

A COMMUNITY PERSPECTIVE

On Human Papillomavirus (HPV)-related cancer among women and, trans and gender diverse people

APRIL 2019

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Acknowledgements

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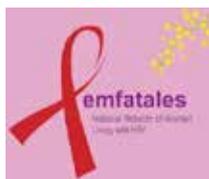
- Femfatales
- Cancer Council NSW
- Cancer Council Australia
- The Anal Cancer Advocacy Group³
- National Association of People with HIV Australia (NAPWHA)
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1. Positive Life NSW is the state-wide peer led organisation representing and advocating for 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 in Australia.
3. The Anal Cancer Advocacy Group is a groups of community representatives, clinicians and researchers working in the field of HPV-related cancer. The Anal Cancer Advocacy Groups works to increase awareness of, screening for, and prevention of HPV-related cancer. The group is currently chaired by Positive Life NSW.

Images used in this publication are sourced stock photography and are used for illustrative purposes. They do not imply any particular HIV status, sexuality, attitudes or behaviours.

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Definitions

Trans and gender diverse: An umbrella term used to describe all those whose gender is different to the sex they were assigned at birth, including individuals who identify as non-binary gender.

Cis-gender: Where a person's gender identity corresponds with their birth sex (cis is the opposite of trans).

Where there is reference to only a single gender, for example "compared with the general female population" this is in part due to the lack of meaningful data on trans and gender diverse people, moreover those living with HIV. We have also used specific gender markers where the data cited has indicated specific gender markers.

Executive summary

Human papillomavirus (HPV) is a common virus which can be passed through skin to skin contact during sexual activity. Even sexually active people who use condoms can become infected with HPV, as condoms do not cover all areas of skin.¹ There are many different types of HPV. Some types cause wart like conditions and other types can cause cancer. While cervical cancer is the most common HPV-related cancer among people with a cervix, long term infection with some types of high-risk HPV can lead to vaginal, vulvar, anal, and mouth, throat and tongue (oropharyngeal) cancers.²

Evidence to date shows that women living with HIV are 3 to 6 times more likely to develop cervical cancer than the general female population.³ They are also at greater risk of developing anal, vaginal, oropharyngeal and vulvar cancers.⁴ Studies have shown that the incidence of invasive anal cancer in women living with HIV could be anywhere between 7 to 28 times higher than in the general female population.⁵ Those who have had other HPV-associated cancers (cervical, vaginal, vulvar or oropharyngeal cancer) as well as those who have received a solid organ transplant are at higher risk for developing anal cancer.⁶ There is evidence to suggest that if HPV is present anywhere in the genital tract, it can be spread to the anal tract by non-sexual behaviours like front-to back wiping after using the toilet.⁷ Therefore, it's a misconception that anal sexual activity is the only risk factor for anal HPV infection.

There are other groups who may have a higher but preventable risk because they are often left out of the conversation about HPV and related cancers. Trans men are less likely to be up-to-date with Pap tests to screen for cervical cancer.⁸ Furthermore, several studies have highlighted that trans and gender diverse people, and lesbian and bisexual cis-gendered women are often disregarded as not being at risk.⁹



Evidence to date shows that women living with HIV are 3 to 6 times more likely to develop cervical cancer than the general female population

Prevention of HPV infection through vaccination and early detection of HPV-related abnormalities through regular screening are two important ways of ensuring positive health outcomes.¹⁰ National cervical screening programs like Australia's have resulted in lower rates of cervical cancer. Australia has had very high uptake levels of HPV vaccination since its introduction in young women in 2007 and young men in 2013, and this will lead to reductions in HPV-related cancers in the future.¹¹ Although it is most effective to vaccinate people when they are young and before they have become sexually active, there is evidence to suggest that the 4-valent HPV vaccine is effective for women up to 45 years of age, and the 2-valent vaccine is effective in women up to 55 years of age.¹² The Australian Technical Advisory Group on Immunisation (ATAGI) states that immunocompromised people should be vaccinated against HPV at any age.¹³

In Australia, about 63% of anal cancers are diagnosed when the cancer is larger and more advanced.¹⁴ Individuals who receive a late diagnosis of anal cancer are routinely treated with chemotherapy and radiotherapy and are more likely to experience negative outcomes in terms of poorer long-term anal function.¹⁵ There were 241 Australian females in 2015 diagnosed with anal cancer. 51 of these individuals died.¹⁶ That's why early detection through screening is important. Surveillance studies are predicting that incidence rates of anal cancer in NSW could double by the year 2032, highlighting the importance of creating awareness of screening for this rare cancer among people who are at risk.¹⁷

In December 2017, the National Cervical Screening Program (NCSP) released new screening guidelines specifically for women living with HIV and solid organ transplant recipients. These groups have been defined as sufficiently immune-deficient to warrant more frequent screening than the general female population. Other groups could also be considered for screening every 3 years with an HPV test in accordance with the recommendations for HIV-positive women and solid organ transplant recipients. These groups include women with congenital (primary) immune deficiency and women who are being treated with immunosuppressant therapy for autoimmune disease (e.g. inflammatory bowel disease, systemic lupus erythematosus, rheumatoid arthritis, neuromyelitis optica, sarcoidosis and allogenic bone marrow transplant recipients treated for graft versus host disease). For the first time in Australia, the new screening guidelines include entire lower anogenital tract screens if any HPV is detected on the cervix.¹⁸

In 2016, Positive Life NSW (Positive Life) conducted an anonymous online anal cancer awareness survey. Results from this survey highlighted a significant lack of data on women and, trans and gender diverse people. Only 1 cis-gendered women and 3 trans men living with HIV participated in the survey. The low response rate showed that engaging women and, trans and gender diverse people around the issues of anal and other HPV-related cancers would be an important next step in assessing awareness of HPV related cancers and improving health equity for all people living with HIV (PLHIV).

In 2018, Positive Life and Femfatales (the Australian National Network of Women Living with HIV), developed an anonymous online survey targeting: 1) women and, trans and gender diverse PLHIV, and 2) other HIV-negative women and, trans and gender diverse people across Australia. The survey aimed to assess whether these populations were equipped with enough information and strategies to prevent HPV-related cancer, detect HPV-related cancer early, and stay cancer free post-treatment and/or recovery. We also sought to understand and assess the experiences of respondents when accessing services to prevent, treat, and recover from HPV-related cancers, and to identify any potential health care access barriers.

Methods

Positive Life and Femfatales developed a cross-sectional study to:

- Assess awareness and knowledge of HPV infection and risk for 4 HPV-related cancers (cervical, vaginal, vulvar, and anal) among women and, trans and gender diverse people in Australia;
- Assess the knowledge gaps to inform the development and implementation of population-specific educational resources to increase community and healthcare professional awareness of HPV and related cancers;
- Assist with the prevention of morbidity and mortality by increasing screening, early detection and treatment of HPV-related cancers, and;
- Assess rates of HPV vaccination in women and, trans and gender diverse people.

An electronic anonymous survey included a combination of quantitative and qualitative questions was developed. This survey was peer-reviewed by a group of key informants listed in the acknowledgements section of the report (page 2). They included: HIV-positive women, academics, clinicians and cancer specialists caring for HIV-positive and HIV-negative women and, trans and gender diverse people, and researchers working in the field of HPV and HPV related cancer. Eastern Sydney Local Health District Human Research Ethics Committee reviewed the survey and assessed it to be a quality improvement activity.

The survey included a total of 48 questions. Depending on the survey logic, some participants answered fewer than 48 questions. Respondents spent an average of 7 minutes completing the online survey which was divided into 7 sections in the following order: 1) About you, 2) Level of awareness of HPV-related cancers, 3) Patient/doctor communication and interaction, 4) Screening and Diagnosis, 5) Staging and Treatment, 6) Vaccination, and 7) Information, resources, and support.

The questionnaire was distributed online via a SurveyMonkey link and in paper format (on request), from 9 March to 11 May 2018. Promotion and dissemination of the survey involved engaging with and mobilising HIV sector partners and sexual health clinics across Australia, utilising social media networks, and leveraging promotion at events and on national awareness days. The survey was open to all women and, trans and gender diverse people in Australia, however respondents who were assigned male gender at birth were excluded from the analyses. This report is therefore based on 355 responses from women and, trans and gender diverse people who were assigned female gender at birth.

Statistical analyses were performed using Microsoft Excel formulas and SurveyMonkey functions. Thematic analysis was used to identify patterns across the short-answer, qualitative response dataset. We coded responses by themes and reported the themes by frequency. Some qualitative responses had multiple themes per response. While we performed thematic analysis of qualitative responses for each risk group, we chose to only report the thematic analysis of qualitative responses by total responses, due to the relatively low sample size of the 2 qualitative responses, and the risk of reidentification.

Summary of key findings

1. The results from this survey highlighted a lack of awareness of risk, prevention, symptoms, and early detection of HPV-related vaginal, vulvar, and anal cancers.
2. Approximately 28% of HIV-positive respondents were unaware that a vaccination against HPV exists and 71% of HIV-positive respondents had not been vaccinated against HPV.
3. Over half (60%) of HIV-positive respondents believe their risk of anal cancer was either 'about the same', 'lower', or 'much lower' than the general female population's risk.
4. While all HIV-positive respondents had screened for cervical cancer at some point in their lives, 91.7% had never had an anal examination for anal cancer.
5. Among HIV-positive and HIV-negative but immunocompromised respondents who had undergone staging or treatment for either cervical, vaginal, or vulvar cancer, none had ever screened for anal cancer.
6. Of the HIV-positive respondents who do not receive screening reminder notifications, none were aware of the new 3 yearly National Cervical Screening Guidelines and changes.
7. Qualitative responses indicated that respondents generally preferred having clinician-initiated conversations with female doctors or nurses who were non-judgemental, non-dismissive, clear, and made them feel comfortable.
8. In an open-ended short-answer question, 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.



Results

Characteristics of the sample

Immunocompromised status

Of the 355 women and, trans and gender diverse people who responded to the survey, 14.4% were HIV-positive (n=51), and 5.6% identified themselves to be HIV-negative but immunocompromised by an immune condition, organ transplant, chemotherapy, or medication (n=20). Respondents who indicated their HIV-status to be “unknown” were grouped with HIV-negative respondents. Accordingly, 76.6% of respondents were non-immunocompromised (n=272). The final 3.4% of respondents consisted of women and, trans and gender diverse people who preferred not to disclose their HIV status or immune status or were not sure of their immune status (n=12).

Immunocompromised status was determined by self-report and based on the following question: “Do you have any conditions or are you taking any medication that affects your immune system (i.e. Lupus, taking prednisone, organ transplant recipient, undergoing chemotherapy, etc.)?”

