

HIV futures NZ²

Mate āraikore a muri ake nei (Tuarua)



A GUIDE TO THE REPORT FOR PLWHA

This is a guide to report of the 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.

The HIV Futures New Zealand 2 Survey was funded by the New Zealand Ministry of Health and was supported by funds from the Australian Government Department of Health and Ageing and the New Zealand AIDS Foundation.

The investigators on the study and authors of the report are Jeffrey Grierson, Rachel Thorpe, Marian Pitts, Tony Hughes, Peter Saxton, Jonathan Smith, Eamonn Smythe and Mark Thomas.

WHY THIS SURVEY?

The survey is a way to get some understanding of the current state of health and well being among the HIV positive population of New Zealand. This is a diverse group of people, living different lives and having different experiences of living with HIV. Service providers and health professionals come into contact with certain PLWHA at certain times for specific needs. Having an idea of what the broad spectrum of HIV positive people's lives and experiences are like helps us all put our experience of HIV into perspective. This is why the survey was distributed through many different places, and why the survey asked about a broad range of issues. What we have attempted to capture through this survey is both the diversity of positive lives, and the commonalities in experience.

WHAT'S IN THE REPORT?

The main project report presents the basic findings for each of the areas covered by the survey. The findings are presented as simply as possible- usually in tables giving either the number or percentage of people giving each of the responses to each of the questions. This allows us to see how things are most commonly experienced and the extent of uncommon experience. For example, when we ask about general health, we can see that most people (50%) rate their health as 'good', but we can also see that around 19% rate



Positive Women



their health as 'poor'. At some points in the report we also compare different groups of people where the differences may be important- for example we compare gay men, women and heterosexual men's sexual lives and we compare employed and unemployed people's financial hardship. At other times we compare the findings from this survey to those from other populations- for example we compare income to that of the New Zealand population as collected through the census and we compare use of antidepressants with use in the population collected through other surveys. Often there is no information from the general population to compare these findings with, so we don't know whether the rates among HIV positive people are higher or lower than among other people. The findings are still important and useful though, because they tell us what the needs of positive people are in an absolute sense. The report also includes a section at the beginning that compares the findings of the current study to the one we conducted in 2001.

WHO COMPLETED THE SURVEY?

The HIV Futures New Zealand 2 survey was completed by 261 HIV positive people from across New Zealand. 75% were male, 24% were female, and one person was transgender. 61% were gay men, 23% heterosexual women, 10% heterosexual men, 6% bisexual men, and 0.4% lesbian women. Ages ranged from 23 to 88 years with an average of 46 years.

Most people were New Zealand born (70%) and 90% of spoke English at home. One hundred and seventy two were European/Pakeha (66%), 49 were African (19%), 17 were Maori (7%), nine were Asian (3%) and five were Pacific Islanders (2%).

Note: The analyses presented in the report 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.

WHAT DOES THE REPORT TELL US ABOUT HEALTH ISSUES?

Overall most people with HIV in New Zealand rate their health as 'good (51%) or excellent (27%). Similarly most people rate their overall well-being as 'good' (47%) or 'excellent' (28%). The report includes information on CD4 levels and viral load, diagnosis with HIV related conditions and other health conditions. There is information on hepatitis A, B and C and conditions like lipodystrophy. There is also information on mental health concerns including diagnosis with mental health conditions and prescription of medications for things like depression.

WHAT INFORMATION IS THERE ON TREATMENTS?

Around three quarters of the HIV positive people surveyed are on antiretroviral treatments, and most people are on a combination of three drugs. Around 44% of people on treatments are experiencing some difficulties with the treatments. About one quarter experience some side effects and one quarter have difficulty remembering to take drugs on time. The report includes details about the medications and combinations people are currently using, the difficulties they are experiencing, information about resistance and treatment compliance, and information about people's attitudes around treatment. Generally most people have a positive view of these treatments, but this is tempered by concerns about the harm that may result from long term use or side-effects. There is also a section on treatment breaks. About one third of people had taken a break from treatment at some point, and while this resulted in a greater sense of health and well-being in the



short term, the consequences in terms of CD4 and viral load were often negative. There is also a section on the use of complementary therapies.

