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# **HIV Futures 3 Regional Reports: Western Australia**

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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 and a detailed methodology of the study are reported in the document HIV Futures 3: Positive Australians on Services, Health and Well-Being (Grierson, Misson, McDonald, Pitts & O'Brien 2002).

Sixty-three PLWHA from Western Australia completed the HIV Futures Survey. PLWHA from Western Australia have been deliberately over-sampled so that meaningful conclusions to be made about this group. We are grateful for the assistance provided by the following individuals and organisations who helped distribute the survey in Western Australia: AIDS Pastoral Care, Lindisfarne Medical Group, Social Work Department - Royal Perth Hospital, Western Australian AIDS Council (WAAC), Mark Reid at WAAC, WAAC Women's Project, Trudy Matthews, and Dr Ric Chaney.

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 Western Australia contained 87% males and 13% females. The ages of the Western Australian respondents ranged from 20 years to 77 years. The average age for Western Australian PLWHA was 39.7 years – significantly younger than PLWHA from other states (43.1). On average, PLWHA living in Western Australia had been HIV seropositive for 9.3 years.

The vast majority of respondents had been infected with HIV through sexual contact: 76% cited homosexual or bisexual contact as the most likely transmission route and 11% cited heterosexual contact, while 7% were people with haemophilia infected through contaminated blood products, 3% reported injecting drug use, 2% reported homosexual/bisexual contact and injecting drug use, 2% didn't know how they were infected.

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 Western Australia with PLWHA from other states of Australia combined, i.e. the rest of the sample minus the Western Australian respondents.

### Current health

Most respondents reported that they currently feel healthy: 28% said that their health is “*excellent*”, 41% said that their health is “*good*”, 23% said that their health is “*fair*”, and 8% said that their health is “*poor*”. When asked about their well being 23% described it as “*excellent*”, 44% as “*good*”, 21% as “*fair*” and 12% as “*poor*”. Ten percent of the respondents from Western Australia 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 Western Australian PLWHA reported receiving pre-test counselling, most commonly provided by a doctor (5 of the 9 that reported receiving such counselling). Most (78%) of these PLWHA were happy with the information they received from this counselling, while 78% were happy with the support they received. These proportions are similar to those reported by PLWHA from other parts of Australia.

Fifty-five percent of Western Australian PLWHA reported receiving post-test counselling, again most commonly provided by a doctor (27% of those receiving such counselling) or a counsellor/psychologist (23%). Most (85%) of these PLWHA were happy with the information they received from this counselling, while 90% were happy with the support they received. These proportions are similar to those reported by the rest of the sample.

Thirty-five percent of respondents from Western Australia have a major health condition other than HIV/AIDS. The most frequently cited “other” health conditions included hepatitis C and haemophilia.

One third (32%) of respondents from Western Australia reported having been diagnosed with a mental health condition – a similar proportion reported by respondents from other states. These respondents had most commonly been diagnosed with depression (92%), followed by

anxiety/panic disorders (26%). Thirty-four percent of respondents are on medication for anxiety, while 34% are on medication for depression and 5% are on anti-psychotic medication.

Fifteen percent of PLWHA from Western Australia have had hepatitis A, and slightly more (29%) had been diagnosed with hepatitis B. Half (50%) the respondents had been vaccinated against hepatitis B and 40% had been vaccinated against hepatitis A. Seventy-six percent of Western Australian PLWHA have been tested for hepatitis C: 36% have had an anti-body test; 9% have had a diagnostic PCR test; and 42% reported that they didn't know what type of test they had. Ten respondents (19%) of respondents from Western Australia indicated that they had been diagnosed with hepatitis C, of whom only one reported that they had subsequently tested negative on a PCR test. Due to the low number of Western Australian respondents that reported being infected with hepatitis C no further results will be reported in this report. More detailed analyses of HIV/Hepatitis C co-infection are reported in "HIV Futures 3: Positive Australians on Services, Health and Well-Being" (Grierson et al, 2002).

All (100%) of the Western Australian respondents reported having taken a CD4/T-cell test, and 100% have also 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 Western Australian 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	47
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	66
low	500 - 9,999	16
moderate	10,000 - 49,999	7
high	over 50,000	12

Thirty-nine percent of Western Australian respondents have had a viral resistance test, with 56% of these having their most recent viral resistance test in 2001. Among the eighteen respondents from Western Australia who had taken a viral resistance test, 9 reported that their most recent test found resistance to a drug with 7 of these reporting that they changed medications due to this result. Of these 7 respondents, 4 reported that their viral load decreased and 3 reported that their CD4/T-cell count increased.

