

research **six** futures

HIV futures six Making Positive Women's Lives Count

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ABOUT THE SURVEY

The HIV Futures research program is the largest of its kind in Australia. It is designed to provide HIV, health and funding agencies and HIV-positive people themselves with a regular and up-to-date picture of the overall health, well-being and social situation of people living with HIV/AIDS (PLWHA).

The Living with HIV team, in collaboration with a broad range of health and community organisations, distributed the HIV Futures 6 Survey nationally in 2008. The survey asked PLWHA about their health; use of antiretroviral, complementary and other treatments; sources of information and support; and, their housing and financial situation. It also asked about sex and relationships, social support, recreational drug use, work and financial situation and future planning. The research team consulted extensively with PLWHA, HIV and health organisations around Australia in order to ensure that the survey was asking the most important questions in the most appropriate and useful way.

This report is a summary of the major findings from the HIV Futures 6 Survey specific to women living with HIV/AIDS in Australia. To ensure the findings presented in this report are representative of the broader population of women living with HIV/AIDS in Australia, the results presented in this report (with the exception of the demographics section) have been weighted against Australian HIV Surveillance data (National Centre in HIV Epidemiology and Clinical Research, 2008). Where relevant, we have also compared the experiences of women with other sub-populations of HIV-positive people: gay/bisexual men and heterosexual men. Any statistically significant differences between these sub-populations have been reported at a significance level of $\alpha=0.05$.

An electronic version of this report can be downloaded from our website, as can the full and brief reports that report the findings of the HIV Futures 6 Survey for PLWHA in Australia overall (see back page for further details).

RESEARCH RESULTS

DEMOGRAPHICS

The HIV Futures 6 Survey was completed by 1106 HIV-positive Australians from all states and territories. Nine hundred and twenty respondents (86.9%) reported that they were gay or bisexual men, 81 respondents (7.3%) identified themselves as women and 58 respondents (5.5%) identified themselves as heterosexual men. The remaining 4.2% of respondents fitted into other categories or did not specify their gender and/or sexuality.

Of the women who responded to the survey, 85.9% identified themselves as heterosexual, 6.4% as lesbian and 7.7% as bisexual. The women ranged in age from 21 to 74 years with a mean age of 44.4 years and a median age of 43.5 years. Over one quarter (28.7%) of women were born in countries other than Australia. Three (3.7%) women were of Aboriginal/Torres Strait Island origin.

One third (33.8%) of women lived in a capital city/inner suburban area, while 22.5% lived in an outer suburban area, 31.3% in a regional centre and 12.5% in a rural area. Women and heterosexual men were less likely than gay/bisexual men to live in a capital city/inner suburban area, but more likely to live in an outer suburban or regional area (64.7% of gay/bisexual men lived in a capital city/inner suburban compared to only 32.1% of heterosexual men and 33.8% of women).

IDENTITY

Just over half of the women (57.4%) reported that their HIV status was important to their identity; 13.0% of women said that it was essential to their identity. There was no statistically significant difference in the role that HIV played in the identity of gay/bisexual men, heterosexual men and women; however, more heterosexual men rated their HIV status as being essential to their identity (25.4% of heterosexual men versus 18.4% of gay/bisexual men and 13.0% of women).

Parenthood, family and religion were more important to the identity of women than gay/bisexual and heterosexual men. In contrast, sexuality and gender were more important to the identity of gay/bisexual men than heterosexual men and women.

HEALTH AND HIV

Participants were asked about their diagnosis experience, their general health and well-being, as well as the impact of HIV on their health.

HIV Antibody Testing

The national HIV testing policy guidelines (Department of Health and Ageing, 2006) recommend individuals undergoing HIV testing receive pre- and post-test counselling. Only 17.0% of women reported that they had received pre-test counselling (21.6% of those testing positive in the last two years), while 55.2% received post-test counselling (78.7% of those testing positive in the last two years).

Current Health Status

More than two thirds (71.7%) of women rated their health as good or excellent. A lower proportion of women (56.8%) rated their general well-being as good or excellent. Women and gay/bisexual men were more likely than heterosexual men to rate their health as good or excellent (71.7% of women and 74.0% of gay/bisexual men rated their health as good or excellent versus only 59.7% of heterosexual men).

