

# POSITIVE HEALTH

THEN AND NOW ...  
FOLLOWING HIV-POSITIVE  
PEOPLE'S LIVES OVER TIME

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Patrick **Rawstone**  
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National Centre in HIV Social Research  
National Centre in HIV Epidemiology & Clinical Research  
Australian Research Centre in Sex, Health & Society



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# INTRODUCTION

*Positive Health* is a longitudinal cohort study of HIV-positive men and women living in NSW and Victoria. A major focus of *Positive Health* is the impact of HIV and associated treatments on health and, more generally, on the lived experience of People Living with HIV and AIDS (PLWHA) over time. The study is funded by the Commonwealth Department of Health & Ageing and the New South Wales Department of Health, and began recruiting in late 1998. This report covers two data collection periods, which we have called *Time 1* (1998/1999) and *Time 2* (2000/2001). While 517 people were interviewed at *Time 1* or *Time 2*, this report examines data from the 307 participants who we interviewed at **both** *Time 1* and *Time 2*.<sup>1</sup> Questions that were asked of participants at *Time 1* and *Time 2* were essentially the same.<sup>2</sup>

Conceived in 1997 in the period following the introduction of highly active antiretroviral treatment (HAART), *Positive Health* was designed to examine the uptake and use of various therapies (including antiretroviral (ARV) therapy), and access to treatment and care among people with HIV in New South Wales and Victoria. In addition, the study focuses on side effects, treatment practices, clinical markers and quality of life. It also explores knowledge of HIV treatments among PLWHA, and pill-taking practices in relation to clinical and bodily experiences of HIV and AIDS. In addition to treatments, *Positive Health* collects data on identity in relation to HIV serostatus and attachment to PLWHA organisations and HIV-positive communities.

An advantage of a prospective longitudinal cohort study is the ability to analyse data about the *same group of people* across time. This enables an examination of patterns of change or stability at both a population and individual level. Unlike a cross-sectional study—which may show a correlation between factors but is unable to infer causation—a longitudinal cohort study makes possible the inference of causation by establishing a temporal order of events, one of a few necessary conditions for inferring causation. A longitudinal design also provides the means to assess whether changes across time are due to developmental (e.g. age) or historical effects (e.g. time of diagnosis). Thus *Positive Health* is an ideal research design for studying the long-term lived experience of HIV.

*Positive Health* has been funded up to 2005 in New South Wales, and to 2004 in Victoria, and thus has the potential to follow participants for a minimum of six years. Despite some participants being lost to follow up, in some cases due to death, each year we seek to recruit a further 100 young HIV-positive men and women to the study to maintain an optimal size and to maintain some younger participants as the cohort ages.

*Positive Health* provides valuable information for the development of policy and service provision at a national, state and community level. By identifying changes in the lives of people living with HIV it also provides important information for organisations and individuals working in health promotion and education.

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<sup>1</sup> This report is the second part of a series. The first series comprised two reports: a description of the study and the methodology, and baseline data for the initial 425 participants at *Time 1* (see Prestage, et al., 2001a & 2001b).

<sup>2</sup> At *Time 2*, however, participants were invited to complete an optional sexual behaviour questionnaire. This questionnaire is designed to explore knowledge about the impact of clinical markers on sexual practice, and levels of sexual risk, including reduction strategies. The information collected in this part of the study is also designed to be comparable with the parallel cohort study of HIV-negative men, called the *Health In Men (HIM) Study*. As the sexual behaviour questions were only included from *Time 2* onwards, these results are not included in this report. Separate publications will be used to disseminate results from the sexual behaviour questions as well as new data pertaining to questions that were introduced for the first time during the second administration of the questionnaire. Detailed analyses of the data will be published as they are completed.

The project is administered collaboratively through the National Centre in HIV Social Research (NCHSR), the National Centre in HIV Epidemiology and Clinical Research (NCHECR), the Australian Research Centre in Sex, Health and Society (ARCSHS), the National Association of People Living with HIV/AIDS (NAPWA) and the Australian Federation of AIDS Organisations (AFAO).

The descriptions of the data presented here are not necessarily final and further analyses may require some reinterpretation of the findings.

# KEY FINDINGS

## HIV-COMMUNITY INVOLVEMENT

- Participation in gay-community subcultures and HIV-positive functions was reasonably widespread.
- Sexuality, gender and HIV status were considered important aspects of participants' self-identity (81%, 77% and 74%, respectively).
- The number of people that participants knew who had HIV or AIDS decreased over time.
- The amount of free time spent with friends who are HIV-positive has decreased. Conversely the amount of time spent with HIV-negative friends has increased.
- Participants, however, are less likely to receive emotional support from HIV-negative people than they were in the past. Instead, the likelihood that they received emotional support from their doctor increased over time. The level of emotional support from other HIV-positive people has remained stable over time.

## TREATMENT INFORMATION

- The majority of people in the cohort read the HIV treatment press and HIV community press.
- At *Time 2*, participants were more likely to access HIV and treatment-related information through the internet, and less likely to read printed HIV community publications, HIV treatment publications and other sources of HIV-related print materials.

## HIV SERVICES

- Participants are now seeing their key doctor less frequently than in the past—in general, a shift from monthly to quarterly visits. However, participants are monitoring CD4 count and viral load more frequently than in the past.
- Fewer participants are using hospital services.
- Around one-quarter of the cohort experienced some problem accessing services. Participants were most likely to experience access difficulties at hospital pharmacies.

## HEALTH

- Approximately half of the participants had a CD4 count of 500 at their most recent test and there has been no significant change in CD4 count over time. However, over half the respondents reported a fluctuating CD4 count over the past year.
- Almost half of the participants had an undetectable viral load result at their most recent test, and 61% reported at undetectable viral load at some time in the previous year. There has been no change in average viral load over time, although almost half of the cohort reported a fluctuating viral load over the past year.

- Participants' rating of their own health has improved—with an increase in the proportion rating their health as excellent.
- Indicators of general health and quality of life remained stable in the cohort in relation to appetite, sleeping patterns, overall level of energy, concentration and libido.
- There was however a decline in self-rated mood over time, and one in five participants reported a clinical diagnosis of depression.

## **ANTIRETROVIRAL (ARV) THERAPY**

- There has been an overall decline in the proportion of participants taking ARV drugs (82.7% to 73.3%). There has also been a decline in the number of ARV drugs respondents reported taking—especially in the proportion taking four or more different ARV drugs, and a decline in the number of separate doses of ARV drugs taken each day with over three-quarters of the cohort now taking twice-daily regimens.
- The most common reason for stopping ARV therapy completely, or changing treatment regimens, was the experience of side effects. Other reasons for stopping therapy were concerns about the long-term effects of the drugs, and being 'fed up' with the treatment regimen.
- The most commonly experienced symptoms over the past year were gastrointestinal (diarrhoea, vomiting, nausea). These were also the symptoms that participants were most likely to attribute to ARV drugs.
- Two-thirds of the cohort has experienced symptoms associated with lipodystrophy—sunken cheeks, increased abdominal girth and prominent vein on arms and legs—in the previous year. Of those who had experienced such symptoms, 20% reported that the change in their appearance was severe. The proportion reporting prominent veins on their arms and legs has increased over time.
- Almost a third of participants reported raised cholesterol or triglyceride levels.

## **INCOME AND EMPLOYMENT**

- About 60% of the cohort reported an annual income of \$26000 or less.
- Less than half the participants were in some form of paid employment. Only 30% of the cohort was in full-time employment.

## **RECREATIONAL DRUGS AND ALCOHOL**

- There has been a decrease in the frequency with which participants take recreational drugs, and also a decrease in the total number of different drugs used by participants. The proportion of participants who injected drugs has decreased over time. About three-quarters of participants took any recreational drugs.
- Of the participants who were on ARV therapy and also reported taking recreational drugs, one-third said they were 'unconcerned' about potential drug interactions, one-quarter said they worked their ARV therapy around their recreational drug use, while one-fifth reported working their recreational drug use around their ARV therapy.
- Although there was no decrease in the numbers of times per week participants drank alcohol, there was a significant decrease in the number of times participants were intoxicated with alcohol.

# REPORT LAYOUT

The remainder of this report is divided into nine major sections. The first section, *Methodology*, provides a brief outline of the study design; the way in which the study was conducted, including information about the questionnaire instrument, participant recruitment, and a brief description of the participants<sup>3</sup>. That section is followed by *Community*, which reports on levels of engagement with HIV positivity as well as participation in sub-cultural socio-sexual groups. The largest section in the report is the *Health of People Living with HIV and AIDS*, which reports on a range of health-related issues including frequency of blood testing, connection with health services, ratings of general health, experience of symptoms and side effects, clinical markers of health, etc. Following that section is *Access to Treatment Services*, which focuses on both the need for services and barriers to such services. The next section, *Antiretroviral Treatment*, reports on the proportion of people taking treatments and coming off treatments, as well as some of the reasons why people make changes to their treatment regimens. *Treatment Practices* follows and provides details about dosing and adherence to treatments. *Other Treatments and Lifestyle Strategies* covers a range of issues including alternative/complementary therapies as well as strategies that participants have adopted to improve or maintain their health. Frequency and extent of recreational drug and alcohol use is the focus of the section called *Recreational Drug Use*. Finally, the *Discussion* section outlines some of the key findings of the report and provides an interpretation of the findings.

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<sup>3</sup> A separate document describing the demographics of the cohort in more detail will be provided upon request.

# METHODOLOGY

In order to assess change in a longitudinal study it is important to ask the same questions of the same people on at least two different occasions. As such, the *Positive Health* questionnaire at *Time 2* underwent minimal change from the instrument used at *Time 1* (details of these changes are reported below). Apart from some minor changes to the questionnaire and the recruitment of additional participants to the study, the methodology is otherwise unchanged from that reported in Prestage, et al., (2001a). For more details about these aspects of the study, we refer the reader to this earlier publication. This section will not repeat what is contained in the earlier report, but will instead focus on the most important methodological aspects of the study.

## SAMPLE SELECTION

*Positive Health* is primarily a study of people who are most likely to be in contact with HIV-related services and support networks, especially those who exist within the gay community. Special efforts have been made to include women, young people, people from non-English-speaking backgrounds, Indigenous people and Torres Strait Islanders, as well as HIV-positive people who live outside the inner-city areas of Sydney and Melbourne.

## RECRUITMENT

Participants were recruited into the study in the following ways:

- 1 Promotion of the study through the HIV and gay media
- 2 Distribution of flyers and reply-paid contact cards at venues and events
- 3 Production and distribution of a project newsletter
- 4 Distribution of newsletters and cards to medical practitioners with large HIV caseloads
- 5 Direct recruitment from participants in other relevant studies
- 6 Personal networking
- 7 Direct recruitment through community organisations, social groups, events and venues
- 8 'Snowballing' through friends and acquaintances of participants
- 9 Inviting HIV-positive participants from the now completed SMASH (Sydney Men and Sexual Health) study to enrol in the project
- 10 Direct referrals from medical practitioners

Overall, the *Positive Health* cohort is drawn from a wide variety of sources. Similarly broad reaching methods to those described above were used in the recruitment of participants in the SMASH study (Prestage et al., 1995). Of the 307 PLWHA who were interviewed at both *Time 1* and *Time 2*, almost one-quarter was recruited from the previous SMASH study (see Table 1). The majority of the remaining participants were recruited from HIV organisations, HIV-positive events, AIDS councils, gay events, and through doctors' clinics.

**Table 1: Sources of recruitment**

	n	%
SMASH participant	72	23.5
Doctor's clinic	32	10.4
Other	29	9.4
Gay-community event	28	9.1
HIV-positive organisation	27	8.8
AIDS Council	26	8.5
HIV-positive social function	23	7.5
Other community organisation	13	4.2
Friends	12	3.8
Through other studies	10	3.3
HIV-positive magazine	10	3.3
Gay press	9	2.9
Through SMASH	7	2.3
Gay organisation	4	1.3
Health centre	3	1.0
Unsure/No response	2	0.7
<b>Total</b>	<b>307</b>	<b>100</b>

## PARTICIPATION

The first round of interviews for the study (*Time 1*) saw 425 HIV-positive people interviewed between September 1998 and April 1999. Of these 425 people, 307 were interviewed again between September 2000 and April 2001 (*Time 2*). This report is based on the analysed responses of these 307 people for whom there are data for both *Time 1* and *Time 2*. In this report, these 307 people will be referred to variously as *the cohort*, *PLWHA*, *participants*, *respondents* or *people*.

Confining this report to only 307 of the 517 people who have participated in the study up to the end of *Time 2* was done so that data for each person could be matched across time. This enables analyses to be conducted that address questions about genuine change across time, rather than sample changes. Retention of participants between phases of a longitudinal study is therefore extremely important to the validity of the analyses. In this study, the loss-to-follow-up rate was relatively high (28%) between *Time 1* and *Time 2*; partly due to five participants who were known to have died. Loss-to-follow-up is not atypical of cohort studies of this type, especially those with long periods between interviews, but the coordinators of *Positive Health* are trying to minimise the loss-to-follow-up rate in the future.

With any loss-to-follow-up there is a concern that the loss is not randomly distributed; that the people who have left the study are different in some important ways to those who have been retained in the study. As a way of assessing the level of randomness in the loss-to-follow-up, the 113<sup>4</sup> people who completed the questionnaire at *Time 1* but not at *Time 2*, were compared on a number of key dimensions at *Time 1* with the 307 people who completed the questionnaire at both times. These comparisons, which were all conducted using *Time 1* data, showed no differences between these two groups of PLWHA on length of period since diagnosis, most recent CD4 count and viral load results, the number of HIV-related illnesses and symptoms experienced, whether or not they were taking ARV therapy, a range of quality of life dimensions, and self-rated health. Age was the only dimension on which there was a difference between the two groups, with those who had left the study being slightly younger (M=39) than those retained in the study

<sup>4</sup> There were actually 118 people who completed the questionnaire at *Time 1* but not at *Time 2*; however five of these people died during the period between *Time 1* and *Time 2* and so were not included in the comparison.

( $M=42$ ). These results provide a degree of confidence that the 113 people who left the study are not significantly different from the 307 people who are reported on here.

*Positive Health* is an open cohort study that means that the study regularly recruits new participants—particularly younger and more recently diagnosed PLWHA. There are two major reasons for ongoing recruitment. First, new recruits can be included in longitudinal analyses for subsequent time periods in order to minimise the long-term impact of loss-to-follow-up. Second, younger people brought into the study offsets the ageing effect in the cohort.

## BRIEF DESCRIPTION OF PARTICIPANTS

Three hundred and seven PLWHA—drawn predominantly from the inner metropolitan areas of Sydney, the North Coast of New South Wales, and Melbourne—participated in the study at *Time 1* and *Time 2*. Participants lived primarily in private accommodation in urban areas, generally alone or with a partner. The cohort is comprised mostly of men who identified as gay or homosexual, who were diagnosed with HIV prior to 1995. The average age of participants was 43 years. Most were born in Australia or other predominantly English-speaking countries such as New Zealand, the United Kingdom, the United States or Canada. They were well educated. Less than half the participants were in some form of paid employment, mostly full-time employment. Among those employed, there was a high proportion working in professional or managerial roles and in the clerical, para-professional and sales fields. About 60% of all participants reported an income of \$26,000 or less per year.

Sexuality, gender and HIV status were considered important aspects of participants' self-identity (81%, 77% and 74%, respectively). Participation in gay-community subcultures and HIV-positive functions was reasonably widespread.

## THE QUESTIONNAIRES

The initial questionnaire used in the study was the product of many months of deliberation and consultation, and was adapted from instruments used in previous studies, particularly the questionnaire used in the SMASH study. In developing this questionnaire, the *Positive Health* Project Committee consulted with a variety of HIV organisations and medical practitioners.

For the second round of data collection, for *Time 2*, the original questionnaire was edited to omit items that had become redundant or did not need to be asked again, and new questions were inserted on topics that had become important in the intervening period. In addition, questions that proved unclear or difficult to administer during *Time 1*, were modified or expanded for clarity of data collection and analysis.

### Interview Questionnaire

The questionnaire used at *Time 2* contained about 1000 questions and took between 90 minutes and two hours to complete. It was administered in a face-to-face interview primarily because the questionnaire is necessarily complex and because an interview format has the capacity to seek clarification on questions and responses.

Major areas covered in the interview were:

- 1 Demographic details
- 2 Contact with HIV-positive people and organisations
- 3 Disclosure of serostatus
- 4 Use of health and support services
- 5 Personal health and serological testing
- 6 Use of alternative/natural therapies
- 7 Use of ARVs
- 8 Use of other medical treatments
- 9 Recreational drug use
- 10 Relationships with service providers
- 11 Clinical trials
- 12 Beliefs about medicine and HIV
- 13 Involvement in community subcultures

# COMMUNITY

The Australian response to HIV is characterised by a strong sense of 'community'. From very early on in the epidemic, community-based organisations (CBOs) provided care and support to those affected, and played an active and influential role in shaping government policies. While CBOs have undoubtedly contributed to the building of an HIV community, they are not the only source of community for PLWHA. 'Community' is experienced in the relationships one has with friends, sexual partner(s), volunteer home help, meeting with other PLWHA at drop-in groups, etc. 'Community', here, refers to a symbolic feeling of belonging, rather than a fixed geographic location in time and place (Brotherton, 1996).

One of the benefits of community involvement is the entry it provides into social networks. Social networks provide the means by which norms of trustworthiness and reciprocity flourish (Putnam, 2000). For example, Putnam describes how reciprocity functions out of a sense of 'giving' to others with an expectation that the favour will at some stage be returned—if not from the person to whom it was given, then at least by someone else. Social connectedness is also strongly associated with outcomes of health, happiness and wellbeing.

Experiences of community and levels of community engagement are not static: people move in and out of social groups; their circumstances, ideas and needs change, as do social norms. This section explores the different types of communities experienced by the cohort and whether participation and a sense of belonging in community have changed over time.

## POSITIVE COMMUNITY AND CONTACT WITH THE EPIDEMIC

### Connectedness with HIV-positive people

The majority of participants at both *Time 1* and *Time 2* knew more than ten people with an HIV or AIDS-related illness. Among those who knew somebody with an HIV infection or AIDS-related illness at *Time 2* (n=298), 93% indicated them to be a friend or relative, and 63% said they were either a current, or former, sex partner. Participants reported knowing significantly fewer people with HIV or AIDS-related illnesses at *Time 2* than at *Time 1* (Wilcoxon: n=306; z=-3.72, p < .001) (Table 2). Changes in the epidemic in the post-HAART environment mean that fewer people are dying from AIDS-related illnesses and so the actual prevalence of HIV in the affected populations has increased: median survival time among people diagnosed with AIDS increased from 19.5 months in 1994 to 46.9 months in 1997 (National Centre in HIV Epidemiology and Clinical research, 2002, p.23). So when these respondents report knowing fewer people infected with HIV, this is most likely due to changes in their own behaviour or at least changes in their perception of their social relationships, rather than changes in the population. Indeed, if changes in the population had influenced the level of connectedness with HIV-positive people, one would have been expected in the opposite direction: greater connectedness, consistent with an increase in the prevalence of HIV in the affected populations.

**Table 2: Number of people known by participants to have HIV or AIDS illness**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
None	4	1.3	8	2.6
1 – 5	38	12.4	63	20.6
6 – 10	53	17.2	41	13.4
More than 10	212	69.1	194	63.4
<b>Total</b>	<b>307</b>	<b>100</b>	<b>306<sup>1</sup></b>	<b>100</b>

<sup>1</sup> Missing data: n=1

## Serostatus of friends

The cohort generally had more HIV-negative friends than HIV-positive friends at both data collection periods (Table 3). Across the two data collection periods, there was no significant change in the number of HIV-positive friends and HIV-negative friends of participants.

