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# HIV futures five

Life as we know it

Jeffrey Grierson,  
Rachel Thorpe and  
Marian Pitts

The Living with HIV Program at  
The Australian Research Centre  
in Sex, Health and Society  
La Trobe University

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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/hiv-futures](http://www.latrobe.edu.au/hiv-futures) 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>AIHW</b>	Australian Institute of Health and Welfare
<b>AIVL</b>	Australian Injecting and Illicit Drug Users League
<b>ANCHARD</b>	Australian National Council on HIV/AIDS, Hepatitis C and Related Diseases
<b>ARCSHS</b>	Australian Research Centre in Sex, Health and Society
<b>ARV</b>	Antiretroviral therapy
<b>CAM</b>	Complementary and alternative medicine
<b>CTTAC</b>	Clinical Trials and Treatments Advisory Committee
<b>HIV</b>	Human Immunodeficiency Virus
<b>IAESR</b>	Institute of Applied Economics and Social Research
<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>pH</b>	Positive Health Study
<b>PLWHA</b>	People living with HIV/AIDS

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# EXECUTIVE SUMMARY

## DEMOGRAPHICS

The HIV Futures 5 survey was completed by 982 HIV positive Australians from all states and territories. This represents approximately 6.4% of the estimated HIV positive population.

91.0% were male (876), 8.7% were female (84), 0.2% were transgender (2) and one was intersex.

80.6% were gay men, 8.1% heterosexual women, 5.3% heterosexual men, 3.7% bisexual men, 0.3% lesbian and 0.3% bisexual women and the remaining 0.3% fell into other categories.

The respondents' ages ranged from 19 to 78 years with a mean of 45.8 years and a median of 45.0 years.

The majority of participants were Australian born (76.6%)

Eighteen respondents (1.9%) indicated they were of Aboriginal/Torres Strait Island origin.

## HEALTH

### HIV Antibody Testing

- 24.0% tested for HIV because they became ill
- 15.8% tested as part of routine health screening
- 13.2% tested because of a particular risk episode
- 11.0% tested because they were a member of a risk group
- 2.0% were tested without their knowledge

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

- 28.5% had received pre-test counselling/ engaged in pre test discussion
- 36.4% of those testing positive in the last two years received pre-test counselling/ engaged in pre test discussion
- 58.9% received post-test counselling
- 73.7% of those testing positive in the last two years received pre-test counselling

Pre and post test counselling was most often provided by medical personnel and respondents were generally satisfied with the information and support received from this person.

## Current Health Status

68.1% rated their health as good or excellent and 60.1% rated their general well being as good or excellent.

Almost all PLWHA had taken a CD4/T-cell test and a viral load test. 21.9% of respondents had been diagnosed with an AIDS defining illness, 14.3% in the last two years.

## HIV-related and other health conditions

29.3% of respondents indicated that they had experienced HIV-related illnesses. 44.6% indicated that they had a major health condition other than HIV/AIDS. The most common conditions reported were hepatitis C, cardiovascular disease and asthma.

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

- 81.8% reported low energy or fatigue
- 65.8% experienced a sleep disorder
- 48.0% experienced confusion or memory loss
- 43.7% experienced weight loss
- 36.8% reported experiencing Lipodystrophy

## Mental Health

In the last six months 28.5% of respondents had taken prescribed medication for depression and 25.7% for anxiety. 43.0% had ever had a diagnosis of a mental health condition.

39.0% of all respondents had ever been diagnosed with depression, 6.3% in the last two years.

## Hepatitides

- 27.6% had at some point had hepatitis A
- 55.5% had been vaccinated against hepatitis A
- 24.6% had at some point been diagnosed with hepatitis B, of whom:
  - 71.1% had cleared the infection
  - 19.1% had ongoing infection and
  - 5.0% had a chronic infection
- 66.8% had been vaccinated against hepatitis B
- 15.2% of respondents said they had tested positive for hepatitis C
- 27 of those with hepatitis C had ever had medical treatment for this

## Prophylaxis

20.0% were currently taking prophylaxis for opportunistic infections.

# TREATMENTS

## Antiretroviral Therapy

### Antiretroviral use:

- 75.5% were currently using ARV, most commonly one NNRTI and two NRTIs
- 85.2% had used ARV at some time
- 73.5% commenced ARV on the advice of their doctor
- 47.5% of respondents were using a combination of three drugs

## Difficulties of Taking ARV

- 52.5% of those participants currently taking ARV reported that they experienced difficulties taking them of which the major problems were:
  - 29.7% side effects
  - 27.8% remembering to take the drugs on time
  - 21.9% transporting medication
  - 20.0% taking medication in public
  - 16.6% organising meals around the drugs
  - 12.1% taking large numbers of tablets

Side effects from ARV are still a significant concern for those on treatment with 29.7% reporting that they experienced these. The most common were diarrhoea (23.6%), nausea (21.9%), and fatigue (12.3%).

## Attitudes to Antiretroviral Therapy

### Does ARV mean better prospects for PLWHA?

- 80.7% of respondents agreed that combination antiretroviral drugs mean better prospects for PLWHA
- 11.1% believed that it is still too soon to tell
- 37.8 agreed that combination antiretroviral drugs are harmful
- 21.5% agreed that the side effects outweigh the benefits of antiretroviral drugs

## Treatment Breaks

- 40.9% of those currently on ARV had taken a break from ARV
- The median length of break was six months
- Most breaks were taken for a combination of lifestyle and clinical reasons
- Doctors were less likely to be consulted before a break than during or afterward
- 59.3% saw their doctor before, during and after the treatment break

## Antiretroviral Resistance

- 35.3% of those that had ever used ARV had taken a resistance test
- 65.2% of those tested found resistance to one or more drugs
- 56.6% of those with resistance changed treatments

## Dosing and Adherence

- 55.1% of the sample were taking ARV twice daily
- 4.4% were taking ARV three times a day
- 26.7% were taking ARV once a day
- 55.7% had not missed a dose of ARV in the two days prior to completing the survey.

## Clinical Trials

- 33.1% had participated in a clinical trial for HIV related treatment
- 17.1% had participated in a clinical trial in the last two years

## Complementary Therapies

- 59.1% used vitamin and mineral supplements, most commonly a multivitamin
- 18.5% used herbal therapies
- 20.5% used marijuana for medicinal purposes
- Complementary therapies tended to be used in conjunction with allopathic treatment

## SERVICES

### Health Services

- For HIV specific treatment 43.2% saw an HIV GP/S100 prescriber and 32.4% saw an HIV specialist/physician
- For general health care treatment 46.7% of PLWHA saw an HIV GP/S100 prescriber and 25.1% saw a non-HIV GP
- For 37.7% 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:

- 46.7% treatment advice
- 40.4% social contact
- 35.1% counselling
- 32.2% peer support
- 24.4% complementary therapies
- 14.5% advice on legal matters

### Information

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

- 60.2% said HIV GPs/S100 prescribers
- 56.8% HIV specialists
- 45.4% HIV magazines and newspapers
- 41.3% HIV/AIDS organisation publications
- 34.9% HIV positive friends
- 31.1% articles in the gay press

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

- 49.1% said HIV magazine/ newspaper
- 47.3% HIV positive friends
- 44.7% publications from HIV/AIDS groups
- 32.3% HIV GP
- 27.9% 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

66% had some contact with HIV/AIDS organisations, mostly receiving newsletters or being clients of these organisations. 8.1% were employees of HIV/AIDS organisations.

## THE SOCIAL WORLD OF PLWHA

### Contact with Other PLWHA

- 92.3% knew another PLWHA
- 17.4% had a spouse/partner with HIV
- 54.6% had acquaintances with HIV
- 75.0% spent at least some time with other PLWHA
- 16.4% spent a lot of time with other PLWHA

- 24.0% spent no time with other PLWHA
- 17.9% had been involved with the care of someone with HIV/AIDS
- 72.5% said someone close had died of AIDS related causes

For 48.9% of respondents HIV was an important part of their identity, while for 17.0% 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.

For 51.8% of respondents, their HIV status had been disclosed to another person when they did not want it to be (24.9% in the last two years).

## Social Support

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

- 76.9% partners/spouse
- 60.1% pets
- 49.6% doctors
- 47.0% close friends

## Planning for the Future

18.9% planned only one day at a time, while 54.2% planned at least one year ahead.

## Relationships and Sex

Over one quarter (30.3%) of PLWHA were not having sex at present.

45.8% of PLWHA were in a regular relationship, and a slightly smaller number had sex within the relationship (40.8%). Just under half of this group also had sex with casual partners (17.3%). 29% of respondents had casual partners only.

Of those in a regular relationship 42.6% had a partner who is also HIV positive, 54.6% had an HIV negative regular partner and 2.8% a partner of unknown status. Nearly all (99.9%) PLWHA had disclosed their status to their regular partner, usually when they were diagnosed, at the time of, or prior to the commencement of the relationship.

44.3% 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.

53.7% of the sample had sex with casual partners in the past six months. 34.6% 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 over half the sample. Vaginal or anal intercourse took place in 79.0% of these instances.

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

- 17.7% of those who had sex with an HIV+ partner
- 72.6% of those who did not know their partner's HIV status
- 87.5% of those who had sex with an HIV negative partner

There were only 26 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 1 instance with an HIV negative casual partner.

There were only 14 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 5 instances with an HIV negative casual partner.

48.8% of PLWHA would prefer to be in a relationship with someone who is also HIV positive. 61.8% of PLWHA expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLWHA (65.8%) felt HIV had a negative effect on their sexual pleasure.

Only 13.9% 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 new treatments make safe sex less important than it was (10.2%) or that undetectable viral load means HIV is unlikely to be transmitted (13.7%). However, 29.3% of PLWHA agreed with the statement *If there was a vaccine which prevents HIV I would not practice safe sex.*

## Recreational Drug Use

Alcohol was the drug most commonly used by PLWHA (77.0%), and 47.6% had used tobacco in the previous 12 months. Over two thirds of respondents reported that they had never injected illegal drugs and of those respondents who had injected illegal drugs less than one half had done so in the last 12 months. Of PLWHA who reported injecting drugs, 94.4% had not shared injecting equipment in the past twelve months.

### Circumstances of sharing injecting equipment:

- 9 used the equipment last
- 8 did not have access to other needles
- 7 washed or bleached the needle
- 6 shared with a sexual partner
- 6 shared with another HIV positive person
- 3 shared with an hepatitis C positive person
- 2 shared in a group

Of the 17 who shared injecting equipment in the last 12 months 15 did so with at least one risk reduction strategy like using the needle last or washing/bleaching or using with another person who was HIV positive.

Approximately one quarter of respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and 9.1% reported having had a bad experience as a result of using both illegal drugs and ARV.

## HOME, WORK & MONEY

### Accommodation

- 38.2% were in private rental accommodation 35.2% owned or were purchasing house or flat
- 15.6% were in public rental accommodation (government owned)
- 4.8% lived rent-free (e.g. provided by friends, family, etc.)
- 2.6% were in community housing/housing co-operative

84.2% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable, the main reasons given were that it was too expensive, too small or lacked privacy.

- 43.2% of PLWHA lived by themselves
- 48.4% of PLWHA lived with pets
- 72.4% of respondents had access to a car

31.6% had ever changed their accommodation as a result of having HIV/AIDS and 10.4% had in the last two years.

### Employment

Just over half of respondents were currently in paid employment (51.2%), the majority of these being in full-time work (34.1% 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.

### Impact of antiretroviral therapy on employment:

- 14.4% stopped work
- 12.3% anticipated a longer time in the workforce
- 5.2% went back to work

51.6% of respondents reported that they have stopped work at some time in the past for reasons relating to having

HIV/AIDS. Low energy levels was the most commonly cited reason for this, followed by stress, depression or anxiety and poor health

Of those respondents who had left work, 47.7% had returned to work and this was most commonly for financial reasons.

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.

49.0% of PLWHA currently in work had not disclosed their HIV status to anyone at their workplace, while 12.5% 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**

Just under half of respondents identified their main source of income as a government benefit or pension. As well, 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:**

- 51.6% difficulty paying for clothing
- 60.4% difficulty paying for utilities
- 56.6% difficulty paying for housing
- 51.6% difficulty paying for food
- 51.7% difficulty paying for transport

35.9% of those on a government benefit had been assessed by a Commonwealth Medical Officer in the past 2 years. While this resulted in termination of benefits or change in conditions for few respondents, it caused distress for 60.3% of those assessed.

## **Poverty**

28.3% 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**

6.8% experienced less favourable treatment in relation to accommodation, 3.5% in the last two years

27.2% experienced less favourable treatment because of HIV in relation to health services, 10.1% in the last two years

12.5% of hepatitis C co-infected respondents experienced less favourable treatment because of hepatitis C in relation to health services, 3.7% in the last two years

18.6% experienced less favourable treatment in relation to insurance, 30 in the last two years.

# INTRODUCTION

With the increasing availability of antiretroviral treatments in many parts of the world has come increased surveillance of the lives and behaviours of PLWHA. In part, the concern of much of this surveillance has been the monitoring of antiretroviral compliance and sexual practice. While small scale research and advocacy has examined the extant lived experience of positive lives, this has rarely been on a scale that allows national planning of service delivery and social reform. Some research (for example Anderson and Weatherburn 2004, EMHF 2005) has provided national data on the broader social aspects of PLWHA's lives, but the bulk of research, limited by funding and infrastructure, has focused on limited aspects of either clinical or social experience.

The specific nature of samples obtained in a number of studies concerning the well-being of PLWHA has also limited their utility, both in terms of planning and advocacy. Data obtained from clinical samples generally tend to over-represent the more problematic aspects of living with HIV, both clinical and social, and data obtained solely from community convenience samples tend to over-represent both service utilisation and community engagement. While we do not presume to have obtained an entirely representative sample through our methodology, we do believe that the broad sector involvement in both promotion and recruitment for this project has given us one of the most comprehensive pictures of life with HIV in Australia. This is important for service providers, in that it gives them an understanding of the diversity of positive lives beyond the clients that they most commonly see, and it gives them some sense of the lives of their clients that they may not generally encounter. Similarly for clinicians, this diversity offers some context into which they can place the health behaviours of their patients. Understanding the social context of a treatment break may be just as important as understanding its clinical consequences. For health and community planners, appreciating the range of ways in which HIV has an impact on people's lives allows a more considered approach to the building and maintenance of services, legal reforms and community education.



## 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 5 survey was completed by 982 HIV positive people (9 responses were unable to be entered due to late arrival, therefore the sample analysed is 973). Given current estimates of HIV infection in Australia (NCHECR, 2006) this represents approximately 6.4% of the HIV positive population. Of the total respondents, 77.2% completed a paper copy of the survey, while 22.8% completed the survey on-line (see Appendix for a comparison of these two samples).

Of the survey respondents, 91.0% were male (876), 8.7% were female (84), 0.2% were transgender (2) and one was intersex. This sample consisted of 80.6% gay men, 8.1% heterosexual women, 5.3% heterosexual men, 3.7% bisexual men, 0.3% lesbian women and 0.3% bisexual women. The remaining 0.3% fell into other categories.

Respondents ranged in age from 19 to 78 years with a mean of 45.8 years and a median of 45.0 years.

The majority of participants were Australian born (76.6%) and 97.1% of the participants spoke English at home, with European languages accounting for most of the remainder. Eighteen respondents (1.9%) indicated they were of Aboriginal/Torres Strait Island origin. This compares to the Australian Census figure of 2.4% ATSI in the Australian population (ABS, 2002). Ninety nine percent (99.1%) of respondents indicated that Australia was their official country of residence.

The three most common ancestries that respondents identified with were English (40.2%), British (30.0%), Australian (25.0%) and Irish (18.9%). This compares with the ancestry data from the 2001 Census, in which 35.9% of the population identified their ancestry as Australian, 33.9% as English, 10.2% as Irish and only 0.06% as British (Trewin, 2001). These differences may be explained by the high number of Futures 5 respondents who identified their ancestry as Anglo-Saxon, counted as British in the Census codebook. A total of 1.4% of respondents stated South-East Asian ancestry, specifically Thai, Indonesian, Filipino or Vietnamese. This compares with the Census data, which reports that 1.7% of the Australian population had either Thai, Indonesian, Filipino or Vietnamese ancestry.

Respondents came from all Australian states and territories, with the majority coming from NSW, Victoria and Queensland

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

State/territory	Frequency	Percent of Sample
NSW	478	50.0
VIC	218	22.8
QLD	129	13.5
WA	55	5.8
SA	45	4.7
ACT	17	1.8
TAS	9	0.9
NT	5	0.5

The majority (63.6%) of respondents were from urban areas of capital cities, while 10.8% lived in outer suburban areas, 16.6% lived in larger regional centres and 8.9% lived in rural areas.

79.2% of participants were living in the same state or territory in which they were infected with HIV, while the remainder lived 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 24 years with a mean of 1.8 years and a median of a year. 37.9% 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**

Year	Tested HIV Positive	Presumed Infected
Pre 1985	6.6	16.6
1985-1989	24.3	21.4
1990-1994	20.9	20.8
1995-1999	20.1	17.5
2000-2004	23.1	19.9
2005+	5.0	3.9

401 respondents (45.7%) indicated that they were atheist/agnostic, 42.8% indicated mainstream religious identification and the remainder indicated that they either had 'other' (10.7%) or New Age spiritual beliefs (7.3). Over one third of respondents (37.2%) indicated that religious beliefs were not important to them, while one third (30.7%) indicated that these were of little importance, 22.6% that they were very important and 9.5% 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**

Level	Frequency	Percent of sample
University degree	281	29.7
Tertiary diploma/ Trade Certificate/TAFE	267	28.3
Leaving certificate/HSC/Year 12	168	17.8
4th form/year 10	140	14.8
Up to 3 years high school	77	8.1
Primary school only	12	1.3



# 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. Australia currently has high testing rates among 'at-risk' populations like gay and homosexually active men (around 80%) (Van de Ven et al, 2003).

HIV antibody testing is available free of charge in Australia and although legislation differs from state to state, pre- and post-test counselling forms an integral part of this testing procedure (ANCARD/IGCARD, 1998). 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, 24.0% of the respondents had taken the test as a result of illness, 13.2% as a result of a particular risk episode and 11.0% because they were a member of a risk group. It is interesting to note that 15.8% gave the reason for testing as routine health screening. Gay or bisexual men were somewhat more likely to give this reason than others (16.5% of these participants versus 15.4% for heterosexual men and 10.9% 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 (26.1%) than by gay or bisexual men (7.1%) or heterosexual men (3.1%).

Of those who had tested positive in the last two years, 35.6% had taken a test due to illness, while 19.2% as a result of a particular risk episode, 16.4% as a part of a routine health screening and 9.6% at the suggestion of a doctor.

**TABLE 4 Reasons for testing**

Reason	Frequency	Percent
Became ill/ongoing illness	198	24.0
Routine health screening	131	15.8
Particular risk episode	109	13.2
Member of risk group	90	11.0
Doctor's suggestion	85	10.3
Partner tested positive	76	9.2
Starting new relationship	35	4.3
Other	26	3.1
Tested without knowledge	17	2.0
Required to (eg for migration)	11	1.3
As part of other test/research	11	1.3
Contact tracer/other health worker's suggestion	10	1.2
Wanted to know	8	1.0
Travelling overseas	7	0.9
Availability of new treatments	4	0.4
Insurance	4	0.4
Antenatal	2	0.2

## Pre- and Post-Test counselling/discussion

Participants were asked “Did you receive counselling (or a detailed discussion) about HIV before you were tested for HIV?”. Current Australian HIV testing guidelines (ANCARD/IGCARD 1998) recommend that people engage in a HIV test discussion prior to testing. This is defined in the guidelines as:

“[an] informed discussion ... between practitioner and client/patient before testing. After assessment, this should include giving appropriate information about risk and related matters, referral if necessary, assurances about confidentiality and privacy, and assessment of the client’s preparedness to be tested. Specifically, the HIV test discussion should provide accurate information about safe practices that is appropriate to the person’s gender, culture, behaviour and language” (p32)

28.5% 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, 36.4% had received pre-test counselling. The counselling was generally provided by a doctor (54.3%), and less commonly by staff at a sexual health centre (12.7%), a nurse (12.4%), or a counsellor (8.8%). No other response accounted for more than 5% of responses. When asked if they were satisfied with the counselling/discussion, 94.0% reported they were satisfied with the information they received from this person and 91.1% said they were satisfied with the level of support they received.

