

HIV FUTURES NEW ZEALAND

Mate āraikore a muri ake nei

It's your story

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In collaboration with the New Zealand AIDS Foundation, Body Positive, Positive Women
and Refugee Health Education Programme



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CONTENTS

ACRONYMS USED IN THIS REPORT	i
ACKNOWLEDGMENTS	iii
EXECUTIVE SUMMARY	v
INTRODUCTION	ix
INSTRUMENT AND METHOD	xi
Sample Demographics	xvi
Further Analysis.....	xviii
SECTION 1: Data set without refugees' responses	xix
HEALTH	1
Health Status	1
HIV Antibody Testing	1
Pre- and Post-Test counselling.....	3
CD4 and Viral Load.....	3
Experience of Health and General Well Being.....	4
AIDS Defining Illnesses.....	6
HIV/AIDS Related Conditions	6
Other health conditions	7
Hepatitis	7
Hepatitis A.....	8
Hepatitis B.....	8
Hepatitis C	8
Other Health Monitoring	8
Health Maintenance	9
Prophylaxis.....	9
Attitudes to Health Management.....	9
Antiretroviral Therapy	11
Use of Antiretroviral Therapy	11
Those Currently Using ARV (mono-therapy and combination therapy)	12
Difficulties of Taking ARV	14
Attitudes to ARV	14
Health Status of Those Using ARV	15
Those on Combination Therapy	17
Different Combinations	18
Those Not Currently Taking ARV	20
Difficulties of Taking ARV	20
Health Status of Those Not Using ARV	21
Those Who Have Never Used Antiretroviral Drugs	21

Attitudes to Antiretroviral Therapy.....	21
Treatment Decision Making.....	22
Relationship with Treating Doctor.....	22
Treatment Optimism.....	22
Treatment Breaks.....	25
Most Recent Treatment Break.....	25
Antiretroviral resistance.....	28
Clinical Trials.....	29
Vaccines.....	29
Complementary Therapies.....	30
Other Medication.....	32
Dosing and Compliance.....	32
Prescriptions.....	32
SERVICES.....	35
Health Services.....	35
Treatment.....	35
Services Used in the Last Six Months.....	36
Other Services.....	37
Information.....	39
Sources.....	39
Information about Treatments.....	40
Information about HIV Management.....	41
Information on Living with HIV.....	41
Lack of information.....	42
Publications.....	43
Involvement with AIDS Organisations.....	45
WELL-BEING.....	47
The Social World of PLWHA.....	47
Contact with Other PLWHA.....	48
Disclosure.....	49
Specific Sub-Groups.....	49
Unwanted Disclosure.....	50
The Place of HIV in People's Lives.....	50
Social Support.....	52
Mental Health.....	54
Psychiatric Medications.....	54
Symptoms of Depression.....	54
Attitudes to HIV status.....	55
Planning for the Future.....	57

Relationships and Sex.....	59
Relationships.....	59
Regular Partners	60
Casual Partners	62
HIV, Sex, Relationships and Treatments	65
HIV disclosure and legal issues	68
Children	69
Recreational Drug Use	71
Practices.....	71
Attitudes Relating to Drug Use.....	72
Accommodation.....	73
Employment.....	77
Employment Status	77
Impact of HIV and Treatment on Employment.....	78
Interruptions to Employment	78
Those Currently in Paid Employment	80
Anticipated Changes in Work Life for Those Working and Those Not Working	82
Leisure.....	83
Finances	85
Income.....	85
Expenditure and Debts.....	86
Assessments of Benefits.....	87
Poverty	87
Correlates of Poverty	88
Costs	88
Poverty and Services	91
Discrimination	93
Accommodation	93
Health Services	93
Insurance.....	94
CONCLUDING COMMENTS.....	95
SECTION 2: Refugees	97
Health.....	97
Services	99
Well-Being	101
Concluding Comments	104
REFERENCES	105
LIST OF TABLES AND FIGURES.....	107
Tables.....	107

Figures	110
INDEX	111

ACRONYMS USED IN THIS REPORT

AEG	AIDS Epidemiology Group
AIDS	Acquired Immune Deficiency Syndrome
ARCSHS	Australian Research Centre in Sex, Health and Society
ARV	Antiretroviral therapy
ASHM	Australasian Society for HIV Medicine
CTTAC	Clinical Trials and Treatments Advisory Committee
HIV	Human Immune-deficiency Virus
MAC	Microbacterium Avium Complex
NZAF	New Zealand AIDS Foundation
PLWHA	People living with HIV/AIDS
RHEP	Refugee Health Education Programme

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226 people living with HIV / AIDS completed the HIV Futures New Zealand survey. We are grateful for their interest in this research project, and thank them for their willingness to participate.

This project was conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) of La Trobe University, Melbourne, in partnership with the New Zealand AIDS Foundation (NZAF), Body Positive (NZ), Positive Women and the Refugee Health Education Programme.

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EXECUTIVE SUMMARY

Background

The HIV Futures New Zealand Survey is the **first** large-scale, comprehensive examination of the health and social experiences of HIV positive New Zealanders. 226 HIV positive men and women from completed the HIV Futures New Zealand Survey across the country. This represents **24.8% of the New Zealand HIV positive population**.

Key Findings

Health:

- Most PLWHA are engaged in regular health monitoring including CD4 testing and HIV viral load testing
- One third of PLWHA currently have both an undetectable viral load and a high CD4 count indicating successful viral suppression and a good immune response
- 45% of respondents rate their current health as *good* and 31% as *excellent*
- 44% of respondents rate their current well-being as *good* and 29% as *excellent*
- 28% currently have a major health condition other than HIV/AIDS

Treatments:

- 64% are currently using antiretroviral (ARV) therapy
- 13% have never used ARV
- Side-effects are experienced by 44% of those on ARV
- Most respondents are concerned about the future efficacy of their treatments
- 36% of those on ARV have changed treatments due to severe side effects
- 4.6% perceive that they have no effective combinations of ARV remaining
- 74% believe that ARV will provide better health prospects for most PLWHA

Treatment Breaks

- 34% have taken a break from ARV treatments at some point
- 51% indicated that there were lifestyle reasons for taking breaks including depression, travel and dosing problems
- 58% indicated that there were clinical reasons for taking breaks including their doctor's recommendation, side effects and drug resistance
- Treatment breaks led to improved well being but negative health outcomes

Drug Resistance

- 19% had had a test to look for resistance of their HIV strain to one or more ARV drugs.
- 74% of these tests had identified drug resistance

Health Care

- 79% of respondents say they work with their doctor to make treatment decisions
- 81% say they see a HIV specialist for their HIV management
- 44% see a GP for their non-HIV related health care
- Respondents use a range of health and ancillary services, both HIV specific and generalist

Information

- Clinicians are an important source of information on HIV management and treatments
- Community organisations and peers are the most important sources of information on living with HIV
- 76% had some contact with AIDS community organisations

Social support

- 16% do not know anyone else with HIV
- 70% have had someone close to them die of AIDS
- 22% have been involved in the nursing and care of someone with AIDS
- 84% have disclosed their HIV status to at least one other person
- 54% have had their HIV status disclosed without their permission
- 33% have had their HIV status disclosed without their permission in the last 2 years
- 53% consider their HIV status an *important* part of their identity
- 18% consider HIV to be an *essential* part of their identity
- 80% of those with a partner get *a lot* of support from this person
- Other major sources of support include friends, family, health workers and pets

Mental health

- 23% were currently taking anti-depressants
- 15% were currently taking anti-anxiety medication
- 7% of respondents rated high on a measure of symptoms of depression

Planning

- 25% of PLWHA plan only one day at a time
- 12% plan 10 years or more into the future

Relationships

- 40% currently have no sexual relationships
- 63% of positive women currently have no sexual relationships
- 41% have a current regular sexual partner
- 21% of sexual partners are also HIV positive
- Partners are generally supportive around HIV issues
- HIV positive people employ a range of strategies to prevent their sexual partners becoming infected
- 12% have dependent children
- 19% were considering having children

Accommodation

- 37% own or are purchasing their home
- 28% live in private rental accommodation
- 18% live in public rental accommodation
- 32% said their accommodation was unsuitable for their needs

Employment

- 53% were currently employed (38% full time)
- 20% said their career ended when they received their HIV diagnosis
- 53% of those who have worked have at some time stopped work due to HIV/AIDS

Finances

- 47% are currently on a pension or benefit
- The median income was \$NZ330 per week
- 62% of those on a benefit had been assessed by a WINZ Medical Officer
- This resulted in changes to benefits for 58% and distress for 48%
- 14% found it *very difficult* to pay for food
- 32% found it *very difficult* to pay for medical services
- 52% found it *very difficult* to pay for holidays

Discrimination

- 12% had experienced discrimination in relation to housing (5% in the last 2 years)
- 31% had experienced discrimination in relation to health services (20% in the last 2 years)
- 36% had experienced discrimination in relation to insurance

INTRODUCTION

The HIV Futures New Zealand Survey is the **first** large-scale, comprehensive examination of the health and social experiences of HIV positive New Zealanders. 226 HIV positive men and women completed the HIV Futures New Zealand Survey across the country. This represents **24.8% of the New Zealand HIV positive population**.

To date, there has been little comprehensive information on the social and clinical experience of HIV positivity in New Zealand. Community based research such as the *HIV Positive Campaign Survey* (Reid, 2001) has suggested that there are substantial differences between People Living with HIV/AIDS (PLWHA) in New Zealand in terms of their informational needs and service experiences. The clinical and social aspects of living with HIV/AIDS change quickly. In the past five years there have been dramatic advances in the effectiveness of HIV/AIDS treatment. Understanding the long-term consequences of living with HIV/AIDS and the effectiveness of treatment is increasingly important. While advances in treatment may give hope to many PLWHA, issues such as social isolation, personal relationships, employment, housing and finances are also important.

The survey is based on two recent studies carried out with PLWHA in Australia. It was conducted by the Australian Research Centre in Sex, Health & Society (ARCSHS) of La Trobe University, Melbourne in partnership with the New Zealand AIDS Foundation (NZAF), Body Positive (NZ), Positive Women and the Refugee Health Education Programme. The study is supported by the New Zealand Ministry of Health (MOH), and the Australasian Society for HIV Medicine Inc (ASHM).

The Researchers on this project are Dr Jeffrey Grierson, Research Fellow, Professor Marian Pitts, Director, and Sebastian Misson, Research Assistant, at the Australian Research Centre in Sex, Health and Society, La Trobe University, Tony Hughes, Research Director, Peter Saxton, Researcher and Matthew Whyte, Project Officer, New Zealand AIDS Foundation and Dr Mark Thomas, Infectious Disease Specialist, Auckland Hospital.

The first two HIV Futures surveys carried out in Australia in 1997 (N=925) and 1999 (N=924) provided valuable insights into the experience of antiretroviral treatments and the social and personal impact of HIV on the lives of Australian PLWHA. These studies have made a significant contribution, both nationally and internationally, at both academic and community level. The third Australian survey was carried out in September 2001 and coincided with the first New Zealand study. The New Zealand Futures study provides significant insight into the lives of PLWHA in this country.

INSTRUMENT AND METHOD

Methodology

This section describes the methodology of the study including the research design, the survey instrument, recruitment and sampling issues and the analysis of the data.

Overview

HIV Futures New Zealand is a **cross-sectional** study of a sample of HIV positive New Zealand residents. A cross-sectional study is one in which a new sample is collected on each occasion. The cross-sectional methodology was chosen for a number of important reasons.

First, the HIV Futures New Zealand Survey is **anonymous**. HIV/AIDS remains a sensitive issue for many PLWHA in New Zealand. Allowing the survey to be completed anonymously helps to allay PLWHA's concerns that the confidentiality of the information about their HIV status and the other issues addressed in the survey may be compromised.

Secondly, the survey is **national**. It would not be possible to achieve this with a cohort design, since the relative ratios of participants recruited from different regions would require adjustment for each survey. The distribution of the survey also relies on diffusion through community groups in a manner that maintains the anonymity of respondents, particularly those in regional areas.

Thirdly the survey is **self-completed**. This means that PLWHA can complete the survey in a setting that is comfortable and safe for them and at their own pace. Feedback from participants during this study indicated that some people completed the survey over a number of days or weeks, and that individuals consulted their medical practitioners and other records to verify some of the details included in the survey.

Fourthly, the population of HIV positive New Zealanders is constantly **evolving**. A cross-sectional survey allows us to include newly HIV positive individuals and to increase the likelihood that our findings reflect all positive people, those who have recently become infected as well as those who have been positive for some time.

There are certain limitations in the methodology used. In terms of **sample representativeness**, caution must be exercised in the applications of the findings of this research in reference to individuals who are less likely to be included in the sample, for example people with limited literacy, people of non-English speaking background, and those who are particularly geographically or socially isolated. We have taken a range of measures to address these issues. For example, participants were offered the option of completing the survey over the telephone either directly with the researchers using a free call number, or with service providers. Surveys were also completed with the assistance of service providers or community agency workers for those with literacy problems or those with

physical impairment. The combination of clinical and community setting for study recruitment was intended to optimise access to the study. This means that people were not disadvantaged from entering the study if they were not currently using anti-retroviral therapies (ARV) or not currently in contact with one of the main HIV treatment providers. Non-English speaking individuals were encouraged to participate using community-based interpreter services approved by the Refugee Health and Education Programme

It cannot be stressed strongly enough that no piece of research should be used in isolation. Each study gives a different perspective on the HIV epidemic, and collectively they lead to a greater understanding of the dynamics of the epidemic and the issues affecting New Zealand PLWHA.

The Survey instrument

Design

The instrument was based in large part on the Australian HIV Futures surveys (Ezzy et al., 1998; Grierson et al., 2000; Grierson et al. 2002). The instrument used for HIV Futures 3 in Australia was modified in consultation with a range of local organisations to reflect the New Zealand context.

Consultations

Consultation around the HIV Futures New Zealand Study was undertaken in three ways:

1: A *HIV Futures New Zealand* Community Reference Group consisting of members of HIV community organisations, health professionals and members of the affected communities provided advice on survey content, recruitment and interpretation of data and strategies for disseminating the findings. A *Maori HIV Futures Reference Group* was established to facilitate consultation, ownership and involvement of Maori, particularly HIV positive Maori, in the research project. This group is constituted of members with established relationships within Maori communities and experience in community consultation around culturally sensitive issues.

2: Consultations were conducted with regional and national bodies in person and by mail prior to the finalisation of the research instrument. This included feedback on the survey content and on recruitment strategies.

3: Consultation was also undertaken with key individuals around the country including clinicians, treatments officers, mental health workers and service providers.

Items and measures

The HIV Futures NZ survey was a self complete, mail back questionnaire consisting of 250 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 was 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 was pre-tested with New Zealand PLWHA.

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

Recruitment and Sampling

Principles of recruitment

Recruitment for this study was undertaken on the basis of voluntary involvement and optimal access. To this end, recruitment took place using a set of strategies that maximised the potential of the survey to reach the diverse population of HIV positive New Zealanders. This multi-pronged approach meant that some participants received multiple copies of the survey from different sources. Recruitment was also combined with a promotion strategy that increased community awareness of the research and its utility.

Strategies

1. Community sites

The success of this project owes an enormous debt to the active involvement of the community sector. This is critical to ensuring that the study sample reflects the diversity of the population of PLWHA, and does not over-represent those in contact with clinical services or those receiving treatment. Community organisations were not simply involved in the distribution of surveys to members, but in promoting the study, in encouraging clients and members to complete surveys, in assisting people to complete surveys.

Mail-outs

A number of community organisations mailed out copies of the surveys to members and clients. These were accompanied by a covering letter from the organisation explaining the purpose of the study and encouraging participation.

On-site availability

The survey forms were made available on-site at numerous community organisations around the country. These organisations also distributed copies of the survey to sites and venues they felt were appropriate and with whom they have ongoing relationships.

Organisational promotion

Promotion within and by organisations was undertaken by staff and volunteers within the community sector. This included the promoting the survey at staff and volunteer meetings, the placement of news items or articles in newsletters, the inclusion of links to the study website and items about the study on organisational websites and the distribution of study postcards.

2. Clinical sites

Clinicians working in general practice and at each of the hospitals where PLWHA receive care were informed about the study in a series of meetings conducted before the survey began. These clinicians then offered the survey materials to PLWHA when they attended the general practice or the outpatient clinic at which the clinicians worked.

3. Promotion and Marketing

A key element of the HIV Futures New Zealand Study was the promotional strategy that accompanied the distribution of surveys. This included press releases, advertisements, links placed on community websites, articles placed in community newsletters, a promotional post-card and other, more low key promotion within agencies. This strategy had four main aims:

1. To increase community awareness of the study so that when potential participants encountered a survey they would be more likely to complete and return it;
2. To increase community acceptance of the study's legitimacy and utility by highlighting the institutional setting for the research and the ethical protection that brings, and to emphasise the impact that it is expected to have on policy and services;
3. To recruit participants directly through the website and freecall number;
4. To enhance the participation of community and service organisations by increasing participant demand and service provider awareness.

4. Direct distribution

Requests

Potential participants were able to request a copy of the survey by telephoning the free call number, emailing the researchers or completing an on-line request form. The survey was also available for download as a pdf file on the study website.

Table 1 below gives the sources identified by respondents as the *primary* site that they obtained the survey, or information about the survey. It should be noted that many participants would have obtained copies of the survey and information about the research from multiple sources.

Table 1 Data on primary site of survey collection

Site	Frequency	Percentage
Mail-out from Body Positive	88	39.8
Mail-out from NZAF	74	33.5
Picked up a copy at a medical centre/hospital	33	14.9
Recruited by researcher	10	4.5
Picked up a copy at HIV/AIDS-related organisation	6	2.7
Mail-out from Positive Women	5	2.3
Mail-out from other HIV/AIDS-related organisation	5	2.3
Article or ad in Collective Thinking	4	1.8
Postcard picked up at Medical Centre/Hospital	4	1.8
Article or ad in gay newspaper or magazine	3	1.4
Positive Women's Organisation	2	0.9
Completed Futures survey in Australia	2	0.9
Mail-out from Refugee Health Education Program	1	0.5
Told about it by another respondent	1	0.5
Postcard picked up at HIV/AIDS-related organisation	1	0.5
Haemophilia Association	0	0.0
Other	35	15.8

We were also interested in the extent to which we were accessing HIV positive people who had participated in other research projects including the Australian HIV Futures Surveys (see Table 2). 63% did not indicate that they had participated in any of the listed research projects, while 33% had participated in other New Zealand research.

Table 2 Data on previous research involvement

Study	Frequency	Percentage
HIV Futures I	6	3.4
HIV Futures II	4	2.3
Male Call/ Waea Mai Tane Ma	30	16.9
HIV Positive Campaign Survey	16	9.0
Other NZ AIDS studies	26	14.7
Other Australian AIDS studies	5	2.8

Analysis

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 most $\alpha=.05$.

SAMPLE DEMOGRAPHICS

The following section provides an overview of the characteristics of the HIV Futures New Zealand sample.

The HIV Futures New Zealand survey was completed by 226 HIV positive people.

There is no register of HIV positive New Zealanders, as HIV testing is voluntary and anonymous. The most reliable data on the demographics of the HIV positive population are from epidemiological statistics collected by the Otago group. The AIDS Epidemiology Group at the University of Otago estimate that there had been 1742 HIV infections reported in New Zealand to the end of December 2001, of which there were 912 HIV positive people still living (AEG, 2002). Mills et al (2002) estimate that there are currently 801 HIV positive people in New Zealand under active clinical management. Given these estimates the sample recruited for this study represents approximately 24.8% of the positive population and 28.2% of the population of HIV positive people under active clinical management.

Of the survey respondents, 171 were male (75.7%) and 54 were female (23.9%) and 1 was transgender (0.4%). Of the sample 56.0% were gay men, 14.8% heterosexual men, 6.0% bisexual men, 1.4% lesbian, 20.8% heterosexual women, 0% bisexual women and the remaining 0.9% fell into other categories.

The respondents' age ranged from 18 to 68 years with a mean of 40.5 years and a median age of 40 years.

In order to compare the sample to the population represented in the New Zealand HIV surveillance reports (AEG, 2002), participants were asked how they believe they were infected with HIV. The results, grouped by the categories used by the AIDS Epidemiology Group (AIDS Epidemiology Group, 2002) are given below in Table 3.

Table 3 Respondents' reported mode of transmission

Mode of Transmission	Frequency	Percentage
Male homosexual or bisexual contact	117	51.8
Heterosexual contact	43	19.5
Injecting drug use (female and heterosexual males)	10	4.5
Receipt of blood components/tissue	4	1.8
Health care setting	3	1.4
Male homosexual/ bisexual contact and injecting drug use	1	0.5
Haemophilia/ coagulation disorder	1	0.5
Other/Don't know	42	19.0

The 38 individuals who indicated that they did not know how they were infected included 30 refugee participants.

The majority of participants were New Zealand born (71.0%) and 80.5% of the participants spoke English at home, with Northern African languages accounting for most of the remainder. 96.8% of respondents indicated that New Zealand was their official country of residence. Of the total sample, 221 indicated their ethnicity. One hundred and fifty one were European (66.8%), 34 were African (15%), 25 were Maori (11.1%), six were Asian (2.7%) and five were Pacific Islanders (2.2%).

Respondents came from all regions of New Zealand, with the majority coming from the Auckland area (see Table 4).

Table 4 Respondents' place of residence

Area	Frequency	Percent of sample
Auckland	112	50.2
Wellington	32	14.3
Christchurch	18	8.1
Hamilton	6	2.7
Other city	17	7.6
Provincial Town	21	9.4
Rural	17	7.6

The majority (50.2%) of respondents were from Auckland, while 14.3% live in Wellington, 27.8% live in other cities and towns and 7.6% live in rural areas.

One third (33.9%) of participants are living in the same area in which they were diagnosed with HIV infection, while the remainder live in a different area.

Table 5 below shows the years in which respondents tested HIV positive and in which they believe they were infected with HIV. Overall these patterns match those of the New Zealand epidemic. The time difference between year of presumed infection and year of diagnosis ranged from 0 to 18 years with a mean of 2.3 years and a median of 1 year. There are 17.9% of respondents in the sample who had tested positive in the last two years.

Table 5 Years of respondent's testing positive and presumed infection (percentage of sample)

Year	Tested HIV positive	Presumed infected
Pre 1985	4.0	17.5
1985-1989	15.2	23.1
1990-1994	22.0	23.1
1995-1999	40.8	28.8
2000+	17.9	7.5

When asked about their religious beliefs 81 respondents (36.4%) indicated that they were atheist/agnostic, 45.9% indicated mainstream religious identification and the remainder were either adherents of new age belief systems or had other spiritual beliefs. Around 30.9% indicated that religion or spirituality was of no importance to them. A further 23.5% indicated that this was of little importance, 21.2% that it was very important and 24.4% extremely important.

