

HIV Futures: State Reports

Western Australia

Living with HIV Program*
Australian Research Centre in Sex, Health and Society

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Introduction

The HIV Futures Survey was developed out of a pilot study of issues of accommodation, employment and treatments for people living with HIV/AIDS [PLWHA] conducted in 1996 (Ezzy, Grubb, de Visser, & McConachy, 1997), and through a range of consultations with community interest groups. The questionnaire took about 40 minutes to complete. It included questions on demographics, current health, treatments usage, housing, employment history, community participation, sexual practice and finances. The study was approved by the La Trobe University Human Ethics Committee.

Recruitment of study participants throughout Australia involved distribution of self-administered mail-back questionnaires through HIV/AIDS organisations, and a targeted advertising campaign. Questionnaires were also distributed via a number of mailing lists, including the mailing lists of two magazines that provide information about living with HIV/AIDS. It is not possible to know what proportion of the recipients of these magazines are HIV positive, and as a consequence response rates cannot be calculated. Additional targeted distribution occurred in order to ensure the sample included sufficient numbers to enable statistical comparisons from groups that have distinctive issues and experiences who may not have been contacted through the main distribution channels, including women, people living with Haemophilia, and people living outside of New Western Wales and Victoria. The recruitment period was from 1st July 1997 to 5th September 1997.

To assess the degree to which the sample recruited for this study is representative of all PLWHA in Australia, comparisons were made with the Australian HIV Surveillance Report (National Centre in HIV Epidemiology and Clinical Research [NCHECR], 1997). The results discussed in this report are weighted to take account

of an under-representation of PLWHA from NSW, and the over-representation of women, people with medically acquired HIV and people with AIDS.

The people who completed the survey

The survey was completed by 925 respondents. This sample represents 8.3% of all PLWHA in Australia. Respondents reported ages between 18 and 77 years (median = 38.0 years, mean = 39.3 years). On average, respondents had been HIV seropositive for 7.5 years (median = 8.0 years). The results relating to the total sample are reported in the document “HIV Futures Community Report: Health, Relationships, Community, and Employment” (Ezzy, de Visser, Bartos, McDonald, O’Donnell, & Rosenthal, 1998).

Fifty Western Australian PLWHA completed the HIV Futures Survey. This figure is significantly greater than the number we would have expected in a representative sample of PLWHA in Australia. The large number of Western Australian respondents is a reflection of the great efforts made by AIDS Pastoral Care, Royal Perth Hospital, and the Western Australian AIDS Council, and the distribution of the survey via the magazine Positive Life (PL). Among Western Australian respondents, 45 were male (90%) and 5 were female (10%) - similar proportions to those found in other States.

The ages of the Western Australian respondents ranged from 18 years to 72 years. The average age was 37.0 years, which is similar to that of the rest of the sample. The average number of years since Western Australian PLWHA first tested HIV seropositive was 7.6 years. This is similar to the 7.5 years reported by the rest of the sample.

The vast majority of respondents had been infected through sexual contact: 70% cited homosexual or bisexual contact as the most likely transmission route, 8% reported injecting drug use, 14% cited heterosexual contact, 4% were haemophiliacs infected through contaminated blood products, and 4% were infected by blood products or in a health care setting.

Current health

Most respondents reported that they currently feel healthy: 10% said that their health is “excellent”, 56% said that their health is “good”, 29% said that their health is “fair”, and 5% said that their health is “poor”.

Approximately one in six (16%) of the Western Australian respondents have been diagnosed with an AIDS-defining illness. Respondents from Western Australia are no more or less likely than respondents from other States to report that they have been diagnosed with an AIDS-defining illness.