The ANCARD/IGCARD guidelines recommend that post-test counselling be given to all individuals taking a HIV antibody test, regardless of the test result. They state that this should include:

“giving the test result in person and in a manner that is sensitive and appropriate to gender, culture, behaviour and language; re-assessing support mechanisms and requirements of client; If the result is negative, reinforcing positive education and information messages about safe behaviours, and examining any difficulties or issues that the client may have in practising safe behaviours; If the result is positive, discussing at an appropriate time issues such as: immediate needs and support; safe behaviours – education, information and support; who to tell and how; managing or understanding strong emotions, feelings, reactions and changes; options in drug treatments and medical management; ongoing counselling or therapy if required; complementary/alternative management options; ways to deal with loss and grief, depression, anger and anxiety; strategies for managing HIV which are flexible and appropriate to the person’s needs; and legislative requirements (notification, contact tracing, storage and coding)” (pp32-33).

58.9% of respondents indicated that they had received post-test counselling. Of those who tested positive in the last two years 73.7% had received post-test counselling, a significantly greater proportion than for those who were diagnosed earlier than this. The counselling was generally provided by a doctor (45.8%), but was also commonly provided by a staff at a sexual health centre (13.6%), a nurse (11.1%), or a counsellor (9.4). No other response accounted for more than 5% of responses. When asked if they were satisfied with the counselling they received, 86.9% said they were satisfied with the information they received and 83.8% said they were satisfied with the support they received.

## 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 Tables 5 and 6 below. Close to half of the sample (44.0) rated their physical health as good and 24.1% as excellent. This is less than the Australian population norm reported in the National Health Survey (ABS, 2006) where 86.6% of the population rated their health as good, very good or excellent<sup>1</sup>. Almost one-third of respondents to HIV Futures 5 rated their health as fair or poor (31.9%).

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

	Frequency	Percent
Poor	46	4.9
Fair	249	27.0
Good	406	44.0
Excellent	222	24.1

1 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 5 sample was aged 19-78.

The ratings for well being were of a similar pattern to those for health. Almost two thirds (60.1%) rated their well being as either good or excellent, while 32.5% rated this as fair and 7.4% as poor.

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

	Frequency	Percent
Poor	84	7.4
Fair	301	32.5
Good	459	40.7
Excellent	178	19.4

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  $p=0.69$  ( $p<0.001$ ). Almost one in four participants (24.3%) rated their well-being as worse than their health and 11.6% 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 ( $\chi^2$  (6, N=833) = 78.87,  $p<0.0001$ ) and better overall well-being ( $\chi^2$  (6, N=829) = 43.19,  $p<0.0001$ ). However there was no correlation between health and most recent viral load result, and a moderate association between well-being and most recent viral load ( $\chi^2$  (3, N=829) = 8.12,  $p<0.05$ ).

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

Wellbeing	HEALTH			
	Poor	Fair	Good	Excellent
Poor	3.1	3.2	1.1	0.1
Fair	1.5	18.2	11.1	1.6
Good	0.3	5.5	27.6	7.2
Excellent	0.1	0.0	4.1	15.2

## CD4 and Viral Load

As with the previous three surveys, almost all PLWHA had taken a CD4/T-cell test (98.4%) and a viral load test (98.4%). Most respondents had their most recent CD4 test in the six months prior to survey (92.6%) (58.6% in the last three months) and their most recent viral load test in the six months prior to survey (90.7%) (57.0% in the last three months). On average participants had taken four viral load tests in the preceding twelve months. Among those PLWHA who had taken a CD4 test, 89.4% reported that they have at some time had a CD4 count of less than 500 cells/ $\mu$ l and 61.2% reported a count of less than 250 cells/ $\mu$ l.

Results for PLWHA's most recent CD4/T-cell test ranged from 10 to 1980 cells/ $\mu$ l with a mean of 519.40 cells/ $\mu$ l and a median of 485.48 cells/ $\mu$ l.

Among those PLWHA who have taken a viral load test, 84.6% reported that at some point they have had a result of over 10,000 copies/ml and 65.0% a result of over 50,000 copies/ml.

Results for PLWHA's most recent viral load test ranged from below detectable levels to 1,000,000 copies/ml with a mean of 130,050 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 count	500+	37.7	3.5	5.6	1.8	48.6
	250-499	26.1	1.8	3.5	4.9	36.3
	0-249	9.5	2.3	1.0	2.3	15.1
	Total	73.3	7.6	10.1	9.0	100.0

## HEALTH CONDITIONS IN ADDITION TO HIV

While there is often uncertainty about whether a particular illness may be related to HIV, treatments or other factors, we offered participants the opportunity to record these conditions within the categories of AIDS defining illnesses (ADI), HIV-related illnesses, major health conditions other than HIV/AIDS and mental health conditions. We asked respondents to indicate whether they had experienced conditions in these categories and to specify the condition and the year in which it was diagnosed. Some recoding was undertaken, for example for a condition that did not meet the criteria for ADI, the data were transferred to either HIV related conditions or other health conditions. Regardless of the uncertainty about the aetiology of these conditions among PLWHA (and indeed physicians) we can see that there is a considerable burden of illness that goes beyond HIV infection for a significant proportion of the survey respondents.

Participants were also asked to select from a list of 10 HIV-related illnesses those that they had experienced in the 12 months prior to survey. This section will also cover co-infection with hepatitides, attitudes towards body changes and health maintenance activities.

### AIDS Defining Illnesses

AIDS is a notifiable condition in all states and territories in Australia. The case definition for AIDS requires both laboratory evidence of HIV infection and clinical confirmation of one of 25 specific conditions (ANCA 1994). These conditions are therefore known as AIDS defining illnesses. 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 3 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 (21.9%) said they had been diagnosed with an AIDS defining illness at some point with 14.3% having been diagnosed with one in the last two years. Respondents had been diagnosed with an AIDS defining illness on average 8.1 years ago (median 9 years). The most common illnesses listed by respondents in this category were Pneumocystis Pneumonia (46.8%), Kaposi's Sarcoma (23.2%), Cytomegalovirus (10.3%) and Microbacterium Avium Complex (MAC) (10.3%).

### HIV/AIDS Related Conditions

Almost thirty percent of respondents (29.3%) indicated that they had experienced an HIV-related illness at some point. Within this group the most common conditions mentioned were shingles (20.1%), skin problems (such as rashes) and 14.6%, candida/thrush (10.7%).

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. In order to gain a clearer picture of respondents' burden of illness, this list was expanded from previous HIV Futures surveys to include five additional conditions.

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

Condition	Percent
Low energy/fatigue	81.8
Diarrhoea	66.6
Sleep disorder	65.8
Nausea or vomiting	48.1
Confusion/memory loss	48.0
Weight loss/underweight	43.7
Raised cholesterol/triglycerides	41.4
Lipodystrophy/lipoatrophy	36.8
Peripheral neuropathy	30.3
Insulin resistance	2.2

Those reporting weight loss were significantly more likely to have a body mass index (BMI) of less than 20 (85.9% versus 14.1%,  $\chi^2(1, N=643) = 61.70, p < 0.001$ ).



## Attitudes towards body image

Lipodystrophy and lipoatrophy have created additional difficulties for positive people (see for example Persson 2003). 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 disagree	14.1	19.5	20.6
	disagree	32.1	18.7	40.2
	agree	34.2	44.9	27.6
	strongly agree	19.3	32.2	11.4
I am happy with the way my body looks.	strongly disagree	14.2	22.8	9.0
	disagree	39.4	44.9	36.1
	agree	37.6	25.5	44.8
	strongly agree	8.8	6.7	10.1
Body changes due to lipodystrophy make it obvious to others that people have HIV	strongly disagree	16.3	3.4	24.4
	disagree	32.1	29.9	33.4
	agree	35.7	41.3	32.2
	strongly agree	15.9	25.4	10.0

## Other Health Conditions

44.6% 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 (7.9% of the total sample), cardiovascular disease (eg high blood pressure) (9.5%), asthma (4.5%), and hepatitis B (1.9%).

## Hepatitides

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

Over one quarter of the participants (27.6%) had at some point had hepatitis A, and 55.5% had been vaccinated against this virus. This means that 16.9% of the respondents may currently be at risk of hepatitis A infection

## Hepatitis B

A total of 24.6% of respondents had at some time been diagnosed with hepatitis B. Of these, 71.1% had cleared the infection, 19.1% had an ongoing infection and 5.0% had a chronic infection. In addition to those who had experienced hepatitis B infection, 66.8% had been vaccinated against this virus. This means that 10.4% may currently be at risk of being infected with hepatitis B.

Table 11 shows the experience of hepatitis B related symptoms for those who had ever been diagnosed with this virus.

**TABLE 11 Experience of hepatitis B related symptoms, by disease status**

Experience symptoms?	Cleared infection (n=144)	Ongoing infection (n=38)	Chronic infection (n=11)
Yes	2.1	15.8	45.5
No	85.4	71.1	0.0
Don't know	12.5	13.2	54.5

The most common symptoms reported by those with hepatitis B were cirrhosis of the liver and fatigue or lethargy.

## Hepatitis C

Around one fifth (21.7%) 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, suggesting testing among Australian PLWHA is continuing to increase. In fact 77.6% of the most recent hepatitis C antibody tests were taken in the last two years and 19.5% of participants' first hepatitis C antibody tests were taken in this period.

In previous HIV Futures surveys we used a series of items including test results, year of diagnosis with hepatitis C, and designation of hepatitis C as a major health condition to determine the percentage of respondents with hepatitis C. In HIV Futures 5 we also asked respondents if they had ever had hepatitis C, and 15.2% (N=135) said that they had. Of these, 30 people (22.2%) said they had received a negative PCR test. Therefore the estimated prevalence of current hepatitis C infection amongst respondents was 11.3%. This compares with the current estimate of the prevalence of hepatitis C co-infection amongst Australian PLWHA of 13.1% (Dore and Sasadeusz, 2003, Sasadeusz, 2004) and the estimated prevalence of hepatitis C in the Australian population of 1.3% (NCHECR, 2006).

Respondents had first been diagnosed with hepatitis C between less than 1 and 26 years ago<sup>2</sup> (mean=1994, median=1995) and believed they had been infected between less than 1 and 34 years ago (mean=1991, median=1992). Two fifths of the co-infected respondents (40.0%) had taken a genotype test for hepatitis C. Of these, 26.0% did not know what the result of this test was, while 40.8% said type 1, 7.3% type 2, 21.0% type 3, and 4.8% type 4, 5 or 6.

When asked how they believe they were infected with the hepatitis C virus, 54.5% said injecting drug use, 24.4% during sex, 6.2% blood transfusion or the receipt of blood products, 1.7% through tattooing and 0.8% through other means. 12.5% of respondents did not know how they were infected. No respondents selected body piercing as mode of infection with hepatitis C.

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

Injection Drug Use (IDU)	54.5
During Sex	24.4
Don't know	12.5
Blood transfusion/ Blood Products	6.2
Tattooing	1.7
Other	0.8

When asked if they currently experienced any hepatitis C related symptoms, 23.9% said they did, while 55.9% said they did not and one-fifth of people with hepatitis C (20.2%) did not know whether they were experiencing symptoms related to this virus. The most commonly mentioned symptom was fatigue or lethargy.

27 respondents had ever undertaken medical treatment specifically for hepatitis C. This comprised 4 who had undertaken treatment with interferon monotherapy, 15 who had undertaken treated with combination therapy of interferon and ribavirin and 8 who said they had undergone both monotherapy and combination therapy. 11.1% of co-infected respondents had taken some form of complementary therapy.

Hepatitis C co-infected participants were also asked about health monitoring and management. Around one fifth (21.3%) of co-infected PLWHA did not currently see a doctor for hepatitis C treatment or management, while 61.3% of this group saw their primary HIV doctor and 17.4% saw a separate hepatitis C doctor or specialist.

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

Co-infected PLWHA were asked whether they had received less favourable treatment at medical services as a result of having hepatitis C. While 16.3% had ever had this experience, 5.2% had had this experience in the last 2 years. Most respondents co-infected with hepatitis C found that HIV community services met their needs (74.2%), while 25.8% said that they did not.

**TABLE 13 Reasons HIV community services do not meet needs of co-infected respondents (percentage of all HIV/hep C co-infected participants)**

They have a poor understanding of hep C co-infection	6.7
They have a poor understanding of IDU issues	1.5
I don't want to disclose my Hep C status	3.7
I don't want to disclose that I have injected drugs	1.5
Other	7.4

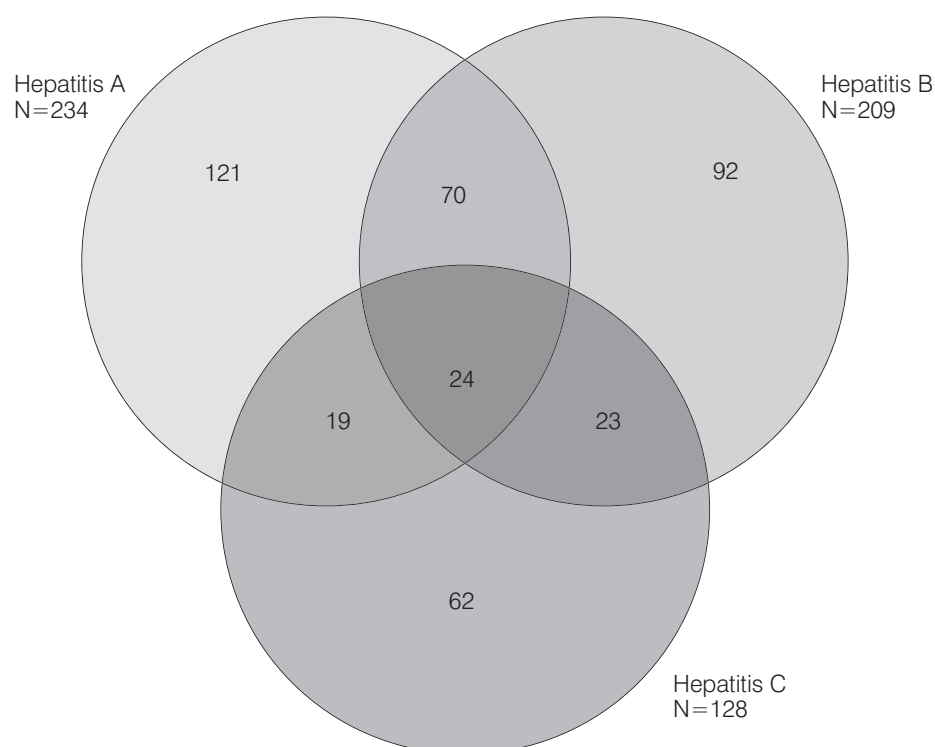
(Multiple responses possible)

## Multiple Hepatitides

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 hepatitides (44.3% 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 the total sample, 7.6% reported having ever had both hepatitis A and B, 2.5% hepatitis B and hepatitis C, 2.0% hepatitis A and hepatitis C, while 2.6% reported having had hepatitis A, B and C. Over one-third (35.3%) of respondents reported never having had any form of hepatitis, while missing data accounted for the remaining one-fifth of responses (20.4%).

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



## Testing

We asked respondents who had any of the three major viral hepatitides whether they had been given a liver function test or had undergone liver biopsy, and the results of these tests. We have given the findings for these questions in tables 14 and 15 below, organised by individuals' co-infection status/ history. Given the information presented below, one can see that the majority of those in this table with a hepatitis A or B co-infection status were not in an active stage of the infection.

The majority of participants with a history of hepatitis infection reported having had an LFT (around 90% for all categories). Abnormal results were most common in the presence of hepatitis C infection, with up to 27% being unsure of the results of this test.

**TABLE 14 Participants undergoing Liver Function Test (LFT) and results of this test by co-infection history with hepatitides**

	N	Had LFT (%)	Abnormal result (%)	Don't know result (%)
hepatitis A only	121	91.0	11.2	17.3
hepatitis B only	92	88.1	18.5	20.6
hepatitis C only	62	90.9	36.8	26.8
hepatitis A and B	70	88.0	10.9	14.5
hepatitis A and C	19	84.1	15.1	23.6
hepatitis B and C	23	100.0	44.0	20.7
hepatitis A, B and C	24	95.5	37.4	19.8

The proportion of participants with a co-infection history reporting having undergone a liver biopsy was variable, and was more likely to have occurred in the presence of hepatitis C infection and only rarely for hepatitis A only (2.9%) or hepatitis B only (10.0%). Of the respondents reporting past or current hepatitis C infection (N=135) 38.3% had undergone liver biopsy, with half of these reporting liver fibrosis (49.9%) and a further 37.6% reporting that they did not know the results of this test. As is shown in Table 15 below, this figure includes 43% of those with hepatitis C only and over half of those with hepatitis C and A, hepatitis C and B and hepatitis A, B and C. Up to 45% of respondents in these groups reported not knowing the results of their liver biopsy. The stage of liver fibrosis was only reported by a small number of respondents and will therefore not be discussed in this report.

**TABLE 15 Participants undergoing liver biopsy procedure and results of this by co-infection history with hepatitides**

	N	Had Liver biopsy (%)	Fibrosis (%)	Don't know result (%)
hepatitis C only	62	36.5	43.0	37.3
hepatitis A and C	19	36.1	62.6	24.8
hepatitis B and C	23	47.9	58.1	32.9
hepatitis A, B and C	24	38.0	55.0	45.0

## **Mental Health**

Issues around mental health 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.

## **Psychiatric Medications**

In the six months prior to completing the survey, 28.5% of PLWHA said they had taken medicines prescribed for depression. In a question about the specific medicines that people were taking at the time of survey, 15.7% listed an antidepressant. This is considerably higher than the 5.2% of the Australian population who reported having taken antidepressants in the previous 2 weeks in the National Health Survey (ABS, 2006).

Around one quarter of respondents (25.7%) reported having taken medicines prescribed for anxiety in the past 6 months, while 3.0% wrote anti-anxiety medicines in the question about use of medicines at the time of the survey. This compares with the National Health Survey in which 2.0% of respondents reported using medicines for anxiety in the past two weeks (ABS, 2006). 17.0% of respondents reported taking medications for both depression and anxiety in the past 6 months. In addition 4.6% 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 43.0% reported that they had had such a diagnosis. Of those reporting a diagnosis, the vast majority had been diagnosed with depression

(91.4%, 39.0% of the total sample). 16.6% (6.3% of the total sample) of people receiving a diagnosis of depression reported having received this diagnosis in the past 2 years. The next most common condition was anxiety, reported by 51.1% of those with a mental health condition (22.0% of the total sample). 18.8% of those (3.9% of the total sample) reported having received this diagnosis over the past 2 years. Other conditions commonly reported were post-traumatic stress disorder (4.0% of those with a mental health condition) and schizophrenia (3.8% of those with a mental health condition).

