

**HIV Futures: The social aspects of
living with HIV/AIDS in South Australia.**

**A report prepared for the
South Australian Health Commission**

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HIV Futures: State Reports

South Australia

Living with HIV Program*

Australian Research Centre in Sex, Health, and Society

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

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

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

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

Seventy-eight South Australian PLWHA completed the HIV Futures Survey. This figure is significantly greater than the number we would have expected in a representative sample of PLWHA in Australia. The large number of South Australian respondents is a reflection of the great efforts made by the HIV/AIDS Women’s Project, Rosemont - PLWHA(SA), the Royal Adelaide Hospital, and the AIDS Council of South Australia. The high number of South Australian respondents is also an outcome of funding from the South Australian Health Commission which allowed the employment of Shaun McCausland to recruit study participants. Among South Australian respondents, 72 were male (92%) and 6 were female (8%) - similar proportions to those found in other states.

The ages of the South Australian respondents ranged from 23 years to 63 years. The average age was 38.6 years, which is similar to that of the rest of the sample. The average number of years since South Australian PLWHA first tested HIV seropositive was 6.7 years. This is slightly less than the 7.5 years reported by the rest of the sample, but it is not a statistically significant difference.

The vast majority of respondents had been infected through sexual contact: 82% cited homosexual or bisexual contact as the most likely transmission route, 9% reported injecting drug use, 4% cited heterosexual contact, 3% cited

both sexual contact and injection drug use, 1% were haemophiliacs infected through contaminated blood products, and 1% were infected by blood products or in a health care setting.

Current health

Most respondents reported that they currently feel healthy: 33% said that their health is “excellent”, 42% said that their health is “good”, 26% said that their health is “fair”, and 4% said that their health is “poor”.

Approximately one in six (15%) of the South Australian respondents have been diagnosed with an AIDS-defining illness. Respondents from South Australia are no more or less likely than respondents from other states to report that they have been diagnosed with an AIDS-defining illness.

Slightly less than one-third (30%) of respondents from South Australia have a major health condition other than HIV/AIDS - a similar proportion to the 29% reported by PLWHA from other states. The most frequently cited “other” health conditions included back injury, cancer (non-Kaposi sarcoma), diabetes, hypertension, and psychological/psychiatric conditions. One in five (20%) PLWHA from South Australia have had Hepatitis A, and 28% have had Hepatitis B. Of the 57% of South Australian PLWHA who have been tested for Hepatitis C, 26% have tested positive, 71% have tested negative, and 3% do not know the result of their test. Extrapolating from these figures approximately, up to 26% of PLWHA in South Australia are positive for Hepatitis C.

Nearly all (97%) of the respondents from South Australia have taken a CD4/T-cell test, and 88% have taken a viral load test. The results of respondents’ most recent CD4/T-cell tests and viral load tests are displayed in Table 1

(below). It is interesting to note that 5% of South Australian PLWHA have a CD4/T-cell count below 250 and a viral load above 50,000.

Table 1 Results of serological testing

Description	Copies/mL blood	Proportion
CD4/T-cell count		
little or no immune damage	over 500	40%
moderate immune damage	250 - 500	36%
severe immune damage	below 250	24%
Viral load		
below detectable level	below 200 / 500	47%
low	500 - 10,000	24%
moderate	10,000 - 50,000	19%
high	over 50,000	11%

Antiretroviral treatments for HIV/AIDS

Two-thirds (66%) of the respondents from South Australia are using antiretroviral drugs for HIV/AIDS. This figure is lower than the 78% of PLWHA from the rest of Australia using antiretroviral drugs, but it is not a statistically significant difference. Amongst the PLWHA who use antiretroviral drugs, 17% use two drugs in combination, and 83% use three or more drugs in combination. No respondents use monotherapy. Overall, 55% of South Australian PLWHA are using triple combination therapy. PLWHA from South Australia are as likely as PLWHA from other states to use triple combination therapy.

