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HIV Futures 3 Regional Reports: Queensland

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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).

One hundred and thirty-six PLWHA from Queensland completed the HIV Futures Survey. We are grateful for the assistance provided by the following individuals and organisations who helped distribute the survey in Queensland: the AIDS Medical Unit, Brisbane Sexual Health Clinic, Gladstone Road Medical Centre, Gold Coast District Health Service, Gold Coast Sexual Health Clinic, Nambour Hospital, Queensland Positive People (QPP), QPP Gold Coast, QPP Mackay, QPP Rockhampton, QPP Sunshine Coast, the Queensland AIDS Council (QuAC), QuAC Cairns, QuAC Townsville, QuAC Gold Coast, QuAC Sunshine Coast, Queensland Intravenous AIDS Association, Sunshine Coast Intravenous AIDS Association, Cairns Sexual Health Service, Ipswich Sexual Health Service, Mackay Sexual Health Service, Toowoomba Sexual Health Service, Townsville Sexual Health Service, Rockhampton Sexual Health Service, Sunshine Coast Sexual Health Clinic, and Wide Bay Public Health Unit.

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 Queensland contained 87% males and 13% females. The ages of the Queensland respondents ranged from 22 years to 73 years. The average age for Queensland PLWHA was 43.0 years. On average, PLWHA living in Queensland had been HIV seropositive for 9.6 years.

The vast majority of respondents had been infected with HIV through sexual contact: 73% cited homosexual or bisexual contact as the most likely transmission route and 12% cited heterosexual contact, while 7% reported injecting drug use, 2% reported homosexual/bisexual contact and injecting drug use, 2% were infected by blood products or in a health care setting, 3% were people with haemophilia infected through contaminated blood products and 1% were infected by other means.

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

Current health

Most respondents reported that they currently feel healthy: 19% said that their health is “*excellent*”, 53% said that their health is “*good*”, 23% said that their health is “*fair*”, and 5% said that their health is “*poor*”. When asked about their well being 18% described it as “*excellent*”, 49% as “*good*”, 26% as “*fair*” and 7% as “*poor*”. Fourteen percent of the respondents from Queensland 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-one percent of Queensland PLWHA reported receiving pre-test counselling, most commonly provided by a doctor (41% of those receiving such counselling) or a nurse (18%). Almost all (97%) of these PLWHA were happy with the information they received from this counselling, while 93% were happy with the support they received. These proportions are similar to those reported by PLWHA from other parts of Australia.

Fifty-seven percent of Queensland PLWHA reported receiving post-test counselling, again most commonly provided by a doctor (37% of those receiving such counselling), but also commonly provided by a nurse (15%), a counsellor/psychologist (11%) or an AIDS organisation employee (11%). Most (90%) of these PLWHA were happy with the information they received from this counselling, while 85% were happy with the support they received. These proportions are similar to those reported by the rest of the sample.

Forty-four percent of respondents from Queensland 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, cardiovascular disease, back pain and asthma.

One quarter (26%) of respondents from Queensland reported having been diagnosed with a mental health condition – a similar proportion reported by respondents from other states. Most (81%) of these respondents had been diagnosed with depression, with no other diagnosis being

reported by more than two respondents. Around a fifth (20%) of respondents are on medication for anxiety, 23% for depression, and 2% are on anti-psychotic medication.

Around one in four (24%) PLWHA from Queensland have had hepatitis A, and slightly more (30%) had been diagnosed with hepatitis B. Over half the respondents (61%) had been vaccinated against hepatitis B and 49% had been vaccinated against hepatitis A. Seventy-one percent of Queensland PLWHA have been tested for hepatitis C: 46% have had an anti-body test; 6% have had a diagnostic PCR test; and 24% reported that they didn't know what type of test they had. Nineteen percent of respondents from Queensland indicated that they had been diagnosed with hepatitis C, with 8% of these reporting that they had subsequently tested negative on a PCR test.

Queensland respondents with hepatitis C reported that they were diagnosed on average in 1991 and were infected on average in 1986. Queensland respondents tended to have been diagnosed earlier than those in other states. They most commonly reported becoming hepatitis C positive through IDU (39%), blood products (21%) and sex (16%).

Almost all (99%) of the Queensland respondents with hepatitis C have taken a liver function test, and 24% have had a liver biopsy. One eighth (12%) reported having taken either interferon monotherapy or interferon and ribavirin combination therapy. Forty-three percent said they had experienced symptoms of hepatitis C, while a further 24% said they were unsure about this. The most common symptoms experienced by co-infected respondents from Queensland were fatigue (83%) and pains in the liver (37%). Almost a third (30%) of coinfected Queensland respondents felt that HIV community services didn't meet their needs as someone with both HIV and hepatitis C.

