
HIV Futures Community Report

**Health, Relationships, Community,
and Employment**

1998

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Acronyms Used in the Report

AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
IAESR	Institute of Applied Economics and Social Research
NAPWA	National Association of People Living With HIV/AIDS
NCHSR	National Centre in HIV Social Research
NCHECR	National Centre in HIV Epidemiology and Clinical Research
PLWHA	People Living with HIV/AIDS

1 Executive Summary

The HIV Futures Survey draws together the largest sample of people with HIV/AIDS to have been surveyed in Australia. The survey was conducted from 1 July 1997 to 5 September 1997. The 925 respondents represents over eight percent of the current population of PLWHA in Australia. While a substantial number of the participants are gay men living in Sydney, the survey includes significant numbers of PLWHA from smaller sub-populations such as women, and people living outside NSW and Victoria. The survey has good national coverage with respondents from all states and territories, and from both rural and urban locations.

The survey examines five main issues: health, relationships, community life, finances, and employment. The section on health focuses on PLWHA's experiences of, and attitudes toward, the new anti-retroviral treatments, in particular the new class of protease inhibitor drugs which have become increasingly available since the latter part of 1995. The section on relationships explores the changing nature of relationships with family, friends and partners, as well as sexual practice. The section on community examines the role of HIV/AIDS-related organisations and publications. The section on finances examines the experience of poverty and changes in accommodation. The section on employment explores the movement of PLWHA in and out of the work force.

Health Status and Management

The survey reveals that 99% of PLWHA have taken a CD4/T-cell test and 96% have taken a viral load test. This provides a strong indication that PLWHA are actively engaged in monitoring their health status. This includes those who may not be currently using anti-viral treatments.

The majority of PLWHA rate their health positively with nearly three-quarters describing their health as excellent or good. Despite this, nearly one-third of PLWHA - a very significant minority - report having at least one major health condition other than HIV/AIDS. The most common other conditions reported were Hepatitis C (6%) and psychological or psychiatric conditions (6%). The coexistence of major health conditions as described poses considerable challenges for the coordination and delivery of health services.

PLWHA have long had a reputation for being pro-active in the management of their own health and for their high levels of engagement with new medical information about the management of HIV. The results of this survey support this reputation, showing that over 80% of PLWHA like to find out as much as they can about medical aspects of HIV and that over one-third consider themselves to be more knowledgeable about the treatment of HIV than the doctors who treat them. Not surprisingly, most (85%) people with HIV/AIDS work together with their doctors in their decision-making around treatments.

Despite significant educational efforts encouraging early treatment, respondents remain unconvinced about the optimal time to begin treatments. When asked whether people with HIV/AIDS should begin treatments as early as possible, over half either disagreed (26%) or were unsure (27%).

Anti-viral Treatments, Prophylaxis and Complementary Therapies

Given the complexity and novelty of current treatment regimes, the survey reveals extremely high rates of use of anti-viral treatments. Seventy eight per cent of respondents were using anti-viral treatments, and of these, 85% were using three or more in combination. Nonetheless, among those not using anti-virals, there remains a substantial group of PLWHA (38% of those not using anti-virals) who current evidence suggests are at high risk of disease progression.

The high rates of anti-viral use are especially noteworthy given that over two-thirds of respondents experience side-effects from the treatments and that over three-quarters experience difficulties such as remembering to take medications on time and organising medications around meals.

The significance of the relationship PLWHA have with their doctors is revealed in the finding that despite high levels of treatments knowledge among PLWHA themselves, over three-quarters of respondents began treatments on the advice of their doctor.

Among those respondents who were not using anti-viral treatments, over one-quarter had used them at some stage in the past. Problems with side-effects were by far the most common reason for ceasing anti-viral use. Most (84%) PLWHA who were not currently treating were open to the possibility of commencing treatment in the future, and most of these (83%) would be influenced by signs that their health was deteriorating.

The majority of PLWHA (59%) believe that the new treatments have brought hope and better prospects. However, over one-third of PLWHA say that it is too soon to tell whether the new treatments mean better prospects. Individual PLWHA see themselves as more uncertain about the new treatments than the broader HIV community.

The current moment in the HIV/AIDS epidemic has been characterised by many commentators as encompassing both hope and uncertainty. These sentiments were reflected in the responses of PLWHA to a series of attitude statements about anti-viral treatments. For instance, while most (66%) PLWHA agree that new treatments have made life better, a similar number (75%) report being worried that their medication may stop working for them at some stage in the future. These anxieties are tempered by the hope many (72%) PLWHA have that, despite the absence of data on their long-term effectiveness, the treatments may assist them to remain well.

Complementary therapies remain an important part of most PLWHA's treatment regime. Half of all PLWHA use some form of complementary therapy and spend on average \$20 per week. About half of all PLWHA use vitamin or mineral supplements and about one-quarter use massage, herbal therapies, or meditation.

Relationships and Sex

One in five PLWHA are not presently having sex, while 50% have sex within a regular relationship - half of whom have casual partners as well, and slightly less than one-third have casual sex only.

Half of the respondents said they are in a regular relationship. Of these slightly more than half are in sero-nonconcordant relationships.

The great majority of PLWHA (97%) who are in regular relationships have disclosed their HIV status to their regular partner. Most partners (67%) were supportive in reaction to this disclosure.

Generally new treatments are having a positive impact on relationships. More than half reported that they are more able to plan their future and two-thirds agreed that they are more optimistic about the future than they were a year ago.

PLWHA generally do not believe that HIV/AIDS is a hindrance to developing long-term relationships but slightly more than half do worry about rejection by potential sexual partners in response to disclosure of their HIV status. More than two-thirds agree that they are afraid of infecting their partner, or potential partner, with HIV.

The availability of the new treatments does not appear to have made PLWHA more confident about having unprotected sex. However, the impact of the new treatments environment in other areas was less certain. PLWHA tended to agree that people with

HIV now have a better chance to form relationships, but only one-third agree that relationships with family and friends are improving due to new treatments.

Slightly more than half of the respondents said they would prefer to have a relationship with another PLWHA. These people tended to be bisexual and homosexual men.

Compared to PLWHA in seroconcordant relationships, PLWHA in sero-nonconcordant relationships were significantly more likely to report that they always use condoms and less likely to report that they never use condoms. Almost two-thirds of PLWHA who reported unprotected anal and/or vaginal sex with a regular partner in the 6 months prior to the survey sometimes or always withdrew before ejaculation and this practice was not related to the serostatus of the partner.

Of those PLWHA who engaged in anal and/or vaginal sex with a casual partner in the six months prior to completing the survey, more than half had sex with both HIV-positive and HIV-negative casual partners, or did not know their partner's status. Almost all respondents who had casual sex said they always or sometimes used condoms. Of those PLWHA who sometimes had unprotected sex only a small number said they never withdrew before ejaculation. Again this practice was not related to the serostatus of the partner.

Community Life and Community Organisations

Almost all PLWHA (99%) have disclosed their status to at least one person. Of those with dependant children, half have told their children they are HIV-positive. One in ten respondents said that they have experienced discrimination at some stage.

Half of the respondents said they have changed their plans for the future in the last two years. The majority of these changes were positive but one in five were negative due to declining health.

When seeking advice for both treatment and living with HIV/AIDS respondents most commonly cite their doctor as an important source of information (91%). PLWHA also relied heavily on HIV/AIDS media, the gay press and other HIV-positive friends for information.

Over three-quarters of the respondents had some involvement with HIV/AIDS organisations. Two-thirds of the respondents are in contact with an AIDS Council and over half have contact with a PLWHA organisation (this finding is likely to be influenced by the fact that these organisations were a distribution source for the survey). Contact with organisations tends to be in the form of newsletters and mail-outs, and many PLWHA receive treatments advice and social contact. PLWHA who do not have contact with any HIV/AIDS organisations said this is so because they do not wish to be involved or are not interested. However, a small number (15% of those not involved) said they feel excluded and 7% are unable to have contact because of where they live or the lack of transport available to them.

Most respondents (96%) know at least one other HIV-positive person, mostly friends, acquaintances and past or present sexual partners. Likewise most PLWHA (85%) spend at least some of their free time with other HIV-positive people and just over half have, at some time, been involved in the care of another person with HIV/AIDS. The majority of respondents (81%) said they have lost someone to HIV/AIDS - most commonly a close friend or relative.

Over two-thirds of respondents see themselves as being part of the gay community and, not surprisingly, most of these people are homosexual men. Half of the respondents are also members of gay organisations, and the majority of respondents go to gay venues such as nightclubs, bars and saunas.

Finances

The majority of respondents have difficulty meeting the expenses of day-to-day living. This is not surprising given that over half of respondents reported a government benefit as their main source of income.

One-third (32%) of respondents reported incomes below the poverty line. One-third of respondents share financial resources with a partner, and this protects PLWHA from some of the extremes of economic hardship. Very few people who are earning an income from paid employment reported incomes below the poverty line.

People with incomes below the poverty line have fewer assets and are more likely to rely on HIV/AIDS-related organisations for a variety of services and facilities. A significant minority of respondents (11%) have incomes below the poverty line and assets worth less than \$5,000.

Housing and accommodation

Slightly fewer than half of PLWHA live alone, and just over half live in rental accommodation, typically private rental accommodation. Forty per cent of PLWHA live in inner city Sydney where the average weekly rent or mortgage cost is \$136.

Nearly half of all PLWHA felt their accommodation was too expensive. Many PLWHA had changed their living arrangements as a result of having HIV/AIDS, typically for reasons related to finances.

Employment

Over half of PLWHA are not in paid employment, although the majority were in paid employment at the time they were diagnosed HIV-positive. Most PLWHA left their career or in some way reduced their career goals after their diagnosis.

Over one-third of PLWHA have not disclosed their HIV status to anyone at their workplace, and most have difficulty maintaining their confidentiality. Thirteen per cent of respondents have experienced workplace discrimination.

Nearly two-thirds of respondents have stopped work at some time in the past for reasons related to having HIV/AIDS. Three-quarters cited stress, depression or anxiety as the reason for stopping work, and half cited poor health. Over half of the respondents changed their accommodation arrangements within a few months of leaving work. Of those who had left work, one-third returned to work, typically for financial reasons.

The effects of the new anti-virals on PLWHA's employment appears to be largely positive, with many PLWHA considering staying at work or returning to work.

One-quarter of those working said that HIV/AIDS has affected their capacity to work. Over one-third of respondents are considering changing the amount of work they do. About half of these want to work less - to reduce stress, or due to poor health. About half want to increase the amount of work they do, mainly for financial reasons.

The majority of PLWHA who are not working are considering returning to the workforce, but most think that this will be difficult to do so. Just under half of PLWHA cited improved health as a reason for wanting to return to work, while the majority cited financial reasons, and psychological, emotional or social reasons for wanting to return to work.

2 Introduction

In many ways Australia leads the world in its response to HIV/AIDS. Australia's early responses to the HIV/AIDS crisis significantly limited the impact of the epidemic in comparison to similar countries elsewhere in the world. They laid the groundwork for continuing successful efforts in both limiting the spread of HIV and in ameliorating its impact. In the late 1990s, new challenges are appearing. Advances in treatments hold out the hope of longer life expectancies and are provided within a medical system which promises universal access to these medications. In this broader context, the longer-term consequences of living with HIV/AIDS are becoming an increasingly important issue for people living with HIV/AIDS (PLWHA) in Australia. While new treatments remain a central concern for many PLWHA, relationships, community identity, employment, finances and housing are also of major importance. For example, many PLWHA are considering returning to work as a consequence of improved health. The interlocking 'HIV Futures' studies, of which the HIV Futures Survey reported here is one part, take as their starting point an investigation of the various ramifications of the changed perception and experience of HIV on the ways that people living with HIV/AIDS live their lives.

The HIV Futures Survey draws together the largest sample of PLWHA to have been surveyed in Australia. The 925 respondents represent over eight per cent of the current population of PLWHA in Australia. While a substantial number of the participants are gay men living in Sydney, the survey includes significant numbers of PLWHA from smaller sub-populations such as women and people living outside New South Wales and Victoria. The survey has good national coverage with respondents from all states and territories, and from both rural and urban locations.

This report aims to further our understanding of how the longer-term impacts of HIV/AIDS and the new treatments affect the choices made by PLWHA about

relationships and sexual behaviour, moving in and out of work, and community participation. We hope that this report will provide PLWHA and government and community bodies with a better understanding of the issues facing PLWHA. We also hope that this increased understanding can be used to inform decisions and develop strategies and policy.

The survey examines five main issues: health, relationships, community life, finances, and employment. The section on health focuses on PLWHA's experiences of, and attitudes toward, the new anti-viral treatments, in particular the new class of protease inhibitor drugs which have become increasingly available since the latter part of 1995. The section on relationships explores the changing nature of relationships with family, friends and partners, as well as sexual practice. The section on community examines the role of HIV/AIDS-related organisations and publications. The section on finances examines the experience of poverty and changes in accommodation. The section on employment explores the movement of PLWHA in and out of the work force.

This report is the first of a number of planned reports as part of the HIV Futures Study. It provides the basic descriptive data from the survey, together with analysis of some of the most important associations which the data reveal. Future reports will examine in more detail the interactions between treatments, health, relationships, community, finances and work as they shape the lives of Australian PLWHA. Among the important issues identified in this report, but requiring more detailed analysis, is the number of PLWHA who also have another major health condition, such as Hepatitis C. Similarly, reports will be prepared in relation to specific sub-populations of PLWHA, such as those living in particular regions, women, heterosexual men and gay/bisexual men. Information from the HIV Futures Survey will also be added to other HIV Futures studies. Two sets of qualitative interviews have been conducted along with the survey. One provides additional close-focus data on relationships and sexual practice and another focuses on movements in and out of work.

3 About the Sample

3.1 Recruitment

A stratified purposive sampling strategy was utilised to sample people living with HIV/AIDS in Australia. Recruitment involved distribution of self-administered mail back questionnaires through HIV/AIDS organisations, a number of mailing lists, and through a targeted advertising campaign. The mailing lists included those of four free publications that provide information about living with HIV/AIDS. These publications were *Talkabout* (New South Wales), *PL* (Western Australia), *QPP Alive* (Queensland), and *Positive Living* (Victorian recipients of the national newspaper insert). It is not possible to know what proportion of the recipients of these magazines are HIV-positive, and as a consequence response rates cannot be calculated.

The recruitment period was from 1 July 1997 through 5 September 1997. Additional targeted distribution occurred in order to ensure the sample included sufficient numbers to enable statistical comparisons from groups which have distinctive issues and experiences and who may not have been contacted through the main distribution channels. These groups included women, people living with Haemophilia, and people living outside of New South Wales and Victoria.

3.2 Sample demographics

The survey was completed by 925 respondents: 834 men and 84 women (seven respondents did not indicate their sex). The sample represents 8.3% of the current population of people living with HIV/AIDS in Australia as estimated by the *Australian HIV Surveillance Report* (National Centre in HIV Epidemiology and Clinical Research [NCHECR], 1997).

Respondents' ages ranged from 18 to 77 years (median = 38.0 years, mean = 39.3 years). Respondents' ages at the time of diagnosis with HIV ranged from 4 to 70 years (median = 31.0 years, mean = 31.8 years). The average length of time since respondents first tested HIV-positive was 7.4 years. Half of the respondents have been HIV-positive for 8 or more years, and half have been HIV-positive for less than 8 years. One-third have been HIV-positive for 10 years or more.

Of the 925 PLWHA who completed the survey, 74% said they are homosexual, 16% are heterosexual and 8% are bisexual. Men and women were distributed through these categories. Three respondents (< 1%) said they are asexual, and 1 respondent (<1%) said they are celibate. Fourteen respondents (2%) did not indicate their sexual orientation.

Respondents were asked to indicate how they believe they were infected with HIV. Table 1 presents these results, grouped into the categories used by the National Centre in HIV Epidemiology and Clinical Research in the Australian HIV Surveillance Report.

Table 1 Mode of transmission of HIV

Perceived mode of transmission	n	%
Male homosexual/bisexual contact	707	(76%)
Heterosexual contact	73	(8%)
Male homosexual/bisexual contact and injecting drug use	36	(4%)
Injecting drug use (female and heterosexual male)	33	(4%)
Haemophilia/coagulation disorder	24	(3%)
Receipt of blood components/tissue	21	(2%)
Health care setting	13	(1%)
Not specified	18	(2%)

n = 925

Of the 925 PLWHA who completed the survey 404 (44%) reside in New South Wales, 213 (23%) in Victoria, 135 (15%) in Queensland, 78 (8%) in South Australia, 50 (5%) in Western Australia, 9 (1%) in the Northern Territory, 12 (1%) in the Australian Capital

Territory, and 8 (1%) in Tasmania. Sixteen respondents (2%) did not indicate in which state they live.

Most respondents (62%) live in the inner suburbs of capital cities, while 18% live in outer suburban areas, 12% live in a regional centre, 8% live in a rural area.

Approximately three-quarters (76%) of respondents identify their ethnic/racial background as Anglo-Australian. The most frequently cited other ethnic/racial background was European (19%), with 3% citing an Aboriginal/Torres Strait Islander background, and 1% citing an Asian background.

Generally, respondents reported high levels of education. Half of the respondents have completed some form of tertiary education. One-quarter (26%) have completed a university degree and 22% have completed a tertiary diploma or TAFE education. A further 24% have completed secondary education, 27% have completed some secondary education, and 1% have completed primary school.

Nearly one-third (30%) of the PLWHA who completed the survey said they have no religious beliefs or that they are atheists. A further 8% said that they are agnostic. Approximately one-third profess Christian beliefs. Of those respondents, 13% are Catholic, 12% are Anglican/Church of England, and 13% have *other Christian* beliefs. Ten per cent of respondents have *new age* religious beliefs, and 5% are Buddhist. While more than half of the sample profess some religious belief, fewer than half attend religious meetings. Most (56%) respondents do not attend religious meetings, while 16% attend less than once a year, 13% attend at least once a year, 8% attend at least once a month, and 7% attend religious meetings at least once a week.

3.3 Representativeness of the sample

To assess the degree to which the sample recruited for this study is representative of all PLWHA in Australia, comparisons were made with the *Australian HIV Surveillance Report* (NCHECR, 1997). As a consequence of the deliberate sampling strategy to include larger numbers of marginalised groups, the Futures survey under-represents PLWHA from New South Wales. The survey over-represents women, people who have had an AIDS-defining illness, and people infected through: receipt of blood products; haemophilia/coagulation disorder and in health care settings.

The results reported in the remainder of the Report below are weighted to take account of the under-representation of PLWHA from NSW, and the over-representation of women, people with medically acquired HIV and people with AIDS. The data were weighted to take into account the differences in demographic data reported in the *Australian HIV Surveillance Report* (NCHECR, 1997).

A range of statistical comparisons are made in this report. For clarity, the results of these analyses (χ^2 -tests, t-tests, ANOVA, and logistic regression) are not reported in this report. All significant differences reported are significant at $p < .01$.

3.4 Further analysis

The analyses reported here include some detailed comparisons of the experiences of different subgroups of PLWHA. However, future publications will examine some issues in more detail than is possible in this first report. For example, the distinctive experience of women, and of PLWHA also infected with Hepatitis C are occasionally commented on, but the experiences of both of these groups will be analysed in greater detail in future reports.

4 Health Status and Health Management

Key Findings

The survey reveals very high rates of CD4/T-cell and viral load testing among PLWHA. This provides a strong indication that PLWHA are actively engaged in monitoring their health status. This includes those who may not be currently using anti-viral treatments.

The majority of PLWHA rate their health positively with nearly three-quarters describing their health as excellent or good. Despite this fact, nearly one-third of PLWHA - a substantial minority - report having at least one major health condition other than HIV/AIDS. The most common other conditions reported were Hepatitis C and psychological or psychiatric conditions. The coexistence of major health conditions as described poses considerable challenges for the coordination and delivery of health services.

PLWHA have long had a reputation for being pro-active in the management of their own health and for their high levels of engagement with new medical information about the management of HIV. The survey supports this reputation, showing that over 80 per cent of PLWHA like to find out as much as they can about medical aspects of HIV and that over one-third consider themselves to be more knowledgeable about the treatment of HIV than the doctors who treat them. Not surprisingly, the vast majority of people with HIV/AIDS work together with their doctors in their decision-making around treatments.

Despite significant educational efforts encouraging early treatment, PLWHA remain unconvinced about the optimal time to begin treatments. When asked whether people with HIV/AIDS should begin treatments as early as possible, over half either disagree or are unsure.

4.1 Health status of respondents

4.1.1 What do PLWHA know about their CD4 and viral load counts?

Nearly all of the PLWHA who completed the survey (99%) have taken a CD4/T-Cell test. The results of respondents' most recent CD4/T-Cell tests ranged from 0 to 1400 cells/mL (median = 390 cells/mL, mean = 418 cells/mL).

Among the PLWHA who have taken a CD4/T-Cell test, 82% reported that at some time in the past they have had a CD4 /T-Cell count below 400 cells/mL, and 54% reported that at some time in the past they have had a CD4 /T-Cell count below 200 cells/mL.

The number of PLWHA who have taken a viral load test was also high (96%). The results of respondents' most recent viral load tests ranged from an undetectable level to 6,000,000 copies/mL (median = 1,000 copies/mL, mean = 58,585 copies/mL).

Table 2 Serological testing

Test	copies/mL blood	n	%
CD4/T cells			
little/no immune system damage	more than 500	264	(31%)
moderate immune system damage	250 - 500	340	(40%)
severe immune system damage	less than 250	249	(29%)
Viral load			
below detectable level	less than 500	367	(46%)
low	500 - 10,000	212	(26%)
moderate	10,000 - 50,000	112	(14%)
high	more than 50,000	114	(14%)

1 - n = 903 for CD4/T-cell test; n = 872 for viral load test

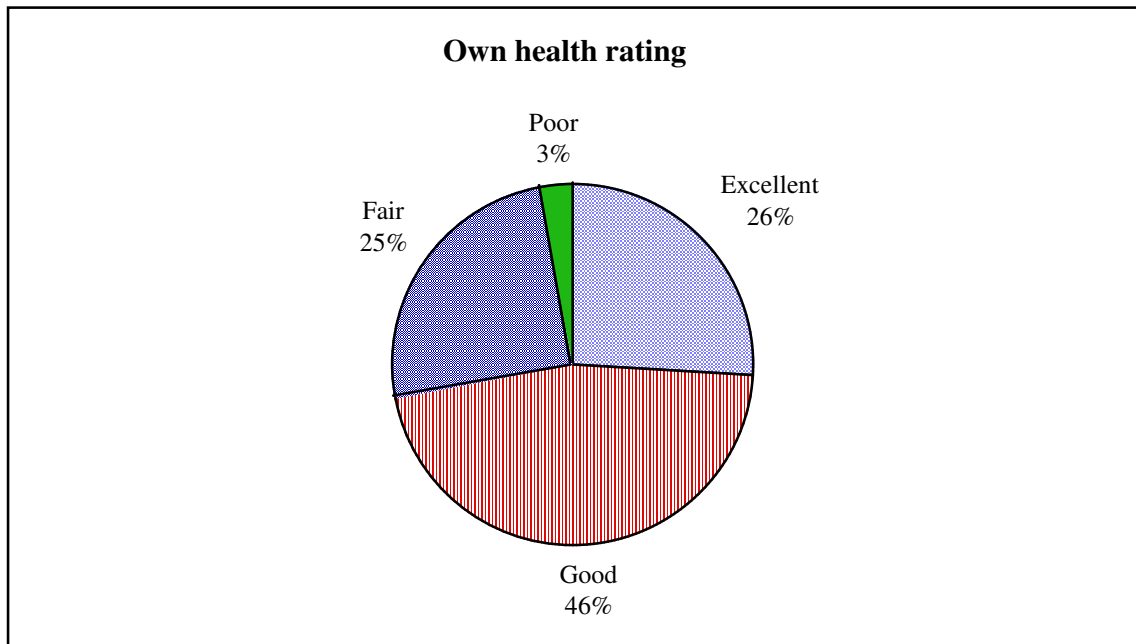
The 4% of participants in the study who have not taken a viral load test gave the following reasons for not having done so: *I don't believe that I need one* (47%); *I don't know enough about viral load tests* (18%); *I'm scared of the results* (18%); *I haven't been*

offered one (9%); I haven't gotten around to it (6%); and I don't know how to obtain one (6%).

