



Victorian Aboriginal Cancer Journey Strategy

2023-2028



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The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) acknowledges the strength of Aboriginal people across the Country and the power, resilience and knowledge that is shared as members of the world's oldest living culture.

We acknowledge Aboriginal people as Australia's First Peoples who have never ceded their sovereignty. We acknowledge the Wurundjeri Woi Wurrung people as the Traditional Custodians of the land on which this strategy was written. We extend the same acknowledgement to the Traditional Custodians of the lands on which data was collected, and to all Aboriginal and Torres Strait Islander people who read this strategy.

We pay our deepest respect and gratitude to our ancestors, Elders, and leaders – past and present. They have paved the way, with strength and fortitude, for our future generation.

Contents

Acknowledgements	4
Foreword from VACCHO CEO, Jill Gallagher AO	5
Foreword from Minister for Health, The Hon Mary-Anne Thomas MP	6
Executive Summary	7
Foundational Principles	8
Principle 1: Trust	8
Principle 2: The Social, Cultural, Political and Historical Determinants of Health	9
Strategic Directions	11
Strategic Direction 1: Self-determination	11
Focus Area 1.1: Aboriginal leadership and decision-making	12
Focus Area 1.2: Recognising and valuing the cultural strengths of Aboriginal workers	13
Strategic Direction 2: A strong and supported Aboriginal workforce	14
Focus Area 2.1: Aboriginal Cancer Coordination	15
Focus Area 2.2: Wrap-around support in hospital	16
Focus Area 2.3: Wrap-around support in Community	18
Strategic Direction 3: Cultural Connection	21
Focus Area 3.1: Culture in prevention	22
Focus Area 3.2: Culture in screening and early detection	24
Focus Area 3.3: Culture in the treatment and care journey	26
Focus Area 3.4: Thriving in survivorship	28
Focus Area 3.5: The Journey to Dreaming	30
Focus Area 3.6: Support for carers and family	32
Strategic Direction 4: A culturally safe and responsive health system	35
Focus Area 4.1: Cultural safety in all settings of care	36
Focus Area 4.2: Equitable access to treatment, therapies, and clinical trials	38
Research Governance and Data Sovereignty	40
Monitoring, Evaluation and Learning	40
References	42
Appendices	43
Appendix A: Policy Context	43
Appendix B: Methodology	44
Appendix C: Themes Report	45
About the artwork	51



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VACCHO would like to thank the Aboriginal and Torres Strait Islander community members who shared their cancer journey story, or that of a family member, as part of the development of this strategy. Without your voice, this strategy and the initiatives stemming from it would not be possible. Your generosity will help to improve the experience of Community members across the state.

We thank the Aboriginal workforce, particularly all the Aboriginal Hospital Liaison Officers, who provided insights and experiences to making this strategy meaningful and grounded in a real understanding of the current state of cancer treatment and care.

VACCHO also thanks the members of our Cancer Journey Advisory Group, which has included lived experience advisors and service users, members of the health workforce, and Aboriginal researchers, along with representatives of the cancer agencies and health services across the state. We thank you for your dedication and

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VACCHO would like to thank Keagan Mallia, Wamba Wamba, for his deadly artwork depicting the Cancer Journey and importance of Community connection.

We would also like to thank our deadly Cancer Journey team at VACCHO who have already been diligently working on early initiatives during the development of this strategy.

CEO's Foreword

Ngatta (which means hello in my traditional Gunditjmara language)


I feel incredibly proud and privileged to present the *Victorian Aboriginal Cancer Journey Strategy*.

The quality of life of Aboriginal and Torres Strait Islander Communities is enhanced when families are healthy, enriched by culture and kinship, and supported by culturally safe and trustworthy health services. In the Aboriginal community-controlled sector, we have a long and proud history of achieving these outcomes. We are a sector that has grown over recent decades to support and respond to the needs of Aboriginal and Torres Strait Islander people in every aspect of their health and wellbeing.

One of our biggest challenges has been Closing the Gap in cancer outcomes. In part, this is because we rely heavily on the mainstream health system for treatment and care, and in that reliance, we have endured a lot of Sorry Business because of a lack of understanding, trust, and cultural safety. This strategy presents the pathway for us to change that for good.

In treatment and care, we need holistic and coordinated approaches that incorporate the cultural strengths of our Communities and address the social and economic determinants of so many of the outcomes we see. We need treatment and care services that are not only free from racism, but which recognise that our culture is a protective factor, and its strength is key to achieving successful outcomes. To enable individuals and their families to engage with prevention, cancer screening and early detection, we need approaches that are developed by our Communities, for our Communities. More than ever before, we need to further empower and grow our dedicated and determined Aboriginal health workforce.

VACCHO is committed to implementing this strategy through our Strategic Plan *On Solid Ground 2021-2026*. Our implementation approach will privilege Aboriginal Ways of Knowing, Being and Doing, and will involve our Communities in guiding our work at every stage. We ask our partners in the mainstream health system to follow our lead, to support us, and to commit to their actions identified in this strategy. Together we can Close the Gap.



I'd like to take this opportunity to pay tribute to the Community for sharing their Cancer Journey and personal stories, which have been instrumental in helping guide and inform the development of this strategy.

We must continue to be bold. We must continue to be brave.



VACCHO CEO, Jill Gallagher AO

Minister's Foreword

Cancer affects the lives of all Victorians in some way, but not every Victorian is impacted equally. We need to ensure that all Victorians have access to high-quality cancer care regardless of who they are, where they live or what resources they have. We are proud to have partnered with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) to ensure that Aboriginal Victorians can access culturally safe and appropriate cancer care across the whole cancer journey.

This strategy combines Aboriginal ways of Knowing, Being and Doing with the best available evidence to create local, strengths-based approaches to close the care gap across the cancer journey. VACCHO worked in partnership with Aboriginal Victorians with experience of cancer, Aboriginal Community Controlled Organisations, the Victorian Government and the cancer care system. First Nations voices are at the heart of the strategy through yarning with Aboriginal people diagnosed with cancer, their families, carers as well the Aboriginal health workforce to understand the truths in navigating the cancer system in Victoria.

We know that cancer diagnosis and mortality rates are significantly higher for Aboriginal and Torres Strait Islander people in Victoria. Alarming, the gap in mortality between Aboriginal and non-Aboriginal Victorians is widening. However, we have seen the strength of self-determination by empowering Aboriginal people to improve their own outcomes. The successful 'Beautiful Shawl Project' provides cultural shawls featuring local Aboriginal artists' artwork, unique to each community, to help Aboriginal women feel more empowered, respected, and safe during their breast screen. This collaboration between VACCHO, local Aboriginal Community Controlled Organisations and BreastScreen Victoria increased the number of Aboriginal clients who screened for the first time or caught up with their regular screening. The Victorian Aboriginal Cancer Journey uses this model to embed culture and kinship to close the care gap outcomes across the entire cancer journey.

The new strategy will support commitments in the *Victorian Cancer Plan 2020-2024* and the *Victorian Closing the Gap Implementation Plan 2021-2023* to achieve equitable cancer outcomes so that Aboriginal and Torres Strait Islander people enjoy long and healthy lives.



The publication of this self-determined Victorian Aboriginal Cancer Journey Strategy is a testament to the advocacy and leadership from VACCHO's CEO, Jill Gallagher AO. I also acknowledge and thank the Aboriginal and Torres Strait Islander people who shared their personal and professional stories with cancer.

Let's create an equal future for all people diagnosed with cancer, one that is free of racism and discrimination, where individuals and their families are empowered to have the best experience of care across the entire cancer journey.

A handwritten signature in black ink, appearing to read 'M. Thomas'.

The Hon Mary-Anne Thomas MP
Minister for Health

Executive Summary

In 2020, VACCHO initiated and led the development of this *Victorian Aboriginal Cancer Journey Strategy*. This action has been a response to the widening gap in cancer outcomes between Aboriginal and non-Aboriginal Victorians. With the support of the Department of Health, enabled through the Victorian Cancer Plan, VACCHO has commissioned and directly undertaken wide ranging research and Community engagement in the development of a pathway to Closing the Gap. This strategy presents that pathway.

VACCHO comprises 33 member organisations across Victoria, all of which are Aboriginal Community Controlled Organisations (ACCO). Alongside VACCHO's leadership, they work collectively and collaboratively to provide equitable, culturally safe health and wellbeing services, and they achieve remarkable outcomes for Aboriginal and Torres Strait Islander communities. While ACCOs provide a key role in supporting Community members on their cancer journeys, most treatment and care takes place in a mainstream health setting.

This strategy aims to identify which areas require investment and development to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples. It also aims to identify where improvements and changes are needed in the regular healthcare system.

This strategy is comprised of two Foundational Principles, four Strategic Directions, and 14 Focus Areas. The Foundational Principles are trust, and the need to address the social, cultural, political, and historical determinants of health. These principles need to be considered and incorporated in all implementation activity undertaken under this strategy. The Strategic Directions and Focus Areas encompass:

1

Self-determination

- Aboriginal cancer coordination.
- Wrap-around support in hospital.
- Wrap-around support in Community.

2

A strong and supported Aboriginal workforce

- Aboriginal leadership and decision-making.
- Recognising and valuing the cultural strengths of Aboriginal and Torres Strait Islander workers.

3

Cultural Connection

- Culture in prevention.
- Culture in screening and early detection.
- Culture in the treatment and care journey.
- Thriving in survivorship.
- The Journey to Dreaming.
- Support for carers and family.

4

A culturally safe and responsive health system

- Cultural safety in all settings of care.
- Equitable access to treatment, therapies, and clinical trials.

Without exception, all these elements are essential to ultimately Closing the Gap in cancer outcomes.

Foundational Principles

Principle 1: Trust

Closing the Gap in cancer outcomes for Aboriginal and Torres Strait Islander people cannot be achieved without improving trust in mainstream health and human services. The Strategic Directions and Focus Areas of this strategy aim to improve the participation of Aboriginal and Torres Strait Islander people in initiatives such as clinical trials, cancer screening, and treatment and care plans. Success in these objectives will depend on the level of trust that Aboriginal and Torres Strait Islander people feel confident placing in the health and human services they interact with.

Aboriginal and Torres Strait Islander communities have sound reasons for mistrusting mainstream services. Historically, the providers of health and human services have been complicit in inflicting severe harm. This included, but was not limited to:

- the systematic theft of children from families
- the abuse of children in institutional care
- deaths in custody and care
- the collection of data for the purpose of excluding Aboriginal and Torres Strait Islander people from services¹.

The provision of health and human services has historically been inseparable from exposure to systemic racism, discrimination, judgement, stigma, and trauma. Even today, experiences are often poor. Racism remains a pervasive barrier to engaging with services, and the cultural strengths of Aboriginal and Torres Strait Islander peoples are often unrecognised or devalued².