All Queensland respondents reported having taken a CD4/T-cell test (100%), and 99% 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 10% of Queensland PLWHA have a CD4/T-cell count below 250 and a viral load above 10,000.

Table 1 Results of serological testing

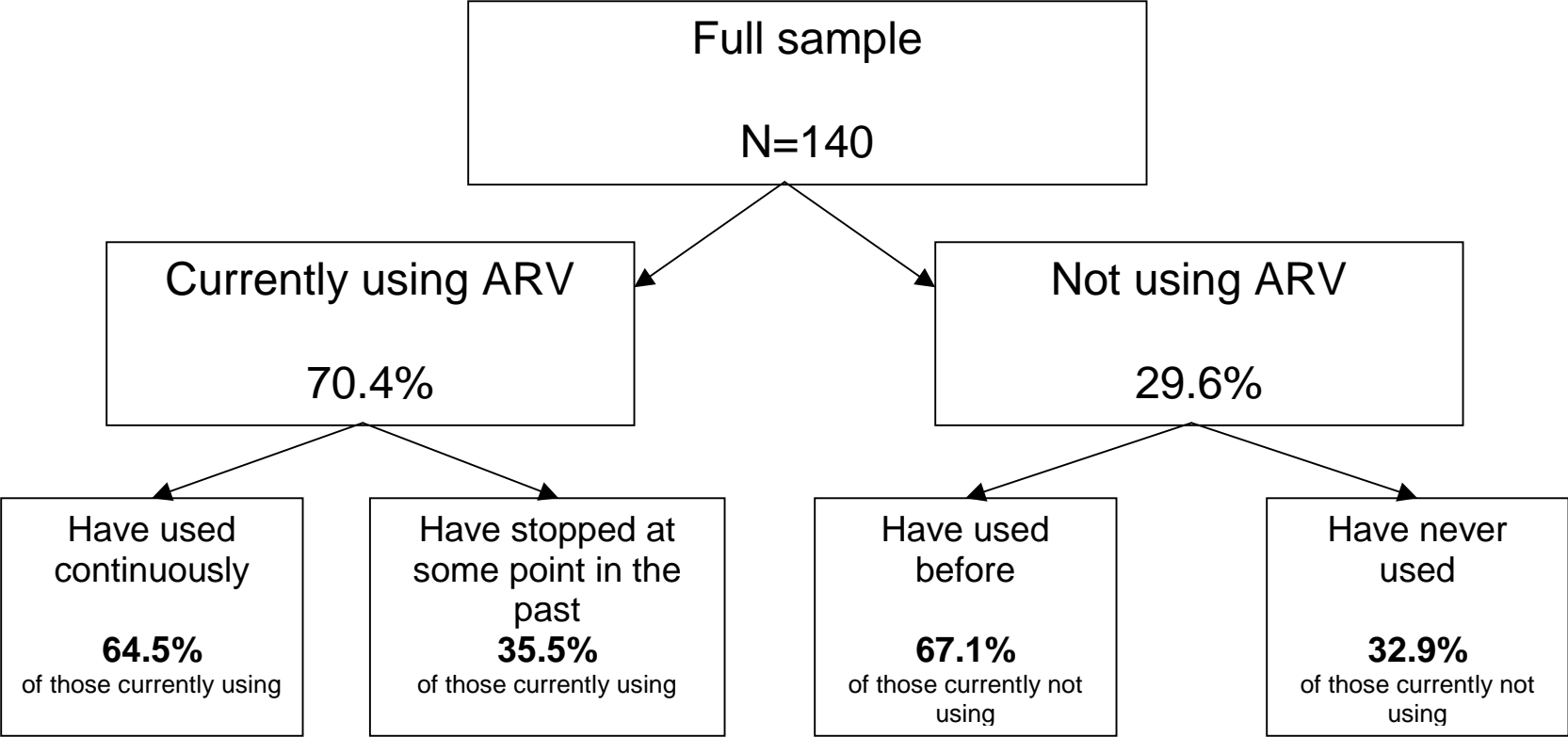
Description	Result	Percentage
CD4/T-cell count	cells/ml blood	
little or no immune damage	over 500	46
moderate immune damage	250 – 499	35
severe immune damage	below 250	19
Viral load	copies/ml blood	
below detectable level	below 500	60
low	500 - 9,999	17
moderate	10,000 - 49,999	9
high	over 50,000	14

Seventeen percent of Queensland respondents have had a viral resistance test, with 57% of these having their most recent viral resistance test in 2001. For Queensland respondents who had taken a viral resistance test, 85% reported that their most recent test found resistance to a drug with 62% of these reporting that they changed medications due to this result. Of this proportion 55% reported that their viral load decreased and 35% reported that their CD4/T-cell count increased.

