

LINKAGE TO CARE PROJECT REPORT

IDENTIFYING THE BARRIERS AND FACILITATORS FOR PEOPLE LIVING WITH HIV TO TREATMENT AND CARE

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Contents

- 4** Acronyms | Acknowledgements
- 5** Introduction
- 7** Background
- 8** What did we do?
- 9** Key findings
- 10** Diagnosis and referral
- 13** Equitable access to treatment and care
- 17** Treatment reviews, side effects and continuity of care
- 20** Living long-term with the virus
- 22** Old and alternative ideas about treatments and HIV
- 24** Peer supports are crucial
- 27** Keeping the door open
- 30** Conclusions and recommendations
- 31** References

Acronyms

ART	Antiretroviral therapy
ATRAS	Australian HIV Observational Database Temporary Residents Access Study
CALD	Culturally and Linguistically Diverse
GP	general practitioner
HIV	Human Immunodeficiency Virus
LCP	Linkage to Care Project
NAPWHA	National Association of People with HIV Australia
NGO	Non-government organisation
PLHIV	People Living with HIV
TASP	Treatment-as-Prevention
VIPER	Victorian Initiative for Patient Engagement and Retention
VMO	visiting medical officer

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NAPWHA

NAPWHA is the national peak organisation representing people living with HIV in Australia. Through leadership in advocacy, policy, education and prevention, NAPWHA strives to minimise the adverse personal and social effects of HIV. By championing the participation of HIV-positive people at all levels of the national response we aim to build a positive future for all people living with HIV.

Introduction

The number of people living with HIV in Australia who are diagnosed, engaged in care, taking antiretroviral therapy (ART), and virally suppressed is relatively high. Annual surveillance data estimates there were 26,444 people living with HIV in Australia in 2016. Of those, an estimated 23,648 (89%) were diagnosed; 22,465 (95% of those diagnosed) were engaged in care; 20,440 (86% of those diagnosed) were receiving ART; and 19,013 (93% of those on antiretroviral therapy) had suppressed viral load (less than 200 HIV1 RNA copies/mL) (Kirby Institute, 2017). While these figures show Australia is doing well compared to many other countries, there are gaps at all stages in the HIV continuum of care. In 2016, there were an estimated 2796 (11%) people living with HIV who were undiagnosed; 7431 (28%) of all HIV-positive people did not have suppressed viral load. Of these, 32% were undiagnosed; 17% were diagnosed but not in care; 30% were in care but not on antiretroviral therapy; and 21% were on antiretroviral therapy but had not achieved suppressed viral load (Kirby Institute, 2017).

The Linkage to Care Project (LCP) responds to an ongoing issue in the HIV response in Australia: how to engage and retain all people living with HIV in treatment and care when early initiation of ART is clinically recommended and that, once commenced, ART is for life. The early and ongoing uptake of ART by people living with HIV has benefits for individual health outcomes and for HIV prevention – Treatment as Prevention (TASP) – at the population level (The Insight START Group, 2015; Cohen et al., 2011). To maximise these health and prevention benefits all people living with HIV need to be linked to and maintained in care and taking ART. As Murphy and colleagues, 2017, have observed that in the Australian context:

With the policy, financial and other structural barriers to commencing and maintaining HIV treatment minimised, psychosocial and service-related factors that influence individuals' progression through the continuum of care, and their sexual behaviours, are likely to become the key indicators of successful patient and community health outcomes (2017,8).

The Linkage to Care Project aims to better understand the psychosocial and service-related factors that influence engagement in the HIV continuum of care by people with diagnosed HIV. NAPWHA has maintained a persistent focus on linkage to care and treatment over many years and the current project continues this focus and builds on previous NAPWHA campaigns and work – including *Start the Conversation*, *The Wait is Over*, and *Good Quality of Life*.

The project was funded by ViiV Health Care Australia through the Positive Action Grant Scheme. NAPWHA conducted consultations with people living with HIV and HIV service provider organisations around Australia. These consultations aimed to identify and understand some of the reasons why people living with HIV who have been diagnosed with HIV disconnect from care, and/or discontinue or delay ART. Further, the project aimed to identify strategies that could support ongoing linkage to care and lifelong use of ART.

This report summarises the key outcomes of the consultation. The consultations revealed a range of factors associated with disconnection from treatment and care, including ageing; psychosocial pressures linked to living long-term with HIV; the quality of clinical care and instances of discrimination experienced by people living with HIV at point-of-care; and the existence of outdated understandings of current scientific evidence about the optimum use of ART. The report also highlights the key role of peer support in linking and re-linking people living with HIV to care.

