

# **JUGGLING WITH HIV**

## **The intricacies of positive women's lives in Australia today**

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

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*I suppose in terms of when I was first diagnosed, it was like okay that's it; I'm going to die. And then when I didn't die it was okay, I've got a couple of years and then I'm going to get -- I'm going to get sick. So I didn't get sick and then it was okay, well I didn't die, I haven't got sick, I better get off my butt and do something with my life. But then it was difficult planning for more than a year again. I remember the first time that I decided that's what I want to do; it was a major event for me. And then, I got to the 10 year diagnosis and I thought okay this is it, it's 10 years, statistically it's going to -- the lightning's going to come out of the sky and hit you. [But] my doctors were all confident and a few other things happened and I thought well okay I'm not going to die. Even if I do start getting sick right now I've got with treatments and what have you, my level of wellness right now, I've still got at least seven years of juggling. So I didn't go onto treatments for a couple of years until after the 10-year mark. But my T cells went down and I thought okay this it, I've got to start treatment now. I've probably got about seven years. And then when I started treatments and they started working and I got into a new relationship, had a new baby; ... I was planning a year ahead. Then I started planning five years ahead and I just, I want my daughter to sit her finals -- so she gets her HSC and then she's established somewhere. I'd really like to see my son ... he needs to get his HSC. ... Now that I've achieved what I want to -- my two children are old enough to look after themselves if I die, there isn't like a time limit. There's sort of like a tunnel that I see into the distance. It's not in a year and it's not five years. It's like there's this tunnel here and I'm looking into it and I'm thinking oh the kids might have children or we'll get old together. But there isn't like a plan for me. So, I see it, but I don't plan like I used to.*

*Patricia, 45, diagnosed 1985*

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## **ACRONYMS USED IN THIS REPORT**

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

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This is the third report on women from the Living with HIV program at La Trobe University. *Standing on shifting sand: Women living with HIV/AIDS in Australia* (1998) and *A complex uncertainty: Women on hope, health and HIV* (2000) arose from out of the original HIV Futures Studies conducted in 1997 and then again in 1999. We would like to acknowledge the other researchers on those projects, Doug Ezzy, Richard de Visser, Michael Bartos, Darryl O'Donnell and Doreen Rosenthal. Thanks also to Miranda Misson for the data entry.

## **EXECUTIVE SUMMARY**

The HIV Futures 3 survey was completed by 894 HIV positive Australians from all states and territories, of whom 75 (8.3%) were women.

### **HIV antibody testing and counselling:**

Around one fifth of women (15) had taken an HIV antibody test as a result of illness. Fourteen women reported that they tested because their partner or ex partner was HIV positive. A further 10 women tested because of a particular risk episode and nine women tested due to routine screening. Four women said they tested because they were pregnant.

When asked about pre- and post-test counselling, 22.4% of women received pre-test counselling while 55.8% received post-test counselling. Medical personnel most often provided pre-and post-test counselling and the women were generally satisfied with the counselling they received. Women were no more or less likely than men to receive pre- or post-test counselling nor were there any differences between women and men in relation to the satisfaction levels with pre- and post-test counselling.

### **Health Status and Health Management**

Most women regularly monitor their CD4/T-cell counts and viral loads. Women's most recent test results indicate that 57.7% have viral loads below detectability and 54.1% have CD4/T-cell counts indicative of little damage to their immune system. However, 18.6% have a high viral load and 22.9% have a CD4/T-cell count indicative of severe immune system damage.

Almost three quarters rated their health as good or excellent and similar proportions rated their general well-being as good or excellent. However, 17.6% of the women had been diagnosed with an AIDS defining illness. Women also reported health problems related to HIV (39.7%) including: low energy or fatigue (76.0%); sleep disorders (40.9%); confusion or memory loss (32.6%); lipodystrophy (32.6%); and weight loss (18.8%).

Forty percent also indicated that they had a major health condition other than HIV/AIDS. The most common of these was hepatitis C (22.3%). Women were significantly more likely than men (13.2%) to report hepatitis C co-infection. Smaller numbers of women had also had hepatitis A (9.7%) and 7.1% had at some point been diagnosed with hepatitis B. More than one third (38.8%) had been vaccinated against hepatitis A; and 59.9% had been vaccinated against hepatitis B.

All of the women had taken a pap test at some time, and 87.7% had taken at least one within the last 12 months. Most women (80.5%) reported that the results of their last smear were clear, however, 13.8% reported abnormal smears including CIN1 (4 women) and CIN2 (1 woman).

### **Use of Antiretroviral therapy**

As in previous HIV Futures surveys women reported a lower level of antiretroviral use than men (63.7% versus 72.6%). However, in this survey this difference was no longer statistically significant, suggesting the gap may be closing. Women were still significantly less likely than men to have ever used antiretroviral therapy (78.5% versus 87.7%). Three quarters of women (75.5%) were using a combination of three drugs and the median number of ARV doses the women were taking daily was two.

Many women (85.4%) currently taking ARV reported that they experienced difficulties taking them. The major problems were: remembering to take the drugs on time (43.3%); taking large numbers of tablets (37.4%); organising meals around the drugs (35.0%); taking medication in public (29.0%) and; transporting medication (23.0%).

Side effects from ARV are a significant concern for those women on treatment with 50.6% reporting that they experienced these. The most common were nausea, diarrhoea, fatigue and lipodystrophy. Despite these difficulties, most women (85.1%) had not missed a dose of ARV in the two days prior to completing the survey.

Less than half of the women (42.7%) of those currently on ARV have taken a break from ARV therapy. The median length of break was 90 days. Breaks often resulted in improved well-being, but deterioration of clinical markers. Fourteen out of 20 women saw their doctor during the treatment break; however, doctors were less likely to be consulted before a break than afterward.

In all three HIV Futures surveys women have less commonly agreed that ARV means better prospects for PLWHA, however this difference was not significant in this survey, with 70.2% of women agreeing and 75.9% of men agreeing. Importantly 17.6% of women believe that it is still too soon to tell.

Around one fifth (20.5%) of women who had ever used ARV had had a resistance test. Of the 14 women tested, 11 found resistance to one or more drugs. Nine women with resistance changed treatments.

Two thirds of women (67.2%) used some form of complementary therapy. Vitamins and mineral supplements are the most popular. Similarly to previous HIV Futures Surveys, women were significantly more likely than men to be using complementary therapies (67.2% versus 51.5%).

### **Services**

For general health care treatment 35.0% of women see an HIV GP/S100 prescriber, whereas for HIV specific treatment 44.0% see an HIV specialist/physician prescriber and 32.7% see an HIV GP/S100. Most women had visited either a GP who specialises in HIV or an HIV specialist in the last six months.

Almost half of the women (43.9%) reported having to go to two places for prescription medication. A further 31.9% go to three or more places for prescription medication whilst 24.2% pick up all of their prescription medication at one place.

Peer support is the most used service for women at AIDS organisations (61.8%) while around half reported social contact (54.5%) and treatment advice (53.4%). Almost one third (34.1%) of women utilise counselling services at AIDS organisations and 27.4% access complementary therapies. One quarter (25.3%) of women access AIDS organisations for financial assistance and 17.6% seek advice on legal matters.

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

All of the women have disclosed their HIV status to at least one person, generally partners, close friends and family. However, for 64.5% of women, their HIV status had been disclosed to another person when they did not want it to be (42.0% in the last two years).

HIV was an important part of the identity of 56.2% of women and an essential part of the identity of 19.1%. HIV status tended to be less important to women than identities based on sexuality, gender, family or parenthood.

Partners or spouses were sources of 'a lot' of support for many women with partners (71.6%). Parents (59.3%), pets (58.6%) children (58.3%) and close friends (51.1%) were also significant sources of 'a lot' of support.

In the last six months 16.8% of the women have taken prescribed medication for depression and 19.4% have taken medication for anxiety.

One fifth (21.4%) plan only one day at a time and 17.4% plan only a few months ahead. More than half of the women plan for at least one year ahead.

Most women (88.6%) have some contact with HIV/AIDS organisations, mostly by receiving newsletters or being clients of these organisations while 10.3% were employees of AIDS organisations.

Most women (93.6%) said they know another person living with HIV/AIDS. Three quarters of women (75.0%) said they have acquaintances with HIV and (72.6%) someone close has died of AIDS related causes. Around one fifth of women (21.2%) have been involved with the care of someone with HIV/AIDS. One quarter of women (25.7%) reported that they do not spend any time with other PLWHA.

### **Women and children**

Half of the women (50.2%) have dependent children. These children ranged in age from less than 12 months to 32 years of age, with the average age being 10 years. Twenty-three women have had a total of 29 children born to them since becoming HIV positive. Four women have HIV positive children.

A small number of women said they have plans to have children in the future. Three women were pregnant at the time of the survey and a further three were attempting to conceive.

Importantly, 13 women reported that they did not feel they had enough information to make a decision about having children.

### **Relationships and Sex**

More than half of women (58.6%) are currently in a regular relationship, and a smaller number group have casual partners (9.6%). Forty percent of women are not having sex at present.

Of those in a regular relationship, 26.3% have a partner who is also HIV positive, 66.1% have an HIV negative regular partner and 7.7% have a partner of unknown status. All the women have disclosed their status to their regular partner, usually when they were diagnosed or at the

time of, or prior to, the commencement of the relationship. In the majority of cases the partner's reaction to disclosure was positive and in one third of cases it brought the partners closer together, but 34.6% also reported that their partner was worried or scared.

Just over half the women had vaginal or anal intercourse with a regular partner in the past six months. Condom use with regular partners was strongly related to the HIV-status of the partner.

Only 10 women reported sex with casual partners in the past six months. Nine of these reported that none of their partners was HIV positive, while one reported that she did not know the HIV status of her partners. Six women reported always using condoms with casual partners.

Information about the most recent episode of sex with a casual partner in the previous six months was provided by 10 women. All of these episodes occurred with partners of unknown or negative HIV status and involved vaginal or anal intercourse. Six of these encounters involved condoms and three did not.

Around a quarter of the women would prefer to be in a relationship with someone who is also HIV positive. Over half of the women expressed some fear of rejection from potential partners if they disclose their HIV status. The majority of women (59.3%) felt HIV had a negative effect on their sexual pleasure. Only 8.6% of the women agreed with the statement *I feel more confident about unprotected sex because of the new treatments.*

### **Recreational Drug Use**

Alcohol is the most commonly used drug by women (82.8%), while 42.2% use tobacco. Most women (80.5%) reported that they had never injected illegal drugs, and of the 14 women who had only two had done so in the last 12 months. Of the women who reported injecting drugs, none had shared injecting equipment in the past twelve months.

A small number of women (11.1%) reported having missed a dose of ARV at some point as a result of using illegal drugs and 5.2% reported having had a bad experience as a result of using both illegal drugs and ARV. Women were significantly less likely than men to use recreational drugs.

### **Accommodation**

Two thirds of women either own or are purchasing their house or flat (30.7%) or are in private rental accommodation (33.0%). One fifth of women (19.9%) live in public rental accommodation.

More than half (53.6%) of women live with children, 38.5% live with their partner or spouse and 66.0% said they live with pets. One quarter of women (25.4%) live by themselves. Most women (70.8%) said that their accommodation was suitable for their current needs. However, 52.6% had changed their accommodation as a result of having HIV/AIDS and 11.7% had done so in the last two years.

### **Employment**

Slightly more than one half of the women (50.5%) are currently in paid employment, with almost two-thirds of this number being in part-time work (32.1%). The majority of the remainder described themselves as either doing home duties (16.1%) or as unemployed (15.3%). Compared with working men, women who worked were more likely to be in part time employment (63.5% versus 41.5%).

Most women said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis. Antiretroviral therapy also had an affect on women's employment with 13.2% anticipating a longer time in the workforce. Smaller numbers said they had stopped work due to ARV (8.6%), were considering going back to work (4.3%) or have gone back to work (4.3 %).

Around a third of the women that had ever worked reported that they have stopped work at some time in the past for reasons relating to having HIV/AIDS. Low energy levels and psychological ill health were the most commonly cited reasons for this, followed by poor physical health.

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

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

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

### **Finances**

Around half of the women (50.7%) identified their main source of income as a government benefit or pension. The average weekly income for women was \$351.70. This was significantly lower than men's average weekly income (\$445.29).

More than half of women reported experiencing some difficulty with meeting the cost of daily living. Many women reported difficulty with paying for the following: clothing (83.1%), childcare (76.2%), utilities (75.2%), transport (70.3%), housing (59.9%), and food (54.9%).

One quarter of those women (6) on a government benefit had been assessed by a Commonwealth Medical Officer. While this resulted in a change in conditions for one woman and it caused distress for four of the six women assessed, no-one had their benefits terminated.

Forty percent of women are living below the poverty line. Paid employment did not exempt women from poverty with 27.0% who are earning an income from paid employment reporting incomes below the poverty line. However for those women on government benefits, 53.0% are living in poverty.

### **Discrimination:**

A small number of women (12.5%) had experienced less favourable treatment in relation to accommodation. Three of these 10 women reported having experienced such discrimination in the last two years.

More than half of the women (58.1%) had experienced less favourable treatment because of HIV in relation to health services, 34.7% in the last two years.

More than one third of women (37.5%) co-infected with hepatitis C had experienced less favourable treatment because of their hepatitis C in relation to health services. Three women said this had occurred in the last two years.

A small number of women (14.0%) had also experienced less favourable treatment in relation to insurance, with three of the six women who specified when this happened reporting that it was in the last two years.

## INTRODUCTION

*Juggling with HIV* aims to further our understanding of the experiences of women living with HIV/AIDS in Australia today. It is an analysis of data from the HIV Futures 3 national survey of people living with HIV and AIDS in Australia (Grierson *et al.* 2002). It is the third major report from the HIV Futures Surveys to specifically address the status of women with HIV/AIDS. It extends and updates the experiences described in the previous two reports on women, *A complex uncertainty: Women on hope, health and living with HIV in Australia* (McDonald *et al.* 2000) and *Standing on shifting sand: Women living with HIV/AIDS in Australia* (McDonald *et al.* 1998).

The HIV Futures studies are carried out by the *Living with HIV Program*, at the Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne. The HIV Futures Surveys are a major part of a broader program of research into the clinical, social and psychological aspects of living with HIV. The survey gathers information on health and treatment, well-being and social support, sex and relationships, recreational drug use, accommodation and finances as well as community involvement, sources of information and experiences of discrimination.

The program of research recognises that the experiences of living with HIV for women are often fundamentally different from those of both homosexual and heterosexual men. Issues such as child bearing and child rearing, disclosure of HIV status, relationships and community involvement do have different meanings and priorities for many women. However, the research also acknowledges the commonalities between these different groups of people living with HIV, consequently this report acknowledges both similarities and differences in experience.

In Australia women make up 6% of the total population of PLWHA yet globally women make up nearly half of the estimated 40 million people living with HIV/AIDS (UNAIDS, 2002). The 1,119 women (NCHESR, 2002) living with HIV in Australia are widely dispersed throughout major capital cities, regional and rural areas. Despite the considerable efforts of positive women's organisations to provide support and links for women living with HIV in Australia, many women still experience isolation and are often not visible within the social and clinical representations of the epidemic.

*Juggling with HIV* provides an overview of the lives of women living with HIV in Australia at a time when advances in treatments are fraught with complexity and uncertainty and yet are welcomed by many women as the opportunity to *get on* with their lives as partners, lovers, mothers, friends and employees. In doing so, the women represented in this report detail their latest challenge of juggling with HIV and all of its intricacies with wider non-HIV roles, responsibilities and issues.

These women have gone from a time of *standing on shifting sands*, with all of its ambiguities to a time where much more is known about the virus with which they live. With this knowledge has come unforeseen intricacies and the challenges of repositioning HIV in their lives.

## **INSTRUMENT AND METHOD**

### **Methodology**

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

### **Overview**

HIV Futures is a **cross-sectional** study of a sample of HIV positive Australian residents. A cross-sectional study is one in which a new sample is collected on each occasion. While a proportion of the sample may have completed the previous surveys, the responses for each survey are not formally linked, so that direct comparison between individuals' responses over time is not possible.<sup>2</sup>

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

First, the HIV Futures Surveys are **anonymous**.<sup>3</sup> HIV/AIDS remains a sensitive issue for many PLWHA in Australia. Our previous research and that of our colleagues tell us that PLWHA still experience stigma and discrimination. Allowing the survey to be completed anonymously helps to allay PLWHA's concerns that information about their HIV status and the other issues addressed in the survey may be compromised.

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

Thirdly the survey is **self-completed**. This means that PLWHA can complete the survey in a setting that is comfortable and safe for them and at their own pace. Feedback from participants during this study indicated that some people completed the survey over a number of days or weeks, and that individuals consulted their medical practitioners and other records to verify some of the details included in the survey.

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

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

Fourthly, the population of HIV positive Australians is constantly **evolving**. A cross-sectional survey allows us to include newly HIV positive individuals and ensure that our findings reflect all positive people, those who have recently seroconverted and those who have been positive for some time. These groups may have an overall similar experience of living with HIV, but the differences between them can be profound.

There are certain limitations in the methodology used. In terms of **sample representativeness**, caution must be exercised in the applications of the findings of this research in reference to individuals who are less likely to be included in the sample. This includes people with limited literacy, people of non-English speaking background, and those who are particularly geographically or socially isolated. We have taken a range of measures to address these issues. For example, participants were offered the option of completing the survey over the telephone either directly with the researchers using a free call number, or with service providers. In addition, the Telephone Interpreter Service (TIS) was promoted as a way of completing the survey for non-English speakers, either by telephone or in person. Surveys were also completed with the assistance of service providers or community agency workers for those with literacy problems or those with physical impairment. The combination of clinical and community setting for study recruitment was intended to optimise access to the study. This means that people are not disadvantaged from entering the study if they are not currently using anti-retroviral therapies or not currently in contact with one of the main HIV treatment providers.

Nevertheless it must be acknowledged that this methodology will never be appropriate for some members of the PLWHA community. This is particularly so for those from culturally and linguistically diverse backgrounds who may be marginalised even within their own communities, and those for whom invisibility is the key to their continuing safety. Community development methodologies are currently being explored in order to establish how the very real needs of these people can be understood and documented over time within an action research framework 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 II Survey (Grierson et al., 2000) with most items retained in their original format to allow comparisons between the three studies. Additional sections and items were included to reflect the changes in both the personal experiences of living with HIV/AIDS, and the changes in policy and service context in the past two years. These included information on antibody testing, an expanded section on treatment breaks, additional items on the experience of discrimination and an expanded section on hepatitis C co-infection.

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

The HIV Futures 3 survey was a self complete, mail back questionnaire consisting of 250 items organised into eight sections: demographics; accommodation; health and treatments; services and organisations; sex and relationships; employment; recreational drug use; and finances. Each section included an explanation of the purpose of the items. Most items in the survey were closed-coded with either single or multiple response options. *Other* categories were included for most items to ensure that significant experiences of living with HIV were not excluded. There 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 (Prestage et al. 2001). The responses to the HIV Futures Study were linked by a confidential non-identifying code to the data collected by the pH study.

An additional large-scale mail-out of the survey with the magazine *Talkabout* was conducted mid-recruitment. This magazine is NSW-based and is focused on HIV issues, although it has a wider distribution than just PLWHA. The magazine is mailed directly to subscribers and distributed on-site to numerous organisations and venues around NSW.

### *Requests*

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

### *2. Promotion and Marketing*

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

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

### *3. Community sites*

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

a. Mail-outs

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

b. On-site availability

The survey forms were made available on-site at numerous community organisations around the country. These organisations also distributed copies of the survey to sites and venues they felt were appropriate and with whom they have ongoing relationships.

c. Organisational promotion

Promotion within and by organisations was undertaken by staff and volunteers within the community sector. This included 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<sup>4</sup>.

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

b. Hospital settings

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

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

## c. Other clinical sites

Surveys were also distributed through sexual health centres and community health centres including those with a specific HIV focus. Generally these were available in waiting rooms, although some distributed them directly to clients.

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

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

Site	Number	Percentage
Mail-out from HIV/AIDS organisation	25	33.0
Completed previous Futures questionnaire	24	31.6
Positive Women's Organisation	14	18.2
Picked up from HIV/AIDS organisation	7	8.7
Picked up from a medical centre or hospital	1	1.5
Recruited by researcher	1	1.5
Told about it by other participant	1	1.5
Other	3	4.0

N=75

We were also interested in the extent to which we were accessing HIV positive people who had participated in previous HIV Futures Surveys and other research projects (see Table 2). Thirty-one women (40.8%) did not indicate that they had participated in any of the listed research projects, while 58.4% of women had participated in either HIV Futures or HIV Futures II.

**Table 2 Data on previous research involvement**

Study	Number	Percentage
HIV Futures II	43	57.3
HIV Futures I	36	47.8
Positive Health (pH)	15	19.9
None	31	40.8

N=75

(Multiple responses possible)

### Weighting

In order to ensure that the results reported in this document accurately represent the Australian population of PLWHA, comparisons were made to the Australian HIV Surveillance Report

(NCHECR, 2001) and the data were weighted to conform with the demographic profile of the Surveillance Report. A weighting algorithm based on mode of infection, gender, state of residence and diagnosis of AIDS defining illness has been applied to all the analyses that follow. Consequently, findings are presented in terms of sample percentages rather than frequencies. Sample sizes (Ns) are given when the table represents a subset of the total sample. These Ns are weighted.

**Analysis**

Statistical comparisons including ANOVA and chi-square have been employed in the analysis of the data, although for clarity the details of these are not included in this report. All significant differences reported have a probability of  $\alpha=0.05$ .

### SAMPLE DEMOGRAPHICS

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

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

The sample contained 75 (8.3%) women, with 818 (91.5%) men and two (0.2%) transgendered people. Of the women, 57 were heterosexual, nine were bisexual and four were lesbians. The sample of women represents 7% of all HIV positive women in Australia today (NCHCER, 2001).

Women's ages ranged from 20 to 66 years with a mean of 38.2 years and a median of 38 years.

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

**Table 3 Women's reported mode of transmission**

<b>Mode of Transmission</b>	<b>Number</b>	<b>Percentage</b>
Heterosexual contact	59	79.4
Injecting drug use	11	14.9
Receipt of blood components/tissue	3	4.1
Don't know	1	1.4

The majority of the women were Australian born (77.8%) and 98.6% of the participants spoke English at home. None indicated they were of Aboriginal/Torres Strait Islander origin. Most women (98.6%) indicated that Australia was their official country of residence.

The women came from all Australian states and territories with the exception of Tasmania. The majority coming from NSW, Victoria and Queensland (see Table 4).

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

**Table 4 State or Territory of women's residence**

State/Territory	Number	Percent
Vic	20	27.0
NSW	19	25.7
Qld	18	24.3
WA	8	10.8
SA	5	6.8
ACT	3	4.1
NT	1	1.4

The majority (43.8%) of women were from inner urban areas of capital cities, while 27.4% live in outer suburban areas, 17.8% live in larger regional centres and 11.0% live in rural areas.

Fifty (79.4%) women are living in the same state or territory in which they believe they were infected with HIV, while the remainder live in a different state or territory.

Table 5 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 11 years with a mean of 2.0 years and a median of one year. There are three women in the sample who had tested positive in the last two years.