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

Figure 1 shows the uptake of antiretroviral treatment for Western Australian PLWHA. Nine out of ten (91%) Western Australian PLWHA have taken antiretroviral drugs at some stage, while 81% are using them currently. These figures are similar to those for PLWHA from other states. Of those PLWHA from Western Australia who are currently taking antiretrovirals 43% report that their health has improved, 19% report that their health has stayed the same, 36% that it fluctuated, and 3% that it has deteriorated, while 38% said their well-being improved, 13% that it stayed the same, 37% that it fluctuated and 13% that it had deteriorated.

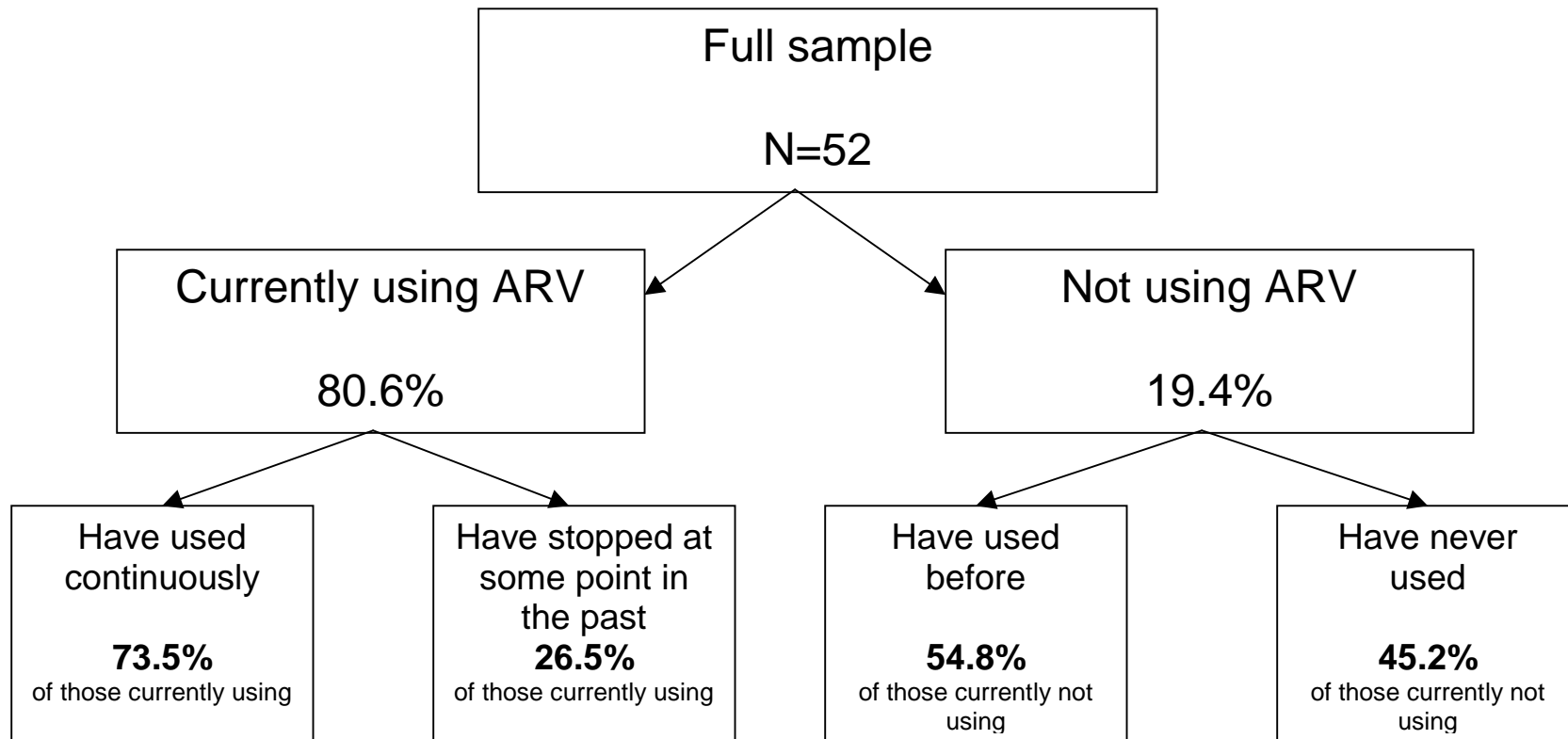
Fifty-five percent of the PLWHA from Western Australia who use antiretroviral drugs reported that they experience side-effects from these drugs - a similar figure to that reported by PLWHA in other States. The most commonly reported side-effects from antiretroviral drugs were: diarrhoea (experienced by 48% of Western Australian PLWHA who experience side effects), nausea (29%), fatigue/lethargy (34%) and lipodystrophy (23%).