Over half (58%) of the PLWHA from South Australia who use antiretroviral drugs reported that they experience side-effects from these drugs. As was found with the full sample of all PLWHA who completed the survey, the most commonly reported side-effects from antiretroviral drugs are: nausea (experienced by 20% of PLWHA using antiretroviral drugs), headaches

HIV/AIDS. Using these questions it was possible to create a scale of confidence in antiretroviral drugs ranging from 1 to 5, where higher scores indicated greater confidence. The average scale score for South Australian PLWHA was 3.56 which indicates that they generally have confidence in antiretroviral drugs. PLWHA from South Australia express a similar degree of confidence in antiretroviral drugs as PLWHA from other states.

Other treatments for HIV/AIDS

Over half (58%) of the respondents from South Australia are using prophylaxis for opportunistic infections - prophylaxis for *Pneumocystis carinii* pneumonia (PCP) and/or prophylaxis for other opportunistic infections.

Over half (52%) of the respondents from South Australia are using complementary or alternative therapies for HIV/AIDS. The most commonly used complementary/alternative therapies are vitamin/mineral supplements (used by 37% of all PLWHA), massage (31%), herbal remedies (23%), meditation/visualisation (19%), and acupuncture (12%).

PLWHA from South Australia are no more or less likely than PLWHA from other areas of Australia to be using prophylaxis for opportunistic infections, or complementary/alternative therapies.

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

Attitudes toward personal involvement in health management were measured on a 5-point scale, where higher scores indicate a greater desire to be actively

involved health management. The average score for South Australian PLWHA was 4.10, which indicates that they are keen to take an active part in decision-making about their health management.

Information and support services

Over three-quarters (78%) of South Australian respondents have some direct contact with an HIV/AIDS-related organisation. This is a similar proportion to that found amongst PLWHA in the rest of the country. Half (50%) of the South Australian respondents have contact with the Rosemont PLWHA centre, and one-third (35%) have contact with the AIDS Council of South Australia. South Australian PLWHA are significantly less likely than PLWHA from the rest of the country to report that they have contact with their state AIDS Council, however they are no more or less likely to report that they have contact with their State's PLWHA organisation. It should be noted, however, that the differences reported above in terms of reliance on PLWHA organisations may be a reflection of the recruitment strategy, which in South Australia relied heavily on the cooperation of the Rosemont PLWHA centre. There did not appear to be any relationship between whether or not PLWHA had contact with the AIDS Council of South Australia and/or Rosemont and whether or not they have had an AIDS-defining illness, or whether they live in an inner urban area as opposed to an outer urban area, regional centre or rural area. Furthermore, the PLWHA's extent of involvement in the HIV community and the gay community was not related to whether or not he/she had contact with the AIDS Council of South Australia and/or Rosemont.

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

organisations for social contact and social support, and for financial advice or assistance.

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

Service	Proportion
Newsletters / mail-outs	68%
Social contact	59%
Treatments advice	57%
Alternative therapies, massage, etc.	49%
Library	42%
Counselling	36%
Financial assistance	33%
Peer support group	33%
Transport services	30%
Informal peer support	28%
Financial advice	22%
Domestic help	14%

Most of the respondents from South Australia read HIV/AIDS-related magazines and newspapers such as Positive Living, Talkabout, National AIDS Bulletin, and Accent: 53% read HIV/AIDS-related press regularly, 34% read it occasionally, and 13% never read HIV/AIDS-related press.

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

of information about treatments for HIV/AIDS. Again, this result may reflect the fact the many study participants were recruited through the Rosemont PLWHA centre.

Table 3 also displays the responses of PLWHA to questions they were asked about who they rely upon for information about living with HIV/AIDS (but not about treatments). Again, the PLWHA’s doctor was the most frequently cited information source, but half also cited HIV positive friends as an important source of information about living with HIV/AIDS, a finding which highlights the importance of the PLWHA’s social network. Compared to PLWHA from other states, South Australian PLWHA are significantly more likely to report that PLWHA organisation staff are an important source of information about living with HIV/AIDS, and significantly more likely to report that a positive women’s organisation is an important source of information about living with HIV/AIDS.

