



NACCHO

National Aboriginal Community
Controlled Health Organisation
Aboriginal health in Aboriginal hands

www.naccho.org.au

Equitable access
to diagnosis and
treatment for
individuals with
rare and less
common cancers

Submission to the
Senate Standing
Committee on
Community Affairs

October 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 cancers that are considered rare and less common 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 care, ensuring Aboriginal and Torres Strait Islander people and their families receive culturally safe care and support following a cancer diagnosis and treatment.
4. **NACCHO recommends** changing the legislation to allow Schedule 8 medications to be included under the Remote Area Aboriginal Health Service (RAAHS) S100 scheme and allow Highly Specialised Drugs (HSD) S100 medications to be covered under the Closing the Gap Pharmaceutical Benefits Scheme and RAAHS S100 scheme.
5. **NACCHO recommends** State and Territory Governments review their PATS services to increase funding, including for multiple family members to accompany individuals with suspected or diagnosed cancer who are required to travel for treatment and appointments.
6. **NACCHO recommends** greater accountability of mainstream service providers to eliminate institutional racism and discrimination to deliver culturally safe services to Aboriginal and Torres Strait Islander people and Communities.
7. **NACCHO recommends** additional resourcing to strengthen the existing ACCHO workforce, including to employ additional Aboriginal and Torres Strait Islander and non-Indigenous staff to provide cancer diagnosis and treatment services in the ACCHO sector.
8. **NACCHO recommends** collaboration and partnerships between ACCHOs and cancer treatment facilities, to ensure culturally safe continuity of care exists for Aboriginal and Torres Strait Islander people and their family impacted by cancer.
9. **NACCHO recommends** the Commonwealth Government introduce an agreement between State and Territory Governments to ensure culturally safe care is provided to Aboriginal and Torres Strait Islander people across all levels of the healthcare system, particularly tertiary care centres.
10. **NACCHO recommends** a focus on increasing human papillomavirus (HPV) vaccinations in Aboriginal and Torres Strait Islander children and young adults. Methods to increase HPV vaccination rates should be co-designed with the ACCHO sector and Community.
11. **NACCHO recommends** funding to support ACCHO sector-led development of tailored programs to enhance health literacy.

12. **NACCHO recommends** Aboriginal and Torres Strait Islander people have access to culturally safe cancer screening programs and informed participation is supported.
13. **NACCHO recommends** ensuring equitable access to diagnosis and treatment for Aboriginal and Torres Strait Islander people with cancer, including increased availability and access to place-based cancer services.
14. **NACCHO recommends** funding the ACCHO sector to provide survivorship programs that allow Community to share lived experience, connect with others in support groups and receive ongoing post-treatment care, as needed.
15. **NACCHO recommends** funding the ACCHO sector to provide holistic and culturally safe palliation and end-of-life services to support people with cancer.
16. **NACCHO recommends** implementation of data strategies that align to the *National Agreement on Closing the Gap* Priority Reform Four to ensure commitment to the collection, handling, and reporting of data is at sufficient levels of disaggregation, and in an accessible and timely way.
17. **NACCHO recommends** investment in Aboriginal and Torres Strait Islander cancer research using Indigenist research methods, led by Aboriginal and Torres Strait Islander cancer researchers.

Acknowledgements

NACCHO welcomes the opportunity to provide a response to the Senate inquiry into the equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer (the inquiry).

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

National Agreement on Closing the Gap

At the meeting of National Cabinet in early 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 people 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, and which are more likely to achieve meaningful outcomes for our people 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 people 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 people, achieve better results, employ more Aboriginal and Torres Strait Islander people 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 people, support truth telling about agencies' history with Aboriginal and Torres Strait Islander people, and engage fully and transparently with Aboriginal and Torres Strait Islander people 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. **Error! Bookmark not defined.**

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 people, and improving accountability and transparency.

NACCHO recommends any interventions to address cancers that are considered rare and less common 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 people. 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 people.

