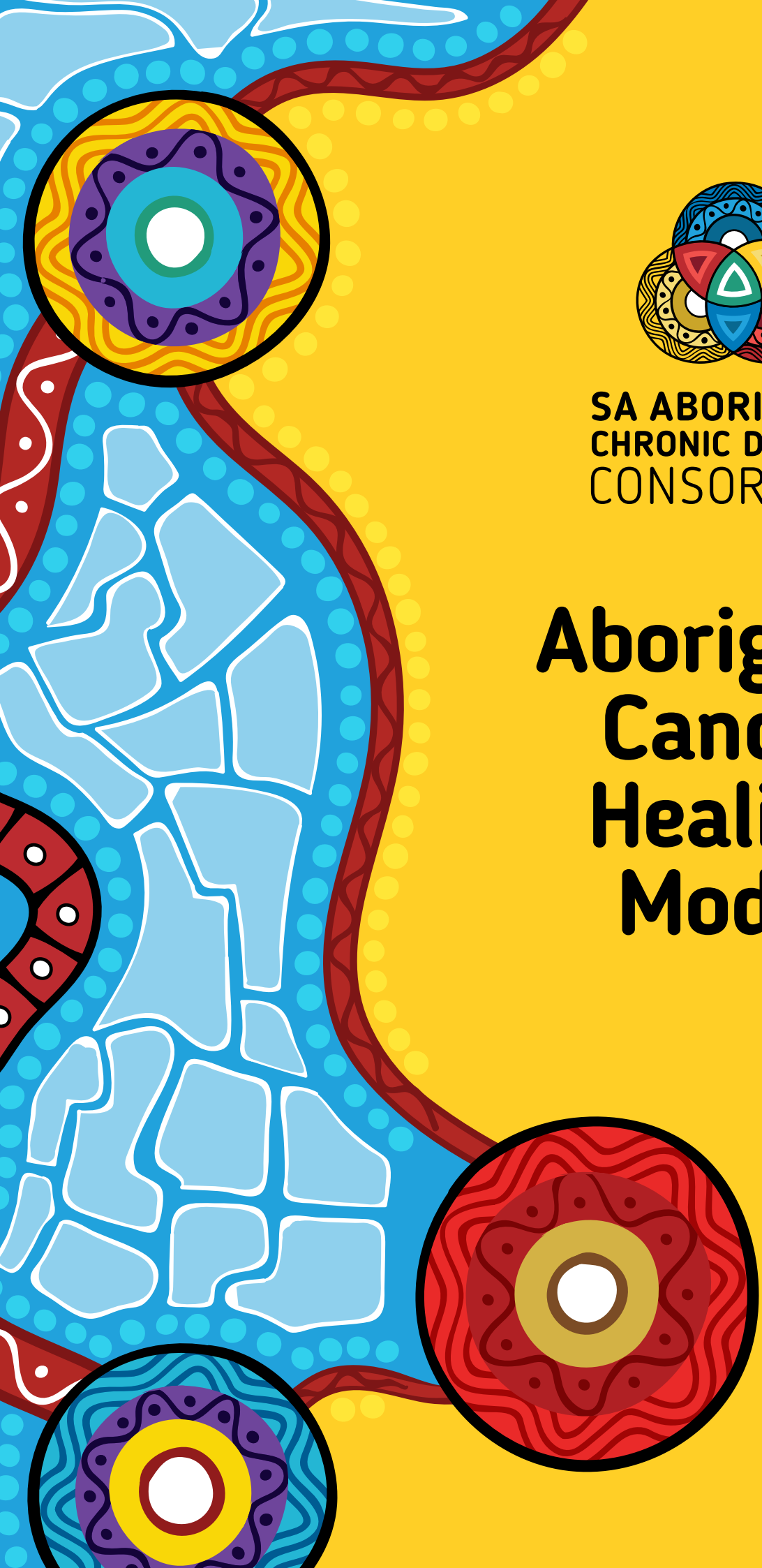


SA ABORIGINAL CHRONIC DISEASE CONSORTIUM

Aboriginal Cancer Healing Model

Aboriginal Cancer Healing Model, September 2019.

© South Australian Aboriginal Chronic Disease Consortium.

Ownership of intellectual property rights in this publication Copyright and any other intellectual property rights in this publication are owned by the South Australian Aboriginal Chronic Disease Consortium.

Please direct enquiries to:

The Consortium
South Australian Aboriginal Chronic Disease Consortium
P (08) 8128 4893
E theconsortium@sahmri.com

North Terrace, Adelaide, South Australia 5000
PO BOX 11060, Adelaide, South Australia 5001
www.aboriginalhealthconsortium.org

ACKNOWLEDGMENT OF COUNTRY

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

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

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

Contents

Acknowledgment of Country 3

Introduction 5
- Cancer disparities 5
- Limitations of the medical model to cancer care 6
- The concepts of healing and wellbeing 7

The Aboriginal Cancer Healing Model 8
- The structure of the model 8
- The community's vision for Aboriginal Cancer Healing 9
- Core characteristics of Aboriginal Cancer Healing 9
- The community's needs and the strength of Aboriginal people and culture 10
  - Spiritual and cultural needs 10
    - Traditional healing: Ngangkaris and bush medicine 10
    - Connection to Country 11
  - Mind and emotions 12
  - Involving the family 12
  - Recognising the value of a skilled Aboriginal workforce 12
  - Considering the strengths of the community 13
  - Non-health related challenges 13
- Service elements 14
- The physical environment 15
- Enablers 16
  - Organisational capacity 16
  - A culturally safe, capable and appropriate workforce 16
  - A Governance structure 16
  - Technology 17
  - Telehealth 17
  - Monitoring and evaluation 17

Implementation 18

Appendices 19
- Background 19
  - Aboriginal Chronic Disease Consortium 19
  - Research translation 19
  - Country Chemotherapy Units 19
  - Optimal Care Pathways 20
  - National Safety and Quality Health Standards 20
- Evidence 22
  - South Australian Aboriginal Cancer Control Plan 2016-2021 22
  - Cancer Data and Aboriginal Disparities (CanDAD) Study 23

Introduction

Aboriginal and Torres Strait Islander people (referred to here as 'Aboriginal people') are a minority population within South Australia, estimated at 2.5%[1]. Aboriginal people experience disproportionately poorer health outcomes and mortality from chronic disease. The average 10-year-gap in life expectancy has been attributed largely to chronic disease, and cancer is estimated to account for 15% of this disparity[2].

