

# **HIV FUTURES 3**

## **Positive Australians on Services, Health and Well-Being**

**Jeffrey Grierson, Sebastian Misson, Karalyn McDonald, Marian Pitts and Mary O'Brien**

**The Living with HIV Program  
at The Australian Research Centre in Sex, Health and Society  
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## ACRONYMS USED IN THIS REPORT

AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
AIHW	Australian Institute of Health and Welfare
AIVL	Australian Injecting and Illicit Drug Users League
ANCHARD	Australian National Council on HIV/AIDS, Hepatitis C and Related Diseases
ARCSHS	Australian Research Centre in Sex, Health and Society
ARV	Antiretroviral therapy
BRASH	Brisbane Region Men and Sexual Health Study
CTTAC	Clinical Trials and Treatments Advisory Committee
HIV	Human Immune-deficiency Virus
IAESR	Institute of Applied Economics and Social Research
IDU	Injecting Drug User
MMASH	Melbourne Men and Sexual Health Study
NAPWA	National Association of People Living With HIV/AIDS
NCHSR	National Centre in HIV Social Research
NCHECR	National Centre in HIV Epidemiology and Clinical Research
pH	Positive Health Study
PLWHA	People living with HIV/AIDS
SMASH	Sydney Men and Sexual Health Study





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## EXECUTIVE SUMMARY

The HIV Futures 3 survey was completed by 894 HIV positive Australians from all states and territories.

### HIV antibody testing and counselling:

- 19.1% tested for HIV because they became ill;
- 15.8% tested as part of routine health screening;
- 13.6% tested because they were a member of a risk group;
- 12.9% tested because of a particular risk episode;
- 3.7% were tested without their knowledge.

When asked about pre- and post-test counselling:

- 20.9% had received pre-test counselling;
- 22.4% of those testing in the last two years received pre-test counselling;
- 53.7% received post-test counselling;
- 75.8% of those testing in the last two years received post-test counselling.

Pre and post test counselling was most often provided by medical personnel and respondents were generally satisfied with the counselling they received.

### Health Status and Health Management

Almost all PLWHA have taken a CD4/T-cell test and a viral load test. Over three-quarters rate their health as good or excellent and similar proportions rate their general well-being as good or excellent. One in five respondents had been diagnosed with an AIDS defining illness.

Health problems related to HIV:

- 38.4% report experiencing lipodystrophy;
- 30.7% experience weight loss;
- 68.5% low energy or fatigue;
- 52.2% have a sleep disorder;
- 33.8% experience confusion or memory loss.

Two-fifths of respondents indicated that they had experienced AIDS related illness. Two fifths also indicated that they had a major health condition other than HIV/AIDS. The most common other conditions were hepatitis C, cardiovascular disease, asthma and hepatitis B.

**Hepatitis:**

- 27.9% had at some point had hepatitis A;
- 44.9% had been vaccinated against hepatitis A;
- 31.9% had at some point been diagnosed with hepatitis B;
- 53.9% had been vaccinated against hepatitis B;
- 13.9% of respondents were hepatitis C positive;
- 10.7% of those with hepatitis C had ever taken medical treatment for this;
- 16.1% of those with hepatitis C had ever taken complementary therapy for this

The activities to improve and maintain health were healthy eating, sleep, compliance with medication, exercise and social activities.

**Use of Antiretroviral therapy**

**Antiretroviral use:**

- 71.7% are currently using ARV;
- 86.9% have used ARV at some time;
- 77.1% commenced ARV on the advice of their doctor;
- 65.8% of respondents were using a combination of three drugs;
- 60.4% of the sample were taking ARV twice daily;
- 11.8% were taking ARV three times a day;
- 82.8% had not missed a dose of ARV in the two days prior to completing the survey.

**Difficulties taking antiretrovirals:**

- 87.1% of those participants currently taking ARV reported that they experienced difficulties taking them of which the major problems were:
  - 45.0% remembering to take the drugs on time;
  - 30.4% organising meals around the drugs;
  - 30.7% taking medication in public;
  - 28.2% transporting medication;
  - 24.6% taking large numbers of tablets.

Side effects from ARV are a significant concern for those on treatment with 43.9% reporting that they experienced these. The most common were diarrhoea, nausea, fatigue and lipodystrophy.

Breaks from antiretroviral therapy:

- 41.3% of those currently on ARV have taken a break from ARV therapy;
- The median length of break was 90 days;
- Most breaks were taken for a combination of lifestyle and clinical reasons;
- Breaks often resulted in improved well-being, but deterioration of clinical markers;
- Doctors were less likely to be consulted before a break than afterward;
- 67.1% saw their doctor during the treatment break.

Does ARV mean better prospects for PLWHA?

- 75.2% agree;
- 16.2% believe that it is still too soon to tell.

Antiretroviral Resistance

- 24.9% of those who had ever used ARV had had a resistance test;
- 75.4% of those tested found resistance to one or more drugs;
- 57.6% of those with resistance changed treatments.

Complementary therapies

- 52.9% use some form of complementary therapy;
- Vitamins and mineral supplements are the most popular;
- Complementary therapies tend to be used in conjunction with allopathic treatment.

**Services**

For general health care treatment 49.9% of PLWHA see an HIV GP/S100 prescriber, whereas for HIV specific treatment 47.9% see an HIV GP/S100 prescriber and 35.6% see an HIV specialist/physician. Most respondents had visited either a GP who specialises in HIV or an HIV specialist in the last six months.

Experiences of health care:

- 34.5% pick up all of their prescription medication at one place;
- 41.9% go to two places for prescription medication;
- 23.7% go to three or more places for prescription medication.

Services used at AIDS organisations:

- 46.9% treatment advice;
- 38.8% social contact;
- 30.6% counselling;
- 30.1% peer support;
- 22.6% complementary therapies;
- 18.3% advice on legal matters;
- 12.0% advice on financial matters.

### **Well-being and Information**

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

For 52.0% of respondents, their HIV status had been disclosed to another person when they did not want it to be (29.7% in the last two years).

HIV was an important part of the identity of 52.1% of respondents and an essential part of the identity of 19.0%. HIV status tended to be less important to PLWHA than identities based on sexuality, gender or family.

Sources of support:

- 81.0% partners/spouse;
- 58.7% pets;
- 50.6% doctors;
- 46.6% close friends;

In the last six months slightly less than one third of respondents have taken prescribed medication for depression and over one quarter for anxiety.

One fifth plan only one day at a time, while 52.5% plan at least one year ahead.

71.4% have some contact with HIV/AIDS organisations, mostly by receiving newsletters or being clients of these organisations. 11.5% were employees of AIDS organisations.



**Involvement with other PLWHA:**

- 95.0% know another PLWHA;
- 18.0% have a spouse/partner with HIV;
- 64.8% know acquaintances with HIV;
- 79.2% spend at least some time with other PLWHA;
- 15.4% spend a lot of time with other PLWHA;
- 19.3% spend no time with other PLWHA;
- 25.9% have been involved with the care of someone with HIV/AIDS;
- 81.7% someone close has died of AIDS related causes.

**Relationships and Sex**

A quarter (25.4%) of PLWHA are not having sex at present. 47.6% of PLWHA are currently in a regular relationship, and a slightly smaller number have sex within their relationship. A smaller group, comprising mainly gay men, has both a regular relationship and casual partners (19.8%) and 28.2% have casual partners only.

Of those in a regular relationship 40.5% have a partner who is also HIV positive, 57.9% have an HIV negative regular partner and 1.6% a partner of unknown status. Nearly all (98.3%) PLWHA have disclosed their status to their regular partner, usually when they were diagnosed or at the time of, or prior to, the commencement of the relationship. In the majority of cases the partner's reaction to disclosure was positive and in one third of cases it brought the partners closer together, but 26.9% also reported that their partner was worried or scared.

Under half 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.

**Condoms always used with regular partners by:**

- 0% of women with male HIV positive partners;
- 52.0% of women with male HIV negative or unknown partners;
- 8.2% of men with male HIV positive partners;
- 58.9% of men with male HIV negative or unknown partners;
- 12.5% of men with female HIV positive partners;
- 75.0% of men with female HIV negative or unknown partners.

Forty-three per cent of the sample had sex with casual partners in the past six months. 41.0% of the men reported that they always used condoms with casual male partners and 58.8% with casual female 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 75.0% of these instances.

Condom use with the most recent casual partner:

- 30.4% with an HIV positive partner;
- 71.1% with a partner of unknown HIV status;
- 74.1% with an HIV negative partner.

There were only 16 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 2 instances with an HIV negative casual partner.

Around half of PLWHA would prefer to be in a relationship with someone who is also HIV positive. Over half of PLWHA expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLWHA (60.9%) felt HIV had a negative effect on their sexual pleasure.

Only 13.1% 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* (9.4%) or that *undetectable viral load means HIV is unlikely to be transmitted* (11.7%). However, 30.7% of PLWHA agreed with the statement *If there was a vaccine which prevents HIV I would not practice safe sex*.

### **Recreational Drug Use**

Alcohol is the most commonly used drug by PLWHA (81.1%), and more than half (54.6%) use tobacco. Almost three-quarters of respondents reported that they had never injected illegal drugs and of those respondents who had injected illegal drugs approximately half had done so

in the last 12 months. Of PLWHA who reported injecting drugs, 93.3% had not shared injecting equipment in the past twelve months.

All of those who shared injecting equipment in the last 12 months (N=15) did so with at least one risk reduction strategy such as using the needle last or washing/bleaching or using with another person who was HIV positive.

Circumstances of sharing injecting equipment:

- 63.8% washed or bleached the needle;
- 60.7% did not have access to other needles;
- 57.2% shared with a sexual partner;
- 47.5% used the needle last;
- 40.3% the other person was HIV positive;
- 12.4% the other person was hepatitis C positive;

Approximately one fifth of all respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and one in fifteen reported having had a bad experience as a result of using both illegal drugs and ARV.

### **Accommodation**

Current accommodation:

- 36.1% own or are purchasing their house or flat;
- 35.3% are in private rental accommodation;
- 15.8% are in public rental accommodation.

Households:

- 49.1% live by themselves ;
  - 35.2% live with their partner or spouse ;
  - 6.3% lived with dependant children;
  - 50.8% live with pets.
- 
- 79.6% of respondents stated that their accommodation was suitable for their current needs;
  - 40.3% had ever changed their accommodation as a result of having HIV/AIDS ;
  - 36.5% had changed their accommodation as a result of having HIV/AIDS in the last two years.

## **Employment**

Slightly less than one half of respondents are currently in paid employment, with more than half of this number being in full-time work. 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:

- 13.7% stopped work;
- 11.3% anticipate a longer time in the workforce;
- 7.6% are considering going back to work;
- 6.5% have gone back to work.

Almost two thirds 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, anxiety and poor health

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

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

One half of PLWHA currently in work had not disclosed their HIV status to anyone at their workplace, while a quarter do not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work are gossip and explaining absences from work.

## **Finances**

Slightly less than half of the respondents identified their main source of income as a government benefit or pension. As well, more than one half of PLWHA reported experiencing some difficulty with meeting the cost of daily living.

Difficulty with meeting the cost of daily living:

- 63.9% difficulty paying for clothing;
- 64.4% difficulty paying for utilities;
- 52.7% difficulty paying for housing;
- 51.6% difficulty paying for food;
- 50.8% difficulty paying for transport.

One quarter of those on a government benefit had been assessed by a commonwealth medical officer. While this resulted in termination of benefits or change in conditions for few respondents, it caused distress for around half those assessed.

Over thirty percent 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 over one half of those on government benefits are living in poverty.

**Discrimination:**

- 11.1% experienced less favourable treatment in relation to accommodation, 4.5% in the last two years;
- 37.7% experienced less favourable treatment because of HIV in relation to health services, 18.0% in the last two years;
- 25.6% of hepatitis C co-infected respondents experienced less favourable treatment because of hepatitis C in relation to health services, 16.2% in the last two years;
- 22.1% experienced less favourable treatment in relation to insurance, 15.4% in the last two years.



## INTRODUCTION

It is now four years since the original HIV Futures report was released and we had for the first time a comprehensive picture of the complexity and diversity of the lives of HIV positive Australians. The first survey came at a time when antiretroviral drugs were starting to change the landscape of HIV. The second survey came at a time when many PLWHA were re-evaluating their relationship to these treatments in the light of side-effects, failure of treatments and the harshness of regimens. This survey, HIV Futures 3, is another two years on, at a time when the complexities of viral resistance have begun to dominate the clinical discourse, when the management of HIV increasingly involves fraught decisions around interruptions to treatment and balancing the effects of treatments against quality of life, at a time when management of HIV identity plays a critical role in negotiating the workplace and the health system, at a time when AIDS appears to have dropped off the agenda and yet can dominate the lives of those whom it affects.

In the consultations we undertook in preparation for this survey it was apparent that the clinical experience of living with HIV was becoming increasingly complex and the relationship of clinical experience to social experience was becoming more problematic. Finding a way to provide appropriate continuity of care for a diverse client group was a common theme among clinicians and service providers. Understanding the meanings and consequences of interruptions to treatment and difficulties with treatment, and structuring services to respond to these has been a key concern for many in the sector. Finding a voice for the social experience of HIV positivity in the sector and mobilising responses to the critical issues of poverty, mental health and marginalisation, has been far from easy and the consultations reinforced the need for data that address these issues with adequate depth. While the most pressing needs may be for the data that explicate the problematics of HIV, there is also a keen desire to see the positive elements of HIV positive life represented in the research.

Among HIV positive people, the management of HIV identity in home life, social relations, work and health services remains a challenge. This is not simply an issue of disclosure, but involves managing a sense of self that acknowledges the importance of HIV, but does not diminish the richness of personal experience. In the face of continued demonisation of HIV positive people in debates around HIV transmission, and talk of community complacency, being HIV positive is no simple exercise. It requires a constant balance between the need for social action and the need for self-preservation.

It was in response to these issues that we modified and expanded the HIV Futures questionnaire. The length of the survey is itself testament to the breadth of information that those in the AIDS sector

now need in order to appropriately respond to the needs of HIV positive people. The complexity of the survey speaks to the diversity of the HIV positive population.

HIV Futures is a survey that evolves and is not simply replicated. There are five significant changes to the survey in this round: an expanded section of HIV antibody testing; an expanded analysis of interruptions to treatment; an in-depth examination of the experience of co-infection with HIV and hepatitis C; a separate section dealing with discrimination; and a section dealing with issues of unwanted disclosure.

HIV Futures aims to reflect the socio-economic, political, pharmaceutical, legislative, and geographic contexts of living with HIV. It complements behavioural surveillance, epidemiology, analyses of treatment practices, care and support, and specific social and clinical interventions and provides the opportunity for community organisations, service providers, professionals, policy makers and individual positive people to reflect on the complexity of the experiences of PLWHA and to tailor their practices to meet current and emerging needs. We hope that whichever hat you wear, that you may find something in this report that stimulates you and heightens your resolve to work toward a positive future for HIV positive people.



## INSTRUMENT AND METHOD

### Methodology

This section describes the methodology of the study including the research design, the survey instrument, recruitment and sampling issues and the analysis of the data.

### Overview

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.<sup>2</sup>

The cross-sectional methodology was chosen for a number of important reasons.

First, the HIV Futures Surveys are **anonymous**.<sup>3</sup> 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-completed**. This means that PLWHA can complete the survey in a setting that is comfortable and safe for them and at their own pace. 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.

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<sup>2</sup> Comparisons can be made between population data over time and through a technique known as pseudo-cohort comparison where responses are matched on key responses. Analyses of this kind were made between the HIV Futures 1 and 2 Surveys and are presented in the report Changes (Grierson and Misson 2002). Data from a small subset of HIV Futures respondents that participated in the positive Health (pH) Study are also able to be matched and compared across the HIV Futures 2 and 3 Surveys.

<sup>3</sup> With the exception of pH study participants where the responses to the HIV Futures Survey are linked to their pH data with their consent. See below under recruitment.

Fourthly, the population of HIV positive Australians is constantly **evolving**. A cross-sectional survey allows us to include newly HIV positive individuals and ensure that our findings reflect all positive people, those who have recently seroconverted and 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 certain limitations in the methodology used. In terms of **sample representativeness**, caution must be exercised in the applications of the findings of this research in reference to individuals who are less likely to be included in the sample. This includes 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 that 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.

## **The Survey instrument**

### ***Design***

The instrument was based in large part on the original HIV Futures survey (Ezzy et al., 1998) and the HIV Futures II Survey (Grierson et al., 2000) with most items retained in their original format to allow

comparisons between the three studies. Additional sections and items were included to reflect the changes in both the personal experiences of living with HIV/AIDS, and the changes in policy and service context in the past two years. These included information on antibody testing, an expanded section on treatment breaks, additional items on the experience of discrimination and an expanded section on hepatitis C co-infection.

### ***Items and measures***

The HIV Futures 3 survey was a self complete, mail back questionnaire consisting of 250 items organised into eight sections: demographics; accommodation; health and treatments; services and organisations; 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 were 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 survey, once completed, was returned in a reply-paid envelope to the Living with HIV program. In addition participants were given the option, via a separate mail-back for adding their contact details to the program mailing list to receive reports and to participate in further research.

### ***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.

## Recruitment and Sampling

### *The study population*

There is no register of HIV positive Australians, as HIV testing is voluntary and anonymous. The most reliable data on the demographics of the HIV positive population are from epidemiological statistics collected by NCHECR. We can compare the sample recruited into the HIV Futures Study to the HIV positive population on these characteristics only (see also below under *weighting of the data*). As the survey was anonymous and as multiple recruitment strategies were employed a simple response rate cannot be calculated.

### *Principles of recruitment*

Recruitment for this study was undertaken on the basis of voluntary involvement and optimal access. To this end, recruitment took place using a set of strategies that maximised the potential of the survey to reach the diverse population of HIV positive Australians. This multi-pronged 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.

### *Strategies*

#### *1. Direct distribution*

##### *Mail-out*

The Living with HIV program at ARCSHS maintains a mailing list of individuals who have expressed interest in contributing to research projects in this area. Two copies of the survey were mailed to each person on this list. Individuals were encouraged to pass one of the surveys on to someone they knew who might not otherwise have received a copy. This was one of the ways of extending the reach of the study.

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 (Prestage et al. 2001). The responses to the HIV Futures Study were linked by a confidential non-identifying code to the data collected by the pH study.

An additional large-scale mail-out of the survey with the magazine Talkabout was conducted mid-recruitment. 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.

*Requests*

Potential participants were able to request a copy of the survey by telephoning the free call number, emailing the researchers or completing an on-line request form. The survey was also available for download as a pdf file on the study website.

*2. Promotion and Marketing*

A key element of the HIV Futures Study was the promotional strategy that accompanied the distribution of surveys. This included press releases, advertisements, links placed on community websites, articles placed in community newsletters, a promotional post-card and other, more low key promotion within agencies. This strategy had four main aims:

1. To increase community awareness of the study so that when potential participants encountered a survey they would be more likely to complete and return it;
2. To increase community acceptance of the study's legitimacy and utility by highlighting the institutional setting for the research and the ethical protection that brings, and to emphasise the impact that it has on policy and services;
3. To recruit participants directly through the website and freecall number;
4. To enhance the participation of community and service organisations by increasing participant demand and service provider awareness.

*3. Community sites*

The success of this project owes an enormous debt to the active involvement of the community sector. This is critical to ensuring that the study sample reflects the diversity of the population of PLWHA, and does not over-represent those in contact with clinical services or those receiving treatment. Community organisations were not simply involved in the distribution of surveys to members, but in promoting the study, in encouraging clients and members to complete surveys, in assisting people to complete surveys.

*a. Mail-outs*

A number of community organisations mailed out copies of the surveys to members and clients. These were accompanied by a covering letter from the organisation explaining the purpose of the study, explaining the value of the research, and encouraging participation.

*b. On-site availability*

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.

#### c. Organisational promotion

Promotion within and by organisations was undertaken by staff and volunteers within the community sector. This included promoting the survey at staff and volunteer meetings, the placement of news items or articles in newsletters, the inclusion of links to the study website and items about the study on organisational websites and the distribution of study postcards.

#### 4. Clinical sites

##### a. General Practitioners

Copies of the survey 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<sup>4</sup>.

A new initiative for the HIV Futures 3 Study was the active involvement of ASHM (Australasian Society for HIV Medicine) in the promotion and distribution of the survey. This included the awarding of CME (continuing medical education) points to NSW clinicians who requested copies of the survey from ASHM for distribution to clients.

##### b. Hospital settings

There was limited capacity to distribute surveys in hospital settings due to issues of confidentiality and ethical approval. However a number of HIV and Infectious Disease clinics made the surveys available in waiting areas or distributed them directly to clients. Para-medical services were also involved in survey distribution and promotion, particularly social work departments and Haemophilia workers.

##### 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 1 below gives the sources identified by respondents as the *primary* site that they obtained the survey, or information about the survey. It should be noted that many participants would have obtained copies of the survey and information about the research from multiple sources.

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<sup>4</sup> An S100 Prescriber is a clinician who is registered to prescribe S100 medications - highly specialised drugs for the treatment of HIV.

**Table 1 Data on primary site of survey collection**

Site	Frequency	Percentage
Completed previous Futures questionnaire	332	37.8
Mail-out from HIV/AIDS organisation	198	22.5
Picked up from HIV/AIDS organisation	97	11.1
Picked up from a medical centre or hospital	76	8.7
Haemophilia Association	8	0.9
Positive Women's Organisation	14	1.6
Positive Living	4	0.5
Gay newspaper/magazine	8	0.9
Recruited by researcher	19	2.2
Told about it by other participant	16	1.9
Postcard at HIV/AIDS organisation	4	0.5
Postcard picked up in medical centre or hospital	2	0.2
Postcard picked up at gay venue	3	0.4
Postcard picked up at some other location	1	0.1
Other	94	10.7

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 2). 36.8% did not indicate that they had participated in any of the listed research projects, while 45.8% had participated in either HIV Futures or HIV Futures II.

**Table 2 Data on previous research involvement**

Study	Frequency	Percentage
HIV Futures II	386	43.1
HIV Futures I	320	35.8
SMASH	213	23.9
Periodic Survey	151	16.9
Positive Health (pH)	119	13.3
MMASH	33	3.7
BRASH	24	2.7

(Multiple responses possible)

**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 (NCHECR, 2001) 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  $\alpha=0.01$ .