The success of this Strategy depends on a genuine and authentic commitment by mainstream services by acknowledging and reconciling this harm and building trust. This requires accepting where there is need for change, investing in each Strategic Direction of this Strategy, and demonstrating a wider commitment to healing the past with Aboriginal-led solutions for the future.

¹ Lowitja Institute. 2020. Culture is Key: Towards cultural determinants-driven health policy – Final Report. Lowitja Institute, Melbourne.

² Thurber, K. A., Colonna, E., Jones, R., Gee, G. C., Priest, N., Cohen, R., Williams, D.R., Thandrayen, J., Calma, T., Lovett, R., et al. 2021. 'Prevalence of Everyday Discrimination and Relation with Wellbeing among Aboriginal and Torres Strait Islander Adults in Australia'. International Journal of Environmental Research and Public Health, 18, 6577. <https://doi.org/10.3390/ijerph18126577>



Social, cultural, political and historical determinants of health



(L to R) Nola Baxter and Stephanie Charles at the Beautiful Shawl Project visit to Mallee District Aboriginal Services – Swan Hill, May 2022
Latji Latji, Tati Tati, Wemba Wemba, Barapa Barapa and the Wadi Wadi Country

Men's 'Yarning about Bowel Cancer' group at Bendigo & District Aboriginal Co-Operative. December 2022, Dja Dja Wurrung Country



Principle 2: The Social, Cultural, Political and Historical Determinants of Health

For Aboriginal and Torres Strait Islander people, the concept of health encompasses the physical, social, emotional, and cultural wellbeing of individuals, families, wider kinship groups, and entire Communities³. While physical health is important, equal value is placed on strengthening connections to mind, emotions, family, kinship, Community, culture, country, spirituality, and ancestors. Developing connectedness across all these domains empowers Community self-esteem, belonging, and pride. These are critical elements in the development of health literacy, health-seeking behaviour, and resilience for individuals and families embarked, and newly embarking, on journeys of healing.

This holistic understanding of physical, social, emotional, and cultural wellbeing is central to the development of a responsive Aboriginal Cancer Journey Strategy. It recognises that cancer outcomes in Aboriginal and Torres Strait Islander communities are often driven by social, cultural, political, and historical determinants. These considerations are interwoven throughout the Strategic Directions and Focus Areas of this strategy. Success however will ultimately depend on complementary strategies aiming to create equitable outcomes in housing, education, employment, the empowerment of Community leadership and self-determination, the advancement of anti-racism and truth telling, and the restoration of the dispossessed wealth and prosperity of Communities.

³ Victorian Aboriginal Community Controlled Organisation. 2020. Balit Durn Durn. Victorian Aboriginal Community Controlled Health Organisation. Melbourne.

Strategic Directions

Strategic Direction 1: Self-determination

A key theme that emerged in the development of this Strategy was the need for Aboriginal and Torres Strait Islander people to be in control of their cancer journey. In the past, a range of factors have precluded individuals and families from exercising autonomy and agency in decisions that affect treatment and care, and these have negatively impacted outcomes. They include:

- A lack of trust in health information and services.
- A lack of support to understand and navigate the scale and complexity of cancer treatment and care.
- A fundamental lack of responsiveness in the health system to the cultural strengths, considerations, and values of Aboriginal and Torres Strait Islander people.

To change this, a dedicated focus is needed on empowering Aboriginal leadership and decision-making, and in recognising and valuing the cultural strengths of Aboriginal workers.

Focus Area 1.1: Aboriginal leadership and decision-making

Affirmative action is required to operationalise the empowerment of Community at all levels within the health system. The involvement of Aboriginal and Torres Strait Islander leaders in processes of governance, prioritisation, service design, and implementation are key to ensuring that services are accessible, culturally safe, trauma informed, and are developing and maintaining the capability to facilitate the self-determination of individuals and families.

Investing in Aboriginal and Torres Strait Islander leadership demonstrates a genuine and authentic commitment to Closing the Gap, which fosters trust and reciprocal relationships between services and Communities. The resulting improvements to the accessibility of information and services will lead to better engagement and outcomes in cancer prevention, early detection, treatment, and care.

PRIORITY ACTIONS

Action:	Responsible:
1.1.1 Implement the Aboriginal Health and Wellbeing Workforce Strategy (2022-2026) recommendations related to leadership development.	<ul style="list-style-type: none"> VACCHO
1.1.2 Take affirmative action to appoint more Aboriginal and Torres Strait Islander people to the boards of Victorian public hospitals.	<ul style="list-style-type: none"> Department of Health
1.1.3 Implement guidelines to ensure that Health Service Partnerships and Hospital Community Advisory Committees engage with ACCOs and maintain the participation of Aboriginal and Torres Strait Islander perspectives.	<ul style="list-style-type: none"> Department of Health Mainstream health services
1.1.4 Ensure ACCOs are funded adequately to engage with and participate in partnership activities, e.g. to maintain representation in Health Service Partnerships and Hospital Community Advisory Committees.	<ul style="list-style-type: none"> Department of Health VACCHO ACCOs

Focus Area 1.2: Recognising and valuing the cultural strengths of Aboriginal workers

In addition to leadership, Closing the Gap requires recognising and valuing the cultural strengths of Aboriginal and Torres Strait Islander identified workers. Many Aboriginal and Torres Strait Islander workers in cancer services hold knowledge, experience, and cultural authority that is not always recognised or valued by their employers. These cultural strengths may include:

- The ability to connect the cancer journey with culture, kinship, Community, country, spirituality, ancestors, and other culturally important linkages.
- Understanding of cultural protocols, such as those which may apply in Sorry Business, or in Men’s and Women’s Business.
- Deep insight or direct lived experience of racism, discrimination, intergenerational trauma, poverty, or other barriers of access to health services.
- Understanding the possible context behind disengagement from treatment and care, for example, anxiety about child removal, reactivation of trauma from past interactions with health services, fear of diagnosis, or the anticipation of culturally unsafe experiences.
- Providing access to traditional medicines and care on country.

These strengths are examples of core competencies in delivering culturally safe, trauma informed care. Recognising and valuing them in the design of Aboriginal and Torres Strait Islander identified roles would demonstrate greater respect for their importance. Integrating these strengths into service models enables self-determination by equipping individuals and families with greater control over decision-making throughout their cancer journeys.

PRIORITY ACTIONS

Action:	Responsible:
1.2.1 Support mainstream health services to understand, recognise and value the cultural strengths of Aboriginal and Torres Strait Islander identified workers, in particular Aboriginal Hospital Liaison Officers. This includes support to understand and limit cultural loading.	<ul style="list-style-type: none"> • VACCHO • Mainstream health services
1.2.2 Ensure that Aboriginal and Torres Strait Islander identified workers have access to cultural supervision, debriefing, vicarious trauma counselling, peer support, and measures that ensure cultural loading is recognised and managed.	<ul style="list-style-type: none"> • Mainstream health services • Cancer agencies • VACCHO

Strategic Direction 2: A strong and supported Aboriginal workforce

The complexity of cancer treatment and care was repeatedly raised throughout the development of this strategy. The stress of interacting with services that are often culturally unsafe can be made worse by the emotional distress of a cancer diagnosis. The experiences that follow are often characterised by feeling overwhelmed, feeling powerless, feeling unable to make informed decisions or understand their implications, and feeling rushed into a course of action⁴.

Another common theme in the development of this Strategy was the disruption to life caused by cancer treatment and care. It requires time away from work, home, family, and other parts of daily life. When someone is being treated for cancer, they need to focus their time and attention on their health. But this can make them and their family worried and stressed about other important things in their life that they may not have time for. Low incomes, carer obligations, insecure housing, and cultural obligations all present challenges to hospital admissions and follow-up appointments⁵.

Services need to be responsive to these factors, which act as social determinants of care and treatment outcomes. Greater access to wrap-around services is essential, especially to ease the stress experienced by patients during periods of hospital admission. It is therefore critical that health services are resourced with a strong Aboriginal workforce, able to provide support that is culturally safe and trauma informed, and incorporates the strengths outlined in Focus Area 1.2. Services should also work in partnership to map and connect their service models, and a dedicated role for Aboriginal Cancer Coordinators should be developed to support seamless navigation of the whole of the cancer journey.

“ I had my ALO there with me. She was amazing. And the whole team was amazing there at the time. So I think without that I would have been a bit of a mess. ”

– Aboriginal person with lived experience

⁴ Couch, D. 2018. Let's yarn about cancer: Loddon Mallee: final report. Loddon Mallee Aboriginal Reference Group (LMARG). Bendigo.

⁵ Couch, D. 2018. Let's yarn about cancer: Loddon Mallee: final report. Loddon Mallee Aboriginal Reference Group (LMARG). Bendigo.

Focus Area 2.1: Aboriginal Cancer Coordination

Cancer coordination involves facilitating self-determination for Aboriginal and Torres Strait Islander individuals and families throughout their cancer treatment and care journeys. Coordinators are Aboriginal and/or Torres Strait Islander identified workers who provide continuous, long-term support including information, knowledge translation, advocacy where needed, and support to manage things at home. Rather than being contained within a single service, cancer coordination covers the whole of the cancer journey, in all settings of care and across all services, to ensure seamless access to clinical, cultural, and psychosocial supports as required⁶.

A statewide model for Aboriginal Cancer Coordination should be developed, involving the resourcing of roles for Aboriginal Cancer Coordinators in appropriate services within identified regions. To enable this in practice, partnership frameworks between ACCOs and mainstream acute and sub-acute services and cancer agencies should be developed to advance joint commitments, including:

- Working together to improve the cancer journey for Community and their families.
- Integrating Cancer Coordination into their respective service models, especially at points of intersection between services or settings of care, e.g. acute, sub-acute, primary care, home.
- Employing Cancer Coordinators to work closely with staff across all services and protecting those coordinators from being absorbed into other functions.
- Ensuring that Aboriginal Cancer Coordinators have the capability and authorisation to advocate for equity, access, and improved patient outcomes, including involvement in continuous quality improvement.

The statewide model should include a method for determining which partners are best placed to employ the coordinating function, giving special consideration to each partner's capability to attract and retain Aboriginal and/or Torres Strait Islander identified staff. The method should consider the circumstances in which Cancer Coordinators might be employed in mainstream settings rather than ACCOs, e.g. in a region where there is no local ACCO.