Providing effective cancer services from prevention and early detection, to acute care and survivorship and/or end-of-life care is critical to improving health outcomes for Aboriginal South Australians who are affected by cancer. However, the level of cultural safety and appropriateness varies and is often under-developed, and cancer services are therefore not as accessible to the Aboriginal community as they should be.

As a result, the uptake of cancer services by Aboriginal people is low and the morbidity and mortality gaps remain high. The South Australian Aboriginal Chronic Disease Consortium consulted the Aboriginal communities in South Australia and Aboriginal health system and service professionals to determine the appropriate course of action and identified the development and trial of an Aboriginal Cancer Healing Model as a priority action area in the Consortium's "Road Map for Action"[3].

Cancer disparities

In South Australia, cancers among the Aboriginal population occur at young ages, with the median diagnosis occurring approximately ten years younger in comparison to the broader population (Banham et al, 2017). Cancer outcomes are significantly determined by stage of the disease at diagnosis, and the South Australian Cancer Data and Aboriginal Disparities (CanDAD) study found that cancers are more advanced in Aboriginal people at diagnosis compared to non-Aboriginal people.

The SA Aboriginal Health Needs and Gaps Analysis for the Northern Adelaide Local Health Network (Gibson et al, 2017) also found a higher proportion of the Aboriginal cohort were diagnosed with cancer at a later stage, where it had progressed to regional or distant spread.

At the same time, SA Health internal reviews of the uptake of acute cancer treatment at country-based chemotherapy units by Aboriginal people has been lower than expected.

Cancer outcomes and survival rates are further influenced by geographical factors, including living in rural and remote areas, where people experience barriers to accessing health services. A study by Condon et al (2006) further found that language and cultural barriers also influence cancer outcomes for Aboriginal people. Finally, the significantly higher degree of chronic disease comorbidities experienced by Aboriginal people also contribute to cancer mortality (Banham et al, 2018).

Further information about the disparities in cancer between Aboriginal and non-Aboriginal people, refer to Appendix 1.

[1] Australian Bureau of Statistics (2018), Estimates of Aboriginal and Torres Strait Islander Australian, June 2016, https://www.abs.gov.au/ausstats/abs@.nsf/mf/3238.0.55.001

[2] Australian Institute of Health and Welfare. Australian Burden of Disease Study: Impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011. Canberra: AIHW, 2016 23 September 2016. Report No.: Contract No.: Australian Burden of Disease Study series no. 6. Cat. no. BOD 7

[3] South Australian Aboriginal Chronic Disease Consortium (2016), Road Map for Action, http://aboriginalhealthconsortium.org/wp-content/uploads/2017/09/SA-Aboriginal-Chronic-Disease-Consortium-Road-Map-for-Action.pdf

Limitations of the medical model to cancer care

South Australia delivers high quality multidisciplinary cancer services. Many cancers need several types of interventional treatment (surgery, chemotherapy and radiotherapy). Increasingly, there has been an emphasis on the provision of care closer to home through Country Health SA's regional chemotherapy units. These units are used to reduce patients' need for travel; help to retain patients' connection with their families and communities; and reduce disruptions to patients' daily lives as much as possible.

However, some specialist diagnostic services such as positron emission tomography (PET) scans and magnetic resonance imaging (MRI) scans may still require travel to urban centres, as may radiotherapy treatments or complex surgery. Access to this type of cancer care may be culturally challenging for Aboriginal patients unless the services have accounted for their specific needs. To enhance service accessibility, it is also important to ensure that for relatives or carers who need to travel, the logistics and support are available to facilitate access to cancer diagnosis and treatment services.

The acute health system's primary focus on the treatment of cancer, and the range of support services available to patients can and must be improved to accommodate the needs of Aboriginal people, their families and the community at large. Research has found that there are a range of common themes related to Aboriginal people's beliefs and concerns related to cancer which need to be considered and accommodated to ensure that treatment is culturally safe and accessible, such as a feeling of disconnect from clinicians, fear about leaving home and cultural beliefs that underpin patients' understanding of their disease and their preferences for treatment and care.

It is important that care providers gain a level of cultural awareness that enables them to provide care that can be considerate of Aboriginal people's beliefs and to tailor their conversation with Aboriginal patients and their care accordingly[4].

Rather than assuming that an individualised approach to the treatment of disease is required, it is important that clinical and other cancer care staff consider patients' preferences as to the involvement of their families and their communities. Consideration also needs to be given to patients' sense of safety and security in an unfamiliar environment and a system that is difficult to navigate. The Aboriginal Cancer Healing Model outlines how to apply a holistic lens through a focus on supporting the healing process, inclusive of family and community, to complement the biomedical approach to cancer care.

Through this holistic approach, the Aboriginal Healing Model can address the spiritual, cultural, emotional and various social needs of Aboriginal people and build on the strengths of Aboriginal culture.

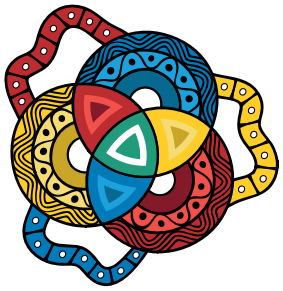
This model has been designed to complement medical treatment of cancer through chemotherapy, radiation therapy, surgery and post-surgery care in acute service settings. It also aims to provide guidance to amend, improve and enhance the approach of services in providing social supports to Aboriginal patients and families.

Although specifically tailored for the acute setting, key elements of the model and findings from implementation trials could be used to inform the provision of cancer services throughout the patient journey in primary and tertiary settings. In addition, the identified key elements of providing culturally safe health care services can be applied to chronic disease and health care more broadly.

[4] Van Schaik et al (2012), Indigenous beliefs about biomedical and bush medicine treatment efficacy for indigenous cancer patients: a review of the literature, International Medicine Journal

The concepts of healing and wellbeing

The Aboriginal concept of "healing" refers to achieving strong mind and spirit, staying strong mentally and culturally. Healing is a process that involves cultural identity and the restoration and reaffirmation of cultural pride, connectedness to country and community involvement to achieve a holistic state of wellbeing[5].



