

uresNZ<sup>2</sup> futures

# HIV futures NZ<sup>2</sup>

Mate āraikore a muri ake nei (Tuarua)

Jeffrey Grierson  
Rachel Thorpe  
Marian Pitts  
Tony Hughes  
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The Living with HIV Program

The Australian Research Centre  
in Sex, Health and Society

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Positive Women





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The Living with HIV Program is a part of the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. The program conducts social research into the lived experience of HIV. This research is guided by the Australian National Strategies on HIV, the Living with HIV Reference Group and the ARCSHS Scientific Advisory Committee. All research conducted is approved by the La Trobe University Human Ethics Committee and additional institutional and community ethics committees where appropriate. This project was also approved by the Multi-Region Ethics Committee of the New Zealand Ministry of Health. Full details of the Living with HIV research program can be found on the HIV Futures website: [www.latrobe.edu.au/hiv-futures](http://www.latrobe.edu.au/hiv-futures) and details of ARCSHS can be found at [www.latrobe.edu.au/arcshs](http://www.latrobe.edu.au/arcshs)

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## **ACRONYMS USED IN THIS REPORT**

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>AEG</b>	AIDS Epidemiology Group (University of Otago)
<b>ARCSHS</b>	Australian Research Centre in Sex, Health and Society
<b>ARV</b>	Antiretroviral therapy
<b>CAM</b>	Complementary and alternative medicine
<b>CART</b>	Community AIDS Resource Team
<b>HIV</b>	Human Immunodeficiency Virus
<b>IDU</b>	Injection Drug Use(r)
<b>NNRTI</b>	Non-Nucleoside Reverse Transcriptase Inhibitors
<b>NRTI</b>	Nucleoside Reverse Transcriptase Inhibitors
<b>NtARTI</b>	Nucleotide Analogue Reverse Transcriptase Inhibitors
<b>NZAF</b>	New Zealand AIDS Foundation
<b>PI</b>	Protease Inhibitor
<b>PLWHA</b>	People living with HIV/AIDS

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## **DEDICATION**

We would like to dedicate this report to Matt Whyte. Matt was the project officer on the original HIV Futures New Zealand survey and a valued staff member of the New Zealand AIDS Foundation. Matt died from an HIV related illness in October 2004. Matt's commitment and contribution to the positive community was inestimable. He is sadly missed, as a colleague and a friend.

# EXECUTIVE SUMMARY

## DEMOGRAPHICS (whole sample)

The HIV Futures New Zealand 2 survey was completed by 261 HIV positive people.

75.7% were male (196), 23.9% were female (62), and one person was transgender. 60.7% were gay men, 22.7% heterosexual women, 10.1% heterosexual men, 6.1% bisexual men, and 0.4% lesbian women.

The respondents' ages ranged from 23 to 88 years with a mean of 45.6 years and a median of 44.0 years.

The majority of participants were New Zealand born (69.4%) and 89.8% of the participants spoke English at home, with North African languages accounting for most of the remainder. Of the total sample, 255 indicated their ethnicity. One hundred and seventy two were European/Pakeha (65.9%), 49 were African (18.8%), 17 were Maori (6.5%), nine were Asian (3.4%) and five were Pacific Islanders (1.9%).

## HEALTH

### HIV Antibody Testing

- 26.7% tested for HIV because they became ill
- 20.8% tested as part of routine health screening
- 8.4% tested because of a particular risk episode
- 7.9% tested because they were a member of a risk group
- 3.5% were tested without their knowledge

### When asked about pre and post test counselling/discussion

- 25.8% had received pre-test counselling/engaged in pre-test discussion
- 22.0% of those testing positive in the last two years received pre-test counselling/engaged in pre-test discussion
- 66.8% received post-test counselling
- 79.6% of those testing positive in the last two years received post-test counselling

Pre and post test counselling was most often provided by medical personnel and respondents were generally satisfied with the information and support received from this person.

## Current Health Status

77.2% rated their health as good or excellent and 75.1% rated their general well being as good or excellent.

Almost all PLWHA had taken a CD4/T-cell test and a viral load test. 21.6% of respondents had been diagnosed with an AIDS defining illness, 14.3% in the last two years.

## HIV-related and other health conditions

24.9% of respondents indicated that they had experienced HIV-related illnesses. 29.8% indicated that they had a major health condition other than HIV/AIDS. The most common conditions reported were cardiovascular disease, hepatitis C and asthma.

## When asked if they had experienced any of the following conditions in the previous 12 months:

- 80.9% reported low energy or fatigue
- 64.2% experienced a sleep disorder
- 43.7% experienced confusion or memory loss
- 40.0% experienced weight loss
- 34.7% reported experiencing lipodystrophy

## Mental Health

In the last six months 18.6% of respondents had taken prescribed medication for depression and 22.9% for anxiety. 28.8% had ever had a diagnosis of a mental health condition.

25.1% of all respondents had ever been diagnosed with depression, 7.2% in the last two years.

## Viral Hepatitis infections

- 11.1% had at some point had hepatitis A
- 54.3% had been vaccinated against hepatitis A
- 13.8% had at some point been diagnosed with hepatitis B, of whom:
  - 60.9% had cleared the infection
  - 26.1% had ongoing infection and
  - one respondent had a chronic infection
- 57.4% had been vaccinated against hepatitis B
- 7.7% of respondents said they had been diagnosed with hepatitis C

## Prophylaxis

10.0% were currently taking prophylaxis for opportunistic infections.

# TREATMENTS

## Antiretroviral Therapy

### Antiretroviral use:

- 72.9% were currently using ARV, most commonly two NRTIs, one NNRTI and one PI (54.1% of those on ARV, N=79);
- 79.0% had used ARV at some time;
- 64.3% commenced ARV on the advice of their doctor;
- 73.6% of respondents were using a combination of three drugs;

## Difficulties of Taking ARV

- 44.3% of those participants currently taking ARV reported that they experienced difficulties taking them of which the major problems were:
- 26.1% side effects
- 23.6% remembering to take the drugs on time;
- 16.6% transporting medication
- 15.9% taking large numbers of tablets
- 12.7% taking medication in public
- 8.3% organising meals around the drugs

## Attitudes to Antiretroviral Therapy

- 75.7% of respondents agreed that combination antiretroviral drugs mean better prospects for PLWHA
- 10.3% believed that it is still too soon to tell
- 26.0% agreed that combination antiretroviral drugs are harmful
- 19.8% agreed that the side effects outweigh the benefits of antiretroviral drugs

## Treatment Breaks

- 32.5% of those currently on ARV had taken a break from ARV
- The median length of break was one month
- Most breaks were taken for a combination of lifestyle and clinical reasons
- 65.3% consulted their doctors before a break
- 87.5% consulted their doctors after a break
- 45.2% saw their doctor before, during and after the treatment break

## Antiretroviral Resistance

- 22.4% of those who had ever used ARV had taken a resistance test.
- 51.4% of those tested found resistance to one or more drugs
- 100% of those with resistance changed treatments

## Dosing and Adherence

- 53.4% of the sample were taking ARV twice daily;
- 22.7% were taking ARV three times a day;
- 9.7% were taking ARV once a day.
- 92.4% had not missed a dose of ARV in the two days prior to completing the survey.

## Clinical Trials

- 7.1% had participated in a clinical trial for HIV related treatment in the last two years

## Complementary Therapies

- 47.0% used vitamin and mineral supplements
- 14.0% used herbal therapies
- 17.7% used marijuana for medicinal purposes
- Complementary therapies tended to be used in conjunction with allopathic treatment

# SERVICES

## Health Services

- For HIV specific treatment 80.0% saw an HIV specialist at an outpatient clinic and 6.7% saw a doctor at a sexual health centre.
- For general health care, 52.1% of PLWHA saw a GP, 20.6% saw a GP with a high HIV caseload and 18.0% saw an HIV specialist at an outpatient clinic.
- For 70.7% of respondents these were different doctors.

### **Respondents had used the following services in the six months prior to survey:**

- 79.1% an HIV specialist in an outpatient setting
- 55.8% a GP
- 21.9% a dentist
- 20.0% a GP with a high HIV caseload

## Other Services

### **Services used at HIV/AIDS organisations:**

- 34.4% treatment advice
- 30.7% counselling
- 20.0% social contact
- 20.0% peer support
- 12.1% complementary therapies
- 14.9% treatments information

## Information

### **Important sources of information on treatments/HIV management:**

- 83.3% HIV specialist at outpatient clinic
- 33.0% publications from HIV/AIDS groups
- 29.8% internet
- 28.4% HIV magazine/newspaper
- 27.9% GP
- 21.9% treatments-specific NZAF staff
- 25.1% GP with high HIV caseload
- 24.7% HIV specialist nurse
- 20.9% HIV positive friends

### **Important sources of information on living with HIV:**

- 37.7% HIV specialist at outpatient clinic
- 32.6% publications from HIV/AIDS groups
- 32.6% HIV positive friends
- 28.8% HIV magazine/newspaper
- 28.4% Body Positive staff
- 27.0% treatments-specific Body Positive staff

## Publications

Gay and HIV press were accessed by sizable proportions of the sample, as were HIV community publications.

## Involvement with HIV/AIDS Organisations

62.4% had some contact with HIV/AIDS organisations, mostly receiving newsletters (78.2%) or being clients of these organisations (60.9%). 4.5% were employees of HIV/AIDS organisations.

# THE SOCIAL WORLD OF PLWHA

## Contact with Other PLWHA

- 79.5% knew another PLWHA
- 41.9% had HIV-positive acquaintances
- 11.6% had an HIV-positive spouse/partner
- 55.5% spent at least some time with other PLWHA
- 8.5% spent a lot of time with other PLWHA
- 44.5% spent no time with other PLWHA
- 16.0% had been involved with the care of someone with HIV/AIDS
- 38.1% said someone close had died of AIDS related causes

For 55.9% of respondents HIV was an important part of their identity, while for 14.2% it was an essential part. HIV status tended to be less important than identities based on sexuality, gender or family.

## Disclosure

Almost all respondents (95.3%) had disclosed their HIV status to at least one person, generally partners, close friends and family.

For 47.7% of respondents, their HIV status had been disclosed to another person when they did not want it to be (19.0% in the last two years).

## Social Support

Sources of 'a lot' of social support:

- 78.0% partners/spouse;
- 51.4% PLWHA groups;
- 51.3% close friends;
- 46.5% parents;

## Planning for the Future

19.9% planned only one day at a time, while 60.2% planned at least one year ahead.

## Relationships and Sex

- 31.9% of PLWHA were not having sex at present
- 42.5% of PLWHA were in a regular relationship
- 16.2% had a regular partner and had sex with casual partners
- 25.0% of respondents had casual partners only

Of those in a regular relationship, 27.6% had a partner who was also HIV positive, 65.3% had an HIV negative regular partner and 7.1% a partner of unknown status. Nearly all PLWHA (97.9%) had disclosed their status to their regular partner, either when they were diagnosed, or at the commencement of the relationship.

40.4% of the respondents reported having anal or vaginal intercourse with a regular partner in the previous six months. Condom use with regular partners was strongly related to the HIV-status of the partner.

51.7% of the sample reported having sex with casual partners in the past six months. Most male respondents reported always using condoms with casual male partners.

49.3% of the sample provided information about the most recent episode of sex with a casual partner in the previous six months. Vaginal or anal intercourse took place in 70.5% of these instances.

### Condom use with the most recent casual partner:

- 100.0% (n=9) of those who had sex with an HIV+ partner
- 66.7% (n=4) of those who did not know their partner's HIV status
- 89.7% (n=52) of those who had sex with an HIV negative partner

26.7% of PLWHA said they would prefer to be in a relationship with someone who is also HIV positive. 58.9% of PLWHA expressed some fear of rejection from potential partners due to disclosing their HIV status. The majority of PLWHA (65.5%) felt HIV had a negative effect on their sexual pleasure.

Only 6.7% of PLWHA agreed with the statement *I feel more confident about unprotected sex because of the new treatments*.

Very few PLWHA agreed that undetectable viral load meant that HIV was unlikely to be transmitted (10.3%). However, 20.2% of PLWHA agreed with the statement *If there was a vaccine which prevents HIV I would not practice safe sex*.

## Legal Issues around disclosure of HIV status

63.1% agreed that *it is legally OK for someone to use a condom for anal or vaginal sex and not to tell their partner about HIV status*.

61.1% of respondents disagreed that *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*.

## Recreational Drug Use

Alcohol was the drug most commonly used by PLWHA (75.3%), while 37.7% had used tobacco in the previous 12 months. 84.8% of respondents reported that they had never injected illegal drugs and of those who had injected illegal drugs only 23.8% had done so in the last 12 months. Of PLWHA who reported injecting drugs, none had shared injecting equipment in the past twelve months.

11.1% of respondents reported having missed a dose of ARV at some point as a result of using illegal drugs and 4.4% reported having had a bad experience as a result of using both illegal drugs and ARV.

# HOME, WORK & MONEY

## Accommodation

- 30.7% were living in private rental accommodation
- 45.6% owned or were purchasing a house or flat
- 13.0% were living in public rental accommodation (government owned)
- 6.5% lived rent-free (e.g. provided by friends, family, etc.)

88.7% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable, the main reasons given were that it was too small or too expensive.

- 29.8% of PLWHA lived by themselves
- 50.9% of PLWHA lived with pets
- 81.9% of respondents had access to a car

23.3% had ever changed their accommodation as a result of having HIV/AIDS, 9.3% in the last two years.

## Employment

Over half of respondents were in paid employment (61.7%), the majority of these being in full-time work (43.9% of total sample). The majority of the remainder described themselves as either unemployed, not working or retired.

Most respondents (62.9%) said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis.

### Impact of antiretroviral therapy on employment:

- 12.8% stopped work;
- 13.5% anticipated a longer time in the workforce;
- 5.8% went back to work.

41.5% of respondents had stopped work at some time in the past for reasons related to having HIV/AIDS. Poor health and diminished energy levels were the most commonly cited reasons for this.

Of those respondents who had left work, 66.2% had returned to work and this was most commonly for financial reasons.

Around two-thirds of respondents who were working said that HIV has had an impact on their capacity to perform their work duties. Most commonly respondents reported that they tired more quickly, that they had difficulty concentrating and that they had to reduce their work hours.

50.8% of PLWHA currently in work had not disclosed their HIV status to anyone at their workplace, while 12.6% did not try to keep their HIV status confidential. The most common difficulties for those wanting to maintain confidentiality at work were gossip, visible signs of illness and explaining absences from work.

## Finances

Just under half of respondents (45.7%) identified their main source of income as salary, while around one-third relied on government pensions or benefits (35.6%). The median weekly in-hand income for respondents was \$486. Median incomes were lower than New Zealand National averages, but had increased since the first survey at a rate greater than the Consumer Price Index.

### Items that respondents found it somewhat or very difficult to pay for were:

- 56.4% clothing
- 50.3% utilities
- 53.4% housing
- 46.5% food
- 51.8% transport

34.6% (n=53) of those on a government benefit had been assessed by a WINZ Medical Officer in the past 2 years. 24 respondents said that it had caused them distress, while 22 said that the conditions of their benefit had changed.

## Financial Hardship

Compared with those in the top quartile of the income distribution, those in the bottom quartile were less likely to be in paid employment and more likely to have a government benefit as their primary source of income. This group also rated their overall health and well-being worse and experienced significantly greater difficulty paying for food, housing and utilities.

## Discrimination

3.8% experienced less favourable treatment in relation to accommodation, 1.9% in the last two years

22.4% experienced less favourable treatment because of HIV in relation to health services, 11.0% in the last two years

Four Hepatitis C co-infected respondents experienced less favourable treatment because of Hepatitis C in relation to health services.

25.9% of respondents had experienced less favourable treatment in relation to insurance, 10 in the last two years.

14.0% of respondents had experienced less favourable treatment in the workplace as a result of having HIV, 5.8% in the last two years.

# PARTICIPANTS OF AFRICAN DESCENT

## Health

Pre-test counselling/discussion was rare in this sample and half reported receiving post-test counselling. Most respondents reported that their current health and well being was good or excellent. Almost all respondents had regular CD4 and viral load tests. Median viral load was at an undetectable level. AIDS defining illnesses, HIV related illnesses and other major health conditions were reported by few of the respondents.

## Treatments

Thirty respondents (70%) had used ARV at some point, and twenty six (61%) were currently using these treatments. The most common combination was 2 NRTIs and 1 NNRTI (10 of those on ARV). There were few reports of difficulties taking ARV. Most respondents reported some concern over the future efficacy of their treatments.

## Services

Hospital-based HIV specialists were the primary providers of HIV specific and general treatment for a large majority of respondents. Few participants in this population used any of the services listed in the survey, either at HIV/AIDS organisations or at other organisations. Clinical sites were the most commonly reported source of information in relation to HIV management, and few reported seeking information on issues concerned with living with HIV.

## The social world of PLWHA

54% did not personally know anyone else with HIV.

40% have had someone close to them die from HIV/AIDS. 20% spent at least some time with other positive people. 17% had not disclosed their HIV status to anyone.

Participants were most likely to have nominated their health care workers as providing social support.

## Relationships and Sex

54% were currently in a regular relationship. Of those, 43% (n=9) reported that their partner was also HIV positive. Most respondents reported consistent condom use with regular partners. 33 participants had children.

## Accommodation

Twelve respondents were living in private rental accommodation, while twenty-nine (63%) lived in public rental accommodation. Only four owned or were purchasing a home.

## Employment

Twenty four respondents (52.2%) were currently employed, with eighteen being in full-time work and six in part-time work. 21 of the 24 working said no-one in the workplace knew that they were HIV positive.

## Finances

Twenty-one participants were receiving a salary and seventeen had a government pension or benefit as their main source of income. The median weekly in-hand income was \$380. Participants in this group reported higher rates of difficulty in paying for the costs of items in all categories compared with other PLWHA.

## Discrimination

Six respondents had experienced less-favourable treatment at a medical service as a result of having HIV, all in the previous two years. Two respondents indicated that they had experienced less favourable treatment in relation to accommodation. Six respondents indicated that they had experienced less favourable treatment in relation to insurance. Two respondents had experienced less-favourable treatment in the workplace.

# KEY COMPARISONS WITH HIV FUTURES NEW ZEALAND 2001

## HEALTH

### HIV Antibody Testing

A higher proportion of respondents reported having received pre-test counselling or engaging in a pre-test discussion than in 2001. This includes those testing positive in the two years prior to survey, where this increased from 6% to 22%. Post-test counselling rates remained the same.

### Current Health Status

General ratings of health status and well being were similar across the two surveys. A greater proportion of respondents had been diagnosed with an AIDS defining illness in the two years prior to survey in 2007 than in 2001 (14% vs 5%).

### HIV-related and other health conditions

A smaller proportion of respondents reported HIV related illnesses (2001: 36%, 2007: 25%).

### Mental Health

In 2007 a slightly smaller proportion of respondents reported taking antidepressant medication in the prior six months (2001: 23%, 2007: 19%) while a greater proportion reported taking anti-anxiety medication (2001: 15%, 2007: 23%).

### Viral Hepatitis

Vaccination rates were higher for hepatitis A (2001: 44%, 2007: 54%) and hepatitis B (2001: 48%, 2007: 57%). Lifetime diagnoses were slightly lower for hepatitis A (2001: 14%, 2007: 11%) and hepatitis B (2001: 18%, 2007: 14%). Hepatitis C rates were similar.

## TREATMENTS

### Antiretroviral Therapy Use

Similar proportions of respondents had ever used antiretroviral treatments (2001: 78%, 2007: 79%), while current use was slightly higher (2001: 64%, 2007: 73%).

A smaller proportion of PLWHA reported having difficulties using these treatments (2001: 79%, 2007: 44%). This was reflected in lower proportions reporting side-effects (2001: 44%, 2007: 26%) and difficulties with drug timing (2001: 44%, 2007: 24%).

### Attitudes to Antiretroviral Therapy

Overall, the profile of attitudes to antiretroviral treatment was similar.

### Treatment Breaks

Similar proportions of respondents in the two studies had ever taken a break from antiretroviral treatments. The median length of the most recent break was shorter (2001: 45 days, 2007: 28 days). Respondents were more likely to have discussed this break with their doctor before taking it (2001: 43%, 2007: 65%).

### Antiretroviral Resistance

A slightly higher percentage of people had undergone resistance testing in the most recent survey (2001: 19%, 2007: 22%). However, a smaller proportion reported that testing had identified resistance to any treatments (2001: 74%, 2007: 51%).

### Dosing and Adherence

A smaller proportion of participants reported taking antiretroviral medication twice daily (2001: 66%, 2007: 53%) while a higher proportion reported taking treatment three times per day (2001: 9%, 2007: 23%).

Adherence, measured by the proportion not missing any doses in the two days prior to survey, was slightly higher in the most recent survey (2001: 80%, 2007: 92%).

### Complementary Therapies

Use of complementary therapies was similar across the two surveys, although in 2007 more reported taking vitamin or mineral supplements (2001: 30%, 2007: 47%).

## SERVICES

### Health Services

A higher proportion of PLWHA reported seeing an HIV outpatient specialist as their primary HIV physician in 2007 (2001: 77%, 2007: 80%). A slightly lower proportion saw a different doctor for HIV specific and general health care (2001: 74%, 2007: 71%). Slightly fewer had visited an outpatient HIV specialist in the six months prior to survey (2001: 82%, 2007: 79%).

### Other Services

Generally, service use was lower across all services at HIV organisations and other organisations in the most recent survey. For example, at HIV/AIDS organisations: treatments advice (2001: 55%, 2007: 34%); treatments information (2001: 26%, 2007: 15%); and counselling (2001: 48%, 2007: 31%).

### Information

Participants cited similar organisations and sites as important sources of information in the two surveys. There were slight differences in the proportions citing HIV magazines and newspapers (2001: 32%, 2007: 28%) and internet sources (2001: 24%, 2007: 30%).

## **Involvement with HIV/AIDS Organisations**

Fewer had contact with HIV/AIDS organisations (2001: 77%, 2007: 62%), although the type of contact was consistent across surveys.

## **THE SOCIAL WORLD OF PLWHA**

### **Contact with Other PLWHA**

A slightly smaller proportion of respondents reported that they knew other PLWHA (2001: 84%, 2007: 80%) and a slightly higher proportion said they spent no time with other positive people (2001: 40%, 2007: 45%). A smaller proportion had been involved in the care of someone else with HIV (2001: 22%, 2007: 16%), and a smaller proportion also said that someone close to them had died of HIV/AIDS (2001: 70%, 2007: 62%).

### **Disclosure**

Disclosure of HIV status to others was similar across the two surveys. A smaller proportion reported ever experiencing unwanted disclosure (2001: 54%, 2007: 48%) and unwanted disclosure in the previous twelve months (2001: 33%, 2007: 19%).

### **Social Support**

Patterns of social support differed somewhat between the two surveys. Similar proportions reported 'a lot' of support from partners (2001: 80%, 2007: 78%) and close friends (2001: 53%, 2007: 51%), while more reported this for PLWHA groups (2001: 13%, 2007: 52%).

### **Planning for the Future**

The percentage of respondents reporting that they planned only one day at a time had decreased slightly (2001: 25%, 2007: 20%) and the proportion planning more than one year in the future had increased (2001: 55%, 2007: 60%).

### **Relationships and Sex**

A slightly lower percentage reported having no sexual relations at present (2001: 40%, 2007: 32%). Similar percentages were in regular relationships (2001: 41%, 2007: 43%). Slightly more reported casual partners plus a regular relationship (2001: 13%, 2007: 16%) or casual partners only (2001: 23%, 2007: 25%).

A smaller proportion said they would prefer a relationship with someone who is also HIV positive (2001: 34%, 2007: 27%). Similar patterns were observed regarding the impact of HIV on sexual relationships and sexual pleasure. A considerably smaller proportion of participants reported that they would not practice safe sex if a vaccine became available (2001: 70%, 2007: 20%).

Slightly more of those in regular relationships had an HIV positive partner (2001: 21%, 2007: 28%). Larger proportions reported having anal or vaginal sex with their regular partner in the previous six months (2001: 29%, 2007: 40%).

A higher proportion of respondents reported having sex with a casual partner in the previous six months (2001: 36%, 2007: 52%).

### **Most recent casual partner**

A higher proportion of participants provided data on their most recent casual partner in the six months prior to survey (2001: 22%, 2007: 49%). Fewer of these sexual episodes involved anal or vaginal sex (2001: 89%, 2007: 71%). Patterns of condom use with most recent casual partner were, however, the same.

### **Legal Issues around disclosure of HIV status**

There were some noticeable changes in the response to items concerning the legal issues around disclosure. A considerably higher proportion of participants agreed with the statement *it is legally OK for someone to use a condom for anal or vaginal sex and not to tell their partner about HIV status* (2001: 38%, 2007: 63%), while a smaller proportion agreed with the statement *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* (2001: 70%, 2007: 61%).

## Recreational Drug Use

Rates of recreational drug use were similar between the two surveys, with the exception of tobacco use (2001: 46%, 2007: 38%)

## HOME, WORK & MONEY

### Accommodation

A greater proportion of participants owned or were purchasing their own home in the most recent survey (2001: 37%, 2007: 46%). More were also in private rental accommodation (2001: 28%, 2007: 31%) and fewer were in public rental accommodation (2001: 18%, 2007: 13%). A higher percentage reported that their current accommodation was suitable for their needs (2001: 78%, 2007: 89%). A higher percentage of participants lived by themselves (2001: 30%, 2007: 37%) and with pets (2001: 51%, 2007: 59%) and had access to a car (2001: 75%, 2007: 82%).

### Employment

In 2007 a higher proportion of participants reported being in paid employment (2001: 53%, 2007: 62%), particularly in full time employment (2001: 38%, 2007: 44%). Among those working, more reported that HIV had an impact on their capacity to perform their work duties (2001: 44%, 2007: 67%). Smaller proportions of respondents reported that they had disclosed their HIV status to at least one person in their workplace (2001: 54%, 2007: 49%), and that they did not try to keep their HIV status confidential at work (2001: 22%, 2007: 13%).

