



SA ABORIGINAL  
CHRONIC DISEASE  
CONSORTIUM

# South Australian Aboriginal Cancer Plan

2022 – 2027

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*The South Australian Health and Medical Research Institute acknowledges, that the revised South Australian Aboriginal Cancer Plan 2022-2027 has been funded and supported by the Government of South Australia through the Department for Health and Wellbeing.*

*The content is solely the responsibility of the authors and does not necessarily represent the official views of the Government of South Australia.*

South Australian Aboriginal Heart and Stroke Plan 2022-2027.

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**Produced by the SA Aboriginal Chronic Disease Consortium**



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## ACKNOWLEDGMENT OF COUNTRY

The South Australian Aboriginal Chronic Disease Consortium acknowledges and celebrates that Aboriginal and Torres Strait Islander people are the Traditional Custodians of the land, known as Australia.

We recognise that Aboriginal and Torres Strait Islander people are the First Peoples of Australia and that within these two distinct cultural groups, there is great cultural diversity.

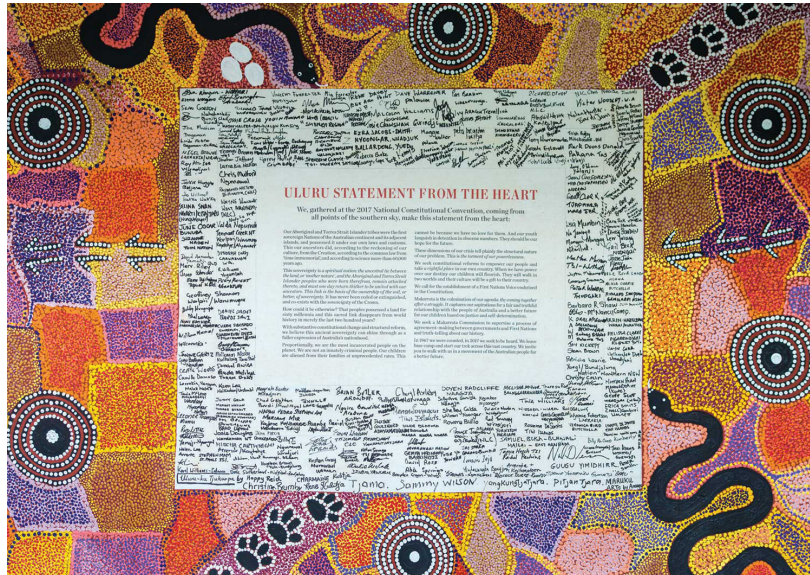
We acknowledge and pay our respects to the Aboriginal people across South Australia, Elders, past and present, their continuing connection to this land and thriving cultural practices and knowledge.

# Preface

The First People of Australia, the Aboriginal and Torres Strait Islander people, were living strong and well within what is now called South Australia. In large part, this was a consequence of maintaining strong connections to lore, Country, culture, health, family, kinship, ceremony, and spirit prior to the dispossession and dispersal of the First People of Australia. The policies that led to the active disempowerment and disenfranchisement of Aboriginal people are directly linked to the types of differential outcomes that can be seen in Aboriginal health, housing, employment and education outcomes now. It is worth noting that poor health and wellbeing also leads to a reduced economic base for Aboriginal families and communities in South Australia, and that the strength of a community's economic base is itself a determinant of health. These dynamics are important considerations for a strategic, statewide approach to cancer care in South Australia.

## The Uluru Statement From the Heart

Over 250 Aboriginal and Torres Strait Islander delegates from across Australia, gathered at the First Nations National Constitutional Convention held in Mutitjulu, located at the base of Uluru, in May 2017. The Uluru Statement from the Heart (Uluru Statement) was released by delegates of this Convention. The Uluru Statement was an invitation for all Australian people to walk with Aboriginal and Torres Strait Islander people, to create a better future for all Australians. This future can only be achieved once the effects of colonisation are acknowledged and Aboriginal and Torres Strait Islander people can share their truths, their history.



The SA Aboriginal Chronic Disease Consortium recognises the generous invitation from Aboriginal and Torres Strait Islander people through the Uluru Statement and remains supportive of the call for greater self-determination and truth telling. The path towards rightful recognition of Aboriginal and Torres Strait Islander people in Australia's history needs to be re-forged now that the referendum on constitutional recognition was unsuccessful. Regardless of this, and now more than ever, the Consortium remains committed to listening to the voices of Aboriginal and Torres Strait Islander people, and we are pleased to see the South Australian Voice to Parliament progress. The Consortium also recognises the importance of Aboriginal and Torres Strait Islander people's self-determination, which is inevitably linked with health outcomes. An improvement is seen in health outcomes when Aboriginal and Torres Strait Islander people take control of their health.

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# Acknowledgements

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## The Revised Plan

The SA Aboriginal Chronic Disease Consortium would like to acknowledge and pay respect to the traditional custodians of the area now called South Australia. We recognise the first peoples of Australia and the longest continuous living culture in the world. We recognise the injustices of the past and that Aboriginal people do not experience the same equality of rights and life expectancy as other Australians. We respect the resilience of Aboriginal people in the face of adversity.

We would like to acknowledge the South Australian Aboriginal Chronic Disease Consortium Cancer Leadership Group and other key stakeholders (see Appendix A) for their oversight and expert advice that has informed the revision of the SA Aboriginal Cancer Plan 2022-2027.

We acknowledge our funder SA Health.

## Use of the Term ‘Aboriginal’

The plan uses the term ‘Aboriginal’ to describe the people and communities, for whose benefit this plan is written, in recognition of the traditional owners of the lands now called South Australia.

The authors of the plan acknowledge the diversity of the people, families and communities, who live in South Australia, which includes people from various Aboriginal and / or Torres Strait Islander backgrounds. The impacts of colonisation and past policies, still felt by many Aboriginal and Torres Strait Islander people today, have resulted in some complexities associated with traditional ownership, country and a sense of home and belonging. The authors would like to iterate that this plan is for the benefit of all, and the choice of terminology intends to respectfully acknowledge custodianship in accordance with Aboriginal traditions and customs.

Other terms, including “Torres Strait Islander”, “Aboriginal and Torres Strait Islander”, “Indigenous”, “First Nations” etc. are used where culturally appropriate, where reference is made to Aboriginal and / or Torres Strait Islander people at a national level and where they are used in position titles and source publications.

# Background and Methodology

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The SA Aboriginal Chronic Disease Consortium (the Consortium) was established in 2017 to implement the original SA Aboriginal Cancer Control Plan 2016-2021 in conjunction with the SA Aboriginal Diabetes Strategy 2017-2021 and the SA Aboriginal Heart and Stroke Plan 2017-2021. The Consortium is a collaboration between Aboriginal communities, services, providers, organisations and system managers to reduce the impact of chronic disease experienced by Aboriginal people through delivery of coordinated, evidence-based and culturally responsive care.

The revised Plan builds on the work from the SA Aboriginal Cancer Control Plan 2016-2021.<sup>1</sup>

The SA Aboriginal Cancer Control Plan 2016-2021 was built on the work and achievements of the first plan (Aboriginal Companion Document to the Statewide Cancer Plan 2011-2015). It was developed by the South Australian Cancer Service (SACS), SA Health in partnership with the following organisations: Aboriginal Health Council of South Australia (AHCSA), Cancer Council SA and Cancer Data and Aboriginal Disparities (CanDAD) National Health and Medical Research Council (NHMRC) Partnership Project, Wardliparingga Aboriginal Health Research Unit at the South Australian Health and Medical Research Institute (SAHMRI).

The focus of the SA Aboriginal Cancer Control Plan 2016-2021 was on implementation and outcome monitoring initiatives that reduced preventable cancers, detect cancers at an early stage and improved coordination and access to culturally sensitive care pathways. It was guided by Aboriginal people with lived experience, including family members and carers, as well as a range of stakeholders that included clinicians, researchers, health service managers and other key stakeholders.

For the revision of this plan, the Consortium Coordinating Centre (CCC) identified and invited a broad range of stakeholders into the review process. These included the Aboriginal Community Controlled Health Sector, the SA Aboriginal Consortium's Cancer Leadership Group and Consortium Executive Group, the Department for Health and Wellbeing Senior Officers Group on Aboriginal Health (SOGAH) and other stakeholders, including Aboriginal health professionals with expertise in cancer care, stakeholders who were either program leads or involved in cancer programs or initiatives and representatives from metropolitan, rural and remote South Australia. Stakeholders were invited to provide feedback to the CCC through written response or verbally via a face-to-face or online meeting.

Updates and amendments have been made to actions under most priority areas and new evidence has been included where available. A dedicated section with key enablers has been developed and structured to align with the revised SA Aboriginal Heart & Stroke Plan 2022-2027 and the SA Aboriginal Diabetes Plan 2022-2027, to enable implementation of priorities, that span across the 3 plans, through collaborative partnerships, and to facilitate cross-plan monitoring and evaluation. The purpose, vision and goal remained unchanged from the original plan.

# Abbreviations

<b>ACCHO</b>	Aboriginal Community Controlled Health Organisation
<b>AHCSA</b>	Aboriginal Health Council of South Australia
<b>AHW/P</b>	Aboriginal Health Workers/Practitioner
<b>AYA</b>	Adolescents and Young Adults
<b>BCCC</b>	Bragg Comprehensive Cancer Centre
<b>CanDAD</b>	Cancer Data and Aboriginal Disparities
<b>CCC</b>	Consortium Coordinating Centre
<b>CTG</b>	Closing the Gap
<b>CQI</b>	Continuous Quality Improvement
<b>GP</b>	General Practitioners
<b>Health Check</b>	Aboriginal and Torres Strait Islander Peoples Health Check (MBS 715 or similar)
<b>Hep B</b>	Hepatitis B
<b>HPV</b>	Human Papilloma Virus
<b>ICT</b>	Information and Communications Technology
<b>LHN</b>	Local Health Network
<b>MATOD</b>	Medication Assisted Treatment for Opioid Dependence
<b>MBS</b>	Medicare Benefits Schedule
<b>NBCSP</b>	National Bowel Cancer Screening Program
<b>NHMRC</b>	National Health and Medical Research Council
<b>OCPs</b>	Optimal Care Pathways
<b>PATS</b>	Patient Assistance Transport Scheme
<b>PHC</b>	Primary Health Care
<b>PHN</b>	Primary Health Network
<b>PREM</b>	Patient Reported Experience Measures
<b>PROM</b>	Patient Reported Outcome Measures
<b>RTO</b>	Registered Training Organisation
<b>SA</b>	South Australia
<b>SACS</b>	South Australian Cancer Services
<b>SAHMRI</b>	South Australian Health and Medical Research Institute
<b>SDH</b>	Social Determinants of Health



# Executive Summary

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The South Australian Aboriginal Cancer Plan 2022-2027 (hereafter referred to as “the Cancer Plan”) has **7 priority areas** with **24 actions** and **8 enablers** that are essential for effective delivery of this Plan.

These actions set the direction for the next five years and focus on implementing models of care that reduce preventable cancers, detect cancer early and provide timely access to culturally appropriate treatment and culturally sensitive pathways. It also considers the preventative and health promotion strategies required to raise awareness of cancer in the community and dispel myths and misconceptions associated with this disease. The initiatives recommended in the Cancer Plan will aim to meet the diverse needs of age groups, communities, and location with a particular focus on accessibility for Aboriginal people living in rural and remote parts of SA.

Recognising the specific needs of children and adolescents and young adults (AYAs) affected by cancer, this plan includes a number of actions aimed at this age group. However, preliminary discussions with relevant stakeholders in the field, highlight that further work is required to fully explore the needs of Aboriginal children and AYAs and identify the appropriate systems, policy, and service responses for these age groups.

The Cancer Plan is a document that responds to the needs of Aboriginal communities. However, partnerships need to be established not only with Aboriginal organisations but with mainstream services and other non-Aboriginal organisations to ensure that the health system is responsive and accountable to meet the needs of community. To do this will require a coordinated approach across all services and care level types. This means that the system will need to work together and communicate effectively with each other if real change is to be achieved.

