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HIV Futures 3 Regional Reports: Victoria

Jeffrey Grierson and Sebastian Misson

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The Living with HIV Program can be contacted at

The Australian Research Centre in Sex, Health and Society,
LaTrobe University
215 Franklin Street
Melbourne 3000
Australia

Phone: +61 3 9285 5382
Email: hivfutures@latrobe.edu.au

HIV Futures community reports can be found on the HIV Futures website:
www.latrobe.edu.au/hiv-futures

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).

One hundred and fifty-six PLWHA from Victoria completed the HIV Futures Survey. The number of Victoria respondents is 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 following individuals and organisations who helped distribute the survey in Victoria: Access Information Centre, AIDS Care Association, ALSO Foundation, AIDS Housing Action Group, AIDS Prevention Team Inner South Community Health Service, Australian AIDS Fund Inc., Barkly Street Medical Clinic, Country AIDS Network Resource Centre, Carlton Clinic, Gippsland Gay and Lesbian Support Group, Melbourne Sexual Health Centre, People Living with HIV/AIDS - PLWHA (Vic), Stephanie Moore and Positive Women (Vic), Resourcing Health and Education in the Sex Industry (RHED), Royal Melbourne Hospital HIV Services, Straight Arrows, Victorian AIDS Council (VAC), Jim Arachne and Colin Batrouney at VAC, VIVAIDS, Mattie Sempert, Lisa McPherson, Dr Ralph Ballard, Vincent Boyd, Dr Darren Russell at the Prahran Market Clinic, The Royal District Nursing Service and the AIDS Housing Action Group.

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 Victoria contained 87% males and 13% females. The ages of the Victorian respondents ranged from 21 years to 70 years. The average age for Victorian PLWHA was 41.7 years. On average, PLWHA living in Victorian had been HIV seropositive for 9.2 years.

The vast majority of respondents had been infected with HIV through sexual contact: 74% cited homosexual or bisexual contact as the most likely transmission route and 13% cited heterosexual contact, while 6% reported injecting drug use, 1% reported homosexual/bisexual contact and injecting drug use, 3% were infected by blood products or in a health care setting and 1% were people with haemophilia infected through contaminated blood products.

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

Current health

Most respondents reported that they currently feel healthy: 20% said that their health is “*excellent*”, 45% said that their health is “*good*”, 26% said that their health is “*fair*”, and 9% said that their health is “*poor*”. When asked about their well being 14% described it as “*excellent*”, 49% as “*good*”, 29% as “*fair*” and 9% as “*poor*”. Twenty-one percent of the respondents from Victoria 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. Twenty-three percent of Victorian PLWHA reported receiving pre-test counselling, most commonly provided by a doctor (62% of those receiving such counselling) or a nurse (21%). Most (77%) of these PLWHA were happy with the information they received from this counselling, while 79% were happy with the support they received. These proportions are similar to those reported by PLWHA from other parts of Australia.

Fifty-six percent of Victorian PLWHA reported receiving post-test counselling, again most commonly provided by a doctor (48% of those receiving such counselling), but also commonly provided by a counsellor/psychologist (16%), a doctor and a counsellor/psychologist (8%), a nurse (6%) or an AIDS organisation employee (6%). Most (78%) of these PLWHA were happy with the information they received from this counselling, while 75% 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 Victoria have a major health condition other than HIV/AIDS - a similar proportion to that reported by PLWHA from other States. The most frequently cited “other” health conditions included hepatitis C, arthritis, cardiovascular disease, diabetes, and asthma.

Over one quarter (27%) of respondents from Victoria reported having been diagnosed with a mental health condition – a similar proportion reported by respondents from other states. Most (93%) of these respondents had been diagnosed with depression, with no other diagnosis being reported by more than two respondents. Around a third (30%) of respondents are on medication for anxiety, 26% for depression, and 4% are on anti-psychotic medication.

Around one in six (16%) PLWHA from Victoria have had hepatitis A, and slightly more (23%) had been diagnosed with hepatitis B. Both these proportions are significantly lower than those reported by PLWHA in other states. Over half the respondents (53%) had been vaccinated against hepatitis B and 47% had been vaccinated against hepatitis A. Sixty-six percent of Victorian PLWHA have been tested for hepatitis C: 45% have had an anti-body test; 5% have had a diagnostic PCR test; and 23% reported that they didn't know what type of test they had. Twelve percent of respondents from Victoria indicated that they had been diagnosed with hepatitis C, with 6% of these reporting that they had subsequently tested negative on a PCR test.

Victorian respondents with hepatitis C reported that they were diagnosed on average in 1993 and were infected on average in 1990, which was similar to coinfecting respondents in other states. They most commonly reported becoming hepatitis C positive through IDU (66%), with no other response accounting for more than two respondents.

Almost all (97%) of Victorian respondents with hepatitis C have taken a liver function test, and 28% have had a liver biopsy. One fifth (21%) reported having taken either interferon monotherapy or interferon and ribavirin combination therapy. About a third (29%) said they had experienced symptoms of hepatitis C, while a further 39% said they were unsure about this. Almost a quarter (24%) of coinfecting Victorian respondents felt that HIV community services didn't meet their needs as someone with both HIV and hepatitis C.