### Finances

A considerably greater percentage of respondents reported their main source of income as a salary (2001: 39%, 2007: 46%) and less reported this as a government benefit (2001: 47%, 2007: 36%). Median weekly personal income has increased (2001: \$330, 2007: \$486), and this is greater than the change in consumer price index (HIV Futures 47.2%, NZ CPI + 16.4%) indicating that there has been an increase in the purchasing power of this population. Median income, however, remains lower than the remainder of the New Zealand population.

Difficulty paying for goods and services has reduced between the two surveys. The proportion reporting that it is somewhat or very difficult to pay for basic needs is lower in the most recent survey: clothing (2001: 66%, 2007: 56%); utilities (2001: 63%, 2007: 50%); housing (2001: 60%, 2007: 53%); food (2001: 54%, 2007: 47%); transport (2001: 55%, 2007: 52%). While these changes are in a positive direction, it should be noted that there is still considerable financial hardship for PLWHA.

A smaller percentage of respondents on a government benefit reported that they had received an assessment from a WINZ medical officer (2001: 62%, 2007: 35%).

### Discrimination

Fewer reported experiencing less favourable treatment in relation to accommodation (ever 2001: 12%, 2007: 4%), (two years prior 2001: 5%, 2007: 2%).

Fewer reported experiencing less favourable treatment at health services (ever 2001: 31%, 2007: 22%), (two years prior 2001: 20%, 2007: 11%).

Fewer reported experiencing less favourable treatment in relation to obtaining insurance (ever 2001: 36%, 2007: 26%).

## PARTICIPANTS OF AFRICAN DESCENT

Caution must be exercised when comparing the findings on refugees in the 2001 report and those of African descent in the current report. While the populations are similar, the criteria for inclusion are somewhat different in the two reports (see page 71).

Overall circumstances appear to have improved for this population. People were more likely to be in employment and were earning more. However, this group is still disadvantaged in comparison to other PLWHA and the New Zealand population. Access to health care services remained high, as did reliance on clinical services for information and support. Disclosure of HIV status remained low.

# INTRODUCTION

Here, for the second time, we are given a privileged insight into the lives of people living with HIV in this country. In the pages that follow you are offered a rare opportunity to see some of the complexity and diversity of individual and collective experiences of being HIV positive. People from around the country have provided details of their histories, their daily lives, their hopes and fears. This is not something that people have done lightly - completing this survey requires commitment, courage and honesty. It asks that people relive some of the darkest times in their lives and to share with us things they may have never shared with the people closest to them. It asks people to stand up and be counted among the positive people of New Zealand. And it asks you to take notice. These lives are presented to you, not for your interest, not out of obligation, not just so they are documented, not just so you care. These lives are presented to you with the expectation that you will respond - that you will take action. There is a responsibility that comes with reading this report, just as there is a responsibility with conducting this study. Whatever your relationship to the community of HIV positive people in this country, whether you are in government, service provision, policy development, whether you are a clinician, a researcher, a friend, a partner, a person with HIV, whether you have lived through many years of this pandemic or have recently found yourself in its midst, this report demands that you act. It demands that you work to counter the disadvantages and that you work to preserve the hard won achievements. This is a time to take stock. This is a time to ask: What have we achieved since the first time we were told these things? What do we want to hear, when in five years time we hear them again? What do we want that story to be? Will our actions have made this a better story?

## DEMOGRAPHICS

This section provides an overview of the sample characteristics of the HIV Futures New Zealand 2 sample.

### Sample Demographics

The HIV Futures New Zealand 2 survey was completed by 261 HIV positive people. Of the total respondents, 77.8% completed a paper copy of the survey, while 22.2% completed the survey on-line (see Appendix A on page 86 for a comparison of these two samples).

There is no register of HIV positive New Zealanders, as HIV testing is voluntary and anonymous and HIV is not a notifiable condition in New Zealand. Recently the AIDS Epidemiology Group at the University of Otago has provided an updated estimate of the number of people living with diagnosed HIV in this country. Based on antiretroviral therapy use recorded by Pharmac, and information from the Infectious Disease Unit at Auckland District Health Board, the AEG estimates that as of the end of 2007 there were 1230 individuals living with diagnosed HIV in New Zealand (AEG 2008).

Given this estimate, the sample recruited for this study represents approximately 21% of the diagnosed HIV positive population.

There is limited information in New Zealand on the demographic characteristics of people diagnosed with HIV prior to 1996. However, since 1996 the information available about new HIV diagnoses has expanded. Individuals who were diagnosed between 1.1.96 and 30.11.07, and who were still believed to be living in New Zealand (i.e. were not believed to have died or have moved overseas) can provide us with a snapshot against which the HIV Futures New Zealand 2 sample can be compared (AEG 2007).

Of the survey respondents, 75.7% were male (196), 23.9% were female (62), and one person was transgender. This sample consisted of 60.7% gay men, 22.7% heterosexual women, 10.1% heterosexual men, 6.1% bisexual men, and 0.4% lesbian women. The AEG estimates the gender breakdown of the current HIV positive population diagnosed since 1996 to be 78.4% male and 21.6% female (AEG 2007).

Respondents ranged in age from 23 to 88 years with a mean of 45.6 years and a median of 44.0 years.

The majority of participants were New Zealand born (69.4%) and 89.8% of the participants spoke English at home, with East African languages accounting for most of the remainder. Of the total sample, 255 indicated their ethnicity. One hundred and seventy two were European (65.9%), 49 were African (18.8%), 17 were Maori (6.5%), nine were Asian (3.4%) and five were Pacific Islanders (1.9%). This is generally consistent with the AEG figures since 1996 which suggest the population consists of 49.8% European/Pakeha, 23.7% African, 10.9% Asian, 7.5% Maori, 2.8% Pacific Islander and 5.2% other/unknown (AEG 2007).

Respondents came from all regions of New Zealand, with the majority coming from the Auckland area. Again this is reasonably consistent with AEG figures since 1996 which indicate that 51.1% of the HIV infected population live in Northland and Auckland.

**TABLE 1 Respondents' place of residence**

Area	Frequency	Percent of Sample
Auckland	141	54.4
Wellington	30	11.6
Christchurch	23	8.9
Hamilton	6	2.3
Other city	16	6.2
Provincial Town	20	7.7
Rural	23	8.9

65.8% of participants were living in the same area in which they were diagnosed with HIV infection, while the remainder were living in a different area.

Table 2 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 25 years with a mean of 2.7 years and a median of one year. 31.6% of the sample tested positive in the same year they believe they were infected. There are 51 respondents in the sample who had tested positive in the two years prior to survey and 8 respondents who believe they were infected in the previous year.

**TABLE 2 Year of respondents' HIV diagnosis and presumed year of infection**

Year	Tested HIV Positive	Presumed Infected
Pre 1985	2.3	13.5
1985-1989	10.8	13.5
1990-1994	13.5	20.2
1995-1999	21.9	19.7
2000-2004	31.9	21.2
2005+	19.6	11.9

81 respondents (32.3%) indicated that they were atheist/agnostic, 53.9% indicated mainstream religious identification and the remainder indicated that they either had 'other' (10.4%) or New Age (3.6%) spiritual beliefs. Less than one third of respondents (30.3%) indicated that religious beliefs were not important to them, while a similar proportion (26.0%) indicated that these were of little importance, 21.3% that they were very important and 22.4% that they were extremely important. Data from the New Zealand Census indicate that 32.2% of the population had no religious beliefs (Statistics New Zealand).

The educational level of respondents was somewhat higher than the general population, as is usual in research requiring a moderate level of literacy and engagement with the research process. New Zealand census data indicates that 14.2% had graduate or post-graduate education (Statistics New Zealand). The participants' educational levels are shown in Table 3 below.

**TABLE 3 Educational level of respondents**

Level	Frequency	Percent of sample
Graduate or postgraduate degree	32	12.5
Bachelors or undergraduate degree	39	15.2
Professional/technical/trades certificate or diploma	64	25.0
HSC, UE, Bursary or NCEA level 3	20	7.8
6th form certificate, NCEA level 2	30	11.8
School certificate, NCEA level 1	38	14.8
No school qualification	33	12.9

**NOTE ON THE ANALYSIS IN FOLLOWING SECTIONS.**

The analyses from this point forward are divided into two populations. The responses of HIV positive New Zealanders of African descent are analysed separately in the section commencing on page 71. This recognises the particular experiences of this population and allows a meaningful comparison with findings presented in the first HIV Futures New Zealand report. The analyses of the remainder of the sample are presented in the following sections. Where appropriate and where sample sizes permit, comparison is made between specific populations within sections. Often the sub-populations of respondents become too small for comparison, particularly when there are a number of response categories. In these cases, sub-population comparisons are likely to be misleading and are not included.

# HEALTH

This section of the report deals primarily with the physical health and experience of health of New Zealand PLWHA. The chapter includes a discussion of the experiences of testing positive for HIV, the current health status of participants measured both by clinical markers and self-reported health and well being, the health burden in terms of concomitant health conditions and health maintenance strategies.

## HIV ANTIBODY TESTING

HIV antibody testing in New Zealand 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. Rapid testing became available through the New Zealand AIDS Foundation in December 2006. 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, 2004). These guidelines also detail the best practice procedures for pre-test discussion and post-test counselling.

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 (Ministry of Health 2004). We asked respondents about the circumstances surrounding the time that they tested positive for HIV.

As can be seen from Table 4, 26.7% of the respondents had taken the test as a result of illness, 20.8% as part of routine health screening and 8.4% as a result of a particular risk episode. Gay or bisexual men were more likely to say that they tested as a result of illness (28.8%) compared with 17.2% of women and 12.5% of heterosexual men. Only gay or bisexual men gave the reason ‘Member of risk group’ (10.6%). The reason ‘My partner tested positive’ was more likely to be given by women (17.2%) than by gay or bisexual men (9.4%) or heterosexual men (none).

Of those who had tested positive in the last two years, 32.6% had taken a test due to illness, while 25.6% said they were tested as part of a routine health screening and 11.6% because of a particular risk episode.

**TABLE 4 Reasons for testing**

Reason	Frequency	Percent
Became ill/ongoing illness	52	25.7
Routine health screening	35	17.3
Particular risk episode	21	10.4
Partner tested positive	20	9.9
Other	20	9.9
Member of risk group	16	7.9
Doctor’s suggestion	15	7.4
Tested without knowledge	7	3.5
Starting new relationship	6	3.0
Antenatal	3	1.5
Contact tracer/other health worker’s suggestion	2	1.0

### Pre- and Post-Test counselling/discussion

The experience of HIV testing and the receipt of a positive diagnosis can be highly emotionally charged events. Those providing testing for HIV must be aware of the practical, informational and emotional needs of those taking the test, even when this is something they have done on a number of occasions. Pre-test discussion provides an opportunity to clarify their knowledge around transmission and the technical aspects of the test itself (for example, window periods, specificity, costs). There may also be discussion of the events that led to testing, ongoing concerns about maintaining protective behaviours, imagined consequences of receiving a positive result, managing relationship issues and managing the period while waiting for test results. Post-test counselling when the test is positive is often not a single event but a process that includes a number of consultations and referrals to address health, emotional and social support issues. In New Zealand, there are guidelines for those providing HIV testing that outline the key issues that need to be considered before and after testing for both those who test negative and those who test positive (Ministry of Health 2004). Clearly the needs and responses of individuals vary enormously

on receipt of a positive test result, and practitioners need to be able to tailor their response to these. The introduction of rapid testing has provided additional challenges in this regard, where an interim positive rapid test needs confirmation through full blood Western Blot testing. The blood test may confirm or contradict the rapid test, leading to a degree of uncertainty.

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.

25.8% of respondents indicated that they had received pre-test counselling or engaged in an HIV test discussion. Of those who had tested positive in the last two years, 22.0% had received pre-test counselling. The counselling was generally provided by a doctor (28.0%), and less commonly by staff at an HIV/AIDS organisation (24.0%), a counsellor (18.0%) staff at a sexual health clinic (10.0%), or a doctor and a counsellor (6.0%). No other response accounted for more than 5% of responses. When asked if they were satisfied with the counselling/discussion, 86.4% reported they were satisfied with the information they received from this person and 85.9% said they were satisfied with the level of support they received.

66.8% of respondents indicated that they had received post-test counselling. Of those who tested positive in the last two years 79.6% had received post-test counselling, a significantly greater proportion than for those who were diagnosed earlier than this. The counselling was generally provided by a doctor (36.0%), but was also commonly provided by staff at an HIV/AIDS organisation (25.7%) a counsellor (16.9%) or a nurse (6.6%). No other response accounted for more than 5% of responses. When asked if they were satisfied with the counselling they received, 89.6% said they were satisfied with the information they received and 83.8% said they were satisfied with the support they received.

## CURRENT HEALTH STATUS

### Experience of Health and General Well-Being

We asked respondents how they would best describe their current state of physical health and overall sense of well-being on a four point scale. The results are shown in Table 5 and Table 6 below. Half of the sample (50.2%) rated their physical health as good and 27.0% as excellent. There were no significant gender differences in the ratings of health and well-being.

**TABLE 5 Respondents' self ratings of general health status**

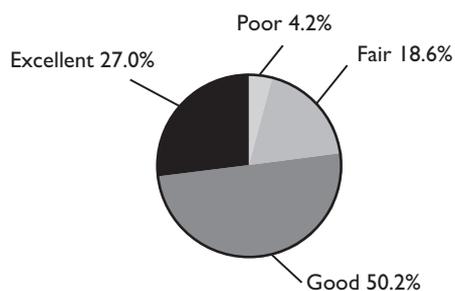
	Frequency	Percent
Poor	9	4.2
Fair	40	18.6
Good	108	50.2
Excellent	58	27.0

The ratings for well being were of a similar pattern to those for health. Three-quarters of respondents (75.1%) rated their well-being as either good or excellent, while 20.7% rated this as fair and 4.2% as poor.

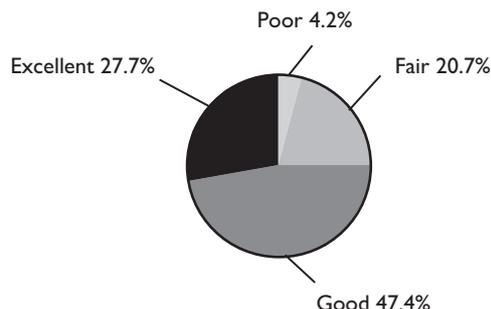
**TABLE 6: Respondents' self ratings of general well-being**

	Frequency	Percent
Poor	9	4.2
Fair	44	20.7
Good	101	47.4
Excellent	59	27.7

**FIGURE 1 Self rated Health**



**FIGURE 2 Self rated well-being**



When we look at the relationship between these two measures, we can see overall that better health was related to greater well-being (see Table 7). This is, however, not a clear and direct relationship. The correlation between the two measures is  $p=0.696$  ( $p<0.001$ ). Some respondents (16.4%) rated their well-being as worse than their health and 14.6% rated their health as worse than their well-being. Having a higher CD4 count at the most recent test was associated with having better health ( $\chi^2(6, N=178) = 13.80, p<0.05$ ), however was not significantly associated with better overall well-being ( $\chi^2(6, N=176) = 11.49, p=0.074$ ). However there was no correlation between health and most recent viral load result, or between well-being and most recent viral load.

**TABLE 7 Relationship between ratings of overall health and well-being (% of total sample)**

Wellbeing	HEALTH			
	Poor	Fair	Good	Excellent
Poor	1.9	1.4	0.9	-
Fair	1.4	11.7	7.5	-
Good	0.5	5.6	34.7	6.6
Excellent	0.5	-	6.6	20.7

## CD4 and Viral Load

As with the previous three surveys, almost all PLWHA had taken a CD4/T-cell test (96.7%) and a viral load test (94.4%). Most respondents had taken their most recent CD4 test in the six months prior to survey (87.5%) (56.1% in the last three months) and their most recent viral load test in the six months prior to survey (82.1%) (50.3% in the last three months). On average participants had taken three viral load tests in the preceding twelve months. Among those PLWHA who had taken a CD4 test, 93.0% reported that they have at some time had a CD4 count of less than 500 cells/ $\mu$ l and 64.0% reported a count of less than 250 cells/ $\mu$ l.

Results for PLWHA's most recent CD4/T-cell test ranged from 10 to 1190 cells/ $\mu$ l with a mean of 521.61 cells/ $\mu$ l and a median of 480.00 cells/ $\mu$ l.

Among those PLWHA who have taken a viral load test, 54.1% reported that at some point they have had a result of over 10,000 copies/ml and 38.8% a result of over 50,000 copies/ml.

Results for PLWHA's most recent viral load test ranged from below detectable levels to 10,000,000 copies/ml with a mean of 68,466 copies/ml and a median of below detectable level. 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 (500+), moderate damage (250-499) and severe damage (0-249), and four levels of viral load: below detectable levels (<500), low (500-9,999), moderate (10,000-49,999) and high (50,000+). 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 serological tests, (percentage of total sample)**

		HIV VIRAL LOAD				Total
		<500	500-9999	10000-49999	50000+	
Cd4/T-cell count	500+	37.1	3.6	3.0	0.6	44.3
	250-499	36.5	2.4	3.0	2.4	44.3
	0-249	10.2	-	-	1.2	11.4
	Total	83.8	6.0	6.0	4.2	100

## HEALTH CONDITIONS

While there is often uncertainty about whether a particular illness may be related to HIV, treatments or other factors, we offered participants the opportunity to record these conditions within the categories of AIDS defining illnesses (ADI), HIV-related illnesses, major health conditions other than HIV/AIDS and mental health conditions. We asked respondents to indicate whether they had experienced conditions in these categories and to specify the condition and the year in which it was diagnosed. Some recoding was undertaken, for example for a condition that did not meet the criteria for ADI and the data were transferred to either HIV related conditions or other health conditions. Regardless of the uncertainty about the aetiology of these conditions among PLWHA (and indeed physicians) we can see that there is a considerable burden of illness that goes beyond HIV infection for a significant proportion of the survey respondents.

Participants were also asked to select from a list of 10 HIV-related illnesses those that they had experienced in the 12 months prior to survey. This section will also cover co-infection with hepatitises, attitudes towards body changes and health maintenance activities.

### AIDS Defining Illnesses

AIDS is a notifiable condition in New Zealand. According to Ministry of Health guidelines: “[A]n AIDS defining event determines when a person should be notified to the local Medical Officer of Health. A positive HIV test result is not notifiable. Once the diagnosis of AIDS has been established, there is a statutory duty to notify the case to the Medical Officer of Health using the recommended notification form and special code” (Ministry of Health 2004).

The case definition for AIDS requires both laboratory evidence of HIV infection and clinical confirmation of one of 25 specific conditions (Ministry of Health 2004). These conditions are therefore known as AIDS defining illnesses. The category system for defining the stages of HIV disease progression was in large part based on an understanding of the progress of the disease as degenerative with little backwards 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.

Around one in five respondents (21.6%) said they had been diagnosed with an AIDS defining illness at some point. The most common illnesses listed by respondents in this category were Pneumocystis Pneumonia and Kaposi's Sarcoma.

### HIV/AIDS Related Conditions

One-quarter of respondents (24.9%) indicated that they had experienced an HIV-related illness at some point. Within this group the most common conditions mentioned were skin problems (such as rashes), shingles and candida /thrush.

In a separate question, participants were asked to select from a list of 10 conditions commonly associated with HIV infection those that they had experienced in the 12 months prior to survey. In order to gain a clearer picture of respondents' burden of illness, this list was expanded from the previous HIV Futures New Zealand survey to include six additional conditions.

**TABLE 9 Health conditions experienced in the past 12 months**

Condition	Percent
Low energy/fatigue	80.9
Diarrhoea	69.3
Sleep disorder	64.2
Weight loss/underweight	40.0
Confusion/memory loss	43.7
Nausea or vomiting	38.9
Lipodystrophy/lipoatrophy	34.7
Raised cholesterol/triglycerides	33.1
Peripheral neuropathy	16.8
Insulin resistance	4.4
AIDS neurological syndrome	1.5

Those reporting weight loss were significantly more likely to have a body mass index (BMI) in the underweight (18.5) or normal (18.5-25) categories (63.6% v 42.7%,  $\chi^2(6, N=184) = 13.38, p < 0.01$ ) (everybody.co.nz, 2007<sup>1</sup>).

### Attitudes towards body image

Lipodystrophy and lipoatrophy have created additional difficulties for positive people (see for example Persson 2003). While there is still some debate over the most appropriate clinical case definition for these conditions, self-reported body changes remain an important component of diagnosis (Carr et al 1999, Behrens et al 2000). 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 experienced lipodystrophy or lipoatrophy in the past 12 months. As can be seen, over half of the sample (58.7%) disagreed with the statement Body changes due to lipodystrophy make it obvious to others that people have HIV, while just over half of the sample agreed with the other two items. The responses of those with lipodystrophy/lipoatrophy were more likely to be suggestive of a poorer body image.

**TABLE 10 Attitudes around body image  
(percentages of total sample, those with and without lipodystrophy)**

		% of total sample	% of those with lipodystrophy	% of those without lipodystrophy
Changes in my body due to HIV / AIDS have made me feel sexually unattractive.	strongly disagree	10.6	2.0	15.2
	disagree	35.2	28.0	39.1
	agree	35.9	38.0	34.8
	strongly agree	18.3	32.0	10.9
I am happy with the way my body looks.	strongly disagree	9.3	18.4	4.4
	disagree	34.3	51.0	25.3
	agree	47.1	28.6	57.1
	strongly agree	9.3	2.0	13.2
Body changes due to lipodystrophy make it obvious to others that people have HIV	strongly disagree	15.8	4.3	21.8
	disagree	42.9	26.1	51.7
	agree	30.8	50.0	20.7
	strongly agree	10.5	19.6	5.7

### Other Health Conditions

29.8% respondents indicated that they had been diagnosed with a major health condition other than HIV/AIDS. The most common conditions listed under this heading were cardiovascular disease (e.g. high blood pressure), hepatitis C, asthma and diabetes.

1 Note that BMI in New Zealand differs slightly for people of Maori and Pacific Island background. There is no difference in the classification of 'underweight (BMI < 18.5) and only slight differences for the other categories.

## Viral Hepatitis

Hepatitis is a term that refers to inflammation of the liver. Six different types of viral hepatitis have been identified so far. Hepatitis A, B and C are more commonly known in New Zealand but hepatitis D, E and G have also been identified. For HIV positive people, co-infection with hepatitis may affect both people's health and/or their decisions in relation to antiretroviral treatments (Mijch 2003).

Vaccination is available for hepatitis A and B, but not for hepatitis C. Hepatitis B vaccination is available free of charge in New Zealand for children under 16 years old, household and sexual contacts of known carriers and for participants in a nationwide screening program (Ministry of Health)

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

Over one quarter of the participants (11.1%) had at some point had hepatitis A, and 54.3% had been vaccinated against this virus. This means that 34.6% of the respondents may currently be at risk of hepatitis A infection. Population data indicates that the incidence rate of hepatitis A was 2.9 per 100,000 (122 cases, 0.003%) (Population and Environmental Health Group, 2007)

### Hepatitis B

A total of 13.8% of respondents had at some time been diagnosed with hepatitis B. Of these, 60.9% had cleared the infection, 26.1% (n=6) had an ongoing infection and one person had a chronic infection. The majority of those who had been diagnosed with hepatitis B said they did not experience any symptoms related to hepatitis B (80.6%).

In addition to those who had experienced hepatitis B infection, 57.4% had been vaccinated against this virus. This means that 28.8% may currently be at risk of being infected with hepatitis B. Population data indicates that the incidence rate of hepatitis B was 1.5 per 100,000 (0.002%) (Population and Environmental Health Group, 2007).

### Hepatitis C

Almost half (46.9%) of respondents had not been tested for hepatitis C, slightly lower than the figure reported in the first HIV Futures New Zealand survey (53.8%). In the previous survey we used a series of items including test results, year of diagnosis with hepatitis C, and designation of hepatitis C as a major health condition to determine the percentage of respondents with hepatitis C. In HIV Futures New Zealand 2, we also asked respondents if they had ever had hepatitis C, and 7.7% (N=15) said that they had.

Population data indicates that the incident rate of hepatitis C was 0.8 per 100,000 (34 cases in 2006, 0.001%) (Population and Environmental Health Group, 2007).

## 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 six months prior to completing the survey, 18.6% of PLWHA said they had taken medicines prescribed for depression. Population data suggests that this is higher than the New Zealand average. At a population level 5.9% had been prescribed an anti-depressant (Ministry of Health, 2007) in the previous year.

Just over one-fifth of respondents (22.9%) reported having taken medicines prescribed for anxiety in the past 6 months. In addition 2.9% of the sample indicated that they had taken anti-psychotic medication.

### Diagnosis of a Mental Health Condition

We asked respondents if they had been diagnosed with a mental health condition and 28.8% reported that they had had such a diagnosis. Of those reporting a diagnosis, the vast majority had been diagnosed with depression (25.1% of the total sample). 28.5% of people had received this diagnosis in the past 2 years. The next most common condition was anxiety, reported by 14.1% of the total sample. 40.7% of those reported having received this diagnosis over the past 2 years. The New Zealand Mental Health Survey (Oakley Browne et al 2006) gives some comparative data for the New Zealand population. In this survey, 14.8% reported diagnosis with any anxiety disorder in the previous 12 months, with 2.0% specifically reporting a generalised anxiety disorder. Lifetime diagnosis with any anxiety disorder was 24.9%. The survey reports 8.0% diagnosis with any mood disorder in the 12 months prior to survey and 5.7% with a major depressive disorder. Lifetime diagnosis was 20.2% with any mood disorder and 16.0% with a major depressive disorder.

## 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 11, 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 (22.3%) agreed or strongly agreed with item 1 (crying all the time), and 15.7% 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, 53.0% agreed or strongly agreed with none of these items, 16.0% with one item, 15.3% with two items, 7.1% with three items, and 8.1% of the sample agreed with all four items. Agreement with all four items may be suggestive of clinical depression.

