Anal Cancer Screening: the Perspectives of People Living with HIV

ASHM Conference

4D. Affiliate Organisation Session: Screening for anal cancer in PLHIV: a call for action

15 September 2025

Positive Life NSW

We acknowledge the traditional owners of the country on which we meet today,
the Kaurna people of Tarntanya Wama, and pay our respects to Elders, past and present.

We also extend that respect to Aboriginal and Torres Strait Islander people here today.

We acknowledge the ongoing connection that Aboriginal people have to land, water, culture and heritage, and recognise Aboriginal people as the original custodians of the land.

We recognise and acknowledge that sovereignty was never ceded, and always was,
and always will be Aboriginal Land.

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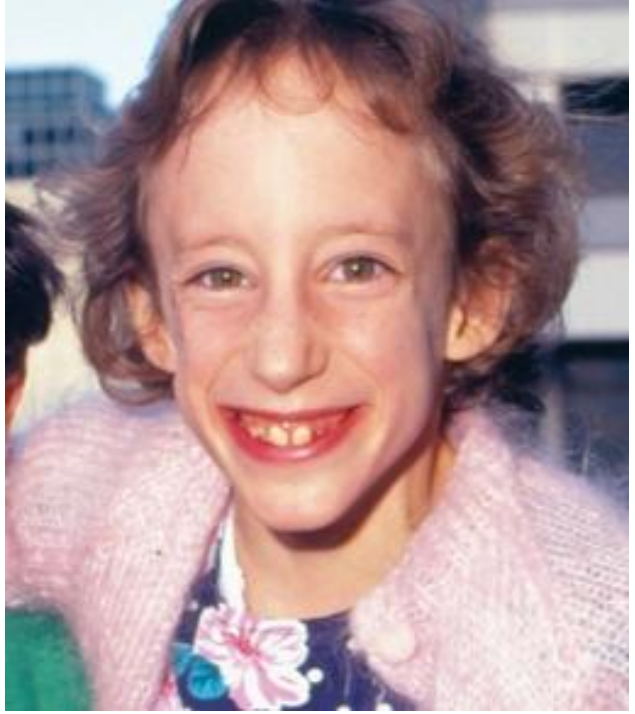

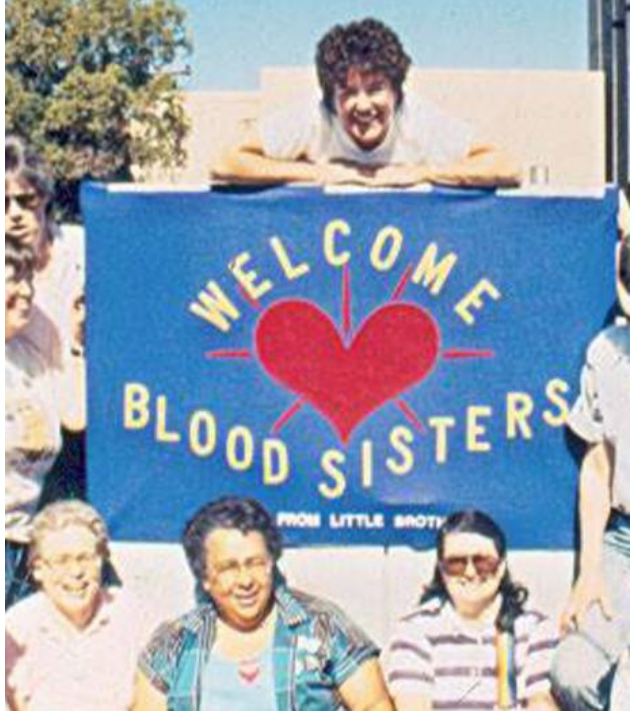

Women, mothers, children, people of diverse genders, people of diverse sexualities, sex workers, people of colour, people who use drugs, people who are marginalised, fathers, and men, put their life experiences, reputations, bodies, hearts, and minds, on the line to advance the modern understanding of HIV and AIDS, treatments, stigma and co-morbidities.