Table 3 Important sources of information for PLWHA

Information source	Source of information about:	
	Treatments for HIV/AIDS	Living with HIV/AIDS
Doctor	83%	61%
HIV/AIDS press	63%	46%
HIV positive friends	53%	49%
Gay press	50%	39%
PLWHA organisation staff	38%	37%
AIDS Council treatments officer	30%	26%
AIDS Council staff	26%	23%
Partner/lover	24%	27%
Nurse	17%	13%
Alternative therapist	15%	13%
Friends (not HIV positive)	12%	22%
Positive women’s organisation	10%	11%
Internet	5%	2%
Family	4%	6%

Respondents were asked to indicate how much of their free time they spend with other HIV seropositive people. The results in Table 4 (below) show that while many South Australian PLWHA spend no free time with other positive people, nearly a quarter spend a lot of time with other positive people. There was no difference between South Australian PLWHA and PLWHA from other states in terms of the amount of free time they spend with other HIV seropositive people.

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

Amount of free time	Proportion
None	14%
A little	35%
Some	28%
A lot	23%

Employment

Nearly two-thirds (64%) of South Australian PLWHA were not in paid employment at the time of completing the survey. Of the PLWHA who are working, 67% work full-time and 33% work part-time. The % of respondents who are working have been in their current job for an average of six-and-a-half years, and work between 12 and 60 hours per week (average = 37.7 hours). The respondents who are not working have been out of work for an average of 4 years and eight months, and they worked an average of 37.9 hours in their last job.

Given the large number of PLWHA in South Australia who are not in paid employment, it is not surprising that 62% of respondents reported that their main source of income is a government benefit, pension, or social security

payment. One-third (35%) of respondents reported that a salary is their main source of income, while 2% reported superannuation or an annuity as their main source of income, and 2% reported that their partner supports them. Respondents' incomes are displayed in Table 5. Over half of the South Australian respondents reported annual incomes below \$15,000. Respondents' incomes are displayed in Table 5 (below).

Table 5 Income reported by PLWHA

Weekly income	Yearly income	Proportion
\$0 - \$150	\$0 - \$7800	24%
\$151 - \$270	\$7801 - \$14040	41%
\$271 - \$390	\$14041 - \$20280	10%
\$391 - \$510	\$20281 - \$26520	6%
\$511 - \$630	\$26521 - \$32760	10%
\$631 - \$750	\$32761 - \$39000	6%
\$751 -	\$39001 -	2%

The poverty lines published by the Institute for Applied Economics and Social Research [IAESR] take into account an individual's income as well as whether or not they are in a relationship and the number of dependent children they have. The data for the June quarter of 1997 (IAESR, 1997) were used to calculate the proportion of PLWHA who reported incomes below the poverty threshold. Amongst South Australian PLWHA, 41% reported incomes below the poverty line. This figure is higher than the 32% for the rest of the sample, but it is not a statistically significant difference.

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 6 (below) demonstrate that while many PLWHA reported difficulties in meeting the costs of social activities such as entertainment and eating and drinking out,

a large proportion reported that it is very difficult for them to meet the costs of some of the “basics” of life such as housing, utilities, food, and clothing.

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

Item	Not at all difficult	A little difficult	Very difficult
Prescribed medication	42%	33%	26%
Medical services	66%	19%	16%
Complementary therapies	48%	25%	27%
Support services	58%	20%	22%
Entertainment	28%	33%	38%
Eating / drinking out	26%	32%	42%
Sport / exercise	39%	20%	41%
Recreational drugs	31%	17%	51%
Travel / holidays	33%	29%	48%
Rent / mortgage / housing	41%	33%	26%
Utilities (phone, gas, etc.)	30%	38%	32%
Food	47%	30%	23%
Clothing	30%	29%	40%
Transport	42%	35%	22%

Particularly noteworthy is the finding that a quarter of South Australian PLWHA find it “very difficult” to meet the cost of food, and that a third find it “very difficult” to meet the cost of utilities (telephone, gas, electricity). It is also interesting to note that a quarter of respondents who are using complementary/alternative therapies find it very difficult to meet the cost of this treatment.