## Priority Areas and Actions

### Awareness and Prevention

1. Collaborate with Aboriginal Community Controlled Health Organisations (ACCHOs), Wellbeing SA, the Adelaide and Country SA Primary Health Networks (PHNs), Cancer Council SA and Cancer Australia to improve

knowledge within Aboriginal communities to act on cancer risk and symptoms through specific preventive programs.

2. Work with non-government organisations, other agencies and SA Aboriginal communities through narratives and positive stories to dispel myths and stigma around cancer, being respectful of cultural beliefs.
3. SA Health and Cancer Council SA will continue to work in partnership with ACCHOs, community organisations, Elders, and communities to decrease smoking prevalence and alcohol consumption in the Aboriginal population.
4. Pursue opportunities to collaborate on public health strategies to maximise and develop strategies that promote regular exercise, healthy weight and a diet rich in fruit and vegetables to not only decrease cancer incidence but also impact on or prevent many other chronic diseases.

### Screening and Early Detection

5. Work with the ACCHO sector, the Adelaide and Country SA PHN, the Local Health Networks (LHNs) and Cancer Council SA, to increase screening rates for people living in rural and remote areas.
6. Prioritise initiatives that facilitate collaboration between cancer screening programs in SA, drawing on learnings, experiences and resources to promote awareness of, overcome barriers to and encourage greater participation rates in cancer screening.
7. Continue to promote and implement national screening programs (e.g., National Bowel Cancer Screening Program), state screening programs (e.g., Well Women’s Program, Breast Screen SA Mobile Screening unit) and other innovative models (e.g., “One Stop Screening Shop”) that increase participation of Aboriginal men and women in cancer screening within SA.
8. Lower the age eligibility criteria for bowel cancer screening of Aboriginal people and support the ACCHO sector to implement alternative pathways.

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## Diagnosis and Staging

9. Include Aboriginal status on all screening diagnosis pathology, radiology and other requests and reports.
10. Support initiatives that enable coordinated and timely access to diagnostic services for Aboriginal people, particularly those living in remote areas.

## Treatment

11. Develop, implement and monitor utilisation of telehealth consultations for/by Aboriginal people to enable understanding of current usage and future potential whilst promoting ongoing and increased utilisation.
12. Utilise Clinical Service Capability Frameworks to guide and maximise access to safe and appropriate cancer care as close to home as possible.
13. Engage in activities and initiatives that promote greater understanding and collaboration between Aboriginal Traditional Healers and health professionals in SA.

## Care Coordination

14. Collaborate with PHNs Closing the Gap (CTG) programs to strengthen cancer coordination pathways across the cancer care continuum.
15. Identify, implement and evaluate culturally appropriate and acceptable tools and templates (including needs assessment tools) for Aboriginal people with cancer and cancer survivors to be incorporated within the SA Survivorship Framework and cancer registries.
16. Collaborate with PHNs to further promote and encourage the uptake of incentives available to GPs to provide supportive and follow-up care for Aboriginal people within the Primary health care (PHC) setting and ACCHO Sector.

17. Collaborate with PHNs to further promote culturally appropriate, community-based conversations about the care of Aboriginal people whose cancer is incurable, including conversations about the importance of identifying who would speak on the person's behalf if they were unable.
18. Increase awareness and uptake of Aboriginal people in SA with cancer having an Advance Care Directive.

## Services Outcomes Data Research

19. Support initiatives that facilitate Aboriginal health services and community services to establish and maintain Aboriginal cancer support groups or Yarning Circles across SA.
20. Develop Aboriginal Cancer Patient Reported Experience Measures (PREM) and Aboriginal Patient Reported Outcome Measures (PROM) to routinely capture the quality and outcomes of care from the perspective of Aboriginal clients to inform care delivery.
21. Develop and utilise specific Aboriginal quality indicators that are sensitive to Aboriginal client needs to monitor and evaluate care along Optimal Care Pathways (OCPs).
22. Scope opportunities for further collaborative research to understand and address specific needs of Aboriginal children, adolescents and young adults with cancer, cancer survivors and their families.
23. Continue to conduct high quality cancer research to inform evidence-based, continually improving practice.
24. Provide where appropriate, easy-to-understand cancer information that supports Aboriginal people experiencing cancer, their families and carers to be involved with cancer research.

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## Enablers

### 1. Governance: Aboriginal Leadership and Partnerships

Establish and maintain robust governance structures, led by Aboriginal professionals and organisations, equipped to foster partnerships and collaboration between the wide range of organisations and stakeholders responsible for implementing this Plan.

### 2. Sustainable Funding

Appropriate levels of funding to be available for implementation of projects and services within appropriate timeframes.

### 3. A Strong Cancer Workforce

Increase the capacity and capability of the Aboriginal and non-Aboriginal workforce to provide high quality, culturally responsive, collaborative cancer care.

### 4. Transport and Accommodation Support

Improve access to health care through transportation (ensuring Aboriginal people have safe and appropriate home-to-care-to-home journeys) and culturally appropriate accommodation options for Aboriginal people.

### 5. Information and Communications Technology (ICT) Solutions

Invest in resources, coordination and systems for telehealth and virtual care. Also improve the utilisation and communication of information across patient information management systems.

### 6. Community Engagement

Meaningful engagement of Aboriginal people, families and communities must underpin the design and implementation of projects and services associated with this Plan.

### 7. Integrated and Coordinated Services

Achieve continuity of care for Aboriginal people with cancer through culturally responsive, integrated and coordinated services.

### 8. Monitoring and Evaluation

Monitor and evaluate the implementation of the Plan and health system changes that result in better health care of Aboriginal people.

# Introduction

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Identified barriers to cancer care for Aboriginal people, span a broad range of logistical and socio-cultural issues relating to access, the health system environment, misunderstandings due to language and cultural differences and distress because of separation from family and community.

Evidence shows that existing models of care and service delivery can be improved to meet the needs of Aboriginal people, resulting in them being more likely to participate in screening programs, reduce the experience of delayed or incomplete treatment, and improve engagement with the health system.

Although this plan does not have a priority area for children and AYAs with cancer, further work will be conducted with relevant stakeholders to identify actions specific to children and AYAs with cancer.

To improve upon cancer outcomes for Aboriginal people in South Australia (SA), the original Cancer Plan was reviewed in 2022 to reflect changes in evidence, policy and practice.

## Purpose

The purpose of the Cancer Plan is to provide guidance to all SA health system players to achieve a reduction of preventable cancers, detect cancer at an early stage, improve access to timely treatment and culturally sensitive pathways and service models and address supportive care (including palliative care and survivorship) needs. It also provides direction on important enablers to achieve those improvements and cancer-related health outcomes for Aboriginal people in SA.

## Vision

To prevent cancer in Aboriginal people in SA and improve the social, emotional, and cultural wellbeing, as well as to reduce morbidity and mortality of Aboriginal people who are affected by cancer.

## Audience

The Cancer Plan has been developed for policy makers, government and non-government organisations, health care professionals and researchers who are involved in the prevention, treatment, management and monitoring of cancer.

## Time Frame

The time frame for the Cancer Plan is five years (2022-2027). At the time of writing this plan, it reflected the current health system and its structure. The authors acknowledge that during the five-years of implementation, there are likely to be changes to the health system and its structure. Therefore, the Cancer Plan will need to adapt to these changes as they occur. It is expected that at the end of each year (commencing from 2023), an annual review will be conducted to map which activities have been completed against each of the actions and priority areas and whether any adaptations to the Cancer Plan are required. This work will be conducted by the member organisations of the SA Aboriginal Chronic Disease Consortium in partnership with the CCC.

## Measuring Progress

The Cancer Plan contains a monitoring progress table that is located on pages 45-47 of this document. At the end of each implementation year, the progress made against each action will be mapped using a traffic light system approach. This work will be conducted by the CCC in partnership with member organisations of the SA Aboriginal Chronic Disease Consortium.

The monitoring and evaluation framework developed for the three chronic disease plans (2016-2021), will be reviewed by the CCC in partnership with the Aboriginal Community Reference Group, Executive Group and the Cancer Leadership Group. The aim of this review is to identify key indicators that can be used by stakeholders to measure progress against the SA Aboriginal Cancer Plan 2022-2027.

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## A snapshot of Cancer in the Aboriginal Population

### Nationally

- Cancer contributes for 15% of the gap in fatal burden.<sup>2</sup>
- Aboriginal and Torres Strait Islander people experience a higher burden of disease from cancer than that of other Australians.<sup>3</sup>
- Aboriginal and Torres Strait Islander people experience a 10-year lower life expectancy compared to other Australians.<sup>4</sup>
- Although the age-adjusted cancer incidence rate is similar for Aboriginal and Torres Strait Islander people and other Australians, Aboriginal and Torres Strait Islander people experience a 50% higher cancer mortality rate and a 70% higher cancer burden from premature mortality.<sup>4</sup>
- Aboriginal and Torres Strait Islander people are diagnosed with cancer at a younger age.<sup>5</sup>
- There is a higher incidence of cervical cancer and lung cancer for Aboriginal and Torres Strait Islander people and survival is worse compared to other Australians.<sup>6</sup>
- Aboriginal and Torres Strait Islander women have poor breast cancer outcomes than other Australian women.<sup>7</sup>
- Cervical cancer incidence for Aboriginal and Torres Strait Islander women were two times that of other Australian women (age-standardised incidence rate of 20 new cases per 100,000 women compared to 10 new cases per 100,000 women).<sup>8</sup>
- Cervical cancer mortality rate for Aboriginal and Torres Strait Islander women was more than three times that for other Australian women (age-standardised mortality rate of 8 deaths per 100,000 women, compared to 2 deaths per 100,000 women).<sup>8</sup>

## Foundations for a healthy life

The National Aboriginal and Torres Strait Islander Health Plan 2021-2031<sup>9</sup>, identifies four foundations that are key for a healthy life. These include;

### 1. Holistic health and wellbeing

‘Supporting Aboriginal and Torres Strait Islander people’s close connections and interactions with the mental, physical, cultural, environmental and spiritual health of their communities, and with society more broadly.’<sup>9</sup>

### 2. Cultural determinants of health

Protective factors that support good health and wellbeing, strengthen, identity and enhance resilience (see protective factors page 13). It has also referred to as ‘the ways of knowing, being and doing that encompass a holistic Aboriginal and Torres Strait Islander understanding of health and wellbeing.’<sup>9</sup>

### 3. Social determinants of health

To achieve health equity of Aboriginal and Torres Strait Islander people, the social determinants of health (SDH) need to be addressed. The SDH ‘are the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics.’<sup>10</sup> It contributes to the health gap (34%) between Aboriginal and Torres Strait Islander people and non-Aboriginal people.<sup>9</sup>

### 4. A life course approach

Aboriginal and Torres Strait Islander people view health and wellbeing as involving the whole community throughout the entire life course.’ This perspective places the emphasis on wellbeing and health factors that occur at particular transition points at different stages of life.<sup>9</sup>

## Risk factors contributing to the onset of cancer

There are known risk factors for developing cancer. However, there are known **protective factors** that can support good health of Aboriginal people. The Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing<sup>9</sup>, identified a series of cultural determinants that act as protective factors. In addition to supporting good health, these factors support social and emotional wellbeing, strengthen identity, and enhance resilience.

Below is a brief list of protective, modifiable, and non-modifiable risk factors.

### Protective factors

- Connection to Country
- Language
- Family, kinship and community
- Leadership
- Beliefs and knowledge
- Self-determination
- Cultural expression and continuity.

### Modifiable risk factors

Factors that can usually be controlled by lifestyle modification and/or medication. Examples are:

- Poor nutrition
- Physical inactivity
- Smoking
- Consumption of alcohol and drugs.

### Non-modifiable risk factors

Factors that cannot be controlled. Examples are:

- Biomedical factors (genetic susceptibility and hormonal factors)
- Family history
- Ethnicity

## The SA Aboriginal Cancer Plan 2022-2027

As in the previous Plan, there are **7 priority areas** with **24 actions** and **8 enablers** that need to be implemented. These actions provide a roadmap for service providers across SA on how to increase prevention, particularly for people at high risk and to improve cancer outcomes for Aboriginal people living and receiving cancer care in this state.

## Guiding Principles for the SA Aboriginal Cancer Plan

The following 14 principles should guide the implementation of the Cancer Plan.

