



utures six future

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The Living with HIV Program is a part of the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. The program conducts social research into the lived experience of HIV. This research is guided by the Australian National Strategies on HIV, the Living with HIV Reference Group and the ARCSHS Scientific Advisory Committee. All research conducted is approved by the La Trobe University Human Ethics Committee and additional institutional and community ethics committees where appropriate.

Full details of the Living with HIV research program can be found on the HIV Futures website: [www.latrobe.edu.au/hivfutures](http://www.latrobe.edu.au/hivfutures) and details of ARCSHS can be found at [www.latrobe.edu.au/arcshs](http://www.latrobe.edu.au/arcshs)

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## ACRONYMS USED IN THIS REPORT

<b>ADI</b>	AIDS defining illness
<b>AFAO</b>	Australian Federation of AIDS Organisations
<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>AIVL</b>	Australian Injecting and Illicit Drug Users League
<b>ARCSHS</b>	Australian Research Centre in Sex, Health and Society
<b>ARV</b>	Antiretroviral therapy
<b>CAM</b>	Complementary and alternative medicine
<b>HIV</b>	Human Immunodeficiency Virus
<b>IDU</b>	Injection Drug Use(r)
<b>NAPWA</b>	National Association of People Living With HIV/AIDS
<b>NCHSR</b>	National Centre in HIV Social Research
<b>NCHECR</b>	National Centre in HIV Epidemiology and Clinical Research
<b>NNRTI</b>	Non-nucleoside reverse transcriptase inhibitors
<b>NRTI</b>	Nucleoside reverse transcriptase inhibitors
<b>PLWHA</b>	People living with HIV/AIDS
<b>STI</b>	Sexually Transmitted Infection

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# EXECUTIVE SUMMARY

## DEMOGRAPHICS

The HIV Futures 6 survey was completed by 1106 HIV positive Australians from all states and territories. This represents approximately 6.6% of the estimated HIV positive population.

92.4% were male (1018), 7.4% were female (81) and 0.3% were transgender (3).

78.5% were gay men, 7.5% heterosexual women, 7.0% heterosexual men, 4.5% bisexual men, 0.5% lesbian women and 0.7% bisexual women. The remaining 1.3% fell into other categories.

The respondents' ages ranged from 18 to 80 years with a mean of 48.0 years and a median of 47.0 years. The majority of participants were Australian born (75.0%).

Twenty five respondents (2.3%) were of Aboriginal/Torres Strait Island origin.

## HEALTH

### HIV Antibody Testing

- 25.1% tested for HIV because they became ill
- 16.9% tested as part of routine health screening
- 10.4% tested because they were a member of a risk group
- 12.3% tested because of a particular risk episode
- 2.9% were tested without their knowledge

### When asked about pre- and post-test counselling/discussion

- 22.9% had received pre-test counselling/ engaged in pre-test discussion
- 26.2% of those testing positive in the last two years received pre-test counselling/ engaged in pre-test discussion
- 55.8% received post-test counselling
- 74.8% of those testing positive in the last two years received post-test counselling

## Current Health Status

72.6% rated their health as good or excellent and 66.2% rated their general well being as good or excellent.

Almost all PLWHA had taken a CD4/T-cell test and a viral load test.

## HIV-Related and Other Health Conditions

21.1% of respondents had been diagnosed with an AIDS defining illness, 9.6% in the last two years.

24.7% of respondents indicated that they had experienced HIV-related illnesses.

46.1% indicated that they had a major health condition other than HIV/AIDS. The most common conditions reported were hepatitis C (5.0% of the total sample), cardiovascular disease (9.9%), asthma (3.9%), and type II diabetes (3.7%).

## When asked if they had experienced any of the following conditions in the previous 12 months:

- 77.6% reported low energy or fatigue
- 60.7% experienced a sleep disorder
- 40.1% experienced confusion or memory loss
- 31.9 % experienced weight loss
- 29.0% reported experiencing Lipodystrophy

72.6% of respondents reported that they had undergone sexual health screening in the 12 months prior to survey.

14.6% said they had been diagnosed with an STI in the previous 12 months.

## Mental Health

In the last six months, 27.0% of respondents had taken prescribed medication for depression and 28.6% for anxiety.

44.6% had ever had a diagnosis of a mental health condition.

40.5% of all respondents had ever been diagnosed with depression, 8.8% in the last two years.

## Viral Hepatitis

- 23.6% had at some point had hepatitis A
- 61.6% had been vaccinated against hepatitis A
- 23.4% had at some point been diagnosed with hepatitis B, of whom:
  - 77.5% had cleared the infection
  - 16.0% had ongoing infection and
  - 2.9% had a chronic infection
- 69.9% had been vaccinated against hepatitis B
- 12.7% of respondents said they had tested positive for hepatitis C
- 28.3% of those with hepatitis C had ever had medical treatment for this

# TREATMENTS

## Antiretroviral Therapy

Antiretroviral use:

- 79.6% were currently using ARV
- 85.0% had used ARV at some time
- 32.7% of respondents were using a combination of three drugs

## Difficulties of Taking ARV

- 39.1% of those participants currently taking ARV reported that they experienced difficulties taking them of which the major problems were:
  - 19.2% side effects
  - 20.2% remembering to take the drugs on time
  - 15.0% transporting medication
  - 13.1% taking medication in public
  - 11.5% organising meals around the drugs
  - 8.2% taking large numbers of tablets

## Attitudes to Antiretroviral Therapy

Does ARV mean better prospects for PLWHA?

- 83.5% of respondents believed that combination antiretroviral drugs mean better prospects for PLWHA
- 7.3% believed that it is still too soon to tell
- 30.0% believed that combination antiretroviral drugs are harmful
- 23.3% believed that the side effects outweigh the benefits of antiretroviral drugs

## Treatment Breaks

- 38.1% of those currently on ARV had taken a break from ARV
- The median length of break was four months
- Doctors were less likely to be consulted before a break and during than afterward
- 30.6% saw their doctor before, during and after the treatment break

## Antiretroviral Resistance

- 42.1% of those that had ever used ARV had taken a resistance test
- 44.3% of those tested found resistance to one or more drugs
- 81.6% of those with resistance changed treatments

## Dosing and Adherence

- 45.1% were taking ARV once a day
- 46.4% of the sample were taking ARV twice daily
- 2.1% were taking ARV three times a day
- 98.3% had not missed a dose of ARV in the two days prior to completing the survey

## Complementary Therapies

- 56.6% used vitamin and mineral supplements
- 16.0% used herbal therapies
- 18.0% used marijuana for medicinal purposes
- Complementary therapies tended to be used in conjunction with allopathic treatment

## SERVICES

### Health Services

- For HIV specific treatment, 46.5% saw an HIV GP/S100 prescriber and 32.3% saw an HIV specialist/physician
- For general health care treatment, 42.0% of PLWHA saw an HIV GP/S100 prescriber and 27.4% saw a non-HIV GP
- For 36.5% of respondents, these were different doctors
- Most respondents had visited either a GP who specialises in HIV or an HIV specialist in the last six months

### Other Services

#### Services used at AIDS organisations:

- 35.3% treatment advice
- 29.5% social contact
- 22.4% counselling
- 22.5% peer support
- 14.2% complementary therapies
- 10.6% advice on legal matters

### Information

#### Important sources of information on treatments/HIV management:

- 51.3% HIV GPs/S100 prescribers
- 56.4% HIV specialists
- 43.0% HIV magazines and newspapers
- 37.5% HIV/AIDS organisation publications
- 32.3% HIV positive friends
- 27.7% articles in the gay press

#### Important sources of information on living with HIV:

- 45.4% HIV magazine/ newspaper
- 41.4% HIV positive friends
- 42.8% publications from HIV/AIDS groups
- 27.8% HIV GP
- 31.4% HIV specialist

### Publications

Gay and HIV press were accessed by large proportions of the sample, as were HIV community publications (particularly within their constituency area).

### Involvement with AIDS Organisations

- 63.2% had some contact with HIV/AIDS organisations, mostly receiving newsletters or being clients of these organisations.
- 7.3% were employees of HIV/AIDS organisations

# THE SOCIAL WORLD OF PLWHA

## Contact with Other PLWHA

- 90.8% knew other PLWHA
- 15.0% had a spouse/partner with HIV
- 53.1% had acquaintances with HIV
- 67.5% spent at least some time with other PLWHA
- 11.9% spent a lot of time with other PLWHA
- 32.5% spent no time with other PLWHA
- 15.2% had been involved with the care of someone with HIV/AIDS in the last two years
- 68.7% said someone close had died of AIDS related causes

For 47.2% of respondents, HIV was an important part of their identity, while for 18.6% it was an essential part. HIV status tended to be less important than identities based on sexuality, gender or family.

## Disclosure

Almost all respondents had disclosed their HIV status to at least one person, generally partners, close friends and family.

51.4% of respondents said their HIV status had been disclosed to another person when they did not want it to be (22.0% in the last two years).

## Social Support

### Sources of 'a lot' of social support:

- 78.6% partners/spouse
- 65.8% pets
- 44.8% doctors
- 41.7% close friends

## Planning for the Future

20.6% planned only one day at a time, while 53.6% planned at least one year ahead.

## Relationships and Sex

Almost one third (30.7%) of PLWHA were not having sex at present. 43.2% of PLWHA were in a regular relationship, and a slightly smaller number had sex within the relationship (38.4%). Just under half of this group also had sex with casual partners (14.6%). 30.9% of respondents had casual partners only.

Of those in a regular relationship, 37.7% had a partner who is also HIV positive, 59.2% had an HIV negative regular partner and 3.1% a partner of unknown status. Nearly all (96.3%) PLWHA had disclosed their status to their regular partner.

34.0% of the respondents had anal or vaginal intercourse with a regular partner in the past six months. Condom use with regular partners was strongly related to the HIV-status of the partner.

55.3% of the sample had sex with casual partners in the past six months. 29.5% of male respondents reported always using condoms with casual male partners.

Information about the most recent episode of sex with a casual partner in the previous six months was provided by around half the sample. Vaginal or anal intercourse took place in 79.7% of these instances.

### Condom use with the most recent casual partner:

- 16.1% of those who had sex with an HIV positive partner
- 64.2% of those who did not know their partner's HIV status
- 77.6% of those who had sex with an HIV negative partner

There were only nine instances reported of insertive anal or vaginal intercourse with ejaculation with the most recent casual partner where that partner was of unknown HIV status and only one instance with an HIV negative casual partner.

There were only 25 instances reported of receptive anal or vaginal intercourse with ejaculation with the most recent casual partner where that partner was of unknown HIV status and only six instances with an HIV negative casual partner.

51.2% of PLWHA would prefer to be in a relationship with someone who is also HIV positive. 57.1% of PLWHA expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLWHA (62.3%) felt HIV had a negative effect on their sexual pleasure.

Only 18.3% of PLWHA agreed with the statement, *I feel more confident about unprotected sex because of the new treatments*. Those who agreed were no more likely than others to be on antiretroviral treatment or to be confident about treatments, but they were more likely to have unprotected sex.

Very few PLWHA agreed that undetectable viral load means HIV is unlikely to be transmitted (18.8%). However, 29.0% of PLWHA agreed with the statement, *If there was a vaccine which prevents HIV I would not practice safe sex*.

## Legal Issues around Disclosure

- 42.4% agreed with the statement, *I am worried about disclosing my HIV status to sexual partners because of the current legal situation*.
- 28.4% expressed some concern about the legal implications of disclosure of sexual practices to service providers.

## Recreational Drug Use

Alcohol was the drug most commonly used by PLWHA (75.7%) and 42.3% had used tobacco in the previous 12 months.

Over one quarter of respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and 6.7% reported having had a bad experience as a result of using both illegal drugs and ARV.

# HOME, WORK & MONEY

## Accommodation

- 36.2% were in private rental accommodation
- 38.1% owned or were purchasing house or flat
- 13.4% were in public rental accommodation (government owned)
- 3.3% were in community housing/housing co-operative
- 40.1% of PLWHA lived by themselves
- 52.2% of PLWHA lived with pets
- 75.3% of respondents had access to a car
- 23.0% had ever changed their accommodation as a result of having HIV/AIDS and 5.5% had in the last two years.

## Employment

Just over half of respondents were currently in paid employment (54.7%), the majority of these being in full-time work (37.4% of total sample). The majority of the remainder described themselves as either not working or retired.

Most respondents said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis.

Around half of respondents who were working said that HIV has had an impact on their capacity to perform their work duties. Most commonly respondents reported that they tired more quickly, that they had difficulty concentrating and that they have had to reduce their work hours.

52.0% of PLWHA currently in work had not disclosed their HIV status to anyone at their workplace, while 16.5% did not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work were gossip and explaining absences from work.

## Finances

42% of respondents identified their main source of income as a government benefit or pension. More than one half of PLWHA reported experiencing at least some difficulty with meeting the cost of daily living.

### Difficulty with meeting the cost of daily living:

- 63.4% difficulty paying for clothing
- 62.1% difficulty paying for utilities
- 60.4% difficulty paying for housing
- 52.7% difficulty paying for transport
- 54.3% difficulty paying for food

34.2% of those on a government benefit had been assessed by a Commonwealth Medical Officer in the past two years. While this resulted in termination of benefits or change in conditions for few respondents, it caused distress for 39.3% of those assessed.

## Poverty

31.0% of PLWHA are living below the poverty line. Just under one quarter of respondents have a partner with whom they share financial resources and this protects some from extreme economic hardship. Very few respondents who are earning an income from paid employment reported incomes below the poverty line whereas around half of those on government benefits are living in poverty.

## Discrimination

- 7.9% experienced less favourable treatment in relation to accommodation, 2.6% in the last two years
- 26.4% experienced less favourable treatment because of HIV in relation to health services, 9.9% in the last two years
- 17.3 % experienced less favourable treatment in relation to insurance.



# INTRODUCTION

It's now twelve years since the first HIV Futures survey. In that time, almost 6,000 surveys have been completed by Australian people living with HIV. That means that people have collectively answered around 70,000 questions giving us over 450,000 pieces of information about their lives. That's equivalent to getting 100 pieces of information about living with HIV every day for twelve years. In this report alone, you will find over 2,000 results summarising those pieces of information (not to mention the 30,000 words that go with them).

So what's with all this counting? What's with all these numbers? Why do we collect this massive amount of information? And, why do people continue to spend their precious time providing it? This enterprise that we - the researchers, the positive community and the HIV sector - have been involved in for the past twelve years has been about using the power of information to enhance the lives of positive people and to improve the way in which the rest of society deal with people with HIV.

Central to this enterprise has been a recognition that there is no such thing as a 'typical' person with HIV. There are some characteristics and some experiences that many people with HIV share, but there is also great diversity. In harnessing the power of information contained in studies like this we have to respect both the similarities and the uniqueness of people's experience. The depth of this study helps us to achieve this. It provides us with the tools to examine the patterns of experience, the inter-relationships between different aspects of people's lives and the variability in all of these things.

So, far from reducing people to numbers, we use the power of the numbers in these studies to make each positive life count for all positive people. And, maybe that's why we all continue to contribute to this project, why we continue to collect these experiences, and why people continue to share them so generously.

## DEMOGRAPHICS

This section provides an overview of the sample characteristics. The data in this section are not weighted. For a full description of the project methodology and data weighting algorithms please refer to the Appendix.

### Sample Demographics

The HIV Futures 6 survey was completed by 1106 HIV positive people. Given current estimates of HIV infection in Australia (National Centre in HIV Epidemiology and Clinical Research, 2008) this represents approximately 6.6% of the HIV positive population. Of the total respondents, 69.3% completed a paper copy of the survey, while 30.7% completed the survey on-line.

Of the survey respondents, 92.4% were male (1018), 7.4% were female (81) and 0.3% were transgender (3). This sample consisted of 78.5% gay men, 7.5% heterosexual women, 7.0% heterosexual men, 4.5% bisexual men, 0.5% lesbian women and 0.7% bisexual women. The remaining 1.3% fell into other categories.

Respondents ranged in age from 18 to 80 years with a mean of 48.0 years and a median of 47.0 years.

The majority of participants were Australian born (75.0%) and 97.7% of the participants spoke English at home, with Asian and European languages accounting for most of the remainder. Twenty five respondents (2.3%) indicated they were of Aboriginal/Torres Strait Island origin. This compares to the Australian census estimate for 2008 of 2.5% ATSI in the Australian population (Australian Bureau of Statistics, 2008). Almost all respondents (98.4%) indicated that Australia was their official country of residence.

The four most common ancestries that respondents identified with were English (21.5%), Australian (19.2%), British (12.1%) and Irish (6.0%). This compares with the self-reported ancestry data from the 2006 census in which 37.1% of the population identified their ancestry as Australian, 31.6% as English, and 9.1% as Irish (Australian Bureau of Statistics, 2008).

A total of 1.0% of respondents stated South-East Asian ancestry, specifically Thai, Indonesian, Filipino or Vietnamese. Respondents came from all Australian states and territories, with the majority coming from NSW, Victoria and Queensland (see Table 1).

**TABLE 1 State or Territory of respondents' residence**

State/territory	Frequency	Percent of Sample
NSW	494	45.4
VIC	248	22.8
QLD	193	17.7
WA	56	5.1
SA	44	4.0
ACT	25	2.3
TAS	17	1.6
NT	12	1.1

The majority (61.0%) of respondents were from urban areas of capital cities, while 13.3% lived in outer suburban areas, 17.6% lived in larger regional centres and 8.1% lived in rural areas.

76.4% of participants were living in the same state or territory in which they were infected with HIV, while 21.1% reported living in a different state or territory.

Table 2 below shows the years in which respondents tested HIV positive and in which they believe they were infected with HIV. Overall these patterns match those of the Australian epidemic. The time difference between year of presumed infection and year of diagnosis ranged from 0 to 18 years with a mean of 1.5 years and a median of a year. 48.0% of the sample tested positive in the same year they believe they were infected. There are 61 respondents in the sample who had tested positive in the last two years and 38 respondents who believe they were infected in the past year.

**TABLE 2 Years of respondent's testing positive and presumed infection**

<b>Year</b>	<b>Tested HIV Positive</b>	<b>Presumed Infected</b>
Pre 1985	6.8	15.5
1985-1989	21.3	19.8
1990-1994	17.6	16.5
1995-1999	16.2	15.4
2000-2004	20.4	18.3
2005+	17.7	14.5

476 respondents (48.8%) indicated that they were atheist/agnostic, 37.4% indicated mainstream religious identification and the remainder indicated that they either had 'other' (7.2%) or New Age spiritual beliefs (6.5%). Of those with religious beliefs, 15.9% indicated that religious beliefs were not important to them, while 35.2% indicated that these were of little importance, 34.8% that they were very important and 14.0% that they were extremely important.

The educational level of respondents to the survey was somewhat higher than the general population, as is usual in research requiring a moderate level of literacy and engagement with the research process. The educational levels are shown in Table 3 below.

**TABLE 3 Educational level of respondents**

<b>Level</b>	<b>Frequency</b>	<b>Percent of sample</b>
University degree	367	34.0
Tertiary diploma/ Trade Certificate/TAFE	291	27.0
Leaving certificate/HSC/Year 12	178	16.5
4th form/year 10	144	13.4
Up to 3 years high school	79	7.3
Primary school only	19	1.8



# HEALTH

This section of the report deals primarily with the physical health and experience of health of Australian PLWHA. The chapter includes a discussion of the experiences of testing positive for HIV, the current health status of participants measured both by clinical markers and self-reported health and well being, the health burden in terms of concomitant health conditions and health maintenance strategies.

