

THE JOURNEY CONTINUES

Women living with HIV/AIDS in Australia

HIV FUTURES 4

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EXECUTIVE SUMMARY

DEMOGRAPHICS

The HIV Futures 4 survey was completed by 1064 HIV positive Australians from all states and territories, of whom 96 (9.0%) were women. This represents approximately 8.0% of HIV positive women in Australia.

There was a wide age range, with a mean of 40.5 years and a median of 39.5 years.

The majority of women were Australian born (73.7%). Two women (2.1%) indicated they were of Aboriginal/Torres Strait Island origin.

HEALTH

HIV Antibody Testing

- 17 women (20.3%) tested for HIV because they became ill
- 17 women tested because their partner either tested positive or died
- 16 women tested because of a particular risk episode
- 8 women tested as part of a routine health screening
- 5 women were tested without their knowledge

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

- 25.3% of women had received pre-test counselling/engaged in pre-test discussion
- 67.8% received post-test counselling

Pre- and post-test counselling was most often provided by medical personnel and most women were satisfied with both the information and support received. However women were significantly more likely than men to say that they were not satisfied with the information received during pre-test counselling.

Current Health Status

- 67.7% of women rated their health as good or excellent and 57.9% rated their general well-being as good or excellent.

While the proportion of women rating their health as poor or fair is similar to that in previous Futures surveys, the proportion rating their well-being as poor or fair has almost doubled from 22.5% in 2001 to 42.1% in 2003.

Almost all of the women had taken a CD4/T-cell test and a viral load test. 19.5% of women (17) had been diagnosed with an AIDS-defining illness, 2 in the last 2 years.

HIV-related and other health conditions

40.3% of women indicated that they had experienced HIV-related illnesses and 38.4% indicated that they had been diagnosed with a major health condition other than HIV/AIDS. The most common condition reported by women was Hepatitis C.

When asked about the following conditions:

- 77.1% of women reported low energy or fatigue
- 39.4% experienced a sleep disorder
- 36.7% reported lipodystrophy
- 35.0% experienced confusion or memory loss
- 30.8% had experienced weight loss

Hepatitis

- 8 women (8.7%) had at some point had Hepatitis A and 38.3% had been vaccinated against Hepatitis A
- 11 women (12.7%) had at some point been diagnosed with Hepatitis B, of whom:
 - 7 had cleared the infection
 - 3 had ongoing infection
 - 1 had a chronic infection
- 56.3% had been vaccinated against Hepatitis B
- 27 women (30.3%) were Hepatitis C positive
- Women were significantly more likely than men to be Hepatitis C positive (30.3% vs 14.5%)
- 2 women had ever undertaken medical treatment for Hepatitis C

Prophylaxis

- 21.4% of women were taking prophylaxis for opportunistic infections

Cervical smear

- 98.7% of women had had a cervical (pap) smear test, 95.7% in the last year

TREATMENTS

Antiretroviral Therapy

- 69.9% of women were currently using ARV, most commonly one NNRTI and two NRTIs
- 80.5% had used ARV at some point
- 65.5% were on a combination of three drugs

In contrast to the findings of Futures 1, 2 and 3 where the rate of ARV use was lower amongst women, in 2003 the proportions of men and women currently using ARV were the same (70%).

Difficulties of taking Antiretroviral Therapy

81.7% of women currently taking ARV reported difficulties taking them. The main difficulties were:

- Remembering to take drugs on time (47.2%)
- Side-effects (42.7)
- Organising meals around medication (40.7%)
- Taking medication in public (40.0%)
- Taking a large number of tablets (35.7%)
- Transporting medication (26.1%)

Side-effects were experienced by 35% of women who were currently using ARV. The most common were nausea or vomiting (13 women) and diarrhoea (7 women).

Attitudes to Antiretroviral Therapy

76.3% of women agreed or strongly agreed with the statement “I am worried that in the future my medication will stop working for me”, an increase from 58.8% in 2001.

58.1% of women agreed or strongly agreed with the statement “Taking tablets gives me an unwanted reminder that I have HIV”, the same proportion as in 2001 (58.0%).

Treatment Breaks

- 45.2% of women currently on ARV had taken a break from ARV (27 women)
- The median length of the break was 3 months
- 18 women gave clinical reasons for taking the break, 12 gave lifestyle reasons and 5 gave both clinical and lifestyle reasons
- Breaks often resulted in deterioration of clinical markers but improved well-being
- Doctors were less commonly consulted before a treatment break than during or after the break
- 63.0% saw their doctor before, during and after the treatment break

Antiretroviral Resistance

- 26.8% of women who had ever used ARV had taken a resistance test (21 women)
- 17 women found resistance to one or more drugs
- 15 women changed drugs as a result of the resistance test

Dosing and Adherence

- 73.4% of women were taking ARV twice daily
- 15.0% were taking ARV three times daily
- 3.4% were taking ARV once a day

62.8% of women had not missed a dose of ARV in the two days prior to completing the survey

Clinical Trials

- 24.5% of women had participated in a clinical trial for HIV-related treatment
- 10.7% had participated in a clinical trial in the past three years

Complementary Therapies

- 55.8% of women were using vitamin or mineral supplements
- 41.7% used massage
- 29.5% used meditation or visualisation practices
- 26.8% used marijuana for therapeutic purposes
- 83.4% of women believed that complementary therapies can improve well-being
- The median amount spent on complementary therapies per week was \$20.00

SERVICES

Health Services

- 81.6% of women saw either a HIV GP/S100 prescriber or HIV specialist for HIV specific treatment
- 54.6% saw either a HIV GP/S100 prescriber or HIV specialist for general medical treatment

Women were significantly more likely than men to see different doctors for HIV-specific and general medical treatment (56.1% compared with 44.1% of men). The majority of women had visited either a HIV GP/S100 prescriber or HIV specialist in the last six months.

Other Services

Services most commonly used by women at HIV/AIDS organisations:

- 60.4% peer support
- 58.4% social contact with other PLWHA
- 55.6% treatments advice
- 46.4% treatments information
- 37.3% financial assistance

38.0% of women said there were services they felt they needed but did not have access to.

Information

Important sources of information about treatments:

- 53.5% HIV GP/S100 prescriber
- 59.7% publications from HIV/AIDS groups
- 53.4% HIV magazine/newspaper
- 49.8% HIV specialist at outpatient clinic
- 31.6% positive women's organisations

Important sources of information about HIV management:

- 60.4% publications from HIV/AIDS groups
- 53.3% HIV magazine/newspaper
- 48.6% HIV GP/S100 prescriber
- 36.0% HIV positive friends
- 35.3% positive women's organisations

Important sources of information about living with HIV:

- 57.4% publications from HIV/AIDS groups
- 52.8% HIV magazine/newspaper
- 52.3% HIV positive friends
- 49.7% positive women's organisation
- 28.1% HIV GP/S100 prescriber

Publications

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

Involvement with AIDS organisations

85.3% of women had some contact with HIV/AIDS organisations, most of whom received newsletters and mail outs, or were clients of the organisations. 12.3% of women were employees of HIV/AIDS organisations.

THE SOCIAL WORLD OF WOMEN

Contact with other PLWHA

- 92.9% of women know another PLWHA
- 46.4% had an HIV positive friend
- 21.3% had a partner or spouse with HIV
- 2.2% of women had an HIV positive child
- 69% of women spent at least some time with other PLWHA
- 11% spent a lot of time with other PLWHA

Disclosure

Almost all of the women (96.8%) had disclosed their HIV status to at least one person, most commonly to close friends, family and partners. 76.6% of women said that their HIV status had been disclosed without their permission (37.5% in the last 2 years). Women were significantly more likely than men to report unwanted disclosure both in the past 2 years and more than 2 years ago. Women were also significantly more likely than men to report unwanted disclosure from a worker in a health care setting.

Social Support

When asked which sources provided ‘a lot’ of support:

- 74.2% of women said their partner/spouse
- 63.1% said children
- 50.1% said pets
- 48.8% said close friends
- 47.5% said parents

Mental Health

- 23.2% of women had taken prescription medication for depression in the six months prior to completing the survey.
- 21.8% of women had taken prescription medication for anxiety in the six months prior to completing the survey.
- 21.9% of women had been diagnosed with a mental health condition, most commonly depression

Planning for the Future

- 56.2% of women said that they planned at least a year in advance
- 30.6% planned only a few months ahead
- 13.2% planned only one day at a time

Women and Children

- 63.8% of women had children, ranging in age from babies to 62 years of age
- 45.3% have dependent children
- 43.4% have dependent children living with them, with an average age of 10 years
- 2 women have a child who is also HIV positive
- 64.9% of women with children had told their children about their HIV status
- 60.6% of the women with dependent children were in regular relationships

Women with dependent children were significantly more likely to rate their health as good or excellent than those without dependent children

Future Planning for Children

- 53.0% of women were not currently considering having (more) children
- 13 women had thought about having a child but had not decided
- 5 women had decided to have a child in the future
- 3 women were trying to get pregnant at the time of completing the survey
- 2 women were pregnant at the time of completing the survey

RELATIONSHIPS AND SEX

- 63.8 % of women were in a regular relationship
- 35.1% of women said they were not having sex at present

Of those with a regular partner:

- 32.6% said their partner was also HIV positive
- 62.5% said their partner was HIV negative
- 4.9% had a partner of unknown serostatus
- 98.4% of women had told their partner that they were HIV positive

Most women said that their partner either already knew their HIV status, or that they had disclosed to them when they found out they were HIV positive or at the start of the relationship.

55.0% of women had vaginal or anal intercourse with a regular male partner in the past six months. Condom use was strongly related to the HIV status of the partner.

15 women reported having sex with a casual partner in the past six months, nine with a male partner. Six women said that they always used condoms with casual male partners.

13 women reported on their most recent sexual encounter with a casual partner. 10 women said they had sex with a man, one with a woman, and two did not say.

29.6% of women agreed with the statement “I prefer to have a relationship with someone who also has HIV”. Compared with men, women were significantly more likely to disagree, strongly disagree or say they don’t know in response to this statement.

30.7% of women agreed that “If I know my partner is HIV positive I find sex more pleasurable”. Compared with men, women were significantly more likely either to disagree or to say they don’t know in response to this statement

58.7% of women agreed that “HIV has had a negative effect on my sexual pleasure”, however women were significantly more likely to say they don’t know in response to this statement, compared with men.

RECREATIONAL DRUG USE

The substances most commonly used by women over the last 12 months were:

- Alcohol (69.2%)
- Cigarettes (43.0%)
- Marijuana (35.3%)

Almost two thirds (65.6%) of women reported never having injected illegal drugs. Of those who had, half (15 women) had done so in the last 12 months. 13 women had not shared injecting equipment in the last 12 months.

- 12.0% of women reported having missed a dose of ARV as a result of using recreational drugs
- 6.3% reported having a bad experience from using both illegal drugs and ARV.

HOME, WORK & MONEY

Accommodation

- 32.9% owned or were purchasing their own home or flat
- 29.9% lived in private rental accommodation
- 24.2% lived in public rental accommodation
- 5.6% lived in community housing/housing co-operative
- 5.1% were living rent-free (e.g. provided by friends, family etc)

71.1% of women stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable the main reason given was that it was too small.

- 19.3% of women lived by themselves
- 41.4% lived with a partner or spouse
- 43.4% lived with dependent children
- 66.8% lived with pets
- 79.3% had access to a car

38.9% of women had ever changed their accommodation as a result of having HIV/AIDS, 12.4% (11 women) in the past 2 years.

Employment

- 56.1% of women were in paid employment
- 27.9% were in part-time work
- 22.6% were in full-time work

The remainder described themselves as either unemployed or occupied with home duties. Women were significantly more likely than men to be working part time and to be occupied with home duties. Women were significantly less likely than men to be not working or retired.

Most women said that their initial HIV diagnosis affected their career plans:

- 34.0% said it was more difficult to plan for the future
- 15.0% said they had changed careers
- 14.1% said their career had ended or they stopped work

When asked about the impact of ARV on their career plans, 40.6% said there had been no change to their plans, while 18.6% said they anticipated a longer time in the workforce.

53.0% of women who have worked said that they had stopped work at least once for HIV-related reasons. The most common reason for this was low energy levels, followed by stress, depression or anxiety and poor health.

Of the women who had stopped working, 42.7% had returned to work, and all of these women said this was for financial reasons.

Around half of women said their work was unaffected by HIV, however 12 women said they tired more quickly, six that they worked shorter hours and five that they have difficulty concentrating.

54.5% of women currently in work had not disclosed their HIV status to anyone. 6 women said they do not try to keep their HIV status confidential.

The most common difficulties experienced by women in the workplace were explaining absences and taking medication.

Finances

49.1% of women said that their primary source of income was a government benefit or pension. Almost all of the women (89%) reported at least some difficulty with meeting the cost of daily living.

Difficulty meeting the cost of living:

- 78.5% had difficulty paying for clothing
- 69.9% difficulty paying for housing
- 70.4% difficulty paying for utilities
- 64.8% difficulty paying for child care
- 59.7% difficulty paying for food

Poverty

33.0% of women were living below the poverty line. Women who shared financial resources with a partner were significantly less likely to be living below the poverty line. Women who identified salary as their primary source of income were significantly less likely to report an income below the poverty line.

Discrimination

7 women had experienced less favourable treatment in relation to accommodation, 3 in the last two years.

53.8% of women had experienced less favourable treatment at a medical service as a result of having HIV, 20.0% in the last two years. Women were significantly more likely than men to report having experienced discrimination at a medical service.

3 Hepatitis C co-infected women had experienced less favourable treatment at a medical service as a result of having Hepatitis C, 1 in the last 2 years.

8 women had experienced less favourable treatment in relation to insurance.

INTRODUCTION

The journey continues: Women living with HIV/AIDS in Australia

HIV is a complex virus of unknown predictability and only 1200 women were living with this virus in Australia in 2003. Despite this small number, women are an important group within the population of people living with HIV in Australia. Their experiences differ in many ways from those of men living with HIV and sometimes this can result in isolation or a sense of being alone. Yet the women making this journey are not alone. There are nearly 20 million women living with HIV/AIDS worldwide, comprising half of the total number of people living with this virus. Like the women overseas, women living with HIV in Australia are incredibly diverse in their experiences, values, needs and expectations. This report is an attempt to recognise and acknowledge the diversity of HIV positive women.

Drawn from data collected in *HIV Futures 4: state of the [positive] nation* (Grierson et al, 2004), this is the 'numbers' story of women living with HIV in Australia. HIV Futures 4 saw 96 women (more than ever) spend the time to fill in a long and sometimes intrusive survey, to tell us about their lives in detail and with openness. In doing so, their experiences are noted and their differences recorded. As the fourth report of its kind, we hope that these data provide commonality and validation for the positive women who read it; information and knowledge for those people who work to serve the needs and requirements of positive women; and a broad picture of the ordinary, yet extraordinary, women living with this virus.

We remind the reader that the numbers reported here represent only a part of these women's stories and cannot do justice to the diversity of experiences of all of the women who participated in this research. Yet, each of these women had in common the courage and determination to tell us what it was like for them to be living in Australia in 2003 as women with HIV. As with previous reports, we believe these 'number stories' go some way in speaking for all women living with HIV in this country, for whom the journey continues.

DEMOGRAPHICS

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

Sample Demographics

The HIV Futures 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. 96 women participated in the survey and this represents approximately 8.0% of HIV positive women in Australia.

Of the women, 91.2% were heterosexual women, 4.4% lesbian, 3.3% bisexual women and the remaining 1.1% fell into another category.

There was a wide age range, with a mean of 40.5 years and a median of 39.5 years.

TABLE I Women's reported mode of transmission

Mode of transmission	Number	Percent
Heterosexual contact	64	71.9
Injecting drug use	10	11.1
Receipt of blood components/tissue	5	5.9
Other/don't know	10	11.1

The majority of women were Australian born (73.7%) and 98.9% of women spoke English at home. Two women (2.1%) indicated they were of Aboriginal/Torres Strait Island origin. 98.9% of women indicated that Australia was their official country of residence.

The three most common ancestries that women identified with were English (25.5%), Australian (18.2%), Irish (13.6%) and British (10%). A total of 4.5% of women stated South-East Asian ancestry, specifically Thai, Malay or Filipino.

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

TABLE 2 State or territory of women's residence

State/territory	Frequency	Percent of Sample
NSW	40	41.7
VIC	22	22.9
QLD	17	17.7
SA	8	8.3
WA	6	6.3
ACT	1	1.0
NT	1	1.0
TAS	1	1.0

41.5% of women were from urban areas of capital cities, while 26.6% lived in outer suburban areas, 20.2% lived in larger regional centres and 11.7% lived in rural areas.

78.6% of women were living in the same state or territory in which they were contracted HIV, while the remainder lived in a different state or territory.

Table 3 below shows the years in which women tested HIV positive and in which they believe they were infected with HIV. The time difference between year of presumed infection and year of diagnosis ranged from 0 to 18 years with a mean of 2.21 years and a median of 1.0 year. 39.3% of women tested positive in the same year they believe they were infected. There are 11 women in the sample who had tested positive in the last two years and 4 women who believe they were infected in the past year.

TABLE 3 Years of respondent's testing positive and presumed infection

(% of sample)

Year	Tested HIV Positive	Presumed Infected
Pre 1985	1.0	11.9
1985-1989	18.8	27.4
1990-1994	36.4	30.9
1995-1999	28.1	17.9
2000+	16.7	11.9

23 women (24.7%) indicated that they were atheist/agnostic, 53.8% indicated mainstream religious identification and the remainder were either adherents of new age belief systems or had other spiritual beliefs. 20 (21.1%) indicated that religion or spirituality was of no importance to them. A further 36.8% indicated that this was of little importance, 27.4% that it was very important and 14.7% extremely important.

The educational level of women who completed 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 4 below.

TABLE 4 Educational level of women

Level	Frequency	Percent of women
University degree	23	24.2
Tertiary diploma/Trade Certificate/TAFE	13	13.7
Leaving certificate/HSC/Year 12	26	27.4
4 th form/Year 10	21	22.1
Up to 3 years high school	9	9.5
Primary school only	3	3.2

HEALTH

This section of the report deals with the physical health status and the experience of health of women living with HIV/AIDS in Australia. The chapter includes a discussion of the experiences of testing positive for HIV, the current health status of women as measured by clinical markers and general sense of health and well-being, the health burden in terms of concomitant health conditions and health maintenance strategies.

HIV Antibody Testing

The experience and meanings of testing positive for HIV have changed over the twenty years of the HIV/AIDS epidemic. In the early years of HIV in Australia, testing did not offer any particularly great advantage in treatment options and often led to increased anxiety, stigma and discrimination. With the advent of more effective treatments, the advantages of early testing have become clearer, not only in terms of medication, but also in health monitoring and social support. For women who may be tested during pregnancy, treatments and care can help reduce the chance of vertical transmission.

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 5, 20.3% of women had taken the test as a result of illness, 20.0% because their partner had tested positive or died and 18.9% as a result of a particular risk episode.

