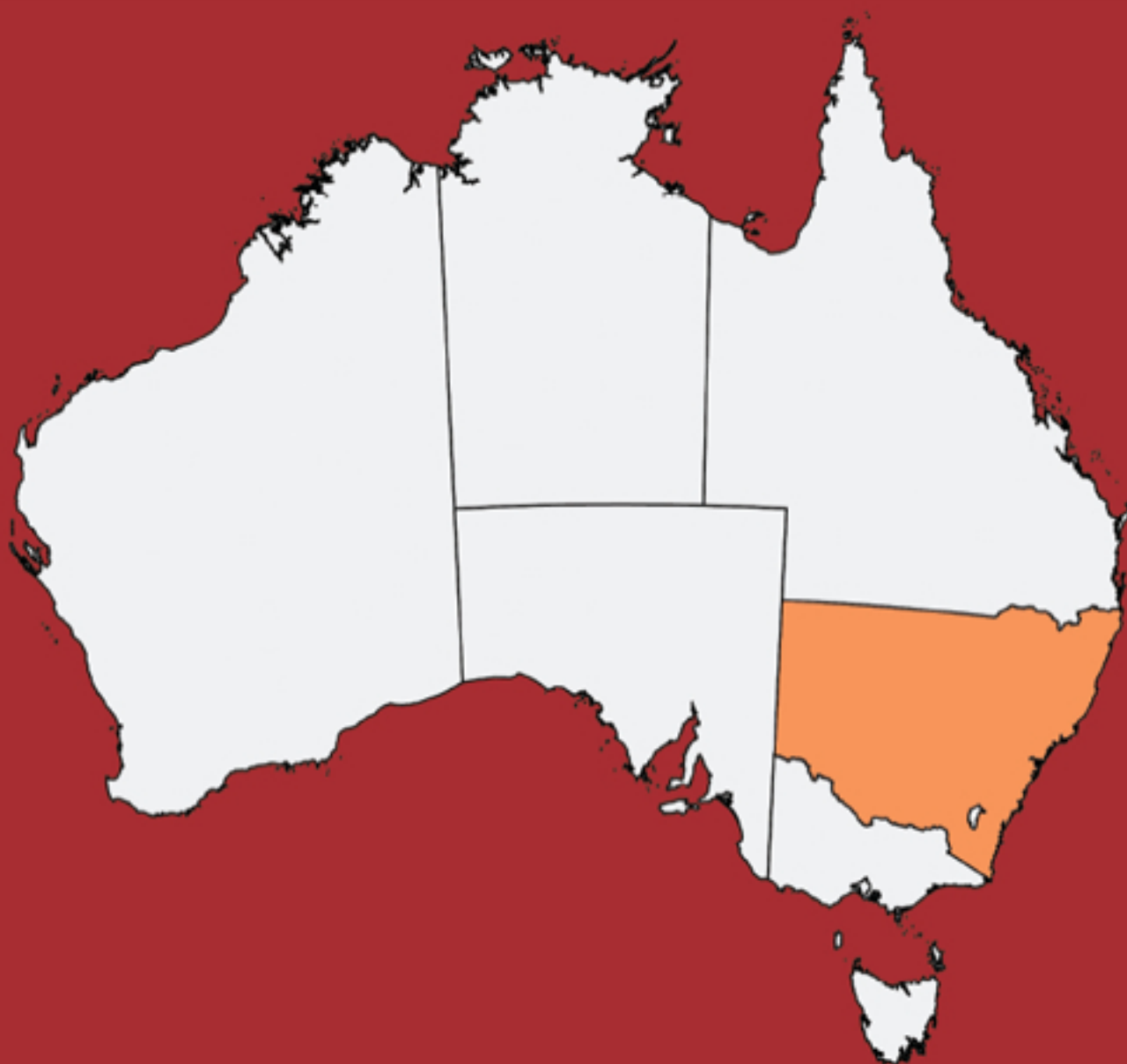


AUSTRALIAN RESEARCH CENTRE IN SEX, HEALTH AND SOCIETY

HIV FUTURES 4

Regional Reports 2005: New South Wales



THE LIVING WITH HIV PROGRAM

Jeffrey Grierson & Rachel Thorpe



AUSTRALIAN RESEARCH
CENTRE IN SEX,
HEALTH AND SOCIETY



LA TROBE
UNIVERSITY

HIV Futures 4 Regional Reports:

New South Wales

Jeffrey Grierson and
Rachel Thorpe.

The Living with HIV Program
at The Australian Research Centre in Sex, Health and Society
La Trobe University

Funded by the Australian Government
Department of Health and Ageing

October 2005

Monograph Series Number 56
ISBN 1920948201
©Latrobe University 2005

The Living with HIV Program is a part of the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. The program conducts social research into the lived experience of HIV. This research is guided by the Australian National Strategies on HIV, the Living with HIV Reference Group and the ARCSHS Scientific Advisory Committee. All research conducted is approved by the La Trobe University Human Ethics Committee and additional institutional and community ethics committees where appropriate. Full details of the Living with HIV research program can be found on the HIV Futures website: www.latrobe.edu.au/hiv-futures and details of ARCSHS can be found at www.latrobe.edu.au/arcshs

The HIV Futures Studies are funded by the Commonwealth Department of Health & Ageing.

Suggested citation:

Suggested citation:

J Grierson and R Thorpe (2005) HIV Futures 4 Regional Reports: New South Wales, Monograph series number 56, The Australian Research Centre in Sex, Health and Society, Latrobe University, Melbourne, Australia

CONTENTS

DEMOGRAPHICS	1
HEALTH.....	1
CURRENT HEALTH STATUS.....	2
TREATMENTS	4
SERVICES.....	7
INFORMATION.....	10
THE SOCIAL WORLD OF PLWHA.....	12
RELATIONSHIPS AND SEX	15
RECREATIONAL DRUG USE.....	15
HOME, WORK & MONEY	16
EMPLOYMENT.....	18
FINANCES.....	20
POVERTY.....	21
DISCRIMINATION	22

DEMOGRAPHICS

The HIV Futures 4 survey was completed by 1064 HIV positive Australians from all states and territories. This represents approximately 8.1% of the HIV positive population. The results for the total sample are reported in the document HIV Futures 4:State of the [positive] nation (Grierson, Thorpe, Saunders and Pitts, 2004).

