LA TROBE
UNIVERSITY

HIV FUTURES 8

Health and wellbeing of people living with HIV

Australian Research Centre in Sex, Health and Society

2016

INTRODUCTION

HIV Futures 8 is a survey about the health and wellbeing of people living with HIV (PLHIV) in Australia. The study forms part of a series of cross-sectional surveys that have been run every two to three years since 1997. Funded by the Australian Government Department of Health, the aims of the study are to provide information about factors that support physical and emotional wellbeing among PLHIV. The study is designed to inform the Australian National HIV Strategy and guide community and clinical service provision for PLHIV.

In order to explore the complexity of factors that support health and wellbeing among PLHIV, HIV Futures 8 is a broad survey covering issues such as financial security, housing status, antiretroviral treatment use, general health issues, stigma and discrimination, clinical and support service use, aging, drug and alcohol use, sexual health, relationships, and social connectedness.

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. Findings from HIV Futures 8 are presented as a series of short reports. These, along with more information about the study and copies of reports from previous HIV Futures surveys, can be found on the ARCSHS website: **latrobe.edu.au/arcshs**

SUGGESTED CITATION

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METHODS

HIV Futures 8 is a cross-sectional survey of PLHIV. The survey was open to people aged 18 years or older who were currently living in Australia. Data were collected using a self-complete survey that could be filled in online or using a booklet that was supplied to prospective participants with a reply-paid envelope. 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 Facebook including targeted posts to Facebook groups for PLHIV; advertisements on 'dating apps' used by gay men and other men who have sex with men and; flyers and posters displayed in HIV clinics. Hard copies of the survey were distributed through the mailing lists of HIV community organisations and made available in the waiting rooms of HIV clinics and community services. Data were collected between July 2015 and June 2016.

Full details of the study protocol and method have been published elsewhere and are available on the ARCSHS website: **latrobe.edu.au/arcshs**

ACKNOWLEDGEMENTS

We thank all study participants for their interest and willingness to participate in this project. There are many community organisations that have provided ongoing support to the HIV Futures project, including the following peak HIV organisations and their members: the National Association of People with HIV Australia, the Australian Federation of AIDS Organisations and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine. Many researchers from the Australian Research Centre in Sex, Health and Society at La Trobe University have worked on this project since 1997. In particular, we acknowledge Michael Bartos, Richard de Visser, Douglas Ezzy, Jeffrey Grierson, Rachel Koelmeyer, Karalyn McDonald, Darryl O'Donnell, Marian Pitts and Doreen Rosenthal. This study is funded by the Australian Government Department of Health.

Australian Research Centre
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SAMPLE

HIV Futures 8 was completed by 895 people living with HIV in Australia. Of these, 90.5% (n=804) were men, 8.3% (n=74) were women, six people identified as transgender and four people described their gender in other terms.

The majority of the sample were men who identified as gay (78.7%, n=697), 5.6% (n=50) identified as bisexual and 4.3% (n=38) as heterosexual.

There were 21 participants (2.3%) who identified as Aboriginal or Torres Strait Islander.

The age of participants ranged from 19 to 86 years. The average age was 51 years. Over half (56.3%, n=485) were aged 50 years or older.

The majority of participants were born in Australia (74.7%, n=649) and spoke English as their first language (91.2%, n=792).

Participants came from all states and territories in Australia as detailed in Table i.

The majority of participants were working (53.8%, n=474) either full-time (38.6%, n=341) or part-time (15.2%, n=134). There were 18.1% (n=160) who were retired/no longer working.

There were 234 (26.7%) participants who had tested positive to HIV within the five years prior to the survey (from 2010 onward). Of these, the majority (77.0%) were under 50 years of age. However, there were 51 participants (23.0%) aged 50 or older who had been diagnosed in 2010 or more recently.

There were 844 participants (96.6%) currently using antiretroviral therapy. Of these, 756 (91.0%) reported they had an undetectable viral load as of their most recent test. (Note, these figures exclude missing data).

Full details of the study sample are available on the ARCSHS website **latrobe.edu.au/arcshs**

Table i. States and territories in which participants currently live

	n	%
ACT	20	2.3
NSW	306	34.5
NT	6	0.7
QLD	136	15.3
SA	65	7.3
TAS	10	1.1
VIC	265	29.9
WA	78	8.8

*Nine participants did not identify their state/territory

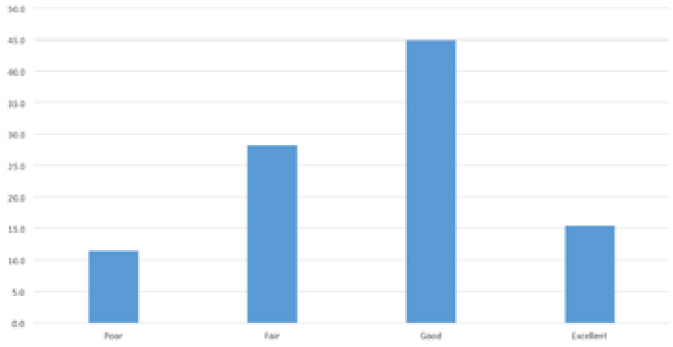
BACKGROUND

The Seventh National HIV Strategy in Australia includes as one of its objectives to, "improve quality of life of people living with HIV" (Australian Government Department of Health, 2014, p5). General health and wellbeing are important indicators of health related quality of life among people living with HIV. This short report focuses on relevant measures of health and wellbeing among HIV Futures 8 survey participants, including self-reported physical and mental health, along with factors that may influence health such as tobacco, alcohol and other drug use. We look at these findings with reference data from previous HIV Futures surveys as well as other surveys of the general Australian population to get a sense of how Australian PLHIV are tracking at this point in time.

HEALTH AND WELLBEING OVER TIME

Participants were asked to report their overall sense of wellbeing (incorporating physical, mental and emotional wellbeing). The majority of participants (60.4%, n=533) reported their overall sense of wellbeing to be good or excellent (see Figure 1).

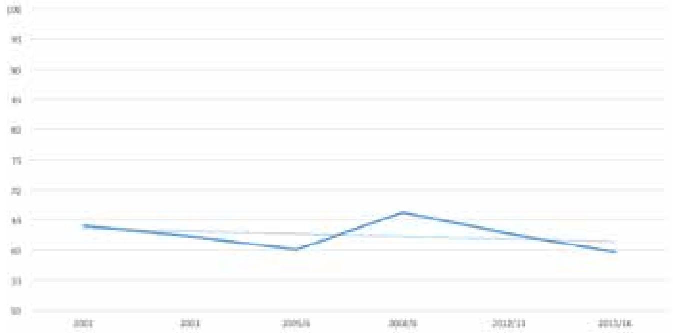
Figure 1. Overall wellbeing (%)



There were no significant differences in reported wellbeing between age groups (see Table 1).

Figure 2 shows the percentage of people who reported their wellbeing to be good or excellent in previous HIV Futures surveys, from 2001 onward. A lower percentage of participants in HIV Futures 8 identified their wellbeing to be good or excellent than in previous years, although it is worth noting that the scores ranged between 58 and 68% in all years.

Figure 2. Self-reported overall wellbeing over time (% reporting wellbeing to be good or excellent)



Participants were asked to rate their current state of physical health using a five-point scale (poor to excellent). Over half the sample (n=495, 55.6%) rated their health as very good or excellent (see Figure 3). This finding is consistent with the Australian National Health Survey in which 56.2% of Australian aged 15 years or older rated their health as very good or excellent (Australian Bureau of Statistics, 2016). In HIV Futures 8, older people were significantly less likely to consider their health to be excellent or very good (see Table 1).

Figure 3. Self assessed physical health (%)

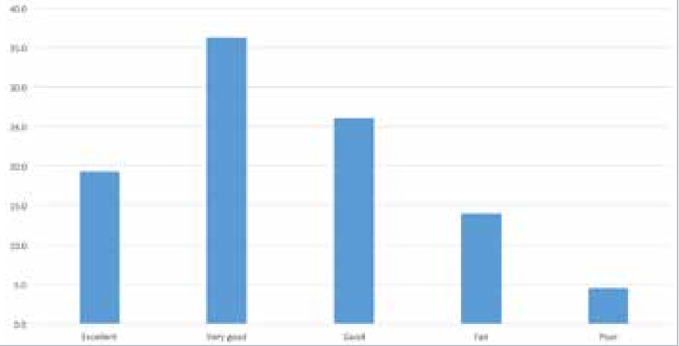
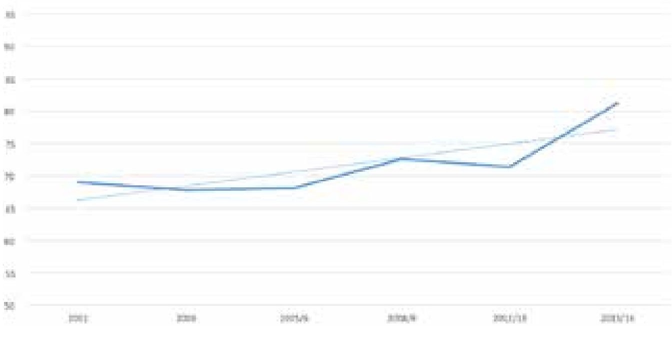


Figure 4 shows physical health over time. In previous HIV Futures surveys, physical health has been measured using a four point scale (poor, fair, good, excellent). In HIV Futures 8, a five point scale (poor, fair, good, very good, excellent) was used to align the question with the Australian National Health Survey and other national datasets. To compare over time, we have collapsed ‘excellent’, ‘very good’ and ‘good’ into one category for HIV Futures 8 and for previous years collapsed ‘very good’ and ‘excellent’. This may have skewed responses toward a more favourable assessment of health as the number of people reporting their health to be good/very good/excellent in HIV Futures 8 is substantially higher than those reporting their health to be good/excellent in previous years. However, Figure 4 shows a general upward trend toward better health between 2001 and 2016.

Figure 4. Self-reported general physical health over time



HIV FUTURES 8 FINDINGS

Overall health

In HIV Futures 8, participants were asked to report their general health using the RAND SF-36, a widely used, standardised measure of physical and mental health (RAND, 2016). Within the SF-36 there is a subscale measuring general health using five questions related to perceptions of current and likely future physical health. Scores for this subscale range from 0-100, with higher scores showing better reported general health.

The median physical health subscale score for the HIV Futures 8 sample was 65 with a mean of 60.8. The mean score was highest among people aged under 35 and lowest among those aged 50-64 years (see Table 1).

To compare these findings with that of the general Australian population, we looked at published reports from the Household, Income and Labour Dynamics Australia (HILDA) study, a major study which involves a representative sample of Australian households (Wilkins, 2015). A recent report indicated the median score for the SF-36 general health subscale among HILDA participants was 72 (Wilkins, 2015). This is considerably higher than the HIV Futures 8 median score of 65.

This difference likely reflects a higher level of healthcare need among PLHIV than the general Australian population. It may also indicate greater concern among PLHIV about their future health. The difference is also likely due to the high average age of HIV Futures 8 participants. HILDA includes people aged 15 years and older. In general, younger people report better physical health. However, the mean scores for HILDA participants aged over 50 were higher than for HIV Futures 8. In HILDA, the mean SF-36 general health score for people aged 50-59 was 65.5 and for people aged 60-69 it was 61.3 (Wilkins, 2015). In HIV Futures 8, the mean score for people aged 50 or older was 57.4.

Mental health

The SF-36 subscale for mental/emotional wellbeing includes five questions which ask participants how much of the time during the past four weeks they have felt particular ways including ‘nervous’, ‘down in the dumps’, ‘calm and peaceful’ and ‘happy’. Scores for this subscale range from 0 to 100 with higher scores representing better mental health.

For HIV Futures 8 participants, the median mental subscale health score was 71, and the mean was 67.3 (see Table 1). By comparison, the median mental health subscale score reported in recent findings from the HILDA data was 76 (Wilkins, 2015). This is consistent with our previous research which has indicated PLHIV may experience poorer mental health than the general population (Heywood and Lyons, 2016).

Unlike physical health, self-reported mental health among HIV Futures 8 participants improved with age. The mean score for people aged 65 or older was the highest mean score for all age groups (see Table 1).

Diagnosed mental health conditions

More than half the participants in HIV Futures 8 (51.8%, n=454) indicated they had been diagnosed with a mental health condition at some point in their life, while 31.9% (n=277) had taken medication for a mental health condition within the past six months.

Depression and anxiety were the most common conditions reported by participants:

- 42.4% (n=379) had ‘ever’ been diagnosed with depression, while 11.5% (n=103) had been diagnosed since 2010
- 28.5% (n=255) had ‘ever’ been diagnosed with anxiety, while 9.7% (n=87) had been diagnosed since 2010.

Less prevalent conditions were reported by a smaller number of participants: bipolar disorder (4.3%, n=38), post-traumatic stress disorder (7.0%, n=63), psychosis (2.8%, n=25).

Physical impairment/disability

To assess physical impairment or disability, we asked five questions related to impairment or disruption to everyday life as a result of physical ill-health. Results are presented in Table 2.

Four of these questions were part of the SF36 and formed a subscale on ‘role limitation due to physical health’. Scores range from 0 to 100 with higher scores indicating better physical functioning.

The overall mean score for participants was 68.3%. Older people were significantly more likely to report limitations in physical functioning due to health (see Table 1).

There were 42 people who indicated they needed regular assistance with daily tasks due to long term illness or disability. Despite this, only 12 people indicated they received formal home-based care. Four people indicated they required home based care but it was not available in their area, while seven required home based care but found it unaffordable.

Table 2. Physical impairment/role limitation due to physical health

Activities	% (n)
Cut down amount of time spent on work or other activities	25.7 (224)
Accomplished less than you would like	36.7 (321)
Were limited in the kind of work or other activities	30.2 (262)
Had difficulty performing work or other activities	33.9 (294)
Regularly need help with daily tasks because of long term illness or disability	4.8 (42)

Other health conditions including viral hepatitis

Managing multiple health conditions and treatments can become complicated for PLHIV. We asked participants if they had ever been diagnosed with a range of health conditions other than HIV and if they were currently receiving medication. Responses are listed in Table 3. The most common conditions for which people were currently receiving treatment were hypertension, cardiovascular disease and arthritis.

There were 113 people (12.6%) who had been diagnosed with hepatitis B. Of these, 69.9% (n=79) had cleared the virus, 15.0% (n=17) had ongoing hepatitis B infection while 6.2% (n=7) had chronic hepatitis B. More than half the sample (67.9%, n=584) had been vaccinated against hepatitis B.

There were 104 people (11.6%) who had been diagnosed with hepatitis C. Of these, 46 people indicated they had taken interferon or interferon/ribavirin combination treatment. Data were collected for this survey before new direct acting antiretroviral treatments for hepatitis C became available in Australia.

Table 1. Self-rated physical health, overall wellbeing and general health and age		**<35 years**	**35-49 years**	**50-64 years**	**65+ years**	**Total**
		% (n)				
Overall sense of wellbeing	Excellent/good	61.8 (63)	58.8 (160)	58.5 (209)	69.9 (86)	60.7 (518)
	Fair/poor	38.2 (39)	41.2 (112)	41.5 (148)	30.1 (37)	39.3 (336)
Physical Health	Excellent/very good	69.9 (72)	61.3 (168)	47.6 (170)	51.6 (64)	55.2 (474)
	Good	19.4 (20)	26.6 (73)	28.6 (102)	25.8 (32)	26.5 (227)
	Fair/poor	10.7 (11)	12.0 (33)	23.8 (85)	22.6 (28)	18.3 (157)
		Mean score				
SF-36 General Health Subscale	Score range, 0-100	68.9	63.4	56.8	59.3	60.8
SF-36 mental health subscale	Score range, 0-100	68.2	66.3	65.5	73.9	67.3
SF-36 Role limitation due to physical health	Score range, 0-100	84.1	72.0	61.5	65.9	68.3
Excludes missing data						

Sexually transmissible infections

We asked participants if they had been screened for sexually transmissible infections (STIs) within the past 12 months. There was 77.7% (n=684) who indicated they had. There were also 534 participants (60.5%) who indicated they had been screened for syphilis at their last (HIV) viral load test.

There were 197 participants (22.3%) who indicated they had been diagnosed with a STI in the past 12 months. The number diagnosed with each of a range of common STIs is shown in Table 4.

Of these who had been diagnosed with a STI, 92.4% (n=182) received treatment. Those who did not receive treatment were those who had been diagnosed with non-curable conditions such as genital herpes for which treatment may not always be of benefit. There was 4.5% (n=40) who indicated they had been diagnosed with syphilis more than once in the past five years.

Table 4. Participants diagnosed with sexually transmissible infections diagnosed within the past 12 months

	% (n)
Gonorrhoea	10.5 (94)
Chlamydia	9.9 (89)
Syphilis	9.9 (89)
Genital herpes	1.8 (16)
Shigella	<1 (5)
Lymphogranuloma venereum (LGV)	<1 (4)
HPV (warts)	<1 (4)

Advanced HIV disease (AIDS-defining illness)

There are a number of health conditions which are indicative of advanced HIV disease or an AIDS-defining illness. Many PLHIV in Australia today may have experienced one or more of these conditions at some point, but due to improved treatment efficacy would now be classed at a less severe stage of HIV progression. We asked participants if they had experienced any of a range of possible AIDS-defining illnesses within the past 12-months in order to assess current burden of illness.

In the past twelve months: 3.0% (n=27) had been diagnosed with pneumonia, 2.6% (n=23) with cognitive impairment, 1.2% (n=11) with HIV-related psychosis, 1.1% (n=10) with candidiasis of the lower respiratory tract or oesophagus, 1.0% (n=9) with AIDS-related dementia, <1% (n=5) with CMV or retinitis, and <1% (n=3) with Karposi's Sarcoma.

Tobacco, alcohol and other drug use

We asked participants about their use of tobacco. There were 213 participants (24.3%) who indicated they currently smoke daily and 323 (36.9%) who had previously smoked daily but quit. This is higher than figures for the Australian population as a whole. The 2013 National Household Drug Survey indicated that 12.8% of Australians smoke daily (Australian Institute of Health and Welfare, 2014).

