

# HIV futures five

## Life as women know it

Women living with HIV in Australia

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# INTRODUCTION

*Life as women know it* is the fifth report from the HIV Futures surveys that specifically addresses the status of women living with HIV/AIDS in Australia. The data presented here are taken from the 2005 survey HIV Futures 5: Life as we know it. This report is designed to provide women, organisations, government and policy makers with the most recent data on the health, social lives, and financial situation of women living with HIV/AIDS in Australia. As this is the fifth report of its kind, we are now able to examine changes that have occurred at a population level over the nine years since the first HIV Futures Survey was conducted in 1997.

Over those years approximately 219 different women from all states and territories and widely varying social circumstances have participated in this research. Many of these women have participated more than once and some have participated in all five surveys. This is evidence of the longstanding commitment that positive women have shown towards this research. We are extremely grateful to all of the women who have made this research possible - the 86 women who participated in HIV Futures 5, and all of the women who have ever completed an HIV Futures survey. We thank you for completing this long and often personal survey, and in doing so, sharing very intimate details of your lives with us. We are also indebted to the organisations and individuals who assisted with survey recruitment, and particularly to the positive women's organisations who provided us with feedback about the content of this report. We hope that this briefer format continues to provide the reader with a broad overview of the current situation for positive women in Australia as well as knowledge and understanding about what has changed and what still needs to change.

# 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 full HIV Futures 5 report (Grierson et al, 2005).

## **Sample Demographics**

The HIV Futures 5 survey was completed by 982 HIV positive people (nine responses were unable to be entered due to late arrival, therefore the sample analysed is 973). Given current estimates of HIV infection in Australia (NCHECR, 2006) this represents approximately 6.4% of the HIV positive population. Of the total respondents 22.8%, including nine women, completed the survey on-line, an option offered for the first time in 2005. 84 women participated in the survey, representing approximately 5.8% of HIV positive women in Australia.

Of the women, 91.6% were heterosexual women, three women were lesbian, three were bisexual and one fell into another category.

There was a wide age range, with a mean of 45.0 years and a median of 43.0 years (range 25 to 78 years).

**TABLE 1 Women's reported mode of transmission**

Mode of transmission	Number	Percent
Heterosexual contact	64	78.0
Other/don't know	12	14.6
Injecting drug use	4	4.9
Receipt of blood components/tissue	1	1.2
Health care setting	1	1.2

The majority of women were Australian born (69.9%) and 89.0% of women spoke English at home. Two women (2.4%) indicated they were of Aboriginal/Torres Strait Island origin. 96.1% of women indicated that Australia was their official country of residence.

The most common ancestries identified with were English (27.4%), Australian (12.3%), Northern European (12.3%) and Irish (9.6%)

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

**TABLE 2 State or territory of women's residence**

State/territory	Frequency	Percent of Sample
NSW	37	45.1
VIC	22	26.8
WA	11	13.4
QLD	7	8.5
SA	2	2.4
ACT	2	2.4
NT	1	1.2

45.2% of women were from urban areas of capital cities, while 21.4% lived in outer suburban areas, 17.9% lived in larger regional centres and 15.5% lived in rural areas.

62.2% of women were living in the state or territory in which they had first tested positive for HIV, while 8.5% lived in a different state or territory. 29.3% of women did not provide information about either the state they were living in, or the state they were living in when first diagnosed.

Table 3 below shows the years in which women tested HIV positive and in which they believe they were infected with HIV. The median length of time between becoming infected and receiving an HIV positive diagnosis was one year (range less than one year to seven years). 42.9% of women tested positive in the same year they believe they were infected. One woman in the sample had tested positive in the last two years.

**TABLE 3 Years of respondent's testing positive and presumed infection**  
(% of women)

<b>Year</b>	<b>Tested HIV Positive</b>	<b>Presumed Infected</b>
Pre 1985	0	2.6
1985-1989	10.8	26.0
1990-1994	41.0	32.5
1995-1999	24.1	19.5
2000+	24.1	19.5

20 women (28.2%) indicated that they were atheist/agnostic, 53.4% indicated mainstream religious identification and the remainder were either adherents of new age belief systems or had other spiritual beliefs. 22 (26.5%) indicated that religion or spirituality was of no importance to them. A further 37.3% indicated that this was of little importance, 24.1% that it was very important and 12.0% 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 (ABS, 2006). The educational levels are shown in Table 4 below.

**TABLE 4 Educational level of women**

<b>Level</b>	<b>Frequency</b>	<b>Percent of women</b>
Leaving certificate/HSC/Year 12	20	25.6
University degree	18	23.1
Tertiary diploma/Trade Certificate/TAFE	15	19.2
4 <sup>th</sup> form/Year 10	17	21.8
Up to 3 years high school	6	7.7
Primary school only	2	2.6

# 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 general sense of health and well-being, the health burden in terms of concomitant health conditions and health maintenance strategies.

## **HIV Antibody Testing**

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, 29.9% of women had been tested because their partner had tested positive, while 26.9% had taken the test as a result of illness.

**TABLE 5 Reasons for testing**

Reason	Frequency	Percent
Partner tested positive/partner died	21	29.9
Became ill	19	26.9
Other	9	11.4
Routine health screening	8	11.1
Particular risk episode/member of risk group	7	9.2
Doctor's suggestion	3	3.8
Contact tracer/other health worker's suggestion	2	2.7
Starting new relationship	2	2.6
Antenatal	1	1.7
Tested without knowledge	1	1.2

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

- 19.7% of women indicated that they had received pre-test counselling or engaged in a HIV test discussion. The counselling was provided by a doctor, nurse, counsellor, a staff member at a sexual health centre or a social worker.
- 89.0% of women said they were satisfied with the information they received from this person while 89.0% said they were satisfied with the level of support they received.
- 69.0% of women (n=60) indicated that they had received post-test counselling. The counselling was generally provided by a doctor (19%) or social worker (19%), but was also commonly provided by a counsellor, staff at a sexual health clinic or staff at an HIV/AIDS organisation.
- 80.9% of women said they were satisfied with the information they received while 74.3% said they were satisfied with the support they received.