PRIORITY ACTIONS

Action:	Responsible:
2.1.1 Develop a state-wide model of Aboriginal Cancer Coordination. This should include comprehensive consultation with relevant stakeholders including AHLOs, ACCOs, mainstream health services, cancer agencies and experts from other contexts or jurisdictions where similar models have been implemented.	<ul style="list-style-type: none"> • VACCHO
2.1.2 Develop a partnership framework for the implementation of this Strategy. This should include the mapping of key strategic partners across the health system, and the development of place-based partnerships to improve coordination and continuity of care.	<ul style="list-style-type: none"> • VACCHO • Mainstream health services • Cancer agencies • ACCOs

⁶ Cunningham, J., Green, M., Jaenke, R and Garvey, G. 2021. Desktop Review to consolidate the knowledge and evidence for three priority issues in the cancer care system: 1) Improving Aboriginal participation in clinical trials and research; 2) Improving culturally safe and effective cancer treatment for Aboriginal people with cancer; and 3) Improving Aboriginal people's self-identification and the quality of cancer data. Report prepared for the Victorian Aboriginal Community Controlled Health Organisation by the Menzies School of Health Research. Victorian Aboriginal Community Controlled Health Organisation and Menzies School of Health Research, Melbourne.

Focus Area 2.2: Wrap-around support in hospital

Hospital services are an essential part of the cancer treatment and care journey. Specialist interventions such as surgery, chemotherapy, and radiotherapy generally require hospital admission, often for extended periods of time. Trauma in this part of the cancer journey is often triggered or exacerbated because of cultural safety deficits in hospitals. Exposure to racism and discrimination, whether explicit or perceived, has a significant impact upon the experience of Aboriginal and Torres Strait Islander patients in hospitals, and can determine treatment outcomes⁷.

Public hospitals in Victoria are resourced with Aboriginal Hospital Liaison Officers (AHLO) who act as culturally safe intermediaries between the hospital and the patient, and their family. The exact scope of an AHLO differs between hospitals. In some hospitals, AHLOs form part of multi-disciplinary care coordination teams that support Aboriginal and Torres Strait Islander patients throughout hospital admission and discharge. They are assigned to patients upon admission if not prior. Other hospitals utilise AHLOs in more limited ways. Their involvement in care may be restricted to certain circumstances, and their access to patient information may be limited. This is often the result of a failure by the hospital to recognise the importance of incorporating the cultural strengths offered by AHLOs (outlined in 1.2) into the delivery of treatment and care⁸.

All hospitals need to empower AHLOs in the delivery of multi-disciplinary treatment and care. They should be involved throughout every stage of the hospital pathway, ensuring that patients have access to internal advocacy and that referrals and linkages to wrap-around supports are being made and fulfilled. This involves linking patients to service models such as Hospital in the Home, and to non-clinical complementary supports provided by hospitals such as social workers, grief counsellors, spiritual services, and support for carers. AHLOs should also have access to brokerage funding to help remove barriers of access to hospital facilities or services. This should include coverage for parking, transportation, meals, and emergency accommodation including for carers.

It is also critical that AHLOs and Aboriginal Cancer Coordinators work together to ensure that continuity of care is provided throughout pre-admission, admission, discharge planning, and post-discharge. While AHLOs provide a critical and often longitudinal role in the coordination of care in hospital, it is important that their role is distinct from that of the Cancer Coordinator. This is to ensure that the cancer journey is contextualised as a life journey rather than a hospital journey. The cancer journey may involve hospital admissions as part of a holistic approach to healing, but effort should be made to ensure that the hospital pathway is not seen as the entirety of the cancer journey.

Hospitals should also invest in the development of culturally safe spaces within cancer-related settings of care. The visibility of Aboriginal and Torres Strait Islander cultures can be a source of comfort and strength for patients and their families in hospital. Investment in spaces where Community can feel connected to and wrapped within their culture can help to reduce anxiety and fear about remaining in settings where patients and their families may otherwise feel unsafe⁹.

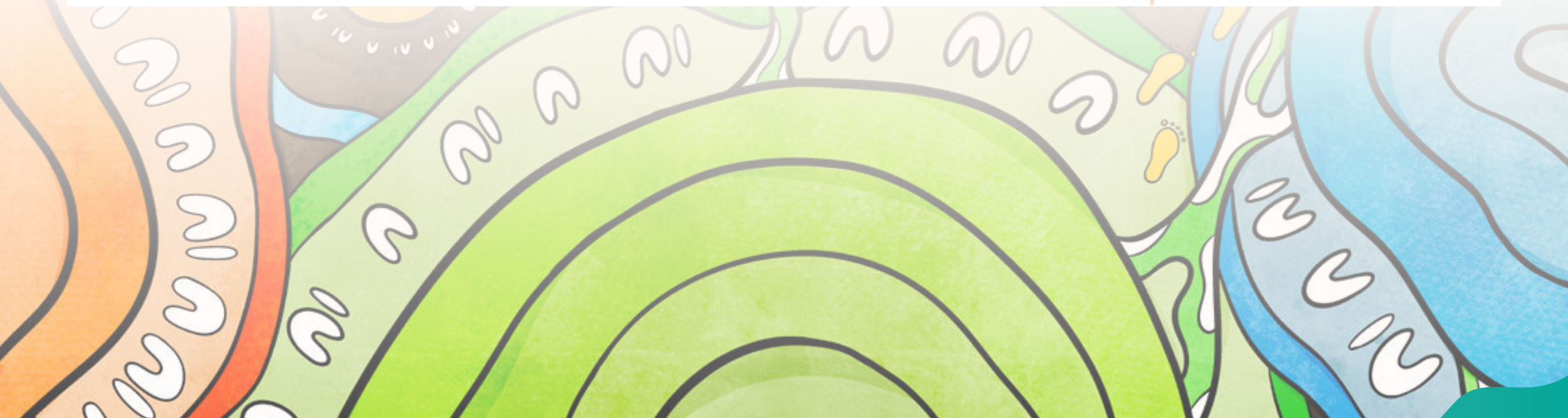
7 Department of Health and Human Services. 2021. Part 1: Aboriginal and Torres Strait Islander cultural safety framework. The Victorian Government. Melbourne.

8 Department of Health and Human Services, and Social Compass. 2016. Improving Cultural Responsiveness of Victorian Hospitals – Final Report. Social Compass prepared this report for the Department of Health and Human Services. The Victorian Government and Social Compass.

9 Knoche D, Clarke A, and Shanahan, N, Rowley K. 2012. Treating us right: a summary report describing and evaluating Wadja's new model of care for Aboriginal children and families at the Royal Children's Hospital Melbourne. Onemda VicHealth Koori Health Unit, The University of Melbourne. Melbourne.

PRIORITY ACTIONS

Action:	Responsible:
<p>2.2.1 Expand the Improving Care for Aboriginal Patients (ICAP) program through which AHLOs are employed in hospitals. This should include the development of guidelines for the AHLO role to be more consistently defined and integrated into multidisciplinary treatment and care.</p>	<ul style="list-style-type: none"> • Department of Health • VACCHO • Mainstream health services
<p>2.2.2 Develop a cancer training and education program for AHLOs and other hospital-based staff to further strengthen their capability to support Aboriginal people and their families on their cancer journey.</p>	<ul style="list-style-type: none"> • VACCHO
<p>2.2.3 Develop culturally appropriate care pathways that ensure hospital pre-admission and post-discharge stages are integrated with Community and home-based supports.</p>	<ul style="list-style-type: none"> • Mainstream health services
<p>2.2.4 Expand access to Hospital in the Home options and ensure that these programs are encompassed in cultural safety action plans.</p>	<ul style="list-style-type: none"> • Mainstream health services



Focus Area 2.3: Wrap-around support in Community

A cancer diagnosis, and the treatment that follows, are often the cause of psychological distress and fear. They can reorient an individual or a family's values and priorities, and potentially introduce changes to their identity, in a short period of time. This can compound existing stresses in life as described in the introduction to this strategic direction. Support in Community is therefore important throughout the entirety of the cancer journey from prevention, screening and early detection, diagnosis, treatment, and into survivorship or the Journey to Dreaming¹⁰.

Wrap-around supports in Community are provided by carers, family members, kin, and the wider Community, including Primary Care and social services from ACCOs and other providers of choice. The purpose of wrap-around support is to ensure that access to essential services continue outside of acute and sub-acute settings. It also aims to provide emotional support to people who may be feeling stressed, alone, or hopeless, by offering help, positivity, and hope. For this to be effective, it is essential that ACCO staff are trained and supported to develop deeper understandings of cancer and the stages in a cancer journey. Aboriginal Health Workers (AHW) and Aboriginal Health Practitioners (AHP) should have the capability to confidently yarn with Community members about their experiences undergoing cancer treatment and care. ACCO-based GPs, nurses, allied health professionals, and AHP should work collaboratively to ensure that Primary Care is cohesive, that interactions with the service are well coordinated, and that overall care is continuously linked with acute and sub-acute treatment and care. Aboriginal Cancer Coordinators have a key role in ensuring that care is centred around the needs, convenience, and level of support needed by the person with cancer and their carers and family.

Access to Social and Emotional Wellbeing (SEWB) services in ACCOs is critical, both for the person with cancer, for their carers, and family. SEWB services involve clinical mental health planning and treatment, but also therapeutic and traditional healing approaches centred in the connection to kinship, spirituality, country, and traditional cultural practices associated with healing¹¹. Financial counselling, transport, grief counselling, carers respite, relationship counselling, and housing support may be required. Cancer Coordinators should work closely with ACCOs and other service providers to ensure that culturally safe services are identified and engaged.

¹⁰ Couch, D. 2018. Let's yarn about cancer: Loddon Mallee: final report. Loddon Mallee Aboriginal Reference Group (LMARG). Bendigo.

¹¹ Victorian Aboriginal Community Controlled Organisation. 2020. Balit Durn Durn. Victorian Aboriginal Community Controlled Health Organisation. Melbourne.

“ We offer social emotional support. We involve families or carers when need be. We connect people to outside services. We understand the role of Elders and provide the Elders, particularly extra special care at times, making sure that they're not being sent home on a bloody bus or something. Provide cultural supports, cultural safety, financial practice- all those things there, is what an ALO does, or a good ALO should do. ”

**– Aboriginal Hospital
Liaison Officer**

PRIORITY ACTIONS

Action:	Responsible:
2.3.1 Develop a cancer training and education program for ACCO staff to further strengthen their capability to support Aboriginal and Torres Strait Islander people and their families on their cancer journey. This should include a focus on AHP and Aboriginal SEWB Workers.	<ul style="list-style-type: none">VACCHO
2.3.2 Identify critical roles in mainstream social services and improve their uptake of cultural safety training. At a minimum, this should include Financial Counsellors and Financial Capability Workers.	<ul style="list-style-type: none">VACCHOMainstream social services
2.3.3 Map the ecosystem of wrap-around Community and home-based supports in health and social services and ensure that these are integrated into the state-wide model of Aboriginal Cancer Coordination.	<ul style="list-style-type: none">VACCHO
2.3.4 Increase investment in culturally safe home-based cancer care and treatment services. Where funding is already allocated to mainstream services for initiatives like Hospital in the Home, provide clearer direction to improve cultural safety and access for Community.	<ul style="list-style-type: none">Department of Health



Smoking Ceremony at the Victorian Koori Surfing Titles, promoting sun safe behaviour. February 2023. Wadawurrung Country. Photo credit: Surfing Victoria

Strategic Direction 3. Cultural Connection

Public health discussions about Aboriginal health outcomes often position the issue in terms of deficits. Examples of this include framing such as high 'burden' of disease, and rates of 'disengagement from' or 'failure to complete' treatment. These perspectives insinuate blame and contribute to the positioning of poorer health outcomes as a problem of behaviour and low health literacy. In addition to external determinants, the health outcomes of Aboriginal and Torres Strait Islander people are also affected by a healthcare system that does not communicate well and is not culturally responsive. This system does not focus on prevention in a way that is culturally appropriate, and does not acknowledge the strengths and assets of Aboriginal and Torres Strait Islander communities.

