

# **HIV FUTURES II**

## **The Health and Well-being of People with HIV/AIDS in Australia**

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**The Living with HIV Program**

**at The Australian Research Centre in Sex, Health and Society**

**LaTrobe University**

**March 2000**

Monograph Series Number 17

ISBN 1864465018

The Living with HIV Program is a part of the Australian Research Centre in Sex, Health and Society (ARCSHS) at LaTrobe University.

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

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

Suggested citation:

Grierson, J., Bartos, M., de Visser, R. and McDonald, K. (2000) *HIV Futures II: The Health and Well-being of People with HIV/AIDS in Australia*. Monograph Series Number 17. The Australian Research Centre in Sex, Health and Society, LaTrobe University, Melbourne, Australia.

## CONTENTS

Acronyms used in the report.....	i
Acknowledgments .....	iii
Executive Summary .....	1
Introduction .....	11
Instrument and Method	
The survey instrument .....	13
Recruitment .....	14
Sample demographics .....	14
Weighting of the sample .....	16
Further analysis and reports .....	16
HEALTH.....	17
Health Status.....	17
CD4 and viral load .....	18
Experience of health .....	19
HIV/AIDS related conditions .....	20
Other health conditions .....	20
Hepatitis .....	20
Other health monitoring .....	21
Health maintenance.....	21
Prophylaxis.....	21
Attitudes to health management .....	21
Antiretroviral Therapy .....	23
Use of antiretroviral therapy.....	24
Those currently using ARVs (mono- and combination therapy) .....	25
Difficulties of taking ARV .....	26
Attitudes .....	27
Health status of those using ARV .....	28
Those on combination therapy .....	30
Different combinations.....	32
Those not currently taking ARV .....	34
Difficulties of taking ARV .....	34
Health status of those not using ARV .....	35
Those who have never used antiretroviral drugs .....	36
Attitudes to antiretroviral therapy .....	36
Complementary Therapies .....	41

WELL-BEING.....	43
Health Services.....	45
Treatment.....	45
Prescriptions .....	46
Services used in the last six months.....	47
Other Services .....	48
Information.....	51
Sources.....	51
Publications.....	54
The Social World of PLWHA.....	55
Involvement with AIDS organisations .....	55
Contact with other PLWHA.....	55
Disclosure .....	56
The place of HIV in people’s lives .....	57
Social support .....	60
Mental Health.....	61
Psychiatric medications .....	61
Symptoms of depression .....	61
Planning for the future.....	64
Accommodation.....	67
Sex and Relationships .....	69
Relationships .....	71
Regular partners .....	71
Casual partners.....	74
HIV, sex, relationships and treatments .....	76
Children .....	80
Recreational Drug Use.....	81
Practices .....	81
Attitudes relating to drug use.....	84
Employment.....	87
Employment status.....	87
Those currently in paid employment.....	90
Anticipated changes for those working and those not working.....	93
Finances.....	97
Income .....	97
Poverty.....	100
Costs.....	102
Poverty and services.....	106
Concluding Comments.....	109
References .....	111
List of Tables and Figures.....	113

## **ACRONYMS USED IN THIS REPORT**

AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
AIHW	Australian Institute of Health and Welfare
ARCSHS	Australian Research Centre in Sex, Health and Society
ARV	Antiretroviral therapy
HIV	Human Immune-deficiency 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



## **ACKNOWLEDGMENTS**

Nine hundred and twenty-four people living with HIV/AIDS completed the HIV Futures II Survey. We are grateful for their interest in research conducted by the Australian Research Centre in Sex, Health & Society, and thank them for their willingness to participate.

We wish to thank the National Association of People Living with HIV/AIDS (NAPWA), the Australian Federation of AIDS Organisations (AFAO), the Haemophilia Foundation of Australia and its State affiliates.

In New South Wales distribution of the survey was assisted by the AIDS Council of New South Wales (ACON), Mark Bebbington and Brent Allen at ACON, ACON Community Support Network, ACON Women's project, ACON Hunter, ACON Illawarra, ACON Northern Rivers, ACON Western Sydney, Albion Street Centre, Bigge Park Centre, Blue Mountains PLWHA Centre, Bobby Goldsmith Foundation, Coffs Harbour Sexual Health Centre - Ralph Waldsax, Foley House, Gender Centre, Grafton Community Health Centre, Kempsey Community Health Centre, Karumah Day Centre, Livingstone Road Clinic, Luncheon Club AIDS Support Group, Macquarie Area Health Service, Mid North Coast Area Health Service - Robert Baldwin, Moruya Community Health Centre, New England Area Health Service, New South Wales Department of Health, New South Wales Users and AIDS Association (NUAA), North AIDS, Options Employment Service, Parramatta Sexual Health Centre, Positive Living Centre, People Living with HIV/AIDS - PLWHA (NSW), Pozhet West, Positive Employment Service, Positive Heterosexuals - David Barton, St George Sexual Health Centre, SMASH Project, Sydney PLWHA Day Centre, Talkabout, Wentworth Area Health Service, Wollongong HIV Prevention Service, Peter de Ruyter, and Paul Burr.

Thanks are due to the following individuals and organisations who helped distribute the survey in Victoria: Access Information Centre, AIDS Care Association, ALSO Foundation, Barkly Street Medical Clinic, Country AIDS Network Resource Centre, Melbourne Sexual Health Centre, Mountfield Clinic, People Living with HIV/AIDS - PLWHA (Vic), Stephanie Moore and Positive Women (Vic), Prostitutes' Collective Victoria, Royal Melbourne Hospital HIV Services, Straight Arrows, Victorian AIDS Council (VAC), Jim Arachne at VAC, VIVAIDS, Mattie Sempert, Lisa McPherson, Dr Ralph Ballard and Vincent Boyd.

A number of organisations and individuals aided distribution of the survey in Queensland. Thanks to the AIDS Medical Unit, Brisbane Sexual Health Clinic, Brunswick Street Medical Centre, Gladstone Road Medical Centre, Nambour Hospital, Queensland Positive People (QPP), Simon O'Connor at QPP, QPP Bundaberg, QPP Gold Coast, QPP Mackay, QPP Rockhampton, QPP Sunshine Coast, the Queensland AIDS Council (QAC), QAC Cairns, and QAC Townsville.

In South Australia we were assisted by the Adelaide Diocesan AIDS Council, AIDS Council of South Australia (ACSA), HIV/AIDS Programs - South Australian Health Commission, HIV/AIDS Women's Project, Infectious Diseases Unit - Royal Adelaide Hospital, People Living with HIV/AIDS - PLWHA (SA), and Peter Evans at PLWHA (SA).

A number of organisations and individuals aided distribution of the survey in Western Australia. Thanks to AIDS Pastoral Care, Lindisfarne Medical Group, Social Work Department - Royal Perth Hospital, Western Australian AIDS Council (WAAC), Mark Reid at WAAC, WAAC Women's Project, Trudy Matthews, and Dr Ric Chaney.

Thanks are due to the following individuals and organisations who helped distribute the survey in Tasmania: HIV/AIDS Unit Tasmanian Health Department, Royal Hobart Hospital, Rose Cottage, the Tasmanian Council on AIDS and Related Diseases (TasCARD), and Marilyn Marks at TasCARD.

In the Australian Capital Territory we were assisted by the AIDS Action Council (AACACT), Infectious Diseases Unit - Canberra Hospital, Interchange General Practice, and People Living with HIV/AIDS - PLWHA (ACT).

We are grateful for the assistance of the following individuals and organisations who helped distribute the survey in the Northern Territory: Northern Territory AIDS Council (NTAC), Bill McMahon at NTAC, AIDS Council of Central Australia (ACOCA), Alice Springs Therapeutic Health Centre, Alice Springs Health and Relaxation Centre, Miranda Coates, and Anna Gray.

We would like to express our appreciation for the support of the founding director of the Australian Research Centre in Sex, Health and Society (ARCSHS), Professor Doreen Rosenthal, the acting director of ARCSHS, Professor Gary Dowsett, and the input and assistance of the staff of ARCSHS. We would particularly like to thank the community liaison officers, Anne Mitchell, Jenny Walsh and Philomena Horsley for their invaluable assistance throughout the project. Thanks also to Belinda La Rocca for the data entry.



We are grateful for the advice and assistance provided by Professor Fiona Judd of the Royal Melbourne Hospital around mental health issues and that of Dr Mary O'Brien of ARCSHS around recreational drug issues. Thanks also to Tony Maynard of VAC for advice on treatment issues.

We would like to thank our funding agencies, the Commonwealth Department of Health and Aged Care, who fund the Living with HIV Program and the Victorian Health Promotion Foundation (VicHealth) who provide funding for the Australian Research Centre in Sex, Health and Society.

We would like to express our appreciation for the input and advice provided by the members of the reference group: Jim Arachne, John Paten, Graham Norton, Colin Batrouny, Brent Allen, Michelle Humphreys, John Daye and Phillip Medcalf.

This report arose out of the original HIV Futures Study conducted in 1997 and we would like to acknowledge the researchers on that project, Doug Ezzy, Richard de Visser, Michael Bartos, Karalyn McDonald, Darryl O'Donnell and Doreen Rosenthal.



## **EXECUTIVE SUMMARY**

### **Health Status and Health Management**

Almost all PLWHA have taken a CD4/T-cell test and a viral load test. Three quarters rate their health as excellent or good. Despite this, one fifth had been diagnosed with an AIDS defining illness at some point and one-third reported experiencing HIV related illnesses.

Health problems related to HIV:

- ▶ 28.5% report experiencing Lipodystrophy;
- ▶ 33.9% experience weight loss;
- ▶ 44.3% have a sleep disorder;
- ▶ 30.6% experience confusion or memory loss.

Additionally, two out of every five respondents reported that they had at least one other major health condition other than HIV/AIDS. The most common other conditions were hepatitis C, psychological disorders, cytomegalovirus disease, asthma, hepatitis B, arthritis, respiratory illness and diabetes.

The most common activities to improve and maintain health were sleep, relaxation, taking medication at the correct dosing time, exercise, spending time with pets and taking complementary therapies. Other important activities were maintaining a positive attitude, spending time with partner/friends or family, gardening, creative activities and sex.

### **Use of Antiretroviral therapy**

Almost three quarters of the sample were currently using antiretroviral therapy (ARV). Of those, three quarters experience difficulties taking ARV. Side effects are experienced by more than half those on ARV and are an important reason both for taking breaks from ARV and for ceasing ARV. Cautious optimism characterises beliefs about ARV.

Antiretroviral use:

- ▶ 73.6% are currently using ARV;
- ▶ 86.5% have used ARV at some time in the past;
- ▶ 82.5% commenced ARV on the advice of their doctor;
- ▶ 69.2% of respondents were using a combination of three drugs;

- ▶ 63.6% of the sample were taking ARV twice daily;
- ▶ 25.0% were taking ARV three times a day;
- ▶ 87.4% had not missed a dose of ARV in the two days prior to completing the survey.

Difficulties taking antiretrovirals:

- ▶ 73.5% of participants reported that they experienced difficulties taking ARV of which the major problems were:
  - ▶ 47.8% remembering to take the drugs on time;
  - ▶ 31.9% organising meals around the drugs;
  - ▶ 26.3% taking medication in public;
  - ▶ 24.1% transporting medication;
  - ▶ 22.4% taking large numbers of tablets.

More than one half of the sample reported experiencing side effects from ARV. One fifth reported diarrhoea and one sixth reported nausea.

Breaks from antiretroviral therapy:

- ▶ 63.0% have not taken a break from ARV therapy;
- ▶ 46.0% of those who had said it was due to the severity of side effects;
- ▶ 32.3% reported taking a break to *clean out their system*;
- ▶ 24.6% reported having a *drug holiday*.

Drug resistance, compliance difficulties and non-performance were also cited as reasons for breaks from ARV therapy.

For those currently on combination ARV, two thirds had been taking combination ARV for more than three months. Most started when their viral load was high and their CD4 count was low. The majority of respondents have used one or two combinations of ARV during their entire treatment. For those who had changed combinations the severity of side effects was the most commonly reported reason for the change.

Most (87.0%) believed they still had access to *a few* or *many* combinations of ARV. However, those with *none* or only *one* combination treatment option remaining were likely to have either a higher viral load or lower CD4 count and to rate their health as *fair* or *poor*.

Of those respondents who were not using ARV therapy, almost half had done so in the past. More than three quarters reported having difficulty taking ARVs and side effects were reported by the great majority of these respondents. Severe side effects were also the most commonly reported reason for stopping ARV therapy, followed by taking a break to *clean out my system*.

Only 13.5% of PLWHA have never used ARV therapy, of whom 86.8% said they would consider doing so at some point in the future. Reasons for considering commencing ARV therapy were generally based on clinical markers such as illness, CD4 count and viral load.

Does ARV mean better prospects for PLWHA?

- ▶ 69.6% agree;
- ▶ 23.6% believe that it is still too soon to tell;
- ▶ 66.0% are worried that their medication will stop working for them.

More than one half of the sample reported using some form of complementary therapy, most notably vitamin/mineral supplements, massage, meditation and acupuncture.

### **Well Being and Information**

PLWHA visit a mixture of General Practitioners specialising in HIV and HIV specialist physicians.

For general health care treatment 45.7% of PLWHA see a GP who specialises in HIV whereas for HIV specific treatment 38.5% see a GP who specialises in HIV and 30.9% see an HIV specialist/physician. Most respondents had visited either a GP who specialises in HIV or an HIV specialist in the last six months.

Experiences of health care:

- ▶ 31.8% have experienced less favourable treatment at a medical service as a result of having HIV;
- ▶ 60.7% pick up all of their prescription medication at one place;
- ▶ 34.5% go to two places for prescription medication;
- ▶ 3.9% go to three or more places for prescription medication.

Services used at AIDS organisations:

- ▶ 45.4% treatment advice;
- ▶ 39.5% social contact;
- ▶ 30.6% peer support;
- ▶ 31.1% counselling;
- ▶ 25.0% advice on financial matters;
- ▶ 19.4% advice on legal matters;

- ▶ 23.6% alternative therapies.

Organisations other than AIDS Councils tended to be used for the provision of pharmacy services, housing assistance, mental health services and employment services.

Almost all PLWHA sought advice on treatments from their doctor. For advice about living with HIV/AIDS, PLWHA relied mostly on HIV/AIDS media. Respondents reported reading a variety of national and state based publications, with over half reading gay newspapers and Positive Living. One quarter of PLWHA said they had problems with a lack of information on managing side effects and nearly as many nominated a lack of information on taking a break from ARV and interactions between ARV and other medications.

Almost all respondents have disclosed their HIV status to at least one person, generally partners, close friends and family. Many (59.9%) respondents said their HIV status had been disclosed to another person when they did not want it to be.

Sources of support:

- ▶ 77.4% partners/spouse;
- ▶ 67.3% pets;
- ▶ 53.4% close friends;
- ▶ 53.4% had no one from whom they received a *lot* of support.

Three quarters of respondents said they have some contact with HIV/AIDS organisations. (This finding is likely to be influenced by the fact that these organisations were a major distribution source for the survey). Most commonly respondents receive newsletters and mail-outs but many respondents also seek treatment advice and social contact through these organisations. Most of those who did not have any contact said they do not wish to be involved, although 16.8% said they felt excluded from the organisations.

Involvement with other PLWHA:

- ▶ 95.7% know another PLWHA;
- ▶ 19.9% have a spouse/partner with HIV;
- ▶ 70.4% know acquaintances with HIV;
- ▶ 28.7% spend some time with other PLWHA;
- ▶ 18.7% spend a lot of time with other PLWHA;
- ▶ 28.2% spend no time with other PLWHA;
- ▶ 28.2% have been involved with the care of someone with HIV/AIDS;
- ▶ 74.5% someone close has died of AIDS related causes.

HIV status is important to their sense of identity for 57.6% of PLWHA, and essential to 16.4%. In contrast, sexuality is important to identity for 47.4% and essential to a further 33.9% of respondents, and gender is important to 38.7% and essential to 30.7%. Notably over half agreed that changes in their body image makes them feel unattractive.

In the last six months slightly less than one third of respondents have taken prescribed medication for depression and over one quarter for anxiety.

Half of the sample said they plan at least one year ahead and only one in ten said they plan more than 10 years ahead. Over one third of respondents said they had changed their time frame for future planning in the last two years. Over two thirds now use a longer time frame and this is usually due to improved health (due to new treatments or other reasons) or taking new treatments. Over one quarter use a shorter time frame and this is usually due to declining health.

### **Sex and Relationships**

Over one quarter of PLWHA are not having sex at present. Around half the sample of PLWHA is currently in a regular relationship, and a slightly smaller number have sex within their relationship. A smaller group, comprising mainly gay men, has both a regular relationship and casual partners (18%) and 29% have casual partners only.

Of those in a regular relationship 40.5% have a partner who is also HIV positive, 57.9% have an HIV negative regular partner and 1.6% a partner of unknown status. Nearly all (98.3%) PLWHA have disclosed their status to their regular partner, usually when they were diagnosed or at the time of or prior to the commencement of the relationship. In the majority of cases the partner's reaction to disclosure was positive and in one third of cases it brought the partners closer together, but 27.2% also reported that their partner was worried or scared.

Under half the respondents had anal or vaginal intercourse with a regular partner in the past six months. Condom use with regular partners was strongly related to the HIV-status of the partner.

Condoms always used with regular partners by:

- ▶ 38.5% of women with male HIV+ partners;
- ▶ 58.3% of women with male HIV negative or unknown partners;
- ▶ 16.5% of men with male HIV positive partners;
- ▶ 65.3% of men with male HIV negative or unknown partners;

- ▶ 30% of men with female HIV positive partners;
- ▶ 71.4% of men with female HIV negative or unknown partners.

Fifty-four per cent of the sample had sex with casual partners in the past six months. Almost half (47.9%) of the men reported that they always used condoms with casual male partners and 52.6% with casual female partners.

Information about the most recent episode of sex with a casual partner in the previous six months was provided by over half the sample. Vaginal or anal intercourse took place in 77.2% of these instances.

Condom use with the most recent casual partner:

- ▶ 35.5% with an HIV+ partner;
- ▶ 79.8% with a partner of unknown HIV status;
- ▶ 85.7% with an HIV negative partner.

There were only 14 instances reported of insertive anal or vaginal intercourse with ejaculation with the most recent casual partner where that partner was of unknown HIV status and only 1 instance with an HIV negative casual partner.

Around half of PLWHA would prefer to be in a relationship with someone who is also HIV positive. Over half of PLWHA expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLWHA (60.5%) felt HIV had a negative effect on their sexual pleasure.

Only 9.3% of PLWHA agreed with the statement *I feel more confident about unprotected sex because of the new treatments*. Those who agreed were no more likely than others to be on antiretroviral treatment or to be confident about treatments, but they were more likely to have unprotected sex.

Very few PLWHA agreed that new treatments make safe sex less important than it was (5.5%) or that undetectable viral load means HIV is unlikely to be transmitted (5.8%). However, around 30% of PLWHA agreed with the statement *If there was a vaccine which prevents HIV I would not practice safe sex*.



## Recreational Drug Use

Alcohol is the most commonly used drug by PLWHA, in proportions comparable to the general population. However, tobacco use among respondents is twice that of the general population and other *party* drugs, such as amyl, ecstasy, non-injected speed and LSD are also used more frequently by PLWHA than by the general population.

More than two thirds of respondents reported that they had never injected illegal drugs and of those respondents who had injected illegal drugs approximately one half had done so in the last 12 months. Of PLWHA who reported injecting drugs, 86.1% had not shared needles in the past twelve months.

Circumstances of needle sharing:

- ▶ 24.7% shared with a sexual partner;
- ▶ 76.2% used the needle last;
- ▶ 48.8% did not have access to other needles;
- ▶ 40.4% washed or bleached the needle;
- ▶ 39.0% the other person was HIV positive;
- ▶ 3.4% in a group.

Only 1.4% of those who shared needles in the last 12 months did so without at least risk reduction strategy by using the needle last or washing/bleaching or using with another person who was HIV positive.

Approximately one fifth of respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and one in twenty reported having had a bad experience as a result of using both illegal drugs and ARV.

## Employment

Slightly less than one half of respondents are currently in paid employment, with one quarter of this number being in full-time work. The majority of the remainder described themselves as either not working or retired.

Most respondents said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis.

Impact of antiretroviral therapy on employment:

- ▶ 15.5% stopped work;
- ▶ 12.4% anticipate a longer time in the workforce;
- ▶ 11.4% are considering going back to work;
- ▶ 6.4% have gone back to work.

Almost two thirds of respondents reported that they have stopped work at some time in the past for reasons relating to having HIV/AIDS. Stress, depression or anxiety were the most commonly cited reasons. Low energy levels were also cited by more than half of respondents followed by poor health.

Of those respondents who had left work, half had returned to work and this was most commonly for financial reasons.

Just under half of those respondents working said that HIV has had an impact on their capacity to perform their work duties. Most commonly respondents reported that they tire more quickly, that they have had to reduce their work hours and that they have difficulty concentrating.

One third of PLWHA had not disclosed their HIV status to anyone at their workplace while an equal number do not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work are gossip, storing and taking medication and explaining absences from work.

## **Finances**

More than one half of respondents identified their main source of income as a government benefit or pension. As well, more than one half of PLWHA reported experiencing some difficulty with meeting the cost of daily living.

Difficulty with meeting the cost of daily living:

- ▶ 54.4% difficulty paying for food;
- ▶ 56.8% difficulty paying for housing;
- ▶ 51.0% difficulty paying for transport;
- ▶ 43.9% difficulty paying for medical services.

Almost one third of PLWHA are living below the poverty line. Just over one quarter of respondents have a partner with whom they share financial resources and this protects some

from extreme economic hardship. Very few respondents who are earning an income from paid employment reported incomes below the poverty line whereas over one half of those on government benefits are living in poverty.

Women are significantly more likely than men to fall below the poverty line despite being no less likely to be in paid employment. However, women were more likely to have dependent children as well as a lower average income and this may help explain this discrepancy.

PLWHA who have been HIV positive for longer are also more likely to fall below the poverty line as are those who have had an AIDS defining illness.

Less than one quarter of respondents reported that they currently own their own home. A small number are in the process of paying off their own home but the vast majority is in rental or other forms of accommodation.

### **Major differences between 1997 and 1999**

There are a number of significant differences between the results of the HIV Futures I survey conducted in 1997 and the HIV Futures II survey in 1999, although the two samples were very closely matched. A separate report will be produced detailing these differences over time. Anticipating that report, some of the major differences in the findings are as follows.

**Health conditions other than HIV:** two out of every five respondents reported that they had at least one other major health condition other than HIV/AIDS. This is considerably more than the Futures I sample where only one in three reported having at least one other major health condition.

**Use of ARV:** Uptake of antiretroviral therapy differs significantly from the 1997 survey with 77.7% currently using antiretrovirals in 1997 and 73.6% currently using antiretrovirals in 1999. The difference is accounted for by the larger numbers in 1999 of PLWHA who have used antiretrovirals in the past but are no longer using them.

**Side effects from ARV:** more than one half of the sample reported experiencing side effects from ARV. This is slightly less than reported in 1997 where more than two thirds of the sample reported side effects. Similar to 1997, more than one fifth reported diarrhoea, however, only one sixth of respondents reported nausea in 1999 compared with one third in 1997.