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.¹ This is true across urban, regional and remote areas. The consequent disparity in health outcomes between Aboriginal and Torres Strait Islander people and other Australians remains significant – 34% of the health gap between Aboriginal and Torres Strait Islander people 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 people. 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.

A Health in All Policies approach would require consideration of the impact on health outcomes for Aboriginal and Torres Strait Islander people 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 Productivity Commission 2023, Review of the National Agreement on Closing the Gap, Draft Report, Canberra, July.

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>].

*'... 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.'*³

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 people and diagnosis rates are significantly higher in Aboriginal and Torres Strait Islander people compared to other Australians.⁴ 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 people.⁵

In Australia, rare cancers are defined as those which have '*fewer than 6 diagnoses per 100,000 people*' and less common cancers are defined as those which have '*fewer than 12 diagnoses per 100,000 people*'.⁶ Some examples of rare cancers in the Australian population include oesophageal, oropharyngeal and head and neck cancers such as lip, tongue and mouth. Less common cancers include bladder, liver cancer and cancer of unknown primary site (CUP).⁷ Rare and less common cancers tend to be diagnosed at a later stage and have higher mortality rates.

While high quality, disaggregated data for rare and less common cancers are largely unavailable, data that is available demonstrates that Aboriginal and Torres Strait Islander people are disproportionately affected by rare and less common cancers when compared to other Australians. When analysing Aboriginal and Torres Strait Islander people's cancer incidence data, only one type of cancer (bladder cancer) meets the definition of a less common cancer, and none meet the definition of a rare cancer.⁷

Data from the AIHW shows that between 2012-2016, the aged-standardised rate (ASR) for incidence of liver cancer and CUP in Aboriginal and Torres Strait Islander people are both *greater* than 12 diagnoses per 100,000 (16.9 and 18.2 respectively). Non-Indigenous Australians both are lower than 12 diagnoses per 100,000 (7.3 and 8.5 per 100,000 respectively).⁷

³ 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)

⁴ 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].

⁵ 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>.

⁶ Cancer Council Australia. Understanding Rare and Less Common Cancers: A guide for people with cancer, their families and friends [Internet]. Sydney: CCA; 2021. Available from: [understanding-rare-and-less-common-cancers](https://www.cancer.org.au/understanding-rare-and-less-common-cancers)

⁷ Australian Institute of Health and Welfare. Cancer in Australia 2021: data [Internet]. Canberra: AIHW; 2021. Available from: [Cancer in Australia 2021, Data - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://www.aihw.gov.au/cancer-in-australia-2021/data)

The disproportionate impacts of rare and less common cancers in Aboriginal and Torres Strait Islander people are also observed in higher mortality rates. Data from the AIHW shows that between 2015-2019, the ASR for mortality of liver cancer and CUP in Aboriginal and Torres Strait Islander people are 15.7 and 15.6 per 100,000 respectively, while for non-Indigenous Australians they are 6.7 and 9 per 100,000 respectively.⁷

The data shows that what constitutes rare and less common cancers for non-Indigenous Australians, are common cancers for Aboriginal and Torres Strait Islander people.

As noted above, only bladder cancer impacts Aboriginal and Torres Strait Islander people at rates which qualify as a rare or less common cancer. This highlights the significant need for a more equitable approach to support for Aboriginal and Torres Strait Islander people impacted by cancer.

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 people. 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 people in the following areas:

- equity in access to 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.

NACCHO is currently conducting an evidence review and leading Community consultations to develop recommendations for the Commonwealth Department of Health and Aged Care in culturally safe palliative care services.

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

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. They are trusted, accessible and help overcome many of the barriers to access health services experienced by Aboriginal and Torres Strait Islander people (see barriers section below).

There is a clear preference for Aboriginal and Torres Strait Islander people 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.⁸

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 support services.

NACCHO recommends sustainable funding to all areas of the ACCHO sector to achieve equity in the provision of holistic care, ensuring Aboriginal and Torres Strait Islander people and their families receive culturally safe care and support following a cancer diagnosis and treatment.

