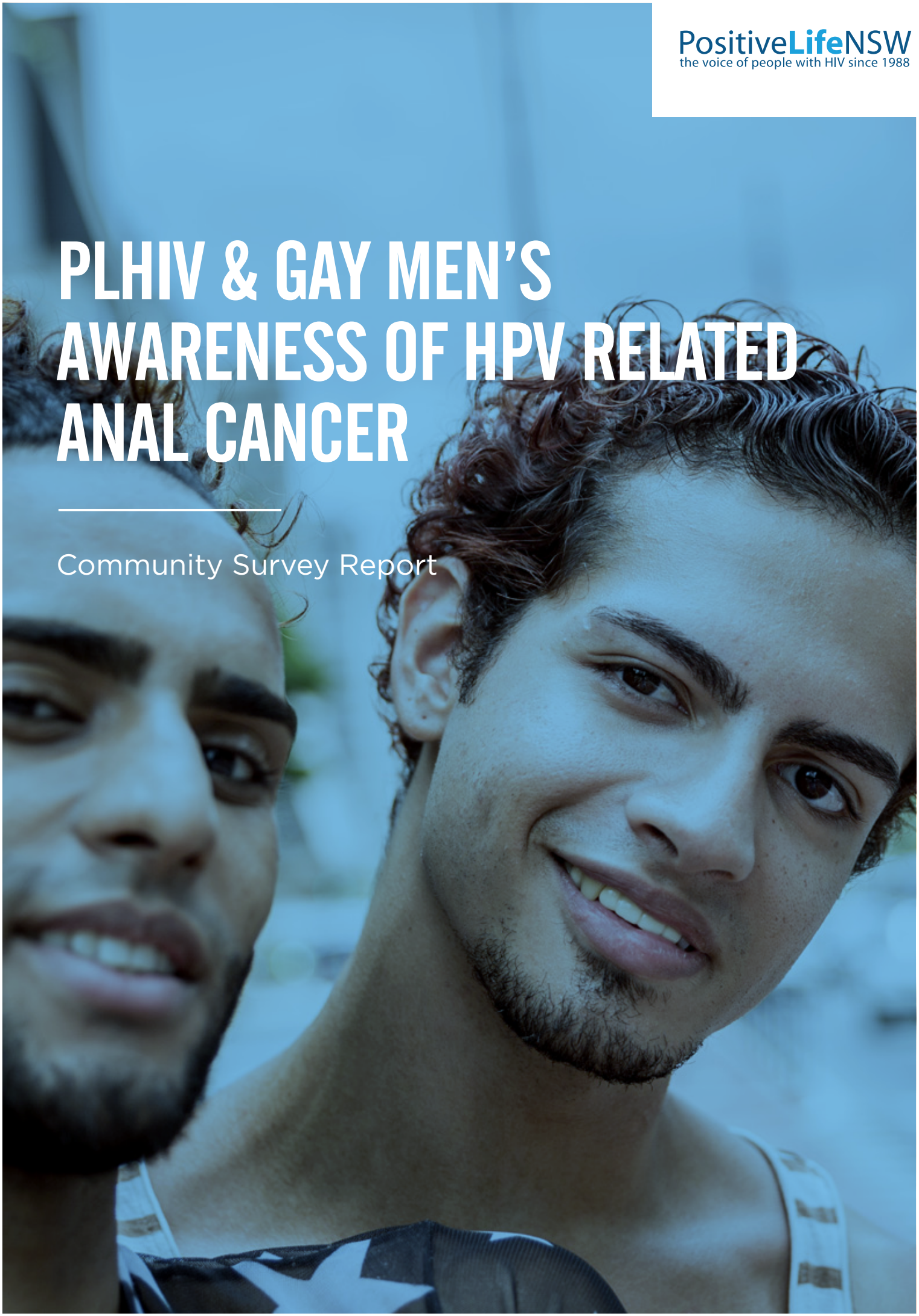
PositiveLifeNSW
the voice of people with HIV since 1988

PLHIV & GAY MEN'S AWARENESS OF HPV RELATED ANAL CANCER

Community Survey Report



Acknowledgements

Thank you to the people who took time to answer the survey, share their knowledge and experience of anal HPV and anal cancer, and contributed to this valuable community study.

Positive Life acknowledges and thanks the following individuals for contributing their time and expertise to the community study and report:

Author and project coordination: Mr Lance Feeney, Consultant.

Questionnaire development: Mr Matthew O'Dwyer, Dr Richard Hillman, Dr David Templeton, Mr Craig Cooper, Mr David Crawford.

Participant recruitment: Mr Craig Andrews.

Preliminary methodology, data analysis and reporting: Mr Matthew O'Dwyer.

Assistance with final methodology, data analysis and reporting: Dr Jeff Jin, Dr Mary Poynten, Dr Richard Hillman.

Review: Mr Craig Cooper, Dr Mary Poynten, Mr David Crawford, Ms Elizabeth Sutherland, Mr Craig Andrews, Mr Joel Murray.

Other assistance: Mr Craig Cooper, Mr David Crawford, Ms Jane Costello, Ms Elizabeth Sutherland, Mr Craig Andrews.

Ethics: South Eastern Sydney Local Health District Human Research Ethics Committee.

Positive Life NSW

Suite 5.2, Level 5, 414 Elizabeth Street, Surry Hills NSW 2010
Phone (02) 9206 2177 Email contact@positivelife.org.au Website www.positivelife.org.au

Contents

List of Acronyms

ACAG	Anal Cancer Advocacy Group
AFAO	Australian Federation of AIDS Organisations
ASHM	Australasian Society of HIV, Viral Hepatitis & Sexual Health Medicine
DARE	Digital Ano Rectal Examination
GBM	Gay, Bisexual Men
HPV	Human Papillomavirus
HSIL	High grade squamous intra epithelial lesions
NAPWHA	National Association of People with HIV Australia
NSW	New South Wales
PLHIV	People Living With HIV
SPANC	Study of the Prevention of Anal Cancer – Kirby Institute, University of NSW
UNSW	University of NSW
HIV	Human Immunodeficiency Virus

1.0 Executive Summary

1.1 Background

- In the context of rising numbers of people living with HIV (PLHIV) being diagnosed with anal cancer, Positive Life NSW (Positive Life) surveyed PLHIV and gay, bisexual men (GBM) via an anonymous online questionnaire, to assess awareness of, screening for, and prevention of anal human papillomavirus (HPV) infection and anal cancer in New South Wales, Australia.
- A total of 1,660 responses were received to the survey.
- Survey results were intended to inform development of education resources to raise awareness of anal cancer in at-risk NSW populations, clinicians and service providers.

1.2 Method and Data Analyses

- The majority of responses were received from people who indicated they were assigned male sex at birth (n=1,574) and predominately GBM (n=1,535, 97.5%). Only a small number of responses were received from HIV positive people who indicated they were assigned female sex at birth (n=4) and HIV negative/unknown women (n=33). Analyses therefore focused on HIV positive and HIV negative/unknown people who indicated they were assigned male sex at birth.
- Results for people living with HIV and HIV negative/unknown people who indicated they were assigned female sex at birth were reported separately in this report, and in less detail.
- Awareness of anal cancer risk, knowledge of symptoms suggestive of anal cancer, experience with anal cancer screening and HPV vaccination were assessed in relation to HIV status and age.
- Results were reported as percentages and numbers.
- Respondents who participated in the SPANC study were excluded from the analysis due to their increased exposure to information about HPV and anal cancer.
- HIV unknown respondents were grouped with HIV negative.

1.3 Results for HIV negative/unknown and HIV positive people who indicated they were assigned male sex at birth

- Responses from 1,574 HIV negative/unknown and PLHIV who indicated they were assigned male sex at birth were included in these analyses. Of these, 1,564 (99.5%) reported their current gender identity as men and eight (0.5%) reported their current gender identity as women.
- 1,349 (85.7%) identified as '*Gay/Homosexual/Queer*', 186 (11.8%) identified as '*Bisexual*' and 39 (2.5%) identified as '*Other*'. Of the 39 individuals who identified as '*Other*', further analysis revealed that 23 (1.5%) were '*Heterosexual*' and 16 (1%) identified as '*Pansexual*' or '*Gay*'.
- The majority of respondents were aged 25–54 years (77.2%).
- 1,309 (84.4%) identified HIV negative/unknown status, 243 (15.7%) identified HIV positive status and 105 (6.8%) identified HIV unknown status.
- Across all age groups, the majority of respondents underestimated their risk of developing anal cancer. When respondents of different HIV status were compared, over two thirds of HIV negative/unknown (68.1%) and half of HIV positive (51.8%) respondents underestimated their risk of developing anal cancer.
- Most respondents correctly identified anal bleeding, anal lump and anal pain as symptoms suggestive of anal cancer. Diarrhoea, constipation, tiredness, fever and headaches were less commonly identified as symptoms suggestive of anal cancer by both HIV negative/unknown and HIV positive respondents
- Across all age groups, most respondents had not talked with their doctor about HPV and anal cancer (range: 83.9% to 93.3%). Younger men were more likely to not have talked with their doctor about HPV and anal cancer than older men. More HIV negative/unknown men (89.2%) than HIV positive men (72.3%), had not talked with their doctor about HPV and anal cancer.
- Where there had been a discussion about anal HPV and anal cancer between doctor and patient, in more than half of cases (56.6%), the conversation was patient initiated.
- Approximately one third (31.8%) were either '*Uncomfortable*' or '*Very uncomfortable*' discussing anal HPV and anal cancer with their doctor.
- The majority across all age groups could not recall ever having had an anal cancer examination. The proportion ranged from 95.7% of those aged 18–24 years to 70.5% of those aged 55 years and older. When results were compared by HIV status, most HIV negative/unknown and HIV positive men had not had an anal examination for anal cancer (88.6% and 71.1% respectively), however HIV negative/unknown men were significantly less likely to have had an anal examination for anal cancer than HIV positive men (p=>0.001).
- The proportion of men who had never had a digital anal rectal examination (DARE) increased from 68.2% of those aged 55 years and older to 95.1% of those aged 18–24 years. When HIV status of respondents was compared, HIV negative/unknown men were less likely to have ever had an anal cancer examination (89.4%) than HIV positive men (72.4%).
- Across all age groups, the majority of men were unaware of HPV vaccination (59.5% – 64.9%). HIV negative/unknown men were more likely (62.9%) than HIV positive men (55.5%) to be unaware of HPV vaccination. The majority of men across all age groups had not received HPV vaccination and the proportion increased from 91.1% of those respondents aged 18–24 years, to 100.0% of those respondents aged 55 years and older.

