

8.5 PEOPLE WITH DISABILITY: 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 with 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.
 - 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.



Vaccination

2. **Optimise the delivery of school-based HPV immunisation programs in all jurisdictions to maximise equity and achieve high coverage for *students with disability*.**
 - 2.1 Review and revise communication planning *materials for students with disability and their communities* and provide educational opportunities in both mainstream and special schools to improve adolescent, parent, family and caregiver, and school staff understanding of HPV vaccination and the elimination strategy. This should occur through strong partnerships between health and education to provide an integrated approach to HPV vaccination literacy that spans key learning areas, is supported by a whole-of-school approach, and fosters health literacy.¹⁹
 - 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 receive clear remedial instructions, including how to access *vaccination locally through services that meet the needs of students with disability*.
 - 2.3 Provide in-school vaccination catch up opportunities where possible. Should a single dose vaccination strategy be introduced, ensure that the implementation plan does not reduce opportunities for in-school vaccination given the reduction in required doses; 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 disability health services, peak bodies and community*.
3. **Optimise the reach and funding of complementary out-of-school HPV immunisation programs to achieve equity in delivery for all, including *people with disability* 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, *including for people with disability*.
 - 3.2 Fund and promote HPV vaccine catch up strategies *with out-of-school adolescents including those with disability, 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, pharmacies, and community events. Develop workforce strategies to expand reach, for example, *inclusion of HPV vaccination in the scope of disability service providers and expansion of HPV vaccination nursing workforce to include community outreach*.
 - 3.3 Implement GP and *disability service 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. **Develop a method to enable annual reporting of HPV vaccination coverage for *people with disability* and medically high-risk populations to monitor equity in immunisation.**
 - 4.1 Leverage data linkage through the MADIP, to monitor engagement, elimination progress and *outcomes for people with disability, using demographic and other variables and a reference group to develop community-accepted definitions as to whether a person is identified as with disability 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 co-designed by people with disability*, complemented by evidence-based, inclusive population-wide public awareness activities and mass media delivered through appropriate channels²⁰.
- 5.2 Work with *people with disability, and those who support them*, including cervical cancer survivors, and community-controlled organisations who serve these communities, to co-create, design and test best approaches to reach the community, including the content of campaigns and information materials. *Ensure information on appointments, reminders, results and follow-up is accessible to people with disability and people who support them*. Ensure campaigns are informed by the success and implementation strategies from previous campaigns and formative research, noting that materials may need to enhance community health literacy about HPV and cancer of the cervix.
- 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. *Ensure these technologies are accessible to people with disability and people who support them*.

6. Increase access to screening, colposcopy and follow-up for people with disability 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 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 such as peer-led and community-developed services. Work with community-controlled organisations *that serve people with disability* to develop models, scale up successful models, and share best practice approaches. *Provide services that feel and are trustworthy and safe (from appointment through to screening and follow up) and make people aware of what to expect at a screening visit. Consider their needs holistically and deliver services in a way that is integrated with the provision of services to people with disability who have other complex needs and healthcare requirements, and ensures continuity of disability-inclusive care*.

²⁰ 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 with disability.*

- 7.1 Routinely report all program indicators stratified by key population demographics, expand reporting to include all priority populations, *including people with disability*, and introduce routine monitoring of performance against the WHO precancer treatment indicator.
- 7.2 Promote the importance of data collection, 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 National Cancer Screening Register (NCSR) *such as on disability and information that affects clinical management such as immune status. Consult with people with disability, and people who support people with disability, on appropriate ways and opportunities to use data about disability captured on the NCSR or other health systems, such as tailoring routine communication from the NCSR.*
- 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 *which includes data from the National Disability Insurance Scheme (NDIS) and Survey of Disability, Ageing and Carers.*
- 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 indicating 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. *Provide information about how and where to find colposcopy services, considering an individual's physical access needs and any needs for additional support or tailored information (for example Easy English, Braille, pictograms, large-print materials, videos and/or, access to Auslan interpreters and face-to-face conversations) and ensure continuity of disability-inclusive care.*



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 elimination, *including campaigns and activities specifically focussed on and designed by people with disability.*²¹
- 8.2. Provide information, consultation, and support such that patients and their families/support people fully understand and contribute their own preferences and needs to their individual care pathway. *Particularly accounting for an individual's physical access needs and any needs for additional support or tailored information (for example, low vision, hearing impairment).*
- 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 support person/people/*assistance animal as required*, accompanying them whenever needed.
- 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 *information* collected captures patient diversity and experiences according to their sex, gender and sexual orientation, ethnicity, Aboriginal and Torres Strait Islander *and disability* status. Ensure this information accords to national standards for data collection.

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.
- 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, *NDIS*).
- 9.3. Optimise a hub-and-spoke model ensuring continuity of care for those diagnosed with screen-detected cancer and bring "quality to patients" where possible (for example palliative care) and "patients to quality" where necessary for highly specialist care (for example brachytherapy), *tailoring the approach to the patient's disability to ensure quality care is always delivered*. 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.

²¹ Coordinated with actions 2.1 and 5.1



- 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).
- 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.