



AUSTRALIAN RESEARCH CENTRE IN **SEX, HEALTH AND SOCIETY**

DECEMBER 2000



HIV Futures II Regional Reports New South Wales



A COLLABORATING CENTRE TO THE NATIONAL CENTRE IN HIV SOCIAL RESEARCH

FUNDED THROUGH A CARG COLLABORATING CENTRE GRANT FROM THE
COMMONWEALTH DEPARTMENT OF HEALTH AND AGED CARE

*AUSTRALIAN RESEARCH CENTRE IN SEX, HEALTH AND SOCIETY
December 2000*

HIV Futures II Regional Reports: New South Wales

Jeffrey Grierson, Sebastian Misson and Philomena Horsley

Monograph Series Number 22
ISBN 1864465263



A COLLABORATING CENTRE TO THE NATIONAL CENTRE IN HIV SOCIAL RESEARCH

FUNDED THROUGH A CARG COLLABORATING CENTRE GRANT FROM THE
COMMONWEALTH DEPARTMENT OF HEALTH AND AGED CARE

Suggested citation

Grierson, J., Misson, S. and Horsley, P. (2000) *HIV Futures II Regional Reports: New South Wales*, Monograph Series Number 22, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia.

The Living with HIV Program can be contacted at

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

Phone: +61 3 9285 5382

Email: hivfutures@latrobe.edu.au

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

Introduction

The HIV Futures Study is the largest of its kind in Australia. It is designed to provide HIV, health and funding agencies, as well as the affected community, with a picture of the overall situation of people living with HIV/AIDS (PLWHA) in Australia.

The *HIV Futures II* survey was conducted by the Living with HIV research program at the Australian Research Centre in Sex, Health and Society, La Trobe University, in the second half of 1999. The survey asked PLWHA about their health, use of antiretroviral and complementary treatments, use of information and support services, and their housing and financial situation. It also asked about sex and relationships, people's social supports, recreational drug use, work situation and future planning.

This is the second time this national survey has been conducted. The research team held consultations with PLWHA and HIV organisations around the country in order to improve this follow-up survey.

The results of this study have been reported in the document *HIV Futures II: The Health and Well-Being of People with HIV/AIDS in Australia*. The HIV Futures Community Report contains a vast amount of information about the social impacts of HIV/AIDS including: treatment uptake and health management; the impact of HIV/AIDS on sexual practice; the involvement of respondents in community organisations, and the importance of HIV/AIDS organisations to PLWHA; the impact of HIV/AIDS on work and employment participation; and the financial impact of living with HIV/AIDS. This report relates specifically to people who were resident in New South Wales at the time of the survey.

We recognise the importance of providing analysis of data for specific communities to assist with planning and policy. The series of state reports give an overview of findings for those states where there were a sufficient number of respondents. The reports cover the major areas of the main report and should be read in conjunction with it.

The people who completed the survey

The survey was completed by 924 respondents. This sample represents 8% of all PLWHA in Australia. Respondents ages ranged from 18 to 77 years (median = 38.0 years, mean = 41 years). The average number of years since respondents first tested HIV seropositive for 9.8 years. The results relating to the total sample are reported in the document *HIV Futures II: Health, The Health and Well-Being of People with HIV/AIDS in Australia* (Grierson, Bartos, de Visser and McDonald, 2000).

The national sample under-represents gay men from NSW and over-represents women, heterosexual men, those from non-metropolitan areas and those from outside NSW when compared to the Australian HIV Surveillance Report (NCHCER, 1999). Accordingly, all data in the remainder of this report have been weighted based on mode of infection, gender, state of residence and diagnoses of AIDS defining illness.

Four hundred and forty PLWHA from NSW completed the HIV Futures II Survey. The number of NSW respondents is significantly fewer than would have been expected in a representative sample of PLWHA in Australia. However the sampling procedure was designed to include large numbers of PLWHA from states other than New South Wales and Victoria. We are grateful for the assistance provided by the AIDS Council of NSW [ACON], Mark Bebbington and Brent Allen at ACON, ACON Community Support Network, ACON Women's Project, ACON Hunter, ACON Illawarra, ACON Northern Rivers, ACON Western Sydney, Albion Street Centre, Bigge Park Centre, Bobby Goldsmith Foundation, Coffs Harbour Sexual Health Centre – Ralph Waldsax, Foley House, Gender Centre, Grafton Community Health Centre, Kempsey Community Health Centre, Karumah Day Centre, Livingstone Road Clinic, Luncheon Club AIDS Support Group, Macquarie Area Health Service, Mid North Coast Area Health Service – Robert Baldwin, New South Wales Department of Health, New South Wales Users and AIDS Association [NUAA], North AIDS, Options Employment Service, Parramatta Sexual Health Centre, Positive Living Centre, People Living With HIV/AIDS – PLWHA (NSW), Pozhet West, Positive Employment Service, Positive Heterosexuals – David Barton, St George Sexual Health Centre, SMASH Project, Sydney PLWHA Day Centre, Talkabout, Wentworth Area Health Service, Wollongong HIV Prevention Service, Peter de Ruyter, and Paul Burr.

The sample from NSW contained 93% males and 7% were females. This is a significantly greater proportion of males than the sample from the other states combined. The ages of the NSW respondents ranged from 26 years to 68 years. The average age for NSW PLWHA was 43.7 years, which is similar to that of the rest of the sample. On average, PLWHA living in NSW had been HIV seropositive for 10.3 years - a significantly longer time to that reported by PLWHA from other States (mean = 9.3 years).