We asked participants about their use of alcohol by use of the AUDIT-C scale which includes three questions related to frequency and volume of alcohol consumption. From this scale, a total score is derived ranging from 0-12 with higher scores indicating greater risk of alcohol-related harm. In women, a score of three or higher is considered medium to high risk and, in men, a score of 4 or more is considered medium to high risk (Royal Australian College of General Practitioners, 2016). In HIV Futures 8 there were:

- 30 women with an Audit C score of 3 or higher (69.8% of respondents to this question, n=31 did not respond).
- 355 men with an Audit C score of 4 or higher (60.0% of respondents to this question, n=212 did not respond).

Participants were asked whether they had used any of a range of drugs for non-medical purposes within the past 12 months. The results are listed in Table 5. Pain killers, sleeping pills and marijuana were most likely to be used occasionally or regularly by participants.

There were 30 participants (3.4%) who had been diagnosed with a substance dependence disorder in the past 12 months. There were 26 participants (4.0%) who indicated that non-medical use of drugs limited their capacity to participate in work or other activities on a regular or daily basis.

We asked participants whether they had injected drugs for non-medical purposes within the past 12 months. There were 97 (11.2%) who had injected meth/amphetamine, nine (1.2%) who had injected heroin, four who had injected steroids and four who had injected cocaine. The most common social context in which participants injected drugs was at home with friends/partner (51.9%, n=56), alone at home (22.2%, n=24) or at a party (15.7%, n=17).

Table 3. Health conditions other than HIV according to age	Ever been diagnosed		Currently receiving treatment	
	Aged <50 (N=377)	Age 50 or over (N=485)	Aged <50 (N=377)	Age 50 or over (N=485)
	% (n)			
Hypertension	7.7 (29)	27.2 (132)	5.8 (22)	25.1 (122)
Arthritis	6.6 (25)	26.6 (129)	2.4 (9)	12.8 (62)
Hepatitis B	3.2 (12)	20.8 (101)	1.1 (4)	3.1 (15)
Cardiovascular disease	2.4 (9)	17.7 (86)	1.3 (5)	15.3 (74)
Asthma	17.5 (66)	17.1 (83)	8.8 (33)	11.3 (55)
Hepatitis C	10.6 (40)	13.2 (64)	2.6 (10)	2.3 (11)
Respiratory disease	3.4 (13)	12.0 (58)	1.6 (6)	4.7 (23)
Osteoporosis	2.1 (8)	11.8 (57)	<1 (3)	8.2 (40)
Diabetes	2.9 (11)	8.9 (43)	2.4 (9)	6.2 (30)
Kidney disease	2.4 (9)	5.8 (28)	1.1 (4)	1.8 (9)
Haemophilia	<1 (2)	<1 (4)	<1 (1)	<1 (2)
Cancers				
Prostate cancer	<1 (1)	2.3 (11)	0	1.0 (5)
Breast cancer	0	<1 (1)	0	0
Other cancer	4.5 (17)	14.6 (71)	1.3 (5)	1.2 (6)

Excludes missing data

Table 5. Drugs used for non-medical purposes in the past 12 months

	Used occasionally	Used regularly
	% (n)	
Pain killers/ analgesics	22.4 (192)	8.6 (74)
Tranquilisers/ sleeping pills	13.7 (116)	6.1 (52)
Marijuana	10.6 (90)	10.6 (90)
Meth/amphetamine	7.1 (60)	3.9 (33)
Inhalants	5.7 (48)	1.5 (13)
GHB	3.0 (25)	0.9 (8)
MDMA/ecstasy	3.8 (32)	0.2 (2)
Steroids	1.4 (12)	0.8 (7)
Opioids other than heroin (morphine, oxycodone)	1.2 (10)	1.1 (9)
Ketamine	1.1 (10)	<1% (1)
Cocaine	<1% (7)	<1% (5)
Heroin	<1% (6)	<1% (3)
Synthetic cannabis	<1% (1)	<1% (3)
Hallucinogens	<1% (2)	0

Excludes missing cases

SUMMARY AND CONCLUSIONS

Overall, PLHIV who participated the HIV Futures 8 survey reported high levels of physical health and good general health overall. As would be expected, people who were older were more likely to report poorer physical health, more likely to have co-morbidities and more likely to report limitations in their capacity to undertake daily tasks due to poor health. This points to a need for the HIV sector and the mainstream health and aged care sectors to ensure appropriate services are available to PLHIV. This will require clinical and support staff to have skills in HIV management as well as an understanding of social issues related to HIV, including stigma and discrimination.

Over half the participants in this study had been diagnosed with a mental health condition in their lifetime – most commonly anxiety or depression. Given most PLHIV are likely to be engaged with medical care for the clinical management of HIV, inclusion of mental health screening and care at this point of contact could be an important strategy to improve mental health among PLHIV. Previous research has found that concerns about stigma or discrimination are associated with poorer mental health among PLHIV (Heywood and Lyons, 2016). Programs which address HIV-related stigma within the community, or which aim to challenge the impact of stigma among PLHIV, are likely to also be an important strategy to improve mental health.

There is an ongoing need to pay attention to tobacco and other drug use among PLHIV. Daily tobacco use was high among survey participants. This has been a consistent finding in HIV Futures surveys over the years and quit smoking programs have been initiated by a number of community based HIV services in Australia in response. In this survey we found a relatively high number of people reporting occasional or regular use of prescription drugs (pain killers and sleeping pills) for non-medical purposes. There was also a relatively high number of participants (over 10% of the sample) who had injected meth/amphetamine within the past 12 months. Recreational drug use is not necessarily problematic for all individuals. Only a small number reported drug use interfered with their everyday life in a negative way. However, harm minimisation programs which support safe use of recreational drugs and which challenge stigma or discrimination associated with drug use may help to reduce potential risks associated with some drug use, such as a greater likelihood of unsafe sex or unsafe injecting practices.

THOUGHTS AND COMMENTARY

The responses from the Australian community of People Living with HIV (PLHIV) to the latest HIV Futures survey, HIV Futures 8, provide a necessary and compelling insight into where we, as a sector and a community, are 'at' in regard to HIV.

Since HIV Futures 7 was released over three years ago, there has been a significant increase in the visibility of HIV, including Melbourne's hosting of AIDS 2014. There have also been radical changes in the ways PLHIV can access treatment, as well as the trialling of PrEP, the rollout of "ENDING HIV" in some jurisdictions, as well as a new wave of activists and advocates. In short, the HIV landscape in Australia has shifted since the previous HIV Futures survey and, as such, it is with great interest that we view the results of the latest survey.

While the makeup of survey respondents was not a completely accurate reflection of the Australian PLHIV community (overwhelmingly, respondents were MSM, with an average age of 51, and Women Living with HIV were slightly under-represented), the survey raises some vital questions about the direction of the Australian HIV response.
The following points bear noting, with commentary/response beneath:

- Over half the participants in this study had been diagnosed with a mental health condition in their lifetime – most commonly anxiety or depression.
- Programs which address HIV-related stigma within the community, or which aim to challenge the impact of stigma among PLHIV, are likely to also be an important strategy to improve mental health.

This is a crucial piece of information to take from HIV Futures 8. Programs that are designed to reduce the impact of HIV stigma must continue, be they aimed at reducing social isolation, fostering new leadership, or creating pathways for long-term survivors to process their experiences. Stigma has been identified since the 2012 Stigma Audit, which was at the time invaluable. Now, four years later, the work delivered by the HIV sector to deal with stigma perhaps requires a scaling up.
In the last four years, we have become very good at identifying stigma, however, pathways to develop community and individual resilience needs greater focus.

Of these who had been diagnosed with an STI, 92.4% (n=182) received treatment.

This is an important point to press. Namely, that PLHIV are responsible, sexually active people. Since HIV Futures 7, community dialogue around what it means to live with an undetectable viral load has risen dramatically, particularly for MSM.

There were 42 people who indicated they needed regular assistance with daily tasks due to long term illness or disability. Despite this, only 12 people indicated they received formal home-based care.

If the Australian HIV response is to engage with the broad spectrum of PLHIV, it is vital that it extends service delivery beyond the ever-shrinking community of people classed as "high needs clients". This is a precarious scenario, as service delivery for high needs PLHIV are at risk of being folded into other forms of service delivery often managed by potentially ignorant, faith-based providers that may alienate or isolate PLHIV.

However, while the sector remains beholden to servicing this aspect of the PLHIV community at the expense of engagement with more recently diagnosed/low needs PLHIV, it will become increasingly difficult to claim state-funded organisations truly represent the PLHIV community.

Nic Holas, Co-Founder of The Institute of Many (TIM) and Positive Leadership Development Institute (PLDI) facilitator

There a range of factors that can impact upon the health and wellbeing of people living with HIV. Our physical health is improving, in line with advances in HIV medicine that means more of us are able to achieve an undetectable viral load. However, when it comes to emotional and mental wellness, people living with HIV face additional challenges, particularly stigma and discrimination.

Stigma can be both internal and external. Many people living with HIV internalise stigma. Stigma and discrimination, be it malicious or unintended, from our friends, colleagues, family members, health care providers sexual partners and the media can contribute to the internalised stigma we may feel. However, over time people living with HIV can build resilience through self-acceptance, social connectedness and empowerment. Resilience is not about being in a perpetual state of wellness – some days are easier than others living with a chronic manageable illness like HIV.

As many people living with HIV begin to age with the virus, we as a community need to ensure that people remain socially connected. We know that connected individuals face better health outcomes.

Recreational substance use within some subpopulations of people living with HIV is more prevalent compared with the general population. While the data on substance use in Futures 8 is consistent with other studies, some subpopulations within the sample, such as gay and bisexual men, use may be higher than reported for the entire sample. Prevalence of substance use is not necessarily an indicator for misuse nor harm. There are a range of reasons why some subpopulations of people living with HIV choose to use substances, such as for pleasure in association with some sexual subcultures and practices. Harm reduction initiatives and education about safer substance consumption (including safer injecting practices) should therefore be priority for our community. Such initiatives should also have mental health components, acknowledging the mental health findings in Futures 8.

Joel Murray

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HIV FUTURES 8

Experiences of antiretroviral treatment

Australian Research Centre in Sex, Health and Society

2016

INTRODUCTION

HIV Futures 8 is a survey about the health and wellbeing of people living with HIV (PLHIV) in Australia. The study forms part of a series of cross-sectional surveys that have been run every two to three years since 1997. Funded by the Australian Government Department of Health, the aims of the study are to provide information about factors that support physical and emotional wellbeing among PLHIV. The study is designed to inform the Australian National HIV Strategy and guide community and clinical service provision for PLHIV.

In order to explore the complexity of factors that support health and wellbeing among PLHIV, HIV Futures 8 is a broad survey covering issues such as financial security, housing status, antiretroviral treatment use, general health issues, stigma and discrimination, clinical and support service use, aging, drug and alcohol use, sexual health, relationships, and social connectedness.

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. Findings from HIV Futures 8 are presented as a series of short reports. These, along with more information about the study and copies of reports from previous HIV Futures surveys, can be found on the ARCSHS website: **latrobe.edu.au/arcshs**

METHODS

HIV Futures 8 is a cross-sectional survey of PLHIV. The survey was open to people aged 18 years or older who were currently living in Australia. Data were collected using a self-complete survey that could be filled in online or using a booklet that was supplied to prospective participants with a reply-paid envelope. 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 Facebook including targeted posts to Facebook groups for PLHIV; advertisements on 'dating apps' used by gay men and other men who have sex with men and; flyers and posters displayed in HIV clinics. Hard copies of the survey were distributed through the mailing lists of HIV community organisations and made available in the waiting rooms of HIV clinics and community services. Data were collected between July 2015 and June 2016.

Full details of the study protocol and method have been published elsewhere and are available on the ARCSHS website: **latrobe.edu.au/arcshs**

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Australian Research Centre in Sex, Health and Society

SAMPLE

HIV Futures 8 was completed by 895 people living with HIV in Australia. Of these, 90.5% (n=804) were men, 8.3% (n=74) were women, six people identified as transgender and four people described their gender in other terms.

The majority of the sample were men who identified as gay (78.7%, n=697), 5.6% (n=50) identified as bisexual and 4.3% (n=38) as heterosexual.

There were 21 participants (2.3%) who identified as Aboriginal or Torres Strait Islander.

The age of participants ranged from 19 to 86 years. The average age was 51 years. Over half (56.3%, n=485) were aged 50 years or older.

The majority of participants were born in Australia (74.7%, n=649) and spoke English as their first language (91.2%, n=792).

Participants came from all states and territories in Australia as detailed in Table i.

The majority of participants were working (53.8%, n=474) either full-time (38.6%, n=341) or part-time (15.2%, n=134). There were 18.1% (n=160) who were retired/no longer working.

There were 234 (26.7%) participants who had tested positive to HIV within the five years prior to the survey (from 2010 onward). Of these, the majority (77.0%) were under 50 years of age. However, there were 51 participants (23.0%) aged 50 or older who had been diagnosed in 2010 or more recently.

There were 844 participants (96.6%) currently using antiretroviral therapy. Of these, 756 (91.0%) reported they had an undetectable viral load as of their most recent test. (Note, these figures exclude missing data).

Full details of the study sample are available on the ARCSHS website **latrobe.edu.au/arcshs**

Table i. States and territories in which participants currently live

	n	%
ACT	20	2.3
NSW	306	34.5
NT	6	0.7
QLD	136	15.3
SA	65	7.3
TAS	10	1.1
VIC	265	29.9
WA	78	8.8

*Nine participants did not identify their state/territory

BACKGROUND

Highly active combination antiretroviral treatment (ART) became available in Australia in 1996. This was a major advance in HIV treatment, which significantly increased health and life expectancy for people living with HIV. Since 1996, there have been improvements in the efficacy and tolerability of treatments, while new combinations have become much simpler to take (in some cases just one pill per day). Nevertheless, being on ART involves a structured protocol that requires medication to be taken at specific times. Treatment can also result in side-effects for some people.

In Australia, clinical guidelines regarding prescription of ART were changed in 2015 (ASHM, 2015). Previous guidelines had indicated ART was appropriate only for people whose CD4 count was less than 500 units per cubic millilitre. Today, there are no such stipulations and research increasingly points to the long term individual and public health benefits of early ART uptake.

Effective HIV treatment can lead to full or near full suppression of the virus. The risk of onward HIV transmission from a person on ART who has achieved full viral suppression is very low (some studies suggest it may be close to zero) (Rodger et al, 2016). Given this, encouraging the early and sustained use of ART among people living with HIV has become central to prevention strategies (often referred to as ‘treatment as prevention’). ‘Treatment as prevention’ now sits alongside behavioural prevention interventions including condom use, promotion of HIV testing and provision of pre – and post-exposure prophylaxis (PrEP and PEP).

International and Australian targets aim for 90% of people living with HIV to be on ART and 90% of these people to have achieved viral suppression. In 2014, it was estimated that 73% of Australians diagnosed with HIV were taking ART and, of these, 92% had achieved viral suppression (The Kirby Institute, 2015).

In this short report, we present findings from the HIV Futures 8 survey related to participants’ experiences of using ART.

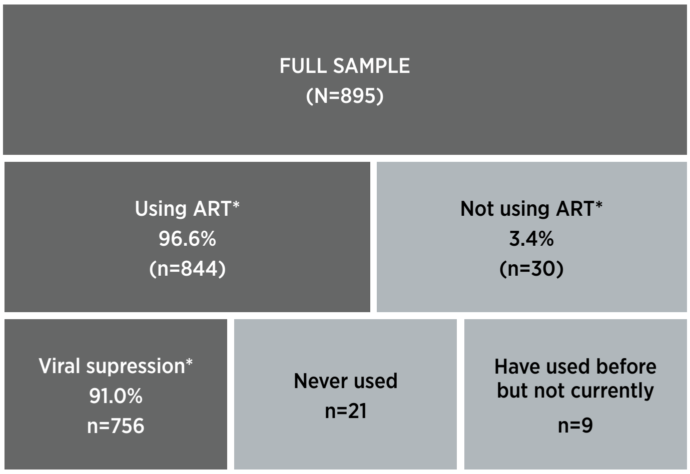
FINDINGS

Current use of ART and viral suppression

There were 844 participants (96.6%) currently using ART (see Figure 1). Of these, 756 (91.0%) reported they had an undetectable viral load as at their most recent test. (Note, these figures exclude missing data).

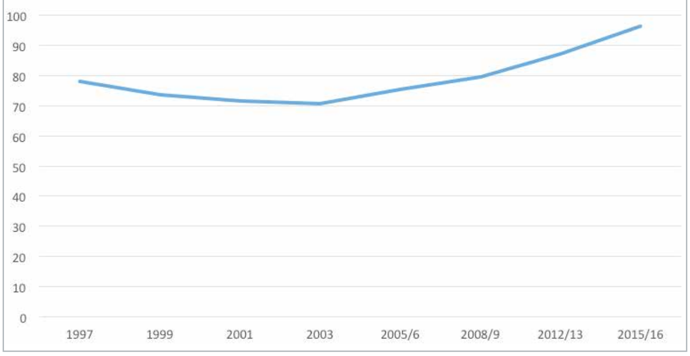
Figure 2 shows the percentage of current ART use over time, drawing data from previous HIV Futures surveys. There was a slight decrease in the proportion of participants using ART between 1997 and 2003. Since this time the figure has steadily increased.

Figure 1. Current use and non-use of ART*



*figures exclude missing data

Figure 2: ART use over time (% using ART at time of survey)



CD4 count

As with previous HIV Futures surveys, almost all participants (n=861, 98.5%) reported having a T-cell/CD4 test in the past 12 months.

Among people who had never used ART, the percentage of people with a CD4 count above 500 cells per µL was higher than among people who were using ART (see Table 1). This may indicate some people waiting for their CD4 count to drop below 500 cells per µL before commencing ART, despite changes in clinical guidelines regarding this. However, the number of people in this category is very small, so these figures should be interpreted with caution.

Table 1. CD4 count (cells per μL) according to current use of ART (%)

% (n)	>500	500-350	<350	Don't know
Currently taking	66.3 (552)	18.4 (153)	9.1 (76)	6.1 (51)
Past	33.3 (3)	11.1 (1)	44.4 (4)	11.1 (1)
Never	71.4 (15)	9.5 (2)	9.5 (2)	9.5 (2)

Excludes missing data

Viral load

On average, respondents had taken three viral load tests in the past 12 months (range 0-12).

