



NACCHO

National Aboriginal Community
Controlled Health Organisation

Aboriginal and Torres Strait Islander Cancer Plan

This Aboriginal and Torres Strait Islander Cancer Plan supports a cancer journey for each and every Aboriginal and Torres Strait Islander person that matches their life course, needs and values. While it is an individual who receives a cancer diagnosis, this Plan optimises individual connection to family, culture and Community. This Plan combines population-level approaches that build on the collectives of Community and culture with individual treatments based on evidence to optimise clinical cancer outcomes.

Enablers for real change

Cancer prevention

Timely cancer screening and early diagnosis

Improving the health system at all stages of individual cancer journeys

Culturally informed evidence base

Foreword

Many of you reading this Aboriginal and Torres Strait Islander Cancer Plan already acknowledge the need to work together to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples. Aboriginal and Torres Strait Islander peoples experience different health outcomes to non-Indigenous Australians. Not only are Aboriginal and Torres Strait Islander peoples more likely to be diagnosed with cancer, but they are also likely to receive care that doesn't meet their needs and have worse cancer outcomes. This requires specific and urgent attention.

This **Aboriginal and Torres Strait Islander Cancer Plan** has been written to change cancer experiences and create a new foundation for partnership in Australia's national approach to cancer control. We cannot expect to close the gap in cancer outcomes if we keep doing the same thing.

To develop this **Aboriginal and Torres Strait Islander Cancer Plan**, the National Aboriginal Community Controlled Health Organisation (NACCHO) undertook extensive consultations with stakeholders across the country. Consultations highlighted the need to focus on structural reform including sustainable funding, increasing accessibility of services and ensuring mainstream cancer centres are culturally safe and responsive. We also learned from the lived experience of Aboriginal and Torres Strait Islander individuals, their families and Community leaders.

This **Aboriginal and Torres Strait Islander Cancer Plan** was also informed by NACCHO's evidence review, 'Navigating the Evidence' which brought together the most recent data and evidence on cancer relevant to Aboriginal and Torres Strait Islander peoples.

Synergies exist between this **Aboriginal and Torres Strait Islander Cancer Plan** and the broader **Australian Cancer Plan** recently developed by Cancer Australia, a national government agency. By working together, these two plans will achieve better outcomes for more Aboriginal and Torres Strait Islander peoples, their families and Communities at a faster pace.

Given the complexity of cancer and the inequities experienced by Aboriginal and Torres Strait Islander peoples, it is time to share this dedicated **Aboriginal and Torres Strait Islander Cancer Plan** widely and at all levels of the health system. For some, this **Aboriginal and Torres Strait Islander Cancer Plan** could be their first introduction to the Aboriginal and Torres Strait Islander community-controlled primary health care system as a national network of highly regarded community-based services.

NACCHO supports strategic ways of working collaboratively to reduce the inequitable burden of cancer currently experienced by Aboriginal and Torres Strait Islander peoples. By working in partnership with others in full alignment with the *National Agreement on Closing the Gap*, we can drive the sustainable, scalable change required to improve cancer outcomes in our Communities.

Culturally informed, community-led solutions offer the greatest hope for change.

To support effective governance and practical action, NACCHO will work with the sector and state and territory governments to identify the most practical approach to collective action. There will be a focus on accountability as NACCHO works with key stakeholders to accelerate the priorities of the First Nations Cancer Program funded through the Commonwealth Government from July 2023.

This Plan begins our national journey towards the elimination of inequitable and avoidable differences between Aboriginal and Torres Strait Islander peoples and other Australians in cancer prevention, screening, treatment and supportive care. We thank everyone who joins us on the journey ahead. Cancer is challenging. There is no time to waste. Working together must start today.

Dr Dawn Casey PSM FAHA
Deputy Chief Executive Officer
October 2023

Through collective community-led action and sustained partnerships, inequitable and avoidable differences between Aboriginal and Torres Strait Islander peoples and other Australians in cancer prevention, screening, treatment and supportive care will be addressed

The **Aboriginal and Torres Strait Islander Cancer Plan** must be different. It is a unique call to action unprecedented in Australian health care.

Everyone can say cancer has touched their lives in some way.

Everyone should see themselves in the Aboriginal and Torres Strait Islander Cancer Plan.

This vision for the **Aboriginal and Torres Strait Islander Cancer Plan** must be sufficient to sustain effort across all components of the Australian health care system. It must meet the needs of all Aboriginal and Torres Strait Islander peoples, including intersectional groups such as people with a disability or other chronic conditions and people who identify as lesbian, gay, bisexual, transgender, intersex, queer, asexual and other sexually or gender diverse identities (LGBTQIA+). This ensures equitable, culturally safe, holistic and evidence-based cancer prevention, screening, treatment and supportive care can be accessed by all Aboriginal and Torres Strait Islander peoples.

To do so, the four Priority Reforms of the *National Agreement on Closing the Gap 2019–2029* (National Agreement) show the way. In addition, the framework of the *National Aboriginal and Torres Strait Islander Health Plan 2021–2031* has been used to align collaborative effort across the country.

Aboriginal and Torres Strait Islander Cancer Community and key stakeholders

Figure 1 Who will see themselves in the Aboriginal and Torres Strait Islander Cancer Plan

With the Aboriginal and Torres Strait Islander Community at the centre, it will take a broad range of stakeholders, working together with Community to deliver culturally safe and holistic

cancer prevention, screening and treatment services and support to achieve improved cancer outcomes for Aboriginal and Torres Strait Islander peoples and Communities.



Contents

Foreword	2		
Aboriginal and Torres Strait Islander Cancer Community and key stakeholders	4		
Summary	6		
Strategic outcomes and objectives	8		
Introduction	10		
Shared policy foundations of the Aboriginal and Torres Strait Islander Cancer Plan	12		
What are the determinants of health?	15		
Principles for addressing cancer inequities	17		
Five Areas of Focus	19		
Area of Focus 1			
Enablers for real change	20		
1.1 Shared decision-making and partnerships at all levels of the healthcare system and Community	20		
1.2 Skilled and stable health workforce performing at highest scope of practice and in place proportionate to need	20		
1.3 Awareness, communication and coordination across the cancer continuum	21		
1.4 Sustainable investment in continuity of care through Aboriginal and Torres Strait Islander community-controlled primary health care services with streamlined funding and reporting processes to reduce inequities	21		
1.5 Aboriginal and Torres Strait Islander peoples are advocates in their health journey	22		
Area of Focus 2			
Cancer prevention	23		
2.1 'Whole-of-community', culturally informed, place-based health promotion to change the cancer narrative, raise awareness and create supports for the Community	23		
2.2 Environmental and individual factors increasing cancer risk are widely known and addressed	23		
Area of Focus 3			
Timely cancer screening and early diagnosis	25		
3.1 High participation rates in cancer screening programs	25		
3.2 Emerging cancer screening technologies are universally accessible once proven	26		
3.3 Prompt investigation in a supportive patient-led clinical environment of any sign or symptom suspicious of cancer	27		
Area of Focus 4			
Improving the health system at all stages of individual cancer journeys	28		
4.1 Continuity of care based on high-trust relationships in primary care as first point of entry to the rest of the health system	28		
4.2 Culturally safe mainstream services	29		
4.3 Meaningful rapport and relationships between Community members and treating teams to achieve integration and coordination of care	30		
4.4 Holistic approach to navigating cancer services and wrap around care	30		
4.5 Support for individuals, their carers and treating teams in their Communities, including peer support and psycho-oncology	31		
4.6 Palliative care	31		
Area of Focus 5			
Culturally informed evidence base	32		
5.1 Indigenous Data Sovereignty and timely data sharing across sectors	32		
5.2 Indigenist research and evaluation methods	32		
5.3 Sharing stories of lived experience	33		
5.4 Information systems strengthened, including Patient Information Management Systems, and users supported to access data to identify Community needs	33		
5.5 Safe and relevant cancer clinical trials with high participation rates of Aboriginal and Torres Strait Islander peoples	33		
Implementation and next steps	34		
Conclusion	35		
Glossary	36		
References	39		

Summary

Shared vision

Through collective community-led action and sustained partnerships, inequitable and avoidable differences between Aboriginal and Torres Strait Islander peoples and other Australians in cancer prevention, screening, treatment and supportive care will be addressed

Focus area

Enablers for real change

Cancer prevention

Timely cancer screening and early diagnosis

Improving the health system at all stages of individual cancer journeys

Culturally informed evidence base

Strategic outcomes

- 1.1** Shared decision-making and partnerships at all levels of the healthcare system and Community
- 1.2** Skilled and stable health workforce performing at highest scope of practice and in place proportionate to need
- 1.3** Awareness, communication and co-ordination across the cancer continuum
- 1.4** Sustainable investment in continuity of care through Aboriginal and Torres Strait Islander community-controlled primary health care services with streamlined funding and reporting processes to reduce inequities
- 1.5** Aboriginal and Torres Strait Islander peoples are advocates in their health journey
- 2.1** 'Whole-of-community', culturally informed, place-based health promotion to change the cancer narrative, raise awareness and create supports for the Community
- 2.2** Environmental and individual factors increasing cancer risk are widely known and addressed
- 3.1** High participation rates in cancer screening programs
- 3.2** Emerging cancer screening technologies are universally accessible once proven
- 3.3** Prompt investigation in a supportive patient-led clinical environment of any sign or symptom suspicious of cancer
- 4.1** Continuity of care based on high-trust relationships in primary care as first point of entry to the rest of the health system
- 4.2** Culturally safe mainstream services
- 4.3** Meaningful rapport and relationships between Community members and treating teams to achieve integration and co-ordination of care
- 4.4** Holistic approach to navigating cancer services and wrap around care
- 4.5** Support for individuals, their carers and treating teams in their Communities, including peer support and psycho-oncology
- 4.6** Palliative care
- 5.1** Indigenous Data Sovereignty and timely data sharing across sectors
- 5.2** Indigenist research and evaluation methods
- 5.3** Sharing stories of lived experience
- 5.4** Information systems strengthened, including Patient Information Management Systems, and users supported to access data to identify Community needs
- 5.5** Safe and relevant cancer clinical trials with high participation rates of Aboriginal and Torres Strait Islander peoples

Strategic outcomes and objectives

1.1 Shared decision-making and partnerships at all levels of the healthcare system and Community

- ▶ To achieve genuine partnership with Aboriginal and Torres Strait Islander Communities and organisations by all national, state, regional and local bodies to improve health systems and cancer outcomes
- ▶ To ensure place-based approaches are co-designed with local Aboriginal and Torres Strait Islander peoples

1.2 Skilled and stable health workforce performing at highest scope of practice and in place proportionate to need

- ▶ To engage, recruit and retain a strong, skilled Aboriginal and Torres Strait Islander workforce across mainstream health services and the community-controlled sector
- ▶ To prioritise leadership through Aboriginal and Torres Strait Islander peoples and support their career development
- ▶ To strengthen meaningful career progression pathways for Aboriginal and Torres Strait Islander peoples

1.3 Awareness, communication and co-ordination across the cancer continuum

- ▶ To ensure access to culturally safe cancer treatment and support for Aboriginal and Torres Strait Islander peoples and their families throughout the cancer journey across all health care systems
- ▶ To increase understanding of the importance of local context and how this relates to Aboriginal and Torres Strait Islander Communities
- ▶ To promote cancer communication, care planning and coordination led by Aboriginal and Torres Strait Islander peoples
- ▶ To maximise options to receive effective and safe cancer treatments on Country
- ▶ To ensure Aboriginal and Torres Strait Islander peoples receive and can discuss cancer-related information in their language of choice

1.4 Sustainable investment in continuity of care through Aboriginal and Torres Strait Islander community-controlled primary health care services with streamlined funding and reporting processes to reduce inequities

- ▶ To improve mechanisms and co-designed processes at national, jurisdictional, regional and local levels for Aboriginal and Torres Strait Islander community-controlled primary health care services to meet local needs, including place-based cancer care
- ▶ To reduce overburden of activity reporting in cancer-specific funding by moving to outcomes-focused programs
- ▶ To secure sustained long-term funding for cancer programs
- ▶ To realise larger social, health and economic benefits through stable, sustained health programs

1.5 Aboriginal and Torres Strait Islander peoples are advocates in their health journey

- ▶ To enable Aboriginal and Torres Strait Islander peoples with lived experience to be leaders in planning, development and Continuous Quality Improvement (CQI) processes across the cancer continuum

- ▶ To enable Aboriginal and Torres Strait Islander Communities to be advocates and leaders in determining patient-led models of care
- ▶ To fulfill the seven rights of the *Australian Charter of Healthcare Rights* in every cancer journey

2.1 'Whole-of-community', culturally informed, place-based health promotion to change the cancer narrative, raise awareness and create supports for the Community

- ▶ To embed population health approaches to cancer prevention in Aboriginal and Torres Strait Islander Communities that are tailored to local needs
- ▶ To enhance health literacy through targeted health promotion activities co-designed with Aboriginal and Torres Strait Islander peoples to promote healthy behaviours across the life course
- ▶ To support community-led, holistic health promotion activities that are strengths-based, support positive behaviour change and respond to local cultural needs