The results in this report are for respondents from New South Wales.

550 PLWHA from NSW completed the HIV Futures 4 survey. 92.7% were male (510) and 7.3% were female (40). Of these 79.5% were gay men, 6.9% heterosexual men, 6.2% heterosexual women, 5.6% bisexual men, 0.6% lesbian and 0.2% bisexual women. The remaining 1.1% fell into other categories.

The respondents ranged in age from 21 to 92 years (mean 44.1 years, median 43.0 years).

Almost three-quarters of NSW participants were Australian born (73.4%), 99.4% spoke English at home and 99.4% indicated that Australia was their official country of residence. Eight respondents from NSW (1.5%) indicated they were of Aboriginal/Torres Strait Islander origin.

Table 1 below shows the years in which respondents tested HIV positive and in which they believe they were infected with HIV.

TABLE 1 Years of NSW respondent's testing positive and presumed infection (%)

Year	Tested HIV Positive	Presumed Infected
Pre 1985	9.8	25.3
1985-1989	30.2	26.9
1990-1994	25.7	22.5
1995-1999	20.2	15.5
2000+	14.0	9.8

HEALTH

HIV Antibody Testing

Table 2 shows the reasons NSW respondents had taken an HIV test at the time of first testing positive.

TABLE 2 Reasons for testing

Reason	Frequency	Percent
Became ill	85	18.2
Other	81	17.3
Routine health screening	79	16.9
Particular risk episode	64	13.7
Member of risk group	61	13.0
Doctor's suggestion	49	10.5
Starting new relationship	21	4.5
Tested without knowledge	17	3.6
Contact tracer/other health worker's suggestion	8	1.7
Availability of new treatments	2	0.4
Insurance	1	0.2

Pre- and Post-Test counselling/discussion

24.8% of NSW respondents had received pre-test counselling or engaged in an HIV pre-test discussion. Of those who tested positive in the last two years, 17.9% had done so.

Pre-test counselling was most commonly provided by:

- Doctor (50.8% of those receiving pre-test counselling)
- Nurse (12.7%)
- Counsellor/psychologist (12.7%)
- 79.3% of those who received counselling were satisfied with the information they received from this person
- 75.6% were satisfied with the level of support they received.

51.3% of respondents had received post-test counselling. Of those who tested positive in the last two years 64.3% had received post-test counselling.

Post-test counselling was most commonly provided by:

- Doctor (43.7% of those receiving post-test counselling)
- Counsellor/psychologist (17.5%)
- Nurse (6.1%)
- 81.8% were satisfied with the information they received
- 81.5% were satisfied with the support they received.

CURRENT HEALTH STATUS

Experience of Health and General Well Being

We asked respondents to indicate on a four point scale their current state of physical health, and their overall sense of well-being. The results are shown in Tables 3 and 4 below.

TABLE 3 NSW Respondents’ self ratings of general health status

	Frequency	Percent
Poor	33	6.1
Fair	151	28.0
Good	246	45.6
Excellent	110	20.4

TABLE 4 NSW Respondents’ self ratings of general well-being

	Frequency	Percent
Poor	48	8.9
Fair	173	32.1
Good	227	42.1
Excellent	91	16.9

CD4 and Viral Load

The results of respondents' most recent CD4/T-cell tests and viral load tests are displayed in Table 5 (below).

TABLE 5 Results of most recent serological tests (% of NSW sample)

		HIV Viral load				
		Below detectable levels	500-9999	10000-49999	50000+	Total
Cd4/T-cell count	500+	32.2	6.4	5.4	2.6	46.6
	250-499	19.6	4.7	4.7	5.2	34.3
	0-249	32.2	1.4	2.4	5.9	19.1
	Total	61.2	12.5	12.5	13.7	100.0

Health Conditions in addition to HIV

- 29.0% of respondents had been diagnosed with an AIDS defining illness
- 40.3% had experienced HIV/AIDS related illnesses other than those classified as AIDS defining illnesses.
- 47.3% of NSW respondents had been diagnosed with a major health condition other than HIV/AIDS

We also asked if participants had experienced any of five specific conditions.

- 42.5% had experienced lipodystrophy
- 36.5% weight loss
- 79.7% low energy or fatigue
- 58.8% a sleep disorder
- 38.4% confusion or memory loss.

Hepatitides

32.4% of NSW respondents had at some time been diagnosed with hepatitis A, and 51.5% had been vaccinated against this virus.

33.2% had at some time been diagnosed with hepatitis B. Of these, 73.6% had cleared the infection, 15.7% had an ongoing infection and 2.5% had a chronic infection. 60.0% of NSW respondents had been vaccinated against hepatitis B.

