

Australian Consensus Statement on Person-Centred HIV Care

Background

On 28 August 2022, ASHM, the national peak body representing the blood-borne virus (BBV) and sexual and reproductive health workforce, and the National Association of People with HIV Australia (NAPWHA) convened a high-level roundtable on the Sunshine Coast, Queensland. The roundtable brought together clinicians, community, government and industry representatives to forge consensus on person-centred care in Australia.

Key Statement

Clinicians, community, government and industry delegates agree that person-centred principles should guide the delivery of HIV-related care to ensure the highest attainable standard of health for people living with HIV and people at risk of HIV acquisition. Person-centred approaches:

- > centre a person's autonomy, dignity and rights
- > respect a person's decisions and experiences
- > support a person to lead the dialogue about their health
- > build relationships grounded in understanding and trust

These are holistic approaches that centre people and their goals, beyond a narrow focus on disease control, prevention and viral suppression. Person-centred care is about people having the space to articulate their priorities, and working cooperatively with healthcare providers to make decisions that work for them.

Peer navigators and support workers model person-centred practices by working alongside people living with HIV. Peer workers demonstrate the effectiveness of holistic, multi-disciplinary, non-stigmatising and personalised care and are critical to implementing a person-centred approach in Australia.

People living with HIV deserve to flourish but still face discrimination, criminalisation, insecurity, isolation and stigma. Healthcare providers and policymakers should understand HIV not only as a biomedical phenomenon but also as a social one, where treatment is more than adherence and good quality of life is a goal in itself.

Ultimately, a person is an expert on their own needs. Healthcare providers and policymakers can best help people living with HIV and people at risk of HIV acquisition by centring their concerns, desires and experiences. Respecting people's autonomy empowers them to take control of their health, promotes good quality of life, and instils hope.



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napwha national association of people with hiv australia

Priorities to ensure Person-Centred Care

1

Shift from disease control model of care to one focusing on the well-being of the individual seeking care

2

Shift from strict biomedical understanding of HIV and co-morbidities to one which captures psychosocial and structural determinants of health, and incorporates quality of life

3

Ensure a holistic, rights-based approach that centres people's autonomy

4

Build systems that integrate peer support workers into care models and service delivery

5

Enable and listen to people living with HIV lead the dialogue about their health

Roundtable on Person-Centred Care in Australia

Summary Report

Purpose and aims of the roundtable



On 28 August 2022, ASHM, the national peak body representing the blood-borne virus (BBV) and sexual and reproductive health workforce, and the National Association of People with HIV Australia (NAPWHA) convened a high-level roundtable on the Sunshine Coast, Queensland, on person-centred care (PCC). The roundtable brought together clinicians, community, government and industry representatives from across the country to forge consensus on the definition, best practice, successes and challenges of PCC in Australia. This unanimity is captured in the Consensus Statement, which ASHM and the wider sector can use to support national and state advocacy, policy and strategy development that furthers the mission of a fairer life for people living with HIV (PLHIV).

Roundtable Summary



- > Key themes: autonomy, respect, improved quality of life, stigma, peer support
- > There is a need to move beyond prevention and disease control toward a more holistic approach that centres patients and their goals
- > HIV needs to be understood as a social phenomenon and not only a biomedical one
- > Treatment is more than adherence and 'health-related quality of life' is a limited lens compared to overall quality of life
- > PCC is a holistic, multi-disciplinary, non-stigmatising and personalised form of care that centres a person's autonomy and life experiences
- > PCC is about people having the space to articulate what is important to their health, having healthcare providers listen, and working cooperatively to make decisions
- > PCC isn't necessarily secular and can incorporate anti-racist, intersectional, risk-reduction, sex-positive and trauma-informed approaches
- > Adopting PCC means that it is sometimes appropriate and necessary to respect a person's decision to not engage in care or treatment
- > In PCC, a person may lead the conversation and work cooperatively with their doctors, but it is the clinician's responsibility to enable this process
- > Peer navigation and support provide existing models of PCC in Australia