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

Year	Tested HIV positive	Presumed infected
Pre 1985	0.0	7.7
1985-1989	23.0	36.9
1990-1994	43.2	35.4
1995-1999	29.7	18.5
2000+	4.1	1.5

Twenty-two women (30.6%) indicated that they were atheist/agnostic, 47.2% indicated mainstream religious identification and the remainder were either adherents of new age belief systems or had other spiritual beliefs. Fifteen (20.8%) indicated that religion or spirituality was of no importance to them. A further 37.5% indicated that this was of little importance, 29.2% that it was very important and 12.5% extremely important.

The educational level of women to the survey was somewhat higher than the general population, as is usual in research requiring a moderate level of literacy and engagement with the research process. The educational levels are shown in Table 6 below.

**Table 6 Educational level of women (percentage of women- unweighted)**

<b>Level</b>	<b>Number</b>	<b>Percent of sample</b>
Primary school only	1	1.4
Up to three years high school	5	6.8
4 <sup>th</sup> Form/ Year 10	14	19.2
Leaving Certificate/HSC/ Year 12	18	24.7
Tertiary Diploma/ Trade Certificate/ TAFE	13	17.8
University Degree	22	30.1

*I've always had hope anyway but I've enjoyed seeing all the little new wrinkles and little spider veins on my face and say, "Oh wow I'm getting old," you know. I never thought I'd see twenty-five but I'm thirty-three now so I'll probably see forty-five.*

*Lyn, 33, diagnosed 1987*

# HEALTH

*.... my periods were all changing. They were going from like twenty-eight days, they dropped right down to twenty-one days and I had twenty-one cycles for a while. And I've had my tubes tied. So I went to the doctor and she said 'There's one way to regulate it and that's to put you back on the pill'. And I said, 'No, I've got enough pills to take. I don't want to take another pill'. I mean I know it's only little but it's why I had my tubes tied!*

*Catherine, 31, diagnosed 1990*

## **HEALTH**

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

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

HIV positivity is an extraordinarily medicalised experience; an important component of this study is the exploration of how the clinical aspects of HIV interact with psychological and social experiences. While the coverage of these issues in a report such as this is necessarily limited, further attention will be paid to these in subsequent reports and journal publications. These can be accessed through the study website: [www.latrobe.edu.au/hiv-futures](http://www.latrobe.edu.au/hiv-futures).

## **HEALTH STATUS**

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### **Summary:**

#### **HIV antibody testing and counselling:**

Around one fifth of women (15) had taken an HIV antibody test as a result of illness. Fourteen women reported that they tested because their partner or ex partner was HIV positive. A further 10 women tested because of a particular risk episode and nine women tested due to routine screening. Four women said they tested because they were pregnant.

When asked about pre- and post-test counselling, 22.4% of women received pre-test counselling while 55.8% received post-test counselling. Medical personnel most often provided pre-and post-test counselling and the women were generally satisfied with the counselling they received. Women were no more or less likely than men to receive pre- or post-test counselling

nor were there any differences between women and men in relation to the satisfaction levels with pre- and post-test counselling.

### **Health Status and Health Management**

Most women regularly monitor their CD4/T-cell counts and a viral loads. Women's most recent test results indicate that 57.7% have viral loads below detectability and 54.1% have CD4/T-cell counts indicative of little damage to their immune system. However, 18.6% have a high viral load and 22.9% have a CD4/T-cell count indicative of severe immune system damage.

Almost three quarters rated their health as good or excellent and similar proportions rated their general well-being as good or excellent. However, 17.6% of the women had been diagnosed with an AIDS defining illness. Women also reported health problems related to HIV (39.7%) including: low energy or fatigue (76.0%); sleep disorders (40.9%); confusion or memory loss (32.6%); lipodystrophy (32.6%); and weight loss (18.8%).

Forty percent also indicated that they had a major health condition other than HIV/AIDS. The most common of these was hepatitis C (22.3%). Women were significantly more likely than men (13.2%) to report hepatitis C co-infection. Smaller numbers of women had also had hepatitis A (9.7%) and 7.1% had at some point been diagnosed with hepatitis B. More than one third (38.8%) had been vaccinated against hepatitis A; and 59.9% had been vaccinated against hepatitis B.

All of the women had taken a pap test at some time, and 87.7% had taken at least one within the last 12 months. Most women (80.5%) reported that the results of their last smear were clear, however, 13.8% reported abnormal smears including CIN1 (4 women) and CIN2 (1 woman).

### HIV Antibody Testing

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

We asked respondents why they had taken the antibody test. As can be seen from Table 7, 15 women had taken the test as a result of *illness*, 14 as a result of a partner or ex partner that was positive, 10 as a result of a *particular risk episode*, and nine as part of routine health screening.

**Table 7 Women's reasons for testing**

	Number
Became ill	15
Partner/ex-partner was positive	14
Particular risk episode	10
Routine health screening	9
Blood donor	6
Doctor's suggestion	5
Pregnancy	4
Tested without knowledge	3
Contact tracer/other health worker's suggestion	2
Starting new relationship	2
Immigration requirement	2
Member of risk group	1
Curiosity/interest	1

Of particular concern are the 14 women (18.7%) who said they tested as a result of ill health. Testing as a result of ill health may include those experiencing sero-conversion illness, but examination of the presumed length of infection indicates that there is still a significant proportion of individuals tested late.

A commitment to pre- and post-test counselling has formed a critical part of this country's efforts in care and support of PLWHA and prevention education, both for those who test positive and

negative. While there is some discussion about changing the name of this service to pre-and post-test discussion, currently counselling is the term used and the one we will employ here.

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

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

Seventeen (22.4%) of the women indicated that they had received pre-test counselling. Of the 11 women that reported who gave them this counselling, five received counselling from a nurse, three from a doctor and the remainder from people in other positions. When asked if they were satisfied with the counselling they received, 11 out of 15 reported they were satisfied with the information they received from this person and the same proportion said they were satisfied with the level of support they received. There were no significant differences between women and men either in the level of pre-test counselling they received or their satisfaction with the counselling.

Around half (55.8%) of the women indicated that they had received post-test counselling. The counselling was generally provided by a counsellor or psychologist (20.5%), but was also commonly provided by a doctor (19.8%) or a nurse (15.8%). When asked if they were satisfied with the counselling they received, 80.5% said they were satisfied with the information they received and 79.2% said they were satisfied with the support they received. Again there were no significant differences between women and men either in the level of post-test counselling they received or their satisfaction with the counselling.

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

1. Is HIV antibody testing in Australia currently being promoted in such a way as to maximise early diagnosis of HIV infection? The data above suggest that a significant proportion of women are being tested late and in a state of ill health.

2. Is there adequate pre-test counselling being offered at every testing occasion? Nine women identified routine testing as their reason for being tested for HIV antibodies. Seven of these women said they were given pre-test counselling. Particular consideration needs to be given to the issue of repeat or routinised testing among populations at higher risk of HIV. This remains an important issue, as there is a danger that the presumption of preparedness for a positive result automatically increases with repeat testing, and this could be both erroneous and damaging.
3. Is there adequate community understanding of what constitutes appropriate pre-and post-test counselling? Is this matched by adequate training and resourcing in testing settings, and are health consumers empowered to demand appropriate support and counselling around HIV testing?

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

### **CD4 and Viral Load**

All the women had taken a CD4/T-cell test (100.0%) and a viral load test (100.0%) at some point. Most women had their most recent CD4 test in the last six months of 2001 (95.0%) (80.7% in the last three months) and their most recent viral load test in the last six months of 2001 (90.6%) (74.2% in the last three months). On average women had taken 3.7 viral load tests in the preceding twelve months.

Two thirds (68.5%) of women reported that they have at some time had a CD4/T-cell count of less than 250 cells/ $\mu$ l and 93.8% reported a count of less than 500 cells/ $\mu$ l. Results for women's most recent CD4/T-cell test ranged from 5 to 1400 cells/ $\mu$ l with a mean of 502.0 cells/ $\mu$ l and a median of 521 cells/ $\mu$ l.

Over half (58.5%) of the women reported that at some point they had a result of over 50,000 copies/ml and 79.6% a result of over 10,000 copies/ml. Results for women's most recent viral load test ranged from below detectable levels to 750,000 copies/ml, with a mean of the log viral load of 693.4 copies/ml and the median result below detectable levels. Table 8 shows the most

recent CD4 and viral load results for women. The results are grouped by three levels of CD4 count: little damage, moderate damage and severe damage, and four levels of viral load: below detectable levels, low, moderate and high. As different assays would have been used to assess the respondent's viral loads we have defined *below detectable levels* as being those responses that were less than 500 copies/ml and those where the respondent wrote in *zero* or *below detectable level*.

**Table 8 Results of women's most recent serological tests, (percentage of all women)**

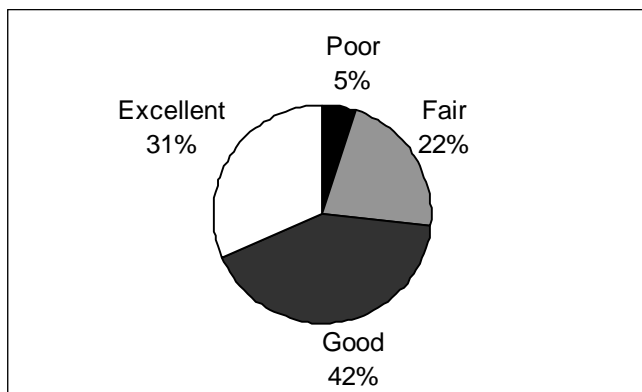
Description	Result	Proportion
<b>CD4/T-cell count</b>	<b>cells/ml blood</b>	
little or no immune damage	over 500	54.1
moderate immune damage	250 – 499	23.0
severe immune damage	below 250	22.9
<b>Viral load</b>	<b>copies/ml blood</b>	
below detectable level	below 500	57.7
low	500 - 9,999	14.0
moderate	10,000 - 49,999	9.7
high	over 50,000	18.6

Based on available data (CTTAC, 1997) antiretroviral treatment is recommended for patients with less than 500 CD4 cells or a viral load greater than 10,000 copies/ml. This means that 49.7% of those in the table above would be recommended to be on ARV. Of those in this situation (CD4<500, VL>10,000) 64.2% are currently on ARV and an additional 77.3% have been on ARV previously.

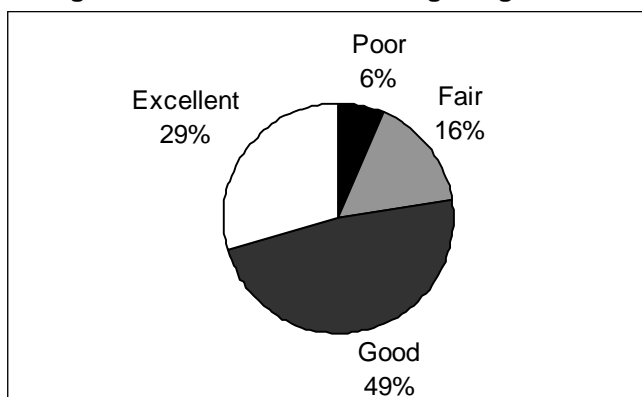
### Experience of Health and General Well-being

We asked respondents to indicate on a four-point scale their current state of physical health, and their overall sense of well-being. The results for the women are shown in Figures 1 and 2 below. Around two-fifths (42.0%) of the women rated their physical health as *good*. A further 26.7% rated their health as *fair* or *poor*, and 31.3% as excellent. More women are rating their health as excellent than in the 1999 survey (18.3%). A similar pattern is found in the ratings of well-being.

**Figure 1 Women's self ratings of general health status**



**Figure 2 Women's self ratings of general well-being**



When we look at the relationship between these two measures, we can see overall that better health is related to greater well-being (see Table 9). However, this is not a clear and direct relationship. The correlation between the two measures is .72. One in six women (16.7%) rate their well-being as worse than their health and 17.1% rate their health as worse than their well-being. Similarly, ratings of general health are related to CD4 and viral load, but not in a completely clear way. Better health is somewhat related to lower log viral load (correlation=-.33) and higher CD4 (correlation=.47), but is clearly mediated by the experience of side-effects, the burden of medication and co-existent conditions.

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

		Health			
		Poor	Fair	Good	Excellent
Well-being	Poor	4.1	2.7	0.0	0.0
	Fair	0.0	12.2	4.1	1.4
	Good	1.4	6.8	29.7	9.5
	Excellent	0.0	0.0	8.1	20.3

### AIDS Defining Illnesses

With the advent of antiretroviral therapies the significance of the experience of an AIDS defining illness is less clear than it once was. The category system for defining the stages of HIV disease progression in large part was based on an understanding of the progress of the disease as degenerative with little backwards movement through the categories. There are now numerous HIV positive people who have at some time experienced an AIDS defining illness but would now be classed at a less severe stage of disease progression. We ask respondents if they have ever experienced an AIDS defining illness for three 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.

Less than one fifth of women (17.6%) have been diagnosed with an AIDS defining illness at some point, with three out of these 13 women having been diagnosed with one in the last two years. On average they had been diagnosed four years ago. The most common illnesses in this category for these women were Pneumocystis Pneumonia and Microbacterium Avium Complex (MAC) (four women each).

### HIV/AIDS Related Conditions

We asked respondents if they had experienced any other HIV related illness, and 39.7% of the women said that they had. Of these the most common were shingles (5 out of 26 women that specified other HIV related illnesses) and oral thrush (4).

We also asked if participants had experienced any of five specific conditions. Three quarters (76.0%) of women reported low energy or fatigue, 40.9% reported a sleep disorder, 32.6% reported confusion or memory loss, 32.6% had experienced lipodystrophy and 18.8% had

experienced weight loss. There were no significant differences between men and women in the experience of these specific conditions.

**Other Health Conditions**

Lipodystrophy and lipoatrophy have created additional difficulties for positive people. To assess the impact of these we asked participants to respond to a series of statements about their body image. These are presented in Table 10 for both the total sample of women, and for those women who indicated that they had lipodystrophy. As can be seen, the majority disagreed that body changes due to lipodystrophy make it obvious that people have HIV, and gave responses to the other two questions that indicated they had a negative body image. The responses of those with lipodystrophy were more likely to be suggestive of poor body image. However, women (73.1%) were significantly more likely than men (43.9%) to disagree that body changes due to lipodystrophy make it obvious that people have HIV.

**Table 10 Women’s attitudes around body image (percentage)**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<b>Full Sample of women</b>				
Changes in my body due to HIV have made me feel sexually unattractive	16.5	21.3	46.7	15.5
I am happy with the way my body looks	17.9	38.7	28.5	14.8
Body changes due to lipodystrophy make it obvious to others that people have HIV	10.3	16.9	49.7	23.1
<b>Those women with lipodystrophy (N=20)<sup>a</sup></b>				
Changes in my body due to HIV have made me feel sexually unattractive	35.4	41.2	20.3	3.1
I am happy with the way my body looks	4.4	23.1	44.1	28.4
Body changes due to lipodystrophy make it obvious to others that people have HIV	22.0	21.6	46.4	9.9

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

 see also Other Medications page 38, Mental Health page 64

Around a third (29.4%) of the women indicated that they had been diagnosed with a major health condition other than HIV/AIDS. The most common major health condition for women was hepatitis C (5 out of 22 that specified other health conditions)<sup>6</sup>. No other disease was specified by more than two women.

### **Hepatitis**

Hepatitis is a term that refers to inflammation of the liver. There are currently six different types of viral hepatitis. Hepatitis A, B and C are more commonly known in Australia but hepatitis D, E and G have also been identified. For HIV positive people, co-infection with hepatitis may affect both people's health and/or their decisions in relation to antiretroviral treatments. We asked about diagnosis of, and vaccination against, hepatitis A and B, and some more detailed questions about diagnosis and experience of hepatitis C. A separate report will be produced to examine the experience of HIV and hepatitis C co-infected individuals that will expand on the findings of the HIV Futures II survey on this issue as presented in *Living with HIV when co-infected with hepatitis C* (O'Brien et al. 2002).

### **Hepatitis A**

Only 9.7% of women had at some point had hepatitis A, and 38.8% had been vaccinated against this virus. This means that 54.9% of women may currently be at risk of hepatitis A infection.

### **Hepatitis B**

A total of 7.1% of women had at some time been diagnosed with hepatitis B and a further 59.9% had been vaccinated against this virus. This means that 38.0% may currently be at risk of being infected with hepatitis B.

### **Hepatitis C**

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

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

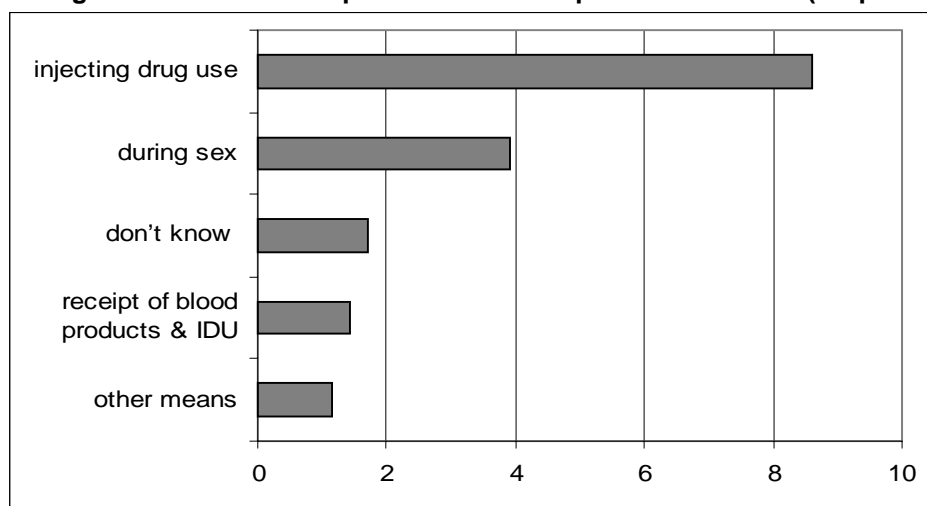
(positive/negative). In this survey we expanded this section to obtain more detail on testing practices, diagnosis and health and social issues.

A quarter (24.8%) of women had not been tested for hepatitis C. We used a series of items from the survey including test results, year of diagnosis with hepatitis C, and designation of hepatitis C as a major health condition to determine that 22.3% of the women had hepatitis C. This compares to the 2001 estimate of the prevalence of hepatitis C co-infection amongst all Australian PLWHA which is 13.7% (Sasadeusz, 2002). As in previous Futures samples, women are significantly more likely than men (13.2%) to report hepatitis C co-infection.

Women had first been diagnosed with hepatitis C between 0 and 19 years ago<sup>7</sup> (mean=9.4, median=10) and believed they had been infected between 0 and 21 years ago (mean=12.7, median=11).

When asked how they believe they were infected with the hepatitis C virus, nine women said injecting drug use, one the receipt of blood products & IDU, four during sex, two through other means and one didn't know how they were infected. See Figure 3. There were no significant differences in transmission mode of hepatitis C between women and men.

**Figure 3 Women's reported mode of hepatitis C infection (frequencies)**



N=17

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

Ten of the hepatitis C positive women said they had experienced symptoms, with four saying they did not know and two that they definitely had not. The most commonly mentioned symptoms were lethargy (7) and pains in the liver (3).

Sixteen women answered questions about treatments for hepatitis C. Only one of the women with hepatitis C was currently taking medical treatment specifically for hepatitis C (Interferon and Ribavirin), however, six reported having used complementary therapies.

Hepatitis C co-infected participants were also asked about health monitoring and management. Of 17 women, one did not currently see a doctor for hepatitis C treatment or management, 15 saw their primary HIV doctor and one saw a separate hepatitis C doctor or specialist. Women co-infected with hepatitis C were asked whether they had received less-favourable treatment at medical services as a result of having hepatitis C. While six women had ever had this experience, three had had this experience in the last two years (see page 117).

Women co-infected with HIV and hepatitis C were evenly split on whether HIV community services met their hepatitis C needs, with eight saying they did and eight saying that they did not. Of those women who reported that HIV community services did not meet their hepatitis C needs, five said that these organisations had a poor understanding of hepatitis C co-infection, three said the organisations had a poor understanding of intravenous drug use, two did not want to disclose their intravenous drug use, one did not want to disclose her hepatitis C status, one said that the organisations had an HIV focus and ignored hepatitis C and one woman said she doesn't use the organisations and doesn't need them.

 **see also Discrimination page 117, Health services page 46**

### **Other Health Monitoring**

We asked a series of questions about other health monitoring activities. A small number of women (15.5%) had had a bone density test in the last two years and 3.8% had had a test more than two years ago. More than one third (34.8%) had had a fasting cholesterol test in the last two years and 8.5% had had one more than two years ago. The long term effects of living with HIV and medication have made health concerns such as high cholesterol, cardiovascular difficulties and osteoporosis increasingly important for positive people.

All the women had had a cervical smear (Pap) test and 87.7% had had at least one in the last twelve months. Generally women had one test in the last year (62.2% of those tested in the last year). On their most recent test, 58 (80.5%) reported that the result was negative, and five (6.9%) abnormal. One (1.4%) woman reported high-grade intraepithelial abnormality (CIN2) while four (5.5%) reported low-grade intraepithelial abnormality (CIN1), three (4.3%) reported inconclusive results, and one woman (1.4%) was still waiting for her results. The Victorian Cervical Cytology Registry estimates that around 1% of women record high grade abnormalities and 5.7% record low grade abnormalities (Dwyer, 2002).

 **see also Resistance Testing page 35**

### Health Maintenance

We asked participants about a range of activities that they may engage in to improve their health. The results are shown in Table 11 below. The most common health-enhancement activity undertaken by women was healthy eating, followed by sleep and exercise.

**Table 11 Health improvement strategies of women**

	Number	Percentage
Healthy eating	64	84.5
Sleep	58	77.7
Exercise	50	66.5
Taking pills on time	47	62.6
Spending time with friends	47	62.1
Relaxation	47	63.0
Spending time with family	44	58.6
Complementary therapies	36	47.9
Spending time with pets	31	41.6
Spending time with partner	30	40.4
Other	26	34.3

Women were significantly more likely than men to report that spending time with family and complementary therapies were important health improvement strategies (58.6% versus 27.5% and 47.9% versus 30.2% respectively).

### Prophylaxis

Around one quarter of women (26.8%) were currently taking prophylaxis for opportunistic infections. Those women using prophylaxis were no more likely than other women to have a higher viral load or CD4 count, experienced an AIDS defining illness or to have been HIV positive for longer. In previous Futures surveys women have been significantly less likely than men to be using prophylaxis, however, this is no longer the case with 25.0% of men reporting prophylaxis use in Futures 3.

 See also Other Medications page 38, Complementary Therapies page 37

### Attitudes to Health Management

Participants responded to a number of statements about health management in relation to health improvement strategies, antiretroviral therapies and complementary therapies. The items on antiretroviral and complementary therapies are presented in the relevant sections of the report. When asked about health management strategies, almost all women agreed that exercise, healthy eating and an optimistic outlook were important or very important strategies (see Table 12). Women were no more or less likely than men to agree with the following statements.

