HIV Futures 10

Quality of life among people living with HIV in Australia

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GLOSSARY

ACCHO — Aboriginal Community Controlled Health Organisation

AIDS — Acquired immune deficiency syndrome; AIDS is a condition caused by untreated HIV

ART — Antiretroviral therapy; this is a combination of medications that prevent retroviruses such as HIV from replicating, thereby supressing the virus

DAA — Direct-acting antiviral (in this report this is referred to in the context of treatment for the hepatitis C virus)

Female — For this report, 'female' refers to people who identified their gender as female regardless of their sex assigned at birth, except where otherwise specified

Gender fluid — For this report, 'gender fluid' refers to a person who identified their gender as 'gender fluid'; this generally refers to people who do not identify as having a fixed gender category

HAND — HIV-associated neurocognitive disorder

HCV — Hepatitis C virus

HIV — Human immunodeficiency virus

Hepatitis — An illness that causes inflammation of the liver; there are different forms of hepatitis

HIV positive — A person who has tested positive for HIV

Intersex — Intersex people have innate sex characteristics that don't fit medical and social norms for female or male bodies, and that creates risks or experiences of stigma, discrimination and harm

LGBTQA+ — Lesbian, gay, bisexual, transgender, queer, asexual and other gender and sexually diverse people

LGBTIQSB — Lesbian, gay, bisexual, transgender, intersex, queer, sistergirl, brotherboy

Male — For this report, 'male' refers to people who identified their gender as male regardless of their sex assigned at birth, except where otherwise specified

Man/men — For this report, 'men' refers to any adult person who identifies as male/man, regardless of sex assigned at birth, except where otherwise specified

MSM — Men who have sex with men

Non-binary — For this report, 'non-binary' refers to people who identified their gender as non-binary; generally, a non-binary person is someone whose gender identity does not fit within the binary categories of 'male' or 'female'

Pansexual — For this report, 'pansexual' refers to people who identified their sexuality as pansexual; generally, a pansexual person is someone who is attracted to people of all genders

PozQoL — The PozQoL scale is a validated tool to measure quality of life for PLHIV, incorporating the domains of physical health, physiological health, social connection and functional ability

PLHIV — People living with HIV

QoL — Quality of life

Questionnaire — The HIV Futures 10 questionnaire was a tool used to collect the data presented in this report; it was available in hard copy and online, with both formats including the same questions

SD — Standard deviation

SF-36 — The 36-Item Short Form Survey, a widely used measure of health-related quality of life; the HIV Futures 10 questionnaire included the questions relating to general health and emotional wellbeing so that scores could be calculated for these two subscales

SF-36 GH — The SF-36 general health subscale

STI — Sexually transmissible infection

Survey — HIV Futures 10 used a survey methodology to collect self-reported data from people living with HIV through the HIV Futures 10 questionnaire

TIM — The Institute of Many, an online community network run by, and for, people living with HIV

Transgender — For this report, 'transgender people' refers to people who wrote 'transgender' when asked to define their gender identity. This report also uses the phrase 'transgender men' to refer to people whose gender is male and sex assigned birth was female, and 'transgender women' to refer to people whose gender is female and sex assigned at birth was male. People who identified as non-binary or gender fluid are referred to in these terms.

U=U — Undetectable equals untransmissible. This is in reference to HIV viral load. If viral load is undetectable, then HIV is not sexually transmissible.

Undetectable viral load — A viral load that is not detectable by standard testing, such as when standard HIV viral load tests are unable to detect HIV in the blood of a person living with HIV

Viral load — The number of copies of a virus in the blood

Woman/women — For this report, 'women' refers to any adult person who identifies as female/woman regardless of sex assigned at birth, except where otherwise specified

EXECUTIVE SUMMARY

HIV Futures 10 is a study of quality of life (QoL) among people living with HIV (PLHIV) in Australia that forms part of a series of surveys on this topic that have been running since 1997. In each iteration of the HIV Futures study, a cross-sectional survey of the Australian population of PLHIV is conducted. Data were collected for HIV Futures 10 from May 2021 until July 2022. Participants completed a questionnaire using a self-complete online or hard copy form. The survey instrument comprised questions related to QoL, financial security, health, wellbeing, treatment, support, sex, relationships, HIV-related stigma, COVID-19, telehealth and substance use.

Demographic characteristics

The HIV Futures 10 survey was completed by 816 people, which is approximately 3% of people living with diagnosed HIV in Australia in 2021 (approximately 27,390 people) (King et al., 2022). Of these 816 people:

- 88.7% identified as men/male; 9.6% identified as women/female, including five transgender women; 1.4% identified as non-binary or gender fluid
- 86.5% were cisgender men who identified as gay, which is consistent with the population of PLHIV in Australia in which the majority of HIV transmissions have occurred through male-to-male sex
- The average and median age was 54 years, although the average age of women was substantially lower, at 48 years
- 2.8% indicated that they were Aboriginal and/or Torres Strait Islander
- 72.2% were Australian born, while 96% spoke English at home
- 56.1% lived in inner city or outer suburban areas
- 57.6% were in the paid workforce, working either full-time, part-time or casual hours

Quality of life

QoL was measured utilising the PozQoL scale, a QoL measure developed specifically for PLHIV. Overall, 71.8% of HIV Futures 10 participants reported they had 'good' QoL (using a PozQoL score of 3.0 or higher, from a range of 1-5 in which higher scores indicate better QoL).

Approximately half (50.5%) reported their overall wellbeing (including physical, emotional and mental wellbeing) to be 'good' or 'excellent'.

Factors associated with better QoL included: higher income, no recent financial stress, living in inner city areas, better general health, a greater level of social connectedness, living with a partner/spouse, and not perceiving the COVID-19 pandemic to have had a significant impact on wellbeing. People in the 65+ age bracket were significantly more likely to report higher QoL than those in other age brackets.

Financial and housing security

As financial security is strongly linked to better QoL, the HIV Futures 10 survey included key indicators of financial security: household income, recent financial stress, current accommodation/housing situation, and ability to afford healthcare. The overall picture suggests that, as a group, PLHIV are more vulnerable to financial insecurity than the general Australian population with one in three reliant on government benefits for income, and one in three reporting recent financial stress. Specifically:

- 30.3% reported their main source of income to be social security (including a pension, disability pension or other government benefits)
- 26.5% reported an annual household income of less than $30,000, and the majority of these people (78.7%) were reliant on social security/pension as their main source of income
- 69% reported an annual household income of less than $100,000
- 17.2% were classified as having experienced financial stress in the past 12 months (using standard measures of financial stress that include difficulty paying bills or rent/mortgage) – women were more likely than men to report recent financial stress
- 31.7% were living in private rental accommodation, while 49.5% owned their home (with or without a mortgage), and 12.0% lived in public housing; this rate of home ownership is substantially lower than 2020-21 Australian population figures in which 31% lived in rental accommodation and 67% lived in a home they owned (with or without a mortgage) (Australian Bureau of Statistics, 2022)
- People living in private rental accommodation were more likely to report recent financial stress than those living in their own home, while people who were homeless or living in public/community housing were most likely to report recent financial stress
- 4.7% indicated they had not taken HIV medication at least once in the last 12 months due to financial reasons
- 29.5% indicated that it was 'somewhat' or 'very' difficult to access medication for financial reasons
- 17.9% indicated it was 'somewhat' or 'very' difficult to access healthcare for financial reasons

HIV diagnosis, treatment and viral suppression

The majority of participants had been diagnosed with HIV within 2 years of having acquired the virus, although women were significantly more likely than men to have been diagnosed 2 or more years after they acquired HIV.

Of the HIV Futures 10 sample:

- 98% were currently taking antiretroviral therapy (ART)
- 94.7% of those on ART reported an undetectable viral load (viral suppression) as of their most recent test (this figure was lower among women, with 94.6% of women reporting an undetectable viral load as of their most recent test)
- 81% were happy with their current ART and 79% found it convenient, although 40.9% indicated some dissatisfaction with side effects from ART

COVID-19 and telehealth

Participants were asked if they had contracted COVID-19 in 2020 or 2021:

- 4.7% had contracted COVID-19
- Of this subsample, 5.7% (n = 2) reported being hospitalised due to the illness

An overwhelming majority of participants (91%) reported being vaccinated against COVID-19, while a further 5.9% (n = 44) indicated that they had not yet been vaccinated against COVID-19 but intended to.

A substantial proportion of participants (41.9%) reported that due to the COVID-19 pandemic they accessed health services less often than they felt was needed.

A majority of participants (70.8%) reported using telehealth services in the past (either before, during or after the COVID-19 pandemic; 60.8% via telephone, 10% via video).

- Of these participants, 91% reported having utilised telehealth for the first time during the COVID-19 pandemic.
- Most participants who had used telehealth (71.5%) reported being 'satisfied' or 'very satisfied' with the quality of care they had received, while approximately one in 10 participants (9.8%) reported being 'unsatisfied' or 'very unsatisfied' with their telehealth care.
- Most participants (78.3%) indicated that they would like to continue using telehealth in combination with face-to-face appointments, while 1.7% indicated they would like to exclusively use telehealth services, and 20% indicated they did not wish to use telehealth appointments at all.

Health and wellbeing

General health. The general health of the HIV Futures 10 sample as a whole was comparable to that of the Australian population (Hawthorne et al., 2007), although people aged 50-64 reported poorer general health than other age groups, as did people who had been living with HIV for a longer time.

Mental health. Among HIV Futures participants:

- 33.1% reported a current or past diagnosis of depression
- 30.4% reported a current or past diagnosis of anxiety conditions
- 11.8% report a current or past diagnosis of post-traumatic stress disorder
- 35.8% had a current diagnosis of more than one mental health condition

A mental health diagnosis was highly correlated with poorer QoL among participants.

Sexually transmissible infections (STIs) and viral hepatitis. Rates of screening for STIs other than HIV were high among participants, with 81.1% of those who were sexually active having been tested for STIs at least once in the past 12 months. With respect to STI diagnoses:

- 18.1% of participants had been diagnosed with an STI in the past 12 months: 9.2% with chlamydia, 6.9% with gonorrhoea and 6.6% with syphilis
- Chlamydia, gonorrhoea and syphilis were most common among people aged 35 or younger

There were 78 (9.6%) participants who indicated they had tested positive for hepatitis C antibodies. Of these, 36% had never received treatment for hepatitis C (which may include those who had never developed chronic hepatitis C infection and so had not required treatment), while 59% had taken direct-acting antivirals and cleared the virus.

Over one in 10 participants (13.7%) had never been screened for hepatitis C.

Smoking. The rate of tobacco smoking among HIV Futures 10 participants was considerably higher than that of the Australian population (AIHW, 2022), with 20.8% reporting they were smokers, and 74.7% of this subsample reporting they were daily smokers (15.5% of the total sample, compared to 10.7% of Australian adults overall) (AIHW, 2022). However, the reported smoking rate among participants of HIV Futures 10 surveys has dropped dramatically over time. Over 50% of the total sample were daily smokers in the early 2000s (HIV Futures 3 and 4).

Stigma and discrimination

More than a third of the HIV Futures 10 participants (36.6%) reported at least one experience of HIV-related stigma or discrimination in the past 12 months, while 29.8% reported that they had been treated differently by a healthcare worker due to their HIV in the past 12 months.

Social connectedness

A greater sense of social connectedness was correlated with better QoL among HIV Futures 10 participants. Variables associated with greater social connectedness were: sexual orientation, residing in inner urban areas, being employed full-time, no financial stress, higher

annual household income, cohabiting with partner(s)/spouse, and living with other people. Looking at each of these variables, we can see that a large proportion of HIV Futures 10 participants may be vulnerable to low levels of connectedness, or loneliness. Specifically:

- 43.5% of participants live alone. This will not lead to social isolation or loneliness for everyone, but as a general trend it is associated with lower social connectedness.
- 52.4% are single (not in a current relationship). As with living alone, being single isn't associated with social isolation or loneliness for everyone, but as a general trend, cohabiting with a partner does appear to be a buffer against social disconnection.
- 26.5% reported an annual income of less than $30,000. Of these people, 69% were living alone. The combination of living alone and a low income may make someone vulnerable to social isolation. It is also possible these people are reliant on social security due to disability or illness, which could be a further barrier to social connection.
- 42.4% are not in the paid workforce. While this includes people who are retired (not necessarily people who want to be working), it is still possible that lack of daily contact with colleagues – combined with lower incomes – makes people out of the workforce more vulnerable to social disconnection.

Peer connection and support

Most HIV Futures 10 participants had connections with other PLHIV and indicated that they valued these connections:

- 57.7% knew in their social/informal networks at least one other person living with HIV who they could talk to about HIV
- 56.5% agreed that knowing other PLHIV was important to them
- 45.4% were interested in being part of a community of PLHIV

Despite this, there were some participants who found it more difficult to connect with other PLHIV:

- 42.3% indicated they did not have any other PLHIV in their social/ informal networks who they could talk to about HIV
- 73.4% did not feel like part of a community of PLHIV
- 24.2% felt isolated or cut off from other PLHIV
- 34.6% felt it was hard to meet other PLHIV

Peer-based programs and services play an important role in connecting PLHIV with each other and providing support for PLHIV, especially those who may be vulnerable due to recent HIV diagnosis, ill health, ageing or social isolation. Among HIV Futures 10 participants:

- 56.5% agreed that community-based services played an important role in connecting PLHIV with each other
- 30.0% agreed that connecting online with other PLHIV was an important source of support for them

In the past 12 months:

- 25.1% had accessed advice or support from a peer worker
- 21.5% had participated in an online forum or network for PLHIV
- 13.3% had participated in a peer support program or workshop
- 9.7% had used a peer navigator programs

Women living with HIV

Women participants in HIV Futures 10 differed in some key areas when compared to the sample overall, and when compared to men, notably:

- The sample of women was more culturally diverse, with 41.9% having been born outside of Australia
- While 97.2% of women were currently taking ART, they were slightly less likely to have an undetectable viral load, with 94.6% reporting they had an undetectable viral load as of their most recent test
- Women reported a longer period between their HIV acquisition and diagnosis than men (2.4 years, compared to 1.2 for men)
- Women were more likely to have experienced financial stress in the past 12 months than men, with 26% reporting recent financial stress

Asian-born gay and bisexual men (and other men who have sex with men) who have migrated to Australia: A qualitative exploration of experiences

In the Australian context, we know very little about the ways in which migrant experiences, and the experiences of gay and bisexual men from culturally and linguistically diverse communities (including second generation migrants), shape experiences of living with HIV. In HIV Futures 10, we conducted a series of in-depth interviews with Asian-born gay and bisexual men (and other men who have sex with men) living with HIV (n = 8) and with advocates and educators who work with these communities (n = 10). The aim was to:

- Identify issues or challenges that may place unique pressure on recent migrants who are living with HIV
- Identify ways in which the HIV service sector can provide more appropriate support for gay and bisexual men from culturally and linguistically diverse backgrounds living with HIV

We know that factors that sustain QoL relate to a sense of connection, social support and community, good health and access to secure finances. Findings from the interviews showed that the combined experiences of migration and being diagnosed with HIV can both challenge and undermine QoL for this group. Migration, particularly waiting for a visa outcome, makes life less certain, which limits people's ability to plan their future, develop their career or build social networks. Migration also often means people are distant from their existing friendship or family networks, which can lead to isolation and a greater sense of instability. All of this becomes more challenging for people who are diagnosed with HIV, because the process of obtaining a permanent visa becomes slower, less certain and more complex. It also leaves people more vulnerable to judgement, stigma and unwanted disclosure of their HIV status. Participants in this qualitative study described the ways this uncertainty, vigilance and fear left them feeling anxious and vulnerable and, for some, lonely and isolated. Despite this, participants described personal resources, skills and strengths that helped them manage uncertainty and stress. These were people already navigating the complexities of moving to Australia, adapting to work or study within a new culture and with a new language, and holding connections and intimacies across two or more countries. These strengths and experiences were important for coping with HIV. For some, this was augmented by HIV support services and peer networks, which assisted participants to develop a sense of belonging and hope for the future.

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FOREWORD FROM THE NATIONAL ASSOCIATION OF PEOPLE WITH HIV AUSTRALIA

This, the 10th edition of HIV Futures, marks an important milestone for the Australian HIV response and for all people living with HIV in Australia. HIV Futures 10 represents 25 years of telling our story through research, describing the impact of HIV on lives, and chronicling the changing nature of the Australian epidemic and the response to it.

HIV Futures connects our diverse community through research. People living with HIV across various age groups, genders, sexual orientations, and cultures are afforded the opportunity to share common experiences as well as the unique circumstances of our intersectional identities on topics including treatments, health, U=U, quality of life, stigma, sexual satisfaction, drug use, experiences in the workplace and the social aspects of our lives. Below are some of the significant findings from HIV Futures 10.

- In HIV Futures 10, 71.8% (n = 586) of the total sample reported a 'good' quality of life, contrasted with 63.1% (n = 492) in HIV Futures 9 (2018-19).
- Of the total sample, 98% (n = 742) reported being on antiretroviral therapy (ART). Of these individuals, 94.7% (n = 702) had an undetectable viral load at last test.
- The majority of participants (81%, n = 518) agreed that they were happy with their ART treatment, and that they find their treatment convenient (79%, n = 501). Relative to HIV Futures 9 (2018-19), this was a 3.8% and 9.4% increase, respectively.
- One in four participants (25.1%, n = 176) indicated they had accessed advice or support from a peer worker at least once in the past 12 months.
- A substantial proportion of participants (41.9%, n = 310) reported that due to the COVID-19 pandemic they accessed health services less often than they felt was needed.
- Most participants (70.8%, n = 526) reported using telehealth services in the past. Of these participants, 91% (n = 477) reported having utilised telehealth for the first time during the COVID-19 pandemic, and most participants who had used telehealth (71.5%, n = 363) reported being satisfied or very satisfied with the quality of care they had received.
- Of the total sample, 20.8% (n = 150) were current tobacco smokers (down from 28.1% in HIV Futures 9 [2018-19]). The majority of current alcohol drinkers (82.3%, n = 592) drank moderately, with 57.1% (n = 292) indicating they consumed no more than two standard drinks per day. Painkillers/analgesics were the non-prescribed drug most likely to be used by participants at least weekly (26.2%, n = 186), followed by sleeping pills/tranquilisers (14.6%, n = 104) and cannabis (13.8%, n = 98).
- Over half of the total sample (52.3%, n = 390) either agreed or strongly agreed that their sense of wellbeing had been significantly reduced due to the COVID-19 pandemic and associated lockdowns.

Futures 10 is the first report in the to collect data within a syndemic (COVID-19 and HIV). COVID-19 and the Australian response to it has impacted every person in Australia and changed the way we interact with each other. For people living with HIV, the COVID experience presented us with many challenges, some new and some all too familiar. We began engaging with healthcare in different ways, as telehealth became the norm. Seeing our friends and family was limited by local restrictions on movement, which varied depending on which state or territory we call home. Our ability to meet in spaces that celebrate the diversity of our communities was halted. Sex, intimacy and connection were once again wrapped in fear of passing on an invisible enemy (an experience people living with HIV know about well). For some within the body positive, COVID reignited memories of friends lost, and lives lived in fear of illness and death. Throughout it all, people living with HIV have demonstrated our resilience – and we have shown that we know better than most how to roll with the punches when our lives are placed under stress.

The past 3 years have presented challenges for HIV community organisations and the way we work but have presented us with just as many opportunities. While we worked from home, disconnected from our peers, we started running workshops and peer support online, attended multiple morning check-ins with our colleagues, and took part in many, many Zoom meetings. We adapted and found innovative ways to work and service our communities. These changes facilitated greater access for many – particularly for people living with HIV in regional and remote locations who have traditionally been unable to access in-person services and peer support.

As we come out of the COVID pandemic, it is important to remember that HIV is still with us and still presents many unique challenges, particularly as people age with HIV. The opportunity to end HIV is real; however, we won't end HIV until HIV is ended for everyone. We must remember that HIV is as much social as it is clinical, and that HIV stigma still exists. Criminalisation of HIV must end, and social attitudes must change for people living with HIV to achieve the best quality of life possible. Access to treatment must be universal for its full benefit to be realised and undetectable = untransmissible (U=U) must be ubiquitous in all our health messaging.

As I mentioned at the beginning of this foreword, HIV Futures 10 is a milestone. It tells our story. A story of lives lost and lives lived, of moments shared and connections made, and of futures planned and hope envisioned. HIV Futures also represents the success of the Australian partnership response and is integral in the planning of services, peer support, policy and further research. All people living with HIV in Australia should be proud of the HIV Futures study and the partnership shown by all researchers involved in past and current editions of this important study.

Brent Clifton

Deputy Director, National Association of People with HIV Australia (NAPWHA)

FOREWORD FROM POSITIVE LIFE NSW

Australian people living with HIV are a diverse population from all ages, ethnicities, and sexualities. While all people living with HIV (PLHIV) share a common experience of HIV, living with HIV can be different for men and women who identify as heterosexual and/or are from culturally and linguistically diverse backgrounds (CALD).

HIV Futures 10 provides a valuable snapshot and insight into the needs of all people living with HIV in Australia, and is a critical tool to highlight inequities, missed opportunities and gaps in the HIV response, and areas in which we need to do more work if we are to realise our goals of eliminating HIV transmission, ensuring a good quality of life for all PLHIV, and a future free from stigma and discrimination.

Of the approximately 26,830 people living with diagnosed HIV in Australia in 2021, the Kirby Institute's HIV surveillance data estimates that 6,030 of those PLHIV identify as heterosexual, comprising 22.47% of the total PLHIV population. Women make up approximately 12.41% of the total numbers. Heterosexually identifying women living with HIV are disproportionately under-represented in HIV programmatic work and research. One of the main factors contributing to heterosexual HIV notifications continues to be late diagnosis. Women often miss out on accessing timely screening and support despite advancements in HIV treatments. As noted in Futures 10 this has changed little from that reported in 2018-19 in HIV Futures 9. 'The length of time between acquisition and diagnosis was longer for women than men: an average of 2.4 years for cisgender women and 2 years for transgender women compared to an average of 1.2 years for cisgender men'. This may be due to differences in awareness of HIV between gay men and heterosexual women, the targeting of public health messaging, and/or assumptions by doctors that heterosexual women are at lower risk of HIV leading to delays in testing. Another risk factor for women living with HIV is gender-based violence and power imbalances which place woman at a greater vulnerability to HIV acquisition. We urgently need to change the conversation around HIV to raise awareness within communities of men and women who identify as heterosexual, to understand that HIV does not discriminate and that they are also at risk of contracting HIV. Heterosexually-identifying PLHIV must also play our own role by participating in surveys like Futures 10 to ensure we are recognised and included in research and service provision.

In 2021, the number of overseas-born PLHIV was 6,330, or 23.59% of the PLHIV population in Australia. However, as the commentary in Futures 10 states, 'the category of 'overseas born' tend to ignore diversity in culturally and linguistically diverse people's experiences, backgrounds and identities.' Further, there is a paucity of research undertaken on women living with HIV in particular, as well as migrants and their lived experience. While women, heterosexual men and people born outside of Australia constitute a significant proportion of individuals within the sample of HIV Futures 10, the report provides a cautionary note that our 'stories are often harder to tell through cross-sectional surveys such as HIV Futures.'

As a woman living with HIV from a culturally and linguistically diverse (CALD) background, it is pleasing to see that the representation of women participants in Futures 10 is more culturally diverse than in previous iterations, with 41.9% having been born outside Australia. This is particularly pertinent as I have often heard those of us born overseas for whom English is not our first language described as unlearned or illiterate, as if this is a rationale to explain our HIV acquisition. In many CALD communities', issues relating to sexuality, sexual behaviour and gender are simply not discussed, much less countenanced. A number of countries actively discriminate on the grounds of gender, sexuality or HIV status, and others have enacted legislation that regulates, controls and/or criminalises people on these grounds. While such values are not fully explanatory of HIV acquisition in these populations, the issues of stigma and discrimination as barriers to accessing testing and treatment need to be identified and more qualitative research undertaken if we are to truly understand the complex and very nuanced reasons for this.

Similarly, HIV stigma and discrimination continues to impact the health and wellbeing of PLHIV from culturally and linguistically diverse backgrounds. It is common to hear these communities described as 'hard to reach', when in reality it is these barriers that pose a significant risk to health and lives. While language, culture, and religion are some of the contributing factors when navigating the Australian health system, given the few culturally appropriate and peer-based HIV services and programs, these communities have an uphill battle to seek out equitable and relevant health services. It is all the more reason that person-centered, trauma-informed, timely and culturally appropriate physical, emotional, social, and psycho-social support be offered to women living with HIV and PLHIV from CALD backgrounds. This in turn will increase our self-determination and self-confidence to have agency in our own healthcare decisions and address the social determinants of health, combat social isolation, and increase our sense of community connection, engagement, access and retention in healthcare.

It's time for all of us to make sure no one is left behind in the fight against HIV, by shining a light on HIV stigma and discrimination, and addressing gender-based violence broadly while acknowledging the full diversity of PLHIV in Australia. In doing so we will make greater strides to reach our goal of good quality of life for everyone living with HIV, regardless of gender or sexual orientation.

Priscilla Njeri

Peer Navigation and Ageing Support Officer, Positive Life NSW

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE LIVING WITH HIV: A STATEMENT FROM PATSIN

Over the last 5 years, the rate of HIV diagnosis has been between 1.3 and 1.9 times higher among Aboriginal and Torres Strait Islander people than Australian-born non-Indigenous people. We feel we have been left behind in eliminating HIV for all.

The testing, and uptake, of treatment messaging that has worked for the non-Indigenous community has not reached our communities, especially messages like U=U. This is due to not enough funding and the messages not being culturally appropriate. Our communities need to be aware of the messages around U=U and to get tested for HIV early, so we too can have a better quality of life with family.

There are many other barriers that prevent our community from accessing appropriate healthcare. Stigma and discrimination and racism affect many who identify as LGBTIQSB in the community. Funding is needed to educate our Elders and the community about HIV and other STIs. There needs to be an investment from the Commonwealth for research about HIV and the impacts on our communities, and for ACCHOs to provide a sexual health service that includes S100 prescribers.

We need more culturally appropriate HIV prevention resources that promote the use of Pre-Exposure Prophylaxis (PrEP) and Post-Exposure Prophylaxis (PEP) for our communities who may be at risk of HIV. We too would like to eliminate new HIV infections from Aboriginal and Torres Strait Islander communities.

PATSIN (Positive Aboriginal and Torres Strait Islander Network) supports and advocates for Aboriginal Torres Strait Islander people living with HIV, and we work with non-Indigenous PLHIV organisations to enable them to provide culturally sensitive services.

Michelle Tobin
PATSIN Convenor

INTRODUCTION

A central aim of the HIV Futures 10 study is to track quality of life (QoL) among people living with HIV (PLHIV) in Australia and to improve our understanding of factors that affect QoL. *The Eighth National HIV Strategy 2018–2022* includes a target of 75% of PLHIV reporting good QoL by 2022 (Australian Government Department of Health, 2018). HIV Futures provides data to inform progress against this indicator and to offer some insight into how we can best support QoL among PLHIV at a service level.

