

Australian Consensus Statement on HIV Treatment Initiation

Background

On 11 November 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 in Melbourne, Victoria, on initiation of antiretroviral therapy (ART) for HIV. The roundtable brought together clinicians, researchers, community, government and industry representatives from across the country to forge consensus on initiation of ART in Australia.

Key Statement

Australia has had significant success with treatment for people with HIV, but it still has much to do. The status quo will not work. It will take incredible effort and innovation to reach the last 5% of people in the UNAIDS 95-95-95 targets: 95% of people with HIV knowing their status, 95% of those people on treatment, and 95% of those people virally suppressed¹.

Along with these treatment targets, Australia's National HIV Strategy also includes a target for people with HIV reporting good quality of life. Clinicians, community, government, researchers and industry agree that ART improves overall quality of life for people with HIV and should be initiated as close to seroconversion as possible. While gaps in HIV testing contribute to the number of people with HIV who are not on treatment as they do not know their status, there continues to be a core group of people who have received a HIV diagnosis but are not on treatment.

Initiating ART is not always the only, or even the main, priority for people with HIV, who might also contend with employment and housing insecurity, dependent substance use, family and study commitments, family violence and restrictive visa rules. Moreover, even where starting ART is a priority, some may struggle with initiation due to challenges navigating the health system, the 'daily reminder' of their status, fears about side effects or unwanted sharing of health information, and stigma.

Nevertheless, the best-practice approach in all cases is to support people with HIV and provide the best, non-stigmatising, person-centred care available. Best practice entails educating, listening to, and empowering people with HIV. To this end, peer navigators are invaluable. Peers can encourage treatment initiation and support retention in care, and work in partnership with healthcare providers.

People with HIV have done the heavy lifting to keep transmission numbers low and demonstrate the benefits of ART for individuals and the broader community, but these benefits are not equitably distributed among people with HIV. Instead of expecting people to fit healthcare models, it is time to provide person-centred care that is tailored to the individual needs of the person with HIV.

¹ UNAIDS (2020), Prevailing Against Pandemics by Putting People at the Centre, Report: [aidstargets2025.unaids.org](https://www.unaids.org/en/presscentre/featurestories/2020/11/11/20201111_01)

HIV Treatment Initiation Framework Care

Adopt

- 1 Early and rapid ART initiation as key to achieving good health and quality of life for people with HIV.
- 2 Non-stigmatising and person-centred approaches to care provision and client education that are person-centred, trauma-informed and culturally competent.

Implement

- 3 Peer support that compliments and augments other care models and services.
- 4 Novel practices such as after-hours appointments, client coding (i.e. using aliases for tests) and opt-out peer navigation referrals.
- 5 The use of clinical indicators to identify opportunities for testing, rather than risk factors, to enable treatment initiation as soon as possible after diagnosis.
- 6 Strategies that address treatment scepticism and misinformation and promote the benefits treatment uptake and U=U.

Pursue

- 7 More people with HIV on treatment and fewer late diagnoses, especially for women and heterosexual men.
- 8 People with HIV are supported to take their treatment consistently.
- 9 Improved quality of life for all people with HIV.



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ASHM & NAPWHA Treatment Initiation Roundtable Summary Report

Purpose and aims of the roundtable



On 11 November 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 in Melbourne, Victoria, on initiation of antiretroviral therapy (ART) for HIV. The roundtable brought together clinicians, community, government, and industry representatives from across the country to forge consensus on the barriers, challenges, and successes of ART initiation in Australia. The agreement among participants is captured in the Consensus Statement, which ASHM and the wider sector can use to support advocacy and policy development that furthers the mission of a fairer life for people with HIV.

