

HIV FUTURES 4

STATE OF THE [POSITIVE] NATION

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

www.latrobe.edu.au/hiv-futures

and details of ARCSHS can be found at:

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FOREWORD

2003 saw: the beginning of the war in Iraq, Chinese President Hu Jintao addressing the Australian parliament, the discovery of 160,000 year-old Homo sapiens skulls in Ethiopia, the arrest of both Martha Stewart and Michael Jackson, Australia defeating Spain in the Davis Cup, the arrival of an epidemic called severe acute respiratory syndrome, Nicole Kidman winning the Oscar for best actress, the death of Nina Simone, Don Bradman's baggy green selling for \$425,000, Time magazine announcing that it's Person of the Year was "The American Soldier", Sue Fear becoming the first Australian woman to climb Mount Everest, the film Ken Park banned in Australia, the space shuttle Columbia disintegrating, the arrest of Saddam Hussein, the Brisbane Lions winning their third AFL grand final, and Britney kissing Madonna.

2003 also saw over 1,000 People living with HIV tell us about their lives, in detail and with candour. They told us about their health, their sex lives, their relationships, their fears and their aspirations, their financial state and their beloved pets. Over 1,000 HIV positive Australians took the time to complete and return a forty page questionnaire that often asked them to relive some of the worst times in their lives, to speak about things that some would rather forget and some had never spoken about to anyone. They did this, not because it was required, not for money, not because a service depended on it, not even because they knew the researchers. They did it because the experiences of HIV positive people matter, because these stories need to be told, because these answers to these questions give shape and texture to the diverse lives of Australian PLWHA.

This commitment, and this breadth and depth of information gives us an enormous responsibility. This report is, as always, our first step in honouring that responsibility. We trust that you will read it with cognisance of the contribution of Australian PLWHA and use it in their service.

Jeffrey Grierson



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EXECUTIVE SUMMARY

DEMOGRAPHICS

The HIV Futures 4 survey was completed by 1059 HIV positive Australians from all states and territories. This represents approximately 8.1% of the HIV positive population.

90.7% were male (960), 9.1% were female (96) and 0.3% were transgender (3).

77.0% were gay men, 6.9% heterosexual men, 5.4% bisexual men, 0.4% lesbian, 8.0% heterosexual women, 0.3% bisexual women and the remaining 1.9% fell into other categories.

The respondents' ages ranged from 18 to 92 years with a mean of 44.1 years and a median of 43.0 years.

The majority of participants were Australian born (78.4%)

Thirty one respondents (2.9%) indicated they were of Aboriginal/Torres Strait Island origin.

HEALTH

HIV Antibody Testing

- 20.2% tested for HIV because they became ill
- 15.8% tested as part of routine health screening
- 13.2% tested because of a particular risk episode
- 11.3% tested because they were a member of a risk group
- 3.5% were tested without their knowledge

When asked about pre and post test counselling/ discussion

- 25.5% had received pre-test counselling/ engaged in pre test discussion
- 24.2% of those testing positive in the last two years received pre-test counselling/ engaged in pre test discussion
- 53.2% received post-test counselling
- 70.0% of those testing positive in the last two years received pre-test counselling

Pre and post test counselling was most often provided by medical personnel and respondents were generally

satisfied with the counselling they received.

Current Health Status

47.5% rated their health as good or excellent and 62.3% rated their general well being as good or excellent.

Almost all PLWHA had taken a CD4/T-cell test and a viral load test. 25.9% of respondents had been diagnosed with an AIDS defining illness, 11.4% in the last two years.

Health problems related to HIV

- 35.7% reported experiencing lipodystrophy;
- 29.6% experienced weight loss;
- 68.4% low energy or fatigue;
- 49.3% have a sleep disorder;
- 32.1% experienced confusion or memory loss.

Other health conditions

39.3% of respondents indicated that they had experienced AIDS related illness. 44.4% indicated that they had a major health condition other than HIV/AIDS. The most common other conditions were hepatitis C, cardiovascular disease and asthma.

Hepatitides

- 27.4% had at some point had hepatitis A
- 51.4% had been vaccinated against hepatitis A
- 30.8% had at some point been diagnosed with hepatitis B, of whom:
 - 72.0% had cleared the infection
 - 6.8% had ongoing infection and
 - 2.4% had a chronic infection
- 58.8% had been vaccinated against hepatitis B
- 15.9% of respondents were hepatitis C positive
- 5.4% of those with hepatitis C had ever had treatment for this

Prophylaxis

23.3% were currently taking prophylaxis for opportunistic infections.

TREATMENTS

Antiretroviral Therapy

- 70.6% are currently using ARV, most commonly one NNRTI and two NRTIs;
- 87.0% have used ARV at some time;
- 71.1% commenced ARV on the advice of their doctor;
- 63.7% of respondents were using a combination of three drugs;

Difficulties of Taking ARV

- 76.5% of those participants currently taking ARV reported that they experienced difficulties taking them of which the major problems were:
 - 53.0% remembering to take the drugs on time;
 - 49.6% side effects;
 - 34.4% transporting medication;
 - 30.9% taking medication in public;

- 28.3% organising meals around the drugs;
- 24.0% taking large numbers of tablets.

Side effects from ARV are still a significant concern for those on treatment with 49.6% reporting that they experienced these. The most common were diarrhoea (23.6%), nausea (21.9%), and fatigue (12.3%).

Attitudes to Antiretroviral Therapy

Does ARV mean better prospects for PLWHA?

- 77.4% agreed;
- 5.9% believed that it is still too soon to tell;

38.5% believed combination antiretroviral drugs are harmful

23.9% said the side effects outweigh the benefits of antiretroviral drugs

Treatment Breaks

- 46.7% of those currently on ARV have taken a break from ARV therapy;
- The median length of break was 60.7 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
- 49.8% saw their doctor before, during and after the treatment break

Antiretroviral Resistance

- 30.3% of those that had ever used ARVs had had a resistance test.
- 75.0% of those tested found resistance to one or more drugs
- 80.5% of those with resistance changed treatments

Dosing and Adherence

- 78.6% of the sample were taking ARV twice daily;
- 7.3% were taking ARV three times a day;
- 8.9% were taking ARV once a day.

65.0% had not missed a dose of ARV in the two days prior to completing the survey.

Clinical Trials

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

Complementary Therapies

- 51.5% used vitamin and mineral supplements;
- 16.7% used herbal therapies
- 28.2% used marijuana for medicinal purposes
- Complementary therapies tended to be used in conjunction with allopathic treatment

SERVICES

Health Services

- For HIV specific treatment 45.3% saw a HIV GP/S100 prescriber and 32.9% saw an HIV specialist/physician.
- For general health care treatment 50.2% of PLWHA saw a HIV GP/S100 prescriber and 22.3 saw a non-HIV GP.
- For 54.7% of respondents these were different doctors.
- Most respondents had visited either a GP who specialises in HIV or an HIV specialist in the last six months.

Other Services

Services used at AIDS organisations:

- 48.1% treatment advice;
- 42.9% social contact;
- 33.7% peer support;
- 32.9% counselling;
- 20.8% advice on financial matters;
- 17.5% advice on legal matters;
- 20.1% complementary therapies.

Information

Important sources of information on treatments:

- 64.6% said HIV GPs/S100 prescribers;
- 48.6% HIV specialists;
- 44.8% HIV magazines and newspapers;
- 43.5% HIV/AIDS organisation publications;
- 36.4% articles in the gay press;
- 26.8% HIV positive friends.

Important sources of information on HIV management:

- 60.3% said HIV GPs;
- 44.8% HIV magazine/ newspaper;
- 41.9% HIV organisation publications;
- 36.4% gay press;
- 26.8% HIV positive friends.

Important sources of information on living with HIV:

- 45.3% said HIV magazine/ newspaper;
- 44.6% publications from HIV/AIDS groups;
- 43.8% HIV positive friends;
- 38.6% HIV GP;
- 24.2% HIV specialist.

Publications

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

Involvement with AIDS Organisations

71.5% had some contact with HIV/AIDS organisations, mostly receiving newsletters or being clients of these organisations. 9.5% were employees of AIDS organisations.

THE SOCIAL WORLD OF PLWHA

Contact with Other PLWHA

- 93.2% knew another PLWHA;
- 18.2% had a spouse/partner with HIV;
- 62.3% knew acquaintances with HIV;
- 78.1% spent at least some time with other PLWHA;
- 17.6% spent a lot of time with other PLWHA;

- 21.9% spent no time with other PLWHA;
- 22.9% had been involved with the care of someone with HIV/AIDS;
- 80.8% said someone close had died of AIDS related causes.

HIV was an important part of their identity for 52.7% of respondents and an essential part for 16.9%. HIV status tended to be less important than identities based on sexuality, gender or family.

Disclosure

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

For 55.0% of respondents, their HIV status had been disclosed to another person when they did not want it to be (29.8% in the last two years).

Social Support

Sources of 'a lot' of social support:

- 80.8% partners/spouse;
- 62.6% pets;
- 51.5% doctors;
- 48.8% close friends;

Mental Health

In the last six months 33.2% of respondents had taken prescribed medication for depression and 30.8% for anxiety.

34.5% had ever had a diagnosis of a mental health condition. 7% had had such a diagnosis in the last two years.

26.5% of all respondents had ever been diagnosed with depression.

Planning for the Future

21.8% planned only one day at a time, while 50.7% planned at least one year ahead.

Relationships and Sex

Over one quarter (27.3%) of PLWHA were not having sex at present.

45.6% of PLWHA were currently in a regular relationship, and a slightly smaller number had sex within their relationship. A smaller group, comprising mainly gay men, had both a regular relationship and casual partners (19.0%) and 30.6% had casual partners only.

Of those in a regular relationship 38.4% had a partner who is also HIV positive, 59.0% had an HIV negative regular partner and 2.6% a partner of unknown status. Nearly all (96.8%) PLWHA had disclosed their status to their regular partner, usually when they were diagnosed, at the time of, or prior to the commencement of the relationship.

37.9% of the respondents had anal or vaginal intercourse with a regular partner in the past six months. Condom use with regular partners was strongly related to the HIV-status of the partner.

58.0% of the sample had sex with casual partners in the past six months. 36.6% of the men reported that they always used condoms with casual male partners.

Information about the most recent episode of sex with a casual partner in the previous six months was provided by over half the sample. Vaginal or anal intercourse took place in 73.2% of these instances.

Condom use with the most recent casual partner:

- 33.9% with an HIV+ partner;
- 72.4% with a partner of unknown HIV status;
- 78.2% with an HIV negative partner.

There were only 13 instances reported of insertive anal or vaginal intercourse with ejaculation with the most recent casual partner where that partner was of unknown HIV status and only 1 instance with an HIV negative casual partner.

There were only 27 instances reported of receptive anal or vaginal intercourse with ejaculation with the most recent casual partner where that partner was of unknown HIV status and only 5 instances with an HIV negative casual partner.

49.6% of PLWHA would prefer to be in a relationship with someone who is also HIV positive. 61.2% of PLWHA expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLWHA (64.4%) 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 (7.8%) or that undetectable viral load means HIV is unlikely to be transmitted (10.1%). However, 27.8% of PLWHA agreed with the statement *If there was a vaccine which prevents HIV I would not practice safe sex*.

Recreational Drug Use

Alcohol was the drug most commonly used by PLWHA (76.3%), and 48.3% use tobacco. Over two thirds of respondents reported that they had never injected illegal drugs and of those respondents who had injected illegal drugs approximately one half had done so in the last 12 months. Of PLWHA who reported injecting drugs, 98.0% had not shared injecting equipment in the past twelve months.

Circumstances of sharing injecting equipment:

- 52.6% washed or bleached the needle;
- 57.9% did not have access to other needles;
- 47.3% shared with a sexual partner;
- 36.8% used the needle last;
- 21.1% shared with another HIV positive person;
- 5.3% shared with an hepatitis C positive person;
- 5.3% shared in a group.

Of the 19 who shared injecting equipment in the last 12 months 14 did so with at least one risk reduction strategy like using the needle last or washing/bleaching or using with another person who was HIV positive.

Approximately one quarter of respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and 8.0% reported having had a bad experience as a result of using both illegal drugs and ARV.

HOME, WORK & MONEY

Accommodation

- 32.8% owned or were purchasing house or flat
- 35.9% were in private rental accommodation
- 18.4% were in public rental accommodation (government owned)
- 5.5% lived rent-free (e.g. provided by friends, family, etc.)
- 3.1% were in community housing/housing co-operative

77.3% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable, the main reasons given were that it was too expensive, was too small and lacked privacy.

- 40.7% of PLWHA lived by themselves
- 49.5% of PLWHA also lived with pets
- 67.9% of respondents had access to a car

40.3% had ever changed their accommodation as a result of having HIV/AIDS and 11.1% had in the last two years.

Employment

Slightly less than one half of respondents were currently in paid employment (43.1%), 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:

- 16.5% stopped work;
- 12.2% anticipated a longer time in the workforce;
- 7.9% went back to work.

58.1% 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, 46.9% had returned to work and this was most commonly for financial reasons.

Just over 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 tired more quickly, that they had difficulty concentrating and that they have had to reduce their work hours.

43.0% of PLWHA currently in work had not disclosed their HIV status to anyone at their workplace, while 25.2% did not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work were gossip and explaining absences from work.

Finances

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

Difficulty with meeting the cost of daily living:

- 68.2% difficulty paying for clothing;
- 68.2% difficulty paying for utilities;
- 63.5% difficulty paying for housing;
- 55.5% difficulty paying for food;
- 52.5% difficulty paying for transport;

43.8% 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 65.3% of those assessed.

Poverty

26.9% of PLWHA are living below the poverty line. Just under one quarter of respondents have a partner with whom they share financial resources and this protects some from extreme economic hardship. Very few respondents who are earning an income from paid employment reported incomes below the poverty line whereas around half of those on government benefits are living in poverty.

Discrimination

12.0% experienced less favourable treatment in relation to accommodation, 5.4% in the last two years

33.5% experienced less favourable treatment because of HIV in relation to health services, 16.7% in the last two years

18.1% of hepatitis C co-infected respondents experienced less favourable treatment because of Hep C in relation to health services, 13.3% in the last two years

23.2% experienced less favourable treatment in relation to insurance, 3.7% in the last two years.

INTRODUCTION

The HIV Futures Study is ambitious in two major respects: it attempts to represent the experience of living with HIV for as diverse a population as possible; and it attempts to represent the lived experience of HIV across multiple health, social and psychological domains.

An effective cross-sector response to HIV/AIDS requires a broad understanding of the complexities of the lived experience of people with HIV. Typically, HIV services and medical practitioners encounter specific sub-populations of PLWHA, often those most in need of a particular service, from a specific socio-geographic context, or with particular health or welfare needs. Documenting the breadth of experience of HIV positivity allows us to plan more effectively for the whole HIV positive population and place the experiences of those engaged with services in a broader context. Most research that attempts to document the health and/or well-being of PLWHA samples from specific clinical or services sites. While these projects may offer a characterisation of the service clientele at the site of recruitment, and establish relationships between observed characteristics, their utility in informing broad policy and planning parameters is substantially limited. Constraining our understanding of PLWHA to those in contact with services or clinical settings may also present a substantially 'problematised' characterisation of the life circumstances of this population. HIV Futures uses a comprehensive 'wide-net' national recruitment strategy to attempt to represent the diversity of HIV positive experience. Thus, while clinical and community settings are utilised in recruitment, extensive time and effort is committed to attracting and supporting the participation of individuals not in contact with these institutions.

Similarly, much research with PLWHA is restricted to clinical, social or psychological experiences and is unable to characterise HIV positive experiences across all these domains. HIV Futures offers a unique opportunity to place the clinical experiences of HIV within social and psychological contexts. In this way the data on each of these contexts can inform policy and service responses that might otherwise rely on a less holistic understanding of clients or constituents.



DEMOGRAPHICS

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

Sample Demographics

The HIV Futures 4 survey was completed by 1064 HIV positive people (5 responses were unable to be entered due to late arrival, therefore the sample analysed is 1059). Given current estimates of HIV infection in Australia (NCHECR, 2003) this represents approximately 8.1% of the HIV positive population.

Of the survey respondents, 90.7% were male (960), 9.1% were female (96) and 0.3% were transgender (3). Of the sample 77.0% were gay men, 6.9% heterosexual men, 5.4% bisexual men, 0.4% lesbian, 8.0% heterosexual women, 0.3% bisexual women and the remaining 1.9% fell into other categories.

The respondents' ages ranged from 18 to 92 years with a mean of 44.1 years and a median of 43.0 years.

The majority of participants were Australian born (78.4%) and 99.0% of the participants spoke English at home, with European languages accounting for most of the remainder. Thirty one respondents (2.9%) indicated they were of Aboriginal/Torres Strait Island origin. This compares to the Australian Census figure of 2.4% ATSI in the Australian population (ABS, 2002). Ninety nine percent (99.5%) of respondents indicated that Australia was their official country of residence.

The three most common ancestries that respondents identified with were English (29.2%), British (21.8%), Irish (15.0%) and Australian (14.1%). This compares with the ancestry data from the 2001 Census, in which 35.9% of the population identified their ancestry as Australian, 33.9% as English, 10.2% as Irish and only 0.06% as British (Trewin, 2001). This difference may be explained by the high number of respondents who identified their ancestry as Anglo-Saxon, which was counted as British in the Census codebook. A total of 0.85% of respondents stated South-East Asian ancestry, specifically either Thai, Vietnamese, Malay or Filipino. This compares with the Census data, which reports that 1.7% of the Australian population had either Thai, Vietnamese, Malay or Filipino ancestry.

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

TABLE 1 State or Territory of respondents' residence

State/territory	Frequency	Percent of Sample
NSW	550	51.9
VIC	193	18.2
QLD	157	14.8
WA	59	5.6
SA	58	5.5
ACT	16	1.5
NT	13	1.2
TAS	13	1.2

The majority (60.3%) of respondents were from urban areas of capital cities, while 12.5% lived in outer suburban areas, 17.0% lived in larger regional centres and 10.2% lived in rural areas.

78.2% of participants were living in the same state or territory in which they were infected with HIV, while the remainder lived in a different state or territory.

Table 2 below shows the years in which respondents tested HIV positive and in which they believe they were infected with HIV. Overall these patterns match those of the Australian epidemic. The time difference between year of presumed infection and year of diagnosis ranged from 0 to 24 years with a mean of 1.8 years and a median of 1.0 year. 37.9% of the sample tested positive in the same year they believe they were infected. There are 61 respondents in the sample who had tested positive in the last two years and 38 respondents who believe they were infected in the past year.

TABLE 2 Years of respondent's testing positive and presumed infection (percent of sample)

Year	Tested HIV Positive	Presumed Infected
Pre 1985	9.0	21.7
1985-1989	28.6	27.7
1990-1994	26.1	23.4
1995-1999	21.8	16.6
2000+	14.5	10.5

344 respondents (39.9%) indicated that they were atheist/agnostic, 42.1% indicated mainstream religious identification and the remainder were either adherents of new age belief systems or had other spiritual beliefs. 367 (35.7%) indicated that religion or spirituality was of no importance to them. A further 28.3% indicated that this was of little importance, 23.8% that it was very important and 12.2% extremely important.

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

TABLE 3 Educational level of respondents

Level	Frequency	Percent of sample
University degree	276	26.2
Tertiary diploma/Trade Certificate/TAFE	271	25.7
Leaving certificate/HSC/Year 12	213	20.2
4th form/year 10	171	16.2
Up to 3 years high school	110	10.4
Primary school only	14	1.3

HEALTH



HEALTH

This section of the report deals with the physical health status and the experience of health of Australian PLWHA. The chapter includes a discussion of the experiences of testing positive for HIV, the current health status of participants as measured by both clinical markers and general sense of health and well being, the health burden in terms of concomitant health conditions and health maintenance strategies. The emphasis in this chapter is primarily on physical health, while other sections of the report take up the challenge offered by the official WHO definition of health: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948).

HIV Antibody Testing

The experience and meanings of testing positive for HIV have changed over the twenty years of the HIV/AIDS epidemic. In the early years of HIV in Australia, testing did not offer any particularly great advantage in treatment options and often led to increased anxiety, stigma and discrimination. With the advent of more effective treatments, the advantages of early testing have become clearer, not only in terms of medication, but also in health monitoring and social support. Australia currently has high testing rates among 'at-risk' populations like gay and homosexually active men (around 80%) (Van de Ven et al, 2003).

HIV antibody testing is available free of charge in Australia and although legislation differs from state to state, pre- and post-test counselling forms an integral part of this testing procedure (ANCARD/IGCARD, 1998). We asked respondents about a number of circumstances surrounding the time that they tested positive for HIV antibodies.

As can be seen from Table 4, 20.2% of the respondents had taken the test as a result of illness, 13.2% as a result of a particular risk episode and 11.5% because they were a member of a risk group. It is interesting to note that 15.8% gave the reason for testing as routine health screening. Gay or bisexual men were somewhat more likely to give this reason than others (16.7% of these participants versus 15.5% for heterosexual men and 10.7% for women) which may suggest that 'routine testing' may imply testing on the basis of group membership or risk activity. The reason 'a particular risk episode' was more likely to be given by women (17.3%) than gay or bisexual men (13.4%) or heterosexual men (5.2%).

Of those who had tested positive in the last two years, 35.7% said this was due to illness, 2.0% said this was at a doctor's suggestion, 20.2% said it was routine screening, and 24.3% as a result of a particular risk episode.

