



NACCHO

National Aboriginal Community
Controlled Health Organisation
Aboriginal health in Aboriginal hands

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Public
Consultation for
Australian
National Cervical
Screening
Program
Guidelines

Submission to Cancer
Council Australia

November 2023

About NACCHO

NACCHO is the national peak body representing 145 Aboriginal Community Controlled Health Organisations (ACCHOs). We also assist a number of other community-controlled organisations.

The first Aboriginal medical service was established at Redfern in 1971 as a response to the urgent need to provide decent, accessible health services for the largely medically uninsured Aboriginal population of Redfern. The mainstream was not working. So it was, that over fifty years ago, Aboriginal people took control and designed and delivered their own model of health care. Similar Aboriginal medical services quickly sprung up around the country. In 1974, a national representative body was formed to represent these Aboriginal medical services at the national level. This has grown into what NACCHO is today. All this predated Medibank in 1975.

NACCHO liaises with its membership, and the eight state/territory affiliates, governments, and other organisations on Aboriginal and Torres Strait Islander health and wellbeing policy and planning issues and advocacy relating to health service delivery, health information, research, public health, health financing and health programs.

ACCHOs range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services which rely on Aboriginal health practitioners and/or nurses to provide the bulk of primary health care services. Our 145 members provide services from about 550 clinics. Our sector provides over 3.1 million episodes of care per year for over 410,000 people across Australia, which includes about one million episodes of care in very remote regions.

ACCHOs contribute to improving Aboriginal and Torres Strait Islander health and wellbeing through the provision of comprehensive primary health care, and by integrating and coordinating care and services. Many provide home and site visits; medical, public health and health promotion services; allied health; nursing services; assistance with making appointments and transport; help accessing childcare or dealing with the justice system; drug and alcohol services; and help with income support. Our services build ongoing relationships to give continuity of care so that chronic conditions are managed, and preventative health care is targeted. Through local engagement and a proven service delivery model, our clients 'stick'. Clearly, the cultural safety in which we provide our services is a key factor of our success.

ACCHOs are also closing the employment gap. Collectively, we employ about 7,000 staff – 54 per cent of whom are Aboriginal or Torres Strait Islanders – which makes us the third largest employer of Aboriginal or Torres Strait people in the country.

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Recommendations

1. **NACCHO recommends** any interventions to address cervical cancer screening align with the National Agreement on Closing the Gap and its Four Priority Reform Areas.
2. **NACCHO recommends** government adopts a 'Health in All Policies' approach, recognising that health outcomes are influenced by a wide range of social, commercial, political, environmental, and cultural determinants.
3. **NACCHO recommends** sustainable funding to all areas of the ACCHO sector to achieve equity in the provision of holistic, culturally appropriate cancer screening services and care for Aboriginal and Torres Strait Islander peoples and their families.
4. **NACCHO recommends** explicitly stating the target audience of the National Cervical Cancer Screening Program (NCSPP) Guidelines, including Aboriginal Health Practitioners and Aboriginal Health Workers.
5. **NACCHO recommends** ensuring healthcare provider terminology within the NCSPP Guidelines is consistent.
6. **NACCHO recommends** chapters of the Guidelines that are specifically relevant to Aboriginal and Torres Strait Islander peoples are co-designed with Aboriginal and Torres Strait Islander organisations and healthcare professionals in keeping with Priority Reform 1 of the National Agreement on Closing the Gap.
7. **NACCHO recommends** the NCSPP Guidelines recognise a Community members decision to proceed with treatment for a positive cervical cancer case is dependent on various factors
8. **NACCHO recommends** the NCSPP Guidelines recognise cultural, historical, and social factors which influence Aboriginal and Torres Strait Islander women and people with a cervix participation in cervical screening.
9. **NACCHO recommends** the NCSPP Guidelines state that all mainstream health organisations must participate in on-going cultural awareness training to ensure culturally appropriate care is continually provided to Aboriginal and Torres Strait Islander women and people with a cervix. This aligns with Priority Reform 3 of the National Agreement on Closing the Gap.
10. **NACCHO recommends** specific guidance on how healthcare professionals in mainstream health organisations can ensure equity in cervical screening participation.
11. **NACCHO recommends** the updated NCSPP guidelines recommend that clinicians providing cervical screening services should consider the local and cultural context in which the participant lives, in addition to the new recommendations laid out in these updated Guidelines.
12. **NACCHO recommends** investment in Aboriginal and Torres Strait Islander cancer research using Indigenous research methods, led by Aboriginal and Torres Strait Islander cancer researchers.
13. **NACCHO recommends** implementation of data strategies that align to the National Agreement on Closing the Gap Priority Reform 4 to ensure commitment to the collection, handling, and reporting of data occur at sufficient levels of disaggregation, and in an accessible and timely way.
14. **NACCHO recommends** collaboration with ACCHOs and Aboriginal and Torres Strait Islander organisations to improve cervical screening data collection and Aboriginal and Torres Strait Islander identification status in the NCSPP and National Cancer Screening Register (NCSR).
15. **NACCHO recommends** updating the NCSPP Guidelines to include a caveat that healthcare professionals in the ACCHO sector can also use other tools and avenues of communication to invite eligible Aboriginal and Torres Strait Islander peoples to participate in screening outside of the NCSR.

16. **NACCHO recommends** updating the NCSP Guidelines to reflect the amendments listed in Appendix A.

Acknowledgements

NACCHO welcomes the opportunity to participate in public consultation to provide feedback to Cancer Council Australia on the draft Australian National Cervical Screening Program Guidelines.

NACCHO's submission is based on wide-ranging feedback from our sector about Aboriginal and Torres Strait Islander experiences and is underpinned by the Priority Reforms of the National Agreement on Closing the Gap (National Agreement).

National Agreement on Closing the Gap

At the meeting of National Cabinet in February 2023, First Ministers agreed to renew their commitment to Closing the Gap by re-signing the National Agreement, first signed in July 2020. The reforms and targets outlined in the National Agreement seek to overcome the inequality experienced by Aboriginal and Torres Strait Islander peoples and achieve life outcomes equal to all Australians.

