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# **HIV Futures 3 Regional Reports: New South Wales**

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## **INTRODUCTION**

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

This report is one of a series that provides an analysis of a sub-population of the HIV Futures 3 respondents. The set of reports presenting data specific to individual Australian states are intended as an aid to local planning, and as an acknowledgement of the local differences in policy, services and history. While there are some differences between the states, it is also important to recognise the many similarities and the common purpose that these can build.

HIV Futures aims to reflect the socio-economic, political, pharmaceutical, legislative, and geographic contexts of living with HIV. It complements behavioural surveillance, epidemiology, analyses of treatment practices, care and support, and specific social and clinical interventions and provides the opportunity for community organisations, service providers, professionals, policy makers and individual positive people to reflect on the complexity of the experiences of PLWHA and to tailor their practices to meet current and emerging needs.

## **INSTRUMENT AND METHOD**

### **The Survey instrument**

A detailed description of the design of the survey instrument can be found in the main community report HIV Futures 3: Positive Australians on Services, Health and Well-being. In brief, 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.

### **Recruitment and Sampling**

A full description of the recruitment and sampling for the study can be found in the main community report HIV Futures 3: Positive Australians on Services, Health and Well-being. 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.

### **Weighting**

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

### **Analysis**

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

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. 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.

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 PEOPLE WHO COMPLETED THE SURVEY

The survey was completed by 894 respondents. This sample represents 6% of all PLWHA in Australia. Respondents ages ranged from 20 to 77 years (median = 42 years, mean = 42.9 years). The average number of years since respondents first tested HIV seropositive for 10.0 years. The results relating to the total sample are reported in the document HIV Futures 3: Positive Australians on Services, Health and Well-Being (Grierson, Misson, McDonald, Pitts & O'Brien 2002).

Four hundred and forty PLWHA from NSW completed the HIV Futures Survey. The number of NSW respondents is significantly fewer than would have been expected in a representative sample of PLWHA in Australia. However the sampling procedure was designed to include large numbers of PLWHA from states other than New South Wales and Victoria. We are grateful for the assistance provided by the AIDS Council of New South Wales (ACON), Mark Bebbington at ACON, ACON Community Support Network, ACON Women's project, ACON Hunter, ACON Illawarra, ACON Northern Rivers, ACON Western Sydney, Albion Street Centre, Bigge Park Centre, Bligh Street Clinic, Blue Mountains PLWHA Centre, Bobby Goldsmith Foundation, Central Coast Area Health Service, Central Sydney Area Health Service, Coffs Harbour Sexual Health Centre - Ralph Waldsax, Far West Area Health Service, Foley House, Gender Centre, Grafton Community Health Centre, HIV Prevention – Ryde, Hume Phoenix Inc., Illawarra Area Health Service, John Hunter Hospital, Kempsey Community Health Centre, Karumah Day Centre, Livingstone Road Clinic, Luncheon Club AIDS Support Group, Macquarie Area Health Service, Mid-Western Public Health Unit, Mid North Coast Area Health Service - Robert Baldwin, Moruya Community Health Centre, New England Area Health Service, New South Wales Department of Health, New South Wales Users and AIDS Association (NUAA), North AIDS, Northern Rivers Area Health Service, Northern Sydney Health, Options Employment Service, Parramatta Sexual Health Centre, Positive Living Centre, Positive Support Network, People Living with HIV/AIDS - PLWHA (NSW), Pozhet West, Positive Employment Service, Positive Heterosexuals - David Barton, St George Sexual Health Centre, SMASH Project, South Eastern Sydney Area Health Service, South Western Sydney Area Health Service, Southern Health Service, Sydney Sexual Health Centre, Talkabout, Town and Country MIA Gay + Lesbian Support Service, Wentworth Area Health Service, Western Sydney Area Health Service, Wollongong HIV Prevention Service, Peter de Ruyter, and Paul Burr.

We would also like to thank our colleagues at the NCHECR and NCHSR on the positive Health Study for assistance with recruitment, particularly to Garrett Prestage.

The sample from NSW contained 96% males and 4% females. This is a significantly greater proportion of males than the sample from the other states combined. The ages of the NSW respondents ranged from 23 years to 70 years. The average age for NSW PLWHA was 43.9 years, significantly older than the rest of the sample. On average, PLWHA living in NSW had been HIV seropositive for 10.5 years - a significantly longer time to that reported by PLWHA from other States (mean=9.5 years).

The vast majority of respondents had been infected with HIV through sexual contact: 85% cited homosexual or bisexual contact as the most likely transmission route and 6% cited heterosexual contact, while 3% reported injecting drug use, 2% reported homosexual/bisexual contact and injecting drug use, 1% were infected by blood products or in a health care setting, and less than 1% were people with haemophilia infected through contaminated blood products. Compared to PLWHA living in other states, NSW PLWHA were significantly more likely to report homosexual or bisexual sex as their mode of infection, and significantly less likely to report haemophilia as their mode of infection.

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.

## MAJOR FINDINGS

The results reported below compare PLWHA from NSW with PLWHA from other states of Australia combined, i.e. the rest of the sample minus the NSW respondents.

### Current health

Most respondents reported that they currently feel healthy: 22% said that their health is “*excellent*”, 48% said that their health is “*good*”, 26% said that their health is “*fair*”, and 3% said that their health is “*poor*”. When asked about their well being 18% described it as “*excellent*”, 46% as “*good*”, 31% as “*fair*” and 5% as “*poor*”. Twenty-one percent of the respondents from NSW have been diagnosed with an AIDS-defining illness - a similar proportion to that reported by PLWHA from the other states combined.

Respondents were asked about their experiences around testing positive for HIV. Nineteen percent of NSW PLWHA reported receiving pre-test counselling, most commonly provided by a doctor (55% of those receiving such counselling), a counsellor/psychologist (13%), a nurse (11%) or an employee of an AIDS organisation (7%). Almost all (92%) of these PLWHA were happy with the information they received from this counselling, while 82% were happy with the support they received. These proportions are similar to those reported by PLWHA from other parts of Australia.

Fifty-one percent of NSW PLWHA reported receiving post-test counselling, again most commonly provided by a doctor (37% of those receiving such counselling), a counsellor/psychologist (24%), a social worker (8%), an AIDS organisation employee (8%) or a nurse (7%). Most (78%) of these PLWHA were happy with the information they received from this counselling, while 77% were happy with the support they received. These proportions are similar to those reported by the rest of the sample.