**Optimism about ARV:** there is an increase in the number of PLWHA in Futures II who believe that ARV has brought hope and better prospects for most PLWHA (69.6%) compared to respondents from Futures I (59%).

**Sources of information:** Futures II respondents said they relied on HIV/AIDS media for information about living with HIV/AIDS which contrasts slightly from Futures I respondents who cited their doctors as their main source of information about living with HIV/AIDS followed by HIV/AIDS media and HIV positive friends.

**Confidence about unprotected sex:** 9% of PLWHA agreed with the statement *I feel more confident about unprotected sex because of the new treatments*. This proportion has increased since 1997 when it was only 6%. The decrease has been in the numbers unsure about the statement, while the numbers disagreeing remained about the same.

**Return to work:** of those respondents who had left work, half had returned to work and this was most commonly for financial reasons. This is considerably higher than in 1997 where only one third reported having returned to work.

**Workplace disclosure of HIV:** Similarly to 1997, almost one third of respondents said they had not disclosed their HIV status to anyone at their workplace. However, one third of respondents in Futures II reported that they do not try to keep their HIV status confidential compared with one in fifty in Futures I.

**Women in poverty:** in contrast to the 1997 survey, Futures II has found that women are significantly more likely than men to fall below the poverty line despite being no less likely to be in paid employment. In Futures I women were no more likely than men to report incomes below the poverty line.

## INTRODUCTION

The first HIV Futures study was published at a very particular time in the history of living with HIV. A new range of treatment options had arrived on the scene, and for the first time people with HIV/AIDS could, collectively, imagine a future where HIV was a manageable illness. It was a time when we started to see people who had been quite ill begin to get well, a time when the death notices started disappearing from the gay press, a time when there was talk of returning to work, of building new relationships and of dismantling the AIDS industry. It was a time when the meaning of being HIV positive changed. Optimism about these new treatments was probably at its peak around the time of the first survey which was conducted in the second half of 1997, although it was a cautious optimism. Not everyone was doing well on the treatments, many experienced debilitating side-effects, some developed resistance to the drugs and the rigours and complexity of dosing were burdensome. Returning to work was not a simple matter, complicated by fatigue, issues around confidentiality, and the difficulties of finding work after an extended absence. AIDS organisations had to respond to the changing needs of their constituencies, while maintaining the capacity to respond quickly should the treatments not be as effective as everyone hoped.

The expectations of a community that wanted to see an end to the epidemic were another factor in the response of positive people and AIDS organisations to the new treatments. A vigorous debate was underway around whether the AIDS crisis was over or not, with some claiming that the new treatments and the fall in death rates (at least in developed countries) signalled an end to the crisis-focussed response to AIDS that had characterised the epidemic and a move toward the mainstreaming of AIDS as just another chronic illness. Others claimed that by calling a (premature) end to the AIDS crisis, the needs of PLWHA would be neglected, services downgraded, leaving little capacity to respond to those whom the treatments were failing. As it turned out, the community infrastructure in Australia was not disbanded, although many organisations are undergoing considerable re-assessment of their roles and purposes. The real effect of the debate in this country was to highlight the diversity of the experience of living with HIV. This included recognising that there were both those for whom HIV/AIDS had become a chronic manageable infection, who did not need or desire HIV specialist services, as well as those for whom HIV/AIDS was, as it had always been, a physically and psychologically devastating illness that set them apart from the rest of society, and for whom specialist HIV/AIDS services were a critical factor in their survival and quality of life.

In developing this study, we expected to find a shift in the ways in which PLWHA were engaging with the medical community and with AIDS organisations. We expected to find that a proportion of the positive population were managing their HIV without much reference to the HIV/AIDS

*community*, utilising specialist medical care when needed, but otherwise living their lives much the same as their HIV negative peers. We also expected to find a sector of the positive population for whom HIV was a critical part of the way they organised their lives and for whom the HIV/AIDS *community* was essential.

This second survey, then, comes a little further down the treatment track from HIV Futures I. HIV Futures II builds on the original survey and attempts to explore some of the diversity of PLWHA's experience of HIV/AIDS. Antiretroviral treatments still feature in the survey, as they feature in the lives of many PLWHA. We have asked about the experience of using these treatments and the ways in which people have changed treatment regimens or taken structured breaks from treatments. We have also looked at the impact of these treatments on people's lives, from the physical effects of treatments, to the way they have changed relationships, work and finances.

We have maintained the emphasis on PLWHA's lives outside of medicine, recognising the contribution of sex and relationships, of home and work, of friends and pets, of drugs and community, to people's health and well being. We have asked about many different things for many different reasons, some areas are designed to allow service providers to evaluate the needs of their constituencies, some to inform the development of policy, some to provide a social dimension to what is an increasingly medicalised field, and some are simply to broaden our understanding of the place that HIV has in the lives of positive people.

In part HIV Futures is designed to show how things have changed since the first survey, but it is also designed to show how things are now for people living with HIV in Australia. We hope this report is useful, for governments and AIDS organisations, to assist in their planning, for others to understand the ways in which HIV has an impact on all aspects of people's lives, and for positive people themselves to reflect on their place in the epidemic and the HIV *community*.

## INSTRUMENT AND METHOD

### The Survey Instrument

The HIV Futures II survey was an anonymous, self complete, mail back questionnaire consisting of 193 items organised into eight sections: demographics; accommodation; health and treatments; services and organisations; sex and relationships; employment; recreational drug use; and finances. Each section included an explanation of the purpose of the items. Most items in the survey were closed-coded with either single or multiple response options. *Other* categories were included for most items to ensure that significant experiences of living with HIV were not excluded. There were a number of attitude/ belief items scored using a four and five point Likert scales. There were also write-in and open ended items.

The survey, once completed, was returned in a reply-paid envelope to the Living with HIV program. In addition participants were given the option, via a separate mail-back, of adding their contact details to the program mailing list to receive reports and to participate in further research.

The instrument was based in large part on the original HIV Futures survey (Ezzy et al., 1998) with most items retained in their original format to allow comparisons between the two studies. Additional sections and items were included to reflect the changes in both the personal experiences of living with HIV/AIDS, and the changes in policy and service context in the past two years.

A series of community consultations with organisations and individuals around the country was conducted prior to the development of the instrument. Particular attention was paid to the strengths and weaknesses of the original survey, and to the changes that had been observed in the intervening period. A community reference group with members drawn from State and national AIDS and PLWHA organisations was established early in the development of the instrument. This group ensured that the instrument was appropriate in language, style and focus. The group also provided feedback on the meaning and implication of the findings prior to the preparation of this report.

A copy of the survey instrument is available for perusal on the website [www.latrobe.edu.au/hivfutures](http://www.latrobe.edu.au/hivfutures).

### **Recruitment**

As the broad aim of this study was to represent the collective and individual experiences of people with HIV/AIDS in Australia, a purposive, multi-faceted community sampling strategy was employed. Participants were recruited using a multi-pronged approach including mail-out, organisational distribution, and advertisement. Participants from the original HIV Futures study mailing list were sent two copies of the survey and were asked to pass the second copy onto anyone they knew who may not have received a copy. Advertisements inviting PLWHA to participate in the study were placed in HIV/AIDS, gay and lesbian and injecting drug use publications. Press releases were issued to both mainstream and community press promoting the launch of the study. A website was established where PLWHA could either request a copy of the survey or download one. Central to the recruitment strategy was the involvement of community organisations who distributed copies of the surveys to their members and promoted the surveys in their publications. Copies of the survey were mailed out in issues of *Talkabout*, *Positive Life* and *QPP Alive*.

Active recruitment took place between August and October 1999, although a small number of surveys were returned during November and early December and these were included in the analysis.

In order to allow for meaningful comparisons between specific populations of PLWHA, it was necessary to target recruitment to ensure over-sampling of marginalised groups. These populations included women, people with Haemophilia, those living outside NSW and Victorian metropolitan areas and injecting drug users.

### **Sample Demographics**

The HIV Futures II survey was completed by 924 HIV positive people. Given current estimates of HIV infection in Australia (NCECR, 1999) this represents approximately 8% of the positive population.

Of the survey respondents, 828 were male (90.0%) and 89 were female (9.7%) and three were transgender (0.3%). Of the sample 76.7% were gay men, 7.5% heterosexual men, 5.7% bisexual men, 1.1% lesbian, 7.9% heterosexual women, 0.5% bisexual women and the remaining 0.6% fell into other categories.

The respondents' age ranged from 18 to 75 years with a mean of 42.1 years and a median age of 41 years. This is somewhat older than the sample in the original HIV Futures study (mean age=39.3 years) and probably reflects an aging population of PLWHA in Australia.



In order to compare the sample to the population represented in the Australian HIV Surveillance Reports, participants were asked how they believe they were infected with HIV. The results, grouped by the categories used by the National Centre in HIV Epidemiology and Clinical Research are given below in Table 1.

**Table 1: Respondents' reported mode of transmission**

<b>Mode of Transmission</b>	<b>Frequency</b>	<b>Percentage</b>
Male homosexual or bisexual contact	692	76.5
Heterosexual contact	79	8.7
Male homosexual/ bisexual contact and injecting drug use	12	1.3
Injecting drug use (female and heterosexual males)	40	4.4
Haemophilia/ coagulation disorder	32	3.5
Receipt of blood components/tissue	41	4.5
Other	9	1.0

The majority of participants were Australian born (74.4%) and 98.1% of the participants spoke English at home, with European languages accounting for most of the remainder. Twenty-two respondents (2.4%) indicated they were of Aboriginal/Torres Straight Island origin.

Respondents came from all Australian states and territories, with the majority coming from NSW, Victoria and Queensland (see Table 2).

**Table 2: State or Territory of respondents' residence**

<b>State/Territory</b>	<b>Frequency</b>	<b>Percent of sample</b>
NSW	440	47.9
Vic	184	20.0
Qld	137	14.9
WA	72	7.8
SA	56	6.1
Tas	15	1.6
ACT	10	1.1
NT	5	1.1

The majority (62.1%) of respondents were from inner urban areas of capital cities, while 14.7% live in outer suburban areas, 14.6% live in larger regional centres and 8.6% live in rural areas.

Three quarters (77.9%) of participants are living in the same state or territory in which they were infected with HIV, while the remainder live in a different state or territory.

Over one third (40.2%) of respondents indicated that they were atheist/agnostic, 42.0% indicated mainstream religious identification and the remainder were either adherents of new age belief systems or had other spiritual beliefs. Around one third (33.7%) indicated that religion or spirituality was of no importance to them. A further 30.8% indicated that this was of little importance, 22.8% that it was very important and 12.7% extremely important.

### **Weighting of the Sample**

In order to ensure that the results reported in this document accurately represent the Australian population of PLWHA, comparisons were made to the Australian HIV Surveillance Report (NCHECR, 1999) and the data was weighted to conform with the demographic profile of the Surveillance Report. As we had deliberately over-sampled marginalised populations to allow for statistically meaningful comparisons in this and further analysis, compared to the estimated national population of PLWHA the sample under-represents gay men from NSW and over-represents women, heterosexual men, those from non-metropolitan areas and those outside NSW. A weighting algorithm based on mode of infection, gender, state of residence and diagnosis of AIDS defining illness has been applied to all the analyses that follow. Consequently, findings are presented in terms of sample percentages rather than frequencies. Sample sizes (Ns) are given when the table represents a subset of the total sample. These Ns are weighted. Statistical comparisons including ANOVA and chi-square have been employed in the analysis of the data, although for clarity the details of these are not included in this report. All significant differences reported have a probability of at least  $\alpha=0.01$ .

### **Further Analysis and Reports**

As with the original HIV Futures survey the capacity of this community report to detail the experiences of specific populations of PLWHA is limited. A report examining the specific experiences of HIV positive women will be produced in the first half of 2000 and reports covering the experience of heterosexual men and those who use recreational drugs will follow. State-specific data will also be made available.

Comparisons between the 1997 and 1999 surveys will be included in the summary sections at the beginning of each section of this report. More detailed comparisons between the two surveys will be undertaken and made available in the near future.

## HEALTH

The first half of this report is concerned with the physical health of people with HIV/AIDS. Here we are not concerned just with the clinical indicators of health (CD4 counts and viral load), but with the experience of health. We have asked about general sense of physical well-being, about side-effects and changes in people's bodies. There is considerable emphasis on the uptake of, and taking of antiretroviral therapy, as this has been one of the dominant themes in any discussion of living with HIV in the past few years. But again, not simply in terms of the treatments themselves, but how they fit (or don't fit) into people's lives, what changes they have made to people's quality of life (both positive and negative) and what it means to take them. We have also looked at health management including complementary therapies, an important part of many PLWHA's lives.

## HEALTH STATUS

### Summary:

Almost all PLWHA have taken a CD4/T-cell test and a viral load test. Three quarters rate their health as excellent or good. Despite this, one fifth had been diagnosed with an AIDS defining illness at some point and one third reported experiencing HIV related illnesses.

Health problems related to HIV:

- ▶ 28.5% report experiencing Lipodystrophy;
- ▶ 33.9% experience weight loss;
- ▶ 44.3% have a sleep disorder;
- ▶ 30.6% experience confusion or memory loss.

Additionally, two out of every five respondents reported that they had at least one other major health condition other than HIV/AIDS. The most common other conditions were hepatitis C, psychological disorders, cytomegalovirus disease, asthma, hepatitis B, arthritis, respiratory illness and diabetes.

The most common activities to improve and maintain health were sleep, relaxation, taking medication at the correct dosing time, exercise, spending time with pets and taking complementary therapies. Other important activities were maintaining a positive attitude, spending time with partner/friends or family, gardening, creative activities and sex.

**CD4 and Viral Load**

As with the 1997 survey, almost all PLWHA had taken a CD4/T-cell test (99.4%) and a viral load test (99.2%). Most respondents had their most recent CD4 test within the last six months (95.8%) (77.1% in the last three months) and their most recent viral load test within the last six months (95.9%) (77.4% in the last three months). On average participants had taken four viral load tests in the preceding twelve months.

Among those PLWHA who had taken a CD4 test, 90.8% reported that they have at some time had a CD4 count of less than 500 cells/ml and 61.2% reporting a count of less than 250 cells/ml. Results for PLWHA's most recent CD4/T-cell test ranged from 0 to 1,300 cells/ml with a mean of 231.4 cells/ml and a median of 200.0 cells/ml.

Among those PLWHA who have taken a viral load test, 82.8% reported that at some point they have had a result of over 10,000 copies/ml and 59.6% a result of over 50,000 copies/ml. Results for PLWHA's most recent viral load test ranged from below detectable levels to 14,000,000 copies/ml with a mean of 65,305.49 copies/ml and a median of 500 copies/ml. It is important to note that at the time of the survey viral load assays of differing sensitivity were being used, thus it is possible that some of those PLWHA who reported undetectable viral load results may have had a measurable (though low) level if a more sensitive assay had been used. Table 3 shows the combined CD4 and viral load results of the sample. The results are grouped by three levels of CD4 count: little damage, moderate damage and severe damage, and four levels of viral load: below detectable levels, low, moderate and high. As different assays would have been used to assess the respondent's viral loads we have defined *below detectable levels* as being those responses that were less than 500 copies/ml and those where the respondent wrote in *zero* or *below detectable level*.

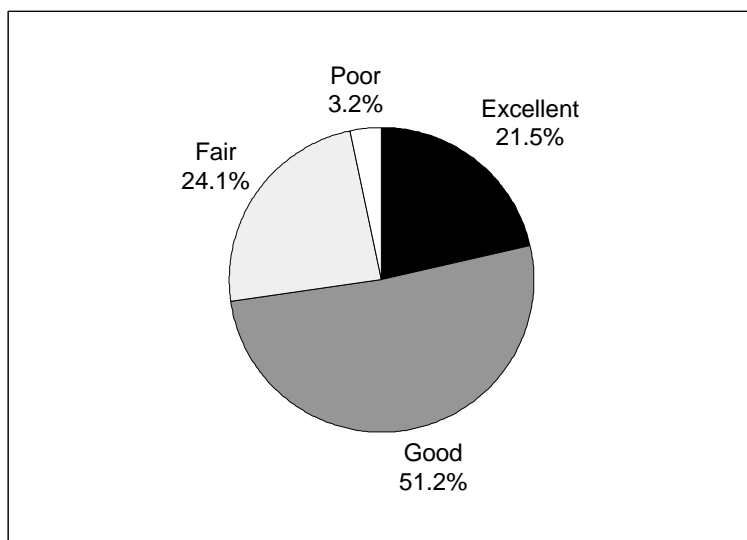
**Table 3: Results of most recent serological tests, percentage of total sample**

			Viral load			
			Below detectable levels	Low 500 to 9,999	Moderate 10,000 to 49,999	High 50,000+
			54.9	18.6	11.5	14.9
CD4/T-cell	Little damage 500+	44.0	29.1	8.9	4.2	1.9
	Moderate damage 250-499	36.3	19.0	7.4	5.0	5.0
	Severe damage 0-249	19.7	6.9	2.4	2.4	8.1

Approximately one in five (21.3%) participants indicated that they had been diagnosed with an AIDS defining illness at some point. They were most likely to have received this diagnosis in 1995 (18.6%) with only 9.2% having received such a diagnosis in the last two years. The most commonly reported AIDS defining illness when diagnosed was Pneumocystis carinii pneumonia (PCP) (41.3%) followed by Kaposi’s Sarcoma (13.9%), Mycobacterium avium complex (MAC) (16.1%), Oesophageal Candidiasis (13.8%) and Cytomegalovirus (CMV) (12.2%). For those diagnosed with an AIDS defining illness in the last two years (9.2% of the sample), the most common illness was PCP (45.6%) followed by Kaposi’s Sarcoma (24.7%) and Toxoplasmosis (24.7%).

**Experience of Health**

Respondents were asked to rate their current state of physical health on a four point scale. The majority of PLWHA rated their general health as *good* (51.3%), while only 3.2% rated their health as *poor* (see Figure 1). Those respondents with an AIDS defining illness were significantly more likely to rate their health as *poor* or *fair* than were those who did not have an AIDS defining illness.



**Figure 1: Respondents' self ratings of general health status**

### HIV/AIDS Related Conditions

PLWHA were asked if they had experienced any HIV related illnesses and 32.7% reported that they had. Respondents were specifically asked about a number of conditions that have been identified as being of concern among PLWHA. Over one quarter (28.5%) of respondents reported that they have experienced Lipodystrophy, 33.9% have experienced weight loss, 44.3% have had a sleep disorder, and 30.6% have experienced confusion or memory loss.

### Other Health Conditions

More than one third (40.2%) of respondents reported that they had at least one major health condition other than HIV/AIDS. Of these the most common was hepatitis C (10.2%), a psychological disorder (6.3%)<sup>1</sup>, Cytomegalovirus disease (4.6%), asthma (3.8%), hepatitis B (2.7%), arthritis (2.2%), respiratory illness (1.9%) and diabetes (1.6%).

### Hepatitis

Most PLWHA had not had hepatitis A (70.7%) or hepatitis B (61.2%). Almost two thirds (63.8%) had been tested for hepatitis C. Of these 65.8% tested negative and 28.0% tested positive. In other words 17.2% of the total sample have tested positive for hepatitis C. Testing for hepatitis C is more likely among those at higher risk of infection, and it is unlikely that there is a large undiagnosed incidence of this virus.

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<sup>1</sup>See also the section on mental health page 61

### Other Health Monitoring

Genotypic antiretroviral testing (GART) is a relatively recent technique that assesses drug resistance. As an indication of the degree of health monitoring in this population, 13.4% of PLWHA reported that they had already taken a GART.

Almost all (97.0%) of the women surveyed have had a pap smear and 76.5% had done so in the last 12 months. Most had one test in the last year (53.8% of those tested), while 36.9% had taken two tests. Women reported the result of their most recent test; 75.7% had come back clear and 14.7% abnormal. A very small number of women reported low-grade intraepithelial abnormality (1.5% reported CIN1). However, a larger number of women reported high-grade intraepithelial abnormality (1.1% reported CIN2 and 5.7% reported CIN3). A small number (1.4%) said their tests results were inconclusive.

### Health Maintenance

When asked to identify the types of things they did to improve their health, the most commonly reported activities were sleep (68.0%); relaxation (67.3%); taking medication at the right time (66.3%); exercise (66.1%); spending time with pets (37.7%); and complementary therapies (37.0%). Other activities included maintaining a positive attitude, spending time with partner/friends or family, gardening, creative activities and sex.

### Prophylaxis

Only one third of the sample (33.1%) were currently using prophylactic medication for conditions like PCP. Those that were using prophylaxis were significantly more likely: to have a lower CD4 count (325.34 copies/ml as compared to 574.91 copies/ml among those not using prophylaxis); to have a higher viral load (mean of 143,983.1 versus 25,777.65); to have been diagnosed with an AIDS defining illness (43.7% versus 11.7%); and to have been HIV positive for longer (9.5 years versus 8.4 years).

### Attitudes to Health Management

Respondents were asked to respond to a number of statements about health management, antiretroviral treatment and complementary therapies. The items on treatments will be discussed in the following section. Almost all respondents agree with the statement *looking after my physical fitness is an important part of managing my HIV infection* (52.2% agree, 42.2% strongly agree) (see Table 4). Those who engage in exercise to improve their health are significantly more likely to agree with this statement than those who do not. Similarly, almost all agree with the statement *keeping an optimistic frame of mind is an important part of managing my HIV infection* (44.9% agree, 51.7% strongly agree). Those who disagreed with these two

statements were more likely to rate their health as *good* or *excellent*, and less likely to use complementary therapies.

**Table 4: Attitudes to health management: percentage of total sample**

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
Looking after my physical fitness is an important part of managing my HIV infection	0.9	4.8	52.2	42.2
Keeping an optimistic frame of mind is an important part of managing my HIV infection	0.7	2.8	44.9	51.7



## ANTIRETROVIRAL THERAPY

### **Summary:**

Almost three quarters of the sample were currently using antiretroviral therapy (ARV). Of those, three quarters experience difficulties taking ARV. Side effects are experienced by more than half those on ARV and are an important reason both for taking breaks from ARV and for ceasing ARV. Cautious optimism characterises beliefs about ARV.

### Antiretroviral use:

- ▶ 73.6% are currently using ARV;
- ▶ 86.5% have used ARV at some time in the past;
- ▶ 82.5% commenced ARV on the advice of their doctor;
- ▶ 69.2% of respondents were using a combination of three drugs;
- ▶ 63.6% of the sample were taking ARV twice daily;
- ▶ 25.0% were taking ARV three times a day;
- ▶ 87.4% had not missed a dose of ARV in the two days prior to completing the survey.

### Difficulties taking antiretrovirals:

- ▶ 73.5% of participants reported that they experienced difficulties taking ARV of which the major problems were:
  - ▶
  - ▶ 31.9% organising meals around the drugs;
  - ▶ 26.3% taking medication in public;
  - ▶ 24.1% transporting medication;
  - ▶ 22.4% taking large numbers of tablets.

More than one half of the sample reported experiencing side effects from ARV. One fifth reported diarrhoea and one sixth reported nausea.

### Breaks from antiretroviral therapy:

- ▶ 63.0% have not taken a break from ARV therapy;
- ▶ Of those who had, 46.0% said it was due to the severity of side effects;
- ▶ 32.3% reported taking a break to clean out their system;
- ▶ 24.6% reported having a drug holiday.

Drug resistance, compliance difficulties and non-performance were also cited as reasons for breaks from ARV therapy.

