HIV Futures 9

Quality of life among people living with HIV in Australia

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GLOSSARY

ADI
AIDS-defining illnesses

AIDS
Acquired Immune Deficiency Syndrome; AIDS is a set of symptoms and illnesses caused by untreated HIV

ART
Antiretroviral Therapy; these are medications that prevent retroviruses such as HIV from replicating, thereby supressing the virus

Cisgender
Refers to a person whose gender identity aligns with their sex assigned at birth

DAA
Direct-acting antiviral in this report refers to treatment for the hepatitis V virus, DAAs is a highly effective and well tolerated treatment for HCV

Detectable viral load
Where HIV is detectable in the blood of a person living with HIV

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
An intersex person is born with sexual anatomy, reproductive organs, and/or chromosome patterns that do not fit the typical definition of male or female

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/person living with HIV

QoL
Quality of life

Questionnaire
The HIV Futures 9 questionnaire was a tool used to collect the data presented in this report; it was available in hardcopy and online with both formats including the same questions

SD
Standard deviation

SF-36
36-Item Short Form Survey, a widely-used measure of health related quality of life; the HIV Futures 9 questionnaire included the questions relating to general health and emotional wellbeing so that scores could be calculated for these two subscales

SF-36 GH
SF-36 General Health subscale

STI
Sexually transmissible infection

Survey
HIV Futures 9 used a survey methodology to collect self-reported data from people living with HIV through the HIV Futures 9 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

Undetectable
A viral load that is not detectable by standard testing

U=U
Undetectable = untransmissible. The U=U campaign highlights evidence showing HIV is not sexually transmissible if a person's viral load is undetectable

Viral load
The number of copies of the HIV 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 9 is a study of quality of life among people living with HIV (PLHIV) in Australia that forms part of a series of studies 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 9 from December 2018 until May 2019. Participants completed a questionnaire using a self-complete online or hardcopy form. The survey instrument comprised 148 questions related to quality of life, financial security, health, wellbeing, treatment, support, sex, relationships, HIV-related stigma, and ageing.

Demographic characteristics

The HIV Futures 9 survey was completed by 847 people, which is approximately 3% of people living with diagnosed HIV in Australia in 2017/2018 (approximately 28,000). Of these 847 people:

- 88.1% identified as men/male including one transgender man; 10.6% identified as women/female, including seven transgender women; 1.3% identified as non-binary or gender fluid
- 1.5% indicated that they were Aboriginal and/or Torres Strait Islander
- 74.0% were cisgender men who identified as gay, 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 50 years, although the average age of women was substantially lower, at 45 years
- 71.4% were Australian born, while 87.6% spoke English at home
- 78.1% lived in inner city or outer suburban areas
- 56.1% were in the paid workforce, working either full-time, part time or casual hours.

Quality of life

Utilising the PozQol scale (a quality of life measure developed specifically for PLHIV), 63.1% of HIV Futures 9 participants reported they had "good" quality of life (using a PozQol score of 3.0 or higher, from a range of 1-5 in which higher scores indicate better quality of life).

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

Factors associated with better quality of life and overall wellbeing included: being in the paid workforce, a higher income, higher levels of education, no recent financial stress, better general health, living with a partner/spouse, and higher levels of social connectedness.

Financial and housing security

As financial security is strongly linked to better quality of life, the HIV Futures 9 survey included key indicators of financial security: household income, recent financial stress, current accommodation/housing situation, food security, 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:

- 35.3% reported their main source of income to be social security (including a pension, disability pension or other government benefits)
- 33.3% reported an annual household income of less than $30,000, and the majority of these people (71.5%) were reliant on social security/pension as their main source of income
- 77.6% reported an annual household income of less than $100,000 (lower than the average Australian household income in 2018, which was approximately $110,000)
- 31.0% 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
- 42.7% were living in private rental accommodation, while 33.5% owned their home (with or without a mortgage), and 16.4% lived in public housing; this is substantially lower than 2016 Australian population figures in which 30.9% lived in rental accommodation and 65.5% lived in a home they owned (with or without a mortgage)
- 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
- Approximately 25-30% indicated that they often or sometimes ran out of food or could not afford to eat balanced meals, indicators of food insecurity

- 7.8% indicated they had not taken HIV medication at least once in the last 12 months due to financial reasons
- 38.2% indicated that it was somewhat or very difficult to access medication for financial reasons
- 26.4% 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 two years of having acquired the virus, although women were significantly more likely than men to have been diagnosed two or more years after they acquired HIV.

Findings from HIV Futures 9 indicate that Australia is on target to meet the goal of 95% of PLHIV on treatment by 2022. Among the HIV Futures 9 sample:

- 98.4% were currently taking antiretroviral therapy (ART)
- 89.3% of those on ART reported an undetectable viral load (viral suppression) as of their most recent test. This figure was lower among women, with 81.0% of women reporting an undetectable viral load as of their most recent test, while 9.0% reported either a detectable viral load or they were unsure of their current viral load
- 77.2% were happy with their current ART (treatment) and 69.6% found it convenient, although 31.9% indicated some dissatisfaction with side effects from ART.

Health and wellbeing

General health. The general health of the HIV Futures 9 sample as a whole was comparable to that of the Australian population, 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. Consistent with previous HIV Futures surveys, rates of mental health problems were higher among HIV Futures 9 participants than the Australian average. Specifically:

- 55.2% reported a current or past diagnosis of depression
- 43.0% reported a current or past diagnosis of anxiety conditions
- 20.4% report a current or past diagnosis of post-traumatic stress disorder
- 22.3% had a current diagnosis of more than one mental health condition

Transgender women reported higher rates of mental health problems than cisgender respondents: 57.1% of transgender women had a past or current diagnosis of depression, while 71.4% had a past or current diagnosis of anxiety.

A mental health diagnosis was highly correlated with poorer quality of life among participants.

Sexually transmissible infections and viral hepatitis. Rates of screening for sexually transmissible infections (STIs) other than HIV were high among participants, with 84.8% of those who were sexually active having been tested for STIs at least once in the past 12 months. With respect to STI diagnoses:

- 28.6% had been diagnosed with an STI in the past 12 months: 17.1% with chlamydia, 15.0% with gonorrhoea and 10.0% with syphilis
- Chlamydia and gonorrhoea were most common among people aged 35 or younger, syphilis was most common among people aged 50-64 years.

There were 118 (13.9%) participants who indicated they had been diagnosed as hepatitis C antibody positive. Of these, 28.0% had never received treatment for hepatitis C (which may include those who had never developed chronic hepatitis C infection and so not required treatment), while 36.4% had taken direct acting antivirals and cleared the virus.

Around one in three participants (31.1%) had never been screened for hepatitis C. Of those who had been screened, the majority (58.3%) had only been screened once.

Smoking. The rate of tobacco smoking among HIV Futures 9 participants was considerably higher than that of the Australian population, with 28.1% reporting they were smokers and 18.4% reporting they were daily smokers (compared to 14.5% of Australians overall). However, the reported smoking rate among participants of HIV Futures 9 surveys has dropped dramatically over time. Over 50% were daily smokers in the early 2000s (HIV Futures 3 and 4).

Stigma and discrimination

More than half the HIV Futures 9 participants (56.6%) reported at least one experience of HIV-related stigma or discrimination in the past 12 months, while 38.0% 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 quality of life among HIV Futures 9 participants. Variables associated with greater social connectedness were: a higher income, no recent financial stress, being in the paid workforce, and living with a partner or other adults. Looking at each of these variables, we can see that a large proportion of HIV Futures 9 participants may be vulnerable to low levels of connectedness, or loneliness. Specifically:

- 44.7% 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.
- 61.5% 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.
- 33.3% reported an annual income of less than $30,000. Of these people, 66.1% 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.
- 43.9% 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 9 participants had connections with other PLHIV and indicated that they valued these connections:

- 66.8% knew at least one other PLHIV in their social/informal networks who they could talk to about HIV
- 59.9% agreed that knowing other PLHIV was important to them
- 49.2% 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:

- 33.2% indicated they did not have any other PLHIV in their social/informal networks who they could talk to about HIV
- 37.9% did not feel like part of a community of PLHIV
- 25.6% felt isolated or cut off from other PLHIV
- 32.9% 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 9 participants:

- 59.5% agreed that community-based services played an important role in connecting PLHIV with each other
- 31.0% agreed that connecting online with other PLHIV was an important source of support for them.

In the past 12 months:

- 34.0% had accessed advice or support from a peer worker
- 26.6% had participated in an online forum or network for PLHIV
- 18.7% had participated in a peer support program or workshop
- 12.9% had used a peer navigator programs.

Ageing

People aged over 50 years were more financially secure than younger people, being more likely to own their homes and less likely to report recent experiences of financial stress. However, there were some signs of financial stress among people in the 50-64 age group, with 31.2% living in private rental (which can be a sign of financial stress as people move into retirement) and 32.4% living in public/community housing or other housing situations such as boarding houses (something that was associated with higher levels of financial stress).

People aged 50-64 also stood out as a potentially vulnerable group with respect to overall health and wellbeing. Compared to other age groups (including those aged 65+), people aged 50-64 reported poorer general health, poorer overall wellbeing, poorer quality of life and lower levels of social connectedness.

As expected, people aged over 50 were significantly more likely than younger people to be dealing with at least one chronic health condition as well as HIV. Multiple comorbidities were associated with poorer quality of life. Among people aged over 50:

- 79.7% of people aged 50-64 reported living with at least one chronic condition as well as HIV
- 88.1% of people aged 65+ had at least one other chronic condition.

The most common conditions were hypertension, cardiovascular problems, asthma and arthritis as well as mental health conditions.

Women living with HIV

Women participants in HIV Futures 9 differed in some key areas when compared to the sample over all, and when compared to men, notably:

- The sample of women was more culturally diverse, with 31.7% having been born outside of Australia
- While 98.8% of women were currently taking ART, they were less likely to have an undetectable viral load, with 81.0% reporting they had an undetectable viral load as of their most recent test
- Women reported a longer period between their HIV acquisition and diagnosis (2.4 years, compared to one year or less for men)
- Women were more likely to have experienced financial stress in the past 12 months, with 52.0% reporting recent financial stress.

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FOREWORD

Whenever the HIV Futures Study round is announced it mobilises HIV positive people, their organisations, their advocates and those who seek to generate knowledge about living with HIV. Why did 847 people with HIV think this project so worthy of the effort that, for the Futures 9 Study, they sat down and spent (sometimes up to an hour) of their own time, self-completing a series of questions about how HIV impacts on their lives?

My feeling is that this effort is made because HIV positive people see an outcome. HIV positive people are invested in seeing our lived experience represented; owning our own 'future', both as individuals and collectively. In the Futures Studies, HIV positive peoples' lives are represented as multi-dimensional and multi-faceted. Futures reports' provide a breadth of insight about living with HIV; a comprehensive picture of the complexity and diversity of the lives of HIV positive Australians emerges.

HIV Futures is a national study of people living with HIV (PLHIV) in Australia, conducted through a series of cross-sectional surveys that have been repeated periodically since 1997. The study feeds information back to the community, to program planners, policy makers, researchers and anyone interested in the reality of the experience of living with HIV in Australia. Since its inception 8,694 people have completed the survey, around 1,000 people each time it has been conducted – by any standards making this research project unique and impressive.

The first Futures survey, over 20 years ago, came at a time when antiretroviral (ARV) drugs were starting to change the landscape of HIV. The second survey came at a time when many PLHIV in Australia were re-evaluating their relationship to these treatments in the light of side-effects, failure of treatments and the harshness of regimens. Fast-forward to 2019 and who could have predicted the dramatic changes: HIV is now generally regarded and experienced as a chronic manageable illness; there are multiple regimens, fewer pills, safer classes of ARVs available, and longer-acting or extended-release ARVs on the horizon. In addition, many people have an undetectable viral load – meaning that they cannot transmit HIV to their sexual partners. Who could have predicted the HIV prevention landscape would be radically altered with the introduction of Pre-exposure Prophylaxis (PrEP) and scientific confirmation of the knowledge that HIV cannot be sexually transmitted when HIV positive people who consistently take ARVs have an undetectable viral load (known by the expression Undetectable = Untransmissible)?

The biomedical advances have been enormous and welcome. What though of the social world and the actual, daily experience of living with HIV in 2019? Has that changed or improved over time?

In the first Futures survey nearly three-quarters described their health as excellent or good. Despite this, nearly one-quarter (a very significant minority) reported having only fair or poor health, most with at least one major health condition other than HIV/AIDS. In the second Futures, conducted in 2000, again one quarter reported only fair or poor health. In the third Futures, more than one-quarter (over 30%) rated their health as only fair or poor. Again, in the fourth Futures, conducted in 2004, more than one-third rated their health as only fair or poor. In HIV Futures 9, it is noted that 63.1% of the respondents self-reported they had a good quality of life but that means at least one-third did not rate their quality of life as good. For up to one in three HIV Futures respondents, the experience of living with HIV has a profound and negative impact on their life experiences. Over 20 years, the same percentage of PLHIV survey respondents are 'doing it tough'.

In 2019, one in three respondents are struggling – some with finances, food security or housing tenure, some with relationships and disclosure, some with the effects of multi-morbidities and others with access to or affordability within the health system, some have still reported experiencing discrimination within the health system.

Why haven't our health, care and service systems bought everyone along?

Some of the information found in Futures 9 is very sobering. Consider these facts:

- More than 30% of HIV positive people who filled out this survey can be classified as experiencing significant financial stress, making this population more vulnerable to financial insecurity than the general Australian population, and HIV positive women are more likely to be in this situation

- HIV positive people have self-reported that they experience homelessness at 1.7%, a higher rate than the general community

- 7.8% of the survey respondents indicated that they had not taken their HIV medication at least once in the last 12 months due to financial reasons

- Mental health problems amongst those who responded to the survey are higher than the Australian average: 55.2% reported a current or past diagnosis of depression; 43% reported a current or past diagnosis of anxiety conditions; 20.4% report a current or past diagnosis of post-traumatic stress disorder; and 23.3% had a current diagnosis of more than one mental health condition at the time of completing the survey

- Rates of tobacco smoking among HIV Futures 9 participants were nearly double that of the Australian population

- More than half of participants (56.6%) reported at least one experience of HIV-related stigma or discrimination in the past 12 months

- Multiple co-morbidities were associated with poorer quality of life and, in the HIV Futures sample, 79.9% of people aged 50-64 reported living with at least one chronic health condition as well as HIV.

More examples could be drawn from the report, the narrative is clear, living with HIV and living long term with HIV, continue to have negative impacts, not for everyone but for a significant portion of the HIV positive population.

Whilst there is currently an exciting narrative about biomedical advances and HIV prevention, Futures now spanning over twenty years uncovers many areas of concern – mental health, social isolation and the negative impact of other social determinants of health. More investment is needed to ensure good quality of life for all PLHIV in Australia, particularly now that the population is living longer with HIV.

The importance of the HIV Futures studies cannot be overstated. It makes visible some uncomfortable dimensions of our HIV positive lives and suggests there is so much more work to be done. The publication of HIV Futures 9 in 2019 is a great achievement – for what it tells us about our lives, it also sadly reminds us that many friends never saw this future. The report is welcome and provides information from which action can continue.

Congratulations to the ARCSHS team and the many people who have made the production of this report possible.

John Rule PhD

Senior Research Manager, National Association of People with HIV Australia (NAPWHA)

Around 10.6% of the population of people living with HIV in Australia are women, but as the HIV landscape has changed greatly over the years the profile of women living with HIV (WLHIV) has remained relatively unnoticed.

In my role as chair of Femfatales women's network, I am passionate about providing a platform where the diverse and relevant issues for woman living with HIV can be represented and considered in the Australian HIV response. For far too long WLHIV have been a minority living with inequality and often their lives are surrounded with secrets and silence further adding to the unwanted experience of HIV related stigma and discrimination which is often not reported.

Thanks to the HIV Futures surveys we know about the health and wellbeing of PLHIV in Australia. HIV Futures 9 gives a valuable snapshot of positive women's life histories in Australia. Leadership and input into national HIV policy and advocacy work is vital and national studies such as HIV Futures 9 are important as they provide valuable information about PLHIV experiences of living with HIV. Importantly they also shine a needed lens on women's unique experiences and provide data about our overall health and wellbeing. It is due to this research that we can highlight the depth and diversity of the real issues, struggles and discrimination that people face, especially women.

As a woman who has lived openly with HIV uninvited in my life for 32 years my key focus is women, families and their journey. In the current Australian National HIV Strategy, women are included as part of the general HIV population but are not named separately as a priority population. Consequently woman do not see themselves as "at risk" of HIV.

This is unfortunate because for woman living with HIV there are gender differences and we need to understand these differences to ensure we are addressing the issues and unmet needs that specifically women face. Futures 9 provides us with evidence to advocate for women, increase their national profile and lobby for much needed services that are women-specific and family friendly.

HIV Futures 9 shows us that the average age of positive woman is 45 years old. Overall woman's ages ranged between 24 to 69 years. Within this age range woman had lived with HIV from less than one year to through to 35 years. This broad age range and experience living with HIV shows that there is a diversity of lived experiences among participants. This also highlights there is a broad range of knowledge, experience and needs to be considered.

Of the woman surveyed just over two in three were born here in Australia, including woman descendant from Asian, African, European and Pacific countries. These data reflects what we already know about people living with HIV who came to Australia as migrants. Many of these woman report as heterosexual but are often not aware of their HIV status or are not considered to be at risk for HIV testing. There is a need to support people from a diverse range of cultural and ethnic backgrounds and provide appropriate specialised programs and services that will respectfully address their needs.

Important targets have been set by the Australian government under the Australian National HIV Strategy. While the measure is as "people living with HIV" it is vital that women are considered within these targets.

The Strategy goals are:

- 95% of people living with HIV are diagnosed
- 95% of people living with HIV are on ART
- 95% of people living with HIV have an undetectable viral load

Under these ambitious targets HIV Futures reflects that in terms of treatment 98.8% of the surveyed woman are on ART. This is above the set target for ART. Unfortunately the targets are not met around viral suppression with only 81% of the woman surveyed. This is well below the 95% target and below the overall Futures sample of 89%.

Another gender difference from the survey was that for women the average time between HIV acquisition and diagnosis was 2-4 years. By comparison this was 1 year or less for men. This supports what we already know about women being diagnosed late. This is a major concern as it means woman being diagnosed late may have already damaged their immune system and been affected by poor health. This situation around woman's overall health care needs is unacceptable and services and programs to address this are required. The lack of HIV awareness and education for woman and among GP's needs to be flagged as a priority issue of concern.

Another important target in the National HIV Strategy is 75% of people living with HIV reporting a good quality of life. For woman who are often the main carer or parent of children, or ageing parents or partner, 62% reported a good quality of life and overall sense of wellbeing. Programs that can enhance one's overall quality of life need to be available while encouraging women to build up their own resilience to flourish.