Seventy-six percent of Western Australian PLWHA who use antiretrovirals report other difficulties taking this medication. The most common difficulties among these respondents are taking medication in public (53%), remembering to take drugs on time (49%), organising meals around medication (46%) and taking a large number of tablets (38%).

Fifteen percent of Western Australian PLWHA missed at least one dose on the day before they filled out the survey, with a similar proportion (15%) missing a dose the day before that. Only 8% missed a dose on both days.

Twenty-seven percent (11 respondents) of Western Australian PLWHA currently on antiretrovirals have taken a break from them at some stage, a similar proportion to that for other states. On average, these breaks started 20 months ago and lasted for 108 days. Most Western Australian PLWHA (9 respondents) considered this break to be a short-term one, with the remainder saying it was a long-term break. Five of the 11 respondents that had taken a break gave lifestyle reasons for their most recent break. Among the full sample the most common lifestyle reasons for treatment breaks were to clean out their system (14% of those that had taken a break) and taking treatments at the right time being too difficult (12%). Seven of the 11 Western Australian respondents who had taken a break from antiretroviral therapy had clinical reasons for their most recent break. Among the full sample the most common among these were side effects (29% of those who had taken a break) and a doctors recommendation (20%).

**Figure 1 The uptake of antiretroviral drugs**



Five of the Western Australian current antiretroviral users who had taken a break talked to a doctor about it before this break, while 7 saw a doctor during the break and 10 talked to their doctor after their break. The outcome of these breaks for respondents from all states can be seen in Table 2. Respondents most commonly reported that their viral load increased and their CD4 count dropped. Despite this, respondents most commonly reported their health and well-being was stable, and commonly reported that their well-being improved.

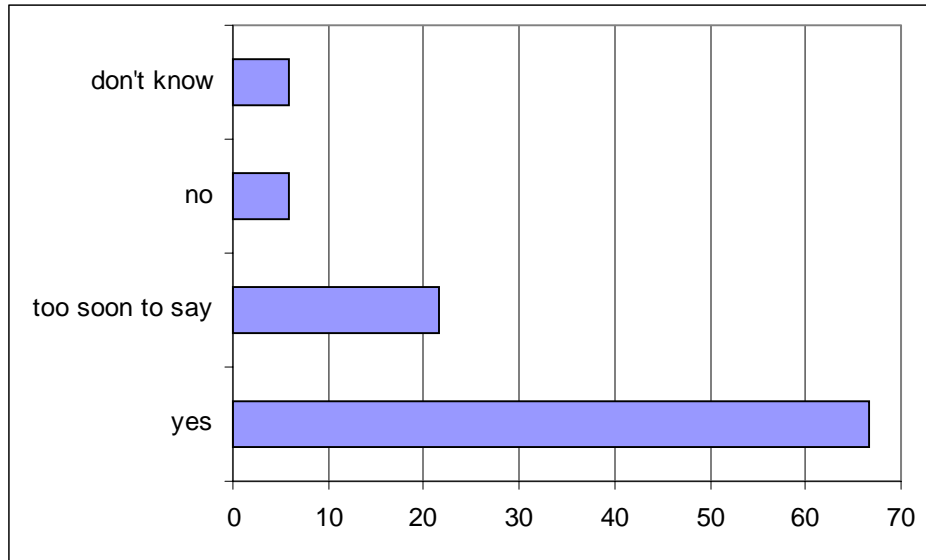
**Table 2 Percentage reporting various outcomes of treatment break**

	Stayed same	Improved	Fluctuated	Deteriorated
<b>Health<sup>a</sup></b>	35	19	22	23
<b>Well-being<sup>b</sup></b>	34	32	22	13
	Stayed same	Increased	Fluctuated	Decreased
<b>Viral load<sup>c</sup></b>	20	59	12	9
<b>CD4<sup>d</sup></b>	25	7	14	55

a: N=249; b: N=248; c: N=230; d: N=237

Figure 2 (below) shows that most (68%) of Western Australian PLWHA agree that antiretroviral drugs have improved the prospects of most PLWHA, while 6% believe they haven't improved the prospects of PLWHA, 6% do not know and 21% believe it is too soon to tell.