As a result of their many sacrifices, many of us including myself are able to live openly and authentically as people living with HIV, and we are well supported by our colleagues and friends.

Some of these trailblazers are here today. Sadly, many are not.

We thrive today because of their formative sacrifices. They gave their minds, bodies, souls and spirits to help guarantee a brighter tomorrow. We honour them today and everyday.

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Considerations Around Anal Cancer

- Anal cancer typically presents late, where treatment options are limited
- Early diagnosis and screening can potentially avoid this
- Precancerous lesions have the potential to transform to anal cancer, but most do not
- Highly stigmatised
- Misconception that anal sexual activity is the only risk factor for anal HPV infection
- Rare in the general community – hence awareness is very limited amongst the general population and health care workers including GPs
- In Australia, about 500 people are diagnosed with anal cancer each year — 60% of them women
- HPV vaccine is recommended for MSM of any age who have not previously been vaccinated
- HPV 9-valent vaccination recommended for WLHIV up to 45 years, but cost only covered to those aged up to 26 years, so potential gap

Anal Cancer Awareness Survey – PLHIV and MSM (2018)

Background & Methodology

- Survey attracted 1660 responses – mostly from HIV+/HIV negative/unknown GBM (n=1574)
- Due to the low response from women (n=37), they were excluded from analyses
- 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
- HIV status was categorised as 'HIV positive' or 'HIV negative/unknown'
- SPANC study participants were also excluded from the analyses
- Ethics approval

Anal Cancer Awareness Survey – PLHIV and MSM Findings

- Across all age groups, **the majority of male respondents underestimated their risk of developing anal cancer**
- Most male respondents correctly identified anal bleeding, anal lump and anal pain as symptoms suggestive of anal cancer, but other symptoms suggestive of anal cancer (diarrhoea, constipation, tiredness, fever and headaches were less commonly identified by both HIV negative/unknown and HIV positive respondents
- **The majority of men across all age groups had not had an anal examination for anal cancer**
- Most male respondents of all ages had not talked with their doctor about HPV and anal cancer
- **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

Anal Cancer Awareness Survey – PLHIV and MSM Conclusions

- Despite the elevated risk of anal cancer, PLHIV and GBM showed low levels of awareness of anal cancer risk and experience with anal cancer screening practices such as DARE
- Our survey results also demonstrated low levels of HPV vaccination uptake among all men, including younger GBM
- Highlighted there was a clear need to raise awareness of anal cancer in PLHIV and GBM and to increase rates of routine screening for anal cancer and rates of HPV vaccination in populations at risk of HPV related cancer

HPV-Related Cancer Among Women and Trans and Gender Diverse People Survey (2019)

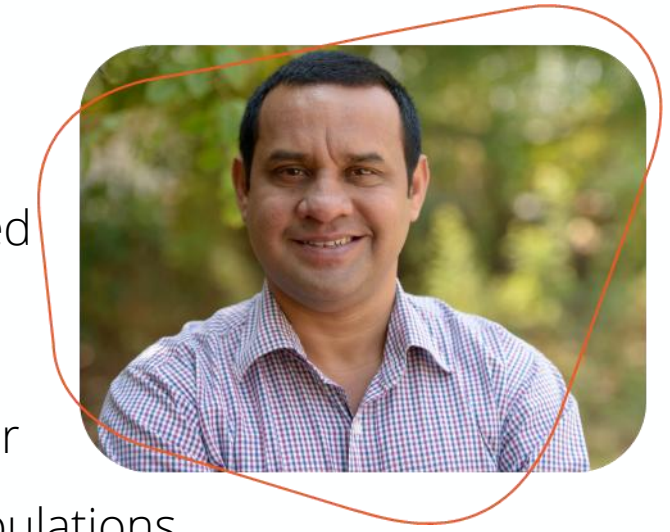
The survey attracted over 335 women and, trans and gender diverse people