The ingrained deficit framing of Aboriginal health outcomes causes health professionals in mainstream services to often be perceived to be communicating with prejudice and judgment. As a result, a cancer diagnosis is often stigmatised with fear and shame. This stigma contributes to a lack of trust in mainstream health services, creating barriers to uptake of cancer screening and early detection initiatives. To address this, greater investment is urgently needed in strength-based approaches to prevention, screening and early detection, treatment, supportive care and journey to Dreaming care. Central to this is a major focus on developing and strengthening cultural connections.

Culture is a powerful source of strength for Aboriginal and Torres Strait Islander people. Connection to culture is strengthened when people feel closer to Community, kinship, country, spirituality, and ancestors. It creates feelings of safety, belonging, identity, pride, and self-esteem. These elements protect from the demoralising and harmful impacts of racism, discrimination, prejudice, stigma, and shame. Incorporating culture into prevention, screening and early detection is therefore key to the improvement of communication about cancer and to challenging the stigma, shame, and fear. In treatment, care, survivorship, and the Journey to Dreaming, cultural connection provides a basis of strength from which empowerment and self-determination can be achieved.

“ As First Nations people we were considered last... often there would be times where I would be scrambling to get things done, try and bring our culture to people’s attention, and it was like they’d never heard of Aboriginal people. [It’s] obviously incredibly important to us and is the core of our being, but for those that aren’t of our background, [culture is not] appreciated or thought of as something that’s significant or important ”

– Aboriginal person with lived experience

Focus Area 3.1: Culture in prevention

Culturally responsive communication is essential for developing health literacy and increasing awareness of cancer prevention messages. Education initiatives should be developed with Community through co-design and should amplify lived experience voices where appropriate. At a minimum, effective messaging needs to be co-designed across:

- Quitting smoking.
- SunSmart behaviour.
- Healthy eating and active living.
- Uptake of immunisation that protects against cancers, e.g. HPV and Hepatitis B.
- Regular health checks

ACCOS should also be funded to explore self-determined programs that develop health literacy through increased cultural connectedness, especially in young people. Examples of such initiatives may include:

- Providing opportunities for young people to spend time on country, or with Elders and knowledge holders, promoting knowledge exchange and the sharing of life experience.
- Aunties programs that connect young Aboriginal and Torres Strait Islander women to a supportive cultural wrap-around, where health and wellbeing advice can be delivered within a high-trust environment by a cultural authority.
- The development of community gardens in ACCOs to connect nutrition education with caring for country and the promotion of traditional knowledge.
- The revival of Aboriginal languages, offering the potential for Communities to decolonise the language around cancer, imbuing strength-based and empowering meanings into renewed and self-determined labels, narratives, and stories about the cancer journey.

Empowering ACCOs to explore this approach involves trusting in Communities to manage their own affairs and priorities in health. In these examples, Aboriginal health is placed into Aboriginal hands, the traditional roles of Elders and knowledge holders are honoured, and country and language are empowered to drive positive health outcomes, as they did prior to colonisation¹².

Balancing this approach with a strong primary prevention program is key. ACCOs must be funded for health promotion drives and for prevention and early intervention coordination (PEIC). Health promotion should include messaging about the importance of health checks, cancer risk awareness, and ensuring that cancer is understood as survivable. The Primary Health workforce should receive ongoing training and professional development to remain aware of key messages and be confident in delivering them.

Multi-media awareness campaigns are also important, but messages will only be effective if designed and delivered by Community. Awareness campaigns should have a presence in positively framed or celebratory spaces such as at sports carnivals or festivals or local ACCOs, to help remove negative associations or stigma. Health promotion should be supported by highly organised PEIC programs, involving smarter clinical record-keeping, high data literacy and data-driven decision making, proactive outreach and follow-up, and prompt patient recalls. Successful PEIC is interdependent on continuous quality improvement (CQI).

PRIORITY ACTIONS

Action:	Responsible:
3.1.1 Increase investment in self-determined, Aboriginal-led initiatives that build connection to Community, Culture, Country and Kinship.	Department of Health VACCHO
3.1.2 Increase investment in Aboriginal-led co-design of health information resources and omnichannel health promotion campaigns.	Department of Health VACCHO
3.1.3 Establish or expand Prevention and Early Intervention (PEIC) programs in ACCOs to improve data-driven decision making, proactive patient outreach and follow-up, and prompt patient recalls	Department of Health VACCHO

¹² Victorian Aboriginal Community Controlled Health Organisation. 2023. Culture + Kinship Evaluation Report. Victorian Aboriginal Community Controlled Health Organisation. Melbourne.

Focus Area 3.2: Culture in screening and early detection

The Victorian Cancer Screening Framework (VCSF) 2022–26 has been developed to increase participation in screening programs, with improved Aboriginal and Torres Strait Islander cultural safety a key objective. The framework is supported by Australian Government funding for national population cancer screening programs across three tumour streams:

- The National Bowel Cancer Screening Program.
- BreastScreen Australia.
- The National Cervical Screening Program.

Screening programs are generally tailored to different population segments according to age and gender, but there are barriers that preclude access for many Community members, including reliance on people having a fixed address or a regular doctor to provide consistent follow-up and make recommendations and referrals. There are also barriers related to stigma and shame, past trauma, and lack of local and culturally appropriate screening options. These barriers must be removed to increase rates of screening in Aboriginal and Torres Strait Islander communities.

Incorporating culture into cancer screening approaches is effective in replacing stigma and shame with empowerment and celebration. The Beautiful Shawl project implemented by VACCHO and BreastScreen Victoria (BSV) is an example of incorporating culture into breast screening. Through the project, partnerships are formed with ACCOs across Victoria and an outreach model sees BSV bring mobile screening clinics to Communities, staffed by clinicians and health promotion workers who have completed cultural safety training. Women presenting for breast screens are gifted a Beautiful Shawl, featuring artwork by local Aboriginal and Torres Strait Islander artists. The women can use the shawl to cover themselves during screening to reduce any feelings of embarrassment or shame around breast screening in front of a stranger. The shawl is both a literal and symbolic wrap-around, empowering women with physical and cultural protection and dignity throughout the screen¹³. The project has recently expanded to include other Community led settings.

In partnership with the Australian Centre for the Prevention of Cervical Cancer (ACPCC), VACCHO has developed cervical screening resources that incorporate culture as a protective factor, both for clinician-collected cervical screening tests (CST) and for self-collected CST. For clinician-collected CST, the resources include a towel featuring artwork by a local Aboriginal artist, which provides privacy and the protective element of culture throughout collection. For self-collected CST the resources include a patient instruction card specifically developed for Community, a Women's Business brochure developed by VACCHO and Cancer Council Victoria (CCV), a zip-up pouch, also featuring artwork, and a non-transparent specimen bag with the swab. Uniquely, these are examples of resources that incorporate culture in supporting clinical conversations, as opposed to health promotion.

¹³ Victorian Aboriginal Community Controlled Health Organisation, Victorian Aboriginal Health Service, and BreastScreen Victoria. 2022. The Beautiful Shawl Implementation Model. Victorian Aboriginal Community Controlled Health Organisation, Victorian Aboriginal Health Service and BreastScreen Victoria. Melbourne.

Further investment should be made in partnerships such as those between VACCHO and BSV, ACPC, and CCV. These partnerships are examples of how mainstream health services and cancer agencies can be introduced into Community spaces through a Community-controlled intermediary that informs the cultural safety of the approach. Initiatives that incorporate culture should receive substantial funding for expansion, including for new initiatives for cancers other than breast, bowel and cervical. Further investment is also needed to increase the participation of men in bowel cancer screening, awareness of prevention measures, and ensuring men's voices inform the messages developed for men.

PRIORITY ACTIONS

Action:	Responsible:
3.2.1 Increase investment in Aboriginal-led co-design of cancer screening and early detection resources and omnichannel campaigns that incorporate culture.	<ul style="list-style-type: none"> • Department of Health • VACCHO
3.2.2 Expand existing partnerships with cancer screening agencies and explore new partnerships to increase rates of early detection.	<ul style="list-style-type: none"> • VACCHO
3.2.3 Expand outreach and Community engagement initiatives, with a focus on approaches tailored to reaching priority groups, e.g. men, and people reaching ages of eligibility for national screening programs.	<ul style="list-style-type: none"> • VACCHO
3.2.4 Consider mechanisms to increase cancer screening data accuracy at ACCOs.	<ul style="list-style-type: none"> • VACCHO • ACCOs

Focus Area 3.3: Culture in the treatment and care journey

In this Focus Area, care is not limited to clinical care. It encompasses any interaction with health and human services along the cancer journey, across any setting of care including acute, sub-acute, community-based or home-based. Throughout the treatment and care journey, cultural values and practices should guide respectful communication, understanding of options, and informed decision-making. This

includes ensuring that health information and resources are designed by, and message tested with Community. The content they contain should be highly relatable and strength-based, and messages should resonate with the experience of Community at various stages of their cancer journeys.

In clinical settings, this Focus Area involves ensuring that the cultural strengths of Aboriginal and Torres Strait Islander identified workers outlined in 1.2 are embedded in service models and in communication with patients and their families. As noted in 1.2, many Aboriginal and Torres Strait Islander workers in cancer services hold knowledge, experience, and cultural authority that is not always recognised or valued by their employers. These capabilities can be a source of comfort and strength for Aboriginal and Torres Strait Islander people on their Cancer Journey and should be recognised as critical elements in high quality person-centred models of treatment and care.

As outlined in 2.2, services should also invest in the development of culturally safe spaces within cancer-related settings of treatment and care, as the visibility of Aboriginal and Torres Strait Islander cultures is another source of comfort and strength for patients and their families. This could involve designing spaces to incorporate art, light, nature, and Country, where connection to culture can be felt. This can help reduce anxiety and fear about remaining in places that could otherwise feel unsafe, and can support talking about treatment, care, and decision-making. By allowing space for yarning, Dadirri, and other cultural practices, these spaces can enrich relational activities including clinician-patient dialogue, peer support, interactions with wrap-around services, and family activities.