## HIV ANTIBODY TESTING

The experience and meanings of testing positive for HIV have changed over the twenty years of the HIV/AIDS epidemic. In the early years of HIV in Australia, testing did not offer any particularly great advantage in treatment options and often led to increased anxiety, stigma and discrimination. With the advent of more effective treatments, the advantages of early testing have become clearer, not only in terms of medication, but also in health monitoring and social support. Testing rates remain high among community attached gay and homosexually active men in Australia (over 80%), although testing is down in Perth and Canberra (NCHSR, 2008).

Since November 2005, HIV antibody testing has been available on the Medicare Benefits Schedule and is available free of charge and pre- and post-test discussion are integral to the testing procedure (Department of Health and Ageing, 2006).

We asked respondents about a number of circumstances surrounding the time that they tested positive for HIV antibodies.

As can be seen from Table 4, 25.1% of the respondents had taken the test as a result of illness, 12.3% as a result of a particular risk episode and 10.4% because they were a member of a risk group. It is interesting to note that 16.9% gave the reason for testing as routine health screening.

Gay or bisexual men were somewhat more likely to give this reason (routine health screening) than others (17.7% of these participants versus 12.5% for heterosexual men and 12.7% for women) which may suggest that 'routine testing' may imply testing on the basis of group membership or risk activity. The reason, 'My partner tested positive' was more likely to be given by women (18.2%) than by gay or bisexual men (7.3%) or heterosexual men (5.4%).

Of those who had tested positive in the last two years (2006 or later), 35.1% had taken a test due to illness, while 15.2% as a result of a particular risk episode, 11.1% as a part of a routine health screening and 9.4% at the suggestion of a doctor.

**TABLE 4 Reasons for testing**

Reason	Frequency	Percent
Became ill/ongoing illness	264	25.1
Routine health screening	178	16.9
Particular risk episode	129	12.3
Doctor's suggestion	116	11.0
Member of risk group	110	10.4
Partner tested positive	80	7.6
Other	64	6.1
Starting new relationship	33	3.1
Tested without knowledge	31	2.9
Required to (e.g. for migration)	7	0.7
As part of other test/research	7	0.7
Contact tracer/other health worker's suggestion	7	0.7
Antenatal	7	0.7
Insurance	6	0.6
Availability of new treatments	2	0.2

## Pre- and Post-Test Counselling/Discussion

Participants were asked if they had received counselling or had had a detailed discussion with their practitioner prior to being tested for HIV. Australia's current HIV testing policy (Department of Health and Ageing, 2006) recommends that health care providers engage the patient in a discussion that, apart from obtaining the individual's informed consent, also assures them of the confidentiality of the test, provides accurate information in a culturally and gender appropriate way, and assesses the patient's readiness for an HIV test.

22.9% of respondents indicated that they had received pre-test counselling or engaged in an HIV test discussion. Of those who had tested positive in the last two years, 26.2% had received pre-test counselling.

The national HIV testing policy guidelines (Department of Health and Ageing, 2006) recommends that a post-test discussion be provided for all individuals who have had an HIV antibody test, even if the result is negative. The guidelines recommend that a post-test discussion following a negative result reinforce HIV education messages about safe behaviours. Positive test results must be given face-to-face and the discussion which is aimed at managing the impact of a positive diagnosis on the individual, should help to identify the patient's options for support and to provide them with a referral to a suitable support agency.

55.8% of respondents indicated that they had received post-test counselling. Of those who tested positive in the last two years, 74.8% had received post-test counselling. This a significantly greater proportion than for those who were diagnosed earlier than this.

## CURRENT HEALTH STATUS

### Experience of Health and General Well Being

We asked respondents how they would best describe their current state of physical health and overall sense of well being on a four point scale. The results are shown in Table 5 and Table 6 below. Close to half of the sample (47.4%) rated their physical health as good and 25.2% as excellent. This is less than the Australian population norm reported in the 2007-08 National Health Survey (Australian Bureau of Statistics, 2009) where 84.9% of the population rated their health as good, very good or excellent.<sup>1</sup> Almost one-third of respondents to HIV Futures 6 rated their health as fair or poor (27.4%).

**TABLE 5 Respondents' self ratings of general health status**

	Frequency	Percent
Poor	56	5.1
Fair	244	22.3
Good	520	47.4
Excellent	276	25.2

The ratings for well being were of a similar pattern to those for health. Two thirds (66.2%) rated their well being as either good or excellent, while 25.6% rated this as fair and 8.2% as poor.

**TABLE 6 Respondents' self ratings of general well being**

	Frequency	Percent
Poor	90	8.2
Fair	281	25.6
Good	496	45.2
Excellent	230	21.0

<sup>1</sup> It should be noted that the National Health Survey uses a five point scale: poor, fair, good, very good, excellent. The figure quoted above is for Australians aged 18-64, whereas the HIV Futures 6 sample was aged 18-80.

When we look at the relationship between these two measures, we can see overall that better health was related to greater well being (see Table 7). This is, however, not a clear and direct relationship. The correlation between the two measures is  $r=0.69$  ( $p<0.001$ ). Almost one in four participants (22.7%) rated their well being as worse than their health and 11.4% rated their health as worse than their well being. Self-rated health and well being were also related to CD4 count. Having a higher CD4 count at most recent test was associated with having better health ( $r=0.17$ ,  $p<0.001$ ) and better overall well being ( $r=0.08$ ,  $p<0.05$ ). However, there was no significant correlation between health and most recent viral load result or between well being and most recent viral load.

**TABLE 7 Relationship between ratings of overall health and well being (percentage of total sample-unweighted)**

Well being	Health			
	Poor	Fair	Good	Excellent
Poor	3.6	1.5	0.1	0.0
Fair	2.9	13.7	5.1	0.5
Good	1.3	9.3	32.5	4.2
Excellent	0.5	1.1	7.6	16.0

## CD4 and Viral Load

As with the previous three surveys, almost all PLWHA had taken a CD4 T-cell test (98.8%) and a viral load test (98.1%). Most respondents had their most recent CD4 test in the six months prior to survey (89.8%) (42.4% in the last three months) and their most recent viral load test in the six months prior to survey (89.2%) (41.4% in the last three months). On average participants had taken four viral load tests in the preceding 12 months.

Results for PLWHA's most recent CD4/T-cell test ranged from 1.5 to 2740 cells/ $\mu$ l with a mean of 559.12 cells/ $\mu$ l and a median of 505.48 cells/ $\mu$ l.

Results for PLWHA's most recent viral load test ranged from below detectable levels to 1,000,000 copies/ml with a mean of 9,135 copies/ml and a median of below detectable level. Table 8 shows the combined CD4 and viral load results of the sample. The results are grouped by three levels of CD4 count: little damage, moderate damage and severe damage and four levels of viral load: below detectable levels, low, moderate and high. As different assays would have been used to assess the respondents' viral loads we have defined below detectable levels as being those responses that were less than 500 copies/ml and those where the respondent wrote in zero or below detectable level.

**TABLE 8 Results of most recent serological tests (percentage of total sample)**

		HIV Viral load				Total
		<500	500-9999	10000-49999	50000+	
CD4/T-cell	500+	44.9	4.5	2.9	1.2	53.5
	250-499	27.4	3.3	3.6	1.9	36.2
	0-249	7.4	1.2	0.7	1.0	10.3
	Total	79.7	9.0	7.2	4.1	100.0



## HEALTH CONDITIONS IN ADDITION TO HIV

### AIDS Defining Illnesses

The Australasian Society for HIV Medicine (Australasian Society for HIV Medicine, 2004) lists 26 AIDS-defining conditions in their HIV management manual. These include opportunistic infections, as well as neurological and malignancy disorders. AIDS-defining illnesses are notifiable conditions in all states and territories in Australia, and a confirmation of a case requires both laboratory and clinical evidence (Department of Health and Ageing, 2004).

The category system for defining the stages of HIV disease progression was, in large part, based on an understanding of the progress of the disease as degenerative with little backwards movement through the categories. There are now numerous HIV positive people who have at some time experienced an AIDS defining illness but would now be classed at a less severe stage of disease progression. We asked respondents if they have ever experienced an AIDS defining illness for three reasons: to match and weight the data according to surveillance data; to examine issues around the burden of illness; and to understand the current health status of participants.

Around one in five respondents (21.1%) said they had been diagnosed with an AIDS defining illness at some point with 9.6% having been diagnosed with one in the last two years. Respondents had been diagnosed with an AIDS defining illness on average 9.8 years ago (median 10 years). The most common illnesses listed by respondents in this category were Pneumocystis Pneumonia (40.7%), Kaposi's Sarcoma (18.2%), Cytomegalovirus (8.7%), Microbacterium Avium Complex (MAC) (6.3%) and Oesophageal Candidiasis (6.2%).

### HIV/AIDS Related Conditions

Almost thirty percent of respondents (24.7%) indicated that they had experienced an HIV-related illness at some point. Within this group the most common conditions mentioned were shingles (17.7%), skin problems (such as rashes) (14.6%), peripheral neuropathy (9.9%) and candida/thrush (8.1%).

In a separate question, participants were asked to select from a list of 10 conditions commonly associated with HIV infection those that they had experienced in the 12 months prior to survey.

**TABLE 9 Health conditions experienced in the past 12 months**

Condition	Percent
Low energy/fatigue	77.6
Diarrhoea	59.1
Sleep disorder	60.7
Nausea or vomiting	37.5
Confusion/memory loss	40.1
Weight loss/underweight	31.9
Raised cholesterol/triglycerides	42.3
Lipodystrophy/lipoatrophy	29.0
Peripheral neuropathy	22.9
Insulin resistance	3.6

Those reporting weight loss were significantly more likely to have a body mass index (BMI) of less than 20 (21.9% versus 4.6%,  $\chi^2(3, N=862) = 99.0, p<0.001$ ).

### **Attitudes towards Body Image**

Lipodystrophy, a side effect of treatment, is a significant quality of life issue for people on treatment. Persson (2004) has pointed out that the paradox of ART treatments is that while it removes HIV from the inside, for some, it makes it more visible on the outside, making the treatment a marker of disease.

Positive people who experience lipoatrophy have been found to score significantly lower than HIV positive people without lipoatrophy on a quality of life measure (Rajagopalan et al., 2008). These quality of life issues can be significant and Lenert et. al., (2002) have found in a study of HIV positive people that most would trade years of life to avoid lipodystrophy.

While there is still some debate over the most appropriate clinical case definition for these conditions, self reported body changes remain an important component of diagnosis (Carr et al., 1999, Behrens et al., 2000). To assess the impact of these we asked participants to respond to a series of statements about their body image. These are

presented in Table 10 for both the total sample, and for those who indicated that they had experienced lipodystrophy or lipoatrophy in the past 12 months. As can be seen, approximately equal numbers of the total sample of people agreed and disagreed with the other two items, while the responses of those with lipodystrophy/lipoatrophy were more likely to be suggestive of a poorer body image.

**TABLE 10 Attitudes around body image  
(percentages of total sample, those with and without lipodystrophy)**

		% of total sample	% of those with lipodystrophy	% of those without lipodystrophy
Changes in my body due to HIV/AIDS have made me feel sexually unattractive.	strongly agree	22.2	41.5	15.2
	agree	33.5	44.3	29.6
	disagree	33.5	11.4	41.5
	strongly disagree	10.8	2.7	13.7
I am happy with the way my body looks.	strongly agree	9.8	4.7	11.6
	agree	37.4	17.5	44.4
	disagree	39.0	50.1	35.1
	strongly disagree	13.8	27.7	8.9
Body changes due to lipodystrophy make it obvious to others that people have HIV	strongly disagree	17.6	29.9	12.9
	agree	32.7	45.0	28.1
	disagree	33.9	23.1	38.1
	strongly disagree	15.7	2.0	21.0

### **Other Sexually Transmitted Infections**

There has been an increase in the diagnoses of sexually transmitted infections (STIs) other than HIV in Australia, and particularly syphilis among homosexually active men (NCHECR, 2008). Amongst gay men in Sydney, research has found a higher prevalence of some STIs – namely syphilis and anal gonorrhoea among HIV positive men compared to HIV negative men in Sydney (Jin et al., 2007). A similar discrepancy was observed in rates of syphilis amongst Melbourne men where the authors estimate that HIV positive men were 4.7 times more likely to be diagnosed with syphilis than negative men (Allen et al., 2008).

We asked about sexual health screening and 72.6% of respondents reported that they had undergone such a screening in the 12 months prior to survey.

We included a question in the HIV Futures 6 survey about sexually transmitted infections, 14.6% said they had been diagnosed with an STI in the previous 12 months.

**TABLE 11 Participants diagnosed with a sexually transmitted infection in past 12 months**

	Frequency	Percentage
Gonorrhoea	40	3.7
Chlamydia	54	5.4
Genital Herpes	37	3.9
Syphilis	66	6.6
Other	16	1.6

The co-infection of HIV and other STIs is a concern in several ways. While it has been long known that being infected with other sexually transmitted infections is known to increase both HIV infectiousness and susceptibility to HIV infection (Fleming and Wasserheit, 1999), recent research has shown that coinfection with other STIs has implications for the health and well being of positive people. Syphilis, for example, has been shown to increase viral load and decrease CD4 counts in HIV positive people (Palacios et al., 2007). Furthermore, HIV positive people co-infected with syphilis have been shown to remain asymptomatic for a longer time but progress more rapidly, with the result that HIV positive people presented with more advanced syphilis infection (Karp et al., 2009).

Current guidelines set out by the Australasian Chapter of Sexual Health Medicine (AChSHM) recommend yearly STI testing for men who have sex with men, and half yearly to quarterly testing for men with multiple partners, drug use, unprotected sex (AChSHM, 2008). The guidelines note that HIV positive gay men are at particularly high risk of anal STIs, but do not specifically make recommendations for testing HIV positive men.

## **Other Health Conditions**

46.1% of respondents indicated that they had a major health condition other than HIV/AIDS. The most common conditions listed under this heading were hepatitis C (5.0% of the total sample), cardiovascular disease (e.g. high blood pressure) (9.9%), asthma (3.9%), type II diabetes (3.7%) and hepatitis B (1.6%).

## **Viral Hepatitis**

Hepatitis is a term that refers to inflammation of the liver. Six different types of viral hepatitis have been identified so far. Hepatitis A, B and C are more commonly known in Australia but hepatitis D, E and G have also been identified. For HIV positive people, co-infection with hepatitis may affect both people's health and/or their decisions in relation to antiretroviral treatments. We asked about diagnosis of, and vaccination against, hepatitis A and B, and some more detailed questions about diagnosis and experience of hepatitis C.

### **Hepatitis A**

Around one quarter of the participants (23.6%) had at some point had hepatitis A and 61.6% had been vaccinated against this virus. This means that 14.8% of the respondents may currently be at risk of hepatitis A infection.

### **Hepatitis B**

A total of 23.4% of respondents had at some time been diagnosed with hepatitis B. Of these, 77.5% had cleared the infection, 16.0% had an ongoing infection and 2.9% had a chronic infection. In addition to those who had experienced hepatitis B infection, 69.9% had been vaccinated against this virus. This means that 6.7% may currently be at risk of being infected with hepatitis B.

### **Hepatitis C**

Around one fifth (23.5%) of respondents had not been tested for hepatitis C. This is lower than in the previous HIV Futures survey, where 27.1% of respondents had not been tested. 73.0% of the most recent hepatitis C antibody tests were taken in the last two years and 16.4% of participants' first hepatitis C antibody tests were taken in this period.

We asked respondents if they had ever had hepatitis C, and 12.7% (N=120) said that they had. Of these, 33 people (27.2%) said they had since received a negative PCR test.

The incidence of hepatitis C co-infection amongst HIV positive people in Australia is estimated to be 13.1% (Australasian Society for HIV Medicine, 2006), while the incidence in the general Australian population is estimated to be 1.4% (NCHECR, 2008).

Respondents had first been diagnosed with hepatitis C between less than one and 24 years ago<sup>2</sup> (mean=1996, median=1998) and believed they had been infected between less than one and 41 years ago (mean=1993, median=1995). Two thirds of those who have had hepatitis C (66.7%) had taken a genotype test for hepatitis C. Of these, 39.5% did not know what the result of this test was, while 33.8% said type 1, 5.9% type 2, 15.7% type 3, and 5.1% type 4, 5 or 6.

When asked how they believe they were infected with the hepatitis C virus, 44.0% said injecting drug use, 23.2% during sex, 7.9% blood transfusion or the receipt of blood products, 1.5% through tattooing and 3.8% through other means. 18.9% of respondents did not know how they were infected. Only one respondent selected body piercing as mode of infection with hepatitis C (See Table 12).

2 This would include those originally diagnosed with non-A, non-B hepatitis which was later revised to hepatitis C

**TABLE 12 Respondents' reported mode of hepatitis C infection (percentage of those with hepatitis C)**

Injection Drug Use (IDU)	44.0
During Sex	23.2
Blood Transfusion/ Blood Products	7.9
Tattooing	1.5
Body Piercing	0.7
Other	3.8
Don't Know	18.9

34 respondents had ever undertaken medical treatment specifically for hepatitis C. This comprised four who had undertaken treatment with interferon monotherapy, nine who had undertaken treated with combination therapy of interferon and ribavirin and 21 who said they had undergone both monotherapy and combination therapy.

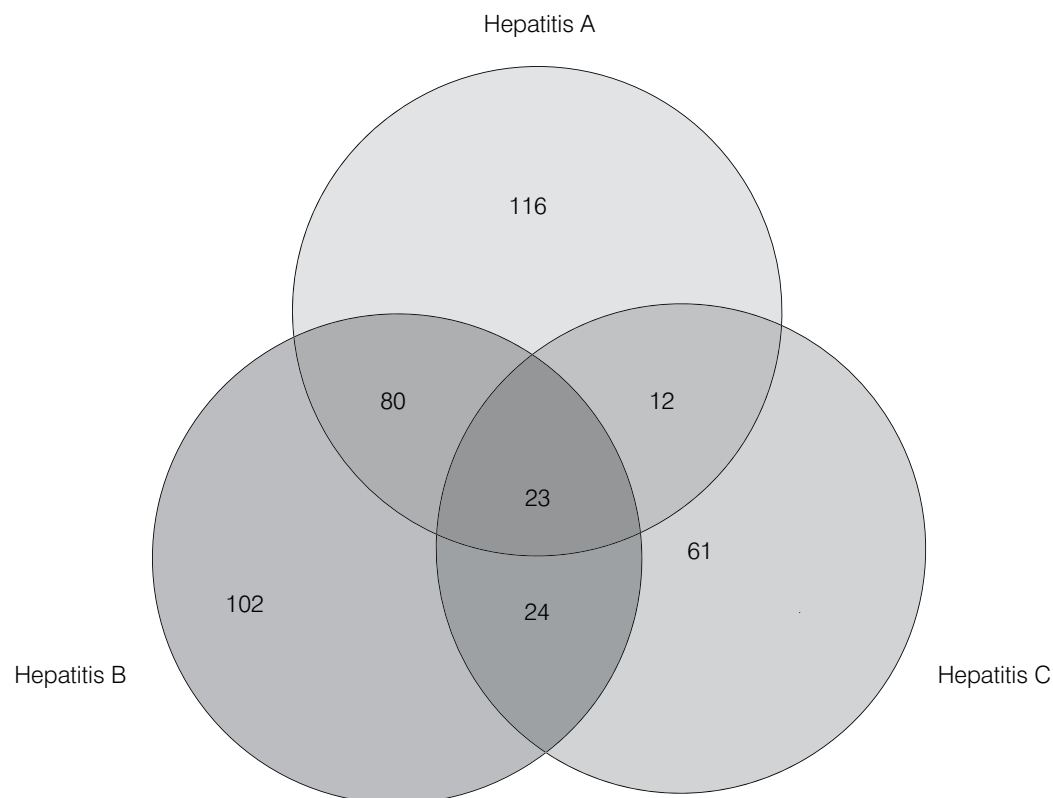
Hepatitis C co-infected participants were also asked about health monitoring and management. Around one fifth (21.1%) of co-infected PLWHA did not currently see a doctor for hepatitis C treatment or management, while 57.1% of this group saw their primary HIV doctor and 21.8% saw a separate hepatitis C doctor or specialist.