- 14.4% were HIV-positive, 5.6% were HIV- but immunocompromised
  76.6% of respondents were non-immunocompromised, and the final 3.4% of respondents consisted of women and trans and gender diverse people who preferred not to disclose their HIV status, immune status, or were unsure
- 80% identified as heterosexual, 10% bisexual, 10% queer
- 2/3 were born in Australia
- 65% thought their risk of anal cancer is about the same, lower or much lower than the general population
- 35% had not talked with their doctor about HPV-related cancer
- While high percentages of respondents had regular screening for cervical cancer, the opposite was true for anal cancer screening

HPV-Related Cancer Among Women and, Trans and Gender Diverse People Survey Conclusions

1. Increasing screening for anogenital HPV-related cancers and particularly anal cancer
2. Increasing vaccination rates
3. Increasing awareness of the new National Cervical Screening Guidelines
4. Increasing clinician awareness of the need for entire lower anogenital tract examinations
5. Increasing clinician-initiated discussion of HPV-related cancers
6. Raising awareness of HPV-related cancer risk and symptoms (cervical, vaginal, vulvar, and anal)
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

Research Working Groups



Positive Life NSW established the Anal Cancer Advocacy Group in 2013 to:

- Raise awareness of HPV-related anal cancer in high-risk populations (and the need for regular screening and early detection of anal cancer
- Raise awareness of HPV-related anal cancer in clinicians treating high risk populations and the need for regular screening and early detection of anal cancer
- Advocate for referral services at hospitals (a few major hospitals in centres of populations at high risk) where High Resolution Anoscopy (HRA) can be performed as a diagnostic service
- Advocate for expanded access to HPV vaccination in high-risk population groups
- Group made up of clinicians, researchers, and representatives from a range of HIV sector organisations

Positive Life NSW established the Positive Life NSW Human Papillomavirus (HPV) Working Group in 2019 to:

- Implement key recommendations from both surveys
- Increase screening for anogenital HPV-related cancers and particularly anal cancer
- Increase HPV vaccination rates
- Group made up of health professionals, researchers, stakeholders, and women and trans and gender diverse people with a cervix/vulva/vagina including those living with HIV

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Advocacy

- Anal Cancer Advocacy Group held the Anal Cancer Symposium at ASHM in 2017
- Presented at an invited speaker session at the ASHM Conference in 2022 on Cancer Screening and Treatment: Recent Learnings and How This Impacts Australian Practice
- Published a scientific paper in Sexual Health in 2019 (Awareness and knowledge of anal cancer in a community recruited sample of HIV-negative and HIV-positive gay and bisexual men. Feeney L, Poynten M, Fengyi J, Cooper C, Templeton DJ, O'Dwyer MR, Grulich A, and Hillman RJ. Sexual Health, 2019, 16, 240–246 https://doi.org/10.1071/SH18219)
- Positive Life NSW advocated for ASHM to implement the DARE guidelines
- Positive Life NSW regularly promotes the need for anal examinations in PLHIV through social media and other health promotion activity
- Positive Life NSW has produced resources that educate PLHIV and MSM about self-performing or partner-performing DARE

