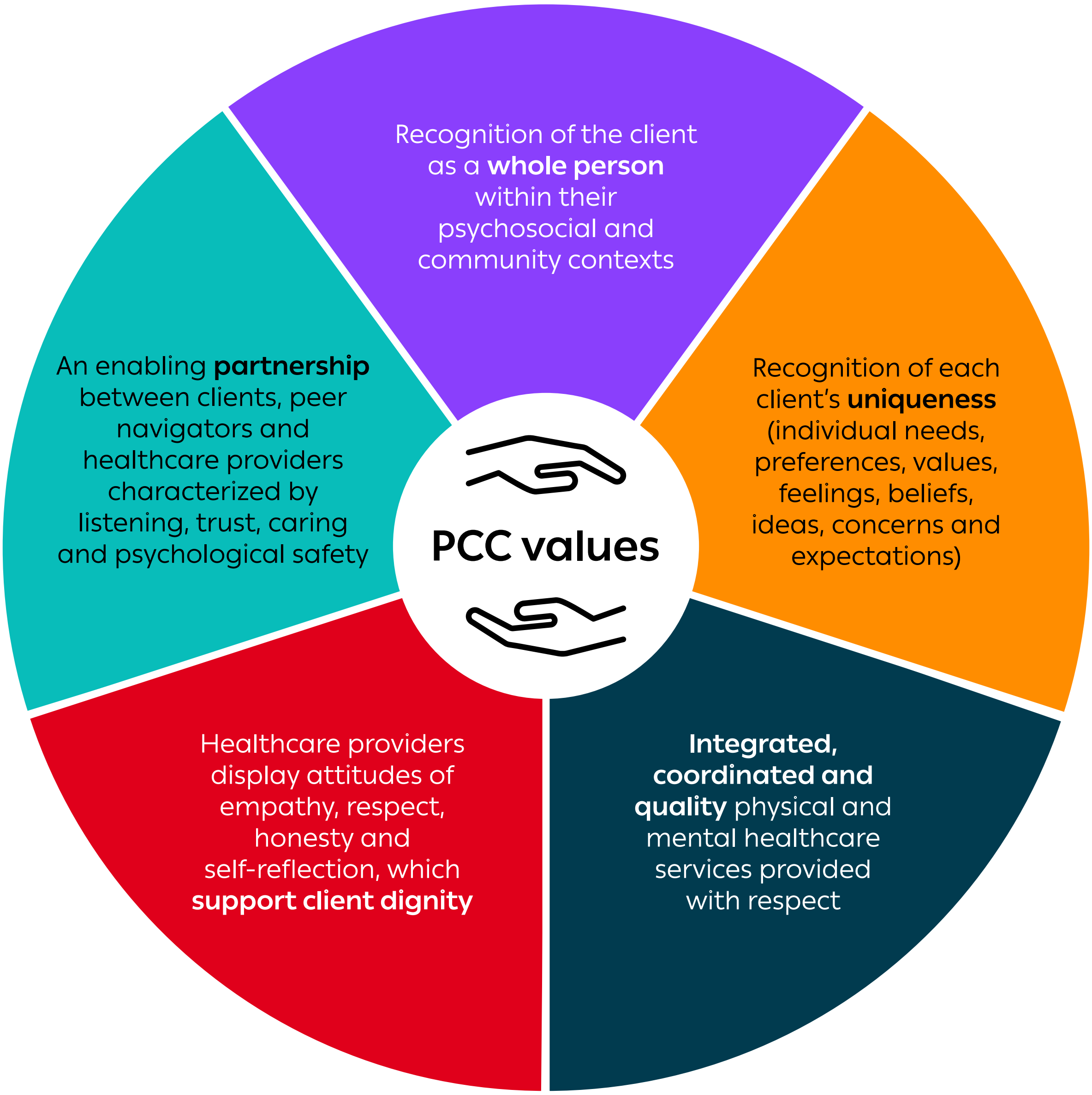
L **Legitimization**
"Most people in your position would feel the same way"

S **Support**
"I'm going to stick with you through this"

Source: CIDRZ

Session 3: The five core elements of person-centred care

In this framework, the client and their relationship with the healthcare provider are placed at the centre of their care while helping people manage their health. It is not just only about the mechanics of the service; it also includes the relationship and care that underpins the service , as illustrated by the following diagram adapted from the Scholl[13] framework. Five breakout groups explored each of these elements in more detail:



Recognition of the client as a **whole person** within their psychosocial and community contexts

Recognition of each client's **uniqueness** (individual needs, preferences, values, feelings, beliefs, ideas, concerns and expectations)

Integrated, coordinated and quality physical and mental healthcare services provided with respect

Healthcare providers display attitudes of empathy, respect, honesty and self-reflection, which **support client dignity**

An enabling **partnership** between clients, peer navigators and healthcare providers characterized by listening, trust, caring and psychological safety

PCC values

1. Empathy and respect

Sharon Kruger (Family Centre for Research with UBUNTU, Stellenbosch University, South Africa) led this discussion. She defined empathy as the ability to recognize and validate a person's concerns, apprehensions, anxieties, fears and pains. It is distinct from pity. The group explored the cognitive component of empathy (understanding the other's feelings), its emotional component (perceiving how it may feel for them), and finally its behavioural component through a range of pro-social actions (for example, verbal and non-verbal responses, active listening, validation and self-disclosure). The group also discussed the benefits of empathy in healthcare for clients and professionals in order to build trust, calm anxieties and improve outcomes. Understanding the person's emotions and feelings and their situations helps with making an accurate diagnosis and developing treatment plans that work for the client.

Sharon reiterated that learning to be empathetic takes time; it requires patience and practice to build it into care approaches. She shared a mnemonic (NURSE) to remember useful strategies to help healthcare providers be empathetic:

Name or mirror the emotion

"You seem stressed."

Understand the emotion

"Waiting for results are stressful."

Respect the client

"I appreciate you telling us how you feel and coming here to do blood tests."

Support the client using powerful words

"As soon as the results are available, I will let you know, and we'll decide the next steps together."

Explore the emotion further

"Is there anything else worrying you that I need to be aware off?"

2. Engagement and relationship

This discussion group, led by Chanda Mwamba (CIDRZ, Zambia), explored the relationships involved in providing care at many different levels, for example, client–provider, provider-provider, provider–policy maker and provider–strategic partners. A key takeaway was that policy development needs the engagement of all stakeholders. The group concluded that PCC principles that drive the development of PCC approaches need to be included in guidelines, and the input of stakeholders should be prioritized to ensure that these principles and approaches are appropriately context specific.

3. Communication, shared decision making and discretionary power

Njekwa Mukamba (CIDRZ, Zambia) built on his earlier session on the essentials of "good" communication, leading this group discussion as it explored the role of discretionary power as a part of professional judgement and how this can be leveraged to support clients' well-being while complying with care guidelines. The group also explored the dichotomy of meeting the needs of young sex workers within the constraints of age of consent policies, for example. This group shared a memorable communications philosophy mantra – "you have one mouth, two ears and two eyes!" This means you should spend twice as long observing and actively listening than you do talking.

4. Integrated care with holistic focus

This group, led by Sandra Simbeza (CIDRZ, Zambia), explored the need to consider aspects like physical space and healthcare infrastructure, as well as staffing needs, training and commodities to support effective and holistic integrated care.

5. Coordinated care with individualized focus, providing continuity of care and relationships

Juddy Wachira (Department of Mental Health and Behavioral Sciences, School of Medicine, Moi University, Kenya) led this group discussion, which explored the scenario of a client regularly attending a facility and, each time, seeing a different provider. To prevent uncoordinated care or client frustration, the group explored possible measures, such as informing the client in advance that in the public system, there is no personal provider, but that they will be cared for by providers who are a part of the same team. It also helps to proactively explain the process of referrals and to ensure a strong referral system is in place. This means that as clients receive follow-up care, they know what to expect and when to speak out if their needs are not being met. The group also reiterated that clinicians should know their limitations and refer to colleagues in specialized care when necessary.