**Table 12 Attitudes to health management: percentage of all women**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Looking after my physical fitness is an important part of managing my HIV infection	44.2	51.6	4.3	0.0
Healthy eating is an important part of managing my HIV infection	56.4	39.4	3.2	1.0
Keeping an optimistic frame of mind is an important part of managing my HIV infection	70.8	29.2	0.0	0.0

*It's nice to know the treatments are there; as a safety net. But I'd like to wait as long as I can ... I'm wary about it, for sure, because I mean I don't mind taking things that are short term, but something that's long term like that really puts me off. Health wise. And then I see people and hear lots of stories about the side effects. Particularly to women. And it scares me. But my health comes first and I want to live a long life. So if that means I have to go that way then I will take treatment.*

*Narelle, 30, diagnosed 1997*

*I'm still grateful that I can access them and that they're free. I do feel they're terribly toxic and I can see it's so easy once you open that door to all those treatments to actually have everything that's on the menu, sort of thing. And I think that's quite frightening.*

*Carmen, 35, diagnosed 1985*

*Well, I don't get all the side effects I used to have like the physical side effects like the headaches, the nausea, the vomiting. Just the dry retching really. I used to have a bad menstrual cycle. It was horrible. I'd be bleeding three weeks out of the month and had a weaker stomach. Just the smell of something a little bit off and I'd be throwing up. I never used to go anywhere for months, months, months. I wouldn't leave the house. I just didn't feel like going anywhere else, just not good. I said to the doctor I was sick of being a toxic zombie. I was just off my face tripping half the time on medication but now we've sorted it all out and the new drugs don't seem to have all the side effects. It's wonderful living life again. It's great. It doesn't make HIV the focal point anymore.*

*Lyn, 33, diagnosed 1987*

## ANTIRETROVIRAL THERAPY

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

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### Summary:

As in previous HIV Futures surveys women reported a lower level of antiretroviral use than men (63.7% versus 72.6%). However, in this survey this difference was no longer statistically significant, suggesting the gap may be closing. Women were still significantly less likely than men to have ever used antiretroviral therapy (78.5% versus 87.7%). Three quarters of women (75.5%) were using a combination of three drugs and the median number of ARV doses the women were taking daily was two.

Many women (85.4%) currently taking ARV reported that they experienced difficulties taking them. The major problems were: remembering to take the drugs on time (43.3%); taking large numbers of tablets (37.4%); organising meals around the drugs (35.0%); taking medication in public (29.0%) and; transporting medication (23.0%).

Side effects from ARV are a significant concern for those women on treatment with 50.6% reporting that they experienced these. The most common were nausea, diarrhoea, fatigue and lipodystrophy. Despite these difficulties, most women (85.1%) had not missed a dose of ARV in the two days prior to completing the survey.

Less than half of the women (42.7%) of those currently on ARV have taken a break from ARV therapy. The median length of break was 90 days. Breaks often resulted in improved well-being, but deterioration of clinical markers. Fourteen out of 20 women saw their doctor

during the treatment break; however, doctors were less likely to be consulted before a break than afterward.

In all three HIV Futures surveys women have less commonly agreed that ARV means better prospects for PLWHA, however this difference was not significant in this survey, with 70.2% of women agreeing and 75.9% of men agreeing. Importantly 17.6% of women believe that it is still too soon to tell.

Around one fifth (20.5%) of women who had ever used ARV had had a resistance test. Of the 14 women tested, 11 found resistance to one or more drugs. Nine women with resistance changed treatments.

Two thirds of women (67.2%) used some form of complementary therapy. Vitamins and mineral supplements are the most popular. Similarly to previous HIV Futures Surveys, women were significantly more likely than men to be using complementary therapies (67.2% versus 51.5%).

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### **Use of Antiretroviral Therapy**

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

Of the women, 78.5% had used ARV at some point, and 63.7% were currently using these treatments.

The data on treatments will be presented in four sections: those currently using ARV (mono-therapy and combination therapy); those currently on combination therapy only; those not currently using ARV who have in the past; and those who have never used ARV. An additional section on the experience of interruptions to treatments follows. A summary diagram of the uptake of antiretrovirals can be found on page 20.

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

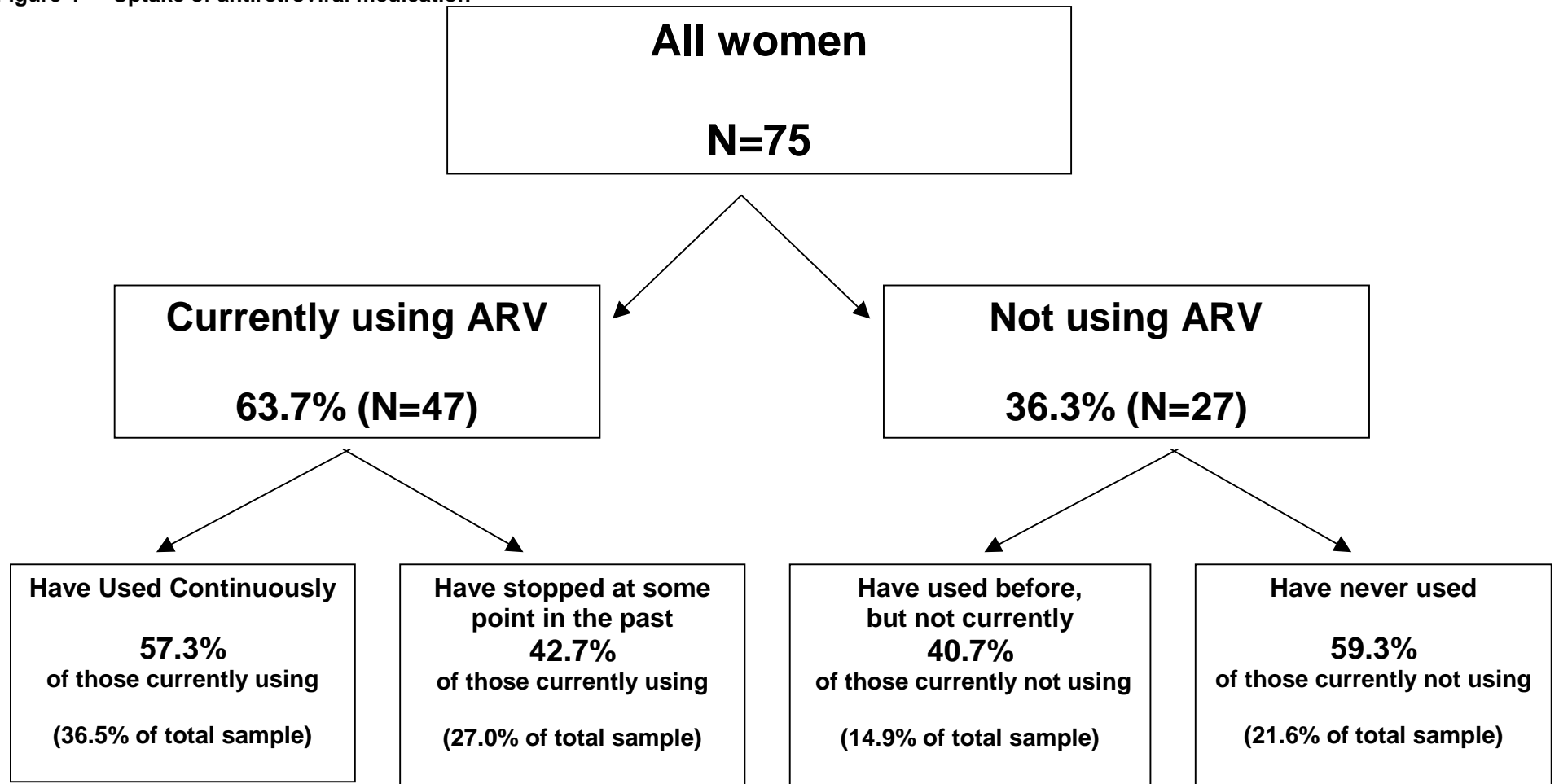
The majority of women (75.5%) were on a combination of three antiretroviral drugs, with 21.8% on more than three antiretroviral drugs, and 2.7% on two.<sup>8</sup> Table 13 below lists the antiretroviral treatments that participants were using at the time of the survey.

**Table 13 Antiretroviral drugs used by women:**

<b>Drug</b>	<b>Number</b>	<b>Percentage</b>
3TC (Epiriv, Lamivudine)	23	51.1
Nevirapine (Viramune)	18	39.1
d4T (Zerit)	14	30.4
AZT & 3TC (Combivir)	12	26.9
1592 (Abacavir, Ziagen)	10	22.7
Efavirenz (Sustiva)	9	19.9
ddl ec (Videx ec, didanosine ec)	8	16.7
Nelfinavir (Viracept)	7	16.2
AZT (Retrovir, zidovudine)	6	12.8
ddl (Videx, didanosine)	6	12.8
Saquinavir (Fortovase) - soft gel	5	10.9
Ritonavir (Novir)	4	9.1
ABT-378/r (Lopinavir, Kaletra)	4	9.1
Indinavir (Crixivan)	3	6.6
Tenofovir	3	6.6
Sauqinavir (Invirase) - hard gel	1	2.3
Amprenavir	1	2.3
Delavirdine (Rescriptor)	1	2.3

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

Figure 4 Uptake of antiretroviral medication



**Table 14** ARV use by gender and year

<b>Drug</b>	<b>Women</b>	<b>Men</b>
1997 <sup>a</sup> Using ARV	61%	79%
1999 <sup>b</sup> Using ARV	60%	75%
2001 <sup>c</sup> Using ARV	64%	73%

a:n=921; b:n=925; c:n=894

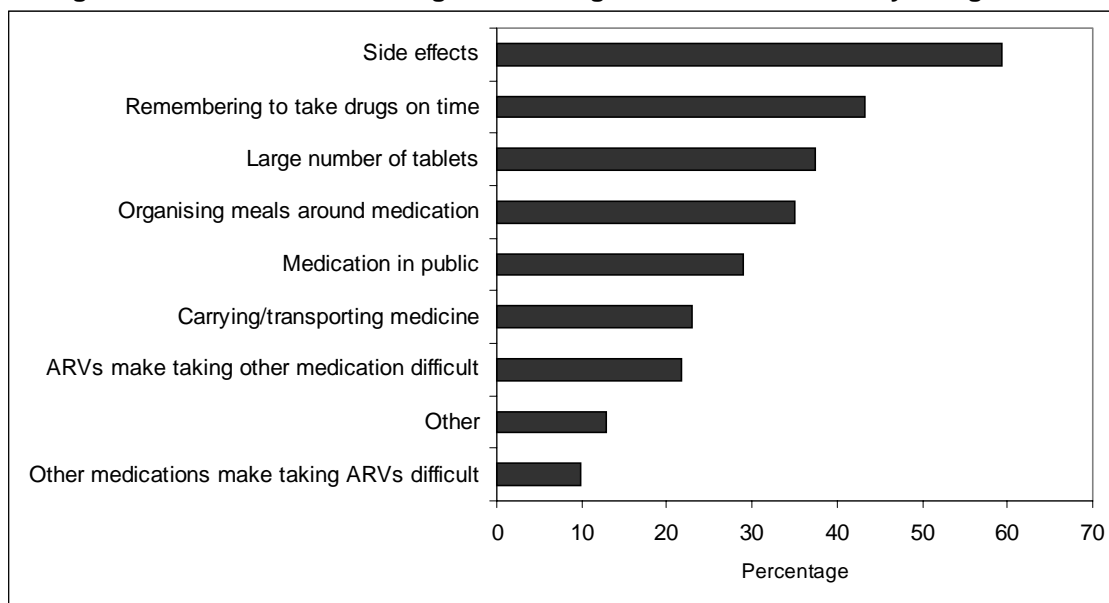
In 1997 women were significantly less likely than men to be using ARV (61% versus 79%). This pattern continued in 1999 where there was still a significant difference between women and men (60% versus 75%). This difference held even when health status was taken into account. However, in 2001 whilst there is still a difference, it is no longer statistically significant, and this suggests the gap between women and men in ARV use is continuing to close.

Respondents were also asked specifically about their use of the two immune stimulants Interleukin-2 and Hydroxyurea: only one woman was using Interleukin-2 and no women were using Hydroxyurea.

#### *Difficulties of Taking ARV*

Overall, 85.4% of women reported that they had some difficulty taking ARV. Of these, side effects were reported by 50.6% of women currently using ARV. The most commonly reported problems were nausea (9 out of 20 women specifying side effects), diarrhoea (8), fatigue or lethargy (5) and lipodystrophy (5). Women were no more or less likely than men to report experiencing difficulties taking ARV or side effects from ARV.

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



N=37

Other difficulties taking ARV included 43.3% of women who said they had difficulty remembering to take the drugs on time, 35.0% said they had difficulty organising meals around medications, 29.0% taking medication in public, 23.0% transporting medication, and 37.4% taking a large number of tablets (see Figure 5). In addition, 21.7% reported that taking ARV made it difficult to take medication for other health conditions and 9.8% that taking other medications made taking ARV difficult.

*Attitudes to ARV*

Most women reported concern over the future efficacy of their treatments. Over half of the women agreed or strongly agreed the statement *I am worried that in the future my medication will stop working for me.* (see Table 15). When asked to respond to the statement *Taking tablets gives me an unwanted reminder that I have HIV,* 58% indicated agreement and 41% indicated disagreement.

**Table 15 Attitudes to medication: percentage of those women currently using ARV**

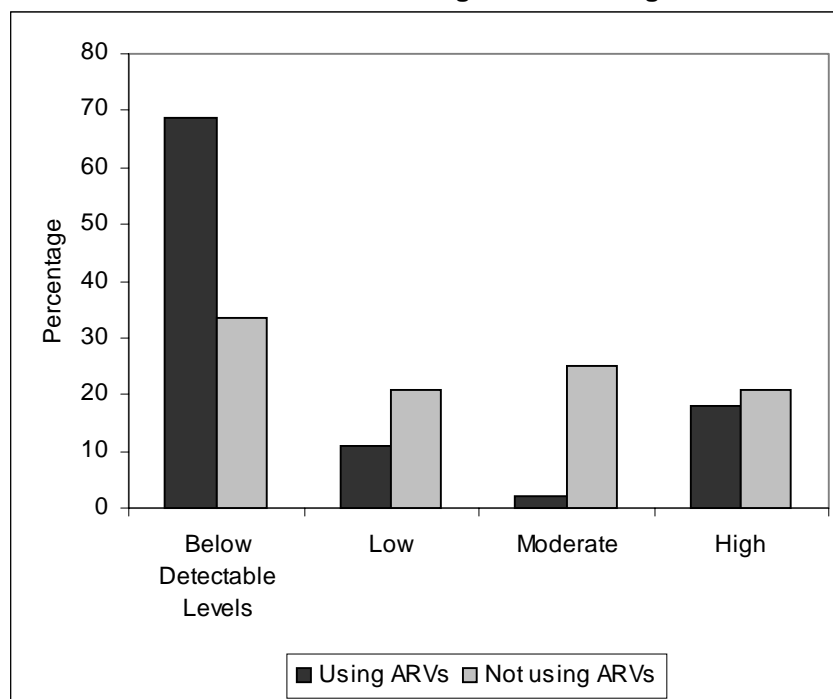
	Strongly Disagree	Disagree	Agree	Strongly agree	Don't know
I am worried that my medication will stop working for me <sup>a</sup>	2.5	30.9	42.6	16.2	7.8
Taking tablets gives me an unwanted reminder that I have HIV <sup>b</sup>	9.5	31.9	35.2	22.8	0.6

a: N=47, b: N=46

*Health Status of Those Using ARV*

Those women taking ARV had significantly lower viral loads (log mean of 383.4 cells/μl compared to 2550.4 cells/μl among those not taking any antiretroviral medication). This difference is mainly explained by the large proportion of those women on ARV with a viral load below detectable levels as can be seen in Figure 6.

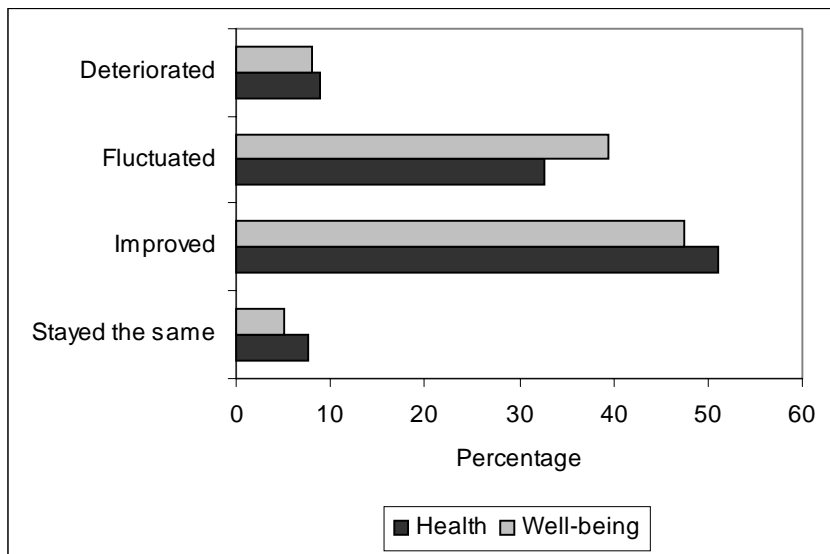
**Figure 6 Viral load of those women taking and not taking antiretroviral therapy.**



Women taking ARV did not have significantly different CD4 counts (mean of 496.0 copies/ml) to those women not taking antiretrovirals (mean of 520.0 copies/ml). There was no difference between these two groups in the ratings they gave of their general health status or well-being.

When asked to rate the effect of commencing ARV on their physical health, 51.0% of women said that their health improved, 32.6% said it fluctuated, 7.6% said it stayed the same and 8.9% said it deteriorated. When asked about the impact of ARV on their overall feeling of well-being, 47.5% said it had improved, 39.3% said it had fluctuated, 5.1% said it had stayed the same and 8.0% said it had deteriorated (see Figure 7).

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



***Those on Combination Therapy***

The most commonly used combinations were 3TC, d4T & Nevirapine, AZT, 3TC & Nevirapine, and AZT, 3TC and Efavirenz (each used by four women of a possible 45). This means that most commonly used combinations for women consisted of two nucleoside analogues and one non-nucleoside reverse transcriptase inhibitor. The most commonly used combination for men was AZT, 3TC & Nevirapine (7.4% of those men currently using antiretrovirals), followed by 3TC, d4T & Nevirapine (6.3%) and 3TC, 1592, and Nevirapine.

Most of those women (88.5%) on combination therapy had been on it for at least the second half of 2001. Most started combination therapy at a time when their viral load was high (log mean = 40,373 copies/ml) and their CD4 count was low (mean = 213.1, 100% below 500 cells/ $\mu$ l, 64.3% below 250 cells/ $\mu$ l). All of the women had commenced combination therapy at a time when treatment would be strongly indicated by the CTTAC guidelines (1997).

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 (72.1%), although the importance of clinical indicators, treatment developments and treatment information is also clear.

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

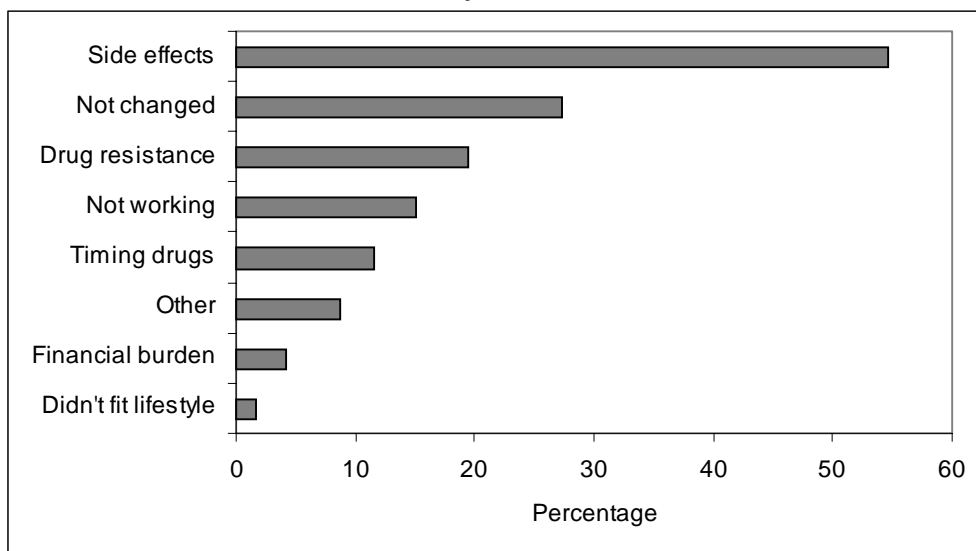
Circumstance	Percentage of those on combination therapy	
	Number	
My doctor advised me to begin this treatment	33	72.1
I had a big drop in my CD4 count	26	55.8
I had a big rise in my viral load	16	34.9
Information showed the treatment was effective	14	29.3
I became very ill	12	25.6
New drugs became available	12	25.1
I was hospitalised due to HIV	8	17.1
Positive friends started treatment	4	9.3
A treatments officer advised me to begin treatment	4	8.6
I had just tested positive to HIV	4	8.0
Close friends advised me to begin treatment	3	7.3
My partner advised me to begin treatment	1	3.2
N=46	Multiple responses possible	

#### *Different Combinations*

Among those currently using combination therapy, women had tried between one and 10 combinations (median = 3). Within the last 12 months, 60.6% of women had used the one combination and 23.0% had used two.

Respondents currently on combination ARV were asked to describe the circumstances surrounding their most recent change in combination. For a large proportion of women (54.6%) the side effects became too severe. Drug resistance (19.5%) and drugs not working (15.0%) were the next most common responses (see Figure 8).

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



N=32

When asked how many combinations they believed they still had access to, 37.6% of women (17) felt they had *many*, 24.0% (11) indicated that they thought they had a *few*, 5.5% (3) believed they had no combinations remaining, and 3.4% (2) believed they only had one. Almost one third of women (13) currently on combination therapy said they did not know how many combinations they had left.

**Those Not Currently Taking ARV**

Of the 28.3% of women who currently are not using any antiretrovirals, 40.7% (11) had done so in the past. The mean length of time these women had been using ARV was one year and nine months (range 0 months to five years) and on average they had ceased using ARV one year and 10 months prior to completing the survey (range 0 to 10 years). At the time that they stopped using ARV, six of these women were using a combination of three drugs and three were using two drugs.

*Difficulties of Taking ARV*

All of the women that had stopped taking antiretrovirals reported that they experienced difficulties while taking these medications. Of 10 women, six had difficulties remembering to take drugs on time, four taking a large number of tablets, three organising meals around

medications, three taking medication in public, one transporting their medication, three taking antiretrovirals made taking other medication difficult, and one found that taking other medication made taking antiretrovirals difficult. Eight women also reported difficulties with side effects and two reported other difficulties. The most common side effects experienced were diarrhoea and nausea (four women each).

*Health Status of Those Not Using ARV*

Those women not currently using ARV were asked to describe changes in their health when they had used ARV in the past. Five of the women said that it had improved, three said it fluctuated, two said it stayed the same, and one that their health deteriorated.

When asked about the impact of ARV on their overall feeling of well-being, three women said it had improved, two said it had fluctuated, two said it had stayed the same and three said it had deteriorated.

Respondents were asked whether they had lifestyle or clinical reasons for ceasing their use of antiretroviral therapy. Nine out of eleven women gave lifestyle reasons for stopping treatment. The most commonly cited reason was to clean out their system (3), with no other reason accounting for more than two responses.

Seven women gave clinical reasons for ceasing ARV treatment. The most common of these were side effects (3), a doctor's recommendation (3), and liver toxicity (three women, two of whom are co-infected with hepatitis C).