The educational level of respondents to the survey is shown in Table 6. As can be seen there is a range of educational levels, with 40.2% holding post secondary qualifications.

Table 6 Educational level of respondents (percentage of sample)

Level	Frequency	Percent of sample
No school qualification	47	21.3
5th Form School Certificate	42	19.0
6th Form Certificate or University Entrance	19	8.6
Higher School Certificate or bursary	24	10.9
Professional/Technical/trades certificate/diploma	52	23.5
Bachelors or undergraduate degree	19	8.6
Masters or postgraduate degree	18	8.1

FURTHER ANALYSIS

There have been shown to be specific issues around the experiences of HIV positive refugees in New Zealand (Worth et al. 2001, Reid et al. 1997). These have included different experiences of testing, of disclosure, stigma, social support and health care access. Initial analyses of the HIV Futures New Zealand data suggested that the pattern of responses was systematically different for refugees. For these reasons we have decided to present the refugee data separately to allow us both to reflect more accurately the refugee experience and to be able to consider the remainder of the responses independently. Refugee respondents were recruited via the Refugee Health Education Programme and surveys were completed with the assistance of an interpreter, where necessary. Thirty-three surveys were returned from refugee respondents.

SECTION 1: Data set without refugees' responses

HEALTH

HEALTH STATUS

The first section of this report deals with the health status and the experience of health of New Zealand PLWHA. There is a particular emphasis on the use and experience of antiretroviral therapy as this continues to be one of the key health issues for PLWHA. We examine the uptake of these therapies, the health and lifestyle consequences of them and the meanings of antiretrovirals in their lives. An issue that has become increasingly important in recent years is interruption of treatment.

We also look beyond antiretroviral therapy and explore health in terms of co-existent conditions, health maintenance and monitoring, health enhancement, complementary therapies, and testing practices. We also examine attitudes to health and treatments, and the experience of health and well-being.

HIV positivity is an extraordinarily medicalised experience; an important component of this study is the exploration of how the clinical aspects of HIV interact with psychological and social experiences. While the coverage of these issues in a report such as this is necessarily limited, further attention will be paid to these in subsequent reports and journal publications. These can be accessed through the study website (www.latrobe.edu.au/hiv-futures).

Summary:

- Most PLWHA are engaged in regular health monitoring including CD4 testing and HIV viral load testing
- One third of PLWHA currently have both an undetectable viral load and a high CD4 count indicating successful viral suppression and a good immune response
- 45% of respondents rate their current health as *good* and 31% as *excellent*
- 44% of respondents rate their current well-being as *good* and 29% as *excellent*
- 28% currently have a major health condition other than HIV/AIDS

HIV Antibody Testing

We asked respondents why they had taken the antibody test. Currently in New Zealand, HIV antibody testing is available from general practitioners and HIV specialists, sexual health clinics and New Zealand AIDS Foundation regional centres. This service is provided free in the latter three settings, and anonymously through NZAF. Viral load and resistance testing has been available in New Zealand since 1996 and can be ordered by specialist clinicians through four laboratories. Counselling before or after an HIV test is not legally required, although it is strongly recommended in the health practitioner guidelines (Ministry of Health, 1999).

Reporting of HIV diagnoses is not mandatory in New Zealand, however demographic information relating to a positive diagnosis is sought through a system of “enhanced surveillance” involving laboratories, the clinician who requested the test and the AIDS Epidemiology Group (Paul et al., 2000). AIDS is a notifiable disease and is thus reportable by law to the local Medical Officer of Health. This is conducted by way of a ten-digit code to retain anonymity and help identify duplicate records.

As can be seen from Table 7, 25% of the respondents had taken the test as a result of *illness*, 12% as a result of a particular risk episode and 11% because they were a member of a *risk group*. It is interesting to note that 12% gave the reason for testing as *routine health screening*. Of those who gave this reason, 91.3% were gay or bisexual men, which may suggest that respondents’ interpretation of the phrase may include regular testing on the basis of group membership or risk activity. Of those who had tested positive in the last two years (N=34), 32.4% said this was due to *illness*, 26.5% said this was due to a *doctor’s suggestion*, 8.8% were *tested without their knowledge*, 5.9% said it was *routine screening*, and 5.9% as a result of a *particular risk episode*.

Table 7 Reasons for testing

	Frequency	Percentage
Became ill	48	25.1
Doctor’s suggestion	26	13.6
Particular risk episode	23	12.0
Routine health screening	23	12.0
Member of risk group	21	11.0
Tested without knowledge	8	4.2
Contact tracer/other health worker’s suggestion	4	2.1
Starting new relationship	4	2.1
Insurance	1	0.5
Availability of new treatments	0	0.0
Other	33	17.3

Of particular concern is the 25% who said they tested as a result of the category *became ill*. Testing as a result of ill health may include those experiencing sero-conversion illness, but examination of the presumed length of infection indicates that there is still a significant proportion of individuals tested late.

A commitment to pre- and post-test counselling has formed a critical part of New Zealand’s efforts in care and support of PLWHA and prevention education, both for those who test positive and negative.

Pre- and Post-Test counselling

We asked respondents if they had received pre- and/or post-test counselling at the time they tested positive, who provided this counselling and how satisfied they were with the information and support they received at the time.

20.5% of respondents indicated that they had received pre-test counselling. Of those who tested positive in the last two years 5.9% had received pre-test counselling, significantly fewer than those tested earlier.

The counselling was generally provided by a doctor (35.3%), but was also commonly provided by an HIV/AIDS organisation staff member (23.5%), a counsellor or psychologist (20.6%), or a nurse (17.6%). No other response accounted for more than 1 response.

When asked if they were satisfied with the counselling they received, 75.0% reported they were satisfied with the information they received from this person and 75.0% said they were satisfied with the level of support they received.

68.6% of respondents indicated that they had received post-test counselling. Of those who tested positive in the last two years 73.5% had received post-test counselling.

The counselling was generally provided by a staff member at an HIV/AIDS organisation (33.3%), but was also commonly provided by a doctor (23.3%), a counsellor or psychologist (22.5%), or a nurse (5.8%). No other response accounted for more than 4 responses.

When asked if they were satisfied with the counselling they received, 83.1% said they were satisfied with the information they received and 77.4% said they were satisfied with the support they received.

There are clearly some issues around the understandings and expectations of pre- and post-test counselling and the training and institutional support for counselling that need to be addressed.

CD4 and Viral Load

Almost all PLWHA had taken a CD4/T-cell test (97.9%) and a viral load test (97.9%). Most respondents had their most recent CD4 test within the last six months (93.8%) (69.3% in the last three months) and their most recent viral load test within the last six months (95.1%) (68.3% in the last three months). On average participants had taken 3.1 viral load tests in the preceding twelve months.

Among those PLWHA who had taken a CD4 test, 92.7% reported that they have at some time had a CD4 count of less than 500 cells/ml and 67.9% reported a count of less than 250 cells/ml. Results for PLWHA's most recent CD4/T-cell test ranged from 2 to 1390 cells/ml with a mean of 495.2 cells/ml and a median of 445 cells/ml.

Among those PLWHA who had taken a viral load test, 77.7% reported that at some point they have had a result of over 10,000 copies/ml and 62.1% a result of over 50,000 copies/ml. Results for PLWHA's most recent viral load test ranged from below detectable levels to 2,500,000 copies/ml with a mean of the log viral load of 371.2copies/ml and 55.9% of tests coming back at 50 copies/ml or less. Table 8 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 respondents' 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 8 Results of most recent blood tests, (percentage of total sample)

			Viral load			
			Below detectable levels	Low 500 to 9,999	Moderate 10,000 to 49,999	High 50,000+
			68.6	12.9	8.6	10.0
CD4/T-cell	Little damage 500+	44.3	33.6	5.7	3.6	1.4
	Moderate damage 250-499	39.3	26.4	4.3	4.3	4.3
	Severe damage 0-249	16.4	8.6	2.9	.7	4.3

Experience of Health and General Well Being

We asked respondents to indicate on a four point scale their current state of physical health, and their overall sense of well-being. The results are shown in Figure 1 and Figure 2 below. Around half the sample rated their physical health as *good*. A further 24% rated their health as *fair* or *poor*, and 31% as *excellent*. A similar pattern is found in the ratings of well-being.



Figure 1 Respondents' self ratings of general health status

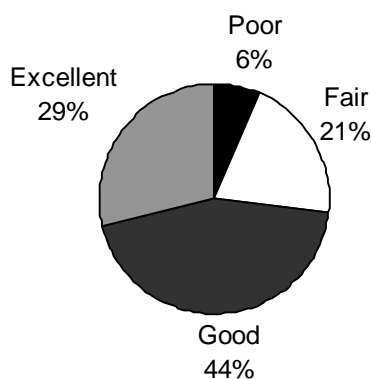


Figure 2 Respondents' self ratings of general well being

When we look at the relationship between these two measures, we can see that overall better health is related to greater well-being. This is, however, not a clear and direct relationship. The correlation between the two measures is .689. One in five participants (21.7%) rate their well being as worse than their health and 16.3% rate their health as worse than their well being. Better health is related to higher CD4 count (correlation=.36)¹, but not viral load (correlation=.07), and is clearly mediated by the experience of side-effects, the burden of medication, history of HIV and co-existent conditions.

¹ Correlation measures the strength of association between variables. It can range from 0.0 to 1.0; the higher the figure, the stronger the association between the variables.

Table 9 Relationship between ratings of overall health and well being (percentage of total sample)

		Health			
		Poor	Fair	Good	Excellent
Well being	Poor	2.6	2.6	1.1	0.0
	Fair	2.6	9.5	7.4	1.1
	Good	0.0	5.8	28.9	9.5
	Excellent	0.0	.5	7.4	21.1

AIDS Defining Illnesses

With the advent of antiretroviral therapies the significance of the experience of an AIDS defining illness is less clear than it once was. The category system for defining the stages of HIV disease progression were in large part based on an understanding of the progress of the disease as relentlessly progressive with little retrograde movement through the categories. There are now numerous HIV positive people who have at some time experienced an AIDS defining illness but would now be classed at a less severe stage of disease progression. We ask respondents if they have ever experienced an AIDS defining illness for three reasons: to assess the sample against surveillance data; to examine issues around the burden of illness; and to understand the current health status of participants.

Around one in five respondents (20.6%) have been diagnosed with an AIDS defining illness at some point and 5.2% have been diagnosed with one in the last two years. The average duration since diagnosis was 4.4 years. The most common AIDS defining illnesses were Pneumocystis carinii Pneumonia (60.0%), Kaposi's Sarcoma (20.0%) and Microbacterium Avium Complex (MAC) (14.3%).

HIV/AIDS Related Conditions

We asked respondents if they had experienced any other HIV-related illnesses, 36.1% said that they had. Of these the most common were shingles (24.6%), skin problems (24.6%), Herpes simplex disease (13.8%) and oral thrush (12.3%).

We also asked if participants had experienced any of five specific conditions. 21.6% had experienced lipodystrophy, 28.9% weight loss, 64.7% low energy or fatigue, 41.1% a sleep disorder and 31.1% confusion or memory loss.

Other health conditions

Lipodystrophy and lipoatrophy have created additional difficulties for positive people. To assess the impact of these we asked participants to respond to a series of statements about their body image. These are presented in Table 10 for both the total sample, and for those who indicated that they had lipodystrophy. As can be seen, the majority (70.7%) disagreed that body changes due to lipodystrophy do make it obvious that people have HIV, while approximately equal numbers of people agreed and disagreed with the other two items. The responses of those with lipodystrophy were more negative and suggest that there are particular social barriers to intimate relations that are associated with body image for this group.

Table 10 Attitudes around body image (percentage of sample)

	Strongly agree	Agree	Disagree	Strongly Disagree
Full Sample				
Changes in my body due to HIV have made me feel sexually unattractive	17.3	36.8	33.0	13.0
I am happy with the way my body looks	8.6	44.3	37.3	9.7
Body changes due to lipodystrophy make it obvious to others that people have HIV	3.7	25.6	50.0	20.7
Those with lipodystrophy (N=41)^a				
Changes in my body due to HIV have made me feel sexually unattractive	30.0	45.0	17.5	7.5
I am happy with the way my body looks	7.5	27.5	52.5	12.5
Body changes due to lipodystrophy make it obvious to others that people have HIV	7.5	40.0	40.0	12.5

a: Actual Item Ns may vary



See also Other Medications page 32, Mental Health page 54

Around one quarter (28.3%) of respondents indicated that they had been diagnosed with a major health condition other than HIV/AIDS. The most common included hepatitis C (5.2%), asthma (3.1%) cardio-vascular disease (2.1%), and hepatitis B (2.1%)².

Hepatitis

Hepatitis is a term that refers to inflammation of the liver. Hepatitis A, B and C viruses are the most common causes of hepatitis in New Zealand. For HIV positive people, co-infection with a hepatitis virus may affect both their health and/or their decisions in relation to antiretroviral treatments. We asked about diagnosis of, and vaccination against, hepatitis A and B, and some more detailed questions about diagnosis and experience of hepatitis C.

Hepatitis A

Around one in eight of the participants (13.5%) had at some point had hepatitis A, and 44.0% had been vaccinated against this virus. This means that 47.1% may currently be at risk of hepatitis A infection.

Hepatitis B

A total of 17.7% of respondents had at some time been diagnosed with hepatitis B and a further 48.0% had been vaccinated against this virus. This means that 41.2% may currently be at risk of being infected with hepatitis B.

Hepatitis C

Diagnosis of hepatitis C in HIV positive people is more problematic than in those who are HIV negative (Mijch 2001). Co-infection with HIV may result in false negatives on the hepatitis C antibody test. Hepatitis C may also be cleared in a proportion of individuals. Over half (53.8%) of respondents had had no test to determine their hepatitis C status. A total of 24.9% had had an antibody test, 1.8% had had a diagnostic PCR test and 21.3% had had some sort of test for hepatitis C, but were unsure which sort. We used a series of items from the survey including test results, year of diagnosis with hepatitis C, and designation of hepatitis C as a major health condition to determine that 7.3% of the sample had hepatitis C infection.



See also Health Services page 37

Other Health Monitoring

We asked a series of questions about other health monitoring activities. 4.8% of respondents had had a bone density test in the last two years and 1.8% had had a test more than two years ago. 25.9% had had a fasting cholesterol test in the last two years and 6.5% had had one more than two years ago. The long-term effects of living with HIV and treatment with some ARV drugs have made health concerns such as high cholesterol, cardiovascular difficulties and osteoporosis increasingly important for positive people.

All the female respondents had had at least one cervical smear (Pap) test and 86.7% had had one in the last twelve months. Generally women had one test in the last year (65.4% of those tested in the last year). On their most recent test, most (81.8%) reported that the result was

² Please see the section below for diagnosis with hepatitis A, B and C. The discrepancy between the responses to this open ended item and the specific questions below can to some extent be explained by what participants consider to be a *major* health condition

negative, and 12.1% abnormal. 3.0% of women reported high-grade intraepithelial abnormality (all were CIN3) while 3.0% reported inconclusive results.

 **See also Resistance Testing page 28**

Health Maintenance

We asked participants about a range of activities that they might engage in to improve their health. The results are shown in Table 11 below. The most common health-enhancement activity was healthy eating, followed by sleep, exercise and relaxation.

Table 11 Health improvement strategies

	Frequency	Percentage
Healthy eating	157	82.2
Sleep	148	77.5
Exercise	136	71.2
Relaxation	131	68.6
Taking pills on time	127	66.5
Spending time with friends	117	61.3
Spending time with pets	86	45.0
Spending time with family	82	42.9
Spending time with partner	69	36.1
Complementary therapies	62	32.5
Other	52	27.2

Prophylaxis

27.7% of respondents were currently taking prophylaxis for opportunistic infections. Those using prophylaxis were more likely to have a lower CD4 count.

 **See also Other Medications page 54, Complementary Therapies page 30**

Attitudes to Health Management

Survey participants were asked to respond to a number of statements about health management in relation to strategies, antiretroviral therapies and complementary therapies. The items on antiretroviral and complementary therapies are presented in the relevant sections of the report. When asked about health management strategies, almost all participants agreed that exercise, healthy eating and an optimistic outlook were important or very important strategies (see Table 12). Those who indicated that they took exercise (see Table 11 above) agreed more strongly with the first two of these statements and those that ate well agreed more strongly with all three statements.

Table 12 Attitudes to health management: percentage of total sample

	Strongly agree	Agree	Disagree	Strongly disagree
Looking after my physical fitness is an important part of managing my HIV infection	48.4	46.3	4.3	1.1
Healthy eating is an important part of managing my HIV infection	42.2	51.3	4.8	1.6
Keeping an optimistic frame of mind is an important part of managing my HIV infection	52.4	41.7	4.8	1.1

ANTIRETROVIRAL THERAPY

Antiretroviral therapy has been a central plank in the management of HIV disease in most developed countries for the last six years. While the treatments are by no means unproblematic, mortality rates have declined dramatically. The experience of antiretroviral treatments is increasingly one of disparity with a proportion of the population benefiting enormously from the treatments and an increasingly large number for whom treatments are failing or causing health difficulties and challenges to day to day life. The data from this study demonstrates that the move toward greater optimism tempered by greater caution identified in our Australian work (Grierson, de Visser and Bartos 2001) may also be the case in New Zealand. This section addresses some of that complexity by examining the *experience* of antiretrovirals both in clinical and social terms.

Summary:

- 64% are currently using antiretroviral (ARV) therapy
 - 13% have never used ARV
 - Side-effects are experienced by 44% of those on ARV
 - Most respondents are concerned about the future efficacy of their treatments
 - 36% of those on ARV have changed treatments due to severe side effects
 - 4.6% perceive that they have no effective combinations of ARV remaining
 - 74% believe that ARV will provide better health prospects for most PLWHA
-

Use of Antiretroviral Therapy

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 (ARV).

Of the full sample, 78.1% had used ARV at some point, and 64.2% were currently using these treatments.

The data on treatments will be presented in four sections: those currently using ARV (monotherapy and combination therapy); those currently on combination therapy only; those not currently using ARV who have in the past; and those who have never used ARV. An additional section on the experience of interruptions to treatments follows. A summary diagram of the uptake of antiretrovirals can be found on page 13.

Those Currently Using ARV (mono-therapy and combination therapy)

The majority of participants (70%) were on a combination of 3 antiretroviral drugs, with 16.9% on more than three antiretroviral drugs, 12.3% on two, and 0.8% on monotherapy.³ Table 13 below lists the antiretroviral treatments that participants were using at the time of the survey.

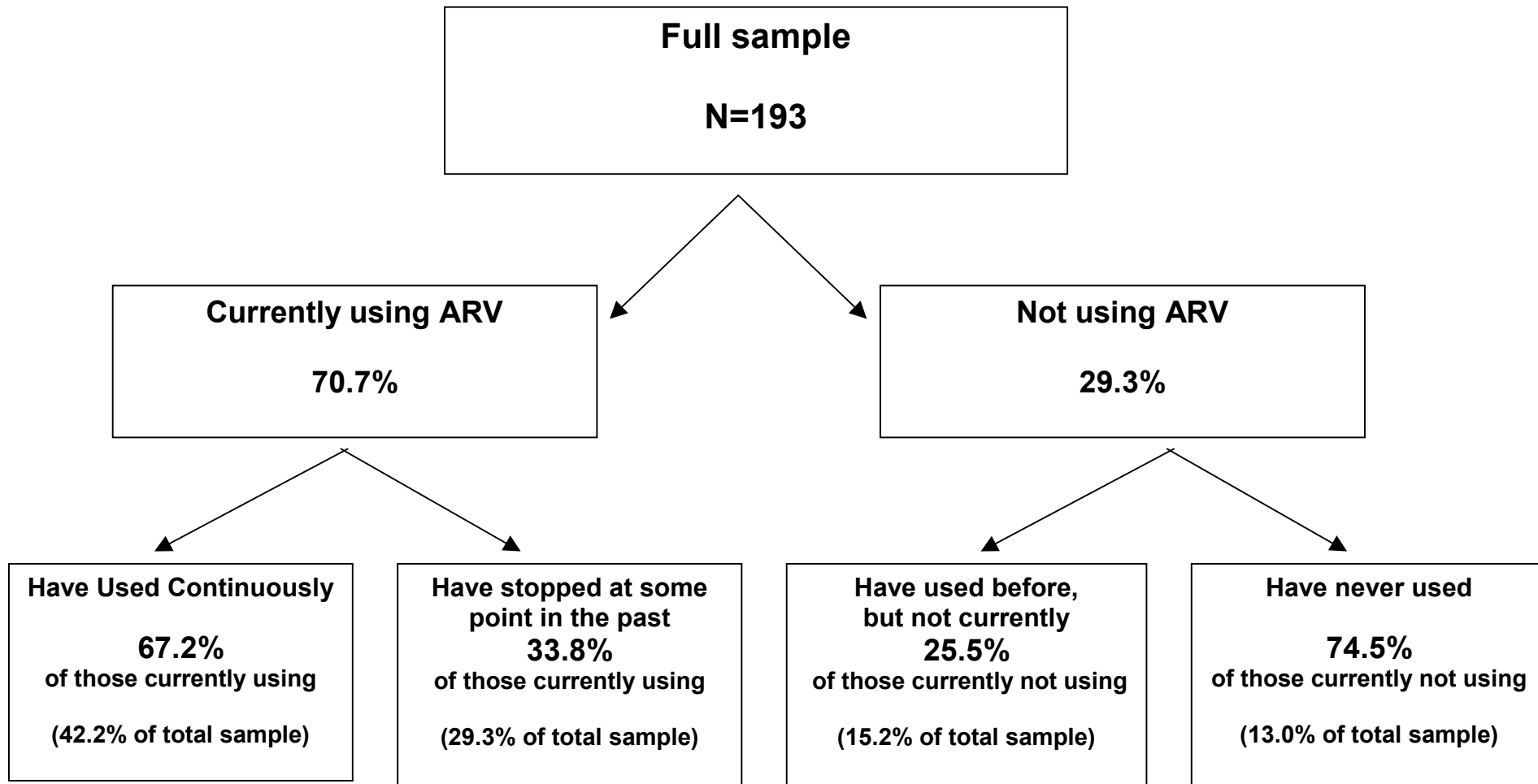
Table 13 Antiretroviral drugs used by respondents: percentage of total sample

Drug	Percentage of those using ARV
AZT & 3TC (Combivir)	44.6
d4T (Zerit)	32.3
3TC (EpiVir, Lamivudine)	30.0
Efavirenz (Sustiva)	26.9
Nevirapine (Viramune)	23.1
Indinavir (Crixivan)	20.8
Ritonavir (Novir)	19.2
Nelfinavir (Viracept)	19.2
ddl (Videx, didanosine)	14.6
Abacavir (1592, Ziagen)	6.9
AZT (Retrovir, zidovudine)	6.2
Saquinavir (Fortovase) - soft gel	4.6
AZT & 3TC & Abacavir (Trizivir)	1.5
Saquinavir (Invirase) - hard gel	1.5
Lopinavir + Ritonavir (Kaletra, ABT-/378r)	1.5
ddl ec (Videx ec, didanosine ec)	0.8
Amprenavir	0.8
Tenofovir	0.8
ddC (Hivid)	0.0
Delavirdine (Rescriptor)	0.0
T-20	0.0

Respondents were also asked specifically about their use of Interleukin or of Hydroxyurea: no respondents were currently using either of these medications.