## Symptoms of Depression

We included a set of four items modified from those in the Beck Depression Inventory (BDI), a widely used depression assessment instrument. These were: (1) I cry or feel like crying all the time; (2) I don't enjoy things the way I used to; (3) I have lost interest in other people; and (4) I don't feel it's worth going on. It was not our intention to compare PLWHA to the community norms for depression provided by the BDI - this would have required inclusion of the full sixteen item scale. However, these four items do provide an indication of some of the major symptoms associated with depression. These are also items that are often used in general practice as reasonable indicators for the prescription of anti-depressants.

As can be seen in Table 16, a considerable proportion of PLWHA agreed or strongly agreed with each of the items. The strongest level of agreement was with item 2 (not enjoying life as much), followed by 3 (losing interest in others). Over one fifth of the respondents (22.3%) agreed or strongly agreed with item 1 (crying all the time), and 14.7% agreed or strongly agreed with item 4 (not worth going on). We can look at the number of these items that people agreed with as a way of measuring the extent of depressive symptoms. Overall, 38.5% agreed or strongly agreed with none of these items, 24.0% with one item, 16.7% with two items, 8.9% with three items, and 8.6% of the sample agreed with all four items. Agreement with all four items may be suggestive of clinical depression.

**TABLE 16 BDI depression symptomology items: percentage of total sample**

	Strongly agree	Agree	Disagree	Strongly disagree
I cry or feel like crying all the time	3.7	18.6	48.9	28.8
I don't enjoy things the way I used to	13.2	38.8	32.5	15.5
I have lost interest in other people	7.4	27.3	45.4	19.9
I don't feel it's worth going on	3.9	10.8	37.5	47.8

## 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 17 below. The most common health-enhancement activity was eating healthily, followed by exercise, relaxation and compliance with medication. Those with better self rated health were significantly more likely to indicate that they engaged in exercise, healthy eating and spending time with friends and spending time with family. Those with better well being were significantly more likely to indicate that they engaged in exercise, healthy eating, spending time with friends, relaxation, spending time with pets and spending time with family.

**TABLE 17 Health improvement strategies**

Healthy eating	77.7
Relaxation	71.4
Taking pills on time	70.9
Exercise	67.3
Spending time with pets	54.2
Spending time with friends	53.7
Complementary therapies	35.6
Spending time with partner	34.1
Spending time with family	32.7
Sleep	27.2

(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 18). Those who indicated that they exercised and ate well were more likely to agree with the respective statements.

**TABLE 18 Attitudes to health management: percentage of total sample**

Looking after my physical fitness is an important part of managing my HIV infection	strongly agree	47.0
	agree	47.8
	disagree	4.8
	strongly disagree	0.4
Healthy eating is an important part of managing my HIV infection	strongly agree	43.3
	agree	52.1
	disagree	3.7
	strongly disagree	0.8
Keeping an optimistic frame of mind is an important part of managing HIV infection	strongly agree	50.7
	agree	46.6
	disagree	2.0
	strongly disagree	0.7
As long as I am well I prefer not to think about HIV/AIDS	strongly agree	15.3
	agree	40.5
	disagree	35.6
	strongly disagree	8.6
Life has become more meaningful since I became HIV positive	strongly agree	11.5
	agree	30.8
	disagree	39.5
	strongly disagree	18.1

## Prophylaxis

20.0% of respondents were taking prophylaxis for opportunistic infections. Those using prophylaxis were more likely to have experienced an AIDS defining illness, to have a lower CD4 count and to have been HIV positive longer.

## Other Health Monitoring

We asked a series of questions about other health monitoring activities. 19.5% had had a bone density test in the last two years and 10.4% had had a test more than two years ago. 59.6% had had a fasting cholesterol test in the last two years and 8.3% 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.

All female respondents who answered this question had undergone a cervical smear (Pap) test (100.0%) and 79.5% said they had taken one in the last twelve months. On average women had undergone one test in the previous year. On their most recent test, most women (92.8%) reported that the result was 'normal', while 1.5% reported atypia.

## Other Medication

Participants used a range of other prescribed medication. In all 55.2% of respondents were using other type of prescribed medication other than antiretroviral therapies including antidepressants and other medicines for mental health conditions (refer to page 9). The main medications being used were the antiviral agents Valtrex, Famvir and aciclovir (11.8% of the total sample), lipid-lowering agents (7.2%), antihypertensive agents (6.6%) and medicines for reflux and ulcers (5.0%).

## 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 three-quarters of respondents (76.5%) indicated that they had used some kind of complementary medicine or therapy in the previous six months. Over half of the sample (59.1%) had taken vitamin or mineral supplements, most commonly a multivitamin (24.1%), while considerably fewer had taken B group vitamins (8.0%) and fish oil capsules (7.9%). Over one-third (34.5%) of respondents had used massage, while 19% had used meditation. Around one-fifth (20.5%) of respondents indicated that they had used marijuana for therapeutic purposes

**TABLE 19 Use of complementary therapies in the past six months (percentage of total sample)**

Vitamin/mineral supplements	59.1
Massage	34.5
Marijuana for therapeutic purposes	20.5
Meditation/visualisation	19.0
Herbal therapies/supplements	18.5
Acupuncture	8.2
Traditional Chinese Medicine	6.2
Other traditional Medicine	3.5
Other complementary therapy	9.1

(Multiple responses possible)

Participants were asked where they obtained these services or supplements. Over one-third of those using complementary therapies obtained them from a health food shop, while slightly less obtained them from private practices (29%) and one-fifth from an AIDS community organisation (19.7%).

**TABLE 20 Source of complementary therapies (percentage of those using complementary therapies)**

Health Food Shop	38.7
Private practice	29.0
AIDS community organisation	19.7
Health Service	9.8
PLWHA organisation	9.1
Supermarket	6.2
Pharmacy	4.3
Friends	2.9
Other	8.6

(Multiple responses possible)

More than three-quarters of PLWHA (81.8%) agreed that complementary therapies can improve well-being, while almost two-thirds (65.0%) agreed that complementary therapies can boost the immune system and over half (59.1%) that complementary therapies can reduce side effects and delay the onset of illness due to HIV (56.7%) (see Table 21 below). 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 \$25.50 per week on them (median=\$15), and took them 1.2 times per day (median 1.0).

**TABLE 21 Attitudes to complementary therapies: percentage of total sample**

Complementary therapies can delay the onset of illness due to HIV	strongly agree	3.6
	agree	9.3
	disagree	36.6
	strongly disagree	20.1
	don't know	30.4
Complementary therapies can improve well-being	strongly agree	2.0
	agree	1.9
	disagree	45.3
	strongly disagree	36.5
	don't know	14.3
Complementary therapies can reduce the side effects of conventional medical treatments	strongly agree	2.6
	agree	4.4
	disagree	37.5
	strongly disagree	21.6
	don't know	33.8
There is not enough evidence to be sure about the benefits of complementary therapies	strongly agree	8.1
	agree	34.0
	disagree	30.5
	strongly disagree	7.4
	don't know	20.0
Medicine's focus on anti-HIV drugs is very limited	strongly agree	7.4
	agree	32.0
	disagree	24.2
	strongly disagree	11.4
	don't know	25.0
Complementary therapies can boost the immune system	strongly agree	2.2
	agree	5.6
	disagree	39.4
	strongly disagree	25.6
	don't know	27.2
Complementary therapies are a central part of my anti-HIV treatments	strongly agree	14.6
	agree	26.9
	disagree	24.3
	strongly disagree	17.8
	don't know	16.4





# TREATMENTS

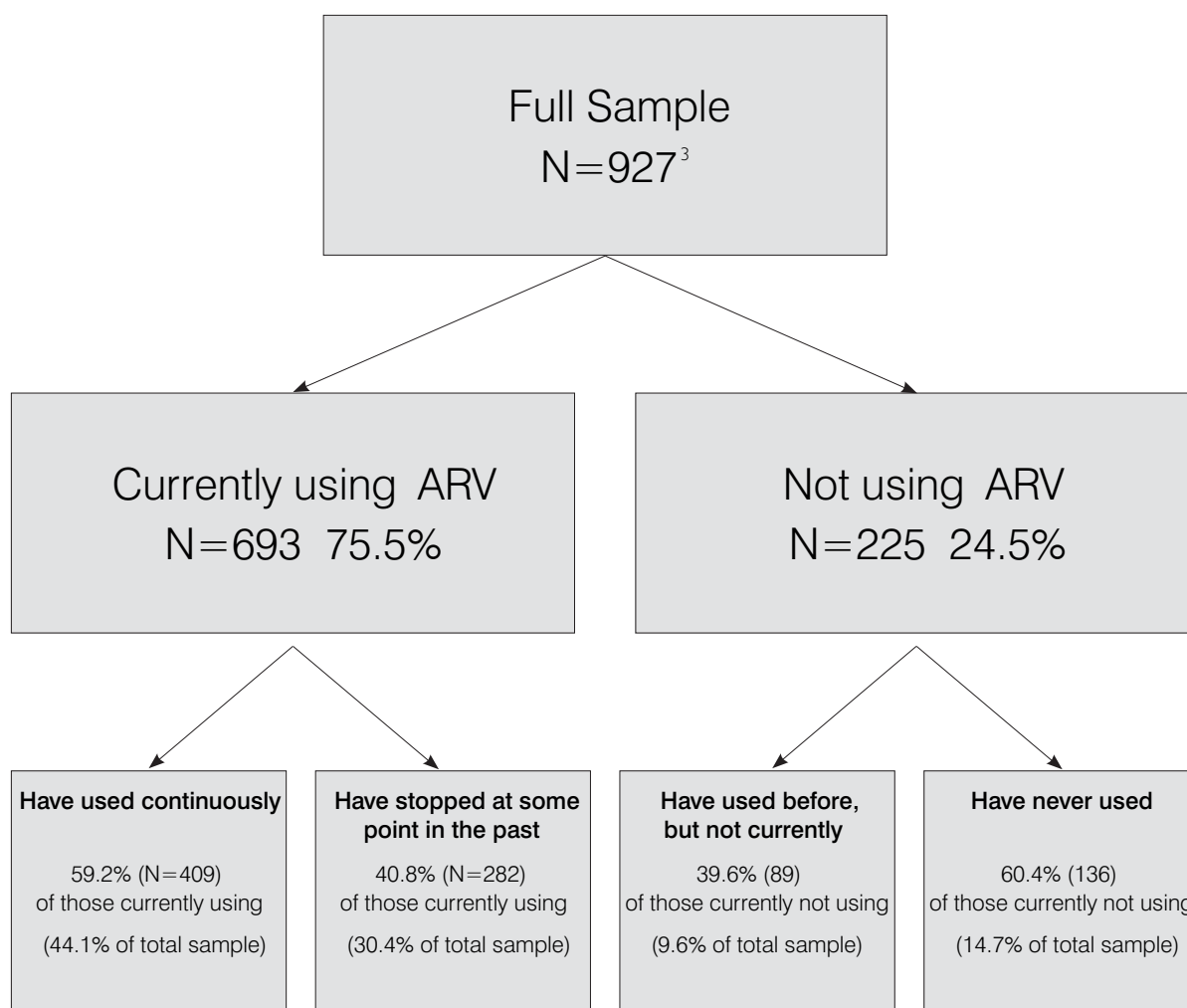
This chapter reports on the treatment experiences of PLWHA. The main emphasis is on antiretroviral treatments, as these are dominant in the lives of HIV positive people. There is also some discussion of medicines taken for other health conditions. While we have seen a reduction in the number of medicines taken and the frequency of taking them over the past few years (see for example Fogarty et al 2003), the burden of medicine (largely pill based) remains high.

## 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 and nations and resource poor settings. The ten years in which these treatments have been available have seen improvements in the efficacy and tolerability of treatments, but this period has also shown us that they are complex in clinical and pharmacokinetic consequences. In the following section we examine some of these consequences from the perspective of PLWHA, but we also examine the psychological and social impacts of the treatments.

Of the full sample, 85.2% had used ARV at some point, and 75.5% 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

<sup>4</sup> Combivir counts as 2 drugs, Trizivir as 3 drugs, Kaletra as 2 drugs, Kivexa as 2 drugs

## Those Currently Using ARV (mono-therapy and combination therapy)

The majority of participants (47.5%) were on a combination of 3 antiretroviral drugs, with 28.6% on more than three antiretroviral drugs, 20.1% on two and 3.8% on monotherapy.

**TABLE 22 Antiretroviral drugs used by respondents: percentage of those currently using ARV**

<b>Nucleoside Reverse Transcriptase Inhibitors (NRTIs)</b>	
Lamivudine (3TC, Epivir)	48.8
Abacavir ,1592 (Ziagen)	18.0
Stavudine, d4T (Zerit)	7.5
Zidovudine, AZT (Retrovir)	6.5
Didanosine, ddl (Videx)	4.9
ddl ec (Videx ec, didanosine ec)	3.0
Emtriva (emtricitabine)	2.9
Zalcitabine, ddC (Hivid)	0.4
<b>Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)</b>	
Nevirapine (Viramune)	31.0
Efavirenz (Sustiva, Stocrin)	20.0
Delavirdine (Rescriptor)	0.8
<b>Nucleotide Analog Reverse Transcriptase Inhibitors</b>	
Tenofovir (Viread)	43.2
<b>Protease Inhibitors</b>	
Ritonavir (Norvir)	22.7
Atazanavir (Reyataz)	18.3
Saquinavir (Invirase, Fortovase)	4.8
Nelfinavir (Viracept)	4.4
Indinavir (Crixivan)	3.8
Tipranavir	1.9
Telzir (fosamprenavir)	1.2
Amprenavir (Agenerase)	0.7
<b>Fusion Inhibitor</b>	
T-20	3.8
<b>Combination Medications</b>	
ABT-378/r (Lopinavir, Kaletra)	22.0
AZT & 3TC (Combivir)	18.9
AZT & 3TC & Abacavir (Trizivir)	6.9
Kivexa (abacavir and lamivudine)	4.1
Other	3.3

Respondents were also asked specifically about their use of the immune stimulant Interleukin 2 and 0.4% of respondents (n=3) were using it.

## Difficulties of Taking ARV

Overall, 52.5% of those currently using antiretroviral treatments reported that they had some difficulty taking them. Of those currently using antiretroviral treatments, 27.8% indicated they had difficulty remembering to take the drugs on time, 16.6% said they had difficulty organising meals around medications, 20.0% taking medication in public, 21.9% transporting medication, and 12.1% taking a large number of tablets. In addition, 7.3% reported that taking ARV made it difficult to take medication for other health conditions and 3.5% that taking other medications made taking ARV difficult.

**TABLE 23 Difficulties of taking ARV among those currently using ARV**

Side effects	29.7
Remembering to take drugs on time	27.8
Carrying/transporting medication	21.9
Taking medication in public	20.0
Organising meals around medication	16.6
Taking a large number of tablets	12.1
ARV drugs make it difficult to take medication for other health conditions	7.3
Medication taken for other health conditions makes it difficult to take ARV	3.5
Other	5.1

(Multiple responses possible)

Side effects were reported by 29.7% of respondents currently using ARV. The most commonly reported problems were diarrhoea (10.5% of those using ARV, 35% of those reporting side-effects), nausea or vomiting (9.8%/32.5%), fatigue or lethargy (4.0%/13.4%), sleep disturbances (2.6%/8.6%).

### Attitudes to ARV

Most respondents reported concern over the future efficacy of their treatments. Almost two thirds (58.9%) 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*, 54.5% indicated agreement and 42.2% indicated disagreement.

**TABLE 24 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	4.6	22.0	42.9	16.0	14.4
Taking tablets gives me an unwanted reminder that I have HIV	11.5	30.7	36.2	18.3	3.4

### Health Status of Those Using ARV

Those taking ARV had marginally significantly lower viral loads (mean of 19,004 cells/ $\mu$ l compared to 47,552 cells/ $\mu$ l among those not currently taking ARV but who had previously and 853,134 cells/ $\mu$ l among those who have never taken ARV,  $F_{(2,825)} = 3.097$   $p = 0.046$ ). This difference is mainly explained by the large proportion of those on ARV with a viral load below detectable levels as can be seen in Table 25.

**TABLE 25 Viral load 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	89.6	4.0	1.9	4.5
	Past	22.7	18.7	33.3	25.3
	Never	13.9	18.5	44.4	23.1

$\chi^2(6,1) = 410.95$   $p < 0.001$

Those taking ARV had marginally significantly lower CD4 counts (mean of 517 copies/ml compared to 665 copies/ml among those not currently taking ARV but who had previously, and 557 copies/ml among those who have never taken ARV  $F_{(2,830)} = 3.440$   $p = 0.033$ ).

**TABLE 26 CD4 of those taking and not taking antiretroviral therapy (percentage within rows)**

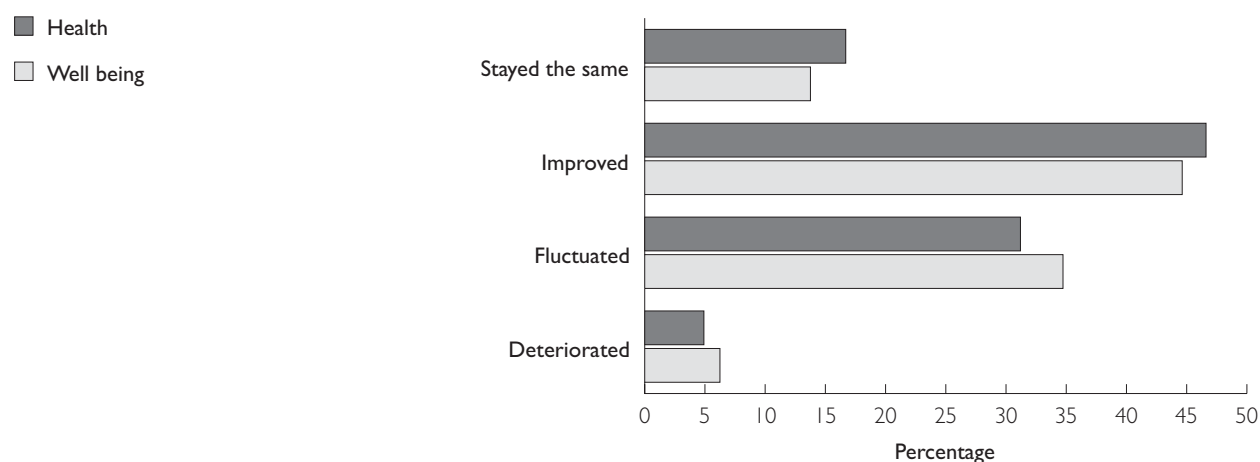
		CD4 on most recent test		
		0-249	250-499	500+
ARV Use	Current	16.5	36.3	47.1
	Past	18.0	33.3	48.1
	Never	1.8	42.3	55.9

$\chi^2(4,1) = 17.487$   $p=0.002$

Those currently taking antiretroviral treatments were more likely to have had an AIDS defining illness (27.3% compared to 20.2% among those currently not taking antiretrovirals and 2.2% among those who have never taken ARV). They had tested HIV positive more years ago (mean=1992 compared with mean=1995 for those not taking antiretrovirals and mean=2000 among those who have never taken ARV).

When asked to rate the effect of commencing ARV on their physical health, 46.9% said that their health improved, 31.4% said it had fluctuated, 16.7% said it had stayed the same and 4.9% said it had deteriorated. When asked about the impact of ARV on their overall feeling of well-being, 44.9% said it had improved, 35.0% said it had fluctuated, 13.9% said it had stayed the same and 6.2% said it had deteriorated.

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



## THOSE ON COMBINATION THERAPY

There was considerable variation in the combinations currently in use by respondents. The most common combination was 1 NNRTI and 2 NRTI used by 20.7 % of ARV users (n=145), followed by 1 NARTI, 1NNRTI and 1 NRTI used by 14.6%, 1 NARTI, 2 PI and 1 NRTI used by 10.5%, and 2 PI and 2NRTI used by 7.4%.