Measuring QoL is a complex task. There is no consensus on what constitutes 'quality'. For some people, a 'good life' is about material attainment and surety of resources. For others it is about quality of relationships or time to pursue hobbies or leisure. For some, it is about feeling their life has meaning or that they are contributing to their community. For many people, all these factors are important. When we talk about measuring QoL in HIV Futures, we are referring to subjective measures that ask people to report on how they perceive their overall sense of wellbeing and the life experiences or circumstances that they feel detract from, or support, QoL.

There are multiple factors that may affect how good an individual's life is, and how they perceive their QoL in relation to other people's. This may include a person's physical and mental health, their socio-economic status, quality of relationships, sense of connectedness to others and whether they have access to employment that they find meaningful or enjoyable. Of course, over 2020 and 2021, many people's QoL was impacted by the COVID-19 pandemic and associated social lockdowns, which limited people's contact with others and created unsettling national and global circumstances. For people living with HIV, QoL may also be affected by HIV-related stigma or discrimination, or the ongoing stress of living with a chronic condition and managing a daily treatment regimen. When gathering data for HIV Futures 10, we asked PLHIV about a wide range of issues and life circumstances. The aim was to build a comprehensive story about QoL and explore where there might be opportunities for services and programs to better support PLHIV to build QoL.

HIV Futures surveys have been running periodically since 1997. The study was established to look at how PLHIV were coping financially and emotionally following the introduction of highly active antiretroviral therapy (ART) in 1996. This was a time when the HIV community had to refocus interventions and advocacy to accommodate the new reality of people living long term with HIV. As the name suggests, HIV Futures was about looking to the future – to ask what life was like going forward for PLHIV and how best to support people to live well. While the terminology of QoL is a recent addition to HIV Futures, the study has always been about understanding wellbeing. The aim is not to document poor health or poverty (although it is important to draw attention to areas of need, which we do in this report), but to ask how all PLHIV can best be supported to achieve good health and meaningfully participate in relationships, family and community life.

Of course, attending to the needs of all PLHIV means we need to focus on equity and diversity. The HIV epidemic in Australia has changed shape in recent years, as Australian-born gay and bisexual men have benefited from the wide rollout of PrEP and treatment as prevention. This is an incredible success story as rates of new HIV diagnosis continue to fall. However, it has also drawn attention to communities for which the rate of new HIV diagnoses has not changed and PLHIV who are less supported in the HIV response. This includes First Nations people as well as people with a migrant or refugee background.

It has always been a challenge to meaningfully represent the experiences of diverse communities in HIV Futures. A national omnibus survey such as HIV Futures is not the best method for engaging with First Nations communities in ways that build relationships, research capacity and leadership in communities and which document the unique experiences of PLHIV in these communities. There is an urgent need in Australia for more resources to be dedicated to research, led by Aboriginal and Torres Strait Islander people, that supports improved sexual health promotion, HIV prevention and care for PLHIV.

HIV Futures surveys are also limited in the extent to which they capture complexity and nuance with respect to the impact of racism or the experience of migration in the lives of PLHIV. In part, this is due to the 'blunt instrument' of a tick box survey. It is also because there is such wide diversity in Australia's migrant population that it is difficult to pull together enough data from each community. As we can see in HIV surveillance reporting, PLHIV come from all regions of the world and many different countries (King et al., 2022). In HIV Futures, we generally receive only a handful of responses from any particular region or country, and within each region or country group, there will be diversity in gender, sexuality and age. While we could group people under the category of 'overseas born' for the sake of general statistics, this is a meaningless category when it comes to understanding people's experiences. The experiences of a young woman living with HIV who has migrated from Southeast Asia, for example, will be very different to that of a heterosexual man who has migrated from a Middle Eastern or African country.

To address this deficit, in HIV Futures 10 we have introduced to the study a qualitative, interview-based component that aims to enhance our understanding of the experiences and needs of PLHIV who have migrant or refugee backgrounds. For this part of the study, on advice from community partners, we have focussed on gay and bisexual men from Southeast Asian countries. This is a group who have notably high rates of late diagnosis of HIV (King et al., 2022). Better understanding of the experiences of this group may offer insight into HIV prevention as well as the needs of PLHIV. In future iterations of HIV Futures, we will expand the qualitative research to other groups.

Data for HIV Futures 10 were collected in mid to late 2021 and early 2022. Parts of Australia were still in lockdown at this time due to COVID-19, and there were significant restrictions on public events. This means that the bulk of data collection for HIV Futures 10 was online. In previous HIV Futures surveys, around one in three responses to the survey were received via hard-copy survey booklets distributed to PLHIV via events and relevant mailing lists. As lockdowns limited the number of events where these booklets could be distributed, we focussed promotion efforts online, using social media and email lists. As a result, only around one in eight survey responses to HIV Futures 10 were received via the hard-copy booklets; the rest were completed using the online survey. Consequently, the demographic make-up of HIV Futures 10 may be slightly different to previous years. Hard-copy booklets tend to reach users of HIV services, such as peer-support services, whereas online networks are broader and tend to reach people who may be younger and less in need of financial or social support services.

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS), based at La Trobe University in Melbourne, and is funded by the Australian Government Department of Health. Since its inception, community advocates and organisations have played a critical role in the success of HIV Futures. A range of PLHIV peer-based organisations and HIV advocacy/community agencies based in every state and territory of Australia are actively involved in the project – providing guidance on the survey instrument, facilitating participation through their membership and community networks, and offering input to analysis priorities. This includes Living Positive Victoria, Positive Life NSW, Queensland Positive People, Positive Living SA, ACON, Thorne Harbour Health, WAAC, Meridian ACT, TasCAHRD, NTAHC and The Institute of Many (TIM), along with many other supportive agencies and individuals. The project is officially endorsed and supported by the National Association of People with HIV Australia (NAPWHA), the Australian Federation of AIDS Organisations (AFAO), and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM).

A NOTE ABOUT QUOTATIONS

Quotations have been included throughout chapters 1-9 of this report as brief illustrations of individual experiences. These were derived from an open text question in the HIV Futures 10 survey where we asked people if there was anything else they would like to tell us about their experience living with HIV. The quotes do not represent the cohort as a whole and are not a presentation or summary of findings. Rather, they are included to give a voice to some of the participants. To protect anonymity, identifying details have been removed and demographic labels have not been attributed to quotes. In some cases, typos or grammatical errors have been edited to ensure clarity. In Chapter 10, we present more extensive quotations from in-depth interviews. Non-identifying demographic characteristics are included with these quotations to provide some detail and context.

1. DEMOGRAPHIC CHARACTERISTICS

In Australia, there are around 27,390 people who live with HIV and around 500-800 new cases each year (King et al., 2022). The majority of PLHIV in Australia are men who have sex with men (MSM). However, the whole population of PLHIV is diverse.

Number of participants

There was a total of 816 valid responses to HIV Futures 10, approximately 3% of the population of PLHIV in Australia in 2021.

Participants completing less than 20% of the survey instrument (n = 171), or who did not meet the criteria (18 years or older [n = 0], living in Australia [n = 7] and diagnosed with HIV [n = 0]), were excluded.

Not all participants responded to every question, and hence the n value differs for some questions. Throughout this report, unless otherwise stated, we present the 'valid percentage' of responses – that is the percentage of those who responded to a question.

Gender

Participants were asked their gender, sex assigned at birth, and whether they had intersex traits. The survey did not explicitly ask whether people identified as transgender, but some participants indicated in the 'free text' field that they used the term 'transgender' to describe their gender. We were also able to identify individuals whose gender differed from their sex assigned at birth. Participants who selected the 'non-binary' or 'gender fluid' gender option were retained as a separate gender group except where specified below. The gender of participants is as follows:

● 88.7% (n = 715) identified as men/male
● 9.6% (n = 77) identified as women/female
● 1.4% (n = 11) identified as non-binary or gender fluid
● 0.4% (n = 3) used a different term to describe their identity

Five participants (0.6%) identified as female but were assigned male at birth. These individuals have been collapsed into the 'female' gender category for subsequent analyses (unless otherwise specified).

Five participants (0.6%) reported that they had an intersex variation. This is slightly lower than what is known about the proportion of people born with intersex variations in the general population. The estimate used by Intersex Human Rights Australia is 1.7% (Intersex Human Rights Australia, 2013).

Sexuality

When asked about their sexuality, 810 participants responded to the question as follows:

● 77.3% (n = 625) identified as gay/homosexual
● 10.5% (n = 85) identified as heterosexual or straight
● 5.9% (n = 48) identified as bisexual
● 3.6% (n = 29) identified as queer
● 0.7% (n = 6) identified as pansexual
● 0.6% (n = 5) identified as asexual
● 1.4% (n = 11) used a different term

Three-quarters of participants were gay cisgender men (75.5%, n = 616). The next largest group was heterosexual cisgender women (7.4%, n = 61). Details of gender and sexuality are in Table 1 below.

Table 1: Gender and sexuality of participants

Gender response	Sexuality response						Total
	Gay or homosexual	Straight	Bisexual	Pansexual	Queer	Asexual or used a different term	
Men (cisgender)*	86.5%	3.2%	5.3%	0.3%	2.9%	1.7%	100%
Women (cisgender and transgender)	0%	79.2%	11.7%	1.3%	6.5%	1.3%	100%
Non-binary or gender fluid	18.2%	0%	9.1%	27.3%	18.2%	27.3%	100%
Used a different term	66.7%	0%	0%	0%	33.3%	27.3%	100%
Total	77.2%	10.5%	6%	0.7%	3.6%	2%	100%

* No participants who identified as male had a different sex assigned at birth

Age

Participants' ages ranged from 18-88, with an average age of 54 years (n = 816).

The mean age of the sample has increased steadily since the HIV Futures project first started in 1997, from 41 in 1997 to 54 in HIV Futures 10 (2021-22), with the exception of a small decrease in 2018-19 (see Figure 1).

Figure 1: Mean age of HIV Futures participants
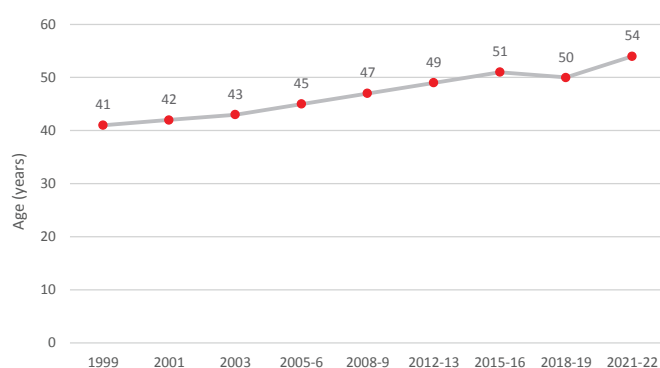
In the HIV Futures 10 sample, the average age of women was 7 years lower than that of men (48 years compared to 55 years, respectively). The average ages of gay and bisexual men (55 and 57 years, respectively) were slightly higher than for heterosexual participants (48 years). This is consistent with the national trend of new HIV diagnoses falling among Australian-born MSM, meaning the overall population of MSM living with HIV is ageing, but other groups are not.

Participants identifying as pansexual or queer were younger than average (47 and 49 years, respectively), which might reflect an increasing fluidity in sexuality or a trend away from binary (gay/straight) labelling of sexuality among younger people (Sinclair-Palm & Gilbert, 2018).

Language and cultural diversity

The majority of participants were born in Australia (72.2%, n = 571), and 88.1% (n = 712) spoke English as a first language and 96% (n = 763) spoke English at home. Of those born outside Australia, the most common countries of birth were the United Kingdom (6.8%, n = 54), New Zealand (5.3%, n = 42) and South Africa (1.3%, n = 10). Overall, 12.3% (n = 100) of participants were born in European countries, 4.3% (n = 35) in Asian countries, and 2.8% (n = 23) in African countries (see Figure 2). Fifty-two countries of birth were listed in total.

"Unlucky to have HIV; however, VERY lucky to be in Australia."

Figure 2: Region of birth for people born outside of Australia
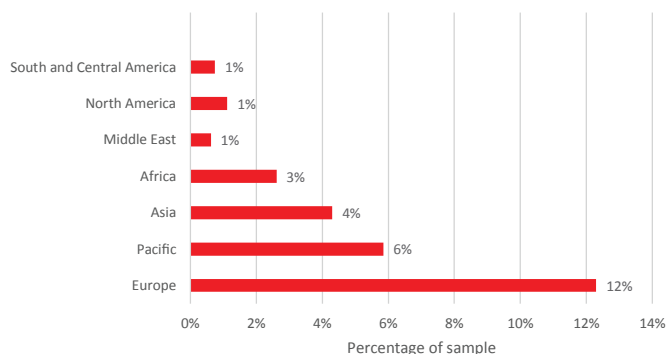
"I have been living in Australia as an international student for the past 8 years. I feel like this country is a home. I am so glad the medication is provided at no cost, even if I am not an Australian citizen. I am very grateful for that."

The proportion of participants born in Australia has been roughly constant over time; however, HIV Futures 10 had a slightly smaller proportion of participants born overseas than the previous survey, as shown in Figure 3 below.

Figure 3: Proportion of overseas-born participants in HIV Futures surveys over time
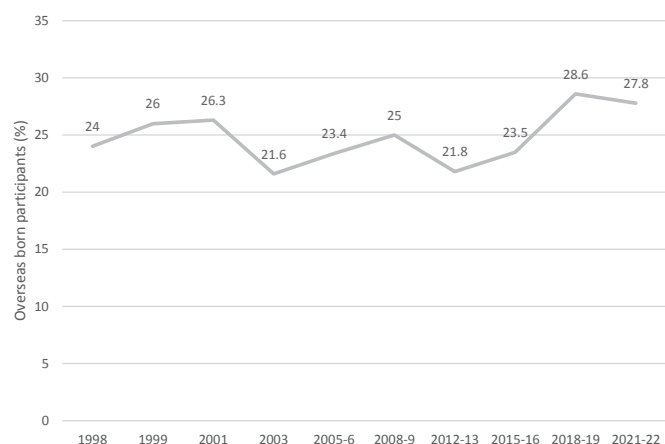
Citizenship, residency, and visa status

The majority of participants (72.7%, n = 588) were Australian citizens and 22.4% (n = 181) were permanent residents. There was a small number of participants (4.9%, n = 40) who were not citizens or permanent residents. Of those who provided details of their visa status, 13 were students, six had working visas, six had protection visas and the remainder had other types of visas.

Of those who were not born in Australia (n = 259), most (63.3%, n = 164) had been living in Australia more than 20 years, while 7.7% (n = 30) had been in Australia for less than 5 years.

> "Since getting my permanent residency, I feel more settled and less anxious."

Aboriginal and Torres Strait Islander participants

Nineteen participants indicated that they were Aboriginal (2.4%), two indicated they were Torres Strait Islander (0.3%) and one indicated that they were both Aboriginal and Torres Strait Islander (0.1%).

Of participants who were Aboriginal and/or Torres Strait Islander, one was aged under 35, 11 were 35-49, six were 50-64, and one was aged over 65. Nine lived in New South Wales, three in Victoria, five in Queensland, one in Australian Capital Territory and one in South Australia.

The rate of new HIV diagnoses among Aboriginal and Torres Strait Islander people is higher than among the non-Indigenous population (King et al., 2022). Unfortunately, the small number of Aboriginal and Torres Strait Islander participants in this survey makes it difficult to present meaningful data in a way that does not risk identifying individual participants. There is an urgent need for more research, led by Indigenous researchers, to build understanding of how best to support PLHIV from Aboriginal and Torres Strait Islander communities.

Location of residence

Most participants resided in inner urban areas (56.1%, n = 453) with smaller proportions from regional centres (18.1%, n = 146), outer suburban areas (15.6%, n = 126) and rural areas (10.3%, n = 83). The largest number of responses came from New South Wales (39.8%, n = 323) and Victoria (26.8%, n = 218), reflecting the larger population of PLHIV living in these states. The breakdown of responses by state is shown in Table 2.

Table 2: State or territory of participants' residence

State/territory	Frequency n	Percentage %
NSW	323	39.8
Vic	218	26.8
Qld	128	15.8
SA	35	4.3
WA	55	6.8
ACT	20	2.5
Tas	20	2.5
NT	13	1.6
Total	812	100

Education

The level of education among participants was diverse. Ten (1.2%) had attended primary school only, while 21.5% (n = 175) had postgraduate degrees. Educational levels are shown in Table 3 below.

Table 3: Highest educational level attained

Level	Frequency n	Percentage %
Primary school only	10	1.2
Up to four years' high school	101	12.4
Leaving certificate/HSC/VCE	112	13.8
Tertiary diploma/trade certificate/TAFE	249	30.6
Undergraduate university degree	166	20.4
Postgraduate university degree	175	21.5
Total	813	100

Employment and income

Just over half the participants (57.6%) were in paid work, either full-time (44.6%, n = 360), part-time (8.4%, n = 68) or casual (4.6%, n = 37) (Table 4). Close to one in four were not working/retired (23.3%) or not looking for work (4.1%). The comments provided in open text response indicate that many of those not working were on disability pensions or otherwise injured or unwell, while some were full-time carers for parents or partners, volunteers, or unable to work due to the COVID-19 vaccine mandate:

- 'Disability support pension'
- 'Currently unable to work due to broken leg'
- 'No working due to illness'
- 'Employed but about to be unemployed due to vaccine mandate'
- 'Unpaid carer'
- 'Volunteer 4 hours per week'

Table 4: Main employment/activities

Main employment/activities	Frequency n	Percentage %
Work full-time (30+ hours per week, including self-employment)	360	44.6
Not working, including retired	188	23.3
Unemployed, not looking for work	33	4.1
Work part-time (less than 30 hours per week)	68	8.4
Unemployed, looking for work	40	5
Work casual	37	4.6
Student	12	1.5
Home and/or caring duties	16	2
Other	53	6.6
Total	843	100

Consistent with the employment patterns of participants, the most common income source was salaries or wages (54.5%, n = 441), followed by benefits, pension or social security (30.3%, n = 245) (Table 5).

Table 5: Main income source

Main income source	Frequency n	Percentage %
Salary/wages	441	54.5
Benefits/pension/social security	245	30.3
Savings	26	3.2
Superannuation	59	7.3
Partner supports me	11	1.4
Family/friends support me	4	< 1
Annuity	2	< 1
Other	21	2.6
Total	809	100

The most common reported household income was below $30,000 per annum (26.5%, n = 197), although almost one in five reported an income of $50,000 to $79,999 per year (18.9%, n = 152). A majority of the sample (57.6%, n = 527) reported a household income less than $80,000 per annum (Table 6). As a point of comparison, in 2018, the average Australian household income was approximately $110,000 per annum: 60% of Australian households had an income of less than $85,000, while 20% had incomes less than $25,000 (Australian Bureau of Statistics, 2019; Mccrindle, 2019).

Table 6: Annual household income

Annual household income	Frequency n	Percentage %
Negative or zero income	16	2
$1 to $29,999	197	24.5
$30,000 to $49,999	98	12.2
$50,000 to $79,999	152	18.9
$80,000 to $99,999	92	11.4
$100,000 to $124,999	66	8.2
$125,000 to $149,999	39	4.9
$150,000 to $199,999	41	5.1
$200,000 or more	57	7.1
Total	804	100

Details of household income compared with main source of income are shown below in Figure 4. Those earning under $30,000 were most likely to report social security as their main source of income.

Figure 4: Income source by household income
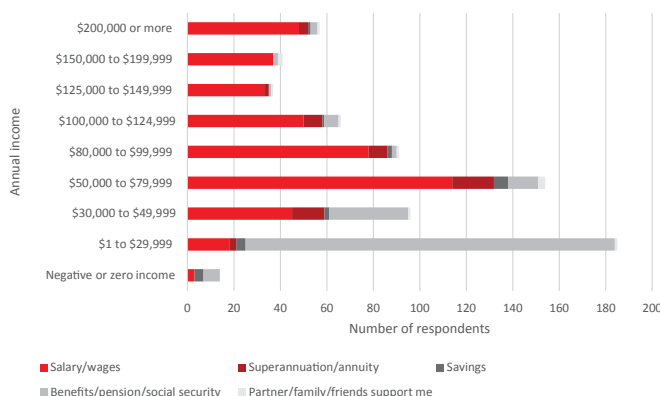
Living arrangements

Close to half of the participants lived alone (43.5%, n = 355), one-third lived with their partner (35.3%, n = 212), 9.4% (n = 77) with friends and 7.8% (n = 64) with other family members (Table 7).

There were 31 (3.8%) who lived with children, including 1.8% (n = 15) who lived with their partner and children and 1.9% (n = 16) who lived with their children without a partner.

On average, people living in single-person households had a lower income than those living with a partner or family (Figure 5).

Table 7: Living arrangements

Living arrangements	Frequency* n	Percentage* %
Live alone	355	43.5
Live with partner/spouse with no children	288	35.3
Live with partner and children	16	2.1
Live with children, no partner	23	3.0
Live with friends/flatmates	122	15.8
Live with other family members	77	10.0
Live with other	15	1.9

* Note that the sum of responses is greater than the total number of participants because some participants live with people in multiple categories, for example, living with both friends and family

Figure 5: Household income, by number of people in household
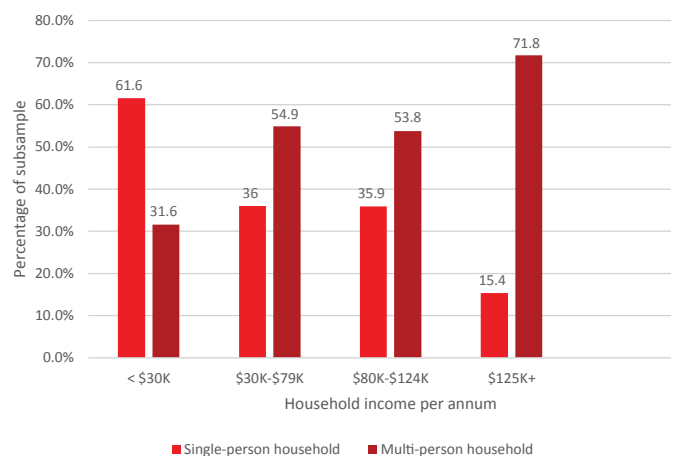
A considerable number of participants reported that they did not live alone because they lived with their pet(s), or people indicated they lived with both pets and other adults (Table 8). Overall, 10.6% (n = 85) of participants reported living with a pet.

Table 8: Number of participants living with pets

Pet(s) or no pets	One-person household	Multi-person household	Total
No pets	330	385	715
Pet(s)	25	60	85
Total	355	445	800

2. QUALITY OF LIFE

The Eighth National HIV Strategy aims to achieve 75% of PLHIV reporting good quality of life (QoL) by 2022 (Australian Government Department of Health, 2018). This goal complements the 95:95:95 goals in the national strategy that are focussed on rates of HIV testing, treatment and viral suppression.

A target relating to QoL is significant as it asserts the importance of building an environment in which care for PLHIV is integral to the success of the HIV response. Concern for PLHIV is part of prevention, given HIV treatment is now a central plank of biomedical prevention, while caring for people most affected by HIV is fundamental to good public health and to challenging HIV-related stigma.

In HIV Futures 10, we used two measures to determine how many people identified their QoL as 'good': the PozQoL scale (Brown et al., 2018) and a one-item measure of overall wellbeing. PozQoL is a 13-item scale that was developed specifically to assess QoL among PLHIV across four domains or aspects of wellbeing: psychological, social, functional, and health concerns. The measure was developed in Australia and has been validated with Australian PLHIV. The PozQoL scale is used to calculate a QoL score that ranges from 1-5, with higher scores indicating better QoL. A score of 3 or higher is considered 'good' QoL. It is important to note that PozQoL measures health-related QoL specific to PLHIV. It gives us information about the extent to which HIV affects wellbeing, capturing the impact of HIV-related stigma, treatment management and concerns about health. It is not a general measure of QoL. This is the second time PozQoL has been included in HIV Futures, and in this chapter we comment on changes since HIV Futures 9.

Along with PozQoL, we report on responses to a single item that asked HIV Futures 10 participants how they would describe their overall emotional, mental and physical wellbeing. This item has been used in all HIV Futures surveys (from 1997 onward), and here we report on change over time.

"Stigma is still one of our biggest issues impacting on quality of life."

Quality of life – Progress toward national targets

Responses to each item in the PozQoL scale were recorded using a 5-point Likert scale (1 = 'not at all', 2 = 'slightly', 3 = 'moderately', 4 = 'very', and 5 = 'extremely'). The PozQoL score is the average of each participant's response to the 13 items. A PozQoL score of 3.0 or higher indicates a generally good quality of life, given the participant would have scored 3 or higher ('moderately', 'very' or 'extremely') in response to the majority of items in the scale – that is, they would have scored the midpoint of 3 or higher for each item on the 5-point scale.

In HIV Futures 10, 71.8% (n = 586) had a PozQoL score of 3.0 or higher, contrasted with 63.1% (n = 492) in HIV Futures 9 (2018; Figure 6). While the National HIV Strategy target to achieve 75% of PLHIV reporting 'good' QoL by 2022 was not met, there has been a substantial increase in the proportion of participants reporting a good QoL.

In HIV Futures 10, **71.8%** (n = 586) reported a good quality of life (PozQoL score of 3.0 or higher).

Change in quality of life between HIV Futures 9 and HIV Futures 10

In HIV Futures 9 (2018-19) the percentage of PLHIV reporting 'good' QoL, according to PozQoL, was 63.1%. This increased to 71.8% in HIV Futures 10. Below we present findings on factors that predict 'good' QoL. However, with cross-sectional data such as this, we cannot tell definitively what led to an increase in QoL between 2018-19 and 2021-22. It is possible that global and national support for PLHIV, including the U=U campaign and increasing use of PrEP among HIV-negative people, has had an impact on stigma and QoL for PLHIV. It is also possible that other factors, such as the COVID-19 pandemic, have changed perceptions of QoL in relation to HIV or provided some new supports for PLHIV, such as access to telehealth.

The COVID-19 lockdowns meant the bulk of survey promotion was done online, and as a result, the sample we reached was slightly different to that of HIV Futures 9. In past iterations of HIV Futures, hard-copy surveys were completed by people at HIV services or events where there is often a high representation of people who are reliant on financial support. We did not have access to face-to-face services or these events during COVID-19 lockdowns. In HIV Futures 10, 44.6% of participants were working full-time, compared to 41.5% in HIV Futures 9. There were also fewer participants in HIV Futures 10 who were reliant on social security/benefits for their income (30.3%, compared to 35.3% in HIV Futures 9). Access to a liveable wage and other benefits that come from working, such as social connection and a sense of purpose, can contribute to better QoL.

The PozQoL survey will be repeated in HIV Futures 11, with data collection taking place in 2023-24. These data will provide an important point of comparison from which we will better be able to assess whether there is an upward trend in reporting of QoL among PLHIV.

Components of quality of life

The overall average PozQoL score for HIV Futures 10 participants was 3.42 (SD = 0.82).

The PozQoL scale contains four separate subscales: psychological, functional, social, and health concerns. The psychological domain is about a person's general mood and outlook (not specific to HIV). The functional domain is about the extent to which HIV interrupts everyday living. The social domain is about a person's sense of belonging and concerns about the impact of HIV on social relationships, including fear of being rejected by others. Health concerns relates to the extent to which people worry about the impact of HIV on their current or future health.