³ Combivir is counted as two drugs, and Trizivir as three drugs

Figure 3 Uptake of antiretroviral medication



Difficulties of Taking ARV

Overall, 78.6% reported that they had some difficulty taking ARV. Of these, 43.5% indicated they had difficulty remembering to take the drugs on time, 26.7% said they had difficulty taking medication in public, 26.7% transporting medication, 26.0% organising meals around medications, and 19.1% taking a large number of tablets (see Figure 4). In addition, 10.7% reported that taking ARV made it difficult to take medication for other health conditions and 4.6% that taking other medications made taking ARV difficult.

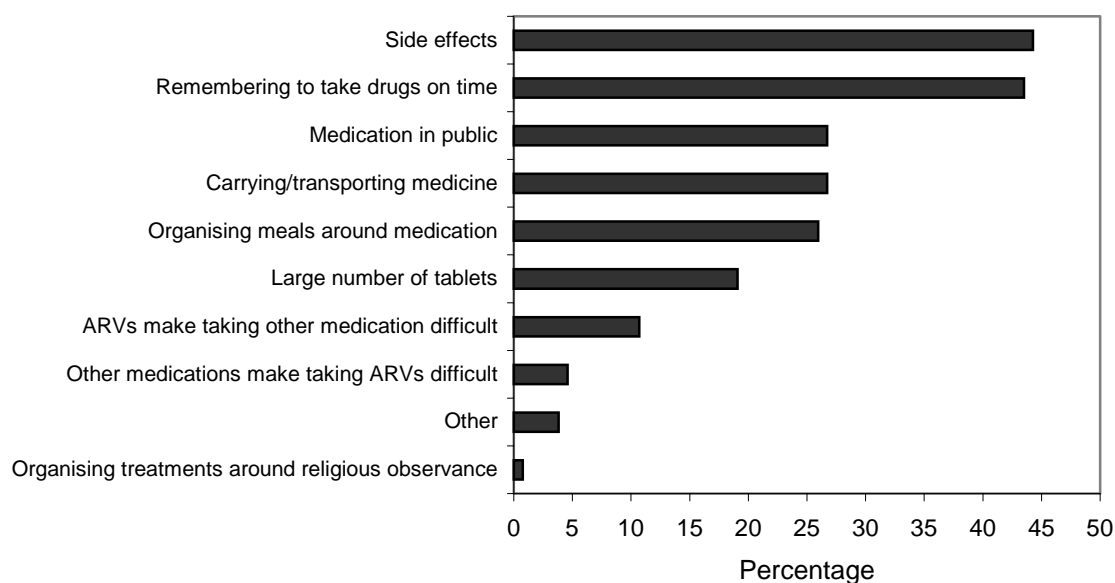


Figure 4 Difficulties of taking ARV

N=131

Side effects were reported by 44.3% of respondents currently using ARV. The most commonly reported problems were diarrhoea (10.4% of those using ARV), nausea (10.4%), fatigue or lethargy (5.7%), and lipodystrophy (3.6%).

Attitudes to ARV

Most respondents reported concern over the future efficacy of their treatments. Over half agreed or strongly agreed with the statement *I am worried that in the future my medication will stop working for me*, (see Table 14).

When asked to respond to the statement *Taking tablets gives me an unwanted reminder that I have HIV*, 65% indicated agreement and 34% indicated disagreement.

Table 14 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 ^a	3.0	12.0	51.9	24.1	9.0
Taking tablets gives me an unwanted reminder that I have HIV ^b	8.3	25.6	45.1	19.5	1.5

a: N=121, b: N=131

Health Status of Those Using ARV

Those taking ARV had significantly lower viral loads (log mean of 182.2 HIV/µl compared to 2846.4 HIV/µl 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 5.

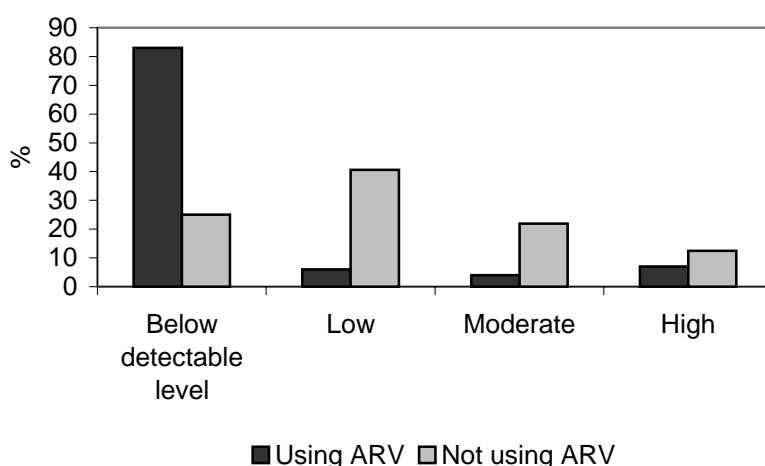


Figure 5 Viral load of those taking and not taking antiretroviral therapy.

Those taking ARV did not have significantly different CD4 counts (mean of 485.7 copies/ml compared to 533.3 copies/ml among those not taking antiretrovirals). They were more likely to have had an AIDS defining illness (26.5% compared to 7.4% among those not taking antiretrovirals) and had been HIV positive for longer (mean=7.9 years for those taking antiretrovirals compared with mean=5.2 years for those not taking antiretrovirals). There was, however, no difference between these two groups in the ratings they gave of their general health status.

When asked to rate the effect of commencing ARV on their physical health, 61.4% said that their health improved, 21.2% said it fluctuated, 13.6% said it stayed the same and 3.8% said it deteriorated. When asked about the impact of ARV on their overall feeling of well-being, 50.8%

said it had improved, 32.3% said it had fluctuated, 10.0% said it had stayed the same and 6.9% said it had deteriorated (see Figure 6).

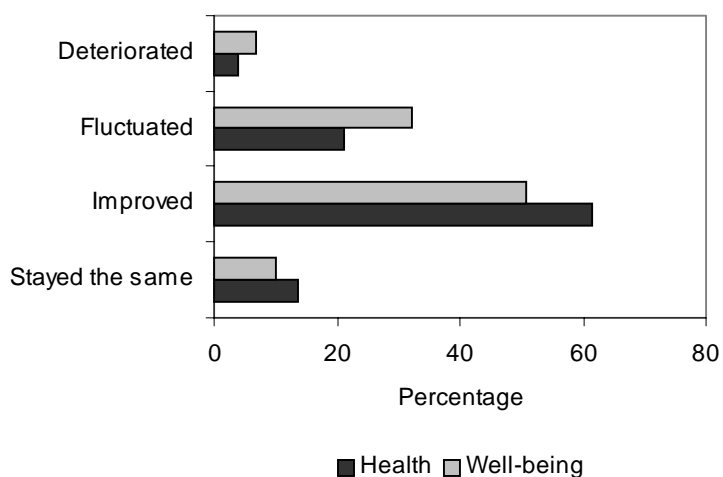


Figure 6 Effect of commencing antiretroviral medication on health

Those on Combination Therapy

The majority of participants (70.0%) were on a combination of 3 antiretroviral drugs, with 16.9% on more than three antiretroviral drugs, 12.3% on two, and 0.8% on monotherapy.⁴ The most common combination was AZT, 3TC & Nevirapine used by 12.4% of those on combination therapy, followed by AZT, 3TC and Efavirenz used by 9.3%, AZT, 3TC & Nelfinavir used by 6.2% and AZT, 3TC & Indinavir (5.4%). No other combination accounted for more than 5%.

89.3% of those on combination therapy had been on it for at least the second half of 2001. Most started combination therapy at a time when their viral load was high (log mean = 49,340 copies/ml) and their CD4 count was low (mean = 181.4, 61% below 250 copies/µl, 94% below 500 copies/µl). As can be seen in Table 15 below, most people had commenced combination therapy at a time when treatment would be strongly indicated (see CTTAC, 1997).

Table 15 Results of most recent serological tests: percentage of those on combination 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+
			8.7	10.9	13.0	67.4
CD4/T-cell prior to commencing combination therapy (%)	Little damage 500+	6.5	0.0	2.2	0.0	4.3
	Moderate damage 250-499	32.6	2.2	2.2	6.5	21.7
	Severe damage 0-249	60.9	6.5	6.5	6.5	41.3

N=46

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 (78%), although the importance of clinical indicators, treatment developments and treatment information is also clear.

Table 16 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	78.3
I had a big drop in my CD4 count	45.7
I had a big rise in my viral load	39.5
I became very ill	39.5
New drugs became available	31.0
I was hospitalised due to HIV	25.6
Information showed the treatment was effective	18.6
I had just tested positive to HIV	17.8
A treatments officer advised me to begin treatment	10.1
My partner advised me to begin treatment	7.8
Positive friends started treatment	6.2
Close friends advised me to begin treatment	6.2
Multiple responses possible N=129	

Different Combinations

Among those currently using combination therapy, respondents had tried between 1 and 15 combinations, with the median being 2. Within the last 12 months, 59.1% had used one combination and 25.2% had used two.

Respondents currently on combination ARV were asked to describe the circumstances surrounding their most recent change in combination. For a large proportion of PLWHA (36.0%) the side effects became too severe. Drug resistance (16.8%) and drugs not working (11.2%) were the next most common responses (see Figure 7).

⁴ Combivir is counted as two drugs, and Trizivir as three drugs

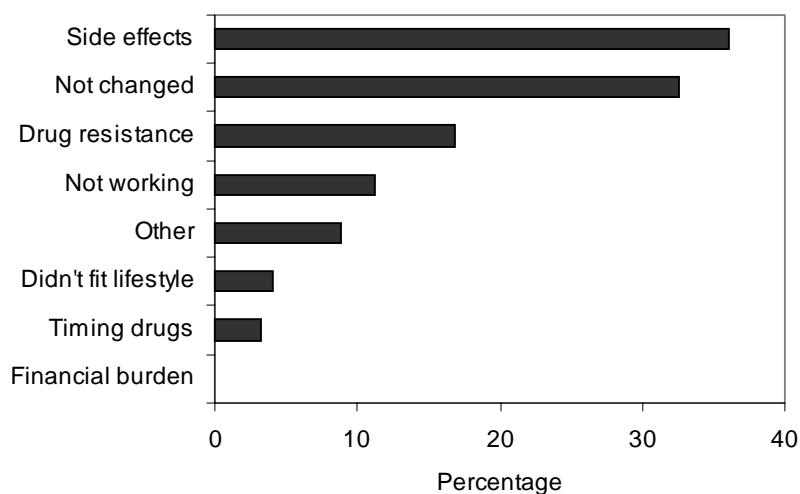


Figure 7 Circumstance surrounding most recent change in combination among those currently on combination ARV

When asked how many combinations they believed they still had access to, 26.2% indicated that they thought they had *a few* and 23.1% felt they had *many*, while 40.0% said they didn't know how many combinations they had left. 4.6% of those currently on combination therapy believed they had no combinations remaining (see Table 17).

Table 17 Correlates of number of remaining combinations for those on ARV

Combinations remaining	Mean years positive	Mean CD4	Log Mean Viral load
None	6.3	467.8	708.8
One	11.5	407.0	628.3
A Few	8.0	492.6	195.2
Many	7.6	538.7	206.8

When we examine the health status of PLWHA with regard to their perceptions of the combinations remaining, we can see that the pattern differs for each of these categories (see Figure 8). Those who perceived that they had a few or many combinations remaining were more likely to rate their health as *good* or *excellent*.

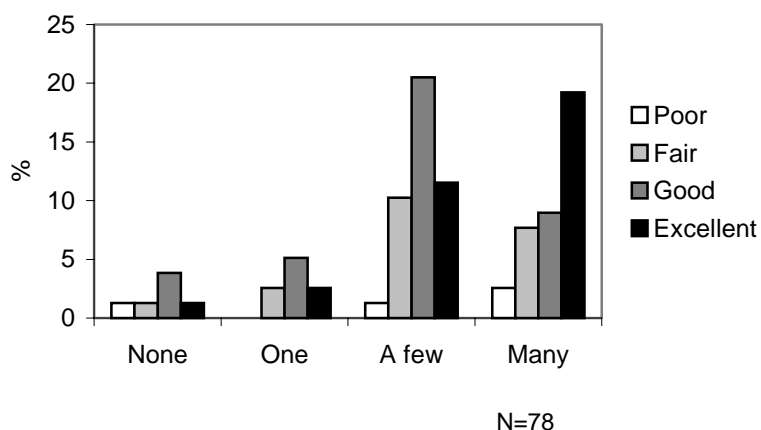


Figure 8 General health status for PLWHA with regard to their perceptions of the numbers of combinations of ARV remaining: percentage of those on ARV

Those Not Currently Taking ARV

Of the 29.3% of the sample who currently are not using any antiretrovirals, 25.5% had taken ARV in the past. The mean length of time these PLWHA had been using ARV was 2 years and 10 months (range 1 month to 12 years) and on average they had ceased using ARV 1 year and 7 months prior to completing the survey (range 1 month to 5 years). At the time that they stopped using ARV, most were using a combination of 3 drugs (61.5%), 30.8% were using two drugs and 7.7% were on mono-therapy.

Difficulties of Taking ARV

There is some variation in the difficulties experienced by those who have stopped antiretroviral therapy and those currently taking them (see Table 18). Overall, those who had stopped taking antiretroviral drugs nominated almost all of the difficulties more often than those currently using the drugs. This is particularly noticeable for the experience of side-effects, taking a large number of tablets and organising meals around medication.

Table 18 Difficulties experienced by those currently on ARV and those who have stopped ARV treatment

Difficulties experienced	Those taking ARV now ^a	Those who have taken ARV in the past, but not now ^b
Side effects	44.3	73.3
Remembering to take drugs on time	43.5	46.7
Medication in public	26.7	20.0
Carrying/transporting medicine	26.7	40.0
Organising meals around medication	26.0	60.0
Large number of tablets	19.1	40.0
ARVs make taking other medication difficult	10.7	0.0
Other medications make taking ARVs difficult	4.6	6.7

a: N=131, b: N=15

Health Status of Those Not Using ARV

Those not currently using ARV were asked to describe changes in their health when they had used ARV in the past. Nearly one-half (46.7%) said that it had deteriorated, 33.0% that their health improved, 13.3% said it fluctuated and 6.7% said it stayed the same.

When asked about the impact of ARV on their overall feeling of well-being, 26.7% said it had improved, 26.7% said it had fluctuated, 6.7% said it had stayed the same and 40.0% said it had deteriorated.

When asked their reasons for stopping antiretroviral therapy, 33.3% of previous users gave lifestyle reasons and 76.9% gave clinical reasons.

Those Who Have Never Used Antiretroviral Drugs

21.9% (N=41) of the respondents had never used antiretroviral treatments. Of these 82.5% said they would consider using antiretroviral drugs in the future. When asked what circumstances would lead to their commencing ARV, the principal reasons were clinical (see Table 19).

Table 19 Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used antiretroviral drugs

Circumstance	Percentage of those not on ARV.
If I was hospitalised due to HIV	84.8
If I became very ill	84.8
If my doctor advised me to begin this treatment	78.8
If I had a big drop in my CD4 count	75.8
If I had a big rise in my viral load	57.6
If information showed the treatment was effective	39.4
If a treatments officer advised me to begin treatment	36.4
If new drugs became available	21.2
If my partner advised me to begin treatment	18.2
If close friends advised me to begin treatment	3.0
If positive friends started treatment	0.0

Multiple responses possible N=41

Attitudes to Antiretroviral Therapy

Antiretroviral treatments have an impact on many parts of people's lives, not just on their physical health. We asked respondents to respond to a series of statements about treatments. These fall into three broad areas: decision making around treatments, relationship with their doctor, and optimism about treatments. These findings can be seen in Table 20 on page 23.

Treatment Decision Making

Most respondents indicated that they disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (68.1%). Those who agreed with this statement were more likely to be those not currently using any antiretroviral drugs and who rated their physical health more positively. Respondents were more likely to disagree than agree with the statement *People with HIV should start using antiretroviral drugs as soon as possible*. There were however one in four respondents who indicated that they were unsure about this. Those who agreed with this statement were more likely to be using antiretrovirals.

Relationship with Treating Doctor

Most respondents (79.2%) agreed with the statement *My doctor and I work together to find the best treatment for me*, with few expressing uncertainty. However, most respondents (72.8%) agreed with the statement *My doctor knows more about the treatment of HIV than I do*. The combined effect of these data suggest that treatment decision making is negotiated, although doctors are seen as having expertise beyond that of their patients.

Treatment Optimism

Respondents were generally optimistic about combination therapy. Only 10% of respondents agreed with the statement *Combination antiretroviral drugs are ineffective*, while fewer respondents agreed than disagreed with the statement *Combination drugs are harmful*. Furthermore, one fifth of respondents agreed or strongly agreed with the statement *The side effects of antiretroviral drugs outweigh the benefits*. Those currently using antiretrovirals were more likely to agree with all three of these statements.

There was considerable uncertainty about the long term benefit of treatment. Almost one third of respondents said they were unsure when asked to respond to the statement *New treatments will be developed in time for me to gain benefits*, with most of the remainder agreeing. Similarly, over one third were uncertain when asked if *HIV treatments will stop me dying from AIDS*. Agreement with this statement was indicated by 34.6% of respondents.

Over half (56.1%) agreed with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*, while 21.3% were uncertain.

Table 20 Attitudes to antiretroviral drugs: percentage of total sample

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am healthy now and don't need to use antiretroviral drugs	41.1	27.0	11.4	14.6	5.9
Combination antiretroviral drugs are harmful	20.9	28.0	19.2	7.1	24.7
Combination antiretroviral drugs are ineffective	40.0	33.0	5.9	3.8	17.3
Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term	5.6	16.9	34.8	21.3	21.3
New treatments will be developed in time for me to gain benefits	1.7	5.0	43.6	19.3	30.4
HIV treatments will stop me dying from AIDS	6.5	22.2	22.2	12.4	36.8
My doctor knows more about the treatment of HIV than I do	3.7	16.0	39.6	33.2	7.5
People with HIV should start using antiretroviral drugs as soon as possible	17.3	28.6	14.6	13.0	26.5
My doctor and I work together to find the best treatment for me	3.8	9.3	49.5	29.7	7.7
The side effects of antiretroviral drugs outweigh the benefits	14.9	48.1	13.8	5.0	18.2

Respondents indicated how much they and their friends agree with the statement *Antiretroviral drugs mean better prospects for most people*. Most (74.2%) agreed with the statement, and believed their friends would agree with it (63.7%). Approximately one in seven respondents believe that *it's too soon to tell* (14.0%), although they were less likely to believe their friends think this (8.1%) (see Figure 9).

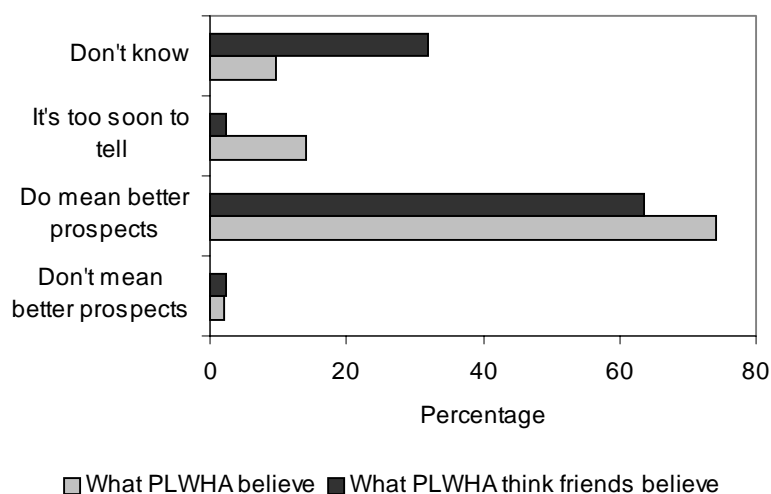


Figure 9 Respondents' and respondents' social networks response to the statement *Antiretroviral drugs mean better prospects for most people*.

TREATMENT BREAKS

Interruption of antiretroviral treatment is an important and increasingly complex issue. Treatment breaks may take a number of forms and be undertaken for a number of reasons. While there is considerable discussion in the medical community about the potential benefits and dangers of treatment interruptions, our main emphasis is on the motivations, experiences and consequences of breaks for HIV positive people. In all, 33.8% of those respondents currently using antiretroviral medication had taken a break from these at some point. To understand the experience of breaks, we asked respondents to give us some detailed information about their most recent break.

Summary:

- 34% have taken a break from ARV treatments at some point
 - 51% indicated that there were lifestyle reasons for taking breaks including depression, travel and dosing problems
 - 58% indicated that there were clinical reasons for taking breaks including their doctor's recommendation, side effects and drug resistance
 - Treatment breaks led to improved well being but negative health outcomes
-

Most Recent Treatment Break

The date of the most recent break ranged from currently taking one to 12 years ago. The mean length of break was 126.9 days with a median of 45 days. Most respondents described their most recent break as short term (78.6%) with smaller numbers describing it as long term (16.7%) or a cycle/pulse interruption (4.8%).

We asked participants to describe the reasons for taking the break within two major categories: lifestyle reasons; and clinical reasons. Just over half (51.1%) indicated that there were lifestyle reasons for taking a break. The specific reasons are given in Table 21 below. The most common reason given was difficulties around timing of drugs (15.6%) followed by the medications not suiting the client's lifestyle (8% of those taking breaks).

Table 21 Lifestyle reasons for taking breaks

Reason	Percentage of those who have taken a break
Taking drugs at the right time was too difficult	15.6
Travel	15.6
Depression/fed up	11.1
Didn't fit lifestyle	8.9
Special event	6.7
Clean out system	6.7
Financial burden became too heavy	2.2
Religious reasons	0.0
Other	4.4

N=45

When asked if there was a clinical reason for taking the break, 58.1% indicated that there was. (16.3% gave both lifestyle and clinical reasons). Table 22 below details the clinical reasons for breaks. The most commonly cited reason was that the side effects of treatment became too severe (31.1% of all those taking breaks), while just under a quarter indicated that the break was on the recommendation of their doctor.

Table 22 Clinical reasons for taking breaks

Reason	Percentage of those who have taken a break
Side effects	31.1
Recommended by doctor	24.4
Changing regimens	22.2
Drug resistance	15.6
Recommended by other health professional	6.7
Complications with Hep C	2.2
Liver toxicity problems	0.0
Other	4.4

N=45

We also asked about the involvement of the participant's doctor in these breaks. Participants were less likely to talk to their doctor about the break prior to taking it (43.2%) or during the break (43.2%) than they were afterwards (84.1%). This may suggest that these breaks are not just from the treatments, but from the clinical experience of HIV.

