

# South Australian Aboriginal Cancer Control Plan 2016-2021

Translating knowledge into action to improve the  
lives of Aboriginal people affected by cancer



Government  
of South Australia

SA Health

## Cover Artwork

# Into the Bloodstream

**Artist: Allan Sumner**

**Title: Into the Bloodstream**

**Inspired by Uncle Archie Roach's song  
'Into the bloodstream'**

The cover artwork is a story of my cancer journey. The footprints represent my journey travelling through different stages of my life from diagnosis, to treatment and survival.

My family was the most important part of my journey. They were the ones who pulled me through the good times and the bad times but most importantly, I felt loved. You can see my family pictured by the 'U' shaped symbols at the beginning and the end of my journey.

At the age of 19, I first noticed an ache and small bump on my testicle. I wasn't sure at first, I thought it would just go away. A few more weeks went by and I realised that the pain was not going away, so I decided to see my local GP and he examined me. My GP said that it was only a cyst and that it should soon go away by itself. So, being young and easily convinced I went back home hoping that the pain would just go away.

But within three days, I realised that there was something more wrong and I went back there to see my GP again. This time he didn't even examine me, he just sent me straight to a specialist at the Lyell McEwin hospital.

It was here that the specialist examined me and within minutes he told me that he thought I had testicular cancer. I was taken aback, and so shocked. I thought, how could this be happening to me? Within three days of seeing the specialist, I was examined further by ultrasound and after seeing a range of different cancer specialists it was decided that surgery was going to go ahead along with 9 months of follow up treatment.

Being only 19, I didn't really know what was going on. I didn't know what to expect and I didn't know what questions I needed to ask. My mother and father really didn't know what was going on either and couldn't understand the practitioners' language as the doctors were trying to explain my planned treatment.



It was so scary, I didn't know whether I was going to live or die. I had only been married to my wife 9 months prior to finding out about my cancer. As a young couple, we were faced with making some big decisions, which included taking a trip to the sperm bank. At the time, it was such an embarrassing situation and a very sensitive issue to talk about.

The artwork is a true reflection of my journey in hospital, meeting many different practitioners and doctors who talked to me about my treatment. I sat for hours in the chemotherapy suite as I was injected with a cocktail of chemotherapy drugs. Thankfully, I got to know a lady in the chemotherapy suite who, over the next six to eight months, talked to me about what to expect. She talked to me about the side-effects and some coping strategies.

Only two months into the treatment, I started losing my hair, I lost my eyebrows, my pubic hair and my facial hair. It was at this moment that I found out my wife was pregnant with my first son. Despite all the challenges I had to face, this gave me something to live for. I named my son Isaac, which means 'miracle child'.

It was only six months after I finished my treatment that my wife became pregnant with my second son, Samuel. My oncology doctor said that I would only have a five percent chance of having any children after treatment, but I guess I proved him wrong!

After five long years, I finally got the 'all clear' and my wife fell pregnant again with our youngest child, a daughter, Alanah. My family were there in the beginning and they were there in the end.

**Now I live my life like there's no tomorrow. I live for my children and I live for my family. It has been 20 years since my diagnosis with testicular cancer. I can truly say that I won the race and beat the odds.**

# Contents

Acknowledgements	2
Introduction	3
Executive Summary	4
Cultural Context	12
Features of Person-Centred Care for Aboriginal Peoples	14
Guiding Principles	16
Guiding Plans, Policies and Guidelines	18
National Aboriginal and Torres Strait Islander Cancer Framework	18
The South Australian Public Health Act (2011)	19
SA Public Health Plan (2013)	19
Snapshot of Cancer in Aboriginal Peoples	20
South Australian Priorities and Actions	21
Personal Stories from Aboriginal Community Members	38
APPENDIX A Cancer in Aboriginal South Australians	40
APPENDIX B Cancer Data and Aboriginal Disparities Research Project	46
APPENDIX C Consultation Process	47
APPENDIX D List of Contributors	49
APPENDIX E Acronyms	50
References	51

The South Australian Cancer Service Aboriginal Cancer Control Program, including the development of the South Australian Aboriginal Cancer Control Plan 2016-2021, was funded by the Closing the Gap Program through SA Health's Aboriginal Health Branch.

#### SA Cancer Service Project Team:

- Tracey Doherty, Service Director
- Janet Stajic, Senior Project Officer, Aboriginal Cancer Control
- Chantelle Hislop, Senior Project Officer, Survivorship
- Kate Cameron, Professional Nurse Lead
- Rama Ramanathan, Manager

For further information, please email:  
health.sacancerservice@sa.gov.au



# Acknowledgements

We acknowledge and respect the traditional custodians of Country throughout South Australia and acknowledge the deep feelings of attachment and relationship they have to their ancestral lands.

The South Australian Aboriginal Cancer Control Plan 2016-2021 was developed by the South Australian Cancer Service (SACS), SA Health in partnership with the following organisations:

- Aboriginal Health Council of South Australia Inc. (AHCSA)
- Cancer Council SA
- Cancer Data and Aboriginal Disparities (CanDAD) NHMRC Partnership Project, Wardliparingga Aboriginal Health Research Unit, South Australian Health and Medical Research Institute (SAHMRI)

We are particularly thankful for the contributions of Aboriginal people with cancer, their carers and family members. We acknowledge the sensitivity of the topic and appreciate their willingness and generosity in sharing their personal stories to improve cancer outcomes and experiences of Aboriginal people living with cancer and their families.

Thank you to the clinicians, researchers, administrators and health service managers, health workers and professionals from government and non-government organisations, including the Aboriginal Community Controlled Health Organisation (ACCHO) sector. We appreciate the wealth and depth of knowledge shared.

A special thank you to the members of the following committees which provided research, clinical, strategic and cultural guidance and advice in relation to the development of this plan:

- SA Aboriginal Cancer Control Governance Committee
- CanDAD Aboriginal Community Reference Group
- SACS Strategy Committee
- SA Aboriginal Health Partnership

We also acknowledge the previous work and contributions that informed the development of this plan, in particular:

- Perko Ngurratti 'Healing Messages' South Australia Aboriginal and Torres Strait Islander Cancer Forum, September 2006
- South Australia Aboriginal Cancer Control Planning Day, February 2015

For more information on the consultation process please see APPENDIX C – Consultation Process.

We assure all participants that their input through the consultation process is highly valued and has been taken on board. This plan includes priorities identified as having the greatest potential to generate action and achieve tangible outcomes over the next five years. Input received that may not be obvious in the plan will be used in the development of the implementation plan. We acknowledge and thank all contributors.

**Tracey Doherty**  
Acting Service Director  
SA Cancer Service

## FINDINGS

Findings from the CanDAD Project and quotations from participants, who were interviewed, are included in this Plan under conditions that were approved by the Aboriginal Health Research Ethics Committee (AHREC), SA Health HREC and University of South Australia HREC:

- SA Health (SA Cancer Service and BreastScreen SA) is an acknowledged Partner in the CanDAD NHMRC Partnership Project
- Each participant will own their data, having control over how it is used and stored (Sections G and H of AHREC Application)
- Signed consent forms having been collected from participants including:
  - Statements on the de-identified use of quotations from interviews
  - Consent to use words (but not names) in reports

# Introduction

As many of us know, as Aboriginal people, cancer is one of the hardest things to talk about and we know all too well that it is taking our family, friends and colleagues too often and too young.

This SA Aboriginal Cancer Control Plan demonstrates the commitment from SA Health to unite with its key partners, AHCSA, Cancer Council SA and SAHMRI, to make a difference. *The Aboriginal Companion Document to the Statewide Cancer Control Plan 2011–2015*[4] produced many great results, which have paved the way for this new Plan to advance to the next phase of increasing work in prevention, early intervention and survivorship.

Achievements to date include:

- Aboriginal and Torres Strait Islander Cancer Care Coordinator positions based in the Royal Adelaide Hospital to provide continuity of care through treatment, including surgery, chemotherapy, radiation therapy, and follow-up by facilitating assessment, management and evaluation of clinical and cultural supportive care needs.
- Formation of the Aboriginal and Torres Strait Islander Sub-Committee of the Statewide Cancer Clinical Network (now the SA Aboriginal Cancer Control Governance Committee of SA Cancer Service) to provide advice to SA Health on the best strategies to reduce the burden of cancer on Aboriginal peoples in SA across the cancer continuum by taking a broad system-wide approach and through meaningful engagement with the Aboriginal communities in SA.
- Development of nationally accredited cancer education for Aboriginal Health Professionals (HLTAHW035) to provide information and support around cancer.
- Development of nationally accredited peer support training 10577NAT Course in facilitating an Aboriginal and/or Torres Strait Islander cancer support group.
- Development of the CanDAD Partnership Research Project in SA. This project has a coalition of key organisations, working together to improve outcomes for Aboriginal people affected by cancer in a research environment.
- Increased breast screening participation rates by SA Aboriginal women from 29.5% in 2010-2011 to 41.2% in 2014-2015.

I'd like to acknowledge the driver of these two plans, the Perko Ngurratti *'Healing Messages'* *South Australian Aboriginal and Torres Strait Islander Cancer Forum* in September 2006[5]. The achievements to date came from this Forum, which represented the voices of many Aboriginal people, both community members and workers, on what needed to be done. We appreciate the hard work invested by so many to reach this point, and we now need to pay it forward to ensure that Aboriginal people in SA beat the odds in prevention, early diagnosis and ultimately in improving survival rates.

The SA Aboriginal Cancer Control Governance Committee plays a vital role in advocating for Aboriginal peoples in SA, living with cancer and their families, through a collaborative approach. They provide advice to SA Health at a strategic level for improved system change. This Committee will ensure that the Plan continues to deliver the recommended actions, connect the key stakeholders and partners and to make an impact at service delivery level, ensuring that the patient journey of an Aboriginal person with cancer is improved for the greater good.

Moving forward, there needs to be more work done and the implementation plan will be the vehicle for action. It will be developed in partnership with key policy and organisational stakeholders and in ongoing consultation with the SA Aboriginal community. For all of those we have loved and lost, this is where you can get involved. It is up to all of us to maintain the momentum and to continue the conversations loudly, and often.

We know about the data and the statistics. The next step is to promote survival and how to achieve it. We have dedicated Aboriginal role models in our community, who regularly share their stories of survival. We need to listen and learn to pay it forward. We CAN survive, we CAN live longer, we ARE stronger and we WILL beat cancer.

## **Amanda Mitchell**

Chairperson SA Aboriginal Cancer Control Governance Committee

Deputy Chief Executive Officer,  
Aboriginal Health Council  
of South Australia Inc.



## Executive Summary

The South Australian Aboriginal Cancer Control Plan 2016-2021 builds on the work and achievements of the previous plan (*Aboriginal Companion Document to the Statewide Cancer Control Plan 2011-2015*[4]) from which we have observed improvements in care coordination, breast screening participation rates, development of nationally accredited education for Aboriginal health professionals and the establishment of the CanDAD partnership research project. Whilst these are significant achievements and worthy of celebration, they only represent the beginning of actions and outcomes that need to be delivered in South Australia.

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, distress due to separation from family and community and misunderstandings due to language and cultural differences.

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.

The Plan sets the direction for the next five years with a focus on implementation and outcome monitoring of initiatives to reduce preventable cancers, detect cancer at an early stage and improve coordination and access to culturally sensitive Optimal Cancer Pathways. Alongside timely and effective diagnosis and treatment, current and evolving evidence, frameworks and technology will be used to ensure that supportive care (including palliative care and survivorship) needs are assessed and addressed. This will include initiatives that meet the diverse needs of age groups, community and location with a particular focus on accessibility for Aboriginal people living in remote parts of South Australia.

The Plan identifies nine priority areas and a series of actions identified to achieve each priority and is intended to be a living document. Therefore, there will be opportunities to update, re-align priorities and strengthen it based on new data, evidence, review of progress and input from the South Australian Aboriginal community.

## South Australian Priorities and Actions

### PRIORITY

#### Awareness and Prevention

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 Collaborate with Primary Health Networks in SA 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 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.

---

- 4 SA Health and Cancer Council SA will continue to work in partnership with Aboriginal Community Controlled Health Services, community organisations, Elders, and communities to decrease smoking prevalence and alcohol consumption in the Aboriginal population.

---

- 5 Support research and evaluation on 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.

---

- 6 Pursue opportunities to collaborate on Public Health strategies to maximise, develop and 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.

---

# Executive Summary

## South Australian Priorities and Actions (cont)

### PRIORITY

#### Screening and Early Detection

Increase Aboriginal peoples' participation rates in cancer screening programs.

### ACTIONS

- 7 Work with the Aboriginal Community Controlled Health sector, Country SA Primary Health Network, the Country Health SA Local Health Network and Women's and Children's Local Health Network to increase screening rates for people living in rural and remote areas.

---

- 8 Prioritise initiatives that facilitate collaboration between cancer screening programs in SA to:
  - 8.1 Draw on learnings, experiences and resources to promote awareness of, overcome barriers to and encourage greater participation rates of Aboriginal South Australians.
  - 8.2 Enable SA Health to coordinate the monitoring and reporting of cancer screening participation rates for Aboriginal people across all programs for inclusion in state based evaluation reports.

---

- 9 Continue to promote screening through targeted programs such as the Well Women's Program (cervical screening) and assist women to visit the Breast Screen SA Mobile Screening Unit when it visits remote communities.

---

- 10 Implement and adapt relevant national cancer screening programs and resources to support participation of Aboriginal people in screening within SA.

---

- 11 Explore need for and potential implications of lowering age eligibility criteria for population screening programs for Aboriginal people given that cancer diagnoses on average occur at a younger age.

### PRIORITY

#### Diagnosis and Staging

Ensure coordinated and timely access to diagnostic services.

### ACTIONS

- 12 Include Aboriginal status on all screening, diagnostic pathology, radiology and other requests and reports to:
  - 12.1 Improve the reliability of data on participation rates in screening.
  - 12.2 Enable routine recording and monitoring of stage at diagnosis for all Aboriginal people.

---

- 13 Support initiatives that enable coordinated and timely access to diagnostic services for Aboriginal people, particularly those living in remote areas.



## South Australian Priorities and Actions (cont)

### PRIORITY

#### Treatment

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

### ACTIONS

- 14 Monitor the number of Aboriginal people receiving treatment in the regional chemotherapy units throughout SA.
- 15 Monitor utilisation of telemedicine consultations for/by Aboriginal people to enable understanding of current usage and future potential whilst promoting ongoing and increased utilisation.
- 16 Utilise Clinical Service Capability Frameworks to guide and maximise access to safe and appropriate cancer care as close to home as possible.
- 17 Complete an Aboriginal Health Impact Statement while implementing new Optimal Care Pathways for SA.
- 18 Develop and utilise quality indicators that are sensitive to Aboriginal patient needs to monitor and evaluate care along Optimal Care Pathways.
- 19 Engage in activities and initiatives that promote greater understanding and collaboration between Aboriginal Traditional Healers and health professionals in SA.

### PRIORITY

#### Care Coordination

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

### ACTIONS

- 20 Sustain and continue to develop the current and potential roles that support and optimise cancer care coordination for Aboriginal people.
- 21 Collaborate with Primary Health Networks' Closing the Gap programs to strengthen cancer coordination pathways across the cancer care continuum.
- 22 Continue to evaluate how Aboriginal and Torres Strait Islander Cancer Care Coordinator roles are integrated and utilised to facilitate adoption of Optimal Care Pathways and changing clinical or service needs.
- 23 Implement and monitor usage of appropriate assessment and screening tools to identify clinical and supportive care needs of Aboriginal people from diagnosis through to survivorship or end-of-life care.