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



Those Western Australian PLWHA who are currently using combination therapy have done so for an average of 5 years and 4 months. The mean number of combinations they have tried in this time is 2.7, 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 = 85,173 copies/ml) and their CD4 count was low (mean = 252.3). The most common circumstances surrounding the commencement of

combination therapy for these respondents were doctors advice (76%), a drop in CD4 count (37%), a rise in viral load (34%) and becoming very ill (32%).

Among those who have tried more than one combination, the most common reasons for changing the last time they did so were side effects (55%), timing drugs became too difficult (18%) and drug resistance having developed (18%). Most PLWHA from Western Australia felt they still had treatment options left – 32% reporting they have many options, 24% a few and 1% none. However, there was some uncertainty on this issue, with 43% reporting that they weren't sure how many combinations they had left.

Only four Western Australian respondents had used antiretrovirals and stopped. Among the full sample those who have stopped using antiretrovirals had been using them for an average of 2 years and 10 months and had stopped an average of 1 year and 10 months ago. They have used on average 3.0 combinations. Just under half (46%) had stopped for lifestyle reasons. The most common lifestyle reason given by such respondents from all states was the desire to clean out their system (15% of all ex-antiretroviral users) and taking drugs at the right time was too difficult (13%). A larger proportion (65%) of ex-antiretroviral users from all states had clinical reasons for stopping treatment. The most common of these were side effects (35% of all ex-antiretroviral users), a doctor's recommendation (24%) and drug resistance having developed (11%). Four out of five (80%) ex-antiretroviral users from all states talked to their doctor before they stopped taking antiretrovirals, and most (92%) had talked to their doctor since stopping treatment. The outcomes of stopping treatment for these respondents from all states can be seen in Table 3. Respondents most commonly reported that their health and well-being had improved since stopping treatment. Despite this, respondents most commonly reported that their viral load increased and commonly reported that their CD4 decreased.

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

	<b>Stayed same</b>	<b>Improved</b>	<b>Fluctuated</b>	<b>Deteriorated</b>
<b>Health<sup>a</sup></b>	27	40	27	7
<b>Well-being<sup>b</sup></b>	22	50	25	3
	<b>Stayed same</b>	<b>Increased</b>	<b>Fluctuated</b>	<b>Decreased</b>
<b>Viral load<sup>c</sup></b>	14	44	33	9
<b>CD4<sup>d</sup></b>	21	15	34	30

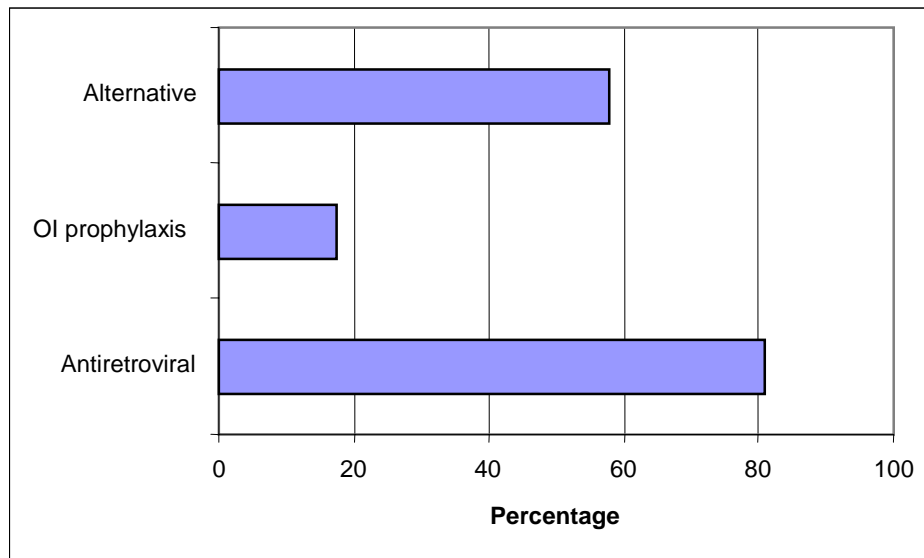
a: N=131; b: N=130; c: N=120; d: N=120

Of the eight Western Australian PLWHA not currently taking antiretroviral medications, all but one reported that they would consider taking them in the future. The most common circumstances among these PLWHA from all states might start antiretrovirals are becoming very ill (78%), a significant drop in CD4/T-cell count (76%), a significant rise in viral load (70%), hospitalisation due to HIV-related infections (67%) or on a doctor's advice (63%).