### 1. Cultural Respect

Respecting the cultural diversity, views, values and expectations of Aboriginal people in the planning, development and implementation of health and wellbeing programs and services.

### 2. Community Control

Acknowledging Aboriginal peoples' rights to control health and wellbeing approaches and services in their local community and/or region.

### 3. Holistic Approach

Attending to the physical, spiritual, mental, cultural, emotional and social wellbeing and its role in contributing to health outcomes for Aboriginal people; including the environmental determinants of health such as food, water, housing and unemployment; including the SDH and wellbeing such as racism, marginalisation, history of dispossession and loss of land and heritage.

### 4. Local Planning

Involving Aboriginal people in planning, development and implementation of strategies for better health and wellbeing. Planning takes place at the local level to develop local responses to local needs and priorities, as determined by the local Aboriginal population/community.

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## **5. Partnerships**

Combining the efforts of government, non-government and community-controlled sectors and working in partnership with communities to provide the best method in improving the broader determinants of health.

## **6. Recognition of Diversity**

Recognising the diversity within and between Aboriginal communities in the development of programs and services; supporting the provision of differing approaches according to region, age and gender.

## **7. Zero tolerance of racism**

Individuals and health service staff must actively work to reduce racism within health services. Leaders in health care must actively work to reduce institutional racism.

## **8. Resources**

Ensuring that resources are sufficient to improve the health and wellbeing of Aboriginal people, sustainable resource building for communities through strengthening community expertise and capacity building of health services and communities.

## **9. Capacity Building**

Providing information, skills development and/or knowledge acquisition to assist and support individual change; building the capacity of a community, families or individuals to manage change and/or maintain resilience.

## **10. Recognition of Diversity**

Supporting the effective use of funds by community controlled and mainstream health services and programs; ensuring accountability for effective resource application through long term funding; establishing genuine and meaningful planning and services, development of partnerships with communities; government maintaining responsibilities for ensuring all Aboriginal people have access to appropriate and effective healthcare.

## **11. Diversity**

Recognising the diversity of Aboriginal people and the impact of this on cultural and physical accessibility of programs and services including variations in metropolitan, rural and remote needs.

## **12. Integrating Service Delivery**

Delivering services and programs that are appropriate, coordinated, flexible and avoid duplication, including: fostering opportunities for Aboriginal delivered services; maximising the effectiveness of action at the local, regional and state level through whole of Government approaches; recognising the need for services to take account of local circumstances and be informed by appropriate consultations and negotiations with local representatives; joint planning of services and programs at state, regional and local levels.

## **13. Access to a Set of Core Services**

Access to a core set of prevention, PHC and acute services to every community, delivered by a range of methods including on-site, visiting service, or requiring reasonable and supported travel.

## **14. Teamwork**

An interdisciplinary approach to PHC, which involves the employment of Aboriginal community members, and includes continuous training and support; including, where appropriate, regionally organised service delivery and outreach services to dispersed populations.

# Cultural Context

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It is understood that there is no single Australian Aboriginal or Torres Strait Islander culture or group and that there are many diverse communities, language groups and kinships throughout Australia. It is also recognised that Aboriginal and Torres Strait Islander people currently live in metropolitan, rural and remote settings, practice westernised, traditional or other lifestyles, and may frequently move between these ways of living. The strong connection to culture is important to Aboriginal and Torres Strait Islander people and should be both acknowledged and respected for each individual and their cancer story/pathway, especially the link between culture, land and cancer.

## What is Aboriginal Health?

In the National Aboriginal and Torres Strait Islander Health Plan, Aboriginal Health is defined in the following way;

'Aboriginal health means 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.'<sup>9</sup>

The Aboriginal Cancer Patient Pathway Wellbeing Model (see diagram 1) was developed by the South Australian Cancer Services (SACS) to support the Aboriginal health definition – that is Aboriginal health is holistic.<sup>10</sup> The Aboriginal person experiencing cancer is at the centre and the inner circle shows the cancer care pathway with the Supportive Care circle indicating survivorship and supportive care across the pathway. The next circle, coloured dark grey contains the enablers to an Aboriginal client with cancer's wellbeing from the system level, and the outer light grey circle lists the overarching enablers from a personal and cultural perspective.



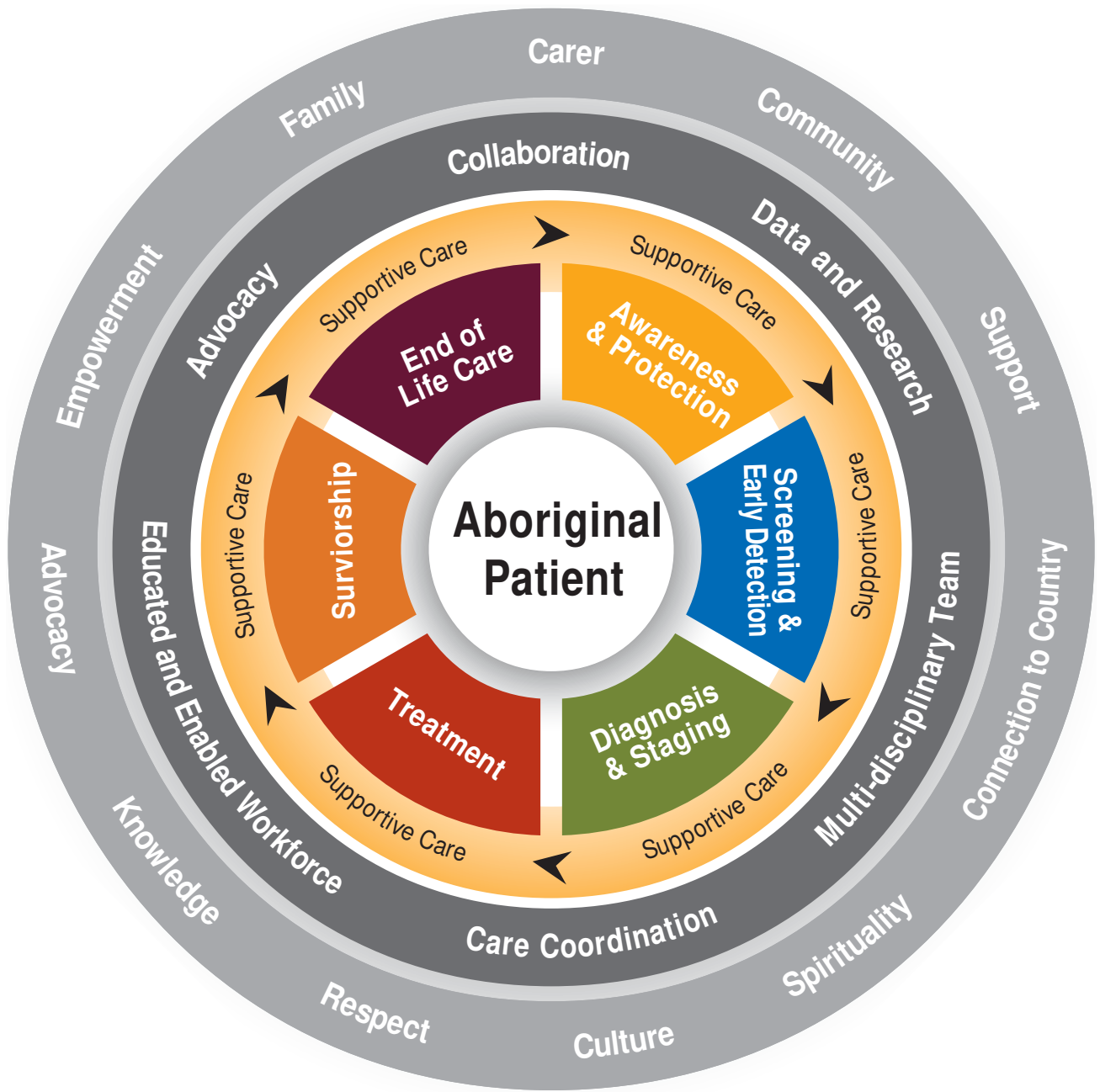


Diagram 1: Aboriginal Cancer Patient Pathway – Wellbeing Model<sup>10</sup>

## A Wellbeing Framework for Aboriginal and Torres Strait Islander People living with Chronic Disease

A study was undertaken by the Centre for Research Excellence, Intervention Research in Chronic Disease, Kanyini Vascular Collaboration through SAHMRI, to develop a Wellbeing Framework to assist healthcare services in improving the quality of life and quality of care, and health outcomes, for Aboriginal and Torres Strait Islander people living with chronic disease. The study resulted in a Wellbeing Framework incorporating not just physical but also social, emotional, cultural and spiritual aspects of health and wellbeing.

### Structure of the Wellbeing Framework

The Wellbeing Framework consists of two core values fundamental to the provision of care for Aboriginal and Torres Strait Islander people. It also sets out four essential elements to assist healthcare services to support the wellbeing of Aboriginal and Torres Strait Islander people living with chronic disease. Every element is supported by four principles. Underpinning each principle is several practical and measurable applications that suggest ways in which the principle could be applied. Healthcare services, in consultation with the communities they serve, are encouraged to use the elements, principles and applications within this Wellbeing Framework to shape their own Wellbeing Model which specifically addresses the needs of their communities.<sup>11</sup>

#### **Element 1: Wellbeing is supported by locally defined, culturally safe primary health care services.**

- Creating culturally welcoming places.
- Developing trusting relationships with clients and communities.
- Understanding and accepting cultural diversity within communities.
- Delivering flexible PHC services both within and outside of healthcare facilities.

#### **Element 2: Wellbeing is supported by an appropriately skilled and culturally capable healthcare team.**

- Ensuring that all staff are culturally capable.
- Equipping staff with suitable skills to support people with chronic disease.
- Valuing and supporting Aboriginal and Torres Strait Islander staff.
- Developing effective cultural leadership.

#### **Element 3: Wellbeing is supported by holistic care throughout the life span.**

- Applying holistic approaches that address priorities determined with clients.
- Life-course approach from preconception to post-mortality.
- Ensuring appropriate resources are available to meet local priorities and need.
- Responding to family, community, cultural and spiritual responsibilities, and obligations.

#### **Element 4: Wellbeing is supported by best practice care that addresses the particular needs of a community.**

- Utilising cultural and scientific evidence to provide best practice healthcare.
- Ensuring that PHC services are available, accessible and acceptable.
- Empowering communities to be involved in determining local healthcare priorities.
- Developing interdisciplinary teams that support holistic care.

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## What is culturally appropriate care?

All care provided by services for Aboriginal people should be conducted in a manner which is tailored to an individual in connection with their family, community, culture, spirituality and Country. It is important to recognise and understand the diversity of Aboriginal people across SA. There are many differing cultural profiles, norms and practices operating within this state and for Aboriginal people who travel from interstate. Care must be respectful and culturally sensitive to take account of their particular circumstances.

Diagram 2 shows the relationship between services that are available, accessible, acceptable and affordable (outermost circle) and also highlights four main features that are vital to delivering culturally appropriate care: culturally safe services; holistic care; clinically and culturally competent workforce; and best practice care (adapted from Davy et al 2016; see diagram 2)<sup>12</sup>. The needs of individuals and communities should be considered in relation to each feature.

