

CHANGES:

Comparative analyses of HIV Futures I and II

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April 2002

Monograph Series Number 35

ISBN 1920697063

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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.

ARCSHS is funded by the Victorian Health Promotion Foundation to undertake a program of social research into social, psychological and cultural aspects of human sexuality and sexual health.

The Living with HIV Program at ARCSHS is funded by the Commonwealth Department of Health & Ageing as a collaborating centre with The National Centre in HIV Social Research at the University of New South Wales.

Suggested Citation:

Misson S and Grierson J (2002) Changes: Comparative analyses of HIV Futures I and II, Monograph Series Number 35, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia.

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INTRODUCTION

This report presents analyses comparing the first two national studies of the lived experience of HIV in Australia, HIV Futures (Ezzy et al, 1998) and HIV Futures II (Grierson et al, 2000). These studies were self-complete, mail-back, questionnaires covering eight major domains of information about living with HIV: demographics; accommodation; health and treatments; services and organisations; sex and relationships; employment; recreational drug use; and finances. The HIV Futures survey was completed in 1997 by 925 respondents and the HIV Futures II survey was completed in 1999 by 924 respondents. In each case this represents approximately 8% of the Australian population of PLWHA. Full details of the studies' findings can be found in the community reports listed above and these and other reports are available on the study website www.latrobe.edu.au/hiv-futures.

The survey instrument used in HIV Futures II was based in large part on that used in the original study, but was modified and expanded to reflect the changing treatment and social environment in Australia, and to address some emerging issues. The analyses presented in this report cover the core sections that were common to both surveys. These analyses represent two systematic ways of examining the differences between the data sets. The findings from the analyses are largely consistent and should be read together to contribute to an understanding of the types of changes that have been observed in the experience of the Australian epidemic.

The primary difference between the two analyses is that the first examines changes at the population level, while the second examines changes for a cohort of PLWHA. The strength of the first analysis is that it takes into account changes in the demography of the population of Australian PLWHA. That is HIV Futures II may include individuals who became infected between the two data collections and HIV Futures may include individuals who died in the intervening period. It gives an overview of how the constituency of the AIDS community and service sector has changed, and the issues that have emerged or faded over time. The strength of the second analysis is that it explores how experiences have changed for individuals. When no difference is observed at a population level, it may be because nothing has indeed changed, or because changes have occurred in two directions, cancelling each other out. For example, this analysis shows that even though there has been no change in the profile of types of accommodation for the population as a whole, thirteen percent had changed their type of accommodation in the two-year period, some to public housing and some from public housing. Neither analysis is more correct; each simply gives different perspective on the same situation.

Overall, it can be seen that the treatment environment has become more intricate and consequently, the experiences of health have become complex. The health consequences of living with HIV now, more than ever, include the experience of side effects and iatrogenic effects of medication. Health status, as measured by clinical markers like viral load and CD4, and life expectancy may have improved at the population level, but health experience has become more

problematic. The same is true of the social experience of living with HIV. There have been shifts in the engagement with services and in the sources of information, shifts in experience of employment and finances. Options have improved in many of these areas, but so too have uncertainty and complexity.

COMPARISON OF TOTAL SAMPLES

Introduction

This analysis is a comparison of the total sample in the two studies on the core items present in both. Data in this section are weighted to conform to the epidemiology of HIV infection in Australia and percentages are used to make the comparisons more interpretable. Recruitment for the two studies was undertaken along similar lines and included promotion and distribution of the surveys in both clinical and community settings. In addition a number of participants in the original study elected to have their names placed on a mailing list and received copies of the second survey. In total, 392 individuals (42%) in the second survey indicated that they had completed the first. HIV Futures II also included 58 individuals who had tested HIV positive for the first time in the period between the two surveys. We are confident that the two samples are comparable and are a reasonable representation of the Australian population of PLWHA who have been tested and are in contact with either a community or clinical service. Those groups less likely to be represented include those for whom access to English language material is problematic (due to cultural background, education or disability), those who are not in contact with services, and those experiencing major episodes of ill health or hospitalisation. Significant differences between the two samples (at $\alpha=0.01$) are indicated by the marks \wedge higher value in 1999 and \vee lower value in 1999.

Demographics

The samples were well matched on most demographics. There were no significant differences in gender, mode of infection (see Table 1), proportions of Aboriginal and Torres Strait Islander respondents, state of residence, educational level, and religious affiliation. However a significant difference was found in the ages of the samples, with the 1999 cohort (mean=42.1, SD=8.9) being older than the 1997 one (mean=39.3, SD=8.7).

Table 1 Mode of transmission (percentage of samples)

	1997	1999
Male homosexual or bisexual contact	75.9	76.5
Heterosexual contact	8.0	8.9
Male homosexual/bisexual contact and injecting drug use	1.6	1.3
Injecting drug use (females and heterosexual males)	5.2	4.4
Haemophilia/Coagulation disorder	2.9	3.5
Receipt of blood components/tissue	4.5	4.5
Other	1.9	0.9

Accommodation

No significant differences were found between the samples in the types of accommodation the respondents were living in (see Table 2). No differences were found in proportions of respondents who lived by themselves, with a partner or spouse, dependent children, other family members, and friends or housemates.

Table 2 Types of accommodation (percentage of samples)

	1997	1999
Own or purchasing own house or flat	35.3	35.1
Private rental	40.2	37.3
Public rental	14.7	16.0
Living rent-free	6.0	6.4
Community housing/housing cooperative	1.6	3.6
Other	2.2	1.5

There was also no difference in the proportions in each sample that rated their accommodation as being suitable for their needs or who had moved due to their HIV status. However, among those who had moved due to HIV, the 1999 sample contained a smaller proportion (28%) of those who had moved due to having stopped working than the 1997 sample (41%).

Health

The 1999 sample (mean=10.8, SD=5.2) had been infected for longer at the time of filling out the survey than the 1997 sample (mean=9.3, SD=4.4), and had known of their HIV status for a longer time (mean=8.8, SD=4.5 v mean=7.4, SD=4.0). Given that the studies were two years apart and that the population of people with HIV is aging, this difference seems quite explicable. No significant differences were found between the samples in participants' ratings of their health (see Table 3).

Table 3 Ratings of health (percentage of samples)

	1997	1999
Poor	3.3	3.2
Fair	25.0	24.1
Good	46.0	51.3
Excellent	25.7	21.5

Respondents from the 1999 sample were more likely to have a major health condition other than HIV/AIDS (40% v 28%). It should be noted that this was an open-ended item, with conditions nominated and written in by respondents. Therefore, this should be read as conditions considered

by respondents to be major and not the incidence of the conditions themselves. Table 4 shows the most common other health conditions that were mentioned in both samples.

Table 4 Other major health conditions nominated by respondents (percentage of sample)

Hep C	8.2
Psychiatric illnesses	6.2
Cardiovascular disease	3.4
Asthma	3.1
Hep B	2.4
Arthritis	2.2
Back injury/pain	1.7
Haemophilia	1.3

(Multiple responses possible)

Table 5 shows the results of the respondents last CD4 and viral load tests. There was no difference in the proportions of respondents in each sample who had obtained a CD4 test, however significantly more of the 1999 sample had had a viral load test (99.3% v 96.2%). The most recent CD4 test of the 1999 sample was significantly less likely to be less than 250 and significantly more likely to be above 500, and their most recent viral load was significantly more likely to be below detectable levels and were significantly less likely to be between 500 and 9999. The 1999 sample also had a significantly smaller proportion of respondents (51.9%) that had at some point received a CD4 count below 200 than the 1997 sample (58.7%).