*Those Who Have Never Used Antiretroviral Drugs*

One fifth of women (21.5%) had never used antiretroviral treatments. Of these, 10 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 17).

**Table 17** Circumstances that would lead to the commencement of antiretroviral therapy among those women who have never used antiretroviral drugs.

Circumstance	Number for those who have never used ARV.
If I became very ill	10
If I was hospitalised due to HIV	10
If I had a big rise in my viral load	6
If I had a big drop in my CD4 count	5
If my doctor advised me to begin this treatment	4
If my partner advised me to begin treatment	1
If close friends advised me to begin treatment	1
If new drugs became available	1
N=10	Multiple responses possible

Of the six women who said they would not consider using antiretroviral drugs in the future, two women said it was because of the side effects, two said they distrusted the drugs and/or drug companies, one said she was healthy now and would stay that way and one woman said she believed she was healthier without them. Women are still significantly less likely than men to have ever used antiretroviral therapy (78.5% versus 87.7%)

### **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 participants to respond to a series of statements about treatments. These fall into three broad areas: decision making around treatments, relationship with their doctor, and optimism about treatments. These findings can be seen in Table 18 on page 30.

#### ***Treatment Decision Making***

Most women indicated that they disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (58.5%). However, women were significantly more likely than men to agree with this statement (38.3% versus 22.2%). Women were also significantly more likely than men to disagree with the statement *People with HIV should start using antiretroviral drugs as soon as possible* (67.4% versus 43.8%).

***Relationship with Treating Doctor***

As with previous surveys, most women (84.8%) agreed with the statement *My doctor and I work together to find the best treatment for me*, although a small proportion expressed uncertainty about this. However, around a third of women (32.3%) disagreed with the statement *My doctor knows more about the treatment of HIV than I do*. Women were significantly more likely than men to disagree with this statement (32.3% versus 15.3%). The combined effect of these data suggests that treatment decision making is both informed and negotiated.

***Treatment Optimism***

Optimism about the value and effectiveness of antiretroviral treatments continues to characterise the Australian experience, but tempered as always with concerns about the impact and long term effectiveness of these treatments.

Most women (84.8%) disagreed with the statement *Combination antiretroviral drugs are ineffective*. However, this belief in effectiveness is tempered by an awareness of the potential harm of these therapies as evidenced by the level of agreement with the statement that *Combination drugs are harmful* (39.1% agree, 8.9% strongly agree). This harm may in part be the experience of side-effects. Almost one third of women (29.2%) agreed or strongly agreed with the statement *The side effects of antiretroviral drugs outweigh the benefits*, while 19.6% were unsure.

However, there was some evidence in the long term benefits of treatment. More than half of the women said they agreed or strongly agreed with the statement *New treatments will be developed in time for me to gain benefits*. However, only 35.4% reported agreement with the statement *HIV treatments will stop me dying from AIDS*, and a further 32.8% were unsure. These responses suggest women feel that there are benefits to treatments, but are sceptical about treatments preventing them from ultimately dying from AIDS.

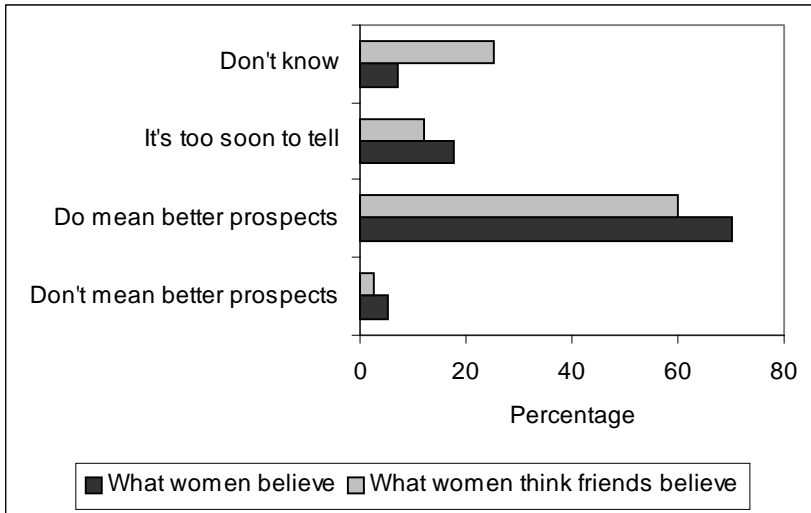
Just over half of the women (58.2%) agreed with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*, while 22.9% disagreed with this statement.

**Table 18 Attitudes to antiretroviral drugs: percentage of all women**

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't know</b>
I am healthy now and don't need to use antiretroviral drugs	28.9%	29.6%	17.8%	20.5%	3.2%
Combination antiretroviral drugs are harmful	8.9%	33.9%	29.3%	17.9%	9.9%
Combination antiretroviral drugs are ineffective	35.3%	49.5%	1.7%	.0%	13.5%
Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term	6.8%	16.1%	30.9%	27.3%	18.9%
It's easy for me to get combination antiretroviral drugs	6.5%	10.4%	39.1%	36.5%	7.5%
New treatments will be developed in time for me to gain benefits	1.4%	9.2%	44.7%	12.1%	32.6%
HIV treatments will stop me dying from AIDS	11.3%	20.5%	20.3%	15.1%	32.8%
My doctor knows more about the treatment of HIV than I do	5.7%	26.6%	39.2%	23.7%	4.8%
People with HIV should start using antiretroviral drugs as soon as possible	28.3%	39.1%	8.2%	8.7%	15.6%
The side effects of antiretroviral drugs outweigh the benefits	15.8%	35.2%	19.2%	10.1%	19.6%
My doctor and I work together to find the best treatment for me	3.3%	8.7%	42.5%	43.1%	2.5%

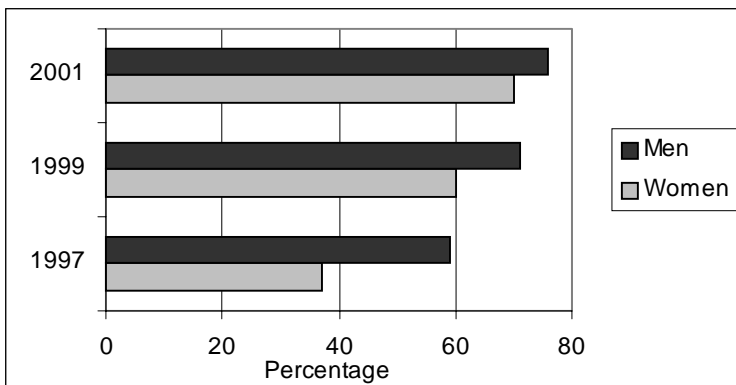
Respondents indicated how much they and their friends agree with the statement *Antiretroviral drugs mean better prospects for most people*. Most women (70.2%) agreed with the statement, and believed their friends would agree with it (59.9%). Almost one in five women believe that *It's too soon to tell* (17.6%) (see Figure 9).

**Figure 9 Women and women's social networks' response to the statement Antiretroviral drugs mean better prospects for most people.**



In both the 1997 and 1999 Futures Surveys women were significantly less optimistic than men about ARV meaning better prospects for most PLWHA (1997: 37% versus 59%; 1999: 60% versus 71%). However, the data from Futures 3 suggests that this gap between women and men is starting to close (2001: 70% versus 76%) (see Figure 910).

**Figure 10 Agreement with the statement ARV means better prospects for most PLWHA by gender and year.**



## TREATMENT BREAKS

Interruption to antiretroviral treatment is an important and increasingly complex issue. Treatment breaks may take a number of forms and be undertaken for a range of reasons. While there is considerable discussion in the medical community about the potential benefits and dangers of treatment interruptions, our main emphasis is on the motivations, experiences and consequences of breaks for HIV positive people. In all, 42.7% of those women currently using antiretroviral medication had taken a break from these at some point. To understand the experience of breaks, we asked respondents to give us some detailed information about their most recent break.

### Most Recent Treatment Break

The date of the most recent break for women ranged from currently taking one to having taken one 17 years ago. The mean length of break was 83 days with a median of 90 days. Most women described their most recent break as short term (15 out of 17) with one woman describing it as long term and one woman describing it as cycle/pulse interruption.

We asked participants to describe the reasons for taking the break within two major categories: lifestyle reasons and clinical reasons. Thirteen out of 20 women indicated that there were lifestyle reasons for taking a break. The specific reasons are given in Table 19 below. The most common reasons given were a *special event* and to *clean out the system*.

**Table 19 Lifestyle reasons for women taking breaks**

Reason	Number
Clean out system	3
Special event	3
Didn't fit lifestyle	2
Taking drugs at right time too difficult	2
Depression/fed up	2
Financial burden	1
Sick of taking pills	1
Just took a break	1

N=20

When asked if there was a clinical reason for taking the break, 12 out of 20 women that had taken a break indicated that there was. (Five gave both lifestyle and clinical reasons). Table 20 below details the clinical reasons for breaks. The most commonly cited reason was that the side

effects of treatment became too severe (35.2% of all those taking breaks), while just under a fifth indicated that the break was on the recommendation of their doctor.

**Table 20 Clinical reasons for women taking breaks**

<b>Reason</b>	<b>Number</b>
Side effects	7
Recommended by doctor	5
Drug resistance	3
Changing regimens	3
Liver toxicity problems	2
Complications with hepatitis C	1
Recommended by other health professional	1
Problems obtaining prescription/medications	1

N=20

We also asked about the involvement of the participant's doctor in these breaks. Women were less likely to talk to their doctor about the break prior to taking it (13 out of 20) than they were during the break (14) or afterwards (18). This may suggest that these breaks are not just from the treatments, but also from the clinical experience of HIV.

We were also interested in the outcome of the treatment breaks, both in terms of clinical markers and experience of health and well-being. Table 21 below gives the results of the four questions asked. Around one third of women said that their health remained stable, while the remainder were spread fairly evenly across the categories of *improved*, *fluctuated* and *got worse*. When asked about their general well-being, the majority said that it had improved.

The impact of these breaks on clinical markers was less positive. Women most commonly indicated that their viral load had increased, and their CD4 count had either stayed the same or decreased as a result of the break.

**Table 21 Effect of break on women's clinical markers (numbers)**

	Stayed same	Improved	Fluctuated	Deteriorated
Health	7	5	5	4
Well-being	3	11	3	2
	Stayed same	Increased	Fluctuated	Decreased
Viral load	6	8	1	3
CD4	9	1	2	7

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

#### **ANTIRETROVIRAL RESISTANCE**

The development of resistance to antiretroviral treatments is an ever increasing concern for HIV positive people. HIV can develop resistance to one or more treatments as a result of its continual mutation and this resistance can result in the failure of treatments (Averitt and Thiemann, 2001). Resistance can result from a lack of early and persistent suppression of viral replication, missed doses of antiretrovirals or infection with a resistant strain. There are a number of resistance tests available but they generally fall into two categories: genotypic resistance tests that look for mutations of the virus in its genetic code; and phenotypic resistance tests where the virus is cultured and the performance of drugs tested directly. We asked respondents whether they had had resistance tests and what the clinical and treatment outcomes of these were.

Of the 58 women who had ever used antiretroviral treatments, one quarter (14) indicated that they had some sort of ARV resistance test. The average length of time since the most recent resistance test was 12 months. Twelve out of 14 women had had their most recent test in the last two years.

Of those 14 women who had resistance testing, 11 found resistance to one or more antiretroviral drugs. This resulted in a change of drugs for nine women where resistance was shown.

Table 22 shows the changes in clinical markers for those women who underwent resistance testing and specifically for those who changed treatments.

**Table 22 Effect of resistance testing on women's clinical markers (number)**

	Stayed the same	Decreased	Increased	Don't know
<b>All who tested for resistance</b>				
Viral load	1	7	2	5
CD4	2	4	4	6
<b>Those who changed medications</b>				
Viral load	0	5	2	3
CD4	1	2	4	3

**CLINICAL TRIALS**

A total of 18.0% (13) of the women had participated in a clinical trial for HIV related treatment and of these, three quarters (73.0%) had participated in a clinical trial in the last two years. The only trials in which more than one woman had participated were Interlukin-2 and CREST (two women each). They had, on average, been on these trials for 30 months. The circumstances surrounding participation in the trial are given in Table 23 below. These data show that involvement of doctor was important in this decision, as was an altruistic intent.

**Table 23 Reasons for participating in clinical trials (Number of those women who have participated in a trial)**

Reason	Number of those who have been involved in trials
Decided with doctor	10
Felt experience could benefit others	5
No other treatment options	2
Other treatments weren't working	2
Only way to get treatment	2
Felt pressure to go on trial	1
Had enough information about the trial	1
Other	1

N=13

Multiple responses possible

Women were significantly less likely than men to have participated in a clinical trial (18% versus 33%).

## **VACCINES**

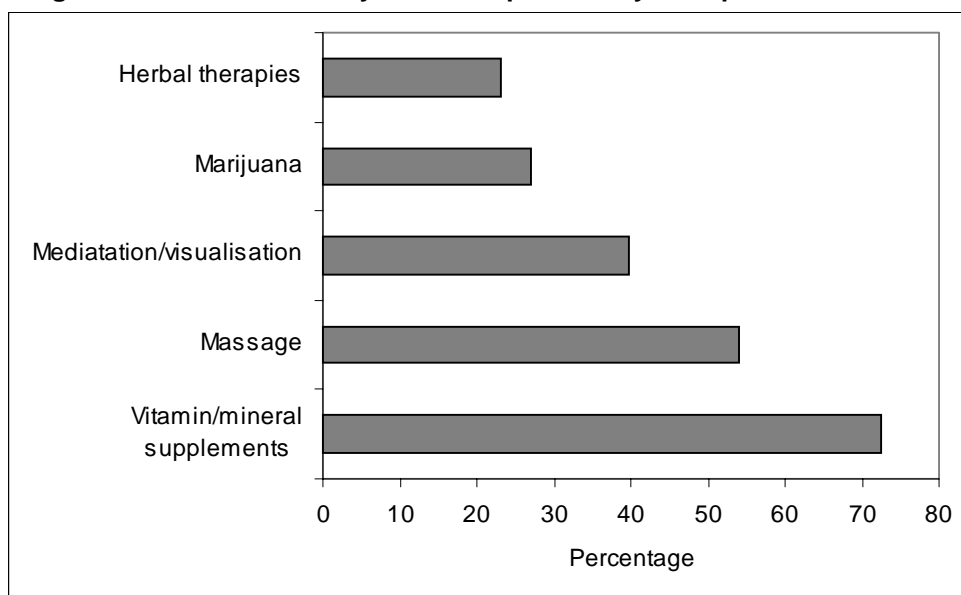
While the development of readily available therapeutic vaccines for HIV positive people is still some way off, we were interested in participants' perspectives on this. We asked respondents to indicate their agreement with the statement *I would be willing to participate in a HIV vaccine trial*. Almost one third of women (32.6%) said they did not know, while 40.6% either agreed or strongly agreed with the statement. A further 18.6% disagreed and 8.2% disagreed strongly. Women were significantly less likely than men to agree with this statement (41% versus 63%).

 **See also Vaccines page and Sexual Practice page 84**

### COMPLEMENTARY THERAPIES

Two thirds (67.2%) of the women were currently using complementary therapies for HIV. The most common complementary therapy was vitamin or mineral supplements (72.5% of those reporting complementary therapy use), followed by massage (54.0%), meditation (39.6%), medicinal marijuana (27.0%), and herbal therapies (23.1%) (see Figure 11). Other complementary therapies included acupuncture (11.9% of those using complementary therapies), traditional Chinese medicine (10.3%) and other traditional medicines (8.2%). Similarly to previous surveys, women were significantly more likely than men to be using complementary therapies (67.2% versus 51.5%). Those women using complementary therapies were no more or less likely to be using ARV.

**Figure 11 Most commonly used complementary therapies**



N=50

Almost all of the women (95.4%, N=71) of the women believe that complementary therapies can improve well-being (see Table 24). Women were significantly more likely than men to agree with this statement (95.4% versus 77.4%). Around two thirds of women also believe *Complementary therapies can delay the onset of illness due to HIV* and that *Complementary therapies can reduce the side effects of conventional medical treatments*. Again women were significantly more likely than men to agree with these statements (67.6 versus 49.3% and 66.9% versus 53.7%). However, around half of women didn't believe that complementary therapies could boost the immune system.

Around half of the women disagreed that there is insufficient evidence on the benefits of complementary therapies and generally women disagreed with the statement that medicine's focus on anti-HIV drugs is very limited. On average, those women who use complementary therapies spend \$19.82 per week on them.

**Table 24 Attitudes to complementary therapies: percentage of all women**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Complementary therapies can delay the onset of illness due to HIV	1.8	4.5	42.2	25.4	26.1
Complementary therapies can improve well-being	.0	.0	48.8	46.5	4.6
Complementary therapies can reduce the side effects of conventional medical treatments	.0	.0	33.2	33.7	33.0
There is not enough evidence to be sure about the benefits of complementary therapies	15.1	38.8	28.2	1.2	16.7
Medicine's focus on anti-HIV drugs is very limited	3.0	13.5	33.5	12.4	37.6
Complementary therapies can boost the immune system	1.8	.0	34.8	46.1	17.4
Complementary therapies are a central part of my anti-HIV treatments	4.9	30.2	25.5	28.3	11.1

### OTHER MEDICATION

Women used a range of other medication. In all, 48.8% of women were using some other type of medication than antiretroviral therapies. The main medications being used are Bactrim (6), and Losec (4).

### Dosing and Compliance

Respondents were asked the number of times they took a range of medication per day. On average, women were taking medication 2.3 times per day (range 0 to 6, median=2). The number of times they were taking specific types of medication is shown in Table 25 below.

**Table 25 Number of times women take medications**

Reason	Mean	Median	Range
Antiretroviral drugs	2.0	2	0-18
Complementary therapies	0.8	0	0-6
Medication for health conditions other than HIV	0.8	0	0-4

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

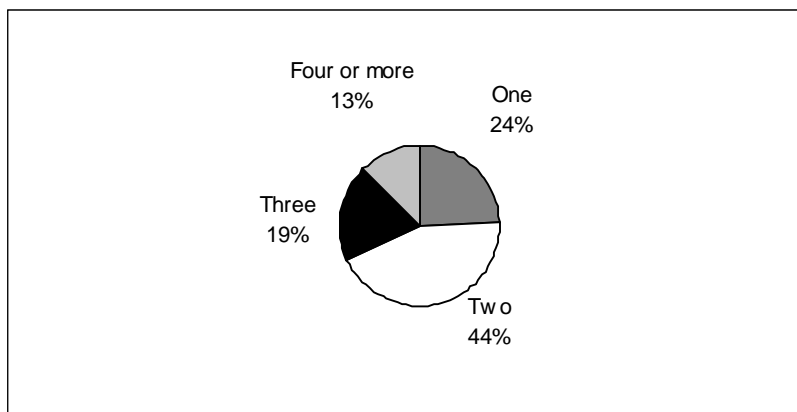
the data from these two measures, 40 women reported missing no doses on the two days, two missed one dose, two missed two doses and two missed more than two doses.

**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. One half (51.6%) of the women obtain their prescription from a specialist in an outpatient clinic, while 35.3% get their prescriptions from a GP who specialises in HIV/ S100 prescriber<sup>9</sup>, 21.0% obtain them from a doctor at a sexual health centre and 10.8% get them from other sources.

Unlike the 1999 survey where over 60% of women collected all their prescriptions from one site, women in this survey were most likely to say two places (43.9%) with slightly fewer saying one place (24.2%) or three or more sites (31.9%) (see Figure 12). When asked how difficult it was to do this, two fifths (41.9%) said it was not difficult, 46.1% said somewhat difficult and 12.0% said very difficult

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



N=44

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

*I take a lot of herbals. I'm under a natural therapist and I put a lot of changes down to the drops she gives me. I think a lot of the coping that I did in the few years beforehand was through her help. And I think she's slowly either adding something or taking something away within those, and it's sort of, made me, wake up to myself I guess. She sort of kept me in a sleep state to get through it. Well that's what I put it down to. That, and time.*

*Allison, 38, diagnosed 1996*

*Treatments. It's a bit damned if you do and damned if you don't. You don't know what to do. Sometimes the side effects are worse than what they're trying to cure. I get lots of dry skin and rashes. It comes out on my skin. And another side effect is having all the weight on your stomach and your hips. They've got special exercise classes for positive women. It's not just our imagination – they've got research into it.*

*Maggie, 33, diagnosed 1986*

**SERVICES**

*Yeah, like for me a very big part of my life is Positive Women ... when I was first diagnosed ... I linked in to Positive Women but I was like terrified of making contact. I don't know why. Maybe once again it was my perception of what these positive people are going to be like.*

*Debbie, 25, diagnosed 1991*

*My daughter's growing so quickly. I'd just like to freeze time just for a little while and just enjoy her at three months. And everyone says 'oh it just gets better, it just gets better'. It's been really wonderful meeting other positive women who have had children too. Because ... when I was first diagnosed I didn't really have time for grief counselling, trauma counselling. The doctor told me to come in and see me, get your results back. And I think it's very hard for women because they don't always have the time. So I've met people along the way who've been really nice to me, really good and I think ... if there's any pregnant women that want to meet another pregnant woman, or woman who has had a child, who was raising a child, I'd do that because I think there was no one there for me. It's really important that you know that you're not the only one. Things are changing a lot but there's still a long way to go.*

*Sharon, 38, diagnosed 1990*

## **SERVICES**

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

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### **Summary:**

For general health care treatment 35.0% of women see an HIV GP/S100 prescriber, whereas for HIV specific treatment 44.0% see an HIV specialist/physician prescriber and 32.7% see an HIV GP/S100. Most women had visited either a GP who specialises in HIV or an HIV specialist in the last six months.

Almost half of the women (43.9%) reported having to go to two places for prescription medication. A further 31.9% go to three or more places for prescription medication whilst 24.2% pick up all of their prescription medication at one place.

Peer support is the most used service for women at AIDS organisations (61.8%) while around half reported social contact (54.5%) and treatment advice (53.4%). Almost one third (34.1%) of women utilise counselling services at AIDS organisations and 27.4% access complementary therapies. One quarter (25.3%) of women access AIDS organisations for financial assistance and 17.6% seek advice on legal matters.

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## HEALTH SERVICES

The increasingly complex management of HIV treatments, side effects and the consequences of long term infection have meant that coordinated and comprehensive clinical management has become critical for positive people. Here we examine the use of, and experience of, a range of health services.

### Treatment

We asked respondents to identify the physician they see for the clinical management of their HIV and for general health issues. HIV GPs (S100 Prescribers) 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. Combined, HIV GPs and specialists are the primary physicians for 76.7% of women for HIV specific management and 46.0% for general health management.

