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HIV FUTURES 4

Regional Reports 2005: Victoria



THE LIVING WITH HIV PROGRAM

Jeffrey Grierson & Rachel Thorpe



HIV Futures 4 Regional Reports: Victoria

Jeffrey Grierson and
Rachel Thorpe.

The Living with HIV Program
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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

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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 Victoria. 193 PLWHA from Victoria completed the HIV Futures 4 survey. 88.6% were male (171) and 11.4% were female (22). Of these 75.7% were gay men, 8.5% heterosexual men, 11.1% heterosexual women, 3.7% bisexual men and 0.5% bisexual women. The remaining 0.5% fell into other categories.

The respondents ranged in age from 22 to 69 years (mean 43.7 years, median 43.5 years).

Over four-fifths of Victorian participants were Australian born (84.5%), 97.4% spoke English at home and all participants indicated that Australia was their official country of residence. 5 respondents from Victoria (2.6%) indicated they were of Aboriginal/Torres Strait Island 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 Victorian respondent’s testing positive and presumed infection (%)

Year	Tested HIV Positive	Presumed Infected
Pre 1985	9.5	20.8
1985-1989	25.4	23.2
1990-1994	25.4	24.4
1995-1999	24.9	18.5
2000+	14.8	13.1

HEALTH

HIV Antibody Testing

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

TABLE 2 Reasons for testing

Reason	Frequency	Percent
Became ill	44	26.6
Particular risk episode	27	23.8
Other	21	12.5
Routine health screening	19	11.2
Member of risk group	19	11.2
Doctor’s suggestion	13	7.8
Starting new relationship	11	6.6
Tested without knowledge	9	5.7
Contact tracer/other health worker’s suggestion	3	1.6
Availability of new treatments	1	0.6

Pre- and Post-Test counselling/discussion

28.6% of Victorian respondents had received pre-test counselling or engaged in a HIV test discussion. Of those who tested positive in the last two years, 16.7% (n=2) had done so.

Pre-test counselling was most commonly provided by:

- Doctor (62.5% of those receiving pre-test counselling)
- Nurse (12.6%)
- Counsellor/psychologist (11.1%)
- 88.7% of those who received counselling were satisfied with the information they received from this person
- 83.7% were satisfied with the level of support they received.

57.9% of respondents had received post-test counselling. Of those who tested positive in the last two years 83.3% had received post-test counselling,

Post-test counselling was most commonly provided by:

- Doctor (44.9% of those receiving post-test counselling)
- Counsellor/psychologist (18.3%)
- Nurse (6.6%)
- 83.3% were satisfied with the information they received
- 81.7% 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 Victorian Respondents' self ratings of general health status

	Frequency	Percent
Poor	12	6.4
Fair	42	21.6
Good	97	50.3
Excellent	42	21.7

TABLE 4 Victorian Respondents' self ratings of general well-being

	Frequency	Percent
Poor	18	9.4
Fair	49	25.6
Good	96	49.5
Excellent	30	15.5

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 Victorian sample)

		HIV Viral load				
		Below detectable levels	500-9999	10000-49999	50000+	Total
Cd4/T-cell count	500+	30.1	10.3	7.1	1.3	48.7
	250-499	15.4	10.3	7.1	5.8	38.5
	0-249	5.8	3.8	1.3	1.9	12.8
	Total	51.3	24.4	15.4	9.0	100.0

Health Conditions in addition to HIV

- 22.8% of respondents had been diagnosed with an AIDS defining illness
- 40.8% had experienced HIV/AIDS related illnesses other than those classified as AIDS defining illnesses.
- 33.5% of Victorian 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.

- 43.7% had experienced lipodystrophy
- 31.6% weight loss
- 78.3% low energy or fatigue
- 54.5% a sleep disorder
- 33.4% confusion or memory loss.

Hepatitides

21.0% of Victorian respondents had at some time been diagnosed with hepatitis A, and 53.8% had been vaccinated against this virus.

24.6% had at some time been diagnosed with hepatitis B. Of these, 69.7% had cleared the infection, 18.8% had an ongoing infection and 4.6% had a chronic infection. 61.3% of Victorian respondents had been vaccinated against hepatitis B.

14.8% of the Victorian respondents had hepatitis C. Only 20.7% (N=6) of those had ever undertaken medical treatment specifically for hepatitis C.