Session 4: Person-centred design discovery phase

What is person-centred design?

Person-centred design, often called "human-centred design"[14], describes a methodology and process that begins and ends with accommodating the needs and desires of clients, families, healthcare providers and staff who each play a part in the co-creation of healthcare. This collaborative, action-oriented and highly visual process is defined by three iterative and often overlapping phases[15]:

- **DISCOVER** involves various types of research activities to learn from our clients about what their experiences are and to synthesize the resulting insights into a clear definition of the problem we are trying to solve.
- **DESIGN** involves creating ideas through sketching and other visual media, as well as building prototypes, which can be tested with clients, to learn quickly and iterate through a series of possible solutions.
- **DELIVER** involves transitioning the solution to the appropriate stakeholders who will manage implementation over the long term. We also determine the appropriate metrics that will help measure impact throughout the project's lifecycle.

What is client journey mapping?

Client journey mapping[16] is a strategic tool used to understand and visually present the experiences, interactions, emotions and pain points that clients or customers experience as they navigate the healthcare system. It helps organizations identify areas for improvement.

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

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

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

Why is client journey mapping important in health?

Client journey mapping is crucial in health for several reasons:

1. **Improving the client experience:** By understanding the client's journey, healthcare providers can identify moments of frustration or confusion and work to improve these experiences, leading to better health outcomes.
2. **Enhancing communication:** A client journey map reveals various points where communication occurs between clients, carers, family members and healthcare providers, helping streamline communication and ensure clarity at each stage.
3. **Identifying friction points in care:** The process can uncover gaps, delays or friction points that might not be immediately obvious, allowing health organizations to address inefficiencies and ensure a more seamless and coordinated care experience.
4. **Personalizing care:** With a detailed understanding of the client journey for specific groups, healthcare providers can design more personalized care approaches, catering to individual client needs and preferences.
5. **Supporting decision making:** Data from client journey maps can inform strategic decisions, helping allocate resources effectively and co-design interventions aligned with client needs.
6. **Driving innovation:** Insights from client journey mapping can identify clear opportunities to improve and spark innovation in service delivery, leading to new tools, technologies and processes that enhance the overall healthcare experience.
7. **Identifying need for systemic change:** It is important to make this an open process that creates an environment that permits clients to express issues that are beyond solving by themselves or the healthcare provider directly.

What does a client journey map include?

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

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

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

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

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

> **"Empathy is the foundation of the human-centred design process. You need to be ready to walk in other people's shoes."**
>
> **– Chanda Mwamba**

Session 5: PCC implementation case studies in real-world contexts

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

CIDRZ Strengthening Quality Improvement through Person-Centred Care Approaches (SQI-PCC) – Njekwa Mukamba

Research demonstrated that clients were willing to travel up to 45 km to see "nice/ kind" healthcare workers, compared with 30 km for longer refills, and only 5 km for a clinic that was open on a Saturday. This insight informed the development of a stepped wedge trial in 24 Ministry of Health facilities in Lusaka[17] which included training and coaching (including communication and stress management), client experience data and feedback, and gentle facility-level incentives. This trial led to a 70% reduction in HIV care visits reported as a bad experience. Prior to a national rollout of these approaches, focus group discussions identified enablers including leadership buy-in, peer to peer mentorship among healthcare providers, positive work attitudes, management support, positive client feedback and love for one's clients and career. Identified barriers included the lack of clear and specific policies and guidelines supporting PCC, lack of funding mechanisms supporting PCC, delivery of healthcare services focusing on biomedical rather than psychological outcomes and the limited availability of PCC resources and training. Finally, identified opportunities included leveraging existing continuous professional development platforms, inclusion of PCC approaches in strategic documents and collaboration among implementing partners.

Community ART Access Points (CAAP) operated by the Network of Zambian People living with HIV and AIDS (NZP+) and Treatment and Advocacy Literacy Campaign (TALC) – Fred Chungu

Fred (NZP+, Zambia) reminded the participants of the important and diverse expectations that clients, as recipients of care, expect. They expect to be involved in treatment planning and to be recognized not only as recipients of care, but as people with the right to own their decisions. Clients also expect to have access to respectful services which are responsive to their wishes, timely access to ART services (reduced waiting time) and ease of access to HIV and health information. Finally, they expect good communication from their healthcare providers and to be treated with dignity, compassion and respect.

A community ART access point (CAAP) is a person-centred care DSD model implemented by NZP+ and TALC through which some of these expectations are met. Clients have a choice of their adherence support worker to manage their CAAP and decide when and where to meet. This means that clients have access to the full information about their appointments for clinical and lab test visits. Lab results are explained to clients in a language they understand, which supports clients in developing the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and healthcare.

The benefits of the CAAP approach are that it reduces:

- Attrition and, therefore, improves retention on treatment
- HIV-related stigma and discrimination
- The need to travel a long distance to the health facilities
- Congestions in the health facilities and, therefore, wait time
- Healthcare provider burnout due to reasonable client load

Community engagement is a structured, supported, meaningful and accountable process that ensures that people living with HIV have a seat at the table and a voice in decision making, planning, implementation, monitoring and evaluation, to achieve access to quality HIV care for all and plays an important role in improving person-centred services.

Academic Model Providing Access to Healthcare (AMPATH), Western Kenya – Juddy Wachira

As background, Juddy outlined the scope of AMPATH's work supporting MoH facilities in eight counties in western Kenya with more than 180,000 clients and an average ratio of one clinician to 482 clients. Care is supported and data are managed via AMPATH's open-source electronic medical record system. Clinicians use real-time point-of-care information for clinical decision making.

Juddy then described a particular research study that used a matched pair instrument, originally developed in Canada, for assessing communication behaviours and which was adapted to the western Kenyan context and amended to include the client's role in communication. The findings of the study illustrated that while clients and clinicians share general expectations to communicate openly, the specific healthcare provider role influenced their expectations and healthcare providers generally lacked adequate training in communication and shared decision making. Client literacy also played an important role. As Juddy reminded participants; "If you don't tell clients what their rights are and their role, then they don't know".

AMPATH's research also showed that improved clinician-client communication increased client satisfaction with care and that providing continuity of care (that is prioritizing the client-clinician relationship) increased appointment adherence. Overall, interventions focused on continuity of clinician-client relationships, enhanced treatment dialogue, improved clients' clinic appointment scheduling and provider-client communication training (such as motivational interviewing) led to improvements in rates of viral suppression.

Planned next steps include more research on definitions, measures, frameworks and implementation strategies for PCC to ensure that health systems have the tools for successful implementation. Additional effort is also required to make both clients and providers understand their role in PCC. Juddy concluded by noting that addressing structural challenges, such as limited capital and human resources, high provider turnover and lack of continuity in care, is of fundamental importance.

CIDRZ Key Population Investment Fund (KPIF) programme, Zambia – Maurice Musheke

Maurice (CIDRZ, Zambia) reiterated the importance of addressing structural challenges and challenged the group to focus on equity of access. "That is the starting point. If you do not provide services as close as possible to where people are, you are missing out on equity of access."

KPIF was established in 2019, with funding provided by the US President's Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC). The KPIF project is aimed at building the capacity of key population civil society organizations (CSOs) to deliver valued and interlinked HIV prevention, care and treatment services to key populations in line with the Zambian national HIV response. Key populations served by KPIF include men who have sex with men, trans people, female sex workers and people who inject drugs.