### SAMPLE DEMOGRAPHICS

The following section provides an overview of the characteristics of the HIV Futures 3 sample. The data in this section are not weighted.

The HIV Futures 3 survey was completed by 898<sup>5</sup> HIV positive people. Given current estimates of HIV infection in Australia (NCHECR, 2001) this represents approximately 6% of the positive population.

Of the survey respondents, 91.5% were male (818), 8.3% were female (74) and 0.2% were transgender (2). Of the sample 79.4% were gay men, 6.8% heterosexual men, 4.1% bisexual men, 0.5% lesbian, 6.5% heterosexual women, 1.0% bisexual women and the remaining 1.7% fell into other categories.

The respondents' ages ranged from 20 to 77 years with a mean of 42.9 years and a median of 42 years.

In order to compare the sample to the population represented in the Australian HIV Surveillance Reports, participants were asked how they believe they were infected with HIV. The results, grouped by the categories used by the National Centre in HIV Epidemiology and Clinical Research (NCHECR, 2001) are given below in Table 3.

**Table 3 Respondents' reported mode of transmission**

<b>Mode of Transmission</b>	<b>Frequency</b>	<b>Percentage</b>
Male homosexual or bisexual contact	717	80.5
Heterosexual contact	77	8.6
Injecting drug use (female and heterosexual male)	41	4.6
Male homosexual/ bisexual contact and injecting drug use	14	1.6
Receipt of blood components/tissue	14	1.6
Other/Don't know	14	1.6
Haemophilia/ coagulation disorder	11	1.2
Health care setting	3	0.3

<sup>5</sup> 4 surveys were unable to be entered due to late arrival, therefore the sample analysed is 894

The majority of participants were Australian born (73.7%) and 98.2% of the participants spoke English at home, with European languages accounting for most of the remainder. Fifteen respondents (1.7%) indicated they were of Aboriginal/Torres Strait Island origin. 99.3% of respondents indicated that Australia was their official country of residence.

Respondents came from all Australian states and territories, with the majority coming from NSW, Victoria and Queensland (see Table 4).

**Table 4 State or Territory of respondents' residence**

<b>State/Territory</b>	<b>Frequency</b>	<b>Percent of sample</b>
NSW	440	49.3
Vic	156	17.5
Qld	136	15.2
WA	63	7.1
SA	58	6.5
ACT	22	2.5
Tas	12	1.3
NT	5	0.6

The majority (62.0%) of respondents were from inner urban areas of capital cities, while 16.3% live in outer suburban areas, 12.5% live in larger regional centres and 9.1% live in rural areas.

643 (78.4%) of participants are living in the same state or territory in which they were infected with HIV, while the remainder live in a different state or territory.

Table 5 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 26 years with a mean of 2.0 years and a median of 1 year. There are 64 respondents in the sample who had tested positive in the last two years.

**Table 5 Years of respondent's testing positive and presumed infection (percentage of sample- unweighted)**

Year	Tested HIV positive	Presumed infected
Pre 1985	9.1	24.8
1985-1989	33.2	31.3
1990-1994	30.1	25.7
1995-1999	20.4	13.9
2000+	7.2	4.3

341 respondents (38.9%) indicated that they were atheist/agnostic, 43.0% indicated mainstream religious identification and the remainder were either adherents of new age belief systems or had other spiritual beliefs. 304 (34.0%) indicated that religion or spirituality was of no importance to them. A further 30.5% indicated that this was of little importance, 22.9% that it was very important and 11.4% 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 6 below.

**Table 6 Educational level of respondents (percentage of sample- unweighted)**

Level	Frequency	Percent of sample
Primary school only	15	1.7
Up to 3 years high school	74	8.4
4 <sup>th</sup> Form/ Year 10	150	17.0
Leaving Certificate/HSC/ Year 12	197	22.4
Tertiary Diploma/ Trade Certificate/ TAFE	213	24.2
University Degree	231	26.3

### FURTHER ANALYSIS AND REPORTS

As with the first two HIV Futures surveys a number of reports analysing specific populations and specific issues will be produced over the next two years. Key reports will include an analysis of the HIV positive women, and those co-infected with HIV and hepatitis C.



**HEALTH**



## HEALTH

The first section of this report deals with the health status and the experience of health of Australian PLWHA. As in the previous two surveys, there is a particular emphasis on the use and experience of antiretroviral therapy as this continues to be one of the key health issues for PLWHA. We examine the uptake of these therapies, the health and lifestyle consequences of them and the meanings of antiretrovirals in their lives. An issue that has become increasingly important in recent years is interruption to treatment. In the HIV Futures 3 survey we expanded the section on treatment interruptions to examine this area in greater depth.

We also look beyond antiretroviral therapy and explore health in terms of co-existent conditions, health maintenance and monitoring, health enhancement, complementary therapies, and testing practices. As with the previous surveys, we also examine attitudes to health and treatments, and the experience of health and well-being.

HIV positivity is an extraordinarily medicalised experience; an important component of this study is the exploration of how the clinical aspects of HIV interact with psychological and social experiences. While the coverage of these issues in a report such as this is necessarily limited, further attention will be paid to these in subsequent reports and journal publications. These can be accessed through the study website.

## HEALTH STATUS

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### Summary:

#### HIV antibody testing and counselling

- 19.1% tested for HIV because they became ill
- 15.8% tested as part of routine health screening
- 13.6% tested because they were a member of a risk group
- 12.9% tested because of a particular risk episode
- 3.7% were tested without their knowledge

When asked about pre- and post-test counselling

- 20.9% had received pre-test counselling
- 22.4% of those testing in the last two years received pre-test counselling
- 53.7% received post-test counselling
- 75.8% of those testing in the last two years received post-test counselling

Pre- and post-test counselling was most often provided by medical personnel and respondents were generally satisfied with the counselling they received.

Almost all PLWHA have taken a CD4/T-cell test and a viral load test. Over three-quarters rate their health as good or excellent and similar proportions rate their general well-being as good or excellent. One in five respondents had been diagnosed with an AIDS defining illness.

Health problems related to HIV:

- 38.4% report experiencing Lipodystrophy;
- 30.7% experience weight loss;
- 68.5% low energy or fatigue;
- 52.2% have a sleep disorder;
- 33.8% experience confusion or memory loss.

Two-fifths of respondents indicated that they had experienced AIDS related illness. Two fifths also indicated that they had a major health condition other than HIV/AIDS. The most common other conditions were hepatitis C, cardiovascular disease, asthma and hepatitis B.

Hepatitis

- 27.9% had at some point had hepatitis A
- 44.9% had been vaccinated against hepatitis A
- 31.9% had at some point been diagnosed with hepatitis B
- 53.9% had been vaccinated against hepatitis B
- 13.9% of respondents were hepatitis C positive
- 10.7% of those with hepatitis C had ever taken medical treatment for this;
- 16.1% of those with hepatitis C had ever taken complementary therapy for this

The activities to improve and maintain health were healthy eating, sleep, compliance with medication, exercise and social activities.

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### HIV Antibody Testing

The receipt of a positive HIV antibody test is a critical and often traumatic time in lives of positive people. HIV antibody testing is available free of charge in Australia and although legislation differs from state to state, pre- and post-test counselling forms a central 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.

We asked respondents why they had taken the antibody test. As can be seen from Table 7, 19% of the respondents had taken the test as a result of *illness*, 13% as a result of a *particular risk episode* and 14% because they were a member of a *risk group*. It is interesting to note that 16% gave the reason for testing as *routine health screening*. Of those that gave this reason, 86.7% were gay or bisexual men, which may suggest that respondents' interpretation of the phrase may include regular testing on the basis of group membership or risk activity. Of those who had tested positive in the last two years, 36.4% said this was due to illness, 18.2% said this was at a doctors suggestion, 15.2% said it was routine screening, and 12.1% as a result of a particular risk episode.

**Table 7 Reasons for testing**

	Frequency	Percentage
Became ill	170	19.1
Other	153	17.2
Routine health screening	140	15.8
Member of risk group	121	13.6
Particular risk episode	115	12.9
Doctor's suggestion	105	11.8
Starting new relationship	39	4.4
Tested without knowledge	33	3.7
Contact tracer/other health worker's suggestion	7	0.8
Insurance	4	0.5
Availability of new treatments	3	0.3

Of particular concern is the 19% that said they tested as a result of ill health. Testing as a result of ill health may include those experiencing sero-conversion illness, but examination of the presumed length of infection indicates that there is still a significant proportion of individuals tested late.

A commitment to pre- and post-test counselling has formed a critical part of this country's efforts in care and support of PLWHA and prevention education, both for those who test positive and negative. While there is some discussion about changing the name of this service to pre and post test discussion, currently counselling is the term used and the one we will employ here.

### ***Pre- and Post-Test counselling***

We asked respondents if they had received pre- and/or post-test counselling at the time they tested positive, who provided this counselling and how satisfied they were with the information and support they received at the time.

20.9% of respondents indicated that they had received pre-test counselling. Of those who tested positive in the last two years 22.4% had received pre-test counselling.

The counselling was generally provided by a doctor (53.7%), but was also commonly provided by a nurse (13.5%), a counsellor or psychologist (11.7%), a staff member at an HIV/AIDS organisation (5.9%) and a worker at a sexual health clinic (2.8%). No other response accounted for more than 2% of responses.

When asked if they were satisfied with the counselling they received, 87.4% reported they were satisfied with the information they received from this person and 82.8% said they were satisfied with the level of support they received.

53.7% of respondents indicated that they had received post-test counselling. Of those who tested positive in the last two years 75.8% 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 (38.2%), but was also commonly provided by a counsellor or psychologist (19.5%), a nurse (8.2%), a staff member at an HIV/AIDS organisation (8.0%), a social worker (5.3%), a doctor and a nurse (3.5%), a doctor and a counsellor (3.3%), a doctor and a social worker (2.7%), and a worker at a sexual health clinic (2.2%). No other response accounted for more than 2% of responses.

When asked if they were satisfied with the counselling they received, 80.6% said they were satisfied with the information they received and 78.8% said they were satisfied with the support they received.

We recognise that the circumstances surrounding the provision of counselling, and the intent and content of that counselling may be understood or remembered differently by PLWHA and service providers. These data, however suggest that serious consideration should be given to three critical issues.

1. Is HIV antibody testing in Australia currently being promoted in such a way as to maximise early diagnosis of HIV infection? The data above suggest that a significant proportion of the population is being tested late and in a state of ill health.
2. Is there adequate pre-test counselling being offered at every testing occasion? Particular consideration needs to be given to the issue of repeat or routinised testing among populations at higher risk of HIV. Although those that gave this as the reason for testing were more likely to have received pre-test counselling (26.4%), this remains an important issue, as there is a danger that the presumption of preparedness for a positive result automatically increases with repeat testing, and this could be both erroneous and damaging.
3. Is there adequate community understanding of what constitutes appropriate pre- and post-test counselling? Is this matched by adequate training and resourcing in testing settings, and are health consumers empowered to demand appropriate support and counselling around HIV testing?

Some of these issues will be addressed in two projects about to be conducted within the Living with HIV program at ARCSHS, one examining current testing practices and the other examining health outcomes associated with different testing modalities. There is however a clear need for the HIV sector to actively address issues of pre and post test counselling, both in terms of client understandings and expectations and physicians' capacity to provide an appropriate service.

### **CD4 and Viral Load**

As with the previous two surveys, almost all PLWHA had taken a CD4/T-cell test (99.1%) and a viral load test (98.4%). Most respondents had their most recent CD4 test in the last six months of 2001 (94.8%) (72.8% in the last three months) and their most recent viral load test in the last

six months of 2001 (93.3%) (70.7% 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, 92.3% reported that they have at some time had a CD4 count of less than 500 cells/µl and 63.8% reported a count of less than 250 cells/µl. Results for PLWHA's most recent CD4/T-cell test ranged from 0 to 2000 cells/µl with a mean of 497.9 cells/µl and a median of 475 cells/µl.

Among those PLWHA who have taken a viral load test, 87.7% reported that at some point they have had a result of over 10,000 copies/ml and 66.7% a result of over 50,000 copies/ml. Results for PLWHA's most recent viral load test ranged from below detectable levels to 5,000,000 copies/ml with a mean of the log viral load of 745.9 copies/ml and a median of 180 copies/ml. 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 respondent's 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)**

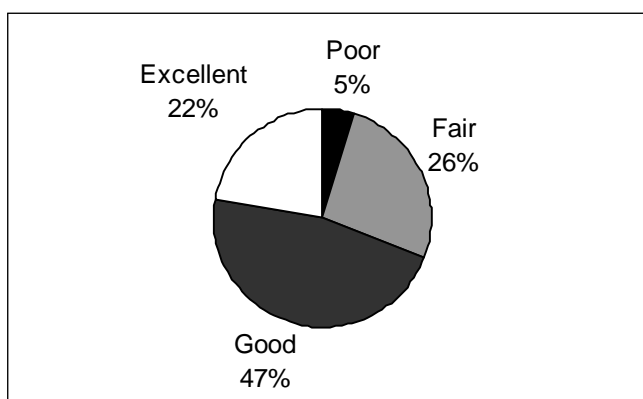
			HIV Viral load			
			Below detectable levels	Low 500 to 9,999	Moderate 10,000 to 49,999	High 50,000+
			57.2	15.4	13.7	13.7
CD4/T-cell	Little damage 500+	47.3	32.7	7.0	4.7	2.9
	Moderate damage 250-499	33.9	15.9	6.1	6.7	5.1
	Severe damage 0-249	18.8	8.6	2.4	2.2	5.7

Based on available data (CTTAC, 1997) antiretroviral treatment is recommended for patients with less than 500 CD4 cells or a viral load greater than 10,000 copies/ml. This means that 60.0% of those in the table above would be recommended to be on ARV. Of those in this

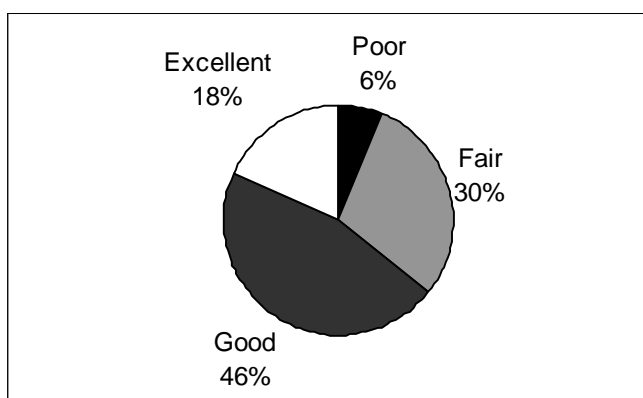
situation (CD4<500, VL>10,000) 67.4% are currently on ARV and an additional 19.3% have been on ARV previously.

**Experience of Health and General Well-being**

We asked respondents to indicate on a four point scale their current state of physical health, and their overall sense of well-being. The results are shown in Figures 1 and 2 below. Around half (46.9%) of the sample rated their physical health as *good*. A further 31.8% rated their health as *fair* or *poor*, and 22.3% as *excellent*. This is similar to the findings in the 1999 survey. A similar pattern is found in the ratings of well-being, although there are slightly fewer rating this as *excellent*.



**Figure 1 Respondents' self ratings of general health status**



**Figure 2 Respondents' self ratings of general well-being**

When we look at the relationship between these two measures, we can see overall that better health is related to greater well-being (see Table 9). This is, however, not a clear and direct

relationship. The correlation between the two measures is .69. One in five participants (21.2%) rate their well-being as worse than their health and 11.9% rate their health as worse than their well-being. Similarly, ratings of general health are related to CD4 and viral load, but not in a completely clear way. Better health is somewhat related to lower log viral load (correlation=-.19) and higher CD4 (correlation=.34), but is clearly mediated by the experience of side-effects, the burden of medication, history of HIV and co-existent conditions

**Table 9 Relationship between ratings of overall health and well-being (Percentage of total sample)**

		Health			
		Poor	Fair	Good	Excellent
Well-being	Poor	2.7	2.8	0.4	0.3
	Fair	1.8	17.5	9.6	0.7
	Good	0.3	5.3	32.9	7.4
	Excellent	0.0	0.3	4.2	13.7

### AIDS Defining Illnesses

With the advent of antiretroviral therapies the significance of the experience of an AIDS defining illness is less clear than it once was. The category system for defining the stages of HIV disease progression in large part were 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 ask 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 (19.6%) have been diagnosed with an AIDS defining illness at some point with 2.2% having been diagnosed with one in the last two years. On average they had been diagnosed 6 years ago. The most common illness in this category were Pneumocystis Pneumonia (41.4%), Kaposi's Sarcoma (17.2%), Cytomegalovirus (15.8%) and Microbacterium Avium Complex (MAC) (12.6%).

### HIV/AIDS Related Conditions

We asked respondents if they had experienced any other AIDS-related illness, and 39.3% said that they had. Of these the most common were shingles (14.3%), skin problems (12.9%) and neuropathy (12.8%).

We also asked if participants had experienced any of five specific conditions. 38.4% had experienced lipodystrophy, 30.7% weight loss, 68.5% low energy or fatigue, 52.2% a sleep disorder and 33.8% confusion or memory loss.

### Other Health Conditions

Lipodystrophy and lipoatrophy have created additional difficulties for positive people. 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 lipodystrophy. As can be seen, the majority agreed that body changes due to lipodystrophy do make it obvious that people have HIV, while approximately equal numbers of people agreed and disagreed with the other two items. The responses of those with lipodystrophy were more likely to be suggestive of poor body image.

**Table 10 Attitudes around body image (percentage of sample)**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<b>Full Sample</b>				
Changes in my body due to HIV have made me feel sexually unattractive	18.4	37.1	32.5	12.0
I am happy with the way my body looks	9.7	39.3	39.9	11.1
Body changes due to lipodystrophy make it obvious to others that people have HIV	15.5	38.0	35.4	11.0
<b>Those with lipodystrophy (N=321)<sup>a</sup></b>				
Changes in my body due to HIV have made me feel sexually unattractive	29.4	47.2	18.4	5.0
I am happy with the way my body looks	6.6	25.3	50.0	18.1
Body changes due to lipodystrophy make it obvious to others that people have HIV	25.3	46.9	24.5	3.3

a: Actual item Ns will be less due to missing data.

 **see also Other Medications page 38, Mental Health page 61**

Around two out of five (38.1%) respondents indicated that they had been diagnosed with a major health condition other than HIV/AIDS. The most common major health conditions included hepatitis C (9.9% of the total sample), cardio-vascular disease (4.6%), asthma (3.6%) and hepatitis B (3.0%)<sup>6</sup>.

### **Hepatitis**

Hepatitis is a term that refers to inflammation of the liver. There are currently six different types of viral hepatitis. 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. A separate report will be produced to examine the experience of HIV and hepatitis C co-infected individuals that will expand on the findings of the HIV Futures II survey on this issue as presented in *Living with HIV when co-infected with hepatitis C* (O'Brien et al. 2002).

### **Hepatitis A**

Over one quarter of the participants (27.9%) had at some point had hepatitis A, and 44.9% had been vaccinated against this virus. This means that 34.8% of the respondents may currently be at risk of hepatitis A infection.

### **Hepatitis B**

A total of 31.9% of respondents had at some time been diagnosed with hepatitis B and a further 53.9% had been vaccinated against this virus. This means that 23.4% may currently be at risk of being infected with hepatitis B.

### **Hepatitis C**

Diagnosis of hepatitis C in HIV positive people is more problematic than in those that are HIV negative (Mijch 2001). Co-infection with HIV may result in false negatives on the hepatitis C antibody test. Hepatitis C may also be cleared in a proportion of individuals. In the two previous HIV Futures surveys, we asked about hepatitis C testing and the result of that test

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<sup>6</sup> Please see the section below for diagnosis with hepatitis A, B and C. The discrepancy between the responses to this open ended item and the specific questions below can to some extent be explained by what participants consider to be a *major* health condition

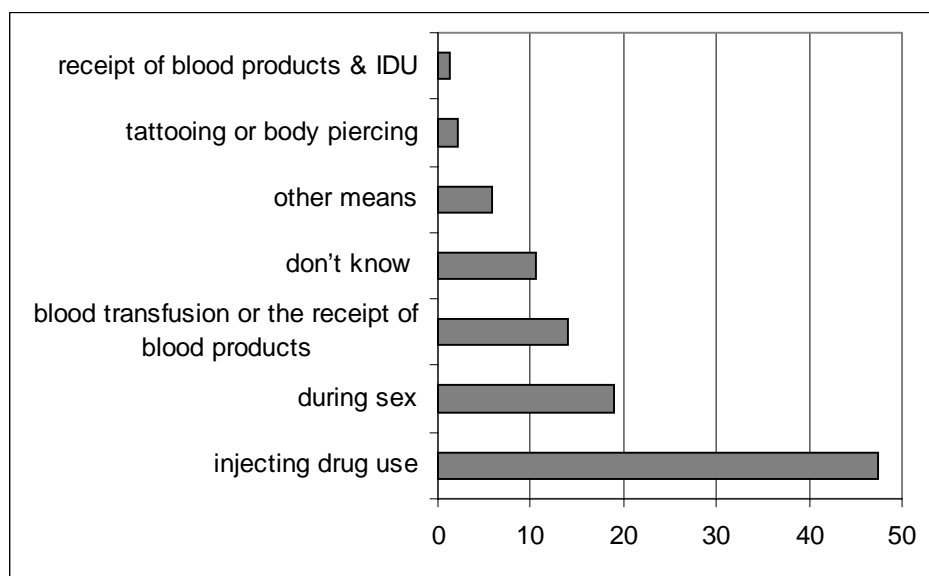


(positive/negative). In this survey we expanded this section to obtain more detail on testing practices, diagnosis and health and social issues.

Over one third (34.6%) of respondents had not been tested for hepatitis C. We used a series of items from the survey including test results, year of diagnosis with hepatitis C, and designation of hepatitis C as a major health condition to determine that 13.9% of the sample had hepatitis C. This compares to the 2001 estimate of the prevalence of hepatitis C co-infection amongst Australian PLWHA which is 13.7% (Sasadeusz 2002).