Participants were asked when their most recent viral load test had occurred. The majority had been tested within the past three months. Responses were as follows:

- 62% (n=546) within the past three months
- 28.6% (n=252) three to six months ago
- 7.6% (n=67) six to 12 months ago
- < 1% (n=8) more than 12 months ago
- <1% (n=8) unsure

Overall, 88.8% (n= 782) reported they had an undetectable viral load at their most recent test. Participants currently taking ART were more likely to have an undetectable viral load than those not using ART (see Table 2). However, the numbers not using ART are very small, so these figures should be interpreted with caution.

Table 2. Results of most recent viral load test according to current use of ART

Most recent viral load test, % (n)	Undetectable	Detectable	Don't know
Currently taking	91.0 (756)	7.8 (65)	1.2 (10)
Past	33.3 (3)	66.7 (6)	0
Never	19.0 (4)	66.7 (14)	14.3 (3)

Use of ART

Commencing antiretroviral treatment

Of those who were currently taking ART, 35.3% (n=293) commenced treatment within three months of their HIV diagnosis, while 30.2% (n=250) commenced more than two years after diagnosis.

There were 109 people (13.1%) who indicated they had started treatment when combination highly active antiretroviral therapy became available (in 1996). Ten (1.2%) could not recall when they had started.

Reflecting current treatment guidelines that recommend initiating treatment for all HIV-infected individuals regardless of CD4 count, 63% of those diagnosed in 2010 or later had started taking ART within three months of diagnosis. This is compared with 25.2% of those diagnosed prior to 2010 (see Table 3) (ASHM, Antiretroviral Guidelines, August 2015).

Table 3: How long after diagnosis did you start treatment by year of diagnosis

% (n)	Within 3 months	3 – 12 months	12 – 24 months	>24 months	Around 1996	Can't recall
Diagnosed before 2010	25.2 (153)	7.6 (46)	10.6 (64)	37.1 (225)	17.8 (108)	1.7 (10)
Diagnosed 2010-2015	63.0 (131)	16.8 (35)	9.6 (20)	10.6 (22)	N/A	0

$\chi^2(3)= 96.0$, $p<0.001$ (chi square statistic excludes 'Around 1996' and 'Can't recall'), excludes missing data

ART combinations

The ART medications used by respondents are reported in Table 4. The majority of respondents were taking one of the pre-formulated combinations (Atripla, Combivir, Eviplera, Kivexa, Stribild, Triumeq and Truvada), either alone (n=413) or in conjunction with one or more other treatments (n=299).

Among those on combinations of individual drugs, the most common combination was one integrase inhibitor, two protease inhibitors and one NNRTI (n=12) followed by two protease inhibitors (n=7).

Table 4: Antiretroviral drugs used by respondents

	%
Nucleoside Reverse Transcriptase Inhibitors (NRTIs)	
Retrovir (zidovudine)	4.2
3TC (lamivudine, Epivir)	3.4
Emtriva (emtricitabine, FTC)	1.3
Ziagen (abacavir)	1.1
Non-Nucleoside Reverse Transciptase Inhibitors (NNRTIs)	
Viramune (nevirapine)	14.9
Intelence (etravirine)	4.1
Stocrin (efavirenz)	2.3
Edurant (rilpivirine)	0.5
Nucleotide Analog Reverse Transciptase Inhibitors	
Viread (tenofovir)	4.7
Protease Inhibitors	
Norvir (ritonavir)	10.0
Prezista (darunavir)	9.6
Reyataz (atazanavir)	7.6
Kaletra (lopinavir +ritonavir)	2.9
Aptivus (tipranavir)	0.4
Telzir (fosamprenavir)	0.2
Combination Medications	
Truvada (tenofovir+emtricitabine)	27.7
Triumeq (dolutegravir, abacavir, lamivudine)	17.2
Kivexa (lamivudine+abacavir)	13.7
Eviplera (emtricitabine+rilpivirine+tenofovir)	11.4
Atripla (tenofovir+emtricitabine+efavirenz)	8.9
Stribild (elvitegravir+cobicistat+emtricitabine+tenofovir)	6.7
Combivir (lamivudine+zidovudine)	1.3
Other	
Isentress (raltegravir)	16.6
Tivicay (dolutegravir)	11.6
Other	2.7
Celsentri (maraviroc)	2.2
Don't know	1.2

ART combination changes

Of the respondents who were taking ART, almost two-thirds (61.3%, n=503) had not changed their treatment combination within the past two years.

Just over one-third (38.7%, n=318) had changed combinations between one and five times during the past two years, with a median of one time. Of these, 74.5% had made just one combination change, while 17.8% had changed twice and 7.0% had changed three times.

The most common reasons given for changing treatments were side-effects and wanting to access a combination with fewer pills (see Table 5).

We asked participants if they had ever initiated a treatment review with their doctor. There were 353 (42.9%) participants who indicated they had initiated a treatment review, while 247 (30.0%) said that they always wait for the doctor to initiate treatment reviews. There were 207 (25.2%) who said that they had never needed to initiate a treatment review.

Table 5. Reasons for changing ART combination

Reason	% (n) of those who had changed combination
Side effects of previous combination	37.1 (118)
To access a combination with fewer pills	34.3 (109)
Other reason	11.6 (37)
Developed resistance to previous combination	4.7 (15)
Advice from doctor	3.8 (12)
A new drug became available	3.1 (10)
Previous combination no longer working	2.8 (9)
To access a cheaper combination	1.3 (4)
To achieve greater CNS penetration	0.9 (3)
Previous combination never worked	0.3 (1)

ART adherence

Participants who were currently using ART were asked to indicate the percentage of their prescribed ART they had taken in the past month using a scale that grouped responses in increments of 5%. The majority, 64.7% (n=515) indicated that they had taken 100% of their doses and 29.5% (n=235) indicated they had taken 90-95% of doses (see Figure 3).

The main reasons given for missing a dose of ART are listed in Table 6. The most common reasons were simply forgetting, a change in daily routine and being away from home.

Figure 3. ART adherence in past month

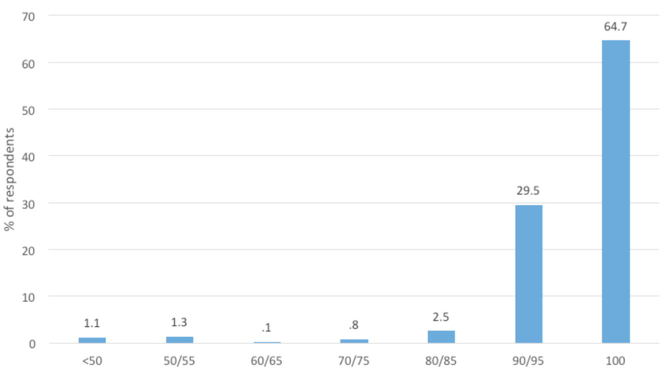


Table 6: Main reasons given for missing a dose of ART in the past month

Reason	% of people using ART (n)
Simply forgot	28.4 (240)
Had a change in daily routine	10.5 (89)
Away from home	9.8 (83)
Busy with other things	7.1 (60)
Fell asleep/slept through dose time	5.6 (47)
Felt depressed or overwhelmed	4.7 (40)
Ran out of pills	4.3 (36)
Felt sick or ill	3.9 (33)
Had problems taking pills at specified times	2.3 (19)
Not wanting others to see them taking medication	2.3 (19)
Wanted to avoid side effects	2.1 (18)
Taking treatment is an unwelcome reminder of HIV status	1.9 (16)
Had too many pills to take	1.5 (13)
Felt like the drug was toxic or harmful	1.1 (9)
Did not want others to know HIV status	0.9 (8)
Felt good	0.6 (5)

ART side-effects

While side-effects were listed as the most common reason for changing treatments, nearly three-quarters of those taking ART (73.3%) said that side-effects did not at all or rarely have an impact upon their daily life or capacity to work or socialise. However 10.5% said that side-effects had an impact upon their lives either regularly or daily (see Table 7).

Table 7. Impact of ART side effects on daily life or capacity to work or socialise

Response	% of people using ART (n)
No impact at all	57.6 (479)
Rarely	15.7 (131)
Occasionally	16.2 (135)
Regularly	6.3 (52)
Daily impact	4.2 (35)

The most commonly reported side effects were fatigue, diarrhoea and depression (see Table 8). Peripheral neuropathy, lipodystrophy or lipoatrophy were much less prevalent and people reporting these were more likely to be aged 50 years or older.

Table 8. ART side effects

Side effect	% of people using ART (n)
Fatigue	26.2 (221)
Diarrhoea	16.6 (140)
Depression	14.6 (123)
Insomnia	14.3 (121)
Headaches	12.2 (103)
Nausea/vomiting	11.5 (97)
Weight gain	9.5 (80)
Other emotional symptoms	7.8 (66)
Peripheral neuropathy	7.7 (65)
Lipodystrophy	6.2 (52)
Lipoatrophy	2.6 (22)

ART prescribers

We asked participants to tell us who prescribed their ART. The most common response was a HIV GP/S100 prescriber, followed by a specialist at an outpatient clinic (see Table 9).

People filled their prescriptions at a range of locations including:

- Sexual health centre (37.1%, n=309)
- Local public hospital (34.6%, n=288)
- Local chemist (14.5%, n=121)
- Other public hospital (8.8%, n=73).

Almost all of those taking ART (89.2%) said that they were satisfied with their current arrangements for obtaining treatment. The reasons given for not being satisfied with the current arrangement included having to travel distances to get there, inconvenient opening hours and long waiting times.

Table 9. Who prescribes your antiretroviral treatment?

Prescriber type	% of people using ART (n)
HIV GP/S100 prescriber	41.9 (349)
HIV Specialist at outpatient clinic	28.7 (239)
Doctor at sexual health centre	20.4 (170)
HIV Specialist while a hospital inpatient	4.4 (37)
Other	2.2 (18)
Other GP	2.0 (17)
Other doctor	0.4 (3)

Table 10. Attitudes to antiretroviral drugs: percentage of total sample

Attitudes to treatments	Strongly disagree/disagree	Agree/strongly agree	Don’t know
I am healthy now and don’t need to use ART	90.1 (793)	5.6 (49)	4.3 (38)
The health benefits of beginning ART soon after diagnosis have not been proven	66.4 (586)	18.8 (166)	14.7 (130)
It is best to begin ART soon after diagnosis	12.1 (107)	77.6 (685)	10.3 (91)
ART drugs are harmful	60.9 (538)	27.6 (244)	11.4 (101)
Delaying the use of ART while you are healthy will have long-term health benefits	55.9 (495)	25.1 (222)	19.0 (168)
I am confident ART drugs will allow me to live a life of normal longevity	12.4 (110)	81.1 (718)	57 (6.4)
The side-effects of ART drugs outweigh the benefits	66.5 (587)	27.0 (238)	6.6 (58)

Cost of ART

The majority of respondents indicated that they did not have to pay for their ART (57.2%, n=476), while 42.8% (n=356) said that they did. The average cost nominated was $30.50 per month (median = $20, range = $2.00 to $345).

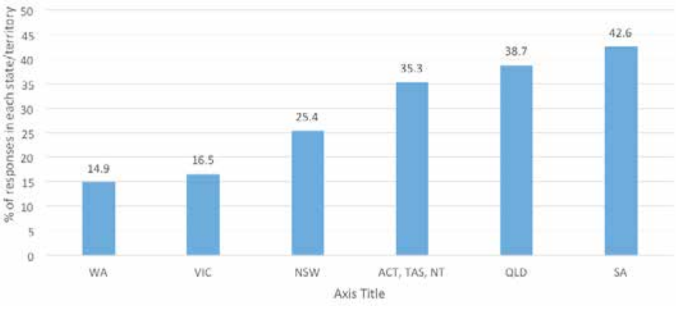
Community pharmacies

Since July 2015 people living with HIV have been able to access HIV medicines from local community pharmacies. Participants were asked to indicate how likely they would be to obtain their ART from a local pharmacy if this were possible. Nearly half of those who were currently taking ART indicated that they were not at all likely to do so (46.3%, n=384). There were 233 (28.1%) who indicated they were somewhat likely or likely to use a community pharmacy, while 213 (25.7%) indicated they were very likely to use a community pharmacy.

The likelihood of using a community pharmacy to obtain ART did not differ significantly according to whether participants lived in capital cities or regional/rural areas. However, it did differ between states and territories. Participants in Western Australia, Victoria and NSW were significantly less likely to indicate they would use a community pharmacy to fill their ART prescription (see Figure 2).

The reasons participants gave for being unlikely to use community pharmacies were confidentiality/privacy, the option to obtain ART at no cost from their current location, and they were satisfied with their current arrangement. Consistent with this, participants who did not currently pay for their ART were significantly less likely to indicate they would use a community pharmacy.

Figure 4. “Very likely” to use community pharmacy to fill ART prescription



Treatment decision-making and optimism

As in previous HIV Futures surveys, we asked participants to respond to a series of statements on treatment decision-making and optimism about treatments. The findings indicated that the majority of participants believed that early treatment with ART was beneficial and expressed positive attitudes towards the long-term use of these treatments.
For example, 90.1% disagreed with the statement I am healthy now and don’t need to use ART, while a slightly lower percentage (77.6%) agreed with the statement It is best to begin ART soon after diagnosis.
Most participants (81.1%) agreed with the statement I am confident ART will allow me to live a life of normal longevity, while 66.5% disagreed with the statement The side effects of ART drugs outweigh the benefits.

People not using ART were more likely to agree with the statement that ART is harmful. Among people not currently using ART, 65.4% (n=17) indicated agreed that ART is harmful. Among people currently using ART, 29.7% (n=220) indicated they agreed. These figures exclude don’t know responses.

People not using ART were more likely to agree with the statement The health benefits of beginning ART soon after diagnosis have not been proven. Among people not using ART, 50% (n=12) agreed with the statement. Among people currently using ART, 20.7% (n=147) agreed with this statement. These figures exclude don’t know responses.

Non-use of ART

Of the 21 respondents who had never used ART, the most common reason given for not doing so was a belief that early uptake of ART would not be beneficial to their health:

- 11 people indicated that “My CD4 count is not low enough to require treatment”
- 10 people indicated that “I do not want to take antiretroviral treatment as long as I am healthy”.
- Smaller numbers expressed concern about the long-term nature of antiretroviral therapy:
- Six people indicated “ I am concerned about the longer term negative health impact of ART”
- Six people indicated “I do not want to commit to a lifelong regime of medication.”

Three recently diagnosed respondents said that they planned to begin treatment soon and three others gave the reason that “My doctor advised me against commencing treatment”. Two respondents indicated that they could not afford to go on treatment.

When asked if they would consider taking ART at any time in the future, the majority of those who had never taken ART indicated that they would (75%, n=15), while 25% (n=5) were unsure. None said that they would not consider taking ART in the future.

Of the nine respondents who had used ART in the past, four indicated that they had stopped due to side-effects, two because of difficulties adhering to the treatment regimen, and two due to cost of co-payments. Of these nine, four indicated that they would use ART in the future, two that they would not, and one was unsure.

SUMMARY AND CONCLUSIONS

The proportion of participants in this study who were currently taking ART (96.6%) clearly exceeds the national target of 90% and is indicative of a high level of acceptance for ART among people living with HIV in Australia today. Among people diagnosed from 2010 onward, over 60% commenced ART within three months of their HIV diagnosis, a significantly higher figure than among those diagnosed prior to this. This suggests a trend toward earlier uptake, which is consistent with current clinical guidelines.

Findings from this study indicate that the majority of participants were on fairly stable ART regimens, with good adherence. Over 94% of survey participants who were currently using ART reported they had missed no more than 5% of ART doses within the past month. Also, over 60% had not changed their ART combination within the past two years. Where people had changed combination, it was often to commence a simpler daily regimen with fewer pills. That said, over 25% of participants did report they experienced side effects associated with ART at least occasionally and in some cases daily. Side effects were the most common reason for changing ART combinations.

The figure of 96.6% of participants currently using ART is substantially higher than the 73% estimated in the 2015 HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia Annual Surveillance Report (The Kirby Centre, 2015). It is likely that people who completed HIV Futures 8 are those who are more likely to be engaged with clinical and support services and, therefore, are more likely to be using ART. HIV Futures 8 may also have a lower proportion of people who are newly diagnosed with HIV and who have not yet commenced treatment.

THOUGHTS AND COMMENTARY

HIV Futures 8 continues to offer an invaluable national insight into the lives of Australians with HIV (PLHIV). It enables us to better understand the socioeconomic status and clinical and support service usage of PLHIV throughout Australia. This report describes the experiences of PLHIV and antiretroviral treatment (ART). It helps us gain a contemporary awareness of levels of optimism about modern HIV treatment, current ART usage and viral suppression rates, when ART is commenced and what combinations are taken, where HIV meds are dispensed and who prescribes them, and if side effects are impacting on our daily life.

Positive Life NSW and other HIV non-government agencies, routinely use HIV Futures data when preparing submissions to government and when developing and seeking funding for health promotion programs and community campaigns. However, arguably HIV Futures greatest benefit lays in its ability to engage community and inform and validate the diverse experiences of living with HIV. Findings from this study describe the continuing rise in acceptance of the benefits of ART – with the majority of PLHIV being stable on therapy, adhering to ART regimens and achieving viral suppression. The report also indicates that less people are experiencing side effects, needing to change regimens and starting treatment earlier.

The lives as PLHIV continue to evolve and change as new scientific breakthroughs influence the treatment and other life decisions of Australians with HIV. Futures 8 charts these changing experiences and remains an invaluable cross-sectional snap shot of what it's like to live with HIV in an ever changing and contemporary context. Positive Life would like to thank the Futures Study team for their dedication in producing HIV Futures Reports, and PLHIV for sharing their lives.

Lance Feeney is the Senior Policy Advisor for Positive Life NSW. He has been living with HIV for more than 30 years.

SUGGESTED CITATION

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HIV FUTURES 8

HIV exposure and testing

Australian Research Centre in Sex, Health and Society

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in Sex, Health and Society

SAMPLE

HIV Futures 8 was completed by 895 people living with HIV in Australia. Of these, 90.5% (n=804) were men, 8.3% (n=74) were women, six people identified as transgender and four people described their gender in other terms.

The majority of the sample were men who identified as gay (78.7%, n=697), 5.6% (n=50) identified as bisexual and 4.3% (n=38) as heterosexual.