Under the KPIF model, HIV services are provided in key population CSO-led safe spaces in the community. Each safe space is linked to a Ministry of Health (MoH) health facility "hub" and serves as an outpost of the "hub" facility. MoH key population-friendly teams from the district provide services at safe spaces and the "hub" facility. Client data is sent to the "hub" facility for entry into health facility's electronic medical record system, SmartCare. This spoke-and-hub approach allows for outreach-based delivery of services to determine hotspots where key populations could be mobilized to access the services.

KPIF used a programme science approach to explore the question : "What effect does decentralizing PrEP service delivery to community-based venues and key population CSO-managed safe spaces have on PrEP uptake, continuation and equity for key populations in Lusaka, Zambia?" The answer is that it has a significant effect. At programme inception, most PrEP initiations occurred in the general population. The share of PrEP initiations among key populations increased significantly (to 60.0%) after introduction of venue-based PrEP provision from 24.8% before ($p < 0.001$), with key populations accounting for most PrEP initiations by the end of the evaluation period. This demonstrated clearly that for individuals who are not able to come to facilities, we need to provide services closer to them. Maurice concluded by advising that for programme science to be impactful, it is important to:

- Nurture equitable partnerships with affected communities to define the programme science question a priori and identify opportunities for innovation.
- Select outcomes aligned with data available from routine data systems.
- Move toward analysis of individual-level, longitudinal data.

Paediatric Adolescent Virus Eradication (PAVE) Martin Delaney Collaboratory, South Africa – Sharon Kruger

Sharon provided an overview of using a participant-centred approach during somewhat invasive medical research procedures in adolescents living with HIV. She highlighted the key role of simplified information to ensure that the consent (and assent) tools were informative and age appropriate. Creating a supportive environment and conducting stakeholder engagement throughout the entire study was also crucial. The study kicked off with an information sharing workshop to engage, inform and enquire about preferences for participation. Healthcare staff were invited to provide input and clarify information.

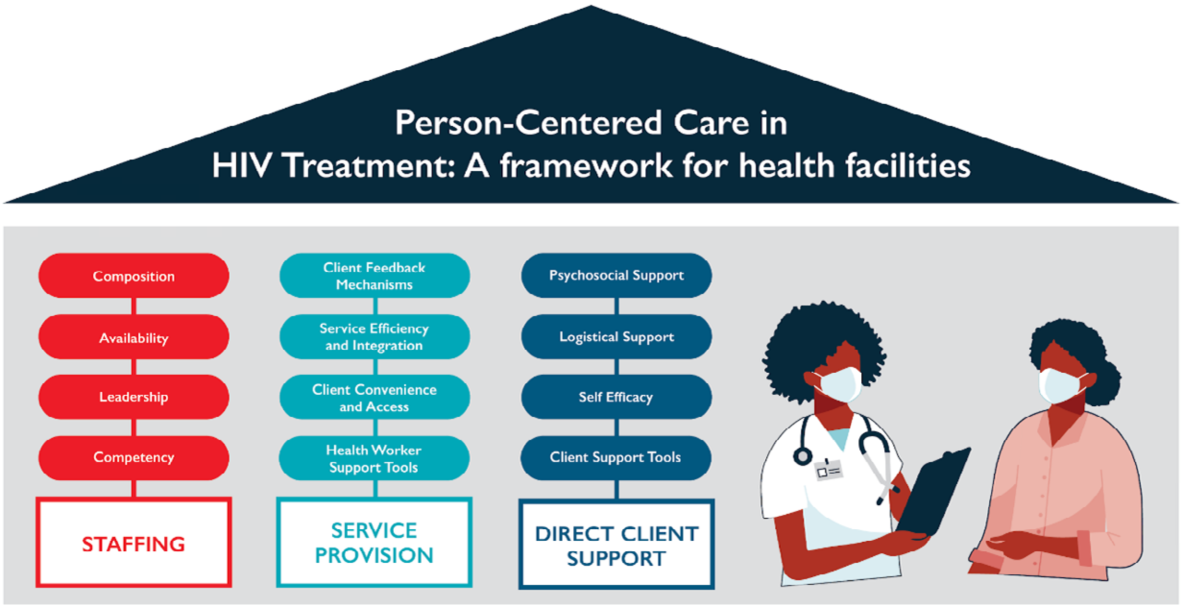
These information exchanges helped make adaptations along the way to ensure that the study remained person-centred. Participants received detailed information about procedures via a video using de-medicalized adolescent friendly language. To create a supportive environment they included a mock scan before conducting the MRI scan and showed participants a video on the MRI procedure. During the lumbar puncture visit, each participant was given a care box with snacks and items to make them more comfortable during the procedure. They could lean against the nurse to stabilise them during the lumbar puncture procedure, and this also offered support and comfort during a potentially uncomfortable procedure.

Using a participant-centred approach improved enrolment and retention via co-learning and the inclusion of advocacy. Repetitive sharing of information reduced apprehension and treating participants with care made a difference. Sharon encouraged other researchers to adapt protocols and procedures to make research more relevant and credible for participants, especially young people.

JSI PCC-Assessment Tool (PCC-AT), Zambia – Lackeby Kawanga

The PCC-AT is an Excel-based tool for service providers and stakeholders for assessing and improving person-centred HIV service delivery in HIV-specific and integrated settings[19]. This tool measures person-centred care at healthcare facilities providing HIV treatment. Lackeby (JSI, Zambia) explained that it is designed for HIV implementers and service providers to collaboratively assess the health facility's ability to provide person-centred HIV treatment, demonstrate areas of strength for organizational learning, and tailor investments in further interventions or improvements. A key feature is that it allows people to self-assess against clear standards in a short time with less subjectivity, which can offer clear direction for action and the ability to track performance over time.

The PCC-AT measures healthcare facility staff perspectives on PCC service delivery in HIV treatment settings. PCC-AT implementation, led by a trained facilitator, requires in-depth discussions among health facility staff to assign a score using a benchmarking approach for each of the 56 performance expectations linked to the three domains and 12 subdomains of PCC. Once scoring is complete, the PCC-AT process concludes with action planning, which guides health facility staff to identify areas of weakness and their causes and to develop strengthening activities to address gaps.



Source: JSI

Session 6: There is no health without mental health

Sandra Simbeza led a session on healthcare provider stress management and introduced the concept of psychological first aid.

Healthcare provider stress management

Healthcare providers in all settings experience stress, which often originates from the discrepancy between what needs to be done and what can actually be accomplished with the resources available. When healthcare providers are stressed, both clients and healthcare workers can have reactions with undesirable outcomes. Participants explored ways that colleagues and the workplace itself can support healthcare providers to manage their stress.

Colleagues	Workplace
○ Listen ○ Understand where others are coming from, what is going on in their lives ○ Teamwork, cooperation, respect ○ Mentor ○ Offer a break ○ Offer time management or organization tips ○ Offer help ○ Be positive ○ Smile, laugh ○ Help each other to learn SmartCare and practice, practice, practice	○ Utilize DSD models ○ Provide sufficient staffing levels ○ Plan the use of limited space ○ Be patient ○ Create compatible work schedules and lunch shifts ○ Clearly define roles and responsibilities ○ Workers participate in decisions affecting their jobs ○ Improved communications ○ Social interaction among workers ○ Temperature, light, noise, space

Healthcare providers also have discretionary power, which is the ability to use judgment when interpreting MoH policy and guidelines in a way that has a positive impact on clients and colleagues.

Look	○ Look for safety and security risks. ○ Assess dangers. ○ Get information about the event/crisis/situation.
Listen	○ Approach the person in need of help and introduce yourself. ○ Pay attention and listen actively. ○ Understand the other person's feelings. ○ Calm the person in crisis/need. ○ Ask about their needs and concerns. ○ Help the person in crisis with their immediate needs and try to solve their issue(s).
Link	○ Make relevant information, services, and other sources of assistance available. ○ Help them connect or reunite with relatives. ○ Provide social assistance. ○ Actively try to help solve the issue(s).