For those currently on combination ARV, two thirds had been taking combination ARV for more than three months. Most started when their viral load was high and their CD4 count was low. The majority of respondents have used one or two combinations of ARV during their entire treatment. For those who had changed combinations the severity of side effects was the most commonly reported reason for the change.

Most (87.0%) believed they still had access to a few or many combinations of ARV. However, those with none or only one combination treatment option remaining were likely to have either a higher viral load or lower CD4 count and to rate their health as fair or poor.

Of those respondents who were not using ARV therapy, almost half had done so in the past. More than three quarters reported having difficulty taking ARVs and side effects were reported by the great majority of these respondents. Severe side effects were also the most commonly reported reason for stopping ARV therapy, followed by taking a break to clean out my system.

Only 13.5% of PLWHA have never used ARV therapy, of whom 86.8% said they would consider doing so at some point in the future. Reasons for considering commencing ARV therapy were generally based on clinical markers such as illness, CD4 count and viral load.

Does ARV mean better prospects for PLWHA?

- ▶ 69.6% agree;
- ▶ 23.6% believe that it is still too soon to tell;
- ▶ 66.0% are worried that their medication will stop working for them.

More than one half of the sample reported using some form of complementary therapy, most notably vitamin/mineral supplements, massage, meditation and acupuncture.

### **Use of Antiretroviral Therapy**

At the time of the 1997 survey antiretroviral therapy in triple combination and with protease inhibitors was relatively new and one key concern of that survey was on the uptake of these drugs. Since 1997, the relationship of PLWHA to antiretroviral drugs has become more complex. People have experienced a range of difficulties in taking the drugs, from problems with drug toxicity, side effects and iatrogenic illness, the development of drug resistance to problems with dosing and compliance. New drugs have been developed and recommendations about combinations, dosage and monitoring have changed as more data has become available. The issue of structured interruptions to treatments, including drug holidays and pulse therapy, has

received considerable attention. There are now PLWHA who have very different experiences of antiretroviral therapy, from those who have only ever used one combination of drugs, to those who have changed combinations frequently, to those who have taken breaks at various times, to those who have never used any of these treatments. In order to adequately reflect this diversity of experience, in 1999 we asked a more comprehensive range of questions about treatment history, with a particular emphasis on the past two years.

PLWHA were asked if they were currently using or had used a range of antiretroviral therapies. On the basis of their answers to these items, they were asked further questions on their experiences of antiretrovirals (ARVs).

Of the full sample, 86.5% had used ARVs at some point, and 73.6% were currently using these treatments. Of the women surveyed, 75.9% had used ARVs at some point, and 59.8% were currently using them, while for men 87.7% had used these drugs at some point and 75.2% were currently using them.

The data on treatments will be presented in four sections: those currently using ARVs (mono-therapy and combination therapy); those currently on combination therapy only; those not currently using ARVs who have in the past; and those who have never used ARVs. A summary diagram of the uptake of antiretrovirals can be found on page 40.

#### ***Those Currently Using ARVs (mono-therapy and combination therapy)***

Of the PLWHA currently using antiretroviral therapies, most (69.2%) were using a combination of 3 drugs<sup>2</sup>, a further 22.2% were using 4 or more drugs, 7.8% were using 2 drugs and 0.8% were on mono-therapy (six individuals). The specific drugs being used are listed in Table 5 below.

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<sup>2</sup>In this analysis, Combivir, which is a combined dose of AZT and 3TC is counted as two drugs.

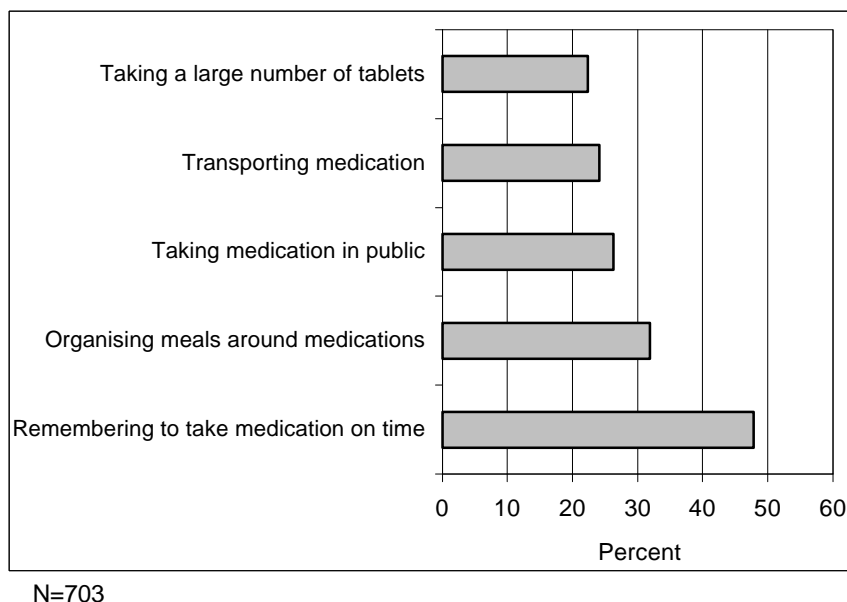
Table 5: Antiretroviral drugs used by respondents: percentage of total sample

Drug	Percentage of those using ARV
d4T	58.5
3TC	49.1
Nevirapine	34.2
ddl	27.9
Nelfinavir	23.7
Indinavir	19.2
AZT & 3TC (Combivir)	18.1
1592	13.3
AZT	12.2
Efavirenz	11.9
Ritonavir	10.4
Saquinavir-soft gel	10.2
Saquinavir-hard gel	10.0
ddC	4.0
Delavirdine	2.1
Adefovir	1.6
Loviride	0.3

Respondents were also asked specifically about their use of the two immune stimulants Interleukin 2 and Hydroxyurea. Only a small proportion of the sample (0.6%) were currently using Interleukin-2 and 4.3% were using Hydroxyurea.

#### ***Difficulties of Taking ARV***

Overall, 73.5% reported that they had some difficulty taking ARVs. Of these, 47.8% indicated they had difficulty remembering to take the drugs on time, 31.9% said they had difficulty organising meals around medications, 26.3% taking medication in public, 24.1% transporting medication, and 22.4% taking a large number of tablets (see Figure 2). In addition, 9.0% reported that taking ARVs made it difficult to take medication for other health conditions and 4.5% that taking other medications made taking ARVs difficult.

**Figure 2: Difficulties of taking ARV**

Most (63.6%) PLWHA were taking ARVs twice per day, while 25.0% were taking ARV three times a day and 10.3% were taking these medications 4 or more times per day.

When asked how many doses of ARV they had missed in either of the two days before completing the survey, 87.4% reported missing no doses, 7.6% missed one dose, 4.0% missed two doses and 0.9% missed three or more doses.

Side effects were reported by 54.8% of respondents. The most commonly reported problems were diarrhoea (24.4% of those reporting side effects), nausea (15.8%), neuropathy (7.8%), fatigue or lethargy (7.8%), lipodystrophy (7.1%), insomnia (6.5%), and headaches (5.8%).

### **Attitudes**

Most respondents reported concern over the future efficacy of their treatments. In response to the statement *I am worried that in the future my medication will stop working for me*, 45.5% agreed and 20.5% agreed strongly. Only 3.3% disagreed strongly with this statement, while 15.9% were unsure (See Table 6).

When asked to respond to the statement *Taking tablets gives me an unwanted reminder that I have HIV*, 55.4% indicated agreement and 42.8% indicated disagreement. Those who agreed with this statement were significantly more likely to have missed a dose of antiretroviral drugs in

the previous two days (strongly disagree: missed a mean of 0.15 doses, disagree: 0.22 doses, agree: 0.43 doses and strongly agree: 0.52 doses).

**Table 6: Attitudes to medication: percentage of those using ARV**

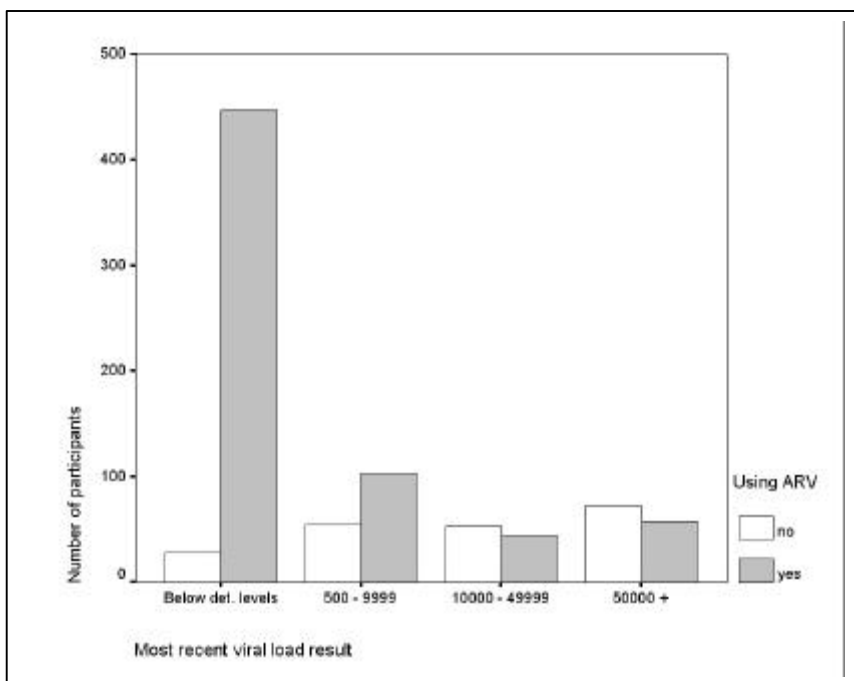
	Strongly Disagree	Disagree	Agree	Strongly agree	Don't know
I am worried that my medication will stop working for me <sup>a</sup>	3.3	15.0	45.3	20.5	15.9
Taking tablets gives me an unwanted reminder that I have HIV <sup>b</sup>	9.8	33.0	37.5	17.9	1.8

a: N=699, b: N=696

#### *Health Status of Those Using ARV*

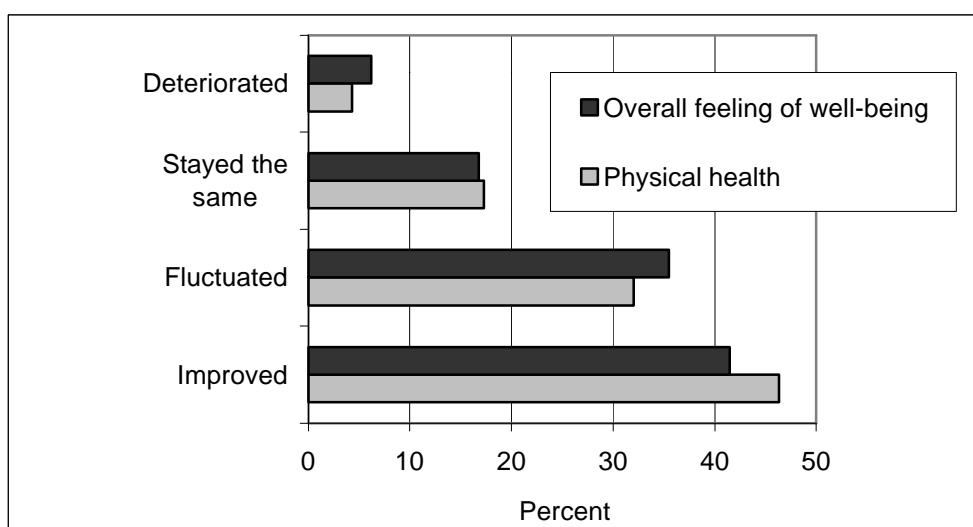
Those taking ARV had significantly lower viral loads (mean of 28,389.9 cells/ml compared to 181,473.4 cells/ml among those not taking any antiretroviral medication). This difference is mainly explained by the large proportion of those on ARV with a viral load below detectable levels as can be seen in Figure 3.

Figure 3: Viral loads for those taking and not taking antiretroviral therapy.



Those taking ARVs did not have significantly different CD4 counts (mean of 478.8 copies/ml compared to 497.8 copies/ml among those not taking antiretrovirals). They were more likely to have had an AIDS defining illness (24.3% compared to 17.6% among those not taking antiretrovirals). There was, however, no difference between these two groups in the number of years they had been HIV positive, nor in the ratings they gave of their general health status.

When asked to rate the effect of commencing ARV on their physical health, 46.3% said that their health improved, 32.0% said it fluctuated, 17.3% said it stayed the same and 4.3% said it deteriorated. When asked about the impact of ARVs on their overall feeling of well-being, 41.5% said it had improved, 35.5% said it had fluctuated, 16.8% said it had stayed the same and 6.2% said it had deteriorated (see Figure 4).

**Figure 4: Effect of commencing antiretroviral medication on health**

N=696

Respondents were asked if they had taken a break from ARV therapy at any time in the past. Most respondents had not taken any breaks (63.0%). Of those that had taken a break, the most commonly cited reason was that side effects had become too severe (46.0%). One third (32.3%) said they had taken a break from treatment to clean out their system and 24.6% to have a drug holiday<sup>3</sup>. Drug resistance was given as a reason by 17.1% and non-performance of ARV by 13.9%. Problems with compliance were also reported (15.7%).

Respondents were specifically asked if they were undertaking pulse therapy, which involves cycles of treatment followed by non-treatment as a therapeutic technique. A very small number of those currently on ARV therapy said this was the case (1.2%).

### ***Those on Combination Therapy***

As noted earlier, almost all of those using ARV were on some form of combination therapy. The most common combinations used were [3TC, D4T and Nevirapine]: 8.4% of those using ARV, [ddi, D4T and Nevirapine]: 6.4%, [3TC, D4T and Nelfinavir]: 5.4%, [3TC, d4T and Indinavir]: 5.2%, [Combivir and Nevirapine]: 4.1%, [Combivir and Indinavir]: 2.8%. This means that most commonly used combinations consisted of two nucleoside analogues and one non-nucleoside reverse transcriptase inhibitor or two nucleoside analogues and one protease inhibitor. The most common two drug combination was 3TC and Indinavir (2.0%).

<sup>3</sup>The proportion of those taking breaks who indicated a structured break for either a drug holiday or to clean out the system was 49.0%



Two thirds (66.6%) of these had been on combination therapy for more than three months. Most started combination therapy at a time when their viral load was high (mean =34,605.7 copies/ml) and their CD4 count was low (mean = 249.6, 50.3% below 250 cells/ml, 88.7% below 500 cells/ml). As can be seen in Table 7 below, most people had commenced combination therapy at a time when treatment would be strongly indicated (see AFAO, 1997).

**Table 7: Results of most recent serological tests: percentage of those on ARV**

			Viral load prior to commencing combination therapy (%)			
			Below detectable levels	Low 500 to 9,999	Moderate 10,000 to 49,999	High 50,000+
			0.0	13.1	24.8	62.1
CD4/T-cell prior to commencing combination therapy (%)	Little damage 500+	11.3	0.0	3.1	4.6	5.4
	Moderate damage 250-499	33.3	0.0	5.9	9.0	17.8
	Severe damage 0-249	55.4	0.0	4.1	11.1	38.9

N=638

When asked about the circumstances surrounding their commencement of combination therapy, respondents were most likely to indicate that they were advised to do so by their doctor (82.5%), although the importance of clinical indicators and treatment information is also clear.

**Table 8: Circumstances surrounding commencement of treatment among those on combination ARV.**

Circumstance	Percentage of those on combination therapy
My doctor advised me to begin this treatment	82.5
I had a big drop in my CD4 count	41.4
New drugs became available	37.6
Information showed the treatment was effective	34.6

Circumstance	Percentage of those on combination therapy
I had a big rise in my viral load	26.5
I became very ill	25.3
I was hospitalised due to HIV	14.7
Positive friends started treatment	10.6
Close friends advised me to begin treatment	8.4
My partner advised me to begin treatment	8.1
A treatments officer advised me to begin treatment	7.3

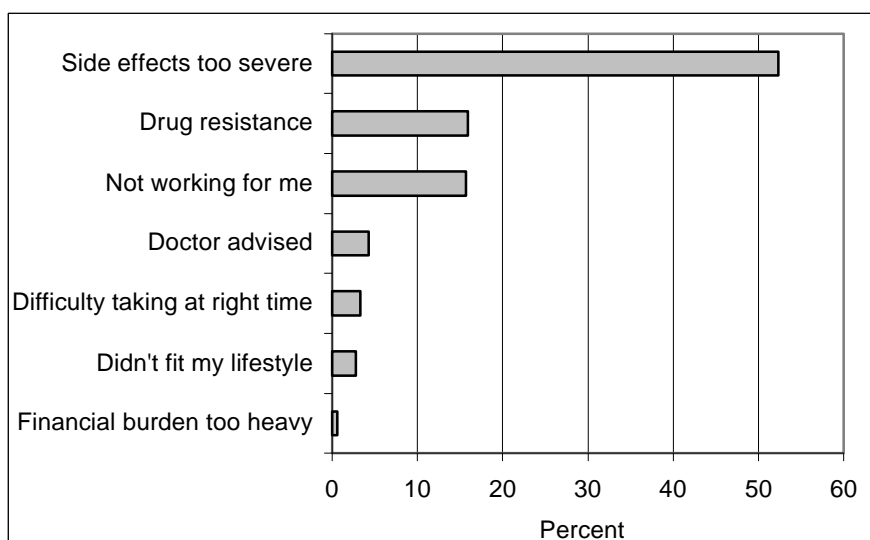
Multiple responses possible N=685

**Different Combinations**

Most of the respondents had used one (27.1%) or two (27.3%) combinations of ARVs during their entire treatment. Within the last 12 months, 58.8% had used the one combination and 27.8% had used two.

Respondents currently on combination ARV were asked to describe the circumstances surrounding their most recent change in combination. For slightly more than half (52.3%) the side effects became too severe. Drug resistance (15.9%) and drugs not working (15.7%) were the next most common responses, followed by doctor advised (4.3%), difficulty taking the drugs at the right time (3.3%), didn't fit lifestyle (2.8%) and financial burden was too heavy (0.6%) (see Figure 5).

**Figure 5: Circumstance surrounding most recent change in combination among those currently on combination ARV**



N=685

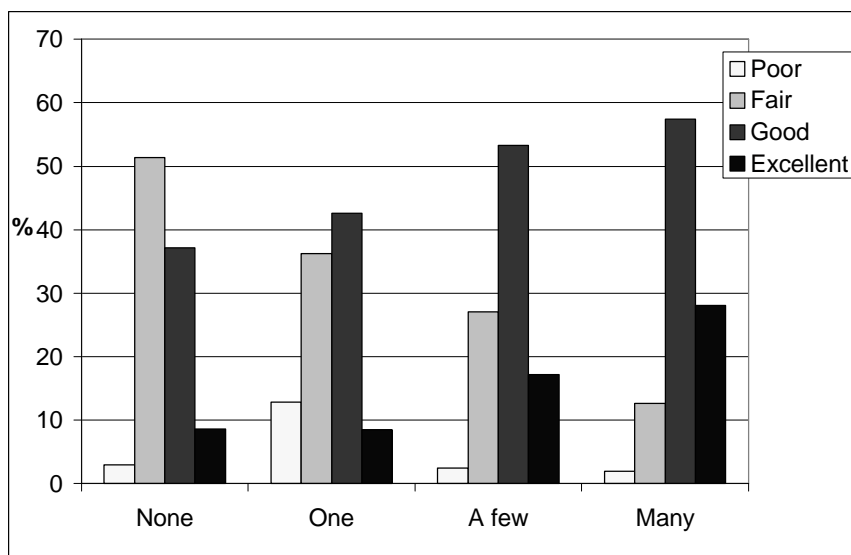
When asked how many combinations they believed they still had access to, 44.9% indicated that they thought they had *a few* and 42.1% felt they had *many*. Importantly, 5.8% of those currently on combination therapy had no combinations remaining. These respondents were significantly more likely to have a higher viral load than those with more therapeutic options and to rate their health as *fair*. The major differences in terms of health status, however, appear to be between those with one remaining combination and the remainder of the sample. Those with one combination remaining were more likely to have been HIV positive longer, to have a lower CD4 count and to rate their health as *poor*. (See Figure 6).

**Table 9: Correlates of number of remaining combinations for those on ARV**

Combinations remaining	Mean years positive	Mean CD4	Mean Viral load
None	8.8	375	185892
One	10.6	321	37240
A Few	9.3	485	22530
Many	8.1	569	13624

N=685

**Figure 6: General health status for those with different numbers of combinations of ARV remaining: percentage of those on ARV**



N=684

**Those Not Currently Taking ARV**

Of the 26.3% of the sample who are currently not using any antiretrovirals, 48.8% had done so in the past. The mean length of time these PLWHA had been using ARVs was 2.5 years (range 1 month to 13 years) and on average they had ceased using ARVs 2 years and 2 months prior to completing the survey (range 0 to 2.2 years). At the time that they stopped using ARVs, most were using a combination of 3 drugs (50.2%), 18.2% were using four drugs and 1.9% were on mono-therapy.

**Difficulties of Taking ARV**

The pattern of difficulties experienced by those who have stopped antiretroviral therapy and those currently taking antiretrovirals differs considerably, as can be seen from Table 10. Overall, of those who have, but are not currently taking antiretrovirals, 82.9% reported that they had some difficulty taking ARVs. Of these 74.2% indicated they had difficulty remembering to take the drugs on time, 49.2% said they have difficulty organising meals around medications, 43.9% taking medication in public, 48.9% transporting medication, and 50.2% taking a large number of tablets. In addition, 15.1% reported that taking ARVs made it difficult to take medication for other health conditions and 9.5% that taking other medications made taking ARVs difficult.

**Table 10: Difficulties experienced by those currently on ARV and those who have stopped ARV treatment.**

<b>Difficulties experienced</b>	<b>Those taking ARV now<sup>a</sup></b>	<b>Those who have taken ARV in the past, but not now<sup>b</sup></b>
Side effects	54.8	80.5
Remembering to take drugs on time	47.8	74.2
Organising meals around medications	31.9	49.2
Taking medication in public	26.3	43.9
Transporting medicine	24.1	48.9
Taking large number of tablets	22.4	50.2
ARV makes taking other medication difficult	9.0	15.1
Other medication makes taking ARV difficult	4.5	9.5

a: N=703, b: N=252

Side effects were reported by 80.5% of respondents, significantly more than for those currently using antiretrovirals. The most commonly reported problems were nausea (35.8% of those reporting side effects), diarrhoea (30.2%), neuropathy (18.6%), fatigue or lethargy (14.4%), headaches (13.1%), lipodystrophy (9.1%), insomnia (10.2%), vomiting (10.1%), skin rash (9.9%), dizziness or blurred vision (8.1%), weight loss (8.0%), and cramps (5.3%).