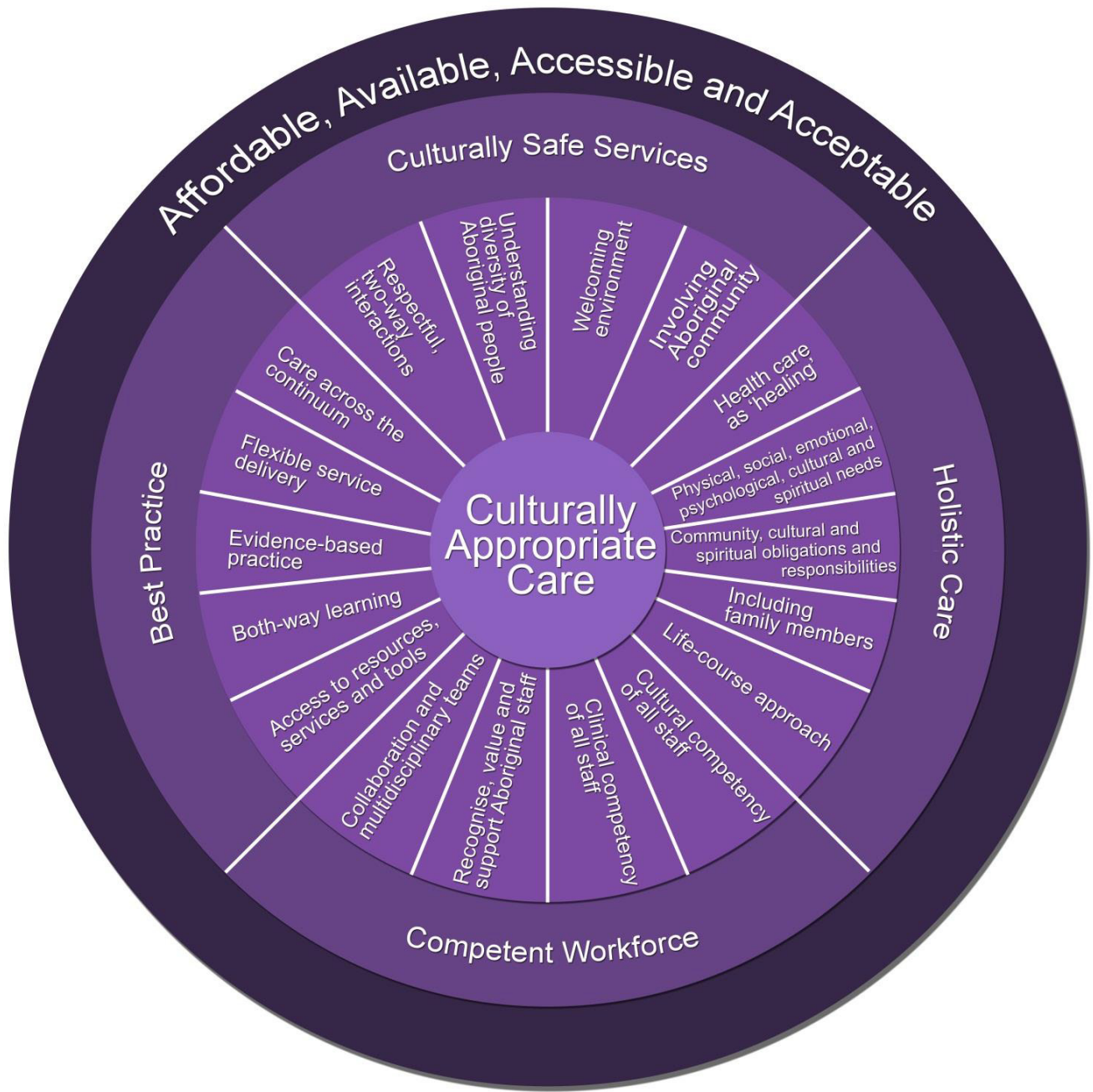


Diagram 2: Adapted from "A Wellbeing Framework for Aboriginal and Torres Strait Islander Peoples Living with Chronic Disease"<sup>12</sup>

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## Defining the features of culturally appropriate services

Four features are described below.

### 1. Culturally safe services

Culturally safe services refer to services that expect and perform zero tolerance for racism at any level. Cultural safety is not defined by health providers, instead it is defined by those who are experiencing the care<sup>13</sup>. Culturally safe care should be embedded within the health system, including private general practice.

Cultural safety is supported by services that:

- Develop and maintain respectful, both-way interactions between staff and clients (and their families and broader communities);
- Recognise and appropriately respond to the diversity of Aboriginal individuals and communities;
- Provide a welcoming environment, both physically and relationally; and
- Actively involve Aboriginal community members or representative groups in priority setting, governance and accountability.

### 2. Holistic care

Holistic care is supported by services that:

- Approach healthcare as 'healing', and support engagement with Traditional Healers and healing practices;
- Respond to holistic and personal needs of clients, including their physical, social, emotional, psychological, cultural and spiritual needs;
- Accommodate the complex family, community, cultural and spiritual obligations and responsibilities that clients or their family members may be experiencing;
- Include family members in planning, decision-making or education, where appropriate; and

- Recognise that for many Aboriginal people, a life-course approach is cyclical, and extends from pre-conception (e.g., adolescent nutritional or sexual health; health promotion) through to post-mortality (e.g. palliative care, end-of-life care, support around grief and loss).

### 3. What is best-practice care?

Best practice care is supported by services that:

- Provide coordinated care across the continuum (i.e., prevention, primary care, acute services, tertiary care, ongoing follow-up or rehabilitation, etc.);
- Approach service delivery in flexible ways that can accommodate diverse needs;
- Support both-way learning regarding Aboriginal cultural knowledges and practices, as well as the best available scientific evidence to inform practice;
- Apply evidence-based practice; and
- Ensure access to all relevant resources, services and tools to support effective delivery of care.

### 4. Culturally and clinically capable workforce

A culturally and clinically capable Aboriginal and non-Aboriginal workforce is supported by services that:

- Recognise the importance of physical as well as social, emotional and cultural wellbeing and place equal importance to cultural and clinical care;
- Foster collaboration within and between multi-skilled or interdisciplinary teams;
- Recognise, value and support the unique contributions of Aboriginal staff members, as well as respect and provide support for the unique challenges they may encounter;
- Ensure clinical capability of all staff, including providing training and support, as required; and
- Ensure cultural capability of all staff, including providing training and support, as required.

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## Features of Person-Centred Care for Aboriginal People

Six features are described below.

### 1. Aboriginal people have a holistic view of health and wellbeing

- Health and wellbeing encompass all aspects of physical, emotional, social, spiritual and cultural wellbeing and a specific kinship with family; and
- There is a belief that wellbeing is determined socially, rather than biologically or pathologically.

### 2. Structured and busy specialist clinical services may not cater well for the cultural needs of Aboriginal people

- This can contribute to a broader sense of disillusionment, indifference and apathy;
- Adherence to unfamiliar treatments that have unpleasant side effects may be poor, especially when there are competing pressures to meet community responsibilities; and
- Clients in unfamiliar environments where cultural and allied support is not provided and their needs are not met, can become lost.

### 3. Many Aboriginal people experience discomfort with health professionals of the opposite gender

- Traditionally, there are divisions in the roles of 'men's and women's business', including differences from western values in relation to reproduction and sexuality; and
- It is important where possible to consider gender balance and gender appropriate service when working with Aboriginal clients.

### 4. Family and community involvement in health decision making is of paramount importance in Aboriginal cultures

- Aboriginal cultures place a high importance on kin, with holistic, family-based care being valued over segregated care; and
- Aboriginal health is more of a collective consideration about family and community, therefore individualistic decision-making rarely occurs within Aboriginal society.

### 5. Support Aboriginal people to have a strong connection to Country (traditional homelands), and value being on Country or close by, particularly when ill

- Aboriginal people have strong links to Country, and this connection can be strong regardless of whether or not they are living a culturally traditional lifestyle or live in metropolitan, regional or remote areas; and
- Some clients may be reluctant to leave their community for treatment, even though this care may only be available in a metropolitan setting.

### 6. The concept of cancer may not be well understood by some Aboriginal people, leading to a number of misconceptions

- It is notable that there is no word meaning 'cancer' in most, if not all Aboriginal languages. Unlike many other illnesses, the concept of cancer is not embedded in traditional Aboriginal stories;
- While cancer 'spreading' is widely understood, there is commonly a difficulty in understanding biomedical cancer language and pathology terminologies; and
- Common misconceptions are that cancer is contagious, only effects non-Aboriginal people, is curable without treatment, and that western treatment is ineffective. It is commonly believed that a diagnosis of cancer is a death sentence, and that cancer is not treatable. Some Aboriginal people may equate cancer with Aboriginal lore, i.e. beliefs that the cancer is due to wrongdoing, punishment and they are deserving of the illness.

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## Aboriginal Cancer Healing Model

The CCC, under the leadership of the Aboriginal Community Reference Group and the Consortium's Cancer Leadership Group, facilitated the co-design of the Aboriginal Cancer Healing Model, to complement medical treatment of cancer through chemotherapy, radiation therapy, surgery and post-surgery care in acute service settings.<sup>14</sup> The model aims to provide guidance to amend, improve and enhance the approach of services in providing social supports to Aboriginal clients and families in culturally safe and responsive ways.<sup>14</sup> The model has three core elements:

- 1. Service elements** to support the individual who is directly affected by cancer diagnosis, including a particular focus on the needs of adolescents affected by cancer, the cancer client's family and the broader community (including prevention and early detection).<sup>14</sup> The service elements are:
  - a. Traditional healing;
  - b. Complementary therapies; and
  - c. Social, family and community support.<sup>14</sup>
- 2. The physical environment** that offers a culturally safe and welcoming clinical, indoor and outdoor spaces.<sup>14</sup> The physical environment elements are:
  - a. Clinical spaces;
  - b. Non-clinical spaces; and
  - c. Outdoor spaces.<sup>14</sup>
- 3. A range of enablers**, critical to the successful implementation of the model. These include organisational capacity, governance structure, technology, telehealth, monitoring and evaluation and a culturally safe, capable and appropriate workforce.<sup>14</sup>

To implement the model, the CCC partnered with stakeholders in Northern Adelaide and Whyalla. It is envisioned that other regions in SA adopt, adapt and implement this model.

## Optimal Care Pathways (OCPs)

The intent of the OCPs is to provide guidance to service planners and health practitioners on what optimal care looks like across the cancer care continuum for Aboriginal clients.<sup>15</sup> The OCPs recognise the importance of having a culturally responsive and culturally safe cancer service for Aboriginal people.<sup>15</sup> As with the Aboriginal Cancer Healing Model, the OCPs complement 'best-practice information in the cancer-specific pathways to facilitate the delivery of culturally safe and competent care for Aboriginal people.'<sup>15</sup> Furthermore, the OCPs can be used by health professionals and services to identify gaps in current services, make quality improvements and to initiate collaboration and discussion between people affected by cancer and health professionals.<sup>15</sup>

# Priority Area 1: Awareness and Prevention

**GOALS:** Increase Aboriginal peoples' awareness and understanding of cancer prevention and treatment strategies through culturally appropriate and effective programs. Increase Aboriginal peoples' participation rates in Human Papilloma Virus (HPV) and Hepatitis B (Hep B) immunisation.

## Actions 1-4

1. Collaborate with Aboriginal Community Controlled Health Organisations (ACCHOs), Wellbeing SA, the Adelaide and Country SA Primary Health Networks (PHNs), Cancer Council SA and Cancer Australia to improve knowledge within Aboriginal communities to act on cancer risk and symptoms through specific preventive programs.
2. Work with non-government organisations, other agencies and SA Aboriginal communities through narratives and positive stories to dispel myths and stigma around cancer, being respectful of cultural beliefs.
3. SA Health and Cancer Council SA will continue to work in partnership with Aboriginal leaders, Elders, ACCHOs, community organisations, and communities to decrease smoking prevalence and alcohol consumption in the Aboriginal population.
4. Pursue opportunities to collaborate on public health strategies to maximise and develop strategies that promote regular exercise, healthy weight and a diet rich in fruit and vegetables to not only decrease cancer incidence but also impact on or prevent many other chronic diseases.

## Rationale

- Understanding the causes of cancer is important for prevention<sup>16</sup>;
- Cervical cancer incidence and mortality rates are higher in Aboriginal and Torres Strait Islander people compared to other Australian women<sup>17</sup>;
- Adolescents and young adults often do not take notice of symptoms or postpone a visit to see a general practitioner (GP) as they do not think it is serious or fear a cancer diagnosis<sup>18</sup>;
- Data shows that 75% of AYA clients with cancer had a delay in their diagnosis and 57% were only referred to a hospital after presenting to a GP three or more times<sup>18,19</sup>;
- Several myths and misconceptions about cancer exist amongst Aboriginal communities; for example, cancer is contagious, it only affects non-Aboriginal people, Western medicine is ineffective, and cancer is a death sentence<sup>20,21</sup>; and
- Primary healthcare providers and several non-government organisations (including Cancer Council SA) have a pivotal role in raising awareness of preventive strategies and supporting the adoption and/or modification of lifestyle factors to reduce the risk of developing cancer or secondary cancers.

