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

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## **INTRODUCTION**

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

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

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

## **INSTRUMENT AND METHOD**

### **The Survey instrument**

A detailed description of the design of the survey instrument can be found in the main community report HIV Futures 3: Positive Australians on Services, Health and Well-being. In brief, the HIV Futures 3 survey was a self complete, mail back questionnaire consisting of 250 items organised into eight sections: demographics; accommodation; health and treatments; services and organisations; sex and relationships; employment; recreational drug use; and finances.

### **Recruitment and Sampling**

A full description of the recruitment and sampling for the study can be found in the main community report HIV Futures 3: Positive Australians on Services, Health and Well-being. Recruitment for this study was undertaken on the basis of voluntary involvement and optimal access. To this end, recruitment took place using a set of strategies that maximised the potential of the survey to reach the diverse population of HIV positive Australians. This multi-pronged approach meant that some participants received multiple copies of the survey from different sources. Recruitment was also combined with a promotion strategy that increased community awareness of the research and its utility.

### **Weighting**

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

### **Analysis**

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

There are certain limitations in the methodology used. In terms of sample representativeness, caution must be exercised in the applications of the findings of this research in reference to individuals who are less likely to be included in the sample. This includes people with limited literacy, people of non-English speaking background, and those who are particularly

geographically or socially isolated. The combination of clinical and community setting for study recruitment was intended to optimise access to the study. This means that people are not disadvantaged from entering the study if they are not currently using anti-retroviral therapies or not currently in contact with one of the main HIV treatment providers.

It cannot be stressed strongly enough that no piece of research should be used in isolation. Each study gives a different perspective on the HIV epidemic, and collectively they lead to a greater understanding of the dynamics of the epidemic and the issues affecting Australian PLWHA.

## THE PEOPLE WHO COMPLETED THE SURVEY

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

Fifty-eight PLWHA from South Australia completed the HIV Futures Survey. PLWHA from South Australia have been deliberately over-sampled so that meaningful conclusions to be made about this group. We are grateful for the assistance provided by the following individuals and organisations who helped distribute the survey in South Australia: the Adelaide Diocesan AIDS Council, Adelaide HIV/AIDS Counselling Team, AIDS Council of South Australia (ACSA), HIV/AIDS Programs - South Australian Health Commission, HIV/AIDS Women's Project, Infectious Diseases Unit - Royal Adelaide Hospital, People Living with HIV/AIDS - PLWHA (SA), Peter Evans at PLWHA (SA), and South Australian Voice for IV Education (SAVIVE).

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 South Australia contained 91% males and 9% females. The ages of the South Australian respondents ranged from 28 years to 60 years. The average age for South Australian PLWHA was 42.2 years. On average, PLWHA living in South Australia had been HIV seropositive for 10.0 years.

The vast majority of respondents had been infected with HIV through sexual contact: 81% cited homosexual or bisexual contact as the most likely transmission route and 7% cited heterosexual contact, while 9% reported injecting drug use and 4% were infected by other means.

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

### Current health

Most respondents reported that they currently feel healthy: 30% said that their health is “*excellent*”, 31% said that their health is “*good*”, 37% said that their health is “*fair*”, and 3% said that their health is “*poor*”. When asked about their well being 24% described it as “*excellent*”, 31% as “*good*”, 41% as “*fair*” and 4% as “*poor*”. Twenty-seven percent of the respondents from South Australia have been diagnosed with an AIDS-defining illness - a similar proportion to that reported by PLWHA from the other states combined.

Respondents were asked about their experiences around testing positive for HIV. Twenty-four percent of South Australian PLWHA reported receiving pre-test counselling, most commonly provided by a doctor (4 out of the 9 respondents receiving such counselling). Most (73%) of these PLWHA were happy with the information they received from this counselling, while 73% were happy with the support they received. These proportions are similar to those reported by PLWHA from other parts of Australia.

Fifty-one percent of South Australian PLWHA reported receiving post-test counselling, again most commonly provided by a doctor (40% of those receiving such counselling), but also commonly provided by a counsellor/psychologist (24%). Most (73%) of these PLWHA were happy with the information they received from this counselling, while 71% were happy with the support they received. These proportions are similar to those reported by the rest of the sample.

Fifty-three percent of respondents from South Australia have a major health condition other than HIV/AIDS. The most frequently cited “other” health conditions included hepatitis C, asthma and herpes.

One quarter (28%) of respondents from South Australia reported having been diagnosed with a mental health condition – a similar proportion reported by respondents from other states. Most (87%) of these respondents had been diagnosed with depression, with no other diagnosis being

reported by more than two respondents. Fifteen percent of respondents are on medication for anxiety, 20% for depression and 1% are on anti-psychotic medication.

Around one in five (21%) PLWHA from South Australia have had hepatitis A, and slightly more (32%) had been diagnosed with hepatitis B. Just under half the respondents (46%) had been vaccinated against hepatitis B and 36% had been vaccinated against hepatitis A. Seventy-two percent of South Australian PLWHA have been tested for hepatitis C: 39% have had an anti-body test; 7% have had a diagnostic PCR test; and 33% reported that they didn't know what type of test they had. Twenty-six percent of respondents from South Australia indicated that they had been diagnosed with hepatitis C, with 4% of these reporting that they had subsequently tested negative on a PCR test. Due to the low number of South Australian respondents that reported being infected with hepatitis C no further results will be reported in this report. More detailed analyses of HIV/Hepatitis C co-infection are reported in "HIV Futures 3: Positive Australians on Services, Health and Well-Being" (Grierson et al, 2002).