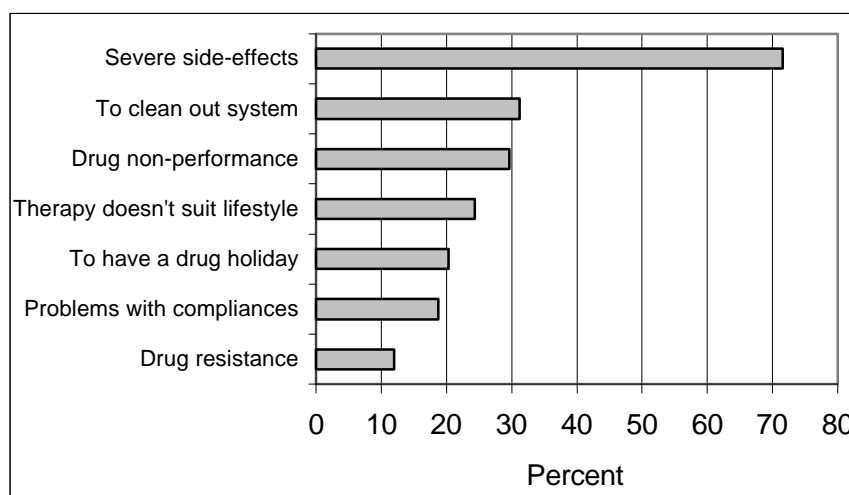
**Health Status of Those Not Using ARV**

Those not currently using ARV were asked to describe the effect on their health when they had used ARV in the past. Nearly one third (31.3%) said that it had deteriorated, 39.8% said it fluctuated, 18.2% said it stayed the same, and 10.7% said that their health improved.

When asked about the impact of ARVs on their overall feeling of well-being, 9.0% said it had improved, 37.5% said it had fluctuated, 13.6% said it had stayed the same and 39.9% said it had deteriorated.

Respondents were asked why they had stopped using antiretroviral therapy. The most commonly cited reason was that side effects had become too severe (71.6%). One third (31.2%) said they had taken a break from treatment to clean out their system and 20.3% to have a drug holiday.<sup>4</sup> One quarter (24.3%) said that the therapy did not suit their lifestyle. Drug resistance was given as a reason by 12.0% and non-performance by 29.6%. Problems with compliance was reported by 18.7% (See Figure 7).

**Figure 7: Reasons for discontinuing combination ARV: percentage of those not currently on ARV**



N=120

Most of the respondents had used one (33.0%) or two (14.9%) combinations of ARVs during their entire treatment and 13.2% had used four or more.

<sup>4</sup> The proportion of those taking breaks that indicated a structured break for either a drug holiday, or to clean out the system was 34.7%

**Those Who Have Never Used Antiretroviral Drugs**

Of the 13.5% of the total sample that have never used antiretroviral drugs, 86.8% said they would consider using antiretroviral drugs in the future. They were asked under which circumstances they would do so. Unlike those currently on treatment, the most important circumstances related to health status, while advice from a doctor is given by only half the percentage as those currently on treatment (47.7% versus 82.5%).

**Table 11: Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used antiretroviral drugs.**

<b>Circumstance</b>	<b>Percentage of those not on ARV.</b>
If I became very ill	71.3
If I had a big drop in my CD4 count	68.3
If I had a big rise in my viral load	63.4
If I was hospitalised due to HIV	62.1
If my doctor advised me to begin this treatment	47.7
If new drugs became available	38.8
If information showed the treatment was ineffective	33.9
If a treatments officer advised me to begin treatment	22.5
If my partner advised me to begin treatment	10.1
If close friends advised me to begin treatment	7.1
If positive friends started treatment	3.4

Multiple responses possible N=105

Among those who would not consider using antiretroviral drugs in the future the main reasons given were concerns around toxicity, belief in alternative therapies, or the power of positive thought.

**Attitudes to Antiretroviral Therapy**

Participants were asked to respond to a range of statements about antiretroviral drugs. These statements fall into two broad areas: treatment uptake and decision making; and treatment optimism.

**Treatment uptake and decision making**

Most of the sample disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (71.9%). Those that agreed with this statement were more likely to be those not currently using any antiretroviral drugs. There was a fairly even spread of responses to the statement *People with HIV should start using antiretroviral drugs as soon as possible*. Those that agreed with this statement were more likely to be using antiretroviral drugs and on average had lower viral load results (but no difference in CD4 results).

Few PLWHA agreed with the statement *Combination antiretroviral drugs are ineffective* (5.5%). They were somewhat more likely to agree that *Combination drugs are harmful* (25.6% agree, 7.3% strongly agree). This may be related to the impact of side effects, as is suggested by responses to the statement *The side effects of antiretroviral drugs outweigh the benefits*, to which 19.4% agreed and 8.7% agreed strongly, while 17.8% were unsure. Response to these items were unrelated to the use of complementary therapies.

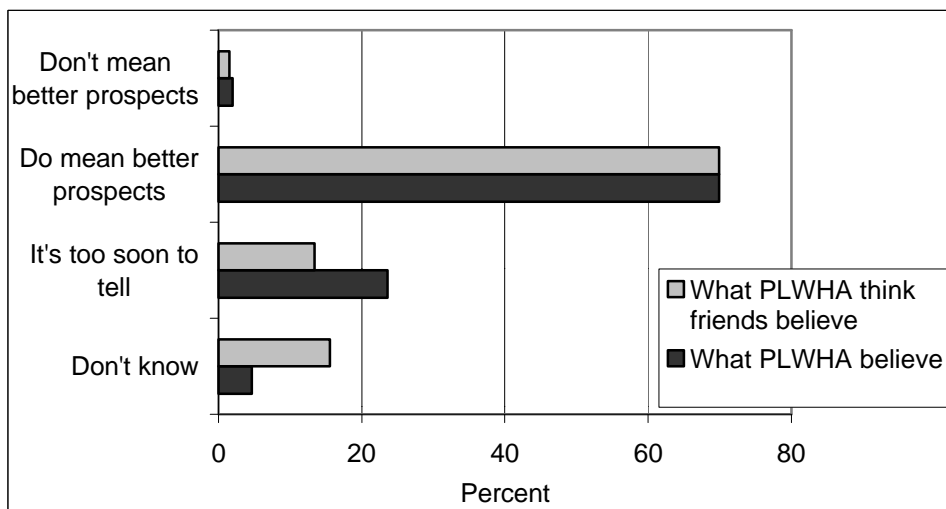
As with the original survey, most respondents (88.7%) agreed with the statement *My doctor and I work together to find the best treatment for me*, although a slightly larger percentage (75% in 1999, 68% in 1997) supported the statement that *My doctor knows more about the treatment of HIV than I do*. This may reflect the increased complexity of HIV treatment regimens.

**Treatment Optimism**

Overall, PLWHA are cautiously optimistic about antiretroviral drugs and their ability to improve their lives. Three fifths (60.0%) agreed with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*. There was greater uncertainty about the impact of these treatments on life expectancy, with 40.6% indicating that they were unsure whether *HIV treatments will stop me dying from AIDS*. In terms of future treatment developments, most respondents agreed that *New treatments will be developed in time for me to gain benefits*.

Participants were also asked to respond to the statement *Antiretroviral drugs mean better prospects for most people*, both in terms of their own beliefs and those of their friends. Most (69.6%) agreed with the statement, and believed their friends would agree with it (69.9%). This is an increase of 10% over the 1997 survey, mostly with a shift from the *It's too soon to tell* category. Almost one quarter of respondents believe that *it's too soon to tell* (23.6%), although they were less likely to think their friends think this (13.4%). Few said they don't know (4.7%) but were more likely to think their friends don't know (15.6%) and only a very small number said no (2.0% respondents and 1.5% friends) (See Figure 8).

**Figure 8: Respondents' and respondents' social networks' response to the statement *Antiretroviral drugs mean better prospects for most people.***

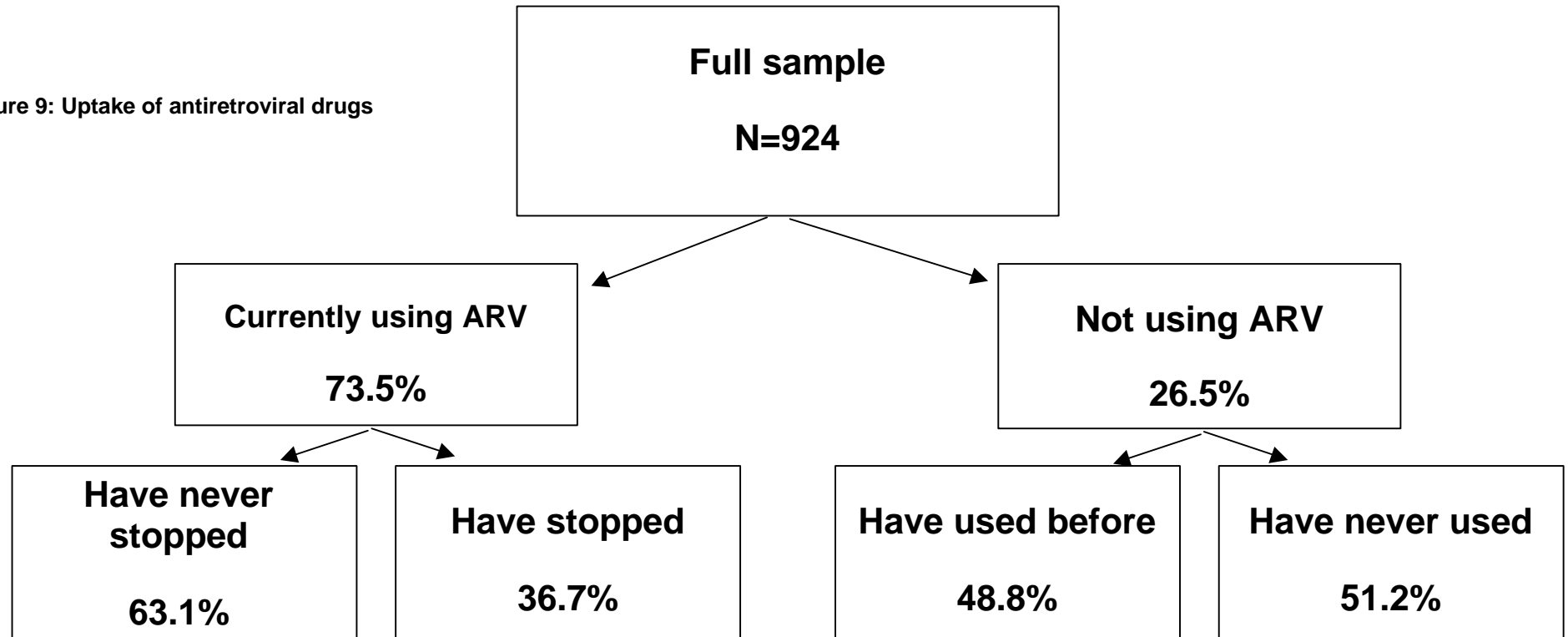




**Table 12: Attitudes to antiretroviral drugs: percentage of total sample**

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't know</b>
I am healthy now and don't need to use antiretroviral drugs	40.8	31.1	11.4	10.3	6.4
People with HIV should start using antiretroviral drugs as soon as possible	11.4	20.5	27.3	16.6	24.2
Combination antiretroviral drugs are ineffective	45.7	39.6	3.7	1.8	9.2
Combination antiretroviral drugs are harmful	18.0	29.8	25.6	7.3	19.3
The side effects of antiretroviral drugs outweigh the benefits	11.6	42.6	19.4	8.7	17.8
My doctor and I work together to find the best treatment for me	2.1	6.4	53.5	35.2	2.9
My doctor knows more about the treatment of HIV than I do	4.1	16.1	46.1	28.9	4.8
Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term	7.5	15.8	36.1	23.9	16.8
HIV treatments will stop me dying from AIDS	7.2	17.8	23.7	10.7	40.6
New treatments will be developed in time for me to gain benefits	1.2	5.5	45.9	15.3	32.1

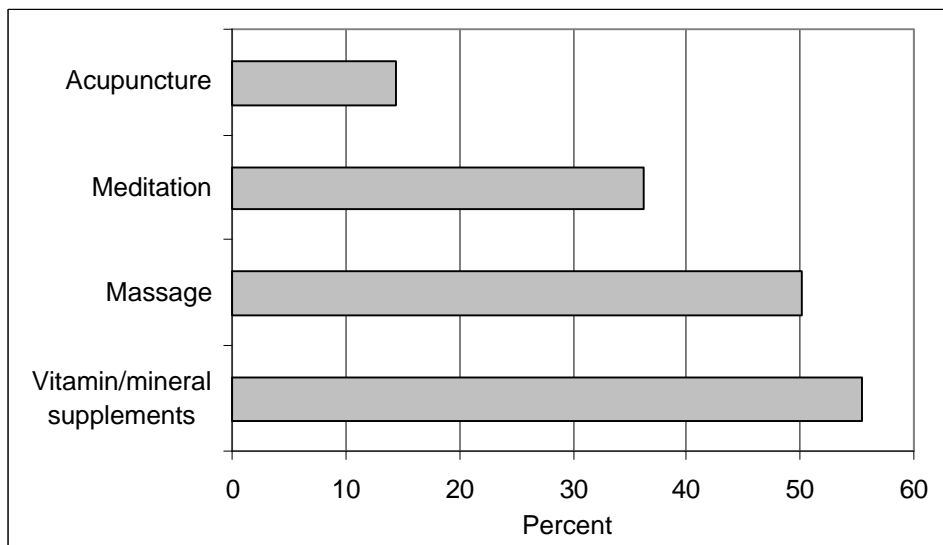
Figure 9: Uptake of antiretroviral drugs



## COMPLEMENTARY THERAPIES

Over half (55.5%) of the respondents were currently using complementary therapies for HIV. The most common complementary therapy was vitamin or mineral supplements (84.0% of those reporting complementary therapy use), followed by massage (50.1%), meditation (36.2%) and acupuncture (14.5%) (see Figure 10). Those using complementary therapies were no more or less likely to be using ARVs.

**Figure 10: Most commonly used complementary therapies**



N=522

Almost all PLWHA believe that complementary therapies can improve well-being (see Table 13). Half also believe complementary therapies can delay the onset of illness due to HIV, can reduce side effects of antiretroviral medication, and can boost the immune system. However, around one third of the respondents were unsure about these three statements and these people were more likely to be those not currently using complementary therapies.

Opinion was somewhat more divided on whether there was sufficient evidence on the benefits of complementary therapies, and on whether medicine's focus on anti-HIV drugs was limited.

Table 13: Attitudes to complementary therapies: percentage of total sample

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Complementary therapies can delay the onset of illness due to HIV	2.9	10.2	33.2	16.8	36.1
Complementary therapies can improve well-being	0.7	2.5	52.4	27.6	16.7
Complementary therapies can reduce the side effects of conventional medical treatments	2.3	7.0	35.8	16.0	39.5
There is not enough evidence to be sure about the benefits of complementary therapies	8.5	29.1	33.4	6.1	23.0
Medicine's focus on anti-HIV drugs is very limited	4.5	26.8	30.5	10.4	27.8
Complementary therapies can boost the immune system	2.6	4.2	39.6	19.2	34.5

On average PLWHA spend \$10.05 per week on complementary therapies.

## WELL-BEING

The following section explores the social aspects of positive peoples lives, both those aspects directly related to having HIV, like the use of medical services, and those aspects that, though not directly related to the physical fact of being HIV positive, are nonetheless influenced by the social fact of being positive, such as employment, finances and relationships. We have examined the way in which PLWHA interact with AIDS services and community organisations that exist to serve the needs of positive people, and with the *HIV/AIDS community*, in the many ways that that can be defined. There are also sections on the mental health of PLWHA, on social support, on recreational drug use, on sources of information about HIV and on the way PLWHA see their future. Our aim with this section is to give a more complete picture of the lives of positive people than is often seen in research of this type, and to relate that to the physical health of PLWHA.

### **Summary:**

PLWHA visit a mixture of General Practitioners specialising in HIV and HIV specialist physicians.

For general health care treatment 45.7% of PLWHA see a GP who specialises in HIV whereas specialist/physician. Most respondents had visited either a GP who specialises in HIV or an HIV specialist in the last six months.

- ▶ 31.8% have experienced less favourable treatment at a medical service as a result of having HIV;
- ▶ 60.7% pick up all of their prescription medication at one place;
- ▶ 34.5% go to two places for prescription medication;
- ▶ 3.9% go to three or more places for prescription medication.

Services used at AIDS organisations:

- ▶ 45.4% treatment advice;
- ▶ 39.5% social contact;
- ▶ 30.6% peer support;
- ▶ 31.1% counselling;
- ▶ 25.0% advice on financial matters
- ▶ 19.4% advice on legal matters;
- ▶ 23.6% alternative therapies.

Organisations other than AIDS Councils tended to be used for the provision of pharmacy services, housing assistance, mental health services and employment services.

Almost all PLWHA sought advice on treatments from their doctor. For advice about living with HIV/AIDS, PLWHA relied mostly on HIV/AIDS media. Respondents reported reading a variety of national and state based publications, with over half reading gay newspapers and Positive Living. One quarter of PLWHA said they had problems with a lack of information on managing side effects and nearly as many nominated a lack of information on taking a break from ARV and interactions between ARV and other medications.

Almost all respondents have disclosed their HIV status to at least one person, generally partners, close friends and family. Many (59.9%) respondents said their HIV status had been disclosed to another person when they did not want it to be.

Sources of support:

- ▶ 77.4% partners/spouse;
- ▶ 67.3% pets;
- ▶ 53.4% close friends;
- ▶ 53.4% had no one from whom they received a lot of support.

Three quarters of respondents said they have some contact with HIV/AIDS organisations. (This finding is likely to be influenced by the fact that these organisations were a major distribution source for the survey). Most commonly respondents receive newsletters and mail-outs but many respondents also seek treatment advice and social contact through these organisations. Most of those who did not have any contact said they do not wish to be involved, although 16.8% said they felt excluded from the organisations.

Involvement with other PLWHA:

- ▶ 95.7% know another PLWHA;
- ▶ 19.9% have a spouse/partner with HIV;
- ▶ 70.4% know acquaintances with HIV;
- ▶ 28.7% spend some time with other PLWHA;
- ▶ 18.7% spend a lot of time with other PLWHA;
- ▶ 28.2% spend no time with other PLWHA;
- ▶ 28.2% have been involved with the care of someone with HIV/AIDS;
- ▶ 74.5% someone close has died of AIDS related causes.

HIV status is important to their sense of identity for 57.6% of PLWHA, and essential to 16.4%. In contrast, sexuality is important to identity for 47.4% and essential to a further 33.9% of respondents, and gender is important to 38.7% and essential to 30.7%. Notably over half agreed that changes in their body image makes them feel unattractive.

In the last six months slightly less than one third of respondents have taken prescribed medication for depression and over one quarter for anxiety.

Half of the sample said they plan at least one year ahead and only one in ten said they plan more than 10 years ahead. Over one third of respondents said they had changed their time frame for future planning in the last two years. Over two thirds now use a longer time frame and this is usually due to improved health (due to new treatments or other reasons) or taking new treatments. Over one quarter use a shorter time frame and this is usually due to declining health.

## HEALTH SERVICES

### Treatment

Respondents were asked about their use of medical services. In order to capture some of the complexity in the ways in which PLWHA use general practice, hospital and community medical services, we asked respondents who they use for general and HIV specialist care, and where they obtain a range of information and services.

For general medical treatment almost half (45.7%) see a General Practitioner (GP) who specialises in HIV. While it is often difficult to distinguish what is and what is not HIV related, some PLWHA choose to go to a different doctor for day to day care than the doctor they go to for HIV specific treatment. One fifth (20.2%) of PLWHA visit a generalist GP for general medical care and 14.6% visit a HIV specialist physician.

For HIV related treatment, 38.5% visit a GP who specialises in HIV, 30.9% visit a HIV specialist physician, and a smaller number visit a doctor at an outpatient clinic or a doctor at an AIDS organisation. Two thirds (66.9%) visit a doctor in a different category for general treatment than they do for HIV specific treatment. One fifth (21.2%) visit a doctor in the same postcode area to their residence. (See Table 14).

**Table 14: Physician used for general and HIV related treatment: percentage of total sample**

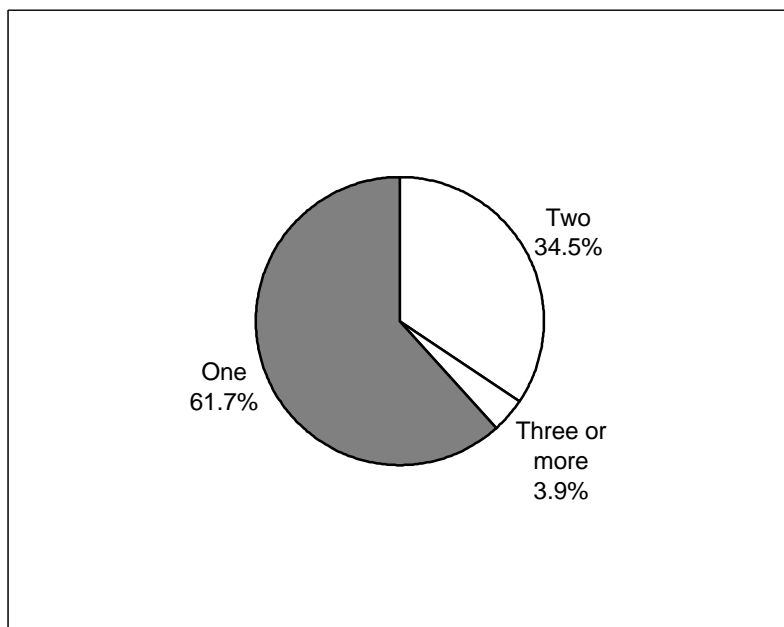
	For general treatment	For HIV specific treatment
GP who specialises in HIV	45.7	38.5
Generalist GP	20.2	3.0
HIV specialist/physician	14.6	30.0
Dr. at hospital/ outpatient clinic	6.6	9.5
Dr. at sexual health centre	6.0	8.2
Dr. at HIV/AIDS organisation clinic	5.7	8.4
Dr. at hospital inpatient clinic	0.6	0.7
Other	0.0	0.6

### Prescriptions

Almost half (43.7%) PLWHA get their prescriptions for antiretroviral drugs from a GP who specialises in HIV, while a further 32.9% get their prescriptions from a HIV specialist. For most people each prescription usually lasts three months (51.4%), while for some it lasts only two months (11.4%) or one month (33.7%). The majority of respondents go to only one place to pick up all of their prescription medication (60.7%). A sizeable number, however must go to two places (34.5%) and a small proportion (3.9%) need to go to three or more sites. (See Figure 11).



**Figure 11: Number of prescription pick-up points**



This situation exists because not all pharmacies are able to dispense antiretroviral drugs, so some people will attend a local pharmacy for most prescription medication and a specific pharmacy or outlet for antiretroviral drugs. Those going to two or more places were more likely than those going to one place to indicate that this was difficult (46.0% versus 23.2%) or very difficult (9.3% versus 1.4%). These people were also more likely to live in rural or regional areas. Table 15 shows the degree of difficulty PLWHA have in obtaining ARV medication.