Almost all Victorian 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 8% of Victorian PLWHA have a CD4/T-cell count below 250 and a viral load above 10,000.

Table 1 Results of serological testing

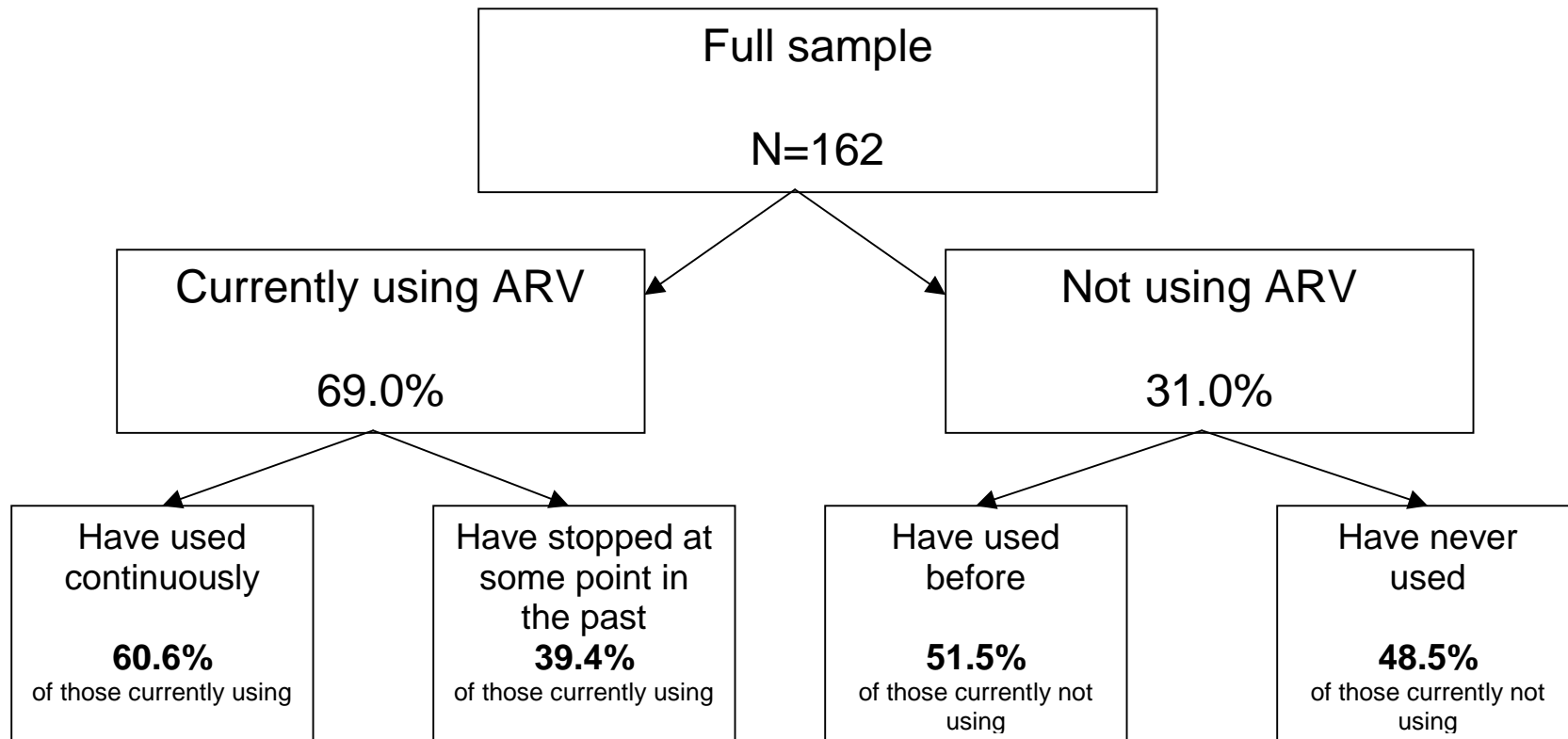
Description	Result	Percentage
CD4/T-cell count	cells/ml blood	
little or no immune damage	over 500	46
moderate immune damage	250 – 499	30
severe immune damage	below 250	24
Viral load	copies/ml blood	
below detectable level	below 500	56
low	500 - 9,999	17
moderate	10,000 - 49,999	16
high	over 50,000	11

Over a third (33%) of Victorian respondents have had a viral resistance test, with 52% of these having their most recent viral resistance test in 2001. Victorian respondents were significantly more likely to have had a viral resistance test at some point than PLWHA from other states. For Victorian respondents who had taken a viral resistance test, 81% reported that their most recent test found resistance to a drug with 79% of these reporting that they changed medications due to this result. Of this proportion 73% reported that their viral load decreased and 61% reported that their CD4/T-cell count increased.