There were 21 participants (2.3%) who identified as Aboriginal or Torres Strait Islander.

The age of participants ranged from 19 to 86 years. The average age was 51 years. Over half (56.3%, n=485) were aged 50 years or older.

The majority of participants were born in Australia (74.7%, n=649) and spoke English as their first language (91.2%, n=792).

Participants came from all states and territories in Australia as detailed in Table i.

The majority of participants were working (53.8%, n=474) either full-time (38.6%, n=341) or part-time (15.2%, n=134). There were 18.1% (n=160) who were retired/no longer working.

There were 234 (26.7%) participants who had tested positive to HIV within the five years prior to the survey (from 2010 onward). Of these, the majority (77.0%) were under 50 years of age. However, there were 51 participants (23.0%) aged 50 or older who had been diagnosed in 2010 or more recently.

There were 844 participants (96.6%) currently using antiretroviral therapy. Of these, 756 (91.0%) reported they had an undetectable viral load as of their most recent test. (Note, these figures exclude missing data).

Full details of the study sample are available on the ARCSHS website **latrobe.edu.au/arcshs**

Table i. States and territories in which participants currently live

	n	%
ACT	20	2.3
NSW	306	34.5
NT	6	0.7
QLD	136	15.3
SA	65	7.3
TAS	10	1.1
VIC	265	29.9
WA	78	8.8

*Nine participants did not identify their state/territory

BACKGROUND

In 2014, it was estimated that there were 27,150 Australians living with HIV. Approximately 1,000 new cases are diagnosed in Australia each year. The HIV epidemic in Australia is predominantly among gay men and other men who have sex with men (GMSM). In 2014, 70% of new HIV diagnoses occurred through male-to-male sexual transmission. This figure has remained consistent over time in Australia. However, there is evidence that the Australian epidemic is diversifying. For instance, there are increasing cases of HIV transmitted via heterosexual sex among people from South East Asian or African countries (The Kirby Institute, 2015).

Of the 27,150 people living with HIV in Australia in 2014, it was estimated that 12% were undiagnosed. Furthermore, of the 1081 new HIV diagnoses in 2014, 28% were classified as a 'late diagnosis'. A 'late diagnosis' is determined by an individual's CD4 count at the time of diagnosis. A count of less than 350 cells/µl is considered a late diagnosis. This is a point at which HIV is likely to have caused damage to the immune system. People who are diagnosed late may have been living with HIV for several years or more without being tested. In 2014, the proportion with a late diagnosis was highest among people born in South East Asia or sub-Saharan Africa and more common among people who acquired HIV through heterosexual sex. However, each year more than half of all late diagnoses are among GMSM (The Kirby Institute, 2015; Wilcock and Frommer, 2014).

A significant proportion of HIV sexual transmissions come from people who are unaware they are HIV positive. There are a number of reasons why people may not present for HIV testing. Many people simply do not feel that they are at risk of acquiring HIV, or they do not test unless they have had a particular risk episode. Fear of a positive diagnosis can also be a barrier to testing, as can stress associated with having to wait for results or return to the clinic for a follow up to obtain results (Conway et al., 2015; Wilcock and Frommer, 2014).

The Seventh National HIV Strategy 2014–2017, includes the objective of decreasing the number of people with undiagnosed HIV infection, with a focus on increasing testing among gay men and injecting drug users (Australian Government Department of Health, 2014). In recent years, a range of new testing initiatives have been introduced in Australia to ensure HIV testing is easy and accessible. This includes community-based HIV and STI screening clinics with extended opening hours, rapid point of care testing sites located in community settings and lifting of the previous ban on home testing (Conway et al., 2015; Wilcock and Frommer, 2014).

This short report looks at findings from the HIV Futures 8 survey related to HIV exposure and testing for HIV and STIs.

FINDINGS

HIV infection

Mode of HIV acquisition

The majority of participants (80.2%) acquired HIV through male-to-male sex. For women, sex with a man was the most common mode of acquisition (85.1% of women). Overall, 9.6% (n=84) indicated heterosexual sexual transmission was the mode by which they acquired HIV (see Table 1).

Table 1. Mode of HIV exposure by gender

Mode of transmission, % (n)	Men	Women	Transgender	Other gender	Total
Sex with a man	88.7 (705)	85.1 (63)	83.3 (5)	75.0 (3)	88.3 (776)
Sex with a woman	2.6 (21)	0	0	0	2.4 (21)
Injecting drugs	2.0 (16)	5.4 (4)	0	25.0 (1)	2.4 (21)
Blood products	<1 (6)	1.4 (1)	0	0	<1 (7)
Sex with a man or injecting drugs	<1 (3)	1.4 (1)	0	0	<1 (4)
Other	3.4 (27)	4.1 (3)	16.7 (1)	0	3.5 (31)
Don't know	2.1 (17)	2.7 (2)	0	0	2.2 (19)
Total	**795**	**74**	**6**	**4**	**879**

Excludes missing cases

Acquisition of HIV outside Australia

There were 156 participants (17.8%) who reported they acquired HIV in a country other than Australia. As expected, people not born in Australia were significantly more likely to have acquired HIV outside of Australia (see Table 2). The regions in which people reported they acquired HIV are shown in Table 3. Women were significantly more likely than men to have acquired HIV outside of Australia (see Table 4).

Table 2. Acquired HIV in Australia by country of birth

	Born in Australia, % (n)	Born outside Australia, % (n)	Total, % (n)
Acquired HIV in Australia	86.8 (551)	67.9 (148)	81.9 (699)
Acquired HIV outside of Australia	13.2 (84)	32.1 (70)	18.1 (154)
Total	**635**	**218**	**853**

Excludes missing data, $\chi^2(1) = 39.1$, p<0.001

Table 3. Regions in which participants contracted HIV if outside of Australia

Region	% (n)
South East Asia	30.2 (45)
United Kingdom, New Zealand	21.5 (32)
United States of America, Canada	19.5 (29)
Africa (including South Africa)	10.7 (15)
Other	10.1 (15)
Europe	8.7 (13)
Total	**149**

Excludes missing data

Table 4. Acquired HIV in or outside of Australia by gender

Country in which acquired HIV	Men, % (n)	Women, % (n)	Total, % (n)
Australia	83.6 (657)	65.8 (48)	82.1 (705)
Overseas (other country)	16.4 (129)	34.2 (25)	17.9 (154)
Total	**786**	**73**	**859**

Excludes missing data, χ^2 (1) = 14.4, p<0.001, excludes transgender and other categories due to small numbers

HIV acquisition and travel

Travelling has been identified as a time at which some people may be more vulnerable to HIV exposure due to changes in routine, a more relaxed attitudes toward safe sex due to a sense of freedom or anonymity, less familiarity with the local area or higher HIV prevalence in the area to which they have travelled (Australian Government Department of Health, 2014; Murphy, 2001).

There were 145 participants (16.7%) who indicated they were travelling interstate or internationally for work or leisure at the time they acquired HIV. Of these, 49 (5.6%) were travelling within Australia while 96 (11.0%) were travelling overseas. The most commonly cited overseas regions in which people were travelling when they contracted HIV were South East Asia (n=34) or North America/Canada (n=21). People born outside of Australia were not more likely than people born in Australia to indicate they had been traveling when they contracted HIV. Among people diagnosed with HIV within the past five years (2010 onward), 24.9% (n=57) indicated that had been traveling when they contracted HIV (see Table 5).

Table 5. Acquired HIV while travelling by year of HIV diagnosis

Travelling at time of HIV acquisition	Year of HIV diagnosis, % (n)		
	Up to 2009	2010 onward	Total, % (n)
Not travelling	85.4 (537)	75.1 (172)	82.6 (709)
Travelling interstate or overseas	14.6 (92)	24.9 (57)	17.4 (149)
Total	**629**	**229**	**858**

Excludes missing data, χ^2 (1) = 12.3, p<0.001

Use of PEP and PrEP prior to HIV diagnosis

There were 70 participants (8.0%) who indicated they had used post-exposure prophylaxis at least once prior to their HIV diagnosis. There were 10 people (1.1%) who had used pre-exposure prophylaxis prior to their HIV diagnosis.

There were 82 participants (9.4%) who indicated they did not know what PEP was and 86 (9.9%) who did not know what PrEP was.

There were 239 participants who had a current sexual partner who was HIV negative. Of these, 37 (15.5%) indicated their partner had used PEP at least one time, while 16 (6.7%) indicated their partner had, or was currently, using PrEP.

HIV DIAGNOSIS AND TESTING

Year of diagnosis

Table 6 shows the years in which participants were diagnosed with HIV. The numbers of years since participants had been diagnosed with HIV (as of 2016) ranged from less than one year to 34 years, with an average of 15 years.

Table 6. Year in which participants were diagnosed with HIV

Year of HIV diagnosis	% (n)
1985 or earlier	8.7 (76)
1986-1995	25.6 (225)
1996-2005	24.4 (214)
2006-2015	41.3 (363)
Total	**878**

Excludes missing data

There were 234 (26.7%) participants who had tested positive to HIV within the five years prior to the survey (from 2010 onward). Of these, the majority (77.0%) were under 50 years of age. However, there were 51 participants aged 50 or older who had been diagnosed in 2010 or more recently (see Table 7). Of these, 42 were men who identified as gay or bisexual, seven were heterosexually identified men and there was one woman.

Table 7. Year of HIV diagnosis by age

Age, % (n)	up to 2009	2010 onward	Total
Under 35	2.7 (17)	37.8 (84)	12.0 (101)
35-49	29.2 (182)	39.2 (87)	31.8 (269)
50-64	50.2 (313)	19.4 (43)	42.1 (356)
65+	17.8 (111)	3.6 (8)	14.1 (119)
Total	**623**	**222**	**845**

Excludes missing data

Time between HIV exposure and HIV diagnosis

We asked participants to report the year they believe they were infected with HIV. We then compared this with the year in which they were diagnosed with HIV as a crude measure of the lag time between participants' exposure to HIV and their diagnosis. Overall, 51.1% (n=425) indicated they had been diagnosed less than one year after their presumed (or known) exposure to HIV. This figure was higher among people diagnosed after 2009 (see Table 8). These figures should be regarded with caution, however, as responses were grouped by year of diagnosis and did not account for the month of diagnosis.

Table 8. Time between presumed HIV exposure and HIV diagnosis

Time between exposure and diagnosis	Year of HIV diagnosis, % (n)		
	Up to 2009	2010 onward	Total, % (n)
Less than 1 year	46.6 (285)	63.6 (140)	51.1 (425)
1-2 years	31.7 (194)	28.2 (62)	30.8 (256)
3-5 years	14.4 (88)	6.4 (14)	12.3 (102)
More than 5 years	7.4 (45)	1.8 (4)	5.9 (49)
Total	**612**	**220**	**832**

Excludes missing data, data should be interpreted with caution due to small numbers in some cells.

Reasons for testing

We asked participants to tell us the main reason they took an HIV test at the time they were diagnosed with HIV. The most common reason for taking an HIV test was becoming ill or experiencing symptoms of seroconversion illness or other HIV-related illnesses (see Table 9). Men were more likely than women to have been diagnosed as part of routine sexual health screening. By contrast, women were more likely to be tested after a sexual partner had tested positive.

Table 9. Reason for taking HIV test when first diagnosed

Reason	% (n)
I became ill/showed symptoms	30.4 (270)
As part of routine sexual health screening	11.7 (104)
A sexual partner tested positive	9.7 (86)
My doctor suggested it	9.5 (84)
I was a member of a risk group	8.5 (75)
As part of routine general health screening	8.5 (75)
I had a particular risk episode or event	8.2 (73)
Other reason	4.7 (42)
Starting a new relationship	2.9 (26)
I was tested without my knowledge	1.8 (16)
Required for visa application/immigration	1.5 (13)
A contact tracer or other health care worker suggested it	1.1 (10)
Insurance	<1 (5)
Availability of rapid testing	<1 (3)
I was tested during pregnancy	<1 (3)
Availability of new treatments	<1 (2)
Total	**887**

Excludes missing data

Prior testing history

For 34.1% (n=301) of participants, the test at which they received their HIV positive diagnosis was the first HIV test they had ever taken (see Table 10). This figure was higher for women at 53.7%. Women were also less likely than men to have been tested within the 12 months prior to their positive HIV test (see Table 11).

Table 10. Most recent test prior to testing positive for HIV

Timing of most recent test	% (n)
Never, I had my first HIV test when I first tested positive	34.1 (301)
Less than 6-months prior	24.1 (213)
Less than a year prior	15.4 (136)
Less than two-years prior	9.1 (80)
Two or more years prior	13.6 (120)
Can't recall	3.6 (32)
Total	**882**

Excludes missing data

Table 11. Most recent test prior to testing positive for HIV by gender

Timing of most recent test, % (n)	Men	Women	Total
Never tested previously	33.8 (259)	53.7 (36)	35.4 (295)
Last test within 12 months prior	43.1 (330)	20.9 (14)	41.3 (344)
Last test more than 12 months prior	23.1 (177)	25.4 (17)	23.3 (194)
Total	**766**	**67**	**833**

Excludes missing data, $\chi^2(1) = 14.4$, $p<0.001$, excludes 'can't recall' option and 'transgender'/'other' due to small numbers.

Prior testing history among people recently diagnosed

Table 12 shows the prior HIV test history of participants diagnosed before and after 2010. Those diagnosed after 2009 were significantly more likely to have been tested for HIV at least once prior to their positive diagnosis, including within the 12 months prior to their diagnosis.

Among people diagnosed after 2009, people aged over 50 years were significantly more likely than younger people to have never previously been tested for HIV. They were also less likely to have been tested for HIV within the 12 months prior to their HIV positive diagnosis (see Table 13).

Table 12. Most recent test prior to testing positive for HIV according to year of diagnosis

Timing of most recent test, % (n)	Up to 2009	2010 onward	Total
Never tested previously	44.0 (269)	12.2 (27)	35.5 (296)
Last test within 12 months prior	35.1 (215)	56.6 (125)	40.8 (340)
Last test more than 12 months prior	20.9 (128)	31.2 (69)	23.6 (197)
Total	**612**	**221**	**833**

Excludes missing data, $\chi^2(2)= 71.6$, $p<0.001$, excludes 'can't recall' option.

Table 13. Most recent test prior to testing positive for HIV among people diagnosed since 2009 by age

Timing of most recent test, % (n)	Under 50	50+	Total
Never tested previously	8.5 (14)	22.9 (11)	11.7 (25)
Last test within 12 months prior	60.0 (99)	45.8 (22)	56.8 (121)
Last test more than 12 months prior	31.5 (52)	31.3 (15)	31.5 (67)
Total	**165**	**48**	**213**

Excludes missing data, $\chi^2(2)= 7.9$, $p=0.019$, excludes 'can't recall' option

Reasons for not testing

We asked the 301 participants who had never taken a HIV test prior to their HIV positive diagnosis to indicate the main reason why they had not tested previously. Nearly half (49.5%, n=149) responded that they did not think they were at risk. There were a range of other reasons reported including tests not being available at the time, not wanting to know the diagnosis and fear.

Location of testing

We asked participants the type of clinic or venue at which they had been tested when they received their HIV positive diagnosis. The most common testing locations were the participant's regular doctor or a sexual health clinic. A small number indicated they had used rapid testing or community-based testing facilities (see Table 14).

Table 14. Location of testing at time of HIV diagnosis

Testing location	% (n)
My regular doctor	44.6 (396)
Sexual health clinic	25.9 (230)
First available doctor	12.0 (106)
Hospital	9.1 (81)
Other location	2.3 (20)
RAPID test at a community organisation	2.0 (18)
Specialist doctor	1.2 (11)
RAPID test at a GP clinic	<1 (5)
Bar, nightclub, sauna	<1 (4)
I did it myself, at home	<1 (3)
Unsure	<1 (3)
Visa/immigration clinic	<1 (3)
Blood bank	<1 (3)
Community event	<1 (2)
RAPID test at a sex-on-premises venue	<1 (2)
Total	**887**

Excludes missing data

Contact tracing

We asked participants a series of questions about their experiences with contract tracing, or notifying previous sexual partners of their HIV diagnosis. Overall, 417 (48.3%) indicated they had notified previous partners of their HIV diagnosis. There were 501 (56.0%) who indicated they received no assistance with contact tracing. Of those who did receive contract tracing assistance, the most common source of this was an HIV specialist (16.9%, n=151) or GP (15.1%, n=135).

Testing for other sexually transmissible infections

The majority of participants (77.7%, n=684) indicated they had been tested for other sexually transmissible infections within the past 12 months. There were 534 participants (60.5%) who had been tested for syphilis when they presented for their most recent (HIV) viral load test.

There were 89 participants who had been diagnosed with syphilis in the past 12 months. We asked these people the reason they had presented for syphilis testing at the time of their diagnosis. The majority (58.0%, n=51) indicated they had been screened as part of routine sexual health screening, while 31.8% (n=28) had be tested because they had symptoms. Of those diagnosed with syphilis, 67.4% (n=60) reported that they notified their previous sexual partners of their diagnosis, while 10.1% (n=9) allowed a contract tracing service to notify previous sexual partners.

SUMMARY AND CONCLUSIONS

Consistent with the general pattern of the HIV epidemic in Australia, the most common mode of HIV acquisition among participants in HIV Futures 8 was male-to-male sex. Among women, heterosexual sex was the most common mode of HIV acquisition, with a small number attributable to injecting drug use. Again, this is consistent with broader patterns of HIV acquisition among women in Australia (The Kirby Institute, 2015).

Just over 16% of participants indicated they had acquired HIV while travelling, most commonly to overseas destinations in South East Asia or North America. Among people diagnosed since 2010, this figure was even higher. This supports research that suggests travelling may be a time in which people are more vulnerable to HIV exposure.

The majority of people diagnosed within the past five years (2010 onwards) had been tested for HIV at least once in the 12 months prior to their HIV positive diagnosis and were diagnosed within 12 months of their exposure to HIV (based on self-reports of known or presumed exposure). This is encouraging with respect to initiatives that aim to reduce the average time between HIV exposure and diagnosis in Australia.

These findings suggest that people aged over 50, including GMSM, may be less likely to present for regular HIV testing and therefore may be more likely to receive a ‘late diagnosis’ of HIV. Women of all ages are also less likely to have been tested for HIV within the 12 months prior to their diagnosis.