**Table 3: Number of HIV-positive and HIV-negative friends of participants**

	HIV-positive friends		HIV-negative friends	
	<i>Time 1</i>	<i>Time 2</i>	<i>Time 1</i>	<i>Time 2</i>
None	38 (12.4%)	32 (10.4%)	6 (2.0%)	4 (1.3%)
Some	194 (63.2%)	189 (61.6%)	140 (45.6%)	141 (46.1%)
Most	63 (20.5%)	73 (23.8%)	117 (38.1)	116 (37.9%)
All	8 (2.6%)	4 (1.3%)	29 (9.4%)	29 (9.5%)
Do not know their status	4 (1.3%)	9 (2.9%)	15 (4.9%)	16 (5.2%)
<b>Total</b>	<b>307 (100%)</b>	<b>307 (100%)</b>	<b>307 (100%)</b>	<b>306<sup>1</sup> (100%)</b>

Note: Those who did not know the HIV status of their friends were excluded from these analyses.

<sup>1</sup> Missing data: n=1

## Time spent with friends, by serostatus

Most participants in the cohort spent 'some' or 'a lot' of time with friends, irrespective of the serostatus of their friends (Table 4). There would appear to have been a shift between *Time 1* and *Time 2*: at *Time 2*, PLWHA were spending less time with HIV-positive friends (Wilcoxon: n=286; z=-2.15, p=.032) and more time with HIV-negative friends in comparison with *Time 1* (Wilcoxon: n=274; z=-2.59, p=.01). Again, whereas the total population of PLWHA has actually increased over time, these respondents report less social contact with HIV-positive friends. This most likely reflects changes in the way they socialise, rather than changes in the population.

**Table 4: Time spent with HIV-positive and HIV-negative friends**

	HIV-positive		HIV-negative	
	<i>Time 1</i>	<i>Time 2</i>	<i>Time 1</i>	<i>Time 2</i>
None	20 (6.7%)	21 (7.2%)	6 (2.1%)	6 (2.1%)
A little	72 (24.2%)	80 (27.4%)	37 (12.8%)	24 (8.3%)
Some	85 (28.5%)	90 (30.8%)	87 (30.1%)	74 (25.6%)
A lot	121 (40.6%)	101 (34.6%)	159 (55.0%)	185 (64.0%)
<b>Total</b>	<b>298 (100%)<sup>1</sup></b>	<b>292 (100%)<sup>2</sup></b>	<b>289 (100%)<sup>3</sup></b>	<b>289 (100%)<sup>3</sup></b>

Missing data: <sup>1</sup> n=9, <sup>2</sup> n=15, <sup>3</sup> n=18

## Connection with people who have died from AIDS

Most participants knew someone who had died from an AIDS-related illness in the 12 months preceding their interview at either *Time 1* or *Time 2* (Table 5). However, significantly fewer PLWHA at *Time 2* than at *Time 1* knew someone who had died of an AIDS-related illness in the previous 12 months (Wilcoxon:  $n=305$ ;  $z=-3.39$ ,  $p=.001$ ; McNemar:  $n=305$ ;  $\chi^2=6.78$ ,  $p=.009$ ). Of those who knew somebody who died from an AIDS-related illness, 8% indicated this person had been a lover or regular sex partner. In addition, 22% of all participants stated they had nursed or personally cared for another person with an AIDS-related illness in the preceding 12 months. Deaths due to AIDS-related illnesses have been significantly less common since the introduction of HAART, so whereas some of the changes reported here may be due to changes in the respondents' patterns of socialising, it may also be due to actual reductions in the number of deaths.

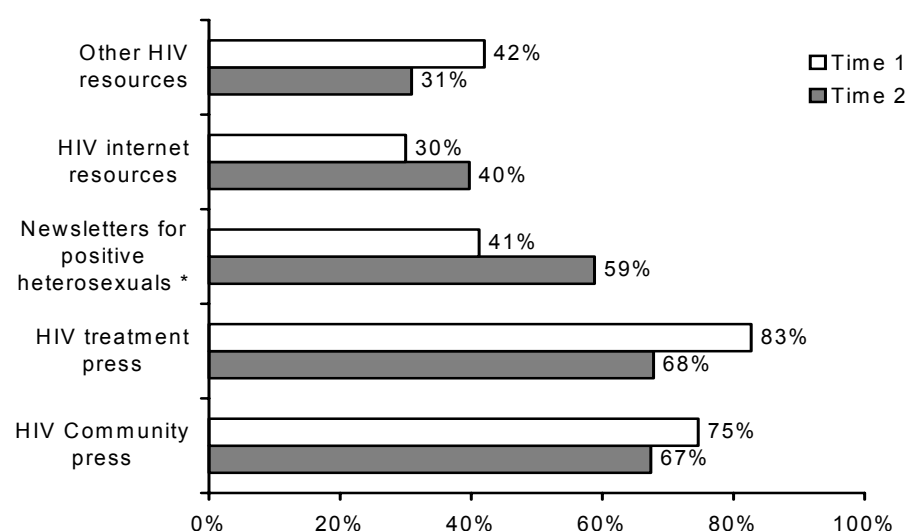
**Table 5: Know someone who has died from AIDS in the previous 12 months?**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
None	116	37.9	141	46.1
1 – 5	160	52.3	146	47.7
6 – 10	15	4.9	12	3.9
More than 10	15	4.9	7	2.3
<b>Total</b>	<b>306<sup>1</sup></b>	<b>100</b>	<b>306<sup>1</sup></b>	<b>100</b>

Missing data: <sup>1</sup> n=1

## SERVICES AND INFORMATION

The majority of people in the cohort read the HIV treatment press and HIV community press (Figure 1). But, in comparing levels of readership in the cohort between *Time 1* and *Time 2*, there was a significant decrease in the number of people who reported reading HIV community-related press (McNemar:  $n=307$ ,  $\chi^2=6.49$ ,  $p=.011$ ), HIV treatment press (McNemar:  $n=307$ ,  $\chi^2=28.13$ ,  $p < .001$ ) and 'other' sources of HIV-related material (McNemar:  $n=307$ ,  $\chi^2=10.27$ ,  $p=.001$ ). Conversely, there has been an overall increase, from *Time 1* to *Time 2*, in the proportion of people who reported using the internet to find HIV and treatment-related material (McNemar:  $n=307$ ,  $\chi^2=10.78$ ,  $p=.001$ ).



**Figure 1: Access to HIV-related sources of information during *Time 1* and *Time 2***

\*Proportion based on only 20 people (those who identified as heterosexual)

These figures are similar to other studies that show PLWHA utilise sources of information that are specifically aimed at HIV (Anderson, et al., 2000). In addition, the increase in the use of internet-related resources is not uncommon, as research indicates that PLWHA utilise the internet for reasons of social connectedness, advocacy, and as an information resource (Reeves, 2001).

## PARTICIPATION IN GAY-COMMUNITY AND OTHER SUBCULTURES

### Gay community and scene

The majority of non-heterosexual men in the cohort participated in the 'gay scene'<sup>5</sup> and/or in informal networks of friends and acquaintances who socialise outside the gay commercial subcultures (the 'gay non-scene') (Figure 2). In addition, a substantial proportion of people were involved in the 'sex venues scene'<sup>6</sup> and the 'leather scene'<sup>7</sup>. Comparatively fewer people were involved in the 'bear scene'<sup>8</sup>, or the 'trannie or drag scene'<sup>9</sup>. Levels of participation in any of the subcultures shown in Figure 2 did not change between *Time 1* and *Time 2* of the study.



**Figure 2: Participation in gay-community subcultures**

Note: Pproportions are based on men who identified as gay, homosexual, bisexual or queer (n=261).

HIV-positive gay men in the cohort are clearly attached to gay community. This is consistent with positive gay men in other parts of the world where, for instance, in a UK study almost 70% of HIV-positive gay men respondents indicated belonging to the 'gay community' (White, 2003).

<sup>5</sup> The term 'gay scene' refers to gay commercial subcultures such as those associated with gay nightclubs and similar venues. Some would argue that this term also has a geographic association with the Oxford Street area in Sydney or the Commercial Road area in Melbourne.

<sup>6</sup> The 'sex venues scene' refers to commercial venues where sex occurs on the premises, such as saunas and sex clubs.

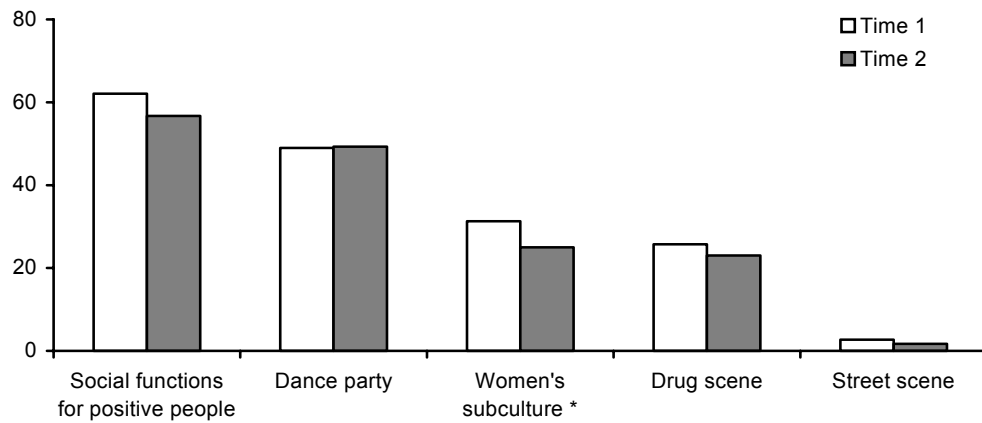
<sup>7</sup> The 'leather scene' refers to venues, events and personal networks in which leather sex is emphasised and leather is a fetish.

<sup>8</sup> The 'bear scene' refers to venues, events and personal networks involving mature men, particularly those who are hirsute.

<sup>9</sup> The 'trannie or drag scene' refers to venues, events and personal networks in which transgender persons are known to participate, particularly those that include the wearing of drag costume and drag performance.

## Other subcultures

Most of the cohort attended social functions aimed specifically at HIV-positive people, as well as dance parties (Figure 3). Almost one-quarter of respondents participated in the drug scene. Although not reported in Figure 14, all women who sexually identified as homosexual, bisexual, queer, lesbian, or gay, indicated that they had participated in the lesbian scene in the period preceding *Time 2*. There were no significant differences in the level of participation in any of the nominated subcultures from *Time 1* to *Time 2*.



**Figure 3: Participation in non-gay-community subcultures**

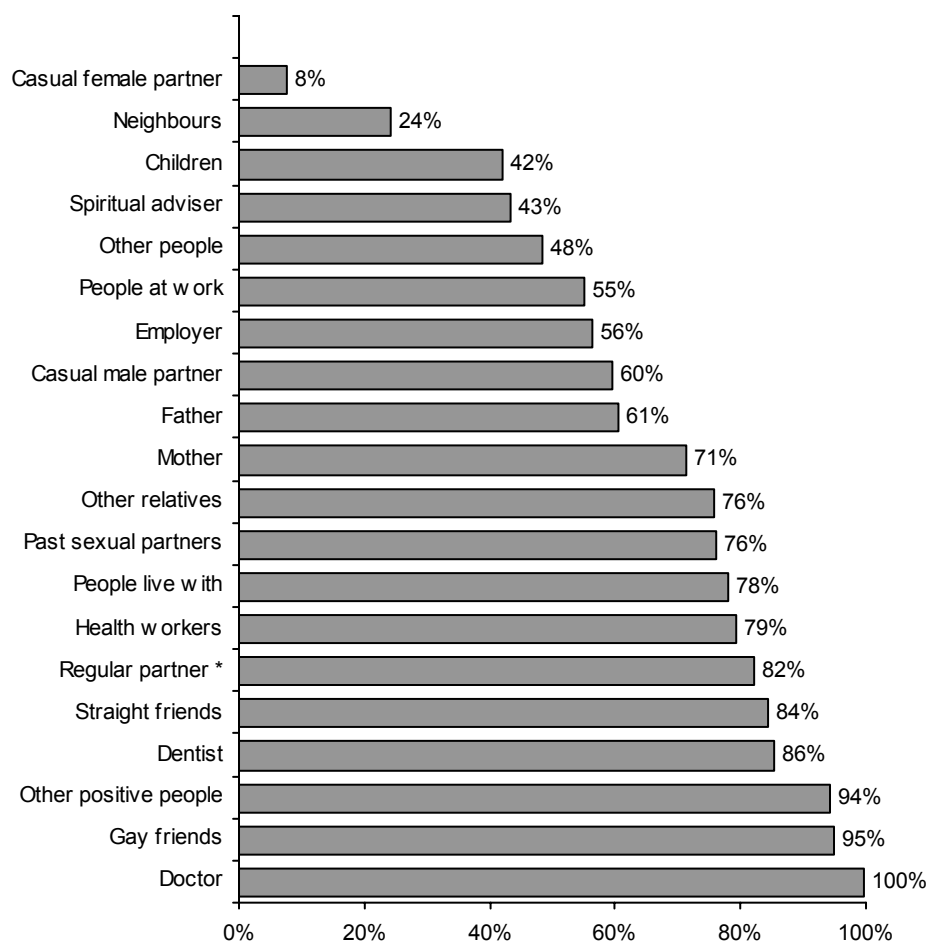
\* Proportion based on women only (n=16).

## PERSONAL SUPPORT NETWORKS

### Disclosure of HIV status

As HIV disclosure is unlikely to occur more than once to the same person, there is little point in comparing HIV disclosure from *Time 1* to *Time 2*. As such, results in this section reflect data from *Time 2* only.

Most participants had disclosed their HIV status to a wide variety of friends, relatives and other personal contacts (Figure 4). Nearly every participant had disclosed their status to their doctor, another HIV-positive person or a gay friend; and almost as many people had disclosed to dentists, regular partners and straight friends.

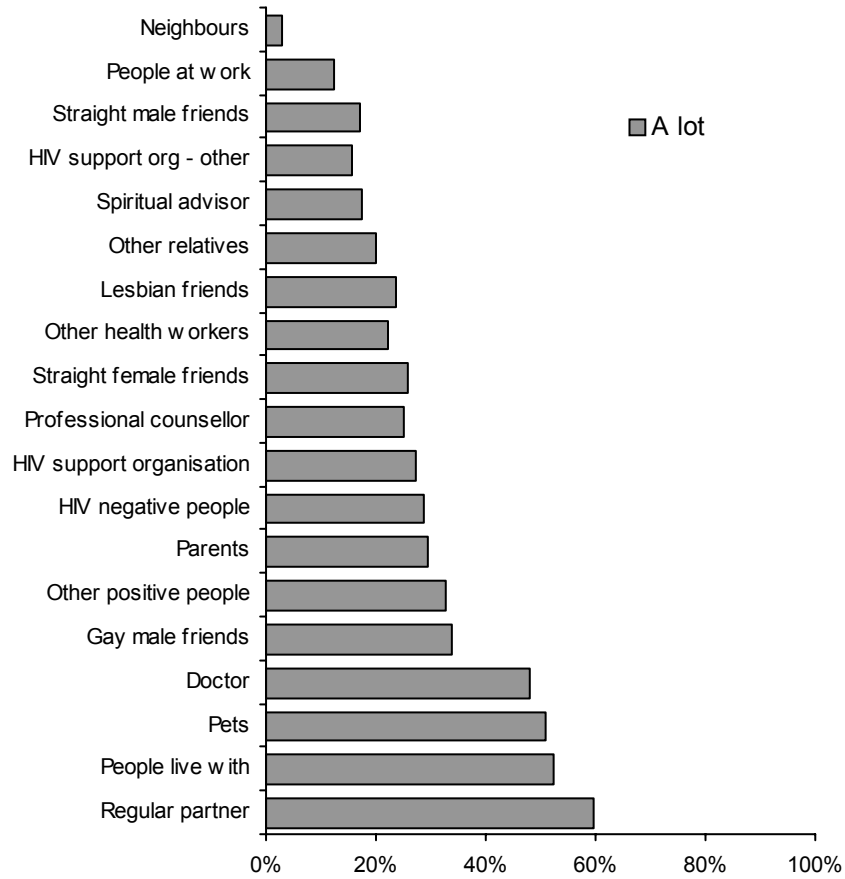


**Figure 4: Disclosure of HIV status**

Note: Percentages were calculated by including only those participants for whom the nominated person(s) in each item existed.

## Sources of emotional support

The most common sources of 'a lot' of emotional support for participants at *Time 2* came from regular partners, others living in the same household, pets, and doctors (Figure 5).

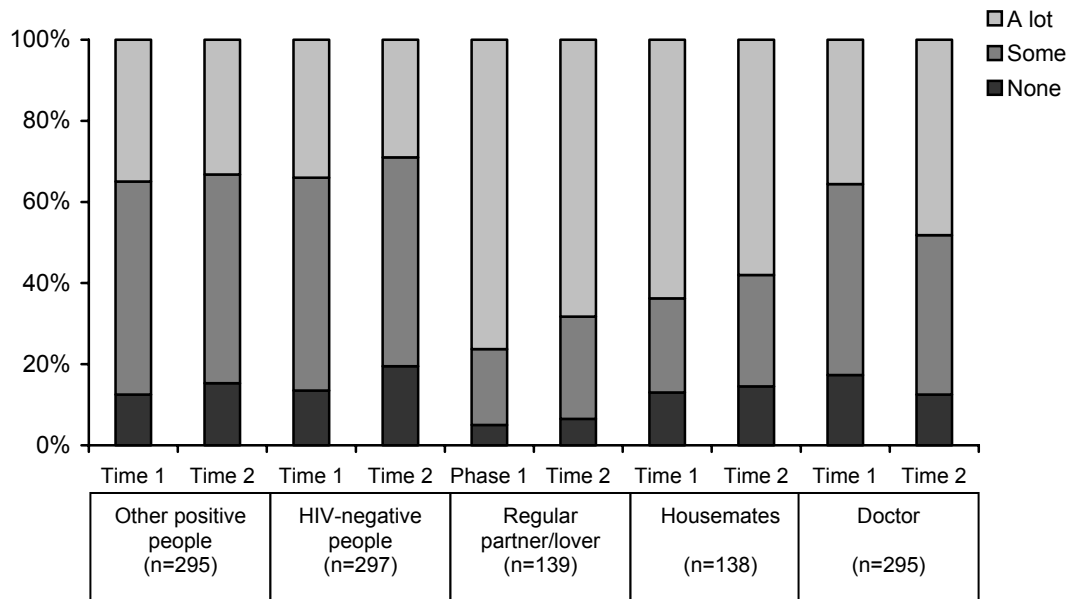


**Figure 5: Sources of 'a lot' of emotional support**

Note: Percentages were calculated by including only those participants for whom the nominated source(s) in each item existed.

## Emotional support

The five main sources of ‘a lot’ of emotional support at *Time 1* were other HIV-positive people, HIV-negative people, regular partners, housemates, and doctors. We explored whether the relative importance of these sources of emotional support had changed across time. At *Time 2*, in comparison with *Time 1*, participants received more emotional support from doctors (Wilcoxon:  $n=295$ ,  $Z=-3.76$ ,  $p < .001$ ) and less emotional support from HIV-negative people (Wilcoxon:  $n=297$ ,  $Z=-2.55$ ,  $p=.011$ ) (Figure 6). The level of emotional support received from the other three sources was relatively consistent across time.



**Figure 6: Sources of emotional support**

Note: Each analysis comparing *Time 1* with *Time 2* included only those people for whom the source of emotional support was applicable at both time periods.

# HEALTH OF PEOPLE LIVING WITH HIV & AIDS

Living with HIV in the 1980s had quite different health implications than it does today. The availability of HAART from 1996/1997 changed the prognosis of PLWHA and the way in which people considered their future. People living with HIV and AIDS in the 1980s, faced a relatively bleak future in which early death was a real probability, while today, the outlook is more positive.

On the other hand, living with HIV over the longer term has not necessarily enabled people to forget about their health in relation to HIV. The nature of the virus, the taking of pills, the possibility of drug resistance, the experience of symptoms and side effects, and the development of medical technologies such as the viral load test, have all meant that issues of health remain in the foreground.

What constitutes 'good health' may differ somewhat from person to person and from service provider to PLWHA. A service provider may be more inclined to rely on objective measures of health such as CD4 counts or viral load results, whereas a person with HIV may focus more on the subjective aspects of how they feel and the impact of HIV on their quality of life (Grierson, 2001). In this section, a range of health-related issues is reported as well as comparisons between measures of health from *Time 1* to *Time 2*.