Antiretroviral treatments for HIV/AIDS

Figure 1 shows the uptake of antiretroviral treatment for Queensland PLWHA. Nine out of ten (90%) Queensland PLWHA have taken antiretroviral drugs at some stage, while 70% are using them currently. These figures are similar to those for PLWHA from other states. Of those PLWHA from Queensland who are currently taking antiretrovirals 49% report that their health has improved, 14% report that their health has stayed the same, 30% that it fluctuated, and 7% that it has deteriorated, while 44% said their well-being improved, 10% that it stayed the same, 43% that it fluctuated and 4% that it had deteriorated.

Figure 1 The uptake of antiretroviral drugs



Under half (45%) of the PLWHA from Queensland 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: fatigue/lethargy (experienced by 27% of Queensland PLWHA who experience side effects of antiretroviral drugs), diarrhoea (24%), nausea (23%), neuropathy (23%) and lipodystrophy (18%).

Two-thirds (69%) of Queensland PLWHA who use antiretrovirals report other difficulties taking this medication. The most common difficulties among these respondents are remembering to take drugs on time (58%), organising meals around medication (47%), taking medication in public (45%) and transporting medication (38%).

Eleven percent of Queensland PLWHA missed at least one dose on the day before they filled out the survey, with the same proportion missing a dose the day before that. Only 5% missed a dose on both days.

Thirty-six percent of Queensland 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 19 months ago and lasted for 84 days. Most Queensland PLWHA (89%) considered this break to be a short-term one, with 7% saying it was long-term and 4% that it was a cycle or pulse break. Over half (59%) 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 a special event (16%) and taking treatments at the right time being too difficult (14%). Forty-seven percent of those Queensland respondents who had taken a break from antiretroviral therapy had clinical reasons for their most recent break. Most common among these were side effects (22% of those who took a break) and a doctor's recommendation (13%).

Over half (51%) of Queensland current antiretroviral users who had taken a break talked to a doctor about it before this break, while 67% saw a doctor during the break and 86% talked to their doctor after their break. The outcome of these breaks can be seen in Table 2. Respondents most commonly reported that their health and well-being were stable during their break although they more commonly reported that their well-being improved than their health. There was a marked effect on clinical markers however, with proportions of respondents who reported a decreased CD4/T-cell count and an increased viral load both exceeded 50%.

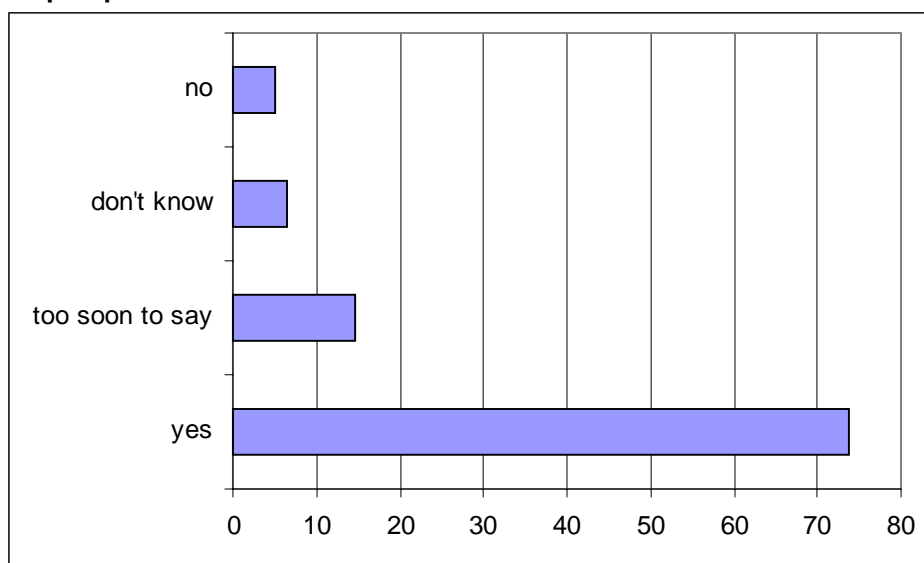
Table 2 Percentage reporting various outcomes of treatment break

	Stayed same	Improved	Fluctuated	Deteriorated
Health ^a	52	14	24	11
Well-being ^b	46	31	14	10
	Stayed same	Increased	Fluctuated	Decreased
Viral load ^c	31	54	12	3
CD4 ^d	30	4	16	50

a: N=33; b: N=32; c: N=28; d: N=30

Figure 2 (below) shows that most (74%) of Queensland PLWHA agree that antiretroviral drugs have improved the prospects of most PLWHA, while 5% believe they haven't improved the prospects of PLWHA, 7% do not know and 14% believe it is too soon to tell.