TABLE 5 Reasons for testing

Reason	Frequency	Percent
Became ill	17	20.3
Partner tested positive/partner died	17	20.0
Particular risk episode	16	18.9
Other	12	14.7
Routine health screening	8	9.8
Tested without knowledge	5	5.5
Doctor's suggestion	4	4.8
Contact tracer/other health worker's suggestion	3	3.3
Member of risk group	1	1.2
Starting new relationship	1	1.4

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).

25.3% of women (n=23) indicated that they had received pre-test counselling or engaged in a HIV test discussion. The counselling was generally provided by a doctor (n=6), or nurse (n=6), or a counsellor/psychologist (n=3).

When asked if they were satisfied with the counselling/discussion, 65.6% reported they were satisfied with the information they received from this person and 82.9% said they were satisfied with the level of support they received. Women were significantly more likely than men to say that they were not satisfied with the information they received during pre-test counselling (34.8% compared with 15.4%). There were no differences between women and men's level of satisfaction with the level of support provided during pre-test counselling.

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).

67.8% of women (n=60) indicated that they had received post-test counselling. The counselling was generally provided by a doctor (38%, n=21), but was also commonly provided by a counsellor or psychologist (17.1%, n=9), a nurse (11.4%, n=6), a doctor and a nurse (7.3%, n=4) or a social worker (6.2%, n=3).

When asked if they were satisfied with the counselling they received, 75.3% said they were satisfied with the information they received and 79.1% said they were satisfied with the support they received. There were no differences between women and men in level of satisfaction with either the information or level of support provided during post-test counselling.

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 6 and 7 below. Around half (50.9%) of women rated their physical health as good and 16.8% 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.

TABLE 6 Women’s self-rated general health status

	Frequency	Percent
Poor	4	4.7
Fair	24	27.6
Good	45	50.9
Excellent	15	16.8

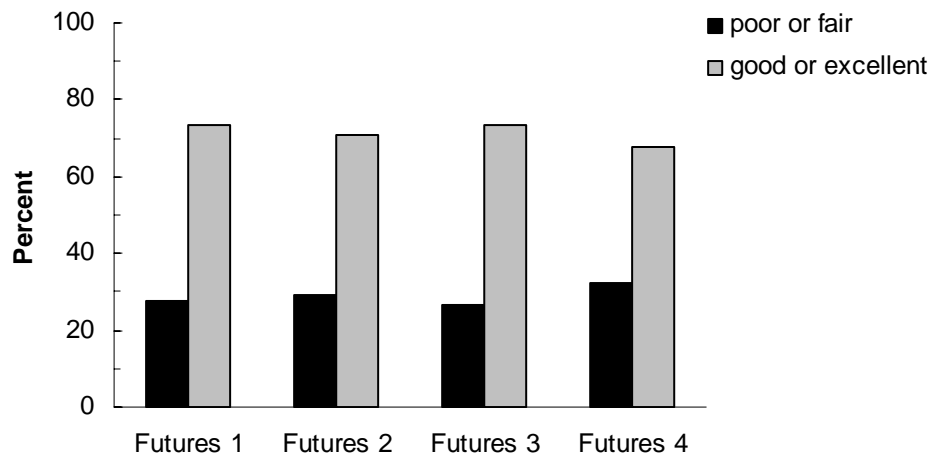
The ratings for well-being were of a similar pattern to those for health.

TABLE 7 Women’s self-rated of general well-being

	Frequency	Percent
Poor	7	7.9
Fair	30	34.2
Good	41	45.5
Excellent	11	12.4

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

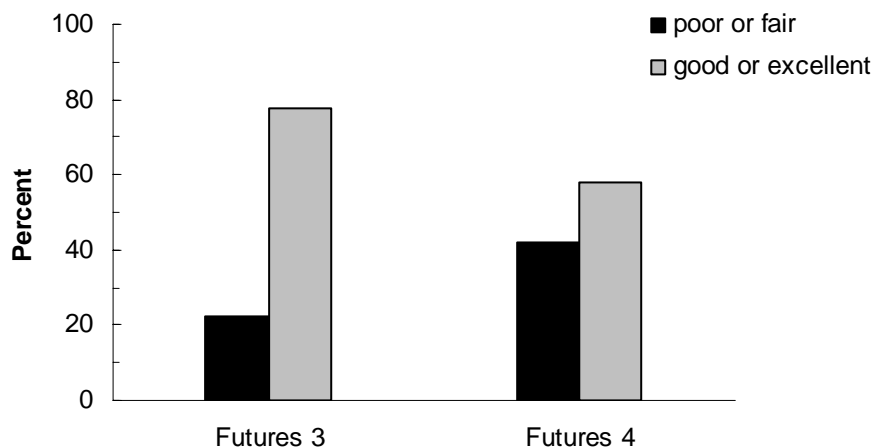
FIGURE 1 Comparison of Women’s self-rated health over four Futures surveys.



Looking at self-rated health over the four Futures surveys (figure 1), we see that at each time point around 70% of women rated their health as good or excellent, with the remaining 30% indicating that their health was poor or fair. Although there is little change between surveys, the proportion of women rating their health as poor or fair has increased from 27.8% in 1997 to 32.3% in 2003.

When we look at self-rated well-being, (figure 2), we see that the proportion of women rating their well-being as poor or fair has almost doubled from 22.5% in 2001 to 42.1% in 2003. The magnitude of this change suggests that while at a population level the physical health of positive women has stabilised over this time period, their sense of well-being has decreased. As we did not collect this information in earlier surveys we cannot tell whether this is an ongoing trend, or is due to other differences between the two samples, however it will be important to take note of whether this change continues in forthcoming surveys.

FIGURE 2 Comparison of women’s self-rated wellbeing over two Futures surveys



When we look at the relationship between these two measures, we can see that better health is related to greater well-being (Pearson correlation coefficient =0.640, $p < 0.001$, see Table 8). Almost one in three women (29.5%) rated their well-being as worse than their health and 11.7% 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.

TABLE 8 Relationship between ratings of overall health and well-being (percent of women)

WELL-BEING	HEALTH			
	Poor	Fair	Good	Excellent
Poor	3 (75%)	4 (16.7%)	0	0
Fair	0	15 (62.5%)	14 (31.1%)	1 (6.7%)
Good	1 (25%)	5 (20.8%)	27 (60.0%)	7 (46.7%)
Excellent	0	0	4 (8.9%)	7 (46.7%)

CD4 and Viral Load

As with the previous three surveys, almost all women had taken a CD4/T-cell test (98.9%) and a viral load test (97.6%). Most women had their most recent CD4 test in the six months prior to survey (94.8%) (65.1% in the last three months) and their most recent viral load test in the six months prior to survey (92.1%) (60.2% in the last three months). On average women had taken 3.8 viral load tests in the preceding twelve months. Among those women who had taken a CD4 test, 95.1% reported that they have at some time had a CD4 count of less than 500 cells/ μ l and 60.7% reported a count of less than 250 cells/ μ l.

Results for women's most recent CD4/T-cell test ranged from 50 to 1100 cells/ μ l with a mean of 497.4 cells/ μ l and a median of 497.0 cells/ μ l.

Among those women who have taken a viral load test, 82.0% reported that at some point they have had a result of over 10,000 copies/ml and 58.0% a result over 50,000 copies/ml.

Results for women's most recent viral load test ranged from below detectable levels to 260,000 copies/ml with a mean of 20663.3 copies/ml and a median of 0 copies/ml. Table 9 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 women'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 9 Results of most recent serological tests (percent of women)

		HIV VIRAL LOAD				
		Below detectable levels	500-9999	10000-49999	50000+	Total
CD4/T-cell count	500+	33.8% (23)	4.4% (3)	8.8% (6)	2.9% (2)	50.0% (34)
	250-499	17.6% (12)	5.9% (4)	7.4% (5)	5.9% (4)	36.8% (25)
	0-249	7.4% (5)	4.4% (3)	0	1.5% (1)	13.2% (9)
	Total	58.8% (40)	14.7% (10)	16.2% (11)	10.3% (7)	100% (68)

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 asked participants to record these conditions within the three categories AIDS defining illnesses (ADI), HIV-related illnesses and other health conditions. Some recoding was undertaken, however, we can see that there is a considerable burden of illness that goes beyond HIV infection for a significant proportion of women.

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 (ADIs). 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 ADI but would now be classed at a less severe stage of disease progression. We asked respondents if they have ever experienced an ADI for 3 reasons: to match and weight the data according to surveillance data; to examine issues around the burden of illness; and to understand the current health status of participants.

Around one in five women (19.5%, n=17) had been diagnosed with an ADI at some point with 2 women 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 (PCP) (n=8), Microbacterium Avium Complex (MAC) (n=4) and Cytomegalovirus (n=3).

The types and frequencies of ADIs were slightly different for men and women. None of the women reported having been diagnosed with Kaposi's sarcoma, compared with 24.8% of the men and a higher percentage of women reporting diagnosis with MAC (21.4% of women, compared with 8.2% of men).

HIV Related and Other Health Conditions

We asked respondents if they had experienced any HIV-related illnesses other than those classified as ADIs and 40.3% of women said that they had. Of these the most common were shingles (n=6), candida (n=6) and neuropathy (n=3).

Thirty-four women (38.4%) indicated that they had been diagnosed with a major health condition other than HIV/AIDS. The most common major health condition affecting women was Hepatitis C, reported by 16 women (46.1% of those experiencing another major health condition).

We also asked if participants had experienced any of five specific conditions. 77.1% of women had experienced low energy or fatigue, 39.4% a sleep disorder, 36.7% lipodystrophy, 35.0% confusion or memory loss and 30.8% weight loss.

Lipodystrophy and lipoatrophy have created additional difficulties for positive people (see for example Persson 2003). While there is still some debate over the most appropriate clinical case definition for these conditions, self-reported body changes remain an important component of diagnosis (Carr et al 1999, Behrens et al 2000). To assess the impact of these we asked participants to respond to a series of statements about their body image. These are presented in Table 10 for all women 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.

Although approximately 40% of both women and men indicated that they had lipodystrophy, women were less likely than men to agree with the statement "Body changes due to lipodystrophy make it obvious to others that people have HIV" (32.1% compared with 51.9%).

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

		% of total sample	% of those with lipodystrophy	% of those without lipodystrophy
Changes in my body due to HIV/AIDS have made me feel sexually unattractive.	strongly disagree	13.4	0 (0)	20.9 (9)
	disagree	40.6	25.9 (7)	37.2 (16)
	agree	25.6	44.4 (12)	20.9 (9)
	strongly agree	20.4	29.6 (8)	20.9 (9)
I am happy with the way my body looks.	strongly disagree	15.1	14.8 (4)	19.6 (9)
	disagree	42.8	59.3 (16)	34.8 (16)
	agree	32.9	18.5 (5)	39.1 (18)
	strongly agree	9.2	7.4 (2)	6.5 (3)
Body changes due to lipodystrophy make it obvious to others that people have HIV.	strongly disagree	21.5	11.5 (3)	22.2 (10)
	disagree	48.8	38.5 (10)	55.6 (25)
	agree	23.7	38.5 (10)	17.8 (8)
	strongly agree	6.0	11.5 (3)	4.4 (2)

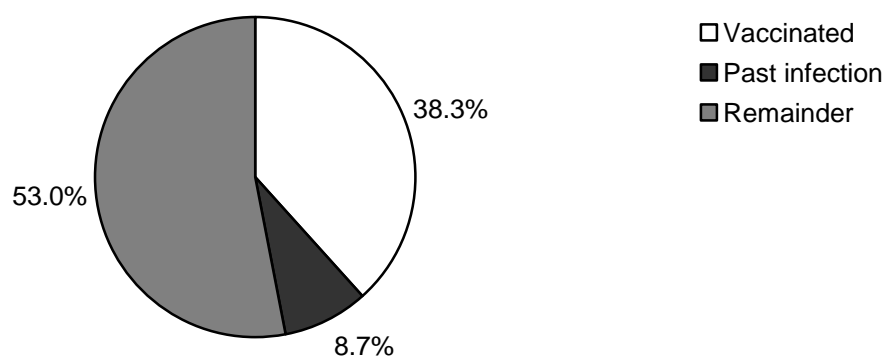
HEPATITIDES

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

8.7% of women (n=8) had at some point had Hepatitis A, and 38.3% had been vaccinated against this virus. This means that 53% of women may currently be at risk of Hepatitis A infection

FIGURE 3 Hepatitis A status

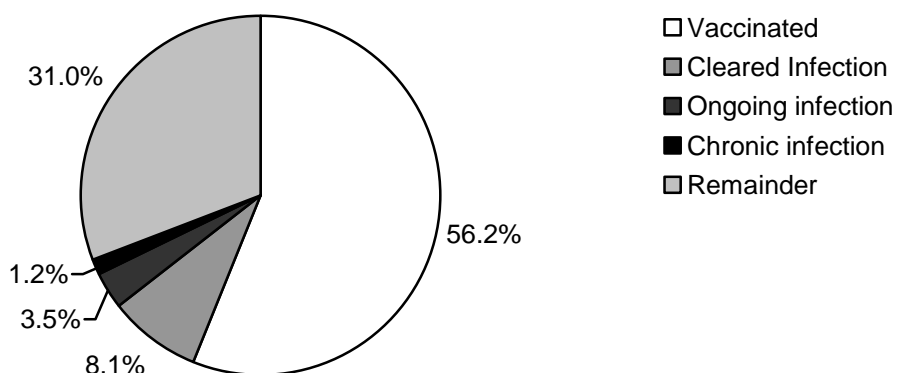


Hepatitis B

A total of eleven (12.7%) of women had at some time been diagnosed with Hepatitis B. Of these, 7 had cleared the infection, 3 had an ongoing infection and one had a chronic infection. Seven women reported experiencing current symptoms.

In addition to those who had experienced Hepatitis B infection, 56.2% of women had been vaccinated against this virus. This means that 31.0% may currently be at risk of being infected with Hepatitis B.

FIGURE 4 Hepatitis B status

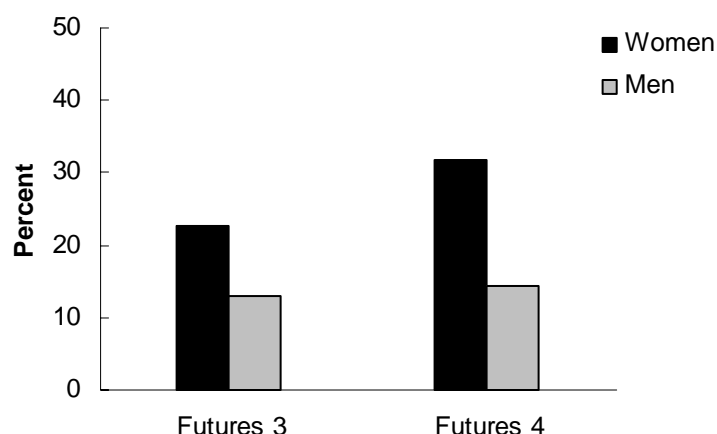


Hepatitis C

Only 13 women (14.6%) had not been tested for Hepatitis C. This is fewer than the 24.8% untested reported in the previous HIV Futures study (2001), suggesting increased testing among Australian PLWHA. 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 30.3% (n=27) of the total sample of women had Hepatitis C. This is 35.6% of women who had been tested for Hepatitis C. Women were significantly more likely than men (14.5%) to have Hepatitis C (30.3% compared with 14.5%).

When we look at co-infection with Hepatitis C by gender across the two most recent HIV Futures surveys (Figure 5), we see that a higher proportion of women than men had Hepatitis C in both 2001 and 2003. The proportion of co-infected women has increased from 22.7% of the Futures 3 sample compared with 30.3% of the Futures 4 sample. The proportion of co-infected men has remained fairly stable, comprising 13.1% of the Futures 3 sample and 14.6% of the Futures 4 sample. These differences may reflect increased testing amongst women, as only 14.6% of women participating in Futures 4 had not been tested for Hepatitis C compared with 24.7% of those from Futures 3, while 28.2% of men from Futures 4 had not been tested, compared with 35.6% of men from Futures 3.

FIGURE 5 Comparison of prevalence of co-infection with Hepatitis C amongst women and men participating in the Futures 3 and Futures 4 surveys.



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).

Women had first been diagnosed with Hepatitis C between 0 and 24 years ago² (mean=11.5 median=10.6) and believed they had been infected between 2 and 28 years ago (mean=14.0, median=13.3).

Eight of the 27 co-infected women (29.6%) had taken a genotype test for Hepatitis C. Of these, 3 did not know what the result of this test was, 2 indicated the result was Type 2, 1 Type 1, 1 Type 3 and 1 Type 4, 5 or 6. Table 11 shows how women believe they were infected with the Hepatitis C virus.

TABLE 11 Women’s reported mode of Hepatitis C infection (number of those with Hepatitis C)

Injection Drug Use (IDU)	16
During sex	4
Don’t know	4
Blood transfusion/Blood products	1

Hepatitis C related symptoms were experienced by 6 (22.2%) women with the Hepatitis C virus, while 7 (25.9%) stated that they did not know if they were experiencing Hepatitis C related symptoms. The most commonly mentioned symptom was fatigue/tiredness, with 5 out of 6 of those who have symptoms reporting this symptom. Only 2 women with Hepatitis C had ever undertaken medical treatment specifically for Hepatitis C and both had been treated with combination therapy of interferon and ribavirin. Three women had taken some form of complementary therapy.

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

Hepatitis C co-infected participants were also asked about health monitoring and management. Two co-infected women did not currently see a doctor for Hepatitis C treatment or management, while 81.5% (22) saw their primary HIV doctor for management of Hepatitis C. No women saw a separate Hepatitis C doctor or specialist.

Co-infected women were asked whether they had received less favourable treatment at medical services as a result of having Hepatitis C. Three women had ever had this experience, one in the last 2 years.

12 (45%) of women co-infected with Hepatitis C found that HIV community services met their needs, while 11 (40.7%) said that they did not, as detailed in table 12 below.

TABLE 12 Reasons HIV services do not meet needs of co-infected women
(percent of all HIV/Hepatitis C co-infected women)

They have a poor understanding of Hep C co-infection	48.1 (n=13)
They have a poor understanding of IDU issues	18.5 (n=5)
I don't want to disclose my Hep C status	3.7 (n=1)

(Multiple responses possible)

Detailed data were collected on testing and treatment history for women and men co-infected with HIV and Hepatitis C 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.

Multiple Hepatitides

One woman reported being infected with both Hepatitis A and C, 5 women with Hepatitis B and C and 3 women reported co-infection with Hepatitis A, B and C.

Hepatitides: 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 hepatitides whether they had been given a liver function test (LFT) 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 women's 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.

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

	N	Had LFT (N)	Abnormal result (N)	Don't know results (N)
Hepatitis A only	3	3	0	1
Hepatitis B only	2	2	0	1
Hepatitis C only	16	13	3	2
Hepatitis A and C	1	1	0	0
Hepatitis B and C	6	5	1	1
Hepatitis A, B and C	3	2	1	1

The majority of women with a history of Hepatitis infection reported having had an LFT (around 84% for all categories). Abnormal results were most common in the presence of Hepatitis C infection.