# Executive Summary

## South Australian Priorities and Actions (cont)

### PRIORITY

#### Supportive Care

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

- 24 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.
- 25 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.
- 26 Collaborate with Primary Health Networks 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 setting and Aboriginal Community Controlled Health Sector.
- 27 Collaborate with Primary Health Networks 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.
- 28 Increase awareness and monitoring of the number of Aboriginal people in SA with cancer having an Advance Care Directive.

### PRIORITY

#### Workforce

Build capacity of the health system to provide cancer care within a culturally safe environment, through optimal services for Aboriginal people with cancer in South Australia.

### ACTIONS

- 29 Build awareness and capacity of Aboriginal Health Workers/Practitioners (AHW/Ps) to deliver patient and community education across the cancer care continuum, including supporting AHW/Ps to undertake relevant cancer related training.
- 30 Support initiatives that facilitate Aboriginal health services and community services to establish and maintain Aboriginal cancer support groups or Yarning Circles.
- 31 Monitor utilisation and outcomes of cultural awareness and competence training for cancer care providers to improve confidence in delivery of cancer care and communication with Aboriginal people in a culturally safe manner.

## South Australian Priorities and Actions (cont)

### PRIORITY

#### Service Outcomes Data and Research

Develop a better evidence base to measure the effectiveness of cancer related services for Aboriginal patients. Identify areas of excellence, service gaps and inform opportunity to improve patient experience.

### ACTIONS

- 32 Utilise or develop Aboriginal Cancer Measures of Experience (ACME) or Patient Reported Outcome Measures (PROM) to routinely capture the quality and outcomes of care from the perspective of Aboriginal patients to inform care delivery.

---

- 33 Develop a participatory monitoring, evaluation and learning framework to measure and report on the impact of the SA Aboriginal Cancer Control Plan 2016-2021 annually.

---

- 34 Implement strategies that improve statewide 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.

### PRIORITY

#### Collaboration and Consumer Engagement

Ensure sustainability of a coalition of health organisations and consumers to advocate for Aboriginal cancer control issues, in collaboration and led by SA Health.

### ACTIONS

- 35 Support the continuation of the SA Aboriginal Cancer Control Governance Committee.

---

- 36 Actively engage with consumers and Primary Health Networks in cancer control decision making in SA.

---

- 37 Broaden existing partnerships between government, community, private and non-government organisations and other agencies to address the social determinants of health and support available for Aboriginal people with cancer, their carers and families.

# Executive Summary

## Next Steps

It is proposed that a SA Aboriginal Chronic Disease Consortium is established to govern the effective implementation of the three statewide chronic disease plans including:

- SA Aboriginal Cancer Control Plan 2016-21
- SA Aboriginal Diabetes Strategy and
- SA Aboriginal Heart and Stroke Plan

With a number of common strategies across the three plans, the Consortium enables a collaborative approach towards implementation and effective use of resources to meet 'across plan priorities' as well as actioning recommendations specific to each chronic disease, to address health outcome disparities for Aboriginal South Australians.

To action the priorities specific to cancer, the Consortium will work in partnership with the SA Aboriginal Cancer Control Governance Committee. It is proposed that the implementation will take place in two phases:

- **Phase 1** Develop the implementation plan for the three plans and 'across plan priorities'. This would be completed by June 2017.
- **Phase 2** Lead, manage and report against the progress of implementation. The time period would be July 2017- June 2021.

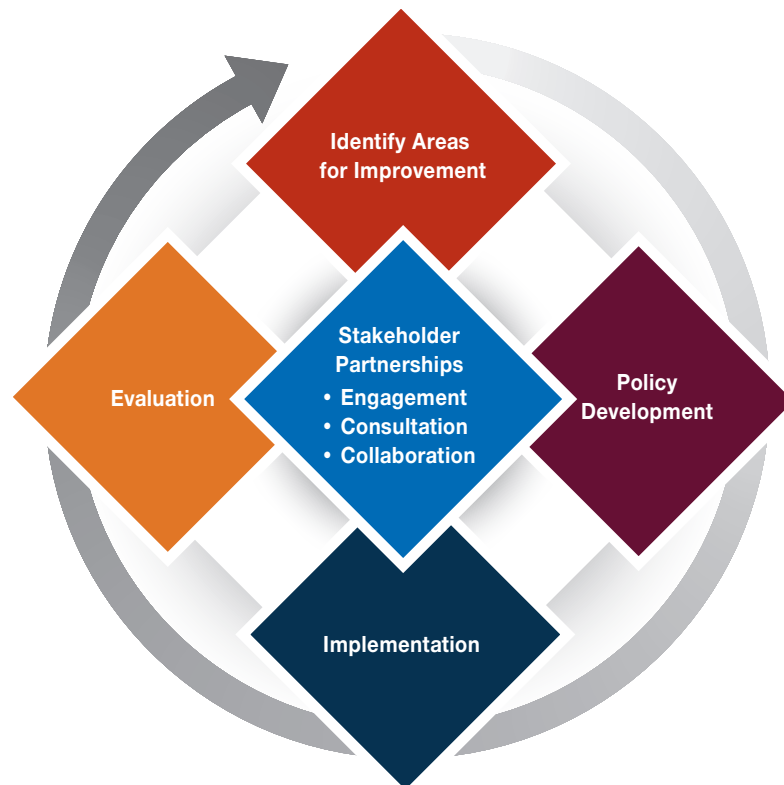
The SA Aboriginal Chronic Disease Consortium would be a working group of the SA Academic Health Science and Translation Centre and hence have a direct reporting line to the Translation Centre Executive Management Committee. The SA Academic Health Science and Translation Centre is a partnership of SA Health, SAHMRI, The University of Adelaide, Flinders University, University of South Australia, AHCSA, Health Consumers Alliance of South Australia, Adelaide Primary Health Network, Country SA Primary Health Network and Cancer Council SA. The vision of the Translation Centre is to continuously enhance the rate of translation of research into healthcare in order to support a cost effective and efficient public health system.

Emerging evidence from research into Aboriginal Health issues and cancer, such as the CanDAD project and associated CanDAD concept mapping process, will also be useful to identify additional areas of focus for Aboriginal cancer control in South Australia (See page 36) into the future.

A patient-reported experience measure (PREM) such as the ACME, under development by SAHMRI and University of South Australia (UniSA) should continue to be developed and tested within health service and community environments to maximise opportunity to enable real-time data linkage for the ongoing monitoring of Aboriginal disparities and inequities in cancer screening, diagnosis, treatment and post-treatment care. This work would ideally be undertaken using a partnership approach including Researchers, Health Service planners and providers, an Aboriginal Community Reference Group, Aboriginal Community Controlled Health Organisations, Non-Government Organisations, other Aboriginal health networks, carers and cancer support groups, and individual survivors.

**Diagram 1: South Australian Aboriginal Cancer Control Plan 2016-2021  
Change Management Model**

This figure indicates the process for change management whereby stakeholder partnerships, relationships and involvement are central for the updating and re-alignment of priorities and strengthening of the Plan based on new data, evidence, review of progress and ongoing input from the community.



# Cultural Context

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 peoples 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 peoples and should be both acknowledged and respected for each individual and their cancer story/pathway, especially the link between culture, land and cancer.

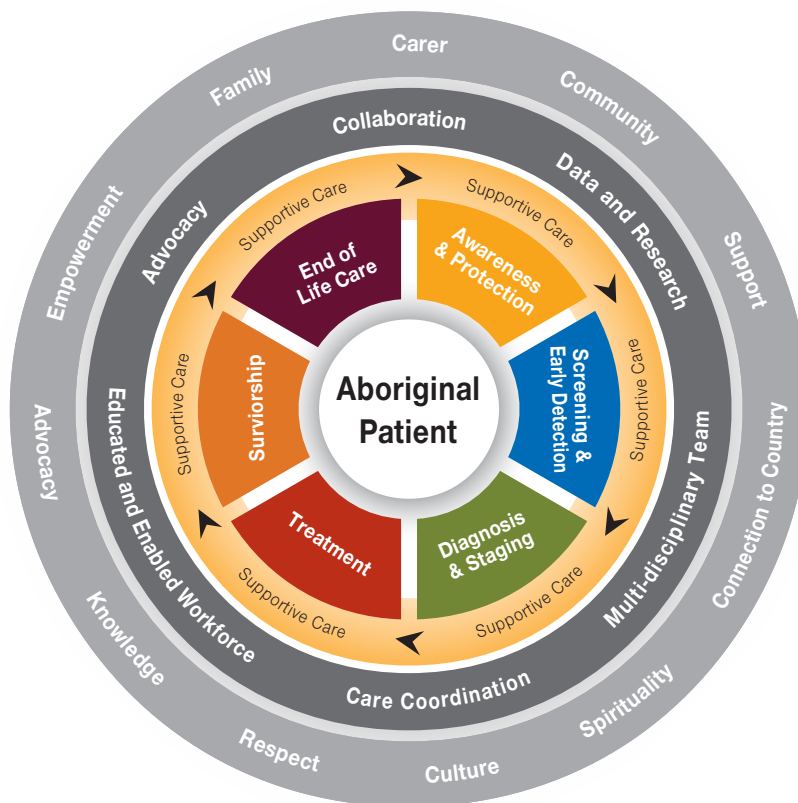
## Use of the Term 'Aboriginal'

As requested by the SA Aboriginal community, the term 'Aboriginal' is used respectively in this Plan as an all-encompassing term for Aboriginal and/or Torres Strait Islander people living in SA. The term Torres Strait Islander is specifically used where reference is made to Aboriginal and/or Torres Strait Islander people at a national level or where it is used in position titles and titles of publications and programs.

## Aboriginal Health Definition

'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. National Aboriginal Health Strategy, 1989.

**Diagram 2: Aboriginal Cancer Patient Pathway – Wellbeing Model**



This model was developed by SACS to support the Aboriginal health definition – that Aboriginal health is holistic.

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 patient with cancer's wellbeing from the system level, and the outer light grey circle lists the overarching enablers from a personal and cultural perspective.

## A Wellbeing Framework for Aboriginal and Torres Strait Islander Peoples 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 peoples 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 peoples. It also sets out four essential elements to assist healthcare services to support the wellbeing of Aboriginal and Torres Strait Islander peoples living with chronic disease. Every element is supported by four principles. Underpinning each principle is a number of 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[6].

WELLBEING FRAMEWORK	
Wellbeing is supported by upholding peoples' identities in connection to culture, spirituality, families, communities and Country. Wellbeing is supported by culturally safe primary healthcare services.	
<b>ELEMENT 1</b>	<p><b>Wellbeing is supported by locally defined, culturally safe primary healthcare services.</b></p> <ul style="list-style-type: none"> <li>• Creating culturally welcoming places.</li> <li>• Developing trusting relationships with clients and communities.</li> <li>• Understanding and accepting cultural diversity within communities.</li> <li>• Delivering flexible primary healthcare services both within and outside of healthcare facilities.</li> </ul>
<b>ELEMENT 2</b>	<p><b>Wellbeing is supported by an appropriately skilled and culturally competent healthcare team.</b></p> <ul style="list-style-type: none"> <li>• Ensuring that all staff are culturally competent.</li> <li>• Equipping staff with suitable skills to support people with chronic disease.</li> <li>• Valuing and supporting Aboriginal and Torres Strait Islander staff.</li> <li>• Developing effective cultural leadership.</li> </ul>
<b>ELEMENT 3</b>	<p><b>Wellbeing is supported by holistic care throughout the life span.</b></p> <ul style="list-style-type: none"> <li>• Applying holistic approaches that address priorities determined with clients.</li> <li>• Life-course approach from preconception to post-mortality.</li> <li>• Ensuring appropriate resources are available to meet local priorities and need.</li> <li>• Responding to family, community, cultural and spiritual responsibilities and obligations.</li> </ul>
<b>ELEMENT 4</b>	<p><b>Wellbeing is supported by best practice care that addresses the particular needs of a community.</b></p> <ul style="list-style-type: none"> <li>• Utilising cultural and scientific evidence to provide best practice healthcare.</li> <li>• Ensuring that primary healthcare services are available, accessible and acceptable.</li> <li>• Empowering communities to be involved in determining local healthcare priorities.</li> <li>• Developing multi-disciplinary teams that support holistic care.</li> </ul>



# Features of Person-Centred Care for Aboriginal Peoples

## **Aboriginal peoples have a holistic view of health and wellbeing**

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

## **Structured and busy specialist clinical services may not cater well for the cultural needs of Aboriginal peoples**

- 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.
- Without cultural and allied support, patients can become lost in unfamiliar health service environments they do not understand and where their needs are poorly understood.

## **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.
- For example, it is often not appropriate for Aboriginal men to discuss any part of their body in the presence of a woman.

## **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.
- Aboriginal health is more of a collective consideration about family and community, therefore individualistic decision-making rarely occurs within Aboriginal society.

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

- Aboriginal peoples 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 remote, regional or metropolitan areas.
- Some patients may be reluctant to leave their community for treatment, even though this care may only be available in a metropolitan setting.



**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 dialects. 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.
- 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 wrong doing, punishment and they are deserving of the illness.

Adapted from the SA Health, *South Australian Lung Cancer Pathway*, 2013[7].



# Guiding Principles

The SA Aboriginal Cancer Control Plan 2016-2021 is underpinned by the following guiding principles which are in line with the *SA Health Aboriginal Health Care Plan*[8] and the *South Australian Aboriginal Health Research Accord*[9].

## **Cultural Respect**

Respecting the cultural diversity, views, values and expectations of Aboriginal peoples within the planning and development of health and wellbeing programs and services.

## **Community Control**

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

## **Holistic Approach**

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

## **Local Planning**

Aboriginal peoples' central involvement 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.

## **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.

## **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.

## **Resources**

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

### **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.

### **Accountability**

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 partnerships with communities; government maintaining responsibilities for ensuring all Aboriginal peoples have access to appropriate and effective healthcare.

### **Diversity**

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

### **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.

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

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

### **Teamwork**

A multidisciplinary approach to primary healthcare in particular, which crucially involves the employment of Aboriginal community members, and includes continuous training and support; includes, where appropriate, regionally organised service delivery and outreach services to dispersed populations.

## Guiding Plans, Policies and Guidelines

The South Australian Aboriginal Cancer Control Plan 2016-2021 has been informed by a number of key national and state source documents to ensure consistency and alignment with the most up to date, evidence – based policies, plans, practices and future directions including:

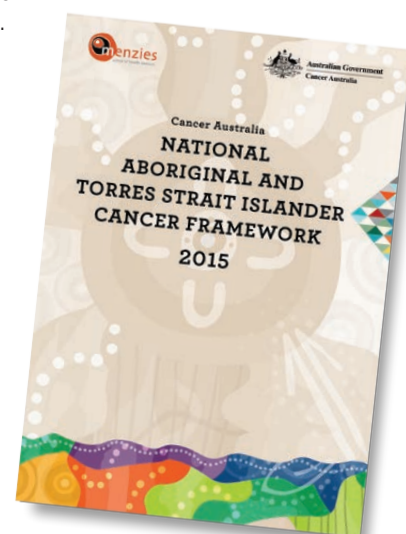
- National Aboriginal and Torres Strait Islander Cancer Framework (2015)
- SA Health Aboriginal Health Care Plan (2013)
- The South Australian Aboriginal Health Research Accord
- The South Australian Public Health Act (2011)
- SA Public Health Plan - South Australia: A better place to live (2013)
- Transforming Health Discussion Paper (2014)
- The Optimal Cancer Care Pathways (OCP)
- SA Health Clinical Service Capabilities Framework
- South Australian Survivorship Framework

## National Aboriginal and Torres Strait Islander Cancer Framework

Nationally, reducing the inequities in cancer outcomes for Aboriginal and Torres Strait Islander peoples is becoming a health priority and recognised within the *National Aboriginal and Torres Strait Islander Health Plan 2013–2023*[10]. In 2015 Cancer Australia released the *National Aboriginal and Torres Strait Islander Cancer Framework*[11]. The framework provides high-level guidance and direction for the many individuals, communities, organisations and governments whose combined efforts are required to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander peoples.