Slightly fewer than one-third (30%) of respondents from Western Australia have a major health condition other than HIV/AIDS - a similar proportion to the 29% reported by PLWHA from other States. The most frequently cited “other” health conditions included back injury, cancer (non-Kaposi sarcoma), diabetes, hypertension, and psychological/psychiatric conditions. One in eight (13%) PLWHA from Western Australia have had Hepatitis A, and 22% have had Hepatitis B. Of the 41% of Western Australian PLWHA who have had a Hepatitis C test, 15% have tested positive, 79% have tested negative, and 7% do not know the result of this test.

Nearly all (94%) of the respondents from Western Australia have taken a CD4/T-cell test, and 88% 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). It is interesting to note that 10% of Western Australian PLWHA have a CD4/T-cell count below 250 and a viral load above 50,000. That is, one in ten Western Australian has a high viral load and severe immune system damage.

Table 1 Results of serological testing

Description	Result	Proportion
CD4/T-cell count	Copies/μL blood	
little or no immune damage	over 500	21%
moderate immune damage	250 - 500	39%
severe immune damage	below 250	40%
Viral load	Copies/mL blood	
below detectable level	below 200 / 500	39%
low	500 - 10,000	21%
moderate	10,000 - 50,000	17%
high	over 50,000	23%

Antiretroviral treatments for HIV/AIDS

Four-fifths (83%) of the respondents from Western Australia are using antiretroviral drugs for HIV/AIDS. This figure is slightly higher than the 78% of PLWHA from the rest of Australia using antiretroviral drugs, but it is not a statistically significant difference. Among the PLWHA who use antiretroviral drugs, 5% are on monotherapy, 17% use two drugs in combination and 78% use three or more drugs in combination. Overall, 65% of Western Australian PLWHA are using triple combination therapy. PLWHA from Western Australia are as likely as PLWHA from other States to use triple combination therapy.

Three-quarters (75%) 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. As was found with the full sample of all

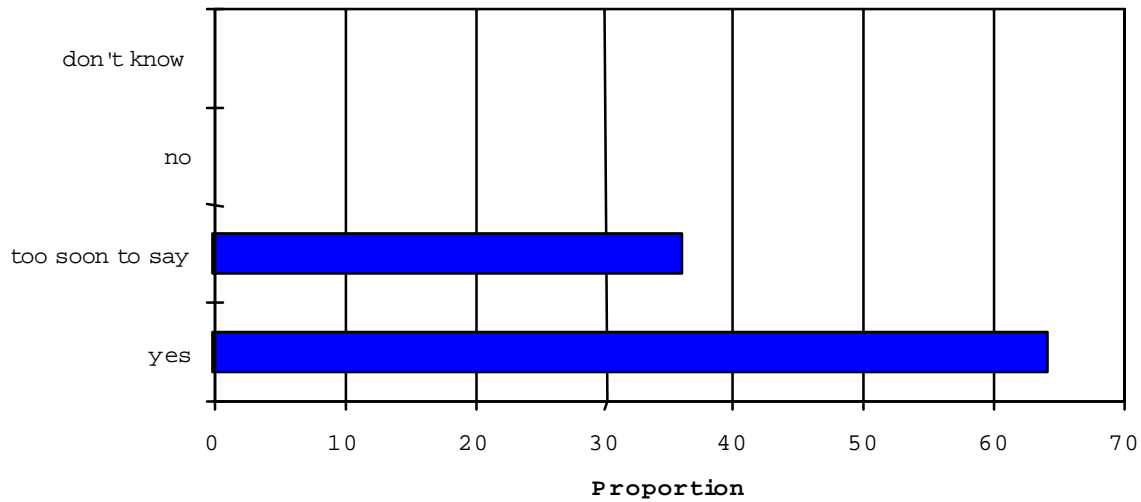
PLWHA who completed the survey, the most commonly reported side-effects from antiretroviral drugs are: nausea (experienced by 62% of PLWHA using antiretroviral drugs), diarrhoea (31%), tingling/metallic taste in mouth (31%), headaches (24%), fatigue/lethargy (17%), skin rashes/dryness (14%), and neuropathy (10%).

