

## 8.4 PEOPLE WHO ARE LGBTQ+ AND PEOPLE WHO ARE INTERSEX: STRATEGIC PRIORITIES AND ACTIONS

*Note: italicised words indicate where the action has been tailored for this population.*

1. **Ensure that Australia has access to timely and accurate cervical cancer incidence and mortality data.**
  - 1.1. Review the timeliness of cervical cancer notifications from each of the state and territory cancer registers to the Australian Cancer Database (ACD) and investigate opportunities to accelerate the availability of national cervical cancer data. Aim to have the data for the preceding year available by November 1st of each calendar year.
  - 1.2. Ensure that this accelerated reporting also includes currently reported stratifications including rates for Aboriginal and Torres Strait Islander people, by remoteness, by socio-economic status, and by state and territory.
  - 1.3. Build on the currently available breakdowns to ensure timely reporting of cancer incidence and mortality for Aboriginal and Torres Strait Islander people in all jurisdictions, people of culturally and linguistically diverse backgrounds, people living disability, *people who identify as lesbian, gay, bisexual, transgender, queer, and asexual, people who are intersex*, and other priority populations as these data become available. *Use Australian Bureau of Statistics (ABS) Standards for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables<sup>15</sup> when recording information to ensure comparability and compatibility between data sets related to the health of LGBTQ+ and intersex people across disease types.*
  - 1.4. Add cancer registry data into the data assets that are included as enduring linkages in the Multi-Agency Data Integration Project (MADIP) to facilitate this. When cancer data are included in MADIP, consider reporting on individual-level socioeconomic status, rather than area-level measures.



15 Australian Bureau of Statistics. Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables [Internet]. Canberra: ABS; 2020 [cited 2022 November 7]. Available from: <https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release>.

## Vaccination

2. **Optimise the delivery of school-based HPV immunisation programs in all jurisdictions to maximise equity and achieve high coverage *including for students who already identify as LGBTQ+ or who are intersex.***
  - 2.1 Review and revise communication planning materials and provide educational opportunities in schools to ***ensure language used is inclusive, and make it clear the HPV vaccination is relevant and important for everyone including students who identify as LGBTQ+ or are intersex.*** These communications should target adolescents, parent, family and caregivers as well as school staff to increase understanding of HPV, HPV vaccination and the elimination strategy through strong partnerships between health and education towards an integrated approach to HPV vaccination literacy that spans key learning areas, is supported by a whole-of-school approach, and fosters health literacy.<sup>16</sup>
  - 2.2 Utilise technology to support digital reminders and put clear communication and follow-up protocols in place to ensure that the school and the consenting carer are aware when a vaccine dose has been missed and then receive clear remedial instructions, including how to access ***vaccination through LGBTQ+ and intersex specific community health services and other LGBTQ+ and intersex-friendly services.***
  - 2.3 Provide in-school vaccination catch-up opportunities where possible. Should a single dose vaccination strategy be introduced, the implementation plan should ensure that the reduction in required doses does not reduce opportunities for in-school vaccination; and that the evidence of equal efficacy is communicated clearly to providers and the community.
  - 2.4 Fund and develop routine program processes that can identify schools with lower coverage and develop tailored solutions to improve HPV vaccination uptake, ***including working in partnership with LGBTQ+ and intersex-friendly health services, peak bodies, community and youth support such as youth mental health and homeless services.***





3. **Optimise the reach and funding of complementary out-of-school HPV immunisation programs to achieve equity in delivery for all, including people *who already identify as LGBTQ+ or who are intersex* and medically high-risk populations (catch up).**
  - 3.1 Fund and promote catch up of an individual's allocated dose of HPV vaccination for adults 19 and over in medically higher risk groups, and *for people who already identify as LGBTQ+ or who are intersex*.
  - 3.2 Fund and promote HPV vaccine catch up strategies with out-of-school adolescents *including those who identify as LGBTQ+ or who are intersex*, their peak bodies, health services and communities. Ensure equity in availability of catch-up opportunities across jurisdictions and for the most marginalised groups, for example, adolescents in youth detention. Consider alternative community locations and providers, for example, GP clinic settings, Aboriginal Community Controlled Health Organisations, **LGBTQ+ and intersex health organisations**, pharmacies and community events. Develop workforce strategies to expand reach, for example, sexual health nurses.
  - 3.3 Implement GP and **LGBTQ+ and intersex health care provider** education, training and quality improvement activities relating to immunisation that support routine use of the Australian Immunisation Register (AIR) data to check HPV vaccination status for all patients aged 14-19 years, address vaccine hesitancy, and assess decision-making capacity among vaccine recipients for the decision to vaccinate.
4. **To monitor equity in immunisation, develop a method to enable annual reporting of HPV vaccination coverage for people *who identify as LGBTQ+ or who are intersex*, and for medically high-risk populations.**
  - 4.1 Leverage data linkage through the MADIP, to monitor engagement, elimination progress and outcomes *for people who identify as LGBTQ+ or who are intersex, using demographic and other variables and reference groups to develop community accepted definitions and a consent process as to whether a person is identified as LGBTQ+ or intersex within the linked dataset.*