# Current Health Status

## Experience of Health and General Well-Being

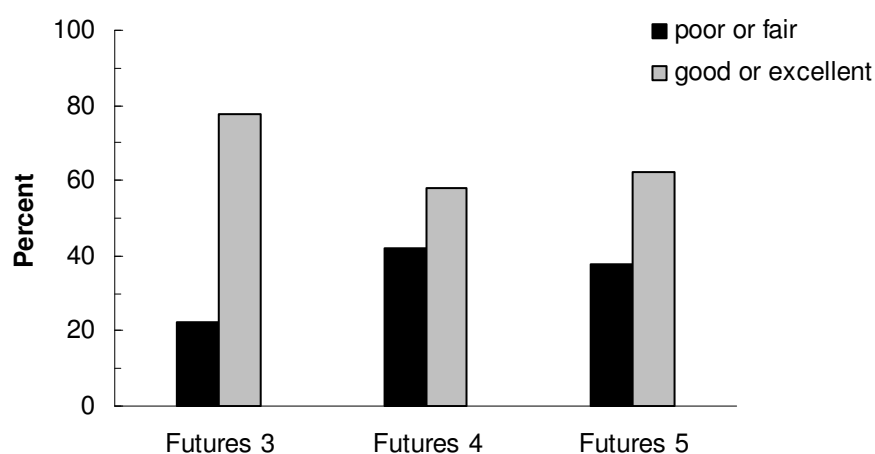
We asked respondents to rate their physical health and sense of well-being on a four point scale. The results are shown in Table 6 (below). The majority of women rated their health as good (48.4%) or excellent (22.3%), and around one-quarter as fair. In comparison, the National Health Survey reported that a slightly higher proportion of the general Australian population (86.6%) rated their health as good, very good or excellent, and only 13.4% as poor or fair<sup>1</sup> (ABS, 2006). The ratings for well-being were of a similar pattern to those for health.

**TABLE 6 Women's self-rated health and well-being (percent)**

	Health status	General well-being
Poor	3.2	7.9
Fair	26.1	29.8
Good	48.4	42.0
Excellent	22.3	20.2

There has been little change in the pattern of self-rated health across the five HIV Futures surveys. 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. However the figures for self-rated well-being have changed across the three surveys in which this item was included, as is indicated in figure 1. The proportion of women rating their well-being as poor or fair almost doubled between 2001 and 2003 but reduced again in 2005. This may suggest that improved health or better tolerance of treatments may be leading to improvements in well-being for women living with HIV.

**FIGURE 1 Comparison of women's self-rated well-being over three Futures surveys**



<sup>1</sup> It should be noted that the National Health Survey uses a five point scale: poor, fair, good, very good, excellent. The figures quotes are for Australians aged 18-64.

## Health Conditions other than HIV

There is often uncertainty about whether a particular illness is related to HIV, treatments or other factors. We asked participants to record these conditions within three categories: AIDS defining illnesses (ADI), HIV-related illnesses and other health conditions. These figures indicate that there is a considerable burden of illness that goes beyond HIV infection for a significant proportion of women.

### **AIDS Defining Illnesses**

Just over one-quarter of women (27.5%) had been diagnosed with an ADI. Diagnosis occurred between 1993 and 2005. The most common illness reported in this category was Pneumocystis Carinii Pneumonia (PCP), reported by 55% of the women who had experienced an ADI.

### **HIV/AIDS Related Conditions**

27.5% of women said that they had experienced an HIV-related illness other than those classified as an ADI, including shingles, oral thrush and herpes.

In a separate question, respondents were asked to select from a list of 10 conditions commonly associated with HIV infection those that they had experienced in the previous 12 months. In order to gain a clearer picture of respondents' burden of illness, this list was expanded from previous HIV Futures surveys to include five additional conditions (see Table 7).

**TABLE 7 Health conditions experienced in the past 12 months**

	Frequency	Percent
Low energy/fatigue	62	85.4
Diarrhoea	41	60.9
Sleep disorder	37	59.7
Nausea or vomiting	37	59.7
Confusion/memory loss	31	52.5
Lipodystrophy/lipoatrophy	28	48.9
Weight loss/underweight	24	41.8
Raised cholesterol/triglycerides	21	35.1
Peripheral Neuropathy	12	24.5

## Other Health Conditions

### **Major health conditions**

Thirty-one women (39.0%) 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.

### **Hepatitides**

10.1% of women (n=8) had at some point had Hepatitis A, and 47.0% had been vaccinated against this virus. This means that 43% of women may currently be at risk of Hepatitis A infection.

11.3% of women (n=9) had at some time been diagnosed with Hepatitis B and 64.1% of women had been vaccinated against this virus. This means that 24.8% may currently be at risk of being infected with Hepatitis B.

24.2% of women (n=18) said that they had ever had hepatitis C. 15 women (18.8%) had not been tested for hepatitis C, slightly higher than the proportion of respondents to the previous HIV Futures survey who had not been tested (14.6%).

### **Mental Health**

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

## Diagnosis of a Mental Health Condition

Just over one-third of women (34.7%,n=28) reported having been diagnosed with a mental health condition, eight in the previous two years. The most common condition diagnosed was depression, reported by 33.2% of women. In comparison the National Health Survey found that six percent of females in the general population reported both anxiety related problems and mood problems (ABS, 2006). As both of these figures are based upon self-reported data it is reasonable to compare them.

## Psychiatric Medications

In the six months prior to completing the survey, 32.7% of women reported having taken medication prescribed for depression. Additionally, in response to a question about current use of medicines, 19.5% of women listed an antidepressant. Both of these figures are considerably higher than the population comparison of 6.6% of females using antidepressant medication in the previous two weeks (ABS, 2006).

13.3% of women reported having taken medication for anxiety in the past six months (population comparison is 2.4%, ABS, 2006), while five women indicated that they had used anti-psychotic medication.

## Health Maintenance

### Prophylaxis

25.4% of women were taking prophylaxis for opportunistic infections.

### 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. 25.6% of women had undergone a bone density test in the last two years and 14.3% more than two years ago. 48.7% reported having a fasting cholesterol test in the last two years, and 8.3% more than two years ago.

All women reported having undergone a cervical smear (Pap) test (98.7%), and 80.0% reported having a test in the last twelve months. The CDC recommends that all HIV-positive women have a pap smear every year. This means up to 20% of women who should have had an annual pap smear had not, although it may be possible that some of these women did not require one. Generally women reported having one test in the last year (72.7% of those tested in the last year). On their most recent test, most (87.4%) of women reported that the result was normal, while 5 women indicated that the test result was abnormal.

## Complementary Therapies

We asked women to indicate the types of complementary therapies they had used in the previous six months. In order to gain an overall picture of complementary therapy use, the question asked participants to indicate all complementary therapies used not only those used for HIV/AIDS. Women were more likely than men to have complementary therapies over this time period (81.6% v 76.1%).