This government's first Closing the Gap Implementation Plan commits to achieving Closing the Gap targets *through implementation of the Priority Reforms*. This represents a shift away from focusing on the Targets, towards the structural changes that the Priority Reforms require, which are more likely to achieve meaningful outcomes for Aboriginal and Torres Strait Islander peoples in the long term:

Priority Reform Area 1 – Formal partnerships and shared decision-making

This Priority Reform commits to building and strengthening structures that empower Aboriginal and Torres Strait Islander peoples to share decision-making authority with governments to accelerate policy and place-based progress against Closing the Gap.

Priority Reform Area 2 – Building the community-controlled sector

This Priority Reform commits to building Aboriginal and Torres Strait Islander community-controlled sectors to deliver services to support Closing the Gap. In recognition that Aboriginal and Torres Strait Islander community-controlled services are better for Aboriginal and Torres Strait Islander peoples, achieve better results, employ more Aboriginal and Torres Strait Islander peoples and are often preferred over mainstream services.

Priority Reform Area 3 – Transformation of mainstream institutions

This Priority Reform commits to systemic and structural transformation of mainstream government organisations to improve to identify and eliminate racism, embed and practice cultural safety, deliver services in partnership with Aboriginal and Torres Strait Islander peoples, support truth telling about agencies' history with Aboriginal and Torres Strait Islander peoples, and engage fully and transparently with Aboriginal and Torres Strait Islander peoples when programs are being changed.

Priority Reform 4 – Sharing data and information to support decision making

This Priority Reform commits to shared access to location-specific data and information (data sovereignty) to inform local-decision making and support Aboriginal and Torres Strait Islander Communities and organisations to support the achievement of the first three Priority Reforms.

Review of Closing the Gap

In its recent review of the National Agreement on Closing the Gap, the Productivity Commission described government progress implementing the Agreement's Priority Reforms as mostly weak. It found no evidence of systemic change and that government policy did not reflect the value of the community-controlled sector. The Productivity Commission noted that few tangible steps had been taken to increase the proportion of services delivered by ACCHOs and that there was a need to improve funding to ACCHOs to provide more flexible and longer-term contracts that cover full costs of services and reduce reporting burdens.¹

The review recommended designating leaders to promote and embed changes to public sector systems and culture, embedding a responsibility in conditions of employment for public sector employees to improve cultural capability and relationships with Aboriginal and Torres Strait Islander peoples, and improving accountability and transparency.

NACCHO recommends any interventions to address cervical cancer screening align with the National Agreement on Closing the Gap and its Four Priority Reform Areas.

Health in All Policies

A broad range of structural, social, commercial, political, environmental, and cultural determinants influence health outcomes for Aboriginal and Torres Strait Islander peoples. Entrenched cycles of poverty, exacerbated by poor education and employment outcomes and increased interaction with the justice system contribute significantly to poorer health outcomes for Aboriginal and Torres Strait Islander peoples.

The Australian Institute of Health and Welfare (AIHW) notes that the links between socioeconomic disadvantages such as poverty, social dysfunction and exclusion, stress, racism and poor health are well established.² This is true across urban, regional and remote areas. The consequent disparity in health outcomes between Aboriginal and Torres Strait Islander peoples and other Australians remains significant – 34% of the health gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians is attributable to social determinant factors.²

Consideration is therefore needed of the impact of all policy decisions on health outcomes for Aboriginal and Torres Strait Islander peoples. This allows scope to identify and address those issues around social disadvantage which contribute to higher rates of chronic health conditions such as diabetes, as well as preventable disease.³

A Health in All Policies approach would require consideration of the impact on health outcomes for Aboriginal and Torres Strait Islander peoples in all policy decisions. Such an approach aligns with the National Agreement on Closing the Gap. It also aligns with the ACCHO holistic model of care which considers factors that contribute to health and wellbeing as well as those that compound the likelihood and/or incidence of health conditions.

¹ Australian Government Productivity Commission, 2023, Review of the National Agreement on Closing the Gap Draft Report [available from <https://www.pc.gov.au/inquiries/current/closing-the-gap-review/draft/closing-the-gap-review-draft.pdf>].

² Australian Institute of Health and Welfare. Determinants of health for Indigenous Australians 2022 [Available from: <https://www.aihw.gov.au/reports/australias-health/social-determinants-and-indigenous-health>].

³ Pan American Health Organization. Health in All Policies: from the local to the global. Washington, D.C.: PAHO; 2017.

*'... an approach that incorporates Health in All Policies is the only way to achieve the health-related goals governments are pursuing. Otherwise, health systems will remain locked in a never-ending struggle as they respond to the ill health that often arises from weaknesses in other sectors.'*⁴

NACCHO recommends government adopts a 'Health in All Policies' approach, recognising that health outcomes are influenced by a wide range of social, commercial, political, environmental, and cultural determinants.

Introduction

Cancer is the leading cause of death for Aboriginal and Torres Strait Islander peoples and diagnosis rates are significantly higher in Aboriginal and Torres Strait Islander peoples compared to other Australians.⁵ In the most recent Australia-wide burden of disease study in 2018, cancer accounted for 9.9% of the total burden of disease for Aboriginal and Torres Strait Islander peoples.⁶

In Australia, the incidence of cervical cancer varies depending on various factors, including people's cultural background.⁷ The introduction of the National Human Papillomavirus (HPV) Vaccination Program in Australia has contributed to reduced cervical cancer incidence rates in Australia. However, the decrease in cervical cancer incidence rates does not apply to all populations of Australian women and people with a cervix as cervical cancer incidence rates for Aboriginal and Torres Strait Islander women and people with a cervix remain high.⁸

The AIHW reported in 2018 that cervical cancer screening participation rates for Aboriginal and Torres Strait Islander women and people with a cervix are lower than non-Indigenous Australians. Additionally, Aboriginal and Torres Strait Islander women and people with a cervix were 2.5 times as likely to be diagnosed with cervical cancer than non-Indigenous Australians and 3 times as likely to die from cervical cancer than non-Indigenous Australians.⁹ Accurate estimation of screening participation for Aboriginal and Torres Strait Islander women and people with a cervix is not possible due to Aboriginal and Torres Strait Islander status not being routinely recorded on pathology forms from which cervical screening register data is collated.¹⁰

While the National Strategy for Elimination of Cervical Cancer in Australia (the Strategy) sees Australia aiming to be the first country to eliminate cervical cancer as a public health issue by 2035, this will not apply to all Australians. For the elimination of cervical cancer in Australia, equity must be achieved across all population groups. To do this, further efforts are required to improve the

⁴ Greer S.L., Falkenback M, Siciliani L, Mckee M, Wismar M, Figueras J. From Health in All Policies to Health for All Policies. Viewpoint, Vol 7, 8, E718-E720, August 2022, doi: [https://doi.org/10.1016/S2468-2667\(22\)00155-4](https://doi.org/10.1016/S2468-2667(22)00155-4)

⁵ Australian Institute of Health and Welfare 2023. Aboriginal and Torres Strait Islander Health Performance Framework: summary report July 2023. Canberra: AIHW. Viewed [11 September 2023].