50.3% of those on combination therapy had been on ARVs for at least seven years (mean =6.61 years). Most started combination therapy at a time when their viral load was high (Median= 100,000, mean = 1,193,139 copies/ml) and their CD4 count was low (median=200, mean = 233.49, with 58.5% below 250 cells/ $\mu$ l, 89.1% below 500 cells/ $\mu$ l). Table 27 below, gives the CD4 and viral load of respondents at the time they commenced combination antiretroviral treatment.

**TABLE 27 Results of serological tests prior to commencement of ARV: percentage of those on ARV**

		HIV Viral load				Total
		Below detectable levels	500-9999	10000-49999	50000+	
Cd4/	500+	2.7	1.2	1.2	5.9	11.0
T-cell count	250-499	2.1	2.4	7.7	18.4	30.6
	0-249	3.3	4.2	7.7	43.3	58.5
	Total	8.0	7.7	16.6	67.7	100.0

Based on available data (Hoy and Pierce: The Draft Australian Antiretroviral Treatment Guidelines 2001) antiretroviral treatment is recommended for patients with less than 200 CD4 cells, should be offered to those with CD4 count between 200 and 350 and is recommended for those with a CD4 over 350, but a viral load greater than 50,000 copies/ml. Table 28 below gives the groupings from these guidelines, the treatment recommendations, the percentage of participants that were in each group at the commencement of antiretroviral treatment and the mean number of years they have been on treatment.

**TABLE 28 Treatment recommendation at commencement of ARV treatment**

Guideline Group: At commencement of ARV combination					
	Symptomatic (ADI)	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
Percentage of those currently on ARV	28.2 (N=142)	29.6 (N=149)	30.6 (N=154)	6.2 (N=31)	5.6 (N=28)
Mean number of years using ARV	8.37	7.20	8.02	7.63	7.75

When asked about the circumstances surrounding their commencement of combination therapy, respondents were most likely to indicate that they were advised to do so by their doctor (73.5%), although the importance of clinical indicators, treatment developments and treatment information is also clear.

**TABLE 29 Circumstances surrounding commencement of combination therapy treatment among all those currently on combination ARV and those commencing combination ARV in the previous 2 years**

	All	Last 2 years (n=135)
My doctor advised me to begin this treatment	73.5	75.9
I had a big drop in my CD4/T-cell count	46.0	53.8
I had a big rise in my viral load	34.0	45.2
I became very ill.	28.0	23.5
New drugs became available	25.8	7.1
Information showed that this treatment is effective	21.5	9.4
I had just tested positive to HIV	17.8	11.2
I was hospitalised due to HIV-related infections	16.3	12.1
A treatments officer advised me to begin this treatment	5.8	7.1
Close friends advised me to begin this treatment	5.3	5.7
A number of my positive friends started this treatment	4.5	2.7
My partner advised me to begin this treatment	4.0	4.2
Other	9.1	14.5

(Multiple responses possible)

## Different Combinations

Among those currently using combination therapy, respondents had used between one and 26 combinations, with the median being three. Within the last 12 months, 66.5% had used the one combination and 21.2% had used two. Respondents currently on combination ARV were asked to describe the circumstances surrounding their most recent change in combination. For a large proportion of PLWHA (41.1%) the side effects had become too severe. Drug resistance (17.7%) and drugs not working (11.9%) were the next most common responses.

**TABLE 30 Primary circumstance surrounding most recent change in combination among those currently on combination ARV who have changed combinations**

Side effects became too severe	41.1
Drug resistance developed	17.7
They were not working for me	11.9
Taking drugs at the right time was too difficult	2.5
It didn't fit my lifestyle	1.9
The financial burden became too heavy	0.6
Other (please specify)	24.4

When asked how many combinations they believed they still had access to, 2.8% indicated that they thought they had only one remaining, 23.1% had a few and 32.4% felt they had many. 38.3% said they didn't know how many combinations they had left. 3.4% of those currently on combination therapy believed they had no combinations remaining. Those respondents reporting no remaining options were significantly more likely to have a lower CD4 than those with more therapeutic options, however, only those who said they had many combinations remaining had a lower CD4 than the rest (see Table 31).

**TABLE 31 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	1989	384	17240
One	1989	328	21126
A few	1991	470	16192
Many	1993	551	414
Don't know	1993	538	34841

1 F(4,630) = 6.534 p < 0.001    2 F(4,588) = 5.119 p < 0.001    3 F(4,596) = 0.484 not significant

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 32 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	9.5	42.9	42.9	4.8
	One	0.0	66.7	27.8	5.6
	A few	4.8	29.0	49.0	17.2
	Many	2.4	26.1	44.0	27.5
	Don't know	6.6	30.7	39.3	23.4

$\chi^2(12,1) = 28.742$  p = 0.004

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.



**TABLE 33 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	9.5	47.6	33.3	9.5
	One	15.8	36.8	42.1	5.3
	A few	4.2	37.3	40.1	18.3
	Many	4.8	30.4	40.1	24.6
	Don't know	8.2	37.4	36.2	18.1

$\chi^2(12,1) = 15.665$   $p = 0.207$  non significant

## THOSE NOT CURRENTLY TAKING ARV

Of the 24.5% of the sample who were not using any antiretrovirals, 39.5% had done so in the past. The mean length of time these PLWHA had been using ARV was 5 years (range 1 to 15 years) and on average they had ceased using ARV 4 years prior to completing the survey (range 1 month to 12 years). At the time that they stopped using ARV, most were using a combination of 3 drugs (67.2%), 15.3% were using four drugs, 9.4% were using two drugs and 2.4% were on mono-therapy.

### Difficulties of Taking ARV

There is some variation in the difficulties experienced by those who have stopped antiretroviral therapy and those currently taking them (see Table 34). Overall, those who had stopped taking antiretroviral drugs nominated all of the difficulties more often than those currently using the drugs. This is particularly noticeable for the experience of side-effects, dosing concerns and difficulties with other medication.

**TABLE 34 Difficulties of taking ARV among those who have stopped ARV treatment**

Side effects	55.9
Remembering to take drugs on time	35.7
Taking medication in public	28.7
Taking a large number of tablets	28.2
Organising meals around medication	27.3
Carrying/transporting medication	26.3
ARV drugs make it difficult to take medication for other health conditions	6.5
Medication taken for other health conditions makes it difficult to take ARV	5.6
Other	10.7

(Multiple responses possible)

### Health Status of Those Not Using ARV

Those not currently using ARV were asked to describe changes in their health when they had used ARV in the past. One in five (20.2%) said that it had deteriorated, 24.7% said it had fluctuated, 21.3% said it had stayed the same, and 33.8% that their health had improved. When asked about the impact of ARV on their overall feeling of well-being, 16.2% said it had improved, 35.8% said it had fluctuated, 21.9% said it had stayed the same and 26.1% said it had deteriorated.

Respondents were asked whether they had lifestyle or clinical reasons for ceasing their use of antiretroviral therapy. 29.8% of respondents gave lifestyle reasons for stopping treatment (see Table 35). The most commonly cited reason was to clean out the system with a slightly smaller proportion saying that taking drugs at the right time became too difficult.

**TABLE 35 Lifestyle reasons for stopping treatment (percent of those previously on ARV)**

It didn't fit my lifestyle	11.1
Taking drugs at the right time was too difficult	10.5
Travel	7.0
Clean out my system	6.3
The financial burden became too heavy	5.7
A special event	0.9
Other	11.7
(Multiple responses possible)	

62.6% of respondents gave clinical reasons for ceasing ARV treatment (see Table 36). Almost one quarter of these said that side effects were a reason for stopping and one quarter said that the cessation was recommended by their doctor.

**TABLE 36 Clinical reasons for stopping treatment (percent of those previously on ARV)**

Recommended by my doctor	25.9
Side effects became too severe	24.9
This is a treatment break	12.6
Complications with Hep C	8.1
Taking part in a clinical trial	7.9
Liver toxicity problems	6.8
Other	5.8
Drug resistance developed	5.6
Recommended by other health professional	3.7
Changing regimens	2.8
(Multiple responses possible)	

### Those who have never used Antiretroviral Drugs

14.7% (N=134) of the respondents had never used antiretroviral treatments. Of these 88.3% said they would consider using antiretroviral drugs in the future.

9.6% (N=89) of the respondents have used antiretroviral treatments in the past but are not currently using them. Of these 90.4% said they would consider using antiretroviral drugs in the future.

When asked what circumstances would lead to their commencing ARV, the principal reasons were clinical (see Table 37).

**TABLE 37 Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used or previously used antiretroviral drugs**

	Never Used (n=134)	Previously used (n=89)
If I had a significant drop in CD4/T-cell count	76.6	68.9
If I became very ill	72.2	66.4
If my doctor advised me to begin this treatment	62.9	64.5
If I was hospitalised due to HIV-related infections	62.3	60.8
If I had a significant rise in my viral load	61.2	55.5
If information showed that combination therapy is effective	32.5	11.8
If new drugs became available	25.2	26.7
If a treatments officer advised me to begin this treatment	20.7	11.7
Other	8.0	10.4
If close friends advised me to begin this treatment	5.6	4.2
If my partner advised me to begin this treatment	4.9	6.0
If a number of my positive friends began to take up combination therapy	2.1	2.0
When my break from treatment is finished	N/A	14.8

(Multiple responses possible)

## ATTITUDES TO ANTIRETROVIRAL THERAPY

Antiretroviral treatments 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 38 below.

**TABLE 38 Attitudes to antiretroviral drugs: 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	37.3	36.6	8.4	13.2	4.5
People with HIV should start using antiretroviral drugs as soon as possible	15.8	31.2	16.3	10.6	26.1
My doctor and I work together to find the best treatment for me	2.2	5.6	50.1	38.3	3.7
My doctor knows a lot more about the treatment of HIV than I do.	4.0	12.5	40.3	38.8	4.4
Combination antiretroviral drugs are ineffective	46.7	40.0	1.6	2.3	9.4
Combination antiretroviral drugs are harmful	16.1	27.5	30.9	6.9	18.6
The side-effects of antiretroviral drugs outweigh the benefits	17.4	42.9	14.1	7.7	17.9
New treatments will be developed in time for me to gain benefits	1.5	4.9	42.0	22.1	29.5
HIV treatments will stop me dying from AIDS	5.5	17.8	26.3	16.6	33.7
Combination antiretroviral drugs have allowed me to plan my life with confidence for the long-term	5.0	15.6	39.6	25.7	14.1

## Treatment Decision Making

Most respondents indicated that they disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (73.9%). Those who agreed with this statement were more likely to be those not currently using any antiretroviral drugs and who rated their physical health more positively. Respondents were more likely to disagree than agree with the statement *People with HIV should start using antiretroviral drugs as soon as possible*. There were however one in four respondents that indicated that they were unsure about this. Those that agreed with this statement were more likely to be using antiretrovirals.

## Relationship with Doctor

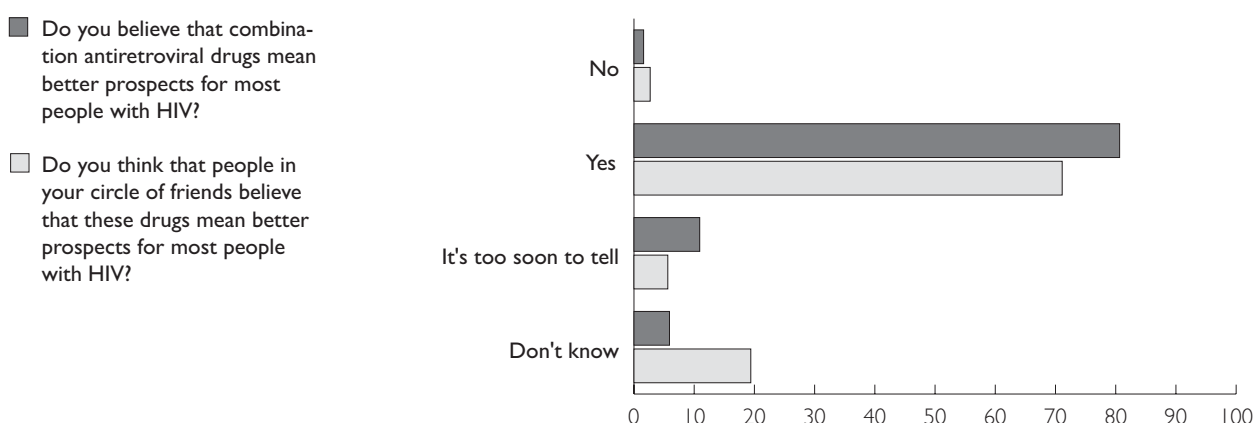
As with previous surveys, most respondents (88.4%) agreed with the statement *My doctor and I work together to find the best treatment for me*, with few expressing uncertainty. Most respondents (79.1%) agreed with the statement *My doctor knows more about the treatment of HIV than I do*.

## Treatment Optimism

Optimism about the value and effectiveness of antiretroviral treatments continues to characterise the Australian experience, but tempered as always with concerns about the impact and long term effectiveness of these treatments. Only 3.9% 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* (30.9% agree, 6.9% strongly agree). This harm may in part be that experienced as side effects. Around one in five (21.5%) respondents agreed or strongly agreed with the statement *The side effects of antiretroviral drugs outweigh the benefits*, while 17.9% were unsure. There was considerable uncertainty about the long term benefit of treatment. 29.5% 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, 33.7% were uncertain when asked if *HIV treatments will stop me dying from AIDS*. Agreement with this statement was indicated by 42.9% of respondents. Almost two thirds (65.3%) agreed with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*, while 14.1% were uncertain.

In addition to these items, respondents were asked to indicate how much they and their friends agree with the statement *Antiretroviral drugs mean better prospects for most people*. Most (80.7%) agreed with the statement, and believed their friends would agree with it (71.5%).

**FIGURE 4 Respondents' and respondents' social networks' response to the statement Antiretroviral drugs mean better prospects for most people**



## TREATMENT BREAKS

Treatment breaks may take a number of forms and be undertaken for a range of reasons (Grierson, Misson and Pitts 2004). 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, 40.9 % of those respondents currently using antiretroviral medication 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 86% of those that had ever taken a break. Of these 35.3% had taken their most recent break in the two years prior to survey and 17.8% in the previous one year. The mean length of break was ten months with a median of six months and a mode of three months (17.2%). Of those ever taking a break, 14.1% described it as a structured treatment interruption, while 49.1% described it as a treatment break. Of those taking a break in the previous two years, 16.5% described it as a structured treatment interruption, while 56.6% described it as a treatment break.

We asked participants to describe the reasons for taking the break within two major categories: lifestyle reasons, and clinical reasons. A discussion of the differences between those taking breaks for primarily lifestyle and primarily clinical reasons can be found in our article on this topic (Grierson, Misson and Pitts 2004). Over half (56.0 %) indicated that there were lifestyle reasons for taking a break. Of those taking a break in the previous two years, 61.2% said there was a lifestyle reason. The specific reasons are given in Table 59 below. The most common reason given was to clean out the system (18.5% of those taking breaks) followed by travel (18.4%).

**TABLE 39 Lifestyle reasons for taking breaks (percent of those taking breaks and percentage of those taking a break in the previous 2 years)**

	Total taking breaks	Last two years (n=86)
Clean out my system	18.5	20.6
Travel	18.4	18.6
Taking drugs at the right time was too difficult	9.0	10.7
It didn't fit my lifestyle	7.5	8.6
The financial burden became too heavy	4.5	6.4
A special event	4.4	6.4
Other	18.9	24.5

(Multiple responses possible)

When asked if there was a clinical reason for taking the break, 49.5 % of those that had taken a break indicated that there was. Of those taking a break in the previous two years, 37.4% said there was a clinical reason. (15.9% of the total group taking breaks and 9.5% of those who took a break in the previous two years gave both lifestyle and clinical reasons). Table 40 below details the clinical reasons for breaks. The most commonly cited reason was that the side effects of treatment became too severe (19.6% of all those taking breaks), 18.0% indicated that the break was on the recommendation of their doctor.

**TABLE 40 Clinical reasons for taking breaks (percent of those taking breaks and percentage of those taking a break in the previous 2 years)**

	Total taking breaks	Last two years (n=86)
Side effects became too severe	19.6	14.5
Recommended by my doctor	18.0	10.1
Drug resistance developed	10.6	9.3
Liver toxicity problems	7.4	2.1
Changing regimens	5.5	6.9
Taking part in a clinical trial	3.1	5.4
Recommended by other health professional	1.5	0.0
Complications with Hep C	0.6	0.0
Other	8.2	9.5

(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 (66.0%) than they were during the break (72.3%) or afterwards (92.0%). Over half (59.3%) talked to their doctor at all three stages of the treatment break. 17.1% spoke to the doctor during and after the break, but not before, and 14.2% 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 (49.6%) during the break (56.8%) and afterwards (84.5%). 43.1% talked to their doctor at all three stages of the treatment break. 20.8% spoke to the doctor during and after the break, but not before, and 23.6% 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. Tables 41 and 42 below gives the results of the four questions asked. Around one third of respondents said that their health remained stable, while the remainder were spread fairly evenly across the categories of improved, fluctuated and got worse. When asked about their general well-being, a similar proportion said that it had remained stable (30.0%). With well-being, there was a more distinct pattern for the remaining categories with decreasing proportions saying that it had improved, (29.1%) fluctuated (23.9%) or got worse (17.0%).

**TABLE 41 Effect of break on health and well being (percentage of those taking break and percentage in last 2 years)**

	Health		Well being	
	(All)	(last 2 years)	(All)	(last 2 years)
Stayed the same	38.1	43.2	30.0	30.5
Improved	14.7	15.2	29.1	31.6
Fluctuated	20.2	17.0	23.9	18.9
Deteriorated	27.1	24.6	17.0	18.9

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 42 and 43 below. Note that the categories are ordered from positive to negative outcome for both tables.

**TABLE 42 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)	3.0	0.0	7.7	5.9	3.3
	Stay the same	20.0	0.0	0.0	5.9	16.1
	Fluctuate	8.5	12.5	30.8	23.5	11.4
	Increase (worsen)	68.5	87.5	61.5	64.7	69.2

**TABLE 43 Effect of break on CD4 (percentage of those taking break)**

		CD4 before break			Total
		500+	250-499	<250	
Change in CD4 due to break	Increase (improve)	3.3	5.3	11.1	6.2
	Stay the same	11.0	14.7	16.7	14.0
	Fluctuate	11.0	22.7	13.9	17.8
	Decrease (worsen)	74.7	57.3	58.3	62.0

## ANTIRETROVIRAL RESISTANCE

The development of resistance to antiretroviral treatments is an ever increasing 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 (Deeks 2003, Prejdova et al 2004). Resistance can result from a lack of early and persistent suppression of viral replication, missed doses of antiretrovirals 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.

35.3% of respondents who had ever used antiretroviral treatments indicated that they had some sort of ARV resistance test. This included 39.6% of those who were currently on antiretroviral treatment and 37.8% of those who were not. The average length of time since the most recent resistance test was two years (median=one year). 66.8% of respondents had had their most recent test in the last two years (65.8% of those currently on ARV, 64.3% of those not). Of those who had resistance testing, 65.2% found resistance to one or more antiretroviral drugs (66.4% of those currently on ARV, 61.3% of those not). This resulted in a change of drugs for 56.6% (N=165) of those where resistance was shown. Tables 44 and 45 show the changes in clinical markers for all those who underwent resistance testing and who changed treatments. The number of participants is given rather than the percentage due to the small overall numbers. Note that the categories are ordered from positive to negative outcome for both tables.