Background

Guy and colleagues (2013) used information from the Australian HIV Observational Database and found that since 2006, there had been a loss to follow-up rate of 3.8% per year pre-2006 and 3.9% per year from 2006–2010; and that treatment interruptions had occurred for a range of reasons including, being in poor/fair current health, mental health, alcohol/party drug use and attitudes to treatment. McMahon and colleagues (2015) cross-referenced clinical data from six sites in Victoria and found a number of reasons for the interruption of HIV care. These reasons included being 'well and busy' and therefore not perceiving a need to stay connected in care; psychosocial barriers such as difficulty accepting diagnosis; stigma and discrimination including negative interactions at a care site; structural barriers such as financial costs of clinical care, and poor access to transport; and extended period of overseas travel. International research by Mugavaro and colleagues (2015) shows that poor engagement in HIV clinical care leads to poor disease outcomes in the cascade of HIV care. Other studies have found that the attitudes of treatment prescribers have an impact on treatment uptake (Mao et al 2015) and in another study Mao and colleagues (2015) found that age, time since diagnosis and non-availability of welfare supports are associated with people living with HIV not accessing care and the non-use of antiretroviral therapy.

Researchers and health service providers continue to grapple with the issue of how to bring into HIV care people living with HIV who are not currently accessing it. In Australia there is currently good work underway to address this issue, for example, the Victorian Initiative for Patient Engagement and Retention (VIPER) continues to publish information about these issues as well as various researchers in Australia, such as, Guy et al (2013) Mao et al (2015) and Newman et al (2015). The NAPWHA Linkage to Care Project aims to continue this work, as the importance of retaining people living with HIV in care and ensuring that there is no loss to follow up are essential components of the Treatments-as-Prevention approach.

What did we do?

Between June–October 2017, we interviewed 26 HIV service providers and people living with HIV. We interviewed nine people living with HIV; the sample included two women, both of whom identified as heterosexual; and seven men, all but one of whom identified as gay. The two women were born overseas, five people lived in capital cities and four in regional Australia. The inclusion criteria for people living with HIV interviews were that they had to have stopped taking treatment since the guidelines changed in 2013; or were diagnosed since 2013 but had never taken treatments, delayed treatment or disconnected from active clinical care in the past five years. The recruitment criteria were intended to exclude any people living with HIV who had delayed ART or discontinued ART during periods when both the scientific evidence and clinical guidelines supported delaying ART and treatment breaks. Seventeen interviews were conducted with service providers and representatives of people living with HIV state-based organisations (in some cases people living with HIV organisations are also service providers). Service providers included those operating direct clinical and care programs. Some of the organisations representing people living with HIV had care and/or peer support programs operating from within their services. All organisations were selected because their representatives would have some in-depth knowledge to contribute to the central concerns of this project.

The interviews were semi-structured, and consent was gained from all participants to digitally record the interviews and to the use of de-identified data in project reporting. Participants were recruited through NAPWHA networks. HIV service providers who worked specifically with individuals and populations who had been identified in the research as facing challenges around retention in treatment and care — such as people living with HIV with cognitive impairment, people living with HIV from CALD communities and people living with HIV who are Medicare-ineligible — were approached to participate. The sample included input from individuals or community-based organisations, and/or government health services from every state in Australia.

To ensure the confidentiality of participants, all quotes have been de-identified, and we use pseudonyms for people living with HIV and do not name specific services. All people living with HIV were given a \$50 voucher to thank them for their time and expertise.

Key findings

from the interviews with service providers and people living with HIV

The interviews revealed a range of factors associated with disconnection from treatment and care including ageing, psychosocial pressures linked to living long-term with HIV, the quality of clinical care and instances of discrimination experienced at point-of-care. Some participants were unaware or unconvinced by current scientific evidence in relation to HIV management. The interviews also identified factors that support linkage to care, including continuity of care, peer-based programs, and doctors and services that can maintain patients in monitoring even when they choose against advice to discontinue ART – what some service providers termed keeping the door open. In this report, we focus on key themes and issues that emerged across the interviews with both people living with HIV and service providers and that influence engagement with the HIV continuum of care:

- **diagnosis and referral**
- **equitable access to treatment and care**
- **treatment reviews, side effects and continuity of care**
- **living long-term with the virus**
- **old and alternative ideas about treatments and HIV**
- **peer support**
- **keeping the door open.**