The national priorities aim to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples by ensuring timely access to good quality and appropriate cancer related services across the cancer continuum. These include:

1. Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum).
2. Focus prevention activities to address specific barriers and enablers to minimise cancer risk for Aboriginal and Torres Strait Islander peoples.
3. Increase access to and participation in cancer screening and immunisation for the prevention and early detection of cancers.
4. Ensure early diagnosis of symptomatic cancers.
5. Ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care.
6. Ensure families and carers of Aboriginal and Torres Strait Islander people with cancer are involved, informed, supported and enabled throughout the cancer experience.
7. Strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people.



Care has been taken to ensure that the SA priorities align to the national priorities and capture the key issues raised via the consultation process.

## The South Australian Public Health Act (2011)

*The South Australian Public Health Act, 2011*[1] provides a broad legislative and policy framework for a whole of government approach to public health action, including disease prevention.

Through this Act, the health sector, including SA Health, has an important leadership role in the prevention of cancer.

The Act identifies opportunities for promoting public health for other key sectors and agencies. For example, workplaces, community organisations, schools and early childhood services provide opportunities to inform people about healthy lifestyles and ensure healthy and safe environments and practices that minimise exposure to harmful elements, such as sun or pollutants.

Government departments responsible for education, public transport, infrastructure and the environment can all contribute to actions that prevent ill health.

Local Councils play a role in the planning, provision and regulation of public spaces that encourage and support safe physical activity; supporting access to healthy food and food security; promoting smoke free areas; and reducing harm from excessive alcohol consumption.

## SA Public Health Plan (2013)

The SA Public Health Plan (2013) – *South Australia: A better place to live*[2] encourages local councils to assist with the prevention of non-communicable diseases, including cancer, by building systems and responses addressing five strategic priorities:

1. Stronger and Healthier Communities and Neighbourhoods for All Generations
2. Increasing Opportunities for Healthy Living
3. Healthy Eating and Being Active
4. Preparing for Climate Change; and
5. Sustaining and Improving Public and Environmental Health Protection.

Council action across these priorities has the potential to reduce non-communicable disease incidence and prevalence, including for cancer, through action to mitigate risks, raise awareness, promote action and improve resilience.

There is also an important role for non-government and community controlled sectors, communities and other agencies, including research institutions engaging in cancer control, to promote, inform and advocate for legislative, policy and structural changes.



# Snapshot of Cancer in Aboriginal Peoples

## Mortality

- Cancer is the second most common cause of death for Aboriginal Australians (20.0%), following cardiovascular disease[12].

## Mortality Rate

- Aboriginal Australians have a slightly lower rate of cancer diagnosis but a 30.0% higher mortality rate than non-Indigenous Australians (221 and 172 per 100,000 respectively, age standardised mortality)[12].

## Burden of Disease

- Rate of cancer burden between 2003 and 2011 increased by 5.7% for Aboriginal Australians (53.9 disability adjusted life years (DALYs) per 1000 in 2011) while non-Aboriginal Australian rates improved, decreasing by 10.6% from 37.9 to 33.9 DALYs per 1000 persons in this same time period[13].

## Stage at Diagnosis

- Aboriginal Australians are more likely than non-Aboriginal Australians to be diagnosed at a more advanced stage of cancer development.

## Survival after Diagnosis

- Aboriginal Australians are much less likely to survive five years following a cancer diagnosis (40.0%) than non-Aboriginal Australians (52.0%), with survival shortfalls particularly evident within the first year (61.0% Aboriginal and 74.0% non-Aboriginal).

## Area Remoteness

- Aboriginal people living in regional or remote areas of Australia have a slightly higher incidence rate than Aboriginal people living in metropolitan areas and are more likely to be diagnosed at a more advanced stage of cancer development.

## Types of Cancer

- Aboriginal Australians have a high incidence of preventable cancers that are more likely to have poorer prognoses (lung, throat and primary liver cancer)[14].
- The most common cancers experienced by Aboriginal Australians following lung cancer are breast cancer (among women), bowel cancer and prostate cancer[14].
- Some cancers occur more commonly for Aboriginal Australians than for non-Aboriginal Australians (lung, liver, mouth, throat and cervical cancers), while others occur less commonly (prostate, bowel, skin, and breast cancer among women)[14].

## Risk Factors

- Aboriginal people in Australia have higher levels of modifiable cancer risk factors including smoking, risky alcohol consumption, poor diet, low levels of physical activity and high levels of infection such as Hep B infection[15].
- Although improving, smoking rates in Aboriginal Australians remain higher than in the wider Australian population with smoking being the major cause of cancer-related deaths in Aboriginal Australians.

## Screening Rates

- Aboriginal Australians are less likely to participate in cancer screening programs than non-Aboriginal people[15].

## Co-morbidities and Treatment

- Aboriginal Australians have higher rates of co-morbidities and are less likely to receive adequate treatment or to be hospitalised for cancer[12].

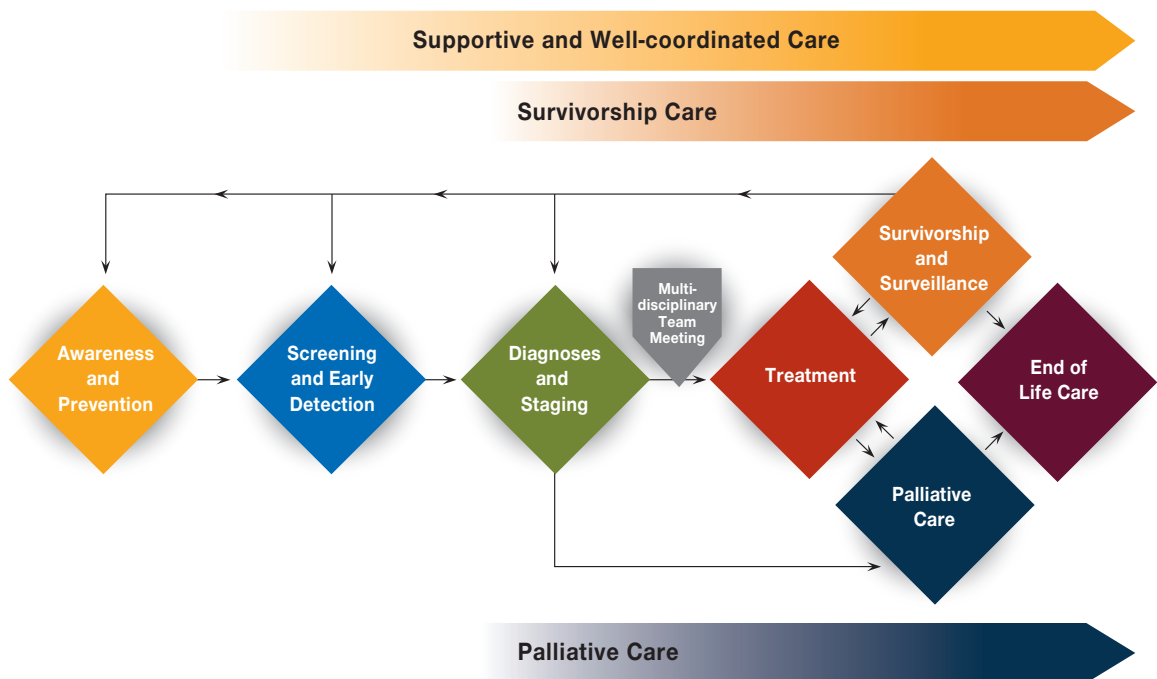
For a more detailed look at data relating to Aboriginal South Australians from the CanDAD Research Project, Aboriginal Cancer Data System (ACaDS), see Appendix A – Cancer in Aboriginal South Australians.

# South Australian Priorities and Actions

## The Cancer Care Continuum

The following diagram depicts the entire cancer care continuum from awareness and prevention through to survivorship and end-of-life care. It acknowledges the common pathways that a person with cancer may experience following diagnosis and includes the ongoing assessment and provision of supportive care throughout the cancer continuum. In this model, both survivorship care and palliative care are considered essential elements of good supportive care. With a focus on wellness in survivorship, preventive and screening practices are further encouraged during cancer surveillance and monitoring.

**Diagram 3: The Cancer Care Continuum**



# South Australian Priorities and Actions

## PRIORITIES

### Awareness and Prevention

Increase Aboriginal peoples' awareness and understanding of cancer prevention and treatment strategies through culturally appropriate and effective programs.

Increase Aboriginal peoples' participation rates in HPV and Hep B immunisation.

## ACTIONS

- 1 Collaborate with Primary Health Networks in SA 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 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.
- 4 SA Health and Cancer Council SA will continue to work in partnership with Aboriginal Community Controlled Health Services, community organisations, Elders, and communities to decrease smoking prevalence and alcohol consumption in the Aboriginal population.
- 5 Support research and evaluation on 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.
- 6 Pursue opportunities to collaborate on Public Health strategies to maximise, develop and 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.

'All of our young kids are losing out on – not on their culture, where they can go out and find out where their bush tucker is. But we can teach our kids that. A lot of mob, more people are coming into the town and living like fast food, a lot of old people are on the pension, drugs. And when they get sick they don't know how it happens, why it happens.' AP020

'...About people passing away with cancer and, I mean, that's a big one – that's why people don't want to know about it and don't want to talk about it as well. Because we do have a lot of people who just don't make it because – you know, late stage diagnosis. And that's a big thing, yeah.' SP001

**CanDAD Research Project**



## Risk Factors

Understanding the causes of cancer is important for prevention. However, the causes are not fully understood. Some factors are known to contribute to the development of cancer including biomedical, environmental and lifestyle.

The World Health Organisation (WHO) estimates that of all cancer cases, one third are preventable with the adoption of healthy lifestyle choices. The number of avoidable cancer deaths has the potential to further reduce to over half, by combining healthy lifestyles with regular screening. From a population-based approach, prevention is the most cost-effective, long-term strategy for cancer control[16].

*Position statement – Lifestyle risk factors and the primary prevention of cancer* released by Cancer Australia (2015), provides the following recommendations to reduce the risk of cancer and stay healthy for adults[17]:

1. Avoid smoking
2. Be active
3. Maintain a healthy weight
4. Eat a balanced and nutritious diet
5. Limit alcohol intake
6. Be sun smart
7. Reduce risk and protect against infection, including vaccinations for Hep B and HPV

According to the *Aboriginal and Torres Strait Islander Health Performance Framework 2014 Report: South Australia*[18] of Aboriginal Australians aged 15 years and over:

- 42.0% reported being a current smoker
- Aboriginal people were less likely to have experienced sufficient activity levels in the past week when compared to non-Aboriginal Australians
- 65.0% were either overweight or obese
- 62.0% and 96.0% reported inadequate daily intake of fruit and vegetables (respectively) when compared to the 2013 National Health and Medical Research Council (NHMRC) guidelines
- 21.0% consumed alcohol at rates that exceeded the 2009 NHMRC lifetime risk guidelines

## Immunisation

Immunisation is a simple, safe and effective way of protecting people against harmful diseases as it not only protects, but also significantly reduces transmission in the community.

Australia has a low prevalence of Hep B infection, although Aboriginal infection rates are comparable to rates in countries with a high prevalence. Although Aboriginal people are no less likely to complete the Hep B vaccination schedule than the wider population, high liver cancer incidence in Aboriginal people suggests that further emphasis should be placed on Hep B vaccination and broader infection control in this population.

HPV infection is a precursor to cervical cancer. HPV vaccination is effective against the two most common types of HPV (types 16 and 18), which are responsible for about 70.0% of cervical cancers. Aboriginal women are up to four times more likely to die of cervical cancer than other Australian women; therefore HPV vaccination for Aboriginal women prior to them becoming sexually active should be a high priority, including increasing awareness of the availability and its role in prevention.

# South Australian Priorities and Actions

The HPV vaccination is available for free for both girls and boys between the ages of 12-13 years, offered within the first year of secondary school (year 8) in South Australia or from a local immunisation provider or doctor. Vaccination at this age is most effective, however, is licensed for males aged 9-26 years and females aged 9-45 years with an associated cost over 14 years. Encouraging the participation of Aboriginal children, particularly between 12-13 years of age in the National HPV Vaccination Program should be a high priority.

## Awareness

Even with the understanding of the role of lifestyle factors in health, Aboriginal people tend to respond to symptoms, rather than focussing on prevention[11].

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[11,19]. These factors together with the traditional beliefs that some Aboriginal people hold such as sickness being caused by spiritual means make cancer a difficult topic to discuss[20].

Primary healthcare providers and a number of non-government organisations (including Cancer Council SA, Heart Foundation and Kidney Health) 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. Collaboration and partnering with these providers may assist in establishing more effective strategies to address misconceptions and promotion of healthy lifestyles.

### PRIORITY

#### Screening and Early Detection

Increase Aboriginal peoples' participation rates in cancer screening programs.

### ACTIONS

- 7 Work with the Aboriginal Community Controlled Health sector, Country SA Primary Health Network, the Country Health SA Local Health Network and Women's and Children's Local Health Network to increase screening rates for people living in rural and remote areas.

---

- 8 Prioritise initiatives that facilitate collaboration between cancer screening programs in SA to:
  - 8.1 Draw on learnings, experiences and resources to promote awareness of, overcome barriers to and encourage greater participation rates of Aboriginal South Australians.
  - 8.2 Enable SA Health to coordinate the monitoring and reporting of cancer screening participation rates for Aboriginal people across all programs for inclusion in state based evaluation reports.

---

- 9 Continue to promote screening through targeted programs such as the Well Women's Program (cervical screening) and assist women to visit the Breast Screen SA Mobile Screening Unit when it visits remote communities.

---

- 
- 10 Implement and adapt relevant national cancer screening programs and resources to support participation of Aboriginal people in screening within SA.
- 
- 11 Explore need for and potential implications of lowering age eligibility criteria for population screening programs for Aboriginal people, given that cancer diagnoses on average occur at a younger age.
- 

'I don't think they really know about what help they can get 'til they get too sick and end up in hospital that it's for them, they could have done early, you know?' APO20

'I think that the understanding is probably based a lot on myth and fear actually because there's even a great fear of entering a screening program in case there's a diagnosis of cancer. So they're really still understanding as a death sentence and also there's a fear of having to move away from your family to get treatment.' SP011

#### **CanDAD Research Project**

Early detection of cancer or precancerous conditions through screening is an important public health measure for reducing the burden of cancer. Currently, sufficient evidence for population screening exists for three types of cancer, with Australia having established national cancer screening programs in the following areas:

1. BreastScreen Australia
2. The National Cervical Screening Program
3. The National Bowel Cancer Screening Program

Evidence indicates that Aboriginal Australians are under-screened in comparison to non-Aboriginal Australians. Contributing factors may include:

- Cultural appropriateness of tests and screening services, including a lack of gender specific health workers (especially for matters relating to female reproductive organs which are considered to be women's business)[21, 22].
- Access to screening services, particularly for people living in rural and remote parts of SA and the logistics of undertaking, privacy, temperature control and storage issues of samples (particularly for bowel screening).
- Awareness and familiarity with cancer screening services, programs and their purpose and benefit for participation.

## **Participation Rates of Aboriginal People in Screening Programs**

### **BreastScreen South Australia**

- Whilst participation in breast screening in SA increased from 36.0% of Aboriginal women between 2010 and 2011 to 41.0% during 2014 and 2015, participation rates remain below those of non-Aboriginal women (54.0%)[23].