One of the major barriers for women when considering a "good quality of life" is living with poverty. We should not underestimate the impact that financial security has on one's quality of life. Most woman who participated in HIV Futures 9 had an income well below the Australian average with more than one in three having a household income of less than $30,000 per year. Women with dependent children were more likely to report financial stress. In the last 12 months more than half of the woman reported or experienced financial stress, such as not able to pay bills or rent, taking loans or needing financial support or not able to afford balanced meals and nutritious food. Living in poverty and experiencing food insecurity make it harder to access good health care which often comes with hidden costs. Having access to appropriate health care and affordable medications is another issue that impacts on overall quality of life.

Most women participants valued connections with other positive people and having another 'peer' to share and connect with was considered valuable. This peer support was a priority for most of the woman. Peer based services and programs played an important role in connections across the positive community.

If we are serious about health equity then we need to address the needs of this marginalised group and advocate loudly. It is important to understand the issues and experiences of the diversity of woman who live with HIV and stand beside them as they navigate the complexities of living with HIV.

Katherine Leane

Chair of Femfatales, the NAPWHA National Network of Women Living with HIV and President of Positive Life South Australia.

ABOUT THIS REPORT

The UNAIDS '90-90-90' goals set international targets for 90% of all PLHIV to know their HIV status, 90% of those diagnosed to receive sustained antiretroviral therapy (ART), and 90% of those receiving ART to be virally suppressed.

The Eighth Australian National HIV Strategy has adopted similar targets including the goals that, by the end of 2022, Australia will (in all priority populations): increase the proportion of people with HIV who are diagnosed to 95%; increase the proportion of people diagnosed with HIV on treatment to 95%; and, increase the proportion of those on treatment with an undetectable viral load to 95%. In addition, the National HIV Strategy focuses on quality of life among PLHIV, setting a target of 75% of PLHIV reporting good quality of life by 2022 (Department of Health 2018). This report aims to provide data to inform progress toward these goals, particularly the quality of life target, by looking at the health and life experiences of PLHIV.

HIV Futures is a study of quality of life among PLHIV in Australia. The study has been running since 1997, having been initiated by community advocates who saw the need for research about how PLHIV were coping socially, emotionally and financially following the introduction of modern highly active combination ART in 1996. HIV Futures involves periodic, cross-sectional surveys of PLHIV, exploring various aspects and indicators of quality of life including: ART use, health, wellbeing, financial security, housing, HIV-related stigma, sex and relationships. This report is of findings from the ninth iteration of HIV Futures.

When the HIV Futures study was established in 1997, highly active combination ART had only been available in Australia for 12 months. This meant that, while ill-health and HIV treatment remained a major issue of concern for many people living with HIV, other life issues were coming into focus again – relationships, identity, employment and housing. Many people living with HIV were considering returning to work as their health improved. For some people, longer life expectancy required reconsideration of their financial situation, and some found themselves struggling financially. As such, the 1997 HIV Futures study was designed to identify and explore needs of PLHIV in the 'new era' of ART.

Since 1997, HIV Futures surveys have been completed every two to three years. The surveys have now tracked the life-experiences of PLHIV for more than 21 years as ART has improved and the landscape of HIV prevention, treatment and care has changed dramatically. Today, one of the biggest issues facing PLHIV as a community is ageing. Increasing numbers of PLHIV are living well into their retirement years. However, there are still some unknowns about the health and social impact of ageing with HIV. Other issues continue to be of concern for many PLHIV including financial stress and the impact of HIV-related stigma and discrimination on everyday lives.

Data for the HIV Futures 9 survey were collected between December 2018 and May 2019. The survey instrument comprised 148 questions related to health, wellbeing, financial security, social connection and relationships. Participants had the choice to respond online or using a hardcopy booklet. The survey was advertised online and through relevant community networks, particularly those of the community PLHIV organisations. Details of the survey method are presented in the appendix.

This report includes a presentation of core findings and some analysis of trends over time. The report cannot and does not aim to express the full diversity of experiences and complexities of the lives of PLHIV. The authors nonetheless hope that it is useful for maintaining, validating and improving policy and service responses to continue to support PLHIV to live healthy, connected and fulfilling lives. There will be further opportunities in the coming months for deeper analysis of these data, and we will continue to make findings available.

The study 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 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 providing input to analysis. This includes The Institute of Many (TIM), Living Positive Victoria, Positive Life NSW, Queensland Positive People, Positive Living South Australia, acon, Thorne Harbour Health, The WA AIDS Council, The AIDS Action Council of the ACT, TasCAHRD and NTAHC, along with many other supportive agencies and individuals. The project is officially endorsed 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).

HIV Futures 9 sample

The HIV Futures 9 survey was completed by 847 PLHIV in Australia. Given current estimates of HIV infection in Australia (The Kirby Institute 2018) this represents approximately 3% of the HIV positive population.

A NOTE ABOUT QUOTATIONS

Quotations have been included throughout this report as brief illustrations of individual experiences. These were derived from an open text question in the HIV Futures 9 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 show the voices of some participants. To protect anonymity, identifying details have been removed and demographic labels have not been attributed to quotes. In some cases, typing or grammatical errors have been amended for clarity.

DEMOGRAPHIC CHARACTERISTICS

In Australia, there are around 28,000 people who live with HIV and around 1,000 new cases each year (The Kirby Institute 2018).

Transmission of HIV in Australia has historically been most common among Australian-born men who have sex with men (MSM), but the population of people living with HIV (PLHIV) in Australia has always been diverse – including people of all ages, genders and sexualities – and it is becoming more diverse. Specifically, the proportion of women, men born overseas, and Aboriginal and Torres Strait Islander people diagnosed with HIV is increasing while rates of more recent HIV diagnoses among Australian born MSM are decreasing (The Kirby Institute 2018).

HIV Futures 9 provides a valuable snapshot of the demographic profile of PLHIV in Australia, giving insight into the socio-economic and other characteristics of the Australian population of PLHIV. However, it is worth noting that there may be some gaps. People, notably, who are not fluent in English may have found it harder to complete the survey instrument, so may be under-represented.

Number of participants

There was a total of 847 valid responses to HIV Futures 9.

Participants completing less than 20% of the survey instrument, or who did not meet the criteria (18 years or older, living in Australia and diagnosed with HIV), 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 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:

- 88.1% (n=731) identified as men/male including one transgender man
- 10.6% (n=88) identified as women/female, including seven transgender women
- 1.3% (n=11) identified as non-binary or gender fluid.

Note that because only one participant was a transgender man, it was not possible to report on trends among transgender men. Therefore responses from the transgender male participant were included in analysis where the broader groupings of "men" or "transgender participants" were used (and in other demographic groupings such as age), but the category of "transgender men" could not be included among the gender groupings in the figures and statistics below because of the extremely low sample size.

Nine participants (1.1%) reported that they had intersex traits. This is roughly consistent with what is known about the proportion of people born with intersex traits 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:

- 74.1% (n=600) identified as gay/homosexual
- 14.9% (n=121) identified as heterosexual or straight
- 5.4% (n=44) identified as bisexual
- 2.7% (n=22) identified as queer
- 1.1% (n=9) identified as pansexual
- 0.7% (n=6) used a different term
- 1.0% (n=8) selected "prefer not to specify".

"I don't describe myself to, or adhere to sexuality, I am simply me."

Almost three in four participants were cisgender gay men (73.8%, n=584). The next-largest group was cisgender heterosexual women (8.8%, n=70). Details of gender and sexuality are in Table 1 below.

Table 1. Gender and sexuality of participants

	Gay or homosexual	Heterosexual or straight	Bisexual or pansexual	Queer or other	Sexuality data missing or chose 'prefer not to say'	Total
Cisgender women	0	70	6	2	3	81
Cisgender men	584	47	43	21	35	730
Non-binary or gender fluid	6	0	1	4	0	11
Transgender men	1	0	0	0	0	1
Transgender women	1	2	3	0	1	7
Gender data missing	8	2	0	1	3	17
Total	600	121	53	28	45	847

Age

Participants' ages ranged from 18 to 85, with an average and median age of 50 years (n=820).

The median age of the sample has increased steadily since the HIV Futures project first started in 1997, from 38 in 1997 to 51 in HIV Futures 8 (2015/16). This is the first time it has decreased (Figure 1).

"Growing older and keeping very fit is fabulous.
Six-pack on a 57 y/o is always gonna look hot"

Figure 1. Median age of HIV Futures participants
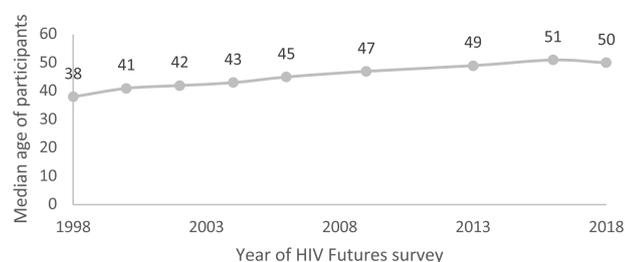
"I can't help but wonder what kind of aged care facilities cater to LGBTQI people, especially outside of the city centres. I don't hear anyone talking about aged care for LGBTQI people and I feel it's an issue that needs addressing particularly for people getting older with HIV."

In the HIV Futures 9 sample, the average age of women was five years lower than that of men (45 years compared to 50 years respectively). The average ages of gay and bisexual men (50 and 51 years respectively) was slightly higher than for heterosexual participants (49 years). This is consistent with the national trend of new HIV diagnoses falling among Australian-born men who have sex with men (MSM), meaning the overall population of MSM living with HIV is ageing, but not other groups.

Participants identifying as pansexual or queer were younger than average (42 and 47 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 and Gilbert 2018).

Language and cultural diversity

The majority of participants were born in Australia (71.4%, n=573). Ninety percent spoke English as a first language and 87.6% (n=742) spoke English at home. Of those born outside Australia, the most common countries of birth were the United Kingdom (8.0%, n=64), New Zealand (5.5%, n=44) and South Africa (1.2%, n=10). Overall, 11.3% (n=91) of participants were born in European countries, 5.2% (n=42) in Asian countries, and 2.6% (n=21) in African countries (Figure 2). Sixty countries of birth were listed in total.

Figure 2. Region of birth for people born outside of Australia
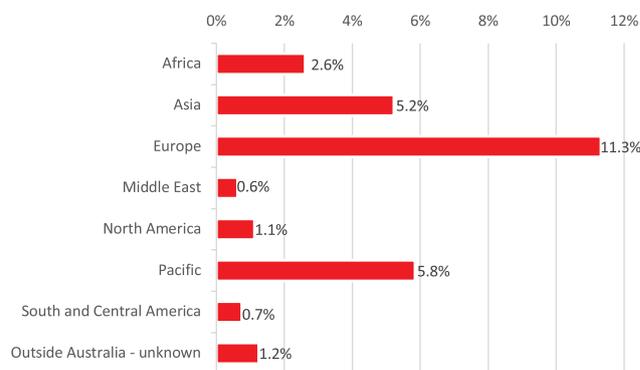
The proportion of participants born in Australia has been roughly constant over time, though this survey had a slightly larger proportion of participants born overseas than any previous survey, as shown in Figure 3 below.

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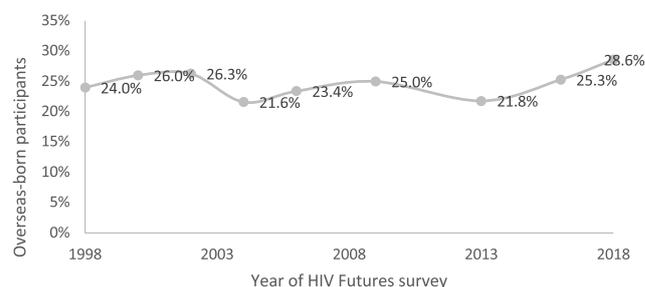
Citizenship, residency, and visa status

The majority of participants (81.2%, n=688) were Australian citizens and 12.7% (n=107) were permanent residents. There was a small number of participants (5.4%, n=46) who were not citizens or permanent residents. Of those who provided details of their visa status, thirteen 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=216), most (57.4%, n=124) had been living in Australia more than twenty years, while 13.9% (n=30) had been in Australia for less than five years.

"As I am on temporary work visa, and contracted HIV after coming back to Australia. My priorities in life have changed. Now I want to stay in Australia because of better medical facilities and less stigma compared to India. I get anxious and depressed about the difficult process and strict restrictions on visa conditions for PLHIV despite the fact that many of us diagnosed with HIV can live healthy life without being a burden on Australian government."

"As an international student, I was afraid to admit my HIV+ statement while I applied for a student visa. When I arrived in Australia it was problem for me to get treatment. But I'm lucky, I found a doctor who can help me."

Aboriginal and Torres Strait Islander participants

Thirteen participants indicated that they were Aboriginal (1.5%) and one indicated that they were both Aboriginal and Torres Strait Islander (0.1%). Of participants who were Aboriginal and Torres Strait Islander, one was aged under 35, five were 35 - 49, seven were 50 - 64, and one was aged over 65. Seven lived in New South Wales, three in Victoria, three in Queensland and one in South Australia.

The rate of new HIV diagnoses among Aboriginal and Torres Strait Islander people is increasing (The Kirby Institute 2018) and there is an urgent need for more resources to be diverted toward HIV prevention, treatment and care for Aboriginal and Torres Strait Islander people in a way that is culturally appropriate and community led. 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 a need for dedicated research to better understand the needs of Aboriginal and Torres Strait Islander people living with HIV.

Location of residence

Most participants resided in inner urban areas (62.4%, n=526) with smaller proportions from outer suburban areas (15.7%, n=132), regional centres (14.9%, n=132) and rural areas (7%, n=59). Response rates were highest in New South Wales (37.7%%, n=317) and Victoria (27.3%, n=230), 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)	Percent (%)
NSW	317	37.7
VIC	230	27.3
QLD	137	16.3
SA	74	8.8
WA	43	5.1
ACT	23	2.7
TAS	12	1.4
NT	5	<1
Total	841	100

Education

The level of education amongst participants was diverse. Ten (1.3%) had attended primary school only, while 22.9% (n=180) had postgraduate degrees. Educational levels are shown in Table 3 below.

Table 3. Highest educational level attained

Level	Frequency (n)	Percent (%)
Primary school only	10	1.3
Up to four years high school	105	13.3
Leaving certificate/HSC/VCE	95	12.1
Tertiary diploma/trade certificate/TAFE	219	27.8
Undergraduate university degree	178	22.6
Postgraduate university degree	180	22.9
Total	787	100

Employment and income

Just over half the participants were in paid work, either full-time (41.5%, n=350), part time (9.1%, n=77) or casual (5.5%, n=47) (Table 4). Around one third were not working/retired (19.6%) or not looking for work (10.3%). The comments provided in open text response indicate that many of those not working were on disability pensions, while some were full-time carers for parents or partners.

Table 4. Main employment/activities

	Frequency (n)	Percent (%)
Work full-time (30+hours per week, including self-employment)	350	41.5
Not working, including retired	165	19.6
Unemployed, not looking for work	87	10.3
Work part time (less than 30 hours per week)	77	9.1
Unemployed, looking for work	59	7.0
Work casual	47	5.5
Student	31	3.7
Home and/or caring duties	19	2.3
Other	8	<1
Total	843	100

Consistent with the employment patterns of participants, the most common income source was salaries or wages (52.0%, n=437), followed by benefits, pension or social security (35.3%, n=297) (Table 5).

Table 5. Main income source

	Frequency (n)	Percent (%)
Salary/wages	437	52.0
Benefits/pension/social security	297	35.3
Savings	35	4.2
Superannuation	38	4.5
Partner supports me	15	1.8
Family/friends support me	5	<1
Annuity	4	<1
Other	10	1.2
Total	843	100

The most common reported household income was $50,000 to $79,999 per year (17.9%, n=150), although 263 (33.3%) reported an income below $30,000 per annum. Overall, 66.7% (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

	Frequency (n)	Percent (%)
Negative or zero income	20	2.5
$1 - $29,999	243	30.8
$30,000 - $49,999	114	14.4
$50,000 - $79,999	150	19.0
$80,000 - $99,999	86	10.9
$100,000 - $124,999	59	7.5
$125,000 - $149,999	38	4.8
$150,000 - $199,999	39	4.9
$200,000 or more	40	5.1
Total	789	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*
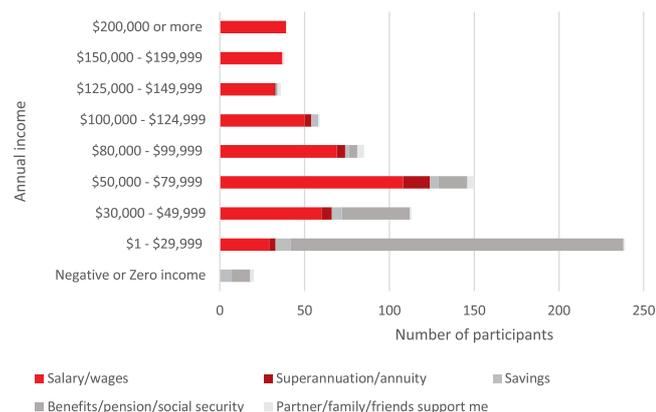
Living arrangements

Almost half the participants lived alone (44.7%, n=345), one in four lived with their partner (27.5%, n=212), 16% (n=122) with friends, and 10.0% (n=77) with other family members, including some who lived with a partner as well as family (n=10) or friends (n=5).

There were 39 who lived with children, including 2.1% (n=16) who lived with their partner and children and 3.0% (n=23) who lived with their children without a partner.

Of those who answered *other*, responses included that they lived with their ex-partner, lived with a carer, or rented a room in their house to boarders or backpackers (Table 7).

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

	Frequency (n)*	Percent* (%)
Live alone	345	44.7
Live with partner/spouse with no children	196	25.4
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
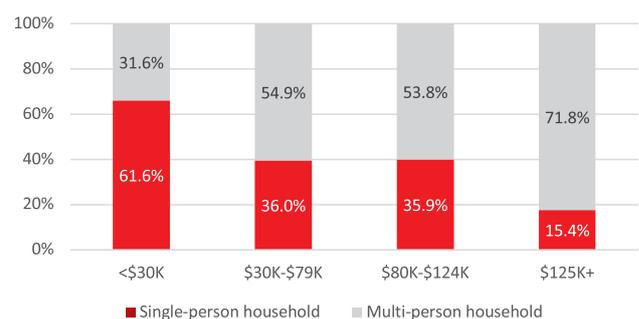
A considerable number of participants reported that they did not live alone because they lived with their pet(s), or people indicated they lived with both pets and other adults (Table 8). Overall 13.6% (n=105) of participants reported living with a pet.

Table 8. Number of participants living with pets

	One-person household	Multi-person household	Total
No pets	299	367	666
Pet(s)	46	59	105
Total	345	426	771

QUALITY OF LIFE

In recent years there have been calls to add a fourth 90% to the UN 90-90-90 goals – that 90% of PLHIV report good quality of life (QoL) (Lazarus, Safreed-Harmon et al. 2016).