Diagnosis and referral

The way in which an HIV diagnosis is initially managed is likely to have a significant influence on the future engagement of HIV-positive people with clinical care and treatment. A key concern for service providers who participated in the project was the loss of follow-up of newly diagnosed people living with HIV because of a negative experience at the point of diagnosis. The negative experiences service providers identified ranged from being given little or no information about HIV, slow referral processes, and discriminatory behaviour by doctors and other staff at the point of care. One service provider described two cases they were aware of where women had felt stigmatised by the diagnosing general practitioner (GP), and as a result delayed contacting HIV specialists they were referred to because they were anxious they would continue to be treated in discriminatory ways by medical professionals. The interviews with service providers show that prejudice in health care settings in relation to HIV still exists – particularly outside of major cities – and this can result in people living with HIV not returning for treatment or not following up on referrals.

Stigma and the shock of being diagnosed with HIV were reported by service providers as issues that are still influencing some HIV-positive people's willingness to seek care and support. One service provider observed that "stigma is a brick wall to building confidence and getting information."

The management of referral pathways post diagnosis were described by many service providers as key factors contributing to disconnection from clinical care and treatment. In some cases, this was related to where and by whom the person was diagnosed. For example, service providers in different jurisdictions described situations where an HIV diagnosis had happened in a general practice service in a country location where the diagnosing GP appeared to the patient to have no knowledge or information about HIV and did not immediately set up a referral pathway to either clinical or peer support:

What we have found out is that returning after diagnosis depends on the way the diagnosis is given. The first interaction sets up conditions for success or failure [in linking the patient into care programs]. This is the case especially in rural and regional settings where we estimate that 40–50% of those diagnosed are diagnosed by a GP. We know of two recent instances where GPs had adopted an attitude that was judgemental when providing the diagnosis, and then those people did not present at the specialist clinic where they had then been referred to.

HIV-positive organisation, care and support worker

Two service providers in different jurisdictions described recent incidents where women had been told at the point of diagnosis that HIV meant that they could never have children. Not only was the information incorrect, but it caused significant and unnecessary distress.

Another service provider reported that geographic and social isolation was especially a problem for older people living with HIV. Compounding issues might be the occurrence of mental health problems and managing multiple comorbidities without easy access to specialist services. Some service providers highlighted that Aboriginal and Torres Strait Islander people living in Far North Queensland, parts of the Northern Territory and South Australia were at a greater risk of disconnecting from care compared to non-indigenous people living with HIV.

Our service does not work with many Aboriginal and Torres Strait Islander [people] however I am currently working with someone from that background who is in extenuating circumstances. He has been HIV [positive] for 12 years, has significant mental health diagnoses (anxiety/depression, panic attacks) and other complex health issues (skin cancer, kidney and cardio-vascular disease). He has no transport of his own, is on the disability support pension, experiences significant social isolation, virtually no network of support and is geographically isolated.

HIV health service delivery project, Queensland

The importance of knowledgeable clinicians and referral pathways at the point of diagnosis is illustrated by the experience of one of the participants, Grace. Grace was diagnosed in 2001; at the time, she was pregnant. The hospital where she was diagnosed advised her to start treatment immediately to prevent mother-to-child transmission, however, Grace was still anxious about whether she should carry on with the pregnancy, given her own diagnosis. The social worker at the hospital organised for Grace to talk with an HIV-positive peer worker who was female and had children:

At that time I asked one of the social workers: “Is there anyone in this area who has children and still lives a normal life?” And she said, “Yes.” And she put me in touch with [name of peer], and, oh my god, that was my biggest support and if it wasn’t for [name of peer], I would not know all that I know now . . . and seeing someone with beautiful children made me feel I could go on with the pregnancy regardless.

Grace

Grace’s experience also highlights the importance of peer support, which will be discussed in more detail below.

Equitable access to treatment and care

While access to ART medication is free in some circumstances, in most jurisdictions in Australia people living with HIV will be required to make a co-payment towards the cost of their ART. Both service providers and people living with HIV noted that for some people with low disposable incomes even a relatively small co-payment could lead to discontinuation of ART:

Costs are a problem for some clients. Some are able to access GPs or HIV prescribers who provide bulk billing but not everyone. The co-payments, not just for ART but payment of scripts for management of other health conditions, means that some clients are making their own decisions about what medications they can afford. Some clients in making their own decisions don't make the best decisions for managing their health.

clinical service provider, NSW

For some people living with HIV, the costs of ART and other medications needed to manage HIV-related comorbidities was a significant cost burden and for some this was a factor in decisions about taking breaks from ART. Grace offered the following when asked about her current decision to take a break from ART:

You know your body, and I was feeling good, and I am paying \$70-100 for treatment and it's a lot of money . . . I wish the treatments could be free, and some weeks it's, "Do you want to pay your bill, or your treatments?"