### **National Cervical Screening Program**

Limited data is available relating to participation rates of Aboriginal women in South Australia in the National Cervical Screening Program. This may be attributable to inconsistencies with the Aboriginal and Torres Strait Islander Identifier not being consistently captured on all pathology forms and translation of this into data systems. Across all South Australian women aged 20 to 69 years, participation rates in the NCSP for 2012-2013 was 58.0%.

# South Australian Priorities and Actions

The Australian Government will be making available a new primary HPV test on the Medicare Benefits Schedule from 1 May 2017, known as the 'Cervical Screening Test'. This will replace the current cytology based Pap test for cervical screening. The renewed National Cervical Screening Program will invite women aged 25 to 69 years with exit testing between 70 and 74 years, both HPV vaccinated and unvaccinated, to undertake a HPV test (Cervical Screening Test) every five years. A HPV test every five years is expected to be more effective, just as safe and to result in a significant reduction (24.0% – 36.0%) in incidence and mortality from cervical cancer in Australian women, compared with the program it replaces[25].

## **National Bowel Cancer Screening**

According to the *Australian Aboriginal and Torres Strait Islander Health Survey 2012-2013 in SA*[24]:

- 87.0% of Aboriginal men and 97.0% of Aboriginal women between the ages of 50 and 74 report that they have either never participated in a bowel screening test or did not know if they have done so, compared with 82.0% and 89.0%, respectively, at the national level.

*The National Bowel Cancer Screening Program 2013-2014 Monitoring Report* noted that overall in Australia:

- Participants who self-identified as Aboriginal and/or Torres Strait Islander had a higher positivity rate (12.1%) than those who reported as non-Indigenous (7.4%) or those who did not state their Indigenous status (9.7%).

## **Current work and projects underway to improve participation rates across screening programs**

Recognising the need to better monitor and further increase participation screening rates across all programs for Aboriginal people, strategies are currently in place at the national, state and territory level including:

- The Aboriginal and Torres Strait Islander Well Women's Screening Program for cervical screening, with one of the key aims to improve engagement with the community and other key stakeholders (government, non-government services, primary healthcare providers) to provide culturally appropriate services and education on the importance of screening and pathways.
- Menzies School of Health Research National Indigenous Bowel Screening Project funded by the Australian Government to develop a coordinated national approach to address bowel cancer awareness and screening for Aboriginal Australian's with an alternative bowel screening pathway, including education and training resources.
- Availability of newly translated resources across a number of community languages (including Pitjantjatjara) to create greater understanding of the reasons for bowel screening and how to use test kits provided.

South Australia will continue to seek opportunities to implement and adapt relevant National Cancer Screening recommendations and resources developed to promote screening amongst Aboriginal people within the SA context.

## Other Considerations

Currently, recommended age ranges for cancer screening programs is the same for Aboriginal and non-Aboriginal Australians irrespective of the knowledge that diagnoses are being made at a younger age for Aboriginal South Australians when compared to non-Aboriginal people, (refer to Appendix A, Figure A1: Age at cancer diagnosis in SA). Exploration of the benefits and potential implications of reducing the eligible age range, specifically for bowel and breast cancer of Aboriginal people to participate in screening programs is required. Doing so may have the potential to assist in reducing disparities, earlier cancer diagnosis and improved outcomes for Aboriginal people.

Opportunities exist for collaborative partnerships to be established between local SA representatives from each of the National Cancer Screening Programs to further explore the needs and create awareness across all programs with Aboriginal communities to improve participation rates.

### PRIORITY

#### Diagnosis and Staging

Ensure coordinated and timely access to diagnostic services.

### ACTIONS

- 12 Include Aboriginal status on all screening, diagnostic pathology, radiology and other requests and reports to:
  - 12.1 Improve the reliability of data on participation rates in screening.
  - 12.2 Enable routine recording and monitoring of stage at diagnosis for all Aboriginal people.
- 13 Support initiatives that enable coordinated and timely access to diagnostic services for Aboriginal people, particularly those living in remote areas.

Aboriginal Australians are often diagnosed with cancer at a more advanced stage (refer to Appendix A4: Stage at cancer diagnosis for further information and data), which can be influenced by poorer access to screening and diagnostic services. Opportunities to address issues and improve earlier diagnosis through access to services exist with the impending implementation of the Optimal Care Pathways in SA.

Even when diagnosed at the same stage, Aboriginal people with cancer generally experience worse outcomes than non-Aboriginal patients. This may be affected by the higher prevalence of risk factors and other health conditions (co-morbidities such as diabetes, heart and kidney disease) amongst the Aboriginal population, negatively impacting upon timely and effective treatment options as well as survival rates. These relationships present a clear need to describe and monitor the prevalence of co-morbid conditions experienced by people with cancer.

Stage at diagnosis is an important factor that further influences outcomes for cancers. The inclusion of Aboriginal status on all diagnostic pathology, radiology and other requests is important to initially monitor participation rates and data systems should be developed to collect stage at diagnosis[26].

Most Australian states and territories, including SA, are working towards collecting stage at diagnosis within the state based population registries. In SA, these data are captured for cancers included in the SA Clinical Cancer Registry.

The ACaDS, a component of the CanDAD project, is integrating SA cancer registry, hospital, radiotherapy and clinical data to comprehensively monitor cancer incidence trends, cancer management and survival. There is the potential for automating the collection of cancer stage information on a routine and ongoing basis for population cohorts covered by ACaDS.

# South Australian Priorities and Actions

## PRIORITY

### Treatment

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

## ACTIONS

- 14 Monitor the number of Aboriginal people receiving treatment in the regional chemotherapy units throughout SA.

---

- 15 Monitor utilisation of telemedicine consultations for/by Aboriginal people to enable understanding of current usage and future potential whilst promoting ongoing and increased utilisation.

---

- 16 Utilise Clinical Service Capability Frameworks to guide and maximise access to safe and appropriate cancer care as close to home as possible.

---

- 17 Complete an Aboriginal Health Impact Statement while implementing new Optimal Care Pathways for SA.

---

- 18 Develop and utilise quality indicators that are sensitive to Aboriginal patient needs to monitor and evaluate care along Optimal Care Pathways.

---

- 19 Engage in activities and initiatives that promote greater understanding and collaboration between Aboriginal Traditional Healers and health professionals in SA.

'We live in the tin shed there, we're talking about health and all that sort of thing, there's a lot of issues in regards to health in terms of people coming out from these sorts of treatments and then, they go back home and live in the environment where the dust and the friggin' wind blows between the sheets of iron, and I'm talking fair dinkum, I'm not romanticising.' AP006

### CanDAD Research Project

Aboriginal people are less likely to have cancer treatment, more likely to wait longer for surgery and be referred later for specialist treatment[27, 28]. They have lower levels of trust of hospitals and may experience institutional barriers to accessing appropriate healthcare[29]. Therefore, it becomes important for hospitals to 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[30].

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. It must be recognised that a significant proportion of cancer care sits outside acute cancer specialist services within Primary Health Networks. 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.

In 2010, the South Australian and Commonwealth Governments announced the provision of \$84.8 million to support increasing access to treatment and services closer to home for cancer patients, particularly for those living in rural and remote areas. Two key initiatives have been implemented since:

**1. Establishment of 15 Country Chemotherapy Units including a regional cancer centre**

Since the opening of the first country chemotherapy unit in 2013, over 7,600 chemotherapy administrations and 6,000 supportive care services (e.g. Iron infusions, blood transfusions) have been provided to country patients. These chemotherapy services have been provided under the supervision of visiting consultants or consultants located in metropolitan Adelaide.

**2. Implementation and utilisation of telemedicine within Country Health SA LHN**

From January 2013 to June 2015, over 1,000 telemedicine consultations have been performed for medical oncology, haematology and radiation oncology patients in country areas, reducing the need to travel. Increasing the use of telemedicine for haematology consultations and working with Aboriginal Health Services and patients to ensure services are provided in a culturally appropriate manner remain key priorities of country chemotherapy services.

Currently limited information is available relating to the usage and acceptability of telemedicine services by Aboriginal cancer patients and these characteristics require further exploration. Monitoring the number of Aboriginal people receiving treatment in regional chemotherapy units across SA is important in relation to access to services and closeness to home.

As SA continues to improve access for all, to safe and effective health services, a key focus over the next five years will be the statewide implementation of the Optimal Care Pathways and the Clinical Services Capability Frameworks:

**1. The Optimal Care Pathways (OCPs)**

These have been developed and led by the National Cancer Expert Reference Group (NCERG) and Victorian Health under the National Cancer Work Plan[31]. The OCPs are tumour specific guides for use by health services, cancer clinicians and patients to help them effectively navigate the complex cancer pathway based on available evidence and best-practice. Implementation of OCPs in SA will increase cost efficiencies, reduce unwarranted disparities in care and improve individual outcomes for cancer patients. Developing an Aboriginal Impact Statement and engaging with relevant stakeholders while implementing the OCPs is essential in addressing the specific needs, additional care coordination requirements and psychosocial complexities for Aboriginal people. This will also assist in promoting a smooth transition between settings and timely access to appropriate services at each stage from prevention and early detection through to end-of-life care for everyone affected by cancer. Monitoring and evaluation of the ability to meet the needs of Aboriginal cancer patients across the OCPs will be enhanced with the identification of sensitive quality indicators.

**2. SA Health Clinical Services Capability Framework (CSCF)**

As a part of Transforming Health[3], the CSCF outlines the minimum service requirements, workforce requirements, risk considerations and support services for health services to provide safe, coordinated, integrated and appropriately supported clinical service delivery. Six (of the 30) CSCF clinical service module speciality areas focus on cancer care, with up to 6 levels of service (1-6) identified within each. One of the key functions of the CSCF is to assess the service level profile of each hospital to ensure that safe and appropriate cancer care is provided closer to home for Aboriginal people living in all areas of SA.

SA Health recognises the important role Aboriginal Traditional Healers (referred to as Ngangkari in some SA Aboriginal language groups) have in contributing to improved health outcomes for Aboriginal South Australians. Traditional Healers have been practising for thousands of years and are esteemed members of the Aboriginal community, having a vital role in influencing and supporting the positive management and nurturing of the physical, social, emotional and cultural wellbeing of Aboriginal people.

# South Australian Priorities and Actions

The SA Health Traditional Healer Brokerage Program provides funding support to SA Health sites including hospitals, health services and clinics for Aboriginal clients to access the services of recognised Traditional Healers. Traditional Healers support Aboriginal clients/patients of SA Health by providing:

- Spiritual, social and emotional healing support and guidance which includes communicating in language and counselling on cultural beliefs and the life journey of an individual patient.
- Physical assessments and treatments.
- Traditional medicine.
- Coaching and education of SA Health staff which includes education on the role and significance of Traditional Healers within Aboriginal culture.

Health Professionals have a key role in facilitating access to the services of a recognised Traditional Healer in partnership with Aboriginal Health Workers/Practitioners across SA Health and across the Aboriginal Community Controlled Health Organisation (ACCHO) sector. Creating greater awareness of the role, availability and funding for Traditional Healers amongst SA Health Staff will enable greater promotion of services for Aboriginal patients with cancer and assist with improving the provision of culturally safe and appropriate services.

## PRIORITY

### Care Coordination

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

## ACTIONS

- 20 Sustain and continue to develop the current and potential roles that support and optimise cancer care coordination for Aboriginal people.
- 21 Collaborate with Primary Health Networks' Closing the Gap programs to strengthen cancer coordination pathways across the cancer care continuum.
- 22 Continue to evaluate how Aboriginal and Torres Strait Islander Cancer Care Coordinator roles are integrated and utilised to facilitate adoption of Optimal Care Pathways and changing clinical or service needs.
- 23 Implement and monitor usage of appropriate assessment and screening tools to identify clinical and supportive care needs of Aboriginal people from diagnosis through to survivorship or end-of-life care.

'(The Aboriginal Cancer Care Coordinator) is good. Especially in them first seven weeks. (They) was here every appointment I come to. (They) come in when I first met with the consultant, when they first said lymphoma. Then (they) come in for that meeting when they said...(they) actually sat in the consultants meeting before I actually met with them and (they'd) be in the waiting room, waiting area and waiting for me, and I said, oh, come in. 'Cause sometimes you know, they'd talk and it would just go over your head. So it's another pair of ears... So (the Aboriginal Cancer Care Coordinator) was there, (they) was really good. Really good.' AP002

'(The Aboriginal Cancer Care Coordinator's) been, (they've) been a rock, (they've) been there all the time, (they're) so lovely. (They) come in with me just in case I miss something and explain everything and explain everything to me.' AP013

**CanDAD Research Project**



The disparity in outcomes for Aboriginal peoples is influenced by a number of modifiable factors. Added to this are complications from diabetes and other chronic disease co-morbidities that are more common in Aboriginal than non-Aboriginal patients meaning that their treatment needs are more complex. As over half the number of Aboriginal people experiencing these cancers live in outer regional and remote SA, their capacity to benefit from available healthcare will be compromised without help.

Support is needed in interpreting medical terminology used, navigating the hospital system, environment and culture, and coordinating hospital care with follow-up and supportive care in the community[32].

Coordination of care for people affected by cancer requires action at a number of levels and engagement of a wide range of health professionals. The cancer care team has a major influence on the extent to which care coordination is achieved. Therefore, it must be embedded as part of standard practice[33]. Dedicated care coordinator positions are one key strategy that would improve care coordination.

The Aboriginal and Torres Strait Islander Cancer Care Coordinator (A&TSI CCC) positions at the Royal Adelaide Hospital were established in response to the known complexities experienced by Aboriginal people with cancer while in hospital in relation to understanding treatment required, and the multiple unique issues relating to co-morbidities, psychosocial, access and cultural issues that Aboriginal peoples are confronted by, particularly those from regional and remote locations. The role of the A&TSI CCCs is to provide continuity of care through treatment (including surgery, chemotherapy and radiation therapy) and follow-up by facilitating assessment, management and ongoing review of clinical and supportive care needs[32].

This model of care is similar to approaches used in nursing (e.g. Breast Care Nursing), however incorporates specific knowledge of culture and community networks as well as clinical knowledge[34]. Greater understanding of the role and opportunities to link with these coordinators by everyone in the cancer team would be beneficial for both the patient and service providers. A supportive professional practice environment and adequate professional development opportunities to enable the cancer care coordinators to continue to function optimally is essential.

## PRIORITY

### Supportive Care

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

- 24 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.

---

- 25 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.

---

- 26 Collaborate with Primary Health Networks 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 setting and Aboriginal Community Controlled Health Sector.

---

# South Australian Priorities and Actions

## PRIORITY (cont)

### Supportive Care

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 (cont)

- 27 Collaborate with Primary Health Networks 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.
- 28 Increase awareness and monitoring of the number of Aboriginal people in SA with cancer having an Advance Care Directive.

'Sometimes families are too scared. Aboriginal families. And yeah they won't talk about it, they won't go – they'll send somebody else to look after the people if they're too scared, or they'll go there and look after them but you'll always get the one person and all the other family will leave it up to that one person. So that person was worn right down.' AP019

'I'm going back, but I'm only going back to my family. I'm not going back to any follow-up support people back there, because they don't exist, only my family. As much as I'm excited to go home this week, for the first time in over three months, it's also scary.' AP008

CanDAD Research Project

The diagram below provides an overview of key components of supportive care (including survivorship care) across the cancer continuum and specific considerations and barriers for Aboriginal people from prevention through to end-of-life care.