This call to renew a focus on QoL among PLHIV is grounded in principles of care and support for PLHIV. It is also drawn from research that suggests attention to QoL among PLHIV will be instrumental in achieving goals relating to maintaining ART adherence and viral suppression. For instance, there is evidence that PLHIV with low psychological and social wellbeing are less likely to adhere to treatment (Katz, Ryu et al. 2013). In line with this, the Australian Eighth National HIV Strategy aims to achieve 75% of PLHIV reporting good quality of life by 2022, emphasising that improving quality of life is an essential part of both HIV management, care and HIV prevention.

The World Health Organisation proposes a comprehensive, and culturally located, definition of QoL:

"(An) individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment" (World Health Organization 1997).

As this definition suggests, there are multiple factors that may affect an individual's QoL, including their physical or mental health, financial status, family and social connections and access to support. In addition, PLHIV may face unique challenges that have an impact on QoL, such as HIV-related stigma, concerns about possible ill-health, treatment effects or comorbidities.

In HIV Futures 9, we used two measures of QoL: the PozQol scale and a one-question measure of overall wellbeing. PozQol is a 13-item scale that was developed specifically to assess QoL of PLHIV across four domains: health concerns, psychological, social, and functional aspects of wellbeing. The measure was developed in Australia and has been validated with Australian PLHIV (Brown, Mikołajczak et al. 2018). Given PozQoL is a newly developed measure, this is the first time we have incorporated it into an HIV Futures survey. The intention is for HIV Futures 9 to provide a baseline measure for the National HIV Strategy of the proportion of PLHIV reporting good quality of life against which change over time can be measured. It will also enable us to identify factors associated with improved quality of life.

Along with PozQoL, we report on responses to a single-question item asking 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), so we are able to measure change over time.

Quality of life – progress toward national targets

Responses to each item in the PozQol scale were recorded using a five-point Likert scale (*1=not at all, 2=slightly, 3=moderately, 4=very, 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 three or higher (*moderately, very or extremely*) in response to the majority of items in the scale – that is, they would have scored the mid-point of three or higher for each item on the five-point scale.

In HIV Futures 9, 63.1% (n=492) had a PozQol score of 3.0 or higher. The Australian National HIV Strategy target is to achieve 75% of PLHIV reporting 'good' quality of life by 2022.

> In HIV Futures 9, 63.1% (n=492) reported good quality of life (PozQol score of 3.0 or higher)

The overall average PozQol score for HIV Futures 9 participants was 3.24 (SD=0.87). The PozQol scale contains four separate subscales: health concerns, psychological, social, and functional aspects of wellbeing. The average scores for each of these subscales was as follows:

- Psychological: 3.3
- Functional: 3.7
- Social: 3.0
- Health concerns: 3.0

Based on this, we can see that scores in the functional and psychological domains were higher (and brought the overall average up). Higher scores in the functional domain suggests that, for many people, HIV has a limited impact on everyday life functions. For example, 36.3% (n=294) indicated that HIV did not at all prevent them from doing as much as they would like, and 30.3% (n=246) indicated that HIV did *not at all* reduce their opportunities in life. In the psychological domain, most people indicated that they felt optimistic about their future (38.5%, n=311, indicating *very* or *extremely* optimistic) and in control of their life (41.4%, n=335, indicating *very* or *extremely* in control) (Figure 6).

Scores were lower in the health concerns and social domains. With respect to health concerns, more than one in five participants indicated they were *very* or *extremely* concerned about the health effects of HIV as they age (29.3%, n=240), while only a small percentage had no concerns about their current or future health (11.3%, n=91, indicated they were not at all concerned). The social domain revealed the negative impact of stigma on quality of life, with nearly half (46.9%, n=380) indicating they were very or *extremely* afraid that people may reject them when they disclose their HIV status. In addition, more than one in four indicated they lack a sense of belonging to people around them (28.2%, n= 228, indicting they *very* or *extremely* lack a sense of belonging). Responses to each of the 13 PozQol items are shown in Figure 6.

Figure 6. Responses to each PozQol items across four domains (psychological, functional, social, health concerns)

Item	Not at all	Slightly	Moderately	Very	Extremely
I feel good about myself as a person (psychological)	8.6	14	33.3	30.5	13.6
I am optimistic about my future (psychological)	10.8	18.7	32	27	11.5
I feel in control of my life (psychological)	9.3	15.6	33.7	31.9	9.5
I am enjoying life (psychological)	5.5	15	40.2	30.3	9
Managing HIV wears me out (functional)	36.7	27.1	19.4	10.3	6.5
Having HIV limits my opportunities in life (functional)	30.3	28.5	17	14.7	9.5
I feel that HIV prevents me from doing as much as I would like (functional)	36.3	25	18	12.9	7.8
I am afraid that people may reject me when they learn I have HIV (social)	15.7	21.1	16.4	18.7	28.1
I lack a sense of belonging with people around me (social)	24.2	25.3	22.2	17.8	10.4
I feel that HIV limits my personal relationships (social)	21	23.1	15.9	18.4	21.5
I fear the health effects of HIV as I get older (health)	11.4	22.4	24	19.8	22.3
I worry about the impact of HIV on my health (health)	13.3	32	25.1	17.6	11.9
I worry about my health (health)	7.3	31.1	34.2	19.5	7.8

■ 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, presence of pets in the household, number of years living with HIV, social connectedness and general health. 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: being in the paid workforce, higher income, no recent financial stress, living in inner city areas, better general health, a greater level of social connectedness, and living with a partner/spouse. People in the 50-64 age bracket were less likely than people in any other age group to report good quality of life.

"I am very appreciative of the medical support and drug availability through the government medical services over nearly 39 years that has provided me with a quality of life and that has meant I have remained happy healthy and productive."

Table 9. Factors significantly associated with PozQol Scores (key differences within groups highlighted)

PozQoL Score	Less than 3.0 (poorer quality of life)	3.0 or higher (good quality of life or higher)	p-value
Age			
<35	41 (35.0%)	76 (65.0%)	
35-49	86 (37.9%)	141 (62.1%)	
50-64	129 (40.2%)	192 (59.8%)	p=0.055
65+	24 (25.0%)	72 (75.0%)	
Employment status			
Not currently in paid work	141 (42.0%)	195 (58.0%)	
Part time or casual work	41 (36.3%)	72 (63.7%)	p<0.05
Full-time work	102 (31.7%)	220 (68.3%)	
Financial stress (in past 2 years)			
Experienced financial stress	111 (52.6%)	100 (47.4%)	p<0.001
No financial stress	145 (32.1%)	307 (67.9%)	
Household annual income			
<$30,000	110 (44.7%)	136 (55.3%)	
$30,000-$79,999	95 (38.9%)	149 (61.1%)	
$80,000-$124,000	38 (27.9%)	98 (72.1%)	p<0.001
$125,000+	22 (20.8%)	84 (79.2%)	
SF-36 general health subscale score*	37.5(19.9)	65.0(20.2)	p<.0.001
Social connection, mean score (SD)**	3.87 (1.10)	5.10 (1.12)	p<0.001
Live with partner/spouse			
Yes	51 (27.0%)	138 (73.0%)	p<0.05
No	210 (39.9)	316 (60.1)	
Residential location			
Capital city/inner suburban	172 (35.3%)	315 (64.7%)	
Outer suburban	57 (47.5%)	63 (52.5%)	p<0.05
Regional/rural	58 (33.7%)	114 (66.3%)	

*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

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 7.

Overall, 50.5% (n=410) reported their wellbeing to be good or excellent. Factors associated with higher wellbeing were: higher levels of education, being in the paid workforce, no recent experience of financial stress, higher household income, better general health, 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 *good* or *excellent* wellbeing.

Figure 7. Overall physical, emotional and mental wellbeing (self-reported)
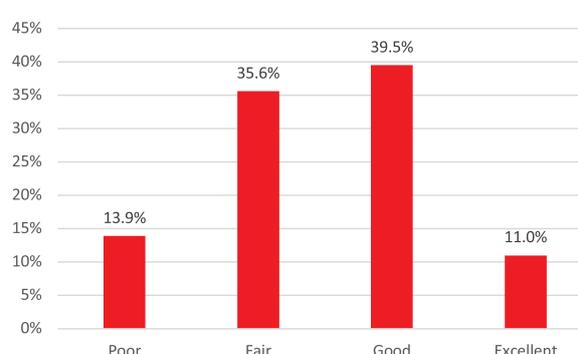
Table 10. Factors associated with self-reported wellbeing* (key differences within groups highlighted)

Overall wellbeing	Poor, n (%)	Fair, n (%)	Good, n (%)	Excellent, n (%)	p-value
Age					
<35	13 (10.7)	42 (34.7)	55 (45.5)	11 (9.1)	
35-49	37 (15.8)	89 (38.0)	84 (35.9)	24 (10.3)	p<0.05
50-64	50 (14.9)	125 (37.3)	128 (38.2)	32 (9.6)	
65+	9 (8.9)	281 (35.5)	49 (48.0)	19 (18.6)	
Education					
Up to high school	37 (18.0)	76 (37.1)	79 (38.5)	13 (6.3)	
TAFE/Diploma/Trade	33 (15.6)	81 (38.2)	76 (35.8)	22 (10.4)	p<0.05
Tertiary Under/Post graduate	38 (11.1)	113 (32.9)	146 (42.6)	46 (13.4)	
Employment status					
Not currently in paid work	73 (20.8)	146 (41.6)	114 (32.5)	18 (5.1)	
Part time or casual work	10 (8.4)	39 (32.8)	50 (42.0)	20 (16.8)	p<0.05
Full-time work	28 (8.4)	100 (30.1)	154 (46.4)	50 (15.1)	
Financial stress (in past 2 years)					
Experienced financial stress	53 (24.1)	94 (42.7)	65 (29.5)	8 (3.6)	
No financial stress	50 (10.7)	156 (33.3)	200 (42.7)	62 (13.2)	p<0.001
Household annual income					
<$30,000	52 (20.1)	105 (40.5)	87 (33.6)	15 (5.8)	
$30,000-$79,999	36 (14.3)	91 (36.3)	93 (37.1)	31 (12.4)	p<0.001
$80,000-$124,000	8 (5.7)	49 (35.0)	64 (45.7)	19 (13.6)	
$125,000+	7 (6.4)	24 (22.0)	57 (52.3)	21 (19.3)	
SF-36 general health subscale score **	28.7 (18.7)	43.5 (19.4)	62.8 (17.6)	81.7 (13.9)	p<0.001
Social connection, mean score***	3.6	4.2	5.1	5.7	p<0.001
Live with partner/spouse					
Yes	15 (7.5)	55 (27.4)	97 (48.3)	34 (16.9)	p<0.001
No	87 (16.0)	205 (37.8)	203 (37.4)	48 (8.8)	

*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

Self-reported wellbeing over time

Figure 8 shows the percentage of people who reported their overall wellbeing to be good or excellent in HIV Futures surveys from 2001 onwards. This percentage is substantially lower in HIV Futures 9 than in previous years and 9% lower than in HIV Futures 8 (2015/16).

Figure 8. HIV Futures participants reporting overall wellbeing to be good or excellent over time
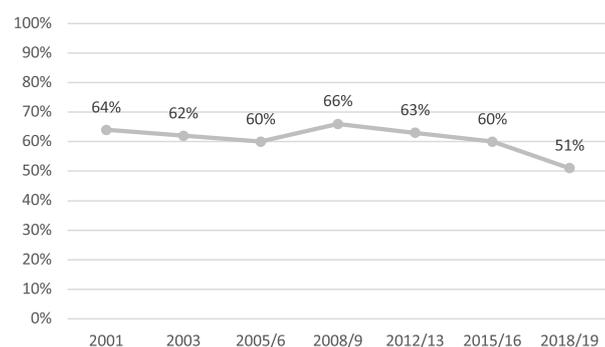
The reasons for this are likely to be complex and related to broader societal issues that we cannot easily identify with these data. However, financial stress may be one factor negatively affecting wellbeing among PLHIV. As noted, factors significantly associated with *poor* wellbeing are being out of the paid workforce, lower levels of education, lower income and recent financial stress (Table 10, above). Comparing responses to HIV Futures 8 (2015/16) with those of HIV Futures 9, there are no substantial differences in the number of people out of the workforce or the proportion in low income brackets. However, there was an increase in the proportion of participants reporting recent financial stress. In HIV Futures 8, 23% reported experiences of financial stress in the past two years, compared to 31% in HIV Futures 9 (for more details on financial stress see the Financial and Housing Security chapter below).

FINANCIAL AND HOUSING SECURITY

Financial security enables access to safe housing and other basic elements of survival – food, clothing and healthcare.

Beyond basic survival, financial security is also core to quality of life because it gives people choice over factors fundamental to everyday life, such as where they live, the type of housing in which they live, or educational and employment opportunities. Financial security also facilitates contact with the social world. For many people, an inability to afford eating out or pay costs associated with events and social gatherings can contribute to social isolation. Some research also shows that basic financial security improves people's subjective sense of quality of life and wellbeing, possibly because it alleviates worry about the future (Howell, Kurai et al. 2013; Baker, Mason et al. 2003).

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 (Colic-Peisker, Ong et al. 2015).

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

Private rental was the most common form of housing among HIV Futures 9 participants, with 42.7% (n=340) indicating they lived in private rental, 17.0% (n=135) owning their home with a mortgage, and 16.5% (n=131) owning their home outright (no mortgage) (Table 11). Compared to Australian averages, participants in HIV Futures 9 were substantially more likely to live in private rental accommodation and less likely to own their own home. In the 2016 Australian census, 30.9% were living in rental accommodation, 34.5% owned their home with a mortgage, and 31.0% owned their home outright (Australian Bureau of Statistics 2017).

"I am homeless [and] have been for 5 years. I have cataracts. As I have no support, my eyes are getting worse. They closed [accommodation service] down here in Adelaide, so nowhere to recover, as the hospital is a 2-hour drive. I did have friends but when they found out, they wanted no part of me or my three kids and stopped talking to me. So I live a very lonely life."

In HIV Futures 9, 1.7% (n=13) of participants reported that they were homeless, including those living in boarding houses or crisis accommodation. This is 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).

Table 11. Current housing arrangement

	Frequency (n)	Percent (%)
Private rental	340	42.7
Home purchaser (with mortgage)	135	17.0
Home owner (own outright)	131	16.5
Public or community housing	131	16.5
Rent-free (e.g. with friends or family)	34	4.3
Boarding house, crisis accommodation or homeless	13	1.7
Institution	2	<1
Other	10	1.3
Total	796	100

"In [my state] it is illegal to live on a boat so I am technically homeless. I get great support from the "station" homeless shelter who obviously deal with many clients with other problems so I fit in."

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 (Figure 9). In all age groups, except for those aged 65+, private rental was the most common form of housing. Among participants aged under 35 years, more than two-thirds (76.3%, n=90) were in private rental accommodation, compared to less than 20% of those aged 65+ (Figure 9). While people aged 50 years and older were more likely than younger people to own a home, close to one third of people aged 50 years or older lived in private rental accommodation (28%, n=120).

"Treatment has improved so very much but I have health issues from early medication (AZT, etc.) and long-term HIV. I live in a nice home which is government housing. Been on DSP for 10yrs and work small amount part time, I lost many friends in the early 1990's. So, doing okay :)"

As shown in Figure 9, people in the 50-64 year age bracket were significantly less likely than those aged 65+ to own a home outright, while one in three were in private rental (31.2%, n=100) or other forms of accommodation (32.4%, n=104), most commonly public housing or community/social housing. 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 (Morris 2009, Colic-Peisker, 2015).

Figure 9. Housing type by age
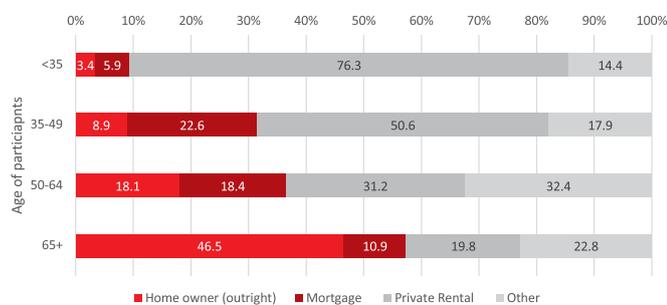
Housing and gender

Men were more likely to own their home than people of other genders (Figure 10). This differs to the general Australian population, where in the 2015-16 Australian Survey of Income and Housing, 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). Cisgender women and transgender, non-binary or gender fluid participants were most likely to be in private rental, 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.

"I am still working 57 hours a fortnight paying private rent, very stressed about this problem."

Figure 10. Housing type by gender
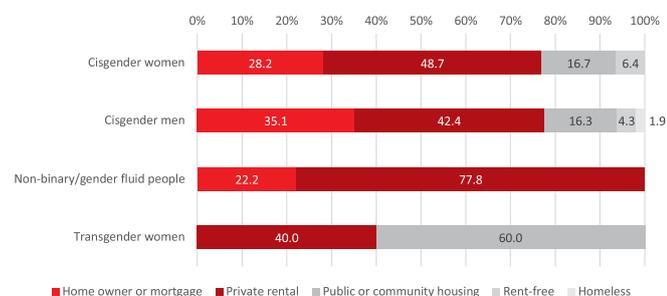
Recent financial stress

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 are considered to have experienced significant financial stress (Wilkins 2016).

"I am near pension age and worked for myself most of my career. After my bashing all those years ago I qualified for disability support, but it was reviewed 3 years ago and decided that I should go onto Newstart. Since I'm no longer a pensioner I don't qualify, and can't afford the specialists and tests to re-apply. My income is not enough for a human to live on, so I stopped taking all my medications, and rarely leave the house, except for medical and Centrelink appointments. These happen often enough for me to get groceries once a week en-route."

Overall, 31.0% (n=225) of HIV Futures 9 participants were classified as experiencing significant financial stress. As a point of comparison, in the Household, Labour, Income Dynamics 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 2018).

In HIV Futures 9, people more likely to have experienced financial stress in the past 12 months were those living in rural or regional areas (Figure 11), people aged under 50 years (Figure 12), and women (including cisgender and transgender women, Figure 13).

"I'm very disappointed the way my life turned out. I have lost everything. Trust, money, friends, family. I feel on my own in this world."