Almost all (99%) South Australian respondents reported having taken a CD4/T-cell test, 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 12% of South Australian PLWHA have a CD4/T-cell count below 250 and a viral load above 10,000.

**Table 1 Results of serological testing**

| <b>Description</b>         | <b>Result</b>          | <b>Percentage</b> |
|----------------------------|------------------------|-------------------|
| <b>CD4/T-cell count</b>    | <b>cells/ml blood</b>  |                   |
| little or no immune damage | over 500               | 34                |
| moderate immune damage     | 250 – 499              | 47                |
| severe immune damage       | below 250              | 19                |
| <b>Viral load</b>          | <b>copies/ml blood</b> |                   |
| below detectable level     | below 500              | 48                |
| low                        | 500 - 9,999            | 17                |
| moderate                   | 10,000 - 49,999        | 15                |
| high                       | over 50,000            | 21                |

Twenty-five percent of South Australian respondents have had a viral resistance test, with 75% of these having their most recent viral resistance test in 2001. Among the 10 respondents who had taken a viral resistance test, 9 reported that their most recent test found resistance to a drug with 7 of these reporting that they changed medications due to this result. Of these, 5 reported that their viral load decreased and 2 reported that their CD4/T-cell count increased.

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

Figure 1 shows the uptake of antiretroviral treatment for South Australian PLWHA. Nine out of ten (91%) South Australian PLWHA have taken antiretroviral drugs at some stage, while 72% are using them currently. These figures are similar to those for PLWHA from other states. Of those PLWHA from South Australia who are currently taking antiretrovirals 36% report that their health has improved, 12% report that their health has stayed the same, 46% that it fluctuated, and 6% that it has deteriorated, while 17% said their well-being improved, 21% that it stayed the same, 55% that it fluctuated and 8% that it had deteriorated.

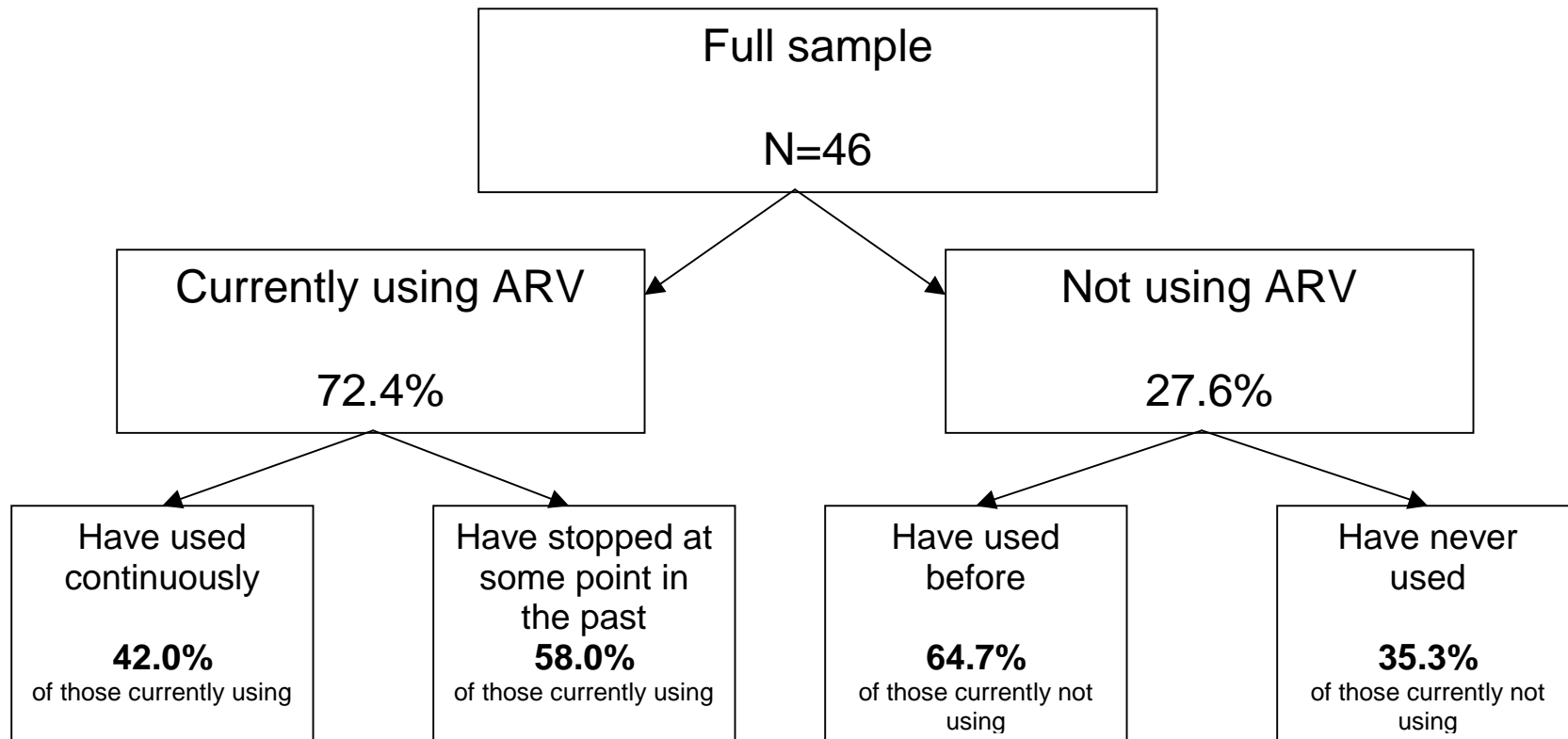
A third (33%) of the PLWHA from South Australia who use antiretroviral drugs reported that they experience side-effects from these drugs - a similar figure to that reported by PLWHA in other States. The side-effects from antiretroviral drugs most commonly reported by the whole sample were: diarrhoea (experienced by 39% of all PLWHA who experience side effects of antiretroviral drugs), nausea (30%), fatigue/lethargy (20%), lipodystrophy (17%) and neuropathy (12%).