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



Those Queensland 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 2.9, with a mean of 1.4 of these having been used in the past 12 months. They started on these therapies when their viral load was high (log mean = 193,152 copies/ml) and their CD4 count was low (mean = 263.1). Queensland PLWHA had a higher log viral load on starting combination therapy than PLWHA from other states (log mean=58,331). The most common circumstances surrounding the commencement of combination therapy for these respondents were doctors advice (74%), a drop in CD4 count (36%), new drugs becoming available (31%), becoming very ill (24%), a rise in viral load (25%), and hearing of the effectiveness of the treatment (22%).

Among those who have tried more than one combination, the most common reasons for changing the last time they did so were side effects (54%), the combination they were changing from not working (28%) and resistance to their combination having developed (15%). Most PLWHA from Queensland felt they still had treatment options left – 40% reporting they have many options, 23% a few, 2% one and 4% none. However, there was some uncertainty on this issue, with 31% reporting that they weren't sure how many combinations they had left.

Those Queensland PLWHA who have stopped using antiretrovirals had been using them for an average of 3 years and 6 months and had stopped an average of 1 year and 11 months ago. They have used on average 2.4 combinations. Of the Queensland PLWHA who had taken antiretrovirals and stopped, only 12% reported that their health improved on the medication, 39% reported that it stayed the same, 28% that it fluctuated and 21% that it deteriorated. Only 4% percent of these respondents reported that their well-being improved while they were on antiretroviral medications, 28% reported that it stayed the same, 40% that it fluctuated and 29% that it deteriorated. Over half (52%) the Queensland 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 (15% of all ex-antiretroviral users) and taking drugs at the right time was too difficult (12%). A similar proportion (57%) of Queensland 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 (24%) and drug resistance having developed (11%). Over three quarters (80%) of ex-antiretroviral users from Queensland talked to their doctor before they stopped taking antiretrovirals, and most (84%) 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 that their health, well-being and clinical markers had fluctuated since stopping treatment. Although, despite the fact that 36% of respondents reported an increased viral load and 35% reported a decreased CD4 count, none of the respondents reported their health or well-being had declined

Table 3 Percentage reporting various outcomes of stopping treatment

	Stayed same	Improved	Fluctuated	Deteriorated
Health^a	34	22	44	0
Well-being^b	31	29	40	0
	Stayed same	Increased	Fluctuated	Decreased
Viral load^c	5	36	52	8
CD4^d	13	4	47	35

a: N=28; b: N=28; c: N=25; d: N=25

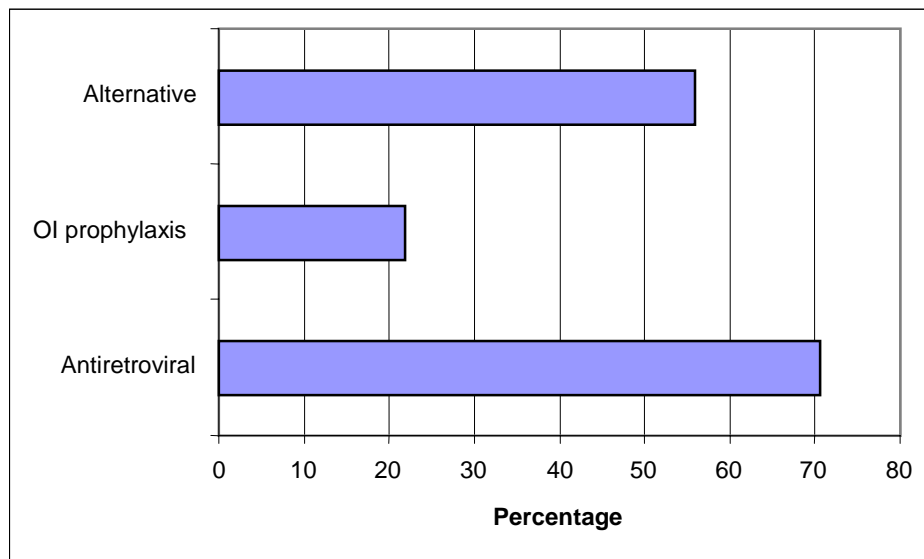
Of all Queensland PLWHA not currently taking antiretroviral medications, 80% reported that they would consider taking them in the future. The most common circumstances which the PLWHA report might make them start antiretrovirals are hospitalisation due to HIV-related infections

(77%), becoming very ill (76%), a significant rise in viral load (76%), a significant drop in CD4/T-cell count (73%) or on a doctor's advice (58%).