Person-centred care and health systems



Jeffrey Lazarus, Associate Professor and Co-director of the Viral and Bacterial Infections Programme at the Barcelona Institute for Global Health, delivered the keynote address on a prior consensus statement on the role of health systems in advancing the long-term well-being of PLHIV. In 2021, an international multidisciplinary group of HIV experts developed a statement that identified the key issues that health systems must address. Professor Lazarus spoke to the need to move past the narrow disease-centred focus on anti-retroviral therapy (ART) and viral suppression toward a holistic, person-centred approach. The discussion brought attention to specific sub-populations of PLHIV, such as homeless people, LGBTI people, people who use drugs, prisoners and sex workers, and questioned the extent to which these groups 'have a say' in their care. Professor Lazarus argued for 'the fourth 90%' within the WHO systems framework, consisting of integrated, coordinated care with robust referral systems that include peer support services.

Professor Lazurus stated that such an approach should include prevention activities but also integrate health-related quality of life measures, noting the latter is not addressed as a quantitative target in international HIV strategies. The presentation indicated that inequalities, such as stigma, discrimination and HIV criminalisation, are critical drivers for poor health-related quality of life outcomes and highlighted removing social and legal barriers to care as priorities. Graham Brown, Associate Professor and Director at the Centre for Social Impact UNSW, reflected on the distinction between person or people-centred care and further commented on how data collection in a clinical context might foster meaningful conversations with patients. He drew attention to inequity as a driver of the HIV pandemic, highlighting that improved quality of life resulted from improved equity.

Defining person-centred care in Australia



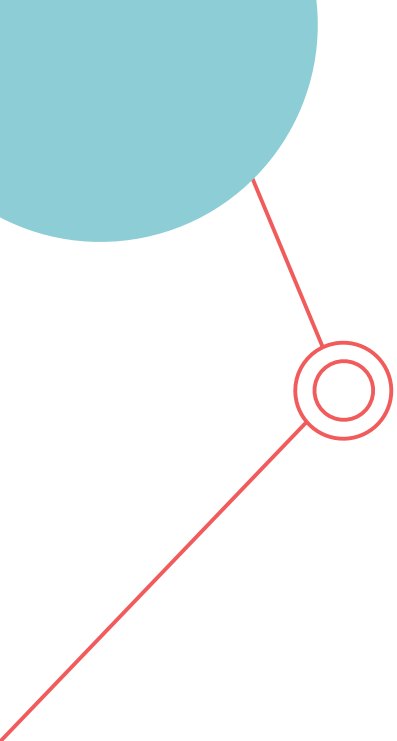
Professor Brown delivered a presentation on health and social patient-reported outcome measures for use in clinical and community services, framing good quality of life as being of value in its own right. He proposed that treatment success is more than adherence and that an undetectable viral load (UVL) does not indicate that someone is thriving. Professor Brown explained that he does not use 'health-related' quality of life as a measure since it is necessarily limiting. He stated that quality of life should apply across the cascades of care and not merely as an optional add-on at the end. Adding to this, the Learning Projects Officer at the National Association of People Living with HIV Australia (NAPWHA) Daniel Reeders introduced the findings of the Positive Perspectives 2 (PP2) study and its related Policy Manifesto. The study concluded that the main protective factors for quality of life are care, belonging, meaning and support, while detrimental factors include distress, insecurity, isolation and stigma. Daniel further highlighted the Manifesto, a call to action for improved quality of life on the PozQol scale for all PLHIV by 2030.