Grace

For people living with HIV on low incomes, meeting the costs of medications, including ART, can come at the expense of meeting other living costs, such as food and accommodation. In interviews with service providers, this was noted a number of

times as a reason there may have been interruptions to care arrangements. One example is provided here as to why discontinuation of ART might occur:

We know of people who have to make choices between paying for food or for their medication . . . there are people who have three or four more scripts to fill, then with other expenses in their lives they have to make a choice. HIV meds aren't free here.

health service provider, South Australia

There are also people living with HIV in Australia who do not have access to Medicare, for example, international students and refugees. While compassionate access to HIV drugs has been possible for a significant portion of those identified as Medicare Ineligible through the Australian HIV Observational Database Temporary Residents Access Study (ATRAS), nearly every organisation spoke of their concerns for people who could not access Medicare as the study comes to a close:

For people from CALD [Culturally and Linguistically Diverse] backgrounds there is a particular psychosocial lens that is not well understood . . . they experience stigma differently, there is fear around disclosure, people often travel from their community or area in which they live to get treatment and to avoid disclosure in their community. When the ATRAS study ends we don't know how some of our clients are going to access medicines because of lack of Medicare access and financial reasons.

service provider, NSW

Several service providers described situations where people living with HIV who are immigrants to Australia faced challenges other than health costs that were potential barriers to retention in care. One example revealed that an HIV-positive person might have to hide the fact that money was being spent on medications, because these expenses might be observed by other family members or others they lived with and they feared this would lead to questions being asked and then eventually being forced into a situation where they had to, unwillingly, disclose that the medical expenses were related to their HIV status and need for particular medications. They were fearful of disclosing to their family or friends, and in some cases they chose not to access medicines or stay in care arrangements:

One young man on a student visa from a South-East Asian country found out he was HIV after arrival in Australia, he must have contracted it here. He couldn't tell his parents who were supporting him. He was living in a shared house but felt he couldn't tell anyone and yet he still wanted to start treatments, but access was the problem. Online purchase was a problem, so he just dropped away.

service provider, NSW

Families who had migrated from other countries often lived in shared households or family situations where the taking of ART could not be hidden, and therefore some people living with HIV did not return for treatment after the initial diagnosis. For others, concerns about immigration status, and feelings of shame and stigma influenced decisions about HIV care. For example Cossie, who at the time of interview in 2017 had been living in Australia for about one year, had been diagnosed with HIV in 2008 while still living in Africa. When she was first diagnosed she took ART for a few months but had discontinued due to side effects. At the time of interview, she did not have permanent residency in Australia and was extremely worried that if her HIV status was known it could negatively affect her being allowed to stay in Australia. Since coming to Australia she had had no contact with clinical care for her HIV. While she had been to see a GP for other health issues since arriving in Australia, anxiety about her visa status coupled with feelings of shame, meant she had not told the GP that she had HIV: **"I can't bring myself to tell them, I feel ashamed."** Not only had Cossie not told any doctors, she had also never disclosed to any of her friends or family in Australia. While Cossie was anxious about disclosing her status, she did have a wish to find out what was happening with her HIV and at the time of the interview she was hoping to connect with HIV clinical care, indeed she thought knowing what was happening with her HIV in a clinical sense might enable her to disclose to other people in her life: **"It's easier to know what is going on and then maybe I can choose who to talk to and tell them what is going on."** At the end of the interview, Cossie was given contact details for a people living with HIV organisation in the city where she was living and a list of S100 prescribers.

Service providers who worked closely with CALD populations suggested that the limited clinic operating hours and/or geographical locations of many services often meant that people who came from overseas and worked long hours could not maintain their health appointments. Further, concerns about unwanted disclosure and difficulties fitting health appointments into inflexible employment situations were substantial barriers for people from CALD backgrounds. This was described as a major barrier in accessing and maintaining linkage-to-care arrangements, even when the person had permanent residency and Medicare eligibility. In two different states, service providers said that rather than going to a local clinic in their own suburb, and being observed going to health facilities in their area, the person accessing clinical care travelled across town, which often took a lot of time.