Barriers to accessing cancer services and support

Aboriginal and Torres Strait Islander people experience significant barriers to accessing cancer services and support. These barriers can include, but are not limited to:

- limited availability of treatment facilities and services in rural and remote areas (see further information in 'diagnosis and treatment' section below)
- inadequate transportation and accommodation options for patients who need to travel for diagnosis and treatment
- out of pocket expenses (see further information in 'out-of-pocket' section below)
- various levels of health literacy (see further information in 'prevention and health literacy' below)
- cultural and family responsibilities that may conflict with treatment schedules
- poor care co-ordination between mainstream health services and the ACCHO sector
- lack of local providers which may require a person to move away from family and Country to access appropriate services
- lack of culturally safe and/or trauma informed provision of care
- experiences of systemic and interpersonal racism (see further information in racism and discrimination below)
- distrust of institutional care because of both personal and historical experiences
- limited access to information technology impacting tele-health services.

Additional information on some of these barriers is provided in this section below and other relevant areas. It is important to address each barrier to reduce the inequities in accessing cancer services and support to improve cancer outcomes for Aboriginal and Torres Strait Islander people.

⁸ 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
NACCHO Submission – Inquiry into rare and less common cancers

Out of pocket expenses

Financial barriers, including out-of-pocket expenses, can deter anyone from seeking cancer screening and diagnostic tests, regardless of their cultural identity. Aboriginal and Torres Strait Islander people already experience inequities in cancer screening and early diagnosis, and this is further exacerbated for people who face socioeconomic disadvantage.

Aboriginal and Torres Strait Islander people are more likely to live in poverty than other Australians, with 53% of Indigenous Australians aged 16 and over receiving some form of income support payment (as at 25 December 2020) – almost twice the proportion of other Australians.⁹ NACCHO urges the Australian Government to consider subsidising the costs associated with diagnostic procedures, including the financial burden of having to travel to and from cancer treatment facilities.

Access to affordable medicines

Timely access to affordable medication is a vital part of treatment for rare and less common cancers. This includes not only chemotherapy but additional medications for symptom control such as antiemetics and analgesics.

Aboriginal and Torres Strait Islander people who live in remote areas can receive medications for free under the RAAHS S100 scheme.

Across Australia, under the Closing the Gap Pharmaceutical Benefits Scheme (CTG PBS), eligible patients can receive medication for free or at very low costs, when holding a valid concession card.¹⁰

Reducing the cost of medication has been proven to improve utilisation of medication.¹¹ Unfortunately, these schemes do not cover chemotherapy medications supplied under the Highly Specialised Drugs (HSD) S100 and the RAAHS S100 scheme currently excludes Schedule 8 medications, including opioids used to treat cancer pain. To add to this complexity, there are variations in State and Territory legislation on how gap payments are applied and collected. This can create inefficiencies and exacerbates already existing barriers to accessing treatment, for example chasing \$7 gap fees.

Ideally, treatment would be received on Country, to ensure Aboriginal and Torres Strait Islander people 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, patients and carers to be up skilled in the safe handling of cytotoxic therapies, and appropriate monitoring.

This ACCHO-led initiative could produce significant savings to the hospital system.

NACCHO recommends changing the legislation to allow Schedule 8 medications to be included under the RAAHS S100 scheme and allow HSD S100 medications to be covered under the CTG PBS and RAAHS S100 scheme.

⁹ AIHW, Indigenous income and finance, www.aihw.gov.au/reports/australias-welfare/indigenous-income-and-finance

¹⁰ Australian Government. 2022. The Pharmaceutical Benefits Scheme, available from www.pbs.gov.au/info/publication/factsheets/closing-the-gap-pbs-co-payment-measure

¹¹ Trivedi AN, Kelahe M. Copayment Incentive Increased Medication Use And Reduced Spending Among Indigenous Australians After 2010. *Health Aff (Millwood)*. 2020 Feb;39(2):289-296. doi: 10.1377/hlthaff.2019.01089. PMID: 32011934. NACCHO Submission – Inquiry into rare and less common cancers

Patient assisted transport

Access to transportation to attend cancer support and services continues to present as a barrier for Aboriginal and Torres Strait Islander people with cancer and their families. Patient Assisted Travel Schemes (PATS) are operated at the jurisdictional level to contribute to travel and accommodation expenses for individuals who are required to travel for treatment. However, in many cases, they do not cover all travel and accommodation expenses, placing additional stress on those impacted by cancer.