Respondents had first been diagnosed with hepatitis C between 0 and 27 years ago<sup>7</sup> (mean=7.8, median=7) and believed they had been infected between 0 and 34 years ago (mean=12.2, median=11).

When asked how they believe they were infected with the hepatitis C virus, 47.4% said injecting drug use, 14.1% blood transfusion or the receipt of blood products, 1.2% receipt of blood products & IDU, 18.9% during sex, 2.2% through tattooing or body piercing, 5.8% through other means and 10.6% didn't know how they were infected See Figure 3.



**Figure 3 Respondents' reported mode of hepatitis C infection (percentage of those with hepatitis C)**

<sup>7</sup> Some respondents would have included non-A non-B diagnosis prior to the development of a hepatitis C specific test. This test became available in Australia in 1990.

Hepatitis C related symptoms were experienced by 30.9% of those with the hepatitis C virus. The most commonly mentioned symptoms were lethargy and pains in the liver.

Only 10.7% of those with hepatitis C had ever undertaken medical treatment specifically for hepatitis C. This comprised 5.5% who had been treated with interferon monotherapy, and 8.1% who had been treated with combination therapy of interferon and ribavirin (some respondents had undergone both monotherapy and combination therapy). Sixteen percent (16.1%) had taken some form of complementary therapy.

Hepatitis C co-infected participants were also asked about health monitoring and management. Sixteen percent (16.4%) of co-infected PLWHA did not currently see a doctor for hepatitis C treatment or management. 72.1% of hepatitis C co-infected PLWHA saw their primary HIV doctor and 11.4% saw a separate hepatitis C doctor or specialist. Co-infected PLWHA were asked whether they had received less-favourable treatment at medical services as a result of having hepatitis C. While 25.6% had ever had this experience, 16.2% had had this experience in the last 2 years (see page 111).

Most (63.6%) people co-infected with hepatitis C found that HIV community services met their needs, while 36.4% said that these did not.

A detailed analysis of the experiences of PLWHA co-infected with hepatitis C will appear in a community report in the second half of 2002.

 **see also Discrimination page 111, Health services page 46**

### **Other Health Monitoring**

We asked a series of questions about other health monitoring activities. 18.3% had had a bone density test in the last two years and 4.1% had had a test more than two years ago. 54.9% had had a fasting cholesterol test in the last two years and 5.9% 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 the female respondents had had a cervical smear (Pap) test and 87.7% had had one in the last twelve months. Generally women had one test in the last year (62.2% of those tested in the

last year). On their most recent test, most (80.8%) reported that the result was negative, and 5.4% abnormal. 1.3% of women reported high-grade intraepithelial abnormality (all were CIN2) while 4.0% reported low-grade intraepithelial abnormality, 3.4% reported inconclusive results, and (1.0%) were still waiting for their results. 3.0% reported some other kind of results.

 **see also Resistance Testing page 35**

### 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 11 below. The most common health-enhancement activity was healthy eating, followed by sleep and compliance with medication.

**Table 11 Health improvement strategies**

	Frequency	Percentage
Healthy eating	702	78.7
Sleep	663	74.3
Taking pills on time	621	69.7
Exercise	600	67.3
Relaxation	588	66.0
Spending time with friends	512	57.4
Spending time with pets	347	38.9
Spending time with partner	335	37.6
Complementary therapies	282	31.6
Spending time with family	269	30.1
Other	206	23.2

### Prophylaxis

25.1% of respondents were currently taking prophylaxis for opportunistic infections. Those using prophylaxis were more likely to have experienced an AIDS defining illness, to have a lower CD4 count, to have been HIV positive longer and to be using complementary therapies.

 **See also Other Medications page 38 , Complementary Therapies page 37**

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

**Table 12 Attitudes to health management: percentage of total sample**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Looking after my physical fitness is an important part of managing my HIV infection	46.4	49.6	4.0	0.1
Healthy eating is an important part of managing my HIV infection	41.2	52.6	4.9	1.2
Keeping an optimistic frame of mind is an important part of managing my HIV infection	53.7	44.4	1.3	0.6

## ANTIRETROVIRAL THERAPY

Antiretroviral therapy has been a central plank in the management of HIV disease in most developed countries for the last six years. While the treatments are by no means unproblematic, mortality rates have declined dramatically. The experience of antiretroviral treatments is increasingly one of disparity with a proportion of the population benefiting enormously from the treatments and an increasingly large number for whom treatments are failing or causing health difficulties and challenges to day to day life. The data from this study demonstrates that the trend toward greater optimism tempered by greater caution identified in our previous work (Grierson and de Visser 2001) continues. This section addresses some of that complexity by examining the *experience* of antiretrovirals both in clinical and social terms.

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### Summary:

Antiretroviral use:

- 71.7% are currently using ARV;
- 86.9% have used ARV at some time;
- 77.1% commenced ARV on the advice of their doctor;
- 65.8% of respondents were using a combination of three drugs;
- 60.4% of the sample were taking ARV twice daily;
- 11.8% were taking ARV three times a day;
- 82.8% had not missed a dose of ARV in the two days prior to completing the survey.

Difficulties taking antiretrovirals:

- 87.1% of those participants currently taking ARV reported that they experienced difficulties taking them of which the major problems were:
  - 45.0% remembering to take the drugs on time;
  - 30.4% organising meals around the drugs;
  - 30.7% taking medication in public;
  - 28.2% transporting medication;
  - 24.6% taking large numbers of tablets.

Side effects from ARV are a significant concern for those on treatment with 43.9% reporting that they experienced these. The most common were diarrhoea, nausea, fatigue and lipodystrophy.

Breaks from antiretroviral therapy:

- 41.3% of those currently on ARV have taken a break from ARV therapy;
- The median length of break was 90 days;
- Most breaks were taken for a combination of lifestyle and clinical reasons;
- Breaks often resulted in improved well-being, but deterioration of clinical markers;
- Doctors were less likely to be consulted before a break than afterward;
- 67.1% saw their doctor during the treatment break.

Does ARV mean better prospects for PLWHA?

- 75.2% agree;
- 16.2% believe that it is still too soon to tell.

Antiretroviral Resistance:

- 24.9% of those who had ever used ARV had had a resistance test;
- 75.4% of those tested found resistance to one or more drugs;
- 57.6% of those with resistance changed treatments.

Complementary therapies:

- 52.9% use some form of complementary therapy;
- Vitamins and mineral supplements are the most popular;
- Complementary therapies tend to be used in conjunction with allopathic treatment.

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### **Use of Antiretroviral Therapy**

PLWHA were asked if they were currently using or had used a range of antiretroviral therapies. On the basis of their answers to these items, they were asked further questions on their experiences of antiretrovirals (ARV).

Of the full sample, 86.9% had used ARV at some point, and 71.7% were currently using these treatments.

The data on treatments will be presented in four sections: those currently using ARV (mono-therapy and combination therapy); those currently on combination therapy only; those not

currently using ARV who have in the past; and those who have never used ARV. An additional section on the experience of interruptions to treatments follows. A summary diagram of the uptake of antiretrovirals can be found on page 18.

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

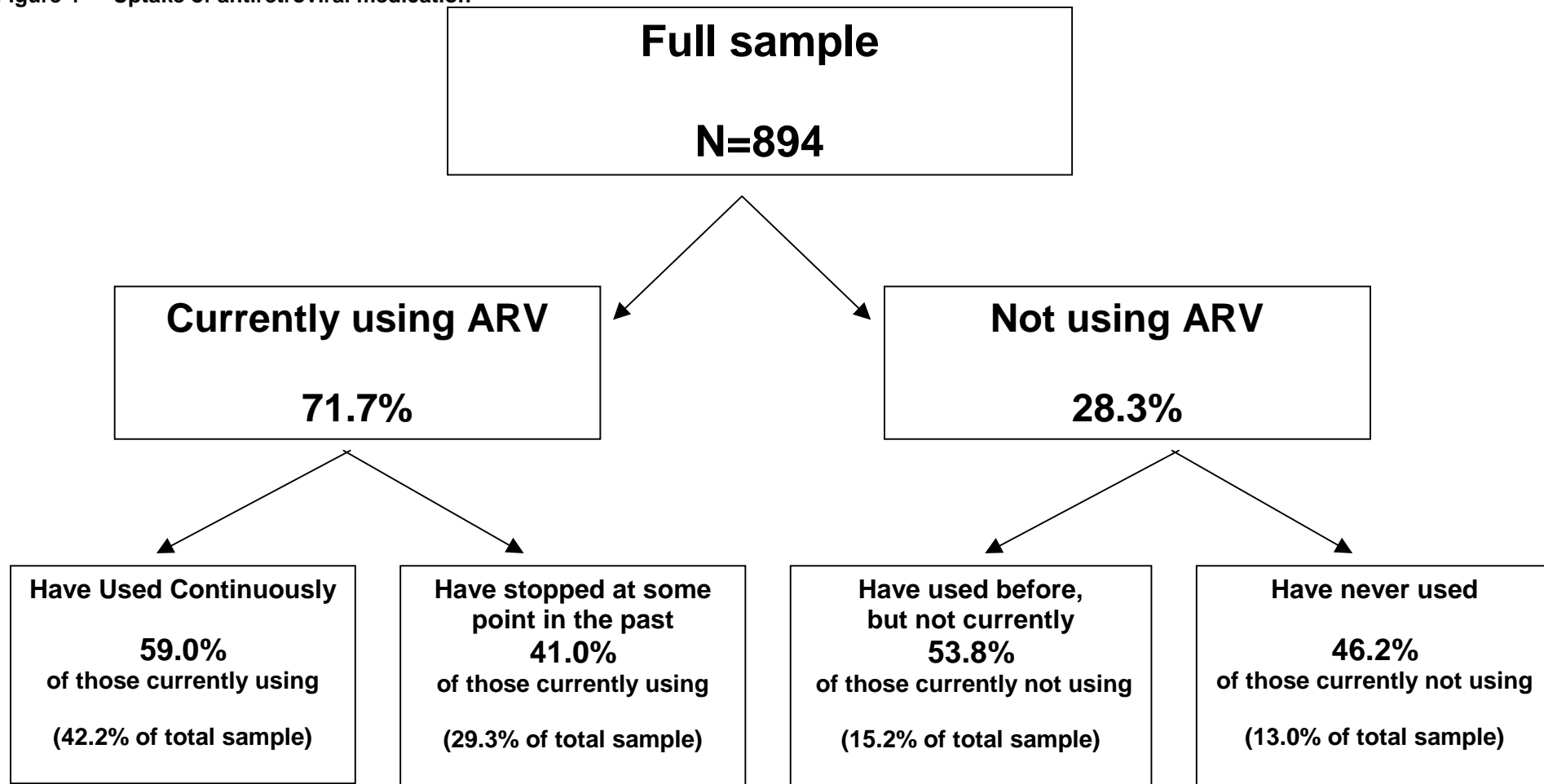
The majority of participants (65.8%) were on a combination of 3 antiretroviral drugs, with 28.4% on more than three antiretroviral drugs, 5.1% on two, and 0.7% on monotherapy.<sup>8</sup> Table 13 below lists the antiretroviral treatments that participants were using at the time of the survey.

**Table 13 Antiretroviral drugs used by respondents: percentage of total sample**

<b>Drug</b>	<b>Percentage of those using ARV</b>
3TC (Epivir, Lamivudine)	47.5
D4T (Zerit)	35.3
Nevirapine (Viramune)	35.2
1592 (Abacavir, Ziagen)	23.9
AZT & 3TC (Combivir)	22.6
Efavirenz (Sustiva)	19.6
Ritonavir (Novir)	18.2
Indinavir (Crixivan)	13.7
Nelfinavir (Viracept)	12.1
ddl (Videx, didanosine)	12.0
ddl ec (Videx ec, didanosine ec)	10.8
ABT-378/r (Lopinavir, Kaletra)	9.9
AZT (Retrovir, zidovudine)	9.5
Saquinavir (Fortovase) - soft gel	6.2
Saquinavir (Invirase) - hard gel	5.1
Amprenavir	4.9
AZT & 3TC & Abacavir (Trizivir)	3.2
Tenofovir	2.0
ddC (Hivid)	1.7
Delavirdine (Rescriptor)	1.4
T-20	1.0

<sup>8</sup> Combivir is counted as two drugs, and Trizivir as three drugs

Figure 4 Uptake of antiretroviral medication

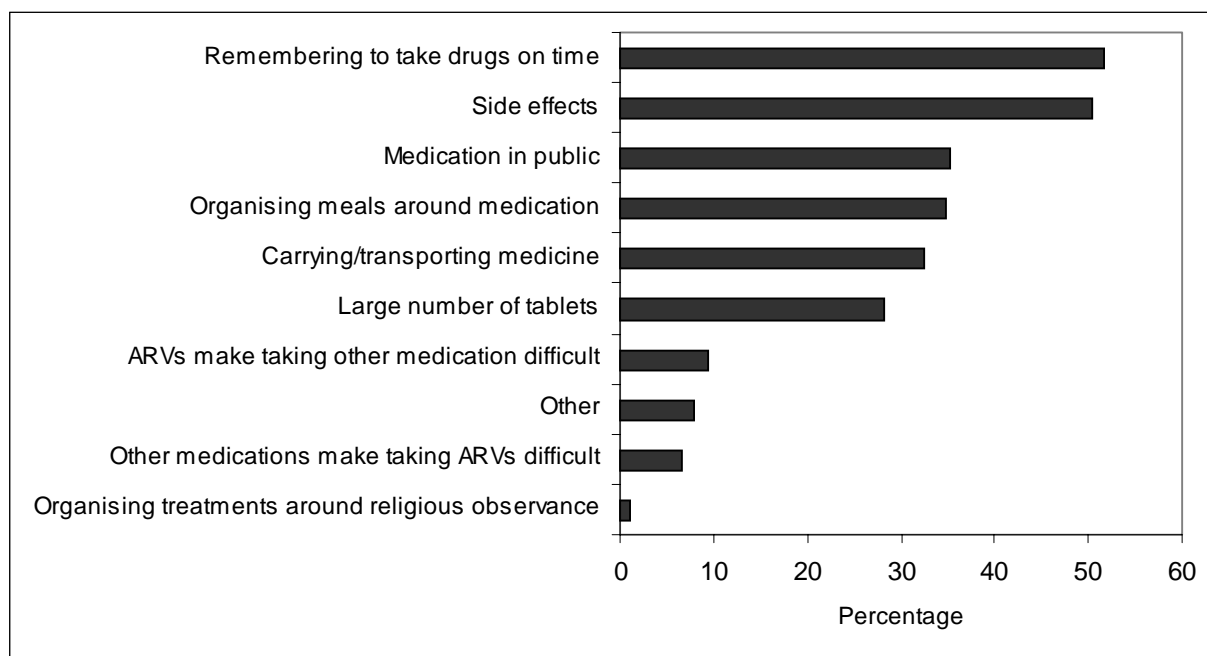




Respondents were also asked specifically about their use of the two immune stimulants Interleukin 2 and Hydroxyurea: 2.0% of respondents were using Interleukin 2 and 0.9% were using Hydroxyurea.

*Difficulties of Taking ARV*

Overall, 87.1% reported that they had some difficulty taking ARV. Of these, 51.7% indicated they had difficulty remembering to take the drugs on time, 34.9% said they had difficulty organising meals around medications, 35.2% taking medication in public, 32.4% transporting medication, and 28.2% taking a large number of tablets (see Figure 5). In addition, 9.4% reported that taking ARV made it difficult to take medication for other health conditions and 6.5% that taking other medications made taking ARV difficult.



N=513

**Figure 5 Difficulties of taking ARV among those currently using ARV**

Side effects were reported by 43.9% of respondents currently using ARV. The most commonly reported problems were diarrhoea (38.7% of those using ARV), nausea (30.1%), fatigue or lethargy (19.6%), lipodystrophy (16.5%), neuropathy (12.2%), headaches (8.9%), and digestive/stomach upsets (7.9%).

Attitudes to ARV

Most respondents reported concern over the future efficacy of their treatments. Over half agreed or strongly agreed the statement *I am worried that in the future my medication will stop working for me*, (see Table 14).

When asked to respond to the statement *Taking tablets gives me an unwanted reminder that I have HIV*, 61% indicated agreement and 36% indicated disagreement.

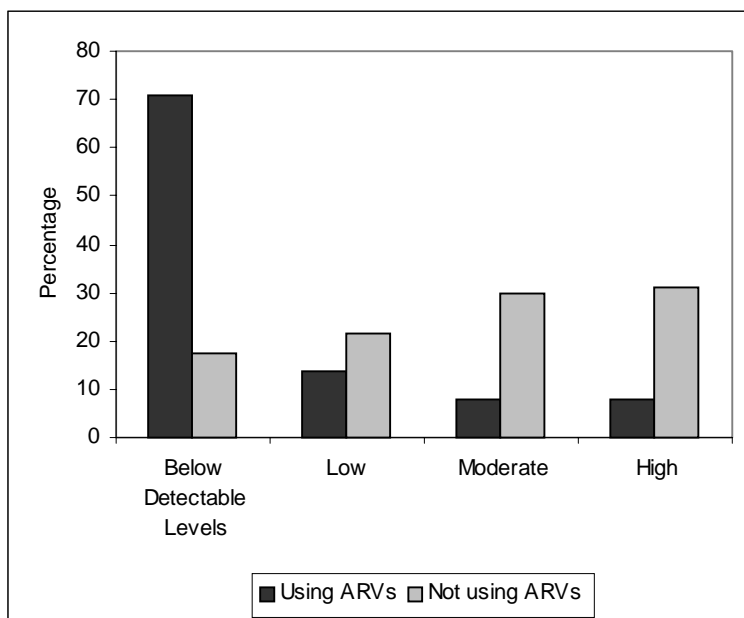
**Table 14 Attitudes to medication: percentage of those currently using ARV**

	Strongly Disagree	Disagree	Agree	Strongly agree	Don't know
I am worried that my medication will stop working for me <sup>a</sup>	4.5	17.9	48.9	16.2	12.6
Taking tablets gives me an unwanted reminder that I have HIV <sup>b</sup>	9.2	26.4	41.2	19.7	3.6

a: N=640, b: N=638

Health Status of Those Using ARV

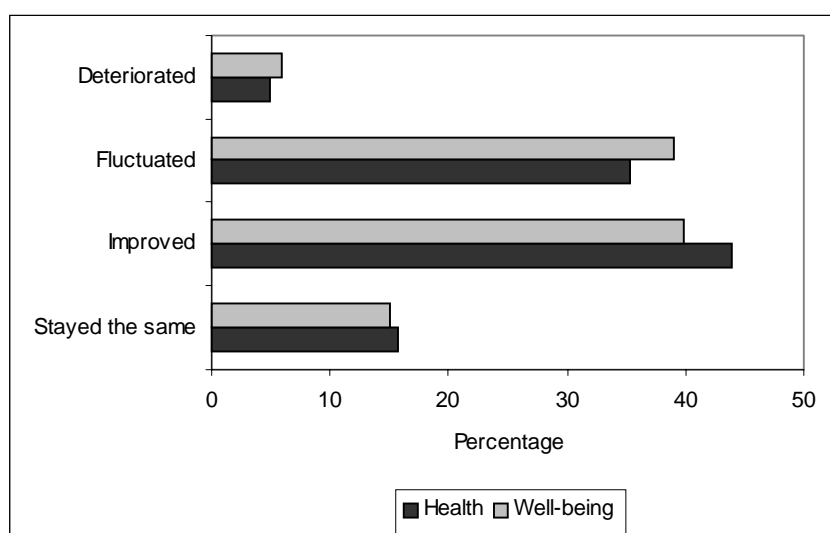
Those taking ARV had significantly lower viral loads (log mean of 305.8 cells/µl compared to 9594.0 cells/µl among those not taking any antiretroviral medication). This difference is mainly explained by the large proportion of those on ARV with a viral load below detectable levels as can be seen in Figure 6.



**Figure 6 Viral load of those taking and not taking antiretroviral therapy.**

Those taking ARV did not have significantly different CD4 counts (mean of 496 copies/ml compared to 505 copies/ml among those not taking antiretrovirals). They were more likely to have had an AIDS defining illness (24.2% compared to 7.7% among those not taking antiretrovirals) and had been HIV positive for longer (mean=10.3 years for those taking antiretrovirals compared with mean=8.8 years for those not taking antiretrovirals). There was, however, no difference between these two groups in the ratings they gave of their general health status.

When asked to rate the effect of commencing ARV on their physical health, 43.9% said that their health improved, 35.3% said it fluctuated, 15.8% said it stayed the same and 4.9% said it deteriorated. When asked about the impact of ARV on their overall feeling of well-being, 39.9% said it had improved, 39.0% said it had fluctuated, 15.1% said it had stayed the same and 6.0% said it had deteriorated (see Figure 7).



**Figure 7 Effect of commencing antiretroviral medication on health**

**Those on Combination Therapy**

The most common combination was AZT, 3TC & Nevirapine used by 7.7% of those on combination therapy, followed by 3TC, d4T & Nevirapine used by 6.5%, 3TC, 1592 & Nevirapine used by 3.6%, AZT, 3TC and Efavirenz used by 2.9%, 3TC, 1592 & Efavirenz used by 2.5%, 3TC, d4T & Efavirenz used by 2.5% and AZT & 3TC used by 2.0%. No other combination accounted for more than 2%. This means that most commonly used combinations consisted of two nucleoside analogues and one non-nucleoside reverse transcriptase inhibitor.

94.4% of those on combination therapy had been on it for at least the second half of 2001. Most started combination therapy at a time when their viral load was high (mean = 68,706 copies/ml) and their CD4 count was low (mean = 238.4, 55% below 250 cells/ $\mu$ l, 89% below 500 cells/ $\mu$ l). As can be seen in Table 15 below, most people had commenced combination therapy at a time when treatment would be strongly indicated (see CTTAC, 1997).

**Table 15 Results of serological tests prior to commencement of ARV: percentage of those on ARV**

			HIV Viral load prior to commencing combination therapy (%)			
			Below detectable levels	Low 500 to 9,999	Moderate 10,000 to 49,999	High 50,000+
			6.9	5.9	21.9	65.4
CD4/T-cell prior to commencing combination therapy (%)	Little damage 500+	11.4	1.6	1.6	3.3	4.9
	Moderate damage 250-499	33.3	2.6	1.3	11.1	18.3
	Severe damage 0-249	55.2	2.6	2.9	7.5	42.2

N=306

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 (77%), although the importance of clinical indicators, treatment developments and treatment information is also clear.