**Table 15: Difficulty in obtaining antiretroviral drugs**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
It is easy for me to get combination antiretroviral drugs	1.9	3.7	52.9	37.5	3.9

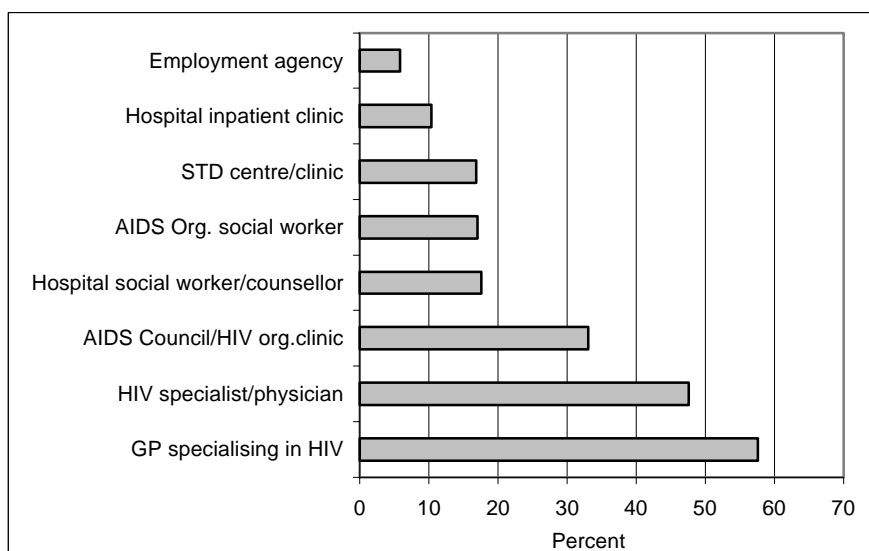
N=935

**Services Used in the Last 6 Months**

Respondents were asked which of a list of services they had used in the past six months (see Figure 12). Not surprisingly, given the levels of health monitoring, most PLWHA had visited either a GP who specialises in HIV (57.6%) or an HIV specialist (47.6%). Approximately one third of the sample had visited a hospital outpatient clinic (33.5%), 10.4% had been to an

inpatient clinic, and 16.8% had been to an STD centre/clinic. One third of PLWHA had visited a clinic at an AIDS council (33.1%), 28.4% of respondents had used the services of a social worker, either at an AIDS council (17.0%) or hospital (17.6) and 5.8% had utilised the services of an employment agency. Almost one third (29.8%) of PLWHA had utilised only one of the clinical services (GP, HIV specialist, Hospital in- or out-patient clinic, STD centre, or AIDS council clinic) in the last six months, while 34.7% had utilised two services, 18.2% had utilised three services and 17.2% had utilised four or more services.

**Figure 12: Services used in the last six months**



(Multiple responses possible)

Just under one third of respondents (31.8%) reported that they had experienced less favourable treatment at a medical service as a result of having HIV at some point in the past. This group were more likely to have been HIV positive for longer than those who had not (mean of 9.4 years as compared to a mean of 8.4 years).

**Other Services**

Participants were asked whether they currently use a range of services and, if so, whether they do so through an HIV/AIDS organisation or through another organisation. The most commonly used service at AIDS organisations was treatment advice, with almost half the respondents selecting this item (see Table 16). AIDS organisations were also used for social contact with other PLWHA, other forms of peer support, counselling and advice on financial and legal

matters. They were also an important source of alternative therapies with 23.6% of the sample (33.8% of those who indicated they used complementary therapies) selecting this category.

Other organisations were more likely than AIDS organisations to be used for pharmacy services, housing assistance, mental health services, employment services and financial advice.

**Table 16: Services used at HIV/AIDS organisations and at other organisations**

	<b>Use service at HIV/AIDS ORGANISATION</b>	<b>Use service at OTHER ORGANISATION</b>
Treatments advice	45.4	20.1
Social contact with other PLWHA	39.5	11.5
Counselling	31.1	20.1
Peer support group	30.6	7.7
Financial assistance	25.0	13.5
Alternative therapies	23.6	20.9
Informal peer support	21.4	12.0
Legal advice	19.4	14.0
Pharmacy services	18.5	35.7
Housing assistance	15.7	19.6
Financial advice	13.8	15.4
Library	10.4	19.0
Internet access	9.4	16.7
Respite care	8.1	7.4
Mental health services	8.1	15.3
Return to work skills	5.3	11.4
Employment services	4.8	12.3
Drug/alcohol treatment	4.0	10.4

(Multiple responses possible)

When asked what services they feel they need but are currently not getting, respondents nominated career planning (2.2%), transport (1.4%) and services in rural areas (0.7%).



## INFORMATION

### Sources

As treatment information becomes more complex, PLWHA must make critical decisions about where they go for such information. Similarly, living with HIV requires that people have information about managing side effects, work, finances, discrimination, and less tangible things such as what being HIV positive means in all aspects of their lives. Respondents were given a list of information sources and asked which of these were important sources of information about treatments, and about living with HIV. They were also asked which single source was the most important for each of these areas.

Doctors specialising in HIV were selected by 94.4% of PLWHA as a source of information about treatments and by 74.9% as the most important (see Table 17). Also important were articles in the HIV/AIDS press (65.5%) and in the gay press (50.7%). Treatments Officers and other AIDS organisation staff were selected by around one quarter of participants.

HIV positive friends were identified by 41.1% as a source of information about treatments. They are also considered an important source of information about living with HIV by 53.6% of the respondents. The highest response in the *living with HIV* section was HIV/AIDS press which was chosen by 61.2% of the participants. Also important was the gay press (49.5%) and doctors specialising in HIV (47.7%). When asked about the single most important source of information about living with HIV, 21.0% chose HIV doctors, while 19.0% chose HIV positive friends.

**Table 17: Sources of information about treatments and living with HIV**

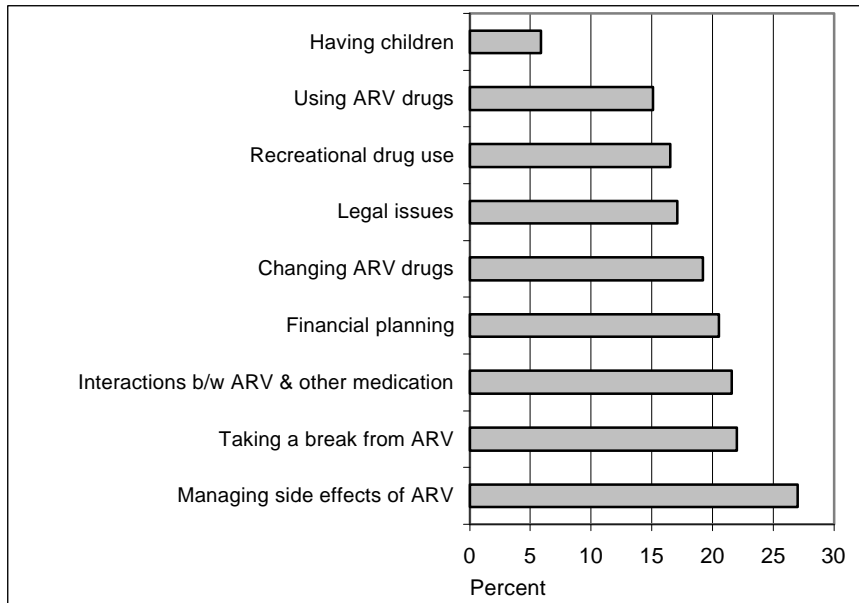
	Information about TREATMENTS	Information about LIVING WITH HIV
Doctor specialising in HIV	94.4	47.7
Other doctor	19.8	14.1
Nurse	19.7	17.9
Pharmacist	18.2	6.7
Alternative therapist	18.3	21.7
Treatments officer	24.3	14.3
Other HIV/AIDS organisation staff	27.2	37.6
Positive women's organisation	6.3	8.3
Injecting drug users' organisation	3.8	5.3
Haemophilia Foundation	2.3	3.1
HIV positive friends	41.1	53.6
Other friends	11.2	23.6
Partner/ lover	13.5	23.7
Family	6.3	15.7
Articles in gay press	50.7	49.5
HIV magazine/ newspaper	65.5	61.2
Internet	22.4	16.4

(Multiple responses possible)

The internet was identified as an important source of information about treatments by 22.4% of the sample. When asked to respond to the statement *HIV information on the internet is unreliable*, 7.1% agreed, 24.2% disagreed and 68.7% said they were unsure. Of those who used the internet for treatment information 9.2% agreed, 72.9% disagreed and 17.9% said they were unsure.

When asked if a lack of information made it difficult to make decisions about a range of issues, the issue selected by most respondents was the management of side effects (27.0%). Around one fifth also indicated difficulties with lack of information about treatment interruptions (22.0%), drug interactions (21.6%), financial planning (20.5%) and changing ARV drugs (19.2%). Lack of information around legal issues (17.1%), recreational drug use (16.5%), use of ARV (15.1%) and issues around having children (5.9%) were also reported. (See Figure 13).

**Figure 13: Problems experienced due to lack of information**



(Multiple responses possible)

### Publications

Respondents were asked which of a range of publications containing AIDS information they read. The results are presented below in Table 18. Most widely read is Positive Living, a regular insert in the gay press, also mailed out to positive people and organisations around the country.

**Table 18: Publications read by PLWHA**

<b>Publication</b>	<b>Percentage</b>
<i>National or non-specific</i>	
National AIDS Bulletin	18.3
Positive Living	55.6
HIV Herald	38.6
Gay newspapers (% of total sample)	68.2
Gay newspapers (% of gay men and lesbians and bisexuals)	77.1
Gay magazines	25.4
Newsletters from community organisations	28.4
Overseas HIV/AIDS magazines (eg POZ)	9.3
National Haemophilia (% of total sample)	0.6
National Haemophilia (% of people with Haemophilia)	36.4
<i>State based publications</i>	
Talkabout (% of total sample)	49.3
Talkabout (% of NSW respondents)	76.9
With Complements (% of total sample)	37.0
With Complements (% of NSW respondents)	47.5
NUAA News (% of total sample)	5.2
NUAA News (% of NSW respondents)	7.4
Positive Life (% of total sample)	10.2
Positive Life (% of WA respondents )	51.9
QPP Alive (% of total sample)	13.3
QPP Alive (% of QLD respondents)	78.3



## THE SOCIAL WORLD OF PLWHA

### Involvement with AIDS Organisations

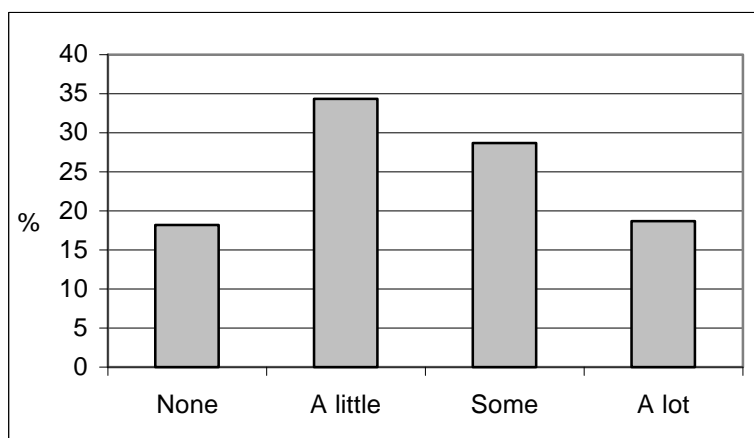
Participants were asked about their involvement with HIV/AIDS organisations. Over three quarters (78.8%) of the sample has some contact with HIV/AIDS organisations. Of these, 84.7% received newsletters and mail outs, 69.8% were clients, 48.5% were members, 13.7% were volunteers and 7.1% were employees. Of those that had no contact with AIDS organisations, 67.1% gave the reason *I do not want to be involved*, 29.3% that *I do not have enough time*, and 12.1% that they had *no transport or are too far away*. Importantly, 16.8% of those who were not involved in AIDS organisations said they *felt excluded from them*.

Just under one third of respondents (30.5%) had at some point held a decision making position in an AIDS organisation.

### Contact With Other PLWHA

When asked how much of their free time they spent with other HIV positive people, respondents were most likely to indicate that they spent *a little time* (34.4%). Around one quarter spent *some time* (28.7%) with other positive people while around one fifth spent either *a lot of time* (18.7%) or *no time* (18.2%) with other PLWHA (see Figure 14). Those who have been HIV positive longer were generally more likely to spend time with other PLWHA.

**Figure 14: Time spent with other positive people**



When asked which other people they knew were HIV positive, only 4.3% indicated that they knew no other positive people. A large proportion (86.2%) had friends that were positive and

over half the respondents had HIV positive acquaintances. Just over a third had an HIV positive former partner (see Table 19).

**Table 19: Other HIV positive persons known by respondent**

<b>Positive persons</b>	<b>Percentage</b>
No-one	4.3
Partner/ spouse	19.9
Former partner/ spouse	34.3
Friend	4.2
Son/ daughter	1.3
Other relative	4.6
Acquaintance/ member of support group	70.1

(Multiple responses possible)

Over one quarter of respondents (28.2%) have been involved in the nursing and care of someone with AIDS in the last two years. Nearly three quarters (74.5%) of the PLWHA had had someone close to them die of AIDS, primarily a friend (86.2%), or an acquaintance (55.2%), but also a former partner (27.7%), or partner (18.4%).

### **Disclosure**

Participants were asked who they had told that they were HIV positive. Only 2% had told no-one. Most had told close friends, and the majority had told siblings, positive friends, parents and partners. Table 20 shows the rates of disclosure for the whole sample and disclosure rates for some specific groups of PLWHA, for example, disclosure to partners among those currently in a regular relationship.

Table 20: People the respondent has disclosed their HIV status to

	Percentage who have disclosed
Close friends	90.5
Brothers or Sisters	71.6
Positive friends	71.4
Parents	60.8
Partner/ spouse	56.0
Other friends	42.7
Work colleagues	35.6
Neighbours	20.3
Son/ daughter	11.1
People from own ethnic community	5.7
No-one	2.1
Partners (% of those in regular relationship)	91.5
Partners (% of those not in regular relationship)	20.2
Work colleagues (% of those currently employed)	44.0
Work colleagues (% of those not employed)	27.0
Son/ daughter (% of those with dependant children)	33.8
People from own ethnic community (% of those who speak a language other than English at home)	30.2

(Multiple responses possible)

A majority (59.9%) of respondents indicated that their HIV status had been disclosed when they did not want it to be.

### The Place of HIV in People's Lives

We were interested in how central HIV was to PLWHA's sense of identity, particularly in comparison to other aspects of themselves. To assess this we asked *When you think of all the things that make you who you are, how important are each of the following aspects of yourself?* The categories and results are given in Table 21. A rating of *essential* indicates that the characteristic is an essential component of the individual's identity. A rating of *important* indicates that the characteristic plays a large part in how PLWHA see themselves, but may have

greater or lesser relevance depending on the context. A rating of *not important* indicates that the characteristic only has very context specific relevance and does not generally enter into their self-image. A rating of *irrelevant* indicates that the characteristic plays no part in their self-image. While our primary focus in this area was on the importance of HIV identity, we have included other characteristics, both as points of comparison and as a way of more fully describing PLWHA. The characteristics examined were sexuality, gender, recreational drug use, ethnicity, parenthood and career.

The majority (57.6%) of positive people in this study consider their HIV status an important, but not essential aspect of their make-up, while 16.4% consider it to be an essential characteristic. This is in contrast to sexuality and gender, where over 30% of the sample consider these to be *essential* characteristics. Those who consider HIV status to be *essential* are more likely to be those who have some involvement with HIV/AIDS organisations (particularly those who work for such organisations), those who spend more time with other PLWHA, and those who have been HIV positive for longer.

**Table 21: Importance of personal characteristics to respondents' sense of identity**

	Essential	Important	Not important	Irrelevant
HIV status	16.4	57.6	19.1	6.9
Sexuality	33.9	47.4	12.5	6.2
Gender	30.7	38.7	16.3	14.4
Drug use (recreational/illegal)	3.6	13.5	31.1	51.8
Ethnicity/ Cultural background	4.9	23.8	30.2	41.1
Parenthood	8.9	15.5	15.6	60.0
Career	12.2	43.8	21.9	22.2

When we look at the importance of HIV status among specific sub groups of PLWHA, we find that there are no significant differences in terms of sexuality, gender, having had an AIDS defining illness, use of antiretroviral drugs or partner sero-status (See Table 22).

**Table 22: Importance of HIV status to sense of identity for different groups of PLWHA**

<b>Importance of HIV status among:</b>	<b>Essential</b>	<b>Important</b>	<b>Not important</b>	<b>Irrelevant</b>
Gay men	17.2	57.1	19.0	6.6
Women	11.1	63.0	19.8	6.2
Heterosexual men	11.5	50.8	26.2	11.5
Those who have had an AIDS defining illness	12.2	65.9	16.6	7.1
Those who have not had an AIDS defining illness	17.7	55.5	19.7	7.1
Those on antiretroviral therapy	17.4	56.8	19.3	6.6
Those not on antiretroviral therapy	13.2	59.9	19.0	7.9
Those in sero-concordant relationships	11.7	54.7	23.5	10.1
Those in sero-nonconcordant relationships	16.5	60.6	16.9	5.9

N varies for each sub group

When the importance of the other attributes are examined for specific sub-groups of PLWHA, we find that there are significant differences between some of these groups (see Table 23).

**Table 23: Importance of personal characteristics to sense of identity for different groups of PLWHA**

	<b>Essential</b>	<b>Important</b>	<b>Not important</b>	<b>Irrelevant</b>
Sexuality- Gay men and lesbians	37.3	48.0	10.7	4.1
Sexuality- heterosexuals	23.7	46.2	16.2	13.2
Sexuality-bisexual and other	15.4	46.0	26.6	12.0
Gender- Women	32.1	42.0	8.9	17.0
Gender- Men	30.7	38.4	16.8	14.1
Drug use- users of illegal drugs	9.2	28.2	43.1	19.5
Drug use- non users	1.2	8.0	27.6	63.2
Ethnicity- Anglo <sup>5</sup>	4.6	23.3	30.3	41.8
Ethnicity- non-Anglo	21.2	43.5	11.6	23.6

<sup>5</sup>Based on language spoken at home

	Essential	Important	Not important	Irrelevant
Parenthood- Dep. children	57.6	35.5	2.7	4.2
Parenthood- No dep. children	4.0	13.6	16.7	65.6
Career- employed	18.4	58.6	16.6	6.4
Career- not employed	6.5	31.3	27.1	35.0

N varies for each sub-group

### Social Support

Overall PLWHA had reasonably high levels of support from those in their social networks (see Table 24). When asked how much support they received from a range of sources, the categories that rated highest were partner/spouse, pets and close friends (these results exclude those who designated the category as *not applicable*). When we examine those who indicated they receive *no support* from the sources, the category ranked highest was religious or spiritual adviser (46.3% - excluding those who designated the category as *not applicable*). Close friends were generally rated as more important sources of support, regardless of their HIV status. Those that rated HIV positive friends as an important source of support were more likely to be those who spend more time with other positive people. For all categories (excluding pets for obvious reasons), those who had disclosed to people within the category were more likely to find them a source of support.

**Table 24: Social support received from different sources: percentage of total sample**

	A lot	Some	A little	None
Partner/ spouse	77.4	11.8	5.5	5.3
Pets	67.3	14.9	10.5	7.4
Close friends	53.5	28.2	13.6	4.6
Parents	45.3	19.8	13.1	21.8
Children	42.2	16.7	14.2	26.9
HIV positive friends	38.2	32.2	21.8	7.9
Brothers and sisters	32.8	23.1	22.9	21.3
Counsellor	30.3	21.0	22.4	21.4
Religious or spiritual adviser	24.1	13.7	15.9	46.3
PLWHA groups	20.6	26.4	31.1	22.0
Other friends	17.2	37.1	25.5	20.2

Respondents were also asked about the number of sources among individuals in social networks (partner, friends, parents, siblings and children) from whom they get a *lot* of support. Possible results range from zero to seven sources of a *lot* of support. Over half (53.4%) of the respondents did not rate any of these individuals as the source of a *lot* of support. This includes those who rated these individuals as giving *some*, *a little* or *none*, as well as those for whom the category was not applicable. This gives a somewhat different picture to Table 24, where, for example, the data on support from a partner is only for those with a partner. A small number (4.5%) said they have one person from whom they receive a lot of support, 4.8% said two people, 10.1% said three people, 9.1% said four people, 7.6% said five people, 9.7% said six people and 0.8% said seven people.

### **Mental Health**

An increasingly important concern in the HIV/AIDS field has been the mental health of PLWHA. There is growing evidence that depression, anxiety, dementia and other general psychological issues are critical factors in the well-being of positive people. We included several items in the survey that addressed PLWHA's mental well-being.

### **Psychiatric Medications**

In the last six months over one quarter (29.7%) of PLWHA had been taking medication prescribed for depression. A similar proportion (26.5%) had taken medication for anxiety. In addition 5.5% of the sample indicated that they had taken anti-psychotic medication.

### **Symptoms of Depression**

We included a set of four items modified from those in the Beck Depression Inventory (BDI), a widely used depression assessment instrument. These were: (1) I cry or feel like crying all the time; (2) I don't enjoy things the way I used to; (3) I have lost interest in other people; and (4) I don't feel it's worth going on. It was not our intention to compare PLWHA to the community norms for depression provided by the BDI - this would have required inclusion of the full sixteen item scale. However, these four items do provide an indication of some of the major symptoms associated with depression. These are also items that are often used in general practice as reasonable indicators for the prescription of anti-depressants. As can be seen in Table 25, a considerable proportion of PLWHA agreed or strongly agreed with each of the items. The strongest level of agreement was with item 2 (not enjoying life as much), followed by 3 (losing interest in others). Over one fifth of the respondents agreed or strongly agreed with the item 1 (crying all the time), and almost 15% agreed or strongly agreed with item 4 (not worth going on).

We can look at the number of these items that people agreed with as a way of measuring the extent of depressive symptoms. Overall, 41.2% agreed or strongly agreed with none of these items, 24.4% with one item, 16.2% with two items, 11.5% with three items, and 6.7% of the sample agreed with all four items. Agreement with all four items is suggestive of clinical depression.

Agreement with a larger number of these items is significantly related to: being on anti-depressant medication; having a poorer self-rating of general health; having less social support; and current use of Efavirenz. Interestingly, it was also related to working for or doing volunteer work with an AIDS organisation. Scores on these items are unrelated to: viral load; CD4 count; having had an AIDS defining illness; use of any antiretrovirals (with the exception of Efavirenz); length of infection; and gender or sexuality.

Of particular interest in terms of well-being are issues around body image, particularly in the light of some of the public discussion about the ways in which antiretroviral medication may or may not change people's body shapes. We included a number of items in the survey that assessed the impact of body changes due to HIV on the mental well-being of PLWHA.

Respondents were asked to respond to the statement *Changes in my body due to HIV/AIDS have made me feel unattractive*. Over half (51.7%) agreed with this statement. Those who were experiencing lipodystrophy were more likely to agree than those who were not. Agreement with this item was also higher among those who have been HIV positive longer.

Agreement with the statement *I am happy with the way my body looks* was higher among those who rated their general state of health higher and younger PLWHA. Overall, about half the sample agreed with this item, although only 10% agreed strongly.

At a more general level we asked for responses to statements about the meaning of HIV in their lives. About half the respondents agreed with the statement *As long as I am well, I prefer not to think about HIV/AIDS*. Agreement with this item was not significantly related to uptake of antiretroviral therapy or to compliance with antiretroviral medication.

As one way of assessing the impact that HIV has had on people's lives, we asked participants to respond to the statement *Life has become more meaningful since I became HIV positive*. Around half the sample agreed with this statement.