### Other treatments for HIV/AIDS

Figure 3 (below) shows that while the majority of Western Australian PLWHA use antiretroviral drugs, just over half use alternative therapies and one in five (18%) of the respondents from Western Australia 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 (63% of Western Australian PLWHA who use alternative therapies), massage (50%) and meditation/visualisation (38%).

**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, Western Australian PLWHA had favourable attitudes toward alternative therapies (mean = 2.9). PLWHA from Western Australia had similar attitudes toward alternative therapies as PLWHA from other states (mean = 2.8).

### Information and support services

Three-quarters of Western Australian respondents (75%) have direct contact with an HIV/AIDS-related organisation. Of those Western Australian PLWHA in contact with HIV/AIDS organisations, 71% receive a newsletter, 61% are clients, 23% are volunteers, 11% are members and 10% are staff. Western Australian PLWHA were significantly less likely than those from other states to be members of HIV/AIDS organisations. Of those PLWHA in the Western Australia sample who do not have contact with and HIV/AIDS organisation the most common reason given was not wanting to be involved (42%). Among Western Australian PLWHA who have contact with an HIV/AIDS-related organisation, respondents most commonly had contact with WAAC (87%).

Table 4 (below) displays the proportion of Western Australian 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 social support services. PLWHA from Western Australia are significantly less likely than PLWHA from other states to report that they make use of pharmacy services provided by HIV/AIDS organisations, and were more likely to get treatments advice from other organisations.

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

Service	HIV/AIDS Organisation	Other service organisation
Treatments advice	43	31
Counselling	37	23
Informal peer support	37	12
Social contact with other PLWHA	36	12
Peer support group	35	10
Alternative therapies	32	26
Treatments information	32	30
Financial assistance	19	16
Financial advice	12	17
Housing assistance	11	12
Community education campaigns	10	10
Respite care	7	8
Volunteer carer	7	10
Legal advice	6	19
Internet access	5	26
Transport	5	19
Internet based information	5	24
Mental health services	3	26
Employment services	2	22
Pharmacy services	1	35
Return to work skills	0	13
Drug/alcohol treatment	0	12
Library	0	23
Paid carer	0	12

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 sources of information about treatments for HIV/AIDS were an HIV specialist at an outpatient clinic, an HIV GP/S100 Prescriber and HIV/AIDS magazine/newspapers. The diversity of responses to this question suggests that PLWHA seek information from a range of different sources. HIV specialists at an outpatient clinic were most commonly cited (39%) as the *most* important source of information, followed by HIV GPs/S100 prescribers (34%).

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 outpatient HIV specialists, followed by HIV magazines and

newspapers and HIV GPs/S100 prescribers. HIV GPs/S100 prescribers were most commonly cited (29%) as the *most* important source of information, followed by outpatient HIV specialists (21%).

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, publications from HIV/AIDS groups and HIV positive friends. When asked about the *most* important source of information the respondents had on living with HIV/AIDS the most common responses were AIDS organisation staff (27%). PLWHA from Western Australia were significantly more likely than PLWHA from other parts of Australia to report AIDS organisation staff as important sources of information about living with HIV/AIDS.

**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	57	43	34
Other GP	13	12	11
Outpatient HIV specialist	61	52	24
Inpatient HIV specialist	9	8	4
Other doctor	3	4	2
Public Health Nurse	0	4	4
Other nurse	4	6	4
Pharmacist	6	2	0
Alternative therapist	17	20	20
Dietician	5	7	10
Dentist	9	7	5
Peer support officer	13	14	20
Sexual health service	5	2	7
Family Planning Association	2	3	3
Sex worker organisation	2	2	7
Treatments officer	26	17	17
Other HIV/AIDS organisation staff	23	25	38
Positive women's organisation	13	13	15
Positive heterosexuals' group	5	5	6
Injecting drug user's organisation	3	5	5
Haemophilia Foundation	10	10	11
HIV positive friends	26	34	42
Other friends	4	2	15
Partner/lover	14	12	24
Family	6	8	20
Gay press	32	31	31
HIV magazine/newspaper	56	50	49
Liver specialist	5	7	7
Hep C Support Group/Organisation	5	3	2
Internet	29	26	23
Publications from HIV/AIDS groups	40	40	48
Publications from other sources	12	10	12

The HIV-related publications most read by Western Australian PLWHA are Positive Life (63%), gay newspapers (50%), and Positive Living (44%).