TABLE 4 Reasons for testing

Reason	Frequency	Percentage
Became ill	178	20.2
Other	154	17.6
Routine health screening	139	15.8
Particular risk episode	116	13.2
Member of risk group	101	11.3
Doctor's suggestion	99	11.2
Starting new relationship	44	5.1
Tested without knowledge	31	3.5
Contact tracer/other health worker's suggestion	12	1.4
Availability of new treatments	3	0.3
Insurance	2	0.2

Pre- and Post-Test counselling/discussion

Participants were asked "Did you receive counselling (or a detailed discussion) about HIV before you were tested for HIV?" We revised this item, which in previous studies referred only to counselling in the light of concerns that the experience is often not understood by patients as formal counselling, but rather a discussion of the implications and consequences of the test.

Current Australian HIV testing guidelines (ANCARD/IGCARD 1998) recommend that people engage in a HIV test discussion prior to testing. This is defined in the guidelines as "[an] informed discussion ... between practitioner and client/patient before testing. After assessment, this should include giving appropriate information about risk and related matters, referral if necessary, assurances about confidentiality and privacy, and assessment of the client's preparedness to be tested. Specifically, the HIV test discussion should provide accurate information about safe practices that is appropriate to the person's gender, culture, behaviour and language" (p32)

25.5% of respondents indicated that they had received pre-test counselling or engaged in a HIV test discussion. Of those who tested positive in the last two years, 24.2% had done so. The counselling was generally provided by a doctor (54.6%), but was also commonly provided by a nurse (14.6%), a counsellor or psychologist (11.2%), a doctor and a nurse (3.5%) a worker at a sexual health clinic (3.1%), a doctor and a counsellor (2.3%), a social worker (2.3%), a staff member at an HIV/AIDS organisation (2%). No other response accounted for more than 2% of responses.

When asked if they were satisfied with the counselling/discussion, 83.1% reported they were satisfied with the information they received from this person and 79.2% said they were satisfied with the level of support they received.

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

53.2% of respondents indicated that they had received post-test counselling. Of those who tested positive in the last two years 70.0% 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 (46.7%), but was also commonly provided by a counsellor or psychologist (15.7%), a nurse (6.2%), a doctor and a nurse (4.9%), a social worker (3.8%), a staff member at an HIV/AIDS organisation (3.6%), a doctor and a counsellor (3.6%), a worker at a sexual health clinic (3.2%), and a doctor and a social worker (2.1%). No other response accounted for more than 2% of responses.

When asked if they were satisfied with the counselling they received, 81.6% said they were satisfied with the information they received and 81.2% said they were satisfied with the support they received.

CURRENT HEALTH STATUS

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 Tables 5 and 6 below. Around half (47.5%) of the sample rated their physical health as good and 20.3% as excellent. This is less than the Australian population norm reported in the National Health Survey (ABS, 2002) where 85% of the population rated their health as good, very good or excellent¹. In the HIV Futures 4 survey, 32.3% rated their health as fair or poor.

TABLE 5 Respondents' self ratings of general health status

	Frequency	Percent
Poor	60	5.9
Fair	270	26.4
Good	486	47.5
Excellent	207	20.3

The ratings for well being were of a similar pattern to those for health. Almost two thirds (62.3%) rated their well being as either good or excellent, while 29.5% rated this as fair and 8.2% as poor.

TABLE 6 Respondents' self ratings of general well-being

	Frequency	Percent
Poor	84	8.2
Fair	301	29.5
Good	459	44.9
Excellent	178	17.4

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 7). This is, however, not a clear and direct relationship. The correlation between the two measures is $\chi^2=0.68$ ($p<0.001$). One in five participants (22.3%) rated their well-being as worse than their health and 12.1% rated 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 related to lower log viral load ($F=5.152$ ($_{3,852}$) $p=0.002$) and higher CD4 ($F=23.320$ ($_{3,877}$) $p<0.001$), but is clearly mediated by the experience of side-effects, the burden of medication, history of HIV and co-existent conditions.

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

WELLBEING	HEALTH			
	Poor	Fair	Good	excellent
Poor	4.0	1.0	0.8	0.1
Fair	3.6	17.0	5.5	0.4
Good	0.5	10.6	32.0	4.3
Excellent	0.2	1.0	6.4	12.7

¹ It should be noted that the National Health Survey uses a five point scale: poor, fair, good, very good, excellent.

CD4 and Viral Load

As with the previous three surveys, almost all PLWHA had taken a CD4/T-cell test (99.3%) and a viral load test (98.5%). Most respondents had their most recent CD4 test in the six months prior to survey (93.3%) (68.8% in the last three months) and their most recent viral load test in the six months prior to survey (92.4%) (66.5% 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, 91.4% reported that they have at some time had a CD4 count of less than 500 cells/ μ l and 63.0% reported a count of less than 250 cells/ μ l.

Results for PLWHA's most recent CD4/T-cell test ranged from 20 to 1800 cells/ μ l with a mean of 499.9 cells/ μ l and a median of 460.0 cells/ μ l.

Among those PLWHA who have taken a viral load test, 84.7% reported that at some point they have had a result of over 10,000 copies/ml and 66.0% a result of over 50,000 copies/ml.

Results for PLWHA's most recent viral load test ranged from below detectable levels to 1,000,000 copies/ml with a mean of 25,479 copies/ml and a median of 0 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	500-9999	10000-49999	50000+	Total
Cd4/T-cell count	500+	31.0	6.3	5.6	2.5	45.4
	250-499	20.0	5.6	6.1	5.7	37.4
	0-249	8.6	2.1	2.0	4.5	17.2
	Total	59.6	14.1	13.7	12.7	

Health Conditions in Addition to HIV

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

AIDS Defining Illnesses

AIDS is a notifiable condition in all states and territories in Australia. The case definition for AIDS requires both laboratory evidence of HIV infection and clinical confirmation of one of 25 specific conditions (ANCA 1994). These conditions are therefore known as AIDS defining illnesses. The category system for defining the stages of HIV disease progression was in large part based on an understanding of the progress of the disease as degenerative with little backwards movement through the categories. There are now numerous HIV positive people who have at some time experienced an AIDS defining illness but would now be classed at a less severe stage of disease progression. We asked respondents if they have ever experienced an AIDS defining illness for 3 reasons: to match and weight the data according to surveillance data; to examine issues around the burden of illness; and to understand the current health status of participants.

Around one in four respondents (25.9%) had been diagnosed with an AIDS defining illness at some point with 11.4% having been diagnosed with one in the last two years. On average they had been diagnosed in 1995 (median=1996). The most common illnesses in this category were Pneumocystis Pneumonia (48.7%), Kaposi's Sarcoma (23.1%), Cytomegalovirus (13.4%) and Microbacterium Avium Complex (MAC) (9.2%).

HIV/AIDS Related Conditions

We asked respondents if they had experienced any AIDS-related illness other than those classified as AIDS-defining illnesses and 39.3% said that they had. Of these the most common were shingles (17.1%), neuropathy (16.7%) and skin problems (10.3%).

We also asked if participants had experienced any of five specific conditions. 35.7% had experienced lipodystrophy, 29.6% weight loss, 68.4% low energy or fatigue, 49.3% a sleep disorder and 32.1% confusion or memory loss. Those reporting weight loss were significantly more likely to have a body mass index (BMI) of 19 or under (15.4% versus 1.4%, $\chi^2_{(3,1)} = 133.422$, $p < 0.001$). The BMI of those reporting lipodystrophy did not differ significantly from the remainder as this condition does not necessarily involve weight loss, but rather redistribution of body fat.

Other Health Conditions

Lipodystrophy and lipoatrophy have created additional difficulties for positive people (see for example Persson 2003). While there is still some debate over the most appropriate clinical case definition for these conditions, self-reported body changes remain an important component of diagnosis (Carr et al 1999, Behrens et al 2000). To assess the impact of these we asked participants to respond to a series of statements about their body image. These are presented in Table 9 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 9 Attitudes around body image (percentages of total sample, those with and without lipodystrophy)

		Percentage of total sample	% of those with lipodystrophy	% of those without lipodystrophy
Changes in my body due to HIV / AIDS have made me feel sexually unattractive.	strongly disagree	20.2	19.5	20.6
	disagree	37.1	35.9	37.9
	agree	32.2	33.1	31.5
	strongly agree	10.5	11.4	9.9
I am happy with the way my body looks.	strongly disagree	8.3	9.8	7.1
	disagree	38.8	34.6	41.2
	agree	40.5	43.1	38.9
	strongly agree	12.4	12.5	12.7
Body changes due to lipodystrophy make it obvious to others that people have HIV	strongly disagree	15.3	17.1	14.1
	disagree	33.7	32.7	34.5
	agree	39.6	40.1	39.3
	strongly agree	11.3	10.0	12.2

44.4% 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 (9.5% of the total sample), cardiovascular disease (4.0%), asthma (3.8%), and hepatitis B (3.0%).

HEPATITIDES

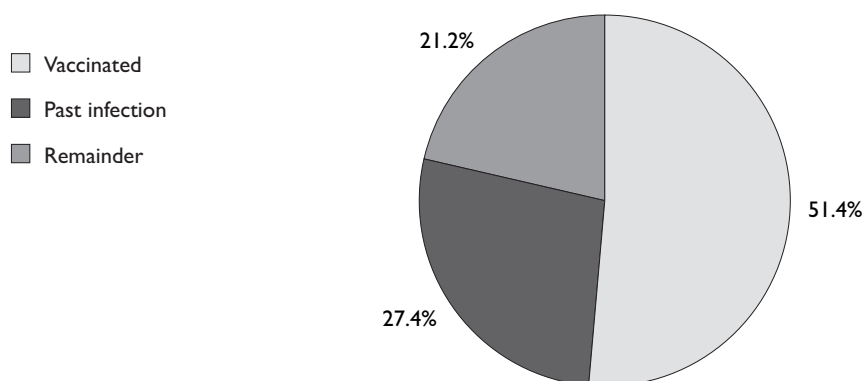
Hepatitis is a term that refers to inflammation of the liver. Six different types of viral hepatitis have been identified so far. Hepatitis A, B and C are more commonly known in Australia but hepatitis D, E and G have also been identified. For HIV positive people, co-infection with hepatitis may affect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

Hepatitis A

Over one quarter of the participants (27.4%) had at some point had hepatitis A, and 51.4% had been vaccinated against this virus. This means that 21.2% of the respondents may currently be at risk of hepatitis A infection

FIGURE 1 Hepatitis A status

	Vaccinated	Past infection	Remainder
Hepatitis A	51.4	27.4	21.2



Hepatitis B

A total of 30.8% of respondents had at some time been diagnosed with hepatitis B. Of these, 72.0% had cleared the infection, 16.8% had an ongoing infection and 2.4% had a chronic infection.

Table xx shows the experience of hepatitis B related symptoms for these three groups.

TABLE 10 Experience of hepatitis B related symptoms, by disease status

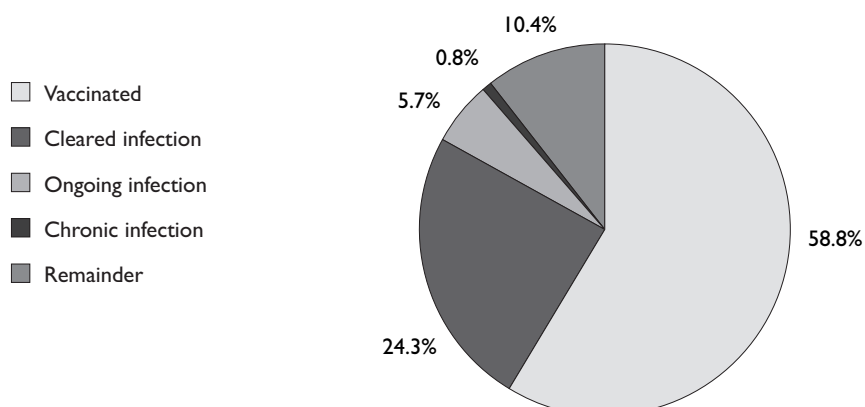
Experienced symptoms?	Cleared infection (n=250)	Ongoing infection (n=58)	Chronic infection (n=8)
Yes	83.1	61.4	37.5
No	2.9	17.5	50.0
Don't know	14.0	21.1	12.5

Symptoms most commonly experienced include: fatigue/lethargy, liver damage/cirrhosis and inflammation of the liver.

In addition to those who had experienced hepatitis B infection, 58.8% had been vaccinated against this virus. This means that 10.4% may currently be at risk of being infected with hepatitis B.

FIGURE 2 Hepatitis B status

	Vaccinated	Cleared Infection	Ongoing infection	Chronic infection	Remainder
Hepatitis B	58.8	24.3	5.7	0.8	10.4



Hepatitis C

Over one quarter (27.1%) of respondents had not been tested for hepatitis C. This is fewer than the 34.6% untested reported in the previous HIV Futures study suggesting increased testing among Australian PLWHA. In fact 71.8% of the most recent hepatitis C antibody tests were taken in the last two years and 25.8% of participants' first hepatitis C antibody tests were taken in this period. 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 15.9% of the sample had hepatitis C.

The NCHECR annual surveillance report (2003) says that "In 2003, an estimated 242,000 people living in Australia had been exposed to hepatitis C virus. Of these, 61,000 people were estimated to have cleared their infection, 143,000 had chronic hepatitis C infection and early liver disease (stage 0/1), 31,000 had chronic hepatitis C infection and moderate liver disease (stage 2/3), and 7,500 were living with hepatitis C related cirrhosis. 12.0% of these respondents had received a negative PCR test since diagnosis with hepatitis C." (p13) This gives a prevalence of hepatitis C in the general Australian population of 1.2%. The current estimate of the prevalence of hepatitis C co-infection amongst Australian PLWHA is 13.1% (Dore and Sasadeusz, 2003, Sasadeusz, 2004).

Respondents had first been diagnosed with hepatitis C between 0 and 26 years ago² (mean=1993, median=1993) and believed they had been infected between 0 and 34 years ago (mean=1989, median=1989).

Two fifths of the co-infected respondents (40.8%) had taken a genotype test for hepatitis C. Of these, 52.4% did not know what the result of this test was, while 29.3% said type 1, 4.8% type 2, 12.6% type 3, and 1.0% type 4, 5 or 6.

When asked how they believe they were infected with the hepatitis C virus, 54.2% said injecting drug use, 9.8% blood transfusion or the receipt of blood products, 16.3% during sex (although this is not generally considered a mode of hepatitis C transmission), 2.2% through tattooing or body piercing, 4.3% through other means and 13.1% did not know how they were infected.

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

Injection Drug Use (IDU)	54.2
During Sex	16.3
Don't know	13.1
Blood transfusion/Blood Products	9.8
Tattooing	1.3
Body Piercing	0.9
Other	4.3

Hepatitis C related symptoms were experienced by 19.5% of those with the hepatitis C virus, although it is worth noting that 15.6% stated that they did not know if they were experiencing hepatitis C related symptoms. The most commonly mentioned symptom was fatigue/lethargy, with 71% of those who have symptoms reporting this symptom. Only 5.4% (N=13) of those with hepatitis C had ever undertaken medical treatment specifically for hepatitis C. This comprised 0.8% who had been treated with interferon monotherapy, and 2.1% who had been treated with combination therapy of interferon and ribavirin and 2.5% who had undergone both monotherapy and combination therapy. 11.5% had taken some form of complementary therapy.

Hepatitis C co-infected participants were also asked about health monitoring and management. Over one third (39.6%) of co-infected PLWHA did not currently see a doctor for hepatitis C treatment or management. 47.0% of hepatitis C co-infected PLWHA saw their primary HIV doctor and 13.4% 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 4.0% had ever had this experience, 2.5% had had this experience in the last 2 years.

Most (61.5%) people co-infected with hepatitis C found that HIV community services met their needs, while 38.5% said that they did not.

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

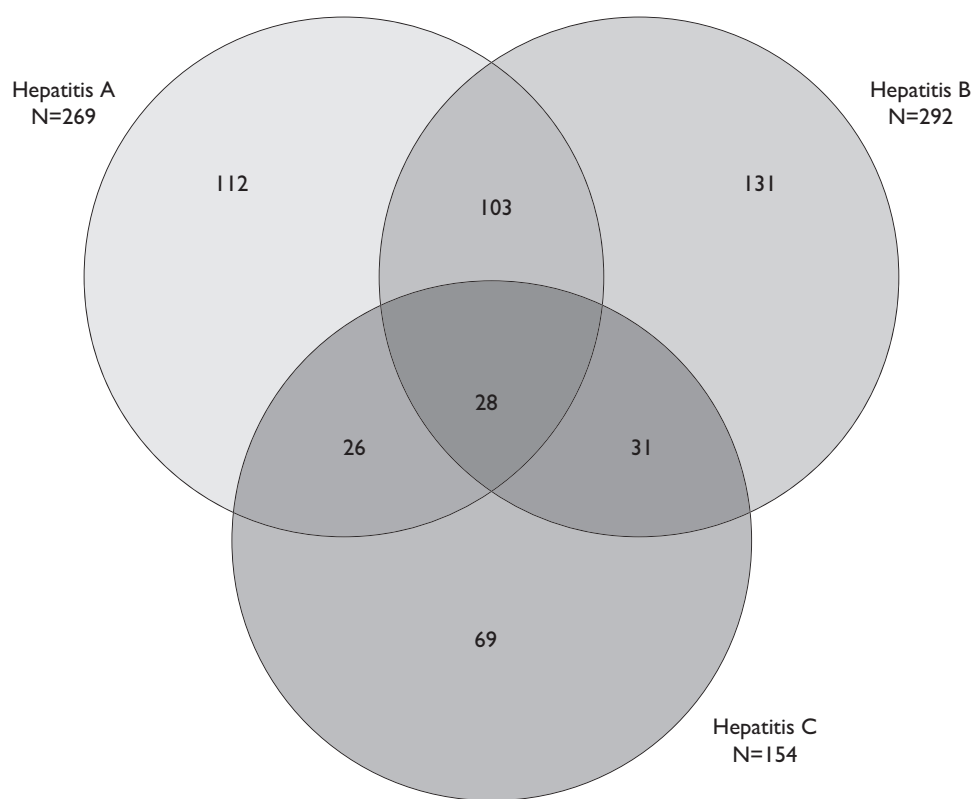
TABLE 12 Reasons HIV services do not meet needs of co-infected respondents (percentage of all HIV/hep C co-infected participants)

They have a poor understanding of hep C co-infection	34.3
They have a poor understanding of IDU issues	9.4
I don't want to disclose my Hep C status	2.5
I don't want to disclose that I have injected drugs	0.6
Other	0.6

(Multiple responses possible)

Detailed data were collected on testing and treatment history for this cohort and will be presented in a subsequent report. That report will, as with previous studies, detail the difference between those living with HIV and hepatitis C co-infection, and others across a range of factors.

FIGURE 3 Multiple hepatitises (Number of respondents)



Hepatitis: Testing

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

We asked respondents who had any of the three major viral hepatitises whether they had been given a liver function test or had undergone liver biopsy, and the result of these tests. We have given the findings for these questions in tables 13 and 14 below, organised by individuals' co-infection status/ history. It should be noted that the co-infection status includes both those currently with the condition and those having had it in the past. Given the information presented above, one can see that the majority of those in this table with a hepatitis A or B co-infection status would not currently be in an active stage of the infection.

The majority of participants with a history of hepatitis infection reported having had an LFT (around 90% for all categories). Abnormal results were most common in the presence of hepatitis C infection, with up to 21% being unsure of the results of this test.

TABLE 13 Participants undergoing Liver Function Test (LFT) and results of this test by co-infection history with hepatitis

	N	Had LFT (%)	Abnormal result (%)	Don't know result (%)
hepatitis A only	112	89.2	15.7	12.0
hepatitis B only	131	85.2	16.1	21.8
hepatitis C only	69	92.2	31.5	11.1
hepatitis A and B	103	88.4	9.0	14.1
hepatitis A and C	26	96.2	25.0	20.0
hepatitis B and C	31	93.3	39.1	17.4
hepatitis A, B and C	28	85.7	36.4	18.2

The proportion of participants with a co-infection history reporting having undergone a liver biopsy varied somewhat more than the LFT, with this most likely occurring in the presence of hepatitis C infection and only rarely for hepatitis A. Fibrosis was reported by over half those reporting a history of hepatitis C, or A and C, although it should be noted that up to 62% of others reported not knowing the results of this biopsy.

TABLE 14 Participants undergoing liver biopsy procedure and results of this by co-infection history with hepatitis

	N	Had Liver Biopsy (%)	Fibrosis (%)	Don't know result (%)
hepatitis A only	112	7.8	0.0	28.6
hepatitis B only	131	13.0	30.8	30.8
hepatitis C only	69	29.7	55.6	33.3
hepatitis A and B	103	11.0	15.4	61.5
hepatitis A and C	26	44.0	54.5	18.2
hepatitis B and C	31	33.3	18.2	45.5
hepatitis A, B and C	28	48.1	35.7	42.9

The stage of liver fibrosis was only reported by a small number of respondents, and so will not be discussed in this report.

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 15 below. The most common health-enhancement activity was exercise, followed by healthy eating, sleep and compliance with medication. Those with better self-rated health or well-being were more likely to indicate that they engaged in; exercise, healthy eating, spending time with friends, relaxation, and spending time with partner.

TABLE 15 Health improvement strategies (percent of sample)

Healthy eating	79.2
Sleep	74.4
Exercise	69.3
Taking pills on time	68.9
Relaxation	63.7
Spending time with friends	57.8
Spending time with pets	38.8
Spending time with partner	34.4
Spending time with family	32.1
Complementary therapies	30.6

(Multiple responses possible)

Prophylaxis

23.3% of respondents were taking prophylaxis for opportunistic infections. Those using prophylaxis were more likely to have experienced an AIDS defining illness, to have a lower CD4 count, to have been HIV positive longer and to be using complementary therapies

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

TABLE 16 Attitudes to health management (percentage of total sample)

Looking after my physical fitness is an important part of managing my HIV infection	strongly agree	49.7
	agree	45.8
	disagree	4.1
	strongly disagree	0.4
Healthy eating is an important part of managing my HIV infection	strongly agree	43.0
	agree	52.6
	disagree	3.7
	strongly disagree	0.7
Keeping an optimistic frame of mind is an important part of managing HIV infection	strongly agree	51.7
	agree	45.2
	disagree	1.8
	strongly disagree	1.3
As long as I am well I prefer not to think about HIV/AIDS	strongly agree	15.1
	agree	35.9
	disagree	40.2
	strongly disagree	8.8
Life has become more meaningful since I became HIV positive	strongly agree	13.4
	agree	30.6
	disagree	39.8
	strongly disagree	16.1

Other Health Monitoring

We asked a series of questions about other health monitoring activities. 18.6% had had a bone density test in the last two years and 8.6% had had a test more than two years ago. 58.3% had had a fasting cholesterol test in the last two years and 8.1% 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.