Eighty-three percent of South Australian PLWHA who use antiretrovirals report other difficulties taking this medication. The most common difficulties among these respondents are remembering to take drugs on time (68%), organising meals around medication (50%), taking medication in public (42%) and taking a large number of tablets (28%).

Nine percent of South Australian PLWHA missed at least one dose on the day before they filled out the survey, with a similar proportion (12%) missing a dose the day before that. Only 5% missed a dose on both days.

Fifty-eight percent of South Australian PLWHA currently on antiretrovirals have taken a break from them at some stage, a similar proportion to that for other states. On average, these breaks started 24 months ago and lasted for 117 days. Most South Australian PLWHA (89%) considered this break to be a short-term one, with 8% saying it was a long-term break and 3% saying it was cycle/pulse break. Just under half (49%) of those respondents that had taken a break gave lifestyle reasons for their most recent break. Among the full sample the most common lifestyle reasons for treatment breaks were to clean out the system (14% of those that had taken a break) and taking treatments at the right time being too difficult (12%). Seventy-four percent of those South Australian respondents who had taken a break from antiretroviral therapy had clinical reasons for their most recent break. Among the full sample the most common among these were side effects (29% of those who had taken a break) and a doctor's recommendation (20%).

**Figure 1 The uptake of antiretroviral drugs**



Over half (58%) of South Australia current antiretroviral users who had taken a break talked a doctor about it before this break, while 56% saw a doctor during the break and 90% 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 deteriorated, along with their viral load increasing and their CD4 count dropping. Despite this respondents commonly reported that their overall sense of well-being improved.

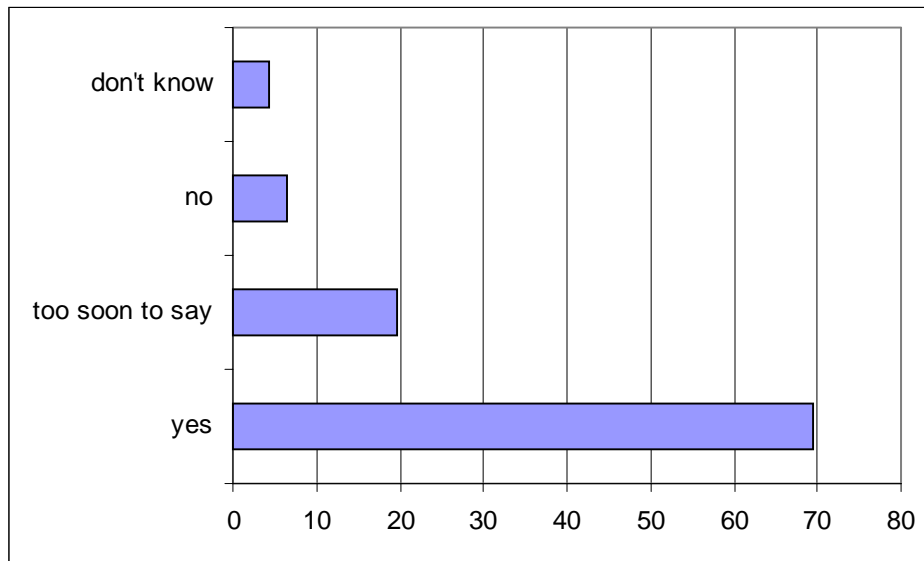
**Table 2 Percentage reporting various outcomes of treatment break**

|                               | Stayed same | Improved  | Fluctuated | Deteriorated |
|-------------------------------|-------------|-----------|------------|--------------|
| <b>Health<sup>a</sup></b>     | 18          | 24        | 20         | 39           |
| <b>Well-being<sup>b</sup></b> | 11          | 36        | 44         | 9            |
|                               | Stayed same | Increased | Fluctuated | Decreased    |
| <b>Viral load<sup>c</sup></b> | 9           | 46        | 6          | 39           |
| <b>CD4<sup>d</sup></b>        | 11          | 13        | 32         | 44           |

a: N=18; b: N=19; c: N=18; d: N=18

Figure 2 (below) shows that most (70%) of South Australian PLWHA agree that antiretroviral drugs have improved the prospects of most PLWHA, while 6% believe they haven't improved the prospects of PLWHA, 5% do not know and 19% believe it is too soon to tell.