⁶ Australian Institute of Health and Welfare. Australian Burden of Disease Study: Impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2018. Australian Burden of Disease Study series no. 26. Cat. no. BOD 32. Canberra: Australian Government; 2022. <https://www.aihw.gov.au/reports/burden-of-disease/illness-death-indigenous-2018/summary>

⁷ Lisa J. Whop, Megan A. Smith, Tamara L. Butler, Anna Adcock, Karen Bartholomew, Marc T. Goodman, Rachel L. Winer, Elizabeth Milosevic, Beverley Lawton,

Achieving cervical cancer elimination among Indigenous women, Preventive Medicine, Volume 144, 2021, 106314, ISSN 0091 7435, <https://doi.org/10.1016/j.ypmed.2020.106314>. (<https://www.sciencedirect.com/science/article/pii/S0091743520303388>)

⁸ Powell, Aime & Morseu-Diop, Ami & Ninomiya, Maya & Yadav, Uday N & Phillips, Emily & Whop, Lisa & Singh, Devendra Raj & Butler, Tamara & Allanson, Emma. (2023). Review of gynaecological cancer among Aboriginal and/or Torres Strait Islander people in Australia. Journal of the Australian Indigenous HealthInfoNet. 4. 10.14221/2653-3219.1029.

⁹ Australian Institute of Health and Welfare (2018) *Cancer in Aboriginal & Torres Strait Islander people of Australia*, AIHW, Australian Government, accessed 06 November 2023.

¹⁰ Whop LJ, Cunningham J, Condon JR. How well is the National Cervical Screening Program performing for Indigenous Australian women? Why we don't really know, and what we can and should do about it. Eur J Cancer Care (Engl). 2014 Nov;23(6):716-20. doi: 10.1111/ecc.12244. Epub 2014 Sep 19. PMID: 25238027.

NCSP to ensure it is culturally appropriate, equitable and meets the needs of Aboriginal and Torres Strait Islander women and people with a cervix.

NACCHO has chosen to provide both general and specific feedback on the draft NCSP Guidelines.

Feedback has been categorised as:

- general feedback
- specific feedback focusing on:
 - cervical screening participation
 - colposcopy and principles of practice
 - research
 - data collection and reporting.

Recommended amendments on the specific feedback can be found in **Appendix A**.

NACCHO Cancer Program

In May 2023, the Australian Government announced the First Nations Cancer Package. The package includes \$197.9m over four years to the ACCHO sector. NACCHO will spend the first twelve months co-designing the program with ACCHOs and key stakeholders. The NACCHO Cancer Program will lay the foundation for scalable, national solutions to improve cancer related health outcomes for all Aboriginal and Torres Strait Islander peoples. Supports will include:

- upskilling and strengthening the Aboriginal and Torres Strait Islander workforce to support Communities and provide culturally safe cancer support services in areas of high burden of disease
- establishing rural and remote chemotherapy clinics to offer Community members treatment on Country and closer to home
- developing health promotion materials and communication campaigns
- supporting the ACCHO sector to deliver tailored health promotion activities that meet the needs of individual Communities.

This is the first time the ACCHO sector has received cancer specific funding. While the funding provides a foundation to begin developing and delivering culturally safe cancer support services, additional funding is required to ensure all Communities have equity in access to services and support. Of concern, gaps in cancer funding and resources continue to exist for Aboriginal and Torres Strait Islander peoples in the following areas:

- equity in access to screening, early diagnosis, and treatment services in all Communities
- Aboriginal and Torres Strait Islander workforce, including cancer specific, across the ACCHO sector and mainstream health services
- ongoing support for cancer survivors following completion of treatment – encompassing social and emotional wellbeing, and living with any longer-term physical side effects of treatment
- culturally safe palliation services.

Sustainable funding and resourcing is needed to ensure mainstream organisations work in partnership with Aboriginal and Torres Strait Islander organisations to deliver culturally safe cancer services, including cancer screening services to Community.

General feedback

Importance of an ACCHO-led approach

The ACCHO sector is a significant component of the cancer ecosystem and plays an essential role in providing holistic, culturally safe comprehensive primary healthcare for Community members and their families. ACCHOs are trusted, accessible and overcome many of the barriers to accessing health services experienced by Aboriginal and Torres Strait Islander peoples.

There is a clear preference for Aboriginal and Torres Strait Islander peoples to access community-controlled services. Over 50% of Community members prefer to attend an ACCHO over a non-Indigenous practice, and this number is growing. Many will bypass mainstream services to access an ACCHO, where they are confident their cultural safety is guaranteed.¹¹ Sustainable funding and resources is required to meet the demand of Community members who are visiting ACCHOs for primary health care.

Aboriginal and Torres Strait Islander women experience a greater burden of cervical cancer with higher incidence and mortality rates compared to other Australians. A gap currently exists in cervical screening participation for Aboriginal and Torres Strait Islander women which can be explained by differences in access to culturally appropriate cervical screening.¹² With sustainable funding and resources, the ACCHO sector is well positioned to expand service delivery to address the gap in availability and accessibility of cancer screening services, including cervical cancer screening.

NACCHO recommends sustainable funding to all areas of the ACCHO sector to achieve equity in the provision of holistic, culturally appropriate cancer screening services and care for Aboriginal and Torres Strait Islander peoples and their families.

Terminology and intended audience

NACCHO note the draft Guidelines state the target audience includes all health professionals involved in cervical screening. This suggests the Guidelines are encompassing of Aboriginal Health Practitioners and Aboriginal Health Workers; however, this is not explicitly stated.