The vast majority of respondents had been infected with HIV through sexual contact: 83% cited homosexual or bisexual contact as the most likely transmission route, 3% reported injecting drug use, 7% cited heterosexual contact, 1% reported homosexual/bisexual contact and injecting drug use; 4% were infected by blood products or in a health care setting; and 2% were people with haemophilia infected through contaminated blood products. Compared to PLWHA living in other states, NSW PLWHA were significantly more likely to report homosexual or bisexual sex as their mode of infection, and significantly less likely to report haemophilia as their mode of infection.

Major findings

The results reported below compare PLWHA from NSW with PLWHA from other states of Australia combined, ie. the rest of the sample minus the NSW respondents.

Current health

Most respondents reported that they currently feel healthy: 20% said that their health is *excellent*, 52% said that their health is *good*, 27% said that their health is *fair*, and 3% said that their health is *poor*. Twenty-three percent of the respondents from NSW have been diagnosed with an AIDS-defining illness - a similar proportion to that reported by PLWHA from the other states combined.

Thirty-eight percent of respondents from NSW have a major health condition other than HIV/AIDS - a similar proportion to the 43% reported by PLWHA from other States. The most frequently cited "other" health conditions included cardiovascular disease, arthritis, mental illnesses, hepatitis B, hepatitis C, and asthma. Around one in three (34%) PLWHA from NSW have had hepatitis A – a significantly greater proportion than that for PLWHA in other states. Forty-two percent of NSW PLWHA have had hepatitis B. Of the 62% of NSW PLWHA who have been tested for hepatitis C, 27% have tested positive, 65% have tested negative, and 8% do not know the result of their test. This means that 17% of NSW PLWHA have tested positive for Hep C. A third (33%) of respondents are on medication for anxiety, 26% for depression, and 5% are on anti-psychotic medication.

All but one respondent from NSW have taken a CD4/T-cell test (99.8%), and all but one respondent has taken a viral load test (99.8%). NSW PLWHA are significantly less likely to have had a genotypic antiretroviral resistance test in the last twelve months compared with PLWHA from other states (11% vs 17%). The results of respondents' most recent CD4/T-cell tests and viral load tests are displayed in Table 1 (below). Not shown in Table 1 is the finding that 8% of NSW PLWHA have a CD4/T-cell count below 250 and a viral load above 50,000.

Table 1: Results of serological testing

Description	Result	Proportion
CD4/T-cell count	cells/ml blood	
little or no immune damage	over 500	47%
moderate immune damage	250 - 500	35%
severe immune damage	below 250	18%
Viral load	copies/ml blood	
below detectable level	below 200 / 500	57%
low	500 - 10,000	16%
moderate	10,000 - 50,000	11%
high	over 50,000	16%

Antiretroviral Therapy

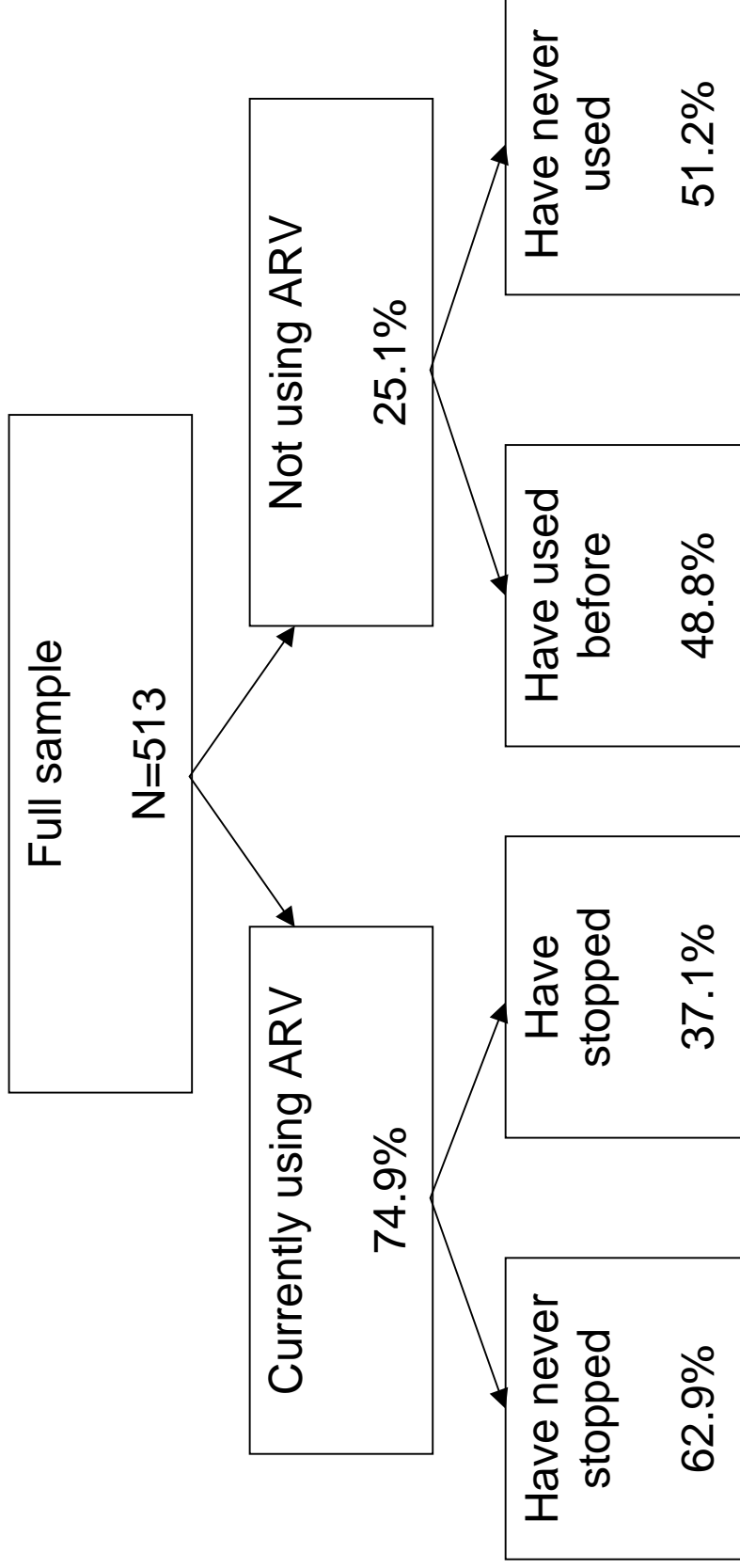
Figure 1 shows the uptake of antiretroviral treatment for NSW PLWHA. Almost nine out of ten (87%) of NSW PLWHA have taken antiretroviral drugs at some stage, of these 86% are using them currently. These figures are similar to those for PLWHA from other states. Of those PLWHA from NSW who have ever taken antiretrovirals about half (46%) report that their health has improved, 15% report that their health has stayed the same, 34% that it fluctuated, and 5% that it has deteriorated.