Other treatments for HIV/AIDS

Figure 3 (below) shows that while the majority of Queensland PLWHA use antiretroviral drugs, just over half use alternative therapies and one in five (22%) of the respondents from Queensland 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 (72% of Queensland PLWHA who use alternative therapies), massage (60%) and marijuana (32%).

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

Information and support services

Over three-quarters of Queensland respondents (78%) have direct contact with an HIV/AIDS-related organisation. Of those Queensland PLWHA in contact with HIV/AIDS organisations, 88% receive a newsletter, 69% are clients, 69% are members, 29% are volunteers and 10% are staff. Queensland PLWHA who are in contact with AIDS organisations are significantly more likely to be members and are more likely to receive newsletters than such respondents from other states.

Of those PLWHA in the Queensland sample who do not have contact with and HIV/AIDS organisation the most common reasons given are not wanting to be involved (56%), feeling excluded (21%), not having time (16%) and not having transport (12%). Eighty-three percent of Queensland PLWHA who have contact with an HIV/AIDS-related organisation have contact with the QuAC and 71% have contact with QPP. Among PLWHA from Queensland there was no relationship between having contact with QuAC or QPP 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	57	22
Treatments information	55	21
Social contact with other PLWHA	50	5
Peer support group	42	5
Counselling	40	15
Informal peer support	36	11
Financial assistance	33	9
Alternative therapies	33	29
Community education campaigns	23	5
Pharmacy services	19	32
Volunteer carer	16	9
Legal advice	16	17
Internet based information	15	17
Financial advice	14	19
Housing assistance	13	21
Transport	13	21
Internet access	12	23
Mental health services	11	11
Library	9	25
Employment services	5	20
Respite care	5	6
Drug/alcohol treatment	5	8
Return to work skills	3	15
Paid carer	1	5

Table 4 (above) displays the proportion of Queensland 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, counselling and peer support. PLWHA from Queensland are significantly more likely than PLWHA from other states to report that they make use of financial assistance, peer support groups, informal peer support, social contact with other PLWHA, alternative therapies, treatments information, internet-based information and community education programs provided by HIV/AIDS organisations. Queensland PLWHA made use of services provided by non-AIDS organisations in similar proportions to those reported by PLWHA in the rest of the country. Among Queensland respondents, those from rural regions are

significantly less likely to use treatments information provided by HIV/AIDS organisations than PLWHA from Brisbane.

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 HIV/AIDS magazine/newspapers, a HIV specialist at an outpatient clinic, a HIV GP/S100 Prescriber and publications from HIV/AIDS groups. The diversity of responses to this question suggests that PLWHA seek information from a range of different sources. Outpatient HIV specialists were most commonly cited (37%) as the *most* important source of information, followed by S100 prescribers (24%). Queensland PLWHA were less likely to cite S100 prescribers as sources of treatments information and were more likely to cite Public Health and other nurses, sexual health services. PLWHA from rural Queensland used similar sources of treatments information as Brisbane 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 were publications from HIV/AIDS groups, followed by outpatient HIV specialists, HIV magazines and newspapers and S100 prescribers. Again, outpatient HIV specialists were most commonly cited (27%) as the *most* important source of information, followed by S100 prescribers (25%). Queensland PLWHA were less likely than other PLWHA to cite S100 prescribers as an important source of information on HIV management, and were more likely to cite Public Health Nurses and sexual health services. PLWHA from rural Queensland used similar sources of HIV management information as Brisbane 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, publications from HIV/AIDS groups and HIV magazines and newspapers. 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 (18%), HIV positive friends (17%) and outpatient HIV specialists (11%). PLWHA from Queensland were significantly more likely than PLWHA from other parts of Australia to report Public Health Nurses and peer support officers as important sources of information about living with HIV/AIDS. Again, PLWHA from rural Queensland used similar sources of HIV management information as Brisbane PLWHA.

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	50	40	27
Other GP	12	9	9
Outpatient HIV specialist	53	43	24
Inpatient HIV specialist	8	6	3
Other doctor	7	5	6
Public Health Nurse	16	18	16
Other nurse	9	6	7
Pharmacist	10	3	3
Alternative therapist	14	23	19
Dietician	8	14	15
Dentist	8	7	4
Peer support officer	11	14	23
Sexual health service	25	21	20
Family Planning Association	2	0	3
Sex worker organisation	3	2	4
Treatments officer	24	17	14
Other HIV/AIDS organisation staff	20	21	24
Positive women's organisation	5	5	9
Positive heterosexuals' group	4	3	5
Injecting drug user's organisation	1	0	3
Haemophilia Foundation	4	4	4
HIV positive friends	33	35	44
Other friends	5	3	11
Partner/lover	11	12	19
Family	4	5	9
Gay press	31	28	28
HIV magazine/newspaper	50	42	43
Liver specialist	4	3	3
Hep C Support Group/Organisation	5	3	2
Internet	22	17	14
Publications from HIV/AIDS groups	45	43	44
Publications from other sources	12	10	10

The HIV-related publications most read by Queensland PLWHA are QPP Alive (83%), gay newspapers (60%), Positive Living (43%). PLWHA from rural Queensland read these publications in similar proportions as those from Brisbane.