1.4 Results: HIV positive people who were assigned female sex at birth

We received four responses from HIV positive people who indicated they were assigned female sex at birth. Three reported their current gender identity as men and one identified as a woman. As the number of respondents was low, no further analyses were undertaken to protect the identity of participants.

1.5 Results: HIV negative/unknown people who were assigned female sex at birth

- Responses from 33 HIV negative/unknown people who were assigned female sex at birth were received.
- Half identified as '*Heterosexual*' 15 (45.5%), nine (27.3%) identified as '*Gay male* or *homosexual*', three (9.1%) identified as '*Bisexual*', three (9.1%) identified as '*Queer*', two (6.1%) identified as '*Lesbian*', and one (3.0%) identified '*Differently*'. No inferences could be drawn from the data.

1.6 Results: HIV positive trans and gender diverse people

- 15 respondents indicated their current gender identity as men, but that they were assigned female sex at birth. This may indicate a trans or gender diverse experience, however, two of these respondents reported they had intersex characteristics. 10 (66.7%) reported their status as '*HIV negative*', three (20.0%) reported their HIV status as '*HIV positive*', one reported their status as '*HIV unknown*' and one 'preferred not to say'.
- Eight respondents indicated their current gender identity as women, but that they were assigned male sex at birth. This may indicate a trans or gender diverse experience. Seven (87.5%) identified their HIV status as '*HIV negative*' and one identified their HIV status as '*HIV positive*'.
- No inferences could be drawn from the data due to the small sample size and no further analyses were undertaken to protect the identity of the participants.

1.7 Conclusions

- Compared to the general population, HIV positive GBM, HIV positive non-GBM and HIV negative GBM, are at substantially increased risk of anal cancer. HIV positive GBM have a 50 fold risk when compared to the general population.
- 63% of anal cancers are diagnosed late and require treatment with chemo/radiotherapy, and in some cases radical surgery. Recovery from chemo/radiotherapy and surgery is often protracted and extremely challenging for the individual treated for anal cancer.
- Despite the increased risk of HPV-related anal cancer, HIV positive and HIV negative GBM demonstrated poor levels of awareness. Two thirds of HIV negative/unknown GBM and half of HIV positive GBM underestimated their risk.
- Rates of screening for anal cancer were also poor. Only a third of HIV positive men and about one tenth of HIV negative/unknown men had received an anal cancer examination (DARE). Of particular concern was the low proportion of older GBM who had received a DARE (~19% of men aged 45–54 years and ~32% of men aged 55 years and older).
- Rates of HPV vaccination were also poor. Less than 9% of men aged 18–24 had received HPV vaccination.
- The low numbers of HIV positive women (cis and trans) who responded to the survey was disappointing. We were therefore unable to assess whether HIV positive women had low awareness and screening for anal cancer, but consider it possible. Further work is necessary to establish levels of awareness and screening for HIV-related anal cancer in HIV positive women.
- The role of doctors is crucial in educating PLHIV and GBM about anal caner and the need for regular screening. However, our survey demonstrated poor levels of doctor-patient communication about anal cancer, with the majority of men never having discussed anal cancer with their doctor.

Despite the increased risk of HPV-related anal cancer, HIV positive and HIV negative gay and bisexual men demonstrated poor levels of awareness

1.8 Anal cancer education and advocacy

- The Study of the Prevention of Anal Cancer (SPANC) has contributed to raising community awareness of HPV related anal cancer in Sydney GBM.
- A range of studies are currently in development to trial the effectiveness of novel therapies to treat HSIL (anal cancer precursor lesions). A further study is being developed to assess the effectiveness of testing HPV genotypes as a screening tool.
- The Anal Cancer Advocacy Group (ACAG) successfully organised an anal cancer symposium at the ASHM Australasian HIV/AIDS Conference 2016 to raise awareness of HPV related anal cancer amongst clinicians and HIV sector service staff.
- Specialist anal cancer diagnostic services have been secured at St Vincent's Hospital and Royal Prince Alfred Hospitals, Sydney, after sustained advocacy by Positive Life and ACON.
- NAPWHA, AFAO and Positive Life have worked to raise community and HIV sector awareness of HPV related anal cancer through education resources and seminars to community and HIV service staff.
- A protocol for self/partner administered DARE has been developed by Positive Life.
- National anal cancer screening guidelines have been implemented by ASHM.

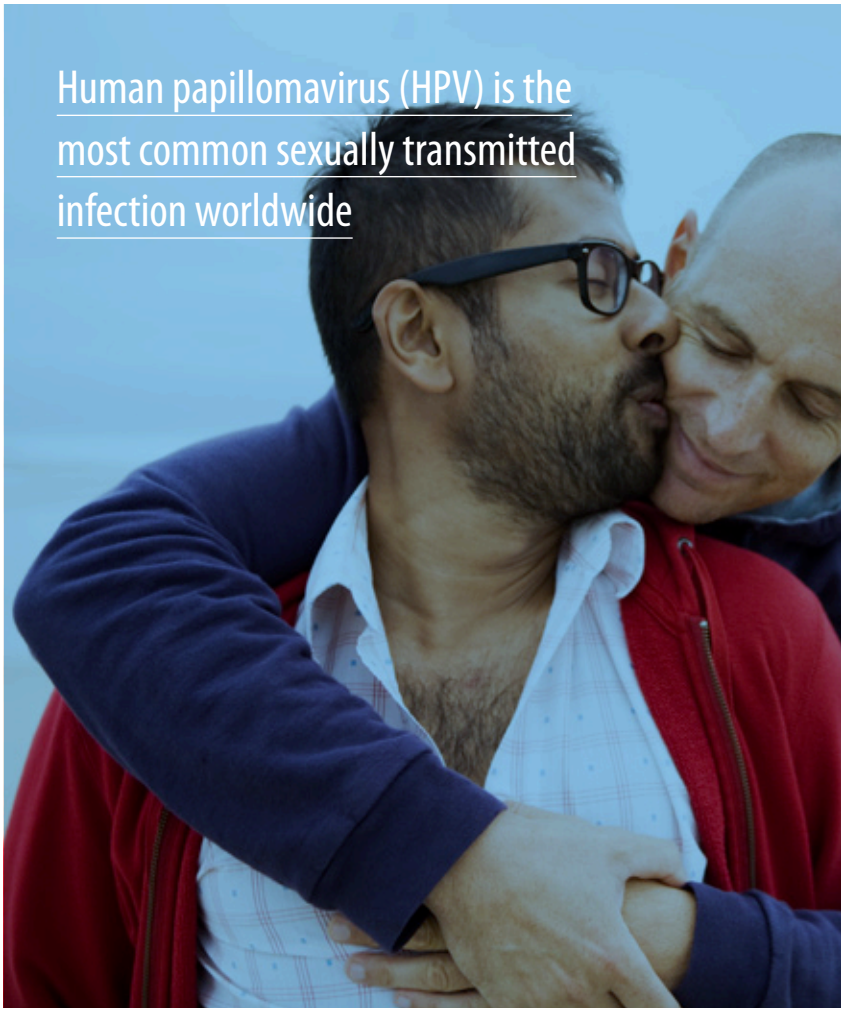
1.9 Recommendations

- State and territory PLHIV organisations, AIDS Councils and their peaks (NAPWHA and AFAO), prioritise the resourcing, development and distribution of education resources that increase awareness of, and screening for anal cancer in Australian PLHIV and HIV negative GBM.
- State and territory PLHIV organisations, AIDS Councils and their peaks (NAPWHA and AFAO) work with ASHM to educate doctors about the need for anal cancer screening in PLHIV and GBM, particularly in GBM living with HIV over the age of 50 years.
- Positive Life, with support from NAPWHA and Femfatales, develops and implements a community-based electronic national survey targeting HIV positive women: 1) to raise awareness of HPV related cancer, including anal cancer, and 2) to assess awareness of risk and knowledge of symptoms suggestive of HPV related cancer, experience with screening and HPV vaccination.
- A working group is convened to: 1) advocate to state and territory health departments for the free provision of HPV vaccination to GBM aged ≤ 26 years at sexual health clinics around Australia, 2) develop education resources to promote self and partner administered DARE in PLHIV and GBM, 3) progress pathology and cytology item numbers for anal cancer diagnostic tests, 4) increase doctor and patient awareness of HPV related anal cancer in PLHIV and GBM via conference presentations, publications and training, and by peer led education sessions at NAPWHA members meetings and the Treatment Outreach Network.

2.0 Introduction

2.1 What causes anal cancer

Human papillomavirus (HPV) is the most common sexually transmitted infection worldwide. HPV is much more infectious than HIV and most people encounter HPV with their first sexual partners. Condoms only marginally reduce transmission. Oral sex and fingering spread HPV. HPV causes anal and genital warts and also about five percent of all cancers. Cervical cancer and anal cancer are two of the more common HPV-related cancers, although HPV can also cause penile, vaginal, vulvar, mouth, and tongue and throat cancer. There are over 100 different genotypes (strains) of HPV; however, HPV strains 16 and 18 are linked with 90% of anal cancers. Most people are unaware they have been infected with HPV and their immune system goes on to clear the virus, although reinfection can occur. Some people are less able to clear HPV infection, especially PLHIV and those that smoke tobacco. Persistent HPV infection leads to pre-cancerous lesions known as high grade squamous intraepithelial lesions (HSIL) and in some cases these pre-cancerous lesions develop into cancer.



