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

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

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

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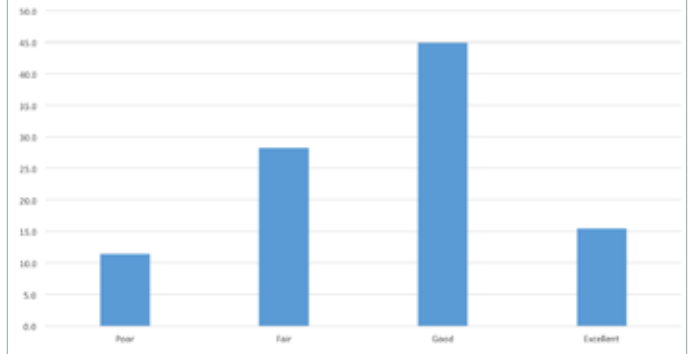
There were no significant differences in reported wellbeing between age groups (see Table 1).

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)
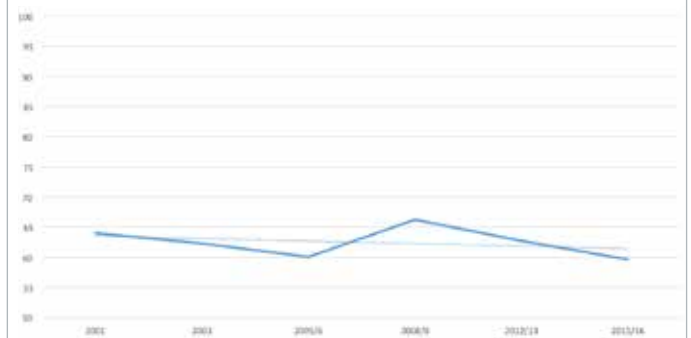
Participants were asked to rate their current state of physical health using a five-point scale (poor to excellent). Over half the sample (n=495, 55.6%) rated their health as very good or excellent (see Figure 3). This finding is consistent with the Australian National Health Survey in which 56.2% of 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).

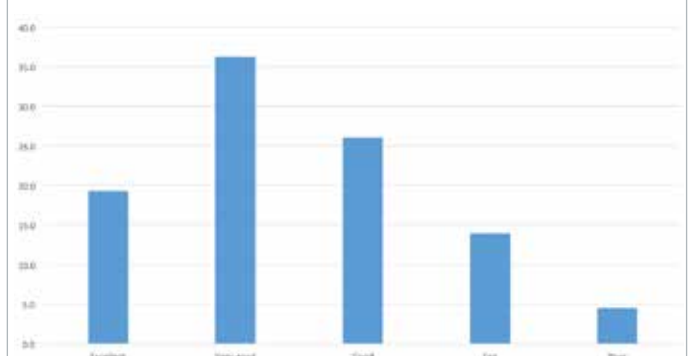Figure 3. Self assessed physical health (%)

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
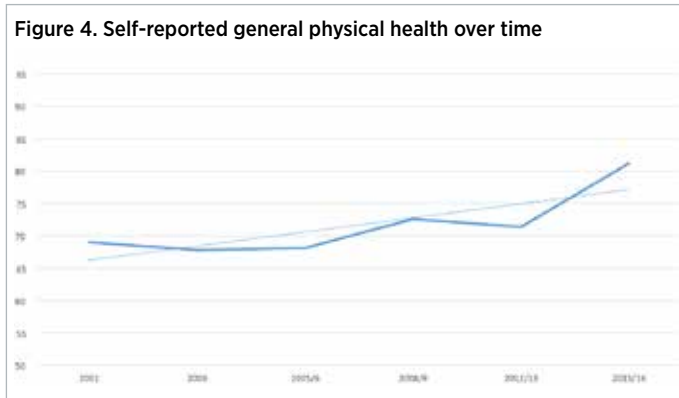
HIV FUTURES 8 FINDINGS

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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