

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

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.

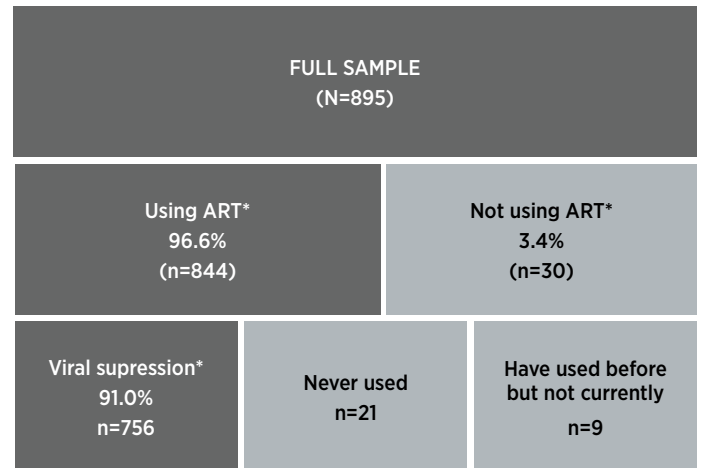
FINDINGS

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).

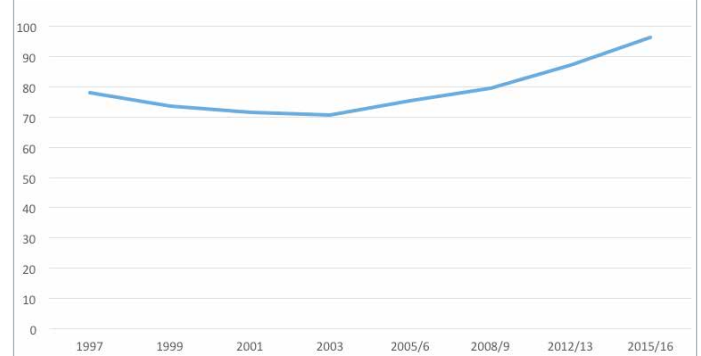
Figure 2 shows the percentage of current ART use over time, drawing data from previous HIV Futures surveys. There was a slight decrease in the proportion of participants using ART between 1997 and 2003. Since this time the figure has steadily increased.

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.

% (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.

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).

% (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, Truemeq 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).

	%
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 Transcriptase Inhibitors (NNRTIs)	
Viramune (nevirapine)	14.9
Intelence (etravirine)	4.1
Stocrin (efavirenz)	2.3
Edurant (rilpivirine)	0.5
Nucleotide Analog Reverse Transcriptase 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).

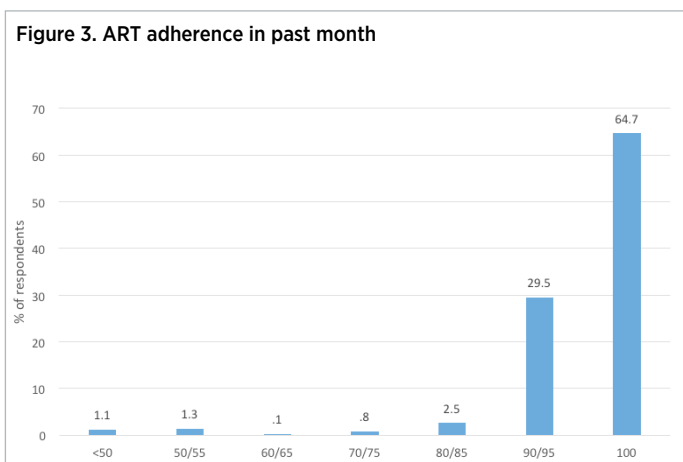
We asked participants if they had ever initiated a treatment review with their doctor. There were 353 (42.9%) participants who indicated they had initiated a treatment review, while 247 (30.0%) said that they always wait for the doctor to initiate treatment reviews. There were 207 (25.2%) who said that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

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.



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).

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.

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.

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)

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

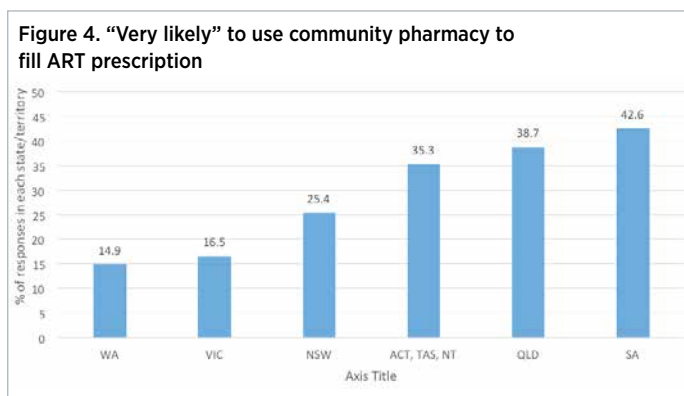
The majority of respondents indicated that they did not have to pay for their ART (57.2%, n=476), while 42.8% (n=356) said that they did. The average cost nominated was \$30.50 per month (median = \$20, range = \$2.00 to \$345).

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.



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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