2.2 The risk of anal cancer in PLHIV, Gay and Bisexual Men

While anal cancer is rare in the general population (there are 1–2 cases per 100,000 individuals per year),[1] anal cancer is significantly more common in PLHIV and GBM. HIV positive GBM experience the highest rates of anal cancer (approximately 50+ times that of the general population or 70–130 cases of anal cancer per 100,000 individuals per year).[2] This makes it one of the most common cancers for HIV positive GBM, after lymphoma and Kaposi's sarcoma.[3] HIV positive heterosexual men and women also have an increased risk of anal cancer with an incidence rate of 10–30 per 100,000 individuals per year, or 10+ times that of the general population.[4] HIV negative GBM have an anal cancer annual incidence rate of 5–20 per 100,000, or a risk rate 5+ -20 times that of the general population.[5] In addition, the risk of anal cancer increases with age, and smoking tobacco is an independent risk factor.

2.3 Diagnosis of anal cancer

Anal cancer often presents late and at an advanced stage, with a large tumour present. The treatment for late presentation of large anal tumours is typically a combination of chemotherapy, radiotherapy and surgery. The five-year life expectancy, post-treatment for anal cancer, is approximately 50–60%. However, tumours of 1cm or less can be treated by surgical incision with near 100% cure, and thus potentially avoiding the necessity for treatment with chemo/radiotherapy and surgery. Early detection of anal cancer is therefore crucial. Why anal cancer is not more often identified in its early stages is thought to be due in part to cultural and societal stigma associated with anal issues and anal sex. Anal stigma is thought to be a contributing factor preventing some people from raising the issue of anal cancer with their doctor and the doctor not raising the issue of anal cancer with their patient.

While doctors can claim the cost of performing a DARE through Medicare, no Medicare item number/s currently exists for anal cancer pathology and cytology testing. This systemic impediment significantly reduces general practice's ability to effectively screen for anal cellular abnormalities associated with infection with high risk strains of HPV and early stage anal cancer. ASHM has agreed to progress the case with the federal government and Medicare, however an outcomes is yet to be achieved.

1. A Grulich, Kirby Institute, 2017 presentation.
2. Ibid.
3. E Lanoy, et al, Int. J. Cancer, 2011 129: 467-475. doi:10.1002/ijc.25903.
4. A Grulich, Kirby Institute, 2017 presentation.
5. Ibid.

3.0 The Survey

3.1 Background, development and implementation of the Anal Cancer Awareness Survey

Positive Life has viewed with increasing concern the number of PLHIV diagnosed with anal cancer and the associated mortality rates. Involvement in the Kirby Institute University of NSW-led *Study for the Prevention of Anal Cancer* (SPANC), and exposure to international anal cancer research, has focused Positive Life's attention on the incidence of chronic anal HPV infection and anal cancer in PLHIV and GBM. The Anal Cancer Advocacy Group (chaired by Positive Life)[6] flagged the need to increase community awareness of anal cancer and screening in populations at increased risk. And so, in 2015 Positive Life with support from members of the ACAG, developed an anonymous electronic survey to assess awareness of and screening for anal HPV infection and anal cancer in PLHIV and GBM in NSW, Australia.

3.2 The Survey

Surveymonkey was used to develop a self-completed anonymous online questionnaire. The survey included 37 questions. Knowledge and awareness of anal HPV, HPV vaccination, anal cancer risk and anal cancer symptoms and screening, were assessed along with a standardised suite of demographic questions.

3.3 Recruitment

Between April and May 2016, respondents were enrolled through a website link hosted by Positive Life. While there were no exclusion criteria and the survey was open to all HIV positive and HIV negative individuals, PLHIV and GBM were primarily targeted and recruited through various sources including HIV community organisations, Gay community social events and sporting groups, Facebook and GBM dating Apps.

3.4 Data collection

The data collected included:

- demographic information (age, current gender identity, sex assigned at birth , sexual orientation, country of birth, identification as Aboriginal and/or Torres Strait Islander, education level etc.)
- HIV status
- perceived risk of anal cancer in relation to the general population
- awareness of signs and symptoms suggestive of anal cancer
- whether respondents had ever had a discussion with their doctor or other health professional about anal HPV and anal cancer, and if so, who instigated the conversation
- levels of comfort/discomfort when discussing anal HPV and anal cancer with a doctor/health professional
- whether they ever had an anal examination for anal cancer, and if so, what type of examination they had
- if they had ever been tested for anal HPV infection
- awareness of HPV vaccination, and if they had been vaccinated against HPV
- if they had participated in the Study of the Prevention of Anal Cancer (SPANC).[7]

6. The ACAG includes representatives from The National Association of People with HIV Australia (NAPWHA), The Australian Federation of AIDS Organisations (AFAO), The Australasian Society of HIV, Viral Hepatitis & Sexual Health Medicine (ASHM), The Cancer Council of NSW, The Kirby Institute, Cancer Specialist Doctors and Consumers. The ACAG is chaired by Positive Life NSW.

7. SPANC is an ongoing study exploring the origin and developmental characteristics of anal HPV and anal cancer in GBM in Sydney Australia. The study has been running since September 2010.

3.5 Method and data analyses

- While there were no exclusion criteria and the survey targeted all PLHIV and GBM, a majority of the 1,660 responses were received from HIV negative/unknown and HIV positive people who were assigned male sex at birth (n=1,574; 94.8%).
- There were also a small number of responses from people living with HIV (n=4) and HIV negative/unknown (n=33) who were assigned female sex at birth.
- Analyses therefore focused on HIV negative/unknown and HIV positive people who were assigned male sex at birth and the results for people living with HIV, negative/unknown people who were assigned female sex at birth were reported separately in this report.
- For male respondents, the association between 1) age and 2) HIV status in relation to: perceived risk of anal cancer, knowledge of symptoms suggestive of anal cancer, experience with anal HPV and anal cancer screening, and HPV vaccination were assessed for HIV positive and HIV negative/unknown men.
- Data were summarised as numbers and percentages.
- HIV status was categorised as '*HIV positive*' or '*HIV negative*' and the HIV negative category included participants who reported their HIV status as '*Unknown*'. Participants who declined to identify their HIV status were excluded from analyses.
- Participants in the Study of the Prevention of Anal Cancer (SPANC) were also excluded from analyses, due to their increased exposure to information about HPV and anal cancer.

3.6 Study Limitations

The small number of HIV positive females who responded to the survey was disappointing. The poor response may indicate even poorer levels of awareness of, and screening for, anal cancer amongst this group. Australian HIV positive females are at increased risk of other HPV related cancers including: cervical, vaginal, vulvar, labial, and neck and mouth cancers. A survey specifically targeting HIV positive females in NSW is therefore urgently needed to assess awareness of HPV related cancers and awareness of risk, knowledge of symptoms, and experience with cancer screening and HPV vaccination.

3.7 Ethics

The survey was approved retrospectively by the South Eastern Sydney Local Health District Human Research Ethics Committee. No identifying data were collected from respondents and therefore formal participant consent was not required.

4.0 Results: HIV negative/unknown and HIV positive men

4.1 Characteristics of survey participants

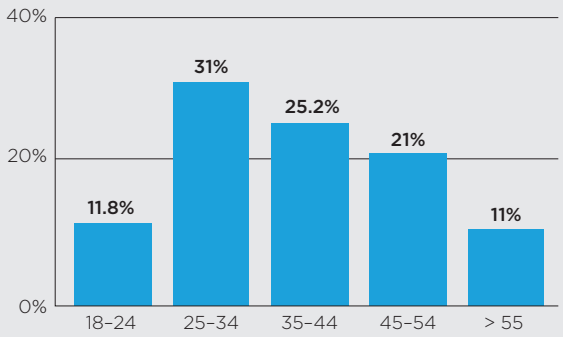
1,574 HIV positive and HIV negative people who reported they were assigned male sex at birth were included in these analyses. Of these, 1,564 (99.5%) identified as men and eight (0.5%) identified as women, which may indicate a trans or gender diverse experience.

4.1.1 Analyses by age

Most respondents were aged between 25–54 years (n=1,215, 77.2%).

There was a minority of respondents aged 18–24 years (n=186, 11.8%) and 55 years and older (n=173, 11.0%), (Figure 1 and Table 1).

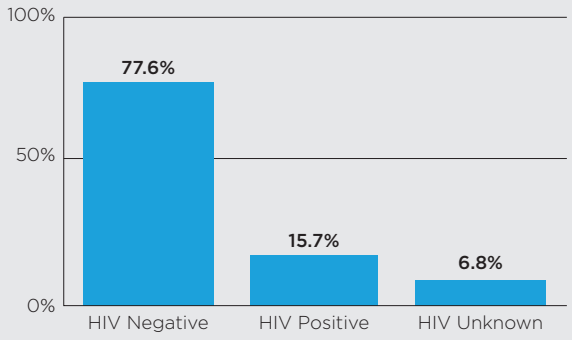
Figure 1: Participants – by age group



4.1.2 Analysis by HIV status

The majority reported their HIV status to be '*HIV negative*' (n=1,204, 77.6%). (n=105, 6.8%) reported their HIV status *as* '*Unknown*' and were grouped together with '*HIV negative*' respondents, making a total of (n=1,309, 84.4%). A minority (n=243, 15.7%) reported their HIV status to be '*HIV positive*' (Figure 2 and Table 1).

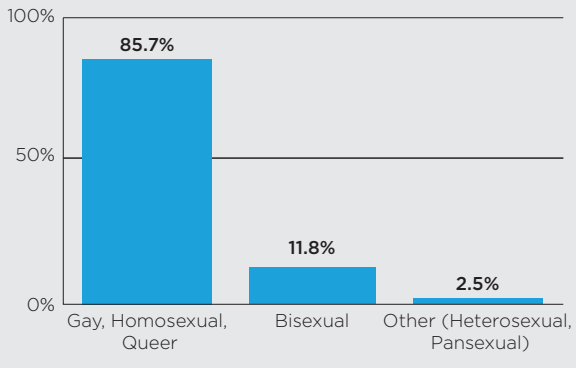
Figure 2: Participants – HIV status



4.1.3 Analysis by sexual identity

Most identified as '*Gay/Homosexual/Queer*' (n=1,349, 85.7%), however, (n=186, 11.8%) identified as '*Bisexual*' and (n=39, 2.5%) identified as '*Other*'. Of those who identified as '*Other*', 23 identified as '*Heterosexual*' and 16 identified as either '*Pansexual*' or an alternate label for '*Gay/Bisexual*'. (Figure 3 and Table 1).