We were also interested in the outcome of the treatment breaks, both in terms of clinical markers and experience of health and well being. Table 23 below gives the results of the four questions asked. Around two fifths of the respondents said that their health remained stable,

30% that it deteriorated, 18% that it improved and 11% that it fluctuated. When asked about their general well-being, 39% said that it improved, 30% that it was stable, 23% that it deteriorated and 9% that it fluctuated.

The impact on clinical markers of these breaks was less positive. The majority of respondents indicated that their viral load had increased, and a large proportion that their CD4 count had decreased as a result of the break.

Table 23 Effect of break on health, well-being and clinical markers

	Stayed the same	Improved	Fluctuated	Deteriorated
Health ^a	40.9	18.2	11.4	29.5
Well-being ^b	29.5	38.6	9.1	22.7
	Stayed the same	Increased	Fluctuated	Decreased
Viral load ^c	35.1	51.4	2.7	10.8
CD4 ^d	32.4	10.8	10.8	45.9

a N=44; b N=44; c N=37; d N=37

These data provide an important insight into the motivations and consequences of treatment breaks. Clearly, while clinical considerations play a part in breaks, lifestyle motivations and improvements in general health and well being are important considerations. They also add to our increasing understanding of the relationship between clinical markers and the experience of health.

ANTIRETROVIRAL RESISTANCE

The development of resistance to antiretroviral treatments is an ever increasing concern for HIV positive people. HIV can develop resistance to one or more treatments as a result of its continual mutation and this resistance can result in the failure of treatments (Averitt and Thiemann, 2001). Resistance can result from a lack of early and persistent suppression of viral replication, missed doses of antiretrovirals or infection with a resistant strain. There are a number of resistance tests available but they generally fall into two categories: genotypic resistance tests that look for mutations of the virus in its genetic code; and phenotypic resistance tests where the virus is cultured and the performance of drugs tested directly. We asked respondents whether they had had resistance tests and what the clinical and treatment outcomes of this were.

Summary:

- 19% had had a test to look for resistance of their HIV strain to one or more ARV drugs.
 - 74% of these tests had identified drug resistance
-

19.4% of respondents who had ever used antiretroviral treatments indicated that they had some sort of ARV resistance test. This included 19.2% of those who are currently on antiretroviral treatment and 7.8% of those who are not. The average length of time since the most recent resistance test was 9.1 months. 90.9% of respondents had had their most recent test in the last two years (88.9% of those currently on ARV, 100.0% of those not).

Of those who had resistance testing, 73.9% found resistance to one or more antiretroviral drugs. This resulted in a change of drugs for 72.0% (N=18) of those where resistance was shown.

Table 24 shows the effects on clinical markers of the information provided by the resistance test. Those who changed treatments were more likely to experience improvements in both markers.

Table 24 Effect of resistance testing on clinical markers

	Stayed the same	Decreased	Increased	Don't know
All resistance testers				
Viral load ^a	13.6	40.9	9.1	36.4
CD4 ^b	9.5	9.5	52.4	28.6
Those who changed medications				
Viral load ^c	0.0	52.9	5.9	41.2
CD4 ^d	0.0	5.9	64.7	29.4

a N=22; b N=21; c N=17; d N=17

CLINICAL TRIALS

A total of 12.3% of the respondents had ever participated in a clinical trial for HIV related treatment and 78.6% of these had participated in a clinical trial in the last two years. The respondents had on average been on these trials for 10.8 months. The reasons given for participating in the trial are given in Table 25.

Table 25 Reasons for participating in clinical trials (percentage of those who have participated in a trial)

Reason	Percentage of those who have been involved in trials
Decided with doctor	65.2
Felt experience could benefit others	39.1
Only way to get treatment	26.1
No other treatment options	21.7
Had enough information about the trial	13.0
Other treatments weren't working	8.7
Felt pressure to go on trial	4.3
Other	4.3

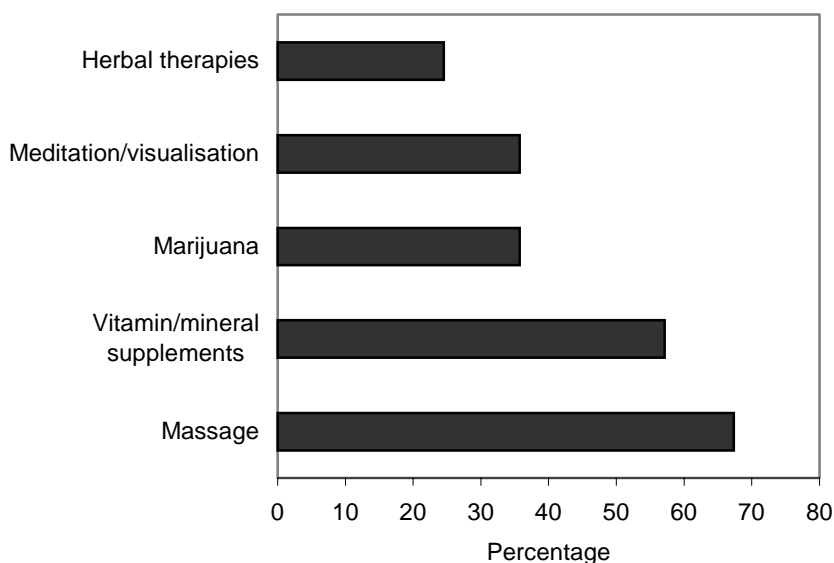
N=23

VACCINES

While the development of readily available therapeutic vaccines for HIV positive people is still some way off, we were interested in participants' perspectives on this. We asked respondents to indicate their agreement with the statement *I would be willing to participate in a HIV vaccine trial*. Almost one fifth (18.3%) said they did not know, while 60.7% either agreed or strongly agreed with the statement. A further 11.8% disagreed and 9.1% disagreed strongly.

COMPLEMENTARY THERAPIES

Over half (53.0%) of the respondents were currently using complementary therapies for HIV. The most common complementary therapy was massage (67.3% of those reporting complementary therapy use), followed by vitamin or mineral supplements (57.1%), medicinal marijuana (35.7%), meditation (35.7%), and herbal therapies (24.5%) (see Figure 10). Other complementary therapies included acupuncture (7.1% of those using complementary therapies), traditional Chinese medicine (4.1%) and other traditional medicines (6.1%). Those using complementary therapies were no more or less likely to be using ARV.



N=98

Figure 10 Most commonly used complementary therapies (percentage of those that use any complementary therapy)

Almost all PLWHA (76.1%) believe that complementary therapies can improve well-being (see Table 26). Around half the sample 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, at least 30% of the respondents were unsure about each of these three statements and these people were more likely to be those not currently using complementary therapies.

Opinion is divided on whether there is sufficient evidence on the benefits of complementary therapies, and on whether medicine’s focus on anti-HIV drugs was limited. Again, there was considerable uncertainty about these issues. On average, those PLWHA who use complementary therapies spend \$24.38 per week on them.

Table 26 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	1.6	8.7	35.5	15.8	38.3
Complementary therapies can improve well-being	1.6	0.0	46.2	29.9	22.3
Complementary therapies can reduce the side effects of conventional medical treatments	1.1	4.4	32.2	13.7	48.6
There is not enough evidence to be sure about the benefits of complementary therapies	2.2	29.0	38.3	5.5	25.1
Medicine's focus on anti-HIV drugs is very limited	2.7	26.9	26.9	3.3	40.1
Complementary therapies can boost the immune system	0.5	3.3	46.7	17.9	31.5
Complementary therapies are a central part of my anti-HIV treatments	12.6	33.0	19.2	14.3	20.9

OTHER MEDICATION

Participants used a range of other medication. In all 35.9% of respondents were using some other type of medication than antiretroviral therapies. The most commonly used medications were Acyclovir (4.7%) and Prozac (2.1%).

DOSING AND COMPLIANCE

Respondents were asked the number of times they took a range of medication per day. Overall, PLWHA were taking medication 2.4 times per day (range 0 to 9, median=2). The number of times they were taking specific types of medication is shown in Table 27 below.

Table 27 Number of times participants take medications

Reason	Mean	Median	Range
Antiretroviral drugs	1.9	2	0-9
Complementary therapies	0.5	0	0-9
Medication for health conditions other health conditions	0.7	0	0-9

Those participants who were currently using antiretroviral medication were asked how many doses they missed on the previous day and the day before that. Combining the data from these two measures, 80.3% reported missing no doses on the two days, 9.1% missed one dose, 6.8% missed two doses and 3.8% missed three or more doses.

PRESCRIPTIONS

We asked participants who prescribes their antiretrovirals. In recognition of the multiple prescribing sites people utilise respondents were able to nominate more than one source. Most PLWHA (88.7%) get their prescriptions for antiretroviral drugs from a specialist in an outpatient clinic, with lower proportions getting their prescriptions from an HIV specialist in a ward at a hospital (6.8%), a doctor at a sexual health centre (4.5%), a GP with a high HIV caseload (3.0%) and another GP (3.0%).

Most respondents (61%) only had to go to one place to pick up all their medications, although over a third said they had to go to multiple outlets (see Figure 11). When asked how difficult it was to pick up all their medication, two-thirds (65.6%) said it was not difficult, 27.5% said somewhat difficult and 6.9% said very difficult.

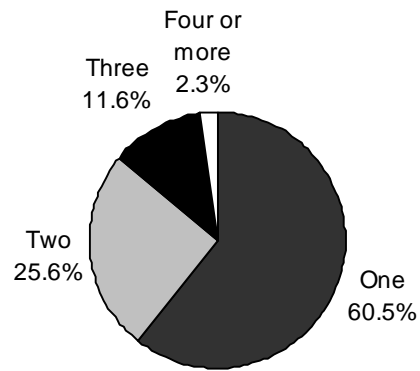


Figure 11 Number of prescription pick-up points

SERVICES

This section covers PLWHA's use of health and other services. New Zealand has had a long history of the provision of culturally and geographically appropriate HIV specific services, and a history of strong community advocacy around access to HIV specific and mainstream services. Here we look at both health services and other services that have been critical for maintaining quality of life for PLWHA.

Summary:

Health Care

- 79% of respondents say they work with their doctor to make treatment decisions
- 81% say they see a HIV specialist for their HIV management
- 44% see a GP for their non-HIV related health care
- Respondents use a range of health and ancillary services, both HIV specific and generalist

Information

- Clinicians are an important source of information on HIV management and treatments
 - Community organisations and peers are the most important sources of information on living with HIV
 - 76% had some contact with AIDS community organisations
-

HEALTH SERVICES

The increasingly complex management of HIV treatments, side effects and the consequences of long term infection have meant that coordinated and comprehensive clinical management has become critical for positive people. Here we examine the use of, and experience of, a range of health services.

Treatment

We asked respondents to identify the physician they see for the clinical management of their HIV and for general health issues. HIV specialists and GPs with high HIV case loads were the key physicians for both HIV specific and general health management. HIV specialists were also the primary provider for a significant proportion of PLWHA. Combined, GPs with high HIV case loads and HIV specialists at outpatient clinics are the primary physician for 82.6% of respondents for HIV specific management and 48.6% for general health management.

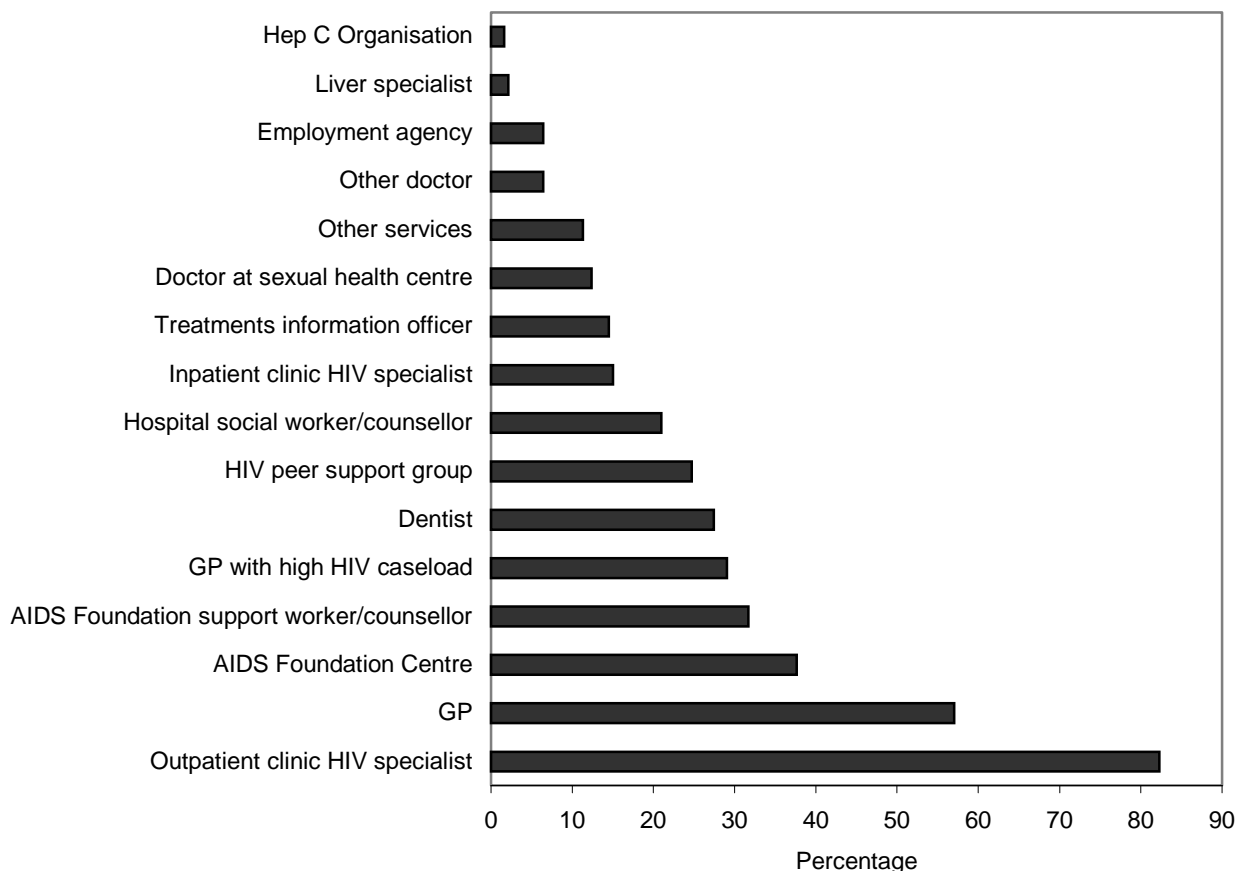
Table 28 Physician used for general and HIV related treatment: percentage of total sample

	For general treatment	For HIV specific treatment
GP	44.3	7.6
GP with high HIV case load	25.4	5.4
HIV specialist at outpatient clinic	23.2	77.2
HIV specialist at inpatient clinic	2.2	3.3
Doctor at sexual health centre	3.8	4.9
Other doctor	0.5	1.1
Other	0.5	0.5

26.1% of respondents said that the doctor they see for general medical services is the same doctor they see for HIV-related treatment. Of those who see a different doctor, 98.5% said that that doctor knows their HIV status.

Services Used in the Last Six Months

We presented respondents with a list of services, both clinical and ancillary and asked which they had used in the last six months. Clinical services were the most utilised: 82.3% had used an HIV outpatient specialist and 57.0% had used a GP without a high HIV caseload (see Figure 12). Significant proportions also used services provided by the New Zealand AIDS Foundation: 37.6% had used an AIDS Foundation Centre and 31.7% had used an AIDS Foundation counsellor or support worker.



(Multiple responses possible)

Figure 12 Services used in the last six months

Other Services

Respondents were also asked if they currently use a range of specific services either at an HIV/AIDS organisations, or at another organisation. (See Table 29) Treatment advice was the service used by most PLWHA at AIDS organisations (55% of respondents), while counselling and social support services were also used extensively. At non-HIV/AIDS organisations, pharmacy services (48%) were the most utilised followed by internet access (30%), and library services (29%). Services more likely to be used at non-HIV AIDS organisations than HIV-AIDS organisations were: pharmacy, financial advice and assistance, legal advice, housing assistance, employment, return to work, drug and alcohol treatment, mental health, library, internet access, internet-based information, transport and paid carers.



See also: Poverty and Services page 90

When asked what services they felt they needed but were currently not receiving, only 21.2% of respondents gave responses. They were most likely to nominate alternative therapies (3.1% of all respondents), social contact/dating services (2.6%) and services for women (2.1%).

Table 29 Services used at HIV/AIDS organisations and at other organisations (percentage of all respondents)

	Use service at HIV/AIDS ORGANISATION	Use service at OTHER ORGANISATION
Treatments advice	54.7	23.5
Counselling	47.5	17.3
Financial advice	3.9	19.6
Financial assistance	16.2	19.0
Peer support group	33.5	7.3
Informal peer support	15.1	12.3
Social contact with other PLWHA	29.1	6.7
Pharmacy services	12.3	47.5
Complementary therapies	27.4	20.7
Respite care	8.4	7.8
Legal advice	5.6	22.3
Housing assistance	8.4	23.5
Employment services	2.2	17.3
Return to work skills	0.6	11.7
Drug/alcohol treatment	0.6	9.5
Mental health services	3.4	12.8
Library	8.4	29.6
Internet access	7.3	28.5
Transport	6.1	23.5
Treatments information	25.7	6.7
Volunteer carer	5.6	2.2
Paid carer	0.6	7.8
Internet based information	8.4	15.1
Community education campaigns	14.5	6.1

(Multiple responses possible)

INFORMATION

One of the most distinctive characteristics of the HIV/AIDS epidemic in developed countries has been the degree to which those infected with the virus have become highly active health consumers. This is reflected not only in the emergence of a strong community sector and advocacy structure, but also in the way in which individual positive people actively engage with their health care providers and actively seek out a diverse range of information on clinical and social aspects of the virus and the epidemic. Clinical information and most specifically information on the efficacy and consequences of treatment in the HIV/AIDS area is neither arcane, nor the sole province of health professionals. In the previous two HIV Futures surveys conducted in Australia and in other research we have conducted, we have demonstrated that positive people access information on HIV treatments, management and social aspects from a range of sources including the medical literature, the community sector, health professionals and peers.

Sources

In recognition of the increasing specificity and distinctiveness of treatments information, we cover three domains: HIV treatments information; HIV management information and information around living with HIV. Respondents were asked to nominate from a list of potential sources, those that were important sources of information in these domains. The results of this can be seen in Table 30 below.

Table 30 Sources of information about treatments and living with HIV (percentage of all respondents)

	Information about TREATMENTS	Information about HIV MANAGEMENT	Information about LIVING WITH HIV
GP with high HIV caseload	26.5	28.1	21.6
Other GP	14.6	13.5	11.9
HIV Specialist at outpatient clinic	81.1	71.9	38.4
HIV specialist at inpatient clinic	21.1	16.8	11.9
Other doctor	7.6	4.3	4.3
Public health nurse	18.9	21.6	17.3
Other nurse	3.2	4.3	5.9
NZAF	41.1	41.6	51.4
Body Positive	37.3	33.5	45.9
Positive Women	7.0	8.1	14.1
Refugee Health Education Program	8.6	2.7	3.8
Pharmacist	13.5	6.5	5.4
Community AIDS Resource Team	17.8	21.6	26.5
Alternative/complementary therapist	10.8	8.1	15.1
Dietician	2.7	6.5	8.6
Dentist	9.7	9.2	9.7
Sexual health service	10.3	11.4	11.9
Family Planning Association	1.6	2.7	4.3
NZ Prostitutes Collective	2.2	4.3	5.9
Treatments officer	24.3	14.6	9.2
Other HIV/AIDS support staff	11.9	10.8	15.1
Injecting drug users' organisation	4.9	4.3	6.5
Haemophilia Foundation	2.2	3.2	5.9
HIV positive friends	19.5	20.5	36.8
Other friends	5.4	8.1	19.5
Partner/lover	10.3	14.6	27.0
Family/Whanau	2.7	7.0	16.2
Gay press	16.8	14.6	20.0
HIV magazine/newspaper	32.4	29.2	31.9
Internet	23.5	21.4	19.3
Publications from HIV/AIDS groups	33.5	34.6	34.1
Publications from other sources	8.6	7.6	8.6

(Multiple responses possible)

Information about Treatments

HIV specialists at outpatient clinics were considered an important source of information on treatments by over 80% of respondents. Pharmacists were the next most nominated at 41% of

the sample. Importantly information from the community sector figured significantly in the responses to this item. These included the New Zealand AIDS Foundation (41%), Body Positive (37%), HIV/AIDS organisation publications (34%) and HIV magazines and newspapers (32%). HIV positive friends were nominated by around a fifth (20%) of respondents.

When asked in a separate question to nominate the *most* important source of information on treatments 59.6% said a HIV specialist at an outpatient clinic, 5.3% said NZAF, and 5.3% said Body Positive. No other response accounted for more than 5% of the sample.

Information about HIV Management

When asked what sources of information around HIV management were important, a similar pattern emerged with HIV specialists at outpatient clinics nominated by 72% of the sample and community sector sources also figuring prominently (New Zealand AIDS Foundation: 42%, HIV organisation publications: 35%, Body Positive: 34%, HIV magazine: 29%). HIV positive friends were also mentioned by 25% of the sample.

When asked to nominate the *most* important source of information on HIV management 46.0% said an HIV specialist at an outpatient clinic, while 15.3% nominated the New Zealand AIDS Foundation, and 7.4% nominated Body Positive.

Information on Living with HIV

The pattern in responses to the question of important sources of information on living with HIV differed somewhat from the previous two items. The source selected by the greatest number of respondents was the New Zealand AIDS Foundation (51%), followed by Body Positive (46%), an HIV specialist at an outpatient clinic (38%), HIV positive friends 37%, publications from HIV/AIDS organisations (34%) and HIV newspapers or magazines (32%).

When asked to identify the *most* important source of information on living with HIV 23.8% nominated the New Zealand AIDS Foundation, 18.5% an HIV specialist at an outpatient clinic, 14.6% Body Positive and 10.6% HIV positive friends.

As the Internet is seen as increasingly important, but problematic source of information on HIV, we included two items to assess how reliable respondents felt the information available was. The responses are presented in Table 31. As can be seen from these data, PLWHA are reasonably sceptical about the reliability of information available on the net. Those who rate the Internet as an important source of information are less sceptical than others.