## HEALTH SERVICES

### Key doctor

By far the majority of participants in the cohort have as their key doctor a general practitioner with a high HIV caseload or a specialist with expertise in the field of HIV (see Figure 7). Only two people stated that they had no key doctor for the management of their infection. There were no differences in the proportions for *Time 1* and *Time 2*.

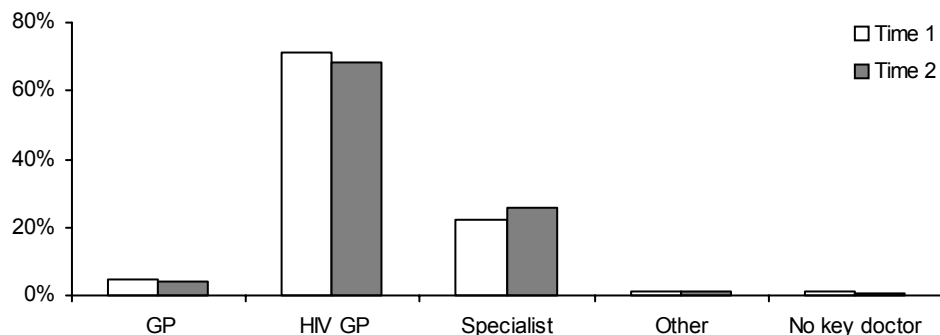


Figure 7: Type of doctor consulted for management of HIV infection

## Frequency of consultation with key doctor

The majority of respondents visited their key doctor at least every three months, and many even more regularly than that (Table 6). There was a significant overall decrease, however, in the frequency with which participants visited their key doctor (Wilcoxon:  $n=288$ ,  $z=-3.97$ ,  $p < .001$ ). The major change was in fewer people seeing their key doctor monthly, with more people seeing their key doctor at least every three months.

**Table 6: Frequency of consultation with key doctor**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
At least monthly	129	43.6	91	30.6
At least every 3 months	149	50.3	178	59.9
At least every six months	16	5.4	22	7.4
At least every 12 months	-	-	6	2.0
Less than once a year	2	0.6	-	-
<b>Total</b>	<b>296<sup>1</sup></b>	<b>100.0</b>	<b>297<sup>2</sup></b>	<b>100.0</b>

Missing data: <sup>1</sup>  $n=11$ ; <sup>2</sup>  $n=10$

## Decision making about participants' health

Most people in the cohort made decisions about their health, jointly with their key doctor (Table 7). At *Time 2*, few people relied solely on their key doctor to make health decisions for them, a finding that is consistent with other studies such as Anderson, et al. (2000) which reported that most PLWHA have some level of involvement in these types of decisions. As these questions were asked differently at *Time 1* and *Time 2*, statistical comparisons across time could not be made.

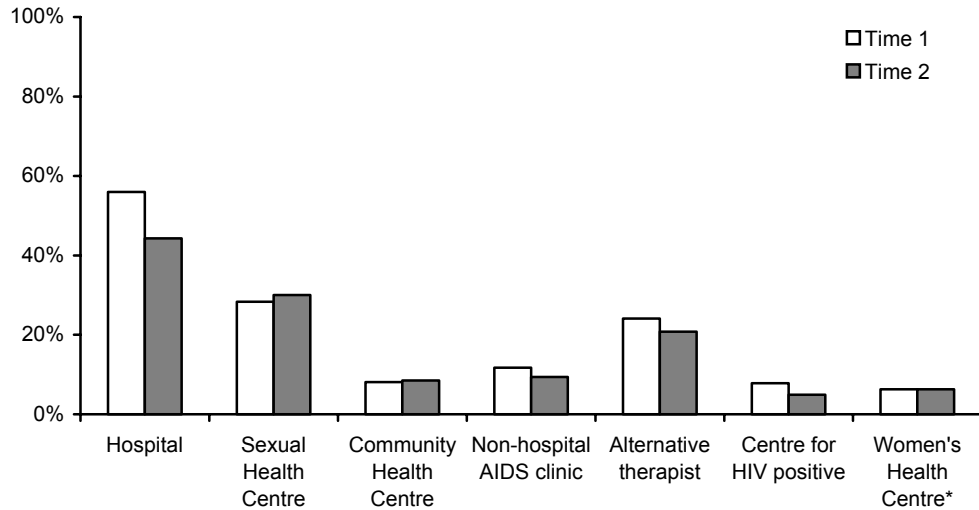
**Table 7: How decisions about participants health are made**

	Frequency	Percentage (%)
My doctor gives me a range of options and I make the choice	51	16.7
I decide and tell my doctor what I want	24	7.9
My doctor and I discuss options and we decide jointly	207	67.9
My doctor decides about treatments for me	18	5.9
I do not consult a doctor about treatments	5	1.6
<b>Total</b>	<b>305<sup>1</sup></b>	<b>100.0</b>

<sup>1</sup> missing data:  $n=2$

## Use of health services

The services most commonly used by PLWHA in the management of their HIV infection included their own specialist doctor, hospitals, sexual health centres and, to a lesser degree, naturopaths and alternative therapists (Figure 8). For the most part, the extent to which people used health services did not change between *Time 1* and *Time 2*, except that significantly fewer people used hospitals in the period before *Time 2* than before *Time 1* (McNemar:  $n=307$ ,  $\chi^2=11.14$ ,  $p < .001$ ).



**Figure 8: Use of health services**

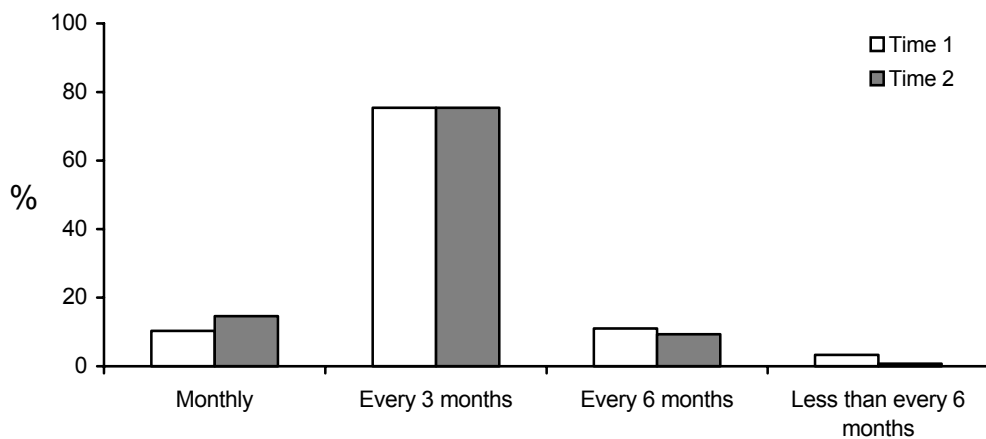
\* Includes women respondents only.

## BLOOD TESTING

Almost all participants reported having their CD4 (t-cell) count and viral load tested on a regular basis, most doing so every three months (Figures 9 & 10). A small proportion (1%) at *Time 2*, reported that they no longer undergo these tests.

### Frequency of CD4 testing, across time

In the period between *Time 1* and *Time 2*, there was a significant increase in the frequency of having CD4 tests (Wilcoxon:  $n=295$ ,  $z=-2.84$ ,  $p=.005$ ) (Figure 9). Slightly more PLWHA were having a CD4 test every month, while fewer people were being tested every six months or less.



**Figure 9: Frequency of CD4 testing**

## Frequency of viral load testing, across time

As with monitoring of CD4 count, most respondents assessed their viral load every 3 months. Overall, there was a significant change, such that participants at *Time 2* had their viral load tested more frequently than at *Time 1* (Wilcoxon:  $n=296$ ;  $z=-2.59$ ,  $p=.01$ ) (Figure 10). When these results are considered alongside participants making fewer visits to their doctor, it suggests that visits to the doctor at *Time 2* were more focussed on CD4 and viral load testing than had been the case at *Time 1*.

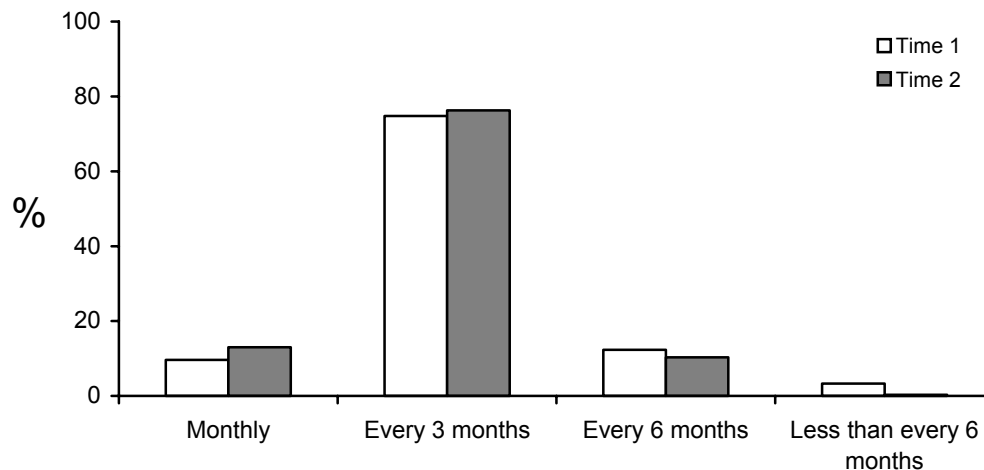


Figure 10: Frequency of viral load testing

## Testing for hepatitis A, B and C

There were similarities among participants pertaining to self-reported testing for hepatitis A, B and C (Figure 11). About 80% of participants had ever been tested for one or more of hepatitis A, B, or C. About one-third of the cohort was tested for hepatitis A, B, or C in the 12 months prior to *Time 1* or *Time 2*. Although not clearly evident from Figure 11, about half the cohort was tested for at least one of the three hepatitis types in the 12 months prior to at least one of the two data collection periods. For each of the three types of hepatitis reported here, there were no significant changes from *Time 1* to *Time 2* in the number of people who reported being tested in the preceding 12 months.

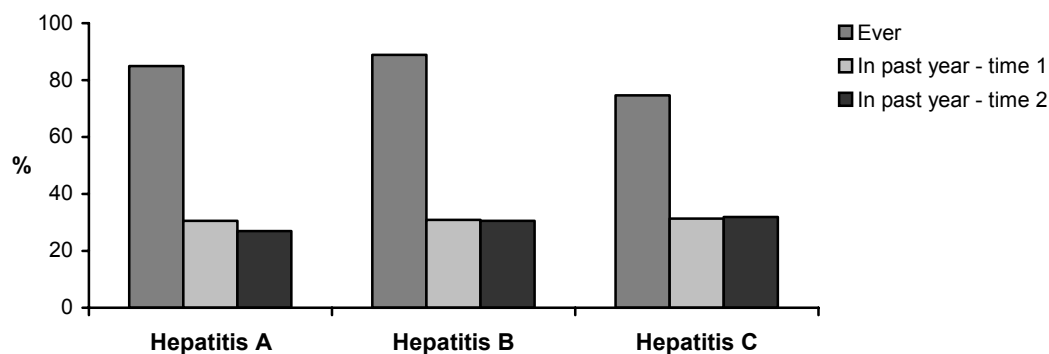


Figure 11: Testing for hepatitis A, B and C in the 12 months prior to *Time 1* and *Time 2*

Note: categories are not mutually exclusive

## Vaccination for hepatitis A and B

Almost half (45.3%) of the cohort stated that they were vaccinated against hepatitis A, and the figure was slightly higher (52.1%) for those ever vaccinated against hepatitis B (Figure 12). Relatively few people—in the vicinity of 10%—stated they were vaccinated for hepatitis A or B, respectively, in the 12 months prior to *Time 1* or *Time 2*. It is likely that the number of people in the cohort who will be seeking a vaccination for hepatitis A or B will decrease over the longer term as the cumulative number of people already vaccinated increases.

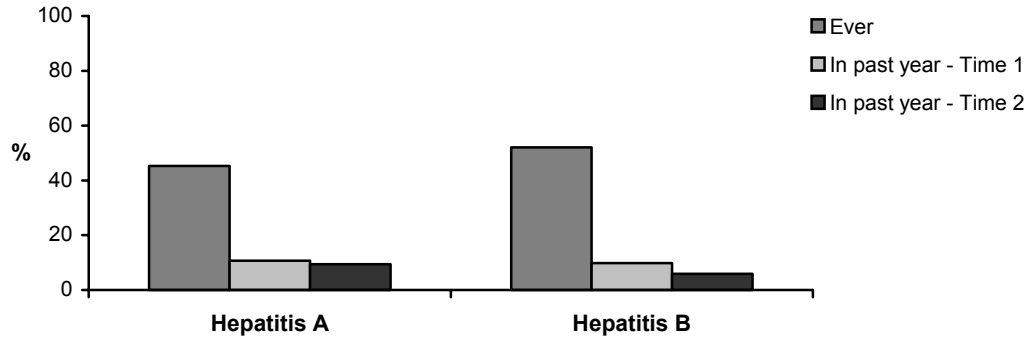


Figure 12: Percentage vaccinated against hepatitis A and B

## GENERAL HEALTH

In this section, the focus is on self-reported health. Participants rated their own health and provided information about their quality of life. At times these indices may seem at odds with their clinical markers of health.

Self-rated health at both *Time 1* and *Time 2* was 'good' or 'excellent' for the majority of PLWHA (see Figure 13). Few respondents rated their health as 'poor'. Overall, ratings of health increased significantly from *Time 1* to *Time 2* (Wilcoxon:  $n=306$ ;  $z=-4.51$ ,  $p < .001$ ). A greater number of respondents rated their health as 'excellent' at *Time 2* than at *Time 1*.

These figures are comparable to other HIV-positive populations, both in Australia, where 64% of respondents rate their health as 'good' or 'excellent' (Grierson et al., 2002), and also the United Kingdom, where one study found that almost 40% of HIV-positive gay men rated their health as 'good' or 'excellent' (White, 2003).

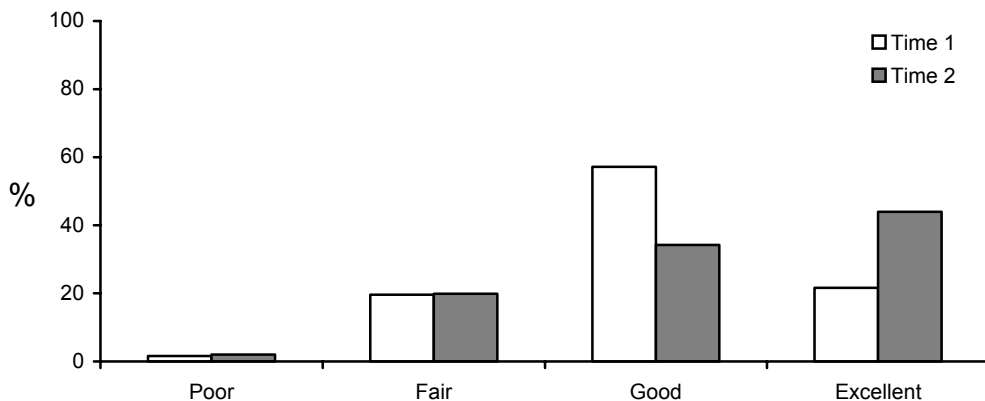
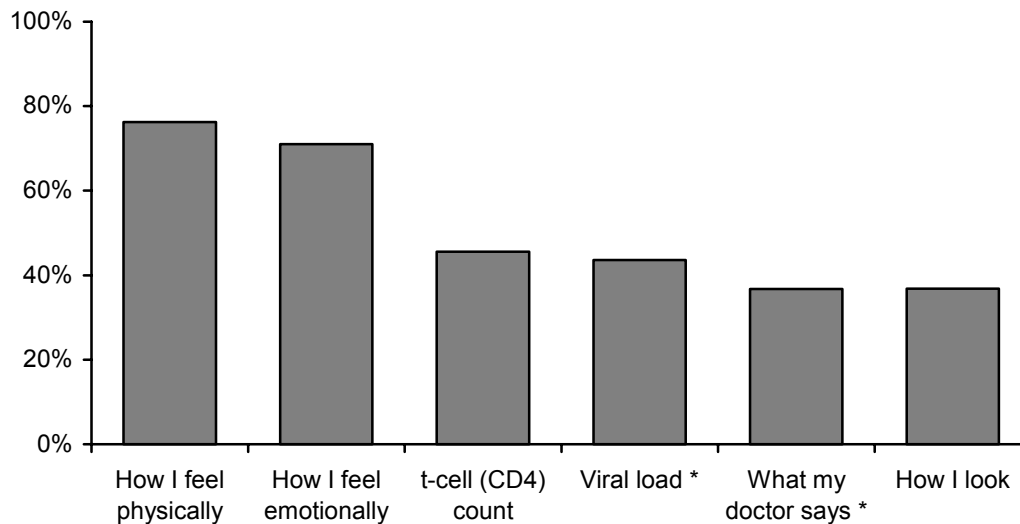


Figure 13: Self-rated health

## Factors important in self-rated health

Participants at *Time 2* were asked which factors, from a list of possible responses, were ‘very important’ in rating their own health. Physical and emotional feelings ranked as the two most important factors in rating ones own health (Figure 14). Clinical markers of health—CD4 count and viral load—were also seen as very important for rating their health by almost half the cohort.



**Figure 14: Factors considered ‘very important’ to self-rated health**

\* missing: n=2

## Indicators of general health and quality of life (QOL)

Respondents were also asked to rate quality of life (QOL) and indicate appetite, sleeping patterns, overall level of energy, concentration, libido and mood, in the 12 months preceding the interview. Based on a response scale ranging from 1 (excellent) to 4 (poor), Figure 15 shows that the average score across the cohort for each of these QOL indicators at *Time 1* and *Time 2* was around the midpoint.

Appetite and mood received the highest mean ratings, with a large proportion of respondents rating their appetite as either ‘excellent’ or ‘good’. About half of the participants rated their concentration as ‘good’ or ‘excellent’, while less than half of respondents indicated the same about their libido, stamina and sleeping patterns. Participants experiencing trouble with a particular aspect of their general health were most likely to indicate libido or sleep patterns as having been ‘poor’ during the previous 12 months.

This picture is both similar to, but also at odds with, other HIV-positive populations. For example, in a UK study (Weatherburn et al., 2002), a large proportion of respondents reported problems with their appetite or ability to eat, unlike this cohort. On the other hand, PLWHA in both studies indicated sleep and libido, or sex, as difficult areas.

Responses to questions about appetite, sleep, stamina, concentration, libido and mood were also examined to determine whether significant changes had taken place between *Time 1* and *Time 2*. With the exception of mood—for which there was a significant worsening of self-rated mood in the cohort from *Time 1* to *Time 2* (Wilcoxon: n=305, Z=-2.93, p=.003)—there were no other significant changes in ratings of these health indicators (Figure 15).

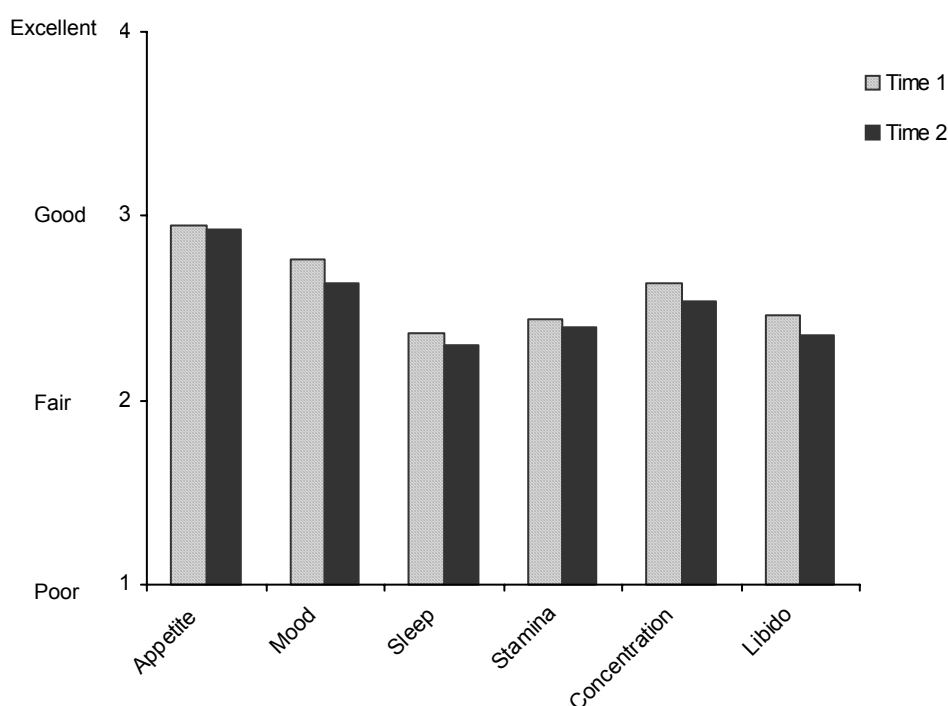


Figure 15: Ratings of aspects of general health

## CLINICAL MARKERS OF HEALTH

### CD4 (t-cell) count

Almost half the cohort had a CD4 count of 500 at the time of their most recent test before *Time 2* (Table 8). Relatively few PLWHA had a CD4 count of less than 100. For the cohort as a whole, there was no significant change in the average CD4 count from *Time 1* to *Time 2*.