Almost all women had taken a CD4/T-cell test and a viral load test to monitor their HIV infection.

Health Conditions in Addition to HIV

Just over one quarter of women (26.3%) had been diagnosed with an AIDS-defining illness, 4.5% in the last two years; 26.2% of women also indicated that they had experienced HIV-related illnesses. More than a third of women (40.9%) indicated that they had a major health condition other than HIV/AIDS.

The most common major health conditions reported were depression (11.2% of women), hepatitis C (8.5%), cardiovascular disease (7.4%), diabetes (6.7%) and cancer (3.6%). There were no differences in the proportion of gay/bisexual men, heterosexual men and women reporting an AIDS-defining illness, HIV-related illness or other major health condition.

Half of the women (49.3%) reported that they had undergone sexual health screening in the 12 months prior to the survey: 6.6% of women said they had been diagnosed with an STI in the previous 12 months.

Mental Health

In the last six months, 28.4% of women had taken prescribed medication for depression and 26.5% for anxiety. Over one third of women (41.9%) reported that they had been diagnosed with a mental health condition at some point: 37.7% had ever been diagnosed with depression, 9.1% in the last two years. There were no differences in the proportion of gay/bisexual men, heterosexual men and women reporting a diagnosis of a mental health condition or use of psychiatric medications in the last six months.

Viral Hepatitis

Around one in ten women (11.7%) had at some point had hepatitis A; 59.2% had been vaccinated against hepatitis A.

A small proportion of women (4.9%) had at some point been diagnosed with hepatitis B, of whom 74.3% had cleared the infection and 25.7% had an ongoing infection.

Almost one quarter of women (22.1%) said they had tested positive for hepatitis C; 27.8% of those with hepatitis C had ever had medical treatment for this.

There were some differences in the likelihood of being diagnosed with hepatitis A, B and C between the three sub-populations of HIV-positive people. Men in general were more likely to have ever been diagnosed with Hepatitis B (25.3% of gay/bisexual men and 23.1% of heterosexual men versus 4.9% of women), while gay/bisexual men specifically were more likely to have ever been diagnosed with Hepatitis A (26.1% of gay/bisexual male respondents versus 11.1% of heterosexual men and 11.7% of women). Women and heterosexual men were more likely than gay men to have ever been diagnosed with Hepatitis C (24.6% of heterosexual men and 19.0% of women versus 10.9% of gay/bisexual men).

TREATMENTS

Antiretroviral Therapy

Over three quarters of women (77.7%) were currently using ARV, with 89.4% of women having used ARV at some time. Most women were taking a combination of two to four ARV drugs: 21.2% were using two drugs, 39.6% of women were using three ARV drugs and 18.8% were using a combination of four drugs. Over half of the women currently taking ARV (57.4%) were taking ARV twice daily; 41.2% were taking ARV once a day.

Of those currently using ARV, 62.7% of women were using at least one nucleoside reverse transcriptase inhibitor, 50.6% were using at least one protease inhibitor, 46.3% at least one non-nucleoside reverse transcriptase inhibitor and 45.2% at least one nucleotide analogue reverse transcriptase inhibitor. Only 3.2% of the women currently taking ARV were using agents from newer drug classes (integrase and fusion inhibitors).

Nearly half of the women currently taking ARV (45.3%) reported that they experienced difficulties taking ARV, of which the major problems were: remembering to take the drugs on time (18.7%), taking a large quantity of tablets (17.7%) and side effects (16.8%).

Side effects continue to be experienced by most women taking ARV. Of the most common adverse events experienced by people taking ARV, 82.2% of women reported low energy or fatigue, 62.9% experienced a sleep disorder, 54.1% experienced diarrhoea, 53.1% experienced nausea, 42.5% had raised cholesterol/triglycerides, 37.6% experienced confusion or memory loss, 28.0% experienced weight loss and 22.5% reported experiencing lipodystrophy or lipoatrophy in the past 12 months.

Three quarters of women (77.7%) believed that combination antiretroviral drugs mean better prospects for PLWHA, while only 7.4% believed that it is still too soon to tell. Almost half of the women (45.3%) believed that combination antiretroviral drugs are harmful and 32.7% believed that the side effects outweigh the benefits of antiretroviral drugs.