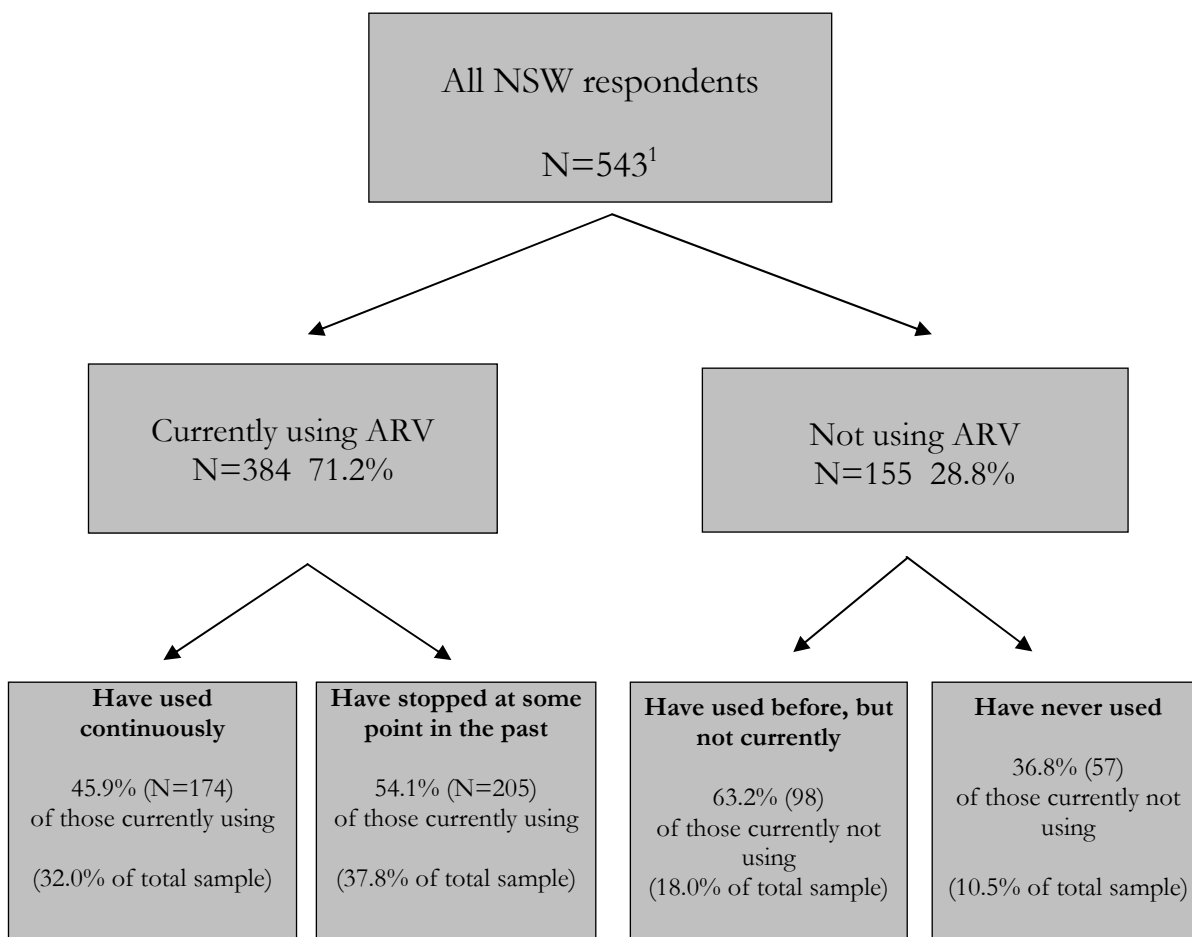
16.4% of the NSW respondents had hepatitis C. Only 16.9% (N=15) of those had ever undertaken medical treatment specifically for hepatitis C, while 23.8% (N=19) had taken some form of complementary therapy for hepatitis C.

TREATMENTS

Antiretroviral Therapy

A summary diagram of the uptake of antiretrovirals for NSW respondents can be found below.

FIGURE 1 Use of antiretroviral therapy



¹Weighted
(Note: Ns may be reduced due to missing data)

Those Currently Using ARV (mono-therapy and combination therapy)

30.5% of participants were taking more than three antiretroviral drugs, while the majority (60.9%) were on a combination of 3 antiretroviral drugs¹, 7.8% were on two, and 0.8% were on monotherapy.

The most common combination was one NNRTI and two NRTIs used by 16.6% of the sample (24.3% of those currently on combination therapy).

Different Combinations

Among those currently using combination therapy, respondents had used between one and 6 combinations in the last 12 months, with the median being 1.

¹ Combivir counts as 2 drugs, Trizivir as 3 drugs

When asked how many other combinations of ARV drugs were available for their treatment, 4.0% of respondents currently on combination therapy indicated that they thought there was only one other combination remaining. 23.7% believed there were ‘a few’ other combinations available and 34.7% said there were ‘many’. 32.9% said they didn’t know how many combinations were available for their future treatment. 4.8% of those currently on combination therapy believed there were no other combinations of ARV treatments other than those they were currently taking, available for their future treatment.

Treatment Breaks

In all, 54.1% of NSW respondents who were currently using antiretroviral medication had taken a break from these at some point.

Most Recent Treatment Break

The date of the most recent break ranged from currently taking one to having taken one 10 years ago. The mean length of break was 226 days with a median of 92 days. 21.5% described the break as a structured treatment interruption, while 59.7% described it as a treatment break.

- 68.0% of respondents talked to their doctor about the break prior to taking it
- 71.1% talked to their doctor during the break
- 90.2% talked to their doctor after the break
- 49.3% talked to their doctor at all three stages of the treatment break.
- 12.7% spoke to the doctor during and after the break, but not before
- 11.7% only spoke to their doctor after the break

Antiretroviral Resistance

34.0% of NSW respondents who had ever used antiretroviral treatments indicated that they had taken a viral resistance test. This included 36.9% of those who were currently on antiretroviral treatment and 23.4% of those who were not. 75.6% of those who had resistance testing said that the test found resistance to one or more antiretroviral drugs (74.8% of those currently on ARV, 78.9% of those not). This resulted in a change of drugs for 75.2% (N=79) of those where resistance was shown.

Dosing and Adherence

On average, NSW PLWHA were taking medication 2.4 times per day (range 0 to 20, median=2.0). The number of times they were taking specific types of medication is shown in Table 18 below. 76.2% of the sample were taking ARV twice daily, 7.4% three times a day and 11.3% once a day.

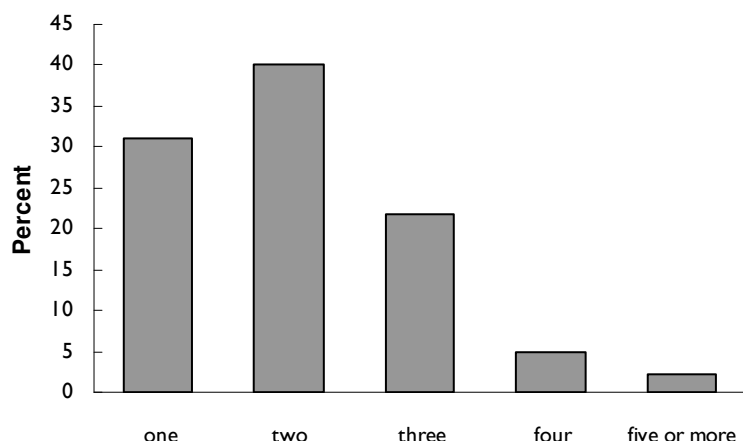
TABLE 6 Number of times participants take medications

	Mean	Median	Range
Antiretroviral drugs	1.91	2.0	0-6
Complementary therapies	1.64	2.0	0-8
Medication for other health conditions	1.75	2.0	0-8

Prescriptions

190 (49%) of PLWHA got their prescriptions for antiretroviral drugs from a HIV GP/S100 prescriber. A similar proportion (37.9%) obtained their prescription from a HIV specialist in an outpatient clinic, while fewer obtained them from a doctor at a sexual health centre (15.7%). The remaining 9.2% got them from either another GP, an HIV specialist while an inpatient, another doctor or another source.