The concept of healing is often discussed and described in the context of intergenerational trauma that stems from colonisation and racism. Healing in this context "involves the application of existing cultural knowledge, as well as the development of new ways to practice this in a contemporary context, in order to address trauma stemming from colonisation and to restore and sustain holistic wellbeing"[6].

"I did have a Ngangkari here when I first got here, and she pulled three black things out of my back. But Ngangkari can't kill cancer."

- ACceSS participant, 2018

While this line of thinking may not be directly related to cancer, it is nonetheless relevant as experiences of trauma are widespread amongst Aboriginal communities, and the approach to healing from trauma provides important insights as to how to design and implement a cancer healing. Mackean (2009) further argues that healing can be experienced during the process of recovery from illness, and that it involves moving forward with hope, energy and enthusiasm.

As such, a model for healing needs to support the process of "reclaiming a sense of balance and harmony in the physical, psychological, social, cultural and spiritual lives"[7] to be truly complementary to the medical approach of treating cancer. Importantly, healing needs to be led by Aboriginal people and defined in accordance with an Aboriginal worldview. It is not suggested that cultural and traditional concepts of healing offer a cure for cancer but rather, that healing is critical to the success of clinical approaches to treating the disease and restore physical health.

[5] Australian Indigenous Health*Info*Net (n.d.), Traditional Healing, available at https://healthinfonet.ecu.edu.au/learn/health-topics/healing/traditional-healing/

[6] Aboriginal and Torres Strait Islander Healing Foundation (2012), "Healing Centres Final Report – 21 December 2012", available at https://www.aph.gov.au/DocumentStore.ashx?id=0cd4a4cc-3352-4bf0-930f-59da07753d42

[7] Mackean, T (2009), A healed and healthy country: understanding healing for Indigenous Australians, Med J Aust 2009; 190 (10): 522-523, available at https://www.mja.com.au/system/files/issues/190_10_180509/mac10409_fm.pdf

The Model

The model for Aboriginal Cancer Healing has been developed with a focus on acute cancer care and to support Aboriginal people who receive clinical treatment, e.g. chemotherapy, radiotherapy and/or surgery, to treat the disease, and to involve, engage and support family members, carers and the Aboriginal community at large. The model seeks to guide the provision of services and the design of an environment that is suitable to enable the healing process that gives Aboriginal people spiritual, cultural, mental and physical strengths throughout the cancer treatment phase and during recovery after the clinical treatment has been completed.

The structure of the Model

The model has three core elements:

1

Service elements to support the individual who is directly affected by a cancer diagnosis, including a particular focus on the needs of adolescents affected by cancer, the cancer patient's family and the broader community (incl. prevention and early detection)

2

The physical environment that offers culturally safe and welcoming clinical, indoor and outdoor spaces

3

A range of enablers, critical to the successful implementation of the model, including workforce and governance requirements, cultural safety, the use of technology for outreach and follow-up and a robust approach to monitoring and evaluation.

The community's vision for Aboriginal Cancer Healing

Cancer has a profound effect on our community, and we are entitled to receiving the best care and support to stay strong during the cancer journey and have the best chances of survival.

We want a place to go, sit down, have a yarn and be comfortable. We want a cultural space, where we can connect with our environment, our country, culture and community. A space with an open fire or under a tree; a separate space in the middle of a clinic, separate from programs and services, where we can go and support each other, and where we can take our families and support the people who do not have family support. A space where we can be Aboriginal women and Aboriginal men, where we can talk things through and share information. That space should be ours, and it should be governed by Aboriginal people. And it needs to have a different atmosphere, so we can be there and cry and deal with our emotions.

We need our treating health professionals to listen to our concerns and understand what is important to us. We want information that we can understand, so we are clear about our options and enabled to make informed decisions about our treatment in equal partnership with the health professionals.

Core characteristics of Aboriginal Cancer Healing

Informed by the Aboriginal and Torres Strait Islander Healing Foundation[8], the core characteristics of an Aboriginal Cancer Healing model should include:

- Aboriginal ownership of the design and implementation of the model;
- holistic and multidisciplinary approaches, addressing the needs of Aboriginal people affected by cancer, their families and communities;
- culture and spirituality at the core of the healing journey;
- a positive, strength-based approach, recognising the strength of Aboriginal people and culture;
- a commitment to the ongoing process of healing; and
- a commitment to adaptability, flexibility and innovation, to cater for Aboriginal people with various cultural needs.

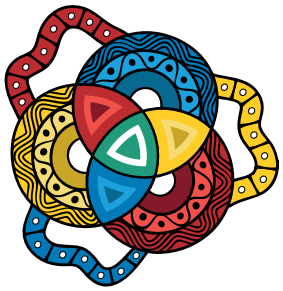
[8] Aboriginal and Torres Strait Islander Healing Foundation (2012), "Healing Centres – Final Report – 21 December 2012".

The community's needs and the strength of Aboriginal people and culture

Research into Aboriginal patients' experiences with cancer services enables us to articulate the needs of Aboriginal people who are affected by cancer. A comprehensive record and analysis of Aboriginal people's narratives, collected as part of the Cancer Data and Aboriginal Disparities (CanDAD) study, has found that there are broadly 4 categories of needs that need to be considered when designing a cancer service model for Aboriginal people.

Spiritual and cultural needs

Traditional healing: Ngangkaris and bush medicine



Receiving "a healing" from a traditional Aboriginal healer, in Central and South Australia often referred to as a "Ngangkari", can support and complement the western approach to the treatment of disease. The process of applying cultural knowledge to restore and sustain holistic wellbeing is central to the Aboriginal Healing Model.

Traditional or "bush medicine" is also used to enable the healing process, and it is another means for Aboriginal people to connect or reconnect with their heritage, land, culture and the spirits of their ancestors. The healing powers of bush medicine relieve stress and anxiety, which is an important aspect for managing the cancer treatment. The rituals associated with the use of bush medicine are furthermore significant to Aboriginal people's identity and connection with country and culture.

Patients may choose to include the use of traditional healing and bush medicine as a complementary treatment strategy alongside western clinical treatments, and patients have also chosen to use traditional healing instead of chemotherapy, radiotherapy or surgery, especially in the context of palliative or end-of-life care, where quality of life increasingly determines patients' choices and decisions[9].

"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."