**TABLE 8 Use of complementary therapies over the past 6 months**

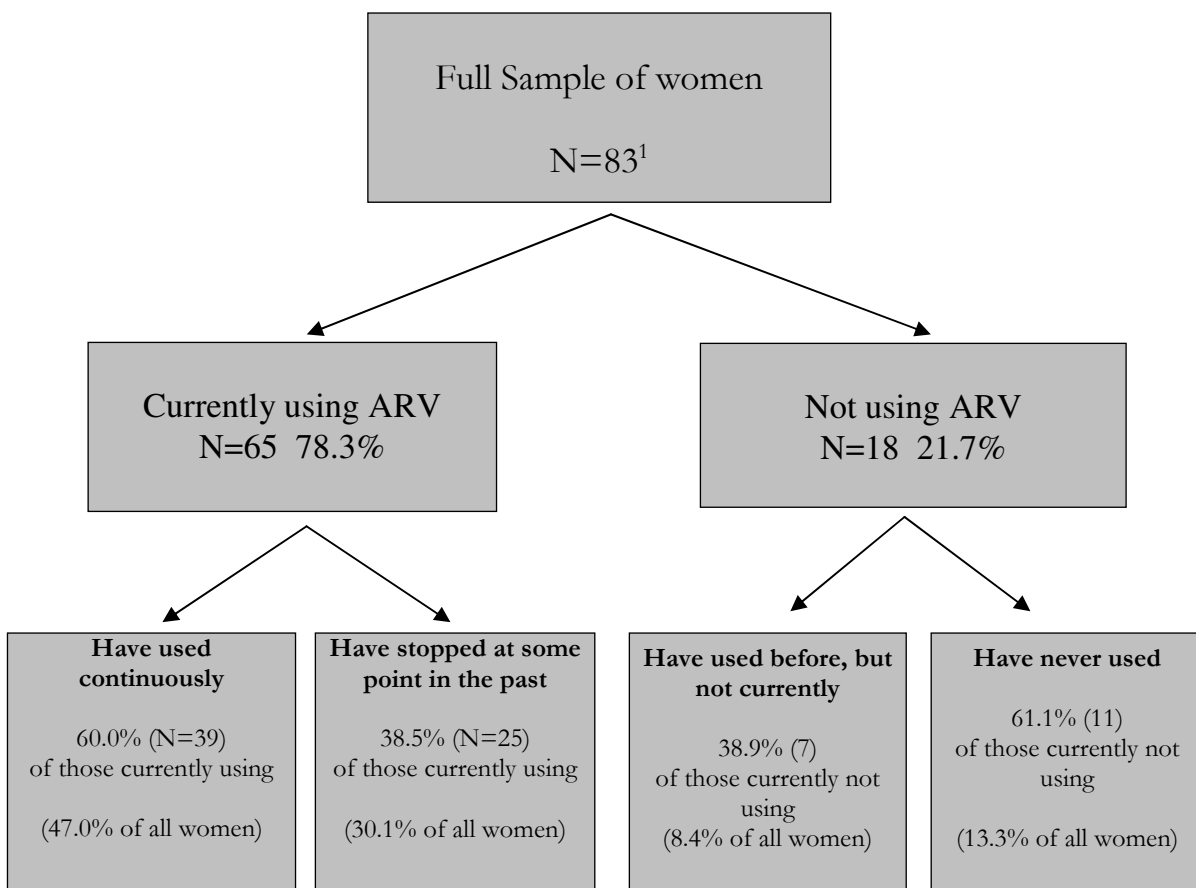
Vitamin/mineral supplements	64.8
Massage	40.2
Meditation/visualisation	20.4
Herbal therapies/supplements	19.5
Marijuana for therapeutic purposes	16.0
Acupuncture	12.5
Other	7.4
Traditional Chinese medicine	6.8
Other traditional medicine	3.6

(Multiple responses possible)

# TREATMENTS

Of the full sample, 86.7% of women had used ARV at some point, and 78.3% were currently using these treatments. Figure 2 below shows the pattern of uptake of ARV among women.

**FIGURE 2 Use of antiretroviral therapy**



<sup>1</sup>(Note: Ns may be reduced due to missing data)

**FIGURE 3 Current use of ARV by gender and year**

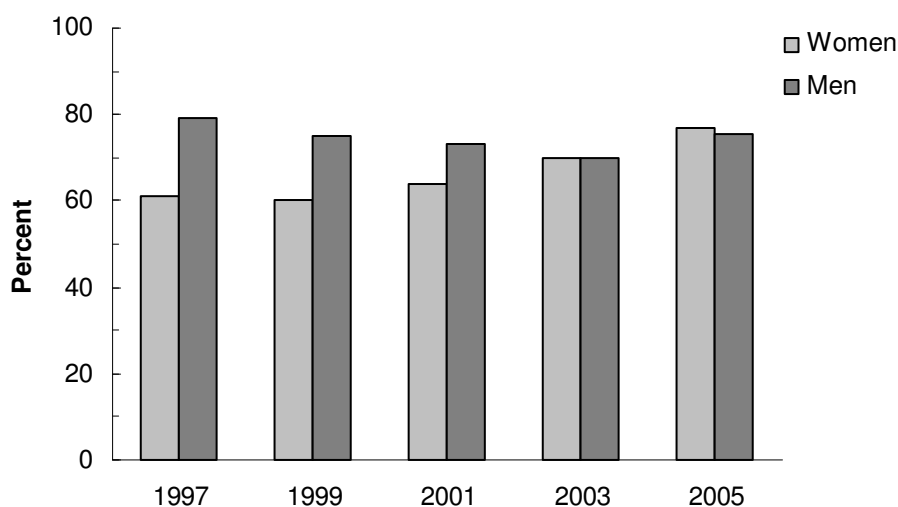


Figure 3 displays the rate of ARV use across all five HIV Futures surveys. Women were significantly less likely to be using ARV than men in 1997 and 1999. By 2001, this difference was no longer significant and in 2003 the proportions of men and women using ARV were the same. In 2005 the proportion of women using ARV was slightly higher than men, and for both men and women was higher than in 2003.