Women were significantly more likely than men to believe that combination antiretroviral drugs are harmful. At the same time, women were also more likely to believe that HIV-positive people should start taking antiretroviral drugs as soon as possible and that combination antiretroviral therapy will stop them dying of AIDS.

Almost half (42.5%) of the women currently on ARV had taken a break from treatment at some point. The median length of the break was nine months. There was no statistically significant difference in the proportion taking a break or the length of break taken by the sub-populations. Doctors were less likely to be consulted before a break than during or afterward, however, 33.2% of women saw their doctor before, during and after the treatment break. There were no differences in the proportion of gay/bisexual men, heterosexual men and women who consulted their doctor before, during or after a break.

Complementary Therapies

Complementary therapies tended to be used in conjunction with allopathic treatment. Vitamin and mineral supplements were used by 68.2% of women, 18.6% of women used herbal therapies and 21.5% used marijuana for medicinal purposes. Women, followed by gay/bisexual men were significantly more likely than heterosexual men to use certain complementary therapies in the past six months, specifically vitamins, meditation and massage.

SERVICES

Health Services

For HIV-specific treatment, 49.3% of women saw an HIV specialist/physician and 19.3% saw an HIV GP/S100 prescriber. For general health care treatment, 45.1% saw a non-HIV GP and 16.4% of women saw an HIV GP/S100 prescriber. For 59.3% of women these were different doctors.

Women and heterosexual men were less likely than gay/bisexual men to see an HIV GP/S100 prescriber for their HIV treatment (19.3% of women and 18.2% of heterosexual men versus 45.5% of gay/bisexual men) or general medical treatment (16.4% of women and 15.6% of heterosexual men versus 46.9% of gay/bisexual men). Women and heterosexual men were more likely to see a HIV specialist for their HIV-specific treatment (49.3% of women and 56.1% of heterosexual men versus 32.9% of gay/bisexual men) and a non-HIV GP for their general medical treatment (45.1% of women and 39.1% of heterosexual men versus 24.7% of gay/bisexual men). This difference in service use can be partly explained by differences in the areas where women, heterosexual men and gay/bisexual men live; however, there also appears to be a difference in preference between women, heterosexual men and gay/bisexual men for the different health professionals available to meet the healthcare needs of PLWHA.

Other Services

The services available at AIDS organisations most often used by women were peer support (42.7% used formal peer support and 30.8% used informal peer support), social contact (42.8%), treatment advice (42.7%), financial assistance (41.3%) and treatment information (35.9%). Women were significantly more likely than men to use financial assistance, peer support and social contact services at HIV/AIDS organisations, indicating that these services still play an important role in the lives of women living with HIV/AIDS.

Information Sources

Only a small number of women (approximately 20% of all female respondents) advised us about their most important sources of information on treatments/HIV management and living with HIV.

Of the women who did respond, the most important sources of information about treatments/HIV management were HIV specialists, sexual health centres, AIDS council staff (treatment-specific and other staff) and HIV-positive friends.

The most important sources of information on living with HIV were HIV-positive friends, tailored PLWHA organisations (e.g., positive heterosexual organisations), the internet, HIV magazines and other unspecified information sources.

The most important sources of information for men and women generally included a combination of health professionals, HIV/AIDS organisations and other sources such as the internet and HIV-positive friends.

Publications

The following publications were most accessed by women: *Positive Living* (National; 54.2% of women), *Talkabout* (43.4%), *HIV Australia* (36.3%) and newsletters from community organisations (29.2%). Gay/bisexual men were more likely than heterosexual men and women to access gay magazines (as expected) while women were more likely to access community organisation publications containing HIV information (27% of women versus 20.6% of heterosexual men versus 15.8% of gay/bisexual men).

Involvement with AIDS Organisations

79.2% of women had some contact with HIV/AIDS organisations, mostly receiving newsletters or being clients of these organisations. 10.3% were employees of HIV/AIDS organisations.