4.1.2 How do PLWHA rate their own health?

Many respondents reported that their current state of physical health is *good* or *excellent*. Compared to respondents who have not been diagnosed with an AIDS-defining illness, respondents who have been diagnosed with an AIDS-defining illness were significantly more likely to report that their health is *poor* or *fair*, and significantly less likely to report that their health is *excellent*. In contrast to a recent American study (Richter et al., 1998), no relationship was found between current health and use of anti-virals.

Graph 1 PLWHA's ratings of their current physical health



n = 914

4.1.3 What major health conditions other than HIV/AIDS do PLWHA report?

Slightly fewer than one-third (29%) of the PLWHA who completed the survey reported that they have at least one major health condition other than HIV/AIDS. The most commonly cited major health conditions were Hepatitis C and psychological/psychiatric conditions (both 6% of total sample). Other commonly cited health conditions included Asthma, Arthritis, Cardiovascular disease, Diabetes, Haemophilia, Hepatitis B, Hypertension (2%); alcoholism/drug dependence, back injury/back pain, Cancer (non-

Kaposi sarcoma), Epilepsy, liver disease and lung disease (eg. Emphysema) (1%). There was no association between diagnosis with an AIDS-defining illness and reporting any major health conditions other than HIV/AIDS.

Of the PLWHA who completed the survey, 29% reported that they have been diagnosed with Hepatitis A, and 36% reported that they have been diagnosed with Hepatitis B. The majority of respondents (53%) have been tested for Hepatitis C. Among those who have been tested, 67% tested negative for Hepatitis C, 27% tested positive for Hepatitis C, and 6% do not know the result of their test. Given the high levels of Hepatitis C among respondents who have tested for it, it may be that there is a small but substantial level of undiagnosed Hepatitis C among PLWHA.

4.2 Attitudes towards health management

Respondents were asked a series of questions which assessed their attitudes toward treatments for HIV/AIDS other than anti-viral drugs, and health management in general. Their responses are displayed in Table 3. The vast majority of respondents agree that looking after their physical fitness and keeping an optimistic frame of mind are an important part of living with HIV/AIDS. Nearly two-thirds (62%) of respondents strongly agree that *Keeping an optimistic frame of mind is an important part of managing my HIV infection*, and over one-third (36%) strongly agree that *Looking after my physical fitness is an important part of managing my HIV infection*. It is interesting to note that although the majority (68%) of respondents think that their doctor knows a lot more than them about treatments for HIV/AIDS, over three-quarters (85%) of the PLWHA who completed the survey reported that they work together with their doctor to determine the best treatment regime for them. A significant relationship was found between responses to these two attitude items such that respondents who believe that their doctor knows more than them about treatments tended to report that they work together with their doctor to find the best treatment for them (94% vs 83%). Respondents seemed to be divided on the issue of when PLWHA should begin using anti-viral drugs. While nearly half (47%) agree that

PLWHA should begin anti-viral therapy as soon as possible, one-quarter (26%) disagree, with the remainder (27%) unsure as to whether early intervention is desirable.

A significant relationship was found between certain attitudes toward health management and whether or not PLWHA are using anti-viral drugs. Compared to PLWHA who are not using anti-virals, PLWHA who were using anti-virals are significantly more likely to agree that:

- their doctor knows a lot more about the treatment of HIV than they do;
- they work together with their doctor to find the best treatment; and
- people with HIV should start using anti-viral drugs as soon as possible .

The last result echoes the results of a study of American PLWHA (Richter et al. 1998) which revealed that PLWHA with more favourable attitudes toward anti-virals were significantly more likely to be using these drugs than PLWHA with less favourable attitudes.

Table 3 Attitudes toward health management

Attitude statement	strongly disagree		disagree		agree		strongly agree		don't know	
	n	%	n	%	n	%	n	%	n	%
As long as I am well I prefer not to think about HIV/AIDS	172	(19%)	397	(44%)	234	(26%)	92	(10%)	11	(1%)
My doctor knows a lot more about the treatment of HIV than I do	75	(8%)	192	(21%)	416	(46%)	196	(22%)	27	(3%)
I like to find out as much as I can about the medical studies of HIV	13	(1%)	108	(12%)	462	(51%)	296	(33%)	27	(3%)
Looking after my physical fitness is an important part of managing my HIV infection	12	(1%)	46	(5%)	502	(55%)	326	(36%)	23	(3%)
Keeping an optimistic frame of mind is an important part of managing my HIV infection	10	(1%)	11	(1%)	313	(34%)	559	(62%)	15	(2%)
My doctor and I work together to find the best treatment for me	14	(2%)	69	(8%)	440	(49%)	351	(39%)	29	(3%)
People with HIV should start using anti-viral drugs as soon as possible	79	(9%)	151	(17%)	193	(21%)	238	(26%)	244	(27%)

n = 903 - 909 n varies from item to item due to missing data

5 Anti-viral Treatments, Prophylaxis and Complementary Therapies

Key Findings

The survey reveals very high rates of use of anti-viral drugs. Seventy-eight per cent of respondents are using anti-viral treatments and of these most are using three or more in combination. Nonetheless, there remains a large number of PLWHA who current evidence suggests are at high risk of disease progression who are not using anti-viral drugs.

The high rates of anti-viral use are especially noteworthy given that over two-thirds of respondents experience side-effects and that over three-quarters experience difficulties such as remembering to take drugs on time and organising medications around meals.

The significance of the relationship PLWHA have with their doctors is revealed in the finding that despite high levels of treatments knowledge among PLWHA themselves, over three-quarters of respondents began treatments on the advice of their doctor.

Among PLWHA who are not using anti-viral treatments, over one-quarter have used them at some stage in the past. Problems with side-effects were by far the most common reason for ceasing anti-viral use. The vast majority of PLWHA who are not treating are open to the possibility of commencing treatments in the future, and most of these would be influenced by signs that their health was deteriorating.

The majority of PLWHA believe that the new treatments have brought hope and better prospects. However, over one-third of PLWHA say that it is too soon to tell whether the new treatments mean better prospects. For example, while most PLWHA agree that new treatments have made life better, a similar number report being worried that their medication

may stop working for them at some stage in the future.

Complementary therapies remain an important part of most PLWHA's treatment regime. Half of all PLWHA use some form of complementary therapy. About half use vitamin or mineral supplements and about a quarter use massage, herbal therapies, or meditation.

5.1 About PLWHA who are using anti-viral treatments

5.1.1 *How many PLWHA are using anti-viral drugs?*

Over three-quarters (78%) of the PLWHA who completed the survey are using anti-viral drugs for HIV/AIDS. This figure is substantially higher than the 68% reported in a study conducted by the NCHSR in November 1996 (Ezzy et al., 1997). It is likely to reflect the continuing clinical evidence of the impact of the treatments, especially in reducing viral load in the period between the two surveys. Women are significantly less likely than men to be using anti-viral drugs (58% vs 79%).

5.1.2 *In what combinations are drugs being taken?*

Among the respondents who are using anti-viral drugs, 2% are using one anti-viral drug, 13% are using two anti-viral drugs, and 85% are using three or more anti-viral drugs. Therefore, 76% of the PLWHA who completed the survey are using two or more anti-viral drugs in combination.

The AFAO guide *HIV Tests and Treatments* recommends starting or changing combination therapy for PLWHA who have:

- a viral load more than 10,000 copies/mL blood and a declining CD4 count; or
- a viral load more than 50,000 copies/mL blood regardless of CD4 count.

Twenty two per cent of respondents were not using anti-viral treatments. By using the respondents' reports of their most recent viral load test result and their CD4 test results during the 12 months prior to completing the survey, it was possible to determine the proportion of PLWHA who should be using anti-viral therapy according to the AFAO guide. Of the 200 people in the survey who were not using anti-virals, 38% should be using anti-virals given their reported CD4 and viral load results.

5.1.3 *Are these data reliable?*

Over three-quarters (76%) of the PLWHA who completed the survey are using combination anti-viral drugs for HIV/AIDS. However, because the survey was distributed through both PLWHA organisations and medical services, PLWHA who have no contact with either PLWHA organisations or medical services may be under-represented. In the absence of any external data on the proportion of PLWHA with no contact with either PLWHA organisations or medical services, it can be assumed that the figure of 76% of PLWHA using two or more anti-viral drugs in combination in this survey is a high estimate of the proportion of all PLWHA using two or more anti-viral drugs in combination in Australia. However, it should be noted that respondents who received a copy of the survey through a HIV/AIDS-related organisation or through a medical service were no more likely than other respondents to use anti-viral drugs.

5.1.4 *Are viral load or CD4 counts different among PLWHA using anti-viral drugs and PLWHA not using anti-viral drugs?*

Participants who have been diagnosed with an AIDS-defining illness are significantly more likely to be using anti-viral drugs for HIV/AIDS (89% vs 75%) than those who have not been diagnosed with AIDS. Use of anti-viral drugs is also related to the results of serological testing. A significant relationship was found between use of anti-viral drugs for HIV/AIDS and CD4/T-cell count. Compared to people who are not using anti-viral drugs for HIV/AIDS, respondents who are using anti-viral drugs are significantly more likely to report *severe* immune damage (CD4/T-cell count less than 250 copies/mL) and significantly less likely to report *little or no* immune damage (CD4/T-cell count greater than 500 copies/mL).

A significant relationship was also found between use of anti-viral drugs for HIV/AIDS and viral load. Compared to people who are not using anti-viral drugs for HIV/AIDS, participants who are using anti-viral drugs are significantly more likely to report

undetectable viral loads, and significantly less likely to report *moderate* or *high* viral loads. Table 4 displays respondents' reports of the results of their most recent CD4/T-cell test and their most recent Viral Load test.

Table 4 Relationship between serological test results and use of anti-viral drugs

Test	copies/mL	using anti-virals			
		yes ¹		no ²	
		n	%	n	%
CD4/T cells					
little / no immune system damage	more than 500	144	(26%)	90	(52%)
moderate immune system damage	250 - 500	227	(40%)	63	(36%)
severe immune system damage	less than 250	193	(34%)	21	(12%)
viral load					
below detectable level	less than 500	304	(54%)	20	(15%)
low	500 - 10,000	146	(26%)	40	(30%)
moderate	10,000 - 50,000	56	(10%)	36	(27%)
high	more than 50,000	56	(10%)	37	(28%)

1 - n = 564 for CD4/T-cell test, n = 562 for viral load test (includes only those using anti-viral drugs for more than 6 months)

2 - n = 174 for CD4/T-cell test, n = 133 for viral load test (includes only those not using anti-viral drugs for more than 6 months)

5.1.5 What side-effects are experienced?

As can be seen in Table 5, over two-thirds (68%) of the respondents who are using anti-viral drugs for HIV/AIDS reported that they experience side-effects. Nearly one-third (31%) of all PLWHA who are using anti-viral drugs experience nausea, and over one-quarter (27%) experience diarrhoea. Many respondents reported that anti-viral drugs affect their nervous system. Nine per cent reported peripheral neuropathy, which, although it may be reversed by a change of drugs, can cause permanent damage to the peripheral nervous system. Although respondents were not asked about side effects they have experienced in the past, many study participants noted on the survey that they have experienced side-effects from different drugs or from different combinations of drugs in the past. Four per cent of respondents also reported that anti-viral drugs conflict with medication taken for conditions other than HIV/AIDS.

Table 5 Side effects and difficulties in taking anti-viral medication

Difficulties	n	%	n	%
Side effects of anti-viral drugs			482	(68%)
nausea	217	(31%)		
diarrhoea	190	(27%)		
headaches	112	(16%)		
fatigue / lethargy	87	(12%)		
skin dryness / rashes / itchiness	69	(10%)		
neuropathy	67	(9%)		
gastric reflux / indigestion	56	(8%)		
metallic taste / tingling / numbness in mouth	50	(7%)		
insomnia	43	(6%)		
vomiting	34	(5%)		
pain (joint and/or muscle)	29	(4%)		
loss of appetite	23	(3%)		
dizziness, blurred vision, etc.	23	(3%)		
bloated stomach	17	(2%)		
depression	16	(2%)		
flatulence	15	(2%)		
mood swings / irritability	15	(2%)		
Anti-viral drugs conflict with other medication			31	(4%)

Multiple responses possible

† - Proportion of those who are using anti-viral drugs, n = 710

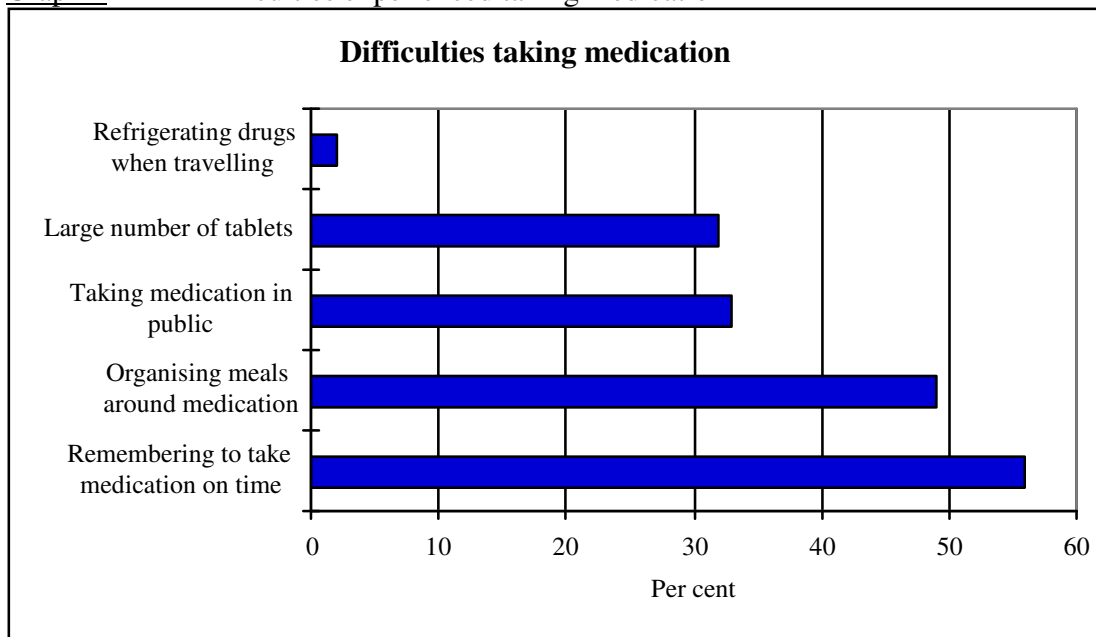
- Side-effects and difficulties reported by less than 2% of respondents not shown in table

5.1.6 What difficulties do PLWHA have using anti-viral treatments?

The majority of respondents (79%) who are using anti-viral drugs reported that they experienced difficulties in taking this medication. Graph 2 shows that over half (56%) of the PLWHA who are using anti-virals have difficulties remembering to take their medication on time or having to adapt normal sleep patterns to the treatment regime, and that half (49%) have difficulties organising their meals around medication (eg, fasting before taking medication). One-third (33%) of the respondents also reported that they have difficulty taking these drugs in public because they do not want people to know their HIV status. When taken with the finding that one in three PLWHA using anti-virals reported that they have difficulties taking large numbers of tablets, the results reported

above have potentially serious implications for long-term compliance with treatment regimes unless less complicated and burdensome treatment regimes can be developed.

Graph 2 Difficulties experienced taking medication



n = 710 Proportion of all PLWHA using anti-viral drugs

Respondents who have been diagnosed with an AIDS-defining illness are just as likely as other PLWHA to report that: they experience side-effects from anti-viral drugs; they have difficulties taking anti-virals; they have difficulties taking this medication in public; and anti-viral drugs conflict with medication taken for other health conditions. There was no gender difference in the proportion of PLWHA using anti-viral drugs for HIV/AIDS who reported side-effects, difficulties taking medication, difficulties taking medication in public, or conflict with medication for other health conditions.

5.1.7 How long have PLWHA been using anti-viral drugs?

The 76% of study participants who are using combination therapy have been doing so for periods ranging from less than 2 weeks to 10 years. However, the median time for which respondents have used combination therapy is 12 months (mean = 17 months). This suggests that the majority of PLWHA using more than one anti-viral drug had started combination therapy after the advent of new treatments, in particular, protease inhibitors.

5.2 About PLWHA who are using combination anti-viral treatments

5.2.1 What were PLWHAs viral load and CD4 counts when they began combination anti-viral treatment?

Table 6 displays the viral loads and CD4/T-cell counts of respondents just before they started combination therapy. The data in the table suggest that few people begin combination therapy with high CD4/T-cell counts and/or viral loads below the detectable level as most respondents (58%) had CD4/T-cell counts indicating severe immune system damage, and nearly half of the respondents (48%) had viral loads categorised as *high*.

Table 6 Serological test results just prior to commencing combination therapy

Test	copies/mL	n	%
CD4/T cells			
little / no damage	more than 500	50	(8%)
moderate damage	250 - 500	217	(34%)
severe damage	less than 250	369	(58%)
Viral load			
test not available	-	149	(25%)
below detection	less than 500	12	(2%)
low	500 - 10,000	42	(7%)
moderate	10,000 - 50,000	100	(17%)
high	more than 50,000	290	(48%)

n = 636 for CD4/T-cell test, n = 593 for viral load test

5.2.2 How do PLWHA rate their health and well-being since beginning combination anti-viral treatment?

Nearly half (46%) of the PLWHA using anti-viral drugs reported that their physical health has improved since they started combination therapy. However, 25% reported that their physical health has fluctuated, 27% reported no change in their physical health, and 2% reported a deterioration in their physical health.

Similarly, nearly half (47%) of the PLWHA using anti-viral drugs reported an improvement in their overall feeling of well-being since starting combination therapy, while 28% reported that their overall feeling of well-being has fluctuated. There was no reported change in their overall feeling of well-being for 21% of respondents, and 4% reported a deterioration in their overall feeling of well-being.

5.2.3 What happened just prior to beginning combination anti-viral treatment?

Participants who are using combination anti-viral drugs were asked to describe the events which occurred just prior to their commencement of combination therapy. Their responses are displayed in Table 7. The influence of the advice of doctors on people's decisions to commence combination therapy is evident - 79% reported that their doctor advised them to. However, it is also important to note that nearly half (47%) of the respondents reported that their decision to commence combination therapy was preceded by a personal decision that combination therapy is effective.

Table 7 Events occurring prior to commencing combination anti-viral therapy

Event	n	%
My doctor advised me to begin this treatment	543	(79%)
I had a significant drop in my CD4/T-cell count	323	(47%)
I decided that combination therapy is an effective treatment for HIV	321	(47%)
I became very ill	144	(21%)
I had a significant rise in my viral load	142	(21%)
A number of my positive friends began to take up combination therapy	142	(21%)
I began to see a doctor or was hospitalised due to HIV-related infections	105	(15%)

n = 687 Multiple response possible

5.3 About PLWHA who are not using anti-viral treatments

5.3.1 How many PLWHA have used anti-viral treatments in the past?

Just over one-quarter (28%) of the PLWHA who are not using anti-viral drugs for HIV/AIDS at the time of completing the survey have used these drugs in the past. Of these respondents, 41% used one anti-viral drug, 21% used two anti-viral drugs, and 39% had used three or more anti-viral drugs.

5.3.2 Why did PLWHA stop using anti-viral treatments?

The reasons these respondents gave for discontinuing use of anti-viral drugs are shown in Table 8. It is interesting to note the importance of side-effects of anti-viral drugs for HIV/AIDS. As noted earlier, over two-thirds of PLWHA using these drugs reported side-effects, and many have difficulties remembering to take drugs on time, spacing meals around medication and/or taking large numbers of pills. As shown in Table 8, among PLWHA who are not using anti-viral drugs but who have used them in the past, the most commonly cited reasons for ceasing use were severe side-effects and onset of neuropathy (another side-effect). Those respondents who had used anti-virals in the past but were not using them at the time of completing the survey had used them for periods ranging from 1 week to 6 years, with a mean of 13 months and a median of 6 months, so it appears that many respondents persisted with anti-viral drugs for some time before stopping taking them. The length of time since respondents had used these drugs ranged from two weeks to 7 years, (media = 13 months, mean = 28 months).

Table 8 Reasons given for discontinuing use of anti-viral drugs given by PLWHA who have used these treatments in the past

Reason for discontinuing use	n	%	n	%
Onset of neuropathy			44	(77%)
Side effects became too severe			34	(60%)
They were not working for me			14	(25%)
as indicated by CD4 and/or viral load tests	10	(18%)		
as indicated by physical health	2	(4%)		
other reasons	2	(4%)		
Taking drugs at the right time became too difficult			10	(18%)
The financial burden became too great			4	(7%)

n = 57

5.3.3 *What would prompt these PLWHA to recommence anti-viral treatments?*

The majority (84%) of PLWHA who were not using anti-viral drugs for HIV/AIDS at the time of completing the survey said that they would consider using these drugs at some time in the future. The answers respondents gave when asked why they would take up anti-viral treatments are displayed in Table 9. The most commonly cited reasons are

related to markers of declining physical health (eg, opportunistic infection, results of serological testing), but it is interesting to note that many people reported that their decision to commence use of anti-viral drugs is influenced by a belief in the efficacy and/or safety of these treatments.