2.2 Environmental and individual factors increasing cancer risk are widely known and addressed

- ▶ To ensure healthcare teams have adequate resources to conduct holistic health assessments to discuss cancer risk factors and increase primary prevention
- ▶ To create healthy environments for Aboriginal and Torres Strait Islander Communities to facilitate individual behaviour change

3.1 High participation rates in cancer screening programs

- ▶ To increase cancer screening through Aboriginal and Torres Strait Islander leadership in planning, delivery and evaluation of screening programs, including application of CQI frameworks
- ▶ To utilise place-based, data-informed partnerships between health services and screening programs to maximise screening participation
- ▶ To ensure informed participation in cancer screening by Aboriginal and Torres Strait Islander peoples
- ▶ To ensure equity in participation by Aboriginal and Torres Strait Islander peoples who live in remote Communities by effectively addressing their geographic and logistical barriers

3.2 Emerging cancer screening technologies are universally accessible once proven

- ▶ To ensure equitable access to emerging screening technologies and different screening approaches once proven and endorsed for national scale-up

3.3 Prompt investigation in a supportive patient-led clinical environment of any sign or symptom suspicious of cancer

- ▶ To promote health literacy to encourage all Aboriginal and Torres Strait Islander peoples to seek health advice for early diagnosis from a health care professional
- ▶ To support health care professionals to access culturally safe training to provide advice on cancer symptoms to Aboriginal and Torres Strait Islander peoples

- ▶ To enhance access to culturally safe and timely diagnostic services whenever required
- ▶ To scale up Aboriginal and Torres Strait Islander co-designed projects and programs that are shown to be effective in improving health outcomes for Communities

4.1 Continuity of care based on high-trust relationships in primary care as first point of entry to the rest of the health system

- ▶ To ensure meaningful and genuine rapport is achieved between mainstream organisations and local Communities to support individual cancer journeys
- ▶ To promote shared care models, coordination and continuity of care for individuals, families and Communities affected by cancer
- ▶ To ensure service delivery across all levels of the health system aligns with Priority Reform 3 of the National Agreement on Closing the Gap
- ▶ To enhance existing career pathways across all levels for Aboriginal and Torres Strait Islander Community members by providing sustainable funding and resources

4.2 Culturally safe mainstream services

- ▶ To ensure place-based, co-designed models of care and referral pathways are implemented and evaluated for cultural safety across all levels of the mainstream health system
- ▶ To identify and eliminate racism by acknowledging, addressing, measuring, reporting, and taking immediate action to eradicate institutional racism across all levels of the mainstream health system
- ▶ To increase funding for cultural safety training developed and led by Aboriginal and Torres Strait Islander peoples as part of healthcare professional development across all mainstream health services
- ▶ To ensure continuity of care and integration of services across all levels of the health system
- ▶ To establish and permanently employ dedicated cancer support officer positions and local champions to enhance and deliver culturally safe cancer care to Aboriginal and Torres Strait Islander peoples

4.3 Meaningful rapport and relationships between Community members and treating teams to achieve integration and co-ordination of care

- ▶ To facilitate and strengthen organisational relationships at all levels of the health system based on co-design, openness, communication and respect
- ▶ To establish holistic respectful relationships and trust between Community members and health care professionals to ensure communication is culturally safe

4.4 Holistic approach to navigating cancer services and wrap around care

- ▶ To expand mechanisms for sustained funding to establish and maintain wrap around services for Aboriginal and Torres Strait Islander Community members and their families
- ▶ To ensure co-designed, culturally safe communication materials are available everywhere to support Community members' understanding of the cancer journey
- ▶ To resolve barriers, including financial costs, available services and infrastructure within local Communities in sustainable and effective ways

4.5 Support for individuals, their carers and treating teams in their Communities, including peer support and psycho-oncology

- ▶ To ensure Aboriginal and Torres Strait Islander peoples with lived experience are at the centre of determining policy, program and service design, implementation and evaluation of social and wellbeing services
- ▶ To secure sustained funding for cancer support groups to be designed and led by Aboriginal and Torres Strait Islander peoples
- ▶ To develop models of care to ensure staff working in cancer-related roles have access to culturally safe peer support services

4.6 Palliative care

- ▶ To ensure palliative care is available whenever and wherever needed on Country and coordinated with primary health care
- ▶ To enable Aboriginal and Torres Strait Islander peoples to die with dignity on the Country of their choosing through co-designed, place-based palliation services

5.1 Indigenous Data Sovereignty and timely data sharing across sectors

- ▶ To improve Indigenous Data Sovereignty so that Aboriginal and Torres Strait Islander health data – including cancer data – are used for shared decision-making, co-design and local leadership
- ▶ To strengthen stakeholder engagement and adoption by mainstream health systems and data custodians of the five agreed principles for Indigenous Data Sovereignty

5.2 Indigenous research and evaluation methods

- ▶ To ensure cancer research and evaluation focuses on priorities identified and led by Aboriginal and Torres Strait Islander Communities
- ▶ To increase the number of Aboriginal and Torres Strait Islander academic scholars and their access to research infrastructure

5.3 Sharing stories of lived experience

- ▶ To acknowledge, share and respect Aboriginal and Torres Strait Islander peoples' cancer journeys and celebrate positive experiences to change the cancer narrative and remove the stigma and fear associated with cancer
- ▶ To listen to and incorporate views and feedback of Aboriginal and Torres Strait Islander peoples affected by cancer and the workforce who manage these issues every day

5.4 Information systems strengthened, including Patient Information Management Systems, and users supported to access data to identify Community needs

- ▶ To support organisations to apply CQI frameworks in evaluating information management system software in order to identify data gaps
- ▶ To ensure ACCHOs receive adequate training and resources to effectively utilise Patient Information Management Systems

5.5 Safe and relevant cancer clinical trials with high participation rates of Aboriginal and Torres Strait Islander peoples

- ▶ To increase engagement of Aboriginal and Torres Strait Islander peoples in co-designed cancer clinical trials

Introduction

Why is an Aboriginal and Torres Strait Islander Cancer Plan needed?

At the time of writing, cancer is the leading cause of death and responsible for 23.4% of all deaths among Aboriginal and Torres Strait Islander peoples.¹

While the cancer incidence rate for other Australians is declining, the rate for Aboriginal and Torres Strait Islander peoples is not. In fact, the gap is widening. Mortality rates have been declining for non-Indigenous people for at least two decades but cancer mortality for Aboriginal and Torres Strait Islander peoples has continued to increase. There are several reasons that contribute towards this inequity including historical and contemporary policy decisions that are imposed on Aboriginal and Torres Strait Islander peoples without their genuine participation in problem-solving and resolution.

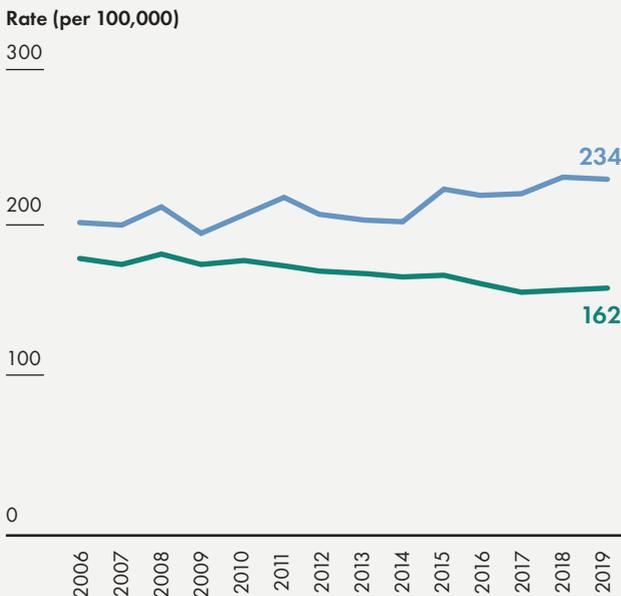
This **Aboriginal and Torres Strait Islander Cancer Plan** takes a holistic approach to overall health and wellbeing and aims to contribute towards reduced rates of cancer incidence, mortality and burden of diseases by advocating for place-based, community-led, and holistic initiatives. Aboriginal and Torres Strait Islander peoples are at the heart of this plan because Community values and cultural connections effectively addressing the major determinants of health are key to better cancer outcomes. This **Aboriginal and Torres Strait Islander Cancer Plan** also seeks to enhance the understanding of non-Indigenous people working in cancer-related roles.

Figure 2 (below) shows this widening gap in cancer mortality. Between 2006 and 2019, the difference in cancer mortality rates between Aboriginal and Torres Strait Islander peoples and non-Indigenous peoples tripled.² These figures suggest that work to improve cancer prevention and care in Australia over the past two decades has not equitably reached Aboriginal and Torres Strait Islander peoples.

Figure 2 Age-standardised mortality rates and changes in the gap due to cancer and other neoplasms by Indigenous status²

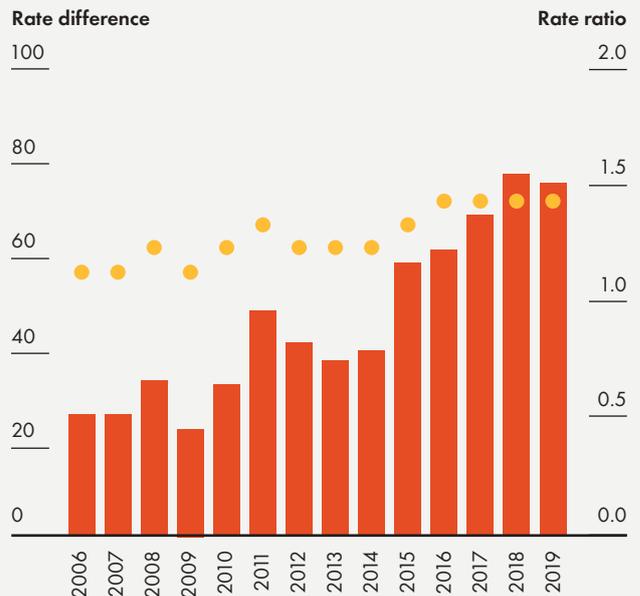
Change in the rate

● Indigenous Australians ● Non-Indigenous Australians



Absolute and relative changes in the gap

● Rate difference ● Rate ratio





For the period 2012–2016, the age-standardised **incidence of all cancers was 14% higher in Aboriginal and Torres Strait Islander peoples** than amongst non-Aboriginal and Torres Strait Islander people (523 versus 459 cases per 100,000 people respectively).³

Cancer among Aboriginal and Torres Strait Islander adolescents and young adults aged 15–24 years is rare but has far-reaching consequences. While there are limited national data available, there is evidence that Aboriginal and Torres Strait Islander adolescents and young adults aged 15–24 years' experience a lower 5-year relative cancer survival rate (see glossary) than other Australians aged 15–24 years (82% v 89% respectively).⁴

Further data on the impact of cancer on Aboriginal and Torres Strait Islander peoples and Communities are synthesised in *Navigating the Evidence*.⁵

Delivering culturally safe, holistic, person-centred care is part of the Core Services and Outcomes Framework (CSOF) Model of Aboriginal and Torres Strait Islander Community Controlled Comprehensive Primary Health Care for Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ACCHOs).⁶ ACCHOs use their community-elected Boards to set out priorities and directions to achieve better health and wellbeing. Innovative actions and achievements led by the Aboriginal and Torres Strait Islander community-controlled health sector are making a difference.

Whether at primary, secondary or tertiary levels of the health system, mainstream organisations have the opportunity to engage with and learn from the ACCHO sector to improve their own cancer services for Aboriginal and Torres Strait Islander peoples. The sector appreciates powerful allies in advocacy and respectful partners in service delivery. Local champions and Community members sharing lived experiences is an important step to help transform the cancer narrative.

Children's cancer

There are no cancer data for Aboriginal and Torres Strait Islander children, despite children being the largest Aboriginal and Torres Strait Islander population group (33.1% of the total Aboriginal and Torres Strait Islander population are 0–15 years).⁷

Cancer among children can be very challenging, especially due to the critical developmental stage of children, and often requires travel to major cities for specialist cancer treatment. The treatment process for a child with cancer often extends over long periods of time, and more resourcing is needed to support a family with a child who has a cancer diagnosis. Appropriate age-specific support and care must be accessible. For Aboriginal and Torres Strait Islander peoples, a childhood cancer diagnosis often removes a family from Country for treatment and follow up care. Culturally appropriate and holistic care must be in place. This includes mainstream services embedding culturally appropriate considerations to caring for Aboriginal and Torres Strait Islander children and families.