Roundtable Summary



- > Key themes: autonomy, peer support, quality of life, 'the status quo will not work'.
- > ART improves overall quality of life for people with HIV and should be initiated as close to the time of seroconversion as possible, or as close to the time of diagnosis.
- > Initiating ART is not always the only or even the main priority for people with HIV, who might also contend with, for example, employment and housing insecurity, dependent substance use, family and study commitments, family violence and restrictive visa rules.
- > Even where starting ART is a priority for people with HIV, some may struggle with initiation due to challenges navigating the health system, the 'daily reminder' of their status, fears about side effects or unwanted sharing of health information, and stigma.
- > The best approach in all cases is to support people with HIV and provide the best, non-stigmatising care available.
- > Treatment works best when it is accompanied by education and empowerment.
- > Peer navigators are cost-effective and valuable, can encourage treatment initiation and retention, and can work in partnership with healthcare providers.
- > Clinicians should take great care when discussing positive test results to use person-centred, trauma-informed, culturally competent approaches.
- > Though the proportion of people with HIV diagnosed and not on treatment has decreased substantially over the last 15 years, the 'core group' of people with HIV who have a low CD4 count (<350) remains stable.
- > The main gaps in HIV treatment relate to overseas-born people (especially people of South-East Asian, South American and Caribbean descent) and heterosexual men and women.
- > Novel practices might include: after-hours appointments, at-home HIV tests, client 'coding' (i.e. using aliases for tests), HIV telehealth services, longer appointments (e.g. for 1 hour), longer prescriptions (e.g. for one year), opt-out peer navigation referrals on diagnosis, rapid treatment initiation (same-day or next-day), removal of co-payments, and use of clinical indicators (as opposed to risk factors) for HIV testing.

Opening Comments



NAPWHA Deputy Director Brent Clifton opened the roundtable with some reflection on the previous Person-Centred Care roundtable, noting the special importance of peers and the importance of working collaboratively. He acknowledged the life-changing quality of treatment and linked this to improved quality of life for people with HIV. Dr Lucy Stackpool-Moore, the founder of Watipa, further encouraged participants to explore the challenges, successes, and barriers to early initiation of ART.

HIV Treatment in Australia



In the keynote address, Dr Richard Gray, Senior Research Fellow in the Surveillance and Evaluation Research Program at the Kirby Institute, University of New South Wales, discussed HIV treatment uptake in Australia, explaining that there were 746 new diagnoses in 2021. He described a reduction in transmission among Australian-born men who have sex with men (MSM) but noted that this trend did not extend to overseas-born MSM. Dr Gray explained that among overseas-born individuals, new infections are concentrated among people of South-East Asian, South American and Caribbean descent. He further discussed a modest drop in transmission rates among Aboriginal and Torres Strait Islander people and the relative transmission stability among heterosexual people. One interesting distinction between MSM and heterosexual people is that the former tend to acquire the virus domestically, whereas the latter tend to acquire it overseas. Indeed, Dr Gray reported a growing trend of overseas acquisitions between 2005 and 2021.

Dr Gray detailed the stability of HIV testing rates among MSM during the COVID-19 pandemic, venturing that the recorded drop in transmissions appeared to reflect a real-world decline in transmission rates (as opposed to decreased testing rates). Dr Gray proposed that the 'core group' of individuals with a low CD4 count (<350) remains stable but is an increasingly large cohort as overall transmission rates decrease. He explained that of the roughly 30,000 people with HIV living in Australia, approximately 24,000 are engaged in treatment and virally suppressed. However, that still leaves around 6,000 people who are either not on treatment or not virally suppressed², which is a treatment gap larger than many might expect. Importantly, Dr Gray called attention to the 1,200 people then not eligible for Medicare HIV treatment (access to treatment for this group has since been facilitated by a national HIV treatment access scheme for people ineligible for Medicare). Nevertheless, he explained that the proportion of people diagnosed and not on treatment had shrunk substantially over the last 15 years, partly due to Treatment as Prevention (TasP) and early initiation trials. Dr Gray concluded that the main gaps in HIV treatment related to overseas-born people, heterosexual men and women, and late diagnoses.