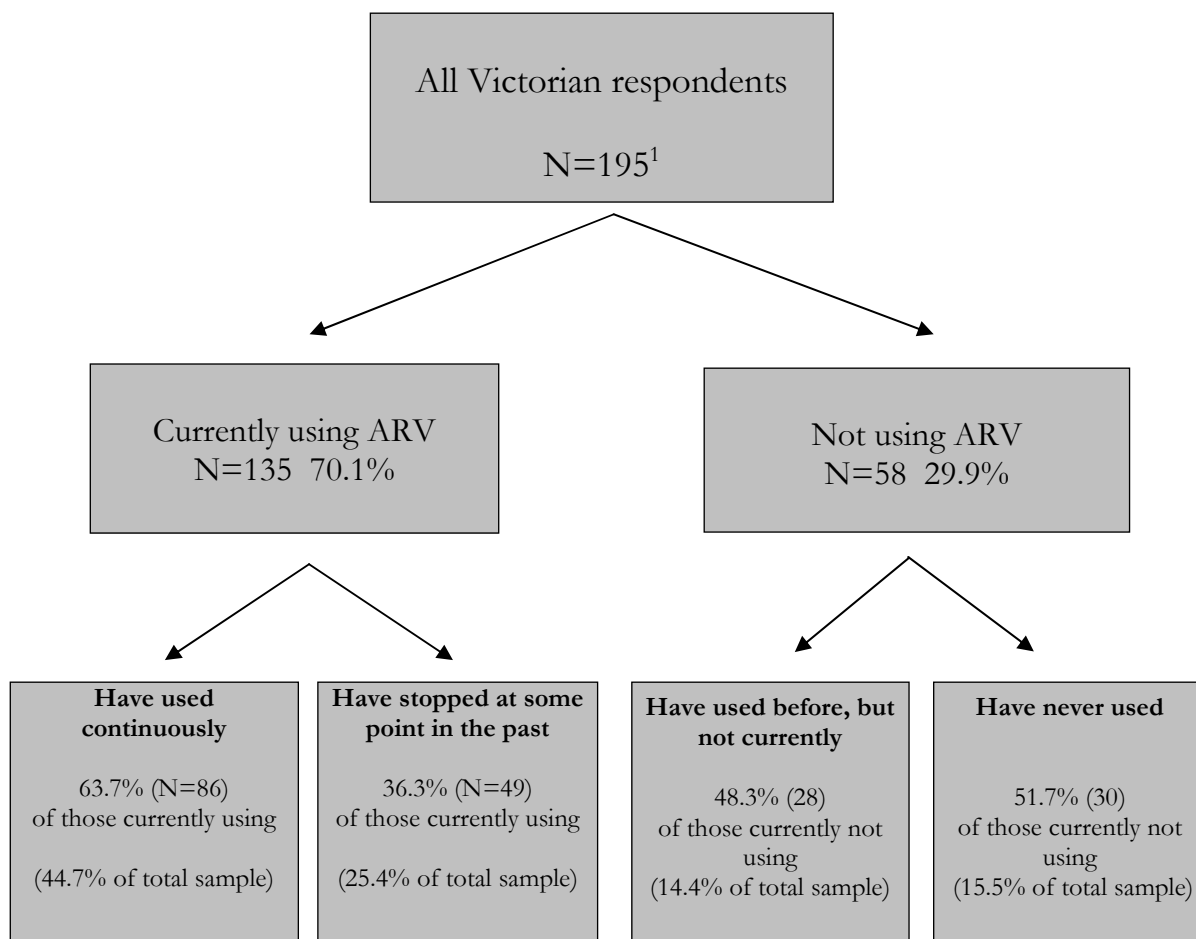
One person had taken some form of complementary therapy for hepatitis C.

TREATMENTS

Antiretroviral Therapy

A summary diagram of the uptake of antiretrovirals for Victorian 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)

29.3% of participants were taking more than three antiretroviral drugs, while the majority (61.7%) were on a combination of 3 antiretroviral drugs¹, 7.1% were on two, and 1.8% were on monotherapy.

The most common combination was one NNRTI and two NRTIs used by 15.8% of the sample (23.2% of those currently on combination therapy).

Different Combinations

Among those currently using combination therapy, respondents had used between one and 7 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 combinations remained available for their future treatment, 38.2% of participants on combination treatment indicated they didn't know, while 29.1% said there were 'a few' and 27.3% 'many'. 3.2% indicated that there was only one other combination available and 2.2% of those on combination therapy said that there were no other combinations available for their future treatment.

Treatment Breaks

In all, 36.3% of those Victorian 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 over 7 years ago. The mean length of break was 208 days with a median of 122 days. 25.2% of those who had taken a break described the break as a structured treatment interruption, while 50.4% described it as a treatment break.