Despite the average CD4 count for the cohort remaining stable from *Time 1* to *Time 2*, the majority of participants (56.4%) reported a fluctuating CD4 count in the 12 months prior to *Time 2*. Overall, 15% of respondents indicated that their CD4 count was falling at the time of their interview at *Time 2*; while slightly more respondents (27.1%) indicated their CD4 count had been rising. Almost two-thirds of the cohort reported a CD4 count below 500 at some stage in the preceding 12 months.

Table 8: Most recent CD4 (t-cell) test results

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Less than 100	19	6.2	20	6.5
101 to 200	28	9.1	23	7.5
201 to 350	63	20.5	52	17.0
351 to 500	59	19.2	67	21.9
501 to 750	70	22.8	56	18.3
Over 750	53	17.3	66	21.6
Unsure	15	4.9	22	7.2
<b>Total</b>	<b>307</b>	<b>100.0</b>	<b>306<sup>1</sup></b>	<b>100.0</b>

<sup>1</sup> missing data: n=1

## Viral load

Almost half the cohort reported an undetectable viral load from their most recent viral load test at *Time 2* (see Table 9). Although it may appear from Table 9 that the average viral load has risen across the cohort from *Time 1* to *Time 2*, there is no statistical support for this suggestion.

Almost half (47%) the cohort reported a fluctuating viral load in the preceding 12 months. For example, there are 50 people who reported a detectable viral load but who at some point during the 12 months had an undetectable viral load. Overall, 61% of the participants reported having an undetectable viral load at some time in the preceding 12 months.

**Table 9: Most recent viral load test results**

	<i>Time 1</i>		<i>Time 2</i>	
	N	%	n	%
Undetectable	160	54.1	151	49.2
Low (less than 10 000)	54	18.2	43	14.0
Moderate (10 000 – 50 000)	39	13.2	36	11.7
High (over 50 000)	41	13.9	51	16.6
Unsure/other	2	0.7	26	8.5
<b>Total</b>	<b>296<sup>1</sup></b>	<b>100.0</b>	<b>307</b>	<b>100.0</b>

<sup>1</sup> missing data: n=11

## Relationship between CD4 count and viral load

Over one-quarter (27.6%) of respondents reported having both an undetectable viral load and a CD4 count above 500 from their most recent tests (see Table 10)<sup>10</sup>.

**Table 10: Relationship between most recent CD4 count and viral load results**

Viral load	CD4 count		
	500 +	200–500	<200
Undetectable (<500)	27.6%	21.6%	5.2%
Low (500 – 10,000)	6.0%	8.2%	1.1%
Moderate (10,000 – 50,000)	4.1%	5.6%	2.2%
High (over 50,000)	6.0%	6.3%	6.0%

Note: Includes only those people who provided information about their CD4 count and viral load result (n=268).

<sup>10</sup> The complex relationships between immune response (as indicated by CD4 count), indices of health, the use of HAART, experience of health, treatments, side effects of medication, and the use of health services will be addressed in future issues papers.

## HIV-RELATED SYMPTOMS AND ILLNESS

### Experience of symptoms

Respondents were asked at *Time 2*, whether they had experienced any of a range of symptoms in the previous 12 months (Figure 16). For each symptom, responses ranged from 1 (never) to 4 (often). Participants were also asked whether they would attribute the experience of a given symptom to the medication used to manage their HIV infection or to HIV itself (Figure 17).

Most participants had experienced at least one of the symptoms listed in Figure 17 in the previous 12 months. The cluster of symptoms most commonly experienced was gastrointestinal in nature (e.g. diarrhoea, vomiting, nausea). One or more of the symptoms in this cluster was experienced by 69.1% of the cohort. The next most common group of symptoms was respiratory-related problems (e.g. coughing, wheezing), experienced by 56.4% of respondents. This pattern is similar to reported trends in another study, where more than half of participants report experiencing diarrhoea or nausea (Mathews et al., 2000).

Feelings of anxiety, depression, or fear were experienced by 55.7% of PLWHA in the previous 12 months. This figure is comparable to HIV-positive populations in the United Kingdom, where one study found 54% of respondents experienced feelings of anxiousness 'now and then' (White, 2003), and another found that 67% of all respondents experienced difficulties with anxiety and depression in the previous 12 months and 45% had ongoing difficulties (Weatherburn et al., 2002).

Owing to changes in the way questions about symptoms were asked between *Time 1* and *Time 2*, it is not possible at this stage to examine changes in the experience of symptoms over time. However, such changes will be examined when *Time 3* data are analysed.

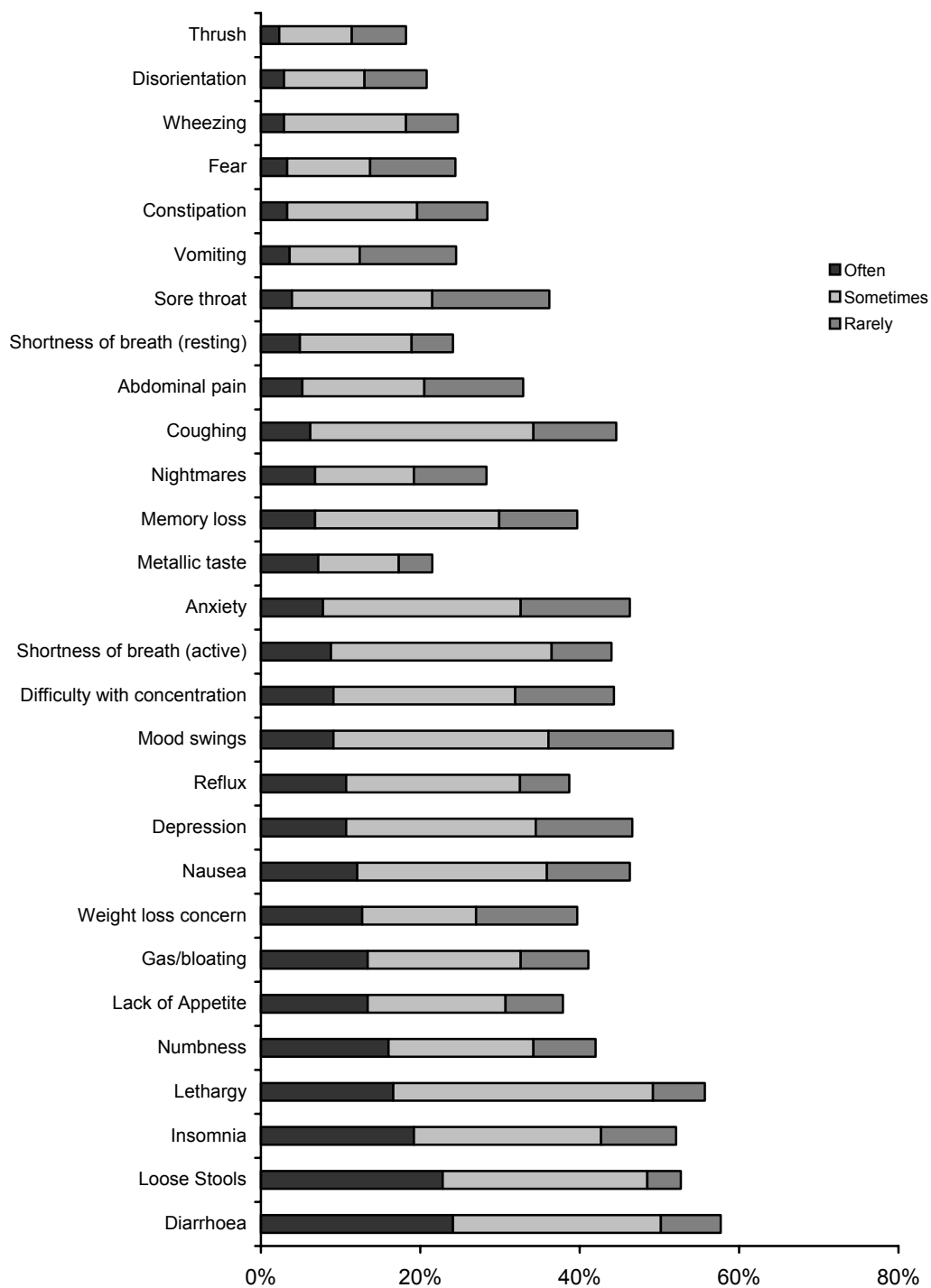


Figure 16: Experience of symptoms in previous 12 months

## Perceived association between symptoms and HIV treatments

The percentage of participants who reported that their experience of symptoms in the previous 12 months were related to taking their HIV treatments is presented in Figure 17. The symptoms most likely to be attributed to taking medication included diarrhoea, bloating, lethargy and nausea. For some of the symptoms, there was a fair degree of uncertainty about whether the cause was directly related to HIV treatments.

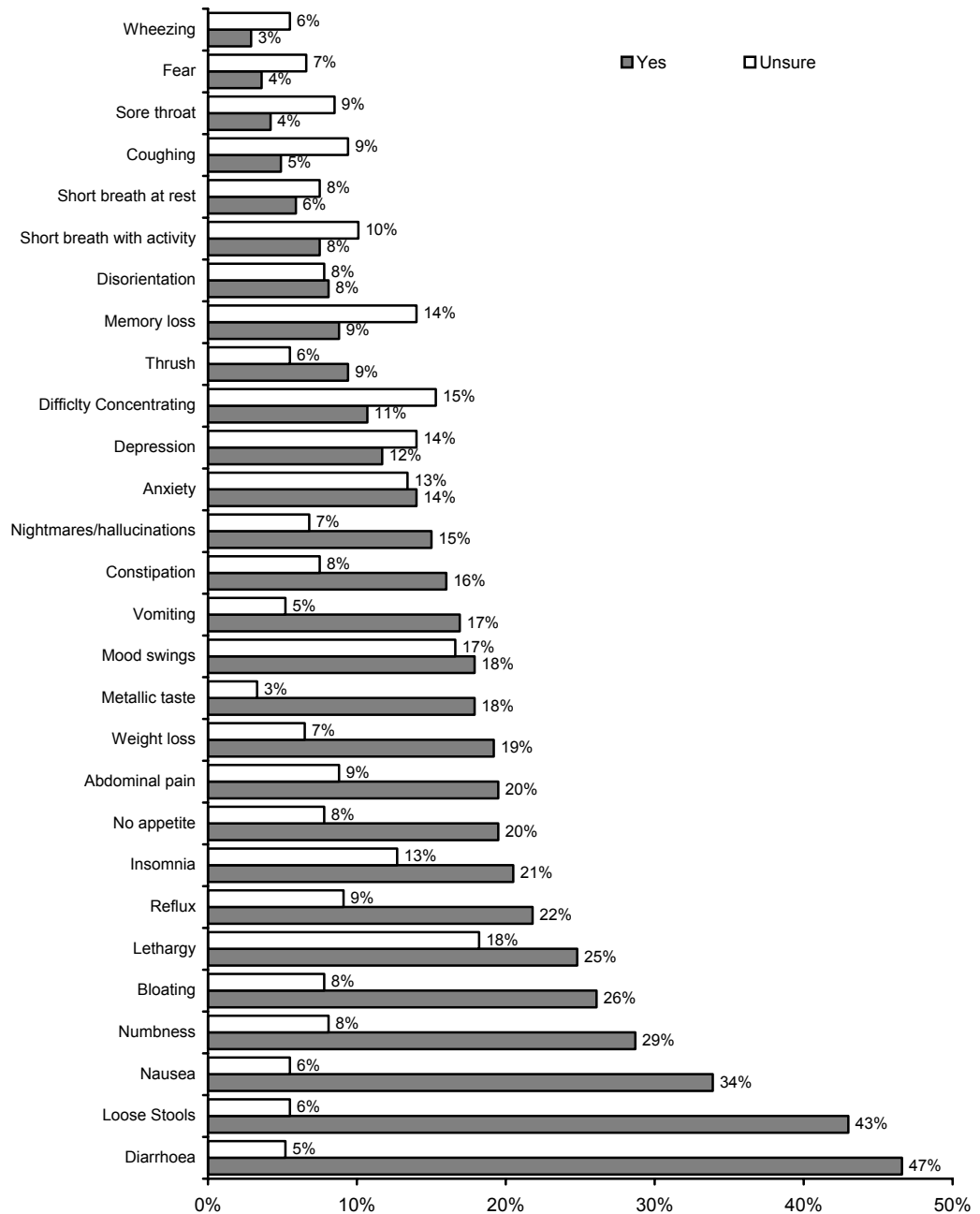
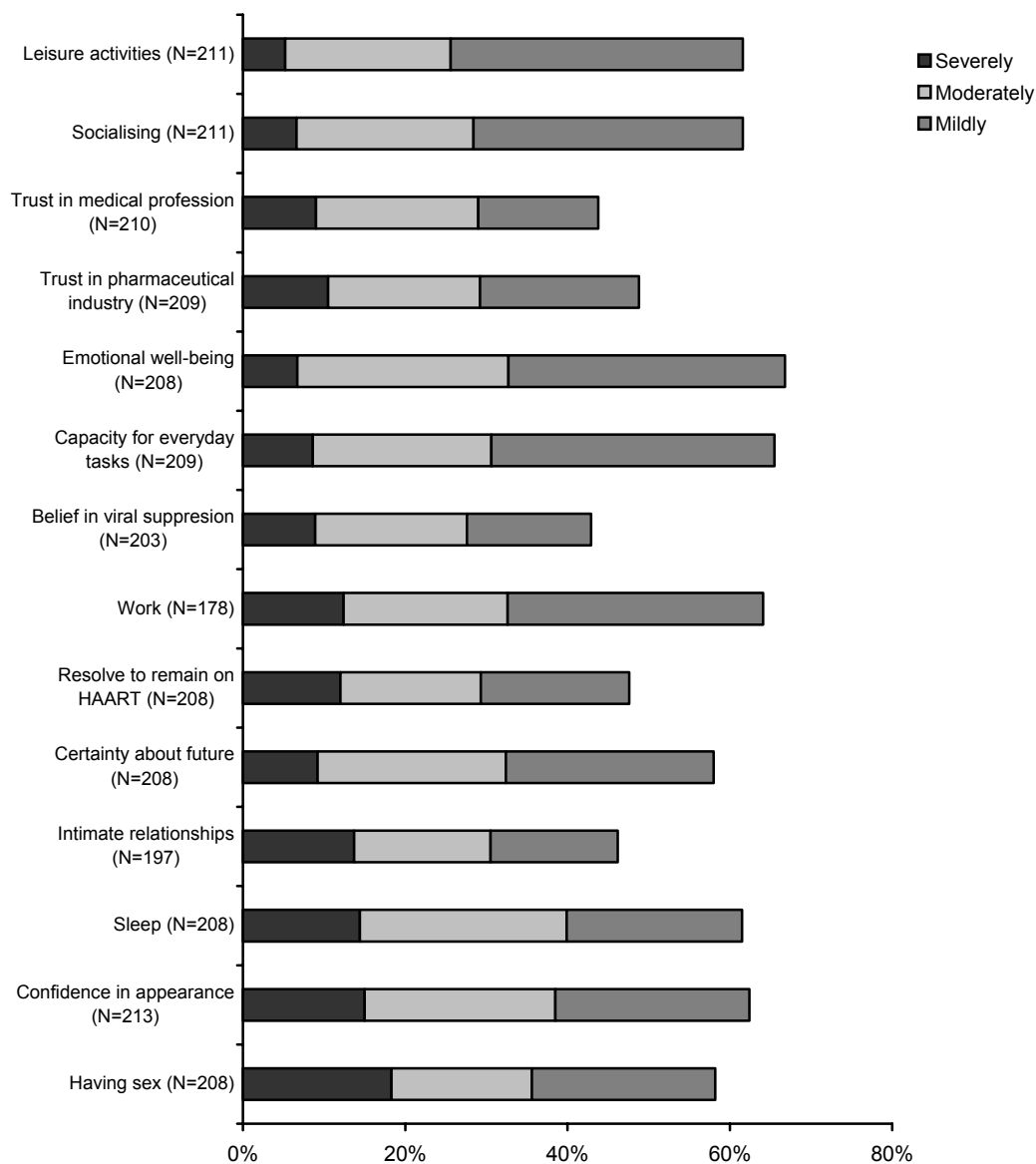


Figure 17: Perceived link between medication and experience of symptoms

## Perceived impact of HIV treatment side effects on aspects of quality of life

Among those people who had taken ARV drugs in the previous 12 months and who had experienced at least one of the symptoms in Figure 17, up to 18% perceived that HIV treatment side effects had ‘severely’ impacted on aspects of their life including sex, sleep, confidence in appearance, intimate relationships, and work (Figure 18). Many more people indicated that HIV treatment side effects had ‘moderately’ or ‘mildly’ affected these aspects of QOL.

Due to differences in the way questions were asked between *Time 1* and *Time 2*, comparing answers across time was not possible. When *Time 3* data are analysed, such comparisons will be made from *Time 1* to *Time 3*.



**Figure 18: Impact of side effects on aspects of quality of life**

Note: Each column includes only those respondents who answered the question and who did NOT endorse the response option of “I have not suffered any side effects”

## Lipodystrophy

Table 11 shows the proportion of people who experienced sunken cheeks, increased abdominal girth and prominent veins on arms and legs in the 12 months prior to data collection at *Time 1* and *Time 2*. Most of the cohort (66.8%) at *Time 2* had experienced at least one of the three symptoms listed in Table 15 in the preceding 12 months. Of these people, (n=205), 20% reported that the change in their appearance was 'severe'.

There were no significant differences in the proportion of people that reported experiencing sunken cheeks or increased abdominal girth from *Time 1* to *Time 2*. There was, however, an increase from *Time 1* to *Time 2* in the number of people who reported increased prominence of veins on their arms and legs (McNemar: n=307,  $\chi^2=6.47$ , p=.01).