The average scores for each of these subscales (out of 5) were as follows:

<div style="background:#e30613;color:#fff;">Psychological: 3.3</div>

The psychological subscale measures broad psychological quality of life, including optimism for the future, whether the participant feels good about themselves as a person, whether they are enjoying life, and how in control of their lives they feel.

<div style="background:#b01c2e;color:#fff;">Functional: 3.9</div>

The functional subscale measures HIV-related functioning: whether managing HIV wears participants out, whether having HIV limits opportunities in life, and whether HIV prevents participants from doing as much as they would like.

<div style="background:#bcbec0;">Social: 3.3</div>

The social subscale measures social quality of life relative to HIV, including whether participants are afraid people may reject them because of their HIV diagnosis, whether HIV limits personal relationships, and whether participants feel they lack a sense of belonging with people around them.

<div style="background:#bcbec0;">Health concerns: 3.2</div>

The health concerns subscale measures HIV-specific and broad health concerns, including whether participants fear the health effects of HIV as they get older, whether they worry about the impact of HIV on their health, and whether they worry about their health.

Figure 6: Mean PozQoL score: 2018-19 versus 2021-22

HIV Futures 9 (2018-19)   HIV Futures 10 (2021-22)
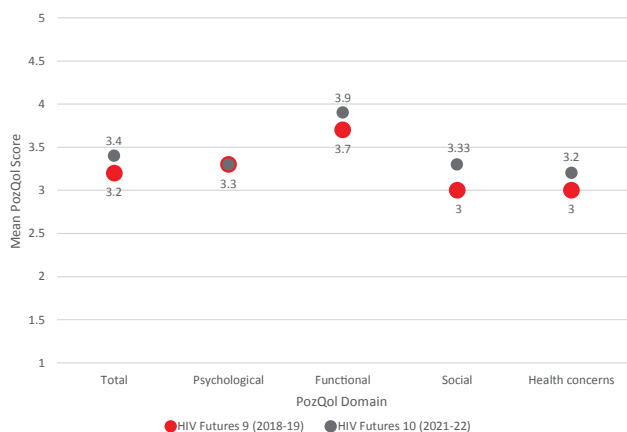
Compared to the HIV Futures 9 sample (2018-19), participants reported greater overall HIV-related quality of life. Specifically, the social, functional and health subscales all saw an increase between 2018-19 and 2021-22, while the psychological subscale remained the same (Figure 6).

In the psychological domain, a large proportion of people indicated that they felt optimistic about their future (41.8% indicating 'very' or 'extremely' optimistic) and in control of their life (44.5% indicating 'very' or 'extremely' in control). However, average scores on the psychological subscale did not increase between 2018-19 (HIV Futures 9) and 2021-22 (HIV Futures 10). Given that the psychological subscale items relate to QoL outside of HIV-specific themes, it is likely that these items would have been most heavily impacted by stressors related to the COVID-19 pandemic.

Scores in the functional domain were highest (and brought the overall average up), and despite also being the highest performing domain in the HIV Futures 9 sample (2018-19), increased relatively. Higher scores in the functional domain suggests that, for many people, HIV has a limited impact on everyday life functions. For example, 43% indicated that HIV did 'not at all' prevent them from doing as much as they would like, and 39% indicated that HIV did 'not at all' reduce their opportunities in life (Figure 7).

With respect to the social domain, scores increased relative to the 2018-19 HIV Futures sample. While responses revealed the negative impact of stigma on quality of life, with nearly two in five (38.1%) indicating they were 'very' or 'extremely' afraid that people may reject them when they disclose their HIV status, this was a substantial decrease from nearly half in the 2018-19 sample (46.9%). However, one in five still indicated they lack a sense of belonging to people around them (22.3% indicting they 'very' much or 'extremely' lack a sense of belonging). It is important to emphasise that these items do not specifically relate to broader social wellbeing (e.g. how much a participant is socialising) but are measures specifically focussed on HIV. Given this, it is unsurprising that scores were not heavily attenuated by COVID-19 and related social restrictions.

While scores were lowest in the health concerns domain, they also increased relative to the HIV Futures 9 sample. More than one in five participants indicated they were 'very' or 'extremely' concerned about the health effects of HIV as they age (34.9%), while only a small percentage had no concerns about their current or future health (7% indicated they were 'not at all' concerned).

Responses to each of the 13 PozQoL items in HIV Futures 10 are shown in Figure 7.

Figure 7: Responses to each PozQoL item across four domains (psychological, functional, social, and health concerns)

Not at all   Slightly   Moderately   Very   Extremely
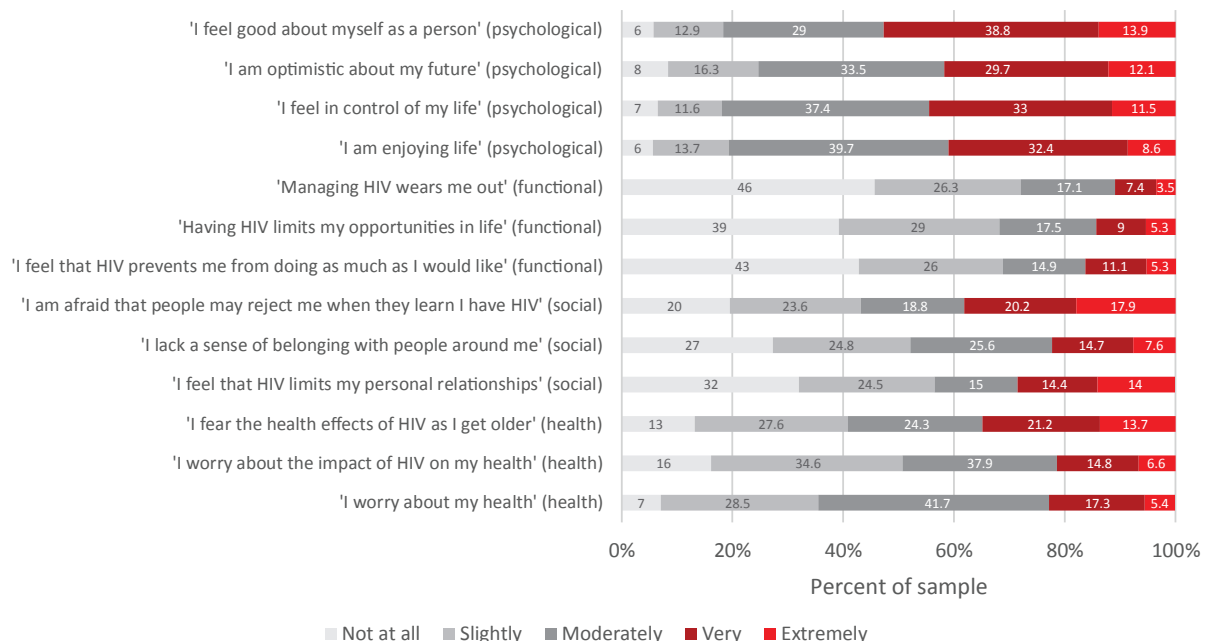
Factors influencing quality of life

To better understand what factors have most influence on quality of life, we explored associations between PozQoL scores and a range of social and demographic variables. In this analysis we used a PozQoL score of 3.0 as a measure of 'good' quality of life. Variables included age, gender, English as a first language, education, income and financial security, living arrangements, number of years living with HIV, social connectedness, general health, and whether participants agreed that the 'COVID-19 pandemic had significantly reduced their wellbeing'. The (statistically) significant (or near significant) factors are presented in Table 9.

PozQoL scores of 3.0 or higher (good quality of life) were associated with: higher income, no recent financial stress, living in inner city areas, better general health, a greater level of social connectedness, living with a partner/spouse, and disagreeing with the statement that the COVID-19 pandemic significantly reduced their wellbeing. People in the 65+ age bracket were significantly more likely to report higher quality of life.

"Things are pretty good, really – but I am in my 70s and have had HIV for half my life.."

Table 9: Factors significantly associated with PozQoL scores (key differences within groups highlighted)

PozQoL score	Less than 3.0, poorer quality of life, n (%)	3.0 or higher, good quality of life or higher, n (%)	p value
Age			
< 35	27 (44.3%)	34 (55.7%)	
35-49	50 (27.9%)	129 (72.1%)	
50-64	126 (31.3%)	276 (68.7%)	p < .001
65+	27 (15.5%)	147 (84.5%)	
Financial stress (in past 2 years)			
Experienced financial stress	85 (60.7%)	55 (39.3%)	
No financial stress	145 (21.4%)	531 (78.6%)	p < .001
Household annual income			
< $30,000	81 (38.0%)	132 (62.0%)	
$30,000 - $79,999	77 (30.8%)	173 (69.2%)	
$80,000 - $124,000	31 (19.6%)	127 (80.4%)	p < .001
$125,000+	17 (12.4%)	120 (87.6%)	
SF-36 general health subscale score*	37.8 (SD = 19.8)	61.9 (SD = 21.2)	p < .001
Social connection, mean score (SD)**	3.8 (1.3)	5.3 (1.1)	p < .001
'My wellbeing was significantly impacted by the COVID-19 pandemic'			
Agree	147 (37.7%)	243 (62.3%)	
Disagree	63 (17.7%)	293 (82.3%)	
Live with partner/spouse			
Yes	55 (19.1%)	233 (80.9%)	
No	175 (33.1%)	353 (66.9%)	
State or territory			
WA	11 (24%)	44 (80%)	
ACT	3 (15.0%)	17 (85%)	
NSW	79 (24.5%)	244 (75.5%)	
NT	1 (7.7%)	12 (92.3%)	
Qld	43 (33.6%)	85 (66.4%)	p = .03***
SA	13 (37.1%)	22 (62.9%)	
Tas	9 (45.0%)	11 (55.0%)	
Vic	68 (31.2%)	150 (68.8%)	
Residential location			
Capital city/inner suburban	112 (24.7%)	341 (75.3%)	
Outer suburban	41 (32.5%)	85 (67.5%)	p < .001
Regional/rural	77 (22.6%)	152 (66.4%)	

* SF-36 general health subscale score ranges from 0-100, with higher scores indicating better general health
** Social connection scores range from 1-7, with higher scores indicating greater social connectedness
*** This figure should be interpreted with caution due to small case numbers in some cells

"It's a lonely and sad place ... especially in a small country town."

Self-reported wellbeing

Participants were asked to describe their overall sense of wellbeing, including physical, emotional and mental wellbeing, using a one-question item in which responses were recorded using a 4-point scale from 'poor' to 'excellent'. This is a less nuanced measure than the validated PozQoL scale but nonetheless gives an indication of wellbeing. Results are shown in Figure 8.

Overall, 50.5% (n = 410) reported their wellbeing to be good or excellent. Factors associated with higher wellbeing were: being in the paid workforce, no recent experience of financial stress, higher household income, better general health (SF-36), living with a partner/spouse, and higher levels of social connectedness. Consistent with PozQoL scores, people aged 65+ were more likely than those in other age groups to report better wellbeing.

Self-reported wellbeing over time

Figure 9 shows the percentage of people who reported their overall wellbeing to be good or excellent in HIV Futures surveys from 2001 onwards. The percentage of respondents who reported good or excellent wellbeing increased 4% between Futures 9 (2018-19) and Futures 10. This was the first increase in wellbeing since 2008-09.

Wellbeing and COVID-19

Over half of the total sample (52.3%, n = 390) either agreed or strongly agreed that their sense of wellbeing had significantly reduced due to the COVID-19 pandemic and associated lockdowns.

Figure 8: Overall physical, emotional and mental wellbeing (self-reported)
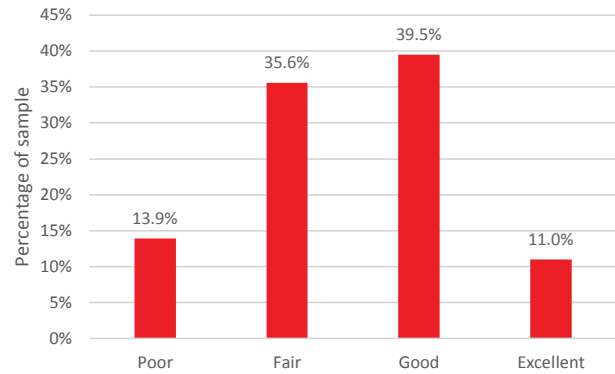
Figure 9: HIV Futures participants reporting overall wellbeing to be 'good' or 'excellent' over time
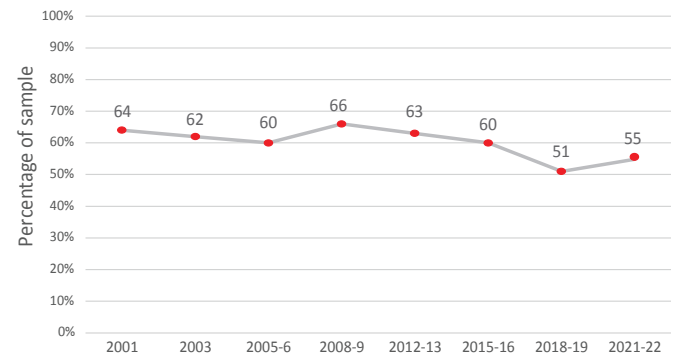
Table 10: Factors associated with self-reported wellbeing* (key differences within groups highlighted)

Overall wellbeing	Poor n (%)	Fair n (%)	Good n (%)	Excellent n (%)	p value
Age					
< 35	8 (13.1)	24 (39.3)	23 (37.7)	6 (9.8)	p = .005
35-49	28 (15.7)	58 (32.6)	68 (38.2)	24 (13.5)	
50-64	48 (12.0)	146 (36.5)	160 (40.0)	46 (11.5)	
65+	7 (4.0)	48 (27.6)	94 (54.0)	25 (14.4)	
Employment status					
Not currently in paid work	45 (15.6)	101 (35.1)	112 (38.9)	30 (10.4)	p < .001
Part time or casual work	7 (6.7)	40 (38.1)	47 (44.8)	11 (10.5)	
Full time work	25 (7.0)	108 (30.1)	168 (46.8)	58 (16.2)	
Financial stress (in past 2 years)					
Experienced financial stress	45 (32.1)	61 (43.6)	29 (20.7)	5 (3.6)	p < .001
No financial stress	46 (6.8)	215 (31.9)	316 (47.0)	96 (14.3)	
Household annual income					
< $30,000	46 (21.7)	76 (35.8)	71 (33.5)	19 (9.0)	p < .001
$30,000 - $79,999	24 (9.6)	90 (36.1)	109 (43.8)	26 (10.4)	
$80,000 - $124,000	9 (5.7)	47 (29.7)	72 (45.6)	30 (19.0)	
$125,000+	6 (4.4)	34 (25.0)	74 (54.4)	22 (16.2)	
SF-36 general health subscale score**	30.0	45.0	61.7	80.6	p < .001
Social connection, mean score***	3.4	4.5	5.3	6.0	p < .001
Live with partner/spouse					
Yes	18 (6.3)	91 (31.8)	138 (48.3)	39 (13.6)	p = .003
No	73 (13.9)	185 (35.1)	207 (39.3)	62 (11.8)	

* A range of demographic characteristics were explored, only those significantly associated with overall wellbeing at the bivariate level are reported
** SF-36 general health subscale score ranges from 0-100, with higher scores indicating better general health, in this case each category was significantly higher than the former (p < 0.001)
*** Scores derived from a 10-item measure of social connectedness and sense of support. Scores range from 1-7 with a higher score indicating greater social connectedness. ANOVA with Tukey's HSD post-hoc test showed that each score was significantly higher than the previous score, p < 0.001.

3. FINANCIAL AND HOUSING SECURITY

Financial security is important to QoL because it affords people choice over core elements of life, such as employment, educational opportunities, housing quality and planning for the future. Financial security also facilitates contact with the social world. An inability to afford costs associated with social life, such as eating out or appropriate clothing, can contribute to isolation and loneliness. Previous HIV Futures studies have shown a higher-than-average level of poverty among PLHIV in Australia.

There may be several reasons for this. People who have been living with HIV for a long time are more likely to have experienced side effects from early HIV treatment and ill health from AIDS-related symptoms. This may have affected people's capacity to work, leaving a long-term negative impact on their earning capacity and financial security. As the population of PLHIV in Australia ages, the negative effects of financial insecurity on health-related quality of life among PLHIV is likely to become more visible. People require greater medical care as they age, and access to income is more limited in retirement. This will be exacerbated for people who live in private rental accommodation or other forms of expensive or insecure housing.

In this chapter, we report on indicators of financial and housing security: housing status, recent financial stress, food security, and healthcare costs.

Housing and homelessness

Private rental accommodation is an insecure housing option for many people in Australia, due to high costs and (often) limited security of tenancy (Beer et al., 2016). However, as the high cost of housing makes purchasing a home unobtainable for increasing numbers of Australians, many are living long term in private rental accommodation (Hulse, 2012).

While private rental accommodation was the most common form of housing among HIV Futures 10 participants (Table 11), with 31.7% (n = 256) indicating they lived in private rental, the number of participants who owned their home with a mortgage (21.9%, n = 177) or owned their home outright (27.6%, n = 223) was substantially higher than in Futures 9. However, compared to Australian averages, participants in HIV Futures 10 were still more likely to live in private rental accommodation and less likely to own their own home. In the 2021 Australian census, 30.6% were living in rental accommodation, 35% owned their home with a mortgage, and 31.0% owned their home outright (Australian Bureau of Statistics, 2022).

In HIV Futures 10, 0.8% (n = 6) of participants reported that they were homeless, including those living in boarding houses or crisis accommodation. This was a decrease of 0.9% compared to Futures 9 (2018-19; 1.7%, n = 16). However, this is still a larger proportion of homeless people than the general population. In the 2016 Australian census, over 116,000 people were experiencing homelessness on census night (approximately 0.49% of the population), including people living in a boarding house or crisis accommodation service as well as other forms of homelessness such as couch surfing, inadequate accommodation or no accommodation (Australian Bureau of Statistics, 2018).

"We need housing to be available to us."

Table 11: Current housing arrangement

	Frequency n	Percentage %
Private rental	256	31.7
Home purchaser (with mortgage)	177	21.9
Home owner (own outright)	223	27.6
Public or community housing	97	12.0
Rent-free (e.g. with friends or family)	30	3.7
Boarding house, crisis accommodation or homeless	6	< 1
Institution	2	< 1
Other	16	2.0
Total	807	100

Housing and age

Housing arrangements were correlated with age, with younger people being less likely than older people to own a home with a mortgage or outright (see Figure 10). Private rental was the most common form of housing for those < 35 and 35-49. Among participants aged under 35 years, more than three-fifths (70%) were in private rental accommodation, compared to approximately 20% of those aged 65+ (see Figure 10). While people aged 50 years and older were more likely than younger people to own a home, close to one-quarter of people aged 50-64 years or older lived in private rental accommodation (24.9%).

As shown in Figure 10, people in the 50-64-year age bracket were significantly less likely than those aged 65+ to own a home outright. Private rental accommodation – which is insecure and unaffordable for many people – is considered an indicator of financial insecurity among older people whose long-term earning capacity will be limited by retirement. Precarious housing is also associated with lower levels of subjective wellbeing and quality of life, as it leads people to feel more insecure and less stable (Colic-Peisker et al., 2015; Morris, 2009).

Figure 10: Housing arrangement, by age
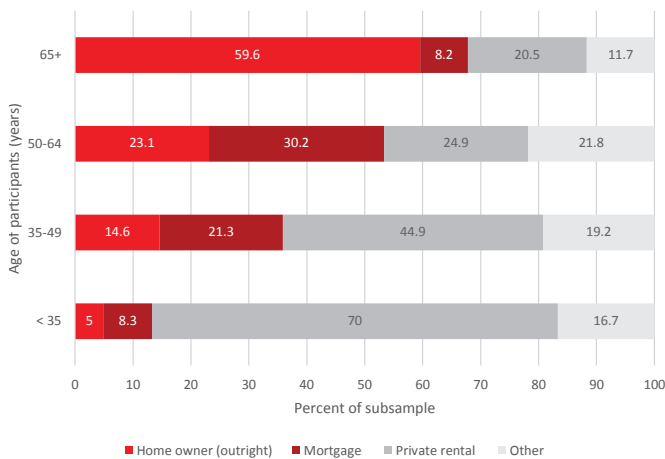
Housing and gender

Men were more likely to own their home than people of other genders (see Figure 11). This differs from the general Australian population where, the 2015-16 Australian Survey of Income and Housing indicates, women were slightly more likely than men to live in a home they owned or were purchasing (60% of women compared with 56% of men; (Australian Bureau of Statistics, 2017). Transgender, non-binary or gender fluid participants were most likely to be in private rental housing, although the low sample size makes it difficult to say if this reflects the housing situation of most transgender, non-binary or gender diverse people.

Figure 11: Housing arrangement, by gender
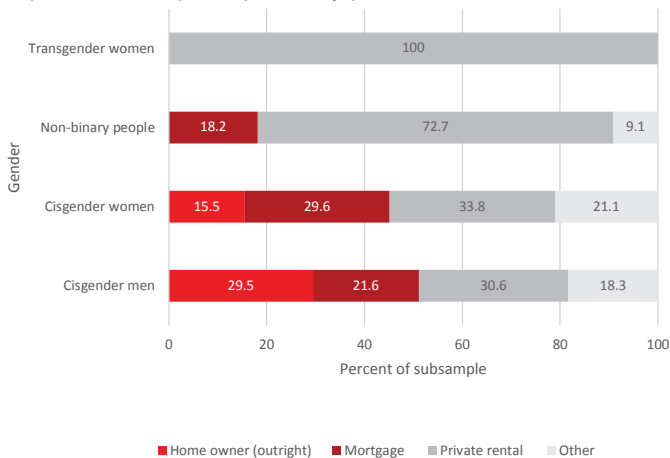
Recent financial stress

Participants were asked whether they had experienced any of a series of financial challenges within the last 12 months, including not being able to pay bills, not being able to pay rent or mortgage on time, going without meals, or needing to ask friends, family or services for financial assistance. These questions are standardised measures of financial stress: if an individual experienced none or one of these events, they are determined to have experienced little or no financial stress; while a person who has experienced two or more events is considered to have experienced significant financial stress (Wilkins, 2016).

Overall, 17.2% (n = 140) of HIV Futures 10 participants were classified as experiencing significant financial stress. As a point of comparison, in the Household, Income and Labour Dynamics in Australia (HILDA) survey, a representative survey of Australian households, an average of 11.5% of participants were classified as experiencing financial stress across all waves of the survey conducted between 2001 and 2015 (Wilkins & Lass, 2018).

In HIV Futures 10, people more likely to have experienced financial stress in the past 12 months were those living in regional locations or the outer suburbs (Figure 12). There was a stepwise trend of financial distress by age; people aged under 35 years experienced the greatest proportion of distress (29.5%), followed by those aged 35-49, 50-64, and finally, those aged 65+ (Figure 13). Women, including cisgender and transgender women, were most likely to have experienced financial distress in the previous 12 months (Figure 14).

Figure 12: Proportion of participants within each location category indicating financial stress
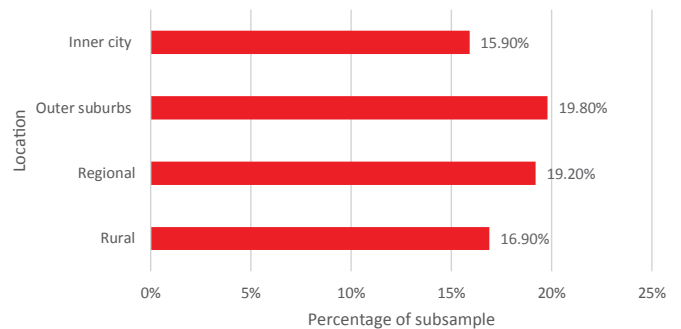
Figure 13: Proportion of participants in each age category indicating financial stress
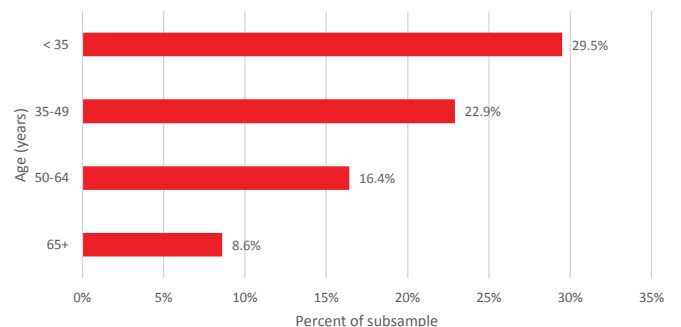
Figure 14: Financial stress, by gender
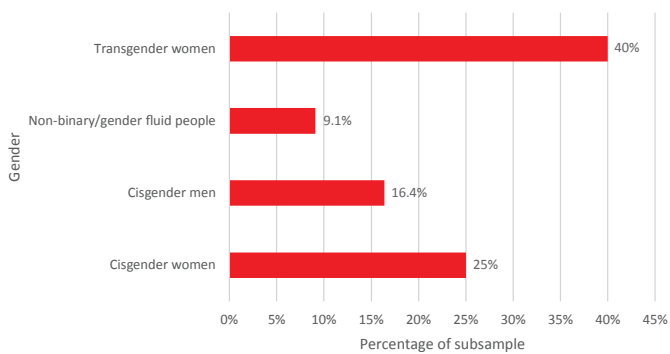
Financial stress was correlated with type of housing arrangement. Participants who were homeless were most likely to have experienced financial stress (Figure 15), although overall numbers were small (100% of three participants). Those who owned their homes outright were least likely to be financially stressed (5.4% of 223 participants). Over one in five participants living in private rental housing had experienced financial stress (22.7% of 256 participants).

Figure 15: Proportion of participants living in each type of housing arrangement reporting recent financial stress*
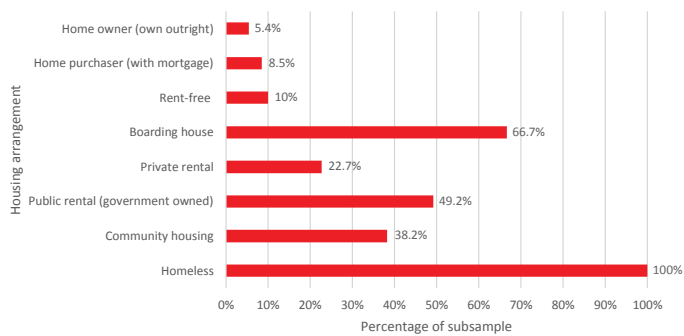
* Note that participants living in boarding houses have been decoupled from homeless participants, and participants living in community housing have been decoupled from those living in public housing

Healthcare costs and access

All Australian citizens and permanent residents have access to HIV-related healthcare. People on temporary or short-term visas do not have this same access. There may be other costs associated with healthcare, including consultation or medication co-payments, that make it difficult for some people to afford.