Figure 11. Proportion of participants within each location category indicating financial stress)
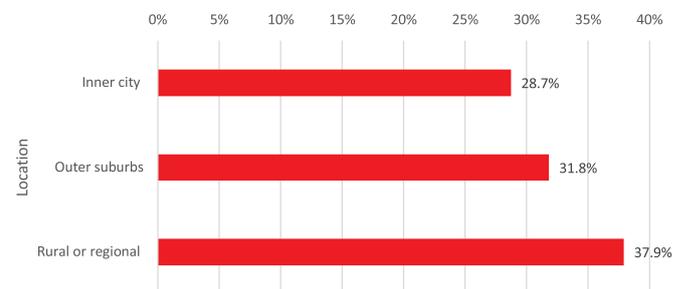
Figure 12. Proportion of participants in each age category indicating financial stress

Financial stress was correlated with housing type. Participants who were homeless were most likely to have experienced financial stress, although overall numbers were small (85.7% of 7 participants).
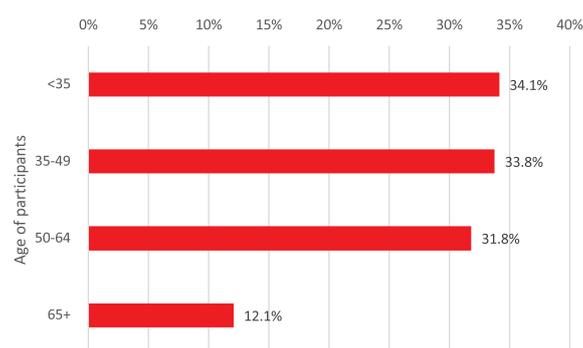
Figure 13. Financial stress by gender

Figure 14. Proportion of participants living in housing types reporting recent financial stress*
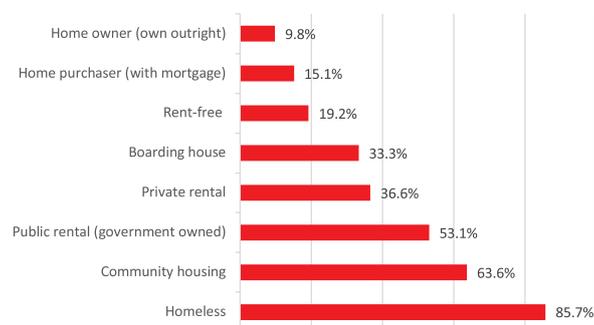
* Note that participants living in boarding houses have been decoupled from homeless participants and participants living in community housing have been decoupled from those living in public housing

Those who owned their homes outright were least likely to be financially stressed (9.8% of 92 participants). More than a third of participants living in private rental had experienced financial stress (36.6% of 309 participants).

Food security

Food security refers to consistent access to good, nutritious food. People may experience "food insecurity" due to a range of factors, including illness or disability, poverty or broader cultural or environmental issues. Food insecurity is associated with lower reported quality of life and poorer general wellbeing, so measures of food (in)security (Campbell 1991) form a valuable part of the picture of quality of life for PLHIV.

HIV Futures 9 participants were asked two questions about their income and food security – whether they had enough income to purchase food and whether they could afford to eat balanced meals regularly. These questions are validated measures of food security among PLHIV (Young, Jeganathan et al. 2009). Overall:

- 6.7% (n=57) of participants reported that in the last 12 months, the food they bought *often* did not last and they did not have money to get more. An additional 20.4% (n=168) reported that this *sometimes* occurs
- 9.2% (n=78) reported that they *often* couldn't afford to eat balanced meals. An additional 22.0% (n=186) reported that this *sometimes* happens.

"Not enough support so can work part time and stay housed, stay healthy by not working overly hard, and have better benefit flexibility / access … not be locked into Newstart rules that don't take into account my needs or capabilities."

Healthcare costs and access

Australian citizens have access to some government-funded healthcare. However, there may be other costs associated with healthcare, including consultation or medication co-payments that make it difficult for some people to access health care.

"The financial assistance with HIV drugs is supremely reassuring and impossible to imagine what would happen for me and others if it were not the case."

The majority of HIV Futures 9 participants had access to bulk-billing services for HIV-related care or treatment (85.5%, n=584) and two in three (63.9%, n=493) were able to access free antiretroviral therapy (ART) treatment.

For those who did pay for ART, the mean cost was $32 per month (SD=$35), with a range from $1.50 to $250 per month. Compared to people in other age groups, costs were highest for those aged 50-64 (average cost of $34 per month for those who paid for ART) but this difference was not statistically significant.

Where PLHIV had access to free or subsidised ART, some still struggled to meet the costs associated with treatment, such as transport to clinics or the fees for specialists to treat comorbidities or other health conditions (including mental health, discussed below). For example:

- 7.8% (n=62) of participants reported that they had not taken their HIV medication at least once in the last 12 months because of financial reasons
- 6.2% (n=47) reported that it was financially *very difficult* to access healthcare, and a further 20.2% (n=152) reported that it was *somewhat difficult*
- 10.5% (n=80) reported that it was financially *very difficult* to access medication, and a further 27.7% (n=211) reported that it was *somewhat difficult*.

"The pension doesn't cover my needs when I have to cover (all my health conditions), if it wasn't for my pharmacist I would not be able to meet my costs"

Medicare and private health insurance

Most participants (96.7%, n=740) were eligible for Medicare, 1.2% (n=9) were covered by a reciprocal health care agreement, and 2.0% (n=15) were Medicare ineligible. Around half (47.1%, n=397) of the participants had a healthcare concession.

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 one in three (39.2%, n=330) participants had private health insurance and 1.9% (n=16) had overseas student health cover. Of those with health insurance, around a third (32.6%, n=112) reported that it was *likely* that they would have to give up health insurance in the next five years due to the expense.

"I feel lucky to be an Australian. I have Housing security, Medicare security, expert HIV doctors and the best treatments. I have access to health support should I need it."

HIV DIAGNOSIS, TREATMENT AND CLINICAL CARE

The targets of 95% of PLHIV diagnosed, on treatment and virally suppressed will only be achieved if all PLHIV have access to affordable treatment and quality clinical care.

However, there may be barriers to this for some people which relate to a range of factors including difficulties with treatment, cost of treatment or care, or geographic distance to clinics (Lea, Anning et al. 2019; Glenister, Disler et al. 2019). In this chapter we report on aspects of HIV diagnosis, ART uptake and clinical care that may help to inform progress toward these targets.

"I feel very lucky that I live in Australia, where I am more than 90% happy with the treatment that I generally receive for my HIV condition!!"

Mode of HIV acquisition

Participants were asked to identify how they acquired HIV, if known. Consistent with national HIV surveillance data (The Kirby Institute 2018), male-to-male sex was the most common mode of transmission (78.1% of participants, n=611) (Table 12).

Years living with HIV

The number of years participants had been living with *diagnosed* HIV ranged from less than one to 37 years (average of 15 years). The average number of years people had been living with HIV (including time prior to diagnosis) was 17 years. The majority of the sample (60.7%, n=408) had been living with (diagnosed) HIV for more than 10 years (since 2008 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 ten people aged 65+ (11.7%, n=11) and one in five people aged 50-64 (20.7%, n=62) had been diagnosed in the past 10 years.

"When I was first diagnosed the HIV clinic was in the bowels of [city hospital]. The nurses were visibly uncomfortable taking blood tests. If a patient needed a room for an overnight stay (for other tests) their meals would be left outside the room on the floor. Having said that [support service] (once up and running) provided a palliative and caring environment, particularly allowing the two hospital cats to roam! Many a friend ended up there and couldn't speak highly enough."

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, although there was a high non-response rate to this question as some participants were unsure about the year they acquired HIV. The majority of participants tested positive for HIV in the same year that they acquired the virus (53.8%, n=313), while 27.1% (n=158) tested positive the following year. The average time between acquisition and diagnosis was 1.1 years (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 (2008 or more recently), 86.5% (n=192) had been diagnosed within two years, and 96.9% (n=215) had been diagnosed within five years.

"When I was diagnosed in… 2000, I was informed that I would only have roughly 6 years to live. This was misinformation and made my introduction to living with HIV extremely difficult. This had a big impact on my life in a negative way. I'm grateful to still be alive but could have done without receiving that information at the time."

Figure 15. Number of years between HIV exposure and diagnosis by year of HIV diagnosis

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	611 (88.6)	64 (77.1)	9 (100)	684 (87.5)
Injecting drugs	21 (3.0)	6 (7.2)	0	27 (3.5)
Sex with a woman	21 (3.0)	2 (2.4)	0	23 (2.9)
Blood products	9 (1.3)	2 (2.4)	0	11 (1.4)
Other	9 (1.3)	5 (6.0)	0	14 (1.9)
Unknown	19 (2.7)	4 (4.8)	0	23 (3.1)
Total	690 (100)	83 (100)	9	782 (100)

The length of time between acquisition and diagnosis was longer for women than men: an average of 2.4 years for cisgender women and 1.2 years for transgender women compared to an average of 1.0 years for cisgender men, as shown in Figure 16. 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 16. Average number of years between acquisition and diagnosis of HIV by gender
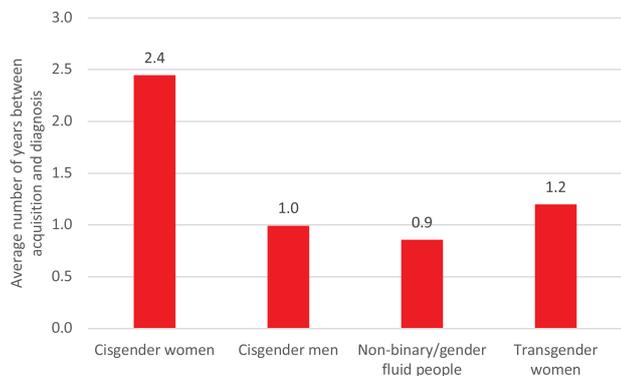
Antiretroviral treatment and viral suppression

Almost all participants (98.4%) were taking antiretroviral treatment (ART). Six people (<1%) had never taken ART, seven were not taking ART of whom two (<1%) were taking a treatment holiday and five (<1%) had taken treatment in the past but were not taking it anymore (Figure 17). Reasons for not taking ART given by participants were:

- "I don't trust big pharma"
- "I consider my health as "good". I never suffer a cold or any other 'minor' illness. I am reluctant to take medication, which I will have to take until the end of my life"
- "Meds are not natural"
- "Relief from the side effects"
- "Toxic side-effects"
- "Not seeing a HIV doctor".

Figure 17. Current use and non-use of ART and viral suppression

FULL SAMPLE (N=847)		
On ART **98.4%** **n=783**	Not on ART 1.7% n=13	
Viral supression **89.3%** **n=691**	Never taken ART n=6	Have taken ART before but not currently n=7
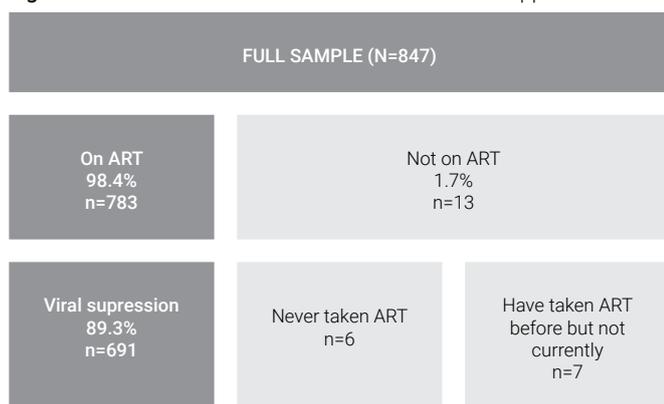
*Note that 88.3% (n=699) of the total sample, including those not on ART, reported and undetectable viral load at their most recent test

Satisfaction with ART

The majority of participants (77.2%, n=609) agreed that they were happy with their ART treatment, and that they found their treatment convenient (69.6%, n=547) (Figure 18).

Figure 18. Satisfaction with ART (%)
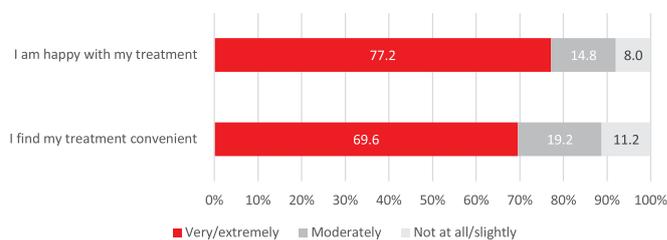
When asked whether they were unhappy about side-effects from ART, close to half indicated that they were *not at all* unhappy (47.5%, n=373), although one in three (31.9%, n=253) indicated they were *moderately*, *very* or *extremely* unhappy with treatment side effects (Figure 19).

Figure 19. 'I am unhappy with side-effects from my treatment' (%)
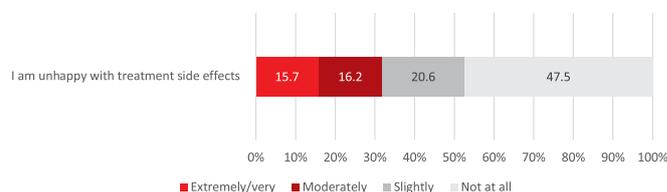
Participants were asked how confident they felt to ask their doctor for a treatment review. The majority (81.6%, n=645) indicated they were *very* or *extremely* confident to ask for a review. However, there were 145 people (18.4%) who did not feel confident asking for a treatment review.

"I was originally put on Atripla (medication) which caused me to become very unwell mentally and physically and ultimately resulted in developing PTSD. I don't think the medical profession has acknowledged the damage that ART does to some people still today, and there really wasn't any support for me specially to cope with the results of this. We get asked about symptoms in clinics but there isn't much mental health support, and we rarely get asked about our experiences. Dental health support is important as well and this isn't funded."

Attitudes toward ART

Most participants agreed that antiretroviral treatment was important for their health. As summarised in Figure 20, 89.0% (n=699) *disagreed* with the statement "I am healthy now and don't need to use ART", while 72.5% (n=568) *disagreed* that "the side-effects of ART outweigh the benefits". Similarly, 75.9% (n=594) agreed that it is best to begin ART soon after diagnosis.

While the majority *disagreed* that ART was harmful (51.6%, n=404), there were 45.3% (n=355) 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.

Figure 20. Attitudes toward ART (%)
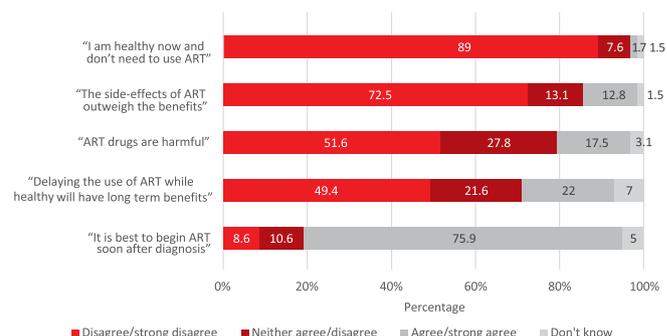
Table 13. Attitudes toward ART over time

Percent of participants who agree/strongly agree with the following statement *	HIV Futures 1 1997	HIV Futures 4 2003	HIV Futures 7 2012/2013	HIV Futures 8 2015/2016	HIV Futures 9 2018
"I am healthy now and don't need to use ART"	22%	26%	14%	6%	2%
"The side-effects of ART outweigh the benefits"	Not asked	29%	32%	29%	13%
"ART drugs are harmful"	32%	45%	29%	27%	18%
"Delaying the use of ART while healthy will have long term benefits"	Not asked			31%	24%
"It is best to begin ART soon after diagnosis"	Not asked			87%	80%

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

Table 13 shows responses to these questions from previous HIV Futures survey as well as HIV Futures 9. 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. For example, participants in HIV Futures 9 were more convinced about the benefits of early ART uptake than in previous years, with only 2% agreeing with the statement "I am healthy now and don't need ART" compared with 26% in 2003.

HIV-related healthcare

"We are so lucky in the urban centers with access and community. I will never take it for granted and will continue to give back to the community as much as I can, making way for our 'hard to reach populations'."

"Thinking back on the questions about where I access HIV treatment and care, I realised how much I depend on the fact that I get free treatment and care at [sexual health clinic]. It really is a godsend to have it, and stressed me out to think about having to access care elsewhere."

In Australia, a limited number of doctors can prescribe ART. For some participants, this was their regular GP (37.4%, n=294) but for the majority (58.2%, n=458) it is a different doctor, most commonly an HIV specialist or doctor at a sexual health centre (Table 14).

The majority of participants (85.5%, n=584) indicated that they were bulk-billed (no co-payment) for HIV-related clinical appointments (although there was a large non-response rate to this question, n=164). More than one in 10 (14.3%, n=98) were not bulk-billed, so paid to see their HIV doctor.

"The lovely people at [sexual health clinic] are just amazing. The work they do and the services they provide are fantastic."

The majority of participants saw their HIV doctor every three or six months (86.7%, n= 641). There were 64 participants (8.7%) who saw their doctor for HIV treatment once per month or more frequently (Table 14).

Table 14. Source of main HIV-related treatment

Source of HIV treatment/care	n (%)	
I do not see a doctor for HIV-related treatment	35 (4.4)	
The same doctor I see for general medical treatment	294 (37.4)	
A different doctor	458 (58.2)	
	HIV specialist	200 (43.7)
	Doctor at sexual health centre	148 (32.3)
	HIV GP/s100 prescriber	73 (15.9)
	Other GP	10 (2.2)
	Other/missing	27 (5.9)

Figure 21. Frequency of visits to doctor for HIV-related treatment*
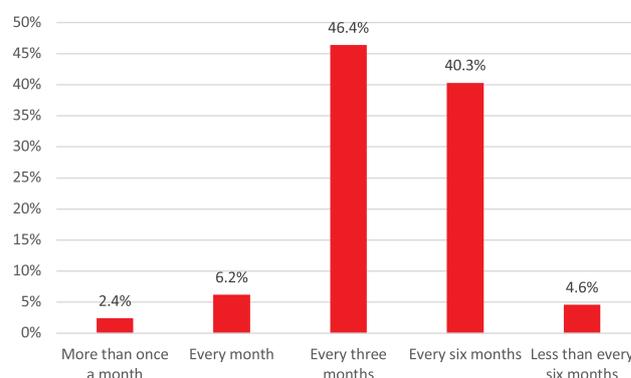
*Note this excludes *other* and *not applicable* responses (n=43)

Participants were asked to indicate the approximate number of kilometres they had to travel to visit their doctor for HIV-related care. The majority (51.0%, n=395) 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, 44% (n=77) travelled more than 50 kilometres to visit their HIV doctor (Figure 22).

"Living in [a remote area] has caused me to feel increasingly isolated. The local GP has extremely limited knowledge of HIV treatment leading me to recently approaching my diagnosing doctor in [a capital city] to take on my treatment plan remotely."

Figure 22. Distance travelled to visit doctor for HIV-related treatment

	<10km	10-20km	20-50km	>50km
Inner city	69.0	24.0	5.4	1.7
Outer suburbs	17.5	39.2	30.8	12.5
Regional/rural	24.6	12.6	18.9	44.0
Total	51.0	23.7	12.4	12.9
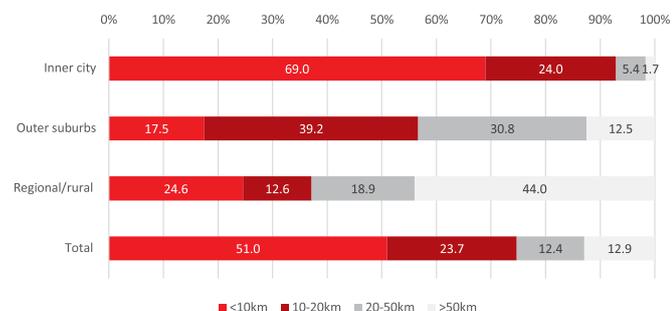
Nursing services

Due to a technical error, data relating to nursing services was only collected from the 244 participants completing the survey in hardcopy. This subsection of the cohort was older on average than those completing the survey online and had higher service use. Of this cohort, 32 participants (13.1%) reported that they had received services from an HIV nurse in the last two years. This comprised:

- 6 (2.5%) who currently receive home-care/district nursing services
- 13 (5.3%) who previously received home-care/district nursing services in the past 2 years but not currently
- 5 (2.0%) who received HIV-nurse care in hospital in the past 2 years
- 8 (3.3%) who reported nursing service use but did not indicate where or when

The most common nursing services received were help getting a referral (n=9), listening when participants needed someone to talk to (n=8), help adhering to medications (n=6) and help with remembering appointments (n=6).