Almost all the female respondents had had a cervical smear (Pap) test (98.9%) and of those that had a test, 95.6% had had one in the last twelve months. Generally women had one test in the last year (70.4% of those tested in the last year). On their most recent test, most (84.3%) reported that the result was 'normal' or 'clear', while 11.2% had an abnormal result.

TREATMENTS

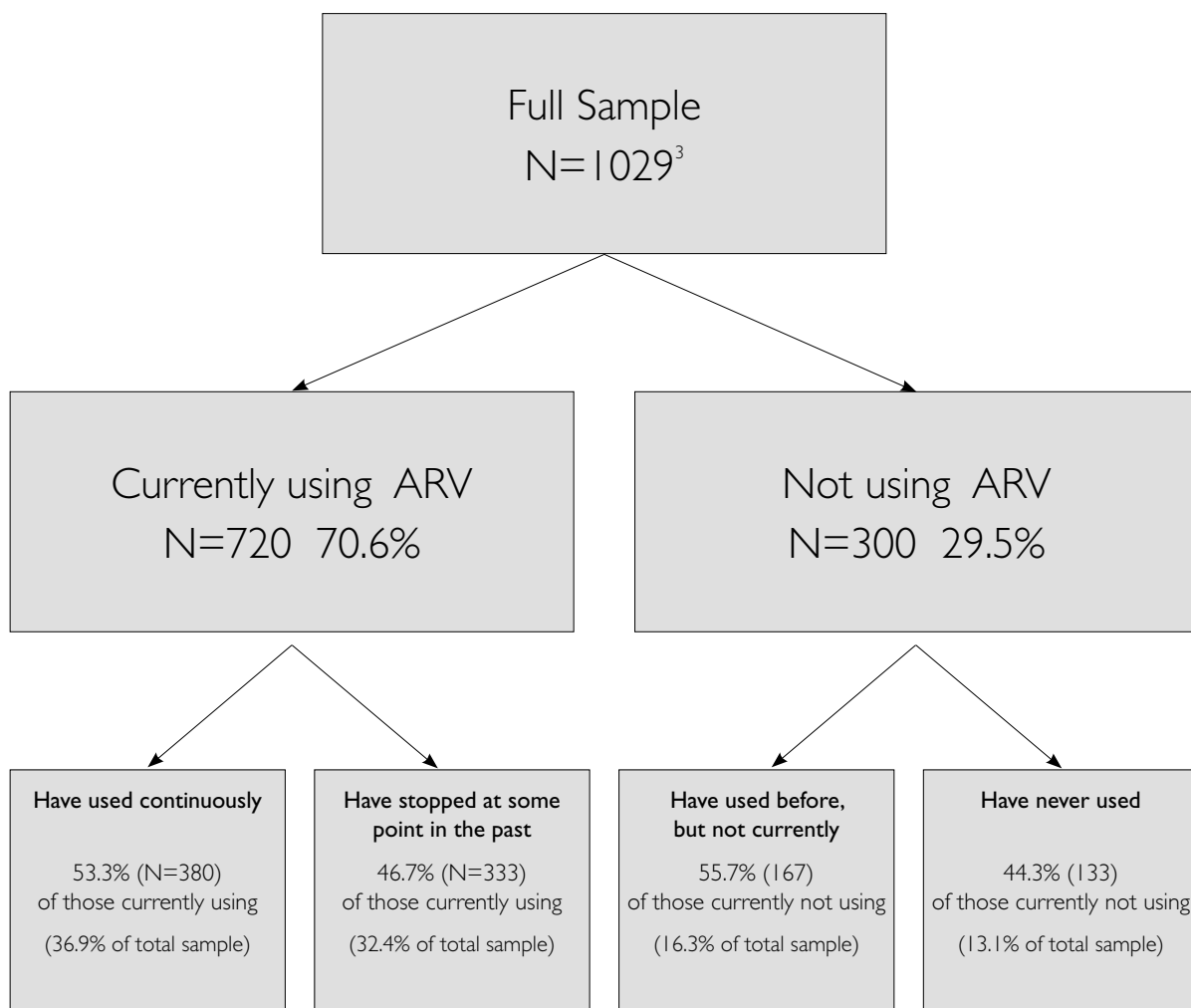
This chapter reports on the treatment experiences of PLWHA. The main emphasis is on antiretroviral treatments, as these are dominant in the lives of HIV positive people. There is also some discussion of complementary medicines and medications for other health conditions. While we have seen a reduction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

Antiretroviral Therapy

It is now eight years since the announcement of the success of combination therapy at the eleventh International AIDS Conference on AIDS held in Vancouver. Since then antiretroviral therapy has reduced the number of deaths from AIDS in countries where these treatments can be afforded. However, problems with these therapies, such as side effects and difficult treatment regimens, have also been well documented. Since the beginning of the widespread use of antiretrovirals, pharmaceutical companies have been refining these drugs to reduce the impact on the lives of PLWHA, however significant problems still remain. The experience of antiretroviral treatments is increasingly one of disparity with a proportion of the population deriving great benefit from the treatments and an increasingly large number for whom treatments are failing or causing health difficulties and challenges to day to day life. This section addresses some of that complexity by examining the experience of antiretrovirals both in clinical and social terms.

Of the full sample, 87.0% had used ARV at some point, and 70.6% were currently using these treatments. A summary diagram of the uptake of antiretrovirals can be found below.

FIGURE 4 Use of Antiretroviral Therapy



³ Weighted

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

The majority of participants (63.7%) were on a combination of 3 antiretroviral drugs⁴, with 27.1% on more than three antiretroviral drugs, 7.6% on two, and 1.5% on monotherapy.

TABLE 17 Antiretroviral drugs used by respondents: percentage of those currently using ARV

<i>Nucleoside Reverse Transcriptase Inhibitors (NRTIs)</i>	
Lamivudine (3TC, Epivir)	42.3
Abacavir, 1592 (Ziagen)	22.7
Stavudine, d4T (Zerit)	15.5
Didanosine, ddl (Videx)	11.1
Zidovudine, AZT (Retrovir)	8.3
ddl ec (Videx ec, didanosine ec)	6.5
Zalcitabine, ddC (Hivid)	1.3
<i>Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)</i>	
Nevirapine (Viramune)	29.1
Efavirenz (Sustiva, Stocrin)	16.5
Delavirdine (Rescriptor)	1.7
<i>Nucleotide Analog Reverse Transcriptase Inhibitors</i>	
Tenofovir (Viread)	30.2
<i>Protease Inhibitors</i>	
ABT-378/r (Lopinavir, Kaletra)	17.3
Ritonavir (Norvir)	15.3
Indinavir (Crixivan)	7.5
Nelfinavir (Viracept)	5.8
Saquinavir (Invirase, Fortovase)	5.6
Amprenavir (Agenerase)	3.1
<i>Fusion Inhibitor</i>	
T-20	2.1
<i>Combination Medications</i>	
AZT & 3TC (Combivir)	19.2
AZT & 3TC & Abacavir (Trizivir)	10.5
<i>Other</i>	7.6

Respondents were also asked specifically about their use of the immune stimulant Interleukin 2 and 1.2% of respondents were using it.

Difficulties of Taking ARV

Overall, 76.5% of those currently using antiretroviral treatments reported that they had some difficulty taking them. Of these, 52.4% indicated they had difficulty remembering to take the drugs on time, 28.3% said they had difficulty organising meals around medications, 31.3% taking medication in public, 34.3% transporting medication, and 23.6% taking a large number of tablets. In addition, 9.3% reported that taking ARV made it difficult to take medication for other health conditions and 5.7% that taking other medications made taking ARV difficult.

⁴ Combivir counts as 2 drugs, Trizivir as 3 drugs

TABLE 18 Difficulties of taking ARV among those currently using ARV (percent)

Remembering to take drugs on time	53.0
Side effects	49.6
Carrying/transporting medication	34.4
Taking medication in public	30.9
Organising meals around medication	28.3
Taking a large number of tablets	24.0
ARV drugs make it difficult to take medication for other health conditions	9.5
Medication taken for other health conditions makes it difficult to take ARV	5.7
Organising treatment around times of religious observance	0.7
Other	7.2

(Multiple responses possible)

Side effects were reported by 49.6% of respondents currently using ARV. The most commonly reported problems were diarrhoea (23.6% of those using ARV), nausea or vomiting (21.9%), fatigue or lethargy (12.3%), lipodystrophy (8.8%), sleep disturbances (7.8%), digestive/stomach upsets (7.0%), headaches (5.0%), neuropathy (4.7%) and hyperlipidaemia (2.5%).

Attitudes to ARV

Most respondents reported concern over the future efficacy of their treatments. Almost two thirds (65.2%) agreed or strongly agreed with the statement *I am worried that in the future my medication will stop working for me*. When asked to respond to the statement *Taking tablets gives me an unwanted reminder that I have HIV*, 40.2% indicated agreement and 59.9% indicated disagreement.

TABLE 19 Attitudes to medication: percentage of those currently using ARV

	strongly disagree	disagree	agree	strongly agree	don't know
I am worried that in the future my medication will stop working for me	3.6	17.4	47.4	17.8	13.8
Taking tablets gives me an unwanted reminder that I have HIV	9.8	30.0	37.9	20.4	1.9

Health Status of Those Using ARV

Those taking ARV had significantly lower viral loads (mean of 14,858 cells/μl compared to 62,821 cells/μl among those not taking any antiretroviral medication, $F_{(1,753)} = 32.193$ $p < 0.001$). This difference is mainly explained by the large proportion of those on ARV with a viral load below detectable levels as can be seen in Table 20.

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

		Viral load on most recent test			
		Below detectable	500-9999	10000-49999	50000+
ARV Use	Current	76.1	11.3	6.3	6.3
	Past	21.6	19.4	30.2	28.8
	Never	16.2	24.2	33.3	26.3

 $\chi^2_{(6,1)} = 252.819$ $p < 0.001$

Those taking ARV had marginally significantly lower CD4 counts (mean of 484 copies/ml compared to 532 copies/ml among those not taking antiretrovirals, $F_{(1,774)} = 3.254$ $p = 0.072$).

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

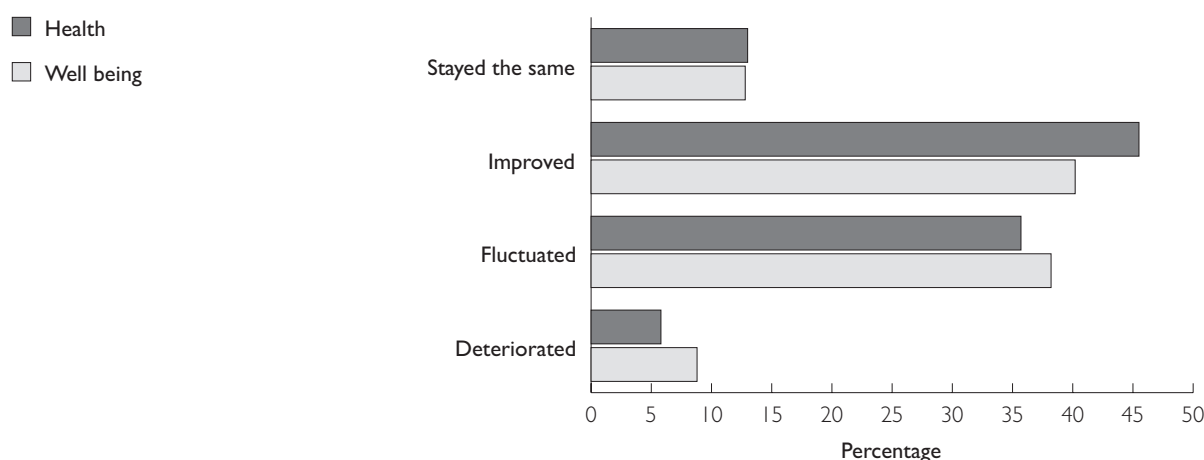
		CD4 on most recent test		
		0-249	250-499	500+
ARV Use	Current	21.5	35.1	43.4
	Past	15.4	37.8	46.9
	Never	5.6	44.9	49.5

$\chi^2_{(4,1)} = 16.778$ $p=0.002$

Those currently taking antiretroviral treatments were more likely to have had an AIDS defining illness (30.1% compared to 10.2% among those currently not taking antiretrovirals and 6.0% among those who have never taken ARV). They had tested HIV positive more years ago (mean=1991 compared with mean=1992 for those not taking antiretrovirals and mean=1995 among those who have never taken ARV). There was, however, no difference between these groups in the ratings they gave of their general health status or well being.

When asked to rate the effect of commencing ARV on their physical health, 45.5% said that their health improved, 35.7% said it had fluctuated, 13.0% said it had stayed the same and 5.8% said it had deteriorated. When asked about the impact of ARV on their overall feeling of well-being, 40.2% said it had improved, 38.2% said it had fluctuated, 12.8% said it had stayed the same and 8.8% said it had deteriorated.

FIGURE 5 Effect of commencing antiretroviral medication on health and well being (percentage of those taking on ARV)



THOSE ON COMBINATION THERAPY

Different Combinations

There was considerable variation in the combinations currently in use by respondents. The most common combination was one NNRTI and two NRTIs used by 15.8% of the sample.

45% of those on combination therapy had been on ARVs for at least seven years. Most started combination therapy at a time when their viral load was high (Median= 80,000, mean = 1,286,128 copies/ml) and their CD4 count was low (median=200, mean = 525, 61.3% below 250 cells/ μ l, 91.2% below 500 cells/ μ l). Table 22 below, gives the CD4 and viral load of respondents at the time they commenced combination antiretroviral treatment.

TABLE 22 Results of serological tests prior to commencement of ARV: percentage of those on ARV

		HIV Viral load				
		Below detectable levels	500-9999	10000-49999	50000+	Total
Cd4/T-cell count	500+	1.1	0.7	2.8	4.2	8.8
	250-499	0.7	1.8	6.7	20.8	29.9
	0-249	2.5	3.2	13.7	41.9	61.3
	Total	4.2	5.6	23.2	66.9	100.0

Based on available data (Hoy and Pierce: The Draft Australian Antiretroviral Treatment Guidelines 2001) antiretroviral treatment is recommended for patients with less than 200 CD4 cells, should be offered to those with CD4 count between 200 and 350 and is recommended for those with a CD4 over 350, but a viral load greater than 50,000 copies/ml. Table 23 below gives the groupings from these guidelines, the treatment recommendations, the percentage of participants that were in each group at the commencement of antiretroviral treatment and the mean number of years they have been on treatment.

TABLE 23 Treatment recommendation at commencement of ARV treatment

	Guideline Group: At commencement of ARV combination				
	Symptomatic (ADI)	Asymptomatic and CD4<200	Asymptomatic and CD4 200-350	Asymptomatic CD4>350, VL>50,000	Asymptomatic CD4>350, VL<50,000
Treatment recommendation	Treat	Treat	Treatment should be offered	Recommend treatment	Defer treatment
Percentage of those currently	33.5 (N= 166)	28.5 (N= 141)	26.4 (N= 131)	6.8 (N= 33)	4.9 (N= 24)
Mean number of years using ARV	7.03	6.75	7.13	6.13	5.00

Table 24 below gives these groupings based on participant's current CD4 and viral load results. While this clearly does not indicate current treatment recommendations, it does give some indication of the shift in clinical markers over time. Of those who were currently taking combination ARV, 44.6% are in the same guideline category as when they commenced therapy, while 42.6% have improved, and 12.8% have deteriorated.

TABLE 24 Treatment recommendation groups by current status

	Guideline Group: Currently				
	Symptomatic (ADI) (N=256)	Asymptomatic and CD4<200 (N=46)	Asymptomatic and CD4 200-350 (N=100)	Asymptomatic CD4>350, VL>50,000 (N=24)	Asymptomatic CD4>350, VL<50,000 (N=332)
Percentage currently using	87.9	79.6	71.1	10.9	68.8
Mean number of years using ARV	7.60	8.67	6.77	8.07	7.16
Percentage previously used	8.7	14.3	16.7	41.3	17.4
Percentage never used antiretro-	3.4	6.1	12.3	47.8	13.8

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 (71.1%), although the importance of clinical indicators, treatment developments and treatment information is also clear.

TABLE 25 Circumstances surrounding commencement of treatment among those currently on combination ARV (percent)

My doctor advised me to begin this treatment	71.1
I had a big drop in my CD4/T-cell count	41.3
I became very ill.	32.3
New drugs became available	31.9
I had a big rise in my viral load	28.9
Information showed that this treatment is effective	23.5
I was hospitalised due to HIV-related infections	16.8
I had just tested positive to HIV	16.0
A treatments officer advised me to begin this treatment	5.8
My partner advised me to begin this treatment	5.8
A number of my positive friends started this treatment	5.7
Close friends advised me to begin this treatment	5.7
Other	12.4

(Multiple responses possible)

Different Combinations

Among those currently using combination therapy, respondents had used between one and 21 combinations, with the median being three. Within the last 12 months, 64.3% had used the one combination and 22.6% 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 (46.6%) the side effects had become too severe. Drug resistance (19.6%) and drugs not working (10.3%) were the next most common responses.

TABLE 26 Primary circumstance surrounding most recent change in combination among those currently on combination ARV who have changed combinations (percent)

Side effects became too severe	37.0
Drug resistance developed	15.8
They were not working for me	8.1
Taking drugs at the right time was too difficult	2.2
It didn't fit my lifestyle	1.3
The financial burden became too heavy	0.2
Other (please specify)	15.8

When asked how many combinations they believed they still had access to, 4.2% indicated that they thought they had only one remaining. 24.5% had a few and 31.6% felt they had many. 35.6% said they didn't know how many combinations they had left. 4.1% of those currently on combination therapy believed they had no combinations remaining. Those respondents reporting no remaining options were significantly more likely to have a higher viral load and lower CD4 than those with more therapeutic options. (See Table 27)

TABLE 27 Correlates of number of remaining combinations for those on ARV [Combinations remaining by Mean years positive; Mean CD4; Mean LogViral load]

	Mean year tested positive ¹	Mean CD4 on most recent test ²	Mean viral load on most recent test ³
None	1989	299	73,946
One	1989	355	58,368
A few	1989	443	11,188
Many	1991	547	5,508
Don't know	1992	503	11,944

¹ $F_{(4,684)}=9.186$ $p<0.001$ ² $F_{(4,611)}=7.890$ $p<0.001$ ³ $F_{(4,594)}=7.979$ $p<0.001$

When we examine the health status of those with varying numbers of combinations remaining, we can see that the pattern differs for each of these categories. Those with 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. Those unsure about remaining combinations were most likely to rate their health as good.

TABLE 28 General health status for those with different numbers of combinations of ARV remaining (Percentages within combinations remaining)

		Health			
		Poor	Fair	Good	Excellent
Combinations remaining	None	10.7	53.6	32.1	3.6
	One	13.3	40.0	46.7	0.0
	A few	6.5	26.8	52.4	14.3
	Many	3.6	20.5	45.0	30.9
	Don't know	6.9	31.2	46.6	15.4

 $\chi^2_{(12,1)}=51.456$ $p<0.001$

A similar pattern can be found when we examine the relationship between number of remaining combinations and self-rated well being. Those with no combinations remaining were more likely to rate their well being as either fair or poor and those with many combinations remaining were more likely to rate it as good or excellent. Those unsure about remaining combinations were most likely to rate their well being as good.

TABLE 29 General well being for those with different numbers of combinations of ARV remaining (Percentages within combinations remaining)

		Well Being			
		Poor	Fair	Good	Excellent
Combinations remaining	None	24.1	44.8	27.6	3.4
	One	12.9	41.9	41.9	3.2
	A few	8.2	27.6	50.6	13.5
	Many	5.0	25.5	40.9	28.6
	Don't know	11.0	31.7	42.7	14.6

 $\chi^2_{(12,1)}=47.347$ $p<0.001$

Those Not Currently Taking ARV

Of the 29.5% of the sample who were not using any antiretrovirals, 55.7% had done so in the past. The mean length of time these PLWHA had been using ARV was 4 years and 8 months (range 15 months to 12 years) and on average they had ceased using ARV 3 years and 1 month prior to completing the survey (range 1 month to 12 years). At the time that they stopped using ARV, most were using a combination of 3 drugs (72.1%), 11.5% were using four drugs, 9.1% were using two drugs and 3.8% 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 30). 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 30 Difficulties of taking ARV among those who have stopped ARV treatment (percent)

Side effects	54.5
Remembering to take drugs on time	45.5
Organising meals around medication	29.1
Taking a large number of tablets	26.0
Carrying/transporting medication	25.6
Taking medication in public	24.7
ARV drugs make it difficult to take medication for other health conditions	4.8
Medication taken for other health conditions makes it difficult to take ARV	4.7
Other	9.6

(Multiple responses possible)

Health Status of Those Not Using ARV

Those not currently using ARV were asked to describe changes in their health when they had used ARV in the past. One in seven (14.6%) said that it had deteriorated, 30.9% said it had fluctuated, 29.3% said it had stayed the same, and 25.2% that their health had improved. When asked about the impact of ARV on their overall feeling of well-being, 13.3% said it had improved, 38.7% said it had fluctuated, 25.1% said it had stayed the same and 22.9% said it had deteriorated. Respondents were asked whether they had lifestyle or clinical reasons for ceasing their use of antiretroviral therapy. 36.9% of respondents gave lifestyle reasons for stopping treatment (see Table 31). 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 31 Lifestyle reasons for stopping treatment (percent of those previously on ARV)

Clean out my system	11.7
Taking drugs at the right time was too difficult	10.5
It didn't fit my lifestyle	10.2
The financial burden became too heavy	4.5
A special event	1.7
Religious reasons	0.0
Other	16.6

(Multiple responses possible)

67.5% of respondents gave clinical reasons for ceasing ARV treatment (see Table 32). Almost one third of these said that side effects were a reason for stopping and over one quarter said that the cessation was recommended by their doctor. Importantly, almost one in ten said that drug resistance was a problem.