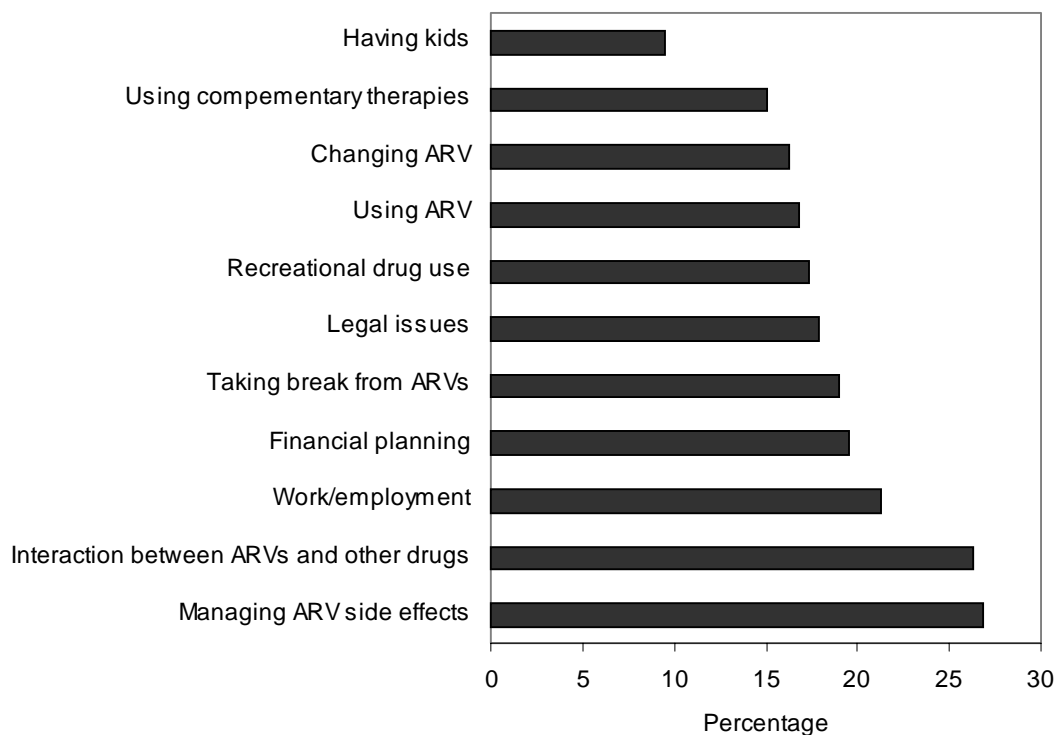
Table 31 Attitudes to HIV information on the Internet (percentage of sample)

	Strongly Disagree	Disagree	Agree	Strongly Agree	Don't know
Full sample					
Information on the internet about living with HIV is unreliable ^b	1.1	16.4	14.8	2.2	65.6
Information on the internet about treatment side effects is unreliable ^b	1.1	18.1	14.3	1.6	64.8
Those who rate the internet as an important source of information					
Information on the internet about living with HIV is unreliable ^c	2.0	42.0	22.0	4.0	30.0
Information on the internet about treatment side effects is unreliable ^d	2.0	44.0	20.0	2.0	32.0

a N=183; b N=182; c N=50; d N=50

Lack of information

When asked to identify domains in which lack of information made it difficult to make decisions, around one quarter of respondents nominated the management of side effects (26.8%) and interactions between antiretrovirals and other medications (26.3%). Employment and financial planning also figured prominently (see Figure 13 below).



(Multiple responses possible)

Figure 13 Problems experienced due to lack of information

Publications

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 32, including breakdowns for specific populations where access or focus is an issue. Gay and HIV press are accessed by large proportions of the sample, as are HIV community publications (particularly within their constituency area). It is clear from these data and that in the previous section that community publications remain an important site for information dissemination and community debate.

Table 32 Publications read by PLWHA

Publication	Percentage
<i>Non-specific</i>	
Positively Positive	58.5
Collective Thinking	56.8
Newsletters from community organisations	29.0
Other websites	15.9
Overseas HIV magazines (eg. Poz)	11.4
Positive Living (Aus)	7.4
NZAF Website	7.4
Overseas gay press	6.3

Publication	Percentage
National AIDS Bulletin (Aus)	5.1
HIV Herald	3.4
With Complements	1.7
Other	5.1
<i>Target group specific</i>	
NZ gay magazines	25.0
NZ gay magazines (% gay men, lesbians and bisexuals)	33.1
Gay newspapers	40.3
Gay newspapers (% gay men, lesbians and bisexuals)	53.5
Australian gay newspapers	5.7
Australian gay newspapers (% gay men, lesbians and bisexuals)	7.9
Australian gay magazines	2.8
Australian gay magazines (% gay men, lesbians and bisexuals)	3.9

Involvement with AIDS Organisations

Participants were asked about their involvement with HIV/AIDS organisations. 76.7% of the sample has some contact with HIV/AIDS organisations. Of these, 84.5% received newsletters and mail outs, 71.1% were clients, 43.7% were members, 12.0% were volunteers and 3.5% were employees. Of those who had no contact with AIDS organisations, 60.0% gave the reason *I do not want to be involved*, 25.0% gave the reason *I do not have enough time*, 7.5% said that they had *no transport or are too far away* and 5.0% said they *do not know how to join*. Importantly, 17.5% of those who were not involved in AIDS organisations said they *felt excluded from them*. 25.8% had at some point held a decision making position in an AIDS organisation (12.1% in the last two years).

WELL-BEING

This section focuses on the lives of HIV positive people beyond the clinical aspects. While the distinction between the clinical and social experiences of being HIV positive is to some extent artificial, we feel it is important, in an environment where HIV positivity is increasingly being represented as a clinical state, to continue to emphasise the psychological and social sequelae of HIV infection, both positive and negative. To this end, we have asked about the experience of HIV within eight domains: the social and community experience of HIV; mental health and social support; accommodation; sex and relationships; recreational drug use; employment; finances; and discrimination. Taken with the information in the previous sections this gives a rounded view of the lives of HIV positive people. Issues around treatment breaks, for example, can be understood in the context of the lived experience of housing, employment and discrimination. We also include two sections, sexual relationships and drug use, which are most often seen in the AIDS literature where HIV positive people are regarded in the context of infection and prevention. While we do examine these issues in that context, if only to demonstrate the extent and complexity of prevention strategies employed, we are also concerned about the place these issues have in HIV positive people's lives and the benefits they bring.

THE SOCIAL WORLD OF PLWHA

This section examines the collective experience of HIV from a number of perspectives. While for some people HIV may be a profoundly isolating experience, within New Zealand the experience of HIV has been overwhelmingly a collective one. HIV is not only experienced by individuals, but also by communities and social networks. HIV identity is managed through contact with other positive people, through the disclosure of status, both willingly and unwillingly, and through engagement with the community sector. Here we explore some of these issues through the experiences of the respondents to this survey.

Summary:

- 16% do not know anyone else with HIV
- 70% have had someone close to them die of AIDS
- 22% have been involved in the nursing and care of someone with AIDS
- 84% have disclosed their HIV status to at least one other person
- 54% have had their HIV status disclosed without their permission
- 33% have had their HIV status disclosed without their permission in the last 2 years
- 53% consider their HIV status an *important* part of their identity
- 18% consider HIV to be an *essential* part of their identity
- 80% of those with a partner get a *lot* of support from this person
- Other major sources of support include friends, family, health workers and pets

Mental Health

- 23% were currently taking anti-depressants
- 15% were currently taking anti-anxiety medication
- 7% of respondents rated high on a measure of symptoms of depression

Planning for the Future

- 25% of PLWHA plan only one day at a time
- 12% plan 10 years or more into the future

Contact with Other PLWHA

A significant minority of HIV positive people (16.1%) do not personally know anyone else with HIV. Many positive people have a HIV positive friend (58%) and many have either a positive partner or ex-partner (23.1% combined). 21.8% of respondents have been involved in the nursing or care of another positive person at some time in the last two years, and 69.5% have had someone close to them die from HIV/AIDS.

Table 33 Other HIV positive persons known by respondent

Positive persons	Percentage
No-one	16.1
Partner/ spouse	10.8
Former partner/ spouse	15.1
Friend	58.1
Son/ daughter	1.1
Other relative	4.3
Acquaintance/ member of support group	52.2

(Multiple responses possible)

Around three-fifths of the respondents spend at least some time with other positive people. Those respondents who spent either 'some' or 'a lot' of time with other HIV positive people were more likely to work for HIV/AIDS-related organisations.

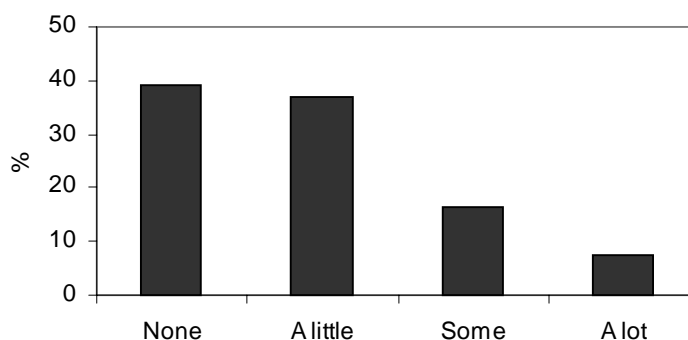


Figure 14 Time spent with other positive people

Disclosure

Respondents were asked who they had disclosed their HIV status to (see Table 34). Not surprisingly, most (84%) had disclosed to close friends, and most (93%) of those in relationships had disclosed to their partner. Within families, people were most likely to have disclosed to siblings (62%) although many had disclosed to parents (55%). Only 3% (N=6) had not disclosed their HIV status to anyone.

☞ **See also Relationships and Sex page 59**

Table 34 Disclosure of HIV status

	Percentage who have disclosed
No-one	3.2
Partner/ spouse	52.2
Positive friends	46.8
Close friends	83.9
Other friends	31.7
Work colleagues	32.8
Neighbours	16.1
Parents	55.4
Brothers or Sisters	61.8
Other family/ Whanau members	32.8
People from own ethnic community	9.7
Son/ daughter	16.5
Specific Sub-Groups	
Partners (% of those in regular relationship)	93.2
Partners (% of those not in regular relationship)	23.4

	Percentage who have disclosed
Work colleagues (% of those currently employed)	39.7
Work colleagues (% of those not employed)	29.1
Son/ daughter (% of those with children)	53.6
People from own ethnic community (% of those who speak a language other than English at home)	50.0

(Multiple responses possible)

Unwanted Disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. 53.8% said that it had at some point, and 33.0% that this had happened in the last two years. Their responses when asked who disclosed their status are shown in Table 35. When asked who disclosed their status, they were most likely to nominate friends, work colleagues and neighbours.

Table 35 Sources of unwanted disclosure (percentage of those experiencing unwanted disclosure)

	Percentage
HIV positive friends	28.9
Close friends	27.8
Work colleagues	20.6
Neighbours	18.6
Partner/spouse	15.5
Brothers/sisters	13.4
Parents	11.3
Other family	11.3
Community organisation staff/volunteers	8.2
People from ethnic community	6.2
Workers in a health care setting	6.2
Son/daughter	1.0
Other friends	1.0
Other	12.4

The Place of HIV in People's Lives

HIV affects many parts of a person's life in both positive and negative ways. Knowledge of one's HIV status can be something that dominates some people's sense of who they are, while for others it will be a minor facet of their self-image. These different experiences of HIV status can

have significant implications for the provision of services and the targeting of education for positive people.

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 36. 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 (53%) of positive people in this study consider their HIV status an important, but not essential aspect of their make-up, while 18% consider it to be an essential characteristic. This is in contrast to sexuality and gender, where over 20% of the sample considers these to be *essential* characteristics.

Table 36 Importance of personal characteristics to respondents' sense of identity

	Essential	Important	Not important	Irrelevant
HIV status	17.5	53.0	19.7	9.8
Sexuality	24.2	50.0	17.6	8.2
Gender	30.2	38.5	21.2	10.1
Drug use (recreational/illegal)	3.4	11.4	28.0	57.1
Ethnicity/ Cultural background	6.3	33.3	23.6	36.8
Parenthood	13.6	19.3	16.5	50.6
Career	14.0	44.9	22.5	18.5
Family/Whanau	34.4	42.8	8.9	13.9
Religious beliefs	13.6	17.0	24.4	44.9

When we look at the importance of HIV status among specific sub groups of PLWHA, we find that men and those that have had an AIDS defining illness see HIV as being less important to their identity, however ratings of importance were unrelated to use of antiretroviral drugs or partner sero-status (See Table 37).

Table 37 Importance of HIV status to sense of identity for different groups of PLWHA

Importance of HIV status among:	Essential	Important	Not important	Irrelevant
Gay and bisexual men	20.5	55.6	17.1	6.8
Women	3.0	48.5	30.3	18.2
Heterosexual men	31.6	47.4	10.5	10.5

N varies for each sub group

When the importance of the other attributes is examined for specific sub-groups of PLWHA, we find that there are significant differences between some of these groups (see Table 38).

Table 38 Importance of personal characteristics to sense of identity for different groups of PLWHA

	Essential	Important	Not important	Irrelevant
Sexuality				
Gay men and lesbians	28.1	52.9	14.0	5.0
Heterosexuals	16.7	40.5	26.2	16.7
Bisexual and other	15.8	52.6	21.1	10.5
Gender				
Women	30.2	39.6	21.5	8.7
Men	30.0	33.3	20.0	16.7
Drug Use				
Users of illegal drugs	5.9	18.8	43.5	31.8
Non users	1.1	4.4	13.3	81.1
Ethnicity				
Anglo	6.4	29.9	24.2	39.5
Non-Anglo	10.0	60.0	20.0	10.0
Parenthood				
Dependent children	59.1	36.4	0.0	4.5
Non dependent children	7.1	16.9	18.8	57.1
Career				
Employed	19.7	59.2	19.7	1.4
Not employed	10.6	36.5	24.0	28.8

N varies for each sub-group

Social Support

We asked participants about the amount of social support they received from a range of sources including household members, social contacts and service providers. The ratings are shown in Table 39 below with those designating the category as not applicable excluded from each row.

The source that participants were most likely to rate as one they receive a *lot* of support from was the participant's partner or spouse (80% of those with partners). This was followed by pets,

where 67% of pet owners rated them highly. Close friends, parents and doctors were also rated highly by around half of the participants.

When we examine those that people receive no support from, the highest ranking category was volunteer carers where 47% of those with such a source said they received no support from them. Religious or spiritual advisors were also considered a source of no support for 33% of those in contact with these.

Participants were more likely to rate a source as supportive if they had disclosed to them for all categories, except acquaintances and children.

The data from this item can be analysed to see the number of categories from whom respondents receive support. If we take the number of sources from whom the respondent received *a lot* of support we have a measure ranging from 0 to 15.⁵ The mean number of sources of *a lot* of support was 3.2 with a median of 3 sources and 15.5% receiving *a lot* of support from no sources. We can repeat this analysis for different degrees of support. For example, the mean number of sources of *a lot* or *some* support is 5.3 (median=5, 8.3% with none) and the mean number of sources of *no* support was 1.5.

⁵ Here we include those who designated the category as not applicable in the analysis, as this still indicates that the respondent does not receive support from this source

Table 39 Social support received from different sources: percentage of those who gave valid responses

	A lot	Some	A little	None
Partner/ spouse	80.2	4.7	5.8	9.3
Pets	66.7	14.3	11.4	7.6
Close friends	52.6	26.3	14.0	7.0
Parents	51.7	20.0	7.5	20.8
Doctor	46.1	29.2	19.1	5.6
Brothers and sisters	40.8	22.5	18.3	18.3
Children	40.4	17.0	17.0	25.5
HIV positive friends	29.9	31.6	23.9	14.5
Volunteer carer	29.8	17.0	6.4	46.8
Health care workers	26.4	28.9	24.0	20.7
Counsellor	26.0	26.9	27.9	19.2
Family/Whanau	24.5	24.5	20.0	30.9
Religious or spiritual adviser	23.3	30.2	14.0	32.6
PLWHA groups	13.2	26.4	33.0	27.4
Other friends	12.6	37.0	28.1	22.2

Mental Health

Issues around mental health continue to figure large in discussions of the needs and status of positive people in many parts of the world. While a survey like this cannot expect to offer a clinical perspective on mental health status, we can give an overview of some of the experiences of positive people that fall within the broad area of mental well being.

Psychiatric Medications

In the last six months just under one quarter (22.5%) of PLWHA had been taking medication prescribed for depression. A smaller proportion (14.5%) had taken medication for anxiety. In addition 5.9% 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 40, 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 13% 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, 45.0% agreed or strongly agreed with none of these items, 18.1% with one item, 19.3% with two items, 10.5% with three items, and 7.0% 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: having a poorer self-rating of general health and being on anti-depressant medication. Scores on these items are unrelated to: CD4 count; viral load; level of social support; having had an AIDS defining illness; use of antiretrovirals; length of infection; gender and sexuality.

Attitudes to HIV status

Two additional items were included that examine an individual's relationship to their HIV. Participants were asked whether they agreed with the statement *As long as I am well I prefer not to think about HIV/AIDS*. More than half the respondents agreed or strongly agreed with this statement. Those in agreement were more likely to be female. The second statement participants were asked to respond to was *Life has become more meaningful since I became HIV positive*. Again, more than half agreed or strongly agreed with this statement. Those in agreement were more likely to report lower levels of both health and well-being.

Table 40 Attitudes on HIV status: percentage of total sample

	Strongly agree	Agree	Disagree	Strongly disagree
I cry or feel like crying all the time	4.3	17.3	50.8	27.6
I don't enjoy things the way I used to	14.4	39.0	29.4	17.1
I have lost interest in other people	6.0	26.2	40.4	27.3
I don't feel it's worth going on	5.0	7.8	31.7	55.6
As long as I am well I prefer not to think about HIV/AIDS	19.5	40.0	33.0	7.6
Changes in my body due to HIV/AIDS have made me feel unattractive	17.3	36.8	33.0	13.0
I am happy with the way my body looks	8.6	44.3	37.3	9.7
Life has become more meaningful since I became HIV positive	16.8	39.5	31.9	11.9

Planning for the Future

A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. Almost a quarter (24.7%) only plan their life one day at a time and 20.4% plan only a few months ahead. More than half of the respondents plan for at least a year with 25.8% planning one year ahead, 17.2% planning five years ahead and 11.8% planning ten years or more ahead. Those with longer time frames tend to be those who have lower viral load and higher CD4 counts.

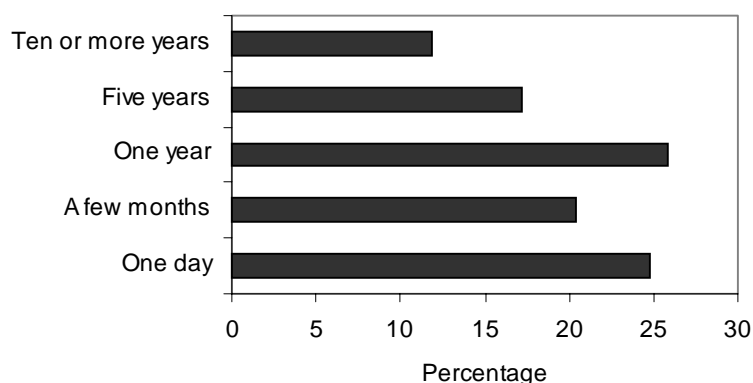


Figure 15 Time frame for future planning

For 45.1% of respondents, the time frame for future planning had changed in the last two years, with 18.0% of all respondents now using a shorter time-frame and 24.6% using a longer time frame.

The major reasons for change for those with a longer time frame were improved health due to treatments (52.3% of those with longer plans), while the major reason for change for those with a shorter time frame was declining health (48.4% of those with a shorter time frame), see Figure 16.

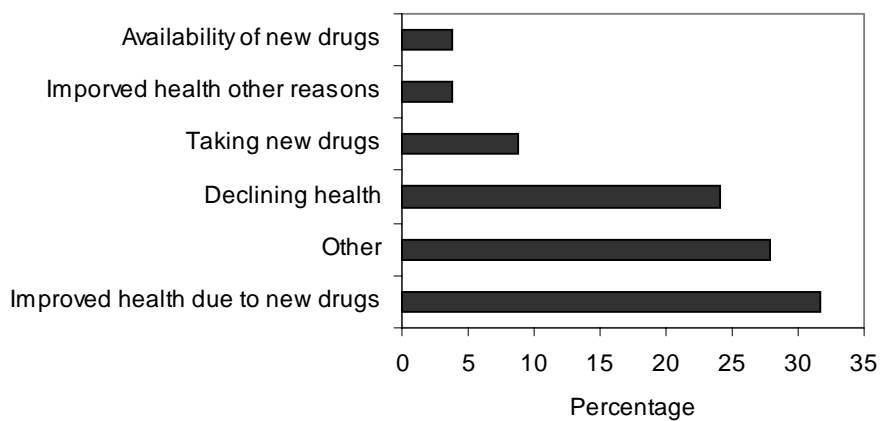


Figure 16 Reasons given for change in time-frame

RELATIONSHIPS AND SEX

Summary:

- 40% currently have no sexual relationships
 - 63% of positive women currently have no sexual relationships
 - 41% have a current regular sexual partner
 - 21% of sexual partners are also HIV positive
 - Partners are generally supportive around HIV issues
 - HIV positive people employ a range of strategies to prevent their sexual partners becoming infected
 - 12% have dependent children
 - 19% were considering having children
-

Relationships

Respondents were asked what sexual relationships they currently have. The results are presented in Table 41 below. Almost two fifths of the sample said that they had no sex at present. Equal proportions reported that they had a regular relationship only and had casual sex only, while slightly fewer that they had a regular relationship plus casual sex. When this item is broken down by sex and sexuality, we find significantly different patterns between three groups of PLWHA. Homosexual and bisexual men were less 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 were the only ones who reported report that they have casual sex only or have a regular sexual partner and also have casual sex.

Table 41 Type of sexual relationship(s) by gender and sexuality of respondent

Sexual relationships	Women	Heterosexual men	Homosexual & bisexual men	Total
No sex at present	62.5	68.4	29.7	39.7
Casual sex only	0.0	0.0	32.0	22.9
Regular relationship plus casual sex	0.0	0.0	18.8	13.4
Regular relationship only	37.5	26.3	18.8	22.9
Regular with two or more people	0.0	5.3	0.8	1.1

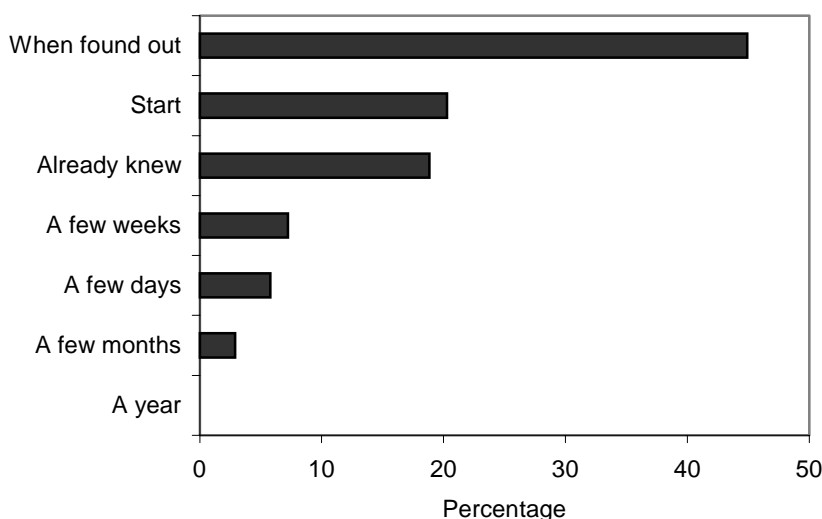
N varies for sub-groups

When asked if they were currently in a regular relationship, around half (41.3%) said they were. This is slightly higher than the proportion of the sample that report having sex with a regular partner in Table 41 (37.4%), as some in a regular relationship do not have sex.