### Multiple Hepatitis experience

Co-infection with a hepatitis virus has important implications for treatment of both HIV and the hepatitis. Co-infection also results in increased clinical management particularly around treatment decisions for both conditions, interpretation of clinical markers and the management of adverse consequences of treatment.

Figure 1 below shows the number of respondents who reported having ever had at least one of the viral hepatitises (41.4% of respondents). This figure includes those with current infection and those having had it in the past, having reported clearing the hepatitis B virus or testing negative on a PCR test for hepatitis C. Of those for whom data was available on all three viruses, 27.7% had experienced of one form of hepatitis infection, 11.5% of two forms and 2.3% had experienced all three.

**FIGURE 1 Multiple hepatitises (Number of respondents)**



## **Mental Health**

Mental health issues continue to figure large in discussions of the needs and status of positive people in many parts of the world. While a survey like this cannot expect to offer a clinical perspective on mental health status, we can give an overview of some of the experiences of positive people that fall within the broad area of mental well being.

In a study of major depressive illnesses among HIV positive and negative gay men in Sydney and Adelaide, Mao et al (2009) found that gay men generally were at high risk of depression whatever their HIV status. While being HIV positive was not independently associated with an increased risk of depression, positive men had higher rates of depression associated with factors such as socio-economic deprivation, isolation and withdrawal.

## **Psychiatric Medications**

In the six months prior to completing the survey, 27.0% of PLWHA said they had taken medicines prescribed for depression. This is considerably higher than the 5.9% of the Australian population who reported having taken antidepressants in the previous two weeks in the National Health Survey (Australian Bureau of Statistics, 2009). Over one quarter of respondents (28.6%) reported having taken medicines prescribed for anxiety in the past six months. 16.2% of respondents reported taking medications for both depression and anxiety in the past six months. In addition, 5.6% of the sample indicated that they had taken anti-psychotic medication.

## **Diagnosis of a Mental Health Condition**

We asked respondents if they had been diagnosed with a mental health condition and 44.6% reported that they had had such a diagnosis. Of those reporting a diagnosis, the vast majority had been diagnosed with depression (88.3%, 40.5% of the total sample). 21.6% of people receiving a diagnosis of depression reported having received this diagnosis in the past two years. The next most common condition was anxiety, reported by 54.1% of those with a mental health condition (24.6% of the total sample). 26.6% of those reported having received this diagnosis in the past two years.

## **HEALTH MAINTENANCE**

We asked participants about a range of activities that they may engage in to improve their health. The results are shown in Table 13. The most common health enhancement activity was eating healthily, followed by exercise, and social activity. Over one quarter reported smoking reduction or cessation.

**TABLE 13 Health improvement strategies (percentage of total sample)**

Healthy eating	79.9
Exercise	71.8
Spending time with friends	60.3
Relaxation	52.4
Spending time with partner	45.6
Spending time with pets	36.3
Spending time with family	36.2
Reduce or stop smoking	28.0

(Multiple responses possible)

## **Attitudes to Health Management**

Participants responded to a number of statements about health management in relation to health improvement strategies, antiretroviral therapies and complementary therapies. The items on antiretroviral and complementary therapies are presented in the relevant sections of the report. When asked about health management strategies, almost all participants agreed that exercise, healthy eating and an optimistic outlook were important or very important strategies (see Table 14). Those who indicated that they exercised and ate well were more likely to agree with the respective statements.

**TABLE 14 Attitudes to health management (percentage of total sample)**

Looking after my physical fitness is an important part of managing my HIV infection	strongly agree	49.9
	agree	46.0
	disagree	3.6
	strongly disagree	0.5
Healthy eating is an important part of managing my HIV infection	strongly agree	44.3
	agree	47.9
	disagree	6.3
	strongly disagree	1.5
Keeping an optimistic frame of mind is an important part of managing HIV infection	strongly agree	61.7
	agree	36.1
	disagree	1.8
	strongly disagree	0.4
As long as I am well I prefer not to think about HIV/AIDS	strongly agree	21.0
	agree	40.4
	disagree	32.7
	strongly disagree	5.9
Life has become more meaningful since I became HIV positive	strongly agree	14.9
	agree	34.1
	disagree	32.7
	strongly disagree	18.3

## Other Health Monitoring

We asked a series of questions about other health monitoring activities. 16.7% had had a bone density test in the last two years and 12.1% had had a test more than two years ago. 67.8% had had a fasting cholesterol test in the last two years and 8.0% had had one more than two years ago. The long term effects of living with HIV and medication have made health concerns such as high cholesterol, cardiovascular difficulties and osteoporosis increasingly important for positive people.

81.8% of female respondents had ever undergone a cervical smear (Pap) test and 75.2% said they had one in the last 12 months. Of those who had a test in the 12 months prior to survey, most (72.5%) reported that the result was 'normal'.

## Other Medication

Participants used a range of prescribed medications. In all 51.4% of respondents were using prescribed medication other than antiretroviral therapies or antidepressants and other medicines for mental health conditions (refer to page 9).

## COMPLEMENTARY THERAPIES

We asked participants if they had used any complementary therapies in the previous six months, including therapeutic use of marijuana, and to indicate the types of therapies used and where these products or services were obtained. In order to gain an overall picture of the use of these modalities, the question asked participants to indicate all complementary therapies they had used, not only those used for HIV/AIDS. Over half the respondents (56.8%) indicated that they had used some kind of complementary medicine or therapy in the previous six months. Over half of the sample (56.6 %) had taken vitamin or mineral supplements. Over one third (33.7%) of respondents had used massage, while 19.6% had used meditation. Around one fifth (18.0%) of respondents indicated that they had used marijuana for therapeutic purposes.

**TABLE 15 Use of complementary therapies in the past six months (percentage of total sample)**

Vitamin/mineral supplements	56.6
Massage	33.7
Meditation/visualisation	19.6
Marijuana for therapeutic purposes	18.0
Herbal therapies/supplements	16.0
Other complementary therapy	8.2
Acupuncture	7.8
Traditional Chinese Medicine	5.9

(Multiple responses possible)

More than three-quarters of PLWHA (77.6%) agreed that complementary therapies can improve well being, while 60.6% agreed that complementary therapies can boost the immune system and around half (54.6%) that complementary therapies can reduce side effects and delay the onset of illness due to HIV (48.4%) (see Table 16). However, up to one third of respondents were unsure about these statements and these people were significantly more likely not to have used complementary therapies. Roughly equal proportions of respondents agreed and disagreed with the statements on whether there is sufficient evidence about the benefits of complementary therapies, whether medicine's focus on anti-HIV drugs was limited and whether complementary therapies constituted a central part of their anti-HIV treatments. Again, there was considerable uncertainty about these issues. On average, those PLWHA who use complementary therapies spent \$31.60 per week on them (median = \$20 per week), and took them 1.3 times per day (median 1.0).

**TABLE 16 Attitudes to complementary therapies: percentage of total sample**

Complementary therapies can delay the onset of illness due to HIV	Strongly Agree	15.8
	Agree	32.6
	Disagree	12.4
	strongly disagree	4.6
	don't know	34.6
Complementary therapies can improve well being	Strongly Agree	32.3
	Agree	45.3
	Disagree	2.5
	strongly disagree	1.8
	don't know	18.1
Complementary therapies can reduce the side effects of conventional medical treatments	Strongly Agree	17.1
	Agree	37.5
	Disagree	6.5
	strongly disagree	2.2
	don't know	36.7
There is not enough evidence to be sure about the benefits of complementary therapies	Strongly Agree	7.5
	Agree	32.4
	Disagree	27.9
	strongly disagree	7.6
	don't know	24.5
Medicine's focus on anti-HIV drugs is very limited	Strongly Agree	7.8
	Agree	22.2
	Disagree	32.9
	strongly disagree	11.2
	don't know	25.9
Complementary therapies can boost the immune system	Strongly Agree	19.9
	Agree	40.5
	Disagree	5.6
	strongly disagree	2.6
	don't know	31.4
Complementary therapies are a central part of my anti-HIV treatments	Strongly Agree	14.4
	Agree	23.8
	Disagree	29.5
	strongly disagree	13.3
	don't know	18.9



# TREATMENTS

In this chapter, we report on the treatment experiences of PLWHA. As antiretroviral treatments are the main way that HIV is managed therapeutically, we focus on participants' experiences of these, but also include a description of the medications that participants take for other health conditions.

## ANTIRETROVIRAL THERAPY

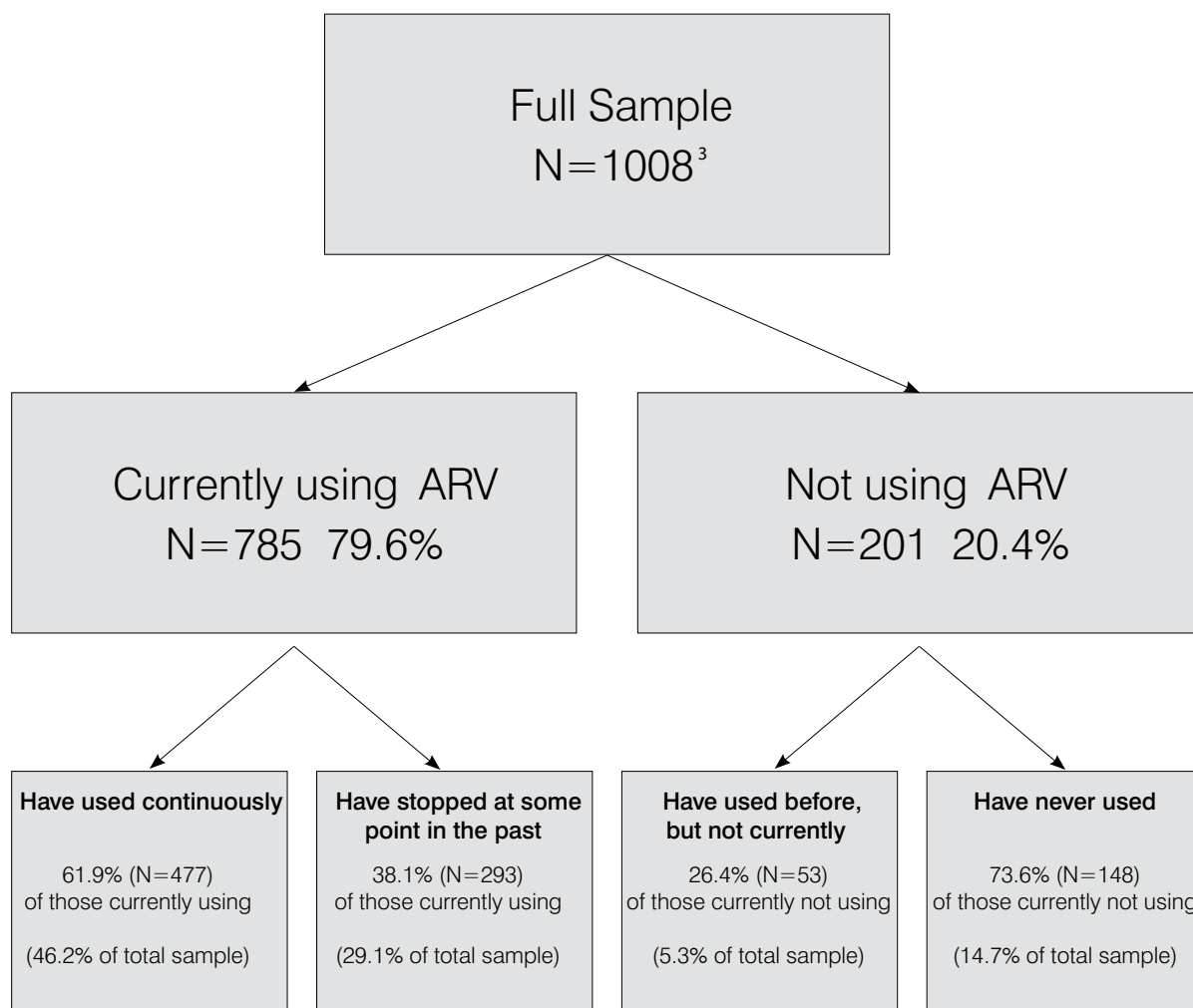
Highly active antiretroviral therapy remains the single factor that has most altered the clinical outcomes for people living with HIV. The introduction of ARV has reshaped the HIV epidemic in developed countries and is increasingly doing so in developing nations and resource poor settings.

In the thirteen years in which these treatments have been available, there have been improvements in the efficacy and tolerability of treatments, while new combinations of drugs have simplified the drug-taking process for PLWHA. Nevertheless, being on antiretroviral therapy involves a highly structured protocol that requires medication to be taken at specific times. Treatment can also result in difficult to manage side effects.

In the following section we examine some of these challenges as well as the psychological and social impacts of treatment.

Of the full sample, 85.0% had used ARV at some point and 79.6% were currently using these treatments. A summary diagram of the uptake of antiretrovirals can be found below.

**FIGURE 2 Use of Antiretroviral Therapy**



(Note: Ns and percentages may be reduced due to missing data)

<sup>3</sup> Weighted

## Those Currently Using ARV (Monotherapy and Combination Therapy)

The majority of participants (32.7%) were on a combination of 3 antiretroviral drugs, with 19.7% on more than three antiretroviral drugs, 18.8% on two and 5.8% on monotherapy<sup>4</sup>.

**TABLE 17 Antiretroviral drugs used by respondents (percentage of those currently using ARV)**

<b>Nucleoside Reverse Transcriptase Inhibitors (NRTIs)</b>	
Lamivudine (3TC)	14.7
Abacavir, 1592 (Ziagen)	10.3
Stavudine, d4T (Zerit)	2.8
Zidovudine, AZT (Retrovir)	4.9
Didanosine (ddl, Videx, Videx EC)	3.0
Emtriva (emtricitabine)	1.9
Zalcitabine, ddC (HIVid)	0.8
<b>Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)</b>	
Nevirapine (Viramune)	29.6
Efavirenz (Sustiva, Stocrin)	19.6
Etravirine (Intelence)	2.5
Delavirdine (Rescriptor)	0.4
<b>Nucleotide Analog Reverse Transcriptase Inhibitors</b>	
Tenofovir (Viread)	31.6
<b>Protease Inhibitors</b>	
Ritonavir (Norvir)	26.2
Atazanavir (Reyataz)	22.3
Lopinavir + Ritonavir (Kaletra)	17.9
Darunavir (Prezista)	4.3
Saquinavir (Invirase, Fortovase)	2.7
Nelfinavir (Viracept)	2.0
Indinavir (Crixivan)	2.2
Tipranavir	0.7
Telzir (fosamprenavir)	1.6
Amprenavir (Agenerase)	0.3
<b>Integrase Inhibitors</b>	
Raltegravir (Isentress)	6.9%
<b>Fusion Inhibitor</b>	
T-20	1.0
<b>Combination Medications</b>	
Abacavir and Lamivudine (Kivexa)	24.4
Tenofovir and Emtricitabine (Truvada)	18.4
AZT & 3TC (Combivir)	8.4
AZT & 3TC & Abacavir (Trizivir)	3.6
Other	7.1

Respondents were also asked about their use of the immune stimulant Interleukin 2 and 0.3% of respondents (n=3) were using it.

## Difficulties of Taking ARV

39.1% of participants who were currently on antiretroviral treatment said that they had some difficulty being on treatment. The most common problems that participants experienced were remembering to take the drugs on time (20.2%) and managing the side effects of medication (19.2%). Difficulties transporting their medication (15.0%) and taking medication in public (13.0%) were the next most common difficulties that participants reported (See Table 18).

4 Combivir counts as 2 drugs, Trizivir as 3 drugs, Kivexa as 2 drugs

**TABLE 18 Difficulties taking ARV among those currently using ARV (percentage of those on ARV)**

Remembering to take drugs on time	20.2
Side effects	19.2
Carrying/transporting medication	15.0
Taking medication in public	13.1
Organising meals around medication	11.5
Taking a large number of tablets	8.2
ARV drugs make it difficult to take medication for other health conditions	4.2
Medication taken for other health conditions makes it difficult to take ARV	2.9
Other	6.3

(Multiple responses possible)

## Attitudes to ARV

Half of respondents were concerned about the future efficacy of their treatments: 48.9% agreed or strongly agreed with the statement, *I am worried that in the future my medication will stop working for me*. When asked to respond to the statement, *Taking tablets gives me an unwanted reminder that I have HIV*, 58.3% indicated agreement and 39.9% indicated disagreement.

**TABLE 19 Attitudes to medication (percentage of those currently using ARV)**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am worried that in the future my medication will stop working for me	8.5	28.9	35.7	13.1	13.7
Taking tablets gives me an unwanted reminder that I have HIV	11.9	28.0	37.2	21.1	1.8

## Health Status of Those Using ARV

As expected, those taking ARV had markedly lower viral loads (mean of 4,443 cells/ $\mu$ l compared to 67,793cells/ $\mu$ l among those not currently taking ARV but who had previously and 19,412 cells/ $\mu$ l among those who have never taken ARV). As Table 20 shows, the overwhelming majority of respondents who were on ARV had an undetectable viral load at their most recent testing.

**TABLE 20 Viral loads of those taking and not taking antiretroviral therapy (percentage within rows)**

		Viral load on most recent test			
		Below detectable levels	500-9999	10000-49999	50000+
ARV Use	Current	93.9	3.4	1.2	1.2
	Past	24.3	15.2	36.8	23.7
	Never	17.9	37.2	28.3	14.4

$\chi^2(3,2) = 497.242, p < 0.001$

Those taking ARV had similar CD4 counts with a mean of 564 copies/ml compared to 471 copies/ml among those not currently taking ARV but who had previously, and 556 copies/ml among those who have never taken ARV. The difference was not significant.

**TABLE 21 CD4 of those taking and not taking antiretroviral therapy (percentage within rows)**

		CD4 on most recent test		
		0-249	250-499	500+
ARV Use	Current	16.5	36.3	47.1
	Past	18.0	33.3	48.1
	Never	1.8	42.3	55.9

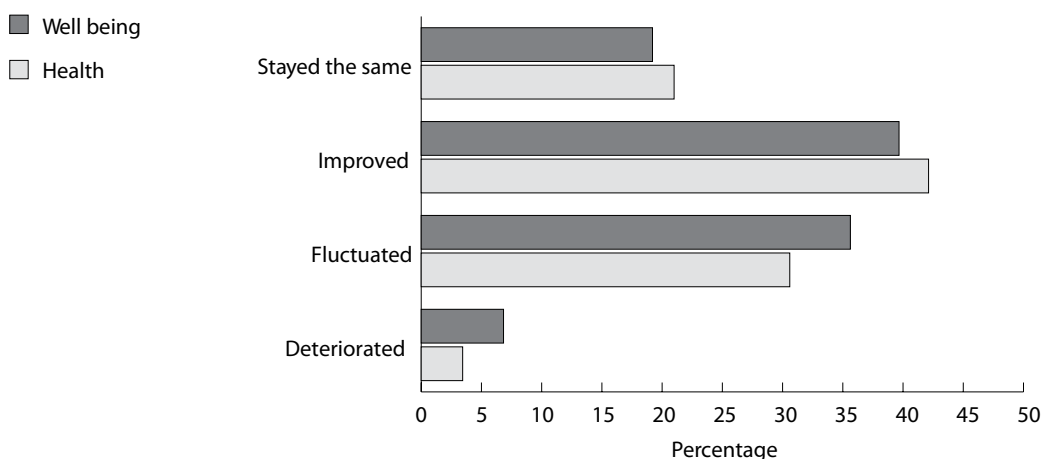
$\chi^2(2,2) = 9.278, p=0.055$

Those currently taking ARV were more likely to have had an AIDS defining illness (25.1% compared to 16.1% among those currently not taking ARV and 3.3% among those who have never taken ARV). They had tested HIV positive more years ago (mean=1994 compared with mean=1996 for those not taking ARV and mean=2003 among those who have never taken ARV).