Antiretroviral treatments for HIV/AIDS

Figure 1 shows the uptake of antiretroviral treatment for Victorian PLWHA. Over eight out of ten (85%) Victorian PLWHA have taken antiretroviral drugs at some stage, while 69% are using them currently. These figures are similar to those for PLWHA from other states. Of those PLWHA from Victoria who are currently taking antiretrovirals 46% report that their health has improved, 15% report that their health has stayed the same, 32% that it fluctuated, and 8% that it has deteriorated, while 38% said their well-being improved, 13% that it stayed the same, 40% that it fluctuated and 8% that it had deteriorated.

Figure 1: The uptake of antiretroviral drugs



Under half (48%) of the PLWHA from Victoria 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: nausea (experienced by 46% of Victorian PLWHA who experience side effects of antiretroviral drugs), diarrhoea (30%), fatigue/lethargy (19%), dizziness (15%), headaches (13%), and memory loss (10%).

Three quarters (76%) of Victorian PLWHA who use antiretrovirals report other difficulties in taking this medication. The most common difficulties among these respondents are remembering to take drugs on time (61%), taking medication in public (46%), organising meals around medication (43%) and taking a large number of pills (42%).

Nine percent of Victorian PLWHA missed at least one dose on the day before they filled out the survey, with a similar proportion (13%) missing a dose the day before that. Only 4% missed a dose on both days.

Thirty-nine percent of Victorian 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 18 months ago and lasted for 160 days. Most Victorian PLWHA (70%) considered this break to be a short-term one, with 22% saying it was long-term and 8% that it was a cycle or pulse break. Just under half (46%) 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 (12% of those who took a break) and taking treatments at the right time being too difficult (11%). Fifty-six percent of those Victorian respondents who had taken a break from antiretroviral therapy had clinical reasons for their most recent break. Most common among these were side effects (27% of those who took a break), drug resistance (15%) and a doctor's recommendation (14%).

Almost three-quarters (72%) of Victorian current antiretroviral users who had taken a break talked to a doctor about it before this break, while 74% saw a doctor during the break and 88% talked to their doctor after their break. The outcome of these breaks can be seen in Table 2. Respondents most commonly reported that their well-being improved while on their break, but less commonly said their overall health improved. This was mirrored by the effect on clinical markers, with proportions of respondents who reported a decreased CD4/T-cell count and an increased viral load both exceeded 55%.

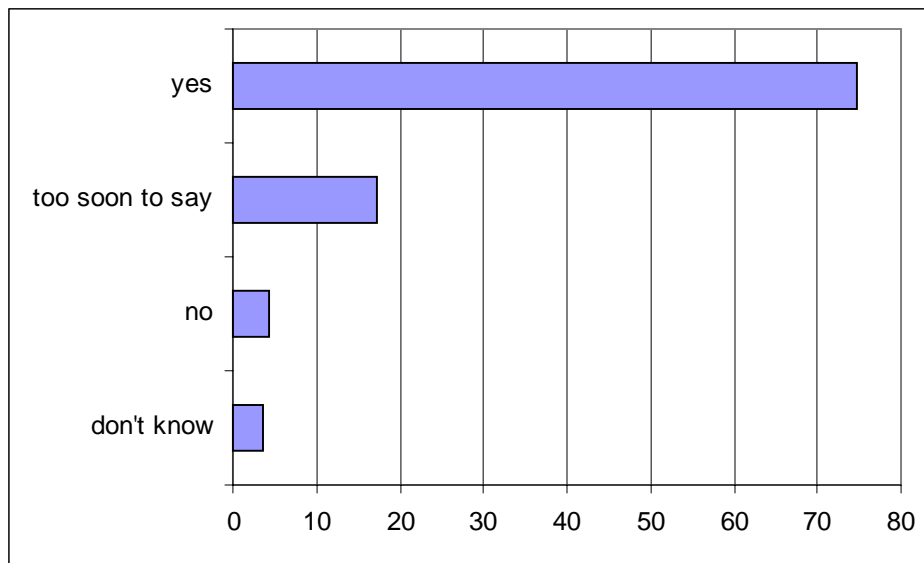
Table 2 Percentage reporting various outcomes of treatment break

	Stayed same	Improved	Fluctuated	Deteriorated
Health^a	23	16	32	30
Well-being^b	26	33	25	16
	Stayed same	Increased	Fluctuated	Decreased
Viral load^c	27	55	8	10
CD4^d	27	7	10	56

a: N=39; b: N=39; c: N=39; d: N=40

Figure 2 (below) shows that most (75%) of Victorian PLWHA agree that antiretroviral drugs have improved the prospects of most PLWHA, while 4% believe they haven't improved the prospects of PLWHA, 4% do not know and 17% believe it is too soon to tell.

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



Those Victorian PLWHA who are currently using combination therapy have done so for an average of 4 years and 10 months. The mean number of combinations they have tried in this time is 3.3, 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 = 73,961 copies/ml) and their CD4 count was low (mean = 200.0). The most common circumstances surrounding the commencement of combination therapy for these respondents were doctors advice (74%), a drop in CD4 count (35%), becoming very ill (34%), hearing of the effectiveness of the treatment (32%), a rise in viral load (32%) and new drugs becoming available (30%).