**TABLE 9 Circumstances surrounding commencement of treatment among women and men currently on combination ARV (%)**

	Women	Men
My doctor advised me to begin this treatment	63.2	74.7
I had a big drop in my CD4/T-cell count	52.0	45.5
I had a big rise in my viral load	26.7	34.9
I became very ill	24.0	28.6
New drugs became available	18.7	26.8
Information showed that this treatment is effective	6.7	23.4
I was hospitalised due to HIV-related infections	26.3	15.1
I had just tested positive to HIV	14.7	18.2
Other	10.7	9.0

(Multiple responses possible)

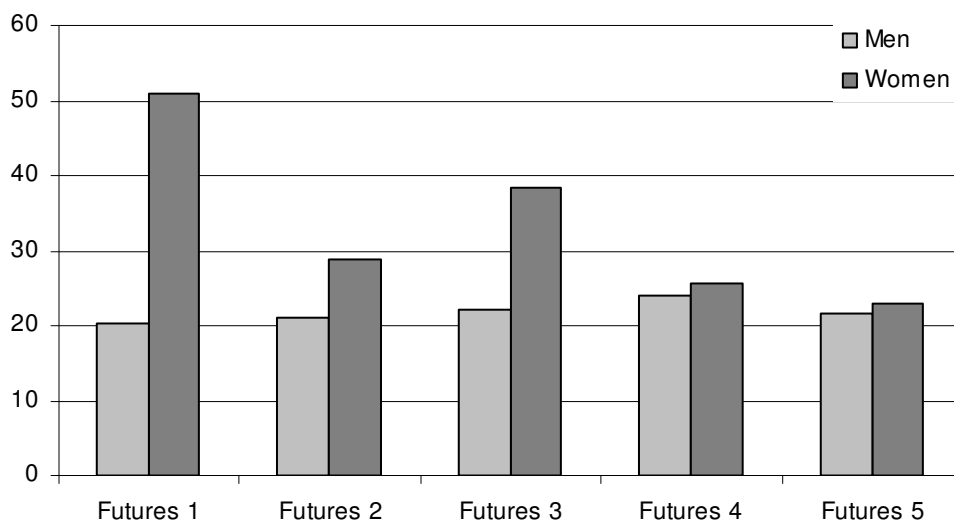
For women and men the most common reason cited for starting on combination ARV was the advice of a doctor, although men were significantly more likely to give this reason (Table 9). Men were also significantly more likely to say that they had started on combination ARV because information showed that these treatments were effective, while women were significantly more likely to say that they had been hospitalised due to HIV-related illness just prior to starting on treatments (26.3% v 15.1%). One woman said that she had started on treatment because she fell pregnant.

### **Those Who Have Never Used Antiretroviral Drugs**

12.5% (N=10) of women had never used antiretroviral treatments. All of these women 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, such as getting ill, a rise in viral load or significant drop in CD4/T-cell count.

## Attitudes to Antiretroviral Therapy

**FIGURE 4: Those agreeing that ‘I am healthy now and don’t need to use combination ARV’**

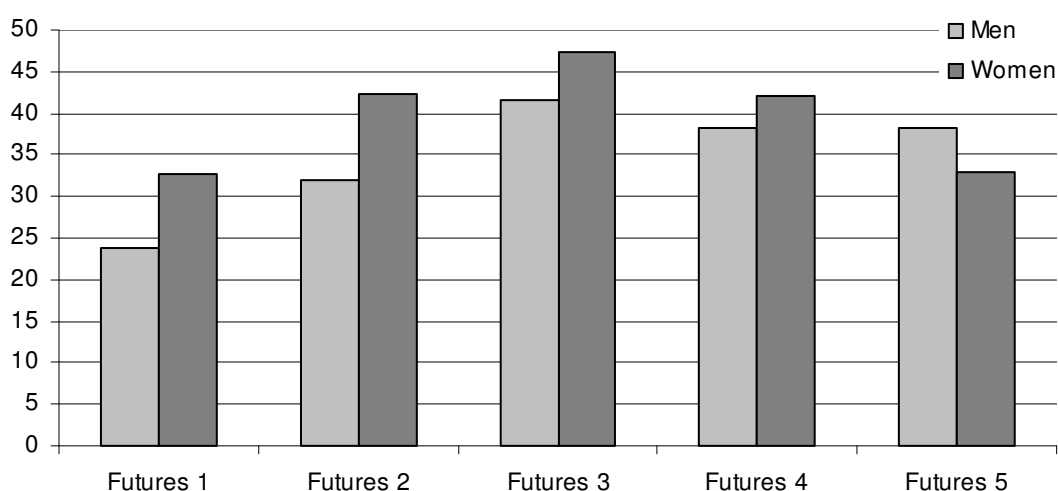


As is displayed in Figure 4, women’s attitudes to the statement “I am healthy now and don’t need to use ARV” have changed considerably over time. As would be expected, this is in part a reflection of the proportion of women who were taking ARV at that time. For example, in 1997 only 58% of women were taking ARV compared with 77% in 2005. Looking at gender differences, women were more likely than men to agree with this statement in 1997, 1999 and 2001, however responses were similar for men and women in 2003 and 2005.

## Treatment Optimism

The Australian experience of using ARV continues to be characterised by optimism about the value and effectiveness of these treatments as well as concern about their long-term impact and effectiveness. Women’s attitudes toward treatments have fluctuated over time, most likely as a function of their experiences of using treatments. In comparing women’s responses to the statement ‘Combination ARV is harmful’ over time, we observe that at least one-third of women agreed or strongly agreed with this statement each time, and this proportion peaked at 47.3% in 2001, before decreasing (Figure 5). Women were more likely than men to agree with this statement in 1997, 1999 and 2001, however in 2003 and 2005 responses were similar among men and women.

**FIGURE 5: Those agreeing that ‘Combination antiretroviral drugs are harmful’**



# SERVICES

This section examines 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 doctor they see for the clinical management of their HIV and for general health issues (Table 10). The most commonly reported doctor for general medical treatment was a generalist GP, while HIV specialists were used by half of the women for HIV specific treatment. Women were significantly less likely than men to see an HIV GP for main general medical treatment and for HIV specific treatment. 55.6% of women saw different doctors for general medical treatment and HIV specific treatment, compared with 35.6% of men.

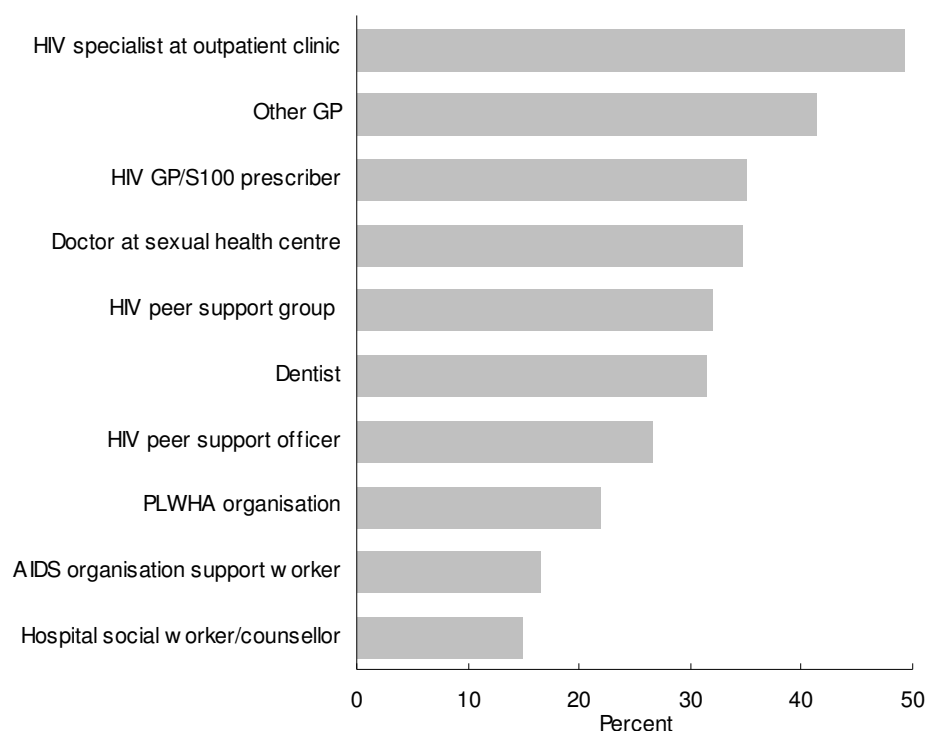
**TABLE 10 Doctor used for general and HIV-related treatment (percent of total sample)**