TABLE 32 Clinical reasons for stopping treatment (percent of those previously on ARV)

Side effects became too severe	31.3
Recommended by my doctor	28.4
Drug resistance developed	11.0
Liver toxicity problems	9.8
Recommended by other health professional	4.9
Complications with Hep C	2.0
Changing regimens	1.7
Other	12.5

(Multiple responses possible)

Those Who Have Never Used Antiretroviral Drugs

13.1% (N=133) of the respondents had never used antiretroviral treatments. Of these 86.4% said they would consider using antiretroviral drugs in the future. When asked what circumstances would lead to their commencing ARV, the principal reasons were clinical (see Table 33).

TABLE 33 Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used antiretroviral drugs (percent)

If I became very ill	63.0
If I had a significant drop in CD4 / T-cell count	54.0
If I was hospitalised due to HIV-related infections	52.6
If I had a significant rise in my viral load	49.3
If my doctor advised me to begin this treatment	45.2
If information showed that combination therapy is effective	24.1
If new drugs became available	15.4
If a treatments officer advised me to begin this treatment	11.1
If my partner advised me to begin this treatment	8.4
If close friends advised me to begin this treatment	5.4
When my break from treatment is finished	3.9
If a number of my positive friends began to take up combination therapy	0.6
Other	15.5

(Multiple responses possible)

Attitudes to Antiretroviral Therapy

Antiretroviral treatments have an impact on many parts of people's lives, not just on their physical health. As in previous surveys, we asked respondents to respond to a series of statements about treatments. These fall into three broad areas: decision making around treatments, relationship with their doctor, and optimism about treatments. These findings can be seen in Table 34.

TABLE 34 Attitudes to antiretroviral drugs: percentage of total sample

	strongly disagree	disagree	agree	strongly agree	don't know
I am healthy now and don't need to use combination antiretroviral drugs	37.2	32.8	13.2	10.8	6.0
People with HIV should start using antiretroviral drugs as soon as possible	14.2	29.8	19.2	14.4	22.3
My doctor and I work together to find the best treatment for me	2.7	5.6	52.9	36.2	2.6
My doctor knows a lot more about the treatment of HIV than I do.	4.1	12.6	43.3	36.8	3.2
Combination antiretroviral drugs are ineffective	46.7	41.2	1.9	2.9	7.4
Combination antiretroviral drugs are harmful	17.7	28.7	30.3	8.2	15.1
The side-effects of antiretroviral drugs outweigh the benefits	16.4	43.4	17.9	6.3	16.1
New treatments will be developed in time for me to gain benefits	2.0	6.5	44.1	18.7	28.8
HIV treatments will stop me dying from AIDS	6.9	22.2	24.4	14.9	31.6
Combination antiretroviral drugs have allowed me to plan my life with confidence for the long-term	4.9	18.7	37.8	25.2	13.4

Treatment Decision Making

Most respondents indicated that they disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (70.0%). 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 (89.1%) agreed with the statement *My doctor and I work together to find the best treatment for me*, with few expressing uncertainty. Most respondents (80.1%) agreed with the statement *My doctor knows more about the treatment of HIV than I do*.

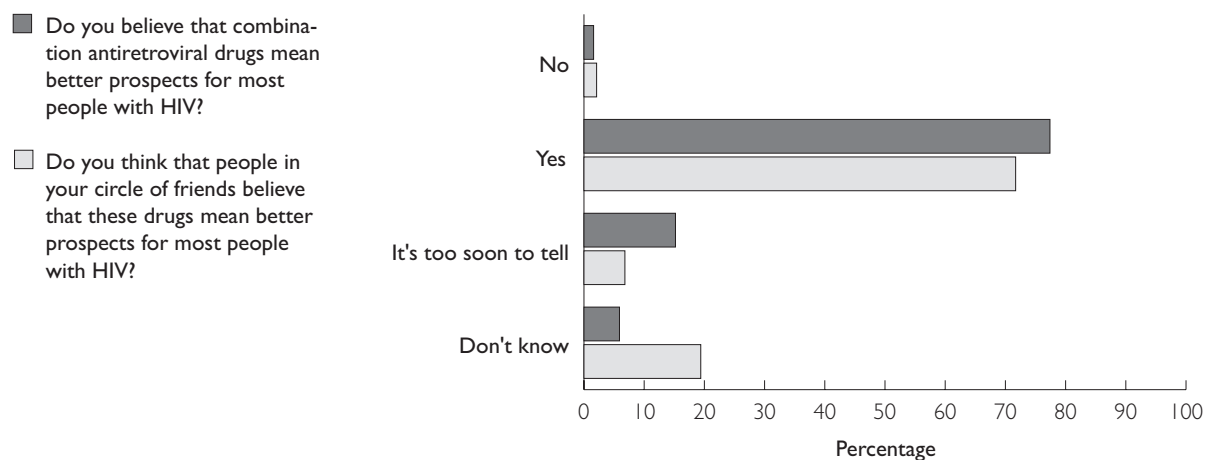
Treatment Optimism

Optimism about the value and effectiveness of antiretroviral treatments continues to characterise the Australian experience, but tempered as always with concerns about the impact and long term effectiveness of these treatments. Only 4.8% of respondents agreed with the statement *Combination antiretroviral drugs are ineffective*. This belief in effectiveness is tempered by an awareness of the potential harm of these therapies as evidenced by the agreement with the statement that *Combination drugs are harmful* (30.3% agree, 8.2% strongly agree). This harm may in part be that experienced as side effects. Around one quarter (24.2%) of respondents agreed or strongly agreed with the statement *The side effects of antiretroviral drugs outweigh the benefits*, while 16.1% were unsure. There was considerable uncertainty about the long term benefit of treatment. 28.8% 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, 31.6% were uncertain when asked if *HIV treatments will stop me dying from AIDS*. Agreement with this statement was indicated by 39.3% of respondents. Almost two thirds (63.0%) agreed with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*, while 13.4% were uncertain.

In addition to these items, respondents were asked to indicate how much they and their friends agree with the statement *Antiretroviral drugs mean better prospects for most people*. Most (77.4%) agreed with the statement, and believed their friends would agree with it (71.7%). Fewer respondents than in previous surveys believed that it's too soon to tell (15.2%), although they were less likely to believe their friends think this (6.8%).

FIGURE 6 Respondents' and respondents' social networks' response to the statement Antiretroviral drugs mean better prospects for most people



Treatment Breaks

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

In all, 46.7% of those respondents currently using antiretroviral medication had taken a break from these at some point.

Most Recent Treatment Break

The date of the most recent break ranged from currently taking one to having taken one ten years ago. The mean length of break was 87.5 days with a median of 60.7 days. Slightly less than one fifth (19.6%) described the break as a structured treatment interruption, while 59.0% described it as a treatment break.

We asked participants to describe the reasons for taking the break within two major categories: lifestyle reasons, and clinical reasons. A discussion of the differences between those taking breaks for primarily lifestyle and primarily clinical reasons can be found in our article on this topic (Grierson, Misson and Pitts 2004). Just under half (49.5%) indicated that there were lifestyle reasons for taking a break. The specific reasons are given in Table 35 below. The most common reason given was to clean out the system (16.8% of those taking breaks) followed by difficulties around timing of drugs (10.6%).

TABLE 35 Lifestyle reasons for taking breaks (percent of those taking breaks)

Clean out my system	16.8
Taking drugs at the right time was too difficult	10.6
It didn't fit my lifestyle	10.4
A special event	6.5
The financial burden became too heavy	5.0
Religious reasons	0.0
Other	30.9

(Multiple responses possible)

When asked if there was a clinical reason for taking the break, 58.4% of those that had taken a break indicated that there was. (15.3% gave both lifestyle and clinical reasons). Table 36 below details the clinical reasons for breaks. The most commonly cited reason was that the side effects of treatment became too severe (27.8% of all those taking breaks), while just over a fifth indicated that the break was on the recommendation of their doctor.

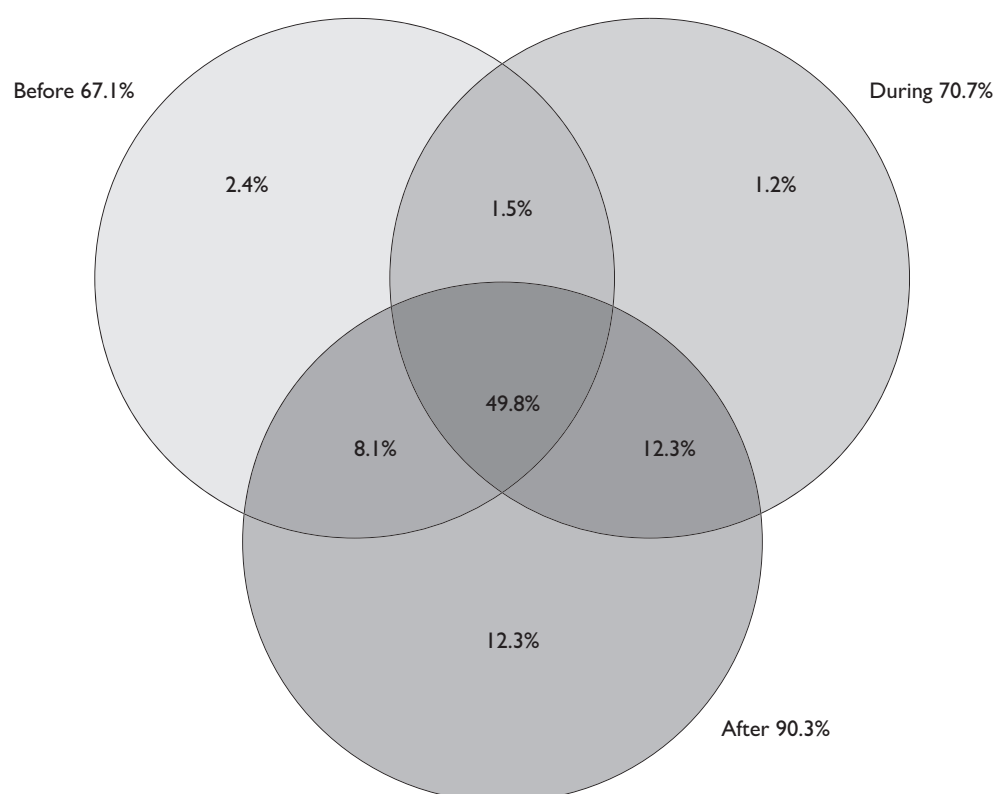
TABLE 36 Clinical reasons for taking breaks (percent of those taking breaks)

Side effects became too severe	27.8
Recommended by my doctor	23.5
Drug resistance developed	9.0
Liver toxicity problems	8.3
Changing regimens	5.9
Complications with Hep C	2.4
Recommended by other health professional	2.4
Other	13.5

(Multiple responses possible)

We also asked about the involvement of the participant's doctor in these breaks. Participants were less likely to have talked to their doctor about the break prior to taking it (67.1%) than they were during the break (70.7%) or afterwards (90.3%). Over half (49.8%) talked to their doctor at all three stages of the treatment break. 12.3% spoke to the doctor during and after the break, but not before, and 12.3% only spoke to their doctor after the break. A graphic representing the patterns of consultations can be seen in Figure 7.

FIGURE 7 Consultations with HIV physician before, during and after treatment break (percentage of those taking breaks)



We were also interested in the outcome of the treatment breaks, both in terms of clinical markers and experience of health and well-being. Tables 37 below gives the results of the four questions asked. Around one third of respondents said that their health remained stable, while the remainder were spread fairly evenly across the categories of improved, fluctuated and got worse. When asked about their general well-being, a similar proportion said that it had remained stable (28.7%). With well-being, there was a more distinct pattern for the remaining categories with decreasing proportions saying that it had improved, (32.2%) fluctuated (24.8%) or got worse (14.3%).

TABLE 37 Effect of break on health and well being (percentage of those taking break)

	Health	Well being
Stayed the same	32.6	28.7
Improved	19.8	32.2
Fluctuated	26.1	24.8
Deteriorated	21.4	14.3

The impact of these breaks on clinical markers was less positive. The majority of respondents indicated that their viral load had increased, and their CD4 count had decreased as a result of the break. These data are presented in Tables 38 and 39 below. Note that the categories are ordered from positive to negative outcome for both tables.

TABLE 38 Effect of break on viral load (percentage of those taking break)

		Viral load before break				Total
		Below detectable levels	500-9999	10000-49999	50000+	
Change in viral load due to break	Decrease (improve)	7.1	0.0	1.6	0.0	8.7
	Stay the same	6.3	2.4	0.0	0.8	9.4
	Fluctuate	9.4	3.1	2.4	2.4	17.3
	Increase (worsen)	41.7	11.8	9.4	1.6	64.6
Total		64.6	17.3	13.4	4.7	

TABLE 39 Effect of break on CD4 (percentage of those taking break)

		CD4 before break			Total
		500+	250-499	<250	
Change in CD4 due to break	Increase (improve)	0.5	2.1	4.2	6.8
	Stay the same	0.5	8.4	8.9	17.8
	Fluctuate	1.0	7.9	10.5	19.4
	Decrease (worsen)	6.3	19.4	30.4	56.0
Total		8.4	37.7	53.9	

Antiretroviral Resistance

The development of resistance to antiretroviral treatments is an ever increasing concern for HIV positive people. HIV can develop resistance to one or more treatments as a result of its continual mutation and this resistance can result in the failure of treatments (Deeks 2003, Prejdova et al 2004). Resistance can result from a lack of early and persistent suppression of viral replication, missed doses of antiretrovirals or infection with a resistant strain. There are a number of resistance tests available but they generally fall into two categories: genotypic resistance tests that look for mutations of the virus in its genetic code; and phenotypic resistance tests where the virus is cultured and the performance of drugs tested directly. We asked respondents whether they had had resistance tests and what the clinical and treatment outcomes of this were.

30.3% of respondents who had ever used antiretroviral treatments indicated that they had some sort of ARV resistance test. This included 37.0% of those who were currently on antiretroviral treatment and 21.1% of those who were not. The average length of time since the most recent resistance test was 25.3 months (median=21 months). 71.7% of respondents had had their most recent test in the last two years (69.6% of those currently on ARV, 84.4% of those not). Of those who had resistance testing, 75.0% found resistance to one or more antiretroviral drugs (75.2% of those currently on ARV, 77.4% of those not). This resulted in a change of drugs for 80.5% (N=161) of those where resistance was shown. Tables 40 and 41 show the changes in clinical markers for all those who underwent resistance testing and who changed treatments. The number of participants is given rather than the percentage due to the small overall numbers. Note that the categories are ordered from positive to negative outcome for both tables.

TABLE 40 Effect of resistance testing and treatment change on viral load
(number of those changing treatments)

		Viral load before change				Total
		Below detectable levels	500-9999	10000-49999	50000+	
Change in viral load due to change	Decrease (improve)	6	17	16	21	60
	No change	1	1	1	3	6
	Increase (worsen)	1	3	2	1	7
	Don't know	1	4	3	1	9
Total		9	25	22	26	82

TABLE 41 Effect of resistance testing and treatment change on CD4
(number of those changing treatments)

		CD4 before change			Total
		500+	250-499	<250	
Change in CD4 due to change	Increase (improve)	6	25	6	61
	No change	3	3	3	11
	Decrease (worsen)	5	4	5	15
	Don't know	2	5	2	10
Total		16	37	16	97

Dosing and Adherence

Adherence to antiretroviral medication continues to be a significant concern for both PLWHA and physicians (Friedland & Williams 1999). The high degree of adherence required for these treatments to be effective and in order to prevent the development of resistance is far greater than that required (or observed) for other health conditions. Respondents were asked the number of times they took a range of medications per day. On average, PLWHA were taking medication 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 42 below. 78.6% of the sample were taking ARV twice daily, 7.3% three times a day and 8.9% once a day.

TABLE 42 Number of times participants take medications

	Mean	Median	Range
Antiretroviral drugs	1.97	2.00	0-6
Complementary therapies	1.59	2.00	0-8
Medication for other health conditions	1.73	2.00	0-8

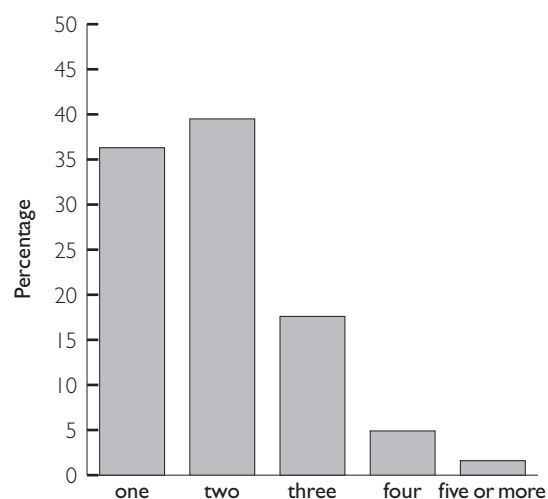
Participants who were currently using antiretroviral medication were asked how many doses they had missed on the day prior to completing the survey and the day before that. Combining the data from these two measures, 65.0% reported missing no doses on the two days, 6.9% missed one dose, 22.8% missed two doses and 5.2% missed three or more doses.

Prescriptions

We asked participants who prescribed their antiretrovirals. In recognition of the multiple prescribing sites people utilise, respondents were able to nominate more than one source. Two fifths (41.6%) of PLWHA got their prescriptions for antiretroviral drugs from a GP who specialises in HIV/ S100 prescriber. A similar proportion (39.2%) obtained their prescription from a specialist in an outpatient clinic, while fewer obtained them from a doctor at a sexual health centre (20.1%), another GP (3.5%), or from a HIV specialist while an inpatient (2.3%).

When asked from how many places participants obtained their medications, they were most likely to say two places (39.5%) with slightly fewer saying one place (36.3%). Fewer went to three or more sites (See Figure 8). When asked how difficult it was to do this, over half (59.1%) said it was not difficult, 35.2% said somewhat difficult and 5.7% said very difficult.

FIGURE 8 Number of prescription pick-up points



Clinical Trials

A total of 33.1% of the respondents had participated in a clinical trial for HIV related treatment and 17.1% of all participants (n=176) had participated in a clinical trial in the last two years. The main treatments that participants had trialed were Il-2 (11.1%), AZT (11.1%) and Atazanavir (7.3%). They had on average been on these trials for 13 months. The circumstances surrounding participation in the trial are given in Table 43 below. These data show that involvement of doctor was important in this decision, as was an altruistic intent.

TABLE 43 Reasons for participating in clinical trials (percentage of those who have participated in a trial)

My doctor and I decided together	58.7
I felt my experience could benefit others	58.5
I felt I had enough information about the trial	28.5
I had no other treatment options	19.4
It was the only way I could get the treatment	18.3
My other treatments were not working	13.2
I felt pressured to go on the trial	3.3
Other	13.3

(Multiple responses possible)

Vaccines

While the development of readily available therapeutic vaccines for HIV positive people is still some way off (Mwau & McMichael 2003), we were interested in participants’ perspectives on this. We asked respondents to indicate their agreement with the statement *I would be willing to participate in a HIV vaccine trial*. Almost one quarter (23.8%) said they did not know, while 56.6% either agreed or strongly agreed with the statement. A further 11.0% disagreed and 8.6% disagreed strongly.

Complementary Therapies

We asked participants to indicate the types of complementary therapies they were currently using and also to indicate where this product or service was obtained. In order to gain an overall picture of complementary therapy use, the question asked participants to indicate all complementary therapies they were currently using, not only those they were using for HIV/AIDS. Over half the sample were currently taking vitamin or mineral supplements, while a significant minority were taking herbal supplements or using other forms of complementary medicine.

TABLE 44 Current use any of complementary medicine (percentage of total sample)

Vitamin / mineral supplements	51.5
Herbal therapies / supplements	16.7
Traditional Chinese Medicine	7.3
Other traditional Medicine	5.4
Other	9.1

(Multiple responses possible)

Participants were asked where they obtained these services or supplements. While one in six obtained these from a private practice, a similar proportion obtained them either from an AIDS community organisation or a PLWHA group. Those that selected the 'other' option mostly obtained these medicines from health food shops or similar establishments.

TABLE 45 Source of complementary medicine (percentage of total sample)

Private practice	16.6
AIDS community organisation	11.7
Health Service	8.1
PLWHA organisation	4.2
Other	26.7

Other complementary therapies used by participants included mind-body therapies such as massage, used by over one-third of the sample, meditation and acupuncture. In addition, over one quarter of the respondents indicated that they used marijuana medicinally.

TABLE 46 Use of other complementary therapies (percentage of total sample)

Massage	36.7
Meditation / visualisation	23.7
Acupuncture	8.2
Marijuana for therapeutic purposes	28.2

(Multiple responses possible)

Many PLWHA (75.7%) believed that complementary therapies can improve well-being (see Table 47). Around half the sample also believed complementary therapies can delay the onset of illness due to HIV, reduce side effects of antiretroviral medication, and boost the immune system. However, around one third of 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 spent \$24.19 per week on them (median=\$20).