For example, some PATS covers the cost for one friend or family member (i.e., escort under the scheme) to accompany the person required to travel, however does not cover the cost for multiple family members to travel. This often places undue emotional and financial stress on the family who must weigh the significant additional cost for family members to travel with the anxiety of separation during a situation where family support is needed.

Family and Community are at the centre of Aboriginal and Torres Strait Islander health. Therefore, it is important that individuals travelling for treatment can be accompanied by more than one member of their family for emotional and cultural support. The availability of PATS escorts is also a concern.

Feedback from the ACCHO sector has reported, *“At present, escorts are inconsistently available for both diagnosis of cancer and ongoing treatment. Mothers with young children should be supported to bring both their children and partner.”*

NACCHO recommends State and Territory Governments review PATS services to increase funding, including for multiple family members to accompany individuals with suspected or diagnosed cancer who are required to travel for treatment and appointments.

Racism and discrimination

Racism and discrimination continue to be a barrier for Aboriginal and Torres Strait Islander people accessing mainstream health services. This creates a culturally unsafe environment and discourages Aboriginal and Torres Strait Islander people from accessing or completing cancer treatment. This contributes to high diagnosis and mortality rates of cancer as people do not feel comfortable accessing or completing their cancer care. Racism and discrimination must be addressed and eliminated in mainstream organisations and tertiary centres, who should be held to account, to allow equitable access to culturally safe cancer support and services for Aboriginal and Torres Strait Islander people.

Barriers to accessing cancer support and services must be addressed if Aboriginal and Torres Strait Islander people are to access and receive the appropriate level of care they deserve.

NACCHO recommends greater accountability of mainstream service providers to eliminate institutional racism and discrimination to deliver culturally safe services to Aboriginal and Torres Strait Islander people and Communities.

Workforce shortages

The ACCHO sector is currently facing critical workforce shortages. Workforce data reported by the AIHW shows a decrease of full time employment in clinical staff per 1,000 population of around 20-

30% in ACCHOs, and a 50% increase in the number of unfilled positions since the start of the COVID-19 pandemic in 2020.¹² Many ACCHOs in rural and remote locations rely on transient general practitioners to provide primary health care which means Community members often find it difficult to build trust and rapport with visiting general practitioners.

The shortage of healthcare professionals, including oncologists and specialists, across the sector further impacts Aboriginal and Torres Strait Islander people accessing culturally safe and appropriate cancer care (and other primary health related) diagnosis and treatment services.

Access to specialist diagnosis and treatment often requires medical specialists not available on Country, or in some cases, not available regionally, thereby requiring travel to major centres to access services. While fly in and fly out models of care may increase access to specialist services, they are not a sustainable solution. A lack of specialists overall, and a lack of local service provision often results in longer wait times, poorer cancer outcomes and perpetuates the widening cancer gap between Aboriginal and Torres Strait Islander people and other Australians.

NACCHO recommends additional resourcing to strengthen the existing ACCHO workforce, including to employ additional Aboriginal and Torres Strait Islander staff and non-Indigenous staff to provide cancer diagnosis and treatment services in the ACCHO sector.

Continuity of care

ACCHOs have a key role to play in advocating for cultural safety of Community members as they navigate a complex cancer system across the cancer continuum. Referral, specialist and tertiary care pathways are often fragmented with poor support mechanisms for Community members, which includes poor communication between providers, hindering continuity of care.