	For HIV specific treatment	For general treatment
HIV GP/S100 Prescriber	13.5	17.4
Other GP	3.8	36.6
HIV specialist at outpatient clinic	50.8	18.7
HIV specialist at inpatient clinic	1.3	0.0
Doctor at sexual health centre	29.4	19.5
Other doctor	13.6	2.8
Other	2.5	5.0

### Services Used in the Last six 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 6). Compared with men, women were more likely to have used the services of a peer support officer (18.3% v 10.7%) and peer support groups (25.0% v 12.5%). Women were less likely than men to have seen an HIV GP over this time period (33.7% v 59.3%).

**FIGURE 6 Services used in the last six months (percent of women, top 10 only)  
(multiple responses possible)**



### **Other Services**

Respondents 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 (see Table 11). Treatments advice was cited as the most commonly used service at HIV/AIDS organisations, followed by social contact with other PLWHA and peer support groups. Women were significantly more likely than men to report that they used HIV/AIDS organisations for treatments advice (59.4% v 46.0%), peer support (47.4% v 31.4%) and social contact with other positive people (54.2% v 39.2%). 36.3% 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 services outside business hours and peer support.

**TABLE 11 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
Treatments advice	60.5	16.2
Social contact with other PLWHA	53.1	2.4
Peer support group	48.5	6.5
Treatments information	45.2	8.8
Informal peer support	41.3	7.4
Counselling	35.4	28.9
Financial assistance	29.9	14.5
Pharmacy services	28.2	40.5
Complementary therapies	26.4	23.1
Community education campaigns	15.8	6.0
Internet based information	12.7	14.6

(Multiple responses possible)

## **Sources of Information**

Respondents were asked to nominate from a list those individuals or organisations that formed important sources of information for them on HIV treatments/management and living with HIV (see Table 12).

**TABLE 12 Sources of information for women about treatments and living with HIV (percent of sample, multiple responses possible)**

	<b>Information about Treatments/Management</b>	<b>Information about Living with HIV</b>
HIV specialist	71.5	31.0
HIV magazine/newspaper	47.8	54.2
HIV GP/S100 prescriber	44.1	29.3
Publications from HIV/AIDS groups	42.1	43.9
HIV positive friends	34.7	44.9
Positive Women's Organisation	32.7	52.0
Sexual Health Service	29.8	31.0
AIDS Council staff (treatments-specific)	22.2	22.2
PLWHA Organisation staff (treatments-specific)	19.2	21.6
PLWHA Organisation staff (others)	19.2	27.6
AIDS Council staff (others)	16.4	24.4
Internet	16.4	20.2
Positive heterosexuals group	13.9	24.4
Family	10.9	22.4
Peer Support Officer	9.7	17.9
Partner/lover	7.6	16.6

## **Information about Treatments/Management**

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

Women were significantly more likely than men to nominate the following as important sources of information about living with HIV: peer support officer (25.6% v 15.9%), family (24.7% v 10.2%) and publications from HIV/AIDS groups (56.8% v 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% v 39.7%).

When asked to identify the most important source of information about 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.

## **Lack of information**

30% of women (n=23) said that lack of information made it difficult for them to make decisions about living with HIV. The most common domains in which this applied were: managing side effects of ARV (n=10), legal issues (n=10), and work (n=8). Six women said they lacked information about having children.

# THE SOCIAL WORLD OF WOMEN

This section 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 helps to reduce this isolation. Here we examine 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.

## **Involvement with AIDS Organisations**

Participants were asked about their involvement with HIV/AIDS organisations. 85.1% of women had some contact with HIV/AIDS organisations. The most commonly mentioned organisations were positive women's organisations, used by 35.4% of those who had contact with at least one organisation; PLWHA organisations (26.2%) and positive heterosexuals groups (24.6%). Of these, 77.4% received newsletters and mail outs, 65.0% were clients, 48.9% were members and 23.9% were volunteers.

## **Unwanted Disclosure**

Respondents were asked if their HIV status had ever been disclosed without their permission. 60.3% of women said that it had at some point, and 23.2% in the last two years. This compares with 37.5% of women from the HIV Futures 4 study reporting unwanted disclosure in the last 2 years. In *The Journey Continues* (McDonald et al 2005) we reported that 27.2% of women reporting unwanted disclosure had nominated a worker in a health care setting as the source. In the current sample, only 11.4% reported this as the source of unwanted disclosure. The previous women's report also reported that women were significantly more likely than men to have experienced unwanted disclosure, however in the current data set there was no gender difference on this item.

## Women and Children

63.6% of women had children ranging in age from babies to 53 years of age. Between them, 50 women had 101 children, and 30 women had 50 children living with them, all of whom were dependent. 13 women had one child living with them, 13 women had two children and four women had three children living with them. The average age of dependent children who were living with the respondent was 13 years. Five dependent children were aged five years or younger and three were aged two years or younger.

Three 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 50 women who had children, 15 (30.5%) said that they had told their child(ren) about their HIV status. This compares with 64.9% of women participating in the previous HIV futures survey who had disclosed to their children. The age of the children at the time of disclosure ranged from two years to 53 years. Of the 30 women with dependent children, 11 (35.5%) said they had disclosed to their children. The age of these children at the time of disclosure ranged from two years to 17 years.

## **Health and children**

There were no differences in self-rated health or wellbeing between women with dependent children and those without dependent children. However, women with children were more likely to be using anti-retrovirals (86.3% v 67.9%).

## **Relationships and children**

Just over half of the women (55.7%) 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 pregnant, all but one were in regular relationships or currently married.

## **Planning to have children in the future**

We were also interested women's plans to have (more) children in the future. Most women (76.1%) were not currently considering having children (Table 13). Table 13 shows the responses given by the remaining women.

