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HIV FUTURES 11

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All research conducted is approved by the La Trobe University Human Ethics Committee and additional institutional and community ethics committees where appropriate.

ACKNOWLEDGEMENTS

The success of the HIV response is built on the continued insight, effort and dedication of people living with HIV. This project relied on input from people living with HIV at all stages of the study process. We are grateful to all participants in HIV FUTURES 11 and mindful of the time and effort it takes for people to complete the survey questionnaire.

A range of peer-based organisations and HIV advocacy/community agencies from every state and territory of Australia have been actively involved in this project, providing guidance on the survey instrument, facilitating participation through their membership and community networks, and advising on analysis and priorities for this report. This includes ACON, WAAC, Positive Life NSW, Living Positive Victoria, Queensland Positive People, Thorne Harbour Health, Positive Life SA, and many other agencies and individuals. The project is officially endorsed, and supported, by the National Association of People with HIV Australia (NAPWA), Health Equity Matters, and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM).

The project is funded by the Australian Government Department of Health, Disability, and Ageing, and run by the Australian Research Centre in Sex, Health and Society (ARCSHS), based at La Trobe University in Melbourne.

This research follows from the previous HIV Futures studies, which commenced in 1997. We would like to acknowledge researchers who contributed to these projects, in particular Stephanie Amir, Michael Bartos, Graham Brown, Richard de Visser, Gary Dowsett, Douglas Ezzy, Jeffrey Grierson, Jen Johnson, Rachel Koelmeyer, Jayne Lucke, Karalyn McDonald, Marian Pitts, Rachel Thorpe, Doreen Rosenthal, Henry von Doussa, and Jimmy Yu-Hsiang Chen.

ACKNOWLEDGEMENT OF COUNTRY



La Trobe University proudly acknowledges the Traditional Custodians of the lands where its campuses are located in Victoria and New South Wales. We recognise that Indigenous Australians have an ongoing connection to the land and we value their unique contribution, both to the University and the wider Australian society.

La Trobe University is committed to providing opportunities for Aboriginal and Torres Strait Islander people, both as individuals and communities, through teaching and learning, research and community partnerships across all of our campuses.

The wedge-tailed eagle (*Aquila audax*) is one of the world's largest.

The Wurundjeri people — traditional owners of the land where the Australian Research Centre in Sex, Health and Society is located and where our work is conducted — know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to 'gamagoen yarrbat' — to soar.

Copies of this and previous reports can be found at www.latrobe.edu.au/arcshs. For enquiries please contact Lead Investigator Dr Thomas Norman: Australian Research Centre in Sex, Health and Society (ARCSHS) Building NR6, La Trobe University, Victoria 3086 Australia

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Suggested citation:

Norman, T., Power, J., Rule, J., Clifton, B., Newman, B., Bourne, A., & Murphy, D. *HIV FUTURES 11*. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University. .

ISBN: 978-1-7642889-5-8

DOI: 10.26181/32390481

CRICOS Provider Code: 00115M

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GLOSSARY

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

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

Cisgender A term used to describe a person whose gender identity is the same as the sex they were assigned at birth

Female Refers to participants who reported their sex assigned at birth as female, except where otherwise specified

HAND HIV-associated neurocognitive disorder

HCV Hepatitis C virus

HIV Human immunodeficiency virus

HPV Human papillomavirus

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

IVSC Innate variations of sex characteristics; natural variations in physical sex characteristics, including chromosomes, hormones, reproductive anatomy, or other bodily features, that differ from typical expectations of female or male bodies

LGBTQA+ Lesbian, gay, bisexual, transgender, queer, asexual, and other gender and sexually diverse people who use different terms to describe their identities

Male Refers to participants who reported their sex assigned at birth as male, except where otherwise specified

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

M Statistical mean (i.e., average)

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 'man' or 'woman'

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 health, psychological, functional, and social

PLHIV People living with HIV

s100 prescriber A medical practitioner authorised to prescribe HIV antiretroviral therapy under Section 100 of the Australian Government's Pharmaceutical Benefits Scheme (PBS), which provides subsidised access to highly specialised medicine

SD Standard deviation

SF-36 The 36-Item Short Form Survey, a widely used measure of health-related quality of life; the *HIV FUTURES 11* questionnaire included the questions relating to general health and emotional wellbeing so that scores could be calculated for these two subscales

SF-36 GH The SF-36 general health subscale

STI Sexually transmissible infection

Transgender This report uses the term transgender men to refer to people whose gender is male and whose sex assigned at birth was female, and transgender women to refer to people whose gender is female and whose sex assigned at birth was male. Unless otherwise specified, references to men and women throughout this report include both cisgender and transgender participants. Participants who identified as non-binary, gender fluid, or another gender diverse identity are reported separately where relevant

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

Undetectable viral load A viral load result that is below the limit of detection by some testing technologies. It is generally defined as having fewer than 200 copies of the virus per millilitre of blood.

Viral load The number of copies of a virus in the blood. It is typically measured as the number of viral particles (copies) per millilitre.

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

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EXECUTIVE SUMMARY

HIV FUTURES 11 is a study of health, wellbeing and quality of life among people living with HIV (PLHIV) in Australia, forming part of a series of *HIV FUTURES* surveys that have been run 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 11* from December 2024 until January 2026. Participants completed a questionnaire using a self-complete online or hard copy form. The survey instrument comprised questions related to quality of life, financial security, health, wellbeing, treatment, support, sex, relationships, HIV-related laws, HIV-related stigma, and substance use.

WHO PARTICIPATED?

HIV FUTURES 11 was completed by 706 PLHIV, representing approximately 2.4% of the estimated 30,890 PLHIV in Australia who are aware of their diagnosis (King et al., 2025). Participants ranged in age from 18 to 89 years, with an average age of 55 years, continuing the long-term upward age trend observed across previous *HIV FUTURES* surveys.

One-third of participants (33.2%) were born outside Australia, representing the highest proportion of overseas-born participants recorded in *HIV FUTURES* to date. Participants reported being born across 53 different countries. Of those born outside Australia, 81.0% reported English as their first language.

QUALITY OF LIFE

Most participants reported encouraging quality of life outcomes, as indicated by responses to the PozQoL scale, a quality of life measure specifically designed for PLHIV. Overall, 69.7% of participants reported 'good' quality of life (PozQoL score ≥ 3.0), substantially higher than *HIV FUTURES 9* (63.1%; 2018–19), although slightly lower than *HIV FUTURES 10* (71.8%; 2021–22). Despite these gains, quality of life remains well below the national target of 95% of PLHIV reporting good quality of life by 2030 (ACDC, 2024).

The mean PozQoL score was 3.36 out of 5. Participants reported the highest quality of life in the functional domain (mean = 3.9), which relates to daily functioning and ability to live life fully. Lower scores were observed in the social domain (mean = 3.2), which is focused on relationships and social connectedness, and health concerns domain (mean = 3.1), which reflects worry about current and future

health. Better quality of life was strongly associated with social connectedness, better general health, higher resilience, higher household income, financial security, and living with a partner or spouse. Participants aged 65 years and over were more likely to report good quality of life than those who were younger. Experiences of HIV-related stigma and/or discrimination in the past 12 months were strongly associated with poorer quality of life. The proportion reporting poorer quality of life increased from 16.1% among participants with no experience of stigma or discrimination to 84.6% among those who had experienced stigma 'often' or more.

Although overall quality of life among participants born outside Australia was comparable to the broader sample, important differences were evident according to residency status. Migrant citizens and permanent residents reported quality of life outcomes comparable to, or higher than, Australia-born participants across all PozQoL domains. In contrast, migrant participants who were not Australian citizens or permanent residents reported substantially lower social, health, and functional quality of life scores than Australia-born participants and migrant citizens or permanent residents.

FINANCIAL AND HOUSING SECURITY

Financial insecurity remained a significant challenge for many participants. More than one in five participants (22.1%) experienced significant financial stress in the previous 12 months, representing an increase from *HIV FUTURES 10* (17.2%) and approximately 10 percentage points above the national average. Financial stress was particularly common among younger participants, people living in outer suburban areas, and those living in private

rental accommodation.

Private rental remained the most common housing arrangement (32.4%), while 28.0% owned their home outright and 19.0% owned their home with a mortgage. A substantial minority relied on public or community housing (12.7%), and 0.8% reported living in boarding houses, crisis accommodation, or were experiencing homelessness.

Healthcare costs remained a source of financial pressure for some participants. Around one in five reported difficulty affording out-of-pocket HIV healthcare costs (22.0%) or HIV medication costs (11.5%), while more than one-third reported difficulty affording non-HIV medication costs (37.5%).

Financial insecurity, housing insecurity, and healthcare affordability are enduring barriers to wellbeing and quality of life for many PLHIV.

HIV DIAGNOSIS, TREATMENT, AND VIRAL SUPPRESSION

Australia continues to perform strongly across the HIV treatment cascade. Reflecting national surveillance data (King, et al., 2025), almost all participants were currently taking antiretroviral therapy (99.1%), and, of those who reported their recent viral load test result, 96.4% reported an undetectable viral load. Most participants (80.4%) had been diagnosed with HIV for more than 10 years, with an average time since diagnosis of 20.9 years.

Satisfaction with HIV treatment and care was high. Eight in ten participants (80.0%) reported being very or extremely happy with their HIV treatment, while 90.0% were satisfied or very satisfied with their HIV clinical care. Confidence engaging with HIV care was also generally high. Most participants had access to bulk-billing HIV-related care (75.2%), although around one in five did not. Travel distance to HIV-related care was also a significant barrier for some participants, particularly those living in regional and rural areas.

While antiretroviral treatment was generally well integrated into participants' daily lives, concerns about the long-term effects of HIV medication was reported by 51.9% of participants.

Reflecting substantial public health messaging over the last decade, participant confidence in U=U was high. Overall, 86.7% of participants agreed or strongly agreed that they were confident they would not transmit HIV to a sexual partner if their viral load was undetectable. However, confidence in U=U did not entirely eliminate concerns about transmission and 42.3% indicated uncertainty or fear about onward transmission of HIV to a sexual partner. Although fears of onward transmission have declined substantially across successive *HIV*

FUTURES surveys, findings from *HIV FUTURES 11* show that concerns about HIV transmission persist for some people despite high levels of confidence in treatment effectiveness.

HEALTH AND WELLBEING

Many participants reported high levels of physical and mental health and strong engagement with healthcare. The average SF-36 general health score was 55.0 out of 100, comparable with Australian population-based studies (Hawthorne et al., 2007).

At the same time, mental health conditions and chronic health conditions were common. Almost half of participants (45.5%) reported a current mental health diagnosis, while 60.5% reported either a current or previous diagnosis. Depression (23.7%), anxiety-related conditions (21.2%), and post-traumatic stress disorder (14.0%) were the most commonly reported current mental health conditions. Participants with multiple mental health diagnoses reported substantially poorer quality of life.

Multimorbidity was also common. More than three-quarters of participants (76.1%) reported at least one major non-HIV health condition, and almost half (47.6%) reported two or more comorbidities. The burden of chronic disease increased substantially with age, with almost half of participants aged 65 years and over reporting three or more chronic non-HIV health conditions.

In *HIV FUTURES 11* we asked participants about their vaccination status for influenza, COVID-19, mpox, and HPV. Vaccination uptake was high for influenza (80.7% vaccinated) and COVID-19 (83.8% vaccinated), although lower for mpox and HPV. One-third of participants (37.7%) were not sure of their HPV vaccination status.

Tobacco smoking was reported by 21.7% of participants. Although smoking prevalence has declined substantially across successive *HIV FUTURES* surveys, rates remained higher than most recent estimates for the general Australian population.

STIGMA, DISCRIMINATION, AND DISCLOSURE

HIV-related stigma and discrimination was commonly reported by participants and had a negative influence on social relationships, healthcare experiences, emotional wellbeing, and decisions about HIV disclosure. Almost half the participants reported at least some experience of HIV-related stigma or discrimination in the previous 12 months.

Experiences of stigma within healthcare settings was common, with 34.2% reporting at least some experience of being treated negatively or differently by health workers because of their HIV status in the previous 12 months. Women living with HIV were significantly more likely than men to report healthcare-related stigma. More than half of women (55.6%) reported being treated negatively or differently by health workers because of their HIV status on more than one occasion in the previous 12 months, compared with 30.5% of men.

In *HIV FUTURES 11* we asked questions about knowledge, and impacts, of HIV-related laws regarding disclosure and prevention of possible transmission. Most participants reported understanding their obligations regarding preventing HIV transmission (95.3%), although fewer reported understanding their rights or responsibilities regarding disclosure (76.4%). Many participants perceived HIV-related laws as contributing to stigma. Almost half (47.6%) agreed that current laws negatively affect what others think about PLHIV, while 35.2% agreed that HIV laws make it difficult to be open about their HIV status. Disclosure concerns were also widespread. Most participants reported being very careful who they told about their HIV status (74.0%) and agreed that telling someone they had HIV was risky (65.0%). More than one in three (41.9%) reported working hard to keep their HIV status secret.

Participants commonly reported experiences of subtle and indirect HIV-related stigma and microaggressions. Around half reported at least sometimes hearing phrases such as “I’m HIV negative, I’m clean” (48.4%) or encountering exclusionary language on dating profiles such as “neg for neg only” (48.3%). These findings suggest that while overt discrimination may be less visible than in previous decades, HIV-related stigma continues to shape everyday experiences.

SOCIAL CONNECTION, PEER SUPPORT, AND SERVICE USE

Social connectedness and peer support were important aspects of wellbeing for many PLHIV. Social connectedness was strongly associated with financial and household circumstances, with lower social connectedness reported among participants experiencing financial stress and those living alone.

Most participants reported some degree of connection with other PLHIV. Around two-thirds reported having at least one other person living with HIV they could talk to about living with HIV (62.0%), while most agreed that knowing other PLHIV was important to them (67.1%).

Peer-based HIV services and remained important sources of support. More than one in three participants (39.1%) reported accessing advice or support from a peer worker in a community organisation or health service in the previous 12 months. Most participants also reported positive views of HIV community services, including their role in connecting PLHIV and supporting wellbeing.

At the same time, experiences of HIV community connection were mixed. More than one-third of participants (37.1%) reported that they did not feel part of a community of PLHIV, while 23.8% reported feeling isolated or cut off from other PLHIV.

Participants identified several priorities for future services and programs, including expanded opportunities for peer connection and social support, greater support for ageing and long-term survivorship, improved mental health and wellbeing services, and increased access to practical supports such as housing, transport, and affordable healthcare. Participants living outside metropolitan areas also highlighted the need for more geographically accessible services and opportunities for community connection.

CONCLUSION

HIV FUTURES 11 paints a mixed but largely encouraging picture of life with HIV in contemporary Australia. Treatment uptake, viral suppression, engagement in care, and treatment satisfaction remain exceptionally high, reflecting the continued success of Australia’s HIV response. Most participants reported good quality of life, and many described strong connections with peers, community, and healthcare services.

At the same time, quality of life remains substantially below the national target of 95% by 2030 and has changed little since *HIV FUTURES 10* (2021–22). Findings from *HIV FUTURES 11* suggest that some of the greatest inequalities in quality of life continue to be concentrated among people experiencing financial hardship, social isolation, poorer physical health, and insecure residency. Improving quality of life for PLHIV in Australia will require sustained investment in strategies that address the social, economic, and structural conditions that shape wellbeing, alongside maintaining Australia’s strong HIV treatment and care outcomes.



FOREWORD

MAURICIO GOMEZ MEJIA (QUEENSLAND POSITIVE PEOPLE)

HIV FUTURES has always been more than a research report. It is a record of our lives, resilience, fears, strengths, and the systems that either hold us or leave us to find our own way.

As someone with lived experience of HIV and migration, and as a peer worker who has walked alongside many people living with HIV, I read *HIV FUTURES 11* with pride, gratitude and urgency. Pride because Australia's HIV response continues to show what is possible when treatment, community leadership, research and advocacy work together. Gratitude because **706 People Living with HIV** gave their time and experiences to this study. Urgency because strong clinical outcomes do not automatically mean people are living well, feeling safe, or feeling connected.

Australia continues to perform strongly in HIV treatment and care. *HIV FUTURES 11* reports that **99.1% of participants were currently taking antiretroviral therapy, and 96.4% of those with a recent viral load result were undetectable.** These are extraordinary achievements, built through decades of activism, science, community leadership, and the courage of people living with HIV.

But HIV has never been only clinical. A diagnosis does not arrive only in the body. It arrives at someone's relationships, language, culture, family, visa situation, housing, mental health, sexuality, faith, work and sense of future. For many people, especially those from culturally and linguistically diverse communities, diagnosis can also arrive with fear of rejection, disclosure, migration consequences, shame, and being misunderstood by the systems meant to provide care.

This is why the quality-of-life findings in *HIV FUTURES 11* matter so deeply. The report shows that **69.7% of participants reported good quality of life,** still well below the national target of **95% by 2030.** That gap is not just a statistic. **It is a call to action.**

Quality of life is shaped by much more than medication. *HIV FUTURES 11* links better quality of life with social connectedness, better general health, resilience, financial security, household income and living with a partner or spouse. It also links HIV-related stigma and discrimination with poorer quality of life. If we want people living with HIV to live well, then our response must be as strong socially, culturally and emotionally as it is clinically.

This matters deeply for culturally diverse people living with HIV. **One-third** of *HIV FUTURES 11* participants were born outside Australia, **the**

highest proportion recorded in *HIV FUTURES* to date, with participants born across 53 countries. Our communities are here, our experiences are part of the national story, and our needs must be visible in research, policy and service design. However, the category of "overseas born" can never capture the full complexity of our lives. It does not show who is waiting for a visa decision, translating medical information, afraid to tell their family, or worried that disclosure could affect their relationship, employment, housing, migration journey or sense of belonging.

My own diagnosis experience was supported... I was lucky ... and I know how much of a difference that can make. But in my work, I have seen that this is not everyone's experience. People come to peer navigation knowing very little about HIV, treatment, U=U, disclosure, rights, services, or what life after diagnosis can look like. Many are trying to process the words "you have HIV" while also trying to understand an unfamiliar health system, often in a language that is not their first.

HIV FUTURES 11 also reminds us that **peer support** is essential. **Around two in five participants reported accessing advice or support from a peer worker in the previous 12 months.** At the same time, more than one-third did not feel part of a community of people living with HIV, and almost one-quarter reported feeling isolated or cut off from other people living with HIV.

Peer support can translate information into hope. It can turn a clinical fact into something a person can live with. It can help someone move from fear to understanding, from shame to dignity, and from isolation to connection. Peer workers do not replace clinicians. We complement them by bringing the lived, human and community knowledge that helps people navigate life beyond the appointment room.

My hope is that every person diagnosed with HIV in Australia is offered early, culturally safe, peer-led support as part of standard care, no matter where they live, what language they speak, what visa they hold, how they acquired HIV, or whether they already know how to ask for help.

HIV FUTURES 11 gives us evidence, but it also gives us responsibility. The next chapter of the HIV response must not only ask whether people are surviving, on treatment, or virally suppressed. It must ask whether people feel connected, respected, informed, safe, and held.

No one should have to navigate HIV alone.



FOREWORD

EDWINA WRIGHT

Australia's HIV response reflects a long-standing commitment to multi-sectoral, community-led partnerships. The fruits of this response include world-leading clinical care, research, guidelines and policies. A key policy example was Australia's early introduction of harm minimisation, including needle-syringe exchange programs. This brave policy – perhaps gifted by the prophet Cassandra – worked and prevented HIV infection from becoming widely established in Australia.

For more than three decades, for those people who have lived with HIV in Australia, *HIV FUTURES* has been an essential chronicler of their lives and the fruits of the partnership response. *HIV FUTURES 11* chronicles a highly comprehensive account of the lives of 706 people living with HIV.

As an infectious diseases specialist, I find this report to be indispensable reading for all clinicians involved in the care of people with HIV. A key reason is because time is now so precious that clinicians are like to routinely address only the most pressing clinical needs during a consultation. This report offers important insights into what clinicians might be missing.

For example, 22.1% of respondents in *HIV FUTURES 11* reported significant financial stress – a topic that is rarely proffered by patients, or that I directly ask about. Another striking finding was that 51.9% of respondents agreed or strongly agreed that they worry about the long-term effects of HIV antiretrovirals. This concern is rarely if ever raised in my experience. Similarly, *HIV FUTURES 11* reports that while the concept of U=U was understood by 86.7% of respondents, only 57.7% were not afraid of transmitting HIV to their partners.

The above examples sit alongside the formal quality-of-life evaluation in *HIV FUTURES 11*. Here we find that 69.7% of people reported good quality of life using the PozQol scale and 54.4% reported that their wellbeing was good or excellent using another scale. PozQol addresses social, functional, psychological and health domains. Factors associated with good quality of life included older age, less financial stress, higher household income, living with a partner, Australian citizenship and fewer experiences of stigma in the previous 12 months. Conversely these factors when flipped track for poorer quality of life. PozQol surveys are embedded in some clinical practices in Australia, but *HIV FUTURES 11* invites clinicians to semi-regularly glimpse their patient's quality of life by doing a roll

call of these factors during a consultation. Notably one third of women reported experiencing stigma at least sometimes. And both men and women report stigma in healthcare settings, which is the responsibility of clinicians and healthcare facilities to address.

Finally, this report provides important insights into how we are tracking in terms of building health prevention into the lives of people with HIV. Of course, the high levels of antiretroviral uptake (99.1%) and viral suppression (96.4%) described in *HIV FUTURES 11* prevent poor health outcomes by maintaining good immune health. But in *HIV FUTURES 11* we learn about use of other key prevention measures e.g. 49% of respondents reported using statins. Statins are lipid lowering agents and a 2023 landmark study, *REPREIVE*, reported that statins reduced cardiovascular disease by 36% over 5 years in men and women living with HIV. At baseline, participants were aged 40–75 years and had low-moderate cardiovascular risk. Given the average age in *HIV FUTURES 11* is 55 years, one suspects that not all people with HIV between 40–75 years are currently receiving the benefits of statins and this should be addressed.

This iteration of *HIV FUTURES* introduced vaccine coverage as an important health prevention measure. Most striking was the finding that only 24% of people reported complete vaccination against human papillomavirus (HPV). This virus causes anal and cervical cancer, which are prevalent health conditions in people with HIV. The HPV vaccine is recommended in Australia for all men who have sex with men and people with significant immunocompromise. However, it is only funded for young people aged 12–13, not older people. Understanding our patients' capacity to pay for the HPV vaccine and advocating for Commonwealth funding for men who have sex with men (MSM) and people living with HIV sits within the remit of clinicians.

Congratulations to the *HIV FUTURES* team on this excellent report. It remains a trusted and much needed companion for clinicians who have the great fortune to care for people living with HIV.

INTRODUCTION

HIV FUTURES investigates the health, wellbeing, and quality of life of people living with HIV (PLHIV). It is the largest and longest-running study of its kind in the world, having started in Australia in 1997. It was born from community advocacy during a pivotal moment in HIV treatment history.

The study is conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University and is funded by the Australian Government Department of Health, Disability and Ageing. Every two to three years, a new survey round gives us a fresh picture of how things are changing for PLHIV across the country. You can read about the impacts of prior iterations of *HIV FUTURES* in this report: <https://opal.latrobe.edu.au/ndownloader/files/62900662>

WHAT DOES THE SURVEY COVER?

HIV FUTURES covers a wide range of topics because the lives of PLHIV are complex and multidimensional. This isn't just a clinical study – it's designed to capture the things that matter to people day-to-day.

- General health & wellbeing
- HIV-related quality of life
- HIV clinical care and antiretroviral therapy
- Mental health
- Stigma, discrimination and disclosure
- Relationships, sexual practices and sexual health
- Alcohol & other drug use
- Social connectedness
- Community & peer support

This round of the survey introduced new questions on HIV treatment experiences and attitudes, HIV-related stigma, resilience, disability, clinical care practices, and use of weight-loss medications and statin drugs. Other questions we added to the survey that are not covered in this report include items on PLHIV/undetectable identity and trust in government and the health system. Informed by community partners as well as new developments, and findings from the international literature, we are always evolving the survey to stay relevant to contemporary experiences of living with HIV.

WHY DOES THIS STUDY MATTER?

HIV FUTURES is a core part of Australia's HIV behavioural surveillance infrastructure. Its findings are important in monitoring progress against the goals of the National HIV Strategy, including specific targets related to quality of life and stigma. The study uses validated tools like PozQoL, a quality-of-life instrument designed specifically for PLHIV, and established measures of HIV-related stigma developed through the Stigma Indicators Monitoring Project (Broady et al., 2019).

But this study is about more than numbers. Collecting data on a community's experiences is itself a meaningful act. It makes people visible, it shapes what questions get asked, and it creates the evidence base for real change. That's why community involvement in every step of this process isn't just nice to have. It's essential.

THE CHANGING EPIDEMIC

The HIV epidemic in Australia has changed shape and continues to do so. At the end of 2024, there were 30,890 PLHIV in Australia (King, et al., 2025). Over the past decade, PrEP and treatment as prevention have led to decreases in transmission of HIV. However, these decreases have also drawn attention to groups and communities in which new HIV diagnoses have not declined – including people with a migrant background and other non-permanent residents. Together, people born in Latin America or the Caribbean, Southeast Asia, or Sub-Saharan Africa now comprise almost one in five (18.74%) of the estimated total PLHIV population in Australia.

It has always been a challenge to meaningfully represent the experiences of diverse communities in *HIV FUTURES*. A national omnibus survey is not the best method for engaging communities in ways that build relationships, research capacity and leadership, or that document the unique experiences of PLHIV from these communities. *HIV FUTURES* surveys are also limited in their ability to capture the complexity and nuance of racism or

the experience of migration. In part, this is due to the ‘blunt instrument’ of a tick-box survey. It is also because Australia’s migrant population is so diverse that it is difficult to gather enough data from any single community to draw meaningful conclusions.

In *HIV FUTURES*, we generally receive only a handful of responses from any particular region or country, and within each group there will be further diversity in gender, sexuality and age. While we sometimes group people under the category of ‘overseas born’ to highlight broad differences, this categorisation is often inadequate when it comes to understanding people’s lived experiences. The experiences of a young woman living with HIV who has migrated from Southeast Asia, for example, will be very different to those of a heterosexual man who from a Middle Eastern or African country. Although also imperfect, some of our analyses draw on additional variables such as first language to make more meaningful distinctions – for example between someone from the UK (the largest single group of overseas-born respondents) and people from the three key regions noted above.

CONTEXT AND DATA COLLECTION

Data for *HIV FUTURES 11* were collected primarily through 2025 and into early 2026 – a period marked by global insecurity, armed conflict, and domestic pressures including the widely discussed ‘cost of living crisis’ and concerns about social cohesion. This context is relevant to some of the findings in this round, particularly around quality of life.

A note on how data are collected: Historically, around one in three responses have come via hard-copy booklets distributed through HIV services and events, with an online option also available. Hard-copy booklets tend to reach people using peer-support and other HIV services, whereas online networks reach a broader group who may be younger and less reliant on those services. The previous round of the survey was collected almost entirely online (90% of responses) due to COVID-19 pandemic restrictions. For *HIV FUTURES 11*, just under one in five participants (18.7%) completed the hard-copy version – a partial return toward pre-pandemic patterns, though online completion remains dominant.

OUR COMMUNITY PARTNERS AND ENDORSERS

Since its inception, community advocates and organisations have played a critical role in the success of *HIV FUTURES*. PLHIV peer-based organisations and HIV advocacy and community



agencies across every state and territory contribute to the survey instrument, facilitate participation through their networks, and provide input into analysis priorities. The project is officially endorsed and supported by the National Association of People with HIV Australia (NAPWHA), Health Equity Matters, and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM).

Active partners include Living Positive Victoria, Positive Life NSW, Queensland Positive People, Positive Living SA, ACON, Thorne Harbour Health, WAAC, Meridian ACT, TasCAHRD, NTAHC, along with many other supportive agencies and individuals.

A MESSAGE TO PARTICIPANTS

Thank you for taking the time to complete this survey. We know it’s long, and we genuinely appreciate your willingness to share your experiences. Your responses help paint a picture of life with HIV in Australia today, and they directly inform the policies and services that affect your community. This study has always been driven by and for the people it serves. That hasn’t changed.

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 11* survey where we asked people if there was anything else they would like to tell us about their experience living with HIV. The quotes do not represent the cohort as a whole and are not a presentation or summary of findings. Rather, they are included to give a voice to some of the participants. To protect anonymity, identifying details have been removed and demographic labels have not been attributed to quotes. In some cases, typos or grammatical errors have been edited to ensure clarity.

I. DEMOGRAPHIC CHARACTERISTICS

At the end of 2024 there were 30,890 people living with HIV (PLHIV) in Australia with around 700 new notifications each year (King et al., 2025).

“Every person’s voice is valuable, important, worth listening to. Every person has their own story and journey. Needs can be vastly different.”

NUMBER OF PARTICIPANTS

There was a total of 706 valid responses to *HIV FUTURES 11*, approximately 2.4% of the population of PLHIV in Australia (King et al., 2025).

Participants completing less than 20% of the survey instrument (n = 109), or who did not meet the criteria (18 years or older [n = 0], living in Australia [n = 0] and diagnosed with HIV [n = 8]), 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.

“I am very grateful and proud to be a person living with HIV in Australia”

GENDER

Participants were asked the term that best describes their gender identity, their sex assigned at birth, and whether they had innate variations of sex characteristics (sometimes called ‘intersex’). The survey did not include a direct question on transgender identity; however, transgender participants were identified where gender differed from sex assigned at birth, and some participants also described themselves as transgender in free-text responses. A small number of participants identified as a gender different from their sex assigned at birth, including six participants (0.9%) who identified as women and were assigned male at birth, and one participant (0.1%) who identified as a man and was assigned female at birth. Given the small numbers, analyses were conducted

using participants’ self-identified gender (unless otherwise specified).

Of the overall sample:

- 82.7% (n = 582) identified as men (n = 581 cis men and n = 1 trans man);
- 14.1% (n = 99) identified as women (n = 92 cis women and n = 6 trans women);
- 2.1% (n = 15) identified as non-binary or gender fluid;
- 0.6% (n = 4) used a different term to describe their identity;
- 0.6% (n = 4) preferred not to answer.

Six participants (0.9%) reported that they had innate variations of sex characteristics (IVSC). This is slightly lower than what is known about the proportion of people born with innate variations of sex characteristics 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 preferred way to describe their sexuality, participants responded as follows:

- 68.3% (n = 389) described their sexuality as gay or homosexual
- 14.9% (n = 85) as heterosexual or straight
- 5.6% (n = 32) as bisexual
- 7.2% (n = 41) as queer
- 1.2% (n = 7) as pansexual
- 0.2% (n = 1) as lesbian
- 2.6% (n = 15) described their sexuality using a different term



Gay or homosexual men comprised the largest group in the sample (54.0%, n = 381), followed by heterosexual women (7.4%, n = 52). Other groups included heterosexual men (4.4%, n = 31), queer men (4.0%, n = 28), bisexual men (2.7%, n = 19), bisexual women (1.1%, n = 8), and queer women (0.8%, n = 6).

Table 1 shows the distribution of sexuality within gender groups among *HIV FUTURES 11* participants. Most men described their sexuality as gay (80.5%;

n = 381), with smaller proportions describing their sexuality as heterosexual or straight (6.6%; n = 31), queer (5.9%; n = 28), or bisexual (4.0%; n = 19). In contrast, most women described their sexuality as heterosexual or straight (69.3%; n = 52), while smaller proportions described their sexuality as bisexual (10.7%; n = 8), queer (8.0%; n = 6), or pansexual (6.7%; n = 5).

Table 1. Gender and sexuality of participants

Gender	Sexuality						
	Gay [^] n (%)	Straight n (%)	Bisexual n (%)	Lesbian n (%)	Pansexual n (%)	Queer n (%)	Use a different term n (%)
Men	381 (80.5)	31 (6.6)	19 (4.0)	0	2 (0.4)	28 (5.9)	12 (2.5)
Women	1 (1.3)	52 (69.3)	8 (10.7)	1 (1.3)	5 (6.7)	6 (8.0)	2 (2.7)
Non-binary or gender fluid	5 (33.3)	0	4 (26.7)	0	0	6 (40)	0
Used a different term	1 (25.0)	1 (25.0)	1 (25.0)	0	0	0	1 (25.0)
Total	388 (68.4)	84 (14.9)	32 (5.6)	1 (0.2)	7 (1.2)	41 (7.2)	15 (2.6)

[^]Gay and homosexual responses have been collapsed into one group.

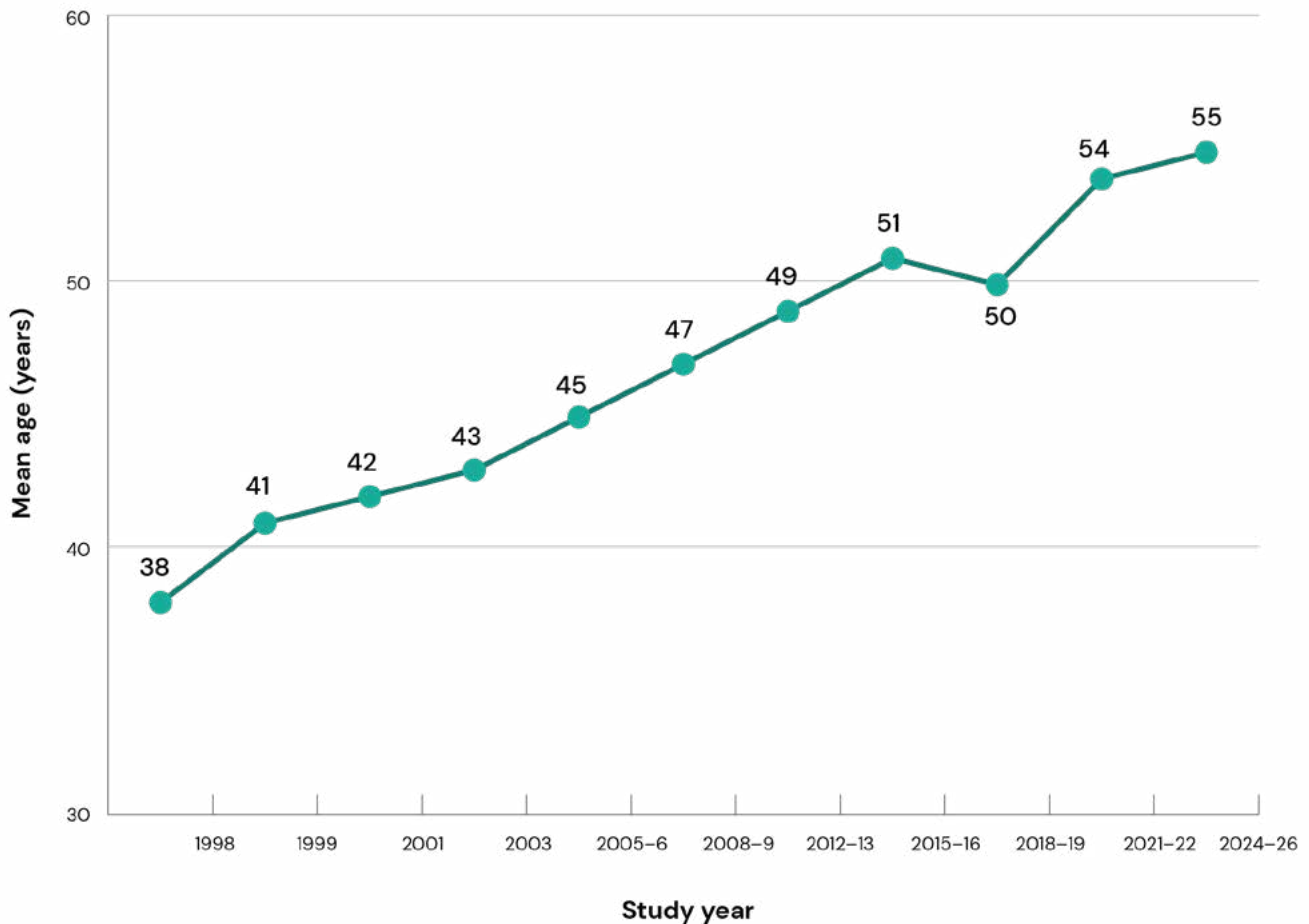
AGE

Participants' ages ranged from 18–89, with an average age of 55 years (n = 695).

The mean age of the sample has increased steadily since the *HIV FUTURES* project first started,

from 38 years in 1998 to 55 years in *HIV FUTURES 11* (2024–26), with the exception of a small decrease in 2018–19 (see Figure 1).

Figure 1: Mean age of *HIV FUTURES* participants by study iteration/year



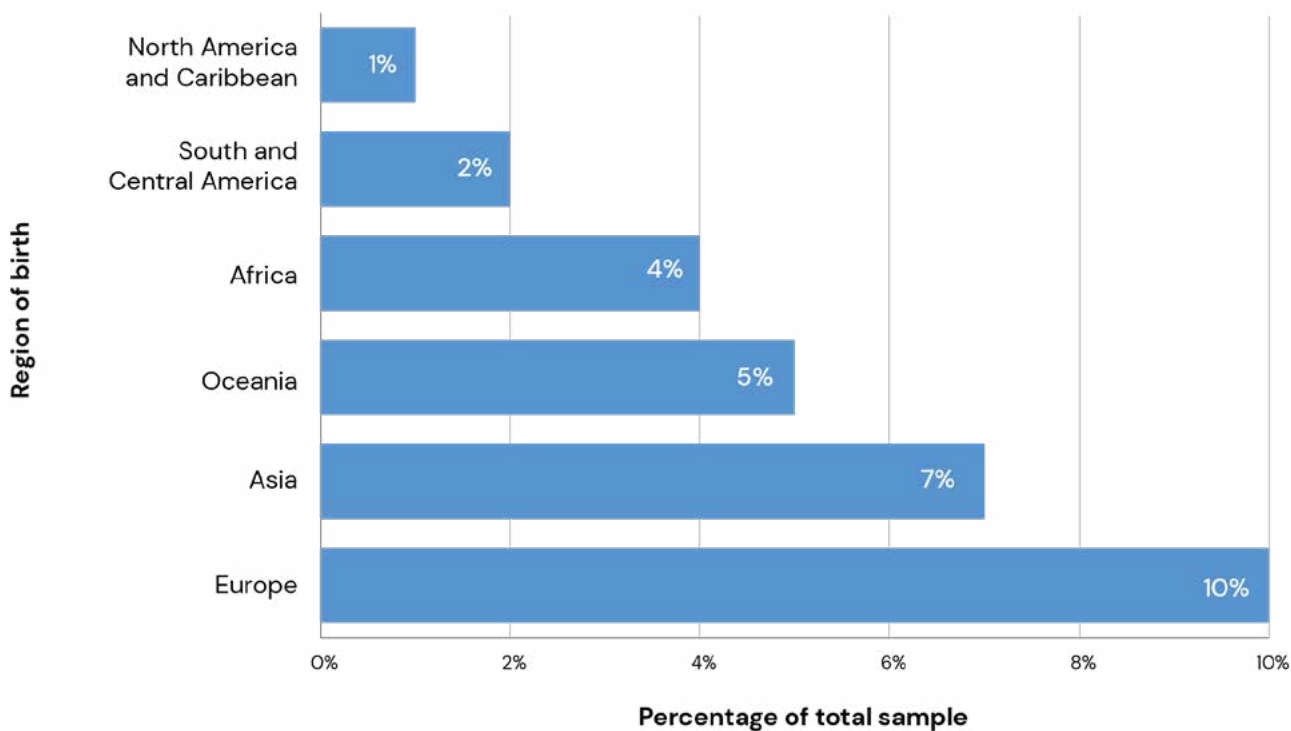
In the *HIV FUTURES 11* sample, the average age of women was five years lower than that of men (51 years compared to 56 years, respectively). The average ages of gay and bisexual men (54 and 53 years, respectively) were slightly lower than for heterosexual participants (55 years).

Participants who described their sexuality as pansexual or queer were slightly younger than the full sample average (52 years, respectively), which might reflect an increasing fluidity in sexuality or a trend away from binary (gay/straight) labelling of sexuality among younger people (Sinclair–Palm & Gilbert, 2018).

LANGUAGE AND CULTURAL BACKGROUND

Most participants were born in Australia (65.4%, n = 462), which was a decrease from 72.2% in the *HIV FUTURES 10* survey (2021–22). Over four-fifths (81%; n = 572) spoke English as a first language (down from 88.1% in 2021–22), and 93.5% (n = 660) spoke English at home. Among participants born outside Australia, the largest proportion were born in Europe (10%), followed by Asia (7%) and Oceania (excluding Australia; 5%). Smaller proportions were born in Africa (4%), South and Central America (2%), and North America or the Caribbean (1%; see Figure 2). Fifty-three countries of birth were listed in total (including Australia).