- 67.4% of respondents talked to their doctor about the break prior to taking it
- 66.7% talked to their doctor during the break
- 95.8% talked to their doctor after the break.
- 53.1% talked to their doctor at all three stages of the treatment break.
- 16.3% only spoke to their doctor after the break.
- 14.3% spoke to the doctor during and after the break, but not before

Antiretroviral Resistance

37.3% of Victorian respondents who had ever used antiretroviral treatments indicated that they had some sort of ARV resistance test. This included 41.9% of those who were currently on antiretroviral treatment and 18.5% of those who were not. Of those who had resistance testing, 81.9% found resistance to one or more antiretroviral drugs (86.3% of those currently on ARV, 50.0% of those not). This resulted in a change of drugs for 75.1% (N=42) of those where resistance was shown.

Dosing and Adherence

On average, Victorian 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.

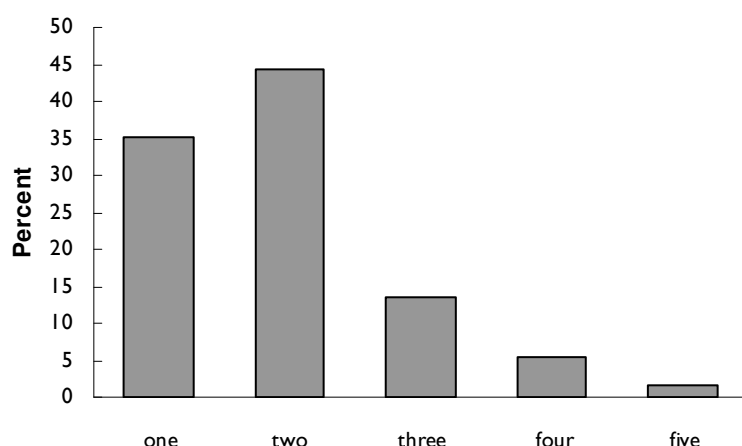
TABLE 6 Number of times participants take medications

	Mean	Median	Range
Antiretroviral drugs	2.04	2.0	0-5
Complementary therapies	1.62	2.0	0-4
Medication for other health conditions	1.76	2.0	0-6

Prescriptions

56 (40.9%) of PLWHA got their prescriptions for antiretroviral drugs from a HIV GP/S100 prescriber. A slightly lower proportion (33.6%) obtained their prescription from a specialist in an outpatient clinic, while fewer obtained them from a doctor at a sexual health centre (23.8%). The remaining 11% got them from either another GP, a HIV specialist while an inpatient, another doctor or another source.

FIGURE 2 Number of prescription pick-up points



Clinical Trials

A total of 33.7% (n=62) of Victorian respondents had participated in a clinical trial for HIV related treatment and 10.9% of all participants (n=20) had participated in a clinical trial in the last two years. The main treatments that participants had trialed were AZT (n=4) and Il-2 (n=4). They had on average been on these trials for 12.7 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)**

I felt my experience could benefit others	26.3
My doctor and I decided together	17.6
I felt I had enough information about the trial	13.4
Other	6.9
It was the only way I could get the treatment	5.6
I had no other treatment options	3.1
My other treatments were not working	2.0

(Multiple responses possible)

Complementary Therapies

76.7% of Victorian respondents reported using at least one kind of complementary therapy, including body-mind therapies such as meditation and massage, but excluding therapeutic use of marijuana. 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. 23.3% of the Victorian participants reported using marijuana for therapeutic purposes.

TABLE 8 Current use any of complementary therapy

Vitamin / mineral supplements	61.7
Massage	35.8
Meditation / visualisation	21.2
Herbal therapies / supplements	19.2
Acupuncture	7.8
Other therapy	7.3
Other traditional Medicine	5.7
Traditional Chinese Medicine	5.2

(Multiple responses possible)

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

Private practice	31.3
Health Service	26.6
AIDS community organisation	11.7
PLWHA organisation	9.4
Other	40.6

Other Medication

61.4 % of Victorian 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)