THE SOCIAL WORLD OF WOMEN LIVING WITH HIV/AIDS

Contact with Other PLWHA

Most women (85.6%) knew another person with HIV: 14.4% had a spouse/partner with HIV; 59.7% had acquaintances with HIV; 56.2% spent at least some time with other PLWHA; 19.8% had been involved with the care of someone with HIV/AIDS in the last two years and 55.4% said someone close had died of AIDS-related causes. Women and heterosexual men were less likely than gay/bisexual men to spend time with other HIV-positive people or know someone who had died of HIV/AIDS.

Disclosure

Almost all women (96.1%) had disclosed their HIV status to at least one person, generally partners, close friends and family. For 73.6% of women, their HIV status had been disclosed to another person when they did not want it to be (31.2% in the last two years). Women were more likely to experience unwanted disclosure in the last two years, with 21.8% of gay/bisexual men and 17.5% of heterosexual men reporting unwanted disclosure in the last two years.

Social Support

The most important sources of social support for women living with HIV/AIDS were partners/spouse, pets, family and health care workers.

Relationships and Sex

Almost half of the women living with HIV/AIDS (42.2%) had not had sex in the past six months, while 52.9% of women were in a regular relationship. Of the women in a regular relationship, 32.1% had a partner who was also HIV-positive.

In the past six months, 91.9% of women in a regular relationship had anal or vaginal intercourse with a regular male partner and 10.9% had anal or vaginal intercourse with a regular female partner. Condom use with regular partners was strongly related to the HIV-status of the partner.

Only a small number of women (7.5%) had sex with casual partners in the past six months. Condoms were used in nearly all cases of anal or vaginal intercourse with a casual partner.

Women were less likely than gay/bisexual men but more likely than heterosexual men to have had sex in the last six months (57.5% of women versus 73.3% of gay/bisexual men versus 38.8% of heterosexual men). Women and heterosexual men were more likely to have stopped having sex due to their HIV status.

Around a third of women (30.8%) would prefer to be in a relationship with someone who is also HIV-positive. Women and heterosexual men showed a weaker preference than gay/bisexual men for having a partner who is HIV-positive, with 55.2% of gay/bisexual men preferring a HIV-positive partner.

Almost two thirds of women (60%) expressed some fear of rejection from potential partners if they tell them of their HIV status. The majority of women (66.2%) felt HIV had a negative effect on their sexual pleasure.

Only 17% of women agreed with the statement "I feel more confident about unprotected sex because of the new treatments".

Less than a quarter of women (22.1%) agreed that undetectable viral load means HIV is unlikely to be transmitted. However, 28.4% of women agreed with the statement “If there was a vaccine which prevents HIV I would not practice safe sex”.

38.3% of women agreed with the statement, “I am worried about disclosing my HIV status to sexual partners because of the current legal situation”; 18.3% expressed some concern about the legal implications of disclosure of sexual practices to service providers.

Children

Almost two thirds of women (61.1%) had children. Of these women, 57.9% had at least one dependent child and 7.9% were also pursuing plans to have another child.

Of the women without children, 20.6% were pursuing plans to have children, 5.9% had thought about having a child but had not decided, 8.8% had decided it was too risky and 61.8% were not considering having a child. The majority of women who did not have children and were not considering having a child were older women (73.9% were 40 years of age or older and 43.5% were 45 years of age or older), which may in part explain why these women were not considering having children. Women with children were no more likely than women without children to be in a regular relationship.

Women and heterosexual men were more likely than gay/bisexual men to have or live with children: 61.1% of women and 56.5% of heterosexual men had children versus 7.8% of gay/bisexual men. In addition, a higher proportion of men who did not already have children (90.2% of gay/bisexual men and 84.6% of heterosexual men) were not considering having children.

Recreational Drug Use

Respondents were asked which of a number of commonly-used substances they had used in the last 12 months: 47.3% of women had used alcohol, 36.3% smoked cigarettes and 25.3% had used marijuana for recreational purposes. Other substances (crystal meth, amyl, prescribed methadone, heroin, non-injected cocaine, ecstasy and speed) were used by only a small minority (<10%) of women. A quarter of the female respondents (26.6%) reported no recreational substance use in the past 12 months.

Approximately one quarter of women reported having missed a dose of ARV at some point as a result of using illegal drugs and 4.0% reported having had a bad experience as a result of using both illegal drugs and ARV.