**Table 11: Lipodystrophy symptoms**

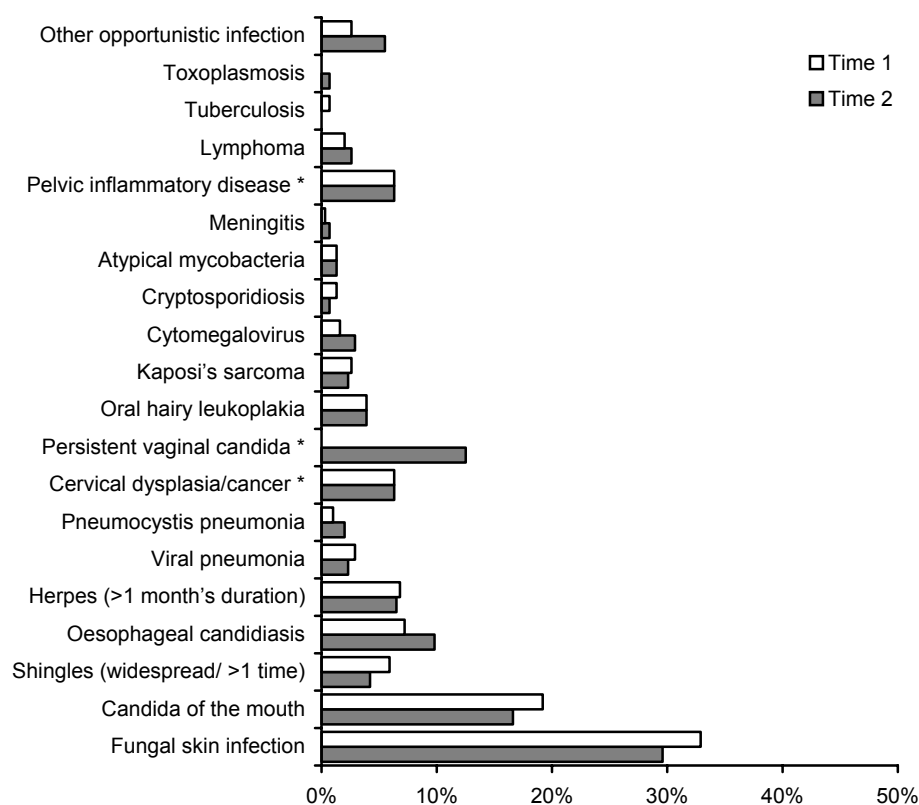
	Sunken Cheeks				Prominent Veins				Increased Abdominal Girth			
	Time 1		Time 2		Time 1		Time 2		Time 1		Time 2	
	n	%	n	%	n	%	n	%	n	%	n	%
Yes, severe	31	10.2	18	5.9	24	7.9	24	7.9	22	7.2	19	6.2
Yes, moderate	23	7.5	27	8.8	35	11.5	46	15.1	27	8.9	42	13.7
Yes, mild	75	24.5	75	24.5	50	16.4	64	21.0	73	24.0	74	24.2
No change / No response	202	66.2	186	60.8	196	64.3	171	56.1	182	59.9	171	55.9
<b>Total</b>	<b>305<sup>2</sup></b>	<b>100</b>	<b>306<sup>1</sup></b>	<b>100</b>	<b>305<sup>2</sup></b>	<b>100</b>	<b>305<sup>2</sup></b>	<b>100</b>	<b>304<sup>3</sup></b>	<b>100</b>	<b>306<sup>1</sup></b>	<b>100</b>

Note: <sup>1</sup> missing data=1, <sup>2</sup> missing data=2, <sup>3</sup> missing data=3

## Opportunistic illnesses

The proportion of people who experienced an opportunistic infection or illness in the 12 months prior to *Time 1* and *Time 2* is shown in Figure 19. The most commonly reported illnesses or infections at *Time 2* were fungal skin infections (29.6%) and candida, or thrush, of the mouth (16.6%). Of those people who experienced an opportunistic infection (n=160), 48.8% had experienced only one illness, 23.8% had experienced two and 12.5% had experienced three illnesses or infections. Around 11.4% of all respondents reported that they had been hospitalised as a result of suffering these infections or illnesses in the previous 12 months. There were no significant differences from *Time 1* to *Time 2* regarding admission to hospital as a result of opportunistic illness or infection.

There were no significant differences in the incidence of individual illnesses from *Time 1* to *Time 2*, nor were there any significant differences in the total number of illnesses, or infections, that the cohort reported experiencing in the preceding year.



**Figure 19: Experience of opportunistic infections and illnesses**

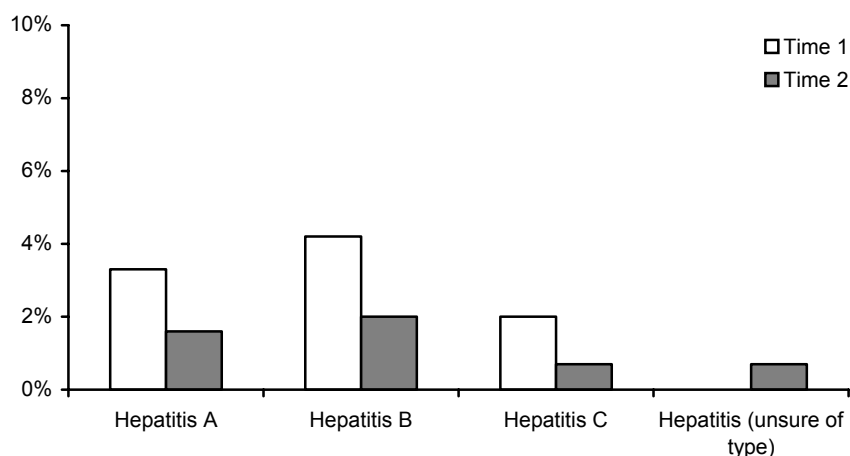
\* Includes only female respondents. There were no cases of persistent vaginal candida during *Time 1*

## OTHER ILLNESSES

### Hepatitis A, B and C

Few people reported a positive diagnosis for hepatitis A, B, or C in the 12 months prior to *Time 1* or *Time 2* (see Figure 20). Altogether, 18% of the cohort had ever had a positive diagnosis for hepatitis C. Comparative analyses were not conducted on changes between *Time 1* and *Time 2* as the results would be rather meaningless. For instance, the percentages are extremely small and are likely to decrease over time, particularly for hepatitis C, as relatively few people clear the hepatitis C virus (Australian Institute for Primary Care, 2001).

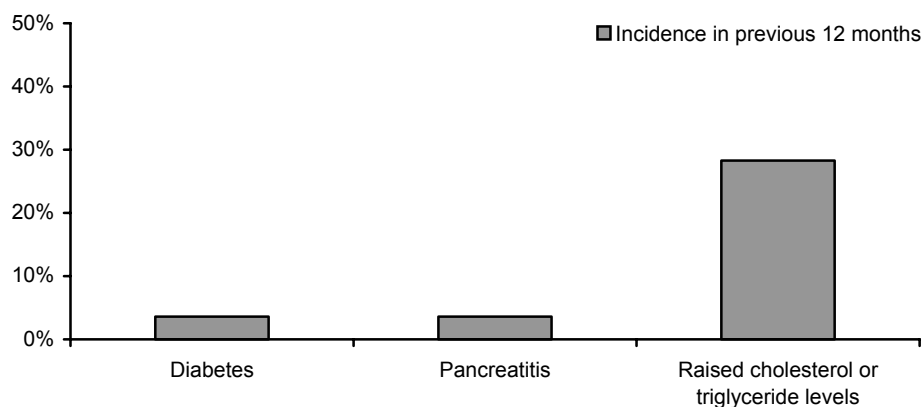
The issue of coinfection with hepatitis, while not addressed in this report, certainly bears further consideration. There is sufficient evidence that coinfection with hepatitis B (HBV) or C (HCV) hastens HBV-related and HCV-related liver disease, respectively (Dore and Sasadeusz, 2003). As well, the likelihood of developing severe ARV therapy related hepatotoxicity is significantly greater in PLWHA who are co-infected with HBV or HCV.



**Figure 20: Diagnosis of Hepatitis A, B and C in the previous 12 months**

### Diabetes, pancreatitis, and cholesterol/triglycerides

Figure 21 illustrates the proportion of PLWHA who were diagnosed with diabetes, pancreatitis or raised cholesterol/triglyceride levels in the preceding 12 months. Few people reported diabetes or pancreatitis, while nearly one in three indicated higher levels of cholesterol and triglycerides. As this question was introduced during *Time 2* interviews, it was not possible to assess changes over time.

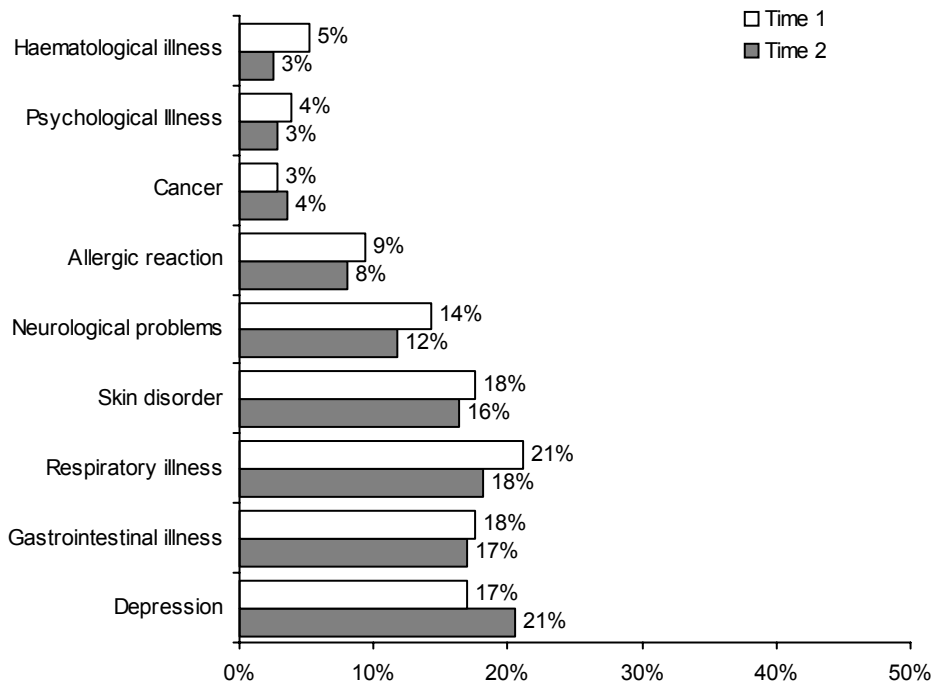


**Figure 21: Other illnesses in previous 12 months**

### Other illnesses not necessarily related to HIV

Participants were asked whether they had experienced any of a variety of illnesses—not necessarily related to their HIV infection—in the 12 months preceding their interview (Figure 22). Skin disorders, respiratory illnesses, gastrointestinal illness and depression were experienced by about 15% to 20% of participants prior to the *Time 1* and *Time 2* interviews. At *Time 2*, around one in five people in the cohort reported a clinical diagnosis of depression. Of these people (n=63), 57.1% were using a prescribed treatment such as Prozac to control their depression.

The number of PLWHA who experienced any of the illnesses listed in Figure 22 did not change significantly between *Time 1* and *Time 2*.



**Figure 22: Other illnesses not necessarily related to HIV**

# ACCESS TO TREATMENT SERVICES

Access to treatment services is essential for the good health of people living with HIV. In this relatively short section, we report on the types of services that participants require and whether they have experienced barriers to accessing those services. Where possible we have compared data from *Time 1* and *Time 2*.

## ACCESS TO SERVICES

Due to changes in the way questions about service access were asked at *Time 2* in contrast with *Time 1*, comparisons across time could not be made. As such, only *Time 2* data are reported here (Table 12).

At *Time 2*, around one-quarter of the cohort was experiencing difficulty in accessing at least one of the services listed in Table 12. Accessing a hospital pharmacy was cited as the most problematic, followed by difficulty accessing psychological counsellors, supportive people or groups, and doctors with HIV experience.

**Table 12: Difficulty accessing services**

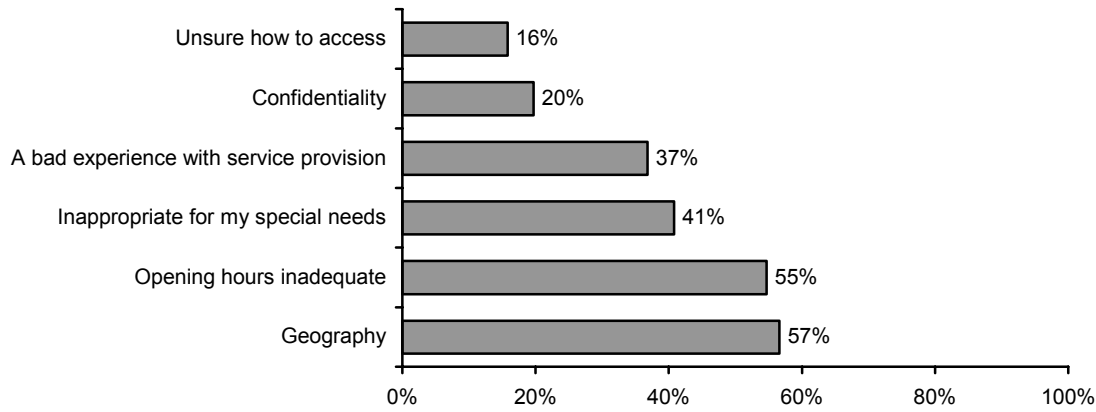
	Frequency	Percentage (%)
Access to hospital pharmacy (N=273)	43	15.8
Access to psychological counsellors (N=207)	28	13.5
Access to doctors with HIV experience (N=303)	33	10.9
Access to supportive people/groups (N=236)	26	11.0
Access to ARV prescribers (N=279)	21	7.5
Access to community pharmacy (N=239)	16	6.7

Note: Proportions are based only on those people who answered the question and reported that they wanted to use the service.

Items are not mutually exclusive.

## Reasons for access difficulties

Of those people who experienced problems in accessing services in the 12 months prior to *Time 2* (n=76), more than half indicated that geography or distance to services was a contributing factor to access difficulties (Figure 23). A large proportion found hours of business inadequate or inappropriate; others indicated the service was inappropriate for their special needs; and some reported that a prior bad experience when accessing a service made it difficult to access that service again. Of less concern, but still contributing to problems in accessing services, were issues regarding confidentiality, as well as levels of uncertainty about how to access and use particular services.

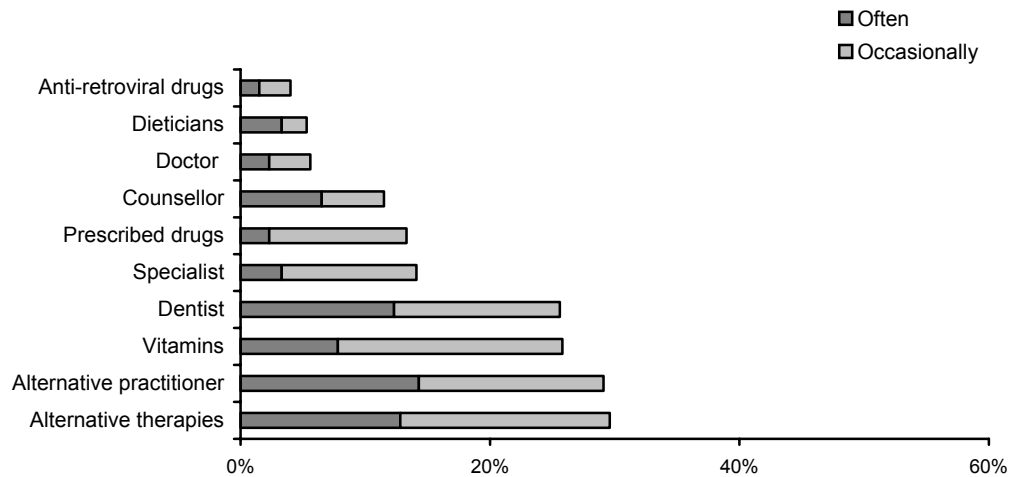


**Figure 23: Factors contributing to services access difficulties at Time 2**

Note: Proportions based only on those who had reported at least 1 instance of access difficulty (n=76)

## Services prevented from accessing due to cost

Figure 24 illustrates the proportion of people in the cohort who were prevented from accessing services and therapies due to the cost. Cost was an important factor in accessing both alternative therapies and alternative health practitioners, with around 15% reporting that cost 'often' prevented them from accessing these services. Relatively few people (4%) reported difficulties obtaining ARV drugs due to cost.



**Figure 24: Financial barriers to treatment services and therapies**

## Financial assistance other than from Medicare or private health insurance

At *Time 2*, about one-quarter of the cohort was receiving some financial assistance, from sources other than Medicare or private health insurance, to assist with accessing services (Table 13). Around one in five people reported financial assistance in the form of a Health Care Card when accessing medical services; almost 11% report the same for dental care. Very few people reported using their Health Care Card for financial assistance with alternative therapies or practitioners (0.3%), where assistance from an alternative source (3.3%) or an AIDS council (1.6%) was more common.

From *Time 1* to *Time 2*, there had been a significant decrease in the amount of financial assistance, other than Medicare or private health insurance, received for both medical costs (McNemar:  $n=307$ ,  $\chi^2=23.11$ ,  $p < .001$ ) and dental costs (McNemar:  $n=307$ ,  $\chi^2=4.40$ ,  $p=.036$ ); while assistance for alternative therapies and psychological counselling changed little in the same period.

**Table 13: Financial assistance received from other than Medicare or private health insurance**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Medical costs	124	40.4	71	23.1
Dental costs	73	23.8	53	17.3
Alternative/complementary health costs	24	7.8	16	5.2
Psychological counsellors	29	9.4	16	5.2

Note: Categories are not mutually exclusive

## Private health insurance

About one-third of participants (33.2%) had private health insurance at *Time 2*. This followed a significant increase in the number of people who had private health insurance from *Time 1* to *Time 2* (McNemar:  $n=306$ ,  $\chi^2=29.76$ ,  $p < .001$ ): 13.7% took up private health insurance in the period between the *Time 1* and *Time 2* interviews, while only 1.3% let their private health insurance lapse in that same period. This change in the number of people privately health insured is likely to have been influenced, at least in part, by Federal Government policy. In the late 1990s, the Federal Government of Australia introduced policy and legislation that provided a tax incentive for people, particularly those on at least relatively high incomes, to take out private health insurance. There was a corresponding disincentive to stay with the public health system.

# ANTIRETROVIRAL TREATMENT

The emergence and availability of HAART in Australia post-1996 led to a dramatic change in the HIV landscape; HAART has been directly associated with reductions in mortality and morbidity and, less directly, influenced the individual and social psyches of those in contact with HIV, changing the prognosis of an HIV infection from an almost certain early death to that of living with a chronic illness.

The continuing influence of ARV drugs on the experience of HIV is characterised by constant flux. In recent years, the early mantra of ‘hit early, hit hard’ has been revised in the wake of drug resistances and the experience of side effects. For many with HIV, the commencement of treatment is being delayed until clinical markers suggest its necessity. In addition, the widespread experience of often debilitating side effects has led many people to take breaks from treatment or to cease treatment altogether. Treatment breaks that are endorsed by doctors have also become more commonplace. In the meantime, studies are being conducted in a quest to determine the efficacy of structured treatment breaks on the immune response.

In this section, we report on ARV treatment practices in the cohort and how such practices have changed, if at all, in the two years between *Time 1* and *Time 2*.

## CURRENT USE OF ARV TREATMENT

At *Time 2*, almost three-quarters of the cohort were taking at least one ARV drug, and about two-thirds reported a HAART regimen of at least three drugs (Table 14). A little over 10% of respondents had never taken any ARV drugs, while 16.3% indicated that they had taken antiretroviral drugs in the past, but did not currently do so. These figures are similar to the United Kingdom, where a relatively small proportion of PLWHA have never taken treatments, or have ceased taking them (Weatherburn et al., 2002).

Between *Time 1* and *2*, there was a significant decrease in the number of ARV drugs respondents reported taking ( $t=3.73$ ,  $p < .001$ ), especially in the proportion of respondents who reported taking four or more drugs. Furthermore, fewer people were taking ARV drugs at *Time 2* than at *Time 1* (McNemar:  $n=306$ ,  $\chi^2=15.37$ ,  $p < .001$ ).

**Table 14: Number of ARV drugs in current combination**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
None	53	17.3	82	26.7
One	11	3.6	1	0.3
Two	18	5.9	16	5.2
Three	124	40.5	130	42.3
Four or more	100	32.7	78	25.4
<b>Total</b>	<b>306<sup>1</sup></b>	<b>100.0</b>	<b>307</b>	<b>100.0</b>

<sup>1</sup> missing data: n=1

## Treatment modifications

Nearly half (42.2%) of participants taking ARV at *Time 2* (n=225) reported that they had changed their treatment regimen in the 12 months prior to the interview at *Time 2* (Table 15). Among those who had modified their treatment, the most common modifications were changes to drug combinations and to the number of drugs used. As these questions were introduced at *Time 2*, it was not possible to examine changes across time.