Table 5 Results of respondents' most recent CD4 and viral load tests (percentage of those with test results)

		1997	1999
CD4			
∨	0-249	30.9	19.9
	250-499	39.9	35.8
∧	500+	29.2	44.4
Viral load			
∧	Below detectable levels	45.6	55.0
∨	500-9999	26.3	18.4
	10000-49999	13.9	11.4
	50000+	14.2	15.2

Table 6 shows the progress of respondents CD4 and viral load counts over the course of the year before they filled out the survey. Respondents in the 1999 sample were significantly less likely to say their CD4 counts and viral loads decreased and were significantly more likely to say their viral load stayed the same.

Table 6 Respondents' most recent CD4 and viral load tests (percentage of samples)

	1997	1999	
CD4			
	Stayed the same	12.7	17.3
	Increased	30.1	34.3
	Gone up & down	43.0	38.1
∨	Decreased	14.1	10.3
Viral load			
∧	Stayed the same	11.5	33.0
	Increased	12.6	14.8
	Gone up & down	32.7	28.9
∨	Decreased	43.2	23.3

There was no difference between the samples in the proportions of respondents who had had hepatitis A and hepatitis B, however significantly more respondents in the 1999 sample had been for a hepatitis C test (63.8% v 55.3%). Among respondents who had been for a test there was no difference between the samples on the results of this test.

Significantly more of the 1999 sample thought that combination antiretroviral drugs had improved the prospects of PLWHA (69.7% v 59.1%), and significantly more of the 1997 sample felt it was too soon to tell (36.3% v 23.6%). However, there were no significant differences in what respondents considered to be their friends' attitudes towards whether combination therapy had improved prospects.

There were no significant differences in the proportions of respondents currently taking prophylaxis for opportunistic infections or alternative therapies. The uptake of antiretrovirals was lower in 1999, but at a borderline significance level ($p=.038$) (see Table 7). Respondents in the 1999 sample were more likely to have taken antiretrovirals at some time in their life (86.5% v 82.1%).

Table 7 Current use of treatments (percentage of samples)

	1997	1999	
	Prophylaxis for opportunistic infections	39.1	34.4
	Alternative therapies	55.7	55.5
∨	Antiretrovirals	77.7	73.6

There was no significant difference between the samples in the proportions of respondents that reported difficulties taking antiretroviral medications. However, among those experiencing difficulties, those in the 1999 sample were less likely to report difficulties with remembering to take drugs on time (47.5% v 55.6%), organising meals around medication (32.1% v 49.2%), the large number of tablets that need to be taken (22.4% v 31.7%), and taking medication in public (26.1% v 32.7%). The 1999 sample was more likely to report difficulties with taking antiretrovirals in conjunction with other medications (13.2% v 4.8%).

Table 8 shows the circumstances surrounding the commencement of combination therapy. Respondents in the 1999 sample were less likely report that at the time of commencing combination therapy that information showed that it was effective and that friends started using it. Additional items in the 1999 survey provide further information about the circumstances surrounding commencement of therapy.

Table 8 Circumstances surrounding the commencement of combination therapy (percentage of those on combination therapy)

	1997	1999
My doctor advised me to begin this treatment	80.2	81.7
I had a big drop in my CD4/T-cell count	47.9	41.9
√ Information showed that this treatment is effective	45.1	34.0
I became very ill	27.7	27.1
I was hospitalised due to HIV infections	21.9	17.1
I had a big rise in my viral load	21.3	26.8
√ A number of my positive friends started this treatment	19.3	10.1
New drugs became available	na	37.8
Close friends advised me to begin this treatment	na	8.3
My partner advised me to begin this treatment	na	7.9
A treatments officer advised me to begin this treatment	na	7.6

(Multiple responses possible)

Among those who had taken antiretroviral at some stage, those in the 1999 sample were significantly more likely to have stopped taking them at the time of the questionnaire (14.9% v 7.5%). Table 9 shows their reasons for stopping. Those in the 1999 sample were significantly less likely to have stopped because the drugs weren't working for them.

Table 9 Reasons for stopping antiretroviral treatments
(percentage of those that had taken ARV at some point)

	1997	1999
√ They were not working for me	100.0	29.6
Side effects became to severe	59.4	71.6
Taking drugs at the right time was too difficult	17.4	18.3
The financial burden became to heavy	7.9	2.3
To have a holiday from taking treatments – clean out my system	na	30.5
It didn't fit my lifestyle	na	23.7
To have a holiday from taking treatments – drug holiday/special event	na	19.8
Drug resistance developed	na	12.4

(Multiple responses possible)

There was no difference between the samples among the respondents who are not taking drugs now in the proportions who would consider taking them in the future. The events that would make these respondents consider taking antiretroviral therapies in the future can be seen in Table 10. The 1999 sample were significantly less likely to consider taking antiretrovirals in the future if information showed them to be effective.

Table 10 Reasons to consider taking antiretroviral treatments in the future
(percentage of those not taking ARV)

	1997	1999
If I had a significant drop in my CD4/T-cell count	68.9	68.3
If I had a big rise in my viral load	67.5	63.4
If I had a big drop in my overall health	64.8	na
√ If information showed that combination therapy is effective	59.2	33.9
If I developed an opportunistic infection	56.7	na
If the drugs were shown to be safe in the long term	46.7	na
If my doctor advised me to begin this treatment	46.5	47.7
If new drugs became available	38.6	38.8
If a number of my positive friends began to take up combination therapy	14.0	3.4
Other	11.2	8.5
If I became very ill	na	71.3
If I was hospitalised due to HIV-related conditions	na	62.1
If a treatments officer advised me to begin this treatment	na	22.5
When my break from treatment is finished	na	11.2
If my partner advised me to begin this treatment	na	10.1
If close friends advised me to begin this treatment	na	7.1

(Multiple responses possible)

Community and services

Sources of information on HIV/AIDS treatments can be seen in Table 11 and sources of information on living with HIV in Table 12. The 1999 sample was significantly more likely to report a doctor as an important source of information on treatments and living with HIV, and were more likely to report an alternative therapist, a Positive Women's Organisation or family members as important sources of information on living with HIV. The 1999 sample was less likely to report HIV positive friends, the gay press and HIV magazines and newspapers as important sources of information on treatments, and less likely to report that other friends were an important source of information on both treatments and living with HIV/AIDS.