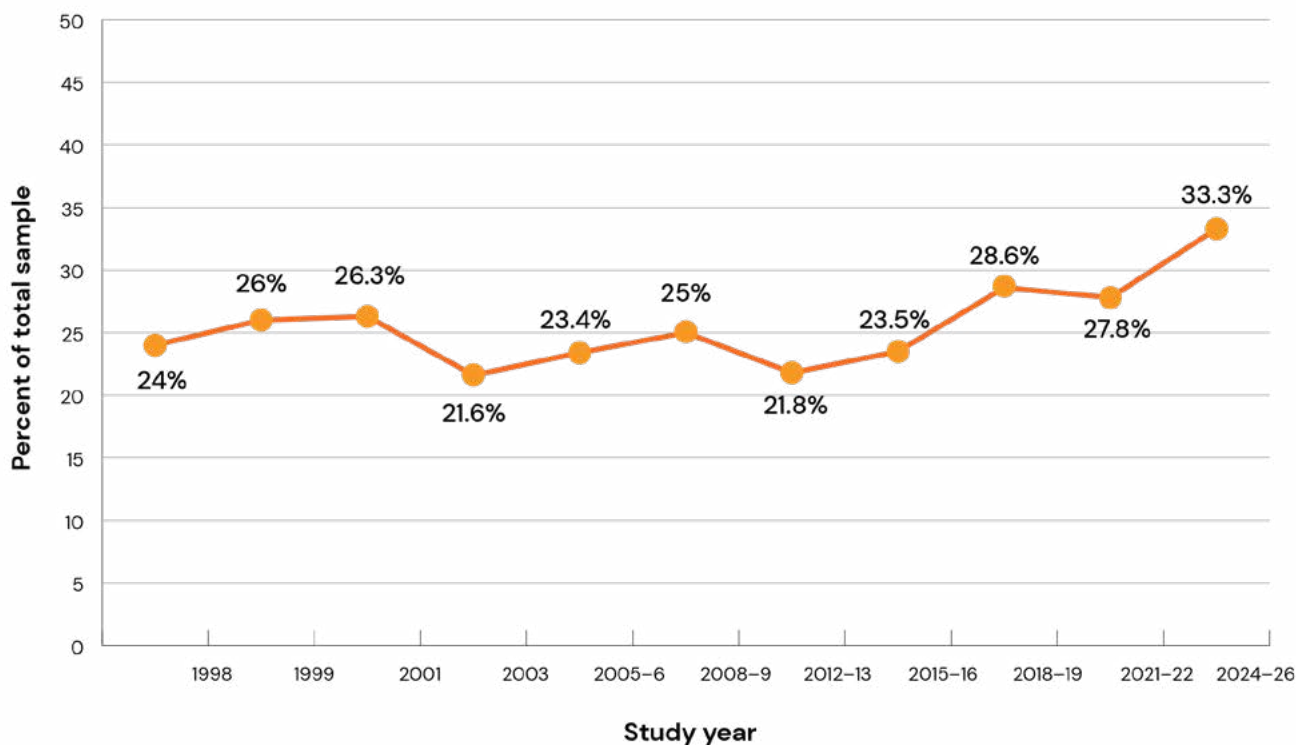
Figure 2: Region of birth for people born outside of Australia (% total sample)



The proportion of overseas-born participants in the *HIV FUTURES* surveys fluctuated between approximately 22% and 26% from 1998 to 2015 (Figure 3), before increasing in more recent waves.

The proportion rose to 28.6% in 2018–19, remained similar in 2021–22 (27.8%), and reached its highest level in 2024–26 (33.3%).

Figure 3: Proportion of overseas-born participants in *HIV FUTURES* surveys by study interation/year



CITIZENSHIP STATUS

The majority of participants (78.0%, n = 542) were Australian citizens and 15.0% (n = 104) were permanent residents. A small number of participants (7.0%, n = 49) were neither citizens nor permanent residents.

ABORIGINAL AND TORRES STRAIT ISLANDER PARTICIPANTS

In 2024 there were 23 HIV notifications among Aboriginal and Torres Strait Islander peoples, representing 3% of the total 757 notifications (King et al., 2025). The HIV notification rate among Aboriginal and Torres Strait Islander peoples in 2024 was 2.8 per 100,000 (a decrease from 6.0 per 100,000 in 2015). By comparison, in 2024, the HIV notification rate was 2.0 per 100,000 among Australian-born non-Indigenous people and 2.8 per 100,000 among all non-Indigenous people (King et al., 2025).

Twenty participants in *HIV FUTURES 11* indicated that they were Aboriginal (2.9%). No participants indicated they were Torres Strait Islander or both Aboriginal and Torres Strait Islander. Of participants who were Aboriginal, one was aged under 35 (5%),

six were 35–49 (35%), 12 were 50–64 (60%), and one was aged over 65 (5%). With respect to state of residence, 13 lived in New South Wales (65%), two in Victoria (10%), two in Western Australia (10%), one in Northern Territory (5%), one in Queensland (5%), one in and one in South Australia (5%).

Unfortunately, the small number of Aboriginal and Torres Strait Islander participants in this survey makes it difficult to present meaningful data in a way that does not risk identifying individual participants. There is an urgent need for more research, led by Indigenous researchers, to build understanding of how best to support PLHIV from Aboriginal and Torres Strait Islander communities.

LOCATION AND STATE/TERRITORY OF RESIDENCE

Most participants resided in inner-urban areas (58.7%, n = 401) with smaller proportions from regional centres (16.7%, n = 114), outer suburban areas (16.4%, n = 112) and rural areas (7.9%, n = 56). The largest number of responses came from New South Wales (39.8%, n = 323) and Victoria (26.8%, n = 218), reflecting the larger population of PLHIV living in these states. The breakdown of responses by state is shown in Table 2.

Table 2. State or territory of participants' residence

State/territory	Frequency n	Percentage %
NSW	281	40.0
Vic	195	27.7
QLD	91	12.9
SA	54	7.7
WA	33	4.7
ACT	29	4.1
Tas	4	0.6
NT	16	2.3

EDUCATION

Educational attainment among participants was relatively high (Table 3). The most common qualification was a tertiary diploma, trade certificate, or TAFE qualification (32.5%). Around one-quarter held a postgraduate degree (24.9%), and a similar

proportion had an undergraduate university degree (23.2%). Smaller proportions reported completing a leaving certificate (19.5%) or up to four years of high school (8.9%), while very few had only primary school education (0.4%).

Table 3. Highest educational level attained

Level	Frequency n	Percentage %
Primary school only	3	0.4
Up to four years' high school	59	8.9
Leaving certificate/HSC/VCE	74	19.5
Tertiary diploma/trade certificate/TAFE	227	32.5
Undergraduate university degree	162	23.2
Postgraduate university degree	174	24.9

EMPLOYMENT AND INCOME

Most participants were engaged in paid work, with 39.3% working full-time (Table 4). A further 8.1% worked part-time and 5.7% were in casual employment. Around one-quarter were not working, including those who were retired (24.8%). Smaller proportions were unemployed and looking for work (6.1%) or not looking for work (4.7%). Few participants were students (2.6%) or engaged in home and/or

caring duties (1.1%), while 7.7% reported other main activities. The open text responses outlined reasons why many of these participants were not working:

- Did not have working rights
- Were self-employed or freelance
- Studying
- Injured or on workers compensation
- On a disability pension

Table 4: Main employment/activities

Main employment/activities	Frequency n	Percentage %
Work full-time (≥ 30 hours per week, including self-employment)	276	39.3
Not working, including retired	174	24.8
Unemployed, not looking for work	33	4.7
Work part-time (< 30 hours per week)	57	8.1
Unemployed, looking for work	43	6.1
Work casual	40	5.7
Student	18	2.6
Home and/or caring duties	8	1.1
Other	54	7.7

The most common main income source was salary or wages (50.1%, $n = 352$), followed by benefits, pensions or social security (29.2%, $n = 205$). One in ten participants reported superannuation as their primary income (10.0%, $n = 70$), while relatively small proportions relied on savings (3.3%, $n = 23$),

partner support (2.4%, $n = 17$), or support from family and friends (0.7%, $n = 5$). One participant reported an annuity as their main income source (0.1%, $n = 1$), and 4.2% ($n = 30$) selected 'other' sources of income (Table 5).

Table 5. Main income source

Main income source	Frequency n	Percentage %
Salary/wages	352	50.1
Benefits/pension/social security	205	29.2
Savings	23	3.3
Superannuation	70	10.0
Partner supports me	17	2.4
Family/friends support me	5	0.7
Annuity	1	0.1
Other	30	4.2

The most commonly reported annual household income was \$1–\$29,999 (21.2%, n = 149), followed by \$50,000–\$79,999 (15.8%, n = 111) and \$30,000–\$49,999 (15.2%, n = 107). Around one in ten participants reported incomes of \$200,000 or more (10.1%, n = 71), \$80,000–\$99,999 (9.8%, n = 69), or \$100,000–\$124,999 (9.4%, n = 66). Smaller proportions reported incomes of \$150,000–\$199,999

(6.8%, n = 48) or \$125,000–\$149,999 (4.4%, n = 31), while 3.4% (n = 24) reported negative or zero income (Table 6). As a point of comparison, average household income in Australia in the 2018–19 financial year was \$121,420 (ABS, 2022).

Table 6: Annual household income

Annual household income	Frequency n	Percentage %
Negative or zero income	24	3.4
\$1–\$29,999	149	21.2
\$30,000–\$49,999	107	15.2
\$50,000–\$79,999	111	15.8
\$80,000–\$99,999	69	9.8
\$100,000–\$124,999	66	9.4
\$125,000–\$149,999	31	4.4
\$150,000–\$199,999	48	6.8
\$200,000 or more	71	10.1

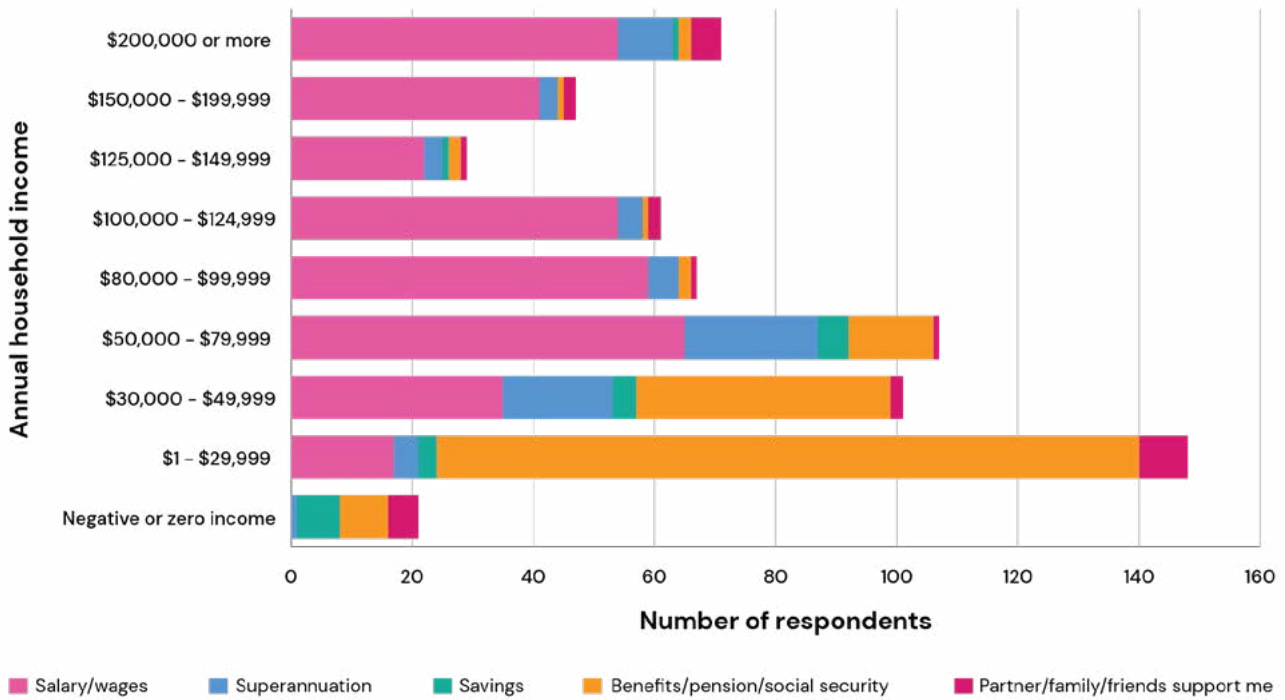
Details of household income by main source of income are shown in Figure 4. Those earning under \$30,000 were most likely to report benefits, pensions or social security as their main source of income, particularly among those earning

\$1–\$29,999. In contrast, salary or wages were the dominant income source across all higher income brackets, especially from \$50,000 upwards. Superannuation contributed modestly across income groups, with relatively higher representation

in the \$30,000–\$79,999 range. Reliance on savings and support from partners, family or friends was generally low across all income levels, though

slightly more common among those with no or very low income.

Figure 4: Income source by annual household income



HOUSEHOLD COMPOSITION

Household composition is demonstrated in Table 7. The highest proportion of participants reported living alone (43.8%, n = 309), followed by living with a partner or spouse (34.4%, n = 243). Smaller proportions reported living with friends or flatmates

(11.0%, n = 78) or other family members (9.1%, n = 64), while relatively few lived with dependent children (3.7%, n = 26) or in other arrangements (1.6%, n = 11). Overall, the findings indicate that participants were most likely to live either independently or with a partner, with less common arrangements involving shared or family-based living.

Table 7: Household composition

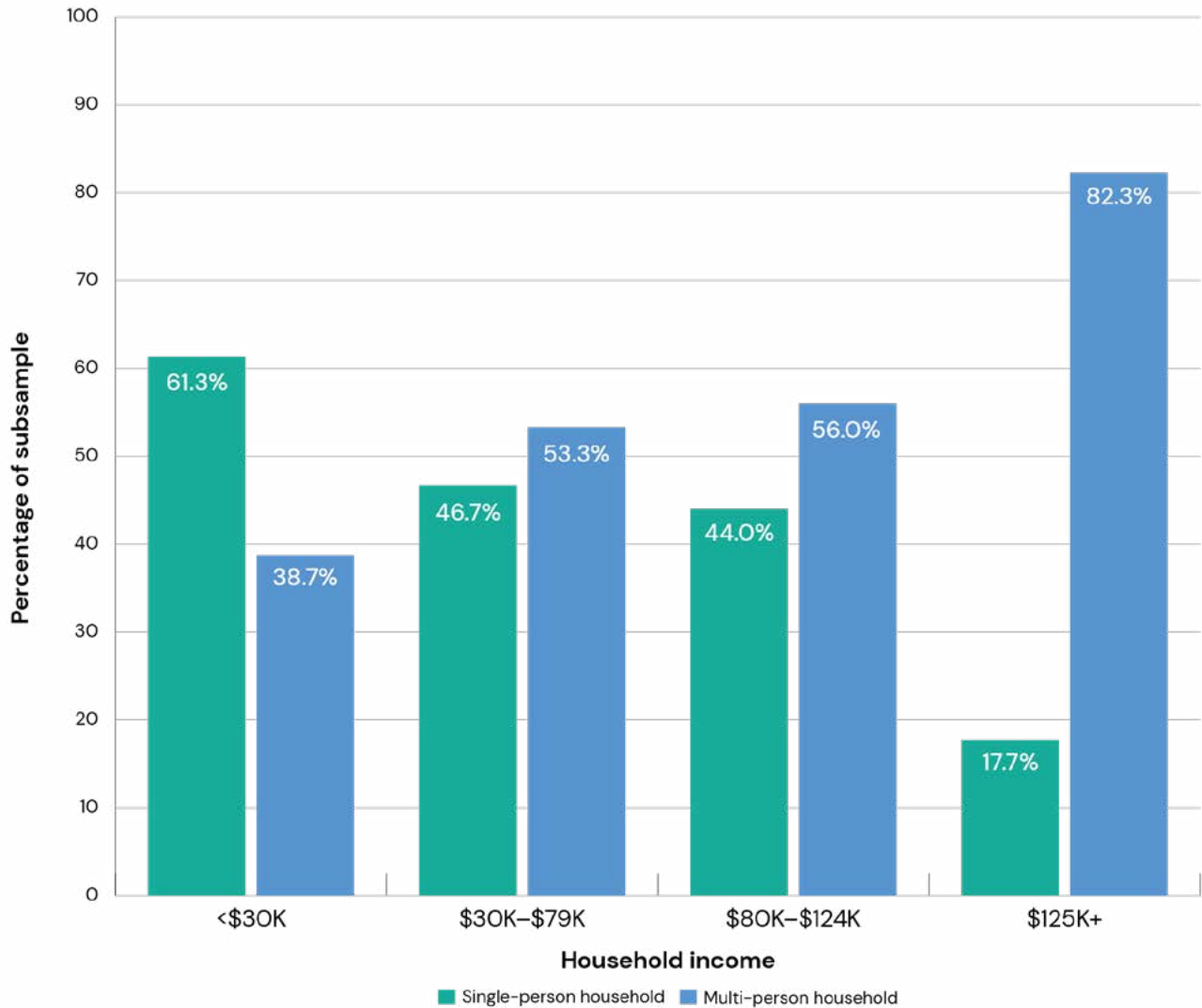
Household composition	Frequency* n	Percentage %
Live alone	309	43.8
Live with partner/spouse	243	34.4
Live with dependent children	26	3.7
Live with other family members	64	9.1
Live with friends/flatmates	78	11.0
Live with pets	77	10.9
Live with somebody else ("other")	11	1.6

* 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.

Household composition varied markedly by income (Figure 5). Participants in the lowest income group (<\$30,000) were more likely to live alone (61.3%) than with others (38.7%). In contrast, from \$30,000 upwards, multi-person households predominated, accounting for 53.3% of those earning \$30,000–

\$79,999 and 56% of those earning \$80,000–\$124,999. This pattern was most pronounced among the highest income group (\$125,000+), where the vast majority lived in multi-person households (82.3%), and only 17.7% lived alone.

Figure 5: Household income, by number of people in household





2. QUALITY OF LIFE

The Ninth National HIV Strategy 2024–2030 positions quality of life as a central measure of the success of Australia’s HIV response. The strategy sets a target of 95% of PLHIV reporting good quality of life by 2030. This target sits alongside ambitious goals relating to diagnosis, treatment uptake, viral suppression, prevention coverage, and stigma reduction in healthcare. The strategy’s broader vision is that HIV transmission will be virtually eliminated in Australia by 2030, while all PLHIV will live well, free from stigma and discrimination. In this way, the strategy recognises that in addition to biomedical developments, care, wellbeing, social inclusion, and freedom from stigma are integral to an effective HIV response.

In *HIV FUTURES 11*, we used two measures to assess the proportion of participants reporting good quality of life: the PozQoL scale (Brown et al., 2018), and a single-item measure of overall wellbeing. PozQoL is a 13-item scale developed in Australia to assess quality of life among PLHIV across four domains: psychological, social, functional and health concerns. It has been validated with

Australian PLHIV and provides a score ranging from 1 to 5, with higher scores indicating better quality of life. Importantly, except for the psychological subdomain, PozQoL measures participants’ HIV-specific, rather than general, quality of life. This is the third time PozQoL has been included in the *HIV FUTURES* series, enabling comparison with findings from *HIV FUTURES 9* (2018–19) and *10* (2021–22).

Alongside PozQoL, we use a single-item measure asking participants to rate their overall emotional, mental and physical wellbeing. This item has been included in all *HIV FUTURES* surveys since 1997, allowing for analysis of trends in self-reported wellbeing since the inception of the study.

“Living with HIV does not change who I am. I keep my treatment up to date and enjoy life to fullest.”

QUALITY OF LIFE: REPORTING AGAINST NATIONAL TARGETS

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

In *HIV FUTURES 11*, 69.7% (n = 486) of participants reported ‘good’ quality of life. This represents a slight decline from *HIV FUTURES 10*, in which 71.8% (n = 586) of participants reported good quality of life, but remains higher than levels observed in *HIV FUTURES 9* (63.1%, n = 492; 2018). While these findings indicate overall improvement over time, they remain well below the target set in the Ninth National HIV Strategy 2024–2030, which aims for 95% of PLHIV to report good quality of life by 2030. Despite sustained progress since 2018–19, substantial gaps persist in achieving optimal quality of life among PLHIV.

IN *HIV FUTURES 11*

69.7%

(n = 486) of the sample reported ‘good’ quality of life (PozQoL score of 3.0 or higher).

COMPONENTS OF QUALITY OF LIFE

The overall mean PozQoL score for *HIV FUTURES 11* participants was 3.36 (SD = 0.83). This was a slight decrease from 3.42 in *HIV FUTURES 10* (2021–22).

For a more nuanced analysis of PozQoL, we also report mean scores for each of the quality of life subscales. The PozQoL scale contains four separate subscales: (i) psychological, (ii) functional, (iii) social, and (iv) health concerns. The psychological domain is about a person’s general mood and outlook (not specific to HIV). The functional domain is about the extent to which HIV interrupts everyday living. The social domain is about a person’s sense of belonging and concerns about the impact of HIV on social relationships, including fear of being rejected by others. The health concerns domain relates to the extent to which people worry about the impact of HIV on their current or future health.

THE AVERAGE SCORES FOR EACH OF THESE SUBSCALES (OUT OF 5) WERE AS FOLLOWS:

Psychological: 3.3

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

Functional: 3.9

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

Social: 3.2

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

Health concerns: 3.1

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

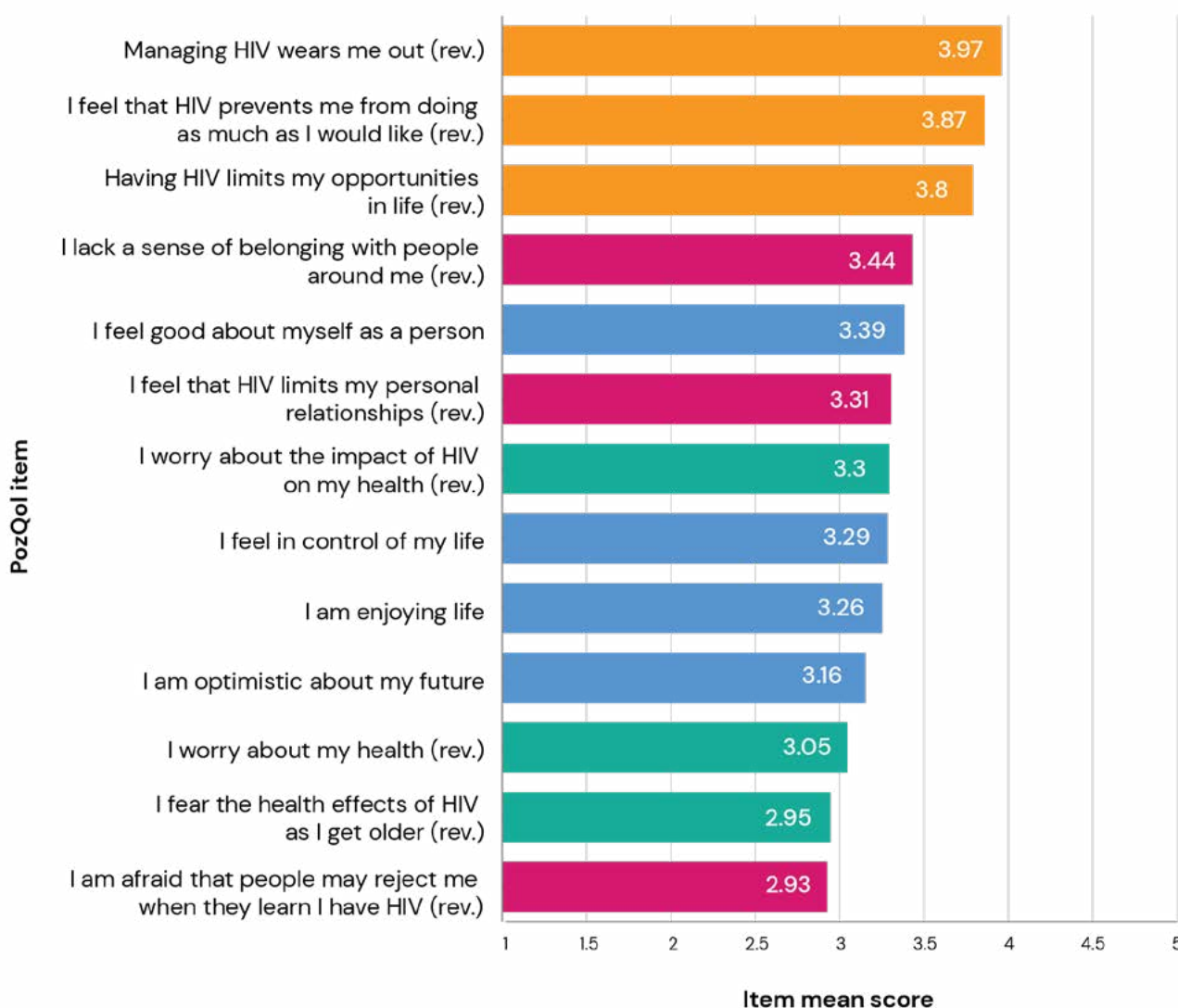
MEAN SCORES ACROSS INDIVIDUAL POZQOL ITEMS

Figure 6 presents mean scores for individual PozQoL items. For ease of interpretation, negatively worded items were reverse scored so that higher scores consistently reflect more positive quality of life outcomes (i.e., even though the item is negatively worded, higher scores here reflect better quality of life).

Overall, participants reported the highest scores for items relating to functional wellbeing and the day-to-day management of HIV, particularly that managing HIV did not wear them out (M = 3.97), that

HIV did not prevent them from doing as much as they would like (M = 3.87), and that HIV did not limit their opportunities in life (M = 3.80). Scores relating to psychological wellbeing and social connection were more moderate, including feeling good about oneself as a person (M = 3.39), not lacking a sense of belonging with others (M = 3.44), and HIV not limiting personal relationships (M = 3.31). Comparatively lower scores were observed for items relating to social stigma and health concerns, particularly not being afraid that others may reject them because of HIV (M = 2.93) and not fearing the health effects of HIV as they get older (M = 2.95).

Figure 6: Mean score of each PozQoL item across four subdomains (psychological, functional, social, and health concerns)

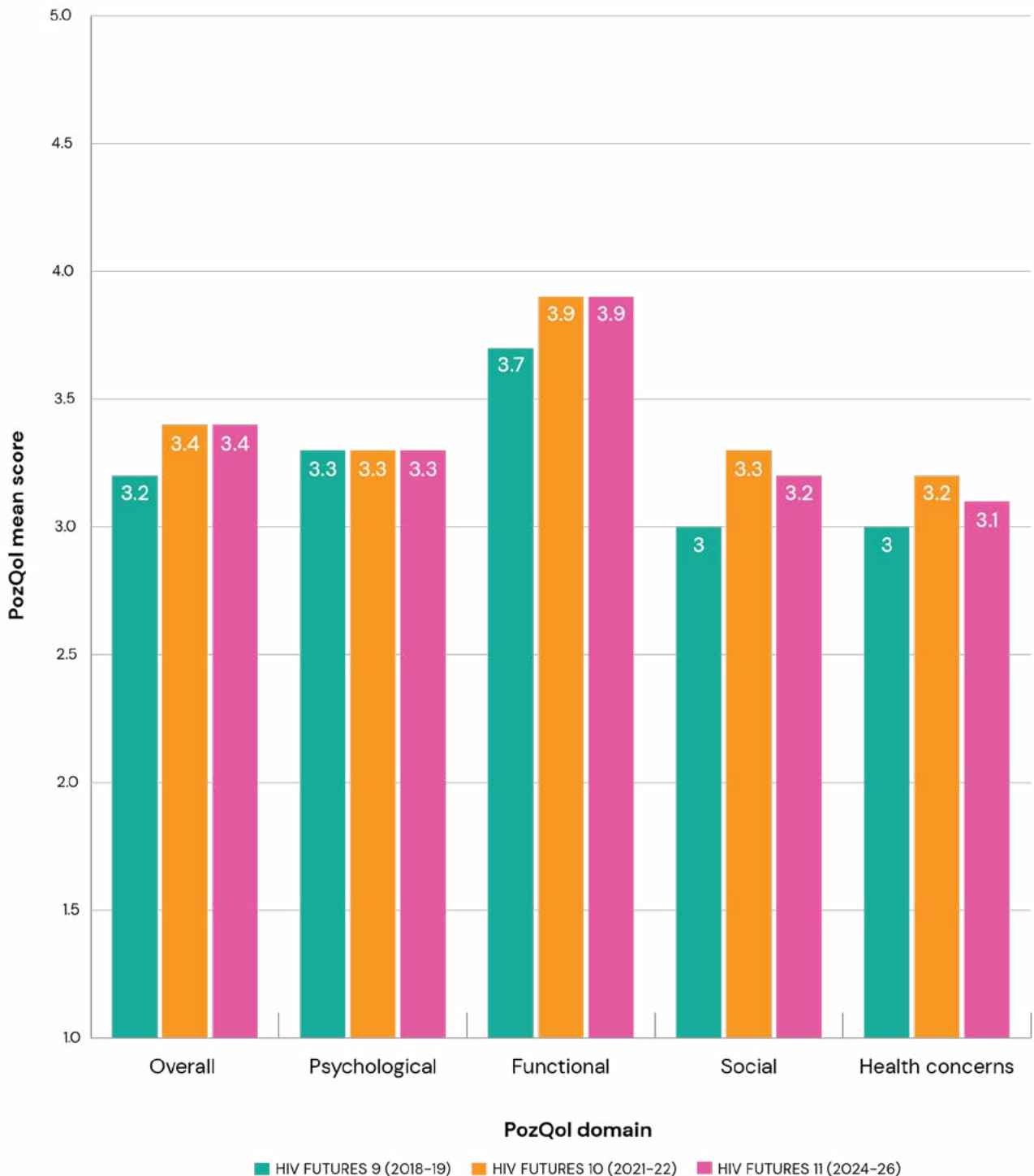


Note: rev. = reverse scored item. Higher mean scores = better quality of life across each item (including reverse scored items). Yellow items = functional subdomain. Blue items = psychological subdomain. Green items = health concerns subdomain. Red items = social subdomain.

TRENDS IN QUALITY OF LIFE OVER TIME

Compared to the *HIV FUTURES 9* sample (2018–19), participants reported greater overall HIV-related quality of life, with improvements observed between *HIV FUTURES 9* (2018–19) and *HIV FUTURES 10* (2021–22) largely maintained in *HIV FUTURES 11* (2024–26) (Figure 7).

Figure 7: Mean PozQoL subdomain scores: trends between 2018–19 and 2024–26



In the psychological domain, mean scores remained stable across all three waves (3.3 in *HIV FUTURES 9*, 3.3 in *HIV FUTURES 10*, and 3.3 in *HIV FUTURES 11*). This suggests little change across samples in broader aspects of wellbeing captured by this domain, such as optimism and perceived control. However, it is important to reiterate that the items in the psychological subdomain do not specifically ask about HIV, but feed into the larger picture of quality of life that is relevant to PLHIV.

Scores in the functional domain were consistently the highest across all subdomains, increasing from 3.7 in *HIV FUTURES 9* (2018–19) to 3.9 in *HIV FUTURES 10* (2021–22) and remaining at 3.9 in *HIV FUTURES 11* (2024–26). This pattern indicates that, in relative terms, HIV continues to have a limited impact on everyday functioning across the overall sample, and that gains observed in this domain have been sustained over time.

With respect to the social domain, mean scores increased from 3.0 in *HIV FUTURES 9* (2018–19) to 3.3 in *HIV FUTURES 10* (2021–22), before declining slightly to 3.2 in *HIV FUTURES 11* (2024–26). While still higher than levels observed in 2018–19, this suggests a softening of gains across samples. Given that the social subscale captures HIV-specific experiences such as stigma, disclosure and belonging, these findings point to the persistence of social challenges affecting quality of life among participants.

A similar pattern was observed in the health concerns domain. Scores increased from 3.0 in *HIV FUTURES 9* (2018–19) to 3.2 in *HIV FUTURES 10* (2021–22), before declining slightly to 3.1 in *HIV FUTURES 11* (2024–26). Although levels remain improved relative to 2018–19, concerns about current and future health continue to represent an area of comparatively lower quality of life within the sample.

The overall pattern across subdomains suggests that improvements in HIV-related quality of life observed between *HIV FUTURES 9* (2018–19) and *HIV FUTURES 10* (2021–22) have been largely sustained in *HIV FUTURES 11* (2024–26), particularly in the functional domain. However, the slight declines observed in the social and health concerns domains highlight areas where gains may be less secure.

The broader context in which *HIV FUTURES* surveys have been conducted is important when interpreting these findings. Over the past decade, PLHIV in Australia have benefited from advances in HIV treatment and prevention, growing awareness and acceptance of U=U, and ongoing efforts to reduce stigma and improve models of care and support. These developments may have contributed to improvements in HIV-related quality of life and wellbeing observed across earlier survey waves. At the same time, *HIV FUTURES 11* was conducted during a period marked by significant social and



economic pressures, including rising housing costs, increased cost-of-living pressures, financial insecurity, and ongoing strain on health and social support systems. Findings throughout this report demonstrate strong relationships between quality of life and broader structural factors such as financial stress, income, disability, social connection, age, and residency status. It is therefore possible that these broader pressures may have limited further improvements in quality of life, despite continuing advances in HIV treatment and prevention.

Quality of life among PLHIV in Australia remains substantially below the national target. There is an ongoing importance to address the social, economic, and structural conditions that shape wellbeing and quality of life among PLHIV.

POZQOL SCORES BY STATE/TERRITORY

PozQol scores (overall and subdomains) were compared across states and territories (Table 8). Scores were broadly similar across jurisdictions. No significant differences were observed in overall PozQoL scores ($p = .172$), psychological quality of life ($p = .330$), social quality of life ($p = .939$), or functional quality of life ($p = .153$).

The only subdomain that differed significantly by state or territory was health-related quality of life ($F(7,686) = 3.19, p = .002, \eta^2 = .032$). Post hoc Tukey tests indicated that participants in South Australia reported significantly lower health-related quality of

life scores than participants in Victoria and Western Australia. While statistically significant, the effect size was small, indicating that jurisdiction accounted for only a modest proportion of variance in health-related quality of life.

Table 8. PozQoL scores by state/territory

State/territory	n	Overall PozQoL	Psychological	Social	Health	Functional
ACT	29	3.19	3.08	3.02	2.87	3.8
NSW	275	3.33	3.23	3.2	3.08	3.84
NT	16	3.47	3.44	3.44	2.96	4.04
QLD	91	3.4	3.29	3.28	3.07	3.98
SA	53	3.13	3.12	3.2	2.68	3.51
Tas	4	3.13	2.88	2.92	3.25	3.58
Vic	194	3.45	3.38	3.26	3.26	3.94
WA	32	3.55	3.36	3.26	3.5	4.15

Note: Scores for NT and Tas should be interpreted with caution due to small cell sizes.

FACTORS ASSOCIATED WITH QUALITY OF LIFE

To better understand factors that relate to 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 ≥ 3.0 as an indication of 'good' quality of life. Variables included age, gender, English as a first language, highest level of education, household income, financial stress, relationship and living arrangements, citizenship status, whether the

participant identifies as living with disability, number of years living with HIV, social connectedness, resilience (measured via the Brief Resilience Scale; (Smith et al., 2008), experience of HIV-related stigma (previous 12 months) and general health (measured via the SF-36). The statistically significant factors are presented in Table 9 (page 32).

"There is a lot of us out there living perfectly wonderful lives."



Age

Older participants were more likely to report good quality of life. While around two-thirds of participants aged under 65 reported good quality of life (62–67%), this increased to 81% among participants aged 65 years and over. This finding may reflect a range of factors, including long-term adaptation to living with HIV, greater financial or housing stability among many older participants, or survivorship effects within the cohort. However, these findings should not be interpreted as suggesting that older PLHIV experience fewer health or support needs. As demonstrated elsewhere in this report, older participants were also more likely to report multiple chronic health conditions and complex healthcare needs associated with ageing with HIV, as well as a substantial proportion who may be living in insecure housing arrangements.

“My antiretroviral medication is very effective, and I am in excellent health apart from being about to enter my 80s and therefore not physically strong anymore. I have a normal social life, and my HIV status never crossed my mind.”

Financial stress

Participants who had not experienced recent financial stress were substantially more likely to report good quality of life. Over three-quarters (77%) of those without recent financial stress reported good quality of life, compared to 44% of those who had experienced financial stress.

Household income

Participants with household incomes of \$125,000 or more were substantially more likely to report good quality of life (83%) than those earning under \$30,000 (57%), with the latter representing the largest income subgroup.

General health

Participants with reporting good quality of life also reported significantly higher scores on the SF-36 general health subscale.

Resilience

Participants reporting good quality of life had substantially higher average resilience scores than those reporting poorer quality of life.

Social connection

Stronger social connection was associated with higher quality of life. Participants with good quality of life reported notably higher average social connection scores than those with poorer quality of life.

“Social connections are very important for my mental well-being. Just having a yarn.”

EXPERIENCE OF HIV-RELATED STIGMA

Experiences of HIV-related stigma were strongly associated with poorer quality of life. While 84% of participants who had never experienced HIV-related stigma in the previous 12 months reported good quality of life, this fell to 65% among those who rarely experienced stigma, 46% among those who sometimes experienced stigma, and just 15% among those who experienced stigma often or more frequently.

Living with a partner

Participants living with a partner or spouse were more likely to report good quality of life than those not living with a partner (79% vs 65%).

“My partner has been indeed a great comfort in my life therefore I am okay.”

Citizenship status

Australian citizens were more likely to report good quality of life (72%) than permanent residents (65%) and participants who were neither citizens nor permanent residents (55%).

“I am worried I might not get permanent residency because of my status”

Living with disability

Participants identifying as living with disability were less likely to report good quality of life (57% vs 75%).

Table 9. Factors significantly associated with PozQoL scores

Characteristic	Less than 3.0, poorer quality of life n (%)	3.0 or higher, good quality of life or higher n (%)	χ^2 / OR
Age			$\chi^2(3,686) = 12.890, p = .005$
< 35	18 (38.3)	29 (61.7)	
35– 49	53 (34)	103 (66)	
50– 64	105 (32.7)	216 (67.3)	
65+	31 (19.1)	131 (80.9)	
Financial stress (in past year)			$\chi^2(1,697) = 59.365, p < .001$
Experienced financial stress	85 (55.6)	68 (44.4)	
No financial stress	126 (23.2)	418 (76.8)	
Household annual income			$\chi^2(3,667) = 27.171, p < .001$
< \$30,000	74 (43.3)	97 (56.7)	
\$30,000–\$79,999	59 (27.2)	158 (72.8)	
\$80,000–\$124,000	39 (29.5)	93 (70.5)	
\$125,000+	25 (17)	122 (83)	
SF-36 general health subscale score*, mean score (SD)	39 (21.8)	63 (22.4)	OR = 1.05, 95% CI [1.04, 1.06], p < .001
Social connection, mean score (SD)**	3.7 (1.1)	5.3 (1.1)	OR = 3.39, 95% CI [2.73, 4.22], p < .001
Resilience (Brief Resilience Scale), mean score (SD)***	2.6 (0.7)	3.5 (0.8)	OR = 4.25, 95% CI [3.25, 5.57], p < .001
Live with partner/spouse			$\chi^2(1,697) = 15.451, p < .001$
Yes	50 (20.8)	190 (79.2)	
No	161 (35.2)	296 (64.8)	
Citizenship status			$\chi^2(2,686) = 7.014, p = .030$
Citizen	151 (28.1)	386 (71.9)	
Permanent resident	36 (35.3)	66 (64.7)	
Neither citizen or permanent resident	21 (44.7)	26 (55.3)	

Characteristic	Less than 3.0, poorer quality of life n (%)	3.0 or higher, good quality of life or higher n (%)	χ^2 / OR
Experienced stigma/discrimination as a result of HIV status (previous 12 months)			$\chi^2(3,588) = 95.457, p < .001$
Never	52 (16.1)	270 (83.9)	
Rarely	49 (34.8)	90 (65.2)	
Sometimes	55 (53.9)	47 (46.1)	
Often or more	22 (84.6)	4 (15.4)	
Identifies as living with disability			$\chi^2(1,679) = 20.433, p < .001$
No	122 (25.2)	363 (74.8)	
Yes	83 (42.8)	111 (57.2)	

* 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

***Brief Resilience Scale scores range from 1-5, with higher scores indicating greater resilience

OR = odds ratio, χ^2 = chi-square



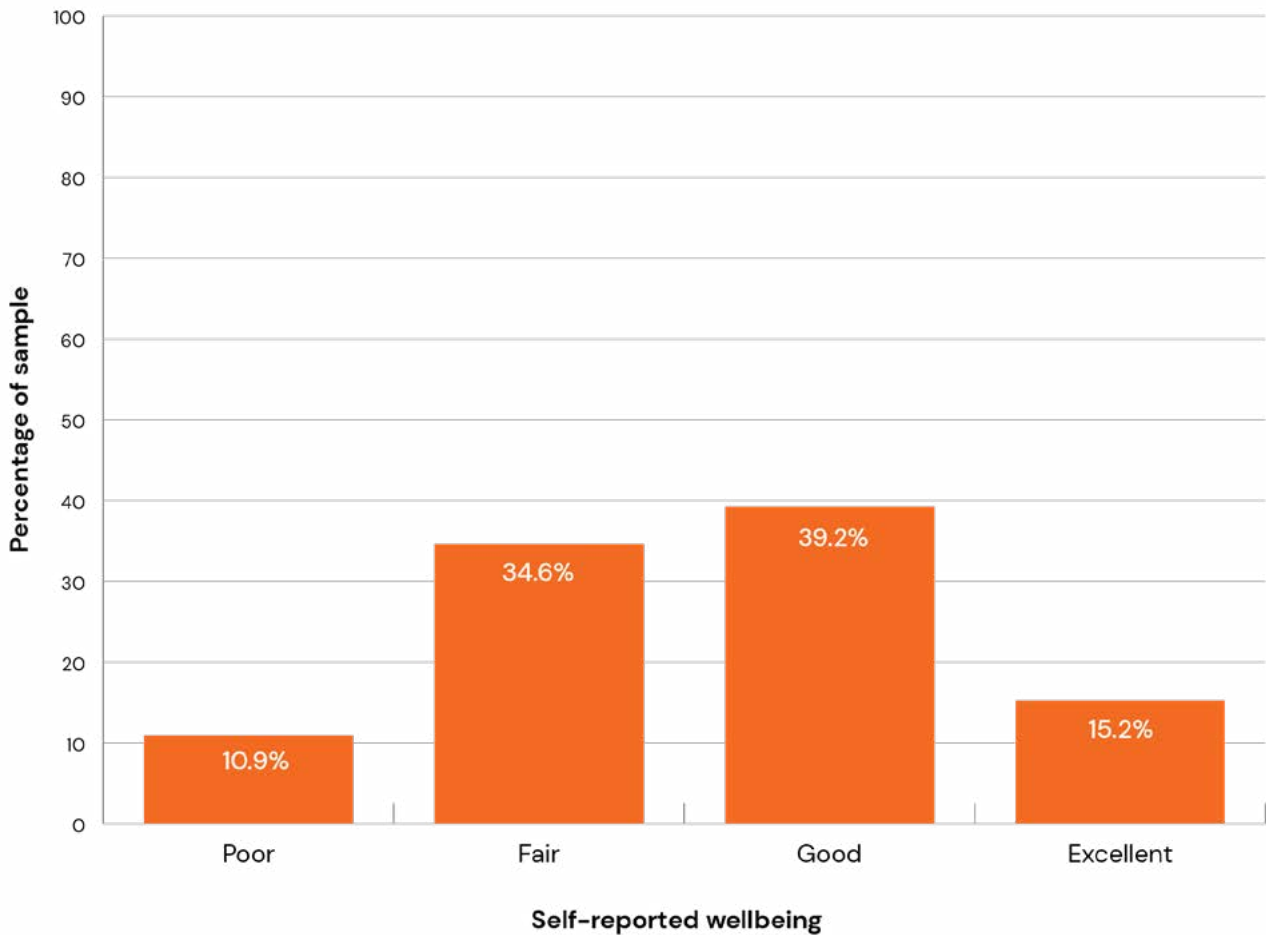
SELF-REPORTED WELLBEING

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

indication of wellbeing. Results are shown in Figure 8. Overall, 54.4% (n = 379) reported their wellbeing to be good or excellent.