When asked to rate the effect of commencing ARV on their physical health, 43.3% said that their health improved, 30.5% said it had fluctuated, 22.2% said it had stayed the same and 4.0% said it had deteriorated.

When asked about the impact of ARV on their overall feeling of well being, 39.7% said it had improved, 35.6% said it had fluctuated, 18.6% said it had stayed the same and 6.0% said it had deteriorated.

**FIGURE 3 Effect of commencing antiretroviral medication on health and well being (percentage of those taking ARV)**



There was considerable variation in the combinations currently in use by respondents. The most common combination was 1 NNRTI and 2 NRTI used by 12.6 % of ARV users (n=98), followed by 2 NNRTIs 7.6%), 1 NARTI + 1 NRTI (7%), and 1 PI + 1 NARTI + 1 NRTI (6.5%).

Current guidelines recommend that antiretroviral treatment be started when a patient's CD4 count drops below 200; those who have 200 to 350 T-cells should be offered treatment; while treatment for those whose counts are more than 350 should be deferred unless they have a viral load of more than 50,000 copies/ml (Australasian Society for HIV Medicine, 2004).

Table 22 gives the groupings from these guidelines, the treatment recommendations, the percentage of participants that were in each group at the commencement of ARV and the mean number of years they have been on treatment.

**TABLE 22 Recommendations for commencement of ARV treatment**

Guideline Group: At commencement of ARV combination

	Symptomatic (ADI) <sup>5</sup>	Asymptomatic and CD4<200	Asymptomatic and CD4 200-350	Asymptomatic CD4>350, VL>50,000	Asymptomatic CD4>350, VL≤50,000
Treatment recommendation	Treat	Treat	Treatment should be offered	Recommend treatment	Defer treatment
Number in Group	45	60	115	20	620
% currently on ARV	88.9	85.0	90.4	5.0	83.4
Mean number of years using ARV	5.57	8.35	9.03	0.00	8.39

## Different Combinations

Respondents who were currently using ARV had used between one and 28 combinations, with a median of three. Within the last 12 months, 66.5% had used the one combination and 21.2% had used two.

When asked how many combinations they believed they still had access to, 1.5% indicated that they thought they had only one remaining, 21.6% had a few and 35.4% felt they had many. 39.5% said they didn't know how many combinations they had left. 2.0% of those currently on combination therapy believed they had no combinations remaining.

Those respondents reporting no remaining options were significantly more likely to have been HIV positive for longer, but were not statistically significantly likely to have different CD4 levels or viral loads. (see Table 23).

**TABLE 23 Correlates of number of remaining combinations for those on ARV (Combinations remaining by Mean years positive; Mean CD4; Mean Viral load)**

	Mean year tested positive <sup>1</sup>	Mean CD4 on most recent test <sup>2</sup>	Mean viral load on most recent test <sup>3</sup>
None	1991	411	31
One	1991	474	3446
A few	1992	530	2762
Many	1995	580	3076
Don't know	1994	577	10457

1 F(4,770)= 6.563 p<0.001 2 F(4,701)= 1.805 not significant 3 F(4,739)=0.858 not significant

<sup>5</sup> Here we classify only those diagnosed with an AIDS defining illness since 2003

When we examine the health status of those with varying numbers of combinations remaining, we can see that the pattern differs for each of these categories. Those with no combinations remaining were equally likely to rate their general health as fair or good, those with one were most likely to select fair, while those with a few or many combinations were more likely to rate their health as good or excellent. Those unsure about remaining combinations were most likely to rate their health as good.

**TABLE 24 General health status for those with different numbers of combinations of ARV remaining (Percentages within combinations remaining)**

		Health			
		Poor	Fair	Good	Excellent
Combinations remaining	None	0.0	13.3	66.7	20.0
	One	8.3	50.0	25.0	16.7
	A few	6.6	22.8	50.9	19.8
	Many	3.3	20.6	50.0	26.1
	Don't know	8.3	25.8	45.7	20.2

The relationship between well being and number of combinations believed to remain is similar, with the more combinations remaining the higher the likelihood that participants will rate their well being as good or excellent (See Table 25).

**TABLE 25 General well being for those with different numbers of combinations of ARV remaining (Percentages within combinations remaining)**

		Well Being			
		Poor	Fair	Good	Excellent
Combinations remaining	None	6.3	18.8	56.3	18.8
	One	8.3	41.7	41.7	8.3
	A few	12.0	21.6	45.5	21.0
	Many	6.2	21.2	53.5	19.0
	Don't know	10.9	32.6	37.8	18.8

## THOSE NOT CURRENTLY TAKING ARV

Of the 20.4% of the sample who were not using any ARV, 26.3% had done so in the past. The mean length of time these PLWHA had been using ARV was four years (ranging from one to 17 years) and on average they had ceased using ARV four years prior to completing the survey (ranging from a month to 12 years). At the time that they stopped using ARV, most were using a combination of three drugs 39.6%, 10.3% were using four drugs, 34.3% were using two drugs and 2.3% were on monotherapy.

### Reasons for Stopping ARV Treatment

Just as the side effects of medication was one of the main difficulties that participants on ARV experienced, this was the most common reason that those who were not currently on treatment gave for stopping ARV therapy (30.8%). A large number (20.9%) also said that they had stopped treatment because their doctor had recommended it. Taking medication in public, having to take a large number of tablets, and difficulty organising meals around medication were not major considerations for PLWHA when deciding to go off treatment (See Table 26).

**TABLE 26 Difficulties of taking ARV among those who have stopped ARV treatment (percentage)**

Side effects	30.8
Recommended by my doctor	20.9
Taking part in a clinical trial	14.2
Difficulty carrying/transporting medication	7.0
Difficulty organising meals around medication	4.1
Difficulty taking a large number of tablets	3.6
Difficulty taking medication in public	1.7
Other	21.0

(Multiple responses possible)

### Those Who Have Never Used Antiretroviral Drugs

15.0% (N=148) of the respondents had never used ARV. Of these 90.9% said they would consider using ARV in the future. 5.4% (N=53) of the respondents have used ARV in the past but are not currently using them. Of these, the majority (94.1%) said they would consider using ARV in the future.



## ATTITUDES TO ANTIRETROVIRAL THERAPY

ARV have an impact on many parts of people's lives, not just on their physical health. As in previous surveys, we asked respondents to respond to a series of statements about treatments. These fall into three broad areas: decision making around treatments, relationship with their doctor, and optimism about treatments. These findings can be seen in Table 27 below.

**TABLE 27 Attitudes to ARV (percentage of total sample)**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am healthy now and don't need to use combination antiretroviral drugs	45.5	31.6	7.6	11.8	3.5
Combination antiretroviral drugs are harmful	21.3	32.4	24.2	5.8	16.4
Combination antiretroviral drugs are ineffective	51.3	35.3	1.7	1.8	9.9
New treatments will be developed in time for me to gain benefits	3.1	5.5	45.2	20.3	26.0
HIV treatments will stop me dying from AIDS	5.7	13.5	31.2	25.3	24.4
My doctor knows a lot more about the treatment of HIV than I do	3.5	9.2	42.7	42.0	2.6
People with HIV should start using antiretroviral drugs as soon as possible	9.7	26.6	24.9	17.9	21.0
My doctor and I work together to find the best treatment for me	2.3	4.5	49.1	40.7	3.4
The side effects of antiretroviral drugs outweigh the benefits	21.2	40.9	14.2	9.1	14.6
Medical treatments for HIV/AIDS make safe sex less important than it was	46.7	35.0	9.4	3.0	5.9
I would be willing to participate in HIV vaccine trials	7.3	11.3	33.7	26.2	21.6
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	35.3	33.0	15.5	3.3	13.0

### Treatment Decision Making

Most respondents indicated that they disagreed with the statement, *I am healthy now and don't need to use antiretroviral drugs* (77.1%). Those who agreed with this statement were more likely to be those not currently using any ARV and who rated their physical health more positively. Respondents were more likely to disagree with the statement, *People with HIV should start using antiretroviral drugs as soon as possible*. There were, however, one in five respondents that indicated that they were unsure about this. Those that agreed with this statement were more likely to be using ARV.

### Relationship with Doctor

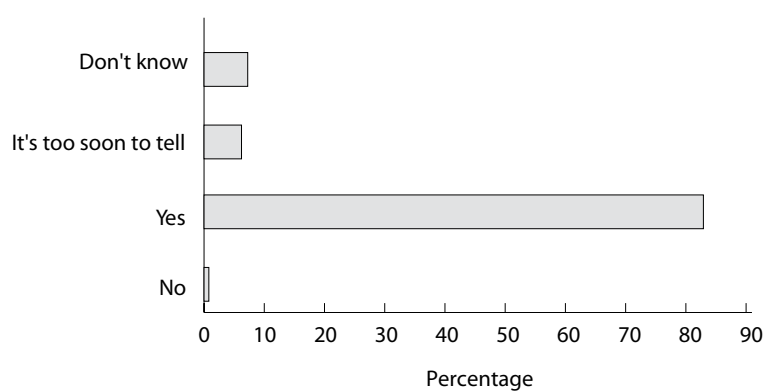
As with previous surveys, most respondents (89.8%) agreed with the statement, *My doctor and I work together to find the best treatment for me*, with few expressing uncertainty. Most respondents (84.7%) agreed with the statement, *My doctor knows more about the treatment of HIV than I do*.

## Treatment Optimism

Optimism about the value and effectiveness of antiretroviral treatments continues to characterise the Australian experience, but is tempered with concerns about the impact and long term effectiveness of these treatments. Only 3.5% of respondents agreed with the statement, *Combination antiretroviral drugs are ineffective*. This belief in effectiveness is tempered by an awareness of the potential harm of these therapies as evidenced by the agreement with the statement that, *Combination drugs are harmful* (24.2% agree, 5.8% strongly agree). This harm may in part be that experienced as side effects. Around one in five (23.3%) respondents agreed or strongly agreed with the statement, *The side effects of antiretroviral drugs outweigh the benefits*, while 14.6% were unsure. There was considerable uncertainty about the long term benefit of treatment. 26.0% of respondents said they were unsure when asked to respond to the statement, *New treatments will be developed in time for me to gain benefits*, with most of the remainder agreeing. Similarly, 24.4% were uncertain when asked if, *HIV treatments will stop me dying from AIDS*. Agreement with this statement was indicated by 56.5% of respondents.

In addition to these items, respondents were asked to indicate how much they agree with the statement, *Antiretroviral drugs mean better prospects for most people*. Most (83.5%) agreed with the statement.

**FIGURE 4 Responses to the statement, *Antiretroviral drugs mean better prospects for most people* (percentage of total sample)**



## TREATMENT BREAKS

Treatment breaks may take a number of forms and be undertaken for a range of reasons (Grierson et al., 2004b). While there is considerable discussion in the medical community about the potential benefits and dangers of treatment interruptions, our main emphasis is on the motivations, experiences and consequences of breaks for HIV positive people. To understand the experience of breaks, we asked respondents to give us some detailed information about their most recent break.

In all, 38.1% of those respondents currently using ARV had taken a break from these at some point.

### Most Recent Treatment Break

The date of the commencement of most recent treatment break was provided by 33.3% of those that had ever taken a break. Of these, 24.7% had taken their most recent break in the two years prior to survey and 12.6% in the previous one year. The mean length of break was ten months with a median of four months and a mode of three months (16.6%). Of those ever taking a break, 19.8% described it as a structured treatment interruption, while 50.3% described it as a treatment break. Of those taking a break in the previous two years, 22.7% described it as a structured treatment interruption, while 40.0% described it as a treatment break.

We asked participants to describe the reasons for taking the break within two major categories: lifestyle and clinical reasons. A discussion of the differences between those who take treatment breaks for lifestyle reasons and those who take breaks for clinical reasons can be found in our article on this topic (Grierson et al., 2004b). Just under half (49.1%) indicated that there were lifestyle reasons for taking a break. Of those taking a break in the previous two years, 53.9% said there was a lifestyle reason. The specific reasons are given in Table 28. The most common reason given was to clean out the system (18.8% of those taking breaks) followed by travel (17.4%).

**TABLE 28 Lifestyle reasons for taking breaks (percentage of those taking breaks and percentage of those taking a break in the previous two years)**

	Total taking breaks	Last two years (n=86)
Clean out my system	18.8	15.1
Travel	17.4	17.2
It didn't fit my lifestyle	10.5	12.0
Taking drugs at the right time was too difficult	9.7	11.4
The financial burden became too heavy	8.0	13.9
A special event	2.1	4.8
Other	23.3	29.3

(Multiple responses possible)

When asked if there was a clinical reason for taking the break, 39.4% of those that had taken a break indicated that there was. Of those taking a break in the previous two years, 33.9% said there was a clinical reason. 8.0% of the total group taking breaks and 5.3% of those who took a break in the previous two years gave both lifestyle and clinical reasons). Table 29 details the clinical reasons for breaks. The most commonly cited reason was that the side effects of treatment became too severe (22.3% of all those taking breaks) and 15.4% indicated that the break was on the recommendation of their doctor.

**TABLE 29 Clinical reasons for taking breaks (percentage of those taking breaks and percentage of those taking a break in the previous two years)**

	Total taking breaks	Last two years (n=75)
Side effects became too severe	22.3	22.1
Recommended by my doctor	15.4	15.6
Drug resistance developed	7.4	7.6
Changing regimens	4.8	6.3
Liver toxicity problems	4.7	7.3
Taking part in a clinical trial	2.5	1.4
Recommended by other health professional	1.4	0.0
Complications with Hep C	0.9	0.0
Other	10.9	9.4

(Multiple responses possible)

We also asked about the involvement of the participant's doctor in these breaks. Participants were less likely to have talked to their doctor about the break prior to taking it (60.8%) or during the break (61.1%) than afterwards (84.5%). Just under half (45.2%) talked to their doctor at all three stages of the treatment break. 20.9% spoke to the doctor during and after the break, but not before, and 16.3% only spoke to their doctor after the break.

For those taking a break in the previous two years, fewer talked to their doctor about the break prior to taking it (50.7%) or during the break (48.4%) than afterwards (77.3%). 30.6% talked to their doctor at all three stages of the treatment break. 13.3% spoke to the doctor during and after the break, but not before, and 22.6% only spoke to their doctor after the break.

We were also interested in the outcome of the treatment breaks, both in terms of clinical markers and experience of health and well being. Around one third of respondents said that their health remained stable, 31.2% said their health worsened, while 18.4% reported fluctuating health and 12.4% improved health. When asked about their general well being, a similar proportion said that it had remained stable (33.2%). With well being, there was a more positive experience, with 26.6% saying that it had improved, 19.3% fluctuated and 21.0% that it got worse.

**TABLE 30 Effect of break on health and well being (percentage of those taking break and percentage in last two years)**

	Health		Well being	
	All	last 2 years	All	last 2 years
Stayed the same	37.9	45.1	33.2	38.9
Improved	12.4	15.2	26.6	23.4
Fluctuated	18.4	14.5	19.3	21.3
Got worse	31.2	24.9	21.0	16.4

The impact of these breaks on clinical markers was less positive. The majority of respondents indicated that their viral load had increased, and their CD4 count had decreased as a result of the break. These data are presented in Table 31 and Table 32. Note that the categories are ordered from positive to negative outcome for both tables.

**TABLE 31 Effect of break on viral load (percentage of those taking break)**

		Viral load before break				Total
		Below detectable levels	500-9999	10000-49999	50000+	
Change in viral load due to break	Decrease (improve)	9.0	13.8	13.8	12.6	9.8
	Stay the same	22.6	11.8	11.8	12.9	20.0
	Fluctuate	10.8	13.0	13.0	22.8	11.2
	Increase (worsen)	57.6	61.4	61.4	51.7	59.0

**TABLE 32 Effect of break on CD4 (percentage of those taking break)**

		Viral load before break			Total
		500+	250-499	<250	
Change in CD4 due to break	Increase (improve)	7.7	8.9	11.4	7.5
	Stay the same	20.2	17.4	13.1	16.9
	Fluctuate	10.6	15.0	10.5	15.9
	Decrease (worsen)	61.5	58.7	65.1	59.7

## ANTIRETROVIRAL RESISTANCE

The potential for developing resistance to ARV is an ever present concern for HIV positive people. HIV can develop resistance to one or more treatments as a result of its continual mutation and this resistance can result in the failure of treatments. Resistance can result from a lack of early and persistent suppression of viral replication, missed doses of antiretroviral drugs or infection with a resistant strain.

There are a number of resistance tests available but they generally fall into two categories: genotypic resistance tests that look for mutations of the virus in its genetic code; and phenotypic resistance tests where the virus is cultured and the performance of drugs tested directly. We asked respondents whether they had had resistance tests and what the clinical and treatment outcomes of this were.

42.1% of respondents who had ever used ARV indicated that they had some sort of ARV resistance test. This included 44.4% of those who were currently on ARV and 41.3% of those who had used them previously and 30.7% of those who had never used them.

Of those who had resistance testing, 44.3% found resistance to one or more antiretroviral drugs (50.8% of those currently on ARV). This resulted in a change of drugs for 81.6% (N=133) of those where resistance was shown.

## DOSING AND ADHERENCE

Adherence to the antiretroviral treatment regime is important for treatment to be effective and to prevent the development of resistance to medications. The degree of adherence required is far greater than that of other health conditions. It is estimated that for the majority of people on antiretroviral treatments, adherence of more than 95% is necessary for successful viral suppression and immune response (Chen et al., 2007).

While the consistency of adherence directly affects the health outcomes for PLWHA, many factors can have an impact on consistency. These include the complexity of the drug regime, a person's emotional well being, the management of side effects, lifestyle fit and communication with friends and doctors (Beusterien et al., 2008). One study has found that adherence consistency tends to decrease over time (Mannheimer et al., 2002).

Respondents were asked the number of times they took a range of medications per day. On average, PLWHA were taking medication twice a day (range 0 to 16, median=2). The number of times they were taking specific types of medication is shown in Table 33. 46.4% of the sample were taking ARV twice daily, 2.1% three times a day and 45.1% once a day.

**TABLE 33 Number of times participants take medications**

	Mean	Median	Range
Antiretroviral drugs	1.52	2.00	0-10
Complementary therapies	1.34	1.00	0-8
Medication for other health conditions	1.50	1.00	0-9

Participants who were currently using ARV were asked how many doses they had missed on the day prior to completing the survey and the day before that. Combining the data from these two measures, 98.3% reported missing no doses on the two days, 0.9% missed one dose, 0.6% missed two doses and 0.2% missed three or more doses.

## PRESCRIPTIONS

We asked participants who prescribed their ARV. In recognition of the multiple prescribing sites people utilise, respondents were able to nominate more than one source. Two fifths (42.4%) of PLWHA got their prescriptions for antiretroviral drugs from a GP who specialises in HIV/ S100 prescriber. A similar proportion (34.9%) obtained their prescription from a specialist in an outpatient clinic, while fewer obtained them from a doctor at a sexual health centre (23%), another GP (2.2%), or from a HIV specialist while an inpatient (3.9%).