Table 11 Sources of information on treatments
(percentage of samples)

	1997	1999
^ Doctor	90.8	95.6
√ HIV magazine/newspaper	76.1	65.5
√ Articles in gay press	61.8	50.7
√ HIV positive friends	55.5	41.1
Other HIV/AIDS organisation staff	29.4	27.2
Treatments officer	20.8	24.3
Nurse	19.1	19.7
Alternative therapist	17.0	18.3
Other friends	16.9	11.2
Partner/lover	12.7	13.5
Positive Women's Organisation	4.9	6.3
Family	4.7	6.3
Internet	na	22.4
Pharmacist	na	18.2
Injecting drug users' organisation	na	3.8
Haemophilia Foundation	na	2.3

(Multiple responses possible)

Table 12 Sources of information on living with HIV
(percentage of samples)

	1997	1999
^ Doctor	64.0	52.3
HIV magazine/newspaper	59.0	61.2
HIV positive friends	58.6	53.6
Articles in gay press	49.6	49.5
Other HIV/AIDS organisation staff	32.1	37.6
Other friends	31.1	23.6
Partner/lover	23.7	23.7
^ Alternative therapist	15.3	21.7
Treatments officer	14.6	14.3
Nurse	13.9	17.1
Family	9.9	15.7
^ Positive Women's Organisation	3.9	8.3
Internet	na	16.4
Pharmacist	na	6.7
Injecting drug users' organisation	na	5.3
Haemophilia Foundation	na	3.1

(Multiple responses possible)

Table 13 shows the publications containing HIV information that are read by each sample. Respondents from the 1999 sample were significantly less likely to read the National AIDS Bulletin, Positive Living, the HIV Herald, Talkabout and With Complements. Those from the 1999 sample were more likely to read Positive Life.

Table 13 Publications read containing HIV information
(percentage of samples)

	1997	1999
✓ Positive Living (National)	63.5	55.6
✓ Talkabout	55.6	49.3
✓ HIV Herald	52.1	38.6
✓ With Complements	46.8	37.0
✓ National AIDS Bulletin	26.0	18.3
^ Positive Life (PL) (WA)	6.7	10.2
Gay newspapers	na	68.2
Community Newsletters	na	28.4
Gay magazines	na	25.4
QPP Alive	na	13.3
Overseas Magazines (e.g. Poz)	na	9.3
NUAA News	na	5.2
National Haemophilia	na	.6

(Multiple responses possible)

Table 14 shows the proportions of respondents who have disclosed their HIV status to various people. Respondents from the 1999 sample were less likely to have told HIV positive friends and work colleagues.

Table 14 Disclosure of HIV status
(percentage of samples)

	1997	1999
Other friends	86.8	89.3
√ Positive friends	79.5	69.9
Siblings	73.2	70.2
Parents	61.4	59.5
Partner/spouse	56.3	54.8
√ Work colleagues	42.7	34.8
Neighbours	20.2	20.0
Son/daughter	9.0	10.8
Ethnic community	7.4	5.5
No-one	1.3	2.1

(Multiple responses possible)

Table 15 shows the proportions of respondents who know other people with HIV/AIDS. A smaller proportion of the 1999 sample had an HIV positive former partner or spouse. A significantly greater proportion of the 1999 sample spent little or no time with other HIV positive people (52.6% v 45.7%).

Table 15 Other PLWHA known by respondents
(percentage of samples)

	1997	1999
Friends	82.0	80.6
Acquaintance	70.4	67.1
Former partner/spouse	50.0	32.9
√ Partner/spouse	22.0	19.0
Other relative	6.0	4.4
No-one	3.8	4.3
Son/daughter	1.2	1.2

(Multiple responses possible)

The 1999 sample were significantly more likely to plan one day at a time than the 1997 sample (21.4% v 15.9%), they were also more likely to have changed how far they planned ahead in the two years before completing the survey (60.7% v 48.9%). Despite this, among those that had changed their time frame for planning, the 1999 sample were significantly more likely to now use a longer time frame (71.6% v 62.0%).

The 1999 sample were significantly less likely to strongly agree that keeping an optimistic frame of mind is an important part of managing HIV infection (51.6% v 62.6%). They were also less likely to agree that, as long as they were healthy, they preferred not to think about HIV/AIDS (50.2% v 63.6%).

There was no significant difference between the samples in the proportion of respondents that had contact with HIV/AIDS organisations. However, among those who do not have contact with such organisations, those in the 1999 sample were more likely to cite not wanting to as the reason (67.4% v 35.0%) and were less likely to cite transport problems (11.6% v 40.7%). Among those who did have contact with HIV/AIDS organisations, respondents in the 1999 sample were more likely to report that they received a newsletter (85.0% v 68.4%) and were less likely to say they did voluntary work for such organisations (12.3% v 31.3%).

The services of HIV/AIDS organisations used by respondents in both samples can be seen in Table 16. Respondents in the 1999 sample were significantly less likely to use HIV/AIDS organisations for treatments advice.

Table 16 Services of HIV/AIDS organisations used
(percentage of samples)

	1997	1999
√ Treatments advice	52.7	45.4
Social contact with other PLWHA	40.6	39.5
Counselling	34.3	31.1
Peer support group	30.8	30.6
Infomal peer support	26.1	21.4
Financial assistance	24.9	25.0
Alternative therapies	23.7	23.6
Library	14.1	10.4
Financial advice	13.5	13.8
Transport services	12.4	na
Domestic help	7.3	na
Legal advice	na	19.4
Pharmacy services	na	18.5
Housing assistance	na	15.7
Internet access	na	9.4
Respite care	na	8.1
Mental health services	na	8.1
Return to work skills	na	5.3
Employment services	na	4.8
Drug/alcohol treatment	na	4.0

(Multiple responses possible)

Sex and relationships

There were no significant differences in the profile of sexualities of respondents between the samples, with similar proportions of gay, heterosexual and bisexual, men and women in both. In terms of current sexual relationships, respondents in the 1999 sample were significantly more likely to not be having sex at the time of the survey (see Table 17). The 1999 sample was significantly more likely to agree or strongly agree that few people would want a relationship with someone who was HIV positive (64.3% v 47.9%). They are also less likely to strongly disagree that they are afraid of telling potential partners about their HIV status in case they are rejected (11.7% v 19.6%) and that they feel more confident about unprotected sex because of the new treatments (62.3% v 55.9%).

Table 17 Relationship type (percentage of samples)

	1997	1999
Casual sex only	29.7	28.8
Regular relationship with one person and casual sex with others	26.1	25.6
Regular relationship with one person	22.5	17.8
∧ No sex at present	20.3	25.5
Regular relationship with two or more people	1.4	2.4

There were no differences between the samples in proportions of respondents who were in a regular relationship or the HIV status of the partners of those in relationships, however the 1999 sample had been in these relationships for longer (1999: Mean=96.1 months, SD=89.0 months; 1997: Mean=68.4 months, SD=71.8 months). Among those who had sex with casual partners in the 6 months prior to completing the survey, there were no differences between the samples in the proportions of their partners who were HIV positive.

Almost all of those in both samples who were in a relationship had disclosed their HIV status to their partner. Reactions of their partner to the news can be seen in Table 18. Respondents from the 1999 sample were significantly more likely to say that it made no difference to their partner, and were significantly less likely to say that their partner was supportive.