In HIV Futures 10, some participants struggled to meet the costs associated with HIV treatment, such as transport to clinics or the fees for specialists to treat comorbidities or other health conditions (including mental health). Specifically:

- 4.7% (n = 30) of participants reported that they had not taken their HIV medication at least once in the last 12 months because of financial reasons
- 4.1% (n = 16) reported that it was financially 'very difficult' to access healthcare, and a further 13.8% (n = 102) reported that it was 'somewhat difficult'
- 5.9% (n = 43) reported that it was financially 'very difficult' to access medication, and a further 23.6% (n = 173) reported that it was 'somewhat difficult'

Medicare and private health insurance

Most participants (98.5%, n = 797) were eligible for Medicare, while 1.4% (n = 11) were Medicare ineligible. Around two-fifths (39.8%, n = 321) of the participants were eligible for healthcare concessions.

One indicator of financial security is being able to afford private health insurance. This also allows access to greater choice in health services and in some cases more rapid treatment when a person becomes unwell or needs to be hospitalised. Just over two-fifths (44%, n = 358) of participants had private health insurance and 0.5% (n = 4) had overseas student health cover.

4. HIV DIAGNOSIS, TREATMENT AND CLINICAL CARE

The Eighth National HIV Strategy includes the following targets:

- Increase the proportion of people with HIV (in all priority populations) who are diagnosed to 95%
- Increase the proportion of people diagnosed with HIV on treatment to 95%
- Increase the proportion of those on treatment with an undetectable viral load to 95%

These targets (often referred to as the 95:95:95 targets) follow those set by UNAIDS with the aim of 'ending HIV'. Australia has yet to reach the first of these targets; in 2021 there was an estimated 91% being diagnosed and 92% of people diagnosed on treatment. However, the third target has been met, with an estimated 98% of those on treatment achieving viral suppression (King et al., 2022). In this chapter we report on aspects of HIV diagnosis, ART uptake and clinical care that may help to inform progress toward these targets. We also look at the impact of the COVID-19 lockdowns on clinical care, including the uptake of telehealth among PLHIV.

Mode of HIV acquisition

Participants were asked to identify how they acquired HIV, if known. Consistent with national HIV surveillance data (King et al., 2022), male-to-male sex was the most common mode of transmission (78.7% of participants; n = 603) (Table 12).

Table 12: Mode of HIV exposure, by gender

Mode of transmission	Men n (%)	Women n (%)	Non-binary/ gender fluid people n (%)	Total n (%)
Sex with a man	603 (88.8)	64 (85.3)	6 (60)	675 (88.1)
Sex with a woman	10 (1.5)	0 (0)	0 (0)	10 (1.3)
Injecting drugs	19 (2.8)	2 (2.7)	0 (0)	21 (2.7)
Blood products	3 (0.4)	0 (0)	0 (0)	3 (0.4)
Other*	23 (3.4)	8 (10.7)	0 (0)	32 (4.1)
Unknown	20 (2.9)	1 (1.3)	4 (40)	25 (3.3)
Total	679 (100)	75 (100)	10 (100)	766 (100)

* Note that many participants who reported 'other' described their exposure as a result of sexual assault or accidental blood contact

Years living with HIV

The number of years participants had been living with *diagnosed* HIV ranged from less than 1 to 39 years (average of 19.8 years, SD = 11.3). The average number of years people had been living with HIV (including time prior to diagnosis) was 21.5 years. The majority of the sample (73.9%, n = 562) had been living with (diagnosed) HIV for more than 10 years (since 2011 or more recently). As expected, older people were more likely to have been living with HIV for a longer period of time. However, one in 10 people aged 65+ (10%, n = 16) and approximately one in five people aged 50-64 (19.4%, n = 72) had been diagnosed in the past 10 years.

Time between HIV exposure and diagnosis

Participants were asked the year that they tested positive for HIV and the year they believe they acquired HIV, but there was a high non-response rate to this question as some participants were unsure about which year they acquired HIV. The majority of participants tested positive for HIV in the same year that they acquired the virus (54.1%, n = 335), while 23.4% (n = 145) tested positive the following year. The average time between acquisition and diagnosis was 1.3 years (SD = 3.1; noting that these are indicative figures only, as participants could only report calendar year, not month).

Among people diagnosed with HIV in the 10 years prior to the survey (2011 or more recently), 85.1% (n = 126) had been diagnosed within 2 years, and 95.2% (n = 141) had been diagnosed within 5 years (see Figure 16).

Figure 16: Number of years between HIV exposure and diagnosis, by year of HIV diagnosis
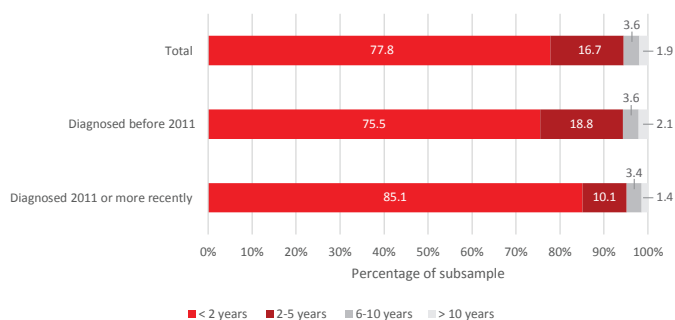
Similar to HIV Futures 9 (2018-19), this study found the length of time between acquisition and diagnosis was longer for women than men: an average of 2.4 years for cisgender women and 2 years for transgender women, compared to an average of 1.2 years for cisgender men, as shown in Figure 17. This may be due to differences in awareness of HIV between gay men and heterosexual women, targeting of public health messaging, and/or assumptions by doctors that heterosexual women are at lower risk of HIV, leading to delays in testing.

Figure 17: Average number of years between acquisition and diagnosis of HIV, by gender
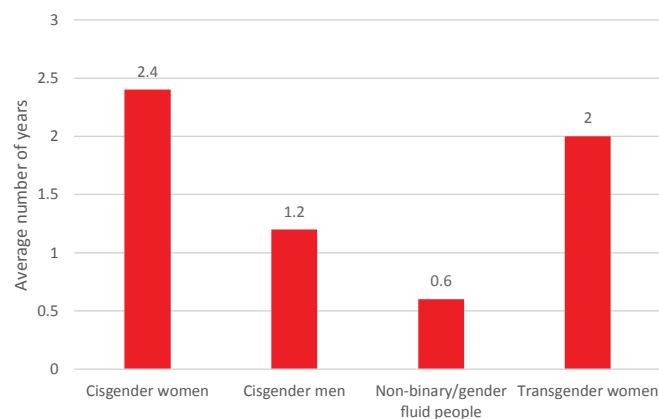
Antiretroviral therapy and viral suppression

Almost all participants (98%) were taking ART. Six people (< 1%) had never taken ART, nine were not taking ART of whom one (< 1%) was taking a treatment holiday, six (< 1%) had taken treatment in the past but were not taking it anymore, and two (< 1%) had not taken it but planned to in the future (Figure 18). Reasons given by participants for not taking ART were:

- 'The side effects.'
- 'My viral load has been undetectable and my CD4 count has been in the normal range since my first diagnosis. I am being classified as an "elite controller" or "long-term non-progressor".'
- 'Undetectable without treatment but have been advised to consider starting treatment.'
- 'I am just having a break and I'll resume taking them in a month.'
- 'I've just been so down since I lost my job that I didn't see the point taking them. I guess part of me was hoping that I'd get sicker and because I was too scared to take my own life that maybe HIV/AIDS would do it for me.'
- 'Prefer not to say.'

Figure 18: Current use and non-use of ART and viral suppression*

FULL SAMPLE
(n = 816)

On ART 98% n = 742	Not on ART 2% n = 15	
Viral supression 94.7% n = 702	Never taken ART n = 8	Have taken ART before but not currently taking it n = 7
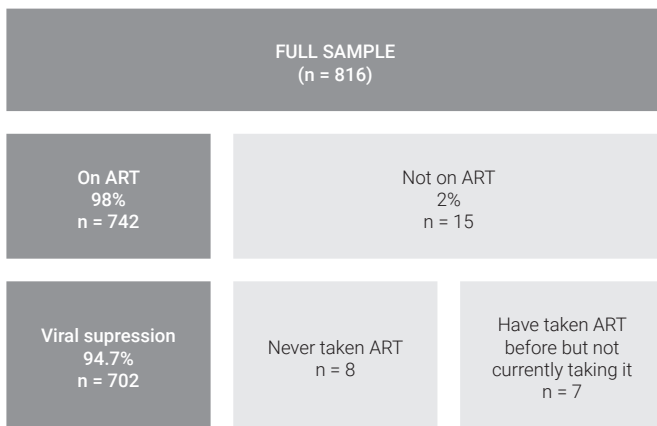
* Note that of the total sample, 93.7% (n = 726) reported an undetectable viral load

Satisfaction with ART

The majority of participants (81%, n = 518) agreed that they were happy with their ART, and that they find their treatment convenient (79%, n = 501) (Figure 19). Relative to HIV Futures 9 (2018-19), this was a 3.8% and 9.4% increase, respectively.

Figure 19: Satisfaction with ART
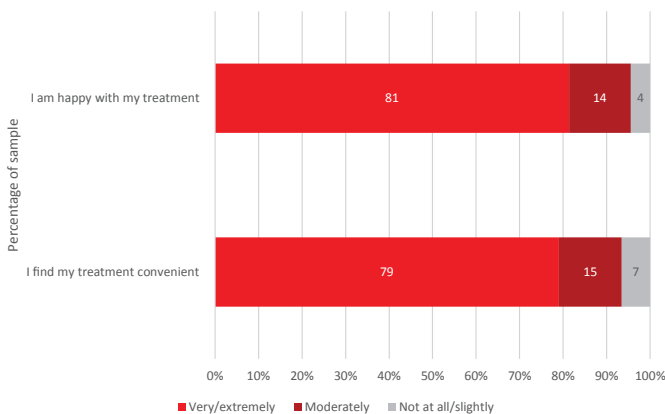
"The support and treatment services in Australia for people with HIV are excellent. Having lived in Asia it was often difficult to find services and health professionals who were knowledgeable about HIV and STIs."

When asked whether they were unhappy about side effects from ART, close to half indicated that they were 'not at all' unhappy (59.1% or n = 376, an increase of 11.6% compared to HIV Futures 9), although one in three (25.5%, n = 162) indicated they were 'moderately', 'very' or 'extremely' unhappy with treatment side effects (Figure 19).

Figure 20: Responses to 'I am unhappy with side effects from my treatment'
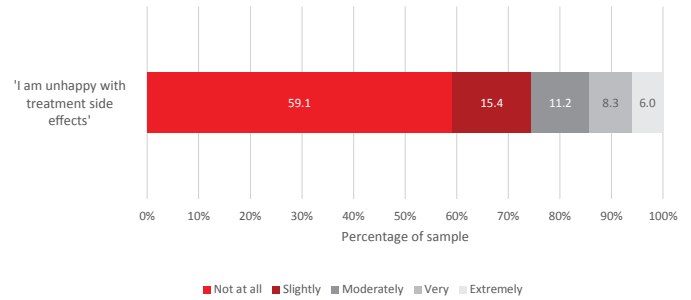
Participants were asked how confident they felt to ask their doctor for a treatment review. The majority (82.1%, n = 620) indicated they were very or extremely confident to ask for a review. However, there were 145 people (17.9%) who did not feel confident asking for a treatment review.

Attitudes toward ART

Most participants agreed that antiretroviral treatment was important for their health. As summarised in Figure 21, 89.3% (n = 671) disagreed with the statement 'I am healthy now and don't need to use ART', while 66.8% (n = 502) disagreed with the statement 'the side effects of ART outweigh the benefits'. Similarly, 80.3% (n = 605) agreed that it is best to begin ART soon after diagnosis.

While the majority disagreed with the statement that 'ART is harmful' (58.8%, n = 444), there were 41.2% (n = 311) who were ambivalent about this statement or agreed that ART is harmful (a much higher proportion than the 2% who are currently not taking ART).

Table 13 shows responses to these questions from previous HIV Futures survey as well as HIV Futures 10. Attitudes towards ART have changed over time in the direction that would be expected as ART has become simpler to use with fewer side effects. However, a greater proportion of participants in HIV Futures 10 agreed that the side effects outweigh the benefits compared to in HIV Futures 9 (2018-20), even though fewer participants believed ART was harmful.

Figure 21: Attitudes toward ART
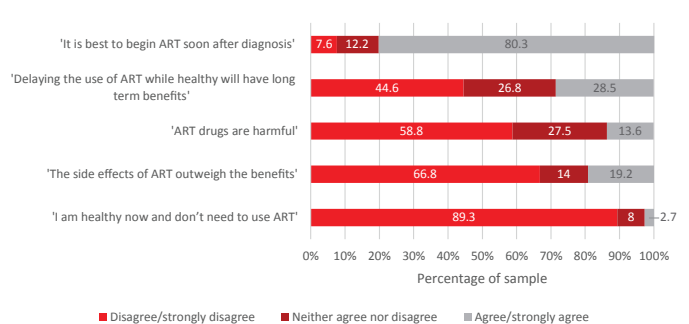
Table 13: Attitudes toward ART, over time

Percentage of participants who agree/strongly agree with the following statement*	HIV Futures 1	HIV Futures 4	HIV Futures 7	HIV Futures 8	HIV Futures 9	HIV Futures 10
	1997	2003	2012-13	2015-16	2018-19	2021-22
'I am healthy now and don't need to use ART'	22%	26%	14%	6%	2%	2.7%
'The side effects of ART outweigh the benefits'	Not asked	29%	32%	29%	13%	19.2%
'ART drugs are harmful'	32%	45%	29%	27%	18%	13.6%
'Delaying the use of ART while healthy will have long-term benefits'	Not asked			31%	24%	28.5%
'It is best to begin ART soon after diagnosis'	Not asked			87%	80%	80.3%

* Note this excludes the 'I don't know' option

HIV-related healthcare

In Australia, a limited number of doctors can prescribe ART. For some participants, this was their regular GP (34.4%, n = 254), but for the majority (61.7%, n = 456) it was an HIV specialist or doctor at a sexual health centre (Table 14).

The majority of participants (88.1%, n = 651) indicated they were satisfied or very satisfied with the clinical care they received for HIV, with just 5.1% (n = 38) indicating they were not satisfied.

The majority of participants (80.8%, n = 584) indicated that they were bulk-billed (not charged a co-payment) for HIV-related clinical appointments. However, more than one in 10 (12.8%, n = 94) were not bulk-billed, paying out-of-pocket costs to see their HIV doctor. A further 6.4% (n = 47) indicated that this question was not applicable to them.

The majority of participants saw their HIV doctor every 3 or 6 months (82.9%, n = 609), which was approximately proportionate with participants in HIV Futures 9 (2018-19). There were 39 participants (5.3%) who saw their doctor for HIV treatment once per month or more frequently (Figure 22).

Table 14: Source of main HIV-related treatment

Source of HIV treatment/care	Number of participants, n (%)
I do not see a doctor for HIV-related treatment	7 (< 1)
The same doctor I see for general medical treatment	254 (34.4)
HIV specialist	265 (35.9)
Doctor at sexual health centre	191 (25.8)
HIV GP/s100 prescriber who is not my usual GP	7 (< 1)
Other doctor	3 (< 1)
Other	12 (1.6)

Figure 22: Frequency of visits to doctor for HIV-related treatment*
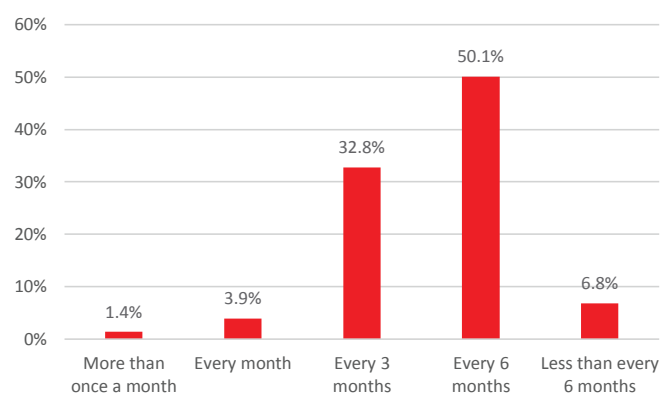
* Note this excludes 'other' and 'not applicable' responses (n = 37)

Participants were asked to indicate the approximate number of kilometres they had to travel to visit their doctor for HIV-related care. The majority (46.5%, n = 343) travelled less than 10 kilometres. However, this pattern understandably differed according to the type of area in which participants resided. Among those living in regional/rural areas, 62.2% (n = 46) travelled more than 50 kilometres to visit their HIV doctor (Figure 23), an increase from 44% in HIV Futures 9 (2018-19).

Figure 23: Distance travelled to visit doctor for HIV-related treatment
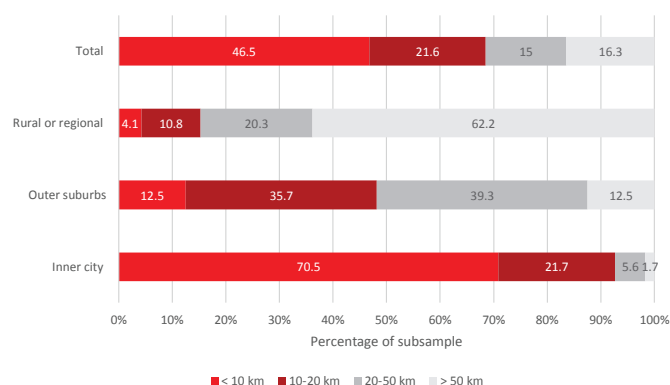
COVID-19 and telehealth

Since HIV Futures 9 (2018-19), the COVID-19 pandemic has had a marked impact on the health and wellbeing of people across the globe, including PLHIV. In HIV Futures 10, we asked a series of questions relating to COVID-19, including about its impact on health service access, the use of telehealth, and intentions to get vaccinated against the disease.

Participants were asked if they had contracted COVID-19 in 2020 or 2021. Of the total sample, 4.7% (n = 35) had contracted the disease. Of this subsample, 5.7% (n = 2) reported being hospitalised during their illness period. It is worth noting that the low proportion of COVID-19 diagnoses is likely to be because the largest outbreaks did not occur in Australia until 2022.

An overwhelming majority of participants (91%, n = 677) reported being vaccinated against COVID-19, while a further 5.9% (n = 44) indicated that they had not yet been vaccinated against COVID-19 but intended to.

With respect to health service access, a substantial proportion of participants (41.9%, n = 310) reported that they accessed health services less often than they felt was needed due to the COVID-19 pandemic.

A majority of participants (70.8%, n = 526) reported using telehealth services in the past (either before, during or after the COVID-19 pandemic; 60.8% via telephone and 10% via video). Of these participants, 91% (n = 477) reported having utilised telehealth for the first time during the COVID-19 pandemic.

Most participants (71.5%, n = 363) who had used telehealth reported being 'satisfied' or 'very satisfied' with the quality of care they had received (Figure 24), while approximately one in 10 participants (9.8%, n = 50) reported being 'unsatisfied' or 'very unsatisfied' with their telehealth care.

Figure 24: Satisfaction with quality of care via telehealth
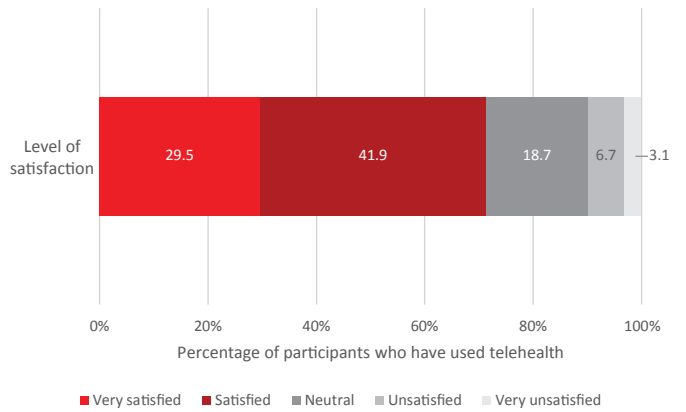
Most participants (78.3%, n = 408) indicated that they would like to continue using telehealth in combination with face-to-face appointments, while 1.7% (n = 9) indicated they would like to exclusively use telehealth services, and 20% (n = 104) indicated they did not wish to use telehealth appointments at all.

5. HEALTH AND WELLBEING

Living with HIV can create challenges that affect physical or mental health. Previous HIV Futures studies have shown that HIV-related stigma, loneliness, social isolation and poverty are associated with poorer health among PLHIV.

Given that managing health is an important component of living well, it is fundamental to the wellbeing of PLHIV. As discussed in the previous chapter, the COVID-19 pandemic, commencing in 2020, markedly decreased participants' access to health services. It is therefore especially pertinent that we continue to monitor the broader health and wellbeing of PLHIV.

This chapter builds on the earlier 'Quality of life' chapter – that looked at overall wellbeing – by focussing on more specific health issues including: general physical and mental health, sexual health and viral hepatitis, and chronic health conditions.

General health

General health was measured using the SF-36 general health (GH) subscale, a validated and commonly used self-report measure that asks people to evaluate their overall health relative to that of other people. The average score for the SF-36 GH subscale was 55.1 out of 100, which is comparable with that of Australian population-based studies (Hawthorne et al., 2007).

SF-36 GH scores varied by age, with participants aged 35-49 reporting the best general health, and participants aged 50-64 reporting the worst general health (see Figure 25). This represents a shift from the previous HIV Futures study (HIV Futures 9, 2018-19), where individuals under the age of 30 reported the highest general health. However, general health scores for those aged 60-64 and 65+ remained relatively stable.

Figure 25: Average general health scores, by age, HIV Futures 9 (2018-19) and HIV Futures 10 (2021-22)
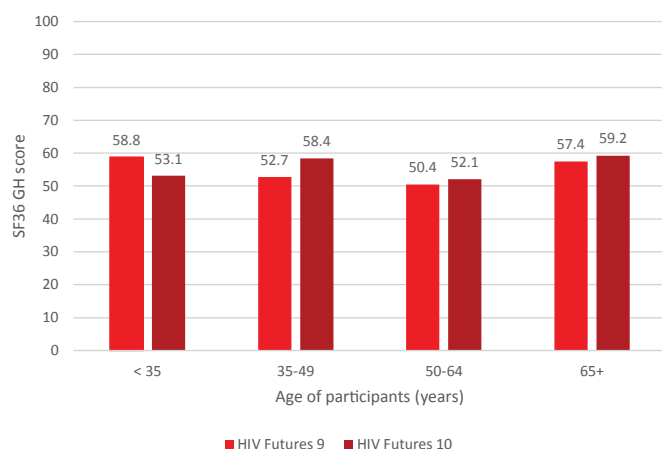
People who had been living with HIV for a longer period of time reported poorer general health scores than those more recently diagnosed. The lowest scores were among those who had been diagnosed in 1998 or earlier (Figure 26).

Figure 26: Average general health scores, by year of HIV diagnosis
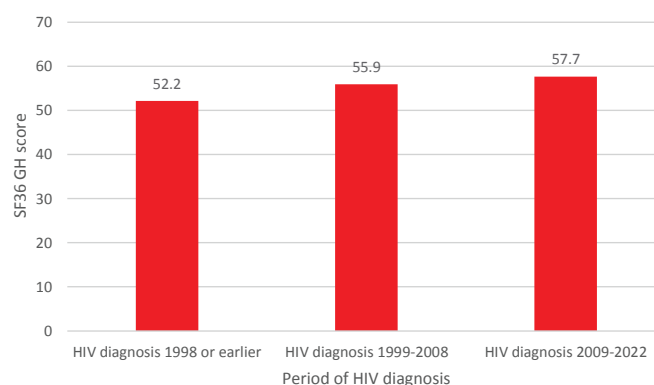
Mental health

Participants were asked to indicate whether they had a 'current' diagnosis of any mental health conditions, or whether they had 'ever' been diagnosed with a mental health condition. Over one in three (35.8%, n = 292) reported that they currently had one or more diagnosed mental health conditions, while almost half (49%, n = 400) reported that they had either a current or previous diagnosis of at least one mental health condition (Table 15). However, the number of participants reporting a current or previous mental illness diagnosis was down 15.2% compared to the HIV Futures 9 sample (2018-19; 64.2%, n = 495).

The most common mental illnesses for which participants had a current diagnosis were:

- Anxiety conditions (22.1%, n = 180)
- Depression (21.4%, n = 175)
- Post-traumatic stress disorder (9.6%, n = 78)

Less prevalent conditions for which participants reported a current diagnosis were:

- Bipolar disorder (2.8%, n = 23)
- Obsessive compulsive disorder (2.0%, n = 16)
- Borderline personality disorder (1.8%, n = 15)

Table 15: Mental health conditions

Mental health condition	Current diagnosis		Lifetime diagnosis	
	Frequency n	Percentage* %	Frequency n	Percentage* %
Depression	175	21.4	270	33.1
Any anxiety condition	180	22.1	248	30.4
Anxiety disorder	*165*	*20.2*	*221*	*27.1*
Panic disorder	*23*	*2.8*	*41*	*5.0*
Social phobia	*39*	*4.8*	*57*	*7.0*
Agoraphobia	*12*	*1.5*	*18*	*2.2*
Post-traumatic stress disorder	78	9.6	96	11.8
Bipolar disorder	23	2.8	35	4.3
Obsessive compulsive disorder	16	2.0	24	2.9
Borderline personality disorder	15	1.8	25	3.1
Mania	4	< 1	12	1.5
Schizophrenia	4	< 1	7	< 1
Other condition	33	4.0	39	4.8

* Note that totals exceed 100% because some participants reported multiple mental illnesses

> *"Sometimes I just can't reach out for help. I have trouble just initiating a phone call when I'm anxious, asking for help adds a layer of complexity I can't get past."*

Rates of mental illness among HIV Futures 10 participants were higher than observed in studies of the general population. In the 2020-21 National Study of Mental Health and Wellbeing (the most recent Australian national mental health survey), 43.7% reported having a mental illness diagnosis within their lifetime, compared to 49% of HIV Futures 10 participants (ABS, 2022). However, this was markedly lower than the 65.3% of reported lifetime mental illness diagnoses in HIV Futures 9 (2018-19). As noted previously, it is likely that we accessed a different cohort of PLHIV with HIV Futures 10 than with HIV Futures 9. This is because lockdowns associated with COVID-19 meant the majority of survey recruitment occurred online rather than through HIV-related services and events. It is possible that people more connected to HIV services are those who have sought help and support due to mental health issues or other concerns.

Multiple mental health conditions

Of the total sample, 19.9% (n = 162) of participants had a *current* diagnosis of two or more mental health conditions. This means that among those with a current diagnosis (n = 297), 57.9% (n = 172) had multiple mental health conditions. The most common comorbidity was anxiety and depression. Of the 180 participants with a current anxiety condition,[1] 58.3% (n = 105) also had a current diagnosis of depression.

Mental health comorbidities were highly correlated with poorer quality of life among HIV Futures 10 participants. As shown in Figure 27, a higher number of diagnosed mental health conditions was associated with poorer quality of life (using the PozQoL average score; see 'Quality of life' chapter for more information).

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1 The phrase 'anxiety condition' includes anyone reporting anxiety disorder, social phobia, panic disorder and/or agoraphobia. It does not include obsessive compulsive disorder or post-traumatic stress disorder, as they are now considered in distinct categories in the official Diagnostic and Statistical Manual of Mental Disorders (DSM−5).