## CLINICAL TRIALS

19.8% of all participants (n=195) had participated in a clinical trial for HIV-related treatment in the last two years.

## VACCINES

While there has been some success on the HIV vaccine front with promising, if modest, results from a study conducted in Thailand released in September 2009 (Cohen, 2009), the development of a useable vaccine is still some way off.

We asked respondents to indicate their agreement with the statement, *I would be willing to participate in a HIV vaccine trial*. Almost one quarter (21.6%) said they did not know, while 59.9% either agreed or strongly agreed with the statement. A further 11.3% disagreed and 7.3% disagreed strongly.

# SERVICES

This section discusses the engagement of PLWHA with a range of services. A key component of the Australian response to HIV has been the establishment of HIV specific services, both within health systems (specialist HIV wards in hospitals, high HIV caseload general practitioners and sexual health services for example) and through community and volunteer organisations. There has also been considerable energy expended on sensitising mainstream services to issues specific to HIV/AIDS and the affected communities.

## HEALTH SERVICES

### Treatment

We asked respondents to identify the physician they see for the clinical management of their HIV and for general health issues. HIV GPs (S100 Prescribers) were the key physicians for both HIV specific and general health management. HIV specialists were also the primary providers for a significant proportion of PLWHA. The distinction between these categories reflects the different healthcare systems in different states and territories and the availability of these physicians in regional areas. HIV GPs were more likely to be nominated as the primary provider of both general and HIV-related treatment by those living in the inner suburbs of capital cities, than those living in the outer suburbs, regional centres or rural areas. Combined, HIV GPs and specialists were the primary physicians for 78.8% of respondents for HIV-specific management and for 58.6% of respondents, for general health management.

**TABLE 34 Physician used for general and HIV-related treatment (percentage of total sample)**

	For general treatment	For HIV specific treatment
HIV GP/S 100 Prescriber	42.0	46.5
Other GP	27.4	3.5
HIV specialist	16.6	32.3
Doctor at sexual health centre	2.5	6.7
Other doctor	8.6	9.5
Other	3.0	2.2

63.5% of respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment. Of those who saw a different doctor, 96.1% said that that doctor knew their HIV status

### Services Used at HIV and Other Organisations

Participants were asked whether they were currently using a range of services and, if so, whether they used them through an HIV/AIDS organisation or through another organisation. Treatments advice was the most commonly used service at HIV/AIDS organisations, with one third of respondents selecting this item. HIV/AIDS organisations were also used for social contact with other PLWHA, treatments information and financial assistance by substantial numbers of respondents. Other organisations were more likely to be used than HIV/AIDS organisations for pharmacy services, transport, housing assistance, internet access, mental health services and employment services.



**TABLE 35 Respondents who use services through HIV/AIDS organisations and other organisations (percent of total sample)**

	Use service at HIV/AIDS organisation	Use service at other organisation
Treatments advice	35.3	15.6
Social contact with other PLWHA	29.5	5.7
Treatments information	27.2	9.4
Peer support group	22.5	4.7
Counselling	22.4	15.5
Financial assistance	19.6	8.6
Pharmacy services	17.8	28.7
Informal peer support	17.6	7.1
Complementary therapies	14.2	16.4
Internet based information	14.2	13.7
Community education campaigns	12.4	5.9
Financial advice	11.0	12.1
Legal advice	10.6	8.9
Housing assistance	9.8	11.0
Mental health services	8.7	14.2
Internet access	8.0	17.9
Transport	4.5	11.5
Volunteer carer	4.2	3.2
Respite care	3.9	4.4
Employment services	3.3	10.0
Library	3.2	14.5
Drug/alcohol treatment	3.1	7.5
Return to work skills	2.5	8.1
Paid carer	1.9	4.1

(Multiple responses possible)

Around one third (33.1%) of respondents indicated that there were services they felt they needed but did not have access to. The services most commonly nominated were peer support groups (10.7%), financial assistance (6.5%) and services for PLWHA in rural, regional and outer suburban areas (4.4%).

## INFORMATION

One of the most distinctive characteristics of the HIV/AIDS epidemic has been the degree to which those infected with the virus have become highly active health consumers. This is reflected not only in the emergence of a strong community sector and advocacy structure, but also in the way in which individual positive people actively engage with their healthcare providers and seek out a diverse range of information on clinical and social aspects of the virus and the epidemic. Clinical information and most specifically information on the efficacy and consequences of treatment in the HIV/AIDS area is not the sole province of health professionals. In the previous HIV Futures surveys and in other research we have conducted, we have demonstrated that positive people access information on HIV treatments, management and social aspects from a range of sources including the medical literature, the community sector, health professionals and peers.

## Sources

Respondents were asked to nominate from a list of potential sources; those that were important sources of information on treatments and HIV management, and living with HIV. This distinction is, in part, based on our and others' qualitative work in this area which suggests that PLWHA make a distinction between HIV as a health condition and the day-to-day management of HIV as a social and psychological experience.

**TABLE 36 Sources of information about treatments and living with HIV (percentage of sample)**

	Information about Treatments/HIV Management	Information about Living with HIV
HIV specialist	56.4	31.4
HIV GP/S100 prescriber	51.3	27.8
HIV magazine/newspaper	43.0	45.4
Publications from HIV/AIDS groups	37.5	42.8
Internet	36.5	36.5
HIV positive friends	32.3	41.4
Sexual Health Service	28.0	18.5
Articles in gay press	27.7	34.4
AIDS Council staff (treatments-specific)	21.0	21.3
PLWHA Organisation staff (treatments-specific)	18.2	22.6
Nurse	16.2	11.8
Other GP	15.9	12.3
Publications from other sources	14.5	16.4
Dentist	14.1	9.3
Partner/lover	13.3	19.3
AIDS Council staff (others)	13.2	21.8
Pharmacist	12.6	4.8
PLWHA Organisation staff (others)	11.5	24.3
Dietician	11.5	12.7
Other HIV/AIDS Organisation staff	10.2	14.2
Alternative/Complementary therapist	9.5	10.2
Peer Support Officer	7.6	14.3
Family	4.8	8.6
Positive heterosexuals organisation	4.7	7.4
Positive women's organisation	3.4	6.9
Multicultural/CALD HIV Service	2.6	3.0
Sex worker association	1.8	3.7
Aboriginal health worker	1.3	2.3

(Multiple responses possible)

## Information about HIV Treatment and Management

HIV specialists were considered to be an important source of information on HIV treatment and management by over half (56.4%) of respondents. HIV GPs/S100 prescribers were nominated by a similar proportion of the sample (51.3%). Importantly, information from the community sector figured significantly in the responses to this item. These included HIV magazines and newspapers (43.0%), HIV/AIDS organisation publications (37.5%), and articles in the gay press (27.7%). HIV positive friends were nominated by around one third (32.3%) of respondents.

When asked in a separate question to nominate their most important sources of information about treatments and health management, 32.8% of respondents nominated their HIV GP as the most important source, followed by an HIV specialist (29.0%) and the internet (9.2%).

## Information about Living with HIV

The pattern in responses to the question of important sources of information on living with HIV differed somewhat from the previous item. The source selected by the greatest number of respondents was HIV magazine/newspaper (45.4%), followed by publications from HIV/AIDS groups (42.8%) and HIV positive friends (41.4%). Clinical sources were also considered important by significant numbers of positive people (HIV GP: 27.8%, HIV specialist: 31.4%).

When asked to identify the most important sources of information about living with HIV, 15.3% nominated the internet, 13.5% their HIV GP and 12.6% an HIV specialist, while 12.0% nominated HIV positive friends.

## Lack of Information

We asked respondents whether lack of information made it difficult for them to make decisions in certain areas and a quarter (26.9%) agreed that this was the case. When asked to identify the domains in which this applied, employment and financial planning figured prominently, with 14.8% of respondents identifying lack of information about work/employment and 12.9% financial planning.

In the clinical realm, 13.3% nominated the management of side effects, while 11.7% nominated interactions between ARVs and other drugs. Information about complementary therapies was identified by 10.7%.

**TABLE 37 Issues where participants lack information (percent of total sample)**

Work/employment	14.8
Managing ARV side effects	13.3
Financial planning	12.9
Legal issues	12.3
Interaction between ARV and other drugs	11.7
Using complementary therapies	10.7
Using ARV	10.4
Changing ARV	9.8
Taking a break from ARV	9.2
Recreational drug use	6.7
Having children	6.0

(Multiple responses possible)

## PUBLICATIONS

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 38, including breakdowns for specific populations where access or focus is an issue. Gay and HIV press were accessed by large proportions of the sample, as were HIV community publications (particularly within their constituency area). It is clear from these data, and those in the previous section, that community publications remain an important site for information dissemination and community debate.

**TABLE 38 Publications read by PLWHA**

Publication	Percentage
<b>National or non-specific</b>	
HIV Australia	28.0
Positive Living	49.0
Newsletters from community organisations	17.1
National Haemophilia	0.9
Overseas magazines (eg POZ)	6.1
Gay newspapers (% of total sample)	49.8
Gay newspapers (% of gay men, lesbians and bisexuals)	39.2
Gay magazines (% of total sample)	28.8
Gay magazines (% of gay men, lesbians and bisexuals)	34.7
<b>State based publications</b>	
Talkabout (% of total sample)	35.0
Talkabout (% of NSW respondents)	42.9
User's News (% of total sample)	2.1
User's News (% of NSW respondents)	3.4
Positive life (% of total sample)	8.8
Positive life (% of WA respondents)	28.0
QPP Alive (% of total sample)	6.7
QPP Alive (% of QLD respondents)	35.5
Spin (% of total sample)	0.6
Spin (% of QLD respondents)	3.1
(Multiple responses possible)	

## INVOLVEMENT WITH AIDS ORGANISATIONS

Participants were asked about their involvement with HIV/AIDS organisations. 63.2% of the sample had some contact with HIV/AIDS organisations. Of these, 66.4% received newsletters and mail outs, 57.6% were clients, 51.3% were members, 13.0% were volunteers and 7.3% were employees. Of those that volunteered, they did so for between one and 66 hours per week (median = 4 hours/week).

# THE SOCIAL WORLD OF PLWHA

This chapter examines the collective experience of HIV from a number of perspectives. While for some people HIV may be a profoundly isolating experience, within Australia the experience of HIV has been overwhelmingly a collective one. HIV is not only experienced by individuals, but also by communities and social networks. HIV identity is managed through contact with other positive people, through the disclosure of status, both willingly and unwillingly, and through engagement with the community sector. Here we explore some of these issues through the experiences of the respondents to this survey.

## CONTACT WITH OTHER PLWHA

Very few HIV positive people (9.2%) did not personally know anyone else with HIV. Gay men were significantly less likely to know no-one else with HIV than other respondents. Most positive people had an HIV positive friend (71.9%) and many had either an HIV positive partner or ex-partner (15.0% and 24.6% respectively). 15.2% of respondents had been involved in the nursing or care of another positive person at some time in the last two years and 68.7% have had someone close to them die from HIV/AIDS.

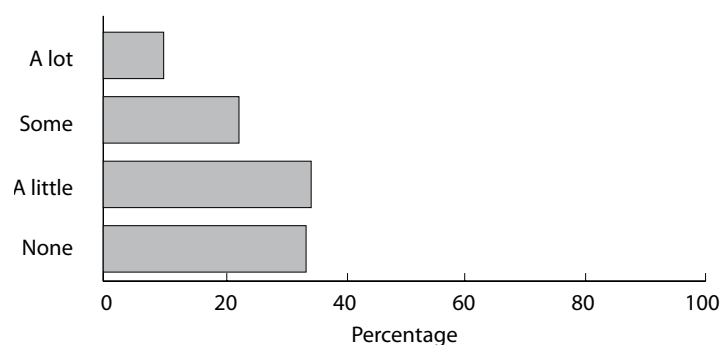
**TABLE 39 Other HIV positive persons known by respondent**

Positive Persons	Percentage
Friend	71.9
Acquaintance/Member of support group	53.1
Former partner/spouse	24.6
Partner/spouse	15.0
No-one	9.2
Other relative	4.1
Son/daughter	0.4
Other	6.2

(Multiple responses possible)

Two thirds of the respondents spent at least some time with other positive people (67.5%). The 11.9% who indicated that they spend a lot of time with other PLWHA were more likely to be those who work or volunteer for an HIV/AIDS organisation.

**FIGURE 5 Time spent with other positive people**



## DISCLOSURE

Respondents were asked who they had disclosed their HIV status to (see Table 40). Not surprisingly, most (84.1%) had disclosed to close friends and most (89.7%) of those in relationships had disclosed to their partner. Within families, people were most likely to have disclosed to siblings (62.6%) although many had disclosed to parents (49.2%). Only 3.7% had not disclosed their HIV status to anyone.

**TABLE 40 People the respondent has disclosed their HIV status to (percentage)**

Close friends	79.0
Positive friends	60.4
Siblings	58.3
Partner/spouse	50.8
Parents	47.6
Other friends	30.1
Work colleagues	29.3
Son/daughter	9.1
Neighbours	13.5
People from own ethnic community	3.7
No-one	3.7
<b>Specific populations</b>	
Partners (% of those in a regular relationship)	90.3
Work colleagues (% of those currently employed full time)	37.2
Work colleagues (% of those currently employed part time)	39.4
Son/daughter (% of those with children)	45.2

(Multiple responses possible)

## Unwanted Disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. 51.4% said that it had at some point and 22.0% said that this had happened in the last two years. When asked if this disclosure had a negative effect, 63.4% said it had. When asked who disclosed their status, they were most likely to nominate friends (see Table 41).

**TABLE 41 Sources of unwanted disclosure (percentage of those experiencing unwanted disclosure)**

	Percent of those who have ever experienced unwanted disclosure (N=492)	Percent of those who have experienced unwanted disclosure in the last 2 years (N=210)
Close friends	14.8	25.9
Other friends	11.4	27.2
Work colleagues	7.3	14.9
Partner/Spouse	8.4	14.8
HIV positive friends	8.0	14.9
Other	5.6	11.3
Sibling	6.7	10.4
Workers in a healthcare setting	8.5	12.1
Parents	4.9	9.3
Neighbour	2.6	4.6
Other family member	3.4	7.4
Staff/volunteers at community organisation	2.5	5.5
Son/daughter	0.4	1.4
People from ethnic community	0.6	1.9

(Multiple responses possible)

## The Place of HIV in People’s Lives

HIV affects many parts of people’s lives in both positive and negative ways. Knowledge of one’s HIV status can be something that dominates some people’s sense of who they are, while for others it will be a minor facet of their self-image. These different experiences of HIV status can have significant implications for the provision of services and the targeting of education for positive people.

To explore this issue, we asked, *When you think of all the things that make you who you are, how important are each of the following aspects of yourself?* The categories and results are given in Table 42. A rating of “essential” indicates that the characteristic is an essential component of the individual’s identity. A rating of “important” indicates that the characteristic plays a large part in how PLWHA see themselves, but may have greater or lesser relevance depending on the context. A rating of “not important” indicates that the characteristic only has very context specific relevance and does not generally enter into their self-image. A rating of “irrelevant” indicates that the characteristic plays no part in their self-image. While our primary focus in this area was on the importance of HIV identity, we have included other characteristics, both as points of comparison and as a way of more fully describing PLWHA. The characteristics examined were sexuality, gender, recreational drug use, ethnicity, parenthood and career. The majority (47.2%) of positive people in this study considered their HIV status an important, but not essential aspect of their make-up, while 18.6% considered it to be an essential characteristic. This is in contrast to sexuality and family, where around 30% of the sample considered each of these to be essential characteristics.

**TABLE 42 Importance of personal characteristics to respondents’ sense of identity**

	Essential	Important	Not Important	Irrelevant
Sexuality	29.1	45.1	17.2	8.6
Family	30.0	46.3	13.7	10.0
Gender	26.7	43.4	18.4	11.5
HIV status	18.6	47.2	23.7	10.5
Career	18.4	40.6	20.3	20.7
Religious beliefs	8.6	20.5	26.7	44.2
Parenthood	8.7	12.8	17.0	61.5
Ethnicity/Cultural background	4.3	19.4	33.3	43.0
Drug use (recreational/illegal)	1.8	11.8	35.3	51.2

## Social Support

We asked participants about the amount of social support they received from a range of sources including household members, social contacts and service providers. The ratings are shown in Table 43 with those for whom the category was not applicable excluded from each row. Participants were most likely to have nominated their partner or spouse as providing a lot of support (78.6% of those with partners), followed by their pets (65.8% of pet owners). Around half of participants also received a lot of support from their doctors (44.8%) and close friends (41.7%). When we examine the sources that people rated as providing no support, the highest ranking category was volunteer carer, where 62.0% of those with a carer said they received no support from them. Religious or spiritual advisors were also considered a source of no support for 50.4% of those with such a source.

Participants were more likely to have rated a source as supportive if they had disclosed to them for all categories (except pets).



**TABLE 43 Social support received from different sources (percentage who gave valid responses for each category)**

	A lot	Some	A little	None
Partner/spouse	78.6	11.0	4.2	6.2
Pets	65.8	17.3	11.0	5.9
Doctor	44.8	33.0	19.5	2.7
Close friends	41.7	32.2	18.3	7.8
Parents	35.3	21.3	17.6	25.8
Children	32.3	17.1	12.0	38.6
HIV positive friends	28.7	33.2	27.2	11.0
Family	26.7	24.7	23.5	25.1
Siblings	26.1	21.8	22.2	29.9
Health care workers	25.9	30.4	21.6	22.1
Counsellor	23.7	24.7	20.8	30.9
Volunteer carer	15.4	11.4	11.2	62.0
Other friends	14.6	33.7	31.6	20.
Religious or spiritual advisor	14.1	19.5	16.0	50.4
PLWHA groups	13.0	22.1	31.2	33.7

### Attitudes to HIV Status

Two additional items were included that examine individual's relationship to their HIV serostatus. Participants were asked whether they agreed with the statement, *As long as I am well I prefer not to think about HIV/AIDS*. Over half the respondents agreed or strongly agreed with this statement. The second statement participants were asked to respond to was, *Life has become more meaningful since I became HIV positive*. Half agreed or strongly agreed with this statement.

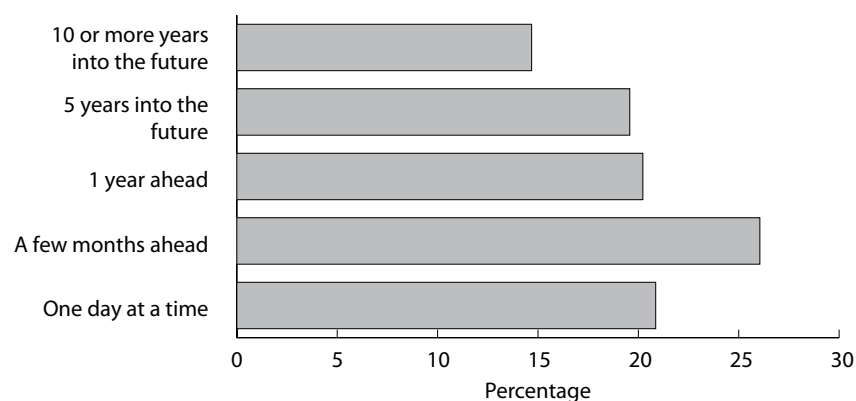
**TABLE 44 Attitudes to HIV status**

	Strongly agree	Agree	Disagree	Strongly disagree
As long as I am well I prefer not to think about HIV/AIDS	21.0	40.4	32.7	5.9
Life has become more meaningful since I became HIV positive	14.9	34.1	32.7	18.3

## Planning for the Future

A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. One fifth (20.6%) planned their life one day at a time and 25.8% planned only a few months ahead. Over half of the respondents planned for at least a year with 19.9% planning one year ahead, 19.3% planning five years ahead and 14.4% planning ten years or more ahead. This profile of the population has changed very little since the first HIV Futures survey. Those with longer time frames tend to be those who have been HIV positive for a shorter period, have lower viral load, higher CD4 counts, and have not had an AIDS defining illness.