Women who had Hepatitis C were more likely to have undergone a liver biopsy than those in the other categories, with 3 women with Hepatitis C only, one with Hepatitis B and C and one with a history of Hepatitis A, B and C, having had a liver biopsy. Of these, all of the women except one with Hepatitis C only, reported having liver fibrosis. One, with Hepatitis C only reported stage 1 fibrosis and one with Hepatitis A, B and C reported stage 4 fibrosis. The other women did not report the biopsy result.

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

TABLE 14 Health improvement strategies (percent of women)

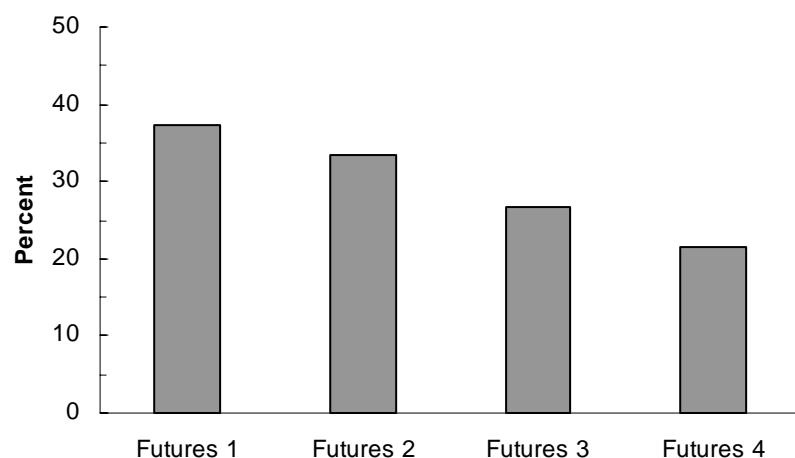
Healthy eating	83.2
Exercise	75.3
Sleep	67.8
Taking pills on time	62.3
Spending time with family	56.5
Spending time with friends	53.5
Relaxation	52.2
Spending time with pets	48.7
Complementary therapies	40.8
Spending time with partner	37.8

(Multiple responses possible)

Prophylaxis

21.4% of women were taking prophylaxis for opportunistic infections. Those using prophylaxis had significantly lower most recent mean CD4 count than those who were not ($t(71)=-3.342, p=0.001$). As figure 6 below shows, the percent of women using prophylaxis for opportunistic infections has decreased steadily from 36% of women in 1997 to 21% in 2003.

FIGURE 6 Women’s use of prophylactic treatments over four Futures surveys (percent of all women)



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 women agreed that exercise, healthy eating and an optimistic outlook were important or very important strategies (see table 15). Those who indicated that they exercised and ate well were more likely to agree with the respective statements.

TABLE 15 Attitudes to health management (percent of all women)

Looking after my physical fitness is an important part of managing my HIV infection.	strongly agree	46.8
	agree	52.1
	disagree	1.1
	strongly disagree	0
Healthy eating is an important part of managing my HIV infection.	strongly agree	48.3
	agree	46.4
	disagree	4.8
	strongly disagree	0
Keeping an optimistic frame of mind is an important part of managing HIV infection.	strongly agree	52.8
	agree	47.2
	disagree	0
	strongly disagree	0
As long as I am well I prefer not to think about HIV/AIDS.	strongly agree	19.0
	agree	33.1
	disagree	44.5
	strongly disagree	3.4
Life has become more meaningful since I became HIV positive.	strongly agree	13.8
	agree	32.7
	disagree	39.0
	strongly disagree	14.4

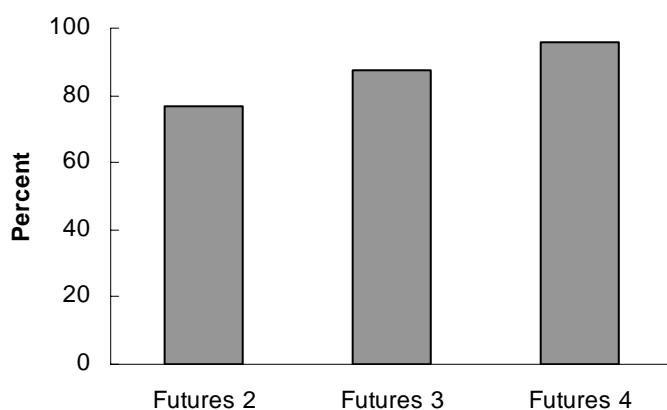
Other Health Monitoring

We asked a series of questions about other health monitoring activities. The long term effects of living with HIV and taking HIV medication have made health concerns such as high cholesterol, cardiovascular difficulties and osteoporosis increasingly important for positive people. 19.6% of women had undergone a bone density test in the last two years and 6.6% more than two years ago. 48.9% reported having a fasting cholesterol test in the last two years, and 8.1% more than two years ago.

Almost all women reported having a cervical smear (Pap) test (98.7%), and 95.7% reported having a test in the last twelve months. Generally women reported having one test in the last year (71.6% 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. Of the abnormal results reported, most women did not specify the test result, indicating only that there were abnormal cells found.

As figure 7 below shows, the percentage of women who reported having a smear test in the 12 months prior to completing the survey has increased consistently from 77% of those who participated in Futures 2, to 88% of those from Futures 3 to 96% of the present sample. This trend may indicate increased awareness amongst positive women of the importance of having regular smear tests.

FIGURE 7: Percent of women who had a cervical smear in the previous 12 months, across three surveys.



TREATMENTS

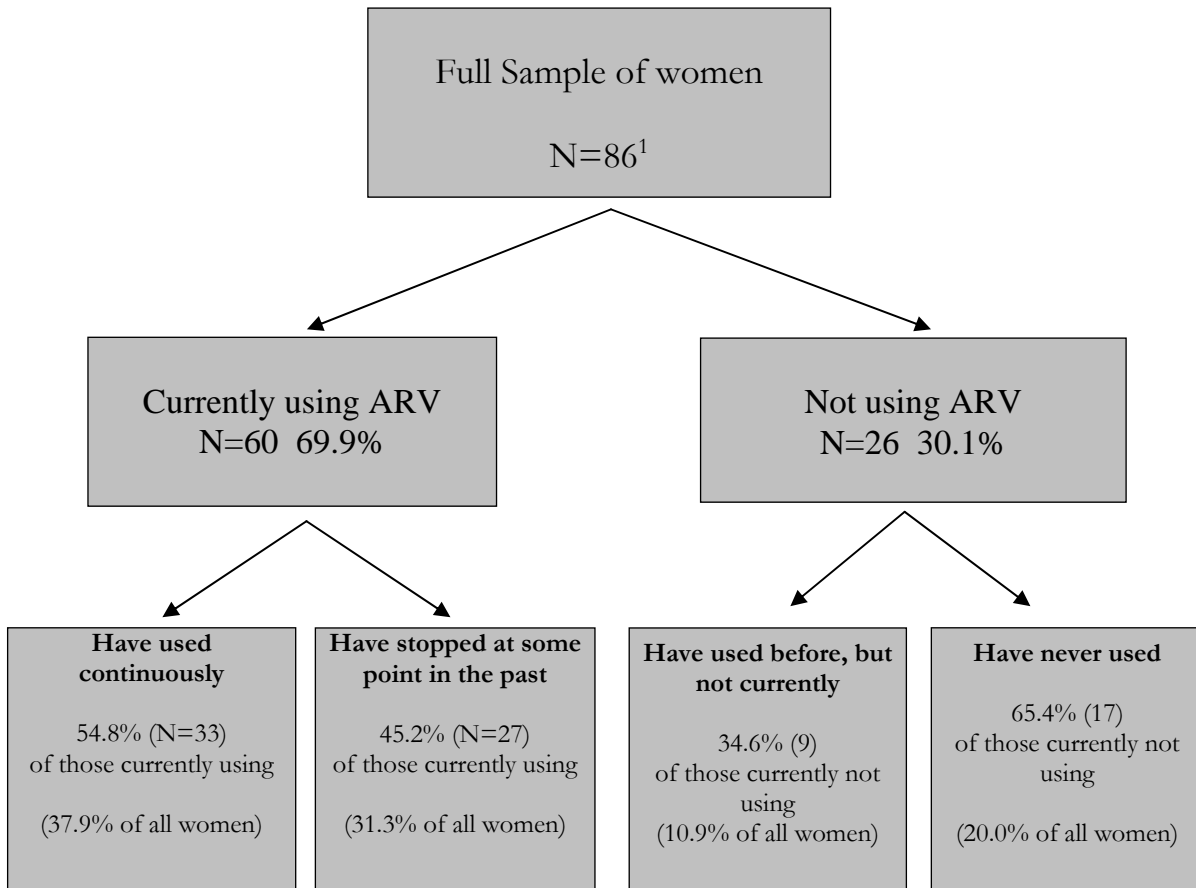
This chapter reports on the treatment experiences of women. The main emphasis is on antiretroviral treatments (ARV), as these are dominant in the lives of HIV positive people. There is also some discussion of complementary medicines and medications for other health conditions. While we have seen a reduction 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 for day to day life. This section addresses some of this complexity by examining the experience of antiretrovirals both in clinical and social terms.

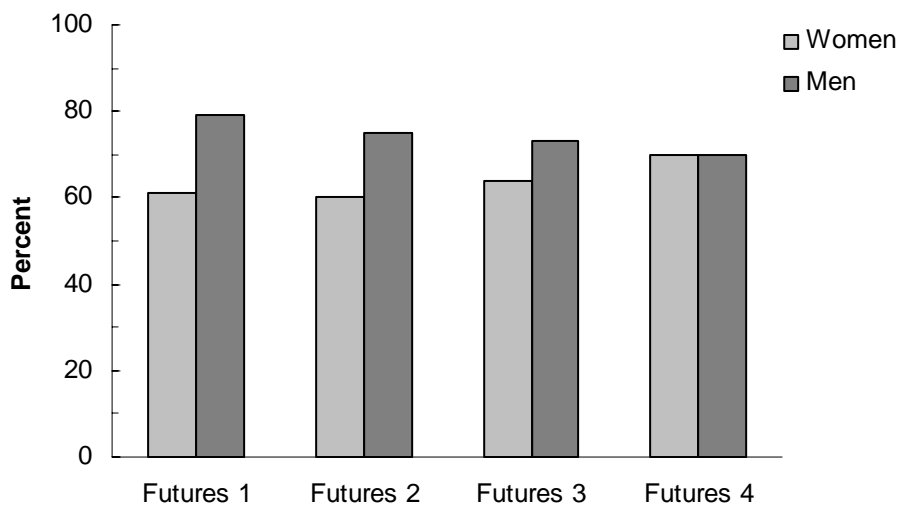
Of the full sample, 80.5% of women had used ARV at some point, and 69.9% were currently using these treatments. A summary diagram of the uptake of antiretrovirals can be found on page 16.

FIGURE 8 Use of antiretroviral therapy



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

FIGURE 9 Current use of ARV by gender and year



As figure 9 shows, in 1997 and 1999 women were significantly less likely to be using ARV than men. By 2001, this difference was no longer significant and in 2003 the proportions of men and women using ARV were the same. We can see that this change in the gendered pattern of ARV use has resulted from a gradual increase in the proportion of women using ARV between 1997 and 2003 from 61% to 70%, alongside a corresponding decrease in the proportion of men using ARV, from 79% to 70%.

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

The majority of women (65.5%) were on a combination of 3 antiretroviral drugs³, with 23.9% on more than three antiretroviral drugs, 6.9% on two, and 3.8% on monotherapy.

TABLE 16 Antiretroviral drugs used by women: percentage of those currently using ARV

Nucleoside Reverse Transcriptase Inhibitors (NRTIs)	
Lamivudine (3TC, Epivir)	18 (29.2%)
Abacavir ,1592 (Ziagen)	7 (11.4%)
Stavudine, d4T (Zerit)	7 (10.5%)
Didanosine, ddl (Videx)	3 (5.2%)
Zidovudine, AZT (Retrovir)	4 (6.2%)
ddl ec (Videx ec, didanosine ec)	5 (8.3%)
Zalcitabine, ddC (Hivid)	0 (0.0%)
Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)	
Nevirapine (Viramune)	13 (20.7%)
Efavirenz (Sustiva, Stocrin)	12 (19.2%)
Delavirdine (Rescriptor)	2 (3.1%)
Nucleotide Analog Reverse Transcriptase Inhibitors	
Tenofovir (Viread)	16 (26.1%)
Protease Inhibitors	
ABT-378/r (Lopinavir, Kaletra)	7 (12.0)
Ritonavir (Norvir)	7 (10.8%)
Indinavir (Crixivan)	3 (4.2%)
Nelfinavir (Viracept)	9 (14.8%)
Saquinavir (Invirase, Fortovase)	4 (6.6%)
Amprenavir (Agenerase)	1 (1.5%)
Fusion Inhibitor	
T-20	0 (0.0%)
Combination Medications	
AZT & 3TC (Combivir)	12 (18.8%)
AZT & 3TC & Abacavir (Trizivir)	11 (17.5%)
Other	
	5 (7.5%)

Respondents were also asked specifically about their use of the immune stimulant Interleukin 2 and no women were using it.

³ Combivir counts as 2 drugs, Trizivir as 3 drugs

Difficulties of Taking ARV

Overall, 81.7% of those women currently using antiretroviral treatments reported that they had some difficulty taking them.

TABLE 17 Difficulties of taking ARV among those currently using ARV
(percent of women experiencing at least one difficulty)

Remembering to take drugs on time	47.2
Side-effects	42.7
Organising meals around medication	40.7
Taking medication in public	40.0
Taking a large number of tablets	35.7
Carrying/transporting medication	26.1
ARV drugs make it difficult to take medication for other health conditions	12.5
Medication taken for other health conditions makes it difficult to take ARV	4.8
Other	13.3

(Multiple responses possible)

Side-effects were reported by 35% of women currently using ARV, or 42.7% of women experiencing at least one difficulty taking ARV. The most commonly reported problems were nausea or vomiting (n=13, 27% of those experiencing at least one difficulty), diarrhoea (n=7, 14%) lipodystrophy (n=6, 12%) and bowel or digestive problems (n=6, 12%).

Attitudes to ARV

Most women currently taking ARV reported concern over the future efficacy of their treatments. Three quarters (76.3%) agreed or strongly agreed with the statement “I am worried that in the future my medication will stop working for me”. This is substantially higher than the proportion agreeing or strongly agreeing with this statement in 2001 (58.8%). This difference was due to an increased proportion strongly agreeing (29% in 2003 compared with 16%) and a decreased proportion disagreeing with the statement (9.7% in 2003 compared with 31%). Over half of the women (58.1%) agreed or strongly agreed with the statement “Taking tablets gives me an unwanted reminder that I have HIV”, which is the same as the proportion who agreed or strongly agreed with the statement in 2001 (58.0%).

TABLE 18 Attitudes to medication: percentage of those currently using ARV

	strongly disagree	disagree	agree	strongly agree	don't know
I am worried that in the future my medication will stop working for me.	4.5	9.7	47.3	29.0	9.0
Taking tablets gives me an unwanted reminder that I have HIV.	8.3	32.2	32.2	25.9	1.4

Health Status of Those Using ARV

Women taking ARV had significantly lower viral loads (mean of 8,451 copies/ml compared to 70,698 copies/ml) than those not taking any antiretroviral medication. This difference is mainly explained by the large proportion of those on ARV with a viral load below detectable levels as can be seen in table 19.

TABLE 19 Viral load of those taking and not taking antiretroviral therapy
(percent within rows)

		Viral load on most recent test			
		Below detectable levels	500-9999	10000-49999	50000+
ARV Use	Current	76.9	11.5	5.8	5.8
	Past	12.5	25.0	25.0	37.5
	Never	16.7	16.7	58.3	8.3

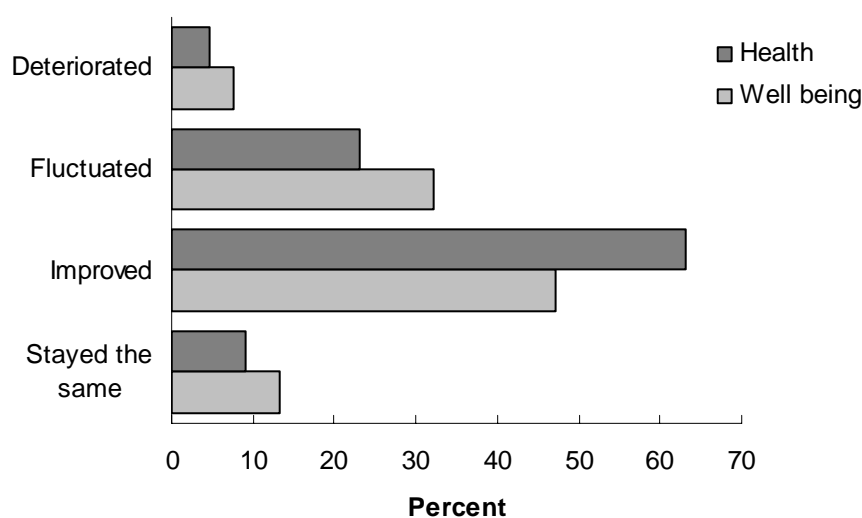
Women taking ARV had marginally lower CD4 counts (mean of 467.1 cells/ μ l compared to 582.4 cells/ μ l) than those not taking ARV (this difference was not statistically significant) (table 20).

TABLE 20 CD4 of women taking and not taking antiretroviral therapy
(percent within rows)

		CD4 on most recent test		
		0-249	250-499	500+
ARV Use	Current	18.9	37.7	43.4
	Past	0.0	37.5	62.5
	Never	0.0	30.8	69.2

26.2% of women currently taking antiretroviral treatments have had an ADI at some point. None of the women currently not taking treatments have ever had an ADI. Women who had had an ADI were more likely to report their health as poor or fair, however, there were no differences in their ratings of well-being. Figure 10 illustrates the effect of commencing antiretroviral medications on women's health and well-being.

FIGURE 10 Effect of commencing antiretroviral medication on health and well-being
(percent of those women taking ARV)



THOSE ON COMBINATION THERAPY

Different Combinations

There was considerable variation in the combinations currently in use by women. The most common combinations were two NRTIs and one NNRTI (15.1%) and two NRTIs and one PI (14.5%). 52.6% of women on combination therapy had been on ARVs for at least six years. Most started combination therapy at a time when their viral load was high (Median= 94,128, mean = 237,192 copies/ml) and their CD4 count was low (median=208, mean = 223). Table 21 below, gives the CD4 and viral load of women at the time they commenced combination antiretroviral treatment.

TABLE 21 Results of serological tests prior to commencement of ARV
(percent of those on ARV)

CD4/T-cell count		HIV Viral load			Total
		500-9999	10000-49999	50000+	
	500+	0.0	0.0	4.0	4.0
	250-499	4.0	12.0	24.0	40.0
	0-249	4.0	12.0	40.0	56.0
	Total	8.0	24.0	68.0	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 22 gives the groupings from these guidelines, the treatment recommendations, the percentage and number of women that were in each group at the commencement of antiretroviral treatment and the mean number of years they have been on treatment.