**Table 25: Attitudes relating to mental health: percentage of total sample**

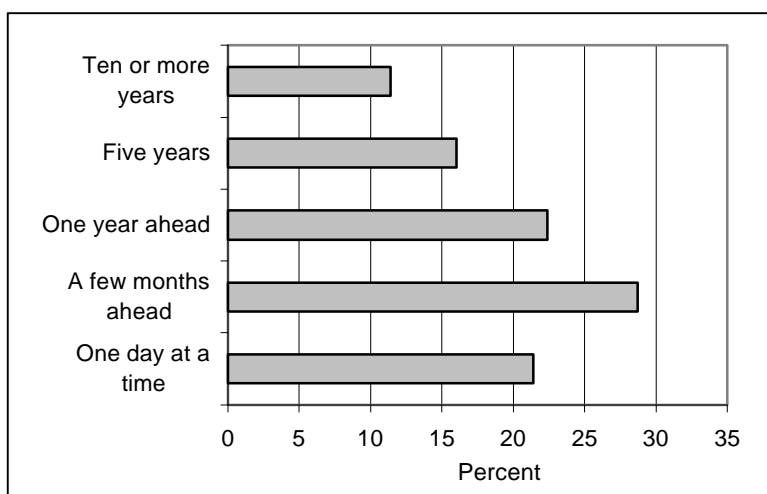
	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
I cry or feel like crying all the time	27.0	50.4	18.1	4.5
I don't enjoy things the way I used to	15.7	32.7	38.2	13.9
I have lost interest in other people	20.6	47.0	25.4	7.0
I don't feel it's worth going on	43.9	41.6	10.5	4.0
As long as I am well I prefer not to think about HIV/AIDS	7.9	41.8	37.6	12.6
Changes in my body due to HIV/AIDS have made me feel unattractive	13.2	35.2	35.1	16.6
I am happy with the way my body looks	10.5	36.3	43.3	9.9
Life has become more meaningful since I became HIV positive	16.4	32.2	34.2	17.2

**Planning for the Future**

One particular interest of this study is the future perspective of PLWHA, that is, when making decisions about their lives, how far into the future do people plan. In the original Futures Survey (1997), we suspected that the introduction of combination antiretroviral therapy would increase the future perspective of HIV positive people. That study found that around half of the respondents had changed their planning time-frame. Of these, slightly less than two thirds were using a longer time frame, mostly as a result of improved health due to antiretroviral drugs. We repeated the questions in this survey, and overall there appears to be a continuation of the trend observed in 1997.

More than one fifth (21.4%) only plan one day at a time and 28.7% plan only a few months ahead. However almost half of the respondents plan for at least a year with 22.4% planning one year ahead, 16.0% planning five years ahead and 11.4% planning ten years or more ahead. Those with longer time frames tend to be those who have been HIV positive for a shorter period, have lower viral load, higher CD4 counts, and have not had an AIDS defining illness.

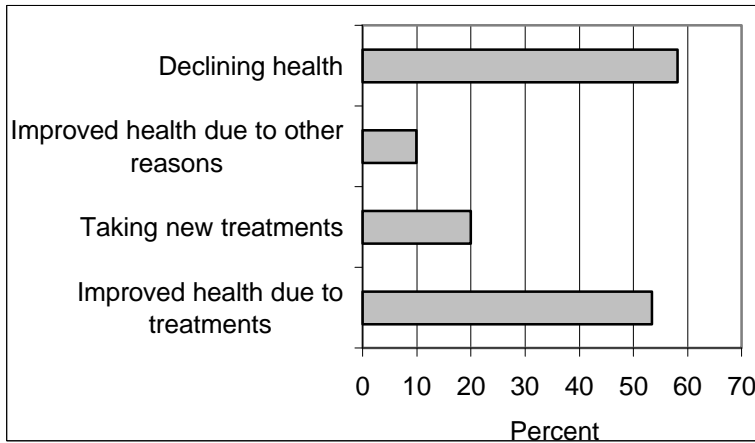
**Figure 15: Time frame for future planning**



For 38.9% of respondents, the time frame for future planning had changed in the last two years. Of those that have changed their time-frame, 28.3% are now using a shorter time-frame and 71.9% are using a longer time frame. Few have made dramatic shifts in their time-frame with most people moving one category in the list given, particularly among those moving to a shorter time-frame.

The major reasons for change for those with a longer time frame were improved health due to treatments (53.4% of those with longer plans), taking new treatments (13.9%) and improved health for other reasons (9.9%). The major reason for change for those with a shorter time frame was declining health (58.2% of those with a shorter time frame). See Figure 16.

**Figure 16: Reasons given for change in time-frame**





## ACCOMMODATION

Approximately one third each of the sample was in rental accommodation (37.3%) or owned their own house or flat (35.1%). One in six (16.0%) PLWHA were in Government rental accommodation, while the remainder lived in housing provided by friends or family (6.4%) or in community housing (3.6%). PLWHA are most likely to live on their own (40.6%) or with a partner/spouse (35.4%). Some lived with friends or a house-mate (17.8%).

Most PLWHA (84.0%) found their accommodation suitable for their current needs. Of those who did not, the most commonly reported problems were that the accommodation was too expensive (38.9%) or too small (34.7%). Around a quarter of respondents also reported that their accommodation did not provide adequate privacy (24.1%) or that it was too far from services (23.4%). When asked if they had ever changed their accommodation as a result of HIV/AIDS, 42.2% said they had. For these PLWHA, the most commonly reported reason was to move to cheaper housing (46.7%) followed by moving closer to health services (34.4%) and moving to a quieter location (32.1%). See Table 26.

**Table 26: Reasons for changing accommodation**

	Percentage of those who had moved
Moved to cheaper housing	46.7
Moved closer to health services	34.4
Moved to a quieter location	32.1
Stopped working	27.9
Planning for illness	25.3
Illness	24.5
Better health	21.0
To avoid harassment	20.1
Moved closer to other services	18.4
Ending of long term relationship	14.2
Moved closer to friends	12.6
Improved finances	9.7
Moved in with family	8.3
Looking for/ returned to work	7.5
Beginning of new relationship	7.1
Moved out of family home	6.9

(Multiple responses possible) N=404



## SEX AND RELATIONSHIPS

### **Summary:**

Over one quarter of PLWHA are not having sex at present. Around half the sample of PLWHA is currently in a regular relationship, and a slightly smaller number have sex within their relationship. A smaller group, comprising mainly gay men, has both a regular relationship and casual partners (18%) and 29% have casual partners only.

Of those in a regular relationship 40.5% have a partner who is also HIV positive, 57.9% have an HIV negative regular partner and 1.6% a partner of unknown status. Nearly all (98.3%) PLWHA have disclosed their status to their regular partner, usually when they were diagnosed or at the time of or prior to the commencement of the relationship. In the majority of cases the partner's reaction to disclosure was positive and in one third of cases it brought the partners closer together, but 27.2% also reported that their partner was worried or scared.

Under half the respondents had anal or vaginal intercourse with a regular partner in the past six months. Condom use with regular partners was strongly related to the HIV-status of the partner.

Condoms always used with regular partners by:

- ▶ 38.5% of women with male HIV positive partners;
- ▶ 58.3% of women with male HIV negative or unknown partners;
- ▶ 16.5% of men with male HIV positive partners;
- ▶ 65.3% of men with male HIV negative or unknown partners;
- ▶ 30% of men with female HIV positive partners;
- ▶ 71.4% of men with female HIV negative or unknown partners.

Fifty-four per cent of the sample had sex with casual partners in the past six months. Almost half (47.9%) of the men reported that they always used condoms with casual male partners and 52.6% with casual female partners.

Information about the most recent episode of sex with a casual partner in the previous six months was provided by over half the sample. Vaginal or anal intercourse took place in 77.2% of these instances.

Condom use with the most recent casual partner:

- ▶ 35.5% with an HIV+ partner;
- ▶ 79.8% with a partner of unknown HIV-status;
- ▶ 85.7% with an HIV negative partner.

There were only 14 instances reported of insertive anal or vaginal intercourse with ejaculation with the most recent casual partner where that partner was of unknown HIV status and only 1 instance with an HIV negative casual partner.

Around half of PLWHA would prefer to be in a relationship with someone who is also HIV positive. Over half of PLWHA expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLWHA (60.5%) felt HIV had a negative effect on their sexual pleasure.

Only 9.3% of PLWHA agreed with the statement I feel more confident about unprotected sex because of the new treatments. Those who agreed were no more likely than others to be on antiretroviral treatment or to be confident about treatments, but they were more likely to have unprotected sex.

Very few PLWHA agreed that new treatments make safe sex less important than it was (5.5%) or that undetectable viral load means HIV is unlikely to be transmitted (5.8%). However, around 30% of PLWHA agreed with the statement If there was a vaccine which prevents HIV I would not practice safe sex.

We have, as in HIV Futures I, asked about the practice and experience of sex among positive people. We have asked about sexual practice, in part, because it is important to continue to affirm that PLWHA have sex, particularly when sectors of society believe this is undesirable. In part this is also because sex is an important part of life for many people, and in order to understand the things that make people who they are, we need to understand the sex they have. We have also asked about sex as it relates to HIV transmission in recognition of the critical role that HIV positive people have in education and prevention. We have asked about the experience of sex, because our previous and current research tells us that being HIV positive can have a profound influence on how people feel about and negotiate their sexual lives and be important for health and well-being. We have asked about the experience of relationships, because we are aware that this too can be profoundly influenced by being HIV positive.



### Relationships

Respondents were asked which types of sexual relationships they currently have. The results are presented in Table 27 below. Overall, about one quarter of the sample either had only casual sex, only a regular relationship or no sex. When this item is broken down by sex and sexuality, we find significantly different patterns between three groups of PLWHA. Heterosexual men were more likely than other PLWHA to report that they had no sex at present. Women were more likely to report that they have one regular sexual partner and no casual sex. Gay and bisexual men are more likely to report that they have a regular sexual partner and also have casual sex.

**Table 27: Type of sexual relationship(s) by gender and sexuality of respondent**

Sexual relationships	Women	Heterosexual men	Homosexual & bisexual men	Total
Casual sex only	6.9	11.1	32.7	28.8
Regular relationship only	46.0	37.3	22.5	25.6
No sex at present	41.4	49.8	21.5	25.5
Regular relationship plus casual sex	5.7	1.9	20.4	17.7
Regular with two or more people	0.0	0.0	3.0	2.5

N varies for sub-groups

When asked if in they were currently in a regular relationship, around half (48.8%) said they were. This is slightly higher than the proportion of the sample that report having sex with a regular partner in Table 27 (45.8%), as some in a regular relationship do not have sex.

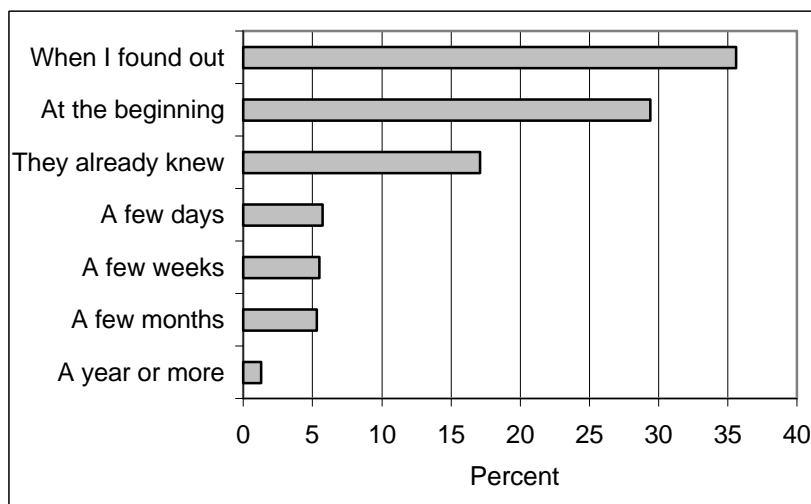
### Regular Partners

Of those in a relationship with a regular partner, 40.5% report that their partner is also HIV positive (generally described as a sero-concordant relationship). The remainder are in sero-nonconcordant relationships. This second group is made up of 57.9% of the sample that report that their partner is HIV negative (a sero-discordant relationship) and 1.6% report that they don't know their partner's HIV status. The proportion who do not know their partner's HIV status is less than half that reported in 1997.

Nearly all PLWHA (98.3%) have told their regular partner that they are HIV positive. Those with HIV positive partners had all disclosed their status to their partner. Of those that had not disclosed their status, three quarters had HIV negative partners, and one quarter did not know their partner's status.

Respondents were asked at what point in the relationship they told their partner. The responses are given in Figure 17 below. Around one third (35.6%) of respondents told their partner when they themselves found out they were positive. Slightly fewer than a third (29.4%) told their partner at the beginning of the relationship and for 17.1% of respondents, the partner knew prior to the start of the relationship. Small numbers of respondents told their partners a few days into the relationship, 5.5% a few weeks into the relationship, 5.3% a few months into the relationship and 1.3% a year or more into the relationship.

**Figure 17: Time HIV status disclosed to partner among those in regular relationships**

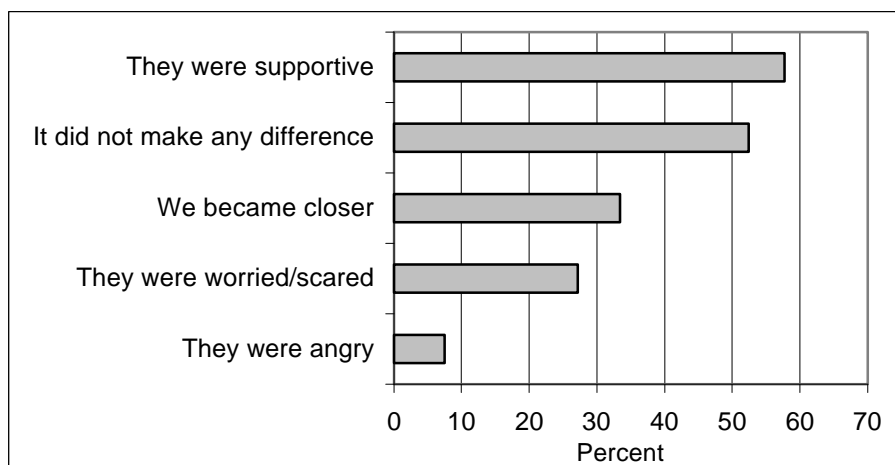


N=438

When asked how their partner responded when told of the respondent's HIV status, the majority (57.7%) reported that the partner was supportive (see Figure 18). Over half (52.4%) also reported that it did not make any difference. One third (33.4%) reported that the disclosure brought them closer together.

Over one quarter (27.2%) reported that their partner was worried or scared and 7.5% said their partner was angry. Those that reported a worried or scared reaction from their partner were more likely to be in sero-nonconcordant relationships (34.1% of those in sero nonconcordant versus 16.9% in sero-concordant). The proportion reporting that their partner was worried or scared (27.2%) is much higher than the 2.0% who reported this in the 1997. In 1997 *worried or scared* as a reaction was not included in the survey as a response item but was written in by respondents.

**Figure 18: Reaction of partner to disclosure: percentage of those in regular relationships**



N=436

In addition, 7.5% reported that their partner was angry upon disclosure. These were more likely to be those in sero-nonconcordant relationships.

PLWHA in regular relationships were asked about the sex they had with their regular partner. Overall, 39.6% had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 3.6% had anal or vaginal sex with a regular female partner in the previous six months. For both male and female partners, about one third of respondents reported that they never used condoms and around 40% reported that they always used condoms (see Table 28). In total, 42.0% had either anal or vaginal sex with a regular male or female partner in the last six months.

**Table 28: Condom use with regular partner by respondent and partner gender**

ALL relationships	Percentage of these that used condom		
	Never	Sometimes	Always
<b>Female respondents<sup>6</sup></b>			
With regular male partner <sup>a</sup>	24.3	24.3	51.4
<b>Male respondents</b>			
With regular male partner <sup>b</sup>	39.2	19.6	41.2
With regular female partner <sup>c</sup>	33.3	12.5	54.2

a: N=41, b: N=331, c: N=32

<sup>6</sup>Only two female respondents reported anal or vaginal intercourse with female partners. For reasons of confidentiality these results are not reported.

If we look at these data in terms of relationship sero-concordance, considerable clarity is given to the patterns of condom use. Unprotected vaginal or anal intercourse is more likely to occur in sero-concordant relationships than in sero-nonconcordant relationships (see Table 29).

**Table 29: Condom use with regular partner by respondents' gender, partner gender, and partner sero-status**

<b>SERO-CONCORDANT</b> Relationships	<b>Percentage of these that used condom</b>		
	Never	Sometimes	Always
<b>Female respondents</b>			
With regular male partner <sup>a</sup>	46.2	15.4	38.5
<b>Male respondents</b>			
With regular male partner <sup>b</sup>	69.4	14.0	16.5
With regular female partner <sup>c</sup>	70.0	0.0	30.0
<b>SERO-NONCONCORDANT</b>			
<b>Relationships</b>			
<b>Female respondents</b>			
With regular male partner <sup>d</sup>	12.5	29.2	58.3
<b>Male respondents</b>			
With regular male partner <sup>e</sup>	9.7	25.0	65.3
With regular female partner <sup>f</sup>	7.1	21.4	71.4

a: N=12, b: N=123, c: N=11, d: N=25, e: N=125, f: N=13

### Casual Partners

Over half (54%) of the sample reported that in the six months prior to completing the survey they had sex with one or more casual partners. When asked the HIV status of their casual partners, 5.4% reported that all of their casual partners were HIV positive, 26.5% reported that some of their casual partners were HIV positive, and 8.5% reported that none of their casual partners were HIV positive. Most (59.6%) respondents who had casual sex reported that they did not know the HIV status of their casual partners.

Respondents were asked about their condom use during anal or vaginal intercourse with casual partners over the previous six months. As can be seen from Table 30 there are considerable variations in condom use when we examine this by sex of respondent and sex of partner.

**Table 30: Condom use with casual partner by respondent and partner gender**

ALL casual partners	Percentage of these that used condom		
	Never	Sometimes	Always
<b>Female respondents<sup>7</sup></b>			
With casual male partners <sup>a</sup>	10.0	0.0	90.0
<b>Male respondents</b>			
With casual male partners <sup>b</sup>	5.9	46.2	47.9
With casual female partners <sup>c</sup>	26.3	21.1	52.6

a: N=10, b: N=414, c: N=22

Again, when we look at these data in terms of the partners' HIV status, a clearer pattern emerges (see Table 31). There is a significant relationship between condom use and partners' HIV status: consistent unprotected anal and vaginal intercourse occurs primarily with HIV positive partners, whereas with HIV negative partners or those of unknown status, condom use is much more likely. It is important to note, however, that one fifth of respondents who only had intercourse with HIV seropositive partners reported that they always used condoms.

**Table 31: Condom use with casual partner by partners' sero-status**

Casual partners' HIV Status	Percentage of these that used condom		
	Never	Sometimes	Always
All HIV positive <sup>a</sup>	40.7	40.7	18.5
Mixture / unsure <sup>b</sup>	4.5	48.0	47.5
All HIV negative <sup>c</sup>	0.0	21.7	78.3

a: N=27, b: N=378, c: N=23

In addition to reporting on their overall patterns of condom use, respondents who had casual sex reported on their most recent sexual encounter with a casual partner. Over half of the survey respondents provided such information. Of these, two thirds of respondents (66.4%) reported that they did not know the HIV status of their most recent casual partner, 20.4% had sex with an HIV positive partner and 13.2% had sex with a HIV negative partner. Respondents who indicated that they knew their partners' HIV status were asked how they knew. Nearly all (95.3%) of these 166 respondents said that their partner told them their status, three said that they knew their partner's status from the type of sex they wanted, two said that a third party told

<sup>7</sup>Only three female respondents reported anal or vaginal intercourse with female partners. For reasons of confidentiality these results are not reported.

them, two said that they could tell from their respondents physical appearance, and one said that they could tell by the bar/venue at which they met.

Of the respondents who had casual sex, 77.2% had vaginal or anal intercourse. Of these respondents 69.6% used a condom and 30.4% did not use a condom. As was found for the overall patterns of condom use, condom use during respondents' most recent sexual encounter was significantly related to the HIV status of the partner. Table 32 below shows that condom use was significantly more likely if the respondent did not know his/her partner's HIV status or if the partner was known to be HIV negative.

**Table 32: Condom use with most recent casual partner by partner sero-status**

Partner status	Condom used	
	Yes	No
HIV Positive <sup>a</sup>	35.5	64.5
Unknown <sup>b</sup>	79.8	20.2
HIV negative <sup>c</sup>	85.7	14.3

a: N=96, b: N=242, c: N=49

Respondents who had vaginal or anal intercourse with their most recent casual partner were also asked about ejaculation. Of the 30.4% who did not use condoms for intercourse with their most recent casual partner, 45.9% reported that their partner ejaculated inside them and 35.9% reported that they ejaculated inside their partner. In other words 64.1% of those not using condoms avoid ejaculating inside their partner, possibly as a strategy to reduce risk. Evidence of withdrawal as a risk reduction strategy is supported by differences according to the HIV status of the partner. Of the 35.9% who report they ejaculate with their partner, less than half (43.5%, n=27) of those who did not use a condom with a positive casual partner ejaculated in that partner, only one person (14.3%) with a negative partner ejaculated in their partner and 28.6% (n=14) of those with a partner of unknown status ejaculated in their partner.

### **HIV, Sex, Relationships and Treatments**

PLWHA were asked to respond to a number of statements about relationships sex and HIV. The results of these items are shown in full in Table 33.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, around half (48.4%) said they would, just over a third (34.4%) said they would not, and the remainder (16.1%) said that they did not know. Those that are currently in sero-concordant relationships were more likely to agree with this statement than either those in sero-non-

concordant relationships or those not in relationships. Gay and bisexual men were more likely to agree with this statement than were women or heterosexual men.

One critical issue for PLWHA is the impact that HIV has on the potential to develop new relationships. Around 60% of respondents agreed with the statement *Few people would want a relationship with someone who has HIV*. This was more pronounced among those PLWHA who were not currently in a regular relationship (63.5% agreement as compared to 54.5% among those in a regular relationship). There is also more agreement with this statement among those with poorer health and, interestingly, less agreement among those currently on antiretroviral therapy.

A similar response was found to the statement *I am afraid of telling potential partners of my HIV status in case they reject me*. Over half the respondents (51.8%) agreed with this statement. Agreement was significantly higher among those not in regular relationships, and among those who have no sex at present. There were also significant gender/sexuality differences on these two items, with women and heterosexual men being more pessimistic about potential relationships.

When asked to respond to the statement *People with HIV now have a better chance to form partnerships and relationships*, just over half agreed, around one third disagreed, and 15% were unsure. Those rating their health as *good* or *excellent* were significantly more likely to agree with the statement, as were those currently in a regular relationship.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (60.5%) agreed with the statement *HIV has had a negative effect on my sexual pleasure*. Over one third (36.4%) disagreed with this statement. There was significantly more agreement with this statement among those who rate their health as *poor* or *fair*. There was no difference on agreement with this item between men and women, or between different sexuality groups.

When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. Almost one quarter were unsure when asked to respond to the statement *If I know that my partner is HIV positive I find sex more pleasurable*. A slightly greater proportion of respondents agreed with this statement (41.7%) than disagreed with it (36.0%). Those that agreed with this statement were also more likely to agree that they would prefer a relationship with someone who was HIV positive, and to agree that HIV has had a negative effect on their sexual pleasure.