We asked respondents whether they thought lack of information made it difficult to make decisions about various issues surrounding living with HIV. Western Australian respondents most felt a lack of information when making decisions on employment (33%), managing antiretroviral side effects (28%), taking a break from antiretrovirals (25%), changing antiretrovirals (24%), recreational drugs (23%) and interactions between antiretrovirals and other drugs (21%).

In the last 6 months the health services that Western Australian PLWHA had most commonly used were an HIV specialist at an outpatient clinic (66%), an HIV GP/S100 prescriber (50%), and a non-S100 prescribing GP (49%), a dentist (40%), an hospital counsellor/social worker (32%), an AIDS organisation support worker (29%). Western Australian PLWHA were more likely to have used an HIV specialist at an outpatient clinic, a hospital social worker or counsellor and an AIDS organisation support worker than PLWHA from other states. Fifty-four percent of Western Australian PLWHA who currently use antiretrovirals have to go to more than one place to get all their prescriptions filled, a similar proportion to that for PLWHA in other states.

Ninety-five percent of Western Australian 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 Western Australian PLWHA spend no free time with other positive people, over a third spend “some” or “a lot” of time with other positive people and a similar proportion spend “a little” time with other PLWHA. Eighteen percent of Western Australian 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**

<b>Amount of free time</b>	<b>Percentage</b>
None	28
A little	35
Some	29
A lot	8

Only 2% of respondents from Western Australia have not disclosed their HIV status to anyone. Over half (54%) have had their HIV status disclosed when they didn't want it to be, with 31% having this happen in the past two years. Western Australian PLWHA most commonly reported that this disclosure came from an acquaintance (32% of those that reported unwanted disclosure). 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 Western Australia received the most support from their partners (mean=1.24), and their doctors (mean=1.76). Western Australian received significantly less support from health care workers than those from other states.

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

	strongly agree	agree	disagree	strongly disagree
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

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 Western Australian respondents can be seen in Table 7 (above). There were no differences between PLWHA from Western Australia 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 Western Australian PLWHA 45% agreed or strongly agreed with none of these items, 22% with one item, 19% with two, 8% with three and 5% with all four. Agreement with all four items is suggestive of clinical depression. Many Western Australian respondents had a negative body image. Over half (51%) of the respondents disagreed or strongly disagreed that they were happy with the way their body looks, and 55% agreed or strongly agreed that changes in their bodies due to HIV/AIDS had made them sexually unattractive. Respondents generally didn't think positively about their HIV. Just over half (51%) report that they don't think about HIV when they are well, and 55% felt that their life hadn't become more meaningful since they were diagnosed with HIV.

### 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 Western Australia. Two-fifths (41%) of Western Australian PLWHA have changed how far they plan into the future in the last two years, of whom 74% had started planning for a longer time frame. Among all 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

(37%). 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 (41%).

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

Time frame used	Percentage
One day at a time	18
A few months ahead	17
1 year ahead	26
5 years ahead	30
10 or more years ahead	9

### Sexual Relationships

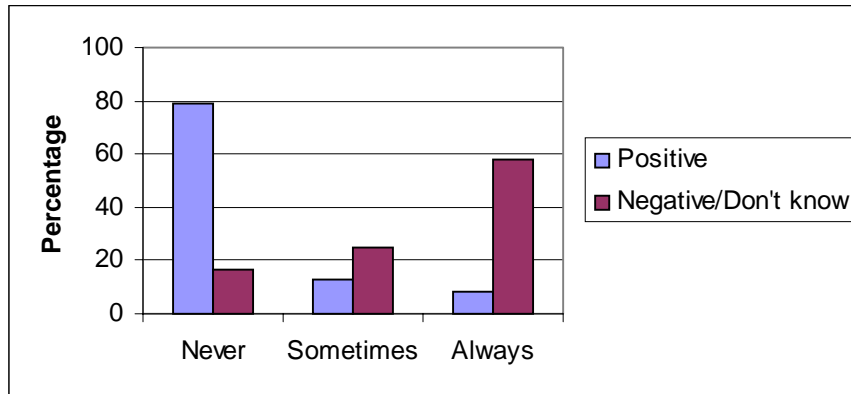
Respondents were asked to describe their sexual orientation or sexual identity. The majority of respondents were homosexual men (67%), followed by heterosexual women (11%) and men (9%), and bisexual men (9%) and women (2%). A further 3% reported having some other type of sexuality. When asked to describe their current sexual relationships, 28% reported that they are not currently sexually active, while 27% reported that they only have casual sex, 35% have sex in a monogamous regular relationship, and 10% have sex in a non-monogamous regular relationship.