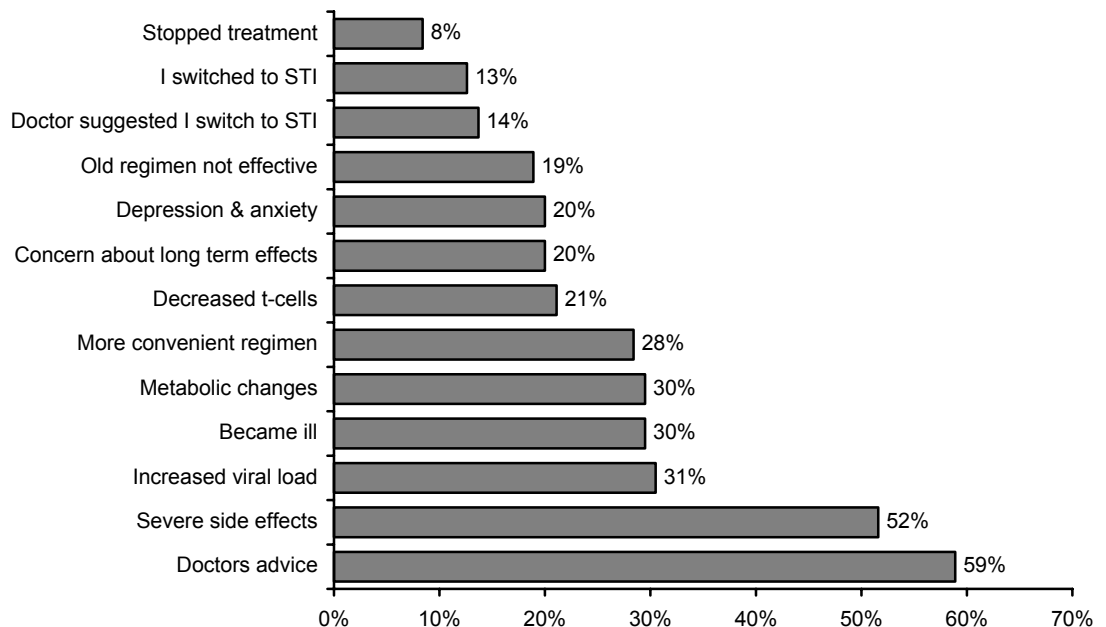
**Table 15: Treatment modifications**

	Frequency	Percentage (%)
Changed drug combination	79	83.2
Reduced or increased the number of drugs used	48	50.5
Started taking again after stopping for a while	23	24.2
Changed to Structured Treatment Interruption	18	18.9
Other modifications	4	4.2

Note: Proportions based only on those who had changed their treatment practice (n=95)

## Reasons for drug combination change

Those in the cohort who indicated they had modified their drug combinations were asked the reasons for this change. Of the 95 participants who had changed their ARV combination in the 12 months prior to the *Time 2* interview, just over half did so at their doctor's suggestion. A similar proportion changed their ARV combination because of the severity of side effects from treatment (Figure 25). The decision was also affected by clinical markers—such as an increased viral load, or decreased CD4 count—or practical concerns, such as the convenience of the regime itself, and its efficacy. It is worth noting that around 12–14% of people switched to a structured treatment interruption scheme in the 12 months prior to the interview, either of their own volition or on their doctor's recommendation. As for above, these questions were introduced at *Time 2*, so it was not possible to examine changes across time.



**Figure 25: Reasons for most recent modification to drug treatment regimen**

Note: proportions based only on those who have modified their treatment regimen (n=95)

## Types of ARV drugs used by the cohort

The proportions of participants using particular types of ARV drugs at *Time 1* and *Time 2* interviews are shown in Table 16. At *Time 2*, the drugs used most commonly by participants included 3TC (EpiVir), d4t (Zerit), and nevirapine. The drugs used by the least number of participants included loviride and adefovir, each used by only three people and delavirdine, used by seven people in the sample.

Between *Time 1* and *Time 2*, certain types of ARV drugs became more widely used while the use of other drugs declined (Table 16). There has been a decrease from *Time 1* to *Time 2* in the use of ddI (McNemar:  $p=.038$ ), 3TC (McNemar:  $p < .001$ ), d4T (McNemar:  $p < .001$ ), saquinavir ( $p < .001$ ), nelfinavir (McNemar:  $p < .001$ ) and adefovir (McNemar:  $p=.023$ ). On the other hand, use of abacavir has significantly increased for the sample overall (McNemar:  $p < .001$ ), as has the use of 'other' antiretrovirals (McNemar:  $p=.034$ ).

**Table 16: ARVs in current use in the 12 months preceding *Time 1* and *Time 2***

	<i>Time 1</i>		<i>Time 2</i>		SIG
	n	%	n	%	
<b><i>Nucleoside Reverse Transcriptase Inhibitors</i></b>					
AZT (zidovudine, Retrovir)	55	17.9	53	17.3	Ns
ddI (didanosine, Videx)	67	21.8	51	16.6	$p=.038$
ddC (zalcitabine, Hivid)	12	3.9	10	3.3	Ns
3TC (lamivudine, EpiVir)	204	66.4	149	48.7	$p < .001$
D4T (stavudine, Zerit)	160	52.1	114	37.1	$p < .001$
abacavir (Ziagen)	31	10.1	63	20.5	$p < .001$
<b><i>Non-nucleoside Reverse Transcriptase Inhibitors</i></b>					
nevirapine (Viramune)	80	26.1	83	27.0	ns
delavirdine (Rescriptor)	8	2.6	4	1.3	ns
DMP (efavirenz or STOCRIN)	27	8.8	40	13.0	ns
Loviride	2	0.7	-	-	-
<b><i>Protease Inhibitors</i></b>					
saquinavir (Invirase and Fortovase)	62	20.2	37	12.1	$p < .001$
ritonavir (Norvir)	34	11.1	46	15.0	ns
indinavir (Crixivan)	43	14	38	12.4	ns
nelfinavir (Viracept)	60	19.5	26	8.5	$p < .001$
<b><i>Nucleotide Reverse Transcriptase Inhibitors</i></b>					
Adefovir (Preveon)	12	3.9	3	1.0	$p=.022$
Other	23	7.5	39	12.7	$p=.034$

Note: Categories are not mutually exclusive

## Beliefs about interactions between ARV therapy and recreational drugs

At *Time 2*, there were 225 participants currently taking ARV therapy, among whom 169 indicated they had also used recreational drugs in the six months prior to the *Time 2* interview (Table 17). These 169 people were asked about their attitude and approach to interactions between their ARV medication and recreational drugs. Among these participants, about one-third was unconcerned about interactions and a further one-third was interested in having more information about interactions.

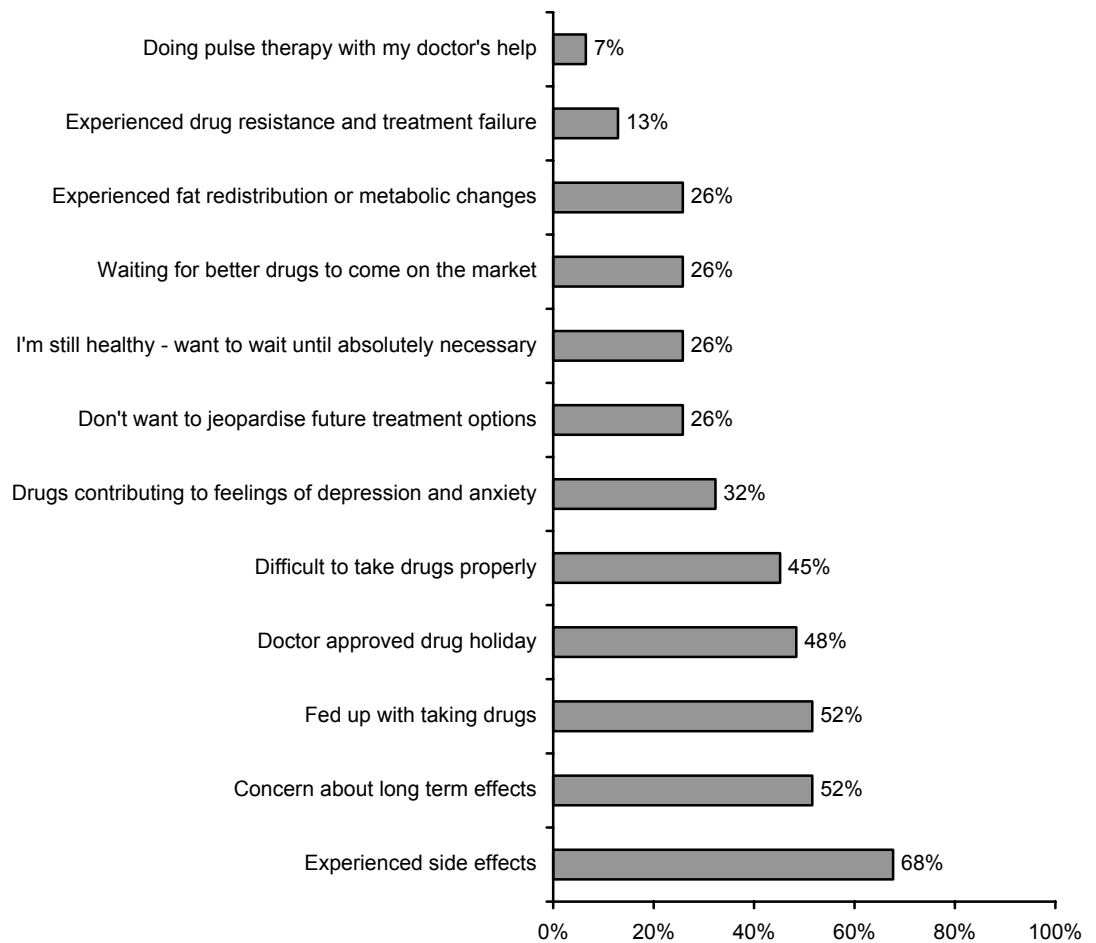
**Table 17: Attitude to interactions between recreational drugs and ARV therapy**

	Frequency	Percentage (%)
Unconcerned about interactions	63	37.3
Need information about interactions	55	32.5
I try to work my recreational drug use around my ARVs	33	19.5
I try to work my ARVs around my recreational drug use	47	27.8

Note: Items are not mutually exclusive. Includes only those who were on antiretroviral drugs 'currently' and had taken any recreational drugs in the previous six months.

## STOPPING ARV THERAPY

A number of participants (n=31) completely stopped taking ARV drugs in the 12 months prior to their interview at *Time 2*. These people were asked to indicate the reasons, from a given list, that contributed to their decision to stop taking ARV drugs (Figure 26). As with reasons for changing or modifying treatment, the most common reason for completely stopping ARV therapy was the experience of side effects, followed by concern regarding the long-term effects of taking the drugs, and being 'fed up' with the treatment regimen. Participants were also taking 'drug holidays', having difficulty taking the drugs, and experiencing emotional consequences like depression and anxiety.



**Figure 26: Reasons for completely stopping ARV therapy in previous 12 months**

Note: Proportions based only on those who completely stopped treatment in previous 12 months and answered the question (n=31).

# TREATMENT PRACTICES

Although adherence to ARV drug regimens has a direct bearing on the efficacy of treatment, greater efficacy may come at a cost: greater efficacy is often associated with higher toxicity. The tension that now exists between efficacy and toxicity is being played out in all sorts of ways—including treatment breaks, structured treatment interruptions, delays in commencing treatment, and in changed attitudes about treatment practices. In this section, we report on a range of treatment practices from the number of pills taken to reasons for missing doses. Where possible, we have compared data from *Time 1* and *Time 2*.

## PRESCRIBED PILLS

Participants were asked how many prescribed pills (including but not limited to ARV drugs) they took each day to treat problems associated with their HIV infection. At *Time 2*, about 40% of respondents were taking more than ten prescribed pills every day, and 11.1% were taking more than 20 pills (see Table 18). The most common number of prescribed pills taken each day was 6–10, with 30.3% of the participants indicating they took this number. There was a significant decrease in the number of pills taken from *Time 1* to *Time 2* ( $t=3.93$ ,  $p < .001$ ).

**Table 18: Number of prescribed pills taken daily during *Time 1* and *Time 2***

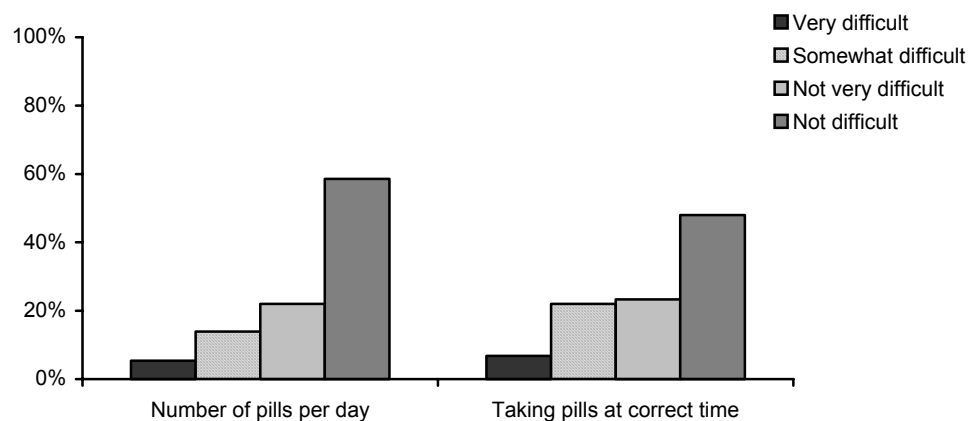
	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
None	47	15.3	67	21.8
1–5	24	7.8	17	5.5
6–10	87	28.3	93	30.3
11–15	58	18.9	49	16.0
16–20	38	12.4	38	12.4
Over 20	51	16.6	34	11.1
Unsure / No response	2	0.7	9	2.9
<b>Total</b>	<b>307</b>	<b>100.0</b>	<b>307</b>	<b>100.0</b>

## Difficulty taking prescribed pills

At *Time 2*, participants taking prescribed pills ( $n=231$ ) were asked whether they found it difficult to take the prescribed number of pills and whether it was difficult to take them at the right time of day. Figure 27 shows the proportion of people who experienced difficulties with their treatment regimen. On the whole, most participants (59.3%) found it was not difficult at all to take the prescribed number of pills. However, 3.9% of those who took pills found it was ‘very difficult’ to take the particular number of prescribed pills. Of those nine people, all took at least six pills per day, and six took more than 20 pills per day,

Of those who take prescribed pills daily, 5.6% reported it was ‘very difficult’ to take their pills at the prescribed times. These were all people who reported taking six or more pills per day (Figure 27). Around one-fifth reported that they found it ‘somewhat difficult’ to stick to the prescribed times when taking their daily medicine, while almost half (48.0%) found no difficulty taking their pills at prescribed times.

These results are similar to other HIV-positive studies, where some people report regular problems with taking their anti-HIV treatments, while others find it relatively easy (Weatherburn et al., 2002; Anderson et al., 2000). As well, adherence can be related to psycho-social measures such as satisfaction with support (Singh et al., 1999) and may not necessarily relate to the number of pills or when they are required to be taken.



**Figure 27: Difficulty in taking the prescribed number of pills and at prescribed times**

From *Time 1* to *Time 2*, there was a significant decrease in the reported difficulty of taking the number of pills prescribed per day (Wilcoxon:  $n=217$ ,  $z=-3.9$ ,  $p < .001$ ). In the same period, there was also a decrease in the reported difficulty of taking pills at prescribed times (Wilcoxon:  $n=218$ ,  $z=-3.64$ ,  $p < .001$ ).

## ARV MEDICATION

At *Time 2*, respondents were asked how many times a day they were required to take ARV medication, and how many doses they had missed in the previous two days.

### Required number of doses per day

Table 19 shows the number of times per day that participants were expected by their doctor to take ARV drugs. The majority of respondents were on a regimen that included twice-a-day medication, while about one in five reported a three-times-a-day medication schedule.

Analyses based on only those participants ( $n=214$ ) who were 'currently taking' ARV therapy at both *Time 1* and *Time 2*, showed that there was a significant decrease across the cohort in the number of separate doses of ARV drugs taken each day (Wilcoxon:  $n=214$ ,  $z=-4.5$ ,  $p < .001$ ) (Table 19).

**Table 19: Number of times each day that participants are expected to take ARV drugs**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Once	3	1.2	4	1.8
Twice	153	62.4	173	77.2
Three times	64	26.1	36	16.1
Four times	15	6.1	7	3.1
More than four times	10	4.1	4	1.8
<b>Total</b>	<b>245<sup>1</sup></b>	<b>100.0</b>	<b>224<sup>2</sup></b>	<b>100.0</b>

<sup>1</sup> missing data: n=9; proportions based only on those who were taking ARV therapy during *Time 1* (n=254) and answered the question

<sup>2</sup> missing data: n=1; proportions based only on those who were taking ARV therapy during *Time 2* (n=225) and answered the question

## Missed doses of ARV medication

The majority of the cohort had not missed any scheduled doses of ARV medication in the day prior to the interview at *Time 2*, or even two days before their interview (Table 20).

**Table 20: Doses of antiretroviral drugs missed on days before the interview**

	1 day prior to interview		2 days prior to interview	
	n	%	n	%
None	256	90.1	246	87.2
One	20	7.0	28	9.9
Two	7	2.5	7	2.5
More than two	1	0.4	1	0.4
<b>Total</b>	<b>284<sup>1</sup></b>	<b>100.0</b>	<b>282<sup>2</sup></b>	<b>100.0</b>

Note: Includes only those respondents who reported taking any ARVs in the previous 12 months (n=288)

Missing data: <sup>1</sup> n=4; <sup>2</sup> missing: n=6

## Average frequency of missed doses

Although over 80% of participants in the cohort missed at least one dose in the six months preceding *Time 2* (Table 21), relatively few of all missed doses were missed intentionally. Around 15% of participants intentionally missed doses of ARV drugs at least every month.

**Table 21: Average frequency of missed doses in the six months preceding *Time 2***

	Any missed doses (accidental or intentional)		Intentionally missed doses	
	n	%	n	%
Once a day or more	3	1.3	2	0.9
At least once a fortnight	46	20.4	12	5.5
Once a month	41	18.4	17	7.8
Once every couple of months	45	20.2	26	12.0
Once every six months	50	22.4	23	10.6
Never	38	17.0	137	63.1
<b>Total</b>	<b>223<sup>1</sup></b>	<b>100.0</b>	<b>217<sup>2</sup></b>	<b>100.0</b>

Note: Includes only those respondents who reported taking any ARVs in the previous 12 months (n=225)

<sup>1</sup> missing: n=2; <sup>2</sup> missing: n=8.

## Reasons for missed doses

The reasons why people missed doses of ARV medication are presented in Table 22. At the *Time 2* interview, the most commonly given reasons for missing doses were forgetting to take the dose; a change in routine; being away from home; being too busy; and feeling sick.

**Table 22: Reasons for missed doses of ARV drugs at *Time 2***

	Frequency	Percentage (%)
I forgot	118	62.4
A change in routine	88	46.6
I was away from home	83	43.9
Too busy	68	36.0
I felt sick	48	25.4
Couldn't be bothered	41	21.7
Eating schedule was out of sync	41	21.7
I was out of it (alcohol/drugs)	40	21.2
Ran out of pills	34	18.0
I wanted to avoid interaction with recreational drugs	33	17.5
I was tired of feeling controlled by drug	31	16.4
I slept through it	28	14.8
I was feeling sick from the drug	28	14.8
I was depressed	18	9.5
I was getting used to new pill routine	18	9.5
I did not want people to know my status	17	9.0
I wanted sex without side effects	13	6.9
I was feeling angry	11	5.8
I was feeling healthy	3	1.6

Note: Items are not mutually exclusive.

## Importance of taking ARV drugs according to prescription

Participants were asked how important they thought it was to take ARV pills according to the prescription (Table 23). The majority of respondents who were taking ARV drugs at the time of either of their two interviews, believed it was 'very important' to take them according to the prescription. Beliefs about the importance of taking ARV drugs according to the prescription did not change from *Time 1* to *Time 2*.