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



Those South Australian PLWHA who are currently using combination therapy have done so for an average of 4 years and 4 months. The mean number of combinations they have tried in this time is 3.2, with a mean of 1.5 of these having been used in the past 12 months. They started on these therapies when their viral load was high (log mean = 33,420 copies/ml) and their CD4 count was low (mean = 251.9). The most common circumstances surrounding the commencement of

combination therapy for these respondents were doctors advice (83%), new drugs becoming available (45%), a drop in CD4 count (39%), a rise in viral load (30%), becoming very ill (23%), and hearing of the effectiveness of the treatment (15%).

Among those who have tried more than one combination, the most common reasons for changing the last time they did so were side effects (43%), resistance to their combination having developed (28%) and the combination they were changing from was not working (26%). Most PLWHA from South Australia felt they still had treatment options left – 33% reporting they have many options, 14% a few, 9% one and 2% reporting they had no options left. However, there was some uncertainty on this issue, with 41% reporting that they weren't sure how many combinations they had left.

Those South Australian PLWHA who have stopped using antiretrovirals had been using them for an average of 3 years and 1 months and had stopped an average of 2 years ago. They have used on average 3.2 combinations. Just under half (43%) the South Australian 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 (13%). Two-thirds (68%) of South Australian 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 (78%) of ex-antiretroviral users from South Australia talked to their doctor before they stopped taking antiretrovirals, and most (68%) had talked to their doctor since stopping treatment. The outcomes of stopping treatment for these respondents from all states can be seen in Table 3. Respondents most commonly reported that their health and well-being had improved since stopping treatment. Despite this, respondents most commonly reported that their viral load increased and commonly reported that their CD4 decreased.

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

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

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

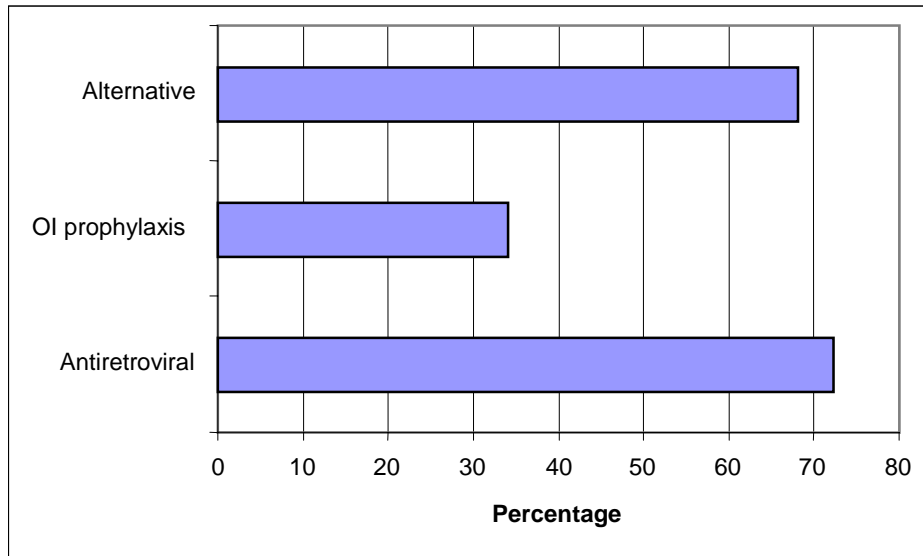
Of all South Australian PLWHA not currently taking antiretroviral medications, 91% reported that they would consider taking them in the future. The most common circumstances among these PLWHA from all states might start antiretrovirals are becoming very ill (78%), a significant drop in

CD4/T-cell count (76%), a significant rise in viral load (70%), hospitalisation due to HIV-related infections (67%) or on a doctor's advice (63%).

**Other treatments for HIV/AIDS**

Figure 3 (below) shows that while the majority of South Australian PLWHA use antiretroviral drugs, a similar use alternative therapies and one in three (34%) of the respondents from South Australia use prophylaxis for opportunistic infections (OI) - prophylaxis for *Pneumocystis carinii* pneumonia (PCP) and/or prophylaxis for other opportunistic infections. The most commonly used complementary/alternative therapies are vitamin/mineral supplements (51% of South Australian PLWHA who use alternative therapies), massage (47%) and marijuana (41%). Respondents from South Australia who use alternative therapies were less likely to use vitamin/mineral supplements than those from other states.

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

**Information and support services**

Over three-quarters of South Australian respondents (77%) have direct contact with an HIV/AIDS-related organisation. Of those South Australian PLWHA in contact with HIV/AIDS organisations, 76% receive a newsletter, 73% are clients, 41% are members, 26% are volunteers and 13% are staff. Of those PLWHA in the South Australia sample who do not have contact with and

HIV/AIDS organisation the most common reason given was not wanting to be involved (66%). Among South Australian PLWHA who have contact with an HIV/AIDS-related organisation, respondents most commonly had contact with PLWHA (SA) (45%), the Adelaide Diocesan AIDS Council (32%) and ACSA (32%).