**TABLE 13 Planning to have children (number)**

Not considering having a child	53
I have decided to have a child/children in the future	5
I am currently trying to conceive/get pregnant	0
I am currently pregnant	1
I have thought about it but I haven't decided	5
I have thought about it but I have decided that it is too risky	4
I was told not to by a doctor/medical professional	0
I don't have enough information to make a decision	1
Other	2

# RELATIONSHIPS AND SEX

## **Relationships**

Respondents were asked about current sexual relationships. The results are presented in Table 14 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 report on women in these categories separately. Women were more likely than other PLWHA to report that they had one regular sexual partner and no casual sex, while heterosexual men were more to report that they had no sex at present. Gay and bisexual men were more likely to report that they had a regular sexual partner and also had casual sex.

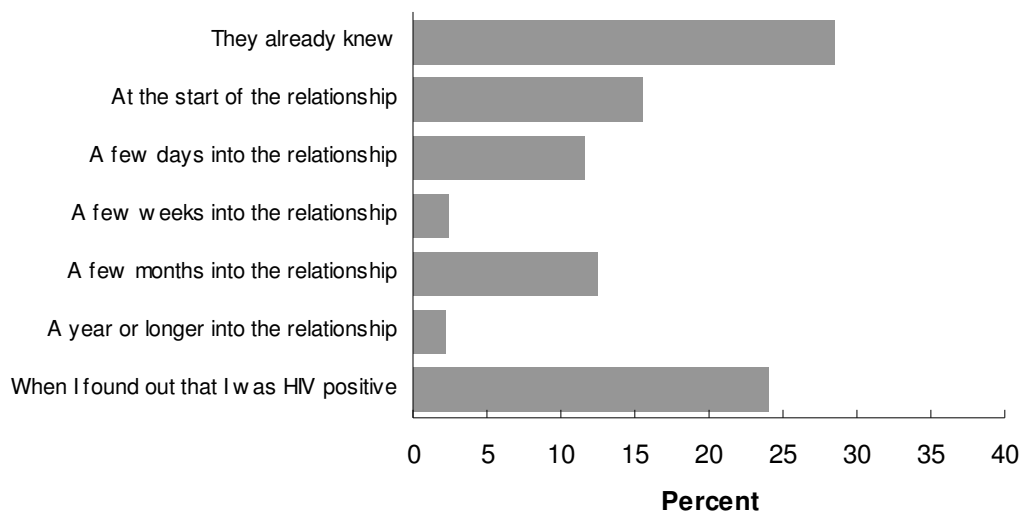
**TABLE 14 Type of sexual relationship(s) by gender and sexuality of respondent (percent)**

	Women <sup>1</sup>	Heterosexual men <sup>2</sup>	Gay or Bisexual Men <sup>3</sup>	Total
I have no sex at present	47.5	55.7	25.5	30.4
I have casual sex only	2.0	10.0	35.0	29.2
I have a regular relationship with one person, and I have sex with other people	0	7.1	20.8	17.4
I have a regular relationship with one person, and I do not have sex with other people	50.5	27.1	16.5	21.2
I have a regular relationship with two or more people	0.0	0.0	2.2	1.8

## **Regular Partners**

Just over half (55.9 %) of women said they were in a regular relationship. Of those in a relationship with a regular partner, 24.6% of women reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remaining group were in sero-nonconcordant relationships. Of these women, 70.5% reported that their partner was HIV negative (a sero-discordant relationship) and 4.9% (two women) that they did not know their partner's HIV status. All of the women had told their regular partner that they were HIV positive. Respondents were asked at what point in the relationship they told their partner. The responses are given in Figure 7 below.

**FIGURE 7 Time HIV status disclosed to partner among those women in regular relationships**



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, 56.5% of women had vaginal or anal sex with a regular male partner in the six months prior to completing the survey and 2.3% (2 women) had vaginal or anal sex with a regular female partner in the previous six months. Condom use is reported in Table 15.

**TABLE 15 Condom use with regular partner by partner sero-status (N)**

	Never	Sometimes	Usually	Always
<b>Sero-concordant relationships</b>				
With regular male partner (N=13)	5	3	1	0
<b>Sero-nonconcordant relationships</b>				
With regular male partner (N=27)	5	4	2	14
With regular female partner (N=3)	2	-	1	-

**Casual Partners**

Five 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, four reported that none of their casual partners were HIV positive and one woman said that she was not sure of her partners' serostatus. Of the five women who reported having sex with casual male partners, three said they always used condoms and one woman said that she sometimes used condoms. The one woman who reported having sex with casual female partners said that she never used condoms.

## **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 16. Compared to men, women were significantly more likely to disagree (51% vs 31.2%) or express uncertainty (25.5% vs 16.7%) about the statement “I prefer to have a relationship with someone who also has HIV”. Women were also significantly more likely than men to agree (63.5 v 53.5) or to be unsure (14.6% 7.9%) that they were afraid of telling potential partners of their HIV status in case were rejected. The majority of both women and men agreed that they were afraid of infecting their partner, or potential partner, with HIV, however women were significantly more likely than men to do so (75.3% v 67.7%).

**TABLE 16 Attitudes to HIV, sex and relationships**

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't know</b>
I prefer to have a relationship with someone who also has HIV	26.5	24.7	10.5	10.7	27.7
Few people would want a relationship with someone who has HIV	3.8	29.0	30.2	20.7	16.4
I am afraid of telling potential partners of my HIV status in case they reject me	6.3	17.5	29.2	29.3	17.6
Being HIV positive has helped me form more satisfying relationships	18.0	46.4	13.9	3.7	18.0
I am afraid of infecting my partner, or potential partner, with HIV	2.9	19.3	43.6	24.8	9.4
I feel more confident about unprotected sex because of the new treatments	49.2	30.2	8.1	3.7	8.8
Medical treatments for HIV/AIDS make safe sex less important than it was	53.7	27.7	2.8	1.1	14.6
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	39.1	39.1	6.3	3.0	12.4
If there was a vaccine which prevents HIV I would not practice safe sex	29.3	33.3	14.3	5.0	18.0
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	35.8	27.7	15.6	2.2	18.8
Knowing a vaccine will become available makes me less anxious about sex	18.8	44.7	10.7	8.0	17.8
I am concerned about becoming infected with another strain of HIV	17.0	41.3	21.0	9.8	10.9
HIV has had a negative effect on my sexual pleasure	6.7	23.6	36.9	30.1	2.7
If I know that my partner is HIV positive I find sex more pleasurable	33.7	16.5	9.6	6.1	34.0
I stopped having sex because of my HIV status	24.8	37.0	17.9	12.8	7.5
HIV has negatively affected my libido	14.7	25.0	35.1	20.7	4.5

## 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. Alcohol was the most commonly used substance, used by 62.5% of women, followed by cigarettes (38.5%) and marijuana (24.0%). This compares with the finding from the most recent National Health Survey that 20% of women were current smokers (ABS, 2006). No other substance was used by more than 5% of women over the past 12 months. Only 6.2% of women agreed with the statement “I drink more alcohol than I would like to”.