Among those who have tried more than one combination, the most common reasons for changing the last time they did so were side effects (37%), resistance to their combination having developed (35%) and the combination they were changing from was not working (26%). Victorian

PLWHA were more likely than PLWHA from other states to report that they changed medications due to resistance having developed, and were less likely to have changed due to side effects becoming too severe. Most PLWHA from Victoria felt they still had options left – 20% reporting they have many options, 31% a few, 8% one and 4% none. However, there was some uncertainty on this issue, with 37% reporting that they weren't sure how many combinations they had left.

Those Victorian PLWHA who have stopped using antiretrovirals had been using them for an average of 3 years and 2 months and had stopped an average of 2 years and 2 months ago. They have used on average 3.3 combinations. Of the Victorian PLWHA who had taken antiretrovirals and stopped, only 14% reported that their health improved on the medication, 14% reported that it stayed the same, 49% that it fluctuated and 24% that it deteriorated. Fourteen percent of these respondents reported that their well-being improved while they were on antiretroviral medications, 5% reported that it stayed the same, 39% that it fluctuated and 42% that it deteriorated. Over two fifths (46%) of Victorian respondents that had stopped using antiretrovirals reported lifestyle reasons for doing so. The most common lifestyle reason given by such respondents from all states was the desire to clean out their system (17% of all ex-antiretroviral users). Two-thirds (69%) of Victorian ex-antiretroviral users had clinical reasons for stopping treatment. The most common of these for the whole sample were side effects (35% of all ex-antiretroviral users), a doctor's recommendation (33%) and drug resistance having developed (11%). Over three quarters (89%) of ex-antiretroviral users from Victoria talked to their doctor before they stopped taking antiretrovirals, and almost all (96%) 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
Health^a	22	45	23	10
Well-being^b	12	59	18	10
	Stayed same	Increased	Fluctuated	Decreased
Viral load^c	18	31	42	9
CD4^d	16	26	38	21

a: N=27; b: N=26; c: N=23; d: N=24

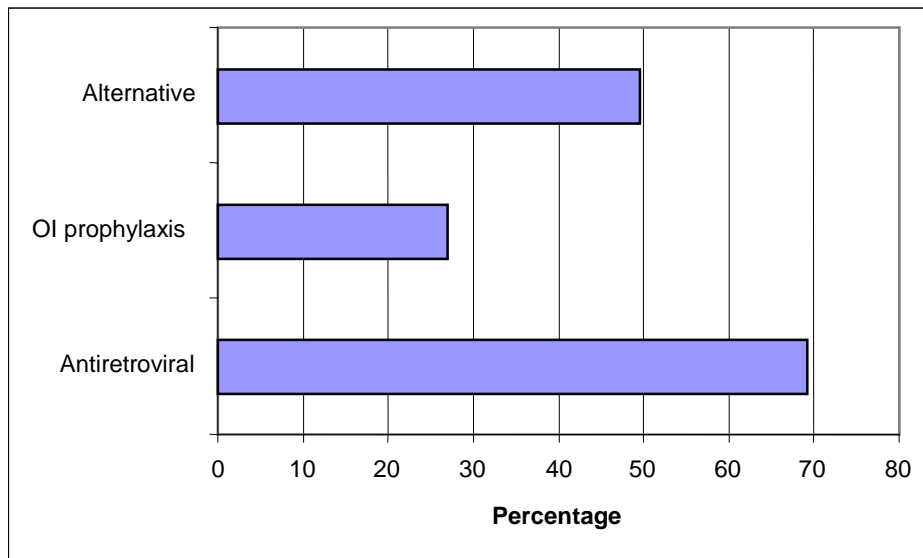
Of all Victorian PLWHA not currently taking antiretroviral medications, 88% reported that they would consider taking them in the future. The most common circumstances which the PLWHA report might make them start antiretrovirals are becoming very ill (77%), on a doctor's advice (70%), hospitalisation due to HIV-related infections (62%), a significant drop in CD4/T-cell count (60%) or a significant rise in viral load (54%). Victorian respondents were less likely than those

from the rest of Australia to cite a rise in viral load and a drop in CD4 count as reasons for commencing combination therapy.

Other treatments for HIV/AIDS

Figure 3 (below) shows that while the majority of Victorian PLWHA use antiretroviral drugs, just under half use alternative therapies and one in four (27%) of the respondents from Victoria 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 (78% of Victorian PLWHA who use alternative therapies), massage (45%) and marijuana (36%). Victorian PLWHA were more likely than PLWHA from other states to use acupuncture (24% v 12%) and traditional Chinese medicine (14% v 6%).

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, Victorian PLWHA had favourable attitudes toward alternative therapies (mean = 2.9). PLWHA from Victoria had similar attitudes toward alternative therapies as PLWHA from other states (mean = 2.8).