Throughout the Guidelines the terms 'clinician', 'healthcare professional' and 'healthcare provider' are used interchangeably which may be confusing for readers.

NACCHO recommends explicitly stating the target audience of the NCSP Guidelines, including Aboriginal Health Practitioners and Aboriginal Health Workers.

NACCHO recommends ensuring healthcare provider terminology within the NCSP Guidelines is consistent.

Consultation

As stated in the draft NCSP Guidelines, development of the NCSP Guidelines has undergone extensive consultation with relevant professional bodies and a broad range of clinicians and consumers. There is no mention in the draft Guidelines of targeted consultation with Aboriginal and Torres Strait Islander groups to ensure Aboriginal and Torres Strait Islander voices are reflected in the Guidelines. It is critical Aboriginal and Torres Strait Islander groups are engaged due to the high

¹¹ Kathryn S Panaretto, Mark Wenitong, Selwyn Button and Ian T Ring, Aboriginal community controlled health services: leading the way in primary care, *Med J Aust* 2014; 200 (11): 649-652. | doi: 10.5694/mja13.00005

¹² Butler TL, Lee N, Anderson K, Brotherton JML, Cunningham J, Condon JR, Garvey G, Tong A, Moore SP, Maher CM, Mein JK, Warren EF, Whop LJ. Under-screened Aboriginal and Torres Strait Islander women's perspectives on cervical screening. *PLoS One*. 2022 Aug 31;17(8):e0271658. doi: 10.1371/journal.pone.0271658. PMID: 36044466; PMCID: PMC9432770.

mortality and incidence rates of cervical cancer in Aboriginal and Torres Strait Islander women and people with a cervix. It is important that organisations and healthcare professionals from all population groups can provide meaningful input into the Guidelines to ensure the Guidelines meet the needs of all target groups.

NACCHO recommends chapters of the Guidelines that are specifically relevant to Aboriginal and Torres Strait Islander peoples are co-designed with Aboriginal and Torres Strait Islander organisations and healthcare professionals in keeping with Priority Reform 1 of the National Agreement on Closing the Gap.

Access to prevention and treatment

NACCHO acknowledges the need for equitable access to cervical cancer prevention strategies and cancer treatment. This includes enabling equitable access for Aboriginal and Torres Strait Islander peoples to receive an HPV vaccination and cancer treatment if diagnosed with cervical cancer. Aboriginal and Torres Strait Islander women experience significant and ongoing disparity in cervical screening participation and treatment outcomes. Aboriginal and Torres Strait Islander peoples who are older than 26 years of age, missed out or did not receive the HPV vaccination for various cultural and social reasons or do not have a Medicare card may need to pay for the HPV vaccine.¹³ Structural reforms are required to enable equitable access to HPV vaccinations and affordable treatment for Aboriginal and Torres Strait Islander peoples.

When a Community member receives a cervical cancer diagnosis, there are factors which can influence their decision to receive treatment such as the cost and accessibility to treatment, and family and cultural considerations. It is important that the decision to treat is a shared decision between the healthcare professional and the Community member with informed consent, including financial consent, to ensure the Community member understands what is involved. Ideally, treatment would be received on Country, to ensure Aboriginal and Torres Strait Islander peoples have easy access to family and cultural supports. Further research into treatments that can be delivered in the home or clinic setting, such as oral chemotherapy is needed. This requires additional resourcing for ACCHOs and Community healthcare professionals to be up skilled in the safe handling of cytotoxic therapies, and appropriate monitoring.

NACCHO recommends the NCSP Guidelines recognise a Community members decision to proceed with treatment for a positive cervical cancer case is dependent on various factors.

Specific feedback

The new chapter in the Guidelines ‘Cervical screening in clinical practice’ is a useful inclusion to the Guidelines to provide information to all healthcare professionals who are performing cervical screening in a primary care setting. However, this chapter could be strengthened by recognising the importance of culturally appropriate, safe, and equitable care for Aboriginal and Torres Strait Islander peoples (see below). Specific recommendations on strengthening the language in chapter 5 to be more inclusive and culturally appropriate can be found in **Appendix A**.

Cervical screening participation

Aboriginal and Torres Strait Islander women and people with a cervix participate in cervical cancer

¹³ Whop LJ, Butler TL, Brotherton JML, *et al* Study protocol: *Yarning about HPV Vaccination: a qualitative study of factors influencing HPV vaccination among Aboriginal and Torres Strait Islander adolescents in Australia*. *BMJ Open* 2021;**11**:e047890. doi: 10.1136/bmjopen-2020-047890

screening at much lower rates compared to non-Indigenous Australians. This is due to various factors which include:

- lack of culturally appropriate cervical screening services across mainstream health organisations
 - mistrust of mainstream health organisations leads to Aboriginal and Torres Strait Islander peoples not identifying Aboriginal and Torres Strait Islander status. Therefore, there may be Aboriginal and Torres Strait Islander peoples participating in screening, however this cannot be confirmed due to Aboriginal and Torres Strait Islander peoples not feeling culturally safe to identify.
- fear, shame, and stigma of cervical screening
- fear of a potential positive result
- lack of culturally appropriate education and information on cervical screening across mainstream health organisations
- accessibility to cervical screening services
- limited co-design and shared decision making with Aboriginal and Torres Strait Islander peoples and organisations in national Guidelines, policies and strategies relating to cancer screening results in a lack of culturally appropriate services
- limited national policies and strategies that focus specifically on gynaecological cancers, including cervical cancer for Aboriginal and Torres Strait Islander peoples.⁷
- social and cultural factors such as having to leave Community and Country to attend appointments or services that are not culturally appropriate and safe.

Culturally appropriate screening

Culturally appropriate and safe care is the foundation of an ACCHO's model of care and cultural factors are particularly important when providing cervical screening. The significance of women's business must be considered. To align with Priority Reform 3 of the National Agreement on Closing the Gap, healthcare professionals providing cervical screening services in mainstream health organisations and clinical practices should undergo cultural awareness training to ensure culturally appropriate care is provided to all Aboriginal and Torres Strait Islander peoples. Cultural safety must also extend throughout the continuum of cervical cancer prevention, screening, diagnosis and management, to ensure access to culturally appropriate services, both in primary and tertiary care centres and to address health inequities which face Aboriginal and Torres Strait Islander peoples.⁸

Projects such as the PREVENT study and Screen Your Way provide helpful insights into how projects that prioritise cultural appropriateness, co-design and are place based can positively influence Aboriginal and Torres Strait Islander women and Communities' participation in cervical screening.