“ *If we had have had the opportunity to have some firsthand knowledge or some access to information of other people’s journeys and stories and how they dealt with situations and what may or may not, what you may or may not expect on this journey, I think is very powerful and would have helped us. It would have equipped us a bit more in what to expect and how to handle it better.* ”

– Aboriginal person with lived experience

Special consideration should be given to ensuring that patients and their families have a clear understanding of the potentially co-occurring health conditions that may need to be treated throughout their cancer journey. It is essential that the role and importance of everyone involved in treatment and care is understood¹⁴. For example, in the treatment of pancreatic cancer, patients and their families should have access to culturally appropriate nutrition information and dietetics services in full understanding of the link between pancreatic cancer and diabetes.

Special consideration also needs to be given to the cancer journeys of young Community members and their families. Addressing the Priority Actions under this Focus Area will require the involvement of children and youth with lived and living experience of cancer, their parents, and broader family networks.

PRIORITY ACTIONS

Action:	Responsible:
<p>3.3.1 Increase investment in Aboriginal-led co-design of information resources about types of cancer and treatment options, to support informed decision-making throughout the cancer journey.</p>	<ul style="list-style-type: none"> • VACCHO • Department of Health • Mainstream health services • Cancer agencies
<p>3.3.2 Ensure AHLOs and Aboriginal Cancer Coordinators work in partnership to provide seamless access to treatment and care support including local cancer yarning groups, tumour specific services and peer support networks.</p>	<ul style="list-style-type: none"> • VACCHO • Mainstream health services • Cancer agencies
<p>3.3.3 Partner with mainstream health services to develop cultural safety resources for Aboriginal and Torres Strait Islander patients, e.g. culturally appropriate advanced care plans, journals, cultural artefacts such as possum skin cloaks, shawls, or commissioned artwork.</p>	<ul style="list-style-type: none"> • VACCHO • Mainstream health services
<p>3.3.4 Develop dedicated culturally safe spaces within mainstream settings of treatment and care, to enable trauma-informed discussion and decision-making to occur within safe environments.</p>	<ul style="list-style-type: none"> • Department of Health • Mainstream health services
<p>3.3.5 Establish strategic partnerships with agencies that support the cancer journeys of young people, e.g. Canteen, to identify opportunities to expand and improve support for young Community members and their families.</p>	<ul style="list-style-type: none"> • VACCHO

¹⁴ Couch, D. 2018. Let's yarn about cancer: Loddon Mallee: final report. Loddon Mallee Aboriginal Reference Group (LMARG). Bendigo.

Focus Area 3.4: Thriving in survivorship

A clear message received throughout the development of this strategy was that the cancer journey continues after survival. For many people, the concept of 'survivorship' was a positive one, but others were not comfortable shaping their identity in relation to cancer. Survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. It includes the physical, social and emotional well-being, and financial impacts of cancer. As discussed in 2.3, the cancer journey is often life altering, and for Community there is a significant need for wrap-around support in Community.

For some, survival means celebration. This may involve sharing their stories or experiences to help others, or simply embracing new opportunities in life. These survivors can play a key role in supporting others on their journey, and health services including ACCOs should ensure that opportunities are made available for employment or volunteering, including in roles as mentors, counsellors, yarning group facilitators, or peer supporters. Lived experience voices should be respected, valued, and empowered to co-design improvements to cancer services.

For many, thriving in survivorship is a struggle. Many of the challenges experienced during the cancer journey continue after survival. Survivors may live with cancer-related changes to their mobility, chronic health, fertility, physical appearance, and mental health including trauma and post-traumatic stress disorder (PTSD). In the development of this strategy, some cancer survivors shared that their cancer journeys involved experiencing strain or loss of careers, intimate relationships, and friendships. Many experienced that services and supports abruptly ended when they entered survivorship, despite a continuing need for psychosocial, financial, and practical support. Positive life transformations were also reported, e.g. stronger connections to culture or spirituality, but in either scenario, ACCOs and Aboriginal Cancer Coordinators should ensure that support continues into survivorship until people feel and demonstrate that such support is no longer needed.

PRIORITY ACTIONS

Action:	Responsible:
<p>3.4.1 Ensure that Aboriginal Cancer Coordination continues into survivorship. This includes facilitating continued access to social services that support re-entry into employment, access to housing, and financial counselling.</p>	<ul style="list-style-type: none"> • VACCHO
<p>3.4.2 Ensure that intensive SEWB supports are accessible to cancer survivors. These should include SEWB responses in mental health, the need for post-traumatic healing, counselling specific to anxiety around the return of cancer, and relationship counselling as needed.</p>	<ul style="list-style-type: none"> • VACCHO • Mainstream health services • ACCOs
<p>3.4.3 Provide opportunities for cancer survivors to share their experiences and support others in prevention messages through to journey to Dreaming. This includes opportunities to take up roles as lived experience advisors, peer supporters, mentors, counsellors, or yarning group facilitators.</p>	<ul style="list-style-type: none"> • VACCHO

Focus Area 3.5: The Journey to Dreaming

The Journey to Dreaming encompasses the end-of-life stage of many cancer journeys. In this stage, it is essential that palliative care services are engaged to assist patients and their families with a range of needs. These services are primarily operated by mainstream providers across a range of settings including inpatient, outpatient clinics, community palliative care, and hospice care. As described by Palliative Care Victoria, they aim to improve quality of life throughout the Journey to Dreaming by¹⁵:

- Reducing the side effects of treatment and some medications.
- Easing discomfort and pain.
- Reducing anxiety, tension, and depression.
- Encouraging restful sleep.
- Enhancing emotional and spiritual wellbeing.

For Community to benefit from the palliative care stage, these services must be culturally safe and capable of connecting people and their families to Community, country, kinship, and experiences that are culturally and spiritually significant. The concept of 'a good death' was raised frequently throughout the development of this strategy. According to Cancer Council Victoria, this concept is characterised by¹⁶:

- Knowing that the Journey to Dreaming has commenced.
- Being able to self-determine where and how death occurs.
- Maintaining a sense of dignity and having some control over pain and other symptoms.
- Having the chance to say goodbye to loved ones, and to reconnect or reconcile with people who may be distant or estranged.
- Having the chance to come to terms with regrets or unfinished business.

To ensure that mainstream services can meet these needs, investment is needed by government and service providers to further implement the Indigenous Program of Experience in the Palliative Approach (IPEPA). This program aims to embed Aboriginal ways of knowing, being, and doing into palliative care resources and worker competencies. It supports expanded uptake of Advance Care Planning and facilitates two-way learning between staff and patients¹⁷. At a minimum, mainstream services should develop bespoke, culturally responsive experiences for Community and their families. Partnering with ACCOs and Aboriginal Cancer Coordinators can support the development of these experiences, but mainstream services should also be capable of recruiting and retaining Aboriginal and Torres Strait Islander identified staff, especially in roles that involve trauma informed counselling or care.

¹⁵ Palliative Care Victoria. What is Palliative Care? Available at: Palliative Care Victoria - What is Palliative Care? (pallcarevic.asn.au). (Accessed: 6 February 2023).

¹⁶ Cancer Council Victoria. 2020. Facing End of Life: A guide for people dying with cancer, their families and their friends. Cancer Council Victoria. Melbourne.

¹⁷ Victorian Aboriginal Community Controlled Organisation. 2019. Understanding the Palliative Care Journey: A guide for individuals, carers, Communities and family. Victorian Aboriginal Community Controlled Health Organisation. Melbourne

Investment is also needed by government to develop a Journey to Dreaming workforce within ACCOs. This would enable ACCOs to explore the development of Aboriginal-led models of palliative care services. In addition to what is provided by mainstream services, these could include:

- Traditional ceremony, healing, and meditation practices.
- Access to SEWB services, including entitlements and services available to survivors of the stolen generations.
- Family reunification.
- Returning to the traditional country of a person’s ancestors.
- Spending time on country.
- Culturally appropriate support for families throughout Sorry Business and beyond.
- Culturally appropriate ways of remembering and showing respect for Community members who have passed to the Dreaming.

PRIORITY ACTIONS

Action:	Responsible:
3.5.1 Fund the establishment and ongoing development of a dedicated workforce within ACCOs to support Community members and their families on the Journey to Dreaming.	<ul style="list-style-type: none"> • Department of Health • VACCHO • ACCOs
3.5.2 Increase investment in Aboriginal-led co-design of information resources for Community members and workers to increase their understanding of the Journey to Dreaming and to increase engagement with Advance Care Planning.	<ul style="list-style-type: none"> • Department of Health • VACCHO
3.5.3 Fund the development of Aboriginal-led models of palliative care that incorporate connection to Community, country, culture, and kinship.	<ul style="list-style-type: none"> • Department of Health • VACCHO

Focus Area 3.6: Support for carers and family

Support for carers, partners and family members throughout the cancer journey was repeatedly raised throughout the development of this strategy. Supporting a partner or family member with cancer has its own unique set of challenges requiring a range of social, emotional and practical life supports to ensure that carers are physically, emotionally, and financially capable of providing care and support.

The greatest gap in carer support was recognised in the home setting, and in the transition of care from acute settings to home. Carers expressed distress about having to take on care roles involving the changing of dressings, provision of medication, and supporting physical mobility. This is exacerbated when the carer has health concerns of their own to navigate, or when the carer has not had access to culturally appropriate health information. Supporting carers to understand the cancer journey can be equally as important as the person with cancer.

Disjointed continuity of care also creates additional stress for carers who find that they may need to take on the roles of advocate, explainer, and system navigator. In rural and regional locations, access to GPs may be limited in the absence of a local ACCO, and many local pharmacies do not store some cancer medications, meaning that carers are left to support a family member with cancer while waiting for Primary Health appointments or for medication to arrive¹⁸. As outlined in Focus Areas 2.1, 2.2 and 2.3, the purpose of the Aboriginal Cancer Coordinator role is to help reduce these burdens and ensure ongoing wrap-around support and continuity of care.

AHLOs in consultation recommended that support for Aboriginal and Torres Strait Islander children on their cancer journey should focus principally on support for their parents. Taking this as a starting point, and in alignment with principles of person and family-centred care, teams would ensure that Aboriginal and Torres Strait Islander families understand the potential referral pathways for children, have access to yarning groups, and have access to culturally appropriate and age-appropriate information. Treatment planning should include ensuring access to entertainment such as books, multimedia, or toys to help children and their families during hospital stays and at home. Similarly, there should also be resources designed and developed specifically to support ways of communicating with Aboriginal and Torres Strait Islander children to help them understand the cancer journey of a parent or family member. Equally important is access to yarning groups and resources to support youth on their cancer journey and when impacted by a family members cancer journey.