Information and support services

Over two thirds of Victorian respondents (69%) have direct contact with an HIV/AIDS-related organisation. This was more common for respondents in Melbourne than those in the rest of the state (75% v 47%). Of those Victorian PLWHA in contact with HIV/AIDS organisations, 79% receive a newsletter, 54% are clients, 74% are members, 25% are volunteers and 5% are staff.

Victorian PLWHA who are in contact with AIDS organisations are significantly more likely to be members than such respondents from other states. Of those PLWHA in the Victorian sample who do not have contact with and HIV/AIDS organisation the most common reasons given are not having transport (34%), not having time (32%), not wanting to be involved (32%) and feeling excluded (31%). Not having access to transport was a reason not to have contact with an HIV/AIDS organisation for significantly more respondents in rural Victoria (67%) compared with those in Melbourne (20%), while feeling excluded was a less common reason (14% v 39%). Fifty-five percent of Victorian PLWHA who have contact with an HIV/AIDS-related organisation have contact with the VAC, 42% have contact with PLWHA (VIC), 29% have contact with the Positive Living Centre, 21% with Straight Arrows and 14% with Positive Women. Among PLWHA from Victorian there was no relationship between having contact with the VAC 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	44	28
Social contact with other PLWHA	41	11
Treatments information	38	14
Peer support group	32	6
Pharmacy services	32	41
Legal advice	27	12
Counselling	25	26
Housing assistance	22	13
Alternative therapies	21	24
Informal peer support	21	8
Financial assistance	18	11
Volunteer carer	11	6
Respite care	11	6
Transport	11	19
Community education campaigns	10	2
Mental health services	8	16
Internet based information	8	18
Internet access	8	27
Library	7	26
Employment services	7	13
Financial advice	7	18
Drug/alcohol treatment	2	5
Return to work skills	2	9
Paid carer	1	3

Table 4 (above) displays the proportion of Victorian 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 peer support. PLWHA from Victoria are significantly more likely than PLWHA from other states to report that they make use of pharmacy services, legal advice and housing assistance provided by HIV/AIDS organisations. Victorian

PLWHA made use of services provided by non-AIDS organisations in similar proportions to those reported by PLWHA in the rest of the country. PLWHA from rural regions in Victoria are significantly less likely to use pharmacy services provided by HIV/AIDS organisations than PLWHA from Melbourne.

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 (46%) as the *most* important source of information. However, significant proportions rely on HIV/AIDS-related newspapers and magazines, publications from HIV/AIDS organisations, outpatient HIV specialists and the gay press, which suggests that PLWHA seek information from a range of different sources. Victorian PLWHA generally cited more sources of information on treatments than PLWHA from other states. Specifically, they were more likely to cite HIV specialists at inpatient clinics, pharmacists, dieticians and their partners as sources of treatments information. PLWHA from rural Victoria used similar sources of treatments information as Melbourne PLWHA.

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 (42%) as the *most* important source of information. Again, significant proportions rely on HIV positive friends, HIV/AIDS-related newspapers and magazines, publications from HIV/AIDS organisations, outpatient HIV specialists and the gay press. Victorian PLWHA were more likely than other PLWHA to cite the HIV specialists at inpatient clinics, pharmacists, dieticians and sex worker organisations as an important source of information on HIV management. PLWHA from rural Victoria used similar sources of HIV management information as Melbourne PLWHA.

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 positive friends, HIV magazines and newspapers and publications from HIV/AIDS groups. 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 (25%), HIV positive friends (21%) and outpatient HIV specialists (14%). PLWHA from Victoria were significantly more likely than PLWHA from other parts of Australia to report pharmacists as important sources of information about living with HIV/AIDS.

Again, PLWHA from rural Victoria used similar sources of HIV management information as Melbourne PLWHA.

PLWHA from Victoria were also significantly more likely to cite positive women's organisations and positive heterosexuals' groups as sources of all three categories of information. These differences can be explained by the larger numbers of women and heterosexuals in the Victorian sample.

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	69	56	32
Other GP	18	12	10
Outpatient HIV specialist	41	33	19
Inpatient HIV specialist	19	13	9
Other doctor	7	4	5
Public Health Nurse	7	8	8
Other nurse	5	7	7
Pharmacist	23	14	11
Alternative therapist	19	18	14
Dietician	15	20	20
Dentist	12	14	9
Peer support officer	8	10	13
Sexual health service	20	19	15
Family Planning Association	3	3	3
Sex worker organisation	2	5	3
Treatments officer	21	17	13
Other HIV/AIDS organisation staff	13	11	17
Positive women's organisation	11	10	12
Positive heterosexuals' group	12	12	12
Injecting drug user's organisation	4	3	4
Haemophilia Foundation	4	5	4
HIV positive friends	37	40	48
Other friends	8	5	12
Partner/lover	19	19	24
Family	6	5	9
Gay press	38	30	32
HIV magazine/newspaper	50	38	43
Liver specialist	5	2	3
Hep C Support Group/Organisation	7	6	4
Internet	26	22	22
Publications from HIV/AIDS groups	41	39	40
Publications from other sources	12	8	9

The HIV-related publications most read by Victorian PLWHA are gay newspapers (66%), Positive Living (64%), the HIV Herald (36%) and newsletters from community organisations (32%). PLWHA from rural Victoria read these publications in similar proportions as those from Melbourne.