Table 18 Reaction of partner to disclosure of HIV status
(percentage of those that had disclosed to partner)

	1997	1999
∨ They were supportive	67.2	57.3
∧ It did not make any difference	43.5	52.3
We became closer	37.3	33.4
They were angry	7.0	7.4
They were worried/scared	na	27.2

(Multiple responses possible)

Employment

No significant differences were found in the employment status of respondents between the samples (see Table 19). Among those who were working the 1999 sample worked significantly fewer hours per week (1999: Mean=32.9, SD=14.4; 1997: Mean=35.8, SD=14.3). Among those who were not working the 1999 sample had stopped working longer ago (1999: Mean=44.1 months, SD=38.7 months; 1997: Mean=58.8 months, SD=41.1 months).

Table 19 Employment status (percentage of samples)

	1997	1999
Not working/retired	36.8	34.5
Full time work	29.0	26.4
Part time work	15.0	19.0
Unemployed	12.0	11.5
Student	3.7	3.7
Home duties	3.0	3.1
Voluntary work	0.5	1.4
Other	0.0	0.4

Among those who had ever been in paid employment, there were no significant differences in the proportions of respondents who had stopped working at some time due to their HIV diagnosis. The reasons respondents in each sample had for stopping work can be seen in Table 20. Among those who had stopped working due to HIV respondents in the 1999 sample were significantly less likely to have stopped due to stress, depression or anxiety and were significantly more likely to have stopped due to poor health or expecting illness. There were no significant differences between the samples in their HIV status at the time they stopped work. Among those who had stopped work, significantly fewer of the respondents in the 1999 sample lived off their superannuation or savings while not working (11.6% v 21.3%), and a significantly greater proportion had returned to the workforce (50.0% v 37.2%).

Table 20 Reasons for stopping work
(percentage of those ever in paid employment)

	1997	1999
√ Stress, depression, anxiety	71.6	61.5
Low energy levels	63.9	57.4
^ Poor health	49.7	58.4
To have more quality time	45.0	na
^ Expecting illness in future	32.6	23.7
To move to a different location	16.2	16.0
Retrenched/sacked	8.1	9.7
To move to a different job	4.0	na
To have more time to myself	na	24.2
To care for another HIV positive person	na	10.0

(Multiple responses possible)

Table 21 shows the difficulties the respondents who work from both samples have in keeping their HIV status confidential. Those in the 1999 sample significantly less commonly experienced problems with keeping and taking medication and explaining absences from work.

Table 21 Difficulties maintaining confidentiality of HIV status at work
(percentage of those in paid employment)

	1997	1999
Explaining absences from work	16.0	7.0
Difficulty keeping and taking medication	15.1	7.7
Visible signs of illness	7.6	5.6
Gossip	na	11.9

(Multiple responses possible)

Table 22 shows the effects of HIV on job performance among those respondents that were working at the time they were surveyed. The 1999 sample significantly less commonly reported that their job performance was not affected by HIV.

Table 22 Effects of HIV on job performance
(percentage of those in paid employment)

	1997	1999
It is not affected	73.1	51.8
I work reduced hours	13.4	16.6
I cannot always go to work	9.4	8.9
I do different duties	3.7	3.6
I tire more quickly	na	38.3
I have difficulty concentrating	na	15.2
I am less productive	na	8.5

(Multiple responses possible)

Respondents from the 1999 sample were significantly less commonly thinking of changing their work arrangements (53.3% v 42.0%). The changes respondents were thinking of making to their work arrangements can be seen in Table 23. Among those considering changing their work arrangements, respondents from the 1999 sample were less likely to be considering returning to work, and were more likely to be considering stopping work or changing the type of work that they do.

Table 23 Changes considered in work arrangements among those considering changes
(percentage of those considering change)

	1997	1999
Start/return to work	59.7	50.6
Change type of work	24.8	46.5
Reduce work hours	14.8	19.9
Increase work hours	14.4	15.0
Stop work	1.5	4.2

Financial Situation

There was no difference in the proportion of respondents living below the poverty line between the two samples. Table 24 shows that the distribution of incomes of respondents in both samples were largely the same, however respondents from the 1999 sample were significantly less likely to have incomes higher than \$750 per week. The income distributions of the respondents' partners were also similar between the samples.

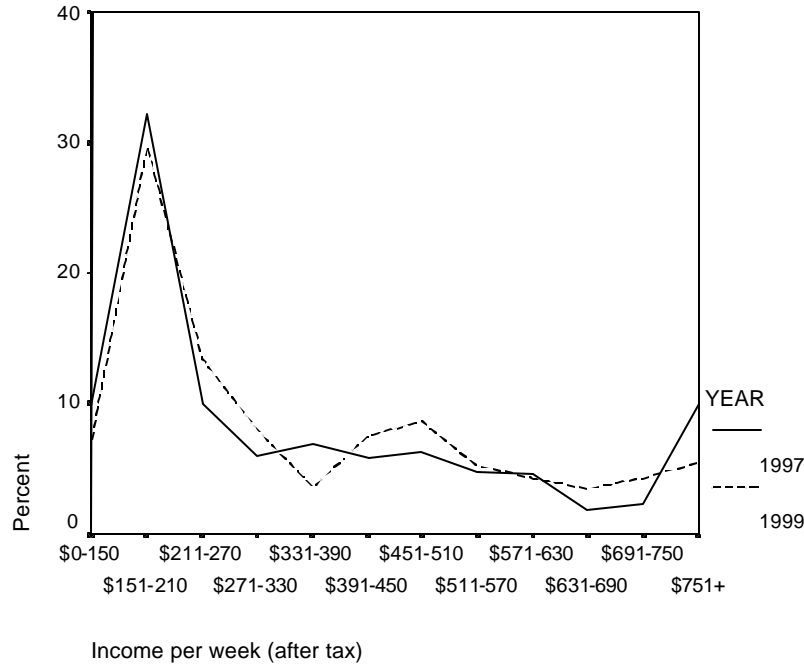


Table 24 Weekly income of respondents

Table 25 shows the main sources of income for respondents from both samples. No significant differences were found between the samples.

Table 25 Main source of income (percentage of samples)

	1997	1999
Benefits/pension/social security	50.9	52.9
Salary	36.9	37.4
Superannuation/annuity/savings	7.2	7.3
Other	5.1	2.3

Table 26 shows the ratings PLWHA in each sample gave to the difficulty of meeting the costs of certain expenses. Items were rated on a 3-point scale (1='not at all difficult' to 3='very difficult'). Respondents in the 1999 sample rated meeting the costs of medical services as being significantly more difficult than respondents in the 1997 sample (1999: Mean=1.61, SD=0.76; 1997: Mean=1.45, SD=0.67).