Ensuring equity in cervical screening

It is essential all population-based screening programs have an equity focus. Guidance on how healthcare professionals providing cervical screening services in mainstream health organisations and clinical practices can ensure equity would be beneficial to include in the Guidelines.

Clinical considerations

In addition to the above, there are clinical factors relating to some of the proposed changes in the new Guidelines which should be considered. Changes have been proposed which relate to the use of self-collected (HPV test only) or clinician-collected samples (HPV and liquid-based cytology), including recommendations for:

- HPV testing only after delayed (> 9 months) follow-up for co-testing following detection of non-16/18 HPV on self-collection,
- HPV testing only as a test of cure following treatment of high-grade squamous intraepithelial lesions, and
- Collection of a sample for LBC at colposcopy for participants with HPV 16/18 detected without LBC result available.

It is acknowledged that these recommendations are based on published literature in situations where data are available, and on expert consensus and international guidelines otherwise. However, some of these recommendations are also based on assumptions regarding access to and acceptability of follow-up appointments including colposcopy. The potential benefits of forgoing co-testing by clinician-collected sample in situations such as those above, including convenience and comfort, need to be weighed against the possible need for follow-up testing and referral to colposcopy, and how timely and accessible these services are in the Community. As such, clinicians working in primary care who are involved in providing cervical screening services should consider the local and cultural context in which the participant lives, in addition to the new recommendations laid out in these updated Guidelines.

NACCHO recommends the NCSP Guidelines recognise cultural, historical, and social factors which influence participation of Aboriginal and/or Torres Strait Islander women and people with a cervix in cervical screening.

NACCHO recommends the NCSP Guidelines state mainstream health organisations and clinical practices should participate in on-going cultural awareness training to ensure culturally appropriate care is continually provided to Aboriginal and/or Torres Strait Islander women and people with a cervix. This aligns with Priority Reform 3 of the National Agreement on Closing the Gap.

NACCHO recommends specific guidance on how healthcare professionals in mainstream health organisations and clinical practices can ensure equity in cervical screening participation.

NACCHO recommends the updated NCSP guidelines recommend that clinicians providing cervical screening services should consider the local and cultural context in which the participant lives, in addition to the new recommendations laid out in these updated Guidelines.

Research

It is important all research, including cancer screening research on Aboriginal and Torres Strait Islander people and Communities is led by Aboriginal and Torres Strait Islander researchers and applies Indigenist research methods¹⁴ Aboriginal and Torres Strait Islander led research is essential because it:

- provides reassurance that the research meets the needs of Aboriginal and Torres Strait Islander Communities
- respects cultural knowledge and practices
- involves Community leaders and champions who understand Community needs
- allows Community members to feel safe
- ensures research translates into action to improve service delivery and outcomes for the Community.

¹⁴ Rix, E. F., Wilson, S., Sheehan, N., Tujague, N. 2019. Indigenist and Decolonizing Research Methodology. Available at https://link.springer.com/referenceworkentry/10.1007/978-981-10-5251-4_69

Under-screened (including never screened) Aboriginal and Torres Strait Islander women's voices are rarely heard in research evidence, despite being a priority group for interventions and programs to increase cervical screening participation.¹⁵ Future investment is needed for Aboriginal and Torres Strait Islander researchers to conduct cancer screening research in Community. This will ensure research conducted is culturally safe and will result in improved cancer outcomes across the cancer continuum for Aboriginal and Torres Strait Islander Communities.

NACCHO recommends investment in Aboriginal and Torres Strait Islander cancer research using Indigenist research methods, led by Aboriginal and Torres Strait Islander cancer researchers.

Data collection and reporting

Cancer data for all cancer types, including cervical cancer for Aboriginal and Torres Strait Islander peoples is not easily accessible. The National Agreement on the Closing the Gap Priority Reform Four should be implemented to ensure commitment to the collection, handling, and reporting of data at sufficient levels of disaggregation, and in an accessible and timely way.¹⁶

Aboriginal and Torres Strait Islander status

The draft Guidelines outline that screening participants should be asked to identify their Aboriginal and Torres Strait Islander status, and this be recorded. This process is complex. It is important for healthcare professionals to understand that some Aboriginal and Torres Strait Islander peoples may choose not to identify for various reasons including social and historical contexts such as colonisation, mistrust with the healthcare system and not knowing how and where the data will be used. This is why healthcare professionals must consider social and historical contexts and why providing culturally appropriate and safe services is critical to ensure people feel safe to declare their status.

Priority Reform Four also recognises access to data and information is crucial for Aboriginal and Torres Strait Islander peoples, Communities, and organisations to set priorities and drive positive change. It also acknowledges that it is an essential element to enable ACCHOs to design and apply Continuous Quality Improvement (CQI) frameworks. Accurate data collection and reporting are critical to understanding the prevalence, incidence, and outcomes of all cancers, including cervical cancer.

National Cervical Screening Program and National Cancer Screening Register limitations

The NCSP and NCSR must be fit for purpose. It is important the NCSP Guidelines recognise that the inability to access data from Patient Information Management Systems (PIMS) on participants using self-collection is challenging. This is a major barrier for services as without data, it is difficult for ACCHOs to know where to focus efforts to encourage and promote screening participation.

The current functionality of the NCSR presents significant barriers which prevent Aboriginal and Torres Strait Islander peoples participating in national screening programs. The challenges and time constraints of logging into the Healthcare Provider Portal (HPP) deter healthcare professionals, including in ACCHOs from using the HPP. This results in data missing from the NCSR. The implications of this are far-reaching and limit the ability to measure baseline cervical screening participation.

¹⁵ Butler TL, Lee N, Anderson K, Brotherton JML, Cunningham J, Condon JR, Garvey G, Tong A, Moore SP, Maher CM, Mein JK, Warren EF, Whop LJ. Under-screened Aboriginal and Torres Strait Islander women's perspectives on cervical screening. *PLoS One*. 2022 Aug 31;17(8):e0271658. doi: 10.1371/journal.pone.0271658. PMID: 36044466; PMCID: PMC9432770.