Thirty-seven percent of respondents from NSW have a major health condition other than HIV/AIDS - a similar proportion to the 40% reported by PLWHA from other States. The most frequently cited “other” health conditions included cardiovascular disease, diabetes, hepatitis B, hepatitis C, and asthma.

One quarter (25%) of respondents from NSW reported having been diagnosed with a mental health condition – a similar proportion reported by respondents from other states. Most (80%) of these respondents had been diagnosed with depression, with anxiety and panic attacks (15%) and post traumatic stress disorder (9%) being the next most common diagnoses. Around a third



(29%) of respondents are on medication for anxiety, 29% for depression, and 4% are on anti-psychotic medication.

Around one in three (35%) PLWHA from NSW have had hepatitis A, and a similar proportion (37%) had been diagnosed with hepatitis B. Both these proportions are significantly greater than those reported by PLWHA in other states. Over half the respondents (53%) had been vaccinated against hepatitis B and 45% had been vaccinated against hepatitis A. Sixty-one percent of NSW PLWHA have been tested for hepatitis C: 41% have had an anti-body test; 5% have had a diagnostic PCR test; and 21% reported that they didn't know what type of test they had. NSW PLWHA had significantly less commonly reported having had a test than PLWHA in other states. Eleven percent of respondents from NSW indicated that they had been diagnosed with hepatitis C, with 12% of these reporting that they had subsequently tested negative on a PCR test.

NSW respondents with hepatitis C reported that they were diagnosed on average in 1994, significantly later than PLWHA from other states, but were infected on average in 1989, which was similar to coinfected respondents in other states. They most commonly reported becoming hepatitis C positive through IDU (49%), but also reported becoming positive through sex (27%), blood products (9%) or both receiving blood products and engaging in IDU (2%). Eleven percent reported they were unsure how they caught hepatitis C.

Almost all (96%) of NSW respondents with hepatitis C have taken a liver function test, and 23% have had a liver biopsy. Only 5% reported having taken either interferon monotherapy or interferon and ribavirin combination therapy. About a quarter (29%) said they had experienced symptoms of hepatitis C, while a further 17% said they were unsure about this. Fatigue and nausea were the most common symptoms reported. Over a third (35%) of coinfected NSW respondents felt that HIV community services didn't meet their needs as someone with both HIV and hepatitis C, most commonly due to a poor understanding of hepatitis C (48% of those who felt their needs weren't being met).

Almost all NSW respondents reported having taken a CD4/T-cell test (99%), and 98% have taken a viral load test. The results of respondents' most recent CD4/T-cell tests and viral load tests are displayed in Table 1 (below). Not shown in Table 1 is the finding that 6% of NSW PLWHA have a CD4/T-cell count below 250 and a viral load above 10,000.

**Table 1 Results of serological testing**

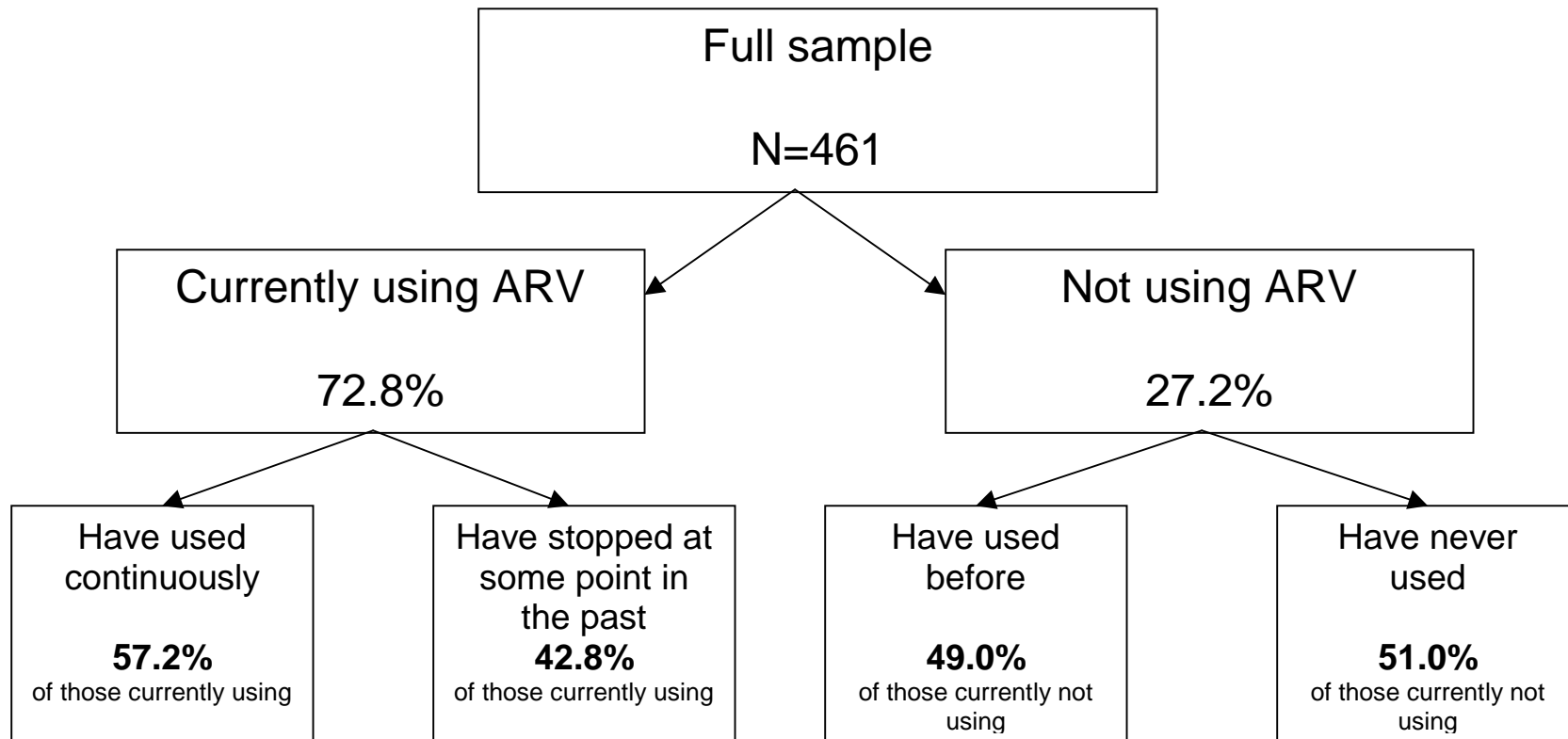
<b>Description</b>	<b>Result</b>	<b>Percentage</b>
<b>CD4/T-cell count</b>	<b>cells/ml blood</b>	
little or no immune damage	over 500	46
moderate immune damage	250 – 499	35
severe immune damage	below 250	19
<b>Viral load</b>	<b>copies/ml blood</b>	
below detectable level	below 500	56
low	500 - 9,999	15
moderate	10,000 - 49,999	15
high	over 50,000	14

Almost a quarter (24%) of NSW respondents have had a viral resistance test, with 70% of these having their most recent viral resistance test in 2001. For NSW respondents who had taken a viral resistance test, 74% reported that their most recent test found resistance to a drug with 62% of these reporting that they changed medications due to this result. Of this proportion 54% reported that their viral load decreased and 52% reported that their CD4/T-cell count increased.