Nearly two-thirds (61%) of Western Australian PLWHA who use antiretroviral drugs report that they have difficulties taking this medication - a similar figure to that reported by PLWHA in other States. As was found with the full sample of all PLWHA who completed the survey, the most commonly reported difficulties are: remembering to take drugs on time (45% of PLWHA using antiretroviral drugs), organising meals around medication schedules (36%), and the large number of tablets (21%).

While large numbers of PLWHA from Western Australia have difficulties taking medication and/or experience side-effects, a smaller proportion (19%) reported that it is difficult for them to take their medication in public, and 3% reported that their medication for HIV/AIDS conflicts with medication for other health conditions. These figures are similar to those reported by PLWHA in other States.

Graph 1 shows that while two-thirds (64%) of the Western Australian PLWHA agree that antiretroviral drugs have improved the prospects of most PLWHA, 36% believe it is too soon to tell. No Western Australian PLWHA think that antiretroviral drugs have not improved the prospects of PLWHA. Similarly, two-thirds (67%) of the Western Australian PLWHA think that their friends believe that antiretroviral drugs have improved the prospects of most PLWHA, while 17% believe their friends think that it was too soon to tell, 15% do not know. None of the Western Australian PLWHA think that their friends believe that antiretroviral drugs have not improved the prospects of PLWHA. Western Australian PLWHA's responses to these questions were similar to those of PLWHA from other States.

Have antiretroviral drugs improved the prospects of most PLWHA?

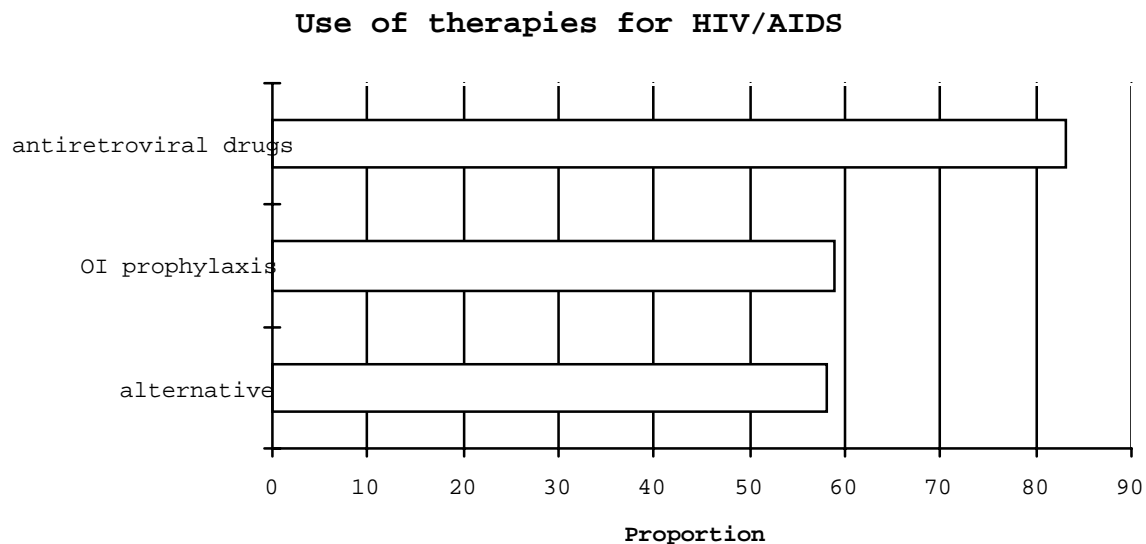


Respondents were asked a number of questions about their attitudes toward antiretroviral drugs and their general attitudes toward treatments for HIV/AIDS. Using these questions it was possible to create a scale of confidence in antiretroviral drugs ranging from 1 to 5, where higher scores indicated greater confidence. The average scale score for Western Australian PLWHA was 3.69, which indicates that they generally have confidence in antiretroviral drugs. PLWHA from Western Australia express a similar degree of confidence in antiretroviral drugs as PLWHA from other States.

