



PositiveWomen

Support and advocacy for women living with HIV

Submission to the Victorian Gender Equality Strategy

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Positive Women

Support and advocacy for women living with HIV

Introduction

Positive Women Victoria welcomes the opportunity to have input into the development of a gender equality strategy for Victoria. As Australia's only community-based organisation specifically funded to support women living with HIV, since 1988 Positive Women Victoria has continually provided support and advocacy to all women living with HIV in Victoria and around Australia.

Positive Women's approach is based on delivering peer support and advocacy within an overarching health promotion framework. In providing peer support to women living with HIV, we see every day the impacts of women's engagement with a gendered social system. Superimposed on this are the challenges these women face as a result of living with HIV and for around two thirds of newly diagnosed women in Victoria, the additional impacts of cultural, sexual and or linguistic diversity.

In advocating for women living with HIV we are working at the individual, community, system and societal levels to have the unique and specific needs of women living with HIV recognised in the context of a health condition that predominantly affects men who have sex with men. Our advocacy efforts are most often targeted at overcoming the stigma and discrimination faced by women living with HIV as they engage with a gendered social system.

Positive Women endorses the submissions to the gender equality consultation made by the Women's Health Association of Victoria (WHAV) and Women's Health Victoria (WHV). Positive Women Victoria is an Associate Member of WHAV and its goals align with the WHAV goals of ensuring equity in health outcomes for women and men and also to achieve equality in outcomes for all groups of women, including women living with HIV.

Positive Women Victoria supports the underpinning fundamentals outlined in the WHAV submission to the gender equality consultation including that gender equality:

- Generates productivity, prosperity and good health
- Is at the core of social and economic wellbeing
- Will be achieved through gender transformative practice
- Will be achieved through intersectionality and inclusivity
- Is a long term goal requiring leadership, expertise and coordination.

Background

Since Positive Women Victoria was established in 1988, the HIV epidemic has evolved from being an almost certainly fatal illness to a virus that, for many, is now a manageable chronic condition. In fact, the change in the epidemic has been so dramatic that we are now envisaging a society that within just a few years, may have no new HIV transmissions.

At a population level, this is, of course, great news. But for the women who are continuing to contract the virus now as well as for those who have been living with the virus for almost three decades since the first reported cases appeared in Australia, the news is less heartening. The stigma, misunderstanding and discrimination that have surrounded the HIV epidemic since the beginning, have not improved at the same pace as clinical progress has been made. In 2016, stigma and discrimination pose greater threats to the wellbeing of people living with HIV than the virus itself. And for women, wellbeing is further compromised by a gender crisis within our broader society, the extent of which is only now becoming apparent to us as a community.

The experience of living with HIV is distinctly different for women than men. The modes of HIV transmission, biological susceptibility, geographical accessibility, socioeconomic status, testing patterns, service use, health seeking behaviours, perceptions of risk and attitudes towards treatment are so markedly different for women than for men that we are almost talking about a different epidemic.

As a minority population within a cohort predominantly comprised of men who have contracted the virus through sexual activity with other men, women tend to be overlooked in the HIV response in Australia. This impacts on HIV prevention, testing, treatment and research and ultimately on the health and wellbeing of women living with HIV in Australia.

Demographic profile – women and HIV

- As at December 31st 2014, there were 556 women estimated to be living with HIV in Victoria
- 3000 of the 27,000 people living with HIV in Australia are women¹
- Almost 50% of women living with HIV are estimated to be living below the poverty line²
- 74% of women living with HIV have experienced unwanted disclosure of their HIV status at some time⁴
- Women are likely to be diagnosed later than men when HIV has already had a significant impact on their health⁴
- Most women are diagnosed during their reproductive years, adding further complexity to their experience of HIV⁴
- Around two thirds of women in Victoria who are newly diagnosed with HIV come from sub-Saharan Africa or Asia

Research and data

- Despite proven sex and gender differences, women continue to be underrepresented in national and international HIV clinical trials and gender analyses in the published HIV literature³
- Epidemiological approaches to research overlook the social impact of the gendered experience of HIV
- Women from indigenous and CALD backgrounds are further under-represented in observational HIV studies⁴

¹ The Kirby Institute. (2014). *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014*. The Kirby Institute, University of New South Wales, Sydney.

² Koelmeyer, R., McDonald, K., Grierson, J. (2012). Beyond the data: Distinct features and experiences of women living with HIV in Australia. *HIV Australia, Vol. 9, No. 4*, 8–10.

³ Heidari, S., Eckert, M. J., Kippax, S., Abdool-Karim, Q., Salif-Sow, P., Wainberg, M. A. (2011). Time for gender mainstreaming in editorial policies. *Int AIDS Soc., Vol. 14, No. 11*. Published online 2011 Mar 8. doi: 10.1186/1758-2652-14-11 PMID: PMC3059266

⁴ Power, J. (2015). Australian women and the 90-90-90 targets: what does the data tell us? *HIV Australia, Vol. 13, No. 1*.

Policy

- Women are not identified as a priority population in Australia's National HIV Strategy⁵
- As the national strategy informs research and data collection priorities, the lack of application of a gendered lens inevitably results in gender-based gaps in our knowledge of women's experiences of living with HIV
- It is upon this partially obscured body of knowledge that policies and strategies are based and priority populations identified and so the cycle continues with HIV in Australia

HIV policy and women

Australia's 7th National HIV strategy

Australia's HIV response is guided at a Commonwealth level by the Seventh National HIV Strategy, one of five national strategies that set the direction for a coordinated, national response to HIV, hepatitis B, hepatitis C and sexually transmissible infections. The strategy creates an environment for Australia to reverse the increasing trend of new HIV diagnoses and works towards the virtual elimination of HIV transmission by 2020.