Table 9 Reasons given for considering commencing use of anti-viral drugs in the future

Reason for considering anti-viral drugs	n	%
If I had a big drop in my overall health	38	(83%)
If I developed an opportunistic infection	32	(70%)
If I had a big drop in my CD4/T-cell count	32	(70%)
If I had a big rise in my viral load	31	(67%)
If I was certain that anti-viral treatment was an effective treatment for HIV	26	(57%)
If the drugs were shown to be safe in the long term	26	(57%)
If new drugs became available	19	(41%)
If a doctor recommended that I take up treatments	14	(30%)
If my positive friends recommended that I take up treatments	2	(4%)

n = 46 Multiple response possible

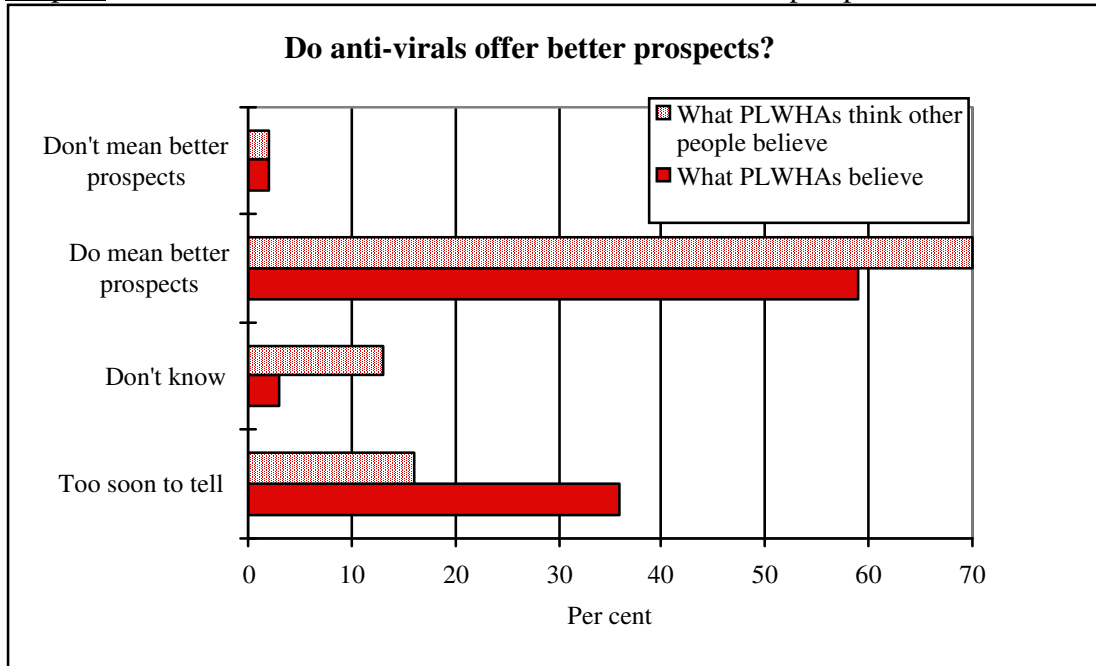
5.4 Attitudes towards anti-viral treatments (all respondents)

5.4.1 What do PLWHA believe others are saying about new anti-viral treatments and what do they think themselves?

Respondents were asked whether they think that combination anti-viral drugs mean better prospects for most people with HIV/AIDS and whether they think that other people believe that combination anti-viral drugs mean better prospects for most people with HIV/AIDS.

Most PLWHA (59%) believe that combination anti-viral drugs mean better prospects for most PLWHA, while 36% say that it is too soon to tell, 3% don't know and 2% do not believe that they mean better prospects. The data also reveal that most PLWHA (69%) think that other people believe combination anti-virals mean better prospects, while 16% think that others think that it is too soon to tell, 13% do not know what others think, and 2% think that other people do not believe that combination anti-virals mean better prospects. In other words, PLWHA as individuals are more cautious about the impact of treatments than they believe PLWHA in general are.

Graph 3 Do PLWHA believe that anti-virals offer better prospects?



n = 912

Responses to these two questions were not influenced by whether or not the respondents have been diagnosed with an AIDS-defining illness, but they were influenced by whether or not the respondent is using anti-viral drugs. Respondents who are using anti-viral drugs are more likely to report that they, and others, think that new treatments for HIV/AIDS mean better prospects for most PLWHA.

5.5 Attitudes towards combination anti-viral treatments

A series of questions assessed all respondents' attitudes toward combination anti-viral drugs. The responses are displayed in Table 10. These responses indicate that while nearly one-quarter (24%) of respondents believe that combination anti-viral drugs are harmful, most (57%) do not. Eighteen per cent of respondents gave a *don't know* response to this statement. Respondents were also asked more directly about the impact of combination anti-viral drugs on their own quality of life. While two-thirds (66%) of respondents agree with the statement *Combination anti-viral drugs have made my life better*, 15% disagree and a further 20% are unsure.

The overall impression given by the data in Table 10 is that most respondents do not think that current good health is a reason to not use anti-viral drugs, that most respondents believe that they have easy access to combination ant-retroviral drugs, and that most respondents believe that combination anti-viral drugs have made their life better.

A number of significant associations were found between use of combination anti-viral drugs and attitudes toward combination anti-viral drugs. Compared to respondents who are not using anti-viral drugs, respondents who are using anti-viral drugs are significantly more likely to strongly disagree that:

- they do not need to use combination anti-virals due to current good health;
- combination anti-viral drugs are harmful; and
- combination anti-viral drugs are ineffective.

Respondents using anti-viral drugs are also more likely than those not using anti-viral drugs to strongly agree that:

- it is easy for them to get combination anti-viral drugs; and
- combination anti-viral drugs have made their life better.

5.6 Attitudes towards anti-viral treatments (among those currently using them)

Respondents who are currently using anti-viral treatments were asked to respond to a number of attitude statements about these treatments. Their responses are displayed in Table 11.

The first row of the table highlights the fact that while many people (36%) believe that anti-viral drugs can restore their immune system, slightly more (42%) do not believe that this is possible, while nearly one-quarter (23%) do not know whether this is possible. In addition, many respondents are worried about the long-term efficacy of current medication

for HIV/AIDS. In fact, one in five (the 19% who gave a *strongly agree* response) appear to be very worried about the long-term efficacy of their current medication. Nevertheless, the majority (72%) of respondents expressed a belief that new anti-viral drugs will be developed in time for them to gain benefits, although one-quarter (24%) do not know whether this will happen.

Table 10 Attitudes toward combination anti-viral drugs

Attitude statement	strongly disagree		disagree		agree		strongly agree		don't know	
	n	%	n	%	n	%	n	%	n	%
I am healthy now and don't need to use combination anti-viral drugs	326	(36%)	322	(36%)	116	(13%)	81	(9%)	48	(5%)
I believe combination anti-viral drugs are harmful	218	(24%)	299	(33%)	161	(18%)	57	(6%)	164	(18%)
I believe combination anti-viral drugs are ineffective	405	(45%)	376	(42%)	30	(3%)	21	(2%)	65	(7%)
Combination anti-viral drugs have allowed me to plan my life with confidence for the long term [†]	47	(6%)	142	(19%)	275	(36%)	185	(25%)	106	(14%)
It is easy for me to get combination anti-viral drugs	27	(3%)	56	(6%)	404	(45%)	348	(39%)	62	(7%)
I have had previous bad experiences with combination anti-viral drugs [†]	142	(19%)	267	(36%)	195	(26%)	108	(15%)	32	(4%)
Combination anti-viral drugs have made my life better	50	(6%)	77	(9%)	308	(36%)	225	(30%)	175	(20%)

n = 743 - 897 n varies from item to item due to missing values

[†] only includes responses by those who have used anti-viral drugs

Table 11 Attitudes toward anti-viral drugs expressed by PLWHA using these drugs

Attitude statement	strongly disagree		disagree		agree		strongly agree		don't know	
	n	%	n	%	n	%	n	%	n	%
Anti-virals can't restore my immune system	59	(9%)	19	(27%)	23	(34%)	58	(8%)	15	(23%)
I am worried that in the future my medication will stop working for me	13	(2%)	92	(13%)	39	(56%)	13	(19%)	78	(11%)
Taking tablets gives me an unwanted reminder that I have HIV	56	(8%)	23	(33%)	30	(43%)	10	(14%)	16	(2%)
Using anti-viral therapy makes me confident that I may stay well	11	(2%)	87	(12%)	39	(56%)	14	(20%)	73	(10%)
I think new treatments will be developed in time for me to gain benefits	9	(1%)	19	(3%)	33	(48%)	17	(24%)	17	(24%)

n = 702 - 708 n varies from item to item due to missing values

5.7 Prophylaxis for Opportunistic Infections

5.7.1 *For which opportunistic infections do PLWHA use prophylaxis?*

A substantial minority (39%) of respondents reported that they are currently using treatments to prevent *Pneumocystis Carinii* pneumonia (PCP) (eg, Bactrim, Dapsone, Pentamidine, Pyrimethamine, Fansidar), while 1% do not know if they are using such treatments. Fewer respondents (30%) are using preventive treatments for opportunistic infections other than PCP (eg, Riboflavin, Acyclovir, Gancyclovir, Fluconazole), while 2% do not know if they were using such treatments. Overall 48% of the PLWHA in this study are using prophylaxis for opportunistic infections (ie, prophylaxis to prevent PCP and/or prophylaxis for other opportunistic infections).

5.7.2 *Which PLWHA are most like to use prophylaxis?*

Compared to PLWHA who have not been diagnosed with an AIDS-defining illness, PLWHA who have had an AIDS diagnosis are significantly more likely to be using prophylaxis for PCP (69% vs 31%), and significantly more likely to be using prophylaxis for other opportunistic infections (62% vs 23%). Overall, PLWHA who have been diagnosed with an AIDS-defining illness are significantly more likely to be using any prophylaxis for opportunistic infections (80% vs 41%). This is not surprising given that a number of opportunistic illnesses are themselves AIDS defining illnesses.

Compared to men, women are significantly less likely to be using prophylaxis for PCP (23% vs 40%), and significantly less likely to be using prophylaxis for other opportunistic infections (17% vs 32%). Overall, women are significantly less likely than men to be using any prophylaxis for opportunistic infections (32% vs 50%).

5.8 Use of Complementary Therapies

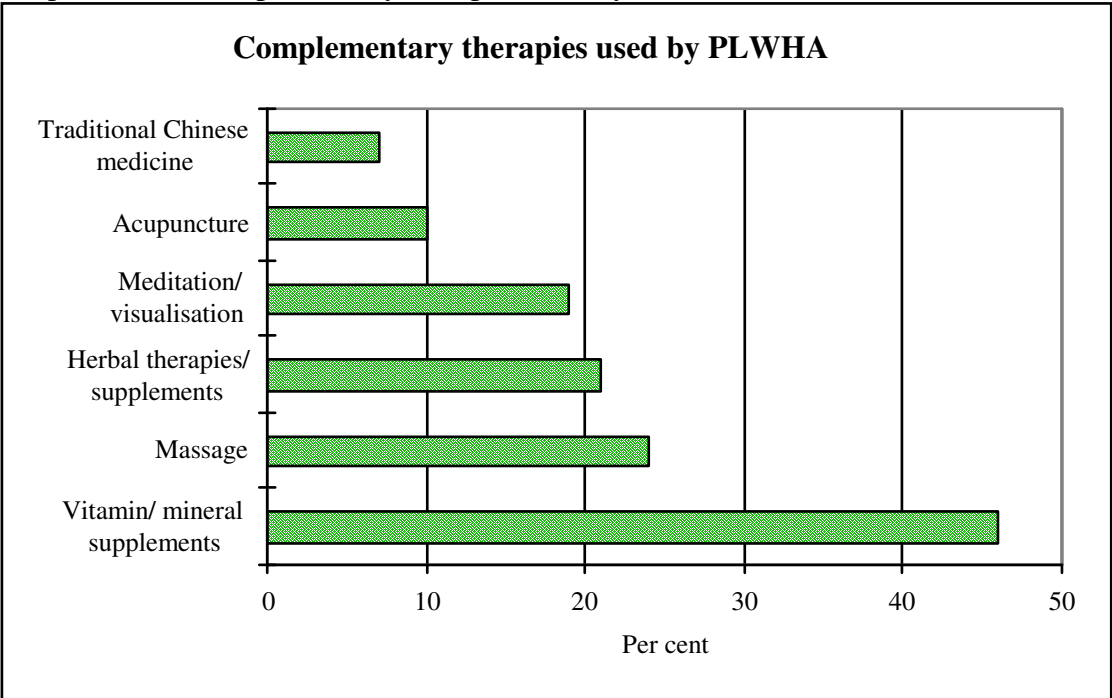
5.8.1 *How many PLWHA use complementary therapies?*

More than half (56%) of the PLWHA who completed the survey are using complementary therapies. It appears that Australian PLWHA are more likely to use complementary therapies than American PLWHA populations. Singh et al. (1996) found that 30% of PLWHA used complementary therapies, and Anderson et al. (1993) reported that 40% of their HIV-positive sample used these treatments. Respondents who have been diagnosed with an AIDS-defining illness are significantly more likely than those who have not to report use of complementary therapies (64% vs 54%). Women were no more or less likely than men to be using complementary therapies for HIV/AIDS.

5.8.2 Which complementary therapies are most commonly used?

Graph 4 shows that respondents reported use of a variety of complementary therapies. The most commonly used complementary therapies are vitamin and mineral supplements, used by nearly half (44%) of all PLWHA. Many PLWHA use massage (24%), herbal remedies (21%), and meditation or visualisation (19%).

Graph 4 Complementary therapies used by PLWHA



n = 914 (all respondents) Multiple response possible
Therapies used by less than 1% of respondents not shown in graph

5.8.3 *How much do PLWHA spend on complementary therapies?*

Respondents who are using complementary therapies reported spending between \$0 and \$140 per week on these therapies. Most respondents, however, spend \$20 or less per week (median = \$20 ; mean = \$23).

5.9 Attitudes Towards Complementary Therapies

In addition to asking PLWHA their beliefs about medical treatments for HIV/AIDS, the survey assessed respondents' attitudes toward complementary/alternative therapies. Their responses are displayed in Table 12. The proportion of *don't know* responses to items assessing attitudes toward complementary therapies is noticeably higher than those for the items which assessed attitudes toward anti-viral treatments and attitudes toward health management for PLWHA. Nevertheless, there appear to be favourable attitudes toward complementary therapies. The majority (76%) of respondents believe that complementary therapies can improve general well-being, with over one-quarter (29%) expressing a strong belief that this is true. In addition, over half (55%) of the sample believe that use of complementary therapies can delay the onset of HIV-related illnesses, with one in five (20%) expressing a strong belief that development of HIV-related illnesses can be delayed via the use of complementary therapies. Study participants also appear to believe that use of complementary/alternative therapies in conjunction with orthodox medical treatments can be beneficial. Nineteen per cent strongly agree that complementary therapies can reduce the side-effects of conventional medical treatments.

Table 12 Attitudes toward complementary and alternative therapies

Attitude statement	strongly disagree		disagree		agree		strongly agree		don't know	
	n	%	n	%	n	%	n	%	n	%
Complementary therapies can delay the onset of illness due to HIV	17	(2%)	74	(8%)	32	(36%)	17	(19%)	31	(35%)
Complementary therapies can improve my well-being	10	(1%)	19	(2%)	43	(47%)	26	(29%)	18	(20%)
Complementary therapies can reduce the side-effects of conventional medical treatments	13	(1%)	44	(5%)	32	(36%)	17	(19%)	34	(38%)
There is not enough evidence to be sure about the benefits of complementary therapies	89	(10%)	25	(28%)	32	(36%)	58	(6%)	17	(19%)
Medicine's focus on anti-HIV drugs is very limited	50	(6%)	23	(26%)	30	(34%)	10	(12%)	20	(23%)
Complementary therapies are a central part of my anti-HIV treatments	10	(12%)	32	(36%)	22	(25%)	14	(16%)	98	(11%)

n = 894 - 908 n varies from item to item due to missing data

5.10 Using anti-viral treatments, prophylaxis for opportunistic infections, and complementary therapies together

Table 13 summarises the various combinations of orthodox medical treatments and complementary treatments used by PLWHA. The most commonly reported combination of therapies used by PLWHA is anti-viral drugs, prophylaxis for opportunistic infections, and complementary therapies (25%), however, a substantial proportion (15%) are using anti-viral drugs only. It is interesting to note that 8% of respondents use no treatments at all, and that 11% are using complementary therapies but not conventional medical therapies for HIV/AIDS. Nearly half (45%) of the PLWHA who completed the survey are using both orthodox medical treatments and complementary therapies which is not surprising given that 55% expressed a belief that complementary therapies can reduce the side effects of conventional medical treatments.

Table 13 Patterns of use of anti-viral drugs, prophylaxis for opportunistic infections (OI), and complementary therapies

Treatments used	n	%
Anti-virals and OI Prophylaxis and Complementary Therapies	226	(25%)
Anti-virals and OI Prophylaxis	179	(20%)
Anti-virals and Complementary Therapies	157	(18%)
OI Prophylaxis and Complementary Therapies	16	(2%)
Anti-virals only	132	(15%)
OI Prophylaxis only	9	(1%)
Complementary Therapies only	102	(11%)
None	73	(8%)

n = 894

6 Relationships and Sex

Key Findings

One in five PLWHA are not presently having sex, 50% have sex within a regular relationship - half of whom have casual partners as well, and slightly less than one-third said they have casual sex only.

Half of the respondents said they were in a regular relationship. Of these, slightly more than half are in sero-nonconcordant relationships.

The great majority of PLWHA who are in regular relationships have disclosed their HIV status to their regular partner. Most partners were supportive in reaction to this disclosure.

Generally, new treatments are having a positive impact on relationships. Most PLWHA reported that they are more able to plan their future and that they are more optimistic about the future than they were a year ago. PLWHA generally do not believe that HIV/AIDS is a hindrance to developing long-term relationships, but most PLWHA worry about rejection by potential sexual partners in response to disclosure of their HIV status. More than two-thirds agree that they are afraid of infecting their partner, or potential partner, with HIV.

The availability of the new treatments does not appear to have made PLWHA more confident about having unprotected sex. However, the impact of the new treatments environment in other areas was less certain. PLWHA tended to agree that people with HIV now have a better chance to form relationships.

Slightly more than half said they would prefer to have a relationship with another PLWHA. These people tended to be bisexual and homosexual men.

With both regular and casual partners, PLWHA are significantly more likely to report that they always use condoms if their partner is HIV-negative or if they do not know their partner's serostatus. Most PLWHA who had unprotected intercourse said that they withdrew before ejaculation. Practice of withdrawal was not related to the partner's serostatus.

6.1 Sexual relationships of respondents

6.1.1 What type of sexual relationships are PLWHA having?

Table 14 displays the kinds of sexual relationships reported by respondents. A significant relationship was found between the type of relationship status reported and the respondent's sex and sexual orientation. Heterosexual men were most likely to report that they do not have sex at present and women were most likely to report that they have a monogamous regular relationship. Compared to other PLWHA, homosexual and bisexual men were more likely to report that they have a regular relationship with one person and casual sex with other people.

Table 14 Sexual relationships reported by PLWHA

Type of sexual relationship	Women ¹		Hetero- sexual men ²		Homo/ bisexual men ³		Total ⁴	
	n	%	n	%	n	%	n	%
No sex	16	(28%)	28	(43%)	12	(17%)	18	(20%)
Casual sex only	4	(8%)	9	(14%)	9	(13%)	26	(30%)
Regular relationship and casual sex	1	(1%)	5	(8%)	5	(7%)	20	(23%)
Regular relationship only	35	(63%)	22	(34%)	8	(11%)	23	(26%)
Regular relationship with two or more people	0	(0%)	1	(1%)	12	(17%)	13	(15%)

1 - n = 57 2 - n = 67 3 - n = 772 4 - n = 906

6.2 Regular relationships

6.2.1 How many PLWHA are in regular sexual relationships?

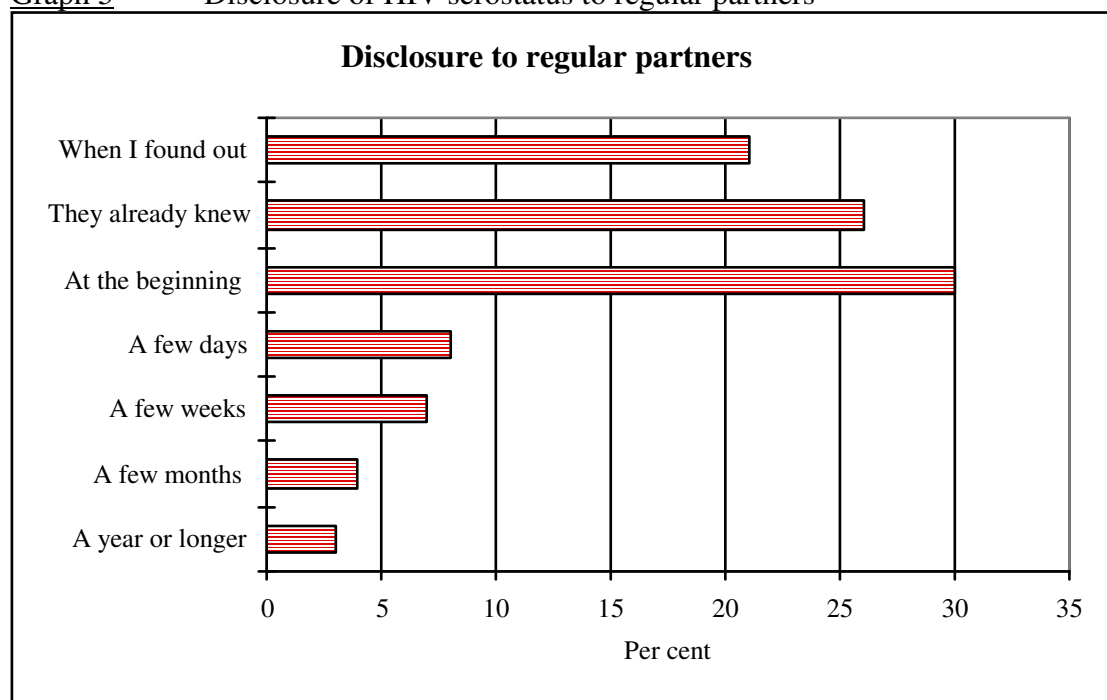
Fifty-one per cent of respondents said they are in a regular sexual relationship or married. The number of respondents who reported that they have sex with a regular partner in Table 14 is slightly lower than 51% because some respondents, whilst in regular relationships, indicated that they are not currently sexually active. Of those

respondents who are in a regular relationship, 40% are in seroconcordant relationships (that is, both partners were HIV-positive) and 60% are in sero-nonconcordant relationships. This 60% comprises 56% of respondents who know that their sexual partner is HIV-negative and 4% who do not know their partner's HIV serostatus.

6.2.2 How many PLWHA in regular sexual relationships have disclosed their status?

The vast majority of PLWHA (97%) who are in a regular relationship have told their partner that they are HIV-positive. Respondents were asked to indicate how far into the relationship they told their partner that they were HIV-positive. Their responses are displayed in Graph 5 and indicate that most PLWHA told their partner that they are HIV-positive when they tested positive (21%) or at the beginning of the relationship (30%). A further 26% reported that their partner knew that they are HIV-positive before the relationship began.