**TABLE 44 Effect of resistance testing and treatment change on viral load (number of those changing treatments)**

		Viral load before change				Total
		Below detectable levels	500-9999	10000-49999	50000+	
Change in viral load due to change	Decrease (improve)	11	18	26	38	93
	No change	59	2	4	4	69
	Increase (worsen)	10	5	1	7	23
	Don't know	8	2	10	4	24
	Total	88	27	41	53	209

**TABLE 45 Effect of resistance testing and treatment change on CD4 (number of those changing treatments)**

		CD4 before change			Total
		500+	250-499	<250	
Change in CD4 due to change	Increase (improve)	16	24	50	90
	No change	22	11	9	42
	Decrease (worsen)	12	5	5	22
	Don't know	9	8	5	22
	Total	59	48	69	176

## DOSING AND ADHERENCE

Adherence to antiretroviral medication continues to be a significant concern for both PLWHA and physicians (Friedland & Williams 1999). The high degree of adherence required for these treatments to be effective and in order to prevent the development of resistance is far greater than that required (or observed) for other health conditions. 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 19, median=2). The number of times they were taking specific types of medication is shown in Table 46 below. 55.1% of the sample were taking ARV twice daily, 4.4% three times a day and 26.7% once a day.

**TABLE 46 Number of times participants take medications**

	Mean	Median	Range
Antiretroviral drugs	1.58	2.00	0-11
Complementary therapies	1.05	1.00	0-8
Medication for other health conditions	1.38	1.00	0-12

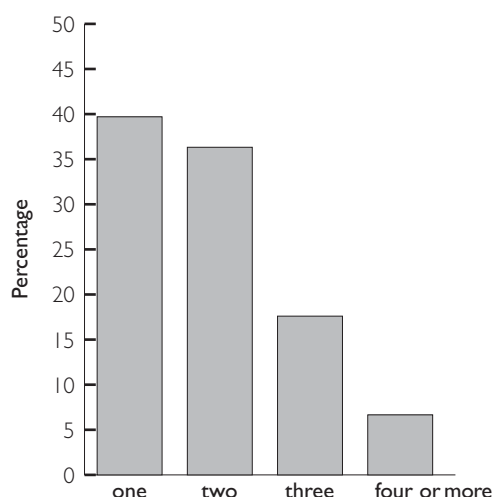
Participants who were currently using antiretroviral medication were asked how many doses they had missed on the day prior to completing the survey and the day before that. Combining the data from these two measures, 55.7% reported missing no doses on the two days, 5.5% missed one dose, 1.0% missed two doses and 0.6% missed three or more doses.

## PRESCRIPTIONS

We asked participants who prescribed their antiretrovirals. In recognition of the multiple prescribing sites people utilise, respondents were able to nominate more than one source. Two fifths (43.8%) of PLWHA got their prescriptions for antiretroviral drugs from a GP who specialises in HIV/ S100 prescriber. A similar proportion (36.9%) obtained their prescription from a specialist in an outpatient clinic, while fewer obtained them from a doctor at a sexual health centre (21.8%), another GP (2.0%), or from a HIV specialist while an inpatient (4.5%).

Participants were most likely to say one place (39.8%) with slightly fewer saying two places (36.2%). Fewer went to three or more sites (See Figure 5). When asked how difficult it was to do this, over half (61.8%) said it was not difficult, 33.4% said somewhat difficult and 4.7% said very difficult.

**FIGURE 5 Number of prescription pick-up points**



## CLINICAL TRIALS

17.5% of all participants (n=159) had participated in a clinical trial for HIV related treatment in the last two years. The main trials that participants had taken part in were the SMART trial (10.3% of those taking part in a trial in the past 2 years), Il-2 (6.2%) and Atazanavir (6.1%) and the CCR5 inhibitor UK-427,857 (5.6%). They had on average been on these trials for 14.5 months (median 10 months). The circumstances surrounding participation in the trial are given in Table 47 below. These data show that involvement of doctor was important in this decision, as was an altruistic intent.



**TABLE 47 Reasons for participating in clinical trials (percentage of those who have participated in a trial)**

My doctor and I decided together	70.0
I felt my experience could benefit others	64.7
I felt I had enough information about the trial	37.3
My other treatments were not working	15.6
I had no other treatment options	12.6
It was the only way I could get the treatment	9.9
I felt pressured to go on the trial	3.5
Other	15.3

(Multiple responses possible)

## VACCINES

While the development of readily available therapeutic vaccines for HIV positive people is still some way off (Mwau & McMichael 2003), we were interested in participants' perspectives on this. We asked respondents to indicate their agreement with the statement *I would be willing to participate in a HIV vaccine trial*. Almost one quarter (22.9%) said they did not know, while 58.3% either agreed or strongly agreed with the statement. A further 11.1% disagreed and 7.8% 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 health care 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 76.0% of respondents for HIV specific management and for 60.6% of respondents, for general health management.

**TABLE 48 Physician used for general and HIV related treatment: percentage of total sample**

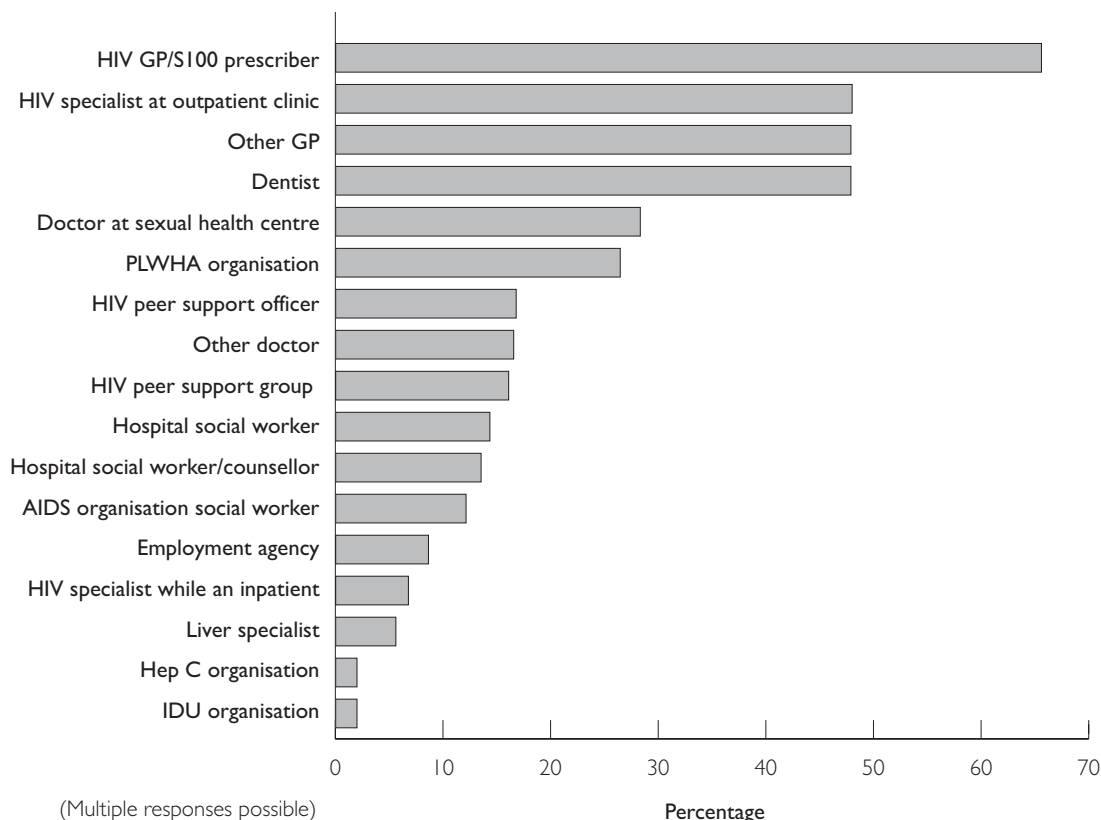
	For general treatment	For HIV specific treatment
HIV GP/S 100 Prescriber	46.7	43.2
Other GP	25.1	4.4
HIV specialist at outpatient clinic	13.7	32.4
HIV specialist at inpatient clinic	0.2	0.4
Doctor at sexual health centre	10.9	17.2
Other doctor	1.8	0.2
Other	1.7	2.1

62.3% 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, 98.2% said that that doctor knew their HIV status.

### Services Used in the Last 6 Months

We presented respondents with a list of services, both clinical and ancillary and asked which they had used in the last six months. Clinical services were the most utilised in the list with 56.3% having used an HIV GP/ S100 prescriber, 41.2% an HIV outpatient specialist, 41.1% another GP, 41.1% a dentist, and 24.3% a doctor at a sexual health service. Support services were also commonly used, with 22.7% reporting having used a PLWHA organisation, 12.3% an AIDS organisation support worker and 11.6% a hospital social worker or counsellor (see Figure 6). People with hepatitis C were more likely to have used a hepatitis C organisation and those with hepatitis B and/or C were more likely to have seen a liver specialist.

**FIGURE 6 Services used in the last six months (percent of total sample)**



### Other Services

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 almost half 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 49 Percent of 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	46.7	18.8
Social contact with other PLWHA	40.4	8.2
Treatments information	38.4	13.7
Counselling	35.1	22.2
Peer support group	32.2	5.7
Financial assistance	26.1	11.6
Informal peer support	25.1	9.1
Complementary therapies	24.4	23.6
Pharmacy services	22.2	38.9
Community education campaigns	15.1	6.3
Financial advice	14.1	16.4
Legal advice	14.5	14.4
Housing assistance	13.0	17.6
Internet based information	12.7	14.1
Internet access	10.7	19.0
Mental health services	10.8	16.6
Transport	8.9	14.9
Library	8.6	21.2
Volunteer carer	7.7	5.0
Respite care	6.4	4.4
Return to work skills	5.5	9.8
Employment services	3.6	15.1
Drug/alcohol treatment	3.1	8.1
Paid carer	2.0	4.3

(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 health care providers and actively 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 50 Sources of information about treatments and living with HIV (percentage of sample)**

	Information about Treatments/HIV Management	Information about Living with HIV
HIV GP/S100 prescriber	60.2	32.3
HIV specialist	56.8	27.9
HIV magazine/newspaper	45.4	49.1
Publications from HIV/AIDS groups	41.3	44.7
HIV positive friends	34.9	47.3
Articles in gay press	31.1	36.6
Internet	29.7	28.6
Sexual Health Service	25.1	18.4
AIDS Council staff (treatments-specific)	21.6	21.6
PLWHA Organisation staff (treatments-specific)	20.1	23.5
Pharmacist	18.1	7.3
Nurse	17.5	11.6
Other GP	16.9	10.5
Publications from other sources	15.2	15.3
Dentist	14.3	11.8
Dietician	13.3	6.6
PLWHA Organisation staff (others)	12.6	25.1
AIDS Council staff (others)	12.2	23.6
Partner/lover	12.0	19.3
Alternative/Complementary therapist	11.5	13.2
Other HIV/AIDS Organisation staff	10.2	14.8
Peer Support Officer	8.2	15.3
Other friends	7.2	14.2
Liver specialist	6.8	3.3
Positive women's organisation	4.2	6.9
Positive heterosexuals organisation	3.7	6.3
Family	3.6	11.5
Sex worker association	2.3	3.4

(Multiple responses possible)

### Information about HIV Treatment and Management

HIV GPs/S100 prescribers were considered to be an important source of information on HIV treatment and management by over half (60.2%) of respondents. HIV specialists were nominated by a similar proportion (56.8%) of the sample. Importantly information from the community sector figured significantly in the responses to this item. These included HIV magazines and newspapers (45.4%), HIV/AIDS organisation publications (41.3%), and articles in the gay press (31.1%). HIV positive friends were nominated by over one-third (34.9%) of respondents.

When asked in a separate question to nominate their three most important sources of information about treatments and health management, 29.7% of respondents nominated their HIV GP as the most important source, followed by an HIV specialist (27.8%) and another GP (11.9%). The responses for the second and third most important information sources were spread more evenly throughout the range of possible sources. An HIV GP was also the most common choice for second most important information source (11.1%), followed by another GP (9.9%), an HIV specialist (9.3%), HIV magazines and newspapers (7.9%). For the third most important source of information about treatments and health management, HIV positive friends were the most common choice (9.4%), followed by HIV magazines and newspapers (9.2%), the internet (8.3%) and other publications (8.2%).

## 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 were HIV magazine/newspaper (49.1%), followed by HIV positive friends (47.3%) and publications from HIV/AIDS groups (44.7%). Clinical sources were also considered important by significant numbers of positive people (HIV GP: 32.3%, HIV specialist: 27.9%).

When asked to identify the three most important sources of information about living with HIV, 11.6% nominated their HIV GP and 10.6% an HIV specialist, while 9.9% nominated HIV positive friends and 8.8% PLWHA organisation staff (non-treatments specific). The most common choice for the second most important source of information about living with HIV was HIV positive friends (10.5%), followed by HIV magazines or newspapers (9.5%) and PLWHA organisation staff (7.9%). Similarly the most common choices for the third most important source of information about living with HIV were HIV positive friends (10.1%) and HIV magazines or newspapers (9.1%).

As the internet is seen as an increasingly important, but problematic source of information on HIV, we included two items to assess how reliable respondents felt the information available was. The responses are presented in Table 51. As can be seen from these data, PLWHA were reasonably sceptical about the reliability of information available on the net. Those that rated the internet as an important source of information were less sceptical than others.

**TABLE 51 Attitudes to HIV information on the Internet (percentage of sample)**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
<b>Full sample</b>					
Information on the internet about living with HIV is unreliable	5.3	30.5	13.4	4.4	46.4
Information on the internet about treatment side effects is unreliable	3.7	29.7	13.0	4.2	49.4
<b>Those who rate the internet as an important source of information</b>					
Information on the internet about living with HIV is unreliable	11.5	62.2	10.7	3.8	11.8
Information on the internet about treatment side effects is unreliable	6.8	60.8	13.3	3.4	15.6

## Lack of information

We asked respondents whether lack of information made it difficult for them to make decisions in certain areas and a third (33.5%) agreed that this was the case. When asked to identify the domains in which this applied, 14.7% nominated the management of side effects (41.3% of those nominating lack of information as a problem), while 14.2% nominated interactions between ARVs and other drugs (40.0% of those nominating lack of information as a problem). Employment and financial planning also figured prominently, with 13.8% of respondents identifying lack of information about work/employment (38.8% of the sub-sample) and 12.9% financial planning (36.2%). Information about complementary therapies was identified by 12.3%, which is important given that over three-quarters of respondents had used these therapies in the past 6 months.

**TABLE 52 Issues where participants lack information (percent of total sample)**

Managing ARV side effects	14.7
Interaction between ARV and other drugs	14.2
Work/employment	13.8
Financial planning	12.9
Using complementary therapies	12.3
Legal issues	12.1
Changing ARV	11.1
Taking a break from ARV	10.8
Using ARV	10.5
Recreational drug use	9.4
Having children	3.8

(Multiple responses possible)

## PUBLICATIONS

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 53, 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 53 Publications read by PLWHA**

Publication	Percent of sample
<b>National or non-specific</b>	
HIV Australia	29.9
Positive Living	55.9
Newsletters from community organisations	21.6
National Haemophilia	0.4
Overseas magazines (eg POZ)	5.0
Gay newspapers (% of total sample)	57.1
Gay newspapers (% of gay men, lesbians and bisexuals)	69.1
Gay magazines (% of total sample)	28.5
Gay magazines (% of gay men, lesbians and bisexuals)	35.0
<b>State based publications</b>	
Talkabout (% of total sample)	39.5
Talkabout (% of NSW respondents)	62.4
User's News (% of total sample)	2.4
User's News (% of NSW respondents)	3.4
Positive life (% of total sample)	7.5
Positive life (% of WA respondents)	42.4
QPP Alive (% of total sample)	7.6
QPP Alive (% of QLD respondents)	49.6
Spin (% of total sample)	1.4
Spin (% of QLD respondents)	9.0
(Multiple responses possible)	

## INVOLVEMENT WITH AIDS ORGANISATIONS

Participants were asked about their involvement with HIV/AIDS organisations. 66.0% of the sample had some contact with HIV/AIDS organisations. Of these, 61.6% received newsletters and mail outs, 61.9% were clients, 46.9% were members, 21.0% were volunteers and 8.1% were employees. Of those that volunteered, they did so for between 1 and 40 hours per week (median = 5 hours/week) Of those that had no contact with AIDS organisations, 51.8% gave the reason *I do not want to be involved*, 19.4% gave the reason *I do not have enough time*, 12.9% said that they had no transport or are too far away, and 12.8% said they did not know how to join. Importantly, 16.2% of those who were not involved in AIDS organisations said they felt excluded from them.

24.0% of respondents had at some point held a decision making position in an AIDS organisation (11.1% in the last year).





# 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 (7.7%) 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 (74.0%) and many had either an HIV positive partner or ex-partner (39.2% combined). 17.9% of respondents had been involved in the nursing or care of another positive person at some time in the last two years, and 72.5% have had someone close to them die from HIV/AIDS.

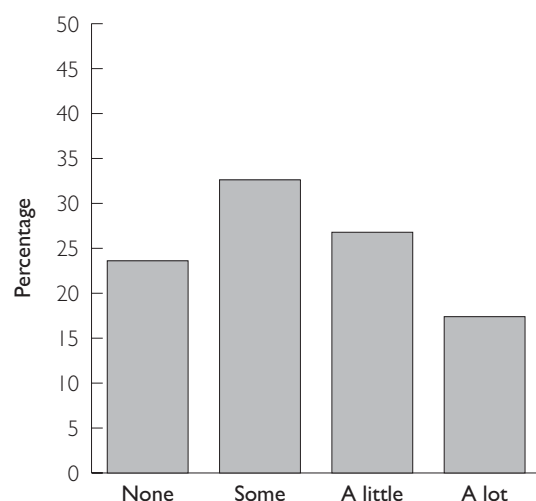
**TABLE 54 Other HIV positive persons known by respondent**

Positive Persons	Percentage
Friend	74.0
Acquaintance/Member of support group	54.6
Former partner/spouse	29.1
Partner/spouse	17.4
No-one	7.7
Other relative	2.5
Son/daughter	0.6
Other	5.5

(Multiple responses possible)

Three quarters of the respondents spent at least some time with other positive people (75.0%). The 16.4% 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 7 Time spent with other positive people**



## DISCLOSURE

Respondents were asked who they had disclosed their HIV status to (see Table 55). 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 3.3% had not disclosed their HIV status to anyone.

**TABLE 55 People the respondent has disclosed their HIV status to**

	Percent who have disclosed
Close friends	84.1
Positive friends	64.2
Siblings	62.6
Partner/spouse	51.7
Parents	49.2
Other friends	36.4
Work colleagues	24.7
Son/daughter	18.1
Neighbours	16.7
People from own ethnic community	3.9
No-one	3.3
<b>Specific populations</b>	
Partners (% of those in a regular relationship)	89.7
Partners (% of those not in regular relationship)	20.6
Work colleagues (% of those currently employed)	28.9
Work colleagues (% of those not employed)	21.8
Son/daughter (% of those with dependent children)	54.3
People from own ethnic community (% of those not born in Australia n=221)	4.9%
(Multiple responses possible)	

## Unwanted Disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. 51.8% said that it had at some point, and 24.9% said that this had happened in the last two years. When asked who disclosed their status, they were most likely to nominate friends. (see Table 56). In part these data reflect those that are most likely to be aware of the respondent's HIV status.