¹⁸ Couch, D. 2018. Let's yarn about cancer: Loddon Mallee: final report. Loddon Mallee Aboriginal Reference Group (LMARG). Bendigo.

PRIORITY ACTIONS

Action:	Responsible:
<p>3.6.1 Map the ecosystem of wrap-around and respite supports for carers, partners, and families, and ensure that these are integrated into the state-wide model of Aboriginal Cancer Coordination. This should include a focus on Community and home-based supports.</p>	<ul style="list-style-type: none"> • VACCHO • Mainstream carer support organisations
<p>3.6.2 Increase investment in Support for Carers programs in ACCOs. This should include support to access respite, financial counselling, relationship counselling, housing and employment support, peer support, and SEWB services.</p>	<ul style="list-style-type: none"> • Department of Families, Fairness and Housing • VACCHO
<p>3.6.3 Increase investment in Aboriginal-led co-design of information resources for carers and families about cancer, including preparation for what to expect and how to effectively support someone with cancer.</p>	<ul style="list-style-type: none"> • Department of Families, Fairness and Housing • VACCHO
<p>3.6.4 Develop culturally appropriate approaches to supporting the parents and families of Aboriginal and Torres Strait Islander young people (children and youth) throughout their cancer journeys. This should include the co-design of age-appropriate information resources, as well as information resources for parents as well as cultural immersion programs for youth.</p>	<ul style="list-style-type: none"> • VACCHO • Mainstream health services
<p>3.6.5 Map the ecosystem of wrap-around and support services for young people and ensure that these are integrated into the state-wide model of Aboriginal Cancer Coordination.</p>	<ul style="list-style-type: none"> • VACCHO



Budja Budja Aboriginal Co-operative's Men's Health Day, August 2022, Djab Wurrung and Jardwadjali Country

Strategic Direction 4: A culturally safe and responsive health system

The Australian Health Practitioner Regulation Agency (AHPRA) defines culturally safe practice as the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practicing behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism. While services and practitioners can strive to be culturally responsive, the determination of whether those services are achieving cultural safety can only be made by Aboriginal and Torres Strait Islander people themselves¹⁹. The Victorian Department of Health's Aboriginal and Torres Strait Islander Cultural Safety Framework²⁰ seeks to embed the following elements of cultural safety into settings of care²¹:

- Shared respect, shared meaning, and shared knowledge.
- The experience of learning together with dignity and truly listening.
- Strategic and institutional reform to remove barriers to the optimal health, wellbeing and safety of Community. This includes addressing unconscious bias, racism, discrimination, and supporting Aboriginal and Torres Strait Islander self-determination.
- Individuals, organisations and systems ensuring their cultural values do not negatively impact on Community, including addressing the potential for unconscious bias, racism and discrimination.
- Individuals, organisations and systems ensuring self-determination for Community. This includes sharing power (decision-making and governance) and resources with Aboriginal and Torres Strait Islander communities. It's especially relevant for the design, delivery and evaluation of services for Community.

Cultural safety is key to Closing the Gap in cancer outcomes for Aboriginal and Torres Strait Islander people. Boards and executive leaders in mainstream health services should understand and champion the need for cultural safety across all settings of care. Authorising environments for culturally safe practice should be explicitly created, communicating expectations and standards to all staff involved in the cancer journey. Greater accountability is needed for services that fall short of the efforts required to provide culturally safe care.

¹⁹ The Australian Health Practitioner Regulation Agency. The National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020-2025. The Australian Health Practitioner Regulation Agency. Australia.

²⁰ Department of Health and Human Services. 2021. Part 1: Aboriginal and Torres Strait Islander cultural safety framework. The Victorian Government. Melbourne.

²¹ Department of Health and Human Services. 2021. Part 1: Aboriginal and Torres Strait Islander cultural safety framework. The Victorian Government. Melbourne.

Focus Area 4.1: Cultural safety in all settings of care

Settings of care are the places where interactions with health and human services happen throughout the cancer journey. Ensuring that these settings are culturally safe for Community is fundamental to the success of this strategy. The Victorian Department of Health's Aboriginal and Torres Strait Islander Cultural Safety Framework²² outlines how health services can work toward achieving cultural safety.

Some examples of initiatives include:

- Internal and external spaces are welcoming, contain formal acknowledgements of Country and culturally appropriate health information as outlined in 3.3.
- All staff should receive cultural safety training. Acknowledging the importance of a welcoming environment, receptionists, ward clerks, and other support staff should be provided with training that highlights:
 - The unique and important role they play in welcoming Aboriginal and Torres Strait Islander families to the organisation.
 - Asking if patients identify as Aboriginal or Torres Strait Islander people.
 - The importance of respectful face-to-face and over-the-phone contact.
 - Use of respectful language.
- Organisational documents reflect knowledge and understanding of local Community organisations, people, their culture, practices, protocols, and historical connections.
- The organisation demonstrates a commitment to celebratory cultural events, and participates in activities such as NAIDOC, Reconciliation Week, Sorry Day, Mabo Day, Aboriginal and Torres Strait Islander Children's Day.

In cancer treatment and care, cultural safety involves ensuring that staff are trauma aware, and that practice is trauma informed. Staff should understand the stressors present in the lives of patients and their families and should be mindful of the determinants of health outlined in Principle 2. Health services should strive to develop relationships characterised by trust, empathy, and respect. In practice, this may require executive sponsorship to create authorising environments for staff to spend more time with Aboriginal and Torres Strait Islander patients and their families, to slow down the pace of busy clinical environments where possible and focus on quality and patient experience, and to take affirmative action to reduce waiting times for Aboriginal and Torres Strait Islander patients and their families.

22 Department of Health and Human Services. 2021. Part 1: Aboriginal and Torres Strait Islander cultural safety framework. The Victorian Government. Melbourne.

PRIORITY ACTIONS

Action:	Responsible:
<p>4.1.1 Mandate the development of action plans by mainstream health services to continuously improve cultural safety, including ongoing performance updates. For transparency and accountability, this should include a requirement for action plans and performance updates to be published.</p>	<ul style="list-style-type: none"> • Department of Health • Mainstream health services
<p>4.1.2 Mandate Aboriginal and Torres Strait Islander Cultural Safety Training for all health professionals and administrative staff employed in mainstream health services.</p>	<ul style="list-style-type: none"> • Department of Health • Mainstream health services
<p>4.1.3 Improve Aboriginal and Torres Strait Islander identified data. This includes ensuring the identifying question is asked, that all health professionals are made aware of and are responsive to Aboriginal identification, and that identified data is incorporated into continuous quality improvement.</p>	<ul style="list-style-type: none"> • Department of Health • Mainstream health services
<p>4.1.4 Take affirmative action to reduce waiting times for Aboriginal and Torres Strait Islander cancer patients.</p>	<ul style="list-style-type: none"> • Department of Health • Mainstream health services
<p>4.1.5 Improve monitoring and assurance of hospital processes to guarantee that Aboriginal and Torres Strait Islander people are provided with the option to access support from an Aboriginal Hospital Liaison Officer upon admission to hospital.</p>	<ul style="list-style-type: none"> • Department of Health • Mainstream health services
<p>4.1.6 Take action to ensure that comprehensive discharge protocols for Aboriginal and Torres Strait Islander patients are developed, implemented, and monitored. This includes ensuring that hospitals achieve post-discharge continuity of care e.g. through referral and shared care partnerships with home and community-based services.</p>	<ul style="list-style-type: none"> • Department of Health • Mainstream health services • ACCOs



Focus Area 4.2: Equitable access to treatment, therapies, and clinical trials

The development of new treatment approaches or therapies that are minimally invasive has the potential to make certain pathways more acceptable for Aboriginal and Torres Strait Islander patients, as seen in self-collected cervical screening. However, equitable access to clinical trials and to newer treatment approaches and therapies is required to ensure that Community can benefit from these developments. This requires the involvement of Community in communicating the benefits of these developments, either as research leaders or as participants in the co-design of culturally appropriate and message tested information resources²³.

Further research is required to investigate the barriers that preclude equitable access to clinical trials for Community. Similarly, research is needed to investigate whether there are systemic barriers to access certain treatment approaches or therapies. For example, gene therapies may provide viable options for the treatment of some cancers, but if there is a trust deficit in the clinician-patient relationship and if clinicians are unable to effectively communicate the benefits of gene therapy, then it may be discounted as a potential pathway. Funding is also required to investigate and develop new or improved methods of cancer screening. In recent years, research has been undertaken to develop improvements and innovations in screening, in particular for lung cancer, bowel cancer, cervical cancer, and other tumour streams. Closing the Gap in cancer outcomes requires renewed and expanded government backing of these efforts, including adequate funding for culturally safe clinical trials²⁴.

All experiences participating in clinical trials should be culturally safe for Community. To ensure this, the Victorian Department of Health should develop an Action Plan to address inequities in access to clinical trials and urgently invest in the development of cultural responsiveness within the clinical trials workforce. Researchers and investigators who lead clinical trials should involve Aboriginal and Torres Strait Islander people in the governance of their work, if they are seeking to enroll Community in trials or partner with ACCOs.

²³ Cunningham, J, Green, M, Jaenke, R and Garvey, G. 2021. Desktop Review to consolidate the knowledge and evidence for three priority issues in the cancer care system: 1) Improving Aboriginal participation in clinical trials and research; 2) Improving culturally safe and effective cancer treatment for Aboriginal people with cancer; and 3) Improving Aboriginal people's self-identification and the quality of cancer data. Report prepared for the Victorian Aboriginal Community Controlled Health Organisation by the Menzies School of Health Research. Victorian Aboriginal Community Controlled Health Organisation and Menzies School of Health Research, Melbourne.

²⁴ Cunningham, J, Green, M, Jaenke, R and Garvey, G. 2021. Desktop Review to consolidate the knowledge and evidence for three priority issues in the cancer care system: 1) Improving Aboriginal participation in clinical trials and research; 2) Improving culturally safe and effective cancer treatment for Aboriginal people with cancer; and 3) Improving Aboriginal people's self-identification and the quality of cancer data. Report prepared for the Victorian Aboriginal Community Controlled Health Organisation by the Menzies School of Health Research. Victorian Aboriginal Community Controlled Health Organisation and Menzies School of Health Research, Melbourne.