Executive Programs Manager at Queensland Positive People (QPP) Chris Howard presented on community perspectives in client-led HIV care. Chris emphasised several interrelated health determinants related to HIV, including economic and housing precarity, employment insecurity, multi-morbidity, social isolation, suboptimal mental health, substance use, stigma, and unresolved trauma. Later, he noted that, in practice, treatment is often a lower priority than more immediate material and social needs. Chris also critiqued policy focused on biomedical issues such as prevention and disease control, noting the way this incorporated neoliberal individual responsibility as a responsibility to self-manage HIV. He suggested moving beyond disease control to focus more on a person's understanding of their needs. This might include, for example, encouraging healthcare providers to refer to formal and informal peer-support services as a matter of routine. Chris noted that peers are translators, bridge-builders and problem solvers who can 'take the time' to ensure high-quality care.

Case studies in person-centred care



Martin Silveira, a Social Worker at Western Sydney Sexual Health Centre, used a case study to explore what PCC looks like in practice. For Martin, PCC is grounded in respect for persons and a commitment to social justice, and aims to instill a sense of control and hope. Notably, while broadly humanistic, PCC is not necessarily secular and may further incorporate anti-racist, intersectional, risk-reduction, sex-positive and trauma-informed approaches. In Martin's case study, the person's first thought was not about HIV but about whether she could still have a child or whether she could still find loving relationships. In this case, PCC necessitated that he accompany his client to police and court appointments, highlighting the extension of PCC outside strictly clinical environments. Martin also noted that PCC might come into tension with public health structures, especially regarding contact tracing or mandatory reporting obligations, but emphasised the need to build rapport and support people on journeys of discovery.



Similarly, Sexual Health & HIV Medicine Medical Unit Manager at Kirketon Road Centre Vincent Cornelisse provided a particularly complex case study involving an Aboriginal man who initially refused HIV treatment. This person had adverse experiences with institutions and was distrustful of healthcare workers. Additionally, he disliked taking pills because they reminded him of his HIV status. Nevertheless, the patient experienced an acute decline in overall health due to HIV-related complications and a subsequent improvement due to treatment. What ultimately enabled treatment initiation in this case was a gradual building of rapport founded on respecting the patient's priorities. Dr Cornelisse emphasised that, while ethically tricky for a clinician, it was crucial to respect the patient's decision to not engage in treatment while also continuing to build a therapeutic relationship. In this case, it was essential to recognise the impact of colonisation concerning his autonomy as a patient.

Denise Cummins, a Clinical Nurse Consultant at Redfern Health Centre, further explored these themes with a case study that emphasised the importance of patient autonomy. For Denise, PCC is a holistic, goal-driven, personalised form of care based on respect for a person and their lived experiences. Denise explained that often people with complex needs are left with a series of rejections from services for 'things they don't do', highlighting the need for a 'shared care' approach. Her case study was about a man ageing with HIV who found clinical consultations challenging to follow and 'would rather people think he was grumpy than stupid'. In this case, what was important was developing skills to maintain independence and cope with living alone with little social support. This included support to access medical care (e.g. attendance at clinical consultations), assistance with technology, and advice on financial and legal issues, all to improve his overall quality of life.

Roundtable discussions



Person-centred care in the Australian context

The first facilitated group discussion aimed to define PCC HIV care in the Australian context.

Clinicians focused less on the conceptual definition of PCC and more on applying it to clinical practice through performance indicators and funding arrangements. There was some agreement about incorporating peer navigation and support into clinical care and discussion about the need to respect identity. Clinicians noted the difference between approaching a person versus a disease and the issues with narrow service provision rather than asking what a person needs.

Community representatives defined PCC as coordinated, holistic and integrated care that places a person's self-identified needs at the centre of care. For them, PCC is about people having the space to articulate what is essential to their health, having healthcare providers listen, and working cooperatively to make decisions. They further noted that treatment and stigma are lifelong experiences for PLHIV and called for the destigmatisation of healthcare systems. Community members explained that PCC goes beyond clinical interactions between them and their doctors and means valuing the voice of PLHIV. Ultimately, this means understanding HIV beyond a narrow biomedical framework and instead as a social (and collective) phenomenon. Community delegates stated that HIV differs from other diseases due to intense stigma and raised peer navigation as an example of best-practice.