FIGURE 2 Number of prescription pick-up points



Clinical Trials

A total of 34.7% (n=182) of NSW respondents had participated in a clinical trial for HIV related treatment and 9.2% of all participants (n=50) had participated in a clinical trial in the last two years. The main treatments that participants had trialed were AZT (11.1%), 3TC (7.6%), Atazanavir (6.6%) and Ruziglitazone (6.3%). They had on average been on these trials for 12.5 months. The circumstances surrounding participation in the trial are given in Table 7 below.

**TABLE 7 Reasons for participating in clinical trials
(% of those who have participated in a trial)**

My doctor and I decided together	20.0
I felt my experience could benefit others	18.1
I felt I had enough information about the trial	8.3
I had no other treatment options	7.8
It was the only way I could get the treatment	6.4
My other treatments were not working	4.8
I felt pressured to go on the trial	1.9
Other	5.7

(Multiple responses possible)

Complementary Therapies

73.1% of NSW respondents reported using at least one kind of complementary therapy, including body-mind therapies such as meditation and visualisation. Table 8 below shows the proportions of the sample that reported using each type of therapy and Table 9 shows the source of these therapies. 30.1% of the NSW participants reported using marijuana for therapeutic purposes.

TABLE 8 Current use any of complementary therapy

Vitamin/mineral supplements	51.4
Massage	37.1
Meditation/visualisation	25.6
Herbal therapies/supplements	17.9
Other therapy	10.9
Acupuncture	8.4
Traditional Chinese Medicine	6.6
Other traditional Medicine	5.7

(Multiple responses possible)

TABLE 9 Source of complementary therapy
(% of those currently using complementary therapies)

Private practice	28.2
AIDS community organisation	25.0
Health Service	11.5
PLWHA organisation	4.7
Other	46.4

Other Medication

53.3 % of NSW respondents were using prescribed medication other than antiretroviral therapies.

SERVICES**Health Services****Treatment**

We asked respondents to identify the physician they see for the clinical management of their HIV and for general health issues (Table 10).

TABLE 10 Physician used for general and HIV related treatment (% of total sample)

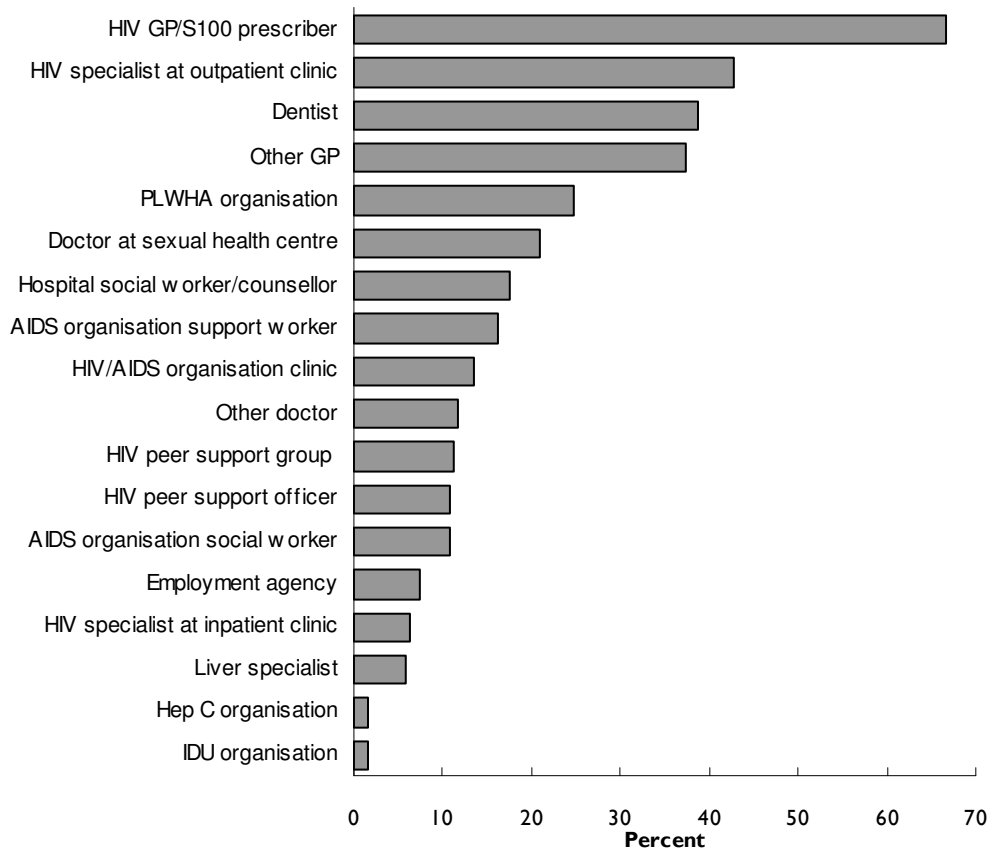
	For general treatment	For HIV specific treatment
HIV GP/S 100 Prescriber	56.5	49.6
Other GP	21.6	4.9
HIV specialist at outpatient clinic	12.4	29.8
HIV specialist at inpatient clinic	0.6	2.0
Doctor at sexual health centre	7.1	4.5
Other doctor	1.4	8.6
Other	0.4	0.6

57.3% of respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment. Of those who saw a different doctor, 97.4% said that that doctor knew their HIV status.

Services Used in the Last 6 Months

We presented respondents with a list of services, both clinical and ancillary and asked which they had used in the last 6 months. Clinical services were the most utilised in the list with 66.6% having used an HIV GP/ S100 prescriber, 42.7% an HIV outpatient specialist, 38.7% a dentist, 37.3% another GP and 20.9% a doctor at a sexual health service. Support services were also commonly used, with 24.8% reporting having used a PLWHA organisation, 17.6% a hospital social worker or counsellor and 16.2% an AIDS organisation support worker (see Figure 3).

Figure 3 Services used in the last six months (% of NSW respondents)



(multiple responses possible)

Other Services

Participants were asked whether they were currently using a range of services and, if so whether they used them through an HIV/AIDS organisation or through another organisation.