Figure 27: PozQoL score by number of current mental illnesses*
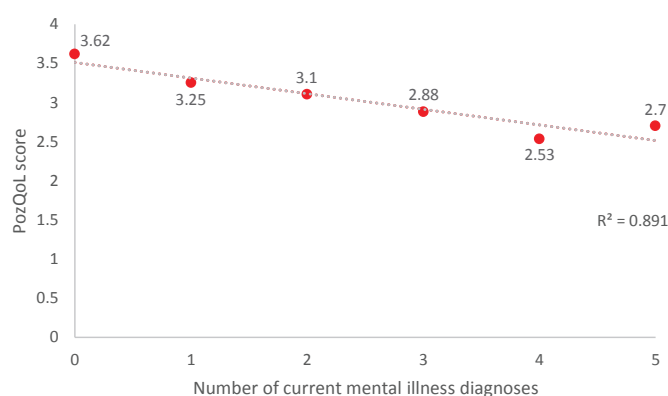
* Note that participants reporting more than five mental health conditions were excluded from the figure below due to small numbers and higher probability of error

Symptoms of mental distress

Participants were asked whether they had experienced symptoms of mental distress, regardless of whether or not they had been clinically diagnosed with a mental disorder. These were: feeling depressed (currently experienced by 17.9% of participants, n = 146); feeling anxious, nervous or tense (also currently experienced by 17.9% of participants, n = 146), and having panic attacks (currently experienced by 8.2% of participants, n = 67) (Table 16).

> *"It's a life-long journey with lots of ups and downs, ebbs and flows!"*

Table 16: Self-reported symptoms of mental distress

Symptom of mental distress	Current experience		Previous experience	
	Frequency n	Percentage %	Frequency n	Percentage %
Feeling depressed	146	17.9	148	18.1
Feeling anxious, nervous or tense	146	17.9	109	13.4
Panic attacks	63	7.7	67	8.2

Treatment for mental health conditions

Of participants who had been diagnosed with a mental health condition, 72.6% (n = 212) reported that they had taken prescription medications to support their mental health in the last 12 months. In the same time-period, 58.7% of these participants (n = 169) received non-pharmaceutical treatment, such as counselling, for a mental health condition. One-fifth (20%, n = 88) of participants who did not have a current mental illness diagnosis received non-pharmaceutical treatment (such as counselling) to support their mental health.

Suicidal ideation and suicide attempts

Participants were asked if they had ever experienced thoughts about suicide, wanting to die, or about ending their life. Of the total sample, 35.9% (n = 293) reported that they had experienced such thoughts, with 28.3% (n = 231) of the total sample reporting experiencing them in the previous 12 months.

Participants were also asked if they had ever attempted suicide or ending their life. Of the total sample, 23.3% (n = 190) reporting having attempted suicide in their lifetime, with 3.8% (n = 31) of the total sample reporting having attempted suicide in the previous 12 months.

Sexual health

Participants were asked to indicate whether they had been tested for, or diagnosed with, any sexually transmissible infections (STIs) other than HIV in the past 12 months. STI screening rates were high, with 81.1% (n = 339) of those who were sexually active having been tested for STIs at least once in the past 12 months (Table 17). Participants who had not been sexually active in the past 6 months were, understandably, less likely to have been tested for STIs. The majority of participants who had multiple sexual partners had been tested for STIs (91.7%, n = 233), with most testing multiple times (64.2% of this group, n = 163).

Table 17: Testing for STIs in the last 12 months, by level of sexual activity in the last 6 months

STI testing	No sex n (%)	One sexual partner n (%)	Multiple sexual partners n (%)	Total n (%)
No STI testing	141 (53.2)	53 (32.3)	21 (8.3)	215 (31.5)
Tested once	77 (29.1)	58 (35.4)	70 (27.6)	205 (30.0)
Tested more than once	41 (15.5)	48 (29.3)	163 (64.2)	252 (36.9)
Unsure	6 (2.3)	5 (3.0)	0 (0)	11 (1.6)
Total	265	164	254	

Less than one-fifth of the sample (18.1%, n = 148) had been diagnosed with an STI in the last 12 months, and two-fifths of this group (39.9%, n = 148) had been diagnosed with more than one STI (see Table 18). This was a marked reduction in STI diagnoses compared to the HIV Futures 9 sample (2018-19), with 28.6% (n = 242) diagnoses in that previous 12 months; likely in part associated with COVID-19-related lockdowns.

Table 18: Number of STIs diagnosed in the last 12 months

Number of STIs	Frequency n	Percentage %
None	668	81.9
One	89	10.9
Two	32	3.9
Three	24	2.9
Four or more	3	< 1

The most commonly diagnosed STIs were chlamydia (9.2%, n = 75), gonorrhoea (6.9%, n = 56) and syphilis (54%, n = 6.6). The prevalence of other STIs is listed in Table 19. Diagnosis of an STI was more common among participants with multiple sexual partners than those with one partner.

Table 19: Number of participants with a STI diagnosed within the past 12 months

STI	Frequency n	Percentage %
Chlamydia	75	9.2
Gonorrhoea	56	6.9
Syphilis	54	6.6
Human papilloma virus (HPV)	20	2.5
Genital herpes	18	2.2
Shigella	2	< 1
Mycoplasma genitalium	6	< 1
Lymphogranuloma venereum	1	< 1
Trichomoniasis	1	< 1
Donovanosis	1	< 1
Other	4	< 1

On average, diagnosis with an STI was more common among younger participants than older participants. However, there was some variability in this. Looking at the most common STIs (gonorrhoea, chlamydia and syphilis), chlamydia and syphilis were more common among younger people, but gonorrhoea was most likely to be reported by people aged 50-64 (Figure 28).

Figure 28: Common STIs, by age (percentage of people in age group)
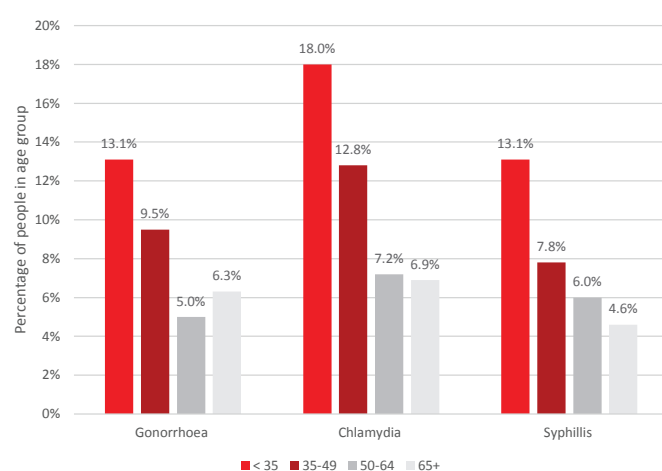
Viral hepatitis

There were 69 participants (9.4%) who indicated they had been diagnosed with chronic hepatitis B, while 33 (4.5%) were unsure. Of the 69 who had been diagnosed with chronic hepatitis B, 65 (94.2%) were aged 50 years or older, likely reflecting vaccination uptake among younger people. It is estimated that up to two-thirds of Australians living with chronic hepatitis B were born overseas (Allard et al., 2015). However, in this sample, the majority of those with chronic hepatitis B were born in Australia (n = 57, 86.4%).

We also asked participants the following: whether they had ever been screened for, or diagnosed with, hepatitis C (HCV); whether they had been diagnosed with chronic HCV; whether they had received interferon-based treatment and/or DAAs; and whether or not treatment was effective.

There were 100 participants (13.7%) who indicated they had never been screened for HCV, and 50 (6.8%) who were unsure if they had ever been screened.

There were 78 (9.6%) participants who indicated they had tested positive for hepatitis C antibodies. Of these:

- 30 (38.5%) indicated they had also been diagnosed with chronic HCV infection (although it is possible that some people were not aware of the difference between testing positive for HCV antibodies and being diagnosed with chronic HCV)
- 27 (36%) had never taken treatment (although a further three individuals did not respond to the treatment question)
- 46 (59%) indicated they had taken DAAs and had now cleared HCV (treatment successful)
- No-one indicated they had taken DAAs and not cleared HCV (treatment unsuccessful)

Other comorbidities

The HIV Futures 10 survey listed 13 chronic illnesses, asking participants to indicate which, if any, they had been diagnosed with. The most common conditions were hypertension (21%, n = 171), asthma (18.8%, n = 153) and cardiovascular disease (14.8%, n = 121) (Table 20).

Table 20: Health conditions other than HIV

Health condition	Frequency n	Percentage* %
No major health condition	184	22.5
Hypertension	171	21.0
Asthma	153	18.8
Cardiovascular disease	121	14.8
Cancer	93	11.4
Osteoarthritis	85	10.4
Diabetes	74	9.1
Osteoporosis	58	7.1
Respiratory disease	52	6.4
Kidney disease	45	5.5
Autoimmune disease	44	5.4
Dementia or related cognitive disorder	7	< 1
Haemophilia	1	< 1
Parkinson's disease	1	< 1
Other	99	12.1

* Note that the total exceeds 100% because some participants reported multiple comorbidities

Of those participants who selected 'Other' (20.4%, n = 134), the most common responses entered were epilepsy (n = 4) or conditions reported elsewhere, including mental health or sexual health diagnoses.

Almost one-third of participants (32%, n = 261) had at least two major health conditions other than HIV (excluding STIs and mental illnesses) and 17.6% (n = 144) had three or more.

Chronic comorbidities accumulated with age. Among participants aged under 35 years, 67.2% (n = 41) had no comorbidities. Among participants over 65, 25.3% (n = 44) had no comorbidities and 62% (n = 54) had three or more (Figure 29). A higher number of comorbidities was correlated with poorer quality of life (PozQoL scores) (r = −0.10, p = 0.006).

Figure 29: Number of chronic comorbidities (other than HIV), by age group
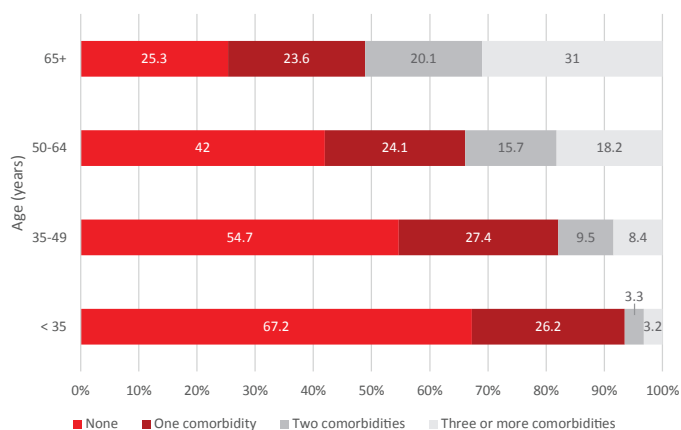
Medication for HIV and comorbidities

HIV Futures 10 participants were asked to report how many pills they took as part of their daily treatment regimen for HIV and other chronic conditions. In total, participants took an average of five pills per day to manage their health conditions, with the range from 0 to 30. The most common conditions for which medication was taken were hypertension (19.5%, n = 159) and cardiovascular conditions (13.1%, n = 107) (Table 21).

Table 21: Conditions for which medication is taken

Condition	Frequency n	Percentage* %
Hypertension	159	19.5
Cardiovascular disease	107	13.1
Asthma	100	12.3
Diabetes	69	8.5
Osteoarthritis	46	5.6
Osteoporosis	36	4.5
Respiratory disease	32	3.9
Autoimmune disease	30	3.7
Kidney disease	18	2.2
Cancer	13	1.6
Dementia or related cognitive disorder	1	< 1
Haemophilia	3	< 1
Parkinson's disease	1	< 1
Other	112	13.7

* Note that multiple responses were permitted, and percentage values show the percentage of responses for each medication category

HIV-associated neurocognitive disorder (HAND)

Previous studies have shown that HIV-associated neurocognitive disorder (HAND) affects around one in five PLHIV in Australia (Carroll & Brew, 2017). In HIV Futures 10, there were 15 participants (2.1%) who had been diagnosed with HAND in the last 2 years, with an additional thirty (4.2%) diagnosed more than 2 years ago. Twenty-six participants (5.4%) had a current diagnosis of HAND.

"I am finding as I get older, the layering of health issues is becoming more complex and my ability to manage conflicting medical issues becomes harder; this really worries me, as HAND makes it harder to manage and I am finding rural GPs less and less competent to manage HIV health."

6. ALCOHOL, TOBACCO AND OTHER DRUG USE

The use of tobacco, alcohol and illicit, or non-prescribed, drugs is generally higher among Australian communities of gay and bisexual men than among the general population, and higher still among gay and bisexual men living with HIV (Hammoud et al., 2017; Lea, 2016). Research on alcohol, tobacco or other drug use among women, heterosexual men, or transgender and gender diverse PLHIV in Australia is more limited.

The potential health and social harms associated with tobacco smoking, high levels of alcohol consumption and recreational drug use are well documented. Unfortunately, the emphasis on 'risks and harms' associated with consumption of alcohol, tobacco or other drugs can conceal the ways that substance use can also be a part of people's sociability or subculture practices, which can play a role in connectedness and wellbeing (Power et al., 2018; Weatherburn P et al., 2017). The focus on risk also stigmatises people who use substances, which potentially makes them more vulnerable to poor wellbeing and isolation (Levy, 2014). It can also create barriers to accessing health services and enacting strategies for safer use, which is against the interests of their wellbeing. It is impossible to untangle harms arising from substance use from the harms arising from the stigma often surrounding substance use.

In this chapter, we report findings from HIV Futures 10 relating to the use of alcohol, tobacco and other drugs. As with previous HIV Futures reports, our aim is not to present a set of 'problems' associated with the use of alcohol, tobacco or other drugs, but to highlight areas where people may be vulnerable to harm or may benefit from seeking more support. This is particularly important in the wake of the COVID-19 pandemic, which in many regions had a marked impact on the way in which people felt and socialised, and in turn, may have impacted the way they used alcohol and other drugs.

Tobacco

The majority of participants (59%, n = 426) had smoked tobacco at some point in their life. However, only 20.8% (n = 150) were current smokers, down from 28.1% in HIV Futures 9 (2018-19). Of these, 74.7% (n = 138) were daily smokers (15.5% of the entire sample). Over one in three (38.2%, n = 276) indicated they were former smokers but did not smoke now. While the overall proportion of current smokers within the HIV Futures has gone down since HIV Futures 9, the proportion of daily smokers has increased.

While the proportion of the HIV Futures sample smoking daily is higher than that of the Australian population as a whole, consistent with Australian population trends, the number of PLHIV reporting that they are daily smokers has decreased over time (see Figure 30) (ABS, 2021).

Figure 30: Daily smoking rates over time, comparing HIV Futures participants with Australian daily smoking rates*
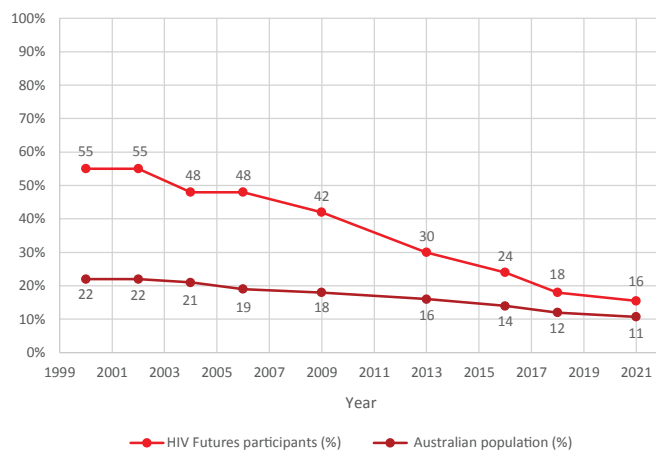
* Smoking rates for the Australian population have been derived from ABS reporting, but should be considered approximate, as the time periods reported on differ slightly from those of HIV Futures reports (ABS, 2021)

People aged 65 years or older were significantly less likely than younger people to be a current smoker ($p < 0.05$) (Figure 31).

Figure 31: Tobacco smoking rates, by age group
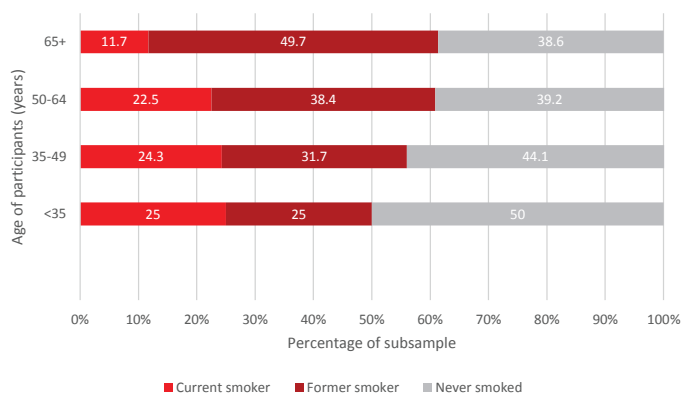
Table 22: Alcohol consumption

How often do you have a drink containing alcohol? n (%)					
Never	127 (17.7)	**How many standard drinks per day? n (%)**		**How often do you consume more than six drinks on any one occasion? n (%)**	
Monthly or less	156 (21.7)	2 or less	292 (57.1)	Never	372 (51.7)
2 to 4 times a month	131 (18.2)	3 or 4	129 (25.2)	Less than monthly	154 (21.4)
2 to 3 times a week	124 (17.2)	5 or 6	61 (11.9)	Monthly	86 (11.9)
4 or more times a week	181 (25.2)	7+	29 (5.6)	At least weekly	108 (16.0)

Alcohol

We asked participants about their consumption of alcohol by use of the AUDIT-C scale, which includes three questions related to frequency and volume of alcohol consumption. Responses to the AUDIT-C are usually considered as a total score indicating whether an individual is at high or low risk of alcohol related harm (Royal Australian College of General Practitioners, 2016). However, for this report we present responses to each question separately as this is more illustrative of the dynamics of alcohol consumption across a group of people than a clinical score.

The majority of participants in HIV Futures 10 consumed some alcohol (82.3%, n = 592). This is marginally higher than the overall Australian population, for which recent data shows 79% of the adult population had consumed alcohol in the past 12 months (AIHW, 2022). There was 17.7% of participants (n = 127) who reported that they did not drink at all, which is a slight increase in non-drinkers compared to HIV Futures 9 (2018-19; 14.6%, n = 110).

Of those HIV Futures 10 participants who drank alcohol, the majority drank moderately, with 57.1% (n = 292) indicating they consumed no more than two standard drinks per day (Table 22).

Participants were asked how often they consumed more than six drinks on one occasion, as this is considered a measure of higher single-instance risky alcohol consumption. Of those who consumed alcohol, more than half (51.7%, n = 372) indicated they 'never' consumed more than six drinks, and 21.4% (n = 154) consumed six or more drinks 'less than monthly'. There were 220 participants (11.9%) who consumed six or more drinks at least monthly: 11.9% (n = 86) monthly, 10.3% (n = 74) weekly, and 4.7% (n = 34) daily.

Use of illicit drugs or non-prescribed pharmaceuticals

Participants were asked which drugs they had used for 'non-medical purposes' in the past 12 months and how frequently (Table 23). Painkillers/analgesics were most likely to be used by participants at least weekly (26.2%, n = 186), followed by sleeping pills/tranquilisers (14.6%, n = 104), and cannabis (13.8%, n = 98). Painkillers and amyl nitrate (poppers) were the most common drugs used at least 'occasionally', with 67.2% indicating they use painkillers at least occasionally, and 39.9% using poppers at least occasionally.

Table 23: Frequency of drug use for recreational purposes, in the past 12 months

Type of drug	At least weekly %	Once per month %	Occasionally %	Never %
Painkillers/analgesics	26.2	16.3	24.6	32.8
Cannabis	13.8	3.2	16.4	66.5
Tranquilisers/sleeping pills	14.6	6.2	14.3	65.0
Amyl nitrate (poppers)	11.0	8.6	20.3	60.1
Crystal methamphetamine	2.8	3.0	12.7	81.5
Steroids	< 1	< 1	2.8	95.9
GHB	1.4	< 1	7.3	91.1
Cocaine	< 1	1.6	10.7	87.4
Other meth/amphetamine (e.g. speed)	< 1	< 1	5.7	93.3
Ketamine	< 1	0	7.9	91.7
Heroin	< 1	< 1	< 1	99.2
Other inhalants	< 1	0	< 1	99.3
MDMA/ecstasy	< 1	< 1	13.9	85.3
Hallucinogens	< 1	< 1	7.5	91.9
Synthetic cannabis	< 1	0	< 1	99.3

Concerns about drug use

Participants who indicated they had used at least one form of drug for non-medical purposes in the past 12 months were asked whether they ever worried about their drug use. The majority (66.2%, n = 186) did not agree that they were worried about their drug use. However, 25.3% (n = 71) agreed or strongly agreed that they were worried about their drug use. Around one in four participants (18.2%, n = 128) indicated that they had missed at least one dose of ART due to alcohol or drug use.

Injecting drug use

Participants were asked if they had injected drugs for recreational (non-prescribed) use in the past 12 months, and 11.9% (n = 84) indicated that they had. A further 16.4% (n = 116) indicated they had injected drugs for recreational use in the past but not within the past 12 months. People who had injected drugs were asked if they had experienced stigma or discrimination as a result of their injecting drug use. Over a quarter (29.0%, n = 20) indicated that they had experienced stigma or discrimination at least sometimes.

7. STIGMA AND DISCRIMINATION

Despite significant advances in treatment and prevention options, HIV continues to be highly stigmatised (Brown et al., 2017). For many PLHIV, the experience of stigma and fear of discrimination can profoundly affect confidence and sense of self, leading to social isolation, poorer mental health and a decreased wellbeing (Earnshaw et al., 2013; Lyons et al., 2016).

Negative responses to HIV disclosure have also been associated with HIV-related stigma, psychological distress, and reduced social support and health satisfaction (Cama et al., 2020). HIV-related discrimination can also affect people's lives in material or financial terms including loss of employment or housing discrimination. People may also struggle to find supportive services or healthcare providers (Friedland et al., 2018; Grierson et al., 2013). While this experience is not universal, with many PLHIV receiving strong support from family and formal services, HIV-related stigma continues to detract from good quality of life for many PLHIV (Earnshaw et al., 2015).

In this section, we look at indicators of stigma and discrimination and explore differences in these variables for people of different genders and sexualities. Stigma was measured using items developed by the Centre for Social Research in Health (UNSW Sydney) for the Australian Stigma Indicators Monitoring Project (Broady, 2019).

Experiences of stigma or discrimination

Participants were asked to describe the extent to which they had experienced stigma or discrimination related to their HIV in the last 12 months (Figure 32). More than one in three (36.6%, n = 259) reported experiencing some form of stigma, although the majority of these participants (32.8%, n = 232) indicated that this occurred rarely or sometimes. There were 27 participants (3.8%) who indicated they experienced HIV-related stigma often or always.

> *"Stigma remains the biggest problem. I never disclose my status and I'm glad to have made that decision. It feels painful when I hear someone gossiping or 'warning me' about a person's status.."*

Figure 32: Experience of stigma or discrimination in relation to HIV status (in the last 12 months)
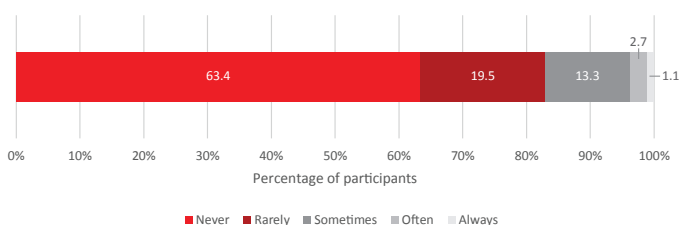
Participants were asked whether they had been treated negatively or differently by healthcare workers because of their HIV status. Just over two in three (70.2%, n = 495) reported that they had not. However, 29.8% (n = 210) indicated they had been treated differently in some instances (Figure 33).

Figure 33: Percentage of participants treated negatively or differently by healthcare workers because of their HIV status (in the last 12 months)
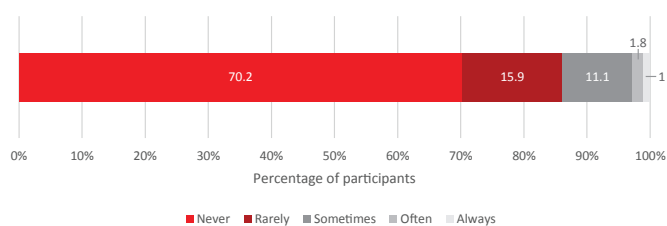
Participants were asked to what extent people did not want to have sex or an intimate relationship because of their HIV status. Responses were mixed: 18.4% (n = 135) indicated this occurred often or always, while 23.0% (n = 169) indicated this never occurred. There were 20% (n = 147) who selected not applicable with comments suggesting that this was because people were not seeking sex or intimate relationships (Figure 34).

Figure 34: Participants reporting that people didn't want to have sex or an intimate relationship with them because of their HIV (in the last 12 months)
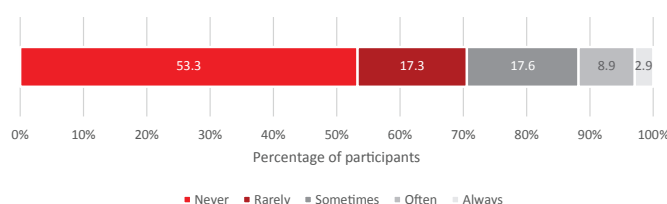
"The stigma and aversion to HIV in regional Australia for sexual encounters is tough."

The most common experience of discrimination was in insurance, with 4.0% (n = 28) of participants reporting that they always experienced discrimination and an additional 7.2% (n = 51) reporting that they sometimes or often experienced discrimination from the insurance sector in the last 12 months. 5.7% (n = 40) reported experiencing work-based discrimination sometimes, often or always (see Table 24).

"I recently applied for total and permanent disability insurance and was unable to get it because of my HIV+. My life insurance premium was doubled because of my HIV+. How this has anything to do with HIV is beyond me."

Table 24: Experiences of discrimination due to HIV status (in the last 12 months)*

Area of discrimination	Never n (%)	Rarely n (%)	Sometimes n (%)	Often n (%)	Always n (%)
Accommodation	565 (80.4)	18 (2.6)	9 (1.3)	3 (< 1)	5 (< 1)
Health services	536 (75.8)	70 (9.9)	52 (7.4)	10 (1.4)	5 (<1)
Employment/ work	476 (67.8)	27 (3.8)	30 (4.3)	2 (<1)	8 (1.0)
Insurance	431 (61.4)	23 (3.3)	36 (5.1)	15 (2.1)	28 (4.0)

*Note that participants responding with 'not applicable' have been excluded, so these figures show the percentage of those who accessed each of these services

Emotional impact of HIV

Participants were asked whether they spent a lot of time thinking about their HIV status and whether this often crossed their mind for no reason (Figure 35). About one in five (19.2%, n = 136) agreed or strongly agreed with the statement 'I spend a lot of time thinking about my HIV'. Agreement with the statement 'My HIV status often crosses my mind for no reason' was more common (36.5%, n = 266).

"I just get on with my life and don't let my HIV status determine how I live it. It's just a part of me and not the whole of me."