Most (55%) of the PLWHA from NSW 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: diarrhoea (experienced by 46% of NSW PLWHA who experience side effects of antiretroviral drugs), nausea (26%), neuropathy (15%), lipodystrophy (15%) and fatigue/lethargy (15%).

Three quarters (73%) of NSW PLWHA who use antiretrovirals report difficulties in taking this medication. The most common difficulties among these respondents are remembering to take drugs on time (44%), organising meals around medication (31%) taking medication in public (26%) and carrying medication (22%). NSW PLWHA are significantly more likely to report that they find taking a large number of tablets a problem.

Thirteen percent of NSW PLWHA missed at least one dose on the day before they filled out the survey, with a similar proportion (11%) missing a dose the day before that. Only 5% missed a dose on both days. Thirty-seven percent of NSW PLWHA have taken a break from antiretrovirals at some stage, a similar proportion to that for other states. The reasons most commonly given for taking a break are side effects (18%) and to clean out their system (13%).

Figure 1: The uptake of antiretroviral drugs



NSW PLWHA are more enthusiastic about the efficacy of new medications compared with PLWHA in other states. Compared with other states, PLWHA from NSW are significantly more likely to agree that HIV treatments will stop them dying from AIDS and PLWHA should start using antiretroviral treatments as soon as possible. They also disagree more strongly that taking tablets is an unwanted reminder of HIV. Figure 2 (below) shows that most (69%) of NSW PLWHA agree that antiretroviral drugs have improved the prospects of most PLWHA, while 2% believe they haven't improved the prospects of PLWHA, 4% do not know and 25% believe it is too soon to tell.

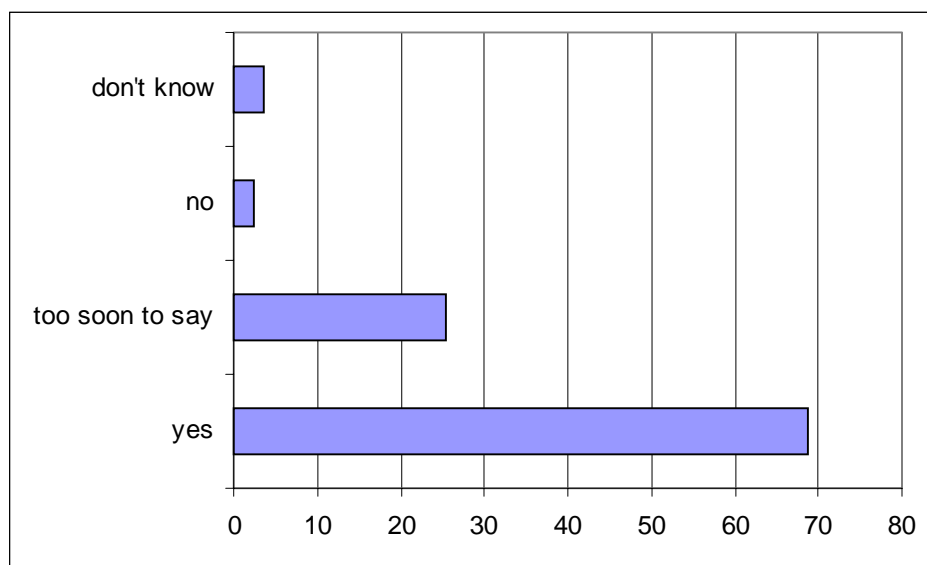


Figure 2: Opinions of NSW respondents on whether antiretrovirals have improved the prospects of PLWHA.