Following the keynote, there was a lively discussion covering various topics. One participant ventured that longer scripts (e.g. one-year scripts) might give the appearance of disengagement in care, especially if they are filled by overseas pharmacies that are not captured by domestic surveillance. One person asked about the demographics of the estimated 2,500 undiagnosed people, who are predominantly overseas-born gay, bi and other men who have sex with men. Later, the facilitated discussion provided further insights. One person explored why some people with HIV might turn to 'natural therapies' instead of ART. Another participant said that it was not enough to be 'on treatment' and that what ultimately mattered for retention in care was meaningful engagement. There was some discussion about how people with HIV not on treatment might merely have other priorities in their lives at that time, e.g. dependent drug use, family commitments, or study. Participants also distinguished between comprehensive sexual health checks and non-specialists ordering limited tests as one reason for people 'slipping through the cracks'. There was also discussion of mandatory or routine testing of all blood samples for HIV, which drew mixed reactions. Some were excited by the prospect of capturing more surveillance data, while others raised concerns about people's human rights and right to consent.

² In July 2023, following the roundtable, the World Health Organisation updated their definition of viral suppression to include any viral load below 1000 copies/mL. Previously, viral suppression was defined by a viral load of <20 copies/mL. See: WHO (2023), The role of HIV viral suppression in improving individual health and reducing transmission, Policy brief: <https://www.who.int/publications/i/item/9789240055179>

Peer Support and HIV Treatment



Anth McCarthy, a peer navigator at Living Positive Victoria (LPV), explored the 'esoteric challenges' of engaging minoritised PLHIV in peer support. McCarthy detailed the role of peer support in treatment initiation and the need to innovate to support treatment uptake. He also noted some challenges, such as the limited but noteworthy number of PLHIV who endorse conspiracy theories that inhibit engagement in care. He summarised the top-level demographics of clients and the kind of work he usually engages in, including events, retreats and workshops. He explained that a significant percentage of male heterosexual clients engage very briefly, sometimes for one single phone call only. He spoke at length about the experiences of heterosexual men; how they typically struggle to connect on the basis of living with HIV. Also, how female peers appear to play an important role for them. Afterwards, there was some spirited discussion about the underlying reasons for this anecdotal trend: is it that heterosexual men feel uncomfortable talking with other men about their status? Or might it be that women carers confirm traditional gender stereotypes? And, in either case, what does this mean for the provision of support?

McCarthy spoke thoughtfully of clients who 'grappled' with the decision to take pills, sometimes because they disliked the 'daily reminder' of their HIV status, sometimes due to fear of unwanted disclosure, and other times owing to difficulties due to travel commitments. He introduced a case study who was 'daunted' by the prospect of starting a medication regimen he'd 'need to do for the rest of his life'. McCarthy further discussed the impact of HIV & AIDS denialism on treatment uptake, discussing an individual who waited 16 years before commencing treatment. He critically discussed the modern 'thriving and living long lives' HIV messaging but noted that it often did not explicitly link to treatment and ART. Without this link, McCarthy raised concerns that a minority of PLHIV may not appreciate the gravity of their diagnosis and may reject the benefits of treatment. McCarthy quoted Assoc Prof Edwina Wright, who contends that the best approach to treatment-hesitant PLHIV is to "stand by them" and do your best to understand where they are coming from. McCarthy concurred, suggesting that some solutions will only be found in the communities left behind. Also, that treatment may not be a priority for PLHIV facing structural disadvantage like forced migration, poverty, homelessness. McCarthy closed by cautioning against constantly problematising others, instead, inviting those of us in the sector (and dominant culture) to 'point the microscope at ourselves occasionally too'.

HIV Treatment and Service Provision



Leah Ward, an HIV s100 prescriber in Townsville, Queensland, presented on the challenges of ART initiation and continuation. Her clinic provides wrap-around services, including outreach to 'bring in clients that get missed' without follow-up. The clinic serves more than 170 people with HIV, including 10 remote and 10 'coded' people, who use fake names when using services. Ward explained that new cases are often complex and may arise, for example, through immigration testing. In addition to the stresses of visa applications, overseas testing, and treatment regimens (that people with HIV expect or are used to) may be outdated or not best practice. In other cases, people present to the clinic due to a general deterioration in their health. Nevertheless, Ward noted that some people with a new HIV diagnosis might need to postpone starting ART due to extenuating circumstances, such as a round of antibiotics for infection precipitated by HIV or advanced-HIV-related complications.