Graph 5 Disclosure of HIV serostatus to regular partners

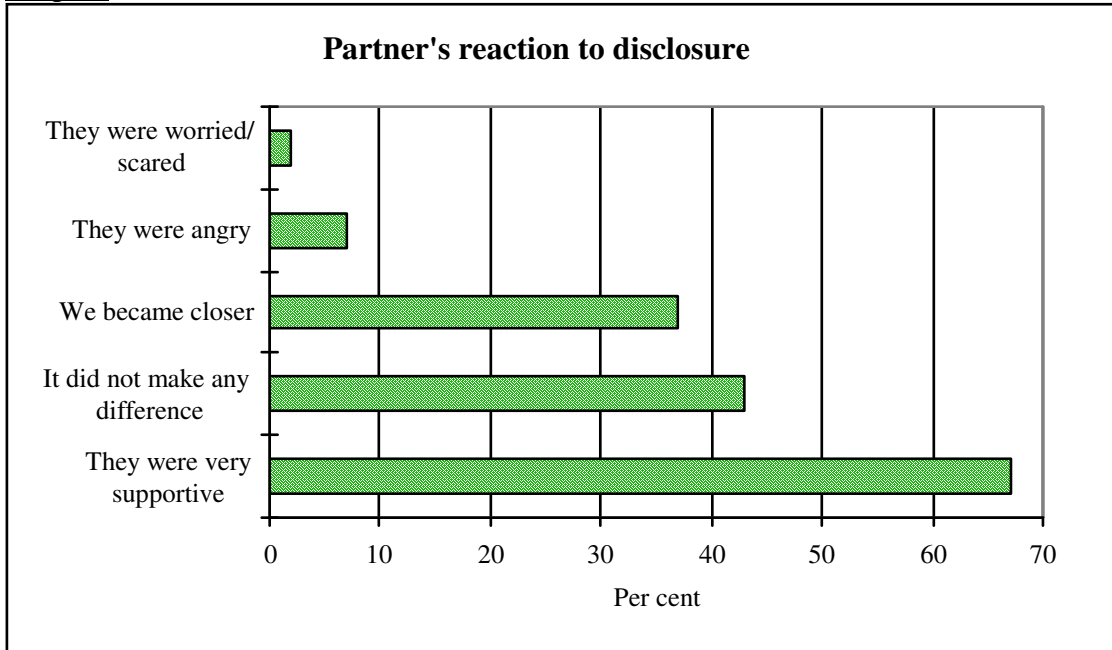


n = 437

6.2.3 How did their regular partner react to their disclosure?

Respondents who have told their partner of their HIV-positive status were asked to indicate how their partner reacted to the disclosure. Their responses are displayed in Graph 6. Most frequently participants said that their partners were very supportive (67%). Forty-three per cent reported that it did not make any difference and 37% said that they became closer to their partner.

Graph 6 Partner's reaction to disclosure of HIV serostatus



n = 437 proportion of respondents who had disclosed their HIV status to their partner
multiple responses possible

6.2.4 What are the impacts of new treatments on the regular relationships of PLWHA?

Respondents who were in a regular relationship at the time of completing the survey were asked to express the extent to which they agreed with a number of statements about the impact of the new treatments for HIV/AIDS on their relationship. Their responses are displayed in Table 15. Overall the impact on relationships of the new treatments environment appears to be positive. More than half (57%) of the respondents reported that they are more able to plan their future and 20% of respondents strongly agree with the statement *We are more optimistic about our future than a year ago*.

Table 15 Regular relationships, optimism and new treatments for HIV/AIDS

Attitude statement	strongly disagree		disagree		agree		strongly agree		don't know	
	n	%	n	%	n	%	n	%	n	%
We now plan our lives together further into the future than we did a year ago	16	(4%)	111	(26%)	177	(41%)	68	(16%)	55	(13%)
We are more optimistic about our future than a year ago	19	(4%)	63	(15%)	199	(47%)	86	(20%)	58	(14%)
New HIV treatments are putting a strain on our relationship	120	(28%)	197	(46%)	55	(13%)	11	(3%)	46	(11%)
We get along much better now there is good news on HIV treatments	39	(9%)	143	(34%)	117	(28%)	22	(5%)	95	(23%)

n = 465 proportion of respondents in a regular relationship

There were no significant differences between men and women in relation to sexual identity and whether couples were in seroconcordant or sero-nonconcordant relationships, in attitudes to the statements: *We plan our lives together further into the future than we did a year ago* and *We are more optimistic about our future than a year ago*.

However, the availability of anti-viral drugs appears to have a stronger effect on the relationships of PLWHA who are using them than on the relationships of PLWHA who are not using them. People using anti-viral drugs were significantly more likely than those were those not using these drugs to agree with the statement *New HIV treatments are putting a strain on our relationship* (18% vs 8%), and significantly more likely to agree with the statement *We get along much better now there is good news on HIV treatments* (38% vs 16%).

6.3 Attitudes towards relationships and sex

6.3.1 What are the impacts of HIV/AIDS on the sexual relationships of PLWHA?

All respondents were asked to express how they feel about a number of statements about relationships and sex (see Table 16). PLWHA do not appear to believe that having HIV/AIDS would be a hindrance to developing long-term relationships - 39% strongly disagree with the statement *I will never be in long-term relationship because of my HIV status*. However, the majority of respondents are worried about rejection by potential sexual partners as a response to disclosure of their HIV/AIDS status - 52% agree with the statement *I am afraid of telling potential sexual partners of my HIV status in case they reject me* - and many are worried about the risk of transmission of HIV - 28% of respondents strongly agree with the statement *I am afraid of infecting my partner, or potential partner, with HIV*.

Table 16 Attitudes toward the impact of HIV on relationships

Attitude statement	strongly disagree		disagree		agree		strongly agree		don't know	
	n	%	n	%	n	%	n	%	n	%
I will never be in long-term relationship because of my HIV status	343	(39%)	295	(33%)	101	(11%)	56	(6%)	95	(11%)
I worry that nobody would want a relationship with someone who has HIV	196	(22%)	254	(29%)	316	(35%)	97	(11%)	28	(3%)
I am afraid of telling potential sexual partners of my HIV status in case they reject me	167	(19%)	223	(25%)	340	(38%)	121	(14%)	36	(4%)
I am afraid of infecting my partner, or potential partner, with HIV	86	(10%)	180	(20%)	361	(41%)	246	(28%)	15	(2%)
I prefer to have a relationship with someone who also has HIV	84	(9%)	192	(22%)	288	(32%)	181	(20%)	145	(16%)
HIV is not an issue for me in present relationship(s)	133	(16%)	269	(32%)	229	(27%)	104	(12%)	109	(13%)

n = 845-893 varies due to missing values

6.3.2 *Is there any association between personal characteristics of PLWHA and their beliefs about the impact of HIV on sexual relationships?*

Whether or not respondents are in regular sexual relationships or married plays a significant role in their attitudes about the list of statements in Table 16. As would be expected, those respondents who reported that they are in a regular sexual relationship/married are significantly more likely than those not in a regular relationship to disagree with the statement *I will never be in a long-term relationship because of my HIV status* (91% vs 52%). However, there was no difference of opinion between males and females. Similarly PLWHA who are in a regular sexual relationship or married are significantly more likely than PLWHA not in a regular relationship to disagree with the statement *I worry that nobody would want a relationship with someone who has HIV* (65% vs 36%). Female PLWHA are significantly more likely than male PLWHA to agree with this statement (65% vs 45%). Respondents who reported that they are in a regular sexual relationship or married are also significantly more likely than PLWHA not in a regular relationship to agree with the statement *HIV is not an issue for me in present relationship(s)* (48% vs 29%).

Not surprisingly, compared to PLWHA in a regular relationship, PLWHA who reported that they are not in a regular sexual relationship were significantly more likely to agree with the statement *I am afraid of telling potential partners of my HIV status in case they reject me* (62% vs 42%).

There was no difference between those who were currently in a regular sexual relationship or married and those who were not when respondents were asked whether they agree with the statement *I am afraid of infecting my partner, or potential partner, with HIV*. However, PLWHA in sero-nonconcordant relationships are more likely to agree with this statement than those in seroconcordant relationships (74% vs 58%). Interestingly, PLWHA who are taking anti-viral treatments are also more likely to agree with this statement than those who are not taking treatments (71% vs 59%).

6.4 Attitudes toward treatments and relationships

6.4.1 *What are the impacts of new treatments on relationships of PLWHA?*

To assess the impact of the new anti-viral treatments on attitudes toward relationships, respondents were asked to think about the new combination treatments in relation to the statements presented in Table 17. The availability of new treatments does not appear to have made respondents more confident about having unprotected sex. Only 6% of respondents agree that they feel more confident about unsafe sex as a consequence of the new treatments while 89% disagree and a further 6% do not know. Other impacts of the new treatments environment are less certain. A majority (53%) agree that people with HIV now have a better chance to form relationships, but a sizeable minority (32%) disagree. One-third (34%) of respondents agree that relationships with family and friends are improving due to new treatments, but a slightly larger group (39%) disagree, and 27% do not know.

Table 17 Attitudes toward the impact of new anti-viral treatments on sexual relationships

Attitude statement	strongly disagree		disagree		agree		strongly agree		don't know	
	n	%	n	%	n	%	n	%	n	%
I feel more confident about unprotected sex because of the new treatments	553	(59%)	268	(30%)	43	(5%)	11	(1%)	50	(6%)
People with HIV now have a better chance to form partnerships and relationships	89	(10%)	199	(22%)	413	(46%)	66	(7%)	137	(15%)
Relationships with friends and family are improving due to the new treatments	91	(10%)	254	(29%)	271	(30%)	36	(4%)	240	(27%)
Many relationships are breaking up due to the new treatments	132	(15%)	255	(28%)	54	(6%)	16	(2%)	441	(49%)

n = 892-905 varies due to missing values

6.4.2 What is the relationship between the personal characteristics of PLWHA and their attitudes toward the impact of new anti-virals on relationships?

PLWHA taking anti-virals were more likely than those who were not to agree with the statements *I feel more confident about unprotected sex because of the new treatments* than those not taking treatments (7% vs 3%), *Relationships with friends and family are improving due to the new treatments* (38% vs 20%) and *Many relationships are breaking up due to the new treatments* (9% vs 3%).

Homosexual and bisexual men are significantly more likely than women and heterosexual men to agree with the statement *People with HIV now have a better chance to form partnerships and relationships* (56% of homosexual and bisexual men agree, compared to 38% of women and 40% of heterosexual men). A significant relationship was found between whether PLWHA are in a relationship, whether they are using anti-viral drugs and their responses to the statement *Many relationships are breaking up due to the new treatments*. Fifty-one per cent of PLWHA in a relationship and using anti-viral drugs disagree with this statement compared to 46% of PLWHA in a relationship but not using anti-viral drugs, 39% of those not in a relationship but using anti-viral drugs, and 29% of those not in a relationship and not using anti-viral drugs.

6.5 Seroconcordant versus sero-nonconcordant relationships

6.5.1 Do PLWHA have a preference for seroconcordant relationships?

As noted previously, 52% of respondents stated that they prefer to have a relationship with another PLWHA. Compared to PLWHA who are not in a regular relationship, PLWHA who are in a regular relationship are significantly less likely to agree with the statement *I prefer to have a relationship with someone who also has HIV*.

Table 18 Preference for a relationship with another PLWHA

	Agree	Disagree	Don't know
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Relationship status	n	%	n	%	n	%
Currently in a regular relationship ¹	201	(45%)	178	(40%)	68	(15%)
Currently not in a regular relationship ²	267	(60%)	48	(22%)	75	(17%)

1 - n = 447

2 - n = 390

The data also revealed a significant association between respondents' sex and sexual orientation and their preference for a relationship with another PLWHA. As can be seen in the table below, homosexual/bisexual men are significantly more likely than other respondents to agree with the statement *I prefer to have a relationship with someone who also has HIV*. Over half (55%) of the homosexual/bisexual men agree with the statement, whereas only 38% of heterosexual men and 31% of women agree with this statement.

Table 19 Preference for a relationship with another PLWHA

Relationship status	Agree		Disagree		Don't know	
	n	%	n	%	n	%
Homosexual / bisexual male ¹	421	(55%)	225	(30%)	114	(15%)
Heterosexual male ²	23	(38%)	22	(37%)	16	(26%)
Female ³	17	(31%)	26	(46%)	13	(23%)

1 - n = 760

2 - n = 61

3 - n = 56

6.6 Sexual behaviour with regular partners

6.6.1 Condom use among PLWHA who had vaginal and/or anal intercourse with regular partners.

Respondents who were in a regular sexual relationship at the time of completing the survey were asked a number of questions about their practice of anal and/or vaginal intercourse in the six months prior to completing the survey. Among the respondents who had engaged in anal and/or vaginal intercourse 50% always used condoms, 23% sometimes used condoms, and 28% never used condoms. Of the PLWHA who sometimes or always had unprotected anal and/or vaginal intercourse, 68% had HIV-positive partners, while the remainder had regular relationships with partners who were HIV-negative.

A significant association was found between use of condoms during anal and/or vaginal intercourse and partner serostatus. Table 20 shows that, compared to respondents in seroconcordant relationships, respondents in serodiscordant relationships were significantly more likely to report that they always used condoms, and significantly less likely to report that they never used condoms. In other words, PLWHA who were in serodiscordant relationships were significantly more likely than PLWHA in seroconcordant relationships to always use condoms.

Table 20 Condom use in regular relationships

Partner serostatus	Frequency of condom use					
	Always		Sometimes		Never	
	n	%	n	%	n	%
Seroconcordant relationship ¹	39	(26%)	28	(19%)	83	(55%)
Serodiscordant relationship ²	131	(72%)	44	(24%)	8	(4%)

1 - n = 150

2 - n = 183

Further analyses revealed that this pattern of results held among homosexual/bisexual men. One-quarter (25%) of homosexual/bisexual men in seroconcordant relationships always used condoms, compared to 77% in serodiscordant relationships. Due to small numbers this association was not statistically significant among the sub-samples of heterosexual men and women. Nevertheless among heterosexual men 12% in seroconcordant relationships always used condoms compared to 85% in serodiscordant relationships, and among women 41% in seroconcordant relationships always used condoms, compared to 54% in serodiscordant relationships.

6.6.2 *Withdrawal during unprotected sex in regular relationships.*

Among the respondents who had unprotected anal and/or vaginal sex with a regular partner in the 6 months prior to completing the survey, 36% never withdrew before ejaculation, while 64% sometimes or always withdrew before ejaculation. No association was found between practice of withdrawal and partner serostatus. The practice of withdrawal was also not related to whether or not their regular partner was also HIV-positive. This was the case for the whole sample of PLWHA who had unprotected intercourse as well as for homosexual/bisexual men separately. This association also held for heterosexual men and women, although due to small numbers it was not a statistically significant difference.

Table 21 Withdrawal during unprotected penetrative sex in regular relationships

Partner serostatus	withdrawal			
	yes		no	
	n	%	n	%
Seroconcordant	69	(62%)	42	(38%)

Serodiscordant	33 (61%)	21 (39%)
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n = 165

6.6.3 Does optimism about new treatments alter condom use in regular relationships?

Analyses were conducted to examine whether respondents' responses to the question *Do you believe that new combination anti-viral drugs mean better prospects for most people with HIV?* were related to their patterns of condom use during sex with regular partners (see Table 22). Beliefs in the efficacy of the new combination anti-viral drugs were not related to patterns of condom use in serodiscordant regular relationships. Thus, it does not appear that greater confidence in new combination anti-viral drugs is related to less safe sexual behaviour. Similar patterns of results were found among homosexual/bisexual men, heterosexual men, and women, although the numbers of respondents were too small to allow statistically significant comparisons.

Table 22 Optimism about new treatments and condom use with regular partners in serodiscordant relationships

Do new anti-virals mean better prospects for people with HIV?	Frequency of condom use					
	Always		Sometimes		Never	
	n	%	n	%	n	%
Yes	96	(75%)	27	(21%)	6	(5%)
No	35	(64%)	17	(32%)	2	(4%)

n = 183

6.7 Sexual behaviour with casual partners

6.7.1 Condom use among PLWHA who had vaginal and/or anal intercourse with casual partners.

Half (53%) of the PLWHA who completed the survey had engaged in anal and/or vaginal sex with a casual partner in the six months prior to completing the survey. Table 23 shows that two-thirds (68%) of the respondents who had casual sex in the six months prior to completing the survey either did not know the HIV serostatus of their partner(s) or knew their partners to be HIV-negative.

Table 23 Penetrative sex with casual partner(s)

HIV Serostatus of Casual Sexual Partner(s)	n	%
All HIV-positive	23	(5%)
Some HIV-positive, some HIV-negative	133	(27%)
All HIV-negative	59	(12%)
Don't Know	279	(56%)

n = 494

Respondents were asked a number of questions about their use of condoms during anal and/or vaginal intercourse with casual partners in the six months prior to completing the survey. Among the respondents who had engaged in anal and/or vaginal intercourse with a casual partner 46% always used condoms, 50% sometimes used condoms, and 5% never used condoms.

A significant association was found between use of condoms during anal and/or vaginal intercourse and casual partner serostatus. The table below shows that 11% of PLWHA who only had sex with HIV-positive casual partners always used condoms, compared to 45% of PLWHA who had sex with HIV-negative and HIV-positive casual partners, and 70% of PLWHA who only had sex with HIV-negative partners. As was the case for condom use with regular partners, these data reveal that PLWHA who have sex with HIV-negative casual partners are significantly more likely to always use condoms than PLWHA who only have sex with HIV-positive casual partners.

Table 24 Condom use in penetrative sex with casual partner(s)

Relationship	Frequency of condom use					
	Always		Sometimes		Never	
	n	%	n	%	n	%
HIV-positive partner(s) only ¹	2	(11%)	7	(37%)	10	(53%)
HIV-positive and HIV-negative partner(s) ²	145	(45%)	172	(53%)	8	(2%)
HIV-negative partner(s) only ³	28	(70%)	11	(28%)	1	(2%)

1 - n = 19

2 - n = 324

3 - n = 40

Further analyses revealed that this pattern of results held among homosexual/bisexual men. Due to small numbers it was not possible to test the statistical significance of this association among the sub-samples of heterosexual men and women.

Nevertheless, it is interesting to note that among heterosexual men none of the PLWHA who only had sex with other PLWHA always used condoms compared to all of the PLWHA who had sex with HIV-negative casual partners, and that among women none of the PLWHA who only had sex with other PLWHA always used condoms compared to 83% of the PLWHA who had sex with HIV-negative casual partners.

6.7.2 *Withdrawal during unprotected sex in casual relationships.*

Of the 55% of respondents who had unprotected anal and/or vaginal sex, 14% never withdrew before ejaculation, while 86% sometimes or always withdrew before ejaculation. No association was found between respondents' practice of withdrawal during unprotected vaginal and/or anal intercourse and the HIV serostatus of their sexual partners. In other words, respondents who had unprotected intercourse with HIV-positive casual partners were no more or less likely to practice withdrawal than respondents who had unprotected intercourse with HIV-negative partners.

Table 25 Withdrawal during unprotected penetrative sex in casual relationships

Partner serostatus	withdrawal			
	yes		no	
	n	%	n	%
HIV-positive partner(s) only ¹	3	(21%)	12	(79%)
HIV-positive and HIV-negative partner(s) ²	24	(14%)	143	(86%)
HIV-negative partner(s) only ³	0	(0%)	8	(100%)

1 - n = 15

2 - n = 167

3 - n = 8

Further analyses revealed no association between partner serostatus and practice of withdrawal during unprotected sex among homosexual/bisexual men. Due to small numbers of respondents, it was not possible to conduct these analyses for heterosexual men or women, but the patterns observed among these respondents were similar to those found for the whole sample.

6.7.3 *Does optimism about new treatments alter condom use in casual relationships?*

Analyses were conducted to examine whether respondents' responses to the question *Do you believe that new combination anti-viral drugs mean better prospects for most people with HIV?* were related to their patterns of condom use during sex with casual partners. Beliefs in the efficacy of the new combination anti-viral drugs were not related to patterns of condom use in serodiscordant regular relationships. Similar patterns of results were found among homosexual/bisexual men, heterosexual men, and women, although the numbers of respondents were too small to allow statistical comparisons.

Table 26 Optimism about new treatments and condom use with casual partners

Do new anti-virals mean better prospects for people with HIV?	Condom use					
	Always		Sometimes		Never	
	n	%	n	%	n	%
Yes	121	(51%)	110	(46%)	8	(3%)
No	54	(37%)	81	(56%)	10	(7%)

n = 383

Key Findings

Almost all PLWHA have disclosed their HIV status to at least one person. Of those with dependent children, half have told their children they are HIV-positive. One in ten respondents said that they have experienced discrimination at some stage. Half of the respondents said they have changed their plans for the future in the last two years. Most of these changes were positive but one in five were negative due to declining health.

When seeking advice for both treatment and living with HIV/AIDS respondents most commonly cited their doctor as their source of information. PLWHA also rely heavily on HIV/AIDS media, the gay press and other HIV-positive friends for information.

Over three-quarters of the respondents have some involvement with HIV/AIDS organisations. Two-thirds of the respondents are in contact with an AIDS Council and over half have contact with a PLWHA organisation (this finding is likely to be influenced by the fact that these organisations were a distribution source for the survey). Most commonly, contact with organisations tended to be in the form of newsletters and mail-outs, but many PLWHA also receive treatments advice and social contact. PLWHA who do not have contact with any HIV/AIDS organisations usually said this was so because they do not wish to be involved. However, a small number said they feel excluded or are unable to have contact because of where they live or the lack of transport available to them.

Most respondents know at least one other HIV-positive person - usually friends, acquaintances and past or present partners. Likewise, most PLWHA spend at least some of their free time with other HIV-positive people and just over half have, at some time, been involved in the care of another person with HIV/AIDS. The majority of respondents said they have lost someone to HIV/AIDS, and this was mostly a close friend or relative.

Over two-thirds of respondents see themselves as being part of the gay community. Half of the respondents are also members of gay organisations and the majority of respondents go to gay venues such as nightclubs, bars and saunas.

7.1 Disclosure

All but 1% of the respondents have told at least one person that they are HIV-positive. Most commonly, respondents have told friends and family that they have HIV/AIDS. Responses to detailed questions about disclosure of HIV serostatus revealed that: 80% have told their HIV-positive friends that they have HIV/AIDS; 87% have told other friends; 61% have told their parents; 73% have told brothers and/or sisters; and 20% have told their neighbours. Among respondents who have dependent children 49% have told their children that they are HIV-positive. Among respondents who were working at the time of completing the survey 54% have told their work colleagues that they are HIV-positive.

7.2 Discrimination

7.2.1 *What is the experience of discrimination among PLWHA?*

One in ten respondents (10%) said that at some stage they have experienced HIV-related discrimination in their local area. Among those who have experienced discrimination, the most commonly cited form of discrimination was verbal abuse (57%) and other people avoiding physical contact (9%). A small proportion of respondents (3%) reported that they currently experienced HIV-related discrimination in the area in which they live and, once again, verbal abuse was most common (74%).