TABLE 22 Treatment recommendation at commencement of ARV treatment

	Guideline Group: At commencement of ARV combination				
	Symptomatic (ADI)	Asymptomatic and CD4<200	Asymptomatic and CD4 200-350	Asymptomatic CD4>350, VL>50,000	Asymptomatic CD4>350, VL<50,000
Treatment recommendation	Treat	Treat	Treatment should be offered	Recommend treatment	Defer treatment
Percentage of those currently on ARV	31.0 (N= 13)	19.0 (N= 8)	38.1 (N= 16)	9.5 (N= 4)	2.4 (N= 1)
Mean number of years using ARV	6.06	6.17	5.44	6.75	7.0

Table 23 gives these groupings based on women'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, 35.1% are in the same guideline category as when they commenced therapy, while 54.1% have improved, and 10.8% have deteriorated.

TABLE 23 Treatment recommendation groups by current status

	Guideline Group: Currently				
	Symptomatic (ADI) (N=16)	Asymptomatic and CD4<200 (N=3)	Asymptomatic and CD4 200-350 (N=6)	Asymptomatic CD4>350, VL>50,000 (N=0)	Asymptomatic CD4>350, VL<50,000 (N=27)
Percentage currently using antiretrovirals	100.00	100.00	75.0	0	87.1
Mean number of years using ARV	6.83	10.72	2.38	0	5.85
Percentage previously used antiretrovirals	0	0	22.2	66.7	10.3
Percentage never used antiretrovirals	11.1	0	11.1	33.3	20.5

When asked about the circumstances surrounding their commencement of combination therapy, women were most likely to indicate that they were advised to do so by their doctor (58.9%), although the importance of clinical indicators, treatment developments and treatment information is also clear.

TABLE 24 Circumstances surrounding commencement of treatment among women currently on combination ARV

My doctor advised me to begin this treatment	58.9
I had a big drop in my CD4/T-cell count	46.5
I had a big rise in my viral load	23.9
I became very ill	21.4
New drugs became available	20.8
Information showed that this treatment is effective	19.3
I was hospitalised due to HIV-related infections	12.1
I had just tested positive to HIV	10.5
A number of my positive friends started this treatment	4.8
Close friends advised me to begin this treatment	4.8
A treatments officer advised me to begin this treatment	4.1
My partner advised me to begin this treatment	3.2
Other	13.9

(Multiple responses possible)

Number of Different Combinations

Among those currently using combination therapy, women had used between 1 and 10 combinations, with the median being 3. Within the last 12 months, 60.7% had used the one combination and 28.7% had used two. Women currently on combination ARV were asked to describe the circumstances surrounding their most recent change in combination (see table 25).

TABLE 25 Primary circumstance surrounding most recent change in combination among women currently on combination ARV who have changed combinations

Side-effects became too severe	43.2
Drug resistance developed	11.4
They were not working for me	2.3
Other (please specify)	11.8

When asked how many combinations they believed they still had access to, 2.8% of women indicated that they thought they had only one remaining, 26.4% had a few and 37.3% felt they had many. 28.5% said they didn't know how many combinations they had left. 5.0% of those currently on combination therapy believed they had no combinations remaining.

TABLE 26 Correlates of number of remaining combinations for those on ARV
(Combinations remaining by Mean years positive; Mean CD4; Mean Viral load)

	Mean year tested positive	Mean CD4 on most recent test	Mean viral load on most recent test
None	1991	204	Not reported
One	1991	312	2,541
A few	1991	461	19,449
Many	1992	492	6,758
Don't know	1994	454	3,642

When we examine the health status of those women with varying numbers of combinations remaining, we can see that the pattern differs for each of these categories.

TABLE 27 General health status for women with different numbers of combinations of ARV remaining
(Percent within combinations remaining)

		Health			
		Poor	Fair	Good	Excellent
Combinations remaining	None	0.0	66.7	33.3	0.0
	One	0.0	100.0	0.0	0.0
	A few	15.4	23.1	38.5	23.1
	Many	0.0	19.0	52.4	28.6
	Don't know	6.3	37.5	50.0	6.3

There was a significant relationship between number of remaining combinations and self-rated well-being. Those women 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 like to rate it as good or excellent. Those unsure about remaining combinations were most likely to rate their well-being as good.

TABLE 28 General well-being for those with different numbers of combinations of ARV remaining (percent within combinations remaining)

		Well-Being			
		Poor	Fair	Good	Excellent
Combinations remaining	None	33.3	66.7	0.0	0.0
	One	50.0	0.0	50.0	0.0
	A few	13.3	26.7	60.0	0.0
	Many	4.8	23.8	42.9	28.6
	Don't know	12.5	31.3	43.8	12.5

Those Not Currently Taking ARV

Of the 30.1% of women who were not using any antiretrovirals, 10.6% had done so in the past. The mean length of time these women had been using ARV was 3 years and 4 months (range 3 months to 6 years) and on average they had ceased using ARV 3 years and 5 months prior to completing the survey (range 6 months to 7 years). At the time that they stopped using ARV, most were using a combination of 3 drugs (n=7), one woman was using two drugs and one woman was on monotherapy.

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 29). Notably the experience of side-effects was the most commonly listed difficulty.

TABLE 29 Difficulties of taking ARV among those who have stopped ARV treatment (N=9)

Side-effects	5
Taking a large number of tablets	4
Remembering to take drugs on time	2
Carrying/transporting medication	2
Other	3

(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. Three said it had fluctuated, three said it had stayed the same, and three that their health had improved. When asked about the impact of ARV on their overall feeling of well-being, three said it had improved, three said it had fluctuated, two said it had stayed the same and one said it had deteriorated. Respondents were asked whether they had lifestyle or clinical reasons for ceasing their use of antiretroviral therapy. Four women gave lifestyle reasons for stopping treatment which included two women who said it was too clean out their system, one who said taking drugs at the right time was too difficult and three women who gave other reasons.

Eight women gave clinical reasons for ceasing ARV treatment (see table 30). Five said that side-effects were a reason for stopping and six said their doctor recommended the cessation. Importantly, two women said that drug resistance was a problem.

TABLE 30 Clinical reasons for stopping treatment (number of women previously on ARV)

Recommended by my doctor	6
Side-effects became too severe	5
Liver toxicity problems	4
Drug resistance developed	2
Complications with Hep C	2
Other	1

(Multiple responses possible)

Those Who Have Never Used Antiretroviral Drugs

19.5% (N=17) of women had never used antiretroviral treatments. Of these 93.3% 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 31).

TABLE 31 Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used antiretroviral drugs (N=15)

If I became very ill	78.0
If I had a significant rise in my viral load	62.9
If I had a significant drop in CD4/T-cell count	61.1
If I was hospitalised due to HIV-related infections	51.1
If my doctor advised me to begin this treatment	34.3
If new drugs became available	27.1
If information showed that combination therapy is effective	21.4
If a treatments officer advised me to begin this treatment	5.7
Other	23.3

(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.

Treatment Decision Making

Two thirds of women indicated that they disagreed with the statement "I am healthy now and don't need to use antiretroviral drugs" (68.9%). Those who agreed with this statement were more likely to be those not currently using any antiretroviral drugs and who rated their physical health more positively. Women were also more likely to disagree than agree with the statement 'People with HIV should start using antiretroviral drugs as soon as possible', however one in four women indicated that they were unsure about this. Those who agreed with this statement were more likely to be using antiretrovirals.

TABLE 32 Attitudes to antiretroviral drugs (percent of all women)

	strongly disagree	disagree	agree	strongly agree	don't know
I am healthy now and don't need to use combination antiretroviral drugs	31.0	37.9	14.0	11.8	5.2
People with HIV should start using antiretroviral drugs as soon as possible	20.6	29.9	8.5	12.6	28.4

Relationship with Treating Doctor

As with previous surveys, most women (95.6%) agreed with the statement "My doctor and I work together to find the best treatment for me", with few expressing uncertainty. Most women (76.1%) agreed with the statement "My doctor knows more about the treatment of HIV than I do".

TABLE 33 Attitudes to antiretroviral drugs (percent of all women)

	strongly disagree	disagree	agree	strongly agree	don't know
My doctor and I work together to find the best treatment for me.	1.3	4.6	55.1	35.5	3.6
My doctor knows a lot more about the treatment of HIV than I do.	5.1	15.7	43.6	32.7	2.9

Treatment Optimism

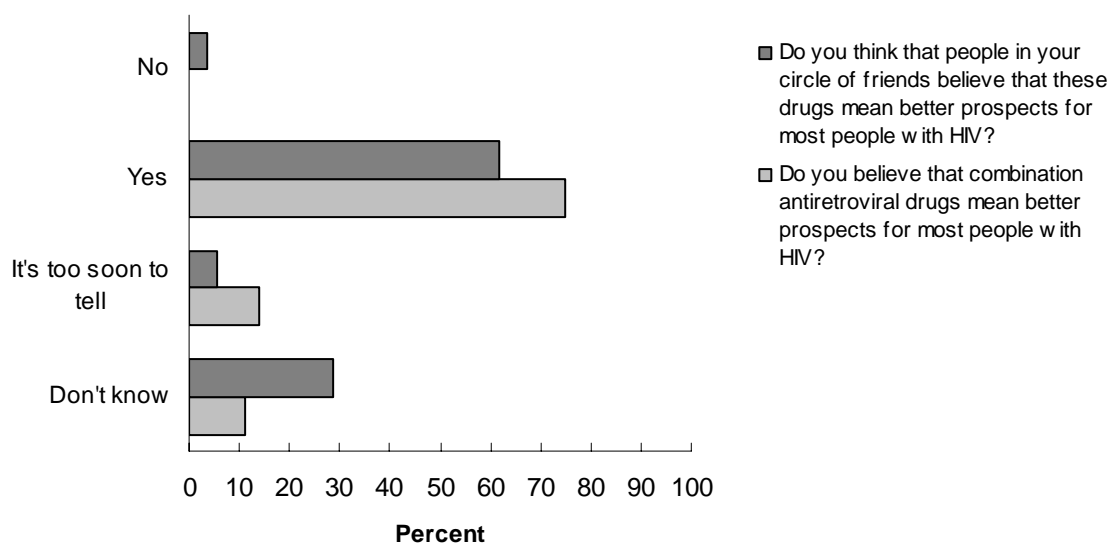
Optimism about the value and effectiveness of antiretroviral treatments continues to characterise the Australian experience, but tempered as always with concerns about the impact and long term effectiveness of these treatments. Only 3.6% of women agreed with the statement “Combination antiretroviral 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” (32.9% agree, 7.5% strongly agree). This harm may in part be that experienced as side-effects. Less than one fifth (15.5%) of women agreed or strongly agreed with the statement “The side-effects of antiretroviral drugs outweigh the benefits”, however, 22.6% were unsure. There was considerable uncertainty about the long term benefit of treatment and if HIV treatments would prevent death from AIDS. However, two thirds (66.8%) agreed with the statement “Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term”, while 14.2% were uncertain.

TABLE 34 Attitudes to antiretroviral drugs (percent of all women)

	strongly disagree	disagree	agree	strongly agree	don't know
Combination antiretroviral drugs are ineffective.	40.5	44.4	1.1	2.5	11.4
Combination antiretroviral drugs are harmful.	14.9	28.7	32.9	7.5	16.0
The side-effects of antiretroviral drugs outweigh the benefits.	13.3	48.6	7.8	7.7	22.6
New treatments will be developed in time for me to gain benefits.	0.0	4.6	39.6	22.2	33.6
HIV treatments will stop me dying from AIDS.	4.6	21.3	19.9	21.5	32.7
Combination antiretroviral drugs have allowed me to plan my life with confidence for the long-term.	3.5	15.5	35.7	31.1	14.2

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’. While three-quarters of women agreed with this statement, 62% agreed that their friends believed that ARV drugs mean better prospects for most people with HIV (see table 34). As figure 11 below shows, the proportion of women agreeing with this statement has increased substantially over time, so that while in 1997 only 42% of women agreed, compared with 60% of men, approximately equal proportions of both women and men agreed in 2003.

FIGURE 11 Women’s and women’s 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, 45.2% of those women currently using antiretroviral medication had taken a break from these at some point (27 women).

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 five months with a median of 3 months. Six women described the break as a structured treatment interruption, while 13 women 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 and Misson 2004). Almost half the women who had taken a break (12/27) indicated that there were lifestyle reasons for taking a break. The specific reasons are given in table 35 below.

TABLE 35 Lifestyle reasons for taking breaks (N=12)

Clean out my system	4
The financial burden became too heavy	2
Taking drugs at the right time was too difficult	1
It didn't fit my lifestyle	1
A special event	1
Other	11

(Multiple responses possible)

When asked if there was a clinical reason for taking the break, two-thirds of those women who had taken a break indicated that there was (18/27). Five women gave both lifestyle and clinical reasons. Table 36 below details clinical reasons for taking breaks. The most commonly cited reason was that the side-effects of treatment became too severe.

TABLE 36 Clinical reasons for taking breaks (N=18)

Side-effects became too severe	8
Recommended by my doctor	4
Drug resistance developed	4
Liver toxicity problems	2
Changing regimens	2
Complications with Hep C	2
Recommended by other health professional	1
Other	5

(Multiple responses possible)

We also asked about the involvement of the participant's doctor in these breaks. Women were less likely to have talked to their doctor about the break prior to taking it (17/27) than they were during the break (21/27) or afterwards (21/27). Over half of the women (17/27) spoke with their doctor at all stages of their treatment break whilst 3 spoke with the doctor only during and after the break and 2 after the break only.

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 and 38 below gives the results of the four questions asked. More than one third of women said that their health had deteriorated. When asked about their general well-being, a similar proportion said that it had improved.

TABLE 37 Effect of break on health, well-being (number of women)

	Health	Well-being
Stayed the same	4	4
Improved	5	9
Fluctuated	8	7
Deteriorated	10	7

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

TABLE 38 Effect of break on CD4 and viral load (percent of those taking a break)

	CD4	Viral load
Stayed the same	19.3	19.4
Increased	7.7	60.5
Went up and down	19.47	15.9
Decreased	53.7	4.2

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.

26.8% of women who had ever used antiretroviral treatments indicated that they had some sort of ARV resistance test. This included 20 women who were currently on antiretroviral treatment and one who was not. The average length of time since the most recent resistance test was 12 months (median=12 months). Almost all (91.7%) women had had their most recent test in the last two years. Of those who had resistance testing, 19 found resistance to one or more antiretroviral drugs. This resulted in a change of drugs for 15 women. Table 39 show the changes in clinical markers for all those who underwent resistance testing and who changed treatments. The number of women is given rather than the percentage due to the small overall numbers.

TABLE 39 Effect of resistance testing and treatment change on viral load and CD4 (number of those changing treatments)

	Change in viral load due to change	Change in CD4 due to change
Decreased*	9	4
No change	4	3
Increased*	3	8
Don't know	4	6
Total	20	21

*Note that an increase in viral load means it worsened whilst a decrease means it improved and that the opposite is true for changes in CD4 counts.

Dosing and Adherence

Adherence to antiretroviral medication continues to be a significant concern for both people living with HIV/AIDS (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, women were taking medication 2.39 times per day (range 0 to 8, median=2). The number of times they were taking specific types of medication is shown in table 40 below. 73.4% of women were taking ARV twice daily, 15.0% three times a day and 3.4% once a day.

TABLE 40 Number of times participants take medications

	Mean	Median	Range
Antiretroviral drugs	2.15	2.00	0-5
Complementary therapies	1.48	1.00	0-5
Medication for other health conditions	1.50	1.00	0-6

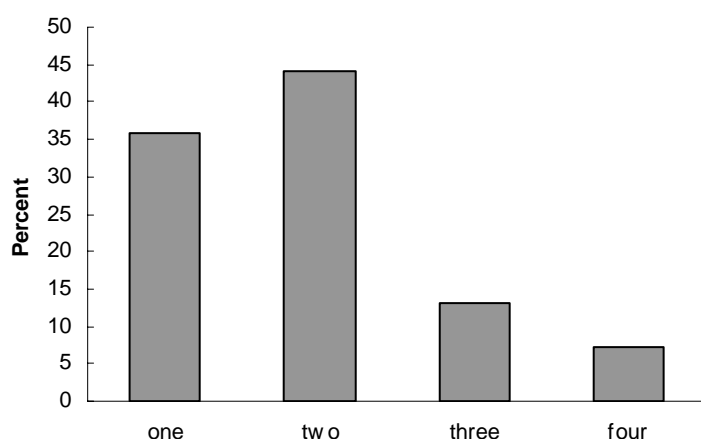
Participants who were currently using antiretroviral medication were asked how many doses they had missed on the day prior to completing the survey and the day before that. Combining the data from these two measures, 62.8% of women reported missing no doses on the two days, 8.7% missed one dose, 20.7% missed two doses and 7.8% 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. Slightly less than half (43.9%) of women obtained their prescription from a specialist in an outpatient clinic. 28.8% obtained got their prescriptions for antiretroviral drugs from a GP who specialises in HIV/S100 prescriber and a similar number obtained them from a doctor at a sexual health centre (25.2%). Fewer obtained their scripts from another GP (1.8%), or from a HIV specialist while an inpatient (4.0%).

When asked from how many places participants obtained their medications, they were most likely to say two places (44.1%) with slightly fewer saying one place (35.7%). Fewer went to three or more sites (See figure 11). When asked how difficult it was to do this, 42.8% said it was not difficult, 47.9% said somewhat difficult and 9.3% said very difficult. Women were more likely than men to say that it was somewhat or very difficult to collect their medications (60.3% compared with 39.3%).

FIGURE 12 Number of prescription pick up points



Clinical Trials

A total of 24.5% of women had participated in a clinical trial for HIV-related treatment and 10.7% of all women (n=9) had participated in a clinical trial in the last three years. The main treatments that women had trialled were AZT (n=4) and 3TC (n=2). They had on average been on these trials for 12.7 months. The circumstances surrounding participation in the trial are given in table 41 below. These data show that altruistic intent as well as involvement of doctor was important in this decision.

TABLE 41 Reasons for participating in clinical trials
(number of those who have participated in a trial)

I felt my experience could benefit others	9
My doctor and I decided together	6
I felt I had enough information about the trial	4
I had no other treatment options	3
My other treatments were not working	3
It was the only way I could get the treatment	2
I felt pressured to go on the trial	2
Other	2

(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". More than one quarter of women (28.1%) said they did not know, while 45.6% either agreed or strongly agreed with the statement. A further 26.3% disagreed or 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 of the women were currently taking vitamin or mineral supplements, while around one quarter were taking herbal supplements or using other forms of complementary medicine. Compared to men, women were more likely to be using herbal therapies (27% compared with 16%).

TABLE 42 Current use any of complementary medicine

Vitamin/mineral supplements	55.8
Herbal therapies/supplements	26.6
Traditional Chinese medicine	7.0
Other traditional medicine	8.2
Other	12.2
(Multiple responses possible)	

Participants were asked where they obtained these services or supplements. One quarter of women obtained these from a private practice and one fifth from a health service. Smaller numbers of women 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. Women were significantly less likely than men to say that they obtained therapies from an AIDS community organisation (10% compared with 21%).

TABLE 43 Source of complementary medicine

Private practice	24.7
Health service	20.0
AIDS community organization	10.2
PLWHA organisation	6.6
Other	51.6

Other complementary therapies used by women included mind-body therapies such as massage, used by over 40% of women, meditation and acupuncture. In addition, over one quarter of women indicated that they used marijuana medicinally.