**TABLE 11 BDI depression symptom items: percentage of total sample**

	Strongly agree	Agree	Disagree	Strongly disagree
I cry or feel like crying all the time	2.4	15.9	49.3	32.4
I don't enjoy things the way I used to	10.7	35.4	35.9	18.0
I have lost interest in other people	5.7	21.3	46.9	26.1
I don't feel it's worth going on	5.2	10.5	35.7	48.6

## HEALTH MAINTENANCE

We asked participants about a range of activities that they may engage in to improve their health. The results are shown in Table 12 below. The most common health-enhancement activity was eating healthily, followed by sleep, exercise, and relaxation. Those with better self rated health were significantly more likely to indicate that they engaged in exercise, spending time with friends and spending time with their partner. Those with better well being were significantly more likely to indicate that they engaged in healthy eating, spending time with friends, relaxation, spending time with their partner and spending time with family.

**TABLE 12 Health improvement strategies**

Healthy eating	78.6
Sleep	74.9
Exercise	69.8
Relaxation	65.1
Spending time with friends	54.4
Spending time with family	36.3
Spending time with partner	35.3
Spending time with pets	35.3

(Multiple responses possible)

## Attitudes to Health Management

Participants responded to a number of statements about health management in relation to health improvement 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 13). Those who indicated that they exercised and ate well were more likely to agree with the respective statements.

**TABLE 13 Attitudes to health management: percentage of total sample**

Looking after my physical fitness is an important part of managing my HIV infection	strongly agree	52.1
	agree	43.2
	disagree	4.2
	strongly disagree	0.5
Healthy eating is an important part of managing my HIV infection	strongly agree	43.9
	agree	50.0
	disagree	4.7
	strongly disagree	1.4
Keeping an optimistic frame of mind is an important part of managing HIV infection	strongly agree	54.5
	agree	42.2
	disagree	2.4
	strongly disagree	0.9

## Prophylaxis

10.0% of respondents were taking prophylaxis for opportunistic infections, while 7.0% said they did not know. Those using prophylaxis were more likely to have experienced an AIDS defining illness, to have a lower CD4 count and to have been HIV positive longer.

## Other Health Monitoring

We asked a series of questions about other health monitoring activities. 15.5% had taken a bone density test in the last two years and 8.5% had taken a test more than two years ago. 42.0% had taken a fasting cholesterol test in the last two years and 13.0% had taken one more than two years ago. The long term effects of living with HIV and medication have made health concerns such as high cholesterol, cardiovascular difficulties and osteoporosis increasingly important for positive people.

All female respondents who answered this question had undergone a cervical smear (Pap) test (100.0%) and 66.6% said they had taken one in the last twelve months. On average women had undergone one test in the previous year. The CDC recommends that all HIV-positive women have a pap smear test every year. This means that up to one-third of women who should have had an annual pap smear had not, although it may be possible that some of these women did not require one. On their most recent test, most women (82.1%) reported that the result was 'normal', while five women reported atypia.

## Other Medication

Participants used a range of other prescribed medication. In all 46.3% of respondents were using other type of prescribed medication other than antiretroviral therapies. A high proportion of participants reported using antidepressants and other medicines for mental health conditions. Please refer to pg 7 for discussion of these medicines.

## COMPLEMENTARY THERAPIES

We asked participants if they had used any complementary therapies in the previous six months, including therapeutic use of marijuana, and to indicate the types of therapies used and where these products or services were obtained. In order to gain an overall picture of the use of these modalities, the question asked participants to indicate all complementary therapies they had used, not only those used for HIV/AIDS. Over three-quarters of respondents (66.5%) indicated that they had used some kind of complementary medicine or therapy in the previous six months. Almost half of the sample (47.0%) had taken vitamin or mineral supplements. Almost one-third (31.2%) of respondents had used massage, while 14.4% had used meditation. 17.7% of respondents indicated that they had used marijuana for therapeutic purposes.

**TABLE 14 Use of complementary therapies in the past six months**

Vitamin / mineral supplements	47.0
Massage	31.2
Marijuana for therapeutic purposes	17.7
Meditation / visualisation	14.4
Herbal therapies / supplements	14.0
Acupuncture	2.8
Traditional Chinese medicine	3.3
Other traditional medicine	-
Other complementary therapy	0.5

(Multiple responses possible)

Participants were asked where they obtained these services or supplements. While one in six obtained these from a private practice, a similar proportion obtained them either from an AIDS community organisation or a PLWHA group. Those that selected the 'other' option mostly obtained these medicines from health food shops or similar establishments.

**TABLE 15 Source of complementary therapies**

Health Food Shop	34.8
Private practice	37.0
AIDS Foundation Centre	9.6
Health Service	9.6
PLWHA organisation	11.9
Friends/family	5.2
Pharmacy/supermarket	3.7
Other	14.8

(Multiple responses possible)

Almost three-quarters of respondents (71.5%) agreed that complementary therapies can improve well-being, while 60.1% agreed that complementary therapies can boost the immune system. Almost half of respondents agreed that complementary therapies can reduce side effects (48.0%) and delay the onset of illness due to HIV (47.1%) (see Table 16. below). However, over one third of respondents were unsure about these statements and these people were significantly more likely not to have used complementary therapies. Roughly equal proportions of respondents agreed and disagreed with the statements on whether there is sufficient evidence about the benefits of complementary therapies, whether medicine's focus on anti-HIV drugs was limited and whether complementary therapies constituted a central part of their anti-HIV treatments. Again, there was considerable uncertainty about these issues.

**TABLE 16 Attitudes to complementary therapies: percentage of total sample**

Complementary therapies can delay the onset of illness due to HIV	strongly disagree	1.9
	disagree	9.7
	agree	29.1
	strongly agree	18.0
	don't know	41.3
Complementary therapies can improve well-being	strongly disagree	1.0
	disagree	1.4
	agree	38.2
	strongly agree	33.3
	don't know	26.1
Complementary therapies can reduce the side effects of conventional medical treatments	strongly disagree	2.0
	disagree	7.4
	agree	29.9
	strongly agree	18.1
	don't know	42.6
There is not enough evidence to be sure about the benefits of complementary therapies	strongly disagree	7.0
	disagree	25.9
	agree	30.3
	strongly agree	7.5
	don't know	29.4
Medicine's focus on anti-HIV drugs is very limited	strongly disagree	3.9
	disagree	26.6
	agree	25.1
	strongly agree	12.8
	don't know	31.5
Complementary therapies can boost the immune system	strongly disagree	1.5
	disagree	3.9
	agree	37.4
	strongly agree	22.7
	don't know	34.5
Complementary therapies are a central part of my anti-HIV treatments	strongly disagree	9.6
	disagree	27.8
	agree	19.7
	strongly agree	11.6
	don't know	31.3

# TREATMENTS

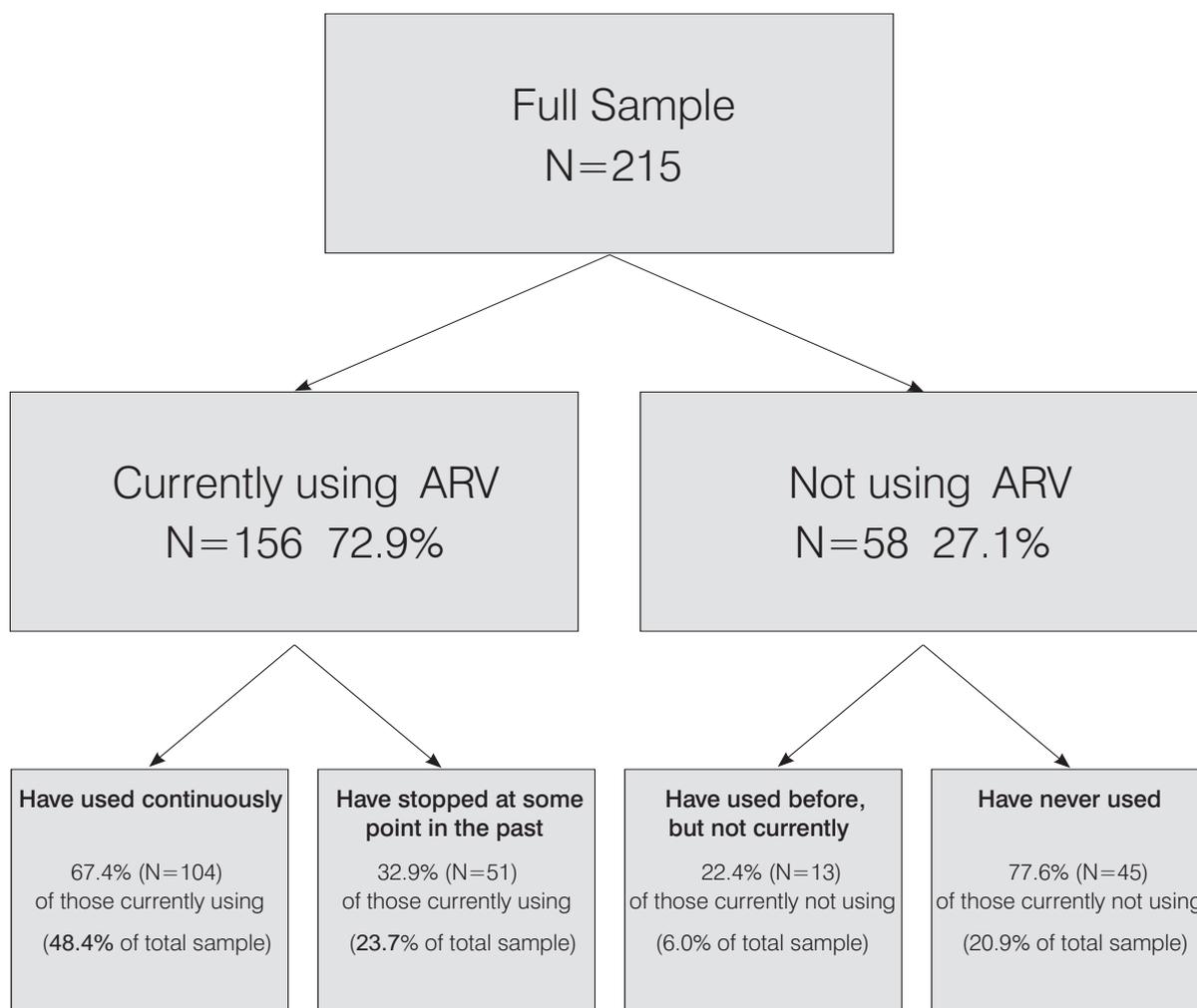
This chapter reports on the treatment experiences of PLWHA. The main emphasis is on antiretroviral treatments, as these are dominant in the lives of HIV positive people. There is also some discussion of medicines taken for other health conditions. While we have seen a reduction in the number of medicines taken and the frequency of taking them over the past few years (see for example Fogarty et al 2003), the burden of medicine (largely pill based) remains high.

## ANTIRETROVIRAL THERAPY

Highly active antiretroviral therapy remains the single factor that has most altered the clinical outcomes for people living with HIV. The introduction of ARV has reshaped the HIV epidemic in developed countries, and is increasingly doing so in developing nations and resource poor settings. The years in which these treatments have been available have seen improvements in the efficacy and tolerability of treatments, but this period has also shown us that they are clinically and pharmacologically complex. In the following section we examine some of these consequences from the perspective of PLWHA, but we also examine the psychological and social impacts of the treatments.

Of the full sample, 79.0% had used ARV at some point, and 72.9% were currently using these treatments. If we look at the gender breakdown of ARV use, we observe that 60.0% (n=18) of women compared with 74.6% (n=135) of men were currently using ARV. A summary diagram of the uptake of antiretrovirals can be found in Figure 3 on page 12.

**FIGURE 3 Use of Antiretroviral Therapy**



(Note: Ns and percentages may be reduced due to missing data)

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

The majority of participants (73.6%) were on a combination of 3 antiretroviral drugs<sup>2</sup>, with 23.7% on more than three antiretroviral drugs and four people (2.7%) on two.

**TABLE 17 Antiretroviral drugs used by respondents: percentage of those currently using ARV**

### Nucleoside Reverse Transcriptase Inhibitors (NRTIs)

Lamivudine (3TC, Epivir)	17.2
Abacavir (Ziagen)	14.9
Stavudine, d4T (Zerit)	4.7
Zidovudine, AZT (Retrovir)	4.7
Didanosine, ddl (Videx)	4.7
ddl ec (Videx ec, didanosine ec)	1.4
Zalcitabine, ddC (Hivid)	-

### Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)

Nevirapine (Viramune)	9.8
Efavirenz (Sustiva, Stocrin)	37.2
Delavirdine (Rescriptor)	-

### Nucleotide Analog Reverse Transcriptase Inhibitors (NtARTIs)

Tenofovir (Viread)	4.7
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### Protease Inhibitors

Ritonavir (Norvir)	4.7
Atazanavir (Reyataz)	5.6
Saquinavir (Invirase, Fortovase)	-
Nelfinavir (Viracept)	2.3
Indinavir (Crixivan)	3.7
Tipranavir	-

### Fusion Inhibitor

T-20	0.5
------	-----

### Combination Medications

Kaletra (lopinavir and ritonavir)	9.8
Combivir (AZT & 3TC)	40.9
Trizivir (AZT & 3TC & Abacavir)	1.4
Other	3.3

Respondents were also asked specifically about their use of the immune stimulant Interleukin 2 and no respondents were using it.

## Difficulties of Taking ARV

Overall, 44.3% of those currently using antiretroviral treatments reported that they had some difficulty taking them (Table 18). Of those currently using antiretroviral treatments, 23.6% indicated they had difficulty remembering to take the drugs on time, 16.6% said they had difficulty transporting medication, 15.9% taking a large number of tablets and 12.7% taking medication in public.

2 Combivir counts as 2 drugs, Trizivir as 3 drugs, Kaletra as 2 drugs, Kivexa as 2 drugs

**TABLE 18 Difficulties of taking ARV among those currently using ARV**

Side effects	26.1
Remembering to take drugs on time	23.6
Carrying/transporting medication	16.6
Taking a large number of tablets	15.9
Taking medication in public	12.7
Organising meals around medication	8.3
ARV drugs make it difficult to take medication for other health conditions	3.2
Medication taken for other health conditions makes it difficult to take ARV	0.6
Other	2.5

(Multiple responses possible)

Side effects were reported by 26.1% of respondents currently using ARV. The most commonly reported problems were diarrhoea, nausea or vomiting and sleep disturbances.

### Attitudes to ARV

Most respondents reported concern over the future efficacy of their treatments. Over half (58.1%) agreed or strongly agreed with the statement *I am worried that in the future my medication will stop working for me*. When asked to respond to the statement *Taking tablets gives me an unwanted reminder that I have HIV*, 53.6% indicated agreement and 45.1% indicated disagreement.

**TABLE 19 Attitudes to medication: percentage of those currently using ARV**

	strongly disagree	disagree	agree	strongly agree	don't know
I am worried that in the future my medication will stop working for me	8.5	21.6	43.1	15.0	11.8
Taking tablets gives me an unwanted reminder that I have HIV	14.4	30.7	38.6	15.0	1.3

### Health Status of Those Using ARV

The mean viral load level among respondents who were taking ARV (2738 copies/ml) was significantly lower than for those who had taken ARV in the past (1,257,055 copies/ml), or those who had never taken ARV (27520 copies/ml),  $F_{(2)} = 10.555$   $p < 0.001$ ). 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 Table 20.

**TABLE 20 Viral load of those taking and not taking antiretroviral therapy (percentage within rows)**

		VIRAL LOAD ON MOST RECENT TEST			
		Below detectable levels	500-9999	10000-49999	50000+
ARV Use	Current	95.1	2.1	0.7	2.1
	Past	63.6	9.1	18.2	9.1
	Never	47.1	17.6	26.5	8.8

$\chi^2(6) = 55.865$   $p < 0.001$

The mean CD4 count among those who were taking ARV was higher than for those who had taken ARV previously (mean of 502 cells/ $\mu$ l compared to 440 cells/ $\mu$ l), and similar to those who had never taken ARV (mean of 507 cells/ $\mu$ l). This difference was not statistically significant  $F_{(2)} = 0.353$ ,  $p = 0.703$ .

**TABLE 21 CD4 of those taking and not taking antiretroviral therapy (percentage within rows)**

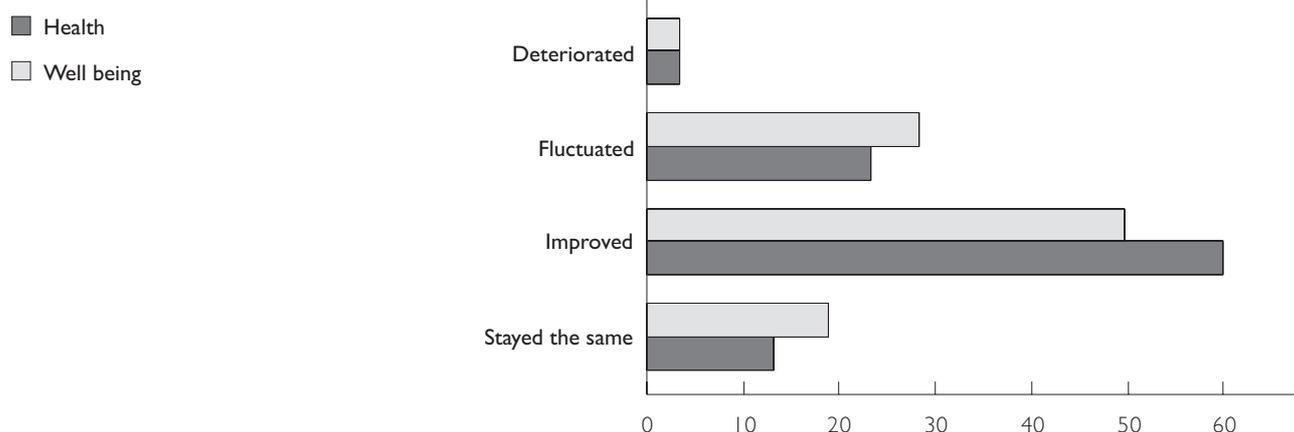
		CD4 ON MOST RECENT TEST		
		0-249	250-499	500+
ARV Use	Current	12.7	46.0	41.3
	Past	32.5	45.5	36.4
	Never	10.0	32.5	57.5

$$\chi^2(4) = 3.774 \quad p = 0.437$$

Those currently taking antiretroviral treatments were more likely to have had an AIDS defining illness (27.5% compared to 15.4% among those currently not taking antiretrovirals and 2.2% among those who have never taken ARV). The average length of HIV diagnosis was 10.6 years for those taking ARV, compared with 13.2 for those who had taken ARV in the past and 3.3 years for those who have never taken ARV.

When asked to rate the effect of commencing ARV on their physical health, 60.0% said that their health improved, 23.3% said it had fluctuated, 13.3% said it had stayed the same and 3.3% said it had deteriorated. When asked about the impact of ARV on their overall feeling of well-being, 49.7% said it had improved, 28.2% said it had fluctuated, 18.8% said it had stayed the same and 3.4% said it had deteriorated.

**FIGURE 4 Effect of commencing antiretroviral medication on health and well being (percentage of those taking ARV)**



## THOSE ON COMBINATION THERAPY

There was considerable variation in the combinations currently in use by respondents. The most common combination was 2 NRTI-1 NNRTI (54.1% of those on ARV, N=79), followed by 2 NRTI-2 PI (10.3%, N=15), 2 NRTI-1 PI (8.2% N=12), 3 NRTI (6.2% N=9)<sup>3</sup>.

On average, respondents had started using combination therapy 5.9 years ago (minimum=1 month, maximum=20.0 years, median=5.5 years). Most started combination therapy at a time when their viral load was high (median= 55,000, mean = 119,576 copies/ml) and their CD4 count was low (median=190, mean = 214). Table 22 below, gives the CD4 and viral load of respondents at the time they commenced combination antiretroviral treatment.

**TABLE 22 Results of serological tests prior to commencement of ARV: percentage of those on ARV**

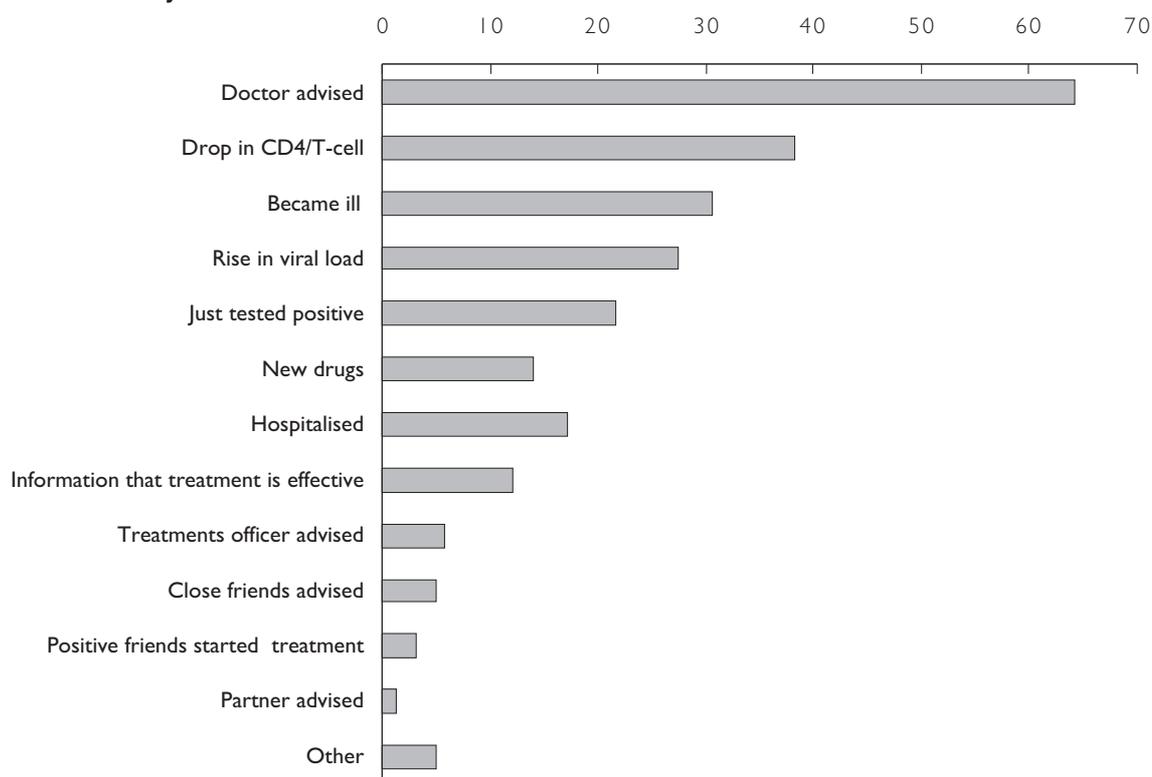
		HIV VIRAL LOAD				Total
		Below detectable levels	500-9999	10000-49999	50000+	
Cd4/ T-cell count	500+	3.6	3.6	1.8	0	8.9
	250-499	7.1	0	7.1	17.9	32.1
	0-249	10.7	5.4	7.1	35.7	58.9
	Total	21.4	8.9	16.1	53.6	100.0

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 (73.5%), although the importance of clinical indicators, treatment developments and treatment information is also clear.

**TABLE 23 Circumstances surrounding commencement of combination therapy treatment among all those currently on combination ARV**

My doctor advised me to begin this treatment	64.3
I had a big drop in my CD4/T-cell count	38.2
I became very ill	30.6
I had a big rise in my viral load	27.4
I had just tested positive to HIV	21.7
New drugs became available	14.0
I was hospitalised due to HIV-related infections	17.2
Information showed that this treatment is effective	12.1
A treatments officer advised me to begin this treatment	5.7
Close friends advised me to begin this treatment	5.1
A number of my positive friends started this treatment	3.2
My partner advised me to begin this treatment	1.3
Other	5.1
(Multiple responses possible)	-

**FIGURE 5 Circumstances surrounding commencement of combination therapy treatment among all those currently on combination ARV**



3 NRTI= Nucleoside Reverse Transcriptase Inhibitors, NNRTI= Non- Nucleoside Reverse Transcriptase Inhibitors, NtARTI= Nucleotide Analog Reverse Transcriptase Inhibitors, PI=Protease Inhibitor

## Different Combinations

Among those currently using combination therapy, respondents had used between one and eight combinations, with the median being two. Within the last 12 months, 60.8% had used one combination and 23.8% 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 (42.5%) the side effects had become too severe. Drugs not working (14.9%) and drug resistance (13.8%) were the next most common responses.

**TABLE 24 Primary circumstance surrounding most recent change in combination among those currently on combination ARV who have changed combinations**

Side effects became too severe	42.5
Drug resistance developed	13.8
They were not working for me	14.9
Taking drugs at the right time was too difficult	5.7
It didn't fit my lifestyle	3.4
The financial burden became too heavy	-
Other (please specify)	19.5

When asked how many combinations they believed they still had access to, 3.6% indicated that they thought they had only one remaining. 23.2% had a few and 26.8% felt they had many. 44.9% said they didn't know how many combinations they had left. Two respondents currently on combination therapy believed they had no combinations remaining.

## THOSE NOT CURRENTLY TAKING ARV

Of the 27.1% of the sample who were not using any antiretroviral medication, only 22.4% had done so in the past (n=13, or 6.0% of the total sample). The mean length of time these respondents had been using ARV was 5.2 years (range 3 months to 18 years) and on average they had ceased using ARV three years prior to completing the survey (range 1 month to 11.3 years). At the time that they stopped using ARV, one-third were using a combination of three drugs (33.3%), one-third were using two drugs (33.3%), one-quarter were using four drugs (25.0%), and 8.3% were on mono-therapy. Of these respondents, 9 (81.8%) said they would consider using antiretroviral drugs in the future.

## Difficulties of Taking ARV

Almost all of those who had taken ARV in the past reported having experienced difficulties taking these drugs (84.6%). There is some variation in the difficulties experienced by this group and those currently taking ARV (see Table 25). Overall, a higher proportion of those who had stopped taking antiretroviral drugs nominated difficulties, particularly difficulties with side effects. However as the number of respondents in this group is very small, the numbers as well as percentages have been provided in the table below.