## Pathways to action

Develop an awareness, prevention and communication campaign for cancer. This must;

- Be co-designed by Aboriginal people;
- Use plain language and explain clearly medical terminology;
- Have specific health promotion and communication campaigns that are children and youth friendly;
- Learn from and build upon existing effective awareness and prevention campaigns (all ages);



- 
- Have a focus on the lifestyle risk factors of smoking, inactivity, obesity, poor diet, alcohol, unprotected sexual activity, not being sun smart, Hep B and HPV and provide examples of social marketing campaigns used for these lifestyle risk factors;
  - Raise awareness of preventative strategies and support the adoption and/or modification of lifestyle factors to reduce the risk of developing cancer through PHC providers and non-government organisations (including Cancer Council SA);
  - Have a focus on dispelling myths and misconceptions about cancer that exist amongst Aboriginal communities;
  - Use a strength-based approach focusing on the stories of survivors, and consider the use of narratives to convey the key health messages;
  - Encourage participation of Aboriginal children in the National HPV Vaccination Program; and
  - Include key programs that can prevent Hep B and C such as the Clean Needle Program and Medication Assisted Treatment for Opioid Dependence (MATOD).

## Enablers for Actions 1-4

- Governance: Aboriginal leadership and partnerships
- Sustainable funding
- Community engagement

# Priority Area 2: Screening and Early Detection

**GOAL:** Increase Aboriginal peoples' participation rates in cancer screening programs.

## Actions 5-8

5. Work with the ACCHO sector, the Adelaide and Country SA PHN, the Local Health Networks (LHNs) and Cancer Council SA to increase screening rates for people living in rural and remote areas.
6. Prioritise initiatives that facilitate collaboration between cancer screening programs in SA, drawing on learnings, experiences and resources to promote awareness of, overcome barriers to and encourage greater participation rates in cancer screening.
7. Continue to promote and implement national screening programs (e.g., National Bowel Screening Cancer Program), state screening programs (Well Women's Program, Breast Screen SA Mobile Screening unit) and other innovative models (e.g., "One Stop Screening Shop") that increase participation of Aboriginal men and women in cancer screening within SA.
8. Lower the age eligibility criteria for bowel cancer screening of Aboriginal people and support the ACCHO sector to implement the alternative pathway.

## Rationale

- Early detection of cancer or precancerous conditions through screening is an important public health measure for reducing the burden of cancer<sup>22</sup>;
- Evidence indicates that Aboriginal and Torres Strait Islander people are under-screened in comparison to other Australians<sup>23</sup>;
- Reducing the eligible age range, for bowel cancer from age 50 to 45, could reduce incidence rates by up to 44% and be cost-effective<sup>24</sup>;
- The national Alternative Pathway pilot showed that the participation rate for Aboriginal and Torres Strait Islander people in bowel screening was 40% compared to 23% entering the traditional pathway<sup>25</sup>; and
- Many AYAs have signs and symptoms that are often attributed to stress, growing pains or fatigue.<sup>18</sup>

## Pathways to action

- Develop sex and gender specific health promotion campaigns that promote participation in national and state screening programs and promote the earlier age eligibility of Aboriginal people;
- Educate clients on the importance of participating in national and state screening programs through the promotion of an annual Health Check (MBS 715 or similar);
- Identify ways to better monitor and further increase participation screening rates across all programs for Aboriginal people;
- Coordinate with existing national screening programs (National Bowel Screening Program and National Cervical Screening Program), state screening programs (Promote Well Women's Program, Breast Screen SA Mobile Screening Unit) and other innovative models ("One Stop Screening Shop" Cancer Screening Program);

- 
- Consider the benefits and potential implications of reducing the eligible age range for bowel cancer of Aboriginal people to participate in screening programs;
  - Encourage adoption of the alternative pathway for bowel cancer screening of Aboriginal people and support ACCHOs to implement it; and
  - Ensure that GPs conduct a comprehensive medical history and medical exam, when children and AYAs present with signs and symptoms typically associated with stress, growing pains or fatigue that could be attributed to a cancer diagnosis.

## Enablers for Actions 5-8

- Governance: Aboriginal leadership and partnerships
- Sustainable funding
- Community engagement
- Integrated and coordinated services
- Monitoring and evaluation

# Priority Area 3: Diagnosis and Staging

**GOAL:** Ensure coordinated and timely access to diagnosis services.

## Actions 9-10

9. Include Aboriginal status on all screening, diagnostic pathology, radiology and other requests and reports.
10. Support initiatives that enable coordinated and timely access to diagnostic services for Aboriginal people, particularly those living in remote areas.

## Rationale

- Aboriginal and Torres Strait Islander people are often diagnosed with cancer at a more advanced stage;<sup>26</sup>
- There are opportunities to improve earlier diagnosis through access to services with implementation of the OCPs<sup>15</sup> in SA; and
- To monitor participation rates, Aboriginal status needs to be included on all diagnostic pathology, radiology and other requests.

## Pathways to action

Establish and maintain a system where identification of all Aboriginal clients occurs as early as possible. This will enable appropriate clinical decision making in recognition of specific risk, and consideration of cultural elements of care to be incorporated into management. The system must be:

- Integrated into electronic patient information management systems, including registries;
- Incorporated into workforce training; and;
- Written into care pathways.

Review existing models of cancer services and develop culturally appropriate services for Aboriginal clients as demonstrated in the Aboriginal Cancer Healing Model.<sup>14</sup> The model must:

- Ensure all clients have timely access to services;
- Ensure coverage across regional and remote SA;
- Involve the family, specialist, PHC practitioner and consider the recovery aspect;
- Have access to screening closer to home as possible;
- Utilise telehealth and/or ICT solutions where appropriate;
- Enable the majority of test, staging and investigations as possible before they are transferred to a tertiary centre; and
- Consider having regional cancer care coordinators and/or Aboriginal Health Workers/Practitioners (AHW/P) specialising in cancer care.

## Enablers for Actions 9-10

- Governance: Aboriginal leadership and partnerships
- Sustainable funding
- A strong cancer workforce
- Transport and accommodation support
- ICT solutions
- Community engagement
- Integrated and coordinated services
- Monitoring and evaluation

# Priority Area 4: Treatment

**GOAL:** Continual improvement of access to safe, timely, optimal, equitable and culturally appropriate treatment services for Aboriginal people in South Australia.

## Actions 11-13

11. Develop, implement and monitor utilisation of telehealth consultations for/by Aboriginal people to enable understanding of current usage and future potential whilst promoting ongoing and increased utilisation.
12. Utilise Clinical Service Capability Frameworks to guide and maximise access to safe and appropriate cancer care as close to home as possible.
13. Engage in activities and initiatives that promote greater understanding and collaboration between Aboriginal Traditional Healers and health professionals in SA.

## Rationale

- Aboriginal people are less likely to have cancer treatment, more likely to wait longer for surgery and be referred later for specialist treatment<sup>27,28</sup>;
- They have lower levels of trust of hospitals and may experience institutional barriers to accessing appropriate healthcare<sup>29</sup>;
- The treatment of cancer is complex and often involves multiple health professionals and services as Aboriginal people move between metropolitan and rural, paediatrics to adult and acute to outpatient and community service settings as part of their cancer pathway; and
- Home and community are increasingly becoming important settings for healthcare service delivery as cancer becomes a treatable, chronic condition with intermittent periods of acute illness.

## Pathways to action

Review existing models of cancer treatment services and be guided by the Aboriginal Cancer Healing Model<sup>14</sup> document. The model must:

- Have established systems to provide clinically and culturally appropriate pre- and post-operative care as close to home as possible;
- Include the wider family in the treatment process;
- Identify culturally appropriate and affordable accommodation options if cancer treatment is provided away from home;
- Recognise the importance of influencing and supporting the positive management and nurturing of the physical, social, emotional and cultural wellbeing of Aboriginal people;
- Link up with the SA Health Traditional Healer Brokerage Program;
- Be culturally safe and provide a welcoming environment;
- Ensure that Aboriginal people do not encounter racist barriers to gaining appropriate care, leave hospital against medical advice or be discharged at their own risk; and
- Utilise telehealth and/or ICT solutions where appropriate (i.e., appointments, education and support).

## Enablers for Actions 11-13

- Governance: Aboriginal leadership and partnerships
- Sustainable funding
- Transport and accommodation support
- A strong cancer workforce
- ICT solutions
- Integrated and coordinated services
- Monitoring and evaluation

# Priority Area 5: Care Coordination

**GOAL:** Improve coordination, assessment and management of clinical and supportive care needs for Aboriginal people with cancer.

## Action 14

14. Collaborate with PHNs Closing the Gap (CTG) programs to strengthen cancer coordination pathways across the cancer care continuum.

## Rationale

- Complications resulting from chronic disease co-morbidities are more common in Aboriginal and Torres Strait Islander people than other Australians, meaning that their treatment needs are more complex<sup>26</sup>;
- Over half of the number of Aboriginal people experiencing these cancers live in outer regional and remote SA<sup>30</sup>; and
- Aboriginal clients need support in interpreting medical terminology used by service providers, navigating the hospital system, and coordinating hospital care with follow-up and supportive care in the community.<sup>31</sup>

## Pathways to action

- Develop resources that explain the medical terminology used to explain cancer;
- Adopt a person-centred approach when communicating with children, AYAs and adults with cancer;
- Have AHW/P present at appointments with clients;
- Develop a spiritual and emotional distress screening tool to utilise along the continuum of care; and
- Link health professionals with Aboriginal Cancer Care Coordinators and/or Aboriginal Liaison Officers to provide better coordination and client outcomes.

## Enablers for Action 14

- Governance: Aboriginal leadership and partnerships
- Sustainable funding
- A strong cancer workforce
- Integrated and coordinated services

# Priority Area 6: Supportive Care

**GOAL:** Increase understanding of, provision of, and access to culturally appropriate supportive care for Aboriginal people with cancer and their families across the cancer care continuum.

## Actions 15-19

15. Identify, implement and evaluate culturally appropriate and acceptable tools and templates (including needs assessment tools) for Aboriginal people with cancer and cancer survivors to be incorporated within the SA Survivorship Framework and cancer registries.
16. Collaborate with PHNs to further promote and encourage the uptake of incentives available to GPs to provide supportive and follow-up care for Aboriginal people within the Primary healthcare setting and ACCHO Sector.
17. Collaborate with PHNs to promote culturally appropriate, community-based conversations about the care of Aboriginal people whose cancer is incurable, including conversations about the importance of identifying who would speak on the person's behalf if they were unable.
18. Increase awareness and uptake of the number of Aboriginal people in SA with cancer having an Advance Care Directive.
19. Support initiatives that facilitate Aboriginal health services and community services to establish and maintain Aboriginal cancer support groups or Yarning Circles across SA.

## Rationale

- GPs are integral in supporting the continuity of care and meeting the diverse range of client needs (including follow-up and management of co-morbidities);
- Aboriginal and Torres Strait Islander people face barriers in accessing care from prevention through to end-of-life (see diagram 3)<sup>10</sup>; and
- Access to high quality palliative care is limited for Aboriginal people.

## Pathways to action

- Identify culturally and age- and gender-appropriate needs assessment tools to use with Aboriginal cancer survivors;
- Identify if further improvements are required to programs and incentives that assist with accessing GPs and other PHC;
- Identify age-appropriate supports required to assist Aboriginal children, AYAs in their cancer journey; BRAGG Comprehensive Cancer Centre (BCCC);
- Develop resources, that are age appropriate and gender specific, for health professionals that can assist with facilitating conversations with Aboriginal people about who they would like to speak on their behalf, if they are in a situation where they lack capacity to make decisions or speak for themselves;
- Educate and train healthcare professionals on how to have culturally sensitive, age- and gender-appropriate discussions with Aboriginal clients and their families and communities, who require palliative and bereavement care;
- Collaborate with PHNs to facilitate culturally respectful and age-appropriate conversations about dying and the role of palliative and end-of-life care in the wellbeing of Aboriginal people;

- Strengthen the role of Cancer Care Coordinators in assessing the palliative care needs of Aboriginal people and facilitate access to age appropriate and gender specific resources to manage those needs;
- Link up Cancer Care Coordinators with specialist palliative care services;
- Improve access to specialist palliative care; and
- Develop culturally appropriate Advanced Care Directives.