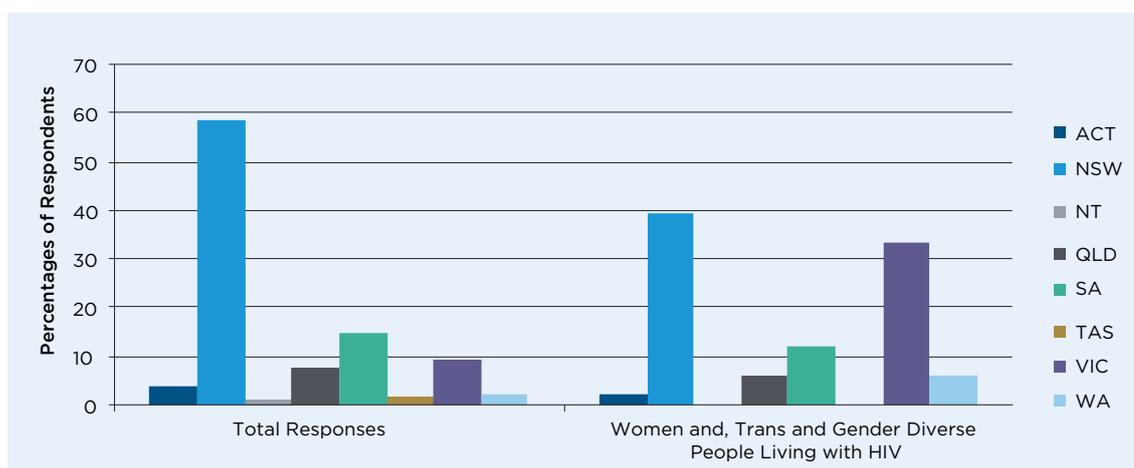
Gender at birth

All respondents in the analysis were assigned female gender at birth.

Gender identity

Most respondents reported their gender identity as “Woman” (n=343 or 96.62%), 2 identified as “Transgender” (0.6%), 8 identified as “Non-binary/gender fluid or other” (2.3%), 1 identified as “Man” (0.3%) and 1 identified as “Other” (0.3%).

Figure 1: Place of residence



The survey sample over-represents people living with HIV in Victoria and South Australia, and under-represents Queensland, Western Australia, the Australian Capital Territory, the Northern Territory and Tasmania.¹⁹ The residential distribution of the HIV-positive Australian population is as follows: New South Wales (41.2%), Victoria (24.5%), Queensland (19.0%), Western Australia (7.1%), South Australia (5.1%), Australian Capital Territory (1.25%), Tasmania (1.0%), Northern Territory (0.7%).

Age

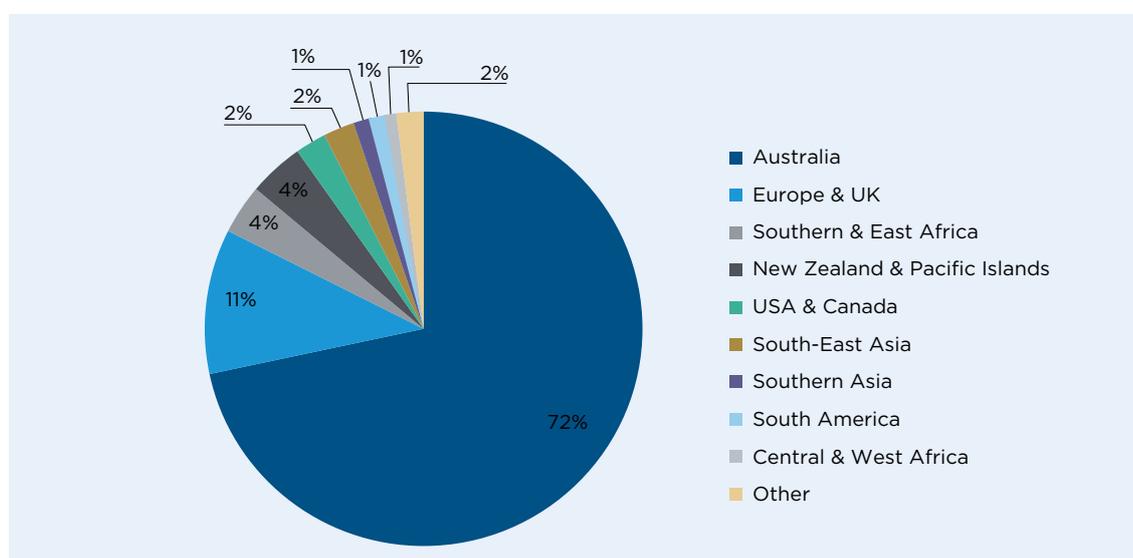
Participants were aged: 18-24 years (6.2%), 25-34 years (24.8%), 35-44 years (26.8%), 45-54 years (24.5%), 55-64 years (14.4%), and 65 years and over (3.4%). Compared to the age structure of the general female Australian population, this survey under-represents participants aged 18-24 years and 65 years and over, and over-represents participants aged 25-34 years, 35-44 years, 45-54 years and 55-64 years. The average age of survey participants was 42.3 years, with a median age of 42 years and a standard deviation of 12.02 years.

Indigenous ethnicity

3.5% of participants identified as Aboriginal, 0.6% identified as Torres Strait Islander, and 1.1% preferred not to say. 94.8% identified as non-Indigenous. These figures indicate that this survey is very slightly over-represented with responses from Aboriginal and/or Torres Strait Islander respondents, when compared to the population of Aboriginal and/or Torres Strait Islander women in Australia (3.3%).²⁰

Country/region of birth

Figure 2: Survey Participant's Country of Birth



When compared with the demographic profile of all women in Australia, the percentages indicate that respondents to the survey were not representative of the cultural diversity within Australia.

Main language spoken at home

Most survey participants spoke English at home (95.6%). Of the 4.4% who spoke a language other than English at home, the most common languages were Spanish, Shona, Greek, Hindi, French, Italian, Gujarati, Thai, Hungarian, Vietnamese, Arabic, and Portuguese. These proportions indicate that the respondents to this survey were not representative of the linguistic diversity within Australia. The Australian Bureau of Statistics reported that in 2016, English only was spoken at home by 72.7% of the Australian population and 20.8% spoke another language other than English at home.

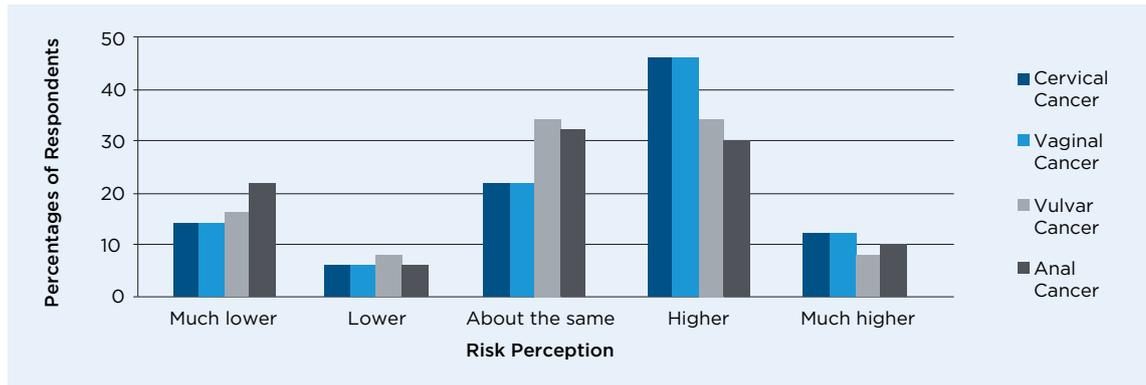
Smoking Status

The rate of daily smoking among HIV-positive respondents was double that of HIV-negative respondents (15.7% vs. 7.4%). In addition, there were fewer 'not at all or 'non-smokers' among HIV-positive respondents (52.9%) than in HIV-negative respondents (65.4%). These numbers affirm other data that indicate people living with HIV smoke tobacco and related products at higher rates than the general population.²¹ This has implications for risk, as smoking is an independent risk factor for most cancers, including HPV-related cancers.

HPV related cancer risk perception

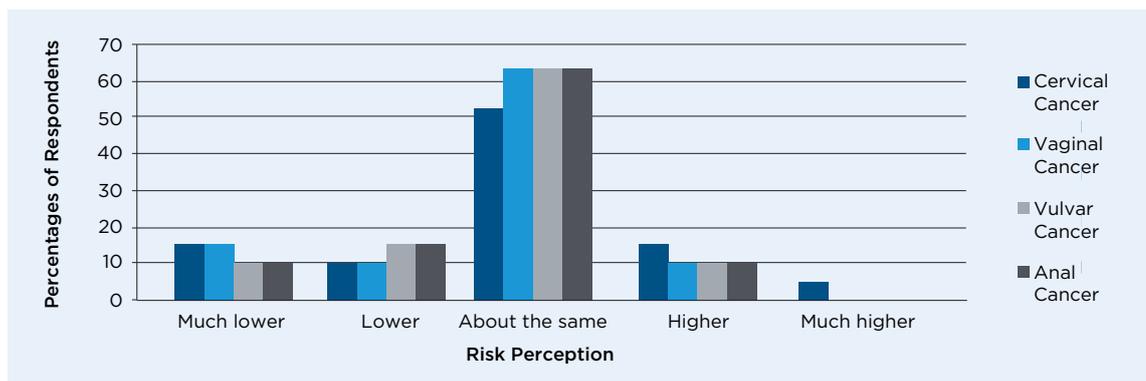
Respondents were asked the question: 'In relation to the general female population, how would you rate your risk of acquiring each of the following cancers?' (Cervical, Vaginal, Vulvar, and Anal). Respondents could choose to rate their risk for each type of HPV-related cancer by selecting either 'much lower', 'lower', 'about the same', 'higher' or 'much higher' than the general female population. Figures 3, 4, 5 and 6 show each respondent groups perceived risk for cervical, vaginal, vulvar and anal cancer.

Figure 3: HPV-Related Cancer Risk Perception among HIV-Positive Women and, Trans and Gender Diverse People



HIV-positive respondents were more likely to rate their risk of cervical, vaginal, vulvar and anal cancer as 'higher' or 'much higher' than other response groups. However, there was a significant proportion of HIV-positive respondents who rated their risk of cervical, vaginal, vulvar and anal cancer to be 'about the same', 'lower' or 'much lower' than the general female population. For example, 22% of HIV-positive respondents rated their risk of anal cancer to be 'much lower' than the general female population.

