

HIV Futures 9

Quality of life among people
living with HIV in Australia

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September 2019
Monograph Series Number 116
ISBN 978-0-9953969-6-8 © La Trobe University 2019

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Suggested citation: Power, J., Amir, S., Brown, G., Rule, J., Johnson, J., Lyons, A., Bourne, A. and Carman, M. (2019) ***HIV Futures 9: Quality of Life Among People Living with HIV in Australia***, monograph series number 116, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

EXECUTIVE SUMMARY

HIV Futures 9 is a study of quality of life among people living with HIV (PLHIV) in Australia that forms part of a series of studies that have been running since 1997. In each iteration of the HIV Futures study, a cross sectional survey of the Australian population of PLHIV is conducted. Data were collected for HIV Futures 9 from December 2018 until May 2019. Participants completed a questionnaire using a self-complete online or hardcopy form. The survey instrument comprised 148 questions related to quality of life, financial security, health, wellbeing, treatment, support, sex, relationships, HIV-related stigma, and ageing.

Demographic characteristics

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

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

Quality of life

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

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

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

Financial and housing security

As financial security is strongly linked to better quality of life, the HIV Futures 9 survey included key indicators of financial security: household income, recent financial stress, current accommodation/housing situation, food security, and ability to afford healthcare. The overall picture suggests that, as a group, PLHIV are more vulnerable to financial insecurity than the general Australian population with one in three reliant on government benefits for income, and one in three reporting recent financial stress. Specifically:

- 35.3% reported their main source of income to be social security (including a pension, disability pension or other government benefits)
- 33.3% reported an annual household income of less than \$30,000, and the majority of these people (71.5%) were reliant on social security/pension as their main source of income
- 77.6% reported an annual household income of less than \$100,000 (lower than the average Australian household income in 2018, which was approximately \$110,000)
- 31.0% were classified as having experienced financial stress in the past 12 months (using standard measures of financial stress that include difficulty paying bills or rent/mortgage) – women were more likely than men to report recent financial stress
- 42.7% were living in private rental accommodation, while 33.5% owned their home (with or without a mortgage), and 16.4% lived in public housing; this is substantially lower than 2016 Australian population figures in which 30.9% lived in rental accommodation and 65.5% lived in a home they owned (with or without a mortgage)
- People living in private rental accommodation were more likely to report recent financial stress than those living in their own home, while people who were homeless or living in public/community housing were most likely to report recent financial stress
- Approximately 25-30% indicated that they often or sometimes ran out of food or could not afford to eat balanced meals, indicators of food insecurity

- 7.8% indicated they had not taken HIV medication at least once in the last 12 months due to financial reasons
- 38.2% indicated that it was somewhat or very difficult to access medication for financial reasons
- 26.4% indicated it was somewhat or very difficult to access healthcare for financial reasons.

HIV diagnosis, treatment and viral suppression

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

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

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

Health and wellbeing

General health. The general health of the HIV Futures 9 sample as a whole was comparable to that of the Australian population, although people aged 50-64 reported poorer general health than other age groups, as did people who had been living with HIV for a longer time.

Mental health. Consistent with previous HIV Futures surveys, rates of mental health problems were higher among HIV Futures 9 participants than the Australian average. Specifically:

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

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

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

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

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

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

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

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

Stigma and discrimination

More than half the HIV Futures 9 participants (56.6%) reported at least one experience of HIV-related stigma or discrimination in the past 12 months, while 38.0% reported that they had been treated differently by a healthcare worker due to their HIV in the past 12 months.

Social connectedness

A greater sense of social connectedness was correlated with better quality of life among HIV Futures 9 participants. Variables associated with greater social connectedness were: a higher income, no recent financial stress, being in the paid workforce, and living with a partner or other adults. Looking at each of these variables, we can see that a large proportion of HIV Futures 9 participants may be vulnerable to low levels of connectedness, or loneliness. Specifically:

- 44.7% of participants live alone. This will not lead to social isolation or loneliness for everyone, but as a general trend it is associated with lower social connectedness.
- 61.5% are single (not in a current relationship). As with living alone, being single isn't associated with social isolation or loneliness for everyone but, as a general trend, cohabiting with a partner does appear to be a buffer against social disconnection.
- 33.3% reported an annual income of less than \$30,000. Of these people, 66.1% were living alone. The combination of living alone and a low income may make someone vulnerable to social isolation. It is also possible these people are reliant on social security due to disability or illness, which could be a further barrier to social connection.
- 43.9% are not in the paid workforce. While this includes people who are retired (not necessarily people who want to be working), it is still possible that lack of daily contact with colleagues – combined with lower incomes – makes people out of the workforce more vulnerable to social disconnection.

Peer connection and support

Most HIV Futures 9 participants had connections with other PLHIV and indicated that they valued these connections:

- 66.8% knew at least one other PLHIV in their social/informal networks who they could talk to about HIV
- 59.9% agreed that knowing other PLHIV was important to them
- 49.2% were interested in being part of a community of PLHIV.

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

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

Peer-based programs and services play an important role in connecting PLHIV with each other and providing support for PLHIV, especially those who may be vulnerable due to recent HIV diagnosis, ill health, ageing, or social isolation. Among HIV Futures 9 participants:

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

In the past 12 months:

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

Ageing

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

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

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

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

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

Women living with HIV

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

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