Thirty-one percent of respondents who have a regular relationship are in a seroconcordant relationship - the remainder (69%) are in a relationship with an HIV seronegative partner, or a partner whose serostatus is unknown. Almost all (97%) 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 were HIV seropositive. Respondents commonly told their partner when they were diagnosed (48%) or that their partner already knew they were HIV positive when they started the relationship (10%). Of the ten Western Australian respondents who told their partner while in a relationship, 6 told their partner at the start of the relationship. Respondents were also asked how their partner reacted when they told them that they are HIV seropositive. Half (51%) said that it did not make any difference. Fifty-two percent also reported that their partner was very supportive, and 35% said that they became closer, while 31% said that their partner was worried or scared and 9% said they were angry. When asked about their own feelings about the disclosure to their partner, 55% reported that they were relieved, 45% that they were worried, 30% that they became closer, 16% that they were angry and 14% that it did not make a difference.

When asked about their patterns of condom use during sex with regular partners in the 6 months prior to completing the survey, 31% reported that they always used a condom, 34% reported that they sometimes used a condom, and 35% reported that they never used a condom. Unfortunately, there were not enough respondents to examine condom use by partner serostatus

for Western Australian respondents. However, when the full sample was analysed a significant association was found between partner HIV serostatus and consistency of condom use (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, 53% reported that they always used a condom, 36% reported that they sometimes used a condom, and 10% never used a condom. Again, small numbers meant that it was not possible to analyse the relationship between casual partner serostatus and consistency of condom use for the Western Australian 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 Western Australian PLWHA, almost all (96%) of these sexual contacts were with male partners, and the majority (71%) involved vaginal or anal intercourse. The respondents most often didn't know the HIV status of their partners (74%). Amongst those who engaged in vaginal or anal intercourse, 72% of Western Australian PLWHA used a condom. Small numbers meant it was impossible to analyse condom use by serostatus on the most recent occasion for Western Australian respondents, however for the full sample 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 Western Australian PLWHA. PLWHA from Western Australia use these drugs in similar proportions to those from the rest of Australia. Most PLWHA from Western Australia were not concerned with the amount of drugs they took. Seventy-nine percent either disagreed or strongly disagreed with the statement that they use more illegal drugs than they would like, and 78% disagreed or strongly disagreed that they drink more alcohol than they would like. Less than one in three (29%) reported ever missing a dose of antiretrovirals due to the use of illegal drugs.

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

	<b>Percentage of sample using in last 12 months</b>
Alcohol	78.6
Cigarettes	49.4
Marijuana	40.5
Amyl	24.8
Ecstasy	16.3
Viagra or similar	11.0
Speed (injected)	10.6
Speed (not injected)	6.0
LSD/trips	3.1
Heroin (injected)	2.9
Methadone (prescribed)	2.9
Cocaine (not injected)	1.5
Steroids (injected)	1.5
Heroin (not injected)	0
Cocaine (injected)	0
Homebake	0
Methadone (non-prescribed)	0
GHB/GBH/Fantasy	0

### Housing

All but one (99%) of the Western Australian respondents live in Perth. Western Australian respondents were significantly more likely than other PLWHA to live in the capital city of their state.

Table 10 (below) shows that while many Western Australian PLWHA own their home or are buying their own home, just under half are living in rental accommodation, while a small number live in community housing. The vast majority (71%) of Western Australian respondents believe that their current housing is suitable for their needs. Thirty-two percent of Western Australian PLWHA have changed their accommodation as a result of having HIV/AIDS. Among such respondents from all states the most common reasons for change were the need for cheaper housing (37%), moving to a quieter location (32%), and moving closer to health services (29%).

**Table 10 Accommodation in which PLWHA live**

<b>Accommodation Type</b>	<b>Percentage</b>
Own or purchasing own house or flat	47
Private rental accommodation	32
Public rental accommodation	13
Live rent-free	8

When asked whom they live with, 32% of Western Australian PLWHA reported that they live alone, 40% live with a sexual partner, 11% live with friends or housemates, 15% live with dependent children and 10% live with other family members.