Table 26 Difficulty of meeting expenses (percentages of those with each expense)

	1997			1999		
	not at all difficult	a little difficult	very difficult	not at all difficult	a little difficult	very difficult
Support services	77.4	15.7	6.8	69.8	19.7	10.6
Medical services	65.0	24.9	10.1	56.1	27.0	16.9
Prescribed medication (all)	56.8	36.7	6.5	na	na	na
Transport	51.8	32.0	16.3	49.0	37.6	13.4
Food	51.0	35.9	13.1	45.6	41.2	13.2
Sport	42.6	26.2	31.2	41.2	30.8	28.0
Complementary therapies	38.2	36.1	25.7	42.8	34.7	22.5
Rent/mortgage/housing costs	37.9	42.1	20.0	43.1	40.5	16.3
Utilities	33.0	43.3	23.7	34.1	42.5	23.4
Clothing	32.3	33.0	34.7	31.2	36.1	32.7
Entertainment	31.6	37.0	31.4	30.5	34.2	35.3
Going out	30.9	34.1	35.0	28.0	32.7	39.3
Recreational drugs	26.9	29.9	43.2	30.4	30.4	39.2
Travel/holidays	18.0	28.6	53.4	19.8	26.2	54.0
Co-payments for HIV medication	na	na	na	62.3	31.4	6.3
Other prescribed medication	na	na	na	56.1	34.7	9.2
Child care	na	na	na	42.7	31.6	25.7

(na= not included in this version of survey)

Concluding remarks

This analysis has shown that while many things remain stable for the Australian population of PLWHA, there have been some significant changes. The reporting of major health conditions other than HIV/AIDS has increased by 12%. The major change in use of antiretrovirals has been in the proportion of people who have stopped using them which is not quite matched by the proportion commencing use. Clinical markers have on average improved and the experience of side-effects, while still high, has decreased slightly. While income has increased, the proportion of PLWHA living below the poverty line has not changed, and the difficulties paying for both the basics of life and the things that enhance quality of life has not improved. While many PLWHA have returned to the workforce, others have retired or become unemployed. Poor health and the expectation of illness now account for more of those stopping work than in 1997 and stress for less. The proportion of people for whom HIV has no effect on their work performance has fallen dramatically. The ways in which PLWHA engage with services has changed. While the proportion engaged with community organisations has not changed, among those who have contact with these services, there was a shift from 31% to 12% saying that they did voluntary work for them. The services that they use has

also changed, with less emphasis on treatments advice. This matches the information provided by services providers during our consultation and feedback on the research, which suggested a changing profile of the client profile of services and increasing difficulty in maintaining a volunteer base.

Further attention will be paid to these issues when the data from the third HIV Futures survey becomes available in mid-2002. Further changes in the treatment environment and the social experience of PLWHA will be reflected in these data and the analysis across the three surveys will inform the evolution of services and policy.

MATCHED SUB-SAMPLE ANALYSIS

Introduction

This section of the report presents an analysis that constructs a cohort from the two cross-sectional samples. It is an exercise designed to explore the extent to which difference observed, or not observed, in the comparison of the two complete samples can be attributed to or is masking difference experienced by individual PLWHA. In total 273 matched pairs of survey data were identified. As this cohort construction was done post-hoc on data that was not designed to be matched, there is some inevitable degree of error involved. We do, however, feel that this exercise is a useful way of unpacking some of the findings from the two studies. It is clear from the qualitative research that we and others have conducted, that for many people with HIV in this country, living with HIV involves constant change. This analysis gives some insight into the nature of some of those changes.

While, as shown below, the demographic profile of this sub-sample closely matches that of the overall sample, the usual precautions should be taken when generalising the findings. Those individuals who first tested positive in the period between the two studies are obviously excluded from this analysis.

Methodology

The data were initially searched for pairs by obtaining a sorted list of cases looking at the variables of year of birth, year tested positive, year infected, sex, whether they were an Aboriginal or Torres Strait Islander, how they thought they were infected, and their sexuality. Those that had similar data on all these variables (usually pairs of cases but occasionally more than two cases matched) were then examined by looking at their postcode, religion, the postcode they were living in at the time of infection (included only in the HIV Futures II survey), the hepatitis A, B and C status, whether or not they had been for a hepatitis C test, whether they had ever had a decision making role in an HIV/AIDS organisation, whether they were in a regular relationship, and if so their partner's HIV status, whether they disclosed their HIV status to their partner and when they did this. This analysis identified approximately 160 pairs, well short of the 392 Futures II respondents that indicated that they had completed HIV Futures I.

In order to identify more pairs a list was generated (still sorted by the original variables of year of birth etc.) which included year of birth, year of infection, year of testing positive, postcode, postcode at time of infection, and whether or not the HIV Futures II respondents had filled in a HIV Futures I questionnaire. The main focus of this search was on finding pairs for those HIV Futures II respondents that claimed to have filled in a HIV Futures I questionnaire. This search identified mainly respondents who had had minor changes in their recall of when they tested positive or in their theory as to when they were infected.

These pairs were then subjected to further checks. Firstly, five pairs were deleted after checking those pairs whose postcode responses disagreed with their response to how long they had been living in the one area (note that area may not necessarily mean the same thing as postcode). Another pair that had different genders on the two surveys was deleted when further examination suggested it was more likely to be two different people than one transsexual. Five pairs were deleted after checking the responses of all those who reported a lower level of education on the second survey than they did on the first.

As a final check, 32 questions that were contained in both questionnaires and would be expected either to: not change (eg year of birth, Aboriginal or Torres Strait Islander identity); change very rarely (eg sexuality, gender identity); or change in predictable ways (eg whether a person had had hepatitis A). A variable was created in the data file of the number of these variables that were answered in ways that were unlikely. This variable had a mean of 1.83 and a standard deviation of 1.51, and ranged from 0 to 7. Looking at the frequency distribution, 2.5% of the sample scored greater than two standard deviations above the mean, and 0.8% scored three standard deviations above the mean. While this distribution is what would be expected it was decided to re-examine all cases more than two standard deviations above the mean. A further two cases were deleted through this process leaving the final tally at 273 cases.

It should be noted that in matching cases some space was left for inaccurate reporting by the respondents, so it couldn't be guaranteed that all pairs were genuinely the same respondent. That said, it should be noted that in these cases the two respondents were at least demographically similar. Conversely, respondents that had changed their situation a great deal in the last two years (eg interstate moves, lost relationships, changes of religion or sexual identity) will be less likely to be included in this analysis. Significant differences between the two samples (at $\alpha=0.01$) are indicated by the marks \wedge higher value in 1999 and \vee lower value in 1999.

The demographic comparisons between this sample and that of Futures II can be seen in Table 27.

Table 27 Demography by sample (percentage of samples)

	Futures I	Futures II	Matched sample*
Gender			
Male	90	90	89
Female	9	10	10
Transgender	0	<0.5	<0.5
Not specified	1	<0.05	<0.5
Age			
Mean	39.3	42.1	42.4
Median	38.0	41.0	41.0
Range	18-77	18-75	26-73
State			
NT	1	1	<0.5
ACT	1	1	<0.5
New South Wales	44	48	42
Victoria	23	20	25
Queensland	15	15	16
South Australia	8	6	8
Western Australia	5	8	6
Tasmania	1	2	2
Not specified	2	1	<0.5
How infected			
Male homosexual/bisexual contact	76	77	81
Heterosexual contact	8	9	7
Male homosexual/bisexual contact and injecting drug use	4	1	1
Injecting drug use (female and heterosexual male)	4	4	4
Haemophilia/coagulation disorder	3	4	2
Receipt of blood components/tissue	2	5	4
Health care setting	1	0	0
Not specified	2	2	1

* Results for matched sample based on respondents' answers to the Futures II study

Results

Demographics

Four percent of respondents had made an interstate move over the past two years, however no state had a significantly positive or negative net migration. Migration to and from urban areas was also approximately equal with 4% of respondents moving to the city from the country and another 3% moving to the country from the city.