WHAT INFORMATION IS PROVIDED ABOUT SERVICES?

The report includes a lot of detail about the health and other services that people with HIV use and where they use them. This information is important for organisations and funding agencies when they are planning the most appropriate services to provide in the future. The information is not used in isolation, but can be combined with findings about people's current circumstances to look at where services are not reaching those in need of them.

Findings about health services includes information on people's primary health care provider for HIV related issues and general issues, and the range of health services they have used recently. Most people see a HIV specialist at an outpatient clinic for HIV specific treatment and a GP for general health care.

There is also information about the use of a broad range of non-health services and ancillary health services and whether these are used at a HIV specific organisation or not.

The report also includes findings about the most important sources of information that people access around HIV treatments and broader issues of living with HIV. These sources include the more formal ones, such as medical practitioners or PLWHA organisations, but also acknowledges the importance of less formal sources like friends, family and other positive people.

WHAT DOES THE REPORT SAY ABOUT THE SOCIAL LIVES OF POSITIVE PEOPLE?

The report covers a lot of areas of life that often neglected in research with HIV positive populations. These are not just about health status and treatments, but are more about quality of life and the impact that HIV can have on many parts of people's lives. The report covers the extent to which people know or are in contact with other people with HIV, both currently and in the past. There is a section on disclosure covering who people have chosen to disclose to and their experience of unwanted disclosure. There is also some information on people's perceptions of the current legal issues around disclosure.

There is information on the most important sources of social support including friends, family, medical practitioners and pets. We also discuss the place that HIV has in people's lives and how far into the future they feel able to plan their lives.

The report discusses sex and relationships, an important aspect of people's lives, and one that can be profoundly affected by having HIV. We discuss issues of condom use in regular and casual relationships, acknowledging the important role of HIV positive people in prevention. We also discuss the ways in which HIV has an impact on people's sex lives and intimate relationships, including issues of disclosure, forming relationships and sexual pleasure.

WHAT DOES THE REPORT SAY ABOUT THE PRACTICALITIES OF DAY TO DAY LIFE?

The survey asked a number of questions about people's housing, employment and finances. These are areas where people's experiences can differ dramatically. The housing section examines the current living arrangements of PLWHA, including who they share their



accommodation with, how long they have lived in their current home, whether they have been forced to move at any point, and whether their housing is suitable. The employment section looks at what people's current work status is, whether this has changed as a result of HIV, the impact that HIV has on their work practices and future prospects. The income section looks at how much people are earning, debt, the degree to which they have financial difficulty in a number of areas and the relationship between financial difficulty and health and well-being.

The report also includes some information on the experience of discrimination- in work, housing, insurance and health services.

WHAT HAPPENS NEXT?

The report is not the end of the story. It now becomes the responsibility of everyone involved in responding to the HIV epidemic in New Zealand to make the best use of these findings. People with HIV have put a lot of time and effort into providing the information in this study, and should expect that their input is treated respectfully and that the issues raised by the report are responded to. Numerous organisations and individuals worked together to make this study successful and they want to see the findings make a positive difference to people's lives. This report now becomes part of the public record. It provides an assessment of how New Zealand has responded to the lives and needs of positive people and a benchmark against which to assess the future response.

Findings are reproduced from:

J Grierson, R Thorpe, M Pitts, A Hughes, P Saxton, J Smith, E Smythe, M Thomas (2008)
HIV Futures New Zealand 2 [Mate āraikore a muri ake nei (Tuarua)], monograph series number 66, The Australian Research Centre in Sex, Health and Society, Latrobe University, Melbourne, Australia.

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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