TABLE 11 Percent of NSW respondents who use services through HIV/AIDS organisations and other organisations (% of total sample)

	Use service at HIV/AIDS organisation	Use service at other organisation
Treatments advice	50.0	20.8
Financial assistance	39.1	8.2
Social contact with other PLWHA	36.6	7.2
Treatments information	35.6	9.4
Counselling	32.0	21.9
Peer support group	28.9	6.5
Financial advice	27.2	13.2
Pharmacy services	23.4	38.6
Legal advice	21.5	15.1
Informal peer support	17.8	10.8
Complementary therapies	17.0	22.5
Housing assistance	17.0	25.5
Volunteer carer	14.8	3.7
Community education campaigns	13.3	5.1
Internet access	12.4	25.7
Mental health services	12.1	17.9
Employment services	11.5	14.0
Return to work skills	10.5	9.5
Transport	8.0	22.8
Internet based information	7.2	13.6
Library	7.2	25.9
Respite care	5.3	6.2
Drug/alcohol treatment	4.7	9.5
Paid carer	3.0	2.8

(Multiple responses possible)

104 (19.2%) of NSW respondents indicated that there were services they felt they needed but did not have access to. The services most commonly nominated were services for PLWHA in rural, regional and outer suburban areas (12.3%), peer support groups (10.3%), access to affordable complementary or alternative therapies (8.0%), and counselling (7.6%)

INFORMATION

Sources

Respondents were asked to nominate from a list of potential sources, those that were important sources of information on treatments, HIV management and living with HIV (see Table 12).

TABLE 12 most popular sources of information about treatments, HIV management and living with HIV (% of NSW sample)

	Information about Treatments	Information about HIV Management	Information about Living with HIV
HIV GP/S100 prescriber	69.3	63.2	40.0
HIV specialist at outpatient clinic	46.9	40.6	20.9
HIV magazine/newspaper	44.2	41.1	43.1
Publications from HIV/AIDS groups	41.3	39.3	42.6
Articles in gay press	36.7	34.7	37.6
HIV positive friends	26.4	30.2	42.8
Internet	21.7	17.5	16.8
Sexual Health Service	14.8	15.7	14.8
Pharmacist	12.9	2.1	1.9
Other GP	11.6	13.1	9.7

(Multiple responses possible)

Information about Treatments

Most important source of information about HIV treatments:

- 38.7% said their HIV GP
- 21.7% said HIV specialist at an outpatient clinic
- 11.7% said another GP
- 5.2% said HIV/AIDS organisation or staff at an HIV/AIDS organisation

Information about HIV Management

Most important source of information on HIV management:

- 31.8% said their HIV GP
- 18.6% said HIV specialist at an outpatient clinic
- 11.9% said another GP
- 7.2% said HIV/AIDS organisation or HIV/AIDS organisation staff

Information about Living with HIV

Most important source of information on living with HIV:

- 15.6% said their HIV GP
- 12.8% said HIV/AIDS organisation or HIV/AIDS organisation staff
- 11.3% said HIV positive friends
- 7.8% said HIV specialist at an outpatient clinic
- 7.4% said HIV/AIDS publications
- 7.1% said another GP
- 6.9% said HIV magazine/newspaper.

Publications

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 13, including breakdowns for specific populations where access or focus is an issue.

TABLE 13 Publications read by NSW PLWHA

Publication	Percent of sample
National, NSW-based or non-specific	
Gay newspapers	70.0
Talkabout (NSW)	65.1
Positive Living	50.0
With Complements (NSW)	21.5
HIV Australia	28.9
Gay magazines	24.8
Newsletters from community organisations	21.5
NUAA News (NSW)	7.5
Overseas magazines (eg POZ)	4.0
National Haemophilia	0.7
Publications from other states	
Positive life (WA)	6.2
QPP Alive (QLD)	1.9
(Multiple responses possible)	

Involvement with AIDS Organisations

73% of NSW respondents had some contact with HIV/AIDS organisations. Of these:

- 64.3% received newsletters and mail outs
- 69% were clients
- 39.6% were members
- 18.0% were volunteers
- 14.5% were employees.

Of those that had no contact with AIDS organisations:

- 55.5% gave the reason I do not want to be involved
- 21.9% gave the reason I do not have enough time
- 9.2% gave the reason I don't know how to join
- 8.0% said that they had no transport or were too far away
- 17.8% of those who were not involved in AIDS organisations said they felt excluded from them.

25.8% of respondents had at some point held a decision making position in an AIDS organisation (11.0% in the last two years).

THE SOCIAL WORLD OF PLWHA

Contact with Other PLWHA

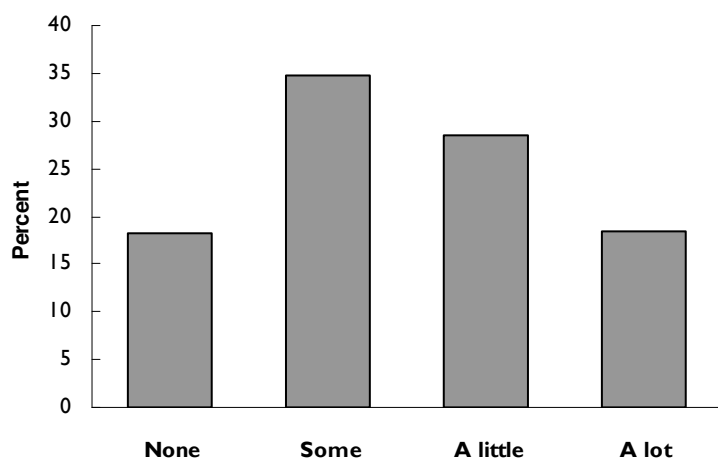
Participants were asked about contact with other HIV positive people and how much of their free time was spent with other HIV positive people (Table 14 and Figure 4). Only 5% of NSW respondents said they did not personally know anyone else with HIV. Around four-fifths of people spent at least some time with other positive people (81.7%), while 18.5% indicated that they spend a lot of time with other positive people.

TABLE 14 Other HIV positive persons known by respondent

Positive Persons	Percent of NSW respondents
Friend	79.6
Acquaintance/Member of support group	58.8
Former partner/spouse	30.5
Partner/spouse	18.5
No-one	5.0
Other relative	4.2
Son/daughter	0.7

(Multiple responses possible)

FIGURE 4 Time spent with other positive people (% of NSW participants)



Disclosure

Participants were asked to nominate who they had told about their HIV status (see Table 15).