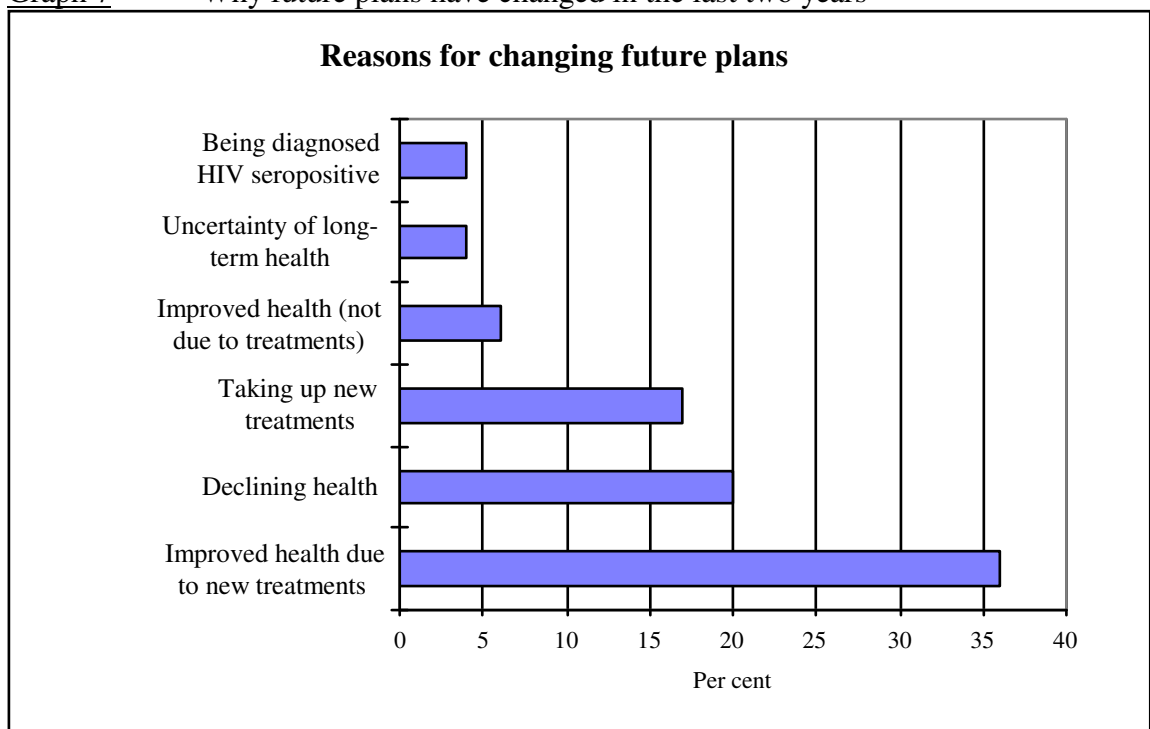
Current experience of discrimination was not related to: whether or not respondents have been diagnosed with an AIDS-defining illness; whether respondents live in an inner urban area, suburban area, regional centre, or rural area; the length of time the respondent have lived where they do; or the length of time since respondents first tested HIV-positive. Women were just as likely as men to report that they had ever experienced discrimination, or that they currently experience discrimination due to HIV/AIDS.

7.3 Planning for the future

7.3.1 *Have PLWHA changed their plans for the future? Why?*

Half (49%) of the PLWHA who completed the survey reported that in the last two years they have changed their plans for the future. Their reasons for doing so are displayed in Graph 7. While many respondents said that their plans had changed for apparently positive reasons such as improved health due to new treatments (36%); taking up new treatments (17%); and improved health for other reasons (6%); others gave less positive reasons for a change of plans, such as declining health (20%).

Graph 7 Why future plans have changed in the last two years



n = 450

7.3.2 *Do PLWHA now plan further into the future?*

Among PLWHA who have changed the time frame they use when planning for major decisions, the most common change was to a longer time frame (see Table 27). The reasons given for the change in planning were related to the type of change in planning. For example, improved health or the prospect of new treatments are associated with changing to a longer time frame, whereas declining health is associated with now using a shorter time frame.

Table 27 Changes made in the last two years in the time frame used when making major decisions about life

Change made	n	%
Use a shorter time frame	167	(19%)
Use the same time frame	457	(51%)
Use a longer time frame	273	(30%)

n = 897

7.4 Information sources

7.4.1 Who do PLWHA rely upon for information about living with HIV/AIDS?

Respondents were asked to indicate which people and/or organisations they rely on for information about living with HIV/AIDS. Respondents were asked whose advice they seek for information about treatments for HIV/AIDS and for information about living with HIV/AIDS (but not about treatments). Responses to these two questions are shown in Table 28. The most commonly cited source of information about both treatments for HIV/AIDS and living with HIV/AIDS was the respondent's doctor. Respondents also rely heavily on HIV/AIDS media (eg., *Positive Living*, *Talkabout*), the gay press, and on HIV-positive friends for information about both treatments for HIV/AIDS and living with HIV/AIDS. It is clear from this table that PLWHA rely on a variety of people and organisations for information about living with HIV/AIDS, and that in addition to health professionals and PLWHA organisations, friends, partners, and family are important sources of information with regard to living with HIV rather than treating HIV.

Table 28 Sources of information for PLWHA

Information source	Source of information about			
	Treatments for HIV/AIDS ¹		Living with HIV/AIDS ²	
	n	%	n	%
Doctor	824	(91%)	574	(64%)
HIV/AIDS press	690	(76%)	530	(59%)
Gay press	561	(62%)	445	(50%)
HIV-positive friends	503	(56%)	526	(59%)
AIDS Council/PLWHA organisation staff	354	(39%)	353	(39%)
Nurse	173	(19%)	124	(14%)
Alternative therapist	154	(17%)	137	(15%)
Friends (not HIV-positive)	153	(17%)	279	(31%)
Partner/lover	115	(13%)	213	(24%)
Positive women's organisation	45	(5%)	35	(4%)
Internet	45	(5%)	14	(2%)
Family	43	(5%)	89	(10%)
Haemophilia foundation	11	(1%)	8	(1%)
Counsellor/psychologist	-	-	49	(5%)
Other health professional	-	-	11	(1%)

1 - n = 907 Multiple responses possible
2 - n = 897 Information sources cited by less than 1% of respondents not shown in table

7.4.2 *Are there differences across groups of PLWHA in where information is sought?*

Not surprisingly, homosexual and bisexual PLWHA said they were significantly more likely than heterosexual PLWHA to seek advice about living with HIV from gay press (55% vs 11%). However, homosexual and bisexual PLWHA were also significantly more likely than heterosexual PLWHA to seek advice about living with HIV from HIV magazines and newspapers (62% vs 39%). This may reflect the distribution of some HIV newspapers (for example *Positive Living*) as inserts within gay newspapers.

7.5 Contact with community organisations

7.5.1 *How many PLWHA are in contact with community organisations?*

Over three-quarters (80%) of the respondents have some involvement with HIV/AIDS organisations. Two-thirds (67%) of the respondents are in contact with an AIDS Council, and over half (53%) have contact with a PLWHA organisation. Once again this finding is no doubt influenced by the fact that these organisations were a vital medium through which the survey was distributed.

Among PLWHA from NSW, 18% have contact with the Bobby Goldsmith Foundation. This probably reflects the high levels of poverty among PLWHA, an issue which is addressed in Section 8. In some other states, financial services are integrated into AIDS Councils.

Table 29 Organisations with which PLWHA have contact

Organisations	n	%
National Organisations		
AIDS Council	422	(56%)
PLWHA Organisation	338	(45%)
AFAO	17	(2%)
NAPWA	8	(1%)
Positive Women's organisation [†]	10	(66%)
NSW-specific organisations^{††}		
Bobby Goldsmith Foundation	81	(18%)
CSN	29	(6%)
Day Centre	29	(6%)
Ankali	21	(5%)
Luncheon Club	21	(5%)
Positive Heterosexuals (formerly Project Clash)	9	(2%)
North AIDS	8	(2%)
Victorian-specific organisations^{††}		
Straight Arrows	6	(5%)
Country AIDS Network	5	(3%)
Positive Attitude	5	(3%)
New Companions	4	(3%)
San Michel Hospice	2	(1%)
Positive Women's organisation	9	(6%)
Queensland-specific organisations^{††}		
AIDS Medical Unit	10	(12%)
South Australia-specific organisations^{††}		
Diocesan AIDS Council	2	(8%)
Positive Women's organisation	2	(8%)
Western Australia-specific organisations^{††}		
Drop-in centre	1	(6%)
AIDS Pastoral Care	7	(46%)
Positive Women's organisation	1	(6%)

[†] - proportion of women in states which have such an organisation

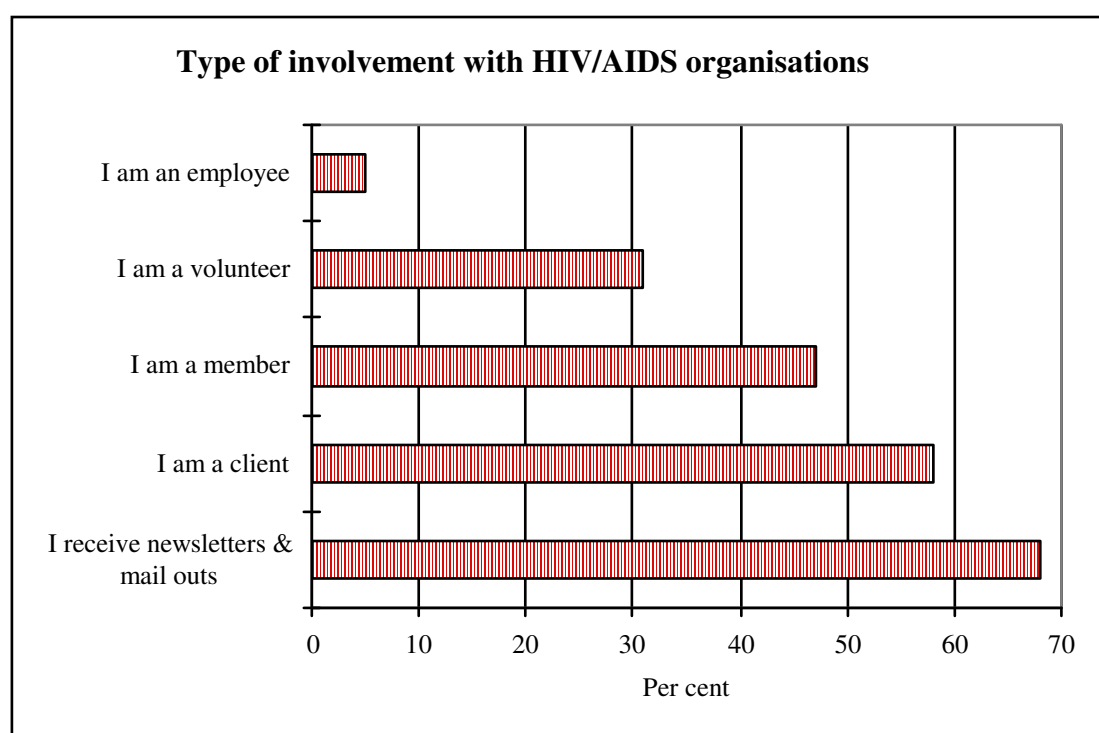
^{††} - NSW n = 447; VIC n = 141; QLD n = 82; SA n = 27; WA n = 15.

7.5.2 What type of contact do PLWHA have with community organisations?

When asked about the type of contact they have with HIV/AIDS organisations, most PLWHA (68%) reported that they receive newsletters or other mail-outs, and 58%

received other services as a client of these organisations. Nearly one-third (31%) of those PLWHA who have contact with an HIV/AIDS organisation work as a volunteer in such an organisation. Among the people who are volunteers in HIV/AIDS-organisations, the number of hours involved in volunteer work ranges from one hour to 50 hours per week and the median number is 5 hours per week. Gay and bisexual PLWHA are significantly more likely than heterosexual PLWHA to be volunteers (34% vs 18%). PLWHA who are members of gay organisations are significantly more likely than other PLWHA to be volunteers (39% vs 23%).

Graph 8 PLWHA involvement with HIV/AIDS organisations



n = 620 Proportion of those in contact with HIV/AIDS organisation

7.5.3 How many PLWHA have held decision-making positions with community organisations?

Slightly less than one-third (31%) of the PLWHA who have contact with HIV/AIDS organisations have ever held a decision-making position in one of these organisations; 14% held a decision-making position at the time of completing the survey.

7.5.4 Which services provided by community organisations do PLWHA use?

The table below displays the proportion of PLWHA who use each of the range of services provided by HIV/AIDS-related organisations. Information and treatments advice were the most commonly used services, but it is clear that the social support provided by HIV/AIDS-related organisations (whether formal or informal) is also used by many PLWHA.

Table 30 Use of services provided by HIV/AIDS-related community organisations

Service	n	%
Newsletter / mail-outs	565	(72%)
Treatments advice	417	(53%)
Social contact	321	(41%)
Counselling	272	(34%)
Peer support group	244	(31%)
Informal peer support	207	(26%)
Financial assistance	197	(25%)
Massage	188	(24%)
Library	111	(14%)
Financial Advice	107	(14%)
Transport services	98	(12%)
Domestic help	57	(7%)
Vitamins	15	(2%)

n = 791

7.5.5 Which HIV/AIDS-related publications do PLWHA read?

The majority of respondents (94%) reported that they read HIV/AIDS-related newspapers or magazines *occasionally* or *regularly*. The HIV/AIDS newspapers and magazines read by these respondents are displayed in Table 31. The data in the table indicate that 62% of all PLWHA who completed the survey read the national publication *Positive Living*, 54% read *Talkabout* (produced by PLWHA (NSW)), 51% read *HIV Herald*, 46% read *With Complements*, and 25% read *National AIDS Bulletin*. Because some publications are not distributed nationally separate analyses were conducted which revealed that 81% of PLWHA in NSW read *Talkabout*, 49% of PLWHA in Queensland read *QPP Alive*, and 70% of PLWHA in Western Australia read *PL*.

Table 31 HIV/AIDS-related newspapers and magazines read by PLWHA

Publication	n	%
<i>Positive Living</i> (national newspaper)	567	(62%)
<i>Talkabout</i>	496	(54%)
<i>HIV Herald</i>	465	(51%)
<i>With Complements</i>	418	(46%)
<i>National AIDS Bulletin</i>	232	(25%)
Gay press	61	(7%)
<i>PL</i> (WA magazine)	60	(7%)

Foreign HIV/AIDS press (eg, <i>Poz</i>)	35	(4%)
Newsletters from community organisations	29	(3%)
<i>QPP Alive</i>	28	(3%)
<i>National Haemophilia</i>	8	(1%)

n = 849 Proportion of total sample

7.5.6 Are some groups of PLWHA more likely to read HIV/AIDS-related publications than others?

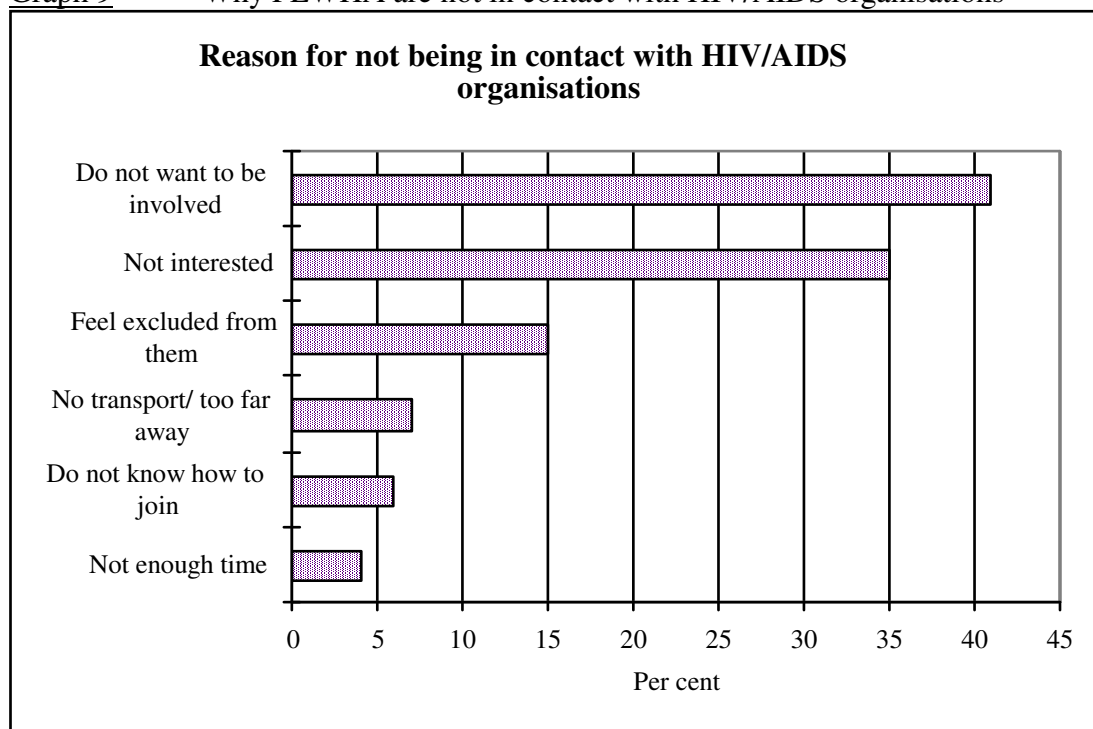
PLWHA who said they feel they are a part of the gay community were significantly more likely than other PLWHA to report that they regularly read HIV/AIDS-related newspapers or magazines (73% vs 55%). There was also a significant association between sexual orientation and whether respondents regularly read gay newspapers or magazines. More than two-thirds (68%) of homosexual PLWHA regularly read HIV/AIDS-related media, compared to 59% of bisexual PLWHA, and 44% of heterosexual PLWHA. Likewise, PLWHA who feel that they are part of the gay community are significantly more likely than other PLWHA to regularly read HIV/AIDS-related media (70% vs 50%).

It is important to note that 17% of heterosexual PLWHA (men and women) never read HIV/AIDS-related newspapers and magazines - significantly more than the 4% of bisexual PLWHA and 3% of homosexual PLWHA.

7.5.7 Why do some PLWHA choose not to be involved with community organisations?

Graph 9 shows that the majority of the respondents who had no contact with HIV/AIDS-related organisations said that they are not involved in these organisations because they do not want to be involved (41%) or because they are not interested in being involved (35%). However, 15% of respondents are not involved because they feel excluded from HIV/AIDS organisations, while 7% are unable to become involved with these organisations because there is no such organisation in their area or because a lack of transport means that it is difficult to gain access. Women and heterosexual men are no more likely than gay/bisexual men to feel excluded from AIDS organisations.

Graph 9 Why PLWHA are not in contact with HIV/AIDS organisations



n = 140

7.6 Contact with other PLWHA

7.6.1 How many PLWHA know others who are living with HIV/AIDS?

Most respondents know at least one other HIV-positive person. Table 32 shows that most respondents know friends and/or acquaintances who are also HIV-positive. A greater proportion of heterosexual PLWHA than homosexual or bisexual PLWHA report that they did not know any other PLWHA (12% vs 3%). PLWHA reporting they did not know any other PLWHA were also significantly more likely to live in outer suburban, regional or rural areas than capital cities or inner suburbs (65% vs 35%).

Table 32 Other HIV-positive people known to PLWHA

Knows other HIV-positive people	n	%	n	%
No			34	(4%)
Yes			870	(96%)
Friend(s) [†]	741	(85%)		
Acquaintance [†]	637	(73%)		
Past sexual partner [†]	452	(52%)		

Present sexual partner [†]	199	(23%)
Other family member [†]	54	(6%)
Child/ren [†]	11	(1%)

n = 904

† - proportion of PLWHA who know at least one other PLWHA

7.6.2 How much time do PLWHA spend with others who have HIV/AIDS?

Most respondents spend at least some free time with other HIV-positive people. Fifteen per cent spend no time with other PLWHA, 31% spend a little time, 33% spend some time, and 22% spend a lot of time with other PLWHA. Compared to PLWHA who have no contact with HIV/AIDS-related organisations, PLWHA who have contact with HIV/AIDS-related organisations are significantly more likely to spend *a lot* of time with other positive people (25% vs 12%).

7.6.3 How many PLWHA have provided care for another person with HIV/AIDS?

Just over half (51%) of the respondents have at some time been involved in the care of another person with HIV/AIDS.

7.6.4 How many PLWHA have lost someone to HIV/AIDS?

The vast majority (81%) of respondents have lost someone to HIV/AIDS. Of these people, 94% had a close friend or relative die as a result of AIDS.

7.7 Contact with the gay community

7.7.1 Do PLWHA consider themselves part of the gay community?

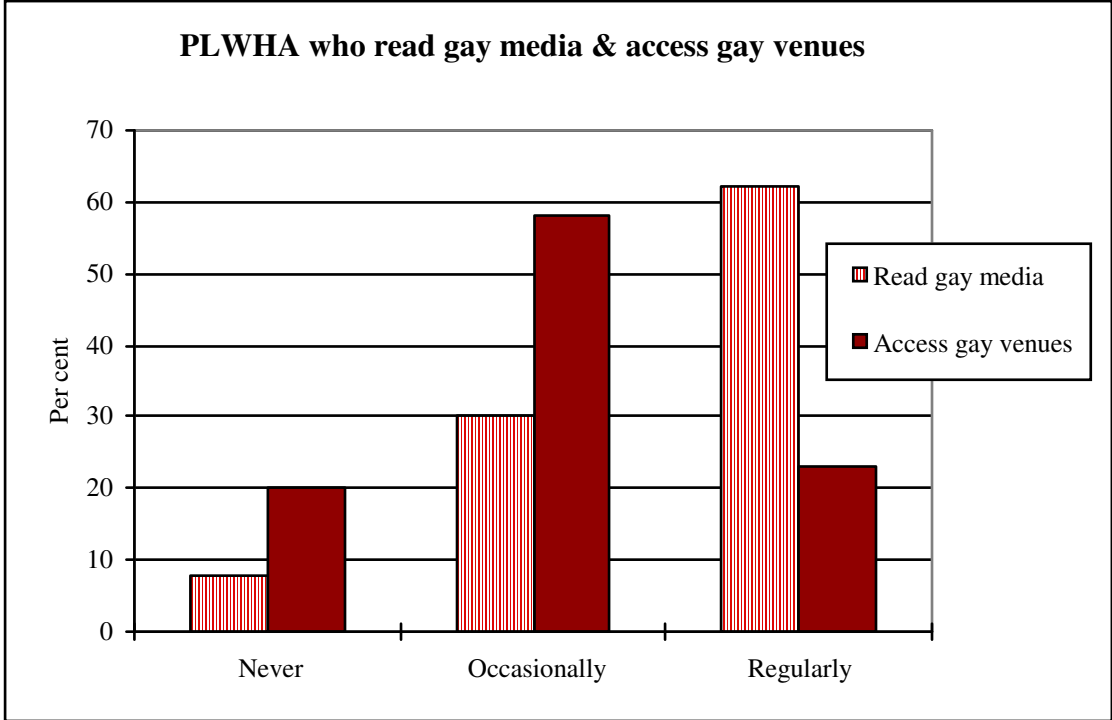
The responses of study participants indicated that many PLWHA are attached to the gay community. Over two-thirds (68%) of respondents see themselves as being part of the gay community. Not surprisingly, almost all (93%) of these people are homosexual men, while 5% are bisexual men. Another way of looking at this is to say that 77% of homosexual and bisexual male PLWHA reported that they feel part of the

gay community. Half (50%) of the respondents are members of gay organisations which are not HIV/AIDS organisations. Again most (91%) of these are homosexual men, while 6% are bisexual men. Most (56%) of the homosexual and bisexual male PLWHA reported that they are a member of a gay organisation which is not HIV/AIDS-related.