**Figure 6 Time frame for future planning**



## RELATIONSHIPS AND SEX

In this section we discuss a range of issues to do with the sexual lives and intimate relationships of PLWHA. While there is some attention paid to sexual practice, our intention is not to characterise PLWHA as a group posing a risk of HIV infection to HIV negative people. To this end, we have taken care to characterise the HIV risk reduction strategies employed by HIV positive people in sexual relations. We have also attempted to address other aspects of sex and relationships that are all too often absent from the literature in this area. This includes issues of sexual pleasure, the establishment of relationships and the consequences of community stigma for both sexual lives and other intimate relationships.

### Relationships

Respondents were asked about current sexual relationships. The results are presented in Table 45. Over one quarter of the sample said that they had no sex at present. A similar though smaller proportion reported that they had a regular relationship only, while slightly more said that they had casual sex only and slightly fewer that they had a regular relationship plus casual sex. When this item is broken down by sex and sexuality, we find significantly different patterns between three groups of PLWHA. Heterosexual men were more likely than other PLWHA to report that they had no sex at present. Women were more likely to report that they had one regular sexual partner and no casual sex. Gay and bisexual men are more likely to report that they had a regular sexual partner and also had casual sex.

**TABLE 45 Type of sexual relationship(s) by gender and sexuality of respondent (percentage)**

	Gay or Bisexual men	Heterosexual men	Women	Total
I have no sex at present	26.6	61.4	42.9	30.7
I have casual sex only	35.7	4.8	3.6	30.9
I have a regular relationship with one person, and I have sex with other people	17.4	0.0	1.3	14.6
I have a regular relationship with one person, and I do not have sex with other people	17.7	33.8	52.2	21.6
I have a regular relationship with two or more people	2.6	0.0	0.0	2.2

When asked if they were currently in a regular relationship, around half (43.2 %) said they were. This is slightly higher than the proportion of the sample that report having sex with a regular partner in Table 45 (38.4%), as some in a regular relationship did not have sex.

## Regular Partners

Of those in a relationship with a regular partner, 37.7 % reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in sero-nonconcordant relationships. This remaining group is made up of 59.2% of those in relationships that report that their partner is HIV negative (a sero-discordant relationship) and 3.1% who report that they don't know their partner's HIV status. Nearly all PLWHA (96.3%) had told their regular partner that they were HIV positive.

We have reported the data in the following tables on sexual practice and condom use in numbers rather than percentages, as the small sub-samples would give an inflated view of the proportions in some categories. PLWHA in regular relationships were asked about the sex they had with their regular partner. Overall, 32.4% of the total sample had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 4.1% had anal or vaginal sex with a regular female partner in the previous six months. Condom use with regular partners can be seen in Table 46.

**TABLE 46 Condom use in penetrative sex with regular partner by respondent and partner sex**

	Number of these that used condom (N=393)			
	Never	Sometimes	Usually	Always
<b>Female respondents N=43</b>				
With regular male partner	12	7	10	14
<b>Male respondents N=282</b>				
With regular male partner	124	28	33	96
With regular female partner	12	1	5	17

If we look at these data in terms of relationship sero-concordance, considerable clarity is given to the patterns of condom use. Unprotected vaginal or anal intercourse is more likely to have occurred in sero-concordant relationships than in sero-nonconcordant relationships (see Table 47).

**TABLE 47 Condom use with regular partner by respondents' gender, partners' gender, and partners' sero-status**

	Number of these that used condom			
	Never	Sometimes	Usually	Always
<b>SERO-CONCORDANT Relationships N=151</b>				
<b>Female respondents N=10</b>				
With regular male partner	4	1	2	3
<b>Male respondents N=100</b>				
With regular male partner	79	3	3	11
With regular female partner	4	0	0	0
<b>SERO-NONCONCORDANT Relationships N=163</b>				
<b>Female respondents N=25</b>				
With regular male partner	3	4	8	10
<b>Male respondents N=138</b>				
With regular male partner	24	13	18	60
With regular female partner	6	1	5	11

## Casual Partners

Over half (55.3%) of the sample reported that in the six months prior to completing the survey they had had sex with one or more casual partners. When asked the HIV status of their casual partners, 9.9% reported that all of their casual partners were HIV positive, 38.5% reported that some of their casual partners were HIV positive, and 6.9% reported that none of their casual partners were HIV positive. Most respondents (44.7%) who had had casual sex reported that they did not know the HIV status of their casual partners. Respondents were asked about their condom use during anal or vaginal intercourse with casual partners over the previous six months. As can be seen from Table 48, there are considerable variations in condom use when we examine this by sex of respondent and sex of partner.

**TABLE 48 Condom use with casual partner by respondent and partner sex.**

	Number of these that used condoms (N=428)			
	Never	Sometimes	Usually	Always
<b>Female respondents N=5</b>				
With casual male partners	0	0	0	5
<b>Male respondents N=423</b>				
With casual male partners	60	138	94	122
With casual female partners	1	1	1	15

Again, when we look at these data in terms of the partners' HIV status, a clearer pattern emerges (see Table 49). There is a significant relationship between condom use and partners' HIV status: consistent unprotected anal and vaginal intercourse occurs primarily with HIV positive partners, whereas with HIV negative partners or those of unknown status, condom use was much more likely.

**TABLE 49 Condom use with male casual partner by partners' sero-status**

		Number of these that used condom (N=418)			
		Never	Sometimes	Usually	Always
Casual partners' HIV Status	All HIV positive	31	7	3	4
	Mixture/unsure	26	128	88	106
	All HIV negative	3	2	4	16

In addition to reporting on their overall patterns of condom use, respondents who had had casual sex reported on their most recent sexual encounter with a casual partner. Around half the survey respondents (47.3%) provided such information. Of the respondents who had casual sex, 79.7% had vaginal or anal intercourse on their last occasion with a casual partner. As was found for the overall patterns of condom use, condom use during respondents' most recent sexual encounter was contingent on the HIV status of the partner. Figure 7 gives a breakdown of the range of protective strategies employed by positive people to protect their most recent casual partner. This includes knowledge of HIV status, condom use and avoidance of ejaculation within their partner. This schematic shows that for the entire set of data available, incidents that involved any risk were very rare and mostly associated with partners of unknown status.

**Figure 7 Sexual practice with the most recent casual partner**

Sex with a casual partner in the last six months? (missing=2)	
No	Yes
387 44.7%	479 55.3%

Anal/vaginal intercourse with the casual partner? (missing=3)	
No	Yes
97 20.3%	379 79.7%

HIV status of casual partner (missing=3)		
HIV positive	HIV Negative	Status Unknown
138 36.7%	58 15.4%	180 47.9%

Condom used? (missing=5)					
Yes	No	Yes	No	Yes	No
22 16.1%	115 83.9%	45 77.6%	13 22.4% (1.2% of total)	115 64.2%	64 35.8% (6.0% of total)

Ejaculated in partner? (male respondents only) (missing=2)					
No	Yes	No	Yes	No	Yes
55 48.7%	58 51.3%	11 91.7%	1 8.3% (0.1% of total)	53 85.5%	9 14.5% (0.8% of total)

Ejaculated in by partner? (male partners only) (missing=2)					
No	Yes	No	Yes	No	Yes
61 52.6%	55 47.4%	5 45.5%	6 54.5% (0.5% of total)	39 60.9%	25 39.1% (2.3% of total)

## HIV, Sex, Relationships and Treatments

PLWHA were asked to respond to a number of statements about relationships, sex and HIV. The results of these items are shown in full in Table 50.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, around half (51.2%) said they would, a third (30.6%) said they would not, and the remainder (18.1%) said that they did not know.

The potential to develop new relationships remains an important issue for PLWHA. While much has been done to reduce stigma and discrimination in formal settings such as workplaces and healthcare settings, the more intimate domains of sex and relationships can still be a site of anxiety and uncertainty for both HIV positive and negative people.

Over three fifths (65.8%) of the respondents agreed with the statement, *Few people would want a relationship with someone who has HIV*. A similar response was found to the statement, *I am afraid of telling potential partners of my HIV status in case they reject me*. Over half the respondents (57.1%) agreed with this statement.

Concerns about transmission of the virus to others and re-infection were apparent in the responses to the next six items. Most respondents (66.8%) agreed with the statement, *I am afraid of infecting my partner, or potential partner, with HIV*, while very few agreed with the statements, *I feel more confident about unprotected sex because of the new treatments*; *Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV*; and *Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom*. Greater concern on these items was expressed by those with HIV negative regular partners, those having only casual partners and those not currently having sex.

Similarly, the impact of potential vaccines on intentions to practice safe sex and anxiety about safe sex is minimal with 29.0% agreeing with the statement, *If there was a vaccine which prevents HIV, I would not practise safe sex*, and 17.3% agreeing with the statement, *Knowing that a vaccine will become available makes me less anxious about sex*.

The response to concerns about re-infection remains mixed, with 46.2% agreeing that, *I am concerned about becoming infected with another strain of HIV* and 44.5% disagreeing.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (62.3%) agreed with the statement, *HIV has had a negative effect on my sexual pleasure*. One third (33.4%) disagreed with this statement.

When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. 18.6% were unsure when asked to respond to the statement, *If I know that my partner is HIV positive I find sex more pleasurable*. More respondents agreed with this statement (49.2%) than disagreed with it (32.2%).

Over one quarter (36.3%) said that they agreed with the statement, *I have stopped having sex because of my HIV status*. Similarly, 57.6% of participants agreed that, *HIV has negatively affected my libido*.

**TABLE 50 Attitudes to HIV, sex and relationships (percentage)**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I prefer to have a relationship with someone who also has HIV	8.7	21.9	28.4	22.8	18.1
Few people would want a relationship with someone who has HIV	5.6	22.0	41.7	24.1	6.6
I am afraid of telling potential partners of my HIV status in case they reject me	12.7	22.7	35.4	21.7	7.3
Being HIV positive has helped me form more satisfying relationships	22.2	38.7	15.7	7.1	16.3
I am afraid of infecting my partner, or potential partner, with HIV	7.9	19.5	32.9	33.9	5.9
My doctor knows a lot more about the treatment of HIV than I do	3.5	9.2	42.7	42.0	2.6
People with HIV should start using antiretroviral drugs as soon as possible	9.7	26.6	24.9	17.9	21.0
My doctor and I work together to find the best treatment for me	2.3	4.5	49.1	40.7	3.4
The side effects of antiretroviral drugs outweigh the benefits	21.2	40.9	14.2	9.1	14.6
Medical treatments for HIV/AIDS make safe sex less important than it was	46.7	35.0	9.4	3.0	5.9
I would be willing to participate in HIV vaccine trials	7.3	11.3	33.7	26.2	21.6
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	35.3	33.0	15.5	3.3	13.0
I feel more confident about unprotected sex because of the new treatments	39.1	35.5	13.8	4.5	7.2
Medical treatments for HIV/AIDS make safe sex less important than it was	46.7	35.0	9.4	3.0	5.9
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	37.6	33.4	17.6	4.9	6.5
If there was a vaccine which prevents HIV I would not practice safe sex	21.9	31.6	19.9	9.1	17.5
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	35.3	33.0	15.5	3.3	13.0

**TABLE 50 CONTINUED Attitudes to HIV, sex and relationships (percentage)**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Knowing a vaccine will become available makes me less anxious about sex	21.6	41.5	13.5	3.8	19.5
I am concerned about becoming infected with another strain of HIV	13.8	30.7	29.8	16.4	9.3
HIV has had a negative effect on my sexual pleasure	10.8	22.6	34.9	27.4	4.3
If I know that my partner is HIV positive I find sex more pleasurable	11.8	20.4	28.8	20.4	18.6
I stopped having sex because of my HIV status	23.0	38.4	21.8	14.5	2.3
HIV has negatively affected my libido	13.0	25.3	32.2	25.4	4.0

## Criminalisation of HIV transmission

Recent high-profile cases of criminal prosecution for HIV transmission in Australia and internationally have changed the landscape in which HIV positive people assess their HIV status and make decisions about how and when to disclose their status. In this year's survey, we included questions to assess the impact of these developments on the experiences of PLWHA.

These cases and their ensuing media coverage, as well as an increase in the number of criminal prosecutions for transmitting HIV (Groves and Cameron, 2009), have intensified the discussion about the criminalisation of HIV transmission. A recently published NAPWA monograph explores these issues in depth (see NAPWA, 2009).

Research has shown that dominant views about criminal prosecution of HIV undermines HIV prevention efforts by placing expectation of responsibility solely on the HIV positive sexual partner (Dodds, 2008) and has the potential to reinforce stigma of HIV/AIDS (UNAIDS, 2008).

In 2008, the Department of Health and Ageing produced the *National Guidelines for the Management of People with HIV who Place Others at Risk* (Dodds, 2008), developed by the Blood Borne Virus and Sexually Transmissible Infections Sub-Committee (BBVSS) of the Australian Population Health Development Principal Committee (APHDPC). The *Guidelines* stated aim is to inform and standardise approaches in the various states and territories to the small number of people for whom coercive measures are needed. It acknowledges that an individual has the responsibility of protecting themselves and others from infection and, that in most cases of potential transmission, prevention is best achieved through information, education, and the provision of resources. The *Guidelines* recommend that the roles of clinician and public health official be kept distinct.

In an AFAO discussion paper, Groves and Cameron (2009) note that the intersection of public health with criminal law is fraught and the authors highlight the need for discussion about the way in which justice and health agencies can work together effectively. They recommend further research on the effects on affected communities and point out the need for developing ways to work with journalists to ensure sensitive and accurate reporting of criminal prosecution. They also point to the need to address potential "fallout" issues such as re-establishing trust with doctors.

In the survey, we asked participants to what extent the current legal situation has had an impact on their decisions to disclose their status to sexual partners and their sexual practices to service providers. Clearly legal issues are important to people, with 42.4% agreeing with the statement, *I am worried about disclosing my HIV status to sexual partners because of the current legal situation*. There was less concern about the legal implications of disclosure of sexual practices to service providers, however, 28.4% expressed some concern and 13% were uncertain.



**TABLE 51 Attitudes toward legal issues**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am worried about disclosing my HIV status to sexual partners because of the current legal situation	15.2	30.2	25.2	17.2	12.1
I am worried about disclosing my sexual practice to service providers because of the current legal situation	18.6	39.3	18.7	9.7	13.7

## CHILDREN

19.5% of those surveyed had children and 6.5% had dependent children. We were also interested in PLWHAs intentions to have children in the future. Most PLWHA (80.3%) were not considering having children. Of the remainder, 18 PLWHA had decided to have children in the future and four were attempting to have children. Twenty-seven were considering having a child, but have not decided and 20 people had considered having a child, but had decided it is too risky. Two respondents were pregnant. Importantly, 18 respondents said they did not have enough information to make a decision. While a greater proportion of women (heterosexual, bisexual and lesbian) were considering, or had considered having children, some of those doing so were gay, bisexual or heterosexual men.

**TABLE 52 Planning to have children (number)**

	Gay or Bisexual Men	Heterosexual men	Women	Total
No	684	47	30	780
No, I already have children	34	10	33	87
I have decided to have a child/children in the future	7	3	7	18
I am currently trying to conceive/get pregnant	-	1	3	4
I am currently pregnant	-	-	2	2
I have thought about it but I haven't decided	22	1	3	27
I have thought about it but I have decided that it is too risky	14	2	3	20
I don't have enough information to make a decision	18	-	-	18
Other	11	2	1	15

## RECREATIONAL DRUG USE

### Practices

Respondents were asked about their use of a range of non-prescription drugs, both those legally available and those that are currently prohibited in Australia. Respondents were asked which of a list of substances they had used in the last 12 months. For those drugs which are commonly injected, differentiation was made between injection and other means of administration. Table 53 gives these results. As can be seen from these data, alcohol was the most commonly used drug followed by tobacco. Other drugs that are popular in the gay and dance party scenes (amyl, ecstasy, non-injected speed and LSD) were also used by PLWHA.

**TABLE 53 Recreational use of drugs (percentage of sample)**

Alcohol	75.7
Cigarettes	42.3
Marijuana	39.7
Amyl	32.2
Ecstasy	23.2
Viagra or similar	25.0
Crystal Meth	15.4
Speed (not injected)	6.4
Speed (injected)	5.7
Cocaine (not injected)	6.9
GHB/GBH/Fantasy	6.7
LSD/trips	3.0
Steroids (injected)	2.0
Heroin (injected)	1.3
Methadone (prescribed)	1.4
Other	2.2

(Multiple responses possible)

It must be noted that we only asked respondents if they had used each of the drugs in the previous 12 months, not how often they use them. Use of many drugs is occasional rather than regular and this may inflate the rates reported here. Gay male respondents were significantly more likely than other groups to have used alcohol, ecstasy, amyl and crystal-meth and less likely to have used heroin (injected) and prescribed methadone.

6.7% of all PLWHA reported that they have had a bad experience from using both ARV and illegal drugs. Just over one quarter of those who have used both ARV and illegal drugs (29.4%) reported that they had missed a dose of ARV at some point as a result of using illegal drugs.

# HOME, WORK & MONEY

## ACCOMMODATION

We asked a series of questions about participants' accommodation status and experiences. These experiences vary considerably among PLWHA, most particularly as a function of whether individuals are in private or public accommodation.

### Current Accommodation

The current type of accommodation of the respondents can be seen in Table 54. Similar numbers of PLWHA were in accommodation that they own or rent through the private system. A smaller number of people were in public rental accommodation. These were more likely to be on a government benefit.

**TABLE 54 Current accommodation of respondents (percentage of total sample)**

Own or purchasing house or flat	38.1
Private rental accommodation	36.2
Public rental accommodation(government owned)	13.4
Rent-free (e.g. provided by friends, family, etc.)	5.4
Community housing/housing co-operative	3.3
Other	3.6

Households varied considerably. 40.1% of PLWHA lived by themselves, while the remainder lived with between one and seven other adults (median=1) and with between one and three children (for those living with children: mode=1 median=1). Around one third (35.0%) lived with a partner or spouse and 5.0% lived with dependent children. These children ranged in age from less than one to 20 (mean=10.6). In addition, 7.6% lived with other family members and 15.5% with a flatmate.

52.2% of PLWHA also lived with pets. The most common pets were dogs and cats. Other companion animals included fish, birds, rabbits and farm animals.

75.3% of respondents had access to a car. When asked how easy it was to access public transportation, 9.7% said it was very difficult, 12.8% difficult, 36.7% easy and 40.8% very easy.

### Changes in Accommodation

Participants were asked if they had ever changed their accommodation as a result of having HIV/AIDS. 23.0% had and 5.5% had in the last two years. On average, PLWHA had changed their accommodation 2.2 times ever as a result of HIV/AIDS (0.6 times in the last two years).

## EMPLOYMENT

The area of employment continues to present challenges to HIV positive people. While the need for financial security, social contact and a sense of worth are critical factors in HIV positive people's wishes to be in paid employment, the management of HIV disclosure, the intermittent effects of illness and the need for flexibility around taking time off can prove substantial barriers to obtaining and retaining employment. There are also considerable obstacles for those who have left employment in the past and are attempting to return to the workforce. These include de-skilling, explaining an extended absence for the workforce, issues of ageing and changes in life goals.