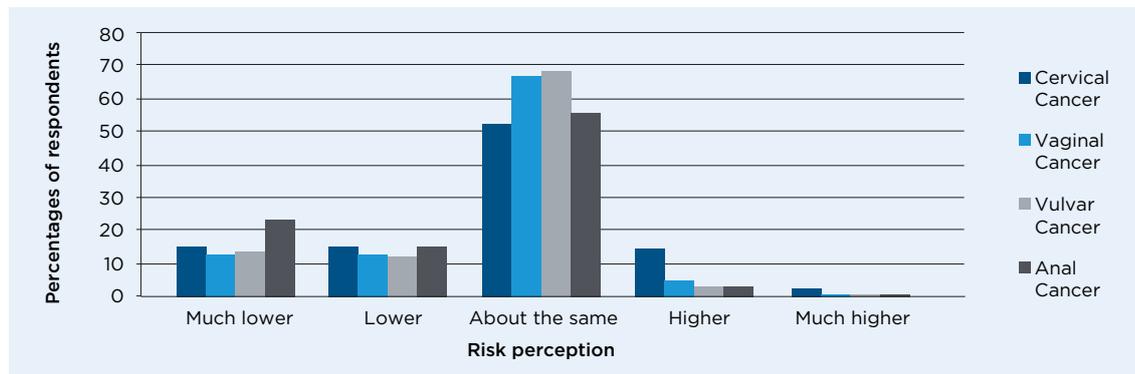
Figure 4: HPV-Related Cancer Risk Perception among HIV-Negative, Immunocompromised Women and, Trans and Gender Diverse People



While a minority of immunocompromised respondents (average 10.5%) rated their risk of cervical, vaginal, vulvar and anal cancer to be 'higher' and 'much higher' than the general female population, a majority (52-64%, average 60.6%) rated their risk of cervical, vaginal, vulvar and anal cancer to be 'about the same'. Between 10.5% and 15.8% of immunocompromised

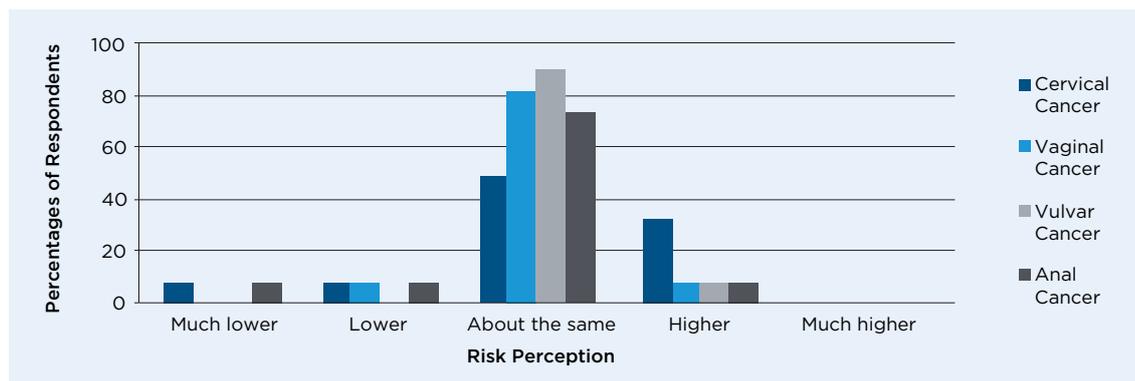
respondents however, thought their risk of cervical, vaginal, vulvar and anal cancer to be 'lower' or 'much lower' than the general female population – depending on the type of cancer.

Figure 5: HPV-Related Cancer Risk Perception among Non-immunocompromised Women and, Trans and Gender Diverse People



Most non-immunocompromised respondents rated their risk of cervical, vaginal, vulvar and anal cancer to be 'about the same' as the general female population. A significant proportion (11.9-23.8%) however, rated their risk of cervical, vaginal, vulvar and anal cancer to be 'lower' or 'much lower' than the general female population, depending on the type of cancer.

Figure 6: HPV-Related Cancer Risk Perception among Women and, Trans and Gender Diverse People Who Preferred Not to Disclose or unsure of Immune-Status



Most respondents who preferred not to disclose or were unsure of their HIV status perceived their risk of cervical, vaginal, vulvar and anal cancer to be 'about the same' as the general female population. This may/may not be the case, depending on HIV status and other factors, including risk profiles.

Anal cancer risk perception

Figure 7: Anal Cancer Risk Perception among the 4 different Risk Groups

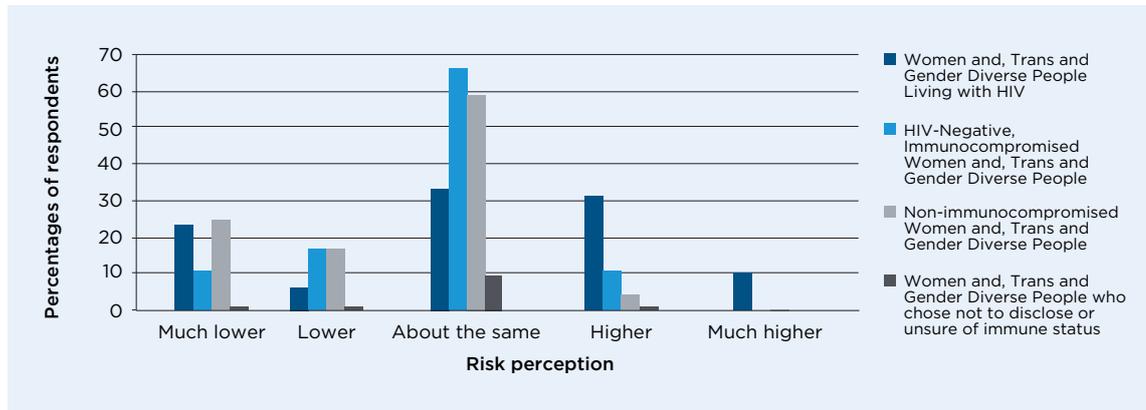


Figure 7 illustrates how each of the 4 risk groups surveyed perceived their risk of developing HPV-related anal cancer. While 40% of HIV-positive respondents were aware they may have a 'higher' or 'much higher' risk of developing anal cancer, 32% perceived their risk to be 'about the same' and 28% perceived their risk to be 'lower' or 'much lower'. In comparison, only 10.5% of HIV-negative and immunocompromised respondents perceived their risk of developing anal cancer as 'higher' or 'much higher' with a majority (63.2%) perceiving their risk to be 'about the same' and 26.3% perceiving their risk to be 'lower' or 'much lower' than the general female population. The majority (56.2%) of non-immunocompromised respondents perceived their risk to be 'about the same' and 39.6% perceived their risk to be 'lower' or 'much lower'.



40% of HIV-positive respondents were aware they may have a 'higher' or 'much higher' risk of developing anal cancer

Prevention

Awareness of HPV vaccine among different risk groups

Respondents were asked 'Are you aware there is a vaccine for HPV (human papillomavirus?)'

47 of the 51 HIV-positive respondents (92%) answered the question. Of the HIV-positive respondents, 68.1% were aware there was a vaccine for HPV, 27.7% were not aware and 4.3% were unsure. HIV-positive respondents who were aware of the HPV vaccine were also asked 'Has there ever been a conversation with your doctor or health professional about vaccination against HPV?' Only 29.4% had spoken with a doctor about the HPV vaccine.

18 of the 20 HIV-negative but immunocompromised respondents (90%) answered the question. Of immunocompromised respondents, 94.4% were aware there was a vaccine for HPV, and 5.6% were not aware. Immunocompromised respondents who were aware of the HPV vaccine were also asked 'Has there ever been a conversation with your doctor or health professional about vaccination against HPV?' Only 35.3% had spoken with a doctor about the HPV vaccine.

254 of the 272 HIV-negative non-immunocompromised respondents (93%) answered the question. Of non-immunocompromised respondents, 90.2% were aware there was a vaccine for HPV, 6.3% were not aware, and 3.5% were unsure. Non-immunocompromised respondents who were aware of the HPV vaccine were also asked 'Has there ever been a conversation with your doctor or health professional about vaccination against HPV?' 38.0% had spoken with a doctor about the HPV vaccine.

11 of the 12 HIV/immune status unknown or undisclosed respondents (92%) answered the question. Of these respondents, 72.7% were aware there was a vaccine for HPV, 27.3% were not aware, and 0% were unsure. Respondents who were aware of the HPV vaccine were also asked 'Has there ever been a conversation with your doctor or health professional about vaccination against HPV?' 37.5% had spoken with a doctor about the HPV vaccine.

Figure 8: Awareness of HPV Vaccine + Rates of Conversations with Doctors about HPV Vaccination

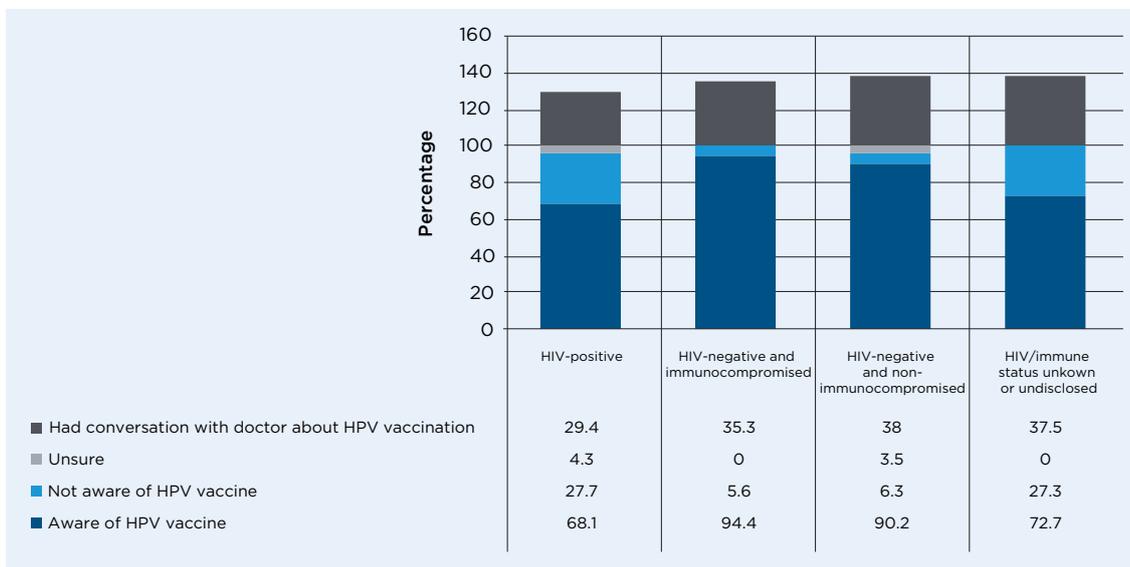


Figure 8 compares HPV vaccination awareness among the 4 risk respondent groups. It also compares the proportion of respondents who had ever had a conversation about HPV vaccination with their doctor. More HIV-positive and HIV/immune status unknown/undisclosed respondents were unaware of HPV vaccination than immunocompromised and HIV-negative/non-immunocompromised respondents (27.7% and 27.3% vs. 5.6% and 6.3%). HIV-positive respondents were also less likely to have talked with their doctor about HPV vaccination (29.4%, vs. 35.3%, 37.5% and 38.0%).