# HOME, WORK and 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 accommodation status of women is shown in Table 17. Similar numbers of women lived in accommodation owned or rented through the private system. A smaller number of women were in public rental accommodation. These women were more likely to be on a government benefit.

**TABLE 17 Current accommodation of women (percent of total sample)**

Own or purchasing house or flat	36.1
Private rental accommodation	36.4
Public rental accommodation(government owned)	20.6
Community housing/housing co-operative	3.4
Other	3.4

Households varied considerably in composition. Almost one-third of women (30.5%) lived by themselves, while the remainder lived with between 1 and 4 other adults (median=1) and between one and three children (median=2). One third (33.6%) lived with a partner or spouse, and 38.0% lived with dependent children.

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.

The vast majority of women (80.5%) stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (n=15), the main reasons given were that it was too small (n=7) or inadequate for their current state of health (n=5).

40.2% of women (n=32) said that they had ever changed their accommodation because of HIV/AIDS, five had done so in the last two years.

## EMPLOYMENT

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

## **Employment Status**

Just over half (55.8%) of the women were in paid employment, with similar numbers engaged in part-time and full-time work (Table 18 below). The remaining women were either not working/retired (15.3%) or occupied with home duties (13.3%), with smaller numbers being unemployed or students. Women were more likely than men to be working part-time (26.0% compared with 17.0%) and to be occupied with home duties (16.0% compared with 1.7%), and less likely to be working full-time (28.0% compared with 34.5%) or not working/retired (17.0% compared with 26.0%).

<b>TABLE 18 Employment status of women</b>	<b>Percent</b>
Work part-time	29.3 (n=22)
Work full-time	26.5 (n=20)
Not working / Retired	15.3 (n=12)
Home duties	13.3 (n=10)
Unemployed	6.0 (n=5)
Student	5.8 (n=4)
Other	3.7 (n=3)

Of those women who were working, the mean number of hours worked was 27.8 (median=30.0). Those working full-time worked an average of 37.1 hours per week (median=38.0) and those in part-time employment worked an average of 19.5 hours/week (median=16.6).

## **Interruptions to Employment**

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those women who have worked, 53.4% had stopped work for reasons related to HIV, 29.9% on one occasion and 8.9% on two occasions. One woman had stopped work six times due to HIV. 13% of women had stopped work in the previous two years. These work interruptions averaged 16.2 months (median= 8.3 months).

The two most common reasons for stopping work were poor health (44.9%) and low energy (43.4%). These circumstances are also reflected in the women's HIV/AIDS status at the time they ceased work. 30.4% said that they were ill at the time and 31% had been diagnosed with an ADI. However 38.6% of women said that they were not ill at the time, perhaps reflecting the anticipation of illness, the psycho-social impact of HIV, or because they had a child.

We asked participants their source of income during their most recent interruption to employment. Almost three quarters of women (71.4%) said they relied on a government benefit of some sort. Of those women who stopped working at some point, 55.1% had returned to work. This was most commonly due to improved physical (77.6% of those who had returned to work) or psychological health (76.6%). A high proportion of women had returned to work in order to do something worthwhile (62.3%), for financial reasons (59.3%) and to have something to do (58.5%).

# 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**

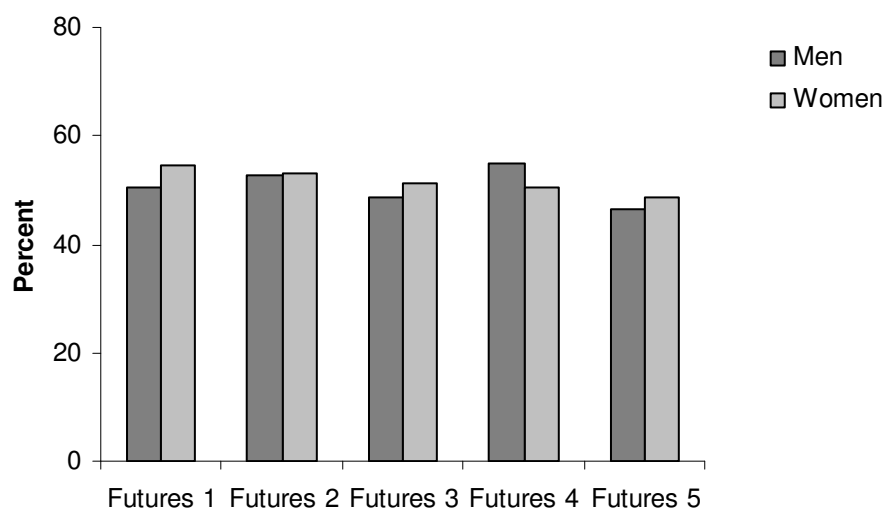
The main source of income for women is shown in Table 19 below. A government benefit was the most common income source, nominated by 46.8% of women, however only a slightly smaller proportion (42.5%) nominated salary in response to this question. Compared with men, women were significantly less likely to nominate their main source of income as salary or superannuation/annuity/savings and more likely to report that their partner supported them.

**TABLE 19 Primary source of income (percent of all women)**

Benefits/pension/social security	46.8
Salary	42.5
Partner supports me	6.4
Other	4.6

As is displayed in Figure 8 below, the proportion of women nominating a government benefit as the main source of income has decreased slightly over time from 54% in 1997 to 48% in 2005. The proportion earning most of their income from salary increased from 20% in 1997 to around 40% in 2001, and has since stayed at this level. In contrast, there has been an increase in the proportion of men nominating salary as their main source of income from 2003 to 2005 (37.2% vs 45.9%) and a concurrent decrease in the proportion receiving a government benefit from 54.9% in 2003 to 46.3% in 2005.

**FIGURE 8: Percentage of men and women describing their main source of income as a government pension or benefit, shown over five Futures surveys.**



The median weekly income for women was \$400. 29.0% of women had a partner with whom they shared financial resources. The partner's median weekly income was \$500.00. There was no significant difference in either individual or household income between women and men.

### **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 21 women (42.4% of those nominating a benefit as their main source of income) had received such an assessment. Fifteen women said that the assessment required documentation from their doctor and fifteen women also said that it caused them distress. Only two women said that this experience clarified concerns.