The goals of the *Seventh National HIV Strategy 2014–2017* (the Strategy) are to:

- Work towards achieving the virtual elimination of HIV transmission in Australia by 2020
- Reduce the morbidity and mortality caused by HIV
- Minimise the personal and social impact of HIV.

Eight priority populations upon which the work of the HIV sector will be focused are identified in the strategy. Whilst women are a subgroup of seven of these eight priority populations they are not identified as a priority population in their own right. As a consequence, the national strategy is strongly focused on approaching the epidemic as it relates to men and almost entirely overlooks the unique experience of women living with HIV. Australia's national HIV strategy is a stark example of gender blind policy making in action and the implications of this for women living with HIV are significant.

As the National Strategy informs research and data collection priorities, funding allocation and development of state strategies the omission of women as a priority population has a number of consequences. These include:

- Women are underrepresented in HIV clinical trials with few clinical trials dedicated to examining issues that are unique to women living with HIV
- Reporting of gender disaggregated surveillance data is minimal and a complete picture of women's experiences of living with the virus is therefore lacking
- As state HIV strategy development is influenced by the Commonwealth policy, this gender blind policy approach flows through to the HIV response in every Australian health jurisdiction.

Significantly, by continuing to omit the unique experiences of women living with HIV from the national narrative we not only fail in our duty of care to support living with HIV, we risk failing to achieve the 90:90:90 targets for new HIV transmissions.

⁵ Australian Government Department of Health. (2014). *Seventh National HIV Strategy 2014-2017*. Commonwealth of Australia, Canberra.

Strategic directions for HIV in Victoria (currently in draft form)

This yet to be released Strategy was developed by the Victorian Department of Health and Human Services (DHHS) in consultation with the HIV sector throughout 2015. In developing these strategic directions, DHHS was clear that it would be aligning these strategic directions with the National Strategy. The most recent version of the draft strategy reviewed by Positive Women aligns with the National Strategy's priority areas for action: prevention; testing; management care and support; workforce; enabling environment; surveillance, research and evaluation and is aimed at reaching the goal of no new HIV diagnoses by 2020.

Overall the strategy is weighted towards the priority populations identified in the National HIV strategy, particularly men who have sex with men and like the national strategy, does not take into consideration the specific and unique needs of women including women from culturally and sexually diverse backgrounds.

The Prevention activities outlined in the Strategy are heavily focused on pre-exposure prophylaxis (PrEP). The focus on this approach to prevention is problematic for women as women are significantly under-represented in current Australian research trials into PrEP and the benefits of PrEP for women in reducing HIV infection rates within the Australian context are as yet unclear. A heavy reliance on PrEP as a means of achieving the goal of reducing new HIV transmissions by 2020 potentially does not take into account the subtle and complex differences between modes of transmission, biological susceptibility and treatment efficacy between men and women.

Beyond prevention, the testing section of the strategy fails to consider specific issues effecting women, the major one of which is that women tend to be tested for HIV later than men, leading to later diagnosis, delayed commencement of treatment and women being more unwell once treatment does commence. Further complicating this is that women are often diagnosed during their reproductive years which adds to the complexity of the treatment picture in women.

Management care and support focuses on service coordination and continuity of care and as with the rest of the Strategy, does not adopt a gendered or cultural lens. The research section fails to address the low participation of women in HIV research both within Australia and globally and does not propose any actions for redressing this.

As this strategy is still in development phase, Positive Women has and will continue to encourage the Victorian Government to incorporate a gender transformative approach to finalising the statewide strategic directions for HIV.

Broader policy environment

Beyond HIV policy, almost every public policy impacts on the lives of women in some way and therefore on the lives of women living with HIV. Positive Women endorses a shift from gender unequal and gender blind policy and programs (which wrongly assume and reinforce the notion that policy is gender neutral) towards gender transformative policies that recognise and respond to the differences between women and men, particularly with regard to the lived experience of HIV.

We concur with the WHAV submission that achieving sustainable gender equality will require an appropriate gender equality architecture within government. It will require partnerships across the whole community in order to succeed. Achieving gender equality will entail increasing the role of

women in leadership, improving women's economic and labour force equality and women's health and wellbeing.

Conclusion

Positive Women Victoria endorses the submissions to the Victorian Gender Equality Strategy consultation made by WHV and WHAV. Further, we have outlined an example of gender blind policy development that has profound implications for women living with HIV in Victoria and flows through from the national to the state level. We have developed some recommendations for addressing the current levels of gender inequality in Victoria.

Recommendations

The following recommendations are targeted at the Victorian Government as action areas for improving gender equality as it applies to the HIV response:

1. Review the draft strategic directions for HIV in Victoria to identify women as a priority population so that the specific needs of this population can be taken into account
2. Partner with community HIV agencies such as Positive Women Victoria, to advocate for the inclusion of women as a priority population in the eighth National HIV Strategy
3. Facilitate the dissemination of gender disaggregated HIV surveillance data to all HIV community, clinical and other services so that evidence on the needs of women living with HIV is available to inform service development and delivery
4. Partner with relevant research institutes and community HIV agencies to develop a Victorian HIV surveillance data-set that is specifically tailored to measure the unique impacts of HIV on women
5. Commit to the development of gender transformative policies in all areas of Victorian public policy
6. As highlighted by WHAV, prioritise the following urgent areas for the focus of gender inequality redress:
 - a. Women living with HIV and women who are culturally, sexually and linguistically diverse
 - b. Women's civic and political participation and leadership;
 - c. The prevention of violence against women;
 - d. Improved sexual and reproductive health for Victorian women.