We asked respondents whether they thought lack of information made it difficult to make decisions about various issues surrounding living with HIV. Queensland respondents most felt a lack of information when managing antiretroviral side effects (29%), taking a break from antiretrovirals (29%) and making decisions on employment (28%).

In the last 6 months the health services that Queensland PLWHA had most commonly used were an HIV specialist at an outpatient clinic (45%), an HIV GP/S100 prescriber (40%), a non-S100 prescribing GP (39%) and a dentist (33%). Queensland PLWHA were more likely to have used an HIV/AIDS organisation clinic, an HIV peer support officer, a doctor at a sexual health centre, an

AIDS organisation social worker, an AIDS organisation support worker than PLWHA from other states, and were less likely an S100 prescriber. PLWHA from Brisbane were more likely to use an S100 prescriber than PLWHA from the rest of the state (51% v 28%). Fifty-six percent of Queensland 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 Queensland 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 Queensland PLWHA spend no free time with other positive people, although over two-fifths "some" or "a lot" of time with other positive people. Twenty-six percent of Queensland PLWHA has been involved in the care or nursing of another PLWHA within the last two years - a similar proportion to that found among respondents from other states.

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

Amount of free time	Percentage
None	23
A little	36
Some	27
A lot	14

Only 2% of respondents from Queensland have not disclosed their HIV status to anyone. Approximately one half (55%) have had their HIV status disclosed when they didn't want it to be (39% in the last two years). Queensland PLWHA most commonly reported this disclosure came from acquaintances (28% of those reporting unwanted disclosure), workers in health care settings (27%) and close friends (23%). They were more likely than the rest of the sample to report unwanted disclosure by HIV positive friends (16% v 6%). 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 Queensland received the most support from their partners (mean=1.47), their doctors (mean=1.62) and their pets (mean=1.67). Queensland respondents rated PLWHA groups as being a significantly greater source of support than PLWHA from other states (mean=2.37 v mean=2.71). Respondents from rural Queensland rated religious or spiritual advisers as being greater sources of support than respondents from Brisbane (mean=2.45 v mean=3.38).

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

	strongly agree	agree	disagree	strongly disagree
I cry or feel like crying all the time	6	11	54	28
I don't enjoy things the way I used to	10	42	27	22
I have lost interest in other people	7	19	50	24
I don't feel it's worth going on	4	8	36	52
As long as I'm well I prefer not think about HIV/AIDS	18	38	38	7
Life has become more meaningful since I became HIV positive	16	36	35	14
I am happy with the way my body looks	8	45	35	12
Changes in my body due to HIV/AIDS have made me feel sexually unattractive	16	40	36	9

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 Queensland respondents can be seen in Table 7 (above). There were no differences between PLWHA from Queensland 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 Queensland PLWHA 39% agreed or strongly agreed with none of these items, 36% with one item, 12% with two, 7% with three and 7% with all four. Agreement with all four items is suggestive of clinical depression. Many Queensland respondents had a negative body image. Just under half (47%) 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 tended to have a positive attitude to their HIV. Just over half (55%) report that they do think about HIV even when they are well, and 51% felt that their life had 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 Queensland. PLWHA from Queensland were more likely to plan 10 years or more ahead than PLWHA from other states. Over a third (31%) of Queensland PLWHA have changed how far they plan into the future in the last two years, of whom 73% had started planning for a longer time frame. Among Queensland 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 (32%). 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 (21%).

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

Time frame used	Percentage
One day at a time	25
A few months ahead	15
1 year ahead	21
5 years ahead	20
10 or more years ahead	20

Sexual Relationships

Respondents were asked to describe their sexual orientation or sexual identity. The majority of respondents were homosexual men (74%), followed by heterosexual women (10%) and men (9%), bisexual men (2%) and women (2%) and lesbians (1%). A further 2% 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 24% reported that they only have casual sex, 28% have sex in a monogamous regular relationship, and 19% have sex in a non-monogamous regular relationship.