**Table 33: Attitudes to HIV, sex and Relationships**

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't know</b>
I prefer to have a relationship with someone who also has HIV	7.5	27.9	30.0	18.4	16.1
Few people would want a relationship with someone who has HIV	4.5	29.9	42.8	16.5	6.3
I am afraid of telling potential partners of my HIV status in case they reject me	10.9	30.0	34.8	17.0	7.3
People with HIV now have a better chance to form partnerships and relationships	9.9	23.4	44.0	7.9	14.9
If I know that my partner is HIV positive I find sex more pleasurable	10.6	25.4	28.7	13.0	22.4
HIV has had a negative effect on my sexual pleasure	11.3	25.1	35.0	25.5	3.1
I am afraid of infecting my partner, or potential partner, with HIV	6.9	20.7	39.9	29.8	2.7
I feel more confident about unprotected sex because of the new treatments	54.3	33.5	5.7	3.6	2.9
New medical treatments for HIV/AIDS make safe sex less important than it was	58.8	30.4	4.0	1.5	5.3
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	54.7	31.4	3.8	2.0	8.0
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	45.7	32.3	13.6	3.7	4.7
If there was a vaccine which prevents HIV, I would not practise safe sex	22.1	29.2	20.2	9.1	19.4



The fear of infecting a partner with HIV is an important issue for those surveyed. Around 70% agreed with the statement *I am afraid of infecting my partner or potential partner with HIV*. There was no difference between those in regular relationships and those not, or between those who have casual sex and those who do not.

Very few respondents (9.3%) agreed with the statement *I feel more confident about unprotected sex because of new treatments*. Most respondents disagreed with the statement, and over half of the sample (54.3%) strongly disagreed. Those who agreed were no more likely to be taking antiretroviral therapy, but were more likely to be having unprotected sex with either regular or casual partners.

Respondents were also asked to respond to the statement *New medical treatments for HIV/AIDS make safe sex less important than it was*. Very few respondents (5.5%) agreed with this statement and few were uncertain (5.3%). Similarly, the statement *Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom* had few who supported it (5.8%) and there were few who were uncertain (8.0%).

Most respondents (78.0%) also disagreed with the statement *Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV*. Those that agreed with this statement were no more likely to have practised withdrawal in their most recent sexual occasion with a casual partner, though they were less likely to have used a condom.

The possibility of a preventative vaccine has raised issues of its potential impact on condom use. Participants were asked if they agreed with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*. There was a high degree of uncertainty in response to this item, with around one fifth saying they were unsure. Just over half the sample disagreed with the statement. Around 30% agreed with this item, but few of these were in the *strongly agree* category. This is clearly an issue that requires careful consideration in any trial or promotion of such a vaccine.

**Children**

As mentioned in the description of the sample earlier in this report, 9.0% of those surveyed currently have dependant children. We were also interested in future plans for children among PLWHA. Most PLWHA (90.7%) were not currently considering having children. Of the remainder, 14 PLWHA have decided to have children in the future and 4 are currently attempting to have children. Thirty-three are currently considering having a child, but have not decided, and 36 people have considered having a child, but have decided it is too risky. One respondent is currently pregnant.

While those who are considering, or have considered having children are primarily women (heterosexual and lesbian), some are gay, bisexual and heterosexual men.

## RECREATIONAL DRUG USE

### Summary

Alcohol is the most commonly used drug by PLWHA, in proportions comparable to the general population. However, tobacco use among respondents is twice that of the general population and other party drugs, such as amyl, ecstasy, non-injected speed and LSD are also used more frequently by PLWHA than by the general population.

More than two thirds of respondents reported that they had never injected illegal drugs and of those respondents who had injected illegal drugs approximately one half had done so in the last 12 months. Of PLWHA who reported injecting drugs, 86.1% had not shared needles in the past twelve months.

Circumstances of needle sharing:

- ▶ 24.7% shared with a sexual partner;
- ▶ 76.2% used the needle last;
- ▶ 48.8% did not have access to other needles;
- ▶ 40.4% washed or bleached the needle;
- ▶ 39.0% the other person was HIV positive;
- ▶ 3.4% in a group.

Only 1.4% of those who shared needles in the last 12 months did so without at least risk reduction strategy by using the needle last or washing/bleaching or using with another person who was HIV positive.

Approximately one fifth of respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and one in twenty reported having had a bad experience as a result of using both illegal drugs and ARV.

### Practices

Respondents were asked about their use of a range of non-prescription drugs, both those legally available and those that are currently prohibited in Australia. The questions were asked in such a way as to allow comparison with the results of the *National Drug Strategy Household Survey* of drug and alcohol use conducted by the Australian Institute of Health and Welfare (AIHW). Respondents were asked which of a list of substances they had used in the last twelve months. For those drugs which are commonly injected, differentiation was made between

injection and other means of administration. Table 34 gives the results of these items and lists the comparable rates for the Australian population from AIHW's 1998 survey (AIHW, 1999).

**Table 34: Use of non-prescription drugs, PLWHA and general population rates<sup>8</sup>**

	Percentage of sample using in last 12 months	General Population rates
Alcohol	82.3	80.7
Marijuana	55.8	17.9
Cigarettes	54.5	26.4
Amyl	39.2	0.8
Ecstasy	22.8	2.4
Speed (not injected)	17.7	3.6 *
LSD/ trips	12.5	3.0
Speed (injected)	10.8	3.6 *
Heroin (injected)	8.1	0.7 *
Cocaine (not injected)	8.0	1.4 *
Methadone (prescribed)	5.8	N/A
Steroids (injected)	5.5	0.2
Cocaine (injected)	3.3	1.4 *
Methadone (other)	1.4	0.2
Heroin (not injected*)	1.1	0.7

\*Rates in the AIHW report do not differentiate between injected and administered through other means. General population rates given are for any use of the substance.

As can be seen from Table 34, while alcohol, the most commonly used drug, is used by a comparable proportion of the PLWHA population to the general population, other recreational drugs are used by considerably greater proportions. As has been much discussed among PLWHA organisations, tobacco use among PLWHA is twice that of the general population. Other drugs that are popular in the gay and dance party scenes (amyl, ecstasy, non-injected speed and LSD) are also used by PLWHA at much higher rates than the general population.

It must be noted that we only asked respondents if they had used each of the drugs in the previous twelve months, not how often they use them. Use of many drugs in the gay scene is

<sup>8</sup>Source: 1998 National Drug Strategy Household Survey AIHW.

occasional rather than regular and this may inflate the rates reported here. The study also deliberately sampled among injecting drug users and this may account for the higher rates of injecting drug use seen here.

Gay men are significantly more likely than other sexuality groups to use speed (not injected), ecstasy and amyl and less likely to use heroin and cocaine. Bisexual men are significantly more likely to use cocaine than others. Gay men and lesbians are more likely to use LSD/trips. Lesbian and bisexual women are more likely to use prescribed methadone. Gay and straight (but not bisexual) men are more likely to use steroids.

When we examine differences in clinical markers among those who do and do not use each of the drugs we find that, for a number of drugs, CD4 levels are higher among users than non users. This is the case for: speed (not injected) (567.1 cells/ml among those who use versus 474.0 among those who do not); ecstasy (562.7 versus 469.1); LSD/trips (603.9 versus 474.6); and amyl (546.1 versus 454.9). There were no significant differences in viral load. This is not to suggest that recreational drugs improve CD4 levels, but is most likely that those in better health are more recreationally active and have greater capacity to take recreational drugs. It is also an effect mediated by sexuality, where gay men have significantly higher usage rates of these drugs, and have significantly higher CD4 counts.

One in twenty (5.7%) PLWHA reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs.

Around one in five PLWHA reported that they had missed a dose of antiretroviral medication at some point as a result of using illegal drugs. This was highest among those that used marijuana, amyl, ecstasy and speed.

Almost three quarters (71.9%) of the sample reported that they had never injected illegal drugs, while 15.7% had done so in the last twelve months and 12.4% had done so more than twelve months ago.

Most (86.1%) of those who inject drugs had not shared needles in the last twelve months. Of the remainder, the circumstances surrounding sharing given by respondents are shown in Table 35.

**Table 35: Circumstance surrounding sharing among those who have shared a needle in the last 12 months**

	Number	Percentage
The person was my sexual partner	6	24.7
I used the needle last	19	76.2
We did not have access to other needles	12	48.8
The person was Hep C positive	11	43.2
The needle was bleached or washed	10	40.4
The person was HIV positive	10	39.0
It was in a group	1	3.4

(Multiple responses possible) N=25

In order to examine the incidence of needle sharing that may risk transmission of HIV, we need to look at those who did not use any of the following risk reduction strategies: that they used the needle last, that the needle was bleached or that the person was HIV positive. When we do this we find that only 1.4% of those who injected in the last twelve months fall into this group (8.0% of those who had shared needles in the last twelve months). When we examine the data in terms of risk of hepatitis C transmission, we find that in all cases at least one of the following risk reduction strategies was used: that they used the needle last, that the needle was bleached or that the person was Hep C positive.

### Attitudes Relating to Drug Use

Almost one fifth (19.7%) of respondents felt that they drank more alcohol than they would like to and 14.0% felt they had used more illegal drugs than they would like to. As specific quantities of drugs used was not asked in this survey, this is not necessarily a measure of substance abuse, but rather gives an indication that there are important areas of health maintenance among PLWHA that need to be addressed.

We asked participants to respond to two items about needle sharing and transmission that were similar to those asked about sex: *I worry about infecting others by sharing needles* and *Sharing needles is not a problem if your viral load is undetectable*. The low number of respondents who have shared needles is reflected in the responses to these items, where most participants chose the *don't know* option. When we look at responses among those who have shared in the last twelve months, most respondents indicated that they were concerned about infecting others through the sharing of needles, and most respondents did not think that undetectable viral load lowered the concern about infection through needle sharing.

**Table 36: Attitudes relating to drug use and infection**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I drink more alcohol than I would like to	29.9	35.0	13.6	6.1	15.4
I use illegal drugs more than I would like to	25.6	29.3	10.1	3.9	31.1
I worry about infecting others by sharing needles	5.0	2.8	4.0	9.5	78.6
I worry about infecting others by sharing needles (% of those who have shared in last 12 months) <sup>a</sup>	3.8	11.5	26.9	38.5	--
Sharing needles is not a problem if your viral load is undetectable	60.5	8.8	0.0	1.7	29.0
Sharing needles is not a problem if your viral load is undetectable (% of those who have shared in last 12 months) <sup>b</sup>	62.5	33.3	4.2	0.0	--

a: N=5, b: N=24





## EMPLOYMENT

### **Summary:**

Slightly less than one half of respondents are currently in paid employment, with one quarter of this number being in full-time work. The majority of the remainder described themselves as either not working or retired.

Most respondents said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis.

Impact of antiretroviral therapy on employment:

- ▶ 15.5% stopped work;
- ▶ 12.4% anticipate a longer time in the workforce;
- ▶ 11.4% are considering going back to work;
- ▶ 6.4% have gone back to work.

Almost two thirds of respondents reported that they have stopped work at some time in the past for reasons relating to having HIV/AIDS. Stress, depression or anxiety were the most commonly cited reasons. Low energy levels were also cited by more than half of respondents followed by poor health.

Of those respondents who had left work, half had returned to work and this was most commonly for financial reasons.

Just under half of those respondents working said that HIV has had an impact on their capacity to perform their work duties. Most commonly respondents reported that they tire more quickly, that they have had to reduce their work hours and that they have difficulty concentrating.

One third of PLWHA had not disclosed their HIV status to anyone at their workplace while an equal number do not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work are gossip, storing and taking medication and explaining absences from work.

### **Employment Status**

Just under half (45.3%) of PLWHA are currently in paid work (26.4% full time, 18.9% part-time). The majority of the remainder described themselves as either not working or retired. Of those that are working, the mean number of hours worked per week is 32.9 (42.2 hours/week among those working full-time and 20.6 hours per week among those working part-time).

**Table 37: Employment status**

	Percentage
Student	3.7
Unemployed	11.5
Not working/ retired	34.5
Home duties	3.1
Working full time	26.4
Working part time	18.9
Other	1.8

Over one third of PLWHA also do volunteer work: 22.3% for an HIV/AIDS organisation; 11.6% for another type of organisation; and 5.4% for both. Volunteer work was more likely among those who were not in paid employment (32.9% versus 21.5% among those employed).

When asked what impact their diagnosis of HIV had on their career plans, nearly half (43.9%) said that they stopped working, or that HIV ended their career, and 15.7% said that they had changed careers. Slightly less than one third (30.1%) reported that they found it more difficult to plan for the future and a similar proportion (28.3%) said that they no longer saw their career as important. Those that had stopped work were also more likely to see their career as less important. Only 17.5% indicated that their HIV diagnosis did not change their career plans, and these were more likely to be those who are currently not in paid employment.

Respondents were asked what impact combination antiretroviral therapy has made on their career plans. Of those who were on antiretroviral therapy, around one third said that there had been no change (see Table 38). For over one third of respondents, there had been no change since their commencement of antiretroviral treatment. Around one in six had stopped work since beginning treatment and 6.0% had returned to work. An additional 11.4% had considered returning to work and 12.4% are anticipating a longer time in the workforce.

**Table 38: Impact of antiretroviral therapy on work**

	Percentage
There has been no change	37.8
Stopped work	15.5
Anticipate longer time in work force	12.4
Considered going back to work	11.4
Went back to work	6.4
Made new career plan	6.4
Considered new career plan	5.7
Considered stopping work	2.7

(Multiple responses possible)

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those who have worked, 59.9% had stopped work for reasons related to HIV at some point. This work interruption averaged for 3 years 8 months (range 1 to 194 months). The circumstances relating to the most recent interruption to employment are given in Table 39 below. The most common response was that psychological health (stress, depression or anxiety) had played an important role in the decision (61.2%). Over one half of the sample also cited diminished energy levels and over one third cited poor health.

**Table 39: Circumstance surrounding last interruption to employment**

	Percentage
Stress/ depression/ anxiety	61.2
Low energy levels	58.2
Poor health	38.7
To have more time to self	24.2
Expecting illness in future	24.0
To move to diff location	16.3
To care for someone with HIV	10.0
Retrenched/ sacked	9.5

(Multiple responses possible) N=550

At the time that participants had most recently stopped working while positive, 18.1% had been diagnosed with an AIDS defining illness, 38.9% had been ill (but not with an AIDS defining

illness) and 43.0% had not been ill. When they were not working, the main source of income for almost three quarters of PLWHA had been a government benefit (73.6%) while smaller numbers relied on superannuation (11.7%), or salary from other sources (11.6%).

Of those that stopped working at some point, 50.0% had returned to work. This was most commonly for financial reasons (see Table 40), although better psychological health, better physical health and the need to perform meaningful tasks were also important. For two fifths of those who returned to work, a shift to part time work was a critical factor.

**Table 40: Reasons for returning to work**

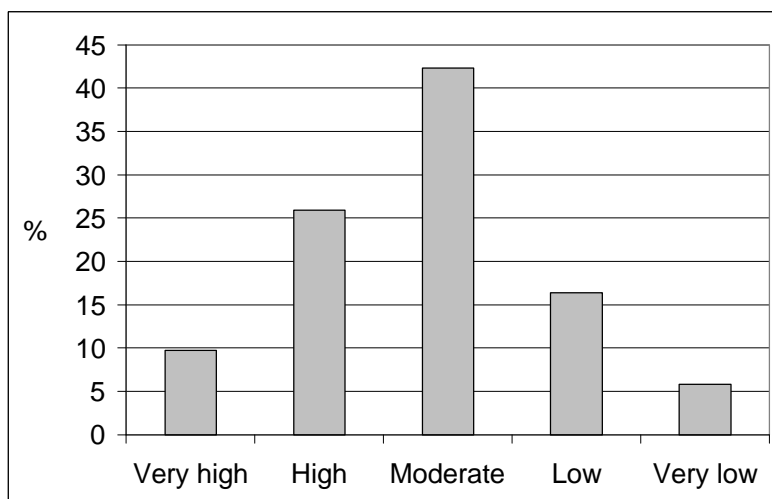
	<b>Percentage</b>
Financial reasons	71.5
Better psychological health	50.6
Better physical health	48.3
To do something worthwhile	45.9
To have something to do	45.2
Possibility of part-time work	40.8
To have more social contact	39.4
Possibility of flexible working hours	29.9
Possibility of full-time work	16.2

(Multiple responses possible) N=271

### **Those Currently in Paid Employment**

Of those currently working, 18.8% do so in an HIV/AIDS related field. Those that work in AIDS related areas tend to rate their HIV status as a more important part of their self concept than those that do not.

Respondents were asked about the level of stress in their current job. Most rated the stress level as moderate (42.3%) while an additional 25.9% said it was high and 9.7% said it was very high. Only 5.8% rated the stress level as very low and 16.4% said there was low stress (see Figure 19). Those working in a HIV/AIDS related area had higher stress levels as did those earning more money and those living in urban areas. Work stress was not related to the length of time people had been HIV positive, nor to their self rating of health or whether they have had an AIDS defining illness.

**Figure 19: Stress at work**

One workplace issue for many HIV positive people is confidentiality around their HIV status, particularly given the proportion that experience HIV discrimination (discussed below). When asked what difficulties they experience around confidentiality at work, around one third said that they do not attempt to keep their status confidential (see Table 41). Just fewer than three quarters said they have experienced no problem in this area (both those who disclose and those who do not). Of those that do experience difficulties, the greatest problem appears to be gossip, followed by issues around medication and explaining absences from work. When we examine the difficulties associated with confidentiality in terms of whether the respondent works in a HIV related job, we find that those in HIV related employment are less likely to wish to keep their status confidential and have fewer problems when they do chose to do so.

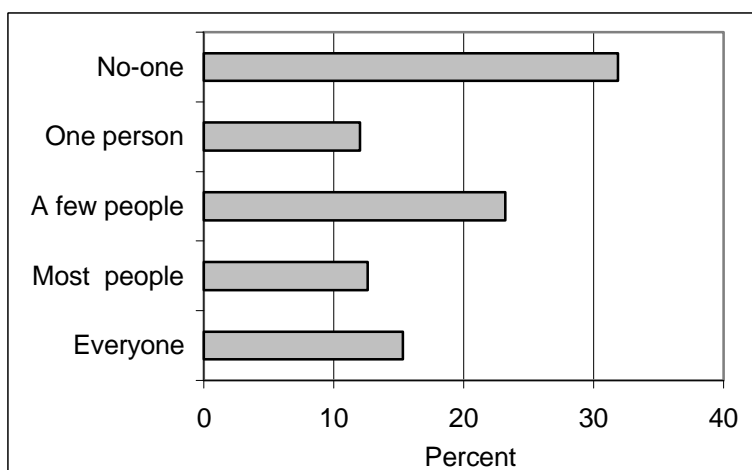
**Table 41: Difficulties with HIV status confidentiality in the workplace: percentages of total and specific samples.**

	Total sample	Those not working in HIV related job	Those working in HIV related job
I do not try to keep my status confidential	33.1	25.1	66.7
No problems	73.8	59.1	29.6
Gossip	17.2	14.1	9.8
Difficulty keeping and taking medication	13.6	10.6	4.9
Explaining absences from work	11.8	10.1	1.2
Visible signs of illness	7.8	7.2	0.0

(Multiple responses possible)

When asked how many people in their workplace knew that they were HIV positive, 15.3% said that everyone knew, 12.6% said most people knew, 23.2% said a few people knew, 12.0% said one person knew and 31.9% said no-one knew (see Figure 20). Those that had not disclosed to anyone in the workplace were more likely to rate their general state of health as good or excellent and to have been HIV positive for a shorter period.

**Figure 20: Disclosure in workplace**



When asked about the impact that HIV has on their capacity to perform their work duties, around half of the sample said that their work was unaffected (see Table 42). Over one third said that they tire more quickly, and a substantial proportion said that they have difficulty concentrating and that they have reduced their work hours. Those that note no impact on their capacity to work tend to be those who rate their general state of health higher, and who are not using antiretroviral medication.

**Table 42: Impact of HIV on work capacity**

	<b>Percentage</b>
Not affected by HIV	51.8
I tire more quickly	38.3
I work reduced hours	17.4
I have difficulty concentrating	15.2
I cannot always go to work	8.9
I am less productive	8.5
I do different duties	3.9

(Multiple responses possible) N=428

Managing HIV infection requires a degree of flexibility in the workplace to attend medical appointments, to manage changes in treatment, side effects of treatments, illness and the psychological impact of HIV. Respondents were asked how much flexibility their workplace gives them to take time off for reasons relating to HIV. Most PLWHA had the capacity to take time off for medical appointments (see Table 43) and illness. There was less capacity to take time off for counselling and few had a large capacity to take time off to engage in volunteer work.

**Table 43: Capacity within workplace for HIV related interruptions**

	Never	Seldom	Sometimes	Often	Always
For medical appointments	5.0	0.9	15.7	1.8	62.8
For counselling	15.2	4.6	12.0	5.4	32.4
When you are sick	3.6	1.7	9.8	9.2	66.5
To do volunteer work	30.4	3.8	9.7	2.8	16.8

Those in HIV related employment had a greater capacity than other respondents to take time off work for each of the circumstances listed.

Respondents were asked if they had ever received less favourable treatment at work as a result of their HIV status. One fifth (20.8%) had experienced this form of discrimination. Those that had were more likely to have been HIV positive for longer (9.4 years as compared to 8.5 years for those who had not), and were more likely to have had an AIDS defining illness.

#### **Anticipated Changes in Work Life for Those Working and Those Not Working**

Respondents were asked if they currently had plans to change their work arrangements, and 42.0% said they did. Of these, around half said they planned to start or return to work and almost as many said they wanted to change the type of work that they do (see Table 44).

**Table 44: Plans for changes to work life and anticipated difficulty**

	Percentage	Difficulty		
		Not at all	Somewhat	Very
I want to start/ return to work	50.7	7.1	53.1	39.8
I want to change the type of work I do	46.7	11.5	58.2	30.2
I want to reduce my work hours	20.0	12.8	66.7	20.5
I want to increase my work hours	14.8	11.9	59.3	28.8
I want to stop work	4.2	31.3	56.3	12.5
Total		11.6	55.7	32.7

The main incentive for changes in work arrangements were financial (see Table 45). Among those that intended start or return to work, the primary motivations were financial or for social reasons and among those planning to stop work, the principle motivations were stress reduction, better psychological health and worse physical health.

**Table 45: Reasons for changes to work plans among full sample, those intending to return to work and those intending to stop work**

	Total	Return to work <sup>a</sup>	Stop work <sup>b</sup>
Financial reasons	65.8	82.2	23.5
Better psychological health	48.5	57.9	35.3
To do something worthwhile	46.8	58.4	12.5
To have more social contact	44.2	60.4	17.6
To reduce stress	39.4	27.4	81.3
Better physical health	35.1	38.1	35.3
To have something to do	34.9	52.3	0.0
Possibility of working part-time	34.3	47.2	23.5
Possibility of flexible work hours	26.9	28.9	5.9
Possibility of working full-time	12.9	15.7	-
Worse psychological health	2.8	0.5	31.3
Worse physical health	2.4	0.5	6.3
To have less social contact	2.1	0.0	25.0

(Multiple responses possible) a: N=197, b: N=17

Respondents were asked how they spent their time while not working. Each respondent indicated the three activities that occupied most of their time. Over half indicated that leisure



activities (for example reading) occupied their time. Slightly fewer (45.5%) identified housework and over a third said they spent their time resting or socialising.