**Table 26 Physician used for general and HIV related treatment: percentage of all women**

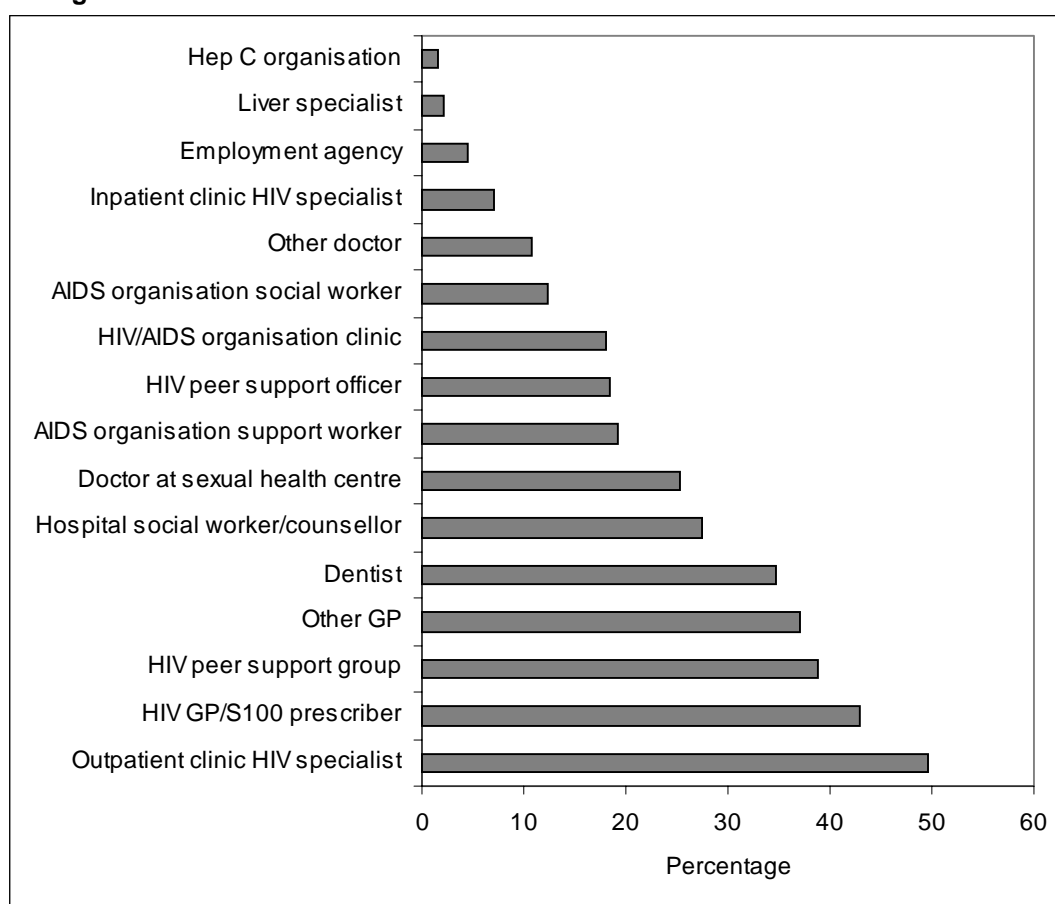
	For general treatment	For HIV specific treatment
HIV GP/S100 Prescriber	35.0	32.7
Other GP	31.6	0.0
HIV specialist at outpatient clinic	11.0	44.0
Doctor at sexual health centre	14.9	21.6
Other doctor	6.3	1.7
No one	1.3	0.0

Almost half of the women (46.3%) said that the doctor they see for general medical services is the same doctor they see for HIV-related treatment. Of those who see a different doctor, 96.8% said that that doctor knows their HIV status. Women were significantly less likely than men to report that they see the same physician for both their general and HIV related treatment (46.3% versus 60.9%).

**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 by women, with 49.6% a HIV outpatient specialist, 42.9% using a HIV GP/ S100 prescriber and 37.1% an other GP 34.7% a dentist (see Figure 13). Women were significantly less likely than men to use a HIV GP/ S100 prescriber (42.9% versus 59.1%) and significantly more likely to use some support services, such as HIV peer support groups (38.7% versus 13.7%) and hospital social workers and counsellors (27.6% versus 14.7%).

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



(Multiple responses possible)

**Other Services**


Participants were asked whether they currently use a range of services and, if so, whether they do so through an HIV/AIDS organisation or through another organisation. The most commonly

used service among women at AIDS organisations was peer support groups, with well over half the women selecting this item (see Table 27). AIDS organisations were also used for social contact with other PLWHA, treatments advice and information, informal peer support and counselling by substantial numbers of women.

**Table 27 Services used at HIV/AIDS organisations and at other organisations (percentage of all women)**

	Use service at HIV/AIDS ORGANISATION	Use service at OTHER ORGANISATION
Peer support group	61.8	6.7
Social contact with other PLWHA	54.5	7.8
Treatments advice	53.4	25.0
Treatments information	52.3	24.9
Informal peer support	41.7	7.0
Counselling	34.1	32.4
Alternative therapies	27.4	43.5
Financial assistance	25.3	21.4
Pharmacy services	20.8	53.5
Legal advice	17.6	17.7
Housing assistance	16.5	18.0
Community education campaigns	15.8	5.2
Transport	15.2	22.9
Library	14.5	43.3
Internet based information	11.2	25.1
Volunteer carer	10.3	8.5
Internet access	10.2	44.3
Financial advice	9.1	18.9
Respite care	8.9	3.6
Mental health services	6.7	17.3
Employment services	3.7	15.3
Return to work skills	1.8	8.6
Drug/alcohol treatment	.8	5.9
Paid carer	.8	7.4

(Multiple responses possible)

 **See also: Poverty and services page 112**

Women were significantly more likely than men to use the following services at AIDS organisations: peer support groups (61.8% versus 27.2%), informal peer support (41.7% versus 19.7%), and social contact with other PLWHA (54.5% versus 37.4%). Similarly, women were significantly more likely than men to use the following services at other organisations; counselling (32.4% versus 19.9%), financial assistance (21.4% versus 11.3%), pharmacy services (53.5% versus 39.1%), alternative therapies (43.5% versus 24.9%), internet access (44.3% versus 22.5%), and treatments information (24.9% versus 15.7%).

When asked what services they felt they needed but were currently not receiving, women nominated a wide range of services such as; transport, services in rural areas, peer support groups, complementary therapies, housing assistance, services for women and services for heterosexuals. None of the nominated services accounted for more than two responses.

## **INFORMATION**

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

## **Sources**

In recognition of the increasing specificity and distinctiveness of treatments information, we modified the section on information sources in the HIV Futures 3 survey to cover three domains: HIV treatments information; HIV management information; and information around living with HIV. Respondents were asked to nominate, from a list of potential sources, those that were important sources of information in these domains. The results of this for women can be seen in Table 28 below.

**Table 28 Sources of information about treatments and living with HIV (percentage of all women)**

	Information about TREATMENTS	Information about HIV MANAGEMENT	Information about LIVING WITH HIV
HIV GP/S100 prescriber	52.8	42.9	28.5
Other GP	10.1	7.0	9.1
HIV specialist at outpatient clinic	59.8	51.0	29.7
HIV specialist at inpatient clinic	16.0	12.2	7.1
Other doctor	4.2	5.0	6.6
Public Health Nurse	7.9	8.8	7.6
Other Nurse	8.3	5.4	5.4
Pharmacist	20.1	10.5	7.6
Alternative therapist	22.0	29.1	29.6
Dietician	17.1	24.0	25.9
Dentist	10.0	17.5	6.6
Peer Support Officer	10.8	14.1	24.5
Sexual health service	23.0	23.4	21.0
Family Planning Association	2.9	4.0	2.9
Sex worker organisation	2.7	2.7	6.9
Treatments officer	22.1	13.0	12.1
Other HIV/AIDS organisation staff	14.1	21.9	22.9
Positive women's organisation	40.6	43.3	56.5
Positive heterosexuals group	24.4	27.1	29.5
Injecting drug users' organisation	6.1	5.5	7.8
Haemophilia Foundation	2.1	3.0	4.7
HIV positive friends	40.9	46.6	61.6
Other friends	3.4	3.5	20.1
Partner/ lover	10.1	10.1	18.7
Family	6.5	13.1	21.6
Articles in gay press	16.5	13.0	16.0
HIV magazine/ newspaper	53.5	51.5	49.1
Hep C Support Group/Organisation	7.3	5.5	6.5
Liver Specialist	4.5	3.7	3.7
Internet	16.6	15.4	17.1
Publications from HIV/AIDS groups	50.4	52.1	48.3
Publications from other sources	14.8	13.7	17.4

(Multiple responses possible)

***Information about Treatments***

HIV specialists were considered an important source of information on treatments by 75.8% of women. HIV GPs/S100 prescribers were nominated by around half of the women. Importantly, information from the community sector figured significantly in the responses to this item. These included HIV magazines and newspapers (53.5%), HIV/AIDS organisation publications (50.4%), and Positive Women's organisations (40.6%). HIV positive friends were nominated by 40.9% of women. Women were significantly more likely than men to report that the following were important sources of information about treatments: Alternative/complementary therapist (22.2% versus 13.1%), Dietician (16.7% versus 8.1%) and HIV positive friends (41.1% versus 28.5%).

When asked in a separate question to nominate the *most* important source of information on treatments 32.6% said a HIV specialist at an outpatient clinic, 31.6% said their HIV GP and 8.5% cited a Positive Women's organisation. No *other* response accounted for more than 5% of responses.

***Information about HIV Management.***

When asked what sources of information around HIV management were important, a similar pattern emerged with outpatient HIV specialists nominated by over half the women (51.0%), HIV GP/S100 prescribers nominated by 42.9% and community sector sources also figuring prominently (HIV organisation publications: 52.1%, HIV magazine: 51.5%, Positive Women's organisations: 43.3%). HIV positive friends were also mentioned by 46.6% of the women. Similarly with treatment information, women were significantly more likely than men to report that the following were important sources of information about HIV management: Alternative/complementary therapist (28.8% versus 14.7%), Dietician (24.3% versus 12.7%) and HIV positive friends (46.6% versus 30.6%). Women were also significantly more likely than men to nominate publications from HIV/AIDS groups as an important source of information about HIV management (52.1% versus 39.6%).

When asked to nominate the *most* important source of information on HIV management 28.9% said their HIV GP, while 16.2% nominated an HIV specialist at an outpatient clinic, and 14.3% nominated Positive Women's organisations.

***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, with women preferring less medical information sources. The source selected by the greatest number of women was HIV positive friends (61.6%) followed by Positive Women's organisations (56.5%), HIV magazine/ newspaper (49.1%), and HIV organisation publications (48.3%). Clinical sources were considered less important (HIV GP: 28.5%, HIV specialist: 29.7%). As with treatment and HIV management information, women were significantly more likely than men to report that the following were important sources of information about living with HIV: Alternative/complementary therapist (29.7% versus 15.6%), Dietician (26.0% versus 15.5%) and HIV positive friends (61.6% versus 41.6%). Women were also significantly more likely than men to nominate peer support officer (24.7% versus 13.2%) and her family (61.6% versus 41.6%) as important sources of information about HIV management

When asked to identify the *most* important source of information on living with HIV 26.1% nominated their a Positive Women's organisations, 24.5% HIV positive friends, 8.2% an HIV GP and 6.3% publications from HIV/AIDS organisations.

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 to be. The responses for women are presented in Table 29. As can be seen from these data, most women are unsure about the reliability of information available on the net.

**Table 29 Attitudes to HIV information on the Internet (percentage of all women)**

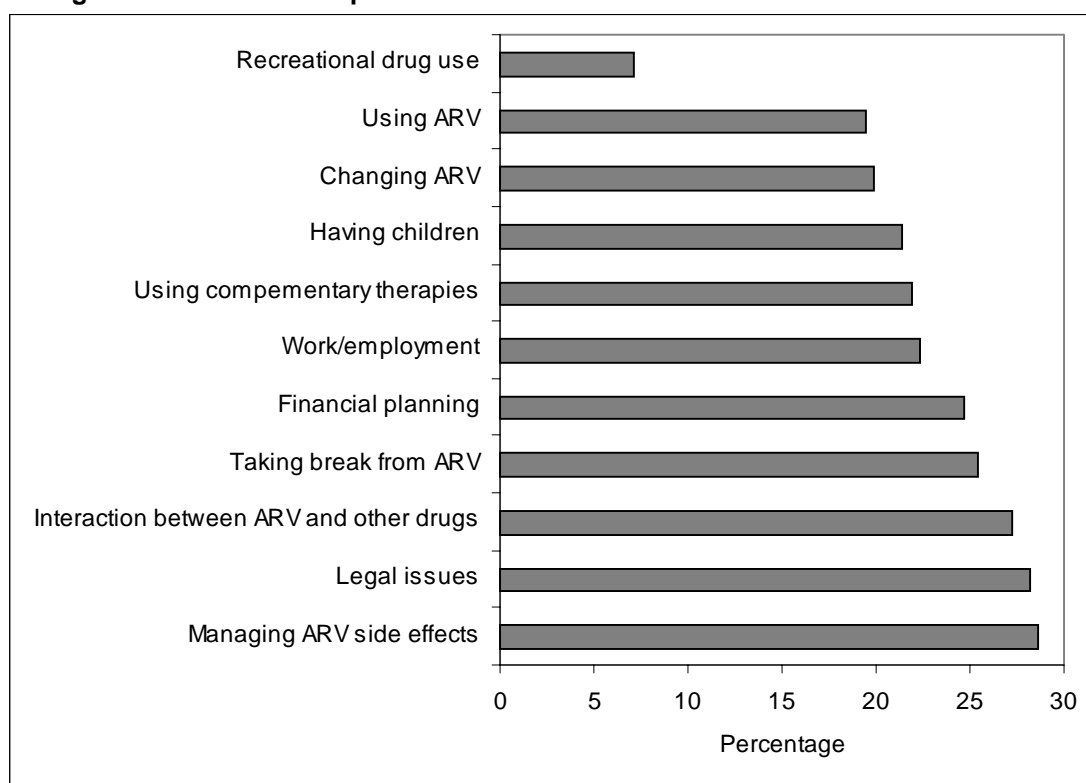
	Strongly Disagree	Disagree	Agree	Strongly Agree	Don't know
Information on the internet about living with HIV is unreliable <sup>b</sup>	3.3	20.3	13.1	6.7	56.6
Information on the internet about treatment side effects is unreliable <sup>b</sup>	3.4	22.9	9.1	5.1	59.5

a N=73; b N=72.

**Lack of information**

When asked to identify domains in which lack of information made it difficult to make decisions, around one quarter of women nominated the management of side effects (28.6%) and legal issues (28.2%). Employment and financial planning also figured prominently. Importantly, interaction between treatments and changing antiretroviral treatments were identified by one in four women (see Figure 14 below).

**Figure 14 Problems experienced due to lack of information**



N=56

(Multiple responses possible)

### Publications

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 30, including breakdowns for specific populations where access or focus is an issue. *Positive Living*, the *HIV Herald* and publications from community organisations are accessed by large proportions of women, as are state-based publications (within their states). 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 30 Publications read by women**

Publication	Percentage
<i>National or non-specific</i>	
National AIDS Bulletin	24.7
Positive Living	58.1
HIV Herald	42.8
National Haemophilia	1.2
Gay newspapers (% of total sample)	14.4
Gay newspapers (% of lesbians and bisexuals)	30.3
Gay magazines	2.7
Gay magazines (% of gay men and lesbians and bisexuals)	6.3
Newsletters from community organisations	44.7
Overseas HIV/AIDS magazines (e.g. POZ)	13.5
<i>State based publications</i>	
Talkabout (% of total sample)	58.2
Talkabout (% of NSW respondents)	94.0
With Complements (% of total sample)	38.1
With Complements (% of NSW respondents)	66.9
NUAA News (% of total sample)	3.6
NUAA News (% of NSW respondents)	12.5
Positive Life (% of total sample)	22.5
Positive Life (% of WA respondents )	77.0
QPP Alive (% of total sample)	27.0
QPP Alive (% of QLD respondents)	100.0

### **Involvement with AIDS Organisations**

Participants were asked about their involvement with HIV/AIDS organisations. Most women (88.6%) have some contact with HIV/AIDS organisations. Of these, 94.4% received newsletters and mail outs, 64.3% were clients, 56.0% were members, 25.2% were volunteers and 10.3% were employees. Of the eight women that had no contact with AIDS organisations, four gave the reason *I do not have enough time*, three gave the reason *I do not want to be involved*, two said that they had *no transport or are too far away* and one women said *I do not know how to join*. Importantly, only one woman of those who were not involved in AIDS organisations said they *felt excluded from them*. A considerable number of women (41.9%) had at some point held a decision making position in an AIDS organisation (26.7% in the last two years).

*With hindsight I was actually quite naive about it. I took AZT during pregnancy so it was my first taste of the treatments I suppose. Because that was for a particular purpose outside of myself in the sense of stopping my child from becoming positive. That was a short-term thing; something that was going to stop us as soon as she was born. When I went on antiretroviral treatments I actually, looking back on it, really didn't have much information. So I hadn't really thought about – I'd heard about the side effects – but hadn't really thought about the implications for the future or implications for every day of taking them. And it's funny I suppose, the more I learnt about them the harder it became to stay on them. I think sometimes you can have too much information. That you've got all this sort of misinformation rolling round in your head about what if I miss a dose, resistance, oh my God. So I think I really wasn't aware, even though I had a good relationship with my doctor. And it's still a thing that frustrates me now when I meet newly diagnosed women who are put on treatments immediately. That they haven't had a chance to even learn to live with HIV let alone to learn about treatments and to learn what's best for them. I mean that's part of women not having much of a community. They don't get to share that information with each other before they go on it. It's usually just a decision they've made with their doctor.*

*Janelle, 32, diagnosed 1991*

**WELL-BEING**

*I'd love to know that I could spend my life watching my daughter grow up and having grandchildren. I suppose I think about the future in one context, but I would never think about it that far ahead that I see myself as an old person in a sense.*

*Janelle, 32, diagnosed 1991*

*There have been other occasions where I've been at dinner parties, and you'll be talking about all sorts of things in general. Perhaps illness may come up. And I remember a time, a friend's mother who'd been a survivor of ovarian cancer for about 20 years. And I know for women to have survived ovarian cancer is quite remarkable. I was saying to her, that what she went through must have been quite remarkable. We were just talking about things in general, and then at the end of it she turned around and she said to me "My dear, I think what you have to do is, is more remarkable." And I literally had no idea what she was talking about, until I asked her to please explain. Then she said that she was aware that I was HIV positive, and blah blah. All those other accolades that go with that, when you're considered to be young and what people consider to be a dreadful disease. And all those other sympathies, and I felt quite vulnerable. And almost betrayed by friends. Obviously this was my friend's mother, and I suppose this friend is very close to his mother. I suppose it was a big ask. No I actually assumed that if, when I told him that he wouldn't tell anybody else.*

*Sally, 33, diagnosed 1994*

## **WELL-BEING**

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

## **THE SOCIAL WORLD OF PLWHA**

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

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**Summary:**

**Well-being and Information**

All of the women have disclosed their HIV status to at least one person, generally partners, close friends and family. However, for 64.5% of women, their HIV status had been disclosed to another person when they did not want it to be (42.0% in the last two years).

HIV was an important part of the identity of 56.2% of women and an essential part of the identity of 19.1%. HIV status tended to be less important to women than identities based on sexuality, gender, family or parenthood.

Partners or spouses were sources of 'a lot' of support for many women with partners (71.6%). Parents (59.3%), pets (58.6%) children (58.3%) and close friends (51.1%) were also significant sources of 'a lot' of support.

In the last six months 16.8% of the women have taken prescribed medication for depression and 19.4% have taken medication for anxiety.

One fifth (21.4%) plan only one day at a time and 17.4% plan only a few months ahead. More than half of the women plan for at least one year ahead.

Most women (88.6%) have some contact with HIV/AIDS organisations, mostly by receiving newsletters or being clients of these organisations while 10.3% were employees of AIDS organisations.

Most women (93.6%) said they know another person living with HIV/AIDS. Three quarters of women (75.0%) said they have acquaintances with HIV and for 72.6% someone close has died of AIDS related causes. Around one fifth of women (21.2%) have been involved with the care of someone with HIV/AIDS. One quarter of women (25.7%) reported that they do not spend any time with other PLWHA.

**Contact With Other PLWHA**

Very few HIV positive women (6.4%) do not personally know anyone else with HIV. Most women have an HIV positive friend (64.3%), while 75.0% have positive acquaintances or have met positive people through support groups. Many have either an HIV positive partner or ex-partner (32.9% combined). One fifth of women (21.2%) have been involved in the nursing or care of another positive person at some time in the last two years. Almost three quarters of women (72.6%) have had someone close to them die from AIDS, primarily friends (52.5%), acquaintances (38.1%) and members from support groups (37.4%), but also partners/spouses (15.8%), former partners/spouses (15.3%), relatives (5.8%) and children (1.0%).

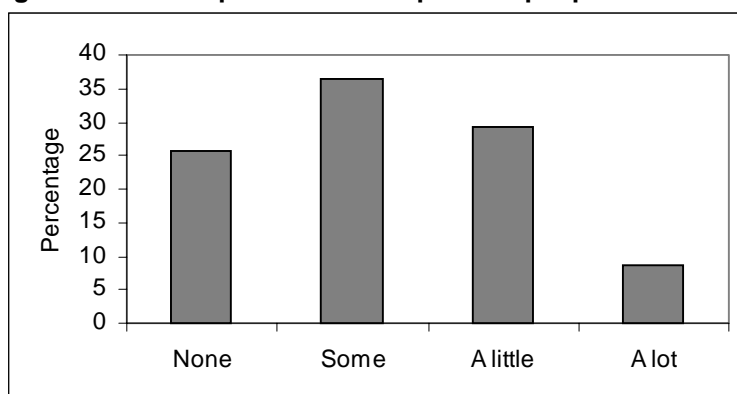
**Table 31 Other HIV positive persons known by women**

Positive persons	Percentage
Acquaintance/ member of support group	75.0
Friend	64.3
Former partner/ spouse	21.6
Partner/ spouse	13.3
No-one	6.4
Son/ daughter	5.2
Other relative	4.2

(Multiple responses possible) N=72

Around four-fifths of the women spend at least some time with other positive people.

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



N=72

### Disclosure

Respondents were asked whom they had disclosed their HIV status to (see Table 32). Not surprisingly, most women (87.1%) had disclosed to close friends, and most women (88.1%) in relationships had disclosed to their partner. Within families, women were most likely to have disclosed to siblings (82.0%) although many had disclosed to parents (70.6%). All of the 72 women who answered the questions about disclosure had disclosed their HIV status to someone. Three women did not respond.

 **see also sex and relationships page 78**

**Table 32** People the women have disclosed their HIV status to

	<b>Percentage who have disclosed</b>
Close friends	87.1
Brothers or Sisters	82.0
Parents	70.6
Positive friends	67.4
Partner/ spouse	65.9
Other friends	38.0
Work colleagues	35.0
Son/ daughter	28.5
Neighbours	11.7
People from own ethnic community	.9
No-one	.0
<i>Specific populations</i>	
Partners (% of those in regular relationship)	88.7
Partners (% of those not in regular relationship)	28.3
Work colleagues (% of those currently employed)	45.1
Work colleagues (% of those not employed)	21.8
Son/ daughter (% of those with dependant children)	46.9

(Multiple responses possible)

**Unwanted Disclosure**

Respondents were asked if their HIV status had ever been disclosed without their permission. Almost two thirds of women (64.5%) said that it had at some point, and 42.0% of women said that this had happened in the last two years compared to 28.6% of men. When asked who disclosed their status, women commonly nominated friends or work colleagues (see Table 33). In part these data reflect those that are most likely to be aware of the woman's HIV status. It is of concern that 26.1% nominated a worker in a health care setting.