Source: CIDRZ

Site visits

University Teaching Hospital (UTH)

The objective of this site visit was to understand the implementation of person-centred care approaches at UTH, including the recent introduction of cabotegravir long-acting (CAB-LA) for HIV prevention. UTH provides comprehensive, integrated HIV testing (facility-based, community-based, index, children's testing, social network strategies and HIV self-test distribution), HIV prevention (PrEP and PEP) and HIV treatment services (ART services and advanced HIV disease screening and treatment). To meet the individual needs of clients, it also provides enhanced adherence counselling; tuberculosis screening, treatment and prevention; viral load monitoring and recency testing; STI screening, treatment and prevention; hepatitis screening, treatment and prevention; cervical cancer and HPV screening and prevention; voluntary medical male circumcision; prevention of vertical transmission and family planning services; nutritional support and management; non-communicable diseases screening and management; and condoms and lubricant distribution.

Oral PrEP was introduced in Zambia in 2017 and was included in national HIV guidelines in 2018; around one million people in Zambia use PrEP today. Preparation for the introduction of CAB-LA began in 2022, with PEPFAR announcing its support in March 2023. CAB-LA was introduced in Zambia in February 2024 with a national MoH-led demand-creation strategy using public announcements on radio and TV to create awareness of the introduction of long-acting HIV prevention products and to share the location of the healthcare sites where CAB-LA would initially be implemented. Following this, it was the responsibility of the individual healthcare sites to follow up with locally based demand creation strategies. UTH has been able to offer CAB-LA to its current client base and expand its client base due to interest in CAB-LA using, for example, social network testing, to reach young people and key populations.

A fellow chats with the inspirational Mundia Mwitumawa, a resident at Lusaka's University Teaching Hospital.

Kabwata Urban Health Centre

Kabwata Urban Health Centre serves a population of 65,827 people. It is surrounded by shops, beerhalls and the Kabwata shopping mall, which makes it a busy and highly accessed healthcare centre. It serves clients from a wide variety of socioeconomic backgrounds, but most are middle-income earners. The facility has the following service departments: outpatient; maternal child health; dental; environmental health; nutrition; chest clinic; and antiretroviral treatment.

Kabwata Urban Health Centre is one of the public health facilities at which CIDRZ implemented a person-centred care trial in collaboration with the Ministry of Health. The PCC trial was implemented from 2019 to 2021 in 24 MoH-operated public health facilities in Lusaka Province and resulted in significant improvements to client experience and retention.

The objective of the visit was to understand how the healthcare providers had integrated PCC principles into their workflows. Participants were impressed that all healthcare cadres were involved in creating a good experience for clients, including, for example, the security guards who are often the first people a client interacts with. A strong sense of teamwork was visible, and participants felt that everyone working at the facility was committed to delivering PCC. To sustain this energy, refresher PCC training was conducted every three months and PCC has been integrated into the clinic workflows. Staff motivation is seen as key, with clinic staff awarded a day of leave as appreciation. Another incentive is the award of "employee of the month". Staff have also been trained to look out for signs of burnout in themselves and their colleagues and know to ask others for help.

Key Population Wellness Centre (Chawama/Kamwala township)

Opened in 2021, this wellness centre is one of the six hubs established by the Key Populations Investment Fund (KPIF), aiming to enhance case identification, ensure comprehension prevention services, and foster retention and viral suppression among key populations (such as female sex workers, men who have sex with men, people who use drugs, and trans people). CIDRZ manages this KPIF initiative, with funding from the CDC, in collaboration with the Ministry of Health and key population civil society organizations. Currently, the Key Population Wellness Centre offers HIV testing, vulnerability awareness counselling, distribution of condoms and lubricants, PEP and PrEP, voluntary medical male circumcision, cervical cancer screening, STI management, family planning, and the mental health intervention, Common Elements Treatment Approach (CETA). As of November 2024, the centre had reached 4,193 clients in the year, of whom 1,330 were newly initiated on PrEP. The centre hopes to extend its facility in 2025 to be able to welcome even more clients.

The objective of this visit was to see how PCC approaches could be applied in service delivery for key populations. Most fellows on this site visit were themselves involved in organizations and initiatives specifically focusing on key populations. They were able to visit the different spaces of the facility, meet staff members, hear testimonies from clients present on the day, and exchange ideas on how to make prevention and care work best for key populations. The Chawama/Kamwala staff provided details of the mapping process and needs' collection initiatives that took place in the communities before the opening of the centre. The staff continue to work with key informants and peer promoters to foster their connections to the communities.

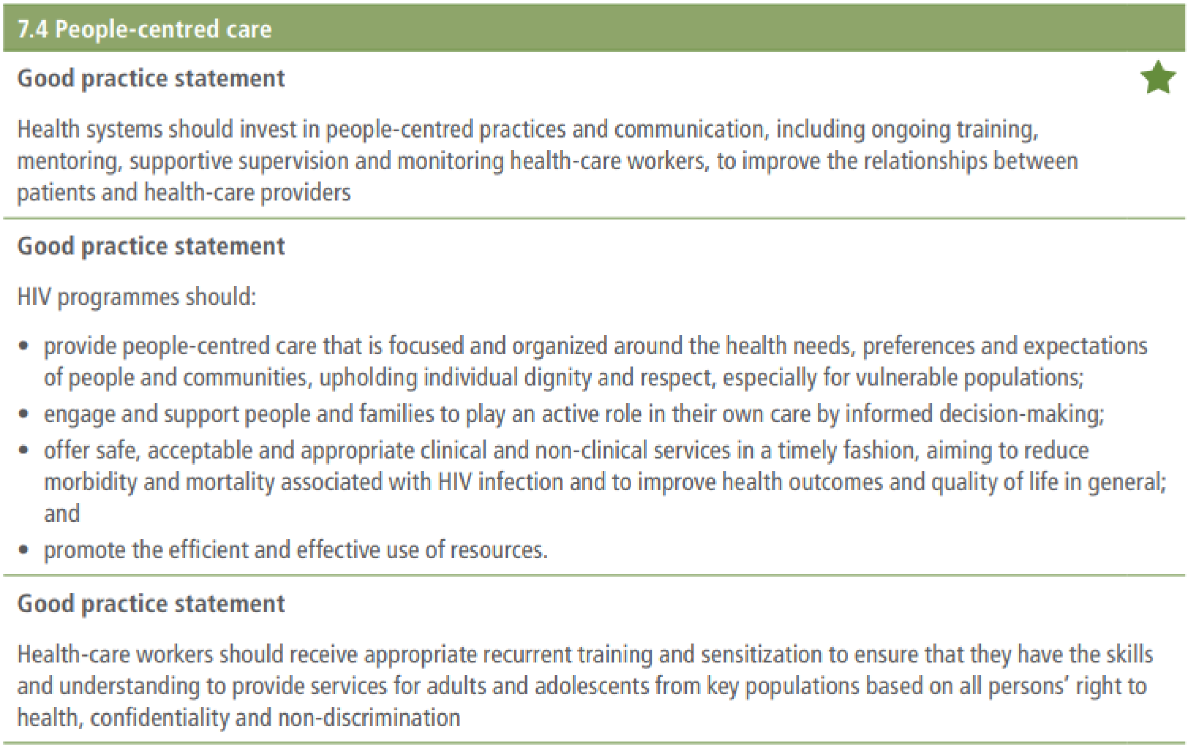
In addition, staff participate in continuous professional education. In June 2024, staff completed a training on gender-based violence and are now working on mainstreaming this learning into day-to-day activities. Additionally, the leadership team pointed out that most staff members come from key population groups themselves, a useful strategy to further engage clients from the communities. During the discussion, the fellows were also able to explore challenges faced by the Key Population Wellness Centre and brainstorm on the difficulties faced by healthcare service providers and activists in their own settings.