When compared to other Australians who require hospitalisation, Aboriginal and Torres Strait Islander people are four times more likely to leave hospital before completing treatment.¹³ The rates of self-discharge are highest in very remote regions in Australia, where Aboriginal and Torres Strait Islander people self-discharge from hospital, against medical advice, at 9.1 times the rate when compared with other Australians.¹⁴ Patients whose care is not completed are more like to re-present to emergency departments and have increased morbidity and mortality rates.¹²

While there is indirect evidence to show how hospital services are meeting patient's needs, the high rates of self-discharge is an indicator Aboriginal and Torres Strait Islander people 'vote with their feet'.¹² There are limited studies available outlining the reasons why Aboriginal and Torres Strait Islander people choose to leave hospital, however common factors include institutional racism, distrust of the mainstream health system, miscommunication, and family and social obligations.¹⁵

¹² Australian Institute of Health and Welfare (2022) Aboriginal and Torres Strait Islander specific primary health care: results from the nKPI and OSR collections viewed 16.11.2022 <https://www.aihw.gov.au/reports/indigenous-australians/indigenous-primary-health-care-results-osrnkpi/contents/osr-introduction>

¹³ Coombes, J., Hunter, K., Bennett-Brook, K., Porykali, B., Ryder, C., Banks, M., Egana, N., Mackean, T., Sazali, S., Bourke, E., and Kairuz, C. 2022. Leave events among Aboriginal and Torres Strait Islander people: a systemic review. Available from: www.ncbi.nlm.nih.gov/pmc/articles/PMC9354286/#:~:text=Of%20all%20leave%20events%20for,compared%20to%20non-Indigenous%20Australians.

¹⁴ Australian Institute of Health and Welfare (2023). [3.09 Discharge against medical advice - AIHW Indigenous HPF](#)

¹⁵ Shaw, C 2016. An evidence-based approach to reducing discharge against medical advice amongst Aboriginal and Torres Strait Islander patients.

Further effort is required to improve cultural safety across tertiary health centres to ensure Aboriginal and Torres Strait Islander people receive appropriate care and support to complete treatment.

To ensure Aboriginal and Torres Strait Islander people with a cancer diagnosis are appropriately supported, and continuity of care is maintained, it is important there are collaborative arrangements with and between treatment facilities, governments, localised primary healthcare networks, external support agencies, and the ACCHO sector. This includes available funding to employ an Aboriginal and Torres Strait Islander workforce into cancer support officer or care coordinator positions within the ACCHO sector.

NACCHO recommends collaboration and partnerships between ACCHOs and cancer treatment facilities, to ensure culturally safe continuity of care exists for Aboriginal and Torres Strait Islander people and their family impacted by cancer.

NACCHO recommends the Commonwealth Government introduce an agreement between State and Territory Governments to ensure culturally safe care is provided to Aboriginal and Torres Strait Islander people across all levels of the healthcare system, particularly tertiary care centres.

Prevention and health literacy

Addressing cancer risk factors

Prevention plays a key role in reducing the incidence rates of cancer. Compared to cancer treatment, prevention and early detection are more cost effective and can be tailored towards individual Communities. Cancer modifiable risk factors such as poor nutrition, unsafe levels of alcohol consumption, being overweight and obese, smoking and low levels of physical activity can increase cancer incidence rates.

While there are no specific preventive measures for less common cancers, such as bladder cancer, there are other opportunities to promote the multi-benefits of preventative health measures. For example, the HPV vaccine which is used to protect Community members against cervical cancer can also be used as a preventative measure to reduce forms of head and neck cancers. As such, there should be a focus on improving the rates of the HPV vaccination, that are currently lower in the Aboriginal and Torres Strait Islander population. The HPV program recommends the vaccine is administered from 9 years of age with the optimal age 12-13 years, prior to exposure of HPV.¹⁶ The rates of HPV vaccinations in 2021 are:

- 73% of Aboriginal and Torres Strait Islander girls had completed a full dose of the HPV vaccine by 15 years of age, compared with 80% of total Australian girls
- 66% Aboriginal and Torres Strait Islander boys had completed a full dose of the HPV vaccine by 15 years of age, compared with 77% of all Australian boys.¹⁷

Therefore, ensuring there is equitable access to this vaccine for Aboriginal and Torres Strait Islander children and young adults is needed to improve vaccination rates before exposure to HPV as part of a broader cancer prevention strategy.