Shared policy foundations of the Aboriginal and Torres Strait Islander Cancer Plan

Shared policy foundations are produced through co-design. This Aboriginal and Torres Strait Islander Cancer Plan builds on priorities and strategies outlined in four highly regarded co-designed national policies that have secured Ministerial endorsement, namely the:

- ▶ National Agreement on Closing the Gap 2019–2029⁸
- ▶ National Aboriginal and Torres Strait Islander Health Plan 2021–2031⁹
- ▶ National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031¹⁰
- ▶ Health Sector Strengthening Plan.¹¹

Other resources led by Aboriginal and Torres Strait Islander community-controlled peak bodies have also been incorporated, namely the:

- ▶ NACCHO Core Services and Outcomes Framework⁷
- ▶ Cultural Safety Framework: National Aboriginal and Torres Strait Islander Health Workers Association¹²
- ▶ NACCHO National Framework for Continuous Quality Improvement in Primary Health Care for Aboriginal and Torres Strait Islander Peoples.¹³

The National Agreement on Closing the Gap 2019–2029

The National Agreement is acknowledged as a critical precursor for full enactment in Australia as part of the United Nations Declaration of the Rights of Indigenous People. Advocating for and securing the National Agreement was a historically significant act of Aboriginal and Torres Strait Islander self-determination.

Careful integration of recommended actions with the four Priority Reforms of the National Agreement (see below) is a focus in this **Aboriginal and Torres Strait Islander Cancer Plan**.

Implementation of the **Aboriginal and Torres Strait Islander Cancer Plan** must align with the commitments made by all signatories to the National Agreement. The National Agreement was agreed to by all Australian Governments and efforts to improve cancer outcomes must occur in full and genuine partnership with Aboriginal and Torres Strait Islander peoples.

National Aboriginal and Torres Strait Islander Health Plan 2021–2031

The vision of the *National Aboriginal and Torres Strait Islander Health Plan 2021–2031* is for Aboriginal and Torres Strait Islander peoples to enjoy long, healthy lives centred in culture, with access to services that are prevention- focused, culturally safe and responsive, equitable and free of racism.⁹ The *National Aboriginal and Torres Strait Islander Health Plan 2021–2031* sets several priorities to achieve its vision that have informed this **Aboriginal and Torres Strait Islander Cancer Plan**.

Four Priority Reforms of the National Agreement

- 1 Strengthen and establish formal partnerships and shared decision-making**
- 2 Build the Aboriginal and Torres Strait Islander community-controlled sector**
- 3 Transform government organisations so they work better for Aboriginal and Torres Strait Islander peoples**
- 4 Improve and share access to data and information to enable Aboriginal and Torres Strait Islander Communities make informed decisions**

National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031

The *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031* recognises that a locally qualified and skilled Aboriginal and Torres Strait Islander health workforce across the health system is required to achieve the vision of the *National Aboriginal and Torres Strait Islander Health Plan 2021–2031*.¹⁰

The *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031* has two objectives, to increase the Aboriginal and Torres Strait Islander health workforce and to strengthen the health system to create and sustain cultural and professional capabilities which have been reflected in this **Aboriginal and Torres Strait Islander Cancer Plan**.¹⁰

Health Sector Strengthening Plan

The three-year Health Sector Strengthening Plan (Health-SSP) outlines 17 transformative sector strengthening actions to support and build the Aboriginal and Torres Strait Islander community-controlled health service sector. As exemplified during the COVID-19 pandemic response, an equal partnership between the sector and governments must continue if Australia is to reduce the burden of disease for Aboriginal and Torres Strait Islander peoples.

NACCHO Core Services and Outcomes Framework (CSOF)

The CSOF outlines the model by which the Aboriginal Community Controlled Health sector delivers comprehensive primary health care across Australia and as such, supports cancer prevention and management.

It is intended for use by three main audiences: ACCHO primary health care services and their staff; Aboriginal and Torres Strait Islander Communities; and policy-makers and other stakeholders seeking to better understand the benefits and nature of community-controlled comprehensive, primary health care.

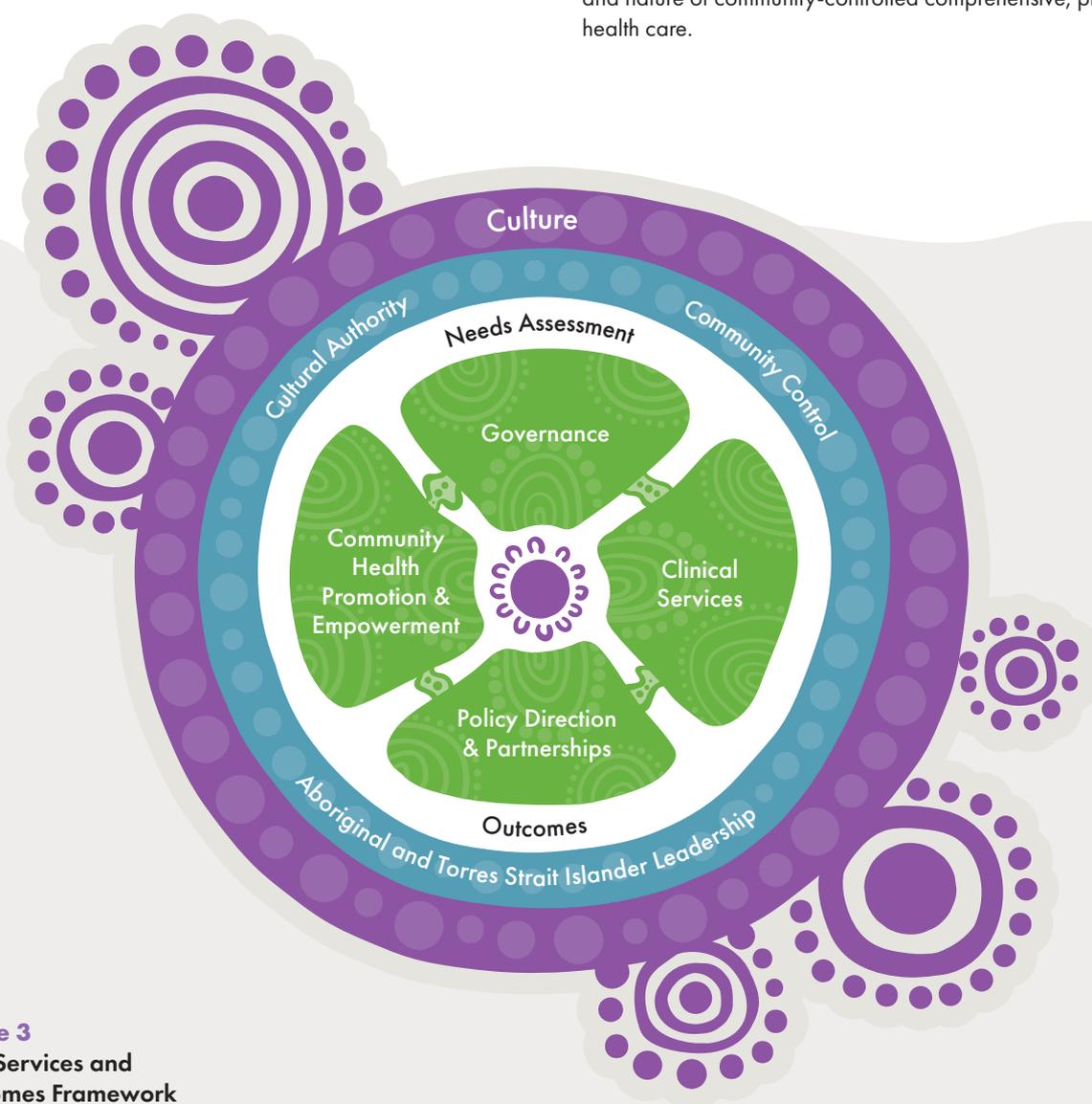


Figure 3
Core Services and Outcomes Framework Model



The CSOF acknowledges the vital importance of peoples, culture, Community control, cultural authority, and Aboriginal and Torres Strait Islander leadership to the success of the ACCHO sector, with needs assessments identifying priorities for action and strong evaluation processes monitoring outcomes. Infrastructure, workforce and continuous quality improvement (CQI) are essential to the sustainability and operation of every ACCHO.

Cultural Safety Framework: National Aboriginal and Torres Strait Islander Health Workers Association

The Cultural Safety Framework was produced by the (then) National Aboriginal and Torres Strait Islander Health Workers Association to increase capability within the Australian healthcare system to deliver culturally safe and responsive health and wellbeing services for Aboriginal and Torres Strait Islander peoples.¹² Cultural safety is based on the experience of the recipient of care (see glossary).

NACCHO National Framework for Continuous Quality Improvement in Primary Health Care for Aboriginal and Torres Strait Islander Peoples

Domains outlined in the National Framework for CQI in Primary Health Care for Aboriginal and Torres Strait Islander peoples are incorporated throughout the **Aboriginal and Torres Strait Islander Cancer Plan**. The framework recognises high-quality, culturally responsive and safe care is vital across primary health care settings to improve health outcomes of Aboriginal and Torres Strait Islander peoples.¹³

CQI encompasses activities to help build the capability of primary health care organisations to deliver high-quality, responsive and culturally safe health services that are place-based and meet the needs of Aboriginal and Torres Strait Islander peoples.

Australian Charter of Healthcare Rights

The *Australian Charter of Healthcare Rights* is another important policy foundation that healthcare providers apply when delivering healthcare to all Australians.¹⁴ Although the *Australian Charter of Healthcare Rights* is not co-designed with Aboriginal and Torres Strait Islander peoples, this Ministerial endorsed document provides a foundation on how healthcare should be delivered to all Australians. The *Australian Charter of Healthcare Rights* is a National Charter that encompasses seven rights to which all Australians are entitled when receiving healthcare. The Charter describes what people can expect when they access, use and receive healthcare in Australia which is critical to ensuring people feel safe and respected in Australia's healthcare system.¹⁴

What are the determinants of health?

Determinants of health are factors that influence a person’s overall health outcomes.

The determinants of health include social, commercial and environment factors which impact a person’s individual characteristics and behaviours.¹⁵ In addition to the social, commercial and environmental determinants of health, there are other factors impacting Aboriginal and Torres Strait Islander peoples’ health and wellbeing, including the perception of mainstream health organisations contributing to:

- ▶ on-going colonisation
- ▶ disempowerment
- ▶ marginalisation
- ▶ trauma.

Acknowledging and addressing these influential determinants of health will be essential to improving cancer outcomes for Aboriginal and Torres Strait Islander peoples.

Consultations confirm that Community understand many of the risk factors associated with cancer, including the importance of eating nutritious foods, maintaining a sensible weight, sufficient exercise, drinking water, avoiding smoking and limiting alcohol intake all well recognised.

Cultural determinants of health

The cultural determinants support a holistic approach to health and wellbeing. Connection is a key component of Aboriginal and Torres Strait Islander culture. It recognises the importance of kinship and connection to Country physically, spiritually, and through traditional knowledge sharing and storytelling.

Cultural determinants such as family kinship and Community, self-determination, Indigenous beliefs & knowledge, connection to Country, Indigenous language, and cultural expression and continuity, are all strongly identified as having a positive impact on the health and wellbeing outcomes of Aboriginal and Torres Strait Islander peoples.

As represented in Figure 4, each cultural determinant of health is interconnected and central to Aboriginal and Torres Strait Islander ways of knowing, doing, and being.

The cultural determinants recognise the inherent strength of Aboriginal and Torres Strait Islander peoples, and self-determination principles to foster improved outcomes at all levels, including to influence positive changes at the individual, structural, political and cultural levels.