Those NSW PLWHA who are currently using combination therapy have done so for an average of 3 years and 1 month. The mean number of combinations they have tried in this time is 3.0, with a mean of 1.6 of these having been used in the past 12 months. They started on these therapies when their viral load was high (mean = 315,649.7 copies/ml) and their CD4 count was low (mean = 258.1). The most common circumstances surrounding the commencement of combination therapy for these respondents were doctors advice (83%), a drop in CD4 count (43%), new drugs becoming available (39%), and hearing of the effectiveness of the treatment (33%).

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 (10%) and their current combination was not working (9%). Side effects were a more common reason for changing combinations among NSW respondents than those in the rest of the sample. Most PLWHA from NSW felt they still had options left – 40% reporting they have many options, 48% a few, 7% one and 7% none.

Those NSW PLWHA who have stopped using antiretrovirals had been using them for an average of 2 years and 7 months and had stopped an average of 1 year and 9 months ago. They have used on average 3.0 combinations. Of the NSW PLWHA who had taken antiretrovirals and stopped, only 11% reported that their health improved on the medication, 18% reported that it stayed the same, 40% that it fluctuated and 31% that it deteriorated. The most common reasons for stopping use

of antiretrovirals were side effects (68%), that they weren't working (31%), taking a break to clean out the respondent's system (29%), they didn't fit in with the respondent's life style (25%), and having a drug holiday (16%).

Of all NSW PLWHA not currently taking antiretroviral medications, 88% reported that they would consider taking them in the future. The most common circumstances which PLWHA report might make them start antiretrovirals are a significant drop in CD4/T-cell count (70%), becoming very ill (65%), a significant rise in viral load (64%), hospitalisation due to HIV-related infections (60%) or on a doctor's advice (49%). These figures are similar to those reported by PLWHA in other states.

Prophylaxis and Complementary Therapies

Figure 3 (below) shows that while the majority of NSW PLWHA use antiretroviral drugs and nearly half use complementary therapies. One in three (32%) of the respondents from NSW use prophylaxis for opportunistic infections - prophylaxis for *Pneumocystis carinii* pneumonia (PCP) and/or prophylaxis for other opportunistic infections.

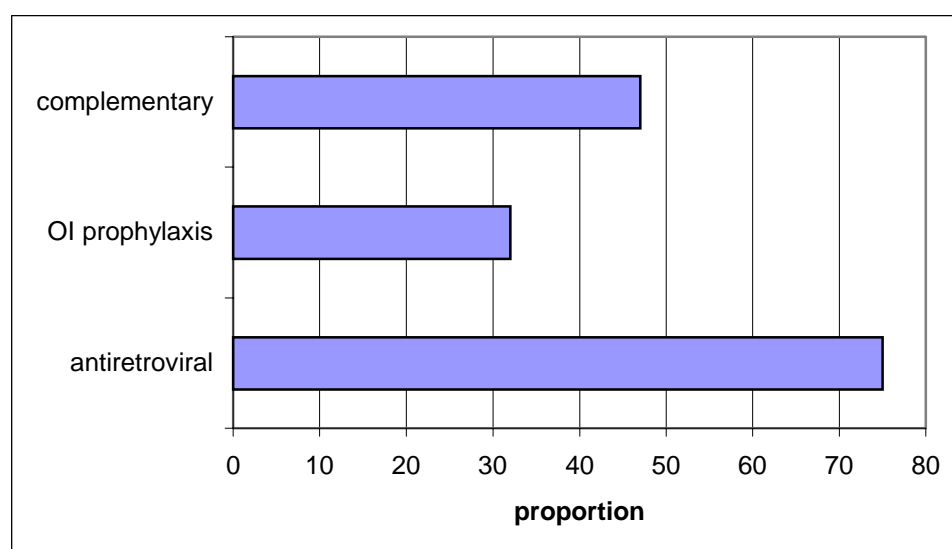


Figure 3: Use of therapies for HIV/AIDS

Just under half (47%) of the respondents from NSW use complementary therapies for HIV/AIDS. The most commonly used complementary therapies are vitamin/mineral supplements (86% of NSW PLWHA who use complementary therapies), massage (48%), meditation/visualisation (36%), and herbal remedies (34%).

Attitudes toward complementary therapies were measured on a scale from 1 to 5, where higher scores indicate more favourable attitudes. Generally, NSW PLWHA had favourable attitudes toward complementary therapies (mean = 3.52). PLWHA from NSW had similar attitudes toward complementary therapies as PLWHA from other States (mean = 3.51).

Health Services

In the last 6 months the health services that NSW PLWHA had most commonly used were a GP who specialises in HIV (61%), an HIV specialist/physician (48%), a hospital outpatient clinic (31%), an HIV organisation clinic (30%), a hospital social worker/counsellor (18%), and an AIDS organisation social worker (16%). These proportions are similar to those for PLWHA from other states combined, although

PLWHA from Sydney were less likely to go to a sexual health centre than PLWHA from rural NSW and PLWHA from other states. Forty-three percent of NSW PLWHA have to go to more than one place to get all their prescriptions filled, a similar proportion to that for PLWHA in other states.

When asked who they usually see for HIV related treatment, PLWHA from New South Wales were most likely to nominate a HIV GP (43%), while 29% nominated a HIV specialist 9% a Sexual Health Centre and 8% a HIV/AIDS organisation clinic. When asked who they see for general (non-HIV) medical care, they were most likely to nominate a HIV GP (50%), followed by a generalist GP (20%) and a HIV specialist (13%). These usage patterns are significantly different to those PLWHA from the other states.