#### **Antiretroviral treatments for HIV/AIDS**

Figure 1 shows the uptake of antiretroviral treatment for NSW PLWHA. Almost nine out of ten (86%) of NSW PLWHA have taken antiretroviral drugs at some stage, with 73% using them currently. These figures are similar to those for PLWHA from other states. Of those PLWHA from NSW who are currently taking antiretrovirals 42% report that their health has improved, 16% report that their health has stayed the same, 38% that it fluctuated, and 4% that it has deteriorated, while 41% said their well-being improved, 16% that it stayed the same, 38% that it fluctuated and 5% that it had deteriorated.

**Figure 1: The uptake of antiretroviral drugs**



Under half (42%) of the PLWHA from NSW who use antiretroviral drugs reported that they experience side-effects from these drugs - a similar figure to that reported by PLWHA in other States. The most commonly reported side-effects from antiretroviral drugs are: diarrhoea (experienced by 48% of NSW PLWHA who experience side effects of antiretroviral drugs), nausea (27%), lipodystrophy (19%), fatigue/lethargy (15%) and neuropathy (10%).

Three quarters (72%) of NSW PLWHA who use antiretrovirals report difficulties in taking this medication. The most common difficulties among these respondents are remembering to take drugs on time (63%), carrying medication (46%), organising meals around medication (38%) and taking medication in public (38%). NSW PLWHA find taking a carrying and transporting medication a problem significantly more commonly than PLWHA in other areas.

Eleven percent of NSW PLWHA missed at least one dose on the day before they filled out the survey, with a similar proportion (11%) missing a dose the day before that. Only 4% missed a dose on both days.

Forty-three percent of NSW PLWHA currently on antiretrovirals have taken a break from antiretrovirals at some stage, a similar proportion to that for other states. On average, these breaks started 23 months ago and lasted for 140 days. Most NSW PLWHA (77%) considered this break to be a short-term one, with 17% saying it was long-term and 6% that it was a cycle or pulse break. Just under half (48%) of those respondents that had taken a break gave lifestyle reasons for their most recent break. The most common lifestyle reasons for treatment breaks were the desire to clean out the system (14% of those who took a break), taking treatments at the right time being too difficult (12%) and the treatments not suiting the respondent's lifestyle (9%). Fifty-nine percent of those NSW respondents who had taken a break from antiretroviral therapy had clinical reasons for their most recent break. Most common among these were side effects (30% of those who took a break), a doctor's recommendation (23%) and drug resistance (12%).

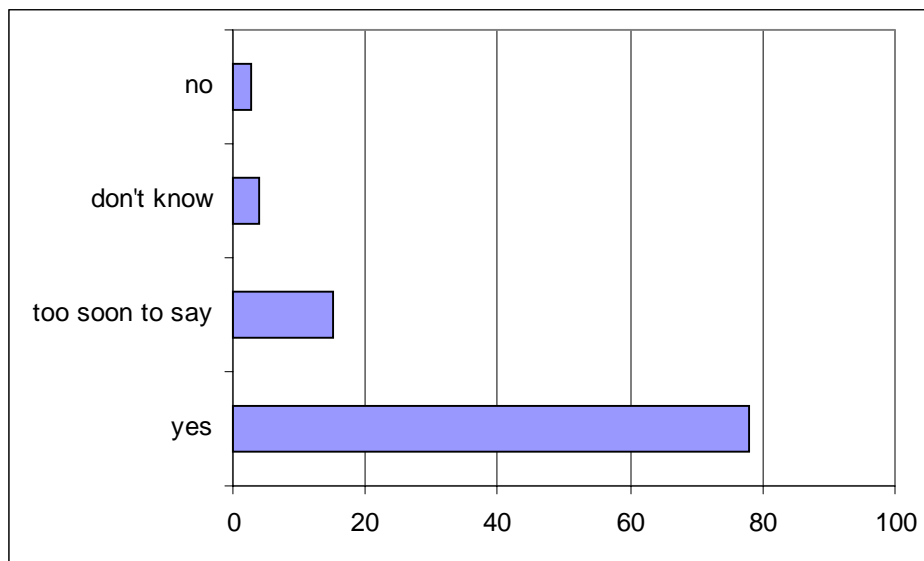
Almost two-thirds (65%) of NSW current antiretroviral users who had taken a break talked to a doctor about it before this break, while 68% saw a doctor during the break and 84% talked to their doctor after their break. The outcome of these breaks can be seen in Table 2. The impact of treatments break on the health and well being of NSW respondents was quite mixed, but the proportions of respondents who reported a decreased CD4/T-cell count and an increased viral load both exceeded 50%.

**Table 2 Percentage reporting various outcomes of treatment break**

	Stayed same	Improved	Fluctuated	Deteriorated
<b>Health <sup>a</sup></b>	36	22	20	21
<b>Well-being <sup>b</sup></b>	37	31	20	13
	Stayed same	Increased	Fluctuated	Decreased
<b>Viral load <sup>c</sup></b>	17	62	14	7
<b>CD4 <sup>d</sup></b>	26	6	12	56

a: N=138; b: N=137; c: N=126; d: N=130

NSW PLWHA are generally slightly more enthusiastic about the efficacy of new medications compared with PLWHA in other states. Compared with PLWHA from other states, PLWHA from NSW disagree significantly more strongly with the statement *Combination antiretroviral drugs are ineffective*. Figure 2 (below) shows that most (78%) of NSW PLWHA agree that antiretroviral drugs have improved the prospects of most PLWHA, while 3% believe they haven't improved the prospects of PLWHA, 4% do not know and 15% believe it is too soon to tell.