"It's always been good and I feel it's got even better in recent years"

Figure 8: Overall physical, emotional and mental wellbeing (self-reported)

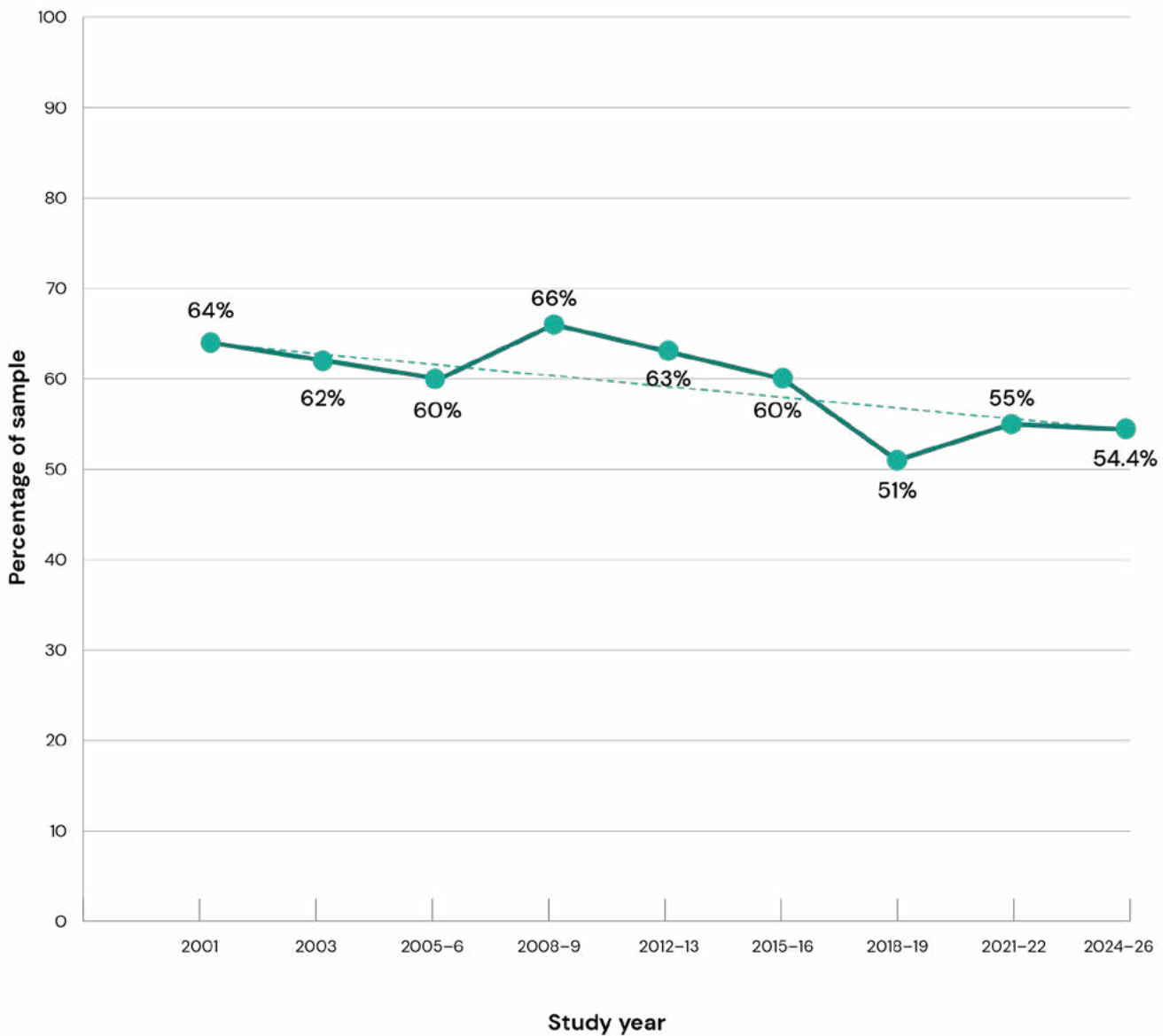


SELF-REPORTED WELLBEING OVER TIME

Figure 9 shows the percentage of people who reported their overall wellbeing to be good or excellent in *HIV FUTURES* surveys from 2001 onwards. The percentage of respondents who

reported good or excellent wellbeing remained relatively stable between *HIV FUTURES 10* (2021–22) and *HIV FUTURES 11* (2024–6), at approximately 55% of the overall sample. When looking at the wider trend, wellbeing gradually declined between 2008–9 and 2018–19 (66% to 51%), before slightly increasing to 55% in 2021–22.

Figure 9: *HIV FUTURES* participants reporting overall wellbeing to be good or excellent over time





3. FINANCIAL AND HOUSING SECURITY

Financial security is a key determinant of quality of life, shaping people's capacity to make choices about employment, education, housing, and future planning. It also underpins social participation: the ability to afford everyday activities plays an important role in preventing isolation and supporting wellbeing. Consistent with this, findings from the previous chapter show that financial stress and lower income are strongly associated with poorer quality of life among PLHIV.

Patterns observed across successive *HIV FUTURES* surveys suggest that these disparities are not incidental, but reflect enduring structural and life course factors. PLHIV in Australia experience persistently elevated levels of financial hardship, shaped by a range of structural factors across the life course. Long-term survivors, for example, are more likely to have experienced periods of ill health and the side effects of earlier HIV treatments, which may have disrupted employment trajectories and reduced lifetime earnings. These impacts can persist even in the context of effective contemporary treatment.

"A long-term survivor of HIV on the pension in a country setting simply cannot afford to do the social things. [...] Seeing the world on television, but not wealthy enough to afford most things people tend to do."

As the population of PLHIV ages, the relationship between financial security and quality of life is likely to become more pronounced. Older adults face increasing healthcare needs alongside reduced income in retirement, intensifying pressure on already limited resources. Housing is a key point of vulnerability, particularly for those in private rental or other insecure arrangements, where costs are high and stability is uncertain. Thus, financial security is a central lever for improving quality of life outcomes, and reinforce the need for responses that extend beyond clinical care to address the social and economic conditions shaping wellbeing.

HOUSING AND HOMELESSNESS

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

Private rental accommodation remains the most common form of housing among *HIV FUTURES 11* participants (Table 10), with 32.4% (n = 227) reporting that they live in private rental. A substantial proportion of participants reported home ownership, with 19.0% (n = 133) owning their home with a mortgage and 28.0% (n = 196) owning their home outright. While this indicates a presence of home ownership within the sample, participants remain more likely to live in private rental accommodation and less likely to own their home compared to the Australian population. In the 2021

Australian Census, 30.6% of people were living in rental accommodation, 35% owned their home with a mortgage, and 31.0% owned their home outright (Australian Bureau of Statistics, 2022).

A further 12.7% (n = 89) of participants reported living in public or community housing, and 4.9% (n = 34) were living rent-free, for example with friends or family, pointing to a broader reliance on non-market or informal housing arrangements.

In *HIV FUTURES 11*, 0.6% (n = 4) of participants reported that they were living in a boarding house, crisis accommodation, or were homeless. This proportion is consistent with *HIV FUTURES 10* (0.8%; 2021–22), but remains higher than estimates for the general population. In the 2021 Australian Census, approximately 0.48% of the population was experiencing homelessness on census night, including those in boarding houses or crisis accommodation as well as other forms such as couch surfing, inadequate accommodation, or no accommodation (Australian Bureau of Statistics, 2022).

“Mental health, housing security and cost of living has become a huge burden on everyone living with HIV in the past 5 years. Social housing accessibility is an area that needs a lot more focus. It is a huge issue that affects the health of PLHIV.”

Table 10. Current housing arrangement

	Frequency n	Percentage %
Private rental	227	32.4
Home purchaser (with mortgage)	133	19.0
Home owner (own outright)	196	28.0
Public or community housing	89	12.7
Rent-free (e.g. with friends or family)	34	4.9
Boarding house, crisis accommodation or homeless	4	0.8
Other	17	2.4

HOUSING BY DEMOGRAPHIC CHARACTERISTICS

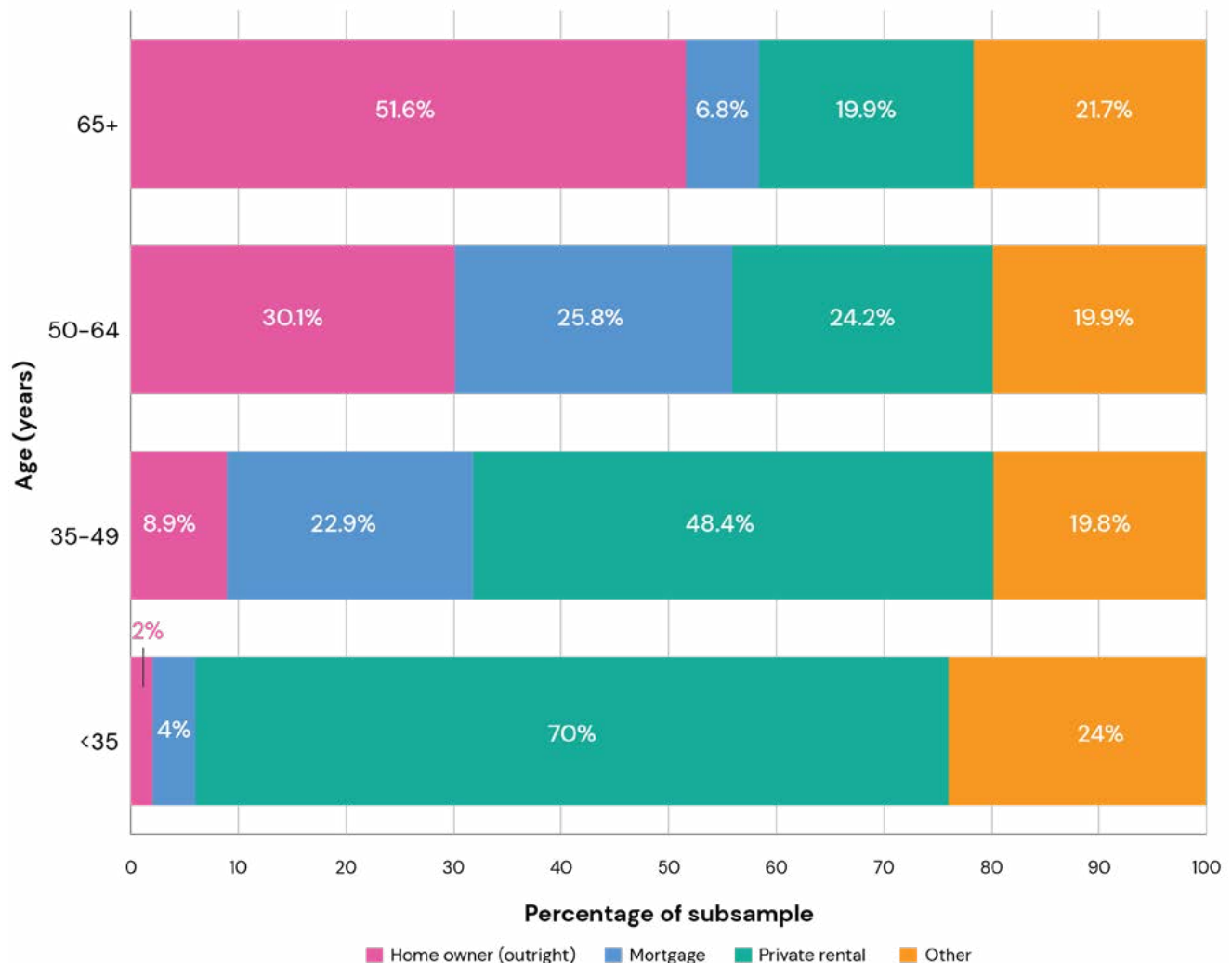
Housing arrangements were patterned by age, with younger participants much less likely than older participants to own their home either outright or with a mortgage (see Figure 10). Private rental was the most common form of housing for those aged <35 and 35–49. Among participants aged under 35 years, 70.0% were living in private rental accommodation, compared to 19.9% of those aged 65 and over. Private rental also remained common among those aged 35–49 (48.4%), before declining substantially in older age groups.

Home ownership increased markedly with age. Among participants aged 65+, just over half (51.6%) owned their home outright, compared to 30.1% of

those aged 50–64, 8.9% of those aged 35–49, and 2.0% of those aged under 35. Mortgage ownership peaked among those aged 50–64 (25.8%) and 35–49 (22.9%), and was less common among younger and older participants.

Despite higher levels of home ownership in older age groups, a substantial minority of participants aged 50–64 (24.2%) and 65+ (19.9%) continued to live in private rental accommodation. As shown in Figure 10, participants aged 50–64 were considerably less likely than those aged 65+ to own their home outright, possibly reflecting a transitional stage between mortgage holding and full ownership. However, the overall percentage of home ownership (outright or mortgage) among those 50–64 was lower than those 65+, and much lower among those 35–49.

Figure 10: Housing arrangement, by age group



Note: 'other' category includes public/community housing, rent-free, boarding house/crisis accommodation/homeless, and other non-specified housing arrangement



Housing arrangement was also analysed by gender. Men were more likely to own their home outright (30.0%) than women (16.2%). Women were the most likely to be paying a mortgage (27.3%), compared with men (18.1%), reflecting 48.1% of men owning a home compared to 43.5% of women overall. Private rental was the most common housing type across all gender groups, with similar proportions of men (32.3%) and women (31.3%) in this category. A higher proportion of non-binary participants were also in private rental (46.7%), although the smaller sample size for this group means these figures should be interpreted with caution.

RECENT FINANCIAL STRESS

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

Over one in five (22.1%, n = 156) participants were classified as experiencing significant financial stress. This was an increase in the proportion of participants reporting financial stress compared to 2020–21 (*HIV FUTURES 10*; 17.2% [n = 140]). As a point of comparison to the general population, in the Household, Income and Labour Dynamics in Australia (HILDA) survey, a representative survey of Australian households, approximately 13% of participants were classified as experiencing financial stress in 2023 (HILDA, 2025).

Financial stress was analysed by location, age, gender, and current housing arrangement:

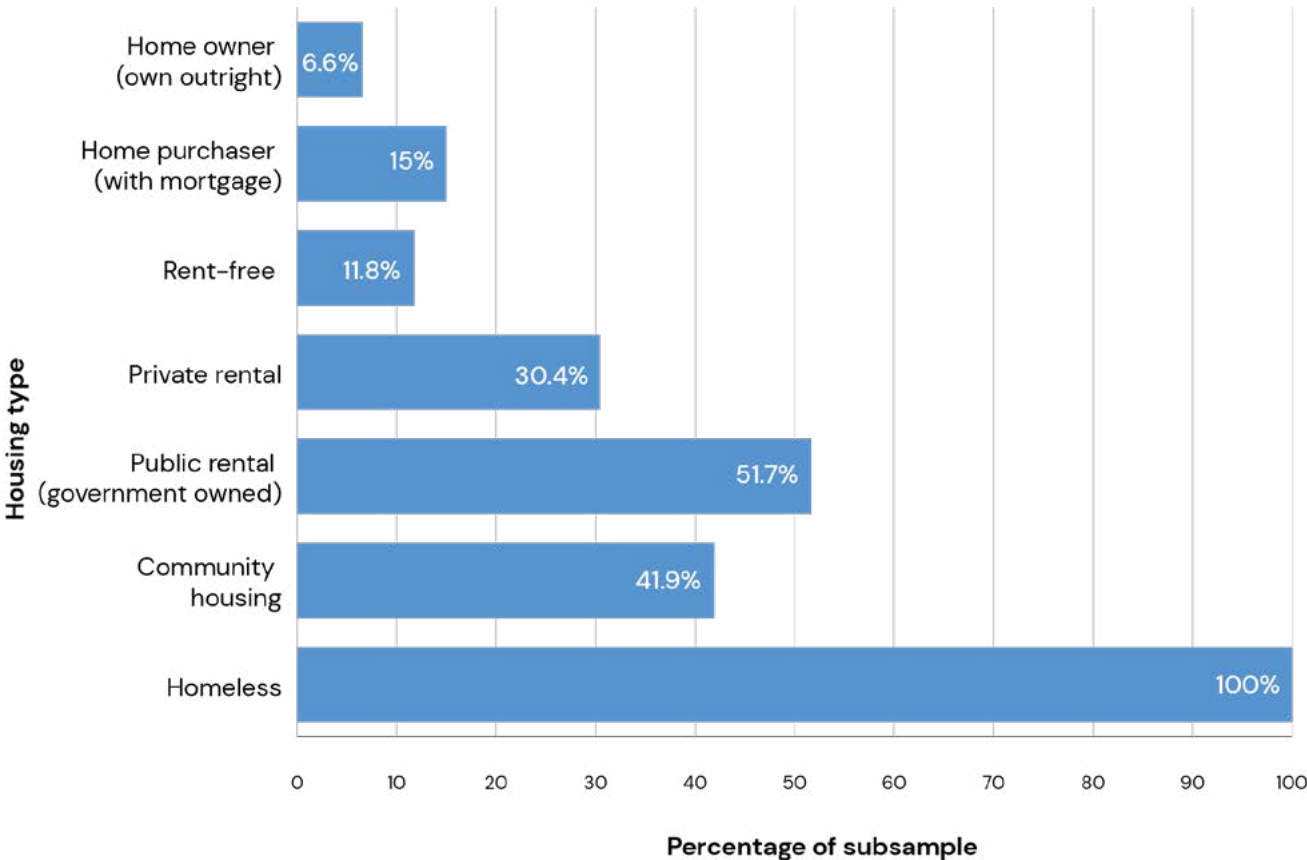
- **Location:** Participants living in outer suburban areas were the most likely to report financial stress in the previous 12 months (32.1%), followed by those living in inner-city areas (22.7%), rural areas (17.9%), and regional areas (11.4%).
- **Age:** Consistent with previous *HIV FUTURES* surveys, financial stress showed a clear age gradient. Participants aged under 35 years were the most likely to report financial stress (36.0%), followed by those aged 35–49 years (24.5%), those aged 50–64 years (22.2%), and those aged 65 years and over (14.8%).
- **Gender:** Differences were also observed by gender. Non-binary and gender-fluid participants

were the most likely to report financial stress in the previous 12 months (33.3%), followed by women (28.3%) and men (21.0%). No participants who used a different term to describe their gender reported financial stress, although findings for this group should be interpreted cautiously due to the very small sample size.

- **Housing arrangement:** Financial stress was unequally distributed by type of housing arrangement. Participants who were homeless

were most likely to have experienced financial stress (Figure 11), although overall numbers were small (100% of two participants). Those who owned their homes outright were least likely to be financially stressed (6.6% of 196 participants). Almost one in three participants living in private rental housing had experienced financial stress (30.4% of 227 participants); and increase from approximately one in five in *HIV FUTURES 10* (2021–22; 22.7%).

Figure 11: Proportion of participants living in each type of housing arrangement reporting recent financial stress*

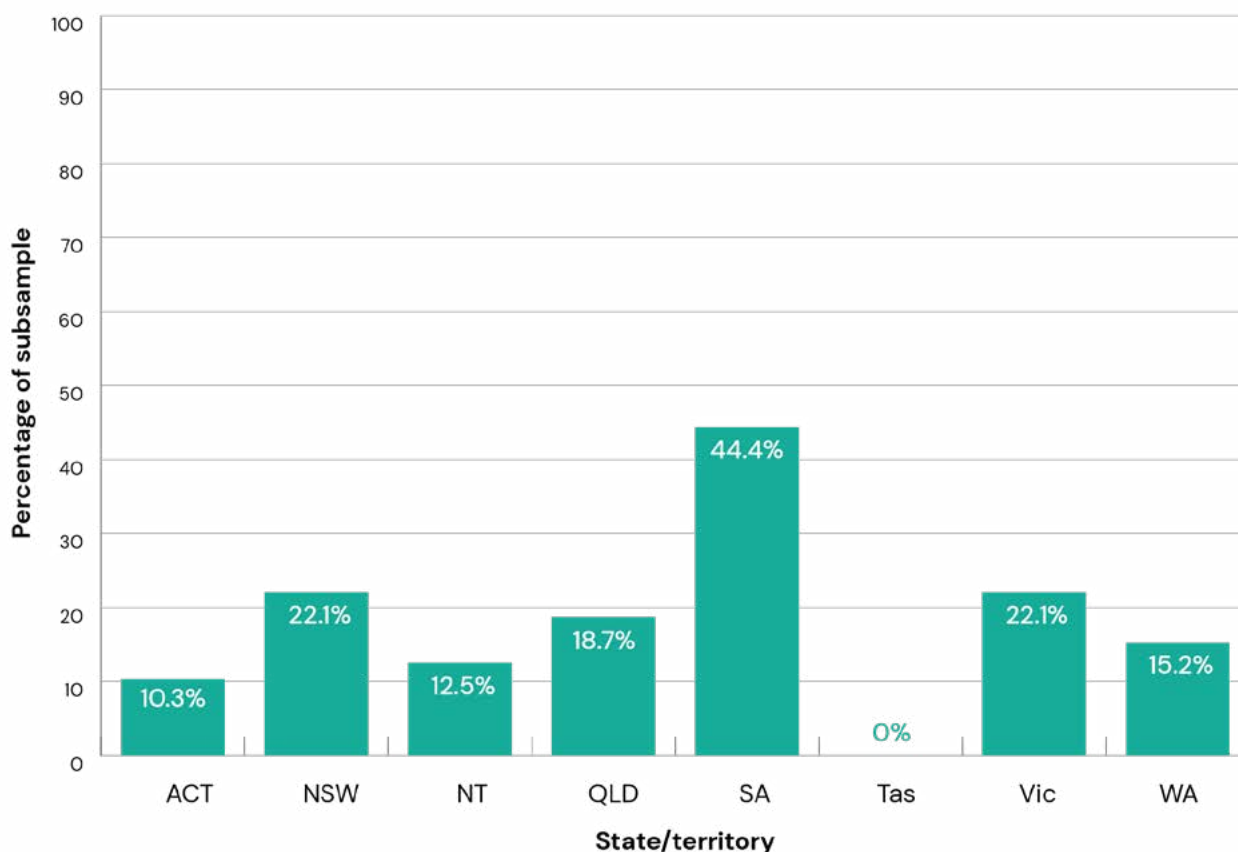


* Note that participants living in community housing have been decoupled from those living in public housing

Financial stress was analysed by state/territory (Figure 12). Financial stress differed significantly by jurisdiction ($\chi^2(7) = 21.46, p = .003$). Participants living in South Australia were the most likely to report experiencing two or more indicators of financial hardship in the previous 12 months (44.4%), more than twice the proportion of the approximately one-fifth of participants in New South Wales (22.1%), Victoria (22.1%), and Queensland (18.7%). Lower proportions were observed in Western Australia (15.2%), the Northern Territory (12.5%), and the

Australian Capital Territory (10.3%). No participants from Tasmania reported two or more indicators of financial hardship, although participant numbers in some jurisdictions were small and findings should be interpreted with caution.

Figure 12: Proportion of participants reporting recent financial stress, by state/territory



Note: Due to small cell sizes in Tas and NT, findings should be interpreted with caution.

HEALTHCARE COSTS AND ACCESS

Australian citizens and permanent residents generally have access to subsidised HIV-related healthcare through Medicare and the Pharmaceutical Benefits Scheme. While HIV treatment is now available free or at low cost to people living with HIV in Australia regardless of Medicare coverage, people on temporary or short-term visas may still face barriers to accessing healthcare, including medical consultations, pathology, and other out-of-pocket costs.

Most participants in *HIV FUTURES II* reported that they were able to afford the costs of treatment and healthcare. However, some participants struggled to meet associated costs, such as transport to clinics or the fees for specialists to treat comorbidities or other health conditions (including mental health). Specifically, in the past 12 months:

- 5.6% (n = 35) reported that it was financially ‘very difficult’ to afford out-of-pocket costs for HIV-related healthcare, and a further 16.4% (n = 102) reported that it was ‘somewhat difficult’
- 2.2% (n = 14) reported that it was financially ‘very difficult’ to afford out-of-pocket costs for HIV

medication, and a further 9.3% (n = 58) reported that it was ‘somewhat difficult’

- 9.4% (n = 59) reported that it was financially ‘very difficult’ to afford out-of-pocket costs for other (non-HIV) medications, and a further 28.1% (n = 176) reported that it was ‘somewhat difficult’

MEDICARE AND PRIVATE HEALTH INSURANCE

Most participants (95.6%, n = 672) reported that they had an Australian Medicare card, while 4.4% (n = 31) did not. Just over one third (36.3%, n = 255) of participants had some kind of healthcare concession card.

One indicator of financial security is being able to afford private health insurance. This also allows access to greater choice in health services and in some cases more rapid treatment when a person becomes unwell or needs to be hospitalised. Just over two-fifths (43.6%, n = 308) of participants had private health insurance and 1.4% (n = 10) had overseas student health cover (OSHC).



4. HIV DIAGNOSIS, TREATMENT AND CLINICAL CARE

The Ninth National HIV Strategy 2024–2030 sets national targets of increasing the proportion of PLHIV (in all priority populations) who are diagnosed to 98% by 2030, as well as increasing the proportion of people diagnosed with HIV on treatment to 98% by 2030, and increasing the proportion of those on treatment with an undetectable viral load to more than 98% by 2030 (ACDC, 2024). These targets build on the UNAIDS 95–95–95 framework, reflecting Australia’s high baseline performance across the HIV care cascade.

Recent national surveillance data indicate that overall Australia is performing strongly in relation to these targets (King, et al., 2025), although there is variation across indicators. It is estimated that approximately 94% of PLHIV have been diagnosed. Of those diagnosed, 97% were retained in care and 95% were receiving ART. And of those receiving ART, 98% (26 870) had a suppressed viral load (less than 200 HIV1 RNA copies/mL). Of all PLHIV in Australia, an estimated 87% had a suppressed viral load. This means that of all PLHIV in Australia, an estimated 87% had a suppressed viral load. These estimates suggest that Australia is close to meeting the 2030 treatment and viral suppression targets, however the proportion of PLHIV who remain undiagnosed remains the key gap.

“Grateful for quality healthcare, access to ART and peer support.”

YEARS SINCE HIV DIAGNOSIS

The number of years since being diagnosed with HIV ranged from less than one year to 43 years (average of 20.9 years, SD = 12.1). The majority of the sample (80.4%, n = 509) had been diagnosed more than 10 years ago (i.e., in 2015 or earlier). The average number of years people reported they had been living with HIV (including time prior to diagnosis) was 23.0 years (SD = 12.4).

Mean years since HIV diagnosis increased with age:

- 7.8 years (SD = 7.7) among participants aged under 35 years
- 12.2 years (SD = 7.2) among those aged 35–49 years
- 23.6 years (SD = 10.9) among those aged 50–64 years
- 27.2 years (SD = 12.0) among those aged 65 years and over.

As expected, older people were more likely to have been living with HIV for a longer period of time. However, approximately one in 10 people aged over 65 years (10.3%, n = 16) and one in ten people aged 50–64 (10.3%, n = 30) had been diagnosed in the past 10 years.

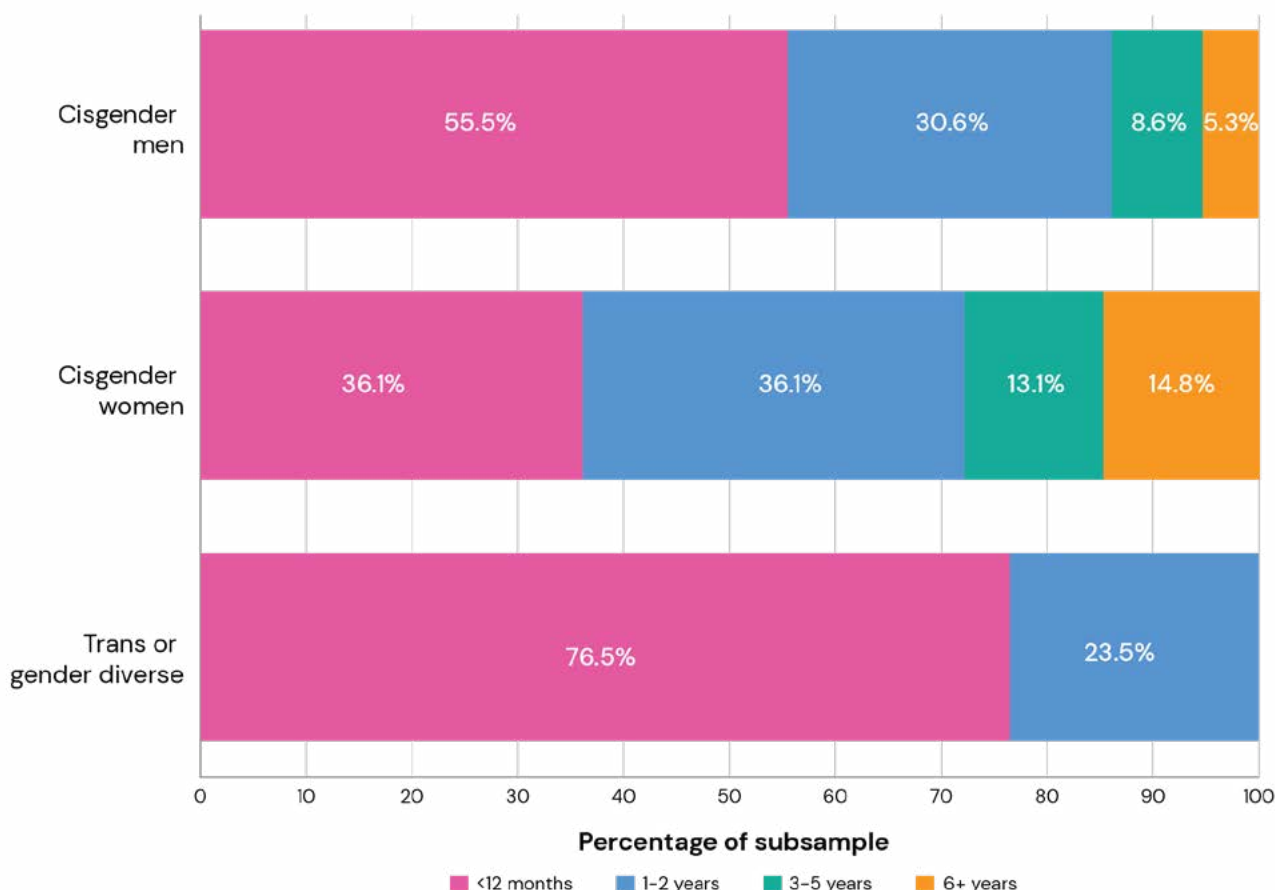
TIME BETWEEN PERCEIVED HIV ACQUISITION AND DIAGNOSIS

Participants were asked the year they were diagnosed with HIV and the year they believe they acquired HIV (**Note:** there was a high non-response rate to this question as some participants were unsure about the year in which they acquired HIV).

Among participants with valid data (n = 492), just over half (53.9%; n = 265) reported being diagnosed within 12 months of when they believed they acquired HIV. A further 30.9% (n = 152) reported a period of 1–2 years between perceived acquisition and diagnosis. Smaller proportions reported longer delays, including 8.5% (n = 42) with a delay of 3–5 years and 6.7% (n = 33) with a delay of six years or more. The average time between perceived acquisition and diagnosis was 1.3 years (SD = 2.6), although these are indicative figures only as participants could only report calendar year, not month.

Similar to *HIV FUTURES 9* (2018–19) and *HIV FUTURES 10* (2021–22), this study found the length of time between acquisition and diagnosis was longer for cisgender women than cisgender men (Figure 13). Among cisgender men, 55.5% (n = 227) were diagnosed within 12 months and 79.0% (n = 323) within two years. Among cisgender women, 36.1% (n = 22) were diagnosed within 12 months and 60.7% (n = 37) within two years, indicating comparatively longer delays. Among trans and gender diverse participants, 76.5% (n = 13) were diagnosed within 12 months, although estimates for this group should be interpreted with caution due to small subsample numbers.

Figure 13: Distribution of time between HIV acquisition and diagnosis, by gender category



ANTIRETROVIRAL THERAPY USE

Engagement in HIV antiretroviral therapy (ART) was high across the sample. Almost all participants (99.1%) reported currently taking ART, with fewer than 1% (0.9%; n = 6) not currently on treatment. Among those not on ART, half (n = 3) reported never having taken treatment, while the remainder (n = 3) had previously taken ART.

“So appreciative of the health support and PBS [Pharmaceutical Benefits Scheme] funding of treatment.”

Participants were asked about their current form of ART, as well as their awareness of newer injectable ART options. Most participants reported currently taking oral ART (92.3%, n = 578). A smaller proportion reported using injectable ART administered every eight weeks (7.5%, n = 47), while only one participant reported using longer-acting injectable options administered every six months (0.2%, n = 1).

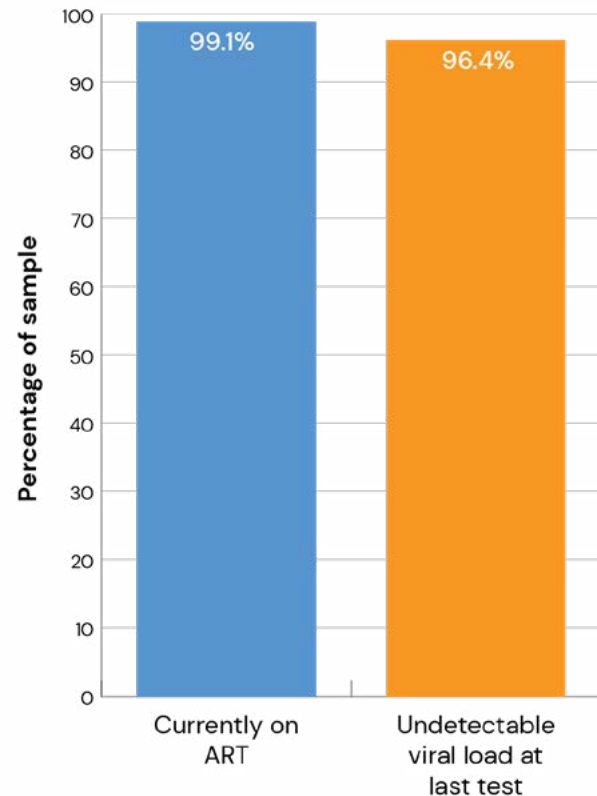
Awareness of injectable ART was relatively high. Around four in five participants (78.0%, n = 449) indicated they had heard of injectable antiretroviral therapy, while one in five (20.0%, n = 115) had not, and a small proportion (2.1%, n = 12) were unsure.

Participants were subsequently asked whether they would consider switching from oral ART to injectable treatment. Responses were mixed. Around two in five participants (44.0%, n = 197) who had heard of injectable ART indicated they would consider switching to injectable ART, while 24.3% (n = 109) reported they would not. A substantial proportion (31.7%, n = 142) were unsure or did not know whether they would consider switching.

VIRAL SUPPRESSION AND MONITORING

Among participants who reported a recent viral load result (n = 635), the vast majority (96.4%; n = 612) indicated that their viral load was undetectable (Figure 14). A small proportion reported a detectable viral load (2.0%; n = 13), while 1.6% (n = 10) were unsure of their most recent result.

Figure 14: Current use of antiretroviral therapy and viral detectability at last test



Participants were asked when they had most recently had a viral load test. The majority of participants reported recent testing, with 60.8% (n = 390) having had a viral load test in the past three months and a further 32.0% (n = 205) between three and six months ago. Smaller proportions reported longer intervals since their last test, including 6.6% (n = 42) who had tested 6–12 months ago and fewer than 1% (0.6%, n = 4) who had not tested in over 12 months.

TREATMENT SATISFACTION

Overall, participants reported high levels of satisfaction with their HIV treatment:

- More than four in five (80.0%; n = 497) indicated that they were ‘very’ or ‘extremely’ happy with their treatment (a comparable proportion to the 81% reported in *HIV FUTURES 10*; 2021–22).
- A further 15.3% (n = 95) reported being ‘moderately’ happy with their treatment.
- Only a small minority reported low levels of satisfaction, with 4.7% (n = 29) indicating they were ‘slightly’ or ‘not at all’ happy.

Perceptions of treatment side effects were more mixed. While over half (57.6%; n = 364) disagreed or strongly disagreed that the side-effects of antiretroviral drugs outweigh the benefits, around one-quarter (25.0%; n = 158) agreed or strongly agreed with this statement, indicating a sizable minority with concerns about treatment. A smaller proportion, 17.4% (n = 110), neither agreed nor disagreed.

UNDETECTABLE = UNTRANSMITTABLE

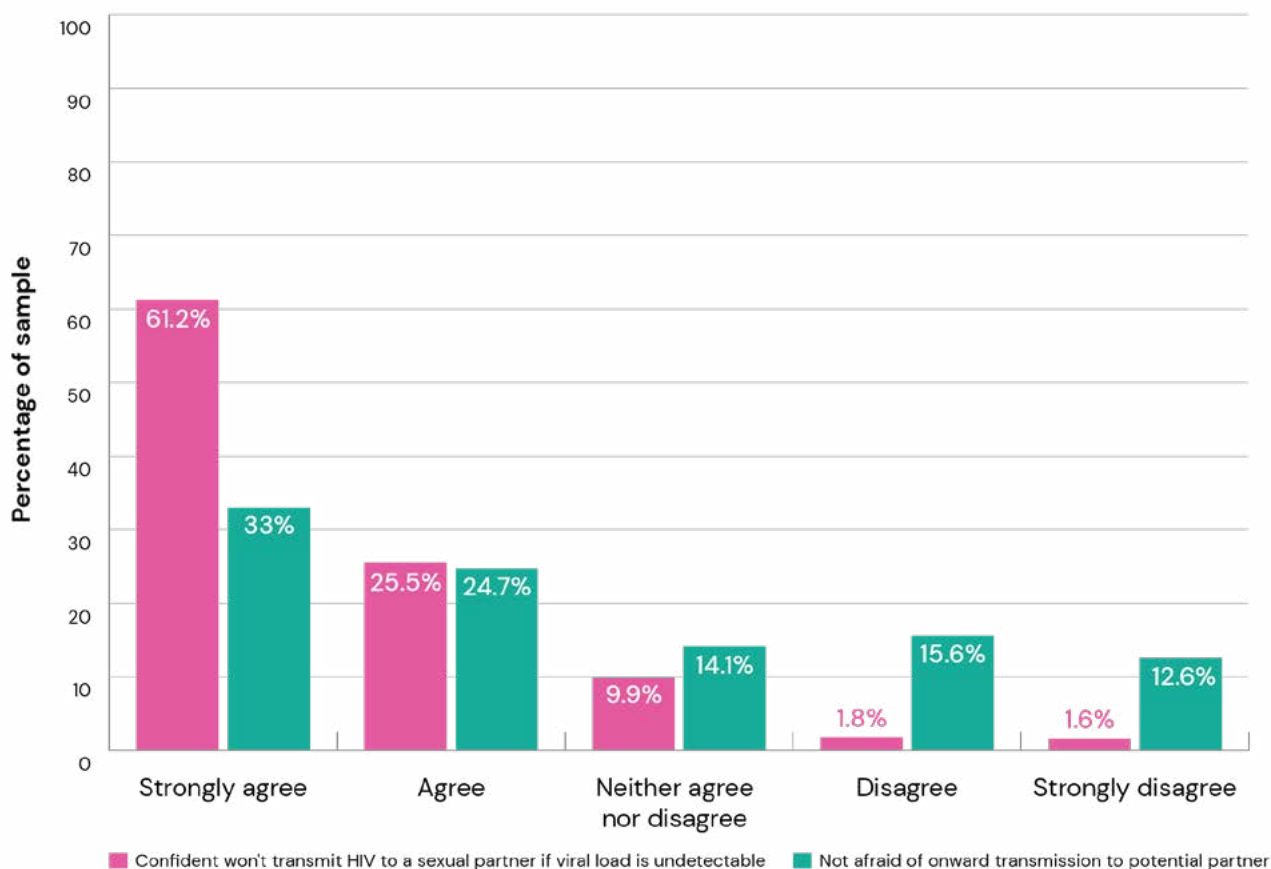
One of the most significant advances in the HIV response has been the establishment of the Undetectable = Untransmittable (U=U) message (Prevention Access Campaign, 2023). U=U reflects the scientific evidence that PLHIV who maintain an undetectable viral load through effective treatment do not transmit HIV through sex (Okamoto et al., 2024). Beyond its prevention benefits, U=U has transformed how HIV is understood: it has reduced uncertainty about transmission risk and challenged long-standing assumptions that PLHIV pose an

inherent risk to sexual partners. As a result, U=U has become a cornerstone of contemporary HIV care, prevention, and stigma reduction efforts.