¹⁶ Australian Government, Closing the Gap Priority Reforms, 2020. Available at: <https://www.closingthegap.gov.au/national-agreement/national-agreement-closing-the-gap>

The communication functionality of the NCSR i.e., invitations and reminder letters to people for screening is not effective for Aboriginal and Torres Strait Islander peoples. It is not uncommon for Aboriginal and Torres Strait Islander peoples to be transient due to various cultural and social factors and therefore do not have a fixed address. This means screening invitations and reminder letters may not reach people. Additionally, sending screening invitations via text message, particularly to older Aboriginal and Torres Strait Islander peoples who may not have access to a phone is not an effective communication tool.

The Bowel Cancer Screening Alternate Access to Kits Model (AAM) is an example of how a national screening program can be adapted by the ACCHO sector to benefit Aboriginal and Torres Strait Islander peoples. Communication approaches used in the AAM to encourage Community members to participate in screening included holistic screening days, yarning circles and ACCHO staff members visiting Community members houses to deliver screening kits. This resulted in 72% of Aboriginal and Torres Strait Islander peoples who participated in screening were never screeners or first-time screeners, compared 47% of never screeners who participated in the AAM outside the ACCHO sector.

NACCHO recommends implementation of data strategies that align to the National Agreement on Closing the Gap Priority Reform 4 to ensure commitment to the collection, handling, and reporting of data is at sufficient levels of disaggregation, and in an accessible and timely way.

NACCHO recommends collaboration with ACCHOs and Aboriginal and Torres Strait Islander organisations to improve cervical screening data collection and Aboriginal and Torres Strait Islander identification status in the NCSP and NCSR.

NACCHO recommends updating the NCSP Guidelines to include a caveat that healthcare professionals in the ACCHO sector can also use other tools and avenues of communication to invite eligible Aboriginal and Torres Strait Islander peoples to participate in screening outside of the NCSR.

Specific amendments

NACCHO has outlined specific language and suggested content amendments for consideration to strengthen the cultural appropriateness of the NCSP Guidelines. NACCHO welcomes the opportunity to discuss these proposed amendments in more detail.

NACCHO recommends updating the NCSP Guidelines to reflect the amendments listed in Appendix A.

Conclusion

The NCSP Guidelines must be strengthened to address the needs and priorities of Aboriginal and Torres Strait Islander peoples. It is important that Aboriginal and Torres Strait Islander peoples and organisations are involved from the inception and throughout the development of the Guidelines to ensure the Guidelines meets the needs of Aboriginal and Torres Strait Islander peoples. Without genuine co-design and partnership, there is a risk that current and future NCSP Guidelines will continue to contribute towards inequitable cervical cancer outcomes for Aboriginal and Torres Strait Islander women and people with a cervix.

Appendix A: Specific language and content amendments

Section	Page number	Recommended amendment
Overall feedback:		
Updating language	Throughout document	The current wording used “ <i>Aboriginal or Torres Strait Islander</i> ” excludes people who are both of Aboriginal and Torres Strait Islander decent. Update language throughout the NCSP Guidelines to “ <i>Aboriginal and Torres Strait Islander peoples</i> ”
Chapter 1: Summary of guidelines		
1.2 Screening process	79	Recommend making the below changes to <i>NCSP Guidelines recommendations</i> : Provide a culturally appropriate service so Ask all screening participants if they identify as Aboriginal and Torres Strait Islander peoples feel culturally safe to and record a person’s Aboriginal and/or Torres Strait Islander record their status on relevant clinical records, including pathology request forms, in accordance with the Australian Bureau of Statistics classification and standards. (Good practice statement).
1.2 Screening process	79	Recommend including: Healthcare providers must consider not all participants may feel comfortable declaring their status due to historical and social contexts and it is critical healthcare professionals create a space so Community members feel safe to declare their status.
Chapter 2: Introduction		
2.1 Cervical cancer in Australia	82	Add additional context to the explanation that higher incidence rates among certain populations are due to differences in accessing screening, as screening accessibility encompasses a broad range of factors including geography, cost and cultural acceptability.
2.2 Target readership	82	State explicitly that healthcare professionals include Aboriginal Health Practitioners and Aboriginal Health Workers.
2.3 Development of these guidelines	82	Co-design chapters of the NCSP Guidelines that relate to Aboriginal and Torres Strait Islander peoples with Aboriginal and Torres Strait Islander organisations and healthcare professionals .
2.6 Towards elimination of cervical cancer	84	Include explanation that although Australia is on track to eliminating cervical cancer by as early as 2035, this does not apply to all Australians. For elimination of cervical cancer in Australia, equity must be achieved across all population groups.

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Section	Page number	Recommended amendment
Chapter 4: Terminology, classification systems and report preparation		
4.3.1 Preparation of cervical screening reports	92	Table 4.2: the “+” in <i>pHSIL/HSIL+</i> be clearly denoted as not meaning “and” – for example, in the <i>Reflex LBC</i> column for Oncogenic HPV (not 16/18), “pHSIL/HSIL+” is entered directly above “Any glandular abnormality”, and this could be interpreted to mean “pHSIL/HSIL <i>and</i> any glandular abnormality” are all required as a finding to meet the finding criterion.
Chapter 5: Cervical screening in clinical practice		
5.1 Understanding the role of HPV and explaining it to participants	112	Include that person-centred care recognises cultural and social determinants of health which need to be respected individually.
5.1 Understanding the role of HPV and explaining it to participants	112	<i>Communication with screening participants</i> . Update second dot point to: <ul style="list-style-type: none"> Recognising the needs and preferences of individual patients and tailoring communication styles to the person’s situation and culture, especially for never- and under-screened groups, is essential.
5.3 National Cancer Screening Register (NCSR) – its role and how to access information	115	Include an additional note to state that healthcare professionals in the ACCHO sector can also use other tools and avenues of communication to invite eligible Aboriginal and Torres Strait Islander peoples to participate in screening.
REC 5.4 Self-collection where self-collection can be performed	120	Suggest including cervical screening on a self-collected vaginal sample can also be performed at home or in a space where the person feels most comfortable.
REC 5.4 Settings where self-collection can be performed	120-121	Suggest that the offer of an appropriate escort or support person be reiterated to keep patient safety and comfort at front of mind.
REC 5.5 Assistance with sample collection		
REC 5.8 Preparation for clinical-collected sampling	122	Recommend including asking if the Community member feels comfortable with the healthcare professional who is performing the test as there may be cultural factors to consider.
5.5 Pathology request forms	122	Recommend updating second dot point to: <ul style="list-style-type: none"> screening participants should be respectfully asked whether they identify as Aboriginal and Torres Strait Islander and their status should be recorded on the pathology request form. Healthcare providers must consider not all participants may feel comfortable declaring their status due to historical and social contexts and it is critical healthcare professionals