Regular Partners

Of those in a relationship with a regular partner, 21.1% report that their partner is also HIV positive (generally described as a sero-concordant relationship). The remainder are in sero-nonconcordant relationships. This remaining group is made up of 69.0% of the sample who report that their partner is HIV negative (a sero-discordant relationship) and 9.9% who report that they don't know their partner's HIV status.

Nearly all PLWHA (97.2%) have told their regular partner that they are HIV positive. Both the respondents who had not disclosed their status had HIV negative partners. Respondents were asked at what point in the relationship they told their partner. The responses are given in Figure 17 below. Almost one half (44.9%) of the respondents told their partner when they themselves found out they were positive. Around one fifth (20.3%) told their partner at the beginning of the relationship and for 18.8% of respondents, the partner knew prior to the start of the relationship. Small numbers of respondents (5.8%) told their partners a few days into the relationship, 7.2% a few weeks into the relationship and 2.9% a few months into the relationship. None of the respondents disclosed their status a year or more into the relationship.



N=69

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

When asked how their partner responded when told of the respondent's HIV status, the majority (70.1%) reported that the partner was supportive (see Figure 18). Two fifths (41.6%) reported

that it did not make any difference and over one third (36.4%) reported that the disclosure brought them closer together. Despite this, almost half the respondents (44.2%) reported that their partner was worried or scared and 15.6% said their partner was angry.

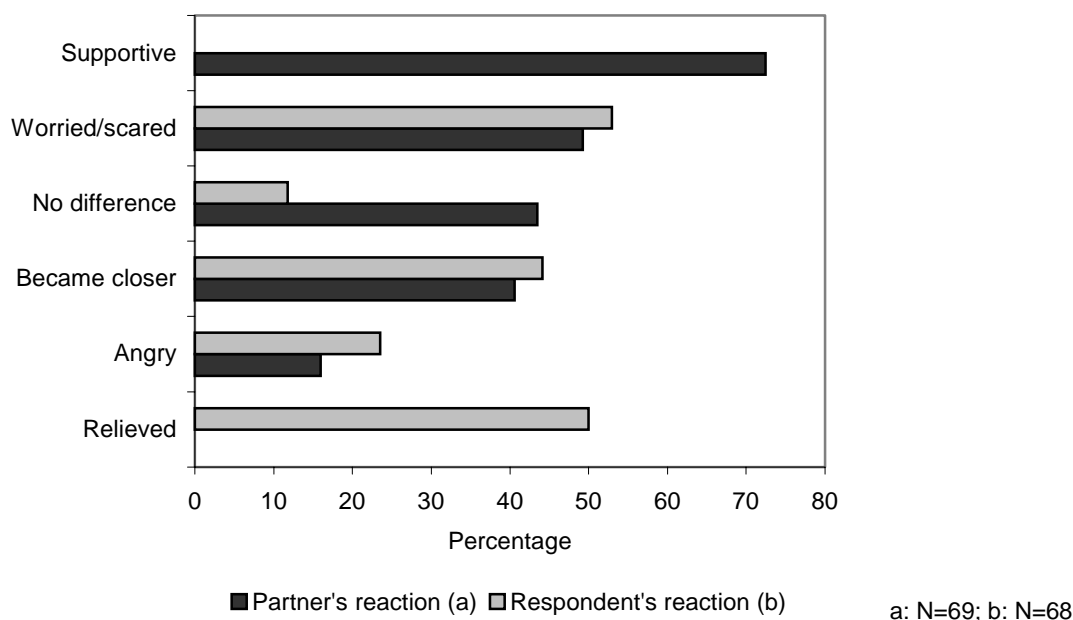


Figure 18 Reaction of partner^a and respondent^b to disclosure: percentage of those in regular relationships

Note: Respondents were not asked if their partner was relieved or whether they themselves were supportive.

We also asked how the respondent themselves felt about this disclosure. In general the patterns matched those of their partners, although respondents were less likely to report that it made no difference to themselves than they were to report that it made no difference to their partners.

PLWHA in regular relationships were asked about the sex they had with their regular partner. In total, 28.7% had penetrative sexual intercourse with a regular partner in the last six months. We have reported the data in the following tables on sexual practice and condom use in numbers rather than percentages, as the small sub-samples would give an inflated view of the proportions in some categories. Table 42 shows patterns of condom use with regular partners by respondent and partner gender.

Table 42 Condom use with regular partner by respondent and partner gender

ALL relationships	<u>Number of these who used condom</u>		
	Never	Sometimes	Always
Female respondents⁶			
With regular male partner	1	4	6
Male respondents			
With regular male partner	5	11	18
With regular female partner	5	2	8

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 43).

Table 43 Condom use with regular partner by partner sero-status: frequency

Partner Serostatus	<u>Number of these that used condom</u>		
	Never	Sometimes	Always
HIV Positive	4	7	4
HIV Negative/Don't Know	3	9	19

Casual Partners

As was shown above, 36.3% of respondents had sex with casual partners. When asked if they had had penetrative sex with a casual partner in the last six months, 24.9% said that they had. When asked the HIV status of their casual partners, 2.9% reported that all of their casual partners were HIV positive, 8.6% reported that some of their casual partners were HIV positive, and 11.6% reported that none of their casual partners were HIV positive. Most respondents (77.1%) 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 44 there are considerable variations in condom use when we examine this by sex of respondent and sex of partner. Unfortunately, there were not enough respondents to compare use of condoms with casual partners of different serostatus.

⁶Only one female respondent reported anal or vaginal intercourse with female partner(s). For reasons of confidentiality these results are not reported.

Table 44 Condom use with casual partner by respondent and partner gender

ALL casual partners	Number of these who used condom		
	Never	Sometimes	Always
Male respondents			
With casual male partners	1	24	23
With casual female partners	2	2	3

Note: No female respondents reported sex with casual partners

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. 27.1% of the survey respondents provided such information.

Of the respondents who had casual sex, 89.4% had vaginal or anal intercourse on their last occasion with a casual partner. Condom use during respondents' most recent sexual encounter was contingent on the HIV status of the partner. Figure 19 gives a breakdown of the range of protective strategies employed by positive people to protect their most recent casual partner. This includes knowledge of HIV status, condom use and avoidance of ejaculation within their partner. This schematic shows that for the entire set of data available, incidents that involved any risk were very rare and mostly associated with partners of unknown status.

Respondents who indicated that they knew their partners' HIV status were asked how they knew. All but one of these fifteen respondents said that their partner told them their status.

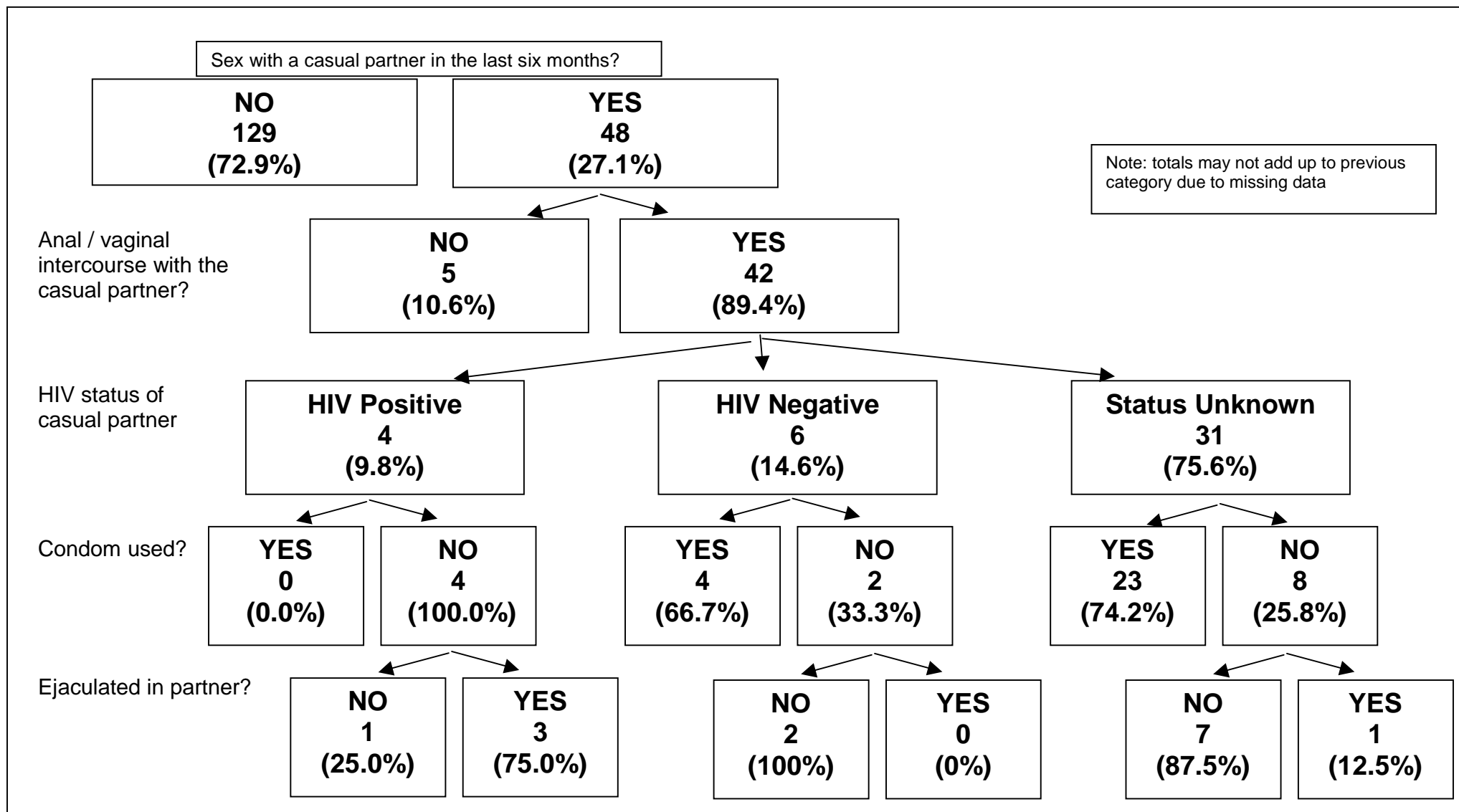


Figure 19 Sexual practice with the most recent casual partner

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 45. The majority of these items are about the negative effects of HIV on people's sexual lives. This is not to suggest that the sexual lives of positive people are inherently problematic, but rather, it is a recognition that these issues are those that are most in need of policy and programmatic response. They are also issues that need to be discussed within affected communities and we hope that this material may facilitate public debate.

The responses that we sought from participants fall into three broad areas: those concerned with relationships; those concerned with HIV transmission; and those concerned with sexual pleasure.

One critical issue for PLWHA is the impact that HIV has on the potential to develop new relationships. Almost three quarters (72.7%) 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. 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 (58.3%) agreed with this statement.

Despite this, when asked whether they would prefer to be in a relationship with someone who is also HIV positive, just under half (44.5%) said they wouldn't, just over a third (34.1%) said they would, while the remainder (21.0%) said that they did not know. When asked to respond to the statement *Being HIV positive has helped me form more satisfying relationships*, around one fifth (21.2%) agreed, while 18.8% said they were uncertain.

Concerns about transmission of the virus to others and re-infection were apparent in the responses to the next six items. Most respondents (80.0%) agreed with the statement *I am afraid of infecting my partner, or potential partner, with HIV*, while very few agreed with the statements *I feel more confident about unprotected sex because of the new treatments*, and *Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV*. Similarly, the impact of potential vaccines on intentions to practice safe sex and anxiety about safe sex is minimal with 15.8% agreeing with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*, and 12.6% agreeing with the statement *Knowing that a vaccine will become available makes me less anxious about sex*. Respondents were also concerned about re-infection, with 56.4% agreeing that *I am concerned about becoming infected with another strain of HIV* and 29.7% disagreeing.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (65.7%) agreed with the statement *HIV has had a negative effect on my sexual pleasure*. Under a third (29.7%) disagreed with this statement. When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. Around a third (33.7%) were unsure when asked to respond to the statement *If I know that my partner is HIV positive I find sex more pleasurable*. More respondents disagreed with this statement (41.0%) than agreed with it (25.3%). Those who agreed with this statement were also more likely to agree that they would prefer a relationship with someone who was HIV positive. Over a third (37.7%) said that they agreed with the statement *I have stopped having sex because of my HIV status* while 56.6% agreed that *HIV has negatively affected my libido*.

Table 45 Attitudes to HIV, sex and relationships

	Strongly Disagree	Disagree	Agree	Strongly agree	Don't know
I prefer to have a relationship with someone who also has HIV	12.5	32.4	23.3	10.8	21.0
Few people would want a relationship with someone who has HIV	3.9	10.6	46.4	26.3	12.8
I am afraid of telling potential partners of my HIV status in case they reject me	8.9	23.8	39.3	19.0	8.9
I am afraid of infecting my partner, or potential partner, with HIV	6.5	8.8	44.1	35.9	4.7
I feel more confident about unprotected sex because of the new treatments	60.3	28.7	2.3	2.9	5.7
If I know that my partner is HIV positive I find sex more pleasurable	16.9	24.1	17.5	7.8	33.7
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	29.2	26.9	24.6	10.5	8.8
HIV has had a negative effect on my sexual pleasure	13.1	16.6	43.4	22.3	4.6
I am concerned about becoming infected with another strain of HIV	9.9	19.8	41.9	14.5	14.0
Being HIV positive has helped me form more satisfying relationships	22.4	37.6	13.3	7.9	18.8
If there was a vaccine which prevents HIV, I would not practise safe sex	34.9	34.9	12.2	3.5	14.5
Knowing that a vaccine will become available makes me less anxious about sex	23.4	40.7	10.2	2.4	23.4
I have stopped having sex because of my HIV status	24.0	36.0	26.3	11.4	2.3
HIV has negatively affected my libido	15.4	21.1	36.0	20.6	6.9

HIV disclosure and legal issues

Interpretation of current New Zealand law as it relates to HIV transmission is not settled in several important respects. It is clear that disclosure of HIV status, and the obtaining of consent, is required to avoid legal liability under several statutes when the risk of transmission is significant; that certainly includes anal and vaginal sex without condoms and also needle sharing. The position is less clear with respect to anal and vaginal sex when condoms are used. However, the Court of Appeal in *R v Mwai* [1995] has indicated that it favours the position that disclosing HIV status and obtaining consent is the primary legal duty, and this could still apply regardless of whether condoms are used or not. Notwithstanding, this specific question remains untested in a New Zealand court to date.

Respondents were asked three questions concerning their attitudes towards these legal issues. As can be seen from Table 46, around 16% of respondents were uncertain about the current legal situation. 13.1% of respondents agreed that disclosure of HIV status obviated the need to use a condom. It is important to note that the current legal situation has led to discomfort and uncertainty around the establishment of close relationships, which may in turn have a negative impact of people's lives.

Table 46 Attitudes to legal issues around disclosure

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Currently it is legally OK for someone to use a condom for anal or vaginal sex and not tell their partner their HIV status	27.2	19.3	27.2	10.5	15.8
Currently it is legally OK for a person to disclose their HIV status to a partner and then not use a condom for anal or vaginal sex	41.2	28.9	9.6	3.5	16.7
The current legal situation about disclosure of HIV status has limited my ability to form new relationships	16.5	31.1	34.0	18.4	0.0

Children

As mentioned in the description of the sample earlier in this report, 12.4% of those surveyed currently have dependent children. We were also interested in future plans for children among PLWHA. Most PLWHA (80.8%) were not currently considering having children. Of the remainder, two PLWHA have decided to have children in the future. Ten are currently considering having a child, but have not decided, nine people have considered having a child, but have decided it is too risky, and a further nine said they didn't have enough information to make a decision. Three respondents are currently pregnant, and another respondent has a pregnant spouse.

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

RECREATIONAL DRUG USE**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 New Zealand. 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 47 gives these results. As can be seen from these data, alcohol is the most commonly used drug followed by tobacco and marijuana. Other drugs that are popular in the gay and dance party scenes (amyl, ecstasy, non-injected speed and Viagra) are also used by PLWHA.

Table 47 Recreational use of drugs

	Percentage of sample using in last 12 months
Alcohol	79.2
Cigarettes	46.1
Marijuana	46.1
Amyl	29.4
Speed (not injected)	13.6
Viagra or similar	11.9
Ecstasy	10.7
LSD/ trips	10.2
Speed (injected)	4.0
GHB/GBH/Fantasy	4.0
Cocaine (not injected)	3.4
Steroids (injected)	3.4
Homebake	1.1
Methadone (prescribed)	1.1
Methadone (other)	0.6
Heroin (injected)	0.0
Heroin (not injected)	0.0
Khat	0.0
Cocaine (injected)	0.0

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 is occasional rather than regular and this may inflate the rates reported here. The study also deliberately sampled among injecting drug users.

Gay male respondents are significantly more likely than other groups to use amyl, but weren't more or less likely to use any other drug.

About one in twenty (5.4%) PLWHA reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs.

Around one in nine (11.1%) 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 who used non-prescribed LSD, cocaine, speed, and ecstasy.

Most respondents (85.6%) reported that they had never injected illegal drugs. Of those respondents who had injected illegal drugs approximately one quarter (26.9%) had done so in the last 12 months. Of the 26 respondents who reported injecting drugs, only 1 respondent shared injecting equipment in the past twelve months.

Attitudes Relating to Drug Use

Almost a quarter (22.9%) of respondents felt that they drank more alcohol than they would like to and 9.0% felt they used more illegal drugs than they would like to. As specific quantities of drugs used were 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 *not applicable* responses to these items.

Table 48 Attitudes relating to drug use

	Strongly disagree	Disagree	Agree	Strongly agree	Not applicable
I drink more alcohol than I would like	26.8	35.2	17.3	5.6	15.1
I use illegal drugs more than I would like	19.7	24.7	7.9	1.7	46.1
Sharing needles is not a problem if your viral load is undetectable	41.6	7.9	.6	1.1	48.9
I worry about infecting others by sharing needles	5.7	1.1	1.7	7.4	84.1

ACCOMMODATION

Summary:

- 37% own or are purchasing their home
 - 28% live in private rental accommodation
 - 18% live in public rental accommodation
 - 32% said their accommodation was unsuitable for their needs
-

The current accommodation of the respondents can be seen in Table 49. Respondents were most likely to own or be purchasing their own house or flat, but were also commonly in private rental accommodation. A smaller number of people are in public rental accommodation; they are more likely to be on a government benefit.

Table 49 Current accommodation of respondents (percentage of total sample)

Accommodation type	Number	Percentage
Own or purchasing house or flat	71	37.0
Private rental accommodation	54	28.1
Public rental accommodation	35	18.2
Rent-free	21	10.9
Community housing/housing co-operative	2	1.0
Other	9	4.7

Households varied considerably. 36.6% of PLWHA lived by themselves, while the remainder lived with between 0 and 20 other adults (mean=1.5, median=1) and with between 0 and 4 children (mean=0.4, median=0). These children ranged in age from 0 to 28 (mean=9.2, median=9).

58.6% of PLWHA lived with pets. The most common pets were cats (41.5% of all respondents), followed by dogs (24.9%). Other companion animals included fish, birds and farm animals.

Respondents most commonly lived in a residence with 2 bedrooms (40.2%), while the remainder had 3 bedrooms (31.2%), 4 or more bedrooms (13.2%), or 1 or fewer bedrooms (15.3%).

74.9% of respondents had access to a car. When asked how easy it was to access public transportation, 16.9% said it was very difficult, 13.2%, difficult, 41.8% easy and 28.0% very easy.

77.5% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (N=43), the main reasons given were that it was too small (56%), lacked privacy (47%) and was too far from health services (35%),

Table 50 Reasons current accommodation is unsuitable (percentage of those with unsuitable accommodation)

Reason	Number	Percentage
Too small	24	55.8
Lack of privacy	20	46.5
Too far from health services	15	34.9
Too expensive	11	25.6
Too far from other services	11	25.6
Poor condition of housing	10	23.3
Inadequate for current state of health	10	23.3
Inadequate facilities for carers	6	14.0
Confidentiality problems	6	14.0
Fear of violence	5	11.6
Harassment	4	9.3
Other	7	16.3

Participants were also asked if they had ever changed their accommodation as a result of having HIV/AIDS and 39.1% had, and 15.1% had in the last two years. On average those PLWHA who had changed their accommodation as a result of HIV/AIDS had done so 2.5 times.

We asked what the circumstances were around participants' last change in accommodation. The results are shown in Table 51. Financial and health issues figured most prominently in response to this question. Of those who had moved in the last two years, the most common reason given was moving to cheaper housing (32%) followed by moving to a quieter location (27%) and moving closer to health services (24%).

Table 51 Reasons for changing accommodation

	Percentage of those who had moved
Moved to cheaper housing	32.4
Moved to a quieter location	27.0
Moved closer to health services	24.3
Planning for illness	24.3
Better health	21.6
Ending of long term relationship	20.3
Stopped working	20.3
Illness	17.6
Moved in with family/Whanau	16.2
To avoid harassment	16.2
Moved closer to friends	13.5
Lack of privacy	13.5
Improved finances	9.5
Moved closer to other services	8.1
Moved out of family home	8.1
Beginning of new relationship	6.8
Looking for/ returned to work	5.4

(Multiple responses possible) N=74

EMPLOYMENT

The area of employment continues to present challenges to HIV positive people. While the need for financial security, social contact and a sense of worth are critical factors in HIV positive people's wishes to be in paid employment, the management of HIV disclosure, the intermittent effects of illness and the need for flexibility around taking time off can prove substantial barriers to obtaining and retaining employment. There are also considerable obstacles for those who have left employment in the past and are attempting to return to the workforce. These include de-skilling, explaining an extended absence from the workforce, issues of aging and changes in life goals.

Summary:

- 53% were currently employed (38% full time)
- 20% said their career ended when they received their HIV diagnosis
- 53% of those who have worked have at some time stopped work due to HIV/AIDS

Employment Status

Just over half the respondents were currently employed, with more than twice as many being in full time work than those in part time work. The remainder tend to describe themselves as either unemployed (18.8%) or retired (12.4%). Of those who are working, the mean number of hours worked is 37.9 (median=40). Those working full time work an average of 45.0 hours per week (median=40) and those in part time employment work an average of 20.5 hours/week (median=22.5). Those who are not working stopped work between 1 and 180 months ago (mean=40.7 months, median=27.5 months).