- Aboriginal Community Reference Group Member, CanDAD

A traditional healing approach can also include the recovery of language and traditions, art, dance, stories, traditional food and medicines and needs to be specific to local regions and led by traditional owners of the country of the trial or implementation site[10].

[9] Shahid, S et al (2010), "If don't believe it, it won't help you": use of bush medicine in treating cancer among Aboriginal people in Western Australia, Journal of Ethnobiology and Ethnomedicine 2010, **6**:18, available at http://www.ethnobiomed.com/content/6/1/18

[10] Australian Indigenous Health*Info*Net (n.d.), Traditional Healing, available at https://healthinfonet.ecu.edu.au/learn/health-topics/healing/traditional-healing/

Connection to Country

The importance of Aboriginal people's relationship with their country cannot be underestimated, and the concept of connecting with country is critical to healing and wellbeing.

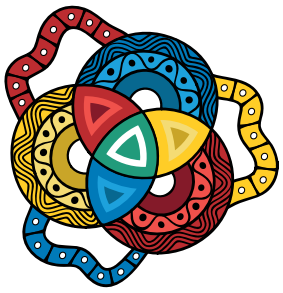
In South Australia, the Healthy Parks Healthy People SA – Connection to Country for Aboriginal Health and Wellbeing Working Group, in collaboration with a broad range of organisational and community representation, released a Joint Statement of Action – Connection to Country for Aboriginal Health and Wellbeing[11]. The statement explains:

> **Aboriginal people have long understood and benefited from a strong relationship with Country. The reciprocal and interdependent relationship between Aboriginal people and their ancestral lands and seas is sustained by cultural knowledge and connection. This relationship, and the cultural practices and customs that strengthen and protect it, vary between places and communities. The relationship with Country is a personal one, Aboriginal people see themselves as belonging to Country, and every aspect of themselves and their life as holistically interconnected with Country. Connection to Country encompasses opportunities to be on and with Country.**
>
> **We know that connection and/or re-connection to Country is a significant determinant of health and wellbeing for Aboriginal people and is part of Aboriginal peoples' sense of belonging and self-determination. Importantly, 'Country' is more than a geographic area: it encompasses the values, places, resources, stories and cultural obligations associated with Aboriginal people's rights and identity. For Aboriginal people, Country, culture and language are intrinsically linked.**

Enabling Aboriginal people to maintain this connection throughout their cancer journey is critical to the Aboriginal Cancer Healing model, and options for practical application need to be explored with and by local Aboriginal communities, to align with local culture and traditional practices, and also consider the cultural needs of visiting Aboriginal patients from adjacent or other Aboriginal nations.

"My own Indigenous understanding of what is broadly conceptualized in a Western context as the environment and more specifically as land, is a meaning or grounding of being and reality that does not even appear in the realm of possibilities in this Western context, much less in actual conversations."

- Burkhart (2019)



[11] SA Health & SA Aboriginal Chronic Disease Consortium (2019), Joint Statement of Action – Connection to Country for Aboriginal Health and Wellbeing, available at https://www.sahealth.sa.gov.au/wps/wcm/connect/0c37d66c-a929-4cee-a950-a4e449895d65/SA+HEALTH+JAS+Digital+-27May19.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-0c37d66c-a929-4cee-a950-a4e449895d65-mIrjft

Mind and emotions

Closely connected with the spiritual and cultural aspects of wellbeing are the aspects that strengthen Aboriginal cancer patients' minds and emotions. The "Aboriginal Cancer Stories Study" (ACceSS) heard a variety of personal experiences and attributes that should be considered when designing an Aboriginal Cancer Healing service model. For example, there were stories of people who displayed exceptional levels of resilience, and who used humour as a coping mechanism. There were people who rose to the challenge to look after themselves and exercise a high degree of self-determination (for example in their treatment decisions), and then there were those who had to learn to be vulnerable and accept help and support.

Common themes also included the importance of avoiding stressors, breaking down myths about cancer and misunderstandings, and remaining positive.

A service model for Aboriginal Cancer Healing needs to put treatment and service options in place that support Aboriginal people and meet the variety of mental health needs in a culturally appropriate, safe and respectful manner. ACceSS heard that Aboriginal people have had positive experiences with yarning circles and hearing from other Aboriginal people who have had experience with cancer, with story-telling and narrative therapy, in group settings and on an individual basis.

Involving the family

For some Aboriginal people, it is important to involve the family in the cancer care journey; however, the extent of involvement can vary, and it is important to discuss the patient's preferences and wishes. We have heard of cases where families and communities would actively participate in the decision-making process regarding treatment choices. Others may prefer a more individualised approach and require a high level of privacy.

Where family is expected to take action, it is important to equip members of the family and the community with the appropriate knowledge, support and resources to support the cancer patient. Consider the use of translators and interpreters where English is not the first language.

Recognising the value of a skilled Aboriginal workforce

A highly skilled Aboriginal health workforce is critical to providing holistic care and to achieving improved health outcomes through effective care coordination that meets the clinical and cultural needs of Aboriginal people affected by cancer. This include ensuring that there is a continuity of care throughout a patient's cancer journey between acute and primary care settings. A dedicated Aboriginal cancer care coordination workforce support patients and families in navigating the health system, organising travel and accommodation, and addressing a variety of needs that may arise, such as providing appropriate clothing and assisting cancer patients and escorts with medications and prescriptions etc. Critically, a skilled Aboriginal workforce is best place to overcome communication barriers and ensure that Aboriginal cancer patients and their families and carers receive the information they require to manage the cancer journey and achieve better health outcomes[12].

[12] Reilly, R et al (2018), Aboriginal experiences of cancer and care coordination: Lessons from the Cancer Data and Aboriginal Disparities (CanDAD) narratives, Health Expectations 2018, 1-10.

Considering the strengths of the community

The community can play a powerful role in the healing process and should build on the strength and the social capital of the Aboriginal community to enable a holistic approach in partnership with an empowered and engaged community. Factors such as cultural protocols, processes and practices, resilience and vulnerability, self-determination and logistical challenges play an important role in the patient journey and can be a significant barrier if not considered and addressed effectively.

A service model to enable cultural, spiritual, emotional and social healing for Aboriginal people affected by cancer also needs to reflect Aboriginal history, culture and family and community structure, and holistic world view to achieve a holistic model of care alongside the physical care provided through a western bio-medical model that involves chemotherapy, radiotherapy and surgery throughout cancer treatment[13].