## Enablers for Actions 15-19

- Governance: Aboriginal leadership and partnerships
- Sustainable funding
- A strong cancer workforce
- Transport and accommodation support
- Community engagement
- Integrated and coordinated services

CANCER CONTINUUM	SUPPORTIVE CARE (SERVICES & RESOURCES) Physical, information, practical, emotional, psychological, social and spiritual needs (1).					
	Survivorship Care					
	<ul style="list-style-type: none"> <li>• Monitoring and follow-up care (recurrence or new cancers)</li> <li>• Managing the effects of treatment (short-term, ongoing and delayed)</li> <li>• Managing physical, social, spiritual and emotional needs</li> <li>• Prevention and management of co-morbidities (e.g. diabetes, obesity)</li> <li>• Promoting general healthy lifestyle guidelines and cancer screening programs</li> </ul>					
	PREVENTION	SCREENING AND EARLY DETECTION	DIAGNOSIS AND STAGING	TREATMENT	END OF TREATMENT	PALLIATIVE/ END-OF-LIFE CARE
CONSIDERATIONS AND BARRIERS	<ul style="list-style-type: none"> <li>• Understanding and perceptions of cancer (stigma, blame)</li> <li>• Transport (access to, particularly rural and remote)</li> <li>• Accommodation (appropriate to family needs)</li> <li>• Language Barriers</li> <li>• Family Isolation</li> <li>• Finances</li> <li>• Access to childcare services</li> <li>• Cultural appropriateness of available services (access to gender specific health professionals)</li> <li>• Advanced care planning</li> </ul>					<ul style="list-style-type: none"> <li>• Communication about prognosis</li> <li>• Importance of returning to traditional lands to pass away</li> <li>• Cost of returning to traditional lands</li> <li>• Family support</li> <li>• Cultural protocols during end-of-life</li> <li>• Ceremonies after life</li> <li>• Impact on communities of delays in repatriating bodies (e.g. when removed for autopsies)</li> </ul>
	ACCESS TO TRADITIONAL HEALERS					
COLLECTIVE DECISION MAKING (INVOLVING FAMILY/COMMUNITY)						

Diagram 3: Supportive Care Considerations for Aboriginal People with Cancer<sup>10</sup>



# Priority Area 7: Service Outcomes Data And Research

**GOAL:** Develop a better evidence base to measure the effectiveness of cancer related services for Aboriginal people. Identify areas of excellence, service gaps and inform opportunity to improve client outcomes and experience.

## Actions 20-24

20. Develop Aboriginal Cancer Patient Reported Experience Measures (PREM) and Aboriginal Patient Reported Outcome Measures (PROM) to routinely capture the quality and outcomes of care from the perspective of Aboriginal people to inform care delivery.
21. Develop and utilise specific Aboriginal quality indicators that are sensitive to Aboriginal people's needs to monitor and evaluate Optimal Care Pathways (OCPs).
22. Scope opportunities for further collaborative research to understand and address specific needs of Aboriginal children, adolescents and young adults with cancer, cancer survivors and their families.
23. Continue to conduct high quality cancer research to inform evidence-based, continually improving practice.
24. Provide where appropriate, easy-to-understand cancer information that supports Aboriginal people experiencing cancer, their families and carers to be involved with cancer research.

## Rationale

- A stronger evidence base will assist in better identifying areas of need and gaps in service provision, support and treatment (all ages).

## Pathways to action

- Develop Aboriginal Cancer Patient Reported Experience Measures (PREM) and Aboriginal Patient Reported Outcome Measures (PROM) for the ongoing monitoring of Aboriginal disparities in relation to cancer screening, diagnosis, treatment and post-treatment care;
- Develop a minimum data for each cancer case, including such elements as place of residence, sex, date of birth, date of diagnosis, cancer site and morphology, means of diagnosis, whether there were multiple primary sites of cancer, Aboriginal status, country of birth, and date, place and cause of death;
- Report routinely Aboriginal cancer data annually;
- Develop culturally responsive and culturally appropriate cancer information that supports Aboriginal people (including children and AYAs) experiencing cancer, their families and carers about taking part in cancer research and/or clinical trials where appropriate;
- Identify opportunities for further research into childhood cancer and the associated oncogenic drivers and risk factors; and
- Identify opportunities to work with the BCCC on their strategic priority areas of research and data.

## Enablers for Actions 20-24

- Governance: Aboriginal leadership and partnerships
- Sustainable funding
- ICT solutions
- Community engagement
- Monitoring and evaluation

# Enablers

## ENABLER 1: Governance: Aboriginal Leadership and Partnerships

**GOAL:** Establish and maintain robust governance structures, led by Aboriginal professionals and organisations, equipped to foster partnerships and collaboration between the wide range of organisations and stakeholders responsible for implementing this Plan.

### Rationale

- Responsible governance based on shared visions and values will be essential to the successful implementation of this Plan;
- Aboriginal leaders need to be involved on every level to fully embed core values such as Aboriginal self-determination and Aboriginal community governance;
- The structures and processes required to ensure the appropriate accountability, transparency and responsiveness of the decisions and actions associated with Aboriginal people with CVD, require the leadership of Aboriginal stakeholders from relevant professional and community backgrounds;
- Governance groups need to be actively engaged and respond flexibly and adaptively to complex and changing environments;
- Involvement of Aboriginal leadership in decisions associated with planning, delivering and evaluating the implementation of actions outlined in this Plan is critical to ensuring cultural safety and effectiveness of health

systems and services to improve heart and stroke; and

- Health system organisations such as funding bodies, policy makers and service providers need to commit to genuine, collaborative partnerships with Aboriginal communities and organisations to build on the strengths of each part of the system and the strengths of the community to create positive change and improvements in CVD outcomes.

### Pathways to action

The governance structure must continue to:

- Recognise the diversity of health services which have a role to play in improving CVD outcomes for Aboriginal people and commit to building genuine partnerships and appropriate governance structures involving Aboriginal leadership;
- Involve representation from all key parties in the continuum of care for Aboriginal people, including representation of the Aboriginal community leaders, organisations, and professional stakeholders;
- Identify existing partnerships and governance structures such as statewide clinical networks, regional health services networks as well as existing community groups and forums to lever support for the implementation of this Plan;
- Include Aboriginal and Torres Strait Islander people who have a lived experience of CVD or have cared for someone with these conditions and demonstrate a commitment to listening to their voices;
- Integrate monitoring and reporting against Plan targets to quantify impact; and
- Maintain the SA Aboriginal Chronic Disease Consortium's Community Reference Group, with both metropolitan and country representation through ongoing engagement and involvement mechanisms to enable the Community Reference Group to oversee, guide and influence the implementation of this Plan.

**GOAL:** Appropriate levels of funding to be available for implementation of projects and services within appropriate timeframes.

### Rationale

- Aboriginal health funding needs to be allocated to projects and services which adhere to the principles of Aboriginal leadership and governance and preference the employment of Aboriginal professionals;
- There are multiple funding sources for Aboriginal health care across all sectors, from federal and state government agencies, which are often fragmented, insufficient and short-term;
- Accessing funding incurs significant operational costs, including identifying appropriate sources of funding, understanding eligibility criteria, and developing funding proposals;
- A further barrier to accessing funding are specific requirements such as financial co-contributions or short turnover times for submissions that prevent appropriate community and stakeholder consultation;
- Compliance with reporting requirements for multiple grant agreements, once secured, can also be a barrier, especially where funding levels are low.
- The short-term nature of many funding agreements allows for limited flexibility to undertake project or service planning and manage operational challenges such as recruitment of staff or staff turnover, engagement of community and other

stakeholders, establishment of formal partnerships with partner organisations and meeting delivery milestones. Negotiating extensions or variations to funding agreements can also come at a significant operational cost;

- Workforce sustainability and appropriate training, professional development and career opportunities are difficult to maintain when funding is limited. The costs associated with the development and maintenance of professional networks to sustain high quality models of care and improve health outcomes is also significant;
- Community engagement also requires appropriate resourcing over the lifetime of services and projects. Similarly, sufficient budgets are required to evaluate projects and services; and
- Out-of-pocket costs for the individual, such as gap payments for medicines, general practice or specialist care, as well as costs associated with transport and accommodation for Aboriginal people from rural or remote communities, can be prohibitive for accessing health services, and reimbursements or subsidy schemes are often difficult to navigate.

### Pathways to action

- Advocate for adequate levels of funding and resources and adequate timeframes to support the implementation of this Plan;
- Advocate for the inclusion of Aboriginal leadership, governance, and workforce as part of funding eligibility criteria. Aboriginal community engagement should also be a prerequisite to developing proposals, to ensure cultural appropriateness and safety and that the proposed project or service associated with the implementation of this Plan meet community priorities and expectations;
- Funding bodies to provide easily accessible information and support for service providers to submit successful funding proposals;

- 
- Funding bodies to streamline reporting requirements and the processes to meet other accountability requirements wherever possible to reduce the administrative burden of managing funding agreements. Embedding flexibility in the management of these agreements is also critical, for example to allow for revision of timeframes, milestones, and ability to carry over or re-allocate funding as priorities shift or newly emerge;
  - Increase knowledge amongst service providers of funding sources and increase their capacity to access funding and manage funding agreements;
  - Identify and promote the uptake of existing funding sources, including through the MBS, hospital loading for Aboriginal clients, and CTG;
  - Provide Aboriginal people with relevant information about reimbursements and supplementary schemes to reduce out-of-pocket expenses; and
  - Work with funding bodies to acknowledge the need for sufficient planning, community engagement, workforce development and evaluation and the flexibility required in deliverables and funding across the life of the project.

### ENABLER 3: A Strong Cancer Workforce

**GOAL:** Increase the capacity and capability of the Aboriginal and non-Aboriginal workforce to provide high quality, culturally responsive, collaborative cancer care.

#### Rationale

- There is agreement from government and Aboriginal community controlled peak bodies that an appropriately skilled, available and responsive Aboriginal and Torres Strait Islander health workforce is critical. Aboriginal healthcare providers connect community members to health care and bring a combination of clinical, cultural and community development skills. Their understanding of holistic care and ability to work as cultural brokers and health system navigators while providing culturally safe care, facilitates access in a disparate health system;<sup>32</sup>
- It is important to recognise that the Aboriginal workforce is diverse and includes many roles such as AHW/P, Aboriginal maternal infant care workers, Aboriginal liaison officers, Aboriginal cultural consultants, care navigator roles etc;
- Aboriginal Health Practitioners have a particularly high level of clinical skills and are trained to work autonomously. In recognition of this they must meet practice standards and be registered under the Australian Health Practitioner Regulation Agency (AHPRA)<sup>32</sup>;
- Cancer is everybody's business, and it is important that all staff working with Aboriginal communities have a foundation understanding of cancer in the context of Aboriginal people's unique history and the impact of colonisation. Furthermore, cancer management should consider factors such as earlier onset of cancer and the additional social, emotional, and cultural requirements of Aboriginal people with cancer;
- To improve outcomes for Aboriginal people it is critical that AHWs and AHPs and other Aboriginal workforce are integrated into interdisciplinary cancer care teams as this will lead to improved access and uptake of services, more effective diagnoses and treatments and earlier intervention and prevention.<sup>32</sup>
- For this to occur we need to educate non-Aboriginal clinicians about their clinical and cultural roles within the interdisciplinary care team and build the capacity of the Aboriginal workforce to fulfill these roles;
- There is a gap in the knowledge and skills in the current workforce in delivering health/cancer education and health promotion initiatives to community;
- There is variable access to training sources that are timely, proximal, appropriate and cost effective . It is important that Aboriginal staff can access disease specific education within their Certificate IV and through ongoing professional development. As part of this there need to be clear career pathways, recognition and remuneration according to skill level, and access to clinical support for Aboriginal staff who have an interest in specialising in cancer education and management; and
- Equip the workforce to deal with social and emotional wellbeing in the context of cancer.