To understand how this message is experienced by PLHIV, *HIV FUTURES II* examined two related but distinct dimensions: participants' confidence in U=U, and their concerns about onward transmission. The first captures acceptance of the scientific evidence; the second captures emotional responses to transmission risk. While closely related, these are not the same thing, and *HIV FUTURES II* measured them separately.

More than 86% of participants agreed or strongly agreed that a person with an undetectable viral load cannot transmit HIV to a sexual partner (Figure 15). However, this confidence does not appear to fully translate into personal feelings about transmission risk. While 86.7% agreed that they would not transmit HIV if undetectable, only 57.7% agreed or strongly agreed that they were not afraid of onward transmission to a potential partner. Conversely, over one-quarter (28.2%) expressed some degree of fear about onward transmission.

Figure 15. Responses to statements about onward HIV transmission



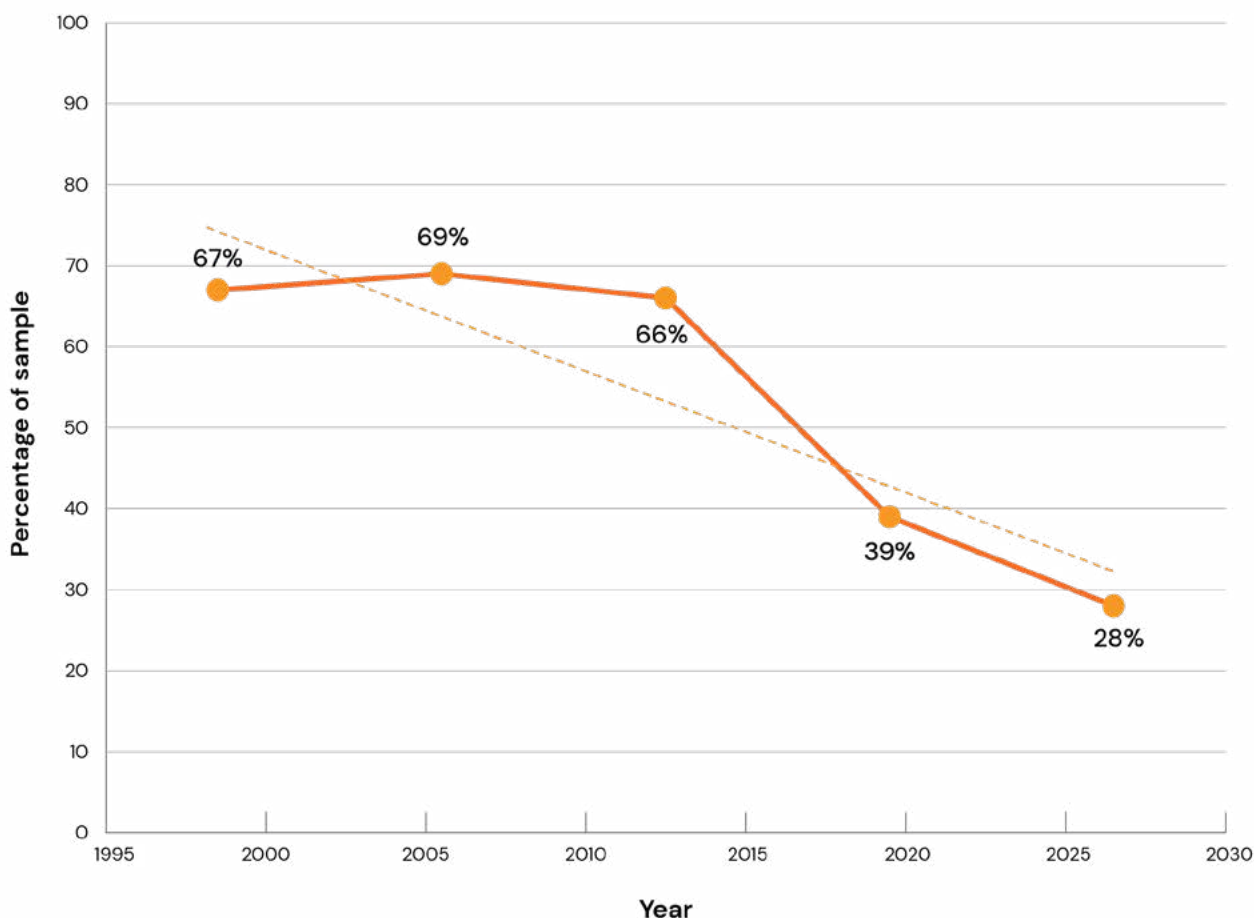
Note: Original item wording for “not afraid of onward transmission to potential partner” was reversed (i.e., afraid of onward transmission).

While concerns about onward transmission remain evident among some PLHIV, these concerns have declined substantially over time (Figure 16). In *HIV FUTURES 1* (1997), approximately two-thirds of participants (67%) agreed or strongly agreed that they were afraid of transmitting HIV to others. Similar proportions were observed in *HIV FUTURES 4* (69%) and *HIV FUTURES 7* (66%). Since then, however, a marked decline has occurred, with the proportion reporting fear of onward transmission falling to 39%

in *HIV FUTURES 9* and 28% in *HIV FUTURES 11*.

This long-term trend likely reflects the profound changes that have occurred in HIV treatment, prevention, and public understanding of transmission risk over the past three decades. Nevertheless, the findings presented in Figure 15 suggest that despite transmission fears diminishing considerably over time, emotional concerns about transmitting HIV continue to affect a substantial minority of PLHIV.

Figure 16. Percent of HIV FUTURES samples who ‘agree’ or ‘strongly agree’ that they are afraid of onward HIV transmission



Note: Data were drawn from *HIV FUTURES 1* (1997), 4 (2004), 7 (2013), 9 (2018–19) and 11 (2024–26).

PERCEIVED NECESSITY OF – AND CONCERNS ABOUT – HIV TREATMENT

As a result of the ambivalence towards treatment identified in the previous *HIV FUTURES* survey, new measures of treatment attitudes were included in *HIV FUTURES 11* to investigate this issue further. Beliefs about HIV treatment were assessed using the

Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 2004; Horne et al., 1999), which conceptualises treatment engagement as shaped by the balance between perceived necessity for medication and concerns about its potential adverse effects.

The BMQ comprises two subscales: Necessity and Concerns. The HIV medications necessity subscale assesses the extent to which participants perceive HIV medication as essential for maintaining current and future health, preventing illness, and

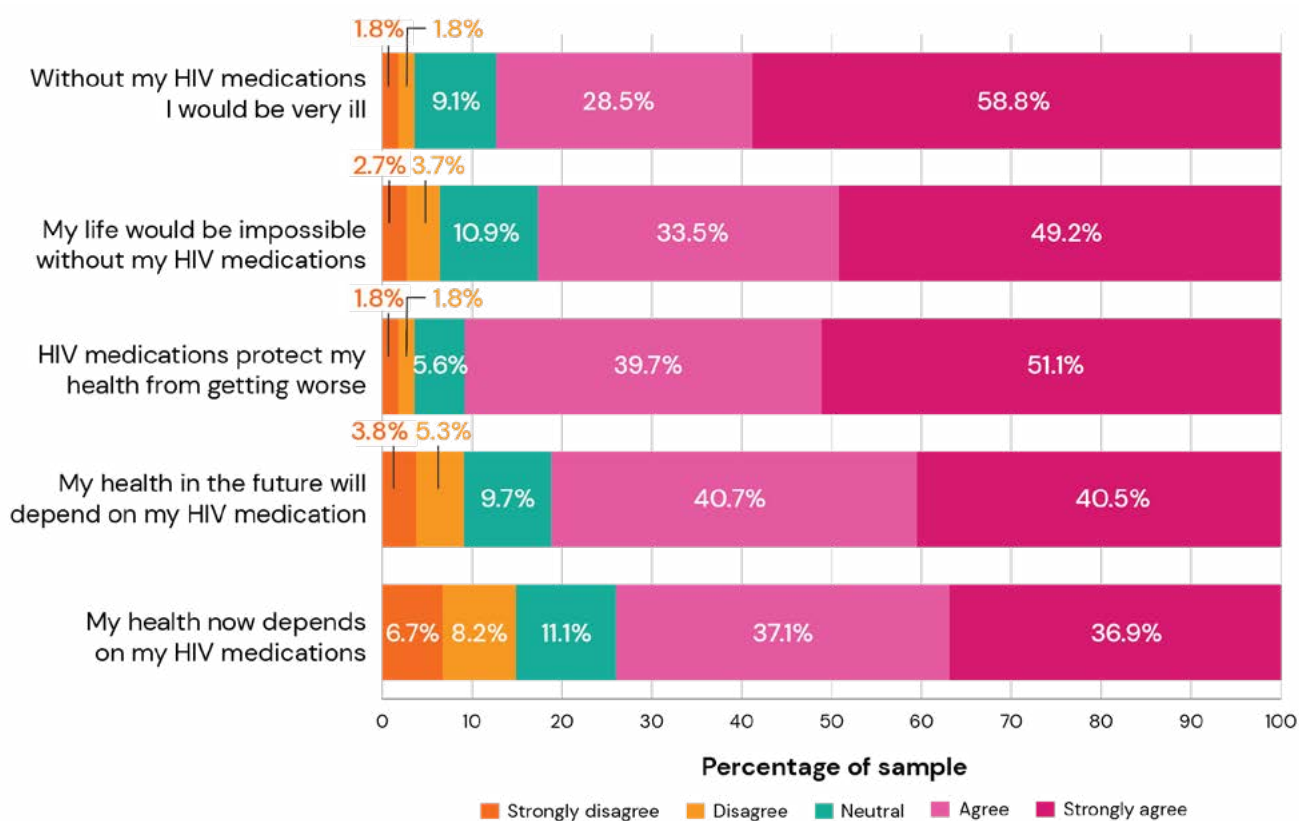
sustaining life. It captures both general beliefs about the importance of treatment and the perceived consequences of not taking medication. Perceived necessity of HIV medication was high across all items, with strong endorsement of the role of treatment in maintaining both current and future health (Figure 17).

A large majority of participants agreed or strongly agreed that their current health depends on their HIV medications (74.0%) and that their future health will depend on them (81.2%). Similarly, over nine tenths agreed that HIV medications protect their health from getting worse (90.8%), indicating widespread recognition of the protective benefits of treatment.

Endorsement was also high for items reflecting the perceived indispensability of treatment. More than four in five participants agreed that their life would be impossible without HIV medications (82.7%), and nearly nine in ten agreed that without their medications they would be very ill (87.3%). These items showed particularly strong intensity of agreement, with around half or more of participants selecting strongly agree.

Levels of disagreement were consistently low across all items (generally below 10%), and neutral responses were also relatively uncommon, suggesting limited ambivalence about the necessity of treatment.

Figure 17. Perceived necessity of HIV treatment



The HIV medications concerns subscale captures specific worries about treatment, including burden, disruption, uncertainty, and long-term effects. Concerns about the practical burden of taking medication were relatively low (Figure 18).

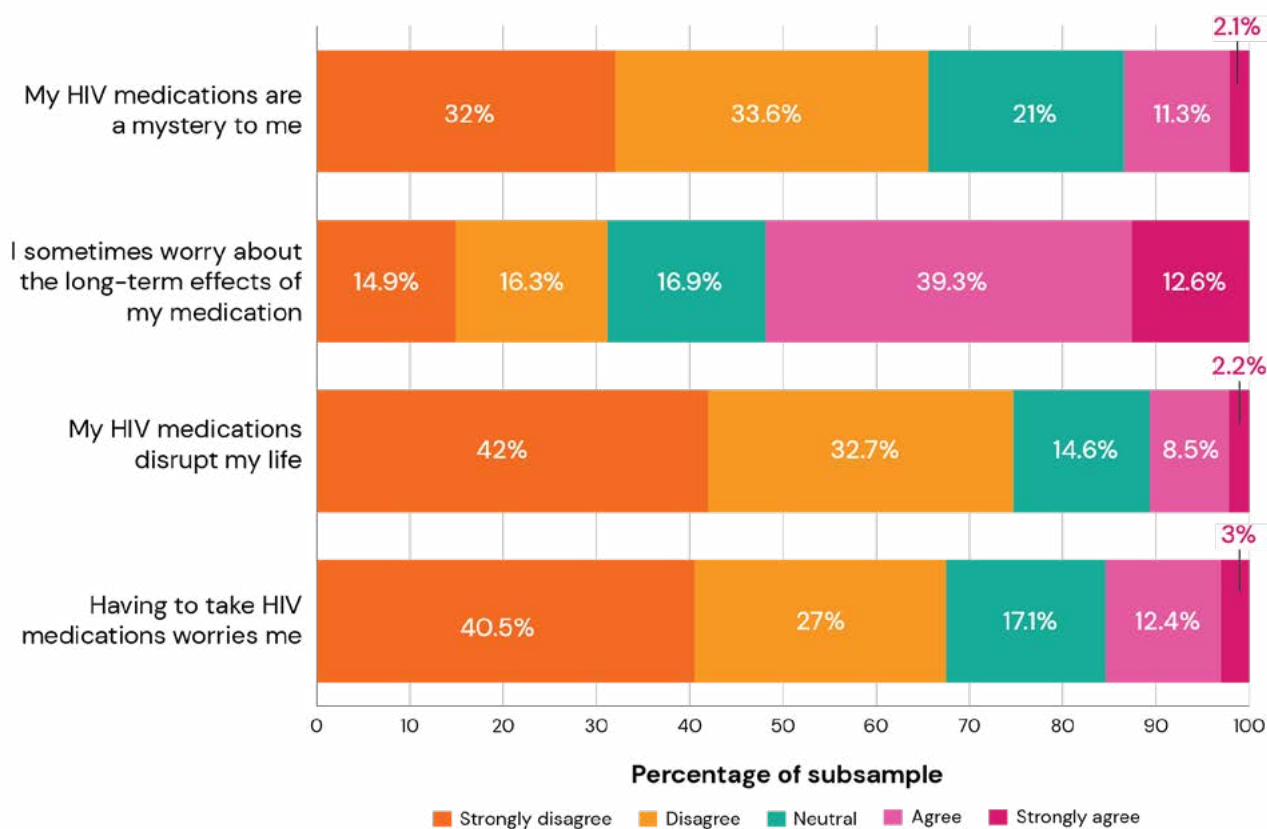
Around two-thirds of participants disagreed that having to take HIV medication worries them (67.5%), and a very similar proportion disagreed that their medications disrupt their life (74.7%). Only a small minority endorsed concerns (15.4% and 10.7% agreeing or strongly agreeing, respectively). This suggests that, for most participants, the day-to-day management of treatment is well integrated into their lives.

In contrast, concerns about long-term effects were much more prominent. Just over half of participants (51.9%) agreed or strongly agreed that they worry about the long-term effects of their medication, while only around one-third (31.2%) disagreed. This marks long-term medication impacts as the most salient area of concern for participants within this scale.

Perceptions of understanding of medication were more mixed. While a majority disagreed that their HIV medications are “a mystery” (65.6%), around one in eight participants (13.4%) expressed uncertainty or lack of understanding (agree/strongly agree), and a further 21% were neutral. This indicates that,

although most feel informed, a notable minority may benefit from clearer information or communication about their HIV treatment.

Figure 18: Concerns about HIV medication



Despite some concerns, particularly around long-term effects, these findings indicate that participants’ beliefs are strongly weighted toward the necessity of treatment. This pattern suggests that, for most participants, concerns coexist with, rather than undermine, a clear recognition of the importance of HIV medication.

THINKING AND ENGAGING WITH HIV-RELATED INFORMATION AND TREATMENT

HIV FUTURES 11 included a 10-item scale assessing the ways in which participants engage in and value technical understandings of HIV and treatment. In previous research, responses to this scale have been found to be associated with health information processing, medication adherence, and self-care decision making (Laws et al., 2020). The scale examined participants’ views on topics including:

- The importance of understanding as much as possible about HIV.

- Understanding how HIV medications work.
- Investing time in learning about HIV and HIV treatments.
- Learning about medications and making informed decisions about treatment.
- Understanding issues relating to medical care.
- Understanding concepts and ideas relating to medical treatments.
- Preferences for active versus passive involvement in healthcare decisions.
- Avoiding or engaging with information about HIV and health.

Scores ranged from 1 to 5, with higher scores indicating greater engagement with HIV-related information and treatment. Overall, participants reported relatively high levels of engagement (M = 3.64, SD = 0.69).

Consistent with the overall scale score, most participants expressed a strong interest in understanding HIV and their healthcare. Around 86% agreed that it is important to understand as much



as possible about HIV, while approximately three-quarters agreed that they like to understand issues related to their medical care (74.8%) and concepts about medical treatments (78.8%). Participants generally favoured an active role in healthcare decision-making, with almost half (48.8%) agreeing that they try to learn about medications and make up their own mind about taking them.

However, engagement was more variable when it came to the time and effort invested in learning. Only 38.8% agreed that they invest a lot of time learning about HIV and its treatments, while 31.0% were neutral and 30.2% disagreed. Similarly, although most participants disagreed that they do not like to think about their health and medical care (65.6%), would rather not think about HIV because it is challenging (61.5%), or are not interested in learning about health and diseases (73.6%), a minority reported preferences for less active engagement with health-related information.

While most participants report that they value understanding and engaging with information about their health and medications, there is variation in how much time and effort people want to invest in learning.

TREATMENT REVIEWS

Participants were asked how confident they felt to ask their doctor for a treatment review. Most reported a high level of confidence in initiating a treatment review if needed. Over four in five participants indicated that they would feel

confident asking their doctor for a review (82.1% reporting “very” or “extremely” confident), including half (50.2%) who felt extremely confident. Only a small minority reported low confidence (7.5% “not at all” or “slightly”), suggesting that most participants feel able to discuss treatment changes with their healthcare provider.

In practice, treatment reviews were also relatively common. Around two-thirds of participants (62.9%) reported having had at least one treatment review in the past three years, including over one-quarter (27.0%) who had undergone more than one review. A further 28.6% reported not having had a treatment review in this period, while a small proportion (8.5%) were unsure

HEALTH LITERACY AND HEALTHCARE NAVIGATION

Participants were asked how confident they felt filling out medical forms by themselves, as an indicator of health literacy and confidence navigating healthcare settings. Most participants reported high levels of confidence completing medical forms independently. Almost three-quarters (72.5%, $n = 424$) reported feeling “totally confident”, while a further 17.1% ($n = 100$) reported feeling “quite confident”. Smaller proportions of participants reported feeling only somewhat confident (7.5%, $n = 44$), only a little confident (1.7%, $n = 10$), or not at all confident (1.2%, $n = 7$).

GP MANAGEMENT PLANS AND CARE COORDINATION

Participants were asked whether they currently had a GP Management Plan (GPMP) or Team Care Arrangement, and whether they had ever had a care plan specifically for HIV. Participation in these types of care plans was mixed: 42.4% reported currently having a plan in place, while a slightly larger proportion (46.3%) reported not having one. A further 11.4% were unsure, which may point to a lack of clarity among patients about whether such a plan exists for their care.

Among participants asked specifically about HIV-related care planning (n = 352), uptake of HIV-specific plans appeared lower than for general care plans. Fewer than one in five (18.2%) reported ever having had a GP Management Plan specifically for their HIV care, while nearly two-thirds (63.6%) reported they had not. A further 18.2% were unsure.

While structured care planning is used by a substantial minority of participants, the use of GP Management Plans specifically for HIV care appears relatively limited. This suggests that awareness of, or access to, HIV-specific care planning arrangements may not be consistent across the sample.

HIV-RELATED HEALTHCARE

Participants most commonly received their HIV care from an HIV specialist (37.6%, n = 233), a doctor

at a sexual health centre (23.1%, n = 143), or their regular GP who can prescribe HIV antiretrovirals (32.7%, n = 203) (Table 11). Very small proportions reported seeing other types of doctors, or no medical professional, for HIV care.

“Doctors are respectful. Happy with the care provided.”

Satisfaction with clinical care was high. Nine in ten participants (90.0%, n = 554) indicated they were satisfied or very satisfied with the care they received for HIV in the past 12 months, including 65.0% (n = 400) who were very satisfied. A small minority (4.2%, n = 26) reported being dissatisfied, while 5.7% (n = 35) were neutral.

“We are very lucky in the HIV care we receive here”

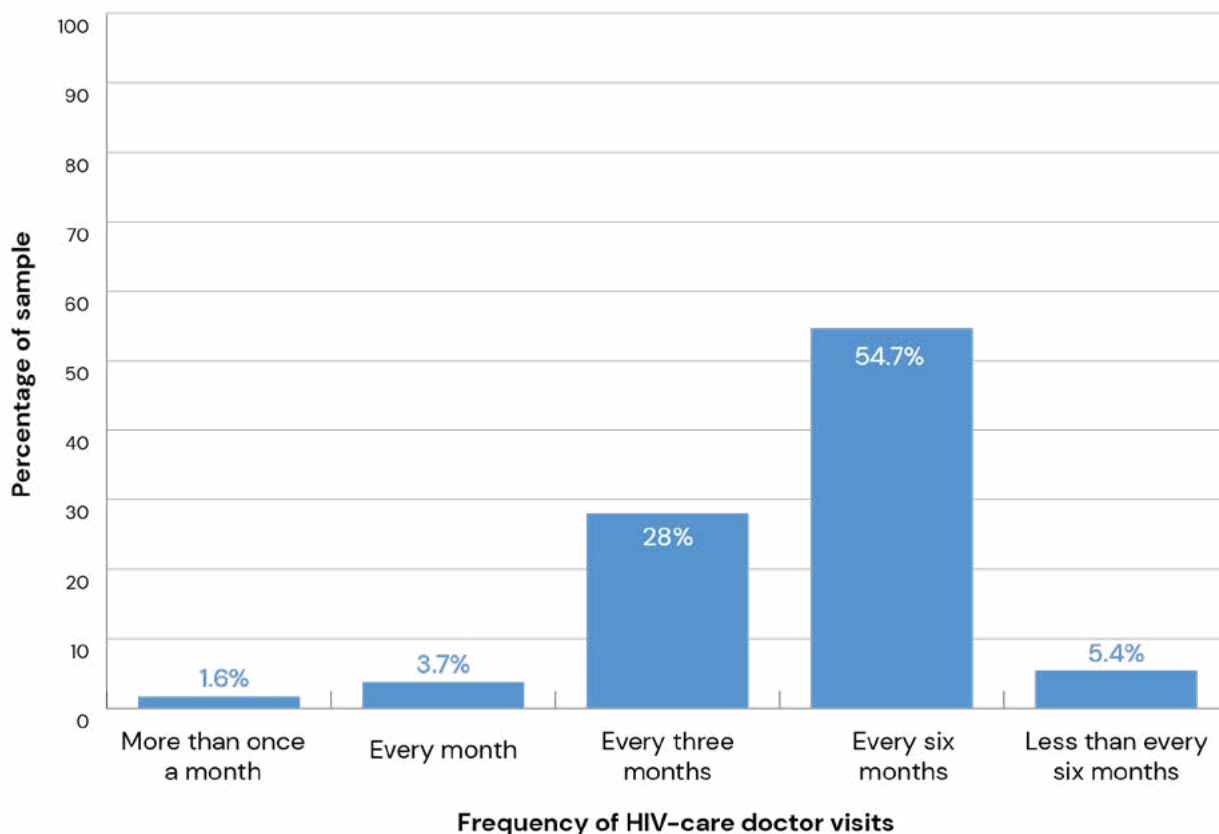
Most participants reported having access to bulk-billed services for HIV-related care (75.2%, n = 463). Around one in five (19.6%, n = 121) indicated they did not have access to bulk billing, while a small proportion (5.2%, n = 32) reported that this question was not applicable to them.

Table 11. Source of main HIV-related care, treatment, and monitoring

Source of HIV treatment/care	Number of participants n (%)
HIV specialist	233 (37.6)
My regular GP who can prescribe HIV antiretrovirals	203 (32.7)
Doctor at sexual health centre	143 (23.1)
Another doctor who can prescribe HIV antiretrovirals (but is not my regular GP)	27 (4.4)
Other	19 (1.5)
Other doctor	3 (< 1)
I do not see a doctor for HIV-related treatment	2 (< 1)

Most participants reported seeing their doctor for HIV-related care every three months or six months (82.7%, n = 508; Figure 19). A smaller proportion reported more frequent visits, including 5.3% (n = 33) who attended monthly or more often.

Figure 19: Frequency of visits to doctor for HIV-related treatment*

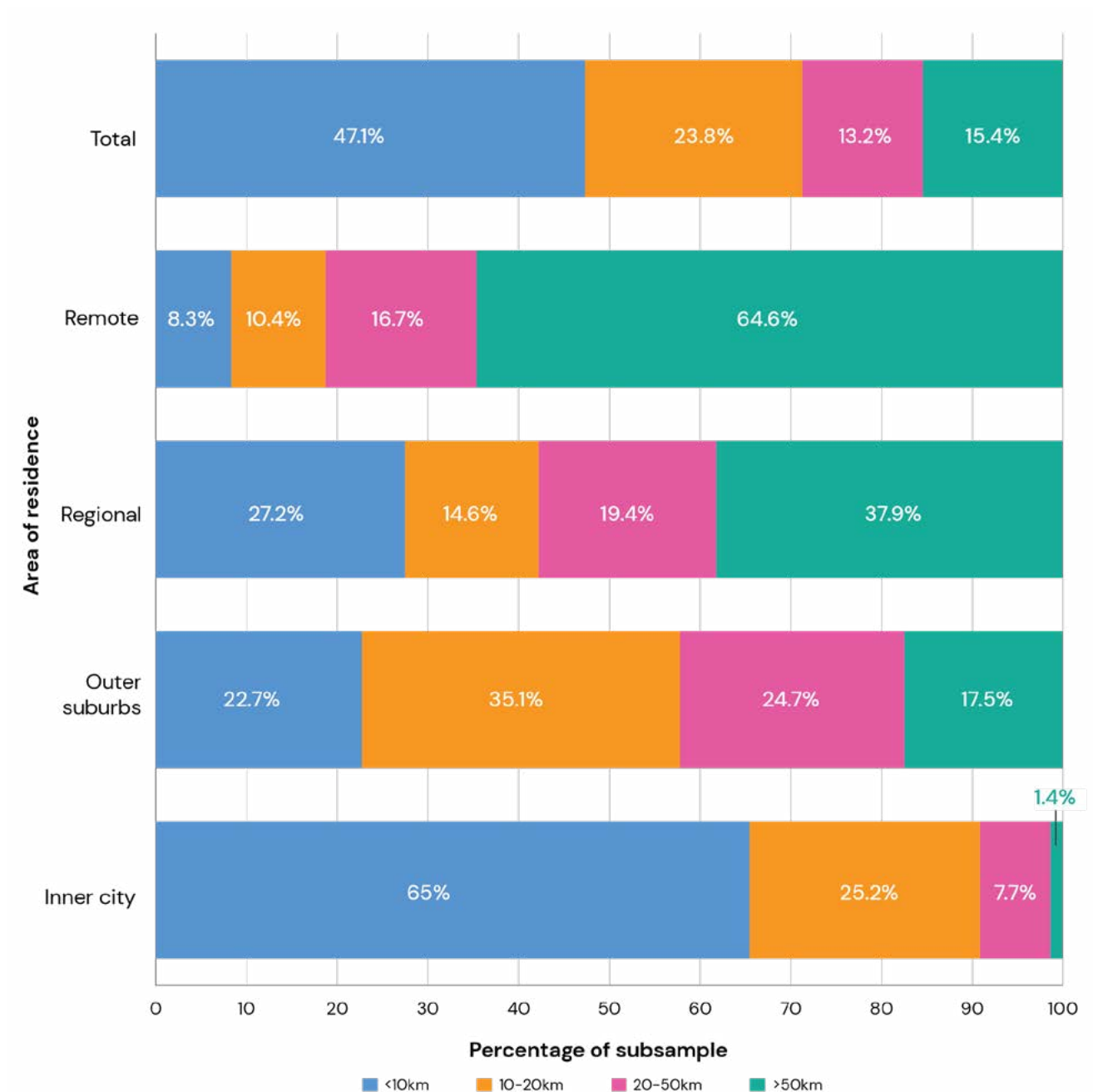


* Note this excludes 'other' and 'not applicable' responses (n = 40)

Participants were asked to indicate the approximate distance travelled to access HIV-related care (Figure 20). Nearly half (47.1%, n = 289) reported travelling less than 10 kilometres, with a further 23.7% (n = 145) travelling between 10 and 20 kilometres. Smaller proportions reported travelling 20–50 kilometres (13.1%, n = 80) or more than 50 kilometres (15.7%, n = 96).

As in previous waves of *HIV FUTURES*, travel distance varied substantially by area of residence. Participants living in capital city or inner suburban areas were most likely to travel short distances, with 65.0% living within 10 kilometres of their HIV doctor. In contrast, those in regional and rural areas experienced a greater travel burden. Over one-third of participants in regional centres (37.9%) and nearly two-thirds of those in rural areas (64.6%) reported travelling more than 50 kilometres for care. This represents a continued increase in travel burden for those outside metropolitan areas compared to *HIV FUTURES 9* (2018–19), where 44% of regional/rural participants reported travelling more than 50 kilometres, rising to 62.2% in *HIV FUTURES 10* (2021–22).

Figure 20: Distance travelled to visit doctor for HIV-related treatment, by area of residence



USE OF TELEHEALTH

The majority of participants reported having used telehealth (72.3%, n = 435), most commonly via telephone (55.8%, n = 344), while a smaller proportion reported using video-based telehealth (14.7%, n = 91). Around one-quarter of the overall sample (27.7%, n = 171) indicated they had not used telehealth.

Among those who had used telehealth services, just over half (51.5%, n = 222) reported having used telehealth for HIV-related appointments, while 45.5% (n = 196) had not. Most participants with experience

using telehealth expressed a preference to continue using telehealth in some capacity. The large majority (81.9%, n = 334) indicated they would prefer a hybrid model combining telehealth with face-to-face care, while a small proportion (3.9%, n = 16) preferred telehealth exclusively. Only 14.2% (n = 58) indicated they would not like to continue using telehealth.



5. HEALTH AND WELLBEING

Living well with HIV is shaped not only by treatment outcomes, but by a range of interconnected physical and mental health experiences. Building on Chapter 2 (Quality of Life), this section examines health more directly, focusing on general physical and mental health, sexual health and viral hepatitis, and the prevalence and management of chronic health conditions among PLHIV.

GENERAL HEALTH

General health was assessed using the General Health subscale of the SF-36 (Ware & Sherbourne, 1992). This measure captures participants' overall perceptions of their health, including current health status, susceptibility to illness, and expectations about future health. The scale comprises five items assessing general perceptions of health:

1. "In general, would you say your health is excellent, very good, good, fair, or poor?"
2. "I seem to get sick a little easier than other people."
3. "I am as healthy as anybody I know."
4. "I expect my health to get worse."
5. "My health is excellent."

The first item uses a five-point rating scale (excellent to poor). The remaining items (2–5) are rated on a five-point agreement scale (definitely true to definitely false). Items were recoded and averaged to produce a score ranging from 0 to 100, with higher scores indicating better perceived health. Negatively worded items were reverse scored.

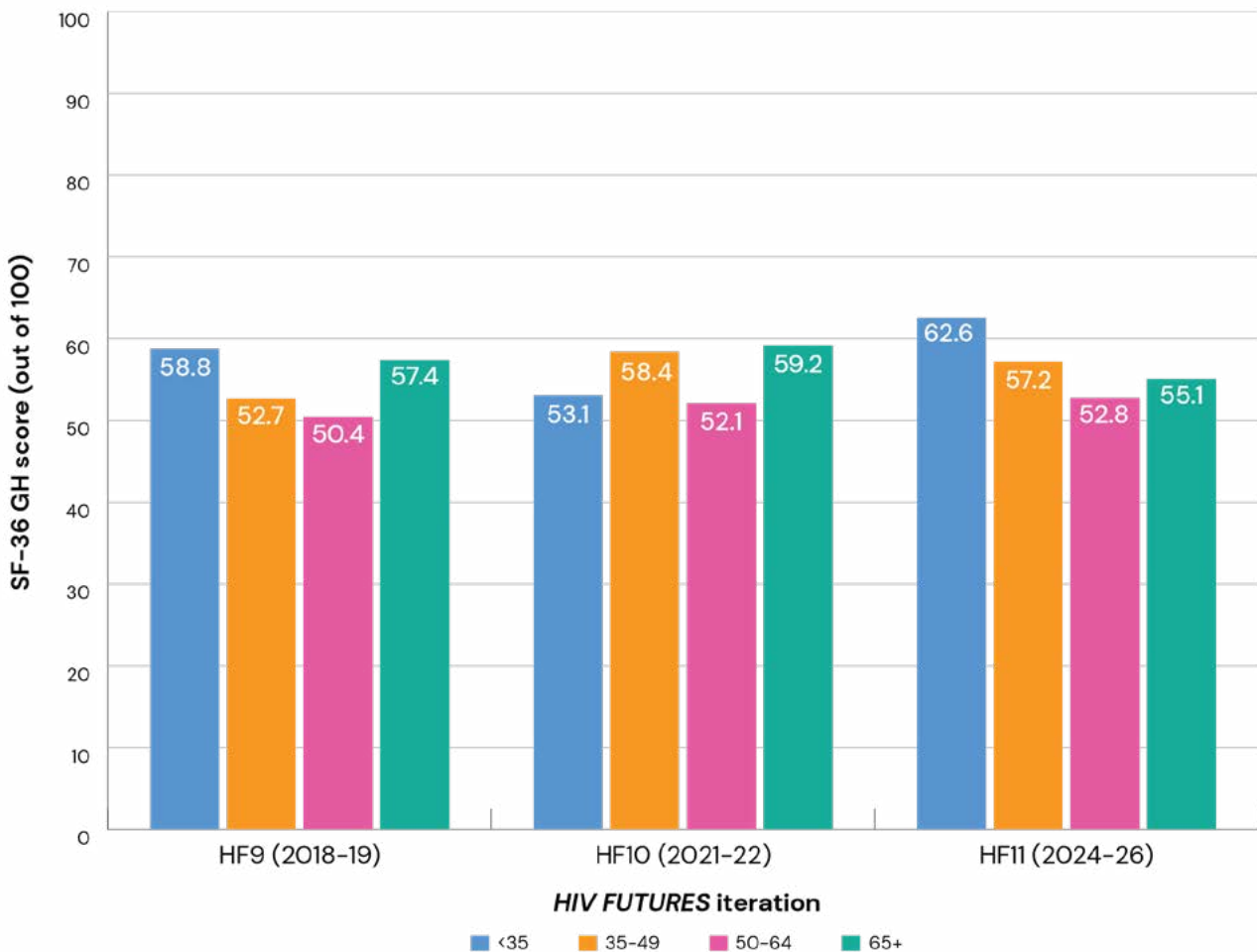
In *HIV FUTURES 11*, the average score for the SF-36 GH subscale was 55.0 out of 100, which is comparable with that of Australian population-based studies (Hawthorne et al., 2007).

When comparing general health scores across age groups in *HIV FUTURES 11* (Figure 21), scores were highest among participants aged under 35 years (62.6), followed by those aged 35–49 years (57.2), 65 years and over (55.1), and 50–64 years (52.8). Similar patterns were evident across recent *HIV FUTURES* waves, with participants aged 50–64 consistently reporting the lowest general health scores and those aged under 35 or 65 years and over generally reporting the highest scores.

Comparing across waves, trends differed somewhat by age group. Among participants aged under 35 years, mean scores declined from 58.8 in *HIV FUTURES 9* to 53.1 in *HIV FUTURES 10*, before increasing to 62.6 in *HIV FUTURES 11*. Scores among those aged 35–49 years increased from 52.7 in *HIV FUTURES 9* to 58.4 in *HIV FUTURES 10* and remained relatively high in *HIV FUTURES 11* (57.2). Among participants aged 50–64 years, scores were relatively stable across waves, ranging from 50.4 to 52.8. Similarly, scores among participants aged 65 years and over remained broadly consistent over time, ranging from 55.1 to 59.2.

“Been a long, complex and often changing journey since diagnosis forty years ago. Unanticipated longevity has been hard to cope with and plan for.”

Figure 21: Average SF-36 general health subscale scores, by age, *HIV FUTURES 9* (2018–19) to *HIV FUTURES 11* (2024–26)

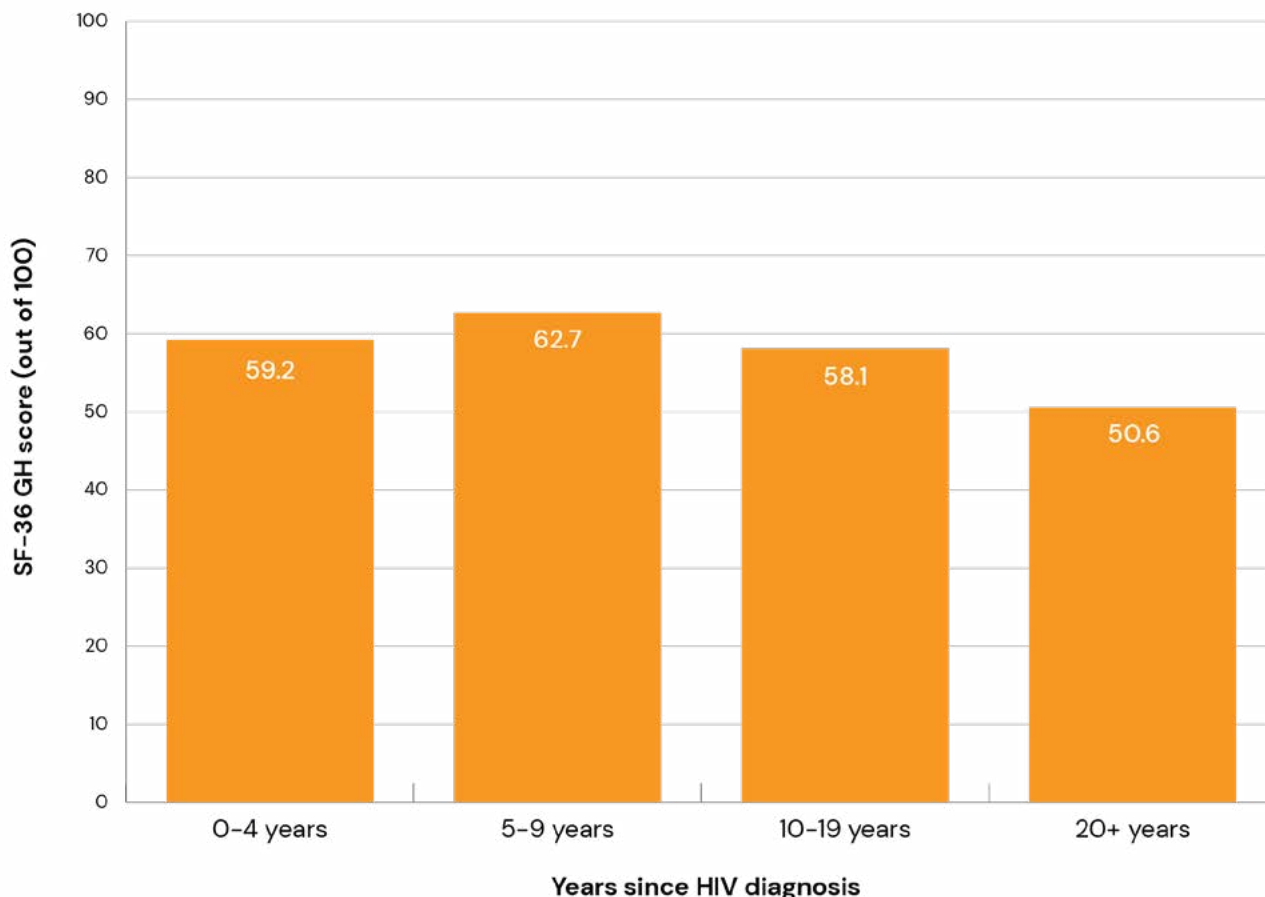


Note. HF = *HIV FUTURES*, SF-36 GH = short form 36 general health

Average general health scores varied by length of time since HIV diagnosis (Figure 22). Scores were highest among participants diagnosed 5–9 years ago (62.7), followed by those diagnosed 0–4 years

(59.2) and 10–19 years (58.1). Participants who had been living with HIV for 20 years or more reported the lowest average general health scores (50.6).