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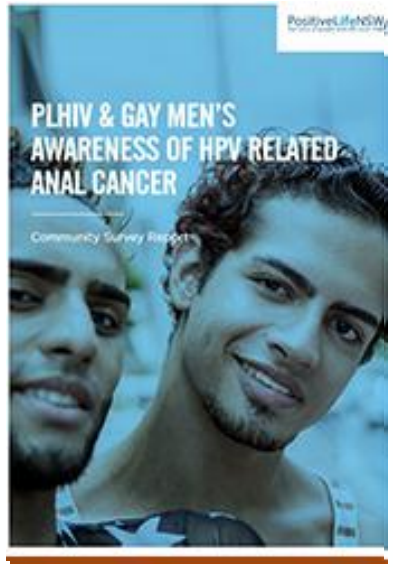
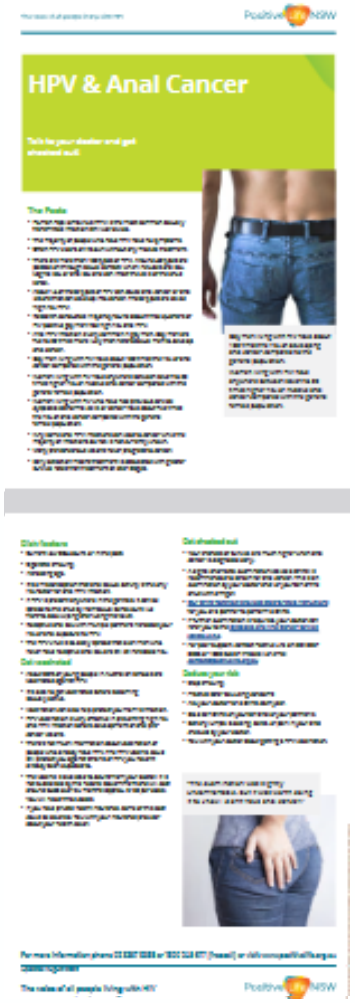
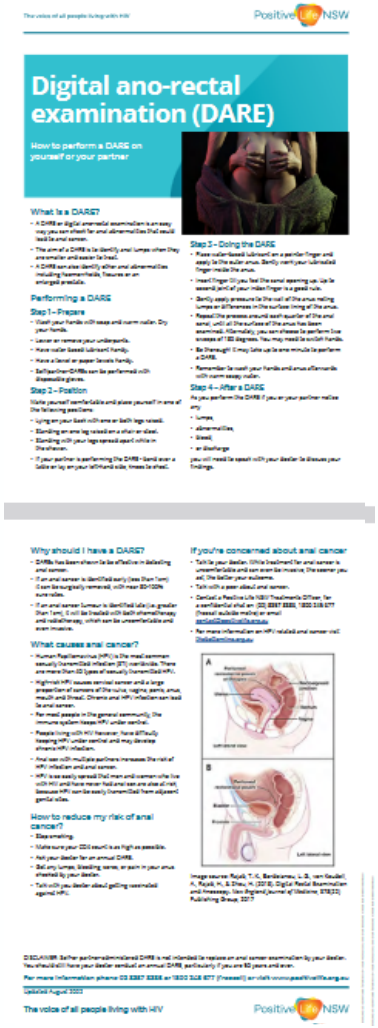
Resources







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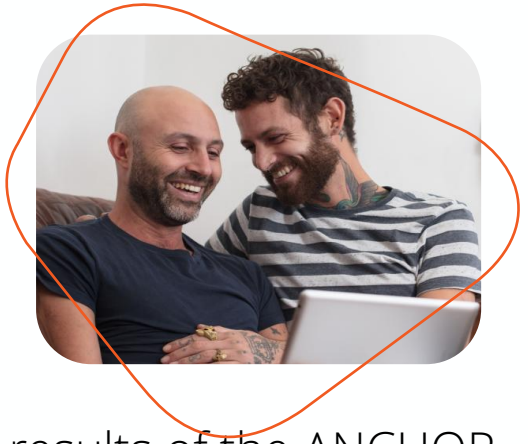
Focus on Anal Cancer



- Considerable impetus around anal cancer research and screening guidelines following results of the ANCHOR Study demonstrating that treating anal cancer precursor lesions reduces cancer risk for PLHIV
- Member of the writing group for the new ASHM Australian Anal Cancer Screening Guidelines
- NHMRC Targeted Call for Research – successful community driven response to anal cancer research
- Submission and support for MSAC application for appraising new medical services/technologies for anal cancer prevention and treatment
- Positive Life NSW held an In The Know Research and Treatments evening for community to appraise of latest developments

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Anal Cancer

The ASHM Anal Cancer Guidelines were published 04 March 2025

These guidelines equip healthcare providers with the latest recommendations for screening, diagnosis, and management of precursor lesions of anal cancer in people living with HIV—ensuring early intervention and better patient outcomes.