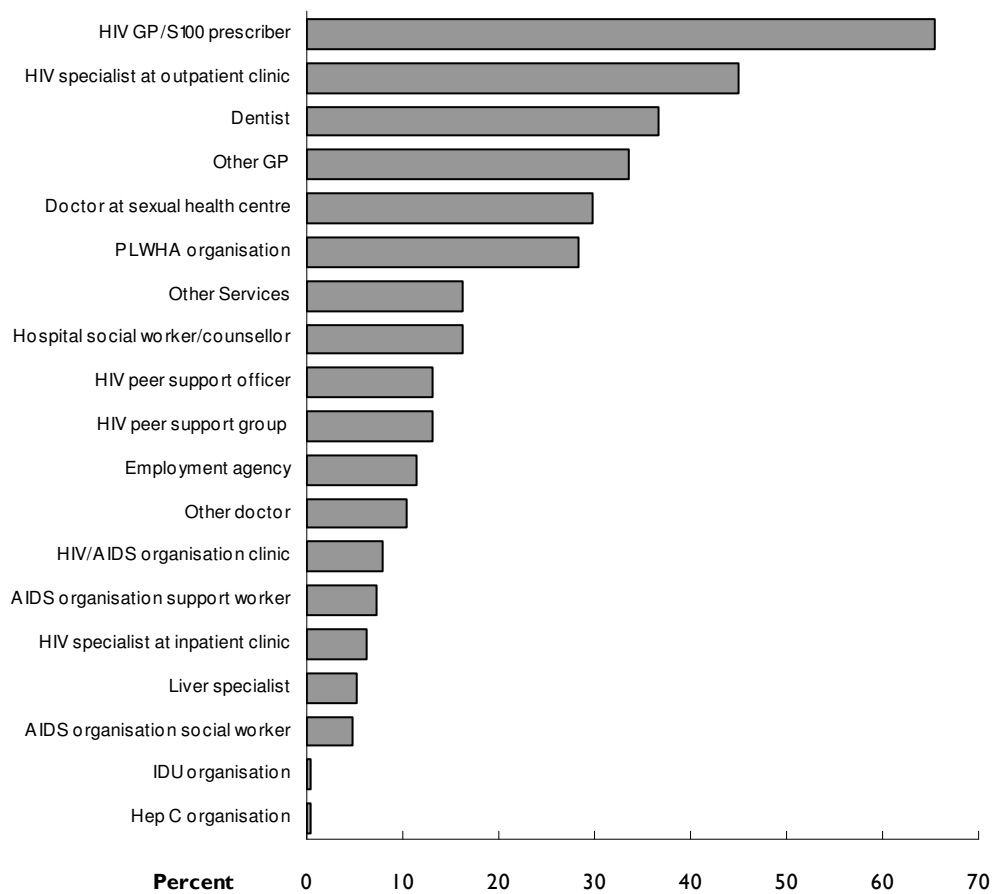
	For general treatment	For HIV specific treatment
HIV GP/S 100 Prescriber	58.8	47.8
Other GP	15.3	3.8
HIV specialist at outpatient clinic	15.3	30.6
HIV specialist at inpatient clinic	0.6	0.5
Doctor at sexual health centre	7.3	3.8
Other doctor	1.7	10.8
Other	1.1	2.7

60.5% 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, 98.6% 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 65.4% having used an HIV GP/ S100 prescriber, 45.0% an HIV outpatient specialist, 36.6% a dentist, 33.5% another GP and 29.8 % a doctor at a sexual health service. Support services were also commonly used, with 28.3% reporting having used a PLWHA organisation, 16.2% a hospital social worker or counsellor and 13.1% an AIDS organisation support worker and an HIV peer support group (see Figure 3).

Figure 3 Services used in the last six months (% of VIC 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 VIC 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
Social contact with other PLWHA	50.0	5.3
Treatments advice	41.3	28.1
Peer support group	35.3	4.0
Treatments information	33.8	11.3
Financial assistance	28.7	10.7
Counselling	27.0	30.5
Informal peer support	26.7	9.3
Complementary therapies	23.8	24.7
Pharmacy services	21.7	43.4
Legal advice	20.0	18.0
Community education campaigns	16.7	3.3
Housing assistance	15.3	9.3
Employment services	12.7	15.3
Internet access	12.4	25.7
Respite care	10.0	7.3
Financial advice	10.0	25.3
Volunteer carer	9.3	3.3
Mental health services	9.3	18.0
Internet based information	9.3	17.3
Return to work skills	7.3	11.3
Transport	6.0	23.3
Library	5.3	28.0
Paid carer	2.0	6.0
Drug/alcohol treatment	1.3	9.3

(Multiple responses possible)

49 (25.4%) of Victorian respondents indicated that there were services they felt they needed but did not have access to. The services most commonly nominated were access to affordable complementary or alternative therapies (n=10), financial assistance (n=8), a carer service (n=7), counselling (n=5) and services for PLWHA in rural, regional and outer suburban areas (n=5).