Martin Zimba, Founder and Executive Director of the Key Populations Alliance of Zambia (KPAZ), managing the Key Population Wellness Centre in Chawama/Kamwala township, proudly standing in front of the entrance.

Session 7: Guidance to support PCC

World Health Organization (WHO) normative guidance

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



7.4 People-centred care

Good practice statement

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

Good practice statement

HIV programmes should:

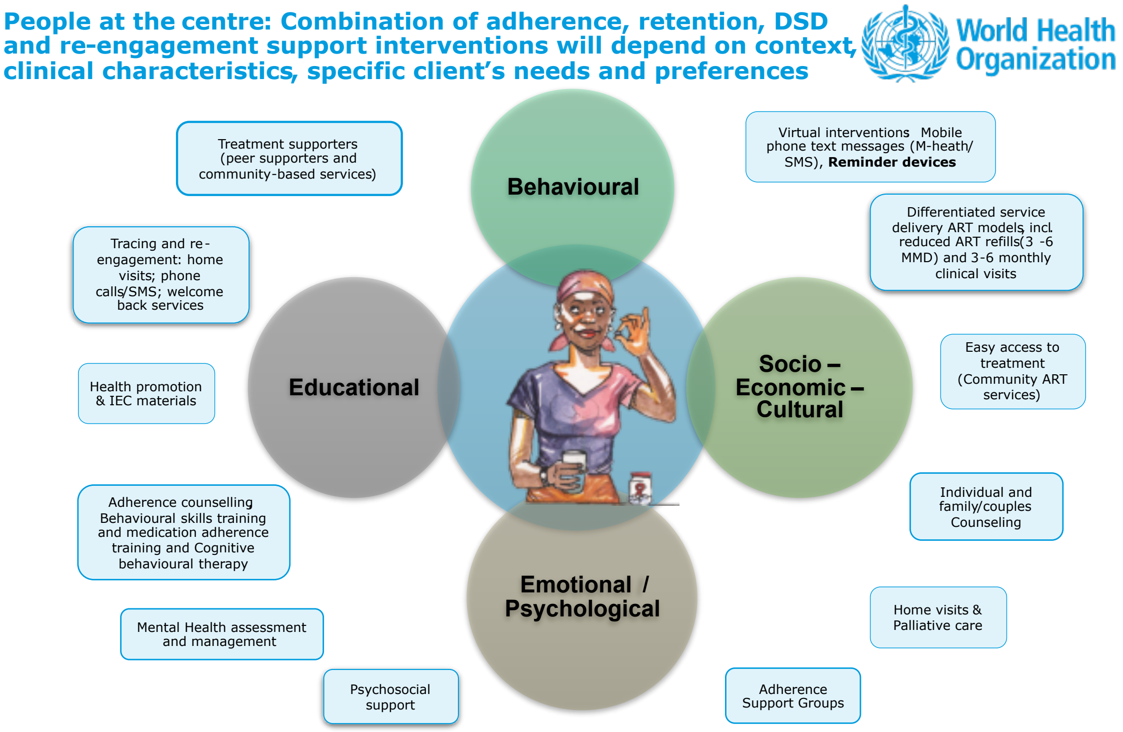
- provide people-centred care that is focused and organized around the health needs, preferences and expectations of people and communities, upholding individual dignity and respect, especially for vulnerable populations;
- engage and support people and families to play an active role in their own care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

Good practice statement

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

> **"People-centred health services are an approach to care that consciously adopts the perspectives of individuals, families and communities and sees them as participants and beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways."**
>
> **— Framework on integrated, people-centred health services – 2016**[32]

WHO emphasizes a person-centred care approach for HIV treatment, addressing four interconnected spheres of support: behavioural; socioeconomic; educational; and emotional/psychological. 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.



People at the centre: Combination of adherence, retention, DSD and re-engagement support interventions will depend on context, clinical characteristics, specific client's needs and preferences

World Health Organization

Treatment supporters (peer supporters and community-based services)

Behavioural

Virtual interventions Mobile phone text messages (M-heath/ SMS), **Reminder devices**

Tracing and re-engagement: home visits; phone calls/SMS; welcome back services

Differentiated service delivery ART models, incl. reduced ART refills(3 -6 MMD) and 3-6 monthly clinical visits

Health promotion & IEC materials

Educational

Socio – Economic – Cultural

Easy access to treatment (Community ART services)

Adherence counselling Behavioural skills training and medication adherence training and Cognitive behavioural therapy

Individual and family/couples Counseling

Emotional / Psychological

Mental Health assessment and management

Home visits & Palliative care

Psychosocial support

Adherence Support Groups

Stigma and discrimination remain major barriers to uptake of and access to HIV services – Erica Spielman

Erica (Department of Global HIV, Hepatitis and STI Programmes, WHO) introduced the fellows to WHO's technical brief, "Ensuring quality health care by reducing HIV-related stigma and discrimination". The brief emphasizes that eliminating stigma within healthcare settings is vital for delivering high-quality, person-centred care (WHO, 2017). By actively involving communities and stakeholders in developing and implementing strategies to combat discrimination, healthcare providers can create a more supportive environment.

The report outlines important interventions to achieve this, including investing and allocating funds at the facility level specifically to reduce stigma through quality improvement processes. It is important to build the capacity of a multidisciplinary healthcare workforce and build trusting relationships and formal engagements with local communities, including developing and scaling up community-based and community-led service delivery. Service networks must be developed and strengthened, including trusted referral pathways to social, legal or other services. The integration of strengths-based and empowering interventions into counselling and the fostering of inclusive, respectful, safe, friendly and non-discriminatory approaches into workplace cultures and healthcare facilities is crucial. All these interventions must be continuously and closely monitored to ensure quality improvement via safe and responsive feedback mechanisms.

Further reading:

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

The People Living with HIV (PLHIV) Stigma Index 2.0 – Keren Dunaway

Keren (International Community of Women Living with HIV, Argentina) provided an overview of the PLHIV Stigma Index 2.0, which is a standardized peer-driven research tool for collecting data on stigma and discrimination. It is designed to be used by and for people living with HIV to reflect the Greater Involvement of People Living with HIV (GIPA) principles to inform data-driven advocacy. It has been supported by an international partnership between ICW, GNP+ and UNAIDS with Johns Hopkins University since 2008. More than 100 countries have completed the study, and over 150,000 people living with HIV have been interviewed.

There are six non-negotiable principles underlying the PLHIV Stigma Index 2.0:

1. Leadership of people living with HIV networks
2. Standard methodology
3. Sampling frame, which includes all sub-populations (above the national age of consent)
4. Quality assurance and review processes
5. Data security and sharing
6. Dissemination of analysis and results

There are six implementation phases:

1. Preparation
2. Research protocol development
3. Preparation for data collection
4. Data collection
5. Data analysis and reporting
6. Dissemination and advocacy

Find out more at https://www.stigmaindex.org/.

Tips for advocating for policy change – Lloyd Mulenga and Suilanji Sivile

This inspiring presentation reiterated that policy advocacy is the number one way to advance social change. Advocates play an important role in informing policy makers about which issues to care about and, therefore, focus on. Planning advocacy and policy dialogue requires understanding how the policy cycle works.

Lloyd and Suilanji (Ministry of Health, Zambia) explained that to be successful, data and research are critical. Effective communications require the right messaging and framing, targeted to the right audiences. It is important to remember that educating and engaging policy makers is important even when you don't have a specific ask.