**Figure 2 Opinions of NSW respondents on whether antiretrovirals have improved the prospects of PLWHA**

Those NSW PLWHA who are currently using combination therapy have done so for an average of 4 years and 11 months. The mean number of combinations they have tried in this time is 3.6, with a mean of 1.6 of these having been used in the past 12 months. They started on these therapies when their viral load was high (log mean = 54638 copies/ml) and their CD4 count was low (mean = 236.5). The most common circumstances surrounding the commencement of combination therapy for these respondents were doctors advice (78%), a drop in CD4 count (38%), new drugs becoming available (37%), hearing of the effectiveness of the treatment (29%) and becoming very ill (27%).

Among those who have tried more than one combination, the most common reasons for changing the last time they did so were: side effects (56%), resistance to their combination having developed (19%) and the combination they were changing from was not working (18%). Most PLWHA from NSW felt they still had options left – 27% reporting they have many options, 27% a few, 7% one and 5% none. However, there was some uncertainty on this issue, with 33% reporting that they weren't sure how many combinations they had left.

Those NSW PLWHA who have stopped using antiretrovirals had been using them for an average of 3 years and 1 month and had stopped an average of 1 year and 6 months ago. They have used on average 3.1 combinations. Of the NSW PLWHA who had taken antiretrovirals and stopped, only 25% reported that their health improved on the medication, 15% reported that it stayed the same, 48% that it fluctuated and 12% that it deteriorated. Twenty-one percent of these respondents reported that their well-being improved while they were on antiretroviral medications, 15% reported that it stayed the same, 36% that it fluctuated and 28% that it deteriorated. Two fifths (41%) of NSW respondents that had stopped using antiretrovirals reported lifestyle reasons for doing so. The most common lifestyle reason given by these respondents was the desire to clean out their system and taking drugs at the right time was too difficult (10% of all NSW ex-antiretroviral users each). Two-thirds (67%) had clinical reasons for stopping treatment. The most common of these were side effects (33% of all NSW ex-antiretroviral users), a doctor's recommendation (26%) and drug resistance having developed (13%). Over three quarters (78%) of ex-antiretroviral users from NSW talked to their doctor before they stopped taking antiretrovirals, and almost all (97%) had talked to their doctor since stopping treatment. The outcomes of stopping treatment for these respondents can be seen in Table 3. Respondents most commonly reported their health and well-being had improved, but their clinical markers had gotten worse.

**Table 3 Percentage reporting various outcomes of stopping treatment**

	Stayed same	Improved	Fluctuated	Deteriorated
<b>Health<sup>a</sup></b>	29	49	15	7
<b>Well-being<sup>b</sup></b>	22	55	21	2
	Stayed same	Increased	Fluctuated	Decreased
<b>Viral load<sup>c</sup></b>	12	53	24	11
<b>CD4<sup>d</sup></b>	20	19	30	32

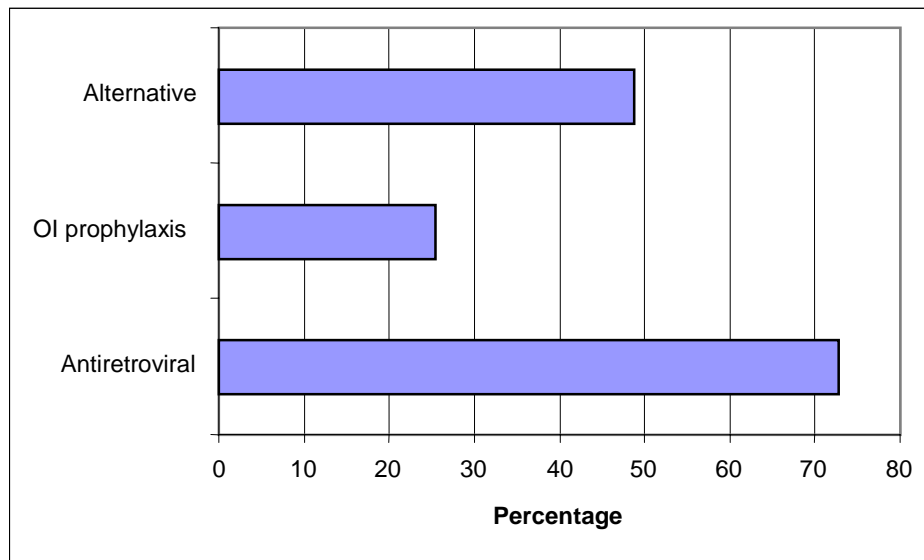
a: N=59; b: N=58; c: N=57; d: N=57

Of all NSW PLWHA not currently taking antiretroviral medications, 94% reported that they would consider taking them in the future. The most common circumstances which the PLWHA report might make them start antiretrovirals are a significant drop in CD4/T-cell count (81%), becoming very ill (76%), a significant rise in viral load (72%), hospitalisation due to HIV-related infections (63%) or on a doctor's advice (63%). These figures are similar to those reported by PLWHA in other states.

### Other treatments for HIV/AIDS

Figure 3 (below) shows that while the majority of NSW PLWHA use antiretroviral drugs, just under half use alternative therapies and one in four (25%) of the respondents from NSW use prophylaxis for opportunistic infections (OI) - prophylaxis for *Pneumocystis carinii* pneumonia (PCP) and/or prophylaxis for other opportunistic infections. The most commonly used complementary/alternative therapies are vitamin/mineral supplements (75% of NSW PLWHA who use alternative therapies), massage (48%) and marijuana (36%).

**Figure 3 Use of therapies for HIV/AIDS**



Attitudes toward alternative therapies were measured on a scale from 1 to 4, where higher scores indicate more favourable attitudes. Generally, NSW PLWHA had favourable attitudes toward alternative therapies (mean = 2.7). PLWHA from NSW had similar attitudes toward alternative therapies as PLWHA from other states (mean = 2.8).

### Information and support services

Over two thirds of NSW respondents (69%) have direct contact with an HIV/AIDS-related organisation. This is a similar proportion to that found among PLWHA in the rest of the country. Of those NSW PLWHA in contact with HIV/AIDS organisations, 69% receive a newsletter, 56% are clients, 44% are members, 24% are volunteers and 15% are staff. NSW PLWHA who are in contact with AIDS organisations are significantly less likely to be members and receive newsletters than such respondents from other states. Of those PLWHA in the NSW sample who do not have contact with an HIV/AIDS organisation the most common reasons given are not wanting to be involved (60%) and not having time (32%). No access to transport was a reason not to have contact with a PLWHA organisation for significantly more respondents in rural NSW

(36%) compared with those from Sydney (4%). Sixty-four percent of NSW PLWHA who have contact with an HIV/AIDS-related organisation have contact with the ACON, 37% have contact with the PLWHA (NSW) and 22% have contact with the Bobby Goldsmith Foundation. Among PLWHA from NSW there was no relationship between having contact with the ACON and having an AIDS-defining illness, or living in an urban area as opposed to a regional centre or rural area.