Figure 3: Participants – by sexual identity



4.2 Awareness of anal cancer risk

4.2.1 Perceived risk of anal cancer

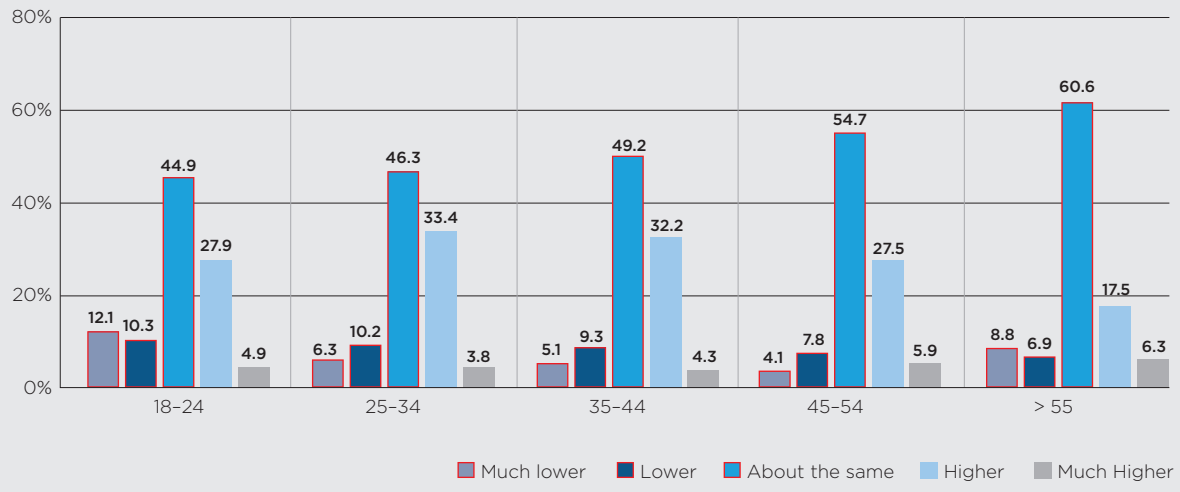
Survey respondents were asked to self-rate their risk of developing anal cancer, in relation to the general population. The options listed were '*Much higher*', '*Higher*', '*About the same*', '*Lower*', '*Much lower*'.

4.2.2 Analysis by Age

The most common response from men across all age groups was '*About the same*' risk (range: 44.9–60.6%). While approximately a quarter (24%) to a third (37%) of all age groups correctly rated their risk of acquiring anal cancer as '*Higher/Much Higher*', approximately two-thirds (63.6%) of those aged 34–44 years and 45–54 years (66.6%), and three-quarters (76.3%) of those aged 55 and older, underestimated their risk of developing anal cancer and perceived their risk to be '*About the same*', '*Lower*' or '*Much lower*' than the general population (Figure 4 [outlined in red] and Table 2).

It should be noted that while the risk of anal cancer is about the same as the general population for HIV positive GBM to age 35 years, and for HIV negative GBM to age 45 years, after reaching these ages, annual anal cancer incidence increases to 70–130 per 100,000, for HIV positive GBM and to 5–20 per 100,000 for HIV negative GBM. Put in another way, this means that approximately 7–13 HIV positive GBM in NSW, who are over 35 years of age, are at risk of an anal cancer diagnosis, each year.

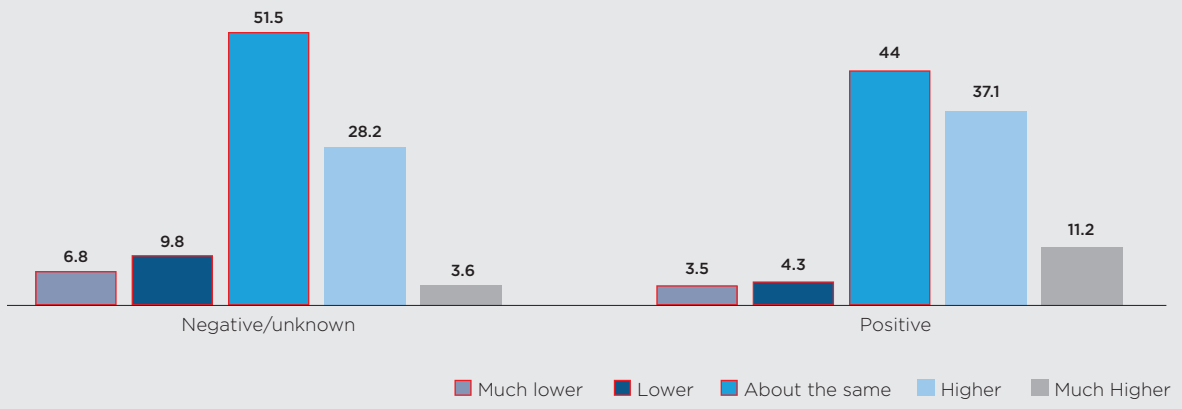
Figure 4: Perceived risk of anal cancer – by age



4.2.3 Analysis by HIV Status

When respondents of different HIV status were compared, the most common response to perceived risk of anal cancer was '*About the same*' (51.5% for HIV negative/ unknown respondents versus 44.0% for HIV positive respondents). While approximately a third (31.8%) of HIV negative/ unknown respondents and nearly half (48.3%) of HIV positive respondents correctly self-rated their risk of anal cancer as '*Higher*' or '*Much higher*' than the general population, analyses indicated that approximately two thirds of HIV negative/unknown participants (n=827, 68.1%) and half of HIV positive respondents (n=120, 51.8%) underestimated their risk of anal cancer and self-rated that risk to be '*About the same*', '*Lower*' or '*Much lower*' than the general population. Significantly, more HIV positive respondents than HIV negative/unknown respondents perceived their risk of anal cancer as '*Higher*' or '*Much higher*' than the general population (p=<0.001) (Figure 5 and Table 2).

Figure 5: Perceived risk of anal cancer – by HIV status



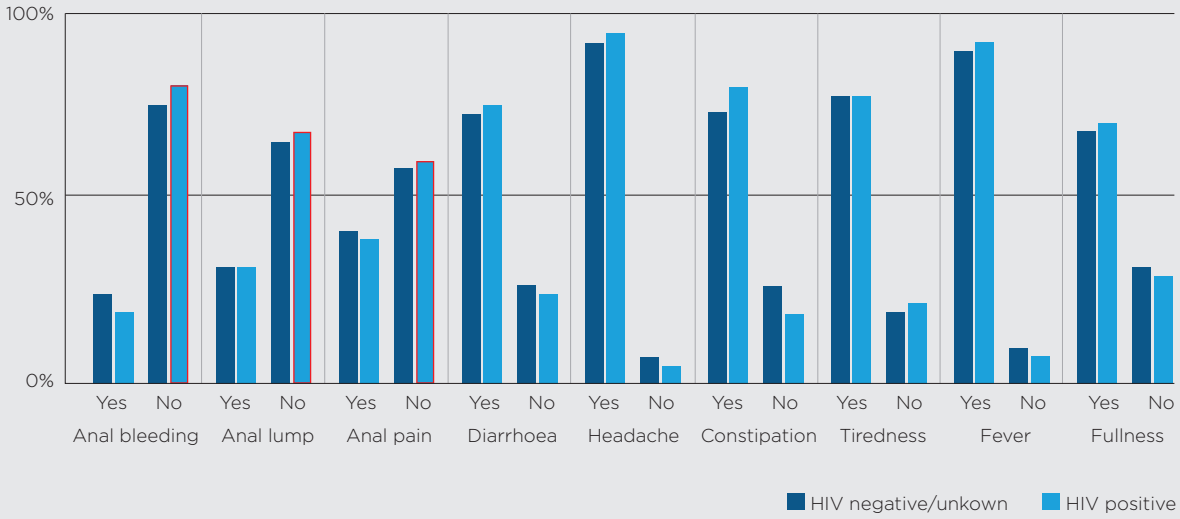
A total of 1,660 responses were received to the survey. A majority of the responses were received from HIV negative/unknown and HIV positive people who were assigned male sex at birth.

4.3 Knowledge of symptoms suggestive of anal cancer

Respondents were presented with a randomly ordered list of symptoms (some suggestive/ some not suggestive of anal cancer) and asked which symptoms would make them concerned about anal cancer. The list of symptoms *included*: '*Anal Bleeding*', '*Anal lump*', '*Anal pain*', '*Diarrhoea*', '*Headache*', '*Constipation*', '*Tiredness*', '*Fever*', and '*A sense of fullness in the bowel*'. Symptoms suggestive of anal cancer include: anal bleeding, anal lump, anal pain, and a sense of fullness in the bowel.

The most common symptoms identified by HIV negative/unknown and HIV positive male respondents were anal bleeding, anal lump and anal pain (Figure 6 and Table 3). HIV positive respondents were slightly more likely than HIV negative/unknown respondents to identify '*Anal bleeding*' (n=196 or 80.75% versus n=983 or 75.1%), '*Anal lump*' (n=166 or 68.3% versus n=875 or 66.8%), and '*Anal pain*' (n=147 or 60.5% versus n=757 or 57.8%) as symptoms suggestive of anal cancer (Figure 6 and Table 3). '*Diarrhoea*', '*Constipation*', '*Tiredness*', '*Fever*' and '*Headache*' were less commonly identified as suggestive of anal cancer by both HIV negative/unknown and HIV positive respondents, and significantly, more HIV negative/unknown respondents reported '*Constipation*' as a symptom suggestive of anal cancer (p=0.010).