7.7.2 How many PLWHA read gay media and attend gay venues?

Graph 10 illustrates that most (80%) of the PLWHA who completed the survey read gay newspapers and/or magazines. Of these respondents, 85% are homosexual men and 7% bisexual men. Among homosexual and bisexual male PLWHA 70% reported that they regularly read gay press, while 29% report that they sometimes read gay press, and 1% reported that they never read gay press. Similarly, most (81%) respondents go to gay venues such as bars, nightclubs and saunas. These respondents were mostly homosexual men (87%) and bisexual men (7%). One-quarter (26%) of the homosexual and bisexual male PLWHA regularly attend gay venues, while 63% occasionally attend and 11% never attend gay venues.

Graph 10 All PLWHA who read gay media and access gay venues.



n = 903

8 Finances

Key Findings

The majority of PLWHA have difficulty meeting the expenses of day-to-day living. This is not surprising given that over half of respondents reported a government benefit as their main source of income.

One-third of respondents reported incomes below the poverty line. One-third of respondents share financial resources with a partner, and this protects them from some of the extremes of economic hardship. Very few PLWHA who are earning an income from paid employment reported incomes below the poverty line.

PLWHA with incomes below the poverty line have fewer assets and are more likely to rely on HIV/AIDS-related organisations for a variety of services and facilities. A substantial minority of respondents have incomes below the poverty line and assets worth less than \$5,000.

8.1 Income

8.1.1 *What is the income of PLWHA?*

Table 33 displays the weekly incomes (and equivalent annual incomes) reported by study participants. Forty-two per cent of respondents reported incomes below \$11,000, a similar finding to that reported in an earlier small-scale study of PLWHA in Australia (Ezzy et al., 1997).

Table 33 Incomes reported by PLWHA

Weekly income	Annual income	n	%
\$210 or less	\$10,920 or less	378	(42%)
\$211 - \$330	\$10,921-\$17,160	142	(16%)
\$331 - \$450	\$17,161-\$23,400	113	(13%)

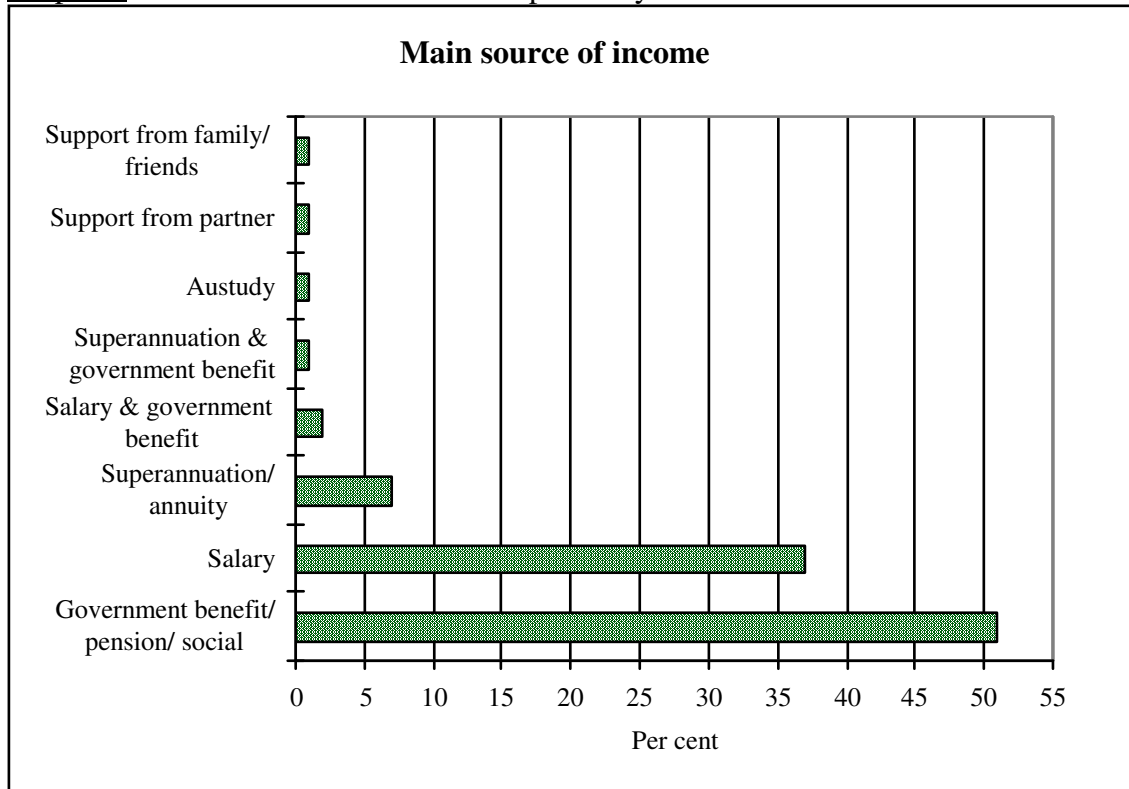
\$451 - \$570	\$23,401-\$29,640	97	(11%)
\$571 - \$690	\$29,641-\$35,880	57	(7%)
\$691 or more	\$35,881 or more	110	(12%)

n = 897

8.1.2 What are the income sources for PLWHA?

The sources from which PLWHA received their income are displayed in Graph 11. The distribution of incomes reported in Table 33 is probably a reflection of the finding that half (51%) of the PLWHA who completed the survey reported that their major source of income is a government benefit, pension (commonly a disability support pension), or social security payment, and that 37% reported that their main source of income is a salary. In total, 54% reported a government benefit as a source of income, whether by itself, or in combination with other income sources.

Graph 11 Main source of income reported by PLWHA



n = 906

Approximately one in three (30%) of PLWHA reported that they share financial resources with a partner. Respondents who are in a relationship were asked their partner's weekly income. The results in the Table 34 indicate that whilst one-quarter (25%) of respondents' partners are earning over \$690 per week, a similar proportion (27%) are earning less than \$210 per week.

Table 34 Income of PLWHA’s partner (For PLWHA who have a partner with whom they shares financial resources)

Weekly income	Annual income	n	%
\$210 or less	\$10,920 or less	72	(27%)
\$211 - \$330	\$10,921 - \$17,160	22	(8%)
\$331 - \$450	\$17,161 - \$23,400	33	(13%)
\$451 - \$570	\$23,401 - \$29,640	36	(13%)
\$571 - \$690	\$29,641 - \$35,880	38	(14%)
\$691 or more	\$35,881 or more	65	(25%)

n = 266

8.2 Poverty

8.2.1 How difficult is it for PLWHA to meet their costs of living?

Respondents were asked a number of questions which assessed the degree of difficulty they have in being able to pay for various expenses. Their responses are displayed in Table 35. A surprisingly high proportion of people (49%) have some difficulty meeting the costs of food. The majority of respondents have some difficulty meeting the costs of eating/drinking out (69%), entertainment (68%), clothing (68%), utilities such as gas and electricity (67%), complementary therapies (62%) and sport/exercise (57%). Furthermore 48% have some difficulty meeting the costs of transport. Of the 20 respondents who noted child care and related costs as an additional expense, 17 said they find meeting these costs to be *very difficult* (not shown in table).

Women were significantly more likely than men to report that it is *very difficult* for them to meet the costs of: prescribed medication (18% vs 6%); medical services (28% vs 9%); support services (22% vs 6%); and clothing (54% vs 33%). Women were more likely to have difficulty meeting the cost of these items despite the fact that women were no more or less likely than men to report an income below the poverty line (see section 8.2.2).

Table 35 Difficulties experienced by PLWHA in meeting various costs of living

Item	very difficult		a little difficult		not at all difficult	
	n	%	n	%	n	%
Travel / holidays	424	(53%)	227	(29%)	143	(18%)
Recreational drugs	175	(43%)	121	(30%)	109	(27%)
Eating / drinking out	300	(35%)	293	(34%)	265	(31%)
Clothing	302	(35%)	288	(33%)	282	(32%)
Entertainment	264	(31%)	311	(37%)	266	(32%)
Sport / exercise	176	(31%)	148	(26%)	240	(43%)
Complementary therapies	114	(26%)	160	(36%)	169	(38%)
Utilities	211	(24%)	387	(43%)	294	(33%)
Rent / mortgage / housing costs	155	(20%)	326	(42%)	293	(38%)
Transport	140	(16%)	275	(32%)	446	(53%)
Food	118	(13%)	321	(36%)	456	(51%)
Medical services	83	(10%)	204	(25%)	534	(65%)
Support services	32	(7%)	74	(16%)	366	(77%)
Prescribed medication	53	(6%)	300	(37%)	464	(57%)

n = 405 - 895

n varies from item to item due to different numbers giving *not applicable* response
Items cited by less than 2% of respondents not shown

8.2.2 How many PLWHA live below the poverty line?

The updated Henderson poverty lines published quarterly by the Institute of Applied Economics and Social Research [IAESR] were used to assess the extent of poverty among PLWHA. Different poverty lines are set for *income units* based on whether the person is single or has a partner with whom they share financial resources, and the number of dependent children. Using the IAESR (1997) data for the June quarter of 1997, it is clear that many PLWHA are living in poverty with almost one-third (32%) of respondents reporting incomes below the poverty line. Women were no more or less likely than men to report an income below the poverty line.

It should be noted that because respondents reported their income in bands of sixty dollar width rather than their precise income, it was not possible to calculate exactly the proportion of respondents with incomes below the poverty line - the results reported here are therefore likely to be a conservative estimate.

Table 36 Proportion of PLWHA with incomes below the poverty line

Income unit	income below poverty line		income above poverty line	
	n	%	n	%
Couple	5	(2 %)	225	(98%)
Couple plus 1 dependent child	3	(16%)	16	(84%)
Couple plus 2 dependent child	2	(18%)	9	(82%)
Couple plus 3 dependent child	1	(100%)	0	(0%)
Couple plus 4 dependent child	0	(0%)	1	(100%)
Single	194	(47%)	221	(53%)
Single plus 1 dependent child	18	(82%)	4	(18%)
Single plus 2 dependent child	2	(50%)	2	(50%)
Single plus 3 dependent child	2	(100%)	0	(0%)
Single plus 4 dependent child	0	(0%)	1	(100%)
Total	226 [†]	(32%)	478 [†]	(68%)

n = 704

[†] - column total does not equal reported total due to rounding in weighting procedure.

There is a striking difference in the proportion of people experiencing poverty among people who are in a relationship in which they shared financial resources with their partner, and among single people. PLWHA who share financial resources with a partner are less likely to report an income below the poverty line

8.2.3 *Is poverty linked to the length of time since being infected?*

On average, respondents who report incomes below the poverty line reported that they have been HIV-positive for a longer time than respondents who report incomes above the poverty line (8 years vs 7 years 1 month). This relationship is likely to be due to the fact that whether or not respondents are in paid employment is related to the number of years since first testing HIV-positive. For example, PLWHA who are not working have been HIV-positive for a longer period than those who are working (7 years 10 months vs 6 years 10 months).

8.2.4 *Is poverty linked to employment status?*

Not surprisingly, a significant association was found between employment status and experience of poverty. Half (51%) of the respondents who are not working reported

incomes below the poverty line, while only 6% of the respondents who are working reported incomes below the poverty line. Given the fact that most (83%) of the unemployed PLWHA stated that their main source of income is a government benefit, these data suggest that the income provided by government benefits is not sufficient for PLWHA.

8.2.5 *What is the link between poverty and health management?*

Reports of income below the poverty line were not related to use of anti-viral drugs, use of prophylaxis to prevent PCP, or use of prophylaxis to prevent other opportunistic infections. However, there was an association between poverty and use of complementary therapies. While 60% of respondents with incomes above the poverty line use complementary therapies, only 50% of respondents with incomes below the poverty line do so.

8.2.6 *How many PLWHA have private health insurance?*

Few respondents have private health insurance - 19% of the PLWHA who completed the survey reported that they have private health insurance. People who reported incomes below the poverty line were significantly less likely than those who did not to report that they have private health insurance (6% vs 26%).

8.2.7 *How difficult is it for PLWHA living in poverty to meet their costs of living?*

Not surprisingly, PLWHA who reported incomes below the poverty line were more likely than other respondents to report that they have difficulties meeting the costs of living with HIV/AIDS. Compared to PLWHA with incomes above the poverty line, PLWHA with incomes below the poverty line are significantly more likely to report difficulties in meeting the costs of:

- prescribed medication;
- entertainment;
- eating/drinking out;
- sport/exercise;

-
- recreational drugs;
 - travel/holidays;
 - rent/mortgage/housing costs;
 - utilities (phone, gas, electricity, etc.);
 - food;
 - clothing; and
 - transport.

Thus, it appears that HIV-related poverty affects not only the ability of PLWHA to pay for the *basics of life* such as housing, food, clothing, and utilities, but it also restricts the ability of PLWHA to engage in social and recreational activities.

Difficulties in meeting the costs of living with HIV/AIDS are affected more by whether or not the individual reports an income below the poverty line than by whether or not he/she has been diagnosed with an AIDS-defining illness. Compared to other PLWHA, respondents who have received an AIDS diagnosis are significantly more likely to report that they have difficulties meeting the costs of entertainment, food, clothing, and transport. Logistic regression analyses were conducted to examine whether difficulties in meeting costs of living are more strongly influenced by having had an AIDS-defining illness or having an income below the poverty line. These analyses revealed that for each of the costs listed, having an income below the poverty line is a greater predictor of financial difficulty than having been diagnosed with AIDS.

Previous studies have found that reports of increasing costs and of difficulties in meeting these costs are influenced by disease progression - people who have been diagnosed with AIDS have been found to be more likely to report increased costs (Bowie et al., 1996; Kass et al., 1994; Lubeck & Fries, 1993). However, it appears that difficulties in meeting the cost of living with HIV/AIDS are more closely related to experience of poverty than having received an AIDS diagnosis. This is a reflection of the fact that although people who have had an AIDS-defining illness are less likely than other PLWHA to be working, and therefore more likely to experience poverty, it is poverty itself, rather than having had an AIDS-defining illness, which is the

strongest determinant of whether or not PLWHA have difficulties in meeting the costs of living with HIV/AIDS.

8.2.8 *Do PLWHA who live in poverty access different HIV/AIDS organisations?*

Analyses were conducted to examine whether or not PLWHA with incomes below the poverty line have contact with different HIV/AIDS organisations than PLWHA with incomes above the poverty line. PLWHA with incomes below the poverty line are just as likely as other PLWHA to have contact with an AIDS Council or PLWHA Organisation. However, they are significantly more likely to have contact with certain organisations. For example, among respondents from New South Wales, PLWHA with an income below the poverty line are significantly more likely than other PLWHA to have contact with the Bobby Goldsmith Foundation (38% vs 11%) and the PLWHA day centre (17% vs 4%).

8.2.9 *Do PLWHA who live in poverty access different HIV/AIDS services?*

Among respondents who use the services of HIV/AIDS-related organisations, PLWHA with incomes below the poverty line are significantly more likely than other PLWHA to use certain services and facilities provided by these organisations. Compared to people with incomes above the poverty line, PLWHA with incomes below the poverty line are significantly more likely to:

- receive financial assistance (52% vs 15%);
- use the organisation for social contact (51% vs 35%);
- receive counselling (46% vs 30%);
- use transport services (22% vs 9%);
- receive financial advice (21% vs 11%); and
- receive domestic help (15% vs 4%).

8.3 Assets

8.3.1 *What is the value of PLWHA's assets?*

Respondents were asked to estimate the total value of all their assets (including savings, home, car and electrical equipment). The reported value of respondents' assets ranged from \$0 to \$2,000,000. The mean asset value of \$126,658.74 and the median of \$35,000 indicate a positively skewed distribution of asset values. Indeed, 25% of respondents reported total asset values of less than \$10,000. Another way of looking at this is to note that only 32% of respondents reported a total asset value greater than the average asset value.

8.3.2 *Do poorer PLWHA have fewer assets?*

A significant association was found between the value of respondents' assets and whether or not they had incomes below the poverty line. The mean asset value of respondents whose incomes were below the poverty line was \$64,673.34, while the mean asset value of respondents whose incomes were above the poverty line was \$155,171.14.

Of the 209 respondents with incomes below the poverty line, one-third (34%) reported assets valued below \$5,000 and nearly half (46%) reported assets valued below \$10,000. In contrast, among respondents with incomes above the poverty line, 11% have assets valued below \$5,000 and 16% have assets valued below \$10,000. Overall, of the 666 respondents who reported their income (and/or their partner's income) and the value of their assets, 11% reported an income below the poverty line and assets less than \$5,000 and 15% reported an income below the poverty line and assets less than \$10,000.

All of the information presented in this section points to the fact that PLWHA with incomes below the poverty line also report significantly less valuable assets than other PLWHA. These data suggest that there exists a group of PLWHA with incomes below the poverty line who also have few assets with which to meet the rising costs of living with HIV associated with disease progression.

9 Housing and Accommodation

Key Findings

Slightly less than half of PLWHA live alone, and just over half live in rental accommodation, typically private rental accommodation. Forty per cent of PLWHA live in inner city Sydney where the average weekly rent or mortgage cost is \$136.

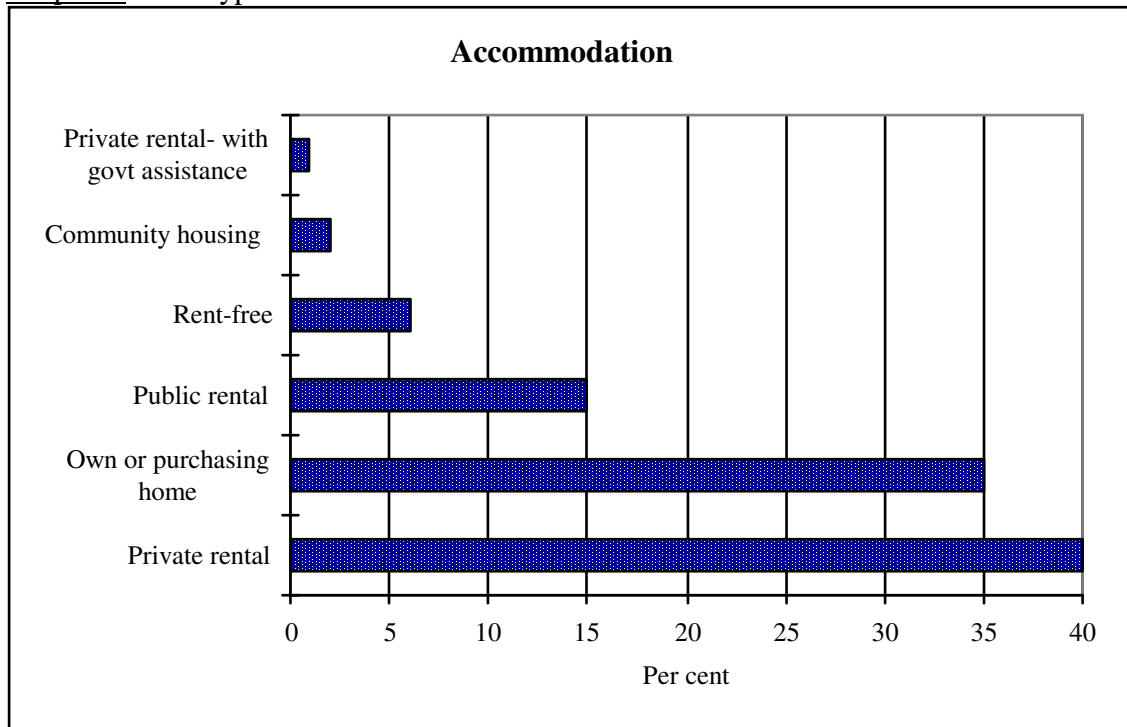
Nearly half of PLWHA feel that their accommodation is too expensive. Many PLWHA have changed their living arrangements as a result of having HIV/AIDS, typically for reasons related to finances.

9.1 Housing and accommodation status

9.1.1 *In what type of accommodation do PLWHA live?*

Graph 12 reveals that most commonly PLWHA are living in rental accommodation with 40% reporting that they live in private rental accommodation, and 15% living in public rental accommodation. Slightly more than one-third (35%) of respondents live in a home they own or are purchasing, while 39% had owned their own home or flat in the past. Among the respondents who do not currently own their own home/flat, 21% had owned a home/flat in the past.

Graph 12 Type of Accommodation



n = 912

9.1.2 How much do PLWHA spend on accommodation?

The mean cost of housing reported by respondents was \$102.13 and the median was \$84.32. However, one-fifth of respondents (21%) indicated that they pay no rent or mortgage expenses. Respondents who do have to pay rent/mortgage expenses reported spending between \$21 and \$600 per week on housing. Excluding respondents who do not have any housing expenses, the mean cost of housing was \$129.94 and the median was \$116.62. There was no difference between men and women in terms of their housing costs.

The cost of accommodation varied considerably depending on whether a person lived in the inner suburbs of a capital city (average weekly rent or mortgage cost of \$117), outer suburbs (\$90), a regional centre (\$67) or in a rural location (\$60). The cost of accommodation also varied depending on the State in which PLWHA lived. In New South Wales the average weekly rent or mortgage cost was \$118, compared to \$104 in Western Australia, \$85 in Queensland, \$73 in Victoria, and \$72 in South Australia (values for the Australian Capital Territory, the Northern Territory and Tasmania are not given due to the small numbers involved). In NSW the number of respondents is

large enough to break down these data even further. In inner suburban Sydney the average weekly rent or mortgage cost was \$136, compared to \$103 in outer suburban Sydney, \$69 in regional centres, and \$65 in rural NSW. Forty per cent of PLWHA live in inner city Sydney where the average weekly rent or mortgage cost is \$136.

Compared to respondents who report incomes above the poverty line, respondents who report incomes below the poverty line are significantly less likely to report that they currently own their own home or flat (23% vs 42%) and significantly less likely to report that they have owned their own home or flat in the past (31% vs 45%).

9.1.3 With whom do PLWHA live?

Table 37 shows that 42% of the PLWHA who completed the survey live alone. Of the remaining 58% of respondents, many lived with a partner or spouse and/or friends or housemates. One in ten respondents lived with dependent children.