PRIORITY ACTIONS

Action:	Responsible:
4.2.1 Develop an action plan to address inequitable access to clinical trials in Victoria, and to improve the cultural responsiveness of the clinical trials workforce.	Department of Health
4.2.2 Fund the development of best practice models of operating clinical trials involving Aboriginal and Torres Strait Islander participants, including guidelines for ethics, governance, and partnerships with ACCOs.	VACCHO Department of Health
4.2.3 Commission new research, or provide additional funding to existing research, to investigate and develop new methods of cancer screening.	Department of Health
4.2.4 Commission research to investigate equity of access to emerging cancer treatment approaches and therapies.	VACCHO Department of Health

Research Governance and Data Sovereignty

VACCHO has been working toward an expansion of capacity and capability to undertake and govern research. In 2023 VACCHO is expected to launch the Victorian Aboriginal Health, Medical and Wellbeing Research Accord. The Accord is an official agreement between Victorian Aboriginal and Torres Strait Islander communities, the Victorian Government, and Victorian research organisations. It aims to improve the way Aboriginal and Torres Strait Islander research is conducted in Victoria and to enhance self-determination. This is achieved through promoting and facilitating Aboriginal and Torres Strait Islander leadership, trusting relationships, localised research priorities, the appropriate use of Indigenous research methodologies, Aboriginal and Torres Strait Islander data governance protocols, and culturally respectful research practices. The Accord will also establish new processes for developing research under the direction of an Aboriginal-led Governance Group (AGG). These will include an Aboriginal-governed ethics process, capability building opportunities for Aboriginal and Torres Strait Islander identified and non-Aboriginal researchers, and an accreditation scheme for research organisations.

Implementation activity under this strategy will be guided by the Accord where applicable to ensure that considerations like ethics, data governance, and research practices are made within an Aboriginal-led framework of governance. In 2022 VACCHO's constitution was also amended to enable becoming an Administering Institution for National Health and Medical Research Council (NHMRC) grants. Adherence to NHMRC guidelines will also apply in the development of any research initiatives that are relevant to the Strategy.

Monitoring, Evaluation and Learning

A Monitoring Evaluation and Learning (MEL) framework will be developed in the early implementation stage of this strategy to monitor actions within the Focus Areas under each Strategic Direction. The MEL framework will be linked to an Implementation Plan and will identify outcomes, measures of success, and methods of tracking and reporting on progress. These should include qualitative methods and evidence such as yarning and stories, in addition to any identified quantitative methods and data. The MEL framework will be developed in line with VACCHO's Monitoring, Evaluation and Learning principles:

- Recognition
- Self-determination
- Community building
- Ethics
- Accountability
- Transparency
- Effectiveness
- Cultural continuity

MEL approaches will be developed under the guidance of the Victorian Aboriginal Health, Medical and Wellbeing Research Accord and any applicable processes that it governs.



VACCHO's Early Detection Campaign
Wurundjeri Country
Photo credit: Think HQ

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Appendices

Appendix A: Policy Context

Momentum is growing across the health system with greater understanding and recognition of self-determination, the importance of Aboriginal and Torres Strait Islander leadership and the integral inclusion of culture and kinship in improving Aboriginal health outcomes. This strategy will be enhanced by the development and implementation of national and state policies, plans and frameworks enabling Aboriginal and Torres Strait Islander voices to lead and guide the sector. A list of these key publications include:

State

- The Victorian Aboriginal Affairs Framework 2018–2023 (VAAF)
- Korin Korin Balit-Djak Aboriginal Health, Wellbeing and Safety Strategic Plan 2017–2027
- Department of Health Aboriginal and Torres Strait Islander Cultural Safety Framework (2019)
- Victorian Cancer Plan 2020–2024
- Victorian Closing the Gap Implementation Plan 2021–2023
- Aboriginal Hospital Liaison Officer program
- Victorian Government Child Safe Standards
- Victorian Cervical Cancer Elimination Strategy

National

- The 2020 National Agreement on Closing the Gap
- Cultural Respect Framework 2016–2026: For Aboriginal and Torres Strait Islander Health
- National Aboriginal and Torres Strait Islander Cancer Framework (2015)
- Optimal Care Pathway for Aboriginal and Torres Strait Islander People with cancer (2018) and implementation guide

International

- The 2007 United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)

In development

- Cancer Australia, National Cancer Plan
- NACCHO Aboriginal & Torres Strait Islander National Cancer Plan
- Cancer Australia, National Cervical Cancer Elimination Strategy

Appendix B: Methodology

Background

VACCHO commissioned Menzies School of Health Research in 2019 to undertake a *Desktop review to consolidate the knowledge and evidence for three priority issues in the cancer care system*¹. In 2022 VACCHO considered additional literature to inform the *Cancer Journey Themes Report*².

In April 2022, VACCHO engaged Karabena Consulting to review the commissioned literature to inform the development of key themes to be discussed with Community members with lived cancer experience and their families and consultations with the Aboriginal workforce. The evidence from the literature were reviewed and summarised into key themes.

VACCHO developed a flyer and distributed widely through existing networks to the Aboriginal workforce and Community with lived cancer experience and their families to invite Community to participate in the yarns. The yarns took place over May 2022 to July 2022 via online group workshops, and telephone and video yarning and interviews. These forums were designed to be culturally safe and trauma-informed. They were led by Aboriginal and Torres Strait Islander people, including Professor Kerry Arabena, Karen Milward, Jack Bulman and Lisa Bulman. Participants received a voucher for sharing their story and cancer resources and supportive care information was made available to participants.

Participant demographics

Karabena Consulting undertook yarns with three groups of people:

- Aboriginal people and their families with lived cancer experience in Victoria
- Aboriginal Hospital Liaison Officers (AHLOs) with experience working with Aboriginal people on their cancer journeys
- Aboriginal leaders in the cancer journey space, staff at cancer agencies and those with cancer research expertise.

A total of 33 Community members participated in the yarns. These consisted of:

- 12 AHLOs from various hospitals around Victoria
- 12 Aboriginal people with lived experience (either as carers or those who had experienced cancer themselves)
- 7 leaders in the cancer field from around the country
- 2 people who participated in multiple consultation groups as AHLOs and as people with lived experience.

Limitations – Recruitment and participation

Karabena were unable to collect demographic data such as gender and age group in the yarns.

A lot of the people who were recruited and participated in the lived experience consultations were health literate and were able to navigate the health system. This might have influenced the types of themes that emerged from the consultations.

1 Cunningham, J, Green, M, Jaenke, R. et al, 2021, Desktop Review to consolidate the knowledge and evidence for three priority issues in the cancer care system – Report prepared for Victorian Aboriginal Community Controlled Health Organisation (VACCHO) by the Menzies School of Health Research, July 2019, VACCHO and Menzies School of Health Research, Melbourne.

2 VACCHO 2022, cancer journey Themes Report and Literature Review to Support the Development of the Victorian Aboriginal cancer journey Strategy, unpublished.

It was challenging to engage participants, in particular Aboriginal Health Workers and male Community members with lived experience. This was possibly due to the consultation fatigue that a lot of health professionals and Community members are currently experiencing. The lack of input from these groups meant that we were unable to explore certain topics such as men's business, which again might have influenced the types of themes that emerged from the consultations.

Note: Since these yarns have been undertaken, the VACCHO Cancer Journey team have engaged men in discussions about bowel cancer screening, prostate awareness and early detection messages. In addition, VACCHO has a newly established network for Aboriginal Health Workers and Aboriginal Health Practitioners. This group has been engaged to better undertake a cancer training needs analysis.

Appendix C: Themes Report

The key themes presented in this report were informed by the yarns with Community with lived cancer experience and their families, the Aboriginal workforce, cancer stakeholder consultations and the review of the literature.

Common themes identified between yarns and literature reviews

- Establish Aboriginal Cancer Care Navigator/Coordinator roles in hospitals.
- Establish peer support programs across all hospitals.
- There are differences in access to cancer treatment and services between Aboriginal and Torres Strait Islander people and non-Aboriginal people which have contributed to poorer health outcomes for Aboriginal and Torres Strait Islander peoples:
 - The barriers to accessing these services include transportation, accommodation, cultural safety problems.
 - Increase Community access to clinical trials.
- More cultural awareness/cultural competency training for hospital staff.
- Increase employment of Aboriginal and Torres Strait Islander staff in hospitals and provide regular training, support and resources for staff.
- The spiritual, emotional, cultural and Community needs of patients must be addressed at all stages of the Cancer Journey, including offering holistic and cultural models of care options such as cultural healing.
- Culturally appropriate educational resources need to be developed and provided to Community.

Key themes – Yarns

A broad range of themes emerged across the Cancer Journey from yarns with Community with lived experience and their families and the Aboriginal workforce. This included identification of gaps and opportunities to enhance the cancer journey experience.

Taking on the cancer journey alone

Many people with lived experience of cancer experienced their journey alone for multiple reasons:

- Not wanting to be a burden on family members.
- Not being able to have family support (e.g. being diagnosed with cancer interstate, lost connections with family). This was particularly prevalent among female cancer survivors.
- The importance of AHLOs throughout the cancer journey.
- They provide cultural, emotional, social, and emotional well-being support 24/7.
- Many AHLOs work with Community members with cancer but have also been touched by cancer themselves (as carers for family members with cancer or they themselves have experienced cancer).
- It is helpful for patients to have consistent support from someone throughout their journey. AHLOs can accompany patients to their appointments and treatments and discuss patients' goals with them.
- AHLOs should be utilised to follow up for a yarn with patients who miss their appointments, rather than being called by a hospital clerk.
- AHLOs are expected to provide support not just to cancer-specific patients but all other patients (they are expected to know everything).

Financial support is valued

- It is financially draining for patients and families with cancer dealing with the expenses of medications, transport, parking, rent etc.
- People experience changes in household incomes (i.e. from two to one income).

The importance of strong Community and family support

Cultural support (not just during weekdays but during weekends too).

Spaces for peer support are needed and valued.

Aboriginal health services are a valuable place of support for patients.

Distribution of resources between general and specialised hospitals

- There are more resources available in specialised cancer hospitals for patients. This includes:
 - peer support groups/ Yarning Circles
 - access to food/coffee vouchers
 - easily accessible specialist supports (psychology, physiotherapy)
- There is more respect and sensitivity of cultural practices in specialised hospitals:
 - No cancer patient dies alone, families are allowed to come into the wards for dying patients. This was the case even during the pandemic.
 - There are dedicated areas for smoking ceremonies.
 - Every First Nations identified patient is given a possum skin pelt.

Role of carers

- Carers have a huge role in looking after people with cancer.
- There is a lot of reliance on them which can be draining for carers.
- When male partners are diagnosed with cancer, many of the manual home care falls on the female partners. There are physical challenges with that (height and weight differences).
- Caring for a family member going through cancer has an impact on the carers' mental health, they can experience burnout too.
- There needs to be more support for carers/families during treatment and ongoing after a cancer patient dies.

Preparation of patients for cancer journey

- There is a lack of information provided to patients on the side effects and long-term effects of cancer treatments such as chemotherapy and radiotherapy.
- These effects include fertility issues. This results in patients not being able to plan ahead for life events (e.g. having children or sperm/egg freezing before going through chemotherapy/radiotherapy).
- There needs to be more education in the community about palliative care.