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 VIC sample)

	Information about Treatments	Information about HIV Management	Information about Living with HIV
HIV GP/S100 prescriber	66.3	64.7	39.5
HIV magazine/newspaper	53.7	54.2	53.2
Publications from HIV/AIDS groups	50.5	48.4	47.4
HIV specialist at outpatient clinic	44.7	41.1	23.2
Articles in gay press	42.1	40.5	44.2
HIV positive friends	28.9	35.8	44.7
Internet	26.3	25.8	22.1
Sexual Health Service	24.2	24.7	22.1
Partner/Lover	14.7	19.5	28.9
Pharmacist	13.7	2.1	1.1
Publications from other sources	13.2	12.1	12.1
Other GP	12.1	10.5	9.5
Peer Support Officer	11.1	15.3	18.9

(Multiple responses possible)

Information about Treatments

Most important source of information about HIV treatments:

- 40.1% said their HIV GP
- 22.0% said HIV specialist at an outpatient clinic
- 12.1% said another GP
- 4.9% said HIV/AIDS organisation or staff at an HIV/AIDS organisation

Information about HIV Management

Most important source of information on HIV management:

- 30.2% said their HIV GP
- 19.6% said HIV specialist at an outpatient clinic
- 13.4% said another GP
- 6.7% said HIV/AIDS organisation or HIV/AIDS organisation staff.

Information about Living with HIV

Most important source of information on living with HIV:

- 16.9% said HIV/AIDS organisation or HIV/AIDS organisation staff
- 11.6% said HIV positive friends
- 10.5 said an HIV GP
- 7.6% said HIV specialist at an outpatient clinic
- 7.6% said HIV/AIDS publications
- 6.4% said another GP

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 Victorian PLWHA

Publication	Percent of sample
National or non-specific	
Gay newspapers	68.9
Positive Living	67.8
Gay magazines	35.6
HIV Australia	27.7
Newsletters from community organisations	27.7
Overseas magazines (eg POZ)	11.9
National Haemophilia	2.3
Publications from other states	
Talkabout (NSW)	18.6
With Complements (NSW)	10.7
Positive life (WA)	9.0
(Multiple responses possible)	

Involvement with AIDS Organisations

73.5% of Victorian respondents had some contact with HIV/AIDS organisations. Of these:

- 78.6% received newsletters and mail outs
- 70.7% were members
- 59.3% were clients
- 15.0% were volunteers
- 10.0% were employees.

Of those that had no contact with AIDS organisations:

- 54.3% gave the reason I do not want to be involved
- 34.8% gave the reason I do not have enough time
- 23.9% (n=11) said that they had no transport or were too far away
- 23.9% (n=11) of those who were not involved in AIDS organisations said they felt excluded from them
- 6.5% (n=3) gave the reason I don't know how to join

27.0% of respondents had at some point held a decision making position in an AIDS organisation (10.6% in the last two years).

THE SOCIAL WORLD OF PLWHA

Contact with Other PLWHA

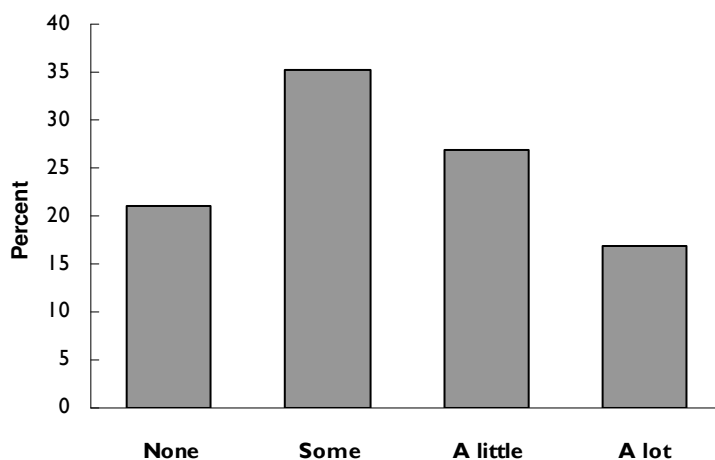
Participants were asked to select from a list which other HIV positive people they knew and how much of their free time was spent with other HIV positive people (Table 14 and Figure 4). Around four-fifths of people spent at least some time with other positive people (78.9%), while 16.8% indicated that they spend a lot of time with other positive people.

TABLE 14 Other HIV positive persons known by respondent

Positive Persons	Percent of Victorian respondents
Friend	72.0
Acquaintance/Member of support group	66.1
Former partner/spouse	25.9
Partner/spouse	19.0
No-one	9.0
Other	6.3
Other relative	3.7

(Multiple responses possible)

FIGURE 4 Time spent with other positive people (% of VIC 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 Victorian respondents
Close friends	89.9
Positive friends	70.9
Siblings	68.3
Partner/spouse	59.8
Parents	52.4
Other friends	41.3
Work colleagues	44.4
Neighbours	21.7
Son/daughter	9.0
People from own ethnic community	3.2 (n=6)
No-one	2.1 (n=4)

Unwanted Disclosure

47.5% of Victorian respondents said that their HIV status had been disclosed when they did not want it to be, 20.6% 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	32.7
Close friends	29.7
Partner/Spouse	14.9
Workers in a health care setting	13.9
Brother/Sister	13.9
Work colleagues	11.9
HIV positive friends	9.9
Parents	9.9
Staff/volunteers at community organisation	6.9
Other family member	6.9
Other person	5.9
Neighbour	4.0

(Multiple responses possible)

Mental Health

Psychiatric Medications

In the six months prior to completing the survey, 27.9% of Victorian PLWHA had been taking medication prescribed for depression. A similar proportion (31.6%) had taken medication for anxiety. In addition 7.4% of the sample indicated that they had taken anti-psychotic medication.