Other treatments for HIV/AIDS

Over half (59%) of the respondents from Western Australia are using prophylaxis for opportunistic infections - prophylaxis for *Pneumocystis carinii* pneumonia (PCP) and/or prophylaxis for other opportunistic infections. Over half (58%) of the respondents from Western Australia are using complementary or alternative therapies for HIV/AIDS. The most commonly used complementary/alternative therapies are vitamin/mineral supplements (used by 49% of all PLWHA), massage (29%), meditation/visualisation (22%), acupuncture (17%), herbal remedies (14%),

and traditional Chinese medicine (10%). PLWHA from Western Australia are no more or less likely than PLWHA from other areas of Australia to be using prophylaxis for opportunistic infections, or complementary/alternative therapies.



Generally, Western Australian PLWHA had favourable attitudes toward complementary or alternative therapies. On a scale of 1 to 5, where higher scores indicate more favourable attitudes, the average score was 3.51. This figure is similar to that for PLWHA from other States.

Attitudes toward personal involvement in health management were measured on a 5-point scale, where higher scores indicate a greater desire to be actively involved health management. The average score for Western Australian PLWHA was 4.21, which indicates that they, like PLWHA in other States, are keen to take an active part in decision-making about their health management.

Information and support services

Over half of the respondents (57%) have some direct contact with an HIV/AIDS-related organisation. This is a similar proportion to that found among PLWHA in the rest of the country. All of the Western Australian respondents who have contact with an HIV/AIDS-related organisation have contact with the Western Australian AIDS Council, and 23% have contact with AIDS pastoral care. Western Australian PLWHA are significantly less likely than PLWHA from the rest of the country to report that they have contact with their State AIDS Council. There did not appear to be any relationship between whether or not PLWHA had contact with the Western Australian AIDS Council and whether or not they have had an AIDS-defining illness, or whether they live in an urban area as opposed to a regional centre or rural area. Furthermore, the PLWHA's extent of involvement in the HIV community and the gay community was not related to whether or not he/she had contact with the Western Australian AIDS Council.

Table 2 (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. While PLWHA most commonly use these organisations for information (newsletters/mail-outs, treatments advice), they also rely on such organisations for social contact, social support, and counselling.

Most of the respondents from Western Australia read HIV/AIDS-related magazines and newspapers such as Positive Living, Talkabout, National AIDS Bulletin, and Positive Life (PL): 54% read HIV/AIDS-related press regularly, 38% read it occasionally, and 8% never read HIV/AIDS-related press.

Table 2 Use of services provided by HIV/AIDS-related organisations

Service	Proportion
Newsletters / mail-outs	52%
Treatments advice	46%
Social contact	35%
Counselling	34%
Alternative therapies, etc.	28%
Peer support group	20%
Informal peer support	19%
Financial assistance	18%
Financial advice	17%
Library	16%
Transport services	15%
Domestic help	9%

Respondents were asked to indicate which people and/or organisations they rely upon for information about treatments for HIV/AIDS. Their responses are shown in the Table 3. The most commonly cited source of information about treatments for HIV/AIDS was the PLWHA's doctor. Three-quarters of the respondents rely on HIV/AIDS-related newspapers and magazines, and over half rely on HIV positive friends, which suggest that PLWHA seek information from a range of different sources. It is interesting to note that PLWHA from Western Australia are significantly more likely than PLWHA in other States to report that PLWHA organisation staff are an important source of information about treatments for HIV/AIDS.

Table 3 also displays the responses of PLWHA to questions they were asked about who they rely upon for information about living with HIV/AIDS (but not about treatments). Again, the PLWHA's doctor was the most frequently cited information source, but over half also cited HIV positive friends as an important source of information about living with HIV/AIDS, a finding which highlights the importance of the PLWHA's social network.