**TABLE 25 Difficulties of taking ARV among those who have stopped ARV treatment**

	% (n)
Side effects	57.1 (8)
Remembering to take drugs on time	35.7 (5)
Taking medication in public	35.7 (5)
Organising meals around medication	28.6 (4)
Carrying/transporting medication	21.4 (3)
Taking a large number of tablets	14.3 (2)
ARV drugs make it difficult to take medication for other health conditions	-
Medication taken for other health conditions makes it difficult to take ARV	-
Other	7.1 (1)

(Multiple responses possible)

## 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. One person (8.3%) said that it had deteriorated, three (25.0%) that it had fluctuated, one (8.3%) that it had stayed the same, and over half (n=7, 58.3%) said that their health had improved. When asked about the impact of ARV on their overall feeling of well-being, three people (23.1%) said it had improved, six (46.2%) that it had fluctuated, two (15.4) that it had stayed the same and two (15.4%) said their well-being had deteriorated.

Respondents were asked whether they had lifestyle or clinical reasons for ceasing their use of antiretroviral therapy. Five respondents (41.7%) gave lifestyle reasons for stopping treatment. The most commonly cited reasons were difficulty taking drugs at the right time (n=3), to clean out the system (n=2) and because taking treatments didn't fit their lifestyle (n=2).

Eleven respondents (84.6%) gave clinical reasons for ceasing ARV treatment. Four respondents said that this was a treatment break, four said that the cessation was recommended by a health professional other than their doctor and two that they had stopped due to liver toxicity.

## THOSE WHO HAVE NEVER USED ANTIRETROVIRAL DRUGS

20.9% (N=45) of the respondents had never used antiretroviral treatments. Of these 87.8% 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 26).

**TABLE 26 Circumstances that would lead to the commencement of antiretroviral therapy among those who have never used or previously used antiretroviral drugs**

	Never used N(%)	Previously used N(%)
If I had a significant drop in CD4 / T-cell count	34 (75.6)	7 (53.8)
If my doctor advised me to begin this treatment	30 (66.7)	8 (61.5)
If I became very ill	29 (64.4)	7 (53.8)
If I was hospitalised due to HIV-related infections	25 (55.6)	7 (53.8)
If I had a significant rise in my viral load	20 (44.4)	4 (30.8)
If information showed that combination therapy is effective	16 (35.6)	-
If a treatments officer advised me to begin this treatment	13 (28.9)	2 (15.4)
If new drugs became available	7 (15.6)	3 (23.1)
If my partner advised me to begin this treatment	6 (13.3)	-
Other	2 (4.4)	2 (15.4)
If close friends advised me to begin this treatment	2 (4.4)	2 (15.4)
When my break from treatment is finished	2 (4.4)	3 (23.1)
If a number of my positive friends began to take up combination therapy	1 (2.2)	-

(Multiple responses possible)

## ATTITUDES TO ANTIRETROVIRAL THERAPY

Antiretroviral treatments have an impact on many parts of people's lives, not just on their physical health. As in previous surveys, 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 27 on page 19.

**TABLE 27 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 combination antiretroviral drugs	42.3	29.1	14.1	11.3	3.3
People with HIV should start using antiretroviral drugs as soon as possible	12.3	31.6	18.4	13.2	24.5
My doctor and I work together to find the best treatment for me	4.3	5.7	50.2	36.8	2.9
My doctor knows a lot more about the treatment of HIV than I do.	5.6	10.7	42.5	36.9	4.2
Combination antiretroviral drugs are ineffective	41.3	33.3	1.4	4.2	19.7
Combination antiretroviral drugs are harmful	20.3	25.5	22.2	3.8	28.3
The side-effects of antiretroviral drugs outweigh the benefits	15.6	42.0	11.3	8.5	22.6
New treatments will be developed in time for me to gain benefits	1.4	2.4	44.3	21.2	30.7
HIV treatments will stop me dying from AIDS	3.3	15.2	30.3	21.8	29.4
Combination antiretroviral drugs have allowed me to plan my life with confidence for the long-term	5.3	8.7	30.9	34.3	20.8

## Treatment Decision Making

Most respondents indicated that they disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (71.4%). Those who agreed with this statement were more likely to be those not currently using any antiretroviral drugs. Respondents were more likely to disagree than agree with the statement *People with HIV should start using antiretroviral drugs as soon as possible*, although one in four respondents that indicated that they were unsure about this. Those that agreed with this statement were more likely to be using antiretroviral medications.

## Relationship with Doctor

As with previous surveys, most respondents (87.0%) agreed with the statement *My doctor and I work together to find the best treatment for me*, with few expressing uncertainty. Most respondents (79.4%) also agreed with the statement *My doctor knows more about the treatment of HIV than I do*.

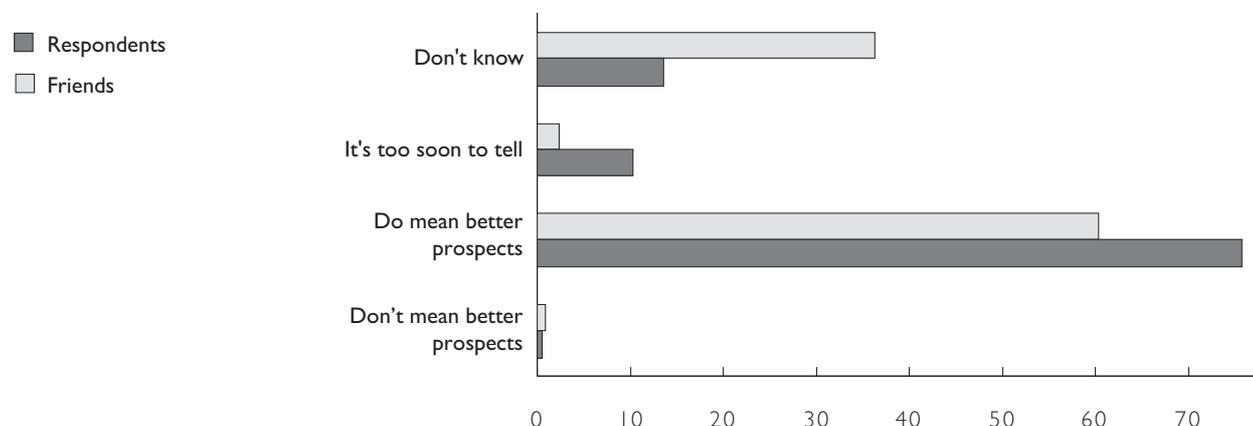
## Treatment Optimism

Optimism about the value and effectiveness of antiretroviral treatments continues to characterise the treatment experience, but tempered as always with concerns about the impact and long term effectiveness of these treatments. Only 5.6% of respondents agreed with the statement *Combination antiretroviral drugs are ineffective*. This belief in effectiveness is tempered by an awareness of the potential harm of these therapies as evidenced by the agreement with the statement that *Combination drugs are harmful* (22.2% agree, 3.8% strongly agree). This harm may in part be that experienced as side effects. Around one in five (19.8%) respondents agreed or strongly agreed with the statement *The side effects of antiretroviral drugs outweigh the benefits*, while 22.6% were unsure. There was considerable uncertainty about the long term benefit of treatment. 30.7% 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, 29.4% were uncertain when asked if *HIV treatments will stop me dying from AIDS*, while around half of respondents agreed with this statement (52.1%). Almost two thirds (65.2%) agreed

with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*, while 20.8% were uncertain.

In addition to these items, respondents were asked to indicate how much they and their friends agree with the statement *Antiretroviral drugs mean better prospects for most people*. Most (75.7%) agreed with the statement, and believed their friends would agree with it (60.3%).

**FIGURE 6 Respondents' and respondents' social networks' response to the statement Antiretroviral drugs mean better prospects for most people**



## TREATMENT BREAKS

Treatment breaks may take a number of forms and be undertaken for a range of reasons (Grierson, Misson and Pitts 2004). 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. To understand the experience of breaks, we asked respondents to give us some detailed information about their most recent break.

In all, 32.5% of those respondents currently using antiretroviral medication had taken a break from these at some point.

### Most Recent Treatment Break

The date of the commencement of most recent treatment break was provided by 84% of those that had ever taken a break. Of these 35.7% had taken their most recent break in the two years prior to survey and 21.4% in the previous one year. Twenty respondents provided information about the length of their treatment break. For these respondents, the mean length of break was 3.7 months with a median of one month. Of those ever taking a break, 21.7% described it as a structured treatment interruption, while 56.5% described it as a treatment break. Of those taking a break in the previous two years, four described it as a structured treatment interruption, while seven described it as a treatment break.

We asked participants to describe the reasons for taking the break within two major categories: lifestyle reasons, and clinical reasons. A discussion of the differences between those taking breaks for primarily lifestyle and primarily clinical reasons can be found in our article on this topic (Grierson, Misson and Pitts 2004). Less than half (44.7%, n=21) indicated that they had lifestyle reasons for taking a break. The specific reasons are given in Table 28 below. The most common reason given was travel (n=11), followed by to clean out the system (n=7).

**TABLE 28 Lifestyle reasons for taking breaks (number of those taking breaks)**

	Total taking breaks
Clean out my system	7
Travel	11
Taking drugs at the right time was too difficult	3
It didn't fit my lifestyle	3
The financial burden became too heavy	1
A special event	3
Other	9

(Multiple responses possible)

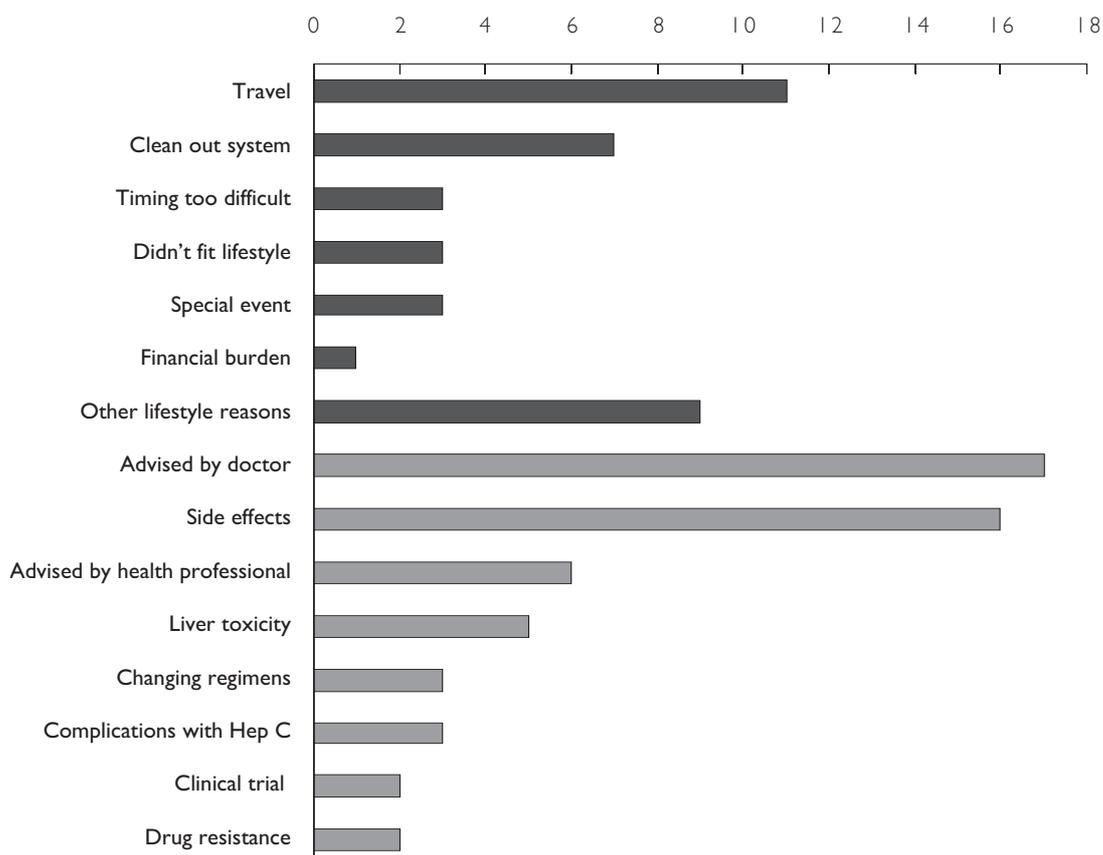
When asked if there was a clinical reason for taking the break, 56.3% (n=27) of those that had taken a break indicated that there was. Table 29 below details the clinical reasons given for breaks. The most commonly cited reason was that the break was recommended by their doctor, followed by that the side effects of treatment became too severe (n=16).

**TABLE 29 Clinical reasons for taking breaks (number of those taking breaks)**

	Total taking breaks
Recommended by my doctor	17
Side effects became too severe	16
Recommended by other health professional	6
Liver toxicity problems	5
Changing regimens	3
Complications with Hep C	3
Taking part in a clinical trial	2
Drug resistance developed	2
Other	4

(Multiple responses possible)

**FIGURE 7 Lifestyle and clinical reasons for taking break**



We also asked about the involvement of the participant's doctor in these breaks. Participants were more likely to have talked to their doctor about the break prior to taking it (65.3%) than they were during the break (52.1%). Almost all of those who had taken a break had talked to their doctor after taking the break (87.5%). Almost half (45.2%) talked to their doctor at all three stages of the treatment break. 14.3% spoke to the doctor during and after the break, but not before, 28.6% spoke to their doctor before and after the break, but not during, and 11.9% only spoke to their doctor after the break.

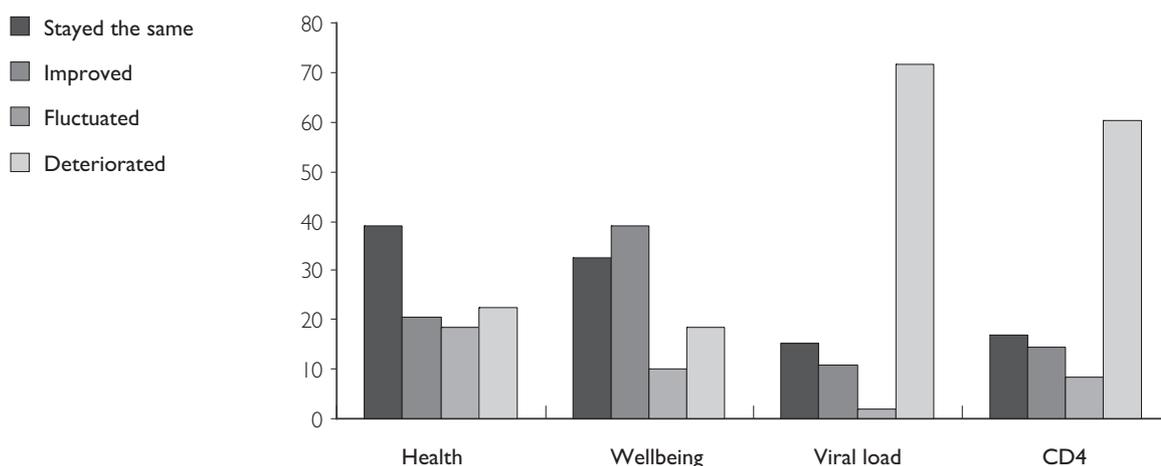
We were also interested in the outcome of the treatment breaks, both in terms of clinical markers and experience of health and well-being. Table 30 below gives the results of the four questions asked. Around one third of respondents said that their health remained stable, while the remainder were spread fairly evenly across the categories of improved, fluctuated and got worse. When asked about their general well-being, a similar proportion said that it had remained stable (30.0%). With well-being, there was a more distinct pattern for the remaining categories with decreasing proportions saying that it had improved, (29.1%) fluctuated (23.9%) or got worse (17.0%).

**TABLE 30 Effect of break on health and well being (percentage of those taking break)**

	Health	Well being
Stayed the same	38.8	32.7
Improved	20.4	38.8
Fluctuated	18.4	10.2
Deteriorated	22.4	18.4

The impact of these breaks on clinical markers was less positive. The majority of respondents indicated that their viral load had increased (deteriorated) (71.7%), while 15.2% said that it had stayed the same and 10.9% (n=5) said that it had decreased (improved). The majority of respondents (60.4%) also indicated that their CD4 count had decreased (deteriorated) as a result of the break, while 16.7% said that it had stayed the same, 14.6% that it had increased (improved) and 8.3% (n=4) said that it had fluctuated.

**FIGURE 8 Impact of treatment break on health, well being and clinical markers**



## 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 (Deeks 2003, Prejdova et al 2004). Resistance can result from a lack of early and persistent suppression of viral replication, missed doses of antiretroviral medications 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.

22.4% of respondents who had ever used antiretroviral treatments indicated that they had taken a viral resistance test. This included 22.1% of those who were currently on antiretroviral treatment and 25.0% of those who were not. The average length of time since the most recent resistance test was 2.3 years (median=1.3 years). 55.8% of respondents had had their most recent test in the last two years (58.0% of those currently on ARV, 33.3% of those not). Of those who had resistance testing, 51.4% found resistance to one or more antiretroviral drugs. This resulted in a change of drugs for all of those (N=19) where resistance was shown.

## DOSING AND ADHERENCE

Adherence to antiretroviral medication continues to be a significant concern for both PLWHA and physicians (Gauchet et al 2007, Chesney 2003). The high degree of adherence required for these treatments to be effective and in order to prevent the development of resistance is far greater than that required (or observed) for other health conditions. Respondents were asked the number of times they took a range of medications per day. On average, PLWHA were taking medication 2.3 times a day (range 0 to 6, median=2). The number of times they were taking specific types of medication is shown in Table 31 below. 53.4% of the sample was taking ARV twice daily, 22.7% three times a day and 9.7% once a day.

**TABLE 31 Number of times participants take medications**

	Mean	Median	Range
Antiretroviral drugs	2.0	2.0	0-4
Complementary therapies	0.9	1.0	0-3
Medication for other health conditions	1.4	1	0-5

Participants who were currently using antiretroviral medication were asked how many doses they had missed on the day prior to completing the survey and the day before that. Combining the data from these two measures, 92.4% reported missing no doses on the two days, 5.1% missed one dose, two people missed two doses and two people missed four or more doses.

## PRESCRIPTIONS

We asked participants who prescribed their antiretroviral medications. In recognition of the multiple prescribing sites people utilise, respondents were able to nominate more than one source. Over three-quarters (85.4%) of respondents obtained their prescription from a specialist in an outpatient clinic, while some obtained them from a doctor at a sexual health centre (5.1%), an HIV specialist while an inpatient (3.8%), another GP (3.8%), or from an HIV GP (3.2%).

Participants were most likely to obtain their prescriptions from one place (60.5%) with fewer saying two places (27.9%), and considerably fewer three or more (8.2%). When asked about the difficulty of obtaining their prescriptions, over half (68.5%) said it was not difficult, 28.2% that it was somewhat difficult and 3.4% (n=5) that it was very difficult.

## CLINICAL TRIALS

7.1% of all participants (n=15) had participated in a clinical trial for HIV related treatment in the last two years. The majority of these indicated that they had decided to participate because their experience could benefit others (n=11), while some said they had made the decision with their doctor (n=8). Two people said they had participated because they felt they had enough information about the trial and one gave the reason that other treatments were not working.

## VACCINES

The attempt to develop a therapeutic vaccine for HIV positive people has been a significant part of the pharmacological research effort in recent years (Steinbrook, 2007, Mwau and McMichael 2003) while the results have been, as yet, far from promising. Nonetheless, we are interested in monitoring participants' perspectives on this issue. We asked respondents to indicate their agreement with the statement *I would be willing to participate in a HIV vaccine trial*. Almost one quarter (22.6%) said they did not know, while 55.2% either agreed or strongly agreed with the statement. A further 13.7% disagreed and 8.5% disagreed strongly.



# SERVICES

# HEALTH SERVICES

## Treatment

We asked respondents to identify the physician they see for the clinical management of their HIV and for general health issues. Generalist GPs were the key physicians for general health management, while HIV GPs and HIV specialists were the primary providers for a significant proportion of PLWHA. Hospital-based HIV specialists were the primary providers of HIV specific treatment for a large majority of respondents, while much smaller numbers nominated other types of doctors (see Table 32). 29.3% of respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment. Of those who saw a different doctor, 99.2% said that that doctor knew their HIV status.

**TABLE 32 Physician used for general and HIV related treatment: percentage of total sample**

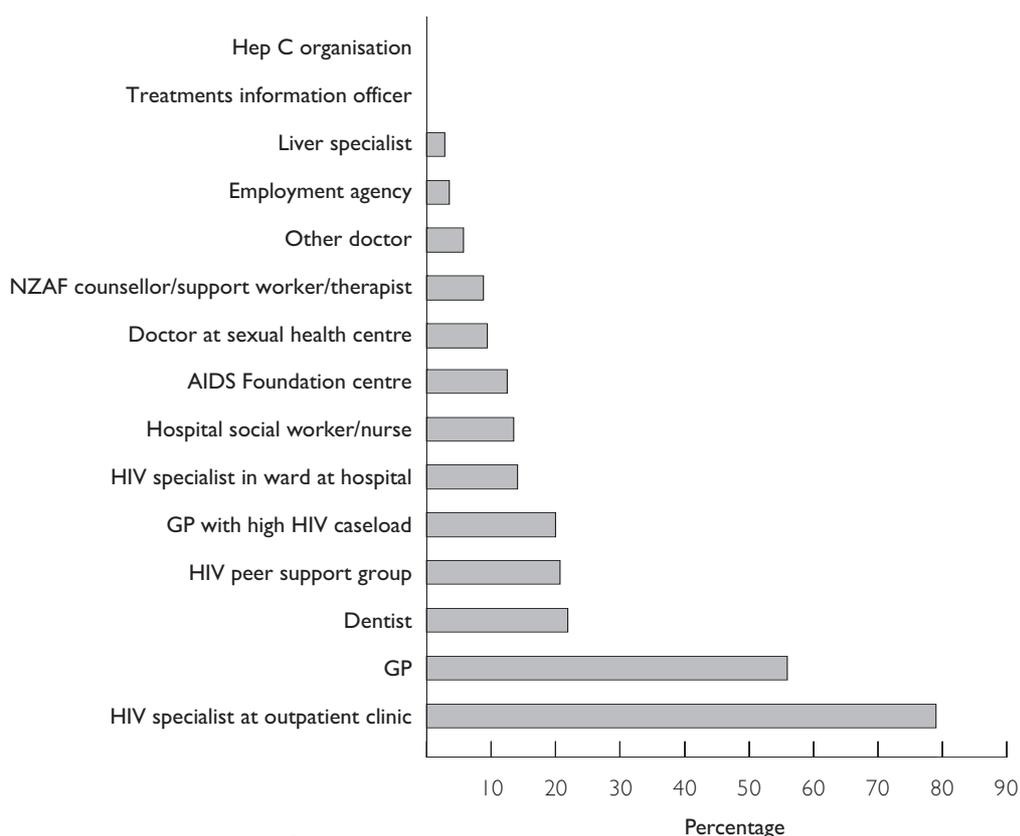
	For general treatment	For HIV specific treatment
GP	52.1	3.0
GP with high HIV caseload	20.6	3.6
HIV specialist at outpatient clinic	18.0	80.0
Doctor at sexual health centre	4.1	6.7
HIV specialist at in ward at hospital	3.6	5.5
Other doctor	0.5	0
Other	1.0	1.2

## Services Used in the Last 6 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 79.1% having used an HIV specialist at an outpatient clinic, 55.8% a GP, 21.9% a dentist and 20.0% an HIV GP. Support services were also used, with 13.5% reporting having used a hospital social worker or nurse, 12.6% the AIDS Foundation centre and 8.8% support staff at NZAF (see Figure 9).

**FIGURE 9 Services used in the last six months (percent of total sample)**

(Multiple responses possible)



## OTHER SERVICES

Participants were asked whether they were currently using a range of services and, if so whether they used them through an HIV/AIDS organisation or through another organisation. Treatments advice was the most commonly used service at HIV/AIDS organisations, with around one-third of respondents selecting this item. HIV/AIDS organisations were also used for counselling, social contact with other PLWHA and peer support by substantial numbers of respondents. Other organisations were more likely to be used than HIV/AIDS organisations for pharmacy services, complementary therapies, financial services, internet access, transport, housing assistance, mental health services, legal advice and employment services.

**TABLE 33 Percent of respondents who use services through HIV/AIDS organisations and other organisations (percent of total sample)**

	Use service at HIV/AIDS organisation	Use service at other organisation
Treatments advice	34.4	17.2
Counselling	30.7	11.6
Social contact with other PLWHA	20.0	3.7
Peer support group	20.0	6.0
Informal peer support	20.0	7.4
Treatments information	14.9	6.0
Pharmacy services	13.0	30.2
Complementary therapies	12.1	20.9
Financial assistance	8.8	14.0
Internet based information	7.9	12.6
Library	7.4	16.3
Community education campaigns	7.0	3.3
Internet access	5.6	17.7
Mental health services	5.1	11.2
Legal advice	4.7	14.4
Housing assistance	4.2	13.0
Respite care	2.8	4.2
Financial advice	2.3	13.5
Transport	2.3	9.3
Volunteer carer	1.9	3.3
Return to work skills	1.4	8.8
Employment services	1.4	9.8
Drug/alcohol treatment	1.4	5.6
Paid carer	0.9	4.2

(Multiple responses possible)

Slightly less than one-fifth (17.6%) of respondents indicated that there were services they felt they needed but did not have access to. The services most commonly nominated were access to affordable complementary therapies, financial advice or assistance, peer support and more information about living with HIV.

## INFORMATION

### Sources

Respondents were asked to nominate from a list of potential sources, those that were important sources of information on treatments and HIV management, and living with HIV. This distinction is in part based on our and others' qualitative work in this area which suggests that PLWHA make a distinction between HIV as a health condition and the day to day management of HIV as a social and psychological experience. We have presented these data in two tables (Table 34 and Table 35) and for each we have reported the percentage of the total sample that selected each source and the percentages of those in and not in paid employment that selected each source.

## Information about HIV Treatment and Management

HIV specialists at outpatient clinics were considered to be an important source of information on HIV treatment and management by the majority of respondents (83.3%), while smaller numbers nominated GP's (27.9%), HIV GP's (25.1%) and HIV specialist nurses (24.7%). Importantly information from the community sector figured significantly in the responses to this item, including HIV/AIDS organisation publications (33.0%) and HIV magazines and newspapers (28.4%). The internet was an important source of information for just under one-third of respondents (29.8%).