TABLE 15 People the respondent has disclosed their HIV status to

	Percent of NSW respondents
Close friends	85.8
Siblings	70.1
Positive friends	69.1
Parents	59.9
Partner/spouse	52.6
Other friends	41.6
Work colleagues	32.5
Neighbours	18.5
Son/daughter	8.8
People from own ethnic community	5.0
No-one	1.1

Unwanted Disclosure

55.7% of NSW respondents said that their HIV status had been disclosed when they did not want it to be, 30.3% in the last two years. Sources of unwanted disclosure are shown in Table 16 below.

TABLE 16 Sources of unwanted disclosure (% of those experiencing unwanted disclosure)

	Percent
Other friends	26.1
Close friends	25.2
Work colleagues	19.9
Workers in a health care setting	18.1
Partner/Spouse	14.2
Brother/Sister	13.4
HIV positive friends	12.0
Other	10.7
Neighbour	8.7
Parents	8.6
Staff/volunteers at community organisation	7.6
Other family member	7.5
Son/daughter	0.9
People from ethnic community	1.0

(Multiple responses possible)

Mental Health

Psychiatric Medications

In the six months prior to completing the survey, 33.6% of NSW PLWHA had been taking medication prescribed for depression. A similar proportion (32.9%) had taken medication for anxiety. In addition 8.2% of the sample indicated that they had taken anti-psychotic medication.

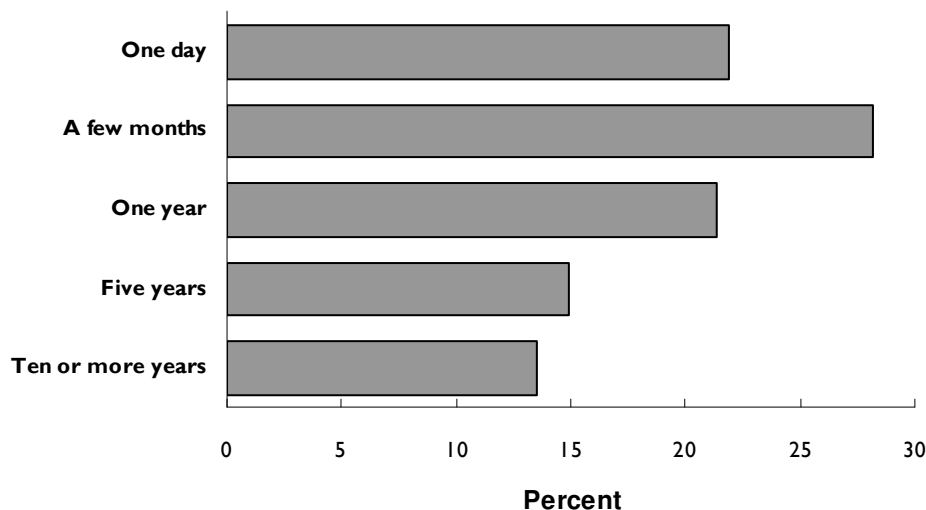
Diagnosis of a Mental Health Condition

37.1% of NSW respondents reported that they had had been diagnosed with a mental health condition, 21.2% in the last 2 years.

Planning for the Future

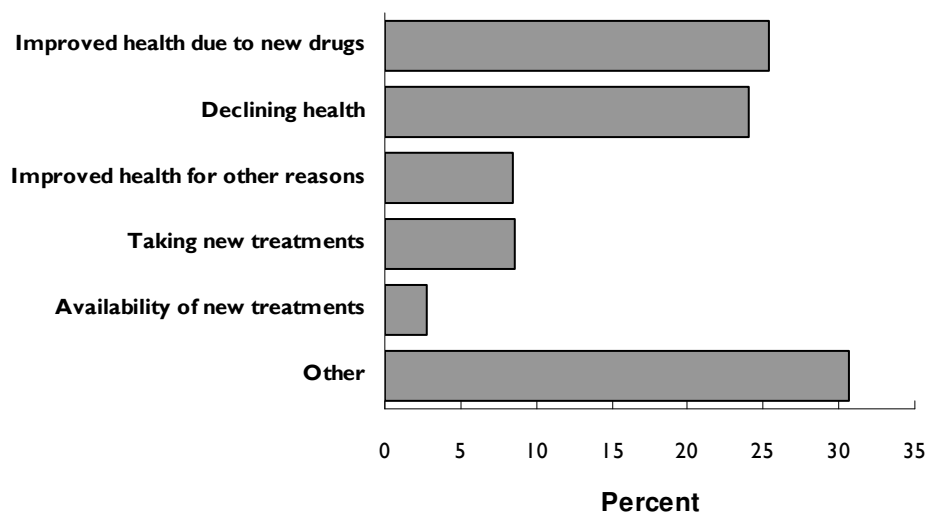
A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. More than one fifth (21.9%) planned their life one day at a time and 28.2% planned only a few months ahead. Approximately half of the respondents planned for at least a year, with 21.4% planning one year ahead, 14.9% planning five years ahead and 13.5% planning ten years or more ahead. This profile of the population has changed very little since the first HIV Futures survey.

FIGURE 5 Time-frame for future planning



32.2% of respondents reported a change in their time frame for future planning in the last two years, with 43.9% of those who reported a change now using a shorter time frame and 52.5% using a longer time frame. The reasons people gave for changing their planning time-frame are in figure 6 below.

FIGURE 6 Reasons given for change in time-frame



RELATIONSHIPS AND SEX

Relationships

42.8% of NSW respondents reported being in a regular relationship or married. Of those in a relationship with a regular partner, 43.3% reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in serononconcordant relationships. This group is made up of 54.8% of the sample that report that their partner is HIV negative (a sero-discordant relationship) and 1.9% who report that they don't know their partner's HIV status.

The average length of time of this regular relationship was 7.6 years (median 5.5 years, range 10 months to 33.2 years).

Children

- 14.5% of NSW respondents have children.
- 5.8% have dependent children
- 4.1% have dependent children living with them.