TABLE 44 Use of other complementary therapies

Massage	41.7
Meditation/visualisation	29.5
Marijuana for therapeutic purposes	26.8
Acupuncture	5.9
(Multiple responses possible)	

Many women (83.4%) believed complementary therapies can improve well-being (see table 45). More than two thirds of women believed complementary therapies can boost the immune system, almost two thirds of women believed complementary therapies can reduce side-effects while around half the women also believed complementary therapies can delay the onset of illness due to HIV. However, around one third of women were unsure about these three statements and these women were more likely to not be 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 women who use complementary therapies spent \$21.60 per week on them (median=\$20.00).

TABLE 45 Attitudes to complementary therapies (percent of total sample)

Complementary therapies can delay the onset of illness due to HIV	strongly disagree	2.5
	disagree	8.6
	agree	40.7
	strongly agree	8.9
	don't know	39.2
Complementary therapies can improve well-being	strongly disagree	1.3
	disagree	0.0
	agree	51.4
	strongly agree	32.0
	don't know	15.3
Complementary therapies can reduce the side-effects of conventional medical treatments	strongly disagree	1.3
	disagree	1.1
	agree	43.7
	strongly agree	19.9
	don't know	34.1
There is not enough evidence to be sure about the benefits of complementary therapies	strongly disagree	4.4
	disagree	35.7
	agree	31.4
	strongly agree	2.5
	don't know	25.9
Medicine's focus on anti-HIV drugs is very limited	strongly disagree	2.6
	disagree	17.0
	agree	33.0
	strongly agree	7.3
	don't know	40.0
Complementary therapies can boost the immune system	strongly disagree	1.3
	disagree	2.6
	agree	50.1
	strongly agree	20.4
	don't know	25.6
Complementary therapies are a central part of my anti-HIV treatments	strongly disagree	8.5
	disagree	32.4
	agree	32.5
	strongly agree	12.1
	don't know	14.5

Other Medication

Participants used a range of other prescribed medication. In all 48.4% of women were using prescribed medication other than antiretroviral therapies. The main medications being used were antidepressants (n=10), contraceptive agents (n=7), anti-anxiety medications (n=4) and cholesterol lowering agents (n=3). A high proportion of women reported using antidepressants and other medicines for mental health conditions. Please refer to page 44 for discussion of these medicines.

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 (for example, specialist HIV wards in hospitals, high HIV caseload general practitioners and sexual health services), 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 81.6% of women for HIV specific treatment and for 54.6% of women, for general health treatment.

TABLE 46 Physician used for general and HIV-related treatment
(percent of total sample)

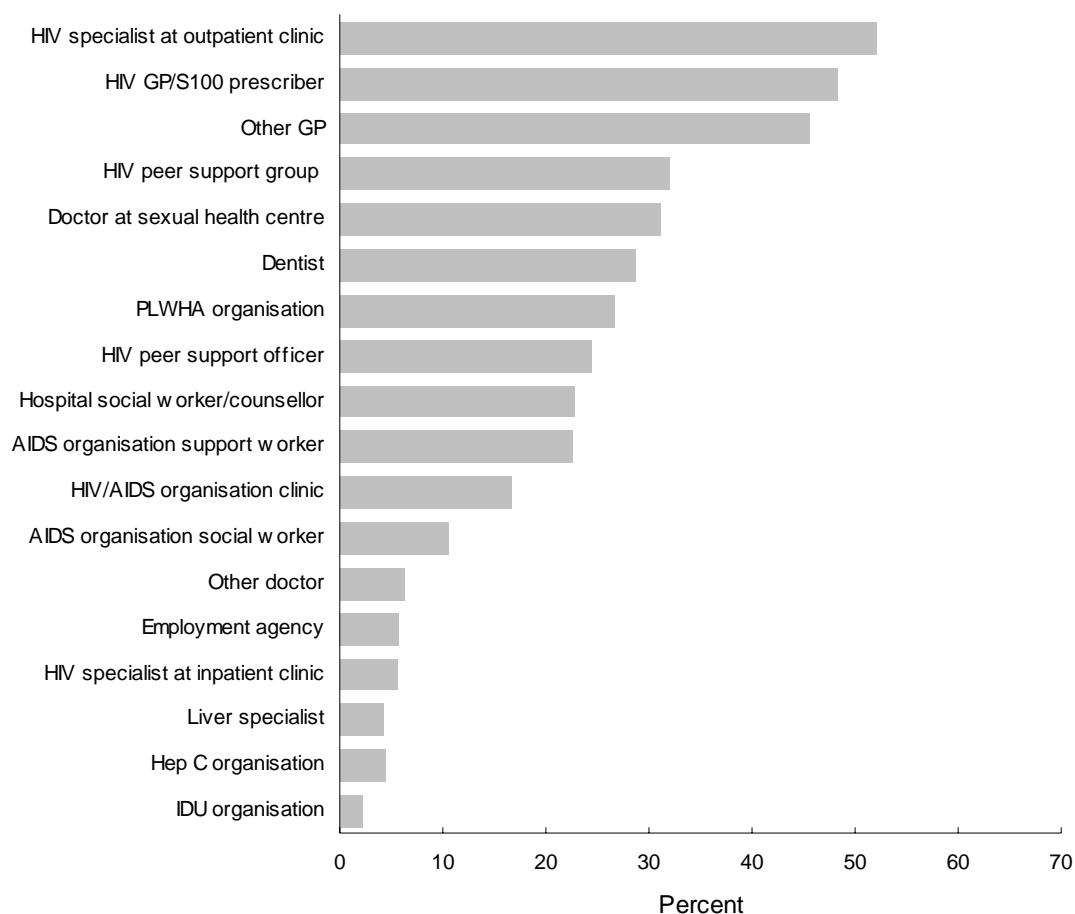
	For general treatment	For HIV specific treatment
HIV GP/S100 Prescriber	36.7	37.0
Other GP	30.9	1.3
HIV specialist at outpatient clinic	17.9	43.3
HIV specialist at inpatient clinic	0.0	1.3
Doctor at sexual health centre	9.9	3.5
Other doctor	3.5	13.6
Other	1.2	0.0

43.9% of women 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, 97.9% said that the doctor they saw for their general health or treatment knew of their HIV status. Women were significantly more likely than men to say that they see different doctors for HIV-related treatment and general medical treatment (56.1% vs 44.1%).

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 (see figure 13). Women 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 13 Services used in the last six months (percent of women)



(Multiple responses possible)

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. Peer support was the most commonly used service at HIV/AIDS organisations by women followed by social contact with other PLWHA which indicates that peer support is still an important function of HIV/AIDS organisations for women. Women were also significantly more likely than men to report that they used HIV/AIDS organisations for peer support (60.0 versus 35.0%). Other organisations were more likely to be used than HIV/AIDS organisations for library or pharmacy services.

TABLE 47 Percent of women who use services through HIV/AIDS organisations and other organisations (percent of all women)

	Use service at HIV/AIDS organisation	Use service at other organisation
Peer support group	60.4	4.4
Social contact with other PLWHA	58.4	3.9
Treatments advice	55.6	23.1
Treatments information	46.4	11.3
Informal peer support	40.7	13.1
Financial assistance	37.3	10.1
Counselling	35.1	27.1
Complementary therapies	22.3	29.8
Financial advice	21.1	17.4
Pharmacy services	19.2	40.6
Community education campaigns	18.2	3.0
Legal advice	16.8	22.7
Volunteer carer	12.3	3.0
Internet based information	11.5	19.7
Transport	9.9	35.4
Respite care	7.3	9.8
Housing assistance	6.1	27.0
Employment services	5.8	22.8
Internet access	5.3	36.3
Return to work skills	2.5	15.8
Library	3.2	43.8
Drug/alcohol treatment	2.8	15.8
Mental health services	1.1	13.8
Paid carer	0.0	5.1

(Multiple responses possible)

38% of women 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 (n=8 women), peer support groups (n=7) women's peer support (n=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 48 Sources of information for women about treatments and living with HIV (percent of sample)

	Information about Treatments	Information about HIV Management	Information about Living with HIV
HIV GP/S100 prescriber	53.5	48.6	28.1
Other GP	4.2	9.7	10.6
HIV specialist at outpatient clinic	49.8	41.0	21.8
HIV specialist at inpatient clinic	17.1	12.2	8.6
Other doctor	0.9	0.0	2.8
Public Health Nurse	0.0	2.0	4.1
Other Nurse	11.5	12.1	12.0
Pharmacist	12.5	1.9	4.2
Alternative/Complementary therapist	2.3	3.0	6.1
Dietician	1.1	7.6	6.4
Dentist	13.1	14.4	11.3
Peer Support Officer	17.9	21.0	24.9
Sexual Health Service	26.0	28.6	18.6
Family Planning Association	0.0	0.8	5.1
Sex worker association	2.2	4.0	6.1
Treatments Officer	7.7	0.0	0.0
Other HIV/AIDS Organisation staff	1.3	1.3	18.8
Positive Women's Organisation	31.6	35.3	49.7
Positive heterosexuals group	20.6	22.8	28.2
Injecting drug users' organisation	0.0	0.0	4.3
Haemophilia foundation	1.1	0.8	0.0
HIV positive friends	29.8	36.0	52.3
Other friends	1.5	0.0	14.5
Partner/lover	6.0	14.7	28.5
Family	5.3	9.5	23.0
Articles in gay press	8.3	10.5	11.8
HIV magazine/newspaper	53.4	53.3	52.8
Hep C Support Group/Organisation	0.0	0.0	1.7
Liver specialist	7.4	8.5	1.9
Internet	23.4	17.6	16.5
Publications from HIV/AIDS groups	59.7	60.4	57.4
Publications from other sources	12.1	13.7	13.1

(Multiple responses possible)

Information about Treatments

HIV specialists were nominated by two thirds (66.9%) of the women as an important source of information on treatments. HIV GPs/S100 prescribers were considered an important source of information on treatments by over half (53.5%) of women. Importantly information from the community sector figured significantly in the responses to this item with 53.4% reporting HIV magazines/newspapers and 31.6% of women reporting positive women's organisations.

Women were significantly more likely than men to report that the following were important sources of treatments information: HIV inpatient specialist (19.8% vs 8.4%), peer support officer (18.5% vs 9.2%), sexual health service (25.9% vs 16.1%) and publications from HIV/AIDS groups (59.3% vs 42.2%). Compared with men, women were significantly less likely to nominate their HIV GP as an important source of treatment information (51.2% vs 65.9%).

When asked in a separate question to nominate the most important source of information about treatments, 39.9% of women nominated their HIV GP, 28.6% an HIV specialist at an outpatient clinic and 5.2% another GP. 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 specialists nominated by over half of the women (53.2%) and almost half (48.7%) relying on HIV GPs. Community sector sources also figured prominently (HIV organisation publications: 60.4% and HIV magazine/newspaper: 53.3%). Positive Women's Organisations were also important (35.3%) as were HIV positive friends (36.0%).

Women were significantly more likely than men to nominate the following as important sources of HIV management information: peer support officer (22.0% vs 11.8%), sexual health service (28.4% vs 17.4%), family (11.0% vs 4.8%), HIV magazine/newspapers (54.9% vs 42.7%) and publications from HIV/AIDS groups (61.0% vs 40.3%). Women were significantly less likely than men to nominate their HIV GP as an important source of HIV management information (47.6% vs 61.7%).

When asked to nominate the most important source of information on HIV management, 25.7% nominated an HIV specialist at an outpatient clinic, while 24.3% said their HIV GP, 9.8% a positive women's organisation and 5.2% a sexual health service.

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 women were publications from HIV/AIDS groups (57.4%), followed by HIV magazine/newspaper (52.8%), HIV positive friends (52.3%) and Positive Women's Organisations (49.7%). Clinical sources were also considered important by significant numbers of positive women (HIV specialist: 30.4%, HIV GP: 28.1%).

Women were significantly likely to nominate the following as important sources of information on living with HIV: peer support officer (25.6% vs 15.9%), family (24.7% vs 10.2%) and publications from HIV/AIDS groups (56.8% vs 43.5%). Women were significantly less likely than men to nominate their HIV GP as an important source of information about living with HIV (26.8% vs 39.7%).

When asked to identify the most important source of information on living with HIV 22.0% of women nominated a positive women's organisation, 12.4% HIV positive friends, 11.4% a positive heterosexuals group and 8.5% an HIV/AIDS organisation or HIV/AIDS organisation staff.

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 49. As can be seen from these data, women 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 49 Attitudes to HIV information on the internet (percent of sample)

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Full sample of women					
Information on the internet about living with HIV is unreliable	3.7	23.3	13.6	0.0	59.4
Information on the internet about treatment side-effects is unreliable	2.4	25.6	12.0	0.0	60.0
Those who rate the internet as an important source of information (N=45)					
Information on the internet about living with HIV is unreliable	4.3	51.2	17.9	0.0	26.7
Information on the internet about treatment side-effects is unreliable	4.3	51.2	17.9	0.0	26.7

Lack of information

When asked to identify domains in which lack of information made it difficult to make decisions, over one third of women nominated financial planning. Legal issues, using complementary therapies, interactions between ARVs and other drugs and having children also figured prominently.

TABLE 50 Issues where women lack information

Financial planning	40.6
Legal issues	30.1
Using complementary therapies	29.6
Interaction between ARV and other drugs	28.8
Having children	27.4
Work/employment	26.6
Using ARV	25.7
Taking a break from ARV	24.8
Managing ARV side-effects	23.0
Changing ARV	22.5
Recreational drug use	13.7

(Multiple responses possible)

Publications

Survey participants were asked which publications containing HIV information they read. The results for participants are shown in table 51, 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 51 Publications read by PLWHA

Publication	Percent of sample
National or non-specific	
Positive Living	61.0
HIV Australia	48.2
Newsletters from community organisations	35.8
Gay newspapers (% of women)	13.8
Overseas magazines (eg POZ)	9.0
Gay magazines (% of women)	5.0
National Haemophilia	0.0
State based publications	
Talkabout (% of women)	73.6
Talkabout (% of NSW women)	85.6
With Complements (% of women)	19.9
With Complements (% of NSW women)	20.4
NUAA News (% of women)	4.5
NUAA News (% of NSW women)	6.0
Positive Life (% of women)	11.9
Positive Life (% of WA women)	48.9
QPP Alive (% of women)	17.7
QPP Alive (% of QLD women)	92.7
(Multiple responses possible)	

Involvement with AIDS Organisations

Participants were asked about their involvement with HIV/AIDS organisations. 85.3% of women had some contact with HIV/AIDS organisations. Of these, 85.3% received newsletters and mail outs, 61.3% were clients, 51.1% were members, 15.4% were volunteers and 12.3% were employees. Of the 13 women who did not have contact with AIDS organisations, 10 gave the reason “I do not want to be involved”, 4 women gave the reason that they did not know how to join, 3 gave the reason “I do not have enough time”, and 1 woman reported that she did not have transport or was too far away. Importantly, 4 of those who were not involved in AIDS organisations said they felt excluded from them. 33.2% had at some point held a decision making position in an AIDS organisation (17.2% in the last two years).

Women were significantly more likely than men (85.3% versus 65.4%) to report that they received newsletters and mail outs from HIV/AIDS organisations.

THE SOCIAL WORLD OF WOMEN

This chapter examines the collective experience of HIV from a number of perspectives. For some women HIV may be a profoundly isolating experience, however for other women, involvement in organisations and the development of social networks is able to provide considerable support. In this chapter we explore issues such as organisational contact and involvement, disclosure, the place of HIV in women's lives as well as issues of mental health, sex and relationships and recreational drug use.

Contact with Other PLWHA

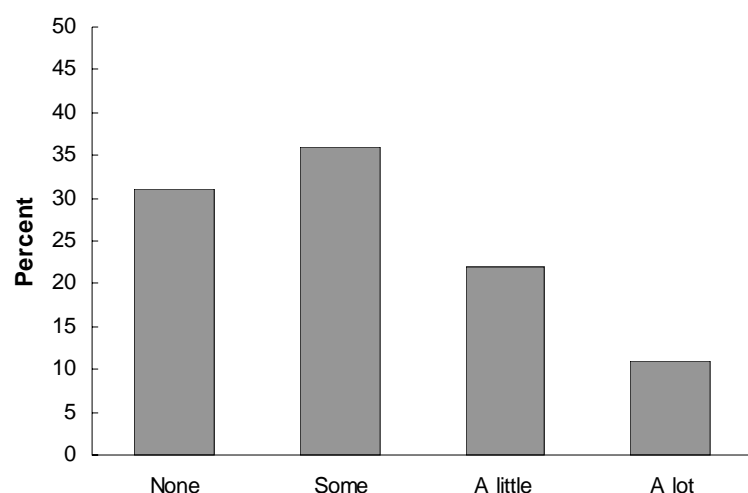
Very few HIV positive women (7.1%) did not personally know anyone else with HIV. 19.1% of women had been involved in the nursing or care of another positive person at some time in the last two years, and 68.7% have had someone close to them die from HIV/AIDS.

TABLE 52 Other HIV positive persons known by respondent

Positive Persons	Percent
Acquaintance/member of support group	76.7
Friend	46.4
Partner/spouse	21.3
Former partner/spouse	13.4
Other person	14.3
No-one	7.1
Son/daughter	2.2

(Multiple responses possible)

Around 59 of the women spent at least some time with other positive people (68.9%) (figure 14).

FIGURE 14 Time spent with other positive people

Disclosure

Respondents were asked who they had disclosed their HIV status to (see table 53). 96.8% of women had disclosed their status to at least one person, although 3 women had not disclosed to anyone.

TABLE 53 People the respondent has disclosed their HIV status to

	Percent who have disclosed
Close friends	78.2
Siblings	72.7
Partner/spouse	71.0
Parents	69.8
Positive friends	60.0
Son/daughter	41.4
Other friends	30.2
Neighbours	19.9
Work colleagues	19.5
People from own ethnic community	3.5
No-one	3.2
Specific populations	
Partners (% of those in a regular relationship)	93.0
Partners (% of those not in regular relationship)	33.3
Work colleagues (% of those currently employed)	30 (n=12)
Son/daughter (% of those with dependent children)	58.5

(Multiple responses possible)

Unwanted Disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. 76.6% of women said that it had at some point, and 37.5% said that this had happened in the last two years. Of particular concern is that 27.2% of women nominated a worker in a health care setting as the source of unwanted disclosure. Women were significantly more likely than men to report unwanted disclosure both in the last two years (37% compared with 29%) and more than two years ago (39% compared with 24%). If we compare the source of disclosure, we find that women are significantly more likely than men to report unwanted disclosure from a worker in a health care setting (27% compared with 17%).

TABLE 54 Sources of unwanted disclosure (percent of those experiencing unwanted disclosure)

Workers in a health care setting	27.2
Other friends	26.6
Close friends	19.6
Partner/spouse	16.5
Brother/sister	15.3
Parents	9.9
Other	8.3
Staff/volunteers at community organisation	6.0
Neighbour	6.0
Work colleagues	5.4
HIV positive friends	4.6
Other family member	4.4
Son/daughter	3.0
People from ethnic community	1.9
(Multiple responses possible)	

The Place of HIV in Women's Lives

HIV affects many parts of women's lives in both positive and negative ways. A woman's HIV status can be all encompassing or just a minor part of her life.