**Table 16 Circumstances surrounding commencement of treatment among those on combination ARV.**

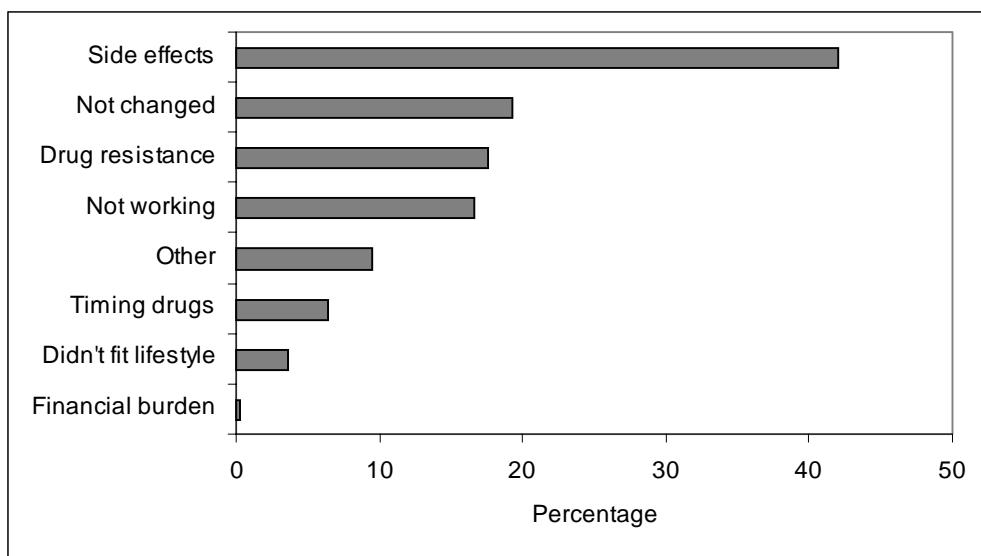
<b>Circumstance</b>	<b>Percentage of those on combination therapy</b>
My doctor advised me to begin this treatment	77.1
I had a big drop in my CD4 count	37.1
New drugs became available	34.4
I became very ill	27.6
Information showed the treatment was effective	26.8
I had a big rise in my viral load	26.3
I had just tested positive to HIV	17.2
I was hospitalised due to HIV	16.0
Close friends advised me to begin treatment	7.1
A treatments officer advised me to begin treatment	6.4
Positive friends started treatment	6.0
My partner advised me to begin treatment	4.6

Multiple responses possible N=613

#### *Different Combinations*

Among those currently using combination therapy, respondents had tried between 1 and 20 combinations, with the median being 3. Within the last 12 months, 63.7% had used the one combination and 24.6% 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 (42.0%) the side effects became too severe. Drug resistance (17.6%) and drugs not working (16.6%) were the next most common responses (see Figure 8).



**Figure 8** Circumstance surrounding most recent change in combination among those currently on combination ARV

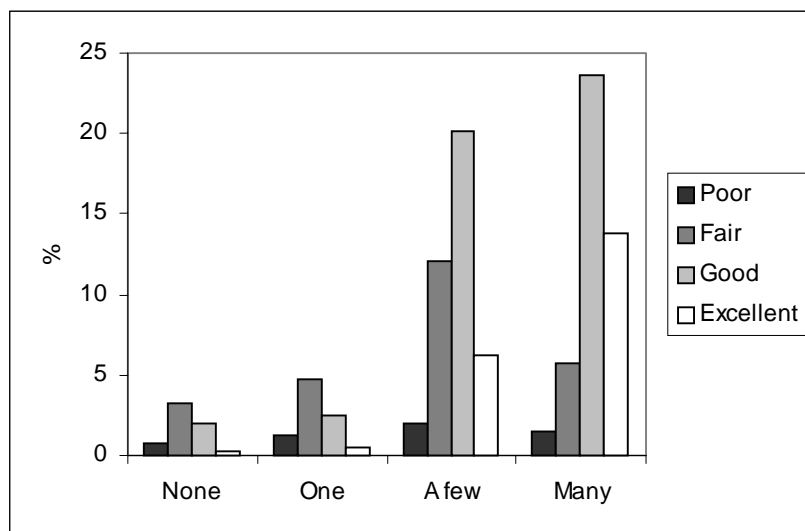
When asked how many combinations they believed they still had access to, 26.5% indicated that they thought they had *a few* and 28.9% felt they had *many*, while 34.4% said they didn't know how many combinations they had left. 4.3% of those currently on combination therapy believed they had no combinations remaining. These respondents were significantly more likely to have a higher viral load than those with more therapeutic options and significantly less likely to rate their health or well-being as *good*. The major differences in terms of health status, however, appear to be between those with one remaining combination and the remainder of the sample. Those with one combination remaining were more likely to have a lower CD4 count and to rate their health as *poor*. (See Table 17).

**Table 17** Correlates of number of remaining combinations for those on ARV

Combinations remaining	Mean years positive	Mean CD4	Mean Log Viral load
None	12.7	251.5	3385.3
One	11.5	411.0	1967.4
A Few	10.9	472.5	297.9
Many	9.5	553.7	201.0

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 (see Figure 9). Those with one

or no combinations remaining were more likely to rate their general health as *fair*, while those with a few or many combinations were more likely to rate their health as *good* or *excellent*.



N=406

**Figure 9 General health status for those with different numbers of combinations of ARV remaining: percentage of those on ARV**

**Those Not Currently Taking ARV**

Of the 28.3% of the sample who currently are not using any antiretrovirals, 53.8% had done so in the past. The mean length of time these PLWHA had been using ARV was 3 years and 3 months (range 0 months to 15 years) and on average they had ceased using ARV 1 year and 10 months prior to completing the survey (range 0 to 11 years). At the time that they stopped using ARV, most were using a combination of 3 drugs (60.2%), 10.1% were using four drugs, 19.0% were using two drugs and 6.0% 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 18). 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 18 Difficulties experienced by those currently on ARV and those who have stopped ARV treatment.**

<b>Difficulties experienced</b>	<b>Those taking ARV now<sup>a</sup></b>	<b>Those who have taken ARV in the past, but not now<sup>b</sup></b>
Remembering to take drugs on time	45.0	47.3
Side effects	43.9	74.8
Medication in public	30.7	33.0
Organising meals around medication	30.4	44.8
Carrying/transporting medicine	28.2	33.9
Large number of tablets	24.6	35.1
ARV make taking other medication difficult	8.2	11.3
Other medications make taking ARV difficult	5.7	5.6

a: N=588, b: N=130

#### *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. Nearly one fifth (19.2%) said that it had deteriorated, 43.0% said it fluctuated, 19.9% said it stayed the same, and 17.9% that their health improved.

When asked about the impact of ARV on their overall feeling of well-being, 14.7% said it had improved, 35.1% said it had fluctuated, 16.4% said it had stayed the same and 33.9% said it had deteriorated.

Respondents were asked whether they had lifestyle or clinical reasons for ceasing their use of antiretroviral therapy. Fifty-nine respondents gave lifestyle reasons for stopping treatment (see Table 19). 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 19 Lifestyle reasons for stopping treatment (percent of those previously on ARV)**

<b>Reason</b>	<b>Percentage of those with lifestyle reasons</b>
Clean out system	32.9
Taking drugs at right time too difficult	28.6
Didn't fit lifestyle	18.4
Financial burden	5.7
Special event	5.1
Religious reasons	1.8

N=59



Eighty-six respondents gave clinical reasons for ceasing ARV treatment (see Table 20). Over half of these said that side effects were a reason for stopping and a third said that the cessation was recommended by their doctor. Importantly, almost one in five said that drug resistance was a problem.

**Table 20 Clinical reasons for stopping treatment (percent of those previously on ARV)**

<b>Reason</b>	<b>Percentage of those with clinical reasons</b>
Side effects	54.5
Recommended by doctor	36.3
Drug resistance	17.3
Liver toxicity	12.4
Recommended by other health professional	6.9
Complications with Hep C	3.2
Changing regimens	3.0

N=86

**Those Who Have Never Used Antiretroviral Drugs**

13.0% (N=116) of the respondents had never used antiretroviral treatments. Of these 90% 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 21).

**Table 21 Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used antiretroviral drugs.**

<b>Circumstance</b>	<b>Percentage of those not on ARV.</b>
If I had a big rise in my viral load	74.1
If my doctor advised me to begin this treatment	71.0
If I had a big drop in my CD4 count	70.1
If I became very ill	63.7
If information showed the treatment was ineffective	60.6
If close friends advised me to begin treatment	32.3
If I was hospitalised due to HIV	30.2
If a treatments officer advised me to begin treatment	24.5
When treatment break is finished	13.3
If my partner advised me to begin treatment	9.5
If new drugs became available	5.3
If positive friends started treatment	2.5
Multiple responses possible      N=97	

**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 22 on page 30.

**Treatment Decision Making**

Most respondents indicated that they disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (70.6%). 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 five respondents that indicated that they were unsure about this. Those that agreed with this statement were more likely to be using antiretrovirals.

### ***Relationship with Treating Doctor***

As with previous surveys, most respondents (79.3%) agreed with the statement *My doctor and I work together to find the best treatment for me*, with few expressing uncertainty. Few respondents (16.7%) agreed with the statement *My doctor knows more about the treatment of HIV than I do*. The combined effect of these data suggest that treatment decision making is both informed and negotiated.

### ***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 5% of respondents agreed with the statement *Combination antiretroviral drugs are ineffective* and there was slightly less uncertainty about this statement than in the 1999 survey. 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* (33.5% agree, 8.5% strongly agree). This harm may in part be that experienced as side-effects. Around one quarter of respondents agreed or strongly agreed with the statement *The side effects of antiretroviral drugs outweigh the benefits*, while 16.9% were unsure.

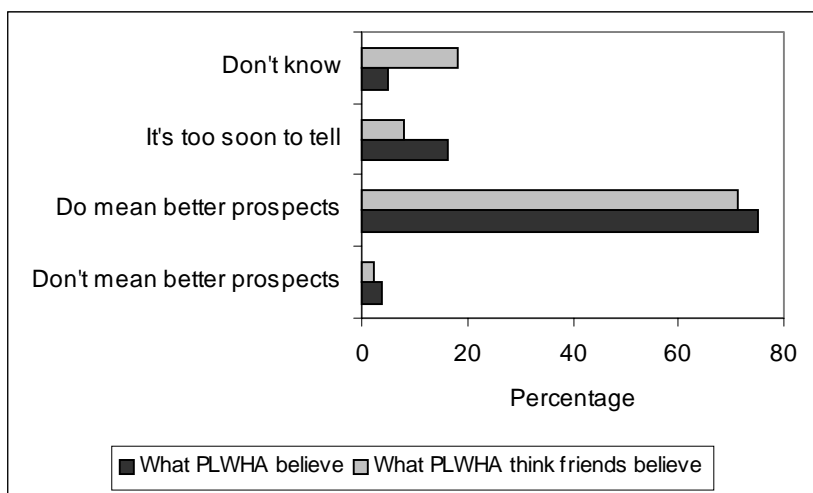
There was considerable uncertainty about the long term benefit of treatment. Almost one third of respondents said they were unsure when asked to respond to the statement *New treatments will be developed in time for me to gain benefits*, with most of the remainder agreeing. Similarly, over one third were uncertain when asked if *HIV treatments will stop me dying from AIDS*. Agreement with this statement was indicated by 38.5% of respondents.

Three fifths (60.0%) agreed with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*, while 14.0% were uncertain.

**Table 22 Attitudes to antiretroviral drugs: percentage of total sample**

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't know</b>
I am healthy now and don't need to use antiretroviral drugs	37.5	33.1	12.2	11.3	5.9
People with HIV should start using antiretroviral drugs as soon as possible	14.4	31.4	18.6	13.8	21.8
My doctor and I work together to find the best treatment for me	2.2	6.2	50.6	38.1	2.8
My doctor knows more about the treatment of HIV than I do	4.9	11.8	48.1	31.2	3.9
Combination antiretroviral drugs are harmful	15.5	28.0	33.5	8.5	14.5
Combination antiretroviral drugs are ineffective	43.3	44.4	2.8	2.2	7.3
The side effects of antiretroviral drugs outweigh the benefits	14.9	44.0	17.5	6.8	16.9
New treatments will be developed in time for me to gain benefits	2.6	5.6	42.9	18.2	30.7
HIV treatments will stop me dying from AIDS	8.7	19.0	23.5	14.0	34.9
Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term	7.0	19.0	36.6	23.4	14.0

Respondents indicated how much they and their friends agree with the statement *Antiretroviral drugs mean better prospects for most people*. Most (75.2%) agreed with the statement, and believed their friends would agree with it (71.4%). Almost one in five respondents believe that *it's too soon to tell* (16.2%), although they were less likely to believe their friends think this (8.1%) (see Figure 10).



**Figure 10 Respondents' and respondents' social networks' response to the statement Antiretroviral drugs mean better prospects for most people.**

## TREATMENT BREAKS

Interruption to antiretroviral treatment is an important and increasingly complex issue. Treatment breaks may take a number of forms and be undertaken for a range of reasons. 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. In all, 41.3% of those respondents currently using antiretroviral medication had taken a break from these at some point. To understand the experience of breaks, we asked respondents to give us some detailed information about their most recent break.

### Most Recent Treatment Break

The date of the most recent break ranged from currently taking one to having taken one 12 years ago. The mean length of break was 135 days with a median of 90 days. Most respondents described their most recent break as short term (78.4%) with smaller numbers describing it as long term (15.9%) or a cycle/pulse interruption (5.8%).

We asked participants to describe the reasons for taking the break within two major categories: lifestyle reasons, and clinical reasons. Just under half (49.1%) indicated that there were lifestyle reasons for taking a break. The specific reasons are given in Table 23 below. The most common reason given was to *clean out the system* (13.7% of those taking breaks) followed by difficulties around timing of drugs (11.9%).

**Table 23 Lifestyle reasons for taking breaks**

Reason	Percentage of those who have taken a break
Clean out system	13.7
Taking drugs at the right time was too difficult	11.9
Didn't fit lifestyle	8.0
Special event	8.0
Financial burden became too heavy	3.0
Religious reasons	0.3
Other	23.4

N=263

When asked if there was a clinical reason for taking the break, 58.1% of those that had taken a break indicated that there was. (16.6% gave both lifestyle and clinical reasons). Table 24 below details the clinical reasons for breaks. The most commonly cited reason was that the side

effects of treatment became too severe (28.9% of all those taking breaks), while just under a fifth indicated that the break was on the recommendation of their doctor.

**Table 24 Clinical reasons for taking breaks**

<b>Reason</b>	<b>Percentage of those who have taken a break</b>
Side effects	28.9
Recommended by doctor	19.8
Drug resistance	12.2
Liver toxicity problems	8.2
Changing regimens	6.7
Recommended by other health professional	4.4
Complications with hepatitis C	1.5
Other	8.5

N=263

We also asked about the involvement of the participant's doctor in these breaks. Participants were less likely to talk to their doctor about the break prior to taking it (61.5%) than they were during the break (67.1%) or afterwards (85.3%). This may suggest that these breaks are not just from the treatments, but from the clinical experience of HIV.

We were also interested in the outcome of the treatment breaks, both in terms of clinical markers and experience of health and well-being. Table 25 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 was stable (34%). With well-being, there was a more distinct pattern for the remaining categories with decreasing proportions saying that it of *improved*, (32%) *fluctuated* (22%) or *got worse* (13%).

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.

**Table 25 Effect of break on clinical markers**

	<b>Stayed same</b>	<b>Improved</b>	<b>Fluctuated</b>	<b>Deteriorated</b>
<b>Health <sup>a</sup></b>	35.3	19.1	22.3	23.2
<b>Well-being <sup>b</sup></b>	33.5	31.7	21.8	13.0
	<b>Stayed same</b>	<b>Increased</b>	<b>Fluctuated</b>	<b>Decreased</b>
<b>Viral load <sup>c</sup></b>	20.0	58.6	12.0	9.5
<b>CD4 <sup>d</sup></b>	24.7	6.7	14.0	54.6

a N=249; b N=248; c N=230; d N=237

These data provide an important insight into the motivations and consequences of treatment breaks. Clearly, while clinical considerations play a part in breaks, lifestyle motivations and improvements in general health and well-being are important considerations. They also add to our increasing understanding of the relationship between clinical markers and the experience of health.



### 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 (Averitt and Thiemann, 2001). 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.

Around one quarter (24.9%) of respondents who had ever used antiretroviral treatments indicated that they had some sort of ARV resistance test. This included 28.2% of those who are currently on antiretroviral treatment and 16.6% of those who are not. The average length of time since the most recent resistance test was 12 months. 90.1% of respondents had had their most recent test in the last two years (89.5% of those currently on ARV, 92.3% of those not).

Of those who had resistance testing, 75.4% found resistance to one or more antiretroviral drugs (60.0% of those currently on ARV, 79.4% of those not). This resulted in a change of drugs for 57.6% (N=68) of those where resistance was shown.

Table 26 shows the changes in clinical markers for all those who underwent resistance testing and specifically for those who changed treatments. Those who changed treatments were more likely to experience improvements in both markers.

**Table 26 Effect of resistance testing on clinical markers (percentages)**

	Stayed the same	Decreased	Increased	Don't know
<b>All who tested for resistance</b>				
<b>Viral load</b> <sup>a</sup>	24.3	43.2	11.9	20.5
<b>CD4</b> <sup>a</sup>	25.4	18.1	36.9	19.6
<b>Those who changed medications</b>				
<b>Viral load</b> <sup>b</sup>	11.1	61.5	10.3	17.1
<b>CD4</b> <sup>b</sup>	14.5	16.2	53.8	15.4

a N=196; b N=117

**CLINICAL TRIALS**

A total of 31.4% of the respondents had participated in a clinical trial for HIV related treatment and of these 56.6% had participated in a clinical trial in the last two years. The main treatments that participants had trialled were Interlukin-2 (12.5%) and AZT (10.5%). They had on average been on these trials for 11 months. The circumstances surrounding participation in the trial are given in Table 27 below. These data show that involvement of doctor was important in this decision, as was an altruistic intent.

**Table 27 Reasons for participating in clinical trials (percentage of those who have participated in a trial)**

<b>Reason</b>	<b>Percentage of those who have been involved in trials</b>
Decided with doctor	64.4
Felt experience could benefit others	62.5
Had enough information about the trial	33.8
Only way to get treatment	19.6
No other treatment options	19.0
Other treatments weren't working	18.2
Felt pressure to go on trial	4.1
Other	9.7

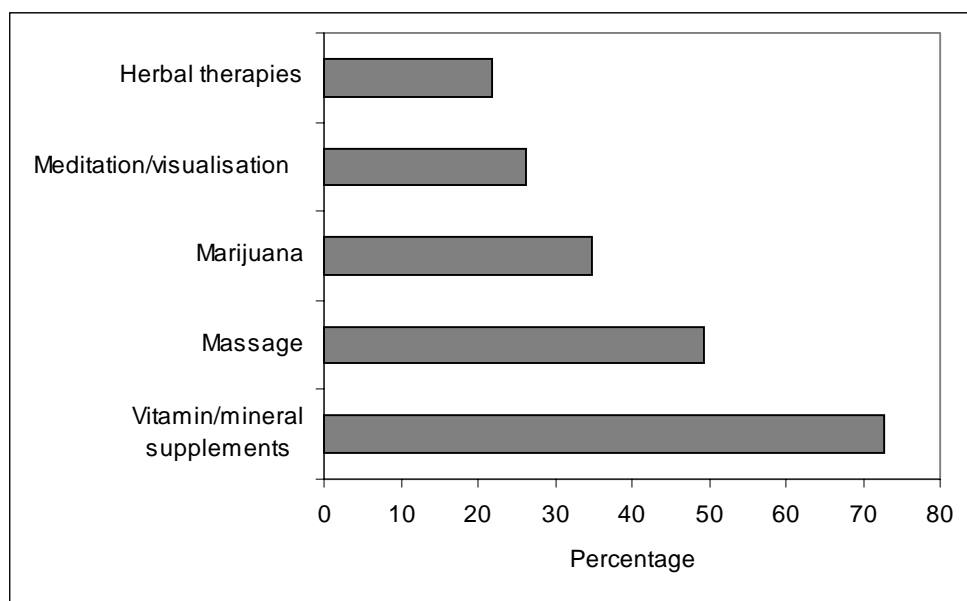
**VACCINES**

While the development of readily available therapeutic vaccines for HIV positive people is still some way off, 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 (22.5%) said they did not know, while 61.1% either agreed or strongly agreed with the statement. A further 10.9% disagreed and 5.7% disagreed strongly.

 **See also Vaccines page and Sexual Practice page 78**

### COMPLEMENTARY THERAPIES

Over half (52.9%) of the respondents were currently using complementary therapies for HIV. The most common complementary therapy was vitamin or mineral supplements (72.8% of those reporting complementary therapy use), followed by medicinal marijuana (34.7%), massage (49.4%), meditation (26.2%), and herbal therapies (21.7%) (see Figure 11). Other complementary therapies included acupuncture (13.8% of those using complementary therapies), traditional Chinese medicine (6.9%) and other traditional medicines (5.8%). Those using complementary therapies were no more or less likely to be using ARV.



**Figure 11 Most commonly used complementary therapies**

N=467

Almost all PLWHA (78.8%) believe that complementary therapies can improve well-being (see Table 28). Around half the sample also believe complementary therapies can delay the onset of illness due to HIV, can reduce side effects of antiretroviral medication, and can boost the immune system. However, around one third of the respondents were unsure about these three statements and these people were more likely to be those not currently using complementary therapies.

Opinion is still divided on whether there is sufficient evidence on the benefits of complementary therapies, and on whether medicine's focus on anti-HIV drugs was limited. Again, there was

considerable uncertainty about these issues. On average, those PLWHA who use complementary therapies spend \$21.30 per week on them.