Figure 22: Average general health scores, by number of years since HIV diagnosis



Note: SF-36 GH = short form 36 general health

MENTAL HEALTH

Participants were asked whether they currently had, or had ever previously received, a diagnosis for a range of mental health conditions (Table 12). Overall, 45.5% of participants (n = 321) reported a current diagnosis of at least one mental health condition, while 60.5% (n = 427) reported either a current or previous diagnosis of at least one mental health condition.

Depression (23.7%, n = 167) and anxiety-related conditions (21.2%, n = 150) were the most commonly reported current mental health diagnoses. Among the specific anxiety-related conditions, 20.0% (n = 141) reported a current diagnosis of anxiety disorder, while smaller proportions reported social phobia (5.0%, n = 35), panic disorder (3.3%, n = 23), and agoraphobia (2.3%, n = 16). Post-traumatic stress disorder

(PTSD) was also relatively common, with 14.0% of participants (n = 99) reporting a current diagnosis.

Less commonly reported current diagnoses included bipolar disorder (3.3%, n = 23), obsessive compulsive disorder (2.5%, n = 18), borderline personality disorder (1.4%, n = 10), mania (<1%, n = 5), and schizophrenia (<1%, n = 5).

Lifetime prevalence estimates were higher across all conditions. More than one-third of participants (36.4%, n = 257) reported a lifetime diagnosis of depression, while 29.3% (n = 207) reported a lifetime diagnosis of any anxiety-related condition. Lifetime diagnoses of PTSD (17.1%, n = 121), bipolar disorder (4.7%, n = 33), obsessive compulsive disorder (3.5%, n = 25), borderline personality disorder (2.7%, n = 19), mania (1.7%, n = 12), and schizophrenia (1.3%, n = 9) were less common.

Table 12. Diagnosed mental health conditions

Mental health condition	Current diagnosis		Lifetime diagnosis	
	Frequency n	Percentage* %	Frequency n	Percentage* %
Depression	167	23.7	257	36.4
Any anxiety condition	150	21.2	207	29.3
Anxiety disorder	141	20	192	27.2
Panic disorder	23	3.3	38	5.4
Social phobia	35	5.0	50	7.1
Agoraphobia	16	2.3	23	3.3
Post-traumatic stress disorder	99	14.0	121	17.1
Bipolar disorder	23	3.3	33	4.7
Obsessive compulsive disorder	18	2.5	25	3.5
Borderline personality disorder	10	1.4	19	2.7
Mania	5	< 1	12	1.7
Schizophrenia	5	< 1	9	1.3
Other condition	40	5.7	50	7.1

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

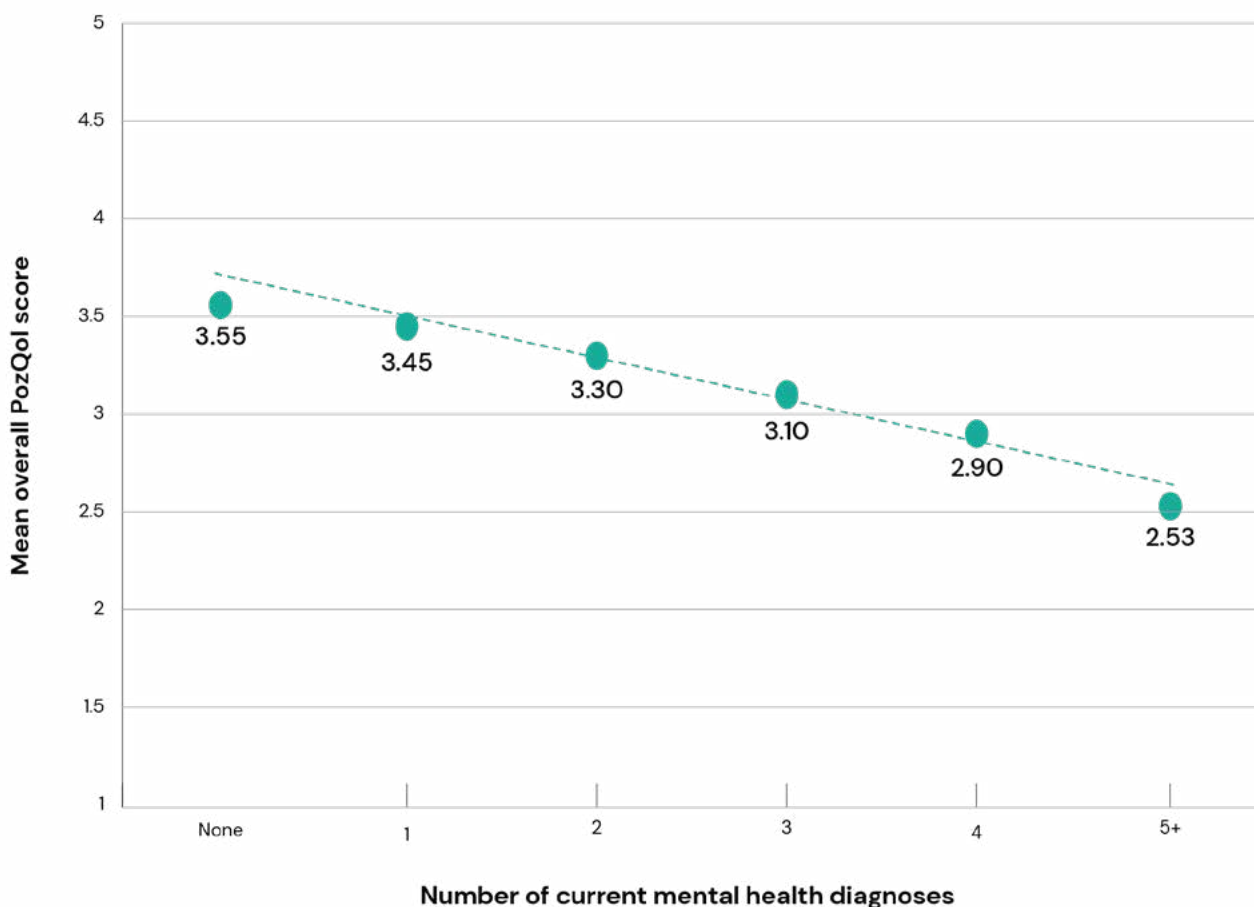
Rates of lifetime mental health diagnoses among *HIV FUTURES 11* participants were higher than those observed in the general Australian population. In the 2020–2022 National Study of Mental Health and Wellbeing, 42.9% of Australians aged 16–85 years reported experiencing a mental disorder at some point in their lifetime, compared with 60.5% of *HIV FUTURES 11* participants who reported a lifetime diagnosis of at least one mental health condition (ABS, 2023). Compared with previous *HIV FUTURES* waves, the prevalence of lifetime mental health diagnoses in *HIV FUTURES 11* was higher than observed in *HIV FUTURES 10* (2021–22; 49.0%), though slightly lower than *HIV FUTURES 9* (2018–19; 64.2%).

MULTIPLE MENTAL HEALTH DIAGNOSES

Of the total sample, 30.7% of participants (n = 217) reported two or more current mental health diagnoses. Among participants with any current mental health diagnosis (n = 321), more than two-thirds (67.6%, n = 217) reported multiple current diagnoses. The most common comorbidity was anxiety-related conditions occurring alongside depression: among participants reporting a current anxiety-related condition, 64.7% (n = 97) also reported current depression.

Beyond the pattern of comorbidity itself, mental health comorbidity was also strongly associated with poorer quality of life among *HIV FUTURES 11* participants. As shown in Figure 23, mean PozQoL scores decreased as the number of current mental health diagnoses increased: participants reporting no current mental health diagnoses had the highest average PozQoL scores, while those reporting five or more current diagnoses had the lowest. This pattern highlights the substantial impact of mental health comorbidity on HIV-related quality of life among PLHIV.

Figure 23: Mean overall PozQoL score by number of current mental health diagnoses



SYMPTOMS OF MENTAL DISTRESS

Participants were asked whether they had experienced symptoms of mental distress, regardless of whether they had received a clinical mental health diagnosis (Table 13). Symptoms of depression and anxiety were relatively common among *HIV FUTURES II* participants. Around one in five participants reported currently feeling depressed (19.3%, n = 136) or feeling anxious, nervous, or tense (18.4%, n = 130). Panic attacks

were less commonly reported, though 6.7% of participants (n = 47) indicated they were currently experiencing them.

Reports of previous (i.e., not current) symptoms were also common. One in five participants (20.8%, n = 147) reported previously experiencing feelings of depression, while 12.5% (n = 88) reported previously feeling anxious, nervous, or tense. Previous experiences of panic attacks were reported by 9.1% of participants (n = 64).

Table 13. Self-reported symptoms of mental distress

Symptom of mental distress	Current experience		Previous experience	
	Frequency n	Percentage %	Frequency n	Percentage %
Feeling depressed	136	19.3	147	20.8
Feeling anxious, nervous or tense	130	18.4	88	12.5
Panic attacks	47	6.7	64	9.1

TREATMENT FOR MENTAL HEALTH CONDITIONS

Among participants with a current mental health diagnosis, 65.7% (n = 209) reported taking prescription medication for a mental health condition in the previous 12 months, and 59.1% (n = 188) reported receiving non-pharmaceutical treatment, such as counselling or psychological support, in the same period. A smaller proportion of participants without a current mental health diagnosis also reported receiving mental health support: 5.0% (n = 14) reported taking medication, and 18.0% (n = 50) reported receiving non-pharmaceutical treatment.

STI TESTING AND DIAGNOSES

Participants were asked to indicate whether they had been tested for, or diagnosed with, any sexually transmissible infections (STIs) other than HIV in the past 12 months. Two-thirds of participants (66.2%; n = 174) had been tested for STIs at least once in the previous 6 months. Frequency of STI testing varied substantially by level of sexual activity (Table 14). Participants reporting multiple sexual partners were most likely to report frequent STI testing, with 69.0% (n = 165) indicating they had been tested more than once in the previous 12 months. In contrast, over half of participants reporting no sexual activity (54.0%, n = 116) reported no STI testing during this period. Participants with one sexual partner showed a more even distribution of testing frequency, with around one-third reporting no testing (35.1%, n = 40), testing once (30.7%, n = 35), or testing more than once (31.6%, n = 36).

Table 14. Testing for STIs in the last 12 months, by level of sexual activity in the last 6 months

STI testing	No sex n (%)	One sexual partner n (%)	Multiple sexual partners n (%)	Total n (%)
No STI testing	116 (54.0)	40 (35.1)	18 (7.5)	174 (30.6)
Tested once	45 (20.9)	35 (30.7)	55 (23.0)	135 (23.8)
Tested more than once	40 (18.6)	36 (31.6)	165 (69.0)	241 (42.4)
Unsure	14 (6.5)	3 (2.6)	1 (0.4)	18 (3.2)
Total	215	114	239	

Most participants reported not being diagnosed with an STI in the previous 12 months (81.9%, n = 668) (Table 15). Around one in ten participants reported being diagnosed with one STI in the previous 12 months (10.9%, n = 89), while smaller proportions

reported being diagnosed with two (3.9%, n = 32) or three STIs (2.9%, n = 24). Less than 1% of participants (n = 3) reported being diagnosed with four or more STIs in the previous 12 months.

Table 15. Number of sexual transmitted infections diagnosed in the last 12 months

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



MPOX

Mpox is a viral infectious disease that can be transmitted through close physical and intimate contact. Participants were asked whether they had ever been diagnosed with mpox. The large majority reported they had never been diagnosed with mpox (96.4%, n = 397), while 2.7% (n = 11) reported a previous diagnosis. A small proportion of participants (1.0%, n = 4) were unsure.

VIRAL HEPATITIS

Participants were asked whether they had ever been screened for or diagnosed with hepatitis C (HCV) and whether they had undergone recent HCV testing.

The majority of participants (84.6%, n = 506) reported that they had previously been tested or screened for HCV, while 6.9% (n = 41) reported they had never been tested and 8.5% (n = 51) were unsure. Among those who had previously been tested for HCV, around half (45.3%, n = 229) indicated they had been screened in the previous 12 months, while a similar proportion (45.0%, n = 227) had not received HCV testing during this period. Around one in ten (9.7%, n = 49) were unsure.

Overall, 10.9% of participants (n = 77) reported having previously tested positive for HCV antibodies, while 3.1% (n = 22) reported having been diagnosed with chronic hepatitis C infection. A further 4.7% (n = 33) were unsure of their hepatitis C status. As in previous *HIV FUTURES* surveys, the higher prevalence of HCV antibody positivity relative to chronic infection likely reflects participants who had spontaneously cleared the virus or successfully completed treatment.

OTHER COMORBIDITIES

Participants were asked whether they had ever been diagnosed with other major health conditions (Table 16). Multimorbidity was common among *HIV FUTURES 11* participants. Among participants, 76.1% reported at least one non-HIV health condition, while almost half (47.6%) reported two or more comorbidities. Around one-quarter of participants (23.9%) reported no major health conditions in addition to HIV.

“My physical health has a much greater effect on my life than HIV.”

The most commonly reported conditions were hypertension (29.0%, n = 164) and asthma (25.5%, n = 144). Cardiovascular disease (other than hypertension) was also relatively common, reported by 18.8% of participants (n = 106). Other frequently reported conditions included gastrointestinal disorders (14.9%, n = 84), osteoarthritis (14.3%, n = 81), diabetes (14.3%, n = 81), and cancer (14.2%, n = 80).

Smaller proportions of participants reported kidney disease (9.6%, n = 54), respiratory disease (9.2%, n = 52), osteoporosis (8.5%, n = 48), and autoimmune disease (6.9%, n = 39). Dementia or related cognitive disorders (1.2%, n = 7) and haemophilia (<1%, n = 3) were uncommon, while no participants reported Parkinson’s disease.

Participants selecting “other” (18.2%, n = 103) most commonly reported neuropathy, pneumonia, emphysema, sleep apnoea, and gout, as well as conditions captured elsewhere in the survey, including mental health and sexual health diagnoses.

Table 16. Health conditions other than HIV

Health condition	Frequency n	Percentage* %
No major health condition	138	24.4
Hypertension	164	29.0
Asthma	144	25.5
Cardiovascular disease	106	18.8
Gastrointestinal disorder	84	14.9
Cancer	80	14.2
Osteoarthritis	81	14.3
Diabetes	81	14.3
Osteoporosis	48	8.5
Respiratory disease	52	9.2
Kidney disease	54	9.6
Autoimmune disease	39	6.9
Dementia or related cognitive disorder	7	1.2
Haemophilia	3	<1
Parkinson's disease	0	0
Other	103	18.2

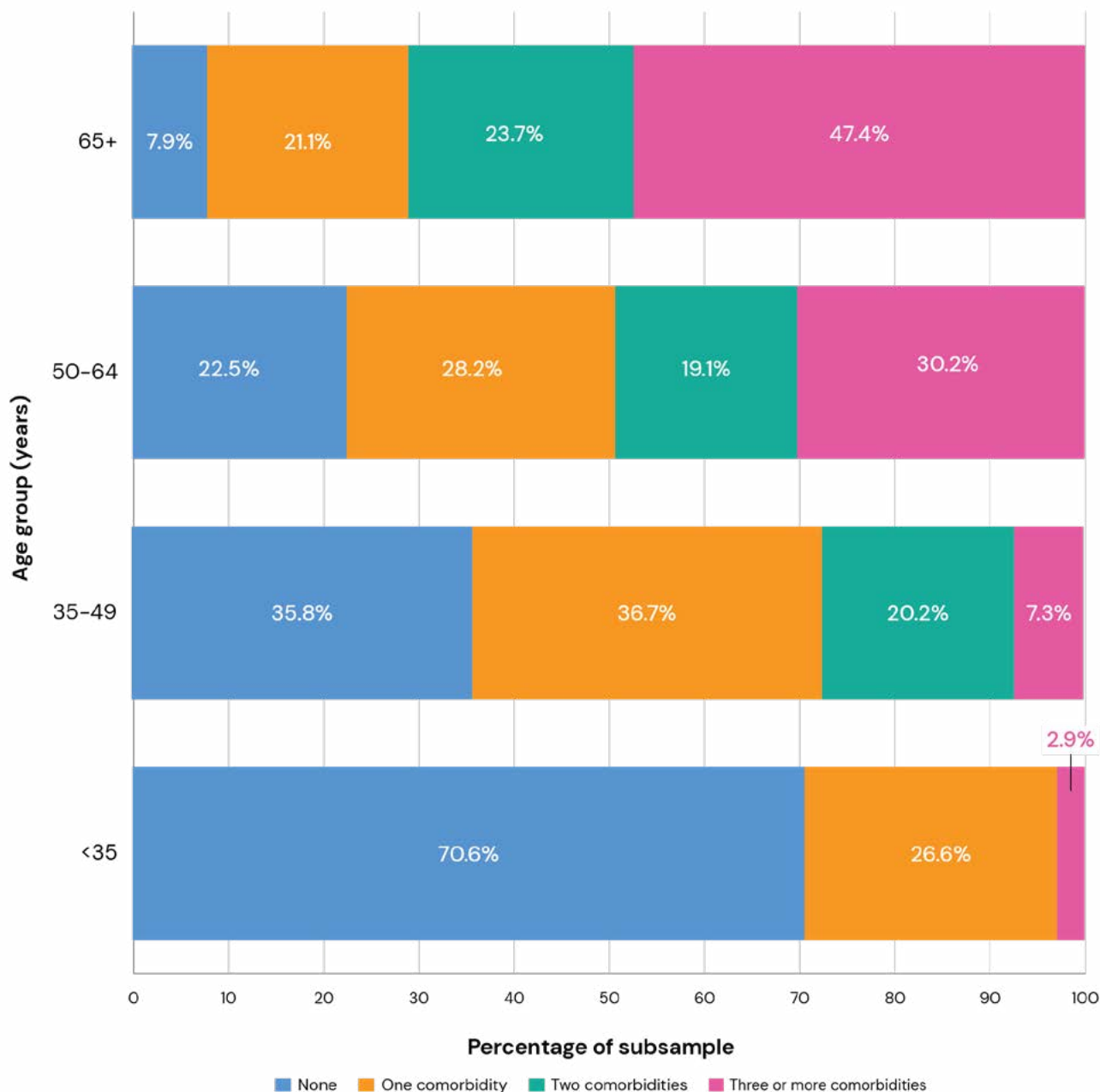
* Percentages are based on participants who responded to the comorbidity checklist (n = 565). Totals exceed 100% because some participants reported multiple comorbidities.



The burden of multimorbidity increased substantially with age among *HIV FUTURES 11* participants (Figure 24). Among participants aged under 35 years, the majority (70.6%, n = 24) reported no additional non-HIV health conditions, and only one participant reported three or more non-HIV health conditions. In contrast, almost half of participants aged 65 years and older (47.4%, n = 72) reported three or more non-HIV health conditions, while fewer than one in ten (7.9%, n = 12) reported none.

Participants aged 50–64 years also reported substantial multimorbidity, with 30.2% (n = 79) reporting three or more non-HIV health conditions. These findings highlight the increasing burden of chronic disease and multimorbidity among older PLHIV.

Figure 24: Number of chronic comorbidities (other than HIV), by age group



MEDICATION FOR OTHER HEALTH CONDITIONS

Participants were asked whether they were currently taking medication for major health conditions other than HIV or viral hepatitis (Table 17). Around one-third of participants (33.6%, n = 184) reported that they were not currently taking medication for any other health condition.

The most commonly reported conditions for which participants were taking medication were hypertension (28.7%, n = 157), cardiovascular disease (18.5%, n = 101), asthma (14.8%, n = 81), and diabetes

(13.0%, n = 71). Medications for gastrointestinal disorders were also relatively common, reported by 10.2% of participants (n = 56).

Smaller proportions of participants reported taking medication for osteoarthritis (7.5%, n = 41), respiratory disease (6.0%, n = 33), osteoporosis (5.1%, n = 28), kidney disease (4.0%, n = 22), and autoimmune disease (2.9%, n = 16). Few participants reported taking medication for cancer (1.1%, n = 6), dementia or related cognitive disorders (<1%, n = 3), haemophilia (<1%, n = 3), or Parkinson’s disease (<1%, n = 1).

Table 17. Comorbid conditions for which medication is taken

Condition	Frequency n	Percentage* %
No medication for other health conditions	184	33.6
Hypertension	157	28.7
Cardiovascular disease	101	18.5
Asthma	81	14.8
Diabetes	71	13.0
Gastrointestinal disorder	56	10.2
Osteoarthritis	41	7.5
Osteoporosis	28	5.1
Respiratory disease	33	6.0
Autoimmune disease	16	2.9
Kidney disease	22	4.0
Cancer	6	1.1
Dementia or related cognitive disorder	3	< 1
Haemophilia	3	< 1
Parkinson's disease	1	< 1
Other	94	17.2

* Percentages are based on participants who responded to the medication checklist (n = 547). Totals exceed 100% because some participants reported medications for multiple conditions.

PREVENTATIVE AND METABOLIC HEALTH MEDICATIONS

Participants were asked whether they currently took statin medications to reduce cholesterol, and whether they used medications intended to support weight reduction, such as semaglutide (Ozempic/Wegovy), liraglutide (Saxenda), or tirzepatide (Mounjaro).

Almost half of participants (49.0%, n = 291) reported currently taking a statin medication, while a similar proportion (49.3%, n = 293) reported that they were not. A small number of participants (1.7%, n = 10) were unsure.

Use of weight-reduction medications was less common. Approximately one in ten participants (10.5%, n = 62) reported currently taking these medications to support weight reduction, while 88.6% (n = 522) reported they were not. A small proportion of participants (0.8%, n = 5) were unsure.

VACCINATION UPTAKE

Participants were asked about vaccination against seasonal influenza, COVID-19, mpox, and human papillomavirus (HPV).

Approximately four-fifths of participants (80.7%, n = 480) reported receiving the current seasonal influenza vaccine. Fewer than one in five participants (18.5%, n = 110) reported they had not received the vaccine.

COVID-19 vaccination uptake was also high. Of responding participants, 83.8% (n = 496) reported being fully vaccinated and a further 10.5% (n = 62) reported being partially vaccinated. Only 3.4% of participants (n = 20) reported that they did not intend to receive COVID-19 vaccination.

Vaccination uptake for mpox was lower. Approximately half of the sample (50.2%, n = 293) reported being fully vaccinated against mpox, while 3.4% (n = 20) reported partial vaccination. A further 10.3% (n = 60) indicated they intended

to be vaccinated. However, over one-quarter of participants (26.4%, n = 154) reported that they did not intend to receive mpox vaccination.

HPV vaccination uptake was comparatively low and characterised by substantial uncertainty. Among participants who responded to the HPV vaccination question (n = 575), 24.0% (n = 138) reported being fully vaccinated and 2.8% (n = 16) reported partial vaccination. Over one-third of participants (37.7%, n = 217) were unsure of their HPV vaccination status, while 22.1% (n = 127) reported they did not intend to receive HPV vaccination.

HIV-ASSOCIATED NEUROCOGNITIVE DISORDER (HAND)

Participants were asked whether they had ever been diagnosed with HIV-associated neurocognitive disorder (HAND), and whether they currently had a diagnosis of HAND. Previous studies have shown that HAND affects around one in five PLHIV in Australia (Carroll & Brew, 2017).

Among participants who responded to the question (n = 595), 6.6% reported having ever received a diagnosis of HAND. This included 1.2% (n = 7) who reported a diagnosis within the past two years and 5.4% (n = 32) who reported a diagnosis more than two years ago. The majority of participants (93.4%, n = 556) reported no previous diagnosis of HAND.

Participants who indicated they had previously been diagnosed with HAND were then asked whether they currently had a diagnosis of HAND. Among these participants (n = 37), 59.5% (n = 22) reported a current diagnosis, while 40.5% (n = 15) reported they did not currently have HAND.



6. ALCOHOL, TOBACCO AND OTHER DRUG USE

Alcohol, tobacco, and other drug use among PLHIV occurs within broader social, cultural, and structural contexts, including patterns of social connection, stigma, pleasure, and community participation. Previous Australian research has consistently found higher rates of tobacco, alcohol, and illicit or non-prescribed drug use among some communities of gay and bisexual men compared to the general population, including among gay and bisexual men living with HIV (Hammoud et al., 2017; Lea, 2016; Takeuchi et al., 2024). More recent work has identified distinct profiles of alcohol and other drug-related risk within LGBTQ communities, highlighting differences by gender, sexual orientation, and age rather than a single uniform pattern of use (Hill et al., 2023; Norman et al., 2024). However, there remains comparatively limited Australian research examining alcohol and other drug use among women, heterosexual men, and trans and gender diverse PLHIV, consistent with broader national data limitations on alcohol and other drug-related harms among LGBTIQ+ populations (AIHW, 2024).

The health impacts of tobacco smoking, high alcohol consumption, and some forms of recreational drug use are well established. At the same time, alcohol and other drug use can also play important social, relational, or community functions, contributing to

sociability, pleasure, intimacy, and connectedness (Power et al., 2018; Weatherburn et al., 2017). A narrow focus on “risk” or “harm” can obscure these broader social contexts and contribute to stigma experienced by people who use alcohol or other drugs.

TOBACCO USE

Over half of participants (59.2%, n = 352) reported having smoked tobacco regularly at some point in their life. Current tobacco smoking was reported by 21.7% of participants overall, including 15.3% (n = 91) who reported smoking daily and 6.4% (n = 38) who reported smoking less than daily. Over one-third of participants (37.5%, n = 223) indicated that they had previously smoked tobacco regularly but did not currently smoke.

While smoking prevalence among *HIV FUTURES* participants remained higher than estimates for

the Australian population overall, rates of smoking among PLHIV have declined substantially over time (Figure 25). In 2000, 55% of *HIV FUTURES* participants reported current smoking, compared with 22% of the Australian population. In *HIV FUTURES 11*, the proportion of participants who reported current daily smoking had fallen to 15.3%, compared with 10.6% in the Australian population (noting that the latest national estimate is from 2022). Despite these substantial declines, smoking prevalence among *HIV FUTURES* participants remains higher than Australian population estimates.

Figure 25: Daily tobacco smoking rates over time, comparing *HIV FUTURES* participants with Australian daily smoking rates*

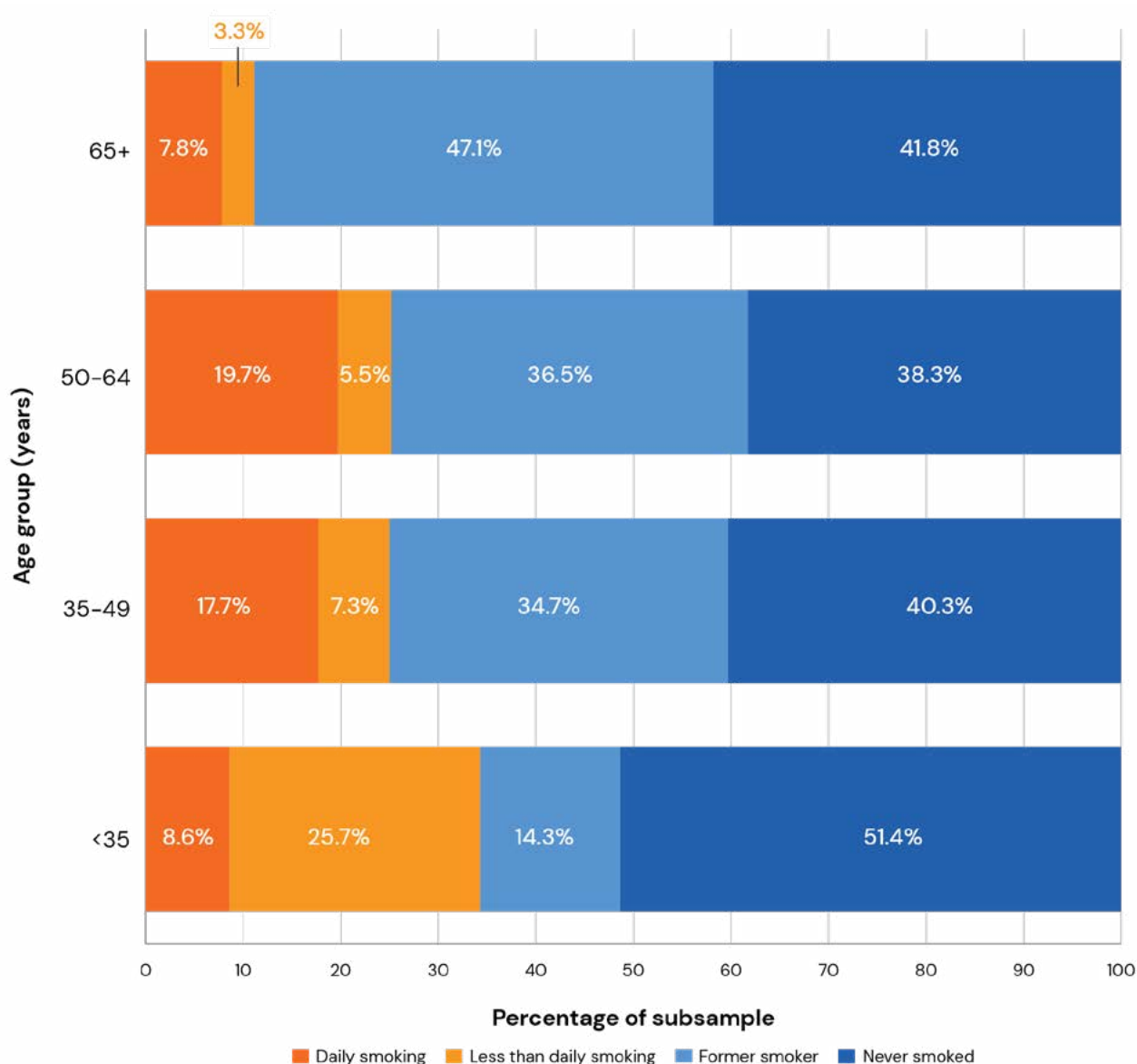


* Smoking rates for the Australian population have been derived from ABS reporting, but should be considered approximate, as the time periods reported on differ slightly from those of *HIV FUTURES* reports (ABS, 2023). Most recent ABS data point is 2022. Does not include other forms of nicotine use (e.g., vaping).

Smoking patterns differed substantially by age (Figure 26). Participants aged under 35 years reported the lowest prevalence of daily smoking (8.6%) and the highest prevalence of never smoking (51.4%). However, younger participants were more likely to report less-than-daily smoking (25.7%)

compared with older age groups. In contrast, former smoking was increasingly common among older participants, particularly those aged 65 years and older (47.1%).

Figure 26: Tobacco smoking rates, by age group



VAPING AND/OR E-CIGARETTE USE

Participants in *HIV FUTURES 11* were asked if they had used a vape or e-cigarette in the last month. Of the total sample, 11.4% (n = 68) indicated that they had used one of these devices.

ALCOHOL USE

We asked participants about their alcohol consumption using the AUDIT-C scale, a brief screening tool that measures patterns of alcohol use, including drinking frequency and quantity. While AUDIT-C responses are commonly combined into a total score indicating potential risk of alcohol-related harm (Royal Australian College of General Practitioners, 2016), in this report we present responses to individual items separately. This approach provides a more detailed picture

of patterns of alcohol consumption among PLHIV, including differences in drinking frequency and intensity across the sample.

Most *HIV FUTURES 11* participants reported consuming alcohol in the previous 12 months, while one in five (20.3%, n = 121) reporting that they never drink. This is broadly comparable to the general Australian population, where 69% of people aged 14 and over reported consuming alcohol in the previous 12 months (AIHW, 2024). Of those asked about their typical daily consumption, the majority did so moderately, with 59.3% (n = 235) reporting they typically consumed no more than two standard drinks per day. A further 24.5% (n = 97) consumed 3–4 drinks on a typical day, and 16.2% (n = 64) reported consuming five or more drinks on a typical occasion.

Participants were also asked how often they consumed six or more drinks on a single occasion, as

an indicator of episodic heavy drinking. Just over half (54.1%, n = 318) reported never doing so. Of those who did, 24.0% (n = 141) did so less than monthly, 8.5% (n = 50) monthly, and 13.4% (n = 79) at least weekly.

USE OF NON-PRESCRIBED PHARMACEUTICALS AND/OR ILLICIT DRUGS

Participants were asked whether they had used any non-prescribed or recreational drugs, excluding alcohol and tobacco, in the previous 12 months with 41.4% (n = 244) reporting recent illicit or non-prescribed drug use, while 58.6% (n = 345) reported no recent drug use.

Participants were then asked about their use of specific recreational drugs (used for non-medical purposes) in the past 12 months. Cannabis was the

most commonly used illicit drug, with 15.1% reporting at least weekly use and 36.3% reporting any use in the past 12 months. Tranquilisers or sleeping pills were also relatively common, with 10.8% reporting at least weekly use and 30.8% reporting any use. Amyl nitrite (poppers) were used at least weekly by 9.1% of participants, with nearly four in ten (39.8%) reporting any use. Opioid painkillers were used by 15.4% of participants, with 4.7% reporting at least weekly use. Crystal methamphetamine was used by 20.0% of participants, with 3.3% reporting at least weekly use. Other drugs including cocaine, MDMA, GHB, hallucinogens, and ketamine were each used by between 9.1% and 16.4% of participants in the past 12 months. Heroin, other inhalants, and synthetic cannabis were rarely reported, with over 95% of participants reporting no use of these substances in the past 12 months.

Table 18. Frequency of drug use for recreational purposes, in the past 12 months

Type of drug	At least weekly %	Once per month %	Occasionally %	Not in past 12 months %
Cannabis	15.1	4.1	17.0	63.7
Tranquilisers/sleeping pills	10.8	5.8	13.9	69.4
Amyl nitrite (poppers)	9.1	8.2	22.6	60.2
Opioids/painkillers (e.g., morphine, codeine)	4.7	<1	10.1	84.6
Crystal methamphetamine	3.3	4.0	12.8	80.0
MDMA/ecstasy	<1	1.0	15.5	83.6
Cocaine	<1	<1	12.9	86.1
Hallucinogens	<1	<1	10.3	88.8
GHB	<1	2.2	10.3	87.0
Ketamine	0	1.0	8.0	90.9
Other meth/amphetamine (e.g., speed)	<1	<1	4.6	94.5
Steroids	<1	0	2.4	95.9
Synthetic cannabis	1.4	<1	3.0	95.2
Heroin	<1	<1	<1	99.1
Other inhalants	<1	<1	1.0	98.5

Note: "At least weekly" combines "once a week or more" and "every day" response options. "Once per month" corresponds to the "about once a month" response option. "Occasionally" combines "once or twice a year" and "every few months" response options. Valid percentages are reported

INJECTING DRUG USE

Participants were asked whether they had ever injected drugs for recreational (non-prescribed) use. Around one-third of participants (33.6%, n = 196) reported having injected drugs at some point in their lives, including 10.8% (n = 63) who reported injecting in the past 12 months and 20.6% (n = 120) who reported previous injecting drug use but not within the past year. A small number of participants (2.2%, n = 13) preferred not to answer.

Among participants who reported injecting drugs in the past 12 months, crystal methamphetamine was by far the most commonly injected substance (95.2%, n = 60). Smaller numbers of participants reported injecting other methamphetamine or amphetamine-type substances (6.3%, n = 4), heroin (4.8%, n = 3), opioids or painkillers other than heroin (1.6%, n = 1), or other drugs (6.3%, n = 4).

SEXUALISED DRUG USE

Sexualised drug use refers to the use of drugs before or during sex to influence sexual experiences, including pleasure, intimacy, confidence, sociability, or endurance. Patterns vary substantially across communities and contexts, and may involve a wide range of substances and practices. While some people describe sexualised drug use as enhancing intimacy, pleasure, or social connection, for others it may be associated with increased vulnerability to physical, sexual, or emotional harm.

Participants who reported using non-prescribed or illicit drugs in the past 12 months were asked how often they had used drugs for sex in the previous six months. Just over half (51.2%, n = 123) reported never having done so, while the remainder reported some level of recent sexualised drug use: almost one-third (31.3%, n = 75) reported doing so once or twice, 14.2% (n = 34) at least monthly, and a smaller proportion (3.3%, n = 8) every week.

Overall, almost half (48.8%) of participants reporting recent illicit or non-prescribed drug use indicated some level of recent sexualised drug use.



7. STIGMA, DISCRIMINATION, AND DISCLOSURE

Although major advances in HIV treatment and prevention — including widespread availability of antiretroviral therapy and growing awareness of Undetectable = Untransmittable (U=U) — have transformed the experiences of many PLHIV, stigma and discrimination continue to shape everyday life for many members of the HIV community. Biomedical progress has not eliminated stigma: even where HIV is well managed clinically, experiences or anticipation of stigma remain a significant challenge. HIV-related stigma can affect social relationships, emotional wellbeing, healthcare experiences, employment, housing security, and community participation, and increasingly plays out in online and digital spaces as well as interpersonal and institutional settings. In recognition of this ongoing burden, recent national and state HIV strategies have set explicit targets for reducing stigma and discrimination experienced by PLHIV.

“More awareness that HIV is no longer a death sentence. More awareness that undetectable equals no transmission. More efforts need to be made to get rid of the stigma that comes with HIV. The general public hears nothing about this.”

This pattern is well evidenced: previous Australian and international research has consistently demonstrated strong associations between HIV-

related stigma and poorer mental health, social isolation, reduced quality of life, and barriers to accessing support and healthcare (Mendonca, et al., 2022). Anticipated stigma, concerns about disclosure, and experiences of discrimination can also shape how people engage socially, access services, and navigate intimate relationships. While many PLHIV report supportive personal and clinical relationships, stigma remains an important social determinant of health and wellbeing.

“More education, less stigma”

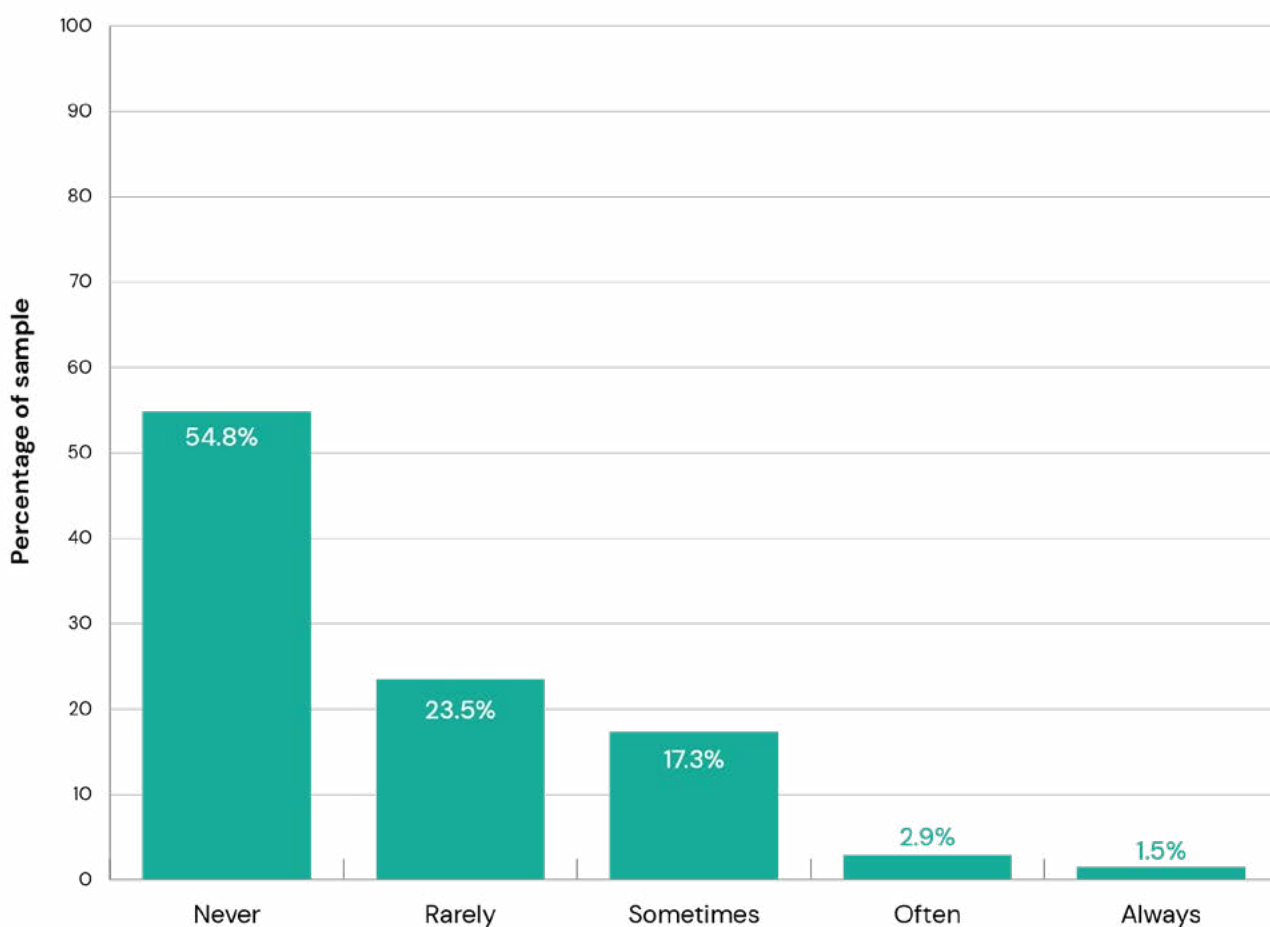
EXPERIENCES OF STIGMA OR DISCRIMINATION

Participants were asked to describe the extent to which they had experienced stigma or discrimination related to their HIV in the past 12 months (Figure 27). Experiences of HIV-related stigma and discrimination remained common among *HIV FUTURES 11* participants. While just over half of participants (54.8%, n = 322) reported that they had not experienced any stigma or discrimination related to their HIV status in the previous 12 months, almost half reported at least some experience of stigma/discrimination during this period.