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 55. 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 they 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.

TABLE 55 Importance of personal characteristics to respondents' sense of identity

	Essential	Important	Not Important	Irrelevant
Family	59.0	37.2	2.7	1.1
Parenthood	36.4	38.6	4.9	20.1
Gender	30.6	45.8	15.2	8.4
Sexuality	24.3	38.4	24.6	12.7
Career	15.5	58.9	13.1	12.5
HIV status	11.2	62.2	15.5	11.1
Religious beliefs	9.8	35.4	31.3	23.5
Ethnicity/cultural background	7.2	26.9	29.2	36.7
Drug use (recreational/illegal)	5.1	14.6	26.1	54.2

As in previous Futures surveys, women are significantly more likely than men to rate family and parenthood as essential to their sense of identity (59.3% versus 26.4) and (35.1% versus 5.3%) respectively.

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 56, with those for whom the category was not applicable excluded from each row.

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, women received a lot of support from 4.0 sources, with 66.7% receiving support from 3 or more out of the 15 sources listed. 8% (n=7) of women did not receive a lot of support from any of these sources.

On average, women received a lot or some support from 6.9 sources, (68.5% from 6 or more sources) and no support from 1.2 out of 15 possible sources of support.

TABLE 56 Social support received from different sources
(percent who gave valid responses for each category)

	A lot	Some	A little	None
Partner/spouse	74.2	9.6	9.4	6.9
Children	63.1	14.5	10.2	12.1
Pets	50.1	28.5	14.2	7.2
Close friends	48.8	26.8	14.8	9.6
Parents	47.5	23.1	10.7	18.8
Doctor	44.0	45.3	9.5	1.2
Family	43.4	20.1	20.1	16.4
Brothers and sisters	38.2	23.8	25.3	12.7
HIV positive friends	32.7	36.5	22.9	7.9
Volunteer carer	32.4	13.4	18.9	35.3
Religious or spiritual advisor	27.5	20.2	11.1	41.1
PLWHA groups	26.9	41.4	18.3	13.4
Health care workers	25.8	31.6	25.9	16.7
Counsellor	18.9	39.4	25.7	16.1
Other friends	12.2	34.2	27.9	25.7

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 the HIV Futures survey cannot expect to offer a clinical perspective on mental health status, we can give an overview of some of the experiences of positive women that fall within the broad area of mental well-being.

Psychiatric Medications

In the six months prior to completing the survey, 23.2% of women 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 (21.8%) had taken medication for anxiety (1.9% in the ABS study), and 11.2% reported taking medications for both depression and anxiety. In addition 2.7% 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 21.9% (n=19) of women reported that they had had such a diagnosis. 7 women had this diagnosis in the previous two years. The most common condition diagnosed was depression (15.1% of all women).

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 antidepressants. As can be seen in table 57, a considerable proportion of PLWHA agreed or strongly agreed with each of the items. 3.4% (n=3) of women agreed with all four items which may be suggestive of clinical depression. There were no differences between men and women in responses to any of these items.

TABLE 57 BDI depression symptomology items (percent of total sample)

	Strongly agree	Agree	Disagree	Strongly disagree
I cry or feel like crying all the time	8.2	18.0	52.4	21.4
I don't enjoy things the way I used to	9.5	39.1	33.0	18.4
I have lost interest in other people	4.6	23.6	52.4	19.4
I don't feel it's worth going on	0	9.1	30.4	60.5

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 of the women 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 of the women agreed or strongly agreed with this statement.

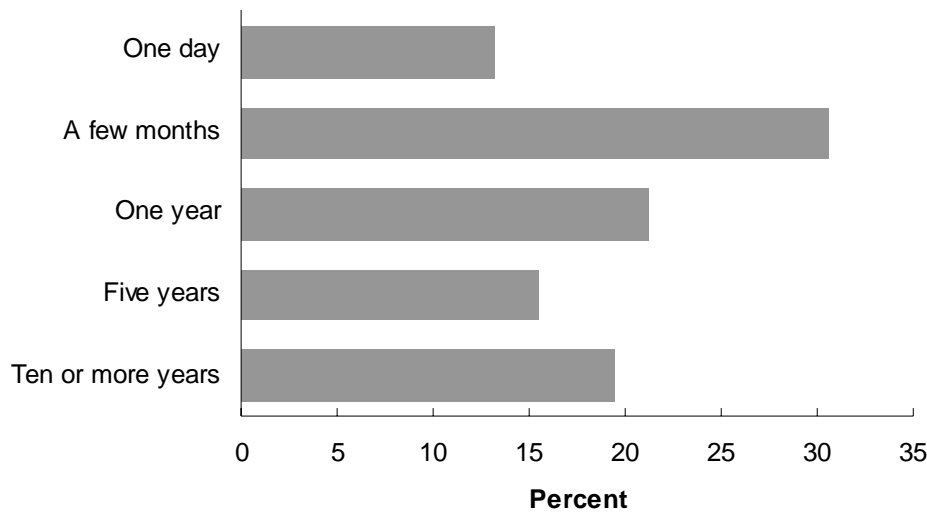
TABLE 58 Attitudes to HIV status

	Strongly agree	Agree	Disagree	Strongly disagree
As long as I am well I prefer not to think about HIV/AIDS	19.0	33.1	44.5	3.4
Life has become more meaningful since I became HIV positive	13.8	32.7	39.0	14.4

Planning for the Future

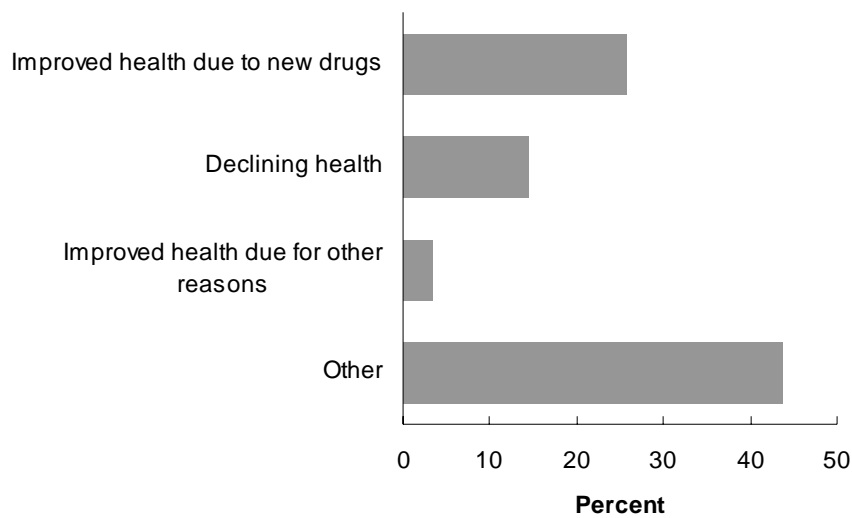
A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. Over half of the women planned for at least a year, with 21.2% planning one year ahead, 15.5% for 2 years and 19.5% for 10 or more years. Around a third of women planned only a few months ahead (30.6%), while just over one-tenth of the women (13.2%) said that they plan their lives one day at a time. This profile of the population has changed very little since the first HIV Futures survey.

FIGURE 15 Time-frame for future planning



40.2% (n=35) of women reported a change in their time frame for future planning in the last two years, with 37.1% of those who reported a change now using a shorter time frame and 60.1% 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 (figure 16).

FIGURE 16 Reasons given for change in time-frame



WOMEN AND CHILDREN

As mentioned in the description of the sample earlier in this report, 63.8% of women had children ranging in age from babies to 62 years of age. Between them, 40 women had 71 children living with them. 19 women had 1 child, 13 women had 2 children, 4 women had 3 children, 1 woman had 4 children and 2 women had 5 children living with them.

Participants were asked to nominate whether they had any dependent children and whether these children were living with them. Of these, 45.3% of women had dependent children and 43.4% had dependent children living with them. These 72 children ranged in age from babies to 29 years old (average age 10 years). Of the women with dependent children, 25.0% of children were aged 5 years of age and under and 9.7% of the children were aged 2 years and under.

Two women had a child who is also HIV positive and one woman said that her child had died from an AIDS-related illness.

Disclosure to children

Of the 57 women who had children, 37 said that they had told their child(ren) about their HIV status (64.9%). The age of the children at the time of disclosure ranged from 2 years to 44 years. Of the 40 women with dependent children, 24 (58.7%) said they had disclosed to their children. The age of these children at the time of disclosure ranged from 2 years to 19 years.

Health and children

Women with dependent children were significantly more likely to rate their health as good or excellent than were women without dependent children. However, there were no differences in the way they rated their wellbeing or their use of antiretrovirals.

Relationships and children

More than half of the women (60.6%) with dependent children were in regular relationships. Two women who were pregnant at the time of the survey were in regular relationships. One of these women reported that her partner was also HIV positive. Of those women who have decided to have children in the future or currently trying to get pregnant, all are in regular relationships or currently married.

Planning to have children in the future

We were also interested women's future plans for children. Most women (53.0%) were not currently considering having children. Of the remainder, 5 women had decided to have children in the future and 3 were trying to get pregnant at the time of completing the survey. 13 women had thought about having a child, but had not decided, 1 has considered having a child, but decided it is too risky and three women said they did not have enough information to make a decision. 2 women were currently pregnant. Seven of the women who chose the 'other' category women already had children and said they were not considering having any more.

While a greater proportion of women (heterosexual, bisexual and lesbian) were considering or had considered having children, some gay, bisexual or heterosexual men were also doing so (table 59).

TABLE 59 Planning to have children (number)

	Heterosexual Women	Lesbian/bisexual women	Heterosexual men	Bisexual men	Gay men
Not considering having a child	38	4	56	39	708
I have decided to have a child/children in the future	4	0	2	2	6
I am currently trying to conceive/get pregnant	3	0	1	0	0
I am currently pregnant	2	0	0	0	0
I have thought about it but I haven't decided	13	0	3	3	11
I have thought about it but I have decided that it is too risky	1	0	3	1	11
I was told not to by a doctor/medical professional	0	0	0	2	0
I don't have enough information to make a decision	2	1	6	2	12
Other	9	2	3	0	10

RELATIONSHIPS AND SEX

In this section we discuss a range of issues to do with the sexual lives and intimate relationships of women living with HIV. 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.

Relationships

Respondents were asked about current sexual relationships. The results are presented in table 60 below. When this item is broken down by sex and sexuality, we find significantly different patterns between three groups of PLWHA. Please note that due to small numbers of lesbian and bisexual women it was not possible to separate women into these categories. Women were more likely to report that they had one regular sexual partner and no casual sex. Heterosexual men were more likely than other PLWHA to report that they had no sex at present. Gay and bisexual men are more likely to report that they had a regular sexual partner and also had casual sex.

TABLE 60 Type of sexual relationship(s) by gender and sexuality of respondent (percent)

	Women ¹	Heterosexual men ²	Gay or Bisexual Men ³	Total
I have no sex at present	35.1	52.1	24.3	27.3
I have casual sex only	1.3	9.9	35.2	30.6
I have a regular relationship with one person, and I have sex with other people	5.2	5.6	21.5	19.0
I have a regular relationship with one person, and I do not have sex with other people	58.4	32.4	17.4	21.8
I have a regular relationship with two or more people	0.0	0.0	1.6	1.4

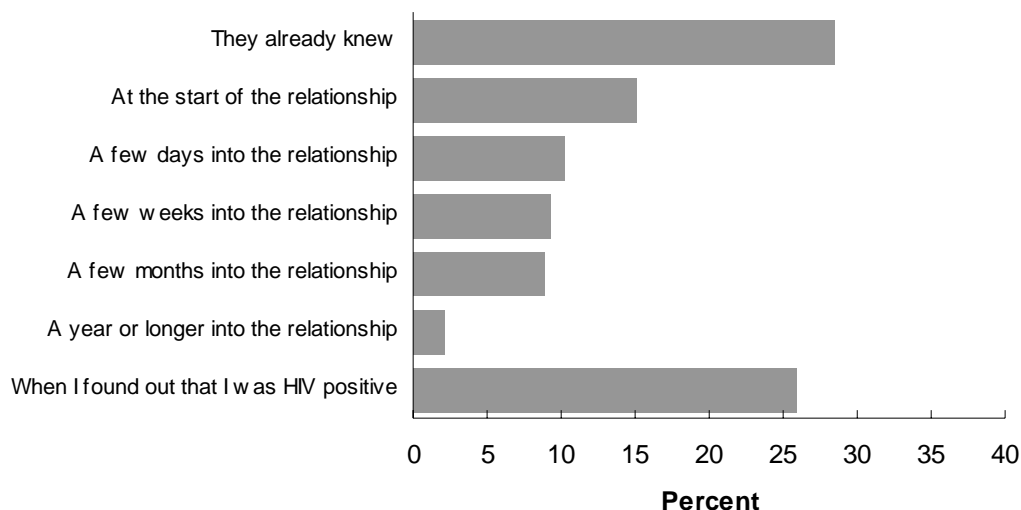
1: n=78, 2:n=73, 3:n=834

Regular Partners

When asked if they were currently in a regular relationship, around almost two thirds (63.8 %) of women said they were. Of those in a relationship with a regular partner, 32.6% of women reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in sero-nonconcordant relationships. This remaining group is made up of 62.5% of

women who report that their partner is HIV negative (a sero-discordant relationship) and 4.9% who report that they don't know their partner's HIV status. Nearly all women (98.4%) had told their regular partner that they were HIV positive. The one woman who had not disclosed her status reported that her partner was HIV negative. Respondents were asked at what point in the relationship they told their partner. The responses are given in figure 17 below.

FIGURE 17 Time HIV status disclosed to partner among those women in regular relationships



When asked how their partner responded when told of the respondent's HIV status, the majority (58.6%) of women reported that the partner was supportive (table 61).

TABLE 61 Reaction of partner to disclosure (percent of women in regular relationships)

They were supportive	58.6
It did not make any difference	47.2
They were worried/scared	35.4
We became closer	27.3
They were angry	10.2

(Multiple responses possible)

We also asked how the respondent themselves felt about this disclosure. 52.7% of women reported feeling relieved once they had disclosed to their partner and 48.3% were worried or scared about making this disclosure. 29.4% said they became closer to their partner as a result of disclosing.

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, 55.0% of women had vaginal or anal sex with a regular male partner in the six months prior to completing the survey and 4.7% had vaginal or anal sex with a regular female partner in the previous six months. See table 62 for condom use.

TABLE 62 Condom use with regular partner (N)

	Never	Sometimes	Usually	Always
With regular male partner (N=49)	13	9	9	18
With regular female partner (N=5)	3	-	2	

Table 63 presents this data by women's sexual partner's HIV status.

TABLE 63 Condom use with regular partner by partner sero-status (N)

	Never	Sometimes	Usually	Always
Sero-concordant relationships				
With regular male partner (N=13)	5	2	3	3
Sero-nonconcordant relationships				
With regular male partner (N=27)	4	5	5	10
With regular female partner (N=3)	2	-	1	-

Casual Partners

Fifteen women 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, 2 reported that all of their casual partners were HIV positive, 2 reported that some of their casual partners were HIV positive, and 9 reported that none of their casual partners were HIV positive. One woman reported not knowing the HIV status of her casual partners. Table 64 shows condom use of the 9 women who reported vaginal or anal sex with their casual male partners and the 2 women who reported vaginal or anal sex with their casual female partners

TABLE 64 Condom use with casual partner (N)

	Never	Sometimes	Usually	Always
With casual male partners (N=9)	1	1	1	6
With casual female partners (N=2)	2	-	-	-

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. Thirteen women reported on this encounter (10 reporting they had sex with a man, 1 reported she had sex with a woman and 2 did not say). Seven women said their partner on this occasion was HIV negative, 4 said their partner was HIV positive and 2 said they did not know. 9 women reported using condoms on this occasion.

Respondents who indicated that they knew their partners' HIV status were asked how they knew. 10 women said that their partner had told them their status and one woman said she could tell by the type of bar/venue where they met.

Six women said they told their most recent casual partner that they were HIV positive, 1 did not and 3 said the partner already knew they were HIV positive.

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 65.

In response to the statement "I prefer to have a relationship with someone who also has HIV", women were significantly more likely than men to either disagree, strongly disagree or say they don't know (35% vs 24%, 15% vs 9.4% and 21.3% vs 15% respectively). Women were also more likely than men to either disagree or say they don't know in response to the statement "If I know that my partner is HIV positive I find sex more pleasurable" (29.3% vs 21.9% and 29.3% vs 16.3%). Women were significantly more likely than men to say "I don't know" in response to the statement "HIV has had a negative effect on my sexual pleasure" (13.2% vs 3.0%).

TABLE 65 Attitudes to HIV, sex and relationships

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I prefer to have a relationship with someone who also has HIV	13.8	35.8	24.1	5.5	20.8
Few people would want a relationship with someone who has HIV	3.8	17.1	45.3	23.1	10.8
I am afraid of telling potential partners of my HIV status in case they reject me	8.5	23.5	39.4	21.3	7.3
Being HIV positive has helped me form more satisfying relationships	22.6	47.3	17.4	1.0	11.6
I am afraid of infecting my partner, or potential partner, with HIV	4.2	23.6	44.9	25.0	2.3
I feel more confident about unprotected sex because of the new treatments	57.4	28.6	9.4	0.0	4.6
Medical treatments for HIV/AIDS make safe sex less important than it was	56.8	34.3	3.6	0.0	5.3
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	37.8	29.5	25.7	1.0	6.0
If there was a vaccine which prevents HIV I would not practice safe sex	35.2	37.2	10.4	4.3	12.9
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	39.3	38.2	15.0	0.0	7.5
Knowing a vaccine will become available makes me less anxious about sex	22.5	51.1	7.6	2.7	16.1
I am concerned about becoming infected with another strain of HIV	13.0	46.8	24.7	8.6	6.9
HIV has had a negative effect on my sexual pleasure	8.7	20.2	34.4	24.3	12.4
If I know that my partner is HIV positive I find sex more pleasurable	11.3	27.8	25.1	5.6	30.2
I stopped having sex because of my HIV status	18.3	40.3	21.1	12.4	7.9
HIV has negatively affected my libido	10.8	24.8	34.5	18.6	11.3

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 66). As can be seen from these data, alcohol was the most commonly used drug followed by tobacco.