Vaccination rates among different risk groups

We asked respondents 'Have you been vaccinated against HPV?'

34 HIV-positive respondents answered the question. 2.9% indicated 'yes-Gardasil', 2.9% indicated 'yes- not sure which vaccine', 70.6% said 'no' and 23.5% were 'not sure'. None of the HIV-positive respondents had received the Cervarix (2-valent) or Gardasil-9 (9-valent) vaccines.

17 HIV-negative and immunocompromised respondents answered the question. 5.9% indicated 'yes-Gardasil', 11.8% indicated 'yes- not sure which vaccine', 76.5% said 'no' and 5.9% were 'not sure'. None of the immunocompromised respondents had received the Cervarix (2-valent) or Gardasil-9 (9-valent) vaccines.

213 non-immunocompromised respondents answered the question. 0.4% indicated 'yes-Cervarix,' 15.2% indicated 'yes-Gardasil', 1.3% indicated 'yes- Gardasil 9', 13.5% indicated 'yes- not sure which vaccine', 64.6% said 'no' and 5.1% were 'not sure'.

8 HIV/immune status unknown/undisclosed respondents answered the question. 12.5% indicated 'yes-Gardasil', 12.5% indicated 'yes- not sure which vaccine', and 75.0% said 'no'. None of the respondents had received the Cervarix (2-valent) or Gardasil-9 (9-valent) vaccines.

Figure 11 illustrates the number and proportion of total respondents by age group who were vaccinated with Ceverix, Gardasil/not sure they were vaccinated/or not vaccinated.

Figure 9: Vaccination Rates among Different Risk Groups

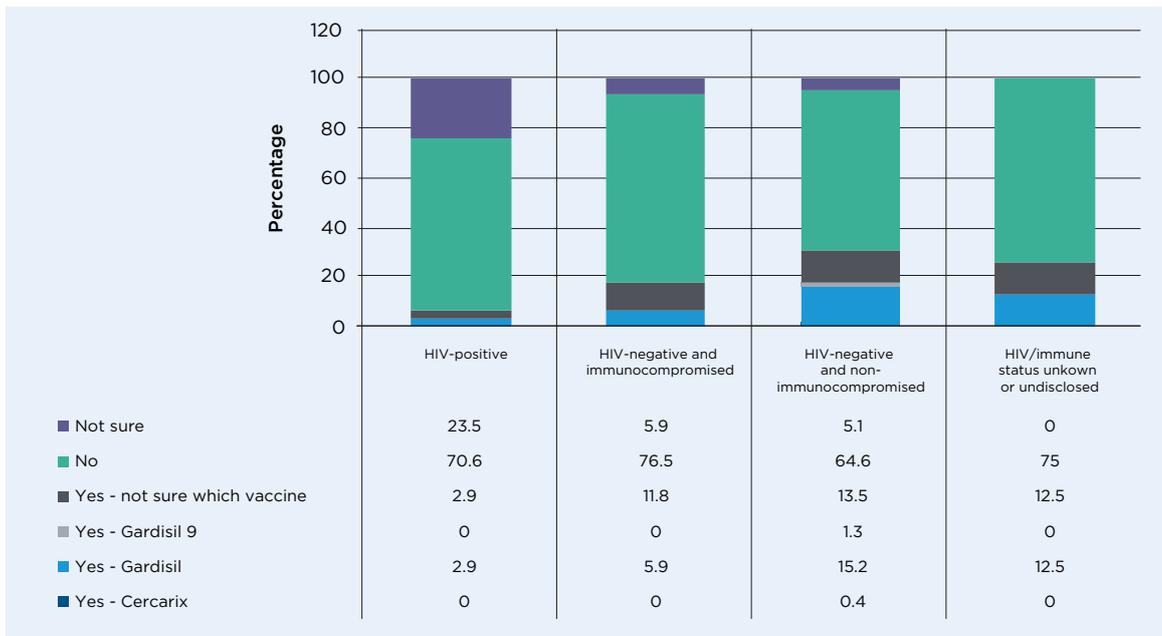


Figure 9 compares vaccination rates among the different risk groups surveyed. While few people in all risk groups had receiving HPV vaccination, the lowest rates were reported by HIV-positive respondents. HIV-positive respondents were also more likely to be unsure whether they had received HPV vaccination. Among those who reported having been vaccinated, the majority received Gardasil (Quadrivalent) or did not know which vaccination they received

Figure 10 and 11, compares HPV vaccination by type and age group in HIV-positive respondents and total respondents. Across all age groups, most HIV-positive respondents had not been vaccinated, including those in younger age groups. Of those who had been vaccinated, all were younger than 34 years of age (Figure 10). Among total respondents (Figure 11), a majority across all age groups had not be vaccinated. Of those who had been vaccinated, most were younger than 34 years and had received Gardasil Quadrivalent vaccine. Very few respondents had received Gardasil.

Figure 10: Vaccination in HIV-Positive Respondents by Age

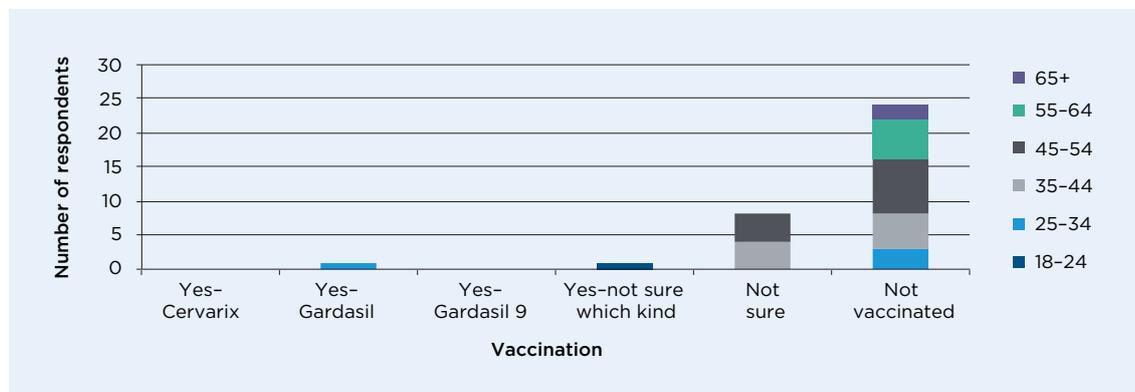
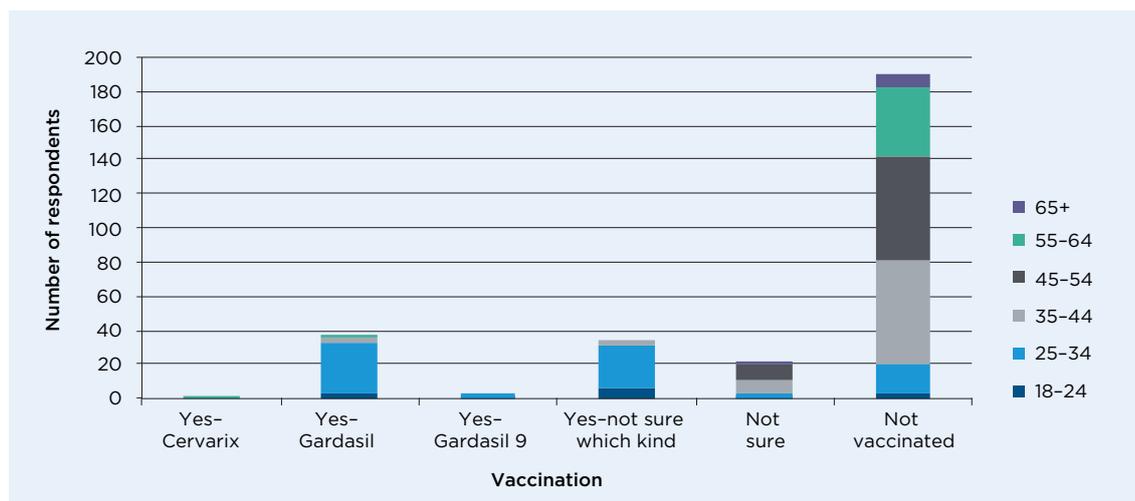


Figure 11: Vaccination in Total Respondents by Age



Cancer symptom awareness

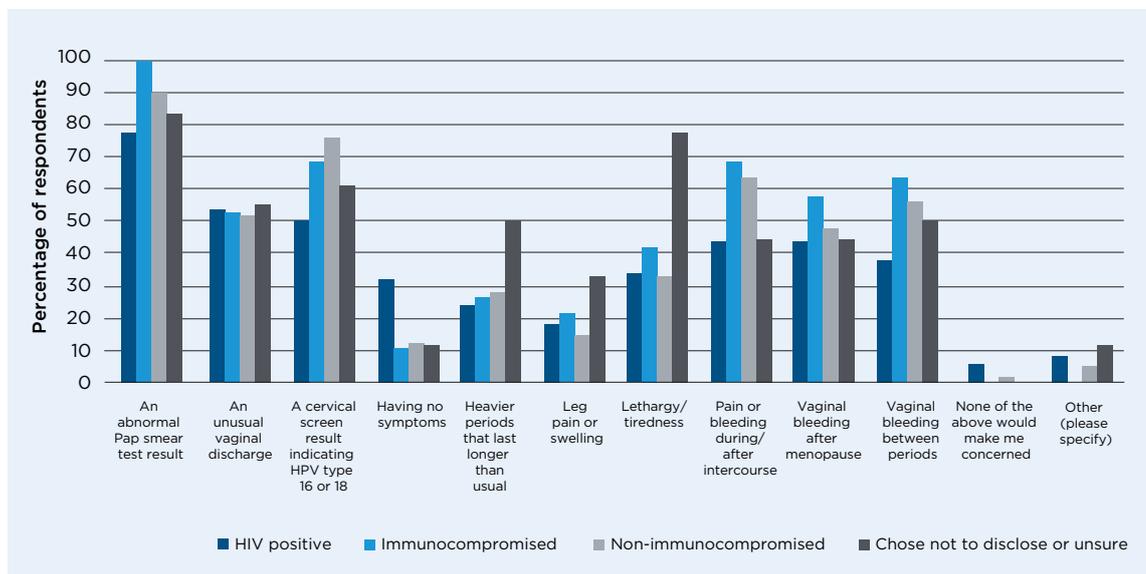
Cervical Cancer

Respondents were asked 'Which of the following would make you concerned about cervical cancer? (Tick as many as you think apply)'. The results indicate that respondents generally had a reasonable understanding of cervical cancer warning signs and symptoms, although 6% of HIV-positive respondents indicated they would not be concerned by any of the listed symptoms, and HIV-positive respondents were generally less likely to be concerned about each of the listed symptoms than immunocompromised, non-immunocompromised and respondents who chose not to disclose, or were unsure of their HIV status. The 'other (please specify)' responses included 'lower back pain', 'STIs or warts', 'abdominal pain or swelling' and 'weight gain around the abdomen'.