### Employment Status

Just over half (54.7%) of the respondents were currently employed, with more being in full-time work (37.4%) than those in part-time work (17.3%). The remainder tended to describe themselves as either not working/home duties/retired (22.9%) or unemployed (9.2%). 12.7% said their work was HIV-related.

Of those who were working, the mean number of hours worked was 34.7 (median=38.0). Those working full-time worked an average of 42.6 hours per week (median=40.0) and those in part-time employment worked an average of 20.6 hours/week (median=20.0). Those who were not working stopped work on average eight years ago.

**TABLE 55 Employment status**

Work full-time	37.4
Not working/Retired /Home duties	22.9
Work part-time	17.3
Unemployed	9.2
Student	2.7
Other	10.4

### Impact of HIV on Employment

We asked respondents how their initial HIV diagnosis affected their career plans. These data are shown in Table 56. A large proportion indicated that their career ended at their time of diagnosis (23.0%).

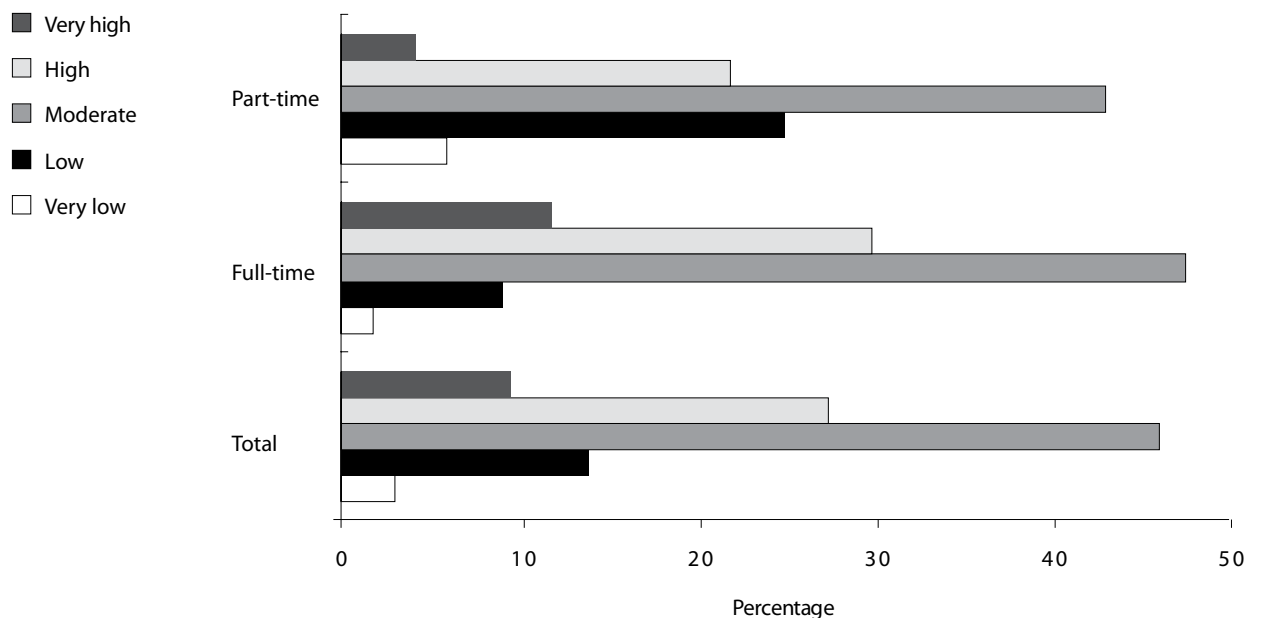
**TABLE 56 Impact of HIV diagnosis on career plans (percentage of sample)**

My career plans did not change	28.9
My career ended/I stopped work	23.0
It was more difficult to plan for the future	24.0
A career was no longer as important	11.0
I changed careers	9.7
I was less likely to change careers	3.3

### Those Currently in Paid Employment

Respondents were asked about the level of stress in their current job. Almost one half rated the stress level as moderate (46.1%) while 27.4% said it was high and 9.5% said it was very high. Only 3.0% rated the stress level as very low and 13.9% said there was low stress (see Figure 8). Those in full-time work were somewhat more likely to report stress.

**Figure 8 Stress at work**



Confidentiality in the workplace remains a critical and complex issue for positive people, particularly given ongoing experiences of discrimination. When asked what difficulties they experience around confidentiality at work, 16.5% said that they did not attempt to keep their status confidential (see Table 57). 63.8% said they have experienced no problem in this area. Of those who did experience difficulties, the greatest problem appeared to be gossip, followed by issues around explaining absences from work and medication. When we examine the difficulties associated with confidentiality in terms of whether the respondent works in an HIV-related job, we find that those in HIV-related employment were less likely to wish to keep their status confidential.

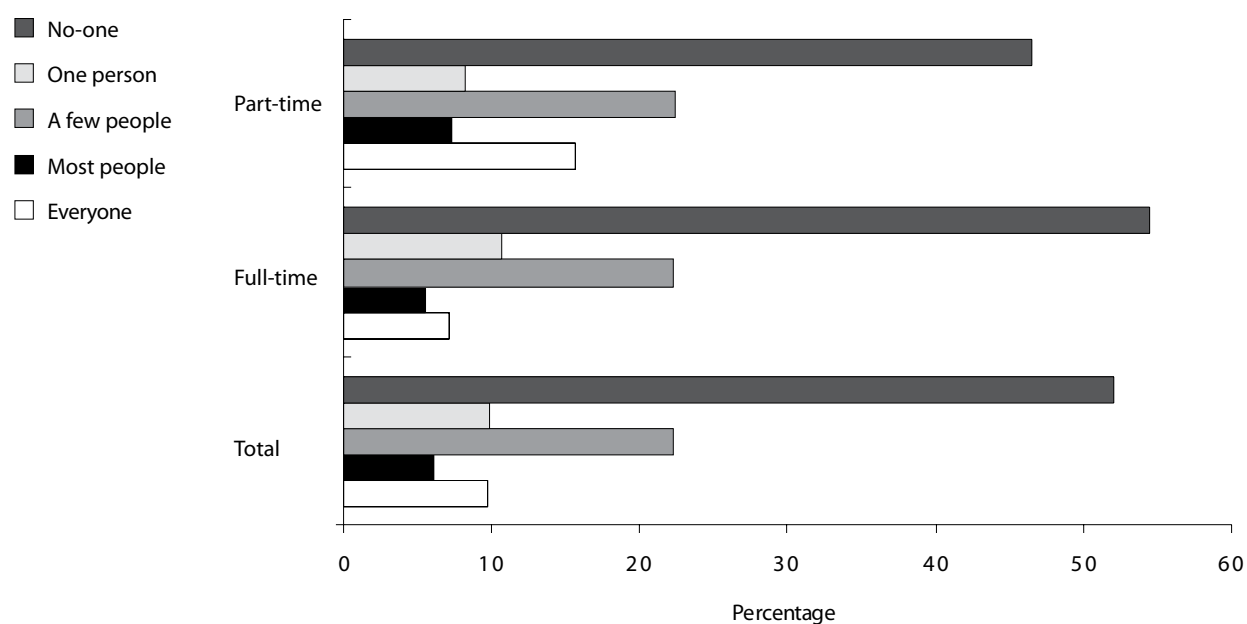
**TABLE 57 Difficulties with HIV status confidentiality in the workplace (percentages of total and specific samples)**

	Total working sample	AIDS related	Non-AIDS related
No problems	63.8	37.7	69.0
I do not try to keep my HIV status confidential	16.5	65.1	10.0
Gossip	9.6	5.2	10.4
Explaining absences from work	11.8	5.5	13.0
Visible signs of illness	7.7	5.6	8.3
Difficulty keeping and taking medication	5.7	6.2	5.8
Other	3.4	2.8	3.5

(Multiple responses possible)

When asked how many people in their workplace knew that they were HIV positive, 9.7% said that everyone knew, 6.0% said most people knew, 22.3% said a few people knew, 9.9% said one person knew and 52.0% said no-one knew (see Figure 9). Those working in a HIV-related job were more likely to say everyone knew their HIV status than those in non HIV-related work (53.3% versus 3.5%) and similarly less likely to say no-one knew their HIV status (4.1% versus 59.2%).

**Figure 9 Disclosure in workplace**



When asked about the impact that HIV had on their capacity to perform their work duties, around half of the sample said that their work was unaffected (see Table 58). Two fifths said that they tired more quickly, and one fifth said that they had difficulty concentrating.

**TABLE 58 Impact of HIV on work capacity (percentage of those in paid employment)**

It is not affected	51.8
I tire more quickly	40.3
I have difficulty concentrating	17.8
I work reduced hours	14.6
I cannot always go to work	13.8
I am less productive	9.8
I do different duties	3.6
Other	2.2

(Multiple responses possible)

Living with HIV often involves intermittent periods of ill health, particularly around treatment changes and the need to access health and other services, often only available during work hours (Prestage et al. 2001). Respondents were asked how much flexibility their workplace gives them to take time off for reasons relating to HIV. Most PLWHA had the capacity to take time off for medical appointments (see Table 59) and illness. There was less capacity to take time off for counselling and few had much capacity to take time off to engage in volunteer work.

**TABLE 59 Capacity within workplace for HIV related interruptions (percentage of those in paid employment)**

	never	seldom	sometimes	often	always
For medical appointments	7.5	2.9	19.7	14.0	56.0
For counselling	22.2	5.9	19.1	8.8	43.9
When you are sick	3.4	2.3	16.0	14.6	63.8
To do volunteer work	45.9	8.5	17.1	5.4	23.1

## FINANCES

The HIV Futures surveys have highlighted the financial difficulties that many PLWHA contend with. These difficulties cannot be explained simply by the proportion of PLWHA relying on government pensions or benefits. There are financial hardships associated with being HIV positive. Some of these are structural and systemic, for example the costs associated with managing the negative consequences of treatment, some result from stigma and disadvantage that result from reduced employment options, while others are the cumulative effects of living for many years with uncertain or fluctuating health and well being.

### Income

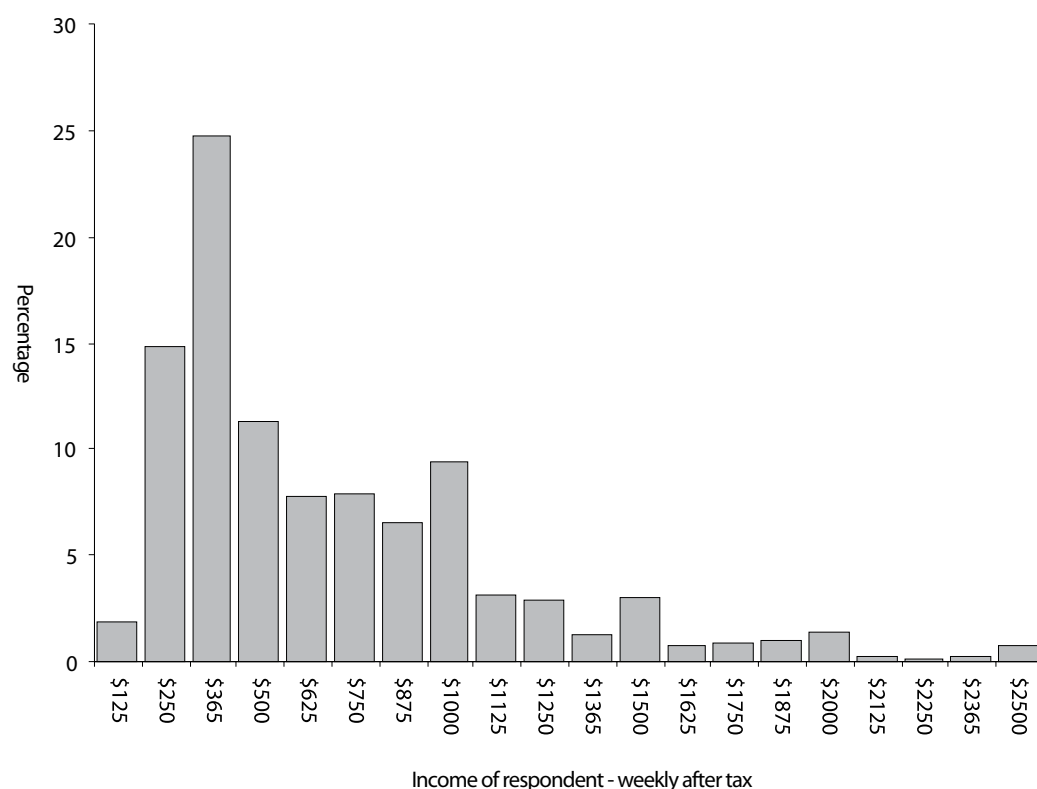
The source of income of the survey respondents is shown in Table 60. For the first time in these surveys, there were more people receiving a salary (48.8%) than on a government benefit (42.0%).

**TABLE 60 Primary source of income (percentage of total sample)**

Salary	48.8
Benefits/pension/social security	42.0
Superannuation/annuity/savings	6.4
Other	1.7
Partner supports me	0.9
Family/friends support me	0.2

The median weekly in-hand income for respondents was \$500. Figure 10 gives the distribution of income in \$125 intervals. The peak of the distribution corresponds to the income that one is likely to receive on a government pension. 23.8% of respondents had a partner with whom they share financial resources. The partner's median weekly income was \$650.

**Figure 10 Histogram of respondents' weekly income after tax**



## Expenditure and Debts

Respondents were asked their weekly expenditure on a range of items. The results are shown in Table 61. The total mean expenditure on medication was \$69 per week. Mean rental or mortgage costs were \$283 with the highest costs being in NSW (mean= \$288) and Western Australia (mean=\$326). Food and utilities accounted for around \$114 and \$72 respectively.

21.6% of respondents owned their own home, while 19.1% were paying off a mortgage on their home. 29.3% received a rental subsidy averaging at \$100 per week (median= \$69).



Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$46,022 with a median of \$6,000. Those who owned their home had a median debt of \$3,987 (mean=\$53,409), those who were currently paying off their home had a median debt of \$11,456 (mean=\$113,935), those in private rental accommodation had a median debt of \$6,000 and those in public rental accommodation had a median debt of \$3,236. 19.2% had used the services of a financial counsellor in the previous two years.

**TABLE 61 Weekly expenditure on medications and essentials (\$AU)**

	Mean	Median
Rent or mortgage repayments	270	175
Food	120	100
Utilities	75	50
Complementary therapies	22	10
Other medication	29	10
Antiretroviral drugs	14	5

## Assessments of Benefits

People receiving a pension may undergo an assessment by a Commonwealth Medical Officer. As there has been considerable community discussion about the impact of these assessments, we asked respondents about their experiences. A total of 34.2% (n=298) of those receiving a benefit in the last two years had received such an assessment. When asked what this experience resulted in, only 2.7% (n=12) said that their benefit was terminated (See Table 62). 16.2% said that the assessment resulted in changes to their conditions of benefit. Importantly the experience of assessment resulted in distress for two fifths of the respondents while it clarified concerns for around one in ten.

**TABLE 62 Consequences of receiving an assessment of benefit from a Commonwealth Medical Officer (percentage of those assessed in last two years)**

Require documentation from your doctor	43.0
Cause you distress	39.3
Result in changes to the conditions of your benefits	16.2
Result in an independent assessment	9.3
Clarify concerns that you had	12.2
Result in a shift from Pension to Newstart allowance	3.9
Result in termination of your benefits	2.7

(Multiple responses possible)

## POVERTY

As with the previous HIV Futures surveys, we have used the quarterly Henderson Poverty Lines published by the Melbourne Institute of Applied Economics and Social Research to assess the extent of poverty among PLWHA. The Henderson Poverty lines are set for specific income units. These units include the individual, any partner with whom they share financial resources and any dependent children. We used the Institute's data for the March quarter (Melbourne Institute of Applied Economic and Social Research, 2009), the time at which the survey was completed.

According to this measure over one quarter (31.0%) of PLWHA were living below the poverty line. That this figure has remained so high across the ten years of the HIV Futures surveys suggests that current resources and strategies are inadequate and decisive action must be taken to address this pocket of severe social disadvantage.

## Correlates of Poverty

We look now at the differences between different groups in their likelihood to be living in poverty. Those in paid employment were significantly less likely to be classified as below the poverty line. Half of those not in paid employment were living in poverty (see Table 63).

**TABLE 63 Poverty by employment status (percentage of employment categories)**

	Below poverty line	Above poverty line
Employed	10.4	89.6
Not employed	55.9	44.1

$\chi^2 (1,1) = 202.375, p < 0.001$

Respondents who identified a salary as their primary source of income were significantly less likely to report an income below the poverty line. Over half of those on a government benefit were living in poverty (see Table 64). There was no gender difference in the proportions of people living below the poverty line.

**TABLE 64 Poverty by income source**

	Below poverty line	Above poverty line
Benefits/pension/social security	64.7	35.3
Partner/family/friends/other	30.8	69.2
Super/annuity/savings	19.6	80.4
Salary	6.9	93.1

$\chi^2 (3,1) = 293.144, p < 0.001$

Those who shared financial resources with a partner were significantly less likely to be below the poverty line than those who did not (see Table 65).

**TABLE 65 Poverty by shared income status**

	Below poverty line	Above poverty line
Sole income	38.4	61.6
Dual income	11.9	88.1

$\chi^2 (1,1) = 56.122, p < 0.001$

There is also a clear relationship between poverty and self-rated health and well being (see Table 66 and Table 67). Those living below the poverty line were significantly more likely to rate these characteristics as poor or fair. This pattern most likely represents an interaction between poverty and these factors, rather than a directional relationship. Worse health and well being limit access to employment and financial security, while poverty creates emotional distress, limits social interaction and damages health.

**TABLE 66 Self-rated health of those above and below the poverty line (percent within poverty group)**

	Below poverty line	Above poverty line
Poor	10.4	3.6
Fair	31.7	17.1
Good	42.9	49.3
Excellent	15.1	29.9

$\chi^2 (3,1) = 49.045, p < 0.001$

**TABLE 67 Self-rated well being of those above and below the poverty line (percent within poverty group)**

	Below poverty line	Above poverty line
Poor	15.1	6.4
Fair	34.4	21.9
Good	39.0	46.1
Excellent	11.6	25.6

$\chi^2 (3,1) = 44.074, p < 0.001$

## Costs

As with previous surveys, we asked respondents about the difficulty they had paying for a range of activities, goods and services. The results are shown in Table 68, with the not applicable responses excluded from the calculation for each item. The items that most respondents rated as very difficult to pay for were quality of life costs like travel, going out, recreational drugs and entertainment. Those items most likely to be rated as not at all difficult were support services, medical services and medication. Importantly substantial proportions rated food, clothing, utilities and rent as very difficult. The experience of difficulty in meeting the costs of these items was rarely restricted to one area. That is, when individuals had difficulty paying for food, they also experienced difficulties with rent, utilities and quality of life items.