**TABLE 34 Sources of information about treatments (percentage of sample)**

Source	In Paid Employment	Not In Paid Employment	Total Sample
HIV specialist (outpatient)	82.6	84.3	83.3
Publications from HIV/AIDS groups	36.4	28.9	33.0
Internet	34.1	22.9	29.8
HIV magazine/newspaper	29.5	25.3	28.4
GP	25.0	31.3	27.9
GP with high HIV caseload	25.0	25.3	25.1
HIV specialist nurse	23.5	25.3	24.7
NZAF staff (treatments-specific)	25.8	16.9	21.9
HIV positive friends	23.5	16.9	20.9
Body Positive staff (treatments-specific)	24.2	15.7	20.9
Body positive staff (others)	22.7	14.5	19.5
HIV specialist (inpatient)	18.2	19.3	19.1
CART	15.2	24.1	19.1
Articles in gay press	18.2	7.2	13.5
NZAF staff (others)	15.2	10.8	13.0
Sexual Health Service	12.9	10.8	12.1
Pharmacist	12.1	12.0	12.1
Dentist	11.4	12.0	12.1
Partner	12.9	8.4	11.2
Publications from other sources	11.4	4.8	8.8
Other doctor	8.3	6.0	7.9
Other HIV/AIDS support organisations	6.8	6.0	6.5
Positive Women	5.3	8.4	6.5
Other friends	6.8	4.8	6.0
Alternative/Complementary therapist	5.3	6.0	5.6
Dietician	5.3	3.6	5.1
Family/Whanau	3.8	6.0	4.7
Other nurse	6.8	1.2	4.7
Refugee Health Education Program	2.3	-	1.4
Family planning association	1.5	1.2	1.4
Haemophilia society	2.3	-	1.4
Injecting drug users organisation	1.5	-	0.9
NZ Prostitutes Collective	0.8	1.2	0.9

(Multiple responses possible)

Differences between participants in and not in paid employment can be seen in a number of the sources listed. Generally those who were not in paid employment listed fewer sources of information and were less likely to list any specific source, with the exceptions of medical staff, CART and family. This is particularly noticeable in nominations of Body Positive staff, NZAF staff and publications. The internet is also nominated by fewer of those not currently in paid employment, perhaps due to limited access.

When asked in a separate question to nominate their three most important sources of information about treatments and health management, 55.5% of respondents nominated a hospital-based HIV specialist. Smaller numbers of

respondents nominated staff at HIV/AIDS organisations, including Body Positive (9.2%) and New Zealand AIDS Foundation (NZAF) (5.6%). The responses for the second and third most important information sources were spread more evenly throughout the range of possible sources. Similar numbers of respondents nominated their GP (16.9%) or HIV specialist (16.4%), while smaller numbers nominated Body Positive staff (11.9%), NZAF staff (6.8%), HIV GP's (6.8%) or HIV specialist nurses (6.2%). HIV positive friends were the most common choice (10.5%) for the third most important source of information about treatments and health management, followed by the internet (9.2%), staff at Body Positive (9.2%), GP's (8.5%) and publications from HIV/AIDS groups (7.8%).

## Information about Living with HIV

Responses to the question of important sources of information on living with HIV were divided more evenly between clinical and non-clinical sources than for the previous item. The source selected by the greatest number of respondents was hospital-based HIV specialist (37.7%), followed by publications from HIV/AIDS groups (32.6%), HIV positive friends (32.6%) and HIV magazines and newspapers (28.8%). Staff from HIV/AIDS organisations were also considered important by significant numbers of positive people (Body Positive staff (others) - 28.4%, Body Positive staff (treatments-specific) - 27.0%, NZAF staff (others) - 25.1% and NZAF staff (treatments-specific) - 24.2%).

**TABLE 35 Sources of information about living with HIV (percentage of sample)**

Source	In Paid Employment	Not In Paid Employment	Total Sample
HIV specialist (outpatient)	40.2	34.9	37.7
Publications from HIV/AIDS groups	34.8	27.7	32.6
HIV positive friends	38.6	22.9	32.6
HIV magazine/newspaper	32.6	22.9	28.8
Body positive staff (others)	31.1	22.9	28.4
Body Positive staff (treatments-specific)	34.8	13.3	27.0
Internet	29.5	19.3	25.6
NZAF staff (others)	28.0	19.3	25.1
NZAF staff (treatments-specific)	27.3	18.1	24.2
HIV specialist nurse	21.2	15.7	19.1
Articles in gay press	25.0	9.6	19.1
CART	15.9	21.7	18.1
Partner	23.5	9.6	18.1
Other friends	18.2	16.9	17.7
GP	14.4	21.7	16.7
GP with high HIV caseload	16.7	18.1	16.7
Positive Women	12.9	15.7	14.0
Family/Whanau	12.1	14.5	13.0
Publications from other sources	11.4	9.6	10.7
Other HIV/AIDS support organisations	12.1	4.8	9.3
Sexual Health Service	9.8	4.8	7.9
Alternative/Complementary therapist	7.6	7.2	7.9
HIV specialist (inpatient)	9.8	3.6	7.4
Other nurse	7.6	3.6	6.0
Dentist	6.1	2.4	4.7
Other doctor	5.3	2.4	4.2
Dietician	5.3	1.2	3.7
Family planning association	3.8	-	2.3
Pharmacist	2.3	1.2	1.9
Refugee Health Education Program	3.0	-	1.9
Haemophilia society	3.0	-	1.9
Injecting drug users organisation	2.3	-	1.4
NZ Prostitutes Collective	2.3	-	1.4

(Multiple responses possible)

A similar pattern of differences between participants in and not in paid employment can be seen here as was noted above for treatment information. The differences between these groups are more pronounced in relation to publications, friends and interestingly, partners.

When asked to identify the three most important sources of information about living with HIV 26.3% nominated a hospital-based HIV-specialist, followed by staff at Body Positive (17.2%), HIV positive friends (9.7%) and NZAF staff (7.5%). The most common choice for the second most important information source was also an HIV-specialist, followed by a GP, staff at Body Positive (10.8%) and HIV positive friends (8.9%). The internet was the most common choice for the third most important source of information about living with HIV (11.1%), followed by HIV-positive friends (9.6%), other friends (8.1%) and a GP (8.1%).

As the internet is seen as an 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 36. As can be seen from these data, PLWHA were reasonably sceptical about the reliability of information available on the net. Those that rated the internet as an important source of information were less sceptical than others.

**TABLE 36 Attitudes to HIV information on the Internet (percentage of sample)**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
<b>Full sample</b>					
Information on the internet about living with HIV is unreliable	7.2	24.0	16.3	3.4	48.6
Information on the internet about treatment side effects is unreliable	7.1	24.1	13.7	1.9	53.3

## Lack of information

We asked respondents whether lack of information made it difficult for them to make decisions in certain areas and a third (37.7%) agreed that this was the case. When asked to identify the domains in which this applied, 15.8% nominated the management of side effects (45.3% of those nominating lack of information as a problem) (refer to Table 37). Employment and financial planning also figured prominently, with 12.6% of respondents identifying lack of information about work/employment (36.0% of the sub-sample) and 12.6% also nominating lack of information about financial planning (36.0%).

**TABLE 37 Issues where participants lack information (percent of total sample)**

Managing ARV side effects	15.8
Work/employment	12.6
Financial planning	12.6
Legal issues	12.1
Interactions between ARV and other drugs	10.2
Using ARV	10.2
Changing ARV	9.3
Using complementary therapies	8.8
Taking a break from ARV	7.0
Having children	6.5
Recreational drug use	4.2

(Multiple responses possible)

## Publications

Survey participants were asked which publications containing HIV information they read. The results are shown in Table 38, including breakdowns for specific populations where access or focus is an issue.

**TABLE 38 Publications read by PLWHA**

Publication	Percent of sample
Collective thinking	44.7
Positively Positive	44.2
New Zealand gay newspapers (% of gay men, lesbians and bisexuals)	38.0
New Zealand gay newspapers (% of total sample)	29.8
New Zealand gay magazines (% of gay men, lesbians and bisexuals)	25.3
New Zealand gay magazines (% of total sample)	20.9
Positive Living (Aus)	17.7
Other websites	16.3
Newsletters from community organisations	13.5
Gaynz.com	11.6
NZAF website	10.7
Overseas HIV magazines (e.g. POZ)	8.8
Overseas gay press	5.6
Australian gay newspapers	4.7
Australian gay magazines	3.3
HIV Australia	2.3
With Complements	1.9

(Multiple responses possible)

## INVOLVEMENT WITH AIDS ORGANISATIONS

Participants were asked about their involvement with HIV/AIDS organisations. 62.4% of the sample had some contact with HIV/AIDS organisations. Of these, 78.2% received newsletters and mail outs, 60.9% were clients, 46.6% were members, 16.5% were volunteers and 4.5% were employees. Of those that volunteered, they did so for between 1 and 20 hours per week (median = 6 hours/week). Of those that had no contact with AIDS organisations, 62.5% gave the reason I do not want to be involved, 17.5% gave the reason I do not have enough time, 15.0% said that they had no transport or are too far away, and 13.8% said they did not know how to join. Only 5% of those who were not involved in AIDS organisations said they felt excluded from them.

19.8% of respondents had at some point held a decision making position in an AIDS organisation (9.4% in the last year).

Respondents were also asked to list the HIV/AIDS organisations that they had contact with. Over half of the respondents who listed an organisation said that they had contact with Body Positive (54.7%), while 36.5% had contact with NZAF, 13.9% with Positive Women, 9.6% with the Burnett centre and 6.6% with CART.



# THE SOCIAL WORLD OF PLWHA

This chapter examines the collective experience of HIV from a number of perspectives. While for some people HIV may be a profoundly isolating experience, 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.

## CONTACT WITH OTHER PLWHA

One-fifth of respondents (20.5%) did not personally know anyone else with HIV. Gay men and heterosexual women were significantly less likely to know no-one else with HIV than other respondents. Over half of respondents had an HIV positive friend (56.7%) and many had HIV positive acquaintances (41.9%). Around one-quarter either had an HIV positive partner or ex-partner (24.2% combined). 16.0% of respondents had been involved in the nursing or care of another positive person at some time in the last two years, and 61.9% have had someone close to them die from HIV/AIDS.

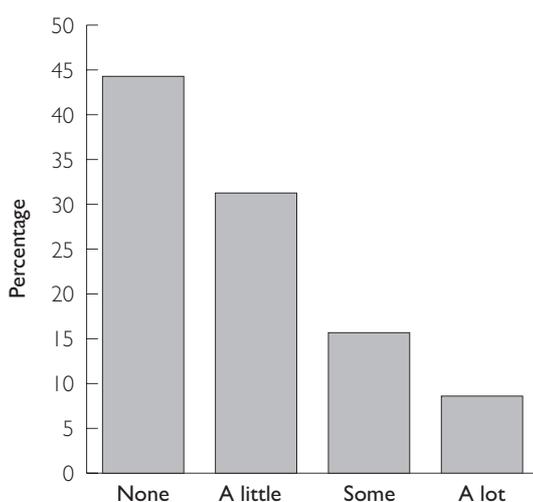
**TABLE 39 Other HIV positive persons known by respondent**

Positive Persons	Percentage
Friend	56.7
Acquaintance/Member of support group	41.9
No-one	20.5
Former partner/spouse	12.6
Partner/spouse	11.6
Other relative/Whanau member	3.3
Son/daughter	0.5
Other	3.7

(Multiple responses possible)

More than half of the respondents spent at least some time with other positive people (55.5%). Those who indicated that they spent either some or a lot of time with other PLWHA were more likely to be those who worked or volunteered for an HIV/AIDS organisation. There were no significant gender differences in the time spent with other positive people.

**FIGURE 10 Time spent with other positive people**



## DISCLOSURE

Respondents were asked who they had disclosed their HIV status to (see Table 40). Not surprisingly, around three-quarters (74.0%) had disclosed to close friends, and most (90.4%) of those in relationships had disclosed to their partner. Within families, people were most likely to have disclosed to siblings (54.9%) although many had disclosed to parents (45.1%). Only 4.7% had not disclosed their HIV status to anyone.

**TABLE 40 People the respondent has disclosed their HIV status to**

	Percent who have disclosed
Close friends	74.0
Positive friends	42.8
Siblings	54.9
Partner/spouse	54.4
Parents	45.1
Other friends	25.6
Work colleagues	26.5
Son/daughter	13.0
Other family/Whanau members	28.4
Neighbours	13.5
People from own ethnic community	5.1
No-one	4.7
<b>Specific populations</b>	
Partners (% of those in a regular relationship)	90.4
Partners (% of those not in regular relationship)	9.6
Work colleagues (% of those currently employed)	27.8
Work colleagues (% of those not currently employed)	25.0
Son/daughter (% of those with dependent children)	20.0

(Multiple responses possible)

### Unwanted Disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. 47.7% said that it had at some point, and 19.0% said that this had happened in the last two years. A higher proportion of women reported having experienced unwanted disclosure more than two years prior to survey (38.7% compared with 25.6% of men), however there was no gender difference in this experience over the previous two years. When asked who disclosed their status, respondents were most likely to nominate friends (see Table 41). In part these data reflect those that are most likely to be aware of the respondent's HIV status. It is concerning that one-fifth (21.4%, 22.5% in the past two years) reported unwanted disclosure from a worker in a health-care setting.

**TABLE 41 Sources of unwanted disclosure (percentage of those experiencing unwanted disclosure)**

	Percent (ever)
Close friends	26.5
Other friends	23.4
Workers in a health care setting	21.4
Work colleagues	18.4
HIV positive friends	17.3
Other family member	13.3
Partner/Spouse	12.2
Parents	12.2
Sibling	11.2
Other	9.2
Neighbour	6.1
Staff/volunteers at community organisation	4.1
Son/daughter	3.0
People from ethnic community	3.0

(Multiple responses possible)

For 65% of those who had had their HIV status disclosed without their permission, this resulted in negative consequences. This varied to some extent among the sources of unwanted disclosure. For example: when a work colleague had disclosed, 15 of the 18 participants (83%) said this had negative consequences; when HIV positive friends disclosed 9 of the 17 (52%) said there were negative consequences; and when a health care worker disclosed 15 of the 21 (71%) reported negative outcomes. The survey did not have the capacity to detail these consequences, and this may be an area that could benefit from some detailed qualitative research.

## THE PLACE OF HIV IN PEOPLE'S LIVES

HIV affects many parts of people's lives 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 explore this issue, 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 42. 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 (48.9%) of positive people in this study considered their HIV status an important, but not essential aspect of their make-up, while 17.0% considered it to be an essential characteristic. This is in contrast to sexuality and gender, where around 30% of the sample considered each of these to be essential characteristics.

**TABLE 42 Importance of personal characteristics to respondents' sense of identity**

	Essential	Important	Not Important	Irrelevant
Sexuality	24.2	45.4	22.7	7.7
Family	35.6	47.8	10.7	5.9
Gender	21.5	46.8	20.5	11.2
HIV status	14.2	55.9	19.6	10.3
Career	20.5	48.0	20.5	11.0
Religious beliefs	11.8	24.0	28.9	35.3
Parenthood	12.1	21.1	16.1	50.8
Ethnicity/Cultural background	8.8	34.8	31.4	25.0
Drug use (recreational/illegal)	5.0	10.4	35.6	49.0

When we look at the importance of HIV status among specific sub groups of PLWHA, we find that there are no significant differences in terms of sexuality, gender, having had an AIDS defining illness, use of antiretroviral drugs or partner sero-status (See Table 43).

**TABLE 43 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	17.6	52.5	18.1	11.8
Women	7.4	59.3	18.5	14.8
Heterosexual men	-	100.0	-	-
Those who have had an AIDS defining illness	14.3	52.4	26.2	7.1
Those who have not had an AIDS defining illness	13.5	58.3	17.3	10.9
Those on antiretroviral therapy	13.5	58.1	18.9	9.5
Those not on antiretroviral therapy	13.3	53.0	19.7	14.1
Those in seroconcordant relationships	11.5	57.7	26.9	3.8
Those in serodiscordant relationships	12.9	51.6	21.0	14.5

## 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 44 below with those for whom the category was not applicable excluded from each row. Participants were most likely to have nominated their partner or spouse as providing a lot of support (78.0% of those with partners), followed by PLWHA groups (51.4%) and close friends (51.3%). When we examine the sources that people rated as providing no support, the highest ranking category was volunteer carer, where 64.3% of those with a carer said they received no support from them. Religious or spiritual advisors were also considered a source of no support for 50.7% of those with such a source.

**TABLE 44 Social support received from different sources: percent who gave valid responses for each category**

	A lot	Some	A little	None
Partner/spouse	78.0	11.0	5.5	5.5
PLWHA groups	51.4	19.6	19.6	9.3
Close friends	51.3	23.8	15.9	9.0
Parents	46.5	17.8	13.2	22.5
Health care workers	44.4	30.2	23.9	1.5
Siblings	42.4	21.8	17.0	18.8
Children	40.0	16.0	12.0	32.0
Pets	39.3	20.7	17.9	22.1
HIV positive friends	37.2	27.7	19.0	16.1
Family/Whanau	26.8	23.6	28.5	21.1
Doctor	20.7	23.0	29.9	26.4
Religious or spiritual advisor	20.3	15.9	13.0	50.7
Counsellor	20.2	22.5	27.0	30.3
Other friends	18.1	31.6	24.5	25.8
Volunteer carer	9.5	14.3	11.9	64.3

## ATTITUDES TO HIV STATUS

Two additional items were included that examine individual's relationship to their HIV serostatus. Participants were asked whether they agreed with the statement *As long as I am well I prefer not to think about HIV/AIDS*. Over half the respondents agreed or strongly agreed with this statement. The second statement participants were asked to respond to was *Life has become more meaningful since I became HIV positive*. Slightly less than half agreed or strongly agreed with this statement.

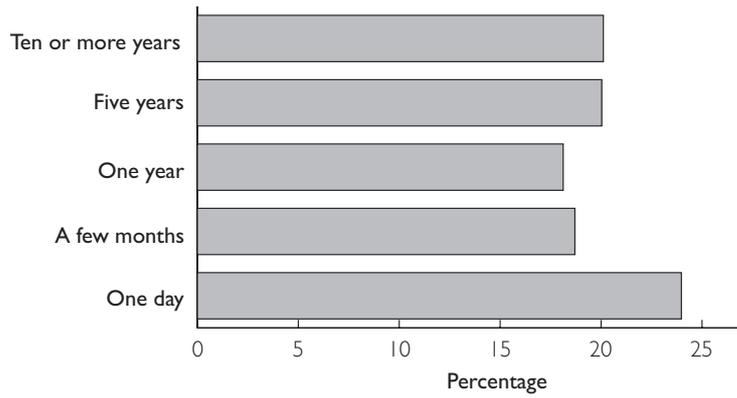
**TABLE 45 Attitudes to HIV status**

	Strongly agree	Agree	Disagree	Strongly disagree
As long as I am well I prefer not to think about HIV/AIDS	18.4	41.1	36.7	3.9
Life has become more meaningful since I became HIV positive	15.0	29.6	38.3	17.0

## PLANNING FOR THE FUTURE

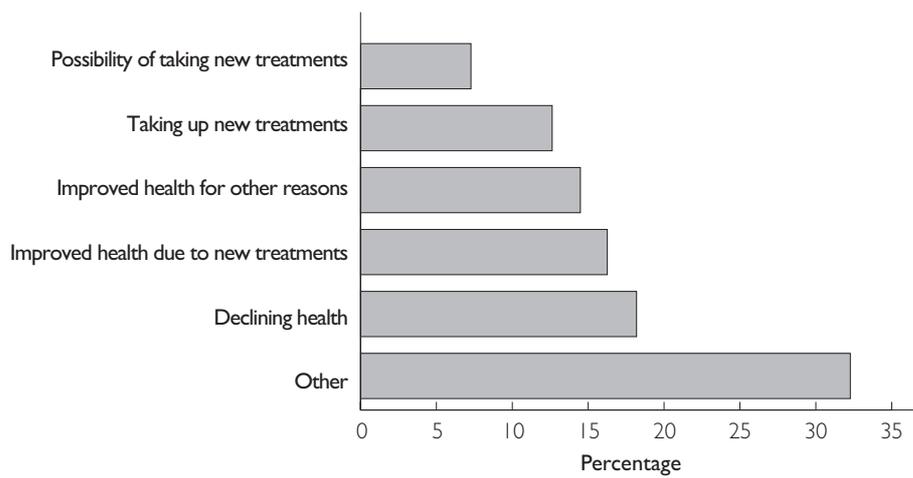
A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. Less than one fifth (19.9%) planned their life one day at a time and the same proportion (19.9%) planned only a few months ahead. Over half of the respondents planned for at least a year with 18.0% planning one year ahead, 18.5% planning five years ahead and 23.7% planning ten years or more ahead. This profile of the population has changed very little since the first HIV Futures New Zealand survey. Those who had shorter planning time-frames tended to have lower CD4 counts and to have had an AIDS defining illness. There were no significant gender differences in time frame for future planning.

**FIGURE 11 Time frame for future planning**



27.5% of respondents reported a change in their time frame for future planning in the last two years. Overall, 11.6% of all participants now use a shorter time frame than 2 years ago and 14.9% use a longer time frame. The major reasons for change for those planning further ahead into the future over a longer time frame were improved health due to new treatments (30.0% of those with longer plans), improved health for other reasons (23.3%) and taking new treatments (16.7%). The major reason for change for those with a shorter time frame was declining health (37% of those with a shorter time frame), see Figure 12.

**FIGURE 12 Reasons given for change in time-frame**





# RELATIONSHIPS AND SEX

This chapter reports on a range of issues related to relationships and sexual practice. The HIV Futures surveys place sexual relationships within the broad context of HIV positive people's lives. While we do address the issues of prevention and transmission, we also address the place that sex and relationships play in the broad social and lived experience of PLWHA. Sex can be a highly emotionally and politically charged issue for people with HIV, but it can also be unproblematic. An omnibus survey such as this can never hope to reflect the diversity and complexity of people's sexual and emotional lives. It can, however, guide us to where there may be concerns that require additional effort in providing services and support, or where additional research may be indicated.

## RELATIONSHIPS

Respondents were asked about current sexual relationships. The results are presented in Table 46 below. Almost one-third of the sample said that they had no sex at present. One-quarter reported that they had a regular relationship only, while one-quarter said that they had casual sex only, and 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. Heterosexual men were more likely than other PLWHA to report that they had no sex at present. Women were more likely to report that they had one regular sexual partner and no casual sex. Gay and bisexual men are more likely to report that they had a regular sexual partner and also had casual sex.

**TABLE 46 Type of sexual relationship(s) by gender and sexuality of respondent (percentage)**

	Gay or Bisexual Men	Heterosexual men	Women	Total
I have no sex at present	25.9	66.7	50.0	31.9
I have casual sex only	31.5	-	-	25.0
I have a regular relationship with one person, and I have sex with other people	20.4	-	-	16.2
I have a regular relationship with one person, and I do not have sex with other people	19.8	33.3	50.0	25.0
I have a regular relationship with two or more people	2.5	-	-	2.0

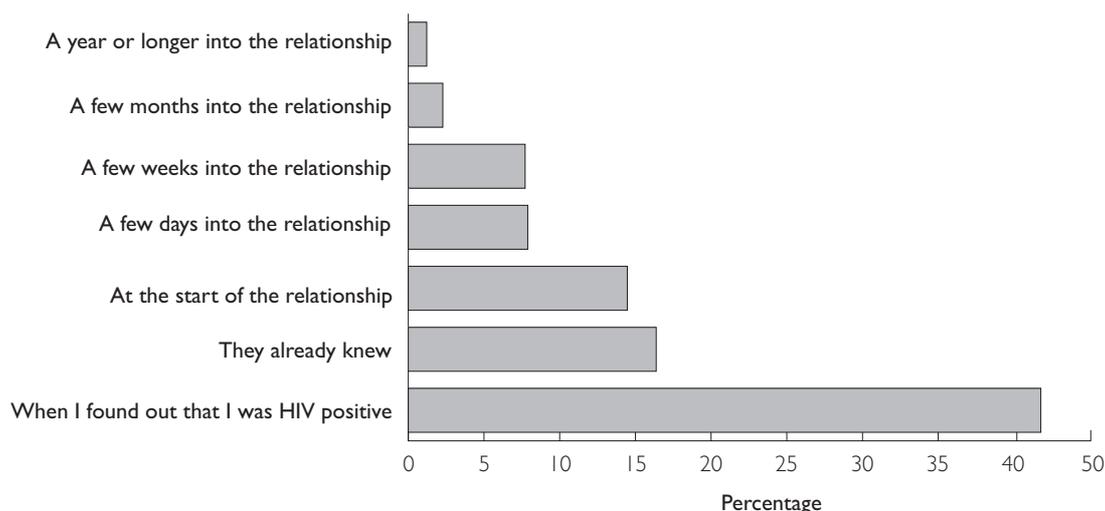
When asked if they were currently in a regular relationship, 42.5% said they were, which is similar to the proportion of the sample that report having sex with a regular partner in Table 25 above (43.2%). The proportion of gay or bisexual men reporting having a regular partner (42.7% from Table 46) is lower than that reported for HIV negative and unknown HIV status MSM in the most recent GAPSS survey (54.1%) (Saxton et al 2006)

### Regular Partners

Of those in a relationship with a regular partner, 27.6% reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in serononconcordant relationships. This remaining group is made up of 65.3% of those in relationships that report that their partner is HIV negative (a sero-discordant relationship) and 7.1% who report that they don't know their partner's HIV status. Nearly all PLWHA (97.9%) had told their regular partner that they were HIV positive.

Respondents were asked at what point in the relationship they told their partner. The responses are given in Figure 13 below. Almost one-half of respondents had told their partner when they themselves found out they were positive (46.3%). 17.9% said that their partner knew their HIV status prior to the start of the relationship, while 15.8% had told their partner when the relationship started. Small numbers of respondents (8.4%) had told their partners a few days into the relationship, 8.4% a few weeks into the relationship, 2.1% a few months into the relationship and 1.1% a year or more into the relationship.