Information and support services

Over three-quarters of NSW respondents (79%) have direct contact with an HIV/AIDS-related organisation. This is a similar proportion to that found among PLWHA in the rest of the country. Of those NSW PLWHA in contact with HIV/AIDS organisations, 80% receive a newsletter, 71% are clients, 42% are members, 13% are volunteers and 11% are staff. Of those PLWHA in the NSW sample who do not have contact with an HIV/AIDS organisation the most common reasons given are not wanting to be involved (65%) and not having time (32%). No access to transport was a reason not to have contact with a PLWHA organisation for significantly more respondents in rural NSW (38%) compared with those from Sydney (0%). Seventy percent of NSW PLWHA who have contact with an HIV/AIDS-related organisation have contact with the ACON, and 42% have contact with PLWHA (NSW). Among PLWHA from NSW there was no relationship between having contact with the ACON and having an AIDS-defining illness, or living in an urban area as opposed to a regional centre or rural area.

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

Service	HIV/AIDS Organisation	Other service organisation
Treatments advice	49%	20%
Social contact with other PLWHA	35%	14%
Counselling	31%	19%
Peer support group	28%	7%
Legal advice	25%	12%
Financial assistance	22%	15%
Pharmacy services	22%	35%
Alternative therapies	20%	22%
Informal peer support	18%	12%
Housing assistance	16%	23%
Financial advice	16%	15%
Library	10%	17%
Internet access	10%	18%
Respite care	8%	7%
Mental health services	8%	14%
Employment services	7%	11%
Return to work skills	6%	11%
Drug/alcohol treatment	3%	11%

Table 2 (above) displays the proportion of NSW 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, social contact, and

counselling. PLWHA from NSW were significantly more likely than PLWHA from other states to report that they make use of pharmacy services, employment services and legal advice provided by HIV/AIDS organisations. They are significantly less likely to use alternative therapies provided by HIV/AIDS organisations than PLWHA in other states. They are also significantly less likely to use HIV/AIDS organisations informal peer support and social contact with PLWHA, however they are more likely to use other organisations for the latter. PLWHA from rural regions are significantly less likely to use pharmacy, respite care, legal advice, housing assistance and employment services provided by HIV/AIDS organisations than PLWHA from Sydney.

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 a doctor specialising in HIV. However, more than two thirds of the respondents rely on HIV/AIDS-related newspapers and magazines, around half rely on HIV positive friends and the gay press, which suggests that PLWHA seek information from a range of different sources. NSW PLWHA were more likely than other PLWHA to cite the gay press as an important source of information. They were less likely to cite nurses, injecting drugs user's organisations and family members. PLWHA from rural NSW were significantly less likely to cite alternative therapists as a source of information on living with HIV/AIDS than PLWHA from Sydney. Both groups cited alternative therapists as a source of information significantly less commonly than PLWHA in other states. NSW PLWHA were also less likely to cite positive women's organisations, although this is likely to be a result of the significantly smaller proportion of women in the NSW sample.

Respondents were also asked which was the *most* important source of information. Doctors specialising in HIV were most commonly cited (73%) as such.

Table 3 also displays the responses of PLWHA to questions they were asked about whom they rely on for information about living with HIV/AIDS (but not about treatments). The sources of information about living with HIV/AIDS most frequently cited as being important were HIV magazines and newspapers, the gay press and HIV positive friends. PLWHA from NSW were significantly more likely than PLWHA from other parts of Australia to report that the gay press as an important source of information about living with HIV/AIDS. Rural PLWHA in NSW were also significantly less likely to use the internet as a source of information on this topic than PLWHA from Sydney and those from other states in Australia.

Respondents were also asked which was the *most* important source of information on living with HIV/AIDS. The most common responses were HIV magazines or newspapers (21%), HIV positive friends (20%) and a doctor specialising in HIV (20%).

Table 3: Important sources of information for PLWHA

Information source	Source of information about:	
	Treatments	Living with HIV/AIDS
Doctor specialising in HIV	95%	46%
Other doctor	21%	13%
Nurse	16%	16%
Pharmacist	18%	8%
Alternative therapist	14%	22%
Treatments officer	22%	13%
Other HIV/AIDS organisation staff	27%	40%
Positive women's organisation	4%	6%
Injecting drug user's organisation	2%	6%
Haemophilia Foundation	2%	3%
HIV positive friends	41%	53%
Other friends	10%	23%
Partner/lover	15%	23%
Family	4%	14%
Gay press	55%	54%
HIV magazine/newspaper	68%	63%
Internet	22%	14%

The HIV-related publications most read by NSW PLWHA are *Talkabout* (77%), gay newspapers (76%), *Positive Living* (52%), *With Complements* (48%), the *HIV Herald* (39%), newsletters from community organisations (29%) and gay magazines (24%). Sydney PLWHA were significantly more likely to read the gay press and overseas HIV-related magazines than PLWHA from rural NSW.

We asked respondents whether they thought lack of information made it difficult to make decisions about various issues surrounding living with HIV. NSW respondents most felt a lack of information when making decisions on managing side effects (26%), taking a break from antiretrovirals (22%), financial planning (21%) and interactions between antiretrovirals and other medication (22%). These figures were similar to those for PLWHA from other states.