In terms of educational attainment 6% reported a lower qualification on the second survey than the first, while 16% reported receiving extra qualifications. These were most commonly university degrees (33% of those who improved their qualifications); followed by tertiary diplomas, trade certificates or TAFE qualifications (30%). Changes of coding in some of the less common belief systems make an accurate count of those who changed religions possible however none of the major systems of belief gained or lost significant numbers.

Accommodation

Table 28 shows the types of accommodation of PLWHA in both years. Thirteen percent had changed their accommodation type in between filling out the surveys. When asked if their accommodation was suitable for their needs most respondents (in both surveys) felt it was (83%), 8% felt it was suitable in 1997 but not in 1999, 5% that it wasn't suitable in 1997 but was in 1999, and 5% that it wasn't suitable in either year. Of those who lived with a partner or spouse in 1997, 23% were no longer living with a partner or spouse in 1999. Twenty-two percent of those with dependent children in 1997 (either living with them or not) had no dependent children in 1999, while 1% of those without dependent children in 1997 had them in 1999. All of those who were living with dependent children in 1997 were still living with dependent children in 1999, however 1% of those not living with dependent children in 1997 were living with them in 1999.

Table 28 Accommodation types by year of survey
(percentage of sample)

	1997	1999
Own or purchasing house or flat	40.4	39.5
Private rental accommodation	37.8	38.6
Public rental accommodation	12.6	13.7
Rentfree	5.8	5.7
Other	3.4	2.5

Health and treatments

There was no significant difference on respondents ratings of their own health in 1997 and 1999 on a four point scale from 1='poor' to 4='excellent'. The correlation between the two ratings of health was .51. Five percent of respondents reported not having had an AIDS defining condition in 1997

but having had one in 1999. However this finding may not be reliable as 12% reported having been diagnosed with an AIDS defining condition in 1997 but not having been diagnosed with one in 1999.

Thirty-one percent of respondents who didn't have a major health problem apart from HIV in 1997 reported having one in 1999. The most common health conditions among this group were depression (16% of those who had a health condition in 1999 who didn't in 1997), asthma (10%) and hepatitis B (10%). Twenty-two percent of respondents who had a major health condition other than HIV/AIDS in 1997 didn't report one in 1999. The most common health conditions reported by this group in 1997 were psychiatric conditions (24% of those who reported a major health condition other than HIV/AIDS in 1997 but didn't in 1999), arthritis (11%), and hepatitis B (10%).

Respondents in this sample had a higher average T-cell count on their most recent test in 1999 (mean=506.5, sd=285.1) than in 1997 (mean=456.1, sd=279.31). The time since their most recent CD4 test had come down from an average of 3.7 months to 2.8 months. No significant differences were found in the average viral load at their last test of respondents in 1997 (mean=359,72.9, sd=286,456.5) and 1999 (mean=58,587.1, sd=182,046.4). The percentage of respondents with a viral load below detectable levels was significantly different between the two times (1997 20.8%, 1999 25.3%). The time since their most recent viral load test had come down from an average of 3.6 months to 2.7 months.

There was an error in reporting hepatitis A, B and C status between the two surveys of approximately 5% (that is some reported that they had it in 1997 and not in 1999). Importantly, 20% of respondents reported never having had a hepatitis C test in 1997 and having had one in 1999. The results of these hepatitis C tests can be seen in Table 29.

Table 29 Hepatitis C test results by year of survey
(percentage of those tested for hepatitis C on both occasions)

	1997		
	Positive	Negative	Don't Know
1999			
Positive	30.1	0.8	2.3
Negative	0.8	58.6	2.3
Don't Know	1.5	3.8	0

Respondents were asked to rate their agreement with certain statements about treatments on a scale of 1='strongly disagree' to 4='strongly agree'. Their responses are summarised in Table 30. Overall respondents were generally more pessimistic about combination therapy in 1999, but felt they had more expertise in making treatment decisions.

Table 30 Attitudes to treatment by year of survey

	1997	1999	Correlation
	Mean	Mean	
I am healthy now and do not need combination antiretroviral drugs	1.81	1.85	.58
Combination antiretroviral drugs are harmful	2.10	2.22	.45
Combination antiretroviral drugs are ineffective	1.48	1.53	.30
√ Combination antiretroviral drugs have allowed to plan my life with confidence for the long term	3.42	2.90	.18
It is easy for me to get combination antiretroviral drugs	3.35	3.40	.35
New treatments will be developed in time for me to gain benefits	3.24	3.08	.41
^ My doctor knows a lot more about the treatment of HIV than I do	2.78	2.94	.56
√ People with HIV should start using antiretroviral drugs as soon as possible	3.28	2.54	.29
My doctor and I work together to find the best treatment for me	3.38	3.26	.23

Tables 23-32 show the use of various types of treatment for HIV/AIDS in the sample in 1997. Respondents were significantly less likely to be taking prophylaxis for opportunistic infections in 1999, and were significantly more likely to be taking antiretrovirals. Thirty-nine percent of those who said that they had never taken antiretrovirals in 1997 reported that they had in 1999, however 3% of those who claimed to have never used antiretrovirals in 1999 said they had done so in 1997.

Table 31 Use of antiretroviral treatments by year of survey (number of respondents)

		1999	
		Yes	No
1997	Yes	188	31
	No	17	39

Table 32 Use of prophylaxis by year of survey (number of respondents)

		1999	
		Yes	No
1997	Yes	85	56
	No	12	124

Table 33 Use of complementary treatments by year of survey
(number of respondents)

		1999	
		Yes	No
1997	Yes	135	37
	No	33	75

Respondents' attitudes to alternative therapies were less positive in 1999 than they were in 1997. They agreed significantly less strongly that complementary therapies could delay the onset of illness due to HIV, could improve well-being, reduce the side-effects of conventional medical treatments, and that medicine's focus on anti-HIV drugs was very limited.

Table 34 shows some of the difficulties experienced by PLWHA in taking antiretroviral drugs in the two years of the survey. Out of all those taking antiretroviral drugs in both years 63% of respondents reported difficulties in both years, 15% just in 1997, 10% just in 1999 and 12% reported no difficulties in either year. Respondents were significantly less likely to cite organising meals around medication and taking medication in public as a difficulty in 1999, and were more likely to cite interactions with other medications as a difficulty.

Table 34 Years in which respondents reported difficulties in taking antiretroviral drugs
(percentage of those using antiretroviral drugs at the time of both surveys)

		Both years	Just 1997	Just 1999	Neither year
√	Organising meals around medication	36	23	9	42
	Remembering to take drugs on time	33	17	14	37
√	Taking medication in public	19	17	8	57
	Taking a large number of tablets	13	15	16	56
^	Interactions with other medications	2	4	18	78

(Multiple responses possible)

Of those respondents that were not using antiretroviral drugs at the time of both surveys 72% reported that they would consider using antiretroviral drugs at some time in the future on both occasions, 17% said they would in 1997 but not in 1999, 6% that they wouldn't in 1997 but would in 1999, and 6% reported that they wouldn't on both occasions. The events that might precipitate use of antiretroviral drugs among those that said that they would consider using them at some time in the future can be seen in Table 35. Respondents were less likely to consider using antiretrovirals if information showed them to be effective in 1999 than they were in 1997.