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

| Service                         | HIV/AIDS Organisation | Other service organisation |
|---------------------------------|-----------------------|----------------------------|
| Treatments advice               | 51                    | 23                         |
| Social contact with other PLWHA | 49                    | 5                          |
| Treatments information          | 48                    | 10                         |
| Financial assistance            | 39                    | 8                          |
| Alternative therapies           | 30                    | 21                         |
| Counselling                     | 28                    | 20                         |
| Transport                       | 25                    | 14                         |
| Informal peer support           | 24                    | 12                         |
| Peer support group              | 23                    | 9                          |
| Library                         | 23                    | 30                         |
| Respite care                    | 21                    | 3                          |
| Volunteer carer                 | 20                    | 5                          |
| Community education campaigns   | 20                    | 11                         |
| Housing assistance              | 15                    | 15                         |
| Internet access                 | 14                    | 29                         |
| Financial advice                | 10                    | 21                         |
| Internet based information      | 8                     | 22                         |
| Employment services             | 6                     | 13                         |
| Drug/alcohol treatment          | 6                     | 8                          |
| Pharmacy services               | 5                     | 58                         |
| Legal advice                    | 5                     | 21                         |
| Mental health services          | 2                     | 18                         |
| Paid carer                      | 2                     | 8                          |
| Return to work skills           | 0                     | 17                         |

Table 4 (above) displays the proportion of South Australian PLWHA who use each of the services provided by HIV/AIDS-related organisations. The data show that PLWHA use HIV/AIDS-related organisations for a wide range of services. PLWHA most commonly use these organisations for treatments advice and information, social contact and financial advice. PLWHA from South Australia are significantly less likely than PLWHA from other states to report that they make use of pharmacy services provided by HIV/AIDS organisations, and were more likely to use them for respite care, library services and transport. South Australian PLWHA made use of services provided by non-AIDS organisations in similar proportions to those reported by PLWHA in the rest of the country.

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, an HIV GP/S100 Prescriber, publications from HIV/AIDS groups and an HIV specialist at an outpatient clinic. The diversity of

responses to this question suggests that PLWHA seek information from a range of different sources. HIV GP/S100 Prescribers were most commonly cited (41%) as the *most* important source of information, followed by outpatient HIV specialists (29%). South Australian PLWHA were more likely to cite a dentist as an important source of treatments information and were less likely to cite a sexual health service.

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 HIV magazines and newspapers followed by publications from HIV/AIDS groups, S100 prescribers and outpatient HIV specialists. Again, S100 prescribers were most commonly cited (31%) as the *most* important source of information, followed by outpatient HIV specialists (20%). South Australian PLWHA were more likely than other PLWHA to cite dentists as an important source of information on HIV management.

Table 5 also displays the responses of PLWHA to questions they were asked about whom they rely on for information about living with HIV/AIDS. The sources of information about living with HIV/AIDS most frequently cited as being important were HIV magazines and newspapers, publications from HIV/AIDS groups, HIV positive friends, and the gay press. When asked about the *most* important source of information the respondents had on living with HIV/AIDS the most common responses were AIDS organisation staff (23%) and HIV positive friends (22%). PLWHA from South Australia were significantly less likely than PLWHA from other parts of Australia to report sexual health services as important sources of information about living with HIV/AIDS.

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

| Information source                 | Source of information about: |                |                      |
|------------------------------------|------------------------------|----------------|----------------------|
|                                    | Treatments                   | HIV Management | Living with HIV/AIDS |
| HIV GP/S100 Prescriber             | 55                           | 49             | 27                   |
| Other GP                           | 7                            | 4              | 13                   |
| Outpatient HIV specialist          | 43                           | 29             | 12                   |
| Inpatient HIV specialist           | 7                            | 6              | 9                    |
| Other doctor                       | 2                            | 0              | 2                    |
| Public Health Nurse                | 13                           | 6              | 4                    |
| Other nurse                        | 4                            | 4              | 10                   |
| Pharmacist                         | 19                           | 10             | 10                   |
| Alternative therapist              | 7                            | 8              | 12                   |
| Dietician                          | 9                            | 6              | 13                   |
| Dentist                            | 33                           | 29             | 17                   |
| Peer support officer               | 11                           | 15             | 8                    |
| Sexual health service              | 0                            | 6              | 0                    |
| Family Planning Association        | 0                            | 0              | 6                    |
| Sex worker organisation            | 0                            | 0              | 6                    |
| Treatments officer                 | 10                           | 11             | 2                    |
| Other HIV/AIDS organisation staff  | 15                           | 18             | 15                   |
| Positive women's organisation      | 2                            | 4              | 10                   |
| Positive heterosexuals' group      | 2                            | 2              | 8                    |
| Injecting drug user's organisation | 1                            | 1              | 7                    |
| Haemophilia Foundation             | 0                            | 2              | 6                    |
| HIV positive friends               | 21                           | 18             | 37                   |
| Other friends                      | 6                            | 5              | 20                   |
| Partner/lover                      | 12                           | 8              | 26                   |
| Family                             | 0                            | 1              | 20                   |
| Gay press                          | 30                           | 25             | 36                   |
| HIV magazine/newspaper             | 58                           | 51             | 53                   |
| Liver specialist                   | 0                            | 0              | 4                    |
| Hep C Support Group/Organisation   | 2                            | 1              | 7                    |
| Internet                           | 19                           | 13             | 12                   |
| Publications from HIV/AIDS groups  | 52                           | 49             | 48                   |
| Publications from other sources    | 12                           | 11             | 15                   |

The HIV-related publications most read by South Australian PLWHA are Positive Living (66%), gay newspapers (60%), and newsletters from community organisations (52%).