 **See also discrimination in health care page 116**

**Table 33 Sources of unwanted disclosure (percentage of those women experiencing unwanted disclosure)**

	Percentage
Other friends	36.5
Workers in a health care setting	26.1
Close friends	23.3
Work colleagues	22.4
Brothers/sisters	19.2
Community organisation staff/volunteers	16.6
Partner/spouse	15.3
Other family	13.6
Parents	11.6
HIV positive friends	8.6
Neighbours	8.6
Other	7.7
Son/daughter	4.6
People from ethnic community	2.6

(Multiple responses possible)

**The Place of HIV in Women's Lives**

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

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 for women are given in Table 34. 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 the women see themselves, but may have greater or lesser relevance depending on the context. A rating of *not important* indicates that the characteristic only has very context specific relevance and does not generally enter into their self-image. A rating of *irrelevant* indicates that the characteristic plays no part in their self-image. While our primary focus in this area was on the importance of HIV identity, we have included other characteristics, both as points of comparison and as a way of more fully describing PLWHA. The characteristics examined were sexuality, gender, recreational drug use, ethnicity, parenthood and career.

The majority (56.2%) of positive women in this study consider their HIV status an important, but not essential aspect of their make-up, while 19.1% consider it to be an essential characteristic. This is in contrast to family and parenthood, which the women most commonly consider to be *essential* characteristics.

**Table 34 Importance of personal characteristics to women's sense of identity**

	Essential	Important	Not important	Irrelevant
Family	52.7	40.7	6.6	.0
Parenthood	38.0	27.2	4.8	30.1
Gender	34.0	38.7	14.4	12.9
Sexuality	26.3	46.1	18.5	9.0
Career	22.5	60.8	4.7	12.1
HIV status	19.1	56.2	19.5	5.1
Religious beliefs	8.8	32.4	21.7	37.0
Ethnicity/ Cultural background	5.6	26.8	20.5	47.1
Drug use (recreational/illegal)	3.0	9.9	19.9	67.2

When we look at the importance of HIV status among specific subgroups of PLWHA, we find that there were no significant differences in terms of sexuality or gender. However, women were significantly more likely than men to rate family and parenthood as essential or important to their

sense of identity. Among women there were no differences based on having had an AIDS defining illness, use of antiretroviral drugs, partner sero-status, or having a dependant child.

**Table 35 Importance of HIV status to sense of identity for different groups of women**

<b>Importance of HIV status among:</b>	<b>Essential</b>	<b>Important</b>	<b>Not important</b>	<b>Irrelevant</b>
Gay and bisexual men	18.3	52.7	21.2	7.8
Women	19.1	56.2	19.5	5.1
Heterosexual men	20.4	49.4	15.7	14.5
Women who have had an AIDS defining illness	21.2	51.0	13.1	14.8
Women who have not had an AIDS defining illness	18.7	57.2	20.8	3.3
Women on antiretroviral therapy	23.8	53.9	16.6	5.6
Women not on antiretroviral therapy	11.2	60.1	24.4	4.3
Women in sero-concordant relationships	8.2	60.1	24.1	7.6
Women in sero-nonconcordant relationships	16.8	61.1	15.1	7.0
Women with dependant children	17.1	54.9	25.6	2.4
Women without dependant children	22.2	58.4	14.6	4.8

### **Social Support**

We asked participants about the amount of social support they received from a range of sources including household members, social contacts and service providers. The ratings are shown in Table 36 below with those designating the category as *not applicable* excluded from each row.

Women were most likely to rate their partner or spouse as a source where they receive a *lot* of support (71.6% of those with partners). This was followed by parents, pets, children and close friends, which were all rated highly by more than half of the women.

When we examine those categories that women receive no support from, the highest ranking category was religious or spiritual advisor; 62.5% of women for whom a religious or spiritual advisor was part of their life said they received *no support* from them. Volunteer carers were also considered a source of *no support* for 34.2% of those with a carer.

The data from this item can be analysed to see the number of categories from whom women receive support. If we take the number of sources from whom the woman received a *lot* of

support we have a measure ranging from 0 to 15<sup>10</sup>. The mean number of sources of a *lot* of support was 4.0 with 56.1% receiving a *lot* of support from four or more sources. Almost one in six women (16.5%) said they do not receive a *lot* of support from anyone.

We can repeat this analysis for different degrees of support. For example, the mean number of sources of a *lot* or *some* support is 6.7 (58.7% with seven or more sources, 8.4% with none) and the mean number of sources of *no* support was 1.5.

**Table 36 Women's social support received from different sources: percent who gave valid responses for each category**

	A lot	Some	A little	None
Partner/ spouse	71.6	14.4	10.1	3.9
Parents	59.3	11.9	12.0	16.8
Pets	58.6	20.0	12.0	9.4
Children	58.3	17.2	11.5	12.9
Close friends	51.1	28.3	14.4	6.2
Family	49.1	17.0	18.7	15.2
Brothers and sisters	47.0	16.7	16.5	19.8
Doctor	45.1	30.4	23.4	1.2
HIV positive friends	32.7	35.9	21.0	10.4
Volunteer carer	30.2	30.2	5.3	34.2
PLWHA groups	22.5	38.9	23.3	15.3
Counsellor	21.5	40.1	18.9	19.4
Health care workers	15.5	41.0	21.4	22.1
Other friends	12.6	37.8	29.5	20.0
Religious or spiritual adviser	5.9	19.4	12.1	62.5

### Mental Health

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

<sup>10</sup> Here we include those who designated the category as not applicable in the analysis, as this still

**Psychiatric Medications**

In the last six months 16.8% of women had been taking medication prescribed for depression. A similar proportion (19.4%) had taken medication for anxiety. In addition 3.8% of women indicated that they had taken anti-psychotic medication. Women were significantly less likely than men to report that they take medication for depression (16.8% versus 28.3%).

**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 positive women to the community norms for depression provided by the BDI - this would have required inclusion of the full sixteen-item scale. However, these four items do provide an indication of some of the major symptoms associated with depression. These are also items that are often used in general practice as reasonable indicators for the prescription of anti-depressants. As can be seen in Table 37, a considerable proportion of women agreed or strongly agreed with each of the items. The strongest level of agreement was with item 2 (*I don't enjoy things the way I used to*), followed by item 3 (*I have lost interest in other people*). Over one fifth of women agreed or strongly agreed with item 1 (*I cry or feel like crying all the time*), and 8% agreed or strongly agreed with item 4 (*I don't feel it's worth going on*).

We can look at the number of these items that women agreed with as a way of measuring the extent of depressive symptoms. Overall, 57.7% agreed or strongly agreed with none of these items, 22.8% with one item, 9.2% with two items, 5.4% with three items, and 4.8% of women agreed with all four items. Agreement with all four items may be suggestive of clinical depression. Women agreed with more of these items than men.

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indicates that the respondent does not receive support from this source.

Among women, agreement with a larger number of these items is significantly related to being on anti-depressant medication and having a poorer self-rating of general health or general well-being.

**Attitudes to HIV status**

Two additional items were included that examine individual's relationship to their HIV serostatus. Participants were asked whether they agreed with the statement *As long as I am well I prefer not to think about HIV/AIDS*. About half the 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*. Over 70% of women agreed or strongly agreed with this statement. Women were significantly more likely than men to agree with this second statement (70.4% versus 45.0%).

**Table 37 Attitudes to HIV status: percentage of all women**

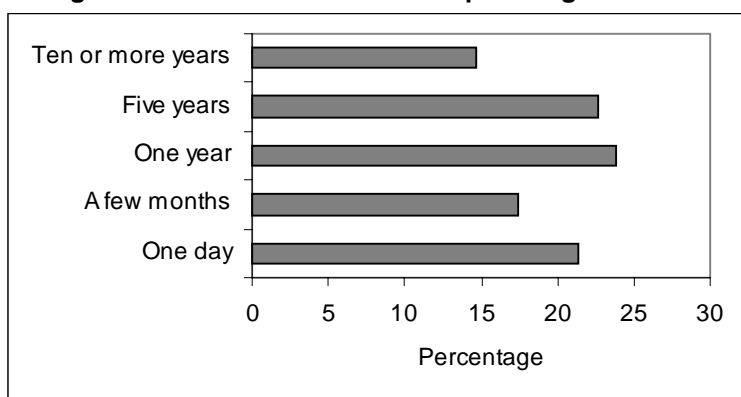
	<b>Strongly agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
I cry or feel like crying all the time	6.5	14.1	52.4	26.9
I don't enjoy things the way I used to	4.3	23.2	44.0	28.5
I have lost interest in other people	8.8	12.5	48.6	30.2
I don't feel it's worth going on	3.5	4.5	24.6	67.4
As long as I am well I prefer not to think about HIV/AIDS	13.6	37.0	42.4	7.0
Changes in my body due to HIV/AIDS have made me feel unattractive	16.5	21.3	46.7	15.5
I am happy with the way my body looks	17.9	38.7	28.5	14.8
Life has become more meaningful since I became HIV positive	22.6	47.8	23.2	6.4

**Planning for the Future**

A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan.

More than one fifth (21.4%) of women only plan their life one day at a time and 17.4% plan only a few months ahead. More than half of the women plan for at least a year with 23.9% planning one year ahead, 22.7% planning five years ahead and 14.7% planning ten years or more ahead.

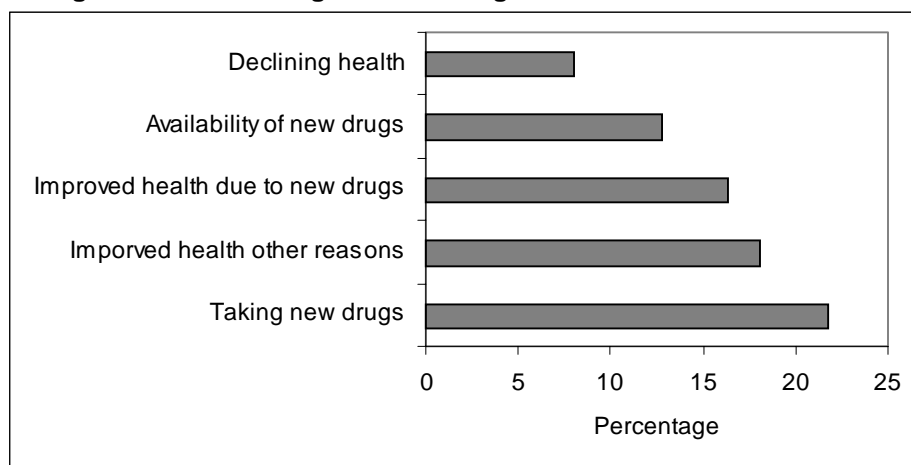
**Figure 16 Time frame for future planning**



For 36.6% of women, the time frame for future planning had changed in the last two years, with 28.5% of all women now using a longer time-frame and 6.8% using a shorter time frame.

The major reasons for change for those with a longer time frame were taking new treatments and improved health for other reasons (5 out of 21 women each). The major reason for change for those with a shorter time frame was declining health (2 out of 5), see Figure 17.

Figure 17 Reasons given for change in time-frame



*I feel more, much more easy with it ... I don't care who knows anything now, and it's great. And I wish other people would realise what incredible relief it is to disclose. Because people ... live their lives so much on a basis of fear and I refuse to have that fear any more. ... The only thing that could ever faze me seriously now is it any time it pertains to my son. It doesn't matter whatever happens to anyone else -- I don't care don't care if my house burns down. I've just got this philosophical attitude now. It's like I've gone through all of those things, to stay healthy and well. I don't have to worry. You know, I'm an Australian, I've got drugs, I can always get enough money for food and housing.*

*Miranda, 48, diagnosed 1991*

*Because I've always said I don't mind who knows, and my mum often asks me 'Can I tell so and so' and it's never bothered me, except where my daughter's concerned. People that are mixing with her through dancing and through school.*

*Allison, 38, diagnosed 1996*

*My daughter has seen me take the treatments and we talk about HIV quite openly. We talk about World AIDS Day and the quilt and that sort of thing, and I suppose I always thought it would be the missing piece in the jigsaw puzzle for her. [That] I'd say, "Well you know the reason we do all these things. I'm HIV positive," and explain to her. But recently at camp a family chose to tell their only child whose both parents are positive and the child's negative. And he had a very similar upbringing to my daughter going to lots of different things, and he didn't have a clue. It was like a bolt out of the blue for him. So that's really challenged my way of thinking now and it's something that I really feel I need to talk to other parents about how they've gone about it. But it's such an individual thing, knowing each child will understand it differently. So there might even be a time -- she asks so many questions now that it'll be something that just comes up one day.*

*Janelle, 32, diagnosed 1991*

## **WOMEN AND CHILDREN**

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### **Summary:**

Half of the women (50.2%) have dependent children. These children ranged in age from less than 12 months to 32 years of age, with the average age being 10 years. Twenty-three women have had a total of 29 children born to them since becoming HIV positive. Four women have HIV positive children.

A small number of women said they have plans to have children in the future. Three women were pregnant at the time of the survey and a further three were attempting to conceive.

Importantly, 13 women reported that they did not feel they had enough information to make a decision about having children.

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### **Children**

Almost two thirds of the women (61.8%) reported that they have children. Women's children ranged in age from less than 12 months to 41 years.

Thirty-eight women (50.2%) have between them 62 dependent children (nominated as dependent by the mother). Twenty-four women have one dependent child, six women have two dependent children, a further six have three dependent children and two women have four dependent children. The ages of the dependent children range from less than 12 months to 32 years of age. The average age of dependent children was 10. Of the women with dependent children, 28.3% of children are aged five years and under and 12.2% of the children are aged two years and under.

Four women reported that their child is HIV positive and one woman reported that her child had died from an AIDS related illness. Twenty-three women have had a total of 29 children born to them since they were diagnosed HIV positive.

### **Disclosure to children**

Twenty women have disclosed their HIV status to their child or children. The women reported that the children's age at time of disclosure ranged from one year to 41 years. Of those women

with dependent children, the children's age at time of disclosure ranged from one year to 22 years.

### **Planning for children in the future**

Six women have decided to have children in the future, three are currently pregnant and three are currently attempting to have children. Five are currently considering having a child, but have not decided, and six people had considered having a child, but decided it was too risky. Four women said they had had enough children already, while one said she had just had a child and one said she was too old. One woman said her doctor told her not to have children. Another woman was sterilised shortly after diagnosis and one felt she did not have enough information to make the decision.

Just over half the women (53.1%) were not currently considering having children. Of these women, 29 (69.0%) already have children.

It is important to note that 13 women (17.5%) feel they do not have enough information about pregnancy and having a child.

### **Health and children**

Women with dependent children were no more likely than women without dependent children to rate their health or wellbeing as excellent or good. Women with dependent children were also no more likely to be using antiretroviral drugs than those women without dependent children. There were also no differences in women's most recent viral load or CD4/T-cell test results.

### **Relationships and children**

More than half of women (63.9%) with dependent children are in relationships. Of the four women who have decided to have children in the future, three are currently in regular relationships or married. All of the three women who are trying to conceive a baby are in regular relationships or married. All of the three women who are currently pregnant are in a regular relationship or married.

### **Sexual identity and children**

Of the four women who have decided to have children in the future, three identified as heterosexual and one as bisexual. The three women who are currently pregnant all identified as heterosexual as did the three women who are currently trying to conceive a baby. Of the five

women who have thought about having children but have not yet decided, four identified as heterosexual and one as bisexual. The six women who said they had considered having children in the future but had decided that it was too risky were all heterosexual. The woman who reported that her doctor/medical professional had told her not to have a child was also heterosexual. Although those who are considering having children are primarily women (heterosexual and bisexual), some gay, bisexual and heterosexual men are also considering having a child (see Table 38).

**Table 38 Decision to have children by gender and sexuality**

	Heterosexual women	Bisexual women	Lesbian women	Heterosexual men	Bisexual men	Gay men
No – I am not considering having a child	29	5	3	39	25	642
I have decided to have a child/children in the future	3	1	0	7	3	0
I am currently trying to conceive/get pregnant	3	0	0	0	0	0
I/we are currently pregnant	3	0	0	1	0	0
I have thought about it but I haven't decided	4	1	0	3	1	10
I have thought about it but I have decided that it is too risky	6	0	0	3	2	14
I was told not to by a doctor/medical professional	1	0	0	0	0	0
I don't have enough information to make a decision	11	0	1	18	5	19

*I first started on treatments when I found out I was pregnant. I was on AZT monotherapy. We wanted to do anything we could to reduce the rate of transmission to Sarah and so I went on treatments ... and I was healthy and didn't breastfeed and all the rest of it. But then there was this other side of me that thought, "Oh, how poisonous is it?" But the thing about protecting Sarah really outweighed anything else so I went on it.*

*Debbie, 25, diagnosed 1991*

*I'd like to have another baby, but no one can give you a definite, yes, everything's going to be okay. And I just could not live with myself, if I got really blasé, oh yeah, let's have another baby, everything's fine, da, da, and the second baby's born positive. It does take a big chunk out of your life, running around hospitals, taking medication. And you know, I'd feel it was all my fault, and I don't want to have to deal with that. So no, we've been lucky for what we've got. We've been blessed with an angel. It's hard though, as she gets to two or three I'll probably be thinking about it, but then, with this pregnancy, it was like, "Well it's now or never, Christina, because you're thirty eight." I was already termed an older mother and I had to go for tests for this that and the other, so in three years time I'll be forty one. It's ambitious to have a three year old! So, I don't know. It would be nice but I don't think we should push our luck.*

*Sharon, 39, diagnosed 1990*



## RELATIONSHIPS AND SEX

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### **Summary:**

More than half of women (58.6%) are currently in a regular relationship, and a smaller group have casual partners (9.6%). Forty percent of women are not having sex at present.

Of those in a regular relationship, 26.3% have a partner who is also HIV positive, 66.1% have an HIV negative regular partner and 7.7% have a partner of unknown status. All the women have disclosed their status to their regular partner, usually when they were diagnosed or at the time of, or prior to, the commencement of the relationship. In the majority of cases the partner's reaction to disclosure was positive and in one third of cases it brought the partners closer together, but 34.6% also reported that their partner was worried or scared.

Just over half the women had vaginal or anal intercourse with a regular partner in the past six months. Condom use with regular partners was strongly related to the HIV-status of the partner.

Only 10 women reported sex with casual partners in the past six months. Nine of these reported that none of their partners was HIV positive, while one reported that she did not know the HIV status of her partners. Six women reported always using condoms with casual partners.

Information about the most recent episode of sex with a casual partner in the previous six months was provided by 10 women. All of these episodes occurred with partners of unknown or negative HIV status and involved vaginal or anal intercourse. Six of these encounters involved condoms and three did not.

Around a quarter of the women would prefer to be in a relationship with someone who is also HIV positive. Over half of the women expressed some fear of rejection from potential partners if they disclose their HIV status. The majority of women (59.3%) felt HIV had a negative effect on their sexual pleasure. Only 8.6% of the women agreed with the statement *I feel more confident about unprotected sex because of the new treatments.*

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### Relationships

Respondents were asked what sexual relationships they currently have. The results are presented in Table 39 below. Around 40% of the women said that they had no sex at present. Almost half reported that they had a regular relationship only, while few said that they had casual sex only, a regular relationship plus casual sex, or a regular relationship with more than one person. Women were more likely to report that they have one regular sexual partner and no casual sex, while heterosexual men were more likely than other PLWHA to report that they had no sex at present and gay and bisexual men are more likely to report that they have a regular sexual partner and also have casual sex.

**Table 39 Type of sexual relationship(s) by gender and sexuality of respondent**

Sexual relationships	Women <sup>1</sup>	Heterosexual men <sup>2</sup>	Homosexual & bisexual men <sup>3</sup>	Total
Regular relationship only	49.1	33.3	20.8	24.1
No sex at present	39.5	46.7	21.4	24.7
Regular relationship plus casual sex	5.2	5.0	23.0	20.3
Casual sex only	4.4	13.3	32.0	28.3
Regular with two or more people	1.8	1.7	2.8	2.6

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

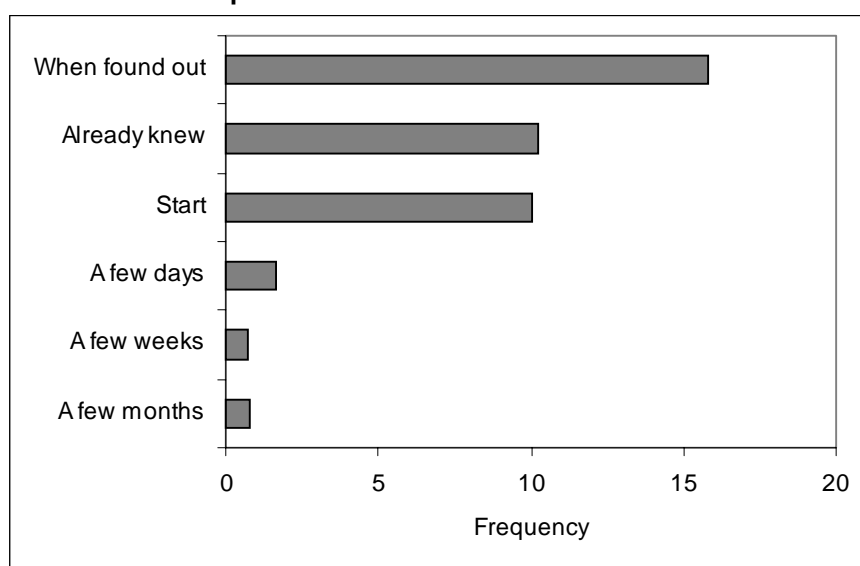
When asked if they were currently in a regular relationship, around half of the women (58.6%) said they were. This is slightly higher than the proportion of the women that report having sex with a regular partner in Table 39 (56.1%), as some of those women in a relationship would not have sex with their partners.

**Regular Partners**

Of those women in a relationship with a regular partner, 26.3% report that their partner is also HIV positive (generally described as a sero-concordant relationship). The remainder are in sero-nonconcordant relationships. This remaining group is made up of 66.1% of the women that report that their partner is HIV negative (a sero-discordant relationship) and 7.7% who report that they don't know their partner's HIV status.

All the women have told their regular partner that they are HIV positive. Women were asked at what point in the relationship they told their partner. The responses are given in Figure 18 below. Two-fifths (40.3%) told their partner when they themselves found out they were positive. Slightly more than a quarter (26.1%) said their partner knew prior to the start of the relationship, while 25.6% told their partner at the beginning of the relationship. Of the remainder, two women told their partners a few days into the relationship, one a few weeks into the relationship, and another a few months into the relationship.