Building a strong, diverse and engaged partnership base will amplify your impact.

Some advocacy strategies are to:

- Organize and mobilize your stakeholders (for example, your coalition partners) to speak up, act and advocate for change.
- Educate policy makers by providing them with data, research, stories and general information about key issues.
- Produce data and research that highlights pressing needs in your community.
- Host educational conferences and trainings to gather, network and share information on policy priorities.
- Educate the public about the process and/or introduce communities and constituencies to policy makers.
- Build public awareness by educating community members on relevant issues that impact them.
- Organize press conferences to build public awareness about an issue and to hold your policy maker accountable.

Equity principles are needed to underpin comprehensive policy advocacy. This requires putting adolescents and young people at the centre as political actors and partners in policy advocacy and decision making. It also means applying a gender and power lens to policy advocacy. This is crucial for ensuring accountability by governments, civil society organizations and other duty bearers.

Do	Don’t
Take a comprehensive approach to advocacy and policy dialogue.	Use stand-alone advocacy activities that will have limited impact.
Analyse the political context by mapping the public agenda, the agenda setting and the key players.	Implement advocacy strategies without deep knowledge of the political context and the likelihood of pushback.
Promote data and evidence-based advocacy and policy dialogue.	Support policy advocacy that promotes ineffective interventions that can do harm.
Incorporate a human rights perspective.	Be blind to policy advocacy proposals that may lead to human rights violations.
Apply a permanent capacity-building, measurement and evaluation and alliance-strengthening approach.	Assume that the coalition has nothing to learn or improve.
Support meaningful youth participation in policy advocacy.	Encourage policy advocacy approaches that are tokenistic, particularly for young people (for example, providing only merchandise like T-shirts or asking them to deliver pamphlets) and that do not embrace their real participation in decision making.
Endorse accountability as a core element of advocacy at all levels.	Tolerate lack of transparency or accountability in policy advocacy.
Embrace a “leave no one behind” approach to advocacy by applying an intersectional approach.	Encourage elite young people in policy advocacy activities, instead of ensuing that the most marginalized young people are able to participate in political matters that affect them.

Session 8: Person-centred design in action

PCC approaches are operationalized through the activities that are put in place to turn these concepts into care that is person centred. These activities fall under different categories, for example, activities that involve changing the structure or organization of the services themselves or activities that involve supporting healthcare providers to provide care that is person-centred[20]. The successful inclusion of PCC into existing services is not without challenges[21], especially in settings with limited resources and diverse client needs. Healthcare providers may question the extent of client involvement in the decision-making process and the practicality between standardized care and individualized treatment approaches[22]. The framework[22] below provides a practical way of thinking about implementation.

Communication and interaction underpin everything. They start with planning and continue through implementation. Evaluation and monitoring allow for flexibility to make the changes needed to ensure that services continue to be person centred. Being person centred is about recognizing the client's ability to improve their health and working with clients to meet their needs[24, 25]. Practically, this is done by:

- Recognizing individuality
- Improving health literacy
- Engaging clients during consultations
- Finding out what is important to clients and making changes
- Including families
- Empowering clients to manage their health and engage in self-care
- Proving a physically and emotionally safe space for care
- Providing continuity of services
- Recognizing goals of healthcare and working in partnership with others to achieve this
- Training healthcare providers to be respectful, compassionate and ethical

Breakout group discussions led by faculty members explored a range of practical tools to design and implement interventions in service delivery and research settings to enhance person-centred care. These were shared in the plenary in breakout group report-backs.

Client and healthcare provider experience measures

Methods to collect and analyse feedback from client and healthcare providers, for example, via suggestion boxes, were explored, along with the deployment of trained mystery clients who can evaluate service quality. Digital tools are also helpful, such as SMS surveys that can send a code to clients with a questionnaire and/or invite clients to participate in more in-depth evaluation interviews with clients. All these methods require careful training for bias-free analysis of the information.

Empowering and counselling for choice using, for example, motivational interviewing

Motivational interviewing[26] is a counselling technique that focuses on behaviours and tries to use the lens of the client as its primary viewpoint. This approach can empower clients and create rapport with clients to try to determine the real, underlying issues with the goal of evoking a response by the client to set clear goals and a step-by-step plan to achieve them. Implementing this approach requires training, practice and patience.

How can effective communication be measured and supported?

Roter Interaction Analysis System (RIAS) is a technique that the CIDRZ team used and documented to quantitatively characterize patterns of person-centred communication behaviours in Zambia. As explained in their published latent class analysis[27], "RIAS is a quantitative method of coding designed to parse and classify client and provider communication into operationally defined codes and standardized dimensions. It has been previously validated across a wide range of clinical and cultural settings, and quantifies aspects of communication that have been associated with outcomes, such as satisfaction and adherence. The RIAS method involves coders assigning each utterance (i.e. a statement representing a complete thought) made by the client or provider into one of 37 mutually exclusive and exhaustive categories based on standardized definitions, such as question-asking (e.g. open vs. closed), information-giving (e.g. clinical vs. psychosocial), socio-emotional communication (e.g. empathy statements and rapport building) and provider : client speech ratio."

The team shared tips for success. These included providing intensive (three-day) training for multi-lingual researchers to conduct the coding and the facility where the research was conducted being made aware of and consulted on the use of the technique to ensure buy-in.

Task shifting

Task shifting means distributing work so that everyone can provide a service and play a role in care, starting from a healthcare centre's security guard and including triaging steps, noting that it can enhance access and linkage to care by reducing the burden on facilities. The group discussed various factors related to implementation of task shifting, including: service integration; the need for open communication and teamwork, oversight via leadership and clear roles and responsibilities; and monitoring via feedback loops with regular meetings set up. The risks of task sharing, such as "task dumping" to community healthcare workers to do everything, were also explored. Community health workers should be sufficiently paid for taking on increased responsibility, and the cost of training them to do so should be factored in.

Safeguarding of participants

Safeguarding participants means making sure the person is safe and free from harm. This includes confidentiality, respect and treating individuals with dignity. It is built on a relationship of trust. It is about making sure people are protected from harm, as well as promoting health and well-being and empowering people to know their rights.

Clients have rights!
Right to be safe
Right to privacy
Right to be treated with respect and dignity
Right to be involved in decisions about their health
Right to be free from abuse and exploitation

Safeguarding actions /steps taken to protect vulnerable people

- Treatment and care, free from harm (discrimination, stigma, abuse)
- Health facilities that are safe and supportive
- People are empowered to make decisions and provide informed consent (information about their treatment and choices)
- Prevention of harm (action before harm occurs)
- Information shared appropriately
- Being transparent about the information you share and the reason for sharing and obtaining consent
- Treatment, including the least intrusive response (proportionate)
- Keeping information confidential and ensuring that information is stored and shared safely (anonymised data)
- Supporting and representing those in greatest need
- Partnering with communities to prevent, detect and report harm
- Being accountable and transparent in your actions

For effective safeguarding, it is important to ensure that there are safeguarding policies and procedures in place. Healthcare providers and administrators should be encouraged to share best practices and develop standard operating procedures that address the specific needs of their client population.

Role of “upstanders”

“Upstanders” are people who call out stigma and discrimination and take proactive, voluntary actions to address them. Discrimination and unfair actions experienced due to stigma are often fuelled by misconceptions (such as lack of education about sexual orientations) and beliefs (moralization). Discriminatory laws and stigma hinder access to services. To overcome this, what is needed is education and sensitization around sexual orientation across all of society, including among healthcare providers. This discussion group explored the persistent stigma around the use of PrEP and perceived promiscuity, and how non-judgemental healthcare providers can play an important role in overcoming this perception.