Figure 35: Responses to statements about living with HIV
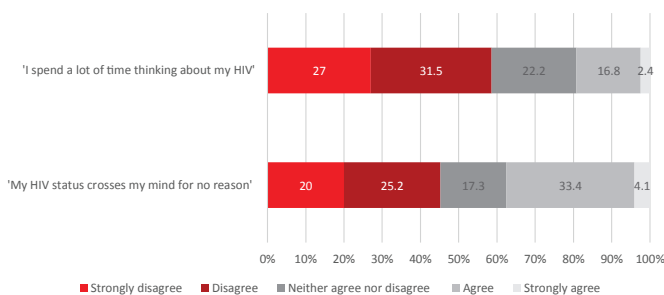
Disclosure of HIV status

It is difficult to measure experiences of HIV disclosure in a quantitative survey format, as most people are open about their status in some areas of life but not others. There are also many reasons why people may choose to disclose, or not disclose, their HIV status. However, in this survey we asked participants to report on the extent to which people around them knew about their HIV status. This measure aims to allow a general assessment of how open people are about their HIV status in their everyday lives. As shown in Table 25, one in four (25.2%, n = 178) indicated almost nobody knows about my HIV, while over one in four (28.7%, n = 203) reported that most of the time, people around me are not aware of my HIV.

"I don't tell anyone, because I'm worried I'd lose my job. And I don't access HIV services, as I worry that people in those organisations will talk to other people and that could get back to my family or, worse, my employer."

Table 25: Openness around HIV status

Statement about disclosure of HIV status	Frequency n	Percentage %
'Almost nobody knows about my HIV'	178	25.2
'Most of the time, people around me are not aware of my HIV'	203	28.7
'About half the time, people around me are not aware of my HIV'	115	16.3
'Most of the time, people around me know about my HIV'	115	16.3
'Just about everybody knows about my HIV'	96	13.6
Total	707	100

Gender and sexual diversity and experiences of stigma and discrimination

An individual's gender or sexual identity may shape the ways in which they experience HIV-related stigma or discrimination, or make them more or less vulnerable to stigma and discrimination. To explore this, we looked at experiences of stigma and discrimination in the past 12 months in relation to gender. Transgender, non-binary and gender fluid people were more likely than cisgender participants to report that they had 'never' experienced HIV related stigma or discrimination, although numbers in this group are small so we cannot determine if this difference is statistically significant (Figure 36). Non-binary and gender fluid people were the most likely to report that they were 'sometimes', 'often' or 'always' treated differently by healthcare workers due to their HIV status (31.3%, n = 3) (Figure 37).

Figure 36: Experienced HIV-related stigma or discrimination in the last 12 months, by gender
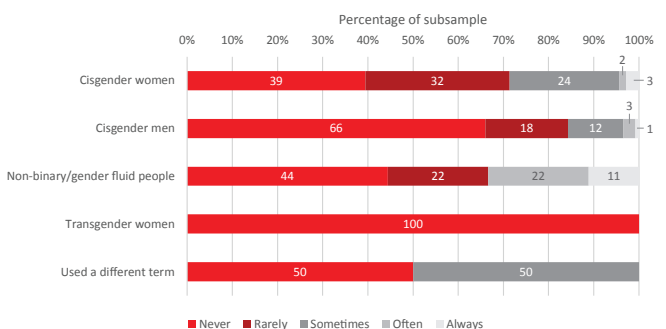
Figure 37: Health workers treated differently because of HIV status in past 12 months, by gender
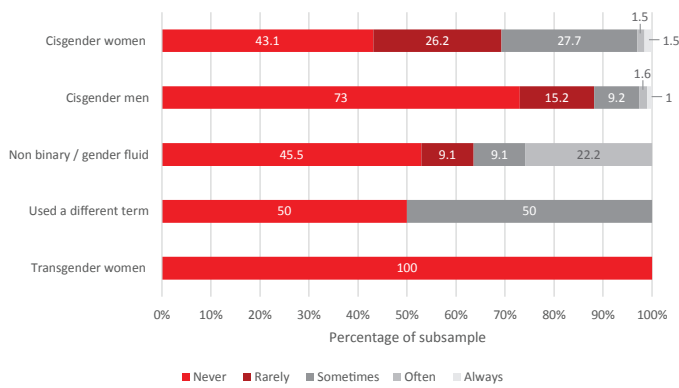
To explore the impact of sexual identity on experiences of HIV-related stigma and discrimination, we looked at the sexuality of cisgender men in relation to stigma and discrimination. Bisexual men were less likely than gay or heterosexual men to report that they 'never' or 'rarely' experienced discrimination and the most likely to report that they 'always' did (Figure 38). Bisexual men were also more likely than gay men to report that healthcare workers treated them differently due to HIV (Figure 39). However, due to the small numbers, we cannot determine if these differences are statistically significant.

Figure 38: Experienced stigma or discrimination in the last 12 months in relation to HIV status, by sexuality of cisgender men
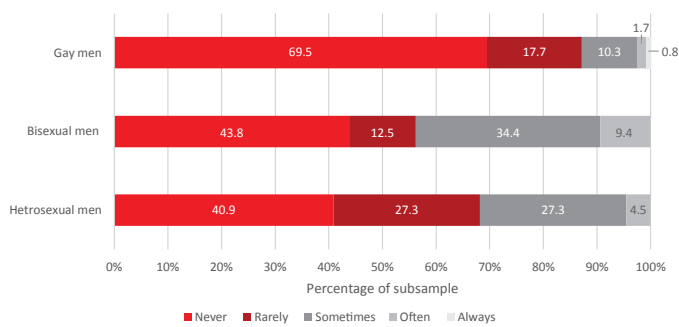
Figure 39: Health workers treated differently because of HIV-status in past 12 months, by sexuality of cisgender men
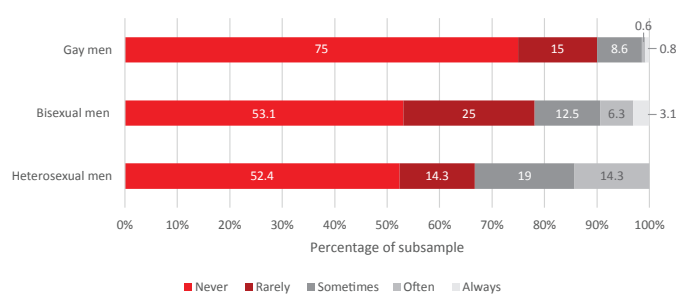
8. SOCIAL CONNECTION, PEER SUPPORT AND SERVICE USE

Access to social networks, friendship and support play an important role in maintaining people's health and wellbeing (Hawkley & Cacioppo, 2013). More specifically, peer-based community services for PLHIV have played an important role in the response to HIV in Australia in past decades and are likely to maintain a central role in supporting good quality of life among PLHIV.

Formal peer-based services for PLHIV are known to be effective in supporting resilience and coping skills and improving clinical-care outcomes (Peterson et al., 2012; Prestage et al., 2016). Peer-based programs continue to evolve as the experiences and needs of PLHIV evolve. The COVID-19 pandemic created or compounded challenging social circumstances for many, with government-mandated social isolation in effect across many regions in Australia. Given this, the nature of and need for social connection, peer support and use of services may have changed since HIV Futures 9 (2018-19), and for some, be more pertinent than ever.

In this chapter we look at social connectedness among HIV Futures 10 participants, and report findings related to engagement in PLHIV peer support networks and programs.

"I require connection and support."

Sex and relationships

We asked participants about their current relationship status and sexual relationships in the past 12 months. Most participants were single (52.4%, n = 370), while 34.6% (n = 244) were in a relationship with one partner (Table 26). It is worth noting that 288 indicated that they cohabit with a partner or spouse, a discrepancy that occurred due to a higher non-response rate to questions about sex and relationships.

Of those participants in a regular relationship, 63.6% (n = 210) reported that their (primary) partner was HIV-negative at the time of their most recent test, 30.9% (n = 102) reported that their partner was HIV-positive and 3.9% (n = 13) didn't know.

Table 26: Current relationship status

Relationship status	Frequency n	Percentage %
Single (not in a relationship)	370	52.4
In a regular relationship with one partner	244	34.6
In a regular relationship with more than one partner	12	1.7
In a regular relationship with a primary partner plus other partners	59	8.4
Other	21	3.0
Total	706	100

About two in five participants (38.8%, n = 274) reported that they had

not been sexually active in the past 6 months (Table 27). Participants aged under 50 years were more likely to have been sexually active than older people, and also more likely to have more than one sexual partner (Figure 40).

"The stigma and lack of awareness about U=U in the heterosexual dating scene is alarming."

Table 27: Sexual partners in the last 6 months

Category of sexual partners	Frequency n	Percentage %
No sex	274	38.8
One regular partner only	169	23.9
More than one regular partner	39	5.5
Regular partner/s plus casual partners	113	16.0
Casual partner/s only	107	15.1
Other	5	< 1
Total	707	100

Figure 40: Sexual partners in the last 6 months, by age
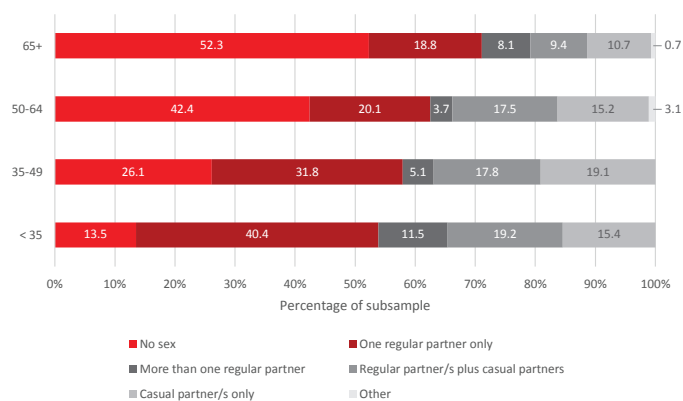
Social connectedness

Participants in HIV Futures 10 were asked to respond to 10 questions about the extent to which they feel connected to, and supported by, others (e.g. 'I seem to have a lot of friends', 'I have no-one to lean on in times of trouble', 'I often feel lonely'). This is a general measure of social connection that has been used in Australian population-based surveys (Wooden, 2001). Responses to each question are recorded on a 7-point scale (1 = 'strongly disagree' to 7 = 'strongly agree'). A scale average was calculated to create a score ranging from 1-7, with higher scores indicating greater perceived connectedness.

> "I feel privileged that I am surrounded by family, friends and a loving partner who support me in every aspect of my life."

The average social connection score for HIV Futures 10 was 4.9 (SD = 1.4). We looked at average scores across a range of demographic and social characteristics to identify factors that may support or limit social connectedness. Results are presented in Table 28. There were no differences in relation to age and gender, but among cisgender men, gay men reported significantly higher levels of connection than both bisexual and heterosexual men. Other factors associated with higher levels of social connectedness mirrored those associated with better quality of life, including:

- Higher income levels
- No recent experiences of financial stress
- Living with others, including a partner or spouse

Table 28: Average social connection scores according to demographic and social variables

Demographic and social variables	Social connection score mean*	p value
Age		
< 35	4.8	
35-49	4.9	**p = 0.689**, no sig differences
50-64	4.9	
65+	5.0	
Gender		
Men	4.9	
Women	4.9	**p = 0.231**, no sig differences
Non-binary and gender fluid	4.1	
Sexuality**		
Gay men	5.0	
Bisexual men	4.2	**p < 0.001**, gay men sig higher than both bisexual men and heterosexual men
Heterosexual men	4.2	
Residential location		
Capital city/inner suburban	5.0	
Outer suburban	4.6	**p < 0.05**, capital city/inner suburban sig higher than outer suburban
Regional/rural	4.9	
Education level		
Up to Year 12	4.7	
TAFE/diploma/trade	4.8	**p < 0.01**, tertiary sig higher than up to Year 12 and TAFE/diploma/trade
Tertiary (undergrad/postgrad)	5.1	
Employment status		
Not currently in paid work***	4.7	
Part-time or casual work	5.0	**p < 0.01**, full-time work sig higher than not currently in paid work
Full-time work	5.1	
Financial stress (in past 2 years)		
Experienced financial stress	4.0	**p < 0.001**
No financial stress	5.1	
Household annual income		
< $30,000	4.5	
$30,000 - $79,999	4.8	**p < 0.001**, $125,000+ category sig higher than < $30,000 and $30,000 - $79,999 category, and $80,000 - $124,999 category sig higher than < $30,000 and $30,000 - $79,999 category
$80,000 - $124,000	5.2	
$125,000+	5.4	
Cohabiting with partner/spouse		
Live with partner	5.3	**p < 0.001**
Do not live with partner	4.7	
Household composition		
Single-person household	4.7	**p < 0.01**
Multiple-person household	5.0	

* Scores range from 1-7, with higher scores indicating greater social connectedness
** Small sample size in other groups mean it is only possible to compare variables according to sexuality of cisgender men
*** Individuals identifying as 'student', 'home duties', 'not working/retired', and 'unemployed' were re-categorised as 'not currently in paid work'

Connecting with other PLHIV

We asked a series of questions about whether, and how, participants connect with other PLHIV and whether this is important to them. Overall, we found that a majority of participants had informal connections with other PLHIV, with 57.7% (n = 407) indicating they had at least one other PLHIV to talk to about HIV – although it is notable that two in five participants (42.3%, n = 298) indicated they did not. Participants also engaged with other PLHIV through formal services or networks, with 25.1% (n = 176) indicating they had accessed advice or support from a peer worker at least once in the past 12 months, and 21.5% (n = 150) indicating they had participated in an online network for PLHIV (Figure 41).

> *"An important part of my connection with other PLHIV has been the role modelling I have received in regard to living openly and without shame. Seeing others live openly and strongly enabled me to realise that I could do it too. Living openly helped me reduce the isolation and fear I experienced for a long time."*

Figure 41: Peer-based sources of information and support about HIV
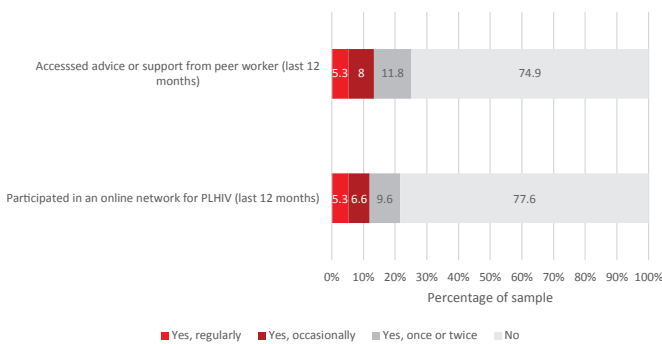
> *"It's a lonely road, despite the services available. I don't want to think about my status more than I have to, so I don't want to be surrounded by people from HIV communities. No-one knows how to deal with HIV in Australia other than by talking about it too much, ignoring it, going over the top in their pity, or cutting me off altogether."*

Friendship and community connection

We also asked participants how many of their friends live with HIV and how much time they spent with other PLHIV. Around two in five spent limited time with other PLHIV, specifically:

- 30.5%, (n = 212) indicated none of their friends were living with HIV
- 46.5% (n = 323) indicated that they did not spend any time with other PLHIV

Connecting with other PLHIV has different levels of importance to individuals. For some people, spending time with other PLHIV is important, while for others it is not something they feel they need. We asked HIV Futures 10 participants a series of questions about whether knowing other PLHIV was important to them and whether they have an interest in, or feel part of, a community of PLHIV. Responses are shown in in Figure 42. While most participants indicated that connecting with other PLHIV was important, these findings suggest that some people found this difficult, specifically:

- The majority of participants (56.5%, n = 392) agreed that knowing other PLHIV was important to them, and nearly half were interested in being part of an HIV community (45.4%, n = 314, disagreed

with the statement 'I have no interest in being part of the HIV community').

- One in four indicated that they felt part of a community of PLHIV (26.6%, n = 275), while the rest of the sample did not feel they were or were more ambivalent (neither agreeing nor disagreeing with the statement).
- One in four (24.2%, n = 168) indicated they felt isolated or cut off from other PLHIV.
- One in three (34.6%, n = 239) felt that it was hard to meet other PLHIV, although responses to this statement were mixed, with about the same number indicating they felt it was easy to meet other PLHIV (28.1%, n = 194).

> *"It is the most fortunate place in the world that I know of to be living with HIV. Free and fully community supported. It's a privilege I don't take for granted."*

Figure 42: Responses to statements about feelings on HIV community connection
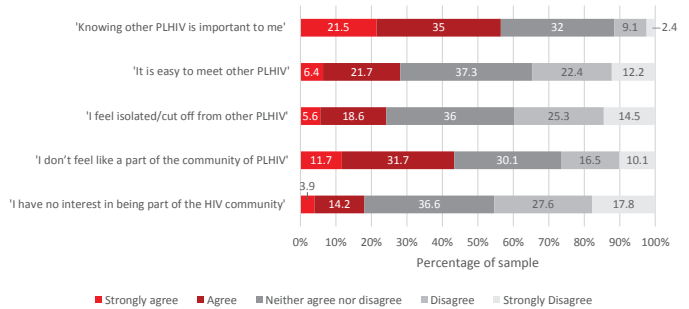
Peer-based programs and services

> *"Once you find the right organisation, everything else pulls together."*

As noted, 25.1% (n = 176) indicated they had accessed advice or support from a peer worker at least once in the past 12 months. About one in 10 participants (9.7%, n = 68) had used a peer navigator program, and 13.3% (n = 93) had participated in a peer education or support workshop.

People who had been diagnosed with HIV in the past 5 years were more likely to have accessed peer navigator programs: 21.8% (n = 31) compared to 10.3% (n = 46) of those diagnosed more than 5 years ago. However, in terms of the total number of people using peer navigator services, the majority had been diagnosed more than 5 years ago.

Similarly, people who had been diagnosed with HIV in the past 5 years were less likely to have accessed peer education/support programs or workshops: 12.3% (n = 64) compared to 16.4% (n = 29) of people who had been diagnosed more than 5 years ago. However, again, the majority of people accessing these programs had been diagnosed more than 5 years ago.

We asked participants if they felt community-based services played an important role in connecting PLHIV with each other, and the majority (56.5%, n = 392) agreed that they did.

Online forums for PLHIV

Participation in online forums or networks for PLHIV was less common than use of face-to-face services, with 21.5% (n = 150) indicating they had used these in the past 12 months. PLHIV were connected to a range of online peer support forums and networks, with 47 people indicating that they were a member of The Institute of Many (TIM; a large online group for PLHIV). Other web-based PLHIV networks with which participants were connected included: ACON, AFAO, Ageing Well with HIV, BlaQ Aboriginal Corporation, the Burnet Institute, the Centre for Social Research in Health, CHINWAG: Positive Connection (a NAPWHA program), [+Connect] (part of Positive Life NSW), Hivsters, ICWAP (international Community of Women Living with HIV Asia & Pacific), the Kirby Institute, La Trobe University, Living Positive Victoria, NAPWHA, NAPWHA Femfatales (National Network of Women Living with HIV), the Positive Asian Network Australia (PANA), the Positive Leadership Development Institute (PLDI), Positive Life NSW, Positive Life SA, Positive Speakers Bureau, Positive Women Victoria, Pozhet, QLife, Queensland Council for LGBTI Health (formerly QuAC), Queensland Positive People, TIM Women, the University of Sydney, the Victorian AIDS Council (now Thorne Harbour Health), and Visual AIDS.

> *"I was previously very isolated and lonely until 2017 when I was introduced to Pozhet and attended two retreats and other face-to-face forums and workshops (and then online since COVID). Having connections with other HIV hetero people has made a massive difference for me."*

We asked participants if connecting online with other PLHIV was a source of support for them, and 30.0% (n = 207) indicated that it was (Figure 43). Of those participants who were a member of The Institute of Many, 78.8% (n = 37) indicated that connecting online was a source of support.

Figure 43: Responses to the statement 'Connecting online with other PLHIV is a source of support for me'
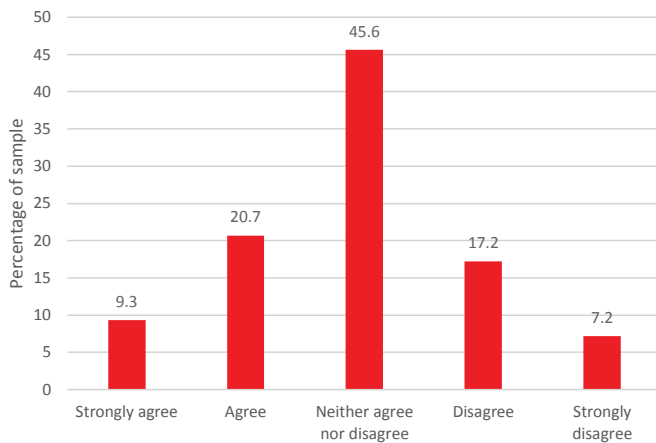
HIV support services

Participants were asked to indicate which formal services they had utilised in the past 12 months and the place at which they accessed the service. The number of people who indicated they used each service is presented in Table 29. Counselling/psychological services was the type of service most commonly accessed (Figure 44).

> *"Lucky that we have such great services in Australia."*

Table 29: Type of HIV service accessed in the past 12 months

Type of HIV service	Participants n (%)*
Counselling/psychological treatment	100 (12.3)
Treatment advice or information	84 (10.3)
Social work services	47 (5.8)
Legal assistance or advice	38 (4.7)
Financial assistance or advice	28 (3.4)
Housing support	26 (3.2)
HIV Work Ready**	3 (< 1)

* Note that percentages of the total sample should be considered approximate as they do not account for the number who missed these questions (due to the way in which data was collected for these items)
** HIV Work Ready is now the Positive Life NSW Employment and Vocational support program

Figure 44: Type of formal HIV service accessed in the past 12 months (% of participants who used each type of service)
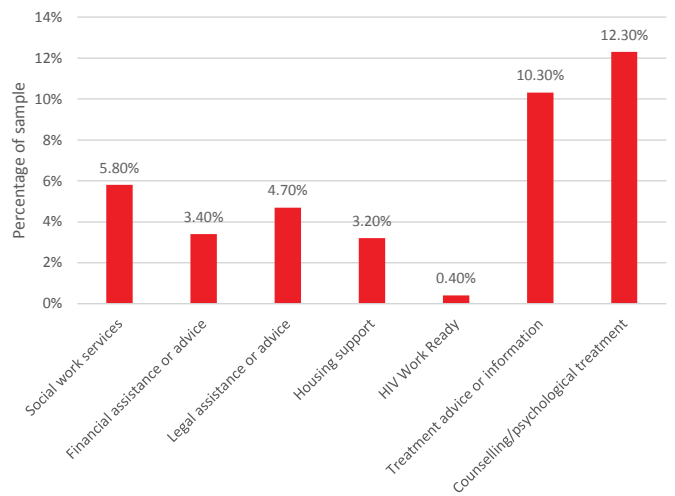
> *"Deconstructing my own shame and stigma is a process made easier with well-run/organised support services. If only there were more."*

9. WOMEN LIVING WITH HIV

In Australia, women living with HIV comprise around 10% of the PLHIV population. Therefore, the community of women living with HIV is much smaller than that of gay men and is highly culturally diverse, with many of these women having been born outside of Australia.

The small number of women living with HIV in Australia means there is currently minimal research on the needs of women living with HIV and only a small number of PLHIV programs and services specifically for women. However, it is important that we pay attention to the unique experiences of women living with HIV, who are likely to encounter unique challenges related to managing HIV in their everyday life, including experiences of sex, relationships, work, pregnancy and mothering.

The experiences of women who participated in HIV Futures 10 are included throughout this report and highlighted separately where the differences to men or people of other genders were of note. This section focuses specifically on the demographics, financial security and health of women living with HIV. Unless otherwise specified, the word 'women' refers to both cisgender and transgender women.

Demographic characteristics

There were 77 women who participated in HIV Futures 10 (9.6% of the cohort), including 72 cisgender women and five transgender women. The demographic characteristics of these women are presented in Table 30.

The average age of women participants was 48 years (7 years less than the average age for men in the study), and ages ranged from 28 to 72 years. The majority of women participants (37.7%, n = 29) were aged 50 to 64 years.

As with the sample overall, response numbers were highest from the most populous states: New South Wales (35.1%, n = 27) and Victoria (33.8%, n = 26). Most women lived either in the inner city or the outer suburbs (71.5 %, n = 55), although about one in four (28.6%, n = 22) lived in a regional or rural area.

Six women indicated they were Aboriginal. Around two-thirds of women (58.1%, n = 43) were born in Australia, three (4.1%) were born in Asian countries, nine in European countries (12.2%), 10 in African countries (13.5%) and seven in Pacific countries (9.5%) (Table 30). Most (77.9%, n = 60) spoke English as a first language.

Most women were heterosexual (79.2%, n = 61), while 13.0% (n = 10) identified as bisexual or pansexual. The sexual orientations of transgender women were more diverse than those of cisgender women (Table 30).

When asked their relationship status, 46.2% (n = 30) of cisgender women and all transgender women reported that they were single, while 46.2% (n = 30) of cisgender women were in a regular relationship with one partner, and five were in some other form of relationship (7.7%).

Table 30: Demographic characteristics of women living with HIV

Demographic characteristics	Cisgender women n (%)	Transgender women n (%)	Total n (%)
Age			
< 35	14 (19.4)	0 (0)	14 (18.2)
35-49	24 (33.3)	1 (20.0)	25 (32.5)
50-64	28 (38.9)	1 (20.0)	29 (37.7)
65+	6 (8.3)	3 (60.0)	9 (11.7)
State/territory			
New South Wales	22 (30.6)	5 (100)	27 (35.1)
Victoria	26 (36.1)	0 (0)	26 (33.8)
Queensland	10 (13.9)	0 (0)	10 (13.0)
South Australia	3 (4.2)	0 (0)	3 (3.9)
Western Australia	7 (9.7)	0 (0)	7 (9.1)
Australian Capital Territory	3 (4.2)	0 (0)	3 (3.9)
Tasmania	0 (0)	0 (0)	0 (0)
Place of residence			
Inner city	29 (40.3)	1 (20.0)	30 (39.0)
Outer suburbs	23 (31.9)	2 (40.0)	25 (32.5)
Regional/rural	20 (27.8)	2 (40.0)	22 (28.6)
Aboriginal or Torres Strait Islander	6 (8.3)	0 (0)	6 (7.8)
English as a first language	56 (77.8)	4 (80.0)	60 (77.9)
Place of birth			
Australia	43 (62.3)	0 (0)	43 (58.1)
Asia	1 (1.4)	2 (40.0)	3 (4.1)
Europe	9 (13.0)	0 (0)	9 (12.2)
Africa	10 (14.5)	0 (0)	13 (13.5)
Pacific	4 (5.8)	3 (60.0)	4 (9.5)
South and Central America	1 (1.4)	0 (0)	1 (1.4)
Middle East	1 (1.4)	0 (0)	1 (1.4)
Sexual identity			
Heterosexual or straight	59 (81.9)	2 (40.0)	61 (79.2)
Bisexual	6 (8.3)	3 (60.0)	9 (11.7)
Pansexual	1 (1.4)	0 (0)	1 (1.3)
Queer	5 (6.9)	0 (0)	5 (6.5)
Gay/homosexual/lesbian	0 (0)	0 (0)	0 (0)
Asexual	1 (1.4)	0 (0)	1 (1.3)
Relationship status			
Currently single	30 (46.2)	3 (100.0)	33 (48.5)
In a relationship with one partner	30 (46.2)	0 (0)	30 (44.1)
Other	5 (7.7)	0 (0)	5 (7.4)

Education, employment and income

Education levels were mixed among the sample. Around one in five had not completed high school (20.2%, n = 18), while more than one in three had a university qualification (37.6%, n = 32).

