

HIV futures NZ²

Mate āraikore a muri ake nei (Tuarua)



EXECUTIVE SUMMARY

Below is a summary of findings from the HIV Futures New Zealand 2 Survey conducted in 2007. The survey was a national self complete omnibus survey of the health and well being of people living with HIV/AIDS in New Zealand. The survey was conducted by the Australian Research Centre in Sex, Health and Society in collaboration with the New Zealand AIDS Foundation. Community partners for the project were Body Positive Inc., Te Hauora Takataapui NZAF, the Positive Health Programme at NZAF, Positive Women Inc., the African Health Promotion Programme NZAF, Absolutely Positively Positive, Poz Plus and the Community AIDS Resource Team at Auckland City Hospital.

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ABOUT THE 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 an average 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%).

Note: The analyses from this point forward are divided into two populations. The responses of HIV positive New Zealanders of African descent are analysed separately. 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 below.



Positive Women



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

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.

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Copies of the full report can be obtained by contacting the New Zealand AIDS Foundation or the Australian Research Centre in Sex, Health and Society at La Trobe University. The report is also available online at www.latrobe.edu.au/hiv-futures

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