Ward stressed the importance, and difficulty, surrounding confidentiality. For instance, people with HIV expressed nervousness about where they could access pathology or buy medications without unwanted disclosure in a small rural or remote community. She explained that flexibility was vital to retention on ART. For this reason, appointments at her clinic were one hour long, and scripts could be for 12 months. Similarly, she described the clinic's measures for people with high support needs, or those wary of accessing the service. For the former, the clinic ran a dedicated outreach team and an internal knowledge-sharing service that helped ensure continuity of care. For the latter, the clinic offered coding of clinical records (i.e. strict anonymity), after-hours appointments, and an option not to forward test results to local clinics. Ward emphasised that some people with HIV want to be on treatment but find it difficult due to stigma and confidentiality concerns. She closed by noting that prescribing alone does not educate or empower a person with HIV or ensure that they actively take their medication.

Challenges and Solutions for HIV Treatment



Deputy Director of NAPWHA Brent Clifton gave a presentation on the value of treatment and proposed some innovations. Clifton applauded Australia's many successes regarding treatment, emphasising that treatment 'enables good health' as well as the importance of initiating treatment 'as close to seroconversion as possible'. He explained that treatment improves the overall quality of life and promotes sexual freedom, allowing people with HIV to have 'the kind of sex they want to have'. Notably, he argued that people with HIV have 'done the heavy lifting' to keep transmission numbers low regarding treatment as prevention or U=U, and demonstrate the benefits of treatment for individuals and the broader community. However, he also recognised several challenges, such as late diagnoses (especially of women), competing health and social issues, health literacy, immigration experiences, service accessibility and capacity, minimal funding of peer services and the 'tyranny of distance' for people with HIV in outer regional, rural, and remote parts of Australia.

Clifton discussed anecdotal evidence around diagnoses related to Medicare ineligibility, injecting drug use and intensive sex partying. He argued in favour of non-stigmatising approaches and those that encouraged cooperation between medical practitioners, nurses, allied health workers and peer navigators. He also argued that 'repeatedly doing the same thing will provide the same result' before introducing a new home testing program. It is crucial, Clifton said, to ensure that diagnoses are provided in a way that does not traumatise a person for life. In closing, he proposed rapid treatment initiation, either same-day or next-day, and opt-out peer navigation referrals upon diagnosis.

In the proceeding session, participants raised the point that many contemporary diagnoses often occur in general practices that may lack specialised knowledge about HIV. However, others highlighted GP 'Phone an Expert' services as one solution. Participants agreed that forming relationships and meeting people in their own spaces is important, especially concerning South-East Asian GBMSM. Similarly, one participant noted that non-gay identifying MSM might hesitate to engage in care via LGBT-specific services. Multiple participants identified non-clinical interventions as particularly effective, such as 'barber shop chats' and HIV testing at The West Ball in Sydney. People agreed there is a strong need for alternative approaches 'that isn't a survey'.

HIV and Migration



Monash University's Associate Professor, Dr Jason Ong gave a presentation on the complex issues around HIV and migration. He opened with the question he gets asked most often: how will this affect my visa? He spoke to fears about ART side effects, medical costs, and unwanted disclosure to overseas family members. He identified recent arrival, sexual minority membership, disconnection from the local community and coming from a culturally conservative country-of-origin as factors that may delay HIV testing and/or initiation of ART. In addition, he talked about the difficulties of psychosocial issues such as internalised homophobia and anxieties about disclosure. Crucially, he clarified that people with HIV in his care often prioritise employment and housing over their health. He also suggested that the choice of antiretroviral is essential, for example, considering whether that specific drug is available in the client's country of origin. Dr Ong argued that it is not enough to have translated materials but that health promotion and resources should be developed by the communities for which they are intended. He commended migration support services such as the NSW HIV/AIDS Legal Centre (HALC). Further, he explained that peer navigators and networks such as the Positive Asian Network Australia (PANA) are highly regarded by clients.