Among participants in HIV Futures 8, the number of people who reported being screened for STIs in the past 12 months was high, there was also a high proportion who had integrated their HIV care with STI testing, reporting that they had been tested for syphilis alongside their most recent (HIV) viral load test.

THOUGHTS AND COMMENTARY

HIV Futures 8 HIV exposure and testing data is consistent with what we see at RAPID, Queensland Positive People’s community based testing program.

The majority of people presenting for testing at RAPID identify as Men who have sex with Men (MSM) with the majority aged below 49 (40% under 28), which supports the Futures 8 conclusion that those MSM aged over 50 are less likely to present for HIV testing and maybe more likely to receive a late diagnosis of HIV. The primary mode of HIV transmission in QLD remains sexual contact between men, so RAPID is a targeted program to increase testing amongst MSM.

We have observed an increasing trend for those at risk of HIV to normalise the testing experience with a majority of people testing within a 12 month time frame. This is consistent with the Futures 8 findings which concludes that the majority of people diagnosed in the past five years had tested for HIV at least once in the 12 months prior to diagnosis.

At RAPID, I have taken on a role as an HIV/STI Test Facilitator and I am also a Peer Navigator. When I was diagnosed at a general clinic I did not have the support in place to help me feel safe and to help me manage and navigate my diagnosis.

Two weeks ago, at RAPID I diagnosed a male in his 40s and he was terrified because of his circumstances and the potential of passing HIV onto his wife. When I told him of the reactive result, the fear in his eyes was something that I really related too. I then went on to disclose my status and shared my story with him, you could see him relax because the connection was there. HIV was normalised instantly.

As part of a seamless continuum of care, from diagnosis to support for treatment and care, I now work with him as a Peer Navigator to provide information and peer support to him around his HIV diagnosis. He can contact me at any stage to discuss his journey of living with HIV.

It is a beautiful thing sharing the experience of HIV with someone who is HIV positive and also newly diagnosed. Now two weeks on, he is linked with an amazing doctor that is right for him and he is also looking to engage with the Treatment Support Facilitators (case managers) at Queensland Positive People for counselling support. Not only is the client now aware of his status but he has the supports he needs to develop the skills to build resilience and normalise the experience of living a healthy life with HIV.

Chris Hallam, Peer Navigator and RAPID HIV/STI Test Facilitator, Queensland Positive People

SUGGESTED CITATION

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LA TROBE
UNIVERSITY

HIV FUTURES 8

Service use, social support and connection among people living with HIV

Australian Research Centre in Sex, Health and Society

2017

latrobe.edu.au

Australian Research Centre
in Sex, Health and Society

INTRODUCTION

HIV Futures 8 is a survey about the health and wellbeing of people living with HIV (PLHIV) in Australia. The study forms part of a series of cross-sectional surveys that have been run every two to three years since 1997. Funded by the Australian Government Department of Health, the aims of the study are to provide information about factors that support physical and emotional wellbeing among PLHIV. The study is designed to inform the Australian National HIV Strategy and guide community and clinical service provision for PLHIV.

In order to explore the complexity of factors that support health and wellbeing among PLHIV, HIV Futures 8 is a broad survey covering issues such as financial security, housing status, anti-retroviral treatment use, general health issues, stigma and discrimination, clinical and support service use, aging, drug and alcohol use, sexual health, relationships, and social connectedness.

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. Findings from HIV Futures 8 are presented as a series of short reports. These, along with more information about the study and copies of reports from previous HIV Futures surveys, can be found on the ARCSHS website: **latrobe.edu.au/arcshs**

METHODS

HIV Futures 8 is a cross-sectional survey of PLHIV. The survey was open to people aged 18 years or older who were currently living in Australia. Data were collected using a self-complete survey that could be filled in online or using a booklet that was supplied to prospective participants with a reply-paid envelope. 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 Facebook including targeted posts to Facebook groups for PLHIV; advertisements on 'dating apps' used by gay men and other men who have sex with men and; flyers and posters displayed in HIV clinics. Hard copies of the survey were distributed through the mailing lists of HIV community organisations and made available in the waiting rooms of HIV clinics and community services. Data were collected between July 2015 and June 2016.

Full details of the study protocol and method have been published elsewhere and are available on the ARCSHS website: **latrobe.edu.au/arcshs/projects/hiv-futures**

ARTICLE FREELY AVAILABLE ONLINE:

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There were 21 participants (2.3%) who identified as Aboriginal or Torres Strait Islander.

The age of participants ranged from 19 to 86 years. The average age was 51 years. Over half (56.3%, n=485) were aged 50 years or older.

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BACKGROUND

An important component of the Australian response to HIV has been the establishment of services for people living with HIV. This includes a range of clinical services and community-based organisations that offer peer-support, professional counselling and wellbeing programs, as well as education and information-based services for PLHIV. More recently, these services have been augmented by online groups and forums designed to provide PLHIV with information and education as well as a forum to connect with others.

Services for PLHIV can be one way in which people living with HIV gain access to social and emotional support. It is well documented that feeling supported and connected to friends and family bolster health and wellbeing (Hawkley and Cacioppo, 2013). In this broadsheet we look at what Australian PLHIV told us about their engagement with HIV community services and clinical services, and their sense of feeling supported by family, friends and community, as well as other PLHIV.

This broadsheet is one of a series of short reports on findings from HIV Futures 8. All of these are available to download from the ARCSHS website: **latrobe.edu.au/arcshs**

COMMUNITY AND SUPPORT SERVICES FOR PLHIV

In HIV Futures 8, we asked survey participants to tell us which community organisations they had used and the type of services they had found most valuable or useful over the years. These questions included both closed and open response questions.

Overall, 61.0% (n=536) indicated they had regular or occasional contact with HIV-related organisations, while 24.9% (n=219) had never had any contact (see Figure 1).

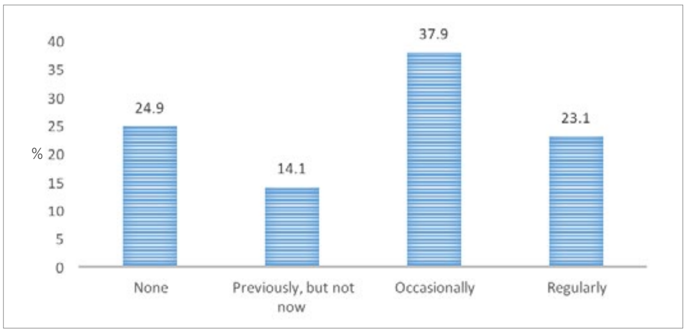

Figure 1. Responses to "Do you have contact with HIV-related organisations?"

People most likely to be in occasional or regular contact with HIV-related organisations were aged over 45 years (66%, compared with 51% of those aged 45 or younger, p<.05), and related to this, reported poorer overall physical health (SF-36 Physical Functioning Sub-scale, range 0-100, M=82.9 v M=87.1 for those not in contact with HIV organisations, p<.05). There were no differences with respect to area of living, with those in regional/rural areas just as likely to be in contact with organisations as those in city areas.

We asked participants to indicate which services provided by HIV organisations they had used in the past 12 months (see Figure 2). Responses revealed the important role that HIV organisations play in provision of peer-based social and support programs. Over half of the participants (56%, n=501) indicated they had used at least one service in the past 12 months. The most common type of services used were those that facilitated social contact between PLHIV (n=215, 43%), along with peer-based support programs 156 (31%). Treatment forums/advice (n=156, 30%) and professional counselling (n=119, 24%) were the next most commonly used services.

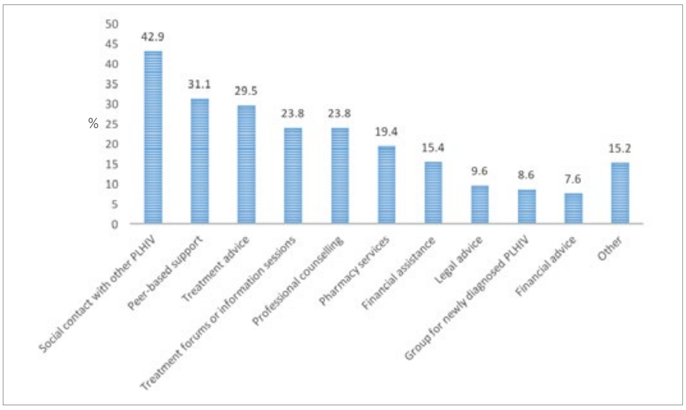

Figure 2: Number of people who used HIV-related services in the past 12-months (total n=501, multiple responses permitted)

We asked participants to tell us in open-ended responses which HIV-related services or programs they *value most*. There were 378 participants (42%) who responded to this question by listing or describing services they found most useful. The remainder either did not respond or indicated they did not use any services. The most common responses were related to social or peer support programs (n=117; 31% of responses). These included formal support groups and less formal opportunities for meeting other PLHIV. Participants' comments indicated that these services were highly valued for the part they played in reducing isolation, normalising the experience of living with HIV, and providing contact with others who shared similar experiences. Counselling services were mentioned by 46 participants (12% of responses), while workshops for people newly diagnosed with HIV, such as Phoenix and Genesis, were cited by 34 (9% of responses). These were valued for provision of information, meeting other PLHIV, and assisting people to adjust to their diagnosis.

What HIV services or programs have you found most useful?

"Anything peer-based. Other positive people are the only ones that know and can relate to information and feelings and emotions. Retreats when available. Conferences and information sharing." (Male, age 61)

"'Planet Positive' group functions Saturday afternoons to meet and talk with other HIV+ people (compare situation, health, knowledge, lifestyle choices, etc) informal social environment/not institution e.g., hospital or centre specific" (Male, age 59)

"Being able to talk to someone living with HIV who actually knows what's going on. When I was diagnosed the people I had access to were very good but none of them were HIV positive and couldn't relate to what I was experiencing. It was an isolating experience and made me feel incredibly alone" (Male, age 32)

"1. Peer support: at the early stage of diagnosis, peer support volunteer made me aware that I am not alone being HIV positive and how this journey will be about. 2. Phoenix workshop: it gave me the basic education I need to know about HIV" (Female, age 28)

"Newly Diagnosed Workshop was really good for me – it quite possibly saved me from spiralling down into a major depression and I learnt so much" (Male, age 45)

"I have found very useful the support groups of HIV positive participants. Especially when you had just been [diagnosed], I think it is very important to be able to talk and know more people that are in your situation" (Male, age 33)

CONNECTING WITH OTHER PEOPLE LIVING WITH HIV

Peer support and connecting with other PLHIV can help people to live well with HIV (Peterson et al. 2012). We asked participants how much time they spent with other PLHIV and the extent to which they received support from other PLHIV. Overall, 68.7% (n=605) reported spending time with other PLHIV, while 57.8% (n=500) reported receiving some support from other PLHIV (ranging from a little to a lot) (see Figure 3). Spending time with other PLHIV and support received from other PLHIV were positively associated with greater emotional wellbeing and higher resilience (see Figures 4 and 5).

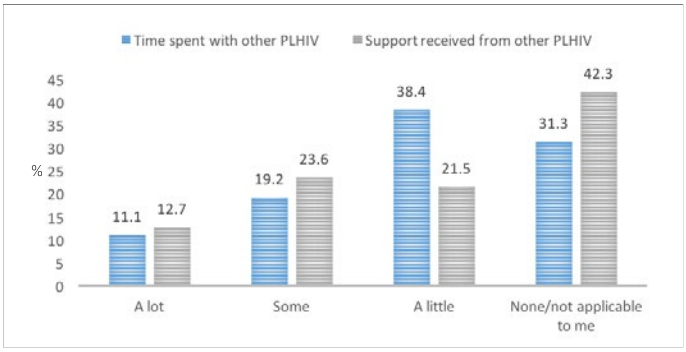

Figure 3. Time spent with, and support received from, other PLHIV

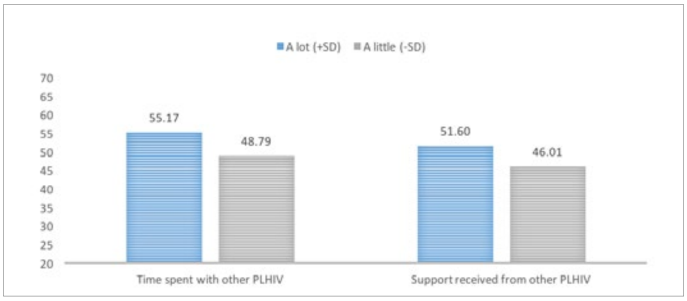

Figure 4. Time spent with, and support received from, other PLHIV and emotional wellbeing
Dependent variable: SF-36 Emotional Wellbeing Sub-scale, range 0-100, with higher scores indicating greater wellbeing (Wu et al 1997)
Time spent with PLHIV: B=3.29, SE=0.74, t=4.46, p<.001
Support from other PLHIV: B=2.56, SE=0.67, t=3.90, p<.001

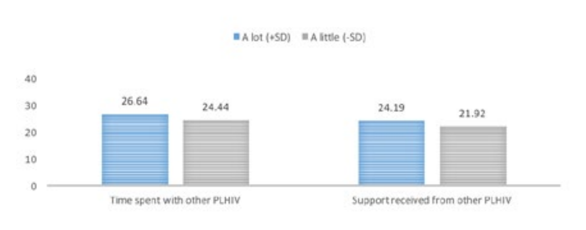

Figure 5. Time spent with, and support received from, other PLHIV and resilience
Dependent variable: Connor-Davidson Resilience Scale, CD RISC-10, scores range from 0-40 with higher scores indicating greater resilience (Connor and Davidson, 2003).

PERCEIVED SOCIAL SUPPORT

Participants rated their assessment of social support and connection using ten survey items related to friendships, access to support, and social connection. Average scores were calculated ranging from -30 to +30, with higher scores indicating a greater perceived sense of social support (Baker, 2012). We compared these scores for different groups of participants (see Figure 6). Result showed that:

- with respect to age, PLHIV aged 65 years or older reported the highest levels of perceived social support (significantly higher than people aged 45-64).
- bisexual men were significantly less likely to report available social support than women, gay men, or heterosexual men (p<.05).
- there were no significant differences in perceived social support based on where participants lived.

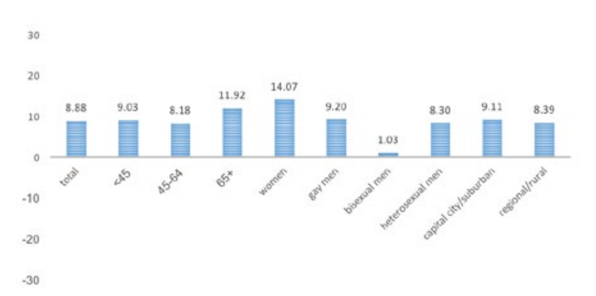

Figure 6. Perceived social support
Dependent variable: Perceived social support, scores ranging from -30 to 30 with higher scores indicating higher levels of perceived social support (Baker, 2012)

Social support and wellbeing

Higher levels of perceived social support were linked to greater emotional wellbeing, resilience and greater physical health among PLHIV (see Figures 7 and 8).

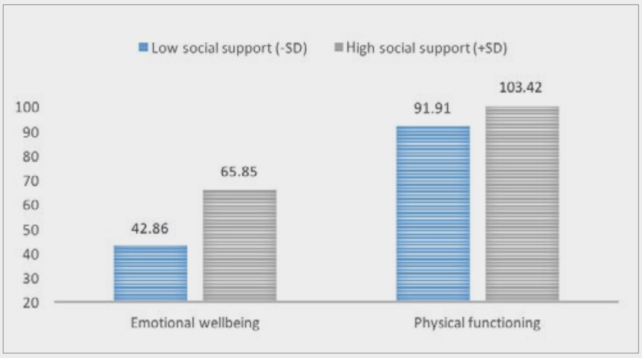

Figure 7. Perceived social support, health and wellbeing.
Dependent variable: Perceived social support, scores ranging from -30 to 30 with higher scores indicating higher levels of perceived social support (Baker, 2012)
Emotional wellbeing, SF 36 subscale (Wu et al, 1997): B=0.89, SE=0.05, t=19.24, p<.001, scores range 0-100 with higher scores indicating greater wellbeing
Physical functioning, SF 36 Subscale (Wu et al, 1997): B=0.45, SE=0.06, t=8.01, p<.001, scores range 0-100 with higher scores indicating better functioning

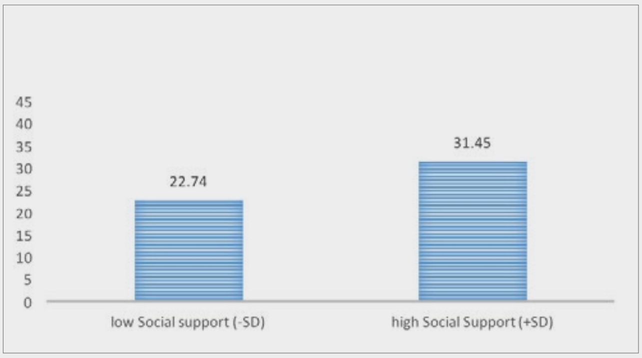

Figure 8. Perceived social support and resilience.
Resilience, CD RISC-10 (Connor and Davidson, 2003): B=0.34, SE=0.02, t=17.47, p<.001, scores range from 0-40 with higher scores indicating higher resilience.

WHAT HELPS PEOPLE COPE AND LIVE WELL?

We asked participants to describe in an open-ended response the main things in their lives that helped them cope or live well with HIV. Six hundred and twenty participants (69%) provided a response to this question. Relationships with partners, family, friends, children and other PLHIV featured most frequently in responses, along with staying healthy and having easy access to good medical care and affordable treatment. The main factors people listed that helped them cope and live well were:

- support from their partner, family or friends (n=259, 42% of responses)
- access to a supportive and/or non-judgemental doctor/medical care (n=81, 13%)
- staying physically healthy through diet and/or exercise (n=81, 13%)
- maintaining a positive attitude toward life (n=77, 12%)
- having a job or professional life to provide focus and motivation and/or a stable income (n=54, 9%)
- access to affordable antiretroviral treatment (n=51, 8%)
- hobbies, activities or creative pursuits and interests (n=45, 7%)
- HIV positive friends (n=38, 6%)
- services for PLHIV (n=33, 5%)
- pets (n=15, 2%)
- faith (n=7, 1%).