**TABLE 56 Sources of unwanted disclosure (percentage of those experiencing unwanted disclosure)**

	Percent (ever)	Percent (last 2 years)
Close friends	25.3	27.3
Other friends	18.7	20.2
Work colleagues	16.3	15.5
Partner/Spouse	15.1	16.5
HIV positive friends	15.0	18.5
Other	14.5	12.9
Sibling	13.3	15.7
Workers in a health care setting	10.9	9.7
Parents	8.8	7.6
Neighbour	6.7	9.1
Other family member	4.8	4.0
Staff/volunteers at community organisation	4.5	4.4
Son/daughter	1.9	0.9
People from ethnic community	1.2	2.1
(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 57. 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 (48.9%) of positive people in this study considered their HIV status an important, but not essential aspect of their make-up, while 17.0% considered it to be an essential characteristic. This is in contrast to sexuality and gender, where around 30% of the sample considered each of these to be essential characteristics.

**TABLE 57 Importance of personal characteristics to respondents' sense of identity**

	Essential	Important	Not Important	Irrelevant
Sexuality	29.6	47.8	14.7	8.0
Family	26.7	48.2	14.6	10.5
Gender	30.1	42.4	16.7	10.9
HIV status	17.0	48.9	21.6	12.6
Career	14.5	43.7	21.7	20.0
Religious beliefs	9.5	23.4	25.7	41.4
Parenthood	9.8	11.3	18.5	60.4
Ethnicity/Cultural background	3.5	23.3	32.9	40.2
Drug use (recreational/illegal)	0.9	12.6	33.9	52.6

When we look at the importance of HIV status among specific sub groups of PLWHA, we find that there are no significant differences in terms of sexuality, gender, having had an AIDS defining illness, use of antiretroviral drugs or partner sero-status (See Table 58).

**TABLE 58 Importance of HIV status to sense of identity for different groups of PLWHA**

Importance of HIV status among:	Essential	Important	Not important	Irrelevant
Gay and bisexual men	14.8	50.8	21.5	12.9
Women	22.9	49.2	19.9	8.0
Heterosexual men	25.1	35.0	22.7	17.1
Those who have had an AIDS defining illness	18.0	54.6	16.5	10.9
Those who have not had an AIDS defining illness	16.6	47.1	23.1	13.2
Those on antiretroviral therapy	17.9	50.0	20.8	11.3
Those not on antiretroviral therapy	14.5	44.9	24.0	16.6
Those in seroconcordant relationships	16.6	45.9	27.6	9.9
Those in serodiscordant relationships	12.8	52.5	25.5	9.2

## 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 59 below 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 (76.9% of those with partners), followed by their pets (60.1% of pet owners). Around half of participants also received *a lot* of support from their doctors (49.6%) and close friends (47.0%). When we examine the sources that people rated as providing no support, the highest ranking category was volunteer carer, where 54.5% 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 49.6% 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 59 Social support received from different sources: percent who gave valid responses for each category**

	A lot	Some	A little	None
Partner/spouse	76.9	12.7	4.6	5.7
Pets	60.1	19.9	11.7	8.2
Doctor	49.6	30.3	17.0	3.0
Close friends	47.0	30.5	16.6	5.9
Parents	37.9	20.7	17.7	23.7
HIV positive friends	33.6	34.6	21.8	10.0
Children	43.5	13.6	15.1	27.7
Siblings	29.4	24.1	20.5	26.0
Family	26.3	22.8	25.0	25.9
Counsellor	24.3	27.1	19.6	29.0
Health care workers	26.7	30.9	21.4	21.1
Volunteer carer	18.4	14.0	13.2	54.5
Religious or spiritual advisor	21.8	14.9	13.7	49.6
PLWHA groups	16.7	25.4	29.4	28.5
Other friends	14.6	33.7	31.6	20.1

## 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*. Under half agreed or strongly agreed with this statement.

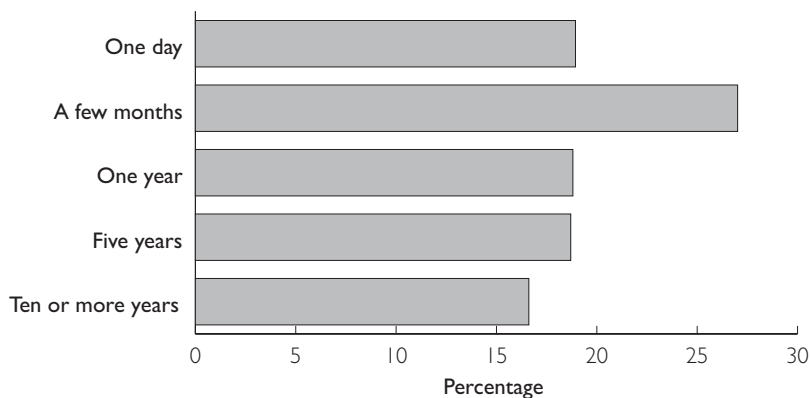
**TABLE 60 Attitudes to HIV status**

	Strongly agree	Agree	Disagree	Strongly disagree
As long as I am well I prefer not to think about HIV/AIDS	15.3	40.5	35.6	8.6
Life has become more meaningful since I became HIV positive	11.5	30.8	39.5	18.1

## Planning for the Future

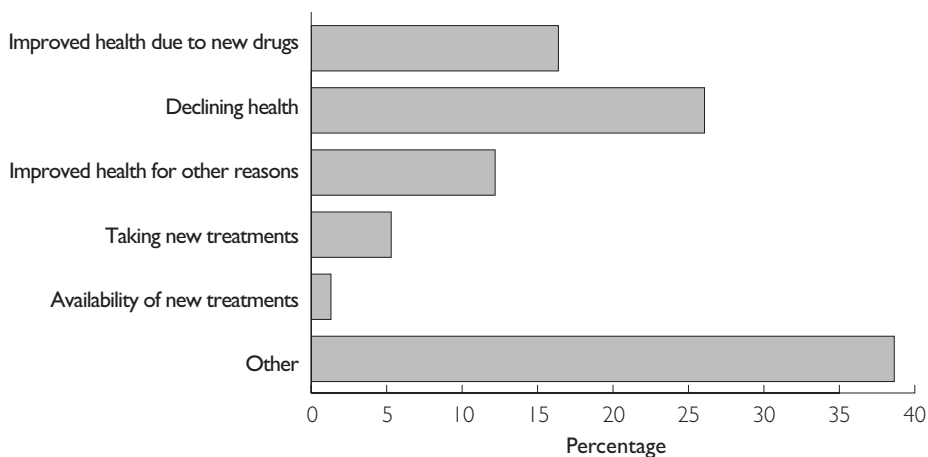
A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. Less than one fifth (18.9%) planned their life one day at a time and 26.9% planned only a few months ahead. Over half of the respondents planned for at least a year with 18.8% planning one year ahead, 18.7% planning five years ahead and 16.7% 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 8 Time frame for future planning**



23.8% of respondents reported a change in their time frame for future planning in the last two years. Overall, 10.6% of all participants now use a shorter time frame than 2 years ago and 13.2% use a longer time frame. The major reasons for change for those planning further ahead into the future over a longer time frame were improved health due to treatments (27.1% of those with longer plans), improved health for other reasons (20.6%) and taking new treatments (8.4%). The major reason for change for those with a shorter time frame was declining health (52.9% of those with a shorter time frame), see Figure 9.

**FIGURE 9 Reasons given for change in time-frame**



## 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 61 below. 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 61 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	25.5	55.7	47.5	30.3
I have casual sex only	35.0	10.0	2.0	29.0
I have a regular relationship with one person, and I have sex with other people	20.8	7.1	0.0	17.3
I have a regular relationship with one person, and I do not have sex with other people	16.5	27.1	50.5	21.6
I have a regular relationship with two or more people	2.2	0.0	0.0	1.9

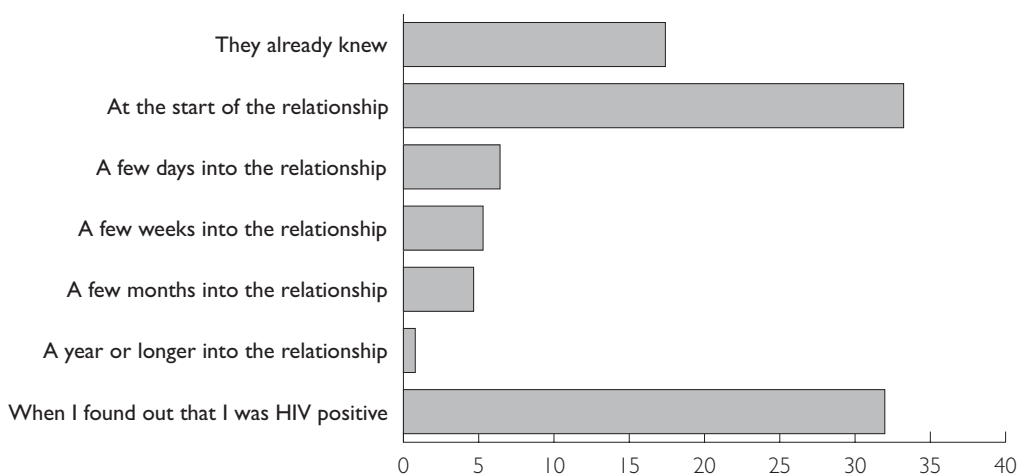
When asked if they were currently in a regular relationship, around half (45.7 %) said they were. This is slightly higher than the proportion of the sample that report having sex with a regular partner in Table 61 above (40.8%), as some in a regular relationship did not have sex.

## Regular Partners

Of those in a relationship with a regular partner, 42.6 % reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in serononconcordant relationships. This remaining group is made up of 54.6 % of those in relationships that report that their partner is HIV negative (a sero-discordant relationship) and 2.8 % who report that they don't know their partner's HIV status. Nearly all PLWHA (98.3 %) had told their regular partner that they were HIV positive.

Respondents were asked at what point in the relationship they told their partner. The responses are given in Figure 10 below. Around one third (33.2%) had told their partner at the beginning of the relationship. Slightly fewer than a third (32.0%) of respondents had told their partner when they themselves found out they were positive and for 17.4% of respondents, the partner knew prior to the start of the relationship. Small numbers of respondents (6.5%) had told their partners a few days into the relationship, 5.3% a few weeks into the relationship, 4.6% a few months into the relationship and 0.9% a year or more into the relationship.

**Figure 10 Time HIV status disclosed to partner among those in regular relationships**





When asked how their partner responded when told of the respondent's HIV status, the majority (51.8%) reported that the partner was supportive (see Table 62). Almost half (46.9%) reported that it did not make any difference, 28.4% reported that the disclosure brought them closer together. Around one quarter (28.9%) reported that their partner was worried or scared and 8.3% said their partner was angry.

**TABLE 62 Reaction of partner to disclosure: percentage of those in regular relationships**

They were supportive	51.8
It did not make any difference	46.9
We became closer	28.4
They were worried/scared	28.9
They were angry	8.3
(Multiple responses possible)	

We also asked how the respondent themselves felt about this disclosure. In general the patterns matched those of their partners.

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, 40.4% of the total sample had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 3.9% 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 63 below.

**TABLE 63 Condom use with regular partner by respondent and partner gender  
Number of these that used condom (N=393)**

	Never	Sometimes	Usually	Always
<b>Female respondents N=52</b>				
With regular male partner	17	9	2	24
<b>Male respondents N=341</b>				
With regular male partner	139	38	29	115
With regular female partner	11	8	5	9

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 64).

**TABLE 64 Condom use with regular partner by respondents' gender, partner gender, and partner sero-status  
Number of these that used condom**

	Never	Sometimes	Usually	Always
<b>SERO-CONCORDANT Relationships N=142</b>				
<b>Female respondents N=13</b>				
With regular male partner	9	3	1	0
<b>Male respondents N=129</b>				
With regular male partner	98	9	4	9
With regular female partner	5	3	1	
<b>SERO-NONCONCORDANT Relationships N=158</b>				
<b>Female respondents N=30</b>				
With regular male partner	7	4	1	18
<b>Male respondents N=128</b>				
With regular male partner	18	10	13	68
With regular female partner	4	3	4	4

## Casual Partners

Over half (53.7%) 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, 6.5% reported that all of their casual partners were HIV positive, 38.5% reported that some of their casual partners were HIV positive, and 5.4% reported that none of their casual partners were HIV positive. Most (49.6%) respondents 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 65 there are considerable variations in condom use when we examine this by sex of respondent and sex of partner.

**TABLE 65 Condom use with casual partner by respondent and partner gender. Number of these that used condom (N=412)**

	Never	Sometimes	Usually	Always
<b>Female respondents N=5</b>				
With casual male partners	0	1	0	4
<b>Male respondents N=407</b>				
With casual male partners	42	126	86	141
With casual female partners	5	4	1	8

Again, when we look at these data in terms of the partners' HIV status, a clearer pattern emerges (see Table 66). 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 66 Condom use with male casual partner by partners' sero-status. Number of these that used condom (N=399)**

Casual partners' HIV Status	Never	Sometimes	Usually	Always
All HIV positive	17	4	1	5
Mixture/unsure	23	121	83	129
All HIV negative	2	2	1	11

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. Over half the survey (53.7%) respondents provided such information. Of the respondents who had casual sex, 79.0% 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 11 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 11 Sexual practice with the most recent casual partner**

Sex with a casual partner in the last six months?					
No			Yes		
413			(46.3%)		
478			(53.7%)		

↙

Anal/vaginal intercourse with the casual partner? (missing=1)					
No			Yes		
9			(20.7%)		
378			(79.0%)		

↙

HIV status of casual partner (missing=12)					
HIV positive		HIV Negative		Status Unknown	
115		40		210	
(30.4%)		(10.6%)		(55.6%)	

Condom used? (missing=13)							
Yes		No		Yes		No	
20		92		35		5	
(17.4%)		(80.0%)		(87.5%)		(12.5%)	
145		55		145		55	
(69.0%)		(26.2%)		(69.0%)		(26.2%)	

↙ ↘ ↘

Ejaculated in partner? (male respondents only) (missing=2)							
No		Yes		No		Yes	
50		40		4		1	
(54.3%)		(43.5%)		(80.0%)		(20.0%)	
						(0.1% of total)	
29		26		29		26	
(52.8%)		(47.3%)		(52.8%)		(47.3%)	
						(2.8% of total)	

Ejaculated in by partner? (male partners only) (missing=2)							
No		Yes		No		Yes	
53		38		5		0	
(58.9%)		(41.3%)		(100%)		(0%)	
						(0% of total)	
40		14		40		14	
(72.7%)		(25.5%)		(72.7%)		(25.5%)	
						(1.5% of total)	

Respondents who indicated that they knew their partners' HIV status were asked how they knew. Nearly all (97.2%) of these respondents said that their partner had told them their status, 16 respondents said that they knew their partner's status from the type of sex they wanted, 14 said that they could tell from their respondents physical appearance, 9 said that a third party had told them, 7 said they could tell by the people they were with and 8 said that they could tell by the bar/venue at which they met.

33.5% of respondents said they told their most recent casual partner that they were HIV positive, 52.1% did not, 8.9% said the partner already knew they were HIV positive and 5.5% could not recall.

## 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 67.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, around half (48.8%) said they would, a third (33.3%) said they would not, and the remainder (17.9%) 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 (61.8%) 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 (54.7%) agreed with this statement.

Concerns about transmission of the virus to others and reinfection were apparent in the responses to the next six items. Most respondents (68.9%) 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*, and *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 29.3% agreeing with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*, and 14.5% 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 48.9% agreeing that *I am concerned about becoming infected with another strain of HIV* and 42.5% disagreeing.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (65.8%) agreed with the statement *HIV has had a negative effect on my sexual pleasure*. One third (30.5%) disagreed with this statement.

When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. 17.7% 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 (50.5%) than disagreed with it (31.8%).

Over one quarter (29.6%) said that they agreed with the statement *I have stopped having sex because of my HIV status*. Similarly, 61.3% of participants agreed that *HIV has negatively affected my libido*.

**TABLE 67 Attitudes to HIV, sex and relationships**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I prefer to have a relationship with someone who also has HIV	10.7	22.6	29.3	19.5	17.9
Few people would want a relationship with someone who has HIV	5.7	24.4	41.2	20.6	8.0
I am afraid of telling potential partners of my HIV status in case they reject me	11.8	24.8	35.6	19.1	8.6
Being HIV positive has helped me form more satisfying relationships	23.3	40.6	16.0	5.6	14.5
I am afraid of infecting my partner, or potential partner, with HIV	7.2	20.3	36.7	31.9	3.9
I feel more confident about unprotected sex because of the new treatments	46.6	35.2	10.9	3.0	4.4
Medical treatments for HIV/AIDS make safe sex less important than it was	49.0	34.5	7.9	2.3	6.5
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	35.2	34.1	20.5	4.0	6.2
If there was a vaccine which prevents HIV I would not practice safe sex	21.0	32.5	20.8	8.5	17.2
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	42.2	34.0	10.6	3.1	10.2
Knowing a vaccine will become available makes me less anxious about sex	19.3	45.8	11.6	2.9	20.4
I am concerned about becoming infected with another strain of HIV	11.3	31.2	34.7	14.2	8.7
HIV has had a negative effect on my sexual pleasure	10.9	19.6	36.1	29.7	3.7
If I know that my partner is HIV positive I find sex more pleasurable	12.7	19.1	30.0	20.5	17.7
I stopped having sex because of my HIV status	27.8	40.4	19.8	9.8	2.3
HIV has negatively affected my libido	13.8	20.7	36.1	25.2	4.3

## CHILDREN

As mentioned in the description of the sample earlier in this report, 20.6% of those surveyed currently have children and 7.1% have dependent children and 6.4% have dependent children living with them. We were also interested in future plans for children among PLWHA. Most PLWHA (77.6%) were not currently considering having children. Of the remainder, 11 PLWHA had decided to have children in the future and 1 was attempting to have children. 23 were considering having a child, but have not decided, and 25 people have considered having a child, but have decided it is too risky. 1 respondent was currently pregnant. Importantly, 20 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 are gay, bisexual or heterosexual men.

**TABLE 68 Planning to have children (number)**

	Gay or Bisexual Men	Heterosexual men	Women	Total <sup>5</sup>
No	628	49	34	719
No, I already have children	28	10	36	79
I have decided to have a child/children in the future	4	0	7	11
I am currently trying to conceive/get pregnant	1	0	0	1
I am currently pregnant	0	0	1	1
I have thought about it but I haven't decided	12	5	5	23
I have thought about it but I have decided that it is too risky	18	2	4	25
I was told not to by a doctor/ medical professional	1	0	0	1
I don't have enough information to make a decision	15	1	3	20
Other	6	3	1	11

## 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 twelve months. For those drugs which are commonly injected, differentiation was made between injection and other means of administration. Table 69 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 69 Recreational use of drugs (percentage of sample)**

Alcohol	77.0
Cigarettes	47.6
Marijuana	44.9
Amyl	33.4
Ecstasy	25.2
Viagra or similar	22.9
Crystal Meth	17.2
Speed (not injected)	12.1
Speed (injected)	9.3
Cocaine (not injected)	6.4
GHB/GBH/Fantasy	4.6
LSD/trips	3.6
Steroids (injected)	3.5
Heroin (injected)	2.7
Methadone (prescribed)	2.1
Homebake	1.1
Cocaine (injected)	1.0
Methadone (other)	0.8
Heroin (not injected)	0.2
Other	3.5

(Multiple responses possible)

5 Total is larger than sum of previous categories due to missing data

It must be noted that we only asked respondents if they had used each of the drugs in the previous twelve 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.

9.1% of PLWHA reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs. Around one quarter (28.7%) reported that they had missed a dose of antiretroviral medication at some point as a result of using illegal drugs. While use of most drugs was related to reporting having ever missed a dose of ARV due to recreational drug use, none of these drugs were related to having missed doses of antiretroviral medications in the 2 days prior to survey .