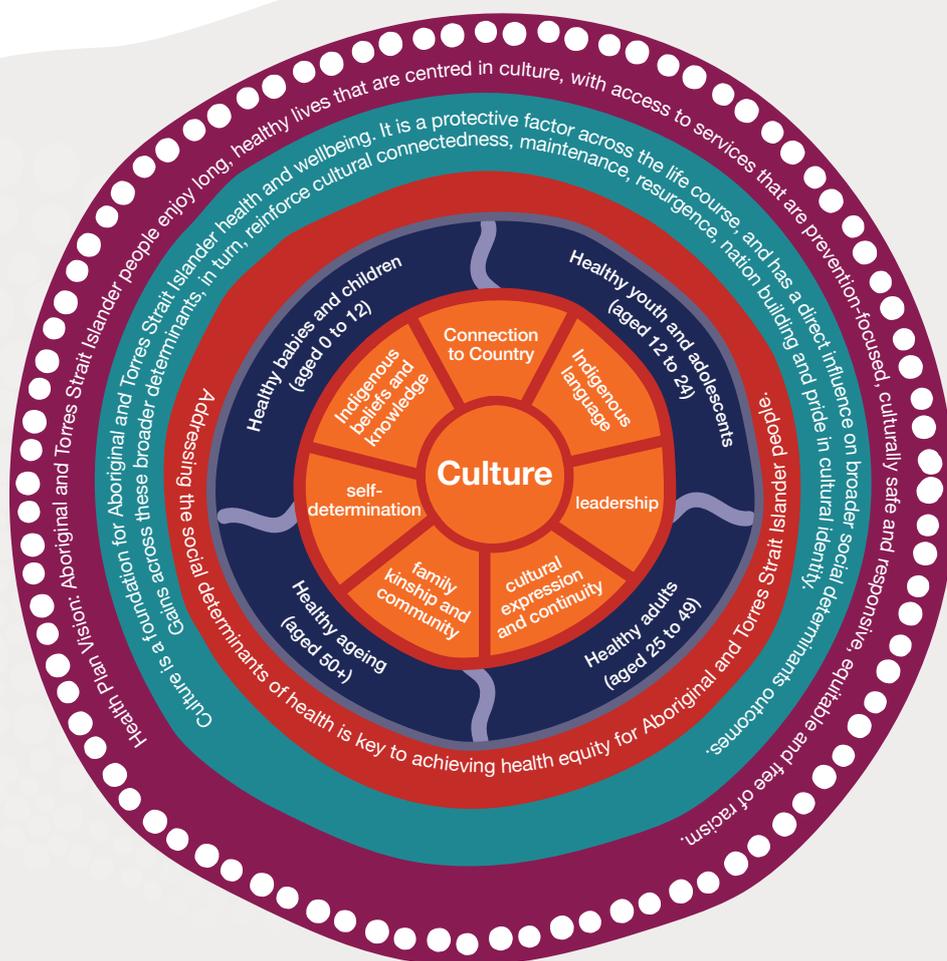


Figure 4
Circular framework
(source National
Aboriginal and Torres
Strait Islander Health
Plan 2021–2031)

The importance of the cultural determinants of health

Somewhere in Australia today, an Aboriginal and/or Torres Strait Islander Community member living in rural or remote Australia will receive a positive cancer diagnosis which requires travel to the nearest major city for treatment. Imagine an Australian health system which adopts culturally appropriate care in incorporating practices to support this cancer patient's Indigenous human rights. This would ensure a strengths-based approach (see glossary) nurturing cultural determinants of health. Imagine this Community member feels willing and safe to travel for treatment accompanied by family members with access to transport subsidies easily obtained. Imagine an outcome when the family returns to Community relieved that the Australian healthcare system has supported their cultural rights and Connection. This is the Australian health system which needs to exist.

Social determinants of health

NACCHO recognises the extensive influence of social determinants of health. These include the conditions in which people are born, grow, work, live, and age.

The Australian Institute of Health and Welfare (AIHW) showed that 34% of the health gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians is attributable to five social determinants,¹⁵ namely:

- ▶ employment and hours worked
- ▶ highest non-school qualification
- ▶ level of schooling completed
- ▶ housing adequacy
- ▶ household income.

The overall poverty rate for Aboriginal and Torres Strait Islander peoples is 31%, and poverty is twice as high for Aboriginal and Torres Strait Islander peoples living in very remote Communities (54%) than those in major cities (24%).¹⁶

Historical factors play a major role in how Aboriginal and Torres Strait Islander Communities interact with mainstream health services. It is not uncommon for Aboriginal and Torres Strait Islander peoples to experience feelings of hesitancy and mistrust towards mainstream health services. Various factors have led to this such as:

- ▶ previous Government policies such as the removal of children from their families
- ▶ on-going racism, discrimination and stigma by mainstream health providers
- ▶ data collected on and from Aboriginal and Torres Strait Islander Communities without the necessary data sovereignty.

The combination of these factors continues to contribute towards cancer inequities experienced by Aboriginal and Torres Strait Islander peoples.

Racism and discrimination still exist and continue to be a barrier for Aboriginal and Torres Strait Islander peoples accessing mainstream health services. It is important historical factors are recognised and considered by healthcare professionals, managers, policy-makers and ministers outside the ACCHO sector to advocate for change so Aboriginal and Torres Strait Islander peoples have equitable, culturally safe experiences when receiving cancer care in mainstream organisations.

Commercial determinants of health

The commercial determinants of health are strategies and approaches used by the private sector to promote products and choices which may be detrimental to health. The commercial determinants of health arise from commercial (profit-based) behaviour of companies rather than the prioritisation of health outcomes. For example, the high concentration and marketing of highly processed foods and sugary drinks, particularly to children, influences unhealthy eating behaviours while driving profits.

Environmental determinants of health

The environmental determinants of health are the physical, chemical, and biological factors that can impact on people's health and wellbeing. The *Compendium of the World Health Organisation and other United Nations guidance on health and environment, 2022 update* (the Compendium)¹⁷ identifies the following environmental determinants of health are cancer risk factors:

- ▶ second-hand tobacco smoke
- ▶ ambient air pollution
- ▶ chemicals
- ▶ radiation.

The Compendium also recognises the direct and indirect effects of climate change that can impact people's health and wellbeing.¹⁷ Direct effects, such as increased UV radiation, and indirect effects, such as changes to food and water security pose a risk to exacerbating existing inequities.

Principles for addressing cancer inequities

Agreed principles were used to inform the development of the **Aboriginal and Torres Strait Islander Cancer Plan** and should continue to guide future actions including implementation plans.

Principles	Implementation
Support self-determination and co-design through partnership	Implementation of this Aboriginal and Torres Strait Islander Cancer Plan should continue to secure the widest possible co-design and co-decision-making with Aboriginal and Torres Strait Islander peoples and their peak representative bodies, giving substance to the four Priority Reforms to which every Australian government is accountable in the National Agreement on Closing the Gap. Partnership guarantees better outcomes. Engagement that enables Aboriginal and Torres Strait Islander peoples to set the agenda and co-design policies and programs in partnership with stakeholders and those with significant resources is essential.
Align with existing co-designed Aboriginal and Torres Strait Islander strategies	This Aboriginal and Torres Strait Islander Cancer Plan must align with co-designed health frameworks and strategies including but not limited to the current <i>National Agreement on Closing the Gap 2019–2029</i> , the <i>National Aboriginal and Torres Strait Islander Health Plan 2021–2031</i> , the <i>National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031</i> , and the <i>Health Sector Strengthening Plan</i> endorsed by Joint Council in November 2021.
Strengthen community-controlled efforts	The Aboriginal and Torres Strait Islander community-controlled primary health care sector is holistic, on-the-ground, and cost-effective in achieving health improvement. This Aboriginal and Torres Strait Islander Cancer Plan illustrates how this sector is critical for improving cancer outcomes and, where this choice is not available to Aboriginal and Torres Strait Islander peoples, indicates how other parts of Australia’s multi-layered health care system must step up to work in partnership and advocate for sector-strengthening.
Grow equity	Implementation of this Aboriginal and Torres Strait Islander Cancer Plan must not exacerbate inequity in the sector. Thoughtful sequencing of strategies and service improvements evident through monitoring and evaluation will demonstrate greater equity over time. This equity will be evident in access, processes of cancer care, and outcomes for Aboriginal and Torres Strait Islander peoples across the life course irrespective of location, income, gender, sexuality, assumed sex at birth, age, or preferred language.
Maximise efficiency	Effective governance partnerships achieving co-design and co-decision making at national, state/territory, and local level are required, resulting in shared implementation plans, agreed models of care, evidence-based patient care pathways, and CQI. Inefficiencies are generally greatest in those initiatives which are short-term, siloed, and disconnected from community-controlled organisations. Investment in community-controlled primary health care as the foundation of service delivery maximises efficiency.
Adopt culturally safe patient-led ,models of care throughout the life course with deliberate integration and continuity of care	Integrated patient-led clinical care pathways and place-based care are effective. Pathways across organisations should be structured based on service delivery models of care that are culturally safe and appropriate, tailored towards the individual and negotiated between all parties. All services should be culturally safe and appropriate when delivering patient-led models of care, including respecting men’s and women’s health business. Anyone with a cancer diagnosis should be able to access their service of choice and receive culturally safe continuity of care from all services across their cancer journey.

Principles	Implementation
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Consider the unique disease and diagnosis features of cancer

Including applying the best available evidence to decision-making for individual care as well as population health programs. Existing cancer infrastructure including the Australian Cancer Database, national cancer screening registers, cancer research networks, and clinical registries collecting and analysing minimum clinical datasets are unique assets with untapped potential to improve outcomes for Aboriginal and Torres Strait Islander peoples. Action on social and cultural determinants of health will also accelerate the pace at which equitable cancer outcomes will be achieved.

Progress Indigenous data sovereignty

Australia has made significant contributions to global knowledge about cancer origins, prevention, clinical treatment and support. Yet research questions raised by Aboriginal and Torres Strait Islander Communities designed to accelerate healing and improve cancer outcomes are rarely prioritised. Co-design is equally important in research, including processes to ensure the translation of findings, and the evaluation of successful models of care that can be replicated. CQI such as clinical practice audits can also be included to ensure organisations have a baseline and can set achievable screening targets. All five principles of the *Maiam Nayri Wingara Indigenous Data Sovereignty Collective*¹⁸ should be operationalised.



Five Areas of Focus

After careful consideration, five Areas of Focus have been adapted from the National Aboriginal and Torres Strait Islander Health Plan 2021–2031 to focus attention and effort through the National Aboriginal and Torres Strait Islander Cancer Plan:

Enablers for real change

Cancer prevention

Timely cancer screening and early diagnosis

Improving the health system at all stages of individual cancer journeys

Culturally informed evidence base

All five must be expressed in every individual's cancer journey to optimise their experience and maximise Community awareness of cancer risks and quality of evidence-based care.

Enablers for real change

1.1

Shared decision-making and partnerships at all levels of the healthcare system and Community

Objectives

- ▶ To achieve genuine partnership with Aboriginal and Torres Strait Islander Communities and organisations by all national, state, regional and local bodies to improve health systems and cancer outcomes
- ▶ To ensure place-based approaches are co-designed with local Aboriginal and Torres Strait Islander peoples.

Community and culture are central to Aboriginal and Torres Strait Islander health and wellbeing. Place-based and strengths-based approaches maximise both. Significant (and growing) numbers of Aboriginal and Torres Strait Islander Communities determine their own health priorities, allocate resources and make decisions through community-elected boards governing community-controlled health care. This self-determination occurs in the context of a broader Australian health care system that is complex, not entirely fit-for-purpose and not always focused on health as a human right.

A commitment to self-determination aligned with the *National Agreement on Closing the Gap* should extend to all levels of the health system including tertiary hospital care. Local partnerships should be accountable to Communities to rectify the impacts of colonisation including:

- ▶ racism
- ▶ intergenerational trauma
- ▶ persistent poverty
- ▶ marginalisation.

When these partnerships function well, all services including jurisdictional governments and their health and hospital services, local ACCHOs, other community-controlled organisations and non-government organisations, private businesses and health practitioners are engaged to work together to improve the delivery of care and cancer outcomes for Aboriginal and Torres Strait Islander Communities.

Negotiation through Aboriginal and Torres Strait Islander community-controlled organisations to determine place-based health partnership arrangements and/or service level agreements including local protocols and models of care will ensure the priorities, values and preferences of Aboriginal and Torres Strait Islander peoples drive service improvements. Local coordination is key. Governments and tertiary centres must build genuine partnerships and engage in shared

decision-making with the ACCHO sector and Aboriginal and Torres Strait Islander organisations from the beginning if there are to be improved cancer-related health outcomes for Aboriginal and Torres Strait Islander Communities.

Community control is especially important in achieving better cancer outcomes. ACCHOs play a significant role in design, delivery and evaluation. Expertise also resides in community-controlled Affiliates which are peak bodies with Aboriginal and Torres Strait Islander community-elected Boards in each state and territory. Investment in Affiliates so they have sustainable capacity to facilitate partnerships for effective planning, co-ordination and knowledge transfer in their respective state or territory level is vital. This includes capacity to co-design data-informed cancer plans from an Aboriginal and Torres Strait Islander perspective with monitoring and evaluation for shared accountability.

1.2

Skilled and stable health workforce performing at highest scope of practice and in place proportionate to need

Objectives

- ▶ To engage, recruit and retain a strong, skilled Aboriginal and Torres Strait Islander workforce across mainstream health services and the community-controlled sector
- ▶ To prioritise leadership through Aboriginal and Torres Strait Islander peoples and support their career development
- ▶ To strengthen meaningful career progression pathways for Aboriginal and Torres Strait Islander peoples.

It is important that the cancer-related health needs of each Aboriginal and Torres Strait Islander Community are matched with the workforce required (in terms of both skills and time available) to improve health. Workforce planning, an appropriate industrial framework and recognised career pathways, will strengthen service capacity on the ground.

To improve cancer outcomes, Aboriginal and Torres Strait Islander Health Workers and Health Practitioners are the highest priority for workforce investment. Each Aboriginal and Torres Strait Islander Community must have a workforce that is sufficient, stable, well-trained, well-resourced and working at maximum scope of practice. Local people should be highly visible as contributing to health outcomes and, through well-paid and satisfying employment, economic prosperity.

Common workforce challenges include:

- ▶ workforce shortages
- ▶ remuneration discrepancies
- ▶ challenges of keeping staff long-term and working efficiently in multidisciplinary teams
- ▶ staff attraction and retention, particularly in smaller ACCHOs located in rural and remote areas
- ▶ staff accommodation in remote areas.