Government representatives defined PCC as holistic, multi-disciplinary, non-stigmatising care that centres patients' self-identified goals. In PCC then, a person leads the conversation instead of being led by a clinician, leading to their being better empowered and informed. This group discussed data, discrimination and competition for resources and how these affected PCC in Australia. They identified Covid-19 and HIV outreach and wrap-around services as examples of best practice.

Industry representatives discussed fragmented health systems and some tensions between clients and healthcare providers in practice. They noted the increasing role of consumer voices, and emphasised empathy-building as a key goal for industry. They agreed that there should be greater awareness of the need for PCC.



Barriers to person-centred care and enabling environments

The second group discussion explored leadership in the HIV sector and how to create enabling and supportive environments.

Clinicians noted several barriers to PCC, including outdated electronic medical record systems, non-integrated digital systems, and passive referrals, while reporting on the increasing challenges of delivering care in a time and resource-scarce environment. They noted co-design, nurses and PozQol as areas to provide sector leadership.

Community identified inflexible health systems, poor knowledge of services, siloed care approaches, suboptimal health literacy, and substandard government consultation as barriers to providing PCC in Australia. They situated PCC in a broader health literacy promotion project among PLHIV and highlighted the need to rethink service provision. They also emphasised the importance of promoting quality of life across the whole sector.

Government representatives discussed policy and service fragmentation, funding and resources, and a need to better understand PCC. They thought that government could help build coalitions beyond the health space and leverage existing knowledge on social inequalities. There was also some discussion regarding streamlining services and expanding peer-based models.

Industry representatives focused on the inaccessibility of care options in regional and remote areas. They agreed that the industry could support events to enable discussions and lead innovations, particularly with collaborations, grants programs and research. They also discussed the need for industry partners to support patient affairs in a general way.



Partnerships and visions for the future

The third and final group discussion revolved around the potential for strategic partnerships and the vision for PCC going forward.

Clinicians focused on partnerships with the community and the need to communicate that healthcare providers hear their needs. There was some discussion that this should involve meaningful representation of peers in healthcare teams.

The community group envisaged the future of PCC as involving connection with people, destigmatisation, and healthcare workforce adaptability. Significant to this discussion was the fact that PLHIV have many different health goals that are social in addition to clinical. They identified funding as the primary challenge facing implementing PCC in Australia and called on clinicians to work with peer services.

According to government representatives, implementation of PCC will require collaboration, time, and resources. Challenges include the approach's labour-intensive nature and difficulties coordinating patient care in a time-limited environment. This group discussed the problems facing GPs due to the Medicare system being at capacity.

Industry partners suggested that PCC is about providing control to the person but is ultimately driven by the provider. They discussed the potential of drop-in care and outreach programs and the need for peer-based connection but questioned who was ultimately responsible for changing the system.

Discussion Takeaways

Stream	Key takeaways
Clinicians	Clinicians agreed that PCC is a best-practice approach to care provision while acknowledging that they face time and resource restrictions. Clinicians were also open to the potential of peer-based methods.
Community	Community delegates insisted that the social aspects of HIV deserve equal attention as the clinical ones. In this respect, peer navigation and support are critical. Community representatives eagerly noted the potential for PCC to improve the quality of life for all PLHIV.
Government	Government officials expressed interest in developing a PCC 'checklist' for Australia and collecting more data. They acknowledged that care is more than biomedical issues and should address a person's self-identified goals. They further recognised the need for more funding and resources.
Industry	Industry representatives conceived of their role in implementing PCC primarily through the lens of supporting innovation. However, they also expressed interest in bringing community voices into dialogue with healthcare providers and helping address service fragmentation.



ASHM is a peak organisation of health professionals in Australia and New Zealand who work in HIV, viral hepatitis, other blood borne viruses and sexual and reproductive health.



The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV (PLHIV). NAPWHA represents the positive voice in Australia.

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