The Cancer Council of Australia website states: 'if early cell changes develop into cervical cancer, the most common signs include:

- Vaginal bleeding between periods
- Menstrual bleeding that is longer and heavier than usual
- Bleeding after intercourse
- Pain during intercourse
- Unusual vaginal discharge
- Vaginal bleeding after menopause
- Excessive tiredness
- Leg pain or swelling
- Low back pain.'

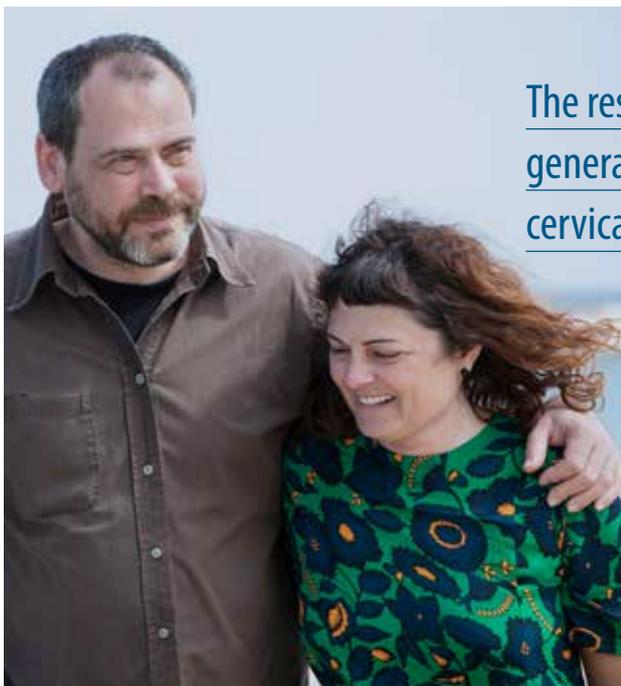
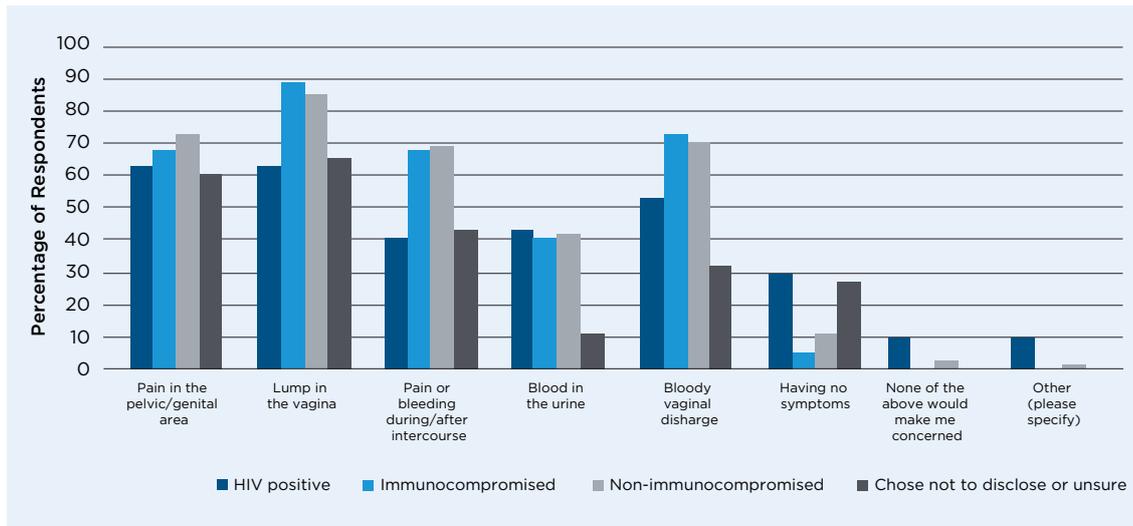
Figure 12: Cervical Cancer Symptoms Awareness among Different Risk Profile Groups



Vaginal Cancer

Respondents were asked 'Which of the following would make you concerned about vaginal cancer? (Tick as many as you think apply)'. The results indicate that respondents had some understanding of vaginal cancer warning signs and symptoms, although 10% of HIV-positive respondents indicated they would not be concerned by any of the listed symptoms. HIV-positive respondents were also less likely to be concerned about the symptoms listed than immunocompromised, non-immunocompromised and respondents who chose not to disclose, or were unsure of their HIV status. The 'Other (please specify)' responses included 'I've never heard of vaginal cancer', 'I would never consider vaginal cancer, I'd consider cervical cancer', 'white patches and irritation' and 'I get extremely bad pains very low near my vagina but it's all internal pain; no hospital has looked into it properly yet'.

Figure 13: Vaginal Cancer Symptoms Awareness among Different Risk Profile Groups

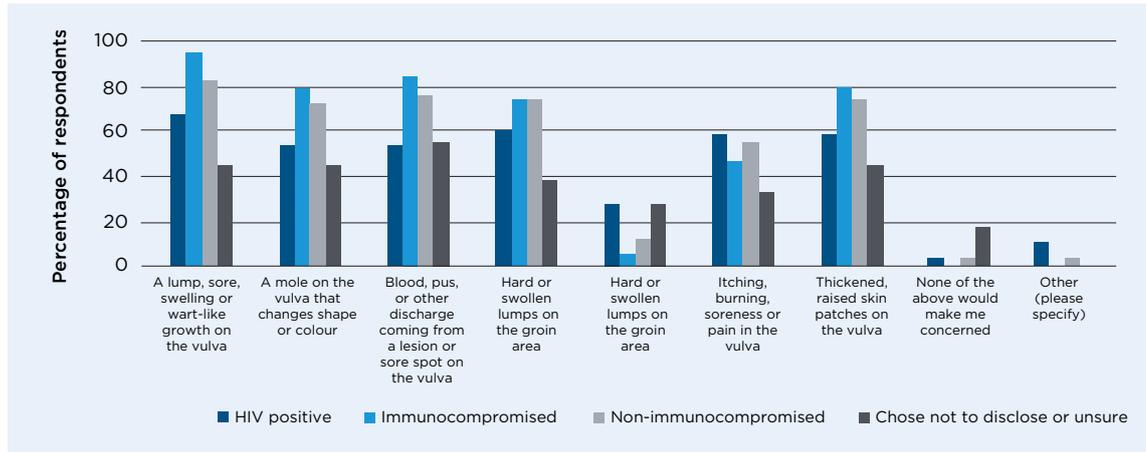


The results indicate that respondents generally had a reasonable understanding of cervical cancer warning signs and symptoms

Vulvar Cancer

Respondents were asked 'Which of the following would make you concerned about vulvar cancer? (Tick as many as you think apply)'. The results indicate that respondents had some understanding of vulvar cancer warning signs and symptoms, although 4% of HIV-positive respondents and 16.65% of respondents who chose not to disclose or were unsure of their HIV status indicated that they would not be concerned by any of the listed symptoms. HIV-positive respondents were also less likely to be concerned than immunocompromised and non-immunocompromised respondents about any of the listed symptoms. The 'other (please specify)' responses included 'I've never heard of vulvar cancer', 'Unsure' and 'Are we meant to check our vulvar for the above listed symptoms?'

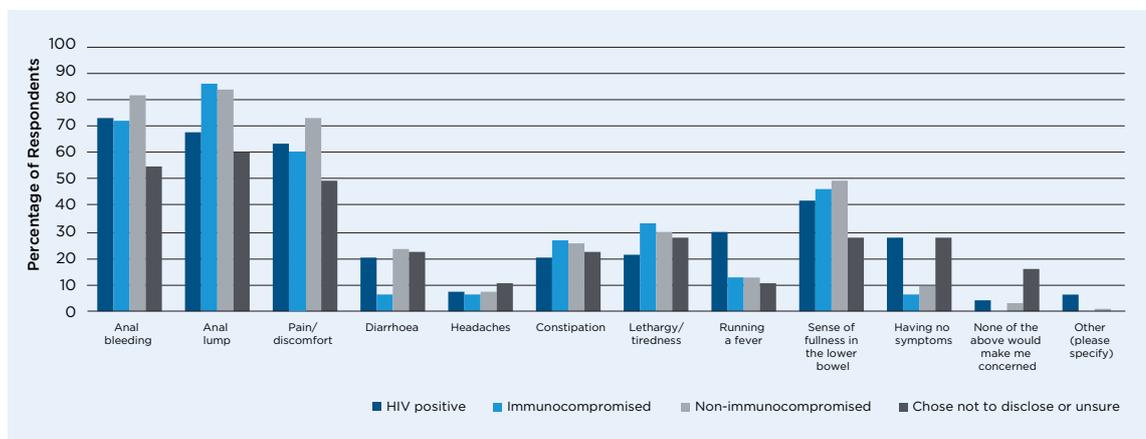
Figure 14: Vulvar Cancer Symptoms Awareness among Different Risk Profile Groups



Anal Cancer

Respondents were asked 'Which of the following would make you concerned about anal cancer? (Tick as many as you think apply)'. The results indicate that respondents had some understanding of anal cancer warning signs and symptoms. 4% of HIV-positive respondents and 16.7% of respondents who chose not to disclose or were unsure of their HIV status indicated that none of the listed symptoms would make them concerned about anal cancer. In addition, HIV-positive respondents were less likely than immunosuppressed and non-immunosuppressed respondents to be concerned about 'anal lump' and 'a sense of fullness in the bowel' as symptoms suggestive of anal cancer. The 'other (please specify)' responses included 'HPV in the anus', 'Mucus discharge from the anus' and 'I have all of the above symptoms all the time, I just cannot determine if it's anal or internal female problems, that scares me to be honest that I don't know'.

Figure 15: Anal Cancer Symptoms Awareness among Different Risk Profile Groups



Screening

Cervical Cancer

Participants were asked *'Have you ever had an abnormal Pap smear test result?'*

Among HIV-positive respondents who answered the question (n=48), 62.5% reported having had an abnormal Pap smear test result and 37.5% reported not having had an abnormal Pap smear test result. None indicated they have never had a Pap smear, highlighting that HIV-positive respondents have good levels of engagement with screening for cervical cancer.

Among HIV-negative but immunocompromised respondents who answered the question (n=19), 31.6% have had an abnormal Pap smear test result, 57.9% have not had an abnormal Pap smear test result, and 10.5% have never had a Pap smear. Considering 10.5% of immunocompromised women had never had a Pap smear, this highlights that there is some lack of understanding of the need for screening for people from higher risk profiles.