**Table 4 Percentage using services provided by HIV/AIDS-related and other organisations**

Service	HIV/AIDS Organisation	Other service organisation
Treatments advice	45	22
Treatments information	39	15
Social contact with other PLWHA	32	10
Counselling	30	21
Peer support group	26	5
Pharmacy services	22	41
Financial assistance	22	14
Legal advice	20	14
Alternative therapies	18	28
Informal peer support	15	9
Housing assistance	14	22
Community education campaigns	13	4
Financial advice	13	17
Volunteer carer	11	3
Mental health services	9	19
Internet based information	7	15
Return to work skills	7	9
Employment services	6	15
Transport	6	17
Internet access	5	24
Library	4	20
Respite care	4	5
Drug/alcohol treatment	3	8
Paid carer	2	3

Table 4 (above) displays the proportion of NSW PLWHA who use each of the services provided by HIV/AIDS-related organisations. The data show that PLWHA use HIV/AIDS-related organisations for a wide range of services. PLWHA most commonly use these organisations for treatments advice and information, social contact, and counselling. PLWHA from NSW are significantly more likely than PLWHA from other states to report that they make use of return-to-work skills education provided by HIV/AIDS organisations. They are also significantly less likely to use HIV/AIDS organisations for alternative therapies, library services, internet access, transport, respite care, peer support groups, informal peer support and social contact with other PLWHA. Additionally, NSW PLWHA use volunteer carers from non-AIDS organisations less frequently than PLWHA from other states. PLWHA from rural regions in NSW are significantly more likely to use treatments advice, peer support groups and internet based information provided by HIV/AIDS organisations than PLWHA from Sydney. They were also more likely to use mental health services provided by other organisations.



Respondents were asked to indicate which people and/or organisations they rely upon for information about treatments for HIV/AIDS, HIV management and living with HIV. Their responses are shown in the Table 5. The most commonly cited source of information about treatments for HIV/AIDS was a HIV GP/S100 Prescriber. S100 prescribers were also most commonly cited (49%) as the *most* important source of information – a significantly higher proportion than that reported by PLWHA in other states. However, significant proportions rely on HIV/AIDS-related newspapers and magazines, outpatient HIV specialists, publications from HIV/AIDS organisations and the gay press, which suggests that PLWHA seek information from a range of different sources. NSW PLWHA were less likely to cite non-public health nurses, sexual health services and treatments officers as sources of treatments information. PLWHA from rural NSW were significantly more likely to cite a sexual health service as a source of information on treatments than PLWHA from Sydney, and were less likely to cite the gay press.

Respondents cited similar sources of information as being important for HIV management as they cited for treatments information (see Table 5). The most commonly cited source of information about HIV management was a HIV GP/S100 Prescriber. S100 prescribers were also most commonly cited (41%) as the *most* important source of information. Again, significant proportions rely on HIV/AIDS-related newspapers and magazines, publications from HIV/AIDS organisations, outpatient HIV specialists and the gay press. NSW PLWHA were more likely than other PLWHA to cite the HIV GP/S100 prescribers as an important source of information on HIV management. They were less likely to cite peer support officers and treatments officers. PLWHA from rural NSW were significantly more likely to cite a sexual health service as a source of information on HIV management than PLWHA from Sydney.

Table 5 also displays the responses of PLWHA to questions they were asked about whom they rely on for information about living with HIV/AIDS. The sources of information about living with HIV/AIDS most frequently cited as being important were HIV magazines and newspapers, HIV positive friends, publications from HIV/AIDS groups and the gay press. When asked about the *most* important source of information the respondents had on living with HIV/AIDS the most common responses were a HIV GP/S100 prescriber (21%), HIV positive friends (17%), HIV magazines or newspapers (13%) and outpatient HIV specialists (11%). PLWHA from NSW were significantly less likely than PLWHA from other parts of Australia to report non-public health nurses and treatments officers as important sources of information about living with HIV/AIDS. Rural PLWHA in NSW were also significantly less likely to use a dietician as a source of information on this topic than PLWHA from Sydney, and were more likely to cite a sexual health service.

PLWHA from NSW were also significantly less likely to cite positive women's organisations and the Haemophilia Foundation as sources of all three categories of information and positive heterosexuals' groups on treatments information. They were also more likely to cite the gay press as a source of information on treatments and living with HIV/AIDS. These differences can be explained by the smaller numbers of women, haemophiliacs and heterosexual men in the NSW sample, and the larger proportion of gay men.

**Table 5 Percentage reporting sources of information as important**

Information source	Source of information about:		
	Treatments	HIV Management	Living with HIV/AIDS
HIV GP/S100 Prescriber	67	59	36
Other GP	13	14	8
Outpatient HIV specialist	46	39	23
Inpatient HIV specialist	7	6	5
Other doctor	7	7	5
Public Health Nurse	8	10	8
Other nurse	1	3	2
Pharmacist	16	6	5
Alternative therapist	13	14	18
Dietician	8	13	17
Dentist	8	11	9
Peer support officer	6	7	12
Sexual health service	11	11	14
Family Planning Association	1	2	1
Sex worker organisation	1	1	2
Treatments officer	14	8	7
Other HIV/AIDS organisation staff	12	14	17
Positive women's organisation	1	2	2
Positive heterosexuals' group	3	4	5
Injecting drug user's organisation	2	2	2
Haemophilia Foundation	0	1	1
HIV positive friends	27	30	43
Other friends	6	6	18
Partner/lover	12	12	22
Family	4	5	13
Gay press	42	35	40
HIV magazine/newspaper	47	45	46
Liver specialist	2	1	3
Hep C Support Group/Organisation	4	3	1
Internet	20	16	15
Publications from HIV/AIDS groups	40	40	41
Publications from other sources	7	6	7

The HIV-related publications most read by NSW PLWHAs are gay newspapers (74%), Talkabout (72%), Positive Living (48%), With Complements (36%), the HIV Herald (29%), gay magazines (24%) and newsletters from community organisations (21%). Sydney PLWHA were significantly more likely to read the gay press than PLWHA from rural NSW.

We asked respondents whether they thought lack of information made it difficult to make decisions about various issues surrounding living with HIV. NSW respondents most felt a lack of information when making decisions on taking a break from antiretrovirals (28%), managing antiretroviral side effects (27%), changing antiretroviral drugs (23%), financial planning (22%) and employment (21%). People from NSW less commonly reported lacking information on whether to have children or not than PLWHA from other states.