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Section	Page number	Recommended amendment
		create a space so Community members feel safe to declare their status.
5.6.1 Identifying under-screened and never screened people	123-124	Not all Community members screening histories are accessible in real-time through the NCSR Healthcare Provider Portal as some Aboriginal and Torres Strait Islander women and people with a cervix who are within the screening age group may not have a Medicare card, therefore screening histories cannot be identified. Additionally, not all ACCHOs have access to or use the NCSR due access and usability barriers that exist of the NCSR. Suggest updating this section to reflect this.
5.6.2 Misperceptions and attitudes interfering with screening participation	124-125	Suggest including the below as an additional dot point: <ul style="list-style-type: none"> cultural beliefs and stigma may deter Community members from participating in cervical screening. Culturally appropriate support and education is important to communicate with Community members to ensure they have the right information and feel supported to participate in cervical screening.
5.6.3 Encouraging under-and never-screened people to participate in NCSP	125	Suggest inclusion of other barriers such as fear, stigma, cultural, social and historical barriers.
5.6.3 Encouraging under-and never-screened people to participate in NCSP	125	Consider updating the below to: Working with participants who face specific, and sometimes multiple, barriers and providing, culturally appropriate , trauma-informed care (see 5.14 Providing trauma-informed care) is a continuous process, requiring respect, building trust and creating a culturally safe space .
5.6.3 Encouraging under-and never-screened people to participate in NCSP	125	Consider updating <i>support for under-screened participant to:</i> Under-screened participants, especially those who have had a self-collected CST, may need additional, culturally appropriate and individualised support to progress along the screening pathway, and may need access and support to follow-up services where they will receive appropriate sensitive treatment. This additional support may involve, for example, reassurance and explanation of the screening pathway and follow-up procedures, wrap around support services , scheduling longer appointments, or providing additional follow-up support contact .
5.6.4 Aboriginal and Torres Strait Islander people	125	Recommend updating to: Aboriginal and Torres Strait Islander women and people with a cervix experience inequitable cervical cancer rate compared to non-Indigenous Australians. Incidence and mortality rates are

Appendix A: Specific language and content amendments

Section	Page number	Recommended amendment
		more than twice as high than non-Indigenous Australians. Cervical cancer incidence and mortality rates are higher among Aboriginal and Torres Strait Islander people than non-Aboriginal and Torres Strait Islander people. (Australian Institute of Health and Welfare 2015) Limited available evidence on participation in cervical screening by Aboriginal and Torres Strait Islander people suggests that they are under-screened.(Zhang, Condon et al. 2011, Australian Institute of Health and Welfare 2015) The Australian Government Department of Health and Aged Care recognises that there are cultural, social, historical, linguistic and access barriers to cervical screening.(Australian Institute of Health and Welfare 2015) Current evidence does not support the use of a more intensive screening strategy for Aboriginal and Torres Strait Islander participants.
5.6.4 Aboriginal and Torres Strait Islander people	125	Recommend including: Healthcare providers must consider not all participants may feel comfortable declaring their status due to historical and social contexts and it is critical healthcare professionals create a space so Community members feel safe to declare their status.
5.6.6 People from culturally and linguistically diverse backgrounds	127	<i>The following sentence can be modified and applied to 5.6.4 Aboriginal and Torres Strait Islander people:</i> Cultural factors can be dynamic and influence a Community members behaviours. It is important to recognise the complexity of people's cultural background and other barriers that may affect their life, like social and historical factors including colonisation, and socioeconomic status. As language may be one of the first barriers, the provision of an Aboriginal Health Practitioner, Aboriginal Health Worker or Aboriginal Liaison Officer when needed, is of utmost importance to ensure a clear, culturally appropriate and trustful communication.
5.6.7 LGBTQ	128	Consider adding to the second dot point: Using a gender-inclusive, culturally appropriate 'parts and practices' approach to sexual history can be a helpful approach to supporting trans and gender-diverse care.
5.6.9 People living in rural and remote locations	129	Recommend adding further detail to this section to provide brief context as to why cervical screening participation rates are lower in rural and remote locations and what considerations are required.
5.14 Providing trauma-informed care	134	Suggest updating sentence to: Trauma can arise from multiple past or present situations, physical, psychological, historical or social that could have been single or repeated over time and may influence cervical screening acceptability

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Section	Page number	Recommended amendment
		and attendance.
5.14 Providing trauma-informed care	134	Recommend adding the following dot point under <i>groups with additional psychosocial risk factors</i> : <ul style="list-style-type: none"> History of colonisation
5.14 Providing trauma-informed care	134	Consider adding the following under <i>Additional information: Groups with additional psychosocial risk factors</i> : <ul style="list-style-type: none"> Aboriginal and Torres Strait Islander peoples may need to be given information in their language of choice, via a trusted healthcare professional, or using culturally appropriate printed visual information resources, to ensure they have a clear understanding of all procedures.
5.15 Managing anxiety and distress with a screening abnormality	135	Considering updating the following sentence: Fear and anxiety about a positive HPV test may result in changes in intention to screen across all population groups, particularly Aboriginal and Torres Strait Islander women and people with cervix.
5.15.1 Management of distress	136	Consider updating the following sentence: Available services vary according to location, but may include women’s health services, LGBTQI+ specific services, culturally appropriate support services , GPs (who can initiate a mental health care plan), or counselling services within the local health facility.
Chapter 7: Screening and management in specific populations		
7.1 Pregnancy	164	Suggest that consideration be given to the type of sample collected, in a shared decision-making process with the person being screened, in the context of their routine antenatal care, and whether access to frequent appointments is an issue or likely to impact follow-up if it is required.
Chapter 8: Colposcopy		
8.1.2 Principles of practice	192	Suggest changing “woman’s record” to “person’s record”.
Rec 8.2 Colposcopy procedure	192	Recommend the second dot point be updated to: <ul style="list-style-type: none"> Surrounding in an appropriate setting that respects the participant’s privacy and cultural needs.
Rec 8.3 Colposcopy procedure	192	Suggest adding line about obtaining informed consent from the Community member and the need for a culturally safe environment. Additionally, suggest considering an additional line or list of healthcare professionals who are eligible to be qualified as colposcopists, including doctors and