Table 3 Important sources of information for PLWHA

Information source	Source of information:	
	Treatments	Living with HIV/AIDS
Doctor	94%	63%
HIV/AIDS press	73%	44%
HIV positive friends	57%	61%
HIV/AIDS organisation staff	40%	30%
Gay press	36%	30%
Nurse	23%	10%
Friends (not HIV positive)	15%	35%
Internet	10%	6%
Alternative therapist	10%	11%
Partner/lover	8%	27%
Positive women's organisation	7%	3%
Family	4%	12%

Respondents were asked to indicate how much of their free time they spend with other HIV seropositive people. The results in Table 4 (below) show that while many Western Australian PLWHA spend no free time with other positive people, over half spend “some” or “a lot” of time with other positive people. There was no difference between Western Australian PLWHA and PLWHA from other States in terms of the amount of free time they spend with other HIV seropositive people.

Table 4 Amount of free time spent with other HIV positive people

Amount of free time	Proportion
None	15%
A little	32%
Some	39%
A lot	15%

Employment

Half (47%) of Western Australian PLWHA were not in paid employment at the time of completing the survey. Of the PLWHA who are working, 50% work full-time and 50% work part-time. The 53% of respondents who are working have been in their current job for an average of three years and three months, and work between 8 and 60 hours per week (average = 32.8 hours). The respondents who are not working have been out of work for an average of 3 years.

Given the large number of PLWHA in Western Australia who are not in paid employment, it is not surprising that 60% of respondents reported that their main source of income is a government benefit, pension, or social security payment. One-third (38%) of respondents reported that a salary is their main source of income, while 2% reported superannuation or an annuity as their main source of income, and 2% reported that their partner supports them. Over half of the Western Australian respondents reported annual net incomes below \$15,000. Respondents' incomes are displayed in Table 5 (below).

Table 5 Income reported by PLWHA

Weekly income	Yearly income	Proportion
\$0 - \$150	\$0 - \$7800	15%
\$151 - \$270	\$7801 - \$14040	46%
\$271 - \$390	\$14041 - \$20280	20%
\$391 - \$510	\$20281 - \$26520	10%
\$511 - \$630	\$26521 - \$32760	4%
\$631 - \$750	\$32761 - \$39000	3%
\$751 -	\$39001 -	3%

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 1997 (IAESR, 1997) were used to calculate the proportion of

PLWHA who reported incomes below the poverty threshold: 34% of Western Australian PLWHA reported incomes below the poverty line, a similar figure to the 32% found for the rest of the sample.

Respondents were asked a series of questions that assessed how difficult it is for them to meet the costs of living with HIV/AIDS. The results in Table 6 (below) demonstrate that while many PLWHA reported difficulties in meeting the costs of social activities such as entertainment and eating and drinking 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 a one in six Western Australian PLWHA find it “very difficult” to meet the cost of food, and that nearly a third find it “very difficult” to meet the cost of utilities (telephone, gas, electricity). It is also interesting to note that over a third of respondents who are using complementary/alternative therapies find it very difficult to meet the cost of this treatment.

Table 6 Difficulties meeting the cost of living reported by PLWHA (proportion of respondents who use each item)

Item	Not difficult	A little difficult	Very difficult
Prescribed medication	70%	27%	3%
Medical services	60%	25%	16%
Complementary therapies	41%	17%	42%
Support services	71%	23%	6%
Entertainment	26%	37%	37%
Eating / drinking out	24%	39%	37%
Sport / exercise	32%	19%	49%
Recreational drugs	14%	30%	55%
Travel / holidays	18%	28%	54%
Rent / mortgage / housing	42%	35%	23%
Utilities (phone, gas, etc.)	31%	42%	28%
Food	47%	38%	16%
Clothing	23%	47%	31%

Transport

37%

37%

25%

Planning for the future

Respondents were asked to indicate how far into the future they plan when making major decisions about their future. Table 7 (below) shows the responses given by PLWHA from Western Australia. Western Australian PLWHA used a longer time frame than PLWHA from other States. Half (50%) of the respondents reported that in the past two years they have changed the time frame they use when making major decisions about their future: 23% now use a shorter time frame when planning for the future, while 27% now use a longer time frame. Among 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, while among respondents who now use a shorter time frame when planning for the future, the most commonly cited reason for the change was declining health.