**TABLE 68 Difficulty paying costs of items and services**

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=690) <sup>6</sup>	59.5	30.6	9.9
Other prescribed medication (n=809)	51.9	37.5	10.6
Medical services (doctor, dentist, etc.) (n=865)	52.4	27.9	19.7
Complementary therapies (n=544)	48.6	31.0	20.3
Support services (counselling, etc.) (n=390)	63.4	21.2	15.3
Entertainment (theatre, movies, concerts, etc.) (n=840)	37.0	28.8	34.2
Going out (eating/drinking) (n=879)	34.6	28.8	36.6
Sport (exercise, gym, etc.) (n=649)	42.8	28.1	29.2
Recreational drugs (n=369)	37.4	27.4	34.9
Travel/holidays (n=789)	26.8	23.9	49.3
Rent/mortgage/housing costs (n=812)	39.5	35.1	25.3
Utilities (telephone/electricity/gas/water) (n=923)	38.0	36.5	25.6
Food (n=953)	45.6	36.3	18.0
Clothing (n=923)	36.6	33.8	29.6
Transport (n=900)	47.3	33.7	19.0
Child care (n=73)	58.1	27.4	14.4

When we examine the ratings of these items for those above and below the poverty line, those living in poverty were more likely to rate all items as very difficult (see Table 69). Disturbingly, among those living below the poverty line, one quarter rated paying for medical services as very difficult, while the proportions that gave this response for co-payments for medication and costs of other prescribed medication are also very concerning. When it comes to the basics of life, substantial numbers of those below the poverty line also rated these as very difficult.

6 Ns refer to the number of participants that identified this as an applicable cost. That is, those selecting "not applicable" or giving no response are excluded from the percentages reported in that row.

**TABLE 69 Difficulty paying costs of items and services by poverty status**

	Below poverty line			Above poverty line		
	Not at all difficult	A little difficult	Very difficult	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=205, 388) <sup>7</sup>	46.9	37.3	15.8	66.6	27.0	6.4
Other prescribed medication (n=223, 469)	31.4	49.5	19.1	62.3	31.6	6.1
Medical services (doctor, dentist, etc.) (n=222, 522)	41.6	27.1	31.3	56.9	29.6	13.6
Complementary Therapies (n=146, 327)	30.0	35.4	34.6	56.9	30.1	13.0
Support services (counselling, etc.) (n=117, 217)	54.3	24.7	21.0	68.8	21.2	10.0
Entertainment (theatre, movies, concerts, etc.) (n=204, 525)	13.7	22.3	64.0	47.5	31.7	20.9
Going out (eating/drinking) (n=219, 536)	12.4	21.4	66.2	44.5	31.4	24.0
Sport (exercise, gym, etc.) (n=163, 398)	22.7	26.8	50.5	52.6	27.8	19.6
Recreational drugs (n=85, 230)	16.4	19.9	63.7	46.3	31.2	22.1
Travel/holidays (n=188, 498)	11.7	13.1	75.2	32.2	28.2	39.6
Rent/Mortgage/Housing costs (n=199, 501)	26.3	30.9	42.8	44.4	37.4	18.0
Utilities (telephone/electricity/gas/water) (n=240, 548)	16.2	36.3	47.4	47.2	37.0	15.8
Food (n=207, 561)	20.3	53.6	26.1	56.4	33.1	10.5
Clothing (n=249, 549)	21.8	44.3	33.9	45.5	34.9	19.7
Transport (n=230, 535)	23.3	42.7	34.0	58.8	28.8	12.5
Child care (n=27, 36)	39.9	41.8	18.4	75.2	19.6	5.2

<sup>7</sup> Ns refer to the number of participants below and above the poverty line respectively that identified this as an applicable cost. That is, those selecting "not applicable" or giving no response are excluded from the percentages reported in that row.

## Poverty and Services

When we examine the use of services at AIDS organisations in the last six months by those above and below the poverty line (see page 28 for the discussion of these services), we see that for all services a significantly greater proportion of those below the poverty line use these than those above (see Table 70). When we examine use of services at other organisations, there are far fewer differences. Notable are the greater proportions of those below the poverty line using housing assistance, mental health services and employment services.

**TABLE 70 Services used at HIV/AIDS organisations by those above and below the poverty line**

	Below poverty line	Above poverty line	Significance <sup>8</sup>
Social contact with other PLWHA	35.0	28.6	*
Treatments advice	40.1	33.7	*
Financial assistance	39.5	9.8	**
Treatments information	31.6	27.4	ns
Peer support group	32.1	18.9	**
Counselling	30.4	20.9	*
Informal peer support	21.5	17.1	ns
Complementary therapies	21.5	11.0	**
Pharmacy services	20.0	17.4	ns
Housing assistance	19.1	5.9	**
Financial advice	21.7	6.7	**
Legal advice	15.2	9.4	*
Community education campaigns	15.2	11.6	ns
Transport	8.5	2.3	**
Internet access	11.0	7.5	ns
Volunteer carer	6.4	2.3	*
Mental health services	14.5	6.8	**
Internet based information	14.6	15.0	ns
Respite care	6.4	2.7	*
Library	3.5	2.8	ns
Return to work skills	5.3	1.6	*
Employment services	7.4	1.6	**
Drug/alcohol treatment	4.9	2.4	*
Paid carer	2.5	1.4	ns

(Multiple responses possible)

8 \*\* significant for  $\chi^2_{(1,1)}$  at  $p < 0.001$ , \* significant for  $\chi^2_{(1,1)}$  at  $p < 0.05$ , ns not significant

**TABLE 71 Services used at other organisations by those above and below the poverty line**

	Below poverty line	Above poverty line	Significance <sup>9</sup>
Pharmacy services	30.8	29.3	ns
Housing assistance	18.4	7.5	**
Library	17.8	14.1	ns
Counselling	15.8	16.3	ns
Complementary therapies	16.8	17.1	ns
Mental health services	21.3	11.7	**
Internet access	18.7	18.8	ns
Employment services	15.6	8.2	**
Transport	14.1	10.2	ns
Treatments advice	17.7	16.2	ns
Return to work skills	12.6	6.4	*
Legal advice	8.4	10.4	ns
Financial advice	9.7	14.4	ns
Internet based information	12.5	15.2	ns
Financial assistance	9.6	8.3	ns
Drug/alcohol treatment	9.7	6.7	ns
Treatments information	11.6	9.0	ns
Community education campaigns	6.4	5.5	ns
Volunteer carer	3.6	2.7	ns
Social contact with other PLWHA	7.0	5.1	ns
Informal peer support	8.0	7.5	ns
Respite care	4.9	4.0	ns
Paid carer	5.3	3.7	ns
Peer support group	5.8	4.7	ns

(Multiple responses possible)

## DISCRIMINATION

Discrimination on the basis of HIV is unlawful in all jurisdictions in Australia. The introduction of anti-discrimination legislation has offered an avenue of redress for those with the energy and courage to pursue it, acts as a deterrent for employers, service providers and the like, and sends a clear message that such discrimination is unacceptable to the Australian population. However, PLWHA continue to experience less favourable treatment in many domains of their lives. While more detailed research is needed to adequately assess the specific impact of this treatment, we can reasonably imagine that the impact goes beyond the direct outcomes of the actions and is detrimental to both health and quality of life. In addition, the anticipation of discrimination may limit people's life choices in subtle but sustained ways. We have asked about the experience of discrimination in a range of settings.

### Accommodation

7.9% of respondents indicated that they had experienced less favourable treatment in relation to accommodation (2.6% in the last two years).

### Health Services

26.4% of respondents had experienced less favourable treatment at a medical service as a result of having HIV. This comprised 9.9% of all respondents that had experienced such discrimination in the last two years and 16.5% that experienced this more than two years ago. When asked what form this discrimination took, the most common responses were avoidance (40.1%), confidentiality problems (36.9%) and increased infection control (32.6%). These experiences are shown in Table 72.

9 \*\* significant for  $\chi^2_{(1,1)}$  at  $p < 0.001$ , \* significant for  $\chi^2_{(1,1)}$  at  $p < 0.05$ , ns not significant

**TABLE 72 Form of HIV-related discrimination experienced at medical service (percentage of those experiencing discrimination)**

	Ever (N=261)	In last 2 years (N=98)
Avoidance	40.1	40.5
Confidentiality problems	36.9	38.3
Increased infection control	32.6	24.7
Refusal of treatment	29.8	31.4
Treated last	28.5	19.3
Rushed through	19.9	31.4
Harassment	7.6	8.0
Abuse	7.4	11.3

(Multiple responses possible)

## Insurance

35.7% of respondents currently had private health insurance and 14.7% currently had some other form of income or mortgage insurance.

17.3% of respondents indicated that they had experienced less favourable treatment in relation to insurance. The most commonly reported example of less favourable treatment was being unable to take out an insurance policy, for example health insurance and travel insurance.

## Workplace

16.3% of respondents had experienced less favourable treatment in the workplace as a result of having HIV. This comprised 5.1% of all respondents that had experienced such discrimination in the last two years and 11.2% that experienced this more than two years ago. When asked what form this discrimination took the comments ranged from unfair dismissal to reduced advancement opportunities or bullying.





# CONCLUDING COMMENTS

The findings presented in this report give an overview of the lives and experiences of over one thousand Australians living with HIV. In conjunction with the previous five reports, the changes and intransigencies in the well being of the positive population can be examined, understood and acted upon. We can see the ways in which the experience of antiretroviral treatments have improved, the extent to which employment prospects have improved, as well as the continuing economic marginalisation of a significant proportion of the population and continuing concerns around stigma and discrimination. These data are powerful. They are provided by the participants in this study in the expectation that they will be used to improve the status of the positive population. It remains the responsibility of all of us in the HIV and related sectors to find ways to address the inequities represented here, to continue strengthening the responses that are proving beneficial and to remain vigilant in the areas where we have had some success.

# APPENDIX

## METHODS AND INSTRUMENT

This section describes the research design, method of recruitment, development of the survey instrument, sampling issues and data analysis.

### The Survey Instrument

HIV Futures is an anonymous, cross-sectional survey of a sample of people living with HIV/AIDS in Australia. The HIV Futures 6 survey ran from October 2008 through April 2009. The survey was available as both a self complete mail back survey and on-line. This is the second time that HIV Futures has been made available on-line, reflecting the growing use of the internet amongst Australian households. On-line surveys have been used successfully to collect health information from GLBTI Australians and same sex attracted young people in Australia (Hillier et al., 2005, Pitts et al., 2006). We hoped that by offering HIV Futures online we would provide an easier way for the usual demographic of respondents to complete the survey and also allow us to access harder to reach PLWHA, such as those living in rural or regional areas, or those not in contact with HIV/AIDS services. The on-line survey was accessed through the website [www.hivfutures.org.au](http://www.hivfutures.org.au). The site was hosted by [Demographix.co.uk](http://Demographix.co.uk), an experienced commercial provider of web-based surveys with excellent attention to the issues of security and privacy.

### Design

The instrument was based in large part on the HIV Futures 5 survey (Grierson et al., 2006), which in turn was adapted from the four previous surveys (Ezzy et al., 1998, Grierson et al., 2000, Grierson et al., 2002, Grierson et al., 2004a). The survey content was developed in consultation with a number of organisations and individuals from the HIV/AIDS sector (see Consultations section). Most items were retained in their original format to allow comparisons between the six studies.

New questions and options were added to reflect changes in the context in which people live with HIV/AIDS in Australia, including policy and service changes over the past three years. Questions were also edited, and some removed, to make the survey easier to fill in.

The survey consisted of 189 items organised into eight sections: demographics; accommodation; health and treatments; services and communities; sex and relationships; employment; recreational drug use; and finances. Each section included an explanation of the purpose of the items. Most items in the survey were closed-coded with either single or multiple response options. 'Other' categories were included for most items to ensure that significant experiences of living with HIV were not excluded. There was a number of attitude/ belief items scored using a four- and five-point Likert scales. There were also write-in and open-ended items. The online survey used identical wording to the paper survey and contained exactly the same items, however, the online survey provided users with

pull-down menus for some items, such as numbers, years and months. These were included in order to ensure relatively clean data. The online survey also had a number of skips built into it so that respondents did not have to see items that were not relevant to them, for example, respondents who were not taking antiretroviral treatments did not have to see the questions about these treatments.

Completed paper surveys were returned in a reply-paid envelope to the Living with HIV program. Respondents were also able to add their contact details to the program mailing list to receive reports and to participate in further research by completing an additional form and sending it in a separate envelope. On-line surveys could be saved and re-opened by respondents so that they could be completed in their own time. Completed surveys were submitted online and stored by demographix.co.uk. Respondents completing the survey online were also able to provide researchers with their contact details by filling in and submitting a separate form, which was stored in a database separate from the survey data.

## RECRUITMENT AND SAMPLING

There is no register of HIV positive Australians, as HIV testing is voluntary and anonymous. The survey was anonymous and multiple recruitment strategies were employed so a simple response rate cannot be calculated. Recruitment took place using a set of methods in order to reach a diverse population of HIV positive Australians. This approach meant that some participants received multiple copies of the survey from different sources. Recruitment was also combined with a promotion strategy that increased community awareness of the research and its utility. The inside front cover of the paper survey also contained the link to the online survey so that each participant receiving a paper copy was also informed about the availability of the on-line survey.

### 1. Direct distribution

One copy of the survey was mailed directly to individuals who participated in HIV Futures 5 and expressed interest in participating in future research conducted by the Living with HIV program at ARCSHS. Potential participants were able to request a copy of the survey by telephoning the free call number or emailing the researchers.

### 2. Promotion and Marketing

#### Paid Advertising

The survey was advertised in a number of gay newspapers with distribution around the country. Banner ads with a direct link to the on-line survey were placed on [www.gaydar.com.au](http://www.gaydar.com.au).

#### Advertising through Community Organisations

The survey was promoted extensively through community organisations. Advertisements, articles and news items were placed in community newsletters, banner ads were placed on community websites and promotional postcards and reception cards were placed at reception desks.

### 3. Community sites

In addition to advertising the survey, community organisations were involved in promoting the study by mailing the survey to members accompanied by a covering letter from the organisation explaining the purpose of the study, explaining the value of the research and encouraging participation. The survey forms were made available on-site at numerous community organisations around the country. These organisations also distributed copies of the survey to sites and venues they felt were appropriate and with whom they have ongoing relationships. Staff at some organisations also assisted people to complete surveys. The survey was also promoted at staff and volunteer meetings.

### 4. Clinical sites

#### a. General Practitioners

Copies of the survey, postcards and reception cards were mailed directly to clinical practices that see a significant number of HIV positive clients. This included, but was not limited to, the S100 prescribers. The survey and the web link was also promoted by ASHM (Australasian Society for HIV Medicine) to its members and email lists.

#### b. Hospital Settings

Where ethical approval was obtained, the survey was available in the waiting areas of a number of HIV and Infectious Disease clinics or distributed directly to clients by staff. Surveys were also available through social workers in some hospitals.

### c. Other Clinical Sites

Surveys were also distributed through sexual health centres and community health centres including those with a specific HIV focus. Generally these were available in waiting rooms, although some distributed them directly to clients.

Table 73 gives the sources identified by respondents as the primary site that they obtained the survey, or information about the survey. The on-line sample is shown separately from the paper sample. It should be noted that many participants would have obtained copies of the survey and information about the research from multiple sources.

**TABLE 73 Data on main four primary sites of survey collection**

	Paper	On-line	Combined
Completed a previous HIV Futures Survey	40.3	14.1	32.1
Mail-out from HIV/AIDS organisation	30.5	16.0	26.0
Picked up a copy at HIV/AIDS organisation	8.3	1.2	6.1
Picked up a copy at Medical Centre or Hospital	11.2	2.5	8.5

## JUSTIFICATION OF STUDY METHODOLOGY

HIV Futures is a cross-sectional study of a sample of HIV positive Australian residents. A cross-sectional study is one in which a new sample is collected on each occasion. While a proportion of the sample may have completed the previous surveys, the responses for each survey are not formally linked, so that direct comparison between individuals' responses over time is not possible. The cross-sectional methodology was chosen for the following reasons.

The HIV Futures surveys are anonymous. HIV/AIDS remains a sensitive issue for many PLWHA in Australia. Our previous research, and that of our colleagues, tell us that PLWHA still experience stigma and discrimination. Allowing the survey to be completed anonymously helps to allay PLWHA's concerns that information about their HIV status and the other issues addressed in the survey may be compromised.

Second, the survey is national. It would not be possible to achieve this with a cohort design, since the relative ratios of states and territories require adjustment for each survey. The distribution of the survey also relies on diffusion through community groups in a manner that maintains the anonymity of respondents, particularly those in regional areas.

Third, the survey is self-complete. This means that PLWHA can complete the survey in a setting that is comfortable and safe for them and in their own time. Feedback from participants during this study indicated that some people completed the survey over a number of days or weeks, and that individuals consulted their medical practitioners and other records to verify some of the details included in the survey.

Fourth, the population of HIV positive Australians is constantly evolving. A cross-sectional survey allows us to include newly HIV positive individuals as well as those who have been positive for some time. These groups may have an overall similar experience of living with HIV, but the differences between them can be profound.

There are also certain limitations associated with the recruitment method used.

Caution must therefore be exercised in the application of the findings of this research to individuals who are less likely to be included in the sample, such as people with limited literacy, people of non-English speaking background, and those who are particularly geographically or socially isolated. We have taken a range of measures to address these issues. For example, participants were offered the option of completing the survey over the telephone either directly with the researchers using a free call number, or with service providers. In addition, the Telephone Interpreter Service (TIS) was promoted as a way of completing the survey for non-English speakers, either by telephone or in person. Surveys were also completed with the assistance of service providers or community agency workers for those with literacy problems or those with physical impairment. The combination of clinical and community setting for study recruitment was intended to optimise access to the study. This means that people are not disadvantaged from entering the study if they are not currently using antiretroviral therapies or not currently in contact with one of the main HIV treatment providers.

Nevertheless it must be acknowledged that this methodology will never be appropriate for some members of the PLWHA community. This is particularly so for those from culturally and linguistically diverse backgrounds who may be marginalised even within their own communities and those for whom invisibility is the key to their continuing safety. Community development methodologies are currently being explored in order to establish how the very real

needs of these people can be understood and documented over time within an action research framework which offers support and strengthens networks as the research proceeds.

It cannot be stressed strongly enough that no piece of research should be used in isolation. Each study gives a different perspective on the HIV epidemic, and collectively they lead to a greater understanding of the dynamics of the epidemic and the issues affecting Australian PLWHA.

## CONSULTATIONS

Consultation around the HIV Futures Study was undertaken in three ways:

**1:** A Living with HIV Community Reference Group consisting of members of state and national PLWHA groups, AIDS councils, and representatives of professional organisations provides advice and support for the suite of research projects conducted by the Living with HIV Program at ARCSHS. This reference group provided advice on survey content, recruitment and interpretation of data.

**2:** Consultations were conducted with State and national bodies in person and by mail prior to the finalisation of the research instrument. This included feedback on the survey content and on recruitment strategies.

**3:** Consultation was also undertaken with key individuals around the country including clinicians, treatments officers, mental health workers and service providers. Particular consultation was undertaken with hepatitis C organisations and clinicians to ensure that the expanded hepatitis C section of the survey was appropriate and useful.

## WEIGHTING

In order to ensure that the results reported in this document accurately represent the Australian population of PLWHA, comparisons were made to the Australian HIV Surveillance Report (National Centre in HIV Epidemiology and Clinical Research, 2008) and the data were weighted to conform to the demographic profile of the Surveillance Report. A weighting algorithm based on mode of infection, gender, state of residence and diagnosis of AIDS defining illness has been applied to all the analyses in this report. Consequently, findings are presented in terms of sample percentages rather than frequencies. Sample sizes (Ns) are given when the table represents a subset of the total sample. These Ns are weighted.

## ANALYSIS

Statistical comparisons including ANOVA and chi-square have been employed in the analysis of the data, although for clarity the details of these are not always included in this report. All significant differences reported have a probability of at most  $\alpha=0.01$ .

## FURTHER ANALYSIS AND REPORTS

As with the previous HIV Futures surveys, a number of reports and specific issues papers analysing specific populations and specific issues will be produced over the next two years. The Living with HIV reference group will play a key role in determining the focus of these publications.

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