**Diagram 4: Supportive Care Considerations for Aboriginal People with Cancer**

		SUPPORTIVE CARE (SERVICES & RESOURCES) Physical, information, practical, emotional, psychological, social and spiritual needs (1).					
CANCER CONTINUUM		<b>Survivorship Care</b> <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)					

Given the obstacles and cultural barriers, Aboriginal people affected by cancer are likely to have high levels of unmet supportive care needs[35].

## Current work and relevant research underway in SA relating to understanding and providing supportive care needs

The CanDAD project has been exploring Aboriginal cancer survivor experiences across the continuum of care, including needs and considerations. This work has focussed upon the adult population and broader community, with little focus on the specific needs of Aboriginal Adolescent and Young Adult (AYA) cancer survivors or children. Researchers from CanTeen and the University of South Australia are currently scoping areas that may need further attention for these age groups.

SA is developing and implementing a Statewide Survivorship Framework that addresses the holistic needs of cancer survivors and their families/carers from the point of diagnosis and beyond (refer to Diagram 4: Supportive Care Considerations for Aboriginal People with Cancer). Further exploration and incorporation of culturally appropriate needs assessment tools for Aboriginal cancer survivors is required and will be a key focus as the Survivorship Framework continues to be progressed.

Recognising the integral role of General Practitioners (GPs) in supporting the continuity of care and meeting the diverse range of patient needs (including follow-up and management of co-morbidities) a number of programs and incentives are available to assist with improving access to GP and other primary healthcare services for Aboriginal peoples.

### Closing the Gap (CTG) Program – Integrated Team Care

In 2008, the Council of Australian Governments (COAG) agreed to a \$1.6 billion National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes to fund a broad package of initiatives addressing the target of closing the life expectancy gap within a generation.

The 'Integrated Team Care' (ITC) program (managed by Primary Health Networks) supports eligible Aboriginal and/or Torres Strait Islander people with chronic disease, including cancer, who need coordinated, multidisciplinary care and support in self-managing their healthcare needs. (This program commenced on 1 July 2016 and combines the former Care Coordination and Supplementary Services program and Improving Indigenous Access to Mainstream Primary care program.)

Key components of the ITC program include:

- Care coordination and support for Aboriginal people to improve chronic condition self-management, and supplementary service funds to assist clients to access medical specialist and allied health services, where these services are not otherwise available within a clinically acceptable time frame.
- Aboriginal and Torres Strait Islander Outreach Workers to assist with care coordination and access to services, and linking clients to cultural and psychosocial supports.
- Mainstream primary health service support to improve cultural responsiveness when caring for all Aboriginal and Torres Strait Islander patients[36].

There is an opportunity to strengthen relationships with Primary Health Networks to explore further collaborations that ensure Aboriginal patients with cancer have awareness of and accessibility to CTG/ITC programs in SA.

# South Australian Priorities and Actions

## Palliative and End-of-life Care

Despite our best efforts and systems of care, some cancers are incurable. The principles of palliative care align well with the holistic Wellbeing Model presented in this Plan (refer to Diagram 2).

There are many reasons why access to high quality palliative care is limited for Aboriginal people. Crucial first priorities in improving the palliative care of Aboriginal people include:

- Collaboration with Primary Health Networks to facilitate culturally respectful conversations about dying and the role of palliative and end-of-life care in the wellbeing of Aboriginal people.
- A focus on 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. This focus will strengthen the chance that mainstream healthcare consults with the appropriate person(s) when consent for medical treatment is sought. Completion of an Advance Care Directive is the formal way in which a person can appoint a Substitute Decision-Maker to speak on their behalf. The *SA Health Advance Care Yarning* booklet and *Help Us, Help You – Essential Contacts* factsheet may be very useful resources if culturally appropriate and inviting.
- Strengthening the essential role of Cancer Care Coordinators in assessing the palliative care needs of Aboriginal people and accessing appropriate resources to manage those needs, including referral to specialist palliative care services when needs are complex. Strong relationships between Cancer Care Coordinators and Specialist Palliative Care Services are essential for bilateral education and skills enhancement, and to improve opportunities for Aboriginal people to access specialist palliative care.

### PRIORITY

#### Workforce

Build capacity of the health system to provide cancer care within a culturally safe environment, through optimal services for Aboriginal people with cancer in South Australia.

### ACTIONS

- 29 Build awareness and capacity of Aboriginal Health Workers/Practitioners (AHW/Ps) to deliver patient and community education across the cancer care continuum including supporting AHW/Ps to undertake relevant cancer related training.
- 30 Support initiatives that facilitate Aboriginal health services and community services to establish and maintain Aboriginal cancer support groups or Yarning Circles.
- 31 Monitor utilisation and outcomes of cultural awareness and competence training for cancer care providers to improve confidence in delivery of cancer care and communication with Aboriginal people in a culturally safe manner.

'If we can start preventing it early, well then hopefully they won't get it in the end, and they'll educate others about it later on down the track. They might even go home and educate their parents about quitting smoking or the dangers of cancer from smoking or other things.' SP014

**CanDAD Research Project**

Aboriginal Health Workers/Practitioners (AHWs) have an important role within the community. They are often the first point of contact for healthcare and vital for Aboriginal people to navigate through the health system effectively. AHWs provide links to other service providers who could help meet the physical, social, emotional and cultural needs of Aboriginal people. Currently in SA, AHWs are located within metropolitan and country areas[37]. Improving AHWs understanding of the cancer care continuum from prevention through to end-of-life care and supporting their delivery of patient and community education would be beneficial in the long run.

Culturally appropriate education and training is available through the following nationally accredited training units developed by Cancer Council SA in partnership with the Aboriginal community controlled health organisation (ACCHO) sector for AHWs (working in both the government and ACCHO sectors) and community advocates:

- HLTAHW035 Provide information and support around cancer
- HLTAHW036 Provide information and support to women with breast cancer
- 10577NAT Course in facilitating an Aboriginal and/or Torres Strait Islander cancer support group

Opportunities need to be explored to ensure that Aboriginal Registered Training Organisations (RTOs) are supported to deliver this training in order to continue expanding and building the capacity of the Aboriginal cancer control workforce in SA.

Compulsory Aboriginal and Torres Strait Islander Cultural Awareness Training should be delivered to all health system staff as part of the induction process, with ongoing educational updates. Additional support through communication skills training and mentoring should be provided to staff to ensure that they are culturally competent to provide cancer care to Aboriginal people.

The *SA Health Aboriginal Cultural Respect Framework*[38] identifies actions to providing cultural awareness and responsiveness training for staff by:

- Ensuring staff participation in localised cultural awareness and responsiveness workshops periodically as part of professional development, particularly where there is substantial contact with Aboriginal people.
- Raising awareness that English is not the first language of many Aboriginal clients and support access to interpreters where required.
- Support education of local Aboriginal communities regarding health providers and protocols to be observed.

Ongoing evaluation of existing SA Health cultural awareness programs and cultural competence of staff should occur to measure their effectiveness and for continuous improvement.

Opportunities may exist to upskill AHWs and other supportive care service providers to facilitate conversations with Aboriginal communities to dispel myths and misconceptions of cancer and improve earlier detection and access to cancer and supportive care services. Learnings, experiences and resources developed (including a 'Cancer Conversation Toolkit') from the 'Yarning about cancer' project, facilitated by Cancer Voices SA in partnership with local Aboriginal community members (2011) may be beneficial for providers[20]. The project proved to be an effective means of providing support and dispelling myths through the sharing of stories (community members and survivors) and health information.

# South Australian Priorities and Actions

## PRIORITY

### Service Outcomes Data and Research

Develop a better evidence base to measure the effectiveness of cancer related services for Aboriginal patients. Identify areas of excellence, service gaps and inform opportunity to improve patient experience.

## ACTIONS

- 32 Utilise or develop ACME or PROM to routinely capture the quality and outcomes of care from the perspective of Aboriginal patients to inform care delivery.
- 33 Develop a participatory monitoring, evaluation and learning framework to measure and report on the impact of the SA Aboriginal Cancer Control Plan 2016-2021 annually.
- 34 Implement strategies that improve statewide 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.

Quality research and data collection systems allow SA to remain at the cutting edge of cancer care provision at a time of rapid evolution and change in cancer diagnosis, treatment and care modalities. A stronger evidence base will assist in better identifying areas of need and gaps in service provision, support and treatment. A greater emphasis should be given to monitoring the epidemiology of cancer and the service provision outcomes in Aboriginal peoples in SA. It is important to improve the quality of recording of Aboriginal status on health records, cancer registries and cancer screening registries and collect population-based data on prognostic factors including cancer stage at diagnosis, treatment accessed and outcomes achieved to better monitor the technical appropriateness of services and service effectiveness. The Monitoring and evaluation of the adoption of Optimal Care Pathways will also strengthen the collection of service outcomes data in SA (please refer to the Treatment section of this Plan).

CanDAD is working on the development of a culturally appropriate PREM, which would provide valuable information in relation to service use, availability, access and satisfaction with treatment and care. The PREM is called the Aboriginal Cancer Measure of Experience ACME.

ACME will be a self-report measure that will ask questions about the key stages of the cancer pathway(s), where the questions are clear, understandable and culturally appropriate. ACME would be used in real-time data linkage for the ongoing monitoring of Aboriginal disparities in relation to cancer screening, diagnosis, treatment and post-treatment care.

Thus, it will assist in the:

- Improvement of quality of care for Aboriginal people with cancer by informing care planning and management.
- Identification of what is working well and areas for improvement from a service perspective.

Also, CanDAD will use Participatory Concept Mapping to clarify stakeholder perspectives on the importance and feasibility of potential strategies designed to improve the quality of Aboriginal patients' cancer pathways in the primary healthcare and hospital systems.

Implementing strategies that improve data collection and monitoring of statewide cancer service utilisation, which inform where Aboriginal people with cancer access services, would be important to guide system level planning and re-orientate services where necessary. This would increase timely access to well-coordinated care that meets the needs of Aboriginal people with the most appropriate provider and location.

The *SA Aboriginal Cardiovascular Disease (SAACD) Profile 2016* documents the cardiovascular health of Aboriginal people in SA, the service availability, and service activity, providing a baseline for future monitoring and evaluation[39]. This approach/model utilised within the SAACD Profile may be adaptable within the context of cancer in SA and enable similar data collection systems and monitoring be developed.

#### PRIORITY

##### **Collaboration and Consumer Engagement**

Ensure sustainability of a coalition of health organisations and consumers to advocate for Aboriginal cancer control issues, in collaboration.

#### ACTIONS

- 
- 35 Support the continuation of the SA Aboriginal Cancer Control Governance Committee.
- 
- 36 Actively engage with consumers and Primary Health Networks in cancer control decision making in SA.
- 
- 37 Broaden existing partnerships between government, community, private and non-government organisations and other agencies to address the social determinants of health and support available for Aboriginal people with cancer, their carers and families.
- 

Health inequalities relate to differences in the presence of disease, health outcomes, or access to healthcare services between population groups. Health inequities are differences in health that are not only unnecessary and avoidable but are considered social injustices that make some population groups more vulnerable to poor health than other groups.

Every person in Australia has the right to equitable health opportunities regardless of their ethnicity, social status, religion, economic situation or geographic location. In situations where this may not occur for Aboriginal people, it is important that support is available to assist them in self advocating or advocating for them on their behalf in resolving issues affecting either themselves, their carer or family members, and to elevate issues where necessary to influence health system change.

Collaboration and partnerships are essential to improving outcomes across the cancer care continuum. SA has an effective model which actively involves the SA Cancer Service, SA Health, Aboriginal Health Council of SA, Cancer Council SA, Cancer Voices SA, University of South Australia, Adelaide University, Flinders University and SAHMRI. Further work to engage with consumers, other non-government organisations, the private sector and the Primary Health Networks needs to be explored to improve cancer control across the continuum, including in critical areas of primary and secondary prevention, and supportive and end-of-life care.

Aboriginal cancer control in SA is governed by the South Australian Aboriginal Cancer Control Governance Committee. Its membership comprises of representatives from AHCSA, Cancer Council SA, SAHMRI, SA Health, Aboriginal Health Branch (Department for Health and Ageing), Adelaide PHN and County SA PHN. The committee has an essential role in providing advice to SA Health on the best strategies to reduce the burden of cancer on Aboriginal peoples in SA across the cancer continuum by taking a broad, system-wide approach and through meaningful engagement with the SA Aboriginal community. The continuation of the committee is vital as it will also actively work with the SA Aboriginal Chronic Disease Consortium that is being established to govern the effective implementation of the three statewide chronic disease plans (SA Aboriginal Cancer Control Plan 2016-21, SA Aboriginal Diabetes Strategy and the SA Aboriginal Heart and Stroke Plan).

## Personal Stories from Aboriginal Community Members



Aunty Roslyn Weetra

I was diagnosed with non-Hodgkins lymphoma more than 10 years' ago. When I was given the news, to my surprise I immediately responded with 'my brother-in-law will heal me.' He is an Aboriginal healer: Ngangkari. I had never experienced this before. When your back is against the wall you can call on your ancestors to hear you. The specialist from the hospital rang and said I should come in straight away to start the chemo treatment. I told him I was waiting for my brother-in-law, Ngangkari to come and see me and heal me before I start the chemo treatment. I felt it was a blessing for me to connect with my cultural background.

**Aunty Roslyn Weetra**, Kurna Elder and CanDAD Aboriginal Community Reference Group Member

My name is Neville Fazulla, I am a 51-year-old man living in Adelaide. I was born and bred in Port Augusta and have lived with a number of chronic conditions. I am trained in Chronic Condition Self-Management, a self-help course developed by Dr Kate Lorig of Stanford University, USA.

I first noticed the cancer as a lump in my left testis after a shower. I felt sore so I took a look at it with a torch and realised that I needed to go see my GP who examined me and advised me that I needed to see an Oncologist at the RAH. Yes, a simple torch can help in this situation but please seek medical attention. I attended the appointment at the RAH and was advised that I needed to have surgery to remove the lump. My head was spinning; I couldn't imagine what was to come as my mind raced everywhere. I started thinking about the long tiring days/sessions of therapy (chemotherapy/radiotherapy).

I wondered as to how I was going to cope with the rigorous regimen of treatment for cancer and my ongoing treatment for renal and diabetic conditions. At this point of time, I was very confused and found it difficult to come to terms with another life threatening diagnosis. I wanted to know a lot about how I would address all of my medical needs for the best outcome. After lengthy discussions with the Oncologist, I set a date for surgery. Yes, I was scared as I didn't know exactly what would be found. I was lucky as the surgeons were able to remove the testes and I didn't have to undergo radiotherapy or chemotherapy. This was a great relief for me and I was able to ask questions, sought responses and discuss options with the doctors. I was told that I had to report to the Oncology department for a 12 month period with weekly visits at first and then once in three months. This was a learning process for me. I was able to take action as soon as I noticed the lump/cyst. This assisted in enabling the removal of the testes without a spread of the cancer through my groin. Seeking medical intervention quickly and promptly is useful.

**Neville Fazulla**, CanDAD Aboriginal Community Reference Group Member



Neville Fazulla





In lots of ways, I was fortunate. I am somebody who knows the importance of maintaining my health, I'm able to navigate my way through the mainstream health system and have the financial means to benefit from private health insurance. When I got cancer, I didn't have any symptoms at all so I had no real concerns when attending a routine mammography screening. When I got told that there was something that needed to be investigated, I had the biopsy done.

Luckily the cancer was picked up early and was still very small. We needed to remove it and the surgeon wanted to book me in as quickly as possible. But I had to put off the operation off for a couple of weeks because a cousin of mine passed away and we had to go away for the funeral. I wasn't really bothered by it because my surgeon was quite relaxed about it as well. She did a good job. Both my surgeon and GP take a personal interest in me and are not there just to treat the symptoms.