Over two thirds (70.8 %) of respondents reported that they had never injected illegal drugs. Of those 29.2% of respondents who had injected illegal drugs 43.2% had done so in the previous 12 months. Of PLWHA who reported injecting drugs, 94.4 % had not shared injecting equipment in the past twelve months. Of the 17 respondents that had shared injection equipment in the last 12 months, 15 had done so with at least one risk reduction strategy (using the needle last, washing/bleaching and/or using with another person who was HIV positive). The circumstances surround sharing injection equipment are shown in Table 70 below.

**TABLE 70 Circumstance surrounding sharing among those who have shared injecting equipment in the last 12 months**

	Number
The person was my sexual partner	6
The needle was bleached and/or washed	7
We did not have access to other needles	8
It was in a group	2
The person was HIV positive	6
The person was Hep C positive	3
I used the equipment last	9

(Multiple responses possible)

## Attitudes Relating to Drug Use

Around one in five (19.2%) of respondents felt that they drank more alcohol than they would like to and 14.0% felt they had used more illegal drugs than they would like to.

As specific quantities of drugs used were not asked in this survey, this does not indicate substance abuse, but rather gives an indication that there are important areas of health maintenance among PLWHA that need to be addressed. We asked participants to respond to two items about needle sharing and transmission that were similar to those asked about sex: *I worry about infecting others by sharing needles* and *sharing needles is not a problem if your viral load is undetectable*. The low number of respondents who have shared needles is reflected in the *not applicable* responses to these items. When we look at responses among those who have shared injecting equipment in the last twelve months, most respondents indicated that they were concerned about infecting others through the sharing of needles, and most respondents did not think that undetectable viral load lowered the concern about infection through needle sharing.

**TABLE 71 Attitudes relating to drug use and infection (percentage of full sample and number of those who shared injecting equipment)**

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
<b>Total sample</b>					
Sharing needles is not a problem if your viral load is undetectable	55.5	6.9	.5	2.4	34.8
I worry about infecting others by sharing needles	4.3	1.5	2.4	12.8	78.9
<b>Those who have shared</b>					
Sharing needles is not a problem if your viral load is undetectable	12	3	1	2	0
I worry about infecting others by sharing needles	1	2	1	12	2

# 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 72. 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 those on a government benefit.

**TABLE 72 Current accommodation of respondents (percentage of total sample)**

Own or purchasing house or flat	35.2
Private rental accommodation	38.2
Public rental accommodation(government owned)	15.6
Rent-free (e.g. provided by friends, family, etc.)	4.8
Community housing/housing co-operative	2.6
Other	3.6

Households varied considerably. 43.2% of PLWHA lived by themselves, while the remainder lived with between 1 and 6 other adults (median=1) and with between 1 and 5 children (for those living with children: mode=1 median=2). Around one third (34.1) lived with a partner or spouse, and 6.4% lived with dependent children. These children ranged in age from less than 1 to 34 (mean=13.4, median=13.5). In addition, 7.1% lived with other family members and 13.0% with a flatmate.

Most lived in a residence with 2 bedrooms (45.2%), while the remainder had 3 bedrooms (28.0%), 1 bedroom (16.9%), 4 or more bedrooms (8.0%) or lived in a bedsit /studio (1.9%).

48.4% of PLWHA also lived with pets. The most common pets were dogs (23.0% of all respondents), and cats (17.5%). Other companion animals included fish, birds, rabbits and farm animals.

72.4% of respondents had access to a car. When asked how easy it was to access public transportation, 11.1% said it was very difficult, 12.6%, difficult, 38.0% easy and 38.3% very easy.

84.2% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (N=146), the main reasons given were that it was too small (38.2%), lacked privacy (33.7%) and was too expensive (27.0%).

**TABLE 73 Reasons current accommodation is unsuitable (percentage of those with unsuitable accommodation)**

Too small	38.2
Lack of privacy	33.7
Too expensive	27.0
Confidentiality problems	22.6
Poor condition of housing	20.5
Fear of violence	18.8
Inadequate for my current state of health	18.7
Too far from health services	18.3
Inadequate facilities for carer(s)	16.0
Too far from other services	15.7
Harassment	15.5
Other	22.8

(Multiple responses possible)

## Changes in Accommodation

Participants were asked if they had ever changed their accommodation as a result of having HIV/AIDS. 31.6% had, and 10.4% had in the last two years. On average all PLWHA had changed their accommodation 0.7 times ever as a result of HIV/AIDS (0.2 times in the last two years).

We asked what the circumstances were around participants' last change in accommodation. The results are shown in Table 74. Financial and health issues figured most prominently in response to this question. When asked if they had any other accommodation options for the future, 66.5% said they did not.

**TABLE 74 Reasons for changing accommodation**

Needed cheaper housing	31.1
Moved to a quieter location	27.9
Moved closer to health services	22.3
Better health	21.0
Planning for illness	18.8
Illness	18.3
To avoid harassment	16.6
Lack of privacy	14.1
Stopped working	13.1
Moved closer to other services	12.5
Ending of relationship	12.3
Moved closer to friends	10.3
Improved finances	9.1
Moved in with family	7.5
Moved out of family home	5.2
Looking for/returned to work	4.7
Beginning of new relationship	4.5
Other	23.8

(Multiple responses possible)

## 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 aging and changes in life goals.

### Employment Status

Just over half (51.2%) of the respondents were currently employed, with slightly more being in full-time work (34.1%) than those in part-time work (17.1%). The remainder tended to describe themselves as either unemployed (10.7%) or retired (19.8%).

Of those who were working, the mean number of hours worked was 34.1 (median=38.0). Those working full time worked an average of 40.5 hours per week (median=40.0) and those in part time employment worked an average of 21.5 hours/week (median=20.0). Those who were not working stopped work between 1984 and 2005 (mean=1999, median=2000).

**TABLE 75 Employment status**

Work full-time	34.1
Not working/Retired	19.8
Work part-time	17.1
Unemployed	10.7
Student	4.2
Home duties	3.3
Other	10.8

## Impact of HIV and Treatment on Employment

We asked respondents how their initial HIV diagnosis affected their career plans and how their plans had changed since then. These data are shown in tables 76 and 77 below. A large proportion indicated that their career ended at their time of diagnosis (19.6%).

**TABLE 76 Impact of HIV diagnosis on career plans (percentage of sample)**

My career plans did not change	29.7
My career ended/I stopped work	19.6
It was more difficult to plan for the future	22.8
A career was no longer as important	16.8
I changed careers	9.1
I was less likely to change careers	1.9

HIV also has a negative impact on the continuing work lives of HIV positive people. When asked what the ongoing impact of HIV was on their work life and career plans, one quarter said that their career ended or they stopped work, while a similar proportion said they found it more difficult to plan their work life.

**TABLE 77 Ongoing impact of HIV on career/work**

My career ended/I stopped work	22.6
It is more difficult to plan for the future	22.1
My career plans have not changed	25.0
A career is no longer as important	14.4
I changed careers	10.7
I am now less likely to change careers	5.3

We asked about the impact of antiretroviral therapy on respondents' career plans (see Table 78 below). Of those that have used antiretrovirals, the most common response was that this had not affected their plans.

**TABLE 78 Impact of antiretroviral therapy on work (percentage of those who have used or are using ARVs)**

There has been no change to my plans	35.4
I stopped work	14.4
I anticipate a longer time in the workforce	12.3
I went back to work	5.2
I considered going back to work	8.3
I made a new career plan	7.0
I considered a new career plan	5.4
I considered stopping work	2.9
Other	9.1

## Interruptions to Employment

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those who have worked, 51.6% had stopped work for reasons related to HIV at some point. Of the entire sample, 27.4% had stopped work on one occasion, 9.2% on two occasions, and 3.6% on three occasions. These work interruptions averaged 5.9 years (median= 4.9 years). The circumstances relating to the most recent interruption to employment are given in Table 79 below. The most common responses were poor health and diminished energy levels. Almost half of the sample reported that psychological health (stress, depression or anxiety) had played an important role in the decision.

**TABLE 79 Circumstance surrounding last interruption to employment**

Poor health	48.3
Stress, depression, anxiety	47.4
Low energy levels	46.5
To have more time to myself	14.1
Expecting illness in the future	13.5
To move to a different location	12.5
Redundant/sacked	10.1
To care for another HIV positive person	5.2
Other	10.6
(Multiple responses possible)	

These circumstances are also reflected in the participants' HIV/AIDS status at the time they ceased work. Nearly half said that they were ill at the time, although importantly, over one third said that they were not ill at the time, perhaps reflecting both the anticipation of illness and the psycho social impact of HIV.

**TABLE 80 HIV/AIDS status at time of last interruption to employment**

I had HIV and had been ill	45.3
I had HIV but had not been ill	39.7
I had been diagnosed with an AIDS-defining illness	15.0

We asked participants their source of income during their most recent interruption to employment. Over two thirds said they relied on a government benefit of some sort.

**TABLE 81 Source of income when not working**

Benefits/pension/social security	71.6
Salary	11.0
Superannuation/annuity/savings	9.4
Partner supported me	3.9
Family/friends supported me	1.1
Other	2.9

Of those that stopped working at some point, 47.7% had returned to work. This was most commonly for financial reasons (see Table 82), although better psychological health, better physical health and the need to perform meaningful tasks were also important.

**TABLE 82 Reasons for returning to work**

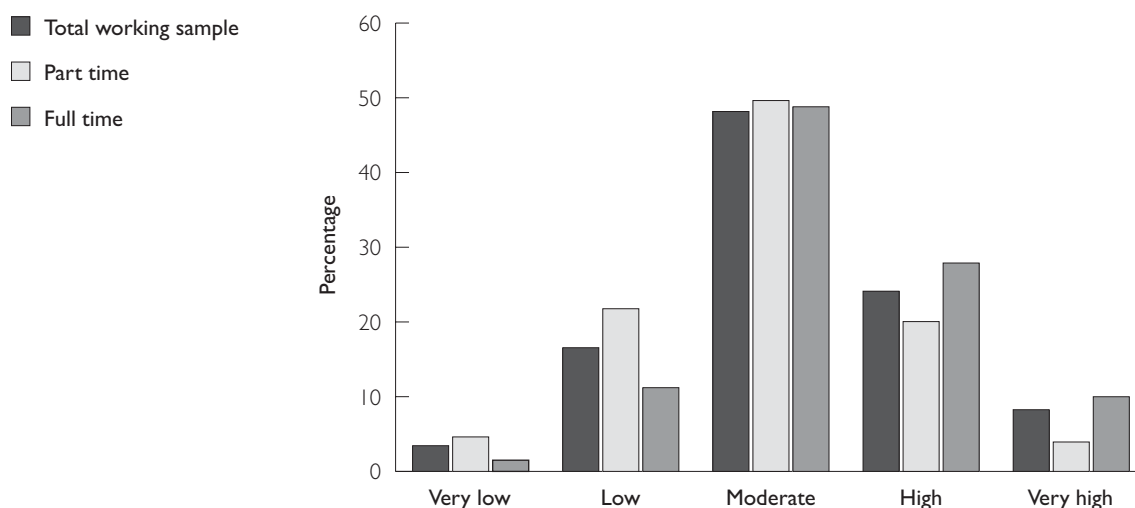
Financial reasons	77.8
To do something worthwhile	56.4
Better psychological health	52.4
To have something to do	51.8
Better physical health	48.8
To have more social contact	44.6
The possibility of working part-time	32.9
The possibility of flexible work hours	27.0
The possibility of working full-time	12.5
Other	14.6

(Multiple responses possible)

### 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 (48.3%) while 24.2% said it was high and 7.9% said it was very high. Only 3.1% rated the stress level as very low and 16.5% said there was low stress (see Figure 12).

**FIGURE 12 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, 12.5% said that they did not attempt to keep their status confidential (see Table 83). 30.4% 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 and had fewer problems when they do chose to do so.

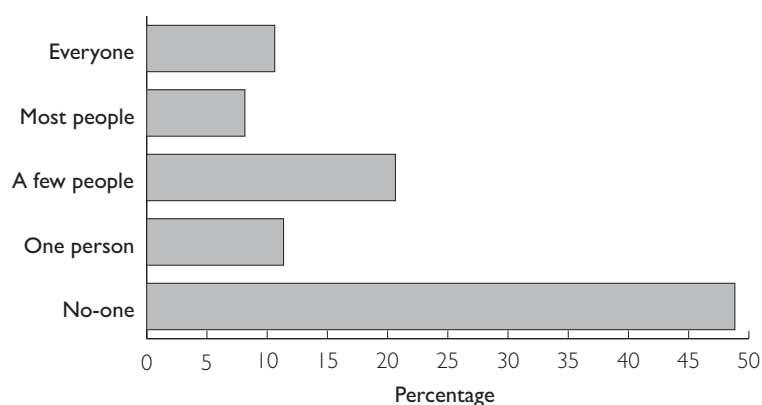
**TABLE 83 Difficulties with HIV status confidentiality in the workplace: percentages of total and specific samples**

	Total working sample	AIDS related	Non-AIDS related
No problems	30.4	27.0	59.7
I do not try to keep my HIV status confidential	12.5	68.3	16.3
Gossip	7.2	11.1	13.3
Explaining absences from work	6.4	7.8	12.2
Visible signs of illness	4.7	4.8	9.0
Difficulty keeping and taking medication	3.9	3.2	7.5
Other	2.2	3.2	4.1

(Multiple responses possible)

When asked how many people in their workplace knew that they were HIV positive, 10.9% said that everyone knew, 7.9% said most people knew, 20.7% said a few people knew, 11.4% said one person knew and 49.0% said no-one knew (see Figure 13). Those working in a HIV related job were more likely to have to say everyone knew their HIV status than those in non- HIV related work (50.8% versus 4.9%) and similarly less likely to say no-one knew their HIV status (4.8% versus 55.7%).

**FIGURE 13 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 84). One third said that they tired more quickly, and one fifth said that they had difficulty concentrating.

**TABLE 84 Impact of HIV on work capacity (percentage of those in paid employment)**

It is not affected	50.5
I tire more quickly	32.5
I have difficulty concentrating	20.2
I work reduced hours	16.5
I cannot always go to work	11.0
I am less productive	10.4
I do different duties	2.5
Other	4.1

(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 85) 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 85 Capacity within workplace for HIV related interruptions (percentage of those in paid employment)**

	never	seldom	sometimes	often	always
For medical appointments	7.6	3.4	14.0	14.2	60.8
For counselling	24.5	6.0	15.7	8.5	45.3
When you are sick	3.6	2.6	12.4	12.3	69.2
To do volunteer work	45.6	8.8	14.4	7.3	23.8

## Anticipated Changes in Work Life for Those Working and Those Not Working

Respondents were asked if they currently had plans to change their work arrangements, and 39.1% said they did. Of those who described themselves as unemployed, 46.9% said they planned to start or return to work.

**TABLE 86 Plans for changes to work life (percentage of employed respondents)**

	Full time	Part time	Total working sample
I want to stop work	3.0	4.9	3.7
I want to change the type of work I do	20.8	23.6	21.8
I want to reduce my work hours	14.1	9.0	12.4
I want to increase my work hours	1.7	16.0	6.5

The main incentives for changes in work arrangements were financial (see Table 87). Among those who intended to start or return to work, the primary motivations were financial and social, and among those planning to stop work, the principle motivations were stress reduction, better psychological health and better physical health.

**TABLE 87 Reasons for changes to work plans among full sample, those intending to return to work and those intending to stop work**

	Intending to return to work	Intending to stop work
Financial reasons	89.5	24.3
To reduce stress	28.0	61.4
To do something worthwhile	63.4	47.4
To have something to do	63.8	4.6
Better physical health	44.5	28.6
Worse physical health	2.1	13.6
Better psychological health	54.3	24.3
Worse psychological health	2.2	9.1
The possibility of flexible work hours	26.4	13.8
The possibility of working part-time	41.2	19.5
The possibility of working full-time	14.4	0.0
To have more social contact	56.7	23.3
To have less social contact	2.1	4.4

(Multiple responses possible)

## Leisure

Respondents were asked how they spend their time while not working. Each respondent indicated the three activities that occupy most of their time. Almost half indicated that leisure activities (for example reading) occupy their time. Slightly fewer identified housework and resting, while one quarter said they spent their time socialising.

**TABLE 88 Activities pursued while not working: percentage of total sample**

Leisure activities (reading, etc.)	46.2
Housework/chores	40.2
Resting	39.7
Socialising with close friends	26.5
Spending time with family	12.3
Socialising with other friends	4.2
Socialising with HIV positive friends	5.7
Volunteer work in HIV/AIDS organisation	5.9
Volunteer work in other organisation	5.7
Looking after children	3.3
Looking after another HIV positive person	0.8
(Multiple responses possible)	

## 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 89 below. As with the previous HIV Futures surveys, around one half had a government pension or benefit as their main source of income. Slightly fewer were receiving a salary and 4.8% had superannuation as their main income source.

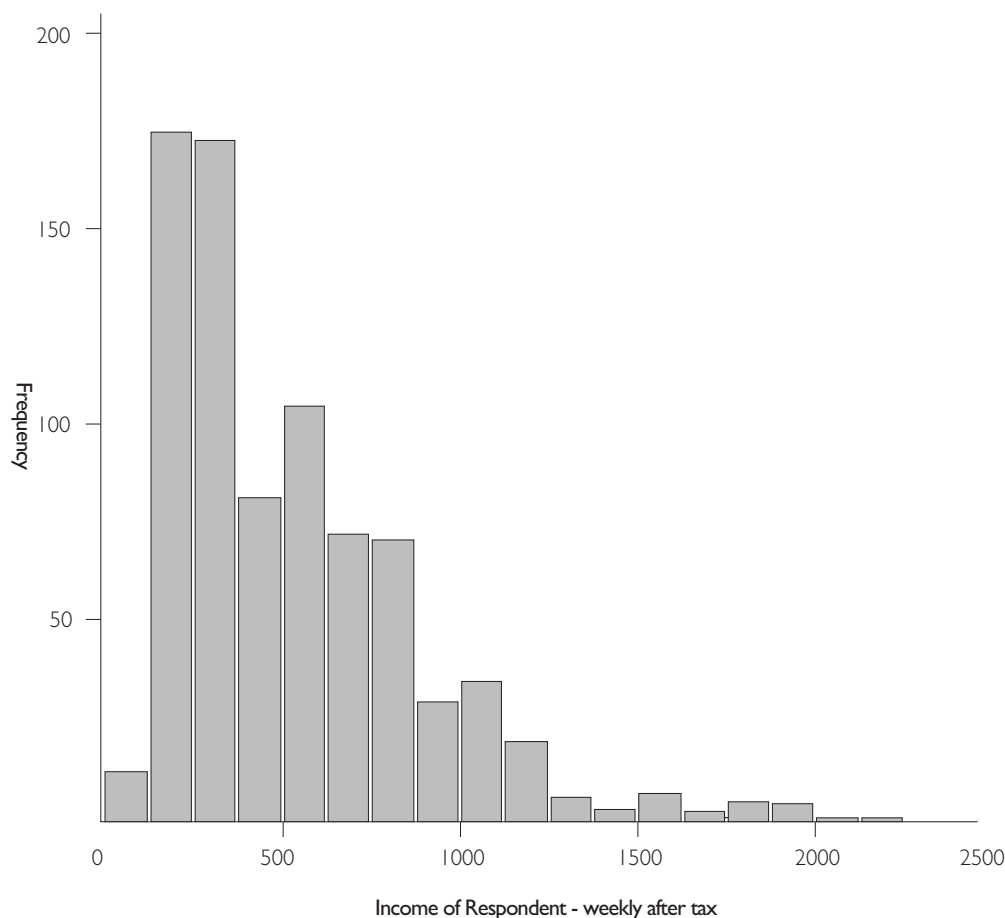
**TABLE 89 Primary source of income: percentage of total sample**

Benefits/pension/social security	45.7
Salary	43.5
Superannuation/annuity/savings	4.8
Partner supports me	2.2
Family/friends support me	0.3
Other	3.5

The median weekly in-hand income for respondents was \$400. Figure 14 below 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. 26.1% of respondents had a partner with whom they share financial resources. The partners' median weekly income was \$550.