Satisfaction with clinical care

The majority of participants (88.6%, n=677) indicated they were *satisfied* or *very satisfied* with the clinical care they receive for HIV, with just 6.1% (n=46) indicating they were *not satisfied*.

"I am grateful for the support of the sexual health doctor and psychologist that I have been fortunate enough to connect with and at their recommendation have an outstanding GP. I feel very privileged to receive the great health support that they provide."

HEALTH AND WELLBEING

Previous HIV Futures studies have shown that most PLHIV in Australia enjoy good health and their self-rated physical health is on par with the general population (Power, Thorpe et al. 2016).

Despite this, living with HIV can create challenges that can negatively affect physical or mental health. This may include HIV-related stigma or discrimination which has been associated with increased social isolation and poorer mental wellbeing (Logie and Gadalla 2009; Gardiner 2018). Ageing may also bring unique health challenges for PLHIV. Many PLHIV who were diagnosed prior to the mid-1990s have experienced periods of ill-health due to advanced HIV-disease or significant side-effects of medication and may now be managing multiple co-morbidities. This can have continued repercussions on people's physical and mental health (Gardiner 2018).

This chapter builds on the earlier 'Quality of Life' chapter – that looked at overall wellbeing – by focusing 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 other people. The average score for the SF-36 GH subscale was 53.4 out of 100, which is comparable with that of Australian population-based studies (Hawthorne, Osborne et al. 2007).

"[I'm] happy and healthy."

"I feel I have access to the right medication, my doctor is knowledgeable and worked in the field for over a decade. I guess I'd like more mental health and relationship support and advice, tools to help with the mental processing and regaining sexual confidence side of things."

SF-36 GH scores varied by age, with participants under 35 reporting the best general health and those aged 50-64 reporting the poorest general health. People aged under 35 years and over 65 reported significantly higher general health than people aged between 35 and 64 (Figure 23). This likely relates to the subjective nature of the SF-36 GH subscale, in which people are asked to rate their health against other people (e.g. 'I seem to get sick a little easier than most people') rather than by more objective measures of physical health (eg. capacity to climb a flight of stairs or walk one kilometre). In the previous HIV Futures study (HIV Futures 8, 2015/16), people aged over 65 years scored lower than other age groups on objective measures of physical health, but higher on general health and mental health. These measures of physical health were not included in HIV Futures 9 to reduce length of the survey instrument.

Figure 23. Average general health scores by age
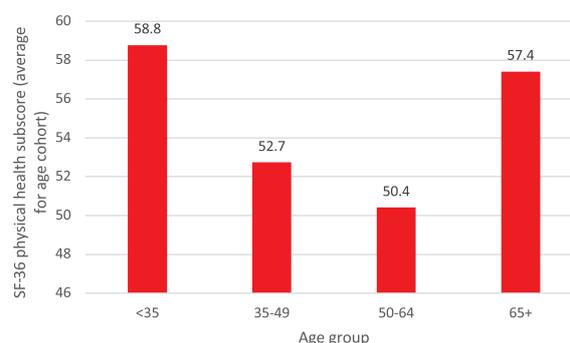
People who had been living with HIV for a longer period of time reported poorer general health scores than those more recently diagnosed. The lowest scores were among those who had been living with HIV for 30 years or more (diagnosed in 1988 or earlier) (Figure 24).

Figure 24. Average general health scores by length of time since HIV diagnosis
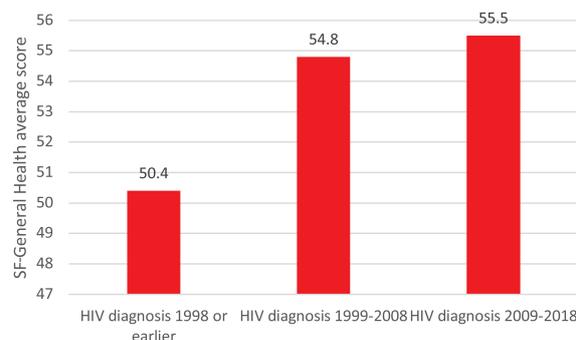
Mental health

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 (37.7%, n=285) reported that they *currently* had one or more diagnosed mental health conditions, while two in three (65.3%, n=495) reported that they had *either a current or previous* diagnosis of at least one mental health condition (Table 15).

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

• Depression (26.2%, n=222)
• Anxiety conditions[1] (24.4%, n=185)
• Post-traumatic stress disorder (9.9%, n=75).

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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 (DSM 5).

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

- Bipolar disorder (4.3%, n=33)
- Obsessive compulsive disorder (3.8%, n=29)
- Borderline personality disorder (2.5%, n=19)
- Schizophrenia (1.7%, n=13).

"I have been positive for 23 years now and experienced some initial stigma and prejudice which caused me some depression. Over the years I have developed techniques to firstly recognise the symptoms of depression and secondly how to deal with them. I am a strong believer in Action Conquers Fear: Depression is really fear in disguise – fear that you are on your own. Fear that no one cares about you and fear that you cannot cope with the situation."

Table 15. Mental health conditions

	Current diagnosis		Lifetime diagnosis	
	Frequency (n)	Percent* (%)	Frequency (n)	Percent* (%)
Depression	222	26.2	420	55.2
Any anxiety condition	185	24.4	326	43.0
Anxiety disorder	157	20.6	275	32.5
Panic disorder	77	10.1	198	26.1
Social phobia	54	7.1	110	14.5
Agoraphobia	21	2.8	55	7.2
Post-traumatic stress disorder	75	9.9	155	20.4
Bipolar disorder	33	4.3	83	10.9
Obsessive compulsive disorder	29	3.8	68	9.0
Borderline personality disorder	19	2.5	39	5.1
Mania	18	2.4	61	8.0
Schizophrenia	13	1.7	40	5.3
Other condition	36	4.7	67	8.8
No mental health condition	472	62.3	263	34.7

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

Rates of mental illness among HIV Futures 9 participants were higher than the general population. In the 2007 National Survey of Mental Health and Wellbeing (the most recent Australian national mental health survey), 45% reported having a mental illness diagnosis within their lifetime compared to 65.3% of HIV Futures 9 participants (Australian Bureau of Statistics 2018, Australian Institute of Health and Welfare 2019). In the 2017-18 Australian National Health Survey, 13.1% had an anxiety-related condition (compared to 24.4% of HIV Futures 9 participants); and 10.4% had diagnosed depression or feelings of depression (compared to 26.2% in HIV Futures 9) (Australian Bureau of Statistics 2018).

Multiple mental health conditions

Of the total sample, 22.3% (n=169) of participants had a *current* diagnosis of two or more mental health conditions. This means that among those with a *current* diagnosis, 59.2% had multiple mental health conditions. The most common comorbidity was anxiety and depression. Of the 130 participants with a current anxiety condition, 67.2% also had a current diagnosis of depression. Participants with lower prevalence conditions were especially likely to have other comorbid conditions. For example, close to 100% (17 of the 18) of participants who had experienced mania had also experienced an anxiety condition.

Mental health comorbidities were highly correlated with poorer quality of life among HIV Futures 9 participants. As shown in Figure 25, a higher number of diagnosed mental health conditions was associated with poorer quality of life (using the PozQol measure). This finding was statistically significant (F=11.4, p<0.01).

Figure 25. PozQol score by number of current mental illnesses*
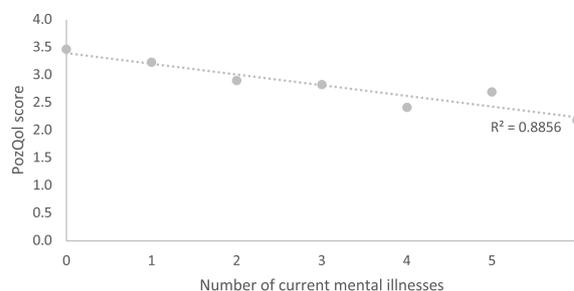
* Note that participants reporting more than six mental health conditions were excluded from the figure below due to small numbers and higher probability of error

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 symptoms were: feeling depressed (currently experienced by 26.6% of participants, n=202); feeling anxious, nervous or tense (currently experienced by 24.3% of participants, n=185), and having panic attacks (currently experienced by 7.9% of participants, n=60) (Table 16).

Table 16. Self-reported symptoms of mental distress

	Current experience		Previous experience	
	Frequency (n)	Percent (%)	Frequency (n)	Percent (%)
Feeling depressed	202	26.6	249	32.8
Feeling anxious, nervous or tense	185	24.3	168	22.2
Panic attacks	60	7.9	67	8.8

Treatment for mental health conditions

In the last 12 months, 74.1% of participants (n=282) who had been diagnosed with a mental health condition reported that they had taken prescription medications to support their mental health. In the same time-period, 63.4% of these participants (n=284) received non-pharmaceutical treatment for a mental health condition, such as counselling. Almost a quarter (22.3%, n=462) of participants who did not have a current mental illness diagnosis received non-pharmaceutical treatment (counselling) to support their mental health.

Sexual health

"My regular sexual health clinic has been providing very impressive care and services to me, there's always a welcoming smile and assistance and also follow up."

Participants were asked to indicate whether they had been tested for, or diagnosed with, any sexually transmitted infections (STIs) other than HIV in the past 12 months. STI screening rates were high, with 84.8% (n=424) 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 six 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 (91.0%, n=344), with most testing multiple times (67.2% of this group, n=254).

Table 17. Testing for STIs in the last 12 months by sexual activity in last six months

	No sex n (%)	One sexual partner n (%)	Multiple sexual partners n (%)	Total n (%)
No STI testing	92 (43.0)	40 (32.8)	32 (8.5)	172 (22.7)
Tested once	58 (27.1)	38 (31.1)	90 (23.8)	204 (26.9)
Tested more than once	54 (25.2)	42 (34.4)	254 (67.2)	366 (48.3)
Unsure	10 (4.7)	2 (1.6)	2 (0.5)	15 (2.0)
Total	214	122	378	

Around one in three participants (28.6%, n=242) had been diagnosed with an STI in the last 12 months, and about half of this group (13.1% of total sample, n=111) had been diagnosed with more than one STI (see Table 18).

Table 18. Number of sexually transmitted infections diagnosed in the last 12 months

Number of STIs	Frequency (n)	Percent (%)
None	519	61.3
One	131	15.5
Two	70	8.3
Three	31	3.7
Four or more	10	1.2

The most commonly diagnosed STIs were chlamydia (17.1%, n=130), gonorrhoea (15.0%, n=114) and syphilis (10.0%, n=76). 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. Participants diagnosed with sexually transmissible infections diagnosed within the past 12 months (n=761)

	Frequency (n)	Percent (%)
None	519	68.2
Chlamydia	130	17.1
Gonorrhoea	114	15.0
Syphilis	76	10.0
Human papilloma virus (HPV)	35	4.6
Genital herpes	27	3.6
Shigella	11	1.5
Mycoplasma genitalium	9	1.2
Lymphogranuloma venereum	1	<1
Trichomaniasis	1	<1
Donovanosis	0	0
Other	8	1.0

On average, diagnosis with STIs 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), gonorrhoea and chlamydia were more common among younger people, but syphilis was most likely to be reported by people aged 50-64 (Figure 26).

Figure 26. Common STIs by age (percent of people in age group)
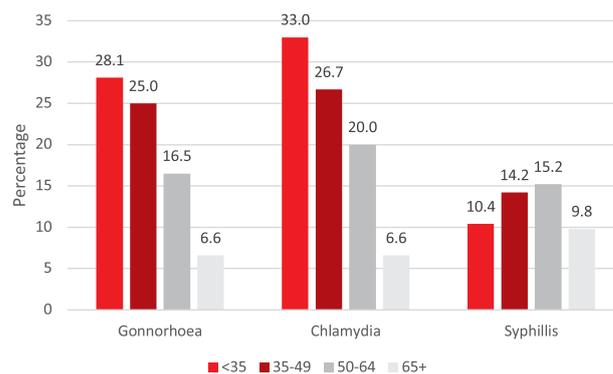
Viral hepatitis

There were 65 participants (7.7%) who indicated they had been diagnosed with chronic hepatitis B, while 24 (2.8%) were unsure. Of the 65 who had been diagnosed with chronic hepatitis B, 55 (84.6%) 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, Maclachlan et al. 2015). However, in this sample, the majority of those with chronic hepatitis B were born in Australia (n=49, 75%). The remaining 16 were born in European countries or country of birth was not identified.

In the previous HIV Futures survey (HIV Futures 8, 2015/16), we asked survey participants if they had ever been diagnosed with, and received treatment for, hepatitis C virus (HCV). There were 104 people (12.6%) who indicated that they had been diagnosed with HCV, of which 46 (44%) had received interferon-based treatment (Power, Thorpe et al. 2016).

In March 2016, direct-acting antiviral (DAA) treatment for chronic HCV was listed on the Pharmaceutical Benefits Scheme. In contrast to interferon-based treatment DAAs are simple to take, have limited side-effects and are highly curative for most people, including those co-infected with HIV (Hajarizadeh, Grebely et al. 2018). In HIV Futures 9, we asked participants the following: whether they had ever been screened for, or diagnosed with, 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 229 participants (31.1%) who indicated they had never been screened for HCV and 78 (10.6%) who were unsure if they had ever been screened. Of those who had been screened (58.3%, n=430), the majority had been screened just once (62.6%, n=269), while 161 (37.4%) had been screened more than once.

There were 118 (13.9%) participants who indicated they had been diagnosed as HCV antibody positive. Of these:

- 44 (37.3%) indicated they had also been diagnosed with chronic HCV infection (although it is possible that some people were not aware of the difference between HCV antibody positive statues and chronic HCV)
- 33 (28.0%) had never taken treatment and 13 (11.0%) were unsure if they had ever received treatment, although a further 29 did not respond to the question
- 43 (36.4%) 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)
- Four indicated they had reacquired HCV after treatment.

Other comorbidities

The HIV Futures 9 survey listed thirteen chronic illnesses, asking participants to indicate which, if any, they had been diagnosed with. The most common conditions were asthma (22.7%, n=149), hypertension (19.7%, n=130) and osteo-arthritis (14.6%, n=96) (Table 20).

"Clear message from Sexual Health doctor is that HIV may bring forward the ageing process but HIV won't cause my death. I will die of normal ageing related illnesses, eg. coronary heart disease etc. This is comforting."

Table 20. Health conditions other than HIV

	Frequency (n)	Percent* (%)
No major health condition	190	28.9
Asthma	149	22.7
Hypertension	130	19.7
Osteo-arthritis	96	14.6
Cardiovascular	92	14.0
Cancer	72	11.0
Osteoporosis	70	10.7
Diabetes	62	9.5
Autoimmune	50	7.6
Respiratory disease	49	7.5
Kidney disease	37	5.6
Dementia or related cognitive disorder	14	2.1
Haemophilia	7	1.1
Parkinson's	4	<1
Other	134	20.4

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

Of those participants who selected "other" (20.4%, n=134), the most common responses entered were liver disease (n=7) and epilepsy (n=5) or conditions reported elsewhere, including mental health or sexual health diagnoses.

Sixteen percent of participants (15.6%, n=103), had at least two major health conditions other than HIV (excluding STIs and mental illnesses) and 19.5% (n=129) had three or more.

"GPs vary in the amount of information they share with you. If everything is good they tell you little about what is happening or what to look out for. There is minimal support and it is very passive in approach. "

Chronic comorbidities accumulated with age. Among participants aged under 35 years, 47.6% (n=40) had no comorbidities. Among participants over 65, 11.9% (n=12) had no comorbidities and 32.7% (n=31) had three or more (Figure 27). A higher number of comorbidities was correlated with poorer quality of life (PozQol scores) (r = -0.11, p=0.003).

"I strongly fear developing HIV related dementia on a near daily basis."

"I have an excellent HIV specialist here who has been taking care of me for 10 years. However the same cannot be said for the GPs I am forced to see for other conditions. I am continuously changing GPs because of their appalling lack of knowledge. (One of them had never heard of U=U)."

Figure 27. Number of chronic commodities by age group (excluding HIV and mental health conditions)

	None	One comorbidity	Two comorbidities	Three or more comorbidities
<35	47.6%	41.7%	7.1%	3.6%
35-49	37.1%	41.1%	12.6%	9.1%
50-64	20.3%	39.0%	14.8%	25.9%
65+	11.9%	25.7%	29.7%	32.7%

Medication for HIV and comorbidities

HIV Futures 9 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 4.8 pills per day to manage their health conditions, with the range from 0 to 40. The most common conditions for which medication was taken were hypertension (17.8%, n=111) and cardiovascular conditions (13.8%, n=86) (Table 21).

"Polypharmacy has become the biggest stress in my life, getting scripts and pills organized given the large number I need to take."

Table 21. Conditions for which medication is taken*

	Frequency (n)	Percent (%)
Hypertension	111	17.8
Cardiovascular	86	13.8
Asthma	75	12.0
Osteo-arthritis	54	8.7
Diabetes	50	8.0
Osteoporosis	38	6.1
Respiratory disease	22	3.5
Autoimmune	19	3.0
Cancer	11	1.8
Kidney disease	8	1.3
Dementia or related cognitive disorder	5	<1
Haemophilia	4	<1
Parkinson's	2	<1
Other	132	21.1

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

HIV-Associated neurocognitive disorder (HAND)

Previous studies have shown that HIV-Associated Neurocognitive Disorder (HAND) affects around one in five PLHIV in Australia (Antonia and Bruce 2017). Among HIV Futures 9 participants, eighteen (2.6%) had been diagnosed in the last two years, with an additional 38 (5.5%) diagnosed more than two years ago. Thirty-six participants (5.3%) had a current diagnosis of HAND.

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 (Lea 2016, Hammoud, Jin et al. 2017).

Research on alcohol, tobacco or other drug use among other PLHIV including heterosexual men, or transgender and gender diverse PLHIV in Australia is more limited. However, results from HIV Futures 8 showed high rates of daily tobacco smoking among women relative to population averages (Thorpe 2017).

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 social lives, which can play a role in connectedness and wellbeing (Weatherburn P, Hickson F et al. 2017, Power, Mikołajczak et al. 2018). 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 using. 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 9 relating to alcohol, tobacco and other drug use. Our aim is not to present a set of 'problems' associated with alcohol, tobacco or other drug use, but to highlight areas where people may be vulnerable to harm or may benefit from seeking more support.

Tobacco

The majority of participants (58.5%, n=439) had smoked tobacco at some point in their life. However, only 28.1% (n=211) were current smokers. Of these, 65.4% (n=138) were daily smokers (18.4% of the entire sample). Just under one in three (30.4%, n=228) indicated they were former smokers, but did not smoke now.