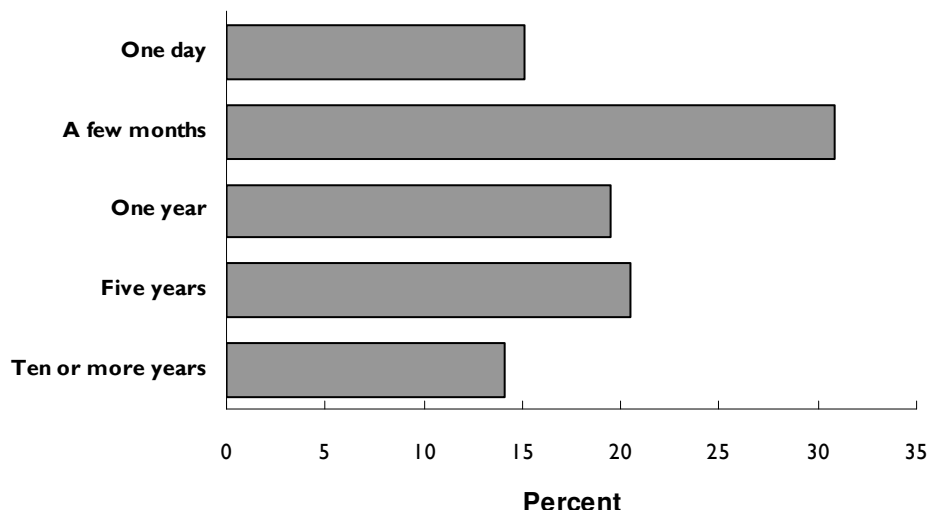
Diagnosis of a Mental Health Condition

37.1% of Victorian respondents reported that they had been diagnosed with a mental health condition, 21.6% in the last 2 years.

Planning for the Future

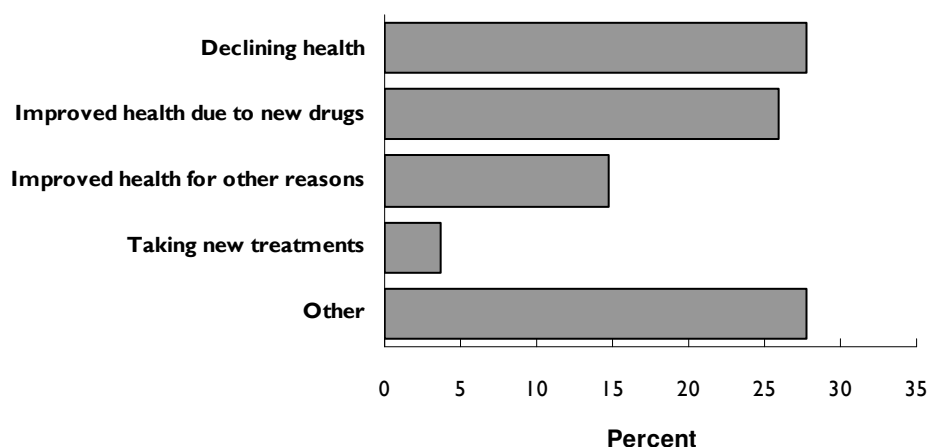
A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. Fifteen percent (15.1%) planned their life one day at a time and 30.8% planned only a few months ahead. Approximately half of the respondents planned for at least a year with 19.5% planning one year ahead, 20.5% planning five years ahead and 14.1% 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



33.7% of respondents reported a change in their time frame for future planning in the last two years, with 38.7% of those who reported a change now using a shorter time frame and 54.9% using a longer time frame.

FIGURE 6 Reasons given for change in time-frame



RELATIONSHIPS AND SEX

Relationships

49.5% of Victorian respondents reported being in a regular relationship or married. Of those in a relationship with a regular partner, 37.8% reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in serononconcordant relationships. This remaining group is made up of 61.1% of the sample that report that their partner is HIV negative (a sero-discordant relationship) and 1.1% who report that they don't know their partner's HIV status.

The average length of time of this regular relationship was 7.9 years (median 6.4 years, range 3 months to 20.3 years).