Non-health-related challenges

Holistic support during the cancer journey is also required for challenges related to Aboriginal cancer patients' and families' transport and accommodation needs, to manage financial challenges and to put in place arrangements and strategies for the responsibilities that are on hold during cancer treatment, including absence from work, family commitments and any other obligations.

Partnerships with social and community service sector agencies should be established to enable a collaborative approach to meet such needs. Consideration needs to be given to the need for a translator and/or interpreter, as previously discussed.

Whilst these needs and strengths are related across categories and cannot be addressed in isolation, it is helpful to articulate them clearly to ensure that the design of a service model and the environment that is required to implement a cancer healing approach successfully can consider all aspects of Aboriginal people's needs and build on the strengths from within culture and community.

A robust and comprehensive local community and stakeholder approach is required to identify and articulate those needs accurately, and to develop an effective service model, design a culturally safe and welcoming environment and put in place the right enablers to ensure a successful implementation of this model.

[13] Australian Indigenous HealthInfoNet (n.d.), Promising Practice, available at https://healthinfonet.ecu.edu.au/learn/health-topics/healing/promising-practice/

The service elements

Aboriginal cancer healing services to complement the clinical approach through the cancer diagnosis and treatment phases should draw on traditional healing, complementary therapies and a range of social and community support services to meet the range of needs that has been identified through community and stakeholder consultation. The service elements outlined below are suggestions for considerations that can be used as a basis for consultations.

Traditional Healing

Traditional healing should be at the core of an Aboriginal Cancer Healing Model, and there is evidence that Aboriginal people actively seek traditional healing for their wellbeing[14,15]. Community leadership is critical to identify the appropriate approach and the providers best suited to provide those services. These can include:

- **Traditional healers,** often called "Ngangkari", male and female healers who apply an ancient practice to support the physical, emotional and social wellbeing of the community[16]
- **Bush medicine** made from healing plants and natural materials
- **Connection to Country** initiatives that enable Aboriginal people to maintain a strong relationship with country and culture which is critical to Aboriginal wellbeing, a sense of belonging, self-determination, culture and community[17]

Complementary therapies

Complementary therapies which are commonly available for people of various cultural backgrounds should be considered their cultural appropriateness discussed with local community and stakeholders. These may include:

- Art therapy, music therapy
- Mindfulness
- Narrative therapy
- Yoga
- Yarning circles
- Peer support groups

Social, family and community support

Social, family and community support should be provided by and in partnership with the social and community support service sector, to address various areas of need, including:

- Transport
- Housing, including for families
- Financial counselling and assistance

[14] Shahid, S et al (2010), "If you don't believe it, it won't help you": use of bush medicine in treating cancer among Aboriginal people in Western Australia, Journal of Ethnobiology and Ethnomedicine 2010, 6:18 http://www.ethnobiomed.com/content/6/1/18

[15] Shahid, S et al (2009), Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impacts on access to cancer services, BMC Health Services Research 2009, 9:132.

[16] NPY Women's Council (n.d.), What we do: Ngangkari – Traditional Healers, available at https://www.npywc.org.au/what-we-do/ngangkari-traditional-healers/

[17] SA Health & SA Aboriginal Chronic Disease Consortium (2019), Joint Statement of Action – Connection to Country for Aboriginal Health and Wellbeing, available at https://www.sahealth.sa.gov.au/wps/wcm/connect/0c37d66c-a929-4cee-a950-a4e449895d65/SA+HEALTH+JAS+Digital+-27May19.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-0c37d66c-a929-4cee-a950-a4e449895d65-mIrjft

The physical environment

Culturally safe and welcoming environments are largely created by the people who provide a service and through the relationships that patients and families have with service providers and with their peers and the local Aboriginal community (for further information, see "Enablers" below). However, physical environments can play a powerful role in providing a culturally safe and welcoming healing space through design, layout and appearance of clinic and treatment facilities, separate (non-clinical) healing spaces, including outdoor spaces such as healing gardens[18]. Access to "Country" and the natural environment is also important, as discussed earlier, in "Traditional healing – Connection to Country initiatives".

The design of indoor and outdoor spaces should be created by or in consultation with local Aboriginal people, to ensure that any design is culturally appropriate and meaningful to the local community. Including local Aboriginal artists and other people from the community early is important to a successful engagement. Inclusion of local artwork, gender-sensitive designs and spaces, display of signage in language and other Aboriginal languages are some of the strategies for consideration. Guidance should be sought from local and visiting Aboriginal people.

Clinical spaces such as chemotherapy units, radiotherapy facilities and various consultancy rooms may benefit from visual design changes, to meet clinical needs and create a less daunting and more welcoming space through the display of flags, maps of Aboriginal country, artwork, signs and resources in Aboriginal languages etc.

Non-clinical healing spaces should be separate from the clinical environment and have a non-clinical "look and feel". These spaces can be used for traditional and complementary treatments, social services, and as gathering spaces for patients, families and members of the community.

Outdoor spaces should be made available, especially for patients who are unable to participate in any "Connection to Country" initiatives. This may include healing gardens, sheltered gathering spaces, fire pits etc. Clinicians and other service providers should be encouraged to use outdoor spaces for consultations as appropriate.

Extract from the community's vision

We want a place to go, sit down, have a yarn and be comfortable. We want a cultural space, with an open fire or under a tree; a separate space in the middle of a clinic, separate from programs and services, where we can go and support each other, and where we can take our families and support the people who do not have family support. A space where we can be Aboriginal women and Aboriginal men, where we can talk things through and share information. That space should be ours, and it should be governed by Aboriginal people. And it needs to have a different atmosphere, so we can be there and cry and deal with our emotions.

[18] Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute. National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health. Sydney: Australian Commission on Safety and Quality in Health Care; 2017.

Enablers

In addition to an appropriate service model and physical environment, a range of strategies should be considered to ensure the effectiveness of an Aboriginal Cancer Healing Model.

Organisational capacity

Organisational capacity, embedded in policy frameworks, operational procedures, service planning and funding structures, which allow the frontline workforce to provide the best possible service to Aboriginal people affected by cancer. This includes:

- Culturally appropriate approaches to Aboriginal staff recruitment, training and retention;
- Cultural capacity building in the non-Aboriginal workforce and a commitment to ensuring cross-cultural collaboration between Aboriginal and non-Aboriginal staff;
- Operational policies and procedures that enable staff to spend appropriate time and have access to the resources required to provide holistic care;
- Partnerships between acute and primary health care services and a cross sector approach which includes a range of social and community service organisation; and
- Sufficient and sustainable funding.