However, my knowledge of the mainstream hospitals meant that I was mentally prepared and sensitised to the likelihood of institutional racism. I personally don't expect the White system to meet my cultural needs. I'll do that myself if I need to do that. So there wasn't anything that I felt I needed from the system. I know what my family obligations are, and I know what my cultural needs are, and I know where to go and get that. And I don't believe it's in the system. Despite this, at the private hospital they really did look after me. On discharge I was happy to be home. Unfortunately, I had a negative reaction to the chemotherapy, which helped confirm my thoughts about my allergies and my mental block to the benefits of medicines. I'm not a good patient. I find it very difficult to take medication. My husband was panicking and called a friend of mine who's a doctor, and she came out to help me manage the side effects of treatment.

I went back to work with no hair. I didn't mind not having hair. In fact I bought a wig, and I just couldn't wear it as it irritated my skin. It was amazing how many people came up to me, having heard that I had breast cancer, to tell me that they did, or their wife did, or their family members, or their colleagues. I really wondered about myself about that, that I hadn't noticed these people being any different. I have sensitive skin and I had some problems with a bad infection at the surgical site. My recovery was enhanced by alternative methods of reconstructive surgery, which was a success. I also used alternative therapies and totally changed my eating habits, having lots of juices and doing fresh juice every day. That's when I decided to give up work. It was too stressful when I was trying to heal, and so I resigned.

I've now got a GP who sees me at the drop of the hat for whatever I need, whether it's about my sinuses or ear infections or for general healthcare. Plus, she monitors that whatever I'm presenting with is not in any way connected to the cancer. And then I've got my surgeon who I'm now seeing once a year. I have to have regular blood tests. I have bone scans, and the mammograms and all of that. It's been 10 years now, and what I'm finding that's missing in my treatment is – How did I get treated? What was I given? What's the mixture that I had? I've got none of those details.

Though my privacy is important to me, I believe it's important to inform the 'system' by sharing cancer stories – that's why I got involved with Cancer Voices SA. Lately, I've been getting called into different sorts of committees and research topics – and I'm okay about it. I am very conscious of it. I've said yes to it, but I always investigate what it is and what's the purpose and what's involved before I commit myself.

**Sandra Miller**, CanDAD Aboriginal Community Reference Group Member

## APPENDIX A

# Cancer in Aboriginal South Australians

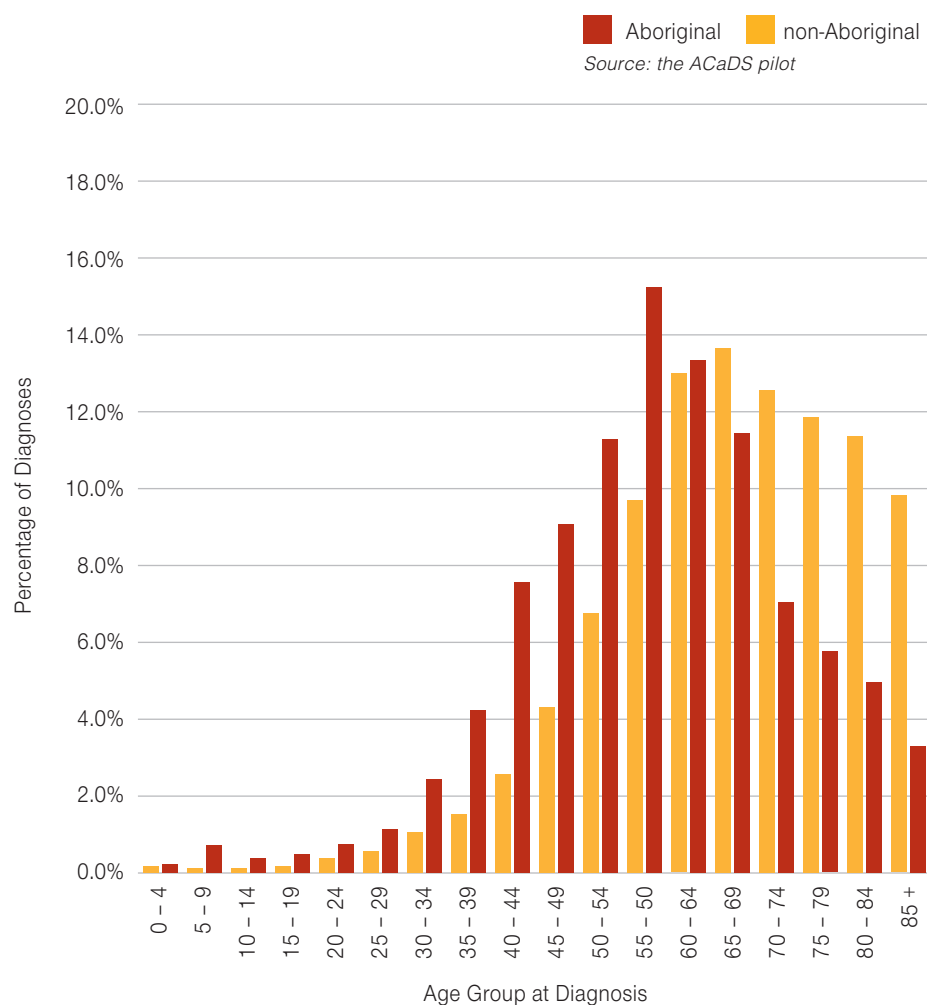
What do we know of cancer epidemiology among Aboriginal South Australians and what else must we learn to inform and monitor improved cancer control initiatives to meet their needs?

### Incidence of Cancer

Incidents of cancer diagnoses are reported by law to states and territory cancer registries. Where information quality allows, reporting by Aboriginality is possible. Taking into account the younger age profile of the Aboriginal communities compared to Australia in general, and grouping all cancers, incidence figures show Aboriginal people experienced slightly lower incidence rates [421 vs 443 per 100,000 people] [40].

South Australia was not included in these figures due to poorer data quality. This highlights the need to improve Aboriginal identification in cancer and other health records in this State. With the data available, we do know that cancer related disparities exist within the South Australian community. For example, cancers diagnosed among Aboriginal South Australians generally occur at younger ages. The median age at diagnosis among Aboriginal South Australians was 10 years younger at 58 years in the period 1990-2010 compared to the wider community (Figure A1). These differences also exist in cancers where screening programs exist. For instance, in colorectal cancers the median age at diagnosis was 60 years for Aboriginal people versus 71 years more generally.

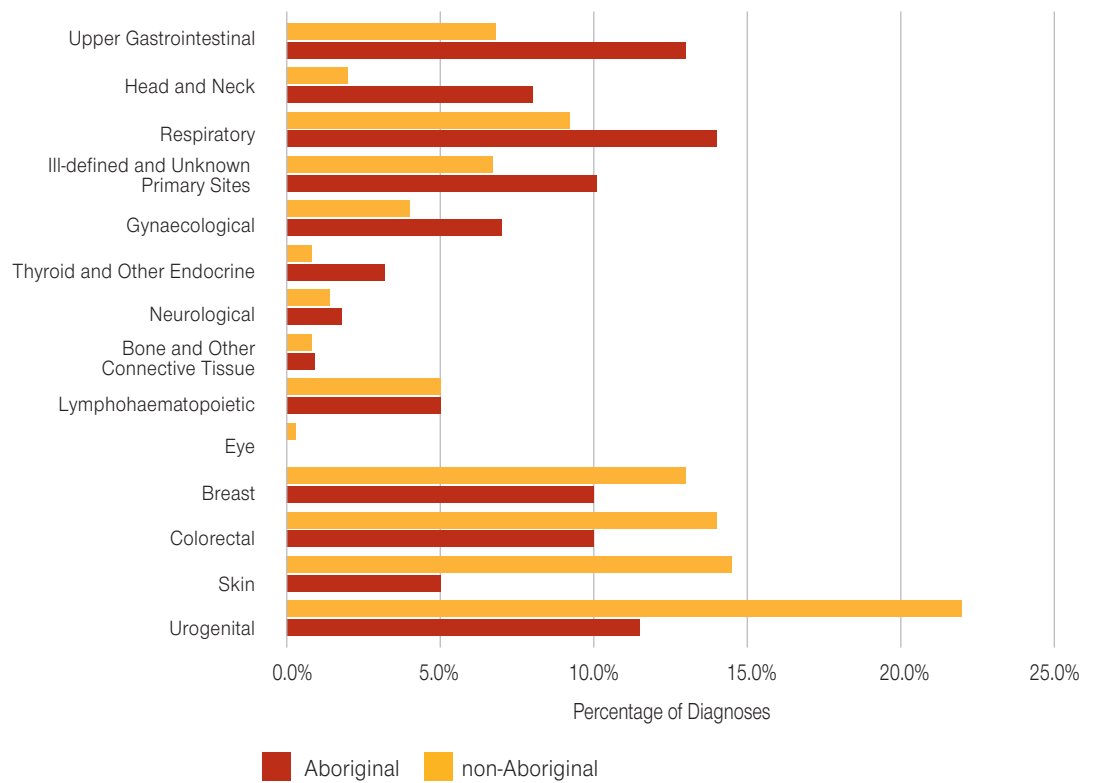
**Figure A1: Age at cancer diagnosis in South Australia**



## Types of Cancer

It is also clear there are a number of important differences in the primary site of cancers diagnosed among Aboriginal and non-Aboriginal people. For example, recent decades in SA show respiratory (particularly lung), and upper gastrointestinal cancers to be relatively common among Aboriginal people, as are head and neck cancers. For other sites, such as skin, the proportion of Aboriginal cancers was markedly lower (Figure A2).

**Figure A2: Cancer incidence by Aboriginality and clinical grouping, South Australia 1990-2010**



Source: the ACaDS pilot

The cancer types more commonly diagnosed among Aboriginal South Australians are generally those associated with poorer survival.

## Survival After Cancer Diagnosis

Aboriginal people diagnosed with cancer had lower chances of survival after diagnosis. Records for 1977 to 2007 show Aboriginal and non-Aboriginal five-year survivals for all cancer sites combined were 40.0% and 56.8% respectively[41].

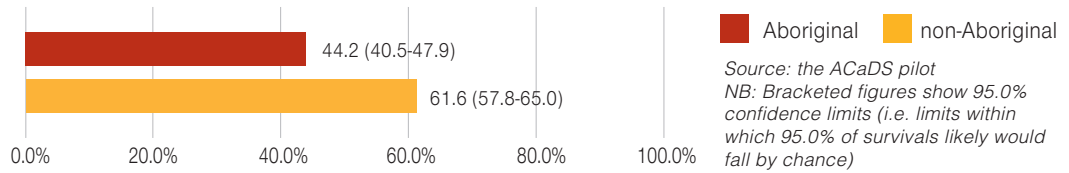
The ACaDS pilot within the CanDAD Research Project identified a cohort of Aboriginal people diagnosed with cancers between the years 1990 and 2010 using a broad, ‘ever identified’ definition of Aboriginality. A non-Aboriginal member was matched by diagnostic year, gender, age at diagnosis, and cancer type to facilitate comparisons by Aboriginal status.

## APPENDIX A

# Cancer in Aboriginal South Australians

Comparison of the cohorts reinforces earlier results with 44.2% (95.0% CI 40.5% to 47.9%) of Aboriginal people surviving cancer within five years of their diagnosis. This represents a major difference to non-Aboriginal people of similar, younger ages, of whom 62% survived at least five years after their cancer diagnosis (Figure A3).

**Figure A3: Percentage five-year crude, disease survival for all cancers combined among Aboriginal South Australians and a matched cohort of non-Aboriginal South Australians**



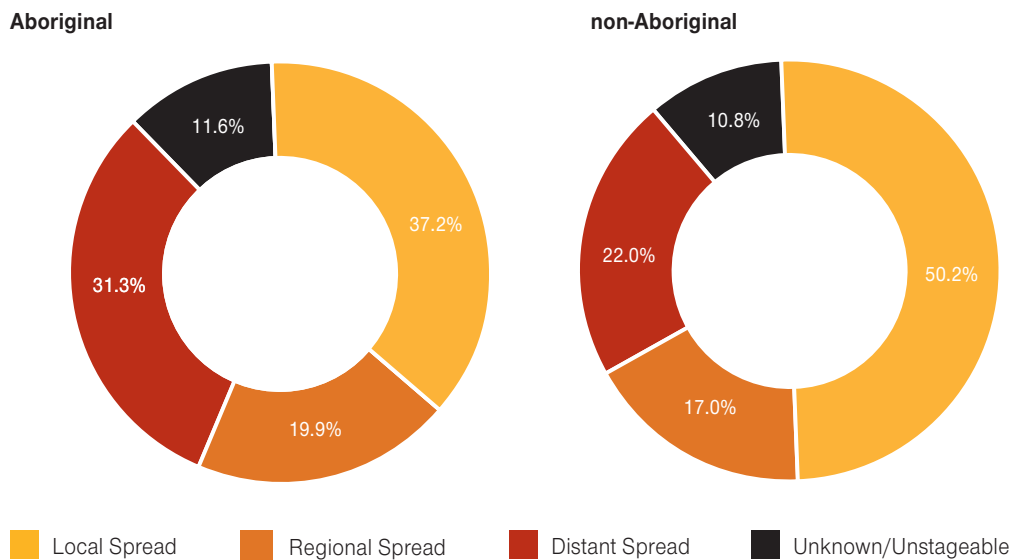
### Stage at Cancer Diagnosis

Information on the stage or degree of spread of a cancer at the time of diagnosis is a valuable indicator of eventual survival. Cancers among Aboriginal people continue to be diagnosed at a later, more advanced, stage[42]. However, information on stage at diagnosis is not yet routinely available through the population cancer registry and this is a further challenge in having critical data items[43]. ACaDS reviewed records for tumours diagnosed among Aboriginal South Australians from 1990 to 2010 and a matched, random selection of non-Aboriginal people with the same year of birth, year of diagnosis and primary site. Cancers among cohort members, using the highest degree of spread recorded within four months of each diagnosis, were categorised as either:

- Localised to the tissue of origin
- Regional, having invaded adjacent tissue
- Distant, having metastasised or disseminated to distant organs
- Unknown or unstageable.

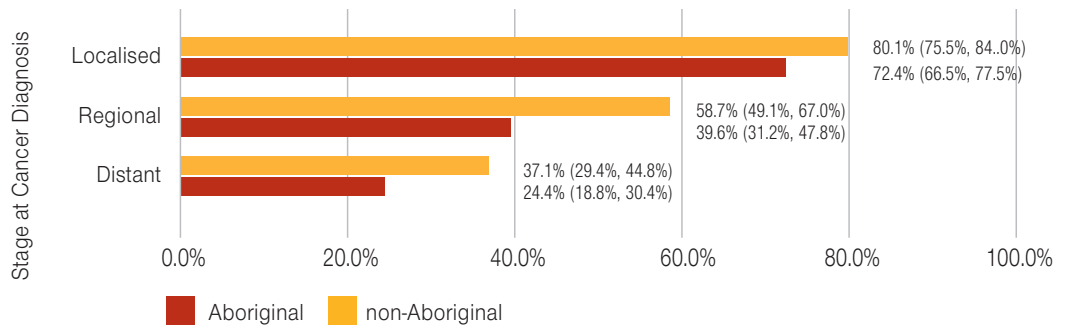
Comparison of stage at diagnosis experienced by the Aboriginal and non-Aboriginal cohorts clearly shows Aboriginal people were much less likely to be diagnosed with localised cancer (37.2% versus 50.2% in the non-Aboriginal cohort) (Figure A4). Conversely, their cancers were much more likely to have been distant, or widely spread (31.3% compared to 22.0%).