Table 52 Employment status

	Percentage
Student	5.9
Unemployed	18.8
Not working/ retired	12.4
Home duties	2.2
Working full time	37.6
Working part time	15.1
Other	8.1

Impact of HIV and Treatment on Employment

We asked respondents how their HIV diagnosis affected their career plans and how their plans had changed since then. These data are shown in Table 53 below. A large proportion indicated that their career ended at their time of diagnosis (20.3%).

Table 53 Impact of HIV diagnosis on career plans (percentage of sample)

	Diagnosis	Subsequent experience
There has been no change	27.5	22.7
A career is no longer as important	15.9	13.1
Changed careers	7.1	9.7
Less likely to change careers	1.1	5.7
More difficult to plan for future	28.0	22.2
Career ended/stopped work	20.3	26.7

We asked about the impact of antiretroviral therapy on respondents' career plans (see Table 54 below). Of those who have used antiretrovirals, the most common response was that this had not affected their plans. The relationship between commencement of antiretroviral therapy and health status may explain the fact that 11.7% said that they stopped work when they commenced ARV, while 15.2% said that they anticipated a longer time in the workforce.

Table 54 Impact of antiretroviral therapy on work

	Percentage
Not used antiretrovirals	18.1
There has been no change	27.5
Considered new career plan	4.7
Made new career plan	5.8
Considered stopping work	1.8
Stopped work	11.7
Considered going back to work	2.9
Went back to work	2.9
Anticipate longer time in work force	15.2

Interruptions to Employment

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those who have worked, 52.8% had stopped work for reasons related to HIV at some point. These work interruptions averaged 35.3 months. The circumstances relating to the most recent interruption to employment are given in Table 55 below. The most common response was that diminished energy levels had played an important role in the decision. Over half of the sample also cited poor physical health and poor psychological health (stress, depression or anxiety).

Table 55 Circumstance surrounding last interruption to employment

	Percentage
Low energy levels	63.0
Poor health	57.6
Stress/ depression/ anxiety	52.2
To have more time to self	30.4
Expecting illness in future	23.9
To move to diff location	16.3
Redundant/ sacked	8.7
To care for someone with HIV	5.4

(Multiple responses possible) N=92

Of those who stopped working at some point, 53.3% had returned to work. This was most commonly for financial reasons (see Table 56), although the need to perform meaningful tasks and better psychological and physical health were also important.

Table 56 Reasons for returning to work

	Percentage
Financial reasons	83.3
To have something to do	54.2
Better physical health	50.0
To do something worthwhile	45.8
Better psychological health	43.8
Possibility of part-time work	33.3
To have more social contact	33.3
Possibility of flexible working hours	29.2
Possibility of full-time work	10.4

(Multiple responses possible) N=48

Those Currently in Paid Employment

Respondents were asked about the level of stress in their current job. Over one third rated the stress level as moderate (38.8%) while 28.6% said it was high and 12.2% said it was very high. Only 3.1% rated the stress level as very low and 17.3% said there was low stress (see Figure 20).

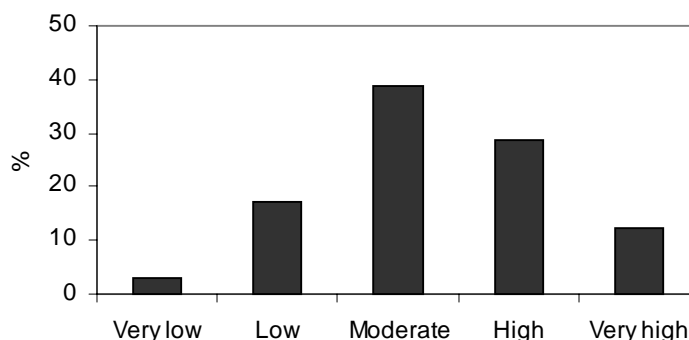


Figure 20 Stress at work

Confidentiality in the workplace remains a critical and complex issue for positive people, particularly given ongoing experiences of discrimination. When asked what difficulties they experience around confidentiality at work, 21.6% said that they do not attempt to keep their status confidential (see Table 57). Over half said they have experienced no problem in this area. Of those who do experience difficulties, the greatest problem appears to be visible signs of illness, followed by issues around explaining absences from work and medication.

Table 57 Difficulties with HIV status confidentiality in the workplace: percentages of total samples

	Total sample
No problems	60.8%
I do not try to keep my status confidential	21.6%
Visible signs of illness	19.6%
Difficulty keeping and taking medication	13.4%
Explaining absences from work	12.4%
Gossip	9.3%

(Multiple responses possible) N=97

When asked how many people in their workplace know that they are HIV positive, 8.2% said that everyone knows, 11.2% said most people know, 19.4% said a few people know, 15.3% said one person knows and 45.9% said no-one knows (see Figure 21).

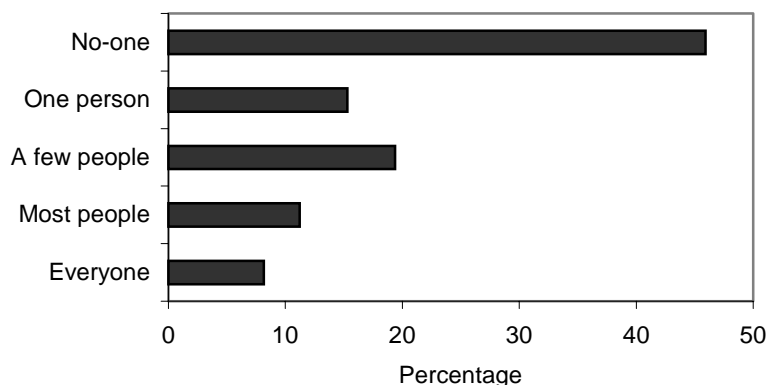


Figure 20 Disclosure in workplace

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 58). Over half also said that they tire more quickly, and almost one quarter said that they have difficulty concentrating.

Table 58 Impact of HIV on work capacity

	Percentage
Not affected by HIV	56.1
I tire more quickly	49.0
I have difficulty concentrating	22.4
I work reduced hours	13.3
I am less productive	13.3
I cannot always go to work	8.2
I do different duties	4.1

(Multiple responses possible) N=98

Living with HIV often involves intermittent periods of ill health, particularly around treatment changes and the need to access health and other services, often only available during work hours (Prestage et al. 2001). 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 59) and illness. There was less capacity to take time off for counselling and few had much capacity to take time off to engage in volunteer work.

Table 59 Capacity within workplace for HIV related interruptions

	Never	Seldom	Sometimes	Often	Always
When you are sick	7.1	2.4	15.5	11.9	63.1
For medical appointments	7.7	3.3	11.0	16.5	61.5
For counselling	28.8	6.8	11.9	8.5	44.1
To do volunteer work	62.7	5.9	7.8	2.0	21.6

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 44.9% said they did. Of these, two fifths said they planned to start or return to work and a similar proportion said they wanted to change the type of work that they do (see Table 60). Importantly, around one in four say they want to reduce the hours they work.

Table 60 Plans for changes to work life and anticipated difficulty

	Percentage who plan to change work life ^a	Difficulty		
		Not at all	Somewhat	Very
I want to start/ return to work	41.0	8.8	55.9	35.3
I want to stop work	4.8	25.0	50.0	25.0
I want to change the type of work I do	47.0	10.3	66.7	23.1
I want to reduce my work hours	25.3	4.8	52.4	42.9
I want to increase my work hours	13.3	18.2	81.8	0.0
Total		13.3	59.0	27.7

a: Multiple responses possible, N=83

The main incentives for changes in work arrangements were financial (see Table 61). Among those who intended to start or return to work, the primary motivations were financial, social and the desire to fill in the day with something meaningful.

Table 61 Reasons for changes to work plans among full sample, and among those intending to return to work

	Total ^a	Return to work ^b
Financial reasons	62.7	82.4
To reduce stress	37.3	20.6
To do something worthwhile	57.8	67.6
To have something to do	38.6	64.7
Better physical health	33.7	50.0
Worse physical health	0.0	0.0
Better psychological health	47.0	52.9
Worse psychological health	1.2	0.0
Possibility of flexible work hours	26.5	26.5
Possibility of working part-time	25.3	35.3
Possibility of working full-time	14.5	14.7
To have more social contact	39.8	64.7
To have less social contact	0.0	0.0

(Multiple responses possible) a: N=83, b: N=34

Leisure

Respondents were asked how they spend their time while not working. Respondents most commonly indicated that housework occupies their time. Slightly fewer identified leisure activities (for example reading) and resting, while half said they spent their time socialising.

Table 62 Activities pursued while not working: percentage of total sample

	Percentage
Housework	71.1
Leisure activities	66.1
Resting	60.6
Socialising with close friends	52.8
Spending time with family/Whanau	36.1
Looking after children	15.6
Socialising with other friends	14.4
Volunteer work in HIV/AIDS organisation	9.4
Socialising with HIV positive friends	8.3
Volunteer work in other organisation	6.7
Looking after another HIV positive person	2.2

(Multiple responses possible, N=180)

FINANCES

Summary:

- 47% are currently on a pension or benefit
 - the median income was \$NZ330 per week
 - 62% of those on a benefit had been assessed by a WINZ Medical Officer
 - This resulted in changes to benefits for 58% and distress for 48%
 - 14% found it *very difficult* to pay for food
 - 32% found it *very difficult* to pay for medical services
 - 52% found it *very difficult* to pay for holidays
-

Income

The source of income of the survey respondents is shown in Table 63 below. Around half have a government pension or benefit as their main source of income. Over one third of PLWHA were receiving a salary and 4% had superannuation as their main income source.

Table 63 Primary source of income: percentage of total sample

Source of income	Percentage
Benefits/ Pension/ Social security	46.8
Salary	38.8
Superannuation	3.7
Partner supports me	2.1
Family/friend support me	1.1
Other	7.4

The mean weekly income for respondents was \$437.54, and the median was \$330. Figure 22 below gives the distribution of income in \$100 intervals. The peak of the distribution corresponds to the income that one is likely to receive on a government pension.

10.9% of respondents had a partner with whom they share financial resources. The partners' mean income was \$525.97 (median = \$505).

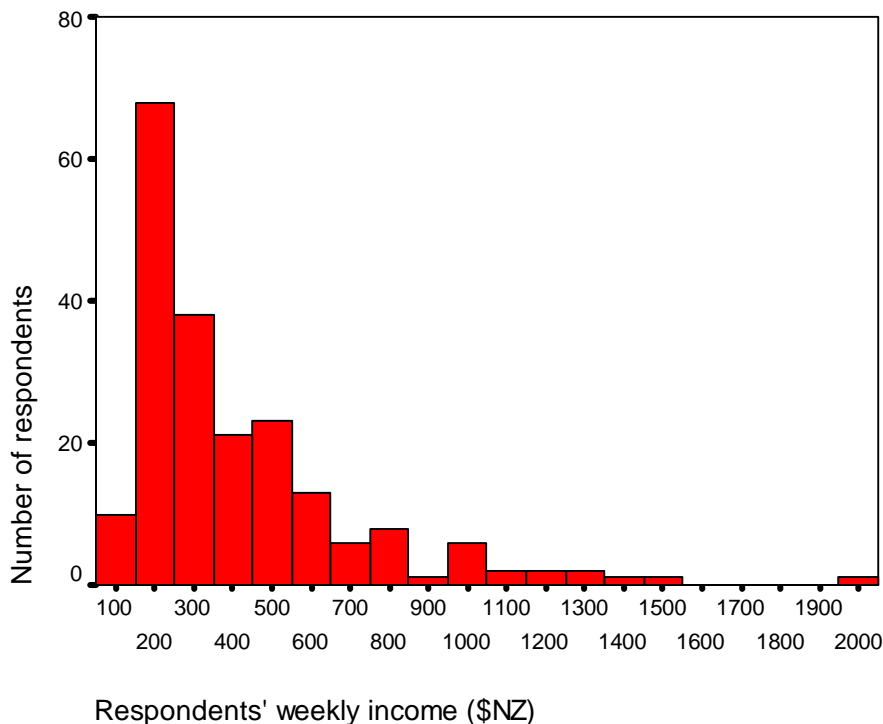


Figure 22 Histogram of respondents' weekly income after tax

Expenditure and Debts

Respondents were asked their weekly expenditure on a range of items. The results are shown in Table 64 below. The total mean expenditure on medication was \$16.31 per week with complementary therapies accounting for most of the total. Mean rental or mortgage costs were the most expensive cost. Food and utilities accounted for around \$83 and \$41 respectively.

23.5% of respondents currently own their own home, while 18.7% are currently paying off their home. 20.1% have owned their own home in the past, but do not currently. 31.5% receive a rental subsidy averaging at \$54.25 per week.

 **See also Accommodation and Discrimination page 94**

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$16,800.13 with a median of \$500. Those who were currently paying off their home had a mean debt of \$51,051.61 while those who were not had a mean debt of \$9,335.88. Nine per cent had used the services of a financial counsellor in the last two years.

Table 64 Expenditure on medications and essentials for full sample

	Mean	Median	Range
Rent/mortgage	133.00	100	0-900
Complementary therapies ⁷	13.37	0	0-500
Antiretroviral drugs	2.94	0	0-60
Other medication	4.05	0	0-79
Food	83.48	80	0-250
Utilities	41.45	30	0-200

Assessments of Benefits

People receiving a pension may undergo an assessment by a WINZ Medical Officer. As there has been considerable community discussion about the impact of these assessments we asked respondents about their experiences. A total of 61.7% of those receiving a benefit had received such an assessment. When asked what this experience resulted in, none of the respondents said that their benefit was terminated. (See Table 65 below) Over half said that the assessment resulted in changes to their conditions of benefit. Importantly the experience of assessment resulted in distress for almost half the respondents while it clarified concerns for around one in four.

Table 65 Consequences of receiving an assessment of benefit from a WINZ (percentage of those assessed)

	Percentage
Termination of benefits	0.0
Changes to benefits or conditions	58.0
Clarified concerns	26.0
Caused distress	48.0

N=50

Poverty

Unlike some countries, New Zealand does not currently have an officially recognised poverty line. However, the Social Policy Research Unit at The Family Centre has developed a poverty line measurement that is becoming more widely used. This establishes the poverty line at 60% of the population's net median income, and is further adjusted for an individual if their living arrangements include a partner and any dependent children. We use this definition of the poverty line in this report, and have adjusted it by the Consumer Price Index (Statistics New Zealand, 2002) to match it to the period in which Futures NZ data was collected. This reveals that 18.8% of the Futures NZ sample was living below the poverty line.

Correlates of Poverty

We look now at the differences between different groups in their likelihood to be living in poverty. Those in paid employment were significantly less likely to be classified as below the poverty line. Almost one third of those not in paid employment were living in poverty (see Table 66).

Table 66 Poverty by employment status

	Below poverty line	Above poverty line
In paid employment ^a	2.9	97.1
Not in paid employment ^b	29.9	70.1

a: N=68, b: N=97

Respondents who identified a salary as their primary source of income were significantly less likely to report an income below the poverty line. Almost a third of those on a government benefit were living in poverty (see Table 67).

Table 67 Poverty by income source

	Below poverty line	Above poverty line
Income from salary ^a	3.0	97.0
Income from government benefit ^b	32.9	67.1

a: N=67, b: N=79

Those who shared financial resources with a partner were slightly less likely to be below the poverty line than those who did not (see Table 68).

Table 68 Poverty by shared income status

	Below poverty line	Above poverty line
Shared financial resources ^a	8.1	91.9
Sole income ^b	21.8	78.2

a: N=37, b: N=133

There was no gender difference in the proportions of people living below the poverty line.

Costs

We asked respondents about the difficulty they had paying for a range of activities, goods and services. The results are shown in Table 69 below, with the *not applicable* responses excluded from the calculation for each item. The items that most respondents rated as very difficult to pay for were quality of life costs like travel, going out, entertainment and recreational drugs. Those items most likely to be rated as *not at all difficult* were medication and support services. Importantly over a third of those with child care needs rated this as very difficult, and substantial

⁷ Mean expenditure on complementary therapies among those using them was \$24.38

proportions rated food, clothing, utilities and rent as *very difficult*. The experience of difficulty in meeting the costs of these items was rarely restricted to one area. That is, when individuals had difficulty paying for food, they also experienced difficulties with rent, utilities and quality of life items.

Table 69 **Difficulty paying costs of items and services**

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS	66.0	26.4	7.6
Other prescribed medication	53.2	34.0	12.8
Medical services	39.3	28.0	32.7
Complementary therapies	44.8	37.5	17.7
Support services	64.5	18.4	17.1
Entertainment	35.6	22.8	41.6
Going out	33.8	21.4	44.8
Sport	38.9	25.0	36.1
Recreational drugs	29.8	29.8	40.4
Travel/ Holidays	23.9	23.9	52.3
Rent/ Mortgage	40.5	44.9	14.6
Utilities	37.1	44.7	18.2
Food	46.0	39.7	14.4
Clothing	33.7	31.4	34.9
Transport	45.5	37.0	17.6
Child care	13.0	52.2	34.8
Supporting family/Whanau	28.6	34.7	36.7

When we examine the ratings of these items for those above and below the poverty line, those living in poverty were more likely to rate all items as *very difficult* (see Table 70 below). Disturbingly, among those living below the poverty line, over two-fifths rated paying for medical services as *very difficult*, while the proportions that gave this response for co-payments for medication and costs of other prescribed medication are also very concerning. When it comes to the basics of life, substantial numbers of those below the poverty line also rated these as very difficult. While the efforts of welfare and financial aid services in community organisations are clearly essential in addressing these needs, it is clear that substantial social action is required to ensure that people living with HIV in New Zealand are not systematically denied the quality of life that other citizens can rightly expect.

Table 70 **Difficulty paying costs of items and services by poverty**

	Below poverty line			Above poverty line		
	Not at all difficult	A little difficult	Very difficult	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS	37.5	50.0	12.5	73.8	19.6	6.5
Other prescribed medication	24.0	44.0	32.0	61.5	28.8	9.6
Medical services	19.2	38.5	42.3	44.9	27.6	27.6
Complementary therapies	16.7	50.0	33.3	51.3	35.9	12.8
Support services	53.8	15.4	30.8	70.4	14.8	14.8
Entertainment	9.1	31.8	59.1	42.6	20.9	36.5
Going out	8.3	29.2	62.5	41.0	19.7	39.3
Sport	14.3	28.6	57.1	45.8	24.1	30.1
Recreational drugs	.0	20.0	80.0	36.6	31.7	31.7
Travel/ Holidays	8.3	16.7	75.0	28.0	27.1	44.9
Rent/ Mortgage	15.4	53.8	30.8	45.8	42.5	11.7
Utilities	17.9	46.4	35.7	42.2	44.5	13.3
Food	27.6	48.3	24.1	51.5	37.1	11.4
Clothing	11.1	33.3	55.6	39.4	31.5	29.1
Transport	12.0	64.0	24.0	52.8	30.4	16.8
Child care	.0	66.7	33.3	18.8	43.8	37.5
Supporting Family/Whanau	16.7	50.0	33.3	31.7	31.7	36.6

Poverty and Services

When we examine the use of services at AIDS organisations in the last six months by those above and below the poverty line, we see a different pattern of service use by those below the poverty line than those above. Those above the poverty line were somewhat more likely to have used AIDS organisations for treatments advice, financial assistance, transport, and treatments information. Those above the poverty line were somewhat more likely to use AIDS organisations for counselling, legal advice, library services and community education campaigns.

Table 71 Services used at HIV/AIDS organisations by those above and below the poverty line

	Below poverty line	Above poverty line
Treatments advice	64.5	50.8
Counselling	38.7	48.5
Financial assistance	32.3	11.5
Treatments information	32.3	21.5
Peer support group	29.0	33.1
Social contact with other PLWHA	25.8	31.5
Complementary therapies	22.6	26.9
Informal peer support	16.1	14.6
Pharmacy services	16.1	10.8
Transport	16.1	3.1
Housing assistance	12.9	6.9
Internet based information	12.9	6.9
Respite care	12.9	6.9
Community education campaigns	6.5	16.2
Internet access	6.5	6.9
Mental health services	6.5	2.3
Financial advice	3.2	3.1
Library	3.2	9.2
Volunteer carer	3.2	6.9
Dug/alcohol treatment	0.0	0.8
Employment services	0.0	3.1
Legal advice	0.0	6.9
Paid carer	0.0	0.0
Return to work skills	0.0	0.0

(Multiple responses possible)

Table 72 Services used at other organisations by those above and below the poverty line

	Below poverty line	Above poverty line
Pharmacy services	58.1	44.6
Counselling	35.5	13.1
Library	35.5	28.5
Financial assistance	25.8	17.7
Employment services	25.8	16.2
Transport	25.8	23.1
Treatments advice	22.6	24.6
Financial advice	22.6	19.2
Complementary therapies	22.6	21.5
Legal advice	22.6	20.8
Housing assistance	22.6	21.5
Mental health services	22.6	11.5
Internet based information	22.6	14.6
Dug/alcohol treatment	19.4	6.9
Internet access	19.4	31.5
Peer support group	12.9	5.4
Informal peer support	12.9	10.8
Return to work skills	12.9	12.3
Treatments information	12.9	5.4
Paid carer	12.9	6.2
Community education campaigns	12.9	4.6
Social contact with other PLWHA	6.5	6.2
Respite care	6.5	6.9
Volunteer carer	3.2	1.5

(Multiple responses possible)

DISCRIMINATION

Summary:

- 12% had experienced discrimination in relation to housing (5% in the last 2 years)
 - 31% had experienced discrimination in relation to health services (20% in the last 2 years)
 - 36% had experienced discrimination in relation to insurance
-

Accommodation

12.2% of respondents indicated that they had experienced less favourable treatment in relation to accommodation (5.3% in the last two years). These were most likely to be those who currently lived in private rental accommodation (20.4% experienced discrimination) but also included 11.4% of those in public rental accommodation, 10.0% of those living rent-free, 4.3% of those who own or are purchasing their own house or flat and 33.3% of those in other types of accommodation.

Health Services

30.9% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This included 19.7% who had experienced such discrimination in the last two years.

When asked what form this discrimination took, the most common responses were additional infection control measures (48.3%), confidentiality problems (44.8%) and avoidance (43.1%). These experiences are shown in Table 73.

**Table 73 Form of HIV-related discrimination experienced at medical service
(percentage of those experiencing discrimination)**

	Percentage
Additional infection control measures	48.3
Confidentiality problems	44.8
Avoidance	43.1
Being treated last	36.2
Being rushed through	25.9
Refusal of treatment	15.5
Harassment	6.9
Abuse	5.2
Other	19.0

(Multiple responses possible, N=58)

Insurance

17.0% of respondents currently had private health insurance and 11.9% currently had some other form of income or mortgage insurance.