**Table 28 Attitudes to complementary therapies: percentage of total sample**

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't know</b>
Complementary therapies can improve well-being	1.3	2.6	49.6	29.2	17.3
Complementary therapies can delay the onset of illness due to HIV	4.1	9.7	35.2	15.6	35.4
Complementary therapies can reduce the side effects of conventional medical treatments	1.6	5.9	36.6	18.2	37.7
Complementary therapies can boost the immune system	2.1	4.5	42.9	17.5	33.0
There is not enough evidence to be sure about the benefits of complementary therapies	7.1	30.9	33.3	6.3	22.4
Medicine's focus on anti-HIV drugs is very limited	4.4	27.6	34.0	7.3	26.7
Complementary therapies are a central part of my anti-HIV treatments	13.2	33.5	24.2	16.1	13.0

### OTHER MEDICATION

Participants used a range of other medication. In all 52.4% of respondents were using some other type of medication than antiretroviral therapies. The main medications being used are valtrex (5.0%), bactrim (4.5%), and acyclovir (3.8%).

### Dosing and Compliance

Respondents were asked the number of times they took a range of medication per day. On average, PLWHA were taking medication 2.5 times per day (range 0 to 22, median=2). The number of times they were taking specific types of medication is shown in Table 29 below.

**Table 29 Number of times participants take medications**

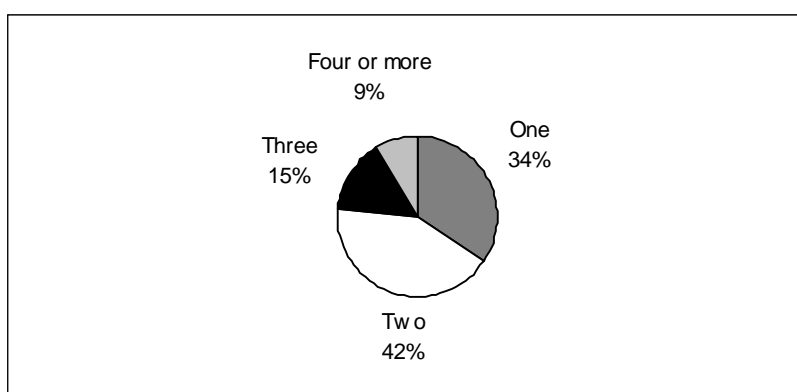
<b>Reason</b>	<b>Mean</b>	<b>Median</b>	<b>Range</b>
Antiretroviral drugs	1.8	2	0-20
Complementary therapies	0.6	0	0-6
Medication for health conditions other than HIV	1.0	0	0-15

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, 82.8% reported missing no doses on the two days, 11.2% missed one dose, 3.0% missed two doses and 2.9% missed three or more doses.

### Prescriptions

We asked participants who prescribes their antiretrovirals. In recognition of the multiple prescribing sites people utilise respondents were able to nominate more than one source. Two fifths (42.6%) of PLWHA get their prescriptions for antiretroviral drugs from a GP who specialises in HIV/ S100 prescriber. A similar proportion (41.9%) obtain their prescription from a specialist in an outpatient clinic, while fewer obtain them from a doctor at a sexual health centre (17.4%), from a HIV specialist while an inpatient (2.5%), or another GP (2.6%).

Unlike the 1999 survey where over sixty percent of participants collected all their prescriptions from one site, participants in this survey were most likely to say two places (41.9%) with slightly fewer saying one place (34.5%). Fewer went to three or more sites (See Figure 12). When asked how difficult it was to do this, over half (58.2%) said it was not difficult, 35.4% said somewhat difficult and 6.4% said very difficult



**Figure 12** Number of prescription pick-up points



**SERVICES**





## SERVICES

This section covers PLWHA's use of health and other services. Australia has had a long history of the provision of culturally and geographically appropriate HIV specific services, and a history of strong community advocacy around access to HIV specific and mainstream services. Here we look at both health services and other services that have been critical for maintaining quality of life for PLWHA.

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### Summary:

For general health care treatment 49.9% of PLWHA see an HIV GP/S100 prescriber, whereas for HIV specific treatment 47.9% see an HIV GP/S100 prescriber and 35.6% see an HIV specialist/physician. Most respondents had visited either a GP who specialises in HIV or an HIV specialist in the last six months.

### Experiences of health care:

- 34.5% pick up all of their prescription medication at one place;
- 41.9% go to two places for prescription medication;
- 23.7% go to three or more places for prescription medication.

### Services used at AIDS organisations:

- 46.9% treatment advice;
  - 38.8% social contact;
  - 30.6% counselling;
  - 30.1% peer support;
  - 22.6% complementary therapies.
  - 18.3% advice on legal matters;
  - 12.0% advice on financial matters;
-

## HEALTH SERVICES

The increasingly complex management of HIV treatments, side effects and the consequences of long term infection have meant that coordinated and comprehensive clinical management has become critical for positive people. Here we examine the use of, and experience of, a range of 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<sup>9</sup>) 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 by those living in capital cities. Combined, HIV GPs and specialists are the primary physicians for 83.5% of respondents for HIV specific management and 66.6% for general health management.

**Table 30 Physician used for general and HIV related treatment: percentage of total sample**

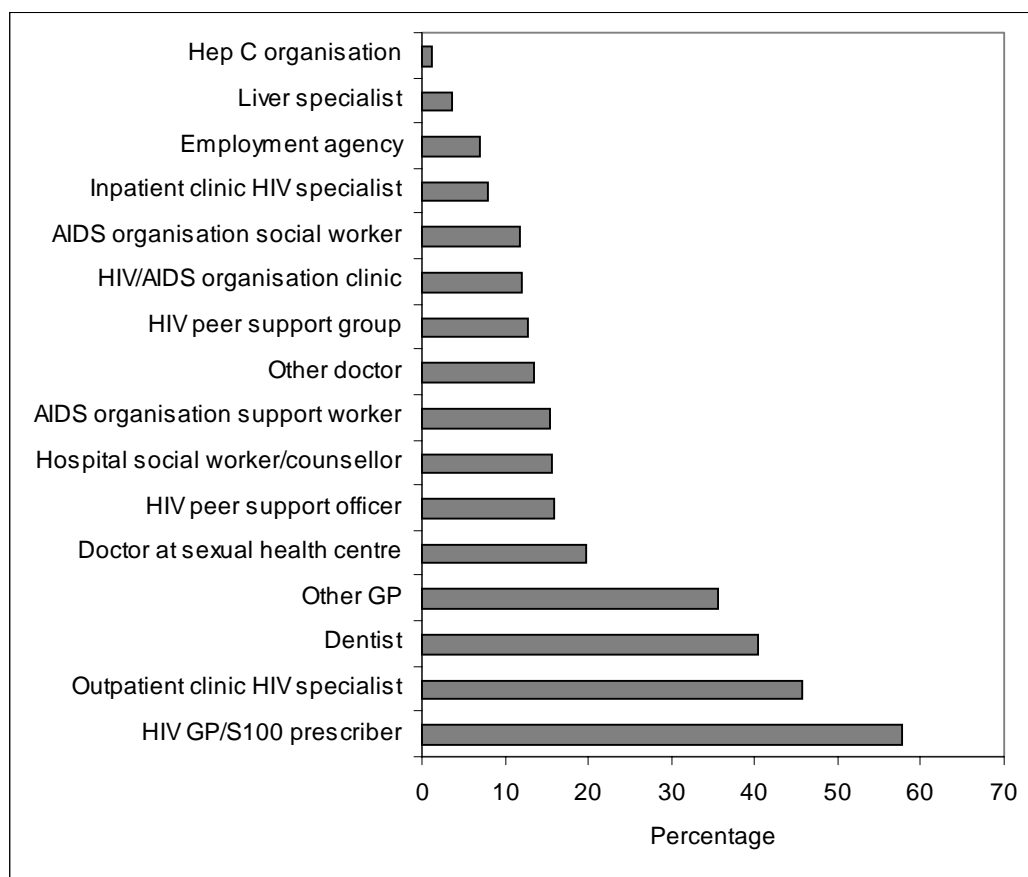
	For general treatment	For HIV specific treatment
HIV GP/S100 Prescriber	49.9	47.9
Other GP	21.9	3.6
HIV specialist at outpatient clinic	16.3	34.6
HIV specialist at inpatient clinic	0.4	1.0
Doctor at sexual health centre	8.6	11.5
Other doctor	2.6	0.7
Other	0.3	0.7

59.5% of respondents said that the doctor they see for general medical services is the same doctor they see for HIV-related treatment. Of those who see a different doctor, 98.0% said that that doctor knows their HIV status.

<sup>9</sup> An S100 Prescriber is a clinician who is registered to prescribe s100 medications - highly specialised drugs for the treatment of HIV.

**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 57.8% using a HIV GP/ S100 prescriber, 45.7% a HIV outpatient specialist, 40.3% a dentist, 35.6% an other GP, and 19.7% using a doctor at a sexual health service (see Figure 13). Smaller proportions used support services including counselling. People with hepatitis C were more likely to use a Hep C organisation and those with hepatitis B and/or C were more likely to have seen a liver specialist.



(Multiple responses possible)

**Figure 13 Services used in the last six months**

**Other Services**

Participants were asked whether they currently use a range of services and, if so, whether they do so through an HIV/AIDS organisation or through another organisation. The most commonly used service at AIDS organisations was treatment advice, with almost half the respondents selecting this item (see Table 31). AIDS organisations were also used for treatment information,

social contact with other PLWHA counselling and peer support by substantial numbers of respondents. Other organisations were more likely than AIDS organisations to be used for pharmacy services, internet services, employment services, housing assistance, mental health services and financial advice.

**Table 31 Services used at HIV/AIDS organisations and at other organisations (percentage of total sample)**

	Use service at HIV/AIDS ORGANISATION	Use service at OTHER ORGANISATION
Treatments advice	46.9	24.2
Treatments information	41.5	16.5
Social contact with other PLWHA	38.8	8.8
Counselling	30.6	21.0
Peer support group	30.1	5.7
Financial assistance	24.3	12.1
Complementary therapies	22.6	26.5
Informal peer support	21.7	9.5
Pharmacy services	20.7	40.2
Legal advice	18.3	14.8
Housing assistance	14.9	19.0
Community education campaigns	14.6	4.7
Volunteer carer	12.2	4.7
Financial advice	12.0	17.7
Transport	9.0	17.6
Internet based information	8.8	16.5
Mental health services	8.1	17.1
Internet access	7.7	24.3
Respite care	6.6	5.4
Library	6.6	22.7
Employment services	5.5	15.5
Return to work skills	4.4	10.8
Drug/alcohol treatment	2.9	7.6
Paid carer	1.9	4.0

(Multiple responses possible)

 See also: Poverty and services page 107

When asked what services they felt they needed but were currently not receiving, respondents were most likely to nominate peer support groups (10.8%), alternative therapies (10.2%), social contact/dating services (8.3%), and counselling (8.0%).

### **INFORMATION**

One of the most distinctive characteristics of the HIV/AIDS epidemic in developed countries 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 two 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**

In recognition of the increasing specificity and distinctiveness of treatments information, we modified the section on information sources in the HIV Futures 3 survey to cover three domains: HIV treatments information; HIV management information and information around living with HIV. Respondents were asked to nominate from a list of potential sources, those that were important sources of information in these domains. The results of this can be seen in Table 32 below.

**Table 32 Sources of information about treatments and living with HIV (percentage of sample)**

	Information about TREATMENTS	Information about HIV MANAGEMENT	Information about LIVING WITH HIV
HIV GP/S100 prescriber	63.5	53.7	32.5
Other GP	13.6	11.8	8.8
HIV specialist at outpatient clinic	46.2	38.5	21.6
HIV specialist at inpatient clinic	9.8	7.9	5.5
Other doctor	6.4	5.2	4.8
Public Health Nurse	9.2	10.1	8.6
Other Nurse	3.6	4.5	4.5
Pharmacist	15.4	7.0	5.7
Alternative therapist	13.8	15.9	16.8
Dietician	8.9	13.7	16.4
Dentist	10.0	11.7	8.6
Peer Support Officer	7.8	9.7	14.1
Sexual health service	13.9	13.1	13.8
Family Planning Association	1.4	1.7	2.2
Sex worker organisation	1.6	2.1	3.0
Treatments officer	17.8	12.2	9.7
Other HIV/AIDS organisation staff	14.7	15.5	19.7
Positive women's organisation	4.2	4.7	6.0
Positive heterosexuals group	5.1	5.2	6.6
Injecting drug users' organisation	2.0	2.0	3.2
Haemophilia Foundation	2.2	2.8	3.3
HIV positive friends	29.5	31.9	43.2
Other friends	6.0	4.8	15.2
Partner/ lover	13.1	13.1	22.2
Family	4.4	5.0	12.1
Articles in gay press	37.3	31.4	35.2
HIV magazine/ newspaper	49.0	43.3	45.0
Hep C Support Group/Organisation	3.0	2.0	3.3

	Information about TREATMENTS	Information about HIV MANAGEMENT	Information about LIVING WITH HIV
Liver Specialist	4.6	3.1	2.2
Internet	21.7	17.9	16.7
Publications from HIV/AIDS groups	41.8	40.6	42.8
Publications from other sources	9.7	7.9	8.9

(Multiple responses possible)

### **Information about Treatments**

HIV GPs/S100 prescribers were considered an important source of information on treatments by almost two-thirds of respondents. HIV specialists were nominated by around half the sample. Importantly information from the community sector figured significantly in the responses to this item. These included HIV magazines and newspapers (49.0%), HIV/AIDS organisation publications (41.8%), and articles in the gay press (37.3%). HIV positive friends were nominated by over a quarter (29.5%) of respondents.

When asked in a separate question to nominate the *most* important source of information on treatments 42.9% said their HIV GP and 29.6% said a HIV specialist at an outpatient clinic. No *other* response accounted for more than 5% of responses.

### **Information about HIV Management.**

When asked what sources of information around HIV management were important, a similar pattern emerged with HIV GPs nominated by over half the sample (53.7%) and community sector sources also figuring prominently (HIV magazine: 43.3%, HIV organisation publications: 40.6%, gay press: 31.4%). HIV positive friends were also mentioned by 31.9% of the sample.

When asked to nominate the *most* important source of information on HIV management 37.6% said their HIV GP, while 24.1% nominated an HIV specialist at an outpatient clinic, and 6.2% nominated HIV positive friends.

### **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 two items. The source selected by the greatest number of respondents was HIV magazine/ newspaper (45.0%), followed by HIV positive friends (43.2%)

and HIV organisation publications (42.8%). Clinical sources were also considered important by significant numbers of positive people (HIV GP: 32.5%, HIV specialist: 21.6%).

When asked to identify the *most* important source of information on living with HIV 17.9% nominated their HIV GP, 16.9% HIV positive friends, 10.9% an HIV specialist at an outpatient clinic, 10.6% AIDS organisation staff other than a treatments officer, 9.9% HIV magazines and newspapers, and 5.4% their partners.

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 33. As can be seen from these data, PLWHA are reasonably sceptical about the reliability of information available on the net. Those that rate the internet as an important source of information are less sceptical than others.

**Table 33 Attitudes to HIV information on the Internet (percentage of sample)**

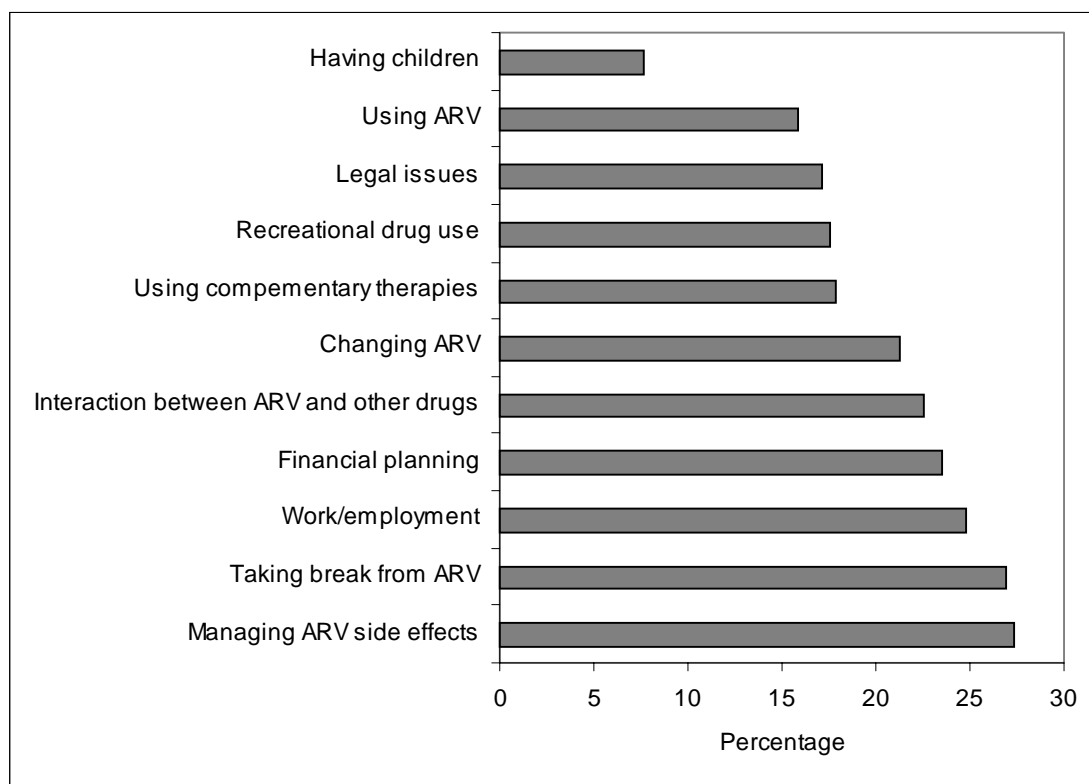
	Strongly Disagree	Disagree	Agree	Strongly Agree	Don't know
<b>Full sample</b>					
Information on the internet about living with HIV is unreliable <sup>b</sup>	3.4	23.7	11.3	3.0	58.6
Information on the internet about treatment side effects is unreliable <sup>b</sup>	2.6	25.7	10.1	2.4	59.2
<b>Those who rate the internet as an important source of information</b>					
Information on the internet about living with HIV is unreliable <sup>c</sup>	7.8	52.9	12.3	3.4	23.6
Information on the internet about treatment side effects is unreliable <sup>d</sup>	6.8	55.6	10.4	2.7	24.5

a N=862; b N=858; c N=216; d N=214.

### Lack of information

When asked to identify domains in which lack of information made it difficult to make decisions, around one quarter of respondents nominated the management of side effects (27.4%) and treatment breaks (27.0%). Employment and financial planning also figured prominently. Importantly, interaction between treatments and changing antiretroviral treatments were identified by one in five respondents (see Figure 14 below).





**Figure 14 Problems experienced due to lack of information**  
(Multiple responses possible) N=718

**Publications**

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 34, including breakdowns for specific populations where access or focus is an issue. Gay and HIV press are accessed by large proportions of the sample, as are 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 34 Publications read by PLWHA**

Publication	Percentage
<i>National or non-specific</i>	
National AIDS Bulletin	18.6
Positive Living	51.3
HIV Herald	29.6
Gay newspapers (% of total sample)	67.5

Publication	Percentage
Gay newspapers (% of gay men and lesbians and bisexuals)	78.1
Gay magazines	24.6
Gay magazines (% of gay men and lesbians and bisexuals)	28.5
Newsletters from community organisations	26.5
Overseas HIV/AIDS magazines (e.g. POZ)	8.5
National Haemophilia (% of total sample)	1.6
National Haemophilia (% of people with Haemophilia)	89.1
<i>State based publications</i>	
Talkabout (% of total sample)	47.6
Talkabout (% of NSW respondents)	71.6
With Complements (% of total sample)	26.2
With Complements (% of NSW respondents)	35.8
NUAA News (% of total sample)	3.4
NUAA News (% of NSW respondents)	5.5
Positive Life (% of total sample)	9.9
Positive Life (% of WA respondents )	62.6
QPP Alive (% of total sample)	15.1
QPP Alive (% of QLD respondents)	82.6

### Involvement with AIDS Organisations

Participants were asked about their involvement with HIV/AIDS organisations. 71.4% of the sample has some contact with HIV/AIDS organisations. Of these, 74.5% received newsletters and mail outs, 59.9% were clients, 51.7% were members, 25.2% were volunteers and 11.5% were employees. Of those that had no contact with AIDS organisations, 53.3% gave the reason *I do not want to be involved*, 30.0% gave the reason *I do not have enough time*, and 14.3% said that they had *no transport or are too far away*. Importantly, 18.0% of those who were not involved in AIDS organisations said they *felt excluded from them*. 29.0% had at some point held a decision making position in an AIDS organisation (16.41% in the last two years).

**WELL-BEING**

## WELL-BEING

This section focuses on the lives of HIV positive people outside the specifically clinical. While the distinction between the clinical and social experiences of being HIV positive is to some extent artificial, we feel it is important, in an environment where HIV positivity is increasingly being represented as a clinical state, to continue to emphasise the psychological and social sequelae of HIV infection, both positive and negative. To this end, we have asked about the experience of HIV within eight domains: the social and community experience of HIV; mental health and social support; accommodation; sex and relationships; recreational drug use; employment; finances; and discrimination. Taken with the information in the previous sections this gives a rounded view of the lives of HIV positive people. Issues around treatment breaks, for example, can be understood in the context of the lived experience of housing, employment and discrimination. We also include two sections, sexual relationships and drug use, that are most often seen in the AIDS literature where HIV positive people are regarded in the context of infection and prevention. While we do examine these issues in that context, if only to demonstrate the extent and complexity of prevention strategies employed, we are also concerned about the place these issues have in HIV positive people's lives and the benefits they bring.

## THE SOCIAL WORLD OF PLWHA

This section 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.

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### Summary:

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

For 52.0% of respondents, their HIV status had been disclosed to another person when they did not want it to be (29.7% in the last two years).

HIV was an important part of the identity of 52.1% of respondents and an essential part of the identity of 19.0%. HIV status tended to be less important to PLWHA than identities based on sexuality, gender or family.

Sources of support:

- 81.0% partners/spouse;
- 58.7% pets;
- 50.6% doctors;
- 46.6% close friends;

In the last six months slightly less than one third of respondents had taken prescribed medication for depression and over one quarter for anxiety.