People living with HIV who migrate to Australia from other countries in some cases also bring very different experiences and understandings of HIV and this can influence their decisions about treatment and trust in health care professionals. In one example provided by a service provider, a recently diagnosed person distrusted the information offered by medical services due to the death of a previous partner in another country from undiagnosed AIDS. This led to a pattern of starting treatments, stopping treatments, getting sick and having to start treatments again.

There were also examples given where people living with HIV who had multiple and complex health matters – sometimes complicated by drug and alcohol use – had been refused services, because dealing with these clients made the workers at services feel vulnerable and unsafe. While the safety of staff is essential, one service provider suggested that some clients had been kicked from ‘pillar to post’; in other words, refused entry into a number of service organisations within the city. The person then lacked entry points into care systems and were then not retained within the care systems available. A ‘non-judgemental attitude’ was referred to often by both service providers and people living with HIV as being an essential factor in retaining people in care:

Sometimes there is an overuse and/or misunderstanding of zero tolerance policy by staff members. I know it has happened at other organisations because some clients end up with us because they have nowhere else to go . . .

clinical care service, NSW

Some service providers also identified that when hospital discharge planning occurred, seamless care arrangements may not have been put into place. Service providers in one state said this was usually done very well. In three other states, service providers noted that discharge planning did not seem to take account of a person’s practical needs regarding, for example, maintaining Centrelink payments during the time when a patient may be at home but might be in a recovery situation. People living with HIV were placed at risk when they returned to their homes and community settings without appropriate follow-up support.

Treatment reviews, side effects and continuity of care

Another potential challenge for maintaining people living with HIV in care was identified by both HIV-positive people and service providers. It was noted that continuity of HIV care had the potential to be disrupted when there were multiple care arrangements for different health issues. For example, where a person with HIV is attending a drug and alcohol treatment centre, another service for mental health management and collecting ART from a hospital pharmacy on prescription from their S100 prescriber.

The trouble is that one agency may give a person with multiple care needs the information that they have dealt with the issue, for example their mental health needs. It's at that point the person may become disengaged from care because they think things are 'sorted' but it's not all 'sorted' at all. Without a doctor or case manager following up regularly that person can get lost.

service provider

Not only does the number of different services represent a significant burden of care for people living with HIV, but there are also challenges in terms of health system coordination, for example, who is responsible for treatment reviews. The absence of a systematic process for medication reviews was of concern, particularly in regional or rural settings where treatments may be prescribed by visiting medical officers (VMO) and where there was a frequent turnover in personnel. In the absence of regular monitoring by one consistent doctor, treatment reviews were not occurring and had led people living with HIV to disconnect from one or all parts of their treatment

programs. Another impact noted was time-limited appointments, especially where people living with HIV were attending under bulk-billing arrangements that do not allow time for a discussion about any concerns regarding the side effects of treatments.

The new classes of drugs available in Australia mean side effects are significantly reduced for the majority of HIV-positive people, but this is not the case for all people living with HIV and it is essential that they have opportunities to have their ART medication reviewed or to discuss any side effects they believe might be related to ART. Angus was encouraged by a doctor at the sexual health clinic he regularly attended to change to a one-pill-a-day regime. However, he experienced side effects, and tried to get an appointment with his regular doctor who he trusted but could not, and after three months discontinued treatment completely:

I made that decision [to stop treatment] myself as I was not confident with the advice I was getting from the so-called professionals and my doctor [name] was always away at conferences overseas, and he was constantly away all the time, so we had to – and not just me but a lot of people in [name of town] – had to go and see [name of another doctor] and I was less confident about his advice.

Angus

Stuart, quoted below, developed mood and behaviour changes six months after being diagnosed with HIV. At the time his doctor did not attribute these to HIV and he was not recommended to start treatment. Stuart continued to feel mentally confused and this led him to disconnect from HIV care. As his cognitive capacity declined he quit his job and eventually became homeless:

I ended up homeless, but I was accessing a place called [name removed] – a drop-in centre for homeless people in the inner city. I had been talking with them, they engage people, clients, whatever, and I am not sure how it happened, but I ended up being assessed by [name of service for people with HIV-related cognitive impairment] and they did a cognitive assessment on me, and from there they organised housing for me, and an appointment with an HIV specialist . . .

Stuart

At the time of interview, Stuart had stable housing, had a case worker to assist him managing the effects of cognitive impairment and was taking ART. Stuart's story serves as a reminder that some people living with HIV have care and support needs that go beyond the provision of ART and clinical monitoring.