## Screening and precancer treatment

### 5. Promote cervical screening regularly with the public and strategically with under-screened groups.

- 5.1 Undertake regular targeted, tailored campaigns and activities for under-screened groups, *including campaigns and activities specifically focussed on and designed by gender-diverse and sexuality-diverse people who have a cervix*, complemented by evidence-based, inclusive population-wide public awareness activities and mass media, delivered through appropriate channels.<sup>17</sup> *Ensure that LGBTQ+ people and people who are intersex are represented in any mass media and resources that are developed. Campaigns, websites and resources should use appropriate language and appropriate imagery (including choice of colours) to represent people with a cervix who are not cisgender women.*
- 5.2 Work with *LGBTQ+ and intersex communities, including respected members, cervical cancer survivors, community-controlled LGBTQ+ and intersex organisations and specialised health services that serve LGBTQ+ and intersex communities*, to co-create, design and test best approaches to reach the community, including the content of campaigns and information materials. Ensure campaigns are informed by the success and implementation strategies from previous campaigns and formative research. Materials may need to enhance community health literacy about HPV and cervical cancer.
- 5.3 Trial and utilise technology to support digital invitations, reminders, and navigation to follow-up activities for people with screening results that require further investigation.

### 6. Increase access to screening, colposcopy and follow-up for people who already identify as LGBTQ+ or who are intersex by expanding who can offer these services, and where and how they are offered, to improve reach and uptake.

- 6.1 Provide a clear pathway to enable appropriately trained registered nurses, Aboriginal Health Workers and Practitioners, and midwives to be able to independently request and sign the pathology form for a cervical screening test (and be eligible for Medicare reimbursement)
- 6.2 Establish a clear national pathway to train and accredit registered nurses and GPs to provide colposcopy
- 6.3 Resource a pilot to scale up point-of-care HPV testing, with links to care, for remote communities
- 6.4 Resource pilots and, where successful, resource scale-up and routine provision of innovative screening models *for people who identify as LGBTQ+ or who are intersex* such as peer-led and community-developed services. Work with *LGBTQ+ and intersex* community organisations to develop models, scale up successful models, and share best practice approaches. *Provide services that ensure culturally safe care from appointment through to screening and follow up. Make people aware of what to expect at a screening visit and consider needs around a screening visit more holistically – for example establish culturally safe terminology, develop strategies that an individual can use to signal to the provider during the procedure if they feel unsafe or want it to stop, and provide post-screening counselling for people who may be triggered by screening. Provide options for people including bringing a friend for support, inserting the speculum themselves, requesting a smaller speculum, and self-collection.*

17 Coordinated with actions 2.1 and 8.1

## 7 Collect, use, and release data to enable and monitor equity of access to cervical screening and precancer treatment services for people who *identify as LGBTQ+ or who are intersex*.

- 7.1 Routinely report all program indicators stratified by key population demographics, expand reporting to include all priority populations, *including people who identify as LGBTQ+ or who are intersex*, and introduce routine monitoring of performance against the WHO precancer treatment indicator. *In order to routinely report on program indicators separately for gender-diverse people with a cervix, this information needs to be captured. The National Cancer Screening Register (NCSR) can record gender, but it is unclear to what extent the data are accurate or complete. Some measures will not be able to be routinely reported until the recommendations for incorporating gender identification are adopted into the national Census.*

*There is not yet the explicit capacity on the NCSR to record diversity of sexuality. Approaches to adequately monitor progress towards elimination targets for this group need to be developed in collaboration with the LGBTQ+ and intersex community, as use of routine data may not be the most appropriate approach.*

*Use ABS standards for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables when recording information to ensure comparability and compatibility between data sets related to the health of LGBTQ+ and intersex people across disease types. The best ways of capturing and reporting data to reflect the experiences of the diverse LGBTQ+ and intersex communities should be developed in consultation with those communities, and may require control by the individual over who can view the data collected.*

- 7.2 Promote the importance of data collection on gender diversity, training all staff to collect demographic data sensitively in order to improve the recording of all demographic fields (Aboriginal and/or Torres Strait Islander status, country of birth, gender), including additional fields not yet captured on the NCSR and information that affects clinical management such as immune status. *Training relating to routinely collecting information about gender should involve gender-diverse people. The best ways of capturing and reporting data on gender, and in enrolling people with a cervix who do not identify as women into the National Cervical Screening Program (NCSP), should be developed in consultation with gender-diverse people. This may require control by the individual over who can view the data collected.*

*Consult with trans men and other gender diverse people on appropriate ways and opportunities to use gender data captured on the NCSR or other health systems, such as tailoring routine communication from the NCSP – for example envelopes without NCSP branding may be preferred by trans men; or an LGBTQI+ health check could be offered (with triggers for GP to do comprehensive screening), to ensure all screening (including cervical screening) is done and individual's needs are identified.*