Table 35 Years in which respondents reported reasons for taking antiretroviral drugs in the future (percentage of those who were not using antiretroviral drugs and said they would consider taking them in the future at the time of both surveys)

	Both years	Just 1997	Just 1999	Neither year
If I had a significant drop in my CD4/T-cell count	57	17	17	10
If I had a significant rise in my viral load	50	17	10	23
If my doctor advised me to begin this treatment	32	16	10	42
√ If information showed that combination therapy was effective	16	45	19	19
If new drugs became available	13	30	17	40
If a number of my positive friends began to take up combination therapy	7	16	7	71

(Multiple responses possible)

Services and communities

Table 36 shows the use of various sources of information on treatments used by the sample in 1997 and 1999. PLWHA in 1999 were significantly more likely to use doctors, and significantly less likely to use HIV/AIDS organisation staff other than treatments officers, positive friends, and the HIV press.

Table 36 Years in which respondents reported sources of information on treatments (percentage of sample)

	Both years	Just 1997	Just 1999	Neither year
^ Doctor	88	3	7	2
√ HIV magazine/newspaper	63	17	9	11
Articles in gay press	46	17	14	24
√ HIV positive friends	33	21	11	36
√ Other HIV/AIDS organisation staff	11	19	13	57
Treatments officer	10	12	15	63
Alternative therapist	8	9	7	76
Nurse	7	12	11	70
Other friends	5	10	6	78
Positive Women's Organisation	3	2	2	92
Partner/lover	3	8	7	82
Family	<.5	4	4	92

(Multiple responses possible)

Table 37 shows the use of various sources of information on living with HIV used by the sample in 1997 and 1999. In 1999 respondents were significantly more likely to use nurses and alternative therapists as source of information on living with HIV, and were significantly less likely to use doctors and non-HIV positive friends.

Table 37 Years in which respondents reported sources of information on living with HIV (percentage of sample)

	Both years	Just 1997	Just 1999	Neither year
HIV magazine/newspaper	48	15	20	18
HIV positive friends	44	16	16	24
√ Doctor	36	26	12	26
Articles in gay press	33	19	21	26
Other HIV/AIDS organisation staff	19	16	14	51
Partner/lover	15	16	11	59
√ Other friends	12	22	9	58
^ Alternative therapist	8	7	13	71
Treatments officer	6	8	11	74
^ Nurse	4	7	12	77
Positive Women's Organisation	2	2	4	93
Family	2	9	10	79

(Multiple responses possible)

Respondents were significantly less likely to read publications that contain HIV information in 1999 than they were in 1997. Ninety percent of respondents read such publications at the time of both surveys, 8% read such publications in 1997, 2% didn't read such publications at either time, and 1 respondent (0.4%) read them in 1999 who didn't in 1997. The publications read by those who read publications containing HIV information in both years can be seen in Table 38. Respondents were significantly less likely to read the National AIDS Bulletin, Positive Living, Positive Life, and the HIV Herald in 1999.

Table 38 Years in which respondents reported reading publications containing HIV information (percentage of sample)

	Both years	Just 1997	Just 1999	Neither year
√ Positive Living (national)	51	18	11	20
Talkabout	44	11	11	35
√ HIV Herald	41	19	10	30
√ National AIDS Bulletin	16	14	8	62
With Complements	12	38	33	17
√ Positive Life (PL) (WA)	3	2	6	90

There was no significant difference in the amount of time respondents spent with other PLWHA at the time of the two surveys. Their relationships to other positive people are shown in Table 39. Respondents were asked whether they had ever been involved in the care of someone with AIDS

in 1997, and in 1999 were asked if they had been involved in caring for someone over the past two years. Twenty-four percent of respondents had cared for someone more than 2 years ago and in the last two years, 33% had cared for someone only more than two years ago, and 7% had cared for someone only in the last two years. Only six percent of people said they had never known anyone who had died of AIDS in either 1997 or 1999 and 82% reported on both occasions having known somebody who died of AIDS.

Table 39 Years in which respondents reported knowing other PL WHA (percentage of sample)

	Both years	Just 1997	Just 1999	Neither year
Friend	77	9	11	3
Acquaintance/member of support group	61	13	13	13
Former partner/spouse	29	27	9	35
Partner/spouse	12	9	4	75
Other relative	2	5	3	90
Son/daughter	1	1	0	99
No-one	2	1	<.5	97

(Multiple responses possible)

When making plans for the future, 31% of respondents reported using a shorter time frame in 1999 than they did in 1997, 41% reported using the same time frame, and 29% reported using a longer time frame. The most common reason for changing time frame for both those using a shorter and longer time frame was improved health due to new treatments.

Respondents were asked to rate their agreement with three statements on their attitudes to their health on a scale of 1='strongly disagree' to 4='strongly agree'. Respondents in 1999 agreed significantly less strongly that looking after their physical fitness is an important part of managing their HIV infection (1997: mean=1.27; 1999: mean=1.74), that keeping an optimistic frame of mind is an important part of managing their HIV infection (1997: mean=1.19; 1999: mean=1.75), and that as long as they were well they preferred not to think about their HIV infection (1997: mean=1.84; 1999: mean=2.52).

When asked if they had contact with any HIV/AIDS related organisations 71% of respondents said yes in both 1997 and 1999, 12% were in contact with HIV/AIDS organisations in 1997 but not in 1999, 6% were in 1999 but not in 1997, and 11% were not in either year. The most common reasons among those who had been in contact with HIV/AIDS service organisations in 1997 who were not in 1999 for not being in contact were not wanting to (70%) and having no transport (23%). Eighteen percent of respondents reported ever having had a decision making position in an HIV/AIDS related organisation in 1999 when they hadn't in 1997. However, 4% of respondents said

they had never had a decision making position in an HIV/AIDS organisation in 1999 after reporting that they had in 1997.

The services of HIV/AIDS-related organisations that respondents used at the time of the surveys can be seen in Table 40. Respondents were significantly less likely to use HIV/AIDS organisations for counselling in 1999 compared with 1997, and were significantly more likely to use them for financial advice.

Table 40 Years in which respondents reported using services at HIV/AIDS-related organisations (percentage of sample)

	Both years	Just 1997	Just 1999	Neither year
Treatments advice	31	21	15	35
Social contact with other PLWHA	24	17	16	43
Peer support group	20	13	10	57
∨ Counselling	15	18	11	56
Informal peer support	12	15	11	61
Alternative therapies	11	9	8	71
∧ Financial assistance	8	9	13	71
Library	5	9	6	80
Financial advice	4	8	12	76

(Multiple responses possible)

Sex and relationships

On a scale of 1='strongly disagree' to 4='strongly agree', respondents in 1999 agreed more strongly that few people would want a relationship with someone who has HIV (1997: mean=2.40, sd=1.01; 1999: mean=2.65, sd=.83) and that they feel more confident about unprotected sex because of new treatments (1997: mean=1.44, sd=.66; 1999: mean=1.70, sd=.84). There were no significant differences in the types of relationships that respondents were having at the time of each questionnaire, however those that were in regular relationships had unsurprisingly been in them for a longer time (1997: mean=89.77 months, sd=92.93months; 1999 mean=98.34 months, sd=96.51 months). No differences were found in the HIV status of the partners of those respondents in regular relationships. Among those having casual relationships in both 1999 and 1997, respondents were significantly more likely to say they were not sure of what proportion of their partners were HIV positive in 1999 (61% v 47%) and were less likely to say that all their partners were HIV negative (4% v 12%).