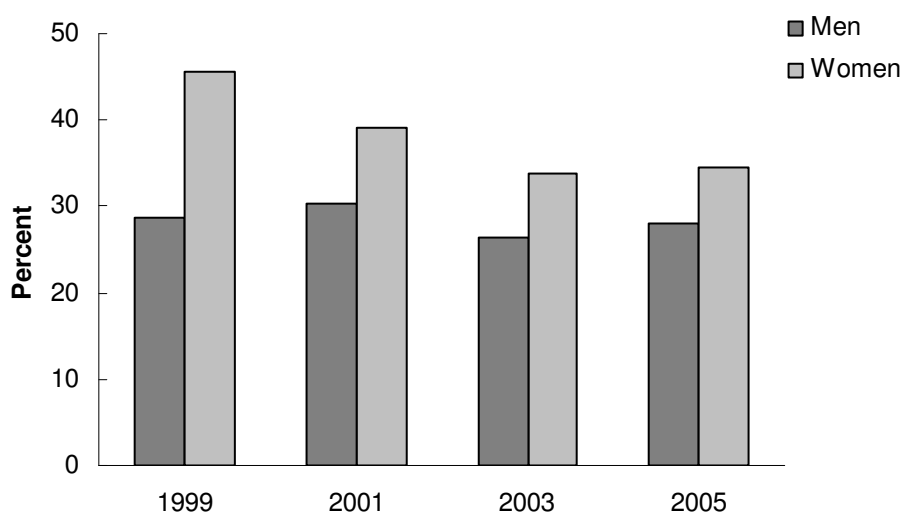
## Poverty

As with the previous HIV Futures surveys, we have used the quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR) to assess the extent of poverty among PLWHA. The Henderson Poverty lines are set for specific income units. These units include the individual, any partner with whom they share financial resources and any dependent children. We used the IAESR (2005) data for the September quarter (the time at which the survey was completed).

According to this measure around one third (34.5%) of women were living below the poverty line. Figure 9 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 the first HIV Futures survey, the poverty line data from that survey (1997) is not included. 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 before falling to the current level, which is slightly higher than the current figure for men (28.1%). The fact that the proportion of PLWHA, especially women, living below the poverty line has remained so high

suggests that current resources and strategies are inadequate and decisive action needs to be taken to address this pocket of severe social disadvantage.

**FIGURE 9 Poverty by gender across four Futures surveys**



## **Costs**

We asked respondents if they experienced difficulty paying for a range of activities, goods and services. The results for the ten most commonly used items are shown in Table 20, with the not applicable responses excluded from the calculation for each item. Importantly, substantial numbers of women 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 20 Difficulty paying costs of items and services**

	<b>Not at all difficult</b>	<b>A little difficult</b>	<b>Very difficult</b>
Medical services (doctor, dentist, etc.) (n=70)	38.9	39.9	21.3
Entertainment (theatre, movies, concerts, etc.) (n=71)	25.7	35.2	39.0
Going out (eating/drinking) (n=70)	26.4	36.0	37.6
Sport (exercise, gym, etc.) (n=55)	32.7	27.6	39.7
Travel/holidays (n=58)	18.6	37.7	43.7
Rent/Mortgage/Housing costs (n=83)	36.1	43.4	20.5
Utilities (telephone/electricity/gas/water) (n=76)	34.0	45.1	20.9
Food (n=76)	37.3	48.6	14.1
Clothing (n=72)	32.0	35.2	32.8
Transport (n=69)	45.1	32.0	22.9

# DISCRIMINATION

Discrimination is a central theme in the history and current state of the HIV/AIDS epidemic and 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 asked about the experience of discrimination in a range of settings.

## **Accommodation**

Six women indicated that they had experienced less favourable treatment in relation to accommodation (three in the last two years).

## **Health Services**

46.5% of women had experienced less favourable treatment at a medical service as a result of having HIV. Of these women, the majority had experienced this discrimination more than two years ago, with only 11.8% reporting discrimination in the last two years. This figure is lower than the 20% of women from HIV Futures 4 who reported experiencing discrimination at a medical service in the last two years.

Compared with men, women were significantly more likely to report having experienced discrimination at a medical service more than 2 years ago (29.4% compared with 15.5%), however the proportion of women and men reporting discrimination in the last 2 years were similar (9.8% v 10.2%).

## **Insurance**

13.8% (11) of women currently had private health insurance and six currently had some other form of income or mortgage insurance. 19.1% (n=13) 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.

# CONCLUDING COMMENTS

*Life as women know it* provides an overview of the lives of women living with HIV in Australia in 2005 as well as some comparisons across time from 1997 to 2005. We have observed gradual changes over time, such as increased uptake of antiretroviral treatments and less unwanted disclosure. However, there has been little change in other important areas such as the proportion of women living below the poverty line.

On average women were five years older in 2005 compared with 2003, with an average age of 45 years. Issues to do with ageing with HIV are expected to become increasingly important as women age, and given the increasing proportion using ARV, it will be important to understand the influence of treatments on women's reproductive health.

Women's self-rated health and wellbeing have slightly improved since 2003 and more women rated their health and wellbeing as excellent. However self-rated health continues to fall below the population comparison for this measure, indicating that whilst HIV is considered by many to be a chronic manageable illness, the negative impact on women's health is ongoing.

We noted in 2003 that peer support services were particularly well utilised by women. In 2005 women continued to be more likely than men to use peer support officers and peer support groups. This finding suggests the importance of ongoing provision of these services by community organisations. Women also continue to use different clinical services to men, being less likely to see HIV GPs both for HIV-related and non HIV-related treatment.

In 2003 we reported high levels of unwanted disclosure of HIV status, particularly in health care settings. We are pleased to observe that in 2005 reports of unwanted disclosure in the previous two years were lower, and reports of unwanted disclosure in health care settings were much lower than in 2003. This suggests that education programs to sensitise mainstream services to issues specific to HIV/AIDS have had some positive effect.

In 2005, over one-third of women were living below the poverty line. Although this figure has come down since 1999, there has been no change since 2003 and this level of poverty remains unacceptable. We found that women were increasingly likely to be engaged in part-time or full-time employment, however a similar number were relying on a government benefit as their main source of income. We hope that as women are increasingly involved in the workforce this translates into improved financial status for these women.

As with all previous Futures reports on women, parenting remains an important issue for many women and probably the single biggest difference between most men and women living with HIV in Australia. Many women are mothers and with this role come many responsibilities. Decisions around having children, disclosure and parenting in the context of treatment and possible illness are complex and some women will continue to need support and information around these issues.

As we look toward the future, we can see that there are many areas in which there are still improvements to be made, in the provision of services, in care and support and in the alleviation of social and economic disadvantage.

**For descriptions of references, acronyms, methodology and appendices, please refer to the full HIV Futures 5 report.**

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