TABLE 47 Attitudes to complementary therapies: percentage of total sample

Complementary therapies can delay the onset of illness due to HIV	strongly disagree	3.4
	disagree	11.1
	agree	36.3
	strongly agree	13.6
	don't know	35.6
Complementary therapies can improve well-being	strongly disagree	1.4
	disagree	2.4
	agree	52.5
	strongly agree	23.2
	don't know	20.5
Complementary therapies can reduce the side effects of conventional medical treatments	strongly disagree	1.6
	disagree	6.6
	agree	39.3
	strongly agree	13.4
	don't know	39.1
There is not enough evidence to be sure about the benefits of complementary therapies	strongly disagree	7.7
	disagree	30.8
	agree	32.1
	strongly agree	4.7
	don't know	24.8
Medicine's focus on anti-HIV drugs is very limited	strongly disagree	5.3
	disagree	27.8
	agree	27.4
	strongly agree	8.1
	don't know	31.5
Complementary therapies can boost the immune system	strongly disagree	1.6
	disagree	5.4
	agree	44.5
	strongly agree	16.4
	don't know	32.1
Complementary therapies are a central part of my anti-HIV treatments	strongly disagree	15.7
	disagree	34.5
	agree	23.2
	strongly agree	12.7
	don't know	13.9

Other Medication

Participants used a range of other prescribed medication. In all 54.5% of respondents were using prescribed medication other than antiretroviral therapies. The main medications being used were the antiviral agents Valtrex, Famvir and aciclovir (12.8%), lipid-lowering agents (6.3%), Bactrim (4.8%), medicines for reflux and ulcers (5.1%), and antihypertensive agents (4.0%). A high proportion of participants reported using antidepressants and other medicines for mental health conditions. Please refer to pg 43 for discussion of these medicines.

SERVICES



SERVICES

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

HEALTH SERVICES

Treatment

We asked respondents to identify the physician they see for the clinical management of their HIV and for general health issues. HIV GPs (S100 Prescribers) were the key physicians for both HIV specific and general health management. HIV specialists were also the primary providers for a significant proportion of PLWHA. The distinction between these categories reflects the different health care systems in different states and territories, and the availability of these physicians in regional areas. HIV GPs were more likely to be nominated as the primary provider of both general and HIV-related treatment by those living in the inner suburbs of capital cities, than those living in the outer suburbs, regional centres or rural areas. Combined, HIV GPs and specialists were the primary physicians for 79.6% of respondents for HIV specific management and for 65.0% of respondents, for general health management.

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

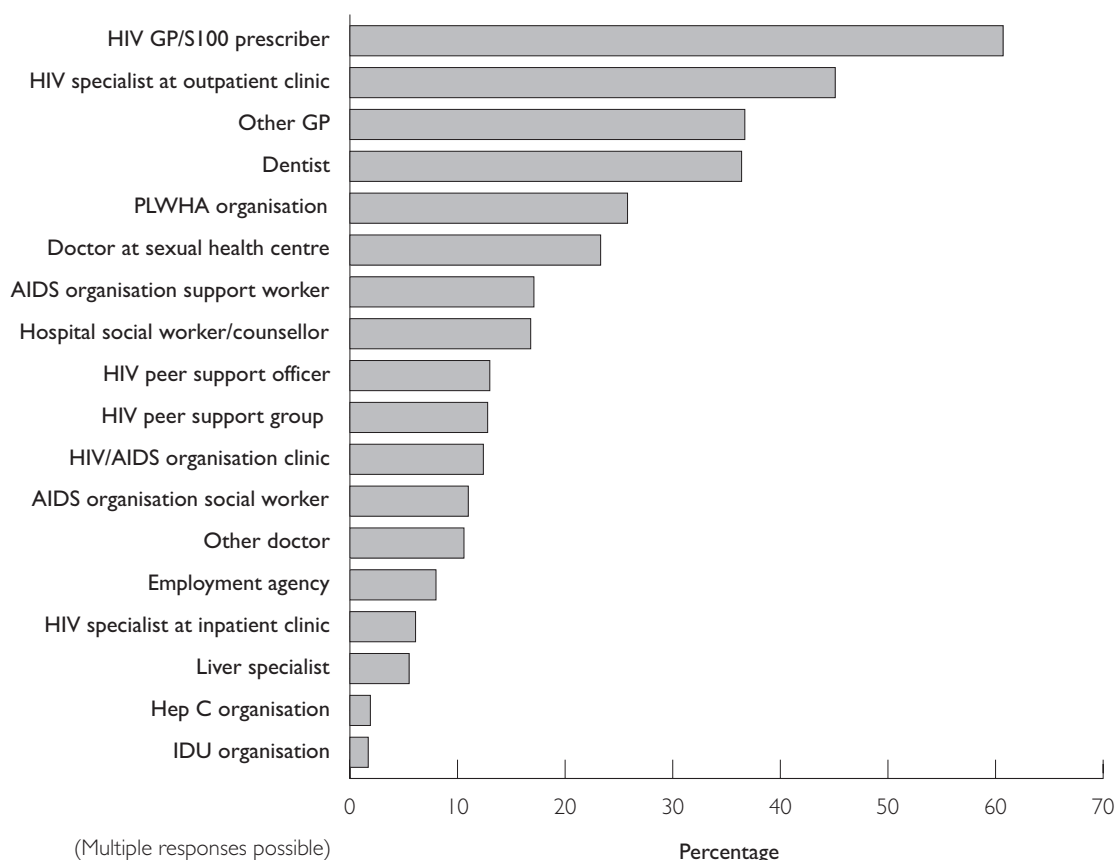
	For general treatment	For HIV specific treatment
HIV GP/S 100 Prescriber	50.2	45.3
Other GP	22.3	4.5
HIV specialist at outpatient clinic	14.8	32.9
HIV specialist at inpatient clinic	0.7	1.4
Doctor at sexual health centre	9.4	5.5
Other doctor	1.8	9.1
Other	0.7	1.2

54.7% of respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment. Of those who saw a different doctor, 98.8% said that that doctor knew their HIV status.

Services Used in the Last 6 Months

We presented respondents with a list of services, both clinical and ancillary and asked which they had used in the last six months. Clinical services were the most utilised in the list with 60.7% having used an HIV GP/ S100 prescriber, 45.1% an HIV outpatient specialist, 36.7% another GP, 36.4% a dentist, and 23.3% a doctor at a sexual health service. Support services were also commonly used, with 25.8% reporting having used a PLWHA organisation, 17.1% an AIDS organisation support worker and 16.8% a hospital social worker or counsellor (see Figure 9). People with hepatitis C were more likely to have used a hepatitis C organisation and those with hepatitis B and/or C were more likely to have seen a liver specialist.

FIGURE 9 Services used in the last six months (percent of total sample)



Other Services

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

TABLE 49 Percent of respondents who use services through HIV/AIDS organisations and other organisations (percent of total sample)

	Use service at HIV/AIDS organisation	Use service at other organisation
Treatments advice	48.1	23.1
Social contact with other PLWHA	42.9	7.4
Treatments information	36.2	11.1
Financial assistance	35.2	8.9
Peer support group	33.7	6.0
Counselling	32.9	22.9
Informal peer support	23.9	10.2
Pharmacy services	22.1	41.2
Financial advice	20.8	16.4
Complementary therapies	20.1	22.3
Legal advice	17.5	17.8
Community education campaigns	15.6	4.7
Housing assistance	15.2	20.0
Volunteer carer	12.9	16.1
Internet access	11.5	27.1
Mental health services	10.0	17.1
Employment services	9.5	15.6
Transport	9.3	21.4
Internet based information	8.7	14.5
Return to work skills	8.0	11.3
Library	7.1	24.9
Respite care	6.8	6.4
Drug/alcohol treatment	3.1	10.3
Paid carer	2.4	4.1

(Multiple responses possible)

One fifth (20%) of respondents indicated that there were services they felt they needed but did not have access to. The services most commonly nominated were access to affordable complementary or alternative therapies (14.6%), peer support groups (11.7%) and services for PLWHA in rural, regional and outer suburban areas (9.5%).

Information

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

Sources

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

TABLE 50 Sources of information about treatments and living with HIV (percentage of sample)

	Information about Treatments	Information about HIV Management	Information about Living with HIV
HIV GP/S100 prescriber	64.6	60.3	38.6
Other GP	12.6	13.5	11.1
HIV specialist at outpatient clinic	48.6	43.3	24.2
HIV specialist at inpatient clinic	9.3	8.6	5.4
Other doctor	2.0	1.4	2.0
Public Health Nurse	1.3	2.2	2.8
Other Nurse	6.2	5.7	5.3
Pharmacist	11.9	1.6	1.8
Alternative/Complementary therapist	3.7	3.0	5.1
Dietician	3.1	5.3	7.2
Dentist	9.6	12.0	11.3
Peer Support Officer	10.0	12.6	16.6
Sexual Health Service	17.0	18.4	16.3
Family Planning Association	0.2	0.3	1.8
Sex worker association	2.1	1.9	2.8
Treatments Officer	5.2	0.9	0.9
Other HIV/AIDS Organisation staff	1.3	1.4	10.2
Positive women's organisation	3.8	4.0	6.1
Positive heterosexuals group	4.5	4.5	6.0
Injecting drug users' organisation	0.1	0.2	1.7
Haemophilia foundation	0.5	0.2	0.8
HIV positive friends	26.8	30.0	43.8
Other friends	1.2	1.2	9.7
Partner/lover	11.7	16.1	23.9
Family	4.2	5.3	11.3
Articles in gay press	36.4	34.0	37.6
HIV magazine/newspaper	44.8	43.7	45.3
Hep C Support Group/Organisation	1.4	0.3	0.6
Liver specialist	6.5	3.6	1.2
Internet	21.7	18.6	17.8
Publications from HIV/AIDS groups	43.5	41.9	44.6
Publications from other sources	9.9	9.2	10.6

(Multiple responses possible)

Information about Treatments

HIV GPs/S100 prescribers were considered an important source of information on treatments by almost two-thirds (64.6%) of respondents. HIV specialists were nominated by around half (48.6%) of the sample. Importantly information from the community sector figured significantly in the responses to this item. These included HIV magazines and newspapers (44.8%), HIV/AIDS organisation publications (43.5%), and articles in the gay press (36.4%). HIV positive friends were nominated by over a quarter (26.8%) of respondents.

When asked in a separate question to nominate which organisation is the most important source of information about treatments, 37.1% of respondents nominated their HIV GP, 24.5% an HIV specialist at an outpatient clinic, 11.1% another GP and 5.6% an HIV/AIDS organisation or staff at an HIV/AIDS organisation. 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 of the sample (60.3%) and community sector sources also figuring prominently (HIV magazine/newspaper: 43.7%, HIV organisation publications: 41.9%, gay press: 34.0%). HIV positive friends were also mentioned by 30.0% of the sample.

When asked to nominate the most important source of information on HIV management 30.7% said their HIV GP, while 20.6% nominated an HIV specialist at an outpatient clinic, 11.9% another GP and 8.2% an HIV/AIDS organisation or staff at an HIV/AIDS organisation.

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 were HIV magazine/ newspaper (45.3%), followed by publications from HIV/AIDS groups (44.6%) and HIV positive friends (43.8%). Clinical sources were also considered important by significant numbers of positive people (HIV GP: 38.6%, HIV specialist: 24.2%).

When asked to identify the most important source of information on living with HIV 15.4% nominated an HIV/AIDS organisation or HIV/AIDS organisation staff, 13.9% nominated their HIV GP, 11.2% HIV positive friends, 9.2% an HIV specialist at an outpatient clinic, 6.1% HIV/AIDS publications and 5.7% HIV magazine/newspaper.

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

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

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
<i>Full sample</i>					
Information on the internet about living with HIV is unreliable	3.7	23.8	12.5	3.1	56.9
Information on the internet about treatment side effects is unreliable	3.3	25.4	10.8	3.1	57.4
<i>Those who rate the internet as an important source of information</i>					
Information on the internet about living with HIV is unreliable	8.9	52.7	10.2	2.0	26.2
Information on the internet about treatment side effects is unreliable	8.8	53.5	10.0	2.4	25.3

Lack of information

When asked to identify domains in which lack of information made it difficult to make decisions, over one-third of respondents nominated the management of side effects (38.3%) and interactions between ARVs and other drugs (34.7%). Employment and financial planning also figured prominently, with around one third of respondents identifying lack of information about work/employment (33.3%), and financial planning (32.4%). Importantly, information about treatment breaks was identified by 28.5% of respondents and changing antiretroviral treatment by 25.9%.

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

Managing ARV side effects	38.2
Interaction between ARV and other drugs	34.7
Work/employment	33.3
Financial planning	32.4
Using complementary therapies	28.7
Taking a break from ARV	28.5
Changing ARV	25.9
Legal issues	25.3
Recreational drug use	22.3
Using ARV	21.3
Having children	8.7

(Multiple responses possible)

Publications

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 53, including breakdowns for specific populations where access or focus is an issue. Gay and HIV press were accessed by large proportions of the sample, as were HIV community publications (particularly within their constituency area). It is clear from these data and those in the previous section that community publications remain an important site for information dissemination and community debate.

TABLE 53 Publications read by PLWHA

PUBLICATION	Percent of sample
<i>National or non-specific</i>	
HIV Australia	29.8
Positive Living	54.5
Newsletters from community organisations	24.4
National Haemophilia	1.3
Overseas magazines (eg POZ)	5.6
Gay newspapers (% of total sample)	67.6
Gay newspapers (% of gay men, lesbians and bisexuals)	77.0
Gay magazines (% of total sample)	28.7
Gay magazines (% of gay men, lesbians and bisexuals)	32.7
<i>State based publications</i>	
Talkabout (% of total sample)	43.4
Talkabout (% of NSW respondents)	65.1
With Complements (% of total sample)	15.6
With Complements (% of NSW respondents)	21.5
NUAA News (% of total sample)	5.5
NUAA News (% of NSW respondents)	7.5
Positive life (% of total sample)	8.8
Positive life (% of WA respondents)	43.1
QPP Alive (% of total sample)	10.8
QPP Alive (% of QLD respondents)	54.7

(Multiple responses possible)

Involvement with AIDS Organisations

Participants were asked about their involvement with HIV/AIDS organisations. 71.5% of the sample had some contact with HIV/AIDS organisations. Of these, 67.2% received newsletters and mail outs, 67.7% were clients, 48.9% were members, 20.0% were volunteers and 13.3% were employees. Of those that had no contact with AIDS organisations, 57.8% gave the reason *I do not want to be involved*, 28.1% gave the reason *I do not have enough time*, and 12.2% said that they had no transport or are too far away. Importantly, 18.8% of those who were not involved in AIDS organisations said they felt excluded from them. 26.6% had at some point held a decision making position in an AIDS organisation (12.3% in the last two years).

THE SOCIAL WORLD OF PLWHA

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

Contact with Other PLWHA

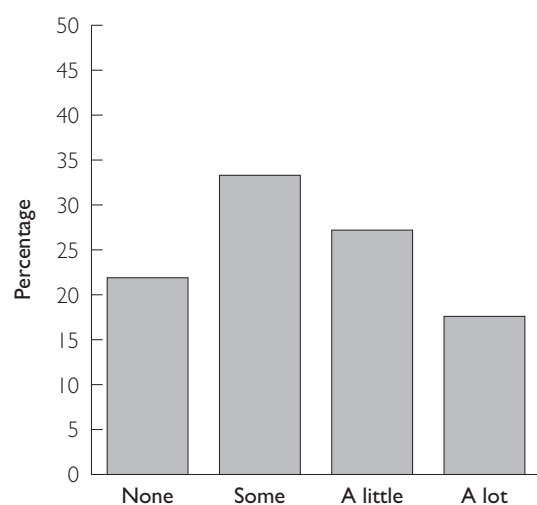
Very few HIV positive people (6.2%) did not personally know anyone else with HIV. Gay men were significantly less likely to know no-one else with HIV than other respondents. Most positive people had an HIV positive friend (75.0%) and many had either an HIV positive partner or ex-partner (39.0% combined). 22.9% of respondents had been involved in the nursing or care of another positive person at some time in the last two years, and 80.8% have had someone close to them die from HIV/AIDS.

TABLE 54 Other HIV positive persons known by respondent

Positive Persons	Percentage
Friend	75.0
Acquaintance/Member of support group	62.3
Former partner/spouse	27.9
Partner/spouse	18.2
No-one	6.2
Other relative	3.8
Son/daughter	0.5

(Multiple responses possible)

Around four-fifths of the respondents spent at least some time with other positive people (78.1%). The 17.6% who indicated that they spend a lot of time with other PLWHA were more likely to be those who work or volunteer for an HIV/AIDS organisation.

FIGURE 10 Time spent with other positive people

Disclosure

Respondents were asked who they had disclosed their HIV status to (see Table 55). Not surprisingly, most (86.5%) had disclosed to close friends, and most (94.2%) of those in relationships had disclosed to their partner. Within families, people were most likely to have disclosed to siblings (69.0%) although many had disclosed to parents (58.3%). Only 1.5% (N=16) had not disclosed their HIV status to anyone.

TABLE 55 People the respondent has disclosed their HIV status to

	Percent who have disclosed
Close friends	86.5
Siblings	69.0
Positive friends	67.3
Parents	58.3
Partner/spouse	54.8
Other friends	39.9
Work colleagues	35.3
Neighbours	18.4
Son/daughter	10.0
People from own ethnic community	4.3
No-one	1.5
Specific populations	
Partners (% of those in a regular relationship)	94.2
Partners (% of those not in regular relationship)	22.6
Work colleagues (% of those currently employed)	44.5
Work colleagues (% of those not employed)	27.1
Son/daughter (% of those with dependent children)	58.4
People from own ethnic community (% of those not born in Australia n=221)	6.3

(Multiple responses possible)

Unwanted Disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. 55% said that it had at some point, and 29.8% said that this had happened in the last two years. When asked who disclosed their status, they were most likely to nominate friends. (see Table 56). In part these data reflect those that are most likely to be aware of the respondent's HIV status. It is of concern that 18.0% nominated a worker in a health care setting.

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

	Percent
Other friends	27.4
Close friends	26.5
Workers in a health care setting	18.0
Work colleagues	16.3
Brother/Sister	14.0
Partner/Spouse	13.3
HIV positive friends	10.9
Other	10.1
Staff/volunteers at community organisation	7.8
Parents	7.8
Other family member	7.0
Neighbour	7.0
Son/daughter	1.4
People from ethnic community	1.2

(Multiple responses possible)

The Place of HIV in People's Lives

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

To explore this issue, we asked *When you think of all the things that make you who you are, how important are each of the following aspects of yourself?* The categories and results are given in Table 57. A rating of essential indicates that the characteristic is an essential component of the individual's identity. A rating of important indicates that the characteristic plays a large part in how PLWHA see themselves, but may have greater or lesser relevance depending on the context. A rating of not important indicates that the characteristic only has very context specific relevance and does not generally enter into their self-image. A rating of irrelevant indicates that the characteristic plays no part in their self-image. While our primary focus in this area was on the importance of HIV identity, we have included other characteristics, both as points of comparison and as a way of more fully describing PLWHA. The characteristics examined were sexuality, gender, recreational drug use, ethnicity, parenthood and career. The majority (52.7%) of positive people in this study considered their HIV status an important, but not essential aspect of their make-up, while 16.9% considered it to be an essential characteristic. This is in contrast to sexuality and gender, where around 30% of the sample considered each of these to be essential characteristics.

TABLE 57 Importance of personal characteristics to respondents' sense of identity (percent of sample)

	Essential	Important	Not Important	Irrelevant
Sexuality	30.5	46.6	14.8	8.1
Family	29.2	45.7	15.0	10.1
Gender	28.5	42.6	17.1	11.8
HIV status	16.9	52.7	20.6	9.9
Career	13.5	41.6	21.3	23.7
Religious beliefs	9.6	24.3	22.5	43.5
Parenthood	7.8	14.0	16.9	61.3
Ethnicity/Cultural background	6.2	21.5	31.6	40.6
Drug use (recreational/illegal)	4.0	16.2	31.7	48.1

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

TABLE 58 Importance of HIV status to sense of identity for different groups of PLWHA (percent)

<i>Importance of HIV status among:</i>	Essential	Important	Not important	Irrelevant
Gay and bisexual men	18.0	52.0	21.3	8.7
Women	11.8	60.5	15.8	11.8
Heterosexual men	13.0	58.0	14.5	14.5
Those who have had an AIDS defining illness	16.7	54.3	17.8	11.2
Those who have not had an AIDS defining illness	17.0	52.3	21.4	9.4
Those on antiretroviral therapy	17.5	54.1	18.8	9.6
Those not on antiretroviral therapy	14.8	49.7	24.8	10.7
Those in seroconcordant relationships	15.5	49.1	22.4	13.0
Those in serodiscordant relationships	13.1	54.2	21.1	10.8

Social Support

We asked participants about the amount of social support they received from a range of sources including household members, social contacts and service providers. The ratings are shown in Table 59 below with those for whom the category was not applicable excluded from each row. Participants were most likely to have nominated their partner or spouse as providing *a lot* of support (80.8% of those with partners), followed by their pets (62.6% of pet owners). Around half of participants also received *a lot* of support from their doctors (51.5%) and close friends (48.8%). When we examine the sources that people rated as providing no support, the highest ranking category was volunteer carer, where 42.2% of those with a carer said they received no support from them. Religious or spiritual advisors were also considered a source of no support for 41.1% of those with such a source.

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

The data from this item can also be used to identify the number of sources from which respondents receive various amounts of support. For example, by taking the number of sources respondents identified as providing *a lot* of support, we have a measure ranging from 0 to 15. [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]. On average, respondents received *a lot* of support from 3.4 sources, with 57.8% receiving support from 3 or more out of the 15 sources listed. 12.1% of respondents did not receive *a lot* of support from any of these sources.