Implementation of the *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031* and updating Vocational Education and Training sector core units to include cancer prevention and care will achieve expert Aboriginal and Torres Strait Islander roles in cancer prevention, cancer screening and the delivery of clinical care pathways.

1.3 Awareness, communication and coordination across the cancer continuum

Objectives

- ▶ To ensure access to culturally safe cancer treatment and support for Aboriginal and Torres Strait Islander peoples and their families throughout the cancer journey across all health care systems
- ▶ To increase understanding of the importance of local context and how this relates to Aboriginal and Torres Strait Islander Communities
- ▶ To promote cancer communication, care planning and coordination led by Aboriginal and Torres Strait Islander peoples
- ▶ To maximise options to receive effective and safe cancer treatments on Country
- ▶ To ensure Aboriginal and Torres Strait Islander peoples receive and can discuss cancer-related information in their language of choice.

Effective communication and sustained engagement with Aboriginal and Torres Strait Islander peoples and Communities across all ages, backgrounds and locations will raise collective understanding and awareness of cancer without stigmatisation or fear.

Every Community deserves to be confident in and have knowledge about the cancer programs and services across the health system to which they must have access for equitable outcomes. Communities and stakeholders have repeatedly identified the need for sustained and co-designed communication, care planning and coordination that places Aboriginal and Torres Strait Islander peoples at the centre of models of care and treatment pathways. For prevention, this means targeting risk through primary health care. For treatment, this means improving access to high-quality, culturally safe tertiary cancer services.

Access to high-quality culturally safe health care is particularly challenging for cancer care given the complexity of cancer as a disease that requires a range of medical specialists, sub-specialists, and allied health professionals to work together as teams to achieve the best patient outcomes. Access to specific treatments such as radiation therapy is also especially challenging for anyone who lives in an Aboriginal and Torres Strait Islander Community poorly served by transportation.

Current inadequacies at the systems-level contribute to inequitable cancer outcomes including high rates of late diagnosis, higher rates of ill-defined and unknown primary sites (due to late diagnosis), lower hospitalisation rates, inequitable outcomes for people living in remote regions, and reduced survival.

Long-term strategies must be co-designed. Where successful projects across the cancer continuum previously demonstrated clear benefit, ongoing funding should automatically follow for sustained implementation and scale-up to achieve equity of outcomes.

1.4 Sustainable investment in continuity of care through Aboriginal and Torres Strait Islander community-controlled primary health care services with streamlined funding and reporting processes to reduce inequities

Objectives

- ▶ To improve mechanisms and co-designed processes at national, jurisdictional, regional and local levels for Aboriginal and Torres Strait Islander community-controlled primary health care services to meet local needs, including place-based cancer care
- ▶ To reduce overburden of activity reporting in cancer-specific funding by moving to outcomes-focused programs
- ▶ To secure sustained long-term funding for cancer programs
- ▶ To realise larger social, health and economic benefits through stable, sustained health programs.

ACCHOs play a significant role in health system design and co-design, delivery and evaluation. ACCHOs are autonomous and work to meet specific local needs. All ACCHOs operate with culture, people and Community at the centre, sharing:

- ▶ a commitment to self-determination and community-controlled governance and service provision
- ▶ integration of clinical and population health perspectives and models of care
- ▶ an Aboriginal and Torres Strait Islander workforce which delivers primary health care

- ▶ recognition of the complex needs of their Community including accurate appreciation of local social and cultural determinants of health
- ▶ provision of an environment where Aboriginal and Torres Strait Islander peoples feel welcomed, understood and culturally safe
- ▶ a partnership approach with mainstream secondary and tertiary health systems.

Because Aboriginal and Torres Strait Islander community-controlled primary health care combines clinical and population health perspectives with genuine Community leadership (see Focus Area 1.5), these settings are especially primed for resources to deliver effective communication and coordination. Successful community-led projects have a powerful and positive influence on Aboriginal and Torres Strait Islander peoples. The evidence is clear that ACCHOs play a pivotal role in driving holistic, comprehensive and culturally safe approaches to cancer prevention and care through:

- ▶ supporting prevention through primary health care, health and wellbeing activities including vaccination against oncogenic viruses and tackling the underlying social and environmental conditions that increase cancer risk
- ▶ delivering screening and targeted initiatives that increase the uptake of screening
- ▶ providing cancer support at all stages of the cancer journey at individual, family and Community levels
- ▶ supporting access to ongoing patient-led 'shared care' models between tertiary cancer services and community-based primary health care
- ▶ enabling local champions and sharing lived experiences with the broader Community
- ▶ early referral to culturally safe palliative care services.

Overburden of activity reporting to funding bodies must be addressed to allow the Aboriginal and Torres Strait Islander community-controlled health sector to focus on outcomes while maintaining accountability. Minimisation and streamlining of reporting requirements will also deliver greater efficiency.

Sustained funding is essential for the ACCHO sector to employ a workforce and deliver cancer programs and services that are based on Community needs and priorities. When sufficiently funded, services promoting continuity of care also offer stable career opportunities for Aboriginal and Torres Strait Islander Health Workers and Aboriginal and Torres Strait Islander Health Practitioners located in their Communities. This employment stability provides even greater economic return on investment for governments.

1.5

Aboriginal and Torres Strait Islander peoples are advocates in their health journey

Objectives

- ▶ To enable Aboriginal and Torres Strait Islander peoples with lived experience to be leaders in planning, development and CQI processes across the cancer continuum
- ▶ To enable Aboriginal and Torres Strait Islander Communities to be advocates and leaders in determining patient-led models of care
- ▶ To fulfill the seven rights of the *Australian Charter of Healthcare Rights* in every cancer journey.

Aboriginal and Torres Strait Islander leadership has been recognised as pivotal to successful co-design, implementation and impact of health programs. This also holds true for this **Aboriginal and Torres Strait Islander Cancer Plan**.

Developing Community self-determination and enhancing health literacy and engagement will allow Community members to be advocates in their own health journey. A steady increase in advocacy and acknowledgement by health service providers of the power of lived experience of Aboriginal and Torres Strait Islander peoples will tailor health services towards the needs of both individuals and Communities.

Mainstream health services need to acknowledge that Aboriginal and Torres Strait Islander peoples are the most effective advocates for their own health journey. This includes a deep and enduring change to fulfill the seven rights of the *Australian Charter of Healthcare Rights* for every cancer journey for every Aboriginal and Torres Strait Islander person navigating the health system.

Cancer prevention

2.1 'Whole-of-community', culturally informed, place-based health promotion to change the cancer narrative, raise awareness and create supports for the Community

Objectives

- ▶ To embed population health approaches to cancer prevention in Aboriginal and Torres Strait Islander Communities that are tailored to local needs
- ▶ To enhance health literacy through targeted health promotion activities co-designed with Aboriginal and Torres Strait Islander peoples to promote healthy behaviours across the life course
- ▶ To support community-led, holistic health promotion activities that are strengths-based, support positive behaviour change and respond to local cultural needs.

Cancer prevention includes primordial, primary, secondary and tertiary prevention (see glossary) to prevent or reduce the burden of disease.

Cancer prevention encompasses promoting healthy behaviours amongst the Community and across the life course. As described in the *NACCHO/RACGP National guide to a preventive health assessment for Aboriginal and Torres Strait Islander peoples*,¹⁹ reducing risk factors for cancer starts at pre-conception and carries through until late adulthood. Examples include:

- ▶ never starting or quitting smoking and vaping
- ▶ alcohol consumption in line with national health guidelines
- ▶ vaccinations
- ▶ preventing over-exposure to ultraviolet radiation
- ▶ maintaining a healthy weight
- ▶ adopting and maintaining a healthy diet, and consistent physical activity.

Place-based planning, clinical needs and population health are integrated to complement and amplify each other through the ACCHO sector. Community-led health promotion benefits the Community, as well as individuals and families within it. A population-based approach can maximise local leadership, targets determinants of health, consider family-centred and group strategies, and utilises local cancer data (see focus area 1.4) to achieve the best outcomes for Community.

2.2 Environmental and individual factors increasing cancer risk are widely known and addressed

Objectives

- ▶ To ensure healthcare teams have adequate resources to conduct holistic health assessments to discuss cancer risk factors and increase primary prevention
- ▶ To create healthy environments for Aboriginal and Torres Strait Islander Communities to facilitate individual behaviour change.

There is a broad range of individual strategies for primary prevention of cancer. Individual behaviours that reduce cancer risk include:

- ▶ alcohol consumption within national recommendations
- ▶ dietary choices
- ▶ physical activity
- ▶ smoking cessation
- ▶ being sun safe
- ▶ safe sexual health practices.

Making healthy choices the easiest choices will maximise the impact of primary prevention. Healthy foods must be readily available and affordable in local stores, walking must be considered a safe and beneficial activity, and Communities must be supported to achieve and maintain low risk levels of alcohol intake.

Limited access to and cost of nutritious food, particularly in rural and remote regions, makes it difficult for people to make healthy food choices. Advocacy is needed to improve access to and reduce the cost of healthy foods. Until these foods are available and affordable, people will have no choice but to continue purchasing unhealthy food. Healthy weight optimises outcomes for cancer and many other diseases. It is also vital that anti-tobacco campaigns expand to address e-cigarettes (also known as 'vapes') marketed to Aboriginal and Torres Strait Islander youth. Vapes contain chemicals and toxins, including those known to cause cancer.



Current prevention initiatives intended to achieve these outcomes are not working, as evidenced by higher rates of many preventable cancers (lung, liver, head and neck) for Aboriginal and Torres Strait Islander peoples.

Efforts focused on improving strengths-based approaches would be more effective. For Aboriginal and Torres Strait Islander peoples, their sense of identity and autonomy reclaim control over nicotine addiction.²⁰

Examples of how increasing vaccination rates can prevent cancer include:

- ▶ Human papillomavirus (HPV) vaccines can prevent HPV infection and progression to cervical cancer
- ▶ Hepatitis C vaccines can prevent Hepatitis C infection and reduce liver cancer risk.

Aboriginal and Torres Strait Islander peoples must be informed of and have access to vaccine programs, such as the HPV vaccination catch-up program for Aboriginal and Torres Strait Islander peoples up to and 25 to have a free HPV vaccination from their GP or immunisation provider.

Annual health checks that are person centred and culturally informed contribute towards positive health outcomes for Aboriginal and Torres Strait Islander peoples. For annual health checks to include cancer risk assessment, healthcare teams must have adequate time and funding to conduct these assessments and support agency and action by individuals and families.

Healthy environments are a prerequisite for health and wellbeing. Continuing to inform and update Communities on cancer-causing environmental risk factors must be tailored and culturally appropriate to share knowledge of risks associated with exposure to environmental substances (e.g., UV light, tobacco smoke, other carcinogens) and how to prevent and/or limit exposure. Environmental health influences all Aboriginal and Torres Strait Islander peoples and Communities – it is the responsibility of all governments and funding organisations to ensure there are resources available to support adequate environmental infrastructure and reduce modifiable environmental risk factors.

A 'one size fits all' approach to primary prevention will not be effective. Activities and programs focused on prevention must be place-based, culturally appropriate, consider intersectionality needs and tailored to meet the needs of each Community. New approaches must be co-designed with Communities.

Timely cancer screening and early diagnosis

3.1 High participation rates in cancer screening programs

Objectives

- ▶ To increase cancer screening through Aboriginal and Torres Strait Islander leadership in planning, delivery and evaluation of screening programs, including application of CQI frameworks
- ▶ To utilise place-based, data-informed partnerships between health services and screening programs to maximise screening participation
- ▶ To ensure informed participation in cancer screening by Aboriginal and Torres Strait Islander peoples
- ▶ To ensure equity in participation by Aboriginal and Torres Strait Islander peoples who live in remote Communities by effectively addressing their geographic and logistical barriers.

There are currently three national population-based screening programs:

- ▶ National Bowel Cancer Screening Program (NBCSP)
- ▶ National Cervical Screening Program (NCSP)
- ▶ BreastScreen Australia Program.

While improved data identification, collection and reporting is required, there is evidence the participation rate of Aboriginal and Torres Strait Islander peoples in each program is less than non-Indigenous populations. In the NBCSP, there is also evidence that there are lower diagnostic assessment follow-up rates and longer median times between a positive screen and diagnostic assessment for Aboriginal and Torres Strait Islander peoples.

Aboriginal and Torres Strait Islander peoples must have access to culturally safe and effective cancer screening programs and be supported to make informed decisions about screening. To help increase peoples' knowledge of participating in cancer screening, it is important that the purpose and benefits of cancer screening are communicated in a way that is culturally appropriate. It is also important that barriers to screening such as stigma and fear are addressed.

Different knowledge translation strategies to raise awareness about how cancer screening works include:

- ▶ yarning circles
- ▶ health and screening apps
- ▶ ambassadors
- ▶ health promotion activities
- ▶ testimonies from those with lived experience and Community champions.

These strategies also ensure that people gain awareness of the need to present promptly to primary health care if symptoms ever develop.