We asked respondents whether they thought lack of information made it difficult to make decisions about various issues surrounding living with HIV. South Australian respondents most felt a lack of information when making decisions on taking a break from antiretrovirals (28%) and financial planning (24%).

In the last 6 months the health services that South Australian PLWHA had most commonly used were a dentist (61%), an HIV GP/S100 prescriber (57%), an HIV specialist at an outpatient clinic (52%), and a non-S100 prescribing GP (39%). South Australian PLWHA were more likely to have used a dentist than PLWHA from other states, and were less likely to have used a doctor at a sexual health service. Sixty-six percent of South Australian PLWHA who currently use

antiretrovirals have to go to more than one place to get all their prescriptions filled, a similar proportion to that for PLWHA in other states.

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

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

| Amount of free time | Percentage |
|---------------------|------------|
| None                | 16         |
| A little            | 36         |
| Some                | 28         |
| A lot               | 21         |

Only 2% of respondents from South Australia have not disclosed their HIV status to anyone. Over half (61%) have had their HIV status disclosed when they didn't want it to be (21% in the last two years). South Australian PLWHA most commonly reported that this disclosure came from workers in a health care setting (25%), close friends (24%), work colleagues (21%) and siblings (21%). 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 South Australia received the most support from their partners (mean=1.29), their pets (mean=1.57) and their doctors (mean=1.65).

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 South Australian respondents can be seen in Table 7 (below). There were no differences between PLWHA from South Australia and those from the other states on these items. We can look at the number of the items from the Beck Depression Inventory (the first four items in the table) the respondents either agreed or strongly agreed with as a way of measuring the extent of depressive symptoms. Among South Australian PLWHA 29% agreed or strongly agreed with none of these items, 24% with one item, 30% with two, 12% with three and 5% with all four. Agreement with all four items is suggestive of clinical depression. Many South Australian respondents had a negative body image. Over half (55%) of the respondents disagreed or strongly disagreed 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 generally didn't think positively about their HIV. Just over half (54%) report that they don't think about HIV when they are well, and 62% felt that their life hadn't become more meaningful since they were diagnosed with HIV.

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

|  | strongly agree | agree | disagree | strongly disagree |
|--|----------------|-------|----------|-------------------|
| I cry or feel like crying all the time                                     | 6              | 18    | 47       | 29                |
| I don't enjoy things the way I used to                                     | 9              | 50    | 29       | 12                |
| I have lost interest in other people                                       | 10             | 40    | 36       | 14                |
| I don't feel it's worth going on   | 4              | 10    | 46       | 40                |
| As long as I'm well I prefer not think about HIV/AIDS                      | 17             | 29    | 47       | 7                 |
| Life has become more meaningful since I became HIV positive                | 6              | 32    | 51       | 12                |
| I am happy with the way my body looks                                      | 15             | 30    | 49       | 5                 |
| Changes in my body due to HIV/AIDS have made me feel sexually unattractive | 16             | 38    | 31       | 14                |

### 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 South Australia. One in five (21%) of South Australian PLWHA have changed how far they plan into the future in the last two years, of whom 85% had started planning for a longer time frame. Among all respondents who now use a longer time frame when planning for the future, the most commonly cited reason for the change was improved health due to new treatments (37%). Among all respondents who now use a shorter time frame when planning for the future, the most commonly cited reason for the change was declining health (41%).

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

| Time frame used        | Percentage |
|------------------------|------------|
| One day at a time      | 28         |
| A few months ahead     | 26         |
| 1 year ahead           | 26         |
| 5 years ahead          | 15         |
| 10 or more years ahead | 6          |

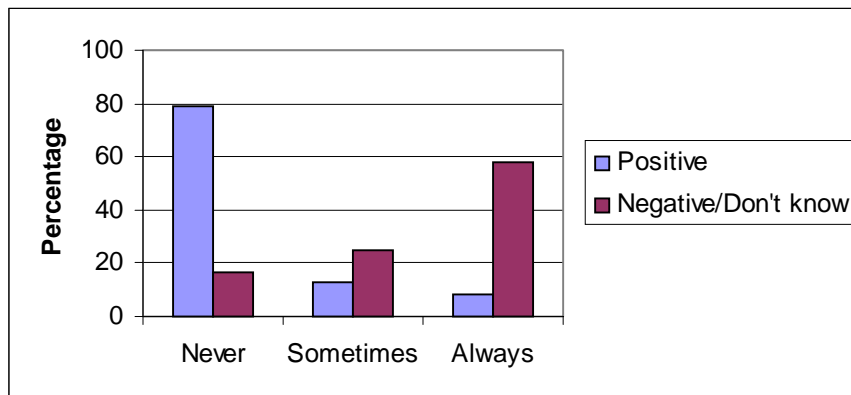
### Sexual Relationships

Respondents were asked to describe their sexual orientation or sexual identity. The majority of respondents were homosexual men (68%), followed by heterosexual women (17%) and men (8%), and bisexual men (6%). A further 2% reported having some other type of sexuality. When asked to describe their current sexual relationships, 30% reported that they are not currently sexually active, while 32% reported that they only have casual sex, 20% have sex in a monogamous regular relationship, and 18% have sex in a non-monogamous regular relationship.