What are the main things in your life that help you cope or live well as a person with HIV?

"Family, a job that affords me good food and a roof over my head, free healthcare so I can access my meds." (Female, age 34)

"A steady relationship, acceptance of myself and my status/flaws/advantages, my two dogs, living in sunny and healthy [place], living in a house I love, doing a job I absolutely love … Basically taking full control of my life and snipping out anything or anyone that threatens my happiness or that of my household. And Empire of the Sun. God, I love that band." (Male, age 32)

"Good sleep routine. Enough money to pay my bills, rent and buy fresh food. Socialising with friends. Healthy sex life. Exercise. Work." (Male, age 31)

"An extremely supportive and non-judgemental HIV specialist doctor. Strong resources and intellectual interests. Good friends, my cat, and my garden." (Male, age 67)

CLINICAL SERVICES

We asked participants a range of questions on their use of, and access to, clinical services for HIV management and general medical care.

Almost two-thirds of participants (62%, n=522) saw their doctor for HIV-treatment at minimum every four months (see Figure 9). The majority of participants indicated they had access to bulk billing services, if needed, for general medical care (76.2%, n=682) and HIV treatment (85.3%, n=740).

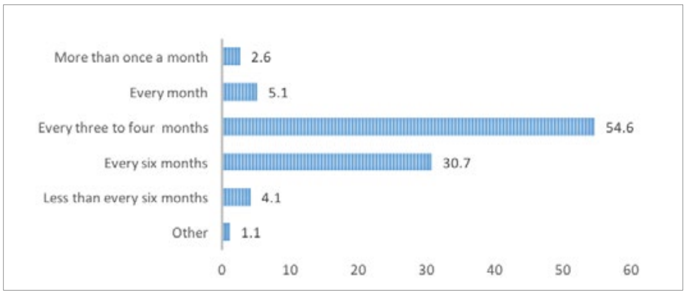

Figure 9: Frequency of doctor visits for HIV-related treatment

In a large country such as Australia, geography can present a barrier to people accessing specific or specialist medical services such as HIV treatment – particularly for those living in regional or rural areas. We asked participants how far they needed to travel to access HIV treatment (see Figure 10). The majority of people living in rural areas had to travel more than 50km to visit their doctor for HIV-related treatment (n=52, 62%). Even within cities, the majority of those living in outer suburban areas indicated they travelled more than 20 km to see a doctor for HIV treatment (n=62, 59%).

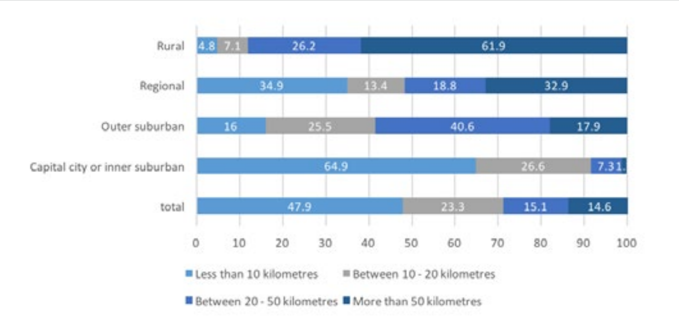

Figure 10: Distance travelled to visit doctor for HIV treatment by area of residence

There were 486 participants (54% of total sample) who indicated they saw their HIV GP/S100 prescriber or HIV specialist for general medical care (see Figure 11). Participants who saw their HIV provider for general medical care felt more supported by their healthcare providers than participants who saw non HIV providers for general medical care (see Figure 12).

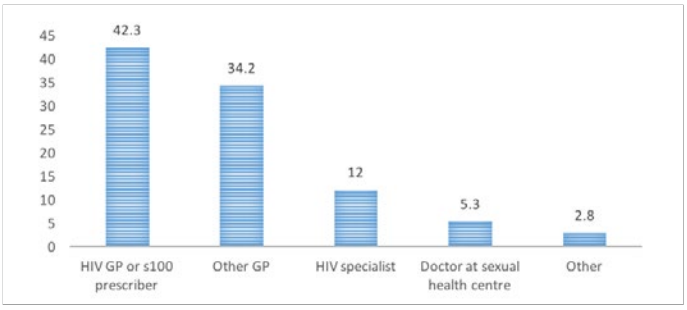

Figure 11: Type of provider seen for general medical care

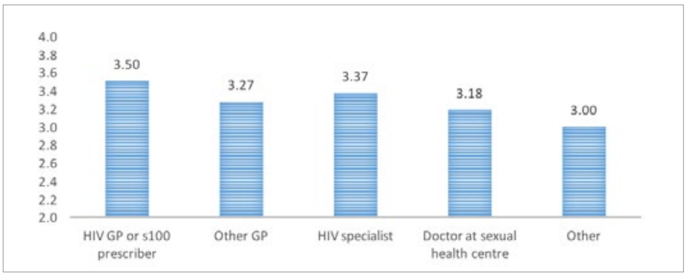

Figure 12: Feeling supported by healthcare providers according to type of provider seen for general medical treatment
Dependent variable: Health Literacy Questionnaire subscale, "Feeling Understood and Supported by Healthcare Providers" (Osbourne et al 2013), scale 1-4 with higher scores indicating a greater sense of support

Connecting Online

One in three participants (33.5%, n = 298) declared they are current members of online PLHIV social networks, including TIM (The Institute of Many Facebook group) or other formal online groups of networks such as the Ending HIV Network. TIM was the most popular network with 185 survey participants (20.7%) indicating they engaged with TIM regularly or occasionally.

Members of online PLHIV social networks tended to be younger than those not using online PHIV networks, but there were no significant differences in gender, sexuality, or location of residence.

Controlling for differences in age, gender, sexuality, and location of residence, members of online PLHIV social networks reported higher perceived support from other PLHIV (M=2.10 v M=1.83, p<.05) than those who do not engage in social networks. Members of online networks also reported higher perceived social support in general (M=9.28 v M=7.50, p<.05).

PLHIV were most likely to join online networks to hear about other people's experiences and to seek information and news relating to HIV (see Figure 13).

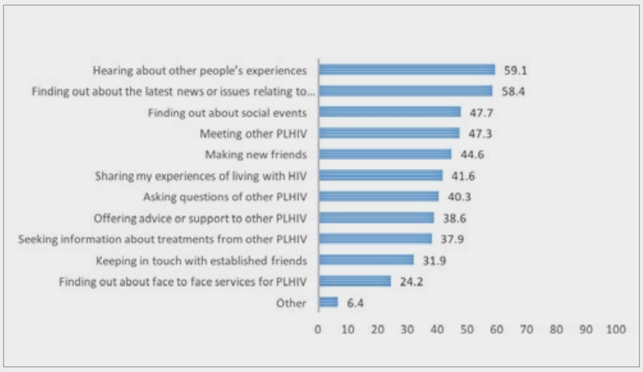

Figure 13: Reasons for connecting online with other PLHIV (% of those who are current members of PLHIV social networks; n = 298)

HETEROSEXUAL MEN

It is difficult to know how many heterosexual men are living with HIV in Australia. Currently national HIV surveillance data is collected on gender and mode of HIV transmission but not sexual identity. This means that within each category, the number of men who identify as heterosexual is unknown. For example, we don't know the sexual identities of men who acquired HIV through injecting drug use. However, relative to the overall number of PLHIV in Australia, the number of heterosexual men living with HIV is very small.

There were 38 heterosexual men who completed the HIV Futures 8 survey. The small sample size makes it difficult to report on these data with sufficient statistical rigour, meaning data from heterosexual men tends to become lost in the overall findings.

We have chosen to include a small subsection on heterosexual men in this report as a way to highlight some of their stories and draw attention to service provision for heterosexual men living with HIV.

Of the 38 heterosexual men who participated in the study, 82% (n=31) were in contact with HIV-related organisations. This is likely to be an over-estimation of the proportion of heterosexual men connected to PLHIV services as participants were recruited for the survey through PLHIV organisations. Despite this, only 51% (n=18) indicated they knew other heterosexual men who were living with HIV, and 37% (n=14) indicated they did not know any other PLHIV. Only a minority (21%, n=8) of these men connected with other PLHIV using social media or online forums. However, most heterosexual male PLHIV still reported that they had good access to social support. On average, heterosexual men were no less likely than women or gay men to report lower levels of social support (see Figure 6).

We asked heterosexual men if there was anything else they would like to tell us about their experiences of living with HIV as a heterosexual man. Twenty-three men (61%) provided a response to this question. The major theme of the responses was that heterosexual men living with HIV in Australia felt like a 'minority within a minority', which led to feelings of isolation and loneliness. There was a sense that the needs of heterosexual men were not adequately met by the HIV sector, given the small number of HIV positive heterosexual men in Australia.

> *"I have only meet one [other] heterosexual male since my diagnosis in 1997 and that took 13 years. Even though I understand the challenges of being in a minority within a minority, I have developed a skill to associate with all PLHIV"*
>
> *"It's somewhat lonely, the gay guys have more fun it seems"*
>
> *"It is very difficult (not fun at all). Makes it almost impossible to have a new relationship as HIV+ gets in the way. Who needs to be rejected by potential life partners it sucks!"*
>
> *"Not enough peer support".*
>
> *"Loneliness".*
>
> *"It's really hard disclosing my relationship to a woman in a relationship beginning – it is easier to break off the relationship before it becomes sexual. At my age... it would be easier just to have a friendship or companionship, but the HIV does come into play – as far as my mindset goes".*
>
> *"Very isolated as the focus is far from on heterosexual men".*
>
> *"While it is understandable that the Australian focus of the HIV sector is on the gay community it bothers me. The global situation is that it affects everyone. Like most things in Australia, we have a self-centred view of HIV that doesn't fit the global situation".*

38
Heterosexual men completed
HIV Futures 8

Ages ranged from 35-73 (average 38)
18 lived with partner or spouse
13 lived alone, 3 lived with friends/flatmates
25 had children, six currently lived with dependent children

51%
Did not know any other
heterosexual men living with HIV

SUMMARY AND CONCLUSIONS

Community-based organisations play a unique role in the provision of social and support services for PLHIV in Australia. The importance of these services is shown in these findings. Survey participants told us that the programs and services they most value are those which facilitate opportunities to meet other PLHIV, either in formal group settings or through informal social events. Developing connections with other PLHIV can reduce a sense of isolation, normalise the experience of living with HIV and allow people to meet others who share similar experiences. This can be important even for people who have strong family connections and broad social and support networks. For participants in this study, spending time with other PLHIV was associated with a greater sense of resilience and emotional wellbeing.

Social support more broadly – from family, friends and communities – was also associated with greater wellbeing and resilience. When we asked participants what helped them cope and live well as a person with HIV, support from a partner or family was the most common response. This is not unexpected. Social connectedness is important for wellbeing in all people (Hawkley and Cacioppo, 2013). From a service-provision perspective, it is worth noting that some PLHIV may have less access to social support than others. Specifically, the findings showed that men who identified as bisexual were significantly less likely to report access to social support than other men or women. Previous studies have shown bisexual Australians report poorer mental health than lesbian or gay people (Leonard et al, 2015). It is possible that this is related to a lower sense of social connectedness or support.

Access to supportive, non-judgemental doctors, affordable clinical services and HIV treatment were also noted by many survey participants as things that helped them cope and live well with HIV. Interestingly, participants who felt most supported by their healthcare providers were those who saw the same doctor for HIV care and general medical care. It is possible that those who felt most supported by their healthcare provider were those who had a longer-term, trusting relationship with one main physician, rather than seeing multiple providers for different health concerns.

These findings show the extent to which PLHIV value access to good information and education about HIV. After social and support services, participants were most likely to utilise community-based HIV services to source information about HIV treatment. Several participants also told us that they highly valued the information about HIV they received at workshops for people newly diagnosed with HIV. This information helped them make sense of their diagnosis and develop confidence to manage HIV into the future.

Finally, these results show the increasing importance of online forums for PLHIV. Approximately one in three participants indicated they are currently part of an online network of PLHIV. The reasons why people went online to connect with other PLHIV were similar to the reasons people sought out face-to-face services. People valued hearing about others' experiences with HIV and connecting with other PLHIV, as well as sourcing news and information about HIV. Further research is needed to explore the ways in which PLHIV benefit from online PLHIV networks and how these complement face-to-face services, but these findings indicate real potential for providing extra support tor PLHIV.

Thoughts and commentary

The way in which HIV positive people connect with each other, find support, build resilience, and flourish has changed somewhat in recent years. This has run parallel with extraordinary changes in the way People Living with HIV (PLHIV) access treatment, live more openly, and have greater confidence in the science of treatment as prevention.

This is due to an extraordinary joint effort from funded organisations, grassroots movements, and researchers. However, what we define as service provision, support, and peer-based organisations (all vital in the fight to end HIV and HIV stigma) is rapidly shifting.

What I call the "circle of chairs" model of peer support is becoming less relevant, while alternative and less formal models of networking are providing much needed space and support As HIV Futures 8 clearly shows: "Controlling for differences in age, gender, sexuality and location of residence, members of online PLHIV social networks reported higher perceived support from other PLHIV (M = 2.10 vs. M = 1.83) than people who do not engage in social networks. Members of online networks also reported higher perceived social support in general (M = 9.28 vs. M = 7.50)."

This is, of course, an imperfect scenario. It is imperfect for the funded PLHIV organisations who are dealing with ever-shrinking funding and ever-shrinking membership engagement as, in a new millennium, younger and/or recently diagnosed PLHIV are more resistant to this "bricks and mortality" model of peer support.

But it is also imperfect for the increasingly marginalised, high-needs PLHIV for whom peer-lead, largely online interventions do not and cannot meet their complex needs.

Nonetheless, it is telling that an independent online movement such as TIM are in some ways performing just as well as (and sometimes better than) funded organisations with arguably greater institutional memory and understanding of state and federal policy, PLHIV behaviours, and HIV treatments.

We are charged with far less responsibility, of course, and we are not interested in replacing pre-existing organisations. However, the independent, grassroots space created by TIM clearly appeals to the PLHIV community who are looking for a different forum for engagement outside the heavier infrastructure of existing organisations, and all the historical weight they carry with them.

The relative instability of independent online movements like TIM and others is a valid concern. All rely completely on contributions of volunteers at every level; most are driven by individuals or small groups of PLHIV. We ask you to just trust us as we operate a 24/7 digital drop-in centre for PLHIV and write the rules on our own terms.

But why wouldn't we? HIV Futures 8 is showing us that many in the PLHIV community have moved online, and are better for it. It's now up to the sector to keep up, make space, and acknowledge that independent movements driven by the PLHIV community aren't "new kids on the block". Rather, we are direct descendants of the same grassroots movement that gave birth to Australia's incredibly effective HIV sector.

Nic Holas
Co-founder, The Institute of Many

At Living Positive Victoria, we are fortunate to be able to offer peer support and social connection activities tailored to heterosexual men living with HIV (HMLHIV). Peer support is delivered by paid staff who are themselves HMLHIV. However, heterosexual men are often reluctant to engage with peer support services. Straight men are vulnerable to feelings of stigmatisation when contemplating accessing HIV services. There is also the influence of deeply held notions of masculinity, and what it means to be a man in contemporary Australian society. For example, "real" men are stoic and tough, and should be able to rely solely upon their own coping ability. We face similar challenges engaging heterosexual men from CALD backgrounds.

While we have a small number of straight men who comfortably access social events alongside gay men, it is more common for straight men to be deterred by the belief that community based HIV sector services are run by gay men for gay men. The challenge is breaking down that perception, and relaxing the mindset that it is problematic for straight men. What we hear from some of these men is entirely consistent with the finding of Futures 8; HMLHIV feel left out by the HIV sector's response. For this reason, it is important to deliver services that cater to the needs of heterosexual men.

Part of Living Positive Victoria's response has been to facilitate a peer led heterosexual male-only 'cook and chat' support group in addition to individual peer support. The group has developed slowly and we are constantly reviewing and assessing our methods to increase participation. We suspect that straight men are partly held back by concerns about confidentiality and being judged by the other men.

When HMLHIV do attend the group their apprehension often dissolves. When basic ground rules are established, including agreeing to a code of confidentiality and respect for each other's opinions, it takes very little to get these men talking, sharing their experiences and sharing humour. Generally, men who attend say that it was a positive experience and that they enjoyed connecting with others. They also report feeling relieved, like a process of normalisation has taken place. This can verge on pride and a sense of having overcome adversity. The men generally value the opportunity to tell their story to the group and hear other straight men's stories.

Disclosure features heavily in discussions; disclosing to romantic partners, sexual partners, family and friends. Navigating sexual relationships is another common theme, particularly the frustration of avoiding sexual encounters and reclaiming sexuality. Internal stigma, feelings of loss, the impact of diagnosis on employment, and living with a secret are also recurring topics. Group attendees say that the group is important to them because they have no other outlet for discussing HIV and receiving support.

As noted in Futures 8, many HMLHIV feel like a minority within a minority. The peer support programs we offer specifically for heterosexual men, along with other programs such as our annual retreat, help these men connect socially and create a pathway to thriving with HIV.

Anth McCarthy
Peer Support Officer, Living Positive Victoria

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HIV FUTURES 8

Women Living with HIV in Australia

Australian Research Centre in Sex, Health and Society

2017

INTRODUCTION

HIV Futures 8 is a survey about the health and wellbeing of people living with HIV (PLHIV) in Australia. The study forms part of a series of cross-sectional surveys that have been run every two to three years since 1997. Funded by the Australian Government Department of Health, the aims of the study are to provide information about factors that support physical and emotional wellbeing among PLHIV. The study is designed to inform the Australian National HIV Strategy and guide community and clinical service provision for PLHIV.

In order to explore the complexity of factors that support health and wellbeing among PLHIV, HIV Futures 8 is a broad survey covering issues such as financial security, housing status, anti-retroviral treatment use, general health issues, stigma and discrimination, clinical and support service use, aging, drug and alcohol use, sexual health, relationships, and social connectedness.

