

WOMEN, HIV AND LIFE

National Day of Women Living with HIV 2019

MARCH 2019

Acknowledgements

Positive Life NSW¹ in partnership with Femfatales² thanks the women who contributed their thoughts, knowledge and experience at the 2019 National Day of Women living with HIV in Sydney.

Further information

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PositiveLifeNSW
the voice of people with HIV since 1988

1. Positive Life NSW is the state-wide peer led organisation representing and advocating for all people living with HIV (PLHIV) in New South Wales (NSW).

2. Femfatales (the National Network of Women living with HIV) is an advisory group, constituted to provide collaboration between those involved in policy and advocacy work for women living with HIV (WLHIV) in Australia.

Executive Summary

The National Day of Women Living with HIV (NDWLHIV) celebrated women living with HIV (WLHIV) as a community event and proved to be a valuable engagement to highlight existing issues of concern and unmet needs of WLHIV in Australia.

Australian WLHIV are a diverse population and come from all different ages, ethnicities and sexualities. The experience of living with HIV is different for women than it is for men. Examples are seen in terms of the female body and experiences with anti-retroviral treatments, hormones, HPV-related and breast cancers and reproductive health including pregnancy, childbirth, menstruation, contraception and breastfeeding. There are also more invisible experiences that WLHIV face which include mental health, domestic violence, stigma and discrimination, cultural and familial influences, isolation and intersectionality. It is only when we understand these differences that we can apply them to areas of health policy, programs, service delivery and research, to begin to address issues and unmet needs which affect WLHIV in their everyday lives.

This National Day attracted a range of empowered, articulate WLHIV for whom the conversation was remained focused on the relative absence of WLHIV from the national discourse and dialogue around HIV in Australia. WLHIV continue to be a marginalised and relatively invisible group in Australia. This inequality has major impacts on the mental and physical wellbeing of WLHIV as well as public health policy and service delivery in Australia, the silence and secrecy that feeds a climate of stigma and discrimination, as well as an assumption that HIV is simply not an issue for women.

WLHIV today

Internationally women account for 52% of all adults living with HIV³. However within Australia, the majority of PLHIV are gay and bisexual men (GBM) with an estimated 3,000 (10%) of people living with diagnosed HIV in Australia being women. Women have had a long history of being left out of the Australian HIV focus and still today are not listed as a priority population within both the *NSW HIV Strategy 2016–2020*⁴ or the recent *Eighth National HIV Strategy 2018–2022*.⁵ Therefore the Australian focus within HIV education and research has been seen to sit mainly within the communities of GBM.

While great advances through advocacy, education and resourcing of the Australian GBM communities has led to successful outcomes of an overall decrease in HIV notifications, in 2017 Australia saw a rise in the rate HIV notifications among people who have heterosexual sex. Unlike the decrease seen among GBM communities, HIV notifications among non-indigenous women, Aboriginal and Torres Strait Islander women and women from culturally and linguistically diverse (CALD) backgrounds have remained the same. HIV awareness is not getting out to all our populations and women are at increased risk of late and under diagnosis. Women often miss out on accessing correct screening and care in a timely fashion, despite advancements in treatment and prevention. Listening to the voice of WLHIV about what needs to be done to improve our lives is vital. At this year's NDWLHIV we heard positive themes of empowerment, strength and resilience as strong headlines, yet at the same time women shared challenging realities of isolation, stigma, loneliness and invisibility. Contributors to the conversation through the word-cloud offered powerful themes of resilience with words such as 'unity', 'inclusion', 'strong' and 'love' at the same time as the more challenging themes of 'domestic violence', 'fear' and 'safety'.

3 UN Women, Facts and Figures: HIV and AIDS, 2018 <<http://www.unwomen.org/en/what-we-do/hiv-and-aids/facts-and-figures>> [accessed 4 April 2019].

4. NSW Ministry of Health, NSW HIV Strategy 2016–2020, 2015 <<http://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2016-2020.PDF>> [accessed 2 April 2019].

5. Australian Department of Health, Eighth National HIV Strategy 2018–2022, 2018 <[http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/\\$File/HIV-Eight-Nat-Strategy-2018-22.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/$File/HIV-Eight-Nat-Strategy-2018-22.pdf)> [accessed 2 April 2019].

Strategies of response

A range of responses and recommendations from this NDWLHIV could be summarised:

- Agencies represented at this NDWLHIV event continue to advocate that women, particularly heterosexual populations, be named as a priority population in the *Australian National HIV Strategy*.
- Individual and agency advocates continue to press for HIV testing as a routine standard in women's sexual health checks across Australia.
- Researchers need to prioritise direct engagement with WLHIV in order to address the paucity of research into the reproductive health of WLHIV, as well as the psychological issues for WLHIV in relation to reproduction and family life.
- Positive Life NSW, Femfatales and other HIV sector agencies must continue to maintain engagement with the ongoing *HIV Futures* surveys and work to increase awareness and participation in this body of research to ensure the inclusion and relevance of the lives of WLHIV in Australia are represented and prioritised.
- Advocates, both individual and organisational, continue the conversation around the needs of WLHIV and advocate in ways that are unified and responsive to the specific needs of WLHIV to improve the health outcomes for WLHIV.

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On Saturday 9 March 2019, Positive Life NSW (PLNSW) and Femfatales collaborated to celebrate the National Day of Women living with HIV (NDWLHIV) at a morning tea in Camperdown, Sydney NSW. This event attracted approximately 31 people from a range of genders and sexualities, including women, men and gender diverse people, people living with HIV (PLHIV) community members, HIV service industry personnel, researchers and other sector representatives.