Almost a third (31%) of NSW PLWHA had experienced less favourable treatment than other people when attending a medical service. This was a similar proportion to PLWHA in other states (32%).

Ninety-six percent of NSW 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 4 (below) show that many NSW PLWHA spend no free time with other positive people, although over half spend *some* or *a lot* of time with other positive people. Respondents from Sydney spend significantly more time with other PLWHA than both respondents from rural NSW and respondents from other States. Thirty-one percent of NSW 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 4: Amount of free time spent with other HIV positive people

Amount of free time	Proportion
None	14%
A little	34%
Some	32%
A lot	20%

Only 1% of respondents from NSW have not disclosed their HIV status to anyone. Three out of five (61%) have had their HIV status disclosed when they didn't want it to be. Respondents were asked to rate the amount of social support they received from different sources on a scale of 1 (*a lot*) to 4 (*none*). PLWHA from NSW received the most support from their partners (mean = 1.35), their pets (mean = 1.60) and their close friends (mean = 1.68). There were no significant differences in the ratings of support given to each group between PLWHA in NSW and those in other states.

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 NSW respondents can be seen in Table 5 (below). No significant differences were found between NSW PLWHA and those from other states on these items. Agreement with the first four items in Table 5 is a measure of the extent of depressive symptoms. Among NSW PLWHA 39% agreed or strongly agreed with none of these items, 26% with one item, 17% with two, 12% with three and 7% with all four. Agreement with all four items is suggestive of clinical depression. Most NSW respondents had a positive body image. Over half (52%) of respondents agreed or strongly agreed that they were happy with the way their body looks, although 54% agreed or strongly agreed that changes in their bodies due to HIV/AIDS had made them sexually unattractive. Respondents also have a positive attitude to their HIV. Most (52%) report that they do prefer to think about HIV even when they are well, and 51% also felt that their life had become more meaningful since they were diagnosed with HIV.

HIV status was rated as being *important* to self-definition by most (60%) of NSW PLWHA, while it was considered *essential* to 16% and irrelevant to 6%. This was not significantly different to the rest of the sample.

Table 5: Responses to mental health and wellbeing attitudinal items from the NSW sample

	strongly agree	agree	disagree	strongly disagree
I cry or feel like crying all the time	5%	16%	50%	29%
I don't enjoy things the way I used to	16%	38%	32%	15%
I have lost interest in other people	6%	25%	46%	22%
I don't feel it's worth going on	4%	11%	42%	43%
As long as I'm well I prefer not think about HIV/AIDS	11%	37%	44%	8%
Changes in my body due to HIV/AIDS have made me feel sexually unattractive	18%	36%	35%	11%
I am happy with the way my body looks	9%	43%	38%	10%
Life has become more meaningful since I became HIV positive	17%	34%	31%	19%

Planning for the future

Respondents were asked to indicate how far into the future they plan when making major decisions about their future. Table 6 (below) shows the responses given by PLWHA from NSW. Two out of five (40%) NSW PLWHA have changed how far they plan into the future in the last two years, of whom 72% 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 (54%). 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 (58%).

Table 6: Time frame use by PLWHA when planning for the future

Time frame used	Proportion
One day at a time	24%
A few months ahead	25%
1 year ahead	23%
5 years ahead	17%
10 or more years ahead	12%

Accommodation

The majority (77%) of NSW respondents live in Sydney, while 14% live in a regional centre or town, and 14% live in a rural area. These proportions are similar to those for other states.

Table 7 (below) shows that while many NSW PLWHA own their home or are buying their own home, half are living in rental accommodation, while a small number live rent-free or in community housing. Compared to PLWHA from other states, NSW PLWHA were significantly more likely to live in private rental accommodation. The vast majority (86%) of NSW respondents believe that their current housing is suitable for their needs. Forty-two percent of NSW PLWHA have changed their accommodation as a result of having HIV/AIDS. Among these the most common reasons for change were moving closer to health services (38%), and moving to a quieter location (37%).

Table 7: Accommodation in which PLWHA live

Accommodation Type	Proportion
Own or purchasing own house or flat	32%
Private rental accommodation	44%
Public rental accommodation	13%
Live rent-free	6%
Community housing	3%

When asked with whom they live, 43% of NSW PLWHA reported that they live alone, 32% live with a sexual partner, 19% live with friends or housemates, 5% live with dependent children, and 5% live with other family members.

Sex and Relationships

Respondents were asked to describe their sexual orientation or sexual identity. The majority of respondents were homosexual men (81%), and also included bisexual men (7%), heterosexual men (6%) and women (5%). There were also another 2% who had other sexual orientations.

When asked to describe their current sexual relationships, 24% reported that they are not currently sexually active, while 33% reported that they only have casual sex, 22% have sex in a monogamous regular relationship, and 19% have sex in a non-

monogamous regular relationship. Compared with PLWHA from rural NSW and PLWHA from other states, Sydney PLWHA are significantly more likely to report only having casual sex and are significantly less likely to report that they are in a monogamous regular relationship.