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. Findings from HIV Futures 8 are presented as a series of short reports. These, along with more information about the study and copies of reports from previous HIV Futures surveys, can be found on the ARCSHS website: **latrobe.edu.au/arcshs**

METHODS

HIV Futures 8 is a cross-sectional survey of PLHIV. The survey was open to people aged 18 years or older who were currently living in Australia. Data were collected using a self-complete survey that could be filled in online or using a booklet that was supplied to prospective participants with a reply-paid envelope. 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 Facebook including targeted posts to Facebook groups for PLHIV; advertisements on ‘dating apps’ used by gay men and other men who have sex with men and; flyers and posters displayed in HIV clinics. Hard copies of the survey were distributed through the mailing lists of HIV community organisations and made available in the waiting rooms of HIV clinics and community services. Data were collected between July 2015 and June 2016.

Full details of the study protocol and method have been published elsewhere and are available on the ARCSHS website: **latrobe.edu.au/arcshs/projects/hiv-futures**

Australian Research Centre
in Sex, Health and Society

SAMPLE

HIV Futures 8 was completed by 895 people living with HIV in Australia. Of these, 90.5% (n=804) were men and 8.3% (n=74) were women while four people described their gender in other terms. There were six people who identified as transgender.

The majority of the sample were men who identified as gay (78.7%, n=697), 5.6% (n=50) identified as bisexual and 4.3% (n=38) as heterosexual.

There were 21 participants (2.3%) who identified as Aboriginal or Torres Strait Islander.

The age of participants ranged from 19 to 86 years. The average age was 51 years. Over half (56.3%, n=485) were aged 50 years or older.

The majority of participants were born in Australia (74.7%, n=649) and spoke English as their first language (91.2%, n=792).

Participants came from all states and territories in Australia as detailed in Table i.

The majority of participants were working (53.8%, n=474) either full-time (38.6%, n=341) or part-time (15.2%, n=134). There were 18.1% (n=160) who were retired/no longer working.

There were 234 (26.7%) participants who had tested positive to HIV within the five years prior to the survey (from 2010 onward). Of these, the majority (77.0%) were under 50 years of age. However, there were 51 participants (23.0%) aged 50 or older who had been diagnosed in 2010 or more recently.

There were 844 participants (96.6%) currently using antiretroviral therapy. Of these, 756 (91.0%) reported they had an undetectable viral load as of their most recent test. (Note, these figures exclude missing data).

Full details of the study sample are available on the ARCSHS website **latrobe.edu.au/arcshs**

Table i. States and territories in which participants currently live

	n	%
ACT	20	2.3
NSW	306	34.5
NT	6	0.7
QLD	136	15.3
SA	65	7.3
TAS	10	1.1
VIC	265	29.9
WA	78	8.8

*Nine participants did not identify their state/territory

BACKGROUND

In 2015, there were just under 3,000 women living with (diagnosed) HIV in Australia, representing around 10% of the overall number of Australians currently living with HIV (The Kirby Institute, 2016). The experience of living with HIV can be very different for women than it is for men. In Australia, the majority of people living with HIV are gay or bisexual men. While support services and networks often have programs for women, the Australian HIV sector is, by necessity, focused on where the majority of the epidemic sits, which is communities of gay men. Women living with HIV may be more isolated from services or other people living with HIV as a result. While this is not necessarily the case for all women, it may mean women navigate their HIV treatment and care (and their everyday lives) differently from gay men – including their use of services, the clinicians they consult, the relationships they form and their feelings about HIV disclosure and stigma.

Women living with HIV are a diverse group. Many were born outside of Australia, most commonly in countries where the HIV prevalence is high, including regions in Africa and South East Asia. Women living with HIV are also diverse with respect to their ages, the length of time they have been living with HIV and the places where they live. So, it is difficult to collect data that represent the needs and experiences of all women, particularly given this is a relatively small group of women who may find it difficult to engage in research due to issues such as language barriers, fear of HIV disclosure, or disconnection from HIV networks and services.

We have been following the experiences of women living with HIV through the HIV Futures surveys since 1997. With each survey, women have represented between six and ten percent of respondents – around 70 to 80 women. While this number is small, it is enough to reveal important information about the lives of Australian women living with HIV. In this report, we present findings from HIV Futures 8 related to women living with HIV.

DEMOGRAPHIC CHARACTERISTICS OF WOMEN

The 74 women who completed the survey were aged between 19 and 80 years, with a median of 49 years. The majority of women were heterosexual (90.4%), while four women identified as bisexual and two as lesbian.

The majority of women were born in Australia (68.5%, n=50), spoke English as their first language (87.3%, n=62) and were Australian citizens (64.8%, n=46) or permanent resident (28.2%, n=20). There were five women (7.0%) who were not permanent residents or citizens. One woman was on a temporary working visa, two were New Zealand citizens and two were on bridging visas. Of the women not born in Australia, 10 were born in Europe or the United Kingdom, six were born in African countries (Kenya, South Africa, Zambia or Zimbabwe), three in South Asian countries (China or Thailand), three in New Zealand and one in the United States.

Two women were of Aboriginal or Torres Strait islander origin.

Respondents came from all states and territories, and most commonly lived in a capital city or inner suburb (42.5%, n=31), regional centre (23.3%, n=17) or outer suburb (20.5%, n=15). A smaller number of women lived in rural areas (13.7%, n=10).

EMPLOYMENT AND HOUSING

Over half of the women were currently working, with 38.9% (n=28) in full-time employment and 16.7% (n=12) in part-time employment. The remaining women were either unemployed (13.9%, n=10), not working or retired (9.7%, n=7), receiving the disability support pension (5.6%, n=5), studying (5.6%, n=4), or they nominated one of the ‘other’ categories.

When asked whom they were currently living with, the most common response was pets (41.5%, n=31), followed by a partner or spouse (36.5%, n=27). Around one-quarter of the women lived alone (27%, n=20), a similar number with dependent children (25.7%, n=19) and 14.9% (n=11) with other family members. Three women (4.1%) lived with friends or flatmates and three (4.1%) selected another response.

Most women lived in housing that they either owned or were purchasing (39.2%, n=29) or were renting privately (36.5%, n=27), while 14.9% (n=11) lived in public housing. The remainder lived rent free, in community housing or selected ‘other’ type of housing (9.5%, n=7).

INCOME AND FINANCIAL SECURITY

Respondents were asked to nominate their main sources of income, with more than one response possible. Just over half of the women nominated a government benefit as a main source (51.4%, n=38), while just under half (48.6%, n=36) nominated a salary or wages. Seven of these women selected salary and a government benefit. Other sources of income were partner support (12.2%, n=9) and savings or superannuation (10.8%, n=8). Two women indicated 'other' categories.

Respondents were asked to estimate their current yearly pre-tax household income. As shown in Table 1, just over one-third of women lived in households in which the yearly income was up to $29,999, while 15.1% lived in households earning between $30,000 and $49,999. In total, just 15% of women lived in households in which yearly earnings totalled $80,000 or more. In comparison, the 2015/16 national average full-time income was approximately $80,000 per year and the average income for all workers (full-time or part-time) was approximately $60,320 per year (ABS, 2016).

Table 1. Annual household income (before tax)

Yearly income	% (n)
Negative or zero income	2.7 (2)
$1-$29,999	34.2 (25)
$30,000-49,999	15.1 (11)
$50,000-79,999	16.4 (12)
$80,000-99,999	4.1 (3)
$100,000-$124,999	4.1 (3)
$125,000-149,999	2.7 (2)
$150,000-199,999	4.1 (3)
Don't know	2.7 (2)
Prefer not to answer	13.7 (10)

The HIV Futures 8 survey included questions about respondents' experience of money difficulties in the past 12 months, such as not being able to pay bills, needing to ask friends or family for money and so forth. These questions are used as indicators of financial stress. If none or one of these events occurred this is classified as *little or no financial distress* and if two or more occurred this is classified as *significant financial distress* (Wilkins, 2016). The Household, Income and Labour Dynamics in Australia (HILDA) survey found that indicators of financial stress are linked to deprivation, i.e. not being able to afford items that are considered essential (Wilkins, 2016).

Of the 74 women, 32 (43%) did not select any of these responses, which may indicate that they had not experienced any financial stress, that none of these specific circumstances applied to them, or that they simply chose not to answer the questions.

Of the 32 women who responded to at least one item, the most common was asking for financial help from friends or family (47.6%, n=20), followed by not being able to pay their electricity, gas or telephone bills on time (38.1%, n= 16), asking for help from welfare or community organisations (28.6%, n=12), pawning/selling something (23.8%, n=10) or going without meals (21.4%, n=9).

Of the 74 women respondents, 29.7% (n=22) were categorised as having *little or no financial stress*, while 27.0% (n=20) were classified as *having significant financial stress* (see Table 2).

Table 2. Percentage of women (n) with financial stress

Little or no financial stress	29.7 (22)
Significant financial stress	27.0 (20)
Did not answer/Not applicable	43.2 (32)

The HIV Futures 8 survey also included a measure of credit constraints, that is, the ability of a person to be able to borrow money (Wilkins, 2016). Respondents were asked if they would be able to raise $3,000 in one week in the event of an emergency. Those who indicated *I would have to do something drastic to raise the money* or *I don't think I could raise the money* are defined as 'credit constrained', while those who indicated *I could easily raise the money* or *I could raise the money but it would involve some sacrifices* are defined as 'not credit constrained' (Wilkins, 2016). According to this measure, 56.1% (n=41) of the women were credit constrained. The most common response to these items was: *I don't think I could raise the money* (39.7%, n=29). Of those who said they could raise the money, one-quarter said *I could easily raise the money* (24.7%, n=18), while 19.2% (n=14) said *I could raise the money but it would involve some sacrifices* and 16.4% (n=12) said *I would have to do something drastic to raise the money*.

HIV TESTING AND DIAGNOSIS

The average number of years women in this study had been living with HIV was 15.5. Some had been living with HIV for less than 12 months, while the longest time living with HIV was 32 years. There were 15 women (20.3%) who had been diagnosed with HIV in the past five years (since 2009).

The majority of women indicated that they contracted HIV through sex with a man (85.1%, n=63). Four contracted HIV through injecting drug use.

Sixteen women (21.6%) indicated they were travelling interstate (n=5) or overseas (n=11) at the time they contracted HIV.

We asked respondents to tell us the main reason they took a HIV test at the time they were diagnosed. The most common reasons were that their partner had tested positive (27%, n=20) or that they became ill (27%, n=20). Four women were tested as part of a visa requirement, four after a particular risk episode and three were tested during pregnancy.

We asked respondents the type of clinic at which they had been tested when they received their HIV diagnosis. The most common testing locations were their regular doctor (27%, n=20) or the first available doctor (21.6%, n=20), while18.9% (n=14) had tested at a hospital and 12.2% (n=9) at a sexual health clinic. Four women indicated that they had used rapid testing clinics.

Around half of the women (53.7%, n=36) had never taken a HIV test prior to receiving their diagnosis, and 80.5% (n=29) of these cited that the reason they had not tested previously was that they did not think they were at risk. The remainder (n=5) selected 'other' in response to this question.

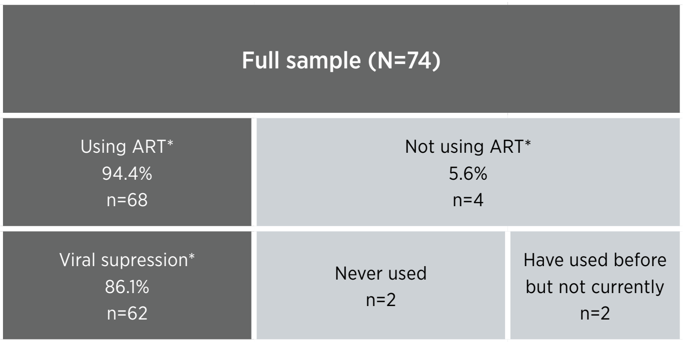
TREATMENT

The majority of women (94.4%, n=68) were currently using antiretroviral treatment (ART) (see Figure 1) and, of these, 86.7% (n=59) indicated they had an undetectable viral load (HIV viral suppression) as of their most recent test (see Figure 1).

Of the women who were currently taking ART, 42.6% (n=29) indicated that they commenced ART more than two years after diagnosis, while 29.4% commenced ART within three months of diagnosis. There were eight women (11.8%) who indicated that they commenced ART when highly active anti-retroviral treatment first became available (around 1996).

Reflecting current treatment guidelines that recommend initiating ART for all HIV-infected individuals regardless of CD4 count (ASHM, 2015), 76.9% (n=10) of women diagnosed in 2010 or later had started taking ART within three months of diagnosis, compared with 15.1% (n=8) of those diagnosed prior to 2010.

Figure 1: Current use and non-use of ART



*figures exclude missing data

HEALTH AND WELLBEING

Participants were asked to rate their current state of physical health using a five-point scale (poor to excellent). The majority of women (62.2%, n=46) rated their health as very good or excellent.

We also asked participants to assess their overall sense of wellbeing (incorporating physical, mental and emotional wellbeing). The majority of women (65.8%, n=48) reported their wellbeing to be good or excellent.

The rate of diagnosis of *mental health conditions* is high among people living with HIV. This was evident in this sample of women with 41.7% (n=30) indicating they had been diagnosed with a mental health condition within their lifetime and 33.8% (n=24) having received medical treatment for a mental health condition in the past six-months. Anxiety and depression were the most common conditions with which women had been diagnosed. As a point of comparison, in the 2014-15 Australian National Health survey, 19.2% of Australian women reported having a mental or behavioural condition (ABS 2016a).

Women cited a range of other health conditions with which they had been diagnosed during their life time including: asthma (n=11), arthritis (n=9), osteoporosis (n=8), hypertension (n=6), diabetes (n=5) or cancers (n=5).

There were four women who had been diagnosed with hepatitis B and 12 who had been diagnosed with hepatitis C.

We asked participants about recent sexual health screening. Just under half the women (46.5%, n=33) had been screened for sexually transmissible infections in the past 12 months, while 27.8% (n=20) were screened for syphilis alongside their most recent HIV viral load test. There were four women who had been diagnosed with a sexually transmissible infection in the past 12-months.

There were 21 women (28.4%) who indicated they currently smoke tobacco (or use tobacco products) on a daily basis, while five (6.8%) smoked tobacco less than daily. By comparison, the 2014-15 National Health Survey indicated 12.1% of Australian women smoked tobacco daily (ABS 2016a).

There were 18 women (40% of the 45 women who responded to this question) who indicated their typical daily alcohol consumption was three or more standard drinks, while 13 women (20%) indicated that, at least monthly, they consumed six or more drinks on any one occasion.

We asked women about their *non-medical* use of a range of drugs. The drugs most commonly used by women *occasionally* or *regularly* were: pain killers or analgesics (29.4%, n=20), marijuana (21.2%, n=14) and tranquilisers or sleeping pills (14.7%, n=10).

PREGNANCY AND CHILDREN

The majority of women (64.9%, n=48) had children, while 19 currently lived with dependent children.

There were 29 women who indicated they had been pregnant while living with HIV. Fourteen women indicated they had, at some point in their life, terminated a pregnancy due to their HIV status.

There were 21 women who had given birth to a baby while they were HIV positive. We asked these women to tell us more about their experience of their most recent pregnancy. One woman did not respond, so there were 20 women who answered these questions. All of these women were living in Australia when they became pregnant and gave birth in Australia. For 10 women (50%) this was an unplanned pregnancy, for 10 (50%) it was planned. The majority of women (90%, n=18) were aware of their HIV status when they conceived the baby and 95% conceived via sexual intercourse (one used home-based artificial insemination).

There were four women (20%) who gave birth vaginally, while 16 (80%) had a caesarean delivery, of which 10 indicated this was an elective caesarean to reduce the risk of mother-to-child HIV transmission.

ART was available to 95% (n=19) of the woman during their pregnancy and 12 women (60%) indicated they used ART during their entire pregnancy. One woman suspended ART for the first trimester while others indicated they used ART in other ways but did not elaborate.

Sixteen women (20%) reported their baby was HIV negative when they were born. One woman reported her baby was born with HIV while others were unsure or did not respond.

Four women (20%) breastfed their baby.

RELATIONSHIPS AND SEX

Approximately half (47.9%, n=34) the women described their relationship status as single. The same number (47.9%, n=34) were in a regular relationship. One of these women indicated she was in a regular relationship with more than one partner (polyamorous). (Six women did not respond to this question or described their relationship status in ‘other’ terms).

Of those women in a regular relationship, 91.7% (n=33) were in a relationship with a man, one was in a relationship with a woman and one responded ‘other’ to this question.

Of those in a regular relationship, 72.7% (n=24) were with a HIV negative partner, while 23.5% (n=8) were with a HIV positive partner. One woman did not know her partner’s status, while one did not respond to this question. None of the women indicated their current partner was using pre-exposure prophylaxis (PrEP), but four women reported their partner had used post-exposure prophylaxis (PEP) at least one time.

When asked about sexual relationships, 54.8% (n=40) indicated they had *no sex* at present, 35.6% (n=26) had a *regular sexual relationship* with one person, while 6.8% (n=5) had *casual sex* only. Two women had sex with a regular partner as well as other sexual or romantic partners.

We asked a series of questions about the impact of living with HIV on women’s sexual lives:

- 51.4% (n=36) indicated their HIV status negatively affected their sexual pleasure
- 43.4% (n=30) reported they had stopped having sex due to their HIV status
- 66.6% (n=46) agreed or strongly agreed with the statement *I am afraid of telling potential partners of my HIV status in case they reject me*
- 65.2% (n=45) of women agreed or strongly agreed with the statement *Few people would want a relationship with someone who has HIV*.
- 55.1% (n=38) disagreed or strongly disagreed with the statement, *Being HIV positive has helped me form more satisfying relationships*, although 31.9% (n=22) agreed/strongly agreed with this statement.

Despite many women reporting that HIV had negatively affected their sexual and intimate relationships, there were some signs that the effectiveness of ART was changing this, with 66.6% (n=46) agreeing/strongly agreeing with the statement *I feel more confident having sex when my viral load is undetectable*.

When asked about experiences of violence, 42.6% (n=29) reported they had experienced being *pushed, grabbed, shoved, kicked or hit*, five of these within the previous 12 months. There were 21 women (31.4%) who reported being forced to take part in unwanted sexual activity (one of these within the past 12 months), while 32.4% (n=22) reported that they had been in a violent relationship with a partner or spouse at some point in their life.

USE OF HIV SERVICES AND NETWORKS

Most women (84.5%, n=60) had regular or occasional contact with at least one HIV organisation. There were five women who had no contact and six who had previous, but not current, contact.