Changing identities

- Being identified by the disease and not as a person.
- The length of time between diagnosis and treatment options are sometimes so short that there is not enough time to process the changes in identity.
- Changing of identity from partner/lover to carer.
- Patients had to be strong for both themselves and their families and friends around them.

Role of pharmacies in home-based care

- Some of the people with lived experience had a high degree of health literacy and they knew to go to their local pharmacies to get them to organise their medications for them.
- Not all pharmacies carry cancer medications.
- Some people might have to wait for the medications to be available - if they are not 'prepared' then there will be gaps in their medication.

The impact of COVID-19

- The cancer journey was quite isolating for patients experiencing cancer during COVID-19.
- When no support person is allowed during therapies or in wards, there is a lot of reliance on AHLOs to be that support person for patients.
- Visitor restrictions meant people had to die alone, without family or cultural considerations.
- A lot of stoic people did cancer post-surgical treatment at home and on their own during COVID-19. As such, people could benefit from having support groups to connect with and ensure they are informed
- Food security was an issue through COVID-19 - People did not know how they would access food during that time.
- Fewer people were screened for cancer or attended their appointments due to fears about COVID-19.
- There was a lot of focus on COVID-19, which pulled focus away from cancer.
- Communication worsened as most services moved online.

Emotional burden carried by patient

- The emotional burden is sometimes carried by the patient who does not want to 'upset' others (e.g. families) – particularly those who are unwell themselves.

Fear of 'not being seen' by hospital services

- Due to non-attendance.
- Difficulty in building routines about health and wellbeing when focusing on disease management.

Gaps identified

The need for Aboriginal in-house support for carers:

- Aboriginal cancer patients need to be supported to remain in their homes as much as possible. Support can look like:
 - Meal prep
 - House cleaning
 - Childcare
 - Laundry
 - Physical supports – particularly for people who are increasingly mobility impaired
 - Respite care
 - Assistance from AHLOs, community palliative care nurses, social workers, allied health (blood tests, treatments, wound management and changing surgical dressings)
 - Transport – private transport is preferred to public transport (e.g. patient transport services).

More cultural education for clinicians

- There is a lack of culturally competent workforce delivering services to Community.
- There needs to be more education for clinicians about cultural practices and trauma-informed care, and education for the Community about available support services.
- All hospital staff require cultural safety training, particularly palliative care, and morgue staff.
- Patients should be asked about their cultural wants and needs in palliative care.

AHLOs need more support and access to resources

- There aren't enough AHLOs available in hospitals to serve Communities.
- There isn't enough education and support for AHLOs to provide care for the Community. They are expected to know everything.
- Additional training for AHLOs is needed around:
 - Palliative care
 - Grief, loss etc.
- Having opportunities to debrief with other AHLOs and having an understanding and sympathetic manager is also useful for AHLOs.

Cancer-specific psychosocial and psychological support

- The wellbeing and emotional support for current cancer patients and their families is not being met.
- There is a need for more mental health support (as opposed to being offered a couple of hospital psychology sessions).
- It's hard for cancer patients to access appropriate psychosocial therapy/support.
- These services are also not readily available for patients.

Transport

- It is very difficult for people to use public transport to attend appointments, particularly when they are feeling unwell.
- Many people don't have a vehicle or family members to drive them to appointments.
- Many people have to travel a long distance to appointments which can be expensive.
- Parking at hospitals has been described as 'impossible' due to the expense and lack of availability.
- There is a need for more patient transport services and parking permits for people to use.

More Aboriginal cancer-specific information (health promotion and cancer treatment)

- Appropriate referral pathways, particularly for children.
- Written and non-written resources such as CDs, audio recordings etc. for patients with low literacy, including children.
- There is a need for professionals to use less medical jargon.
- Gender- and age-specific health promotion information – patient gatherings and group workshops are needed with guest speakers and role models – communitarian rather than individual approaches to

Q & A and information sharing

- Aboriginal health promotion workers.
- Aboriginal-specific resources for children to help them understand their, or their family member's cancer journey (books, support groups etc.).

Establishment of an Aboriginal Cancer Navigator role in hospitals

- Patients and their families can have a wide range of needs and they need someone to advocate for them throughout their cancer journey (from screening to follow-up).

Access to clinical trials

- Patients should have more access to clinicians and there is a need to:
 - encourage clinicians to consider referring someone for clinical trials
 - change the language about clinical trials for Community so people understand that they aren't being treated as a test subject.

Culturally safe screening options and programs

- Cultural safety is an issue in accessing health services, particularly in hospital settings.
- Due to racism within the health system, patients don't feel safe coming in and tend to avoid appointments. Fair skinned Aboriginal people often don't experience the same levels of racism as others.
- Group screening options are valued (e.g. Aboriginal breast screening buses where people can go to be screened together and offered Aboriginal-designed gowns to wear).
- Screening options like bowel cancer tests need to be available at health services, such as ACCOs, rather than just sent to a home address for those in transient housing.
- Some Aboriginal patients would prefer to discuss cancer screening with a doctor of the same gender (e.g. breast and bowel cancer).

Support for regional and remote Communities

- There is a lack of dedicated support for regional and remote communities accessing specialised cancer treatment services in metropolitan Melbourne.
- Considerations need to be given to these patients and their families as more travel and funds are involved to access the same services available for urban Communities. This might include transport and accommodation support.
- Consider utilising telehealth appointments when patients don't need to be seen by clinicians.

Advance care planning

- There is a need for families to discuss treatment and end-of-life preferences early in the process, ensuring all family members are aware of and respect the patient's wishes.
- Considerations include advance care directives, enduring powers of attorney, wills, funerals etc.

Public health waiting times

- People are waiting too long in the public system for screening tests and treatments.
- Patients who have private health or can pay upfront for tests are diagnosed quicker and receive treatment sooner.
- There is a need for affordable private health cover for Aboriginal people.

About the artwork

Keagan Mallia | Wamba Wamba

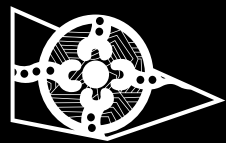
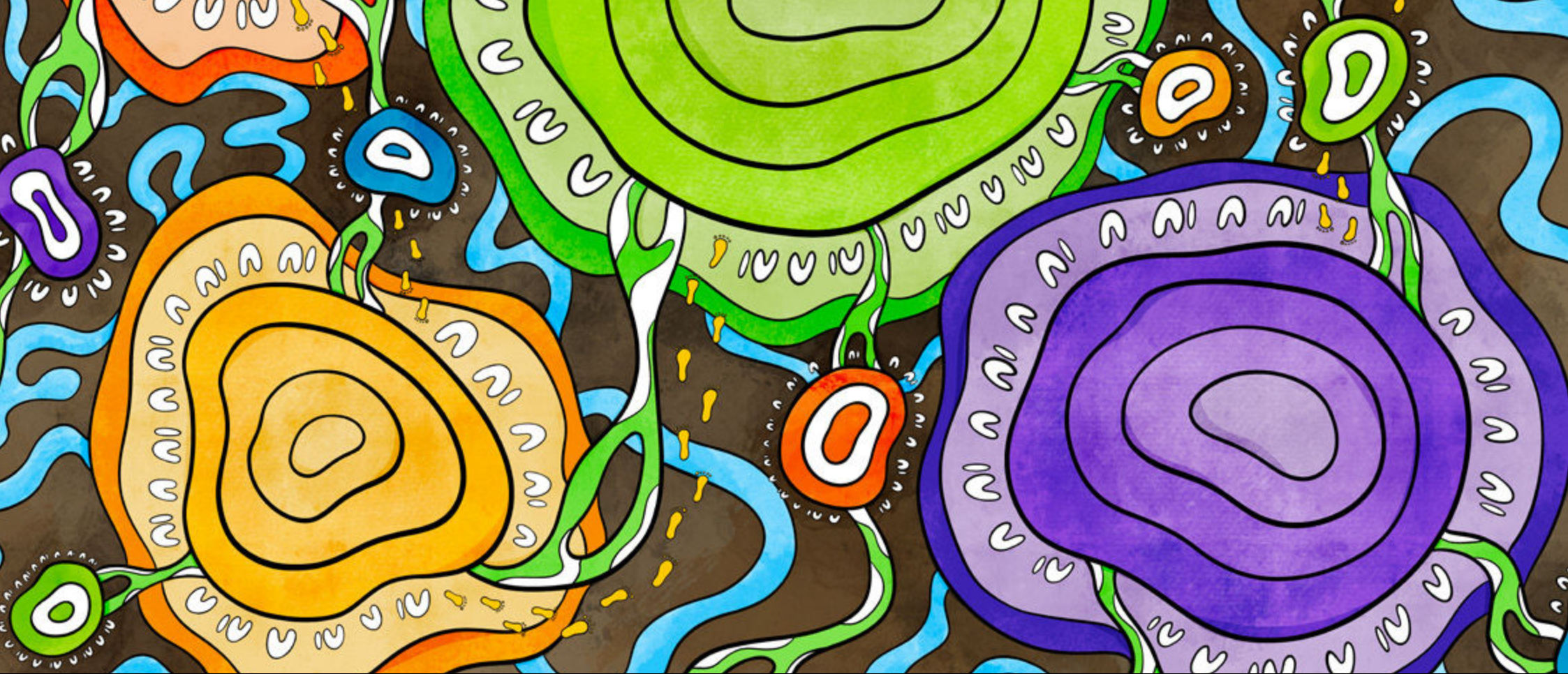
This artwork pictures the story of healing, going through the 5 key priority areas in the cancer journey. Prevention, Cancer Screening and Early Detection, Treatment and Support, Celebrating Survivorship, and Journey to Dreaming. I hope that this artwork can inspire and bring hope to those struggling with cancer who are going through this journey and encourage people to put their own health as a priority.

This journey begins with Prevention, being the first orange meeting spot. Then down to the yellow, representing Cancer Screening and Early Detection. Connecting these 5 key priority areas are travel lines to smaller meeting spots, representing support from mob, family, and friends. Footprints also travel along these lines, representing the individual going through this journey.

This then leads to the largest area, being Treatment and Support. This area depicts elements of uncertainty about what happens next in the journey, whether someone heals, or they pass on. It is the most significant part of the journey for the individual, depicting strength and support from which the person undergoing treatment can draw positive energy and vitality from. It is a place to connect to family past and present, near and far, to ancestors, to stories and significant places and of course the dreamtime. I made this area green representing the treatment and healing the individual is undergoing.

This then leads to the blue and purple meeting spots, Celebrating Survivorship and Journey to Dreaming. The outcome of Cancer is always uncertain, but whichever way it goes, there will always be family and mob waiting on the other side. For this artwork I used lighter colours to emphasise life and the continuation of life in whatever form it takes. I draw my inspiration for meeting places from the journey of my family and ancestors that have gone before me.





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