**Table 23: Importance of taking ARV drugs according to prescription**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Very important	193	79.1	165	73.7
Somewhat important	46	18.9	50	22.3
Not very important	4	1.6	6	2.7
Not at all important	1	0.4	3	1.3
<b>Total</b>	<b>244<sup>1</sup></b>	<b>100.0</b>	<b>224<sup>1</sup></b>	<b>100.0</b>

<sup>1</sup> Includes only those respondents who reported taking any ARVs at the time of their interview: *Time 1* (n=254, missing=10), *Time 2* (n=225, missing=1)

## Perceived consequences to health from missing a dose

Despite the fact that most participants thought it was ‘very important’ to take their ARV medication according to the prescription, a large proportion (42%) at *Time 2* thought that the effects of missing a dose were ‘not very serious’ or ‘not serious at all’. However, around one-fifth thought the effects on their health would be ‘very serious’ and almost 40% thought they would be ‘somewhat serious’ (Table 24).

Participants’ perceptions of the perceived consequences to health from missing doses of ARV drugs were unchanged from *Time 1* to *Time 2*.

**Table 24: Perceived consequences for health from a missed dose**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Very serious	45	18.5	40	18.3
Somewhat serious	98	40.3	87	39.7
Not very serious	92	37.9	77	35.2
Not at all serious	8	3.3	15	6.8
<b>Total</b>	<b>243<sup>1</sup></b>	<b>100.0</b>	<b>219<sup>1</sup></b>	<b>100.0</b>

<sup>1</sup> Includes only those respondents who reported taking any ARVs at the time of their interview: *Time 1* (n=254, missing=11), *Time 2* (n=225, missing=6)

# OTHER TREATMENTS AND LIFESTYLE STRATEGIES

This section brings together, under the one heading, a range of treatments and health strategies other than ARV treatments. These include treatments for HIV-related conditions, the use of alternative and complementary therapies, as well as other lifestyle strategies that participants have adopted in response to HIV.

## USE OF TREATMENT/PROPHYLAXIS FOR PCP

Less than one-third of the cohort used treatment/prophylaxis for *Pneumocystis Carinii* Pneumonia (PCP) in the 12 months preceding the interview at *Time 2* (Table 25). Significantly fewer people had taken PCP treatment/prophylaxis in the 12 months prior to *Time 2* compared with the equivalent period prior to *Time 1* (McNemar:  $\chi^2=18.15$ ,  $n=307$ ,  $p < .001$ ).

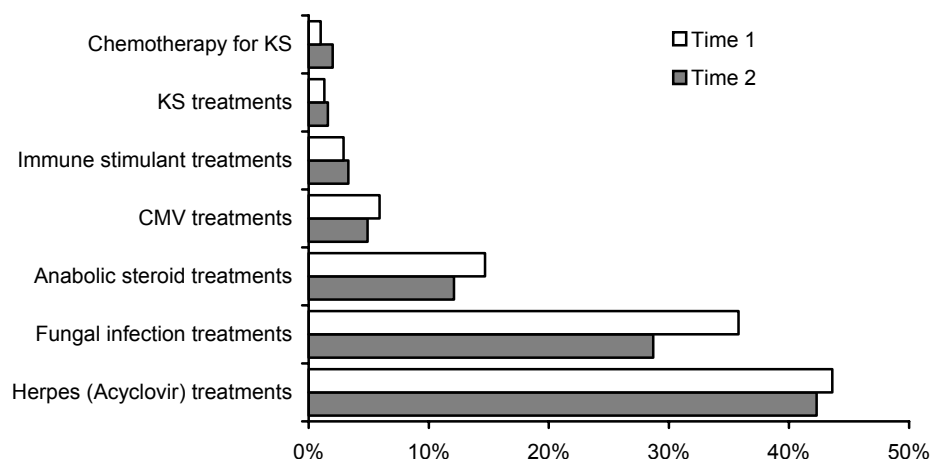
**Table 25: Use of medication to treat PCP in previous 12 months**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Currently using or has used in past 12 months	119	38.8	85	27.7
No use of medication to treat PCP	188	61.2	222	72.3
<b>Total</b>	<b>307</b>	<b>100.0</b>	<b>307</b>	<b>100.0</b>

## TREATMENTS OF OTHER HIV-RELATED CONDITIONS

A large proportion (57.9%) of respondents had taken medication for other HIV-related conditions in the 12 months preceding *Time 1* and *Time 2*. Figure 28 shows the proportion of people who used treatment for a particular condition, for example, fungal skin infections, herpes, and Kaposi's sarcoma. At *Time 2*, 28% were currently taking medication for the prevention and treatment of herpes, while 15.3% were currently using treatments such as Fluconazole, or Nizoral, to treat fungal skin infections. Fewer people reported using anabolic steroids (7.5%), medications such as adefovir for the treatment of cytomegalovirus (CMV; 3.38%), or immune stimulants like interleukin (1.6%).

There were no differences across time in the number of people who received any of the treatments listed in Figure 28. The exception is the treatment of fungal infections, for which fewer people received treatment at *Time 2* than at *Time 1* (McNemar:  $\chi^2=5.01$ ,  $n=307$ ,  $p=.025$ ).



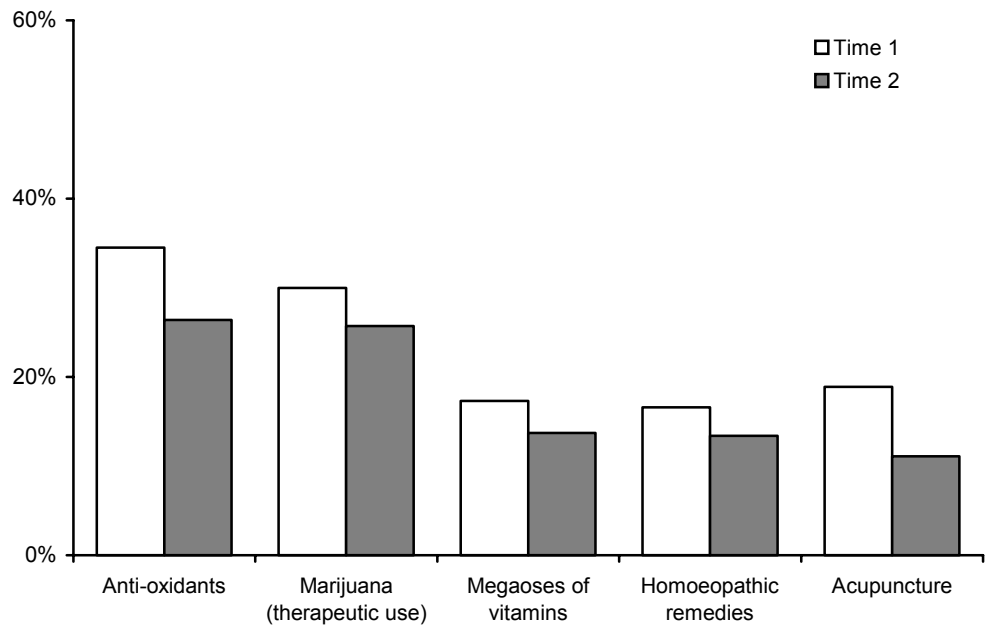
**Figure 28: Treatments of other HIV-related conditions**

Note: Graph includes those who were currently using the treatment at the time of the interview, or had used the treatment in the preceding 12 months.

## ALTERNATIVE/COMPLEMENTARY THERAPIES

The majority of the cohort (52.4%) used at least one alternative/complementary therapy in the 12 months before their interview at *Time 2* (Figure 29). Of those who reported using an alternative therapy in the previous year (n=161), 50.4% used antioxidants and half used marijuana for therapeutic purposes; 24.2% used marijuana ‘regularly’. Slightly fewer than half these people (42.9%) reported using herbal remedies, while megadoses of vitamins (26.1%) and acupuncture (21.1%) were less commonly used. About 6.8% of those people using alternative therapies experienced side effects from the use of such therapies; 37.3% were told of potential side effects before utilising any therapies.

Compared with *Time 1*, fewer people took antioxidants (McNemar: n=307,  $\chi^2=7.68$ , p=0.006) and received acupuncture (McNemar: n=307,  $\chi^2=9.80$ , p=.002) at *Time 2*. Otherwise, the use of alternative therapies was unchanged between *Time 1* and *Time 2*.



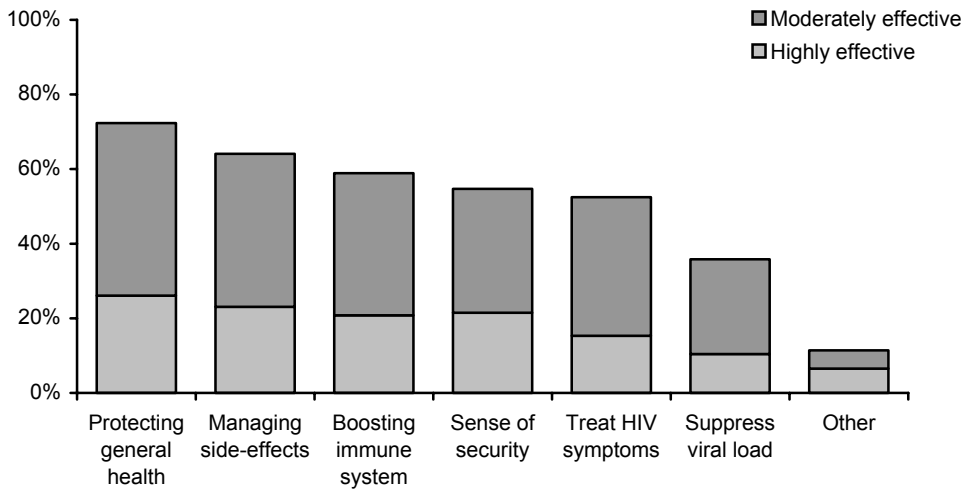
Note: Proportions are based only on those people who reported using an alternative/complementary therapy  
 Note: Proportions depict those who either 'regularly' or 'sometimes' used these remedies in the past year.

**Figure 29: Use of alternative/complementary therapies in previous year**

### **Opinion on the effectiveness of alternative and complementary therapies**

At the *Time 2* interview, participants were asked their opinion on the effectiveness of alternative and complementary therapies in boosting the immune system, suppressing viral load, managing side effects, treating symptoms, providing a sense of security and protecting general health (Figure 30). A large proportion thought that alternative therapies were effective in protecting general health, as well as in managing side effects. Relatively few thought that they were 'highly effective' at suppressing viral load.

These results require further consideration as a recent study has suggested that natural and alternative therapies can inhibit the efficacy of ARV drugs used to treat HIV, and that many HIV general practitioners are unaware their clients are taking complementary and alternative therapies (Hsiao et al., 2003).

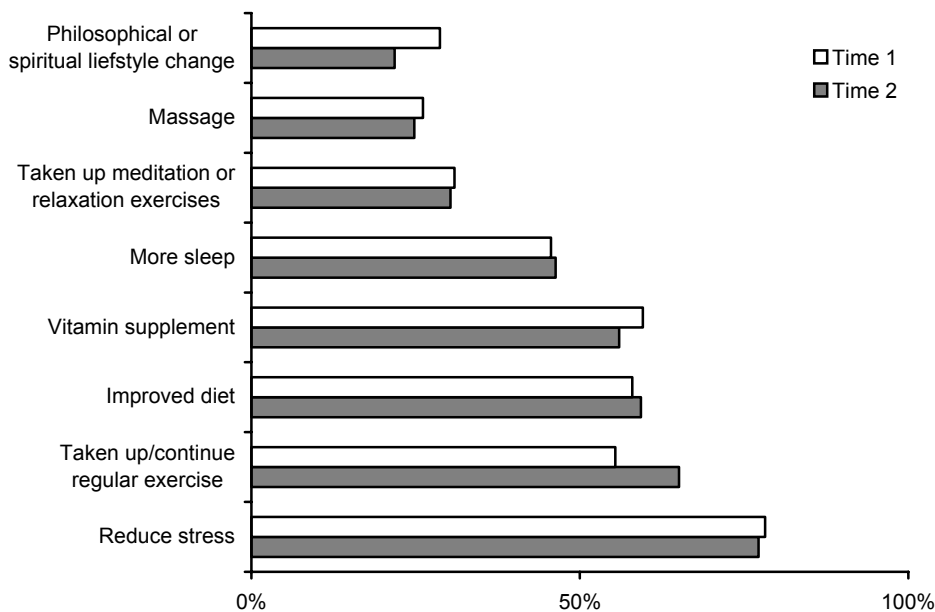


**Figure 30: Opinion on effectiveness of alternative/complementary therapies**

## OTHER STRATEGIES AIMED AT IMPROVING HEALTH

Participants were asked whether they had taken other steps to improve or protect their health in the preceding 12 months. At both *Time 1* and *Time 2*, a large majority of the cohort tried to reduce the amount of stress in their life in order to improve their health (Figure 31). Common strategies aimed at good health outcomes included taking up regular exercise, making improvements to diet, and taking vitamin supplements. Less common strategies, but still popular, were meditation, massage, returning to work or even a philosophical lifestyle change.

In comparison with *Time 1*, fewer PLWHA were considering spiritual/philosophical changes at *Time 2* (McNemar:  $n=307$ ,  $\chi^2=5.63$ ,  $p=.018$ ), and more people were taking physical exercise for health reasons at *Time 2* (McNemar:  $n=307$ ,  $\chi^2=8.09$ ,  $p=.004$ ).



**Figure 31: Strategies aimed at improving and protecting health**

# RECREATIONAL DRUG USE

Recent studies show that recreational drugs are more widely used among gay-community-attached men (Hull, et al., 2003) and HIV-positive people (Grierson, et al., 2002: 81) than by the overall Australian population (Australian Institute of Health and Welfare, 2002). While recreational drug use is relatively normative in the context of some gay-community events and cultures—and the majority of PLWHA in Australia are gay-identified men—the use of recreational drugs may pose dilemmas for some PLWHA. On the one hand, participation in gay-community events and the drug taking that often goes with those events provides opportunities for social connectedness. On the other hand, many PLWHA are concerned that recreational drug use may have a negative impact on their immune systems and they have consequently reduced their use of some recreational drugs, including marijuana (although marijuana is also used as a medicinal drug by some PLWHA). In our baseline report for this study (see Prestage, et al., 2001b) we reported that 29% of participants were taking marijuana for medicinal purposes—particularly for reducing stress, gaining weight by boosting appetite and alleviating pain.

In this section, we report on the use of a range of recreational drugs and, where possible, compare such use from *Time 1* to *Time 2*. Although marijuana use is reported in this section, its use as a therapeutic aid is reported in the earlier section *Other Treatments and Lifestyle Strategies*.

## TOBACCO

Around one-quarter of participants reported being ex-smokers, a proportion similar to Australian rates in the adult population (26.0%; Australian Bureau of Statistics, 2001) (Table 26). However, about half the cohort currently smokes—a proportion twice that found in the adult Australian population (24.0%; Australian Bureau of Statistics, 2001) and similar to what has been found in previous studies of PLWHA in Australia (Prestage, et al., 1995). Among the current smokers, the majority smoked more than 11 cigarettes a day. There were no significant changes in the pattern of smoking reported at *Time 1* and *Time 2*, with comparable rates of smoking at each time.

**Table 26: Tobacco smoking**

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Never	83	27.1	86	28.1
Stopped smoking	72	23.5	73	23.9
Currently smoking	151	49.4	147	48.0
<b>Total</b>	<b>306<sup>1</sup></b>	<b>100.0</b>	<b>306<sup>1</sup></b>	<b>100.0</b>

<sup>1</sup> missing data n=1

## ALCOHOL

Most of the cohort drank alcohol (Figure 32), and among those who did, the majority drank less than once a week, or on one or two days per week. Comparatively fewer people drank alcohol everyday. The amount of alcohol that most participants drank in a given week did not constitute high risk according to the Australian Alcohol Guidelines<sup>11</sup>. While it may appear in Figure 32 that, overall, respondents were drinking less alcohol at *Time 2* than at *Time 1*, these differences are not statistically significant.

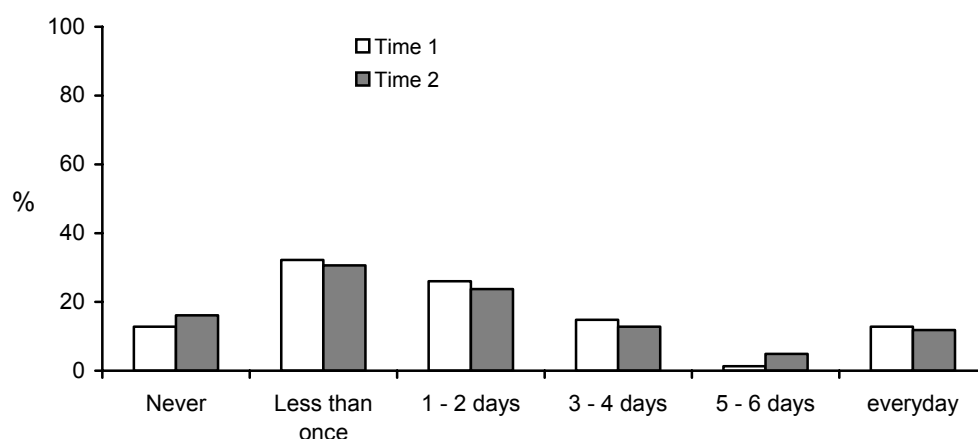


Figure 32: Frequency of alcohol consumption per week

### Frequency of alcohol intoxication

Although the frequency of alcohol consumption per week did not change between *Time 1* and *Time 2*, participants in the cohort reported getting intoxicated with alcohol fewer times in the six months preceding *Time 2* than in the six months preceding *Time 1* (Wilcoxon:  $n=303$ ,  $z=-2.57$ ,  $p=.01$ ) (Table 27).

Table 27: Frequency of alcohol intoxication in the previous six months

	<i>Time 1</i>		<i>Time 2</i>	
	n	%	n	%
Never	155	50.7	169	55.6
Once or twice (six months)	75	24.5	71	23.4
Once a month	43	14.1	41	13.5
Once a week	20	6.5	18	5.9
More than once a week	13	4.2	5	1.6
<b>Total</b>	<b>306<sup>1</sup></b>	<b>100.0</b>	<b>304<sup>2</sup></b>	<b>100.0</b>

<sup>1</sup> missing data:  $n=1$ ; <sup>2</sup> missing data:  $n=3$

11 The Australian Alcohol Guidelines suggest that men who drink up to four standard drinks per day and women who drink up to two standard drinks per day are considered to be at a low risk of harm as a result of alcohol consumption (National Health and Medical Research Council, 2001). However, the level of risk is also determined by the number of days a person drinks per week and how many drinks are consumed in total per week—a person is considered to be at high risk of harm from alcohol consumption if they consume more than seven standard drinks a day, or more than 43 per week for men, and for women, five or more standard drinks per day or more than 29 drinks per week.

## OTHER RECREATIONAL DRUGS

About three-quarters of respondents had used some type of recreational drug in the six months preceding their interview at *Time 2*. The drugs most commonly used at *Time 1* and *Time 2* included marijuana, amyl or ethyl, ecstasy and speed (Table 28). The amount of drug use is higher than for the overall Australian population (Australian Institute of Health and Welfare, 2002), yet consistent with other studies of HIV-positive people in Australia (Prestage, et al., 1995; Grierson et al., 2002: 81), as well as studies of gay-community-attached men in Sydney (Hull, et al., 2003).

In terms of overall drug use, 13% of respondents reported no drug use at either *Time 1* or *Time 2*, 70% indicated drug use at both times, 12% had reduced their use of recreational drugs, while 5% had increased their use of recreational drugs. Overall, there was a significant decrease from *Time 1* to *Time 2* in the frequency with which participants took recreational drugs (McNemar:  $\chi^2=7.84$ ,  $p=.005$ ). As well as overall drug use, participants also reported a significant decrease in the total number of different drugs used from *Time 1* to *Time 2* ( $t=3.69$ ,  $df=306$ ,  $p < .001$ ).

There were also changes in the use of specific drugs from *Time 1* to *Time 2*. Significantly fewer people at *Time 2* than at *Time 1* reported using marijuana, heroin, LSD or cocaine. There was no significant change in the number of people using any of the remaining recreational drugs in the list. The use of crystal meth was not asked of respondents at *Time 1*, so it was not possible to ascertain change across time.