There were 20 women who indicated they regularly or occasionally use online social networking to connect with other people living with HIV. In particular, 14 women were part of The Institute of Many (TIM) Facebook group and 18 women were part of a private online group for HIV positive people.

We asked women to describe, in their own words, what HIV services they found most useful. The most common responses were counselling and peer support services, along with social programs and events, including retreats for HIV positive women and other informal social events. A number of women also mentioned practical services including legal help, financial support and the provision of free grocery items. Information and new knowledge about HIV was also highly valued. Several women noted they appreciated publications produced by HIV organisations as well as websites and discussion groups.

COMMENTARY

By Jane Costello, President of Positive Life NSW and a member of Femfatales, the NAPWHA National Network of Women Living with HIV.

The following is an edited version of an address delivered by Jane Costello at the launch of HIV Futures 8 at the Australasian HIV & AIDS Conference in Adelaide, November 2016.

I have been asked to provide a woman's perspective on Futures 8, and while I acknowledge that Futures 8 is about the lived experience of all people living with HIV, I would like to focus specifically on women living with HIV – a marginalised population that I believe is missing from much of our national discourse and dialogue around HIV, which has major implications for public health policy and service delivery in Australia. Women continue to be largely invisible in our HIV response, and women with HIV are a minority who live with inequality, in silence and secrecy. That inequality, silence and secrecy feeds a climate of stigma and discrimination, as well as an assumption that HIV is simply not an issue for women.

Around 10% of the population of people living with HIV in Australia are women, and Futures 8 does provide a representative sample of women's voices. Of the total number of people who completed the survey (895), just under 10% of these were women. Futures 8 therefore, is a critical piece of research on the health and wellbeing of our community, and gives us evidence and data. This evidence is around testing and treatment, and women's lives more generally.

Additionally, it provides us with a snapshot of the differences within the increasingly diverse community of people living with HIV in Australia. If we don't understand these differences and apply them selectively to the areas of health policy, programs, service delivery and research, we are not going to understand or be able to address the very particular issues and unmet needs that affect that women face in their everyday lives.

I have said it before: there are gender differences in HIV in Australia. We are doing better in terms of research data on HIV aggregated by gender to enable us to better understand gender difference, but there is more that could be done, particularly on treatment initiation, engagement and retention in care. I will touch briefly on testing and treatment. Respondents were asked to state the main reason they took an HIV test the time they were diagnosed with HIV. The most common reasons that women gave for taking a test was that their partner tested positive or they became ill. Most women living with HIV in Australia have been infected as a result of heterosexual sex, and in the 2016 Kirby Institute Annual Surveillance Report 20% of new diagnoses of HIV in Australia were attributed to heterosexual sex. HIV doesn't discriminate.

Arguably, everyone is at risk, and as a heterosexual women living with HIV for the past 22 years, it frustrates me that heterosexuals are still not named as a priority population in the Australian National HIV Strategy. Unsurprisingly, only 2.7% of women completing the Futures 8 survey indicated that it was because they were a member of a risk group, clearly not seeing themselves as part of any of the priority populations.

Around half of the women had never taken an HIV test prior to receiving their HIV diagnosis, and 80.5% of these gave the reason that they did not think they were at risk. As a result, very few women in Australia are diagnosed with newly acquired HIV. Women are often late presenters with advanced HIV, which has already significantly damaged their immune system, and many newly diagnosed women present with an AIDS defining illness.

While there is a relatively well-established culture of HIV testing within the gay community, this is not the case in the wider community where HIV is still most commonly perceived as a gay male disease. I truly believe that we should be setting a better standard for women's health in this country whereby an HIV test is routinely offered as part of a sexual health check across the board. I would go further to say that for all sexually active women a sexual health check should be a part of a comprehensive health check, and we need to empower women to view this as a way of taking control of their own health and wellbeing.

What continues to be shocking in a developed country such as Australia is the substantially disproportionate rate of HIV diagnosis amongst Aboriginal and Torres Strait Islander women compared with non-Indigenous women, and the high rates of diagnosis among women from a CALD background. While Australia has long been recognised for its response to HIV, particularly among gay men and other men who have sex with men, sex workers and people who inject drugs (who are considered the priority populations), we have dropped the ball with our First Nation women and migrant populations.

Futures 8 gives us a clear snapshot of the number of women on treatment and with an undetectable viral load at 94.4% and 86.1% respectively, which is fantastic news, but there are still gaps in research into the efficacy of anti-retroviral treatments and side-effects that are specific to the female body, as well as a lack of research into hormonal differences between men and women and the impact these have on women with HIV and treatments. Additionally, there is a paucity of research on the reproductive health of women living with HIV, as well as the psychological issues for women with HIV in relation to reproduction and family.

There are particular issues for women living with HIV in relation to: disclosure and the negotiation of sexual relationships; reproductive health, as I have already mentioned, including pregnancy, childbirth, breastfeeding and family life; career paths; and coping mechanisms. There is a greater likelihood that women with HIV will live in outer suburban or regional locations and this has an impact on women's access to treatment and care. By comparison with gay men, there is a lack of support networks, both formal and informal for women.

Futures 8 highlights the alarming numbers of women with HIV living in poverty with over one third of women living in households in which the yearly income was less than $29,999. In total, only 15% of the women surveyed lived in households in which yearly earnings totalled $80,000 or more. According to measures defined in Futures 8, 56.1% of women were credit constrained. Women living with HIV are disproportionately affected by family violence, and cultural factors are a further multiplier of women's risk of family violence. Approximately 40% of women in Futures 8 also indicated they had a medium-to-high risk of alcohol-related harm, and there are high rates of women with HIV diagnosed with mental health conditions.

Futures 8, therefore, continues to be an important and increasingly valuable piece of research, providing a critical snapshot of the lives of people living with HIV in Australia. The question is, as researchers, clinicians and community, how do we use its findings and leverage these to prioritise women's health, and to progress items of work that ensure that the needs of a marginalised group of people living with HIV are met? We need to start advocating for women in a way that is thoughtful and responsive to their specific needs if Australia is serious about health equity and improving the health outcomes for women living with HIV.

SUGGESTED CITATION

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HIV Futures 8 is a survey about the health and wellbeing of people living with HIV (PLHIV) in Australia. The study forms part of a series of cross-sectional surveys that have been run every two to three years since 1997. Funded by the Australian Government Department of Health, the aims of the study are to provide information about factors that support physical and emotional wellbeing among PLHIV. The study is designed to inform the Australian National HIV Strategy and guide community and clinical service provision for PLHIV.

In order to explore the complexity of factors that support health and wellbeing among PLHIV, HIV Futures 8 is a broad survey covering issues such as financial security, housing status, anti-retroviral treatment use, general health issues, stigma and discrimination, clinical and support service use, aging, drug and alcohol use, sexual health, relationships, and social connectedness.

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. Findings from HIV Futures 8 are presented as a series of short reports. These, along with more information about the study and copies of reports from previous HIV Futures surveys, can be found on the ARCSHS website: **latrobe.edu.au/arcshs**

METHODS

HIV Futures 8 is a cross-sectional survey of PLHIV. The survey was open to people aged 18 years or older who were currently living in Australia. Data were collected using a self-complete survey that could be filled in online or using a booklet that was supplied to prospective participants with a reply-paid envelope. 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 Facebook including targeted posts to Facebook groups for PLHIV; advertisements on 'dating apps' used by gay men and other men who have sex with men and; flyers and posters displayed in HIV clinics. Hard copies of the survey were distributed through the mailing lists of HIV community organisations and made available in the waiting rooms of HIV clinics and community services. Data were collected between July 2015 and June 2016.

Full details of the study protocol and method have been published elsewhere and are available on the ARCSHS website: **latrobe.edu.au/arcshs/projects/hiv-futures**

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BACKGROUND

Financial security is key to people's wellbeing. It enables access to safe housing and other basics – food and clothing – necessary for survival. It also allows people greater choice with respect to how they live their lives, which in turn supports psychological and social wellbeing. By contrast, poverty can be intensely stressful and isolating. It can also be disempowering, limiting people's capacity to demand quality in services and care. All of this can have a negative effect on people's health and wellbeing.

For people living with HIV in Australia, access to an adequate and secure income supports quality of life by facilitating greater security and choice in the places people live, services they utilise, and healthcare providers with whom they interact. Capacity to choose and demand quality of services is important for good healthcare. It may also reduce the experience of HIV-related stigma.

Some people living with HIV may be vulnerable to poverty due to a combination of poor physical or mental health and stigma. In particular, people who have been living with HIV for a long time are likely to have experienced side effects from early (pre 1996) treatment and/or ill-health from AIDS-related symptoms. This may have affected people's capacity to work, having long-term consequences for their financial security as they move into older age.

In this broadsheet we explore the relationship between income, financial stress, and wellbeing among people living with HIV in Australia. This broadsheet is one of a series of short reports on findings from HIV Futures 8. All of these are available to download from the ARCSHS website: **latrobe.edu.au/arcshs**

SAMPLE

HIV Futures 8 was completed by 895 people living with HIV in Australia. Of these, 90.5% (n=804) were men and 8.3% (n=74) were women, while four participants described their gender in other terms. Six participants identified as transgender.

The majority of the sample comprised men who identified as gay (78.7%, n=697), 5.6% (n=50) as bisexual and 4.3% (n=38) as heterosexual.

There were 21 participants (2.3%) who identified as Aboriginal or Torres Strait Islander.

The age of participants ranged from 19 to 86 years. The average age was 51 years. Over half (56.3%, n=485) were aged 50 years or older.

The majority of participants were born in Australia (74.7%, n=649) and spoke English as their first language (91.2%, n=792).

Participants came from all states and territories in Australia as detailed in Table i.

	n	%
ACT	20	2.3
NSW	306	34.5
NT	6	0.7
QLD	136	15.3
SA	65	7.3
TAS	10	1.1
VIC	265	29.9
WA	78	8.8

Table i. States and territories in which participants currently live

*Nine participants did not identify their state/territory

The majority of participants were working (53.8%, n=475), either full time (38.6%, n=341) or part-time (15.2%, n=134). There were 18.1% (n=160) who were retired/no longer working, and a further 7.2% (n=64) were not working or seeking work due to home duties or other reasons.

The length of time since participants had been diagnosed with HIV ranged from one year or less to 34 years with an average of 15 years. There were 234 (26.7%) participants who had tested positive to HIV within the five years before the survey (i.e. from 2010 onward). Of these, the majority (77.0%) were under 50 years of age. However, there were 51 participants (23.0%) aged 50 or older who had been diagnosed in 2010 or more recently.

The great majority of participants were currently using antiretroviral therapy (96.5%, n=844). Of these, 91.0% (n=756) reported they had an undetectable viral load at their most recent tests. (Note, these figures exclude missing data).

Full details of the study sample have been published elsewhere (Power et al. 2017) and are available on the ARCSHS website: **latrobe.edu.au/arcshs**

HOUSEHOLD INCOME

The 2015/16 average annual income for Australian workers (full-time or part-time) was approximately $60,320 (ABS, 2016). Among participants in HIV Futures, nearly 50% earned less than $50,000 per year (pre-tax household income), while 30% lived in households in which the yearly household income was less than $30,000 (see Table 1).

Income	% (n)
$0–$29,999 per year	29.7 (245)
$30,000–$49,999	16.0 (132)
$50,000–$99,999	31.2 (258)
$100,000–$149,999	12.3 (102)
$150,000+	10.8 (89)
Excluding missing data	

Table 1. Household income

FINANCIAL STRESS

The HIV Futures 8 survey included questions about participants' experience of financial challenges in the past 12 months, such as not being able to pay bills or needing to ask friends/ family for money. These questions are indicators of financial stress. If none or one of these events occurred, this is classified 'as little or no financial stress' and if two or more occurred this is classified as 'significant financial stress' (Wilkins, 2016). The Household, Income and Labour Dynamics in Australia (HILDA) survey findings revealed a relationship between significant financial stress and deprivation (i.e. not being able to afford items that are considered essential) (Wilkins, 2016). In this report, we use financial stress, rather than household income, as an indicator or poor financial means as household income may not always reveal financial means. For example, if people have savings, support from family, or significant assets their financial means may be greater than indicated by income.

Among HIV Futures participants 23% (n=205) had experienced 'significant financial stress' (more than two events) in the past year (see Table 2). Not surprisingly, these participants tended to have lower incomes (50% reported an annual household income of less than $30,000) and the majority (60%) were reliant on social security as their main source of income.

In the past 12 months did any of the following happen to you because of a shortage of money?	% (n)
Asked for financial help from friends or family	21.2 (190)
Could not pay electricity, gas or telephone bills on time	19.8 (177)
Went without meals	13.7 (123)
Asked for help from welfare or community organisations	12.6 (113)
Pawned or sold something	11.1 (99)
Could not pay the mortgage or rent on time	7.8 (70)
Was unable to heat home	6.8 (61)

Table 2. Indicators of financial stress

Participants aged over 50 years were significantly more likely to report experiencing significant financial stress than those under 50. More women and bisexual men reported experiencing significant financial stress than gay or heterosexual men, although these differences were not statistically significant (see Figure 1).

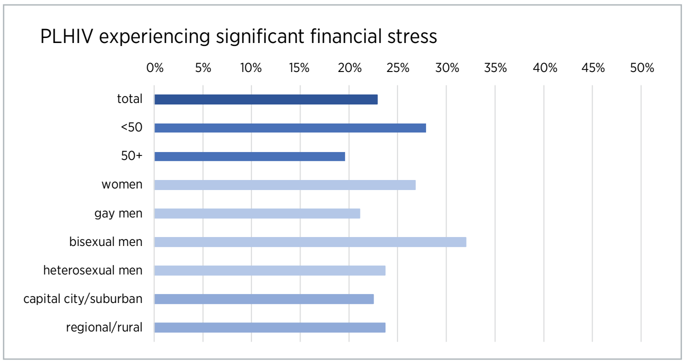

Figure 1. Financial stress among HIV Futures participants

FINANCIAL STRESS AND WELLBEING

People who have limited capacity to work due to ill-health or mobility problems are likely to also live on low incomes. Hence, it is expected that we would find a relationship between financial stress and poorer wellbeing. While financial stress in itself may not cause poor health, it may create added stress in people's lives, reduce their capacity to access health services, and increase social isolation, all of which can further erode health. Either way, there is a clear relationship between poverty and poorer health. Financial stress may be an indicator of people needing support across a range of areas.

In HIV Futures 8, participants who had experienced significant financial stress (vs those with no or low stress, and controlling for differences in age, gender and sexuality), were 'more likely' to:

- report 'poorer mental health' (SF 36 Mental Health Component score, Mean Score =34.34 vs. Mean Score =45.09) (Wu et al., 1997)
- report 'poorer physical health' (SF 36 Physical Health Component score Mean Score = 38.25 vs. Mean Score =46.75)
- have been diagnosed with a 'mental health condition' (74% vs. 45%) and taken medications for a mental health condition in the past six months (53% vs. 26%)
- be diagnosed with an 'ongoing health condition' other than HIV (Mean number of co-morbidities 2.03 vs. 1.73)
- report a lower 'level of resilience' (Connor-Davidson Resilience Scale, Mean Score = 24.72 vs. Mean Score = 28.71) (Connor and Davidson, 2003)
- report 'lower levels of social support' (Social Support Scale; Mean Score = 2.93 vs. Mean Score =11.07) (Baker, 2012)
- report experiencing 'higher levels of HIV-related stigma' (Berger enacted stigma subscale, Mean Score =46.53 vs. Mean Score =38.17; Berger negative self-image scale, Mean Score =31.78 vs. Mean Score =27.32) (Berger et al., 2001).

FINANCIAL STRESS AND ACCESS TO MEDICAL SERVICES

Lack of financial resources may make it difficult for people to access health services. The majority of HIV Futures participants who reported experiencing significant financial stress had a healthcare card (64%) to offset some medical expenses, although only one in five (23%) had private health insurance. Financial stress was associated with a range potential barriers to health service access. Participants who had experienced significant financial stress were 'more likely' than those reporting low or no financial stress to report:

- difficulties 'traveling to places they need to go' (39.6% experience difficulty at least sometimes vs. 14%)
- difficulties 'paying for specialist medical services' (35% vs. 10%)
- having experienced 'long waiting lists' when accessing specialist services (31% vs. 17%)
- having 'experienced discrimination' in a healthcare context (medical services, dentistry, hospital) in the past two years (26% vs. 13%)
- feel 'less capable of engaging actively with healthcare providers' and have lower capacity to navigate the healthcare system (based on the Health Literacy Questionnaire, Osbourne et al 2013).

ACCESS TO HIV SUPPORT SERVICES

A number of support services for PLHIV provide financial assistance and advice. Financial support was one of the services most likely to have been accessed by HIV Futures participants, particularly those experiencing significant financial stress. Among participants in HIV Futures who had experienced significant financial stress, 35% reported having accessed financial assistance provided by HIV related organisations in the past 12 months, 17% had accessed financial advice, while 15% had accessed legal advice.

SUMMARY AND CONCLUSION

HIV Futures 8 findings showed that, of the PLHIV who completed the survey, around half were living on household incomes substantially lower than the average Australian income at the time of the survey, while close to one in four had experienced significant financial stress in the past two years.

People who had experienced financial stress had poorer health, more experiences of HIV-related stigma and lower levels of resilience. This study does not enable us to differentiate between cause and effect when it comes to financial stress and ill-health. But, irrespective of this, we can clearly say from these findings that many Australian PLHIV are living on low incomes and that PLHIV on low incomes are (for whatever reason) likely to face greater challenges when it comes to accessing health services. Barriers to accessing health services may mean PLHIV on low incomes have less choice of healthcare provider, which could explain their greater likelihood of experiencing HIV-related stigma and discrimination in healthcare settings. PLHIV experiencing financial stress may also be socially isolated, which could be a consequence of low income as well as poor health or limited mobility. Services for PLHIV play a vital role in provision of support for people who may be vulnerable because of their financial status. This includes financial advice, financial support, providing access to housing or food, as well as social services aimed at reducing isolation. These services are currently utilised by a number of PLHIV experiencing financial stress, although it may be worth exploring whether there are unmet needs – or unidentified barriers to community service access – for PLHIV experiencing financial stress.

SUGGESTED CITATION

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