We asked respondents whether they thought lack of information made it difficult to make decisions about various issues surrounding living with HIV. Victorian respondents most felt a lack of information when making decisions on financial planning (35%), employment (33%), the interactions between antiretrovirals and other medications (31%) and managing antiretroviral side effects (29%). People from Victoria more commonly reported than PLWHA from other states a lack of information on financial planning (35% v 21%), having children (14% v 7%), using complementary therapies (26% v 16%).

In the last 6 months the health services that Victorian PLWHA had most commonly used were an HIV GP/S100 prescriber (64%), an HIV specialist at an outpatient clinic (43%), a dentist (40%) and a non-S100 prescribing GP (33%). Victorian PLWHA were more likely to have used an HIV specialist at an inpatient clinic and a hospital social worker or counsellor than PLWHA from other states. Sixty-five percent of Victorian 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 Victorian 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 Victorian PLWHA spend no free time with other positive people, although just under half spend "some" or "a lot" of time with other positive people. Twenty-two percent of Victorian PLWHA have 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	17
A little	39
Some	29
A lot	16

Only 2% of respondents from Victoria have not disclosed their HIV status to anyone. Approximately one half (48%) have had their HIV status disclosed when they didn't want it to be (30% in the last two years). Victorian PLWHA most commonly reported that this disclosure came from work colleagues (33% of those that reported unwanted disclosure), acquaintances (31%) and close friends (29%). 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 Victoria received the most support from their partners (mean=1.39), their pets (mean=1.50) and their doctors (mean=1.56).

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 Victorian respondents can be seen in Table 7 (below). There were no differences between PLWHA from Victoria 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 Victorian PLWHA 42% agreed or strongly agreed with none of these items, 21% with one item, 20% with two, 9% with three and 8% with all four. Agreement with all four items is suggestive of clinical depression. Many Victorian respondents had a negative body image. Just under half (50%) of the respondents agreed or strongly agreed that they were happy with the way their body looks, and 54% agreed or strongly agreed that changes in their bodies due to HIV/AIDS had made them sexually unattractive. Respondents tend to have a positive attitude to their HIV. Just over half (52%) report that they do think about HIV even when they are well, and 50% felt that their life had become more meaningful since they were diagnosed with HIV.

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

	strongly agree	agree	disagree	strongly disagree
I cry or feel like crying all the time	5	16	58	21
I don't enjoy things the way I used to	9	41	38	12
I have lost interest in other people	7	30	45	18
I don't feel it's worth going on	3	12	43	42
As long as I'm well I prefer not think about HIV/AIDS	11	38	43	9
Life has become more meaningful since I became HIV positive	15	36	36	13
I am happy with the way my body looks	10	39	40	11
Changes in my body due to HIV/AIDS have made me feel sexually unattractive	15	40	32	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 Victoria. Over a third (36%) of Victorian PLWHA have changed how far they plan into the future in the last two years, of whom 61% had started planning for a longer time frame. Among Victorian 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 (45%). 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 (74%).

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	32
1 year ahead	22
5 years ahead	19
10 or more years ahead	8

Sexual Relationships

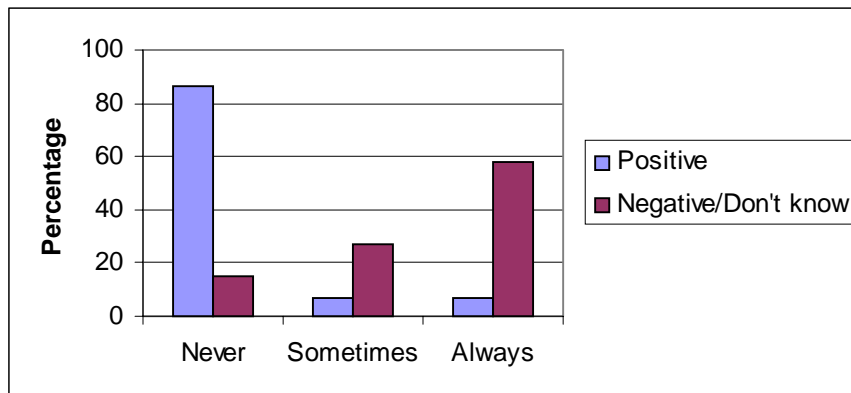
Respondents were asked to describe their sexual orientation or sexual identity. The majority of respondents were homosexual men (75%), followed by heterosexual women (10%) and men (8%), bisexual men (4%) and women (2%) and lesbians (1%). When asked to describe their current sexual relationships, 24% reported that they are not currently sexually active, while 23% reported that they only have casual sex, 29% have sex in a monogamous regular relationship, and 24% have sex in a non-monogamous regular relationship.