**Table 46: Activities pursued while not working: percentage of total sample**

	<b>Percentage</b>
Leisure activities	54.8
Housework	45.5
Resting	38.1
Socialising with close friends	34.5
Volunteer work in HIV/AIDS organisation	9.6
Socialising with other friends	7.1
Socialising with HIV positive friends	6.8
Volunteer work in other organisation	5.8
Looking after children	4.4
Study	3.0
Looking after another HIV positive person	2.2
Exercise	1.4

(Up to three responses per participant possible, % of total sample)



## FINANCES

### **Summary:**

More than one half of respondents identified their main source of income as a government benefit or pension. As well, more than one half of PLWHA reported experiencing some difficulty with meeting the cost of daily living.

Difficulty with meeting the cost of daily living:

- ▶ 54.4% difficulty paying for food;
- ▶ 56.8% difficulty paying for housing;
- ▶ 51.0% difficulty paying for transport;
- ▶ 43.9% difficulty paying for medical services.

Almost one third of PLWHA are living below the poverty line. Just over one quarter of respondents have a partner with whom they share financial resources and this protects some from extreme economic hardship. Very few respondents who are earning an income from paid employment reported incomes below the poverty line whereas over one half of those on government benefits are living in poverty.

Women are significantly more likely than men to fall below the poverty line despite being no less likely to be in paid employment. However, women were more likely to have dependent children as well as a lower average income and this may help explain this discrepancy.

PLWHA who have been HIV positive for longer are also more likely to fall below the poverty line as are those who have had an AIDS defining illness.

Less than one quarter of respondents reported that they currently own their own home. A small number are in the process of paying off their own home but the vast majority is in rental or other forms of accommodation.

### **Income**

The 1997 HIV Futures study showed that many PLWHA were suffering financial hardship, particularly those receiving a government benefit. Respondents were once again asked the source of their income and these data are presented in Table 47. Over half of PLWHA identified their main source of income as a benefit or pension, while just over one third were receiving a salary. This latter figure includes those in full time work and some of those in part time work as described in the previous section.

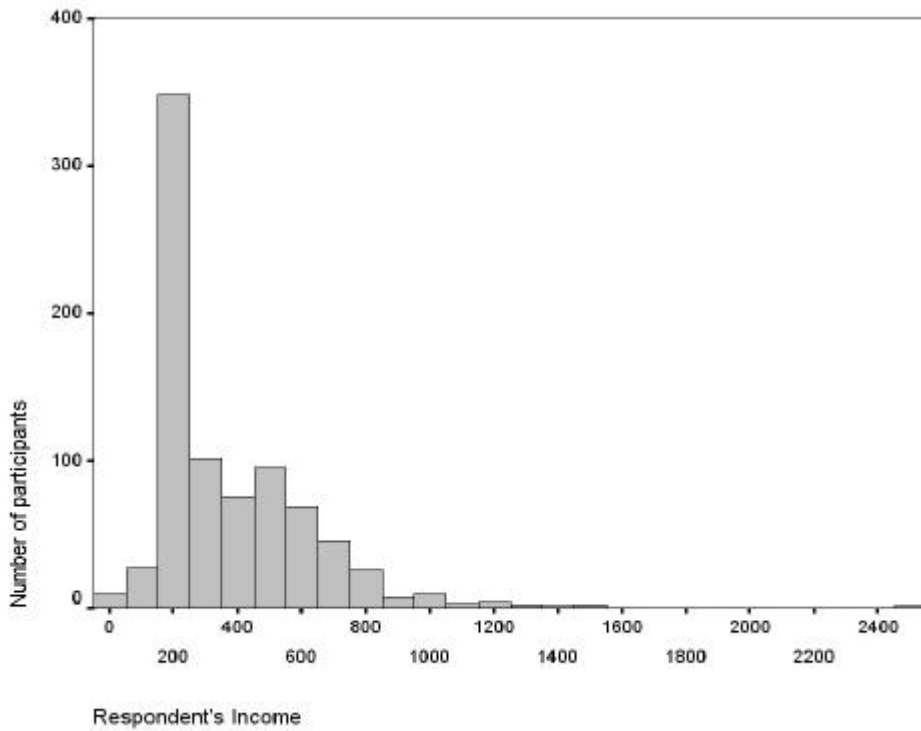
**Table 47: Primary source of income: percentage of total sample**

Source of income	Percentage
Benefits/ Pension/ Social security	52.9
Salary	37.5
Superannuation	7.3
Partner supports me	1.4
Other	0.5
Family/friend support me	0.4

Respondents were asked their weekly after-tax income, responses ranged from \$0 to \$2500 with a mean of \$364.90. Figure 21 shows the distribution of after-tax weekly incomes in blocks of \$100. As can be seen from this figure, most PLWHA have an income well below the mean. The peak of the distribution at \$150-\$250 largely represents those receiving a government benefit.

Women have significantly lower incomes than men in this population (mean weekly after-tax income of \$276.75 compared to \$373.75 for men). Those that have been HIV positive for longer were also more likely to report lower incomes and more likely to report a government benefit as their primary source of income.

Figure 21: Histogram of income



Just over a quarter of respondents (25.4%) had a partner with whom they share financial resources. For these people, their partner’s average weekly after-tax income was \$431.09. Partners’ incomes are shown in Figure 22. Partners who were also HIV positive had a lower average income than those that were HIV negative (mean weekly income after-tax of \$378.24 versus \$494.14)

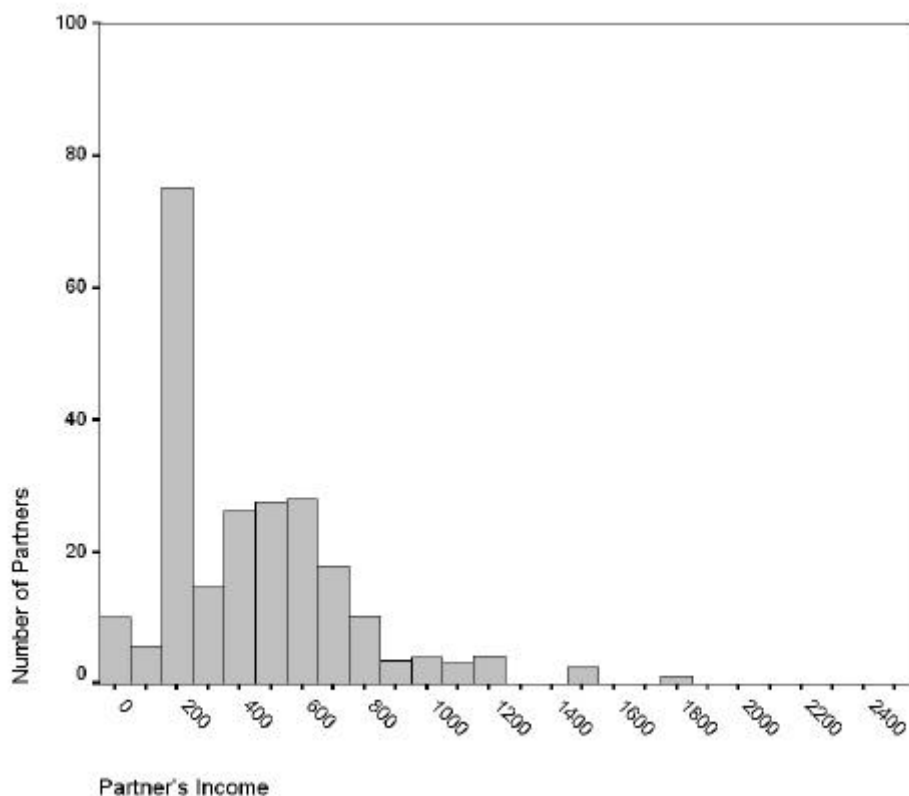


Figure 22: Histogram of partner's income

**Poverty**

As with the 1997 survey, we have used the quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR) to assess the extent of poverty among PLWHA. The Henderson Poverty lines are set for specific *income units*. These units include the individual, any partner with whom they share financial resources and any dependant children. We used the IAESR (1999) data for the September quarter (the time at which the survey was completed). As with the 1997 survey, according to this measure almost one third (30.0%) of PLWHA were living below the poverty line.

Those in paid employment were significantly less likely to be classified as below the poverty line. Half of those not in paid employment were living in poverty. See Table 48.

**Table 48: Poverty by employment status**

	<b>Below poverty line</b>	<b>Above poverty line</b>
In paid employment	8.5	91.5
Not in paid employment	50.0	50.0

Respondents who identified a salary as their primary source of income were significantly less likely to report an income below the poverty line. Over half of those on a government benefit were living in poverty. See Table 49.

**Table 49: Poverty by income source**

	<b>Below poverty line</b>	<b>Above poverty line</b>
Income from salary	3.3	96.7
Income from government benefit	55.0	45.0

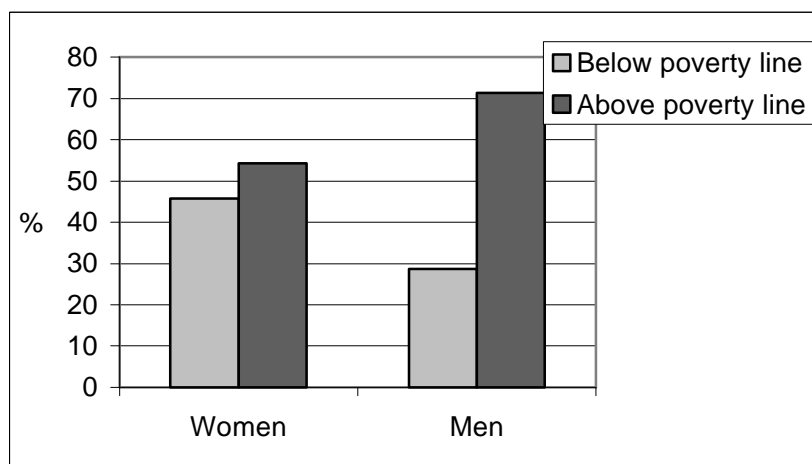
Not surprisingly, those that shared financial resources with a partner were significantly less likely to be below the poverty line than those that did not. The 7.5% of those with a partner with whom they shared financial resources, but who fell below the poverty line, were most likely to have an HIV positive partner. See Table 50.

**Table 50: Poverty by shared income status**

	<b>Below poverty line</b>	<b>Above poverty line</b>
Shared financial resources	7.5	92.5
Sole income	39.2	60.8

In contrast to the 1997 survey, where no gender difference in the proportions of people living below the poverty line was found, this survey has found that women were significantly more likely to fall below the poverty line (45.7% of women versus 28.7% of men – see Figure 23). This was despite the fact that women were no less likely to be in paid employment. Women were, however, more likely to have dependant children and this, in combination with the lower average income reported above, may go some way to explaining the difference. Over two thirds of men (71.3%) and slightly more than half of the women (54.3%) were above the poverty line

Figure 23: Poverty by gender



Those who have been HIV positive for longer are more likely to fall below the poverty line, as are those that have had an AIDS defining illness. This is in part explained by the fact that those who have been positive for a longer period are less likely to be in paid employment and have a lower mean income. Poverty, however, is not related to uptake or discontinuation of antiretroviral therapy, although it is related to the use of complementary therapies, with those below the poverty line less likely to use these options.

Around one fifth (19.3%) of PLWHA currently have private health insurance. Those below the poverty line are, significantly less likely to have private health insurance (7.6% versus 25.7%). Women are no less likely than men to have private health insurance.

Less than one quarter (22.4%) of PLWHA currently own their own home, while an additional 15.6% are in the process of paying off their home. The majority (61.1%) are in rental or other forms of accommodation.

Respondents, on average pay \$100.27 per week toward rental or mortgage. The weekly costs of medication for PLWHA average at \$6.99 for antiretroviral drugs, \$10.05 for complementary therapies and \$8.95 for other medications, such as those used to treat side effects.

### Costs

Participants were asked how much difficulty they had in meeting the costs of various items and activities. These ranged from the basics of life like food, clothing, housing and medication, to those things that improve well-being, health and quality of life. The results are given in Table 51, ordered from those items most likely to be found *very difficult* to afford to those least likely.



Quality of life items are the most difficult for PLWHA to afford, with less than one third finding it easy to pay for travel, socialising, recreational drugs and entertainment. One third of respondents have a lot of difficulty paying for clothing and a further third have some difficulty. Among those with children, two thirds have at least some difficulty paying for child care.

Disturbingly, almost one quarter experience considerable difficulty paying for utilities (gas, electricity and water) and over half the sample experience at least some difficulty with the cost of food, housing, transport and medical services.

**Table 51: Difficulty paying costs of items and services**

	<b>Very Difficult</b>	<b>A little difficult</b>	<b>Not at all Difficult</b>
Travel/ Holidays	54.0	36.2	19.8
Going out	39.3	32.7	28.0
Recreational drugs	39.2	30.4	30.4
Entertainment	35.3	34.2	30.5
Clothing	32.7	36.1	31.2
Sport	28.0	30.8	41.2
Child care	25.7	31.6	42.7
Utilities	23.4	42.5	34.1
Complementary therapies	22.5	34.7	42.8
Medical services	16.9	27.0	56.1
Rent/ Mortgage	16.3	40.5	43.1
Transport	13.4	37.6	49.0
Food	13.2	41.2	45.6
Support services	10.6	19.7	69.8
Other prescribed medication	9.2	34.7	56.1
Co-payments for medication for HIV/AIDS	6.3	31.4	62.3

Those who are below the poverty line are significantly more likely to have difficulty paying for all of these items except support services and child care (see Table 52). Of particular concern is the large proportion of PLWHA below the poverty line that have great difficulty paying for basics like food, utilities and medication.

Women were significantly more likely than men to report difficulty paying for medical services, co-payments for HIV/AIDS medication, other prescribed medication, complementary therapies, support services, transport and entertainment.

**Table 52: Difficulty paying costs of items and services by poverty**

	<b>Below poverty line</b>			<b>Above poverty line</b>		
	Very Difficult	A little difficult	Not at all difficult	Very Difficult	A little difficult	Not at all difficult
Travel/ Holidays	82.0	12.1	5.8	43.6	31.0	25.3
Going out	65.4	26.3	8.3	27.4	34.7	38.0
Recreational drugs	61.6	25.9	12.5	30.9	31.2	37.9
Entertainment	60.3	28.6	11.2	24.4	35.8	39.8
Clothing	51.7	35.7	12.6	25.7	34.5	39.8
Sport	54.1	27.4	18.5	18.9	28.2	52.9
Child care	27.3	45.5	27.3	22.9	28.6	48.6
Utilities	40.2	46.5	13.3	16.2	39.1	44.7
Complementary therapies	33.1	34.6	32.4	18.8	33.3	47.9
Medical services	32.4	20.1	47.5	10.9	27.4	61.6
Rent/ Mortgage	29.1	37.1	33.8	11.5	40.3	48.2
Transport	24.6	50.0	25.4	8.9	32.1	59.0
Food	27.5	48.8	23.8	7.3	36.1	56.6
Support services	11.9	17.8	70.3	9.8	20.1	70.1
Other prescribed medication	17.2	44.5	38.3	5.2	28.4	66.5
Co-payments for medication for HIV/AIDS	10.7	41.5	47.8	4.2	24.8	71.0

### Poverty and Services

Given the relationship between poverty, income, employment and the difficulty in paying for basic needs, it is not surprising that those experiencing poverty differ in the services they access. If we examine the difference between those below and those above the poverty line in terms of the use of services offered by AIDS Councils (see *Service* section page 47), we find that those living in poverty are more likely to access all services except informal peer support, employment services, return to work skills and drug and alcohol treatment. Table 53 shows the differing utilisation of these services for those living below and above the poverty line.

**Table 53: Services used at HIV/AIDS organisations by those above and below the poverty line**

	Below poverty line	Above poverty line
Treatments advice	51.4	41.4
Social contact with other PLWHA	47.8	34.9
Peer support group	42.7	25.7
Financial assistance	40.2	16.4
Counselling	38.6	27.9
Alternative therapies	31.3	19.4
Pharmacy services	26.8	14.5
Legal advice	24.0	16.5
Housing assistance	23.2	10.8
Financial advice	18.6	10.9
Library	14.6	8.6
Internet access	13.4	7.2
Mental health services	12.2	6.5
Respite care	11.8	5.8

(Multiple responses possible)

Those below the poverty line are also more likely to use the following services at other organisations: financial assistance, respite care, housing assistance, mental health services, employment services and drug and alcohol treatment (see Table 54).

**Table 54: Services used at other organisations by those above and below the poverty line**

	<b>Below poverty line</b>	<b>Above poverty line</b>
Financial assistance	19.5	9.9
Respite care	13.8	4.6
Housing assistance	29.7	16.8
Mental health services	23.2	12.3
Employment services	17.4	10.2
Drug and alcohol services	14.2	7.9

(Multiple responses possible)



## **CONCLUDING COMMENTS**

This report attests to the increasing complexity of both disease management and social life for people living with HIV/AIDS in Australia. Nearly all PLWHA monitor their health intensively. Many are on complex antiretroviral regimens and many of those not currently on antiretrovirals have been on them in the past or are monitoring their health indicators with a view to commencing treatment should it seem warranted.

For almost all PLWHA, whether on antiretrovirals or not, HIV impinges on their daily life in the form of the effects of HIV disease. For those on antiretrovirals and other medications, side effects of medication bring with them substantial additional burdens. As well as health management, life requires the management of daily routine including drug taking regimens.

There is some evidence in this report that for many PLWHA it is important to find ways of defining life outside their HIV-status. Here, too, there are many complexities. In the cases of both work and sexual life, for example, there are balances to be sought between the advantages of moving in a world dominated by HIV in terms of greater acceptance and the disadvantages in terms of greater stress and anxiety.

This report has also shown the extent to which poverty and needs across a range of social and health services are key barriers to the well-being of a sizeable group of PLWHA. There appears to be an emerging dichotomy between those PLWHA who have good personal access to resources and support and those who are dependent on inadequate government and community resources. Rectifying these divisions before they are further entrenched would seem to be an urgent task for social policy in the HIV/AIDS field.

This report is designed to provide data concerning the health, social, sexual, and economic lives of PLWHA as a whole in Australia. As a general report it must necessarily neglect some of the differences between different groups of PLWHA. In order to pay appropriate attention to these differences the Living with HIV program at La Trobe University will, in coming months, be producing a further series of reports drawn from the HIV Futures II survey. Reports on the following populations are currently planned: women, heterosexual men, people with haemophilia, injecting and other drug users, and report state by state. As well as reports, the program will be conducting more detailed analysis designed for formal academic publication across emerging issues, including: the nature of community and identity, sexual practice and its relation to treatments, social correlates of treatment success/failure, and predictors and correlates of treatment adherence.

As ever, the capacity of the Program to continue this work depends in equal measure on our funders and on the continuing willingness of Australian men and women living with HIV/AIDS to share details of their lives with us. In both cases we trust that we can repay the support by producing both facts and insights that contribute to making a genuine improvement in the quality of life with HIV.



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## LIST OF TABLES AND FIGURES

### Tables

1: Respondents' reported mode of transmission.....	15
2: State or Territory of respondents' residence .....	15
3: Results of most recent serological tests, percentage of total sample.....	19
4: Attitudes to health management: percentage of total sample .....	22
5: Antiretroviral drugs used by respondents: percentage of total sample.....	25
6: Attitudes to medication: percentage of those using ARV.....	28
7: Results of most recent serological tests: percentage of those on ARV .....	31
8: Circumstances surrounding commencement of treatment among those on combination ARV.....	31
9: Correlates of number of remaining combinations for those on ARV .....	33
10: Difficulties experienced by those currently on ARV and those who have stopped ARV treatment. ....	34
11: Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used antiretroviral drugs.....	36
12: Attitudes to antiretroviral drugs: percentage of total sample .....	39
13: Attitudes to complementary therapies: percentage of total sample.....	42
14: Physician used for general and HIV related treatment: percentage of total sample .....	46
15: Difficulty in obtaining antiretroviral drugs .....	47
16: Services used at HIV/AIDS organisations and at other organisations.....	49
17: Sources of information about treatments and living with HIV.....	52
18: Publications read by PLWHA .....	54
19: Other HIV positive persons known by respondent.....	56
20: People the respondent has disclosed their HIV status to .....	57
21: Importance of personal characteristics to respondents' sense of identity.....	58
22: Importance of HIV status to sense of identity for different groups of PLWHA.....	59
23: Importance of personal characteristics to sense of identity for different groups of PLWHA.....	59
24: Social support received from different sources: percentage of total sample.....	60
25: Attitudes relating to mental health: percentage of total sample.....	63
26: Reasons for changing accommodation.....	67
27: Type of sexual relationship(s) by gender and sexuality of respondent.....	71
28: Condom use with regular partner by respondent and partner gender .....	73
29: Condom use with regular partner by respondents' gender, partner gender, and partner sero-status.....	74
30: Condom use with casual partner by respondent and partner gender.....	75

31: Condom use with casual partner by partners' sero-status .....	75
32: Condom use with most recent casual partner by partner sero-status .....	76
33: Attitudes to HIV, sex and Relationships .....	78
34: Use of non-prescription drugs, PLWHA and general population rates .....	82
35: Circumstance surrounding sharing among those who have shared a needle in the last 12 months .....	84
36: Attitudes relating to drug use and infection .....	85
37: Employment status .....	88
38: Impact of antiretroviral therapy on work .....	89
39: Circumstance surrounding last interruption to employment .....	89
40: Reasons for returning to work .....	90
41: Difficulties with HIV status confidentiality in the workplace: percentages of total and specific samples. ....	91
42: Impact of HIV on work capacity .....	92
43: Capacity within workplace for HIV related interruptions.....	93
44: Plans for changes to work life and anticipated difficulty .....	94
45: Reasons for changes to work plans among full sample, those intending to return to work and those intending to stop work.....	94
46: Activities pursued while not working: percentage of total sample .....	95
47: Primary source of income: percentage of total sample.....	98
48: Poverty by employment status .....	101
49: Poverty by income source .....	101
50: Poverty by shared income status.....	101
51: Difficulty paying costs of items and services .....	103
52: Difficulty paying costs of items and services by poverty .....	105
53: Services used at HIV/AIDS organisations by those above and below the poverty line	106
54: Services used at other organisations by those above and below the poverty line .....	107

## Figures

1: Respondents' self ratings of general health status.....	20
2: Difficulties of taking ARV .....	27
3: Viral loads for those taking and not taking antiretroviral therapy.....	29
4: Effect of commencing antiretroviral medication on health .....	30
5: Circumstance surrounding most recent change in combination among those currently on combination ARV .....	32
6: General health status for those with different numbers of combinations of ARV remaining: percentage of those on ARV .....	33

7: Reasons for discontinuing combination ARV: percentage of those not currently on ARV.....	35
8: Respondents' and respondent's social networks' response to the statement Antiretroviral drugs mean better prospects for most people. ....	38
9: Uptake of antiretroviral drugs .....	40
10: Most commonly used complementary therapies .....	41
11: Number of prescription pick-up points.....	47
12: Services used in the last six months.....	48
13: Problems experienced due to lack of information.....	53
14: Time spent with other positive people.....	55
15: Time frame for future planning .....	64
16: Reasons given for change in time-frame .....	65
17: Time HIV status disclosed to partner among those in regular relationships .....	72
18: Reaction of partner to disclosure: percentage of those in regular relationships.....	73
19: Stress at work .....	91
20: Disclosure in workplace.....	92
21: Histogram of income .....	99
22: Histogram of partner's income.....	100
23: Poverty by gender.....	102