**Figure 18 Time HIV status disclosed to partner among those women in regular relationships**



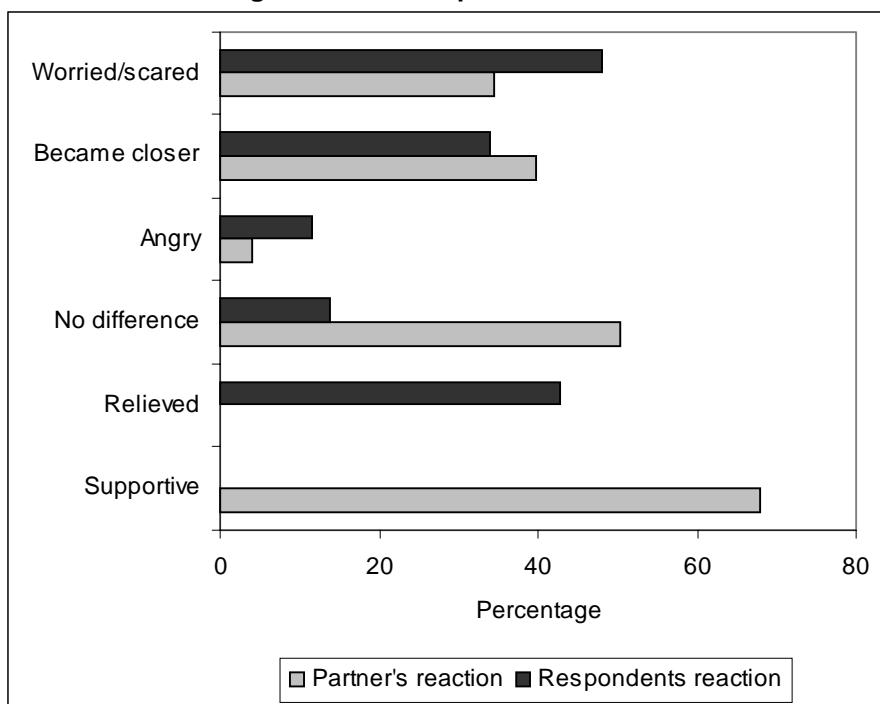
N=39

When asked how their partner responded when told of the women's HIV status, the majority (67.9%) reported that the partner was supportive (see Figure 19). Over half (50.4%) reported

that it did not make any difference. Over one third (39.6%) reported that the disclosure brought them closer together.

Around one third (34.6%) reported that their partner was worried or scared and 4.0% said their partner was angry.

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



Partner's reaction: N=38; Women reaction: N=38

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

We also asked how the respondents themselves felt about this disclosure. In general the patterns matched those of their partners, although the women were less likely to say it made no difference to themselves.

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. Overall, 52.7% of the women had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 8.1% had anal or vaginal sex with a regular female partner in the previous six months. For male and female

partners combined, 10 women reported that they never used condoms, 17 that they sometimes used condoms and 13 reported that they always used condoms. In total, 57.0% had either anal or vaginal sex with a regular male or female partner in the last six months.

If we look at these data in terms of relationship sero-concordance, considerable clarity is given to the patterns of condom use. Unprotected vaginal or anal intercourse is more likely to occur in sero-concordant relationships than in sero-nonconcordant relationships (see Table 40).

**Table 40 Condom use with regular partner by partner sero-status**

	<b>Number of these that used condom</b>		
	Never	Sometimes	Always
HIV positive	4	5	0
HIV negative/Don't know	6	9	13

**Casual Partners**

Only 10 women reported that in the six months prior to completing the survey they had sex with one or more casual partners. Of these, nine reported that none of their casual partners were HIV positive, while one reported that she didn't know the status of her casual partners. Six women reported that they always used condoms with their casual partner(s), two women said they sometimes used condoms and one woman reported that she never used condoms.

Respondents were asked about their condom use during anal or vaginal intercourse with casual partners over the previous six months. Six women reported they always used condoms with their casual partners, two that they sometimes used condoms, and one that they never used condoms.

In addition to reporting on their overall patterns of condom use, respondents who had casual sex reported on their most recent sexual encounter with a casual partner. 10 women provided such information.

Of the women who had casual sex, all 10 had vaginal or anal intercourse on their last occasion with a casual partner. Seven of these women said their partner on this occasion was HIV negative, with the other three reporting that they didn't know their partner's status. Six women reported using condoms with their partner, while three said they didn't. Of those that didn't use a condom, one woman reported having sex with a male and one with a female.

Respondents who indicated that they knew their partners' HIV status were asked how they knew. Six women said that their partner told them their status.

### **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 for women are shown in full in Table 41. The majority of these items are about the negative effects of HIV on people's sexual lives. This is not to suggest that the sexual lives of positive people are inherently problematic, but rather, given the community consultations and our qualitative research, it is recognition that these issues are those that are most in need of policy and programmatic response. They are also issues that need to be discussed within affected communities and we hope that this material may facilitate public debate.

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

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, under a quarter of the women (23.5%) said they would, over a half (57.4%) said they would not, and the remainder (19.1%) said that they did not know. Women were significantly more likely than men to disagree with this statement. Among the women those in sero-concordant relationships agreed more with this statement than both those in sero-discordant relationships and those not in regular relationships. One critical issue for women is the impact that HIV has on the potential to develop new relationships. Half (50.9%) of the women agreed with the statement *Few people would want a relationship with someone who has HIV*.

A similar response was found to the statement *I am afraid of telling potential partners of my HIV status in case they reject me*. Over half of the women (59.3%) agreed with this statement. When asked to respond to the statement *Being HIV positive has helped me form more satisfying relationships*, three-fifths (61.4%) disagreed, while 9.5% said they were uncertain.

Concerns about transmission of the virus to others and reinfection were apparent in the responses to the next six items. Most women (70.0%) agreed with the statement *I am afraid of infecting my partner, or potential partner, with HIV*, while very few agreed with the statements *I*

feel more confident about unprotected sex because of the new treatments, and *Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV*. Similarly, the impact of potential vaccines on intentions to practice safe sex and anxiety about safe sex is minimal with 15.6% agreeing with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*, and 12.6% agreeing with the statement *Knowing that a vaccine will become available makes me less anxious about sex*. Women were significantly more likely to disagree with the former statement than men. The response to concerns about re-infection was mixed, with 27.6% agreeing that *I am concerned about becoming infected with another strain of HIV* and 63.6% disagreeing. Men were more likely to agree with this statement than women.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the women (59.3%) agreed with the statement *HIV has had a negative effect on my sexual pleasure*. One third (34.2%) disagreed with this statement. When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. One in three (31.7%) were unsure when asked to respond to the statement *If I know that my partner is HIV positive I find sex more pleasurable*. More women disagreed with this statement (49.0%) than agreed with it (19.3%). Men were significantly more likely to agree with this statement than women. Among women those in sero-concordant regular relationships agreed with this statement than the rest of the women. One quarter (26.6%) said that they agreed with the statement *I have stopped having sex because of my HIV status* while 52.0% agreed that *HIV has negatively affected my libido*.

*I know you can have a relationship somebody and have sex, and all the rest if it and do it safely. But there's still that underlying thing in the back of your mind. I have actually a couple of times rung an escort agency ... The first time I rang, I just asked the about the price and she said a hundred and eighty. And the second time I rang I said, 'And what about if someone was HIV positive?' and she said 'Oh, I'd have to talk to the boys about that and get back to you'. To whether they would or not, and I just never rung back. So I mean I've thought about it.*

*Allison, 38, diagnosed 1996*

**Table 41 Women's 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	18.7	38.7	13.1	10.4	19.1
Few people would want a relationship with someone who has HIV	12.3	30.9	36.6	14.3	6.0
I am afraid of telling potential partners of my HIV status in case they reject me	14.9	16.5	49.7	9.6	9.2
Being HIV positive has helped me form more satisfying relationships	25.7	35.7	20.7	8.4	9.5
I am afraid of infecting my partner, or potential partner, with HIV	7.6	20.7	44.3	25.7	1.8
I feel more confident about unprotected sex because of the new treatments	57.4	28.2	7.3	1.3	5.8
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	34.4	39.3	13.3	5.4	7.5
If there was a vaccine which prevents HIV, I would not practise safe sex	36.9	34.0	12.5	3.1	13.5
Knowing that a vaccine will become available makes me less anxious about sex	25.7	40.1	12.6	.0	21.6
I am concerned about becoming infected with another strain of HIV	18.0	45.6	19.1	8.5	8.8
HIV has had a negative effect on my sexual pleasure	12.0	24.2	29.0	30.3	4.5
If I know that my partner is HIV positive I find sex more pleasurable	21.2	27.8	8.4	10.9	31.7
I have stopped having sex because of my HIV status	32.4	39.3	18.4	8.2	1.6
HIV has negatively affected my libido	17.6	21.1	31.7	20.3	9.3

## **RECREATIONAL DRUG USE**

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### **Summary:**

Alcohol is the most commonly used drug by women (82.8%), while 42.2% use tobacco. Most women (80.5%) reported that they had never injected illegal drugs, and of the 14 women who had only two had done so in the last 12 months. Of the women who reported injecting drugs, none had shared injecting equipment in the past twelve months.

A small number of women (11.1%) reported having missed a dose of ARV at some point as a result of using illegal drugs and 5.2% reported having had a bad experience as a result of using both illegal drugs and ARV. Women were significantly less likely than men to use recreational drugs.

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### **Practices**

Respondents were asked about their use of a range of non-prescription drugs, both those legally available and those that are currently prohibited in Australia. Respondents were asked which of a list of substances they had used in the last twelve months. For those drugs which are commonly injected, differentiation was made between injection and other means of administration. Table 42 gives these results for women and men. As can be seen from these data, alcohol is the most commonly used drug, followed by tobacco and marijuana. Women were significantly less likely than men to report using marijuana, non-injected speed, ecstasy, LSD/trips, amyl and Viagra.

**Table 42 Use of recreational use of drugs in the last 12 months by female and male respondents (percentages)**

	<b>Women</b>	<b>Men</b>
Alcohol	82.8	81.1
Cigarettes	42.2	55.8
Marijuana	36.3	55.2
Methadone (prescribed)	6.6	2.4
Ecstasy	5.9	27.6
Cocaine (not injected)	3.9	11.3
Speed (injected)	3.3	12.6
Speed (not injected)	2.9	17.6
Heroin (injected)	2.5	3.5
Amyl	1.0	40.2
Homebake	1.0	2.8
Methadone (non-prescribed)	1.0	0.6
Cocaine (injected)	0.9	2.8
Heroin (not injected)	-	0.3
LSD/trips	-	9.2
Steroids (injected)	-	6.5
GHB/GBH/Fantasy	-	4.5
Viagra or similar	-	21.9

It must be noted that we only asked respondents if they had used each of the drugs in the previous twelve months, not how often they use them. Use of many drugs is occasional rather than regular and this may inflate the rates reported here. The study also deliberately sampled among injecting drug users.

Very few women (5.2%) reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs. Eleven percent women reported that they had missed a dose of antiretroviral medication at some point as a result of using illegal drugs.

Most of the women (80.5%) reported that they had never injected illegal drugs. Of the 14 women who had injected illegal drugs approximately only two had done so in the last 12

months. Of the women who reported injecting drugs, none had shared injecting equipment in the past twelve months.

### Attitudes Relating to Drug Use

Around 16% of the women felt that they drank more alcohol than they would like to and 12.3% felt they had used more illegal drugs than they would like to. As specific quantities of drugs used were not asked in this survey, this is not necessarily a measure of substance abuse, but rather gives an indication that there are important areas of health maintenance among women 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 women who have shared needles is reflected in the *not applicable* responses to these items.

**Table 43 Attitudes relating to drug use and infection (percentage of all women)**

	Strongly disagree	Disagree	Agree	Strongly agree	Not applicable
I drink more alcohol than I would like to <sup>a</sup>	34.3	25.2	11.2	4.4	24.9
I use illegal drugs more than I would like to <sup>b</sup>	20.6	15.1	5.7	6.6	52.1
Sharing needles is not a problem if your viral load is undetectable <sup>c</sup>	49.0	6.7	.0	2.3	42.0
I worry about infecting others by sharing needles <sup>d</sup>	4.8	.0	2.9	8.8	83.5

a: N=75, b: N=75, c: N=75, d: N=75

*I have small goals, but I know it can only get better. From my past it can only get better. Staying clean, that's a feat on its own, but having quality in my life and staying clean and having a few good friends. Because I've had some really disastrous things happen in the past two years that if it hadn't for the centre, I would have been – they sort of like mothered me – I would have been totally lost.*

*Rachel, 46, diagnosed 1994*

*Well since I've become a lot more sure of myself, who I am, my place in the world [HIV has] become a stronger part of my life. But then ... I've got to hide that from my neighbours, and that's been a very hard thing to deal with at the moment, especially because [my husband's] deteriorating and before moving here, a year ago, we were very public. We were asked to do more media stuff for this World AIDS Day and we had to say no. On one hand I feel desperate for my neighbours to know so we can just get it out of the way, but we made a conscious decision when we moved here to not tell the neighbours, to protect our daughter, Sarah. So on one hand I want them to know just to get it out of the way but then I'm terrified of the impact on Sarah. I mean I don't give a shit about what they say about me or anything. I mean, I guess I do because this is the first time I've been truly happy, or truly happy in a home ... so I don't want my home threatened in any way. So trying to hide that part is very difficult when it is a very big part of my life.*

*Debbie, 25, diagnosed 1991*

## ACCOMMODATION

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### Summary:

Two thirds of women either own or are purchasing their house or flat (30.7%) or are in private rental accommodation (33.0%). One fifth of women (19.9%) live in public rental accommodation.

More than half (53.6%) of women live with children, 38.5% live with their partner or spouse and 66.0% said they live with pets. One quarter of women (25.4%) live by themselves. Most women (70.8%) said that their accommodation was suitable for their current needs. However, 52.6% had changed their accommodation as a result of having HIV/AIDS and 11.7% had done so in the last two years.

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### Current Accommodation

The current type of accommodation of the respondents can be seen in Table 44. Similar numbers of women are currently in accommodation that they own or rent through the private system. A smaller number of women are in public rental accommodation.

**Table 44 Current accommodation of women (percentage of all women)**

Accommodation type	Number	Percentage
Own or purchasing house or flat	22	30.7
Private rental accommodation	24	33.0
Public rental accommodation	15	19.9
Rent-free	2	2.4
Community housing/housing co-operative	5	6.9
Other	5	6.9

N=73

Households varied considerably. One quarter of the women (24.5%) lived by themselves, while the remainder lived with between 1 and seven other adults (mean=1.1, median=1) and with between 0 and five children (mean=1.1, median=1). Over one third (38.5%) lived with a partner or spouse, and more than half (53.6%) of women live with children of which 42.5% lived with

dependant children. These children ranged in age from infants to 32 years (mean=9.7, median=9).

Most women lived in a residence with three bedrooms (48.5%), while the remainder had two bedrooms (30.6%), four or more bedrooms (16.8%) and one bedroom (4.1%),.

Two thirds of the women (66.0%) also lived with pets. The most common pets were dogs (43.0%), and cats (32.9%). Other companion animals included fish, birds and farm animals.

Most women (89.8%) had access to a car. When asked how easy it was to access public transportation, 11.7% said it was very difficult, 26.0% difficult, 47.1% easy and 15.3% very easy.

Around two thirds of women (70.8%) stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (22), the main reasons given were that it was too small (8), was too expensive (7), and lacked privacy (7).

**Table 45 Reasons women’s current accommodation is unsuitable**

<b>Reason</b>	<b>Number</b>
Too small	8
Too expensive	7
Lack of privacy	7
Inadequate for current state of health	5
Harassment	4
Other	4
Confidentiality problems	3
Too far from health services	2
Too far from other services	2
Poor condition of housing	2
Fear of violence	2
Inadequate facilities for carers	1

N=22 (Multiple responses possible)

**Changes in Accommodation**

Participants were asked if they had ever changed their accommodation as a result of having HIV/AIDS. About half of the women (52.6%) had, and 11.7% had done so in the last two years. The median number of times women had changed their accommodation ever as a result of HIV/AIDS was twice.

We asked what the circumstances were around the women's last change in accommodation. The results are shown in Table 46. Financial and health issues figured most prominently in response to this question. Of those who had moved in the last two years, the most common reason given was moving to cheaper housing (13) followed by moving to a quieter moving closer to health services (11) and illness (10).

**Table 46** **Reasons for women changing accommodation**

	<b>Number</b>
Moved to cheaper housing	13
Moved closer to health services	11
Illness	10
Moved to a quieter location	6
Ending of long term relationship	6
Moved closer to friends	5
Moved closer to other services	5
To avoid harassment	5
Moved in with family	4
Looking for/ returned to work	4
Stopped working	4
Lack of privacy	4
Planning for illness	3
Better health	2
Improved finances	1
Moved out of family home	1
Beginning of new relationship	1

(Multiple responses possible) N=40

 See also accommodation and discrimination page 116

**EMPLOYMENT**

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

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**Summary:**

Slightly more than one half of the women (50.5%) are currently in paid employment, with almost two-thirds of this number being in part-time work (32.1%). The majority of the remainder described themselves as either doing home duties (16.1%) or as unemployed (15.3%). Compared with working men, women who worked were more likely to be in part time employment (63.5% versus 41.5%).

Most women said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis. Antiretroviral therapy also had an affect on women's employment with 13.2% anticipating a longer time in the workforce. Smaller numbers said they had stopped work due to ARV (8.6%), were considering going back to work (4.3%) or have gone back to work (4.3 %).

Around a third of the women that had ever worked reported that they have stopped work at some time in the past for reasons relating to having HIV/AIDS. Low energy levels and psychological ill-health were the most commonly cited reasons for this, followed by poor physical health.

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

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

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

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### Employment Status

Just over half the women were currently employed, with more being in part time work than those in full time work. The remainder tend to describe themselves as either performing home duties (16.1%) or as unemployed (15.3%). Compared with working men, women who worked were more likely to be in part time employment (63.5% versus 41.5%). Of those who are working, the mean number of hours worked by these women is 29.7 (median=29). Those working full time work an average of 41.6 hours per week (median=40) and those in part time employment work an average of 22.8 hours/week (median=20). Those who are not working stopped work between three months and 14 years ago (mean=55.3 months, median=36 months).

**Table 47 Employment status of women**

	<b>Percentage</b>
Working part time	32.1
Working full time	18.4
Home duties	16.1
Unemployed	15.3
Not working/ retired	7.9
Other	5.9
Student	4.3

N=73

### Impact of HIV and Treatment on Employment

We asked respondents how their HIV diagnosis affected their career plans and how their plans had changed since then. These data are shown in Table 48 below. Women most commonly reported that there has been no change.

**Table 48 Impact of HIV diagnosis on career plans (percentage of all women)**

	Diagnosis <sup>a</sup>	Subsequent experience <sup>b</sup>
There has been no change	29.9	36.8
More difficult to plan for future	26.4	14.0
A career is no longer as important	14.2	13.3
Career ended/stopped work	11.9	13.3
Changed careers	10.9	20.3
Less likely to change careers	6.7	2.4

a: N=73, b: N=71

We asked about the impact of antiretroviral therapy on respondents' career plans (see Table 49 below). Of those women that have used antiretrovirals, the most common response was that this had not affected their plans. The relationship between commencement of antiretroviral therapy and health status may explain the fact that 8.6% said that they stopped work when they commenced ARV, while 13.2% said that they anticipated a longer time in the workforce.

**Table 49 Impact of antiretroviral therapy on work for women**

	Number	Percentage
There has been no change	22	31.3
Not used antiretrovirals	13	18.1
Anticipate longer time in work force	9	13.2
Stopped work	6	8.6
Made new career plan	4	6.2
Considered going back to work	3	4.3
Went back to work	3	4.3
Considered new career plan	2	2.6
Considered stopping work	0	0.7

N=69

### Interruptions to Employment

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those women who have worked, 33.6% had stopped work for reasons related to HIV at some point. These work interruptions averaged 32.0 months. The circumstances relating to the most recent interruption to employment are given in Table 50 below. The most common response

was that psychological health (stress, depression or anxiety) and diminished energy levels had played important roles in the decision. Over one third also cited poor health.

**Table 50** **Circumstance surrounding last interruption to employment**

	<b>Number</b>
Stress/ depression/ anxiety	12
Low energy levels	12
Poor health	8
To have more time to self	5
Expecting illness in future	3
To move to different location	3
To care for someone with HIV	1
Retrenched/ sacked	1

N=22 (Multiple responses possible)

Of those women who stopped working at some point, 59.8% had returned to work. This was most commonly due to better psychological health (see Table 51), although the need to perform meaningful tasks, financial reasons, and better physical health were also important.

**Table 51** **Reasons for returning to work**

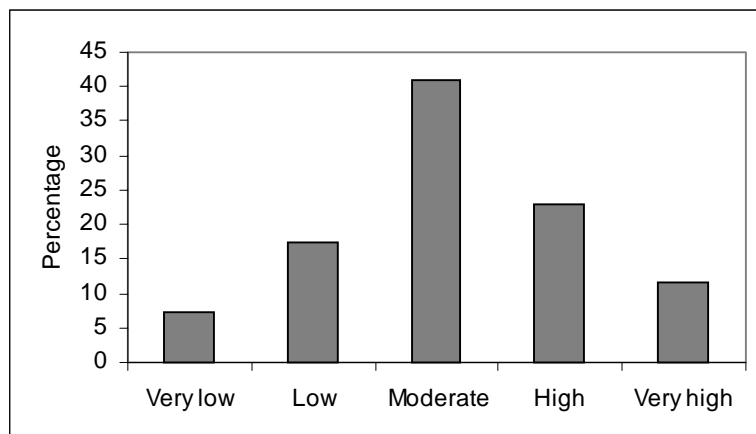
	<b>Number</b>
Better psychological health	10
To have something to do	9
Financial reasons	8
To do something worthwhile	8
Better physical health	7
Possibility of part-time work	7
To have more social contact	7
Possibility of flexible working hours	6
Possibility of full-time work	1

N=13 (Multiple responses possible)

**Those Currently in Paid Employment**

Respondents were asked about the level of stress in their current job. Two-fifths of the women rated the stress level as moderate (41.0%) while 23.1% said it was high and 11.6% said it was very high. Only 7.1% rated the stress level as very low and 17.3% said there was low stress (see Figure 20).

**Figure 20 Stress at work**



N=38

Confidentiality in the workplace remains a critical and complex issue for positive people, particularly given ongoing experiences of discrimination. When asked what difficulties women experience around confidentiality at work, most said that they have no problems or that they do not attempt to keep their status confidential (see Table 52). Of those who do experience difficulties, the greatest problem appears to be issues around explaining absences from work, followed by gossip.

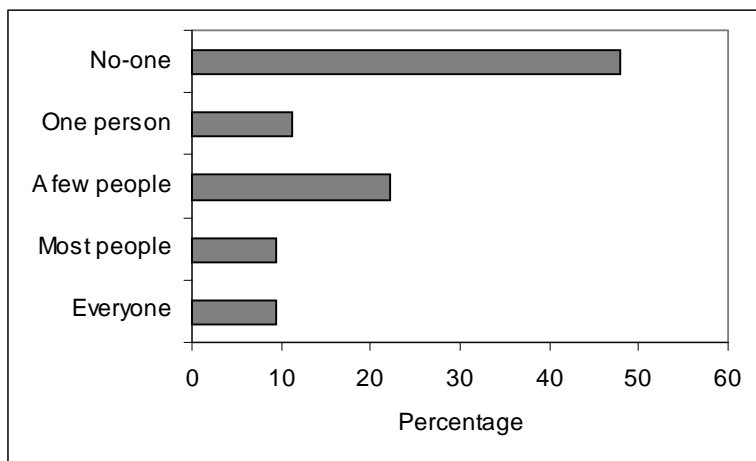
**Table 52 Difficulties with HIV status confidentiality in the workplace.**

	<b>Number</b>
No problems	22
I do not try to keep my status confidential	9
Explaining absences from work	5
Gossip	4
Difficulty keeping and taking medication	1
Visible signs of illness	1

N=37 (Multiple responses possible)

When asked how many people in their workplace know that they are HIV positive, 9.4% of the women said that everyone knows, 9.3% said most people know, 22.2% said a few people know, 11.2% said one person knows and 47.9% said no-one knows (see Figure 21).