A culturally safe, capable and appropriate workforce

A culturally safe, capable and appropriate workforce, with a focus on Aboriginal employment into various leadership, clinical and support service roles and the professional engagement of Elders and local community to provide cultural services, brokerage, liaison and advice.

The non-Aboriginal workforce should be supported in their cultural learning, including through mentoring and other means of professional development, to enable a high level of cultural safety.

A governance structure

A governance structure with strong Aboriginal leadership. It is important that governance groups and processes are committed to favouring Aboriginal perspectives, and that Aboriginal cultural considerations be embedded in organisational and – wherever possible – clinical decision making.

Aboriginal community representatives and Aboriginal clinicians need to lead and guide the governance structure, and all members need to work in partnership to ensure the cultural, clinical and organisational integrity of the Aboriginal Cancer Healing Model is upheld.

Technology

Technology can assist with a range of communication and service needs that may otherwise be challenging to meet in rural and remote contexts.

Communication technology should be considered to enable Aboriginal patients from other communities to maintain family and community relationships during cancer inpatient treatment.

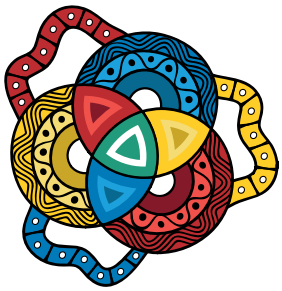
Telehealth

Telehealth can play an important role to delivering long-distance specialist services through the use telecommunication systems and virtual technology. It facilitates patient-to-provider and provider-to-provider remote communication encompassing a range of non-clinical and clinical digital care, from health education and provider training to diagnosis and treatment.

Telehealth reduces the need for travel, allowing patients to receive care closer to home, addresses scarcity of providers and decreases the demands on health care facilities.

Monitoring and evaluation

Monitoring and evaluation are important components of the delivery of any service, to assess the effectiveness of services, measure improvements in health outcomes and enable quality improvement. A robust framework for process, consumer and health service outcomes evaluation needs to be established during the planning phase of the implementation of the Aboriginal Cancer Healing Model, and it is critical to ensure that an Aboriginal lens be applied to guide the development of process and performance indicators to measure success. A long-term approach to monitoring changes in population health over time should also be applied.



"Workforce should be sensitive to the heterogeneity of Aboriginal cultures and the many shades of amalgamation of Aboriginal cultures with western cultures. The population does not comprise those with western cultural values and those with traditional Aboriginal values, with nothing much in between. The workforce needs to be sensitive to this and be able to attune their services appropriately. It is paramount that there be cultural respect, appreciation of its importance in framing appropriate holistic care to achieve good outcomes, and the need for strong Aboriginal involvement in service administration, ranging from meaningful influence to Aboriginal control. The mindset should be service and humility, not one of a top-down expectation that Aboriginal people should fit in."

- Non-Aboriginal service provider, 2019

Implementation

The implementation of this model requires robust planning and preparation, and consideration needs to be given to a range of factors that are critical to the delivery of an effective Aboriginal Cancer Healing Model.

- A commitment to local Aboriginal leadership to ensure cultural safety and appropriateness and a balance of clinical and cultural considerations in the design, ownership and delivery of the model
- A partnership approach across various service providers, and a commitment to building a long-term partnership to achieve outcomes for clients-in-common
- A commitment to capacity building, to support and grow the Aboriginal and the non-Aboriginal workforce
- Integrity to the principles of cultural respect and sensitivity to the heterogeneity of Aboriginal people and cultures to enable the provision of holistic care. This requires commitment from service providers to explore the cultural values of each Aboriginal person to attune and tailor the service and engagement to meet the needs of individuals, families and communities. It also requires Aboriginal involvement in service administration, ranging from meaningful influence to Aboriginal control
- Sustainable funding, and strategies to address funding limitations in the short, medium and long term
- Building on existing structures, to draw on existing capacity
- Using existing resources and building stronger relationships between local services and organisations
- Considering a staged approach (e.g. a trial phase) and a commitment to regular review and quality improvement

Appendices

Background

The Aboriginal Chronic Disease Consortium

The South Australian Aboriginal Chronic Disease Consortium (the Consortium) is a collaborative partnership of government and non-government organisations which shape Aboriginal health policy and service systems to address chronic disease prevention, care and management. The Consortium's vision is to reduce the impact of chronic disease experienced by Aboriginal and Torres Strait Islander people living in South Australia (SA) through the delivery of collaborative, appropriate, well co-ordinated, evidence-based strategies for all chronic diseases and with a particular focus on diabetes, heart disease, stroke and various forms of cancers. The Consortium's member organisations include the Aboriginal Health Council of South Australia, SA Health, the Adelaide and Country SA Primary Health Networks (PHNs), the Adelaide based universities and the South Australian Health and Medical Research Institute (SAHMRI), the Health Consumers Alliance and relevant non-government organisations, including the Cancer Council SA. The Consortium's governance structure includes an Aboriginal Community Reference Group which enables ongoing consultation and oversight by the Aboriginal community, and the Cancer Leadership Group with leading clinical cancer experts and Aboriginal health service professionals experienced in the delivery of cancer services and the development of cancer policy and cancer service planning.

Research Translation

Research translation, often referred to as "knowledge translation" has been defined by the Lowitja Institute as "a series of interactions that connect research evidence to changes in policy and practice. These interactions occur from the initial project idea formulation, through to implementation and project findings". Priorities for research translation projects are set by the Aboriginal community, based on evidence, generate health policy and system change and are monitored and evaluated to ensure projects meet community objectives (https://www.lowitja.org.au/page/research/knowledge-translation).

The Consortium is a business unit of Health Translation SA, one of six NHMRC accredited research translation centres with a mandate to enable research findings to be translated into health system policy, planning and practice, to ensure that health research can positively impact on the health of individuals and the community.