**Table 28: Drug use and changes in pattern of use across time**

	<i>Time 1</i> ( <i>N</i> =307)		<i>Time 2</i> ( <i>N</i> =307)		SIG
	n	%	n	%	
Marijuana or hash	192	62.5	175	57.0	* $p=.034$
Amyl Nitrite or Ethyl Chloride	148	48.2	143	43.3	NS
Valium	42	13.7	43	14.0	NS
Heroin	17	5.5	6	2.0	* $p=.007$
Methadone	6	2.0	4	1.3	NS
MDA	34	11.1	38	12.4	NS
LSD	60	19.5	37	12.1	* $p=.001$
Speed	98	31.9	86	28.0	NS
Ecstasy	100	32.6	100	32.6	NS
Special K	22	7.2	28	9.1	NS
Cocaine	45	14.7	30	9.8	* $p=.033$
GHB	11	3.6	8	2.6	NS
Crystal meth			42	13.6	-

Note: Categories are not mutually exclusive

## Injecting

Comparatively fewer PLWHA (14%) had injected recreational drugs in the six months prior to the interview at *Time 2*. This is slightly lower than, but still comparable with, proportions described in *HIV Futures 3* (Grierson et al., 2002: 83), yet it is higher than figures reported among HIV-negative men in the *Health in Men* (HIM) cohort<sup>12</sup> of approximately 4% (Mao et al., 2002: 26). The drugs most commonly used by the 42 people who had injected any recreational drugs in the six months preceding *Time 2*, were speed (69.0%), crystal meth (38.1%), heroin (14.3%), and cocaine (2.4%)<sup>13</sup>.

The frequency with which participants injected recreational drugs, other than steroids, did not alter significantly from *Time 1* to *Time 2*. However, there was a significant decrease in the number of people who injected cocaine and steroids from *Time 1* to *Time 2* (Table 29).

**Table 29: Drugs injected in previous six months**

	<i>Time 1</i> (N=307)		<i>Time 2</i> (N=307)		SIG
	n	%	n	%	
Injected speed	29	9.4	29	9.4	NS
Injected cocaine	9	2.9	1	0.3	*p=.008
Injected heroin	13	4.2	6	2.0	NS
Injected other drugs	5	1.6	9	2.9	NS
Injected steroids	15	4.9	3	1.0	*p=.008

Note: Categories are not mutually exclusive

<sup>12</sup> HIM is a cohort study of an HIV-negative gay male population

<sup>13</sup> Please note that the percentages reported in this sentence were calculated on a reduced base (i.e. the 42 people who had said they had injected drugs in the six months preceding the *Time 2* interview).

# DISCUSSION

This report provides the first account of some of the key aspects of the lived experience of HIV *across time* in the *Positive Health* cohort. Participants in the cohort were first interviewed in 1998/1999 and then again in 2000/2001. Data from 307 people, who were interviewed on both occasions, were matched across time. Unlike cross-sectional studies, which may also document changes from one sample to the next, longitudinal cohort studies are not susceptible to the suggestion that change over time may simply have been the result of a different sample on each occasion.

For reasons of breadth and brevity, this report has focused on the responses of participants at *Time 2*, and where possible, comparing responses from *Time 1* to *Time 2*. Longitudinal data can also be analysed in other ways to explore more complex relationships across time, in particular the types of analyses that explore issues of causation. While not appearing in this report, these types of analyses are being undertaken for publication in journal articles and issues papers.

A limitation of some longitudinal studies is that the cohort bears little resemblance to the broader population being studied. This may sometimes be the case when a cohort has been in existence for many years and is not being replenished by the intake of new participants. While *Positive Health* is an open cohort study—inviting new participants to join the study each year—the analyses in this report were based on only those people who had participated at *Time 1* and *Time 2*. As such, it is important to judge the representativeness of the *Positive Health* cohort to the broader PLWHA population, and therefore how generalisable the findings are to other PLWHA. As a way of gauging this generalisability we have, in many places in the report, compared our results to those of *HIV Futures 3* (Grierson et al., 2002), the major cross-sectional study of PLWHA in Australia.<sup>14</sup> This comparison shows that in terms of demographics—other than place of residence—the *Positive Health* participants and *HIV Futures 3* participants are reasonably similar (for example, both studies have similar proportions of gay men, of men to women, of those in full-time and part-time employment, and of those with dependent children). These similarities provide greater confidence in generalising the results from *Positive Health* to other PLWHA in Australia. That is, the experiences of the *Positive Health* participants are likely to be similar, though not necessarily the same as, members of the broader PLWHA community. We caution, however, that these similarities will not hold for all situations.

The findings in this report must be considered in light of events that have influenced the cultural and normative aspects of HIV in recent years. For example, the widespread use of HAART in Australia since 1996 has arguably influenced the lived experience of HIV more than any other factor in recent years. It has had a positive impact on morbidity and mortality and, by contributing to a lowered community viral load, has undoubtedly impacted on HIV transmissibility and on sex practice. Along with HAART, medical technologies such as the viral load test have also changed the social experience of HIV. Race (2001) argues that the onus of responsibility for managing HIV since HAART has shifted from communities onto individuals. For example, he contends that the viral load test has led to the creation of new socio-sexual ‘risk’ categories, such as being HIV-positive with undetectable or detectable viral load. Striving to reach or maintain a low viral load has become the responsibility of individuals, at times in partnership with their doctors. This

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<sup>14</sup> While the authors of *HIV Futures 3* acknowledge that that study does not represent all members of the PLWHA community, the study nonetheless provides a reasonably strong representation of PLWHA and is therefore a good point of comparison.

private responsibility plays out in the necessity to adhere to drug regimens and to have one's viral load regularly monitored.

In recent years, new concerns have emerged. Adherence to drug regimens provides the conditions under which ARV drugs appear to be most efficacious, yet strict adherence may also lead to the experience of severe side effects. Illnesses relating to drug toxicity are now a genuine concern of many on HAART. The obvious tension between *drug efficacy* and *drug toxicity* is most evident in the increasing adoption of structured treatment interruptions and in people taking 'drug holidays'. In response to this, researchers are establishing studies to explore the effects of different types of structured treatment interruptions on the immune response. As the experience of HIV is set within a constantly changing landscape, this needs to be borne in mind when interpreting the findings in this report.

In terms of health outcomes, the results presented in this report provide a somewhat paradoxical picture. On some indicators of health the cohort appears to be doing well, while on other indices the picture is not as positive. This level of complexity appears to have much to do with ambiguities that seem to be inherent in current experiences of HIV. For example, clinical markers may suggest that a person is healthy and doing well, whereas the subjective experience—particularly in terms of side effects—may be quite the opposite. Also, as the experience of HIV is not just physical—it is also psychological and social, each with multiple facets—it is perhaps expected that indicators of health may at times be moving in opposite directions. This level of complexity does not make the management of HIV particularly easy for the clinician, the person with HIV, PLWHA organisations, or the social researcher attempting to explain these patterns and discontinuities.

Significant change has occurred in the cohort between *Time 1* and *Time 2*. One notable change is in the contact participants had with the epidemic. For example, at *Time 2* participants knew fewer HIV-positive people and fewer people who had died from AIDS-related illness than they had at *Time 1*. And they were spending less time with HIV-positive friends and more time with HIV-negative friends. Also, participants' access of HIV-related information altered slightly over time. For instance, there has been a significant decrease from *Time 1* to *Time 2* in the number of people who reported reading HIV community-related press, HIV treatment press and 'other' sources of HIV-related material—though it must be stressed that more than 65% of the cohort were reading these publications at *Time 2*. Conversely, there has been an overall increase in the number of people using the internet to find HIV and treatment-related material.

These findings might suggest that HIV positivity was not as prominent in the lives of cohort members at *Time 2* compared with at *Time 1*. However, the findings may also suggest that support networks are dwindling, people are grieving over lost loved ones and protecting themselves from the potential of further loss, and that many people are feeling increasingly isolated. To properly understand the complexity of these issues may require more in-depth analysis of the *Positive Health* data and/or the use of qualitative studies designed specifically to address these issues. If HIV positivity has become less prominent in the lives of many PLWHA in Australia, and it is not possible at this stage to make that conclusion with any certainty, then it would be important to investigate the specific needs of these PLWHA.

One possible explanation for changes in positive community engagement, and certainly not the only explanation, is that participants are generally in reasonable health. Participants would appear to have maintained their health from *Time 1* to *Time 2* or, if anything, health across the cohort may have improved, even though this may not hold for specific individuals. Self-rated health—an overall gauge of how people view their health—was rated better at *Time 2* than at *Time 1*, and was 'good' or 'excellent' for the majority of PLWHA. Few respondents rated their health as 'poor'. Other markers of sustained health are also evident. For example, there has been no change from *Time 1* to *Time 2* in the number of admissions to hospital as a result of opportunistic illness or infection; there were no significant differences in the incidence of individual illnesses from *Time 1* to *Time 2*; nor were there any significant differences in the total

number of illnesses or infections experienced by the cohort in the preceding year. Treatment for HIV-related illnesses was consistent across time except for the treatment of PCP and fungal infections, for which fewer people received treatment at *Time 2* than at *Time 1*. Furthermore, there were no significant differences in the experience of a variety of illnesses unrelated to HIV infection.

Other indications that health has been maintained across the cohort, is evident from both clinical markers of health—CD4 count and viral load—and indicators of QOL. Almost half the cohort had a CD4 count of 500 at the time of their most recent test before *Time 2*. Relatively few PLWHA had a CD4 count of less than 100. Almost half the cohort reported an undetectable viral load from their most recent viral load test at *Time 2*. For the cohort as a whole, there was no significant change in the average CD4 count or viral load from *Time 1* to *Time 2*. Also, QOL indicators—such as appetite, sleeping patterns, overall energy level, concentration, libido and mood—are also suggestive of a consistency of health over time.

Balancing this somewhat positive picture of the health of participants is the reality that for many PLWHA their health neither improved nor was sustained. Even among those whose health may have improved or was sustained, it is quite clear that health was still experienced in ways that many people might consider as ‘poor’. Therefore, contrary to the picture of sustained health is the experience of some participants of continuing ill-effects, worsened health outcomes, and debilitating side effects of HAART. For example, 20% of the cohort reported a clinical diagnosis of depression in the 12 months preceding their interview at *Time 2*. Two-thirds of the participants had experienced lipodystrophy symptoms in the 12 months before their interview. In terms of significantly worsened health outcomes, experienced by a minority of participants, was a worsening of mood as well as increases in the prominence of veins on arms and legs. Also, nearly one in three participants indicated higher levels of cholesterol and triglycerides. Other types of side effects from treatments that were experienced the most, apart from those directly attributed to taking HAART, included diarrhoea, bloating, lethargy and nausea.

It is important to further explore the rationale that health is linked with engagement in HIV-positive community, as there may be other plausible explanations for a reduction in engagement in HIV-positive community. Indeed, further analysis might consider whether a reduction in HIV-positive community engagement has occurred and, if so, what explanations and impacts that might have. Further analyses might explore issues about service utilisation, sexual behaviour, poverty and income, mental health and emotional wellbeing, possible changes in gay-community, changes in treatment taking (e.g. structured treatment interruptions), and the impacts of treatments on daily life.

Not surprisingly, the majority of participants were taking ARV drugs at *Time 2*. However, between *Time 1* and 2, there was a significant decrease in the number of ARV drugs respondents reported taking; fewer people were taking ARV drugs at *Time 2* than at *Time 1*; and many more participants completely stopped taking ARV drugs at *Time 2* compared with those who commenced taking them. The most common reason for completely stopping ARV therapy was the experience of side effects, followed by concerns about the long-term effects of taking the drugs, and being ‘fed up’ with the treatment regimen. Among those who changed their treatment regimen, around 12–14% switched to a structured treatment interruption scheme. At the same time as many people were coming off or having a break from their ARV treatment regimens, there were signs that the pill-taking aspects to ARV treatment regimens improved. For example, there was a decrease in the number of pills participants were prescribed, as well as a decrease in the difficulty of taking pills both in terms of quantity and at prescribed times.

With more people coming off ARV therapy than going on, it might have been expected that participants would look towards other means of maintaining or improving their health. While there is no evidence that those who seek out alternative/complementary treatments are those who are not taking ARV therapy, many participants adopted various strategies, not simply therapies, to maintain or improve their health. A common strategy was to attempt to reduce the amount of

stress in their life; taking up regular exercise, diet improvements, and taking vitamin supplements. With the exception of fewer people considering spiritual/philosophical changes at *Time 2* and more people taking physical exercise at *Time 2*, there were otherwise no differences in the number of participants using these strategies at *Time 1* and *Time 2*. There was also little change from *Time 1* to *Time 2*, in the use of alternative/complementary therapies. If anything, there was a reduction across the cohort in the use of these therapies, with significantly fewer people taking antioxidants and receiving acupuncture.

Other important signs that the cohort has adopted strategies to sustain or improve health seem evident in alcohol and recreational drug use. Participants got intoxicated with alcohol significantly fewer times in the six months prior to their interview at *Time 2* compared with the same period at *Time 1*. Also, there was a significant decrease from *Time 1* to *Time 2* in the frequency with which participants took recreational drugs, and in the total number of different drugs used.

By far the majority of participants in the cohort have as their key doctor a general practitioner with a high HIV caseload or a specialist with expertise in the field of HIV. Although the majority of PLWHA visit their doctor at least every three months, there has been a significant overall decrease in the frequency with which participants visit their doctor—fewer people seeing their doctor monthly, and more people seeing their doctor quarterly. At the same time, participants were having more frequent CD4 and viral load tests at *Time 2* than at *Time 1*, and most people were making decisions about their health, jointly with their doctor. The close participant/doctor relationship is signalled by more than 50% citing their doctor as the source of ‘a lot’ of emotional support, a significant increase from *Time 1* to *Time 2*.

There were few barriers to accessing HIV services. Importantly, very few people were restricted from accessing services due to cost. In the period between *Time 1* and *Time 2*, more *Positive Health* participants took up private health insurance. Perhaps related to this increase, there was a corresponding decrease in the amount of financial assistance, other than Medicare and private health insurance, received for medical and dental costs. The services for which cost had the most bearing on access were alternative therapies and alternative health practitioners, and for these services there were relatively few people who found access difficult. Relatively few people (4%) reported difficulties obtaining ARV drugs due to cost.

Emerging from this report is a complex picture of some of the key aspects of the lived experience of HIV. For some PLWHA the picture is rather positive, while for others, unfortunately, the story is less bright. The dynamic interplay between the physical, social, and psychological experience of HIV means that the lived experience is one of change. The changing medical landscape further increases this complexity; this may change still more as knowledge emerges about the effectiveness of structured treatment interruptions, while on the distant horizon is the possibility of an efficacious vaccine. Within this ever-changing landscape, many in the cohort have maintained their health and QOL yet are also sustaining debilitating side effects and in some cases a worsening in health outcomes. The picture is therefore a mixed one. We hope that this report will be a useful resource for those with an interest in HIV. The *Positive Health* study will continue to document important aspects of living with HIV across time.

# REFERENCES

- Anderson, W., Weatherburn, P., Keogh, P., and Henderson, L. (2000). *Proceeding with care: phase 3 of an on-going study of the impact of combination therapies on the needs of people with HIV*. London: Sigma Research. University of Portsmouth, London.
- Australian Institute of Health and Welfare. (2002). *2001 National Drug Strategy Household Survey: First Results*. AIHW Catalogue Number PHE 35. (Drug Statistics Series No 9). Canberra: AIHW
- Australian Institute for Primary Care, (2001). *National Hepatitis C Resource Manual (2001)*, La Trobe University, Melbourne.
- Australian Bureau of Statistics. (2002). *National Health Survey – Summary of Results*, Australia ABS Catalogue No. 4364.0. Canberra: Australian Government Publishing Service.
- Brotherton, A., (1996). *HIV and gay community: in or out?* Plenary panel presentation at Health in Difference: Proceedings of the First National Lesbian, Gay, Transgender and Bisexual Health Conference, Sydney, 3–5 October, 1996: Australian Centre for lesbian and Gay Research.
- Dore, G., & Sasadeusz, J. (2003). *Coinfection HIV and Viral Hepatitis: a guide for clinical management*. Australasian Society for HIV Medicine Inc. Sydney.
- Grierson, J., de Visser, R, Bartos, M. (2001). More cautious, more optimistic: Australian people living with HIV/AIDS, 1997-1999. *International Journal of STD and AIDS*, 12, 670-676.
- Grierson, J., Misson, S., McDonald, K., Pitts, M., and O'Brien, M. (2002). *HIV Futures III. Positive Australians on Services, Health and Well-Being*. Monograph Series Number 37. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.
- Hsiao, A., Wong, M. D., Kanouse, D. E., Collins, R. L., Liu, H., Andersen, R. M., Gifford, A. L., McCutchan, A., Bozzette, S. A., Shapiro, M. F., & Wenger, N. S. (2003). Complementary and Alternative Medicine Use and Substitution for Conventional Therapy by HIV-Infected Patients. *Journal of Acquired Immune Deficiency Syndromes*, 33, 157–165.
- Hull, P., Van de Ven, P., Prestage, G., Rawstorne, P., Grulich, A., Crawford, J., Kippax, S., Maddedu, D., McGuigan, D., and Nicholas, A. (2003). *Gay Community Periodic Survey: Sydney 1996–2002*. Sydney: National Centre in HIV Social Research, The University of New South Wales.
- Mathews, W. C., McCutchan J. A., Asch, S., Turner, B.J., Gifford, A. L., Kuromiya, K., Brown, J., Shapiro, M.F., & Bozzette, S.A. (2000). National estimates of HIV-related symptom prevalence from the HIV cost and services utilisation study. *Medical Care*, 38(7), pp750–762.
- Mao, L., Van de Ven, P, Prestage, G., Jin, F., Grulich, A., Crawford, J., Kippax, S., Murphy, D., & Allan, B. (2002). *Health in Men: Baseline data* (Monograph 6/2002). Sydney: National Centre in HIV Social Research, The University of New South Wales.
- National Centre in HIV Epidemiology and Clinical Research (2002). *HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia. Annual Surveillance Report 2002*. The University of New South Wales, Sydney, Australia.
- National Health and Medical Research Council (2001). *Australian Alcohol Guidelines: Health Risks and Benefits*. Canberra: Commonwealth of Australia.
- Prestage, G., Kippax, S., Crawford, J., Noble, J., Baxter, D., and Cooper, D. (1995). A demographic, behavioural and clinical profile of HIV-positive men in a sample of homosexually active men in Sydney, Australia. Report B.1. Sydney men and Sexual Health. HIV AIDS & Society Publications, Sydney Australia.
- Prestage, G., Song, A., Grierson, J., Race, K., Grulich, A., & Kippax, S. (2001a). *Positive Health: method and sample*. Monograph 9/2000. National Centre in HIV Social Research, The University of New South Wales, Sydney, Australia.

- Prestage, G., Song, A., Grierson, J., Race, K., Grulich, A., Rawstorne, P., & Kippax, S. (2001b). *Positive Health: treatments, services and health*. Monograph 1/2001. National Centre in HIV Social Research, The University of New South Wales, Sydney, Australia.
- Putnam, R. (2000). *Bowling Alone: The Collapse and Revival of American Community*. Simon and Schuster, New York.
- Race, K. (2001). The Undetectable Crisis: Changing Technologies of Risk. *Sexualities*, 4(2), 167–189.
- Reeves, P. M. (2001). How individuals coping with HIV/AIDS use the Internet. *Health Education Research: Theory & Practice*, 16(6), 709–719.
- Singh, N., Berman, S. M., Swindells, S., Justis, J. C., Mohr, J. A., Squier, C., & Wagener, M. M. (1999). Adherence of Human Immunodeficiency Virus-Infected Patients to Antiretroviral Therapy. *Clinical Infectious Diseases*, 29, 824–830.
- Weatherburn, P., Anderson, W., Reid, D., and Henderson, L. (2002). *What do you need?* Findings from a national survey of people living with HIV. London: Sigma Research.
- White, L (2003). Social networks, social support, health and HIV-positive gay men. *Health and Social Care in the Community*, 11(4), 329–334.