In the last 6 months the health services that NSW PLWHA had most commonly used were an HIV GP/S100 prescriber (62%), an HIV specialist at an outpatient clinic (45%), a dentist (42%) and a non-S100 prescribing GP (34%). NSW PLWHA were more likely to have gone to an HIV GP/S100 prescriber than PLWHA from other states, and were less likely to have seen an HIV specialist as an inpatient and to have attended an HIV peer support group. PLWHA from Sydney were more likely to have seen an HIV GP/S100 prescriber than PLWHA from rural NSW, and were less likely to have seen a non-S100 prescribing GP, a doctor at a sexual health centre or an AIDS organisation support worker. Seventy percent of NSW PLWHA who currently use antiretrovirals have to go to more than one place to get all their prescriptions filled, a larger proportion to that for PLWHA in other states (60%).

Ninety-five percent of NSW PLWHA know other PLWHA - a similar proportion to that found among respondents from other states. Respondents were asked to indicate how much of their free time they spend with other HIV seropositive people. The results in Table 6 (below) show that many NSW PLWHA spend no free time with other positive people, although over half spend "some" or "a lot" of time with other positive people. Twenty-seven percent of NSW PLWHA has been involved in the care or nursing of another PLWHA within the last two years - a similar proportion to that found among respondents from other states.

**Table 6 Amount of free time spent with other HIV positive people**

Amount of free time	Percentage
None	18
A little	34
Some	32
A lot	16

Only 2% of respondents from NSW have not disclosed their HIV status to anyone. Approximately one half (51%) have had their HIV status disclosed when they didn't want it to be (27% in the last two years). NSW PLWHA most commonly reported that this disclosure came from acquaintances (32% of those reporting unwanted disclosure), close friends (27%) and work colleagues (20%). Respondents were asked to rate the amount of support they received from people with different relationships to them on a scale of 1 ('a lot') to 4 ('none'). PLWHA from NSW received the most support from their partners (mean=1.32), their doctors (mean=1.67) and their pets (mean=1.69).

PLWHA from NSW (mean=2.81) reported receiving significantly less support from PLWHA groups than those from other states (mean=2.50).

Items were included in the questionnaire to assess respondents' levels of depression (from the Beck Depression Inventory), body image and the meaning of HIV in their lives. The results from NSW respondents can be seen in Table 7 (below). There were no differences between PLWHA from NSW and those from the other states on these items. We can look at the number of the items from the Beck Depression Inventory (the first four items in the table) the respondents either agreed or strongly agreed with as a way of measuring the extent of depressive symptoms. Among NSW PLWHA 44% agreed or strongly agreed with none of these items, 21% with one item, 17% with two, 9% with three and 9% with all four. Agreement with all four items is suggestive of clinical depression. Most NSW respondents had a negative body image. Under half (48%) of the respondents agreed or strongly agreed that they were happy with the way their body looks, and 56% agreed or strongly agreed that changes in their bodies due to HIV/AIDS had made them sexually unattractive. Respondents tend to minimise the impact of HIV on their lives. Just under half (49%) report that they do prefer to think about HIV even when they are well, and only 45% felt that their life had become more meaningful since they were diagnosed with HIV.

**Table 7 Attitudes to mental health among the NSW sample (percentage)**

	<b>strongly agree</b>	<b>agree</b>	<b>disagree</b>	<b>strongly disagree</b>
I cry or feel like crying all the time	5	16	46	33
I don't enjoy things the way I used to	16	33	33	17
I have lost interest in other people	8	24	46	23
I don't feel it's worth going on	4	13	35	49
As long as I'm well I prefer not think about HIV/AIDS	13	38	43	6
Life has become more meaningful since I became HIV positive	14	30	37	18
I am happy with the way my body looks	10	39	40	12
Changes in my body due to HIV/AIDS have made me feel sexually unattractive	21	34	31	13

### **Planning for the future**

Respondents were asked to indicate how far into the future they plan when making major decisions about their future. Table 8 (below) shows the responses given by PLWHA from NSW. Over a third (36%) of NSW PLWHA have changed how far they plan into the future in the last two years, of whom 57% had started planning for a longer time frame. Among NSW respondents who now use a longer time frame when planning for the future, the most commonly cited reason for the change was improved health due to new treatments (38%). Among all respondents who now use a shorter time frame when planning for the future, the most commonly cited reason for the change was declining health (36%).

**Table 8 Time frame use by PLWHA when planning for the future**

Time frame used	Percentage
One day at a time	20
A few months ahead	29
1 year ahead	22
2 years ahead	17
10 or more years ahead	12

### Sexual Relationships

Respondents were asked to describe their sexual orientation or sexual identity. The majority of respondents were homosexual men (85%), bisexual men (3%) and women (1%), heterosexual men (6%) and women (4%). There was also another 2% who had other sexual orientations.

When asked to describe their current sexual relationships, 23% reported that they are not currently sexually active, while 32% reported that they only have casual sex, 20% have sex in a monogamous regular relationship, and 25% have sex in a non-monogamous regular relationship. PLWHA from NSW were significantly less likely to be monogamous relationships.

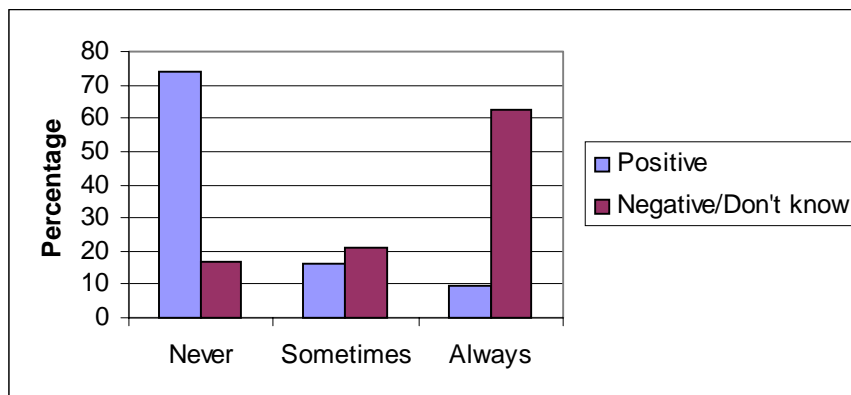
Forty-five percent of respondents who have a regular relationship are in a seroconcordant relationship - the remainder (55%) are in a relationship with an HIV seronegative partner, or a partner whose serostatus is unknown. All but two (99%) of the respondents who are in a regular relationship have told their partner that they are HIV seropositive. Respondents were asked to indicate when they told their partner that they are HIV seropositive. Respondents commonly told their partner when they found out (25%) or that their partner already knew they were HIV positive when they started the relationship (41%). Of the remainder, 70% told their partner at the start of the relationship, 10% within a few days, 13% within a few weeks, 7% within a few months, while 1% took more than a year. Respondents were also asked how their partner reacted when they told them that they are HIV seropositive. Most respondents (53%) said that it did not make any difference. Over one half (54%) of respondents reported that their partner was very supportive, and 33% said that they became closer, while 18% said that their partner was worried or scared and 4% said that their partner was angry. PLWHA from NSW were significantly less likely than PLWHA from other states to report that their partner was worried or scared. When asked about their own reactions to the disclosure to their partner, 48% reported that they were relieved, 37% that they became closer, 34% that they were worried, 27% that it did not make a difference and 7% that they were angry. These proportions are similar to those reported by PLWHA in other states.