**FIGURE 13 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 (52.3%) reported that the partner was supportive (see Table 47). Over one-third (38.5%) reported that it did not make any difference and 29.4% reported that the disclosure brought them closer together. Just under one-third (31.2%) reported that their partner was worried or scared and 6.4% said their partner was angry.

**TABLE 47 Reaction of partner to disclosure: percentage of those in regular relationships**

They were supportive	52.3
It did not make any difference	38.5
We became closer	29.4
They were worried / scared	31.2
They were angry	6.4

(Multiple responses possible)

We also asked how the respondent themselves felt about this disclosure. Half (50.5%) said they were worried about their partner’s reaction, 40.4% said they were relieved and one-third said it brought them closer to their partner.

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. PLWHA in regular relationships were asked about the sex they had with their regular partner. Overall, 40.4% of the total sample had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 3.9% had anal or vaginal sex with a regular female partner in the previous six months. Condom use with regular partners can be seen in Table 48 below.

**TABLE 48 Condom use with regular partner by respondent and partner gender (Number of these that used condom (N=82))**

	Never	Sometimes	Usually	Always
<b>Female respondents N=14</b>				
With regular male partner	2	2	5	5
<b>Male respondents N=68</b>				
With regular male partner	6	9	10	41
With regular female partner	1	0	1	0

We can examine these data in terms of relationship sero-concordance and this gives some additional context to condom use. The small numbers involved, however, mean that this level of detail should be treated with great caution. Unprotected vaginal or anal intercourse is more likely to have occurred in sero-concordant relationships than in sero-nonconcordant relationships (see Table 49).

**TABLE 49 Condom use with regular partner by respondents' gender, partner gender, and partner sero-status (Number of these that used condom)**

	Never	Sometimes	Usually	Always
<b>SERO-CONCORDANT Relationships N=17</b>				
<b>Female respondents N=4</b>				
With regular male partner	1	1	2	-
<b>Male respondents N=13</b>				
With regular male partner	4	1	-	8
With regular female partner				
<b>SERO-NONCONCORDANT Relationships N=43</b>				
<b>Female respondents N=8</b>				
With regular male partner	1	-	3	4
<b>Male respondents N=35</b>				
With regular male partner	2	4	5	23
With regular female partner	1	-	-	-

## Casual Partners

Over half (51.7%) of the sample reported that in the six months prior to completing the survey they had had sex with one or more casual partners. When asked the HIV status of their casual partners, 4.7% reported that all of their casual partners were HIV positive, 14.0% reported that some of their casual partners were HIV positive, and 6.5% reported that none of their casual partners were HIV positive. Most (74.8%) respondents who had 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 50 there is some variation in condom use when we examine this by sex of respondent and sex of partner.

**TABLE 50 Condom use with casual partner by respondent and partner gender (Number of these that used condom (N=88))**

	Never	Sometimes	Usually	Always
<b>Female respondents N=2</b>				
With casual male partners	-	-	-	2
<b>Male respondents N=86</b>				
With casual male partners	2	7	18	54
With casual female partners	-	-	2	3

Again, when we look at these data in terms of the partners' HIV status there is some suggestion that there is a relationship between sero-concordance and condom use (see Table 51). The small numbers involved here mean that these findings should be treated very cautiously.

**TABLE 51 Condom use with male casual partner by partners' sero-status (Number of these that used condom (N=81))**

Casual partners' HIV Status	Never	Sometimes	Usually	Always
All HIV positive	1	-	-	3
Mixture/unsure	1	6	18	50
All HIV negative	-	1	-	1

In addition to reporting on their overall patterns of condom use, respondents who had had casual sex reported on their most recent sexual encounter with a casual partner. Half of the survey respondents (49.3%) provided such information. Of the respondents who had casual sex, 70.5% had vaginal or anal intercourse on their last occasion with a casual partner. As was found for the overall patterns of condom use, condom use during respondents' most recent sexual encounter was contingent on the HIV status of the partner. Figure 14 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.

**FIGURE 14: Sexual practice with the most recent casual partner**

Sex with a casual partner in the last six months?					
No			Yes		
100 (48.3)			107 (51.7%)		

↙

Anal/vaginal intercourse with most recent casual partner? (missing=2)					
No			Yes		
31 (29.5%)			74 (70.5%)		

↙

HIV status of casual partner (missing=0)					
HIV positive		HIV Negative		Status Unknown	
6 (8.1%)		9 (12.2%)		59 (79.7%)	

Condom used? (missing=1)							
Yes		No		Yes		No	
4 (66.7%)		2 (33.3%)		9 (100.0%)		0 (-)	
				52 (89.7%)		6 (10.3%)	

↙      ↙      ↙

Ejaculated in partner? (male respondents only) (missing=0)							
No		Yes		No		Yes	
1 (50.0%)		1 (50.0%) (0.5% of total)		0 (-)		0 (-)	
				5 (83.3%)		1 (16.7%) (0.5% of total)	

Ejaculated in by partner? (male partners only) (missing=0)							
No		Yes		No		Yes	
1 (50.0%)		1 (50.0%) (0.5% of total)		0 (-)		0 (-)	
				2 (33.3%)		4 (66.7%) (1.9% of total)	

Respondents who indicated that they knew their partners' HIV status were asked how they knew. Nearly all (88.9%) of these respondents said that their partner had told them their status, while 48.6% (n=17) said that they knew their partner's status from the type of sex they wanted and 41.2% (n=14) said that someone else told them of their partner's status. Five respondents said they could tell by the people they were with and one said that they could tell by the bar/venue at which they met.

16.0% of respondents said they told their most recent casual partner that they were HIV positive, 66.0% did not, 13.2% said the partner already knew they were HIV positive and 4.7% could not recall.

## LEGAL ISSUES AROUND DISCLOSURE OF HIV STATUS

The law in New Zealand is clear that people who are HIV positive are not criminally liable when there is condom use and disclosure or condom use and no disclosure. Therefore it is not legally necessary for PLWHA to disclose their HIV status to sexual partners if a condom is properly used ([www.nzaf.org.nz/articles.php?id=509](http://www.nzaf.org.nz/articles.php?id=509)). Notwithstanding this, there are provisions under the Crimes Act (1961 §144 and §188(2)) for the prosecution of people with HIV for exposing someone to HIV, or infecting someone else with HIV without taking 'reasonable precautions'. There have been convictions under this legislation where there was no disclosure and no condom use. The existence of this legislation and uncertainty around the implications for PLWHA has led to a degree of anxiety in the positive community (and indeed among the gay male community) around issues of disclosure, negotiated condom use and potential stigma and discrimination. Between the first HIV Futures New Zealand Survey and the current one, this legal situation was clarified to an extent through the outcome of a high profile court case (*Police V Dalley*), where the ruling made clear that condom use in the absence of disclosure constituted 'reasonable precautions' (DC, Wellington, CRI-2004-085-009168, 4 October 2005, Judge SE Thomas).

In order to understand the extent to which they were aware of these laws, respondents were asked to respond to two statements concerning disclosure of HIV status to sexual partners (Table 52). Over half of respondents (63.1%) agreed that *it is legally OK for someone to use a condom for anal or vaginal sex and not to tell their partner about HIV status*. However one-quarter of respondents disagreed with this statement and 11.5% said they didn't know. Gay men were most likely to agree with this statement (72.6%). Similarly, 61.1% of respondents disagreed that *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*. Slightly less than one-quarter (23.0%) agreed with this statement, while 15.8% said they didn't know. There were no differences in responses to this item based upon sexuality.

Respondents were also asked how the legal situation concerning disclosure has affected their relationships. More than half (62.4%) disagreed that *the current legal situation about disclosure about HIV status has limited my ability to form new relationships*. However around one-third (31.0%) agreed with this statement. Again, there were differences in responses to this item based upon sexuality.

**TABLE 52 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 to tell their partner about HIV status	10.5	14.8	41.6	21.5	11.5
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	30.1	31.1	18.2	4.8	15.8
The current legal situation about disclosure about HIV status has limited my ability to form new relationships	16.2	46.2	23.9	7.1	6.6

## 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 53.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, around one-quarter (26.7%) said they would, just under half (47.1%) said they would not, and the remainder (26.2%) said that they did not know.

The potential to develop new relationships remains an important issue for PLWHA. While much has been done to reduce stigma and discrimination in formal settings such as workplaces and healthcare settings, the more intimate domains of sex and relationships can still be a site of anxiety and uncertainty for both HIV positive and negative people. Two-thirds (67.2%) of the respondents agreed with the statement *Few people would want a relationship with someone who has HIV*. 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 (58.9%) agreed with this statement.

Concerns about transmission of the virus to others and re-infection were apparent in the responses to the next six items. Most respondents (72.9%) 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 Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom*. However around one-third agreed with the statement *Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV* (29.8%). Those having casual partners were more likely to agree with this item.

The potential impact of vaccines on intentions to practice safe sex and anxiety about safe sex was minimal with only 20.2% agreeing with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*, and 14.4% agreeing with the statement *Knowing that a vaccine will become available makes me less anxious about sex*.

The response to concerns about re-infection remains mixed, with 51.7% agreed that *I am concerned about becoming infected with another strain of HIV*, while 36.9% disagreed.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (65.5%) agreed with the statement *HIV has had a negative effect on my sexual pleasure*. One third (29.1%) disagreed with this statement.

When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. 27.2% 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 (51.3%) than agreed with it (21.4%). Those who disagreed were more likely to be those who were in a sero-discordant regular relationship, or whose casual sexual partners were mostly HIV negative.

Over a third (35.9%) said that they agreed with the statement *I have stopped having sex because of my HIV status*. Similarly, 56.1% of participants agreed that *HIV has negatively affected my libido*.

**TABLE 53 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	13.1	34.0	14.6	12.1	26.2
Few people would want a relationship with someone who has HIV	1.9	20.3	43.0	24.2	10.6
I am afraid of telling potential partners of my HIV status in case they reject me	9.2	21.5	37.9	21.0	10.3
Being HIV positive has helped me form more satisfying relationships	22.7	38.9	17.7	5.1	15.7
I am afraid of infecting my partner, or potential partner, with HIV	8.5	14.1	37.2	35.7	4.5
I feel more confident about unprotected sex because of the new treatments	62.4	23.8	4.5	2.5	6.9
Medical treatments for HIV/AIDS make safe sex less important than it was	54.7	27.4	7.5	3.3	7.1
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	32.8	28.8	21.7	8.1	8.6
If there was a vaccine which prevents HIV I would not practice safe sex	26.6	36.9	15.8	4.4	16.3
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	49.1	28.0	6.1	4.2	12.6
Knowing a vaccine will become available makes me less anxious about sex	22.6	41.0	11.8	2.6	22.1
I am concerned about becoming infected with another strain of HIV	8.5	28.4	40.3	11.4	11.4
HIV has had a negative effect on my sexual pleasure	6.4	22.7	37.4	28.1	5.4
If I know that my partner is HIV positive I find sex more pleasurable	22.0	29.3	14.1	7.3	27.2
I stopped having sex because of my HIV status	16.9	45.6	21.0	14.9	1.5
HIV has negatively affected my libido	10.7	24.9	33.2	22.9	8.3

## CHILDREN

As mentioned in the description of the sample earlier in this report, 28.2% of those surveyed, including 54.8% of women (n=17) and 22.9% of men (n=40), had children, while 7.0% (9 women and 6 men) had dependent children living with them. We were also interested in future plans for children among PLWHA. Most PLWHA (69.5%) were not currently considering having children. Of the remainder, 9 had decided to have children in the future and 1 was attempting to have children. Eleven were considering having a child, but have not decided, and 7 people have considered having a child, but have decided it is too risky. Two respondents said they did not have enough information to make a decision. As can be seen in Table 54 this was an issue of interest to women, gay men and heterosexual men

**TABLE 54 Planning to have children (number)**

	Gay or Bisexual Men	Heterosexual men	Women	Total <sup>4</sup>
No	127	4	10	141
No, I already have children	17	2	8	27
I have decided to have a child / children in the future	2	3	4	9
I am currently trying to conceive / get pregnant	-	-	1	1
I am currently pregnant	-	-	-	-
I have thought about it but I haven't decided	6	2	3	11
I have thought about it but I have decided that it is too risky	5	-	2	7
I was told not to by a doctor/ medical professional	-	-	-	-
I don't have enough information to make a decision	2	-	-	2

4 Total is larger than sum of previous categories due to missing data



# 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 55 gives these results. As can be seen from these data, alcohol was the most commonly used drug followed by tobacco. The New Zealand Census reports a population cigarette smoking rate of 18.91% (Statistics New Zealand). The 2003 Health Behaviours survey (Ministry of Health 2007b) reports alcohol use among the New Zealand population at 81.2%. Other drugs that are popular in the gay and dance party scenes (amyl and ecstasy) were also used by PLWHA. These drugs are used at higher rates than the New Zealand population as reported by the Health Behaviours Survey (Ministry of Health 2007b) which gives rates in the 12 months prior to survey of 13.7% for cannabis, 2.5% for amphetamines, and 1.9% for ecstasy.

**TABLE 55 Recreational use of drugs in previous 12 months (Percentage of sample)**

Alcohol	75.3
Cigarettes	37.7
Marijuana	34.4
Amyl	28.4
Viagra or similar	14.0
Ecstasy	8.4
Crystal Meth	4.7
Speed (not injected)	1.9
Cocaine (not injected)	1.9
Speed (injected)	1.4
Methadone (prescribed)	1.4
GHB/GBH/Fantasy	0.9
LSD/trips	0.9
Steroids (injected)	0.9
Homebake	0.5
Methadone (other)	0.5
Heroin (injected)	-
Cocaine (injected)	-
Heroin (not injected)	-
Other	2.8

(Multiple responses possible)

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.

4.4% of PLWHA reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs. 11.1% reported that they had missed a dose of antiretroviral medication at some point as a result of using illegal drugs.

Most respondents (84.8%) reported that they had never injected illegal drugs. Of who had injected illegal drugs, 23.8% had done so in the previous 12 months. Of PLWHA who reported injecting drugs, none had shared injecting equipment in the past twelve months.

## ATTITUDES RELATING TO DRUG USE

Around one quarter (23.4%) of respondents felt that they drank more alcohol than they would like, while only 8.2% felt they had used more illegal drugs than they would like.

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 56 Attitudes relating to drug use and infection (percentage of full sample)**

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
<b>Total sample</b>					
Sharing needles is not a problem if your viral load is undetectable	46.3	5.4	-	2.0	46.3
I worry about infecting others by sharing needles	4.9	0.5	2.9	7.8	83.8



# HOME, WORK AND MONEY

## ACCOMMODATION

We asked a series of questions about participants' accommodation status and experiences. These experiences vary considerably among PLWHA, most particularly as a function of whether individuals are in private or public accommodation.

### Current Accommodation

The current type of accommodation of the respondents can be seen in Table 57. Similar numbers of PLWHA were in accommodation that they owned or rented through the private system. A smaller number of people were in public rental accommodation. This group were more likely to be those on a government benefit. There were no significant gender differences in the type of accommodation reported.

**TABLE 57 Current accommodation of respondents (percentage of total sample)**

Own or purchasing house or flat	45.6
Private rental accommodation	30.7
Public rental accommodation(government owned)	13.0
Rent-free (e.g. provided by friends, family, etc.)	6.5
Community housing/housing co-operative	-
Other	4.2

These findings can be compared to data from the New Zealand Census (Statistics New Zealand) which reports that 66.9% of the population own or are paying off their current dwelling, and 33.1% do not own their current dwelling. Rental rates are reported in the census as a proportion of those who do not own their current dwelling (85.9%) (Statistics New Zealand) so this can be read as 28.4% of the population being in a rental arrangement. From these data we can also calculate that 23.2% of the population were living in private rental accommodation and 5.2% in public rental accommodation. Similarly the percentage living rent free can be calculated as 4.2%. The PLWHA population can, therefore, be seen to have lower rates of home ownership and higher rates of public rental than the remainder of the population.

Household composition varied considerably. 29.8% of PLWHA lived alone (compared to the Census rate of 22.6%, Statistics New Zealand), while the remainder lived with between 1 and 15 other adults (median=1) and with between 1 and 5 children (for those living with children: median=2). Two fifths (40.0%) lived with a partner or spouse, and 7.0% lived with dependent children. These children ranged in age from less than 1 to 47 (mean=24.0, median=26.0). In addition, 12.6% lived with other family members and 16.7% with friend(s) or flatmate(s). Half (50.9%) of PLWHA also lived with pets. Respondents with pets were as likely to live on their own as with others, and as likely to have a regular partner as not.

Respondents most commonly lived in residences with three bedrooms (40.2%) (Census 46.3%), while the remainder had 2 bedrooms (29.9%) (Census 19.8%), 1 bedroom (15.0%) (Census 5.8%), 4 or more bedrooms (14.5%) (Census 28.1%) or lived in a bedsit/studio (0.5%) (Census 0.7%).

81.9% of respondents had access to a car (Census 88.1%). When asked how easy it was to access public transportation, 14.6% said it was very difficult, 15.0%, difficult, 40.4% easy and 30.0% very easy.

88.7% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (N=24), the main reasons given were that it was too small (n=12), was too expensive (n=9) and lacked privacy (n=7).

**TABLE 58 Reasons current accommodation is unsuitable  
(number of those with unsuitable accommodation)**

Too small	12
Too expensive	9
Lack of privacy	7
Confidentiality problems	6
Inadequate facilities for carer(s)	5
Too far from other services	5
Too far from health services	4
Poor condition of housing	2
Fear of violence	2
Inadequate for my current state of health	2
Harassment	2
Other	4

(Multiple responses possible)

## Changes in Accommodation

Participants were asked if they had ever changed their accommodation as a result of having HIV/AIDS and 23.3% had, 9.3% in the past two years. On average all PLWHA had changed their accommodation 1.9 times ever as a result of HIV/AIDS (1.7 times in the last two years).

We asked what the circumstances were around participants' last change in accommodation. The results are shown in Table 59 below. Finances, health and location were all important factors in making a decision to move. When asked if they had any other accommodation options for the future, 60.9% (n=14) of those who said their accommodation was unsuitable said they did not.

**TABLE 59 Reasons for changing accommodation (number of respondents)**

Needed cheaper housing	19
Moved closer to health services	13
Illness	13
Moved to a quieter location	11
Lack of privacy	9
Stopped working	9
Better health	8
Planning for illness	7
Moved closer to friends	7
Looking for/returned to work	7
Ending of relationship	6
Improved finances	6
To avoid harassment	4
Moved closer to other services	4
Moved out of family home	4
Moved in with family	3
Beginning of new relationship	1
Other	10

(Multiple responses possible)

## 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 the loss of appropriate skills due to changes in the work environment, explaining an extended absence from the workforce, issues of aging and changes in life goals.

### Employment Status

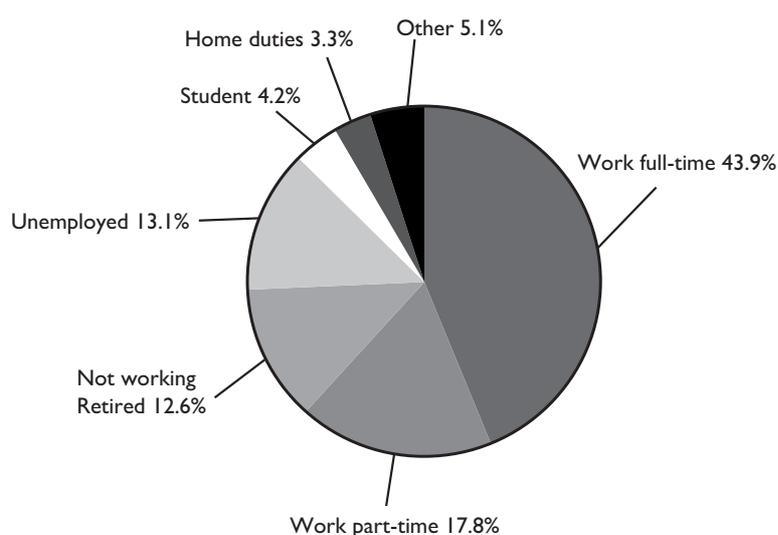
Over half (61.7%) of the respondents were currently employed, with considerably more being in full-time work (43.9%) than in part-time work (17.8%). The remainder tended to describe themselves as either unemployed (13.1%) or not working/retired (12.8%). Compared with the full sample, a smaller proportion of women were employed (45.2%), with 32.3% (n=10) being in full-time work and 12.9% (n=4) in part-time work. This compares with New Zealand Census data that indicate that 48.4% of the adult population is in full time employment and 14.4% in part time employment (Statistics New Zealand)

Of those who were working, the mean number of hours worked was 38.6 (median=40.0) (Census median and mode= 40 hours). Those working full time worked an average of 44.9 hours per week (median=40.0) and those in part time employment worked an average of 24.1 hours/week (median=23.0). Those who were not working stopped work between 1982 and 2006 (mean=2001, median=2004).

**TABLE 60 Employment status (percentage of sample)**

Work full-time	43.9
Work part-time	17.8
Not working / Retired	12.6
Unemployed	13.1
Student	4.2
Home duties	3.3
Other	5.1

**FIGURE 15 Employment status**



## Impact of HIV and Treatment on Employment

We asked respondents how their initial HIV diagnosis affected their career plans and how their plans had changed since then. These data are shown in Table 61 and Table 62 below. A large proportion indicated that their career ended at their time of diagnosis (16.6%).

**TABLE 61 Impact of HIV diagnosis on career plans (percentage of sample)**

My career plans did not change	37.1
It was more difficult to plan for the future	25.4
My career ended/I stopped work	16.6
A career was no longer as important	12.7
I changed careers	6.8
I was less likely to change careers	1.5

HIV also has a negative impact on the continuing work lives of HIV positive people. When asked what the ongoing impact of HIV was on their work life and career plans, one in five (22.1%) said that they found planning for the future more difficult, while smaller numbers said that their career was no longer as important (15.2%) or their career ended/they stopped work (13.2). There were no significant gender differences in the impact of HIV diagnosis or subsequent experience on career plans.

**TABLE 62 Ongoing impact of HIV on career/work**

My career plans have not changed	35.3
It is more difficult to plan for the future	22.1
A career is no longer as important	15.2
My career ended/I stopped work	13.2
I changed careers	8.8
I am now less likely to change careers	5.4

We asked about the impact of antiretroviral therapy on respondents' career plans (see Table 63 below). Of those that have used antiretroviral medication, the most common response was that this had not affected their plans.

**TABLE 63 Impact of antiretroviral therapy on work (percentage of those who have used or are using ARVs)**

There has been no change to my plans	36.5
I anticipate a longer time in the workforce	13.5
I stopped work	12.8
I made a new career plan	9.6
I considered a new career plan	5.1
I went back to work	5.8
I considered going back to work	3.9
I considered stopping work	3.8
Other	7.1

## Interruptions to Employment

Respondents were asked if they had stopped work at any time since their HIV diagnosis. Of those who have worked, 41.5% had stopped work for reasons related to HIV at some point. Of those who had ever stopped work, 53.3% had stopped work on one occasion, 25.3% on two occasions, and 12.0% on three occasions. These work interruptions averaged 3.9 years (median= 2 years). The circumstances relating to the most recent interruption to employment are given in Table 64 below. The most common responses were poor health and diminished energy levels. Around half of those who had ever stopped work due to HIV reported that psychological health (stress, depression or anxiety) had played an important role in the decision.

**TABLE 64 Circumstance surrounding last interruption to employment  
(percentage of those who had stopped work)**

Poor health	69.2
Low energy levels	55.1
Stress, depression, anxiety	52.6
To have more time to myself	20.5
Expecting illness in the future	9.0
To move to a different location	7.7
Redundant/sacked	7.7
To care for another HIV positive person	2.6
Other	7.7

(Multiple responses possible)

These circumstances are also reflected in the participants' HIV/AIDS status at the time they ceased work. Nearly half said that they were ill at the time, although importantly, over one third said that they were not ill at the time, perhaps reflecting both the anticipation of illness and the psycho-social impact of HIV.

**TABLE 65 HIV/AIDS status at time of last interruption to employment**

I had HIV and had been ill	35.5
I had HIV but had not been ill	51.3
I had been diagnosed with an AIDS-defining illness	13.2

We asked participants their source of income during their most recent interruption to employment. Over half said they relied on a government benefit of some sort.

**TABLE 66 Source of income when not working**

Benefits / pension / social security	60.5
Salary	13.2
Superannuation / annuity / savings	10.5
Partner supported me	9.2
Family / friends supported me	2.6
Other	3.9

Of those that stopped working at some point, 66.2% had returned to work. This was most commonly for financial reasons (see Table 67), although better psychological health, better physical health and the need to perform meaningful tasks were also important.

**TABLE 67 Reasons for returning to work**

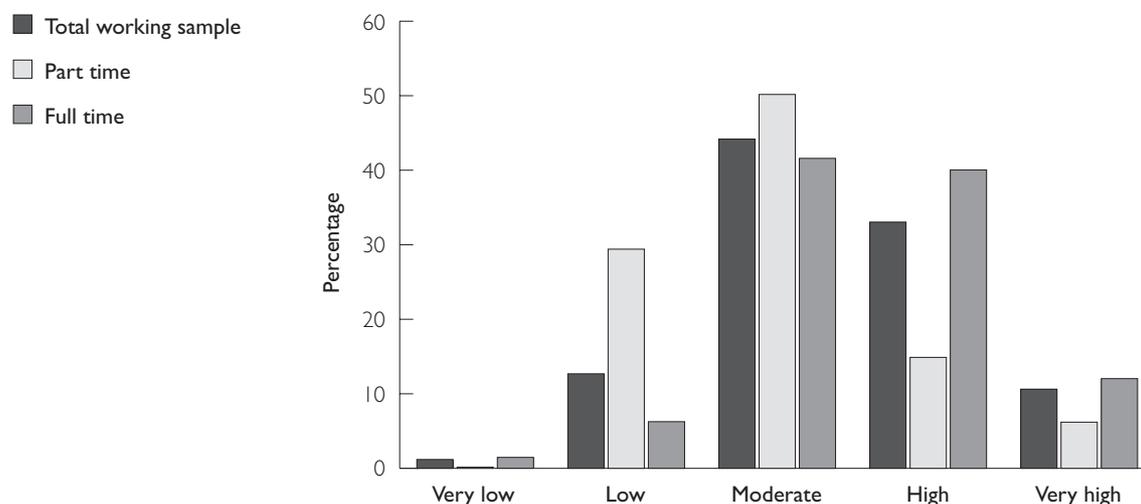
Financial reasons	55.1
Better psychological health	42.3
Better physical health	39.7
To do something worthwhile	37.2
To have something to do	35.9
To have more social contact	25.6
The possibility of working part-time	20.5
The possibility of flexible work hours	15.4
The possibility of working full-time	11.5
Other	6.4

(Multiple responses possible)

## Those Currently in Paid Employment

Respondents were asked about the level of stress in their current job. Almost one half rated the stress level as moderate (43.8%) while 32.8% said it was high and 10.2% said it was very high. Only 0.8% rated the stress level as very low and 12.5% said there was low stress (see Figure 16)

**FIGURE 16 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 experienced around confidentiality at work, 12.6% said that they did not attempt to keep their status confidential (see Table 68). 41.9% said they had experienced no problem in this area. Of those who did experience difficulties, the greatest problem appeared to be gossip, followed by issues around explaining absences from work, and visible signs of illness.