Figure 6: Knowledge of symptoms suggestive of anal cancer



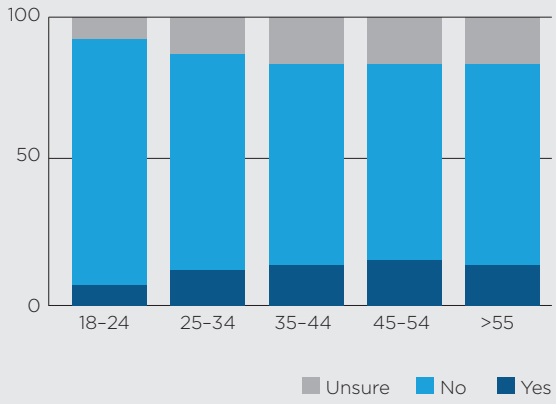
4.4 Discussions with health professionals about anal HPV and anal cancer

Respondents were asked if they had ever had a conversation with their doctor (or other health professional) about anal HPV and anal cancer.

4.4.1 Analysis by age

While a minority of respondents aged 35 years and older (15.4%) had talked with their doctor about HPV and anal cancer, across all age groups, overall, the majority of male respondents (87.0%) had not talked with their doctor about anal HPV and anal cancer, with younger respondents being more likely than older respondents, to not have talked with their doctor (93.3% of those aged 18–24 years, ranging to 85.0% of those aged 55 years and older) (Figure 7 and Table 4). The results were significant (p=007).

Figure 7: Had/had not talked with their doctor about anal HPV and anal cancer – by age



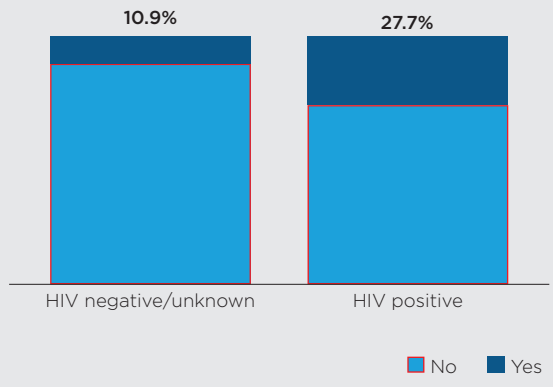
4.4.2 Analysis by HIV status

When data was analysed by HIV status, most men (average = 80.6%) had not talked with their doctor about anal HPV and anal cancer, with more HIV negative/unknown respondents (n=1,076, 89.2%) than HIV positive respondents (n=167, 72.3%) having not talked with their doctor about anal HPV and anal cancer. Only a little more than a quarter (27.7%) of HIV positive respondents and only 10.9% of HIV negative/unknown respondents, had discussed anal HPV and anal cancer with their doctor, or other health professional. The result was highly significant (p=<0.001) and concerning when considering that HIV positive and HIV negative GBM are at an increased risk of HPV related anal cancer and a doctor/patient discussion would be a first step in a process of detecting anal tumours, (Figure 8 and Table 4).

4.5 Who initiated the discussion about anal HPV and anal cancer (doctor or patient)

Those men who reported having had a discussion with their doctor or other health professional about HPV and anal cancer were asked who initiated the discussion. Analysis revealed the discussion was initiated by the patient in more than half of cases (n=133, 56.6%), by a nurse or other health care provider in (n=5, 5.1%) cases, and (n=9, 3.8%) were unsure who initiated the discussion. Conversely, the discussion was initiated by a doctor in only about a third of cases (34.5%).

Figure 8: Had/had not talked with thier doctor about HPV and anal cancer – by HIV status



4.6 Comfort/discomfort discussing anal cancer with a doctor

We asked respondents how comfortable or uncomfortable they were when talking about anal cancer with their doctor. While the most common response to the question was '*Neither comfortable nor uncomfortable*' (n=528, 35.3%), and approximately one-third were '*Comfortable*' or '*Very comfortable*' (n=490, 32.8%), (n=286, 19.1%) were '*Uncomfortable*', and (n=191, 12.8%) were '*Very uncomfortable*' talking with their doctor about anal HPV and anal cancer.

Respondents were then asked, '*What would make the conversation with their doctor more comfortable and less embarrassing?*' 260 respondents provided responses to the question. The table below provides analyses of the responses.

Response	%	n
I would prefer the doctor to raise the issue of anal cancer	23.0	60
Don't know/not sure	16.9	44
More information about anal cancer and its symptoms/risks, and brochures and posters about anal cancer in doctors waiting rooms and Sexual Health Clinics	15.0	39
Having a gay doctor	14.2	37
Open, clear communication with the doctor, and being able to discuss any issue, without embarrassment	10.0	26
Nothing. It is just too embarrassing!	8.5	22
More approachable doctors.	5.0	13
Talking to a dedicated specialist or sexual health doctor	2.3	6
Making it a routine process or part of a sexual health check-up	2.7	7
Other	2.3	6
Total	**100%**	**260**

It can be seen from the table that more than a quarter of the 260 respondents (25.7%) would prefer the doctor to raise the issue of anal cancer, or that discussion about anal cancer becomes part of a routine sexual health check-up. Some respondents (14.2%) thought that having a gay doctor would make the discussion about anal cancer easier, presumably because they were gay or bisexual and felt uncomfortable discussing anal issues with a doctor who they thought to be non-gay. Being able to have open and clear communication about any issue was also identified by 10.0% of respondents. Nevertheless, a proportion of respondents (25.4%) were either unsure, or thought there was nothing that would make the conversation less embarrassing. This result indicates that for some PLHIV and GBM, the subject of anal cancer is just too embarrassing to discuss. If the doctor doesn't raise the issue, the patient most likely won't either and HPV and anal cancer may not get discussed.

4.7 Unsatisfactory responses from doctors when discussing symptoms suggestive of anal cancer

Respondents were additionally asked if they had ever tried to talk with their doctor about anal cancer and/or abnormal anal symptoms, and got an unsatisfactory response. 117 (8.0%) of respondents reported that they had received an unsatisfactory response from their doctor. 75 respondents provided further information about what they considered to be the contextual barriers/issues contiguous to the unsatisfactory response. The most common responses were '*Lack of doctor's knowledge about HPV and anal cancer*' (26.7%), and '*The doctor was dismissive of concerns raised by me about my HPV and anal cancer symptoms*' (25.3%). '*Homophobia*' or perceptions of homophobia were reported by 12.0% of respondents and '*Awkwardness by the doctor about anal issues*' were reported by 12.0% of respondents. Respondents also reported that the '*Doctor told me not to worry*' in 10.7% of cases, they were '*Referred on*' in 8.0% of cases. In 5.3% of cases, the '*Doctor was unwilling to perform an anal examination*.'

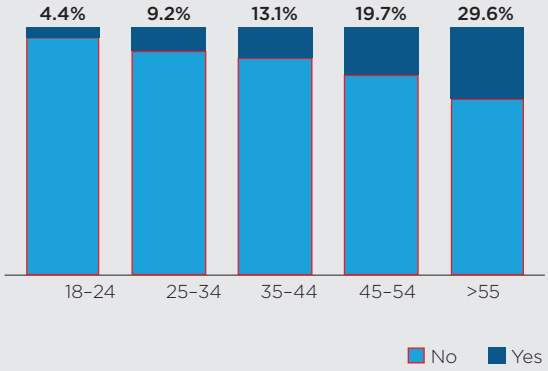
4.8 Screening for anal cancer

Regular screening for anal cancer is crucial if it is to be detected early. This is particularly so for HIV positive GBM over the age of 35 years, and for HIV negative GBM over the age of 45 years. Respondents were therefore asked if they had ever had an anal examination for anal cancer.

4.8.1 Analysis by age

When age groups were compared, younger respondents (those aged 18-24 and 25–34 years) were less likely to have had an anal examination (n=132, 95.7%) and (n=374, 90.8%) respectively, than older respondents. However, (n=291, 86.9%) of those aged 35–44 years, (n=229, 80.4%) of those aged 45–54 years and (n=93, 70.5%) of those age ≥55 years, had not had an anal cancer examination (Figure 9 and Table 4).

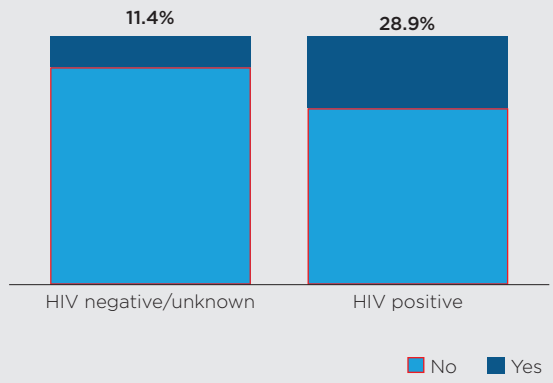
Figure 9: Had an anal examination for anal cancer – by age



4.8.2 Analysis by HIV status

When respondents of different HIV status were compared, there was a significant difference between HIV negative/unknown and HIV positive respondents. While the majority of both HIV negative/unknown and HIV positive respondents had not had an examination for anal cancer (79.8%), HIV negative/unknown respondents were less likely (88.6%, n=960) than HIV positive respondents (71.1%, n=145) to have never have had an anal cancer examination (Figure 10 and Table 3). The results were highly significant (p=<0.001).

Figure 10: Had an anal examination for anal cancer – by HIV status



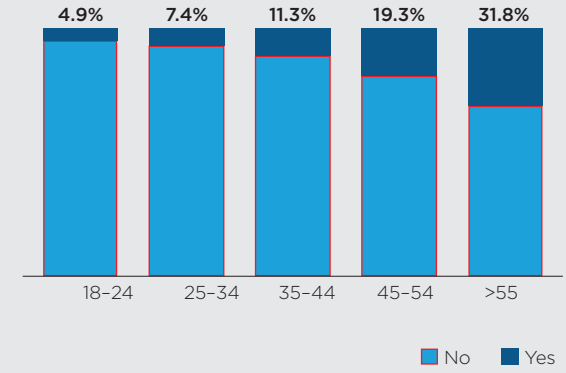
4.9 Digital ano-rectal examination (DARE)

Digital ano-rectal examination (DARE) is a clinical procedure used by doctors to check the anus for signs of anal cancer. The doctor places a lubricated gloved finger in the anus and feels the interior of the anus to detect lumps or abnormalities and then checks the perianal area. If lumps/abnormalities are found, further procedures can be performed to confirm whether the individual has anal cancer. Respondents were therefore asked if they had ever had a DARE.