### **Employment**

Over half (57%) the Western Australian PLWHA were not in paid employment at the time of completing the survey. Of the PLWHA who are working, 60% work full-time and 40% work part-time. Most Western Australian PLWHA (62%) report that being diagnosed HIV positive affected their career plans - 27% report that it was more difficult to plan, 15% report that they stopped work, 13% report that having a career was no longer as important, 7% changed careers because of their diagnosis and 2% report they were less likely to change their career. Since then 61% say HIV has affected their career plans – 17% reported that their career has ended, 17% that it is more difficult to plan, 12% have changed careers, 12% that a career is no longer as important and 3% are less likely to change careers. When asked the effect of antiretrovirals on their work plans, 53% reported some change to their plans. Among respondents from all states the most common changes were stopping work (14% of all respondents) and anticipating a longer time in the workforce (11%). One in five (17%) Western Australian PLWHA report having been discriminated against at work as a result of having HIV/AIDS, with 7% reporting having been discriminated against at work in the last 2 years.

Fifty-two percent of Western Australian PLWHA who have ever worked have stopped doing so at some stage due to their HIV diagnosis. These PLWHA stopped work for an average 1 year and 11 months – a significantly shorter time than that reported by PLWHA from other states. The last time they stopped working the most common reasons were stress or depression (60%), poor health (60%) and low energy (59%). When asked their HIV status at the time they stopped work 36% reported they were HIV positive but had not been ill, 50% 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 most (66%) received government benefits. About two-fifths (38%) of these PLWHA have returned to work. The most common reasons for returning to work among the whole sample were financial (79%), to have something to do (52%), better psychological health (51%) and to do something worthwhile (49%).

The 43% of Western Australian PLWHA who are presently employed work an average of 33.8 hours per week. Most (72%) report that their job involves a moderate to very high stress level. Thirty-three percent of Western Australian PLWHA who are working reported that their capacity to perform their work duties is affected by having HIV/AIDS: among the full sample these respondents most frequently reported that they tire quickly (46%), have difficulty concentrating (22%) and work fewer hours (21%). Seventy-nine percent of Western Australian workers reported that they could 'often' or 'always' get time off work for medical appointments, 69% for counselling, 79% for sick leave, and 45% for volunteer work.

Forty-one percent of Western Australian PLWHA indicated that they are considering changing their work arrangements. For these respondents from all states, 43% of these respondents want to change the type of work they do, 42% of these want to start or return to work, 22% want to reduce their hours, 7% want to increase their hours and 4% want to stop work. Most of the Western Australian PLWHA who want to change their work arrangements perceived that this would be difficult: 11% believe it will be 'very difficult', 71% believe that it will be 'somewhat difficult' and 18% that it will be 'not at all' difficult.

### Finances

Given the large number of PLWHA in Western Australia who are not in paid employment, it is not surprising that 50% of respondents reported that their main source of income is a government benefit, pension, or social security payment, while 40% reported that a salary is their main source of income. Almost two-thirds of the Western Australian respondents reported annual incomes below \$20,000. Respondents' incomes are displayed in Table 11 (below).

**Table 11 Income reported by PLWHA**

Weekly income	Yearly income	Percentage
\$0 - \$150	\$0 - \$7800	10
\$151 - \$270	\$7801 - \$14040	40
\$271 - \$390	\$14041 - \$20280	15
\$391 - \$510	\$20281 - \$26520	21
\$511 - \$630	\$26521 - \$32760	4
\$631 - \$750	\$32761 - \$39000	2
\$751 -	\$39001 -	8

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-eight percent of Western Australian PLWHA were living below the poverty line.

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 travel and holidays, 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 22% of Western Australian PLWHA find it “very difficult” to meet the cost of food, and one in four find it “very difficult” to meet the cost of utilities (telephone, gas, electricity). It is also interesting to note one half of those who need child care find it very difficult to pay for this.

**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	68	20	12
Other prescribed medication	48	39	13
Medical services	49	37	14
Complementary therapies	42	44	14
Support services	61	28	12
Entertainment	24	37	39
Going out	26	37	37
Sport	32	34	34
Recreational drugs	27	35	38
Travel / holidays	15	27	57
Rent / mortgage / housing	24	47	29
Utilities (phone, gas, etc.)	21	51	28
Food	36	43	22
Clothing	22	47	31
Transport	43	40	18
Child care	14	35	51

### Discrimination

Two fifths (43%) of Western Australian PLWHA had experienced less favourable treatment than other people when attending a medical service because of their HIV status, with 21% having experienced such discrimination in the last 2 years. When asked to describe what form this discrimination took respondents most commonly reported being rushed through (38%), followed by confidentiality problems (35%).

Four respondents (7%) from Western Australia had received less favourable treatment due to their HIV status in relation to accommodation, with 3 of these having this happen in the last 2 years. One in five (17%) of respondents in Western Australia had been discriminated against in relation to employment (7% in the last 2 years), and 20% had been discriminated against in relation to insurance.

## REFERENCES

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