**FIGURE 14 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 90 below. The total mean expenditure on medication was \$53.07 per week with complementary therapies accounting for almost half the total. Mean rental or mortgage costs were \$197 with the highest costs being in NSW (mean= \$229) and Western Australia (mean=\$180.11). Food and utilities accounted for around \$118 and \$68 respectively.

20.4% of respondents owned their own home, while 18.1% were paying off their home. 15.3% had owned their own home in the past, but do not currently. 31.0% received a rental subsidy averaging at \$90.86 per week (median= \$60).

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$40,395 with a median of \$4,900. Those who owned their home had a median debt of \$2,000 (mean=\$41,198), those who were currently paying off their home had a median debt of \$50,293 (mean=\$114,556), those in private rental accommodation had a median debt of \$5,000 and those in public rental accommodation had a median debt of \$908. Slightly less than one-fifth (18.8%) had used the services of a financial counsellor in the last two years.

**TABLE 90 Weekly expenditure on medications and essentials (\$AU)**

	Mean	Median
Rent or mortgage repayments	\$197.13	\$140
Food	\$117.62	\$100
Utilities	\$67.91	\$50
Complementary therapies	\$22.70	\$10
Other medication	\$15.45	\$9
Antiretroviral drugs	\$14.92	\$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 35.9% (n=296) of those receiving a benefit in the last two years had received such an assessment. When asked what this experience resulted in, only 4.1% (n=12) said that their benefit was terminated (See Table 91 below). 18.9% said that the assessment resulted in changes to their conditions of benefit. Importantly the experience of assessment resulted in distress for two thirds of the respondents while it clarified concerns for less than one in five.

**TABLE 91 Consequences of receiving an assessment of benefit from a Commonwealth Medical Officer (percentage of those assessed in last 2 years)**

Require documentation from your doctor	69.1
Cause you distress	60.3
Result in changes to the conditions of your benefits	18.9
Result in an independent assessment	14.5
Clarify concerns that you had	15.8
Result in a shift from Pension to Newstart allowance	4.2
Result in termination of your benefits	4.1

(Multiple responses possible)

## POVERTY

As with the previous HIV Futures surveys, we have used the quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR) 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 IAESR (2005) data for the December quarter (the time at which the survey was completed).

According to this measure over one quarter (28.3%) of PLWHA were living below the poverty line. That this figure has remained so high across 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 92).

**TABLE 92 Poverty by employment status (percentage of employment categories)**

	Below poverty line	Above poverty line
Employed	7.1	92.9
Not employed	51.2	48.8

$\chi^2(1,1) = 185.283, p < 0.001$

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 93). There was no gender difference in the proportions of people living below the poverty line.

**TABLE 93 Poverty by income source**

	Below poverty line	Above poverty line
Benefits/pension/social security	58.0	42.0
Partner	14.3	85.7
Super/annuity/savings	7.3	92.7
Salary	3.3	96.7
Family/friends	0.0	100.0
Other	0.0	100.0

$\chi^2(5,1) = 278.303, p < 0.001$

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 94).

**TABLE 94 Poverty by shared income status**

	Below poverty line	Above poverty line
Sole income	35.4	64.6
Dual income	15.4	84.6

$\chi^2(1,1) = 35.659, p < 0.001$

There is also a clear relationship between poverty and self-rated health and well being (see tables 95 and 96). 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 95 Self-rated health of those above and below the poverty line (percent within poverty group)**

	Below poverty line	Above poverty line
Poor	8.1	3.2
Fair	37.6	22.9
Good	39.8	46.4
Excellent	14.5	27.5

$\chi^2(3,1) = 33.904, p < 0.001$

**TABLE 96 Self-rated well being of those above and below the poverty line (percent within poverty group)**

	Below poverty line	Above poverty line
Poor	12.3	5.2
Fair	38.2	29.8
Good	37.3	41.9
Excellent	12.3	23.2

$\chi^2(3,1) = 24.771, p < 0.001$

## 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 97 below, 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 97 Difficulty paying costs of items and services**

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=598) <sup>6</sup>	59.6	31.5	8.9
Other prescribed medication (n=751)	52.2	36.7	11.1
Medical services (doctor, dentist, etc.)(n=769)	52.8	31.5	15.6
Complementary Therapies (n=529)	45.6	35.4	19.0
Support services (counselling, etc.)(n=351)	67.3	22.1	10.6
Entertainment (theatre, movies, concerts, etc.)(n=786)	37.6	31.4	31.0
Going out (eating/drinking)(n=815)	35.7	31.5	32.8
Sport (exercise, gym, etc.)(n=575)	44.2	26.7	29.0
Recreational drugs (n=370)	32.4	31.3	36.3
Travel/holidays (n=726)	24.7	29.2	46.1
Rent/Mortgage/Housing costs (n=764)	43.4	38.6	18.0
Utilities (telephone/electricity/gas/water)(n=859)	39.7	41.1	19.3
Food (n=869)	48.4	37.3	14.3
Clothing (n=843)	36.9	34.8	28.3
Transport (n=816)	48.4	34.5	17.2
Child care (n=71)	48.0	34.4	17.6

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 98 below). 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 98 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=155, 366) <sup>7</sup>	45.8	41.9	12.3	66.9	27.3	5.7
Other prescribed medication (n=182, 472)	33.5	46.7	19.8	61.4	31.4	7.2
Medical services (doctor, dentist, etc.) (n=176, 499)	38.6	36.9	24.4	58.1	29.5	12.4
Complementary Therapies (n=120, 340)	25.0	38.3	36.7	54.1	35.0	10.9
Support services (counselling, etc.) (n=93, 217)	60.2	24.7	15.1	72.8	20.3	6.9
Entertainment (theatre, movies, concerts, etc.) (n=184, 507)	10.9	29.9	59.2	49.3	31.0	19.7
Going out (eating/drinking) (n=184, 529)	8.7	27.7	63.6	46.3	32.3	21.4
Sport (exercise, gym, etc.) (n=127, 379)	18.9	23.6	57.5	54.4	27.2	18.5
Recreational drugs (n=99, 238)	10.1	23.2	66.7	42.0	34.0	23.9
Travel/holidays (n=154, 477)	3.9	25.3	70.8	32.3	30.8	36.9
Rent/Mortgage/Housing costs (n=171, 494)	24.0	46.8	29.2	51.8	34.8	13.4
Utilities (telephone/electricity/gas/water) (n=209, 541)	14.4	52.2	33.5	51.6	35.9	12.6
Food (n=207, 550)	20.3	53.6	26.1	60.9	30.5	8.5
Clothing (n=197, 542)	13.7	37.1	49.2	46.3	33.6	20.1
Transport (n=187, 525)	20.9	43.9	35.3	59.6	30.5	9.9
Child care (n=15, 48)	26.7	0.0	33.3	52.1	35.4	12.5

All categories are significant for  $\chi^2$  (2,1) at the  $p=0.001$  level except support services ( $p=.035$ ) and child care (non-significant, but small numbers)

## 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 49 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 99). When we examine use of services at other organisations, particularly notable are the greater proportions of those below the poverty line using housing assistance (28.1% versus 8.8%) employment services (16.5% versus 8.1%) and return to work skills (13.4% versus 4.9%).

<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.

**TABLE 99 Services used at HIV/AIDS organisations by those above and below the poverty line**

	Below poverty line	Above poverty line
Social contact with other PLWHA	44.0	21.4
Treatments advice	41.1	26.9
Financial assistance	38.6	11.8
Treatments information	35.9	23.1
Peer support group	34.5	16.6
Counselling	33.5	17.5
Informal peer support	25.4	13.4
Complementary therapies	25.0	11.8
Pharmacy services	23.2	12.7
Housing assistance	18.8	5.8
Financial advice	18.3	6.9
Legal advice	17.9	7.1
Community education campaigns	12.9	8.3
Transport	12.6	3.4
Internet access	12.5	4.9
Volunteer carer	11.6	3.5
Mental health services	11.6	5.3
Internet based information	11.6	5.7
Respite care	9.4	3.2
Library	9.0	4.4
Return to work skills	6.3	2.5
Employment services	5.8	2.1
Drug/alcohol treatment	3.1	1.4
Paid carer	1.8	1.2

(Multiple responses possible)

All significant for  $\chi^2$  (1,1) at  $p < 0.001$  except employment services, return to work skills, mental health services, library, internet based information, and community education campaigns all significant at  $p < 0.05$ , and drug/alcohol treatment ( $p = 0.100$ ).

**TABLE 100 Services used at other organisations by those above and below the poverty line**

	Below poverty line	Above poverty line	p
Pharmacy services	30.4	25.8	
Housing assistance	28.1	8.8	**
Library	21.1	12.2	**
Counselling	19.6	13.4	*
Complementary therapies	18.8	16.6	
Mental health services	17.9	10.2	*
Internet access	17.0	12.0	
Employment services	16.5	8.1	**
Transport	15.6	8.8	*
Treatments advice	14.7	11.7	
Return to work skills	13.4	4.9	**
Legal advice	13.0	8.8	*
Financial advice	11.7	11.8	
Internet based information	11.2	7.6	
Financial assistance	9.9	8.3	
Drug/alcohol treatment	9.4	4.6	*
Treatments information	7.6	8.7	
Community education campaigns	5.8	3.5	
Volunteer carer	5.8	3.4	
Social contact with other PLWHA	5.4	6.0	
Informal peer support	5.4	6.0	
Respite care	4.9	2.5	
Paid carer	4.9	2.3	*
Peer support group	4.0	4.1	

(Multiple responses possible) \* significant for  $\chi^2$  (1,1) at  $p < 0.001$ , \*\* significant for  $\chi^2$  (1,1) at  $p < 0.05$

## 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

6.8% of respondents indicated that they had experienced less favourable treatment in relation to accommodation (3.5% in the last two years).

### Health Services

#### HIV

27.2% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This comprised 10.1% of all respondents that had experienced such discrimination in the last two years and 17.1% that experienced this more than 2 years ago. When asked what form this discrimination took, the most common responses were increased infection control (35.6%) avoidance (34.5%) and confidentiality problems (31.6%). These experiences are shown in Table 101.

**TABLE 101 Form of HIV-related discrimination experienced at medical service (percentage of those experiencing discrimination)**

	Ever (N=269)	In last 2 years (N=91)
Increased infection control	35.6	31.8
Avoidance	34.5	33.3
Confidentiality problems	31.6	39.6
Treated last	29.0	17.4
Refusal of treatment	29.0	24.4
Rushed through	27.7	39.4
Harassment	9.3	7.1
Abuse	8.4	9.1

(Multiple responses possible)

## Hepatitis C

12.5% of hepatitis C co-infected respondents had experienced less-favourable treatment at a medical service as a result of having hepatitis C. This included 3.7% (n=7) who had experienced such discrimination in the last two years.

When asked what form this discrimination took, the main experiences were avoidance, additional infection control measures and confidentiality problems. These experiences are shown in Table 102.

**TABLE 102 Form of hepatitis C-related discrimination experienced at medical service (number of those experiencing discrimination)**

	Ever (N=23)	In last 2 years (N=7)
Avoidance	12	6
Increased infection control	9	1
Confidentiality problems	7	2
Rushed through	7	3
Refusal of treatment	6	0
Abuse	6	4
Treated last	4	0
Harassment	3	2

(Multiple responses possible)

## Insurance

29.9 % of respondents currently had private health insurance and 15.4 % currently had some other form of income or mortgage insurance.

18.6 % of respondents indicated that they had experienced less favourable treatment in relation to insurance. This included 30 respondents who had experienced this discrimination in the last two years. The most commonly reported example of less favourable treatment was being unable to take out an insurance policy, for example health insurance (34.1% of those reporting less favourable treatment), followed by refusal of or difficulties taking out travel insurance (17.1% of those reporting less favourable treatment) and ineligibility for life insurance (14.1%). Twelve respondents said they hadn't bothered to apply for insurance because they were told they were ineligible.

## Workplace

15.6% of respondents had experienced less-favourable treatment in the workplace as a result of having HIV. This comprised 5.5% of all respondents that had experienced such discrimination in the last two years and 10.1% that experienced this more than 2 years ago. When asked what form this discrimination took, the most common responses were general discrimination (30.1% of those experiencing less favourable treatment, termination of employment (15.6%) and abuse or harassment (10.1%).



# CONCLUDING COMMENTS

The data presented here begin to give a sense of the diversity of the lives of Australians living with HIV/AIDS. While it is clear that there can be no such construct as the 'typical' PLWHA, there are domains of disadvantage and clusters of experience. The intent of a research project such as this is neither to be mimetic in representing the lived experience of HIV, nor to be reductionist to such an extent that diversity is completely erased. Clearly there are social factors and experiences that influence both health and well being among this population, and it is through data sets such as these that we are able to examine them rigorously.

The experience of economic disadvantage highlighted in this study suggests important initiatives that need to be undertaken by both government and community sector alike. The impact of long term diagnosis on health and well being is available through the examination of these data and will form the basis of future publications. Factors such as aging and the impact that it has on general health and social engagement and the complexities of complementary therapy use have been previously highlighted through these studies.

Adequate planning for the future of our response to HIV/AIDS relies in no small part on our access to detailed information about how the epidemic affects those with the virus, and this information must go beyond concerns with adherence and unprotected sex.

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# 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 5 survey ran from 1 October 2005 until 31 March 2006. The survey was available as both a self complete, mail back survey and as an on-line survey. This is the first time that HIV Futures has been made available on-line, reflecting the growing use of the internet amongst Australian households (ABS). On-line surveys have been used successfully to collect health information from GLBTI Australians and same sex attracted young people in Australia (Pitts et al., 2006; Hillier et al., 2005). 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, an experienced commercial provider of web-based surveys with excellent attention to the issue of security and privacy.

### Design

The instrument was based in large part on the HIV Futures 4 survey (Grierson et al, 2004), which in turn was adapted from the three previous surveys (Ezzy et al., 1998, Grierson et al., 2000, Grierson et al., 2002). The survey content was developed in consultation with a number of organisations and individuals from the HIV/AIDS sector (see Consultations section below). Most items were retained in their original format to allow comparisons between the four studies. Additional options were included in some questions to reflect changes in personal experiences of living with HIV/AIDS, and policy and service changes over the past two years. Some items in question D1 were re-worded and re-ordered in consultation with NAPWA in order to best capture the services provided by staff at AIDS councils and PLWHA organisations.

The survey consisted of 250 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 were able to 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. As the survey was anonymous and as multiple recruitment strategies were employed 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 4 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, emailing the researchers.

Participants in the positive Health (pH) Study conducted by the NCHSR and ARCSHS were mailed a copy of the survey. pH is a cohort study of HIV positive people in NSW and Victoria (Fogarty et al. 2003). The responses to the HIV Futures Study were linked by a confidential non-identifying code to the data collected by the pH study.

### 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 gaydar.com.au, ssonet.com.au, and blazemedia.com.au (check – did we also advertise on-line in QLD)

#### *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 post-cards and reception cards were placed on reception desks. 3000 Postcards were also sent out with the magazine Talkabout. This magazine is NSW-based and is focused on HIV issues, although it has a wider distribution than just PLWHA. The magazine is mailed directly to subscribers and distributed on-site to numerous organisations and venues around NSW. The survey was also promoted on JOY radio (Melbourne).

### 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 direct to clinical practices that see a significant number of HIV positive clients. This included, but was not limited to, the S100 prescribers. The survey 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 103 below 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 103 Data on primary site of survey collection**

	<b>Paper</b>	<b>On-line</b>	<b>Combined</b>
Completed a previous HIV Futures Survey	48.6	16.3	39.9
Mail-out from HIV/AIDS organisation	22.8	16.7	21.2
Picked up a copy at HIV/AIDS organisation	9.4	0.9	7.1
Picked up a copy at Medical Centre or Hospital	8.9	0.9	6.7
Told about it by someone who had already completed it	0.7	5.6	2.0
Gaydar.com.au	0	19.1	5.1
Internet search	0	8.8	2.4
Gay newspaper/magazine	0.3	7.0	2.1

## ON-LINE SURVEY

As expected, the on-line sample was younger, more likely to be male and had a higher level of education compared with those completing the survey on paper, however the combined sample was not different from the HIV Futures 4 sample in terms of expected demographics. (Bandilla and Bosnjak, 2003)

**TABLE 104 Characteristics of online and paper survey samples compared with HIV Futures 4.**

Variable	Paper	Online	Combined	Futures 4
N (%)	751 (77.2)	222 (22.8)	973	1059
Sex(%)				
Male	89.5	95.9	91.0	90.7
Female	10.1	4.1	8.7	9.1
Age, years (Mean, range)	47 ± 9, 19-78	41±9, 19-78	45.8±9.8	44.1±9.3
Aboriginal/Torres Strait Islander n(%)	13 (1.8)	5 (2.4)	18 (1.9)	31(2.9)
Sexuality:				
Gay/lesbian	78.0	90.7	80.9	77.6
Heterosexual	15.8	5.1	13.4	14.9
Bisexual	4.1	3.3	4.0	5.8
Employment status:				
Employed:	44.8	72.3	51.3	44.5
Residential location:				
Capital city/Inner suburban	60.2	75.2	63.6	60.3
Education:				
University degree	24.5	44.3	29.7	26.2
Estimated length of infection, years (Median)	15.0 (<1-36)	6.0 (<1-35)	14.0	13.0 (<1-39)
Use of treatments:				
Currently taking	80.9	58.4	75.8	70.6
Taken in the past	9.3	11.4	9.8	16.5
Never taken	9.8	30.1	14.5	13.0
Most recent CD4 count, cells/μL (Median)	470	540	485.5	460.0
Most recent viral load copies/mL (Median)	12000	11250	11750	0
Most recent viral load undetectable (%)	69.6	54.5	66.2	n/a

Year tested HIV positive	Paper	Online	Combined	Futures 4
Before 1985	7.7	2.8	6.6	9.0
1985-1989	28.3	10.6	24.3	28.6
1990-1994	23.7	11.5	20.9	26.1
1995-1999	20.6	18.3	20.1	21.8
2000-2004	18.1	40.4	23.1	14.5
2005 on	1.6	16.5	5.0	n/a

We were also interested in the extent to which we were accessing HIV positive people who had participated in previous HIV Futures Surveys and other research projects (see Table 105). It is interesting to note that 60% of the sample completing the survey on-line had not participated in any of the listed research projects compared with 40% of the remaining participants. This is likely to be because the most common source of information about the study for the online participants was gaydar.com.au, compared with almost half of the remaining participants having filled in a previous Futures survey.

**TABLE 105 Data on previous research involvement**

	Paper	On-line	Combined
Positive Health (pH)	18.1	13.1	17.0
HIV Futures I (1997)	26.6	11.7	23.2
HIV Futures 2 (1999)	34.1	13.5	29.4
HIV Futures 3 (2001)	42.2	18.9	36.9
HIV Futures 4 (2003)	51.4	23.0	44.9
Periodic survey	19.0	17.6	18.7
None of the above	40.1	60.4	44.7

(Multiple responses possible)

## 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.

Secondly, 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.

Thirdly 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 anti-retroviral 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 (2006) and the data were weighted to conform with 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 that follow. 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 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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