4.9.1 Analysis by age

The majority of respondents across all age groups had never had a DARE (average=85.8%). The likelihood of ever having had a DARE significantly increased with age (p=<0.001). The proportion of those who had received a DARE ranged from (4.9%, n=9) of those aged 18–24 years to (31.8%, n=54) of those aged 55 years and older (Figure 11 and Table 4). Of concern was the proportion of those 45–54 years and 55 years and older who hadn't received a DARE (80.7% and 68.2%) respectively.

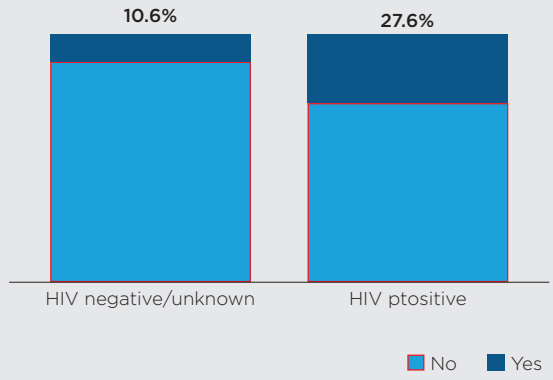
Figure 11: Ever had a Digital Anal Rectal Examination – by age



4.9.2 Analysis by HIV status

When different HIV status were compared, the majority of both HIV negative/unknown (n=1159, 89.4%) and HIV positive respondents (n=173, 72.4%) had never had a DARE. HIV positive respondents (n=66, 27.6%) however, were more likely than HIV negative/unknown respondents (n=137, 10.6%) to have had a DARE. The result was highly significant (p=<0.001), (Figure 12 and Table 4).

Figure 12: Ever had a Digital Anal Rectal Examination – by HIV status



4.10 HPV vaccination

HPV vaccines have been shown to be highly effective at preventing infection with HPV when given before exposure (i.e. ideally before a person becomes sexually active). HPV vaccine is therefore only effective for prophylactic use (as a preventative measure), although some studies have shown that people who have already been exposed to one or more HPV strains (there are over 40 different HPV strains that are sexually transmitted) could still benefit from HPV vaccination by possibly helping protect them against strains they have not yet been exposed to. The vaccine may also help protect from reacquisition or recurrence of HPV strains already exposed to that lead onto the formation of warts and other cell changes, including anal cancer, although more study is needed in the area.

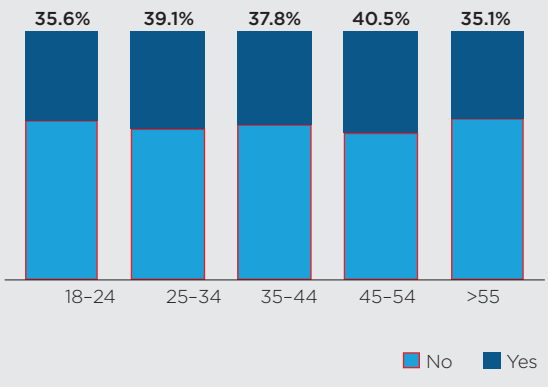
4.10.1 Awareness of HPV vaccination

Respondents were asked if they were aware of HPV vaccination. The majority of respondents were unaware of HPV vaccination.

4.10.2 Analysis by age

The proportions that were unaware of HPV vaccination ranged from (n=243, 60.9%) of those aged 25–34 years to (n=96, 64.9%) of those aged 55 years or older. Almost two thirds (n=85, 64.4%) of young respondents (aged 18–24 years) were unaware of HPV vaccination, which is concerning, since this group would be likely to derive maximum benefit from receiving HPV vaccination and that the HPV vaccination is subsidised for men who have sex with men in this age group. There was no significant difference between vaccine knowledge across age groups (Figure 13 and Table 4) (p=0.975).

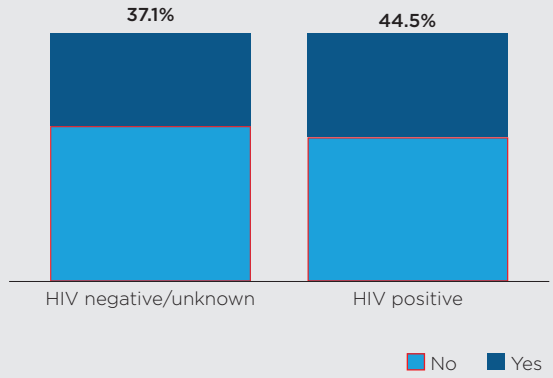
Figure 13: Awareness of HPV Vaccination – by age



4.10.3 Analysis by HIV status

There was a significant difference however between HIV negative/unknown and HIV positive respondents knowledge of HPV vaccination (p=0.045), with (n=398, 37.1%) of HIV negative/unknown and (n=93, 44.5%) of HIV positive respondents being aware of HPV vaccination. Notwithstanding these results, (n=647, 62.9%) of HIV negative/unknown respondents and (n=116, 55.5%) of HIV positive respondents, were unaware of HPV vaccination (Figure 14 and Table 4).

Figure 14: Awareness of HPV Vaccination – by HIV status



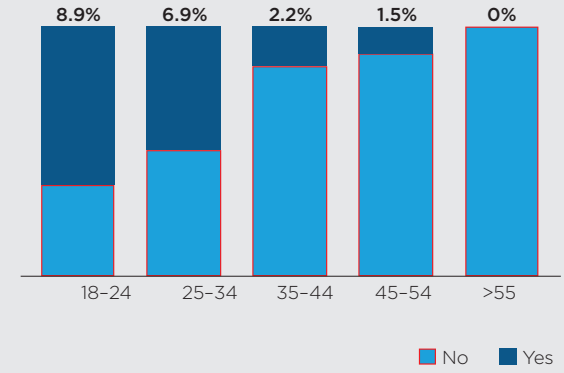
4.11 Received/not received HPV vaccination

Respondents were asked had they been vaccinated against HPV.

4.11.1 Analysis by age

The proportion of those who had not received HPV vaccination incrementally increased from (n=102, 91.1%,) of those aged 18–24 years to (n=134, 100.0%,) of those aged 55 years or over. There was a highly significant difference across age groups (p=<0.001) (Figure 15 and Table 4). There was no significant difference however, between participants with HIV negative/unknown status and HIV positive status (n=968, 95.8% and n=175, 97.2%) respectively (p=0.381) (Table 3).

Figure 15: HPV vaccination – by age



HPV vaccines have been shown to be highly effective at preventing infection with HPV when given before exposure

5.0 Results: HIV positive people who were assigned female sex at birth

5.1 Characteristics of the sample

Four HIV positive people with a cervix responded to the survey. All four, (100%) were assigned female gender at birth, however, three (75.0%) identified as men and one (25.0%) identified as female.

Two (50%) identified as '*Gay male homosexual*', one (25.0%) identified as '*Heterosexual*' and one (25.0%) identified '*differently*' and reporting being '*Intersex*'. None of these four participants identified as Aboriginal and/or Torres Strait Islander and all were born in a country other than Australia. One participant was aged 18–24 years, two were aged 35–44 years and one was aged 45–54 years.

5.2 Levels of risk awareness of anal cancer

Two respondents identified their risk of anal cancer as '*Higher*' and one identified their risk as '*Much lower*'. Pain and discomfort were correctly identified as symptoms suggestive of anal cancer (n=3, 100%) followed by anal bleeding (n=2, 66.6%), anal lump (n=2, 66.6%), and a sense of fullness in the lower bowel n=(1, 33.3%).

5.3 Discussions with a doctor about anal HPV and anal cancer

Of the three respondents who answered the question about whether there had been a discussion with a doctor about HPV and anal cancer, two respondents had not had a discussion and one reported having had a discussion. Two were '*Neither comfortable nor uncomfortable*' about talking with their doctor about HPV and anal cancer and one reported being '*Comfortable*' talking with their doctor about anal cancer.

5.4 Anal cancer examination

None of the three respondents who answered the question reported ever having had an anal cancer examination.

5.5 HPV vaccination awareness

Of the three respondents who answered the question on awareness of HPV vaccine, one was aware there was a HPV vaccine, one was not aware there was a HPV vaccine and one was not sure whether there was a HPV vaccine. None of the respondents had spoken with their doctor about HPV vaccination and none had received HPV vaccination.

5.6 Conclusion

No inferences could be drawn from the data due to the small sample size and no further analyses were undertaken to protect the identity of the participants. However, we want to acknowledge these respondents and thank them for their participation in the survey.

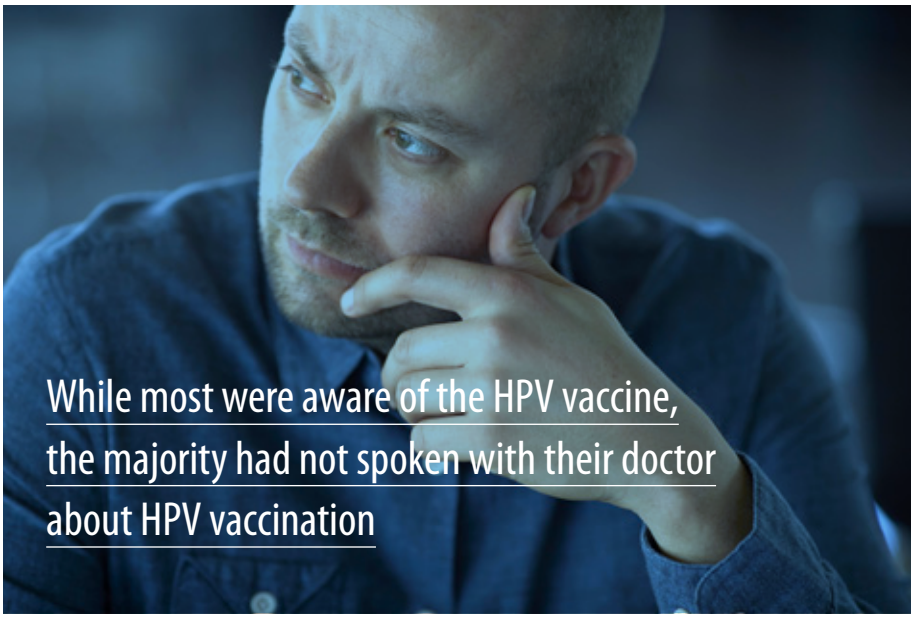
6.0 Results: HIV negative/unknown people who were assigned female sex at birth

6.1 Characteristics of the sample

Responses from 33 HIV negative/unknown people who were assigned female sex at birth were received and included in these analyses. 32 (97.00%) reported being HIV negative and one (3.0%) reported being of '*HIV unknown*' status and was included in these analyses. 22 (66.6%) identified as women, and 11 (33.3%) identified as men.