Table 37 Living Companions

Living companions	n	%	n	%
Live alone			380	(42%)
Live with others			530	(58%)
Partner / spouse [†]	306	(58%)		
Friend(s) / housemate(s) [†]	156	(29%)		
Other family members [†]	64	(12%)		
Dependent children [†]	54	(10%)		

n = 910

[†] - Multiple response possible

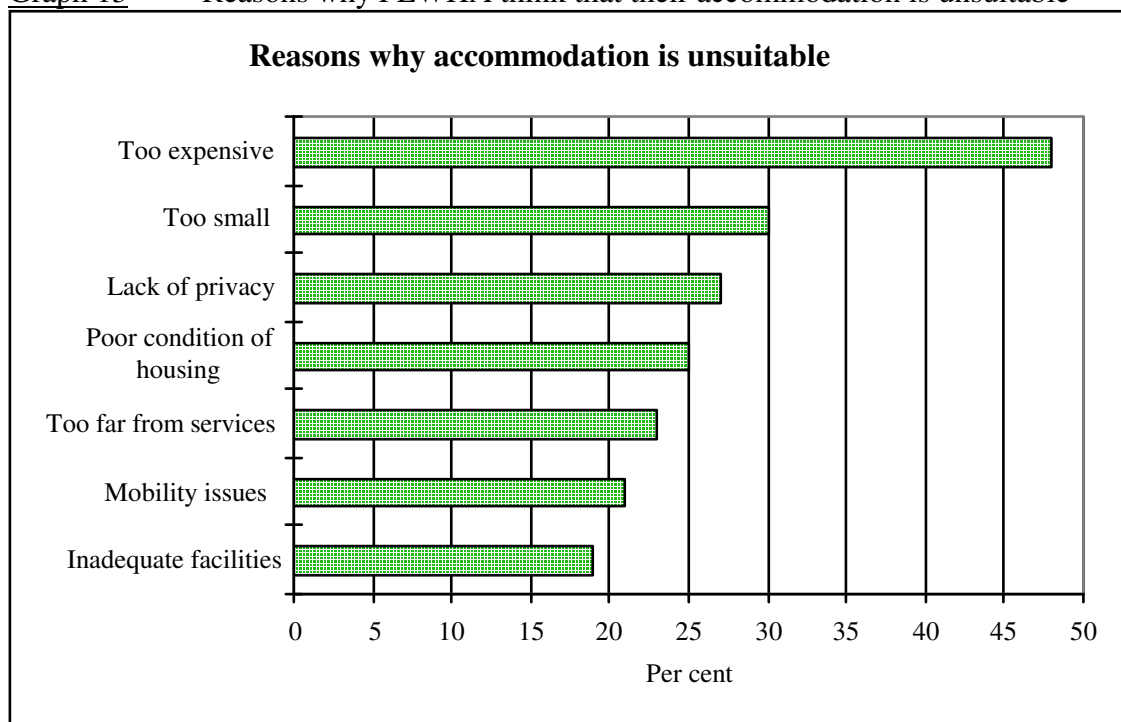
9.2 Suitability of accommodation

9.2.1 Is their current accommodation suitable for PLWHAs' needs?

The great majority (85%) of respondents believe that their current accommodation meets their needs. Respondents who believe that their accommodation is unsuitable gave a number of reasons why they believe their accommodation is unsuitable. These reasons are displayed in Graph 13. The most common reason respondents gave was

that their accommodation is too expensive for them (48%). Many respondents believe that the size (30%) and/or condition (25%) of their accommodation is unsuitable. Twenty three per cent of respondents who think that their accommodation is unsuitable report that this is because their accommodation is too far from services.

Graph 13 Reasons why PLWHA think that their accommodation is unsuitable



n = 127

Multiple responses possible

Whether or not PLWHA have incomes below the poverty line is significantly related to whether or not they believe that their accommodation is unsuitable for their needs. Almost one-quarter (24%) of PLWHA with incomes below the poverty line think that their accommodation is unsuitable compared to 12% of the rest of the sample.

9.2.2 How many respondents have changed their living arrangements due to HIV/AIDS? Why?

A substantial minority (42%) of respondents have at some time changed their living arrangements as a result of having HIV/AIDS. The changes respondents made to their living arrangements the last time they moved are displayed in Table 38. Most commonly respondents changed their accommodation because they stopped working (41%) and/or they needed cheaper accommodation (40%). Nearly one-third (31%) changed their accommodation to move closer to support services, and a large proportion moved because of ill health (21%) or anticipated ill health (30%).

Table 38 Changes in accommodation due to HIV/AIDS

Most recent change in accommodation	n	%
Stopped working	155	(41%)
Needed cheaper housing	150	(40%)
Moved to a quieter location	129	(34%)
Moved closer to support services	119	(31%)
Planning for illness	116	(30%)
Illness	82	(21%)
Better health	73	(19%)
Moved closer to friends	57	(15%)
Ending of long-term relationship	56	(15%)
Improved finances	43	(11%)
Beginning of new relationship	29	(8%)
Moved in with family	23	(6%)
Moved out of family home	22	(6%)
Returned to work	14	(4%)
To avoid harassment	10	(3%)
Moved interstate	6	(2%)

n = 381

Multiple responses possible

Changes cited by less than 2% of respondents not shown

10 Employment

Key Findings

Over half of PLWHA are not in paid employment, although the majority were in paid employment at the time they were diagnosed HIV-positive. Most PLWHA left their career or in some way reduced their career goals after their diagnosis.

Over one-third of PLWHA have not disclosed their HIV status to anyone at their workplace, and most have difficulty maintaining the confidentiality of their HIV status. Thirteen per cent of respondents have experienced workplace discrimination.

Nearly two-thirds of respondents have stopped work at some time in the past for reasons related to having HIV/AIDS. Three-quarters cited stress, depression or anxiety as the reasons for stopping work, and half cited poor health. Over half of respondents changed their accommodation arrangements within a few months of leaving work. Of those who had left work, one-third returned to work, typically for financial reasons.

The effects of the new anti-virals on PLWHAs' employment, while still in early stages, appears to be largely positive, with many PLWHA considering staying at work or returning to work.

One-quarter of those working said that HIV/AIDS has affected their capacity to work. Over one-third of respondents are considering changing the amount of work they are doing. About half of these want to work less - either to reduce stress, or due to poor health. About half want to increase the amount of work they are doing, mainly for financial reasons.

The majority of PLWHA who are not working are considering returning to the workforce, but most think that it will be difficult to do so. Just under half of PLWHA cited improved

health as a reason for wanting to return to work, while more than half cited financial, psychological, emotional or social reasons for wanting to return to work.

10.1 Employment issues (all respondents)

For PLWHA who are working, the data in this section refer to their current job. For PLWHA who are not working, the data in this section refer to their last job.

10.1.1 How many PLWHA are employed?

Over half (56%) of the PLWHA who completed the survey are not in paid employment (see Table 39). Among those who are in paid employment, two-thirds are in full-time employment, while one-third are in part-time or casual work. Whether or not respondents are in paid employment is related to the number of years since first testing HIV-positive. Respondents who are not working have, on average, been HIV-positive for a longer period than those who are working (7 years 10 months vs 6 years 10 months). Compared to other PLWHA, those who have been diagnosed with an AIDS-defining illness are significantly less likely to be working in paid employment (71% vs 52%).

Women were no more or less likely than men to be in paid employment at the time of completing the survey.

Table 39 Employment Status of PLWHA

Employment status	n	%	n	%
Not in paid employment			512	(56%)
Not working / retired	336	(37%)		
Unemployed	110	(12%)		
Student	34	(4%)		
Home duties	27	(3%)		
Community work	5	(1%)		
In paid employment			402	(44%)
Work full-time	265	(29%)		
Work part-time	137	(15%)		

n = 914

The vast majority (91%) of respondents were in paid employment at the time they were diagnosed HIV-positive. Fifty three per cent of the PLWHA who were working

at the time they were diagnosed HIV-positive were no longer working at the time of completing the survey. Twenty four per cent of the PLWHA who were not working at the time of diagnosis were working at the time of completing the survey.

10.1.2 In what occupations are PLWHA employed?

The occupations reported by PLWHA are shown in the table below. The high education levels of the sample are reflected in the large proportion of PLWHA working in professional and managerial occupations.

Table 40 Occupations of PLWHA

Occupation	Working ¹		Not working ²	
	n	%	n	%
Professional	151	(40%)	120	(27%)
Service	66	(18%)	110	(24%)
Managerial	61	(16%)	70	(16%)
Clerical and related	43	(12%)	49	(11%)
Production and related	23	(6%)	59	(13%)
Sales	13	(3%)	23	(5%)
Artist and related	10	(3%)	6	(1%)
Agricultural	7	(2%)	9	(2%)
Sex work	1	(<1%)	4	(1%)

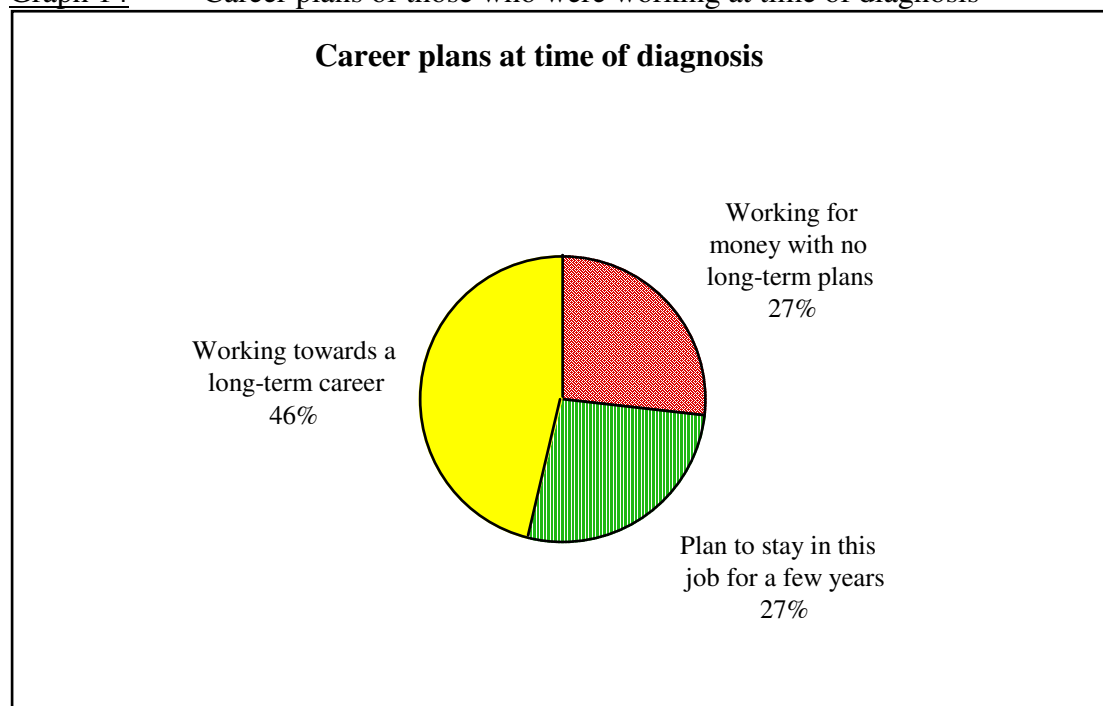
1 - n = 375

2 - n = 451

10.1.3 What were the career plans of PLWHA at the time of their HIV diagnosis?

Respondents who were working when they were diagnosed HIV-positive were asked to describe their long-term career plan at the time of diagnosis. Their responses are displayed in Graph 14, which shows that many PLWHA had a long-term career plan at the time of their diagnosis with HIV. Whether or not these PLWHA were in paid employment at the time of completing the survey was not related to career plans at the time of diagnosis.

Graph 14 Career plans of those who were working at time of diagnosis



n = 814

10.1.4 How did the career plans of PLWHA change after their HIV diagnosis?

Three-quarters (76%) of the PLWHA who completed the survey reported that being diagnosed HIV-positive had affected their work career plans. Respondents explained a number of ways in which their work career plans had changed. The most commonly cited are shown in the table below. Many PLWHA gave reasons which suggest an inability or unwillingness to plan their career for the future.

Table 41 Effect on career plans of being diagnosed HIV-positive

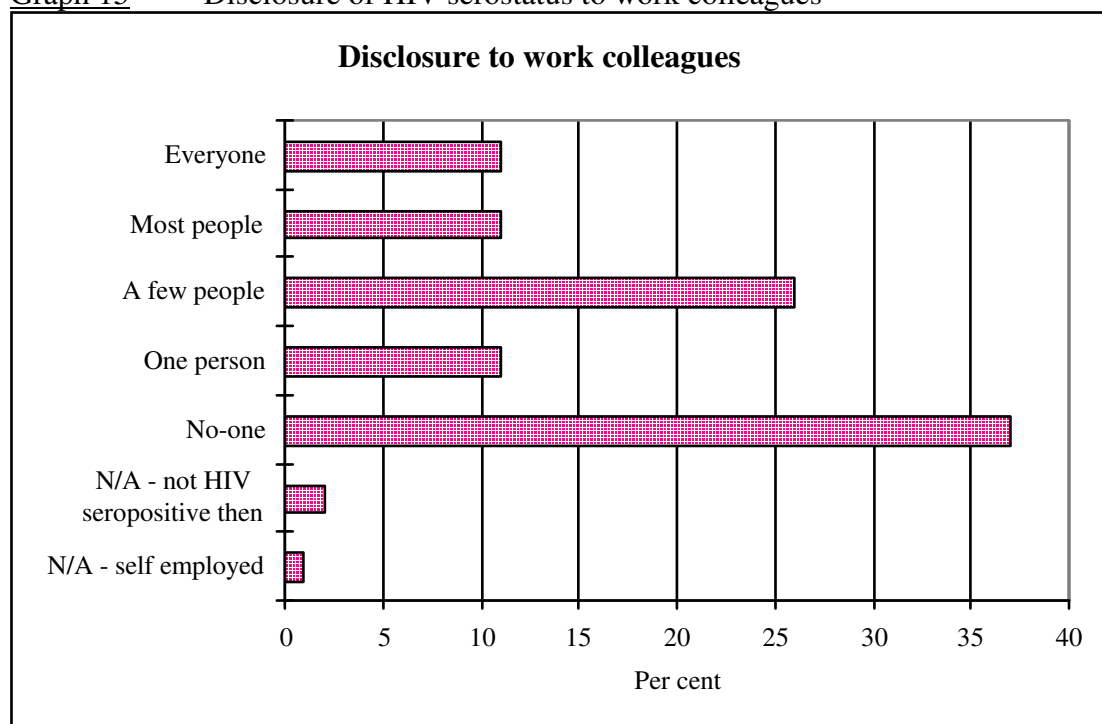
Change in career plans	n	%	n	%
No change to career plans			214	(24%)
Change to career plans			692	(76%)
Career ended / no future career plans	120	(17%)		
Uncertain future due to unpredictable health	72	(10%)		
Lack enthusiasm / drive	41	(6%)		
Started new career / changed career	36	(5%)		
Got priorities in order / career not as important	37	(5%)		
Unable to work full-time	28	(4%)		
Changed to a less demanding/less stressful career	26	(4%)		
Changed to doing something enjoyable	15	(2%)		
Freaked out / lost the plot	11	(2%)		
Less likely to change jobs	11	(2%)		
Changed to part-time work	11	(2%)		

n = 906

10.1.5 How many PLWHA have disclosed their HIV status to colleagues?

The data in Graph 15 show that two-thirds (63%) of respondents reported that people at their place of work know that they are HIV-positive; however many PLWHA have disclosed their HIV serostatus to only one or a few work colleagues. The proportion of work colleagues who know that the respondent has HIV/AIDS is not related to whether or not they are currently working.

Graph 15 Disclosure of HIV serostatus to work colleagues



n = 850

10.1.6 Do PLWHA have difficulties at work keeping their HIV status confidential?

Most respondents (58%) reported that they have no problems keeping their HIV status confidential at work. Only 2% reported that they do not try to keep their HIV status confidential. Table 42 displays the problems encountered by PLWHA who reported that they have difficulty keeping their HIV status confidential at work. The most commonly cited problems are difficulty storing and taking medication at work and having to explain absences when attending medical appointments and when ill. A small number of respondents reported that they are concerned that work colleagues

gossip about their HIV serostatus. Compared to PLWHA who are not working, PLWHA who are working were significantly less likely to report that they have difficulties keeping their HIV status confidential.

Table 42 Problems encountered by PLWHA who find it difficult to keep their HIV serostatus confidential at work

Problems keeping HIV status confidential	n	%
Explaining absences from work due to medical appointments	158	(41%)
Difficulty keeping and taking medication	109	(29%)
Explaining absences from work due to illness	104	(27%)
Visible signs of illness	89	(23%)
Gossip	31	(8%)

n = 381 Multiple responses possible

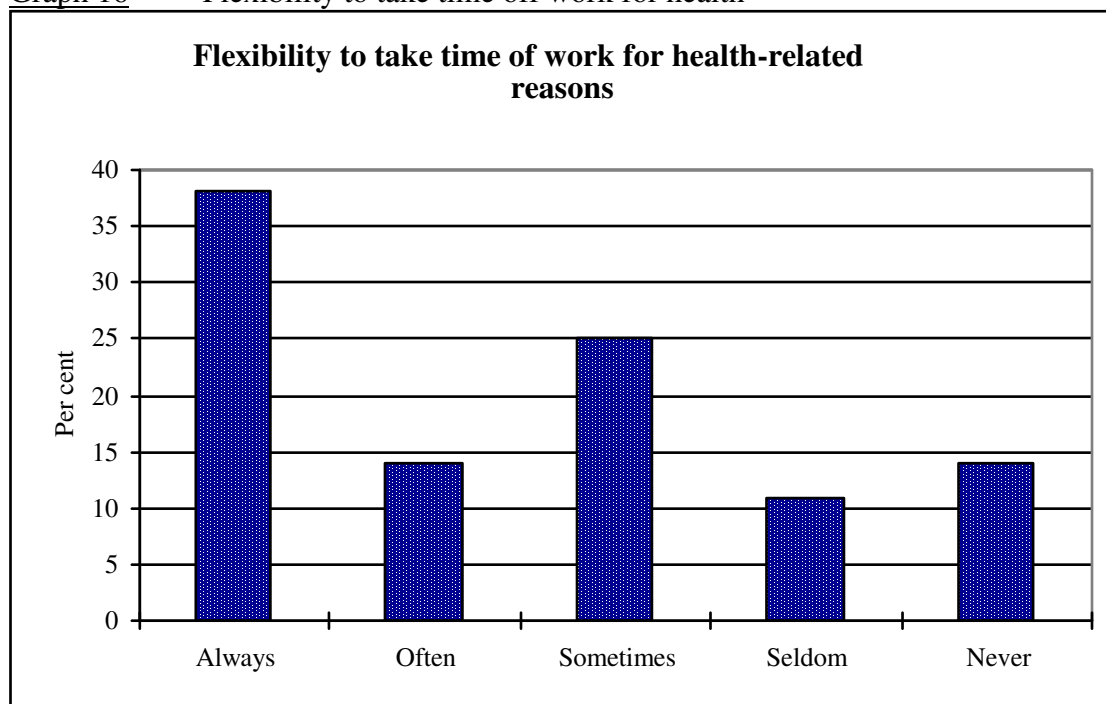
10.1.7 How many PLWHA experience discrimination in the workplace?

The vast majority (87%) of respondents reported that they are *never* given a hard time at work because of their HIV/AIDS status, while 9% said that they *seldom* experience discrimination, 3% *sometimes* experienced discrimination, 1% *often* experienced discrimination, and less than 1% *always* experienced discrimination. There was no relationship between respondents' reports of discrimination at work and whether or not they were working at the time of completing the survey.

10.1.8 How easy is it for PLWHA to take time off work for health-related reasons?

Graph 16 shows that most PLWHA appear to have flexibility to take time off work when they are sick or for health-related reasons. Compared to PLWHA who were not working at the time of completing the survey, PLWHA who were working were significantly more likely to report that they *always* have flexibility to take time off work, and significantly less likely to report that they *seldom* or *never* have this flexibility.

Graph 16 Flexibility to take time off work for health



n = 648

10.1.9 Is it easier for PLWHA to take time off work when colleagues are aware of their HIV status?

A significant association was found between disclosure of HIV serostatus to work colleagues and flexibility to take time off work. Compared to other PLWHA, those who have not told anyone at work about their HIV serostatus are significantly more likely to report that they *never* have flexibility to take time of work; and compared to other PLWHA, those who have told all or most people at work about their HIV serostatus are significantly more likely to report that they *always* have flexibility to take time off work for HIV-related reasons.

10.1.10 How many PLWHA have stopped working and why did they do so?

Nearly two-thirds of respondents (62%) reported that at some time they had left work for reasons related to having HIV/AIDS. Of these respondents, 50% had asymptomatic HIV infection at the time of leaving work, 37% had symptomatic HIV infection, and 12% had been diagnosed with AIDS. The reasons respondents gave for stopping work are shown in Table 43 - respondents who had stopped working more

than once provided information about the most recent occasion on which they left work.

Table 43 Reasons given for leaving work due to HIV/AIDS

Reason for leaving work	HIV+ but no illness ¹		HIV+ and some illness ²		AIDS diagnosis ³		All PLWHA ⁴	
	n	%	n	%	n	%	n	%
Stress / depression / anxiety	202	(75%)	151	(75%)	37	(55%)	389	(72%)
Low energy levels	138	(51%)	164	(81%)	44	(65%)	347	(64%)
Poor health	62	(23%)	153	(76%)	54	(80%)	271	(50%)
To have more quality time	124	(46%)	96	(48%)	25	(37%)	244	(45%)
Expecting illness in the future	76	(28%)	76	(38%)	26	(38%)	177	(33%)
To move to a different location	50	(19%)	29	(15%)	8	(12%)	88	(16%)
Retrenched / sacked	20	(7%)	17	(9%)	4	(6%)	44	(8%)
To move to a different job	17	(6%)	3	(2%)	2	(3%)	22	(4%)
To care for someone	10	(4%)	3	(1%)	2	(3%)	15	(3%)

1 - n = 271

2 - n = 202

3 - n = 67

4 - n = 544

Reasons cited by less than 2% not shown in table

Shaded rows indicate a significant difference between groups

Most commonly, PLWHA left work due to stress, depression, or anxiety (72%). One-third (64%) left work due to low energy levels, and half (50%) cited poor health. One-third of respondents left work because they anticipated illness in the future. For both PLWHA who left work due to poor health and those who did not, psychological and emotional factors such as stress, depression, anxiety, low energy levels, and a desire to have more quality time were important reasons for leaving work.

Analyses were conducted to examine whether the reasons respondents gave for leaving work were related to whether or not they had experienced HIV/AIDS-related illnesses. As can be seen in Table 43, respondents who had been diagnosed with an AIDS-defining illness before they left work were significantly less likely than other respondents to report that they stopped working due to stress, depression, or anxiety. These data suggest that the emotional impact of an HIV diagnosis may be greater than that of an AIDS diagnosis, however it should be noted that over half of the respondents diagnosed with an AIDS-defining illness cited stress, depression, and/or anxiety as factors which influenced their decision to leave work. Respondents who had experienced HIV/AIDS-related illnesses (but who had not had an AIDS diagnosis) were significantly more likely than other respondents to report that they left work because of low energy levels. It is interesting to note that over three-quarters (81%) of respondents who had experienced HIV/AIDS-related illnesses reported that they left

work due to low energy levels. Thus it appears that even in the absence of an AIDS diagnosis, the impact of HIV-related illnesses had an obvious negative effect on the capacity of PLWHA to maintain employment.