A number of those living with HIV interviewed struggled with issues of continuity of HIV care. For example, Ken, who had been living with HIV since 1990, and who while

grateful for the HIV clinical care he received in a public hospital, wished this did not mean seeing a different doctor at every visit and having to repeat information from one appointment to the next:

When I see the HIV doctors, I always see a different one, I just feel like I am a guinea pig for doctors in training, and I am lucky to have that assistance, but sometimes I feel like I am going through the same old story again with another doctor, where I would prefer to have a bit of continuity.

Ken, HIV-positive person

Ken had recently taken a break from taking ART for a few months; he made this decision without discussing it with an HIV doctor and only restarted when he started to feel unwell and had lost weight.

Living long-term with the virus

Many of the service providers interviewed said the negative psychosocial impacts of living through 'the long journey' of HIV were underestimated. This group of people, often called long-term survivors, were initially confronted with a terrible prognosis and then had to manage on treatments that were either difficult to tolerate or had serious side effects. This particular cohort of HIV-positive people had experienced the death of many close friends and sometime partners, creating what has been labelled the survivor syndrome where people feel guilty about having survived a situation when many of their friends had not. Consequently, there are a lot of concerns faced by this particular group:

There are 200 clients who require in-home support. They are ageing with HIV, have done the hard yards and survived through all changes in HIV medicine, including managing serious side effects from the early years. [They] now have many comorbid conditions. They are now confronting the psychosocial impacts of such a long journey and now having to confront other things [that they hadn't anticipated] as they move into old age.

HIV care provider, Victoria

Several service providers suggested that the messaging that 'AIDS is over' did not ring true and for some of their clients AIDS was not over. The goal of achieving an undetectable viral load was not possible for everyone. Some observed that for some HIV-positive people who had lived through the grief and trauma of the early years of the epidemic, enduring psychosocial supports and networks were required. In the absence of this support, it was suggested that these people were at great risk of dropping out of care, or adopting a position of not caring any longer about their health or their lives:

Even in the [inner-city] catchment area for our service there are a number of patients who just 'drop-out' of the care system. Some who have been diagnosed for a long time and on treatments for a long time might just develop some feelings of anxiety, or another mental health issue comes along. Understanding why they have disengaged is not always clear . . . sometimes substance abuse is the problem.

clinical service provider, NSW

Ken, who had been living with HIV for more than 25 years, described his decision to stop taking HIV treatment for a few months in 2016 as stemming from a sense of disillusion with the attitudes of the wider society to HIV and feeling he needed to hide his HIV status:

I was getting really disillusioned about the whole HIV situation, narrow-minded people. Every time someone came over I would have to hide my meds. I didn't know where I was with my health but I was feeling really good, and I thought I would just forget about my meds, and before I knew it I had forgotten about my meds for a few months. And then I noticed I had lost a few kilos and I had a doctor's appointment coming up, so I started again.

Ken

Ken's break from HIV treatment was framed in terms of forgetting about his HIV, wanting to take a time out from HIV, rather than as a conscious decision to stop ART.

Old and alternative ideas about treatments and HIV

While the scientific evidence of the health and prevention benefits of early and lifelong ART is clear, there are people living with HIV and health providers who remain either unaware or unconvinced by this evidence. As noted by one health provider, information gaps remain:

There is a need to get the message across that HIV is treatable and can be managed. This has to happen generally and especially to particular targeted communities.

multicultural health service provider

There continues to be health professionals who provide people living with HIV with incorrect information:

Incorrect information is still being given at different places. We have heard examples [of] you still can't have children naturally, we know of some doctors and health care workers are 'flip-flopping' on what undetectable really means, and there are confusing messages given by some about PreP.

people living with HIV service organisation

Similarly, some HIV-positive people hold onto outdated scientific evidence in relation to optimum ART use or have views of health and HIV that are counter to current scientific evidence in relation to HIV:

When I have ever stopped taking treatment, my body has always been telling me: “No, you don’t need this” . . . I am pretty aware of the symptoms, so I go and get myself checked out, so if I don’t feel sick and I feel vibrant in my life I don’t tend to worry in those periods when I am not taking antiretrovirals.

Angus

Angus had taken breaks from ART at various times since he was diagnosed in the early 1990s, including since the evidence of the benefits of early initiation and continuous use of ART became known. However, he continues to have views about how the HIV virus works that are contrary to the evidence. While at the time of interview Angus was taking ART, he did not believe that all people newly diagnosed with HIV should be prescribed ART. Another person living with HIV, Stuart, who was diagnosed in 2009, was told he did not require treatment as his CD4 was well above 350. However, six months after diagnosis he started to behave in ways he and others experienced as erratic and he felt unwell. Stuart dropped out of care for a number of years, and in that time his cognitive impairment continued, he left work, lost contact with friends and eventually became homeless. When he was eventually reconnected to HIV care through a homeless service that he disclosed his HIV status to, he was offered ART. Stuart described initially declining ART because his clinical tests showed his CD4 was still above 350:

I refused treatment for a while as I had this mantra in my head: “350 – I have to wait until I reach 350.”