Children

- 14.0% of Victorian respondents have children.
- 9.9% have children living with them
- 8.3% have dependent children living with them.

Most Victorian PLWHA (81.3%) were not considering having children. Of the remainder, 3 PLWHA have decided to have children in the future, 2 were attempting to have children, 1 was currently pregnant, 9 have considered having a child, but have not decided, and 4 people have considered having a child, but have decided it is too risky. Importantly, 8 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 x below. 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	83.3
Marijuana	63.0
Cigarettes	62.9
Amyl	44.4
Ecstasy	34.2
Viagra or similar	27.3
Crystal Meth	19.1
Speed (not injected)	16.4
Speed (injected)	13.8
Steroids (injected)	6.6
Cocaine (not injected)	5.9
LSD / trips	4.6
GHB/GBH/Fantasy	3.9
Homebake	3.3
Other	5.3

(Multiple responses possible)

- Only seven (3.7%) of Victorian respondents reported having had a bad experience from using both antiretroviral drugs and illegal drugs.
- 20.3% reported having missed a dose of antiretroviral medication at some point as a result of using illegal drugs.
- 73.4% of respondents reported that they had never injected illegal drugs. Of those respondents who had injected illegal drugs almost one half (44.9%) had done so in the last 12 months.

HOME, WORK & MONEY

Current Accommodation of Victorian respondents

- 41.7% owned or were purchasing house or flat
- 30.7% were in private rental accommodation
- 18.2% were in public (government owned) rental accommodation
- 6.3% lived rent-free (e.g. provided by friends, family, etc.)
- 2.1% were in community housing/housing co-operative
- 1.0% lived in another type of accommodation

74.6% of Victorian respondents stated that their accommodation was suitable for their current needs. 25.4% (n=49) said their accommodation was unsuitable, and 61.4% 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 Most common reasons current accommodation is unsuitable (% of those with unsuitable accommodation)

Too expensive	38.8
Too small	30.6
Lack of privacy	28.6
Too far from health services	28.6
Too far from other services	26.5
Inadequate for my current state of health	25.4
Poor condition of housing	24.4
Harassment	21.2

(Multiple responses possible)

32.8% of Victorian PLWHA lived by themselves while the remainder lived with between 1 and 3 other adults (for those living with other adults: mean=1.3, median=1) and with between 1 and 2 children (for those living with children: mean=1.35, median=1). Over one third (35.9%) lived with a partner or spouse, and 8.3% lived with dependent children. 52.8% of Victorian PLWHA owned pets.

Current Living Situation:

- 11.2% lived in a residence with 1 bedroom
- 55.9% had 2 bedrooms
- 25.5% had 3 bedrooms
- 6.9% had 4 or more bedrooms

78.0% of Victorian respondents had access to a car. When asked how easy it was to access public transportation, 10.4% said it was very difficult, 12.0%, difficult, 29.2% easy and 48.4% very easy.

Changes in Accommodation

37.8% of PLWHA living in Victoria had at some time changed their accommodation as a result of having HIV/AIDS (mean: 2.6 times ever and 1.6 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)

Needed cheaper housing	40.8
Moved to a quieter location	27.8
Moved closer to health services	26.8
Planning for illness	26.4
Illness	19.4
Better health	18.3
To avoid harassment	16.9
Ending relationship	16.9

(Multiple responses possible)

EMPLOYMENT

Employment Status

The employment situation of Victorian respondents is shown in Table 21 below.

TABLE 20 Employment Status (% of VIC respondents)

Work full-time	30.9
Work part-time	21.3
Not working/Retired	20.2
Unemployed	14.2
Other	5.6
Student	5.6
Home duties	2.2

Of those who were working, the mean number of hours worked was 33.2 (median=38.0). Those working full time worked an average of 40.24 hours per week (median=40.0) and those in part time employment worked an average of 22.9 hours/week (median=21.0). Those who were not working stopped work between 0 and 15 years ago (mean=65.5 months, median=60.0 months).

28.9% of Victorian respondents reported doing some volunteer work, 16.7% of these for a HIV/AIDS organisation and 12.2% for another organisation.

Interruptions to Employment

- 53.7% of those Victorian respondents who have ever been in paid employment had at some point stopped work for reasons related to HIV.
- 54.1% of those that had stopped work at some point had returned to work.