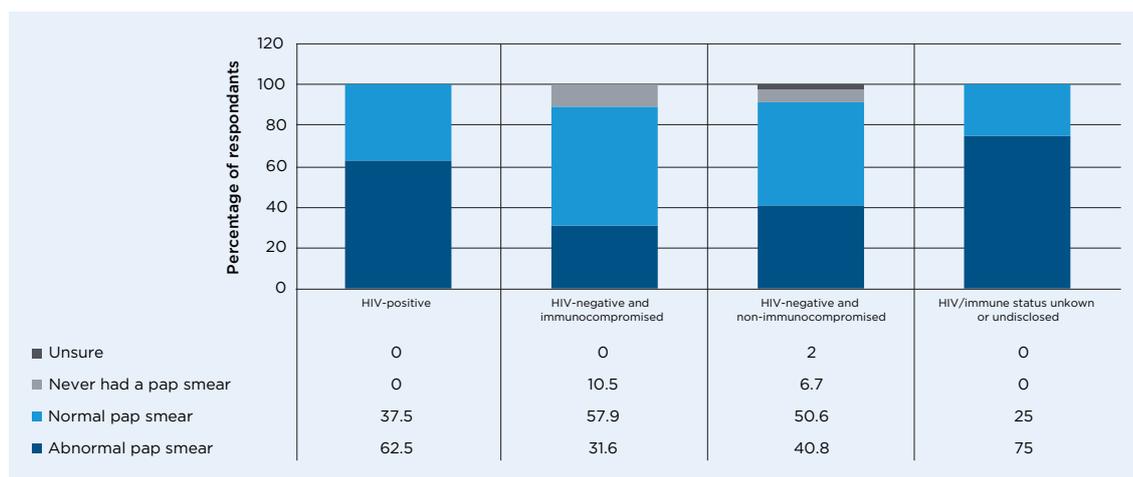
Among HIV-negative, non-immunocompromised respondents who answered the question (n=255), 40.8% have had an abnormal Pap smear test result, 50.6% have not had an abnormal Pap smear test result, 6.7% have never had a Pap smear, and 2.0% were unsure.

Among respondents whose HIV/immune status is unknown or undisclosed who answered the question (n=12), 75.0% have had an abnormal Pap smear test result, and 25.0% have not had an abnormal Pap smear test result.

Cervical Cancer Screening

Figure 16 compares rates of cervical screening in the 4 risk groups surveyed. HIV-positive and HIV/immune status unknown or undisclosed respondents had higher rates of abnormal Pap smear tests than HIV-negative and immunocompromised and non-immunocompromised respondents. According to research, HIV-positive females are more likely to have abnormal Pap smears than HIV-negative females. These abnormal Pap smears are usually associated with low CD4 cell counts and HPV infection. 10.5% of HIV-negative and immunocompromised respondents and 6.7% of non-immunocompromised respondents had never had a Pap smear.

Figure 16 Cervical Cancer Screening in different risk groups



Awareness of new HPV Screening Guidelines and Screening Reminders

Participants were asked *'Do you receive notifications from your doctor or health care provider to let you know when you're due for a cervical screen?'*

Among HIV-positive respondents who answered the question (n=48), 64.6% indicated they do receive screening reminder notifications, while 10.4% organise their own screens and do not receive reminder notifications. 14.6% were not sure if they receive reminder notifications and 10.4% indicated 'other'. The 'other (please specify)' responses included 'No, I don't but I would like to', 'haven't had one for years', and 'I was told I no longer need one at my age'.

Among HIV-negative, immunocompromised respondents who answered the question (n=19), 63.2% receive screening reminder notifications, 26.3% organise their own screens and do not receive reminder notifications, 10.5% indicated 'other'. The 'other (please specify)' responses included 'No' and 'Yes but I also schedule my own every 12 months currently'.

Among non-immunocompromised respondents who answered the question (n=254), 57.1% receive screening reminder notifications, 22.4% organise their own screens and do not receive reminder notifications, 13.0% were not sure and 7.5% indicated 'other'. The 'other (please specify)' responses included 'No', 'I moved and tried, but couldn't get my address changed on the pap smear register', and 'In the UK but not here in Australia', highlighting that mobility is a factor that can impact negatively if someone is signed up to receive screening reminder notifications.

Among HIV/immune status is unknown or undisclosed respondents who answered the question (n=12), 41.7% indicated they do receive screening reminder notifications, while 33.3% organise their own screens and do not receive reminder notifications. 8.3% were not sure if they receive reminder notifications and 16.7% indicated 'other'. The 'other (please specify)' responses included 'So far received reminders from the PAP register', and 'Not since my cervix was removed'.

We then asked those who organise their own screens, *'How often do you plan to ask your doctor for a Cervical Screening (HPV) Test?'* to gauge their awareness of the new screening guidelines. Among HIV-positive respondents, 5.9% plan to ask for a screen every 5 years, none plan to ask for a screen every 3 years (the correct screening guideline for this group), 47.1% were not sure how often to ask for a screen, and 47.1% indicated 'other'. The 'other (please specify)' responses included 'every year', 'every 2 years', and 'can't remember'.

Among HIV-negative, immunocompromised respondents, 14.3% plan to ask for a screen every 5 years, 28.3% plan to ask for a screen every 3 years (the correct screening guideline for some in this group), 28.6% were not sure how often to ask for a screen, 28.6% indicated 'other'. The 'other (please specify)' responses included 'hysterectomy' and 'every 1 to 2 years due to abnormal results last year'.

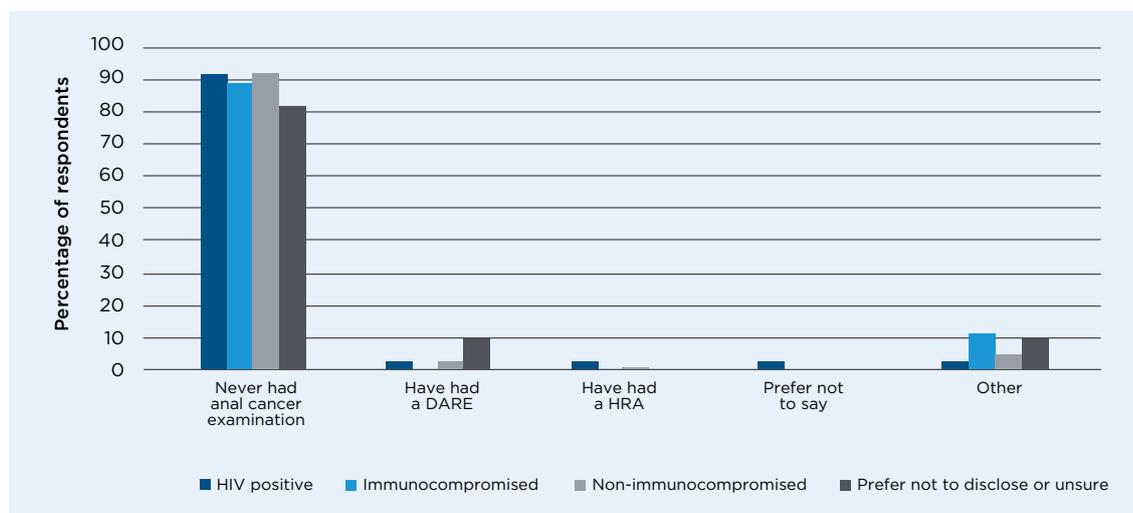
Among non-immunocompromised respondents, 31.2% plan to ask for a screen every 5 years (the correct screening guideline for this group), 14.7% plan to ask for a screen every 3 years, 29.4% were not sure how often to ask for a screen, and 24.8% indicated 'other' (many planned to ask for a screen more frequently than 5 years).

Among HIV/immune status unknown or undisclosed respondents (n=7), 14.3% plan to ask for a screen every 5 years, 14.3% plan to ask for a screen every 3 years, 42.9% were not sure how often to ask for a screen, and 28.5% indicated 'other'. The 'other (please specify)' responses included 'every 6 months to 1 year' and 'I don't'.

Anal Screening

Respondents were asked 'Have you ever had an anal examination for anal cancer?'

Figure 17: Anal Cancer Screening among Different Risk Profile Groups



Among HIV-positive respondents who answered the question (n=48), 91.7% have never had an anal examination for anal cancer, 2.1% have had a Digital Ano-Rectal Examination (DARE), 2.1% have had a High Resolution Anoscopy (HRA), 2.1% preferred not to say, 2.1% have had 'other'. The 'other (please specify)' responses included 'not sure'. In addition, we examined HIV-positive respondents who indicated that they had undergone staging or treatment for either cervical, vaginal, or vulvar cancer (n=8). None of these respondents had ever had an anal examination for anal cancer.

Among HIV-negative, immunocompromised respondents who answered the question (n=18), 88.9% have never had an anal examination for anal cancer, and the remaining 11.1% identified 'other'. The 'other (please specify)' responses included 'colonoscopy' and 'endoscopy'. In addition, we examined responses from HIV-negative, immunocompromised respondents who indicated that they had undergone staging or treatment for either cervical, vaginal, or vulvar cancer (n=3). None of these respondents had ever had an anal examination for anal cancer.

Among non-immunocompromised respondents who answered the question (n=254), 92.5% have never had an anal examination for anal cancer, 2.4% have had a DARE, 0.8% have had an HRA, and 4.3% indicated 'other'. The 'other (please specify)' responses included 'colonoscopy' and 'gastroscopy and endoscopy'.

Among HIV/immune status unknown or undisclosed respondents who answered the question (n=11), 81.8% have never had an anal examination for anal cancer, 9.1% have had a Digital Ano-Rectal Examination (DARE), and the remaining 9.1% have had 'other'. The 'other (please specify)' response included 'colonoscopy'.

When asked 'If you have had an examination for anal cancer, what was it like for you? (optional)', 28.6% of people confused colonoscopy with an examination or screen specifically for anal cancer.

Patient/doctor communication on HPV infection

Respondents were asked *'Has there ever been a conversation between you and your doctor or health professional about HPV-related cancer?'*

Women and, Trans and Gender Diverse People Living with HIV

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.

Among HIV-positive respondents who have had a conversation about HPV-related cancer, 100% had discussed cervical cancer, 14.3% had discussed vulvar cancer, 9.5% had discussed vaginal cancer, and none had discussed anal cancer. When asked, *'Who initiated the discussion?'*, 71.4% indicated a doctor had initiated the discussion, 23.8% indicated they (themselves) initiated the discussion, and 4.8% indicated a nurse or other health care worker initiated the discussion.

Respondents were asked *'How comfortable/uncomfortable are you with talking about cervical, vaginal, vulvar or anal cancers with your doctor?'* Among HIV-positive respondents, 30% felt 'very comfortable', 34% felt 'comfortable', 20% felt 'neither comfortable nor uncomfortable', 2% felt 'uncomfortable', and 14% felt 'very uncomfortable'.