On average, respondents received *a lot* or *some* support from 5.9 sources, (53.3% from 6 or more sources, and 1.7% from none of the 15 sources) and *no* support from 1.4 out of 15 possible sources of support.

TABLE 59 Social support received from different sources: percent who gave valid responses for each category

	A lot	Some	A little	None
Partner/spouse	80.8	10.1	5.2	3.9
Pets	62.6	19.8	10.4	7.2
Doctor	51.5	30.6	15.5	2.4
Close friends	48.8	30.5	14.7	5.9
Parents	40.3	22.6	14.6	22.4
HIV positive friends	36.3	34.1	21.7	7.9
Children	36.2	18.5	14.4	30.9
Brothers and Sisters	31.4	24.6	20.6	23.4
Family	29.6	24.3	22.3	23.8
Counsellor	26.8	28.0	23.9	21.3
Health care workers	24.4	30.0	26.3	19.2
Volunteer carer	23.2	22.1	12.5	42.2
Religious or spiritual advisor	22.5	21.3	15.1	41.1
PLWHA groups	20.7	27.8	28.4	22.9
Other friends	13.4	37.6	30.8	18.2

Mental Health

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

Psychiatric Medications

In the six months prior to completing the survey, 33.2% of PLWHA had been taking medication prescribed for depression. This is considerably higher than the 4.7% of the Australian population as described by the National Health Survey (ABS, 2001). A similar proportion (30.8%) had taken medication for anxiety (1.9% in the ABS study), and 19.4% reported taking medications for both depression and anxiety. In addition 7.1% of the sample indicated that they had taken anti-psychotic medication.

Diagnosis of a Mental Health Condition

We asked respondents if they had been diagnosed with a mental health condition and 34.5% reported that they had had such a diagnosis. 73 respondents (7% of total sample, 25% of those with a diagnosis) had this diagnosis in the previous two years. The majority of conditions diagnosed were depression (26.5% of all respondents) and anxiety (3.8%).

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 60, a considerable proportion of PLWHA agreed or strongly agreed with each of the items. The strongest level of agreement was with item 2 (not enjoying life as much), followed by 3 (losing interest in others). Over one fifth of the respondents (22.3%) agreed or strongly agreed with item 1 (crying all the time), and 14.6% 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, 39.0% agreed or strongly agreed with none of these items, 24.5% with one item, 19.0% with two items, 9.6% 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 antidepressant 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.

TABLE 60 BDI depression symptomology items: percentage of total sample

	Strongly agree	Agree	Disagree	Strongly disagree
I cry or feel like crying all the time	4.9	17.4	50.6	27.2
I don't enjoy things the way I used to	14.5	38.4	32.8	14.3
I have lost interest in other people	7.6	26.7	44.8	20.8
I don't feel it's worth going on	4.3	10.8	35.5	49.3

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*. Just under half agreed or strongly agreed with this statement.

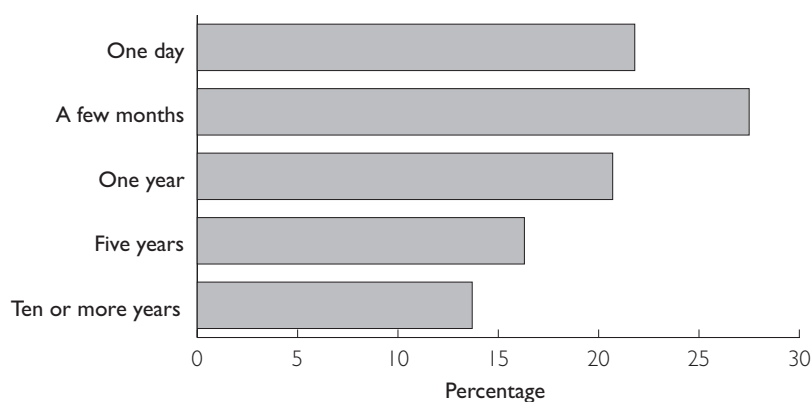
TABLE 61 Attitudes to HIV status: percentage of total sample

	Strongly agree	Agree	Disagree	Strongly disagree
As long as I am well I prefer not to think about HIV/AIDS	14.9	36.5	39.3	9.2
Life has become more meaningful since I became HIV positive	14.2	29.8	39.5	16.4

Planning for the Future

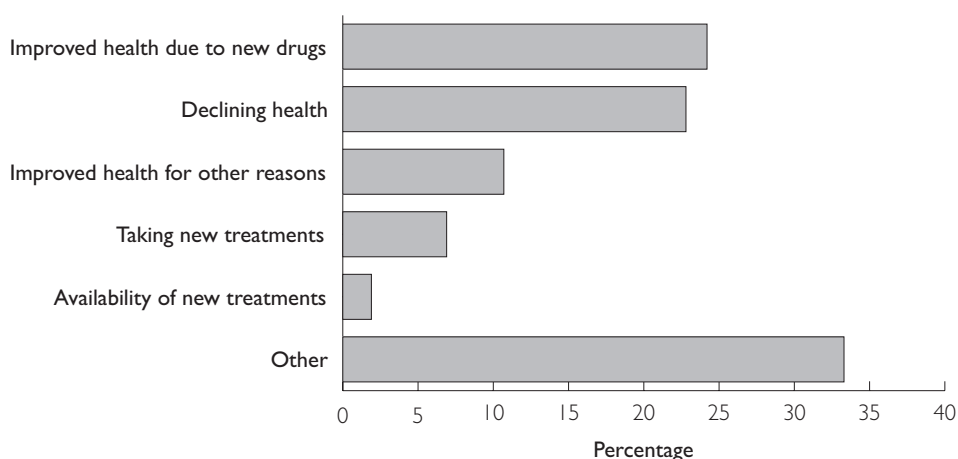
A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. More than one fifth (21.8%) planned their life one day at a time and 27.5% planned only a few months ahead. Approximately half of the respondents planned for at least a year with 20.7% planning one year ahead, 16.3% planning five years ahead and 13.7% planning ten years or more ahead. This profile of the population has changed very little since the first HIV Futures survey. Those with longer time frames tend to be those who have been HIV positive for a shorter period, have lower viral load, higher CD4 counts, and have not had an AIDS defining illness.

FIGURE 11 Time frame for future planning



30.5% of respondents reported a change in their time frame for future planning in the last two years, with 41.1% of those who reported a change now using a shorter time frame and 54.5% using a longer time frame. The major reasons for change for those planning further ahead into the future over a longer time frame were improved health due to treatments (39.4% of those with longer plans), improved health for other reasons (17.5%) and taking new treatments (8.0%). The major reason for change for those with a shorter time frame was declining health (51.9% of those with a shorter time frame), see Figure 12.

FIGURE 12 Reasons given for change in time-frame



RELATIONSHIPS AND SEX

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

Relationships

Respondents were asked about current sexual relationships. The results are presented in Table 62 below. Over one quarter of the sample said that they had no sex at present. A similar though smaller proportion reported that they had a regular relationship only, while slightly more said that they had casual sex only, and slightly fewer that they had a regular relationship plus casual sex. When this item is broken down by sex and sexuality, we find significantly different patterns between three groups of PLWHA. Heterosexual men were more likely than other PLWHA to report that they had no sex at present. Women were more likely to report that they had one regular sexual partner and no casual sex. Gay and bisexual men are more likely to report that they had a regular sexual partner and also had casual sex.

TABLE 62 Type of sexual relationship(s) by gender and sexuality of respondent (percentage)

	Gay or Bisexual Men	Heterosexual men	Women	Total
I have no sex at present	24.3	52.1	35.1	27.3
I have casual sex only	35.2	9.9	1.3	30.6
I have a regular relationship with one person, and I have sex with other people	21.5	5.6	5.2	19.0
I have a regular relationship with one person, and I do not have sex with other people	17.4	32.4	58.4	21.8
I have a regular relationship with two or more people	1.6	0.0	0.0	1.4

When asked if they were currently in a regular relationship, around half (45.6 %) said they were. This is slightly higher than the proportion of the sample that report having sex with a regular partner in Table 62 above (42.4%), as some in a regular relationship did not have sex.

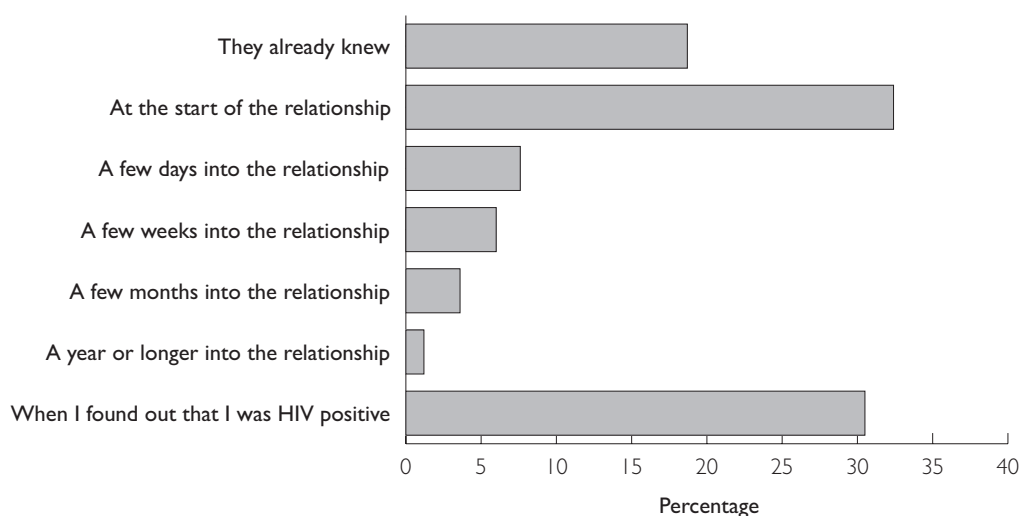
Regular Partners

Of those in a relationship with a regular partner, 38.4% reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in serononconcordant relationships. This remain-

ing group is made up of 59.0% of the sample that report that their partner is HIV negative (a sero-discordant relationship) and 2.6% who report that they don't know their partner's HIV status. Nearly all PLWHA (96.8%) had told their regular partner that they were HIV positive. Of the 14 respondents who had not disclosed their status, 2 had an HIV positive partner, 8 had an HIV negative partner, and 4 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 13 below. Around one third (32.4%) had told their partner at the beginning of the relationship. Slightly fewer than a third (30.5%) of respondents had told their partner when they themselves found out they were positive and for 18.7% of respondents, the partner knew prior to the start of the relationship. Small numbers of respondents (7.6%) had told their partners a few days into the relationship, 6.0% a few weeks into the relationship, 3.6% a few months into the relationship and 1.2% a year or more into the relationship.

FIGURE 13 Time HIV status disclosed to partner among those in regular relationships



When asked how their partner responded when told of the respondent's HIV status, the majority (57.1%) reported that the partner was supportive (see Table 63). Over half (55.0%) reported that it did not make any difference. Over one third (33.5%) reported that the disclosure brought them closer together. Around one quarter (27.6%) reported that their partner was worried or scared and 7.8% 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 (73.5% of those in sero nonconcordant versus 54.8% in sero-concordant).

TABLE 63 Reaction of partner and respondent to disclosure: percentage of those in regular relationships

They were supportive	57.1
It did not make any difference	55.0
We became closer	33.5
They were worried / scared	27.6
They were angry	7.8

(Multiple responses possible)

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

We have reported the data in the following tables on sexual practice and condom use in numbers rather than percentages, as the small sub-samples would give an inflated view of the proportions in some categories. PLWHA in regular relationships were asked about the sex they had with their regular partner. Overall, 39.3% had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 4.0% had anal or vaginal sex with a regular female partner in the previous six months. For male and female partners combined, 35.2% of respondents reported that they never used condoms and around 37.8% reported that they always used condoms (see Table 64). In total, 37.9% had either anal or vaginal sex with a regular male or female partner in the last six months.

TABLE 64 Condom use with regular partner by respondent and partner gender. Number of these that used condom (N=435)

	Never	Sometimes	Usually	Always
<i>Female respondents N=44</i>				
With regular male partner	11	7	9	17
<i>Male respondents N=391</i>				
With regular male partner	130	43	54	132
With regular female partner	4	3	4	21

If we look at these data in terms of relationship sero-concordance, considerable clarity is given to the patterns of condom use. Unprotected vaginal or anal intercourse is more likely to have occurred in sero-concordant relationships than in sero-nonconcordant relationships (see Table 65).

TABLE 65 Condom use with regular partner by respondents' gender, partner gender, and partner sero-status. Number of these that used condom

	Never	Sometimes	Usually	Always
SERO-CONCORDANT Relationships N=132				
<i>Female respondents N=12</i>				
With regular male partner	4	2	3	3
<i>Male respondents N=120</i>				
With regular male partner	79	12	11	18
SERO-NONCONCORDANT Relationships N=170				
<i>Female respondents N=24</i>				
With regular male partner	4	5	5	10
<i>Male respondents N=146</i>				
With regular male partner	15	12	19	75
With regular female partner	1	2	3	19

Casual Partners

Over half (58.0%) of the sample reported that in the six months prior to completing the survey they had had sex with one or more casual partners. When asked the HIV status of their casual partners, 7.0% reported that all of their casual partners were HIV positive, 31.3% reported that some of their casual partners were HIV positive, and 8.6% reported that none of their casual partners were HIV positive. Most (53.2%) respondents who had had casual sex reported that they did not know the HIV status of their casual partners. Respondents were asked about their condom use during anal or vaginal intercourse with casual partners over the previous six months. As can be seen from Table 66 there are considerable variations in condom use when we examine this by sex of respondent and sex of partner.

TABLE 66 Condom use with casual partner by respondent and partner gender. Number of these that used condom (N=494)

	Never	Sometimes	Usually	Always
<i>Female respondents N=9</i>				
With casual male partners	1	1	1	6
<i>Male respondents N=485</i>				
With casual male partners	43	150	101	170
With casual female partners	2	4	2	13

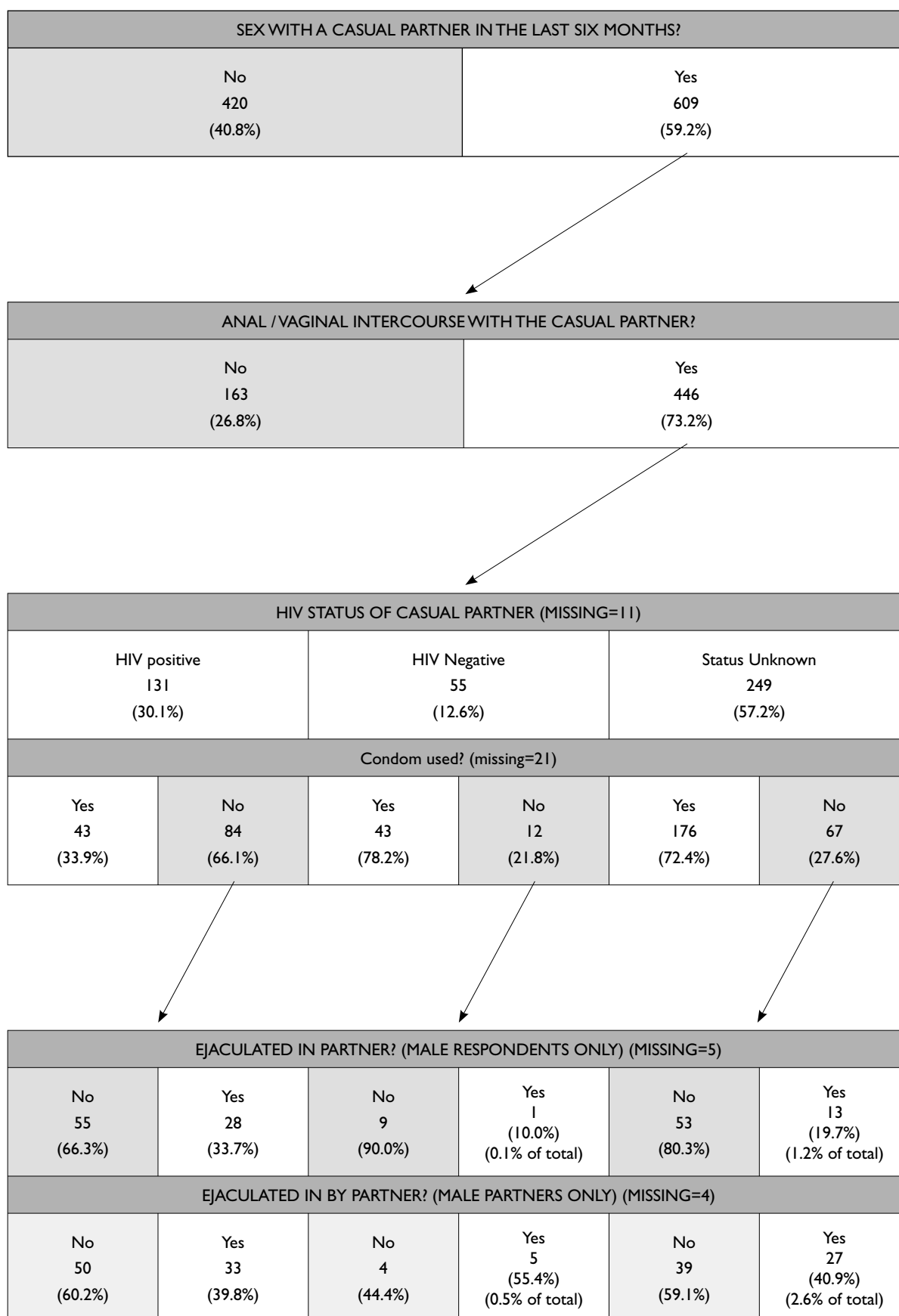
Again, when we look at these data in terms of the partners' HIV status, a clearer pattern emerges (see Table xx). There is a significant relationship between condom use and partners' HIV status: consistent unprotected anal and vaginal intercourse occurs primarily with HIV positive partners, whereas with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

TABLE 67 Condom use with male casual partner by partners' sero-status.
Number of these that used condom (N=468)

<i>Casual partners' HIV Status</i>	Never	Sometimes	Usually	Always
All HIV positive	19	8	2	4
Mixture / unsure	23	140	98	153
All HIV negative	1	2	0	18

In addition to reporting on their overall patterns of condom use, respondents who had had casual sex reported on their most recent sexual encounter with a casual partner. Over half the survey (57.2%) respondents provided such information. Of the respondents who had casual sex, 73.3% 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 14 gives a breakdown of the range of protective strategies employed by positive people to protect their most recent casual partner. This includes knowledge of HIV status, condom use and avoidance of ejaculation within their partner. This schematic shows that for the entire set of data available, incidents that involved any risk were very rare and mostly associated with partners of unknown status.

FIGURE 14 Sexual practice with the most recent casual partner



Respondents who indicated that they knew their partners' HIV status were asked how they knew. Nearly all (90.8%) of these respondents said that their partner had told them their status, 20 respondents said that they knew their partner's status from the type of sex they wanted, 13 said that they could tell from their respondents physical appearance, 2 said that a third party had told them, 5 said that they could tell by the bar/venue at which they met and 9 said they could tell by the people they were with.

32.7% of respondents said they told their most recent casual partner that they were HIV positive, 55.7% did not, 8.9% said the partner already knew they were HIV positive and 2.7% could not recall.

HIV, Sex, Relationships and Treatments

PLWHA were asked to respond to a number of statements about relationships, sex and HIV. The results of these items are shown in full in Table 68.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, around half (49.6%) said they would, just over a third (35.1%) said they would not, and the remainder (15.4%) said that they did not know. Not surprisingly, among those with regular partners this varied by the sero-status of their partner; 75.8% of those with a regular HIV positive partner agreed with the statement, while only 18.8% of those with a negative partner did so. In addition, 39.9% of those without a regular partner agreed with the statement.

The potential to develop new relationships remains an important issue for PLWHA. While much has been done to reduce stigma and discrimination in formal settings such as workplaces and healthcare settings, the more intimate domains of sex and relationships can still be a site of anxiety and uncertainty for both HIV positive and negative people. Over three fifths (61.2%) of the 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 (68.7% versus 41.9% of those in regular relationships, $\chi^2_{(4,1)} = 40.671$, $p < 0.001$). A similar response was found to the statement *I am afraid of telling potential partners of my HIV status in case they reject me*. Over half the respondents (54.3%) agreed with this statement. Agreement was significantly higher among those not in regular relationships (60.7%), and among those who have no sex at present (59.0%). When asked to respond to the statement *Being HIV positive has helped me form more satisfying relationships*, around one quarter (25.6%) agreed, while 11.4% 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 (69.3%) agreed with the statement *I am afraid of infecting my partner, or potential partner, with HIV*, while very few agreed with the statements *I feel more confident about unprotected sex because of the new treatments*, and *Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV* and *Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom*. Greater concern on these items was expressed by those with HIV negative regular partners, those having only casual partners and those not currently having sex.

Similarly, the impact of potential vaccines on intentions to practice safe sex and anxiety about safe sex is minimal with 27.8% agreeing with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*, and 11.7% agreeing with the statement *Knowing that a vaccine will become available makes me less anxious about sex*.

The response to concerns about re-infection remains mixed, with 52.7% agreeing that *I am concerned about becoming infected with another strain of HIV* and 39.4% disagreeing. The concern reported here is greater than was seen in the previous survey, perhaps reflecting the increased community discussion of this issue.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (64.4%) agreed with the statement *HIV has had a negative effect on my sexual pleasure*. One third (31.9%) disagreed with this statement. Agreement with the statement was more pronounced (75.0%) among those who were currently not having sex. There was no difference by partner sero-status.