One fifth plan only one day at a time, while 52.5% plan at least one year ahead.

71.4% have some contact with HIV/AIDS organisations, mostly by receiving newsletters or being clients of these organisations. 11.5% were employees of AIDS organisations.

Involvement with other PLWHA:

- 95.0% know another PLWHA;
- 18.0% have a spouse/partner with HIV;
- 64.8% know acquaintances with HIV;
- 79.2% spend at least some time with other PLWHA;
- 15.4% spend a lot of time with other PLWHA;
- 19.3% spend no time with other PLWHA;
- 25.9% have been involved with the care of someone with HIV/AIDS;
- 81.7% someone close has died of AIDS related causes.

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### **Contact With Other PLWHA**

Very few HIV positive people (5%) do 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 have an HIV positive friend (79%) and many have either an HIV positive partner or ex-partner (37% combined). 25.9% of respondents have been involved in the nursing or care of

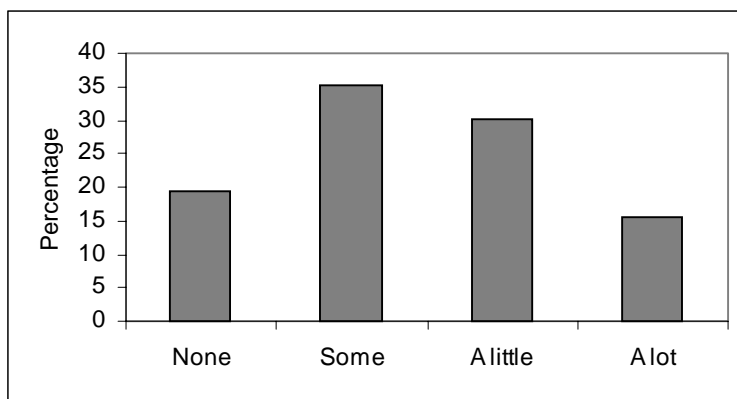
another positive person at some time in the last two years, and 81.7% have had someone close to them die from HIV/AIDS.

**Table 35 Other HIV positive persons known by respondent**

Positive persons	Percentage
Friend	79.4
Acquaintance/ member of support group	64.8
Former partner/ spouse	29.0
Partner/ spouse	18.0
No-one	5.2
Other relative	3.8
Son/ daughter	0.9

(Multiple responses possible) N=878

Around four-fifths of the respondents spend at least some time with other positive people. The 15% who indicated that they spend a lot of time with other PLWHA are more likely to be those who work or volunteer for an HIV/AIDS organisation.



**Figure 15 Time spent with other positive people**

N=878

**Disclosure**

Respondents were asked who they had disclosed their HIV status to (see Table 36). Not surprisingly, most (87%) had disclosed to close friends, and most (92%) of those in relationships had disclosed to their partner. Within families, people were most likely to have disclosed to siblings (70%) although many had disclosed to parents (61%). Only 2% (N=21) had not disclosed their HIV status to anyone.

 see also sex and relationships page 69

**Table 36** **People the respondent has disclosed their HIV status to**

	<b>Percentage who have disclosed</b>
Close friends	86.6
Brothers or Sisters	70.4
Positive friends	68.6
Parents	61.0
Partner/ spouse	55.5
Other friends	41.5
Work colleagues	37.9
Neighbours	18.2
Son/daughter	10.2
People from own ethnic community	3.6
No-one	2.2
<i>Specific populations</i>	
Partners (% of those in regular relationship)	91.6
Partners (% of those not in regular relationship)	22.3
Work colleagues (% of those currently employed)	51.1
Work colleagues (% of those not employed)	25.9
Son/ daughter (% of those with dependant children)	44.3
People from own ethnic community (% of those who speak a language other than English at home)	8.9

(Multiple responses possible)

### ***Unwanted Disclosure***

Respondents were asked if their HIV status had ever been disclosed without their permission. 52.0% said that it had at some point, and 29.7% said that this had happened in the last two years. When asked who disclosed their status, they were most likely to nominate friends or work colleagues (see Table 37). In part these data reflect those that are most likely to be aware of the respondent's HIV status. It is of concern that 18.4% nominated a worker in a health care setting.

 See also discrimination in health care page 110

**Table 37 Sources of unwanted disclosure (percentage of those experiencing unwanted disclosure)**

	Percentage
Other friends	29.7
Close friends	25.7
Work colleagues	20.9
Workers in a health care setting	18.4
Brothers/sisters	15.7
Partner/spouse	12.5
Other	10.1
Parents	9.6
Community organisation staff/volunteers	9.1
Neighbours	8.6
Other family	8.2
HIV positive friends	7.9
Son/daughter	1.3
People from ethnic community	0.9

### 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 38. 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 (52%) of positive people in this study consider their HIV status an important, but not essential aspect of their make-up, while 19% consider it to be an essential characteristic. This is in contrast to sexuality and gender, where over 30% of the sample consider each of these to be *essential* characteristics.

**Table 38 Importance of personal characteristics to respondents' sense of identity**

	Essential	Important	Not important	Irrelevant
Sexuality	34.8	44.2	13.5	7.5
Gender	31.3	39.9	16.1	12.6
Family	27.4	46.5	15.3	10.8
HIV status	19.0	52.1	20.7	8.3
Career	12.3	44.5	21.3	21.9
Religious beliefs	9.7	22.2	25.7	42.4
Parenthood	8.5	14.5	13.3	63.6
Ethnicity/ Cultural background	4.0	20.6	30.5	44.9
Drug use (recreational/illegal)	2.5	16.2	30.5	50.8

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 39).

**Table 39 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	18.3	52.7	21.2	7.8
Women	19.1	56.2	19.5	5.1
Heterosexual men	20.4	49.4	15.7	14.5
Those who have had an AIDS defining illness	20.7	50.0	19.5	9.8
Those who have not had an AIDS defining illness	18.3	53.0	20.7	7.9
Those on antiretroviral therapy	19.0	52.5	20.0	8.5
Those not on antiretroviral therapy	18.8	51.0	22.4	7.8
Those in sero-concordant relationships	11.5	57.6	21.2	9.7
Those in sero-nonconcordant relationships	15.9	53.9	23.7	6.5

N varies for each sub group

### 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 40 below with those designating the category as *not applicable* excluded from each row.

The source that participants were most likely to rate as one they receive a *lot* of support from was the participant's partner or spouse (81% of those with partners). This was followed by pets, where 59% of pet owners rated them highly. Doctors and close friends were also rated highly by around half of the participants.

When we examine those that people receive no support from the highest ranking category was religious or spiritual advisor where 43% of those with such a source said they received no support from them. Volunteer counsellors were also considered a source of no support for 41% of those with a counsellor.

Participants were more likely to rate a source as supportive if they had disclosed to them for all categories (except pets where disclosure is a moot point).

The data from this item can be analysed to see the number of categories from whom respondents receive support. If we take the number of sources from whom the respondent received *a lot* of support we have a measure ranging from 0 to 15<sup>10</sup>. The mean number of sources of *a lot* of support was 3.3 with 55.2% receiving *a lot* of support from 3 or more sources and 13.5% receiving *a lot* of support from no sources.

We can repeat this analysis for different degrees of support. For example, the mean number of sources of *a lot* or *some* support is 5.9 (56.4% with 6 or more sources, 3.6% with none) and the mean number of sources of *no* support was 1.6.

**Table 40 Social support received from different sources: percent who gave valid responses for each category**

	<b>A lot</b>	<b>Some</b>	<b>A little</b>	<b>None</b>
Partner/ spouse	81.0	10.4	4.5	4.1
Pets	58.7	21.7	11.8	7.8
Doctor	50.6	33.5	13.8	2.0
Close friends	46.6	32.7	14.5	6.2
Parents	42.6	20.4	15.1	21.9
Children	35.8	21.8	14.5	27.9
HIV positive friends	32.3	35.2	23.3	9.2
Brothers and sisters	31.0	24.2	20.6	24.2
Family	27.2	25.9	23.7	23.3
Counsellor	25.8	27.0	21.5	25.7
Volunteer counsellor	24.9	17.4	17.0	40.7
Health care workers	24.4	35.2	21.9	18.5
Religious or spiritual adviser	17.9	19.8	19.4	42.9
PLWHA groups	17.2	27.1	29.0	26.7
Other friends	14.0	37.4	30.6	18.0

<sup>10</sup> Here we include those who designated the category as not applicable in the analysis, as this still indicates that the respondent does not receive support from this source.

### **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 last six months 27.5% of PLWHA had been taking medication prescribed for depression. A similar proportion (27.4%) had taken medication for anxiety. In addition 3.4% of the sample indicated that they had taken anti-psychotic medication.

### ***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 43, 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 agreed or strongly agreed with item 1 (crying all the time), and almost 15% 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, 42.2% agreed or strongly agreed with none of these items, 23.7% with one item, 17.5% with two items, 8.7% with three items, and 7.9% of the sample agreed with all four items. Agreement with all four items may be suggestive of clinical depression.

Agreement with a larger number of these items is significantly related to: being on anti-depressant medication; having a poorer self-rating of general health or general well-being; a higher viral load; being male; and having less social support. Scores on these items are

unrelated to: CD4 count; having had an AIDS defining illness; use of antiretrovirals; and sexuality.

**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*. About 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*. Again, around half agreed or strongly agreed with this statement. Those in agreement were more likely to be younger, female and report higher levels of both health and well-being.

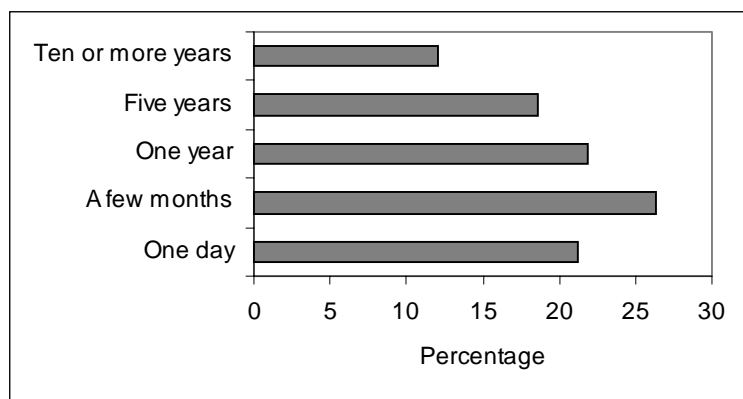
**Table 41 Attitudes to HIV status: percentage of total sample**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
I cry or feel like crying all the time	5.0	15.5	49.8	29.7
I don't enjoy things the way I used to	12.7	38.0	32.8	16.6
I have lost interest in other people	7.1	26.0	45.8	21.1
I don't feel it's worth going on	3.7	11.2	37.6	47.5
As long as I am well I prefer not to think about HIV/AIDS	13.4	37.4	42.2	6.9
Changes in my body due to HIV/AIDS have made me feel unattractive	18.4	37.1	32.5	12.0
I am happy with the way my body looks	9.7	39.3	39.9	11.1
Life has become more meaningful since I became HIV positive	14.7	32.5	37.2	15.6

**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.

More than one fifth (21.2%) only plan their life one day at a time and 26.0% plan only a few months ahead. More than half of the respondents plan for at least a year with 21.9% planning one year ahead, 18.6% planning five years ahead and 12.0% planning ten years or more ahead. This profile of the population has changed very little since the 1999 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 16 Time frame for future planning**

For 32.0% of respondents, the time frame for future planning had changed in the last two years, with 19.9% of all respondents now using a shorter time frame and 12.1% using a longer time frame.

The major reasons for change for those with a longer time frame were improved health due to treatments (37.0% of those with longer plans), taking new treatments (15.6%) and improved health for other reasons (16.2%). The major reason for change for those with a shorter time frame was declining health (40.6% of those with a shorter time frame), see Figure 17.

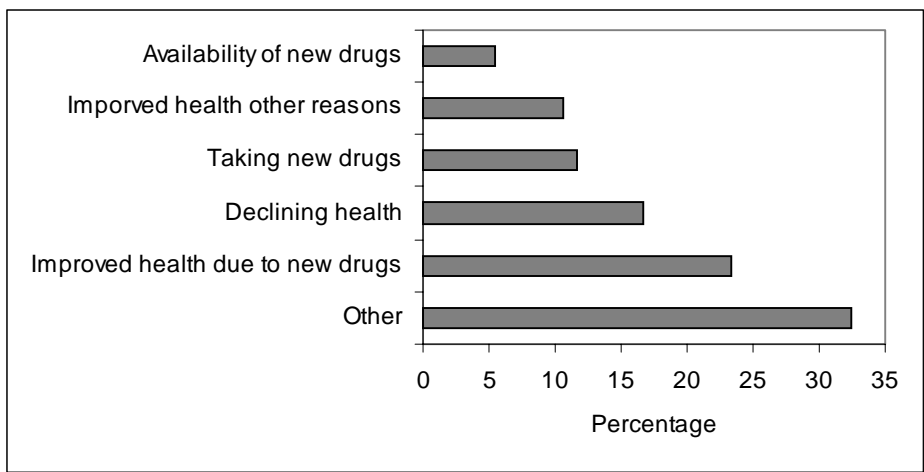


Figure 17 Reasons given for change in time-frame



## RELATIONSHIPS AND SEX

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### Summary:

47.6% of PLWHA are currently in a regular relationship, and a slightly smaller number have sex within their relationship. A smaller group, comprising mainly gay men, have both a regular relationship and casual partners (19.8%) and 28.2% have casual partners only. A quarter (25.4%) of PLWHA are not having sex at present.

Of those in a regular relationship 40.5% have a partner who is also HIV positive, 57.9% have an HIV negative partner and 1.6% a partner of unknown status. Nearly all (98.3%) PLWHA have disclosed their status to their regular partner, usually when they were diagnosed or at the time of, or prior to, the commencement of the relationship. In the majority of cases the partner's reaction to disclosure was positive and in one third of cases it brought the partners closer together, but 26.9% also reported that their partner was worried or scared.

Under half 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.

Condoms are always used with regular partners by:

- 0.0% of women with male HIV positive partners;
- 52.0% of women with male HIV negative or unknown partners;
- 8.2% of men with male HIV positive partners;
- 58.9% of men with male HIV negative or unknown partners;
- 12.5% of men with female HIV positive partners;
- 75.0% of men with female HIV negative or unknown partners.

Forty-three per cent of the sample had sex with casual partners in the past six months. 41.0% of the men reported that they always used condoms with casual male partners and 58.8% with casual female 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 75.0% of these instances.

Condom use with the most recent casual partner:

- 30.4% with an HIV positive partner;
- 71.1% with a partner of unknown HIV status;
- 74.1% with an HIV negative partner.

There were only 16 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 2 instances with an HIV negative casual partner.

Around half of PLWHA would prefer to be in a relationship with someone who is also HIV positive. Over half of PLWHA expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLWHA (60.9%) felt HIV had a negative effect on their sexual pleasure.

Only 13.1% 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 (9.4%) or that undetectable viral load means HIV is unlikely to be transmitted (11.7%). However, 30.7% of PLWHA agreed with the statement *If there was a vaccine which prevents HIV I would not practice safe sex.*

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## Relationships

Respondents were asked what sexual relationships they currently have. The results are presented in Table 42 below. Around one quarter of the sample said that they had no sex at present. A similar 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 have one regular sexual partner and no casual sex. Gay and bisexual men are more likely to report that they have a regular sexual partner and also have casual sex.

**Table 42 Type of sexual relationship(s) by gender and sexuality of respondent**

Sexual relationships	Women <sup>1</sup>	Heterosexual Men <sup>2</sup>	Homosexual & bisexual men <sup>3</sup>	Total
No sex at present	39.4	46.7	21.4	24.7
Casual sex only	4.2	13.3	32.0	28.3
Regular relationship only	49.3	33.3	20.8	24.1
Regular relationship plus casual sex	5.6	5.0	23.0	20.3
Regular with two or more people	1.4	1.7	2.8	2.6

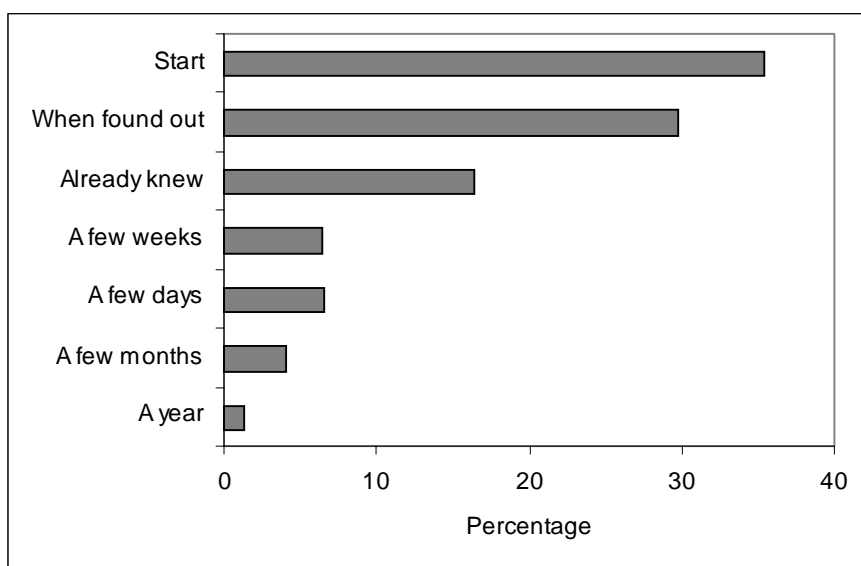
1:N=71, 2:N=60, 3:N=716

When asked if they were currently in a regular relationship, around half (47.6%) said they were. This is slightly higher than the proportion of the sample that report having sex with a regular partner in Table 42 (44.4%), as some in a regular relationship do not have sex.

### Regular Partners

Of those in a relationship with a regular partner, 40.5% report that their partner is also HIV positive (generally described as a sero-concordant relationship). The remainder are in sero-nonconcordant relationships. This remaining group is made up of 57.9% of the sample that report that their partner is HIV negative (a sero-discordant relationship) and 1.6% who report that they don't know their partner's HIV status. The proportion who do not know their partner's HIV status is less than half that reported in 1997.

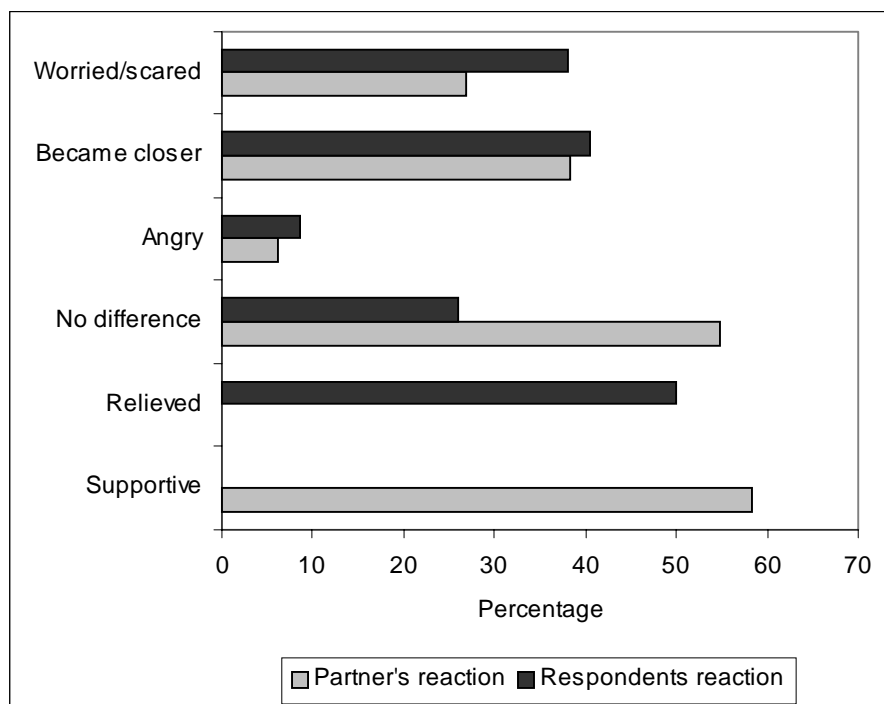
Nearly all PLWHA (98.3%) have told their regular partner that they are HIV positive. Of the seven respondents who had not disclosed their status, one had an HIV positive partner, three had HIV negative partners, and three did not know their partner's status. Respondents were asked at what point in the relationship they told their partner. The responses are given in Figure 18 below. Around one third (35.5%) told their partner at the beginning of the relationship. Slightly fewer than a third (29.8%) of respondents told their partner when they themselves found out they were positive and for 16.4% of respondents, the partner knew prior to the start of the relationship. Small numbers of respondents (6.5%) told their partners a few days into the relationship, 6.5% a few weeks into the relationship, 4.0% a few months into the relationship and 1.3% a year or more into the relationship.



**Figure 18 Time HIV status disclosed to partner among those in regular relationships**  
 N=389

When asked how their partner responded when told of the respondent’s HIV status, the majority (58.4%) reported that the partner was supportive (see Figure 19). Over half (54.8%) reported that it did not make any difference. Over one third (38.4%) reported that the disclosure brought them closer together.

Around one quarter (26.9%) reported that their partner was worried or scared and 6.3% said their partner was angry. Those who reported a worried or scared reaction from their partner were more likely to be in sero-nonconcordant relationships (32.6% of those in sero nonconcordant versus 19.3% in sero-concordant).



**Figure 19 Reaction of partner and respondent to disclosure: percentage of those in regular relationships**

Partner's reaction: N=387; Respondents reaction: N=375

Note: Respondents were not asked if partner was relieved or whether they themselves were supportive.

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, 39.1% had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 4.5% had anal or vaginal sex with a regular female partner in the previous six months. For male and female partners combined, 42.3% of respondents reported that they never used condoms and around 36.1% reported that they always used condoms (see Table 43). In total, 41.1% had either anal or vaginal sex with a regular male or female partner in the last six months.