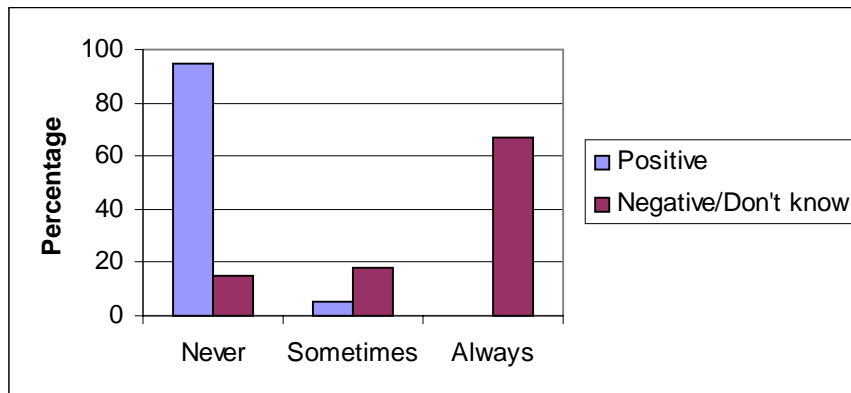
Thirty-four percent of respondents who have a regular relationship are in a seroconcordant relationship - the remainder (66%) are in a relationship with an HIV seronegative partner, or a partner whose serostatus is unknown. PLWHA living in rural Queensland were significantly more likely to have an HIV positive partner. Almost all (94%) 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 (37%) or that their partner already knew they were HIV positive when they started the relationship (24%). Of the remainder, 56% told their partner at the start of the relationship, 30% within a few days and 14% within a few weeks. Respondents were also asked how their partner reacted when they told them that they are HIV seropositive. Half (50%) said that it did not make any difference. Over one half (61%) of respondents reported that their partner was very supportive, and 49% said that they became closer, while 29% said that their partner was worried or scared and 10% said that their partner was angry. PLWHA from Queensland 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, 49% that they became closer, 44% reported that they were relieved, 35% that they were worried, 30% that it did not make a difference and 13% 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, 42% reported that they always used a condom, 16% reported that

they sometimes used a condom, and 43% 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, 54% reported that they always used a condom, 36% reported that they sometimes used a condom, and 10% never used a condom. These proportions are similar to those reported by PLWHA from other states. Small numbers meant that it was not possible to analyse the relationship between casual partner serostatus and consistency of condom use for the Queensland 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 Queensland PLWHAs, almost all (98%) of these sexual contacts were with male partners, and the majority (72%) involved vaginal or anal intercourse. The respondents most often didn't know the HIV status of their partners (70%), while 16% were known to be positive and 13% were known to be negative. Almost all (90%) Queensland respondents who knew their partners status did so because their partner disclosed this information. Amongst those who engaged in vaginal or anal intercourse, 70% of Queensland PLWHA used a condom. Again small numbers meant it was impossible to analyse condom use by serostatus on the most recent occasion for Queensland 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 Queensland PLWHA. PLWHA from Queensland were significantly less likely to use non-injected speed, non-injected cocaine, ecstasy and amyl. PLWHA from Brisbane were significantly more likely than those from other parts of Queensland to use injected speed (20% v 2%). Most PLWHA from Queensland were not concerned with the amount of drugs they took. Eighty-seven percent either disagreed or strongly disagreed with the statement that they use more illegal drugs than they would like, and 80% disagreed or strongly disagreed that they drink more alcohol than they would like. Less than one in five (17%) 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	79.2
Cigarettes	55.7
Marijuana	44.3
Amyl	25.7
Viagra or similar	16.3
Ecstasy	12.6
Speed (injected)	11.4
Speed (not injected)	5.7
Heroin (injected)	4.4
LSD/trips	3.9
Cocaine (not injected)	3.5
Steroids (injected)	2.5
Methadone (prescribed)	2.4
Homebake	2.2
Methadone (non-prescribed)	1.9
GHB/GBH/Fantasy	1.4
Heroin (not injected)	.8
Cocaine (injected)	.8

Housing

The majority (52%) of Queensland respondents live in Brisbane, while 36% live in a regional centre or town, and 11% live in a rural area. Queensland respondents were significantly less likely than other PLWHA to live in the capital city of their state and were more likely to live in a regional centre.

Table 10 (below) shows that while many Queensland 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. The vast majority (75%) of Queensland respondents believe that their

current housing is suitable for their needs. Forty-six percent of Queensland 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 (38%), moving to a quieter location (38%), moving closer to health services (27%) and illness (26%).

Table 10 Accommodation in which PLWHA live

Accommodation Type	Percentage
Own or purchasing own house or flat	38
Private rental accommodation	30
Public rental accommodation	10
Live rent-free	6
Community housing	7

When asked whom they live with, 37% of Queensland PLWHA reported that they live alone, 38% live with a sexual partner, 13% live with friends or housemates, 7% live with dependent children and 10% live with other family members.