"I find a lot less fear and stigma compared to 30 years ago."

Around one-quarter of participants (23.5%, n = 138) reported rarely experiencing HIV-related stigma or discrimination, while 17.3% (n = 102) reported experiencing stigma sometimes. A smaller proportion of participants reported experiencing stigma frequently ('often' 2.9%, n = 17; 'always' 1.5%, n = 9).

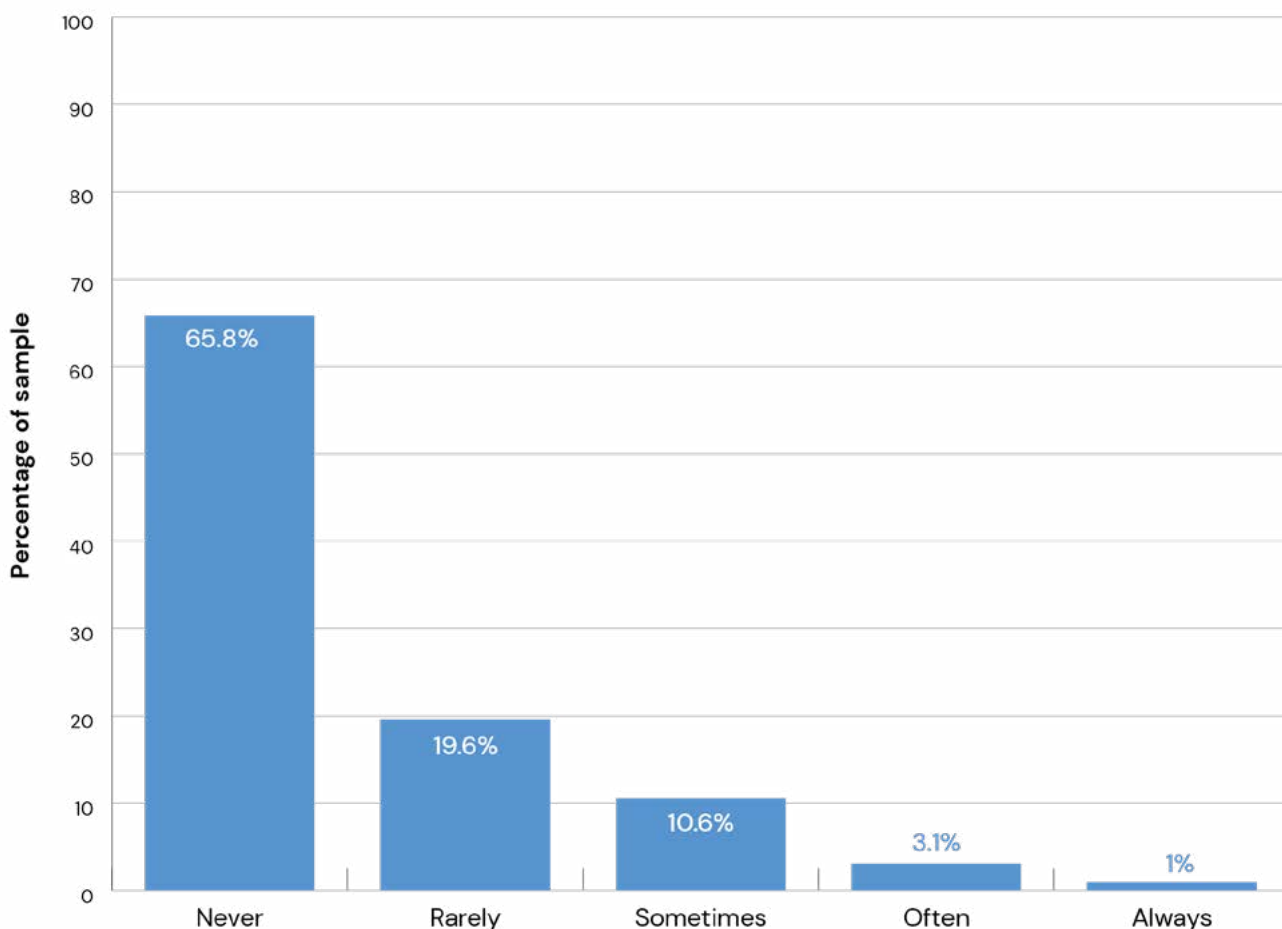
Figure 27: Experience of stigma or discrimination in relation to HIV status (in the last 12 months)



Most participants (65.8%, n = 386) reported that they had not been treated negatively or differently by health workers because of their HIV status in the previous 12 months (Figure 28). However, around one-third of participants reported at least some experience of HIV-related stigma within healthcare settings. Almost one in five participants (19.6%, n = 115) reported rarely experiencing negative treatment

from health workers because of their HIV status, while 10.6% (n = 62) reported such experiences sometimes. Smaller proportions reported experiencing this often (3.1%, n = 18) or always (1.0%, n = 6).

Figure 28: Percentage of participants treated negatively or differently by healthcare workers because of their HIV status (in the last 12 months)

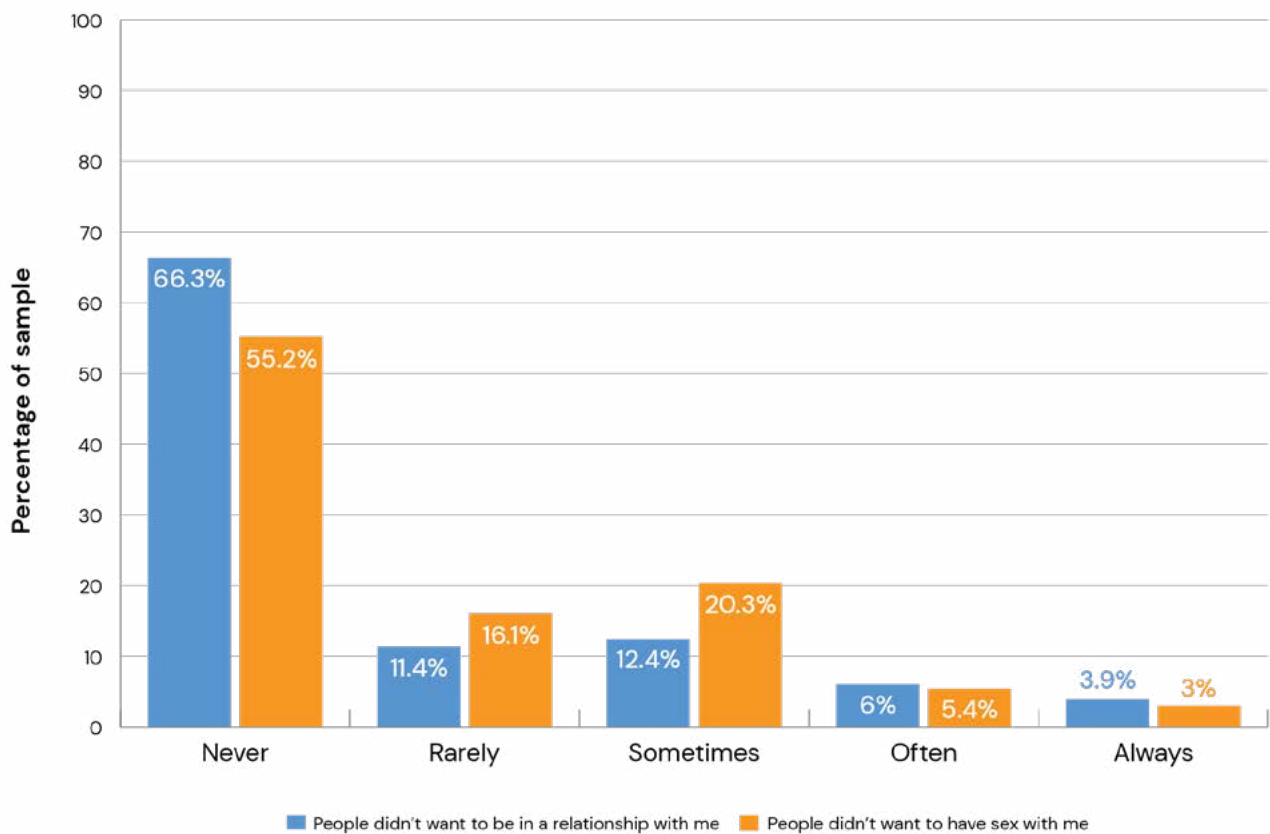


Participants were asked how often in the past 12 months they had experienced someone not wanting to have a relationship with them because of their HIV status (Figure 29). Most participants (66.3%) reported no experience of this. Among the remainder, around one-third reported experiencing this at least occasionally: 11.4% rarely, 12.4% sometimes, 6.0% often, and 3.9% always. Taken together, approximately 22.4% reported experiencing this form of relationship-related stigma sometimes or more often.

Participants were also asked how often a potential partner had not wanted to have sex with them because of their HIV status in the past 12 months. Almost half of participants (44.8%) reported that someone had rarely, sometimes, often, or always not wanted to have sex with them because of their HIV status. One in five (20.3%) experienced this sometimes, while 8.4% reported it often or always. This was more common than relationship rejection (33.7%).

“Living with HIV is like being in the closet again. Lonely. Ashamed. Different. Judged. Misunderstood.”

Figure 29: Participants reporting that people didn't want to have a relationship with them because of their HIV (in the last 12 months)



“My HIV status never bothers me, or those who have found out”

Participants were asked how often, in the last 12 months, they had experienced less favourable treatment because of their HIV status across a range of settings (Table 19). Experiences of discrimination varied across domains, with reports generally highest in health services and insurance

settings. Around one in four participants who had accessed health services reported at least some experience of discrimination, including 9.0% who experienced discrimination sometimes, 2.5% often, and 0.5% always. Insurance-related discrimination was also relatively common, with 6.5% reporting this sometimes, 4.0% often, and 2.5% always. Reports of discrimination were less common in employment/work and accommodation settings, where most participants reported never experiencing less favourable treatment because of their HIV status.

Table 19. Experiences of discrimination due to HIV status (in the last 12 months)*

Area of discrimination	Never n (%)	Rarely n (%)	Sometimes n (%)	Often n (%)	Always n (%)
Accommodation	412 (90.0)	19 (4.1)	18 (3.9)	5 (1.1)	4 (0.9)
Health services	414 (74.7)	73 (13.2)	50 (9.0)	14 (2.5)	3 (0.5)
Employment/work	356 (86.0)	21 (5.1)	25 (6.0)	6 (1.4)	6 (1.4)
Insurance	320 (80.2)	27 (6.8)	26 (6.5)	16 (4.0)	10 (2.5)

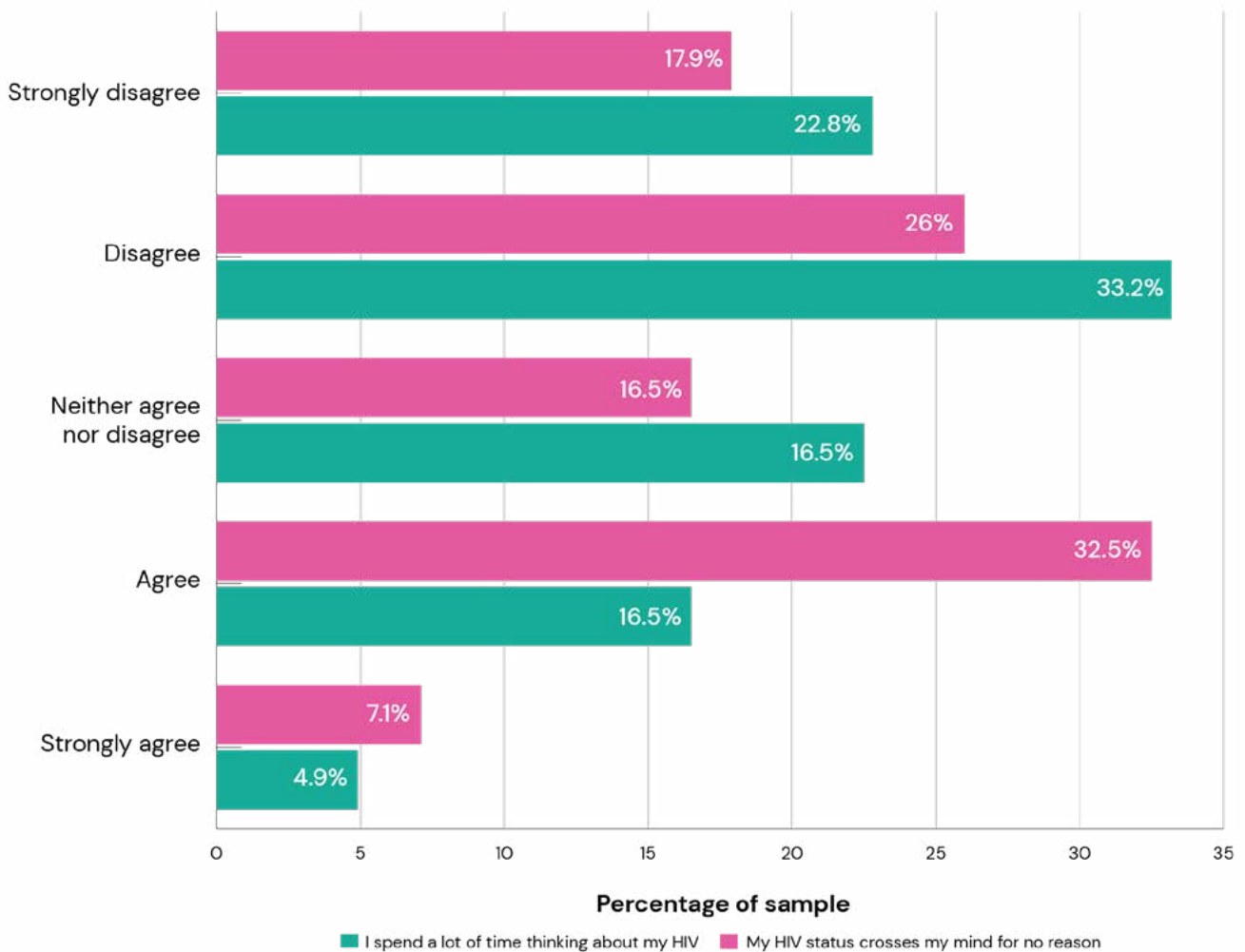
*Note that participants responding with 'not applicable' have been excluded, so these figures show the percentage of those who accessed each of these services

EMOTIONAL IMPACT OF HIV

Participants were asked about the extent to which HIV occupied their thoughts in everyday life (Figure 30). Responses to the statement “My HIV status often crosses my mind for no reason” were relatively mixed. Around two-fifths of participants agreed or strongly agreed with the statement (39.6%, n = 233), including 191 (32.5%) who agreed and 42 (7.1%) who strongly agreed. Similarly, just under half disagreed or strongly disagreed (43.9%, n = 258), while 97 participants (16.5%) neither agreed nor disagreed.

Participants were less likely to agree that they “spend a lot of time thinking about [their] HIV”. Around one-fifth agreed or strongly agreed with this statement (21.4%, n = 126), including 97 (16.5%) who agreed and 29 (4.9%) who strongly agreed. In contrast, more than half disagreed or strongly disagreed (56.0%, n = 329), while 132 participants (22.5%) neither agreed nor disagreed. Together, these findings suggest that, while HIV may intermittently enter participants’ thoughts in everyday life, fewer participants described themselves as spending substantial time thinking about it.

Figure 30: Responses to statements about extent to which HIV occupies thoughts



DISCLOSURE OF HIV STATUS

Participants were asked about the extent to which they were open about their HIV status in their day-to-day lives (Table 20). Overall, levels of disclosure varied considerably across the sample, reflecting a wide range of experiences and approaches to managing HIV visibility. Around one-quarter of participants reported that almost nobody knows about their HIV status (25.9%, n = 150), while a further

169 participants (29.1%) indicated that, most of the time, people around them are not aware of their HIV.

“I keep my HIV status a secret. People do not understand.”

In contrast, around one in seven participants reported that most of the time people around them know about their HIV status (15.3%, n = 89), while 75 participants (12.9%) indicated that just about

everybody knows about their HIV status. A further 97 participants (16.7%) reported that disclosure was more mixed, with about half the time people around them not being aware of their HIV status.

Table 20. Openness around HIV status

Statement about disclosure of HIV status	Frequency n	Percentage %
'Almost nobody knows about my HIV'	150	25.9
'Most of the time, people around me are not aware of my HIV'	169	29.1
'About half the time, people around me are not aware of my HIV'	97	16.7
'Most of the time, people around me know about my HIV'	89	15.3
'Just about everybody knows about my HIV'	75	12.9

"In the years since I was diagnosed, not much has changed. I didn't tell many people because it seemed so irrelevant. Not many of my friends are poz and we rarely talk about HIV. It's a non-event really."

Participants reported varied views regarding HIV status disclosure and knowledge of partners' HIV status in sexual relationships (Figure 31; percentages exclude participants selecting "not applicable to me"). Around one-third agreed or strongly agreed

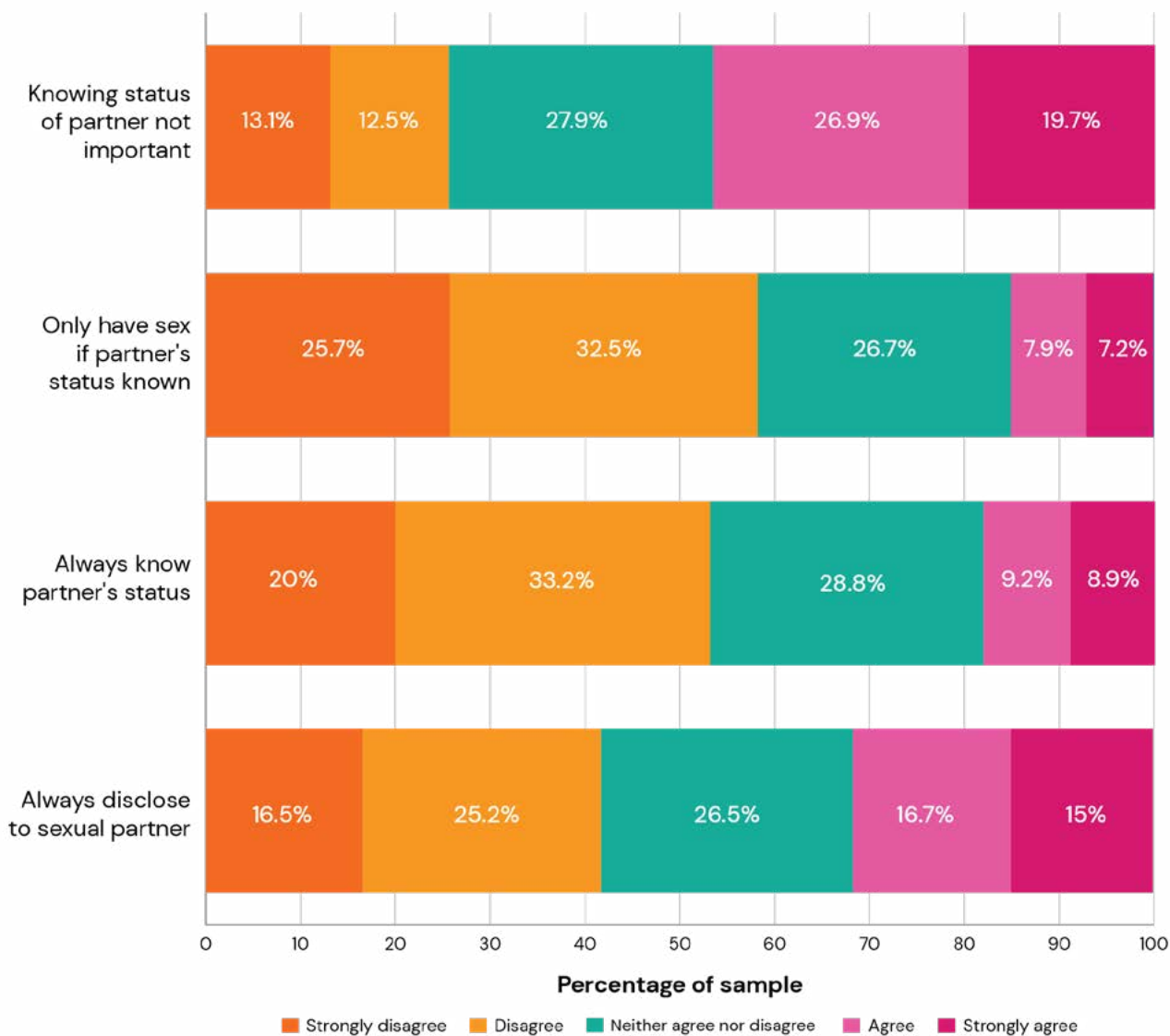
that they always told their sex partner(s) their HIV status before sex (31.7%), while 41.7% disagreed or strongly disagreed with this statement.

Almost one-fifth (18.1%) agreed or strongly agreed that they always knew their sex partners' HIV status before sex, compared with 53.2% who disagreed or strongly disagreed. Around one in seven participants agreed or strongly agreed that they only had sex with someone whose HIV status they knew (15.1%), while 58.2% disagreed or strongly disagreed.

Almost half the sample agreed or strongly agreed that knowing the HIV status of their sexual partners was not important (46.6%), compared with 25.6% who disagreed or strongly disagreed.



Figure 31: Disclosure practices and attitudes



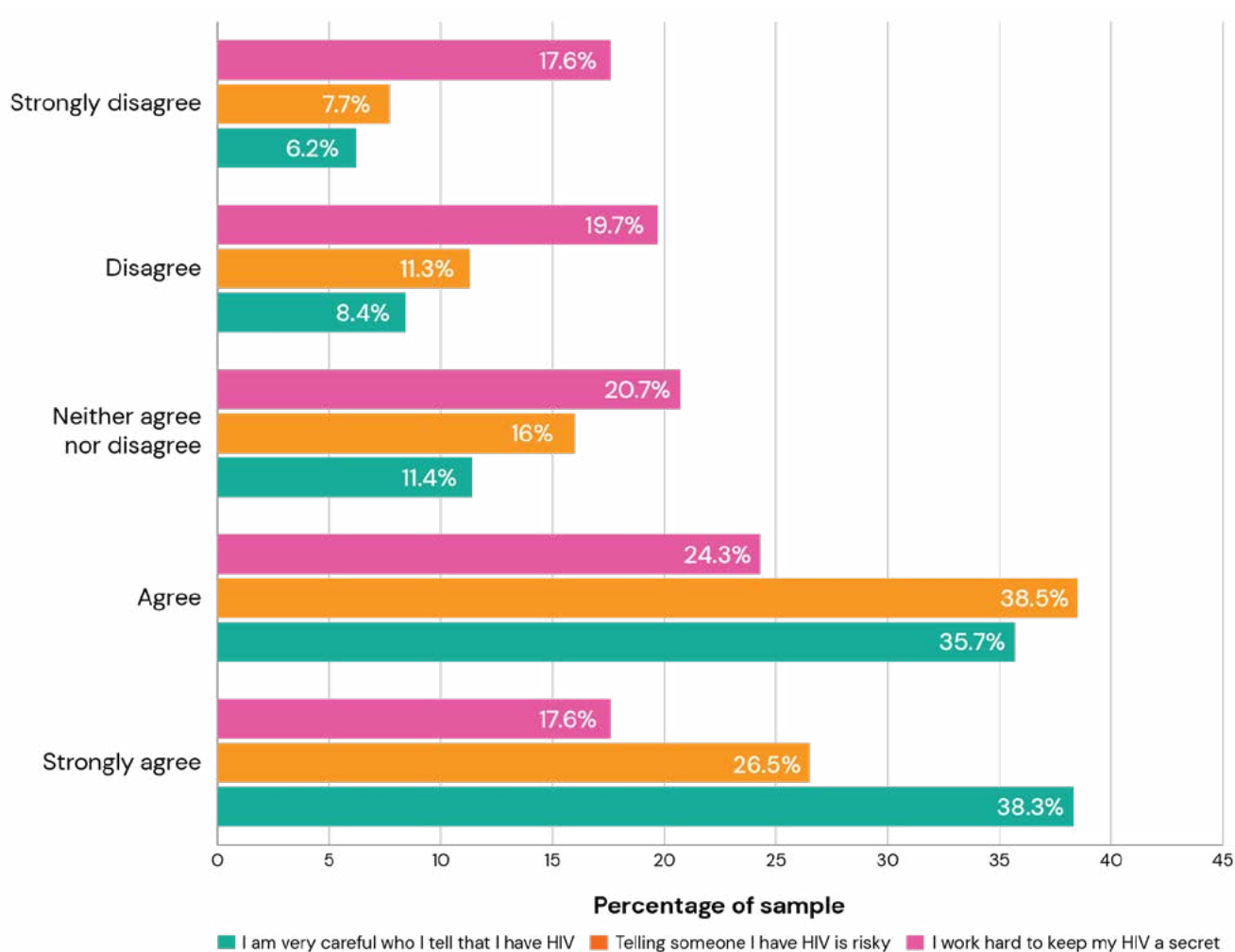
Note: ‘Not applicable’ responses removed. Full item wording: “I always tell my sex partner(s) what my HIV status is before we have sex”; “I always know my sex partners HIV status before sex”; “I only have sex with someone whose HIV status I know”; and “Knowing the HIV status of my sexual partners is not important”. Percentages exclude participants selecting “Not applicable to me”.

Participants in *HIV FUTURES II* were asked about concerns about disclosure, and perceived risks associated with telling others about their HIV status (Figure 32). Most participants agreed or strongly agreed that they were very careful who they told about their HIV status (74.0%; n = 429), while 65.0% (n = 378) agreed or strongly agreed that telling someone they had HIV was risky. Responses relating to keeping HIV status private were more mixed, although 41.9% (n = 245) agreed or strongly agreed that they worked hard to keep their HIV a secret. Together, these findings suggest that concerns about disclosure and anticipated stigma remain highly prevalent, even where complete non-disclosure is less common. The stronger

endorsement of cautious disclosure relative to secrecy may indicate that many PLHIV engage in selective and strategic disclosure management in response to perceived interpersonal or social risks associated with HIV disclosure.

“Living in a small community, being outed can be devastating.”

Figure 32: HIV disclosure attitudes and perceived disclosure risk



KNOWLEDGE AND PERCEIVED IMPACT OF HIV-RELATED LAWS

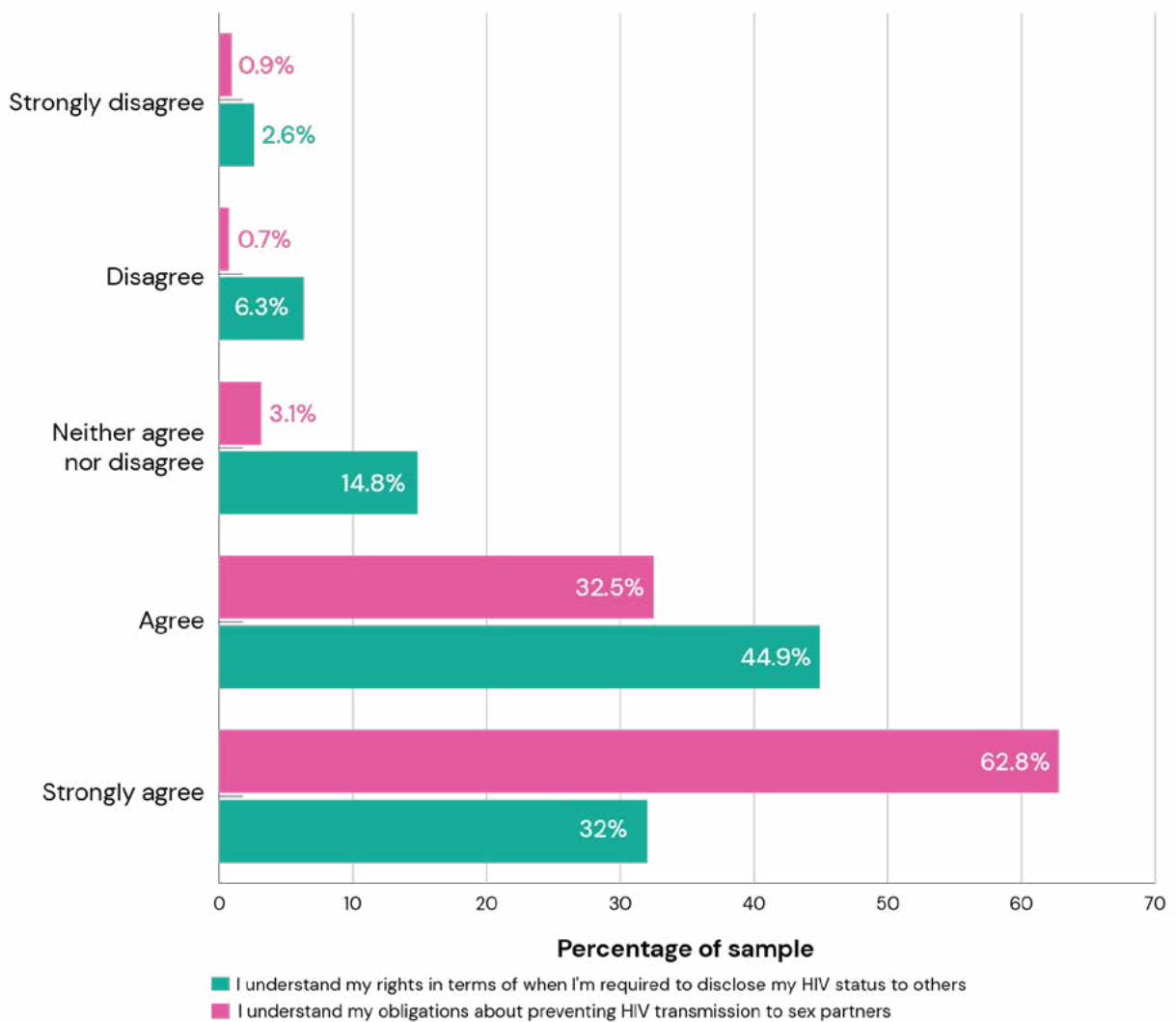
HIV-related legal frameworks form part of the broader context in which PLHIV navigate disclosure, sex, and relationships. In this section we examine levels of legal knowledge, and perceptions of how these laws relate to disclosure, stigma, sexual behaviour, and sexual wellbeing. Newly introduced questions surveyed participants about their confidence in knowing their obligations and rights regarding disclosure and sex, and about their perceptions of the impact of HIV-related laws on sexual behaviour and enjoyment.

“Having the legal right to not disclose my HIV status to sexual and/or romantic partners, so long as I maintain undetectable status, has contributed significantly to my quality of life.”

Participants generally reported high levels of understanding regarding HIV-related prevention and disclosure obligations (Figure 33). Almost all participants agreed or strongly agreed that they understood their obligations about preventing HIV transmission to sex partners (95.3%; n = 578), while over three-quarters agreed or strongly agreed that they understood their rights regarding when they are required to disclose their HIV status to others (76.4%; n = 575).



Figure 33: Perceived understanding of HIV-related rights and legal obligations

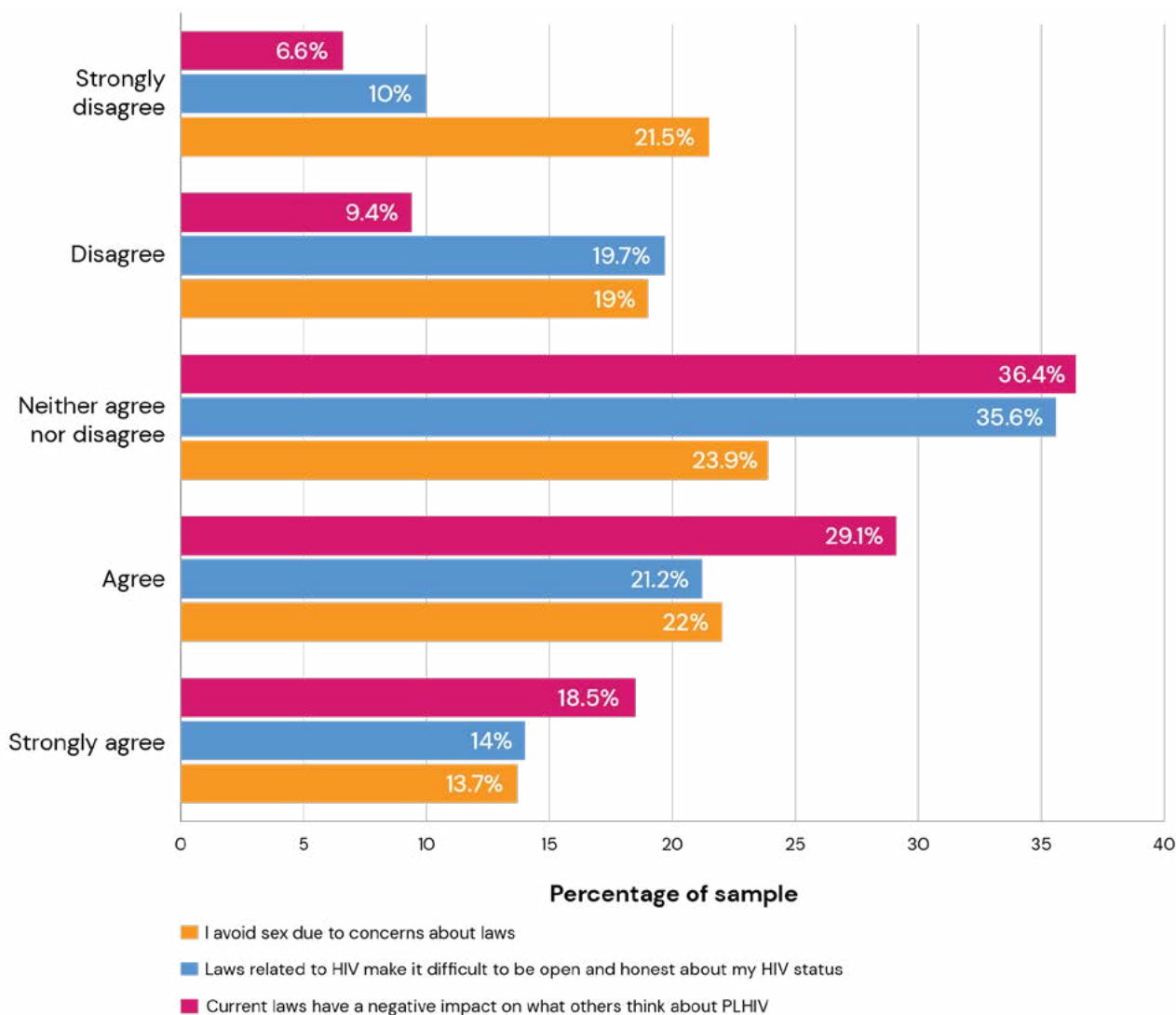


Despite this, many participants perceived HIV-related laws as contributing to stigma and shaping social attitudes towards PLHIV (Figure 34). Almost half agreed or strongly agreed that current laws have a negative impact on what others think about PLHIV (47.6%; n = 574), while 35.2% agreed or strongly

agreed that laws related to HIV make it difficult to be open and honest about their HIV status (n = 579).

“Laws of disclosure are different in each state which is crazy”

Figure 34: Perceived impact of HIV-related laws on disclosure and public perceptions of PLHIV



HIV-related laws were also perceived to affect sexual wellbeing for some participants. Around one-third agreed or strongly agreed that they avoid sex, or limit the type of sex they have, due to concerns about laws regarding HIV and disclosure (35.7%; n = 578). A smaller proportion agreed or strongly agreed that current laws related to HIV affect their enjoyment of sex (24.1%; n = 573).

EXPERIENCE OF HIV-RELATED MICROAGGRESSIONS

Experiences of direct and indirect HIV-related microaggressions were assessed using items adapted from the HIV Microaggressions Scale developed by Eaton et al. (2020), which measures subtle and everyday forms of HIV-related stigma experienced by PLHIV.

INDIRECT MICROAGGRESSIONS

Participants were asked about their experiences of indirect HIV-related microaggressions in the last 12 months. These items assessed broader forms of indirect and structural stigma, including:

- hearing about people trying to make or enforce laws that harm people with HIV
- seeing phrases such as “drug/disease free, UB2 [you must be too]” or “neg for neg only [negative for negative]” on dating profiles
- hearing others express surprise that PLHIV would want to have children
- hearing someone say “I’m HIV negative, I’m clean”
- seeing HIV-positive people portrayed negatively in the media
- hearing about someone being outed about their HIV status

Responses were scored on a scale from 0 ('never') to 3 ('often'), with intermediate values corresponding to 'rarely' (1) and 'sometimes' (2). Participants reported an average indirect microaggressions score of 1.03 (SD = 0.76), suggesting that, on average, participants experienced these forms of indirect HIV-related stigma 'rarely'.

Some forms of indirect microaggressions were more commonly reported than others. Around half of participants reported at least sometimes hearing phrases such as "I'm HIV negative, I'm clean" (48.4%) or encountering exclusionary language on dating profiles such as "neg for neg only" (48.3%) – a similar proportion across both items. Around one-third also reported at least sometimes hearing about PLHIV being outed (31.0%) or seeing PLHIV portrayed negatively in the media (30.6%).

"I did not choose this. Three decades later. I just wish people understood that."

We examined the relationship between indirect microaggression scores and quality of life (overall PozQoL scores <3.0 vs ≥3.0). Participants reporting poorer quality of life reported significantly higher levels of indirect microaggressions than those reporting good quality of life ($p < .001$, $\eta^2 = .083$). This represented a moderate effect, suggesting that experiences of indirect HIV-related stigma are meaningfully associated with quality of life among PLHIV.

DIRECT MICROAGGRESSIONS

Participants were asked about their experiences of direct HIV-related microaggressions in the last 12 months. These items assessed experiences including:

- assumptions that participants must be depressed because of their HIV status
- assumptions that they do not or should not have sex because of their HIV status
- body language indicating others were bothered because of their HIV status
- exclusion from social events because of their HIV status
- perceptions that other health conditions (such as breast cancer or diabetes) were treated more favourably than HIV by the public

Responses were scored on the same 0 ('never') to 3 ('often') scale used for indirect microaggressions. Participants reported an average direct

microaggressions score of 0.78 (SD = 0.77), sitting between 'never' and 'rarely' – somewhat lower than the average score for indirect microaggressions.

Some forms of direct microaggressions were more commonly reported than others. In particular, almost three in five participants (59.0%) reported at least sometimes feeling that other health conditions were treated more favourably than HIV by the public, including 31.5% who reported this "often." Between one in five and one in four participants also reported at least sometimes experiencing assumptions that they do not or should not have sex because of their HIV status (23.8%), assumptions that they must be depressed because of their HIV status (20.5%), or negative body language from others because of their HIV status (21.3%). Experiences of exclusion from social events were less commonly reported, although 11.1% of participants reported this at least 'sometimes'.

We examined the relationship between direct microaggression scores and quality of life (overall PozQoL scores <3.0 vs ≥3.0). There was a statistically significant relationship between more frequent experiences of direct microaggressions and poorer quality of life ($p < .001$, $\eta^2 = .192$), representing a large effect – substantially stronger than the association observed for indirect microaggressions. This suggests that, although less frequently reported than indirect microaggressions, direct experiences of HIV-related stigma may have a particularly important relationship with quality of life among PLHIV in our sample.



8. SOCIAL AND SEXUAL CONNECTION, PEER SUPPORT AND SERVICE USE

Social connection, friendship, and support play an important role in maintaining health and wellbeing among PLHIV. Peer-based community services have also remained central to the HIV response in Australia, supporting social connection, resilience, engagement in care, and quality of life among PLHIV. Recent Australian research confirms this link directly: having a friend living with HIV to talk to is significantly associated with better quality of life, and peer support programs help foster a sense of belonging while offering non-clinical, firsthand perspectives that complement clinical care (Thepsourinthone et al., 2025; Wells et al., 2022). As the experiences and needs of PLHIV continue to evolve, peer-based programs and support services have also adapted to changing social, clinical, and community contexts.

In the contemporary HIV context, a growing number of PLHIV are ageing with HIV and navigating increasingly diverse social, health, and support needs. At the same time, changes in HIV treatment and prevention, shifts in community visibility, and evolving experiences of stigma and disclosure continue to shape how PLHIV engage with peers, social networks, and HIV-related services. Understanding patterns of social connectedness, peer engagement, and service use therefore remains important for informing programs and supports that promote wellbeing and quality of life among PLHIV.

SEX AND RELATIONSHIPS

We asked participants about their current relationship status and sexual relationships in the past 12 months. Over half of participants reported being single and not currently in a relationship (56.1%; n = 323) (Table 21). Around one-third were in a regular relationship with one partner (30.4%), while smaller proportions reported being in a regular relationship with more than one partner (2.3%) or in a regular relationship with a primary partner plus other regular or casual partners (9.4%).

Among participants in a current regular relationship, most reported that their primary partner had most recently tested negative for HIV (67.6%; n = 250), while around one-quarter reported

that their partner was also living with HIV (26.4%). A small proportion reported that their primary partner's HIV status was unknown (5.2%).