Stuart

Another person living with HIV who had experienced severe side effects when he was taking ART, discontinued ART, believing the treatment was doing more harm than HIV:

I made it myself, because I didn’t want to keep on with the medications. I realised the medication was doing more harm than the illness, so I decided to stop the medication and now I only take vitamin tablets and supplements.

The views and experiences of these people living with HIV and the observations of service providers indicate that not only is further work required to promote early initiation of ART, but there is also a need to challenge misconceptions about how the virus works in the body and explain why delayed treatment and treatment breaks are no longer supported. As discussed above, there may also be a need for routine treatment reviews; and where people living with HIV are experiencing side effects, alternative ART regimes are identified or if that is not possible, ways to manage side effects are identified. It is also important to understand that people living with HIV who have lived through shifts in clinical guidelines may continue to see HIV medicine as a site of uncertainty.

Peer supports are crucial

Peer support was regarded as an essential element by many of the service providers interviewed to help connect and reconnect HIV-positive people to care and treatment. The important role peer initiatives have is illustrated by Liam, who was diagnosed in 2005. At the time of diagnosis, he was not recommended to start treatment as his CD4 count was above 500. Over the next few years he engaged periodically with monitoring, but in 2011 he completely disconnected from clinical care. When he was interviewed in 2017, he had recently reconnected with HIV care with the support of a HIV-positive organisation:

I had been really struggling with my mental health and I had been concerned that maybe that is HIV-related, so that is what instigated my contact with [name of HIV-positive organisation] because I was really needing some help and support and it was their encouragement to go and see the specialist . . . They assigned me a peer worker, and I needed to find a new GP and so he [the peer support worker] did some investigating and found a GP, not an S100 prescriber, but HIV friendly, and he [the peer support worker] drove me to my first appointment.

Liam

Through practical and emotional support from a peer organisation, Liam was back receiving HIV care and at the time of interview was about to commence taking ART. Service organisations from every state in which interviews were conducted spoke about the value of a peer support system being established as soon as a diagnosis is given. Expressed very simply by one service provider:

A peer/buddy system established at the point of diagnosis would be a helpful link between counselling and clinical services and the person with HIV.

service provider

A number of service providers also observed that setting up peer support programs and arrangements were difficult in some settings, for example outside capital cities. This was provided as an example of the difficulties of relying on peer support alone:

There's a young man, 21 years of age, we know of who does take HIV treatments but for him it is a completely yo-yo [inconsistent] situation. He lives in a rural area four hours from the capital city. We've tried tele-health with the local GP and linking him to a larger regional hospital and their services. But he is in trauma because of being diagnosed at such a young age. Another young man, same age, has sporadic adherence to therapies, he lives in Department of Housing, relies on Centrelink services and needs detox and rehabilitation services before he can get to a point of stability and adherence to HIV therapies.

people living with HIV organisation service provider

Some of the service providers felt there could be a more formalised arrangement between clinical services and the NGO sector – NGO organisations being those who might be best positioned to follow up in a peer-based role rather than through clinics.

Utilising peers at the point of diagnosis should be systematised. This provides a lighter touch and can help overcome the sense of stigma that might be associated with being case-managed in a clinical setting. It might be just a problem about language, but to be told one is being 'case-managed' causes some people to back off and not continue contact with a particular service.

Trust and consistency of service delivery are essential. Seeing someone who will understand the situation from a peer point of view is essential when situations of mistrust arise with a service provider or health care worker.

people living with HIV organisation support worker, Victoria

While peer support was often highly valued by both people living with HIV and service providers, access to peer support varied between jurisdictions and between urban and regional areas. One HIV-positive person commented that in the jurisdiction where she lived, reductions in funding meant there were no longer any specific services for women with HIV and very limited options for peer support:

Now we don't have any more services, now we have no contacts, there is no contact for mums. Being a mum, having little kids, going through what you are going through and finding a spot where you can talk, relax, have a coffee is important . . . now we only have [name of HIV-positive woman] only one [helping] hand across the whole state. I am not against anyone, I am not against homosexuals, but I want to be with women, with the mums . . .