Equitable participation in screening programs assumes a level of health literacy and access to services. The steps and familiarity with the health system required to move from screening to follow-up investigations and treatment present barriers to equitable participation for Aboriginal and Torres Strait Islander peoples. Adding to these barriers, cancer screening is currently segmented whereby individual screening activities occur across separate screening programs. Such programs are not always coordinated in conjunction with local primary health care services leading to confusion and missed opportunities for effective Community engagement.

To further minimise barriers to screening, screening should be offered to Aboriginal and Torres Strait Islander peoples holistically, with screening programs offered where possible in one session in a culturally safe environment. In line with cultural beliefs about men's and women's health business, these sessions will, at times, need to be divided into single sex activities or groups that address intersectional needs of various priority groups. These sessions must be led by trusted, skilled health professionals of the same sex and Aboriginal and Torres Strait Islander Practitioners. This approach has been piloted by a small number of ACCHOs achieving increased participation in screening.

Some cancer screening (such as HPV testing) can be performed in any primary care location; however, other forms of cancer screening such as mammographic screening cannot. As a result, participation in some cancer screening in remote areas is especially difficult due to logistics, specialised equipment and staff capacity.

Proven cancer screening technology may require dedicated services such as mobile mammographic screening vans to visit Communities. In these circumstances, the greatest opportunities to maximise participation in cancer screening of eligible Aboriginal and Torres Strait Islander peoples will come from active local partnerships and service agreements with screening programs led by the local community-controlled organisations.

For remote and very remote Communities, where breast screening vans are not able to access non-bitumen roads, further coordination and funding are required to enable women who are eligible to participate in cancer screening to do so. Remote and very remote areas should have access to screening infrastructure and Aboriginal and Torres Strait Islander staff trained to support culturally safe engagement with Community members to support informed screening participation. In circumstances where screening infrastructure is not available, it is important that Patient Assistance Travel Schemes include cancer screening in their programs, including support for family and accompanying Community members to (see section 4.1).

Structural changes to increase screening participation and improve follow-up diagnostic interventions are required. The National Cancer Screening Register (NCSR) must be improved so it is fit for purpose, readily accessible from every electronic Patient Information Management System and able to generate data that can be accessed and used by local Communities to promote engagement and inform service based CQI activities.

Significant gains will be achieved by continuing to include specific cancer screening components in the Annual 715 Health Check. It is essential to ensure that healthcare teams are supported with adequate time, resourcing and funding to reach everyone who will benefit from screening programs through Annual 715 Health Checks or other strategies. Current cost-effective cancer screening recommendations are contained in the RACGP NACCHO Preventive Health Guidelines. Confidentiality and cultural safety of health care services will also create opportunities to address intersectionality and any barriers to participation by the Aboriginal and Torres Strait Islander LGBTQIA+ Community.

National cancer screening programs must also consider the age eligibility criteria for Aboriginal and Torres Strait Islander peoples. Given the increased burden of disease, along with higher rates of smoking, different eligibility criteria for screening, including at younger ages, may be warranted.

3.2

Emerging cancer screening technologies are universally accessible once proven

Objectives

- ▶ To ensure equitable access to emerging screening technologies and different screening approaches once proven and endorsed for national scale-up.

Any new screening technologies or different screening approaches endorsed as effective for national scale up need to ensure that:

- ▶ eligibility criteria for the Aboriginal and Torres Strait Islander peoples meet the needs of each Community
- ▶ screening is available in culturally safe settings
- ▶ Aboriginal and Torres Strait Islander leadership is secured at every step.

Active monitoring of new and emerging technologies that could potentially improve the early detection of other cancer types not included in the current national population-based screening programs (see 3.1) is critical, particularly for cancers difficult to diagnosis and/or present late in the course of the disease, such as ovarian cancer.

Aboriginal and Torres Strait Islander peoples need to be fully aware of the benefits and harms for informed decision making and have sovereignty over their own health information. For any proposed genomic testing for example, Aboriginal and Torres Strait Islander peoples must consent for collection of their genetic information.

For success in changing cancer outcomes for Aboriginal and Torres Strait Islander peoples, genuine co-design and Aboriginal and Torres Strait Islander leadership at every stage of development and implementation of new programs must be fully resourced and dynamically in place at local, regional, jurisdictional and national levels.

The anticipated commencement in July 2025 of low-dose computed tomography (CT) scanning to reduce mortality from lung cancer must also be appropriately resourced and co-designed with Aboriginal and Torres Strait Islander leadership at every step of development and implementation to be successful and equitable.

Prompt investigation in a supportive patient-led clinical environment of any sign or symptom suspicious of cancer

Objectives

- ▶ To promote health literacy to encourage all Aboriginal and Torres Strait Islander peoples to seek health advice for early diagnosis from a health care professional
- ▶ To support health care professionals to access culturally safe training to provide advice on cancer symptoms to Aboriginal and Torres Strait Islander peoples
- ▶ To enhance access to culturally safe and timely diagnostic services whenever required
- ▶ To scale up Aboriginal and Torres Strait Islander co-designed projects and programs that are shown to be effective in improving health outcomes for Communities.

Any sign or symptom suggestive of cancer must be investigated thoroughly. For early cancer detection, it is important that Aboriginal and Torres Strait Islander peoples are supported to learn what the symptoms of cancer are, how to seek early medical care and receive investigation and prompt diagnosis. Primary care services must be culturally safe and non-judgmental whenever an Aboriginal and Torres Strait Islander person raises concerns or anxieties about signs and symptoms of possible cancer with clinicians. The importance of 'knowing your body' needs to be emphasised.

Early presentation, referral to appropriate specialist services for prompt investigation and early diagnosis will lead to better cancer staging and treatment, optimising outcomes and survival. These essential steps in the cancer journey must also occur in a culturally safe, compassionate environment with supportive, familiar staff such as cancer support officers employed in the local Aboriginal and Torres Strait Islander community-controlled primary health care service. In at least one jurisdiction, travel by Aboriginal and Torres Strait Islander peoples from a remote Community to a capital city for cancer diagnostic appointments denies travel subsidies for a family member to accompany the patient. Only treatment visits are eligible for a family member travel subsidy. This policy makes it especially difficult for Aboriginal and Torres Strait Islander peoples from remote locations to feel confident and in control of their health care.

As a result of these and other barriers, stage at diagnosis of cancer is typically far more advanced for Aboriginal and Torres Strait Islander peoples. Improving Community understanding of cancer as a diagnosis is imperative. Similarly, breaking the news of a cancer diagnosis and initiating immediate clinical care must be culturally safe and paced to meet that patient's timeframes and cultural needs. To embark on this critical stage of their cancer journey, Aboriginal and Torres Strait Islander peoples may need practical support including transportation for themselves and their family or companions as well as guidance in asserting their health care rights by dedicated cancer support officers and companions.



Improving the health system at all stages of individual cancer journeys

This **Aboriginal and Torres Strait Islander Cancer Plan** acknowledges that there can be a large disconnect between mainstream and community-controlled health services. This has a direct and negative impact on any Aboriginal and Torres Strait Islander person with cancer, and their families and Community. However, genuine relationships between mainstream and community-controlled health services can lead to positive health outcomes. For cancer treatment to be culturally appropriate and accessible to Community it must consider the context of where people live and the conditions in which people live as this impacts the cancer services that are available and needed to people with a cancer diagnosis. This requires effort, cultural sensitivity and institutional commitment.

4.1

Continuity of care based on high-trust relationships in primary care as first point of entry to the rest of the health system

Objectives

- ▶ To ensure meaningful and genuine rapport is achieved between mainstream organisations and local Communities to support individual cancer journeys
- ▶ To promote shared care models, coordination and continuity of care for individuals, families and Communities affected by cancer
- ▶ To ensure service delivery across all levels of the health system aligns with Priority Reform 3 of the National Agreement on Closing the Gap
- ▶ To enhance existing career pathways across all levels for Aboriginal and Torres Strait Islander Community members by providing sustainable funding and resources

Every Aboriginal and Torres Strait Islander person should be able to access culturally safe, high-quality primary level services close to home. These may be community-controlled, private general practice or government-run remote clinics. Best practice cancer care will incorporate a dedicated primary care provider who coordinates the cancer journey. This coordination should also apply to other individual health issues including chronic complex diseases (co-morbidities). Many useful tools to facilitate this coordination include culturally appropriate pathways, My Health Record, structured clinical handover and thoughtful, high-quality discharge summaries from tertiary cancer centres back to primary care.

Structural commitments are required to support further education of health professionals to ensure they work in organisations with an effective focus on family-centred care.

A skilled workforce in multidisciplinary teams with minimal workforce turnover will achieve greater continuity of care by building trust between Community members and health care professionals.

As mentioned in Area of Focus 1.2, the community-controlled sector has sustained professional career pathways for Aboriginal and Torres Strait Islander Health Workers and Aboriginal and Torres Strait Islander Health Practitioners. With support, funding and opportunity, many of these would develop advanced expertise in key aspects of cancer treatment and support in Communities. In environments where workforce shortages are an issue, the creation of 'cancer support officers' offers tangible pathways for Community members to progress to other health careers. With mentoring and customised job descriptions, these client-facing, cancer support officers can:

- ▶ support Community members to attend cancer screening
- ▶ accompany Community members to diagnostic testing, liaising with mainstream medical staff to arrange and confirm appointments
- ▶ accompany Community members to cancer treatments including providing transport where required
- ▶ provide ongoing supportive care between appointments, including ensuring access to medicine, food and other necessities, as well as arrange financial and psycho-oncology support
- ▶ act as an advocate for the Community member
- ▶ facilitate communications between the Community member and their surrounding network of treatment teams and health professionals.

ACCHO staff and cancer support officers play an important role in coordinating appointments for Community members, including arranging travel if cancer care and treatment is delivered outside of the Community. Governments differ in their financial support through Patient Assistance Travel Schemes (known as PATS in some jurisdictions) for Aboriginal and Torres Strait Islander peoples living in remote areas who must travel outside their Community.

Local primary health care can coordinate off-site requirements, however Community members who are required to travel for appointments will often request they are accompanied by family as this promotes a culturally safe and supportive environment when attending mainstream health services. It is important resourcing and funding is available to ACCHOs for cancer support officers and ACCHO staff to navigate transport and accommodation requirements for Community members as it is often complex and requires coordination to ensure continuity of care is provided to Community members.

Objectives

- ▶ To ensure place-based, co-designed models of care and referral pathways are implemented and evaluated for cultural safety across all levels of the mainstream health system
- ▶ To identify and eliminate racism by acknowledging, addressing, measuring, reporting, and taking immediate action to eradicate institutional racism across all levels of the mainstream health system
- ▶ To increase funding for cultural safety training developed and led by Aboriginal and Torres Strait Islander peoples as part of healthcare professional development across all mainstream health services
- ▶ To ensure continuity of care and integration of services across all levels of the health system
- ▶ To establish and permanently employ dedicated cancer support officer positions and local champions to enhance and deliver culturally safe cancer care to Aboriginal and Torres Strait Islander peoples.

The **Aboriginal and Torres Strait Islander Cancer Plan** must lead to a fundamental shift in the experiences of Aboriginal and Torres Strait Islander peoples accessing mainstream health care. This shift is the responsibility of health system leadership across government-managed health facilities and disease-specific charities and philanthropic organisations. There are an increasing number of tools and readiness scales that assist mainstream organisations to assess cultural awareness and respond with effective programs to increase cultural competence. These can be incorporated in Reconciliation Action Plans.

Addressing institutional racism is a priority of the National Aboriginal and Torres Strait Islander Health Plan 2021–2031 and the National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021–2031. Governments and community-controlled peak bodies should also continue to work towards addressing the legal, regulatory and policy barriers which affect Aboriginal and Torres Strait Islander priority groups. Addressing racism in health care institutions will address recorded incidents of racism experienced by Aboriginal and Torres Strait Islander peoples who required surgical and systemic cancer treatments. An active shift towards anti-racism will also reduce cultural burnout, stress and anxiety experienced by Aboriginal and Torres Strait Islander health staff.

An important objective for the **Aboriginal and Torres Strait Islander Cancer Plan** is to address negative and culturally unsafe experiences of individuals and Communities with the healthcare system and other institutions which influence health-seeking behaviours. Many patient-care-providing stakeholders are making efforts to incorporate and promote elements of the priority areas of the National Aboriginal and Torres Strait Islander Health Plan 2021–2031 within their organisation. Cultural awareness training is generally mandatory in patient-care-providing organisations and is commonly delivered by internal staff who identify as Aboriginal and Torres Strait Islander or an external Aboriginal and Torres Strait Islander business or consultant. This training should be prioritised and resourced by mainstream services, continuous and evaluated for impact.

The barriers to comprehensive cancer care for Aboriginal and Torres Strait Islander peoples must be addressed at all stages of the life course and across the cancer care continuum.