HOME, WORK AND MONEY

Accommodation

Over one third of women (37%) were in private rental accommodation, 31.8% owned or were purchasing a house or flat, 13.5% were in public rental accommodation (government owned) and 7.5% were in community housing/housing co-operative.

A quarter of women lived by themselves, 34.8% lived with a partner/spouse, 75.1% lived with children (50.5% lived with one child, 19.1% lived with two children and 5.5% lived with three children) and 64.9% lived with pets.

A third of women (33.6%) had ever changed their accommodation as a result of having HIV/AIDS and 6.7% had done so in the last two years. Most women (84.1%) had access to a car.

Employment

Just over half of the women were currently in paid employment (52.0%), the majority being in part-time work (38.5% of women). The majority of the remainder described their employment situation as either home duties or not working/retired. Women and heterosexual men were less likely than gay/bisexual men to be in full-time work (20.0% of women and 23.4% of heterosexual men versus 40.0% of gay/bisexual men). Women were more likely to be in part-time work (38.5% of women versus 15.3% of gay/bisexual men and 12.5% of heterosexual men). Heterosexual men were the most likely to be unemployed (17.2% of heterosexual men versus 9.0% of gay/bisexual men and 2.5% of women).

Just under three quarters of women (71.3%) said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis.

Around half of the women 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 have had to reduce their work hours.

Nearly half of the women currently in work (47.9%) had not disclosed their HIV status to anyone at their workplace, while 24.0% did not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work were difficulty keeping and taking medication and visible signs of illness.

Finances

Over a third of women (40.2%) identified their main source of income as a government benefit or pension. At least half of the female respondents reported experiencing some difficulty with meeting the cost of daily living: 81.2% had difficulty paying for housing costs; 80.2% expressed difficulty paying for the cost of utilities; 83.7% had difficulty paying for clothing; 64.8% for food; 63.2% for transport; 80.7% had difficulty paying for entertainment and 90.5% had difficulty paying for holidays.

Across almost all living costs, a significantly greater proportion of women and heterosexual men than gay/bisexual men reported difficulty meeting the costs of daily living. A greater proportion of women and heterosexual men reported difficulty meeting the costs of HIV medication co-payments, other prescribed medication, medical services, complementary therapies, going out, housing costs, utilities, food and transport. A greater proportion of women than both gay/bisexual and heterosexual men reported difficulty paying for medical services, complementary therapies, entertainment, sporting activities, travel/holidays, housing costs and clothing.

Almost half of those on a government benefit (42.3%) had been assessed by a Commonwealth Medical Officer in the past two years. While this resulted in termination of benefits or change in conditions for few respondents, it caused distress for 32.7% of women assessed.

Poverty

Half of the women (49.6%) were living below the poverty line. Just over one quarter of women have a partner with whom they share financial resources and this protects some from extreme economic hardship. Those respondents earning an income from paid employment were much less likely to report incomes below the poverty line (31.8% of those in paid employment versus 71.4% of those not in paid employment) whereas 83.3% of women on government benefits were living in poverty.

Women and heterosexual men were more likely than gay/bisexual men to be living below the poverty line (48% of women and 43.8% of heterosexual men versus 27.5% of gay/bisexual men). It appears that this difference is due to the greater proportion of gay/bisexual men in full-time employment and higher weekly after-tax incomes.

Discrimination

Almost half of the women (47.1%) experienced less favourable treatment because of HIV in relation to health services, 25.7% in the last two years. Women were more likely than men to experience health service discrimination in the last two years with only 8.1% of gay/bisexual men and 10.4% of heterosexual men reporting health service discrimination in the last two years.

A much smaller proportion of women experienced less favourable treatment in relation to accommodation (14.5% in total and 4.6% in the last two years) or insurance (7.4% in total). There were no statistically significant differences in the proportion of women and men experiencing discrimination in relation to accommodation or insurance.

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This and other reports from the HIV Futures 6 Survey are available for download from our website: www.latrobe.edu.au/hiv-futures

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The Living with HIV Program

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. The HIV Futures Studies are funded by the Australian Government Department of Health & Ageing.

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