35.5% of respondents indicated that they had experienced less favourable treatment in relation to insurance. This included 43.5% of the total sample who had experienced this discrimination in the last two years.

CONCLUDING COMMENTS

HIV Futures New Zealand represents the first comprehensive, national survey of New Zealand PLWHA. It offers an insight, not only into the clinical experiences of HIV positivity, but the social and cultural experiences of living with HIV. It offers up a challenge to those who serve HIV positive New Zealanders, PLWHA themselves, and the New Zealand community more broadly. It challenges us all to pay attention to the needs of HIV positive people, to work to address the inequities and injustices at personal and structural levels, to celebrate the achievements and diversity of the positive population, to understand the particularities of living with HIV, and to affirm the commonalities and common purpose that must form the core of contemporary community.

The advent of antiretroviral therapies suggested to many that HIV/AIDS was about to become a chronic, manageable illness. The experience of HIV positive people in this research demonstrates quite clearly that that is not the case, not for everyone, and not all the time. It also sounds a warning that the long-term consequences of these treatments may not only include negative health outcomes but negative social outcomes. We do not see the number of deaths that we did before the treatments, but we do see more complex lives as PLWHA face the effects of both HIV and treatments, from lipodystrophy to poverty.

The response to HIV/AIDS in New Zealand has been characterised by a rigorous sense of social justice and a strong commitment to the participation of PLWHA and affected communities. What this report offers is the voices of 226 HIV positive New Zealanders speaking loudly about the place that HIV has in their lives. We ask you to listen to those voices, to reflect on what they mean, and to act.

SECTION 2: Refugees

Introduction

Refugee respondents were recruited via the Refugee Health Education Programme and surveys were completed with the assistance of an interpreter, where necessary. Thirty-three surveys were returned as refugees respondents.

Demographics

The refugee portion of the sample contained 20 (60.6%) women and 13 (39.4%) men. These respondents ranged in age from 21 to 62 with an average age of 31.9. Most (93.8%) of the respondents were heterosexual.

HEALTH

HIV Antibody Testing

Pre- and Post- Test counselling

We asked respondents if they had received pre- and/or post-test counselling at the time they tested positive, who provided this counselling and how satisfied they were with the information and support they received at the time.

6.1% of refugees PLWHA indicated that they had received pre-test counselling. Of the six refugees who tested positive in the last two years, none had received pre-test counselling.

69.7% of respondents indicated that they had received post-test counselling. Of those who tested positive in the last two years 66.7% had received post-test counselling.

CD4 and Viral Load

Almost all PLWHA had taken a CD4/T-cell test (97.0%) and a viral load test (96.8%). Most respondents had their most recent CD4 test within the last three months (95.2%) and their most recent viral load test within the last three months (95.0%). On average participants had taken 3.2 viral load tests in the preceding twelve months.

Refugee respondents generally did not respond to questions about their test results, whether this indicates a refusal to disclose personal information or a lack of knowledge about their specific numbers remains an open question.

Experience of Health and General Well Being

We asked respondents to indicate on a four point scale their current state of physical health, and their overall sense of well-being. Around half the refugees (54.5%) rated their physical

health as *good*. A further 21.2% rated their health as *fair*, and 24.2% as *excellent*. None of the refugees rated their health as being poor. Around half the refugees (51.5%) rated their well being as *good*. A further 27.3% rated their health as *fair or poor*, and 21.2% as *excellent*.

AIDS Defining Illnesses

Very few refugee PLWHA (9.4%) have been diagnosed with an AIDS defining illness at some point.

Hepatitis

Hepatitis A

None of the refugees reported ever being infected with hepatitis A or being vaccinated against the virus. This suggests that all of the respondents could potentially be at risk of hepatitis A infection. However it is likely that many are immune following unrecognised infection, often in childhood.

Hepatitis B

None of the refugees reported ever being infected with hepatitis B or being vaccinated against the virus. This suggests that all of the respondents could potentially be at risk of hepatitis B infection. However, once more, it is likely that many are immune following unrecognised infection.

Hepatitis C

Only 7 refugee respondents answered the questions regarding hepatitis C testing. Of these most (72.4%) reported that they had not been tested to determine their hepatitis C status. A total of 14.3% reported having had an antibody test, none had had a diagnostic PCR test and 3.0% had had some sort of test for hepatitis C, but were unsure which sort. Only one refugee respondent gave any indication of being hepatitis C positive.

Prophylaxis

13.3% of refugee respondents were currently taking prophylaxis for opportunistic infections.

Antiretroviral Therapy

Use of Antiretroviral Therapy

When asked about their use of antiretrovirals, 60.6% of refugee PLWHA reported current use, 3.0% had used them in the past and 36.4% never having used them. Side effects were only reported by one refugee respondent currently using antiretrovirals.

Different Combinations

The majority of refugee participants (55.6%) did not know what antiretroviral drugs they were currently taking. 25.0% were on three drugs, 10.0% on two, and 10.0% on more than three drugs.

Treatment breaks

40.0% of those currently taking antiretrovirals have taken a break from these at some stage. 87.5% gave lifestyle reasons for their break, while 25.0% gave clinical reasons.

Attitudes to Antiretroviral Therapy

When asked if combination antiretroviral therapy had improved the prospects of PLWHA, 45.5% of refugee respondents said it had, 6.1% that it was too soon to tell, 3.0% that it hadn't and 45.5% said that they didn't know. When asked what their social networks thought about this, 9.1% reported that their friends thought that it had improved the prospects for PLWHA, 3.0% that it was too soon to tell and 87.9% that their friends didn't know. Refugees' attitudes to their relationship with their doctor can be seen in Table 74.

Table 74 Relationships with their doctors: percentage of refugees

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
My doctor knows more about the treatment of HIV than I do	0.0	0.0	18.2	75.8	6.1
My doctor and I work together to find the best treatment for me	0.0	3.0	33.3	57.6	6.1

Complementary Therapies

Only one refugee respondent was using any alternative therapy.

Prescriptions

All the refugee respondents who answered the question said they only had to go to one place to pick up all their medications.

SERVICES**Health Services****Treatment**

Most refugee respondents (84.8%) used an HIV specialist at an outpatient clinic for their main general medical treatment, while 9.1% used a GP with a high HIV caseload and 6.1% used a GP without a high HIV caseload. When asked about their main HIV-related treatment 90.6% said they saw an HIV specialist at an outpatient clinic, 6.3% saw a GP with a high HIV caseload and 3.1% saw a GP without a high HIV caseload.

87.5% of respondents said that the doctor they see for general medical services is the same doctor they see for HIV-related treatment. Of the four refugee respondents who see a different doctor, all said that that doctor knows their HIV status.

Services Used in the Last Six Months

We presented respondents with a list of services, both clinical and ancillary and asked which they had used in the last six months. Clinical services were the most utilised in the list with 90.6% using an HIV outpatient specialist and 28.1% using a GP with a high HIV caseload.

Information

Sources

Information about treatments

The most common source of information on treatments was an HIV specialist at an outpatient clinic (90.9%), followed by the Community AIDS Resource Team (48.5%), a GP with a high HIV case load (45.5%), another GP (15.5%) and a public health nurse (15.5%).

Information about HIV management

A similar pattern was reported for information on HIV management with the most common source again being an HIV specialist at an outpatient clinic (90.9%), followed by the Community AIDS Resource Team (48.5%) and a GP with a high HIV case load (39.4%).

Information on living with HIV

A somewhat different pattern emerged when respondents were asked about sources of information on living with HIV/AIDS. No single source of information was used by more than two of the refugee respondents.

Publications

Survey participants were asked which publications containing HIV information they read. Only 20.0% of refugee respondents read any HIV-related publications.

WELL-BEING**Contact With Other PLWHA**

Most of HIV positive refugees (60.6%) do not personally know anyone else with HIV, although 24.2% have either a positive partner or ex-partner and 18.2% of the refugees have a HIV positive friend. 15.2% of the refugees have been involved in the nursing or care of another positive person at some time in the last two years, and 18.8% have had someone close to them die from HIV/AIDS.

Almost all the respondents (97.0%) spent no time with other HIV positive people.

Relationships

The refugee respondents were predominately (93.8%) heterosexual, but there was a small number of gay and bisexual men (6.2%). Most respondents (68.8%) had not had sex over the past 6 months, but 3.1% had had sex with casual partners only and 28.1% had been in a monogamous relationship. All but one of the respondents in relationships (88.9%) had told their partner of their HIV status, and all of those with negative partners always used condoms during anal and vaginal sex.

Disclosure

Respondents were asked to whom they had disclosed their HIV status (see Table 75). Respondents had most commonly told their partners or spouses of their HIV status (55%, 77.8% of those in relationships). Relatively few of the refugees had told other people of their status.

Table 75 Disclosure of HIV status

	Percentage who have disclosed
Partner/ spouse	54.5
No-one	30.3
Close friends	15.2
Positive friends	3.0
Son/ daughter	3.0
Other friends	0.0
Work colleagues	0.0
Parents	0.0
Brothers or Sisters	0.0
Neighbours	0.0
People from own ethnic community	0.0

(Multiple responses possible)

Unwanted Disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. Only 6.1% said that it had at some point, all of these in the last two years.

Social Support

We asked participants about the amount of social support they received from a range of sources including household members, social contacts and service providers. The source that participants were most likely to rate as one that they receive *a lot* of support from was the participant's doctor (93.9%). This was followed by partners, where 37% of those with partners rated them highly, and religious or spiritual advisers, where 36% of those with these rated them highly.

Table 76 Social support received from different sources: percentage of refugees

	A lot	Some	A little	None
Doctor	93.9	3.0	3.0	0.0
Partner/ spouse	36.8	0.0	5.3	57.9
Religious or spiritual adviser	35.7	17.9	32.1	14.3
Children	30.0	10.0	40.0	20.0
Health care workers	26.3	52.6	5.3	15.8
Close friends	10.7	17.9	17.9	53.6
Brothers and sisters	6.3	25.0	18.8	50.0
HIV positive friends	4.8	9.5	9.5	76.2
Other friends	3.6	25.0	28.6	42.9
Family	0.0	0.0	0.0	100.0

Planning for the Future

When asked about the time frame they used when making major decisions about their lives 66.7% of refugees said they planned one day at a time, 21.2% that they planned a decade or more in advance and 12.1% gave responses between these two extremes.

Accommodation

When asked about their accommodation type, 69.7% of refugees reported living in public rental accommodation, 21.2% reported living in private rental accommodation and 9.1% reported living in other types of accommodation. Households varied considerably. 21.9% of refugee PLWHA lived by themselves, while the remainder lived with between 0 and 6 other adults (mean=2.1, median=2) and with between 0 and 4 children (mean=0.7, median=0). These children ranged in age from 0 to 18 (mean=9.6, median=9). None of the refugee respondents lived with pets.

Most lived in a residence with 2 bedrooms (61.3%), while the remainder had 1 bedroom (16.1%), 3 bedrooms (12.9%) or 4 or more bedrooms (9.7%).

39.4% of respondents had access to a car. When asked how easy it was to access public transportation, 15.6% said it was very difficult, 9.4%, difficult, 59.4% easy and 15.6% very easy.

Less than half (46.9%) of the refugees stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (N=17), the main reasons given were that it lacked privacy (47.1%), was too expensive (29.4%), in poor condition (29.4%) and was too small (29.4%). Only one refugee had ever changed their accommodation as a result of having HIV.

Employment

Employment Status

When asked about their employment situation refugees most commonly reported that they were unemployed (42.4%), followed by having part-time work (21.2%), being a student (21.2%), being in full time work (12.1%) and being retired or not working (3.0%).

Those Currently in Paid Employment

Those currently in employment were asked about the stress levels of their job, 22.2% rated it as low, 33.3% as moderate, 33.3% as high and 11.1% as very high.

Finances

Income

Refugees most commonly reported having benefits or pensions as their main source of income (75.8%), followed by salary (21.2%) and other sources of income (3.0%).

Expenditure and Debts

Respondents were asked how much they spent on a range of expenses. Refugee respondents spent an average of \$0.63 per week on antiretrovirals, \$0.19 on alternative therapies and \$0.47 on other medication. On top of this they spent \$66.31 per week on rent or mortgage payments, \$92.34 per week on food and \$25.63 on utilities.

Respondents were also asked what their current debt burden was. For refugees, this averaged at \$3.28 with a median of \$0 and a standard deviation of \$9.12.

Assessments of Benefits

A total of 20.8% of those refugees receiving a benefit had received such an assessment.

Poverty

62.5% of refugees were living below the poverty line.

Discrimination

Accommodation

None of the refugee respondents reported that they had experienced discrimination due to their HIV status in the area of accommodation.

Health Services

None of the refugee respondents reported that they had experienced discrimination while attending health services due to their HIV status.

Insurance

None of the refugee respondents reported that they had experienced discrimination due to their HIV status in the area of insurance.

CONCLUDING COMMENTS

This section has detailed the experience of HIV positive refugees, not to set them apart from other positive people, nor to set them apart from New Zealand community, but to recognise the particular challenges facing those who have come to this country via a different route. The data presented here give an overview of some of the key issues facing this population. We acknowledge the courage of the refugee participants who spoke about their experience of living with HIV. The researchers will be working with the Refugee Health Education Programme and through them, with other service providers, to ensure that these experiences are translated into action that benefits the refugee population.

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LIST OF TABLES AND FIGURES

Tables

Table 1	Data on primary site of survey collection	xv
Table 2	Data on previous research involvement.....	xv
Table 3	Respondents' reported mode of transmission.....	xvi
Table 4	Respondents' place of residence	xvii
Table 5	Years of respondent's testing positive and presumed infection (percentage of sample).....	xviii
Table 6	Educational level of respondents (percentage of sample)	xviii
Table 7	Reasons for testing	2
Table 8	Results of most recent blood tests, (percentage of total sample).....	4
Table 9	Relationship between ratings of overall health and well being (percentage of total sample).....	6
Table 10	Attitudes around body image (percentage of sample)	7
Table 11	Health improvement strategies	9
Table 12	Attitudes to health management: percentage of total sample.....	10
Table 13	Antiretroviral drugs used by respondents: percentage of total sample.....	12
Table 14	Attitudes to medication: percentage of those using ARV.....	15
Table 15	Results of most recent serological tests: percentage of those on combination ARV	17
Table 16	Circumstances surrounding commencement of treatment among those on combination ARV	18
Table 17	Correlates of number of remaining combinations for those on ARV.....	19
Table 18	Difficulties experienced by those currently on ARV and those who have stopped ARV treatment.....	20
Table 19	Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used antiretroviral drugs	21
Table 20	Attitudes to antiretroviral drugs: percentage of total sample.....	23
Table 21	Lifestyle reasons for taking breaks.....	26
Table 22	Clinical reasons for taking breaks	26
Table 23	Effect of break on health, well-being and clinical markers	27
Table 24	Effect of resistance testing on clinical markers	28
Table 25	Reasons for participating in clinical trials (percentage of those who have participated in a trial).....	29
Table 26	Attitudes to complementary therapies: percentage of total sample	31
Table 27	Number of times participants take medications	32

Table 28	Physician used for general and HIV related treatment: percentage of total sample	36
Table 29	Services used at HIV/AIDS organisations and at other organisations (percentage of all respondents).....	38
Table 30	Sources of information about treatments and living with HIV (percentage of all respondents)	40
Table 31	Attitudes to HIV information on the Internet (percentage of sample)	42
Table 32	Publications read by PLWHA	43
Table 33	Other HIV positive persons known by respondent	48
Table 34	Disclosure of HIV status	49
Table 35	Sources of unwanted disclosure (percentage of those experiencing unwanted disclosure)	50
Table 36	Importance of personal characteristics to respondents' sense of identity.....	51
Table 37	Importance of HIV status to sense of identity for different groups of PLWHA	52
Table 38	Importance of personal characteristics to sense of identity for different groups of PLWHA.....	52
Table 39	Social support received from different sources: percentage of those who gave valid responses	54
Table 40	Attitudes on HIV status: percentage of total sample	56
Table 41	Type of sexual relationship(s) by gender and sexuality of respondent	59
Table 42	Condom use with regular partner by respondent and partner gender	62
Table 43	Condom use with regular partner by partner sero-status: frequency	62
Table 44	Condom use with casual partner by respondent and partner gender	63
Table 45	Attitudes to HIV, sex and relationships.....	67
Table 46	Attitudes to legal issues around disclosure	68
Table 47	Recreational use of drugs	71
Table 48	Attitudes relating to drug use.....	72
Table 49	Current accommodation of respondents (percentage of total sample)	73
Table 50	Reasons current accommodation is unsuitable (percentage of those with unsuitable accommodation).....	74
Table 51	Reasons for changing accommodation	75
Table 52	Employment status	77
Table 53	Impact of HIV diagnosis on career plans (percentage of sample)	78
Table 54	Impact of antiretroviral therapy on work	78
Table 55	Circumstance surrounding last interruption to employment.....	79
Table 56	Reasons for returning to work	79
Table 57	Difficulties with HIV status confidentiality in the workplace: percentages of total samples	80
Table 58	Impact of HIV on work capacity.....	81

Table 59	Capacity within workplace for HIV related interruptions.....	82
Table 60	Plans for changes to work life and anticipated difficulty.....	82
Table 61	Reasons for changes to work plans among full sample, and among those intending to return to work	83
Table 62	Activities pursued while not working: percentage of total sample.....	83
Table 63	Primary source of income: percentage of total sample.....	85
Table 64	Expenditure on medications and essentials for full sample	87
Table 65	Consequences of receiving an assessment of benefit from a WINZ (percentage of those assessed)	87
Table 66	Poverty by employment status	88
Table 67	Poverty by income source	88
Table 68	Poverty by shared income status	88
Table 69	Difficulty paying costs of items and services.....	89
Table 70	Difficulty paying costs of items and services by poverty	90
Table 71	Services used at HIV/AIDS organisations by those above and below the poverty line.....	91
Table 72	Services used at other organisations by those above and below the poverty line .	92
Table 73	Form of HIV-related discrimination experienced at medical service (percentage of those experiencing discrimination).....	94
Table 74	Relationships with their doctors: percentage of refugees	99
Table 75	Disclosure of HIV status	101
Table 76	Social support received from different sources: percentage of refugees.....	102

Figures

Figure 1	Respondents' self ratings of general health status	5
Figure 2	Respondents' self ratings of general well being.....	5
Figure 3	Uptake of antiretroviral medication.....	13
Figure 4	Difficulties of taking ARV	14
Figure 5	Viral load of those taking and not taking antiretroviral therapy.....	15
Figure 6	Effect of commencing antiretroviral medication on health	16
Figure 7	Circumstance surrounding most recent change in combination among those currently on combination ARV.....	19
Figure 8	General health status for PLWHA with regard to their perceptions of the numbers of combinations of ARV remaining: percentage of those on ARV	20
Figure 9	Respondents' and respondents' social networks response to the statement Antiretroviral drugs mean better prospects for most people.	24
Figure 10	Most commonly used complementary therapies (percentage of those that use any complementary therapy)	30
Figure 11	Number of prescription pick-up points.....	33
Figure 12	Services used in the last six months.....	37
Figure 13	Problems experienced due to lack of information	43
Figure 14	Time spent with other positive people.....	49
Figure 15	Time frame for future planning	57
Figure 16	Reasons given for change in time-frame	58
Figure 17	Time HIV status disclosed to partner among those in regular relationships.....	60
Figure 18	Reaction of partner a and respondent b to disclosure: percentage of those in regular relationships	61
Figure 19	Sexual practice with the most recent casual partner	64
Figure 20	Stress at work.....	80
Figure 21	Disclosure in workplace	81
Figure 22	Histogram of respondents' weekly income after tax	86

INDEX

A

Accommodation.....	xvii, 73, 93, 102, 104
Age	xvi
AIDS defining illness	6, 98
Analysis	xv
Antibody testing	xvii
Antiretroviral	
and work	78
Breaks	25
Compliance	32
Dosing.....	32
Drugs	12
Impact on work.....	78
Resistance	18, 28
Side effects	20
therapies.....	11, 98
Uptake.....	13
Attitudes	9, 14, 21, 23, 31, 67, 72, 99

B

Benefits.....	87, 103
Body	56
Bone density test.....	8

C

CD4	3, 17, 26, 97
Cervical smear (pap) test	8
Children.....	43, 51, 52, 69, 73, 83, 89, 102
Clinical markers.....	3, 26, 97
Complementary Therapies.....	30, 99
Condom	62, 65, 67
Cost.....	86, 89, 103
Counselling.....	38, 54, 89, 90, 91, 92
Pre and post test.....	3, 97

D

Debt..... 86, 103

Demographics xvi

Depression..... 79

Disclosure..... 80

 HIV..... 60, 80, 81

Discrimination..... 75, 93, 104

Dosing 14, 32

Drugs

 Recreational..... 71, 89

E

Education xviii

Employment 77, 103

 Poverty 88

Ethnicity xvii, 51

F

Family 51, 54, 75, 83, 85, 102

Finances 38, 74, 75, 79, 83, 85, 103

 and poverty..... 88

Friends..... 48, 54, 75, 83, 85, 102

Future perspective 48, 102

G

Gay men 59, 71

H

Haemophilia xvi

Health 1, 4, 16, 97

 Maintenance 9

 Monitoring..... 8

Health care providers 3

Health Services..... 35, 93, 99, 104

Health Status 21

Hepatitis 7, 8, 98

 Hepatitis A 8, 98

 Hepatitis B..... 8, 98

 Hepatitis C..... 8, 98

HIV Antibody Testing..... 1, 97

HIV/AIDS Related Conditions	6
I	
Injection drug use	xvi
Insurance.....	94, 104
L	
Lipodystrophy.....	6
M	
Medications	
Cost.....	89
Psychiatric	54
Mental health.....	38, 48, 80
Methodology.....	xi
O	
Optimism	21, 22
Other health conditions.....	7
Other medication	20
P	
Partner	48, 54, 60, 62, 85, 102
Pension	87, 103
Pets	54, 73, 102
Prescriptions	32, 99
Prophylaxis.....	9, 98
R	
Relationships	59
Religion	xviii, 54, 102
Resistance	18, 28
S	
Services.....	3, 35, 36, 37, 39, 75, 89, 90, 99, 100
Sex	59, 65, 67
Casual	59, 62
Regular	62
Sexuality	xvi, 51, 59
Side effects	14, 18, 20, 98
Survey Instrument.....	xii

T

Testing

Antibody..... 1, 97
 Antibody..... xvii
 CD4 and viral load 3, 97

Therapies

Complementary 30, 89, 99

Transmission xvi

transport 73, 103

Treatment

Breaks..... 25
 Information..... 40

V

Vaccines 65

Preventive..... 65

Viral load..... 3, 15, 17, 26, 97

Volunteer work..... 83

W

Well being 4, 16, 47, 97, 101

Women 52, 59