Most cisgender women were employed either full-time (33.8%, n = 26), part-time (19.5%, n = 15) or in a casual role (9.1%, n = 7). This was not the case for transgender women, with only one transgender woman reporting that she was working in a casual role and the other four reporting that they were not in the workforce.

The income of most women participants was well below the Australian average, with more than a third of women on a household income of less than $30,000 per year (35.8%, n = 29) and 23.5% (n = 19) earning between $30,000 and $49,999 per year. Only 5.3% (n = 4) of cisgender women, and no transgender women, had a household income over $100,000, compared to 21.0% of the sample as a whole (n = 176). Details are listed in Table 31.

Table 31: Education, employment and income of women

Education, employment and income	Cisgender women n (%)	Transgender women n (%)	Total n (%)
Highest level of education			
Primary school only	1 (1.4)	1 (20.0)	2 (2.6)
Up to 4 years' high school	9 (12.5)	0 (0)	9 (11.7)
Leaving certificate/HSC/Year 12	6 (8.3)	0 (0)	6 (7.8)
Tertiary diploma/trade certificate/TAFE	28 (38.9)	0 (0)	28 (36.4)
Undergraduate university degree	13 (18.1)	3 (60.0)	16 (20.8)
Postgraduate university degree	15 (20.8)	1 (20.0)	16 (20.8)
Main employment/activity			
Work full-time	29 (40.8)	1 (20.0)	30 (39.5)
Work part-time	11 (15.3)	0 (0)	11 (14.5)
Not working/retired	6 (8.5)	3 (60.0)	9 (11.8)
Unemployed, not looking for work	6 (8.5)	0 (0)	6 (7.9)
Home duties	9 (12.7)	0 (0)	9 (11.8)
Work casual	1 (1.4)	0 (0)	1 (1.3)
Student	1 (1.4)	0 (0)	1 (1.3)
Unemployed, looking for work	1 (1.4)	1 (20.0)	2 (2.6)
Annual household income			
Negative or zero income	2 (2.8)	1 (20.0)	3 (3.9)
$1 - $29,999 per year	14 (19.7)	3 (60.0)	17 (22.4)
$30,000 - $49,999 per year	10 (14.1)	1 (20.0)	11 (14.5)
$50,000 - $79,999 per year	14 (19.7)	0 (0.0)	14 (18.4)
$80,000 - $99,999 per year	13 (18.3)	0 (0.0)	13 (17.1)
$100,000 or more per year	14 (19.7)	0 (0.0)	14 (18.4)

Financial security

As mentioned earlier in this report, the HIV Futures 10 survey included two indicators of financial security: experiences of financial distress and housing.

About one in four of women participants (26.0%, n = 20) met the criteria for experiencing financial stress in the past 12 months (Table 32).

Table 32: Experiences of financial stress in the past 12 months

Financial stress status	Women n (%)	Men n (%)	Non-binary/ gender diverse people, n (%)
No financial stress	57 (74.0)	597 (83.55)	10 (90.9)
Financial stress	20 (26.0)	118 (16.5)	1 (9.1)
Total	77 (100)	715 (100)	11 (100)

Over a third of women participants were currently living in private rental accommodation (37.3%, n = 28), although two in five (42.7%, n = 32) owned their own home either outright or with a mortgage. Only one of the women over 65 years of age was a home owner (Table 33), suggesting that this cohort may be vulnerable to housing instability.

Table 33: Housing arrangement of cisgender women, by age*

Housing arrangement	Age group				Total
	< 35 n (%)	35-49 n (%)	50-64 n (%)	65+ n (%)	
Home owner (own outright)	1 (7.1)	3 (12.5)	6 (21.4)	1 (11.1)	11 (14.7)
Home purchaser (with mortgage)	0 (0)	11 (45.8)	9 (32.1)	1 (11.1)	21 (28.0)
Private rental	10 (71.4)	5 (20.8)	7 (25.0)	6 (66.7)	28 (37.3)
Public rental	2 (14.3)	2 (8.3)	3 (10.7)	0 (0)	7 (9.3)
Rent-free	0 (0)	1 (4.2)	0 (0)	0 (0)	1 (1.3)
Community housing or cooperative	0 (0)	0 (0)	1 (3.6)	1 (11.1)	3 (4.0)
Boarding house	1 (7.1)	1 (4.2)	1 (3.66)	0 (0)	2 (2.7)
Homeless	0 (0)	1 (4.2)	0 (0)	0 (0)	1 (1.3)
Other	0 (0)	0 (0)	1 (3.6)	0 (0)	1 (1.3)

* Note that figures differ slightly that reported in the text, as it excludes people who did not report their age

Women were less likely than men to own their home. Instead, cisgender women were more likely to be in private rental (33.8%, n = 24) compared to cisgender men (30.6%, n = 216) (Figure 45). No transgender women lived in a home that they owned, all were in private rental.

Figure 45: Housing arrangement, by gender*
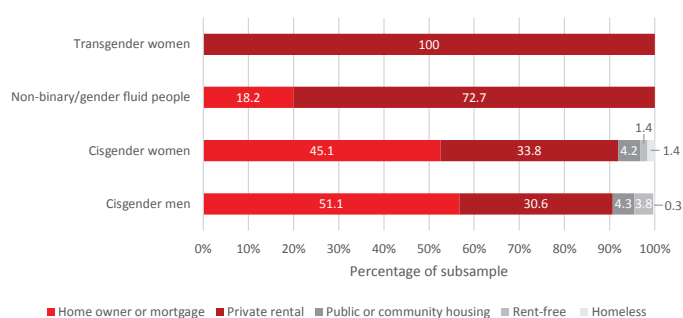
* Participants who did not respond to the question about gender or who selected 'other' housing arrangement were also excluded, except where their response could be clearly re-categorised into one of the above

HIV acquisition and diagnosis

The length of time women participants had been living with HIV ranged from 2 years through to 41 years, with an average time of 21.1 years.

More than 95% of women were currently taking ART (97.2%, n = 70) and, as of their last test, 94.6% (n = 70) of women had an undetectable viral load (viral suppression). This is slightly higher than for the sample as a whole, in which 93.7% had an undetectable viral load.

As noted previously in this report, the average time between HIV acquisition and diagnosis was 2.4 years for women, compared to 1.2 years for men (this difference was statistically significant).

Quality of life

Using the PozQoL measure of QoL, a score of 3.0 or higher is considered 'good' QoL (from a score range of 1-5, in which higher scores indicate better quality of life). In HIV Futures 10, 61.7% of women reported 'good' QoL. The average PozQoL score for women was 3.2, which was slightly lower than the average score for men (3.5), but the difference was not statistically significant.

Using the one-question item in which HIV Futures 10 participants were asked to rate their overall mental, emotional and physical health, 46% of women reported their overall sense of wellbeing to be at least good ('good' or 'excellent') – a lower percentage than that of men (55.9%).

General health and mental health

In HIV Futures 10, we recorded self-reported general health using the SF-36 general health subscale. Among women, the average SF-36 general health score was 54.4, slightly lower than the score reported by men in HIV Futures 10 (although this difference was not statistically significant). Women aged under 35 years reported a higher general health score than women older than 35, but this difference was not statistically significant.

Rates of poor mental health were high among women who participated in HIV Futures 10 compared to general population rates (ABS, 2022). Three in five transgender women in this study reported that they had a current or previous diagnosis of two or more mental health conditions. Bipolar disorder, borderline personality disorder, post-traumatic stress disorder, and obsessive compulsive disorder were equally the most common, with 40.0% (n = 2) reporting a current diagnosis of either bipolar disorder, post-traumatic stress disorder, or obsessive compulsive disorder, and 40.0% (n = 2) reporting a past diagnosis of borderline personality disorder. Although the overall number of transgender women in this study is small, these findings are consistent with previous research that shows transgender women report poorer mental health than cisgender women and men (Hill et al., 2020).

Among cisgender women, 26.4% (n = 19) reported they had a current diagnosis of depression, while 31.9% (n = 23) reported a current or past diagnosis of depression. Twenty per cent (20.8%, n = 15) of cisgender women reported a current diagnosis of anxiety, while 31.9% (n = 23) reported a current or past diagnosis of anxiety.

Multiple mental illnesses were common, with 20.9% of cisgender women (n = 15) reporting two or more current mental health condition and 8.4% reporting three or more (n = 6). Again, the most common comorbidities were anxiety and depression.

Of lower prevalence mental health conditions, the most common condition reported by both cisgender and transgender women was post-traumatic stress disorder, with 12 cisgender and two transgender women reporting a current diagnosis. Rates of bipolar disorder, borderline personality disorder, obsessive compulsive disorder and schizophrenia were low (two or less participants reporting a current diagnosis).

Satisfaction with treatment and clinical care

Most women (83.4%, n = 59) reported that they were satisfied with their clinical care for HIV (see Table 36). Most women were also happy with their HIV treatment, with 75.4% (n = 46) reporting that they were 'extremely happy' or 'very happy' with their treatment. As shown in Figure 46, women were 'less' likely than men to report that they were happy with their treatment (although this difference was not statistically significant). It is unknown whether this was due to a difference in physiological or social factors.

Table 36: Women's satisfaction with clinical care for HIV

Level of satisfaction	Cisgender women n (%)	Transgender women n (%)	Total n (%)
Very satisfied	36 (52.9)	2 (66.7)	38 (53.5)
Satisfied	20 (29.4)	1 (33.3)	21 (29.6)
Neither satisfied nor unsatisfied	7 (10.3)	0 (0)	7 (9.9)
Unsatisfied	4 (5.9)	0 (0.0)	4 (5.6)
Very unsatisfied	1 (1.5)	0 (0.0)	1 (1.4)
Total	68 (100)	3 (100)	71 (100)

Figure 46: Happiness with HIV treatment, by gender (% within each gender category)
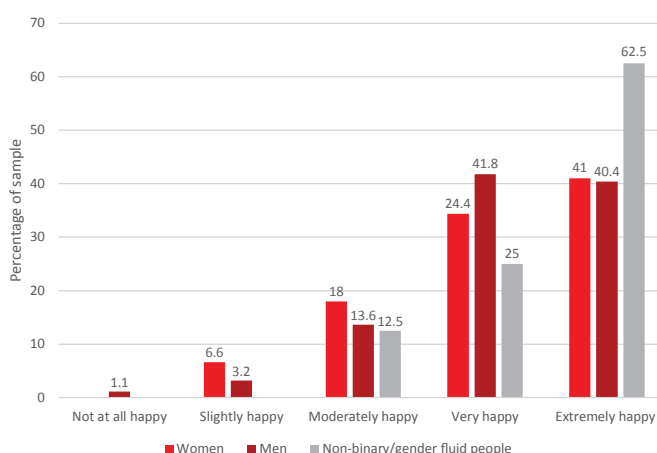
Sex and relationships

Around half of the women participants were in a relationship (44.1%, n = 30), and 29.9% (n = 23) cohabited with their partner/spouse.

Of those women with partners, 67.6% (n = 23) reported that their partner was HIV-negative (as per their most recent test), 26.5% (n = 9) reported that their partner was HIV-positive, and 5.9% (n = 2) were unsure. Around two in five (39.1%, n = 27) reported they had not been sexually active in the past 6 months.

Participants were asked a series of questions about the impact of HIV on their sex lives and about their concerns regarding transmission of HIV to sexual partners. The majority of women (79.1%, n = 53) were confident of not transmitting HIV to a sexual partner and 43.5% (n = 30) did *not* agree that they were afraid of transmitting HIV to a partner (Figure 47). However, two in five (39.1%, n = 27) felt that HIV had a negative impact on their sexual pleasure, while 60.8% (n = 42) had avoided sexual and intimate relationships since being diagnosed with HIV. Having an undetectable viral load increased sexual pleasure for 45.5% (n = 31) of women. Most women (84.1%, n = 58) were ambivalent about whether they would prefer to have a relationship with another person living with HIV or indicated they would not prefer this.

"The hardest part about living in Australia with HIV is that no-one thinks you can get it or may have it. Add that I'm a heterosexual woman to that equation and prepare to forever feel lonely on this journey. People say lots of insensitive and ignorant things without realising the effect it can have on people."

Figure 47: Women's feelings about HIV and sex

Chart data (Strongly agree, Agree, Neither agree or disagree, Disagree, Strongly disagree):

- I am confident that I will not transmit HIV to a sexual partner when my viral load is undetectable: 52.2, 26.9, 19.4, 1.5
- I am afraid of transmitting HIV to my partner or potential partner: 8.7, 23.2, 24.6, 15.9, 27.5
- HIV has had a negative effect on my sexual pleasure: 18.8, 20.3, 15.9, 20.3, 24.6
- I have avoided sexual and intimate relationships since I was diagnosed with HIV: 36.2, 24.6, 7.2, 18.8, 13
- I enjoy sex more when I know my viral load is undetectable: 27.9, 17.6, 44.1, 2.9, 7.4
- I prefer to have a relationship with someone who is also HIV positive: 8.7, 7.2, 46.4, 20.3, 17.4

Percentage of sample

■ Strongly agree ■ Agree ■ Neither agree or disagree ■ Disagree ■ Strongly disagree

By looking at the responses to these and similar questions asked in previous HIV surveys, we can see how these views have changed over time, including since major international research studies were released in 2011 confirming that undetectable viral load equalled zero risk of sexual transmission of HIV (Cohen et al., 2011). As shown in Figure 48, women in the HIV Futures 10 survey were less likely than participants in previous HIV Futures surveys to report fear of transmitting HIV to sexual partners.

Figure 48: Fear of transmitting HIV and preference for relationship with another person living with HIV, over time (percentage of women who agreed/strongly agreed)

Chart data:

I am afraid of transmitting HIV to my partner or potential partner:
- 1997: 69
- 2003: 72
- 2012-13: 69
- 2015-16: 58
- 2018-19: 28
- 2021-22: 32

I prefer to have a relationship with someone who is also HIV positive:
- 1997: 63
- 2003: 58
- 2012-13: 63
- 2015-16: 52
- 2018-19: 15
- 2021-22: 16

HIV Futures report – year of data collection

━●━ I am afraid of transmitting HIV to my partner or potential partner
━●━ I prefer to have a relationship with someone who is also HIV positive

10. QUALITY OF LIFE AMONG ASIAN-BORN GAY AND BISEXUAL MEN LIVING WITH HIV IN AUSTRALIA

In Australia, the HIV epidemic has been concentrated among gay and bisexual men. Around three in four new HIV diagnoses each year in Australia are attributed to sex between men, and this pattern has remained consistent since the epidemic emerged (King et al., 2022). In recent years, there has been a stabilisation, and in some areas a slight decrease, in the annual number of new HIV cases attributed to male-to-male sex.

This has been the result of widespread access to PrEP among HIV-negative gay and bisexual men, an enhanced focus on community-based HIV testing and advances in HIV treatment. However, this stabilisation has only been among gay and bisexual men born in Australia. The proportion of HIV diagnoses attributable to male-to-male sex among men born in China, Southeast Asian and South Asian countries (particularly the Philippines, Vietnam, Malaysia and India) has increased since the early 2000s (Gunaratnam et al., 2019). There is an increasing urgency to ensure that HIV prevention, care and treatment interventions targeting gay and bisexual men adapt their approach to be more inclusive of cultural diversity and migrant experience. However, the disproportionate representation of people born overseas in new HIV diagnoses also suggests a lack of engagement with culturally and linguistically diverse communities across the HIV sector as a whole, including engagement with people who are living with HIV.

In the Australian context, we know very little about the ways in which migrant experiences, and the experiences of gay and bisexual men from culturally and linguistically diverse communities (including second generation migrants), shape experiences of living with HIV. For example, it is likely that being diagnosed with HIV while an individual's visa status is uncertain or impermanent may undermine access to income and stability of relationships, both of which have a significant negative impact on QoL and wellbeing. We also have limited information to advise service providers on ways their service delivery or programs can better accommodate cultural diversity. One recent study indicated that gay and bisexual men born overseas were less likely than men born in Australia to be engaged with LGBTQA+ community events or services, which is where many programs for PLHIV are based. Many people had a low desire to use these services due to concerns about unwanted exposure of either their HIV status or sexuality (Philpot et al., 2021). In this project, we build on this recent study to explore the experiences of living with HIV among gay and bisexual men from Asian backgrounds, including their experiences with clinical and community service providers; the impact of their HIV diagnosis on their migration experience; and the intersection between sexuality, HIV-related stigma and racial or cultural marginalisation or racism. We also explore the ways, if any, that HIV has changed people's lives, for better or worse.

Aim

The category of 'overseas born' tends to ignore diversity in culturally and linguistically diverse people's experiences, backgrounds and identities. It also reduces complex experiences related to ethnicity, community, culture and migration to the simple category of 'place of birth'. The aim of this part of the HIV Futures study is not to identify a set of factors associated with QoL among all PLHIV with migrant experience, rather it is to:

● Identify issues or challenges that may place unique pressure on recent migrants who are living with HIV

● Identify ways in which the HIV service sector can provide more appropriate support for gay and bisexual men living with HIV from culturally and linguistically diverse backgrounds

Method

This part of the HIV Futures study involved in-depth interviews with two groups:

1. **Community interviews:** in-depth interviews with eight Australian PLHIV from Asian countries who have migrated to Australia or whose parents were migrants. In order to contain the scope of the study, we focussed on men (transgender and cisgender) who identify as gay, bisexual, pansexual or queer or other non-heterosexual identities. We chose to focus on PLHIV from Asian countries due to a higher rate of recent HIV diagnoses among this cohort (relative to other regions) and on advice from the HIV community sector that has been working to engage with this group of men in HIV prevention and testing and social/support for PLHIV.

2. **Stakeholder interviews:** in-depth interviews with 10 people who work in advocacy or related areas with PLHIV from culturally and linguistically diverse communities. This included peer navigators, peer support workers or people working in health promotion or advocacy as well as activists or other people who volunteer in the HIV sector to support PLHIV. Many of these advocates and educators also have lived experiences of migration and as PLHIV.

In-depth interviews were conducted via Zoom, telephone or face to face (as per participant preference and what was feasible with respect to both location and COVID restrictions). The community interviews were conducted by a peer worker employed by the National Association of People with HIV Australia (NAPWHA). Stakeholder interviews were undertaken by a member of the HIV Futures research team based at La Trobe University. Interviews were audio recorded with permission of the participant. No participants requested a translator, although this option was available.

The study was advertised through relevant PLHIV networks, including through ACON and NAPWHA's PANA network, as well as on Facebook. Advertisements for community interviews directed prospective interviewees to a website where they could leave their contact details. Interviewees were gifted a $50 voucher to thank them for their time. For the stakeholder interviews, individuals were identified through the research team's networks, and prospective participants were directly invited to take part in an interview.

An iterative approach to analysis of interview data was based on grounded theory principles (Braun & Clarke, 2014). One researcher conducted a preliminary analysis of the findings to create an initial framework. A second researcher independently analysed the findings and created a more extensive set of themes, which are presented here. Pseudonyms are used in the presentation of findings below, with the age of each participant indicated in brackets.

Findings

HIV amplifies the uncertainty of migration

Migration, whether temporary or permanent, will inevitably create significant change and a period of uncertainty and readjustment for people. For those seeking permanent resettlement, the period in which their residency status is uncertain, such as when visa applications are being processed, can be an unsettling and anxious wait. It is difficult for people to make decisions about their future, settle into work or build relationships while their life is, to some degree, in 'limbo' status (Körner, 2007; Robertson & Runganaikaloo, 2013; van Kooy & Bowman, 2019). This was reflected in the findings from this study. Many participants in the study described their experience of navigating Australia's migration system as an extended process of waiting and of uncertainty, which provoked high levels of anxiety. For example, Amir (33), who migrated from Malaysia on a Partner visa, reflected:

"It's always in the back of my mind; I try not to think about it as often as possible. But it's always at the back of my, like, you know, am I going to stay, where am I going to live, will there be a tribunal and all that stuff. And especially because there's no communication at all for that 3 years after signing my health waiver. I think that was like, 'Oh yeah, I'm not sure what's happening.'"

It was difficult for participants to plan for their future while in the migration process, which meant it was difficult to settle into their present life – finding meaningful work or establishing friendships and other networks. Interviews with people who worked in advocacy echoed this sentiment:

"I've seen so many people who live with HIV that don't have visas or citizenship. There's just so much uncertainty in life, you know, like, be it financial, educational, emotional; there is just, like, a constant battle. Even when someone makes all the criteria for an application, there's always going to be that process where they will need to apply for a health waiver, and they may not always succeed." (Community advocate/educator)

The cost of applying for a visa and covering living expenses during this time added to anxiety and uncertainty about the future. For many participants, their HIV diagnosis amplified this uncertainty, because the diagnosis complicates the process of applying for an Australian residency visa, adding extra costs and assessment processes. Amir (33) recounted:

"I had to take out a loan as well when I moved here from Malaysia, just to be able to cover all of my costs, my lawyer costs, my migration costs, because it's quite expensive."

This created stress for participants and left them feeling vulnerable and lacking agency within a system where agency was already limited. Participants felt that, as a person living with HIV, they were less valued or, as one participant put it, the rules are different for those living with HIV – in migration and all other aspects of life. Participants spoke of the complications that their HIV diagnosis produced in their migration journey. Aram (32) explained:

"Had I not been HIV-positive, I could have gone onto other pathways, other visa, which probably I suppose would have been easier […] With the sponsorship visa that I'm on now, it's probably a long journey, and of course, you know when we apply further down the track, the permanent residency, we would need the health waiver and that is also another process. So it's going to be a long journey, that is the uncertainty."

Uncertainty about visa status also left some participants unsure about how they could manage their HIV into the future, including paying for treatments or whether they would be able to access quality and support in their home country. For example, Bin (34) said:

"I worry if my visa got rejected and I need to go back to Indonesia, and then I'm really, really worried about my HIV condition, because back there it's quite difficult to access medication […] It's already hard to live there as a gay man, because we can't come out as gay there. Plus, with the HIV, it's much, much harder, of course."

As mentioned above, some participants described how HIV undermined their sense of being valued as a person. Community advocates also felt this was common among the PLHIV they worked with:

"My clients are saying that 'I have paid my tax, I have two or three jobs that I juggle to survive here, and yet, just because of one diagnosis, I cannot get a permanent residency'." (Community advocate/educator)

HIV meant they had more hurdles to climb, and a greater burden to prove they were worthy, in the immigration process. They also could not assume they could access any subsided healthcare or HIV treatment as a non-resident.

Uncertainty undermines relationships and affects wellbeing

Participants spoke about the negative impact that uncertainty associated with the migration and visa process, amplified by their HIV diagnosis, had on their wellbeing. For some, their visa status imposed practical constraints, such as a limited ability to work and earn money. However, for most participants, uncertainty meant they could not feel settled and plan for their future. HIV also brought uncertainty with respect to relationships with friends, family, and potential partners and lovers. HIV, the uncertainty of the visa process, racial and cultural differences and racism all combined to undermine confidence in relationships, as Jay (42) experienced:

"Coming from an Asian community to the majority of the population being from a Caucasian, white-based community, I think there is a possibility of [romantic relationships] but the chances are lesser, and add to it the possibility that you are also HIV [positive], I think definitely that personal worry is always there."

Some although not all participants also felt that their relationships became more precarious when they were diagnosed with HIV. Participants were concerned about judgement or being rejected by friends, lovers or family. Some described holding back from social connections in order to avoid unwanted disclosure of their sexuality or HIV status. This left them vigilant about who they spoke to and who they were connected to. For example, Amir (33) said:

"I think I'm very cautious about who I tell or who I talk to. As much as I am open to my friends and potential dates, I am not [to others], because I do have an Instagram profile where it's quite public. I haven't come out as HIV-positive but that's also because my family follows me [on social media], and my family doesn't know I'm HIV-positive. So there is always that, you know, what will people think?

Some participants held doubts about whether or how they would be able to seek sexual or romantic partners, and how they would disclose their HIV status to prospective partners. As Aram (32) said:

> "I guess there is a bit of anxiety when it comes to thinking [about] dating, and when you meet someone that you like and that you want to tell."

Participants' confidence to build relationships and connections with others was challenged by HIV. Jay (42) described this issue:

> "Being in a new country, you kind of tend to feel isolated and worried about how your future is going to pan out [...] the future prospects of having a partner or something – those concerns. And I think that concern is normally shared by LGBTQ people, but that gets aggravated when you are also living with HIV, because then that becomes an additional hurdle when you're trying to make meaningful relationships."

HIV-related stigma is intricately connected to sexuality and experiences of coming out or being out. Participants who were more connected to LGBTQA+ communities, including formal services and friendship networks, found it easier to find and engage with HIV support services and felt more affinity with these services. Aram (32) had lived in Australia for 12 years and was well connected with HIV services. He reasoned:

> "I was very, very lucky that I started exploring my sexuality through the coming out [student support] group at the University of Melbourne, because at that point it was run by two facilitators who are actually experienced [...] So I think, you know, my entry to this world of exploring my sexuality was well guided, and I was provided with a safe space and with good information."

Not surprisingly, participants like Aram (32), who had lived in Australia for longer, or who had come out about their sexuality or gender while in Australia, were able to build more connections with LGBTQA+ community and service providers.

Concerns about how people would respond to their HIV diagnosis – especially family or friends in their home country – were, for many participants, inseparable from concerns about family knowing they were gay or bisexual. As Rishi (33) described it, 'Even [my] sexuality they can't accept, so how we can expect they're going to accept the disease?' For many participants, cultural differences between Australia and their home country were expressed in terms of family and community and differing attitudes toward sexuality. Navigating HIV and sexuality in relation to their home and family meant treading carefully through their family's hopes and expectations for them regarding marriage and children and the way their family was viewed in their local community. Migration was often a solution for people to pursue their own identity and relationships while maintaining a connection with their family. For example, Jevan (33) felt like he was living a 'dual life' before he migrated to Australia; he said, 'I was not open to [friends and family], because that's something which no-one would have ever accepted'. He explained:

> "The only reason why I wanted the permanent residency over here was because, you know, I wanted to be myself. In terms of, you know, a lot of people come down to these developed countries – Australia, Canada, US – so that they can be rich and all that stuff. But for me, that thing was never there, because I used to earn really good [money] in India."

Some participants expressed fear that having to return home would result in unwanted disclosure of their sexuality and HIV status, which would destroy their family relationships. Distance, paradoxically, allowed them to retain closer family bonds – in some cases by allowing them and their family to avoid any conversations about their relationship status or sexuality. Unfortunately for some, however, distance (and their visa status and recent COVID-related travel restrictions) meant they had not seen family for some time.

Navigating disclosure of HIV status in workplaces and through the visa process is complex and confronting

Several participants spoke about holding fear of their HIV status being disclosed at work. For example, Rohan (28) was worried that being open about his HIV status at work would impact negatively on his massage therapy business.