**Table 43 Condom use with regular partner by respondent and partner gender**

ALL regular relationships	<u>Number</u> of these that used condom		
	Never	Sometimes	Always
<b><i>Female respondents</i></b>			
With regular male partner	8	16	13
<b><i>Male respondents</i></b>			
With regular male partner	135	59	102
With regular female partner	10	5	18

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 occur in sero-concordant relationships than in sero-nonconcordant relationships (see Table 44).

**Table 44 Condom use with regular partner by respondents' gender, partner gender, and partner sero-status**

SERO-CONCORDANT Relationships	<u>Number</u> of these that used condom		
	Never	Sometimes	Always
<b><i>Female respondents</i></b>			
With regular male partner	4	5	0
<b><i>Male respondents</i></b>			
With regular male partner	101	11	10
With regular female partner	5	2	1
<b>SERO-NONCONCORDANT Relationships</b>			
<b><i>Female respondents</i></b>			
With regular male partner	4	8	13
<b><i>Male respondents</i></b>			
With regular male partner	18	33	73
With regular female partner	4	1	15

### Casual Partners

Over half (48.1%) of the sample reported that in the six months prior to completing the survey they had sex with one or more casual partners. When asked the HIV status of their casual partners, 4.6% reported that all of their casual partners were HIV positive, 30.8% reported that some of their casual partners were HIV positive, and 9.3% reported that none of their casual partners were HIV positive. Most (55.2%) respondents who 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 45 there are considerable variations in condom use when we examine this by sex of respondent and sex of partner.

**Table 45 Condom use with casual partner by respondent and partner gender**

ALL casual partners	Number of these that used condom		
	Never	Sometimes	Always
<b>Female respondents</b>			
With casual male partners	0	2	6
<b>Male respondents</b>			
With casual male partners	39	180	152
With casual female partners	4	3	10

Again, when we look at these data in terms of the partners' HIV status, a clearer pattern emerges (see Table 46). 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 is much more likely. It is important to note, however, that one third of respondents who only had intercourse with HIV seropositive partners reported that they always used condoms.

**Table 46 Condom use with casual partner by partners' sero-status**

Casual partners' HIV Status	Number of these that used condom		
	Never	Sometimes	Always
All HIV positive	8	4	7
Mixture / unsure	29	171	137
All HIV negative	5	8	17

In addition to reporting on their overall patterns of condom use, respondents who had casual sex reported on their most recent sexual encounter with a casual partner. Over half the survey respondents provided such information.

Of the respondents who had casual sex, 75.5% 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 20 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 show that for the entire set of data available, incidents that involved any risk were very rare and mostly associated with partners of unknown status.

Respondents who indicated that they knew their partners' HIV status were asked how they knew. Nearly all (89.1%) of these respondents said that their partner told them their status, 12 respondents said that they knew their partner's status from the type of sex they wanted, 7 said that they could tell from their respondents physical appearance, 5 said that a third party told them, 4 said that they could tell by the bar/venue at which they met and 3 said they could tell by the people they were with.



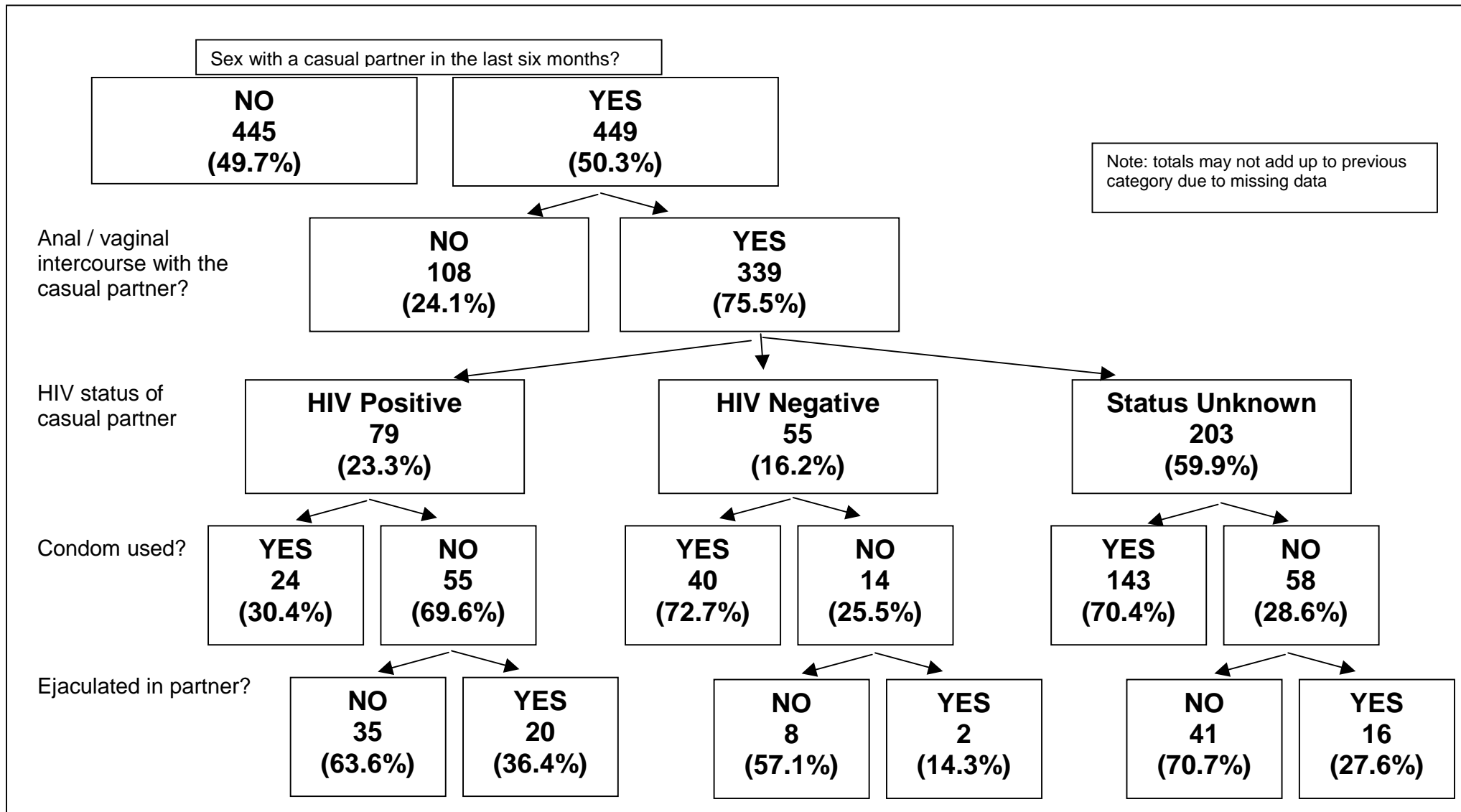


Figure 20 Sexual practice with the most recent casual partner

### 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 47. The majority of these items are about the negative effects of HIV on people sexual lives. This is not to suggest that the sexual lives of positive people are inherently problematic, but rather, given the community consultations and our qualitative research, it is a recognition that these issues are those that are most in need of policy and programmatic response. They are also issues that need to be discussed within affected communities and we hope that this material may facilitate public debate.

The responses that we sought from participants fall into three broad areas: those concerned with relationships; those concerned with HIV transmission; and those concerned with sexual pleasure.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, around half (51.8%) said they would, just over a third (35.2%) said they would not, and the remainder (13.1%) said that they did not know. One critical issue for PLWHA is the impact that HIV has on the potential to develop new relationships. Over half (55.9%) of respondents agreed with the statement *Few people would want a relationship with someone who has HIV*. This was more pronounced among those PLWHA who were not currently in a regular relationship.

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 (53.8%) agreed with this statement. Agreement was significantly higher among those not in regular relationships, and among those who have no sex at present. When asked to respond to the statement *Being HIV positive has helped me form more satisfying relationships*, around one quarter (24.4%) agreed, while 12.5% said they were uncertain.

Concerns about transmission of the virus to others and reinfection were apparent in the responses to the next six items. Most respondents (72.4%) 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*. Similarly, the impact of potential vaccines on intentions to practice safe sex and anxiety about

safe sex is minimal with 30.7% agreeing with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*, and 13.7% agreeing with the statement *Knowing that a vaccine will become available makes me less anxious about sex*. The response to concerns about re-infection was mixed, with 46.5% agreeing that *I am concerned about becoming infected with another strain of HIV* and 43.7% disagreeing.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (60.9%) agreed with the statement *HIV has had a negative effect on my sexual pleasure*. One third (33.3%) disagreed with this statement. When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. One in five (19.5%) 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 (47.2%) than disagreed with it (33.0%). Those who agreed with this statement were also more likely to agree that they would prefer a relationship with someone who was HIV positive. One quarter (25.9%) said that they agreed with the statement *I have stopped having sex because of my HIV status* while 60.8% agreed that *HIV has negatively affected my libido*.

**Table 47 Attitudes to HIV, sex and relationships**

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't know</b>
I prefer to have a relationship with someone who also has HIV	10.2	25.0	32.8	19.0	13.1
Few people would want a relationship with someone who has HIV	7.4	27.8	38.8	17.1	8.9
I am afraid of telling potential partners of my HIV status in case they reject me	13.5	26.7	36.1	17.7	6.0
Being HIV positive has helped me form more satisfying relationships	20.8	42.3	17.5	6.9	12.5
I am afraid of infecting my partner, or potential partner, with HIV	6.2	18.6	43.0	29.4	2.8
I feel more confident about unprotected sex because of the new treatments	45.5	37.0	9.0	4.1	4.4
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	34.4	35.2	19.6	5.8	5.0
If there was a vaccine which prevents HIV, I would not practise safe sex	17.0	33.5	22.8	7.9	18.9
Knowing that a vaccine will become available makes me less anxious about sex	15.4	50.4	11.8	1.9	20.5
I am concerned about becoming infected with another strain of HIV	11.8	31.9	36.3	10.2	9.8
HIV has had a negative effect on my sexual pleasure	10.7	24.4	38.0	22.9	3.9
If I know that my partner is HIV positive I find sex more pleasurable	9.9	23.4	28.7	18.5	19.5
I have stopped having sex because of my HIV status	29.4	42.4	18.5	7.4	2.3
HIV has negatively affected my libido	13.3	21.5	37.9	22.9	4.3

**Children**

As mentioned in the description of the sample earlier in this report, 9.2% of those surveyed currently have dependant children. We were also interested in future plans for children among PLWHA. Most PLWHA (88.7%) were not currently considering having children. Of the remainder, sixteen PLWHA have decided to have children in the future and three are currently attempting to have children. Twenty are currently considering having a child, but have not decided, and twenty-six people have considered having a child, but have decided it is too risky. Three respondents are currently pregnant, and another respondent has a pregnant spouse.

While those who are considering, or have considered having children are primarily women (heterosexual, bisexual and lesbian), some are gay, bisexual or heterosexual men.



## RECREATIONAL DRUG USE

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### Summary:

Alcohol is the most commonly used drug by PLWHA (81.1%), and more than half (54.6%) use tobacco. Almost three-quarters of respondents reported that they had never injected illegal drugs and of those respondents who had injected illegal drugs approximately half had done so in the last 12 months. Of PLWHA who reported injecting drugs, 93.3% had not shared injecting equipment in the past twelve months.

All of those who shared injecting equipment in the last 12 months (N=15) did so with at least one risk reduction strategy such as using the needle last or washing/bleaching or using with another person who was HIV positive.

Circumstances of sharing injecting equipment:

- 63.8% washed or bleached the needle;
- 60.7% did not have access to other needles;
- 57.2% shared with a sexual partner;
- 47.5% used the needle last;
- 40.3% the other person was HIV positive;
- 12.4% the other person was hepatitis C positive.

Approximately one fifth of all respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and one in fifteen reported having had a bad experience as a result of using both illegal drugs and ARV.

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### 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 48 gives these results. As can be seen from these data, alcohol is 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) are also used by PLWHA.

**Table 48 Recreational use of drugs**

	<b>Percentage of sample using in last 12 months</b>
Alcohol	81.1
Cigarettes	54.6
Marijuana	53.6
Speed (injected)	11.9
Speed (not injected)	16.4
Heroin (injected)	3.4
Heroin (not injected)	0.3
Cocaine (injected)	2.8
Cocaine (not injected)	10.7
Ecstasy	25.8
LSD/ trips	8.5
Amyl	37.1
Homebake	2.6
Methadone (prescribed)	2.8
Methadone (other)	0.6
Steroids (injected)	5.9
GHB/GBH/Fantasy	4.2
Viagra or similar	20.1

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. The study also deliberately sampled among injecting drug users.

Gay male respondents are significantly more likely than other groups to use speed (not injected), ecstasy and amyl and less likely to use heroin and cocaine.

About one in fifteen (6.9%) PLWHA reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs.



Around one in five (21.6%) PLWHA reported that they had missed a dose of antiretroviral medication at some point as a result of using illegal drugs. This was highest among those that used non-prescribed methadone, speed, homebake, LSD and ecstasy.

Almost three-quarters (74.2%) of respondents reported that they had never injected illegal drugs. Of those respondents who had injected illegal drugs approximately one half (52.8%) had done so in the last 12 months. Of PLWHA who reported injecting drugs, 93.3% had not shared injecting equipment in the past twelve months. Of the 15 respondents that had shared injection equipment in the last 12 months, all 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. The circumstances surround sharing injection equipment are shown in Table 49 below.

**Table 49 Circumstance surrounding sharing among those who have shared injecting equipment in the last 12 months**

	Number	Percentage
The person was my sexual partner	9	57.2
The needle was bleached or washed	10	63.8
We did not have access to other needles	9	60.7
The person was HIV positive	6	40.3
The person was Hep C positive	2	12.4
I used the equipment last	7	47.5

(Multiple responses possible) N=15

### Attitudes Relating to Drug Use

Over one sixth (16.3%) of respondents felt that they drank more alcohol than they would like to and 12.0% 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 is not necessarily a measure of 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 50 Attitudes relating to drug use and infection (percentage of full sample and percentage of those who shared injecting equipment)**

	Strongly disagree	Disagree	Agree	Strongly agree	Not applicable
I drink more alcohol than I would like to	31.0	34.1	11.8	4.5	18.5
I use illegal drugs more than I would like to	23.4	30.1	9.2	2.8	34.5
I worry about infecting others by sharing needles (% of full sample)	5.5	1.9	3.5	10.3	78.8
I worry about infecting others by sharing needles (% of those who have shared in last 12 months) <sup>a</sup>	0.0	6.7	40.0	40.0	13.3
Sharing needles is not a problem if your viral load is undetectable (% of full sample)	53.8	6.7	0.2	2.2	37.1
Sharing needles is not a problem if your viral load is undetectable (% of those who have shared in last 12 months) <sup>b</sup>	60.0	26.7	6.7	6.7	0.0

a: N=15, b: N=15

## ACCOMMODATION

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### Summary:

Current accommodation:

- 36.1% own or are purchasing their house or flat
- 35.3% are in private rental accommodation
- 15.8% are in public rental accommodation

Households

- 49.1% live by themselves
  - 35.2% live with their partner or spouse
  - 6.3% lived with dependant children
  - 50.8% live with pets
  
  - 79.6% of respondents stated that their accommodation was suitable for their current needs
  - 40.3% had ever changed their accommodation as a result of having HIV/AIDS
  - 36.5% had changed their accommodation as a result of having HIV/AIDS in the last two years
-

### Current Accommodation

The current type of accommodation of the respondents can be seen in Table 51. Similar numbers of PLWHA are currently in accommodation that they own or rent through the private system. A smaller number of people are in public rental accommodation. These are more likely to be those on a government benefit.

**Table 51 Current accommodation of respondents (percentage of total sample)**

Accommodation type	Number	Percentage
Own or purchasing house or flat	321	36.1
Private rental accommodation	314	35.3
Public rental accommodation	140	15.8
Rent-free	47	5.2
Community housing/housing co-operative	37	4.2
Other	31	3.5

Households varied considerably. 49.1% of PLWHA lived by themselves, while the remainder lived with between 1 and 7 other adults (mean=1.3, median=1) and with between 1 and 5 children (mean=1.6, median=1). Around one third (35.2) lived with a partner or spouse, and 6.3% lived with dependant children. These children ranged in age from 0 to 45 (mean=19.3, median=19).

Most lived in a residence with 2 bedrooms (43.6%), while the remainder had 3 bedrooms (29.6%), 1 bedroom (17.3%), 4 or more bedrooms (9.3%) or lived in a bedsit /studio (0.3%).

50.8% of PLWHA also lived with pets. The most common pets were dogs (30.0% of all respondents), and cats (24.3%). Other companion animals included fish, birds and farm animals.

68.3% of respondents had access to a car. When asked how easy it was to access public transportation, 9.5% said it was very difficult, 14.1%, difficult, 42.9% easy and 33.5% very easy.

79.6% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (N=181), the main reasons given were that it was too expensive (34.4%), lacked privacy (32.3%) and was too small (29.2%).

**Table 52** Reasons current accommodation is unsuitable (percentage of those with unsuitable accommodation)

Reason	Percentage
Too expensive	34.4
Lack of privacy	32.3
Too small	29.2
Too far from health services	23.7
Confidentiality problems	22.5
Poor condition of housing	19.2
Inadequate for current state of health	19.1
Harassment	19.0
Fear of violence	18.5
Too far from other services	17.6
Inadequate facilities for carers	12.2
Other	20.4

(Multiple responses possible) N=180

**Changes in Accommodation**

Participants were asked if they had ever changed their accommodation as a result of having HIV/AIDS. 40.3% had, and 36.5% had in the last two years. On average PLWHA had changed their accommodation 2.4 times ever as a result of HIV/AIDS (0.6 times in the last two years).

We asked what the circumstances were around participants' last change in accommodation. The results are shown in Table 53. Financial and health issues figured most prominently in response to this question. Of those who had moved in the last two years, the most common reason given was moving to cheaper housing (36.6%) followed by moving to a quieter location (31.8%) and moving closer to health services (28.6%).

**Table 53 Reasons for changing accommodation**

	<b>Percentage of those who had moved</b>
Moved to cheaper housing	36.6
Moved to a quieter location	31.8
Moved closer to health services	28.6
To avoid harassment	23.9
Illness	20.5
Planning for illness	19.8
Better health	16.3
Stopped working	16.3
Lack of privacy	16.2
Ending of long term relationship	15.3
Moved closer to friends	12.1
Moved closer to other services	11.3
Improved finances	11.0
Moved in with family	8.9
Looking for/ returned to work	7.1
Beginning of new relationship	6.1
Moved out of family home	5.6

(Multiple responses possible) N=355

 **See also accommodation and discrimination page 110**

**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.

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**Summary:**

Slightly less than half of respondents are currently in paid employment, with more than half of this proportion being in full-time work. 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:

- 13.7% stopped work;
- 11.3% anticipate a longer time in the workforce;
- 7.6% are considering going back to work;
- 6.5% have gone back to work.

Almost two thirds 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, half had returned to work and this was most commonly for financial reasons.

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

One half of PLWHA currently in work had not disclosed their HIV status to anyone at their workplace, while a quarter do not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work are gossip and explaining absences from work.

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### Employment Status

Just under half the respondents were currently employed, with slightly more being in full-time work than those in part-time work. The remainder tend to describe themselves as either unemployed (15.0%) or retired (22.5%). Of those who are working, the mean number of hours worked is 32.5 (median=36). Those working full time work an average of 41.9 hours per week (median=40) and those in part time employment work an average of 20.9 hours/week (median=20). Those who are not working stopped work between 0 and 360 months ago (mean=61.8 months, median=54 months).

**Table 54** Employment status

	<b>Percentage</b>
Working full time	27.0
Not working/ retired	22.5
Working part time	20.8
Unemployed	15.0
Other	8.3
Student	3.8
Home duties	2.6

N=879

### Impact of HIV and Treatment on Employment

We asked respondents how their HIV diagnosis affected their career plans and how their plans had changed since then. These data are shown in Table 55 below. A large proportion indicated that their career ended at their time of diagnosis (21.3%).



**Table 55 Impact of HIV diagnosis on career plans (percentage of sample)**

	Diagnosis	Subsequent experience
There has been no change	23.9	20.7
A career is no longer as important	17.9	16.4
Changed careers	9.5	13.1
Less likely to change careers	2.3	4.8
More difficult to plan for future	25.1	19.4
Career ended/stopped work	21.3	25.6

N=829

We asked about the impact of antiretroviral therapy on respondents' career plans (see Table 56 below). Of those that have used antiretrovirals, the most common response was that this had not affected their plans. The relationship between commencement of antiretroviral therapy and health status may explain the fact that 13.7% said that they stopped work when they commenced ARV, while 11.3% said that they anticipated a longer time in the workforce.

**Table 56 Impact of antiretroviral therapy on work**

	Percentage
There has been no change	30.0
Stopped work	13.7
Not used antiretrovirals	11.7
Anticipate longer time in work force	11.3
Considered going back to work	7.6
Went back to work	6.5
Made new career plan	5.4
Considered new career plan	5.0
Considered stopping work	1.2

N=829

### Interruptions to Employment

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those who have worked, 55.1% had stopped work for reasons related to HIV at some point. These work interruptions averaged 40.2 months. The circumstances relating to the most recent interruption to employment are given in Table 57 below. The most common response was that psychological health (stress, depression or anxiety) had played an important role in the

decision. Over half of the sample cited diminished energy levels and over one third cited poor health.

**Table 57** **Circumstance surrounding last interruption to employment**

	<b>Percentage</b>
Low energy levels	58.2
Stress/ depression/ anxiety	56.2
Poor health	54.7
To have more time to self	26.3
Expecting illness in future	24.0
To move to different location	15.2
Retrenched/ sacked	9.1
To care for someone with HIV	7.3

(Multiple responses possible) N=473

Of those that stopped working at some point, 51.6% had returned to work. This was most commonly for financial reasons (see Table 58), although better psychological health, better physical health and the need to perform meaningful tasks were also important.