When asked about their patterns of condom use during sex with regular partners in the 6 months prior to completing the survey, 35% reported that they always used a condom, 23% reported that

they sometimes used a condom, and 42% reported that they never used a condom. These proportions are similar to those reported by PLWHA from other States.

A significant association was found between partner HIV serostatus and consistency of condom use. Compared to respondents whose partner is seronegative or whose HIV serostatus is unknown, respondents whose partner is also seropositive were significantly more likely to never use condoms and significantly less likely to sometimes or always use condoms (see Figure 4).

**Figure 4 Patterns of condom use with regular partners**



When asked about their patterns of condom use during sex with casual partners in the 6 months prior to completing the survey, 39% reported that they always used a condom, 52% reported that they sometimes used a condom, and 10% never used a condom. These proportions are similar to those reported by PLWHA from other states. Small numbers meant that it was not possible to analyse the relationship between casual partner serostatus and consistency of condom use for the NSW respondents. However, when the whole sample was analysed, it was found that respondents were more likely to use condoms with HIV negative partners (or partners of unknown serostatus) than with an HIV positive partner.

Respondents were also asked about their most recent sexual contact with a casual partner. For NSW PLWHAs, almost all (98%) of these sexual contacts were with male partners, and the majority (77%) involved vaginal or anal intercourse. The respondents most often didn't know the HIV status of their partners (63%); of the rest 22% were known to be positive and 15% were known to be negative. Almost all (91%) NSW respondents who knew their partners status did so because their partner disclosed this information. Amongst those who engaged in vaginal or anal intercourse, 61% of NSW PLWHA used a condom. A condom was used significantly more often when the respondent was not sure of their partners HIV status or knew them to be negative.

Detailed analyses of sexual behaviour and condom use are reported in the document [HIV Futures 3: Positive Australians on Services, Health and Well-Being](#) (Grierson et al, 2002).

### Recreational drug use

Table 9 shows the rate of use of non-prescription drugs of NSW PLWHA. NSW PLWHA used steroids and GHB more commonly than PLWHA from the other states combined. Sydney PLWHA also had used speed (not injected), cocaine (not injected), ecstasy, amyl and viagra in significantly greater proportions than both PLWHA from rural NSW and PLWHA from outside NSW. PLWHA from Sydney had also more commonly injected heroin than PLWHA from rural NSW. However, most PLWHA from NSW were not concerned with the amount of drugs they took. Eighty-one percent either disagreed or strongly disagreed with the statement that they use more illegal drugs than they would like, and 80% disagreed or strongly disagreed that they drink more alcohol than they would like. Less than one in four (24%) reported ever missing a dose of antiretrovirals due to the use of illegal drugs.

**Table 9 Use of non-prescription drugs**

	Percentage of sample using in last 12 months
Alcohol	82.7
Marijuana	58.7
Cigarettes	53.4
Amyl	44.3
Ecstasy	33.0
Viagra or similar	23.9
Speed (not injected)	22.0
Cocaine (not injected)	15.2
Speed (injected)	12.1
LSD/trips	8.9
Steroids (injected)	8.8
GHB/GBH/Fantasy	6.3
Cocaine (injected)	3.6
Homebake	3.1
Methadone (prescribed)	2.3
Heroin (injected)	2.0
Methadone (non-prescribed)	0.2
Heroin (not injected)	0.1

### Housing

The majority (80%) of NSW respondents live in Sydney, while 10% live in a regional centre or town, and 9% live in a rural area. These proportions are similar to those for other states.

Table 10 (below) shows that while many NSW PLWHA own their home or are buying their own home, half are living in rental accommodation, while a small number live rent-free or in community housing. Compared to PLWHA from other states, NSW PLWHA were significantly more likely to live in private rental accommodation and were less likely to live in public rental

accommodation. The vast majority (83%) of NSW respondents believe that their current housing is suitable for their needs, a significantly greater proportion than that reported by PLWHA from other states. Forty percent of NSW PLWHA have changed their accommodation as a result of having HIV/AIDS. Among these the most common reasons for change were moving to a quieter location (35%), moving closer to health services (30%), and moving to cheaper housing (30%). Respondents from NSW were less likely to say they moved to cheaper housing.

**Table 10 Accommodation in which PLWHA live**

<b>Accommodation Type</b>	<b>Percentage</b>
Own or purchasing own house or flat	32
Private rental accommodation	44
Public rental accommodation	11
Live rent-free	5
Community housing	4

When asked whom they live with, 48% of NSW PLWHA reported that they live alone, 32% live with a sexual partner, 13% live with friends or housemates, 4% live with dependent children, and 5% live with other family members. Respondents from NSW are more likely than other PLWHA to live alone and less likely to live with dependent children.

### **Employment**

Over half (51%) of NSW PLWHA were not in paid employment at the time of completing the survey. Of the PLWHA who are working, 62% work full-time and 38% work part-time. Most NSW PLWHA (75%) report that being diagnosed HIV positive affected their career plans - 24% report that it was more difficult to plan, 20% report that they stopped work, 20% report that having a career was no longer as important, 9% changed careers because of their diagnosis and 2% report they were less likely to change their career. Since then 79% say HIV has affected their career plans – 26% reported that their career has ended, 20% that it is more difficult to plan, 18% that a career is no longer as important, 11% have changed careers and 5% are less likely to change careers. When asked the effect of antiretrovirals on their work plans, respondents most commonly said (31%) they haven't changed, while 13% reported that they stopped work, 11% that they anticipate a longer time in the workforce, and 11% that they haven't used antiretrovirals. One in five (18%) of NSW PLWHA report having been discriminated against at work as a result of having HIV/AIDS, with 6% reporting having been discriminated against at work in the last 2 years.