**Figure A4: Cancer stage at diagnosis among Aboriginal South Australians and a matched cohort of non-Aboriginal South Australians**



Aboriginal people also experienced significantly lower cancer survival within each stage at diagnosis (Figure A5). For example, while Aboriginal and non-Aboriginal cohort members were diagnosed with similar levels of regionally spread cancers, Aboriginal people only survived two-thirds as long as non-Aboriginal people on average (39.6% compared to 58.7%). Moreover, the outcomes for Aboriginal cohort members with regional spread at diagnosis are on a par with non-Aboriginal cohort members diagnosed with more advanced, distant or metastasised cancers.

**Figure A5: Percentage five-year crude, disease survival by stage among Aboriginal South Australians diagnosed between 1990 and 2010 and a matched cohort of non-Aboriginal South Australians**

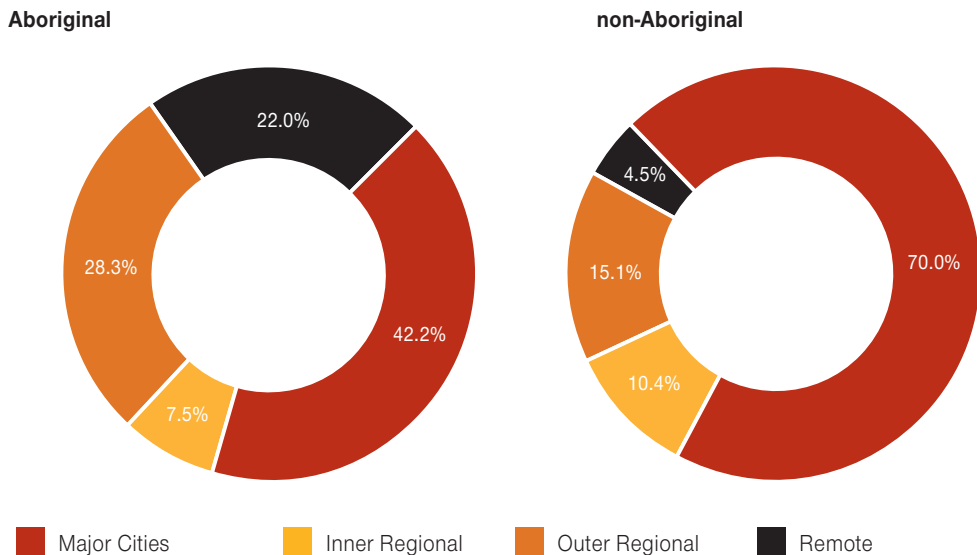


Source: the ACaDS pilot. NB: Bracketed figures show 95.0% confidence limits (i.e. limits within which 95.0% of survivals likely would fall by chance)

### Area Remoteness at Cancer Diagnosis

The Accessibility/Remoteness Index of Australia (ARIA+) takes account of a location’s road distance to the nearest urban centre. Areas are then categorised as belonging to a major city, an inner or outer region, or being remote and very remote[44]. Census 2011 estimated around one-half of Aboriginal South Australians usually lived in regional or remote South Australia. During 1990 to 2010, 57.8% of the cancers among Aboriginal people, involved people usually living in the same areas (Figure A6). Conversely, less than one in three within the non-Aboriginal cohort lived in those areas.

**Figure A6: Geographic remoteness at time of diagnosis, Aboriginal South Australians from 1990-2010 and a matched cohort of non-Aboriginal South Australians**



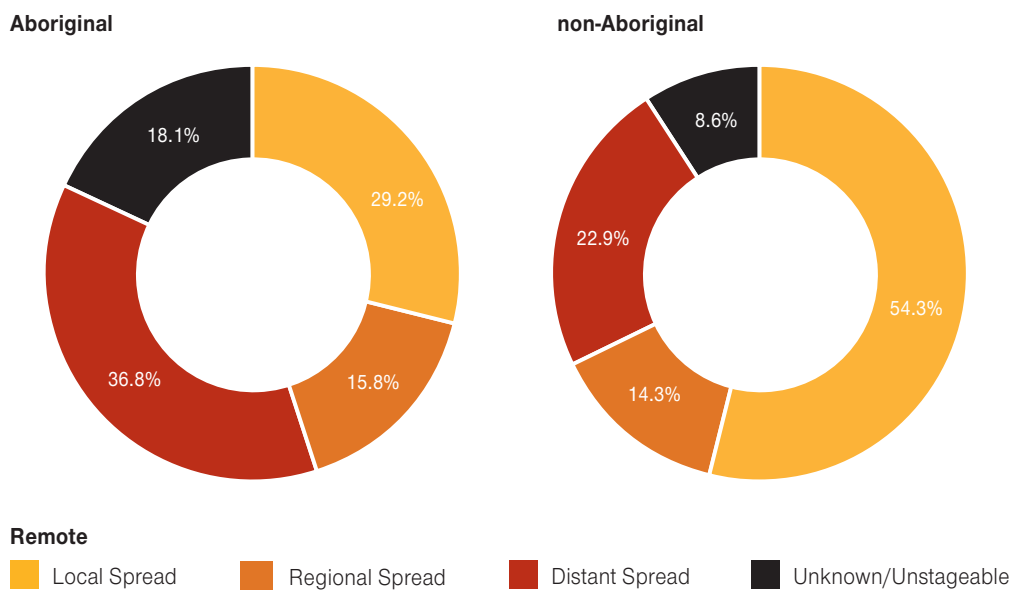
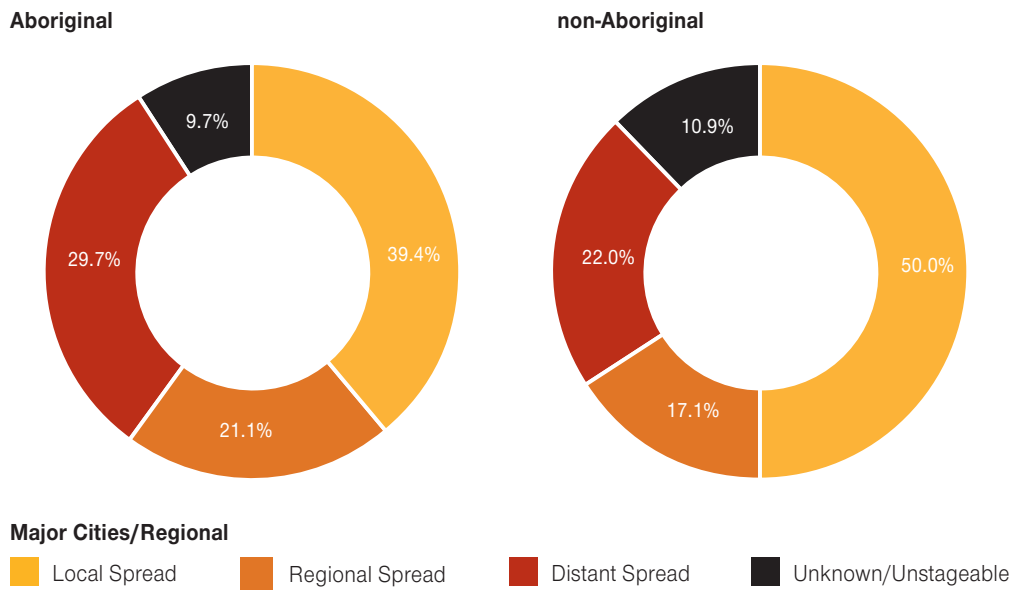
Source: the ACaDS pilot

# APPENDIX A

## Cancer in Aboriginal South Australians

Aboriginal people diagnosed with cancer usually live outside the Adelaide metropolitan area and on average the cancer is more advanced. There are also interrelationships between remoteness and stage at diagnosis (Figure A7). For example, 55.0% of cancers among Aboriginal people living in remote areas were classed as distant, unstageable or of unknown site of origin which is markedly more than the corresponding 39.4% for those living in more urbanised settings.

**Figure A7: Area of residence and stage at diagnosis among Aboriginal South Australians and a matched cohort of non-Aboriginal South Australians**



## Co-morbidities and Cancer Treatment

Stage at diagnosis and area remoteness are important influences on cancer outcomes and our understanding of these issues is improving. However, other factors such as the presence of other health risks and conditions before, or at the time of cancer diagnosis can affect outcomes. These relationships are less understood and present a clear need to describe and monitor comorbid conditions experienced by people experiencing cancer.

We can begin to do this by improving the use of existing information on causes contributing to deaths for instance. Hospital records are another valuable information source. Aboriginal peoples are hospitalised at twice the rate of non-Aboriginal people but not so for cancer care.

These hospital records may help inform of conditions pre-existing cancer diagnoses, and others becoming evident after diagnosis. However, gaps in local data collections exist. Broadening ACaDS data to include Pharmaceutical Benefits Scheme (PBS) and Medical Benefits Scheme (MBS) information will help enumerate critical issues of: chemotherapy uptake; co-morbid disease management in primary care; and enable comparison of actual and recommended treatment pathways.

Analyses of these issues will be provided to iterative planning for cancer control among Aboriginal South Australians.



## APPENDIX B

# Cancer Data and Aboriginal Disparities Research Project

Aboriginal populations carry a significantly greater burden of cancer mortality than other Australians, despite slightly lower overall cancer incidence. Aboriginal people entering the health system for cancer treatment tend to be younger, have more advanced cancer and more lethal types of cancers than other Australians. While the wider Australian population has experienced improvement in cancer outcomes, the same improvement has not been observed in the Aboriginal populations, resulting in a widening of the cancer mortality gap between Aboriginal and non-Aboriginal Australians.

The drivers of these disparities are varied, relating to a higher rate of exposure to risk factors in Aboriginal people, including but not limited to smoking, lower uptake of cancer screening and higher rates of comorbidity. There is also evidence that once diagnosed, Aboriginal people are less likely than other Australians to receive comprehensive and complete cancer treatment. Previous research has identified barriers to care spanning a wide range of logistical and socio-cultural issues relating to transport, the hospital environment, separation from family and country resulting in distress, and potentially dangerous misunderstandings through language and cultural differences.

CanDAD is a large NHMRC-funded Partnership Project including Wardliparingga Aboriginal Research Unit at the South Australian Health and Medical Research Institute, AHCSA, SA Cancer Service, Breast Screen SA, Cancer Council SA, Beat Cancer Project SA, SA-NT Datalink, SA Department for Health and Ageing and University of South Australia. The active engagement of Aboriginal partners and stakeholders is considered paramount to the project and all research is conducted under the under the guidance of an Aboriginal Community Reference Group and in accordance with the SA Aboriginal Health Research Accord.

CanDAD seeks to improve the quality and completeness of SA cancer data and develop a comprehensive cancer monitoring system which incorporates Aboriginal people's experiences with cancer services in SA. The advanced data monitoring system will be explicitly developed with Aboriginal and Torres Strait Islander people to better target and improve their cancer services, strengthen their advocacy and indicate to them the effectiveness of initiatives to reduce disadvantage.

The monitoring system will integrate cancer registry, hospital, radiotherapy, pharmacy, clinical, screening and health insurance data to comprehensively monitor cancer incidence trends, cancer management and survival. Through Aboriginal community engagement, stories from Aboriginal patients, survivors and carers, and reflections on the day-to-day provision of cancer services from health service providers will be utilised to identify issues and areas of prioritisation and feasibility for clinical system change.

Such work will lead to the development of a brief, culturally-sensitive self-report instrument for recording and quantifying Aboriginal cancer patient's satisfaction with system performance that can be deployed as part of routine service delivery in a complex environment where multifaceted interventions at patient, provider and system levels are required.



## APPENDIX C

# Consultation Process

### Background

As a step towards reducing the impact of cancer in Aboriginal communities, the Aboriginal Health Council of SA in partnership with Cancer Council SA, held a state based two-day cancer forum in September 2006 – the Perko Ngurratti ‘Healing Messages’ Aboriginal and Torres Strait Islander Cancer Forum.

This forum provided Aboriginal people in SA with a platform to inform service providers and health professionals of their cancer experience and to raise awareness of issues they face. Recommendations from the forum guided the implementation of a number of Aboriginal cancer control initiatives in SA since 2006 and gave direction to the *Aboriginal Companion Document to the Statewide Cancer Control Plan 2011–2015*.

A Gap Analysis of 13 recommendations from the 2011-2015 Plan was conducted by SACS in collaboration with the CanDAD team in January 2015 and was presented at the Aboriginal Cancer Control Planning Day held in February 2015. During this day, over 60 stakeholders from across SA were in attendance including cancer care providers, other health service providers, Aboriginal Community Controlled Health Organisations, Aboriginal Health project and program officers, researchers, policy and strategy representatives, Aboriginal community members and consumers. This diverse group collectively reflected on achievements and gaps in Aboriginal Cancer Control and identified a number of key priorities and strategies for future focus. Following the forum, SACS recruited an Aboriginal Senior Project Officer (SPO) to build on this work and coordinate the development of South Australian Aboriginal Cancer Control Plan 2016-21.

### Stakeholder Consultations

Other stakeholder engagement included varied and far reaching community consultations led and performed by an Aboriginal project officer. Engagement with the ACCHO sector and community has been positive throughout the process. Quantitative and qualitative data from the CanDAD project provided a sound and local evidence base for the plan and recommendations and strategies from relevant national and state policies and guidelines were also included.

### Writing Group

A writing group was established consisting of members from each of the key partner organisations. The collaborative effort resulted in building and strengthening relationships and a greater commitment and participation from the partner organisations.





## APPENDIX D

## List of Contributors

SA Health would like to thank the following people and organisations who have been instrumental in developing the SA Aboriginal Cancer Control Plan 2016-2021 by contributing to the writing, reviewing and editing of the Plan:

**SA Health**

**Dr Christine Drummond**  
Senior Palliative Medicine Consultant,  
Central Adelaide Palliative Care Service

**Ms Sharon Clarke**  
Senior Project Officer, WCHN

**Ms Karen James**  
Manager Chronic Disease Prevention,  
Public Health Partnerships Branch,  
Public Health and Clinical Systems, SA Health

**Ms Julie Patterson**  
Director, Public Health Partnerships Branch  
Public Health and Clinical Systems, SA Health

**Ms Lyndall Thomas**  
Principal Project Officer, Public Health  
Partnerships Branch, Public Health and Clinical  
Systems, SA Health