Most NSW PLWHA (89.5%) were not considering having children. Of the remainder, 8 PLWHA have decided to have children in the future, 2 were attempting to have children, 9 have considered having a child, but have not decided, and 10 people have considered having a child, but have decided it is too risky. Importantly, 11 respondents said they did not have enough information to make a decision. While a greater proportion of women (heterosexual, bisexual and lesbian) were considering, or had considered having children, some of those doing so are gay, bisexual or heterosexual men.

RECREATIONAL DRUG USE

Practices

Respondents were asked which of a range of non-prescription drugs they had used in the 12 months prior to being surveyed. These results are shown in Table 17 on the next page. As can be seen from these data, alcohol was the most commonly used drug followed by marijuana and tobacco. Other drugs that are popular in the gay and dance party scenes (amyl, ecstasy, non-injected speed and LSD) were also used by PLWHA.

TABLE 17 Recreational use of drugs (% of sample)

Alcohol	81.9
Marijuana	59.9
Cigarettes	58.1
Amyl	38.9
Ecstasy	33.8
Viagra or similar	22.1
Speed (not injected)	19.8
Crystal Meth	18.5
Speed (injected)	16.0
Cocaine (not injected)	7.4
Steroids (injected)	6.6
LSD / trips	5.7
GHB/GBH/Fantasy	4.5
Methadone (prescribed)	3.4
Homebake	2.0
Heroin (injected)	1.9
Cocaine (injected)	1.5
Methadone (other)	1.3
Heroin (not injected)	1.2
Other	3.0

(Multiple responses possible)

- 10.2% of NSW respondents reported having had a bad experience from using both antiretroviral drugs and illegal drugs.
- 27.8% reported having missed a dose of antiretroviral medication at some point as a result of using illegal drugs.
- 65.7% of respondents reported that they had never injected illegal drugs. Of those respondents who had injected illegal drugs almost one half (46.1%) had done so in the last 12 months.

HOME, WORK & MONEY

Current Accommodation of NSW respondents

- 28.8% owned or were purchasing house or flat
- 40.3% were in private rental accommodation
- 18.2% were in public (government owned) rental accommodation
- 4.6% lived rent-free (e.g. provided by friends, family, etc.)
- 3.2% were in community housing/housing co-operative
- 5.0% lived in another type of accommodation

78.7% of NSW respondents stated that their accommodation was suitable for their current needs. 21.3% (n=115) said their accommodation was unsuitable, and 68.8% of this group said that they do not have any other accommodation options for the future. Reasons why accommodation was considered unsuitable are shown below (Table 18).

TABLE 18 Reasons current accommodation is unsuitable (% of those with unsuitable accommodation)

Too small	33.3
Too expensive	27.7
Inadequate for my current state of health	25.4
Lack of privacy	24.6
Poor condition of housing	24.4
Harassment	21.2

(Multiple responses possible)

47.6% of NSW PLWHA lived by themselves while the remainder lived with between 1 and 7 other adults (for those living with other adults: mean=1.2, median=1) and with between 1 and 5 children (for those living with children: mean=1.8, median=2). Around one third (30.6%) lived with a partner or spouse, and 3.7% lived with dependent children. 45.9% of NSW PLWHA owned pets.

Current Living Situation:

- 2.1% lived in a bedsit/studio
- 22.5% lived in a residence with 1 bedroom
- 47.8% had 2 bedrooms
- 21.1% had 3 bedrooms
- 6.6% had 4 or more bedrooms

61.7% of NSW respondents had access to a car. When asked how easy it was to access public transportation, 11.3% said it was very difficult, 12.4%, difficult, 37.8% easy and 38.4% very easy.

Changes in Accommodation

41.6% of PLWHA in NSW had at some time changed their accommodation as a result of having HIV/AIDS (mean: 2.5 times ever and 1.7 times in the last 2 years). The most common reasons given for the last change in accommodation are shown below in Table 19.

TABLE 19. Most common reasons for changing accommodation (% of those who have ever changed accommodation as a result of having HIV/AIDS)

Moved to a quieter location	35.3
Needed cheaper housing	34.9
Moved closer to health services	29.4
Better health	21.6
Planning for illness	23.4
Illness	22.9
To avoid harassment	20.2

(Multiple responses possible)

EMPLOYMENT

Employment Status

The employment situation of NSW respondents is shown in Table 20 below.

TABLE 20 Employment Status (% of NSW respondents)

Work full-time	28.7
Not working / Retired	25.2
Unemployed	16.3
Work part-time	14.9
Other	6.1
Student	6.1
Home duties	2.5

Of those who were working, the mean number of hours worked was 33.4 (median=36.2). Those working full time worked an average of 42.3 hours per week (median=40.0) and those in part time employment worked an average of 21.0 hours/week (median=21.0). Those who were not working stopped work between 0 and 21 years ago (mean=67.1 months, median=60.0 months).

35.2% of NSW respondents reported doing some volunteer work, 19.0% of these for a HIV/AIDS organisation and 16.2% for another organisation.

Interruptions to Employment

- 60.6% of those NSW respondents who have ever been in paid employment had at some point stopped work for reasons related to HIV.
- 46.6% of those that had stopped work at some point had returned to work.

Number of times NSW PLWHA have stopped work due to HIV/AIDS:

- 35.3% had stopped work once
- 13.6% had stopped twice
- 4.3% had stopped three times

These work interruptions averaged 42.7 months (median= 24.0 months). The circumstances relating to the most recent interruption to employment are given in Table 21 below. The HIV/AIDS status of respondents the last time they ceased work is given in Table 22 below.

TABLE 21 Circumstance surrounding last interruption to employment

Poor health	65.9
Low energy levels	63.6
Stress, depression, anxiety	56.5
To have more time to myself	22.3
Expecting illness in the future	18.0
To move to a different location	18.0
Redundant / sacked	12.8
To care for another HIV positive person	6.2
Other	10.2

(Multiple responses possible)

TABLE 22 HIV/AIDS status at time of last interruption to employment (%)

I had HIV and had been ill	50.0
I had HIV but had not been ill	32.9
I had been diagnosed with an AIDS-defining illness	17.1

Those Currently in Paid Employment

8.6% of NSW respondents work in an HIV/AIDS related area (18.8% of those currently in paid employment).

Respondents were asked about difficulties they experience around confidentiality at work (Table 23). The results are displayed as percent of all those currently in paid work, percent of those working in an HIV/AIDS related job and percent of those working in other areas.