Session 9: Pitching your advocacy plan

Each participant shared their advocacy plans in short pitches, and all participants were encouraged to provide constructive feedback for their peers. This session was an opportunity for the fellows to reflect on what they had learnt over the previous three days and to start to imagine how it could be applied in their contexts. It also provided an opportunity to practice public speaking and advocating for PCC initiatives, as well as an opportunity to learn from each other's projects in more detail.

Fellows presented high-quality initiatives supporting diverse key groups and communities, such as young people living with HIV, female sex workers, trans men, people ageing with HIV, and people who use drugs. They brainstormed on concrete initiatives to integrate further services in HIV care (such as non-communicable diseases, mental health, sexual and reproductive health, harm reduction services and urological concerns) and to provide capacity building in person-centred approaches for healthcare providers. They also discussed client empowerment strategies, ranging from health literacy to communication skills. Most fellows planned to focus on a specific region within their country, such as Homa Bay in Kenya or Delta in Nigeria, while others took on a larger perspective, such as addressing the effects of the "anti-LGBT" bill in discussion in Ghana.

The project ideas were varied and of high quality, notably displaying a strong understanding of the PCC assessment tools presented during the academy and a willingness to bring clients and communities to the centre of the design and implementation of their initiatives. Most also included a component addressing healthcare provider well-being, stress management and burnout prevention. All showed thoughtfully developed initiatives, emphasizing the clarity, concreteness and feasibility of such projects within their own contexts.

Next steps

The academy served as a catalyst for collaboration and on-going support of all fellows, both directly from the IAS, as outlined below, and informally via the new peer-to-peer relationships established among the fellows and peer-mentor relationships established among the fellows and faculty members.

Virtual learning events and ad-hoc technical support

- All fellows
- Quarterly themed online meetings
- Ad-hoc reviews of abstracts, manuscripts and grant applications
- LinkedIn group to exchange on opportunities and new evidence or advocacy themes

Seed grants

- Awarded to four projects led by fellows in March 2025
- Feedback provided on projects and collaboration opportunities suggested
- Documentation of project outcomes to be supported

Pilot projects

- Most promising seed grantees
- In 2026, the IAS will support the most promising projects to meet in-person with key stakeholder in their region to further advance investment and scale up of their project activities

List of participants

Fellows

From left to right:

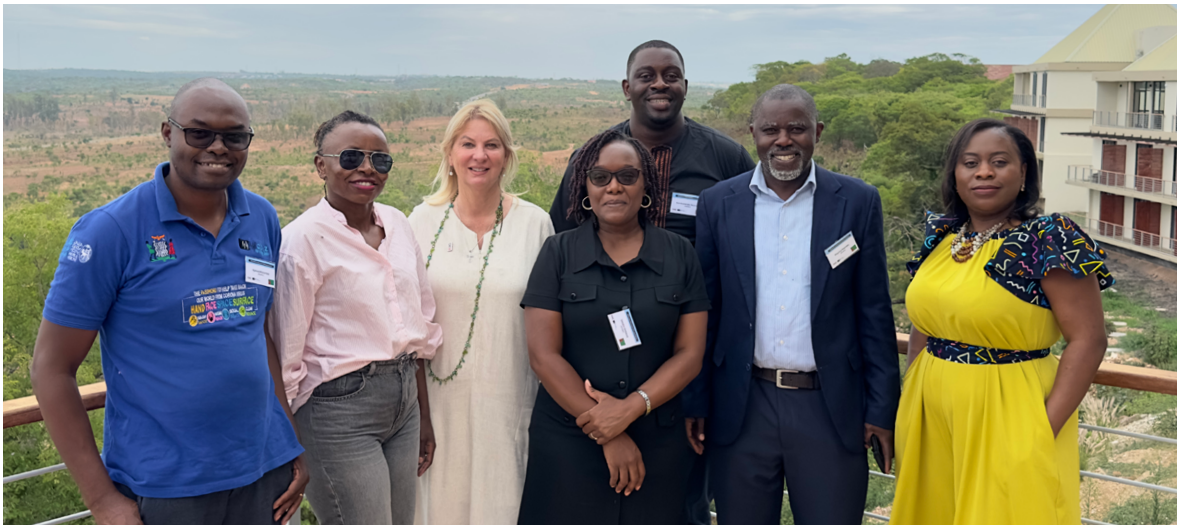
First name	Organization	Country
Vanessa Fozao	Pediatric Adolescent Treatment Africa	Cameroon
Ngwibete Atenchong	AIDS Healthcare Foundation	Nigeria
Bonaventure Ukoaka	Excellence Community Education Welfare Scheme	Nigeria
Wardatou Dine Mourtada	Infectiology Department at Universite Felix Houphouet-Boigny	Ivory Coast
Knowledge Mupembe	Zimbabwe Civil Liberties and Drugs Network	Zimbabwe
Susan Onyango	The Healthy Woman	Kenya
Ishmael Bawa	Korle-Bu Teaching Hospital	Ghana
Daisy Kwala	Bar Hostess Empowerment & Support Programme	Kenya
Misheck Mphande	Partners in Hope	Malawi
Connex Khomba	Ivy Foundation	Malawi
Melody Mwanja	CIDRZ	Zambia
Christina Mmasa	Ciheb	Tanzania
Valentina Trivella	Right to Care	South Africa
Sarah Kobugabe	Action for Integrated Sustainable Development	Uganda
Aafke Kinemo	Henry Jackson Foundation Medical Research International (HJMRI)	Tanzania

First name	Organization	Country
Anthony Chazara	LVCT Health	Kenya
Gadzikanani Gokatweng	Botswana–University of Maryland School of Medicine Health Initiative (Bummhi)	Botswana
Malebogo Thero	Botswana–University of Maryland School of Medicine Health Initiative (Bummhi)	Botswana
Linah Mwango	Ciheb	Zambia

Not pictured:

Natasha Mwila	Network of Zambian People Living with HIV/AIDS	Zambia

Faculty



From left to right:

First name	Organization	Country
Njekwa Mukamba	Implementation coordinator, CIDRZ	Zambia
Juddy Wachira	Senior lecturer in the Department of Mental Health and Behavioral Sciences, School of Medicine, Moi University	Kenya
Sharon Kruger	Researcher, Family Centre for Research with UBUNTU (FAMCRU), Stellenbosch University	South Africa
Sandra Sinzala Simbeza	Public health specialist , CIDRZ	Zambia
Kombatende Sikombe	Implementation scientist, CIDRZ	Zambia
Maurice Musheke	Program Head, Key Population Investment Fund (KPIF), CIDRZ	Zambia
Chanda Mwamba	Social behavioural researcher, CIDRZ	Zambia

Guest speakers

First name	Organization	Country
Lloyd Mulenga	Director of Infectious Diseases, Ministry of Health	Zambia
Suilanji Sivile	National HIV Technical Advisor, Ministry of Health	Zambia
Clarice Pinto	DSD ART Technical Officer, Department of Global HIV, Hepatitis, and STI Programmes, World Health Organization	Switzerland
Erica Spielman	Consultant, Department of Global HIV, Hepatitis, and STI Programmes, World Health Organization	Switzerland
Keren Dunaway	Gender Equity Officer, International Community of Women Living with HIV (ICW)	Argentina
Fred Chungu	Executive Director, Network of Zambian People Living with HIV/AIDS (NZP+)	Zambia
Lackeby Mawanga	Director Technical Services, JSI	Zambia

Observers

From left to right:

First name	Organization	Country
Owen Mulenga	Activist, Treatment Action and Literacy Campaign (TALC)	Zambia
Renny Mulala	Project Coordinator, Latkings Outreach Program	Zambia
Ndingase Phiri	Volunteer, Kaunda Square Clinic	Zambia
Dennis Chibuye	Program Manager, Network of Zambian People Living with HIV/AIDS	Zambia