Key recommendations from the Anal Cancer Screening Guidelines for People Living with HIV

-Gay, bisexual and other men who have sex with men (GBM) and trans women LHIV over 35 years of age should be offered screening

- Cis-women, trans men and other cis-men (not GBM) LHIV over 45 years of age should be offered screening

- The screening modality should be primary HRHPV testing with cytology triage

- Screening should be repeated every 3 years for those who screen negative

- Screening should be discontinued, with shared decision-making, at age 75 years and in individuals with two consecutive negative screening visits who are not currently sexually active

The consortium of agencies made up of Positive Life NSW, NAPWHA, ACON, Living Positive Victoria, Positive Women Victoria, Queensland Positive People and Positive Life SA were successful in their application for the NHMRC Targeted Call for Research relating to Anal Cancer.

5 years, $5mil

The Targeted Call for Research (TCR): Anal Cancer 2025 grant opportunity aims to fund research aimed at improving awareness and to provide further guidance for the prevention, diagnosis and treatment of anal cancer for both consumers and healthcare professionals. Its focus may encompass, but is not limited to, the development and implementation of screening methods, innovative prevention strategies, testing technologies, and health promotion approaches to more broadly address anal cancer.

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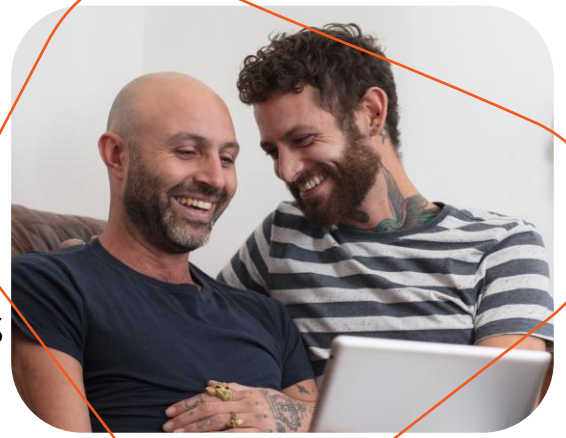
Implementation

- ASHM Australian Anal Cancer Screening Guidelines published March 2025
- Australian Guidelines for Anal Cancer Screening in PLHIV manuscript submitted to HIV Medicine
- Guidelines are for clinician-testing, but self-collection likely to increase acceptability (although evidence suggests that people have lower confidence in self-collected specimens)
- Need to triage to prioritise screening and referral of PLHIV at highest risk while screening and treatment services capacity is expanded in Australia
- Developing Anal Cancer Screening resources online toolkit and printable brochure with ASHM for potential integration into s100 prescriber training
- Updating of the 2016 survey on anal cancer knowledge/perceptions in PLHIV and developing an updated survey with the support of the Glendonbrook Foundation at the Kirby Institute
- Continue to contribute to developing a national program of research on screening and treatment to prevent anal cancer in PLHIV through the NHMRC TCR funding and Scientific Advisory Committee

Discussion Points

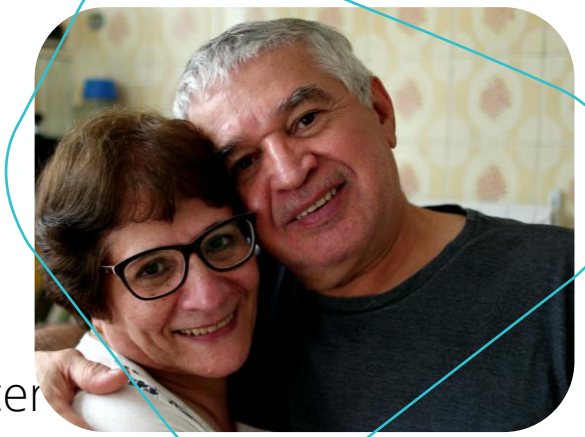
- Lack of awareness around screening/DAREs – will the Anal Cancer Screening Guidelines achieve intended aims?
- Barriers to DARES – difficult to get people to engage, lack of advocates, difficulties in promoting to high-caseload GPs and sexual health clinics
- Research/knowledge gap work on screening and DARES, unmet needs in diverse community of PLHIV as well as GPs who don't have the knowledge, or topic considered too difficult to discuss with patients
- Think about expanded access to HPV vaccination and coverage for PLHIV (HPV vaccine currently recommended for MSM of any age who have not previously been vaccinated, and HPV 9-valent vaccination recommended for WLHIV up to 45 years, but cost only covered to those aged up to 26 years)