The figure of 28.1% being a current smoker, is more than double the proportion of daily smokers in the Australian population as a whole, which in 2014/15 was 14.5% (Australian Bureau of Statistics 2015). However, consistent with Australian population trends, the number of PLHIV reporting that they are daily smokers in previous HIV Futures surveys has decreased over time (Figure 28) (Australian Institute of Health and Welfare 2017, Scollo 2019).

Figure 28. Daily smoking rates over time, comparing HIV Futures participants with Australian daily smoking rates*
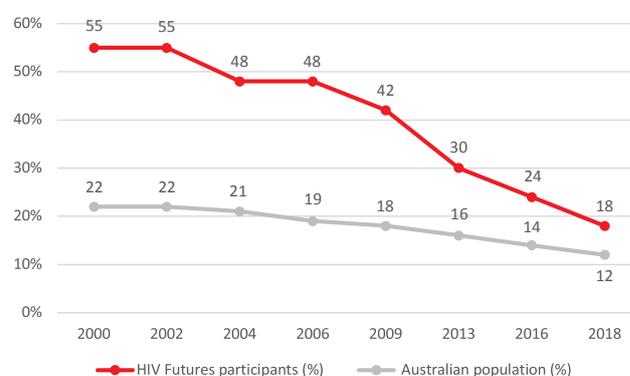
*Smoking rates for the Australian population have been derived from the Australian Bureau of Statistics reporting, but should be considered approximate as the time periods reported on differed slightly to HIV Futures reports (Australian Institute of Health and Welfare 2017, Scollo 2019).

People aged 65 years or older were significantly *less* likely than younger people to be a current smoker (p<0.05) (Figure 29).

Figure 29. Tobacco smoking by age groups
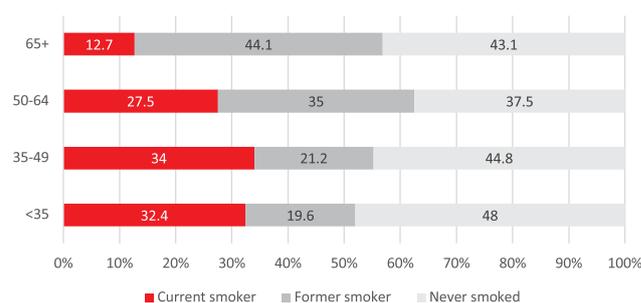
We asked current and former smokers if they had consulted a health professional or service about their tobacco use in the past 12 months, and 26.3% (n=109) said that they had. Of these, 53% (n=58) were current daily smokers, 22.9% (n=25) were current smokers, but not daily, and 23.8% (n=26) were former smokers.

Table 22. Alcohol consumption

How often do you have a drink containing alcohol? n (%)			How many standard drinks per day? n (%)			How often do you consume more than six drinks on any one occasion? n (%)	
Never	110 (14.6)						
Monthly or less	182 (24.2)		2 or less	456 (72.4)		Never	239 (37.2)
2 to 4 times a month	151 (20.1)		3 or 4	147 (15.7)		Less than monthly	183 (28.5)
2 to 3 times a week	156 (20.7)		5 or 6	47 (7.5)		Monthly	89 (13.9)
4 or more times a week	153 (20.3)		7+	28 (4.4)		At least weekly	131 (20.4)

Alcohol

"[Living with HIV] has made me more health conscious, therefore a lot less alcohol, no recreational drugs."

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 consumed some alcohol (85.4%, n=642), with only 14.6% (n=110) reporting that they did not drink at all. This is slightly higher than the overall Australian population, for which recent data shows 77% of the adult population had consumed alcohol in the past 12 months (Australian Institute of Health and Welfare 2017).

Of those HIV Futures 9 participants who drank alcohol, the majority drank moderately with 72.4% (n=456) 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 risk alcohol consumption. Of those who consumed alcohol, more than one in three (37.2%, n=239) indicated they never consumed more than six drinks, and 28.5% (n=183) consumed six or more drinks *less than monthly*. There were 220 participants (34.3%) who consumed six or more drinks *at least monthly:* 13.9% (n=89) *monthly*, 14.3% (n=92) *weekly*, and 6.1% (n=39) *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 (22.3%, n=148), followed by marijuana or cannabis (14.6%, n=98) and sleeping pills/tranquilisers (13.6%, n=89). Pain killers and amyl nitrate (poppers) were the most common drugs used *at least occasionally*, with 56.9% (n=378) indicating they use painkillers *at least occasionally*, and 47.0% (n=325) using poppers *at least occasionally*.

Table 23. Frequency of drug use for recreational purposes (%)

	At least weekly (%)	Once per month (%)	Occasionally (%)	Never (%)
Painkillers/analgesics	22.3	11.1	23.5	43.1
Marijuana or cannabis	14.6	4.5	17.3	63.3
Tranquilisers/sleeping pills	13.6	4.4	13.6	68.4
Amyl nitrate (poppers)	12.9	11.9	22.3	53.0
Opioids other than heroin	6.9	1.9	10.9	80.3
Neuropathic pain medication	6.1	<1	2.8	90.9
Meth-amphetamine (crystal meth)	4.5	5.2	12.3	78.0
Steroids	1.4	0.5	2.0	96.1
GHB	<1	1.4	9.4	88.3
Cocaine	<1	2.0	13.1	84.1
Other amphetamine (eg. speed)	<1	1.1	6.7	91.6
Ketamine	<1	<1	6.2	93.2
Heroin	<1	<1	0	98.6
Other inhalants	<1	<1	0	99.5
MDMA/ecstasy	<1	1.2	16.5	82.1
Hallucinogens	<1	<1	6.3	93.4
Synthetic cannabis	<1	<1	1.1	98.6

Concerns about non-medical 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 (68.1%, n=284), *did not agree* that they were worried about their drug use. However, 21.1% (n=88) *agreed* or *strongly agreed* that they were worried about their drug use. Around one in four participants who used drugs non-medically (26.4%, n=111) indicated that they had missed at least one dose of ART due to alcohol or drug use (note, this question was not asked of people who only consumed alcohol).

Participants were asked whether they had sought help or advice about their drug use within the past 12 months. A small number (14.0%, n=59) indicated that they had consulted a health professional, 16.0% (n=69) had sought advice or information online, and 10.5% (n=45) had attended a self-help group or harm reduction program. When asked where participants would most prefer to seek help or advice regarding concerns about drug use, GPs were by far the most popular option, followed by a specialised drug service or HIV organisation (Figure 30).

"Prior to going into therapeutic community residential rehab (of which I am still connected 20+ months) my self-worth was zero my healthy social connection were zero, self-acceptance was zero .... Substance use off the chart. My point is that if I hadn't engaged in CBT, this survey would have looked very different. If I still viewed myself as a victim, this survey would have looked very different. For me: substance use led to seroconverting (through risky sexual behaviours) which led to poor mental health."

Figure 30. Preferred source of advice or support for concerns about drug use (%)
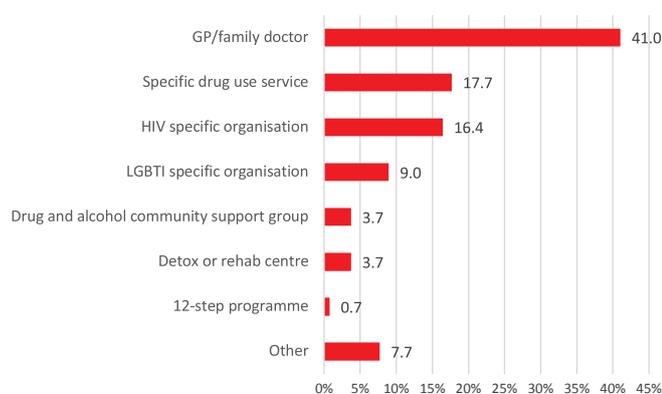
Injecting drug use

Participants were asked if they had injected drugs for recreational (non-prescribed) use in the past 12 months, and 14.2% (n=106) indicated that they had. A further, 16.8% (n=126) 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. Just over a quarter (25.9%, n=53) indicated that they had experienced stigma or discrimination at least sometimes.

"I have been through very difficult times from homelessness and addiction but I'm here resilient & ready for the next challenge. We've/I've come a long way."

STIGMA AND DISCRIMINATION

Despite significant advances in treatment and prevention options, HIV continues to be highly stigmatised (Brown, Leonard et al. 2017).

"It is extremely difficult to talk about HIV as there is so much stigma."

"Having HIV has dramatically changed the way I think about life. I am constantly thinking about my status and am worried about people finding out."

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, Smith et al. 2013, Lyons, Heywood 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. 2017). 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 (Grierson, Pitts et al. 2013, Friedland, Sprague et al. 2018). 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 (Brener, et al. 2013, Earnshaw, Lang 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 et al. 2018). For more information about this project, please see Broady et al 2018.

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 31). More than half (56.5%, n=412) reported experiencing some form of stigma, although the majority of these participants (83%, n=346) indicated that this occurred *rarely* or *sometimes*. There were 66 participants (9.1%) who indicated they experienced HIV-related stigma *often* or *always*.

Figure 31. Experience of stigma or discrimination in relation to HIV status in the last 12 months
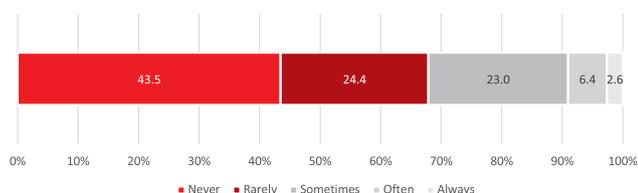
"Mostly my experience being a person living with HIV has been straight forward and not too difficult. I've had some bad experiences with stigma and bullying because of my status but they have been rare… My status has not affected my work, relationships or social life in any way. The people who matter most have accepted me and helped me through."

Participants were asked whether they had been treated negatively or differently by healthcare workers because of their HIV status. Close to two in three (62.0%, n=456) reported that they had not. However, 38.0% (n=243) indicated they had been treated differently in some instances (Figure 32).

Figure 32. Percentage of participants treated negatively or differently by healthcare workers because of their HIV status (the last 12 months)
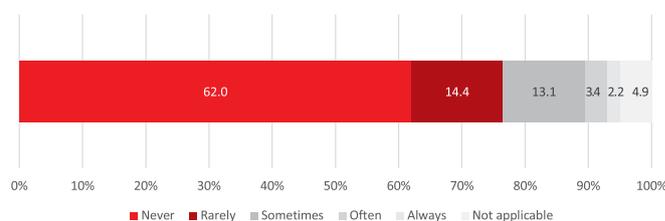
"I am proud of our healthcare system. Paying almost nothing for meds is a lifesaving thing. It has gotten easier as time has gone on. Less stigma and more support."

Participants were asked to what extent other 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 33).

"I felt and feel obliged to tell people my status and protect them (safe sex). And they walk away.... repeat. I think it has affected my ability to find a partner."

Figure 33. Participants reporting that people didn't want to have sex or an intimate relationship with them because of their HIV status (last 12 months)
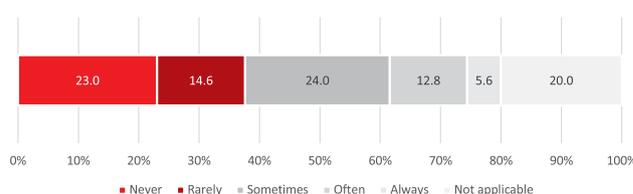
The most common experience of discrimination was in insurance, with 6.9% (n=35) of participants reporting that they *always* experienced discrimination and an additional 12.7% (n=64) reporting that they *sometimes* or *often* experienced discrimination from the insurance sector in the last 12 months. Although numbers were small, 12.7% (n=66) reported experiencing work-based discrimination *sometimes*, *often* or *always* (see Table 24).

Table 24. Experiences of discrimination due to HIV status in the last 12 months*, n(%)

	Never	Rarely	Sometimes	Often	Always
Accommodation	532 (92.0)	22 (3.8)	14 (2.4)	3 (<1)	7 (1.2)
Health services	502 (74.3)	77 (11.4)	74 (10.9)	13 (1.9)	10 (1.5)
Employment/work	422 (81.2)	32 (6.2)	36 (6.9)	14 (2.7)	16 (3.1)
Insurance	378 (75.0)	27 (5.4)	41 (8.1)	23 (4.6)	35 (6.9)

*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 34). Just over one in four (28.4%, n=203) *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 (46.0%, n=327).

Figure 34. Thoughts about living with HIV (% of participants)
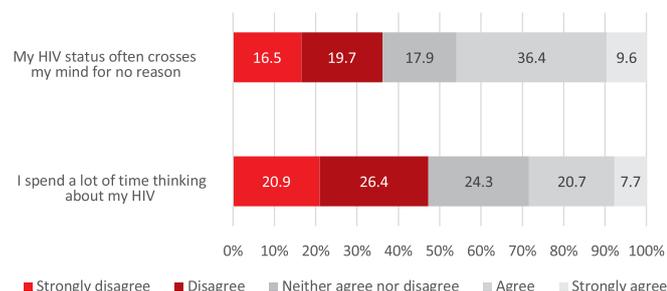
Disclosure of HIV status

Participants were asked about the extent to which people around them knew about their 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, 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, close to one in three (31.8%, n=234) indicated *almost nobody knows about my HIV*, while one in four (25.2%, n=186) reported that *most of the time, people around me are not aware of my HIV.*

Table 25. Openness around HIV status

	Frequency (n)	Percent (%)
Almost nobody knows about my HIV	234	31.8
Most of the time, people around me are not aware of my HIV	186	25.2
About half the time, people around me are not aware of my HIV	89	12.1
Most of the time, people around me know about my HIV	121	16.4
Just about everybody knows about my HIV	107	14.5
Total	737	100

"I'm from an era when it was the gay plague so I've learned to be very secretive about my condition."

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 experienced HIV related stigma or discrimination *sometimes, often* or *always,* although numbers in this group are small so we cannot determine if this difference is statistically significant (Figure 35). Cisgender women were the most likely to report that they were *sometimes, often* or *always* treated differently by healthcare workers due to their HIV status (35.9%, n=33) (Figure 36).

Figure 35. Experienced HIV-related stigma or discrimination in the last 12 months by gender

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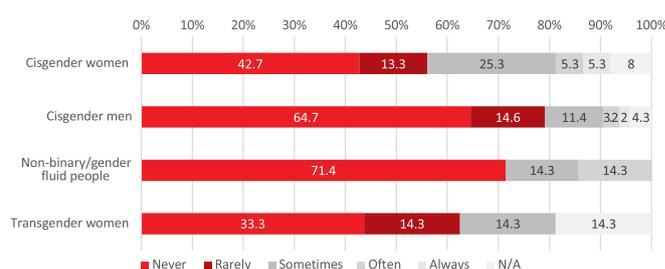
To explore the impact of sexual identity on experiences of HIV-related stigma and discrimination, we looked at the sexuality of cisgender men in relation to stigma and discrimination. Bisexual men were less likely than gay or heterosexual men to report that they *never or rarely* experienced discrimination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

Figure 37. Experienced stigma or discrimination in the last 12 months in relation to HIV status by sexuality of cisgender men
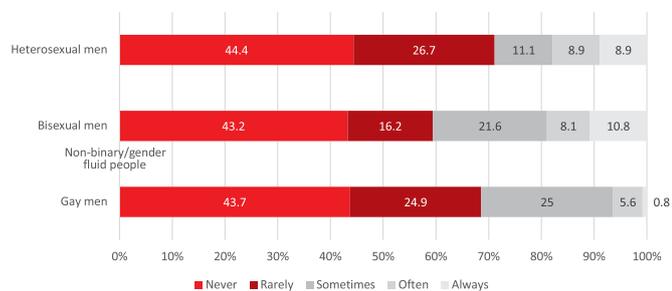
Figure 38. Health workers treated differently because of HIV status in past 12 months by sexuality of cisgender men
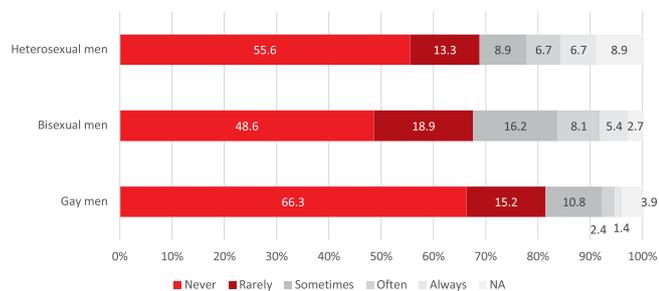
"Many years ago, the media portrayed AIDS as "The Grim Reaper". This was set in people's minds. As a bisexual male living with HIV, when I disclose this to potential female partners before the possibility of intimacy, I am shunned, abused, and asked, 'How can you risk my health this way?' And it makes no difference when I try to explain that the risk of infection is very low through U = U."

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 and 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, Rintamaki et al. 2012; Prestage, Brown et al. 2016). Peer-based programs continue to evolve as the experiences and needs of PLHIV evolve.

In this chapter we look at social connectedness among HIV Futures 9 participants, and report findings related to engagement in PLHIV peer-support networks and programs.

"I want to connect with other people with HIV"

Sex and relationships

We asked participants about their current relationship status and sexual relationships in the past 12 months. Most participants were single (61.5%, n=451), while 27.7% (n=203) were in a relationship with one partner (Table 26) (although it is worth noting that 212 indicated that they cohabit with a partner or spouse, this discrepancy occurred due to a higher non-response rate to questions about sex and relationships).

Of those participants in a regular relationship, 65.5% (n=180) reported that their (primary) partner was HIV negative at the time of their most recent test, 29.8% (n=82) reported that their partner was HIV positive and 4.7% (n=13) didn't know.

Table 26. Current relationship status

	Frequency (n)	Percent (%)
Single (not in a relationship)	451	61.5
In a regular relationship with one partner	203	27.7
In a regular relationship with more than one partner	11	1.5
In a regular relationship with a primary partner plus other partners	65	8.9
Other	3	<1
Total	733	100

One in three participants (30.1%, n=219) reported that they had not been sexually active in the past six 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 39).

Table 27. Sexual partners in the last six months

	Frequency (n)	Percent (%)
No sex	219	30.1
One regular partner only	122	16.8
More than one regular partner	44	6.1
Regular partner/s plus casual partners	161	22.1
Casual partner/s only	179	24.6
Other	2	<1
Total	727	100

Figure 39. Sexual partners in the last six months by age
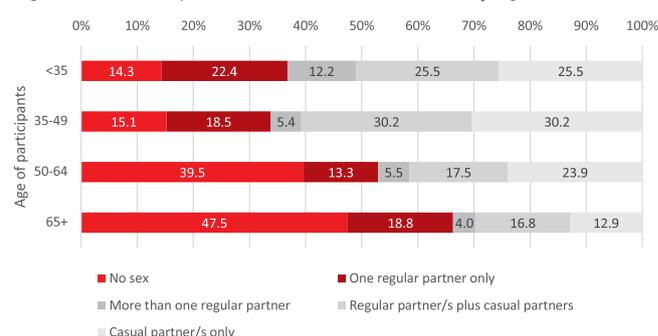
"I feel isolated and alone sexually and emotionally. I have attempted to establish emotional/sexual relationships but because I am told I must declare, I always do early in the friendship and I am rejected, politely."

