

Patient Experience Symposium

29 April 2019

Bella Bushby

Communications and Policy Officer

Barriers for Women, and Trans and Gender Diverse People in Discussing HPV: Related Cancer with Clinicians

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Barriers for Women, and Trans and Gender Diverse People in Discussing HPV: Related Cancer with Clinicians

- How does HPV affect PLHIV?
- Survey Rationale
- Survey Results
- What were the barriers to discussing HPV-related cancer
- Take Home Messages, what do we need to improve.

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Acknowledgments

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- 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)
- Key Informants and Peers: Jane Costello, Kath Leane, Dr. Mary Poynten, Dr. Virginia Furner, A/Prof Sarah Dennis, Dr. Susan Carroll, Professor Jane Ussher, Julia Brotherton, Maxine Lewis, Dr Tanya Ward and Rebekah Puls
- Liz Sutherland, Lance Feeney, Katya Samodurov, Craig Cooper, Joël Murray

HPV and Women and, Trans and Gender Diverse People Living with HIV

- Human papillomavirus (HPV) is a common virus that affects **80% of all women**.
- There has been a rising number of people living with HIV (PLHIV) being diagnosed with HPV-related cancers, particularly anal cancer.
- People with a cervix and living with HIV are **three to six times more likely to develop cervical cancer than the general population** and are also at a greater risk of developing HPV-related anal, vaginal, oropharyngeal and vulvar cancers.
- In December 2017, new guidelines specifically addresses people who are immunocompromised and recommends that these people receive more frequent cervical screening (every three years).



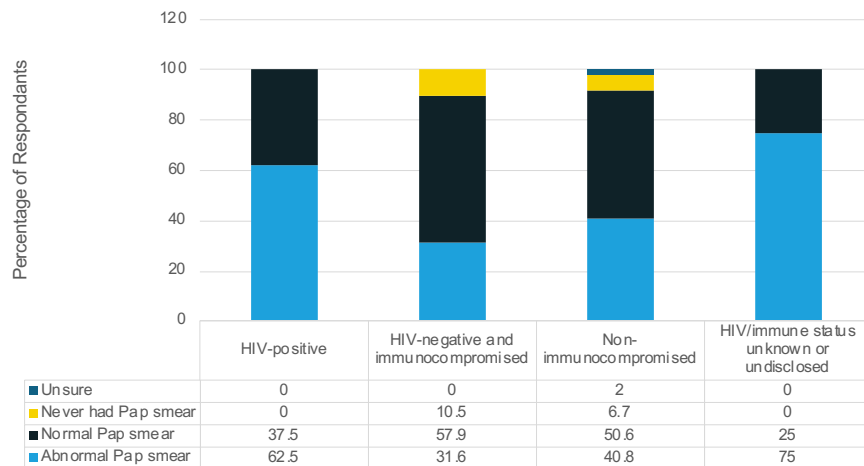


Survey Demographics

- 355 women and, trans and gender diverse 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)
- 58.3% of respondents were NSW residents, 70.1% were Australian born and 72.1% identified as straight or heterosexual.
- Aboriginal and/or Torres Strait Islander people were slightly overrepresented at 4.1% within the survey compared to the population of Aboriginal and/or Torres Strait Islander women in Australia 3.3%.
- People from culturally and linguistically diverse (CALD) backgrounds were underrepresented, 72% were born in Australia and 95.6% spoke English at home.

The Results – Screening Rates for HPV-Related Cancers

Cervical Screening

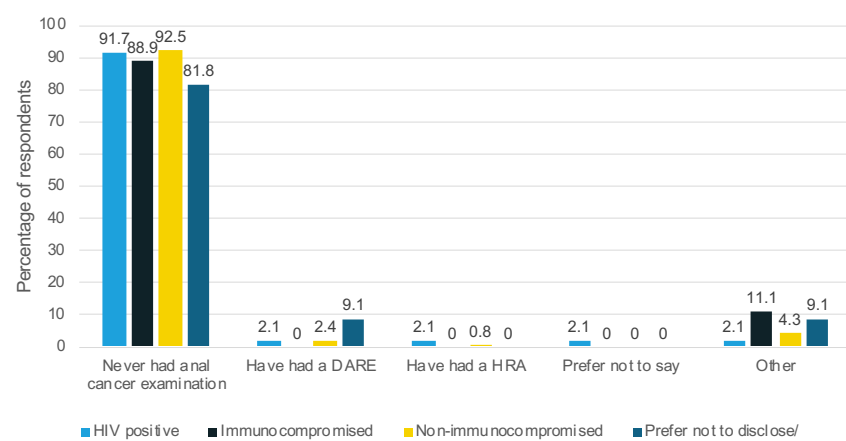


HPV-related Cancer among Women and, Trans and Gender Diverse People

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The Results – Screening Rates for HPV-Related Cancers

Anal Cancer Screening



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Lack of awareness of new screening guidelines

HIV- Positive Women and, Trans and Gender Diverse People

- **none** were aware of the new 3 yearly National Cervical Screening Guidelines and changes

HIV-Negative, Immunocompromised Women and, Trans and Gender Diverse People
- **28.3%** plan to ask for a screen every 3 years (the correct screening guideline for this group).