Forty percent of respondents who have a regular relationship are in a seroconcordant relationship - the remainder (60%) are in a relationship with an HIV seronegative partner, or a partner whose serostatus is unknown. 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 (43%) or that their partner already knew they were HIV positive when they started the relationship (10%). Of the remaining 10 respondents, 5 told their partner at the start of the relationship. Respondents were also asked how their partner reacted when they told them that they are HIV seropositive. Almost two-thirds (62%) said that it did not make any difference. Seventy-two percent reported that their partner was very supportive, and 50% said that they became closer, while 46% said that their partner was worried or scared and 2% said their partner was angry. When asked about their own reactions to the disclosure to their partner, 55% that they were worried, 51% that they became closer, 52% reported that they were relieved, 37% that it did not make a difference and 15% that they were angry.

When asked about their patterns of condom use during sex with regular partners in the 6 months prior to completing the survey, 32% reported that they always used a condom, 11% reported that they sometimes used a condom, and 58% reported that they never used a condom. Unfortunately, there were not enough respondents to examine condom use by partner serostatus for South Australian respondents. However, when the full sample was analysed a significant association was found between partner HIV serostatus and consistency of condom use (see Figure 4).

When asked about their patterns of condom use during sex with casual partners in the 6 months prior to completing the survey, 44% reported that they always used a condom, 37% reported that they sometimes used a condom, and 20% never used a condom. Again, small numbers meant that it was not possible to analyse the relationship between casual partner serostatus and consistency of condom use for the South Australian respondents. However, when the whole sample was analysed, it was found that respondents were more likely to use condoms with HIV negative partners (or partners of unknown serostatus) than with an HIV positive partner.

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

Respondents were also asked about their most recent sexual contact with a casual partner. For South Australian PLWHA, all (100%) of these sexual contacts were with male partners, and the majority (73%) involved vaginal or anal intercourse. The respondents most often didn't know the HIV status of their partners (80%). Amongst those who engaged in vaginal or anal intercourse, 64% of South Australian PLWHA used a condom. Small numbers meant it was impossible to analyse condom use by serostatus on the most recent occasion for South Australian respondents, however for the full sample a condom was used significantly more often when the respondent was not sure of their partners HIV status or knew them to be negative.

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

### Recreational drug use

Table 9 shows the rate of use of non-prescription drugs of South Australian PLWHA. PLWHA from South Australia use these drugs in similar proportions to those from the rest of Australia. Most PLWHA from South Australia were not concerned with the amount of drugs they took. Seventy-three percent either disagreed or strongly disagreed with the statement that they use more illegal drugs than they would like, and 74% 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                    | 76.1   |
| Marijuana                  | 61.1   |
| Cigarettes                 | 57.1   |
| Amyl                       | 21.0   |
| Cocaine (not injected)     | 11.3   |
| Ecstasy                    | 10.6   |
| Speed (not injected)       | 9.5  |
| Viagra or similar          | 9.5  |
| LSD/trips                  | 8.6  |
| Methadone (prescribed)     | 5.0  |
| Heroin (injected)          | 4.5  |
| Speed (injected)           | 4.3  |
| Methadone (non-prescribed) | 1.6  |
| Heroin (not injected)      | 0  |
| Cocaine (injected)         | 0  |
| Homebake                   | 0  |
| Steroids (injected)        | 0  |
| GHB/GBH/Fantasy            | 0  |

### Housing

Almost all (94%) of South Australian respondents live in Adelaide, with the rest living in rural areas (population <5,000). South Australian respondents were significantly more likely than other PLWHA to live in the capital city of their state.

Table 10 (below) shows that while many South Australian PLWHA own their home or are buying their own home, half are living in rental accommodation, while a small number live in community housing. PLWHA from South Australia are significantly more likely to live in public rental accommodation and are significantly less likely to live in private rental accommodation when compared to those from other states. The vast majority (87%) of South Australian respondents believe that their current housing is suitable for their needs. Forty-four percent of South Australian 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 (30%), improved finances (29%) and moving closer to health services (29%).

**Table 10 Accommodation in which PLWHA live**

| Accommodation Type                  | Percentage |
|-------------------------------------|------------|
| Own or purchasing own house or flat | 45         |
| Private rental accommodation        | 9          |
| Public rental accommodation         | 45         |
| Community housing                   | 2          |

When asked whom they live with, 52% of South Australian PLWHA reported that they live alone, 38% live with a sexual partner, 10% live with friends or housemates, 12% live with dependent children and 2% live with other family members.