> "I don't want to be 'Hey, I'm pos and I'm a massage therapist' kind of thing. I don't know what effect that would have on business [...] I think stigma exists and people would be uncomfortable if their massage therapist was positive."

Jay (42) said no-one from his work knew of his HIV status, and 'I prefer not to discuss that with people unless I absolutely have to'. Rishi (33) also said he worried what colleagues would think of him and the discrimination he may encounter, so he preferred 'not revealing anything' at the workplace. For others, this sense of fear was linked to returning to their home country if their Australian residency application were rejected. Medical checks for workplaces (government workplaces, particularly) were common in the home country of some participants, and so their fear of having to return home was linked to knowledge that they would struggle to maintain confidentiality of their HIV status and may struggle to find work as a result. As Aram (32) related:

> "I was actually working with the government [in Malaysia], so I had to go to the private hospital to access treatment, because I didn't want the government to know my status had I gone to a public hospital."

Concerns about unwanted HIV-status disclosure in the workplace were linked to broader fear of disclosure if they worked with people from their home country in Australia. This could be complicated if people needed to disclose their HIV status to employers as part of the visa sponsorship. Aram (32) recounted:

> "I was in a dilemma; [it] was quite troubling for me to tell or not to tell, and then my lawyer advised me that, you know, you don't have to actually tell her, you could just say that I've got a medical condition. Which is what I did; I just told her 'I've got a medical condition', I didn't specify it was HIV.."

While Aram received advice about this and felt supported in their decision not to disclose their HIV status, it was clear in the interview that this was a point of vulnerability. Disclosing HIV status in the workplace can be confronting and challenging in any circumstances, particularly if it also creates a risk that a person's status will be revealed to friends or family. If HIV status is disclosed as part of the process of seeking a work-sponsored visa, people can also be left feeling less confident of their employment or fearing negative repercussions at work, which could also affect their visa outcome.

Positive encounters with health service providers matter

Most participants in this study attended high-HIV-caseload clinics that offered specialised HIV services and expertise. For the most part, participants reported having excellent experiences with these services. Experiences with clinicians early after their diagnosis were incredibly important to participants' ongoing experience and feelings about living with HIV. Participants described how valuable it had been to have clinicians explain to them, immediately after their diagnosis, the pathway to treatment and the significance of undetectability in terms of their health and avoiding onward transmission. Participants felt reassured and more optimistic about their future following an early positive encounter with a clinician. For example, Aram (32) was diagnosed while on a temporary student visa:

> "I guess the great thing about being diagnosed at the Melbourne sexual health clinic was that I was given lots of good information from the start. So I was really well educated before I left Melbourne and went back to Malaysia."

Access to HIV treatment was facilitated for participants though clinics, but payment options varied. Some were able to access it free through a compassionate program or public funding for those who were eligible; others had to pay through insurance. Participants expressed concern that they would not have the same access to quality HIV clinical care or treatment in their home country. Some felt that services in their home country would be less readily available, or they feared judgement from doctors or unwanted disclosure of their HIV status. Some participants also feared they would have less access to the latest treatment options, as many countries only have access to an older generation of drugs that have different side effects. These concerns were integrated with participants' concerns about migration and residency. Access to quality clinical care to manage HIV was linked to living a life free from judgement, stigma and homophobia. Participants generally felt better able to achieve this in Australia due to distance from their family and/ or due to greater availability of services in Australia. However, a major theme that came up in stakeholder interviews was the presence of racism within the gay community and healthcare services. Advocates argued that organisations need to reflect on how racism in healthcare affects the way they function in supporting Asian men living with HIV and other migrants. A peer worker explained:

"I've met service providers who are lovely people, they just don't realise that as a person of colour there are more barriers for me to actually access services that I need, or actually just be able to feel safe."

Another stakeholder reflected on his own experience of receiving treatment, and being made to feel grateful:

"It was great experience, and you get referred to the right services and everything got the right support […] but underlying that there is this sort of … sometimes I feel like a very subconscious kind of, like … it's that politics of belonging, the fact that I can actually access these [services], that I should be thankful for the support that was given to me." (Community advocate/educator)

Living with HIV can be isolating

As mentioned above, for some participants, their HIV diagnosis led them to withdraw from family, friends and potential partners in ways that left them feeling safer with respect to avoiding unwanted disclosure, but also feeling lonely and isolated. Added to this, many participants were living away from family and had few family-based support networks in Australia. Hence isolation and loneliness due to fear of unwanted disclosure of sexuality or HIV status was a major theme in these interviews. For example, Jevan (32) discussed this:

"It's more than 2 years now [since I have seen my family and it has] been really tough for me. But I can't do anything right now; I can't think about going back to India after what happened with me over there, so – so whatever it is, it's the new world to me."

Some participants withdrew from networks of friends from their home country for fear that they would be outed (about their sexuality and HIV status) to their family back home or because it was stressful to build connections with people while holding their sexuality or HIV status as a secret. Rishi (33) described this as feeling like he was deceiving people if he established or sustained friendships. As a result, he deliberately saw friendships or connections with people through work or community as temporary or transient.

People also created distance because HIV added an extra layer to the sense of stigma and pressure many people already experienced as a result of hiding their sexuality. For example, Jay (42) said:

"Coming from South Asia or Asian cultures – when you are not open about your sexuality with your family or the society at large – now you are also not really sure if you want to open up about your HIV diagnosis with your dear friends and friends in the LGBT circle as well. So that definitely creates a bit of a – like, you hide things from people, so already you're used to hiding things from the larger society, and now it also hides certain aspects of your life from the gay society of friends as well [as the people] that you live with or hang out with."

Many participants had withdrawn from dating or building romantic or sexual relationships because of their HIV status. For example, Aram (32) stated:

"I'm not sexually active at the moment because, I think, with the diagnosis, I have chosen to be more careful and not to engage in casual sex with random people […] You know, probably before the diagnosis, I would have gone on casual encounters with people – but not really, anymore."

This was, for some, due to fear of onward transmission, but it was also described in terms of the uncertainty brought by their HIV diagnosis. Acquiring HIV also shaped many participants' sexual and dating practices. For example, following his HIV diagnosis, Ahn (26) made the decision to only have sex with other PLHIV.

Some participants had not yet worked out what their dating or relationship life would look like as a person living with HIV. How would they meet people? Who would they date? At what point would they disclose their HIV status? Would they only date other PLHIV? During an interview, an advocate also spoke of their own personal experience of dating and sex when they first moved to Australia, and how it made them feel:

"Navigating the gay culture in the western society like Australia can also be really daunting. With my lived experience, I can still recall the first few years when I tried to navigate the excitement it brings, but also not knowing how to have, you know, the discussions about sex, and how to form relationships and friendships, and lots of other things."

This was identified as a gap in services that could better support Asian men living with HIV.

Community services can help people build confidence and a sense of belonging

As this study was advertised through support and service networks, we did not speak to PLHIV who were not connected to support services. For this reason, the findings reflect the ways services have been useful for people who have been able to access them. As we know from previous research, many gay and bisexual men from Asian backgrounds are not aware of support services and/or may be unwilling to attend services provided by LGBTQA+ services such as ACON or Thorne Harbour Health (Philpot et al., 2021). Participants who had accessed services spoke about how significant this had been for them when they were first diagnosed. It was important for them to learn about HIV and hear the message that they could live a normal and healthy life, including having a good sex life and relationship. Participants pointed to both clinical and peer/community services as being important in this regard. For example, Jay (42) said:

"You feel you are not the only person, and you see other people also living their life regular and normally. I think it gives you that sense of acceptance as well as the sense of, like, 'okay, this is alright, you're not the only one'. It kind of gives you that relief. Yeah, I think it is good to know some people, so you also know that there are other people like you around and living the similar lifestyles."

Most participants did not know many other PLHIV, except those who they had met through community organisations or groups. For instance, Rohan (28) said:

"I don't know a lot of people living with HIV, but, like, going to that workshop, for example, was good because I met a whole bunch of people who are living with HIV."

Participants, like Rohan, valued these connections, noting that people who were not living with HIV could empathise but not truly understand the experience of living with HIV. Rohan (32) added:

"I definitely don't want to be the only person living with HIV in my life. I think that would be very lonely. So, for me it's quite important to at least know one person or two people, you know, or just have the idea that there are other people out there who live with HIV."

Some participants had a close network of friends who were also living with HIV, and they described the importance of this to them in terms of gaining support but also creating space where they did not have to be vigilant or guarded. For example, Amir (33) said:

> "I do have a circle of friends that, so [it] happens, most of us are HIV-positive, and we can talk about those stuff. So, I guess, I kind of built a little social circle around me [so] that I could gain support."

There were mixed responses from participants about whether they would value or seek out greater connection with other gay and bisexual men or PLHIV from Asian countries. Some were interested in building connections with people likely to have had similar experiences, while others were fearful that this would expose their sexuality or HIV status to their cultural community in Australia or their family back home. Interviews with stakeholders also spoke to this:

> "Invisibility in some ways provides layers of protection for a lot of people, and the reason why I bring this up is that if we look at, you know, who are still at the centre [of] our HIV responses? It's not that diverse, is it?" (Community advocate/educator)

A peer educator spoke of his experience as a facilitator who comes from migrant Asian background, and the way this supported engagement with Asian men living with HIV:

> "I don't think I need to explain to you why ever since I started to facilitate all the HIV workshops and peer navigators, we get more Asian gay men than before. It's not like my colleagues didn't want to engage with us; it's just the fact that when, as a client, if I go to a group, a peer group, a service, and I can see someone of my skin colour there, I know I will be safe. That is why having representation of the groups we're trying to reach in the work is so important."

Advocates spoke of the need to create more meaningful peer roles for Asian men living with HIV, to ensure engagement and cultural safety for Asian men accessing services.

> "I would love to see more paid peer work; I would love to see more full-time positions prioritised to people who are from culturally and linguistically diverse communities. And I would also like the sector to perhaps try to develop and find a new way of engagement, and to encourage people to become community leaders." (Community advocate/educator)

Stakeholders spoke of the need to cultivate a sense of belonging for all people affected by HIV as essential to maintaining a successful HIV response:

> "The HIV [response] in Australia has been successful because of the political movement and all of that, and basically what it all comes down to is that because people feel like we all need to belong to this HIV sector, everyone who [is] affected by HIV needs to belong to the HIV sector. That's basically a key message, right, and so when people are still excluded through all of this sort of social processes, like racism and all that sort of thing, that's challenging." (Community advocate/educator)

It was, however, well recognised by stakeholders that it's challenging to cultivate a politics of belonging for PLHIV from culturally and linguistically diverse backgrounds.

> "How do you support community that may find it difficult to have a political voice and then to advocate for themselves collectively? How do we do that? I think it's just general challenge; even outside of HIV, it's a difficult thing to do." (Community advocate/educator)

Strengths, resources and hope for the future

Despite uncertainty associated with their HIV diagnosis and migration status as described above, many participants felt that their lives were going well. Most were working or studying, and connected to friends or family, and some were dating or in relationships. We did not ask participants directly what strengths they felt they drew on to help them cope with HIV and migration, but it was evident in participants' narratives that managing the complexity of the migration process and their HIV diagnosis required a myriad of skills and strengths. The advocates' interviews attested to this. Indeed, one advocate spoke about how the focus of their work with newly diagnosed PLHIV from migrant backgrounds was building resilience through reflection on experiences and strengths pre-diagnosis and post diagnosis. Almost all participants had insight into how PLHIV could be better supported to navigate systems that were difficult and perpetuated inequality and racism. For many, reflection on this was one way they built more strength as a person living with HIV. For example, one participant spoke about how he felt more capable and confident since his HIV diagnosis, as he had been forced to be a stronger advocate for himself. Another spoke about how he had made new connections and friendships since his HIV diagnosis, while others felt HIV had ultimately influenced their decisions in positive ways. Following his diagnosis, for example, Aram (32) felt 'propelled' to do something meaningful with his life. He explained:

> "I think, you know, because [of] the healthcare system that treated me well when I [was] first diagnosed positive in Victoria, I was inspired to work in the healthcare setting. That's why I've chosen to work in speech pathology."

Despite the complications that an uncertain visa status brought to their lives, many participants felt hopeful about their future and held a sense that they were building a life in Australia. Having a hopeful outlook was also connected to a sense of belonging and feeling supported by the community, including HIV services. For example, Aram (32) said he felt 'absolutely hopeful' about his future in Australia. He added:

> "I think even more hopeful [for] the fact that I'm in [the state in Australia that I live in], I think, because I think [this state in] Australia probably is one of the best places in the world to be positive to live in. So, I think in that sense, because I know there are lots of good advocating being done by different organisations, so yes, very hopeful."

Conclusions

We know factors that sustain QoL relate to a sense of connection, social support and community, good health and access to secure finances. Migration and HIV can both challenge and undermine this for people. Migration, particularly waiting for a visa outcome, makes life less certain, which limits people's ability to plan their future, develop their career or build social networks. Migration also often means people are distant from their existing friendship or family networks, which can lead to isolation and a greater sense of instability. All of this becomes more challenging for people who are diagnosed with HIV, because the process of obtaining a permanent visa becomes slower, less certain and more complex. It also leaves people more vulnerable to judgement, stigma and unwanted disclosure of their HIV status. Participants in this study described the ways this uncertainty, vigilance and fear left them feeling anxious and vulnerable and, for some, lonely and isolated. Beyond this instability, however, many participants held strengths and resources which helped them navigate systems and processes that perpetuated inequality or uncertainty. Support services, including peer networks, were an important part of this process and made a significant difference to people's ability to cope, including gaining a sense of belonging and hope for the future. What is needed are services that are more inclusive of cultural diversity and that draw from the experiences, knowledge and strengths of PLHIV from migrant backgrounds to build support networks.

Acknowledgment

11. IMPLICATIONS FOR PRACTICE

The Eighth National HIV Strategy includes a target of 75% of PLHIV reporting good quality of life (QoL) by 2022 (Australian Government Department of Health, 2018). In HIV Futures 10, with data collected between 2021 and early 2022, 71.8% of participants reported a good QoL. This suggests Australia is not far off achieving this target.

The measure of 'good' QoL used in this survey derives from PozQoL, which is a scale that measures health-related QoL specific to HIV. By using PozQoL, we aim to understand the ways in which living with HIV detracts from QoL. This is an important point when it comes to understanding the implications of these findings for practice. A wide range of factors can affect an individual's QoL – from their financial circumstances through to the characteristics of the community in which they live, the extent to which they feel satisfied in their professional life, and the quality of their relationships. Not all these factors are directly affected by HIV, nor are they within the capacity of the HIV service sector to address. What the HIV sector can attend to, however, is supporting PLHIV to reduce the negative impact on QoL of living with HIV.

This report shows the impact of stigma in two areas: 1) HIV-related discrimination in formal settings and, 2) the less quantifiable, and more hidden, impact of stigma, often experienced as a sense of not belonging with family or community or a fear of being rejected due to HIV.

As reported in these findings, many PLHIV experience HIV-related discrimination in health services, insurance and other formal settings. This urgently needs to be addressed though interventions such as in-service training and policy change to protect against all forms of discrimination in key sectors.

However, the impact of stigma on people's social and relationship lives is more challenging to address. While U=U and PrEP offer some relief from fear of onward HIV transmission, this has not meant that PLHIV no longer experience stigma or rejection in sexual encounters or relationships; nor has it removed people's sense of non-belonging or alienation in some areas of their life. Indeed, the need for programs which support people to cope with, and challenge, the negative impact of stigma is as great as it has ever been.

In an ideal world, there would be funds available to create massive mainstream marketing campaigns to educate the whole of society about the reality of living with HIV and U=U. However, in the absence of this, what the HIV sector can offer are programs that provide social connection, practical support, advice and a sense of belonging for PLHIV. Connecting with peer networks and services also gives PLHIV opportunities to know others in a similar position and learn about the diversity of experiences, skills, knowledge and strengths among PLHIV. It also connects people with advocacy and helps build critical insight into the politics of HIV-related stigma. For all these reasons, continued investment in peer-based programs for PLHIV and peer-led organisations is critical to achieving the goal of improving QoL among PLHIV.

The findings from the PozQoL scale also show us that concerns about health can negatively impact upon QoL. Concerns about health may be related to a person's current state of physical health. However, as we see in these findings, worries about future health that come from living with a chronic illness also have a wearing effect on QoL. Knowledge about the health impact of living long term with HIV and ART is still emerging. As the average age of the population of PLHIV increases (in HIV Futures 10, the average age of participants was 54), we are coming to learn more about how HIV and ART interacts with other chronic conditions or processes of ageing. The HIV community sector continues to play an important role in supporting health literacy among PLHIV. In part, this is about providing information on issues such a treatment. However, it is also about providing PLHIV with the tools they need to engage critically with their healthcare: to ask questions, to find resources and to challenge healthcare that is inadequate. Health knowledge is only useful insofar as people can use it and take action to support their health. To this end, health literacy and advocacy go hand in hand. Supporting health literacy is about supporting QoL among PLHIV. This is the goal of NAPWHA's health literacy project, which you can read more about here: https://napwha.org.au/health-literacy-framework/.

Finally, these findings point to the significance of representation and leadership from diverse communities within the HIV sector. While gay and bisexual men born in Australia are the largest group affected by HIV in this country, the make-up of the HIV Futures sample shows the diversity among PLHIV. Women, heterosexual men, people born outside of Australia, and Aboriginal and Torres Strait Islanders constitute a significant proportion of individuals within the sample of HIV Futures 10. However, cross-sectional surveys such as HIV Futures are not well equipped to tell a diverse range of stories. It is vital that we invest in local, peer-led research to better understand and document the needs of diverse communities, and to respond to these needs. To make this happen, the HIV sector needs to create leadership opportunities for people from different backgrounds and cultures. Strategies that have worked so well in the past to build strong community networks and mentor activists and advocates to fight for equity and justice in the HIV response need to be reinvigorated with a diverse lens. This will build QoL through action in a way that brings all individuals and communities along.

APPENDIX: METHODS

The HIV Futures 10 study was a national cross-sectional survey of people aged 18 years or older, living with HIV in Australia. The survey forms part of a series of cross-sectional surveys of this population that have been repeated periodically (every 2 to 3 years) since 1997. HIV Futures 10 is the 10th iteration of this survey.

Ethics approval

Ethics approval for this study was granted by:

- La Trobe University College of Science, Health and Engineering Human Ethics Committee (HEC21061)
- Thorne Harbour Health Community Research Endorsement Panel
- ACON Research Review Ethics Committee

Sample

Since 1997, HIV Futures surveys have achieved sample sizes of up to 1,200 participants. However, for the most recent versions (HIV Futures 8, 9 and 10), the sample size has been 800-850. Discussions with community organisations suggest that this is likely the result of survey fatigue among PLHIV, given the large number of requests that PLHIV receive to participate in research. It is also possible that PLHIV are less connected to HIV community organisations or networks than they once were, when ART was less effective and many people needed higher levels of support due to ill health or treatment side effects, or that reductions in service provision has led to fewer community connections. COVID-19 similarly made connecting with participants in person much more challenging, with greater reliance on digital recruitment.

As with HIV Futures 8 and 9, participants in HIV Futures 10 were invited to provide information to generate a unique participant code. This code enables their responses to HIV Futures 10 to be paired with their responses to the previous two survey iterations, establishing longitudinal data while also maintaining confidentiality. Participants were not asked to supply contact details within the questionnaire. However, those who completed the questionnaire online were able to open a separate online form in which they could leave their contact details to receive information about subsequent HIV Futures surveys.

Recruitment

Data were collected between May 2021 to July 2022 using a self-complete survey that could be filled in online or using a hard-copy booklet that was supplied to prospective participants with a reply-paid envelope. As an incentive, we offered a prize draw of four $250 vouchers, for which any participant was eligible to enter. Contact details were collected separately from the survey to protect anonymity. Winners were selected at random, and the vouchers were sent via email.

HIV Futures 10 was open to PLHIV, aged over 18 years and currently living in Australia. The study relied on a self-selected sample. Participants were recruited through electronic advertising in a range of forums including: advertisements sent through the email lists of HIV community organisations; advertising on relevant websites; social media advertising, particularly via Facebook; and flyers and posters displayed in HIV clinics. Hard copies of the survey were distributed through the mailing lists of HIV community organisations and made available in the waiting rooms of HIV clinics and community services.

To gauge effectiveness of recruitment techniques, participants were asked where they found out about the study. In contrast to HIV Futures 9, where HIV organisation mail-outs/emails were the most common source (28.2%), 34.2% (n = 279) of the HIV Futures 10 sample found out about the survey from a Facebook advertisement (as opposed to 13.4% in HIV Futures 9). A further 25% (n = 204) found out about the survey via an HIV organisation, and 13.1% (n = 107) from a previous HIV Futures survey.

Instrument and measures

The HIV Futures 10 survey instrument was revised from previous HIV Futures surveys, a process undertaken through consultation with PLHIV, PLHIV advocacy organisations, HIV community organisations, clinicians, and others working in the Australian HIV sector. The HIV Futures 10 instrument contained questions across 16 areas listed below:

- **Demographics:** Standard items were used to measure age, sex, gender, sexuality, place of residence (postcode), highest education level, total household income, current employment, current relationship status, and Australian residency and visa status.

- **Financial and housing security:** Standard items were used to ask participants about their current housing arrangements, including the people with whom they live and type of housing they live in (rental, owned, public, other). Two items asked participants if they had experienced difficulty managing the cost of basic items for living (utility payments, rent, food and so forth) in the past 12 months. This was a modified version of an item used in the Australian Household Income and Labour Dynamics in Australia (HILDA) survey, a national population-based survey of Australian households (Wilkins, 2015).

- **Quality of Life:** QoL was measured with the PozQoL scale, a QoL scale developed specifically for PLHIV and validated with an Australian sample (Brown et al., 2018). PozQoL includes 13 items to assess QoL across four subscales: health concerns, psychological, social, and functional, with each response measured on a 5-point Likert scale. PozQoL generates an average score between 1 and 5. Scores over 3.0 are considered reflective of overall good QoL.

- **HIV diagnosis and viral load:** Participants were asked in which year they tested positive for HIV, in which year they believe they acquired HIV, and the means by which they acquired HIV (sex with a man, sex with a woman, injecting drug use, blood products, other). Participants were also asked the results of their most recent viral load test.

- **HIV treatment:** Participants were asked whether they currently use ART. Participants not currently using ART were asked whether they had used ART in the past and their reasons for not taking ART. To measure attitudes toward use of ART, participants were asked to respond to six statements relating to beliefs and attitudes about beginning ART, and its safety and effectiveness. Several items asked participants to report on any problems they have with use of ART, including experience of side effects.

- **COVID-19 and telehealth:** Participants were asked whether they had contracted COVID-19, whether they had been vaccinated again COVID-19, whether they had accessed telehealth services (either before or during the COVID-19 pandemic), and about their attitudes towards telehealth services.

- **Health and wellbeing:** The survey included the RAND 36-Item Short Form Survey 1.0 (SF-36) general health and emotional wellbeing subscales, which have been validated for use among PLHIV (Wu et al., 1997). Each of these scales are scored so that a total score ranging from 0-100 is calculated. A higher score indicates a more favourable health state. A further item asked participants to rate their overall sense of wellbeing using a 4-point Likert scale.

- **Mental health:** Participants were asked whether they had previously been diagnosed or were currently diagnosed with a mental health condition, whether they had experienced symptoms of depression or anxiety, and whether they were receiving medical or non-medical treatment.

- **Sexual health:** Participants were asked how often they had been screened for sexually transmissible infections (STIs) in the past 12 months and which STIs they had been diagnosed with.

- **Other comorbidities, including viral hepatitis:** Participants were asked whether they had been diagnosed with a range of physical health conditions including HIV-associated neurocognitive disorder (HAND). They were also asked: whether they had ever been diagnosed with chronic hepatitis B, whether they had ever been screened for hepatitis C virus (HCV), whether they had ever tested positive for hepatitis C antibodies or been diagnosed with chronic HCV, whether they had ever received treatment for HCV, and what were the outcomes of any treatment received.

- **Clinical services:** Participants were asked a range of questions about their experience of HIV clinical services including: whether they have access to Medicare, whether they have private health insurance, who they see for HIV-related treatment, whether they have access to bulk-billing services, how far they have to travel for HIV treatment, and how satisfied they are with clinical services.

- **Alcohol, tobacco and non-prescription drug use:** Participants were asked two standard questions about how often they smoked tobacco (Australian Institute of Health and Welfare, 2017) and three questions about their frequency and quantity of alcohol consumption (the AUDIT-C measure) (Dawson et al., 2005). Frequency and impact of other drug use was measured using the following items: frequency of non-prescribed drug use in the past 12 months, the extent to which non-prescription drug use interferes with daily life or ART, whether people had concerns about their non-prescribed drug use, and whether participants had sought information or support to reduce or stop use.

- **Stigma and discrimination:** HIV-related stigma and discrimination were measured using items developed by the Australian Stigma Indicators Project run by the Centre for Social Research in Health at UNSW Sydney (Broady, 2019) and measures developed by Quinn et al. (2014).

- **Relationships and sex:** Participants were asked whether they had a current sexual partner or partners, whether they had a current romantic partner, whether they cohabit with a partner, the HIV status of their sexual partner or partners, whether their sexual partner or partners use PrEP, how satisfied they were with their sex life, and a range of questions related to the impact of HIV on their sexual and romantic lives.

- **Community services and peer support:** Participants were asked whether they are connected to, or spend time with, other PLHIV; whether they have accessed peer support programs or networks in the past 12 months; what community services they utilise; and about their attitudes toward peer-based services.

- **Social connection:** General sense of connectedness to others was measured using 10 items in which participants were asked to signal the extent to which they agree with 10 statements relating to friendship and support. This measure is comparable with the HILDA survey (Baker, 2012).

Data analysis

For this report, data analysis was descriptive, including analysis of frequency, t-tests and ANOVAs (using Tukey's HDS post-hoc tests) to compare means, and chi-square tests to compare categorical differences.

Limitations

There are some limitations to this study that should be noted. The survey instrument for HIV Futures 10 was long and required a reasonably high level of English literacy to complete. This meant it would have been difficult for some people to complete the survey without assistance from a translator or support person. Limited resources meant we did not have capacity to undertake the more intensive recruitment that would be required to engage properly with many non-English-speaking migrant populations in Australia. In addition, the questions asked in HIV Futures 10 are general and not specific to the unique experiences of people from migrant communities. However, we have attempted to overcome some of these issues in HIV Futures 10 by way of an additional qualitative arm of the study, investigating the experiences of Asian-born gay and bisexual men (and other MSM) with migration experience.

For the quantitative survey, the small number of responses for some groups of people, such as Aboriginal or Torres Strait Islander people or people born overseas, limits the analysis that can be done specifically with these groups. This is because the sample is too small for reliable statistical analysis and the risk of identifying individuals is higher when the group is smaller.

A limitation of the sampling method is that it relies heavily on advertising through support organisations for people living with HIV. However, in contrast to previous HIV Futures surveys, recruitment via social media channels made up the largest proportion of recruitment; this was for the first time since the study's inception. While social media advertising may have been effective in targeting people less connected with the HIV service sector, those who are isolated from both services and social media channels (particularly those relating to HIV and/or LGBTQA+ communities), would have had limited exposure to survey advertising.

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