Among non-immunocompromised respondents

- **31.2%** plan to ask for a screen every 5 years (the correct screening guideline for this group).

"If I didn't know better, I'd think the 5 yearly cervical screens were applicable to me, however because of my immune system I need 3 yearly... this information isn't readily available without some prior knowledge to know what to search for..."
Survey Respondent

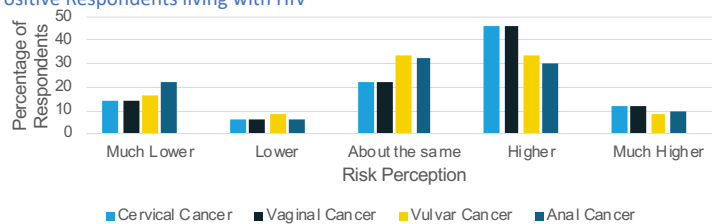
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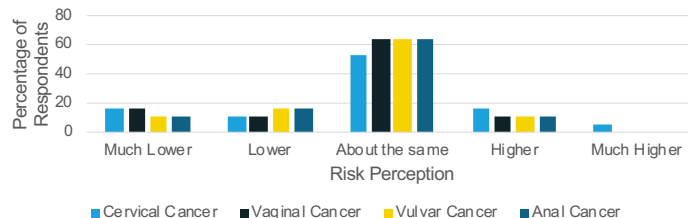
Reasons for Results - Poor Risk Awareness

In relation to the general female population, how would you rate your risk of acquiring each of the following cancers?' (Cervical, Vaginal, Vulvar, and Anal).

HIV- Positive Respondents living with HIV



HIV-Negative, Immunocompromised Respondents

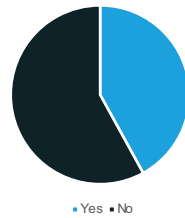


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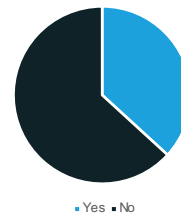
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Respondents who had not discussed HPV-related cancer with their doctor or health professional

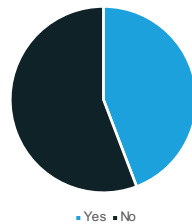
HIV Positive



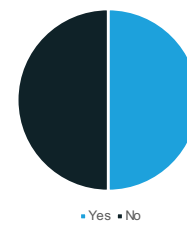
HIV Negative, Immunocompromised



Non-immunocompromised



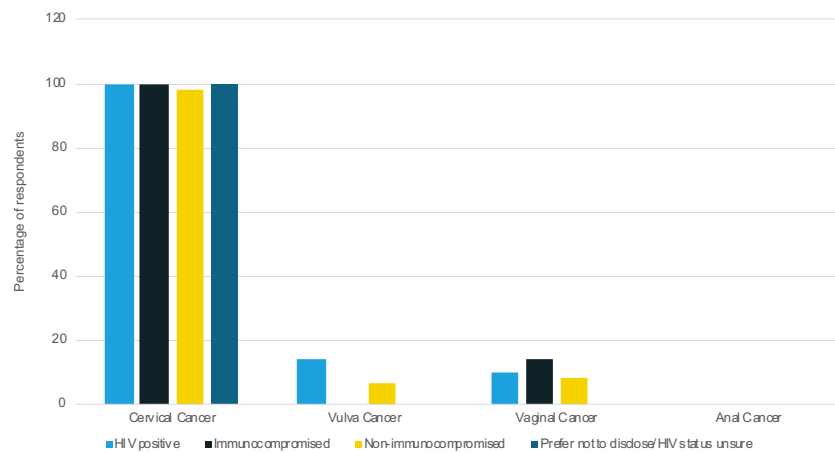
HIV/immune Status Unknown or Undisclosed