Some of the greatest barriers occur for patients in the mainstream hospital system. Treatment usually requires patients to receive diagnostic procedures, surgical interventions, radiotherapy and intensive oncological chemotherapy in capital cities and/or regional centres. Barriers will vary for individuals and Communities but commonly include:

- ▶ long wait times for referral services
- ▶ travel and accommodation
- ▶ lack of funded support for family members to accompany Community members requiring travel to confirm a preliminary cancer diagnosis or adverse screening outcome requiring further investigation
- ▶ experiences of racism and discrimination
- ▶ lack of clear and culturally responsive communications
- ▶ poor coordination
- ▶ culturally unsafe hospital environments
- ▶ conflicting cultural responsibilities
- ▶ lack of holistic care coordination.

Cancer care is impacted by the same structural communication issues that primary care services consistently raise to hospital and specialist services including late and poor-quality discharge summaries after complex admissions. Administrative issues such as travel arrangements and efficient use of appointment schedules need improvement. Using interpreters and Aboriginal Liaison Officers in hospitals is essential and should be resourced by state and territory governments. This **Aboriginal and Torres Strait Islander Cancer Plan** encourages development of a performance management system in hospitals that provides greater accountability on these issues. Patient experience is also central: methodological work is now underway to increase uptake of the University of Queensland Wellbeing Measurement Tool.

Achieving cultural safety requires sustained focus on improving continuity of care, integrating services, and introducing dedicated cancer support officer positions and local champions. This requires co-design of general cancer models of care (including but not limited to 'shared care' models) that:

- ▶ map out the cancer journey in the context of specific Community needs
- ▶ prioritise different treatment and care options available and cancer outcomes
- ▶ prioritise high-incidence cancers which affect Aboriginal and Torres Strait Islander peoples
- ▶ include options and resources to ensure cancer treatment is safely and effectively managed on Country, that include systems established to ensure safe removal of chemical waste.

Developing these models of care will require attention to racism and strategic focus on collaborative partnerships with diverse cancer organisations and advocacy groups, many of whom may not have had previous involvement in supporting cancer services for Aboriginal and Torres Strait Islander peoples. Tertiary referral centres will need to embark on deep, reflective journeys of change to reduce institutional racism and achieve cultural safety if Aboriginal and Torres Strait Islander peoples are to feel confident being referred to these centres.

4.3 Meaningful rapport and relationships between Community members and treating teams to achieve integration and coordination of care

Objectives

- ▶ To facilitate and strengthen organisational relationships at all levels of the health system based on co-design, openness, communication and respect
- ▶ To establish holistic respectful relationships and trust between Community members and health care professionals to ensure communication is culturally safe.

Treating teams must commit to patient-led models of care and building and integrating bridges between services through agreed protocols. Research shows that improved cancer patient experiences for Aboriginal and Torres Strait Islander peoples are linked to the individual's intrinsic strength, their coping strategies and the level of support received. Communication methods and effective patient-provider relationships are also key.

What constitutes 'best' cancer treatment can differ between patients based on cancer stage, evidence, informed patient preferences, logistics and negotiated choice. An emerging opportunity is the safe provision, through clear shared care protocols and professional teams, of cancer treatments such as chemotherapy to Aboriginal and Torres Strait Islander Community members in their local primary health care clinic.

Aboriginal and Torres Strait Islander Community members should also be early and equitable recipients of new therapeutic regimes and cancer treatment modalities. For Community members already experiencing the symptoms of cancer and the side effects of treatment, long-distance travel can be financially, physically and emotionally draining (see Area of Focus 1.3).

4.4 Holistic approach to navigating cancer services and wrap around care

Objectives

- ▶ To expand mechanisms for sustained funding to establish and maintain wrap around services for Aboriginal and Torres Strait Islander Community members and their families
- ▶ To ensure co-designed, culturally safe communication materials are available everywhere to support Community members' understanding of the cancer journey
- ▶ To resolve barriers, including financial costs, available services and infrastructure within local Communities in sustainable and effective ways.

Navigation of cancer services requires significant resources. Stakeholders and ACCHOs have experienced positive outcomes when dedicated positions are funded to give people a single point of contact to support them to understand their care pathway, answer questions and regularly check in. A broad, open focus will consider the impact of cancer on the patient's family members and the broader Community.

Wrap around care means that the individual's needs are met promptly, compassionately and without judgment. An individual's needs may vary across the life course, and this should be considered when planning wrap around services tailored towards the individual and their family. Needs might be material, such as transport; psychological such as mental health services; or social such as a need for legal services. ACCHOs are best placed to provide this support. This is especially critical for those with chronic health issues such as lung or heart disease that can further complicate cancer treatment.

Time must be afforded to partnership building, knowledge exchange, building trust, demonstrating respect and involving stakeholders as early as possible in shaping services. In some regions, integrated care has been achieved through leadership and co-design. Integrated care should be accessible to every Aboriginal and Torres Strait Islander person with cancer. Local agreements must be structured in a way that allows Aboriginal and Torres Strait Islander peoples to agree to the agenda for discussions that lead to any decisions.

4.5

Support for individuals, their carers and treating teams in their Communities, including peer support and psycho-oncology

Objectives

- ▶ To ensure Aboriginal and Torres Strait Islander peoples with lived experience are at the centre of determining policy, program and service design, implementation and evaluation of social and wellbeing services
- ▶ To secure sustained funding for cancer support groups to be designed and led by Aboriginal and Torres Strait Islander peoples
- ▶ To develop models of care to ensure staff working in cancer-related roles have access to culturally safe peer support services.

There is an immediate need for post-treatment to be prioritised as part of the cancer experience even though it is considered “after cancer”. Much of the cancer journey is focused on prevention and treatment with less attention given to the impacts of cancer once a person has completed treatment and is “in remission” or “cured”. Aboriginal and Torres Strait Islander patients can feel abandoned by tertiary services once their cancer has been successfully treated.

Family and peer support is a crucial component in the cancer journey both for those with cancer, their families and Communities. In particular, peer support groups are effective in supporting Aboriginal and Torres Strait Islander peoples to continue to process their experience where they live. While family is important at this time, they typically cannot offer the therapeutic support or insight required. As in mainstream settings, accessible peer support makes a difference to the experience of the cancer journey for individuals, families and Communities impacted by cancer. Aboriginal and Torres Strait Islander peoples should also have access to experienced, compassionate peers at all stages of the cancer journey regardless of their age, sexuality and gender, or location. Support groups are culturally acceptable and need to be funded, resourced and supported through CQI and other approaches.

As culturally safe cancer treatment becomes more accessible, ‘survivorship’ (see glossary) is a term which will have increasing relevance in Aboriginal and Torres Strait Islander Communities. Lived experience is important and opportunities to connect with others in a support group should expand.

Working in cancer-related roles can be mentally and emotionally demanding for health professionals, particularly in tight-knit Communities and/or remote areas. As well as having team-based roles where possible, it is critical that workers have access to appropriate peer support to share ideas, receive mental health support and prevent burnout. Creating a safe space where staff feel supported and comfortable is important for the health and wellbeing of the cancer workforce.

4.6

Palliative care

Objectives

- ▶ To ensure palliative care is available whenever and wherever needed on Country and coordinated with primary health care
- ▶ To enable Aboriginal and Torres Strait Islander peoples to die with dignity on the Country of their choosing through co-designed, place-based palliation services.

Palliative care is more than ‘end-of-life’ care. Many may perceive that ‘palliative care’ is exclusively for those facing death and this shapes how palliative care services are received. Resourcing for palliative care services have traditionally been limited for Aboriginal and Torres Strait Islander peoples and are rarely co-designed to ensure cultural safety. This **Aboriginal and Torres Strait Islander Cancer Plan** acknowledges this viewpoint will not change unless there is significant new investment in skilled, community-based palliative care whenever needed.

Early palliative referral and support will improve quality of life and pain management. Demand has been increasing for culturally safe and co-designed palliative care in Community with dedicated coordinators and in-service learning opportunities for general health care staff. To be provided through the Aboriginal and Torres Strait Islander community-controlled primary health care sector, palliative care requires an investment in education, training, and adequate workforce levels to provide culturally safe care in the patient’s location of choice.

End-of-life-care and dying with dignity are basic human rights. Being unable to die on Country can be distressing for the patient, their family, their Community and health service staff. End-of-life-care should encompass advanced care planning, care coordination, active treatment, symptom management, psychosocial, cultural and spiritual care, and bereavement support. Practical support in preparing Advance Care Directives according to relevant state or territory legislation, personal wills and witnessed powers of attorney have also been identified as unmet needs.

Strategies and programs are needed to ensure access to culturally safe and culturally specific end-of-life care. Strategies and programs should include:

- ▶ support for dying on Country across urban, regional, rural and remote locations
- ▶ activities to enhance the capacity of ACCHOs to deliver palliative care services
- ▶ building a culturally safe end-of-life workforce
- ▶ embedding cultural values in national palliative care education and training for healthcare workers and professionals.

Culturally informed evidence base

5.1 Indigenous Data Sovereignty and timely data sharing across sectors

Objectives

- ▶ To improve Indigenous Data Sovereignty so that Aboriginal and Torres Strait Islander health data – including cancer data – are used for shared decision-making, co-design and local leadership
- ▶ To strengthen stakeholder engagement and adoption by mainstream health systems and data custodians of the five agreed principles for Indigenous Data Sovereignty.

All five principles of the *Maiam nayri Wingara Indigenous Data Sovereignty Collective*¹⁷ must be actioned:

- ▶ Aboriginal and Torres Strait Islander peoples exercise control of the data ecosystem
- ▶ data are contextual and disaggregated
- ▶ data are relevant and empowers sustainable self-determination and effective self-governance
- ▶ data structures are accountable to Aboriginal and Torres Strait Islander peoples
- ▶ data are protective and respects Aboriginal and Torres Strait Islander individual and collective interests.

Regional planning, evaluation of models of care and service enhancements all require contemporary data are accessible to all decision-makers, led by local Aboriginal and Torres Strait Islander Communities. There is a need to work with government and cancer registries to obtain more complete disaggregation of available data and improve data collection, analysis and sharing to support shared decision-making and timely action.

Cancer data can be effectively used to positively influence change, monitor progress and build rather than diminish Aboriginal and Torres Strait Islander peoples' self-determination. Data is needed to help build Community understanding of cancer survival, life expectancy, morbidity, quality of life and the impact of health behaviours, such as smoking and screening rates. It is also critical to ensure access to health system performance indicators such as wait times and discharge without completing treatment.

Australia's health data assets are currently fragmented, siloed and under-utilised, including the NCSR. Data sharing between primary healthcare and other sectors will ensure an integrated approach to cancer diagnosis, treatment and support. Delivery of the **Aboriginal and Torres Strait Islander Cancer Plan** will require structural reforms. Such reforms will include

governance oversight in each institution to enable safe, and nationally consistent cancer data collection and data sharing practices. They will also include simplified pathways to share data across cancer registries, Commonwealth held collections and beyond, with appropriate privacy and protections in place to secure Indigenous data sovereignty.

Having accurate records of Aboriginal and Torres Strait Islander peoples in Australia accessing healthcare, can help to ensure greater understanding of the healthcare issues faced by Aboriginal and Torres Strait Islander peoples and their unmet health needs. Inequities can be monitored and accountability identified. This is an agreed obligation under Priority Reform 4 of the National Agreement on Closing the Gap.

Indigenous identification is a significant risk for Aboriginal and Torres Strait Islander peoples unless Indigenous data sovereignty is in place.

5.2 Indigenous research and evaluation methods

Objectives

- ▶ To ensure cancer research and evaluation focuses on priorities identified and led by Aboriginal and Torres Strait Islander Communities
- ▶ To increase the number of Aboriginal and Torres Strait Islander academic scholars and their access to research infrastructure.

Achievement of equity in cancer outcomes for Aboriginal and Torres Strait Islander peoples requires incorporating Aboriginal and Torres Strait Islander led research and research methodologies. An agreed national cancer research agenda developed in conjunction with Aboriginal and Torres Strait Islander Communities, their community-controlled health services and peak bodies will set a path for research agencies to invest in Aboriginal and Torres Strait Islander scholars and prioritise cancer research valued by those who most stand to benefit. Sustainable funding is needed to ensure research conducted by Aboriginal and Torres Strait Islander scholars contributes to the implementation of findings into policies and programs that benefit Aboriginal and Torres Strait Islander Communities and lead to improved health outcomes.

Research needs to benefit Aboriginal and Torres Strait Islander peoples and should be informed by Indigenist frameworks (see glossary). Community-controlled and other independent Aboriginal and Torres Strait Islander Human Research Ethics Committees (HRECs) accredited by the National Health and Medical Research Council (NHMRC) are best placed to scrutinise research proposals and ensure scientific advances outweigh risks to individual Aboriginal and Torres Strait Islander participants as well as Aboriginal and Torres Strait Islander Communities as collectives. These independent HRECs should review conventional Western research proposals as well as Indigenist approaches which privilege Aboriginal and Torres Strait Islander peoples' ways of being, knowing and doing in generating evidence with the intent to improve cancer outcomes.