Country Chemotherapy Units

Country Health SA Local Health Network (CHSALHN) provides Country Cancer Services in 15 country locations; Berri, Ceduna, Clare, Gawler, Kangaroo Island, Mount Barker, Mount Gambier, Murray Bridge, Naracoorte, Port Augusta, Port Lincoln, Port Pirie, South Coast, Wallaroo, and Whyalla. Both low and medium risk cancer treatment can be administered at the Whyalla Regional Cancer Centre, Mount Gambier Chemotherapy Unit and the Port Pirie Chemotherapy Unit. All other country chemotherapy units administer low risk cancer treatment. While demand for services from these units is consistently high, the uptake of chemotherapy services by Aboriginal people is lower than expected when considering the prevalence of cancer in the community.

Optimal Care Pathways

The Optimal Cancer Care Pathway for Aboriginal and Torres Strait Islander People with cancer[19] has been developed to reduce disparities and enhance the health outcomes and health service experiences across a range of settings (primary, acute and tertiary) for Aboriginal and Torres Strait Islander people affected by cancer. This pathway complements tumour-specific pathways and articulates the provision of culturally safe and responsive care alongside the clinical aspects of cancer care.

The pathway emphasises the importance of understanding the philosophies of holistic health and wellbeing and the role of Aboriginal knowledge, values, beliefs in treatment and ongoing care. Consideration also needs to be given to cultural obligations, travel and accommodation for carers and family, financial implications associated with treatment, and the involvement of spiritual and traditional healing and medicine[20]. Culturally appropriate communication is further required for delivering optimal care, and the provision of targeted resources will increase community health literacy and contribute to better health outcomes short, medium and long term.

The Optimal Cancer Care Pathway for Aboriginal and Torres Strait Islander People with cancer is structured across the cancer stages from prevention and early detection through to survivorship and end of life care. The relevant sections for the Aboriginal Cancer Healing Model are Step 4 "Treatment" and Step 5 "Care after initial treatment and recovery".

National Safety and Quality Health Service Standards

The National Safety and Quality Health Service Standards have been developed to enable health services nationally to provide safe and high-quality care to the community. The standards require services to take six actions specific to Aboriginal and Torres Strait Islander people, to improve the quality of care and health outcomes.

The "User Guide for Aboriginal and Torres Strait Islander Health"[21] outlines these actions, the benefits for Aboriginal people and a suggested approach to assist health service design in meeting these standards in a practical and tangible way. A summary of the relevant standards and six specific actions is provided below. The model will be developed, implemented and evaluated in accordance with these standards and actions.

[19] Cancer Australia (2018), Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer, available at https://canceraustralia.gov.au/system/tdf/publications/optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer/pdf/optimal-care-pathway-for-aboriginal-and-torres-strait-islander-people-with-cancer.pdf?file=1&type=node&id=6156

[20] Kelly, J et al (2012) Managing Two Worlds Together: Stage 2—Patient Journey Mapping Tools, The Lowitja Institute, Melbourne, available at http://www.flinders.edu.au/medicine/fms/sites/health_care_management/mtwt/documents/M2W%20Stage%202-5.pdf

[21] Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute (2017), National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health, Australian Commission on Safety and Quality in Health Care, Sydney, available at https://www.safetyandquality.gov.au/wp-content/uploads/2017/12/National-Safety-and-Quality-Health-Service-Standards-User-Guide-for-Aboriginal-and-Torres-Strait-Islander-Health.pdf

The six actions in the National Safety and Quality Health Service Standards that focus specifically on meeting the needs of Aboriginal and Torres Strait Islander people

Standard	Action
Partnering with Consumers Standard	The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs
Clinical Governance Standard	The governing body ensures that the organisation's safety and quality priorities address the specific health needs of Aboriginal and Torres Strait Islander people
	The health service organisation implements and monitors strategies to meet the organisation's safety and quality priorities for Aboriginal and Torres Strait Islander people
	The health service organisation has strategies to improve the cultural awareness and cultural competency of the workforce to meet the needs of its Aboriginal and Torres Strait Islander patients
	The health service organisation demonstrates a welcoming environment that recognises the importance of cultural beliefs and practices of Aboriginal and Torres Strait Islander patients
Comprehensive Care Standard	The health service organisation has processes to routinely ask patients if they identify as being of Aboriginal and/or Torres Strait Islander origin, and to record this information in administrative and clinical information system

Source: The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute. National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health. Sydney: Australian Commission on Safety and Quality in Health Care; 2017.

Evidence

South Australian Aboriginal Cancer Control Plan 2016-2021

It has been well documented across Australia that there are significant disparities in health outcomes experienced by many Aboriginal and Torres Strait Islander people[22]. A large contribution of this disparity can be attributed to the burden of chronic diseases, with 80% of the mortality gap for Aboriginal people aged 35 to 74 years due to chronic diseases, including various forms of cancer[23].

In South Australia, cancers among the Aboriginal population occur at young ages, with the median diagnosis occurring approximately ten years younger in comparison to the broader population (Banham et al, 2017). Cancer outcomes are significantly determined by stage of the disease at diagnosis, and the South Australian Cancer Data and Aboriginal Disparities (CanDAD) study found that cancers are more advanced in Aboriginal people at diagnosis compared to non-Aboriginal people. Aboriginal people further have higher rates of preventable cancers which are likely to have a poorer prognosis (e.g. lung, throat and primary liver cancer).

Similar finding related to the late stage at diagnosis, and the significant co-morbidities that affect Aboriginal cancer patients have been confirmed in a study of Aboriginal people with cancer in Queensland[24]. Cancer outcomes and survival rates are further influenced by geographical factors, including living in rural and remote areas, where people experience barriers to accessing health services[25]. Language and cultural barriers also influence cancer outcomes for Aboriginal people.

Chronic disease comorbidities, which are experienced at a significantly higher degree by Aboriginal people, also contribute to cancer mortality[26]. The development of a new service model with a holistic approach to chronic disease prevention and management has the potential to increase the early detection of chronic diseases, and support prevention activities.

The South Australian Aboriginal Cancer Control Plan has identified as a priority to improve "access to safe, timely, optimal, equitable and culturally appropriate treatment" and "improve care coordination, assessment and management" and "increase understanding of, provision of, and access to culturally supportive care for Aboriginal people with cancer and their families".