The room was laid out with a mixture of chairs in rows along with high bar stools surrounding circular tables with the aim of encouraging inclusion, discussion and contributing to the free-flowing conversation and discussion among participants. The event was held at the Camperdown Commons, an inviting organic urban community farm and restaurant environment accessible via public transport (buses, Uber, taxi, bikes).

PLNSW Treatments Officer, Maxine Lewis and Femfatales Sydney member, Jane Costello welcomed attendees to share their thoughts, experiences and impressions, and spoke about the themes of the National Day, including safeguards for individuals and group agreements regarding confidentiality and maintaining a 'safe space' for disclosure. This was followed by a *Welcome to Country* by Aunty Ann Weldon.

Positive Life Communications and Policy Officer, Bella Bushby offered a brief outline of the Mentimeter tool www.mentimeter.com and Jane introduced Femfatales' theme for this year's National Day and spoke about the work of Femfatales. Jane also introduced the #LeaveNoOneBehind campaign, which is a national social media campaign between Femfatales, the National Association of People with HIV Australia (NAPWHA) and ViiV Healthcare Australia to raise awareness and show support to the more than 3000 Australian women living with HIV (WLHIV) and posed the first question of the forum: *What do you think living with HIV means for women today?*

Participants were invited to offer as many words, as many times without restriction throughout the forum to populate a Word Cloud. 62 responses were received in total which is an average of two entries per person

[illegible]

Jane introduced the guest speaker, Associate Professor Kathy Petoumenos from the Kirby Institute. Kathy posed the second question of the forum: *What things do you think would be important to research for women living with HIV?* She briefly spoke about current and potential future research, with WLHIV as front and centre in the design and implementation of research, and the importance of this engagement to benefit WLHIV.

[illegible]

Once again, Maxine reflected on the overview of results from the second Mentimeter question along with various members of the audience as she opened the floor up for discussion. The main theme that was raised by the audience was the topic of mental health for WLHIV. This example is reflected in the 2017 *HIV Futures 8 – Women Living with HIV in Australia* data which saw that within the sample of WLHIV surveyed, 41.7% said they had been diagnosed with a mental health condition within their lifetime. This highlights that WLHIV experience higher rates of mental health conditions compared to 19.2% of all women in Australia reporting having a mental condition.⁶

Other themes of ‘disclosure’, ‘stigma’, along with ‘ageing’ and ‘pregnancy’ soon proved to be major topics contributed by participants. Discussion evolved to focus on issues of ‘quality of life’ and ‘domestic violence’. Kathy Petoumenos addressed some questions regarding research

in relation to women’s inclusion in research and some of the parameters that appear to have restricted or influenced women’s participation and representation in research.

Around this time some of the discourse evolved into a community-based discussion about women’s involvement in the sector, education of the wider community and especially women being consulted. Craig Cooper, CEO of Positive Life NSW contributed a comment about the importance of increasing the number of women participating in research to ensure research is sufficiently funded and women’s concerns and needs are addressed and included. Once again, response to the second Mentimeter question was very strong with 83 responses recorded in total, which is an average of 2.6 entries per person.

Maxine posed the third question of the forum: *What do you think we could all do to improve the lives of women living with HIV?* from a perspective of including the strength of allies, such as men and other supporters in the effort to improve the lives of WLHIV.

What do you think we could all do to improve the lives of women living with HIV?



62

6. Thorpe, R, Power, J, Brown, G, Lyons, A, Dowsett, G.W. and Lucke, J, *HIV Futures 8: Women Living with HIV in Australia*. (Melbourne: The Australian Research Centre in Sex, Health and Society, La Trobe University, 2017).

As the word cloud developed, Maxine reflected on issues of inclusion, support and the power of listening to women. Once again, discussion in the room centred on empowering WLHIV and some of the issues that have divided WLHIV to date. Board members and sector allies in the room bought up issues of interagency collaborations and the value of the peer experience including the cross-jurisdictional complexities of these operating across the Australian HIV sector. Other issues of disclosure, experiences of stigma and discrimination specific to WLHIV, and the twin issues of the invisibility of women in the national HIV response alongside the need for the engagement of women, were also hot topics of discussion in the group.

Maxine, Jane and Bella along with the wider group continued to discuss results of all three Mentimeter questions and considered ways to move forward. Response to the third Mentimeter question totalled 46 responses which is an average of 1.4 entries per person. As the event ended over morning tea, the Mentimeter word cloud remained visible until the event concluded. Conversations continue to flow between all participants and several new friendships were struck up between participants, some of whom expressed feelings of validation meeting other WLHIV in a safe and welcoming space.

In conclusion, the event was an opportunity for WLHIV and their supporters to open the dialogue sorely lacking in the HIV response. This event was a safe space and moment for WLHIV to confer together and validate their experiences of living with HIV. Despite the frustration of some participants, attendees worked together to achieve a sense of unity and shared purpose. Some participants expressed surprise that men were present at the event, anticipating it was to be a women-only event, however agreed it was a positive move for the NDWLHIV to be supported by both men and women. From conversations we heard from the community on this day, it is clear the voices of WLHIV need to be heard more, and WLHIV must be visible. WLHIV want to be included in meaningful research about their health to ultimately improve the lives of all WLHIV.

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Appendix A

Mentimeter Questions:

1. What do you think living with HIV means for women today?
2. What things do you think would be important to research for WLHIV?
3. What do you think we could all do to improve the lives of WLHIV?

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