Forty-eight percent of respondents who have a regular relationship are in a seroconcordant relationship - the remainder (52%) are in a relationship with an HIV seronegative partner, or a partner whose serostatus is unknown. PLWHA living in rural Victoria were significantly more likely to have an HIV positive partner. All (100%) 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 (30%) or that their partner already knew they were HIV positive when they started the relationship (16%). Of the remainder, 68% told their partner at the start of the relationship, 9% within a few days, 11% within a few weeks, 6% within a few months, while 5% took a year or more. Respondents were also asked how their partner reacted when they told them that they are HIV seropositive. Most respondents (60%) said that it did not make any difference. Over one half (67%) of respondents reported that their partner was very supportive, and 42% said that they became closer, while 41% said that their partner was worried or scared and 8% said that their partner was angry. PLWHA from Victoria were significantly more 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, 53% reported that they were relieved, 44% that they were worried, 42% that they became closer, 22% 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, 37% reported that they always used a condom, 19% reported that they sometimes used a condom, and 44% 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, 42% reported that they always used a condom, 46% reported that they sometimes used a condom, and 12% 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 Victorian 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 Victorian PLWHAs, almost all (95%) of these sexual contacts were with male partners, and the majority (74%) involved vaginal or anal intercourse. The respondents most often didn't know the HIV status of their partners (69%); of the rest 21% were known to be positive and 10% were known to be negative. Almost all (91%) Victorian respondents who knew their partners status did so because their partner disclosed this information. Amongst those who engaged in vaginal or anal intercourse, 57% of Victorian 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 Victorian PLWHA. There were no significant differences in how commonly PLWHA from Victoria use any of these drugs compared with the rest of the sample. Most PLWHA from Victoria were not concerned with the amount of drugs they took. Eighty-three percent either disagreed or strongly disagreed with the statement that they use more illegal drugs than they would like, and 81% disagreed or strongly disagreed that they drink more alcohol than they would like. One in five (20%) 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	82.4
Cigarettes	58.4
Marijuana	52.7
Amyl	36.2
Ecstasy	26.2
Viagra or similar	19.3
Speed (not injected)	16.2
Speed (injected)	14.3
LSD/trips	11.8
Cocaine (not injected)	8.4
Heroin (injected)	6.3
Steroids (injected)	4.4
Cocaine (injected)	3.7
GHB/GBH/Fantasy	3.7
Methadone (prescribed)	3.6
Homebake	2.4
Heroin (not injected)	0.7
Methadone (non-prescribed)	0.2

Housing

The majority (80%) of Victorian respondents live in Melbourne, while 8% live in a regional centre or town, and 12% live in a rural area. These proportions are similar to those for other states.

Table 10 (below) shows that while many Victorian 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, Victorian PLWHA were significantly more likely to live in public rental accommodation and were less likely to live in private rental accommodation. The vast majority (76%) of Victorian respondents believe that their current housing is suitable for their needs. Forty-one percent of Victorian PLWHA have changed their accommodation as a result of having HIV/AIDS. Among these the most common reasons for change were the need for cheaper housing (50%), avoiding harassment (29%), moving closer to health services (25%) and a lack of privacy (22%).

Table 10 Accommodation in which PLWHA live

Accommodation Type	Percentage
Own or purchasing own house or flat	41
Private rental accommodation	24
Public rental accommodation	24
Live rent-free	4
Community housing	5

When asked whom they live with, 31% of Victorian PLWHA reported that they live alone, 40% live with a sexual partner, 17% live with friends or housemates, 9% live with dependent children and 9% live with other family members. Respondents from Victoria are less likely than other PLWHA to live alone.

Employment

Over half (54%) of Victorian PLWHA were not in paid employment at the time of completing the survey. Of the PLWHA who are working, 47% work full-time and 53% work part-time. Most Victorian PLWHA (80%) report that being diagnosed HIV positive affected their career plans - 27% report that it was more difficult to plan, 23% report that they stopped work, 18% report that having a career was no longer as important, 7% changed careers because of their diagnosis and 5% report they were less likely to change their career. Since then 81% say HIV has affected their career plans – 26% reported that their career has ended, 21% that it is more difficult to plan, 17% have changed careers, 12% that a career is no longer as important and 6% are less likely to change careers. When asked the effect of antiretrovirals on their work plans, respondents most commonly (26%) reported that they haven't changed, while 18% reported that they stopped work, 15% that they haven't used antiretrovirals, 12% that they anticipate a longer time in the workforce. One in four (26%) Victorian PLWHA report having been discriminated against at work as a result of having HIV/AIDS, with 8% reporting having been discriminated against at work in the last 2 years.