[22] Australian Institute of Health and Welfare (2018), Australia's health 2018: in brief, Cat. No AUS 222, Canberra, available at https://www.aihw.gov.au/reports/australias-health/australias-health-2018-in-brief/contents/all-is-not-equal

[23] Australian Institute of Health and Welfare (2010), Contribution of chronic disease to the gap in adult mortality between Aboriginal and Torres Strait Islander and other Australians, Cat. No. IHW 48. Canberra, available at https://www.aihw.gov.au/reports/indigenous-australians/contribution-of-chronic-disease-to-the-gap-in-mort/contents/table-of-contents

[24] Valery, P et al (2006), Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study, Lancet 2006, 367:1842-48.

[25] Department for Health and Ageing (2016), South Australian Aboriginal Cancer Control Plan 2016-21, Adelaide.

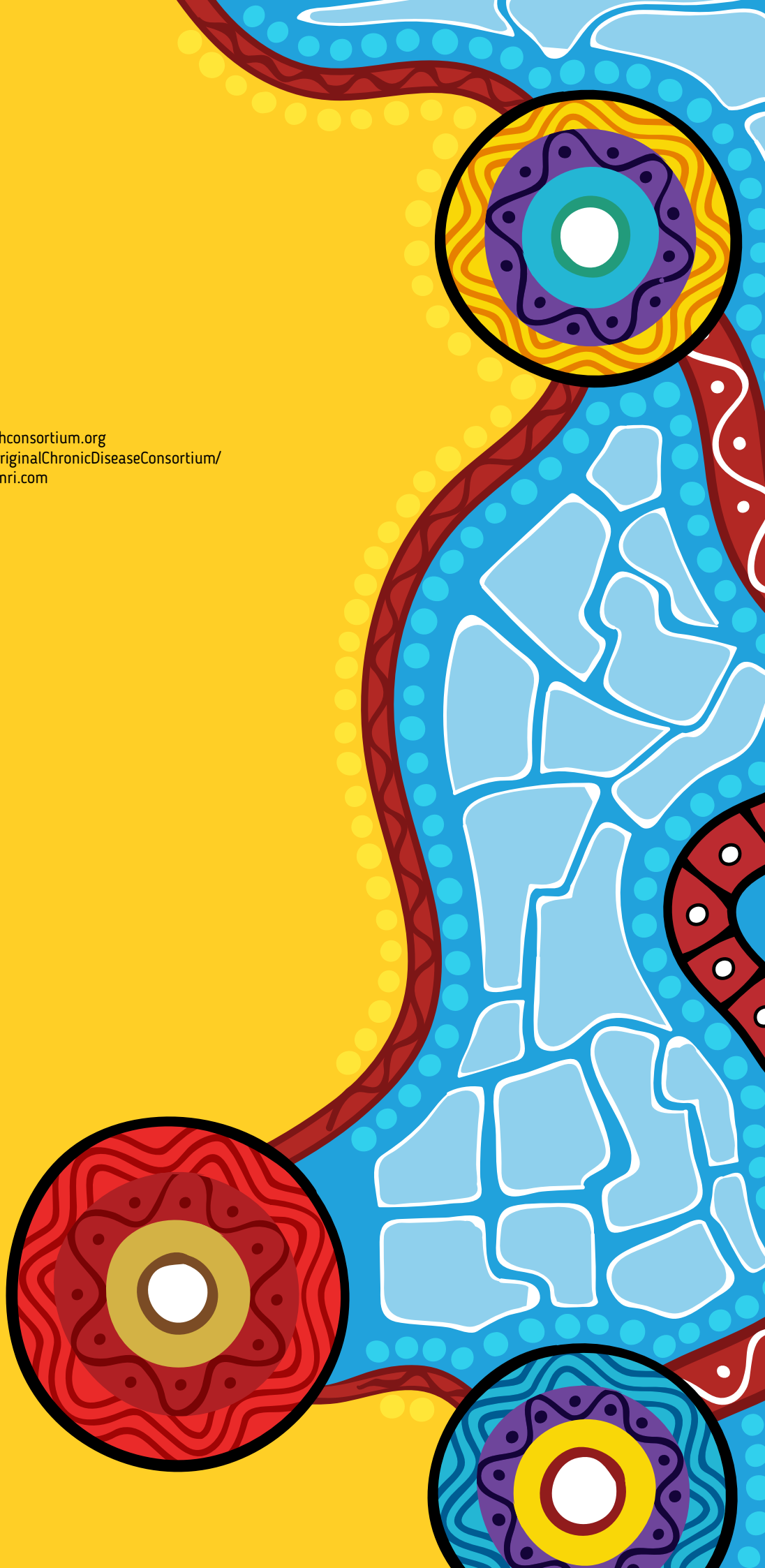
[26] Banham, D et al (2018), Comorbidities contribute to the risk of cancer death among Aboriginal and non-Aboriginal South Australians: Analysis of a matched cohort study, Cancer Epidemiology vol.52, pp.75-82, available at https://www.sciencedirect.com/science/article/pii/S1877782117302047?via%3Dihub

Cancer Data and Aboriginal Disparities (CanDAD)

The CanDAD study sought to develop an integrated, comprehensive cancer monitoring system with a particular focus on Aboriginal people in South Australia that would integrate cancer registry, hospital, radiotherapy, pharmacy, clinical, screening and health insurance data to comprehensively monitor cancer incidence trends, cancer management and survival. Uniquely, the data system incorporated Aboriginal patients' experiences with cancer services to guide continuous service improvement, community engagement, advocacy and outcomes research, providing data infrastructure for health services, population research, and for training Aboriginal (and non-Aboriginal) researchers.

The narratives of Aboriginal people with cancer have been collated as the "Aboriginal Cancer Stories Study" (ACceSS), which forms part of CanDAD. ACceSS enables the contextualisation of the data and findings related to existing service quality and appropriateness, system enablers and barriers and provides a robust framework for the development of a cancer service model. Importantly, the stories articulate the strengths of Aboriginal people and communities, and it is important that the Aboriginal Cancer Healing Model utilises and builds on these strengths to achieve better health outcomes for Aboriginal people undergoing cancer treatment.

SA ABORIGINAL
CHRONIC DISEASE
CONSORTIUM

For more information

Website: www.aboriginalhealthconsortium.org
Facebook: facebook.com/SAAboriginalChronicDiseaseConsortium/
Email: theconsortium@sahmri.com
Phone: 08 8128 4893