5.3 Sharing stories of lived experience

Objectives

- ▶ To acknowledge, share and respect Aboriginal and Torres Strait Islander peoples' cancer journeys and celebrate positive experiences to change the cancer narrative and remove the stigma and fear associated with cancer
- ▶ To listen to and incorporate views and feedback of Aboriginal and Torres Strait Islander peoples affected by cancer and the workforce who manage these issues every day.

Monitoring success in cancer outcomes requires more than quantitative data. A complete picture of cancer in any context must combine quantitative and qualitative insights, acknowledging the vital importance of shared stories and lived experience. This includes asking and listening to the perspectives and knowledge of the Aboriginal and Torres Strait Islander workforce who support Aboriginal and Torres Strait Islander peoples on their cancer journeys. Therapeutic yarning circles led by Aboriginal and Torres Strait Islander peoples with lived experience should be supported.

5.4 Information systems strengthened, including Patient Information Management Systems, and users supported to access data to identify Community needs

Objectives

- ▶ To support organisations to apply CQI frameworks in evaluating information management system software in order to identify data gaps
- ▶ To ensure ACCHOs receive adequate training and resources to effectively utilise Patient Information Management Systems.

CQI can be applied to population-based programs as well as clinical services to measure, plan, respond and review results. Electronic medical records have untapped potential for local data and capacity for ACCHOs to identify and respond to Community needs. Through national leadership at NACCHO, ACCHOs are building capacity and experience in using their electronic medical records for data-informed service improvement, place-based prioritisation and advocacy.

5.5 Safe and relevant cancer clinical trials with high participation rates of Aboriginal and Torres Strait Islander peoples

Objectives

- ▶ To increase engagement of Aboriginal and Torres Strait Islander peoples in co-designed cancer clinical trials.

In 2022, the Australian Commission on Safety and Quality in Health Care (ACSQHC) released *The National Clinical Trials Governance Framework and user guide for health service organisations conducting clinical trials*.²¹ This Framework emphasises how health service organisations should co-design, implement and evaluate clinical trials to meet priorities for Aboriginal and Torres Strait Islander peoples. Currently, Aboriginal and Torres Strait Islander patients have reduced opportunities to participate in cancer clinical trials for wide-ranging reasons including their place of residence, the distribution of cancer types and contraindications to trial recruitment. Researchers' perceptions of eligibility also contribute. Changes to Indigenous data sovereignty and research prioritisation are necessary to promote culturally safe participation in cancer clinical trials that answer clinical questions valued by Aboriginal and Torres Strait Islander Communities.

Implementation and next steps

Synergies between this Aboriginal and Torres Strait Islander Cancer Plan and other national approaches to cancer, need to be pre-negotiated and co-designed throughout implementation and evaluation to achieve better outcomes at faster pace.

NACCHO recommends implementation oversight at each jurisdictional level with structural reform clearly identifying governance and accountability. High level outcomes must be measured including equity in cancer outcomes across the whole cancer pathway such as cancer incidence; participation by Aboriginal and Torres Strait Islander peoples in cancer screening; time to diagnosis and treatment outcomes.

Mainstream institutions should advance their capacity to measure cultural safety, institutional racism and discrimination. This can be undertaken immediately as part of accreditation through the ACSQHC. The number of Aboriginal and Torres Strait Islander health professionals permanently employed in the cancer sector must increase and there must be improved access for their Communities. There needs to be a level of accountability within these objectives in terms of outcomes. NACCHO will hold all stakeholders to account. Data monitoring, coordination and measurable impact all require strengthened processes delivering 'data for governance' and 'governance of data'.

The **Aboriginal and Torres Strait Islander Cancer Plan** adopts a systems approach, acknowledging the links, power-sharing, and partnerships necessary to achieve health outcomes. It focuses more on systems change and service innovation rather than research detached from decision-making. This **Aboriginal and Torres Strait Islander Cancer Plan** also affirms the importance of identifying and celebrating early accomplishments and strengths in the sector that demonstrate 'best practice' for all health systems and organisations.

To support operationalisation of the **Aboriginal and Torres Strait Islander Cancer Plan**, NACCHO will work with each state and territory. Approaches will be co-designed in partnership between governments and jurisdictional community-controlled peak bodies with national support from NACCHO and key stakeholders.

Ongoing evaluation is recommended to audit the quality of new approaches co-designed through these new structures at all levels of partnerships and service enhancement. This should include the necessary leadership of the Aboriginal and Torres Strait Islander community-controlled health sector and its partners.

Developing strategic outcomes

Positive and sustained changes envisaged in this **Aboriginal and Torres Strait Islander Cancer Plan** must affect both individuals and the Community in which they live. Too much focus on individuals will compromise a 'whole-of-community' approach which characterises holistic comprehensive primary health care that benefits Aboriginal and Torres Strait Islander peoples and acts as the foundation of an effective, efficient health care system.

Conclusion

To close the gap, there is an urgent need for improvements in cancer outcomes for Aboriginal and Torres Strait Islander peoples. There is an opportunity to recognise, build on and scale the existing work and successes of the ACCHO sector to achieve such change.

This **Aboriginal and Torres Strait Islander Cancer Plan** presents a series of objectives and anticipated outcomes without prescribing how place-based strategies must be co-designed. Effective and sustained partnerships at all levels of the health system have been emphasised throughout.

This **Aboriginal and Torres Strait Islander Cancer Plan** lays the foundation for implementation planning through

co-design with the community-controlled sector and invites mainstream organisations to reform themselves.

Strategically, this **Aboriginal and Torres Strait Islander Cancer Plan** re-focuses attention on significant place-based initiatives to improve cancer outcomes. It presents a systematic and structured approach to the prevention, treatment and care of cancer for individuals, families and Communities.

Commitment accompanied by significant resource allocations and transparency is key.

Specific strategies and investment into supporting cultural safety and cultural competency across the health workforce is critical. A health workforce that can appropriately and respectfully support the cultural needs of Aboriginal and Torres Strait Islander peoples must be enabled to ensure access to optimal cancer care.

This Aboriginal and Torres Strait Islander Cancer Plan lays the foundation for implementation planning through co-design with the community-controlled sector and invites mainstream organisations to reform themselves.

Glossary

Organisations

Aboriginal and Torres Strait Islander community-controlled health organisations (ACCHOs)

Primary health care services initiated and operated by its local Aboriginal Community to deliver holistic, comprehensive, and culturally appropriate health care to the Community which controls it. Each ACCHO must have a locally elected Board of Directors.

Affiliates

Community-controlled peak bodies at state and territory level, playing a key role in supporting their member ACCHOs through the provision of support and practical advice in the areas of organisational governance and services, CQI, accreditation, program implementation and work health and safety. Affiliates lead jurisdictional cooperation between the ACCHOs, government and the public health sector, working to improve the responsiveness, quality and access to culturally appropriate public health services. Each provides input on a wide range of health and social policies as each is informed by their grass-roots connectivity to Community through the ACCHOs.

NACCHO

The national peak body representing 145 Aboriginal Community Controlled Health Organisations (ACCHOs) and assisting a number of other community-controlled organisations serving their Communities in diverse ways. NACCHO liaises with its thriving membership body to lead Aboriginal and Torres Strait Islander health and wellbeing policy and planning issues. NACCHO is assisted in its leadership of the sector by the eight Affiliate organisations across all States and Territories of Australia (see Affiliates).

Key concepts

Aboriginal and Torres Strait Islander Health

Is not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life.

Cancer support officers

Help Aboriginal and Torres Strait Islander peoples navigate and liaise with cancer services across all aspects of cancer care. They accompany Community members to cancer screening, diagnostic and treatment appointments and liaise with medical staff as required. They also provide ongoing supportive care between appointments, including facilitating access to medicines, food and other necessities, as well as arrange financial and psychological support. Cancer support officers also act as an advocate for the Community member, if appropriate, including attending and contributing to family meetings and case conferences and facilitate communications between the Community member, the community-controlled organisation, mainstream treating teams and families.

Key concepts

Co-design	Requires a sequence of deliberate steps to be negotiated and agreed before embarking on further actions. In all circumstances, a framework for meaningful engagement is recommended as a first step to define the foundations of an effective working relationship between Aboriginal and Torres Strait Islander peoples, their community-controlled organisations and non-Indigenous or mainstream institutions. Co-design requires shifting power and the development of reciprocal relationships. Powerful co-design will embrace activities to 'co-produce' and 'co-decide'. Much more transparency and self-disclosure is required as a foundation for co-design than in usual government, non-government mainstream or academic partnerships. Examples can be found in the annual Partnership Health Checks undertaken by the Joint Council as part of the National Agreement on Closing the Gap.
Cultural competence	Cultural competence usually refers to the ability of an individual health professional to establish effective relationships that overcome any cultural differences by recognising the importance of social and cultural influences on patients, considering how these factors interact, and devising interventions that take these issues into account. While a valuable first step, an approach to cultural competency that focuses on acquiring knowledge, skills and attitudes is problematic because it suggests that competency can be fully achieved through this static process. ²² Cultural competency does not have an endpoint. It rests with the health professional to improve their cultural competency. Cultural competency is not interchangeable as a term with cultural safety.
Cultural safety	Determined as an outcome only by Aboriginal and Torres Strait Islander individuals, families and Communities. Cultural safety is their experience. Culturally safe practice requires ongoing critical reflection by health practitioners but these health practitioners cannot judge cultural safety. Changing attitudes, practicing behaviours, and power imbalances in delivering safe, accessible and responsive healthcare will achieve a health system free of racism. Cultural safety requires healthcare professionals and healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, structures and characteristics that may affect the quality of care provided. Cultural safety requires healthcare professionals and their organisations to influence healthcare to reduce bias and achieve equity within the workforce and working environment.
Indigenist frameworks	Typically used in the context of research and evaluation. In the past, research led by non-Indigenous people have typically dismissed or marginalised Indigenous ways of knowing, doing and being. An Indigenist approach can also be applied to structural change and service development by privileging Aboriginal and Torres Strait Islander perspectives, building mechanisms to recalibrate the power imbalances between mainstream institutions and Aboriginal and Torres Strait Islander peoples, and facilitating reflection often and iteratively by everyone involved.
Intersectionality	A concept to understand the ways in which multiple systems of inequality affect one another at various levels of society. Elements such as race, gender, sexuality and socio-economic status interact at the individual level, resulting in unique identities and outcomes for individuals. Consideration of individual intersectional needs in a person-centred manner should be a hallmark of contemporary health care.
Person-centred care	Care tailored to the specific circumstances of a person, in the context of their family, Community, and life experiences. The 'person' calls for a more holistic approach to care that incorporates the various dimensions to whole wellbeing, including a person's context and individual expression, preferences and beliefs. It is as important to know the person with the disease as it is the disease the person has. This approach treats people with dignity and respect, and involves them in all decisions. While some nuance may be inherent in different terms such as 'person-led' or 'family-centred' care, the common intention is to avoid depersonalising care.

Key concepts

Place-based approach	Policy, program, and service approaches that recognise and respond to the characteristics of the Community in which they operate. For place-based approaches to be successful, the Community and its needs must be at the centre of development and its priorities respected. This includes planning, selecting, designing and governing physical and social infrastructure, as well as for the facilities and services themselves.
Primordial prevention	Works to reduce the environmental, economic, social and behavioural conditions that increase the risk of disease. This includes food security, housing, economic prosperity, general education and literacy.
Primary prevention	Moves towards an individual focus to limit the incidence of disease and disability. It does so by eliminating or reducing the risk factors for poor health and promoting health protective factors. Examples of primary prevention include programs to discourage the uptake of smoking, encourage immunisation, and increase opportunities for healthy eating. Primary prevention targets whole populations, including healthy individuals.
Relative cancer survival rate	Defined by the AIHW as <i>'a measure of the average survival experience of a population of people diagnosed with cancer, relative to the 'average' Australian of the same sex and age, at a specified interval after diagnosis (usually 5 or 10 years).'</i> ⁴
Secondary prevention	Aims to prevent the progression of disease through early detection and/or intervention. Secondary prevention is the foundation for most cancer screening programs identifying individuals with pre-cancerous conditions or cancer at very early stages. Treatment of cancer detected through screening must be evidence-based in tertiary healthcare facilities.
Self-determination	The right of all people to freely determine their political status and freely pursue their economic, social and cultural development.
Strengths-based approach	Focuses on the unique strengths, capabilities and resources of people, places and Communities, and looks for opportunities to capitalise on, complement and support existing strengths. Strengths-based approaches work in opposition to deficit-based discourse and approaches, which focus on areas of problem or concern, and can perpetuate negative stereotyping.
Survivorship	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 peoples. Personalised spiritual care and connection to other Aboriginal and Torres Strait Islander cancer survivors are also key components to survivorship programs.
Tertiary prevention	Aims to reduce the consequences of established disease. This means a diagnosis has been made and disease-treatment plans are explained, negotiated and organised. Cancer care in tertiary centres aims for cure or control using complex multimodal evidence-based treatments.

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