**Table 58** **Reasons for returning to work**

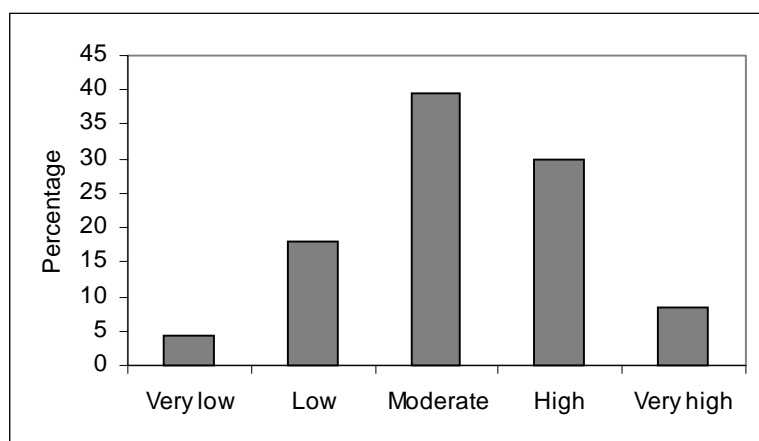
	<b>Percentage</b>
Financial reasons	79.2
To have something to do	51.5
Better psychological health	50.5
To do something worthwhile	49.3
Better physical health	43.2
Possibility of part-time work	39.4
To have more social contact	39.0
Possibility of flexible working hours	25.4
Possibility of full-time work	10.2

(Multiple responses possible) N=245

### **Those Currently in Paid Employment**

Respondents were asked about the level of stress in their current job. Over one third rated the stress level as moderate (39.3%) while 29.9% said it was high and 8.4% said it was very high.

Only 4.3% rated the stress level as very low and 18.0% said there was low stress (see Figure 21).



**Figure 21 Stress at work**

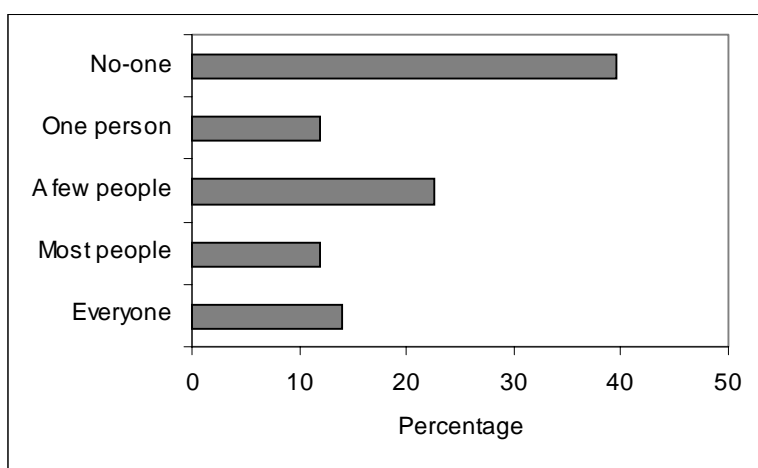
Confidentiality in the workplace remains a critical and complex issue for positive people, particularly given ongoing experiences of discrimination. When asked what difficulties they experience around confidentiality at work, 27.3% said that they do not attempt to keep their status confidential (see Table 59). Over half said they have experienced no problem in this area. Of those who do experience difficulties, the greatest problem appears 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 are less likely to wish to keep their status confidential and have fewer problems when they do choose to do so.

**Table 59 Difficulties with HIV status confidentiality in the workplace: percentages of total and specific samples.**

	Total sample <sup>a</sup>	Those not working in HIV related job <sup>b</sup>	Those working in HIV related job <sup>c</sup>
I do not try to keep my status confidential	27.3	17.8	68.4
No problems	56.9	61.1	38.6
Gossip	12.3	14.4	3.4
Explaining absences from work	11.9	14.7	0.0
Difficulty keeping and taking medication	8.4	10.1	1.4
Visible signs of illness	8.4	9.1	5.4

(Multiple responses possible) a: N=422, b: N=342, c: N=79.

When asked how many people in their workplace know that they are HIV positive, 13.9% said that everyone knows, 11.9% said most people know, 22.6% said a few people know, 12.0% said one person knows and 39.6% said no-one knows (see Figure 22).



**Figure 22 Disclosure in workplace**

N=421

When asked about the impact that HIV has on their capacity to perform their work duties, around half of the sample said that their work was unaffected (see Table 60). Over half also said that they tire more quickly, and almost one quarter said that they have difficulty concentrating.

**Table 60 Impact of HIV on work capacity**

	<b>Percentage</b>
Not affected by HIV	49.2%
I tire more quickly	45.7%
I have difficulty concentrating	22.3%
I work reduced hours	21.1%
I am less productive	11.1%
I cannot always go to work	10.1%
I do different duties	3.1%

(Multiple responses possible) N=421

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 61) 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 61 Capacity within workplace for HIV related interruptions**

	Never	Seldom	Sometimes	Often	Always
For medical appointments	7.9	3.4	16.1	12.0	60.5
When you are sick	4.4	3.5	12.4	10.4	69.4
For counselling	23.7	6.1	13.7	7.9	48.5
To do volunteer work	49.5	7.7	12.5	5.0	25.2

#### 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 43.4% said they did. Of these, two fifths said they planned to start or return to work and a similar proportion said they wanted to change the type of work that they do (see Table 62). Importantly, around one in five say they want to reduce the hours they work.

**Table 62 Plans for changes to work life and anticipated difficulty**

	Percentage	Difficulty		
		Not at all	Somewhat	Very
I want to start/ return to work	41.9	11.5	43.6	44.9
I want to stop work	4.0	26.7	60.0	13.3
I want to change the type of work I do	42.8	8.8	66.3	25.0
I want to reduce my work hours	21.9	11.0	64.6	24.4
I want to increase my work hours	7.1	15.4	65.4	19.2
Total		14.8	55.9	29.2

N=377

The main incentives for changes in work arrangements were financial (see Table 63). 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 63** Reasons for changes to work plans among full sample, those intending to return to work and those intending to stop work

	Total	Return to work <sup>a</sup>	Stop work <sup>b</sup>
Financial reasons	53.1%	75.5%	7.8%
To do something worthwhile	45.9%	58.8%	15.3%
To reduce stress	45.1%	27.2%	88.6%
Better psychological health	43.1%	51.0%	33.1%
To have more social contact	34.7%	54.0%	23.0%
Better physical health	30.2%	33.3%	33.1%
To have something to do	28.5%	56.8%	0.0
Possibility of working part-time	26.1%	40.0%	7.5%
Possibility of flexible work hours	21.5%	24.4%	15.3%
Possibility of working full-time	7.2%	9.9%	0.0
Worse psychological health	2.5%	2.6%	7.7%
Worse physical health	2.1%	0.0	0.0
To have less social contact	1.2%	2.1%	0.0

(Multiple responses possible) a: N=154, b: N=15

### Leisure

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

**Table 64** **Activities pursued while not working: percentage of total sample**

	<b>Percentage</b>
Leisure activities	69.6
Housework	66.5
Resting	62.6
Socialising with close friends	51.4
Spending time with family	25.3
Socialising with other friends	18.0
Socialising with HIV positive friends	15.6
Volunteer work in HIV/AIDS organisation	13.8
Volunteer work in other organisation	10.0
Looking after children	6.6
Looking after another HIV positive person	4.3

(Multiple responses possible, N=842)





**FINANCES**

The two previous HIV Futures surveys have highlighted the financial difficulties that many PLWHA contend with. While the inherent harshness of living on a government pension or benefit, accounts for some of the hardship, something that PLWHA share with other sectors of Australian society, there are other factors that are peculiar to living with HIV. These include a history of uncertainty, the experience of discrimination and disadvantage in employment and the costs of living with a chronic or intermittently debilitating illness that are not covered by the health system.

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**Summary:**

Slightly less than 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 some difficulty with meeting the cost of daily living.

Difficulty with meeting the cost of daily living:

- 63.9% difficulty paying for clothing;
- 64.4% difficulty paying for utilities;
- 52.7% difficulty paying for housing;
- 51.6% difficulty paying for food;
- 50.8% difficulty paying for transport;

One-quarter of those on a government benefit had been assessed by a Commonwealth Medical Officer. While this resulted in termination of benefits or change in conditions for few respondents, it caused distress for around half those assessed.

Over thirty percent 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 over one half of those on government benefits are living in poverty.

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### Income

The source of income of the survey respondents is shown in Table 65 below. As with the previous HIV Futures surveys, around half have a government pension or benefit as their main source of income. Just over one third of PLWHA were receiving a salary and 8% had superannuation as their main income source.

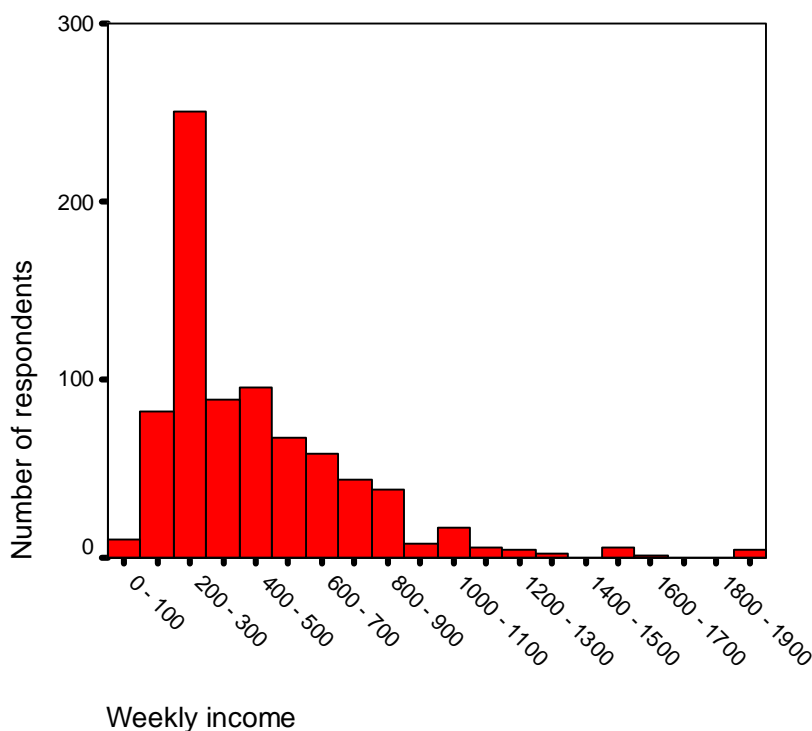
**Table 65 Primary source of income: percentage of total sample**

Source of income	Percentage
Benefits/ Pension/ Social security	48.7
Salary	37.9
Superannuation	7.7
Partner supports me	0.7
Family/friend support me	0.4
Other	4.7

N=881

The mean weekly income for respondents was \$437.25, and the median was \$340. Figure 21 below gives the distribution of income in \$250 intervals. The peak of the distribution corresponds to the income that one is likely to receive on a government pension.

22.0% of respondents had a partner with whom they share financial resources. The partners' mean income was \$543.67 (median =\$500).



**Figure 23 Histogram of respondents' weekly income after tax**

**Expenditure and Debts**

Respondents were asked their weekly expenditure on a range of items. Previous surveys have indicated that PLWHA had difficulty paying for some essentials and these items were included to document the extent of financial burden and to aid further in-depth analysis of the financial impact of HIV on positive people, particularly in light of the GST. The results are shown in Table 66 below. The total mean expenditure on medication was \$27 per week with complementary therapies accounting for almost half the total. Mean rental or mortgage costs were \$127 with the highest costs being in NSW (mean= \$156.52). Food and utilities accounted for around \$85 and \$43 respectively.

22.2% of respondents currently own their own home, while 17.0% are currently paying off their home. 13.6% have owned their own home in the past, but do not currently. 30.5% receive a rental subsidy averaging at \$60.98 per week.

 **See also Accommodation and discrimination page 110**

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$17,244.10 with a median of \$400. Those who were currently paying off their home had a mean debt of \$72,516.21 while those who were not had a mean debt of \$5,783.70. Slightly less than one-fifth (17.6%) had used the services of a financial counsellor in the last two years.

**Table 66 Weekly expenditure on medications and essentials (\$AU)**

	Mean \$	Median \$	Range \$
Rent/mortgage	127.0	90	0-1354
Complementary therapies	12.4	0	0-225
Antiretroviral drugs	6.2	0	0-421
Other medication	8.4	3	0-350
Food	84.5	75	0-600
Utilities	42.8	30	0-300

N=835

### 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 26.9% of those receiving a benefit had received such an assessment. When asked what this experience resulted in, only 3.5% (n=3) said that their benefit was terminated. (See Table 67 below) Over a third said that the assessment resulted in changes to their conditions of benefit. Importantly the experience of assessment resulted in distress for almost half the respondents while it clarified concerns for around one in five.

**Table 67 Consequences of receiving an assessment of benefit from a Commonwealth Medical Officer (percentage of those assessed)**

	Percentage
Termination of benefits	3.5
Changes to benefits or conditions	35.0
Clarified concerns	19.1
Caused distress	48.4

N=92

### 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 dependant children. We used the IAESR (2001) data for the September quarter (the time at which the survey was completed). According to this measure almost one third (31.3%) of PLWHA were living below the poverty line.

### 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 68).

**Table 68 Poverty by employment status**

	Below poverty line	Above poverty line
In paid employment <sup>a</sup>	10.5	89.5
Not in paid employment <sup>b</sup>	51.6	48.4

a: N=373, b: N=386

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 69).

**Table 69 Poverty by income source**

	Below poverty line	Above poverty line
Income from salary <sup>a</sup>	5.0	95.0
Income from government benefit <sup>b</sup>	58.8	41.2

a: N=302, b: N=357

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 70).

**Table 70 Poverty by shared income status**

	Below poverty line	Above poverty line
Shared financial resources <sup>a</sup>	7.5	92.5
Sole income <sup>b</sup>	39.1	60.9

a: N=186, b: N=573

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

### 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 71 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 over a third of those with child care needs rated this as very difficult, and 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 71 Difficulty paying costs of items and services**

	Not at all difficult	A little difficult	Very difficult
Travel/ Holidays	19.1	26.6	54.3
Going out	30.1	31.0	38.9
Recreational drugs	29.8	33.6	36.6
Entertainment	30.9	34.2	35.0
Child care	33.1	32.6	34.3
Clothing	33.4	35.4	31.2
Sport	40.7	29.5	29.9
Complementary therapies	43.0	34.1	22.9
Rent/ Mortgage	39.7	39.0	21.3
Utilities	34.5	44.3	21.2
Transport	46.7	36.7	16.6
Medical services	56.8	27.1	16.0
Food	47.9	37.2	14.9
Support services	66.1	20.6	13.3
Other prescribed medication	54.7	35.0	10.2
Co-payments for medication for HIV/AIDS	63.7	28.4	7.9

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 72 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. While the efforts of welfare and financial aid services in community organisations are clearly essential in addressing these needs, it remains a gross indictment of a wealthy society like Australia that people with HIV continue to suffer this level of privation.

**Table 72 Difficulty paying costs of items and services by poverty**

	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	45.9	40.7	13.5	71.1	24.1	4.8
Other prescribed medication	35.6	48.2	16.2	63.3	29.6	7.1
Medical services	46.1	28.3	25.6	62.7	24.2	13.1
Complementary therapies	28.1	38.4	33.4	49.1	34.5	16.4
Support services	54.7	24.9	20.3	72.0	17.9	10.1
Entertainment	9.5	24.4	66.1	39.5	38.6	22.0
Going out	9.9	23.5	66.6	38.9	34.8	26.3
Sport	18.5	24.7	56.8	50.1	31.6	18.4
Recreational drugs	15.0	21.5	63.5	32.5	36.2	31.3
Travel/ Holidays	5.6	16.4	78.0	23.7	30.1	46.3
Rent/ Mortgage	24.3	36.4	39.3	46.8	39.7	13.4
Utilities	15.1	45.9	39.0	43.7	43.3	13.1
Food	24.7	47.0	28.2	59.2	32.8	8.0
Clothing	13.9	32.7	53.4	42.9	36.0	21.2
Transport	26.0	44.3	29.7	55.8	33.3	10.9
Child care	3.6	36.9	59.4	42.6	33.1	24.4



### 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 46 for the discussion of these services), we see that for all services, a greater proportion of those below the poverty line have used these than those above (see Table 73). While the differences for some services are slight, we note the discrepancies for use of financial assistance, housing assistance, counselling, transport and volunteer carers. When we examine use of services at other organisations, particularly notable are the greater proportions of those below the poverty line using employment services (22.1% versus 14.0%), housing assistance (28.8% versus 15.9%) and respite care (13.9% versus 12.3%).

**Table 73 Services used at HIV/AIDS organisations by those above and below the poverty line**

	Below poverty line	Above poverty line
Treatments advice	53.9	45.7
Counselling	37.0	28.1
Financial advice	15.0	10.9
Financial assistance	37.8	18.0
Peer support group	32.0	28.7
Informal peer support	27.1	20.0
Social contact with other PLWHA	46.0	36.1
Pharmacy services	23.5	19.6
Complementary therapies	28.5	18.5
Respite care	8.7	4.5
Legal advice	21.0	18.0
Housing assistance	24.7	9.5
Employment services	7.4	4.5
Return to work skills	6.3	3.7
Dug/alcohol treatment	2.4	1.9
Mental health services	10.9	6.5
Library	8.5	5.5
Internet access	8.9	7.1
Transport	15.4	4.5
Treatments information	45.9	41.6

	Below poverty line	Above poverty line
Volunteer carer	17.0	8.5
Paid carer	2.3	1.2
Internet based information	9.9	9.1
Community education campaigns	16.9	15.0

(Multiple responses possible)

**Table 74 Services used at other organisations by those above and below the poverty line**

	Below poverty line	Above poverty line
Housing assistance	28.8	15.9
Complementary therapies	25.9	29.5
Employment services	22.1	14.0
Treatments information	20.8	17.0
Counselling	18.0	23.5
Return to work skills	16.9	8.6
Mental health services	16.9	18.2
Financial assistance	13.9	12.3
Legal advice	11.7	16.8
Financial advice	11.5	22.0
Drug and alcohol services	9.0	8.1
Respite care	7.1	5.6

(Multiple responses possible)

## DISCRIMINATION

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### Summary:

- 11.1% experienced less favourable treatment in relation to accommodation, 4.5% in the last two years
  - 37.7% experienced less favourable treatment because of HIV in relation to health services, 18.0% in the last two years
  - 25.6% of hepatitis C co-infected respondents experienced less favourable treatment because of hepatitis C in relation to health services, 16.2% in the last two years
  - 22.1% experienced less favourable treatment in relation to insurance, 15.4% in the last two years
- 

Issues of discrimination remain central to the life of many people who are HIV positive, whether as experiences or as an anticipated and dreaded possibility. We have asked about the experience of discrimination in a range of settings and will follow this report with a more detailed issues paper on this matter.

### Accommodation

11.1% of respondents indicated that they had experienced less favourable treatment in relation to accommodation (4.5% in the last two years). These were more likely to be those that currently lived in public housing (24.6% experienced discrimination) but also included 21.6% of those in housing cooperatives, 17.4% of those living rent-free, 9.6% of those in private rental accommodation, 3.6% of those who own or are purchasing their own house or flat and 16.1% of those in other types of accommodation.

### Health Services

#### *HIV*

37.7% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This included 18.0% that had experienced such discrimination in the last two years.

When asked what form this discrimination took, the most common responses were confidentiality problems (38.1%) and avoidance (37.9%). These experiences are shown in Table 75.

**Table 75 Form of HIV-related discrimination experienced at medical service (percentage of those experiencing discrimination)**

	Percentage
Confidentiality problems	38.1
Avoidance	37.9
Being treated last	27.6
Additional infection control measures	26.9
Refusal of treatment	24.4
Being rushed through	24.0
Harassment	11.9
Abuse	7.5
Other	18.2

(Multiple responses possible, N=330)

### **Hepatitis C**

25.6% of hepatitis C co-infected respondents had experienced less-favourable treatment at a medical service as a result of having hepatitis C. This included 16.2% who had experienced such discrimination in the last two years.

When asked what form this discrimination took, over one third indicated avoidance, being placed last in the treatment queue or being given additional infection control measures to other clients. These experiences are shown in Table 76.

**Table 76 Form of hepatitis C-related discrimination experienced at medical service (percentage of those experiencing discrimination)**

	Percentage
Avoidance	38.8
Being treated last	37.0
Additional infection control measures	34.8
Confidentiality problems	30.5
Refusal of treatment	22.7
Harassment	15.3
Being rushed through	11.8
Abuse	4.7
Other	22.9

(Multiple responses possible, N=31)

### Insurance

30.6% of respondents currently had private health insurance and 16.1% currently had some other form of income or mortgage insurance.

22.1% of respondents indicated that they had experienced less favourable treatment in relation to insurance. This included 15.4% of the total sample who had experienced this discrimination in the last two years.



## **CONCLUDING COMMENTS**

The data presented here speak of the depth of impact that HIV has on all aspects of the lives of those who are HIV positive. In reading a single questionnaire we can gain some insight into the lives of one HIV positive person. In looking at 894 questionnaires we lose some of that depth, but gain an understanding of the collective experience of HIV and the ways in which people's experience is structured by social and cultural forces. We need both these understandings to find our way forward. What these data should also give us is a sense of the import that HIV should have in all our lives, positive or negative. It should speak to us of interrelationship and of commonality.

There is a widening gulf between HIV positive people for whom antiretroviral treatments have meant new hope and new life, and HIV positive people who continue to struggle with the vicissitudes of failing treatments, illness, and viral loads that never reach the holy grail of undetectability. This division is reflected not just in the clinical outcomes, but in the degrees of marginalisation and social disadvantage experienced by these groups. And there are still deaths from AIDS in this country, though they no longer make the front pages of the press, gay or straight. Many of those for whom antiretroviral therapy has meant renewal now have other life priorities that supersede collective action around HIV, while those that are ill experience marginalisation, even within the AIDS sector.

In the face of such diverse experience, how do we maintain the collective response to HIV that has been so critical to the success of the Australian AIDS response? Beyond our own shores, where the gulf between those with socio-political advantage and those marginalised is even more profound, how do we maintain AIDS as a social movement? The ways in which we respond collectively to the needs of people with HIV will depend largely on whether we are able to imagine a shared global responsibility to maximise the health and well-being of all positive people, or whether we construct divisions that allow us to only work to benefit those who we see as ours.

We hope that this report provides more than just a snapshot of positive Australia. We hope that it stimulates community debate and aids us all in our critical reflection on the place of HIV in our lives.





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