Approximately half identified as '*Heterosexual*' (n=15, 45.5%), nine (27.3%) identified as '*Gay male or homosexual*', three (9.1%) identified as '*Bisexual*, three (9.1%) identified as '*Queer*', two (6.1%) identified as '*Lesbian*', one (3.0%) identified '*Differently*'.

Two thirds (n=22, 66.6%) were Australian born and one third (n=11, 33.3%) were born overseas. One identified as Aboriginal. The majority were aged 25–44 years (n=18, 54.6%), seven (21.2%) were aged 45–54 years, four (12.1%) were aged 55–64 years, three (9.9%) were aged 65 or more, and one (3.0%) was aged 18–24 years.



6.2 Risk awareness

When asked about their risk of anal cancer in relation to the general population, the most common response was '*About the same risk*', however, while 5 HIV negative/unknown women (17.3%) self-rated their risk of anal cancer as '*Higher*' or '*Much higher*', 9 (31.0%) self-rated their risk as 'Lower' or '*Much lower*' than the general population. '*Anal bleeding*', '*Anal lump*', '*Anal pain/discomfort*' and a '*sense of fullness in the bowel*' were correctly identified by the majority of HIV negative/unknown females as symptoms suggestive of anal cancer.

6.3 Discussions with a doctor about anal HPV and anal cancer

The majority of HIV negative/unknown people with a cervix had not had a conversation with their doctor about anal HPV and anal cancer (n=22, 78.6%) and for those that had, the conversation was initiated in a third of cases by respondents. While a majority were '*Neither comfortable/uncomfortable*', or '*Comfortable*' talking with their doctor about HPV and anal cancer, 37.0% were 'Uncomfortable' or '*Very uncomfortable*' talking with their doctor about HPV and anal cancer.

6.4 Anal cancer examination

The majority of HIV negative/unknown people with a cervix had never received an anal examination for anal cancer (n=22, 84.6%). Of those who had, three (75.0%) had received a DARE and three (75.0%) reported having had a High Resolution Anoscopy. The majority had never been tested for HPV (n=22, 88.0%) and for those that had, most (n=2, 66.6%) had been tested more than three years prior to participating in the survey.

6.5 HPV vaccination awareness

While most were aware of the HPV vaccine (n=19, 76.0%), the majority had not spoken with their doctor about HPV vaccination (n=19, 76.0%) and only three (12.0%) had been vaccinated against HPV. One of the vaccinated respondents had participated in SPANC.

6.6 Conclusion

No inferences could be drawn from the data due to the small sample size and no further analyses were undertaken to protect the identity of the participants. However, we want to acknowledge these respondents and thank them for their participation in the survey.

7.0 Conclusions

While rare in the general population (annual incidence of 1–2 per 100,000),[8] PLHIV (both men and women) and GBM are at substantially increased risk of HPV-related anal cancer. HIV positive GBM are at the highest risk with an annual incidence of 70–130 per 100,000 and in some US and European studies the annual incidence is 100–150 per 100,000.[9] HIV positive heterosexual men and women are also at elevated risk with an annual incidence of 10–30 per 100,000.[10] The risk of anal cancer in HIV negative GBM is around 20-fold higher than the general population, and the annual incidence prior to the HIV/AIDS epidemic was estimated to be around 35 per 100,000. This is greater than the incidence of cervical cancer prior to the implementation of organised cervical screening programs.[11]

Two thirds (63%) of anal cancers are diagnosed late with a tumour size ≥2cm and require treatment with chemotherapy/radiotherapy and surgery.[12] Chemotherapy/radiotherapy for anal cancer is debilitating, arduous and requires a long recovery time. Anal and penile incontinence associated with damage caused by radiotherapy to the anal and pelvic structures can be extremely challenging and life changing. Conversely, early detection of tumours less than 1cm with surgical incision of the tumour delivers near 100% cure rates and obviates the need for chemo/radiotherapy and its associated morbidity.

Despite the elevated risk of anal cancer in PLHIV and HIV negative GBM, our survey shows that across all age groups, both HIV positive and HIV negative men report low levels of awareness of anal cancer risk, with two thirds of HIV negative/unknown men (68.1%) and approximately half of HIV positive men (51.8%) underestimating their risk of anal cancer. Low rates of discussion between respondents and their doctors about anal cancer is also concerning. Across all age groups, most men (83.9% – 93.3%) had not discussed anal cancer with their doctor, and although HIV positive men were somewhat more likely than HIV negative/unknown men to have had the discussion, less than a third of HIV positive men (27.7%) and approximately one tenth (10.9%) of HIV negative/unknown men had talked with their doctor about anal HPV and anal cancer. For those who had talked with their doctor about anal cancer, in more than half of cases (56.6%), the discussion was patient initiated.

The low rates of doctor/patient anal cancer communication may in part be due to doctor/patient embarrassment and general societal stigma regarding anal sex and cancer generally. Nearly a third (32.8%) of men reported either being '*Uncomfortable*' or '*Very Uncomfortable*' talking with their doctor about anal cancer. When further questioned about what would make the discussion easier, most men reported they would 'Prefer the doctor to raise the issue', and some thought that having a 'gay' doctor would help (14.2%). However, 17% were '*Unsure*' what would make the conversation easier and 8% thought that 'nothing' would make it easier, as the subject was just too embarrassing.

8. National Cancer Institute, (USA) 'Anal Cancer - Cancer Stat Facts', https://seer.cancer.gov/statfacts/html/anus.html.
9. Franceschi S, Clifford GM, et al. Changing patterns of cancer incidence in the early and late HARRT periods: the Swiss HIV Cohort. Br J Cancer 2010; 103:416-422.
10. I Poynten, et al. Cancer Epidemiology and Prevention Biomarkers 2018, 27(7) 768–75. https://doi.org/10.1158/1055-9965.EPI-17-0694.
11. D'Souza G, Wiley DJ, Li X, et al. Incidence and epidemiology of anal cancer in the multicentre AIDS cohort study. J Acquir Defic Syndr 2008; 48:491-499.
12. Reid TR, Hudson KL, Millar JL, et al. Size of anal squamous cell carcinomas at diagnosis: a retrospective case series. International Jounal of STD & AIDS 2013; 24:879-882.

These results are troubling. If neither doctor nor patients raise the subject of anal cancer, an opportunity for awareness raising and screening is lost. This time interval may be the difference between an early diagnosis and a late diagnosis of anal cancer. Further to the issue of communication, 8% of respondents (n=117) had attempted to talk with their doctor about abnormal anal symptoms and/or anal cancer and received an unsatisfactory response from the doctor. While '*lack of knowledge about HPV and anal cancer*' – on the part of some doctors – was cited as the reason for an unsatisfactory response, in more than a third of cases, the doctor was reported to be '*Dismissive*', and even '*Homophobic*' in 12% of cases. For a small number of respondents, the doctor was '*unwilling to perform an anal examination*'.

Regularly performed anal examinations are crucial in early detection of anal tumours, particularly as PLHIV and GBM age and their risk of anal cancer increases. Yet, while older men and HIV positive men were more likely than younger men and HIV negative men to have had an anal cancer examination, less than a third (28.9%) of HIV positive men, and about one tenth (11.4%) of HIV negative/unknown men had received an anal cancer examination. In nearly all cases, the examination procedure was a digital ano-rectal examination (DARE). Of concern was the low rates of DARE being conducted in men over the age of 50 years. Only 19.7% of men aged 45–54 and 31.8% of men aged 55 years and over, reported they had received a DARE. There is clearly a need to increase rates of DARE in PLHIV and GBM, particularly HIV positive men over the age of 50 years, when most anal cancers are detected and detected late.

In relation to prevention, HPV vaccines have been shown to be highly effective in reducing infection with HPV and preventing high grade squamous intraepithelial lesions – which are the precursors to anal cancer. Newer 4 and 9 valent vaccines are predicted to be even more effective at preventing infection with a wider range of HPV strains. Nevertheless, more than half of men in all age groups were unaware of HPV vaccination and its ability to prevent infection with HPV. Only 8.9% of men aged 18–24 years and 6.9% of men aged 25–34 years had received HPV vaccination. There is therefore a need to increase HPV vaccination rates in young GBM. However, even if HPV vaccination rates are substantially increased, it will be more than 20–30 years before we begin to see anal cancer incidence rates in GBM decline. This is due to most cases of anal cancer are diagnosed in GBM over the age of 50 years.

In the intervening period, PLHIV and GBM need to be educated about the risk of anal cancer and the need for regular screening, particularly for PLHIV over the age of 35 years and HIV negative GBM over the age of 45 years when incidence rate start to rise. At present, the use of DARE to detect anal cancer is customarily performed by a doctor. However, there is increasing interest in the feasibility of self or partner administered DARE to detect anal abnormalities including anal cancer. Recent research in the US has demonstrated that self or partner palpation of the anal canal, can be effective in detecting anal tumours of 3mm or larger.

The low numbers of HIV positive and HIV negative/unknown women who responded to our survey was disappointing. Of the four HIV positive people with a cervix who responded, the majority identified as men (75.0%), and only one identified as a woman. In the case of HIV negative/unknown people who were assigned female sex at birth, one third identified as men and the remaining two thirds identified as women. About a half (45.5%) identified as heterosexual, about a third (36.4%) identified as 'gay', 'bisexual', 'queer', and the reminder identified as 'lesbian/other'. The low response rate in HIV positive/HIV negative women, may suggest that awareness of, and screening for, HPV related anal cancer in this population is even poorer than in HIV positive and HIV negative GBM. The poor rates of participation also suggest that there is an urgent need to work with HIV positive and negative females and trans and gender diverse populations, particularly those who are having sex with GBM to increase awareness of, and screening for, anal cancer.