- 7.3 Enhance clinical information systems in primary health care settings to enable automated uploading for relevant demographic information to integrate with NCSR
- 7.4 Add cancer registry data and screening data from the NCSR into the data assets that are included as enduring linkages in the MADIP *including information on gender diversity, when the recommendations for incorporating gender identification are adopted into the national Census.*
- 7.5 Enable clinicians and healthcare services to readily generate reports that can support continuous quality improvement initiatives by identifying patients who are under-screened and indicate current participation rates to inform efforts that drive engagement.
- 7.6 Provide visibility to primary care providers of current waiting times for colposcopy services, so that this can be factored into referrals and improve timeliness of care. *Ensure there are appropriate, safe and inclusive colposcopy services available for people who identify as LGBTQ+ or who are intersex and provide information about how/where to find queer-friendly services for follow-up.*
- 



## Treatment

8. Ensure communities and patients have equitable access to quality information about cervical cancer symptoms and that each cancer patient has tailored information about their diagnosis, intended treatment and planned optimal care pathway.
  - 8.1. Promote public understanding of cervical cancer signs and symptoms, the role of early detection and the opportunity for cure. Campaigns and activities should be specifically focused on and designed by gender-diverse and sexuality-diverse people and LGBTQ+ and intersex people should be represented in any mass media and resources that are developed. *Campaigns, websites and resources should use appropriate language and appropriate imagery (including choice of colours) to represent people with a cervix who are not cisgender women.*<sup>18</sup>
  - 8.2. Provide information, consultation and support (for example, *queer-friendly services and resources*) such that patients and their families/carers fully understand and contribute their own preferences and needs to their individual care pathway.
  - 8.3. Provide patients with the information, access to financial support and support personnel they need to navigate the health system, including informing them that they can have a person/people of their choice accompanying them whenever needed, *as well as provide access to spaces where they feel safe and ensure that they are always addressed correctly. This awareness is particularly important for people with a cervix who are not cisgender women and are required to access care within a "women's health" environment.*
  - 8.4. Enable incremental improvement by conducting routine patient-related evaluation measures (PREMs) to assess patient satisfaction, feeding results back to shape training and development of personnel, patient information materials and health service systems as appropriate. Ensure *sensitively collected information* captures patient diversity and experiences according to their sex, gender and sexual orientation. Ensure this information accords to national standards for data collection.

<sup>18</sup> Coordinated with actions 2.1 and 5.1

## 9. Develop and implement a road map of coordinated care, with communities of practice, to optimise the delivery of safe, quality care to all patients.

- 9.1. Realise a coordinated approach to patient care from diagnosis to survivorship and palliative care that is tailored to local population needs and diversity. This includes identifying and meeting the training and resourcing needs of key professionals (including but not limited to ensuring access to safe services and a supportive workforce *for LGBTQ+ and intersex people reflecting sex, gender and identity-sensitive services and care*). *Consultation with trans men and other gender diverse people to assist with development of training and education of health professionals in trauma-informed care so that people from LGBTQ+ and intersex communities feel safe to access treatment.*
- 9.2. Establish communities of practice, where multidisciplinary teams oversee processes and standards of care, and take responsibility for actively building relationships within and across jurisdictions. This can enable a level of safety and trust when a patient is required to travel to receive quality care. Tertiary centres should actively nurture relationships with services expert in caring for priority populations (for example, *LGBTQ+ and intersex specialised health services*).
- 9.3. Optimise a hub-and-spoke model ensuring continuity of care for those diagnosed with cervical cancer to bring “quality to patients” where possible (for example palliative care) and “patients to quality” where necessary for highly specialist care (for example brachytherapy). *Queer-friendly services are key to ensure that the LGBTQ+ and intersex community feel respected and safe when accessing care.* Noting that palliative care services should be integrated into all levels of health care systems including primary care.
- 9.4. Identify and leverage quick wins by translating successful service models to new jurisdictions and ensure longer-term solutions that may require policy change or workforce reforms. Consider models aimed at addressing workforce issues, such as building an additional supportive role for gynaecologic nurses. Genuine partnership with priority populations and communities will improve the provision of culturally safe care and enhance access to treatment.

## 10. Drive improvements in cervical cancer management through a data collection framework supporting systematic monitoring and enhancement of the quality of care, in alignment with the Australian Cancer Plan.

- 10.1. Enhance and harness the data collected in the National Gynaecological Oncology Registry (NGOR) cervical cancer module to inform continuous improvement in care (equity of access, quality, and safety) based on incidence, stage, and mortality data, key clinical quality indicators, as well as patient reported evaluation and outcome measures (PROMs). *Data on patient gender and sexuality should be routinely collected by NGOR to enable monitoring of key clinical quality indicators to ensure equity for gender diverse and sexually diverse people.*
- 10.2. Conduct annual cervical cancer audits using data from the NSCR, cancer registries and NGOR together with HPV genotype information determined and reported for all cervical cancers
- 10.3. Consolidate current clinical guidance and quality standards through developing national guidelines for the management of cervical cancer and utilise the NGOR to monitor adherence.