IAS staff

First name	Organization	Country
Lina Golob	Senior Project Manager, HIV programmes and advocacy, International AIDS Society	Switzerland
Emma Williams	Project Manager, HIV programmes and advocacy, International AIDS Society	Switzerland
Loena La Goff-Gestin	Associate Project Manager, HIV programmes and advocacy, International AIDS Society	Switzerland
Teddy Bourgeonnier	Associate Communications Officer, International AIDS Society	Switzerland

Academy programme

Day 1 – Monday, 25 November, 17:30 – 20:00

Time	Session
17:30 – 20:00	**Welcome evening**
17:30 – 18:30	Welcome and introductions, with Lloyd Mulenga (MoH Zambia)
18:30 – 20:00	Dinner

Day 2 – Tuesday, 26 November, 08:00 – 17:00

Time	Session	Speaker/moderator
08:00 – 09:30	**Session 1 – Setting your goals for the academy**	
09:30 – 09:45	Break	
09:45 – 12:00	**Session 2 – Foundations needed for person-centred care**	
09:45 – 10:15	Definitions and key terminology	Sharon Kruger
10:15 – 12:00	The foundations for "good" communications	Njekwa Mukamba
12:00 – 13:00	Lunch	
13:00 – 14:30	**Session 3 – The core elements of person-centred care**	
14:30 – 15:00	Break	
15:00 – 17:00	**Session 4 – Person-centred design discovery phase**	
15:00 – 16:00	Introduction to person-centred design	Chanda Mwamba
16:00 – 16:45	Client journey mapping presentations	All
16:45 – 17:00	Group photo	All
18:30 – 20:00	Dinner	

Day 3 – Wednesday, 27 November, 08:00 – 17:00

Time	Session	Speaker/moderator
08:00 – 08:30	**Group check-in**	
08:00 – 08:15	Reflections on yesterday's sessions	Kombatende Sikombe
08:15 – 08:30	Overview of CIDRZ-led PCC initiatives and site visit preparations	Njekwa Mukamba
08:30 – 10:00	**Session 5 – PCC implementation in real-world contexts (case studies)**	
08:30 – 08:50	Community-led initiatives with National Network of Zambian Living with HIV (NZP+) and Treatment Action	Fred Chungu (NZP+) and Owen Mulenga (TALC)
08:50 – 09:00	Academic Model Providing Access to Healthcare (AMPATH) program, Western Kenya	Juddy Wachira
09:00 – 09:10	CIDRZ Key Population Hub, Zambia	Maurice Musheke
09:10 – 09:20	Pediatric Adolescent Virus Elimination (PAVE), South Africa	Sharon Kruger
09:20 – 09:30	JSI PCC-Assessment Tool Implementation, Zambia	Lackeby Kawanga
09:30 – 10:00	Q&A	Kombatende Sikombe
10:00 – 10:30	Break	
10:30 – 12:00	**Session 6 – There is no health without mental health**	
10:30 – 11:15	Healthcare provider stress management	Sandra Simbeza
11:15 – 12:00	Reflections and lessons learnt so far	All
12:00 – 13:00	Lunch	
13:00 – 17:00	**Site Visits**	
18:30 – 20:00	Dinner	

Day 4 – Thursday, 28 November, 08:00 – 17:00

Time	Session	Speaker/moderator
08:00 – 08:30	**Group check-in**	
08:00 – 08:30	Reflections on yesterday's sessions	Njekwa Mukamba
08:30 – 09:30	**Session 7 – Guidance to support PCC**	
08:30 – 08:45	Global PCC normative guidance	Clarice Pinto
08:45 – 09:30	Advocating for policy change: The dos and don'ts	Lloyd Mulenga
09:30 – 10:00	Break	
10:00 – 12:00	**Session 8 – Person-centred design in action**	
10:00 – 10:05	Introduction to the People Living with HIV Stigma Index 2.0	Keren Dunaway
10:05 – 11:00	How to test your hypotheses and design-informed interventions	All faculty
11:00 – 12:00	Building a prototype	Chanda Mwamba
12:00 – 13:00	Lunch	
13:00 – 16:30	**Session 9 – Pitching your advocacy plan**	
13:00 – 14:00	Optional Q&A session / individual reflection	All
14:00 – 15:00	Fellow presentations, part 1	All
15:00 – 15:30	Break	
15:30 – 16:00	Fellow presentations, part 2	All
16:30 – 17:00	**Closing remarks**	
18:30 – 20:00	Dinner	

About the IAS Person-Centred Care programme

The IAS Person-Centred Care programme organized the inaugural Person-Centred Care Advocacy Academy in Lusaka, Zambia. We would like to warmly thank our partner, the Centre for Infectious Disease Research in Zambia (CIDRZ), for helping us organize the event. We also thank our collaborating partner, Gilead Sciences, for its kind support.

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

Person-centred care in action

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

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

Following this inaugural PCC Advocacy Academy, a second edition will take place in the southeastern United States in 2025. These academies will be a catalyst for follow-up seed grants, pilot projects, ongoing good practice sharing and the development of policy recommendations across the African continent and in the United States.

About the Centre for Infectious Disease Research in Zambia (CIDRZ)

CIDRZ is an independent, local, non-governmental health organization that has been an active partner of the Government of the Republic of Zambia through the Ministry of Health and other ministries since 2001. Its mission is to improve access to quality healthcare through innovative capacity development, implementation science and research, and impactful and sustainable public health programmes. CIDRZ experts utilize innovative and collaborative approaches to develop research, health services and training initiatives with measurable results in the following focus areas:

- HIV and AIDS prevention, care and treatment
- Tuberculosis prevention and control
- Women's health
- Newborn and child health
- Community outreach
- Health system strengthening/primary care

Solving multifaceted health issues is complex

It's a complicated process, but CIDRZ is uniquely positioned to guide it. Using its strong technical expertise and years of experience in the field, its strong relationships with the Zambian government, and its ability to leverage funding from multiple international donors, CIDRZ is uniquely positioned to identify and address health problems in the country and on the African continent.

The CIDRZ approach is effective. It conducts intensive needs assessments to understand the ongoing challenges for the local health systems. It engages relevant partners to design and implement realistic solutions. And it monitors its progress towards improved health outcomes, both at the individual and population level. The interplay between each step is critical and the result is a continuous loop that allows CIDRZ to take past experiences to inform future decisions. Through this process, it has steadily expanded access to care and improved healthcare quality across a range of services. In addition, because its sole focus is on Zambia, it has a nuanced understanding of health systems on the ground and is able to nimbly respond to priorities identified by the Ministry of Health and the Ministry of Community Development Mother and Child Health.

CIDRZ works closely with the Government of the Republic of Zambia to address priority health issues in line with the national research agenda and, thus, brings research evidence to practice. CIDRZ believes that research should improve the standard of healthcare, foster collaboration and strengthen in-country expertise. CIDRZ research is designed to inform local, national and international policy and has resulted in changes to global health guidelines. CIDRZ, in collaboration with the Ministry of Health, successfully implemented a person-centred care trial in 24 Ministry of Health public health facilities in Lusaka Province from 2019 to 2021, resulting in measurable improvements in client experience and retention[28,29].

Definitions of key PCC terms

Burnout: This term includes a combination of emotional exhaustion, cynicism, depersonalization and low personal accomplishment caused by chronic stress[30,31].

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[32].

Decentralization of services: This refers to the provision of healthcare services outside of health facilities to enhance access[33].

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[34].

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.

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[35].

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[36].

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[37].

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 those needs shaped by their personal social determinants of health[38].

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[39,40]. 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[41].

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[42,43].

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