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## Pathways to action

- Support the Aboriginal and non-Aboriginal workforce to develop the skills, knowledge and competencies required to provide culturally responsive cancer care and education;
- Grow and sustain the roles that support and optimise cancer care coordination for Aboriginal people;
- Establish strong clinical leadership with primary healthcare services to drive positive and evidence-based changes in prevention, early detection, and management;
- Ensure that non-Aboriginal staff complete cultural safety training;
- Train the non-Aboriginal workforce to know what Aboriginal specific information they need to be aware of when an Aboriginal client presents to clinic and how to work collaboratively with the Aboriginal health care team to meet the client's needs;
- Establish clear transition pathways for Aboriginal students into the workforce;
- Ensure Aboriginal staff can access clear career pathways to specialise in cancer education and management;
- Actively aim for relevant staff to have specifically allocated time to attend training sessions and manage chronic disease;
- Build awareness and capacity of AHW/Ps to deliver client and community education across the cancer care continuum, including support AHW/Ps to undertake relevant cancer related training;
- Advocate for culturally appropriate RTO capacity / options for the state especially for Certificate IV including capacity for optional units such as cancer;
- Take a conscious approach to embedding the Aboriginal workforce as core members of the collaborative cancer care team;
- Develop an Aboriginal Impact Statement and engage with relevant stakeholders while implementing the OCPs; and
- Invest in Aboriginal Specific Cancer Care Coordination and Cancer Care Navigators across the cancer care continuum.

## ENABLER 4: Transport and Accommodation Support

**GOAL:** Improve access to health care through transportation (ensuring Aboriginal people have safe and appropriate home-to-care-to-home journeys) and culturally appropriate accommodation options for Aboriginal people.

### Rationale

- Many community members, both in metropolitan Adelaide and rural and remote communities refer to transport and accommodation as a barrier to accessing primary health, allied health and specialist services;
- SA Health and the Rural Support Service provides a transport and accommodation subsidy through the Patient Assistance Transport Scheme (PATS). Subsidies are provided to assist clients, who are required to travel more than 100 kilometres each way, to access necessary and approved medical specialist services (the specialist must be registered in a speciality under the medical board of Australia) that are not available locally<sup>33</sup>;
- The PATS Aboriginal Engagement Strategy has been established an ongoing Aboriginal Liaison Officer position to help support Aboriginal clients in accessing PATS subsidies.<sup>33</sup> Changes for Aboriginal clients include:

- » Providing subsidies in advance
- » Removal of the concession card requirement for the first night of accommodation subsidy
- » Automatic approval for travel partner subsidies (escorts)
- » Grant payment for advocacy agencies who support clients to complete online claims.<sup>33</sup>
- SA Health has a list of short-term accommodation options for Aboriginal rural and remote clients who are visiting metropolitan hospitals for care.<sup>34,35</sup> However, service providers are often unaware of what accommodation options are available.

### Pathways to action

- Develop a transport process to ensure that Aboriginal clients have safe home-to-care-to-home journeys. The model must:
  - » Minimise out-of-pocket expenses to clients with health care needs;
  - » Provide transportation subsidies for clients attending appointments where PATS are unable to cover (i.e., visiting a non-medical specialist);
  - » Ensure that all clients have access to safe, culturally appropriate transportation that suits their medical condition;
  - » Coordinate transport with the health service;
  - » Ensure that all regional and remote clients who are transferred as an in-patient are transferred back to the closest hospital to their home, as an inpatient;
- Identify existing Aboriginal specific accommodation options and work with housing providers to determine how to share directory with service providers; and
- Advocate for increased culturally safe, appropriate, affordable and more Aboriginal accommodation options (including weekend accommodation options for families) to ensure that clients and family members can access health services as required.

## ENABLER 5: Information and Communications Technology Solutions

**GOAL:** Invest in resources, coordination and systems for telehealth and virtual care. Also improve the utilisation and communication of information across patient information management systems.

### Rationale

- Innovative technologies can help address specific challenges faced by health care including reducing cost and utilisation, delivering better outcomes in a lower cost environment, and improving access and the client experience;
- Innovative technologies, such as telehealth and home monitoring devices have shown to be effective. However, ICT relies on Wi-Fi bandwidth, workforce to be trained in use and the appropriate hardware and software to meet the needs of clinical staff and service users;
- As the efficacy and efficiency of ICT solutions are demonstrated, there should be core funding made available to enable these solutions to be common practice. Where core funding has been temporarily introduced during the COVID-19 pandemic, this should be maintained and expanded where it has been effective and cost-effective;
- There remains limited integration of ICT solutions in a systematic manner into models of care in SA;

- Some ACCHOs across SA, including AHCSA have the infrastructure for telehealth use. However, due to a lack of resources and funding, these facilities are not being utilised extensively; and
- The uptake of My Health Record at ACCHOs is limited and its use is dependent on receiving hospital discharge summary data.

### Pathways to action

- Invest in resources, coordination and systems for telehealth with the aim of embedding it into routine models of care;
- Ensure all health care services statewide have access to functional telehealth;
- Identify funding mechanisms to support innovative technologies so that these services become sustainable;
- Identify what supports are required to embed My Health Record in general practice, allied health, specialists, ACCOs, all community health centres and hospitals. A clear role out strategy should include;
  - » All health services can clearly explain personal control of and potential benefits from My Health Record, to overcome clients' fears;
  - » Targeted and culturally appropriate promotion of My Health Record;
- Ensure hospitals provide discharge summary data to ACCHOs in a timely manner; and
- Provide ongoing support for staff on the use of patient practice software systems, including new and visiting staff.



## ENABLER 6: Community Engagement

**GOAL:** Meaningful engagement of Aboriginal people, families and communities must underpin the design and implementation of projects and services associated with this Plan.

### Rationale

- The engagement of Aboriginal people, families and communities is essential to ensure that projects and services to address CVD are relevant for Aboriginal people and meet community standards and expectations<sup>36</sup>;
- Genuine engagement demonstrates integrity through deep listening, and respect for cultural knowledge and community decisions, which is key to the principle of Aboriginal self-determination<sup>36</sup>;
- Cultural values need to be embedded in the process of engagement. The process of yarning enables collective decision-making and needs to be included in the engagement approach, alongside individual consultations. Considerations of gender and age specific consultations and community members' cultural responsibilities (e.g., caring for Country, kinship bonds, caring for others and cultural belief systems) are also critical to ensure cultural safety<sup>37</sup>;
- Reciprocity and long-term relationships are key to successful and meaningful engagement. Community needs to be kept informed about the impact of their engagement on the design and delivery of projects and services and be given an opportunity to provide oversight on a long-term basis<sup>36,37</sup>;

- A well planned engagement plan must target appropriate stakeholders, taking into consideration Aboriginal language groups and traditional custodianship of Country, key Aboriginal Elders and community leaders and the dynamics and relationships that make up the social and cultural fabric of the community; and
- Community engagement enables health system planners, policy makers and health service providers to action the priorities outlined in this Plan in a way that ensures respect for community values and mindful of community dynamics and cultural norms.

### Pathways to action

- The purpose of the engagement must be well defined, and the engagement approach tailored to meet the objectives of the engagement and the requirements of community stakeholders<sup>38</sup>;
- Involving the appropriate stakeholders and ensuring that the target communities are adequately represented and included in the engagement is also critical. The community may be a Traditional Owner group, or it may be regional or national. Other factors such as gender or age might determine, who the community is, or a particular professional background.<sup>37</sup> For the purposes of this Plan, members of the community, who are affected by CVD or have a lived experience, including carers and family members, need to be considered;
- The level of engagement needs to be determined based on the purpose, and the means of engagement chosen accordingly. "Levels of engagement" are well described in the International Association for Public Participation (IAP2) Spectrum of Public Participation (see diagram 2 below)<sup>38</sup>;


- The means of engagement need to be negotiated with community representatives, to ensure that the “right” approach is chosen to allow for Aboriginal people’s voices to be heard. Opportunities for collective engagement through yarning circles should be considered as well as individual engagement. Involvement of Aboriginal leaders in undertaking the engagement also needs to be carefully considered and community dynamics and sensitivities taken into account<sup>36,37,38</sup>; and
- A commitment to reciprocity needs to be actioned through a long-term commitment to maintain the community engagement

and ensure that the community maintains a level of oversight and ability to continuously influence the implementation of projects and services. Community reference groups or similar mechanisms should be maintained for the duration of projects and services, so the community can oversee the work, ensure their voices are heard, their feedback is incorporated, and integrity maintained. Wherever possible, the community should be empowered to understand the health system and policy context as well as the financial implications associated with the work (e.g., financial limitations, expenditure, any costs and savings associated with the work).<sup>36,37</sup>

## IAP2 Spectrum of Public Participation



IAP2’s Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public’s role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION 					
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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Diagram 4: IAP2 Spectrum of Public Participation<sup>38</sup>

## ENABLER 7: Integrated and Coordinated Services

**GOAL:** Achieve continuity of care for Aboriginal people with cancer through culturally responsive, integrated and coordinated services

### Rationale

- Continuity of Care is defined by the World Health Organization (WHO) as the degree to which people experience a series of discrete healthcare events as coherent and interconnected over time and consistent with their health needs and preferences.<sup>39</sup> A health system, characterised by integrated and coordinated services, focussing on cancer and working collaboratively and harmoniously across multiple providers within interdisciplinary teams and across care settings and sectors, is essential to effectively and holistically address the needs of Aboriginal people affected by cancer, their families and communities<sup>39</sup>;
- Continuity of Care needs to occur on a number of levels to achieve better quality and address the disparities in health outcomes related to cancer<sup>39</sup>:
  - » **Interpersonal**<sup>39</sup> – which refers to the relationship between health service providers, clients and their families or carers, provides a key contact person to assist clients navigating their care, and a commitment by all service providers to meet the clients' and their families' physical, social, emotional and cultural needs;
  - » **Longitudinal**<sup>39</sup> – or continuity over a period of time, which is enabled by discharge and care planning, integrated referral and follow-up systems and by the support from a navigator role to support the clients' journey<sup>39</sup>;
  - » **Cardiovascular disease management**<sup>39</sup> – integrated and coordinated case management across services and sectors (i.e., primary, secondary, tertiary), interdisciplinary team care approaches to enable a collaborative focus on the clients' need over the duration of their care, joint care planning and monitoring of progress;
  - » **Informational**<sup>39</sup> – focussing on communication between health service providers and the clients' and families as well as between services, sectors and within interdisciplinary team, which includes effective patient information management and shared records as well as standardised assessments and models of care for cancer management.
- Access to culturally responsive integrated and coordinated services enables support for chronic disease self-management, early intervention and prevention of complications and improved outcomes;
- Fragmentation of a health system with a large number of service providers across primary, secondary and tertiary care and from government and non-government, including Aboriginal community-controlled, sectors is a common occurrence, as are siloed approaches by health care providers from different professional and specialist background. Opportunities for integration and coordination need to be sought and maximised to achieve better quality and continuity of care, improved health outcomes and also efficient use of resources;

- The SA Government is committed to integrated care through its Wellbeing SA Integrated Care Strategy which includes three priority areas<sup>40</sup>;
  - » putting people at the centre of their care;
  - » delivering connected care and
  - » working together as a system.
- Within the PHNs, integrated and coordinated care is supported through a number of initiatives including the Integrated Team Care Program that supports Aboriginal and Torres Strait Islander people who live with complex chronic conditions; and
- The SA Aboriginal Chronic Disease Consortium, through its governance structures and implementation of projects to implement this Plan, provides an opportunity for coordination and collaboration with a wide range of stakeholder organisations and community stakeholders.
- Focus on interdisciplinary (rather than multidisciplinary) team care approaches, to integrate separate professional discipline approaches into a single consultation, including a team approach to assessment, diagnosis, intervention, setting short- and long-term management goals together with clients and families and jointly monitor progress<sup>41</sup>;
- Explore opportunities to enhance care coordination through dedicated Aboriginal coordinator/navigator roles and aim to allocate the care providers to clients, to establish long-term relationships;
- Work towards integration and alignment of patient information management systems, to enable better flow of information and follow-up of clients-in-common;
- Implement multi-agency service agreements, Memoranda of Understanding, Memoranda of Administrative Agreements and other formal partnerships between services and organisations, to facilitate collaboration on operational matters such as project planning, contract management and reporting; and
- Explore opportunities for collaboration to improve integration and care coordination across chronic disease areas.