TABLE 23 Difficulties with HIV status confidentiality in the workplace (% of total and specific samples)

	Total working sample	AIDS related	Non-AIDS related
I do not try to keep my HIV status confidential	28.7	73.8	18.2
No problems	50.7	26.2	56.4
Difficulty keeping and taking medication	7.6	0	9.4
Explaining absences from work	9.5	0	11.7
Visible signs of illness	12.6	2.4	15.0
Gossip	17.1	4.8	20.0

(Multiple responses possible)

When asked how many people in their workplace knew that they were HIV positive:

- 13.6% said that everyone knew (45.2% of those who worked in an HIV related job)
- 13.4% said that most people know
- 20.0% said that a few people know
- 10.5% said that one person knew
- 42.4% said that no-one knew (4.8% of those who worked in an HIV related job)

Over half of NSW participants who were in paid work said that their workplace always gave them time off for medical appointments and for sickness. There was less capacity to take time off for counselling and only half of the sample could ever take time off to do volunteer work (Table 24).

TABLE 24 Capacity within workplace for HIV related interruptions

	never	seldom	sometimes	often	always
For medical appointments	8.1	2.1	17.1	14.1	58.1
For counselling	24.0	4.3	18.6	7.7	45.4
When you are sick	4.9	2.5	14.2	13.5	65.0
To do volunteer work	44.2	5.9	14.9	7.9	27.1

FINANCES

Income

The main income source of NSW respondents is shown in Table 25 below.

TABLE 25 Primary source of income (% of total sample)

Benefits/pension/social security	56.4
Salary	36.1
Superannuation/ annuity/ savings	4.1
Partner supports me	2.4
Family/friends support me	0.6
Other	0.4

The median weekly income for respondents was \$320.00. 22.7% of respondents had a partner with whom they share financial resources. The partners' median weekly income was \$500.00.

Expenditure and Debts

Participants were asked about their weekly expenditure on a range of items, their current debt burden and whether they owned or were currently paying off their own home. The results are shown below (Table 26).

TABLE 26 NSW respondents; weekly expenditure on medications and essentials (\$AU)

	Mean	Median
Rent or mortgage repayments	\$184.70	\$130.00
Food	\$90.50	\$80.00
Utilities	\$53.00	\$40.00
Complementary therapies	\$24.50	\$20.00
Other medication	\$13.30	\$10.00
Antiretroviral drugs	\$13.50	\$10.00

- 15.5% of respondents owned their own home
- 16.4% were paying off their home
- 13.0% had owned their own home in the past, but do not currently
- 35.5% received a rental subsidy averaging at \$118.60 per week

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$30,838 with a median of \$4000. Those who owned their home had a mean debt of \$94,056, those who were currently paying off their home had a mean debt of \$56,128, those in private rental accommodation had a mean debt of \$10,266 and those in public rental accommodation had a mean debt of \$5417. 28% of participants had used the services of a financial counsellor in the last two years.

Assessments of Benefits

A total of 41.5% of those receiving a benefit in the last two years had received such an assessment. The consequences of this assessment are shown in Table 27 below.

TABLE 27 Consequences of receiving an assessment of benefit from a Commonwealth Medical Officer (percent of those assessed in last 2 years)

Require documentation from your doctor	65.1
Cause you distress	65.1
Result in changes to the conditions of your benefits	29.2
Clarify concerns that you had	17.7
Result in an independent assessment	14.3
Result in termination of your benefits	5.9
Result in a shift from Pension to Newstart allowance	5.0

(Multiple responses possible)

POVERTY

The quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR) was used to assess the extent of poverty among PLWHA (2003). According to this measure, one quarter (26.4%) of NSW PLWHA were living below the poverty line.

Costs

As with previous surveys, we asked respondents about the difficulty they had paying for a range of activities, goods and services. The results are shown in Table 28 below.

TABLE 28 Difficulty paying costs of items and services

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=423) ²	54.7	36.0	9.4
Other prescribed medication (n=469)	49.0	38.9	12.1
Medical services (doctor, dentist, etc.) (n=459)	49.3	31.3	19.4
Complementary Therapies (n=299)	45.1	31.8	23.1
Support services (counselling, etc.) (n=207)	67.9	16.3	15.7
Entertainment (theatre, movies, concerts, etc.) (n=471)	30.7	33.4	35.8
Going out (eating / drinking) (n=500)	27.4	33.7	39.0
Sport (exercise, gym, etc.) (n=371)	35.1	33.1	31.8
Recreational drugs (n=244)	31.8	28.7	39.5
Travel / holidays (n=440)	19.4	24.1	56.5
Rent / Mortgage / Housing costs (n=479)	36.6	41.5	22.0
Utilities (telephone / electricity / gas / water) (n=521)	31.1	42.5	26.5
Food (n=524)	45.7	36.1	18.1
Clothing (n=492)	31.0	34.9	34.1
Transport (n=490)	49.8	33.7	16.5
Child care (n=36)	52.0	22.0	26.0

² Ns refer to the number of participants that identified this as an applicable cost. That is, those selecting “not applicable” or giving no response are excluded from the percentages reported in that row.

DISCRIMINATION

Accommodation

13.6% of NSW respondents reported experiencing less favourable treatment in relation to accommodation ; 6.5% in the last two years. This number comprises:

- 21.4% of those currently living in public housing (11.2% in the last 2 years)
- 18.8% of those in housing cooperatives
- 15.7% of those in private rental accommodation
- 5.3% of those who own or are purchasing their own house or flat.

Health Services - HIV

32.8% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This comprised 17.7% of all respondents that had experienced such discrimination in the last two years and 15.1% that experienced this more than 2 years ago.

TABLE 29 Form of discrimination experienced at medical service (% of those experiencing discrimination)

	Ever (N=171)	In last 2 years (N=92)
Confidentiality problems	42.0	46.2
Avoidance	40.2	40.7
Increased infection control	32.7	35.2
Treated last	33.3	29.8
Refusal of treatment	28.0	28.9
Rushed through	28.0	34.1
Abuse	6.0	10.0
Harassment	6.0	8.9

(Multiple responses possible)

Insurance

- 26.9% of NSW respondents had private health insurance.
- 3.9% had some other form of income or mortgage insurance.
- 20.9% indicated that they had experienced less favourable treatment in relation to insurance.