Challenges for PLHIV



- Impact of early effective ART introduction and its impact on the immune system will only likely be seen once cohorts start 50 years and over
- PLHIV are increasingly receiving immunomodulatory therapies for medical conditions such as psoriasis, rheumatoid or transplantation. While the effect on anal cancer risk is unknown, this is likely to accelerate HPV-related disease
- Although WLHIV have much less of a risk comparatively than MSMLHIV, there is no Australian data on anal HPV prevalence in women. There is a misconception that if they clear CIN/Cervical HPV, then they are 'safe', however, they may still harbour anal HPV
- The decrease in uptake/results of cervical screening in women living with HIV may not be encouraging for the uptake of anal swabbing. Key barriers to uptake include a lack of information, misconceptions about the need for screening, and factors like time constraints and access to healthcare, especially for migrant and multicultural groups
- In women who are not living with HIV, age-specific anal cancer rates overtake the cervical cancer rate when they reach their 60s. This is also likely to be the case in women living with HIV – no Australian data (small numbers)

Managing Expectations



- Evidence that screening for and treatment of HSIL can reduce the risk of anal cancer by an estimated 44-70%
- However, screening does not completely eliminate the risk of anal cancer - need to continue to increase PLHIV community knowledge of their increased risk of anal cancer
- Two groups of PLWHIV to consider – symptomatic people (lump/bleeding etc) and asymptomatic screening populations. They will have different journeys into appropriate care and likely different barriers
- Abnormal screening results require more detailed investigation, ideally with HRA and biopsy, given that pre-cancerous HSIL lesions are typically asymptomatic and impalpable on DARE
- Implementation of any recommendations for screening of PLHIV to prevent anal cancer will be limited by a lack of resources, predominantly of high resolution anoscopists
- Application for Medicare Benefits Schedule listing (MSAC) of anal HPV testing, cytology, HRA and HSIL treatment for detection of anal pre-cancer and cancer currently at final stage of consideration (November 2025?)
- What exactly will Medicare fund? Realistically, any public funding will not occur until at least 2026
- Nevertheless, there will be PLHIV who wish to be screened, and this option should be made available to as many as possible, notwithstanding likely out-of-pocket costs

Ongoing Considerations

- Ageing population of PLHIV (50% aged over 55 years in Australia)
- Increase PLHIV community knowledge of anal cancer screening guidelines
- Potential roles for PLWHIV and Peer Navigators in the roll-out of screening ("buddy system")
- PLWHIV already engaged with health systems, so potentially easy to offer targeted testing and stratified roll-out to those most at risk
- Potential for engaging people in rural and remote areas, and looking at how they might access care/screening
- Think about potential innovations such as postal screening options (posting out a testing kit – US model)
- Learn from other models such as the technology for self-collected cervical screening (HPV Check at-home sample collection test kit?)
- Raise awareness of anal cancer with healthcare professionals
- Value of DARE packs and benefits for their distribution and promotion and sending out to high caseload GPs and sexual health clinics as a way of raising awareness and creating that engagement around anal cancer
- Continue to contribute to developing a national program of research on screening and treatment to prevent anal cancer in PLHIV through the NHMRC TCR funding and Scientific Advisory Committee

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Aspiration

- To quote Professor Richard Hillman – “Let’s make anal cancer history!”

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Thank You

If you have any questions, please let us know:

Positive Life NSW
(02) 8357 8386
1800 245 677 (freecall outside metro areas)

Positive Life NSW