Table 7 Time frame use by PLWHA when planning for the future

Time frame used	Proportion
One day at a time	10%
A few months ahead	10%
1 year ahead	37%
5 years ahead	28%
10 or more years ahead	15%

Housing

The vast majority of Western Australian respondents live in Perth: 66% live in an urban area, while 30% live in a regional centre or town, and 4% live in a rural area. These proportions are similar to those reported by PLWHA in other States.

Table 8 (below) shows that while many Western Australian PLWHA own their own house or are buying their own house, an equivalent number are living in rental accommodation, while a small number live rent-free.

Table 8 Accommodation in which PLWHA live

Accommodation Type	Proportion
Own or purchasing own home	52%
Public rental accommodation	10%
Private rental accommodation	33%
Live rent-free	6%

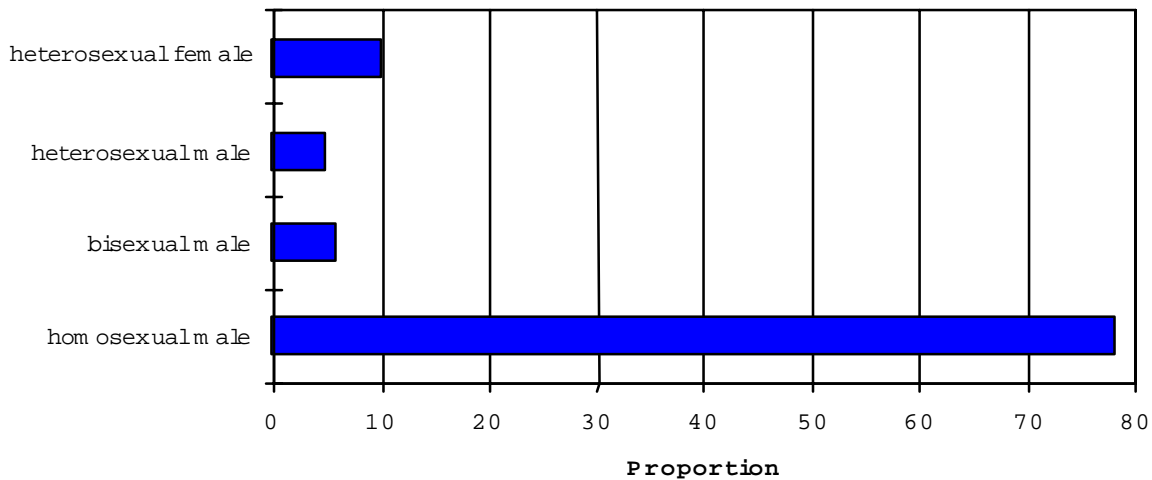
The vast majority (84%) of Western Australian respondents believe that their current housing is suitable for their needs - a similar result to that found among PLWHA from other States. As was the case for the whole sample, few Western Australian PLWHA (8%) reported that they have ever experienced HIV/AIDS-related discrimination in the area in which they live.

When asked who they live with, 42% of Western Australian PLWHA reported that they live alone. Of the remainder, 71% live with a sexual partner, 25% live with dependent children, 18% live with friends or housemates, and 4% live with family members.

Sexual Relationships

Respondents were asked to describe their sexual orientation or sexual identity. Their responses (similar to those of respondents from other States) are displayed in the graph below. The majority of respondents were homosexual men, with smaller numbers of bisexual men, heterosexual men, and heterosexual women.

Sexual orientation of PLW HA



When asked to describe their current sexual relationships, 21% reported that they are not currently sexually active, 30% reported that they only have casual sex, 29% have a monogamous regular relationship, and 20% have a non-monogamous regular relationship.