Fifty-four percent of Victorian PLWHA who have ever worked have stopped doing so at some stage due to their HIV diagnosis. These PLWHA stopped work for an average two years and nine months. The last time they stopped working the most common reasons were stress or depression (61%), low energy (59%) and poor health (56%). When asked their HIV status at the time they stopped work, 35% reported they were HIV positive but had not been ill, 43% they were HIV positive and had been ill, and 22% that they had been diagnosed with an AIDS defining illness. When they were not working most (78%) received government benefits. About half (52%) of these PLWHA have returned to work. The most common reasons for returning to work were financial (85%), better psychological health (59%), to have something to do (58%), to do something worthwhile (53%) and better physical health (46%).

The 46% of Victorian PLWHA who are presently employed work an average of 31.6 hours per week. Most (78%) report that their job involves a moderate to very high stress level. Sixty-one percent of Victorian PLWHA who are working reported that their capacity to perform their work duties is affected by having HIV/AIDS: these respondents most frequently reported that they tire quickly (50%), work fewer hours (29%), and have difficulty concentrating (25%). Sixty-seven percent of workers reported that they could 'often' or 'always' get time off work for medical appointments, 50% for counselling, 77% for sick leave, and 25% for volunteer work.

Forty-one percent of Victorian PLWHA indicated that they are considering changing their work arrangements. Of these 45%, want to change the type of work they do, 44% want to start or return to work, 19% want to reduce their hours, 5% want to increase their hours and 1% want to stop work. Most of the PLWHA who want to change their work arrangements perceived that this would be difficult: 25% believe it will be 'very difficult', 53% believe that it will be 'somewhat difficult' and 22% that it will be 'not at all' difficult.

Finances

Given the large number of PLWHA in Victoria who are not in paid employment, it is not surprising that 51% of respondents reported that their main source of income is a government benefit, pension, or social security payment. Thirty-five percent of respondents reported that a salary is their main source of income, while 10% reported superannuation or an annuity as their main source of income. Almost two-thirds of the Victorian respondents reported annual incomes below \$20,000. Respondents' incomes are displayed in Table 11 (below).

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. Over a third (35%) of Victorian PLWHA were living below the poverty line.

Table 11 Income reported by PLWHA

Weekly income	Yearly income	Percentage
\$0 - \$150	\$0 - \$7800	2
\$151 - \$270	\$7801 - \$14040	41
\$271 - \$390	\$14041 - \$20280	20
\$391 - \$510	\$20281 - \$26520	14
\$511 - \$630	\$26521 - \$32760	8
\$631 - \$750	\$32761 - \$39000	8
\$751 -	\$39001 -	8

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 one in five Victorian PLWHA find it “very difficult” to meet the cost of food, and almost a quarter find it “very difficult” to meet the cost of utilities (telephone, gas, electricity). It is also interesting to note one-quarter of the respondents who use complementary/alternative therapies find it very difficult to meet the cost of this treatment.

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	60	32	8
Other prescribed medication	46	40	14
Medical services	54	33	12
Complementary therapies	42	35	23
Support services	61	24	15
Entertainment	27	35	38
Going out	28	32	40
Sport	35	30	35
Recreational drugs	21	38	41
Travel / holidays	20	26	54
Rent / mortgage / housing	35	41	24
Utilities (phone, gas, etc.)	30	48	23
Food	41	41	18
Clothing	30	33	37
Transport	39	44	17
Child care	35	41	24

Discrimination

Two fifths (39%) of Victorian PLWHA had experienced less favourable treatment than other people when attending a medical service because of their HIV status, with 22% having experienced such discrimination in the last 2 years. Although PLWHA from Melbourne were slightly more likely than rural PLWHA to have experienced discrimination at a medical service in

the last 2 years, there was no difference in the proportions of rural and Melbourne PLWHA to have experienced discrimination overall. This suggests that this situation is improving for rural PLWHA more than it is for Melbourne PLWHA.

When asked to describe what form this discrimination took respondents most commonly reported avoidance (44%), followed by confidentiality problems (35%), refusal of treatment (27%), additional infection control (20%), being rushed through (20%), being treated last (14%), harassment (13%), and abuse (8%). Respondents from Victoria were less likely to report that this discrimination took the form of being treated last.

Thirteen percent of PLWHA from Victoria had received less favourable treatment due to their HIV status in relation to accommodation, with 6% having this happen in the last 2 years. One in four (26%) of respondents in Victoria had been discriminated against in relation to employment (8% in the last 2 years), and 18% had been discriminated against in relation to insurance (8% in the last two years).

REFERENCES

- Grierson, J., Misson, S., McDonald, K., Pitts, M., and O'Brien, M. (2002) **HIV Futures 3: Positive Australians on Services, Health and Well-being**. Monograph Series Number 37. The Australian Research Centre in Sex, Health and Society, Latrobe University, Melbourne, Australia.
- Institute of Applied Economics and Social Research (2002) **Poverty lines: Australia, June quarter 2001**. Melbourne: Institute of Applied Economics and Social Research, University of Melbourne.
- National Centre in HIV Epidemiology and Clinical Research (NCHECR) (2001) **HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia Annual Surveillance Report 2001**. Sydney: National Centre in HIV Epidemiology and Clinical Research, University of New South Wales