Table 21. Current relationship status

Relationship status	Frequency n	Percentage %
Single (not in a relationship)	323	56.1
In a regular relationship with one partner	175	30.4
In a regular relationship with more than one partner	13	2.3
In a regular relationship with a primary partner plus other partners	54	9.4
Other relationship arrangement	11	1.9

Over one-third of participants reported having had no sex in the previous six months (37.3%) (Table 22). Around one in five reported having sex with one regular partner only (19.7%), while similar proportions reported having casual partner(s) only (17.4%)

or regular partner(s) plus casual partners (17.1%). Smaller proportions reported having more than one regular partner (7.1%) or another sexual partnership arrangement (1.4%).

Table 22. Sexual partners in the last 6 months

Category of sexual partners	Frequency n	Percentage %
No sex	216	37.3
One regular partner only	114	19.7
More than one regular partner	41	7.1
Regular partner/s plus casual partners	99	17.1
Casual partner/s only	101	17.4
Other	8	1.4

Participants were asked about the gender of their sexual partners during the previous six months, with participants able to select more than one response option. Most cisgender men reported partners who were men (94.4%), with smaller proportions reporting partners who were women (7.3%), non-binary and/or gender diverse partners (3.0%), or partners who used a different term to describe their gender (0.3%). Most cisgender women also reported partners who were men (97.1%), while 5.7% reported partners who were women and 2.9% reported non-binary and/or gender diverse partners. Among trans and gender diverse participants, 84.6%

reported partners who were men, 23.1% reported partners who were women, and 30.8% reported non-binary and/or gender diverse partners. Because participants could select more than one partner gender, percentages do not sum to 100%.

Participants reported mixed levels of satisfaction with their sex life. Almost half of participants reported being dissatisfied with their sex life (46.8%; n = 564), including 19.1% who were very dissatisfied. In comparison, 53.2% reported being satisfied or very satisfied with their sex life, including 14.7% who were very satisfied.

SOCIAL CONNECTEDNESS

Participants in *HIV FUTURES 11* were asked to respond to 10 questions about the extent to which they feel connected to, and supported by, others (e.g. 'I seem to have a lot of friends', 'I have no-one to lean on in times of trouble', 'I often feel lonely'). This is a general measure of social connection that has been used in Australian population-based surveys (Wooden, 2001). Responses to each question are recorded on a 7-point scale (1 = 'strongly disagree' to 7 = 'strongly agree'). A scale average was calculated to create a score ranging from 1-7, with higher scores indicating greater perceived connectedness.

The average social connection score for *HIV FUTURES 11* was 4.8 (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 23.

"I am fortunate to have a great partner and small circle of friends and poz buddies. Thanks to all the good people out there over the years."

Social connection scores were broadly consistent across age groups, gender identities, sexual orientation, and residential locations, with no statistically significant differences observed across these demographic characteristics (Table 23). Small but statistically significant differences were observed according to education level and employment status.

More substantial differences in social connection were observed across markers of socioeconomic wellbeing and financial stress. Participants with household incomes below \$30,000 reported significantly lower social connection scores than all higher income groups, while those with household incomes of \$125,000 or more reported higher scores than participant who reported a household income between \$30,000–\$79,000. Participants reporting recent financial stress also reported markedly lower social connection scores than those who had not experienced recent financial stress. Similarly, participants living in multi-person households reported higher social connection scores than those living alone. Overall, financial and household circumstances appeared to show stronger associations with social connection than demographic characteristics such as age, gender, sexuality, or residential location.

Table 23. Average social connection scores according to demographic and social variables

Variable	Mean social connection score	F (df, n)	p value	η^2
Age group		2.23 (3, 541)	.084	.012
<35 years	5.0			
35–49 years	4.8			
50–64 years	4.7			
65+ years	5.0			
Gender				
Cisgender men	5.0			
Cisgender women	4.8			
Trans and gender diverse	5.0			
Sexuality**		0.59 (3, 407)	.617	.006
Gay	4.8			
Heterosexual or straight	4.8			
Bisexual	4.6			

Variable	Mean social connection score	F (df, n)	p value	η^2
Queer	5.0			
Residential location		0.55 (3, 537)	.649	.003
Capital city/inner suburban	4.9			
Outer suburban	4.8			
Regional	4.7			
Rural	4.7			
Education level		2.47 (4, 539)	.044	.018
Up to 4-years high school (year 10)	4.4			
Up to Year 12	4.6			
TAFE/diploma/trade	4.7			
Undergraduate university degree	5.0			
Postgraduate university degree	4.9			
Employment status		5.29 (2, 507)	.005	.020
Not currently in paid work	4.7			
Part-time/casual work	4.7			
Full-time work	5.1			
Household income		9.69 (3, 523)	<.001	.053
Not currently in paid work	4.4			
Part-time/casual work	4.8			
Full-time work	4.9			
Not currently in paid work	5.3			
Financial stress		74.17 (1, 551)	<.001	.119
No recent financial stress	5.1			
Recent financial stress	4.0			
Household composition		26.20 (1, 536)	<.001	.047
Single person household	4.5			
Multi-person household	5.1			

* Scores range from 1-7, with higher scores indicating greater social connectedness

** Cell sizes in pansexual, lesbian, and "I use a different term to describe my sexuality" were too small to be included in the analysis

*** Individuals identifying as 'student', 'home duties', 'not working/retired', and 'unemployed' were re-categorised as 'not currently in paid work'

Note: df = degrees of freedom

CONNECTING WITH OTHER PLHIV

Most participants reported having some degree of social connection with other PLHIV, although levels of engagement varied. Over half of participants (57.6%, n = 325) indicated that some of their friends were also living with HIV, while 13.0% (n = 73) reported that at least half of their friends were living with HIV. Conversely, 29.4% (n = 166) reported that none of their friends were living with HIV.

Similarly, around half of participants (50.4%, n = 285) reported spending some of their free time with PLHIV, while 12.9% (n = 73) reported spending at least half of their free time with other PLHIV. Over one-third (36.6%, n = 207) reported spending none of their free time with other PLHIV.

“Support from other positive people has been so good to have.”

Most participants also reported having someone within their social networks with whom they could discuss living with HIV. Approximately two-thirds (62.0%, n = 354) reported having at least one other person living with HIV they could talk to about living with HIV, while 60.6% (n = 345) reported having at least one person they believed was not living with HIV with whom they could discuss HIV-related experiences.

Despite many participants reporting some level of contact with other PLHIV within their social

networks, the importance of these connections and feelings of belonging to HIV community varied considerably (Figure 35). Most participants agreed that knowing other PLHIV was important to them (67.1%, n = 381), and more than half disagreed with the statement “I have no interest in being part of the HIV community” (55.6%, n = 317), suggesting ongoing interest in HIV community connection and engagement for many participants.

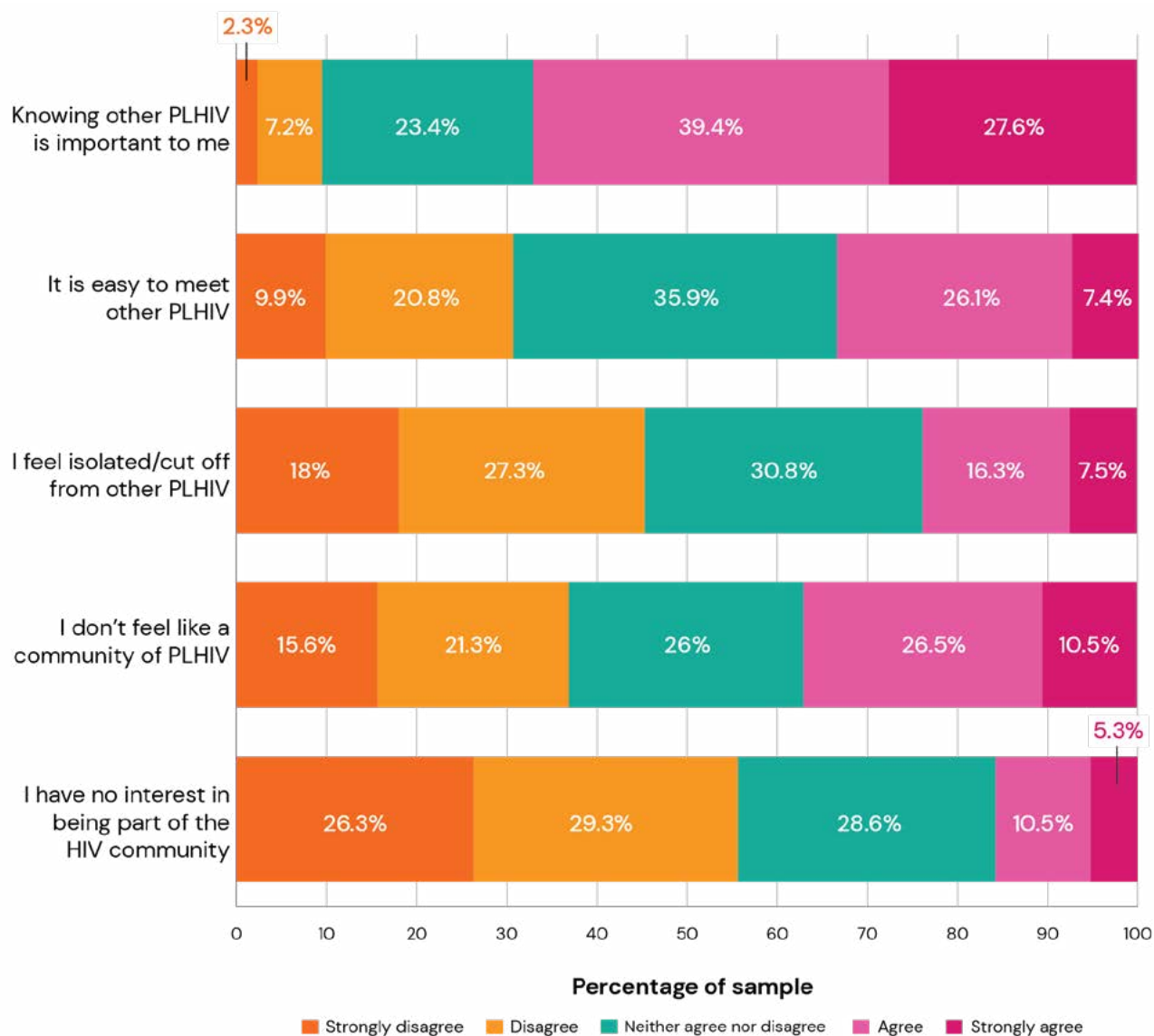
“I would like to find people I can confide in and trust, and are similar to me.”

However, experiences of connection to HIV community were more mixed. More than one-third of participants agreed that they did not feel part of a community of PLHIV (37.1%, n = 211), while almost one-quarter agreed that they felt isolated or cut off from other PLHIV (23.8%, n = 136). Participants also reported mixed views regarding opportunities to connect with other PLHIV. One-third agreed that it was easy to meet other PLHIV (33.5%, n = 190), while 30.6% (n = 174) disagreed and 35.9% (n = 204) neither agreed nor disagreed.

“I like accessing services for HIV but I don't want to make friends or commit to a community.”



Figure 35: Responses to statements about feelings on HIV community connection

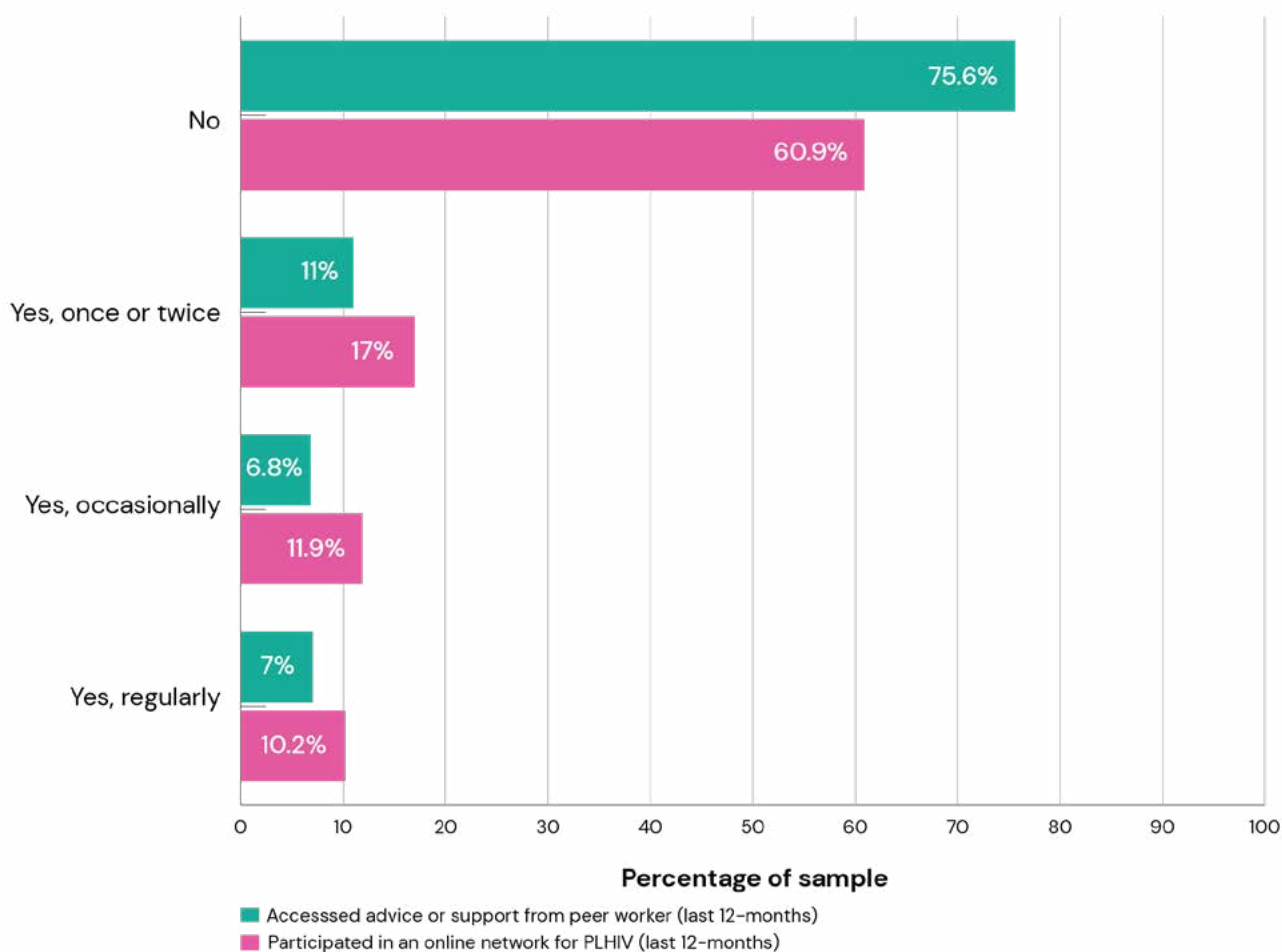


PEER-BASED PROGRAMS AND SERVICES

Participants reported varying levels of engagement with peer-based HIV support and community services in the previous 12 months (Figure 36). Around two in five participants had accessed advice or support from a person living with HIV working within a community organisation or health service (39.1%, n = 223), including 17.0% (n = 97) who had done so once or twice, 11.9% (n = 68) occasionally, and 10.2% (n = 58) regularly. Smaller proportions reported utilising a peer navigator program (15.6%, n = 89) or participating in a peer education or peer support workshop for PLHIV (26.8%, n = 153). Almost one-quarter of participants were currently an employee or volunteer for an HIV community organisation (23.0%, n = 130).

“I get better and better step by step, from the first day of diagnosis, with the support of the health care system and community-based organisations.”

Figure 36: Peer-based sources of information and support about HIV



Participants in *HIV FUTURES 11* generally reported positive views towards HIV community support services (Figure 37). Most participants agreed that community-based services play an important role in connecting PLHIV with one another (67.3%, n = 382), and almost two-thirds reported feeling comfortable accessing community support services for PLHIV (65.8%, n = 374). More than half of participants also agreed that peer support and community services had played an important role in maintaining or improving their wellbeing since being diagnosed with HIV (57.9%, n = 327).

“Prevention and supports need to be maintained”

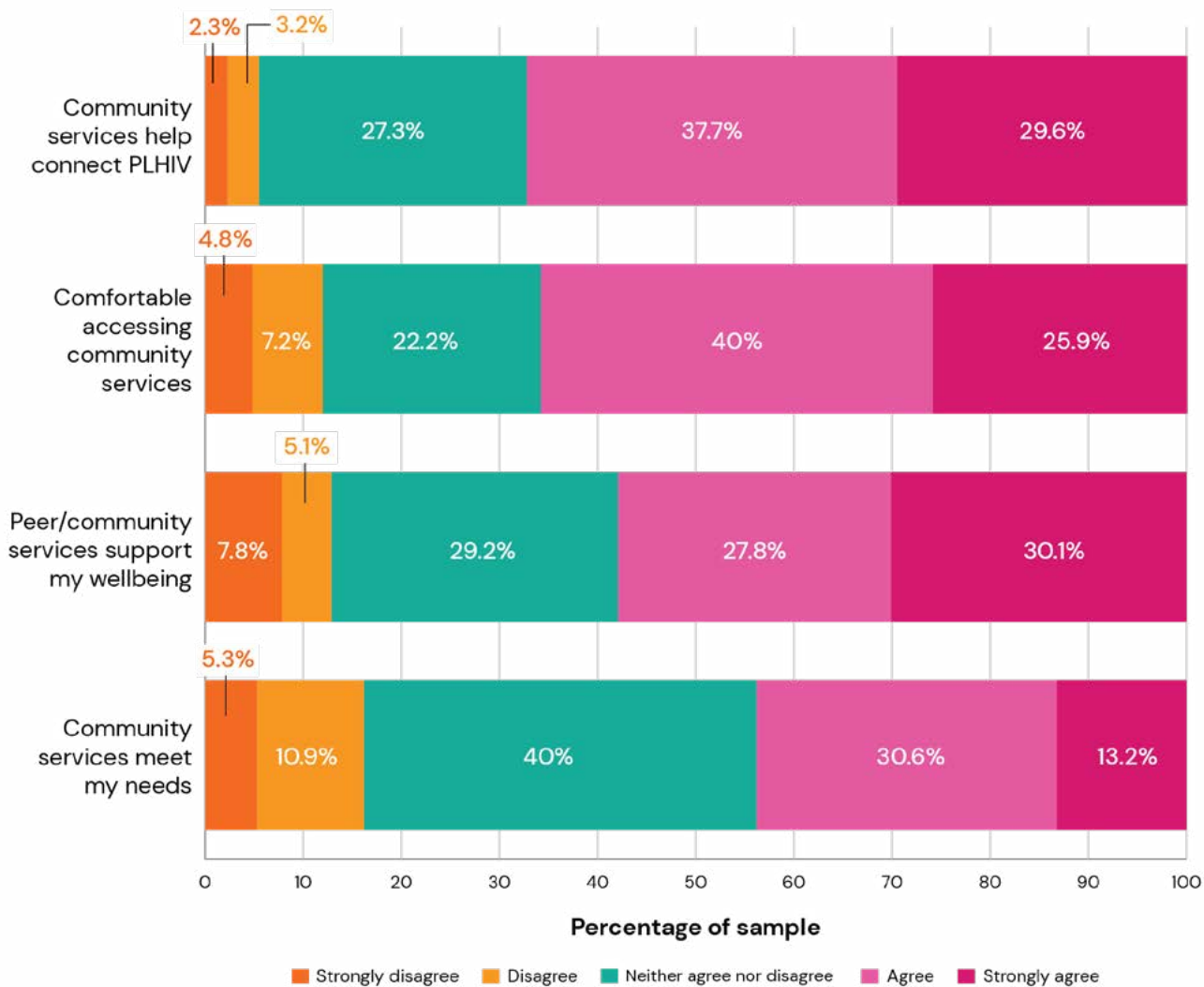
Responses were more mixed when participants were asked whether community support services met their own needs. While 43.8% (n = 246) agreed that community services met their needs, 40.0% (n = 225) neither agreed nor disagreed, and 16.2% disagreed. This pattern suggests that although HIV community services are widely regarded as valuable

and important components of the HIV response, participants were less certain about their personal relevance or adequacy in meeting individual needs.

“There are very few services outside capital cities.”



Figure 37: Perspectives on community support services



Note: Participants were asked to indicate the extent to which they agreed or disagreed with the following statements: “Community support services for PLHIV meet my needs”; “Peer support and/or community services have played an important part in maintaining or improving my wellbeing since being diagnosed with HIV”; “Community-based services play an important role in connecting PLHIV with each other”; and “I am comfortable accessing community support services for PLHIV”. Responses are presented as valid percentages.



OTHER SERVICES FOR PLHIV

Participants reported accessing a range of services for PLHIV in the previous 12 months (Table 24). Counselling or psychological treatment (16.1%, n = 114) and treatment advice or information (15.4%, n = 109) were the most commonly accessed services.

Smaller proportions of participants reported accessing social work services (8.8%, n = 62), legal assistance or advice (5.8%, n = 41), financial assistance or advice (5.1%, n = 36), and housing support (3.8%, n = 27). A further 6.9% of participants (n = 49) reported accessing other forms of HIV-related support or services.

Table 24. Type of HIV service accessed in the past 12 months

Type of HIV service	Participants n (%)*
Counselling/psychological treatment	114 (16.1)
Treatment advice or information	109 (15.4)
Social work services	62 (8.8)
Legal assistance or advice	41 (5.8)
Financial assistance or advice	36 (5.1)
Housing support	27 (3.8)
Other service	49 (6.9)

* Note that percentages of the total sample should be considered approximate as they do not account for the number who missed these questions.

Participants were invited to provide open-text responses to the question: "Are there any other services or programs you would like to see become available for PLHIV?". Responses highlighted a broad range of additional supports and priorities, including:

- Expanded opportunities for social connection and peer support, including more community gatherings, peer groups, retreats, social activities, and opportunities to meet other PLHIV, particularly outside standard business hours and in regional or rural areas.
- Greater support for ageing and long-term survivorship, including programs focused on healthy ageing, loneliness, aged care navigation, and support for older PLHIV.
- Improved mental health and wellbeing supports, including ongoing counselling, trauma-informed services, sexual assault counselling, substance use support, exercise and fitness programs, and broader wellness-focused approaches incorporating physical health, nutrition, and mindfulness.
- Increased access to practical and allied health supports, particularly affordable dental care, housing assistance, transport services, in-home support, and financial assistance for people on low incomes.
- Improved access to services outside metropolitan areas, with participants in regional, rural, and outer suburban areas frequently describing limited local services, long travel times, and reduced opportunities for community connection.
- More inclusive and tailored services for specific groups, including women living with HIV, migrants and people without Medicare access, older PLHIV, heterosexual and bisexual PLHIV, and Aboriginal and Torres Strait Islander communities.
- Expanded migration, visa, and legal support services, particularly for people navigating Medicare ineligibility, visa restrictions, and access to HIV treatment and monitoring while living in Australia.

While there were a number of suggestions across the sample, some participants also reported being satisfied with the current range of available services or indicated that they did not currently require additional support.



9. WOMEN LIVING WITH HIV

Women comprise roughly one in ten PLHIV in Australia (King, et al., 2025), but represent a diverse population with varied cultural, social, and life experiences. Women have experiences and priorities related to HIV that are distinct and differ to that of men across relationships, family life, pregnancy and parenting, financial security, stigma, and engagement with health and support services. In addition, many women living with HIV in Australia were born overseas and have encountered complex experiences relating to migration and visa uncertainty. Despite this, women living with HIV remain comparatively underrepresented within Australian HIV research and community programming.

“Being a straight woman, I have found myself feeling very isolated and alone the past 12 years since my diagnosis. At the time of my diagnosis, there were very limited resources for women living with HIV, so I just got used to dealing with it on my own. It would be nice if there were more resources, especially [for] heterosexual women and older women living with HIV.”

The experiences of women who participated in *HIV FUTURES 11* are included throughout this report and highlighted separately where findings differed meaningfully from men or participants of other genders. This section focuses specifically on the demographics, financial circumstances, health, and wellbeing of women living with HIV. Unless otherwise specified, the term “women” refers to both cisgender and transgender women.

DEMOGRAPHIC CHARACTERISTICS

There were 98 women who participated in *HIV FUTURES 11* (14.1% of the cohort), including 92

cisgender women and six transgender women. The demographic characteristics of these women are presented in Table 25.

Women in the sample were predominantly older, with more than half (57.8%) aged 50 years and over, including 38.9% aged 50–64 years and 18.9% aged 65 years or older. Around one-third of women resided in Victoria (33.7%) or New South Wales (31.6%), while almost half lived in inner-city areas (48.4%) and a further 30.1% lived in outer suburban areas. Smaller proportions lived in regional (14.0%) or rural areas (7.5%). Overall, 5.3% of women identified as Aboriginal and/or Torres Strait Islander.

Approximately two-thirds of women reported English as their first language (64.9%). Most women were Australian citizens or permanent residents, although a smaller proportion reported temporary or other visa arrangements. The majority of women identified as heterosexual or straight (70.3%), particularly among cisgender women, while transgender women reported a broader range of sexual identities, including queer, pansexual, gay, and other identities. Just over half of participants were currently single (53.9%), while 43.4% reported being in a relationship with one partner. A small number of participants reported other relationship arrangements (2.6%).

Table 25. Demographic characteristics of women living with HIV

Demographic characteristics	Cisgender women n (%)	Transgender women n (%)	Total n (%)
Age			
< 35	9 (10)	1 (20.0)	10 (10.5)
35–49	29 (32.2)	1 (20.0)	30 (31.6)
50–64	35 (38.9)	2 (40.0)	37 (38.9)
65+	17 (18.9)	1 (20.0)	18 (18.9)
State/territory			
New South Wales	29 (31.5)	2 (33.3)	31 (31.6)
Victoria	30 (32.6)	3 (50.0)	33 (33.7)
Queensland	10 (10.9)	1 (16.7)	11 (11.2)
South Australia	7 (7.6)	0 (0)	7 (7.1)
Western Australia	4 (4.3)	0 (0)	4 (4.1)
Australian Capital Territory	4 (4.3)	0 (0)	4 (4.1)
Tasmania	0 (0)	0 (0)	0 (0)
Place of residence			
Inner city	43 (49.4)	2 (33.3)	45 (48.4)
Outer suburbs	25 (28.7)	3 (50.0)	28 (30.1)
Regional	12 (13.8)	1 (16.7)	13 (14.0)
Rural	7 (8.0)	0 (0)	7 (7.5)
Aboriginal or Torres Strait Islander	5 (5.6)	0 (0)	5 (5.3)
English as a first language	59 (64.8)	4 (66.7)	63 (64.9)

Demographic characteristics	Cisgender women n (%)	Transgender women n (%)	Total n (%)
Citizenship/visa status			
Citizen	61 (66.3)	3 (50.0)	16 (16.3)
Permanent resident	16 (17.4)	2 (33.3)	18 (18.4)
Neither citizen nor permanent resident	9 (13.0)	0 (0)	9 (12.2)
Sexual identity			
Heterosexual or straight	51 (75.0)	1 (16.7)	52 (70.3)
Bisexual	8 (11.8)	0 (0)	8 (10.8)
Pansexual	3 (4.4)	1 (16.7)	4 (5.4)
Queer	4 (5.9)	2 (33.3)	6 (8.1)
Gay	0 (0)	1 (16.7)	1 (1.4)
Lesbian	1 (1.5)	0 (0)	1 (1.4)
Use a different term	1 (1.5)	1 (16.7)	2 (2.7)
Relationship status			
Currently single	37 (52.9)	4 (66.7)	41 (53.9)
In a relationship with one partner	31 (44.3)	2 (33.3)	33 (43.4)
Other	2 (2.9)	0 (0)	2 (2.6)

EDUCATION, EMPLOYMENT AND INCOME

Women participating in *HIV FUTURES II* reported diverse educational, employment, and financial circumstances (Table 26). Most women had completed some form of post-secondary education, particularly tertiary diploma/trade qualifications (36.4%, n = 28), undergraduate university degrees (20.8%, n = 16), or postgraduate university degrees (20.8%, n = 16).

Around one-third of women reported working full-time (36.7%, n = 36), while smaller proportions reported part-time or casual employment. Some women also reported being unemployed, retired, engaged in home duties, or studying, reflecting varied patterns of workforce participation and economic engagement.

Household incomes also varied considerably across the subsample. While some women reported relatively high household incomes, more than one-

quarter reported annual household incomes below \$30,000 (27.6%, n = 27), including 9.2% (n = 9) who reported negative or zero income.

Table 26. Education, employment and income of women

Variable	Cisgender women n (%)	Transgender women n (%)	Total n (%)
Highest level of education			
Primary school only	0 (0)	0 (0)	0 (0)
Up to 4 years' high school	14 (15.4)	0 (0)	14 (14.4)
Leaving certificate/HSC/Year 12	10 (11.0)	0 (0)	10 (10.3)
Tertiary diploma/trade certificate/TAFE	28 (38.9)	0 (0)	28 (36.4)
Undergraduate university degree	13 (18.1)	3 (60.0)	16 (20.8)
Postgraduate university degree	15 (20.8)	1 (20.0)	16 (20.8)
Main employment/activity			
Work full-time	34 (37.0)	2 (33.3)	36 (36.7)
Work part-time	7 (7.6)	1 (16.7)	8 (8.2)
Not working/retired	9 (9.8)	0 (0)	9 (9.3)
Unemployed, not looking for work	7 (7.6)	0 (0)	7 (7.1)
Home duties	3 (3.3)	0 (0)	3 (3.1)
Work casual	6 (6.6)	0 (0)	6 (6.1)
Student	5 (5.4)	0 (0)	5 (5.1)
Unemployed, looking for work	7 (7.6)	1 (16.7)	8 (8.2)
Annual household income			
Negative or zero income	8 (8.7)	1 (16.7)	9 (9.2)
\$1 - \$29,999 per year	17 (18.5)	1 (16.7)	18 (18.4)
\$30,000 - \$49,999 per year	11 (12.0)	0 (0)	11 (11.2)
\$50,000 - \$79,999 per year	10 (10.9)	0 (0)	10 (10.2)
\$80,000 - \$99,999 per year	18 (19.6)	2 (33.3)	20 (20.4)
\$100,000 - \$124,999 per year	9 (9.8)	0 (0)	9 (9.2)
\$125,000 - \$149,999 per year	3 (3.3)	0 (0)	3 (3.1)
\$150,000 - 199,999 per year	6 (6.5)	0 (0)	6 (6.1)
\$200,000 or more per year	5 (5.4)	1 (16.7)	6 (6.1)

FINANCIAL SECURITY

As outlined in Chapter 3 of this report, the *HIV FUTURES 11* survey included two indicators of financial security: experiences of financial stress

and housing. Over one in four of women participants (28.3%, n = 28) met the criteria for experiencing financial stress in the past 12 months (Table 27); a higher proportion than that of men.

Table 27. Experiences of financial stress in the past 12 months

Financial stress status	Women n (%)	Men n (%)	Non-binary/ gender diverse people n (%)
No financial stress	71 (71.7)	460 (79.0)	10 (66.7)
Financial stress	28 (28.3)	122 (21.0)	5 (33.3)

Women participating in *HIV FUTURES 11* reported a range of housing arrangements (Table 28). Private rental was the most commonly reported individual housing arrangement overall (30.5%, n = 29), followed closely by home purchase with a mortgage (28.4%, n = 27). When home ownership outright and home purchase with a mortgage were combined, 43.4% of women (n = 43) were living in owner-occupied housing.

Patterns of housing arrangement varied by age. Women aged 35–49 years were most likely to report living in a mortgaged home, while women aged 50 years and older were more likely to report owning their home outright. Younger women were more likely to report private rental or rent-free living arrangements. Smaller proportions of women reported living in public or community housing, and one participant reported experiencing homelessness.

Table 28. Housing arrangement of women, by age category

Housing arrangement	Age group				Total
	< 35 n (%)	35–49 n (%)	50–64 n (%)	65+ n (%)	
Home owner (own outright)	0 (0)	2 (6.7)	9 (24.3)	5 (27.8)	16 (16.8)
Home purchaser (with mortgage)	0 (0)	13 (43.3)	11 (29.7)	3 (16.7)	27 (28.4)
Private rental	4 (40.0)	9 (30.0)	10 (27.0)	6 (33.3)	29 (30.5)
Public rental	1 (10.0)	2 (6.7)	3 (8.1)	2 (11.1)	8 (8.4)
Rent-free	2 (20.0)	2 (6.7)	0 (0)	0 (0)	4 (4.2)
Community housing or cooperative	1 (10.0)	1 (3.3)	3 (8.1)	2 (11.1)	7 (7.4)
Boarding house	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Homeless	1 (10.0)	0 (0)	0 (0)	0 (0)	1 (1.1)
Other	1 (10.0)	1 (3.3)	1 (2.7)	0 (0)	3 (3.2)

Housing arrangements were broadly similar across gender groups. Ownership outright or purchasing with a mortgage) was the most common housing tenure category, reported by 48.1% of men (n = 277), 43.4% of women (n = 43), and 42.1% of non-binary/gender

diverse participants (n = 8). Around one-third of men (32.3%, n = 186) and women (31.3%, n = 31), and 42.1% (n = 8) of non-binary/gender diverse participants reported living in private rental accommodation. Smaller proportions of participants across all

gender groups reported living in other or potentially insecure housing arrangements.

TIME LIVING WITH HIV, TREATMENT, AND VIRAL SUPPRESSION

The length of time women had been living with HIV ranged from less than a year through to 40 years, with an average time of 19.0 years.

Almost all women were currently taking ART (98.9%, n = 86) and, as of their last test, 96.5% (n = 83) of women had an undetectable viral load (viral suppression). This was equivalent to the overall sample, in which 96.4% had an undetectable viral load.

QUALITY OF LIFE

Using the PozQoL measure of quality of life, 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 11*, 61.9% of women reported 'good' quality of life. The average PozQoL score for women was 3.3, which was slightly lower than the average score for men (3.4), but the difference was not statistically significant.

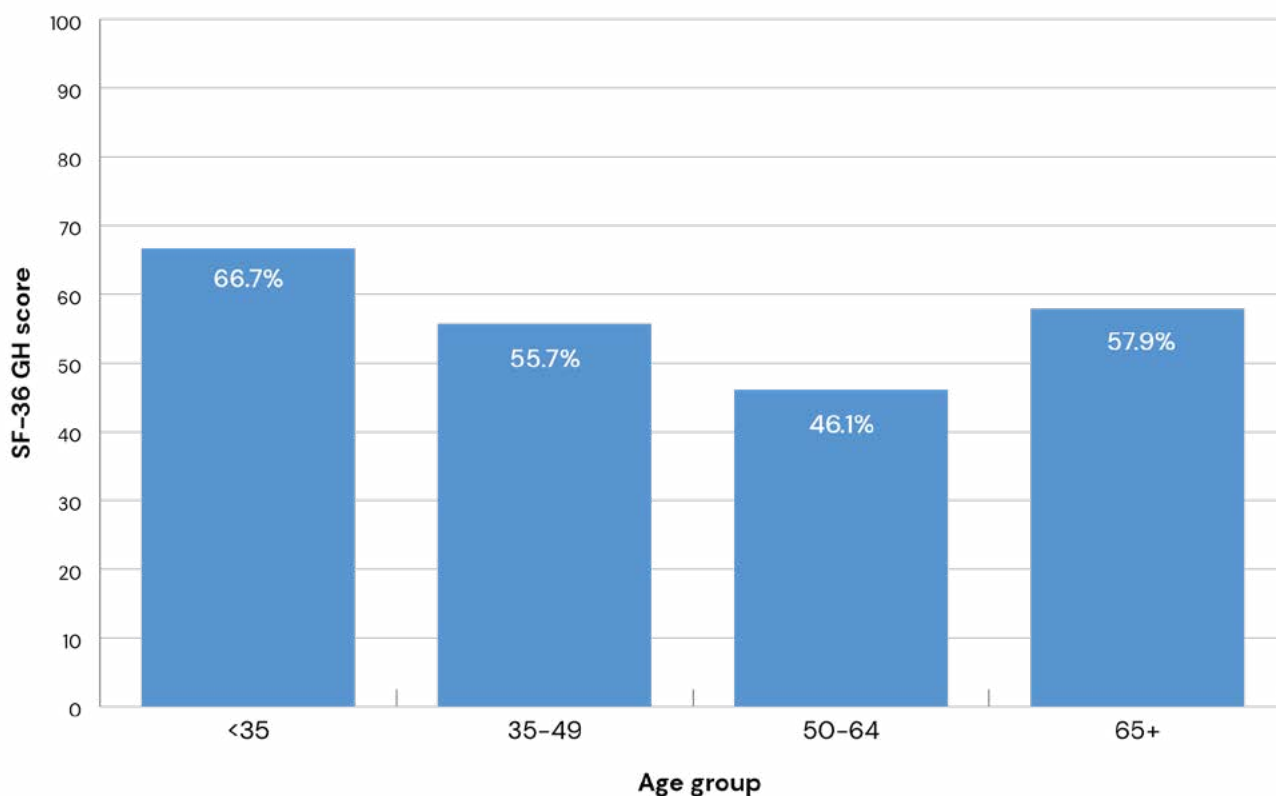
"The lack of acknowledgement that heterosexual people, including women, can get HIV contributes to internalised stigma and limits access to information and support."

Using the one-question item in which *HIV FUTURES 11* participants were asked to rate their overall mental, emotional and physical health, 51.5% of women reported their overall sense of wellbeing to be at least good ('good' or 'excellent'); a slightly lower percentage than that of men (55.2%).

GENERAL HEALTH AND MENTAL HEALTH

We examined self-reported general health among women using the SF-36 general health subscale (Figure 38). Among women, the average SF-36 general health score was 54.4, slightly lower than 54.9 reported by men in (although this difference was not statistically significant). When comparing general health across age groups, women aged 50–64 reported the lowest SF-36 scores (Figure 38), which is comparable with age-related findings of the overall sample.

Figure 38. SF-36 scores among women, by age group



Note: SF-36 GH = Short Form 36 General Health



Women participating in *HIV FUTURES 11* reported on current mental health conditions. Depression was the most commonly reported diagnosis, reported by 20.4% (n = 20) of women, followed by anxiety conditions (17.3%, n = 17) and post-traumatic stress disorder (PTSD) (16.3%, n = 16). Smaller proportions of women reported obsessive-compulsive disorder (3.1%, n = 3), while bipolar disorder (1.0%, n = 1) and borderline personality disorder (1.0%, n = 1) were rarely reported.

Multiple mental health conditions were common among women participating in *HIV FUTURES 11*. While just under half of women (45.9%; n = 45) reported at least one current mental health diagnosis, many women reported experiencing multiple current mental health conditions, including 15.3% (n = 15) reporting two diagnoses and 18.4% (n = 18) reporting three or more diagnoses.

PREGNANCY EXPERIENCES AND REPRODUCTIVE DECISION MAKING

Cisgender women in *HIV FUTURES 11* were asked a series of questions relating to pregnancy experiences and reproductive decision-making following HIV diagnosis. Most women reported that they had been pregnant in their lifetime (73.0%, n = 54). Among those who responded to

questions regarding pregnancy, almost half (47.2%, n = 25) reported having been pregnant since being diagnosed with HIV, and 38.5% (n = 20) reported having given birth following HIV diagnosis, including vaginal or caesarean delivery. Participants were also asked whether they had ever decided to terminate a pregnancy due to their HIV status, with 15.4% (n = 8) indicating that they had.

“Tubal ligation of women was an ‘easy thing’ in the early 90s. Some of us have been robbed of our womanhood and birthing rights. Regardless of how good treatments are, our lives are forever changed. Our sacrifice is long forgotten. Yes, we can now celebrate ageing with HIV, but who will look after us and what is our legacy?”