**Figure 21 Disclosure in workplace**



N=36

When asked about the impact that HIV has on their capacity to perform their work duties, over half of the women said that their work was unaffected (see Table 53). Over a third (36.7%) said that they tire more quickly, and one quarter said that they work reduced hours (25.3%).

**Table 53 Impact of HIV on work capacity**

	Number
Not affected by HIV	20
I tire more quickly	13
I work reduced hours	9
I have difficulty concentrating	5
I cannot always go to work	1
I am less productive	1
I do different duties	0

N=37 (Multiple responses possible)

Living with HIV often involves intermittent periods of ill health, particularly around treatment changes and the need to access health and other services, often only available during work hours (Prestage et al. 2001). Respondents were asked how much flexibility their workplace

gives them to take time off for reasons relating to HIV. Most women had the capacity to take time off for medical appointments (see Table 54) and illness. There was less capacity to take time off for counselling and few had much capacity to take time off to engage in volunteer work.

**Table 54 Capacity within workplace for HIV related interruptions**

	Never	Seldom	Sometimes	Often	Always
For medical appointments <sup>a</sup>	14.4	.0	15.9	11.6	58.1
For counselling <sup>b</sup>	35.2	2.9	21.7	4.9	35.3
When you are sick <sup>c</sup>	8.8	6.1	14.4	18.5	52.2
To do volunteer work <sup>d</sup>	49.8	9.6	16.3	1.8	22.5

a: N=33, b: N=32, c: N=25, d: N=25

**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 47.9% of the women said they did. Of these, over a third (36.9%) said they planned to start or return to work and a similar proportion (39.3%) said they wanted to change the type of work that they do (see Table 55). Importantly, 16.4% say they want to reduce the hours they work.

**Table 55 Plans for changes to work life and anticipated difficulty**

	Number	Difficulty		
		Not at all	Somewhat	Very
I want to change the type of work I do	12	0	10	2
I want to start/ return to work	12	1	5	6
I want to reduce my work hours	6	1	4	1
I want to increase my work hours	2	0	1	1
I want to stop work	1	0	1	0
Other changes	9	3	5	2

N=35 (Multiple responses possible)

The main incentive for changes in work arrangements were financial and to do something worthwhile (see Table 56). Among those women who intended to increase the amount of work they did (either increase their hours or start/return to work), the primary motivations were also financial and to do something worthwhile, as well as to have something to do and have more social contact. Among those that wanted to decrease the amount of work they did (either reduce their hours or stop work altogether), the most common reasons were to reduce stress and to enjoy better physical health. Among those that wanted to change the type of work they

do, the most common reasons for change were to reduce stress and financial reasons, followed by the desire to do something worthwhile and the possibility of flexible working hours.

**Table 56** Reasons for changes to work plans among all women and those intending to change their work arrangements (frequencies)

	Total <sup>a</sup>	More work <sup>b</sup>	Less work <sup>c</sup>	Different work <sup>d</sup>
Financial reasons	18	12	2	8
To do something worthwhile	18	8	2	6
To reduce stress	14	3	5	9
Possibility of flexible work hours	10	4	2	6
Better psychological health	9	5	2	4
To have more social contact	9	8	0	2
To have something to do	7	7	0	0
Possibility of working part-time	7	5	1	1
Better physical health	6	2	4	2
Worse physical health	2	0	1	0
Worse psychological health	2	1	0	1
Possibility of working full-time	1	1	0	1
To have less social contact	0	0	0	0

a: N=34, b: N=14, c: N=6, d: N=14

(Multiple responses possible)

**Leisure**

Respondents were asked how they spend their time while not working. Each respondent indicated the three activities that occupy most of their time. Over two thirds of the women indicated that housework occupies their time. Slightly fewer identified leisure activities (eg reading), while around half spend time with their children, other family members and close friends. Women are more likely than men to care for children and spend time with family as leisure activities and are less likely to spend time resting.

**Table 57** **Activities pursued while not working: percentage of all women**

	<b>Percentage</b>
Housework	67.2
Leisure activities	60.7
Spending time with family	52.2
Socialising with close friends	46.4
Resting	44.0
Looking after children	43.9
Volunteer work in other organisation	14.9
Socialising with other friends	14.6
Volunteer work in HIV/AIDS organisation	12.0
Socialising with HIV positive friends	10.9
Looking after another HIV positive person	6.6
N=72 (Multiple responses possible)	

*I was afraid of being found out at work. It was horrible to live in fear and it was only in the first year that I was diagnosed. I was working in a supermarket while I was studying and I was really afraid of people's reaction if they knew. It was horrible. I felt very lonely. So a job came up here and I decided to go with it. Because I wanted to be out about it. Be open. And I think anywhere else that I work now I would choose it so that I could be open. Also I'm more willing to be open now than I was then. I couldn't handle it then.*

*Narelle, 30, diagnosed 1997*

## **FINANCES**

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

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### **Summary:**

Around half of the women (50.7%) identified their main source of income as a government benefit or pension. The average weekly income for women was \$351.70. This was significantly lower than men's average weekly income (\$445.29).

More than half of women reported experiencing some difficulty with meeting the cost of daily living. Many women reported difficulty with paying for the following: clothing (83.1%), childcare (76.2%), utilities (75.2%), transport (70.3%), housing (59.9%), and food (54.9%).

One quarter of those women (6) on a government benefit had been assessed by a Commonwealth Medical Officer. While this resulted in a change in conditions for one woman and it caused distress for four of the six women assessed, no-one had their benefits terminated.

Forty percent of women are living below the poverty line. Paid employment did not exempt women from poverty with 27.0% who are earning an income from paid employment reporting incomes below the poverty line. However for those women on government benefits, 53.0% are living in poverty.

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**Income**

The source of income of the women is shown in Table 58 below. Around half have a government pension or benefit as their main source of income. Just over two-fifths of women were receiving a salary and 4.0% were supported by their partners.

**Table 58 Primary source of income: percentage of all women**

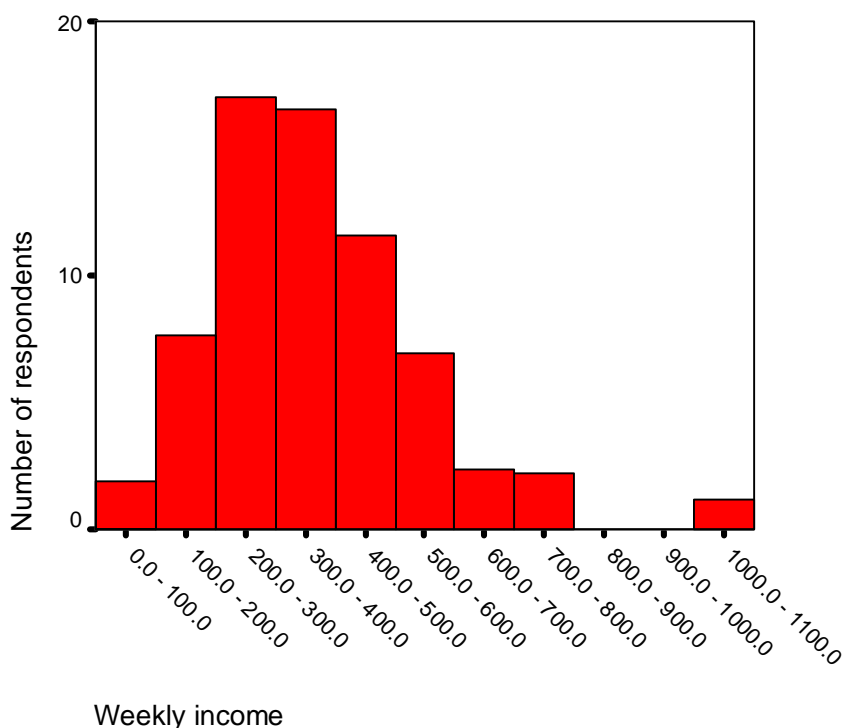
Source of income	Percentage
Benefits/ Pension/ Social security	50.7
Salary	42.0
Partner supports me	4.0
Other	1.7
Superannuation	1.6

N=72

The mean weekly income for women was \$351.70, and the median was \$330. The women's average income was significantly lower than that reported by the men (\$445.29). Figure 23 below gives the distribution of income in \$100 intervals. The peak of the distribution corresponds to the income that one is likely to receive on a government pension.

One quarter of women (25.4%) had a partner with whom they share financial resources. The partners' mean income was \$607.73 (median =\$400).

**Figure 22 Histogram of women’s weekly income after tax**



**Expenditure and Debts**

Respondents were asked their weekly expenditure on a range of items. Previous surveys have indicated that women had difficulty paying for some essentials and these items were included to document the extent of financial burden and to aid further in-depth analysis of the financial impact of HIV on positive people, particularly in light of the GST. The results for women are shown in Table 59. The total mean expenditure by women on medication was \$24 per week, with complementary therapies accounting for more than half the total. Mean rental or mortgage costs were \$135. Food and utilities accounted for around \$90 and \$59 respectively.

Very few women (6.9%) currently own their own home, while 12.7% have owned their own home in the past. Slightly more than one quarter (27.1%) are currently paying off their home. More than one third (39.4%) receive a rental subsidy averaging at \$50.03 per week.

 **See also Accommodation and Discrimination page 116**

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. For women, this averaged at \$15,835.79 with a median of \$700. Those who were currently paying off their home had a mean debt of \$44,020.84 while those who were not had a mean debt of \$4,924.94. Slightly over one-fifth (22.5%) had used the services of a financial counsellor in the last two years.

**Table 59 Weekly expenditure on medications and essentials (\$AU)**

	Mean \$	Median \$	Range \$
Rent/mortgage	135.18	103	0-850
Complementary therapies	13.97	0	0-120
Antiretroviral drugs	3.77	0	0-35
Other medication	5.93	0	0-50
Food	89.78	90	0-250
Utilities	59.39	48	0-300

N=68

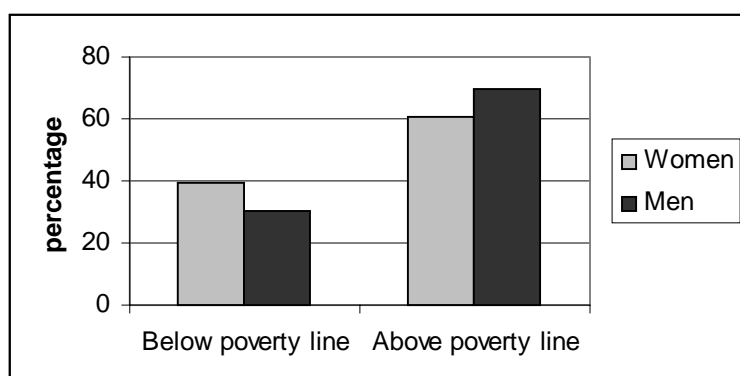
### Assessments of Benefits

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 six out of 23 women receiving a benefit had received such an assessment. When asked what this experience resulted in, one reported that there were changes to their benefits and one woman said the assessment had clarified her concerns. Four reported that it had caused them distress, however, it did not result in the termination of benefits for any of the women.

### Poverty

As with the previous HIV Futures surveys, we have used the quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR) to assess the extent of poverty among PLWHA. The Henderson Poverty lines are set for specific *income units*. These units include the individual, any partner with whom they share financial resources and any dependant children. We used the IAESR (2001) data for the September quarter (the time at which the survey was completed). According to this measure two-fifths of women (39.6%) were living below the poverty line (see figure 24).

**Figure 24: Poverty by gender**



**Correlates of Poverty**

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. Over half of those not in paid employment were living in poverty (see Table 60).

**Table 60 Poverty by employment status**

	Below poverty line	Above poverty line
In paid employment <sup>a</sup>	27.0	66.6
Not in paid employment <sup>b</sup>	53.0	33.4

a: N=25, b: N=39

Women who identified a salary as their primary source of income were significantly less likely to report an income below the poverty line, while those on a government benefit were more likely to be living in poverty (see Table 61).

**Table 61 Poverty by income source**

	Below poverty line	Above poverty line
Income from salary <sup>a</sup>	12.0	59.6
Income from government benefit <sup>b</sup>	83.2	34.4

a: N=25, b: N=39

Among women, there was no significant difference between those shared financial resources with a partner and those who didn't in levels of poverty (see Table 62).

**Table 62 Poverty by shared income status**

	<b>Below poverty line</b>	<b>Above poverty line</b>
Shared financial resources <sup>a</sup>	22.5	25.7
Sole income <sup>b</sup>	77.5	74.3

a: N=25, b: N=39

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

### **Costs**

As with previous surveys, we asked respondents about the difficulty they had paying for a range of activities, goods and services. The results are shown in Table 63 below, with the *not applicable* responses excluded from the calculation for each item. The items that most women rated as very difficult to pay for were quality of life costs like travel, sport, going out, and entertainment. Over three-quarters of women paying for child care reported some level of difficulty in doing so. Those items most likely to be rated as *not at all difficult* were support services and medication. Importantly almost half of those with child care needs rated these as very difficult, and substantial proportions rated food, clothing, utilities and rent as *very difficult*. The experience of difficulty in meeting the costs of these items was rarely restricted to one area. That is, when individuals had difficulty paying for food, they also experienced difficulties with rent, utilities and quality of life items. Women found it more difficult than men to pay for prescribed medicines other than antiretrovirals, medical services, complementary therapies, sport and clothing.

**Table 63** Difficulty paying costs of items and services

	Not at all difficult	A little difficult	Very difficult
Travel/ Holidays	9.6	30.6	59.8
Sport	24.8	17.8	57.4
Going out	21.0	24.0	55.0
Child care	23.8	27.3	48.9
Entertainment	19.8	35.4	44.8
Recreational drugs	14.1	41.4	44.5
Clothing	16.9	44.3	38.9
Complementary therapies	23.2	40.0	36.7
Medical services	40.9	30.0	29.1
Transport	29.7	41.8	28.4
Utilities	24.8	47.4	27.8
Rent/ Mortgage	40.1	35.2	24.6
Support services	46.9	32.0	21.1
Other prescribed medication	33.4	49.0	17.6
Food	45.1	40.0	14.9
Co-payments for medication for HIV/AIDS	47.5	38.0	14.5

When we examine the ratings of these items for those women above and below the poverty line, those living in poverty were more likely to rate most items as *very difficult* (see Table 64 below). When it comes to the basics of life, substantial numbers of those below the poverty line rated these as very difficult. There were significant differences in the ratings of difficulty between women above and below the poverty line for the costs of entertainment and going out. While the efforts of welfare and financial aid services in community organisations are clearly essential in addressing these needs, it remains a gross indictment of a wealthy society like Australia that people with HIV continue to suffer this level of privation.

**Table 64 Difficulty paying costs of items and services by poverty**

	Below poverty line			Above poverty line		
	Not at all difficult	A little difficult	Very difficult	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS	33.9	66.1	.0	55.1	11.2	33.8
Other prescribed medication	17.8	72.4	9.8	43.0	27.8	29.3
Medical services	33.5	34.3	32.2	42.7	22.0	35.3
Complementary therapies	16.9	49.8	33.2	27.4	25.8	46.8
Support services	27.6	47.4	25.0	51.3	25.1	23.6
Entertainment	3.3	21.8	74.8	26.2	45.7	28.1
Going out	3.5	23.2	73.3	29.2	28.2	42.6
Sport	11.3	11.6	77.1	32.8	22.3	44.9
Recreational drugs	.0	32.5	67.5	20.6	49.0	30.4
Travel/ Holidays	.0	28.4	71.6	16.1	32.9	51.0
Rent/ Mortgage	46.8	22.1	31.1	32.1	45.5	22.4
Utilities	21.0	46.7	32.4	23.9	46.2	29.9
Food	36.0	42.4	21.6	49.6	40.0	10.4
Clothing	3.3	42.4	54.3	27.1	41.2	31.7
Transport	21.2	43.0	35.7	38.0	36.0	25.9
Child care	.0	41.7	58.3	25.4	20.8	53.8

### **Poverty and Services**

When we examine the use of services at AIDS organisations in the last six months by those above and below the poverty line (see page 46 for the discussion of these services), we see that for most services, a greater proportion of those women below the poverty line have used these than those above (see Table 65). While the differences for some services are slight, we note the discrepancies for use of financial assistance, social contact with other PLWHA, respite care, legal advice, housing assistance, counselling, mental health services, internet access, transport and volunteer carers. When we examine use of services at other organisations, particularly notable are the greater proportions of those below the poverty line using counselling, financial assistance, respite care, legal advice, housing assistance, mental health services, internet access, transport and volunteer carers.

**Table 65 Services used at HIV/AIDS organisations by those women above and below the poverty line**

	Below poverty line <sup>1</sup>	Above poverty line <sup>2</sup>
Treatments advice	59.2	50.8
Counselling	54.5	21.9
Financial advice	10.7	8.0
Financial assistance	45.5	17.2
Peer support group	66.1	58.1
Informal peer support	40.9	45.1
Social contact with other PLWHA	61.8	49.1
Pharmacy services	21.9	23.2
Alternative therapies	29.8	20.2
Respite care	20.1	1.9
Legal advice	32.9	13.0
Housing assistance	22.1	11.7
Employment services	3.8	4.6
Return to work skills	3.0	1.5
Drug/alcohol treatment	.0	1.5
Mental health services	12.7	4.9
Library	16.7	17.0
Internet access	19.0	5.3
Transport	25.4	10.6
Treatments information	52.2	54.8
Volunteer carer	17.0	9.0
Paid carer	.0	1.5
Internet based information	12.1	11.3
Community education campaigns	11.6	20.5

1: N=39, 2: N=23

(Multiple responses possible)

**Table 66 Services used at other organisations by those above and below the poverty line**

	Below poverty line <sup>1</sup>	Above poverty line <sup>2</sup>
Treatments advice	22.2	28.9
Counselling	36.2	35.2
Financial advice	9.2	25.1
Financial assistance	29.8	17.3
Peer support group	7.9	7.8
Informal peer support	5.6	9.7
Social contact with other PLWHA	7.9	9.7
Pharmacy services	71.8	43.4
Alternative therapies	41.7	47.3
Respite care	5.0	3.7
Legal advice	18.3	19.7
Housing assistance	25.4	13.8
Employment services	21.3	13.1
Return to work skills	10.3	7.3
Drug/alcohol treatment	8.2	4.1
Mental health services	23.0	16.5
Library	50.2	42.7
Internet access	42.1	45.4
Transport	26.6	19.0
Treatments information	25.3	29.1
Volunteer carer	11.2	6.9
Paid carer	6.7	7.5
Internet based information	29.5	19.1
Community education campaigns	3.0	7.8

1: N=39, 2:N=23

(Multiple responses possible)

*My daughter's told a couple of her friends. But I've told her that it's okay to tell your friends but you've got to realise that there may come a time when these kids may go home and tell their parents and their parents will freak out because they won't realise that you don't have it. And they might they tell their kids not to play with you because of it.*

*Catherine, 31, diagnosed 1990*

## **DISCRIMINATION**

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### **Summary:**

A small number of women (12.5%) had experienced less favourable treatment in relation to accommodation. Three of these 10 women reported having experienced such discrimination in the last two years.

More than half of the women (58.1%) had experienced less favourable treatment because of HIV in relation to health services, 34.7% in the last two years.

More than one third of women (37.5%) co-infected with hepatitis C had experienced less favourable treatment because of their hepatitis C in relation to health services. Three women said this had occurred in the last two years.

A small number of women (14.0%) had also experienced less favourable treatment in relation to insurance, with three of the six women who specified when this happened reporting that it was in the last two years.

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

### **Accommodation**

Ten women (12.5%) indicated that they had experienced less favourable treatment in relation to accommodation (three in the last two years). Of those that had experienced discrimination, three were currently living in private rental accommodation, two in public rental accommodation, two in cooperative housing, one woman owned or was purchasing her own accommodation, and two had other arrangements.

## Health Services

### HIV

More than half of the women (58.1%) had experienced less-favourable treatment at a medical service as a result of having HIV. More than one in three of the women (34.7%) had experienced such discrimination in the last two years.

When asked what form this discrimination took, the most common responses were confidentiality problems (62.3%) at the medical service, followed by avoidance by health care providers (36.9%) and additional infection control measures implemented by health care providers (36.4%). These experiences are shown in Table 67. Among those that had been discriminated against at medical services, women were significantly more likely than men to report this had taken the form of confidentiality problems.

**Table 67 Form of HIV-related discrimination experienced at medical service (percentage of those women experiencing discrimination)**

	Percentage
Confidentiality problems	62.3
Avoidance	36.9
Additional infection control measures	36.4
Being treated last	30.1
Other	21.1
Refusal of treatment	18.9
Being rushed through	16.4
Harassment	9.4
Abuse	7.9
N=43 (Multiple responses possible)	

### Hepatitis C

Six out of 16 of hepatitis C co-infected women had experienced less-favourable treatment at a medical service as a result of having hepatitis C. This included three who had experienced such discrimination in the last two years.

When asked what form this discrimination took, the most common responses were confidentiality problems followed by avoidance, being placed last in the treatment queue or

being given additional infection control measures to other clients. These experiences are shown in Table 68.

**Table 68 Form of hepatitis C-related discrimination experienced at medical service (percentage of those women experiencing discrimination)**

	Number
Confidentiality problems	5
Avoidance	4
Being treated last	4
Additional infection control measures	4
Harassment	1
Refusal of treatment	1
N=6 (Multiple responses possible)	

### Insurance

One fifth (21.3%) of the women currently had private health insurance and 8.8% currently had some other form of income or mortgage insurance.

A small number of women (14.0%) indicated that they had experienced less favourable treatment in relation to insurance. Three out of the six women that specified the year that this occurred reported it had happened within the last two years



## CONCLUDING COMMENTS

*Juggling with HIV* provides an overview of the health and social status of women living with HIV in Australia. The data presented in this report suggest that some of the previously noted differences between men and women in relation to antiretroviral uptake and attitude are gradually declining. Whilst women still express caution about the safety of antiretroviral treatments, they are no longer significantly less likely to be using treatments. Caution should be exercised when interpreting this change because the Futures sample is not a cohort. Possible explanation for this change is that two-thirds of the women in this sample have been diagnosed HIV positive for eight years or more and around one fifth have CD4/T-cell counts indicative of severe immune system damage and high viral loads. This means that women's attitudes to treatments may not have changed but their experience of living with HIV has worsened to the extent that they no longer have the choice to avoid treatments.

Co-infection with hepatitis C remains a significant health concern for more than one fifth of women in this sample and their particular health concerns need to be taken into account for appropriate health care.

Other differences between men and women are still prevalent. In particular, the importance of child bearing and child rearing remains at the forefront of many women's lives. More than half of the women in the HIV Futures 3 survey are mothers and the importance of this role in the lives of these women cannot be overemphasised. In addition, a number of women are still considering having children in the future and with this in mind it is noteworthy that around one in six women still felt they lacked information about having a child as a positive woman.

Some of the experiences of the women in this report are indicative of the gender inequalities that exist not just for positive women but for all women. HIV positive women continue to experience poverty at unacceptable levels. Poverty remains a significant barrier to health and well-being and the impact of poverty needs to be considered beyond the narrow context of personal finances.

This report highlights the experiences of positive women and acknowledges both the differences and similarities between women and men living with HIV in Australia. We hope that this report can assist all health care professionals whose work contributes to the care of people living with HIV/AIDS. Finally we acknowledge the tireless contribution of the positive people in Australia and the organisations who represent and serve them in assisting the *Living with HIV Program* in the conduct of this research.

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