¹⁶ [Human papillomavirus \(HPV\) | The Australian Immunisation Handbook \(health.gov.au\)](https://www.health.gov.au/resources/publications/human-papillomavirus-hpv-the-australian-immunisation-handbook)

¹⁷ [3.02 Immunisation - AIHW Indigenous HPE](#)

NACCHO recommends a focus on increasing HPV vaccinations in Aboriginal and Torres Strait Islander children and young adults, before exposure to HPV. Methods to increase HPV vaccination rates should be co-designed with the ACCHO sector and Community.

Health literacy

Health literacy must be enhanced among various Aboriginal and Torres Strait Islander Communities to enable Community members to make informed decisions about cancer prevention, screening, diagnosis, treatment, palliative care and end-of-life or survivorship. Due to the complexities of cancer and health information, it can be challenging for some Community members to feel confident in understanding information that is relayed to them, particularly from mainstream organisations.

This requires investment to improve the health literacy of health professionals in the ACCHO sector, mainstream organisations, and local Community members. Health professionals in mainstream organisations must also have access to culturally safe training and education on how to discuss cancer with Community members to enhance the health literacy of the Community.

All efforts to improve the health literacy and education among Aboriginal and Torres Strait Islander people and Communities must be co-designed and led by Aboriginal and Torres Strait Islander people. For Aboriginal and Torres Strait Islander Communities in particular, information and communications campaigns must be place-based and developed in partnership with the Community.

NACCHO recommends funding to support ACCHO sector-led development of tailored programs to enhance health literacy.

Screening

There are three national population-based cancer screening programs: breast, bowel and cervical cancer. In addition, a national lung cancer screening program is under development, to be implemented in July 2025. This will be the first new national population-based screening program in over 20 years.

There are no national screening programs for cancers considered rare or less common. Without such programs, greater symptom recognition for Aboriginal and Torres Strait Islander people by healthcare providers and the Community is essential. Many cancers can be difficult to identify because they often present like symptoms of common conditions. For example, neuroendocrine cancer has symptoms that can be mis-diagnosed with conditions such as anxiety, asthma and irritable bowel syndrome.¹⁸ In other cases, symptoms may be difficult to identify because they are unusual and less known to individuals and healthcare providers.¹⁹

Feedback from the ACCHO sector indicates that Aboriginal and Torres Strait Islander people can fear cancer, and often view cancer as incurable. This has contributed to low uptake of cancer screening and cancer being treated as a taboo subject in Communities. The NACCHO Cancer Program will work with the ACCHO sector to change the cancer narrative through the development of culturally safe

¹⁸ Neuroendocrine Cancer Australia. (2023). National patient awareness. Retrieved from <https://neuroendocrine.org.au/national-patient-awareness/>

¹⁹ Cancer Council Victoria. (2023). *Rare and less common cancers*. Retrieved from Cancer Council Victoria, <https://www.cancervic.org.au/cancer-information/rare-and-less-common-cancers/overview.html>

information and resources that will also improve health literacy to encourage cancer screening participation.

NACCHO recommends Aboriginal and Torres Strait Islander people have access to culturally safe cancer screening programs and informed participation is supported.

Diagnosis and treatment

A lack of locally available cancer diagnostic services is a significant barrier for Aboriginal and Torres Strait Islander people living in rural and remote Communities. It means people often need to travel long distances to healthcare facilities, and inadequate transportation restricts the ability to access timely screening and diagnostic tests. The inability to access diagnosis and treatment close to home, can not only deter individuals from travelling, but entire Communities who witness the distress experienced by other Community members.

Feedback from the sector has identified key barriers for Aboriginal and Torres Strait Islander people who live in rural and remote locations, including:

- a shortage of cancer treatment services, especially culturally safe treatment services
- long wait times for appointments
- cultural responsibilities and fear of leaving family and Community for treatment.

It is important there is consideration for place-based diagnosis and treatment services that are culturally safe and accessible to all Aboriginal and Torres Strait Islander people.