Fifty-two percent of respondents who have a regular relationship are in a seroconcordant relationship - the remainder (70%) are in a relationship with an HIV seronegative partner, or a partner whose serostatus is unknown. PLWHA from rural NSW are significantly more likely to be in a seroconcordant relationship than both PLWHA from Sydney and PLWHA from other states. All but three (99%) 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 are HIV seropositive. Respondents most commonly told their partner when they found out (31%) or that their partner already knew they were HIV positive when they started the relationship (16%). Of the remainder, 70% told their partner at the start of the relationship, 15% within a few days, 16% within a few weeks, 5% within a few months, while 3% took more than a year. Respondents were also asked how their partner reacted when they told them that they are HIV seropositive. Many respondents (56%) said that it did not make any difference. Over two-thirds (52%) of respondents reported that their partner was very supportive, and 31% said that they became closer, while 24% said that their partner was worried or scared and 9% said that their partner was angry. PLWHA from rural NSW were significantly less likely than PLWHA from other states to report that their partner was supportive, and Sydney PLWHA were more likely to report that they became closer with their partner than rural NSW PLWHA and PLWHA from other states..

When asked about their patterns of condom use during sex with regular partners in the 6 months prior to completing the survey, 41% reported that they always used a condom, 25% reported that they sometimes used a condom, and 35% 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).

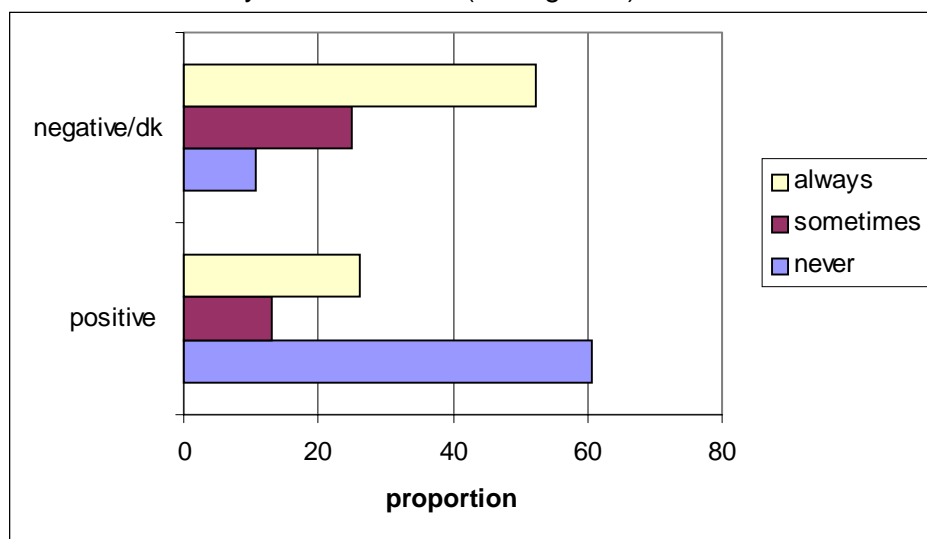


Figure 4: Patterns of condom use with regular partners

When asked about their patterns of condom use during sex with casual partners in the 6 months prior to completing the survey, 46% reported that they always used a condom, 48% reported that they sometimes used a condom, and 6% 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 NSW 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 NSW PLWHA, almost all (96%) of these sexual contacts were with male partners, and the majority (78%) involved vaginal or anal intercourse. The respondents most often didn't know the HIV status of their partners (65%), of the rest 66% were known to be positive and 34% were known to be negative. Almost all (97%) NSW respondents who knew their partner's status did so because their partner disclosed this information. Amongst those who engaged in vaginal or anal intercourse, 68% of NSW PLWHA used a condom. A condom was used significantly more often when the respondent was not sure of their partner's HIV status or knew them to be negative.

Recreational drug use

Table 8 compares the rate of use of non-prescription drugs of NSW PLWHA with the general population using data from the 1998 National Drug Strategy Household Survey (AIHW, 1999). While alcohol, the most commonly used drug, was used by a comparable proportion of NSW PLWHA to the general population, other recreational drugs are used by considerably greater proportions. NSW PLWHA used ecstasy, marijuana, LSD/trips and amyl more commonly than PLWHA from the other states combined. Sydney PLWHA also had used speed (not injected), cocaine (injected and not injected) and steroids in significantly greater proportions than both PLWHA from rural NSW and PLWHA from outside NSW. PLWHA from Sydney had also more commonly injected heroin than PLWHA from rural NSW. However, most PLWHA from NSW were happy with the amount of drugs they took. Seventy-nine percent either disagreed or strongly disagreed with the statement that they use illegal drugs more than they would like, and 75% disagreed or strongly disagreed that they drink more alcohol than they would like. Less than one in four (22%) reported ever missing a dose of antiretrovirals due to the use of illegal drugs.

Table 8: Use of non-prescription drugs, PLWHA and general population rates

	Percentage of sample using in last 12 months	General population rates
Alcohol	81.8%	80.7%
Marijuana	62.1%	17.9%
Cigarettes	54.7%	26.4%
Amyl	45.1%	0.8%
Ecstasy	30.9%	2.4%
Speed (not injected)	22.3%	3.6%*
LSD/trips	17.2%	3.0%*
Cocaine (not injected)	11.5%	1.4%*
Speed (injected)	10.9%	3.6%*
Heroin (injected)	7.9%	0.7%*
Steroids (injected)	7.5%	0.2%
Cocaine (injected)	5.5%	1.4%*
Methadone (prescribed)	5.5%	0.2%
Heroin (not injected)	1.2%	0.7%*
Methadone (non-prescribed)	1.0%	0.2%

*Rates in the AIHW report do not differentiate between injected and administered through other means. General population rates given for any use of substance.