Case Studies and Models of Care



Dr James McMahon, Associate Professor, Infectious Diseases Physician and Head of the Infectious Diseases Clinical Research Unit at the Alfred Hospital and Monash University, presented a case study for the roundtable's consideration. The case was that of a 24-year-old man who had sex with men. He had been on pre-exposure prophylaxis (PrEP) for five years and reported mixed condom use with casual and regular partners. He was diagnosed as part of routine sexual health testing within six months of acquisition. The patient was eager to commence treatment and elected to presume drug resistance and rationalise his medication regimen later. Tests revealed no drug resistance and a good CD4 count. The patient was well informed and had a confident but was later referred to a psychologist for issues concerning rejection and self-worth. For Dr McMahon, this case raised several questions, namely whether the model of PrEP worked for the person before HIV acquisition. The case also highlighted the need to be mindful of drug resistance and for continual mental health evaluation.

Clinical Professor Louise Owen introduced a further case study involving a 44-year-old woman who presented with a rash, weight loss, and decreased appetite and energy. After a referral to a sexual health clinic, the patient was diagnosed with HIV, to which they reacted with 'shock, grief and disbelief'. This case underlined several barriers to care (especially HIV notification), including suboptimal accessibility, wait times, and stigma. Critically, one further barrier was clinicians not testing, or even thinking of testing, for HIV. For Clinical Professor Owen, this revealed a need for clinical reasons for HIV testing beyond sexual history. She highlighted the cheapness of HIV testing, explaining that for \$15, a clinician 'can rule out HIV'. Clinical Professor Owen closed by arguing that clinicians should use 'automatic triggers' based on clinical indicators and not only risk factors. Had the attending clinician in the case study carefully examined the patient's symptoms, they might have thought to order an HIV test. Instead, they prematurely ruled it out since the patient presented no apparent risk factors. Clinical oversight was highlighted in discussion as one of the possible drivers of late diagnoses among women.

The discussion that followed focused on opportunities for the future. Participants highlighted the value and cost-effectiveness of peer support workers, who could support wrap-around services alongside clinicians in a partnership model. This discussion was grounded in recognising that both peers and clinicians provide equally important amenities: an s100 prescriber can tell someone when they are undetectable, but it is peer workers who can talk about when and how to disclose their status. There was some recognition of the need for more training in the health sector, especially concerning women and HIV. There was also a discussion of testing system fragmentation, fragility, and service accessibility. Participants discussed how HIV telehealth might alleviate accessibility issues, including the 'tyranny of distance'. The discussion concluded, emphatically, on the necessity of removing co-payments and the provision of free healthcare. As one roundtable member declared, 'The status quo will not work'.

Closing Discussion and Remarks



Dr Lucy Stackpool-Moore called attention to those so-called 'hardest to reach' and those 'left behind', as well as the twin 'ecosystems' of prevention and treatment. She noted that stigma-free notifications could be transformative for people and referred to several phrases repeated throughout the day, such as 'treatment success' and 'the joy of being undetectable'. Those being the end goal, Dr Stackpool-Moore encouraged roundtable members to enable people to make pro-health decisions, highlighting the importance of outreach, integrated and wrap-around care. Dr Stackpool-Moore suggested that 'bringing care to people' instead of 'demanding they come to you' is an approach that involves, at its most fundamental level, listening to people and what they need. In closing, Brent Clifton highlighted treatment innovations such as long-acting injectable ART and the clinical indicator testing approach proposed by Clinical Professor Owen. He agreed with other roundtable members that the sectors represented in the room had the power to support all people with HIV in Australia and set them up for success.



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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