Half (52%) of the respondents from Western Australia reported that they are in a regular sexual relationship. One-third (33%) of these respondents are in a seroconcordant relationship, the remainder (67%) are in a relationship with an HIV seronegative partner, or a partner whose serostatus is unknown. Respondents in a regular relationship have told their partner that they are HIV seropositive. One third (32%) of respondents said that their partner already knew they were HIV positive, and a quarter (18%) said that they told their partner when they found out (ie. they seroconverted after the formation of the relationship). Of the remainder, most (62%) told their partner at the beginning of the relationship. Respondents also reported how their partner reacted when they were told that the respondent is HIV seropositive. Over half (60%) of the respondents said that it did not make any difference, while slightly less than half (45%) reported that their partner was very supportive, 26% said that they became closer.

When asked about their patterns of condom use during sex with regular partners in the 6 months prior to completing the survey, 58% reported that they always used a condom, 26% reported that they sometimes used a condom, and 17% reported that they never used a condom. Small numbers of respondents meant that it was not possible to analyse the relationship between regular partner serostatus and consistency of condom use for the Western Australian respondents. However, when the whole sample of all the PLWHA who completed the survey was used, it was found that respondents were more likely to use condoms with an HIV negative partner than with an HIV positive partner.

When asked about their patterns of condom use during sex with casual partners in the 6 months prior to completing the survey, 83% reported that they always used a condom, 17% reported that they sometimes used a condom. No respondents reported that they never used a condom when having sex with a casual partner. 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 used, 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.

Detailed analyses of sexual behaviour and condom use are reported in the document “HIV Futures Community Report: Health, Relationships, Community, and Employment”.

Summary and conclusion

One of the most striking findings in this study of Western Australian PLWHA is the similarity of their responses and the responses of PLWHA from other States of Australia. These data suggest that the experience of living with HIV/AIDS is very similar for PLWHA in Western Australia and in other States.

In summary, this survey revealed that two-thirds of Western Australian PLWHA are using antiretroviral drugs for HIV/AIDS as part of a triple combination regimen. In spite of the fact that many PLWHA experience difficulties taking these drugs, and unpleasant side-effects, most respondents believe that antiretroviral drugs have improved the prospects of people living with HIV/AIDS. Furthermore, Western Australian PLWHA generally express confidence in the efficacy and safety of antiretroviral drugs. Most Western Australian PLWHA are using some form of prophylaxis for opportunistic infections, and most are using complementary or alternative therapies.

The results of this study also reveal that the majority of PLWHA in Western Australia have direct contact with an HIV/AIDS-related organisation such as the Western Australian AIDS Council, and that they use these organisations for a range of services.

Only half of the Western Australian PLWHA who completed the survey are in paid employment, and most respondents reported that their main source of income is a government benefit. Of concern is the finding that 34% of Western Australian reported incomes below the poverty line. As a consequence, many respondents reported difficulties affording a range of expenses, including some of the “basics of life”. These findings suggest that many PLWHA may be in need of financial

assistance and/or advice on financial planning to help them meet the costs of living with HIV/AIDS.

Acknowledgments

Nine hundred and twenty five people living with HIV/AIDS completed the survey. We are grateful for their interest in, and contribution to, the study.

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Positive Women (Victoria), Prostitutes' Collective Victoria, Royal Melbourne Hospital, Straight Arrows, Victorian AIDS Council, and the Victorian Intravenous AIDS Association [VIVAIDS].

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Acronyms Used in the Report

AFAO Australian Federation of AIDS Organisations

AIDS Acquired Immune Deficiency Syndrome

HIV Human Immunodeficiency Virus

IAESR Institute of Applied Economics and Social Research

NAPWA National Association of People Living With HIV/AIDS

NCHSR National Centre in HIV Social Research

NCHECR National Centre in HIV Epidemiology and Clinical Research

PLWHA People Living with HIV/AIDS