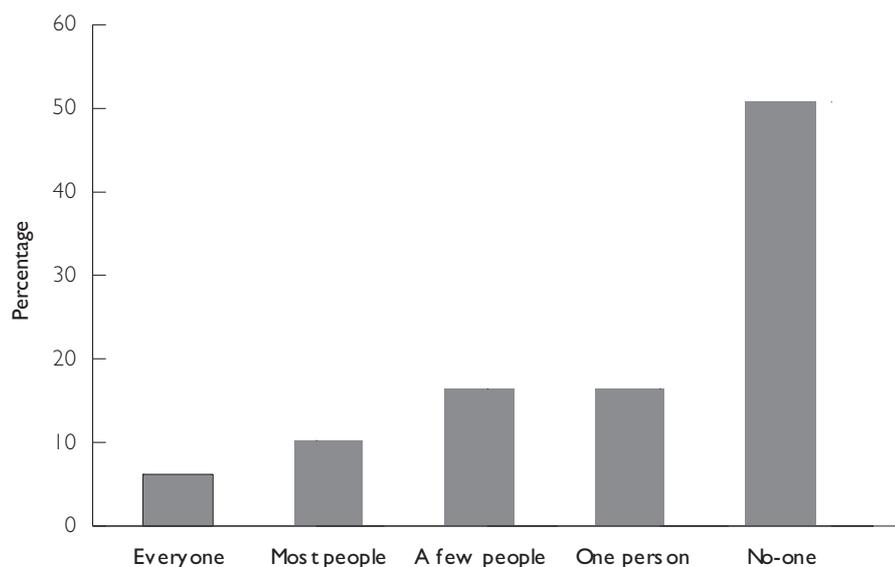
**TABLE 68 Difficulties with HIV status confidentiality in the workplace: percent of total sample**

No problems	41.9
I do not try to keep my HIV status confidential	12.6
Gossip	7.4
Visible signs of illness	7.0
Explaining absences from work	6.5
Difficulty keeping and taking medication	3.7
Other	0.9

(Multiple responses possible)

When asked how many people in their workplace knew that they were HIV positive, 6.3% said that everyone knew, 10.2% said most people knew, 16.4% said a few people knew, 16.4% said one person knew and 50.8% said no-one knew (see Figure 17).

**FIGURE 17 Disclosure in workplace**



When asked about the impact that HIV had on their capacity to perform their work duties, one-third of the sample said that their work was unaffected, while just over one-quarter said that they tired more quickly (see Table 69).

**TABLE 69 Impact of HIV on work capacity (percentage of those in paid employment)**

It is not affected	33.5
I tire more quickly	26.5
I work reduced hours	10.7
I have difficulty concentrating	10.2
I cannot always go to work	6.5
I do different duties	5.1
I am less productive	3.3
Other	1.4

(Multiple responses possible)

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 70) 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 70 Capacity within workplace for HIV related interruptions (percentage of those in paid employment)**

	never	seldom	sometimes	often	always
For medical appointments	5.8	2.5	15.0	15.8	60.8
For counselling	26.9	6.4	12.8	10.3	43.6
When you are sick	3.5	2.6	16.7	14.0	63.2
To do volunteer work	52.1	17.8	12.3	-	17.8

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

Respondents were asked if they currently had plans to change their work arrangements, and 36.8% said they did. Of those who described themselves as unemployed, 50.0% said they were planning to return to work.

**TABLE 71 Plans for changes to work life (percentage of employed respondents)**

	Full time	Part time	Total working sample
I want to stop work	3.2	2.6	3.0
I want to change the type of work I do	14.9	26.3	18.2
I want to reduce my work hours	6.4	15.8	9.1
I want to increase my work hours	1.1	23.7	7.6

The main incentives for changes in work arrangements were financial and social (see Table 72).

**TABLE 72 Reasons for changes to work plans among full sample.**

Financial reasons	22.8
Better psychological health	20.9
To do something worthwhile	18.6
Better physical health	15.3
To reduce stress	14.9
To have more social contact	14.0
To have something to do	11.2
The possibility of flexible work hours	7.0
The possibility of working part-time	5.1
The possibility of working full-time	4.2
To have less social contact	1.9
Worse physical health	0.9
Worse psychological health	-
(Multiple responses possible)	

## Leisure

Respondents were asked how they spend their time while not working. Each respondent indicated the three activities that occupy most of their time. Almost two-thirds indicated that leisure activities (for example reading) occupied their time. Slightly fewer identified housework and resting, while half said they spent their time socialising.

6 Ns refer to the number of participants that identified this as an applicable cost. That is, those selecting "not applicable" or giving no response are excluded from the percentages reported in that row.

**TABLE 73 Activities pursued while not working: percentage of total sample**

Leisure activities (reading, etc.)	63.7
Housework / chores	61.4
Resting	60.0
Socialising with close friends	49.8
Spending time with family	34.0
Socialising with other friends	14.9
Looking after children	10.2
Socialising with HIV positive friends	9.3
Volunteer work in HIV/AIDS organisation	7.9
Volunteer work in other organisation	9.8
Looking after another HIV positive person	2.8
(Multiple responses possible)	

## FINANCES

The HIV Futures surveys have highlighted the financial difficulties that many PLWHA contend with. These difficulties cannot be explained simply by the proportion of PLWHA relying on government pensions or benefits. There are financial hardships associated with being HIV positive. Some of these are structural and systemic, for example the costs associated with managing the negative consequences of treatment, some result from stigma and disadvantage that result from reduced employment options, while others are the cumulative effects of living for many years with uncertain or fluctuating health and well-being.

### Income

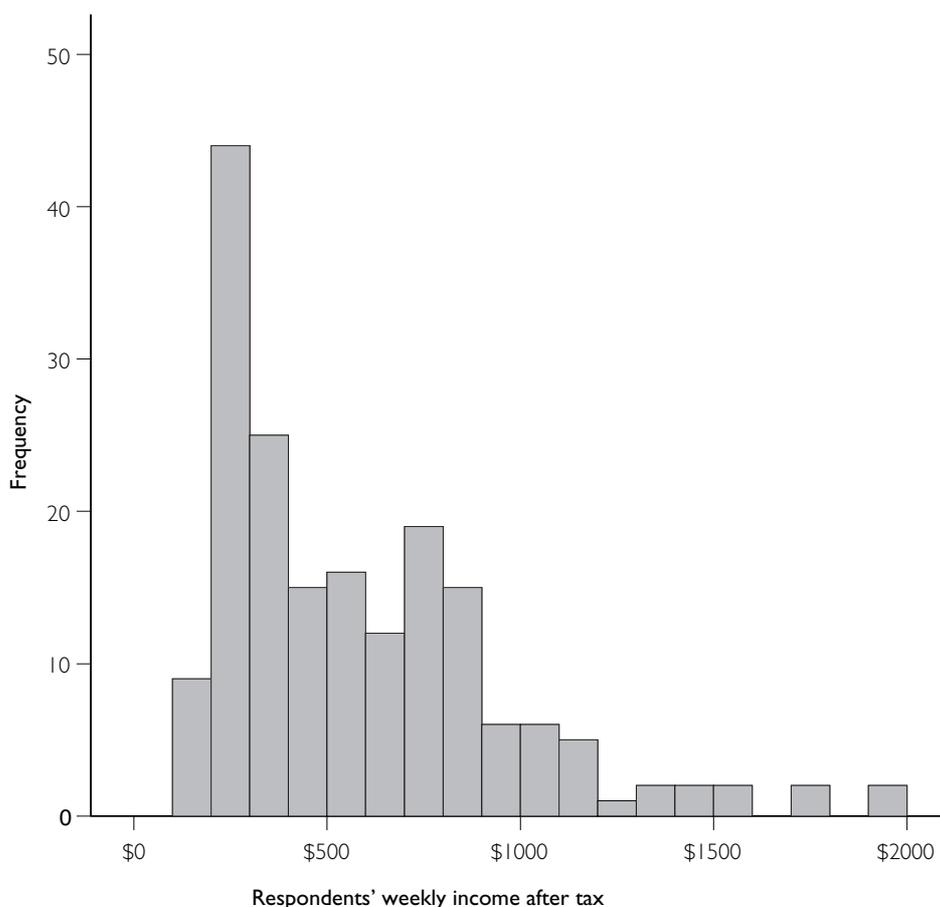
The source of income of the survey respondents is shown in Table 74 below. The most common income source was salary, nominated by just under half of the sample (45.7%) (Census 59.9%), while around one-third relied on government pensions or benefits (35.6%). Compared with the full sample, a smaller proportion of women nominated salary as their main income source (32.3%, n=10), while a higher proportion nominated a benefit (45.2%, n=14) or their partner (16.1%, n=5). Data from the 2006 Census indicate that 18.1% of adults aged 15 years and over received a non-superannuation government benefit, including 2.4% that receive a sickness benefit and 3.1% that receive an unemployment benefit (Statistics New Zealand). The proportion of respondents listing their main income source as salary was higher than in the previous HIV Futures New Zealand survey (45.7% compared with 38.8% in 2001), while the proportion relying on a benefit was lower (35.6% compared with 46.8%). This may be partly due to the increase in the proportion in full-time employment. Much smaller proportions listed superannuation, their partner or family as their main income source.

**TABLE 74 Primary source of income: percentage of total sample**

Salary	45.7
Benefits/pension/social security	35.6
Superannuation/annuity/savings	7.2 (n=15)
Partner supports me	2.9 (n=6)
Family/Whanau/friends support me	1.4 (n=3)
Other	7.2

The median weekly in-hand income for respondents was \$486. Figure 18 below gives the distribution of income in \$100 intervals. 23.3% of respondents had a partner with whom they shared financial resources. The partner's median weekly income was \$600.

**FIGURE 18 Histogram of respondents' weekly income after tax**



### Income Comparison with the New Zealand Population

We can compare the incomes of the PLWHA who completed this survey with those of the New Zealand population through data collected by the New Zealand Income Survey (Statistics New Zealand). In our 2001 report we used a poverty line set at 60% of the median household income to assess financial hardship among PLWHA. Due to complex changes in the distribution of income in New Zealand and the disproportionate impact of tax law, non-salary income and geography, we do not consider this measure to provide a meaningful representation of the relative economic position of PLWHA, nor an adequate method of assessing changes in economic status between the two surveys.

In this report we have chosen to examine financial status by direct comparison with the distribution of New Zealand income, by examining change in income relative to changes in the Consumer Price Index (CPI), by examining adjusted household incomes using the Jensen Equivalence scale values, and as we have in previous surveys by directly asking about financial difficulties experienced.

Median personal disposable income after tax in the HIV Futures New Zealand 2 survey was \$486 per week. Median disposable income after tax for the adult New Zealand population from wages and salaries was \$524 per week (New Zealand Income survey June 2007 quarter).

From this it can be seen that in terms of personal income, PLWHA in New Zealand are economically worse off than the rest of the population.

If we compare the financial status of PLWHA in this survey with the first HIV Futures New Zealand survey (Grierson et al 2002), we can see that the financial situation has improved. Here we compare incomes using the Consumer Price Index (CPI). The CPI is a measure of "the price change of goods and services purchased by private New Zealand households. Often used as a measure of inflation, it covers prices for: food; alcoholic; beverages and tobacco; clothing and footwear; housing and household utilities; household contents and services; health; transport; communication; recreation and culture; education; and miscellaneous goods and services. The CPI is produced quarterly from prices gathered in a range of surveys at 15 urban areas" (Statistics New Zealand website).

The median personal disposable income in 2001 was \$330 and is now \$486 per week. This represents an increase of 47.2%. The CPI in the June Quarter of 2001 was 876.04 and in the June Quarter of 2007 was 1020.00: an increase of 16.4%. Thus the improvement in financial circumstances is greater than the CPI, but the current situation is still worse than the rest of the population.

Similarly if we examine adjusted household incomes<sup>5</sup>, we see a shift from a median of \$317 in 2001 to \$410 in 2007, an increase of 29.3%. Household income can provide a fuller picture of the economic wellbeing of individuals as it takes into account a partner's income as well.

## Expenditure and Debts

Respondents were asked their weekly expenditure on a range of items. The results are shown in Table 75 below. The total mean expenditure on medication was \$53.27 per week with complementary therapies accounting for over half the total. Mean rental or mortgage costs were \$229.72 with the highest costs being in Wellington (mean=\$266.23) and Auckland (mean=\$238.37). Food and utilities accounted for around \$119 and \$77 respectively.

20.4% of respondents owned their own home, while 18.1% were paying off their home. 15.3% had owned their own home in the past, but do not currently. 31.0% received a rental subsidy averaging at \$90.86 per week (median=\$60).

Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at \$56,721 with a median of \$10,000. Those who owned their home had a median debt of \$8,000 (mean=\$87,472), those who were currently paying off their home had a median debt of \$84,500 (mean=\$113,998), those in private rental accommodation had a median debt of \$6,000 and those in public rental accommodation had a median debt of \$7,427. Only a small percentage (7.5%) had used the services of a financial counsellor in the last two years.

**TABLE 75 Weekly expenditure on medications and essentials (\$NZ)**

	Mean	Median
Rent or mortgage repayments	229.72	175.00
Food	118.92	100.00
Utilities	77.37	50.00
Complementary therapies	34.52	20.00
Other medication	11.96	9.00
Antiretroviral drugs	6.79	5.00

<sup>5</sup> Income is adjusted using Jensen Equivalence scale values (Jensen, 1988) based on the number of adults and children in a household. For example two adults with no dependant children require 1.54 times the income of a single adult; two adults with three children require 2.44 times the income of a single person. Thus household incomes are made equivalent to single person incomes by dividing by the equivalence scale values. The household incomes should therefore be read as if they were for a single person.

## Assessments of Benefits

People receiving a sickness benefit 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 34.6% (n=53) of those receiving a benefit in the last two years had received such an assessment. When asked about the outcome of this assessment, 24 respondents said that it had caused them distress, while 22 said that the conditions of their benefit had changed. (See Table 76) Importantly, only 10 people said that the assessment had clarified their concerns.

**TABLE 76 Consequences of receiving an assessment of benefit from a WINZ Medical Officer (percentage of those assessed in last 2 years)**

Cause you distress	24
Result in changes to the conditions of your benefits	22
Clarify concerns that you had	10
Result in termination of your benefits	2

(Multiple responses possible)

## FINANCIAL HARDSHIP

In order to examine the impact of income on other aspects of health and well being we present here a comparison between the bottom income quartile (i.e. the 25% of participants with the lowest incomes) and the top income quartile (i.e. the 25% with the highest incomes). This is a method of contrasting financial situations that avoids the over-complication of examining every small difference. As such, it should be interpreted cautiously. The intention here is to demonstrate that income is related to health and well being. This is not necessarily a direct causal relationship. The vast literature on the social determinates of health makes clear that there is interdependence between health, well being and finances. Lower incomes may mean less access to food, housing, medication etc, and to poorer health. Poorer health may reduce earning capacity and reduce access to these same things. Below, we compare these quartiles of income in relation to employment, source of income, health and well being.

### Correlates of Financial Hardship

As can be seen in Table 77 below, those in the lower quartile are much less likely to be in paid employment. This is unsurprising, but it is important to note that 19% of those in the bottom quartile are actually in paid employment, this being what many commentators refer to as 'the working poor'.

**TABLE 77 Employment status by income (percentage of income quartiles)**

	Bottom Quartile	Top Quartile
Employed	18.6	95.9
Not employed	81.4	4.1

Income source is also unsurprisingly related to absolute income. While almost all of those in the top quartile have an income sourced from salary or superannuation, 83% of those in the lowest quartile have income sourced from a government benefit or pension.

**TABLE 78 Income source by income (percentage of income quartiles)**

	Bottom Quartile	Top Quartile
Salary	4.8	87.8
Super/annuity/savings	2.4	2.0
Benefits/pension/social security	83.3	-
Partner	2.4	-
Family/friends	2.4	-
Other	4.8	10.2

When we examine self-reported overall health (Table 79) and well being (Table 80) using these quartiles we can see a very clear pattern. Those in the bottom quartile of income were far more likely to rate both their health and well being as fair or poor. Over one third (35%) of those in the bottom quartile rated their health as poor or fair, compared with only 10% of those in the upper quartile. Similarly, 37% of those in the bottom quartile rated their well-being as poor or fair, compared with only 8% of those in the top quartile.

**TABLE 79 Self-rated health by income (percentage of income quartiles)**

	Bottom Quartile	Top Quartile
Poor	14.0	-
Fair	20.9	10.2
Good	51.2	40.8
Excellent	14.0	49.0

**TABLE 80 Self-rated well being by income (percentage of income quartiles)**

	Bottom Quartile	Top Quartile
Poor	4.7	2.1
Fair	32.6	6.3
Good	44.2	50.0
Excellent	18.6	41.7

## Costs

As with the previous survey, we asked respondents about the difficulty they had paying for a range of activities, goods and services. The results are shown in Table 81 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 sport. Those items most likely to be rated as not at all difficult were medication and support services. Smaller 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 81 Difficulty paying costs of items and services**

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=167) <sup>6</sup>	76.6	19.8	3.6
Other prescribed medication (n=180)	63.3	26.1	10.6
Medical services (doctor, dentist, etc.) (n=196)	48.0	34.2	17.9
Complementary Therapies (n=108)	50.9	29.6	19.4
Support services (counselling, etc.) (n=76)	69.7	13.2	17.1
Entertainment (theatre, movies, concerts, etc.) (n=174)	48.3	25.3	26.4
Going out (eating/drinking) (n=182)	44.5	26.4	29.1
Sport (exercise, gym, etc.) (n=145)	44.8	28.3	26.9
Recreational drugs (n=126)	50.0	30.3	19.7
Travel/holidays (n=176)	27.8	27.3	44.9
Rent/Mortgage/Housing costs (n=178)	46.6	41.0	12.4
Utilities (telephone/electricity/gas/water) (n=189)	49.7	35.4	14.8
Food (n=198)	53.5	33.8	12.6
Clothing (n=195)	43.6	32.8	23.6
Transport (n=195)	48.2	33.8	17.9
Child care (n=22)	63.6	13.6	22.7

Across all these items those in the lower end of the income distribution were more likely to report difficulty. For example, comparing the top and bottom quartiles as above, we note differences in the percentage reporting that it is somewhat or very difficult to pay for: medical services (upper: 28.2%, lower: 64.8%); support services (9.6%, 37.6%); entertainment (20.4%, 75.8%); housing (32.6%, 61.8%); utilities (25.5%, 75.0%); food (19.1%, 74.4%); and transport (29.8%, 70%).

## DISCRIMINATION

Discrimination is prohibited in New Zealand under provisions of the Human Rights Act 1993. Prohibited grounds for discrimination include: sex; marital status; religious belief; ethical belief; colour, race, or ethnic or national origins; disability; age; political opinion; employment status; family status; and sexual orientation. These grounds apply to a person's past, present or assumed status and in the areas of: government or public sector activities; employment; access to education; access to public places, vehicles and facilities; provision of goods and services; provision of land, housing and accommodation; industrial and professional associations, qualifying bodies and vocational training bodies; and partnerships. HIV positive status is encapsulated within the grounds of disability, specifically, "the presence in the body of organisms capable of causing illness".

### Accommodation

3.8% (n=8) of respondents indicated that they had experienced less favourable treatment in relation to accommodation (1.9% in the last two years).

<sup>6</sup> Ns refer to the number of participants that identified this as an applicable cost. That is, those selecting "not applicable" or giving no response are excluded from the percentages reported in that row.

## Health Services

### HIV

22.4% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This comprised 12.4% (n=26) that had experienced such discrimination in the last two years and 11.0% (n=23) that experienced this more than 2 years ago. As can be seen in Table 82 many individuals experienced multiple instances and forms of discrimination. When asked what form this discrimination took, the most common responses were increased infection control (35.6%) avoidance (34.5%) and confidentiality problems (31.6%).

**TABLE 82 Form of HIV-related discrimination experienced at medical service (number of those experiencing discrimination)**

	More than 2 years ago (n=23)	In last 2 years (n=26)
Increased infection control	10	10
Avoidance	8	10
Confidentiality problems	8	11
Treated last	6	2
Refusal of treatment	7	5
Rushed through	2	7
Harassment	2	3
Abuse	0	1

(Multiple responses possible)

### Hepatitis C

Four respondents had experienced less-favourable treatment at a medical service as a result of having hepatitis C. One of these had experienced such discrimination in the last two years.

### Insurance

21.4% of respondents currently had private health insurance and 21.4% also currently had some form of income or mortgage insurance.

25.9% of respondents indicated that they had experienced less favourable treatment in relation to insurance. This included 10 respondents who had experienced this discrimination in the last two years. The most commonly reported example of less favourable treatment was being unable to take out either a specific insurance policy, for example health insurance, travel insurance or life insurance. Some respondents referred to being generally unable to take out most insurance policies due to exclusion clauses, while others said they hadn't bothered to apply for insurance because they were told they were ineligible.

### Workplace

14.0% of respondents had experienced less-favourable treatment in the workplace as a result of having HIV. This comprised 5.8% of all respondents that had experienced such discrimination in the last two years and 8.2% that experienced this more than 2 years ago. When asked what form this discrimination took, the most common responses were general discrimination.

# PARTICIPANTS OF AFRICAN DESCENT

## INTRODUCTION AND RATIONALE

This section presents an analysis of the survey responses of New Zealand PLWHA of African descent. These analyses are presented separately for three primary reasons. Firstly, the experience of this population is often profoundly different to other positive people. The sample presented here includes those who have arrived in New Zealand as refugees, as part of family reunification provisions or other forms of immigration. The experience of coming from settings with high HIV prevalence, settings with fundamentally different health care services, the process of immigration, testing and resettlement and differences in language, culture, and community all mean that the experience of living with HIV may be profoundly different for this population. In providing guidance for services such as the African Health Promotion Programme, specific data on this population is useful. Secondly, as will be seen from what follows, the findings in many sections of the survey are very different for this population. If we were to include these data in the overall analysis these differences would be masked by the remainder of the data given the relatively small size of this sample. Thirdly, data on African refugees were presented separately in the first HIV Futures New Zealand report. To allow meaningful comparison between the two studies it is sensible that this report present the data in a similar way.

Caution should be noted, however in direct comparison of this section with that in the previous report. The small numbers mean that differences are particularly unstable- a slight change in respondent participation can lead to a large difference for the sample. There are also slight differences in the constitution of these samples between the two studies. In the first HIV Futures New Zealand survey, only African refugees recruited through the, then, Refugee Health Education Programme were included in this section. In the current study a broader recruitment effort and changes in service structure mean that this sample, while largely similar differs from the first.

As this section reports on a small sample of people, not all analyses can be reported. Where the number of participants becomes too small to be meaningful or could potentially identify individuals we have not reported findings. Most analyses in this section are reported by number of people rather than percentages to avoid overstating the differences.

## DEMOGRAPHICS

This portion of the sample contained 31 (67.4%) women and 15 (32.6%) men. These respondents ranged in age from 24 to 67 with a mean and a median of 39.0. All of these respondents were heterosexual (100.0%).

## HEALTH

### HIV Antibody Testing

Twenty-nine (63%) respondents had taken the test as part of routine health screening.

### Pre- and Post-Test counselling/discussion

Eight respondents indicated that they had received pre-test counselling or engaged in an HIV test discussion. Six reported they were satisfied with the information they received from this person and seven said they were satisfied with the level of support they received.

Twenty three (50%) respondents indicated that they had received post-test counselling. Twenty reported they were satisfied with the information they received from this person and nineteen said they were satisfied with the level of support they received.

### Current Health Status

Thirty seven (82%) respondents rated their physical health as good or excellent. Thirty-four (76%) rated their well being as good or excellent.

**TABLE 83 African respondents' self ratings of general health status**

	HEALTH		WELL BEING	
	Frequency	Percent	Frequency	Percent
Poor	2	4.4	3	6.7
Fair	6	13.3	8	17.8
Good	21	46.7	22	48.9
Excellent	16	35.6	12	26.7

## CD4 and Viral Load

Almost all respondents had taken a CD4/T-cell test (94%) and a viral load test (87%). Results for PLWHA's most recent CD4/T-cell test ranged from 204 to 856 cells/ $\mu$ l with a mean of 511 cells/ $\mu$ l and a median of 500 cells/ $\mu$ l. Results for PLWHA's most recent viral load test ranged from below detectable levels to 10,000 copies/ml with a mean of 804 copies/ml and a median of undetectable.

## HEALTH CONDITIONS

### AIDS Defining Illnesses

One respondent said they had been diagnosed with an AIDS defining illness at some point

### HIV/AIDS Related Conditions

Eight respondents indicated that they had experienced an HIV-related illness at some point.

### Other Health Conditions

Seven respondents indicated that they had been diagnosed with a major health condition other than HIV/AIDS.