Employment

Over half (53%) of Queensland 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 Queensland PLWHA (77%) report that being diagnosed HIV positive affected their career plans - 28% report that it was more difficult to plan, 23% report that they stopped work, 13% report that having a career was no longer as important, 11% changed careers because of their diagnosis and 1% report they were less likely to change their career. Since then 83% say HIV has affected their career plans – 26% reported that their career has ended, 18% that it is more difficult to plan, 17% have changed careers, 17% 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 (27%) said they haven't changed, while 14% reported that they haven't used antiretrovirals, 14% that they stopped work and 11% that they anticipate a longer time in the workforce. One in five (19%) Queensland PLWHA report having been discriminated against at work as a result of having HIV/AIDS, with 6% reporting having been discriminated against at work in the last 2 years.

Fifty-three percent of Queensland PLWHA who have ever worked have stopped doing so at some stage due to their HIV diagnosis. These PLWHA stopped work for an average three years and one month. The last time they stopped working the most common reasons were low energy (66%), poor health (57%) and stress or depression (56%). When asked their HIV status at the time they stopped work, 40% reported they were HIV positive but had not been ill, 51% they were HIV positive and had been ill, and 9% that they had been diagnosed with an AIDS defining illness. When they were not working most (82%) received government benefits. About half

(50%) of these PLWHA have returned to work. The most common reasons for returning to work were financial (82%), better psychological health (69%), the possibility of working part time (65%), to have something to do (63%) and to do something worthwhile (52%). PLWHA from Queensland were more likely than those from other states to report the possibility of working part-time as a reason for returning to work.

The 47% of Queensland PLWHA who are presently employed work an average of 30.5 hours per week. Most (80%) report that their job involves a moderate to very high stress level. Fifty-nine percent of Queensland 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 (59%), work fewer hours (26%), and have difficulty concentrating (24%). Eighty-three percent of workers reported that they could 'often' or 'always' get time off work for medical appointments, 61% for counselling, 82% for sick leave, and 34% for volunteer work.

Forty-four percent of Queensland PLWHA indicated that they are considering changing their work arrangements. Of these, 56% want to start or return to work, 32% want to change the type of work they do, 30% want to reduce their hours, 8% want to increase their hours and 6% want to stop work. Most of the PLWHA who want to change their work arrangements perceived that this would be difficult: 30% believe it will be 'very difficult', 55% believe that it will be 'somewhat difficult' and 15% that it will be 'not at all' difficult.

Finances

Given the large number of PLWHA in Queensland who are not in paid employment, it is not surprising that 55% of respondents reported that their main source of income is a government benefit, pension, or social security payment. Thirty-four percent of respondents reported that a salary is their main source of income. PLWHA from Queensland (3%) were less likely than PLWHA in other states (9%) to report superannuation or an annuity as their main source of income. Almost two-thirds of the Queensland respondents reported annual incomes below \$20,000. Respondents' incomes are displayed in Table 11 (below). PLWHA from Queensland (\$371.33/week) had lower incomes on average than PLWHA from other states (\$449.16/week).

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 two-fifths (42%) of Queensland PLWHA were living below the poverty line – a significantly greater proportion than that reported by PLWHA from other states.

Table 11 Income reported by PLWHA

Weekly income	Yearly income	Percentage
\$0 - \$150	\$0 - \$7800	3
\$151 - \$270	\$7801 - \$14040	51
\$271 - \$390	\$14041 - \$20280	10
\$391 - \$510	\$20281 - \$26520	16
\$511 - \$630	\$26521 - \$32760	8
\$631 - \$750	\$32761 - \$39000	4
\$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 seven Queensland 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	64	33	3
Other prescribed medication	55	36	8
Medical services	56	27	16
Complementary therapies	36	38	26
Support services	67	18	15
Entertainment	30	37	33
Going out	28	29	43
Sport	43	25	32
Recreational drugs	24	29	46
Travel / holidays	15	30	55
Rent / mortgage / housing	37	39	25
Utilities (phone, gas, etc.)	31	44	25
Food	50	35	14
Clothing	29	42	29
Transport	38	40	22
Child care	63	12	25

Discrimination

Two fifths (41%) of Queensland PLWHA had experienced less favourable treatment than other people when attending a medical service because of their HIV status, with 23% having experienced such discrimination in the last 2 years. When asked to describe what form this discrimination took respondents most commonly reported confidentiality problems (47%),

followed by being treated last (37%), avoidance (34%), being rushed through (27%), additional infection control (26%), refusal of treatment (19%), harassment (12%), and abuse (10%).

Eight percent of PLWHA from Queensland had received less favourable treatment due to their HIV status in relation to accommodation, with 4% having this happen in the last 2 years. One in five (19%) of respondents in Queensland had been discriminated against in relation to employment (6% in the last 2 years), and 24% had been discriminated against in relation to insurance (9% in the last 2 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