Fifty-seven percent of NSW PLWHA who have ever worked have stopped doing so at some stage due to their HIV diagnosis. These PLWHA stopped work for an average three years and eight months. The last time they stopped working the most common reasons were low energy (55%), stress or depression (55%) and poor health (53%). Rural PLWHA were significantly more likely than Sydney PLWHA to have stopped work due to moving to a new location. When asked



their HIV status at the time they stopped work, 41% reported they were HIV positive but had not been ill, 45% they were HIV positive and had been ill, and 14% that they had been diagnosed with an AIDS defining illness. When they were not working 67% received government benefits, a significantly smaller proportion than that reported in other states (78%). NSW PLWHA (18%) were significantly more likely to have lived off superannuation, annuities or savings than other PLWHA (7%) when they last stopped work. Over half (56%) of these PLWHA have returned to work. The most common reasons for returning to work were financial (78%), to do something worthwhile (46%), to have something to do (44%), better psychological health (43%) and better physical health (41%). NSW PLWHA were less likely than PLWHA from other states to have returned to work to have something to do and because of psychological health.

The 49% of NSW PLWHA who are presently employed work an average of 33.4 hours per week. Most (80%) report that their job involves a moderate to very high stress level. Forty-seven percent of NSW PLWHA who are working reported that their capacity to perform their work duties is affected by having HIV/AIDS: these respondents reported that they tire quickly, work fewer hours, or have difficulty concentrating. Seventy-one percent of workers reported that they could 'often' or 'always' get time off work for medical appointments, 55% for counselling, 81% for sick leave, and 31% for volunteer work.

Forty-four percent of NSW PLWHA indicated that they are considering changing their work arrangements. Of these, 46% want to change the type of work they do, 36% want to start or return to work, 22% want to reduce their hours, 8% want to increase their hours and 4% want to stop work. Most of the PLWHA who want to change their work arrangements perceived that this would be difficult: 32% believe it will be 'very difficult', 57% believe that it will be 'somewhat difficult' and 12% that it will be 'not at all' difficult.

## **Finances**

Given the large number of PLWHA in NSW who are not in paid employment, it is not surprising that 45% of respondents reported that their main source of income is a government benefit, pension, or social security payment. Forty-two percent of respondents reported that a salary is their main source of income, while 9% reported superannuation or an annuity as their main source of income. Just under half of the NSW respondents reported annual incomes below \$20,000. Respondents' incomes are displayed in Table 11 (below). The incomes of rural PLWHA and those of their partners or spouses were both significantly lower than for respondents from Sydney.

The poverty lines published by the Institute for Applied Economics and Social Research [IAESR] take into account an individual's income as well as whether or not they are in a relationship and the number of dependent children they have. The data for the June quarter of 2001 (IAESR, 2001) were used to calculate the proportion of PLWHA with incomes below the poverty threshold. Twenty-three percent of Sydney PLWHA and 39% of PLWHA from rural NSW were living below the poverty line. Poverty was significantly less common among Sydney PLWHA than rural NSW PLWHA and the rest of the sample, however poverty among all three groups is a significant concern.

**Table 11 Income reported by PLWHA**

<b>Weekly income</b>	<b>Yearly income</b>	<b>Percentage</b>
\$0 - \$150	\$0 - \$7800	3
\$151 - \$270	\$7801 - \$14040	33
\$271 - \$390	\$14041 - \$20280	11
\$391 - \$510	\$20281 - \$26520	18
\$511 - \$630	\$26521 - \$32760	12
\$631 - \$750	\$32761 - \$39000	7
\$751 -	\$39001 -	16

Respondents were asked a series of questions which assessed how difficult it is for them to meet the costs of living with HIV/AIDS. The results in Table 12 (below) demonstrate that while many PLWHA reported difficulties in meeting the costs of social activities such as entertainment and going out, a large proportion reported that it is very difficult for them to meet the costs of some of the "basics" of life such as housing, utilities, food, and clothing.

Particularly noteworthy is the finding that one in seven NSW PLWHA find it "very difficult" to meet the cost of food, and that a fifth find it "very difficult" to meet the cost of utilities (telephone, gas, electricity). It is also interesting to note one-fifth of the respondents who use complementary/alternative therapies find it very difficult to meet the cost of this treatment. Rural NSW PLWHA find it significantly harder than Sydney PLWHA and PLWHA from the rest of the country to pay for entertainment, and find it more difficult than PLWHA from Sydney to pay for going out, playing sport, travel, housing, clothing, and transport. PLWHA in Sydney have significantly less trouble than PLWHA from rural NSW and PLWHA from the rest of the country in paying for utilities, and significantly less trouble than PLWHA from the rest of the country in paying for transport.

**Table 12 Difficulties meeting the cost of living reported by PLWHA**  
(Percentage of respondents who use each item)

Item	Not difficult	A little difficult	Very difficult
Co-payment for medication for AIDS	66	26	8
Other prescribed medication	58	33	9
Medical services	58	23	18
Complementary therapies	45	33	22
Support services	69	19	12
Entertainment	33	34	33
Going out	32	32	36
Sport	44	31	25
Recreational drugs	33	33	33
Travel / holidays	22	26	53
Rent / mortgage / housing	43	37	20
Utilities (phone, gas, etc.)	39	41	19
Food	52	35	14
Clothing	38	34	29
Transport	54	32	13
Child care	28	30	42

### Discrimination

Over a third (35%) of NSW PLWHA had experienced less favourable treatment than other people when attending a medical service because of their HIV status, with 14% having experienced such discrimination in the last 2 years. PLWHA from rural NSW were significantly more likely to have experienced discrimination at a medical service at some time than those from Sydney. PLWHA from Sydney were less likely than PLWHA from states other than NSW to have experienced discrimination at a medical service in the last two years. When asked to describe what form this discrimination took respondents most commonly reported avoidance (37%), followed by confidentiality problems (35%), being treated last (30%), additional infection control (27%), refusal of treatment (26%), being rushed through (25%), harassment (12%), and abuse (6%).

Eleven percent of PLWHA from NSW had received less favourable treatment due to their HIV status in relation to accommodation, with 3% having this happen in the last 2 years. One in five (18%) of respondents in NSW had been discriminated against in relation to employment (6% in the last 2 years), and 22% had been discriminated against in relation to insurance (9% in the last two years).

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