### Viral hepatitis infection

One respondent had at some point had hepatitis A, and five had been vaccinated against this virus. None of the respondents had been diagnosed with hepatitis B, and six had been vaccinated against this virus. Thirty-one respondents had been tested for hepatitis C, although primarily via an antibody test. One respondent had ever had hepatitis C.

### Mental Health

In the six months prior to completing the survey, three respondents said they had taken medicines prescribed for depression. Three reported having taken medicines prescribed for anxiety in the past 6 months and none had taken anti-psychotic medication.

## HEALTH MAINTENANCE

The most common health-enhancement activity was eating healthily (34 respondents), followed by exercise (28), sleep (26), and spending time with their partner (12) or family (11).

### Attitudes to Health Management

When asked about health management strategies, almost all participants agreed that exercise; healthy eating and an optimistic outlook were important or very important strategies.

### Complementary Therapies

Six respondents had taken vitamin or mineral supplements and two had used massage in the previous six months.

### Prophylaxis

Four respondents had taken prophylaxis for opportunistic infections in the previous six months.

## Other Health Monitoring

No respondents in this group had taken a bone density test in the previous two years, while nine had taken a fasting cholesterol test in this period. 27 women ( had undergone a cervical smear (Pap) test, and 26 said they had taken one in the last twelve months.

## TREATMENTS

### Antiretroviral Therapy

Of this sample, thirty respondents (70%) had used ARV at some point, and twenty six (61%) were currently using these treatments. The most common combination was 2 NRTI-1 NNRTI (10 of those on ARV).

### Difficulties of Taking ARV

Overall, twenty six participants currently using antiretroviral treatments nine reported that they had some difficulty taking them: five indicated they had difficulty remembering to take the drugs on time, four said they had difficulty transporting medication, six taking a large number of tablets, three had difficulty organising meals around medication, and five taking medication in public. Side effects were reported by two of respondents currently using ARV.

### Attitudes to ARV

Most respondents reported concern over the future efficacy of their treatments. Half (13 out of 26 on ARV) agreed or strongly agreed with the statement *I am worried that in the future my medication will stop working for me*. When asked to respond to the statement *Taking tablets gives me an unwanted reminder that I have HIV*, nineteen indicated agreement and six indicated disagreement.

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 (22 of the 26 currently on ARV).

When asked how many combinations they believed they still had access to, 24 respondents said they didn't know how many combinations they had left.

### Attitudes to Antiretroviral Therapy

Participants in this sample were more likely to report uncertainty in relation to the attitude items in the survey than other PLWHA. Where participants did feel able to respond, there was a clear reliance on clinical sources of guidance around managing HIV. These findings can be seen in Table 84.

**TABLE 84 Attitudes to antiretroviral drugs: Number**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am healthy now and don't need to use combination antiretroviral drugs	11	16	3	12	4
People with HIV should start using antiretroviral drugs as soon as possible	3	7	6	9	21
My doctor and I work together to find the best treatment for me	2	2	6	31	4
My doctor knows a lot more about the treatment of HIV than I do.	1	2	11	31	1
Combination antiretroviral drugs are ineffective	5	6	6	7	22
Combination antiretroviral drugs are harmful	5	6	9	1	25
The side-effects of antiretroviral drugs outweigh the benefits	3	4	9	6	23
New treatments will be developed in time for me to gain benefits	1	1	13	15	16
HIV treatments will stop me dying from AIDS	2	3	10	14	17
Combination antiretroviral drugs have allowed me to plan my life with confidence for the long-term	4	3	9	9	19

In addition to these items, respondents were asked to indicate how much they and their friends agreed with the statement *Antiretroviral drugs mean better prospects for most people*. Eighteen respondents agreed with this statement, and eleven believed their friends would agree with it. However, twenty-six respondents responded “do not know” to this item for themselves and thirty-two “do not know” for their friends.

## Treatment Breaks

In all, ten respondents in this sample had taken a break from antiretroviral medication at some point.

## Antiretroviral Resistance

Four respondents who had ever used antiretroviral treatments indicated that they had taken a viral resistance test. Of those who had resistance testing, all found resistance to one or more antiretroviral drugs and this resulted in a change of drugs.

## Dosing and Adherence

Twenty-two respondents (75% of those using) were taking ARV twice daily. All of the respondents in this sample, except one who reported missing a single dose, reported not missing any doses in the two days prior to survey.

## Prescriptions

Twenty-six (57%) respondents obtained their prescription from a specialist in an outpatient clinic. Participants were most likely to obtain their prescriptions from one place (23 respondents). 15 said obtaining prescriptions was not difficult and 10 that it was somewhat difficult.

## Clinical Trials

Only one participant had participated in a clinical trial for HIV related treatment in the previous two years.

## Other Medication

Eight respondents were using prescribed medication other than antiretroviral therapies.

## SERVICES

### Health Services

#### Treatment

Hospital-based HIV specialists were the primary providers of HIV specific and general treatment for a large majority of respondents, while much smaller numbers nominated other types of doctors (see Table 85). Twenty-nine (78%) respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment.

**TABLE 85 Physician used for general and HIV related treatment: Number**

	For general treatment	For HIV specific treatment
HIV specialist at outpatient clinic	25	26
GP	9	2
Doctor at sexual health centre	1	1
GP with high HIV caseload	1	-
HIV specialist in ward at hospital	1	-

### Services Used in the Last 6 Months

29 had used a GP, 36 an HIV outpatient specialist, and 3 a dentist. Support services: two reported having used NZAF counsellor/support worker/therapist, and six a hospital social worker or counsellor

### Other Services

Few participants in this population had used any of the services listed in the survey, either at HIV/AIDS organisations or at other organisations. One or two respondents indicated that they used services such as peer support, financial assistance or counselling, four used pharmacy services at an AIDS organisation and three used these organisations for social contact with other PLWHA.

Five respondents indicated that there were services they felt they needed but did not have access to, mostly related to the amelioration of isolation and the provision of social support.

## INFORMATION

### Sources

Respondents were asked to nominate from a list of potential sources, those that were important sources of information on treatments and HIV management, and living with HIV. Clinical services were the most frequently mentioned in relation to treatments and HIV management information. Few respondents reported accessing services for information on living with HIV.

**TABLE 86 Sources of information about treatments and living with HIV (Number)**

	Information about Treatments/ HIV Management	Information about Living with HIV
HIV specialist (outpatient)	39	9
GP	32	2
CART	24	4
HIV specialist (inpatient)	7	2
HIV specialist nurse	7	4
Internet	7	7
NZAF staff (treatments-specific)	6	3
Positive Women	6	4
Other HIV/AIDS support organisations	5	1
Publications from HIV/AIDS groups	5	4
GP with high HIV caseload	4	3
HIV positive friends	4	3
Pharmacist	4	1
Refugee Health Education Program	4	1
Sexual Health Service	4	3
HIV magazine/newspaper	3	1
Other doctor	3	1
Other nurse	3	2
Publications from other sources	3	3
Body Positive staff (treatments-specific)	2	1
Dentist	2	1
Family planning association	2	-
Family	2	2
NZAF staff (others)	2	3
Partner	2	-
Alternative/Complementary therapist	1	-
Articles in gay press	1	-
Body positive staff (others)	1	1
Haemophilia society	1	-
Injecting drug users organisation	1	-
NZ Prostitutes Collective	1	-
Other friends	1	1
Dietician	-	1

(Multiple responses possible)

### Information about HIV Treatment and Management

HIV specialists at outpatient clinics were considered to be an important source of information on HIV treatment and management by the majority of respondents.

### Information about Living with HIV

Respondents nominated very few sources of information around living with HIV. The source selected by the greatest number of respondents was hospital-based HIV specialists (9 respondents), followed by the internet (7 respondents).

## Lack of information

Nineteen respondents said that lack of information made it difficult for them to make decisions in certain areas. Eleven nominated issues around using and changing ARV regimens, thirteen nominated taking breaks from ARV, eleven issues around having children and eight the management of side effects.

## Publications

Few respondents in this sample read HIV publications. Six indicated that they read *Collective Thinking* and five that they read *Positively Positive*.

## Involvement with AIDS Organisations

27% had some contact with HIV/AIDS organisations. Of these, seven respondents received newsletters and mail outs and nine were clients. Of those that had no contact with AIDS organisations, 28 gave the reason *I do not want to be involved*, two gave the reason *I do not have enough time*, one said that they had no transport or were too far away, and two said they did not know how to join. None of those who were not involved in AIDS organisations said they felt excluded from them.

# THE SOCIAL WORLD OF PLWHA

## Contact with Other PLWHA

54% of this sample did not personally know anyone else with HIV. 15% had an HIV positive friend and 11% had HIV positive acquaintances. 24% had either an HIV positive partner or ex-partner (combined). Five respondents had been involved in the nursing or care of another positive person at some time in the last two years, and 40% have had someone close to them die from HIV/AIDS. 20% spent at least some time with other positive people.

## Disclosure

Respondents were asked who they had disclosed their HIV status to (see Table 87). All of those who were in a regular relationship had disclosed to their partner. Within families, people were most likely to have disclosed to siblings (13%). 17% had not disclosed their HIV status to anyone.

**TABLE 87 People the respondent has disclosed their HIV status to**

	Percent who have disclosed
Partner/spouse	67.4
No-one	17.4
Siblings	13.0
Close friends	10.9
Son/daughter	10.9
Positive friends	6.5
Parents	6.5
Other family members	6.5
Other friends	-
Work colleagues	-
Neighbours	-
People from own ethnic community	-

(Multiple responses possible)

## Unwanted Disclosure

Seven respondents said their HIV status had ever been disclosed without their permission at some point. Six said that this had happened in the last two years.

## Social Support

Participants were most likely to have nominated their health care workers as providing a lot of support (n=38), followed by their partner/spouse groups (n=20).

**TABLE 88 Social support received from different sources: Number**

	A lot	Some	A little	None
Health care workers	38	6	-	-
Partner/spouse	20	2	-	3
Siblings	5	7	1	5
Religious or spiritual advisor	5	10	10	6
Children	4	8	1	7
HIV positive friends	4	1	1	9
Close friends	3	7	13	5
Parents	3	2	-	2
Family	3	14	3	10
Pets	2	3	2	8
PLWHA groups	1	-	-	-
Doctor	1	1	2	2
Counsellor	1	-	1	-
Other friends	1	8	14	5
Volunteer carer	-	1	-	5

## Attitudes to HIV status

When asked to respond to the statement *As long as I am well I prefer not to think about HIV/AIDS*, 38 indicated agreement and 7 disagreement.

When asked to respond to the statement *Life has become more meaningful since I became HIV positive*, 30 indicated agreement and 13 disagreement.

## Planning for the Future

53% of respondents indicated that they planned only one day at a time, 16% a few months ahead, 2% one year ahead, 13% five years and 16% ten or more years. 64% said this had not changed in the previous two years.

## RELATIONSHIPS AND SEX

### Relationships

When asked if they were currently in a regular relationship, 54% said they were. Of those, 43% (n=9) reported that their partner was also HIV positive. All of those with a regular partner had told their partner that they were HIV positive. Most respondents reported consistent condom use with regular partners.

### Casual Partners

Participants in this group reported very little casual sex. Due to the small numbers involved we will not report data on this here.

## Legal Issues around disclosure of HIV status

Participants were most likely to indicate either agreement with the two legal statements, or that they were uncertain.

**TABLE 89 Attitudes to legal issues around disclosure: Number**

	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 to tell their partner about HIV status	14	2	6	9	14
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	18	3	4	5	15
The current legal situation about disclosure about HIV status has limited my ability to form new relationships	4	7	6	23	1

## Children

72% (n=33) of these respondents had children, 21 women and 12 men. 39.1% (14 women and four men) had dependent children living with them. When asked about future plans, 12 said they were not planning to have children, 9 (8 women and one man) that they have decided to have a child/children in the future, 2 that they are currently trying to conceive or get pregnant, and 4 that they have thought about it but I haven't decided. One respondent said they did not have enough information to make a decision.

## HOME, WORK AND MONEY

### Accommodation

Twenty-nine respondents (63%) were living in public rental accommodation, while twelve were living in private rental accommodation. Four either owned or were purchasing a home. 69.6% of respondents stated that their accommodation was suitable for their current needs. Of those who said their accommodation was unsuitable (N=13), the main reasons given were the poor condition of housing (8), that it had inadequate facilities for carers (5), that it was inadequate for their current state of health (5), that it was too small (4), and was too expensive (4). Three respondents had ever changed their accommodation as a result of having HIV/AIDS.

### Employment

Twenty four respondents (52.2%) were currently employed, with eighteen being in full-time work and six in part-time work. Most respondents (34) reported no change in their career plans at time of diagnosis, as a result of the ongoing impact of HIV (29) or on commencement of ARV (19). Of those who have worked, one respondent had stopped work for reasons related to HIV at some point.

When asked what difficulties they experience around confidentiality at work, 13 of the 24 said they have experienced no problem in this area, although there were no respondents in this group that did not attempt to keep their status confidential (see Table 90).

**TABLE 90 Difficulties with HIV status confidentiality in the workplace**

No problems	13
Difficulty keeping and taking medication	8
Explaining absences from work	4
Gossip	3
Visible signs of illness	1
Other	1
I do not try to keep my HIV status confidential	-
(Multiple responses possible)	

When asked how many people in the workplace knew that participants were HIV positive, 21 of the 24 working said no-one knew and the remaining three that a few people knew. Nineteen of the respondents reported that their work capacity was not affected by HIV/AIDS.

## Finances

The source of income of the survey respondents is shown in Table 91 below. Twenty-one were receiving a salary and seventeen had a government pension or benefit as their main source of income.

**TABLE 91 Primary source of income: Number**

Salary	21
Benefits/pension/social security	17
Partner supports me	2
Other	1

The median weekly in-hand income for respondents was \$380. The partners' median weekly income was \$630. The total mean expenditure on ARV medication was \$8.50 per week, \$12.8 on other medication and \$24 per week on complementary therapies. Mean rental or mortgage costs were \$172. Food and utilities accounted for around \$145 and \$69 respectively. Personal disposable income after tax for this sample had increased by 93% since the previous survey, compared to an increase in the CPI of 16%. Median income, however, was still lower than the remainder of the sample, and the New Zealand population.

Four respondents owned their own home, while 41 were paying off their home. One respondent was receiving a rental subsidy.

## Assessments of Benefits

Seven of the thirty-nine respondents receiving a benefit in the last two years had received an assessment. When asked what this experience resulted in, four said that their benefit was terminated.

## Costs

Participants in this group reported higher rates of difficulty in paying for the costs of items in all categories than other PLWHA.

**TABLE 92 Difficulty paying costs of items and services (Number: Participants of African Descent)**

	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS	9	13	3
Other prescribed medication	9	8	6
Medical services (doctor, dentist, etc.)	6	7	25
Complementary Therapies	4	2	1
Support services (counselling, etc.)	2	1	3
Entertainment (theatre, movies, concerts, etc.)	4	4	26
Going out (eating/drinking)	6	3	30
Sport (exercise, gym, etc.)	8	4	28
Recreational drugs	-	-	1
Travel/holidays	2	3	33
Rent/Mortgage/Housing costs	8	10	22
Utilities (telephone/electricity/gas/water)	5	4	31
Food	8	4	29
Clothing	6	7	28
Transport	6	9	26
Child care	4	2	3

## DISCRIMINATION

### Accommodation

Two respondents indicated that they had experienced less favourable treatment in relation to accommodation, both in the last two years.

### Health Services

Six respondents had experienced less-favourable treatment at a medical service as a result of having HIV, all in the last two years. When asked what form this discrimination took, the most common responses were being rushed through (5), additional infection control (3), and breaches of confidentiality (3). One respondent reported refusal of treatment.

### Insurance

Five respondents currently had private health insurance and three currently had some other form of income or mortgage insurance. Six respondents indicated that they had experienced less favourable treatment in relation to insurance.

### Workplace

Two respondents had experienced less favourable treatment in the workplace as a result of having HIV, both in the last two years

# CONCLUDING COMMENTS

We hope that this report has provided a comprehensive overview of the multiple aspects of lives of New Zealand PLWHA. We have presented findings from the study that cover health and treatments, service engagement, relationship to HIV community, sex and relationships, housing, employment, finances and discrimination. These analyses have implications, both broad and specific for the response to the HIV epidemic in New Zealand. The vision of the authors of this report is that those with responsibilities in each of these areas take serious note of these findings and the implications for their practice. The publication of these findings represents a sharp and critical opportunity for an assessment of the New Zealand response and the ways in which it is serving or disadvantaging people living with HIV/AIDS. Challenges clearly still remain for people living with HIV in New Zealand, even though we note clear improvements since the first survey. We ask that policy makers, legislators, funding agencies, service providers, clinicians, support groups and individuals take advantage of this report and respond within their own ambit to work toward improving the place of PLWHA in New Zealand society. This report does not make direct recommendations on the changes to policy and practice that these findings point to. We ask you to take up that responsibility. We ask that you actively engage with the findings of this report and to do justice to the contribution of people living with HIV that is evidenced here.

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# APPENDIX A: METHODS AND INSTRUMENT

**This section describes the research design, method of recruitment, development of the survey instrument, sampling issues and data analysis.**

## THE SURVEY INSTRUMENT

HIV Futures New Zealand 2 was an anonymous, cross-sectional survey of a sample of people living with HIV/AIDS. The survey ran from February until August 2007. The survey was available as both a self-complete, mail back survey and as an on-line survey. On-line surveys have been used successfully in HIV research in New Zealand (for example Saxton et al 2007) and we have used online methodologies to collect health information from PLWHA and GLBTI people in Australia (Pitts et al., 2006; Grierson et al, 2006, Hillier et al., 2005). We hoped that by offering HIV Futures NZ online we would provide an easier way for the usual demographic of respondents to complete the survey and also allow us to access harder to reach PLWHA. The on-line survey was accessed through the website [www.hivfutures.org.au](http://www.hivfutures.org.au). The site was hosted by Demographix.co.uk, an experienced commercial provider of web-based surveys with excellent attention to the issue of security and privacy.

## DESIGN

The instrument was based in large part on the first HIV Futures New Zealand survey with some modifications based on the most recent Australian survey (Grierson et al, 2006), and modifications reflecting changes in issues of concern, health service structure, community sector structure and clinical issues.

The survey consisted of 250 items organised into eight sections: demographics; accommodation; health and treatments; services and communities; 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 online survey used identical wording to the paper survey and contained exactly the same items, however the online survey provided users with drop-down menus for some items, such as numbers, years and months. These were included in order to ensure relatively clean data. The online survey also had a number of skips built into it so that respondents did not have to see items that were not relevant to them, for example respondents who were not taking antiretroviral treatments did not have to see the questions about these treatments.

Completed paper surveys were returned in a reply-paid envelope to the Living with HIV program at ARCSHS. Respondents were also able to add their contact details to the program mailing list to receive reports and to participate in further research by completing an additional form and sending it in a separate envelope. On-line surveys were able to be saved and re-opened by respondents so that they could be completed in their own time. Completed surveys were submitted online and stored by demographix.co.uk. Respondents completing the survey online were also able to provide researchers with their contact details by filling in and submitting a separate form, which was stored in a database separate from the survey data.

## RECRUITMENT AND SAMPLING

As the survey was anonymous and as multiple recruitment strategies were employed a simple response rate cannot be calculated. Recruitment took place using a set of methods in order to reach a diverse population of HIV positive people. This 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. The inside front cover of the paper survey also contained the link to the online survey so that each participant receiving a paper copy was also informed about the availability of the on-line survey.

### 1. Direct distribution

Copies of the survey could be directly requested by potential participants and mailed either from the Australian office or from NZAF. We did not utilise the mailing list collected as part of the first HIV Futures New Zealand survey for this project, as it had been five years since this was compiled and many contact details would have changed. Surveys were also mailed out as an insert with *Collective Thinking*.

### 2. Promotion and Marketing

#### Paid Advertising

The survey was advertised in a number of gay and HIV publications with distribution around the country. Banner ads with a direct link to the on-line survey were placed on websites that reached gay communities.

#### Advertising through community organisations

The survey was promoted extensively through community organisations. Advertisements, articles and news items were placed in community newsletters, banner ads were placed on community websites and promotional post-cards and reception cards were placed and reception desks.

### 3. Community sites

In addition to advertising the survey, community organisations were involved in promoting the study by mailing the survey to members accompanied by a covering letter from the organisation explaining the purpose of the study, explaining the value of the research, and encouraging participation. The survey forms were made available on-site at community organisations. These organisations also distributed copies of the survey to sites and venues they felt were appropriate and with whom they have ongoing relationships. Special events were held at some community organisations to encourage people to complete the survey with the project officer on site to answer any questions. Staff at some organisations also assisted people to complete surveys. The survey was also promoted at staff and volunteer meetings.

### 4. Clinical sites

Surveys were made available and promoted through posters and postcards at a range of clinical sites around the country. These included HIV specialist services, hospital HIV services, sexual health services and general practitioners. Each service tailored the promotion and distribution of surveys to suit their specific model of practice.

Table 93 below gives the sources identified by respondents as the primary site that they obtained the survey, or information about the survey. The on-line sample is shown separately from the paper sample. It should be noted that many participants would have obtained copies of the survey and information about the research from multiple sources.

**TABLE 93 Data on primary site of survey collection**

	Paper	On-line	Combined
Completed a previous HIV Futures Survey	9.6	5.3	8.5
Mail-out from HIV/AIDS organisation	34.3	35.1	34.5
Picked up a copy at HIV/AIDS organisation	3.4	12.3	5.5
Picked up a copy at Medical Centre or Hospital	18.0	-	13.6
Positive Women's Organisation	5.1	-	3.8
Gay newspaper/magazine	0.6	7.0	2.1
Recruited by researcher	1.1	8.8	3.0
Postcard in medical setting	-	8.8	2.1
From an interpreter	16.9	-	12.8
Other	11.1	17.5	25.5

## ON-LINE SURVEY

Around one-fifth of the sample completed the survey on-line. The on-line and paper samples were similar, however the on-line sample was more likely to be male, gay, employed, to have a university degree, to be taking treatments and to have an undetectable viral load. When combined, the sample was similar to the first HIV Futures New Zealand sample.

**TABLE 94 Comparison of online sample and paper survey sample**

Variable	Paper	Online	Combined	Futures NZ1
N (%)	203 (77.8)	58 (22.2)	261	226
Sex(%)				
Male	70.6	93.1	75.7	75.7
Female	28.9	6.9	23.9	23.9
Age, years (Mean, range)	46.0 (23-75)	44.1 (24-88)	45.6 (23-88)	40.5 (18-68)
European/Pakeha	64.5	70.7	65.9	66.8
Sexuality:				
Gay/lesbian	55.6	76.8	60.2	57.4
Heterosexual	37.4	14.3	32.3	35.6
Bisexual	5.6	7.1	5.9	6.0
Employment status: Employed:	56.4	73.7	61.7	53.0
Residential location: Auckland	53.7	56.9	54.4	50.2
Education: University degree	23.2	43.9	27.7	16.7
Use of treatments:				
Currently taking	68.0	80.7	70.8	64.2
Taken in the past	7.0	5.3	6.6	21.9
Never taken	25.0	14.0	22.6	13.9
Most recent CD4 count, cells/ $\mu$ L (Median)	487.5	405.0	480	445
Most recent viral load copies/ml (Median)	Undetectable	Undetectable	Undetectable	371.2
Most recent viral load undetectable (%)	60.4	77.3	63.7	55.9

Year tested HIV positive	Paper	Online	Combined	Futures NZ1
Before 1985	3.0	-	2.3	17.5
1985-1989	9.9	13.8	10.8	23.1
1990-1994	12.9	15.5	13.5	23.1
1995-1999	23.3	17.2	21.9	28.8
2000-2004	33.2	27.6	31.9	7.5
2005 on	17.8	25.9	19.6	-

We were also interested in the extent to which we were accessing HIV positive people who had participated in previous HIV Futures Surveys and other research projects (see Table 95).

**TABLE 95 Data on previous research involvement**

	Paper	On-line	Combined
HIV Futures NZ1	30.5	29.3	30.3
Australian HIV Futures surveys	2.5	-	1.9
GAPSS 2002	2.5	6.9	3.4
GAPSS 2004	2.5	10.3	4.2
GAPSS 2006	2.5	1.7	2.3
GOSS 2006	2.5	8.6	3.8

### Justification of Study Methodology

HIV Futures is a cross-sectional study of a sample of HIV positive people. A cross-sectional study is one in which a new sample is collected on each occasion. While a proportion of the sample may have completed the previous surveys, the responses for each survey are not formally linked, so that direct comparison between individuals' responses over time is not possible. The cross-sectional methodology was chosen for the following reasons.

The HIV Futures Surveys are anonymous. HIV/AIDS remains a sensitive issue for many PLWHA. Our previous research and that of our colleagues tell us that PLWHA still experience stigma and discrimination. Allowing the survey to be completed anonymously helps to allay PLWHA's concerns that information about their HIV status and the other issues addressed in the survey may be compromised.

The survey is self-complete. This means that PLWHA can complete the survey in a setting that is comfortable and safe for them and in their own time. 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.

Fourth, the population of HIV positive people is constantly evolving. A cross-sectional survey allows us to include newly HIV positive individuals as well as those who have been positive for some time. These groups may have an overall similar experience of living with HIV, but the differences between them can be profound.

There are also certain limitations associated with the recruitment method used. Caution must therefore be exercised in the application of the findings of this research to individuals who are less likely to be included in the sample, such as 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, people who required assistance with translation, 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 are not disadvantaged from entering the study if they are not currently using anti-retroviral therapies or not currently in contact with one of the main HIV treatment providers.

Nevertheless it must be acknowledged that this methodology will never be appropriate for some members of the PLWHA community. This is particularly so for those from culturally and linguistically diverse backgrounds who may be marginalised even within their own communities, and those for whom invisibility is the key to their continuing safety.

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 PLWHA.

## Consultations

A broad range of consultations was undertaken prior to finalising the HIV Futures New Zealand 2 survey instrument. These were conducted with clinical services, HIV services, community based organisations representing broad and specific constituencies of PLWHA and other researchers. Ongoing consultation with these groups and individuals occurred throughout data collection, analysis and report writing.

## 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 least  $\alpha=0.05$ .

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