Not surprisingly, respondents who had experienced HIV/AIDS-related illnesses or an AIDS-defining illness were significantly more likely to report that they left work because of poor health. However, people who had experienced an AIDS-defining illness or who had an HIV/AIDS-related illness were no more likely to report that they left work because of an expectation of illness in the future. This finding suggests that concern about the impact on work of future ill health is a concern for all PLWHA, not only those who have experienced HIV-related illnesses.

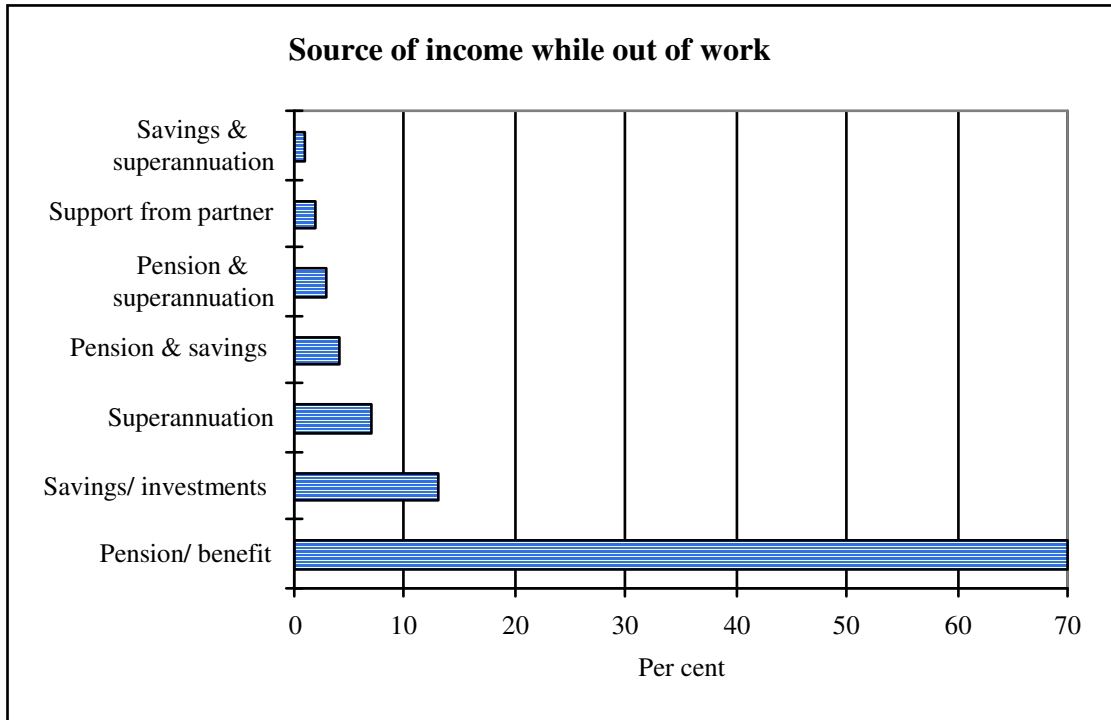
10.1.11 How does leaving work impact on accommodation arrangements?

Slightly more than half (52%) of the PLWHA who had left work due to HIV/AIDS said that their housing arrangements also changed within a few months of stopping work. This is likely to be due to the fact that 70% of respondents reported that upon leaving the workforce their main source of income changed to a government benefit of less value than their salary while in paid employment.

10.1.12 What were the sources of income of PLWHA while out of work?

Graph 17 displays respondents' main source(s) of income during their time out of the workforce. As noted above, most (70%) PLWHA reported that their main source of income was a government benefit.

Graph 17 Sources of income while out of the workforce



n = 534 reasons cited by less than 2% not shown in graph

10.1.13 How do PLWHA spend their time while out of the workforce?

Table 44 shows that PLWHA who had left work engaged in a range of activities during their time out of the workforce. Nearly half (47%) of respondents spent the time recovering from illness. One-third (34%) of PLWHA engaged in volunteer work in an HIV/AIDS-related organisation, and that 17% engaged in volunteer work in other organisations. Many PLWHA cared for others during their time out of the workforce - 22% cared for another PLWHA and 7% cared for children. Given the large proportion of PLWHA who reported low energy levels and/or poor health as reasons for leaving work, it is interesting to observe the substantial number who, upon leaving work, became involved in volunteer work and caring for others.

Table 44 How PLWHA spend their time while out of the workforce

How time is spent	n	%
Recreation / sport / leisure activities	288	(55%)
Illness / recuperating from illness	250	(47%)
Volunteer work in HIV/AIDS-related organisation	178	(34%)
Care of another PLWHA	117	(22%)
Other volunteer work	87	(17%)
Care of children	36	(7%)
Travelling	20	(4%)
Studying / self-education	19	(4%)
Looking for work	14	(3%)
Looking after self	9	(2%)

n = 527 Reasons cited by less than 2% not shown in table
Multiple responses possible

10.1.14 How many PLWHA returned to work and why did they do so?

Over one-third (37%) of all PLWHA who had left work due to having HIV/AIDS later returned to work. The reasons given by the PLWHA for returning to work are shown in Table 45. As can be seen, half (52%) of the PLWHA who returned to work did so for financial reasons. Many (25%) PLWHA also cited improved physical and/or mental health as a reason for returning to work. One-third (34%) of the PLWHA who had left work reported that they returned to work to improve their mental well-being, to enhance their self-esteem, and/or to relieve boredom. When we consider these data

and the light of the finding that many PLWHA wanted to return to work to do something worthwhile (10%), for social contact (6%), and/or due to a dedication to work (5%) we can see that the psychological impacts of leaving work due to HIV/AIDS are important for many PLWHA. The large proportion of people involved in volunteer work while not in paid work and the number of who reported self-esteem, boredom, and the need to do something worthwhile as reasons to return to work suggests that being active and contributing to society are important to many PLWHA. This is an important factor for consideration as people are forced to leave the workforce due to disease progression.

Table 45 Reasons for returning to work given by PLWHA who left work due to HIV/AIDS

Reasons for returning to work	n	%
Money	105	(52%)
Mental well-being / self-esteem / boredom	70	(34%)
Better health / better outlook for the future	51	(25%)
To do something worthwhile	21	(10%)
Chance to work part-time	17	(8%)
Social contact	13	(6%)
Dedication to work	10	(5%)
To be(come) involved in a business	5	(2%)
Found appropriate job	4	(2%)
Need routine	4	(2%)

n = 203 Reasons cited by less than 2% not shown in table
Multiple response possible

10.1.15 How have new anti-viral treatments altered the career plans of PLWHA?

Among the PLWHA who were taking anti-virals in combination at the time of completing the survey, 62% were working when they started using these treatments. Table 46 shows that nearly two-thirds (62%) of the PLWHA who were using anti-virals at the time of completing the survey said that taking up combination anti-virals had affected their career plans. The table also shows that among those whose plans did change, the majority said that commencing combination anti-virals had caused them to consider a longer work career (36%) or a return to work (22%).

Table 46 Effect of starting combination anti-virals on career plans

Change to career plans	n	%
There was no change to my career plans	164	(38%)
I anticipated a longer time in the workforce	99	(23%)
I began to consider going back to work	59	(14%)
I did not plan to go back to work, and this has not changed	49	(11%)
I began to consider a career plan	37	(9%)
I left work	28	(6%)

n = 436

Among the PLWHA who were not using anti-virals in combination at the time of completing the survey, 66% said that they might use them in the future, 9% said that they would not use them in the future, and 25% were unsure whether or not they would use them in the future. Among those who said that they may use combination anti-virals in the future, 28% said that the possibility of using anti-viral drugs has affected their career plans. The ways in which the career plans of PLWHA have been affected by the possibility of starting combination anti-viral therapy are shown in Table 47. Many respondents feel that they are now able to plan a work career for the first time (32%), and/or that they have begun to consider a career plan for the first time (32%).

Table 47 Effect of possibility of starting combination anti-virals on career plans

Change to career plans	n	%	n	%
No change to career plans			104	(72%)
Change to career plans			41	(28%)
now planning a work career for the first time ¹	13	(32%)		
have begun to consider a new work career ¹	13	(32%)		
anticipating a longer time in the workforce ¹	12	(29%)		
considering returning to my previous career ¹	6	(15%)		

n = 145

1 - Multiple response possible

10.2 Employment Issues (Among PLWHA in paid employment at time of completing survey)

Four hundred and one respondents were working at the time of completing the survey and provided information about their current work situation. PLWHA who are in paid employment work for an average of 35.8 hours per week (median = 38 hours). They have been in their current job for periods ranging from less than one month to 40 years (mean = 5 years 1 month; median = 3 years).

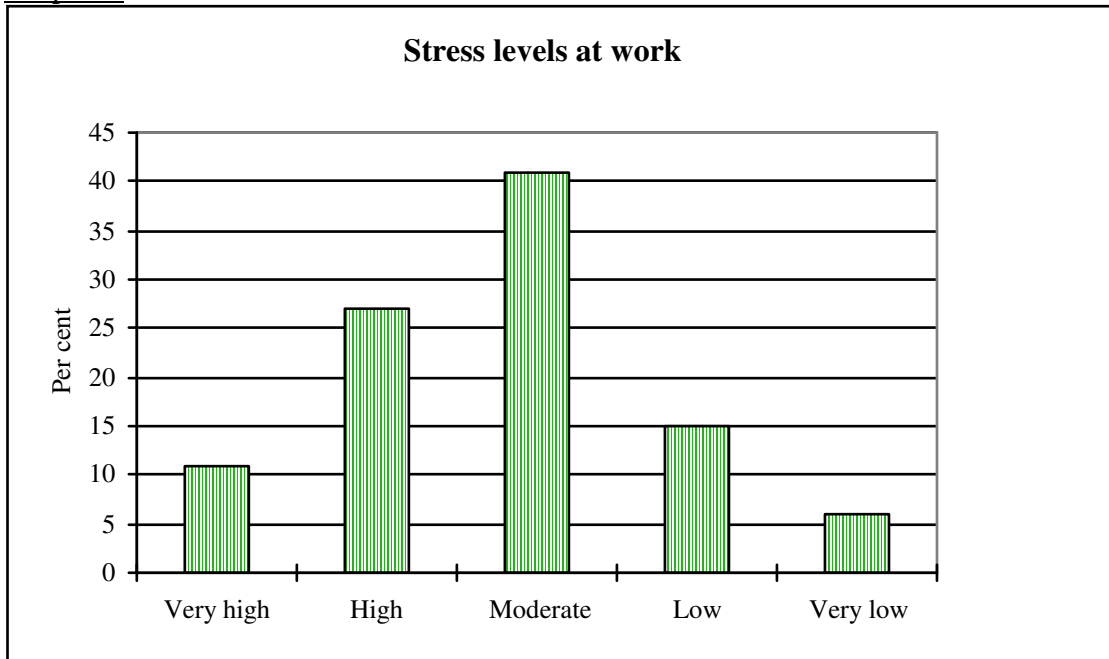
10.2.1 How many PLWHA work in an HIV/AIDS-related area?

The majority (84%) of respondents reported that their everyday work tasks are not HIV-related. However, 15% reported that their everyday work tasks are HIV-related, and 1% said that their everyday work tasks are sometimes HIV-related (eg. nurses). Among PLWHA who are working, 13% are employed by an HIV/AIDS-related organisation.

10.2.2 How stressful are the jobs of PLWHA who are working?

Few of the PLWHA who are working reported low levels of work stress. Graph 18 shows that 11% reported *very high* levels of stress, 27% reported *high* levels of stress, and 41% reported *moderate* levels of stress.

Graph 18 Stress levels at work

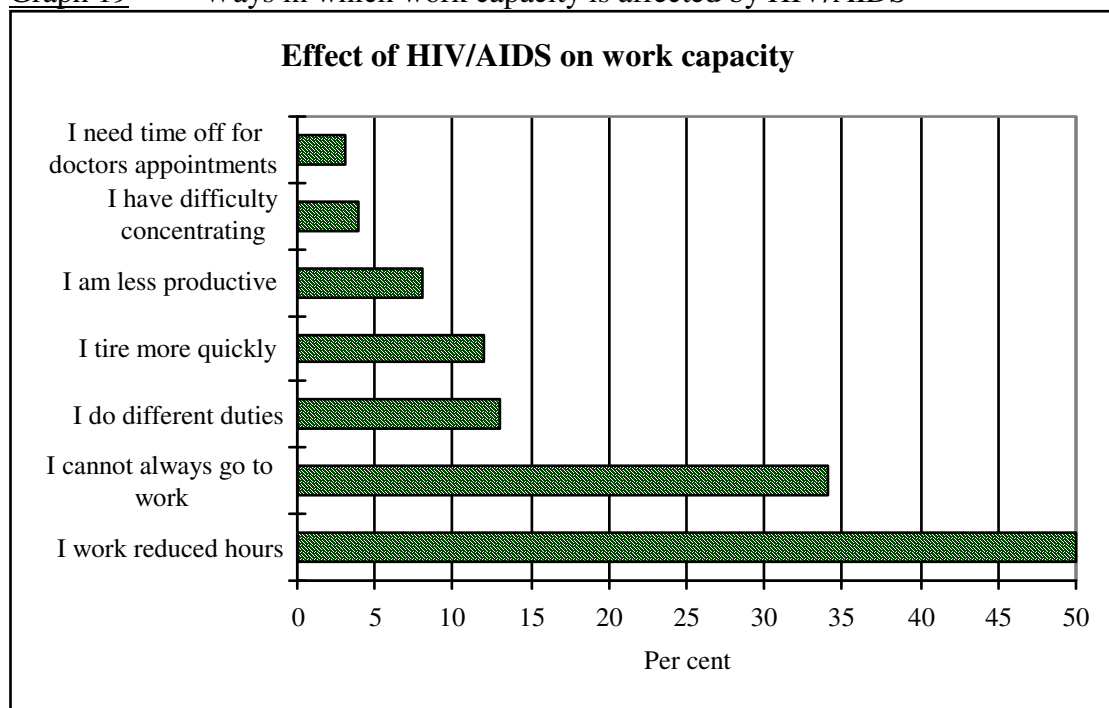


n = 389

10.2.3 How is the work capacity of PLWHA affected by HIV/AIDS?

Just over one-quarter (27%) of the PLWHA who are working said that their capacity to perform their work duties is currently affected by having HIV/AIDS. Graph 19 shows the ways in which respondents' work capacity is affected by HIV/AIDS. Most respondents reported that the amount of time they spend at work has decreased due to either working fewer hours per week (50%) or to not always being able to go to work (34%). In addition, many respondents reported that their physical and mental stamina has been reduced, and that this affects their productivity.

Graph 19 Ways in which work capacity is affected by HIV/AIDS



n = 105
 Multiple responses possible
 Reasons cited by less than 2% not shown

10.2.4 How many PLWHA are considering changing their type of work and why?

Just under one-third (31%) of the PLWHA who are working are considering changing the type of work they do. The main reasons given for wanting to change the type of work are because respondents want more of a challenge (40%), less stress (24%), or more money (8%).

10.2.5 How difficult will it be for PLWHA to change their employment?

Respondents were asked how difficult it will be for them to make the desired change to the type of work they do. Most respondents perceived some difficulty: 17% think that it will be *very difficult*; 58% think that it will be *somewhat difficult*; 17% think that it will be *somewhat easy*; and 8% think that it will be *very easy*.

10.2.6 What type of (re)training will be required for PLWHA to change employment?

Respondents were also asked to explain the type of (re)training they think they may have to undertake to achieve the desired change in their employment situation. Responses to these questions (displayed in Table 48) suggest that most PLWHA feel that they will have to undergo some form of (re)training - whether this is formal education or on-the-job training.

Table 48 Training required to achieve desired change in type of employment

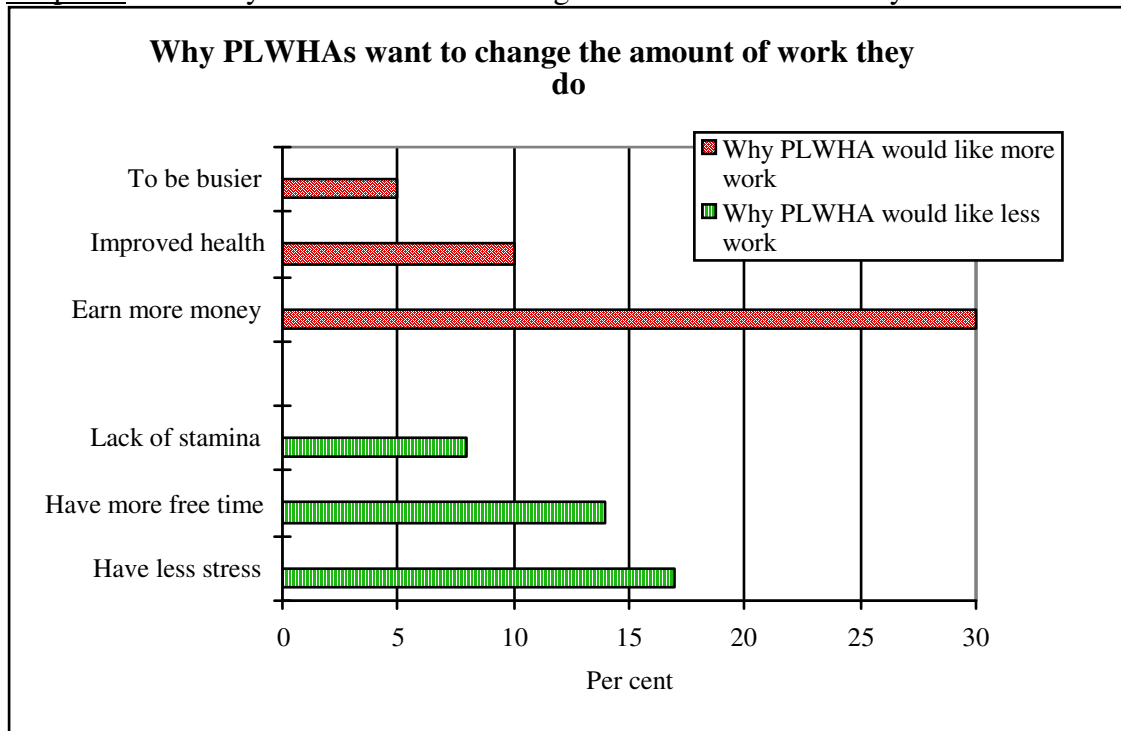
Training required	n	%
Attending short courses	43	(39%)
On-the-job training	32	(29%)
Education in TAFE	23	(21%)
Education at university	23	(21%)
Training in voluntary organisations	1	(1%)
No training	21	(19%)
Don't know	14	(13%)

n = 111 Multiple response possible

10.2.7 How many PLWHA are considering changing the amount of work they do? Why?

Just over one-third (38%) of the PLWHA who are working are considering changing the amount of work they do. Of the respondents who want to change the amount of work they do, 48% want to reduce the hours worked, 47% want to increase the hours worked, and 5% want to stop working. These results indicate that while many PLWHA want to reduce their workload and stress levels, many others want to increase their workload. No association was found between whether or not respondents have been diagnosed with an AIDS-defining illness and whether they want to increase or decrease the number of hours they spend at work.

Graph 20 Why PLWHA want to change the amount of work they do



n = 108

10.2.8 How difficult do PLWHA believe it will be to change the amount of work they do?

When asked how difficult it will be for them to make the desired change in the amount of work they do, most respondents perceived some difficulty: 9% think that it will be *very difficult*; 50% think that it will be *somewhat difficult*; 30% think that it will be *somewhat easy*; and 11% think that it will be *very easy*.

10.3 Employment Issues (Among PLWHA who were not in paid employment at time of completing survey)

Nearly all (99%) of the PLWHA who were not in paid employment at the time of completing the survey had been in paid employment at some time in the past. The majority (59%) of PLWHA who are not working are considering starting work or returning to work.

10.3.1 How difficult do PLWHA believe it will be to return to work?

The majority of unemployed PLWHA who want to (re)enter the workforce think that starting work or returning to work will be difficult: 31% think that it will be *very difficult*; 48% think that it will be *somewhat difficult*; 17% think that it will be *somewhat easy*; and 3% think that it will be *very easy*.

10.3.2 Do PLWHA consider that they will need (re)training?

Approximately half of the respondents who are considering returning to work think that they will need (re)training through on-the-job training and/or short courses. A substantial minority think that they will need (re)training through courses at a TAFE institute and/or university.

Table 49 Training required to start paid employment or return to paid employment

Training required	n	%
On-the-job training	156	(55%)
Attending short courses	137	(48%)
Education in TAFE	92	(32%)
Training in voluntary organisations	66	(23%)
Education at university	42	(15%)
No training	48	(17%)
Don't know	2	(1%)

n = 284 Multiple responses possible

10.3.3 Why do PLWHA wish to return to work?

The main reasons respondents gave for wanting to start or return to work are shown in Table 50. The most commonly cited reasons for (re)entering the workforce are financial considerations, and the second most frequently cited reasons are psychological, emotional, or social - to enhance self-esteem, to relieve boredom, or to enhance mental well-being. This pattern is the same as the pattern of reasons for returning to work given by PLWHA who returned to work after leaving work due to HIV/AIDS. It is obvious that being out of the workforce will have an impact on the financial situation of PLWHA - most (83%) of the PLWHA who are not working

reported that their main source income is a Government benefit, and PLWHA who are working reported significantly higher incomes than PLWHA who are not working. However, it is also important to note the psychological and emotional impacts of being out of the workforce. It appears that many PLWHA are aware of the impact of working on their physical health and general well-being. Over one-quarter (29%) of the respondents said that their desire to (re)enter the workforce is influenced by an increased understanding of the impact of work on health. It does appear, however, that respondents acknowledge the detrimental effects of over-working. Another interesting finding reported in Table 50 is the high proportion of respondents who want to return to paid employment because of the possibility of working part-time (49%) or because of the possibility of working more flexible hours (19%).

Table 50 Reasons given for wanting to (re)enter the workforce

	n	%
Financial reasons	251	(87%)
Psychological / emotional / social reasons	211	(73%)
The possibility of working part-time	140	(49%)
Improved physical health	134	(46%)
Better understanding of the impact of work on health	82	(29%)
The possibility of more flexible work hours	56	(19%)
To contribute to the community	4	(1%)

n = 288 Multiple responses possible

Respondents who had been in paid employment at some time in the past were asked to describe their last job. Respondents had been in their last job for periods ranging from one month to 35 years (mean = 5 years 10 months; median = 3 years 4 months), and worked an average of 39.8 hours per week (median = 40 hours). These respondents have been out of paid work for an average of 3 years 8 months (median = 3 years).