TABLE 66 Recreational use of drugs (percent of women and men)

	Women	Men
Alcohol	69.2	83.6
Cigarettes	43.0	59.8
Marijuana	35.3	60.2
Speed (injected)	9.5	15.3
Speed (not injected)	6.7	18.4
Ecstasy	6.3	30.9
Heroin (injected)	4.6	2.0
Methadone (prescribed)	4.1	2.7
Crystal Meth	1.5	17.1
Methadone (other)	1.5	1.0
Cocaine (injected)	1.3	1.2
Amyl	1.3	39.9
LSD/trips	1.1	5.9
GHB/GBH/Fantasy	1.1	4.3
Homebake	1.1	2.2
Cocaine (not injected)	0.0	6.8
Steroids (injected)	0.0	5.8
Heroin (not injected)	0.0	0.7
Viagra or similar	0.0	23.5
Other	3.1	3.4

(Multiple responses possible)

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. 6.3% of women reported that they have had a bad experience from using both antiretroviral drugs and recreational drugs. 12.0% reported that they had missed a dose of antiretroviral medication at some point as a result of using recreational 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

Almost two thirds (65.6%) of women reported that they had never injected illegal drugs. Of those women who had injected illegal drugs half (n=15) had done so in the last 12 months. Of women who reported injecting drugs, two women had shared injection equipment in the last 12 months. Both had done so with at least one risk reduction strategy (washing/bleaching and/or using with another person who was HIV positive). The circumstances surround sharing injection equipment are shown in table 67 below.

TABLE 67 Circumstance surrounding sharing among the two women who have shared injecting equipment in the last 12 months

	Number
The person was my sexual partner	1
The needle was bleached and/or washed	2
We did not have access to other needles	2
The person was HIV positive	1
I used the equipment last	1

(Multiple responses possible)

Attitudes Relating to Drug Use

Around one in six (17.1%) women felt that they drank more alcohol than they would like to and similar numbers (17.4%) 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.

TABLE 68 Attitudes relating to drug use and infection
(percent of all women and number of those women 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	52.2	7.4	1.2	0.0	39.2
I worry about infecting others by sharing needles	9.5	6.5	4.4	5.2	74.3
The two women who have shared					
Sharing needles is not a problem if your viral load is undetectable	1	1	-	-	-
I worry about infecting others by sharing needles	-	-	1	-	1

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 69. Similar numbers of women were in accommodation that they own or rent through the private system. A smaller number of women were in public rental accommodation. These were more likely to be those on a government benefit.

TABLE 69 Current accommodation of women (percent of total sample)

Own or purchasing house or flat	32.9
Private rental accommodation	29.9
Public rental accommodation(government owned)	24.2
Rent-free (e.g. provided by friends, family, etc.)	5.1
Community housing/housing co-operative	5.6
Other	2.3

Households varied considerably. 19.3% of women lived by themselves, while the remainder lived with between 1 and 7 other adults (for those living with other adults: mean=1.59, median=1) and with between 1 and 5 children (for those living with children: mean=1.83, median=2). Over one third (41.4%) lived with a partner or spouse, and 43.4% lived with dependent children. These children ranged in age from 1 to 24 (mean=10.9, median=11).

Many women (66.8%) also lived with pets. The most common pets were dogs (45.9%) and cats (30.2%). Other companion animals included fish, birds, rabbits and chickens.

79.3% of women had access to a car. When asked how easy it was to access public transportation, 10.5% said it was very difficult, 18.2%, difficult, 48.3% easy and 23.1% very easy.

71.1% of women stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (n=26), the main reasons given were that it was too small (n=14), was too expensive (n=6), and lacked privacy (n=6).

TABLE 70 Reasons current accommodation is unsuitable

(number of women with unsuitable accommodation)

Too small	14
Too expensive	6
Lack of privacy	6
Poor condition of housing	5
Inadequate for my current state of health	4
Too far from health services	4
Confidentiality problems	4
Harassment	3
Too far from other services	2
Other	3
Fear of violence	1

(Multiple responses possible)

Changes in Accommodation

Participants were asked if they had ever changed their accommodation as a result of having HIV/AIDS. 38.9% (n=35) of women had, and 12.4% (n=11) had in the last two years. On average women had changed their accommodation 2.4 times ever as a result of HIV/AIDS (1.4 times in the last two years).

We asked what the circumstances were around participant's last change in accommodation. The results are shown in table 71. Financial and health issues figured most prominently in response to this question. When asked if they had any other accommodation options for the future, 12 women (almost half of those whose current accommodation was unsuitable) said they did not.

TABLE 71 Reasons for changing accommodation

(percent and number of women who changed accommodation)

Moved closer to health services	37.1 (n=13)
Needed cheaper housing	24.2 (n=8)
Planning for illness	17.1 (n=6)
To avoid harassment	17.1 (n=6)
Lack of privacy	17.1 (n=6)
Moved in with family	14.3 (n=5)
Moved closer to other services	14.3 (n=5)
Moved to a quieter location	11.4 (n=4)
Better health	11.4 (n=4)
Illness	11.4 (n=4)
Stopped working	8.6 (n=3)
Ending of relationship	8.6 (n=3)
Improved finances	8.6 (n=3)
Moved closer to friends	8.6 (n=3)
Beginning of new relationship	5.7 (n=2)
Looking for/returned to work	2.9 (n=1)
Other	24.2 (n=8)

(Multiple responses possible)

EMPLOYMENT

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

Employment Status

Just over half (56.1%) of the women were currently in paid employment, with slightly more being in part-time work (27.9%) than those in full-time work (22.6%). The remainder most commonly described their current situation as either unemployed (16.8%) or occupied with home duties (15.9%). Women were more likely than men to be working part-time (27.1% compared with 15.2%) and to be occupied with home duties (15.7% compared with 1.1%), and less likely to be not working or retired (2.9% compared with 25.7%).

TABLE 72 Employment status of women

Work part-time	27.9 (n=22)
Work full-time	22.6 (n=18)
Unemployed	16.8 (n=13)
Home duties	15.9 (n=12)
Not working / Retired	3.5 (n=3)
Student	3.5 (n=3)
Other	9.9 (n=8)

Of those women who were working, the mean number of hours worked was 31.4 (median=35.0). Those working full time worked an average of 40.5 hours per week (median=39.4) and those in part time employment worked an average of 23.6 hours/week (median=24.0).

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 73 and 74 below. A large proportion indicated that it was more difficult to make career plans for the future (34.0%).

TABLE 73 Impact of HIV diagnosis on career plans (percent of women)

My career plans did not change	24.7 (n=20)
My career ended/I stopped work	14.1 (n=11)
It was more difficult to plan for the future	34.0 (n=27)
A career was no longer as important	10.7 (n=8)
I changed careers	15.0 (n=12)
I was less likely to change careers	1.4 (n=1)

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, 29.9% said they found it more difficult to plan their work life, while 17.9% said that a career was no longer as important.

TABLE 74 Ongoing impact of HIV on career/work of women

It is more difficult to plan for the future	29.9 (n=24)
My career plans have not changed	24.3 (n=19)
A career is no longer as important	17.9 (n=14)
My career ended/I stopped work	13.6 (n=11)
I changed careers	11.6 (n=9)
I am now less likely to change careers	2.7 (n=2)

We asked about the impact of antiretroviral therapy on respondents' career plans (see table 75 below). Of those women who have used antiretrovirals, the most common response was that this had not affected their plans.

TABLE 75 Impact of antiretroviral therapy on work**(percent of those who have used or are using ARVs)**

There has been no change to my plans	40.6 (n=23)
I anticipate a longer time in the workforce	18.6 (n=11)
I stopped work	15.8 (n=9)
I considered going back to work	6.3 (n=4)
I made a new career plan	4.6 (n=3)
I went back to work	3.8 (n=2)
I considered stopping work	2.0 (n=1)
Other	8.4 (n=5)

Interruptions to Employment

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those women who have worked, 53.0% had stopped work for reasons related to HIV at some point. Of all the women, 23.7% had stopped work on one occasion, 8.7% on two occasions, and 5.8% on three occasions. These work interruptions averaged 16.2 months (median= 8.3 months). The circumstances relating to the most recent interruption to employment are given in table 76 below.

TABLE 76 Circumstance surrounding last interruption to employment**(percent of women who had stopped work due to HIV)**

Low energy levels	59 (n=25)
Stress, depression, anxiety	50.0 (n=21)
Poor health	45.6 (n=19)
To have more time to myself	19.1 (n=8)
To move to a different location	12.8 (n=5)
Redundant/sacked	10.7 (n=4)
Expecting illness in the future	6.8 (n=3)
To care for another HIV positive person	9.1 (n=4)
Other	23.5 (n=10)

(Multiple responses possible)

These circumstances are also reflected in the women's HIV/AIDS status at the time they ceased work. 41.5% said that they were ill at the time and 9.9% had been diagnosed with an ADI, although importantly, almost half said that they were not ill at the time, perhaps reflecting both the anticipation of illness and the psycho-social impact of HIV.

TABLE 77 HIV/AIDS status at time of last interruption to employment

I had HIV but had not been ill	48.6 (18)
I had HIV and had been ill	41.5 (n=16)
I had been diagnosed with an AIDS-defining illness	9.9 (n=40)

We asked participants their source of income during their most recent interruption to employment. Over two thirds (67.7%) said they relied on a government benefit of some sort. Compared to men, women were significantly more likely to be supported by their partner when they were not working (76% compared with 67%) and significantly less likely to receive a government benefit (2% compared with 9%).

TABLE 78 Source of income when not working

Benefits/pension / social security	67.7 (n=28)
Superannuation/annuity/savings	13.4 (n=6)
Partner supported me	9.0 (n=4)
Salary	4.9 (n=2)
Family/friends supported me	4.9 (n=2)

Of those women who stopped working at some point, 42.7% had returned to work. This was most commonly for financial reasons (see table 79).

TABLE 79 Reasons for returning to work (percent of women returning to work)

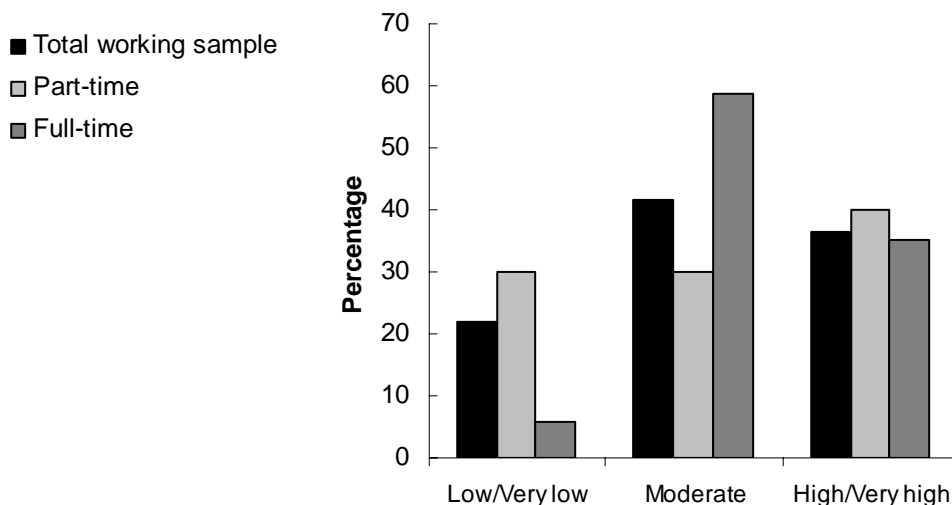
Financial reasons	100 (n=17)
To do something worthwhile	58.8 (n=10)
Better psychological health	52.9 (n=9)
To have something to do	29.4 (n=5)
Better physical health	35.3 (n=6)
To have more social contact	35.3 (n=6)
The possibility of working part-time	5.9 (n=1)
The possibility of flexible work hours	11.8 (n=2)
The possibility of working full-time	5.9 (n=1)
Other	17.6 (n=3)

(Multiple responses possible)

Those Women Currently in Paid Employment

Respondents were asked about the level of stress in their current job (figure 18). As this figure indicates, a greater proportion of the women who were working full-time rated their stress as moderate (58.8% vs 30.0%), and a greater proportion of the women who were working part-time rated their stress as low or very low (30.0% vs 5.9%). The proportions of full and part-time workers rating their level of stress as high or very high were similar (35.3% vs 40.0%).

FIGURE 18 Stress at work



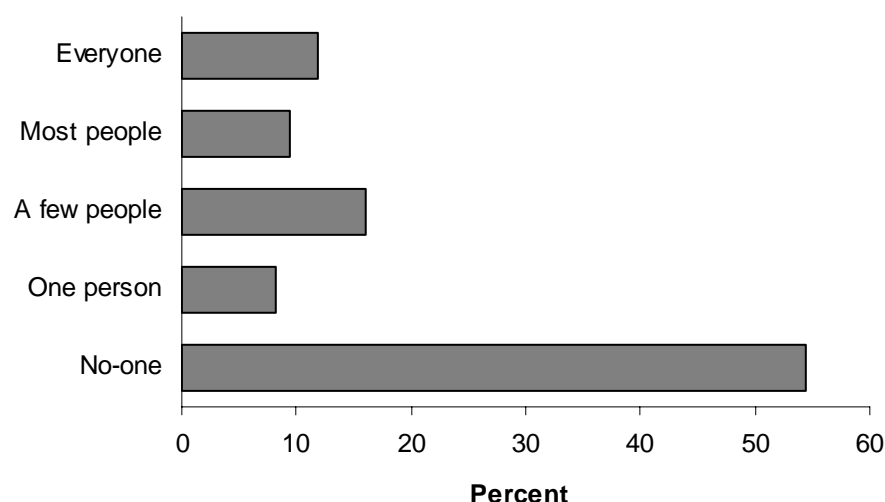
Confidentiality in the workplace remains a critical and complex issue for positive people, particularly given ongoing experiences of discrimination. Table 80 reveals some of the kind of problems women have with confidentiality in the workforce. Not surprisingly those women who work in an HIV related job were less likely to wish to keep their status confidential and had fewer problems when they do chose to do so.

TABLE 80 Difficulties with HIV status confidentiality in the workplace for women (numbers of total and specific samples)

	Total working sample	HIV/AIDS related	Non-HIV/AIDS related
I do not try to keep my HIV status confidential	6	5	1
No problems	26	4	22
Difficulty keeping and taking medication	5	0	5
Explaining absences from work	6	1	5
Visible signs of illness	4	0	4
Gossip	2	0	2

(Multiple responses possible)

Figure 19 shows how many people in their workplace know about their HIV status. Again those women working in a HIV related job were more likely to say everyone knew their HIV status than those in non-HIV related work (55.6% versus 0%) and similarly less likely to say no-one knew their HIV status (0% versus 71.0%).

FIGURE 19 Disclosure in workplace

When asked about the impact that HIV had on their capacity to perform their work duties, around half of the women said that their work was unaffected (table 81).

TABLE 81 Impact of HIV on work capacity (number of those currently working)

It is not affected	26
I tire more quickly	12
I have difficulty concentrating	5
I work reduced hours	6
I cannot always go to work	2
I am less productive	3
Other	3

(Multiple responses possible)

Respondents were asked how much flexibility their workplace gives them to take time off for reasons relating to HIV. Most women had the capacity to take time off for medical appointments and illness (table 82)

TABLE 82 Capacity within workplace for HIV related interruptions (percent of those currently working)

	Never	Seldom	Sometimes	Often	Always
For medical appointments	12.2	8.7	27.0	3.1	49.0
For counselling	36.3	5.3	16.0	4.6	37.9
When you are sick	6.5	12.8	17.3	3.4	60.0
To do volunteer work	52.1	9.0	18.9	0	20.0

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 half of women (49.5%) said they did. Of those women currently not working, 88% said they planned to start or return to work. Importantly, around 5 women said they wanted to reduce the hours they work (table 83).

TABLE 83 Plans for changes to work life (number of employed respondents)

	Full time	Part time	Total working sample
I want to stop work	0	1	1
I want to change the type of work I do	6	4	13
I want to reduce my work hours	3	2	5
I want to increase my work hours	0	7	7

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 women saying they expected this to be very difficult. Returning to work was also rated as very difficult by 4 of women currently without employment (table 84).

TABLE 84 Anticipated difficulty of changes to work status

	Not at all difficult	Somewhat difficult	Very difficult
I want to start work/return to work ^a	1	12	4
I want to change the type of work I do ^b	0	10	2
I want to reduce my work hours ^b	2	2	2
I want to increase my work hours ^b	1	6	2

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 (table 85). Among those women 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 85 Reasons for changes to work plans among women intending to return to work

(number of women)

Financial reasons	16
To reduce stress	13
To have more social contact	11
To do something worthwhile	10
To have something to do	10
Better psychological health	9
The possibility of working part-time	5
Better physical health	4
The possibility of flexible work hours	3
Worse psychological health	1
Worse physical health	0
The possibility of working full-time	0
To have less social contact	0

(Multiple responses possible)

Leisure

Respondents were asked how they spend their time while not working (table 86). Each respondent indicated the three activities that occupy most of their time. Around three quarters of women indicated that housework occupies their time. Fewer identified leisure activities, such as reading (62%) and resting (51%). Women with children were more likely to say they spent time doing housework/chores (86% compared with 58%), looking after children (65% compared with 3%) and spending time with family (51% compared with 38%) than women who did not have children.

Compared with men, women were more likely to indicate that they spent most time doing housework/chores (76% compared with 59%), looking after children (42% compared with 3.4%), spending time with family (46% compared with 22%) and less likely to spend time socialising with close friends (31% compared with 47%).

TABLE 86 Activities pursued while not working (percent of all women)

Housework/chores	75.8
Leisure activities (reading, etc.)	61.9
Resting	50.9
Spending time with family	46.1
Looking after children	42.2
Socialising with close friends	31.4
Volunteer work in HIV/AIDS organisation	16.2
Socialising with other friends	15.6
Socialising with HIV positive friends	10.2
Volunteer work in other organisation	9.0
Looking after another HIV positive person	6.2
(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 main source of income for women is shown in table 87 below. As with the previous HIV Futures surveys, over half had a government pension or benefit as their main source of income, while just over 40% of women were receiving a salary. Compared with men, women were less likely to list their main source of income as Superannuation/annuity/savings (1% compared with 5%), or a government pension or benefit (50% compared with 55%) and more likely to say that their partner supports them (5% compared with 1%).

TABLE 87 Primary source of income(percent of all women)

Benefits/pension/social security	49.1
Salary	41.9
Partner supports me	5.7
Family/friends support me	2.5
Superannuation/annuity/savings	0.8

As figures 20 and 21 below show, the proportion of women nominating a salary as their main source of income increased from 29% in 1997 to 40% in 2003, while the percentage receiving a government benefit decreased slightly from 54% in 1997 to 51% of women in 2003. Interestingly, there was little change in the proportion of men nominating salary as their main source of income (around 37% at each time point), while the proportion nominating a government benefit increased slightly from 50% in 1997 to 55% in 2003.

FIGURE 20: Percentage of men and women describing their main source of income as a government pension or benefit, shown over four Futures surveys.