Planning for the future

Respondents were asked to indicate how far into the future they plan when making major decisions about their future. Table 7 (below) shows that over half of the PLWHA from South Australia reported that they plan “one day at a

time” or “a few months ahead”. Slightly less than half (43%) of the respondents reported that in the past two years they have changed the time frame they use when making major decisions about their future: 19% now use a shorter time frame when planning for the future, while 24% now use a longer time frame. Amongst respondents who now use a longer time frame when planning for the future, the most commonly cited reason for the change was improved health due to new treatments, while amongst respondents who now use a longer time frame when planning for the future, the most commonly cited reason for the change was declining health.

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

Time frame used	Proportion
One day at a time	28%
A few months ahead	26%
1 year ahead	23%
5 years ahead	13%
10 or more years ahead	10%

Housing

The vast majority of South Australian respondents live in Adelaide: 66% live in an inner suburb and 28% live in an outer suburb, while 3% live in a regional centre or town, and 4% live in a rural area. These proportions are similar to those reported by PLWHA in other states. Table 8 (below) shows that while many South Australian PLWHA own their own house or are buying their own house, an equivalent number are living in public rental accommodation, while a small number live rent-free or live in community housing.

Table 8 Accommodation in which PLWHA live

Accommodation Type	Proportion
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Own or purchasing own home	35%
Public rental accommodation	35%
Private rental accommodation	21%
Live rent-free	8%
Community housing / co-op	1%

The vast majority (87%) of South Australian respondents believe that their current housing is suitable for their needs - as was the case for PLWHA from other states. As was the case for the whole sample, few South Australian PLWHA (4%) reported that they have ever experienced HIV/AIDS-related discrimination in the area in which they live.

Sexual Relationships

Respondents were asked to describe their sexual orientation or sexual identity. Their responses (similar to those of respondents from other states) are displayed in Table 9 (below). The majority of respondents were homosexual men, with smaller numbers of bisexual men, heterosexual men, and heterosexual women.

Table 9 Sexual orientation of PLWHA

Sexual orientation / identity	Proportion
Homosexual male	72%
Bisexual male	15%
Heterosexual female	6%
Heterosexual male	5%
Asexual	2%

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of respondents said that their partner already knew they were HIV positive, and a quarter (26%) said that they told their partner when they found out (ie, they seroconverted after the formation of the relationship). Of the remainder, most (55%) told their partner at the beginning of the relationship. Respondents also reported how their partner reacted when they were told that the respondent is HIV seropositive. Most respondents (70%) reported that their partner was very supportive, while 44% said that it did not make any difference, and 38% said that they became closer.

When asked about their patterns of condom use during sex with regular partners in the 6 months prior to completing the survey, 27% reported that they always used a condom, 30% reported that they sometimes used a condom, and 43% reported that they never used a condom. Small numbers meant that it was not possible to analyse the relationship between regular partner serostatus and consistency of condom use for the South Australian respondent

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ò b casual partner. Again, Small numbers meant that it was not possible to analyse the relationship between casual partner serostatus and consistency of condom use for the South Australian respondents. However, when the whole sample was used, it was found that respondents were more likely to use condoms with HIV negative partners (or partners of unknown serostatus) than with an HIV positive partner.

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

Summary and conclusion

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

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

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

Less than half of the South Australian PLWHA who completed the survey are in paid employment, and most respondents reported that their main source of income is a government benefit. Of concern is the finding that 41% of South Australian reported incomes below the poverty line. As a consequence, many respondents reported difficulties affording a range of expenses, including some

of the “basics of life”. These findings suggest that many PLWHA may be in need of financial assistance and/or advice on financial planning to help them meet the costs of living with HIV/AIDS.

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Acronyms Used in the Report

AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
IAESR	Institute of Applied Economics and Social Research
NAPWA	National Association of People Living With HIV/AIDS
NCHSR	National Centre in HIV Social Research
NCHECR	National Centre in HIV Epidemiology and Clinical Research
PLWHA	People Living with HIV/AIDS