Social connectedness Social connectedness

Participants in HIV Futures 9 were asked to respond to 10 questions about the extent to which they feel connected to, and supported by, others (eg.'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 seven-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.

The average social connection score for HIV Futures 9 was 4.7 (SD 1.3). 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. Being older (65+) or younger (<35) was associated with greater social connectedness. There were no differences in relation to gender, but among cisgender men, bisexual men reported significantly lower levels

of connection than gay men. Other factors associated with higher levels of social connectedness mirrored those associated with better quality of life, including:

- Being in paid work (including part time or casual work)
- Higher education and income levels
- No recent experiences of financial stress
- Living with others, including a partner or spouse.

"I check my privilege regularly and am thankful to be so supported on all levels."

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

	Social connection score mean*	p-value
Age		
<35	4.8	
35-49	4.6	p<0.05, 65+ sig higher score than 50-64
50-64	4.5	
65+	4.9	
Gender		
Men	4.6	
Women	4.8	p=0.167, no sig differences
Non-binary and gender fluid	4.1	
Sexuality**		
Gay men	4.7	
Bisexual men	4.1	p<0.01, gay men sig higher score than bisexual men
Heterosexual men	4.3	
Residential location		
Capital city/inner suburban	4.7	
Outer suburban	4.6	p=0.428, no sig differences
Regional/rural	4.5	
Education level		
Up to Year 12	4.5	
TAFE/diploma/trade	4.5	p<0.05, tertiary significantly higher than non-tertiary
Tertiary/under/post graduate	4.8	
Employment status		
Not currently in paid work	4.4	
Part time or casual work	4.9	p<0.001, work significantly higher than not in work
Full-time work	4.9	
Financial stress (in past 2 years)		
Experienced financial stress	4.1	p<0.001
No financial stress	4.8	
Household annual income		
<$30,000	4.3	
$30,000-$79,999	4.7	p<0.001, $125,000+ category sig higher than all others, <$30,000 sig lower than all others
$80,000-$124,000	4.8	
$125,000+	5.3	
Cohabiting with partner/spouse		
Live with partner	5.0	p<0.001
Do not live with partner	4.5	
Household composition		
Single person household	4.5	p<0.001
Multiple person household	4.8	

*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

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 most people had informal connections with other PLHIV, with 66.8% (n=465) indicating they had at least one other PLHIV to talk to about HIV – although it is notable that one in three participants (33.2%, n=231) indicated they did not. Participants also engaged with other PLHIV through formal services or networks, with 34.0% (n=246) indicating they had accessed advice or support from a peer worker at least once in the past 12 months, and 26.7% (n=191) indicating they had participated in an online network for PLHIV (Figure 40).

Figure 40. Peer-based sources of information and support about HIV
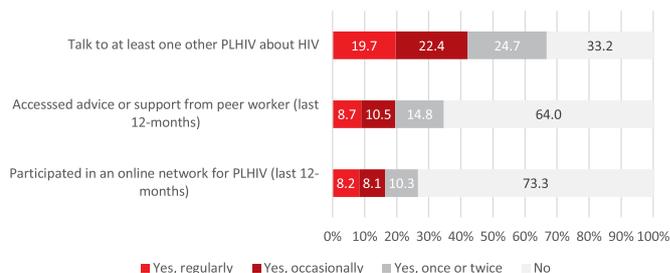
Friendship and community connection

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

- 30.4%, (n=211) indicated none of their friends were living with HIV
- 39.6% (n=281) 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 9 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 Figure 41. 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 (59.9%, n=416) agreed that knowing other PLHIV was important to them, and nearly half were interested in being part of an HIV community (49.2%, n=343, *disagreed* with the statement 'I have no interest in being part of the HIV community')
- One in three indicated that they felt part of a community of PLHIV (32.4%, n=225), while the rest of the sample did not feel they were or were more ambivalent (neither agreeing or disagreeing with the statement)
- One in four (25.6%, n=179) indicated they felt isolated or cut off from other PLHIV
- One in three, (32.9%, n=229) 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 is easy to meet other PLHIV (33.7%, n=234).

"Would love the opportunity to meet other guys in my situation and age group"

Figure 41. Feelings about HIV community (%)
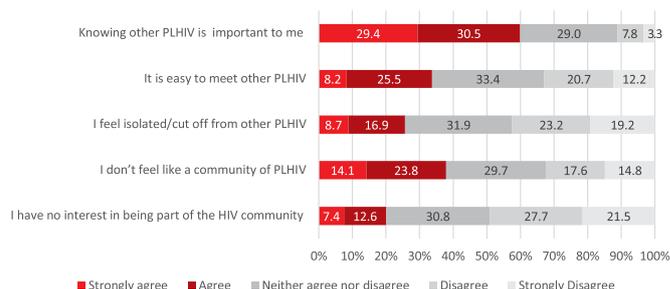
"I think it would be great if there was a "community home" where those with HIV could be accommodated - much like a nursing home/retirement village. That would encourage socialisation and immediate access to professional health services and care. Money better spent than wasting on stadiums."

Peer-based programs and services

As noted, 34% (n=246) indicated they had accessed advice or support from a peer worker at least once in the past 12 months. Just over one in 10 participants (12.9%, n=89) had used a peer navigator program, and 18.7% (n=131) 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 five years ago. However, in terms of the total number of people using peer navigator services, the majority had been diagnosed more than five years ago.

Similarly, people who had been diagnosed with HIV in the past 5 years were more likely to have accessed peer education/support programs or workshops: 25.2% (n=37) compared to 17.5% (n=81) of people who had been diagnosed more than five years ago. However, again, the majority of people accessing these programs had been diagnosed more than five years ago.

We asked participants if they felt community-based services played an important role in connecting PLHIV with each other, and the majority (59.5%, n=413) agreed that they did.

"Having access to a peer worker rather than someone who only has a working knowledge of HIV in my opinion and experience is of (great) benefit to the… well-being of those living with HIV in their lives."

Online forums for PLHIV

Participation in online forums or networks for PLHIV was less common than use of face-to-face services, with 26.7% (n=191) indicating they had used these in the past 12 months. PLHIV were connected to a range of online peer support forums and networks, with 220 people indicating that they were a member of *The Institute of Many* (a large online group for PLHIV). Other web-based PLHIV networks with which participants were connected included: Gen Next, HIVsters, Living Positive Victoria, NAPWHA, Paltalk HIV room, PLDI, PLWHA ACT, Positive Life, POWA, Poz.com, Pozhet, Queensland Positive People, TasPPL, The Body, TIM Women, and Victorian AIDS Council (now Thorne Harbour Health).

We asked participants if connecting online with other PLHIV was a source of support for them, and 31.0% (n=214) indicated that it was. Of those participants who were a member of The Institute of Many, 54.8% (n=120) indicated that connecting online was a source of support.

Figure 42. Responses to the statement 'Connecting online with other PLHIV is a source of support for me' (%)
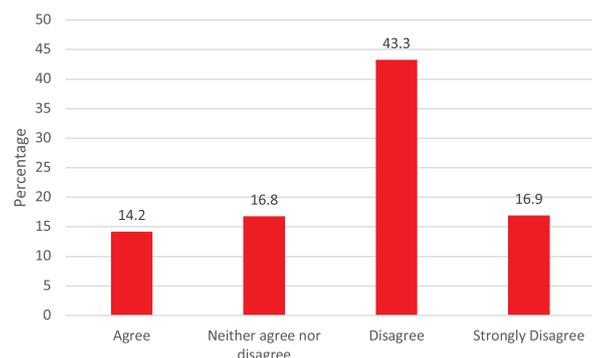
HIV support services

Participants were asked to indicate which formal services they had utilised in the past 12 months and the place at which they access the service. The number of people who indicated they used each service is presented in Table 29. Treatment advice was the service most commonly accessed, usually through an HIV clinic. The services most commonly sought through HIV community-based services were: social work, financial assistance, legal assistance or advice, or housing support (Figure 43).

"We had some good services in the late '90s but now there isn't an AIDS Council which is a real shame. No more women's group and no more help with bills etc. I think South Australia is behind in many areas when it comes down to helping people who are HIV and hep c positive. I sure hope things change in the future."

Table 29. Formal HIV services utilised, and site of access, in the past 12 months (n, % of 847*)

Place accessed	Community-based HIV service, n (%)	HIV clinic, n (%)	Privately, n (%)	Other, n (%)
Treatment advice or information	114 (13.5)	246 (29.4)	79 (9.3)	30 (3.54)
Counselling/ psychological treatment	56 (6.6)	108 (12.8)	88 (10.4)	24 (2.8)
Financial assistance or advice	70 (8.5)	19 (2.2)	32 (3.8)	38 (4.5)
Legal assistance or advice	59 (7.0)	20 (2.4)	31 (3.7)	28 (3.3)
Social work services	58 (6.9)	24 (2.8)	14 (1.7)	29 (3.4)
HIV Work Ready	17 (2.0)	10 (1.2)	7 (<1)	29 (3.4)
Housing Support	40 (4.7)	10 (1.2)	12 (1.4)	34 (4.0)

*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)

Figure 43. Formal HIV services utilised, and site of access, in the past 12 months (% of total who used each service type)
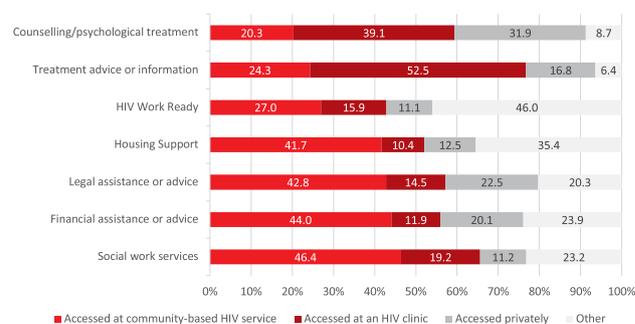
"I feel like anyone living without it. I just wish we could get back our support offices I used to go to where we could also get some groceries, toiletries etc."

WOMEN LIVING WITH HIV

In Australia, women living with HIV comprise around 10% of the PLHIV population.

"As [an HIV positive] woman there is only being cast aside, being invisible, being shunned, by family, by men, by friends. These studies don't highlight the ongoing struggle and discrimination women with HIV face in Australia in 2019."

"We had some good services in the late 90's but now there isn't an AIDS Council which is a real shame. No more women's group and no more help with bills etc."

The community of women living with HIV is much smaller 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, including experiences of sex, relationships, work, pregnancy and parenting.

The experiences of women who participated in HIV Futures 9 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.

"As positive women I often feel that we are excluded from a lot of activities etc, because they are set up for men only. Men have a much bigger presence than women and children in many HIV places."

"The guys need to share resources with women living with HIV. Male privilege impacts this sector too much."

Demographic characteristics

There were 88 women who participated in HIV Futures 9 (10.6% of the cohort), including 81 cisgender women and seven transgender women. The demographic characteristics of these women are presented in Table 30.

The average age of women participants was 45 years (five years lower than the average age for men in the study), and ages ranged from 24 to 69 years. The majority of women participants (59.5%, n=50) were aged under 50 years.

As with the sample overall, response numbers were highest from the most populous states: New South Wales (30.7%, n=27) and Victoria (28.4%, n=25). Most women lived either in the inner city or the outer suburbs (67.8 %, n=59), although one in three (32.2%, n=28) lived in a regional or rural area.

Two women indicated they were Aboriginal. Around two thirds of women (68.3%, n=56) were born in Australia, eight (9.8%) were born in Asian countries, eight in European countries, five in African countries (6.1%) and three in Pacific countries (4.9%) (Table 30). Most (79.5%, n=66) spoke English as a first language.

Most women were heterosexual (84.7%, n=72), while 10.6% (n=9) 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, 50.7% (n=38) of cisgender women and all transgender women reported that they were single, while 48.0% (n=36) of cisgender women were in a regular relationship with one partner, and one was in a regular relationship with multiple partners (1.3%).

Table 30. Demographic characteristics of women living with HIV

Age	Cisgender women, n (%)	Transgender women, n (%)	Total, n (%)
Age			
<35	16 (20.8)	0 (0)	16 (19.0)
35-49	32 (41.6)	2 (28.6)	34 (40.5)
50-64	26 (33.8)	4 (57.1)	30 (35.7)
65+	3 (3.9)	1 (14.3)	4 (4.8)
State/territory			
New South Wales	23 (28.4)	4 (57.1)	27 (30.7)
Victoria	24 (29.6)	1 (14.3)	25 (28.4)
Queensland	19 (23.5)	1 (14.3)	20 (22.7)
South Australia	8 (9.9)	0 (0)	8 (9.1)
Western Australia	5 (6.2)	1 (14.3)	6 (6.8)
Australian Capital Territory	1 (1.2)	0 (0)	1 (1.1)
Tasmania	1 (1.2)	0 (0)	1 (1.1)
Place of residence			
Inner city	32 (40.0)	6 (85.7)	38 (43.7)
Outer suburbs	21 (26.3)	0 (0)	21 (24.1)
Regional/rural	27 (33.8)	1 (14.3)	28 (32.2)
Aboriginal and/or Torres Strait Islander	2 (2.6)	0	2 (2.8)
English as a first language	59 (77.6)	7 (100)	66 (79.5)
Place of birth			
Australia	52 (68.4)	4 (66.7)	56 (68.3)
Asia	8 (10.5)	0 (0)	8 (9.8)
Europe	7 (9.2)	1 (16.7)	8 (9.8)
Africa	5 (6.6)	0 (0)	5 (6.1)
Pacific	3 (3.9)	1 (16.7)	4 (4.9)
North America	1 (1.3)	0 (0)	1 (1.2)
Sexual identity			
Heterosexual or straight	70 (86.6)	2 (33.3)	72 (84.7)
Bisexual	5 (6.3)	1 (16.7)	6 (7.1)
Pansexual	1 (1.3)	2 (33.3)	3 (3.5)
Queer	2 (2.5)	0 (0.0)	2 (2.4)
Gay/homosexual/lesbian	0 (0)	1 (16.7)	1 (1.2)
Prefer not to specify	1 (1.3)	0 (0.0)	1 (0)
Relationship status			
Currently single	38 (50.7)	6 (100.0)	44 (54.3)
In a relationship with one partner	36 (48.0)	0 (0)	36 (44.4)
In a regular relationship with more than one partner	1 (1.3)	0 (0.0)	1 (1.2)

Education, employment and income

Education levels were mixed among the sample. Around one in five women 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 six 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

	Cisgender women, n (%)	Transgender women, n (%)	Total, n (%)
Highest level of education			
Primary school only	5 (3.2)	0 (0)	5 (5.9)
Up to 4 years high school	11 (7.0)	2 (16.7)	13 (15.3)
Leaving certificate/HSC/Year 12	10 (6.3)	0 (0)	10 (11.8)
Tertiary diploma/trade certificate/TAFE	25 (15.8)	0 (0)	25 (29.4)
Undergraduate university degree	14 (8.9)	2 (16.7)	16 (18.8)
Postgraduate university degree	14 (8.9)	2 (16.7)	16 (18.8)
Main employment/activity			
Work full-time	26 (33.8)	0 (0)	26 (31.0)
Work part time	15 (19.5)	0 (0)	15 (17.9)
Not working /retired	8 (10.4)	3 (42.9)	11 (13.1)
Unemployed, not looking for work	7 (9.1)	3 (42.9)	10 (11.9)
Home Duties	9 (11.7)	0 (0)	9 (10.7)
Work casual	7 (9.1)	1 (14.3)	8 (9.5)
Student	4 (5.2)	0 (0)	4 (4.8)
Unemployed, looking for work	1 (1.3)	0 (0)	1 (1.2)
Annual household income			
Negative or zero income	2 (2.6)	0 (0)	2 (2.5)
$1 - $29,999 per year	23 (30.3)	4 (80.0)	27 (33.3)
$30,000 - $49,999 per year	18 (23.7)	1 (20.0)	19 (23.5)
$50,000 - $79,999 per year	15 (19.7)	0 (0.0)	15 (18.5)
$80,000 - $99,999 per year	14 (18.4)	0 (0.0)	14 (17.3)
$100,000 or more per year	4 (5.3)	0 (0.0)	4 (4.9)

Financial security

As mentioned earlier in this report, the HIV Futures 9 survey included three indicators of financial security: housing, experiences of financial stress, and food security.

More than half of women participants (52.1%, n=37) met the criteria for experiencing financial stress in the past 12 months (Table 32). Women were significantly more likely than men to have experienced financial stress in the last 12 months (p<0.01).

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

	Women, n (%)	Men, n (%)	Non-binary/gender diverse people, n (%)
No financial stress	34 (47.9)	444 (70.9)	6 (66.7)
Financial stress	37 (52.1)	182 (29.1)	3 (33.3)
Total	71 (100)	626 (100)	9 (100)

Nearly half of women participants were currently living in private rental (48.6%, n=36), although close to one in three (28.2%, n=22) owned their own home either outright or with a mortgage. None of the women over 65 years of age were home-owners (Table 33), suggesting that this cohort may be vulnerable to housing instability.

"No services can help me with the things I need. I am more worried about being out of work, out of housing than I am my HIV."

Table 33. Housing of cisgender women by age*

	Age group				Total
	<35, n (%)	35-49, n (%)	50-64, n (%)	65+, n (%)	
Home owner (own outright)	0 (0)	3 (9.4)	4 (15.4)	0 (0)	7 (9.5)
Home purchaser (with mortgage)	1 (6.3)	8 (25.0)	6 (23.1)	0 (0)	14 (18.9)
Private rental	12 (75.0)	15 (46.9)	7 (26.9)	2 (66.7)	36 (48.6)
Public rental	0 (0)	4 (12.5)	6 (23.1)	0 (0)	10 (13.5)
Rent-free	1 (6.3)	2 (6.3)	1 (3.8)	1 (33.3)	5 (6.8)
Community housing or cooperative	1 (6.3)	0 (0)	1 (3.8)	0 (0)	2 (2.7)

*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 (48.7%, n=38) compared to cisgender men (42.4%, n=288). No transgender women lived in a home that they owned, all were in private rental or public/community housing.

Figure 44. Housing by gender*

Figure 44. Housing by gender*
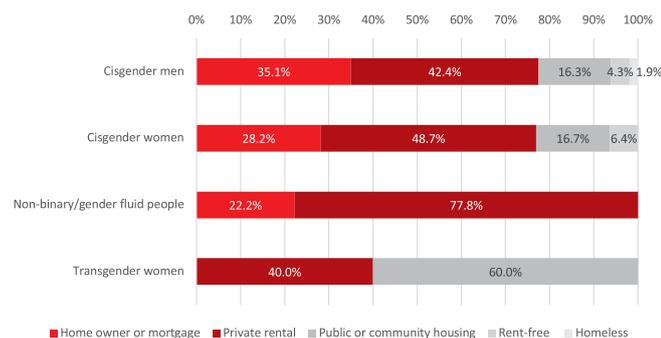
* Participants who did not respond to the question about gender or who selected "other" housing type were also excluded except where their response could be clearly recategorised into one of the above.

