8.3 CULTURALLY AND LINGUISTICALLY DIVERSE PEOPLE: 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 1st November 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 (CALD) 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 from culturally and linguistically diverse backgrounds.*

2.1 Review and revise communication planning materials for *students from CALD backgrounds and their communities, and provide educational opportunities in schools in a culturally safe and appropriate way, and in language, if necessary,* to improve adolescent, parent, family, and caregiver as well as 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.[12]

2.2 Utilise technology to support digital reminders and put clear communication and follow-up protocols in place to ensure that schools and consenting caregivers are aware when a vaccine dose has been missed and receive clear instruction on how to catch up, including how to access *vaccination locally through General Practitioners, community health services and other organisations that provide culturally safe and appropriate services to people from culturally and linguistically diverse backgrounds.*

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 communities.

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12 Coordinated with actions 5.1 and 8.1

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 CALD community health champions, peak bodies and communities. Fund and support CALD and other liaison staff with dedicated time in schools to promote engagement with vaccination. Build on the strengths of the community health sector and their leadership to develop tailored solutions that will support the acceptability, community support for, experience and understanding of school-based HPV vaccination among CALD adolescents.*

3.   Optimise the reach and funding of complementary out-of-school HPV immunisation programs to achieve equity in delivery for all, including *people from culturally and linguistically diverse backgrounds, refugees and asylum seekers* 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 people from culturally and linguistically diverse backgrounds, refugees and asylum seekers.*

3.2   Fund, implement and promote HPV vaccine catch up strategies *with out-of-school adolescents including those from CALD backgrounds, refugees and asylum seekers, 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, events and providers, for example, community health services, and develop workforce strategies to expand reach.

3.3   Implement GP and healthcare 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, *including familiarity with HPV vaccine catch up schedules for migrants, refugees and asylum seekers.*

4.   Develop a method to enable annual reporting of HPV vaccination coverage for people from culturally and linguistically diverse backgrounds 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 from culturally and linguistically diverse backgrounds, using demographic and other variables and a reference group to develop community-accepted definitions as to whether a person is identified as part of a CALD community within the linked dataset.*

Screening and precancer treatment

5. **Promote cervical screening regularly with the public and strategically with under-screened groups** *including culturally and linguistically diverse people.*

5.1 Undertake regular targeted tailored campaigns and activities for under-screened groups *including campaigns and activities specifically focussed on and designed by and for CALD people,* complemented by evidence-based, inclusive population-wide public awareness activities and mass media delivered through appropriate channels.[13]

5.2 Work with priority communities, including *a range of respected members, community influencers, and cervical cancer survivors from CALD peoples, and community-based organisations that serve these communities,* to co-develop campaign and information materials, and come up with best approaches to reach the community, including the content (language and visual) of campaigns and information materials. 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 *CALD people* with screening results that require further investigation.

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13   Coordinated with actions 2.1 and 8.1

6.   **Increase access to screening, colposcopy and follow-up for *culturally and linguistically diverse people* 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-based organisations *that provide services to CALD people* to develop models, scale up successful models, and share best practice approaches. *Deliver targeted solutions to people arriving from countries with no screening programs to address issues/concern/disparities associated with stigma, discrimination and trauma when providing cervical screening.*

7.   **Collect, use and release data to enable and monitor equity of access to cervical screening and precancer treatment services for *culturally and linguistically diverse people*.**

7.1   Routinely report all program indicators stratified by key population demographics, expand reporting to include all priority populations, *including CALD people,* and introduce routine monitoring of performance against the WHO precancer treatment indicator. Work with a reference group representing culturally and linguistically diverse people to develop appropriate stratification of indicators that balance granularity and meaningful differences with the availability, validity and size of data for different measures.

7.2   Promote the importance of data collection *on cultural and linguistic diversity,* and train 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, language spoken at home,* gender). This can be expanded to include additional fields not yet captured on the National Cancer Screening Register (NCSR) and information that affects clinical management such as immune status.

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. *There are limitations with using routinely collected data for this purpose and the different routine data collections may contain differing information about an individual. Data governance should include representatives from CALD communities to optimise how to resolve these differences and maximise the utility and validity of the data, from the perspectives of both monitoring and health care for an individual.*

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 in terms of priority population 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. *Take an individual's cultural and language needs, including for translation, into account when referring.*

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 *including campaigns and activities specifically focussed on, and designed by and for, CALD people. Including providing the information in the primary language of key communities to increase CALD communities' understanding of cervical cancer and reduce the stigma and fear associated with a cervical cancer diagnosis by reiterating that most cervical cancers can be successfully treated if detected early.*[14]

8.2.   Provide information, consultation, and support (for example, utilising the expertise of nurses and allied health professionals) such that patients and their families/carers fully understand, voice their needs, and contribute to a patient-centred care pathway. *The information should be designed by and be specifically for CALD people.*

8.3.   Provide patients with the information and access to financial support and support personnel for navigating the health system. This includes information regarding having a person/people of their choice accompanying them whenever needed *and that an interpreter will always be provided, in person whenever possible. Information provided should be designed by and for culturally and linguistically diverse people.*

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 *relevant for CALD people.* Ensure this information accords to national standards for data collection.

14   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 *in-language culturally relevant resources and provision of care for CALD communities).*

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, *which will require liaising with specialised community-controlled organisations for CALD people. It will also require engagement with community leaders, community influencers and being aware of cultural differences that may prevent some patients from accessing optimal care.*

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). *The design of these models should include representation from CALD people.*

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). Where feasible, data on patients' country of birth, duration of time living in Australia, first language and language spoken at home, should be collected.

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.