Employment

Over half (53%) of NSW PLWHA were not in paid employment at the time of completing the survey. Of the PLWHA who are working, 64% work full-time and 36% work part-time. NSW PLWHA who are working are significantly more likely to be full-time than PLWHA from other states who are working. Most NSW PLWHA (84%) reported that being HIV positive has affected their career plans: 35% report that they stopped work, 25% report that it is more difficult to plan, 25% report that having a career is no longer as important, 14% have changed careers since diagnosis and 7% report they are now less likely to change their career. When asked the effect of antiretrovirals on their work plans 33% said they haven't changed, 14% that they considered stopping work, 13% that they anticipate a longer time in the workforce, 10% that they haven't used antiretrovirals and 10% that they have considered returning to work. One in five (19%) of NSW PLWHA report having been discriminated against at work as a result of having HIV/AIDS. Sydney PLWHA were significantly more likely to have been discriminated against at work than PLWHA from rural NSW.

Sixty-two percent of NSW PLWHA who have ever worked have stopped doing so at some stage due to their HIV diagnosis. These PLWHA stopped work for an average of three years and nine months. The last time they stopped working the most common reasons were stress or depression (62%), poor health (60%) and low energy (56%). Rural PLWHA were significantly more likely than Sydney PLWHA to have stopped work due to moving to a new location. When asked their HIV status at the time they stopped work 43% reported they were HIV positive but had not been ill, 39% they were HIV positive and had been ill, and 18% that they had been diagnosed with an AIDS defining illness. When they were not working 72% received government benefits. About half (52%) of these PLWHA have returned to work. The most common reasons for returning to work were financial (68%), better psychological health (49%), better physical health (47%), and to have something to do (45%).

The 47% of NSW PLWHA who are currently employed work an average of 30.0 hours per week. Most (84%) report that their job involves a moderate to very high

stress level. Fifty-two percent of NSW PLWHA who are working reported that their capacity to perform their work duties is affected by having HIV/AIDS: these respondents reported that they tire quickly, work fewer hours, or have difficulty concentrating. Seventy-five percent of workers reported that they could 'often' or 'always' get time off work for medical appointments, 40% for counselling, 77% for sick leave, and 20% for volunteer work.

Forty-one percent of NSW PLWHA indicated that they are considering changing their work arrangements. Of these 48% want to start or return to work, 45% want to change the type of work they do, 21% want to reduce their hours, 12% want to increase their hours and 5% want to stop work. Most of the PLWHA who want to change their work arrangements perceived that this would be difficult: 28% believe it will be *very difficult*, 60% believe that it will be *somewhat difficult* and 12% that it will be *not at all* difficult.

Finances

Given the large number of PLWHA in NSW who are not in paid employment, it is not surprising that 51% of respondents reported that their main source of income is a government benefit, pension, or social security payment. Forty percent of respondents reported that a salary is their main source of income, while 8% reported superannuation or an annuity as their main source of income, and 1% reported that they receive financial support from their partner and/or family members. Over half of the NSW respondents reported annual incomes below \$15,000. Respondents' incomes are displayed in Table 9 (below). The incomes of rural PLWHA and those of their partners or spouses were both significantly lower than for respondents from Sydney.

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 September quarter of 1999 (IAESR, 1999) were used to calculate the proportion of PLWHA with incomes below the poverty threshold. Among NSW PLWHA, 26% reported incomes below the poverty line. While this figure is significantly smaller than the 36% found for the rest of the sample, it is still a matter for concern.

Table 9: Income reported by PLWHA

Weekly income	Yearly income	Proportion
\$0 - \$150	\$0 - \$7800	6%
\$151 - \$270	\$7801 - \$14040	39%
\$271 - \$390	\$14041 - \$20280	12%
\$391 - \$510	\$20281 - \$26520	16%
\$511 - \$630	\$26521 - \$32760	11%
\$631 - \$750	\$32761 - \$39000	10%
\$751 -	\$39001 -	7%

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 7 (below) demonstrate that while many PLWHA reported difficulties in meeting the costs of social activities such as 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 eight NSW 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 one-quarter of the respondents who use complementary/alternative therapies find it very difficult to meet the cost of this treatment. Sydney PLWHA reported significantly less difficulty than both rural NSW PLWHA and PLWHA from other states in meeting the costs of entertainment, going out, sport, housing costs and transport. Furthermore, rural PLWHA found it more difficult than Sydney PLWHA to meet the costs medical services and utilities.

Table 10: Difficulties meeting the cost of living reported by PLWHA
(proportion of respondents who use each item)

Item	Not difficult	A little difficult	Very difficult
Co-payment for medication for AIDS	62%	31%	6%
Other prescribed medication	56%	35%	9%
Medical services	56%	27%	17%
Complementary therapies	43%	35%	23%
Support services	70%	20%	11%
Entertainment	31%	34%	35%
Going out	28%	33%	39%
Sport	41%	31%	28%
Recreational drugs	30%	30%	39%
Travel / holidays	20%	26%	54%
Rent / mortgage / housing	43%	41%	16%
Utilities (phone, gas, etc.)	34%	43%	23%
Food	46%	41%	13%
Clothing	31%	36%	33%
Transport	49%	38%	13%
Child care	43%	32%	26%

Detailed analyses of sexual behaviour and condom use are reported in the document *HIV Futures II: The Health and Well-Being of People with HIV/AIDS in Australia* (Grierson et al., 2000).