When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. 17.2% 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 (48.9%) than disagreed with it (33.9%). Those with HIV positive regular partners were more likely to agree (65.9%) than those with HIV negative partners (30.3%) ($\chi^2_{(8,1)} = 56.861$, $p < 0.001$). Those who reported that all or most of their casual partners were HIV positive were also more likely to agree with this statement ($\chi^2_{(12,1)} = 61.559$, $p < 0.001$). Those who

agreed with this statement were also more likely to agree that they would prefer a relationship with someone who was HIV positive.

Over one quarter (29.5%) said that they agreed with the statement *I have stopped having sex because of my HIV status*. Not surprisingly agreement with this statement was more pronounced among those currently not having sex (69.2%).

Similarly, 60.2% of participants agreed that *HIV has negatively affected my libido*. Again this was most pronounced among those not currently having sex (72.6% agreement), but did not differ by regular partner sero-status.

TABLE 68 Attitudes to HIV, sex and relationships (percent)

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I prefer to have a relationship with someone who also has HIV	10.0	25.1	30.4	19.2	15.4
Few people would want a relationship with someone who has HIV	5.4	25.5	42.4	18.8	7.9
I am afraid of telling potential partners of my HIV status in case they reject me	11.7	27.5	36.9	17.4	6.5
Being HIV positive has helped me form more satisfying relationships	23.1	39.9	18.6	7.0	11.4
I am afraid of infecting my partner, or potential partner, with HIV	7.2	20.1	41.4	27.9	3.5
I feel more confident about unprotected sex because of the new treatments	48.4	33.4	8.6	4.5	5.1
Medical treatments for HIV/AIDS make safe sex less important than it was	53.1	33.1	6.2	1.6	6.1
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	34.4	31.9	23.8	5.3	4.5
If there was a vaccine which prevents HIV I would not practice safe sex	22.7	33.7	19.9	7.9	15.9
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	48.2	32.9	8.4	1.7	8.7
Knowing a vaccine will become available makes me less anxious about sex	21.8	48.2	9.0	2.7	18.3
I am concerned about becoming infected with another strain of HIV	8.9	30.5	37.2	15.5	7.9
HIV has had a negative effect on my sexual pleasure	9.6	22.3	37.9	26.5	3.8
If I know that my partner is HIV positive I find sex more pleasurable	11.6	22.3	31.4	17.5	17.2
I stopped having sex because of my HIV status	27.0	40.5	18.7	10.8	2.9
HIV has negatively affected my libido	12.2	22.4	35.6	24.6	5.2

Children

As mentioned in the description of the sample earlier in this report, 16.6% of those surveyed currently have children and 7.3% have dependent children and 5.8% have dependent children living with them. We were also interested in future plans for children among PLWHA. Most PLWHA (88.0%) were not currently considering having children. Of the remainder, 15 PLWHA had decided to have children in the future and 6 were attempting to have children. 23 were considering having a child, but have not decided, and 18 people have considered having a child, but have decided it is too risky. 2 respondents were currently pregnant. Importantly, 24 respondents said they did not have enough information to make a decision. While a greater proportion of women (heterosexual, bisexual and lesbian) were considering, or had considered having children, some of those doing so are gay, bisexual or heterosexual men.

TABLE 69 Planning to have children (number)

	Gay or Bisexual Men	Heterosexual men	Women	Total ⁵
No	747	56	40	869
I have decided to have a child / children in the future	8	2	4	15
I am currently trying to conceive / get pregnant	0	1	4	6
I am currently pregnant	–	–	2	2
I have thought about it but I haven't decided	11	0	11	23
I have thought about it but I have decided that it is too risky	14	3	1	18
I was told not to by a doctor/ medical professional	1	0	0	1
I don't have enough information to make a decision	14	6	3	24
Other	12	3	12	31

RECREATIONAL DRUG USE

Practices

Respondents were asked about their use of a range of non-prescription drugs, both those legally available and those that are currently prohibited in Australia. Respondents were asked which of a list of substances they had used in the last twelve months. For those drugs which are commonly injected, differentiation was made between injection and other means of administration. Table 70 gives these results. As can be seen from these data, alcohol was the most commonly used drug followed by tobacco. Other drugs that are popular in the gay and dance party scenes (amyl, ecstasy, non-injected speed and LSD) were also used by PLWHA.

TABLE 70 Recreational use of drugs: percentage of sample

Alcohol	76.3
Cigarettes	48.3
Marijuana	47.6
Amyl	29.4
Ecstasy	23.0
Viagra or similar	17.1
Speed (not injected)	14.0
Crystal Meth	12.4
Speed (injected)	11.8
Cocaine (not injected)	4.9
LSD / trips	4.3
Steroids (injected)	4.2
GHB/GBH/Fantasy	3.2
Methadone (prescribed)	2.3
Heroin (injected)	1.8
Homebake	1.7
Cocaine (injected)	1.0
Methadone (other)	0.8
Heroin (not injected)	0.5
Other	2.7

(Multiple responses possible)

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

It must be noted that we only asked respondents if they had used each of the drugs in the previous twelve months, not how often they use them. Use of many drugs is occasional rather than regular and this may inflate the rates reported here. Gay male respondents were significantly more likely than other groups to have used alcohol, ecstasy, amyl and crystal-meth and less likely to have used heroin (injected) and prescribed methadone. 8.0% of PLWHA reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs. Around one quarter (24.5 %) reported that they had missed a dose of antiretroviral medication at some point as a result of using illegal drugs. While use of most drugs was related to reporting having ever missed a dose of ARV due to recreational drug use, none of these drugs were related to having missed doses of antiretroviral medications in the 2 days prior to survey (see table 71 below).

TABLE 71 Recreational use of drugs and missed doses of ARVs in last 2 days

	Percentage that do not use missing a dose of ARV	Percentage that use missing a dose of ARV	Significance
Alcohol	26.2	36.0	.032
Cigarettes	35.7	37.8	.343
Marijuana	37.7	35.8	.364
Speed (injected)	36.7	39.0	.415
Speed (not injected)	36.9	37.2	.528
Heroin (injected)	37.2	12.5	.142
Heroin (not injected)	37.0	20.0	.393
Cocaine (injected)	36.6	50.0	.389
Cocaine (not injected)	36.9	35.7	.538
Ecstasy	35.5	41.1	.152
LSD / trips	36.7	40.7	.408
Amyl	38.0	34.9	.275
Homebake	36.9	36.4	.620
Methadone (prescribed)	36.9	29.4	.362
Methadone (other)	36.7	60.0	.265
Steroids (injected)	36.9	37.5	.542
GHB/GBH/Fantasy	37.1	31.3	.425
Viagra or similar	36.3	38.5	.386
Crystal Meth	37.0	35.0	.438

Over two thirds (68.5 %) of respondents reported that they had never injected illegal drugs. Of those respondents who had injected illegal drugs almost one half (47.1%) had done so in the last 12 months. Of PLWHA who reported injecting drugs, 98.0% had not shared injecting equipment in the past twelve months. Of the 19 respondents that had shared injection equipment in the last 12 months, 14 had done so with at least one risk reduction strategy (using the needle last, washing/bleaching and/or using with another person who was HIV positive). The circumstances surrounding sharing injection equipment are shown in Table 72 below.

TABLE 72 Circumstance surrounding sharing among those who have shared injecting equipment in the last 12 months

	Number	percentage
The person was my sexual partner	9	47.3
The needle was bleached and/or washed	10	52.6
We did not have access to other needles	11	57.9
It was in a group	1	5.3
The person was HIV positive	4	21.1
The person was Hep C positive	1	5.3
I used the equipment last	7	36.8

(Multiple responses possible)

Attitudes Relating to Drug Use

Around one in five (19.8%) of respondents felt that they drank more alcohol than they would like to and 14.9% felt they had used more illegal drugs than they would like to.

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

TABLE 73 Attitudes relating to drug use and infection (percentage of full sample and number of those who shared injecting equipment)

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Total sample					
Sharing needles is not a problem if your viral load is undetectable	55.1	7.4	.8	1.8	34.9
I worry about infecting others by sharing needles	6.5	2.0	3.8	10.9	76.8
Those who have shared					
Sharing needles is not a problem if your viral load is undetectable	8	10	1	0	0
I worry about infecting others by sharing needles	2	2	5	4	7

HOME, WORK & MONEY

Accommodation

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

Current Accommodation

The current type of accommodation of the respondents can be seen in Table 74. Similar numbers of PLWHA were in accommodation that they own or rent through the private system. A smaller number of people were in public rental accommodation. These were more likely to be those on a government benefit.

TABLE 74 Current accommodation of respondents (percentage of total sample)

Own or purchasing house or flat	32.8
Private rental accommodation	35.9
Public rental accommodation(government owned)	18.4
Rent-free (e.g. provided by friends, family, etc.)	5.5
Community housing/housing co-operative	3.1
Other	4.2

Households varied considerably. 40.7% of PLWHA lived by themselves, while the remainder lived with between 1 and 7 other adults (for those living with other adults: mean=1.3, median=1) and with between 1 and 5 children (for those living with children: mean=1.7, median=2). Around one third (32.7) lived with a partner or spouse, and 5.9% lived with dependent children. These children ranged in age from 1 to 23 (mean=11.2, median=11).

Most lived in a residence with 2 bedrooms (46.4%), while the remainder had 3 bedrooms (26.1%), 1 bedroom (17.5%), 4 or more bedrooms (8.5%) or lived in a bedsit /studio (1.5%).

49.5% of PLWHA also lived with pets. The most common pets were dogs (31.0% of all respondents), and cats (21.5%). Other companion animals included fish, birds, rabbits and farm animals.

67.9% of respondents had access to a car. When asked how easy it was to access public transportation, 10.8% said it was very difficult, 12.8%, difficult, 38.9% easy and 37.4% very easy.

77.3% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (N=232), the main reasons given were that it was too expensive (32.8%), was too small (32.3%) and lacked privacy (32.0%).

TABLE 75 Reasons current accommodation is unsuitable (percentage of those with unsuitable accommodation)

Too expensive	32.8
Too small	32.3
Lack of privacy	32.0
Inadequate for my current state of health	23.2
Poor condition of housing	21.3
Harassment	19.1
Too far from health services	18.4
Confidentiality problems	17.6
Too far from other services	16.4
Inadequate facilities for carer(s)	7.7
Fear of violence	2.4
Other	11.4

(Multiple responses possible)

Changes in Accommodation

Participants were asked if they had ever changed their accommodation as a result of having HIV/AIDS. 40.3% had, and 11.1% had in the last two years. On average PLWHA had changed their accommodation 2.4 times ever as a result of HIV/AIDS (1.6 times in the last two years).

We asked what the circumstances were around participants' last change in accommodation. The results are shown in Table 76. 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 closer to health services (30.7%) followed by moving to a quieter location (36.5%), because of illness (26.8%) and moving to cheaper housing (29.2%). When asked if they had any other accommodation options for the future, 62.8% said they did not.

TABLE 76 Reasons for changing accommodation (percent)

Moved to a quieter location	35.6
Needed cheaper housing	35.4
Moved closer to health services	27.6
Better health	22.8
Planning for illness	21.8
Illness	21.7
Stopped working	19.1
To avoid harassment	18.5
Ending of relationship	18.2
Lack of privacy	16.1
Moved closer to other services	15.7
Improved finances	11.2
Moved closer to friends	10.6
Moved in with family	8.1
Beginning of new relationship	7.5
Looking for / returned to work	6.5
Moved out of family home	4.5
Other	14.6

(Multiple responses possible)

EMPLOYMENT

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

Employment Status

Just under half (43.1%) of the respondents were currently employed, with slightly more being in full-time work (25.7%) than those in part-time work (14.4%). The remainder tended to describe themselves as either unemployed (16.7%) or retired (24.0%).

Of those who were working, the mean number of hours worked was 33.0 (median=36.2). Those working full time worked an average of 41.2 hours per week (median=40.0) and those in part time employment worked an

average of 21.9 hours/week (median=21.0). Those who were not working stopped work between 0 and 28 years ago (mean=68.2 months, median=60.0 months).

TABLE 77 Employment status (percentage of sample)

Work full-time	28.7
Not working / Retired	24.0
Unemployed	16.7
Work part-time	16.0
Other	8.6
Student	3.9
Home duties	2.2

Impact of HIV and Treatment on Employment

We asked respondents how their initial HIV diagnosis affected their career plans and how their plans had changed since then. These data are shown in tables 78 and 79 below. A large proportion indicated that their career ended at their time of diagnosis (24.0%).

TABLE 78 Impact of HIV diagnosis on career plans (percentage of sample)

My career plans did not change	25.1
My career ended / I stopped work	24.0
It was more difficult to plan for the future	21.6
A career was no longer as important	18.1
I changed careers	9.3
I was less likely to change careers	1.9

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

TABLE 79 Ongoing impact of HIV on career/work (percentage of sample)

My career ended / I stopped work	25.1
It is more difficult to plan for the future	21.9
My career plans have not changed	19.6
A career is no longer as important	18.3
I changed careers	10.3
I am now less likely to change careers	4.8

We asked about the impact of antiretroviral therapy on respondents' career plans (see Table 80 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 16.5% said that they stopped work when they commenced ARV, while 12.2% said that they anticipated a longer time in the workforce.

TABLE 80 Impact of antiretroviral therapy on work (percentage of those who have used or are using ARVs)

There has been no change to my plans	34.4
I stopped work	16.5
I anticipate a longer time in the workforce	12.2
I went back to work	7.9
I considered going back to work	6.7
I made a new career plan	6.0
I considered a new career plan	4.5
I considered stopping work	3.7
Other	8.0

Interruptions to Employment

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those who have worked, 58.1% had stopped work for reasons related to HIV at some point. Of the entire sample, 28.3% had stopped work on one occasion, 11.6% on two occasions, and 4.2% on three occasions. These work interruptions averaged 40.9 months (median= 24 months). The circumstances relating to the most recent interruption to employment are given in Table 81 below. The most common responses were diminished energy levels and poor health. Over half of the sample reported that psychological health (stress, depression or anxiety) had played an important role in the decision.

TABLE 81 Circumstance surrounding last interruption to employment (percent)

Low energy levels	65.2
Poor health	62.9
Stress, depression, anxiety	56.5
To have more time to myself	23.1
Expecting illness in the future	18.4
To move to a different location	17.3
Redundant / sacked	11.9
To care for another HIV positive person	6.7
Other	11.7

(Multiple responses possible)

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

TABLE 82 HIV/AIDS status at time of last interruption to employment (percent)

I had HIV and had been ill	48.4
I had HIV but had not been ill	34.6
I had been diagnosed with an AIDS-defining illness	16.9

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

TABLE 83 Source of income when not working (percent)

Benefits / pension / social security	75.0
Superannuation / annuity / savings	11.1
Salary	7.4
Partner supported me	2.4
Family / friends supported me	.4
Other	3.7

Of those that stopped working at some point, 46.9% had returned to work. This was most commonly for financial reasons (see Table 84), although better psychological health, better physical health and the need to perform meaningful tasks were also important.

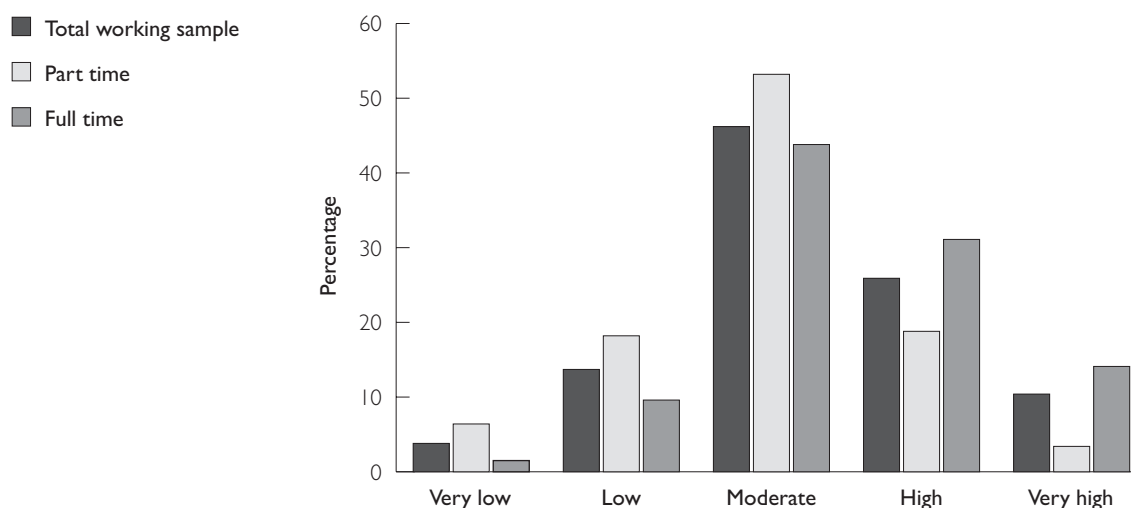
TABLE 84 Reasons for returning to work (percent)

Financial reasons	76.1
To do something worthwhile	52.0
Better psychological health	51.3
To have something to do	45.2
Better physical health	44.8
To have more social contact	41.4
The possibility of working part-time	33.2
The possibility of flexible work hours	24.9
The possibility of working full-time	11.6
Other	6.7

(Multiple responses possible)

Those Currently in Paid Employment

Respondents were asked about the level of stress in their current job. Almost one half rated the stress level as moderate (46.2%) while 25.9% said it was high and 10.4% said it was very high. Only 3.8% rated the stress level as very low and 13.7% said there was low stress (see Figure 15)

FIGURE 15 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, 25.2% said that they did not attempt to keep their status confidential (see Table 85). Over half said they have experienced no problem in this area. Of those who did experience difficulties, the greatest problem appeared to be gossip, followed by issues around explaining absences from work, and medication. When we examine the difficulties associated with confidentiality in terms of whether the respondent works in an HIV related job, we find that those in HIV related employment were less likely to wish to keep their status confidential and had fewer problems when they do chose to do so.

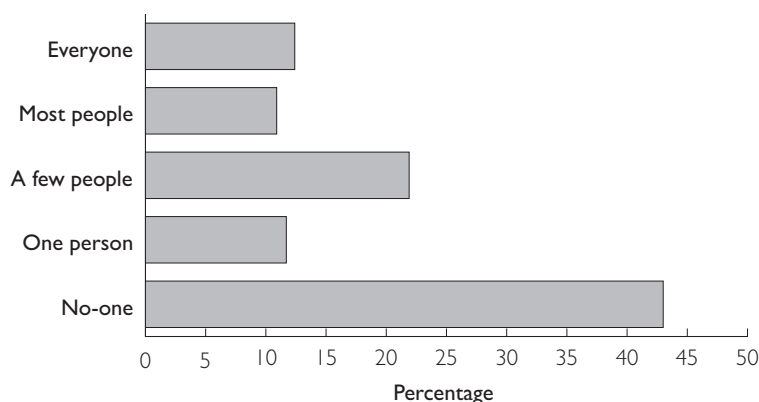
TABLE 85 Difficulties with HIV status confidentiality in the workplace: percentages of total and specific samples

	Total working sample	AIDS related	Non-AIDS related
I do not try to keep my HIV status confidential	25.2	67.2	16.6
No problems	55.2	35.2	59.6
Difficulty keeping and taking medication	8.2	2.7	9.4
Explaining absences from work	12.3	3.0	14.3
Visible signs of illness	11.9	2.6	13.9
Gossip	15.5	5.3	17.3
Other	5.6	5.9	5.6

(Multiple responses possible)

When asked how many people in their workplace knew that they were HIV positive, 12.4% said that everyone knew, 10.9% said most people knew, 21.9% said a few people knew, 11.7% said one person knew and 43.0% said no-one knew (see Figure 16). Those working in a HIV related job were more likely to have to say everyone knew their HIV status than those in non- HIV related work (51.3% versus 4.7%) and similarly less likely to say no-one knew their HIV status (2.7% versus 51.4%).

FIGURE 16 Disclosure in workplace



When asked about the impact that HIV had on their capacity to perform their work duties, around half of the sample said that their work was unaffected (see Table 86). Two fifths also said that they tired more quickly, and one fifth said that they had difficulty concentrating.

TABLE 86 Impact of HIV on work capacity (percent)

It is not affected	49.4
I tire more quickly	42.9
I have difficulty concentrating	20.8
I work reduced hours	19.5
I cannot always go to work	13.0
I am less productive	11.6
I do different duties	3.4
Other	6.6

(Multiple responses possible)

Living with HIV often involves intermittent periods of ill health, particularly around treatment changes and the need to access health and other services, often only available during work hours (Prestage et al. 2001). Respondents were asked how much flexibility their workplace gives them to take time off for reasons relating to HIV. Most PLWHA had the capacity to take time off for medical appointments (see Table 87) 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 87 Capacity within workplace for HIV related interruptions (percent)

	never	seldom	sometimes	often	always
For medical appointments	7.0	4.8	17.6	12.8	57.7
For counselling	25.5	6.0	15.9	8.0	44.6
When you are sick	4.7	4.1	15.4	11.2	64.5
To do volunteer work	46.9	5.6	15.8	7.7	23.9

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

Respondents were asked if they currently had plans to change their work arrangements, and 39.6% said they did. Of those currently not working, 43.1% said they planned to start or return to work. (see table 88).

Importantly, around one in five said they wanted to reduce the hours they work.

TABLE 88 Plans for changes to work life (percentage of employed respondents)

	Full time	Part time	Total working sample
I want to stop work	6.3	9.6	7.7
I want to change the type of work I do	59.4	50.7	55.6
I want to reduce my work hours	40.6	19.2	31.4
I want to increase my work hours	3.1	42.5	20.1

We also asked respondents to indicate the difficulty they expected in making the changes they identified. Stopping work was the most daunting of the changes, with nearly two in five participants saying they expected this to be very difficult. Returning to work was also rated as very difficult by 35.7% of those currently without employment.