## Pathways to action

The following should be considered to achieve better service integration, coordination, and partnerships:

- Engage with the SA Aboriginal Chronic Disease Consortium, Wellbeing SA, Aboriginal community and other key partners to co-design standardised assessments and shared models of care, that enhance the delivery of integrated and coordinated chronic disease care;
- Improve discharge planning and establish agreed referral pathways, communication between professionals and across organisations, including through integrated case management and patient information management to better integrate within and between services and sector;

**GOAL:** Monitor and evaluate the implementation of the Plan and health system changes that result in better health care of Aboriginal people.

### Rationale

- Monitoring and evaluation of this Plan is currently occurring through the SA Aboriginal Chronic Disease Consortium;
  - The existing monitoring and evaluation framework needs to be revised to include indicators and areas that are not currently in the framework;
  - An improvement is needed in the timely release of data to enable effective monitoring and evaluation;
  - It will be important to have in place good systems to monitor the impact of collective efforts at a population level;
  - Aboriginal people should be involved in determining what is important to them and must be involved in monitoring and evaluating the impact of policy initiatives on health and wellbeing;
  - The continuous quality improvement (CQI) process aims to improve the quality of Primary Health Care (PHC), using evidence-based frameworks. Ideally, it is inclusive of all staff and allows for the objective analysis of clinical health results and a staff review of systems, which are used to inform positive improvements in healthcare; and
  - CQI results do show that there are varying degrees of quality across PHC services. Those PHC services in most need should be supported to improve the quality of care they provide.
- ### Pathways to action
- Review and modify the existing monitoring and evaluation framework to measure and report on the impact of the SA Aboriginal Cancer Plan. The following should be monitored and evaluated:
    - Implementation of actions;
    - The CCC partner projects that address priority areas and actions of the Plan;
    - Community involvement and intersectoral partnerships;
    - A process to adapt to the new needs of community; and
    - Maintain an up-to-date evidence based.
  - Develop a system to evaluate the provision of culturally safe care on an ongoing basis in all areas of the health system, including private general practice and its impact on service use by Aboriginal people (use the cultural safety in healthcare for Indigenous Australians: monitoring framework as a guide<sup>42</sup>);
  - Improve processes to accurately identify Aboriginal status across pathways of care (i.e., primary, secondary and tertiary levels of care);
  - Ensure reliability of data on participation rates in screening;
  - Monitor and respond to changes in geographical distribution of the Aboriginal community for future planning and include forced migration to metropolitan areas for health service reasons;
  - Support ongoing engagement and implementation of CQI processes and systems in all PHC services in SA;
  - Integrate CQI into all health services;
  - Investigate with the PHNs establishing a CQI program within the private general practice sector that includes performance-based payments and annual reporting against the national key performance indicators;

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- All SA Health services to complete an Aboriginal Health Impact Statement for all Aboriginal cancer services, projects and programs;
  - Monitor and report on HPV and Hep B immunisation rates in the Aboriginal population with an emphasis on data quality and currency to ensure accuracy and timeliness of reporting;
  - Support research and evaluation on tobacco control, smoking cessation and alcohol harm minimisation programs in Aboriginal communities to improve and gain an understanding as to why and how interventions work with Aboriginal populations;
  - Monitor strategies that promote regular exercise, healthy weight and a diet rich in fruit and vegetables to not only decrease cancer incidence but also impact on or prevent many other chronic diseases;
  - Evaluate the impact of the use of telehealth with Aboriginal clients and carers;
  - Enable SA Health to coordinate the monitoring and reporting of cancer screening participation rates for Aboriginal people across all programs for inclusion in routine reporting;
  - Monitor the number of Aboriginal people receiving treatment in the regional chemotherapy units throughout SA;
  - Identify sensitive quality indicators that allow the monitoring and evaluation of Aboriginal people with cancer across the OCPs;
  - Monitoring of the number of Aboriginal people in SA with cancer having an Advance Care Directive;
  - Implement strategies that improve statewide Aboriginal cancer activity data collection and monitoring to inform and enable system and service level design that increases timely access to well-coordinated care with the most appropriate provider / carer and location; and
  - Continue to evaluate how Aboriginal Cancer Care Coordinator roles are integrated.

# Monitoring Progress of the SA Aboriginal Cancer Plan 2022-2027

The table below lists the **7 priority areas** and its **24 actions** and **8 enablers** of this Plan. To map the progress made against action, a traffic light system approach will be used. Red indicates that there is no work that has commenced against this action, yellow shows that the action has commenced but is not completed and green highlights that the action is completed.

STAGE	ACTION	OUTCOME
<b>Awareness and prevention</b>	1. Collaborate with Aboriginal Community Controlled Health Organisations (ACCHOs), Wellbeing SA, the Adelaide and Country SA Primary Health Networks (PHNs), Cancer Council SA and Cancer Australia to improve knowledge within Aboriginal communities to act on cancer risk and symptoms through specific preventive programs.	Increase Aboriginal peoples' awareness and understanding of cancer prevention and treatment strategies through culturally appropriate and effective programs. Increase Aboriginal people's participation rates in Human Papilloma Virus (HPV) and Hepatitis B (Hep B) immunisation.
	2. Work with non-government organisations, other agencies and SA Aboriginal communities through narratives and positive stories to dispel myths and stigma around cancer, being respectful of cultural beliefs.	
	3. SA Health and Cancer Council SA will continue to work in partnership with ACCHOs, community organisations, Elders, and communities to decrease smoking prevalence and alcohol consumption in the Aboriginal population.	
	4. Pursue opportunities to collaborate on Public Health Strategies to maximise and develop strategies that promote regular exercise, healthy weight and a diet rich in fruit and vegetables to not only decrease cancer incidence but also impact on or prevent many other chronic diseases.	
<b>Screening and Early Detection</b>	5. Work with the ACCHO sector, the Adelaide and Country SA PHN, the 6 Local Health Networks (LHNs) and Women's and Children's LHN to increase screening rates for people living in rural and remote areas.	Increase Aboriginal peoples' participation rates in cancer screening programs.
	6. Prioritise initiatives that facilitate collaboration between cancer screening programs in SA, drawing on learnings, experiences and resources to promote awareness of, overcome barriers to and encourage greater participation rates in cancer screening.	
	7. Continue to promote and implement national screening programs (e.g., National Bowel Cancer Screening Program), state screening programs (e.g., Well Women's Program, Breast Screen SA Mobile Screening unit) and other innovative models (e.g., "One Stop Screening Shop") that increase participation of Aboriginal men and women in cancer screening in SA.	
	8. Lower the age eligibility criteria for bowel cancer screening of Aboriginal people and support the ACCHO sector to implement alternative pathways.	

<b>Diagnosis and Staging</b>	9. Include Aboriginal status on all screening, diagnostic pathology, radiology and other requests and reports.	Ensure coordinated and timely access to diagnostic services.
	10. Support initiatives that enable coordinated and timely access to diagnostic services for Aboriginal people, particularly those living in remote areas.	
<b>Treatment</b>	11. Develop, implement and monitor utilisation of telehealth consultations for/by Aboriginal people to enable understanding of current usage and future potential whilst promoting ongoing and increased utilisation.	Continual improvement of access to safe, timely, optimal, equitable and culturally appropriate treatment services for Aboriginal people in South Australia.
	12. Utilise Clinical Service Capability Frameworks to guide and maximise access to safe and appropriate care as close to home as possible.	
	13. Engage in activities and initiatives that promote greater understanding and collaboration between Aboriginal Traditional Healers and health professionals in SA.	
<b>Care Coordination</b>	14. Collaborate with PHNs Closing the Gap (CTG) programs to strengthen cancer coordination pathways across the cancer care continuum.	Improve coordination, assessment and management, of clinical and supportive care needs for Aboriginal people with cancer.
<b>Supportive Care</b>	15. Identify, implement and evaluate culturally appropriate and acceptable tools and templates (including needs assessment tools) for Aboriginal people with cancer and cancer survivors to be incorporated within the SA Survivorship Framework and cancer registries.	Increase understanding of, provision of, and access to culturally appropriate supportive care for Aboriginal people with cancer and their families across the cancer care continuum.
	16. Collaborate with PHNs to further promote and encourage the uptake of incentives available to GPs to provide supportive and follow-up care for Aboriginal people with the PHC setting and ACCHO Sector.	
	17. Collaborate with PHNs to promote culturally appropriate, community-based conversations about the care of Aboriginal people whose cancer is incurable, including conversations about the importance of identifying who would speak on the person's behalf, if they were unable.	
	18. Increase awareness and uptake of the number of Aboriginal people in SA with cancer having an Advance Care Directive.	
	19. Support initiatives that facilitate Aboriginal health services and community services to establish and maintain Aboriginal cancer support groups or Yarning circles across SA.	



<b>Service Outcomes Data and Research</b>	20. Develop Aboriginal Cancer Patient Reported Experience Measures (PREM) and Aboriginal Patient Reported Outcome Measures (PROM) to routinely capture the quality and outcomes of care from the perspective of Aboriginal clients to inform care delivery.	Develop a better evidence base to measure the effectiveness of cancer related services for Aboriginal people. Identify areas of excellence, service gaps and inform opportunity to improve client outcomes and experience.
	21. Develop and utilise specific Aboriginal quality indicators that are sensitive to Aboriginal people's needs to monitor and evaluate care along Optimal Care Pathways (OCPs).	
	22. Scope opportunities for further collaborative research to understand and address specific needs of Aboriginal children, adolescents and young adults with cancer, cancer survivors and their families.	
	23. Continue to conduct high quality cancer research to inform evidence-based, continually improving practice.	
	24. Provide where appropriate, easy-to-understand cancer information that supports Aboriginal people experiencing cancer, their families and carers to be involved with cancer research.	

ENABLERS	ACTIONS	OUTCOME
<b>Governance: Aboriginal Leadership and Partnerships</b>	Refer to 'Governance' section for a full list of actions.	Establish and maintain robust governance structures, led by Aboriginal professionals and organisations, equipped to foster partnerships and collaboration between the wide range of organisations and stakeholders responsible for implementing this Plan.
<b>Sustainable Funding</b>	Refer to 'Sustainable Funding' section for a full list of actions.	Appropriate levels of funding to be available for implementation of projects and services within appropriate timeframes.
<b>A Strong Cancer Workforce</b>	Refer to 'A Strong Cancer Workforce' section for a full list of actions.	Increase the capacity and capability of the Aboriginal and non-Aboriginal workforce to provide high quality, culturally responsive, collaborative cancer care.
<b>Transport and Accommodation Support</b>	Refer to 'Transport and Accommodation Support' section for a full list of actions.	Improve access to health care through transportation (ensuring Aboriginal people have safe and appropriate home-to-care-to-home journeys) and culturally appropriate accommodation options for Aboriginal people.
<b>Information and Communication Technology (ICT) Solutions</b>	Refer to 'ICT Solutions' section for a full list of actions.	Invest in resources, coordination and systems for telehealth and virtual care. Also improve the utilisation and communication of information across patient information management systems.
<b>Community Engagement</b>	Refer to 'Community Engagement' section for a full list of actions.	Meaningful engagement of Aboriginal people, families and communities must underpin the design and implementation of projects and services associated with this Plan.
<b>Integrated and Coordinated Services</b>	Refer to 'Integrated and Coordinated Services' section for a full list of actions.	Achieve continuity of care for Aboriginal people with cancer through culturally responsive, integrated and coordinated services.
<b>Monitoring and Evaluation</b>	Refer to 'Monitoring and Evaluation' section for a full list of actions.	Monitor and evaluate the implementation of the Plan and health system changes that result in better health care of Aboriginal people.

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# Appendix A

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We would like to thank the following stakeholders and organisations for their contribution to the revision of the SA Aboriginal Cancer Plan 2022-2027. We thank you all for taking the time to share your insights.

- Aboriginal Executive Directors
- Aboriginal Health Council of South Australia (AHCSA)
- Adelaide Primary Health Network
- BreastScreen SA
- Cancer Council SA
- SA Aboriginal Consortium Cancer Leadership Group
- SA Pharmacy
- Women's and Children's Hospital
- Youth Cancer Services SA/NT





SA ABORIGINAL  
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