HIV-negative, Immunocompromised Women and, Trans and Gender Diverse People

Among HIV-negative, immunocompromised respondents who answered the question (n=19), 36.8% have had a conversation about HPV-related cancer, and the remaining 63.2% have not had a conversation about HPV-related cancer with their healthcare professional.

Of those who have had a conversation about HPV-related cancer, 100% had discussed cervical cancer, 14.3% had discussed vaginal cancer, none had discussed vulvar cancer, and none had discussed anal cancer. When asked *'Who initiated the discussion?'*, 71.4% indicated that a doctor had initiated the discussion, 14.3% indicated they (themselves) initiated the discussion, and 14.3% indicated they were not sure who initiated the discussion.

Respondents were asked *'How comfortable/uncomfortable are you with talking about cervical, vaginal, vulvar or anal cancers with your doctor?'* Among HIV-negative, immunocompromised respondents, 21.1% felt 'very comfortable', 15.8% felt 'comfortable', 26.3% felt 'neither comfortable nor uncomfortable', 21.1% felt 'uncomfortable', and 15.8% felt 'very uncomfortable'.

Non-immunocompromised Women and, Trans and Gender Diverse People

Among non-immunocompromised respondents who answered the question (n=257), 44.2% have had a conversation about HPV-related cancer, and the remaining 55.8% have not had a conversation about HPV-related cancer with their healthcare professional.

Among non-immunocompromised respondents who have had a conversation about HPV-related cancer, 98.2% had discussed cervical cancer, 6.2% had discussed vulvar cancer, 8.0% had discussed vaginal cancer, and none had discussed anal cancer. When asked *'Who initiated the discussion?'*, 65.5% indicated a doctor initiated the discussion, 20.4% indicated they (themselves) initiated the discussion, and 7.1% indicated a nurse or other health care worker initiated the discussion, and 7.1% were unsure who initiated the discussion.

Respondents were asked *'How comfortable/uncomfortable are you with talking about cervical, vaginal, vulvar or anal cancers with your doctor?'* Among non-immunocompromised respondents, 26.5% felt 'very comfortable', 32.7% felt 'comfortable', 20.2% felt 'neither comfortable nor uncomfortable', 9.3% felt 'uncomfortable', and 11.3% felt 'very uncomfortable'.

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



Women and, Trans and Gender Diverse People whose HIV/immune Status is Unknown or Undisclosed

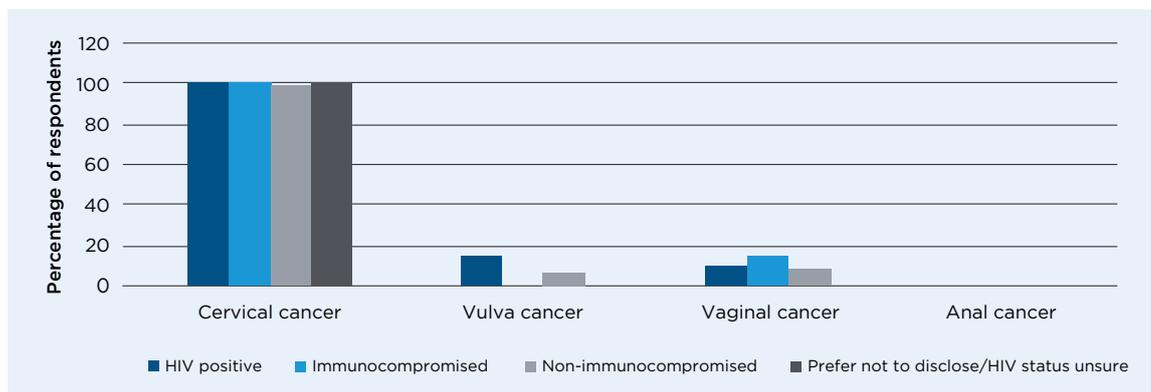
Among HIV/immune status unknown or undisclosed who answered the question (n=12), 50.0% have had a conversation about HPV-related cancer, and the remaining 50.0% have not had a conversation about HPV-related cancer with their healthcare professional.

Among the women and, trans and gender diverse people whose HIV/immune status is unknown or undisclosed who have had a conversation about HPV-related cancer, 100.0% had discussed cervical cancer, and none had discussed vulvar, vaginal or anal cancer. When asked 'Who initiated the discussion?', 50.0% indicated a doctor initiated the discussion, 16.7% indicated they (themselves) initiated the discussion, and 16.7% indicated a nurse or other health care worker initiated the discussion, and 16.7% were unsure who initiated the discussion.

Respondents were asked 'How comfortable/uncomfortable are you with talking about cervical, vaginal, vulvar or anal cancers with your doctor?' Among women and, trans and gender diverse people whose HIV/immune status is unknown or undisclosed who responded, 25.0% felt 'very comfortable', 25.0% felt 'comfortable', 16.7% felt 'neither comfortable nor uncomfortable', 25.0% felt 'uncomfortable', and 8.3% felt 'very uncomfortable'.

Figure 18 illustrates compares the types of HPV-related cancers discussed with health professionals by the different respondent groups. While nearly 100% of respondents from all 4 groups (HIV-positive, immunocompromised, non-immunocompromised and prefer not to disclose/HIV status) had discussed cervical cancer with their doctors, very few respondents had discussed cancer of the vulva or vagina, and no respondents had discussed anal cancer.

Figure 18: Patient/Doctor Discussion about HPV-Related Cancers



Communication Barriers when Discussing HPV-Related Cancers (doctor/patient)

Respondents were asked the open-ended question ‘*What would help make the conversation with your doctor or health professional more comfortable and/or less embarrassing?*’ Table 1 reports the themes from total short answer responses from all risk profile groups (n=215). Please note that some responses had multiple themes.

Table 1: What Would Help Make the Conversation with your Doctor or Health Professional More Comfortable and/or Less Embarrassing?

Responses	n
If the doctor initiated the discussion	34
I am already comfortable having this conversation	29
Nothing, the conversation is uncomfortable regardless	28
A female doctor/nurse	26
Unsure or haven't had the conversation yet	23
Having more information or resources available to prepare myself for a conversation	22
Having the conversation with a doctor I am familiar with, who has built rapport/trust and is comfortable and confident talking to me	20
Making the discussion a routine process or part of a regular check-up	12
A non-judgmental, approachable and open doctor	10
Having a less clinical, clear, and easy-to-understand conversation	9
Normalising talking about HPV/ less stigma	8
A straight-forward, factual, and professional doctor	6
Knowing the doctor is LGBTIQ and gender sensitive, or knowing they have done sensitivity training	5

Clinical Disregard for HPV-Related Cancers and/or Abnormal Symptoms

Participants were asked the open-ended question ‘*Have you tried to talk with your doctor about HPV-related cancers or abnormal symptoms and got an unsatisfactory response?*’ 9.8% of respondents said ‘Yes’. When we asked respondents to describe their health professional’s unsatisfactory response 27 respondents answered the question. Table 2 outlines the themes in responses. Please note that some responses had multiple themes.

Table 2: Have you tried to talk with your doctor about HPV-related cancers or abnormal symptoms and got an unsatisfactory response?

Responses	n
Doctor dismissed symptoms/concerns or did not take me seriously	11
Downplayed risk or did not offer a test when I asked	9
Unclear or unsatisfactory explanation of HPV-related questions	4
I felt the doctor was too clinical or cold	3
Long wait times in between test results and referral/treatment	2

Information, Resources and Support

Participants were asked the open-ended question ‘What information, resources, or support do you need to increase your chance of detecting HPV-related cancer early?’ Table 3 reports the most common themes. Please note that some responses had multiple.

Table 3: What information, resources, or support do you need to increase your chance of detecting HPV-related cancer early?

Responses	n
Nothing	67
More public awareness of general HPV information/ normalising HPV	59
Information/ checklists on symptoms of HPV-related cancers	47
Unsure	46
Information on prevention (vaccination or screening)	34
Information from doctors or at clinics	39
Accessible information online, in the media, or campaigns	31
Receiving screening reminder notifications	27
Being able to get a screen from a GP regularly	13
Information on risk, tailored to specific risk profile	12
Pamphlets, brochures, or leaflets	12
Doctor initiated discussions	11
Information on the new Cervical Screen test and recent changes	8
Information on the rarer cancers: anal, vaginal, vulvar	7
Information on Medicare coverage and cost of the HPV vaccine	5
Gender-neutral information	5
Age-specific information/information for older women or women who are no longer sexually active	5
Finding a non-judgemental doctor, you have a comfortable relationship with	5
Information sent directly to me	5
Making testing less intrusive/ embarrassing; self-swab	3
More sexual health clinics	2
Social support or a network of people who have been through the same things	2

Other Respondent Comments

We have chosen to highlight some specific comments from respondents below when asked *'What information, resources, or support do you need to increase your chance of detecting HPV-related cancer early?'*

People said:

- *'I would like to have tests and more info for all these cancers, so they can be detected and treated early.'*
- *'A checklist of symptoms and a list, say if you do anal, should you get a test every so many years etc. Gay men have heaps of info we women don't.'*
- *'Normalising testing; No need to reschedule for a separate appointment, just do it while you go to the doctor/GP for any health issue.'*
- *'Does the new test have a risk of false positives for trans men using testosterone like the old pap smear test does? i.e. does the atrophying that happens to trans men affect the tests ability to detect?'*
- *'How is it possible that you can screen less for cervical cancer and the new test will save more lives?'*
- *'I'm in a higher risk category. I don't have enough information on the new screening procedure and if it actually applies to me or if I still need to continue having annual pap smears to minimise the risk of HPV-related cancer. Specific information geared towards women in my situation would be helpful to make an informed decision about future prevention-related screenings.'*
- *'More information from credible sources such as Cancer Council, Cancer Institute, NSW Health, etc. that reach younger demographics where we live, work, and socialise. Not just the generic information; 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, but this information isn't readily available without some prior knowledge to know what search for. Some more information on support provided before, during, and after abnormal results, diagnostic tests and surgeries regarding how this will affect my body and my life moving forwards depending on the range of potential outcomes. And potentially a network of people who have been through this process before and know what it feels like so can give first-hand advice.'*
- *'Just a little info? I try to keep up with all that's happening and progressing however this survey has put the importance of HPV back on my radar for my upcoming apt.'*

Discussions and conclusions

HIV-positive and HIV-negative, immunocompromised women and, trans and gender diverse people are at increased risk of HPV-related cancers of the cervix, vagina, vulva, anus, mouth and throat. While significant progress has been made in the early detection of cervical cancer, less progress has been made in the area of anogenital HPV-related cancer, particularly anal cancer. Findings from this survey identify important knowledge deficits in HPV-related cancer risk awareness, symptom recognition, screening and HPV vaccination among these at-risk population groups. With this information, we have the ability to construct targeted education initiatives that address knowledge deficits and help to reduce morbidity and mortality from late diagnosis of HPV related cancers: particularly anal cancer.