HPV-related Cancer among Women and, Trans and Gender Diverse People

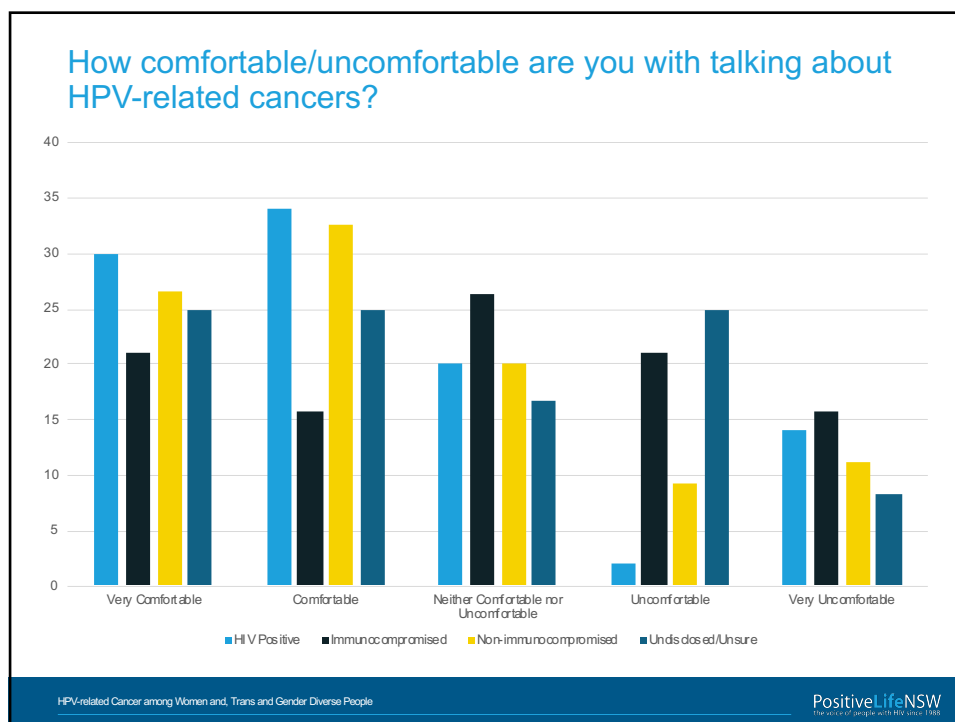
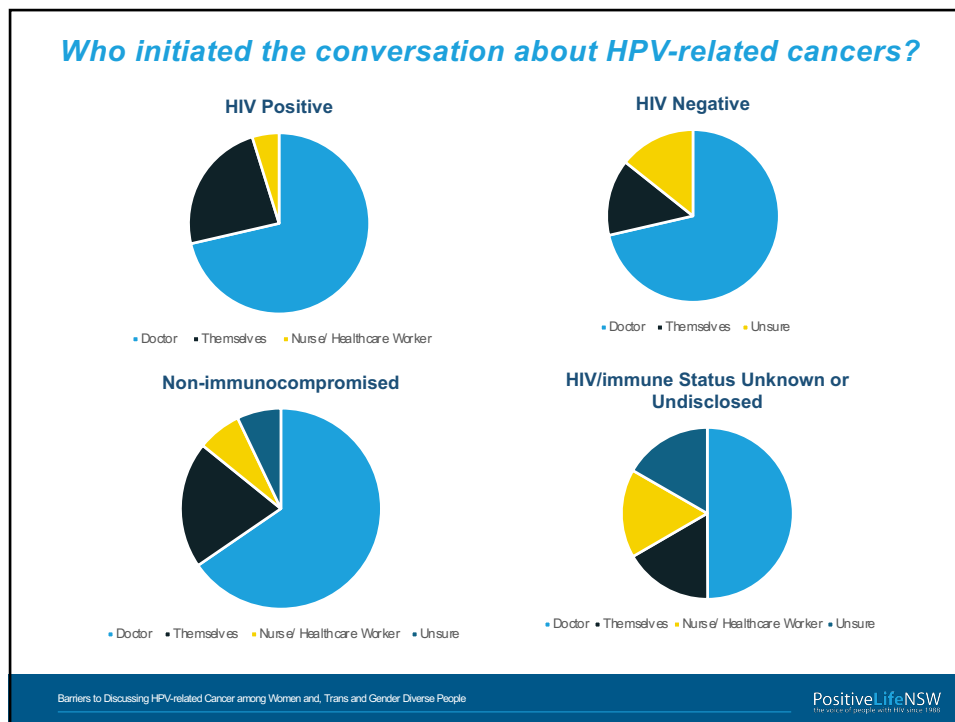
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What did you discuss?



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What we learnt

- **Poor risk awareness** coupled with **poor doctor/ patient communication** about HPV risk places women and trans and gender diverse people at increased risk for HPV- related cancers.
- A **reliance on the clinician** to bring up issues of HPV is coupled with high discomfort talking about HPV related cancers when it is raised. Respondents generally preferred having **clinician-initiated conversations** with female doctors or nurses who were non-judgemental, non-dismissive, clear, and made them feel **comfortable**.
- More than 25% of qualitative respondents felt that **more awareness** and normalising talking about HPV in the public realm would help increase their chance of detecting HPV-related cancer early.
- Respondents indicated a range of barriers to discussing HPV-related cancer with their clinician including a **lack of knowledge** on risk, being **uncomfortable** in raising the topic with their clinician and lack of **clinician-initiated discussion** about HPV related cancers, **particularly anal cancer**.

HPV-related Cancer among Women and, Trans and Gender Diverse People


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What needs to happen

- Increase the 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 anal cancer through more clinician-initiated discussion.

Insert Presentation Title

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*"I try to keep up with all that's happening
...however this survey has put the importance of
HPV back on my radar for my upcoming
appointment."*

Survey Respondent

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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.

Phone 02 9206 2177 or 1800 245 677 (freecall)
Office Suite 5.2, Level 5, 414 Elizabeth St, Surry Hills NSW
Web www.positivelife.org.au

Contact Bella Bushby, Communications and Policy Officer
Email bellab@positivelife.org.au

www.positivelife.org.au

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