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Section	Page number	Recommended amendment
		nurse practitioners.
Rec 8.3 Patient information	192	Recommend updating dot point to: <ul style="list-style-type: none"> “in a culturally and linguistically appropriate format to meet the needs of all population groups” and reordering to be the first dot point.
Rec 8.4 Communication of results	193	Suggest including asking participants the best way to give results, returning to regional or metro centre may be impractical for rural and remote participants who could get results at local ACCHO, via telehealth or at their GP service instead.
8.1.3.1 History	193	<i>Minimum clinical history:</i> Question about dot point 3 –is it Parity (just births) or is it meant to be Gravidity & Parity (pregnancies and births)? Consider adding dot point that relates to “screening participants should be respectfully asked whether they identify as Aboriginal and Torres Strait Islander and their status should be recorded”. Healthcare providers must consider not all participants may not feel comfortable declaring their status due to historical and social contexts and it is critical healthcare professionals create a space so Community members feel safe to declare their status.
8.1.3.3.5 Documentation	198	Not all ACCHOs have access to or use the NCSR due to access and usability barriers that exist with the NCSR. Suggest updating this section to reflect this.
8.1.5 Colposcopy data for the National Cancer Screening Register	208	In the 3 rd paragraph, recommend adding that healthcare providers must consider not all participants may feel comfortable identifying their status due to personal, historical and social contexts.
8.1.7.1 Patient information	211	Suggest including that person-centred care recognises cultural and social determinants of health which need to be respected individually. Where it states “ <i>it is essential that patients be given the opportunity to discuss their management and any concerns they may have time at the time of consultation or treatment.</i> ” Suggest adding in some enabling factors that may help increase participation by Aboriginal and Torres Strait Islander peoples in cervical screening and treatment. Evidence suggests that some enabling factors include: having access to a dedicated women’s health program and a choice of seeing a female practitioner

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Section	Page number	Recommended amendment
		(especially in remote areas); accessibility of health services; and having trust in the health practitioner can increase participation (Indigenous Australian women's experiences of participation in cervical screening PLOS ONE)
Chapter 10: Signs and symptoms of cervical cancer		
REC 10.6 Unexplained Intermenstrual bleeding: persistent or recurrent REC 10.9 Abnormal vaginal discharge and/or deep dyspareunia	274-275	Suggest consideration of a term other than “benign” to describe non-dysplasia/cancer-related diseases, which in this context includes sexually transmitted infections that have the potential to cause significant morbidity and mortality. NACCHO acknowledges the historical use of “benign” in a cancer-specific context, however given its general usage relating to harm, an alternative term may be of benefit in order to avoid labelling other serious, but non-cancerous, conditions as not being harmful.
Chapter 11: Future research and uncertainties		
11.1 Under-screened groups	277	<i>Aboriginal and Torres Strait Islander people</i> Recommend making the following updates to this sentence: Strategies to improve recruitment of Aboriginal and Torres Strait Islander women and people with a cervix should be led by Aboriginal and Torres Strait Islander peoples. Furthermore, existing strategies should be review and evaluated, and if necessary, place-based strategies to improve recruitment must be led by Aboriginal and Torres Strait Islander peoples, including through development, implementation, and evaluation.
11.1 Under-screened groups	277	<i>Aboriginal and Torres Strait Islander people</i> Recommend removing the below extract and instead, consider the bold font: More research is required to determine why cervical screening participation in some specific communities in the Northern Territory and Queensland is higher than in others, and to translate the approaches of the more highly screened communities to the wider Aboriginal and Torres Strait Islander population. Aboriginal and Torres Strait Islander researchers need to be involved in the development of research strategies to provide culturally appropriate evidence base to translate into practice. Approaches to increase cervical screening participation need to consider the place-based context and needs of local Aboriginal and Torres Strait Islander Communities. A one size fits all approach to Aboriginal and Torres Strait Islander health will be ineffective, as this does not consider the

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		<p>uniqueness and diversity among the Aboriginal and Torres Strait Islander population. It is paramount all approaches to increase cervical cancer screening in individual Communities, are co-designed and co-created with local Aboriginal and Torres Strait Islander peoples.</p>
11.1 Under-screened groups	277	<p><i>Aboriginal and Torres Strait Islander people</i> Consider the changes below, including the bold font: Indigenous Aboriginal and Torres Strait Islander cultural status is not always collected on pathology request forms and was not always routinely collected by the state and territory Cervical Screening Registers prior to the move to the NCSR. This lack of data collection prevents the accurate assessment of cervical screening issues in Aboriginal and Torres Strait Islander screening participants. Whilst the NCSR does collect and record data regarding Indigenous Aboriginal and Torres Strait Islander status, these data are incomplete. To ensure accurate data tracking of Aboriginal and Torres Strait Islander status, it is paramount the health service (inclusive of employees) is delivering culturally appropriate and safe practice to all participants, to support Aboriginal and Torres Strait Islander peoples to feel safe to identify their status. and It is not the role of Aboriginal and Torres Strait Islander peoples to actively declare their cultural status, but more the role of health services and workers to take ownership of to provide a culturally safe service so Aboriginal and Torres Strait Islander peoples feel safe to identify it remains the role of the clinician or healthcare provider to make note of Aboriginal and Torres Strait Islander cultural status on relevant clinical records, including pathology request forms.</p>
11.1 Under-screened groups	277	<p><i>Aboriginal and Torres Strait Islander people</i> Consider including the bold font: All approaches to improving Aboriginal and Torres Strait Islander health must align with the National Agreement on Closing the Gap Priority Reforms and the National Aboriginal and Torres Strait Islander Health Plan 2021-2031.</p>