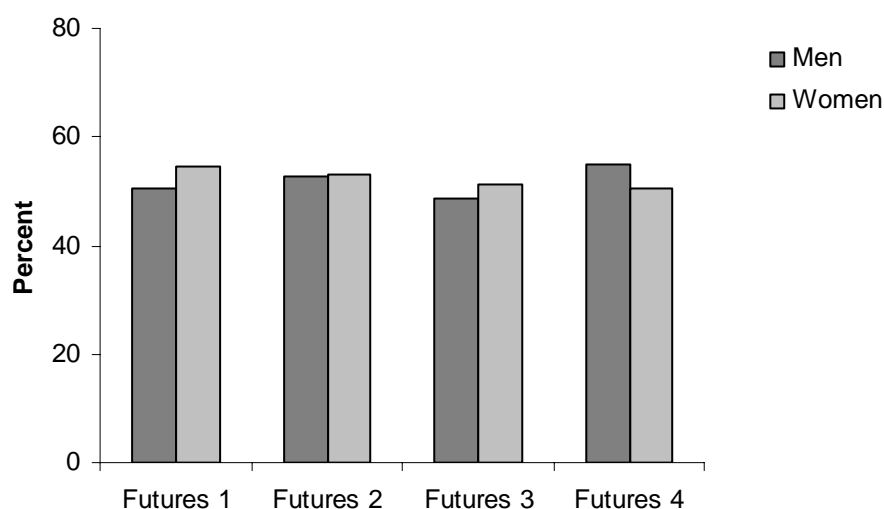
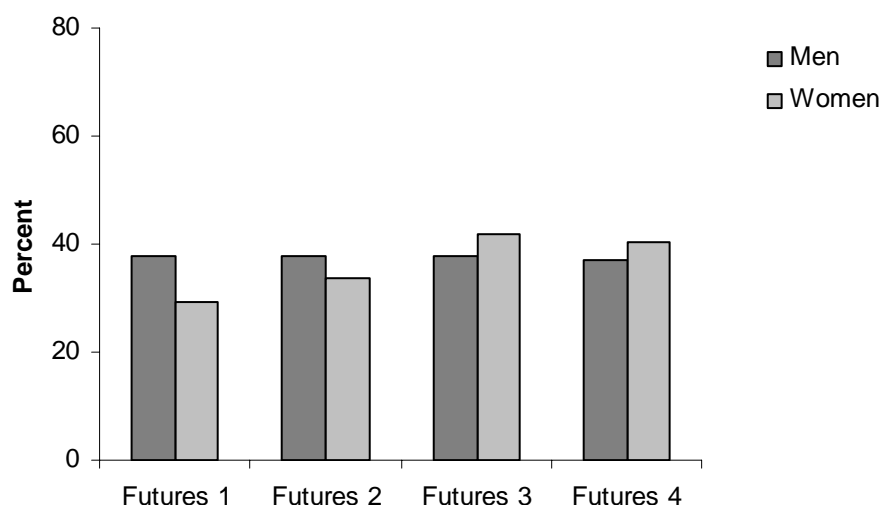


FIGURE 21: Percent of men and women describing their main source of income as salary, shown over four Futures surveys.



The median weekly income for women was \$400. 29% of women had a partner with whom they share financial resources. The partners' median weekly income was \$500.00. There was no significant difference in either individual or household income between women and men.

Expenditure and Debts

Respondents were asked their weekly expenditure on a range of items. The results are shown in table 88. The total mean expenditure on medication was \$52.81 per week with complementary therapies accounting for almost half the total. This is more than double the mean weekly expenditure on these items reported in 2001 (\$24). Mean rental or mortgage costs were \$190.80, also a substantial increase from the amount reported in 2001 (\$135). Food and utilities accounted for around \$98.00 and \$67.83 respectively. Women with children reported spending significantly more on food than those who did not have children (median \$100.00 compared with \$60.00) and significantly less on complementary therapies (median \$10.00 compared with \$20.36).

Ten women (11.7%) owned their own home, while 21 (23.4%) were paying off their home. Twenty-five (29.1%) had owned their own home in the past, but do not currently. Thirty women (34.0%) received a rental subsidy averaging at \$81 per week.

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. For women this averaged at \$29,840 with a median of \$4861. This compares with an average debt level of \$15,836 reported by women in 2001. Those who owned their home had a mean debt of \$25,444 (median \$521) those who were currently paying off their home had a mean debt of \$75,128, (median 19,810) those in private rental accommodation had a mean debt of \$12,182 (median 9426) and those in public rental accommodation had a mean debt of \$4480 (median \$1000). Slightly less than one quarter of women (22.5%) 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 one woman (1.1%) said that she strongly agreed, 5 (5.7%) agreed, 27 (31.6%) disagreed and 54 (62%) strongly disagreed.

TABLE 88 Weekly expenditure on medications and essentials (\$AU)

	Mean	Median
Rent or mortgage repayments	190.81	150.00
Food	98.00	100.00
Utilities	67.83	50.00
Complementary therapies	21.60	20.00
Other medication	16.80	10.00
Antiretroviral drugs	14.41	10.00

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 thirteen women (14.5% of those receiving a benefit in the last two years) had received such an assessment. When asked what this experience resulted in, seven said that it required documentation from their doctor and five that it caused distress (table 89 below). Only one woman said that this experience clarified concerns.

TABLE 89 Consequences of receiving an assessment of benefit from a Commonwealth Medical Officer (number of women)

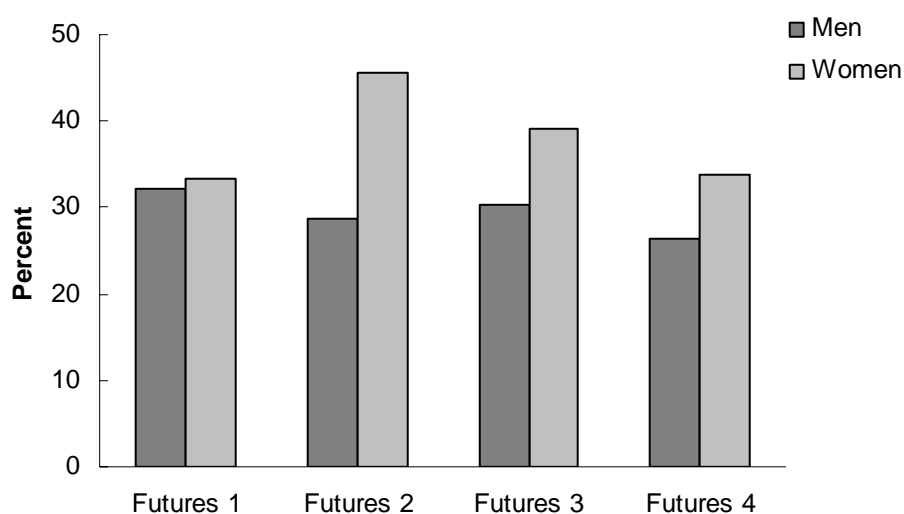
Require documentation from your doctor	7
Cause you distress	5
Result in changes to the conditions of your benefits	2
Result in an independent assessment	2
Clarify concerns that you had	1
Result in a shift from Pension to Newstart allowance	0
Result in termination of your benefits	0

(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 one third (33%) of women were living below the poverty line. Figure 22 below shows the proportion of participants from each HIV Futures survey who were living below the poverty line. It is important to note that due to a difference in the way this question was asked in Futures 1, the proportions for Futures 1 are likely to be a conservative estimate of the actual numbers (see figure 22). While around 30% of men were living below the poverty line at each time point, the proportion of women living in poverty peaked at 46% in 1999, and has since decreased to the current level of 33%. This is slightly higher than the current figure for men, which is 26%, although this difference is not statistically significant. This decrease in the proportion of women living below the poverty line may be due to an increasing proportion of women having a salary as their main source of income. However the fact that the proportion of PLWHA living below the poverty line 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.

FIGURE 22 Poverty by gender across the four Futures surveys

Correlates of Poverty for Women

We look now at the differences between different groups in their likelihood to be living in poverty. Those women 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 (table 90).

TABLE 90 Poverty by employment status (number in each employment category)

	below poverty line	above poverty line
Employed	5	10
Not employed	33	10

Women who identified a salary as their primary source of income were significantly less likely to report an income below the poverty line. Over half of those on a government benefit were living in poverty (table 91).

TABLE 91 Poverty by income source

	below poverty line	above poverty line
Benefits/pension/social security	58.8 (n=20)	41.2 (n=14)
Salary	8.3 (n=3)	91.7 (n=33)

Those women who shared financial resources with a partner were significantly less likely to be living below the poverty line than those who did not (table 92).

TABLE 92 Poverty by shared income status

	below poverty line	above poverty line
Sole income	41.2 (n=21)	58.8 (n=30)
Dual income	16.7 (n=4)	83.3 (n=20)

Tables 93 and 94 show the relationship between poverty and self-rated health and well-being. While the numbers in each category are small, women living below the poverty line were more likely to say that their health was fair and less likely to say that it was excellent compared with the other women. Women living below the poverty line were more likely to rate their wellbeing as poor or fair compared with the other women. None of these differences were statistically significant.

**TABLE 93 Self-rated health of women above and below the poverty line
(percent and number of women)**

	below poverty line	above poverty line
Poor	4.0 (1)	6.3 (3)
Fair	28.0 (7)	22.9 (11)
Good	60.0 (15)	54.2 (26)
Excellent	8.0(2)	16.7 (8)

**TABLE 94 Self-rated wellbeing of women above and below the poverty line
(percent and number of women)**

	below poverty line	above poverty line
Poor	12 (3)	6 (3)
Fair	44 (11)	26 (13)
Good	28 (7)	56 (28)
Excellent	16 (4)	12 (6)

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 95 below, with the not applicable responses excluded from the calculation for each item. Importantly over a quarter 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 women had difficulty paying for food, they also experienced difficulties with rent, utilities and quality of life items.

TABLE 95 Difficulty paying costs of items and services

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=53) ⁴	53.5	32.9	13.6
Other prescribed medication (n=61)	47.4	32.3	20.3
Medical services (doctor, dentist, etc.) (n=71)	37.4	34.6	28.1
Complementary therapies (n=54)	36.1	28.2	35.7
Support services (counselling, etc.) (n=38)	72.9	12.5	14.6
Entertainment (theatre, movies, concerts, etc.) (n=71)	18.8	33.8	47.3
Going out (eating/drinking) (n=68)	24.3	25.4	50.3
Sport (exercise, gym, etc.) (n=56)	21.9	32.9	45.1
Recreational drugs (n=30)	21.2	27.9	50.9
Travel/holidays (n=67)	12.3	36.5	51.2
Rent/Mortgage/Housing costs (n=83)	30.1	41.1	28.8
Utilities (telephone/electricity/gas/water) (n=83)	29.6	35.2	35.2
Food (n=86)	40.3	36.0	23.7
Clothing (n=80)	21.5	41.2	37.3
Transport (n=79)	36.7	38.7	24.6
Child care (n=24)	35.2	39.0	25.8

Women were significantly more likely than men to say that it was ‘very difficult’ to meet the costs of the following items: other prescribed medications (20% vs 11%), entertainment (47% vs 34%), sport (45% vs 32%) and utilities (35% vs 24%).

⁴ 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.

Poverty and Services

When we examine the use of services at HIV/AIDS organisations in the last six months by those above and below the poverty line (see page 34 for discussion of these services), we see that for many services a greater proportion of those below the poverty line have used these than those above (table 96). While the differences for some services are slight, we note the discrepancies for use of financial assistance and advice, volunteer carers, mental health services and peer support. When we examine use of services at other organisations, particularly notable are the greater proportions of those below the poverty line using housing assistance, drug and alcohol treatment service, mental health services, return to work skills and library services (table 97).

TABLE 96 Services used at HIV/AIDS organisations by those women above and below the poverty line (number and percent of women)

	Below poverty line	Above poverty line
Peer support group	73.9 (n=17)	51.2 (n=21)
Financial assistance	68.2 (n=15)	19.5 (n=8)
Treatments advice	56.5 (n=13)	54.8 (n=23)
Informal peer support	54.5 (n=12)	39.0 (n=16)
Treatments information	50.0 (n=11)	42.9 (n=18)
Financial advice	45.5 (n=10)	9.8 (n=4)
Volunteer carer	31.8 (n=7)	2.4 (n=1)
Counselling	30.4 (n=7)	41.5 (n=17)
Mental health services	26.1 (n=6)	2.4 (n=1)
Pharmacy services	20.8 (n=5)	17.1 (n=7)
Alternative/complementary therapies	17.4 (n=4)	22.0 (n=9)
Transport	13.0 (n=3)	7.3 (n=3)
Legal advice	13.6 (n=3)	19.0 (n=8)
Community education campaigns	8.7 (n=2)	17.1 (n=7)
Respite care	8.7 (n=2)	4.9 (n=2)
Employment services	8.7 (n=2)	4.9 (n=2)
Housing assistance	4.3 (n=1)	4.9 (n=2)
Social contact with other PLWHA	4.3 (n=1)	2.4 (n=1)
Drug/alcohol treatment	4.3 (n=1)	2.4 (n=1)
Return to work skills	4.3 (n=1)	0
Internet based information	0	14.6 (n=6)
Internet access	0	9.8 (n=4)
Library	0	4.9 (n=2)
Paid carer	0	0

(Multiple responses possible)

TABLE 97 Services used at other organisations by those women above and below the poverty line

	Below poverty line	Above poverty line
Library	65.2 (n=15)	34.1 (n=14)
Pharmacy services	47.8 (n=11)	39.0 (n=16)
Housing assistance	47.8 (n=11)	12.2 (n=5)
Transport	43.5 (n=10)	31.7 (n=13)
Internet access	39.1 (n=9)	36.6 (n=15)
Alternative/complementary therapies	34.8 (n=8)	30.2 (n=13)
Counselling	34.8 (n=8)	19.5 (n=8)
Legal advice	31.8 (n=7)	12.2 (n=5)
Treatments advice	30.4 (n=7)	17.1 (n=7)
Mental health services	26.1 (n=6)	2.4 (n=1)
Drug/alcohol treatment	26.1 (n=6)	4.9 (n=2)
Return to work skills	21.7 (n=5)	9.8 (n=4)
Internet based information	17.4 (n=4)	19.5 (n=8)
Financial advice	17.4 (n=4)	17.1 (n=7)
Informal peer support	17.4 (n=4)	7.3 (n=3)
Respite care	17.4 (n=4)	4.9 (n=2)
Employment services	13.0 (n=3)	22.0 (n=9)
Treatments information	8.7 (n=2)	14.6 (n=6)
Financial assistance	8.7 (n=2)	9.8 (n=4)
Community education campaigns	4.3 (n=1)	2.4 (n=1)
Social contact with other PLWHA	4.3 (n=1)	2.4 (n=1)
Paid carer	4.3 (n=1)	2.4 (n=1)
Peer support group	4.3 (n=1)	4.9 (n=2)
Volunteer carer	4.3 (n=1)	0

(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, women continue to experience less favourable treatment in many domains of their lives. In addition the anticipation of discrimination may limit women's life choices in subtle but sustained ways. We have asked about the experience of discrimination in a range of settings.

Accommodation

Seven women indicated that they had experienced less favourable treatment in relation to accommodation (three in the last two years). Of these three, one owned or was purchasing her own home, one was living in public rental accommodation and one in rent-free accommodation.

Health Services

HIV

53.8% of women had experienced less favourable treatment at a medical service as a result of having HIV. This comprised 20.0% of all women who had experienced such discrimination in the last two years and 33.8% who experienced this more than 2 years ago (table 98).

Compared with men, women were significantly more likely to report having experienced discrimination at a medical service, both in the last 2 years (20% versus 16%) and more than 2 years ago (33% compared with 16%).

TABLE 98 Form of HIV-related discrimination experienced at a medical service (percent and number of those experiencing discrimination)

	Ever (N=43)	In last 2 years (N=16)
Confidentiality problems	55.8% (24)	93.8% (15)
Avoidance	41.9% (18)	87.5% (14)
Increased infection control	39.5% (17)	81.3% (13)
Refusal of treatment	25.6% (11.0)	43.8% (7)
Treated last	27.9% (12)	43.8% (7)
Other	23.3% (10)	50% (8)
Rushed through	18.6% (8)	18.8% (3)
Harassment	7.0 % (3)	12.5% (2)
Abuse	4.7% (2)	0

(Multiple responses possible)

Hepatitis C

Three Hepatitis C co-infected women had experienced less-favourable treatment at a medical service as a result of having Hepatitis C, one in the last two years. All three women reported avoidance and additional infection control measures, while two reported being treated last and confidentiality problems and one woman reported harassment, being rushed through and refusal of treatment.

Insurance

19.5% (17) of women currently had private health insurance and 10.8% (n=10) currently had some other form of income or mortgage insurance. 10% (n=8) of women indicated that they had experienced less favourable treatment in relation to insurance. The most commonly reported example of less favourable treatment was being refused insurance, such as life, mortgage protection, travel and health insurance.

Compared with men, women were significantly less likely to have experienced less favourable treatment in relation to insurance (10% compared with 24%).

CONCLUDING COMMENTS

The journey continues provides an overview of the health and social circumstances of women living with HIV in Australia in 2003. Whilst the overall picture for many women living with HIV/AIDS in Australia has significantly improved since the advent of treatments eight years ago, the proportion of women rating their well-being as fair or poor has doubled since Futures 3 (2001). Furthermore, more than three quarters of the women who participated in this research reported having health conditions related to being HIV positive and almost one third of women living with HIV are also living with Hepatitis C.

These data indicate a further closing of the gap between men and women in their use of, and attitudes towards, antiretroviral treatments. As in Futures 3, women are no longer significantly less likely than men to be using treatments, although most women are still experiencing difficulties taking treatment, including side-effects.

The single biggest difference between most men and women living with HIV in Australia remains child bearing and rearing and the importance attached to this role. As in previous Futures Surveys, many women are or are hoping to become mothers, and with this role come many responsibilities. It is important to note that one in four women reported they felt they lacked information about having a child.

Peer support remains a very important service used by more half of the women who participated in this survey. Perhaps this is due to the small numbers of women living with HIV in Australia and the need for women to connect with other women with similar experiences. HIV/AIDS organisations and services still have an important role to play in providing this unique form of support.

More than three quarters of women had experienced unwanted disclosure and more than one third of women had this experience in the last two years. This was most likely to occur within a health care setting. Similarly more than half of the women believe they experienced discrimination with a health care setting due to their HIV status. This signifies the importance of education and training for health professionals to ensure the appropriate care and support of HIV positive women within these settings.

The level of poverty among women continues to be unacceptable. Whilst the number of women living in poverty has gradually declined since HIV Futures 2 in 1999, a third of women still experience poverty and decisive action is essential to address this social disadvantage.

We hope that this report can assist all those people whose work contributes to the care of women living with HIV in Australia. We also hope that the HIV positive women who read this report are left with both a sense of shared experience and an appreciation of the diversity of women living with HIV.

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

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

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

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

Table 99 Data on primary site of survey collection (percent)

Completed a previous HIV Futures Survey	32.8
Mail-out from HIV/AIDS organisation	32.8
Positive Women's Organisation	9.0
Picked up a copy at HIV/AIDS organisation	6.0
Picked up a copy at Medical Centre or Hospital	4.5
Told about it by someone who had already completed it	3.0
HIV information centre	1.5
Other	10.9

We were also interested in the extent to which we were accessing HIV positive women who had participated in previous HIV Futures Surveys and other research projects (see table 100). 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 100 Data on previous research involvement (percent)

Positive Health (pH)	13.5
HIV Futures 1 (1997)	32.3
HIV Futures 2 (1999)	41.7
HIV Futures 3 (2001)	44.8
Periodic survey	8.3

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 ADI 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 least $p < 0.05$.

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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