Raising HPV-related cancers awareness among women and, trans and gender diverse people living with HIV – a community survey

Authors: Bushby B[1], Sutherland L[1], Feeney L[1], Costello J[2], Cooper C[1], Murray J[1] **1.**Positive Life NSW. **2.** Kirby Institute UNSW Sydney.

Background

Positive Life NSW (Positive Life) and Femfatales: the Australian National Network of Women Living with HIV, developed a survey to increase our understanding of women and, trans and gender diverse (TGD) people and their knowledge and experiences of Human Papillomavirus (HPV) and related cancers.

Methods

- Women and, TGD people were central to survey development and recommendation implementation.
- Survey development and final report peer-reviewed by key informants.
- Anonymous survey was comprised of quantitative and qualitative questions.
- Responses were collected between 9 March to 11 May 2018 using Survey Monkey.
- Survey monkey results were analysed using Microsoft Excel.
- A report was published both in print and online.
- South Eastern Sydney Local Health District (SESLHD) Human Research Ethics Committee considered this project a quality improvement activity.

Results

Survey results identified a range of barriers and gaps in knowledge that could contribute to low rates of vaccination and vaginal, vulvar and anal screening, subsequently increasing the likelihood of higher rates of HPV-related cancers, particularly among people living with HIV (PLHIV).

355 women and TGD people responded to the survey:

- 14.4% were HIV-positive (n= 51).
- 5.6% were HIV-negative but immunocompromised (n= 20).
- 76.6% were HIV-negative (n= 272).
- 3.4% preferred not to disclose/unsure of their HIV status or immune status (n=12).

Responses across women and TGD people living with HIV showed:

- Extremely low awareness of the recommended three-yearly screening guidelines for immunocompromised women.
- Low risk awareness, lack of discussion with clinicians or treating medical specialists and low screening of vaginal, vulva and anal cancer.
- Among HIV-positive respondents who answered the question (n=50), 42% have had a conversation about HPV-related cancer, and the remaining 58% have not had a conversation about HPV-related cancer with their healthcare professional.
- Of the 42% who had a conversation about HPV-related cancer with their healthcare professional, 100% discussed cervical cancer, 14.3% discussed vulvar cancer, 9.5% discussed vaginal cancer and 0% discussed anal cancer.
- Low HPV vaccination rates of PLHIV, 70.6% hadn't been vaccinated and 23.5% were not sure if they'd been vaccinated or not.
- Respondents are uncomfortable to discuss HPV related cancer with clinicians. 20% felt 'neither comfortable nor uncomfortable', 2% felt 'uncomfortable', and 14% felt 'very uncomfortable'.
- Qualitative responses indicated that respondents would prefer increased public awareness of HPV; and clinician-initiated non-judgmental conversations with female doctors or nurses who were non-dismissive, clear and made them feel comfortable.

How can we improve?

- Increase frequency of screening and vaccination for PLHIV, immunocompromised people and those who are not vaccinated against HPV through improved identification of specific risk profiles and relevant guidelines for HPV related cancers.
- Increase discussion about and screening for vaginal, vulvar and anal cancer through more clinician-initiated discussion.

Conclusions

Survey results indicate women and, TGD PLHIV require targeted resources, engagement and communication about HPV-related cancers risk. The survey results will be used to develop educational resources and advocate for women and, TGD PLHIV. This survey initiates the collection of meaningful women and, TGD PLHIV data, and aims to improve their health, while increasing the visibility of the populations need.

Acknowledgments

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- Organisations: Femfatales, Cancer Council NSW, Cancer Council Australia, The Anal Cancer Advocacy Group, National Association of People with HIV Australia (NAPWHA), Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM).
- Survey analysis and report formulation: Liz Sutherland, Lance Feeney, Katya Samodurov, Craig Cooper, Joël Murray and Bella Bushby.

"I did talk to my doctor about the HPV vaccine but was not vaccinated because of the cost. Similarly as an immigrant in Australia not on the state health insurance, the cost of even basic STI testing is quite expensive."

– Survey respondent

58% of HIV-positive respondents **have not** had a conversation with their healthcare professional about HPV-related cancer

42% of HIV-positive respondents **have** had a conversation with their healthcare professional about HPV-related cancer

- **100%** discussed **cervical cancer**
- **14.3%** discussed **vulvar cancer**
- **9.5%** discussed **vagina cancer**
- **0%** discussed **anal cancer**

Responses show low HPV vaccination rates of PLHIV:

70.6% hadn't been vaccinated

23.5% are unsure if they'd been vaccinated

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Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information, targeted referrals and advocate to change systems and practices that discriminate against people living with HIV (PLHIV), our partners, friends, family and carers in NSW.

Phone (02) 9206 2177 **Mail** 414 Elizabeth Street, Surry Hills NSW 2010 **Email** contact@positivelife.org.au **Web** www.positivelife.org.au

femfatales
National Network of Women Living with HIV