Grace

Grace's observation also highlights that peer services need to be diverse and recognise that women, gay men and heterosexual men will have different needs and experiences.

Keeping the door open

A consistent message from both health service providers and from HIV-positive people interviewed was that there needed to be systems in place so that there was always somewhere that support could be found. In *Equity of Access to Treatment and Care* (pages 13-17), it was noted that due to (sometimes misreading) of occupational health and safety requirements, clients were excluded from attending services. Another way it was expressed was that clients may have been placed in the too-hard basket and had the experience of being kicked from pillar to post. This is why the report highlights the importance of keeping the door open. This is to enable those living with HIV to have confidence there will be support available somewhere in the system. An experience of complete rejection by a person living with HIV can lead to disengagement from the systems of care that are available.

Identifying the characteristics of people before they disengage from care is crucial. This is not always possible and in our catchment area it is not uncommon for people to disappear because they become unwell or it could be because of mental health matters, anxiety or erratic behaviour due to drug and alcohol use. Sometimes even keeping an appointment is difficult. Flexible drop-in arrangements, where a range of primary health care services can be accessed, is essential. This needs to be backed by a multidisciplinary team on site where no costs are required.

hospital outpatient clinic

Some engage and disengage. This might be because suddenly they find themselves homeless, or mental health issues arise, or [there may be] drug and alcohol use (or maybe both). We have also noticed that adherence might become erratic with ageing and management of multiple health conditions. They have so many things going on in their lives then they get to a crisis point and come back.

HIV community organisation

It depends on how the person chooses to access the service, however, generally speaking, a conversation is had with the individual to understand how we can assist them and to understand what their needs are. This will assist us to identify which is the most appropriate program and who is the most appropriate support person to work with them. We have a 'no wrong door' philosophy, so if we are not funded to provide the service we will still work with that person to link them into a service that can support them with their needs.

HIV community organisation

Grace, who was diagnosed with HIV in the early 2000s, described regularly taking breaks from treatment; at the time of interview she was currently on a three-month break. In the past, her breaks from ART had been accompanied by disconnection from clinical care, because she felt the doctors did not respect her decisions on treatment, and her autonomy, and were "always trying to put the fear in her". Eventually, through a peer contact, she found an HIV doctor she trusted and could work with. Her doctor did not necessarily agree with her taking breaks, and was clear that just feeling well did not mean the virus was doing no harm, but he also acknowledged her agency and this allowed the care relationship to continue.

He [doctor] said it is not good to do it [go off treatment]. Some people they think [treatments are] good, but [I think] they don't know inside what the body is doing. He [the doctor] encourages me. He said, "You know what, I can see you have been doing this for a long time, I can see you are healthy, you look really well, but just remember sometimes suddenly things can happen." He says it is my choice, but he gives me peace of mind.

Grace

In contrast, Alonzo stopped taking ART without even discussing it with his doctor:

I broke off from the doctor because I knew he would try to use the fear psychology, and I don't want to be manipulated into taking medication, if I can do it well without the medication.

Alonzo

Clinical services and doctors who can respect decisions by people living with HIV to discontinue ART, even when they disagree with them, may be more successful in maintaining HIV-positive people in monitoring. However, it needs to be recognised that supporting HIV-positive people who stop taking ART is likely to be challenging for clinicians when they know the potential of such decisions to have a negative impact on health and HIV disease progression.

Conclusions and recommendations

The findings of this research identify the need for additional health promotion and follow-up mechanisms to support linkage to care. There continues to be a need for community accessible information about the current scientific evidence in relation to health and ART. This information is needed as some HIV-positive people continue to perceive HIV medicine as experimental and uncertain. Therefore, this information needs to not only promote new scientific evidence in relation to ART, but also explain why the previous science is no longer supported.

- **Flexibility and adaptability of services is necessary.**
- **Connectedness of various service providers needs work.**
- **Involvement of people living with HIV in consultation of development of services, especially for vulnerable communities.**
- **Ongoing education about the latest recommendations in relation to ART that specifically target people who have been subject to different clinical guidelines and scientific wisdom. Information that is able to clearly explain why previous scientific evidence is no longer correct, for example, delaying treatment.**
- **Key role for peer-based support, for example, peer navigation programs and specialist services for people with cognitive impairment.**
- **Development of strategies to address continuity of care issues, particularly in hospital-based services.**

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PEOPLE LIVING WITH HIV ORGANISATION SERVICE PROVIDER

LINKAGE TO CARE PROJECT REPORT

napwha national association of
people with hiv australia