Employment

The employment status of respondents can be seen in Table 41. Significantly more respondents reported that being HIV positive had affected their work plans in 1999 than in 1997. Seventy-five percent of respondents said that HIV had affected their work plans on both occasions, 6% said it had in 1997 but not in 1999, 12% said it had in 1999 but not in 1997, and 8% said it hadn't on both occasions.

Table 41 Employment status by year of survey
(percentage of sample)

	1997	1999
Not working/retired	42	36
Full time work	25	27
Part time work	19	22
Unemployed	9	7
Student	4	4
Home duties	2	2
Other	0	2

Fifty-one percent of respondents reported in both surveys having stopped work for reasons relating to their HIV diagnosis, 12% reported doing so in the 1997 survey but not the 1999 one, 11% in just the 1999 survey, and 26% reported never having stopped work due to HIV in both surveys. Table 42 shows the reasons respondents had for stopping work on the last occasion they did so before each survey. A significantly greater proportion of those who had stopped work had returned to work at the time of the 1999 sample than that of the 1997 one.

Table 42 Years in which respondents reported reasons for stopping work
(percentage of those who had stopped work at some point)

	Both years	Just 1997	Just 1999	Neither year
Stress, depression, anxiety	58	15	9	19
Low energy levels	51	20	16	13
Poor health	43	17	15	25
Expecting illness	16	20	16	48
To move to a different location	5	5	9	81
Retrenched/sacked	1	4	4	91

(Multiple responses possible)

A significantly greater proportion of respondents who were working had jobs that were HIV-related in 1999 compared with 1997. Thirteen percent had an HIV-related job on both occasions, 3% just in 1997, 11% just in 1999, and 72% on neither occasion. Table 43 shows the difficulties experienced

by respondents in keeping their HIV status confidential. Respondents reported experiencing all three of these problems in significantly lower proportions in the 1999 survey than the 1997 one.

Table 43 Years in which respondents reported difficulties in keeping HIV status confidential at work (percentage of those in paid employment)

	Both years	Just 1997	Just 1999	Neither year
Difficulty keeping and taking medication	18	28	10	45
Explaining absences from work	18	36	5	41
Visible signs of illness	15	18	3	64

(Multiple responses possible)

Table 44 shows the effect of HIV on respondents' capacity to perform their work duties. Respondents were significantly less likely to say their work capacity was unaffected by HIV in 1999 compared with 1997.

Table 44 Years in which respondents reported effects of HIV on capacity to perform work duties (percentage of those in paid employment)

	Both years	Just 1997	Just 1999	Neither year
It is not affected	33	31	6	31
I work reduced hours	12	9	11	67
I cannot always go to work	4	6	4	85
I do different duties	2	5	3	90

(Multiple responses possible)

Significantly fewer respondents wanted to change their work arrangements in 1999 compared with 1997. Twenty-one percent wanted to change their work arrangements on both occasions, 38% just in 1997, 22% just in 1999, and 19% didn't want to change their arrangements on either occasion. The changes they wanted to make can be seen in Table 45. Respondents wanted to start or return to work or change the type of work they do less commonly in 1999.

Table 45 Years in which respondents reported desired changes to work arrangements (percentage of sample)

	Both years	Just 1997	Just 1999	Neither year
I want to change the type of work I do	6	22	15	58
I want to start work/return to work	4	22	15	59
I want to reduce my work hours	2	6	9	83
I want to increase my work hours	<.5	8	5	86
I want to stop work	0	2	3	95

(Multiple responses possible)

Financial situation

Table 46 shows respondents sources of income in 1997 and 1999. Respondents' weekly household after tax income was significantly higher in 1999 (mean=\$525.72, sd=\$353.86) than in 1997 (mean=\$578.47, sd=\$359.58). No significant differences were found in the proportions of respondents with health insurance in 1997 (18%) and 1999 (20%). Nineteen percent of respondents were living below the poverty line at the times of both surveys, 7% were living below the poverty line in 1997 but not 1999, 5% were living below the poverty line just in 1999, and 69% weren't living below the poverty line on either occasion. There was no significant change in the levels of poverty between the surveys. Thirty-six percent owned their own home or were paying it off at time of both surveys, 4% just in 1997, 7% just in 1999, and 54% owned their own home or were paying it off on neither occasion.

Table 46 Main source of income by year of survey (percentage of sample)

	1997	1999
Benefits/pension/social security	49	46
Salary	37	41
Superannuation/annuity/savings	10	10
Other	3	5
Partner supports me	1	2
Family/friends support me	<0.5	1

Respondents were asked to rate the difficulty of paying for certain expenses on a scale of 1='not at all difficult' to 3='very difficult'. Their responses in 1997 and 1999 are summarised in Table 47. Respondents in 1999 found it significantly more difficult to pay for food and medical services, but had less trouble paying for recreational drugs.

Table 47 Difficulty of meeting expenses by year of survey
(those with each expense)

		1997	1999	p	Correlation
		Mean	Mean		
^	Medical services	1.43	1.63	.00	.355
	Complementary therapies	1.87	1.87	.96	.381
	Support services	1.38	1.48	.25	.397
	Entertainment	1.94	1.98	.51	.515
	Going out	2.00	1.99	.85	.503
	Sport	1.90	1.81	.22	.465
∨	Recreational drugs	2.20	1.99	.02	.470
	Travel/holidays	2.34	2.30	.45	.516
	Rent/mortgage/housing costs	1.76	1.66	.06	.359
	Utilities	1.85	1.82	.44	.481
^	Food	1.53	1.61	.05	.509
	Clothing	1.95	1.98	.50	.502
	Transport	1.63	1.61	.82	.373

Concluding remarks

The changes observed in this matched cohort analysis of this sub-sample largely parallel those in the analysis of the two complete samples. We can see in this analysis, however, some of the changes that individuals experience that are masked by the larger-scale comparison. Clearly for many people with HIV there are frequent changes in health, treatments and the social and psychological experience of living with HIV. The development of services and policy needs to recognise that change itself may present specific challenges for PLWHA, and that these may not always be evident in population-based data. The different perspectives offered by cross-sectional and cohort quantitative research and those offered by qualitative projects allow us to more fully understand the lived experience of HIV and respond in a critical manner to the changing experiences and needs of the population.

A separate study, the positive Health (pH) Study is tracking a cohort of PLWHA in New South Wales and Victoria and includes detailed data on the experience of health and treatments (Prestage et al 2001) and this will be particularly informative on these issues. The findings of the HIV Futures 3 survey will be released in 2002, bringing the finding presented here up to date and examining some of the emerging issues in greater detail. In addition there is a cohort of PLWHA for whom these two data sets are linked and analysis of these data will give even greater depth to some of the issues discussed in this report.

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