A substantial proportion of HIV-positive and HIV-negative and immunocompromised respondents to this survey incorrectly perceived their risk of cervical, vaginal, vulvar and anal cancer to be the same or lower than the general female population (for example, 60% of HIV-positive and 89% of HIV-negative and immunocompromised respondents perceived their risk of anal cancer to be the same/lower/much lower than the general female population. 22% of HIV-positive respondents perceived their risk of anal cancer to be much lower than the general female population). The incidence of anal cancer in HIV-positive women is anywhere between 7 and 28 times higher than the general female population and the incidence of anal cancer in solid organ transplant recipients is 12.3 per 100,000 or approximately 6 times higher than the general population. There is therefore a need to raise awareness of HPV-related cancer risk among HIV-positive and HIV-negative and immunocompromised women and, trans and gender diverse people.

While all risk groups had some understanding of the signs and symptoms of cervical, vaginal, vulva and anal cancer, HIV-positive respondents and respondents who chose not to disclose or were unsure of their HIV status, generally were less likely than immunosuppressed and non-immunosuppressed respondents to be concerned about the listed signs and symptoms for cervical, vaginal, vulvar and anal cancer (for example, 4% of HIV-positive respondents and 16.7% of HIV-negative and immunocompromised respondents thought that none of the listed symptoms would make them concerned about anal cancer). In addition, HIV positive respondents were less likely than other respondents to be concerned about 'anal lump' and 'a sense of fullness in the bowel'. Both these symptoms are highly associated with invasive anal cancer. These results indicate a need for education and awareness raising about the signs and symptoms of all HPV-related cancers, but particularly anal cancer in HIV-positive and immunocompromised women and trans and gender diverse people.

In relation to screening: high percentages from all risk groups surveyed reported having had Pap smear tests. However, with the introduction of new cervical screening guidelines, there is confusion about how often to have a Pap smear test. For example, 47.1% of HIV-positive respondents and 28.6% of HIV-negative, immunocompromised respondents (who organise their own screens) were not sure how often to request a Pap smear. There is a need for education on the new screening guidelines among higher risk groups, and a need for health care providers to discuss screening intervals with their patients, particularly those who organise their own screening regimens. The results also highlight a significant number of respondents who intended to request cervical screens more frequently than needed under the new guidelines.

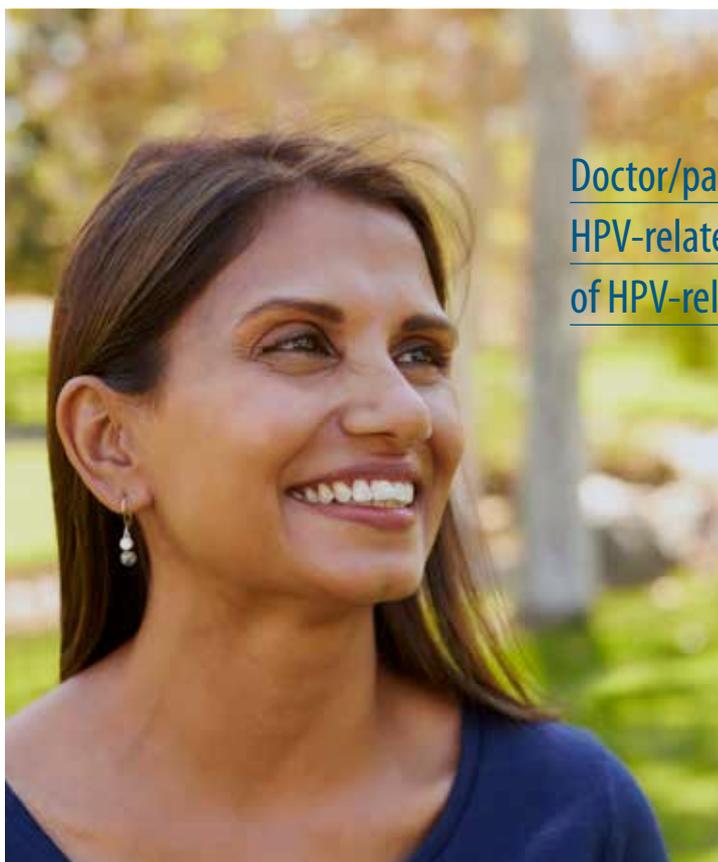
HIV-positive and HIV-negative,
immunocompromised women and, trans
and gender diverse people are at increased
risk of HPV-related cancers



While high percentages of respondents from all risk groups had regular screening for cervical cancer, the opposite was true for anal cancer screening. Very high proportions from all risk groups had never been screened for anal cancer (for example, 92% of HIV-positive respondents and 89% of HIV-negative and immunocompromised respondents had never had an anal cancer examination). Those who reported having been screened for anal cancer, reported having either a DARE or HRA. There was some confusion however between what constituted an anal cancer examination. For example, some respondents thought a colonoscopy, gastroscopy or endoscopy constituted an anal cancer examination. These results indicate the need for education and awareness raising initiatives to increase rates of anal cancer screening in at risk groups and to differentiate between anal cancer screening procedures (DARE and HRA) and other gastrointestinal examinations.

Doctor/patient communication on HPV-related cancer is vital in raising awareness of HPV-related cancer symptoms, screening for HPV-related cancers and preventing infection with high risk HPV via vaccination. While nearly all respondents had talked with their doctor about HPV and cervical cancer, very few had discussed cancer of the vulva or vagina with their doctor, and none had discussed anal cancer. HIV-negative and immunocompromised respondents and respondents who either were unwilling to disclose their HIV status or did not know their HIV status, were also more likely to be uncomfortable or very uncomfortable talking about HPV-related cancers with their doctor. These results indicate the need for clinicians caring for HIV-positive and immunocompromised women and trans and gender diverse people to initiate discussion with their patients about regular screening for cancer of the vulvar, vagina and anus, and to undertake anogenital examination. Furthermore, 27 respondents reported trying to talk with their doctor about HPV-related cancers or abnormal symptoms and getting an unsatisfactory response. The most frequently reported response was 'the doctor dismissed their concerns and did not take them seriously, or they downplayed the risk and did not offer a test or screening'. These findings point to the need for clinicians to be more proactive and responsive regarding HPV-related cancer among these population groups and to discuss the risks, symptoms and need for screening with their patients.

Rates of HPV vaccination were also concerning. HPV vaccines have been shown to be highly effective in preventing infection and reinfection with a range of HPV genotypes, including high risk HPV genotypes. While rates of HPV vaccine awareness were generally high in all risk groups surveyed, particularly HIV-negative and immunocompromised respondents, rates of discussion with doctors about HPV-vaccination were generally low (less than 38%). HIV-positive respondents were less likely to have discussed HPV vaccination. They were also less likely to be aware of HPV vaccination along with HIV/immune status unknown/undisclosed respondents. Rates of HPV vaccination amongst all groups surveyed were very low. For example, only 5.6% of HIV-positive respondents and 17.7% of HIV-negative and immunocompromised respondents had received Gardasil Quadrivalent or Gardasil 9 valent. Rates of HPV vaccination were higher in HIV-negative non-immunocompromised respondents (30.4%). We also noted of those who had not been vaccinated, a half of total respondents and one third of HIV-positive respondents were under 44 years. 10% were under 25 years. These findings identify a need to raise awareness of the benefits of HPV vaccination in all risk group, but particularly among younger women and, trans and gender diverse people.



Doctor/patient communication on HPV-related cancer is vital in raising awareness of HPV-related cancer symptoms

Limitations

While the survey results have given Positive Life NSW and Femfatales a better understanding of knowledge and practice deficits and the need for education and advocacy for women and, trans and gender diverse people living with HIV and those who are immunocompromised: the study does have limitations. Cross-sectional, self-reported surveys can be susceptible to bias due to low response rates and recall bias.

While the survey was open for approximately 2 months, we were only able to engage with 51 HIV-positive women and, trans and gender diverse people. This is a relatively low sample size and may not be representative of the targeted Australian population groups (3,349 women were living with HIV in Australia in 2017).²³ Unfortunately, data on Australian trans and gender diverse people is inadequately captured within the national HIV surveillance data.

The survey respondent sample is also not representative of the cultural and linguistic diversity of women and, trans and gender diverse people living with HIV. While the survey was disseminated to HIV community organisations (both National: Femfatales and NAPWHA, and state and territory PLHIV organisations: New South Wales, Queensland, Victoria and South Australia), dissemination was primarily through membership networks where contact with women and, trans and gender diverse people from cultural and linguistically diverse backgrounds is limited. We also failed to get broad support from mainstream clinical networks where access to a more representative sample may have been achieved. In addition, the survey was not available in any language other than English.

The respondent sample under-represents participants aged 18–24 years and 65 years and over and over-represents participants in the middle age-brackets (25–34 years, 35–44 years, 45–54 years and 55–64 years). The sample also over-represents women and, trans and gender diverse people living with HIV in Victoria and South Australia, and under represents women and, trans and gender diverse people living with HIV in Queensland. Aboriginal and/or Torres Strait Islander respondents are over-represented, comparative to the general female Australian population. The sample also over-represents participants who identify as bisexual, queer, lesbian, gay or homosexual, comparative to the general Australian population. We also acknowledge that trans and gender diverse people living with HIV who do not identify as women may be underrepresented due to the survey design and promotion strategy. As the survey was primarily promoted online, this may have excluded certain people with low computer literacy skills or people who do not have internet access and may not have had a clinical appointment scheduled within the 2-month time frame when access to a paper copy of the survey was available.

The survey concentrated on anogenital HPV-related cancers and did not investigate awareness and screening for oropharyngeal cancer. This decision was made to limit the length of the survey and the time taken by respondents.

Implications and significance

The results of this survey have identified 7 key areas that warrant action:

1. Raising awareness of HPV-related cancer risk and symptoms (cervical, vaginal, vulvar, and anal) among women and, trans and gender diverse people living with HIV, and immunocompromised women and, trans and gender diverse people;
2. Increasing screening for anogenital HPV-related cancers and particularly anal cancer among women and, trans and gender diverse people living with HIV, and immunocompromised women and, trans and gender diverse people;
3. Increasing vaccination rates among HIV-positive and immunocompromised women and, trans and gender diverse people;
4. Increasing awareness of the new National Cervical Screening Guidelines;
5. Increasing clinician awareness of the need for entire lower anogenital tract examinations among women and, trans and gender diverse people living with HIV, and immunocompromised women and, trans and gender diverse people;
6. Increasing clinician-initiated discussion of HPV-related cancers; among women and, trans and gender diverse people living with HIV, and immunocompromised women and, trans and gender diverse people; and
7. Increasing awareness of HPV-related cancers in the general public and sexual health for women (cis and trans), trans men and gender diverse people.

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