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

- 21.8% had stopped work once
- 14.0% had stopped twice
- 5.7% had stopped three times

These work interruptions averaged 40.5 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

Low energy levels	65.7
Poor health	56.9
Stress, depression, anxiety	54.9
To have more time to myself	25.5
Expecting illness in the future	22.5
To move to a different location	12.7
Redundant / sacked	10.8
To care for another HIV positive person	9.8
Other	14.7

(Multiple responses possible)

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

I had HIV and had been ill	45.0
I had HIV but had not been ill	38.0
I had been diagnosed with an AIDS-defining illness	17.0

Those Currently in Paid Employment

13.1% of those in paid employment worked in an HIV/AIDS related area

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	19.4	69.2	11.2
No problems	60.2	46.2	61.9
Difficulty keeping and taking medication	12.2	7.7 (n=1)	13.1
Explaining absences from work	15.3	0	17.9
Visible signs of illness	10.2	0	11.9
Gossip	7.1	0	8.3

(Multiple responses possible)

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

- 14.3% said that everyone knew (84.6% of those who worked in an HIV related job)
- 7.1% said that most people know
- 19.4% said that a few people know
- 12.2% said that one person knew
- 46.9% said that no-one knew

Over half of Victorian 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 less than 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	4.4	6.6	19.8	13.2	56.0
For counselling	20.6	4.8	17.5	9.5	47.6
When you are sick	4.5	5.6	14.6	9.0	66.3
To do volunteer work	57.1	3.6	17.9	5.4	16.1

FINANCES

Income

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

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

Salary	46.7
Benefits / pension / social security	42.3
Superannuation / annuity / savings	7.1
Partner supports me	1.6
Other	2.2

The median weekly income for respondents was \$350.00. 27.3% of respondents had a partner with whom they share financial resources. The partners' median weekly income was \$450.00.

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 Victorian respondents weekly expenditure on medications and essentials (\$AU)

	Mean	Median
Rent or mortgage repayments	\$156.35	\$130.00
Food	\$94.17	\$100.00
Utilities	\$61.72	\$50.00
Complementary therapies	\$24.10	\$20.00
Other medication	\$15.46	\$10.00
Antiretroviral drugs	\$13.70	\$8.00

- 22.9% of respondents owned their own home
- 17.6% were paying off their home
- 39.2% had owned their own home in the past, but do not currently
- 27.1% received a rental subsidy averaging at \$72.12 per week

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$23,303 with a median of \$5000. Those who owned their home had a mean debt of \$28,749, those who were currently paying off their home had a mean debt of \$50,167, those in private rental accommodation had a mean debt of \$10,198 and those in public rental accommodation had a mean debt of \$4661. 19.4% of participants had used the services of a financial counsellor in the last two years.

Assessments of Benefits

A total of 24.3% 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	78.9
Cause you distress	68.4
Result in changes to the conditions of your benefits	18.4
Result in an independent assessment	15.8
Clarify concerns that you had	10.5 (n=4)
Result in a shift from Pension to Newstart	7.9 (n=3)
Result in termination of your benefits	5.3 (n=2)

(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, nearly one third (29.1%) of Victorian 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=115) ²	68.7	24.3	7.0
Other prescribed medication (n=158)	57.0	33.5	9.5
Medical services (doctor, dentist, etc.) (n=160)	50.0	30.6	19.4
Complementary Therapies (n=104)	44.2	31.7	24.0
Support services (counselling, etc.) (n=82)	54.9	35.4	9.8
Entertainment (theatre, movies, concerts, etc.) (n=171)	31.6	36.3	32.2
Going out (eating / drinking) (n=175)	32.0	31.4	36.6
Sport (exercise, gym, etc.) (n=124)	35.5	34.7	29.8
Recreational drugs (n=84)	29.8	29.8	40.5
Travel / holidays (n=159)	18.9	22.6	58.5
Rent / Mortgage / Housing costs (n=164)	38.4	37.8	23.8
Utilities (telephone / electricity / gas / water) (n=186)	34.4	43.5	22.0
Food (n=188)	44.1	40.4	15.4
Clothing (n=185)	32.4	35.1	32.4
Transport (n=179)	44.1	39.7	16.2
Child care (n=11)	45.5	36.4	18.2

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

- 9.4% (18) of Victorian respondents reported experiencing less favourable treatment in relation to accommodation ; 4.2% (8) in the last two years.

Health Services

23.5% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This comprised 14.5% of all respondents that had experienced such discrimination in the last two years and 19.0% that experienced this more than 2 years ago.

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

Confidentiality problems	45.6
Avoidance	33.3
Increased infection control	36.8
Treated last	29.8
Refusal of treatment	15.8
Rushed through	21.1
Abuse	12.3
Harassment	14.0

(Multiple responses possible)

Insurance

- 21.5% of Victorian respondents had private health insurance
- 17.2% had some other form of income or mortgage insurance.
- 21.7% indicated that they had experienced less favourable treatment in relation to insurance.