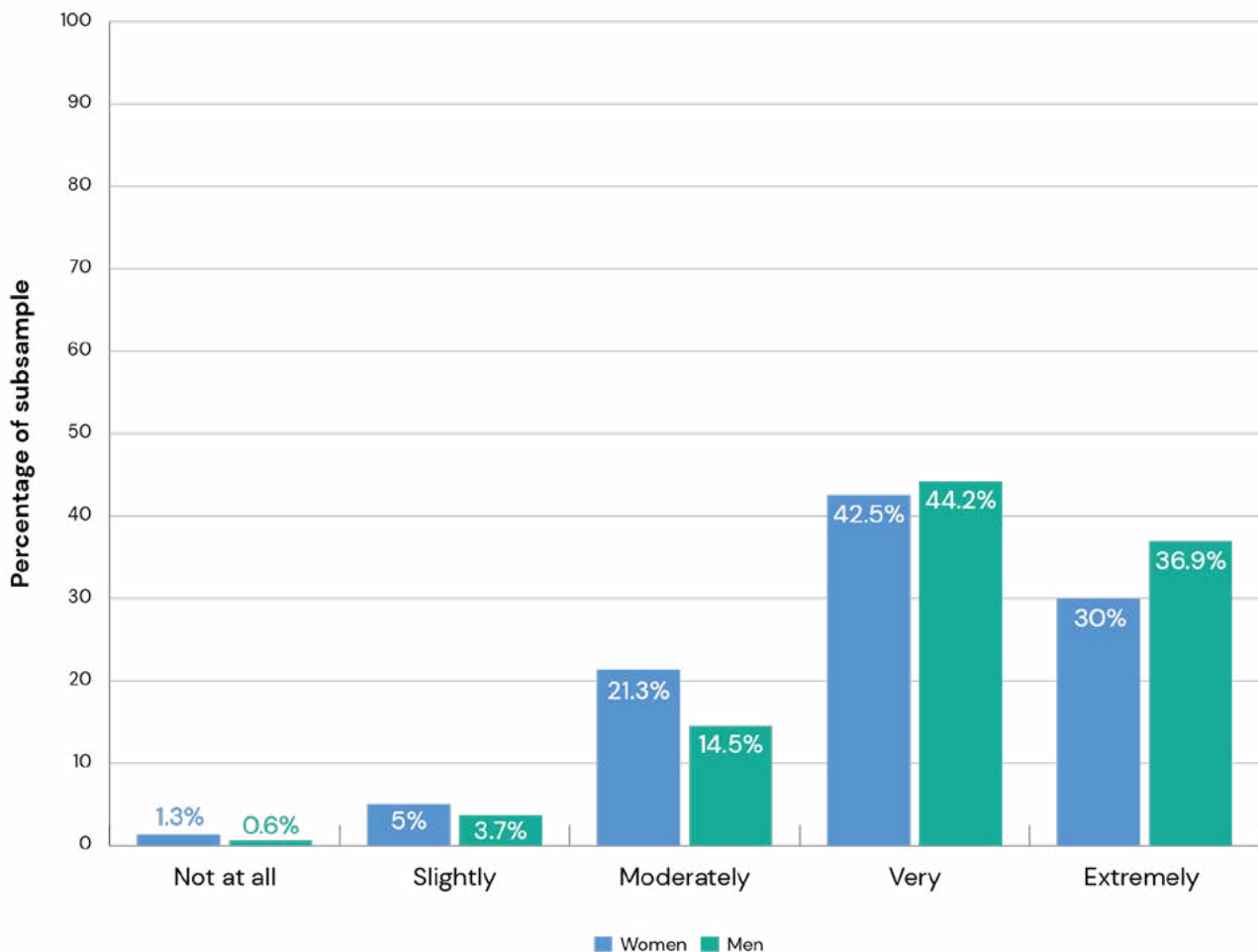
Participants were asked about future pregnancy intentions. Most reported that they did not intend to become pregnant in the future (80.8%, n = 42), while smaller proportions reported intending to become pregnant (11.5%, n = 6) or were unsure (7.7%, n = 4).

SATISFACTION WITH TREATMENT AND CLINICAL CARE

Most women participating in *HIV FUTURES 11* reported positive views regarding their HIV treatment (Figure 39). Overall, 72.1% of women (n = 62) reported being either 'very' or 'extremely' happy with their treatment, including 72.5% (n = 58) of cisgender women

and 66.7% (n = 4) of transgender women. Smaller proportions of women reported feeling moderately happy with their treatment (20.9%, n = 18), while few reported low levels of treatment satisfaction. When comparing women to men, women were less likely than men to report that they were 'extremely' or 'very' happy with their treatment (although this difference was not statistically significant).

Figure 39: Happiness with HIV treatment, by gender



SEX AND RELATIONSHIPS

Women participating in *HIV FUTURES 11* reported diverse relationship and sexual experiences. Just over half of women reported being single and not currently in a relationship (53.9%, n = 41), while 43.4% (n = 33) reported being in a regular relationship with one partner. Among women with a primary partner, almost all reported that their partner was male (97.2%, n = 35). Most women in a regular relationship reported that their main partner was HIV negative (77.1%, n = 27), while a smaller proportion reported having a partner living with HIV (17.1%, n = 6).

Women's sexual practices in the previous six months also varied. Almost half of women reported not having sex during this period (48.7%, n = 38), while 37.2% (n = 29) reported sex with one regular partner only. Smaller proportions reported sex with multiple regular partners, casual partners, or both regular and casual partners.

Women reported mixed experiences regarding the impact of HIV on sexuality and relationships. Around one-third of women agreed that HIV had negatively affected their sexual pleasure (30.6%, n = 22), while half disagreed (50.0%, n = 36). Similarly, around one-third of women reported being afraid

of transmitting HIV to a partner or potential partner (32.9%, n = 24), while more than half disagreed (56.2%, n = 41). The proportion of women reporting that they were afraid of transmitting HIV to a partner was higher than the overall sample. Despite this, most women expressed confidence that they would not transmit HIV to a sexual partner when their viral load was undetectable (86.5%, n = 64).

EXPERIENCES OF STIGMA/ DISCRIMINATION

More than half of women (55.0%, n = 44) reported experiencing HIV-related stigma or discrimination at least 'rarely' in the previous 12 months, while 32.5% (n = 26) reported experiencing stigma 'sometimes', 'often', or 'always'. Experiences of healthcare-related stigma in the previous 12 months were also common, with 55.6% (n = 45) reporting that health workers had treated them negatively or differently because of their HIV status at least 'rarely', including 30.9% (n = 25) who reported these experiences 'sometimes', 'often', or 'always'.

Women were significantly more likely than men to report negative treatment from health workers because of their HIV status ($\chi^2(4, 567) = 26.61, p < .001$). Less than half of women (44.4%, n = 36) reported never experiencing healthcare-related stigma, compared with 69.5% of men (n = 338). Women were also more likely than men to report that health workers had treated them negatively or differently at least sometimes (30.9%, n = 25 vs 11.9%, n = 58).

Experiences of rejection in sexual and intimate relationships related to HIV status were less common. Approximately one-third of women (32.4%, n = 23) reported that someone had not wanted to have sex with them because of their HIV status, while 29.3% (n = 22) reported that someone had not wanted to have a relationship with them. Most women reported 'never' experiencing HIV-related rejection in relation to sex (67.6%, n = 48) or relationships (70.7%, n = 53). This was broadly similar to men's reported experiences of rejection or stigma in relationships.



10. PLHIV BORN OUTSIDE AUSTRALIA

The changing epidemiology of HIV in Australia – marked by a substantial decline in new diagnoses among Australian-born gay and bisexual men without a comparable decline among people born overseas – highlights the need for prevention, treatment, and care responses that are responsive to cultural diversity and migration experiences. People born outside Australia may encounter multiple, intersecting barriers to HIV testing, treatment, and care, including language barriers, unfamiliarity with health systems, limited knowledge of available services, cultural misunderstandings within healthcare settings and minimal social contacts or connection with other PLHIV or community organisations. For those with temporary or uncertain visa status, an HIV diagnosis may also generate additional stress related to concerns about residency, healthcare eligibility, and the prospect of returning to countries where stigma, discrimination, or access to HIV care may be more limited.

These challenges are often compounded by broader experiences of racism, economic disadvantage, homophobia, and HIV-related stigma in Australia. As a result, the experiences of PLHIV who were born outside Australia are shaped not only by clinical needs but also by a range of social, structural, and migration-related factors that influence health and wellbeing.

At the same time, it is important to recognise the limitations of the category “overseas-born.” While widely used as an epidemiological category for monitoring the HIV epidemic in Australia, this broad grouping encompasses highly diverse populations whose experiences differ substantially according to

factors such as country of origin, language, gender, family or relationship status, migration pathway, visa status, and socioeconomic circumstances. People from English-speaking, high-income countries are likely to have experiences that differ markedly from those born in lower-income or non-English-speaking countries, reflecting differences in language barriers, experiences of racism, and the ways they are perceived and treated within Australian society and healthcare systems. In this section, we examine the responses of PLHIV who were born outside Australia, using overseas birth as a broad indicator of migration background while acknowledging the diversity of experiences contained within this category.

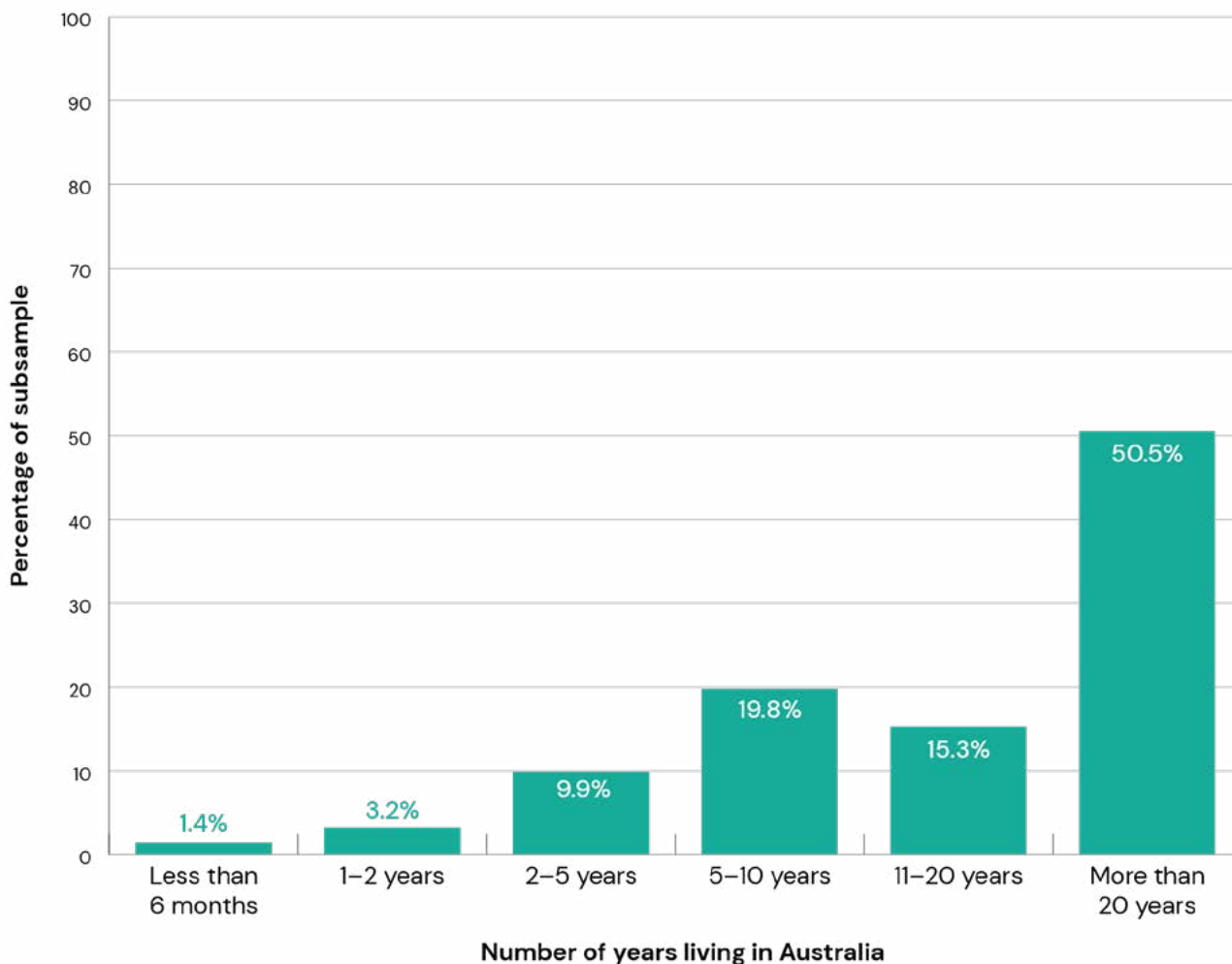
DEMOGRAPHIC CHARACTERISTICS

Participants represented diverse migration and settlement experiences, including differences in language background, length of time living in Australia, residency status, and access to services and supports.

One-third of participants in *HIV FUTURES II* were born outside Australia (33.2%, n = 230). Among these

participants, around half (50.5%, n = 112) reported having lived in Australia for more than 20 years, while others reported more recent migration experiences, including 19.8% (n = 44) who had lived in Australia for between five and 10 years and 15.3% (n = 34) who had lived in Australia for between 11 and 20 years (Figure 30). Smaller proportions reported living in Australia for less than five years, including 1.4% (n = 3) who had arrived within the previous six months.

Figure 40. Number of years living in Australia among people who were born outside of Australia



Participants born outside Australia ranged in age from 23 to 86 years, with a mean age of 51.5 years (SD = 14.6). This was somewhat younger than the overall *HIV FUTURES II* sample, which had a mean age of approximately 55 years. Around half (49.1%, n = 113) reported that English was not their first language, compared with 2.6% (n = 12) of participants born in Australia.

Most participants born outside of Australia were cisgender men (74.0%, n = 168), while smaller proportions were cisgender women (19.4%, n = 44), transgender women (2.2%, n = 5), non-binary/gender

diverse people (3.1%, n = 7), or used another term to describe their gender (1.3%, n = 3).

Most participants born outside Australia identified as gay (62.0%, n = 116), while one in five identified as heterosexual or straight (21.4%, n = 40). Smaller proportions identified as bisexual (5.3%, n = 10), queer (5.3%, n = 10), pansexual (1.6%, n = 3), homosexual (2.1%, n = 4), or used another term to describe their sexuality (2.1%, n = 4).

Most participants lived in metropolitan areas, including 62.6% (n = 139) in capital city or inner suburban areas and 15.8% (n = 35) in outer

suburban areas. A further 15.8% (n = 35) lived in regional centres and 5.9% (n = 13) in rural areas. Participants were drawn from all Australian states and territories, although the largest proportions resided in New South Wales (43.9%, n = 100) and Victoria (28.5%, n = 65) which reflected the distribution of the overall sample.

Educational attainment was generally high. More than half had completed a university qualification, including 25.0% (n = 57) with an undergraduate degree and 31.6% (n = 72) with a postgraduate degree. A further 25.9% (n = 59) reported completing a tertiary diploma, trade certificate, or TAFE qualification.

CITIZENSHIP, RESIDENCY, AND VISA STATUS

“Permanent visa applications are a stressful and near impossible task.”

The majority of participants born outside Australia were Australian citizens (57.5%, n = 130) or permanent residents (21.7%, n = 49), although around one in five (20.8%, n = 47) reported that they were not Australian permanent residents or citizens. Of those who provided details of their visa status, 14 had protection visas, 12 had student visas, ten had work visas, and two had working holiday visas. Nine reported having ‘other’ visa types.

Among participants not born in Australia, most reported having adequate support and information about Australian visa and residency requirements (76.4%), while 23.6% reported that they did not. Participants on a temporary visa were more likely to report that they lacked adequate support and information about Australian visa and residency requirements (33.3%, n = 16) compared to participants who were permanent residents (17.3%, n = 13).

“The only concern I have is the impact of HIV on opportunities to migrate to Australia. Especially for those who have contracted HIV in Australia. It should be easier for them migrate.”

MEDICARE ACCESS

Most participants reported having an Australian Medicare card (88.7%, n = 204), while 11.3% (n = 26) did not have Medicare access.

QUALITY OF LIFE

Quality of life among the overall sample of PLHIV is described in detail in Chapter 2. This chapter builds on those findings by examining the experiences of participants born outside Australia.

Participants born outside Australia reported a mean overall PozQoL score of 3.42 (SD = 0.81). Among the PozQoL subdomains, mean scores were highest for functional quality of life (M = 3.85, SD = 1.08), followed by psychological quality of life (M = 3.42, SD = 0.83) and social quality of life (M = 3.31, SD = 1.09). Health-related quality of life had the lowest mean score (M = 3.10, SD = 0.99).

When looking at the PozQoL threshold outlined in the Ninth National HIV Strategy, 69.5% (n = 157) of participants born outside Australia were classified as having good quality of life (≥ 3.0), closely aligning with the overall *HIV FUTURES II* estimate of 69.7%, substantially lower than the 95% target in the National Strategy.

Quality of life was examined by migration and residency status, comparing Australia-born participants, migrant participants who were Australian citizens or permanent residents, and migrant participants who were neither Australian citizens nor permanent residents (Figure 41). Significant differences were observed across overall quality of life, $F(2, 676) = 6.60, p = .001, \eta^2 = .019$, psychological quality of life, $F(2, 676) = 5.17, p = .006, \eta^2 = .015$, social quality of life, $F(2, 674) = 7.43, p < .001, \eta^2 = .022$, health-related quality of life, $F(2, 676) = 3.36, p = .035, \eta^2 = .010$, and functional quality of life, $F(2, 676) = 10.22, p < .001, \eta^2 = .029$.

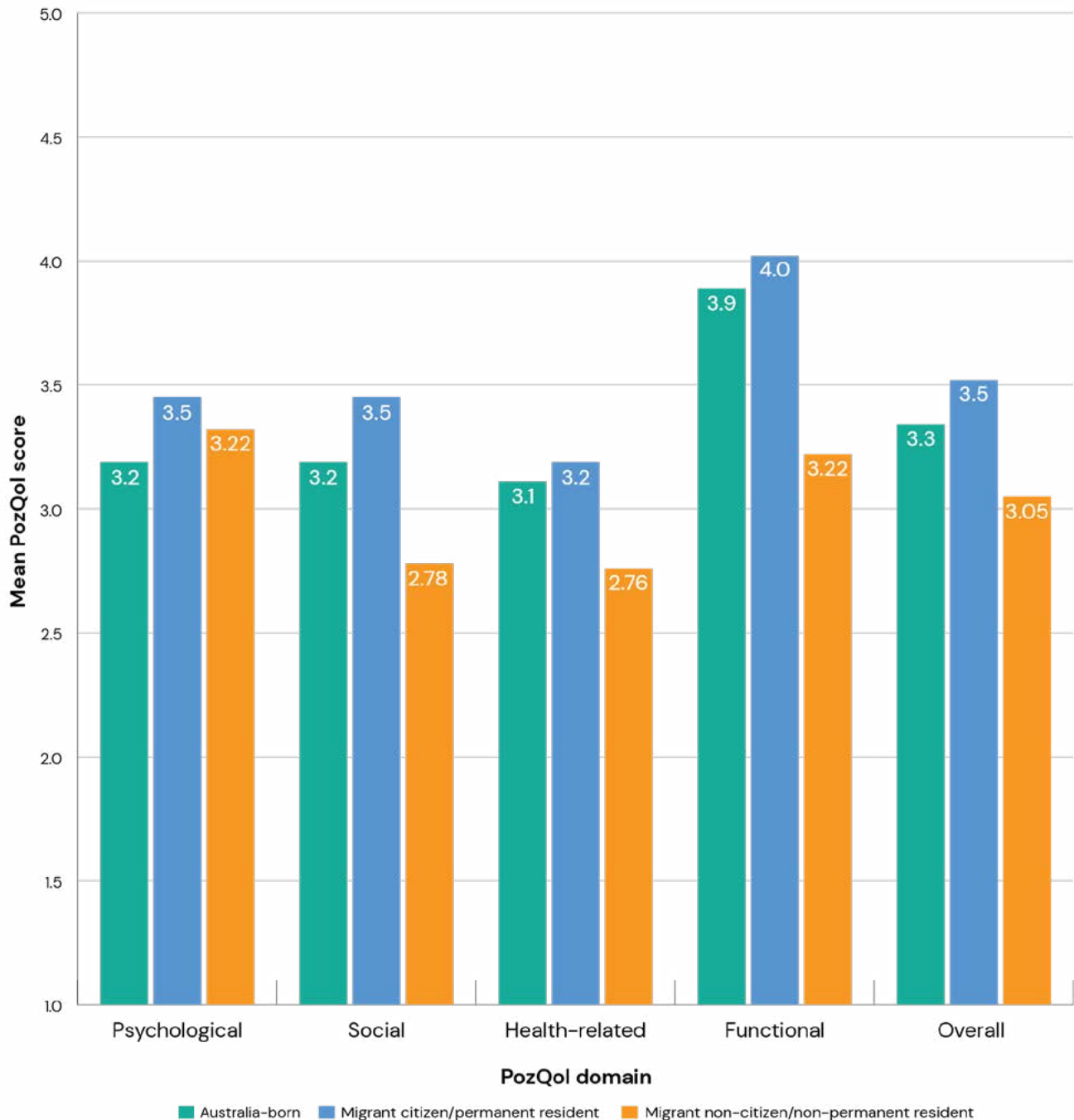
Post hoc analyses indicated that migrant participants who were Australian citizens or permanent residents reported significantly higher overall quality of life (M = 3.52), psychological quality of life (M = 3.45), and social quality of life (M = 3.45) than Australia-born participants (Ms = 3.34, 3.19, and 3.19, respectively). In contrast, migrants who were neither Australian citizens nor permanent residents reported the lowest quality of life across all domains.

Differences were most pronounced for social and functional quality of life. Migrant non-citizens/non-permanent residents reported significantly lower social quality of life (M = 2.78) than both Australia-born participants (M = 3.19, $p = .045$) and migrant citizens/permanent residents (M = 3.45, $p < .001$). Functional quality of life was also significantly lower among migrant non-citizens/non-permanent residents (M = 3.22) than among Australia-born

participants ($M = 3.89, p < .001$) and migrant citizens/permanent residents ($M = 4.02, p < .001$). For health-related quality of life, migrant non-citizens/non-permanent residents reported significantly lower scores ($M = 2.76$) than migrant citizens/permanent residents ($M = 3.19, p = .027$). While the difference in health-related quality of life between migrant non-citizens/non-permanent residents and Australia-born participants did not reach statistical significance, the trend was in the same direction ($M = 3.11, p = .063$).

These findings suggest that residency status is an important correlate of quality of life among migrants living with HIV. While migrant citizens and permanent residents generally reported comparable or better quality of life than Australia-born participants, migrants without citizenship or permanent residency consistently reported poorer outcomes, particularly in social, functional, and health-related domains.

Figure 41. Mean PozQol subdomain scores among people born outside of Australia, by migration background and residency status



Note: Means significantly differed for the functional, social, and health-related quality of life domains

EMPLOYMENT, INCOME, AND FINANCIAL SECURITY

Almost half (46.1%, n = 106) of people born outside of Australia reported working full-time, while smaller proportions reported part-time (8.7%, n = 20) or casual work (5.7%, n = 13). Around one in five participants were not working, including 16.5% (n = 38) who were retired or not working and 12.2% (n = 28) who were unemployed, either looking for work or not looking for work. Smaller proportions reported being students (3.9%, n = 9).

Most participants reported salary or wages as their main source of income (60.9%, n = 140), while 18.3% (n = 42) relied primarily on benefits, pensions, or social security payments. Smaller proportions reported superannuation (7.8%, n = 18), savings (3.9%, n = 9), or support from partners, family, or friends as their primary income source.

Household income levels varied across the sample. Around one-quarter of participants reported annual household incomes below \$30,000 (23.6%, n = 52), while 34.5% (n = 76) reported household incomes between \$30,000 and \$79,999. Approximately two in five participants reported household incomes above \$80,000 per year, including 20.5% (n = 45) reporting incomes between \$80,000 and \$124,999 and 21.4% (n = 47) reporting incomes of \$125,000 or more.

Despite relatively high levels of workforce participation, almost one in five participants born outside Australia (19.6%, n = 45) reported experiencing recent financial stress. This was roughly comparable to the overall sample (22.1%). Experiences of financial stress were similar among participants born outside of Australia regardless of whether English was their first language, with around one in five participants in both groups reporting two or more indicators of financial stress (19.5% among participants for whom English was not their first language and 19.7% among those for whom English was their first language).

HIV TREATMENT AND CARE

Participants born outside Australia generally reported high levels of engagement with HIV treatment and care. Almost all participants were currently taking antiretroviral treatment for HIV (99.0%, n = 203), and around two-thirds reported having had at least one treatment review in the previous three years, including 31.8% (n = 64) who had undergone one review and 30.8% (n = 62) who had undergone more than one review. Participants also reported high levels of confidence in managing their HIV care, with 83.0% (n = 167) reporting that they felt very or extremely confident asking their doctor for a treatment review if needed.

“Speaking as a migrant I can say that Australia is one of the best countries to be living with HIV. I can access a lot of services, from diagnosis to treatment, and support from peer workers and psychologists. I can’t get that in my own country”

Overall satisfaction with HIV treatment and clinical care was high. More than 80% of participants reported being very or extremely happy with their current HIV treatment (82.3%, n = 163). Most participants also disagreed that the side-effects of antiretroviral medications outweighed the benefits of treatment (51.5%, n = 104), although around one-quarter agreed or strongly agreed with this statement (27.7%, n = 56). Satisfaction with HIV clinical care was similarly positive, with 94.9% (n = 187) reporting being satisfied or very satisfied with the care they had received in the previous 12 months, including two-thirds who reported being very satisfied (66.5%, n = 131).

Most participants also reported access to bulk-billing services for HIV-related care (72.1%, n = 142), although around one in five participants indicated that they did not have access to bulk-billing HIV-related care (19.8%, n = 39).

EXPERIENCES OF STIGMA/ DISCRIMINATION AND CONCERNS ABOUT DISCLOSURE

“Living with HIV in Australia as a migrant is isolating, scary, and unfair. I just want to build a life here like anyone else, but instead I feel punished every single day for something I never chose.”

Participants born outside of Australia were asked how often they had experienced HIV-related stigma or discrimination in the previous 12 months, including experiences such as avoidance, pity, blame, shame, rejection, verbal abuse, or bullying. While most participants reported never experiencing HIV-related stigma or discrimination (58.9%, n = 109), around two in five participants reported experiencing stigma at least rarely (41.1%, n = 76). This included 21.1% (n = 39) who reported experiencing stigma rarely, 16.2% (n = 30) sometimes, and 3.8% (n = 7) often or always.

Experiences of HIV-related stigma and discrimination differed according to language background. Participants born outside of Australia who reported English as their first language were more likely than those whose first language was not English to report 'never' experiencing HIV-related stigma or discrimination in the previous 12 months (66.0% vs 51.1%). Conversely, participants whose first language was not English were more likely to report experiencing stigma or discrimination at least 'sometimes'. Overall, the association between language background and experiences of stigma or discrimination was statistically significant, $\chi^2(4)=10.46$, $p = .033$.

"The dilemma of stigma and the thought of being cut off from family and culture is still an issue for me, and I have not found a solution for it."

Participants born outside of Australia were also asked whether they had experienced negative treatment from health workers because of their HIV status in the previous 12 months. Most participants reported never experiencing this type of treatment (69.6%, $n = 128$). However, around one-third of participants reported experiencing negative treatment from health workers at least rarely (30.4%, $n = 56$), including 17.4% ($n = 32$) who reported this occurring rarely, 10.3% ($n = 19$) sometimes, and 2.7% ($n = 5$) often or always. There was no statistical difference in experiences of negative treatment from health workers based on language background (i.e., English as first language vs English not first language).

MENTAL HEALTH

Anxiety conditions (17.8%, $n = 41$) and depression, including persistent depressive disorder (17.0%, $n = 39$), were the most commonly reported current mental health diagnoses among participants born outside Australia. One in ten participants reported a current diagnosis of PTSD (10.0%, $n = 23$). Smaller proportions reported bipolar disorder (2.2%, $n = 5$) or obsessive-compulsive disorder (2.2%, $n = 5$), while borderline personality disorder (1.3%, $n = 3$) and schizophrenia (0.4%, $n = 1$) were rarely reported.

Many participants also reported recent use of mental health treatments or supports. Around one-third of participants reported taking medication for a mental health condition in the previous 12 months (31.1%, $n = 59$), while 40.5% ($n = 77$) reported receiving non-pharmaceutical mental health support such as counselling or psychological treatment.

SOCIAL AND PEER CONNECTION

Participants born outside Australia reported a range of social and peer connections relating to HIV. Most participants reported having at least one other person living with HIV in their friendship or social networks who they could talk to about living with HIV (68.6%, $n = 127$). Similarly, 65.0% ($n = 119$) reported having at least one person they believed was not living with HIV who they could talk to about their experiences of living with HIV.

"I feel I have more support here in Australia than my own country. I feel comfortable with the health services I get in Australia. It is good to have peer support."

Participants also commonly reported having friends who were living with HIV. More than half of participants reported that at least some of their friends were living with HIV (70.1%, $n = 129$), including 9.2% ($n = 17$) who reported that around half of their friends were living with HIV and 4.3% ($n = 8$) who reported that almost all or all of their friends were living with HIV. Around three in ten participants reported that none of their friends were living with HIV (29.9%, $n = 55$).

Peer support and peer-based services were also commonly utilised. Around one-third of participants reported accessing advice or support from a peer worker, peer educator, or peer navigator associated with a community organisation or health service in the previous 12 months, including 21.7% ($n = 40$) who had done so once or twice, 8.7% ($n = 16$) occasionally, and 14.7% ($n = 27$) regularly. Around one in five participants reported having utilised a formal peer navigator program in the previous 12 months (22.2%, $n = 41$).

Participants born outside Australia reported moderate-to-high levels of social connectedness overall, with a mean social connection score of 5.02 out of 7 (SD = 1.28). This was broadly comparable to the overall *HIV FUTURES 11* sample mean (4.9). No statistically significant differences in social connectedness were observed according to whether participants reported English as their first language ($F(1,177)=0.55$, $p = .458$).

II. IMPLICATIONS FOR PRACTICE

HIV FUTURES 11 paints a mixed but largely encouraging picture of life with HIV in contemporary Australia. Most participants reported good quality of life. Confidence in U=U was high. Fears of onward transmission have fallen substantially over three decades. Engagement in care, treatment uptake, and viral suppression all remain high. These findings reflect the remarkable achievements of the Australian HIV response, and the profound shift in what it now means to live with HIV. Yet the proportion of participants reporting good quality of life has stalled in recent years — and remains well below the national target of 95% by 2030.

This points to something more complex than clinical success alone can explain. Many PLHIV are living well, but quality of life is not shared equally. Poorer quality of life was concentrated among participants facing financial hardship, social isolation, poorer physical and mental health, stigma and discrimination, and uncertainty about the future. These experiences rarely stand alone. They intersect and accumulate, narrowing people's opportunities to live well with HIV.

Nowhere was this inequity more stark than among PLHIV with insecure residency status. While many participants born outside Australia reported outcomes comparable to those born here, participants who were not Australian citizens or permanent residents reported substantially poorer quality of life across multiple domains. *HIV FUTURES* cannot capture the full complexity of migration experience — but these findings make clear that belonging, security, access to services, and economic opportunity are no longer peripheral questions for Australia's HIV response. They are central to it.

Australia's population of PLHIV is living longer, and growing more diverse. *HIV FUTURES 11* reflects this diversity in the range of needs it surfaces: ageing, multimorbidity, and the long-term effects of treatment for some; financial stress, housing insecurity, isolation, poor mental health, stigma, or the experience of migration and settlement for others. Meeting this diversity will require services that are localised and targeted, not one-size-fits-all — an approach consistent with Australia's long history of community-led, peer-based, flexible HIV programs. The task now is to ensure these partnerships reach as far as the diversity they serve.

Some of the challenges facing PLHIV have not diminished — they have simply become harder to see. Overt discrimination was relatively uncommon

among *HIV FUTURES 11* participants. Yet disclosure anxiety, fear of rejection, and subtler forms of stigma continued to shape relationships and everyday life — and stigma remained strongly associated with poorer quality of life. Likewise, while confidence in U=U was high and transmission fears have fallen sharply over two decades, a substantial minority of participants still carried concerns about passing on HIV. Science has transformed the reality of living with HIV. Social and emotional experience has not always kept pace.

Advances in treatment, care, and prevention remain fundamental to Australia's HIV response, and have transformed the health and wellbeing of PLHIV. But *HIV FUTURES 11* suggests, with increasing clarity, that the next gains in quality of life will not come from biomedicine alone. What's needed now is sustained attention to the social, economic, psychological, and structural conditions that shape how PLHIV live. As the epidemic continues to change, so too must how we understand it, measure it, and respond.



APPENDIX: METHODS

The *HIV FUTURES 11* 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 (approximately every 2 to 3 years) since 1997. *HIV FUTURES 11* is the 11th iteration of this survey.

ETHICS APPROVAL

Ethics approval for this study was granted by:

- La Trobe University Human Research Ethics Committee (reference: HEC24187)
- Thorne Harbour Health Community Research Endorsement Panel
- ACON Research Review Ethics Committee

SAMPLE

Since 1997, *HIV FUTURES* surveys have achieved sample sizes of up to 1,200 participants. However, more recent survey waves have achieved smaller samples, with *HIV FUTURES 11* including 706 participants. Discussions with community organisations and researchers suggest this may partly reflect increasing survey fatigue among PLHIV, given the large number of requests to participate in research and consultation activities. More broadly, recruiting participants through online and community-based approaches may also be becoming increasingly challenging over time due to changes in social media use, online engagement, and research participation patterns.

It is also possible that PLHIV are less connected to HIV community organisations or networks than in earlier periods of the epidemic, when HIV treatment was less effective and many people required greater levels of practical and psychosocial support. Changes in HIV treatment, ageing with HIV, and shifts in community infrastructure and service provision may all have contributed to changes in patterns of community connection and research participation over time.

As with *HIV FUTURES 8, 9, and 10*, participants in *HIV FUTURES 11* were invited to provide information to generate a unique participant code. These codes enable participant responses to be linked across successive survey waves while maintaining confidentiality and anonymity, supporting future longitudinal analyses examining changes in health, wellbeing, and quality of life over time. Participants

were not required to provide contact details within the survey itself. However, participants completing the survey online were able to access a separate form to provide contact details if they wished to receive information about future *HIV FUTURES* studies.

RECRUITMENT

Data were collected between December 2024 and January 2026 using a self-complete survey that could be filled in online or using a hard-copy booklet that was supplied to prospective participants with a reply-paid envelope.

HIV FUTURES 11 was open to PLHIV, aged over 18 years and currently living in Australia. The study relied on a self-selected sample. Participants were recruited through electronic advertising in a range of forums including: advertisements sent through the email lists of HIV community organisations; advertising on relevant websites; social media advertising, particularly via Facebook and Instagram; and flyers and posters displayed in HIV clinics (as well as from S100 prescribers directly).

To gauge the effectiveness of recruitment techniques, participants were asked how they found out about the study. The most commonly reported recruitment source was a mail-out or email from an HIV organisation, selected by 27.9% (n = 197) of participants. Advertisements on Facebook were reported by 17.8% (n = 126) of participants, while 13.5% (n = 95) reported finding out about the survey through a previous *HIV FUTURES* survey. Other commonly reported sources included receiving a copy of the survey from an HIV organisation (10.3%, n = 73) or another source (10.2%, n = 72). Smaller proportions of participants reported hearing about the study through word of mouth (5.4%, n = 38), advertisements on websites (2.7%, n = 19), copies of the survey available at clinics (2.1%, n = 15), email from a friend (1.6%, n = 11), advertisements on TIM (1.3%, n = 9), advertisements in the gay press (1.0%, n = 7), or hookup and dating applications (0.3%, n = 2).

In contrast to *HIV FUTURES 10* (2021–22), where Facebook advertisements were the most commonly reported recruitment source (34.2%), HIV organisation mail-outs and emails were the most commonly reported source in *HIV FUTURES 11* (27.9%). The proportion of participants reporting Facebook advertisements as a recruitment source declined substantially between *HIV FUTURES 10* (34.2%) and *HIV FUTURES 11* (17.8%), while the proportion reporting recruitment through HIV organisations increased slightly (25.0% and 27.9%, respectively).

Participants were also asked whether they had completed a previous *HIV FUTURES* survey. More than half of respondents (54.0%, $n = 303$) reported having previously completed an *HIV FUTURES* survey, while 32.3% ($n = 181$) reported that they had not, and 13.7% ($n = 77$) were unsure.

INSTRUMENT AND MEASURES

The *HIV FUTURES 11* survey instrument was revised from previous *HIV FUTURES* surveys, a process undertaken through consultation with PLHIV, PLHIV advocacy organisations, HIV community organisations, clinicians, and others working in the Australian HIV sector. The *HIV FUTURES 11* instrument contained questions across 16 areas listed below:

- **Demographics:** Standard items were used to measure age, sex, gender, sexuality, place of residence (postcode), highest education level, total household income, current employment, current relationship status, and Australian residency and visa status.
 - **Financial and housing security:** Standard items were used to ask participants about their current housing arrangements, including the people with whom they live and type of housing they live in (rental, owned, public, other). Two items asked participants if they had experienced difficulty managing the cost of basic items for living (utility payments, rent, food and so forth) in the past 12 months. This was a modified version of an item used in the Australian Household Income and Labour Dynamics in Australia (HILDA) survey, a national population-based survey of Australian households (Wilkins, 2015).
 - **Quality of Life:** Quality of life was measured with the PozQoL scale, a quality of life scale developed specifically for PLHIV and validated with an Australian sample (Brown et al., 2018). PozQoL includes 13 items to assess quality of life 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 quality of life.
- **HIV diagnosis and viral load:** Participants were asked in which year they tested positive for HIV, in which year they believe they acquired HIV, and the means by which they acquired HIV. Participants were also asked the results of their most recent viral load test.
 - **HIV treatment:** Participants were asked whether they currently use ART. Participants not currently using ART were asked whether they had used ART in the past and their reasons for not taking ART. To measure attitudes toward use of ART, participants were asked to respond to six statements relating to beliefs and attitudes about beginning ART, and its safety and effectiveness. Several items asked participants to report on any problems they have with use of ART, including experience of side effects.
 - **Health and wellbeing:** The survey included the RAND 36-Item Short Form Survey 1.0 (SF-36) general health and emotional wellbeing subscales, which have been validated for use among PLHIV (Wu et al., 1997). Each of these scales are scored so that a total score ranging from 0–100 is calculated. A higher score indicates a more favourable health state. A further item asked participants to rate their overall sense of wellbeing using a 4-point Likert scale. Participants were also asked to report on their current vaccination status for seasonal influenza, COVID-19, mpox, and HPV.
 - **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 (e.g., pharmaceutical) or non-medical (e.g., psychological) treatment. Resilience was measured using the Brief Resilience Scale (Smith et al., 2008).
 - **Sexual health:** Participants were asked how often they had been screened for sexually transmissible infections (STIs) in the past 12 months and whether they had recently been diagnosed with a STI.
 - **Other physical comorbidities, including viral hepatitis:** Participants were asked whether they had been diagnosed with a range of chronic physical health conditions including HIV-associated neurocognitive disorder (HAND). They were also asked: whether they had ever been diagnosed with chronic hepatitis B, whether they had ever been screened for hepatitis C virus (HCV), whether they had ever tested positive for hepatitis C antibodies or been diagnosed with

chronic HCV, whether they had ever received treatment for HCV, and what were the outcomes of any treatment received.

- **Clinical services:** Participants were asked a range of questions about their experience of HIV clinical services including: whether they have access to Medicare, whether they have private health insurance, who they see for HIV-related treatment, whether they have access to bulk-billing services, how far they have to travel for HIV treatment, and how satisfied they are with clinical services.
- **Alcohol, tobacco and non-prescription drug use:** Participants were asked two standard questions about how often they smoked tobacco (Australian Institute of Health and Welfare, 2017) and three questions about their frequency and quantity of alcohol consumption (the AUDIT-C measure) (Dawson et al., 2005). Frequency of non-prescribed drug use in the past 12 months was assessed. Participants were also asked whether they had engaged in sexualised drug use in the previous 12 months.
- **Stigma and discrimination:** HIV-related stigma and discrimination were measured using items developed by the Australian Stigma Indicators Project run by the Centre for Social Research in Health at UNSW Sydney (Broady et al., 2019) and measures developed by Quinn et al. (2014). Experience of direct and indirect microaggressions were also assessed using the HIV Microaggression Scale (Eaton et al., 2021).
- **HIV-related laws:** Novel items assessed participants' understanding of their obligations regarding HIV transmission prevention and their rights regarding HIV status disclosure. Additional items examined perceptions of the impact of HIV-related laws, including whether such laws negatively affect what others think about PLHIV, make it difficult to be open and honest about HIV status, lead people to avoid sex or limit the type of sex they have, or affect enjoyment of sex.
- **Relationships and sex:** Participants were asked whether they had a current sexual partner or partners, whether they had a current romantic partner, whether they cohabit with a partner, the HIV status of their sexual partner or partners, whether their sexual partner or partners use PrEP, how satisfied they were with their sex life, and a range of questions related to the impact of HIV on their sexual and romantic lives.
- **Community services and peer support:** Participants were asked whether they are connected to, or spend time with, other PLHIV; whether they have accessed peer support programs or networks in the past 12 months;

what community services they utilise; and about their attitudes toward peer-based services, including whether services had contributed to or maintained wellbeing since being diagnosed with HIV.

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

DATA ANALYSIS

For this report, data analysis was descriptive, including analysis of frequency, t-tests and ANOVAs (using Tukey's HSD 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 11* 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.

The small number of responses for some groups of people, such as Aboriginal or Torres Strait Islander people, transgender and gender diverse people, or those reporting specific sexual orientations, limits the analysis that can be done specifically with these groups. This is because the sample is too small for reliable statistical analysis and the risk of identifying individuals is higher when the group is smaller.

A limitation of the sampling method is that it relies heavily on advertising through support organisations for PLHIV, HIV clinics, and online community networks. This means that people who are more socially connected to HIV community organisations or engaged in HIV care may have been more likely to participate in the survey. Conversely, people who are less connected to HIV services or community networks, more socially isolated, living in rural or remote areas, or experiencing greater stigma or disadvantage may be underrepresented in the sample.

As with previous *HIV FUTURES* surveys, the findings are based on self-reported data and may therefore be influenced by recall bias, social desirability bias, or differences in how participants interpreted survey questions. In addition, the cross-sectional design of the survey means that findings describe associations at a single point in time and

cannot be used to determine causality or changes in individuals' experiences over time.

Despite these limitations, *HIV FUTURES II* remains one of the largest and longest-running national studies examining the health and wellbeing of PLHIV in Australia and provides important insights into the experiences, needs, and priorities of PLHIV across diverse areas of life.

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