The role of doctors in providing education and anal cancer screening cannot be underestimated. Clinicians will need to understand the implications of anal HPV infection and its association with anal cancer risk. They will also need to become proficient in raising the subject of anal cancer with their at-risk and embarrassed patients, and be able to perform digital anal rectal examination when necessary. As the levels of community awareness of anal cancer increase, doctors and nurses will need to be ready to examine their patients upon request, explain issues associated with HPV infection and anal cancer and be able to make appropriate referrals to anal cancer specialists for follow-up.

8.0 Anal cancer related education and advocacy 2010–2018

The Study of the Prevention of Anal Cancer (SPANC), led by investigators at the Kirby Institute in Sydney NSW, has made a significant contribution to HPV and anal cancer awareness and knowledge raising not only for the 617 Sydney-based HIV positive and negative GBM who are participating in the study, but also for their partners, friends and the gay, bisexual community generally. Before the advent of SPANC, very little was known about HPV related infection and its association with anal cancer outside of research institutions. Now, SPANC study investigators hold regular feedback evenings where study participants receive updates on the latest study findings and are able to ask questions and become better informed. These feedback sessions have significantly contributed to an increased awareness of anal cancer risk amongst Sydney GBM and for the need for ongoing screening. In addition, the SPANC investigation team who include doctors, researchers, laboratory professionals (some from other states, such as Victoria and Queensland) and representatives from Positive Life and ACON meet bi-annually to review and discuss the latest SPANC study findings and how those finding can be used to reduce morbidity and mortality in populations at increased risk of anal cancer.

The Anal Cancer Advocacy Group (ACAG) was formed in 2013 in response to the need for more board-based education and health service coordination and mobilisation around the issue of HPV related anal cancer. The group brings together representatives from NSW HIV community organisations (Positive Life NSW, ACON, NAPWHA, AFAO, ASHM), and anal cancer doctors and researchers, to advance an advocacy agenda including community awareness raising of anal cancer, increasing doctor awareness of anal cancer, and increasing access to HPV vaccination. The ACAG organised the Anal Cancer Symposium at ASHM in 2016 to raise awareness of HPV related anal cancer in HIV and sexual health doctors and allied healthcare professionals. The ACAG also identified the need to maintain and increase anal cancer diagnostic services at Sydney's St Vincent's Hospital and Royal Prince Alfred Hospital. Positive Life and ACON, with support from members of the ACAG, successfully advocated for an expansion of existing anal cancer diagnostic services at these two facilities.

HIV national and state peak organisations (the National Association of People with HIV Australia (NAPWHA) and the Australian Federation of AIDS Organisations (AFAO)), have made a significant contribution to raising awareness of anal cancer in PLHIV and GBM. AFAO developed 'The Bottom Line', a website providing information about HPV related anal cancer for GBM. The website includes information on HPV infection, screening for anal cancer, how to understand HPV and anal cancer clinical results, the benefits of HPV vaccination, and

links to support services. NAPWHA has worked to raise awareness of anal cancer amongst its member organisations by inviting anal cancer experts to present on anal cancer during bi-annual meetings and through its Treatment Outreach Network. In addition, state-based peaks such as Positive Life have produced anal cancer education resources, published numerous articles in PLHIV publications and presented the results of this community survey to health professionals at national HIV conferences and to peers at research based feedback sessions and community events.

The absence of anal cancer screening guidelines persuaded ASHM to commission a subcommittee to look at the role of screening for anal cancers in Australian GBM. The subcommittee reviewed the evidence and made a recommendation to ASHM's HIV Treatment Committee that: "*Men having sex with men and living with HIV aged 50 years and above should have a digital ano-rectal examination annually as part of their routine health care*." The HIV Treatment Guidelines Committee supported the recommendation of the subcommittee on 17 November 2016.

So, while there is still much to do before awareness of, and screening for, anal cancer in at risk populations reach satisfactory levels and younger people routinely receiving HPV vaccination; progress has been made. Research institutions and community organisations (PLHIV organisations, AIDS Councils and their peaks) continue to play a crucial role in spreading the word about the risk of HPV related anal cancer and the need for regular screening of PLHIV and GBM. Doctors caring for PLHIV and GBM also play a crucial role in raising the subject of anal cancer with their patients, performing DARE to detect anal cancer in the very early stages when 100% cure rates are possible, and encouraging younger GBM to receive HPV vaccination.

The challenge however, will be to maintain momentum and raise awareness of anal cancer and the need for regular and ongoing screening. To achieve these aims, programs will require funding, commitment and collaboration. It would be regrettable if PLHIV and GBM – having lived through and survived the HIV/AIDS epidemic – were to unnecessary experience morbidity and mortality from anal cancer, because other priorities prevented the necessary community mobilisation and prevention programs that are needed.

Tables

Table 1: Characteristics of the sample

Participant Demographics (n = 1,574)

Characteristics	n	%
Age		
18–24	186	11.8
25–34	488	31.0
35–44	396	25.2
45–54	331	21.0
>55	173	11.0
HIV status		
Negative	1,204	77.6
Positive	243	15.7
Unknown	105	6.8
Sex assigned at birth		
Male	1,574	100.0
Gender Identity		
Man	1,564	99.5
Woman	8	0.5
Sexual identity		
Gay, Homosexual, Queer	1,349	85.7
Bisexual	186	11.8
Other (Pansexual [41%], Heterosexual [59%])	39	2.5
Aboriginal or Torres Strait Islander		
Aboriginal	33	2.1
Aboriginal and Strait Islander	5	0.3
Neither	1,504	97.5
Country of Birth		
Australia	1,065	67.7
Other	509	32.34

Table 2: Perceived risk of anal cancer

	Much lower		Lower		About the same		Higher		Much higher		P value*
	n	%	n	%	n	%	n	%	n	%	
Age											0.001
18–24	20	12.1	17	10.3	74	44.9	46	27.9	8	4.9	
25–34	28	6.3	45	10.2	205	46.3	148	33.4	17	3.8	
34–44	19	5.1	35	9.31	185	49.2	121	32.2	16	4.3	
45–54	13	4.1	25	7.8	175	54.7	88	27.5	19	5.9	
≥55	14	8.8	11	6.9	97	60.6	28	17.5	10	6.3	
HIV status											<0.001
Negative/unknown	83	6.8	119	9.8	625	51.5	342	28.2	44	3.6	
Positive	8	3.5	10	4.3	102	44.0	86	37.1	26	11.2	

* P value for heterogeneity

Table 3. Symptoms suggestive of anal cancer

	HIV negative/unknown		HIV positive		P value
	n	%	n	%	
Anal bleeding					0.062
No	326	24.9	47	19.3	
Yes	983	75.1	196	80.7	
Anal lump					0.655
No	434	33.2	77	31.7	
Yes	875	66.8	166	68.3	
Anal pain					0.439
No	552	42.1	96	39.5	
Yes	757	57.8	147	60.5	
Diarrhoea					0.433
No	943	72.4	181	74.5	
Yes	366	28.0	62	25.5	
Headache					0.121
No	1,201	91.8	230	94.7	
Yes	108	8.3	13	5.4	
Constipation					0.010
No	952	72.7	196	80.7	
Yes	357	27.3	471	19.3	
Tiredness					0.570
No	1,034	79.0	188	77.4	
Yes	275	21.0	55	22.6	
Fever					0.220
No	1,167	89.2	223	91.8	
Yes	142	10.9	20	8.2	
Fullness					0.568
No	886	67.7	169	69.6	
Yes	423	32.3	74	30.5	

Table 4. Experience with anal HPV and anal cancer screening in relation to age and HIV status

	No		Yes		OR	P value
	n	%	n	Yes	(95% CI)	
Had talked to your doctor about anal HPV						
Age						0.007
18–24	154	93.3	11	6.7		
25–34	388	88.0	53	12.0		
35–44	317	84.8	57	15.2		
45–54	266	83.9	51	16.1		
≥55	136	85.0	24	15.0		
HIV status						<0.001
Negative/unknown	1076	89.2	131	10.9		
Positive	167	72.3	64	27.7		
Had an anal cancer examination						
Age						<0.001
18–24	132	95.7	6	4.4		
25–34	374	90.8	38	9.2		
35–44	291	86.9	44	13.1		
45–54	229	80.4	56	19.7		
≥55	93	70.5	39	29.6		
HIV status						<0.001
Negative/unknown	960	88.6	123	11.4		
Positive	145	71.1	59	28.9		
Had received a digital anal examination						
Age						<0.001
18–24	174	95.1	9	4.9		
25–34	450	92.6	36	7.4		
35–44	347	88.8	44	11.3		
45–54	264	80.7	63	19.3		
≥55	116	68.2	54	31.8		
HIV status						<0.001
Negative/unknown	1159	89.4	137	10.6		
Positive	173	72.4	66	27.6		

	No		Yes		OR	P value
	n	%	n	Yes	(95% CI)	
Had heard of HPV vaccination						
Age						0.975
18–24	85	64.4	47	35.6		
25–34	243	60.9	156	39.1		
35–44	211	62.2	128	37.8		
45–54	166	59.5	113	40.5		
≥55	96	64.9	52	35.1		
HIV status						0.045
Negative/unknown	647	62.9	398	37.1		
Positive	116	55.5	93	44.5		
Had received HPV vaccination						
Age						<0.001
18–24	102	91.1	10	8.9		
25–34	350	93.1	26	6.9		
35–44	306	97.8	7	2.2		
45–54	266	98.5	4	1.5		
≥55	134	100	0	0.0		
HIV status						0.381
Negative/unknown	968	95.8	42	4.2		
Positive	175	97.2	5	2.8		

Location Suite 5.2, Level 5, 414 Elizabeth Street, Surry Hills NSW 2010
Mail PO Box 831, Darlinghurst NSW 1300
Phone 02 9206 2177 **Freecall** 1800 245 677 **www.positivelife.org.au**

PositiveLifeNSW
the voice of people with HIV since 1988