NACCHO recommends ensuring equitable access to diagnosis and treatment for Aboriginal and Torres Strait Islander people with cancer, including increased availability and access to place-based cancer services.

Survivorship

Survivorship is the stage of an individual's cancer journey that follows cancer diagnosis and treatment. Culturally safe follow up care and support is pivotal to helping Community survive and thrive with cancer. Culturally tailored survivorship programs that are Community based can strengthen cancer care for Aboriginal and Torres Strait Islander people.

It is important to provide Community the opportunity to share their lived experience and connect with others in support groups. Personalised spiritual care and connection to other Aboriginal and Torres Strait Islander cancer survivors are also key components to survivorship programs.

Community members who have completed cancer treatment may also require consideration of and support for any cancer-related physical side effects. For example, any ongoing swallowing issues post head and neck cancer treatment.

NACCHO recommends funding the ACCHO sector to provide survivorship programs that allow Community to share lived experience, connect with others in support groups and receive ongoing post treatment care as needed.

Palliative and end-of-life care

In Australia, Aboriginal and Torres Strait Islander people experience disproportionately high cancer mortality rates. Despite this, most Aboriginal and Torres Strait Islander people do not have access to culturally safe palliation services.²⁰ There is a need to ensure palliative care services for Aboriginal and Torres Strait Islander people in residential aged care and hospital settings accommodate cultural needs, which may include supporting the Community member return to Country as part of end-of-life considerations. There is a significant need for investment in palliation and end-of-life services so Aboriginal and Torres Strait Islander people can die with dignity.

Through on-going conversations with the ACCHO sector and some mainstream palliation services, it is clear there is a need for more widely available culturally safe palliation services.

NACCHO recommends funding the ACCHO sector to provide holistic and culturally safe palliation and end-of-life services to support people with cancer.

Data collection and reporting

Cancer data for all cancer types for Aboriginal and Torres Strait Islander should be easily accessible, which currently is not the case. 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.²¹

Priority Reform Four also recognises access to data and information is crucial for Aboriginal and Torres Strait Islander people, 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 frameworks. Accurate data collection and reporting are critical to understanding the prevalence, incidence, and outcomes of all cancers.

Improvements to data collection and reporting will facilitate evidence-based policy development and inform targeted interventions to improve overall health outcomes.

Aboriginal and Torres Strait Islander Communities have rights to the collection, ownership, and application of their data.

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

²⁰ Bernardes, C.M., Beesley, V., Shahid, S. *et al.* End-of-life care for Aboriginal and Torres Strait Islander people with cancer: an exploratory study of service utilisation and unmet supportive care needs. *Support Care Cancer* **29**, 2073–2082 (2021). <https://doi.org/10.1007/s00520-020-05714-4>

²¹ Australian Government, *Closing the Gap* Priority Reforms, 2020. Available at: <https://www.closingthegap.gov.au/national-agreement/national-agreement-closing-the-gap>
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Funding for research

It is important all research, including cancer research on Aboriginal and Torres Strait Islander people and Communities is led by Aboriginal and Torres Strait Islander researchers and applies Indigenist research methods.²² Aboriginal and Torres Strait Islander led research is essential because it:

- provides reassurance that the research meets the needs of 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.

Future investment is needed for Aboriginal and Torres Strait Islander researchers to conduct cancer 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.

Conclusion

As reiterated throughout the submission, the high incidence rate of cancer in Aboriginal and Torres Strait Islander people translates to only bladder cancer meeting the definition of a rare or less common cancer. This highlights the inequities experienced by Aboriginal and Torres Strait Islander people.

It is a pivotal that measures to prevent cancer, such as an increase in HPV vaccination rates, are prioritised to reduce the cancer incidence in Aboriginal and Torres Strait Islander people. Furthermore, addressing the barriers across the cancer continuum and ensuring there is sustainable cancer funding for the ACCHO sector, Aboriginal and Torres Strait Islander people and researchers is essential to reducing the disparities faced by Aboriginal and Torres Strait Islander people with cancer and their Communities.

²² 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
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