**Mr Archie Baker**  
Senior Project Officer,  
Aboriginal Health Directorate, CHSALHN

**SA Cancer Service (SACS)**

**Ms Tracey Doherty**  
Acting Service Director

**Dr Kate Cameron**  
Professional Nurse Lead (formerly)

**Mr Rama Ramanathan**  
Manager

**Ms Chantelle Hislop**  
Senior Project Officer, Survivorship

**Ms Janet Stajic**  
Senior Project Officer,  
Aboriginal Cancer Control

**SA Aboriginal Cancer Control Governance Committee**

**Ms Amanda Mitchell**  
Deputy CEO, AHCSA

**Ms Nola Whyman**  
Manager Aboriginal Health, SALHN

**Mr Kurt Towers**  
Director Aboriginal Health, NALHN/CALHN

**Ms Jackie AhKit**  
Director Aboriginal Health, WCHN

**Mr Rob Zadow**  
Executive Director Aboriginal Health, CHSALHN

**Ms Tanya McGregor**  
Manager Aboriginal Health Branch, SA Health

**Ms Kirsty Delguste**  
Acting/Director Aboriginal Health,  
NALHN & CALHN

**Ms Sandra Miller**  
CanDAD Aboriginal Community  
Reference Group, SAHMRI/Consumer

**Dr Paul Yerrell**  
CanDAD Senior Research Fellow, SAHMRI

**SA Cancer Service Strategy Committee**

**Dr Jacqui Adams**  
Director of Cancer Services, CHSALHN

**Ms Jane Burden**  
General Manager, BreastScreen SA

**Dr Kate Cameron**  
Nursing Director, WCH

**Mr Allan Hayward**  
Program Manager, SA-NT  
Youth Cancer Service

**Professor Ian Olver**  
Director, Sansom Institute for Health Research,  
University of South Australia

**Ms Julie Marker**  
Consumer/SA Cancer Voices

**Associate Professor  
Chris Karapetis**  
Clinical Director, Cancer Services, SALHN

**Ms April Lawrie-Smith**  
Director, Aboriginal Health Branch

**Dr Rahul Mukherjee**  
Medical Oncologist, CALHN

**Dr Oliver Frank**  
General Practitioner

**Dr Michael Osborn**  
Lead Clinician, Haematology/Oncology WCHN

**Ms Kate Swetenham**  
Service Director, Palliative Care, SALHN

**Mr Dale Thompson**  
Pharmacist, CALHN

**Ms Tracey Doherty**  
Acting Service Director, SACS

**Ms Monica Byrnes**  
Manager, Cancer Support, Cancer Council SA

**Dr Bik To**  
Clinical Director, SA Health

**Ms Amanda Mitchell**  
Deputy CEO, AHCSA

**Dr Sudrasha Selva-Nayagam**  
Medical Oncologist, CALHN

**Cancer Council SA**

**Ms Carmel McNamara**  
Coordinator, Aboriginal Cancer Control Program  
(formerly)

**Ms Lauren Maksimovic**  
Manager, Tobacco Control (formerly)

**Mr Nathan Rigney**  
Quitline Educator/Counsellor

**Mr Greg Sharplin**  
Manager Research

**Ms Monica Byrnes**  
Manager Cancer Support

**Aboriginal Health Council of South Australia (AHCSA)**

**Ms Amanda Mitchell**  
Deputy CEO

**Primary Health Network (PHN)**

**Ms Michele Robinson**  
Health Policy Coordinator,  
Country SA LHN (formerly)

**SAHMRI CanDAD Research Team**

**Dr Paul Yerrell**  
Senior Research Fellow

**Dr Rachel Reilly**  
Post-Doctoral Research Fellow

**Dr Jasmine Micklem**  
Post-Doctoral Research Fellow

**Mr Michael Norris**  
Administration Officer

**Dr Kim O'Donnell**  
Post-Doctoral Research Fellow

**Mr David Banham**  
Epidemiologist

**Mr Harold Stewart**  
Senior Cultural Advisor

**CanDAD Aboriginal Community Reference Group (ACoRG)**

**Ms Sandra Miller**  
ACoRG Member

**Aunty Roslyn Weetra**  
ACoRG Member

**Aunty Cynthia Weetra**  
ACoRG Member

**Ms Arlene Burgoyne**  
ACoRG Member

**Uncle George Kenmore**  
ACoRG Member

**Mr Neville Fazulla**  
ACoRG Member

**CanDAD Associate Investigators**

**Ms Lauren Maksimovic**  
Manager, Tobacco Control, Cancer Council SA,  
Cancer Council SA (formerly)

**Ms Carmel McNamara**  
Coordinator, Aboriginal Cancer Control  
Program, Cancer Council SA (formerly)

**Ms Kim Morey**  
Manager, Knowledge Translation  
& Exchange, SAHMRI

**CanDAD Chief Investigators**

**Professor Alex Brown**  
Aboriginal Research Program Leader, SAHMRI and  
Professor of Population Health & Research Chair  
Aboriginal Health, University of South Australia

**Professor David Roder**  
Chair of Cancer Epidemiology and  
Population Health, Division of Health  
Science, University of SA

**Professor Marion Eckert**  
Cancer Care Research Group, School of  
Nursing and Midwifery, Division of Health Sciences,  
University of South Australia

**Associate Professor  
Margaret Cargo**  
School of Health Sciences, University of SA

**Professor Gelareh Farshid**  
Senior Consultant Pathologist, SA Pathology

**Professor Dorothy Keefe**  
Clinical Ambassador, Transforming  
Health, SA Health

## APPENDIX E

# Acronyms

<b>ACaDS</b>	Aboriginal Cancer and Data System (part of CanDAD)
<b>ACCHO</b>	Aboriginal Community Controlled Health Organisation
<b>ACME</b>	Aboriginal Cancer Measures of Experience
<b>AHCSA</b>	Aboriginal Health Council of South Australia Inc. (ACCHO Peak Body in South Australia)
<b>AHLO</b>	Aboriginal Hospital Liaison Officer
<b>AHW/P</b>	Aboriginal Health Worker/Practitioner
<b>AI</b>	Associate Investigator
<b>AIHW</b>	Australian Institute of Health and Welfare
<b>APPO</b>	Aboriginal Patient Pathways Officer
<b>A&amp;TSI</b>	Aboriginal and Torres Strait Islander
<b>CALHN</b>	Central Adelaide Local Health Network (SA Health)
<b>CanDAD</b>	Cancer Data and Aboriginal Disparities (Research Project)
<b>CCSA</b>	Cancer Council South Australia (or Cancer Council SA)
<b>CEO</b>	Chief Executive Officer
<b>CHSALHN</b>	Country Health South Australia Local Health Network (SA Health)
<b>CI</b>	Chief Investigator
<b>COAG</b>	Council of Australian Governments
<b>CTG</b>	Closing the Gap
<b>DHA</b>	Department for Health and Ageing (SA Government)
<b>DoHA</b>	Department of Health and Ageing (Australian Government)
<b>HPV</b>	Human Papilloma Virus
<b>QI</b>	Quality Indicator
<b>LHN</b>	Local Health Network (SA Health)
<b>MBS</b>	Medical Benefits Schedule
<b>NALHN</b>	Northern Adelaide Local Health Network (SA Health)
<b>NCSP</b>	National Cervical Screening Program
<b>NGO</b>	Non-government Organisation
<b>NHMRC</b>	National Health and Medical Research Council
<b>PBS</b>	Pharmaceutical Benefits Scheme
<b>PIP IHI</b>	Practice Incentives Program Indigenous Health Incentive
<b>PHN</b>	Primary Health Network
<b>PREM</b>	Patient Reported Experience Measure
<b>PROM</b>	Patient Reported Outcome Measure
<b>SA</b>	South Australia
<b>SA Health</b>	South Australian Health (SA Government)
<b>SACS</b>	South Australian Cancer Service (SA Health)
<b>SAHMRI</b>	South Australian Health and Medical Research Institute
<b>SALHN</b>	Southern Adelaide Local Health Network (SA Health)
<b>SEWB</b>	Social and emotional wellbeing
<b>SPO</b>	Senior Project Officer
<b>WCHN</b>	Women's and Children's Health Network (SA Health)
<b>WHO</b>	World Health Organisation

## References

1. Government of South Australia, *South Australian Public Health Act 2011*, SA Health, Editor. 2011, Government of South Australia: Adelaide SA.
2. Government of South Australia, *South Australian Public Health Plan 2013*, SA Health, Editor. 2013, Government of South Australia: Adelaide SA.
3. Government of South Australia. *SA Health – Transforming Health*. 2016[cited 2016 24/06/2016]; Available from: <http://transforminghealth.sa.gov.au/>
4. Government of South Australia, *Aboriginal and Torres Strait Islander Companion Document to the Statewide Cancer Control Plan 2011-2015 and Cancer Care Pathway*, SA Health, Editor. 2011, Government of South Australia: Adelaide SA.
5. Aboriginal Health Council of South Australia and Cancer Council South Australia, Perko Ngurratti “Healing Messages’ *South Australian Aboriginal and Torres Strait Islander Cancer Forum 2006 Report*. 2008, Aboriginal Health Council of South Australia and Cancer Council South Australia: Adelaide SA.
6. Davy, C., E. Kite, L. Sivak, T. Ahmat, G. Brahim, A. Dowling, S. Jacobson, T. Kelly, K. Kemp, F. Mitchell, T. Newman, M. O’Brien, J. Pitt, K. Roesch, C. Saddler, M. Stewart, T. Thomas and A. Brown. (2015). *A Wellbeing Framework for Aboriginal and Torres Strait Islander Peoples Living with Chronic Disease*. <http://www.kvc.org.au/projects-and-studies/towards-wellbeing-model-aboriginal-torres-strait-islander-peoples-living-chronic-disease/>
7. Government of South Australia, *South Australian Lung Cancer Pathway*, SA Health, Editor. 2013, Government of South Australia: Adelaide SA.
8. Government of South Australia, *Aboriginal Health Care Plan 2010-2016*, Department of Health Statewide Service Strategy Division, Editor. 2010, Government of South Australia: Adelaide SA.
9. South Australian Health and Medical Research Institute, *South Australian Aboriginal Health Research Accord: Companion Document*. 2014.
10. Commonwealth of Australia, *National Aboriginal and Torres Strait Islander Health Plan 2013-2023*. 2013, Commonwealth of Australia: Canberra ACT.
11. Cancer Australia, 2015. *National Aboriginal and Torres Strait Islander Cancer Framework*, Cancer Australia, Surry Hills, NSW.
12. Australian Institute of Health and Welfare 2015. *The health and welfare of Australia’s Aboriginal and Torres Strait Islander peoples 2015*. Cat. no. IHW 147. Canberra: AIHW.
13. Australian Institute of Health and Welfare 2016. *Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011*. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.
14. Australian Institute of Health and Welfare 2014. *Cancer in Australia: an overview 2014*. Cancer series No 90. Cat. no. CAN 88. Canberra: AIHW.
15. Australian Institute of Health and Welfare & Cancer Australia 2013. *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview*. Cancer series no.78. Cat. no. CAN 75. Canberra: AIHW.
16. World Health Organisation. *Cancer Prevention*. [cited 2016 23/06/2016]; Available from: <http://www.who.int/cancer/prevention/en/>
17. Cancer Australia, 2015. *Position Statement – Lifestyle risk factors and the primary prevention of cancer*, Cancer Australia, Surry Hills, NSW.
18. Australian Institute of Health and Welfare 2015. *Aboriginal and Torres Strait Islander Health Performance Framework report 2014: South Australia*. Cat. no. IHW 164. Canberra: AIHW.
19. Shahid S, Finn L, Bessarab D, Thompson SC. (2009) *Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services*. BMC Health Services Research 9: 132.
20. Cancer Voices SA, *Walked the walk to talk the talk: yarning about cancer, in Cancer conversations in Aboriginal communities with cancer survivors*. 2011, Cancer Voices SA: Adelaide SA.
21. Angus S, *A model for engaging and empowering Indigenous women in cancer screening*. Cancer Forum, 2005. 29(1): p. pp. 13-17.
22. Queensland Government, Queensland Health. *Queensland Aboriginal and Torres Strait Islander Women’s Cervical Screening Strategy 2006-2010*, Brisbane 2007.
23. Government of South Australia, *BreastScreen Program Data. 2016*, BreastScreen South Australia: unpublished.
24. Australian Bureau of Statistics, *Australian Aboriginal and Torres Strait Islander Health Survey 2012-2013*. [cited 2016 23/06/2016]; Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4727.0.55.001>

## References

25. Department of Health, Australian Government, *National Cervical Screening Program*. [cited 2016 24/06/2016]; Available from: <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/content/cervical-screening-1>
26. Australian Institute of Health and Welfare 2013. *The inclusion of Indigenous status on pathology request forms*. Cat. no. IHW 103. Canberra: AIHW.
27. Condon JR, Barnes T, Armstrong BK, Selva-Nayagam S, Elwood JM. (2005) *Stage at diagnosis and cancer survival for Indigenous Australians in the Northern Territory*. *Med J Aust*. 182(6): 277-280.
28. Valery PC, Coory M, Stirling J, Green AC. (2006) *Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study*. *Lancet*. 367: 1842-8.
29. Australian Institute of Health and Welfare 2011. *The health and welfare of Australia's Aboriginal and Torres Strait Islander people, an overview 2011*. Cat. no. IHW 42. Canberra: AIHW.
30. Australian Health Ministers' Advisory Council, 2012, *Aboriginal and Torres Strait Islander Health Performance Framework 2012 Report*, AHMAC, Canberra.
31. COAG Health Council 2012, *COAG Improving Cancer Care Initiative: National Cancer Work Plan*, prepared by the National Cancer Expert Reference Group (NCERG).
32. SAHMRI, *Cancer Data and Aboriginal Disparities (CanDAD) Research Project – Preliminary Findings*. 2016, South Australian Health and Medical Research Institute.
33. Clinical Oncology Society of Australia, *Cancer Care Coordinator Position Statement*. 2015.
34. Government of NSW, *Evaluation of the role of Cancer Care Coordinator Summary Report*, Cancer Institute NSW, Editor. 2011, Government of NSW: Sydney NSW.
35. Garvey et al.: *The development of a supportive care needs assessment tool for Indigenous people with cancer*. *BMC Cancer* 2012 12:300.
36. Adelaide Primary Health Network. *Closing the Gap: Improving Indigenous Access to Mainstream Primary Care Program*. 2016 [cited 2016 23/06/2016]; Available from: <http://adelaidephn.com.au/what-we-do/development-and-commissioning/closing-the-gap/>
37. Government of South Australia, *Aboriginal Health Services: Aboriginal Health Workers Locations* [cited 2016 24/06/2016]; Available from: <http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+services/aboriginal+health+services/aboriginal+health+workers>
38. Government of South Australia, *SA Health Aboriginal Cultural Respect Framework*, SA Health, Editor. 2009, Government of South Australia: Adelaide SA.
39. Brown, A; Keech W; McBride, K; Kelly, J; Stewart, S; Dowling, A; on behalf of the SA Aboriginal Heart and Stroke Plan 2017-2021 Steering Committee. *South Australian Aboriginal Heart and Stroke Health Plan 2017- 2021*. SAHMRI, Adelaide.
40. Australian Institute of Health and Welfare, *Cancer in Australia: an overview 2014*. 2014, AIHW: Canberra.
41. Chong, A and Roder D. (2010) *Exploring differences in survival from cancer among Indigenous and non-Indigenous Australians: implications for health service delivery and research*. *Asian Pac J Cancer Prevention*. 11(4): 953-61.
42. Tervonen, HE, Aranda S, Roder D, Walton R, Baker D, You H, Currow D. (2016) *Differences in impact of Aboriginal and Torres Strait Islander status on cancer stage and survival by level of socio-economic disadvantage and remoteness of residence—A population-based cohort study in Australia*. *Cancer Epidemiology*. 41: 132-138.
43. Health Performance Council, *What's working, what's not: Review of the South Australian Health System Performance for 2011–2014*. 2014, Health Performance Council: Adelaide.
44. Australian Bureau of Statistics, *Statistical Geography Volume 1 – Australian Standard Geographical Classification (ASGC)*. 2006, ABS: Canberra.



**South Australian Health  
and Medical Research  
Institute (SAHMRI)**

North Terrace  
Adelaide  
South Australia 5000

**Postal**

PO Box 11060  
Adelaide, SA 5001  
Tel 08 8128 4000  
[www.sahmri.org](http://www.sahmri.org)

**SA Health**

Citi Centre Building  
11 Hindmarsh Square  
Adelaide South Australia 5000

**Postal**

PO Box 287 Rundle Mall  
Adelaide SA 5000  
Tel 08 8226 6000  
[www.sahealth.sa.gov.au](http://www.sahealth.sa.gov.au)

**Aboriginal Health Council  
of South Australia Inc.**

220 Franklin Street  
Adelaide  
South Australia 5000

Tel 08 8273 7200  
[www.ahcsa.org.au](http://www.ahcsa.org.au)

**Cancer Council  
South Australia**

202 Greenhill Road  
Eastwood  
South Australia 5063

Tel 08 8291 4111  
[www.cancersa.org.au](http://www.cancersa.org.au)