## Employment

Almost two-thirds (63%) of South Australian PLWHA were not in paid employment at the time of completing the survey. Of the PLWHA who are working, 55% work full-time and 45% work part-time. Most South Australian PLWHA (88%) report that being diagnosed HIV positive affected their career plans - 24% report that it was more difficult to plan, 24% report that they stopped work, 19% report that having a career was no longer as important, 14% changed careers because of their diagnosis and 6% report they were less likely to change their career. Since then 89% say HIV has affected their career plans – 25% reported that their career has ended, 22% that it is more difficult to plan, 21% that a career is no longer as important, 15% have changed careers and 7% are less likely to change careers. When asked the effect of antiretrovirals on their work plans, 62% reported some change to their plans. Among respondents from all states the most common changes were stopping work (13% of all respondents) and anticipating a longer time in the workforce (11%). One in five (21%) South Australian PLWHA report having been discriminated against at work as a result of having HIV/AIDS, with 9% reporting having been discriminated against at work in the last 2 years.

Fifty-one percent of South Australian PLWHA who have ever worked have stopped doing so at some stage due to their HIV diagnosis. These PLWHA stopped work for an average three years and nine months. The last time they stopped working the most common reasons were low energy (62%), poor health (50%) and stress or depression (45%). When asked their HIV status at the time they stopped work, 42% reported they were HIV positive but had not been ill, 50% they were HIV positive and had been ill, and 6% that they had been diagnosed with an AIDS defining illness. When they were not working most (93%) received government benefits. About half (42%) of these PLWHA have returned to work. The most common reasons for returning to work among the whole sample were financial (79%), to have something to do (52%), better psychological health (51%) and to do something worthwhile (49%).

The 37% of South Australian PLWHA who are presently employed work an average of 30.1 hours per week. Most (61%) report that their job involves a moderate to high stress level. Sixty-eight percent of South Australian PLWHA who are working reported that their capacity to perform their work duties is affected by having HIV/AIDS: among the full sample respondents most frequently reported that they tire quickly (46%), have difficulty concentrating (22%) and work fewer hours (21%). Seventy-seven percent of South Australian workers reported that they could 'often' or 'always' get time off work for medical appointments, 61% for counselling, 77% for sick leave, and 26% for volunteer work.

Forty-three percent of South Australian PLWHA indicated that they are considering changing their work arrangements. For these respondents from all states, 43% of these respondents want to change the type of work they do, 42% of these want to start or return to work, 22% want to reduce their hours, 7% want to increase their hours and 4% want to stop work. Most of the South Australian PLWHA who want to change their work arrangements perceived that this would be difficult: 29% believe it will be 'very difficult', 61% believe that it will be 'somewhat difficult' and 10% that it will be 'not at all' difficult.

### Finances

Given the large number of PLWHA in South Australia who are not in paid employment, it is not surprising that 63% of respondents reported that their main source of income is a government benefit, pension, or social security payment, while 28% reported that a salary is their main source of income. Over two-thirds of the South Australian respondents reported annual incomes below \$20,000. Respondents' incomes are displayed in Table 11 (below).

**Table 11 Income reported by PLWHA**

| Weekly income | Yearly income     | Percentage |
|---------------|-------------------|------------|
| \$0 - \$150   | \$0 - \$7800      | 12         |
| \$151 - \$270 | \$7801 - \$14040  | 47         |
| \$271 - \$390 | \$14041 - \$20280 | 12         |
| \$391 - \$510 | \$20281 - \$26520 | 6          |
| \$511 - \$630 | \$26521 - \$32760 | 15         |
| \$631 - \$750 | \$32761 - \$39000 | 3          |
| \$751 -       | \$39001 -         | 6          |

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. One half (50%) of South Australian PLWHA were living below the poverty line.

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

Particularly noteworthy is the finding that 8% of South Australian PLWHA find it "very difficult" to meet the cost of food, and one in six find it "very difficult" to meet the cost of utilities (telephone, gas, electricity). It is also interesting to note one-third 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            | 29                 | 11             |
| Other prescribed medication        | 57            | 29                 | 14             |
| Medical services                   | 59            | 39                 | 1              |
| Complementary therapies            | 53            | 15                 | 32             |
| Support services                   | 55            | 32                 | 13             |
| Entertainment                      | 28            | 27                 | 45             |
| Going out                          | 24            | 23                 | 53             |
| Sport                              | 31            | 26                 | 43             |
| Recreational drugs                 | 35            | 37                 | 28             |
| Travel / holidays                  | 14            | 22                 | 65             |
| Rent / mortgage / housing          | 46            | 44                 | 10             |
| Utilities (phone, gas, etc.)       | 31            | 52                 | 16             |
| Food                               | 43            | 49                 | 8              |
| Clothing                           | 30            | 32                 | 38             |
| Transport                          | 34            | 38                 | 28             |
| Child care                         | 19            | 63                 | 19             |

### Discrimination

Two fifths (41%) of South Australian PLWHA had experienced less favourable treatment than other people when attending a medical service because of their HIV status, with 24% having experienced such discrimination in the last 2 years. When asked to describe what form this discrimination took respondents most commonly reported avoidance (46%), followed by confidentiality problems (45%), additional infection control (34%) and being treated last (28%).

Thirteen percent of PLWHA from South Australia had received less favourable treatment due to their HIV status in relation to accommodation, with 7% having this happen in the last x years. One in five (20%) of respondents in South Australia had been discriminated against in relation to employment (9% in the last 2 years), and 27% had been discriminated against in relation to insurance.

### REFERENCES

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