More than one in three women reported that they experienced food insecurity. Specifically:

- 38.1% (n=32) of women reported that it was *sometimes* or *often* true that the food they bought did not last, and they did not have money to get more, and
- 45.1% (n=37) of women reported that it was *sometimes* or *often true* that they couldn't afford to eat balanced meals.

Women were significantly more likely than men to report experiencing food insecurity (Tables 34 and 35).

Table 34. Response to the statement: "The food I/we bought just didn't last, and I/we didn't have money to get more"

	Women, n (%)	Men, n (%)	Non-binary/ gender diverse people, n (%)
Never true	52 (61.9)	531 (74.3)	7 (63.6)
Sometimes true	24 (28.6)	138 (19.3)	3 (27.3)
Often true	8 (9.5)	46 (6.4)	1 (9.1)
Total	74 (100)	715 (100)	11 (100)

Table 35. Response to the statement "I/we couldn't afford to eat balanced meals"

	Women, n (%)	Men, n (%)	Non-binary/ gender diverse people, n (%)
Never true	45 (54.9)	497 (69.5)	7 (63.6)
Sometimes true	28 (34.1)	151 (21.1)	3 (27.3)
Often True	9 (11.0)	67 (9.4)	1 (9.1)
Total	82 (100)	715 (100)	11 (100)

HIV acquisition and diagnosis

The length of time women participants had been living with HIV ranged from less than one year through to 35 years, with an average time of 14.9 years.

More than 95% of women were currently taking ART (98.8%, n=83) and, as of their last test, 81.0% (n=68) of women had an undetectable viral load (viral suppression). This is lower than the sample as a whole, in which 89.3% 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 one year or less for men (this difference was statistically significant).

Quality of life

In the PozQol measure of quality of life among PLHIV, a score of 3.0 or higher is considered "good" quality of life (from a score range of 1-5, in which higher scores indicate better quality of life). In HIV Futures 9, 61.7% of women reported "good" quality of life. The average PozQol score for women was 3.2, which was slightly higher than the average score for men (6.3), although the difference was not statistically significant.

Using the one-question item in which HIV Futures 9 participants were asked to rate their overall mental, emotional and physical health, 51% of women reported their overall sense of wellbeing to be at least good (*good* or *excellent*) – a similar percentage to men.

Health

In HIV Futures 9, we recorded self-reported general health using the SF-36 general health subscale. Among women, the average SF-36 general health score was 55.9, which is comparable to the general Australian population, and slightly higher than the score reported by men in HIV Futures 9 (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 9 compared to general population rates. All transgender women in this study reported that they had a current or previous diagnosis of two or more mental health conditions. Depression was most common, with 42.9% (n=3) reporting a current diagnosis of depression and 57.1% (n=4) reporting a past or current diagnosis of depression, while 71.4% (n=5) reported a past or current anxiety condition. 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, including lesbian, gay or bisexual cisgender people (Leonard, Pitts et al. 2012, Leonard 2015).

Among cisgender women, 27.4% (n=20) reported they had a current diagnosis of depression, while 54.8% (n=40) reported a current or past diagnosis of depression. Twenty-six percent (26.0%, n=19) of cisgender women reported a current diagnosis of anxiety, while 43.8% (n=32) reported a current or past diagnosis of anxiety.

Multiple mental illnesses were common, with 40% (n=29) of cisgender women reporting two or more current mental health conditions and 31% reporting three or more (n=20). Again, the most common comorbidities were anxiety and depression.

Of the lower prevalence mental health conditions, the most common condition reported by both cisgender and transgender women was post-traumatic stress disorder, with 10 cisgender and two transgender women reporting a current diagnosis. Rates of bipolar disorder, borderline personality disorder, obsessive-compulsive disorder and schizophrenia were low (three participants or less reporting a current diagnosis).

Satisfaction with treatment and clinical care

Most women (83.3%, n=70) reported that they were satisfied with their clinical care for HIV (see Table 36). Most women were also happy with their HIV treatment, with 65.0% (n=54) reporting that they were *extremely* or *very happy* with their treatment. As shown in Figure 45, women were significantly less likely than men to report that they were happy with their treatment (p<0.05), though it is unknown whether this was due to a difference in physiological or social factors.

Table 36. Satisfaction with clinical care for HIV

	Cisgender women, n (%)	Transgender women, n (%)	Total n (%)
Very satisfied	45 (58.4)	4 (57.1)	49 (58.3)
Satisfied	18 (23.4)	3 (42.9)	21 (25.0)
Neither satisfied nor unsatisfied	3 (3.9)	0 (0)	3 (3.6)
Unsatisfied	8 (10.4)	0 (0.0)	8 (9.5)
Very unsatisfied	3 (3.9)	0 (0.0)	3 (3.6)
Total	77 (100)	7 (100)	84 (100)

"Australian pregnancy & breastfeeding guidelines are long overdue. My pregnancy and birth experiences differed depending on which health service/professional I encountered. I spent a lot of my Antenatal appointment time educating staff about HIV. Whilst pregnant, I refused to take one of the two [medications] my HIV doctor prescribed as it had made me very ill during my previous pregnancy. My VL blipped - went from undetectable to 42 (forty two!) and my HIV doctor reported me to Dept of Child Safety. My next result was undetectable again. This was incredibly traumatic, I changed my whole care team, gave birth at a different hospital in a capital city. Well informed, motivated WLHIV need to be supported to breastfeed their children. While I was being browbeaten and told I couldn't breastfeed, another WLHIV in another state was breastfeeding with the full support of her care team. This is unacceptable."

Figure 45. Happy with HIV treatment by gender (% within each gender category)

Legend: Women, Men, Non-binary/gender fluid
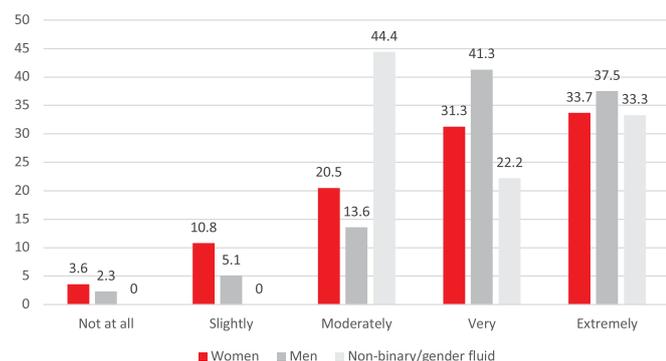
Sex and relationships

Around half of the women participants were in a relationship (45.6%, n=37), and 32.9% (n=26) cohabited with their partner/spouse.

Of those women with partners, 64.9% (n=24) reported that their partner was HIV negative (as per their most recent test), 27.0% (n=10) reported that their partner was HIV positive, and 8.1% (n=3) were unsure.

Around one in three (36.4%, n=28) reported they had not been sexually active in the past six months. The majority (68.9%, n=51) indicated that they were having sex *less often* than they desired, while 54.6% (n=47) were dissatisfied with their sex lives. Women who were not in a current relationship were more likely to be dissatisfied with their sex lives.

Participants were asked a series of questions about the impact of HIV on their sexual lives and concerns about transmission of HIV to sexual partners. The majority of women (74.0%, n=57) were confident of not transmitting HIV to a sexual partner and 49.4% (n=38) did not agree that they were afraid of transmitting HIV to a partner. However, close to half (48.8%, n=38) felt that HIV had a negative impact on their sexual pleasure, while 46.1% (n=36) had avoided sexual and intimate relationships since being diagnosed with HIV. Having an undetectable viral load increased sexual pleasure for 41.8% (n=33) of women. Most women (81.0%, n=64) were ambivalent about whether they would prefer to have a relationship with another PLHIV or indicated they would not prefer this.

Figure 46. Feelings about HIV and sex

Legend: Strongly agree, Agree, Neither agree or disagree, Disagree, Strongly disagree
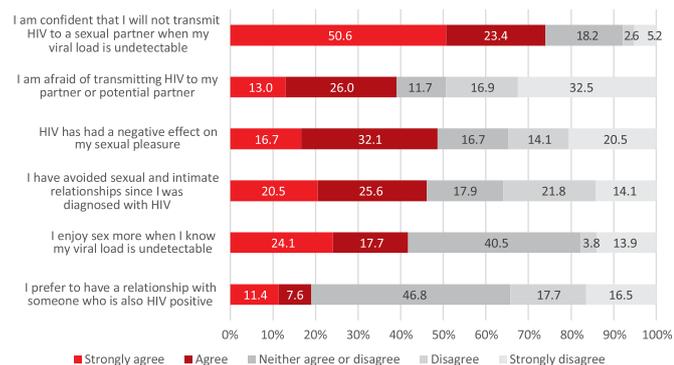
IMPLICATIONS FOR PRACTICE

Findings in HIV Futures 9 suggest that Australia will remain on track to achieve the global 90-90-90 targets if it maintains current levels of investment in HIV testing, treatment and clinical care.

However, viral suppression alone does not ensure quality of life among PLHIV (Power et al. 2016). For Australia to meet its own ambitious targets (Department of Health 2018), which include 75% of PLHIV with good quality of life, investment in programs and services targeted toward QoL among PLHIV must be prioritised.

Strengthening quality of life and wellbeing

In HIV Futures 9, 63.1% of participants' PozQoL scores indicated a good quality of life overall. These people reported that HIV did not limit their choices or opportunities in life. However, when asked specifically about wellbeing only 50.5% reported their wellbeing to be good or excellent – a lower proportion than any other HIV Futures cohort. Poorer QoL and poorer wellbeing was associated with poverty, financial insecurity (including meeting the costs of HIV healthcare), lower levels of social connectedness and concerns about HIV-related stigma. These findings suggest that wellbeing is more closely linked to the social determinants of health than to the biomedical aspects of living with HIV and there is an ongoing need for community support programs for PLHIV which address these issues.

Financial support: Over one in three respondents to the HIV Futures survey were reliant on government benefits as their main income, and many that were living on low incomes, particularly women, reported experiencing recent financial stress. It is possible that this does not accurately reflect the patterns of incomes among the whole population of PLHIV in Australia as we were more likely to hear from people who are connected to services and support programs through which we promoted the survey. The community-based HIV sector has always provided material support to PLHIV in the form of assistance with daily living costs, food and financial support. This began as a service for people who were seriously unwell. The form of these services has changed as treatment has improved and fewer PLHIV require intensive home care. However, these findings suggest an ongoing need for the HIV sector to be resourced to provide services that aim to mitigate the material, health and social impact of poverty, which often includes greater social isolation.

Social connectedness: Social connection – friendship, housemates, family, partners and general social support – is key to good QoL, and was strongly associated with QoL for HIV Futures 9 participants. Connecting with other PLHIV was also highly valued by HIV Futures 9 participants. This is where the community sector continues to play a major role in improving QoL. Participants utilised and appreciated community and peer programs as an avenue for meeting other PLHIV. Both face-to-face and online forums were important in providing complementary (although different) opportunities for connections. Online forums can offer wide reach and broad connection, however face-to-face connection is still vital for many PLHIV, particularly those who may be experiencing stigma and isolation.

Focus on mental health: The rates of diagnosed and undiagnosed mental health conditions were significantly higher among HIV Futures 9 participants than the general Australian population. These rates are higher than those reported in HIV Futures 8 (Power et al. 2016).

These data highlight the link between precarity of circumstances and mental ill health. Mental ill health is disproportionately linked to socioeconomic disadvantage (WHO 2014) and worsened by the negative emotional impact of HIV-related stigma. Capacity building partnerships between the HIV and mental health sectors could strengthen policies and services that address the mental health and wellbeing of PLHIV.

PLHIV aged 50-64: In all the above areas, HIV Futures 9 participants aged 50-64, were a vulnerable group. People in this age group reported poorer quality of life than any other age group and were more likely to have experienced financial uncertainty and other health and social vulnerabilities. PLHIV in this age range are often ineligible for services for older people due to their age (under 65) or because their functional impairment does not exceed the required thresholds. These data point to a role for services and policies to prioritise PLHIV in this age group to address this gap.

Considerations for HIV prevention, treatment and care

HIV Futures 9 reveals a number of priorities and challenges for policy makers and service providers working to reduce the impact of HIV in Australia.

HIV treatment: While most people in the sample were on (and believed they needed to be on) ART, the data suggests a broader ambivalence about ART for some PLHIV: 45.5% were ambivalent or agreed that ART is harmful, and 31.9% were unhappy with treatment side effects. HIV Futures data tell us that satisfaction with ART has increased over time but as Australia moves towards achieving treatment and viral suppression goals it is important that clinicians and policy makers recognise that some PLHIV continue to experience challenges with ART.

Women: Women participating in HIV Futures 9 reported an average of 2.4 years between HIV acquisition and diagnosis (compared to 1 year or less for men) and were less likely to be virally supressed. These findings, along with national surveillance data (Kirby, 2018), remind us that women test less frequently, are diagnosed later, and face additional barriers to viral suppression. Initiatives that support providers to normalise HIV testing among all women are essential for increasing rates of diagnosis and reducing late diagnosis.

Injecting and harm reduction: Recent national surveillance data shows a small increase in HIV notifications among men who have sex with men who also inject (Kirby 2018). Over 30.0% of HIV Futures 9 participants had ever injected drugs, 14.2% of these in the past 12 months.

A renewed focus on HIV prevention among people who inject drugs is needed to maintain the low levels of HIV among this population. Undetectable = Untransmissible (U=U) applies only to sexual transmission and has not yet been proven in the context of injecting. HIV organisations, sexual health and harm reduction services should ensure that HIV health promotion is inclusive of people who inject

drugs and make explicit that while viral suppression lowers the risk of HIV transmission, U=U cannot be applied in injecting settings. Likewise, harm reduction campaigns for people who inject drugs need to be inclusive of HIV.

Hepatitis C coinfection: Hepatitis C Direct Acting Antivirals (DAAs) are highly curative, well tolerated and strongly indicated in people coinfected with HIV and hepatitis C. While 36.4% of HIV Futures 9 participants diagnosed with hepatitis C reported that they had completed DAA treatment, there is scope to increase efforts to link people with HIV/hepatitis C coinfection into hepatitis C treatment. Initiatives that increase coverage of hepatitis C testing among PLHIV are also essential. PLHIV with increased risks for hepatitis C should be tested for hepatitis C at least annually.

HIV Futures and diverse communities

Historically, many HIV-affected people and communities have been underserved by the Australian HIV response.

While HIV Futures 9 had a larger than ever proportion of non-Australian born participants, it is still not representative of the diversity of PLHIV in Australia. In particular, people from culturally diverse backgrounds have always been under-represented in HIV Futures surveys, especially PLHIV for whom is English is not their preferred language. HIV Futures heavily relies on HIV community organisations to promote the survey to PLHIV, and the gaps in the data may reflect gaps in service delivery for culturally diverse communities (Johnson 2018). There is an ongoing need for stronger research, policy and practice collaborations with under-represented key populations, particularly women, Aboriginal and/ or Torres Strait Islander communities, people from migrant communities, asylum seekers and mobile populations, and heterosexual people

APPENDIX: METHODOLOGY

The HIV Futures 9 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 two to three years) since 1997. HIV Futures 9 is the ninth 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 (S15-100)
- South Eastern Sydney Local District Health Human Research Ethics Committee (15/292 (LNR/15/POWH/559))
- Alfred Hospital Ethics Committee (608/18)
- Thorne Harbour Health Ethics Committee (THH/CREP/18/004)
- ACON Research Review Ethics Committee (2018/26).

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 and 9), the sample size has been approximately 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.

As with HIV Futures 8, participants in HIV Futures 9 were invited to provide information to generate a unique participant code. This code enables their responses to HIV Futures 9 to be paired with their responses to HIV Futures 8, 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 December 2018 and May 2019 using a self-complete survey that could be filled in online or using a hardcopy 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 9 was open to people living with HIV, aged over 18 years and currently living in Australia. The study relied on a self-select 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; advertisements on 'dating apps' used by gay and bisexual men; and flyers and posters displayed in HIV clinics. Social media advertising also included posts on The Institute of Many (TIM) Facebook page. These were done in consultation with the managers of TIM and a donation was made to TIM as a gesture of appreciation. 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.

The majority of participants completed the survey on-line (71%, n=601), while 29% (n=246) completed a hard-copy of the survey.

To gauge effectiveness of recruitment techniques, participants were asked where they found out about the study. The most common response was an email or (hardcopy) mail out from an HIV organisation (28.2%, n=150), being sent information because they had completed a previous HIV Futures survey (27.8%, n=148), seeing a Facebook advertisement (13.6%, n=72), seeing a post on The Institute of Many Facebook page (13.4%, n=71), seeing an advertisement on a 'hook-up' or dating app (8.9%, n=47) or seeing an advertisement on a phone 'app'.

Instrument and measures

The HIV Futures 9 survey instrument was significantly 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. Following this feedback, the updated instrument was shorter than the previous HIV Futures 8 survey, while continuing to capture information relevant to the contemporary situation and allowing for comparisons over time with previous versions of HIV Futures. The HIV Futures 9 survey instrument contained 148 questions across fifteen 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, 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 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 which year they tested positive for HIV, the 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 ART use, 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 ART use, including experience of side-effects, whether they had recently changed treatment combination and cost of filling prescriptions.

Health and wellbeing: The survey included the RAND Short Form 36 1.0 (SF-36) general health and emotional wellbeing subscales, which have been validated for use among PLHIV (Wu, Hays 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 screened for sexually transmissible infections (STI) in the past 12 months and which STIs they had been diagnosed with.

Other co-morbidities, including viral hepatitis: Participants were asked whether they had been diagnosed with a range of physical health conditions including HIV-associated neurocognitive disorders (HAND). They were also asked: whether they had ever been diagnosed with chronic hepatitis B, how often they had ever screened for hepatitis C virus (HCV), whether they had ever been diagnosed HCV antibody positive or with chronic HCV, whether they had ever received treatment for HCV, and 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, whether they have seen a nurse for HIV-related treatment and service type, and satisfaction with clinical services.

Alcohol, tobacco and non-medical drug use: Participants were asked two standard questions about how often they smoked tobacco (Australian Institute of Health and Welfare 2017) and three questions frequency and quantity of alcohol consumption (the AUDIT-C measure) (Dawson, Grant 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 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 and Health at the University of NSW (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 sexual partner/s, whether their sexual partner/s uses PrEP, satisfaction 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 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).

People over 50: People aged over 50 years were asked to complete an extra section of the survey instrument that asked about: access to online support, social contact,

service use including specialist services, challenges accessing services, use of community support services, concerns about future health and long term care and support needs. (Note, responses to these questions will be published elsewhere.)

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 9 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 9 are general and not specific to the unique experiences of people from migrant communities. This would be more suited to a qualitative study.

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 relied heavily on advertising through support organisations for people living with HIV. While we made efforts to promote the survey through broader networks, particularly social media, people not connected to such organisations may have been less likely to be aware of the study. Further, 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 LGBT communities), would have had limited exposure to survey advertising.

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