TABLE 89 Anticipated difficulty of changes to work status (percent)

	Not at all difficult	Somewhat difficult	Very difficult
I want to start work / return to work ^a	11.2	53.1	35.7
I want to stop work ^b	23.1	38.5	38.5
I want to change the type of work I do ^b	18.3	60.2	21.5
I want to reduce my work hours ^b	19.2	51.9	28.8
I want to increase my work hours ^b	17.6	55.9	26.5

a) Those currently working who gave this response

b) Those not currently working who gave this response

The main incentives for changes in work arrangements were financial (see Table 90). 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 90 Reasons for changes to work plans among full sample, those intending to return to work and those intending to stop work

	Intending to return to work	Intending to stop work
Financial reasons	83.2	28.0
To reduce stress	27.3	58.1
To do something worthwhile	58.5	26.9
To have something to do	54.0	11.2
Better physical health	31.3	26.7
Worse physical health	2.7	5.5
Better psychological health	53.4	38.9
Worse psychological health	2.1	0.0
The possibility of flexible work hours	26.8	16.7
The possibility of working part-time	34.3	17.0
The possibility of working full-time	14.6	0.0
To have more social contact	55.8	27.8
To have less social contact	1.2	5.8

(Multiple responses possible)

Leisure

Respondents were asked how they spend their time while not working. Each respondent indicated the three activities that occupy most of their time. Around 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 91 Activities pursued while not working: percentage of total sample

Leisure activities (reading, etc.)	65.9
Housework / chores	60.2
Resting	59.5
Socialising with close friends	45.4
Spending time with family	23.7
Socialising with other friends	16.4
Socialising with HIV positive friends	14.8
Volunteer work in HIV/AIDS organisation	13.7
Volunteer work in other organisation	9.2
Looking after children	6.4
Looking after another HIV positive person	2.7

(Multiple responses possible)

FINANCES

The previous HIV Futures surveys have highlighted the financial difficulties that many

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

Income

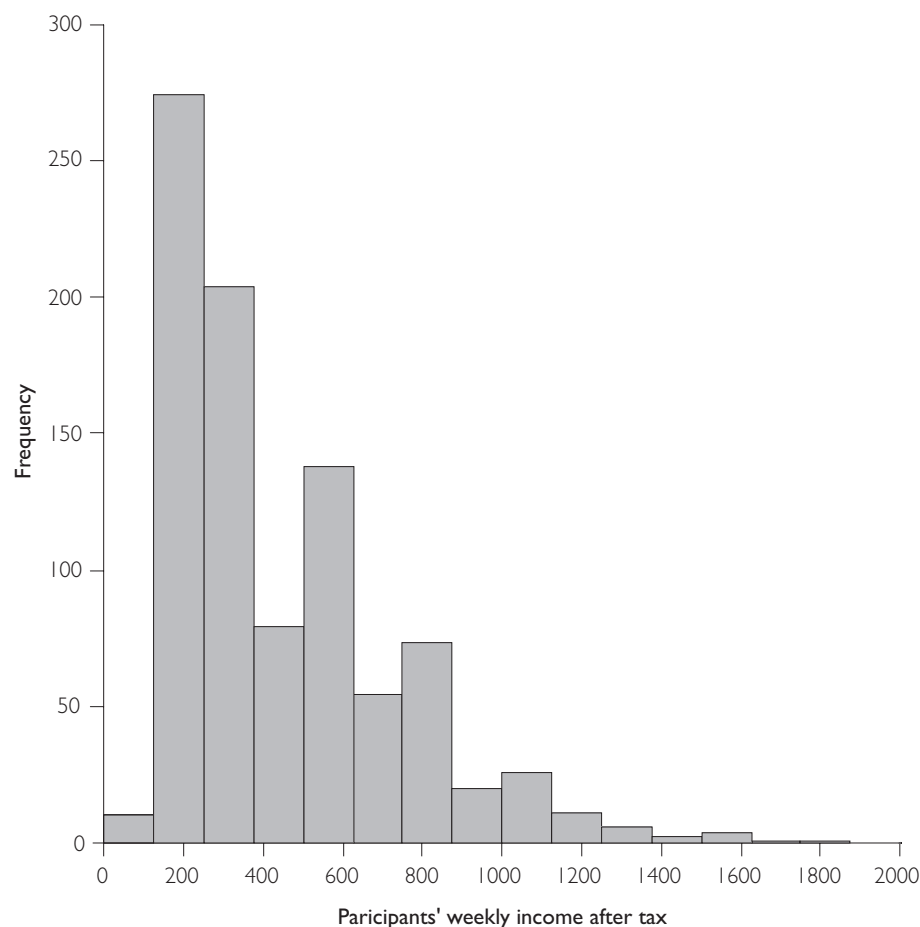
The source of income of the survey respondents is shown in Table 92 below. As with the previous HIV Futures surveys, over half had a government pension or benefit as their main source of income. Just over one third of PLWHA were receiving a salary and 4.7% had superannuation as their main income source.

TABLE 92 Primary source of income: percentage of total sample

Benefits / pension / social security	54.6
Salary	37.3
Superannuation / annuity / savings	4.7
Partner supports me	1.0
Family / friends support me	0.3
Other	2.1

The median weekly income for respondents was \$320. Figure 17 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. 24.2% of respondents had a partner with whom they share financial resources. The partners' median weekly income was \$450.

FIGURE 17
Histogram of respondents' weekly income after tax



Expenditure and Debts

Respondents were asked their weekly expenditure on a range of items. The results are shown in Table 93 below. The total mean expenditure on medication was \$50.90 per week with complementary therapies accounting for almost half the total. Mean rental or mortgage costs were \$171 with the highest costs being in the ACT (mean=\$199) and NSW (mean= \$185). Food and utilities accounted for around \$89 and \$54 respectively.

17.7% of respondents owned their own home, while 17.8% were paying off their home. 14.1% had owned their own home in the past, but do not currently. 33.4% received a rental subsidy averaging at \$93.69 per week.

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$30,072 with a median of \$4,000. Those who owned their home had a mean debt of \$61,300, those who were currently paying off their home had a mean debt of \$65,966, those in private rental accommodation had a mean debt of \$12,432 and those in public rental accommodation had a mean debt of \$4,838. Slightly less than one-fifth (24.1%) had used the services of a financial counsellor in the last two years.

Participants were asked to respond to the statement: 'I gamble more than I would like to'. Only 3.0% said that they strongly agreed, 9.9% that they agreed, 27.4% that they disagreed and 59.7% that they strongly disagreed.

TABLE 93 Weekly expenditure on medications and essentials (\$AU)

	Mean	Median
Rent or mortgage repayments	\$171.90	\$130
Food	\$89.00	\$80
Utilities	\$53.70	\$50
Complementary therapies	\$23.70	\$20
Other medication	\$14.10	\$10
Antiretroviral drugs	\$13.10	\$10

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 43.8% of those receiving a benefit in the last two years had received such an assessment. When asked what this experience resulted in, only 5% (n=11) said that their benefit was terminated. (See Table 94 below) Around 30% said that the assessment resulted in changes to their conditions of benefit. Importantly the experience of assessment resulted in distress for two thirds of the respondents while it clarified concerns for less than one in five.

TABLE 94 Consequences of receiving an assessment of benefit from a Commonwealth Medical Officer (percentage of those assessed in last 2 years)

Require documentation from your doctor	68.8
Cause you distress	65.3
Result in changes to the conditions of your benefits	29.7
Result in an independent assessment	18.2
Clarify concerns that you had	13.7
Result in a shift from Pension to Newstart allowance	5.2
Result in termination of your benefits	5.0

(Multiple responses possible)

Poverty

As with the previous HIV Futures surveys, we have used the quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR) to assess the extent of poverty among PLWHA. The Henderson Poverty lines are set for specific income units. These units include the individual, any partner with whom they share financial resources and any dependent children. We used the IAESR (2003) data for the September quarter (the time at which the survey was completed).

According to this measure over one quarter (26.9%) of PLWHA were living below the poverty line. That this figure has remained so high across the HIV Futures surveys suggests that current resources and strategies are inadequate and decisive action must be taken to address this pocket of severe social disadvantage.

Correlates of Poverty

We look now at the differences between different groups in their likelihood to be living in poverty. Those in paid employment were significantly less likely to be classified as below the poverty line. Half of those not in paid employment were living in poverty (see Table 95).

TABLE 95 Poverty by employment status (percentage of employment categories)

	below poverty line	above poverty line
Employed	2.9	97.1
Not employed	46.3	53.7

$$\chi^2_{(1,1)}=189.286, p<0.001$$

Respondents who identified a salary as their primary source of income were significantly less likely to report an income below the poverty line. Around half of those on a government benefit were living in poverty (see Table 96). There was no gender difference in the proportions of people living below the poverty line.

TABLE 96 Poverty by income source (percent)

	below poverty line	above poverty line
Benefits/pension/social security	49.3	50.7
Super/annuity/savings	5.4	94.6
Salary	1.5	98.5
Partner	0.0	100.0
Family/friends	0.0	100.0
Other	6.3	93.8

$$\chi^2_{(5,1)}=237.770, p<0.001$$

Those who shared financial resources with a partner were significantly less likely to be below the poverty line than those who did not (see Table 97).

TABLE 97 Poverty by shared income status (percent)

	below poverty line	above poverty line
Sole income	34.0	66.0
Dual income	7.9	92.1

$$\chi^2_{(1,1)}=60.109, p<0.001$$

There is also a clear relationship between poverty and self-rated health and well being (see tables 98 and 99). Those living below the poverty line were significantly more likely to rate these characteristics as poor or fair. This pattern most likely represents an interaction between poverty and these factors, rather than a directional relationship. Worse health and well being limit access to employment and financial security, while poverty creates emotional distress, limits social interaction and damages health.

TABLE 98 Self-rated health of those above and below the poverty line (percent)

	below poverty line	above poverty line
Poor	8.9	3.7
Fair	39.0	19.7
Good	39.8	53.0
Excellent	12.3	23.6

$$\chi^2_{(3,1)}=51.547, p<0.001$$

TABLE 99 Self-rated well being of those above and below the poverty line (percent)

	below poverty line	above poverty line
Poor	11.7	5.8
Fair	41.4	24.9
Good	36.0	49.4
Excellent	10.9	19.9

$\chi^2_{(3,1)} = 39.500, p < 0.001$

Costs

As with previous surveys, we asked respondents about the difficulty they had paying for a range of activities, goods and services. The results are shown in Table 100 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 100 Difficulty paying costs of items and services (percent)

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=718) ⁶	58.0	33.7	8.3
Other prescribed medication (n=858)	51.0	37.2	11.8
Medical services (doctor, dentist, etc.) (n=862)	48.7	30.8	20.5
Complementary Therapies (n=548)	43.5	33.9	22.6
Support services (counselling, etc.) (n=405)	63.4	21.8	14.8
Entertainment (theatre, movies, concerts, etc.) (n=890)	30.8	33.6	35.6
Going out (eating / drinking) (n=931)	28.2	32.4	39.4
Sport (exercise, gym, etc.) (n=671)	35.0	32.4	32.6
Recreational drugs (n=445)	29.5	28.6	41.9
Travel / holidays (n=837)	19.8	24.3	55.9
Rent / Mortgage / Housing costs (n=882)	36.5	41.6	21.9
Utilities (telephone / electricity / gas / water) (n=980)	31.8	43.0	25.2
Food (n=989)	44.5	38.9	16.6
Clothing (n=948)	31.8	34.1	34.1
Transport (n=962)	47.5	34.9	17.6
Child care (n=67)	46.3	28.5	25.1

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

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 101 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.

TABLE 101 Difficulty paying costs of items and services by poverty status (percent)

	BELOW POVERTY LINE			ABOVE POVERTY LINE		
	Not at all difficult	A little difficult	Very difficult	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=161,461) ⁷	46.4	41.3	12.3	62.3	30.7	7.0
Other prescribed medication (n=195,557)	37.0	43.3	19.7	57.3	34.1	8.7
Medical services (doctor, dentist, etc.) (n=189,563)	48.1	27.0	24.8	38.8	30.3	30.9
Complementary Therapies (n=123,354)	29.8	37.6	32.6	49.1	32.4	18.6
Support services (counselling, etc.) (n=91,266)	55.6	27.3	17.2	64.5	21.7	13.7
Entertainment (theatre, movies, concerts, etc.) (n=203,585)	8.4	27.0	64.6	39.5	34.7	25.8
Going out (eating / drinking) (n=219,600)	9.1	23.2	67.7	35.7	34.5	29.8
Sport (exercise, gym, etc.) (n=163,431)	11.6	36.4	52.1	44.3	30.7	25.0
Recreational drugs (n=102,294)	10.2	23.3	66.6	37.1	30.8	32.2
Travel / holidays (n=189,550)	5.0	7.9	87.1	24.5	30.5	45.0
Rent / Mortgage / Housing costs (n=193,572)	21.1	42.7	36.2	42.1	41.8	16.2
Utilities (telephone / electricity / gas / water) (n=226,624)	14.9	39.3	45.8	38.1	43.8	18.1
Food (n=228,631)	21.9	44.4	33.8	53.4	36.5	10.2
Clothing (n=216,613)	12.5	30.0	57.5	37.6	36.1	26.3
Transport (n=217,598)	29.5	38.7	31.8	52.8	35.1	12.1
Child care (n=16,42)	11.2	35.8	52.9	56.1	27.5	16.4

All categories are significant for $\chi^2_{(2,1)}$ at the $\alpha.001$ level except *support services* (non-significant) and *child care* ($p=0.005$)

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

Poverty and Services

When we examine the use of services at AIDS organisations in the last six months by those above and below the poverty line (see page 34 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 102). While the differences for some services are slight, we note the discrepancies for use of financial advice, housing assistance, transport and volunteer and paid carers. When we examine use of services at other organisations, particularly notable are the greater proportions of those below the poverty line using drug and alcohol treatment service (16.5% versus 7.9%), housing assistance (29.9% versus 17.0%) and return to work skills (14.2% versus 9.2%).

TABLE 102 Services used at HIV/AIDS organisations by those above and below the poverty line (percent)

	Below poverty line	Above poverty line
Treatments advice	49.6	47.0
Social contact with other PLWHA	42.4	42.3
Counselling	35.7	31.1
Treatments information	35.3	36.1
Peer support group	33.7	34.1
Financial advice	29.7	18.0
Financial assistance	25.4	27.6
Informal peer support	25.4	24.9
Volunteer carer	22.6	8.3
Alternative/Complementary therapies	21.3	19.2
Pharmacy services	19.9	20.7
Legal advice	19.6	15.9
Housing assistance	19.1	13.0
Transport	16.4	5.9
Internet access	14.2	11.1
Community education campaigns	14.0	16.5
Respite care	13.4	3.2
Mental health services	10.9	9.8
Employment services	9.6	10.2
Return to work skills	8.4	7.9
Internet based information	8.3	8.3
Library	6.1	7.8
Paid carer	4.6	1.7
Drug/alcohol treatment	4.4	2.9

(Multiple responses possible)

TABLE I03 Services used at other organisations by those above and below the poverty line (percent)

	Below poverty line	Above poverty line
Pharmacy services	41.3	44.7
Housing assistance	29.9	17.0
Library	28.1	25.5
Transport	23.0	21.9
Counselling	22.2	24.6
Internet access	22.2	31.6
Mental health services	21.1	17.0
Treatments advice	17.8	27.0
Alternative/ complementary therapies	17.1	26.6
Drug/alcohol treatment	16.5	7.9
Employment services	16.1	14.7
Legal advice	15.7	17.3
Return to work skills	14.2	9.2
Internet based information	13.9	16.2
Financial advice	12.1	19.8
Treatments information	11.5	12.6
Informal peer support	8.3	11.8
Community education campaigns	7.7	3.9
Social contact with other PLWHA	6.7	8.3
Financial assistance	6.0	9.8
Respite care	6.0	7.2
Paid carer	5.3	3.4
Peer support group	4.1	7.1
Volunteer carer	4.0	3.5

(Multiple responses possible)

DISCRIMINATION

Discrimination is a central theme in the history and current state of the HIV/AIDS epidemic. While the worst excesses of the early years of HIV are now rare, PLWHA continue to experience less favourable treatment in many domains of their lives. In addition the anticipation of discrimination may limit people's life choices in subtle but sustained ways. We have asked about the experience of discrimination in a range of settings.

Accommodation

12.0% of respondents indicated that they had experienced less favourable treatment in relation to accommodation (5.4% in the last two years). These were more likely to be those that currently lived in public housing (19.7% experienced discrimination, 8.5% in the last 2 years) but also included 20.0% of those in housing cooperatives, 15.1% of those in private rental accommodation and 4.5% of those who own or are purchasing their own house or flat.

HEALTH SERVICES

HIV

33.5% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This comprised 16.7% of all respondents that had experienced such discrimination in the last two years and 16.9% that experienced this more than 2 years ago. When asked what form this discrimination took, the most common responses were confidentiality problems (43.1%) and avoidance (37.3%). These experiences are shown in Table 104.

TABLE 104 Form of HIV-related discrimination experienced at medical service (percentage of those experiencing discrimination)

	Ever (N=328)	In last 2 years (N=163)
Confidentiality problems	43.1	44.7
Avoidance	37.3	38.8
Treated last	29.7	34.3
Increased infection control	33.2	31.2
Refusal of treatment	25.5	24.0
Rushed through	24.3	31.2
Harassment	9.5	12.0
Abuse	9.8	12.3

(Multiple responses possible)

Hepatitis C

18.1% of hepatitis C co-infected respondents had experienced less-favourable treatment at a medical service as a result of having hepatitis C. This included 13.3% 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 105.

TABLE 105 Form of hepatitis C-related discrimination experienced at medical service (number of those experiencing discrimination)

	Ever (N=30)	In last 2 years (N=22)
Avoidance	18	8
Confidentiality problems	12	6
Treated last	12	5
Increased infection control	10	5
Rushed through	10	7
Harassment	11	4
Refusal of treatment	7	4
Abuse	5	2

(Multiple responses possible)

Insurance

26.2% of respondents currently had private health insurance and 13.9% currently had some other form of income or mortgage insurance.

23.2% of respondents indicated that they had experienced less favourable treatment in relation to insurance. This included 39 respondents who had experienced this discrimination in the last two years. The most commonly reported example of less favourable treatment was ineligibility for life insurance (23.5% of those reporting less favourable treatment), followed by difficulties taking out any insurance policy (21.7%) and ineligibility for travel insurance (17.2%).

CONCLUDING COMMENTS

While the overall picture for people living with HIV in Australia is optimistic, there remain clear patterns of health and social disadvantage that require ongoing policy vigilance and service provision.

Clinical issues such as co-existing health conditions, mental health problems and treatment failure continue to remind us that HIV is far from a simple and manageable chronic illness for many PLWHA. The high rates of poverty noted in the HIV Futures Surveys are yet to be significantly reduced despite broad and sustained community response. The experience of discrimination in health care and other settings alerts us to the continued need for education and active policy implementation as well as broad community sensitisation.

The increasing reliance on the clinical sector for information and support demonstrates, not only the need for sustained education and training among health care professionals, but also suggests that the (re-)medicalisation of HIV presents continuing challenges to the community sector.

We hope that these national surveys of PLWHA continue to provide a valuable tool to health care professionals, community sector worker, policy makers and PLWHA themselves to reflect on the diversity and complexity of living with HIV/AIDS.

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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
CAM	Complementary and alternative medicine
CTTAC	Clinical Trials and Treatments Advisory Committee
HIV	Human Immunodeficiency Virus
IAESR	Institute of Applied Economics and Social Research
IDU	Injection Drug Use(r)
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



APPENDIX: 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.

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

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

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

Thirdly the survey is self-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.

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 optimize access to the study. This means that people are not disadvantaged from entering the study if they are not currently using anti-retroviral therapies or not currently in contact with one of the main HIV treatment providers.

Nevertheless it must be acknowledged that this methodology will never be appropriate for some members of the PLWHA community. This is particularly so for those from culturally and linguistically diverse backgrounds who may be marginalised even within their own communities, and those for whom invisibility is the key to their continuing safety. Community development methodologies are currently being explored in order to establish how the very real needs of these people can be understood and documented over time within an action research framework which offers support and strengthens networks as the research proceeds.

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

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 2 (Grierson et al., 2000) and HIV Futures 3 (Grierson et al., 2002) surveys 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 4 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 was a number of attitude/ belief items scored using a four- and five-point Likert scales. There were also write-in and open-ended items.

The 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 (Fogarty et al. 2003). The responses to the HIV Futures Study were linked by a confidential non-identifying code to the data collected by the pH study.

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 the 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.

An important aspect of the HIV Futures 4 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 106 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.

TABLE 106 Data on primary site of survey collection

Completed a previous HIV Futures Survey	40.3
Mail-out from HIV/AIDS organisation	23.5
Picked up a copy at HIV/AIDS organisation	11.4
Picked up a copy at Medical Centre or Hospital	11.0
Recruited by researcher	2.0
Told about it by someone who had already completed it	1.9
Other	9.7

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 107). 50.7% indicated that they had not participated in any of the previous HIV Futures Studies, while 24.4% had participated in all three.

TABLE 107 Data on previous research involvement

Positive Health (pH)	18.9
HIV Futures 1 (1997)	27.5
HIV Futures 2 (1999)	36.2
HIV Futures 3 (2001)	44.1
Periodic survey	17.3

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 (2003) and the data were weighted to conform with the demographic profile of the Surveillance Report. A weighting algorithm based on mode of infection, gender, state of residence and diagnosis of AIDS defining illness has been applied to all the analyses that follow. Consequently, findings are presented in terms of sample percentages rather than frequencies. Sample sizes (Ns) are given when the table represents a subset of the total sample. These Ns are weighted.

ANALYSIS

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

FURTHER ANALYSIS AND REPORTS

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

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